

*A discourse analyses of persons living with  
Psychotic Like Experiences in Ireland.*

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## Abstract

A growing number of epidemiology studies have determined significant rates of psychotic experiences throughout general/non-clinical populations. Typically, the term used to classify these phenomena is 'Psychotic Like Experiences' described in terms of aberrations, attenuated psychosis or magical ideation. In accordance with Social Constructionist theory, it is expected that there are various interpretations and applications of this knowledge. These range from identification of a psychosis phenotype in order to ascertain those at risk of transition into psychotic illness; to an anti-separation, a normalisation approach whereby the existence of psychotic experiences is portrayed as integral to the human condition, 'as part of ordinary mental life'. The former is promoted as a route to develop early intervention and prevention health programmes; the latter as part of an anti-stigma and social inclusion agenda. However, there are few qualitative studies into the lives of those living with PLEs beyond the 'professional, statutory health domain' and certainly none that attempts to explore the conceptualisations, the social impact and subsequent discourses created by those living with PLEs specifically in Ireland. As part of Social Constructionist theory language and discourse are the primary source that shape the human world where social objects such as psychotic experiences are deliberated. Through the deployment of discourse analysis this thesis sets out to explore discursive devices that arise from texts created by a number of participants living with PLEs in Ireland. Discourse Analysis can help participant groups develop their discourse through consciousness raising including the identification of compromises and contradictions that destabilise social agendas - that of normalisation. The identification of discursive repertoires revealed participant positioning and a number of compromises and dilemmas. Summarily, these were found to be: The continuation

of social exclusion through Othering; internalization of a social phenomenon; the individualization of a universal experience; accountability and responsibility and absorption of neo-liberal ideals. I conclude with suggestions to enhance a truth claim, or ‘candidate for knowledge’ through the symbiosis of knowledge, experience and expertise from within the very thing they resist – the meta/grand narratives of psychosis.

## Chapter One - Introduction

There is a wide divergence on estimated prevalence of psychosis in Ireland. Bowe (2012) estimates that 75,000 people are affected by psychosis, whereas DETECT (2012), an early intervention service in Ireland for people who are at risk of developing psychotic disorder estimate that “*Schizophrenia and other psychoses, affect over 120,000 people in Ireland*” (p9). However, both DETECT and Bowe do not describe how they came about these figures. Noteworthy is that both sources fail to qualify their estimates in terms of whether or not all individuals captured have ever been formally diagnosed with psychotic disorder and whether or not this accounts for life-time prevalence or the incidence of psychosis at a given time<sup>1</sup>. This lack of clarity is indicative of the ambiguity, divisive nature and complexity involved in establishing an objective measure that captures psychotic experiences.

International research on PLEs in general populations have reported incident and prevalence rates ranging from 1- 17.5%, with a systematic review reporting a median prevalence rate of 5% (van Os et al., 2009).

Given the lack of consensus and clarity on estimates of the presence of PLEs in Ireland, yet taking into consideration international studies on the subject, a reasonable determination can be made that Ireland, has significant incident rates of PLEs in the general population (more on this in chapter 2).

Following the assumptive remark above and to put psychosis in a social context, Johns et al (2014) and Boumans et al (2017) note that it is not necessary nor an inevitability for people living with PLEs to require ‘professional’ support. This indicates that a significant number of people living with psychotic experiences do not

come to the attention of statutory mental health services. There is also evidence that rates of psychiatric disorders in populations (including psychosis) is more common than originally believed, prone to significant underreporting (Moffitt et al., 2010). Shortcomings in data analysis, data collection and stigma attached to the disorders are given as reasons for underreporting. The observations hitherto referred to signifies a lack of engagement and meagre knowledge base with/about non-clinical populations living with psychotic experiences. Psychosis as a conceptual 'template' representative of patterns of human behaviours and experiences has historically been propelled into a controversial social space where it is coupled with 'madness'; characterised in terms of significations of the fragility of the human mind, an escape from the constraints of rationality, of 'psychic' objection to societal oppression emanating from modern rationality, or a sign of incoherence regards inferences and incompatibility with normal experiences (Stompe and Ritter, 2009). Psychosis as a single entity, categorised and rationalised has become increasingly questionable, deliberated, challenged and opposed (Boyle., 2000; Fee., 2000); (see more in the succeeding chapter 2). By way of example, there is a wide range of social variance as to whether or not the primary basis from which we should approach psychosis should be that of health (illness or disease), society, culture or spiritualism (Read, Mosher, and Bentall, 2004; British Psychological Society, 2014).

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<sup>1</sup> Population studies have found life-time prevalence rates for psychotic disorders, specifically Schizophrenia and Bipolar Type 1, to exceed 3% (Perälä et al., 2007). (Prevalence rates typically refer to the number of individuals identified at some stage in life with psychotic disorder). The population of Ireland stood at 4.58m in 2011 (Central Statistics Office Ireland, 2012). 3% of this population equates to 137,400 individuals. Based on figures provided by Bowe and DETECT a reasonable conclusion could be that these are at best crude estimations, representative of prevalence rates in Ireland for people who have, through time, been identified with psychotic disorders, and/or that they are potentially significant underestimations. Either way, they do not seem to represent incident rates of psychosis in Ireland which include people who do not receive a diagnosis of psychotic disorder.

The contested space where disputes arise, depend very much on diversity of interpretations and representations which are in turn governed by the availability and usage of language. It is this contested space, from the perspective of those living with psychotic experiences who live outside/beyond statutory mental health services that this thesis sets out to explore. Participants sought for this study comprise of individuals within Ireland who live independently in the community with PLEs, yet, have not necessarily received a diagnosis of psychotic disorder. The limited engagement with this cohort and lack of knowledge about their interpretations, representations and personal accounts leaves an incomplete picture in understanding challenges faced in finding social acceptance as a consequence of social biases and acts of social exclusion directed at the psychotic experience (Boumans et al., 2017; Lawrence, Jones and Cooper, 2010) To date, such challenges have not been studied at the levels of language and discourse.

The term Psychotic Like Experience (PLE) has been used to capture a range of experiences, similar to clinically defined symptoms, found throughout/within general populations. Psychotic Like Experiences include perceptual aberrations and magical ideation (van Os et al, 2009). The former can be compared to hallucinatory events, the latter similar to a delusory experience. Experiences at this level tend not to cause any significant impairment or distress (Linscott and van Os, 2010) and can even be life enhancing (Jackson and Fulford, 2002). Those who are not unduly distressed by PLEs tend not to come to psychiatric attention (Fonseca-Pedrero et al., 2011). In other words, their experiences do not typically become clinically defined. For instance, one study carried out on the Irish population with 11 to 13-year old children found that 20% report verbal hallucinations (Kelleher et al., 2010). For the majority

of children, the experience disappears as they grow older (Escher et al., 2002) supporting a continuum of psychosis hypothesis, below.

Descriptions of psychosis include hallucinations, delusions and a variety of cognitive deficits (Andreasen and Black, 2006). Over recent years studies have shown psychotic experiences to be commonly distributed across a variety of populations indicating a continuum of psychosis (Hanssen et al., 2005; Rössler et al., 2007, 2015; Unterrassner et al., 2017; Verdoux and van Os, 2002; van Os, 2003). These range from the benign, and often short lived - described by Chapman and Chapman (1980) as “*Attenuated versions of psychosis*”, (or more specifically put ‘Exceptional Experiences’ that include: “*Odd beliefs, dissociative anomalous perceptions, and hallucinatory anomalous perceptions.*”; Unterrassner et al., 2017, p1) - to a graduation of experiences that potentially become overwhelming, disruptive and enduring – a process defined by van Os et al (2009) as psychopathological alteration. Ascertaining which individuals will progress from the benign lower end of the psychotic spectrum to that which becomes fractious and personally disruptive (potentially involving clinical intervention) has been argued to be problematic and challenging (Jackson, 2001; Lawrie et al., 2010).

Psychosis (and by association PLEs) continues to be a disputed concept, filled with inconsistencies and conflictual subject positions (Burgoyne, 2008; Smith, 1998). It is therefore open to a variety of interpretations and ongoing constructions which are played out in every-day discourses: •

*“Different models derive from different constructions of the world and events with it, but none is ‘true’ in an absolute sense. There is nothing ‘truer’ about assorted*

*neurotransmitters that there is about intrapsychic processes, inner child or various deities”*

(Perkins 1999; cited in Repper and Perkins, 2003, p.23)

It is the cogent use of language in the context of PLEs, in the face of the above acceptance of plural and complex understanding, that I now turn to.

### **1.1 The persuasive power of language**

Language, as Anderson and Goolishian (1988) would have it, is something human beings “*live in ... in the same way fish live in water*” (p56). Language is therefore an important medium to study, as a ‘social substance’ from which meaning and various strategies for living (eg; coping with illness) can be postulated (de Guzman et al, 2009). Foucault describes-how language can become an impetus to influence behaviour, used to “*shape, guide or affect the conduct of a person or persons*”. (Gordon, 1991, p5). Certain discourses raise awareness of risks to health encouraging behaviours that are preventative in nature, in some cases driven by political determinates (Finer, Thurén and Tomson, 1998; Porter, 2007; Walsh et al., 2008). The person becomes a source of knowledge and ‘subjectified’, in that s/he may find themselves portrayed as deficient, in need of remedial intervention (Walsh et al., 2008). For example, self-help literature engages language that can induce a sense of self-mastery and self-improvement in one’s life (Effing, 2009). Rhetorical devices are activated drawing the reader into a world of metaphors full of mechanistic connotations eg; stress as life’s enemy to be defused; a flow of information to be dealt with through the ‘mental computer’ (Brown, 1999). Texts can provide powerful

discourses able to influence individual comprehension and associated coping with a particular human state. Brown (1999) found self-help literature on stress to include constructions of stress and related “*regimens*” conjuring up the “*art of making oneself*” or “*realizing one’s full potential*” (p35) in order to achieve a ‘product’ (the self) engaging in a wholly technical activity. Levels of influence are exposed, designed to encourage people to relate to their experiences in a certain manner, giving direction as to how they might learn to live with them. Even though such discourses have been found to be potentially counter therapeutic they continue to be accepted wielding power and influence over the individual (Haefel, G. 2010; Cook et al., 2012). Participants for this study will have an awareness of at least some discourses that will impact on how they interpret, intercept and how they live with PLEs. Levels of participant awareness, influence and impact of various discourse on PLEs is significant to this study helping to understand discursive constructions at interview.

## **1.2 Discourse, objectivity and psychosis**

Discourse is a loosely bound concept involving production and comprehension of language. This comprises language in use at a micro level, for example what individuals are doing with their speech (Cameron, 2013); to a macro level where dominance over ways of describing aspects of the world exists (Ogden, 2002). The former involves performances that allows individuals to position themselves in relation to social objects; the latter involves practices “that systematically form the objects of which we speak” (Foucault, 1972, p49). To simplify further, discourses are units of text (written, spoken) socially constructed and socially informed, that aim to explain and persuade. Macro discourses permeate discourse generated at the individual, micro level (Ogden, 2002) and therefore influence how we tend to talk about aspects of the

world. The effects and consequences of discourse is studied through discourse analysis which considers the context that allows or inhibits certain discourses to gain social purchase. As part of understanding the context that allows a dominant discourse to exist around psychotic experiences, I begin describing some of the social and historical factors that govern the way we measure and therefore apprehend this human experience.

Traditionally, the dominant research paradigm from which major mental health problems (including psychosis) has operated under is within the tradition of positivism, a philosophical system that regards methodologies of a reductionist kind, such as epidemiological studies and the causative effects of genetics, above and beyond those that are of a sociological, qualitative nature (Kutney, 2006; Thomas, Bracken and Yasmeen, 2007). This includes statistical and quantitative methods that rely heavily on ‘facts’ that are observable and quantifiable (Weaver and Olson, 2006) playing down the significance of meaning, morals, values and belief systems that are engaged when people with major mental health problems come to interpret and understand associated experiences (Bracken and Thomas, 2001; Bracken and Thomas 2005). Simply put, positivism tends to look objectively at lives lived - a paradigm that Bracken et al (2012) term ‘Technological’. These methodologies can for instance, be deployed to try and determine the frequency and intensity of psychotic experiences in the general population using the continuum model of psychosis as a theoretical framework to hypothesise transitions to psychotic illness (Yung et al., 2009; Kelleher and Cannon, 2011; Binbay et al., 2012; Nelson, Fusar-Poli and Yung, 2012). A growing number of qualitative studies have been carried out to facilitate understanding of psychotic experiences from the first-person perspective (Boydell et al., 2010; McCarthy-Jones et al., 2012). Few, however, have captured these experiences by studying the

construction and functionality of language in providing accounts of psychotic experiences, particularly in relation to social resources at the person's disposal and how these are utilised to provide credible accounts (Crowe and Alavi, 1999; Hamilton and Manias, 2006). One study based on the above approach is Harper (1996) who examined discourses on paranoia from the first person and dominant (mainly psychiatric) institutional perspectives. The author found that constructions served particular political interests. For instance, one consequence was that scientific explanations offered by clinicians (pertaining to pathology) obscured the variable nature of discourse closing off or discrediting alternative accounts. 'Objective scientific facts' that positivism relies upon are power laden and persuasive. They can and do trump first person evaluations and descriptions, influencing social and political landscapes (for instance linking health and risk, justifying state sanctioned institutionalisation and coercive practices toward the psychotic person; Sashidharan and Saraceno, 2017). This has alienating consequences levelled at self-experience:

*“ the first-person perspective, the views, positions and experiences of persons in distress, who in the dominant paradigm are treated as objects of expert discourses and actions, which define, classify and intervene in the experience of distress, imposing predetermined scientific and professional concepts, which are foreign to experience itself.”*

(Georgaca, 2013, p407).

Georgaca may have a point, but discourses are never static and those directly under their influence have been shown to counter, resist or/and construct their own 'version of events' (see for example reference to Intervoice and Recovery chapter 2).

Resistance to the orthodoxy of the day, can uncover acts of protectionism against a particular concept and/or practice. Resistance is not straight forward though. It is capillary like, involving a network of social relations. One can never have full control over a discourse, its effects, the direction it takes, the transformations that may result; nor does a discourse sit neatly in opposition to another. The *“Discourse we are in is often a matter of negotiation, contestation, and “hybridity”, involving a complexity of players, ‘thoughts, words, deeds, bodies, tools, and objects”* (Gee, 2008, p182).

Resistance, at the individual level is revealed through discursive use of social resources, positioning and identity formation that takes place during social exchanges, in particular among persons who seek legitimacy and social recognition (Andreouli, 2010). With this in mind, first person reporting of psychosis has become increasingly significant for a number of researchers, activists and practitioners seeking to acknowledge, appreciate and promote the lived experience as a stimulus for social change (Parker et al., 1997; Georgaca, 2013).

In the context of this thesis, the importance of language as a transformative medium is of great significance. Studying language in use can reveal issues of power and influence at work, such as consequences of historical and dominant discourses bearing down on persons directly affected (van Dijk, 2008). It also provides us with momentary glimpses into the linguistic performances involved (such as adaptive processes) in order to maintain a credible identity in the midst of social indifference. Therefore, studying language in use can reveal how: *“people may resist the way they are positioned by others, as subordinates or as members of a group they do not wish to be identified with”* (Cameron, 2013, p178). This of course relies on qualitative methodology beyond positivist assumptions, capable of capturing and interpreting language as a purposeful tool.

This study is of an exploratory and descriptive nature. It applies qualitative methodology to apprehend and make sense of discourse in relation to psychotic experiences with a number of individuals residing in Ireland who live with PLES outside/beyond statutory mental health services. This includes those who at some stage have been diagnosed with a psychiatric disorder and likely ‘used’ statutory mental health services; and others who have never received a psychiatric diagnosis who likely never engaged statutory mental health services. The fundamental inclusion criteria for this study, regardless of receiving a psychiatric diagnoses or experience of statutory mental health services is that participants self-declare as having experienced psychotic experiences and are ‘successfully’ living with PLEs in their respective community (see Chapter 3, 3.20 for more on participant criteria). Successful living with psychotic experiences combined with participants assertion that they live with PLEs without professional support indicates that they are not part of a distinct psychiatric population but belong to general society (Lawrence, Jones and Cooper, 2010; Boumans et al, 2017). Further, studies as already alluded to above and further described in Chapter 2 demonstrates that psychotic experiences are distributed throughout general populations. This gives additional credence to the claim that the participant group for this study are not to be marked socially or communally distinctive. Related to the latter is that there is ample evidence that persons who live with psychotic experiences, in particular those who live outside/beyond mental health services, believe them to be within the range of normal human experiences (often seen as adaptive strategies), seek social acceptance preferring not to be seen as significantly different from others in general society (see for example 2.2 Chapter 2). For reasons given, I therefore contend that the participant group sought for this study

belong to general society and believe that participants would concur with this categorisation.

Qualitative data was collected, firstly from a self-assessment questionnaire, followed by a one-to-one audio taped interview. Interview data was transcribed and analysed using discourse analysis as described by Potter and Whetherwell, (2007). Discourse analysis enables the examination of linguistic (discursive) practices that appear during conversation involving: *“the construction and reflection of social realities through actions that invoke identity, ideology, belief, and power.”* (Young, 2008, p1).

Discourse analysis is not concerned with language structures such as rules and formation of grammar, but the larger unit of text where meaning is created, the context with which it is constructed considered; where language is understood in terms of social action and performance. It considers the interrelationship between language and society (Slembrouck, 2003). As with Brown (1999) and self-help literature, discourse analysis considers the impact of social influences on the generation of text eg; the use of available discourses on psychotic experiences.

Discourse analysis is ideal in revealing participant’s use of and reliance on social (collaborative) resources; the discursive practices that influence positioning, coping and relating with regards PLEs. Attention will be given to construction of accounts by studying language in use and discursive resources the individual engages to position and socially situate themselves. Discourse analysis will be utilised to achieve an understanding of the nature of discourse under construction, the challenges therein including the identification of nuances, inconsistencies, contradictions, compromises. Particular attention will be given to repertoires as part of discursive practices, as:

*“available symbolic resources which particular individuals or groups can draw on in their attempt to make sense of their own specific situation and construct a viable identity”*, (Burman and Parker, 1993, p95).

It is hoped that by studying the construction of accounts through the functionality and application of language, including resources referred to, that there would be potential to open up dialogical spaces to help create new discourses around psychotic experiences.

Willig (1999) suggests that the process of conducting a discourse analytic study can be used either *“therapeutically”*, as a way of shifting participants’ subjectivities through reflexively examining their positioning, or as a form of consciousness raising, where participants can discern the ways in which they have been constrained by certain discourses. In this way, socially oppressed and/or marginalized groups can benefit from discourse studies, by exploring and revealing the subtle ways in which they have been subjugated by dominant symbolic systems and practices (Willig, 1999). That said, this study is starting from a point that the participant group is relatively empowered (see methodology chapter), living ‘successfully’ with their psychotic experiences, able to provide self-assured accounts of their experiences. However, they may unknowingly produce text that are equivalent to or correspond with the very systems and practices they oppose. This thesis sets out to explore the extent with which this occurs and the effects of discourse created by participants at interview and its consequences.

### ***1.3 A Reflexive note***

Before proceeding it is worth noting that the author (referred to in first person terms from here on in) has personal experience in the subject matter. I have self-experience of PLEs and for approximately 20 years been involved in what is described by some as the ‘Survivor Movement’ or the ‘Consumer Movement’ - a social movement primarily consisting of psychiatric patients and ex-patients seeking to improve the social status of people with mental health problems and influence statutory services encouraging liberal practices through advocacy, petitioning and lobbying (Oaks, 2006; Rissmillar and Rismillar, 2006). A major driving force behind the ‘movement’ was to achieve social acceptance of psychiatric symptoms as part of normal human experience.

Following the above, I will spend the remainder of this chapter summarising what has informed and motivated my own positioning on PLEs; what has led me to conduct this study with reference to positioning and reflexivity.

### ***1.4 Motivating factors and the journey to positioning***

Discourse analysis is not so much attentive toward content and information found within text, but the context and interactions between various bodies that inform and influence the discursive nature of the text. It is therefore important for me to discuss my own positioning as anyone involved in conversation becomes part of the discourse created. It follows that my input becomes part of the analysis.

Specifically, positioning:

•  
*'considers that all interaction is discursive or narrative; and, secondly, because it understands that this is a changing, fragmented and absolutely contextual phenomenon.'*

(Tirado and Gálvez, 2007).

My influence on text generated may be blurred; interactions can be woven or blend into the text which are in danger of being overlooked, taken as sole productions of the research participant. The construction of face to face discourse should be taken as 'Situated activity', something created between persons, at a given moment in time, its course and production unforeseen: 'never something based and maintained *a priori*' (Tirado and Gálvez, 2007). The presence of the author, my level of interaction impacting the discursive construction of text created during interview requires attention.

My journey involved institutional settings where I was treated for a psychiatric disorder, use of day care facilities and community support provided by mental health professionals over a period of approximately 14 years (1990-2004). During this period, and beyond, I conversed with people with mental health problems who were disgruntled with mental health services - in particular, where they felt their human rights were breached; their autonomy threatened; being subject to coercive and condescending practices. The power of psychiatric diagnoses appeared to be a constant component that allowed these breaches to transpire ie; being diagnosed mentally ill assumed the individual (patient) a site of risk, having difficulty/incapacity to make decisions. Despite the level of discontent and protestation, there was an inability and/or reluctance for these individuals to move beyond psychiatric services.

There appeared to be objections and resistance to the authority of psychiatry on the one hand, and on the other, what appeared to be a dependency, a reliance for support and recognition of mental anguish. This is reflective of Speed (2006) who notes the presence of different levels of agency and acceptance in discourse constructed by mental health service users. Agency and acceptance lay on a continuum utilised according to the perspective the service user wanted to convey at any given time - the use of 'Patient' indicating passivity; 'Consumer' active involvement in care and treatment and 'Survivor', actively resisting services.

During the latter stages of using statutory mental health services I began to hear of, then 'mix with', an increasing number of people who 'lived with' what appeared to be considerable psychiatric symptoms (hearing voices, unusual beliefs) who lived beyond psychiatric services. Some had been through the system, 'survived' and moved on; others had never engaged with them. Their discourse was one of resistance to and denunciation of psychiatry; of 'alternative' meaning making systems and supports, liberalisation, normalisation and social acceptance of 'psychiatric symptoms', (with particular emphasis on psychosis). These narratives, as they were shared and presented, inspired me to move beyond psychiatric services.

My own journey from crisis point, ultimately leading me into psychiatric services, involved a period of reflection on the power of language and how public discourse continued to be dominated by a persistent message of deficiency in character and hopelessness attached to persons diagnosed with a psychotic disorder. At first, I was 'intrigued' as to how a diagnosis might be able to represent a person who is in need of support, acceptance and understanding. However, I became indifferent over time to

psychiatric labels, rendering them meaningless in my life, non-representative of who I am, or my ability to create a rewarding future. This tendency to be indifferent carries over into various life circumstances including my current employment involving peer advocacy where a non-judgemental approach toward others, 'peers' with mental health issues is ritually practiced. Consequently, I detach myself as far as possible from judging others who might have a different view of receiving a psychiatric diagnosis eg; those that appear to believe that a psychiatric diagnosis is representative of their mental health problems. I respect their right to define their needs, describe their personal circumstances and origin of their psychotic experiences. In other words, my approach when interacting with peers, is to isolate my own experience, suspend opinions and beliefs about psychotic experiences, allowing people to come to their own 'meaning making decisions'.

It is this 'standoffish', slightly detached or reserved position that informs regular interactions I have with people who, whether inside or outside of services, have personal experience of mental health challenges and one I maintained during interviews with study participants. That said, even though this is my general approach when interacting with peers, I reserve my right to hold a cynical and sceptical opinion on diagnoses and would generally subscribe to the view that 'accepting' or 'yielding' to a diagnoses 'for life' (Tucker, 2009) signifies the power and authority of psychiatry in 'making subjects' (Roberts, 2005). In making subjects the psychiatric enterprise satisfies a modern world that measures human performance in accordance with standards of rationalisation, rejecting behaviours and experience it judges unreasonable or irrational (psychotic experiences).

I must add here that personally, unlike many others I have spent time with, I have not experienced coercion or adverse practices whilst under the care of psychiatric services. I often question though if what was provided to me could not have been provided in a different environment; where the approach to care was not dependent on nor overly influenced by diagnoses, categorisation and corrective interventions. A secondary part of my journey involved working for the very mental health services I initially engaged. My first paid role was as a day care worker in a community drop-in centre, then as a ‘Coordinator’ being responsible for bringing together service users, carers/family members and service providers in developing local mental health services. I worked constructively with this service trying to bridge experience with (professional) expertise but found this task impossible. The traditional structures of power and authority stubbornly persisted; the bottom up approach desired by service users was never realized. Moving from service user to provider of sorts has undoubtedly influenced my view of all things related to mental health services. My experience leaves me feeling sceptical about the readiness, or indeed willingness of some working within the mental health system in shifting the locus of control, of reordering the hierarchy of power and authority assumed by psychiatry, bestowed by the state (Barker and Stevenson, 2000). Given the number of years I have been involved in the survivor movement and efforts made to change mental health services I am left concerned about the capacity of ‘resisters’ of traditional mental health systems to shift this locus of control. The hierarchy of power and authority not only turns service users into subjects but allows public discourse on psychotic experiences to remain pessimistic and guarded, enabling the persistence of marginalisation and social exclusion against persons living with psychotic experiences (Bonnington and Rose, 2014; Timimi, 2014).

It will come as no surprise then that I remain sympathetic to narratives of resistance, believing psychotic experiences to be “*part of ordinary mental life*” (Garret et al., 2006, p605). However, what has become apparent over time, up to the point of deciding on the given study, was the inconsistencies, nuances and numerous versions of accounts of psychotic experiences that the ‘survivors of the system’ presented. There was no overarching theory pertaining to the existence of psychotic experiences, their causality or how they should be personally or socially integrated. That said, there was a consensual belief, borne out by people’s experiences, that due to the psychiatric system a common public response to psychotic experiences involves suspicion, social distance and the need for intrusive practices as sanctioned by the state. If this common response was to change, there would be a requirement to challenge the meaning making systems responsible for this public perception (in short psychiatric interpretations; diagnoses, labels). Meaning making systems involve language at the macro level. Therefore, the primary ‘challenge’ for the cohort described was at a linguistic level ie; to find ways to change public discourse on psychotic experiences. To put it another way, words matter, they influence our understanding of and in turn shape common responses to human experiences (Cameron, 2007). If psychotic experiences are to be normalised; to find social acceptance and prompt an empathetic public response, then the language thereof would need to change. To help unravel why this dominant meaning making system had not changed in accordance with assertions made by this cohort, studying language as a performative act would be required. This would include effects and consequences of the incohesive nature of narratives as naturally occurs; the inconsistencies, compromises, nuances and numerous versions of accounts presented

during conversation. Discourse analysis, as the chosen methodology for this study can help reveal limitations and constraints to discourse created by groups that seek to challenge meaning making systems that negatively impact them, and in doing so assist them in developing a new strategy or a more effective or efficient way to counter discourses that they seek to amend. I refer back to Willig (1999) who suggests that the application of discourse analyses can benefit disenfranchised social groups through consciousness raising, where they can become more aware of the way they have been constrained by certain discourses and be in a position to counter unforeseen effects or consequences of their own subjectivities and positioning.

Finally, Willig (2013) describes Personal reflexivity as: *“the ways in which our own values, experiences, interests and beliefs, political commitments, wider aims in life and social identities that shape the research”* (p55). This list comprises motivating factors involved in developing and conducting research. Given the above, personal motivation for this study is to try and understand what these linguistic challenges consist of and if there might be a way of breaking the linguistic impasse in order to try and pave a pathway of social acceptance toward the psychotic experience.

### **1.5 Study Aims and Objectives**

The significance of this study is underscored by the numbers of persons living with Psychotic experiences, ‘hidden’ in general populations. Their lived experience, their accounts outside/beyond the mental health system is rarely considered or expressed even though they potentially outnumber those caught up in the system. In essence, it appears that this cohort have become marginalised and silenced. The social environment (stigma, discrimination and institutional ideology) has been found to be particularly problematic for those caught up in the psychiatric system, those who have

moved through it and those described as ‘non-clinical’; who live with PLEs.

Psychosis is associated with experiences that are socially suspect, linked with human deficits that are wholly undesirable, marking the ‘host’ as undesirably different, creating an exclusive environment with alienating consequences. There has to date been few qualitative studies designed and carried out to explore challenges faced by ‘non-clinical’ populations living with PLEs, and as far as the author is aware, none with a particular focus at the linguistic level. It is at the linguistic level, in particular the discursive formations, where issues of social power surface, vis-a-vis; control over meaning of experience takes place. It is the struggle to control meaning and create a positive identity for those living with PLEs in Ireland that is significant to this study that the author wishes to explore. This will be achieved through the application of Discourse Analysis where discursive formations are identified in text generated during one-one; face to face interviews. The identification of repertoires, participant positioning, contradictions and compromises (eg; dilemmas) present in discourse created by participants at interview that will help unravel issues of social power at play. To conclude, the overarching aim is to give a voice to those living with PLEs outside the psychiatric system; raise awareness of their own discourse that runs contrary to their intended consequences. I begin with a literature review, Chapter 2 below, presenting evidence and various theories associated with PLEs. This will help contextualise PLEs unravelling the potential impact of various discourses (in particular those that are socially dominant), on the study participant group, the positions they take up and the formation of discourse during interview.

To conclude this section and to help bring clarity, combined summary aims and objectives for this study are to:

- Interview persons self-declared living with PLEs in Ireland in order to understand the construction, personal positioning and orientation of their discourse,
- Reveal the effects and consequences of participant discourse on perceptions and interpretations of PLEs,
- Identify communicative social systems that support and enhance the discourses on psychotic experiences constructed by the cohort of research participants

## ***1.6 Summary of the remainder of the thesis***

Below I present a summary of the remainder of the thesis. This will help bring clarity and act as a rough guide as to what follows.

Firstly, Chapter 2, Literature Review, provides context to the subject of study (psychotic experiences) where a number of representations on psychosis and by extension PLEs are presented. In part A, Chapter 2 I present historical background to psychosis as a concept including the rise of epistemological parameters as defined by a paradigm that dominates social discourse on psychotic experiences – the meta/grand narratives of psychosis. The meta/grand narrative identified is determinist and essentialist in nature restricting circumstances for positive meaning making to take hold for the individual living with psychotic experiences. The meta/grand narrative is primarily expressed through the scientific enterprises of psychiatric and psychological knowledge. In part A, Chapter 2 I also present interventions, commonly practiced and socially sanctioned operating within and through this dominant paradigm. In section B, Chapter 2, I present the case that PLEs are commonly experienced across general populations introducing ideas, beliefs and evidence that psychotic experiences are a natural part of mental life, non-determinist, subject to social and cultural

milieus. A number of models, theories and culturally inspired meaning making arrangements are offered up as more attractive to people living with PLEs in the general population. These arrangements are presented as more humane than the dominant paradigm, facilitating better understanding and improved ways to apprehend and engage the psychotic experience. I conclude Chapter 2 with examples how those with lived experience of psychotic experiences maintain or reclaim identity and shake off the negative labels and stereotypes that, at least for a significant number of people, are associated with the meta/grand narratives of psychosis. In presenting the various circumstances, approaches and theories on psychotic experiences I identify available discourses to study participants when speaking about their PLEs that will potentially appear in the text they generate at interview.

In the Methodology Chapter, Chapter 3 I return to the theoretical concepts fundamental to this study, Social Constructionism and Discourse Analysis, how they consolidate a theoretical arrangement to meet the aims and objectives of this study. Repertoires are put forward as the primary unit of text that make up a discourse, with discursive performances appearing within each repertoire revealing how the repertoire was achieved. The identification of these units and revelation of linguistic performances enabled analysis where I could uncover orientation, positioning, effect and consequences of participant discourse. As part of establishing credibility to the technical end of the chosen methodology a system of transcription was identified, methods of coding and analysis presented, and a standard to ensure validation presented. The significance of the researcher as interviewer and potential to influence participant discourse at interview is explored in a section on reflexivity. Following the section on reflexivity, ethical concerns are addressed, sample size and criteria to participate rationalised. Methods of recruitment, selection process and interview schedule were described with Chapter 3 ending in a number of tables providing demographic and

experiential information on participants.

In Chapter 4 I present findings, post analysis. Here I identify a number of repertoires and discursive acts that reveal participant positioning, orientations, effects and consequences of text generated at interview. Positioning revealed that participants believe themselves to have a unique, unquestionable expertise securely attached to the lived experience of PLEs. The orientation of participant discourse highlighted a desire to normalise the psychotic experience by shifting public opinion and attitudes toward the psychotic experience and discourse thereof; effects and consequences of the repertoires and discursive performances at interview resulted in a number of dilemmas and compromises to their claims to expertise and ultimately the silencing of the psychotic experience.

Chapter 5, Discussion, considers the implications for the discourse constructed and discursive performances enacted by participants at interview. I begin by considering personal gains for participants emanating from these constructions and performances. I then focus on the participant's primary orientation (desire) to change public responses, attitudes and ultimately discourse on psychotic experiences from a deficit, disability, risk-oriented discourse to one that normalises and accepts the psychotic experience as part of a common human state, in reach of and shared by all. I go on to consider the current context where this discourse of normalisation and public acceptance is proposed to take place. I highlight constraints to participant's primary orientation, imposed via the social dominance of neoliberalism including complimentary and corroborative institutional arrangements and practices. The constraints highlighted are essential to achieve the study aims ie; to reveal the compromises, unforeseen effects and consequences of participant discourses. I

deliberate the current social system, dominated by neoliberalism, and potential to move public discourse on psychotic experiences in the direction as desired by participants. This involves the identification of an interpretative community, deliberating the level of reliance on the individual experience as the only authentic representation of the psychotic experience, to one that leads to dialogue and potential social change.

In Chapter 6 I conclude the thesis reflecting on the potential for individual representations and collective action required to achieve the necessary shift in public discourse on psychotic experiences in the direction desired by participants. Here, I suggest converging knowledge and expertise found within the very system and establishments they resist ie; those working within the meta/grand narratives. This, I suggest would add weight to participant claims to truth, achieved in dialogical spaces where a credible blending of expertise can counter misrepresentations and public concerns surrounding psychotic experiences. I end with an epilogue, where I express personal struggles of consciousness encountered whilst carrying out the study and raise personal concerns for persons who continue to be caught up in psychiatric systems.

## Chapter 2 - Literature Review

To begin, the literature review below is taken from a position of scepticism. A sceptical approach has been noted as “*a method, not a position*”, involving “*a tacit and desirable state of critical engagement*” (Gurney, 2017, p3); for its ability to facilitate constructive doubt and raise awareness over variances that exist between ideals and practices (Midgley, 1998). Ideals come into play with regards to the various theoretical positions to psychotic experiences; practices as to how beneficial, facilitative and attractive are the consequences of these ideals impacting those with lived experience. This approach is informed by the author’s personal experience, both living with PLEs and being part of a social movement that is highly critical of established ‘truths’ about psychotic experiences (Zucker, 2014). This involves ‘problematizing’ a number of defining sources (ie; critiquing their claims to truth) considering why someone with psychotic experiences might or might not be attracted to a given knowledge resource, identifying dominant world views that might impede an optimistic outlook for participants living with psychotic experiences, safeguarding identity. Problematizing knowledge is an ‘inquisitory’ activity bringing it in line with epistemological notions affiliated with Social Constructionism (Burr, 2001). Social Constructionism considers all truths to be questionable and negotiable. Truths are not dependent on ‘facts’ that rise above human experience and social activities thereof. They are subject to, and change, according to the ever-present forces of history, culture and social context that lead to shifting discourses. This highlights:

*“the idea of language as much more than a mere mirror of the world and phenomena ‘out-there’, and the conviction that discourse is of central importance in constructing the ideas, social processes, and phenomena that make up our social world.”*

(Nikander, 2008, p413)

Finally, in keeping with a position of scepticism, problematising theories, models and core constructs that make up various discourses on psychotic experiences I have chosen a literature review that is 'Integrative' (Khoo, Na and Jaida, 2011). An integrative literature review summarises results derived from topics and subtopics that sketch prevailing ideas around a subject matter. At this level, evaluation of research evidence in accordance with critical analyses of research methods and interpretation is not required. The prevailing ideas can be uncovered in the rhetorical functions of discourse arising from research studies and other relevant literature. In other words, topics and subtopics tend to create a distinct representation of a subject matter, taken up as a position creating a specific discourse. According to Khoo, Na and Jaida, (2011) an integrative literature review also allows the 'reviewer's voice' to become dominant. In accordance with the integrative literature review I will identify topics, subtopics and ideas around psychosis and psychotic experiences, present the rhetorical functions they serve that enable me to locate discourses that offer a particular representation of the psychotic experience (eg; are psychotic experiences presented as faulty biology or a shared human experience?). Further, in accordance to Khoo, Na and Jaida's, (2011) examination of literature reviews, the reviewers voice will be allowed to dominate in assessing each idea and its claim to truth, enabling a position of scepticism to prevail during the literature review. This will allow me to present established discourses that serve various functions potentially influencing participants' own discourses presented at interview.

Further to this, a linear writing structure is usually expected whilst presenting research at this level eg; introduction, literature review, methodology, research design, findings,

conclusion (Uncles, 1998). Davis (2007) observes that this is not always applicable - in his case 'unsatisfactory'. Traditional research structures can get in the way of innovation inhibiting levels of creativity necessary in generating meaningful observations and interpretation at particular junctures of the research process. Using Davis's experience of conducting a doctoral research I will weave "back and forth" between relevant literature, data analysis and interpretation during Chapter 4 Findings. This will allow the research cycle to reflect the study as it evolved allowing relevant observations to present when necessary. Therefore, literature presented in Chapter 3 will sometimes augment with the Findings Chapter 4 or vis versa.

## ***2.1 Literature review – scoping search parameters***

In this chapter I will review a range of literature on psychosis and psychotic like experiences (PLEs). Psychosis, is commonly associated with clusters of intense human experience and behaviours whose primary descriptions include hallucinations, delusions and disordered thought (Costello, 1993, Bentall, 2003, Burgy, 2008). As a disputed concept, psychosis is opened up to competing positions operating within scientific, political and social spheres (Berrios and Beer, 1994; Janzarik, 2003; Burgy 2008). Given the range of positions and theories on psychosis - for instance emphasis on social (Sharpley et al, 2001) vs biological (Arsenhault et al, 2004) causation - each in turn motivating an abundance of research activity, a substantial weight of materials is available on the subject. Leff (2008), points out that most theories on psychosis include social, psychological and/or biological features indicating the wide variety of ontological factors involved. Boundaries have therefore to be set in order that a manageable and appropriate volume of information is thoroughly reviewed. In order to manage the information available on psychosis I suitably apply three items on

Gough's (2007) Weight of Evidence criteria choosing literature for its appropriateness, relevance and finally assessment of knowledge contribution presided by the study aims. Literature reviews are often used to summarise the most up-to-date research evidence to inform policies and practices. However, in this case the literature review needs to reflect discourses on psychosis that are culturally available; that filter their way into social discourses, also impacting and potentially influencing/orientating discursive accounts at interview. Consequently, given the various domains and broad range of perspectives on psychosis the scope of search terms is necessarily broad and generic to include literature on: theoretical constructs; empirical evidence; biographical and autobiographical materials; media and health professional opinions and practices. Core constructs, primary/dominant paradigms and 'less known'/'fringe' ideas of psychosis have to be factored.

In sticking to the aims and objectives of the study and having outlined the broad remit for the literature review I chose to apply a non-systematic approach where concepts and core constructs determine the framework (Webster and Watson, 2002) or to put it another way "*key concepts are transformed into keywords*" (Ferrari, 2015, p232).

Core constructs on psychosis are found within and throughout established authoritative expertise (eg; psychiatry, psychology, psychotherapy); fringe/less known notions (eg; spiritual explanations), often being found in 'marginal' discourses.

Discourses are seldom (if ever) singularly fixed, made up of a synthesis of knowledge including the subjective (lived experience) institutional, allied bodies and practices (professional groups), public discourses and perceptions (Sharp et al., 2013). The intention here is to draw upon associated concepts, theories, perceptions and practices that influence discourses on psychotic experiences. This review will focus on subject

areas relevant to the research question, critically examining their claims as representative of the psychotic experience. Areas to be covered in the literature review, set within the confines of this study, are taken from various perspectives including first person accounts, scholarly, academic and/or practitioners. These are presented below:

1. What constitutes psychosis and psychotic like experiences (PLEs)
2. Models of psychosis
3. Major theories on psychosis
4. Social and political impacts of psychosis as a concept
5. Living with psychotic experiences, responses and coping

Search terms within the conceptual and theoretical bounds above include: psychotic like experiences, theoretical models of psychosis, interpretations and representations of psychosis (psychiatric, psychological, psychoanalytic, spiritual, sociological); stigma, discrimination and exclusion; identity and discourse; narratives and the lived experience; psychosis and recovery. Data bases; SocIndex (a Sociology research database); Psychology & Behavioural Sciences Collection covering areas such as psychiatry and psychology, mental processes, anthropology, observational and experimental studies and Google Scholar were primarily exploited to achieve the broad search required for this literature review. Google search engine was used to explore the potential to include what might be 'less known'/'fringe' ideas of psychosis.

Given issues of social power (control over meaning) as discussed in the previous chapter, it is important that levels of influence on social discourse, from each source, be reported. This specifically exposes the impact of dominant/grand narratives (see 2.5 below) on those living with psychotic experiences. Although PLEs in terms of diversity of human encounters are the primary interest of this study, psychosis as a single entity (pathology) will also be explored as this may overlap or at the least impact on participant discourses where awareness of links between the psychotic experience and pathology is revealed.

I will review and present critiques to a number of models/representations, empirical and positivistic sources on psychosis and PLEs. These are available as social resources, each one in turn offering a particular comprehension of psychotic experiences. Exposure to knowledge influences people's positioning on particular issues in their lives (Harre and van Langenhove, 1991) and has direct consequences on the discourses they cultivate.

It is the aim of this study to explore psychotic experiences with a number of participants within Ireland who have lived with PLEs for a significant amount of time. In order to get to grips with sources that may have shaped their individual discourse on PLEs a number of well-known theories will be presented. It is not however the intention here to construct a knowledge base that would risk invalidating or pre-empt participant responses to the research questions nor generate preconceived analysis of data. The intention is to exhibit prevailing views on the nature of psychosis which may appear and impact on the construction of participant discourses and comprehension of the self (Moulding, 2003; Tucker, 2009).

A note on terminology. Given the continuity between psychotic experiences and PLEs identified in this chapter I have purposely chosen to use both terms interdependently. As a continuum of psychotic experiences has been identified across general populations (Johns and van Os, 2001) difficulties with differentiating between ‘genuine’ symptoms of psychotic illness and those that are identified as PLEs exists (Thapar et al., 2012). Adams (2007) found psychosis proneness (ie; evidence of psychotic symptoms suggesting pathology) among African-Americans and Caucasians being assessed for PLEs indicating elevated probability to developing psychotic illness. Though an increase of risk of developing psychopathology has been associated with high levels of distress directly caused by psychotic experiences, difficulty remains with separating PLEs from clinically significant psychotic experiences (Hanssen et al, 2005; Kelleher and Cannon, 2010; Lawrie et al, 2010). Given the blurred boundaries between PLEs and psychotic symptoms I will be referring to health care terminology when using the term psychosis - ie; pathology, mental illness and cognitive deficits - psychotic experiences that appear in non-clinical populations when referring to PLEs (Kelleher and Cannon, 2010). Reasons for the distinction will hopefully become increasingly clear during the remainder of this chapter as will the history of the psychosis as a modern behavioural and experiential concept.

Prompted by noticeable criteria that set out standards in interpreting psychotic experiences, in turn influencing how the psychotic experience should be apprehended I have decided to divide part of this chapter into two distinct sections, A and B. These criteria provide starting points from which meaning making systems and approaches influence the ability for individuals to interpret and integrate their psychotic

experiences. For the purposes of this study a meaning making system can move in one of two directions. A top down system that tends to impose meaning upon cohorts of people whom it identifies as being deficit laden, where faults in communication, sense of self and reality are assumed. A bottom up, meaning making system is one that tends to be fluid, facilitative toward the individual's communicative efforts, and sense making processes. I take my lead from Alpern (2013) when referring to a meaning-making approach, described as: '*methods of support and treatment that engage with the content of the individual's de-centering or psychotic experiences*' (p10).

### ***Introducing parts A and B***

In part A of this chapter I identify a paradigm that, through historical events and consequential systems or approaches to meaning making, has created a meta/grand narrative dominating public discourse on psychotic experiences. The meta/grand narrative, I argue, is driven by a top down meaning making system that judges psychotic experiences in terms of personal failings generating meaning-making approaches where correction or cure is required. I refrain from being overly critical at the early stage of Part A, being descriptive, summarising historical context that has provided conditions where the interpretative authority of the meta/grand narrative has emerged and taken hold. Understanding conditions that have 'facilitated' the emergence and continuance of the meta/grand narrative will enable measured critique involving the constructive scepticism described above. This helps introduce variances that exist in understanding and engaging psychotic experiences. I end part A with a critique of the meta/grand narrative and a corroborative meaning making approach.

In part B I describe meaning making systems and approaches that tend to sit outside the paradigm as constructed by the meta/grand narrative. These I present as being less restrictive and less likely to be attached to personal failings or individual deficits as represented by the meta/grand narrative. I contend that these ‘ulterior’, ‘alternative’ or counter meaning making systems and approaches are more liberal and potentially more attractive to individuals living with psychotic experiences beyond/outside statutory mental health services.

## ***A 2.1 The emergence of psychosis***

The meanings we attach to words are important in defining our social environment with the application of language contingent upon historical and social contexts (Burr, 2001). To put it another way, words may serve particular purposes at particular historical and social junctures. From this perspective, inconsistency in definitions and application of psychosis as a categorisation of human experience should come as no surprise. Smith (1998) notes: •

*“The term psychotic has historically received a number of different definitions, none of which has achieved universal acceptance”.* (p895)

And:

In tracing some of the developments involved in the evolution of the concept Burgy (2008) concludes that: *“The consideration of the concept of psychosis is a conflict charged domain of dichotomies”* (p1208).

What follows is an exploration of the emergence of psychosis as a concept with various ontological consequences. Each source of knowledge explored here makes

use of corresponding reference points in framing psychotic experiences. For example, to varying degrees, much of psychology and psychiatry frame psychosis within biological, neurological and sociological parameters (Morgan, McKenzie and Fearon, 2008). However, it is the dominant discourse within each parameter that I will focus on and try and define. Discourse in these terms is taken from the use of language inherent within each source; that is:

*“language identified by the social conditions of its use, by who is using it and under what conditions.”* (Henry and Tator, 2002, p2).

Key influences that have shaped our understanding of psychotic experiences will be identified including some defining periods and key philosophical concepts that have led up to a particular framing of psychosis. It is psychosis as a concept that the author is primarily interested in, including the social structures that have shaped our response to psychotic experiences and/or PLEs. The analysis will focus on periods leading up to modernity through to current times. •

At this juncture, it must be noted that it is beyond this study to carry out a detailed account of changes that have taken place in conceptualising psychosis over time. Presented is a summary of selective readings in order to illustrate variations in relation to current understandings of psychosis evident within discourse as appears in the written word from a number of sources described above. Efforts will concentrate on sketching out the history of ideas, a method of enquiry corroborating the *“motivation and the meanings of words ... social context”* and; *“the complex ways that the persons and ideas of the past have influenced the present”* (Hamillton, 1993, p47).

Historical and social forces that have shaped current framing of psychotic experiences, with particular emphasis on ideologies that have had significant impact within ‘modernised’ societies<sup>2</sup> such as Ireland, the site of this study will be considered. Given the diverse positioning and constant flux inherent within discourse it may be possible that a number of available resources with regard to the framing of psychosis and PLEs will escape the attention of the author.

Some sources may be taken as dominant narratives (also known as grand or meta narratives) ie; those that have greatest influence on how we speak about a given subject (Gutting, 2005). Some will be presented as counter narratives, potentially more meaningful and more attractive to people experiencing psychotic experiences who, for reasons explored, do not engage traditional health systems supposedly designed to provide support and care for this ‘sub-population’ in Western societies.

## ***A 2.2 What do we mean by psychosis?***

Some scholars have traced descriptions of experiences and behaviours that they believe provide evidence of mental illness (from which psychosis is inferred) beyond the time of the Greeks (see for example, Porter 2002). However, we can-not say for sure if these descriptions are comparable to psychosis as it was first introduced or indeed, how these early descriptions might have influenced our current understanding. That said; we can be relatively confident in tracing the introduction of psychosis in modern times which marks distinctions between particular abnormal from normal behaviours and experiences.

Experiences and behaviours associated with psychosis may be interpreted in different ways in accordance with social and cultural environments (Jenkins and Barrett, 2004). However, when considering the development of psychosis as a concept, its usage stems from Westernised systems of rationalisation (see 2.3 below). It is therefore difficult to describe psychosis without acknowledging this historical context and therefore warranted that I begin with this framework in mind. Saravanan et al (2004) are mindful of the level of influence Westernised systems of rationalisation has had on conceptualizations of psychosis: “*Globalisation and colonisation in various guises introduce new social effects and spread biomedical systems of thought, including causal explanations*” (p109). It is the search for casual explanations within certain social demarcations that has had major influence on our usage of the term psychosis.

The word psychosis derives from the Greek roughly translating into: abnormal condition of the mind. Karl Friedrich Canstatt has been credited with introducing the word into psychiatric literature in 1841 (Burgy, 2008.) It was first used in 1845 by Ernst von Feuchtersleben to differentiate disorders of the mind from what was understood to be disorders of the nervous system – neurosis (Berrios, 1991; Beer, 1995). Since the introduction of psychosis in depicting a dysfunctional mind, debates have taken place whether it indicates a unitary disease or a variety of diseases or syndromes (Berrios and Beer, 1994; Goel, 2007).

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<sup>2</sup> Here I refer to Giddens (1991) while making use of the term Modernised cultures. Fundamental to his description of modernisation is of societies that have gone through industrialisation/urbanisation including a process of rationalisation involving an expansion of scientific and technological influences often leading to an individualised society that values choice over and above unconditional conviction to ‘traditional’ structures such as religion, family and gender.

Classic descriptions of psychosis include: hallucinations, delusions, disordered thinking and impaired insight (Jaspers, 1997).

Psychosis is often distinguished in terms of positive and negative symptoms (Andreasen and Black, 2006). Negative symptoms include emotional and cognitive deficits eg; blunted emotion and affect, low motivation, poverty of speech and inability or lack of willingness to form relationships. Negative symptoms are likely to be detrimental to quality of life and social functioning (Dikeos et al, 2006), shown to have significant impact on social relations including those engaged in care giving for individuals with clinically defined psychotic illness (Velligan and Alphas, 2008). Positive symptoms involve false perceptions including hallucinations, delusions and thought disorder (inability to think rationally and clearly). In summary, negative symptoms involve experiences that are lacking in individuals yet expected to be present in 'normal' populations (motivation, expressed emotion, willingness to socially engage etc). Positive symptoms include the presence of experiences that tend not to be present in 'normal' populations. Both can impact negatively on the individual's ability to communicate and negotiate the social world (Fusar-Poli et al, 2009).

Hallucinations are typically described as sensory perceptions that occur in the absence of external stimuli and can impact all five senses (Laroi et al, 2014; National Institute of Mental Health, 2014). The most common hallucinations experienced are: auditory, visual, olfactory and tactile. Delusions are strongly held beliefs, even though there is evidence to the contrary. This does not include beliefs that are constructed due to false or incomplete evidence. The two main categorisations of delusions are grandiose and persecutory. Although hallucinations and delusions are described

above in terms of psychopathology they are known to exist in non-clinical populations (see for example Nuevo, 2012) and subject to social variables such as culture as to their acceptability and variance of prevalence (Laroi, 2014). Within the realm of psychopathology, hallucinations and delusions are associated with non-consensual realities at odds with socio-cultural norms where the individual resides (American Psychiatric Association, 2013). They can also co-occur (Zanghellini Rückl et al, 2011). For example, some people experience verbal hallucinations and believe that it is evidence of demonic possession or the voice of God (false claims.) Thought disorder includes disconnected and incomprehensible speech, flight of ideas and thought stopping (Barrera and Berrios, 2009). According to psychopathology the psychotic individual is believed to lack self-awareness (also called insight) of how their experiences and behaviours might impact on functioning and is at odds with the social environment (McCormack et al, 2013).

Distinctions are also made between functional psychosis and organic psychosis. The former relating to categorisations of mental illnesses (of which a definitive physical cause is yet to be established - Bentall, 2003; Joseph, 2010,;Whitaker, 2010), the latter structural defects caused by physiological dysfunction of the brain (for example psychotic experiences that occur among dementia populations). To summarise, psychosis as traditionally defined has been subject to Westernised systems of conceptualisation tending to frame it within pathology marking psychotic experiences against 'normal' experiences (and behaviours). This was made possible due to certain philosophical and historical transformations. •

### ***A 2.3 The rise of positivism and the segregation of psychotic experiences***

Positivism was borne out of the Enlightenment, a period in Western history when it was asserted that the legitimate use of reason would free the individual and secure their autonomy (Bracken and Thomas, 2001). The Enlightenment provided opportunities for reason and logic to flourish, a time when positivism, as a particular belief system developed. Positivism rests on the assumption that objectivity and scientific inquiry are the most reliable methods at our disposal in accessing and establishing facts about the world. Foucault (1965) associates the Enlightenment with the rise of the clinician. He points out that even though psychiatry lacked any theoretical framework from which to work from, it was accepted as a medical profession developing its own classification systems.

One of the defining moments in the history of psychiatry, in its endeavours to categorise human experiences and behaviours, was the introduction of Dementia Praecox as a mental illness. In 1902 Kraepelin arrived at this diagnostic construct by dividing what he observed to be severe mental illnesses with good prognosis (manic depression) and those with poor prognosis (dementia praecox; (Angst, 2002; Jablensky, 2007). Kraepelin believed psychiatric illnesses to be caused by biological and genetic defects, a conviction that would later underpin the psychiatric position (Noll, 2013).

Psychotic behaviours and experiences were most evident in manic depression and dementia praecox, with the latter believed to be more severe and degenerative. Bleuler later renamed dementia praecox, Schizophrenia (literally meaning splitting of the mind) leading to the development of sub-categories such as hebephrenic,

catatonic, paranoid schizophrenia (Boyle, 2002.) Bracken and Thomas (2005) note that, since Kraepelin, psychiatry attached itself to a classification system with phenomenology at its core. This set a trajectory for psychiatry to privilege symptoms and pathology over and above the effects of interpersonal experiences of the ‘patient’ (Evans, 1996). There is no singular approach or definition of phenomenology and it is beyond the scope of this study to explore the various positions. However, it warrants a brief description in the context of leading models of psychosis.

Broadly speaking phenomenology is the study of the quality or nature of subjective experience, the study of consciousness as experienced through the first person (Moran, 2000). From a psychiatric position phenomenology is employed to describe mental life. Bracken and Thomas (2005) note that Jaspers, a significant figure in the history of psychiatry, advocated a form of phenomenology that isolated the internal mental experience from context and body. In order to examine mental events in their purist form, it was necessary to separate them from social influences. The objectification of the subjective experience, the segregation of mental events where the subjective becomes the object – the ‘other’ - was established (eg; constructions of mental illness; Berrios, 1999). This translated into representational models of the mind that traverse across much of psychology and psychiatry today and includes major theories associated with linguistics and cognitivism where language has tended to become an internalised individual phenomenon (Bracken and Thomas, 2005). The history of psychiatric and psychology disciplines is tainted with erstwhile challenges to the separation of mental events from context - for example the histories of social psychiatry (Uchtenhagen, 2008) and the behaviourist movement within psychology

(Bargh and Ferguson, 2000) - as a principle framework from which human experiences and behaviours could be understood.

That said, there are some significant figures within the field of psychiatry who have influenced, via phenomenology, the focus of concern for the psychotic person. For instance, Parnas and Henriksen (2014) advocate the subjective, first person perspective using psychometrics and self-reporting as ways to apprehend and understand the psychotic experience. This shifts the focus of interest from one that imposes an exclusive 'outside-in', objectively charged interpretation, to an 'inside-out' perspective (centred on personal experience, self-perception and personal reporting). Laing (1967, discussed at the end of this section) expanded the phenomenological domain to include the impact of the social environment as a pretext to developing psychosis and, for some individuals, its persistence. Here, Laing presents that psychosis is a strategy in response to interpersonal challenges, and a reasonable attempt at repair. In turn, a phenomenological approach should help apprehend the psychotic experience from the first-person perspective building empathy, understanding psychosis as part of the human condition (Englander, 2018). However, even though these approaches to understanding psychosis have been put forward by significant figures in the history of psychiatry, its methodologies and systems of meaning making has continued to be governed by a phenomenology that imposes an outside-in, objectification of the psychotic experience (Read, Bentall and Fosse, 2015). This in turn dominates social discourse that leads to public distance and suspicion of the psychiatrically identified person (Farrelly<sup>a</sup>, 2015; Casstevens, 2010; Ohlsson, 2018).

Consequences of an internalised view of mental life is that emotional and psychological problems can only be addressed at the individual level by one of two means – through the encouragement of self-control or by being controlled (Rose, 1999). This is significant for individuals who are labelled psychotic. Various brain imaging techniques associate psychosis with a biological vulnerability to cognitive deficits impacting on social functioning (Bellani and Brambilla, 2008). The individual is a victim of internally generated events, unable to resist the provocation of spontaneous psychotic experiences such as command hallucinations (Leudar and Thomas, 2002). This marks the psychotic individual as someone not to be trusted, to be monitored and governed by a supervisory social system (Moncrieff, 2010). Personal accounts are scrutinised and subject to social discourses informed by objectively charged notions that can devalue and invalidate individual accounts leading to social inequality (Cromby and Harper, 2009).

Other disciplines such as anthropology and sociology have raised concerns and presented challenges to this model of personhood. However, such challenges tend to sit at the periphery of social and politic discourses. Haslam (2000) argues that essentialist ideology is involved in the notion of mental illness as a biological and genetic entity engaging abstract and conceptual thinking. He illustrates how this has had a significant impact on lay people's perceptions of psychotic experiences:

*“in principle these essences are scientifically describable, presumably genetic or atomic microstructures of some sort, so that a division of labor exists in which laypeople, who do not know the relevant essences, should grant scientists the last word in determining what qualifies as an instance of a kind. ... because natural kinds*

*share deep similarities, "carving nature at the joints," they are particularly rich sources of inferences, having considerable "inductive potential."*

(Haslam, 2000; p1038)

In accordance with Haslam's remark, public perception of psychotic experiences are heavily influenced by the power and authority of scientific discourse, socially accepted, directly impacting how 'we' tend to talk about psychosis or psychotic experiences. This allows those who claim specialist (scientific) knowledge of psychosis privilege and dominance over the experience eclipsing self-knowledge or/and self-experience. This is of interest to this study as the power and authority bequeathed to science and its proponents may present at interview as repertoires of resistance to, of compliance with or appear as ambiguous, inconsistent or/and contradictory accounts toward scientific loaded discourse on psychotic experiences. Gelman (2003) explains how cognitive psychology is also essentialist in nature. For instance, psychotic symptoms are believed to be the result of a breakdown of typical mental processing (the essential essence signified here would be the mind/brain, an entity closed off from social life). Focusing on the functions of the individual mind and internalised dysfunctions diverts cognitivism away from the importance of socially constructed realities:

*"Cognition is as much to do with relational things as with what is whizzing around in private... You can only think because of your place in networks of relationships with other people and because of patterns of discourse that give shape to your image of the world and of yourself"*

(Parker and Burman, 2008, p109)

Psychosis and psychotic experiences have been subjected to the phenomenological and positivistic approaches as described above. These are the dominant forces that have shaped the current discourses on psychosis and psychotic experiences in Western society. Referring to Sakalys (2000), in the context of a literature review of 'The Meaning of Madness', Casey and Long (2003) note that within healthcare *"metanarratives or grand narratives"* act as *"socially sanctioned ways of interpreting experiences in order to achieve uniformity and social order"* (p92). This is in turn linked with an explanation of psychosis pertaining to illness which *"constructs what society can expect to be normal behaviour"* (Crowe 2000, p.584). As this study is conducted in a Westernised society, Ireland, it is these dominant forces surrounding psychosis that I begin to describe.

## ***A 2.4 Dominant contemporary discourse***

As psychosis (and by association PLEs) has become a health concern, they cannot be detached from the political and social phenomena that have been created by psychiatric (Szasz, 2008) and psychological (Smail, 2005) discourses. Within literature and Western Culture, psychotic experiences are principally defined as a sign of illness or cognitive malfunction; the health expert has therefore set the 'benchmark' from which associated experiences are compared and described at the individual and societal level (Szasz, 1970; Rose 1998). Rose (1998) refers to the 'psy' models that influence modern cultures, shaped by science or/and psychotherapeutic theories of human thought and/or behaviours. Disciplines wedded to the psy models ('Psy disciplines'); in particular psychology, psychiatry and to an extent psychotherapy become primary sources that have shaped various institutions, how we understand and intercept ourselves in modern times. This inevitably

influences our identity, response to and interaction with psychotic experiences. Below are descriptions of psychosis from a medical and cognitive perspective, generally taken as ‘meta’ or ‘grand narratives’ (referred as meta/grand-narratives hereafter).

### ***A 2.5 Psychosis as sign of illness***

Psychiatric assessments are designed to identify signs and symptoms of mental disorders. They are based on an overarching theory that certain behaviours and experiences are indicative of underlying pathology. There are two main classifications systems that are applied in psychiatric settings, that can also be used for research purposes such as comparative epidemiological studies between Western ‘developed’ countries and ‘non-Western’ developing countries.

The Diagnostic and Statistical Manual of Mental Disorders (DSM) was first published in 1952 by the American Psychiatric Association. It evolved from an accumulation of psychiatric hospital statistics combined with a manual developed by the United States Army. The International Statistic Classification of Diseases and Related Health Problems (ICD) is produced by the World Health Organisation (see WHO, 1992).

There have been stringent attempts to correspond the coding systems of the DSM and ICD. However, because both systems have been revised at different times this has not been possible (Dalal and Sivakumar, 2009). Dalal and Sivakumar (2009) observe conflicts between DSM and ICD with regards to the practical interpretation of mental illnesses and failures inherent within both in making distinctions between related syndromes, symptoms and normality:

*‘But, the existence of two parallel nomenclatures and sets of definitions does help to emphasize that most of psychiatry’s illness concepts are still provisional and that their definitions are arbitrary.’ (p316)*

The shift in conceptualisation of mental disorders between DSM-I, DSM-II and subsequent versions of DSM provide further evidence of significant changes in interpreting their casual nature and presentation. DSM-I and DSM-II maintained a psychodynamic framework. Mental disorders were a consequence of relational problems such as past family conflicts and traumatic life events. The DSM III and DSM IV indicated a shift in emphasis from a psychodynamic interpretation to mental disorders (in particular psychotic experiences) to one that was decidedly biological and genetically centric (Read et al, 2004). Brief flirtations with an environmental understanding of mental disorders (for instance the bio-psycho-social model) tended to be short lived signifying an enduring desire for systems of classification and categorisation that would justify psychiatry as a medical profession (Pilgrim, 2002; Blazer, 2005).

A shift of emphasis from nurture to nature indicated a desire to develop a stringent scientific framework from which to understand biological and genetic factors involved in mental illnesses<sup>3</sup>.

Among the mental disorders listed in DSM-5, where psychotic experiences appear (eg; personality disorder, post-traumatic stress disorder, bi-polar disorder, depressive disorders) Schizophrenia receives the most attention. Influential online sources and media representations of Schizophrenia are available describing it as a “*chronic, severe, and disabling brain disorder*” (National Institute of Mental Health, 2014) and

by some from within psychiatry as the “*most disabling mental illness*” (The Hindu, 2013).

According to the DSM-5 Schizophrenia belongs to a functional class of psychosis whereby illness and brain disease is inferred (Ahveninen et al, 2006; Gottesman and Gould, 2003)

(Note: I use the word inferred here as according to a number of commentators eg; Belzeaux, (2011) and Kendler, (2005) there remains deficient knowledge of specific aetiology, cause(s) to psychotic experiences and behaviours.) The criteria to receive a diagnoses of schizophrenia has been altered since the introduction of DSM-5. Its predecessor, DSMIV stated that a diagnoses of schizophrenia could be given if one psychotic symptom was present for six months, during which at least one positive symptom is persistent over a given month.

These include the following:

1. delusions 2.hallucinations 3. disorganized speech (e.g., frequent derailment or incoherence) 4. disorganized or catatonic behaviour (occurrence of significant immobility and stupor) 5. negative symptoms, i.e., flattened affect, avolition (severe lack of motivation) and alogia (inability or poverty of speech).

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<sup>3</sup> Note: the construction of the newly published DSM-5 (American Psychiatric Association, published May 2013) has been subject to various criticisms, in particular the potential for over drugging and over diagnosing mental illnesses prescribed by a system that emphasises ‘user acceptability over validity’ (Balt, 2011).

DSM-5 insists that an individual exhibit at least two of three positive symptoms ie; hallucinations, delusions, disorganised speech. Subtypes of schizophrenia (eg; catatonia, paranoia), whereby psychotic symptoms irregularly appear making a full diagnoses difficult, has been removed from DSM-5. Clinical experience highlighted a tendency of symptoms to shift over time resulting in a change in diagnoses and the occurrence of overlapping of subtypes. According to DSM-5 subtypes are indicative of ‘specifiers’ to schizophrenia. ‘Attenuated psychosis syndrome’ or ‘psychosis risk syndrome’ appear in Section III of the DSM-5. These are described in terms of moderate or mild versions of symptoms of psychosis yet underline a group at risk of developing psychotic disorder. As a result anyone with psychotic experiences (including those with PLEs) can be subject to the ‘clinical gaze’ whereby medical experts are presumed to be able to detect an ‘underlying reality’ and/or ‘hidden truth’ associating certain experiences (in this case psychotic) with illness (Shawver, 1998). Surveillance techniques to identify at risk groups can be developed (Walsh et al., 2008) and necessity for early intervention justified (Tsuang et al., 2013). People living with psychotic experiences (PLEs), remote from the clinical gaze, may become conscious of the prospective ‘intrusion’ to personal autonomy, identity and way of life and resist or avoid its clutches by making behavioural and/or linguistic adjustments eg; create alternative stories involving their psychotic experiences or/and ‘learn’ to be discreet with whom such experiences are shared.

Furthermore, the process of validating mental illnesses, assuming biological and genetic links to psychosis, underplays social consequences of such a system. The tendency to medicalise mood and behaviour has been observed to lead to stigmatisation, create negative outcomes and lead to the creation of social distance from the general public

(Martin, Pescosolido, and Tuch, 2000). In particular toward those diagnosed with a psychotic disorder:

*“The sense of separation between ‘us’ and ‘them’ could be increased by pointing out a genetic, unchangeable aetiology and the hope for recovery could be reduced”*

(Rusch, Angermeyer and Corrigan, 2005, p233).

Kvaale, Gottdiener, and Haslam (2013) and Lee et al (2014) note that social distance from the general public can be exacerbated in accordance with assumed levels of genetic influence on psychiatric diagnoses. Those with a diagnoses of psychotic illness, in particular schizophrenia, are more likely to be judged dangerous than those diagnosed with an affective (mood) disorder, resulting in significantly greater levels of social isolation for the former.

## **A 2.6 Beyond psychotic disorders .**

Medical conditions such as Alzheimer’s Disease (DeMichele-Sweet and Sweet, 2010) and Parkinson’s Disease (Rabey, 2009) can include psychotic symptoms. The influence of disease and psychoactive drugs are excluded before a psychiatric disorder can be diagnosed (Oliver, 2012). Alcohol abuse can also cause psychotic symptoms (Pera“ la” et al., 2010). Oliver (2012) places the above into a secondary category of psychosis with primary categories including schizophrenia and bipolar disorders belonging to a ‘psycho-pathological’ pathway. Although hallucinations and delusions regularly appear in other psychiatric disorders eg; bipolar disorder (Potash, 2001; Pavuluri et al., 2004); major depression and anxiety disorders (Varghese et al., 2011); they are most commonly attached to a primary diagnosis of psychosis as described above. It is difficult to attain accurate records of the level of psychosis identified

within psychiatric populations, partly because of the crossover between and within diagnoses, partly because of changes in diagnoses that individuals with psychiatric histories undergo and partly because of their instability in presentation (Gelder et al, 2005). However, in the general population McGrath et al (2008) in an analysis of systematic reviews on incidence rates, mortality and prevalence of schizophrenia conclude the median incidence of schizophrenia to be 15.2/100,000 population. Perala et al (2007) found the life-time prevalence of psychotic and bipolar disorders to exceed 3% in the general population. Delusions and hallucinations ascribed to psychosis and mental illness within DSMV and ICD10 try to take into account cultural influences on both.

Even though there are obvious schisms within the meaning making system that governs the meta/grand narratives, it continues to be systemically warranted and publicly accepted. The public associate the psychotic experience with risk to health and safety, where social conditions allow coercive practices that threaten liberty and autonomy of the psychotic person to persist. To put it another way, imposing meaning on to the psychotic experience that illness, biological impulses, brain lesion or faulty brain functioning is at work allows practices of control to persist: 'Doing unto' as opposed to 'Doing with' (Walsh et al, 2008). Before shifting the focus of the psychotic experience beyond psychiatric populations I introduce meaning making systems and approaches steeped in positivism, fixed to the meta/grand narrative of psychosis. I argue that these are allied to the illness (deficit) model, corroborate with the meaning making system and subsequent approaches that is psychiatry, with specific consequences for anyone living with psychotic experiences potentially leading to acts of resistance and avoidance.

## ***A 2.7 Psychological and Cognitive model of Psychosis***

As with the identification of mental illness within the psychiatric paradigm, psychological assessments are designed to objectively evaluate an individual's sense of reality (Leudar and Thomas, 2000) - whereby an individual's internal world (primarily made up of feelings, thoughts and perceptions) is matched against the external world: *"a set of perceptual, cognitive and sensorimotor acts that enables one to determine one's relationship with the external physical and social environments"* (Reber, 1995, p640). Reality testing is therefore employed to ascertain primary psychological and emotional faults which are indicative of underlying cognitive dysfunction (Bentall, 2003). A break in normal cognitive schema is used to situate a person experiencing psychotic experiences within a cognitive framework (Birchwood et al., 2004) utilising for example psychometric measures (Fowler et al., 2006). As an example, Bentall et al (1991) assert that 'hallucinators' have difficulty in applying cognitive effort in determining internally generated from environmentally generated stimuli. The authors conclude that among a group of psychiatric patients diagnosed with psychotic illness hallucinations are self-generated and misattributed. Faulty appraisal has also been underscored by So et al (2012) who found that among seventy-three individuals experiencing clinically defined psychosis two models of reasoning biases are involved in the creation and persistence of delusions (Jumping to Conclusions and Belief Inflexibility). The ability for these individuals to question their belief processes or reconsider their explanations of events was minimal.

Frith (1995) proposed a psychological framework based on social cognition to explain symptoms of schizophrenia. Parrot and Madoc-Jones (2009) describe social cognition in terms of systems of encoding, storage, retrieval, and processing of data

that take place in the brain. From Frith's perspective, psychotic experiences inhibit the individual's ability to deploy empathy toward the mental state of another or speculate reflexively what the individual might be communicating – a process he called (defective) meta-representations. As McCabe et al (2005) would have it:

*'the primary representation becomes detached from the patient's knowledge about it so that, for example, other's intentions are no longer interpreted in the context of one's knowledge about them but in isolation from it'* (p1443).

In other words, the delusional and hallucinatory system is somewhat closed, cutting the individual off from 'normal' social exchange. Customary human response to interactions with others is lacking as the ability to apprehend the intentions of others through the complex contrasting between one's own mind and another's is beyond the individual experiencing psychosis. The inability to accomplish reasonable conclusions and appreciate another's view of the world in relation to personal beliefs (primarily due to delusional and hallucinatory dispositions) leads to social dysfunction, a classic consequence of psychosis.

Bentall (2003) and Boyle (2002) promote cognitive models of psychosis and strongly oppose the diagnostic criteria asserted within the biomedical model of psychotic illness. They are quick to point out that there is no conclusive evidence of a direct causative link between biological/genetic faults and psychosis. Conversely, Garety et al (2007) in a review of cognitive models of psychosis propose that a biological element be incorporated. This includes the influence of genes and the role of neurobiology eg; brain dysfunction influencing 'dopamine dysregulation' resulting in improper deployment of attention leading to cognitive biases. The authors propose an

*“interactive causal model”* factoring genes/biology; environment and cognition/emotion. Garety et al (2007) acknowledge that a negative view of self, based on personal belief of being weak, vulnerable and inadequate is at play in the development and persistence of psychotic experiences (see also Taylor et al., 2014). However, there appears little consideration of the creation and maintenance of this negative view of ‘self’ beyond the emotional and psychological impact of historical social adversity (including care giver’s negative response) experienced by a significant number of those with psychotic experiences. While attempts appear to be directed at reversing the processes that lead to problematic psychotic experiences, the cognitive model of psychosis, by emphasising faulty mental processes and highlighting environmental and biological/genetic linkages, makes distinctions between normal (healthy) and abnormal (unhealthy - psychotic) populations. The civic power of discourse that underlines social and behavioural deficits among a distinct group of people cannot be underestimated. As with the illness (biological) model, social meaning in relation to discourse that promotes acceptance, equality, normalisation and social justice is wanting (Friedli and Stearn, 2015).

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In a review of Richard Bentall’s cognitive model on psychosis and hallucinations Marius Romme, a social psychiatrist involved in a social movement seeking to normalise psychotic experiences responded: *“I really like your research on hallucinations, Richard. But the trouble is, you want to cure hallucinators, whereas I want to liberate them. I think they are like homosexuals in the 1950s -- in need of liberation, not cure.”* (Bentall, 2003, p.511). The ‘correctional’ usage of cognitive theory referred to by Romme is illustrated in its therapeutic application. In some cases the cognitive approach to therapy has been developed to

supplement/compliment biological interventions in those diagnosed with schizophrenia. Cognitive behaviour therapy in combination with low dose cognitively enhancing psychiatric medications has been shown to improve symptom management and achieve symptom reduction (Rathod and Turkington, 2004; Turkington et al., 2006). Emphasis is placed on reducing relapse and achieving adherence to treatment with reality testing engaged. Others included in the individual's social circle (eg; family members) are encouraged to support this model of care. Not to dispute the success of the combined intervention, but in focusing on symptom reduction and management; reducing incidences of relapse while engaging reality testing and striving for treatment adherence the combined approach described could be construed as socially inhibitive. Any meaning attached remains within the realms of a misattribution of experiences, cognitive biases, genetic and biological dispositions. The interventions and theoretical frameworks described in this section deduce that psychotic experiences are characteristic of faulty schemas requiring modification through chemical or/and cognitive interventions with limited reference to context.

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Bracken and Thomas (2005) believe the level of reductionism involved in traditional illness and cognitive models to be unethical: "*It is just as wrong to say that someone is mistaken to believe in what they think is true about themselves, as it is to say there is no meaning in what they say*" (p, 162). Kramer, Rajah, and Sung (2013) go further and illustrate how cognitive treatment can be employed to incapacitate social groups who are "*perceived to embody risks to society*" (p537). They demonstrate how a cognitive treatment model developed to rehabilitate young offenders can be implemented to preserve economic inequalities through the promotion of Neoliberal ideologies. 'Correctional officers' were trained to convince young offenders of the

merit of remaining compliant to prison service policies as a means to achieving stability through employment, when in reality employment opportunities for young offenders are rarely offered or achieved. The individual with a ‘faulty’ world view is encouraged to accept and adapt to a particular notion of the social environment. In the case of Cognitive models of psychosis, a correctional basis for treatment has been evidenced. This has shifted emphasis from diagnoses to symptoms (specific experiences). Parker et al (1997) in considering this new emphasis warn of its consequences noting that an “*alternative schizophrenia research programme*” by focusing on “*symptoms (such as hearing voices), rather than gross diagnose ... are now the subject and symptom of a new pathology*” (Parker et al., 1997, p123)

The authors assert that shifting from diagnoses to symptoms impacts on stigma and social exclusion as the individual ‘experiencer’ remains subject to discourses that underline individual deficits emphasising the social undesirability of psychotic experiences. Those with PLEs who prefer to look beyond statutory mental health systems for social support may not agree with a cognitive view of psychosis due to its ‘invalidatory’ leanings designed to expose personal deficiencies. Resistance to this model is perhaps understandable; however exposure to unconventional or marginal discourses would be required to avoid a ‘knowledge vacuum’. There is certainly evidence that exposure to an ‘alternative’ world view of psychosis enables people living with psychotic experiences to successfully side-step popularized institutional and conventional wisdom (Heriot-Maitland et al., 2011). In comparing two groups of people with psychotic experiences (clinical (C) and non-clinical (NC)) these authors found that “*prior conceptual knowledge*” (usually supernatural) and “*open attitudes*” helped NC participants integrate their experiences enabling an optimistic outlook and avoidance of psychiatric services. These unconventional discourses may be more

positive, accepting and even celebratory of psychotic experiences and therefore potentially more attractive. For instance, some people find relief and contentment in framing their psychotic experiences within a non-material spiritualistic realm (Jackson and Fulford, 1997), some believing their psychotic experiences lead to ‘gifts’ providing insight into a world beyond normal human consciousness (McCarthy-Jones et al., 2013).

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Further to this, a number of cognitive models have been hypothesised lending support to the continuum hypothesis above (chapter 1) and below (part B); associating psychosis with adversity and trauma, linking persistent negative emotional processes with the development and continuation of psychotic experiences (Garety et al., 2007). The cognitive model of psychosis has therefore been expanded to include the possibility of linking environmental and social causations to psychotic experiences taking into consideration the emotional impact on the likelihood of psychotic experiences to appear and endure. Garety et al (2007) believe that this will lead to: “*A better understanding of the relationship of social adversity and trauma with psychosis, and the mediating role of emotional processes, schemas and information processing abnormalities*” (p1388) in order to improve therapeutic attempts to ameliorate said processes. However, mention of ‘information processing abnormalities’ may indicate a persistent focusing on symptom reduction and encourage a continuing dichotomy between ‘normal’ and ‘abnormal’ human experiences that some people with PLEs oppose, resist and try to avoid.

Laing (1964) believed that a transcendental process whereby existential meaning could be derived from psychotic experiences, leading to renewal and liberation for the

psychotic person – a ‘break down to break through’. The psychotic experience is essentially meaningful and needs to be engaged, not challenged and labelled as reality alien from naturally adaptive human occurrences as prescribed by the biological and cognitive models described above. Liberation for the individual is achieved primarily through therapeutic means whereby psychotic experiences are understood as: “*a special strategy that a person invents in order to live in an unliveable situation*” (Laing, 1967, p95). For Laing and others like him, psychosis is a product of unbearable social life that finds expression through symbolic speech and behaviours. Psychotherapy, and in particular psychodynamic therapy has evolved to engage this symbolism creating its own approaches and language that is impacted on and by social discourses (Carruthers, 2009)

## **2.8 Psychosis, Psychotherapeutics and Psychodynamics**

Here I refer to Psychotherapeutics as ‘talking therapies’ practiced within the fields of psychotherapy, psychology and counselling (Parker, 1998; Rose, 1999). This includes Cognitive Models of therapy as referred to above.

Psychotherapeutics have been developed to alleviate mental and emotional distress through the raising of self-awareness, self-reflection and appropriate change in behaviour by the ‘client’ facilitated by the therapist (Palmer, 2015). The application of psychotherapeutics involves reconstruction and ‘meaning making’ which has an obvious dependency on language, observed to be temporal (Avdi and Georgaca, 2007). It has been pointed out that psychotherapeutics, as with all human interventions, do not operate in a closed space but responds to and is impacted on by socio-cultural environments (Avdi and Georgaca, 2007; Carruthers, 2007). In other

words, psychotherapeutics does not operate in a vacuum; is influenced by the world beyond the constructed therapeutic space and language therein.

There is an ever-expanding range of approaches and techniques involved in the application of psychotherapeutics influenced by a number of overarching theoretical frameworks (Garfield, 2006; Engel, 2008)<sup>4</sup>. However, it is not the therapeutic orientation that is of real issue here, but the impact psychotherapeutics may have on discourse around psychosis.

Below, particular attention is paid to psychoanalyses and psychodynamics. Their impact on prevailing notions surrounding human nature has been substantial and enduring (Cluely and Desmond, 2015). The assumption that conflicts of consciousness are at the heart of psychological and emotional distress is consistent within both camps. Their compatibility is such that the two terms are interchangeable in the context of this section of the thesis. Their influence on psychotherapeutics (in particular alluded to in the introductory lines of this section) is that psychoanalysis is the originator of “*insight oriented therapy*” (Silver, 2001) - the rationale for most psychotherapeutic work.

Contrary to social constructionism, psychoanalytic and psychodynamic theorists tend to believe that there are core elements to being a person eg; the psyche, personality. Personality and Psyche are believed to be made up of core non-material structures and energies that motivate toward particular decisions and actions. The Psyche involves

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<sup>4</sup> (Richie, 1980 records over 250 approaches to psychotherapy; Garfield, 2006 notes over 800 approximately 25 years later)

‘psychic processes’ where conscious and unconscious conflicts arise; personality is described in terms of a relatively permanent yet fluid fixture belonging to the individual eg; a “*functional complex*” (Jung, 1971).

The goal of psychodynamic therapy is to help the client become aware of unconscious, psychic driven conflicts that lead to personal distress. It is unconscious conflicts that have the greatest impact on human behaviours, where traumatic, or other life experiences such as those involving problematic transitions during key stages of emotional and psychological development, are ‘enclosed’. Correspondingly, socially objectionable beliefs and desires can be hidden from view and can be addressed through a number of therapeutic techniques. The therapeutic objective is an increase in awareness and appropriate behavioural change for the client. The capacity for psychological and behavioural insight is a prerequisite for successful psychodynamic work.

Sigmund Freud, founder of psychoanalysis divided neurosis and psychosis, making distinctions as to the route to these potentially problematic conditions: “*in neurosis the ego suppresses part of the id out of allegiance to reality, whereas in psychosis it lets itself be carried away by the id and detached from a part of reality*” (as cited by Altamura et al., 2009, p490) <sup>5</sup>

Therefore, individuals experiencing psychosis have difficulty with emotional and behavioural regulation becoming somewhat uninhibited by social convention.

Freud consequently believed that an element of control and self-awareness is available to people with neurotic problems (for example phobias and psychosomatic complaints) through an attachment with reality; with limited control and self-

awareness (due to a disconnect with reality), available to individuals experiencing psychosis.

He also believed that psychotic symptoms such as delusions were akin to dream states when a “*time sense*” was lacking (Kumar, Soren and Chaudhury, 2009). Freud held that interpretation of dreams could reveal unconscious conflicts that lead to emotional and psychological problems. During sleep, conscious efforts to suppress (or repress) noteworthy memories or hidden desires are diminished. The content of the dream is symbolic of a desire for something that is often socially inhibited. This leads to unconscious and preconscious tensions. Clients who are encouraged to remember dreams could begin to make associations between their content, underlying problematic psychological and emotional states. As the psychotic individual is regularly involved in a mental state akin to ‘sleep’ their ability to engage in this component of psychoanalytic work is greatly restricted.

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<sup>5</sup> Freud, described three main components of human personality – the id, ego and super-ego. The id represents inherent natural instincts and drives of our being such as desires and impulses that motivate us toward personal gratification and pleasure. Unlike the id which operates at an unconscious level, the ego adheres to the ‘reality principle’ acting as a social barometer as to how and under what conditions the id may be discharged. Finally, the Super-Ego is involved in maintaining a relation with the ‘outer world’ through the repression of the id in order to enable social acceptance. The super-ego develops during a stage in development where an awareness and requirement to social convention is compelled such as morals and values that are expected of the individual. The ego attempts to moderate the passions of the id and defines what is realistic in relation to moral expectations that inform the superego. The ego therefore separates what are socially acceptable and personally achievable (realistic) behaviours from natural drives.

Although Freud questioned the capacity for individuals suffering from psychosis to engage reality, he believed symptoms of psychosis had a potential healing function:

*“The delusional formation, which we take to be the pathological product, is in reality an attempt at recovery, a process of reconstruction.”* (Freud 1910, cited by

McGlashan, 2009, p478). The process of reconstruction described here has undergone further development within the field of psychodynamic theory. Lacan proposed that psychotic delusions and hallucinations are part of the development of a stabilization strategy. He puts forward the case that a break between the signifier and signified occurs during psychotic states ie; objects are misinterpreted, misrepresented, responded to inappropriately or never affirmed with the experience and knowledge of the ‘real’ becoming disjointed and distorted. From initial confusion and a struggle for meaningful language the psychotic person reattaches themselves to a form of social reality; eg; paranoid and/or delusional beliefs (Redmond, 2013).

Jung, like Freud also compared psychotic experiences to a dream state. Similar to Lacan and Freud he believed the psychotic experience had a compensatory effect, that of rebalancing that which has become intolerably unbalanced and that the psychotic experience is understandable, almost universal and not beyond the reach of rationalisation:

*“These forces did not originate in our patient out of nowhere. They are most emphatically not the result of poisoned brain cells, but are normal constituents of our unconscious psyche. They appeared in numberless dreams, in the same or a similar form, at a time of life when seemingly nothing was wrong. And they appear in dreams*

*of normal people who never get anywhere near a psychosis” (Jung, 1939, cited by Unger, 2012).*

*“More than once I have seen that even with such patients there remains in the background a personality which must be called normal. It stands looking on, so to speak...Through my work with patients I realized that paranoid ideas and hallucinations contain a gem of meaning” (Jung, 1995, cited by Unger, 2012).*

The therapist role within psychodynamics, is to observe then assist the interpretation of conscious/unconscious/preconscious declarations in order to resolve past/present experiences that have led to personal distress. This can place the therapist in a privileged position; that of an enabler to help the unravelling of problematic psychic experiences.

## **2.9 Psychotherapeutics on the couch**

An ambivalent relationship between society and psychotherapeutics exists. On the one hand society desires the therapeutic space extending beyond the usual social interactions where the client’s private and ‘true self’ is explored; protected by confidentiality involving trust and meaningful engagement with another human being. This is ‘marketed’ as a process that facilitates necessary and healthy readjustments for the individual client (Rose, 1999). The therapeutic encounter pledges ‘life-changing’ and life affirming outcomes (Carruthers, 2007; Harari, 2014). In contrast, public confidence and significant criticism of psychotherapeutics exists including public doubt on the benefits and limitations of psychotherapy (Furnham and Wardly, 1991; Furnham et al., 1992; Carruthers, 2007). Noted also is an often-unacknowledged esoteric characteristic to psychotherapeutic theories that maintains the

status quo of expert (professional) and non-expert (patient). The status quo is often preserved by language that is abstruse and cryptic, beyond the reaches of everyday descriptions of life events and experiences (Hallenstein, 1978). This can be illustrated by presenting commonly used vocabularies within the world of psychotherapeutics eg; Ego, Mirroring, Transference, Schemas. Each in turn have special meaning with regards to observations, responses and the nature of engagement taken up by the therapist. Their usage in psychotherapeutic terms can only be understood, become meaningful and influential during human encounters if one is in possession of specialist knowledge. Guilfoyle (2002) and Roy-Chowdhury (2003) through the study of discourse during psychotherapy sessions observe how therapists can influence client's framing of problems by encouraging an adaption of discourses within a particular psychotherapeutic framework. Gerhardt and Stinson (1995) describe this process in terms of: "*demand characteristics*"; *in that they structure the therapist's mode of intervention and thus, ultimately, how the therapeutic work is carried out.*" (p619) Some practitioners have gone as far as rejecting the fundamental basis of their psychotherapeutic training. Dylan Evans, an adherent of Lacanian Psychoanalytic descent for over a decade found his teachings to be full of "*internal contradictions*", "*bizarre rhetoric*" and "*obfuscatory language*", concluding: "*This obscurity [of most Lacanian writing] has been seen as deliberate attempt to ensure the Lacanian discourse remains the exclusive property of a small intellectual elite*" (2005, p142)

Society's ambivalent relationship with psychotherapeutics along with evidence of theoretical 'impermeability' points to 1. public misgivings and 2. a general inaccessibility of the discourses therein.

In response to concerns of elitism and intrusive practices, attempts have been made to remove the therapist as observer/commentator/interpreter in the guise of Narrative Therapy whereby the therapist becomes ‘witness’, facilitating alternative, positive, constructive and empowering stories, ultimately led by the client (Combs and Freedman, 2012). However, a problem persists for the therapist:

*“How does the counsellor tell the difference between her or his efforts to encourage empowering alternative stories and unexamined participation in oppressive discourse? How does re-storying work if it is not just taking up a different subject position in a different social discourse?”* (Blevins, 2009; p45)

Even within a psychotherapeutic interventionist model developed to liberate and deliberately avoid discourse contamination from the therapist the ‘entanglements of social discourses’ remains (Blevins, 2009). The therapist can only hold a certain level of consciousness on the influence of their socially informed discourse over another.

Critical misgivings aside as to the privileged position of the therapist during therapy, doubts have been expressed on the presence of psychotherapeutics within a meaning making structures dominated by the meta/grand narrative governed by a medical system of categorisation warranting coercive and socially alienating practices. The system is prohibitive, restricts access to psychotherapeutics to anyone in the throes of a psychotic episode, convenient to its hierarchical structures.

## **2.10 Psychotherapeutics and prohibitive factors**

Within institutional settings, psychotherapeutics have been noted for their exclusionary leanings away from psychosis; in particular psychotherapeutic

interventions are typically suspended whilst someone is in an acute psychotic state and only become available when the psychosis dissipates and the patient judged ready to engage (Lakeman, 2006). This typically follows a period of intense pharmacological treatment leading to compliance and recommendations whereby psychological and pharmacological interventions can be combined (Gabbard, 2007; Donker et al., 2013; Malmberg, Fenton and Rathbone, 2001). According to Silver, (2001) the lasting impact of this standard response is that: “*the patient is not worth talking to, is somehow preverbal or perhaps subhuman*” (p25). The Schizophrenia Commission (2012) go further noting that it is quite rare for someone diagnosed with psychotic illness to be offered ‘talking therapy’ at any stage of their psychosis. The exclusivity implied here is not necessarily the choice of the therapist. It is integral to a system that is governed by a hierarchical programme of care where causative models of psychosis are inextricably linked to biological faults, in turn dominating the nature of the response to someone in a psychotic state. It is no surprise then that there is a pervading doubt from within psychiatry of the merits and efficacy of psychotherapeutic practices, in particular those that propose to exclude pharmacological interventions in helping someone with psychosis. In this vein, as with cognitive therapy models discussed above, Gabbard, (2007) argues for psychotherapy to be brought in line with an interventionist model of mental illness that is attentive to the effects of psychotherapeutic practices on changes within the brain. Perhaps, as Parker et al (1997) note there are strategic and political drivers to any acceptance of psychotherapeutics into institutional settings:

*“The spread of para-medical institutions offering psychoanalyses or psychotherapy as a treatment alongside or as an alternative to drugs gives psychiatry a human face, and then directs attention to the importance of talking things through”. (p 12)*

To conclude, the above discussion on psychotherapeutics does not amount to an outright dismissal or rejection of its merits; nor is it motivated by a devaluing of its underlying principles and theoretical underpinnings. Indeed, it is acknowledged that there is a growing demand from people with psychosis to access psychotherapy (Garety, 2003; Schizophrenia Commission, 2012) and testaments that insight orientated therapy has been of great benefit to some people struggling with psychotic experiences. Pertaining to this Cantin (2009) below presents a patient’s discourse:

*“In psychoanalysis, one of the things that you do is to try to investigate all your memories and dreams – what is the color, what is the scenario, what repeats itself; and when one discovers what repeats itself; one realizes that it is certainly not reality that makes something repeat, it is our perception, it is or experience, it is not reality”*  
(p292)

What is highlighted is the number of impediments, within and without the psychotherapeutic domain, that thwart access to the language and concepts thereof. It is not that someone with psychosis might or might not find a branch of psychotherapeutics helpful or unhelpful, liberating or inhibitive in the course of making sense of and anchoring their experiences. The issue raised is their tendency to be, for the greater part, inaccessible and of course overshadowed by the meta/grand narrative associated with the medicalisation of psychosis.

As noted previously, psychotherapeutics is more likely to be embraced within traditional institutional care settings if they complement, confirm or become consumed within a biological framework eg; a cognitive-therapeutic model. The biological model of psychosis relies on its promotion of a one dimensional relatively simplistic model that tends to promote pessimism (Walsh et al., 2008), the necessity for pharmacological intervention, in turn justifying social control (Lüllmann, et al., 2011). This relegates social and psychotherapeutic perspectives of psychosis. The absorption of an elementary message that psychosis is underpinned by biological faults located within the individual is one that is accessible and readily digested by the public (Read et al., 2006). The challenge for psychotherapeutics in its attempt to influence discourse around psychosis is that of credibility and acceptance in a world that seeks stability and consistency. The biological model of mental health (of which psychosis belongs) satisfies the governance of public health which endorses standardisation of performance, measurements and outcomes (Wainwright, 2015). These target driven arrangements are themselves driven by fear of risk to the very fabric of society:

*“Therapy has been institutionalised as a legitimate and enduring cultural practice, integrated into networks of other institutionalised practices (eg. medical, mental health, child protection and legal systems). As therapy is supported and maintained by its participation in these and other networks, it may be considered an effect of power. But it is also itself productive of effects: of discourses, practices, subjects and further power relations that become part of the broader cultural network”.*

(Guilfoyle, 2005, p103)

The epistemological grounds of psychotherapeutics is therefore challenged by social demand for robust public health and safety systems. For reasons outlined their potential to liberate or empower the individual experiencing psychosis is limited due to institutional arrangements. Finally, there is a danger of psychotherapy, in declining the person in the throes of psychosis to be judged as another technology that is part of the ‘broken dialogue’ between the mad and the sane, the mentally ill and the psychologically well (Foucault, 2006). The acceptance or rejection of the suitability of psychotherapeutics for people experiencing a ‘psychotic break’ is as much a political battle as it is a conceptual one. At risk of contradiction, systemic therapy manifested within a system of ‘Open Dialogue’ has been developed to engage individuals in acute psychotic state. This approach appears to have promising consequences (Duff, 2013) and has to an extent been accepted within some concentrated areas of public health services. This has been referred to already and will reappear at the end of this chapter. In the meantime, interest in Social Causation of psychosis in the form of life adversity has been growing, specifically among those who claim that psychosis is a product of significant negative life events and social injustices and should be addressed appropriately at cultural and political levels.

### ***A 2.11 Beyond the meta/grand narrative***

The illness and/or medical and biological model as many refer to, has met with significant challenges. Szasz (1961; 1970) denies mental illness (and by association psychotic illnesses) exist. He argues that the term mental illness is a metaphor for ‘problems of living’. Individuals experiencing extreme human states such as psychosis are grappling with moral dilemmas in relation to their conduct and

apprehension of the world. Indeed Szasz (2004) believes hallucinations to be examples of self-deception and calls delusions “*lies*”, social strategies in order to deceive and mitigate social failure: “*I view hallucinations as disowned self-conversations and delusions as stubborn errors or lies.*” (p234). Psychiatric diagnoses rely on observation and illness cannot be presupposed from behaviour. Similar arguments have followed. A number of scholars, academics and health professionals point out that there is no irrefutable evidence that psychotic symptoms are comparable to medical conditions ie; illness or disorder (Boyle, 2002; Ingleby, 1981). There is no physical test to ascertain this and the history of medical treatments for psychotic disorders are at the least suspect, with deficient evidence for chemical or biological cures (Moncrieff, 2007).

The convincing nature of the assertion that psychotic experiences are indicative of illness stems from the rise of positivism and categorisation. As a scientific enterprise, what is termed the bio-medical model of psychosis (Read, Mosher and Bentall, 2004) enables “*psychiatric power and medical metaphors associated with it*” to manufacture ‘madness’ across a growing number of societies (Roberts and Hitten, 2006, p.786) Even though this view is highly persuasive and influential creating a meta-narrative linking psychotic experiences with illness, universal acceptance is wanting. There are a number of alternative narratives, or meaning making systems and approaches, available that can influence ‘stories’ constructed by those who have personal experience. These will be explored later in part B of this chapter onwards.

Before doing so evidence indicating the prevalence of psychotic experiences among ‘non-psychiatric’ populations is expanded upon. This will enable an exploration of psychotic experiences beyond medical interpretation, opening up world views that lie

outside the physical and practical confinements offered up by the illness model that dominates the meaning making systems that make up the meta/grand narrative of psychotic experiences.

### **A 2.12 Psychotic Like Experiences.**

Clinical need, as defined by psychiatry, is often used to distinguish between normally distributed psychotic experiences (PLEs) and psychotic illness. Psychotic like experiences have been reported among the general population (see for example van Os et al., 2000; Johns and van Os, 2001) described in terms of a “*dimension of the human experience*” (Stip and Letourneau, 2009). From an evolutionary perspective on the incidence of psychosis in the general population and possible links with psychotic illness, Kelleher et al (2010) suggest: ‘*the limited success in findings in schizophrenia to date may be a result of shared genetic variation between the clinical (disease) phenotype and the non-clinical (symptom) phenotype*’ (p167).

Among 12,992 house-hold respondents in New Zealand Gale et al (2011) found 7.3 % had experienced psychotic-like events. Visual and auditory hallucinations were most commonly reported - 5.3% and 2.8% respectively. The authors imply that thresholds exist whereby conversion from PLEs and psychotic illness potentially occurs. This would depend on, for instance, the number of times a psychotic-like event is experienced. According to van Os et al (2009) PLEs are on the whole transitory subclinical states. It is postulated that PLEs are governed by a psychosis phenotype that can express itself, triggered, by as yet to be fully understood circumstances.

Escher (2010) observes that 5% of undiagnosed children experience verbal hallucinations. In a three-year longitudinal study involving 80 children (mean age, 12.9 years) who hear voices, of which 50% were not receiving mental health care,

Escher et al (2002) found that approximately 60% experienced a gradual reduction over time, with the majority ending in discontinuation. It was found that the majority of verbal hallucinations were associated with major life events and that favourable outcomes depended on appraisal of the voices by parent(s) and child and less to do with the perception itself. Remberk (2017) in reviewing literature on PLEs makes a similar conclusion that for most children and adolescents the experience disappears over time. These findings would support van Os et al's continuum hypothesis. In order for the phenotype to 'reveal' itself and indeed find resolution, exposure to significant environmental influences or events needs to occur.

Estimates for the prevalence of PLEs in the general population vary from 1% (Eaton et al., 1991) to 17.5% (van Os et al., 2000). Johns and van Os (2001) argue that psychosis is not a separate state removed from normal consciousness. Rather, it is a state that sits on a continuum in normal consciousness. In a systematic review of literature on the psychosis continuum van Os et al (2009) found that *'The data therefore suggest that subclinical psychotic experiences are prevalent, but mostly self-limiting and of good outcome, although a small proportion go on to develop a clinical psychotic disorder'* (p190) Similarly, Kline et al (2014) in assessing 66 adolescents and young adults experiencing PLEs found if respondents described their PLE as *"neutral or positive"* the need for clinical high-risk screening and therefore intervention was deemed unnecessary. Persistence and severity of psychotic experiences, exposure to environmental risk and ability to cope and relate appear to be significant factors in determining if the individual reaches a state of clinical need (van Os et al., 2009).

Notwithstanding the evidence presented above, PLEs continue to be associated with psychiatric disorders, in particular the onset of severe mental illness such as schizophrenia. It has been noted that when an individual approaches a psychiatrist and reports psychotic experiences, there is a strong likelihood that they will be diagnosed with a mental illness and receive treatment - most likely pharmacological. For instance, Romme and Escher (2000) estimate there is an 80% chance of being diagnosed schizophrenic if you tell a psychiatrist that you hear voices. Boyle (2002) comments: "*voice hearing is likely to lead to a diagnostic label whose social functioning has already been devalued*" (p266) pointing to a dual pathway to becoming schizophrenic. Rosenhan (1973) found that presenting at a psychiatric unit and reporting hearing a single word 'thud' in their head was enough to be hospitalised and receive a psychiatric diagnosis. With population estimates for auditory hallucinations varying between 2-4% (Eaton et al., 1991; Tien 1991) a large number of voice hearers could potentially receive treatment for a psychotic disorder.

There has been much focus on early phase psychosis among much of the academic and clinical research applying terms such as 'psychosis proneness', 'schizotypy' or 'at-risk mental states'. Yet, Kuipers (2008) in a review of literature on early intervention informs us that during the early phase of psychosis: "*we have no way of yet knowing what markers, biological or social, predict better or worse outcomes, or would respond to less treatment*" (p148). The upshot of Kuiper's review, Romme and Esher's observation and the association between PLEs in the general population and the psychosis phenotype is that people sharing their PLE experiences with others could potentially be subjected to psychiatric classification. Certainly, speculation prevails

linking the presence of PLEs with the onset of psychotic illness attached to biological or/and genetic defects inherent in the individual.

Causal links between PLEs, in particular genetic and biological deficits, are assigned to such experiences even though PLEs are not uncommon among general populations. A population-based survey in Australia found that 11.7% of 10641 respondents endorsed one or more items designed to identify delusion-like experiences (Scott et al., 2006).

What is commonly termed the biological or medical model of mental illness has gone through a process of globalisation where the physical or material world is placed over and above non-material conceptions (spirit, soul) and has, to a large extent, become publicly accepted wisdom and an authoritative discourse on psychosis (Kirmayer, 2006). Indeed, the public imagination on a materialist representation of human behaviour and experience has been promoted at the highest political level.

President George Bush announced in July 1990 that the 1990s would be designated “*The Decade of the Brain*”. In considering the impact, Jones and Mendell (1999) state that:

*“Public recognition of the importance of studies of the spinal cord, brain, behaviour and mind is evident in the remarkable bipartisan congressional support for the National Institutes of Health (NIH) in general and neuroscience in particular, during the past few years. There has also been more media attention to breakthroughs in neuroscience during Decade of the Brain”* and that: *“We believe that the DOB has*

*strongly enhance(d) public awareness of the benefits to be derived from brain research” (p739).*

Particular attention is given to neuropsychiatric diseases, worthy of receiving much consideration within this scientific enterprise.

To summarise, the continuum hypothesis places serious doubts in establishing a clear demarcation between those with PLEs from those with a distinct psychotic illness (Stip and Letourneau, 2009). Further to this, studies demonstrate that individuals with no history of psychotic experiences can begin to hallucinate if placed in particular settings eg; studies where participants are subjected to sensory deprivation environments (see for example Mason and Brady, 2009; Daniel, Lovatt and Mason, 2014) or under significant stress and/or experiencing disruptions to normal sleep behaviour (Barnes et al., 2011). The implications of such studies, that potentially anyone is able to hallucinate, could have far reaching consequences influencing how we understand, relate to and construct discourses around psychotic experiences. A normalisation process may follow which a number of ‘alternative’ discourses, ulterior meaning making systems and approaches to the deficit models of psychotic experiences purport to be offering. Other descriptions that appear in the literature involve theories and ideologies that lay challenges to or ‘problematize’ the dominant discourse that is the meta/grand narrative. These as I described earlier comprise of bottom-up meaning making systems and approaches. I introduce these in Part B below.

## **Part B 2.13 Psychosis and life adversity**

In an 18-month follow-up of a national survey (office for national statistics, 2000) carried out in Great Britain, Wiles et al (2006) found a 4.4% incidence rate of psychotic experience adding more weight behind a normalising trajectory of psychotic experiences. Further, delusional like experiences were found to be relatively common among the general population (Varghese et al., 2008). The authors found over a third of the 310 'non-psychotic individuals' experienced significant levels of psychotic experiences and that there was a correlate between delusional like experiences and other psychotic symptoms. Those who reported delusional like experiences were likely to experience hallucinations and thought disorder. Surveys and studies above have prompted interest into reasons why psychotic experiences occur in the first place, who is most likely to experience psychotic events and what causalities are involved.

Leaving aside arguments around evidence and the strength of theories aligned with positivistic notions above, there is substantive proof that psychotic experiences are associated with life events where a direct causation is implied. It has become common place to bracket this causative link within a trauma model of psychosis inferring universal application (McGrath et al., 2017). However, I will present that the 'trauma model' has its own bearing on persons living with psychotic experiences.

### **B 2.13.1 The undesired consequences of the trauma model**

There are a range of theories and conditions influencing trauma studies, usually involving biological, psychological and sociological dimensions. According to Lacqueur (2010) these have become so broad in application that trauma, has become *"a 'floating signifier' that denotes any number of ills which have little in common*

*other than the name*" (p19). From a positioning perspective trauma is *"to some extent a discursive or epiphenomenal construction with political and strategic effects"* (Eagle, 2014, p3). Trauma as a concept is compelled by a social system that builds hierarchies of worthiness ie; who is most likely or more deserved to be believed to experience a traumatic response to life events (Eagle, 2014). It must be noted that even though evidence of causative links between life events and onset of psychosis is growing, not everyone who experiences significant life adversities will develop psychosis, and not everyone who develops psychotic experiences has reported major life adversities (Bentall, 2011). Moreover, there is a danger that all psychotic events become associated with trauma, deep suffering and personal casualty discouraging positive dimensions thereof. The hierarchy referred above is often built upon models of illness and disorder, with those acknowledged and categorised left with a *"previous sense of identity unstable"* reluctantly propelled to take up a *"subject position of victim"* (Eagle, 2014, p18). This compromised subject position reduces the prospect of presenting a positive perspective on psychotic experiences.

Following the above, the discursive nature of trauma as a concept leaves wide open questions on its everyday applicability. Rather than becoming embroiled in a debate on what constitutes trauma, its appropriate usage and applicability regarding psychotic experiences, or of being accused of taking up a personal position, I have chosen to refer to evidence of an array of life adversities that demonstrate increased risk of experiencing psychotic events. As noted, PLES have been found to have a beneficial and positive impact on individuals which may be lost if an automatic assumption of traumatic causality leading to 'disablism' and taking on the 'sick role' is made. (Under the section titled 'Recovery, resistance, self-preservation and reclaiming

identity' below I explore further the concept and implications of 'disablism' and resistance to the 'sick role').

These studies indicate a trajectory of normalising and humanising the psychotic experience ie; causality of the psychotic experience is fixed on the environment, beyond the individual. Reasons for their occurrence are understandable, with potential to change public discourse and response to the psychotic experience in a favourable direction. However, as I present later below public discourse, dominated by the meta/grand narratives does not necessarily flow in that direction.

### **B 2.14 Life events, life adversities and psychotic experiences**

As described above, by focusing on internal deficits the cognitive and biological models of psychosis tend to underplay the potential impact of the environment on psychotic experiences. Concerns with environmental risk to developing psychosis have been highlighted by a variety of empirical studies. In a review of childhood adversity, psychosis and schizophrenia Read et al (2005) found a high incidence of past neglect, physical and sexual abuse among people diagnosed with psychotic disorder. In a retrospective study involving 17,337 participants, Whitfield et al (2005) found a five-fold increase in reporting of hallucinations among people who experienced adverse childhood events compared to those reporting no adverse childhood events. Romme and Escher (2006) found that 77% of people diagnosed with schizophrenia heard voices that were associated with past traumatic experiences (eg; childhood neglect, bullying and marital violence). Read et al (2013) included deprivation, isolation and emigration to be contributing factors to developing problematic psychotic experiences. The impact of stressful life events such as bereavement (Rees 1971; Olson et al., 1985) is also associated with psychotic

experiences. Stress Vulnerability (Zubin and Springer, 1997) models (whereby an increase of life stresses increases the risk of mental ill health) may have something to offer here. Surveys carried out in Britain have shown that within 6 months of a negative life event a significant number of individuals experienced psychotic symptoms (Johns et al, 2004; Wiles et al., 2006) and that the greater number of adverse events an individual is exposed to the more likely they are to develop psychotic experiences (Shevlin et al., 2008; Rosen et al., 2017).

Reasons for the occurrence of PLEs becomes understandable, with potential to change public discourse and respond to the psychotic experience empathetically. However, in my presentation of public discourse below the meta/grand narrative presides over much of the public perceptions of psychotic experiences and in turn how people tend to speak about these human experiences.

### ***B 2.15 The social divide***

Moskowitz and Corstens (2007) reviewed characteristics of voices encountered by non-psychiatric patients, psychiatric patients with dissociative experiences and those formally diagnosed with schizophrenia. The authors found non-specific differences between the voices each group experienced. Heriot-Maitland et al (2011) also found little qualitative differences between clinical and non-clinical groups experiencing hallucinations and delusions. One major difference between these groups was the level of validation of psychotic experiences received from participant's social worlds. As with studies quoted in the above section where a positive discourse might enable those with psychotic experiences to live more harmoniously with delusions and hallucinations, if validation was present, the likelihood for clinical intervention was dissipated. Escher et al (2004) found that among 80 children who heard voices most

(85%) associated them with negative life events such as physical and sexual abuse; bullying and major loss. The authors were quick to note that the majority were able to cope without professional support. Similarly, Kelleher et al (2013) in a longitudinal study of 13-16 year olds found a dose response to exposure of physical assault and bullying - the more severe and prolonged participants were exposed to these traumatic events the higher the risk in developing psychosis. They also found the dose response where cessation in exposure to trauma tended to lead to a significant reduction in psychotic experiences.

Further to the above and at odds with the genetic theory of psychosis Fisher et al (2014) in a comparative study found that among 172 "*first presentation psychosis cases*" familial risk did not account for any significant association between childhood physical abuse and psychotic disorder. In other words, childhood abuse was shown to be causatively associated with onset of psychosis independent of genetic factors.

Fisher et al (2014) (also see 2.14.2 above) point to the importance of the social environment in 'making or breaking' psychosis. Notwithstanding divergent views on the levels of significance of genetic and social effects influencing the onset of psychosis (van Os and McGuffin, 2003) there is reason to believe that theories of social causation of psychosis is more beneficial to those with psychotic experiences as personal deficiencies can be extinguished, redirected toward external forces ie; life events, social circumstances and cultural contexts. Certainly, a significant number of people diagnosed with a psychotic disorder have long expressed frustrations with ideologies that have colonised discourses associated with psychotic experiences (eg; the 'biomedical' model; Speed, 2011). Dillon (2013a,b) a self-professed voice hearer and ex-psychiatric patient believes that "*Clinically loaded language*" has led to the

silencing of a group in society that would be better served if public recognition of social injustices, such as personal trauma, were acknowledged and ‘reclamation’ via ‘personal storytelling’, counter narratives and decolonisation of language took place. The emancipatory process described involves a shift in culture where subjectivity comprising life events, adversity and social environments take precedence over neurobiological and genetic causative explanations as primary routes to psychosis (Barrantes-Vidal, 2014; Read, Dillon and Lampshire, 2014).

## **2.16 Psychosis and culture**

As demonstrated above, theories on psychotic experiences tend to be understood as environmentally provoked inextricably linked with internal (biological and psychological) failings. Models aligned to these ‘illness’ or deficit driven theories have been shown to create a restrictive and disapproving framework of psychotic experiences. There is ample evidence demonstrating high levels of stigma attached to mental illness, in particular psychosis, throughout Westernised countries (Kelly, 2006; Thornicroft, 2006; Lakeman et al., 2012; Macgabhann et al., 2010). Psychotic experiences are on the whole unacceptable and threatening to ‘normal’ society (Thornicroft et al., 2007). This high level of unacceptability stems from media reporting of psychotic experiences often informed by the deficit models described above rendering them beyond and “*outside moral order*” (Leuder and Thomas, 2001). Genetic dispositions and cognitive deficits portray the individual as helpless to resist impulses brought on by psychotic events. However, psychotic experiences are sometimes acceptable and in some social settings encouraged (Jackson and Fulford, 1997).

Psychotic experiences have been associated with mystical experiences, particularly in relation to religious practices (Jackson and Fulford, 1997; Bret, 2003.) These authors argue that there is significant similarity between mystical experiences and psychotic symptoms. It is therefore difficult to ascertain if they are signs of pathology.

Shamanistic practices encourage and have been shown to induce psychotic experiences - such as hearing voices (eg; of the dead) and visions (Stephen and Suryani, 2000). Shamanistic rituals are in some cases described as cultural invitations to psychotic experiences such as visions and hallucinations in order to connect with the 'world beyond' for example through spirit possession. Cultural invitations to 'other worldly' experiences also occur where spiritual training takes place as in Tibetan vision meditation and among congregations of Christian Charismatic Churches eg; hearing the voice of God (Dein and Littlewood, 2007; Luhrmann, 2010.) Differences between reporting rates of auditory and visual hallucinations are also evident. Bauer et al (2011) highlight diversities between cultures such as rates of reporting of visual hallucinations among West African populations (54% Ghanians and 51% Nigerians) against a low rate of 4% among Islamic Pakistanis. Luhrmann (2011) posits that the impact of culture on psychotic experiences is its influence on representations of the mind and the learning environment that focuses on particular experiences. Absorption is the ability to focus on the mind's 'power' to imagine while diminishing external distractions of every-day life and is applied when 'accessing' psychotic experiences in ritualistic and religious settings. The important point to note here is that psychotic experiences can be influenced, encouraged and prompted by social occasions. How people interpret and react to these is greatly influenced by expectations set by cultural and social biases. In the situations described the psychotic experience tends to be short lived, benign, managed through ritualistic acts.

Devereux (2000[1956]) is adamant that: *“the shaman is mentally deranged”* (p. 226). Stephen and Suryani (2000) and Luhrmann (2010) however make the point that there is a fundamental difference between pathological and non-pathological hallucinations. In accordance to these observations psychotic experiences that occur, prompted and encouraged in religious and ritualistic settings belong to the latter category. Given the distinction made here between psychotic events that occur via ritualistic inducement, managed through social settings and those that are brought on by life events out of a person’s control it would be reasonable to conclude that they likely belong to the category of Psychotic Like Experiences ie; perceived as benign.

Castillo (2003) argues that functional psychoses can be interpreted as a trance like state. Those experiencing transient functional psychoses in non-Western cultures, particularly where ritualised meditative trance states are practiced, are 10 times more likely to achieve recovery than Western counterparts. Castillo concludes that:

*“egocentrism and a loss of spiritual explanations for psychosis in Western cultures constructs a clinical situation in which persons with functional psychoses are treated for a biogenetic (incurable) brain disease rather than a curable spiritual illness.”*

And that:

*“Recognizing cultural differences in symptoms, indigenous diagnoses, and treatment for functional psychoses can help explain the dramatic cross-cultural differences in outcome.”* (p9)

A number of reviews have indeed shown considerable variations in prevalence and

incidence rates of schizophrenia across cultures (Jablensky, 2000; Goldner et al., 2002; Saha et al., 2005; McGrath et al., 2008). The heterogeneity of incidence and prevalence rates puts in question a purely biological basis of schizophrenia highlighting strong cultural and societal influences. However, there are those that insist that schizophrenia is a cross cultural, global phenomenon.

### ***2.17 Cross cultural psychiatry***

Psychiatric diagnoses have also been argued to be relevant to and applicable regardless of conceivable cultural clashes with psychiatric classification systems (Barrett, 2004). Mzimkulu and Simbayi (2006) investigated Xhosa speaking African traditional healers note that symptoms identified by healers were close to DSM-IV criteria suggesting that Western and traditional healing systems are able to co-exist. The traditional healers believed that casual explanations of psychotic experiences involved witchcraft, spirit possession, angered ancestors and genetic predispositions. Healing methods used included washing, steaming and inducement to vomit in managing and treating psychosis. Mzimkulu and Simbayi (2006) suggest that in these contexts attempts to understand and address psychotic behaviours, engages a common response sequence of diagnoses, aetiology and treatment. Culture, according to these authors cannot be used to deny the existence of psychosis and psychotic illness yet variances in established systems (eg; Western interventions vs traditional interventions) in addressing these specific human experiences exist.

Stein (2008) identified three perspectives in comparing Western medicine and traditional healing. The first highlights a stark mismatch between Western medicine and traditional healing; the second questions the privileged view of Western medicine pointing out that both systems have an element of efficacy; the third that Western

medicine and traditional healing comprise social activities reflecting cultural values. Each perspective will undoubtedly create different discourses with regards psychosis, influencing how society should react to these human experiences. However, even though in some parts of the world traditional healing is commonly utilised by those with psychotic experiences, evidence would suggest that Western interventions in the form of conventional treatments is becoming increasingly globalised with minimum consideration given to cultural diversity (Kirmayer, 2006). Muga and Jenkins (2008) surveying public views of mental health policy in Kenya found that although the public endorsed a biopsychosocial view of mental illness (a ‘holistic’ model incorporating biology/genetics, psychological and social/environmental influences) they expected mental health services to focus on one interventional component – that of a biological/pharmacological nature. Public discourse on mental illness, and by association psychosis, it would seem is increasingly dominated by empiricist accounting and scientific models with biological underpinnings, largely ignoring cultural contexts. Bracken and Thomas (2010) see this as a major challenge to psychiatry: *“The fundamental question that faces psychiatry is: ... can a discourse be produced that ... is sensitive to the complexity of our embodied, encultured nature?”* (p222)

The individual’s ability to relate and cope with psychotic experiences is therefore significantly influenced by cultural and social milieus. These milieus, as demonstrated above, are able to provide social circumstances where meaning making systems and approaches that embrace and facilitate the psychotic experience can be introduced transforming systems and approaches that currently dominate public response to the psychotic experience. Recently, ‘Recovery’ has become part of a new,

hopeful and optimistically loaded shift in discourse linked with all that is mental health including psychotic experiences.

### ***B 2.18 Recovery, coping and relating***

The idea of recovery originated from patient narratives and is a relatively new, imprecise concept in the world of modern mental health services (Bracken, 2007; Bellack and Drapalski, 2012). Recovery has been defined many times and there does not appear to be a consensus as to a single definition (Ralph and Corrigan, 2007). The idea of recovery has challenged the pessimistic view of psychosis, its association with illness and long-term disability (Barker et al., 1999; Coleman, 1999; Thornhill et al., 2004; Ralph and Corrigan, 2007). According to Pilgrim (2008) there are three usages of the term recovery:

1. Recovery from invalidation (survival)
2. Recovery from impairment (rehabilitation)
3. Recovery from illness (treatment)

Numbers 2 and 3 tend to be institutionally orientated. They emphasise mental illness (including psychotic illness) as indicative of disability to be ‘treated’ with actions required for rehabilitative purposes. Number 1 orientates toward social influences on recovery. Invalidation toward psychotic persons and strivings to cope (survival) involves the individual socially situating themselves, as someone who, among other things, critique language used to define them. Discourses of resistance are at work and coping with psychotic experiences are often non-institutional. Much of the recovery literature is written by individuals who have redefined themselves beyond psychiatric systems and psychiatric diagnoses (eg; Deegan, 1993; May, 2000; Bassman, 2007). The

social consequences for non-psychiatric populations who live with psychotic experiences is that they find relief and support through non-institutional means. Based on 100 narrative interviews with individuals diagnosed with schizophrenia and in reviewing qualitative research on the disorder Davidson (2003) concludes that:

*“most of the work of recovery happens in the person’s life outside of treatment relationships and settings”*. P203

Social variables therefore play an important part in ‘living outside and beyond mental illness’ (Timander and Möller, 2016)

### ***B 2.19 Recovery, resistance, self-preservation and reclaiming identity***

Over recent years three studies have been conducted on recovery and mental illness in Ireland (Roberts, 2009; Karatlova and Doherty, 2010; Watts, 2012). Although diagnoses of participants was not always specified the importance of social opportunities in redefining a place in the world after mental breakdown was highlighted, as was discovering communities where social acceptance was found and self-acceptance allowed to flourish. Social opportunities often provided structure to cope with the aftermath of major mental health problems (psychosis included) and facilitated the relating of experiences – most significantly with peers who have experienced their own major mental health problems. Similarly, Philbin (2009) found a level of resistance to psychiatric identification among a group of people who were diagnosed with psychotic illness in Ireland. Several modes of responding to unwanted identities were activated. These involved vindications of a ‘preferred self’, preserving particular self-notions and resisting negative consequences of labelling.

The level of resistance to psychiatric identity is illustrated by Timander and Möller (2016) in a cross national comparative research project (Sweden and the UK) on recovery, where they interviewed 33 participants, self-identified as having gone through the recovery process and having used mental health services for a significant period. Participants rejected disablism associated with their mental health problems, in particular that which is prescribed by dominant biomedical ideologies; “*reclaimed and (re)constructed positive identities*” (p1056) by attaching and relating their recovery to social justice, community (re)connection and healing. In rejecting illness and disablism (or deficits as per the meta/narratives above), social and institutional invalidation was resisted. In all study cases above, discourses tend to focus on nonpathological descriptions of mental health problems to achieve revalidation of the person. Recovery involves ‘starting points’ to re-evaluate as to what a person might be or/and will become.

Slade and Longden (2015) provide a specific list as to why someone with psychotic experiences may choose to resist, avoid and not have contact with the mental health system:

1. they are either not distressed by their experiences, or actively value them
2. they have a good support network
3. they choose not to disclose because they fear being stigmatised if they are given a diagnosis of a mental illness
4. they have a non-medical or non-psychological framework for their experiences (e.g. supernatural, spiritual, cultural, technological) and do not identify with models used in mental health services’ (p22)

There is a noteworthy addition to the above list. Beyond the number of explanations described above lies the danger of becoming subservient to and subsumed within a paternalistic mental health system where the person with psychosis will be required to perform the 'sick role' (Moncrieff and Middleton, 2015); or to put it another way acquiesce with disablism. The sick role involves deployment of established rights to access expert and state support (such as medical and welfare assistance); being excused from a meaningful social role with the 'sick' person exempt from responsibility for their illness (Parsons, 1991). The sick role is open to social appraisal ie; social norms will dictate what constitutes illness, who is worthy of specific supports and what social roles might be expected according to the illness described. Although the 'sick' person is not held responsible for their illness, a paradox arises as they are expected to demonstrate willingness and exert effort in getting well. In the case of the person labelled psychotic, getting well may involve the idea of recovery which is open to a variety of interpretations and outcomes, none of which guarantee social inclusion and equality for the psychotic person (McLean, 2003). The meta/grand narrative determined by a medical (biological) perspective, has long associated psychosis with enduring disability or at the least long-term continual threats to mental ill-health and social functioning. In other words, most people identified with psychotic illness are assumed ill or in remission, (Ciudad, 2009; Lambert et al., 2010; Chang et al., 2013). Choosing to resist, avoid and not have contact with the mental health system could involve anticipation of the sick role, consequences of long-term dependency, social distance and stigma leading to service avoidance. The 'service avoider' may also be aware that once caught up in the mental

health system the ‘psychotic person’ becomes marked as an individual who remains at risk of relapse and continually in remission.

## ***B 2.20 Recovery and remission***

There has been a marrying of the concept of Recovery with Remission with both shown to have mutually desirable outcomes (for example social integration - see Ahmed, Mabe and Buckley, 2011). However, a distinct difference between the two ideologies remains (Emsley et al., 2011). Whereas Recovery tends to emphasise human and social processes regardless of symptomatology; Remission emphasises maintenance and symptom reduction. For the individual attempting to scribe an identity beyond the meta/grand narrative of illness, disability, deficit laden language and long-term frailty; coping and relating one’s psychotic experiences becomes embroiled in a continuous effort in defining oneself against a backdrop of suspicion and social disapproval.

Fisher and Ahern (2002) observe inherent resistance to recovery within scientific and positivist traditions:

*“Currently the bench mark for evidence-based practice is maintenance: symptom reduction and medication compliance” (p633).*

As above, individuals who have declared recovered from psychosis point out that it involves a deeply personal journey of self-discovery. It is neither outcome orientated nor depends on being symptom free (May, 2004; Timander and Möller, 2016). A challenge has been laid before the idea of recovery with evidence of continued existence of chronicity and high remission rates among some of the more severely

affected psychiatric patients ie; those with psychotic illnesses. In a review of longitudinal research Jobe and Harrow (2005) conclude:

*“long-term studies that compare schizophrenia patients with other types of patients have produced data indicating that, even with current treatments, schizophrenia patients as a group show poorer outcome than patients with other types of psychiatric disorders; in this sense, schizophrenia is a poor-outcome disorder.”* (p898).

Nasrallah (2008) states that;

*“Recovery is possible but appears to occur in a minority of patients. Many patients can achieve remission, which enables them to gradually regain various degrees of functioning.”* (p20).

According to these authors, any idea of recovery should be mindful of this and that recovery does not apply to certain psychiatric populations, in particular those diagnosed with psychotic illness. Others disagree, regarding all such conclusions as evidence of persistent discrimination among those who do not understand what is required, socially and culturally, to make recovery a reality for people experiencing psychosis. There is an inherent denial of the impact of their own outcome orientated research programmes and practices that emphasise stability and maintenance over recovery processes (Barker, 2003; Bellack and Drapalski, 2012; Bracken and Thomas, 2005; Moncrieff and Middleton, 2015; Perkins and Slade, 2012; Timander and Möller, 2016; Weiden, 2010) Consumers of mental health services have contested outcome orientated measures of recovery concluding that:

*“In the emerging field of “evidence-based practice,” we know from our full range of lived experiences what works because WE ARE THE EVIDENCE!”*

(National Coalition for Mental Health Recovery)

Much of the literature on recovery and psychosis feature practical, and in many cases, observable behaviours in engaging with processes and/or achieving specific outcomes (see for example, Roe et al., 2006; Philips et al., 2009.) These include coping styles, techniques and strategies. However, the practical rarely takes into account sources of knowledge that potentially influence the reforming of identity that takes place during recovery. Identifying sources of knowledge that individuals are exposed to and how this can be applied to socially situate the individual with regards psychotic experiences, coping and relating can be achieved by studying the use of language. Yanos et al (2010) illustrate how the language of psychiatric illness can impede people's recovery by imposing an identity of illness and disability. Morrison (1998) concludes that the psychotic experience is not the problem, but the individual's relationship with them, a view echoed by Romme and Escher (2000); Leudar and Thomas (2000.) Yanos et al and Morrison's observation would indicate that discourses are at work with regards understanding and relating to psychotic experiences.

Language dysfunction has been emphasised among those diagnosed with schizophrenia, asserted through empirical means (Kuperberg and Caplan, 2003; Stephane et al., 2007). In highlighting significant problems with communicating, a danger arises in creating discourses that places the individual experiencing psychosis in a position where they may be "*considered unworthy or incapable of conversation*" (Buck-Zerchin, 2007, p19). On the other hand, promoting 'Open Dialogue' during psychotic episodes has been emphasized and shown to be fruitful in achieving recovery (Seikkula et al., 2000; Seikkula et al., 2003; Seikkula and Alakare, 2007).

The Open Dialogue approach facilitates familial discourse to communication encouraging the flow of conversation between social actors (usually family, patient and health professional). The aim is to contextualise and better understand the psychotic process. During crisis, attention is paid to linguistic expression and construction of language by the individual experiencing psychosis. Open Dialogue does not dwell on thought disordered speech acts (ie; see them as meaningless declarations) but engages positively with the psychotic world. Affirmative discourses on the psychotic experience can be constructed and promoted maintaining everyday social attachments with the person's naturally occurring communal world.

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Broome (2004) also asserts that individuals in the throes of psychosis can conceivably continue to engage in everyday social discourse:

*“The delusional system would be a language game with one player in a solitary solipsistic community, but there is no reason why such an individual could not take part, as indeed they do, in other discourses within a wider community”* (p39)

Therefore, tensions between various discourses on psychosis exist. The point here is that each discourse has the potential to impact upon our understanding and readiness to relate to people experiencing psychosis. This in turn impacts on the individual's capacity to engage in meaningful social exchange around their psychotic experiences.

As Eisenberg (1988) would have it: *“what is believed to be true about behaviour affects behaviour that it purports to explain”* (p1)

To conclude this section, the ability for someone to recover from problematic psychotic experiences, including capacity to cope and ability to relate, is not just

reliant on taking action, but in repositioning one's identity through engagement at the level of speech and language.

## **2.21 Summary conclusion**

A number of 'models', frameworks and theories on psychosis and psychotic experiences have been presented with an aim to illustrate the extent of knowledge, number of depictions and multiple discourses potentially available to people affected by this human state. Each, as described above, have their own challenges and as argued their own appeal to people living with psychotic experiences beyond statutory mental health systems.

The conceptualisation of psychosis, as a modern phenomenon in Westernised thought has, over several centuries, been subject to change. It has emerged that there is no agreed definition or consensus as to causes or pathways into or out of psychotic states; or indeed whether they should be feared or revered; facilitated or regulated. However, there appears no doubt that 'Westernised' belief systems (and therefore discourse) is dominated by a meta/grand-narrative that 'offers'<sup>6</sup> up to the general public a credible and convincing account of biological determinism at work, enabling a top-down meaning making system and approach implying faults and deficits inherent with psychotic experiences.

What is also clear is that most attention has been given to psychotic experiences from the subjective, internalised viewpoint. The illness model, and to an extent, cognitive models have tended to highlight deficits within a normal/abnormal dichotomy by

deploying reality testing techniques and through the development of specific criteria that relies heavily on a specific use of phenomenological reporting and objective measures. The social perspective, including the number of cultural studies and theories cited have emphasised systems and approaches that have captured the subjective experience from single point perspective, drawing attention to the context from which psychotic experiences originate and are encountered.

Environmental risks have in some cases been highlighted, social and cultural differences and influences have been demonstrated and individualised pathways to recovery have been explored. By linking adverse life events (such as childhood neglect) with problematic psychotic experiences; observing the role of rituals in ‘encouraging’ and facilitating psychotic experiences or studying recovery from the first-person perspective the individual’s experience is forever exposed to a number of conceptual narratives and in turn specific experiential knowledge bases. That is to say,

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<sup>6</sup> I use the word ‘offer’ here as some of the most persuasive high impacting ‘regimes of truth’ have been found to induce a sense of choice in what is to be believed. Yet the choices we make about what we believe is compelled, legitimised and sanctioned through methods that are deemed credible at a given time, often serving political and societal purposes (Rose, 1999). For example, science as a human enterprise involves a significant degree of rhetoric on what constitutes truth (Reeves, 1998; Ceccarelli, 2011); in this instance the offering up of a narrative that psychosis is underpinned by biological determinates evidenced through scientific practices and methodologies. The public are left to decide what should be believed in relation to this human state, yet deciding on what we are to believe is predisposed toward the authoritative voice of medicine and science, in turn gratifying systems and institutions with responsibility for public health and safety (Moon, 2000).

language and discourse is generated around the concepts being studied (in the case above constructed through culture, adverse life events and recovery) with limited room for alternative accounts to be presented.

The dichotomy of abnormal/normal; irrational/rational; mad/sane between the respective psychotic and otherwise human experience is well established contributing to social distance, stigma and discrimination experienced by those living with psychotic experiences. The main issue is that the psychotic experience is not the real concern, but the ‘site’ of the experience – the psychotic person. Not only is this a concern for Westernised/developed countries but has been observed to be a growing problem for developing countries where modernisation of mental health services is being attempted even though limited access to professional help remains (Sadik et al., 2010). The biological determinism inferred is buoyed up by a persuasive authority bestowed to medicine, publicly warranted through contemporary health systems where accountability and concern for patient and public safety is paramount. What follows is the delivery of care designed to satisfy a system that requires clear and transparent assessments of health and behaviour including measurements concerning outcomes where monitoring the consequences of evidence-based interventions becomes the primary focus (Thomas et al., 2012). Whether intentional or not, portraying the person with psychotic experiences as vulnerable and dependent; susceptible to biological determinism and faulty processing, therefore requiring intervention can have a silencing effect on those with PLEs. The ‘marked’ individual can take up a position of resistance or avoid making themselves ‘known’ to statutory services electing to live at the margins of public life in order to escape scrutiny and what might be perceived as intrusive practices (Swartz et al., 2003; Van Dorn, et al., 2006).

The power to define one's experiences, and therefore receive a desired response from one's social domain involves careful use of language. Well established definitions, regulation and customary portrayals have the utmost influence over social responses to shared experiences associated with challenges to personal wellbeing (Liu, Keeling and Hogg, 2016). Sharing self-experience(s) that have been defined as alien or threatening toward the social fabric is to risk exposure to public demise:

*"The struggle for definition is veritably the struggle for life itself. In the typical Western two men fight desperately for the possession of a gun that has been thrown to the ground: whoever reaches the weapon first shoots and lives; his adversary is shot and dies. In ordinary life, the struggle is not for guns but for words; whoever first defines the situation is the victor; his adversary, the victim. For example, in the family, husband and wife, mother and child do not get along: who defines who as troublesome or mentally sick? [the one] who first seizes the word imposes reality on the other: [the one] who defines thus dominates and lives; and [the one] who is defined is subjugated and may be killed."*

(Szasz, 1973, p24-25)

The challenge for someone living with psychotic experiences, in this instance those living beyond statutory services, is the ability to cope with invalidation (Pilgrim, 2008) which has obvious consequences on how they might relate this 'human state' with others. This is not just a matter of regulating one's behaviour but being careful as to how one might speak about oneself, choosing carefully who and in what circumstances psychotic experiences can be shared. The importance of language

comes into play in order to socially situate oneself through discursive means with the aim to maintain a credible and acceptable identity.

The above comprises 'identity work' involving the act of positioning oneself in relation to another through social representation (Andreouli, 2010). The resources used for purposes of positioning are believed to be examples of discursive objects which are "*real*" and "*out there*" (Willig, 1999). Given the stigma surrounding mental health problems, in particular psychotic experiences, it may be the case that discourses revealed among a group of people with PLEs could be categorised as "*alternative accounts*" (Willig, 1999) ie; outside conventional descriptions. This is a pertinent point. Public misgivings toward the psychotic person's expression of reality may create a substantial challenge while composing credible accounts in order to maintain an identity that is socially appropriate. Discourse analysis can help illuminate the discursive nature of constructing discourses that are associated with socially and culturally suspect experiences and behaviours - in this case PLEs – in order to protect or defend personal identity.

This study is designed not to understand PLEs per se, but to explore the use of (spoken) language by those with PLEs in order to enrich our appreciation of the knowledge and discourses they apply to shape their responses when asked about them. Discourse analysis as a research methodology takes language as a basis from which to extract constructions of accounts of events (Potter and Wetherell, 2007). It is hoped that by studying language and construction of discourse, levels of influence from various sources will be revealed, the positions people with PLEs take up will be uncovered, effects and consequences of discourse generated at interview revealed. Discourse analysis, through consciousness raising, can also help cohorts of socially

alienated persons by revealing contradictions and dilemmas within discourses they generate that compromise their position and claim to truth (Willig, 1999).

Willig (2008) informs us that the arbitration of human experience is processed by way of history, culture and language. All three shape and influence the discourse we apply in given social situations. If someone enquires about our recovery our response is inevitably based on historical and cultural influences and includes personal experience and knowledge of that particular subject. The same applies to adverse life events and culturally generated experiences. Our use of language is therefore context specific.

Potter and Wetherell (1987) assert that language is not so much descriptive but constitutive. When we communicate with others our use of language will depend on who we are addressing, and what it is we want them to know. To understand this fluid process we need to study language in use. Ogden (2002) refers to one approach to discourse which “*does not study the individual words spoken by people but the language used to describe aspects of the world*”.

Harper (1999) acknowledges challenges to studying discourse in that it has been accused of having little practical application. However, he refers to ‘usefulness’ when considering the practical applications of discourse analysis:

*“By usefulness here I do not mean a technical utility in the sense of developing new treatment technologies, but refer to whether a particular idea or intervention leads to richer understanding and to just and socially responsible outcomes”* (p128).

Considering Harper’s point above and taking into account Willig’s reference to discursive objects and alternative accounts this study aims to achieve the following from one to one interviews with persons residing in Ireland who self-declare living with PLEs:

To summarise, the aims and objectives for this study are:

Aim:

- To capture and analyse discourses generated at interview by persons self-declared as living with Psychotic like Experiences residing in Ireland
- To understand the discursive constructions of participant discourse at time of interview

Objectives:

- To reveal positioning and overall orientation of discourse as appears in text generated by participants
- To reveal the consequences and effects of participant discourse at interview such as compromises to positioning and orientation
- To reveal the presence of systems of power and authority in participant discourses that destabilise their intended effects and consequences

Given the lack of qualitative knowledge or information on people living with PLEs, the study will be exploratory with potential for action considered during the concluding chapters. The possibility of ‘usefulness’ (or fruitfulness as Potter and Wetherell, 2007 put it) to this study lies with the methodology.

## Chapter 3 - Methodology

The previous chapter demonstrates that language is a concern for people who experience PLEs, is subject to esoteric and public deliberation and that psychosis is contested and of interest to a range of interested parties. While exploring the various epistemological and ontological parameters in relation to psychosis and PLEs it has been established that they are primarily framed within empirical and positivist traditions. It was also established that there is a range of perspectives from which to understand people with psychotic experiences, their lives; ability to cope and relate. The range of perspectives available to those who self-identify as having PLEs can be called upon when asked to frame these experiences. These are culturally and socially bound, stimulating discourses on PLEs engaging various linguistic mechanisms. Theoretical concepts pertaining to the nature and presentation of discourses need to be carefully chosen if we are to grasp the usefulness, the constraints, social boundaries and degree of linguistic resources available to the person with PLEs. The remainder of this chapter will be spent describing the theoretical constructs and methodology that will enable achievement of the aims and objectives as described at the end of the previous chapter.

In this chapter two theoretical concepts fundamental to this study are presented. Literature will be offered as a way to demonstrate that each concept is complimentary to the other in the pursuit of capturing and appreciating meaning embedded in the texts from data collection sources.

1. Social constructionism, as an overarching theoretical framework from which broad contextual meaning can be derived. Social constructionism is

facilitative toward understanding competing and at times contradictory social and cultural frames of reference.

2. Discourse analysis as a method to systematically analyse texts in order to appreciate the functionality of individual and wider social accounts of events, experiences, interpretations and descriptions.

Each concept will be discussed and presented in order to satisfy the justification for the methodological requirements of this study. I begin with a brief discussion on the philosophical positioning in order to provide a rationale for the chosen theoretical framework.

### **3.1 Social constructionism**

Although social constructionism is not strictly integral to the methodology for this study (ie; it is neither a part of the practical administration nor data analysis) it is inextricably linked to the overall theoretical positioning helping make sense of findings in relation to a wider social perspective. It therefore warrants a brief mention in order to clarify its relationship with methods of analysis and practical administration of certain research activities.

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Within the methodological framework for this study social constructionism is used as a point of reference from which social phenomena derived from findings can be understood within social contexts. Social constructionism considers that what we know; our sense of reality and course of learning is influenced by the social world we inhabit (Burr, 1995). Unlike social constructivism, which is interested in “*methods of constructing the self ... how it is talked about and theorized in discourse*” (Potter and Wetherell, 2007: 102), social constructionism focuses on the development of social

phenomena in relation to social exchange within given contexts. Notably, Gergen and Gergen (1991) describe social constructionism in terms of social meaning created through language; with constructivism concerned with cognitive processes that lead to personal meaning. Kenneth et al (2008) in contrasting social constructionism and social constructivism point out that:

*'The term constructivism is sometimes used interchangeably, but most scholarship associated with constructivism views processes inherent in the individual mind as opposed to human relationships, as the origin's of people's constructions of the world' (p160).*

The focal point for social constructionism is not the individual as a centre of learning, and 'knowing', but the interaction between the individual, the social world they inhabit and the various meanings that are created as a direct consequence of relationships with the social environment. Therefore, processes of influence, knowledge and meaning exchange between individuals, within a variety of social contexts are highlighted. •

As social constructionism is concerned with knowledge and experience of the world derived from social intercourse (not internal states or cognitive processes as it were eg; emotions, cognitions, decision making) it should help identify social and communal influences on the individual's ability to live with PLEs. This might include what the individual believes to help or hinder relating to personal experiences involving influential relationships, types of knowledge and/or learning that have played a role in this process. It is language that is primarily responsible for making

possible the exchange of knowledge, experience and learning that create and maintain particular world views. Language, as a fundamental medium from which knowledge and various social influences can flow is significant within social constructionism:

*“Language is capable of transcending the reality of everyday life altogether. It can refer to experiences pertaining to finite provinces of meaning; it can span discrete spheres of reality”.*

(Berger and Luckmann, 1966, p40).

From a constructionist perspective Tuominen et al (2002) describe discourse as: *“the vehicle through which the self and the world are articulated, and on the way different discourses enable different versions of selves and reality to be built”* (p. 273).

Studying language in use can therefore expose knowledge and linguistic resources inherent in discourses around a given subject matter (in this instance PLEs) and associated socialisation that takes place. Social Constructionism, with its emphasis on the fickle nature of social reality corresponds with the theoretical leanings of discourse analysis where language in use is taken as a variable performative act, fluctuating in accordance with the social environment. In this context studying language helps bring to light what might be at stake for participants, such as personal identity and social status, revealed through interpretation of text generated at interview. Social and interpersonal context is similarly taken into account where issues of power and resistance, at micro and macro levels, can begin to be explored.

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### **3.2 Choosing the most appropriate methodology**

At time of writing the author has found that there are few qualitative studies into the lives of those living with psychotic experiences living outside/beyond statutory services and certainly none that attempt to explore the conceptualisations, the social impact and associated discourses created by those living with PLEs in general populations. Further, qualitative studies on psychosis are in danger of taking the subjective experience at face value/for granted lacking interpretative power; in particular where nuanced data presents itself and technical claims about language usage is missing (eg; thematic analysis; see Braun and Clarke, 2006). I have specifically chosen discourse analysis as it has the critical depth required to move beyond the descriptive leanings of more popular qualitative research methodologies and to factor the complex and shifting nature of social reality as found in language, specifically how it effects those with PLEs.

Some analytic techniques are more appropriate to unveiling the discursive nature of social influences on discourse than others. With this in mind I will apply the most appropriate method to the task at hand, with superiority of available research positions (qualitative, quantitative or mixed design) becoming less of an issue (Johnson and Christensen, 2010).

Mixed methodology, though sometimes preferred, is not always necessary or always superior to mono-method research: “*multi-strategy research should not be considered as an approach that is universally applicable or as a panacea ... There is no point in collecting more data simply on the basis that more is better.*” (Bryman, 2010: 52).

Bryman (2010) brings a common-sense approach to research design. What is most important is ensuring that the chosen methodology is relevant and applicable to meet the demands of this study. Data collected in a descriptive study such as this one (Koopowitz et al 2003) requires analysis that considers the meaning, accounts and significance of participants' (linguistic) practices presented at interview. Furthermore, mixed methodology often requires proficient and specialist knowledge requiring several experts to be involved in the design and delivery of a variety of methodologies adding pressure and additional time to the research process (Bryman, 2010). For purpose of clarity and analytic focus I have chosen discourse analysis as a mono-method approach for this study.

### ***3.3 Discourse analysis***

Burr (2001) and White (2004) are explicit that DA orientates toward Social Constructionism in that knowledge and meaning to life experiences is constructed through language. In this sense DA does not accost language in abstract terms, but looks to the pragmatic implications of language in use. Edwards and Middleton (1986) assert that discursive analysis adapts a social viewpoint to phenomena often taken from a cognitive perspective. However, the examination of discursive practices informed by socially situated influences and interrelatedness is more appropriate here, generally overlooked when a purely cognitive approach is taken (Potter and Wetherell, 1987)

Taken from the perspective of Potter and Wetherell (2007) DA as an analytic qualitative technique is designed to make sense of language use in terms of individual application, social influences and various social constructions that impact upon this

process. The authors take into account any variability in what is being communicated and in turn what is trying to be achieved (performance). Variability, function and construction of social texts are important aspects when trying to understand motives and social influences impressing upon the construction of language. Repertoires within texts can be identified, discursive usage and participant resources revealed.

As an analytic technique capable of making sense of social texts in relation to social context, variation in accounts, nuances and functionality (eg; motives of the speaker) discourse analysis can make sense of varying social realities. Unlike some traditional research methods with a primary aim to categorise responses and identify similarities between participant accounts (eg; surveys, polls, thematic analysis), DA looks for inconsistencies and compromises, encourages a diversity of interpretations and in turn appreciates the fluidity that is required when trying to explore social meaning through studying discourse. As described by White (2004) a cyclical process takes place between accounts and action: “*descriptive actions and associated actions enabled by those descriptions*”.

Discourse analysis as described by Potter and Wetherell, (2007) has been chosen for analytic purposes because of its focus upon language that is socially constructed and action (performance) orientated. This is important given the pragmatic potential presented at the end of the previous chapter that may arise from findings. Discourse analysis from Potter and Wetherell’s perspective is itself dependent on neither a developed notion of society nor of human beings and therefore aligned with social constructionism. Willig (1999) presents how discourse analysis can unravel social influences and provide social critique which exposes “*the ways in which language*

*conspires to legitimate and perpetuate unequal power relations”* (p10). Discourse analysis focuses on inconsistencies and nuances that can appear in spoken discourse (Cameron, 2013) and can reveal dominant discourse(s) that influence the discursiveness of participant accounts.

To summarise I have chosen DA as an analytic technique for this study because:

1. It is aligned with social constructionism and therefore facilitative to the discursive nature of discourse
2. Its application leans to mono-methodology bringing clarity and purpose
3. It is able to reveal the functionality and intentionality motivating application of language (eg; how speakers and authors construct social objects)
4. It is able to reveal effects and consequences of discourse created by identified groups in relation to social context

Gee (1999) maintains that DA as an analytic method can bring to light how language is able to “*enact specific social activities and social identities*” (p1). Positioning involves a social activity that engages linguistic strategies in order to preserve a sense of identity. DA can expose the positions social actors assume when taking into consideration social contexts (Tirado and Galvez, 2007).

To conclude this section and as part of introducing the succeeding sections of this chapter, I will summarily introduce the discursive elements and analytic concepts further justifying the chosen methodology and defining what can be achieved.

Up to this point in the thesis it has been established that persons sought for this study are personally challenged, primarily due to the dominance of deficit laden discourses (the meta/grand narrative) that devalues their psychotic experiences. Social conditions and the overall social discourse that is dominated by the meta/grand narrative tends to differentiate psychotic experiences from normal human experience creating various barriers for persons living with PLEs in achieving social acceptance. The meta/grand narrative is well established in Westernised societies, commonly found in everyday social discourse attached to a negative assessment of psychotic experiences. Discourse impacts significantly on the processes that “make up” people where categories of persons come into being and “new ways for people to be” materialise (Hacking 1986: 223) creating a scenario of subjectivity where identity formation takes place (Shoshana, 2012). Discourses that impact on people’s identity are often opposed initiating ‘re-constructions’ and counter representations through discursive means. In accordance with the above analyses’ opposition to assessments and interpretations that associate psychotic experiences with personal deficits is anticipated from study participants who find themselves living under its gaze. Opposition involves the ‘reconstruction’ of discourses participants are found to oppose. It is the attempts at reconstruction and counter representations of the psychotic experiences, the intention behind these discursive acts that I want to capture during one-one conversations with persons living with PLEs beyond/outside statutory mental health services. In particular, the positioning taken up by participants, their orientation, the effects and consequences of discourses presented at interview.

However, as already stated, discourses are never detached or fully removed from social context. Social conditions impact on the way we can speak about social objects

(eg; psychotic experiences) and determines the availability of knowledge from which we can draw on in order to construct a credible account of events. Accordingly, discourses are essentially discursive and to an extent adaptable toward social conditions involving compromises, ideological dilemmas and various levels of inconsistency. Variability and fluidity therefore comprise discourse formation which I expect to find in participant discourse at interview. This involves discursive constructions where I can identify resistance and opposition to a discourse through positioning taken up by participants in relation to other discourses. Having established the means by which participants have positioned themselves, I will be able to reveal the orientation of discourse constructed at interview ie; how and what participants oppose, the direction they want to take the discourse and their intended aims. There are of course consequences and effects of discourse and these will be generated by participants which I will be able to reveal through analysing the discursive performances captured at interview ie; how successful they are likely to meet the intended aims as established through participant orientation. In establishing the orientation of discourse generated at interview and in revealing the effects and consequences of discursive performances I am in a position to consider how these are impacted, influenced, compromised by wider social conditions and dominant meaning making systems. Through the 'layered' application of discourse analyses just described, I finish with a fruitful ending exploring and identifying social systems and dialogical spaces that potentially further the direction of a discourse desired by participants. Below I provide a more detailed definition of the conceptual and technical elements involved in the chosen methodology that enable me to meet the aims and objectives of this study and reach the end point whereby a level of fruitfulness can be achieved.

In summarising the sequence of analyses as described above and in order to achieve maximum clarity the aims and objectives of the study are:

Aims:

- To interview persons residing in Ireland who volunteer to share their experiences living with PLEs
- To capture and analyse discourses generated at interview by persons self-declared as living with Psychotic like Experiences residing in Ireland

Objectives:

- To reveal the discursive constructions of participant discourse at time of interview
- To reveal positioning taken up and overall orientation of discourse as appears in text generated by participants
- To reveal the consequences and effects of participant discourse at interview such as compromises and dilemmas in relation to positioning and orientation

### **3.4 Role and positioning**

As highlighted on a number of occasions maintaining a credible identity is a persistent challenge for anyone wishing to share their psychotic experiences. Wetherell (1998) describes how identity is heavily influenced by social determinates involving the availability of knowledge resources: *“Subject positions, and thus the identities of participants in social life, are determined by discourses and in this sense are prior, already constituted, and could be read off or predicted from knowledge of the relevant*

*discourse.*” (p400) That said, Davies and Harre (1990) describe positioning in terms of agency:

*“Once having taken up a particular position as one’s own, a person inevitably sees the world from the vantage point of that position... made relevant within the particular discursive practice in which they are positioned...a possibility of notional choice is inevitably involved because there are many and contradictory discursive practices that each person could engage in.”* (p 46)

Being an active agent during conversation requires a number of linguistic mechanisms. Knowledge and linguistic resources have the potential to socially situate the individual implying roles in the form of stereotypes and social identity (Sabat and Harre, 1999). The notion of role has been shown to be inadequate in linguistic and social constructionist terms. For example, according to expectant roles, enactments between patient and psychiatrist are believed to be typical and relatively static - the paternal practitioner; the passive patient (Ziółkowska, 2012). Yet, through linguistic analysis psychiatric patients have been shown to assert their identity through disengagement/engagement strategies (Chase et al., 2010). During conversations people often assume ‘positions’ which are understood as *“discursive constructions of personal narrations”* (Tirado and Galvez, 2007.) Orientation toward particular expertise and linguistic resources can help reveal the formation of subject positions that take place during social intercourse (Wetherell, 1998). Acts of positioning confirm people as active agents during interactions where actual socialisation and the construction of discourse unfold (Tirado and Gálvez, 2007). With regards participants for this study, the adaptation of a particular position on psychotic experiences (eg;

medical or spiritual interpretation or account) will be dependent on linguistic systems that are able to maximise the utilization of available knowledge resource.

Mickenausch (2012) describes knowledge as that which, “*has been defined as true and justified belief*” (p6). In discourse terms this translates into what the participant believes to be true, making conscious effort in justifying this belief through discursive means; accordingly adapting a particular position toward a social object (the psychotic experience).

### **3.5 Subject positions and discursiveness**

People tend to believe they have a “*sense of who they are*” (Djité, 2006). However, Wetherell (1998) asserts fluidity and incompleteness of personal identity. In conversation this involves participant orientations in response to ‘troubled and untroubled subject positions.’ Here it is important to distinguish between subjectivity and subject positions in the context of discourse.

Subjectivity involves consensual regulation via “*pre-existing discourses that structure the field of possible actions*”; subject position “*refers to a position within a discourse*” (Epstein, 2011, p343). In other words, subjectivity is that which is already ‘out there’ (eg; the psychosis meta/grand narrative referred to earlier) made available throughout and within the bounds of social and political configurations; a subject position is taken up by a social actor in relation to or in response to discourses that impacts them.

Epstein goes on to explain: “*Only subject-positions are produced by discourses ... It is a place-holder, a linguistic category, the I/we of a discourse.*” By contrast, “*subjectivity is a much more extensive, and consequently unwieldy, category, where all the hyperindividualized characteristics of identity are relegated — including those*

*that are not so readily transferable*” (Epstein, 2011, p343). Discourse encountered during subject position supposes agency with regards to knowledge and choice of language used, during for example, defence of one’s identity. This can be captured at a discursive level. Epstein (2011) states that: “*The distinction between subject-positions and subjectivities becomes operative once the analysis shifts beyond the individual level.*” (p344).

This research is designed to study discourse at the individual level. However, subjectivity, as something that might be warranted/unwarranted; accepted or resisted needs to be factored in order to conceive social pressures on participants in relation to their ability to account for their psychotic experiences.

To facilitate and capture the complex ‘richness’ of spoken data involving a socially defined ‘problematic’ human experience (in this case psychotic experiences) I take my lead from Wetherell (1998) who recommends a synthetic and eclectic approach to discourse analysis. A broadened approach facilitates and captures the formation and meaning behind texts paying attention to the discursive nature at one end and the social, contextual backdrop at the other. Wetherell (1998) includes in the list of potential criteria involved in an evaluation of text: variability, ideological dilemmas and interpretative repertoires. To this list, for the purpose of this study, I include consistency and will explain later why I emphasise ‘Lived’ ideologies within the realm of ideological dilemmas and have chosen discursive repertoires over interpretative repertoires. Variability, consistency, (lived) ideological dilemmas and discursive repertoires are deemed appropriate units arising out of text in order to account for subjectivity (*pre-existing discourses* found in participant’s accounts) and

subjective positioning (*position taken up within a discourse*) involved in the construction of discourse during interview. These units will be duly described and rationalised within the parameters of this study.

### **3.6 Variability and consistency**

Although, as already noted, people with PLEs are liable to share a sense of (to varying degrees) invalidation of their experiences, presentations of events, explanations and meaning making is not expected to be homogenous among participants. Patterns involving similarities and disparities, found within and between texts produced, helps contextualise “*functions and effects*” of discourses therein involving “*two closely-related phases*; 1) ‘*variability – differences in either the content or form of accounts*’ 2) *consistency – the identification of features shared by accounts*” (Elliott, 1996, p66). The effect of each account is understood in terms of observable impact; the function in terms of what is the perceived objective of the participant’s account. Elliott warns that: “*for much of the time functions are not available for study but must be hypothesized and become the end-point of the analysis*” (Elliott, 1996, p66). In other words, an attempt to understand the tensions and interface between context, proximal and distal influences on the construction of discourse emanating from participant accounts of PLEs will be applied here.

### **3.7 ‘Lived’ ideological dilemmas**

Discourse involves discussions around ‘social objects’. A social object can be an idea, practice, a concept, a belief, a ‘truth’ about the world that engages social interaction between persons. Conversations revolve around social objects and discourses emerge. As an example, with regards this thesis, at the stage of interview

the primary social object between interviewer and interviewee is psychotic experiences. However, dilemmas arise out of social objects, in particular those that are contestable and socially problematic - where ideologies clash. Weinberg (2014, citing Billig et al., 1998) describes ideological dilemmas as:

*“contradictory principles and practices that emerge as discourses in the society or culture as a whole, taken as the common sense of those communities, and not necessarily perceived by a person as simultaneously contradictory ideologies ... ideological ideals and principles may be fought out internally by an individual but they are present in the culture at large as well, making them the building blocks available for individuals’ thoughts on a matter, as well as on the construction of individual identity. They are the taken-for-granted notions in a society ... The discourses that develop as the common sense of a society contain both their ‘own thesis and antithesis” (p89)*

Challenges that arise from day to day interactions with ‘contradictory principles and practices’, at individual and cultural levels, involves ongoing transitory processes and human activity that is referred to as: ‘Lived ideology’. Lived ideologies are therefore different to the traditional conceptualisation of ideologies where they are believed to be relatively permanent, consistent and fixed conceptualisations as how ‘things should be’. Lived ideology is described in terms of *“non-formalised consciousness”* (Billig et al., 1998). ‘Contradictions’, ‘thesis and antithesis’ that appear in (lived) ideological dilemmas surfaced at interview, within the confines of this study as variabilities (above) and/or discursive repertoires described below. Also noteworthy is Weinberg’s observation that dilemmas *“may not necessarily (be) perceived by a*

*person as simultaneously contradictory*". This opens up the possibility that participants may not always be aware of contradictions within their own representations of events (or indeed positioning). I tended to these 'preconscious/subconscious' oversights that can be revealed through careful reading and re-reading of the text. By way of illustration, Tucker (2009) using discursive analysis noted that a small number of service users initially spoke positively about having received a diagnoses of schizophrenia (it provided a helpful framework to explain experiences of personal distress). However, they were found having to readjust their narratives to avert the negative consequences of a "diagnoses for life" linked with long term risk to self and the public. Self-control was of issue here where participants positioned themselves as having no control over initial levels of distress yet claiming control and autonomy over actions beyond crisis. An argument could therefore be made that schizophrenia, was an illness imposing distress on sufferers, but not linked with endangerment. This is a paradoxical duality of sorts, a dilemma that people with psychotic experiences frequently encounter and one linked to this study. Weinberg (2014) describes the detection of "*contradictory themes*" that can arise within the text in identifying lived ideological dilemmas. Participants may enact a lived ideological dilemma through discursive means using a variety of knowledge sources which are often enveloped within repertoires. Cultural repertoires are evident in delusional thinking and have been shown to be integral to the meaning making process engaged by people experiencing psychotic symptoms (Larsen, 2004). In revealing influences of wider social systems and subsequent compromises within participant positioning I will identify the presence of lived ideologies, variability and consistency found in their discourse. These discursive acts can be commonly found in repertoires constructed by participants at interview – described below.

### **3.8 Repertoires**

Burr (1995) refers to repertoires as elements of discourse such as rhetorical devices able to imbue agency to a speech actor in order to achieve effect. Grayson (1998) defines repertoires in terms of symbolic capital - coherent ways of describing something, such as a set of words; use of metaphor, facts in order to present credible accounts on particular states of the world. Potter and Wetherell (2007) describe repertoires in terms of metaphors and figures of speech. Repertoire usage is influenced by the various positions adopted by social players. It stands that they are neither socially neutral nor value free.

There is a certain social familiarity with repertoires. However, variability and ideology exists through-out their usage. Gergen (1989) uses the terms “*warranting convention*” and “*warranting voice*” to depict the intentionality behind repertoire usage that appear within discourses. In order for repertoires to be effective, knowledge and experience available to the actor is utilized and discourse engaged. Repertoires can be used to present a credible moral position or defend a particular perspective on a given topic/social object. These are often inconsistent as the actor presents different accounts according to the social environment and audience engaged. Studying spoken discourse can include the exploration of the usage of language in order to understand what is being said and achieved - in this case through the presentation of repertoires by participants of this study in relation to PLEs.

### **3.9 Discursive repertoires, not interpretative repertoires?**

The term interpretative repertoire has been used to study an “*interpretative community’s*” construction of theories, ideas and rhetoric as might appear within scientific communities (Gilbert and Mulkay, 1984) or schoolteachers (McCreary, 2011). However, given the exploratory nature of this study and that participants may not necessarily present as a single social entity (therefore not appear as an obvious community or social movement) interpretative repertoires may not apply. Taken from Wetherell et al (2001) Enberg (2011) describes discursive repertoires which are:

*“patterns of meaning which evaluate our experiences and narrate events from a personal view-point. They create versions of reality which are always ideological, that is, constructed according to the values of the author or speaker.”* (p83).

In analytic terms, locating discursive repertoires is not necessarily dependent on taken for granted, identifiable or well-known communities. Coherent patterns are merely taken from individuals with comparable experiences or similar social situations (Dean, 2003; Lin, 2007). Given the ‘hidden’ nature of PLEs in the community it is expected that study participants will come from a range of backgrounds; not necessarily within specific social circles or a homogenous collective. For reasons given discursive repertoires are chosen for this study as opposed to interpretative repertoires. Presupposing that the targeted participant group make up an interpretative community would restrict the exploratory nature of this study, including the inhibition of variabilities involved in positions taken up and assuming a collective identity prior to analyses.

The discursive nature of the identified repertoires can bring to bare the intentionality of the speaker and functionality inherent in discourses presented. To understand the

social influences in relation to PLEs, meaning can be derived not from direct experience, but accounts of lived experience validated through repertoire usage.

Below is a list of repertoires (identified by Edwards and Potter, 1992) that speech actors may utilize in order to present a credible account of events. These were chosen for their wide applicability and particular focus on discursive nature of the creation of discourse during interview, found as major components during analysis:

### **1. Category entitlement**

Expert knowledge is often expected from a person having a certain position (role). In the case of this study experience of PLEs may be presented by participants as a form of expertise.

### **2. Vivid description**

To make an account appear authentic by providing concrete details.

### **3. Narrative**

If an account might be doubted, its plausibility can be increased by making it appear inevitable in a sequence of events.

### **4. Systematic vagueness**

The use of vague and inexplicit accounts to defend an account against refutation. The account does not offer an argument and so cannot easily lend itself to criticism.

### **5. Empiricist accounting**

The use of scientific (objective) language in an argument, to raise the power of 'phenomena' over the power of people, who are seen as passive agents.

## **6. Rhetoric of argument**

Presenting an account as a series of logical statements, so that the agent is seen as something external to the speaker/actor.

## **7. Extreme case formulation**

The drawing of extreme examples to make a version of events appear more plausible and the account more effective.

## **8. Consensus and corroboration**

Noting the agreement between different witnesses to give an account more credibility and plausibility

Additional to the list of repertoires above are linguistic patterns that may arise during analysis. These include utterances that do not change the meaning of an account, but can enhance its impact by adding a punctuation effect in order to emphasise or change direction of discourse. This is achieved by drawing attention to a significant moment during an account, strategically shift the topic or reformulate the effect of a repertoire. These are typically called discourse markers (Castro, 2009) examples of which are: ‘you know’, ‘well then’, but can also appear in the form of laughter (Doona, 2016). Laughter and discourse markers highlight linguistic twists found during analysis when participants appear to be managing the structure and course of conversation; moments that generally operate at a conscious level.

In conclusion, an eclectic approach to discourse analysis was applied, having the incumbent flexibility to facilitate, encourage and make sense of diverse social realities that appear in discourses around PLEs from a first-person perspective. Variability, consistency, lived ideological dilemmas and discursive repertoires that emerge from

texts, produced by participants, were noted. These were analysed and ‘coupled’ with ‘social stimulants’ (eg; application of knowledge and wherewithal) at a macro level that have impacted on discourses that emerged during interview. This approach, as argued, facilitates the exploratory nature of this thesis with regards social burdens on those who experience PLEs, such as invalidation, revealed by way of positioning taken up by participants at interview. This enhanced the appreciation of invalidation as expressed through language by those with PLEs, and to explore how these might become representative of living with and accounting for PLEs in Western societies at a discourse level.

Transcriptions, data collection procedures and techniques for analysing texts derived from interview, were adapted and proceduralised according to instructions set out by Potter and Wetherell, (2007) below.

### **3.10 Interviews**

#### **Apprehending variability and invoking participant positioning**

In order to meet the aims of this study facilitation of one-to-one semi structure interviews that invokes variability and diversity among a number of individuals with PLEs residing in Ireland needs to take places. DA allows for active intervention during interview to achieve maximum exposure of discursive accounts (Potter and Wetherell, 2007). Interviewers are active participants and can ‘intervene’ during interview in order to exploit interpretative contexts. In essence, the interviewer is integral to the discourse produced during interview and can shape questions in order to appeal to levels of diversity and variation that participants present. Potter and Wetherell (2007) suggest constructing a “*confrontative arena than is normal*,

*dropping the formal procedures which act as a device to restrict variation” by generating interpretative accounts such as “alternative or problematic views or facts”, (p164).*

This allows me in my role as interviewer to draw out potential *“troubled and untroubled subject positions”* taken up by interviewees as referred to earlier. I presented a number of accounts of PLEs (taken from the literature review) to the interviewee in order to draw out the discursive nature of their presentation of experiences and further illuminate declared social influences. This will help clarify positioning that participants assume, elicit intentions behind the accounts offered and allowing participant’s interpretative resources to be fully explored and engaged. For instance, if the respondent seems to be offering up a non-biological/non-medical interpretation of their PLEs I will offer up a biological/medical interpretation as an alternative in order to expose the extent of the discursive nature of their account. However, Potter and Wetherell (2007) insist that interview questions need to be well planned and consistent, and that any intended intervention from the interviewer needs to be scheduled to achieve a level of coherence for purposes of analysis. The interview schedule can be found in appendix A with the intended intervention for purposes described offered near the end of the interview after interviewees have communicated descriptions, explanations, and social and relational influences over their interpretations of their PLEs.

### **3.11 Transcription**

Transcribing qualitative data from an audio recorder is an interpretative act and not a technical exercise (Baily, 2008). There is a danger of trying to emulate positivistic

research in the belief that something objective can be derived from interview texts (Scollon, 2003). Bucholtz (2007) makes the point that standardisation is becoming less of a requirement. Strategically, transcription of spoken text should be modified and adapted to meet study aims and objectives. Some analysts talk in terms of arguing for a more summative interpretation and presentation of text that might constitute more “*accurate*” representations of participants’ “*voices*”. (Jaffe, 2007). For the purposes of this thesis “*content and context ... resembled to normal texts*” is deemed the appropriate level for interpretation (Bondarouk and Ruël, 2004, p9) in order that “*pragmatic acts (e.g. directive, prohibition, claim*” can be identified (Edwards, p322).

Careful reading and re-reading of the text is always emphasised. The transcription should be as detailed as is necessary:

*“for many sorts of research questions, the fine detail of timing and intonation are not crucial, and indeed they can interfere with the readability of the transcript, particularly when dealing with extended sequences and for people unused to the system”*

(Potter and Wetherell, 2007, p166).

Potter and Wetherell (1987) describe repertoires in terms of the same phenomenon accounted for within text or among a number of speakers that is a: “*relatively internally consistent, bounded language unit*” (p.171). In other words, they tend to appear as units of texts where statements and rhetoric might appear. Lived ideological dilemmas are also likely to appear as units of text (see for example Weinberg, 2014).

The discursive performance of repertoires and lived ideological dilemmas are appeared along lines of variability and consistency. Micro-interpretation of transcripts (intonations, phonetics) is not required in the case of this study as the focus will be on ‘sizable’ portions of text. In the findings chapter I present transcripts in paragraphs and sequences of talk between interviewer and interviewee with a minimum of grammatical interpretation or influence. Tucker’s (2009) adaptation of Potter and Wetherell’s (2007) recommended technique was applied. This is inserted immediately below.

***Transcript Notation taken from Tuckers (2009) adaptation of Potter and Wetherell (2007)***

(.)	short pause, less than one second; numbers used in brackets to indicate number of seconds of pause
[]	square brackets used for brief comments by other person
—	underlining refers to emphasis
F	capitals with underlining to indicate severe emphasis
""	quote marks used when speaker drawing on third party talk
()	used when that section of talk was not entirely clear; inaudible sections marked by stating inaudible in brackets

This allowed for sufficient flexibility to facilitate the exploratory nature of this thesis. As transcription involves significant time and intimate interaction with data it benefits and becomes an integral part of analysis (Potter and Wetherell, 2007; Cameron, 2013).

### **3.12 Coding**

Chunks of text are initially categorised in order to create a manageable amount of information to rigorously decipher at a later stage. Categories were carefully coded according to the research question. In the case of this study repertoires, discursive performances (eg; discourse markers) and ideological dilemmas related to social influences associated with PLEs was selected. Potter and Wetherell (2007) insist that analysis involves identifying instances in relation to the subject matter, not the frequency of categories as occurs in other qualitative analysis. Identifying frequency of category tends to place boundaries on the interpretation of text. DA allows even vaguely related texts to be considered for categorisation. The same body of text may appear in a number of categories. In line with these recommendations, categorisation was recorded according to discursive patterns, associated repertoires and ideological dilemmas with noted intentions (eg; positioning) made by participants.

### **3.13 Analysis**

Potter and Wetherell (2007) assert that analysis that takes place within the discourse analysis paradigm is novel and difficult to describe. Looking at text from transcripts is not like an academic exercise such as reading a book, working on the gist of the message conveyed and summarising. The person(s) analysing text in the spirit of discourse analysis needs to get out of the habit of reading texts in this way and concentrate on identifying such things as nuances, contradictions and vagueness. This

helps decipher intentions of the participant, potential influences on the accounts they are offering, linguistic compromises and adjustments they might make. As a discourse analyst and as part of the process of reflexivity as described in 3.15, I critically reflected on my own 'sense making' of the text to minimise contamination of subjective values and techniques: "*The analyst asks: Why am I reading this passage in this way? What features produce this reading?*" (Potter and Wetherell, 2007, p168)

Several phases of analysis are engaged at this stage. Patterns, function and consequence are identified. The analysis forms a hypothesis based on functions and effects identified within the text with linguistic evidence produced.

### **3.14 Validation**

Once hypothesis are generated validation of findings is required. Potter and Wetherell (2007) describe several techniques to validate findings - coherence, participants' orientation, new problems and fruitfulness.

- 1. Coherence** involves looking for exceptions to a hypothesis in order to confirm or challenge an explanatory framework. If the exceptions noted are significantly removed from the explanatory framework assessment will become necessary. If there are special features of the exception that indicates obvious differences between the exceptions and hypothesis then the explanatory framework is confirmed. If no special features of the exceptions are identified, then the exclusive nature of the arrangement is scrutinised.

Approval and refutation of the explanatory framework depend on the plausibly in explaining differences.

2. **Participants' orientation** requires the analyst match their noted consistencies/inconsistencies that takes place during interaction against that of what the participant notices. This is evidenced through participant attempts to resolve, for example, contradictory accounts that appear through for example an 'interpretative device' presented at the same point of conversation. If the participants' orientation does not include inconsistencies that the analyst notes as significant then validity of the findings is in question. The analyst should not be led by their own interpretation, but that which the participant orientates toward with regards their own practice.
3. **New problems** involve the participant's resourcefulness to solve linguistic problems that occur during interaction and new problems that arise from the solution offered. The secondary (latter) system acts as a validity check to the primary (former). This indicates that linguistic resources are being applied, therefore orientation is being enacted.
4. **Fruitfulness** is according to Potter and Wetherell the most prevailing element of validity check in discourse analysis. If the scope of an analytic scheme is proven to make sense of new kinds of discourse, generate novel explanations ie; generate fresh solutions to the problems in a particular research area validity is likely to be assured.

In applying these validity checks I am confident that the production of findings is credible and in writing up the remainder of the thesis.

### **3.15 Reflexivity and intersubjectivity**

Much of the credibility that qualitative research hinges on is based on the ability (and willingness) of the researcher(s) to demonstrate that they have reflected on and addressed potential and “*actual*” influences on participant responses where “*social identity and that of the speaker is impacting on the intelligibility to her of what [the speaker] is saying and how she is saying it*” (Fricker, 2007, p. 169, as cited by LeBlanc and Kinsella, 2016, p73). The researcher must be transparent, admit to being in a position to transfer their own biases onto participants including personal values, beliefs, ideologies and experiences (Willig, 2013). However, ‘taking sides’, where the analyst chooses to sympathise or censure text during analysis will allow an antithetical approach to discourse analysis to develop. Taking sides comes from a researcher’s sense of duty or moral obligation toward a social cause ending with their analysis presented in a way that their aim appears to be to ‘enlist’ the reader (Antaki et al., 2003). Potter and Wetherwell (2007) claim that the discourse analyst should be transparent about their intentions about the research and honest about consequences of their influence over research design, implementation and analysis. In other words, my involvement in the aforementioned process of conducting discourse analysis should exhibit self-critique and self-appraisal in order to protect the credibility of their research inquiry. Conclusions need to be believable and plausible. There are several other ways that credibility of any research project can be maintained:

- 
- 1. That, I, the researcher provides a detailed description of method and context,

thereby thinking about the ways certain knowledge was selected in the first place

2. That, I, the researcher acknowledges potential biases emanating from his own experiences/interpretation (in relation to PLEs) and clearly states these where/when appropriate. Alvesson and Skoldberg (2009) conclude that "*This could be arranged at the beginning of the project, in the middle of it, just before starting composing a text, and/or during its final revision*" (p315).
3. These often appear under the umbrella of reflexivity; as significant and necessary in the validation process. In qualitative research terms reflexivity relates to issues that arise when researchers become part of the social world they are studying (Koch and Harrington, 1998).

The effects are wide ranging:

*"A researcher's background and position will affect what they choose to investigate, the angle of investigation, the methods judged most adequate for this purpose, the findings considered most appropriate, and the framing and communication of conclusions"* (Malterud, 2001, p. 483-484).

Potter and Wetherwell (2007) state that reflexivity as traditionally defined does not apply to discourse analysis, that the task of the researcher is:

*'not to document or describe problems of reflexivity but to give a practical demonstration of their effect'* (p183).

Noted below are two areas of related concern – 1. the impact of the presence of the interviewer and interactions between interviewer and participant on discursive accounts as presented at interview; 2. the potential for personal orientation of the researcher to dominate the analyses of data and presentation of findings. Below, as an additional step of achieving credibility for this study, I take a further reflexive step involving ethical dilemmas to be considered including my own role and positioning as interviewer, analyser and in presenting findings.

### ***3.16 Presence of the interviewer and interactions during interview***

Following from the above, significant is the recruitment for this study whereby the researcher declares his self-experience. There is a strong possibility that recruits assume that he has comparable experiences to their own thereby positioning him as an ‘insider’; someone who naturally understands and accepts their interpretation of accounts. Beresford (2005) suggests that this “*closeness*” exists and is a significant factor in improving the quality of research adding that the traditional belief that ‘*distance, neutrality and objectivity*’ are the only currencies to achieving findings of any real worth are at risk of delivering distorted evidence. The practice of objectivity creates distance in what should be a collaborative, non-hierarchical arrangement between researcher and participant (Dowling, 2006) creating barriers to participants providing open, authentic and genuine responses to questions at interview. In contextual and discourse terms, as described, the potential consequence of closeness is that participants may be particularly open to share their experiences with the researcher with an expectation of non-confrontation or questioning of their accounts;

or indeed reciprocal exchange of experiences taking place at interview. Identification of the researcher's influence on discursive accounts presented at interview (as per participant expectations) will become part of the analysis and presented in the findings eg; participants assuming consensus or corroboration between researcher/interviewer and interviewee.

My own role and positioning also had a bearing on the discursive constructions and discourse as presented by study participants at interview. As described in chapter 1 (1.4) I adapted a reserved position during interviews, as is my general approach when interacting with peers on a regular basis. It is my presence as someone who declares having 'lived history of mental health problems' (Recruitment Flier, Appendix C) that most likely impacted on participant responses, not necessarily the line of questioning.

Rapport between interviewer and interviewee has been shown to materialise during research where peer to peer interviewing with 'hardest to reach' groups takes place (eg: the homeless and persons with chronic drug addiction; Harding, Whitfield and Stillwell, 2010). Based on the likelihood for rapport to be built up between myself and participants, ethical challenges can arise. Rapport involves assumed or built up trust between myself and participant with the potential for participants to believe I am, by virtue of having similar experiences, 'on their side' when it comes to personal positioning or accounts of psychotic experiences. To put it another way, participants likely assumed I am an 'insider' (Zempi, 2016; Pustulka, Bell and Trabka, 2019) corroborating their version of events. I reveal incidences when participants identify with me as an insider during analyses of text generated at interview and will present their significance in the findings. Given the chosen methodology, aims and objectives

it is possible tensions would arise for myself as interviewer and researcher as my intentions, having carried out the analyses and presented findings, is to question the effectiveness and consequences of participant discourse, particularly through orientation. I am aware that this level of critique and critical analyses may go against expectations that participants may have of me; specifically, those found to position myself as insider acting as corroborator to participant's version of events. According to Pustulka, Bell and Trabka (2019) researchers identified as insiders are often conflicted in their role, with nuanced positionality taking place during the research process. I was and continue to be conscious of this ethical challenge and will discuss this when presenting findings and near the end of the thesis. Below I present similar challenges when analysing data and how I propose to overcome these.

### ***3.17 Researcher orientation during analyses and presentation of findings.***

Further to and specific to analysis, Potter and Wetherell (2007) acknowledge potential problems:

*“our accounts of how people's language use is constructed are themselves constructions”* (p,182).

Notable, is the researcher's personal experience of PLEs (referred to the first person here on in); over 20 years' active involvement with the 'user/survivor movement' with a shared concern about the power of psychiatry, its practices and its ideological dominance over mental health systems (Hölling, 2001; Morrison, 2003). I continue to engage and collaborate with a range of stakeholders (service users, ex-service users,

carers/family members, academics and professional groups) in pursuing a 'rights based' and citizenship informed mental health system. The user/survivor movement, of which I belong is acknowledged as a 'complex social movement' involving a diversity of views, political positions and ideologies (Hölling, 2001; Morrison, 2003). It is this diversity that I have witnessed, engaged and at times facilitated and will use my advantage in the context of this study - in particular my willingness and ability to hold a number of different views, opinions, positions and experiences from a range of stakeholder groups. Here participant orientation, as per validity check above, acted as a 'buffer' to encourage relegation of my (the analyst) personal orientation whilst interpreting the data. It is the participants orientation that is used to guide and safeguard the analyses from interpretative bias.

Finally, one often understated aspect to reflexivity is the influence and role of research supervisor over design, implementation and analysis of data. Dowling (2006) contends that:

*“reflection on reflexivity is not disputed” yet: “self-reflexivity is not the achievement of 'introspection' as an isolated mind in private contemplation, but always involves an intersubjective process of vibrant tension between oneself as a subject and as an object. To create this tension, a relationship with a research supervisor such as that achieved in clinical supervision is needed” (p8).*

It is time spent with the researcher's supervisors that was added to the reflexive dimension to this study. Supervisors are expected to critically examine analysis of text, questioning the researcher on their presentation and interpretation of data. On this basis and considering reflexivity as presented above the credibility of this research should stand up to scrutiny.

### **3.18 Ethics**

Research involving interviews with potentially vulnerable people is best suited to the 'ethics as process' approach (Cutcliffe and Ramcharan, 2002; Ramcharan, 2006), requiring continuous consent and an ongoing option to withdraw. This approach will be applied during interaction with participants.

Ethics was granted from DCU ethics committee, originally June 2011. The methodology has since been revised. It was agreed between the student and supervisors, that Participatory Action Research (PAR) was not essential to the aims of the research as was originally proposed. The methods of recruitment, data collection and discourse analysis remain the same. The discernible difference, apart from theoretical framework for the methodology, is the extent and pattern of engagement with the study sample once they have been recruited. In PAR it is necessary to engage the sample group in a collective participatory research activity where they would have a principal role in determining the onward process in the research inquiry (Kendon, Pain and Kesby, 2007). Although, in the revised methodology the same number of participants would be recruited, it is no longer necessary to engage them in a participatory process as part of the overall study. It was agreed that PAR would present an unnecessary challenge in terms of time and effort to the already intensive process involved in data analysis of complex discourses. See Appendix B for ethical approval after submitting revision of methodology.

It was made clear to participants that, beyond interview, data collected would become the intellectual property of the researcher, subject to his interpretation and

representation (Nunkoosing, 2005). Participants were required to agree to individual interviews before proceeding and that would be their sole involvement. It is acknowledged that research participants can become distressed as a direct consequence of questions presented at interview. However, based on the experience of the researcher's involvement in user-led research (Walsh and Boyle, 2009) and a large-scale study in which participants became troubled about questions that were of a personal nature (experiences of trauma), participants tend to be positive and optimistic about the potential impact of the research and their role therein, usually deciding to proceed (Cromer et al., 2006). Further, Knapik (2006) notes that contrary to some concerns that study participants may be passive during interview, they tend to seek and expect interaction, use the time to create dialogue, being curious, keen to explore the research topic. I have found this to be the case in studies that I have been involved in, as interviewer or interviewee and in the case of this particular study.

Even though optimistic implications for participants have been noted, there remains a potential risk that they would become distressed or withdraw due to the personal nature of the subject matter which, as presented in Chapter 2 can invoke life events that are distressing (see for example 2.24). Measures to counter such an event and/or provide support to participants post interview was offered prior to proceeding with the interview, below.

1. Ethics as process was applied (Cutcliffe and Ramcharan, 2002; Ramcharan, 2006 above) ensuring continuous consent and that participants were aware of the ongoing option to withdraw during interview.

2. Participants were offered a number of supports in the event they became upset or distressed as a consequence of the conversation during interview.

(Appendix F)

3. As part of the number of support options, participants were also invited to contact the researcher, post interview, if they reconsidered consent and/or if additional support was required. Regarding the former, the option of withdrawing consent would be discussed and if required transcripts of the interview destroyed. In the event the latter occurred, the researcher would discuss the nature of concern expressed by the participant, and if necessary, explore options for appropriate support using competencies and knowledges the researcher acquired working in the world of peer advocacy. It was made clear to participants that a timeline to contact the researcher and rectify any of the above, post interview, was three months in accordance to length of time expected to transcribe the interview and, in some cases, begin analysis. However, the researcher explained that this timeline was not strict and that the participant could contact the researcher with personal concerns outside the three month timeline.

The selection and interview schedule below address specific ethical concerns such as safety, wellness to participate, transparency and choice to engage/disengage.

The revised methodology was passed by DCU ethics committee, March 2012 (Appendix B).

### **3.19 Sample size**

Sample size is rationalised according to the analytic framework described below.

Within Discourse Analysis sample size depends on the “*analytic objective and the data source*” (Starks and Trinidad, 2007) and is not “*dependent on sample size*” (Potter and Wetherell, 2007). Given figures on the incidences of PLEs in the general population it might appear that there is a large number of people living in the community who could potentially volunteer to participate. However, Potter and Wetherell (2007) state that with regard to DA:

*“Because one is interested in language use rather than the people generating the language and because a large number of linguistic patterns are likely to emerge from a few people, small samples or a few interviews are generally quite adequate for investigating an interesting and practically important range of phenomena”.*

(p161)

The authors also assert that DA is labour-intensive and that there is a danger of getting “*bogged down*” in “*large bodies of transcript*”. Worth highlighting is the likelihood that people experiencing PLEs would belong, in research terms, to the category of “*hard to reach groups*” or “*hidden populations*” (Shaghghi et al., 2011). This is based on a high probability of personal experience of social invalidation, potential alienation and isolation as alluded to earlier and the dispersed nature of this group.

Given these words of caution and that meaningful data is not necessarily dependent on sample size the researcher believes between 15 and 20 to be a realistic and manageable number of participants, ideally made up of equal numbers of both gender representing groups 1 and 2 included in the participant criteria below. Large numbers of participants are also not required given that this study is exploratory and therefore

anticipated to lead to wider investigation into the lives of those with PLEs in Western societies. Similarities in world views and subsequent meaning within discourse between those who have used services and those who have not should surface during the analytic process.

### **3.20 Participant criteria**

Minimum age of participants was 18 years; all self-identified as having significant experience of PLEs and belong to any gender. Those who express florid psychotic experiences/states or significant impairments during interview will be excluded.

Inclusion criteria:

1. 'dropped out' of mental health services or
2. never used them.

They must declare living with PLEs with no professional support for at least three years up to the period of selection and self-identify as successfully living with their experiences. This length of time is used to indicate that the individual has been a 'successful avoider' - someone who has over time learnt how to integrate their psychotic like experiences within their daily living. This length of time has been applied to indicate successful coping in a research project (sometimes referred to as *stichting weerklank*) targeting a similar participant group. *Stichting weerklank* is described as: "a foundation for people who hear voices, see visions or other unusual perceptions" (<http://www.stemmenhoren.nl/welkom>). Romme and Escher (1989) and Bak et al (2003) provide evidence that it is the severity of psychotic experience (not necessarily associated distress) and coping strategies deployed that distinguishes between those who need and seek out care and those who do not. In accordance with

the above, three years living with Psychotic Like Experiences without professional indicated successful coping strategies deployed by the individual.

Participants were also expected to be willing to share their PLEs with the researcher.

### **3.21 Recruitment**

Participants will be recruited via advertisements distributed among organisational and individual networks and posted on social networking internet sites.

Purposive sampling will be initiated using the following mediums, where a standard advertisement will be posted and utilised for recruitment (Appendix E):

1. Social networking internet sites eg; face book linked to various mental health groups and organisations (see Appendix D)
2. Direct advertising through already established organisational and individual networks. See Appendix D for a list of organisations that the principal investigator targeted.
3. From the above recruitment strategies numbers of recruits would potentially increase through naturally occurring ‘word of mouth’ and snowballing activities - recommended by Shaghaghi et al (2011) to recruit hard to reach groups or hidden populations, ie; initial participants encouraged to pass on information and invites to peers and similar others throughout their social networks to take part in the study.

A standardised advert was placed/disseminated for recruitment purposes. This included an invite for volunteers to register interest in participating using contact details provided. Participants were able to choose from several means to register interest (email, text or phone) where they were expected to leave a telephone number

and a preferred time for the researcher to contact them. A follow up telephone call was then initiated by the principal investigator to ensure volunteers are fully aware of what the selection process and interview entails and arrangements to meet agreed. They were asked a number of questions in order to establish that they meet some initial criteria in order to proceed and also to provide some useful demographics prior to interview (Appendix E). If, having listened to an explanation about the research and the individual decided to proceed, a meeting was arranged for interview purposes.

### **3.22 Selection and interview schedule**

An assessment schedule was utilised for the purposes of selection, with volunteers asked to complete two assessments/questionnaires to ensure they meet the criteria to participate. The CAPE (1 below) was used to identify the presence of PLEs and provide some descriptive information on the participant group. A Brief Psychiatric Rating Scale (2 below) was then used for the purposes to assess capacity to participate.

1. The Community Assessment of Psychic Experiences developed by van os, Verdoux and Hanssen (see CAPE42: <http://www.cape42.homestead.com/>). The CAPE is a self-report questionnaire rating affective and nonaffective psychotic experiences (positive, negative and depressive features). The CAPE measures frequency of, as well as distress associated with, subclinical psychotic experience based on a score measured on a 4-point scale. In testing the CAPE, Konings et al (2006) found it to be both reliable and valid as a selfreport instrument within the dimensional (spectrum) of psychotic experiences. The dimensional approach is concerned with variances of

experiences on a continuum across populations and sub-groups. The dimensional approach, of which the CAPE is framed, is applicable to non-clinical groups and is therefore appropriate to this research.

The CAPE will be scored according to instructions set out by van Os, Verdoux and Hanssen

(<http://cape42.homestead.com/files/CAPEdimensionscore2003.pdf>). The researcher has been in correspondence with the team of developers of the CAPE. They agreed to give advice as to scoring if required. This was not necessary. The CAPE was used to verify people's descriptions of their PLEs and from which to compare incidences of PLEs against that reported in general populations.

## 2. The Brief Psychiatric Rating Scale.

The Brief Psychiatric Rating Scale (BPRS, Overall and Gorham, 1962) is an 18 item assessment scale. It is applicable for research rated purposes, with an anchored 7 point scale for each item used to measure positive, negative and affective psychiatric symptoms. This includes mood, behavioral indicators and psychic experiences that signify levels of psychiatric difficulties. The first 14 items are self-assessment, with the final 4 completed according to the assessor's observations. The BPRS is one of the most commonly used instruments to evaluate levels of psychopathology in individuals (Leucht et al, 2005; Rush et al, 2008). In assessing the 'cut off values' of the BPRS Leucht et al (2005) determined that an individual score of 53 or more suggested that the individual's psychotic experiences, at time of interview, is of clinical significance raising concern for their mental health. This may lead to termination of the interview with advice to seek professional help and

encouragement to use a contact provided where guidance and support would be offered to the individual.

However, a clinically significant score on the BPRS does not indicate ability to cope and live successfully with psychotic experiences. Studies previously presented in the literature review showed that it is not the level of distress or nature of the psychotic experience that is of issue but the ability to cope and integrate experiences into normal, everyday life. The BPRs was therefore used to elicit concern for the individual and prompt a discussion as to progressing to interview for any volunteer found to emulate this score. The ethics as a process approach comes firmly into focus here where a participant is found to emulate the BPRS score of 53 prompting a discussion if progression to interview is appropriate.

It must be noted at this stage that four participants were found to emulate a score of 53 on the BPRS prior to interview (53, 58, 57 and 64) and were presented with this information as being potentially problematic. However, all described their 'mental state' at interview as normal, nothing exceptional according to their every-day experience, seeking to proceed on this basis. At this point, choice to discontinue the interview at any stage was offered, with participants encouraged to use any of the supports or interventions as appears in the list at the end of the Ethics section of this chapter. All volunteers decided to proceed with no-one contacting the researcher post interview. Having gone through the sequence above participants were asked to sign a consent form (appendix G).

Both the CAPE and BPRS are in the public domain, no longer copy righted or under license. Permission to use them is therefore not necessary.

Recruitment, selection and interviews were conducted over a 12-month period, August 2012 – July 2013, following ethical approval.

Interviews were expected to take no more than one hour and were audio taped. Data was transcribed in accordance with Tucker's (2009) adaptation of Potter and Wetherell's (2007) guidelines, then analysed as described above by Potter and Wetherell (2007). A total of 16 volunteers participated in the interview. Tables 1 below illustrates the range of PLEs participants recorded using the self-reporting questionnaire CAPE, Table 2 illustrates levels of distress as recorded in CAPE associated with PLEs; table 3 presents demographic and historical information on participants. The significance of the information presented in these tables is summarily discussed at the end of this section.

The CAPE was utilised to confirm experience of PLEs with volunteer participants prior to interview ie; help ascertain eligibility to participate. Tables 1 and 2 below are used for illustrative purposes indicating cumulative range and breadth of participant's experience of PLES including associated distress levels. PLES are itemised under three dimensions, below. It must be emphasised that the presentation of this information is for descriptive purposes only. However, as explained below there is an interesting offshoot to this information, specifically related to ethics.

Items under the positive dimension are associated with positive symptoms of

psychosis (eg; hallucinations, ‘unusual/bizarre’ experiences, paranoia, grandiosity and magical thinking); the depressive dimension associated with depressive symptoms; the negative dimension associated with negative symptoms of psychosis (the latter two dimensions capturing experiences such as social withdrawal, flattening or absence of mood (emptiness and avolition), (Schlier et al., 2015).

Table 1 represents; 1. the total number of items selected by participants across the 3 dimensions, against a maximum number available; 2. The lowest number of items selected by a participant across the dimensions and highest number selected by a participant; 3. the mean items across the dimensions selected by participants against that which is available. With a significant number of items across the dimensions selected/self-reported by participants, each volunteer progressed to interview.

At a personal level, as someone who has conducted research into mental health, specifically where I declare my personal experience of significant mental health problems, I have found the general approach taken by ethics committees to be overly paternalistic. On the face of it, there appears to be a disproportionate concern for researchers with self-experience and the impact of study proposals that capture first person perspectives. My experience is borne out by Holland (2007), an academic researcher and someone declared as being diagnosed with a mental health problem, who has found, at least on one occasion, university ethics committees to be overly cautious toward researchers who have no professional background or clinical expertise, questioning their ability to deal with emergency situations, emphasising the need for screening. Holland presents this as an example of ‘ethics creep’ with a “framework designed for medical research being applied to qualitative research”

(p897). She also presents the case that participants with mental health problems are assumed and readily positioned as “vulnerable others”. With this in mind, my approach to gain ethical approval for this study was guarded, aimed to appease and address any foreseen concerns or paternal reactions from the ethics committee. I wanted to proceed without delay, keen to progress and interact with study participants. The Cape, and in particular the BPRS were included in the research proposal in direct response to my previous research experiences, accumulated knowledge and established relationships with other researchers with self-experience of mental health problems. On reflection, the screening tools were perhaps excessive and unnecessary with potential to influence participant responses such as mistrust and discourse contamination. However, as I present later, these potential effects on participant responses were not borne out during interview. Below I have summarised the scores from the screening tools as I believe it would be disingenuous or dishonest not to declare, present, or at least briefly remark on these. In doing so I etch out anything significant that arise related to this study.

**3.23 Table 1: CAPE 3 - dimension summary scores**

<b>Dimension</b>	<b>1. Total number of items selected by participants  N=16</b>	<b>2. Highest and lowest numbers of items selected across range per participant</b>	<b>3. Mean total of items selected by participants</b>

<b>Positive dimension (20 items available)</b>	197 (out of a possible total 16x20 = 320)	Lowest number of items selected - 3  Highest number of items selected - 20	12 (out of 20)
<b>Depressive dimension (8 items available)</b>	96 (out of a possible total 16x8 = 128)	Low – 4  High - 8	6 (out of 8)
<b>Negative dimension (14 items available)</b>	152 (out of a possible total 16x14 = 224)	Low – 3  High - 13	9.5 (out of 14)
<b>Total</b>	345 (out of a possible total maximum 672)	Low – 16  High – 40	27.5 (out of 42)

### ***3.24 Levels of distress per dimension as reported by participants***

Table 2 reveals levels of distress against each dimension of PLE as reported by participants. As CAPE was used primarily to help determine eligibility to participate in the interview through detection of personal experience of PLEs, distress levels as part of CAPE were deemed irrelevant regards progress to interview. From an ethical point of view levels of distress and psychotic experiences that may impact the ability

of volunteers to participate was determined by the Brief Psychiatric Scale (see above). However, given the CAPE captures levels of distress, it was deemed reasonable and prudent to score these as reported by participants post interview, consider and relate anything significant that arises from this data set.

<b>Dimension</b>	<b>1. Total distress levels reported by 16 participants against each PLE dimensions</b>	<b>2. Highest and lowest level of distress reported per dimension</b>	<b>3. Mean level of distress reported per dimension</b>
<b>Positive dimension (maximum score of</b>	114 (out of possible 960)	Lowest level of distress reported – 0 (x4)	7 (out of possible maximum of 60)
<b>distress - 20x3x16 = 960)</b>		Highest level of distress reported – 32 (out of possible 20x3 = 60)	

<b>Depressive dimension (maximum score of distress - 8x3x16 = 384)</b>	63 (out of possible 384)	Lowest level of distress reported – 0 (x2)  Highest level of distress reported – 11 (out of possible 8x3 = 24)	4 (out of possible maximum of 24)
<b>Negative dimension (maximum score of distress - 14 x3x16 = 672)</b>	96 (out of possible 672)	Lowest level of distress reported – 0 (x3)  Highest level of distress reported – 17 (out of possible 14x3 = 42)	6 (out of possible maximum of 42)
<b>Total</b>	<b>273 (possible maximum score of distress - 2016)</b>	N/A	17 (out of possible 126)

With a total accumulative distress score of 273 reported by the 16 participants against a possible maximum 2016 (column 1); a mean total across participant distress scores of 17 out of a possible maximum 126 (column 3), distress levels would appear to be minimal. This may be indicative of successful coping/living with PLEs giving further justification to interview those who emulated BPRS scores that would raise clinical concern. Worth noting is that two out of the four participants emulating the BPRS

score of 53 (the latter 57 and 64 BPRS scores above) had average distress scores on the CAPE in accordance with mean scores of the group as per Table 1 (respectively - 8 on the positive dimension, 5 depressive dimension, 8 negative dimension; 6 on the positive dimension, 5 depressive dimension, 8 negative dimension). This illustrates the point above that elevated presence of psychosis (symptoms in terms of BPRS) are not indicative of the ability of individuals to live successfully and integrate psychotic experiences in their everyday life.

### **3.25 Demographics**

As part of data collection some basic demographic and historical information was collected prior to interview. This is summarised below comprising gender ratio (row 1), age range and mean (row 2); information provided by the 9 participants who have experience of mental health services including last time they accessed these services (represented as range), extent of experience using services representing as time spent using services (row 3). Worth noting and perhaps significant to this study is that the range and mean age of participants represents a mid to elderly age group and that no one from what might be termed younger generations (30 years and below) are represented in the study.

<b>1. Gender</b>	10 male; 6 female		
<b>2. Age</b>	Range – 41 - 67	Mean – 51.5	

<p><b>3. Experience of Service use</b></p>	<p>9 participants</p>	<p>Range - Last time accessed services 3 years – 50 years prior to interview</p>	<p>Length of time using services – minimum 6 months; maximum 50 years</p>
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To summarise this section, participants were asked to complete the CAPE questionnaire to help confirm they had experience of PLEs prior to interview. All volunteers were felt to meet the criteria and progress to interview. Table 1 represents accumulative experiences of PLEs as reported by participants over the three dimensions within the CAPE questionnaire. This was used for illustrative purposes revealing the breadth and range of PLEs participants experienced. Score Levels of distress associated with the three dimensions across CAPE (table 2) were minimal, indicating participant ability to cope, live with and integrate PLES in their day to day life. To highlight this point, two of the highest recorded levels of psychosis, as indicated through BPRS scores (potentially raising clinical and therefore ethical concern) threw up an anomaly whereby the same individuals self-recorded close to the group mean levels of distress through CAPE. This illustrates the point raised that elevated presence of psychosis (symptoms in terms of BPRS) do not necessarily correlate with the ability of individuals to live successfully and integrate psychotic experiences in their everyday life. Lastly, demographics revealed that participants represented an age group corresponding with middle to old age. The ‘younger generation’ of 30 years and below are therefore not represented in this study. This may be significant and will be discussed later in the thesis.

### **3.26 Chapter Summary**

Before presenting findings, chapter 4, I want to summarise how my approach to data collection and analysis lends credibility in establishing findings. Greckhamer and Cilesiz (2014) make the point that although transparency is vital in helping readers understand how qualitative researchers arrive at a particular interpretation of data, an inevitable simplification in articulating this process exists. These authors raise a specific case for discourse analysis involving a certain level of idiosyncrasy lending itself toward *“interpretation and judgement ... shaped by an individual researcher’s epistemological assumptions and values”* (p425) The high dependency on interpretation is extenuated by the lack of ‘formulaic or mechanical’ approaches that accompanies other qualitative approaches such as thematic analysis. To achieve an appropriate level of transparency researchers applying discourse analysis need to present decision-making processes that have moved them from interpretation to findings. With this in mind, I am confident that I have presented an adequate level of transparency and trustworthiness regards my analysis of data and that the findings I arrive at are credible.

Firstly, specific to decision-making whilst interpreting data I have presented in appendix H an example of analysis that transpired, contributing to a specific finding. I also presented a number of validity checks (3.14) I applied in order to help validate findings.

Secondly, I have described my role and position in the research process and potential to influence participant expectations and responses to questions during interview (1.4, 3.15, 3.16). To restate, I remain sympathetic with anyone who constructs narratives of resistance against the meta/grand narratives, but respect and accept another’s meaning making

decision making regardless of my own epistemological commitments, personal values or inclination to 'taking sides' (more below). I believe I reserved my own opinion and judgements during interview and remained impartial to participant's personal construction and discursive accounts of psychotic experiences. That said, during analysis I was vigilant toward any comment I might make, or of any evidence of any influence that my presence may have (ie; as an insider, 3.16 above) on participant responses and presented this in the findings.

Further, I will describe the practical steps taken to ensure the analyses of data I carried out is further understood. Throughout this process I re-examined and critically reviewed my analysis, whilst reflecting on my own interpretative biases and influence during interview on participant responses. This is in line with discourse analysis, as analysis of text does not allow a linear process to arise such as weighting of one piece of text over another, or a hierarchy of patterns and categorisation to develop, but rather to appreciate and identify the interdependence of text as naturally occurs in everyday speech.

Having transcribed the text, I examined elements of the data such as potential meaning of words and sentences. From these elements I developed themes and identified patterns that make up various repertoires related to the research question. This was done on computer using the text highlighting function on word. Discursive patterns were identified such as the function of discourse markers which helped reveal discursive strategies, positioning and orientation of the discourse found within the text. The presence of compromises, contradictions and dilemmas allowed me to reveal the challenges and barriers to constructing a discourse in line with participant orientation at interview. This served as a broadening of context beyond the spoken word, helping to meet the aims and objectives of

the study. The validation criteria 3.14 was used to ensure analysis was meeting the aims and objectives expected of a study applying discourse analysis. To risk repetition, an example of analyses of a small piece of transcript can be found in appendix H.

Finally, an added dimension to research credibility is authenticity. Authenticity is dependent on expectations - to paraphrase Daza (2008) and in context of this thesis - of 'being a good researcher', whilst continuing to be a 'good peer' with similar persons who have lived experience of PLEs - participants. The position as researcher is not fixed, but discursively shaped, his/her role being 'played out' during interview (how the researcher might be imagined), and a shift in positioning taking place whilst conducting analysis and presenting findings. As a researcher taken as an insider, I am aware that expectations from participants will likely err on 'naturalized discourse' where they assume a solution to a problem. However, I am applying a methodology that 'denaturalizes' participant discourse (Greckhamer and Cilesiz, 2014), drawing their discourse into a wider context uncovering discursive performances that are found to be contrary to and compromise participant intentions as revealed through their orientation. The process of denaturalizing participant discourse goes against my own 'naturalized' position as someone who feels a strong affiliation with anyone who lives with PLEs and 'chooses' to live with these experiences outside culturally dominant meaning making systems. Daza (2008) describes situations where researchers are expected to reciprocate world views of the participant group, yet their chosen methodology presents findings contrary to this expectation. Researchers in this position often experience personal discomfort, ambivalence and complications in their positioning whilst conducting discourse analysis (Daza, 2008). I can report that I experienced discomfort during analysis and presenting findings as discourse constructed by participants were found to be greatly compromised in accordance with the wider social

context. As a result, my own positioning, as someone who had optimistic notions that the participant discourses might present something radical and new shifted. I describe my personal discomfort, and to an extent frustration whilst going through analyses and presenting findings in an epilogue at the end of this thesis. Regardless of levels of personal discomfort, ambivalence and complications to my positioning I remained committed to the chosen methodology. I argue that my commitment, regardless of personal struggles and apprehensive shift in positioning brings a certain trustworthiness and authentication to findings below and indeed successive chapters.

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## Chapter 4 – Findings

To restate from directly above, Dominance or subordination of any element of discourse should not become part of ‘doing discourse analysis’ (Antaki et al., 2003).

There is a danger of organising patterns or categorisation of features of speech hierarchically, interfering with the discursive nature of discourse - a simplification of the natural production of text.

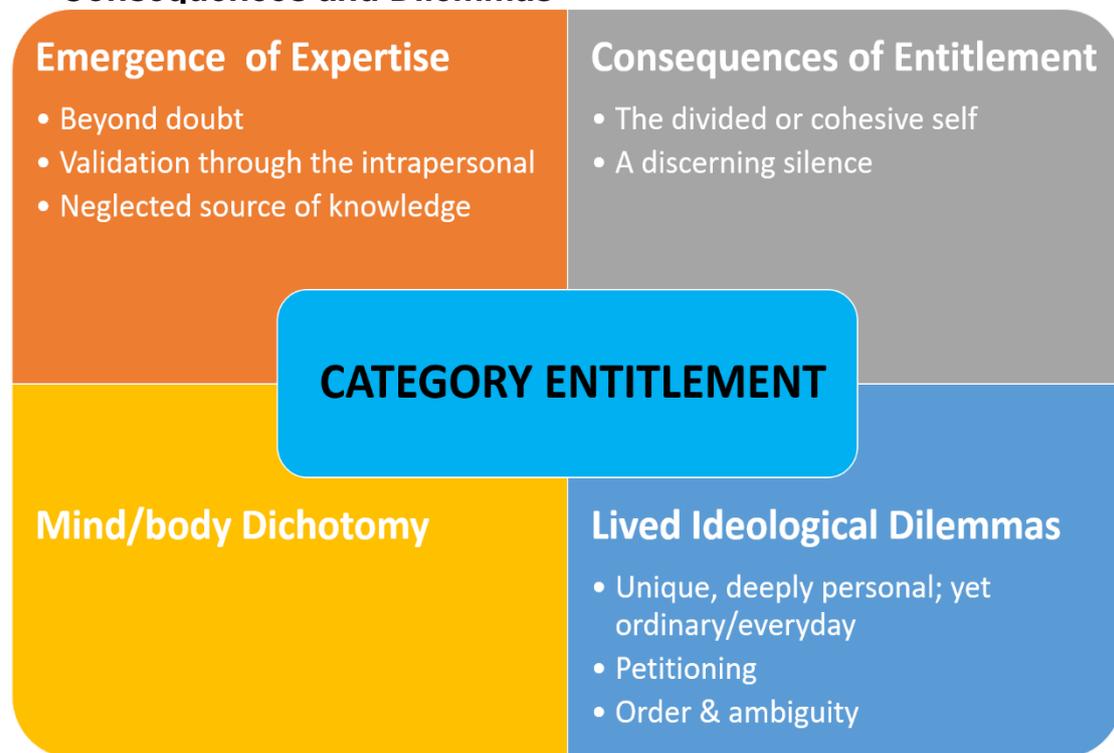
Allowing dominance or subordination during discourse analysis can indicate ‘taking sides’ as already alluded above, Chapter 3, where the aim of the researcher is to draw the reader into a social cause.

Considering the above, the sequencing of the findings below is presented to satisfy the aims and objectives of this study. While groupings of patterns of talk/features of speech are presented, distinct hierarchies, privileging or taking sides is avoided through the validation process described in chapter 3 and acknowledgement of the interrelatedness that occurs throughout the text presented in the findings below. The identification of repertoires is the primary focus of this analysis; unravelling of their usage (revealing various discursive practices) with regards linguistic performance in identity work, participant positioning and their usage leading to consequences and effects involving dilemmas. These interrelated elements are revealed to highlight issues of social power and tensions that arise during the course of ‘meaning in use’ (Holzscheiter, 2013) that took place at interview. Vis a vis: 1. Formation of identity 2. How/what positioning was achieved through the aforementioned; 3. personal and social consequences; leading to: 4. A number of dilemmatic challenges (eg; undesired compromises and unforeseen consequences). Direct quotes from participants appear

in italics, in inverted commas. Anonymisation maintained by representing participants according to the order they were interviewed ie; first participant interviewed is P1, the final becomes p17.

I begin with Figure 1 below illustrating the discursive patterns identified during analyses; their interrelatedness made visible. This is presented as an aid to help the reader follow the sequence of categorisation as presented in the findings below.

#### 4.1 Figure 1 Category Entitlement as Core Positioning, Consequences and Dilemmas



*Figure 1*

#### 4.2 Summary description of Figure 1

At the centre of Figure 1 the repertoire Category Entitlement represents participants' core positioning claiming an expertise through the lived experience. From this central core stems various sub-categories arising from discursive performances to achieve and

defend the category entitlement. The Emergence of Expertise (top left) is made up of discursive patterns that reveal how participants account for their acquisition of expertise through various knowledges and experiences secured to an individualised, personalised and internalised space. Here participants create a barrier to inquisition from external, objective forces in order to maintain credibility and protect their identity. Top right represents Consequences of Entitlement made up of a number of dilemmas at stake, involving social impact on participants holding and maintaining this expertise given communal and social settings they operate, the main effect being the silencing of the PLE and a number of ‘challenges’, namely diminished certainty to participant claims of expertise centred on the lived experience. The dilemmas bring discursive performances into a wider context by revealing their orientation. Bottom right, Dilemmas (Ideological and Lived Ideological), reveals contradictions, ambiguities and inconsistencies with regards principles and practices participants appended to their positioning. This includes a specific dichotomy (mind/body dualism, bottom left) detracting from sources of power and authority participants would be required to address if transformations are to take place to accomplish facilitation and social acceptance of the psychotic experience. Below I present findings from analyses of the data. More illustrations will appear throughout this Chapter to help bring clarification at significant junctures of the findings.

### ***4.3 The lived experience as Category Entitlement***

Contradiction in talk is a common occurrence. It often signifies issues a speaker is encountering when tending to matters of context and social interaction.

Contradictions were found throughout the data, most notably over interpretations and representations of psychotic experiences. Several discursive patterns emerged from

the data highlighting efforts made by participants to get to an end point of building credible knowledge of psychotic experiences, whereby the right of the person with direct experience to define and interpret their PLEs was promoted and defended. Multi layering of linguistic performances accompanied this complex endeavour. Discursive patterns to achieve Category Entitlement (expert knowledge proclaimed from a particular position) were engaged; presented below. An Emergence of expertise and confirmation of Lived Experience as Category Entitlement came about through discursive acts leading to the following repertoires: 1. Neglected Source of Knowledge 2. Validation through the Intrapersonal 3. Beyond doubt.

#### ***4.4 The emergence of expertise***

During interviews participants presented their PLEs as needing to be accepted; experiences that, with the passing of time were believed to be a natural part of the human condition, described as; “*ordinary*”, “*normal*”, “*everyday*”. In contrast, participants also described their psychotic experiences as very personal, individual, unique and exceptional often referring to their “*specialness*”. There was a distinct orientation of participant discourse toward ownership over the psychotic experience with entitlement to define, interpret and find acceptance contingent upon the lived experience. Entitlement to expertise in psychotic experiences could only emerge from a personal ‘journey’ toward validation resulting in a realisation that psychotic experiences were to be valued, ‘embraced’. One could not get to the point of expertise without having gone through this journey.

Whether participants began their journey into the world of psychotic experiences through early environments such as family heritage, childhood inquisitiveness in

nature, mythology or major life events; narratives that positioned them as an expert in their own right were constructed, primarily through rhetorical devices. In terms of discursive repertoires this would present as events or accounts that were often fateful, subject to destiny. Expertise has traditionally been associated with knowledge, qualifications, skills and experience sufficient enough to demonstrate competency and trustworthiness beyond what would be expected of a novice or layperson.

Grundmann (2017) notes that prestige and legitimacy precedes a request for expert advice or guidance and that expertise is relational “*mediating between knowledge production and application*” (p45). The challenge for participants is to build a personal profile that would satisfy the above criteria.

#### ***4.5 A neglected source of knowledge***

Overall, scientific (objective) measures were rarely used to bolster participant claims to expertise. However, there was a notable use of empiricist accounting in positioning people with self-experience as bequeathed with an aptitude neglected by the greater community. In the lead up to the excerpt below P11 draws upon an anthropological study carried out in Ballybran, Co Kerry, by Nancy Scheper-Hughes in the 1970s.

P11 described how Scheper-Hughes “*ran all sorts of psychological tests on the people in the village*” only to find those with the greatest insights “*into the cracks in the Ballybran community weren’t anybody who’d gone to university or were supposed to know something (1) they were these people*” (the institutionalised):

*“ they were hopeless cases as far as they were concerned (.) in Tralee mental hospital (.) very hopeless and some of them were very very depressed from what I could see (1) so what is it that they could see (1) is it that they were a more sensitive or what? (.) is it like you (.) D.E Bird before he got the minor’s lamp (.) Sir Humphreys Davy’s invention (.) in order to see there was gas in the mines they were bringing birds in so they’d fall down first (.) or they’d fall out (1) now maybe now they have modern equipment I don’t know (1) are these people more sensitive to things and they pick up the cracks in society which everyone else is denying (1) do you understand me? (1) possibly so (.) that was her (.) she was an American (.) she had no axe to grind (.) she wasn’t a protestant (.) Catholic dissenter or anything like that (.) she was just an anthropologist (.) she ran a number of psychological tests and that was her opinion.”*

Above P11 uses corroborating evidence and rhetorical devices advocating a re-evaluation of the social worth of patients from Tralee mental hospital. He initially presents psychological tests applied by a renowned academic as a credible source implying that those residing in a local mental hospital have greater insight than the general population. People with mental health problems are often believed to lack insight, but in this case, it is the general population that is labelled with this mental deficit. Qualifications or social status is irrelevant (or may even be a barrier) to achieving this insight. When P11 describes the hospital population as being “*very (.) very depressed from what I can see*” he leaves no doubt that the origins of their depression is inextricably linked to social contexts. The description of the birds that would “*fall down first (.) or they’d fall out*” provides a useful analogy of the fate of people who are exposed to environmental (social) toxics. It follows that the

institutionalised act as a social barometer to the harmful “*cracks*” in society that the local population is in denial of. It is unclear if their ‘insight’ into the “*cracks*” of society lead to their downfall, or if they gained insight because of their downfall. Either way, society would do well to acknowledge and listen to their plight with the discernible question: “*what it is they could see that others could not?*” They are victim to the failings of society and representative of a social conscience that requires attention.

Describing the institutionalised as ‘*hopeless*’, “*as far as they were concerned*” implies that those residing in Tralee mental hospital were being judged by the local community to be of little value, condemned to long-term dependency. Given P11’s positioning of the Tralee mental hospital population of the time, it would be reasonable to assume that the statement whereby he asks if they are “*more sensitive to things*” was of a rhetorical nature ie; was not delivered to elicit an answer. The real question that P11 asks appears at the end of the sentence: “*do you understand me?*” appealing to the interviewer to agree with the former part of his statement. Finally, the credentials of Scheper-Hughes and the credibility of her work was boosted by declaring objectivity and independence to her conclusions by stating that she had “*no axe to grind*”, had no affiliation, religiously or patriotically, toward the local community.

The examples of corroboration, the use of analogy and rhetorical question ending in appeal for agreement encourages the interviewer to regard the mental health inpatient, as being undervalued, potentially possessing a ‘gift’; an authority in their own right.

The discursive formation that shaped P11's account of the mental patient, was apparent across interviews. The result of this linguistic twist is that persons living with mental health problems, and by association psychosis, are 'truth holders', who, if given the opportunity could become 'truth tellers'. The truth they hold could benefit society. In these circumstances the 'truth holder' is afforded little credibility as their reality is enveloped by a social order that has negative social consequences. The social order does not only involve institutionalised care as above, but an attachment (whether accepted or not), to established orders of truth. If a person becomes attached to this social order, trustworthiness and competency is no-longer social currency. Moving from truth holder to truth teller requires a break, a questioning, a challenge, a modification, a (re)positioning of one's relationship with the order. Participants in their discursiveness shifted from a truth told, via others, to one that is individual, personalised used to good effect to further substantiate the authority of the truth holder validated through the intrapersonal.

#### **4.6 Validation through the intrapersonal**

Conventional knowledge and public perception of psychosis proposes to rid the individual from the experience ie; cure. However, if cure is unachievable, managing or integrating the experience is the next best option. This includes a requirement to reject or challenge the experience comprising an assumption that it is intolerable or unacceptable to the individual living with the psychotic experience. Under these conditions, positive aspects of the psychotic experience becomes "*a neglected secondary discourse*" (Riehards, 2008, p24). People living with psychotic experiences are implicated in a social milieu subverting their ability to know what is in their best interest. In accordance with this there is no learning to be derived from

persons living with psychotic experiences who might have an alternative perspective to the meta/grand narratives. Constructing a positive account of the psychotic experience ie; attaching value to the experience (even though it may create distress for the individual) becomes difficult and challenging. If the source of expertise (self-experience) is devalued through social disapproval, then the task becomes one of repositioning the source of knowledge and subsequent expertise. The extract below demonstrates an awareness of this particular challenge and how it can be overcome by attaching value, at an intrapersonal level, to psychotic experiences:

P12: *“Why do I live inside my head so much? (.) Why do I listen to voices? (1) And I was dismissed a lot as a child (.) teenager (.) young man (1) I was dismissed (.) you know that idea of being dismissed and I was never dismissed by the voices in my head (1) they pay loads of attention to me (.) I get a lot from them even if it’s not always positive (1) they never dismiss me”*

Prior to making the above statement P12 shared a life of rejection, trauma and misadventure. The voices he describes distressed him greatly, to a point where he attempted to drill a hole in his skull to release the resulting mental anguish. He begins by asking two questions *“Why do I live inside my head so much? (.) Why do I listen to voices?”* These are rhetorical questions, as he leaves no space for a reply, responding to the questions in a continuous sequence of talk. Rhetorical questions are described by Rhode (2006) as biased, statements that are: *“assertive, yet uninformative: instead of informing any discourse participant, rhetorical questions are redundant and serve to synchronize Speaker and Addressee beliefs.”* (p134). Further, Rhode notes that they imply an answer with an anticipated obviousness and

predictability. Putting this in context, the intention behind the sequence of talk above is to move efficiently from the initial question to an answer corresponding to: 'I'll tell you why.' This is an assertive act using irony to position the participant as victim to circumstances, having no choice but to trust and accept something that is personally hurtful and injurious due to the extent of social rejection experienced (the lesser of two evils). Synchronization is achieved as the interviewer is denied the chance to respond, becoming a silent conspirator deterred from questioning P12's assertion of truth. The psychotic experience is assured through the intrapersonal value declared. This establishes self-experience as a credible and incontrovertible source of knowledge of psychotic experiences. The 'truth holder' is afforded unique status in making a truth claim, providing impetus for the individual to protect their integrity by claiming expertise through specialist (self) knowledge.

As with the use of empiricist accounting, previously presented by P11 above, other acts of corroboration were reported. These served to endorse the social benefits of psychotic experiences with consequences to becoming an expert intrinsically linked with self-experience. Claims to specialist knowledge (ultimately expertise) was also used to denounce a single measure of psychosis (purely physiological) in order to broaden understanding of its origin and dismiss any negative consequences thereof. In the lead up to the below, P1 narrated his life's experiences involving interpersonal struggles with family and friends and battles with the psychiatric system. Throughout this sequence of talk he questions the expert opinions from practicing psychiatrists. What he called '*survivors*' of the psychiatric system led him to an independent therapist whom he found aggregable to his needs:

“[name of therapist] said that people like me were special (.) I believe that (1) I firmly believe that now (1) the organizations that I’m involved with (.) what I’m reading and what’s coming across in all these organizations is there is a spiritual thing (.) mind (.) body and soul and it’s not a chemical imbalance”

P1

P1 uses a statement from his therapist to confirm that he and others like him are “special”. He adds that what he is reading and from organisations that he is “involved with” confirm his belief that the origin of psychotic experiences is “not a chemical imbalance” but holistic, involving spirit, “mind (.) body and soul”. Given that he does not elaborate on each concept or how they might interact, a vagueness prevails. However, the inclusive manner with which P1 challenges and ultimately rejects medical terminology includes a multi-layering of corroborative sources (practitioner, literature, groups) substantiating a claim to consensual knowledge greater than that from a single point - medical expertise. The validation of self-experience, the positive remarks from his therapist combined with sources of self-learning (‘what I’m reading’) and interaction with organizations confirms his claim to specialness, including others like him. This serves to discredit medical expertise and protect his identity against negative consequences of a medical explanation of psychotic experiences.

The above discourses (P11, P12 and P1) place people with psychotic experiences in a privileged position through the exclusive knowledge dependent on self-experience.

The self-contained, private nature, interiority involved with self-experience, makes it difficult or potentially impossible to refute. This creates a secure and self-assured knowledge base from which to claim a ‘specialism’ (expertise) on psychotic

experiences. Through discursive means (corroboration, consensus, metaphors, rhetoric, category entitlement) a truth claim toward an authoritative position is achieved. The basis for the truth claim, as presented by participants, is knowledge co-existing/dependent on personal experience; the subjective. Taking the subjective as the foundation of truth provides an impetus for the establishment of an expertise outside/beyond traditional conceptions - the Expert by Experience. The 'neglected secondary discourse' becomes foregrounded through the lived experience.

Establishing the truth that lies 'within' involves the cementing of its foundation, beyond doubt.

Category Entitlement lay a foundation for an unquestionable Truth, as presented by participants.

#### **4.7 *Beyond doubt***

In order to create a discourse that serves to elevate one's identity, one needs to have an understanding as to the standards and conditions with which it is measured. This includes what might be believable and socially acceptable. It also involves knowledge from which one can attach one's identity to. Knowledge that is likely to be at odds with social conditions and standards of measurement may be met with incredulity; subject to ridicule. Knowledge does not operate in a vacuum nor can it exist in total isolation from social discourses or social convention. It therefore follows that the attachment of personal identity to sources of knowledge requires a level of awareness; conscious effort in order to address public doubt, disbelief or suspicion. This is of particular importance to those who hold a reality that is judged dubious in nature, in this instance psychotic (like) experiences. Creating a discourse from this difficult starting point requires persuasive accounts of alternate realities and world

views involving high levels of conviction and commitment to personal beliefs. In the extracts below this included performances that involved denouncement, differentiation and diversionary performances.

When asked to describe their psychotic experiences or consider a contrary theory from what they presented at interview (eg; medical or cognitive) participants invariably rejected the terminology outright and/or pointed to an intrinsic bias or predisposed consequences of the language. Below P4 responds to an offering up of an alternative view of his PLEs; in terms of biology and cognition ('faulty processing'):

*"You see (.) it depends on the frame of reference (1) like if you take that frame of reference which you (.) that you're a physical body and you can't escape those (.) and therefore that's the reality you have to answer within that reality (.) and that causes problems for me because I don't subscribe to that reality so much anymore"*

P4

P4 refers to the biological theory of psychosis as a *"frame of reference"* that fails to look beyond the body. The *"frame"* is restrictive: *2you can't escape those (.) and therefore that's the reality you have to answer within that reality"* personally damaging closing off the possibilities beyond itself. This demonstrates an awareness, on behalf of participants, of the rational structures and evaluative terms that accompany the meta/grand narratives of psychosis. It is as if the physical body is literally or figuratively trapped within these terms and structures. By rejecting frameworks that are steeped in particular rational methodologies, pointing to loaded and problematic language that causes personal problems, the opening for an

alternative, less restrictive understanding of psychosis is anticipated. A world beyond the physical, the material, creates an ontological opening for participants to create a world that may not be accessible through conventional means (eg; objectivity) or/and open to alternative ways of testing.

Discursive accounts also involved the use of metaphors and abstract ideas used to reinforce a “*truth claim*” that is “*beyond doubt*” (Holbraad, 2012); one with self-experience at the centre purposefully preserving a preferred self (Potter and Wetherell, 2007; Andersson, 2008). In discourse, metaphors are often linked with abstract ideas. The application of a metaphor involves the comparison of a familiar concept or idea with a more complex one, thereby helping others understand what is being expressed ultimately creating meaning around an experience that is significant, or preferable to the user. By way of example this includes improved understanding of biological processes related to health and wellbeing (Reisfield and Wilson, 2004). Metaphors can also indicate limitations of rationality and attract an emotional response from others (Welcomer et al, 2000; Nguyen and McCallum, 2016).

Participants deployed metaphors, analogies and corroborative statements while describing the occurrence or origin of psychotic experiences. These included words and terminologies comprising energies, spirits (animal or human), nature, mystical, mythical and ‘otherworldly’ domains with metaphysical subtexts. They were inclined to be difficult to confront due to their reliance on individual experiences, personal beliefs and their tendency to be mind-dependent ie; constructed through narratives involving the ‘imagination’<sup>7</sup>. As confirmation to the significance of the imagination to participant accounts P9, prior to the extract below, confirms that the world with which

he operates has imaginary quality, one by its very nature is difficult to demolish: *“if its less visible(.) it means it becomes a harder place to destroy”*. This leaves little doubt of the conscious power, of the level of diffusion, of commitment to and strength of belief, to an authority bestowed to the psychotic experience.

Below P9, someone familiar with Shamanism, describes how people can be affected when they become overwhelmed by personal experiences and how the Shaman culture appreciates their plight:

*“in my observation (.) when they’re traumatic experiences they fall into that category of lower world experiences and the lower world for the Shama’s is understand that things can be quite messy (.) things are very undifferentiated (1) for me it’s where the energy of creation itself are being pushed up in through the bedrock of consciousness (.) and as a consequence (.) if you meet those energies you can get messed around because they haven’t differentiated like the way lava hasn’t differentiated yet to lava rock” P9*

P9 begins with a self-avowed corroborative statement - that what is to follow is based on personal observation. Not only has he lived with PLEs, but has also supported and witnessed others living through the experience.

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<sup>2</sup> Here imagination is taken as descriptions and depictions designed to draw audiences into a narrative where ‘locations, objects, and events in the scenes (are) to be imagined’. The presentation of an event transports audiences into ‘new worlds’ compartmentalized from the ‘real world’ (Clark and Van Der Wege, 2015, p419)

This amounts to a 'layering' of corroboration to his views. Through Shamanism he *"understands that things can be quite messy"*, that traumatic experiences are compelled; *"being pushed up through the bedrock of consciousness"* and that a consequence is a struggle with realities, hence the differentiation. The use of metaphors and analogy provides graphic imagery that draws upon natural sources *"bedrock"*, *"lava"* etc providing examples of the *"energy of creation"* presenting little doubt that psychotic experiences belong to natural processes and that the worlds with which Shamanism operates and conceives exists, is genuine and appropriate to facilitate the psychotic experience.

The vivid, somewhat imaginary description of such events is appealing, framed as natural occurrences taking the psychotic experience beyond rational structures and evaluative terms normally associated with a materialism that determines biological and cognitive theories. This enables participants to take the functioning and interpretation of psychotic experience to another place, one that is diffuse; somewhat uninhibited by standard convention.

Presenting a moral and conceivable response to psychotic experiences where it is attached to an 'imagining' consciousness may not be enough to satisfy social conditions, or to put it another way demands from a dominant Westernised system of logic and rationality. What would be considered a psychotic experience would therefore warrant corroboration from sources beyond the experience itself, from reliable witnesses, in order to garner credibility to accounts. Additional to renunciation of the terms and structures with which medical and cognitive models of psychosis are aligned were discourses that defused or neutralised any chance of a

counterchallenge to a reality involving an event that might be judged psychotic.

Laughter combined with corroboration from credible observers were used to defuse any dispute to an event involving a PLE.

In the extract below laughter is used in triumphalist terms. At the request of the interviewer to describe ‘extraordinary, or ‘exceptional’ experiences which others may judge psychotic P15 describes a recurring event in his life where his clairvoyant abilities come to life. Prior to this he recalls how as a child his mother “*said*” he was “*special*”, leading him to believe he was ‘unique’, “*very open and sensitive to a lot of things*”:

*“Well it’s like me going to a film (1) and I sit down and I try to stop myself from knowing the end of it (.) cos I’d go tu tu tu and I’d say (.) and I’d write it on my hand (2) myself and my wife we’d watch the film and I’d put me hand up and I’d say this is the ending (1) that’d be two hours later (1) [laughs] and she’d say why do you watch films in the first place.” P15*

At first glance it may appear that laughter serves to play down the clairvoyant event described ie; making light of the (inevitable) outcome. However, what precedes the laughter is a vague description of events (for instance P15 could have been specific about the name of a film when this occurred), and corroboration from a witness; his wife. Both combined work to support the accuracy of the sequence presented.

Laughter arrives at a point where P15’s predictions unfold followed by a wry comment from his wife where she shares her frustration with his predictive adeptness.

Laughter is used to mark a significant occurrence in the account – of a triumphalist

moment, where the story arrives at an 'aha' or a 'gotcha' moment involving a frustrated bystander. P15's wife acts as a credible and trustworthy witness to P15's predictive abilities. Her frustration is presented as an independent authentic response to P15's predictive powers. An alternative interpretation could have been that P15 was lucky to have guessed the ending of the film. However, potential to question the account or any vagueness is overcome by the level of corroboration achieved through his wife, making it difficult to question the narrative offered up thereby, at least from P15's perspective, safeguarding the account. The account is presented as authentic, a reality beyond doubt, not to be judged or dismissed.

At this point it is worth restating the case that participants are likely to accept the interviewer as an 'insider' (as per Chapter 3, Methodology). Knapik (2006) noted that study participants tend not to be passive during interview, actively seek and anticipate interaction, willingly enter into meaningful dialogue, tending to be curious about the research topic. The interviewer's self-experience and subsequent circumstances created around the interview, the high likelihood of self-determined involvement may well have produced conditions where participants would not expect an examination (questioning) of their accounts. The likelihood of participants to present accounts that they would not normally share is increased, converse to satisfying social norms.

Beresford's (2005) emphasises, as per methodology chapter, on the closeness between peers involved in research (interviewer and interviewee) of high probability of receiving an open and genuine response also comes into play here. Given observations noted here and the expectation that the interviewer would be accepted as an insider, the interviewer/researcher believes he is assumed, by participants, a natural corroborator to accounts and realities presented at interview. In such circumstances

vagueness as applied by P15 above would be expected to go unchallenged; find acceptance, be believable. Additional, as already alluded, is awareness on behalf of participants that their PLEs sit outside ‘normal’, culturally acceptable experience. That they are sharing their experiences in the study context where they admit to being discerning when deciding to share their PLEs beyond certain social parameters provides further evidence that the researcher interviewer is accepted as an ‘insider’.

As a result of the above extracts, self-experience, whether through bodily sensations or mental activity, holds a special place. For participants, self-experience is sacrosanct. The reality that lies therein is irrefutable, cannot be judged by others; beyond criticism. Corroboration, denouncement, empiricist accounting, rhetoric and competent use of metaphors and analogies serve to protect the deeply personal PLE from cynical enquiry, diverting alternative interpretations. These discourses are deployed to achieve ‘fact constructions’ through substantiation that those living with PLEs are reliable and credible sources of knowledge (Potter, 1996) and self-experience. This demonstrates a high level of participant commitment in defending their PLEs (beyond the meta/grand narratives) situating them within other narratives or world views eg; incorporating spiritual domains. Category Entitlement, the core position of expert (by experience) is staked through the lived experience, fixed to an internal space that is impossible to penetrate or/and difficult to contest. The core positioning of category entitlement acts as a defence for the individual against social forces that might question their reality, specifically those that judge the psychotic experience as a sign of personal deficit or associate it with malfunction. I present later the individual benefits of this core positioning in maintaining emotional and psychological equilibrium (Chapter 5, Discussion, 5.1 – 5.3.5).

Below, Figure 2 brings clarity, in the order of findings as they are presented so far. I illustrate what participants, to this point have discursively achieved.

**Figure 2 Establishing and defending the right to an expertise through experience and Orientation**



Discursive performances establish and validate an assured expertise (by experience; ‘specialism’). Moving clockwise from the top of the diagram, *The Emergence of Expertise* can only be achieved through the lived experience, where a realisation and legitimisation of the psychotic experience takes place. The legitimisation of the psychotic experience involves various declarations that the experience is a *Neglected Source of Knowledge*, socially valuable, held by those with self-experience (Truth Holders) corroborated by independent observers (eg; P11). The Truth Holders are the only ones in a position, through their lived experience, to speak an inconvenient social truth, becoming Truth Tellers. A secondary layer of *Validation* occurs through the *Intrapersonal* where a repositioning of expertise is achieved, challenging traditional conceptions thereof, where self-knowledge (subjectivity, Expert by Experience) trumps external, objective sources of expert knowledge; again corroborated through independent observers (eg; P12 and P1). From establishing the journey to establish this expertise, participants place the truth held by the Truth Holder, *Beyond doubt*, out of reach of material rationalisation. This is once more corroborated by an independent observer (P15). Overall, the expertise (or specialism), knowledge derived from the lived experience is presented as reliable, reflecting a social reality that is neglected, yet socially valuable. Through the application of rhetorical devices participants were able to present situations where their expertise, attached to personal gifts, corroborated by others is irrefutable, beyond doubt creating a defence against inquisitions that might discredit their identity.

Although this is significant for the individual, the primary objective here is to reveal the effects and consequences of their discourse drawing this out into a wider context. One of the major effects of maintaining positioning, via category entitlement is a number of ‘dilemmas at stake’ (Edwards and Potter, 1992) that participants face.

Dilemma at stake comprises the possibility of an account being undermined as a product of the speaker or inferred self-interest. It follows that dilemma at stake suggests 'identity work'. Orientation begins to surface where participants present accounts of events that protect and maintain their integrity leading to compromises with social convention. Dilemmas at stake were revealed through participant accounts involving interactions with the social world, with specific pragmatic consequences. It is these dilemmas that draw participant discourse into a wider context. Performances involving dilemmas revealed participant orientation where they seek social change in favour of the psychotic experience. However, efforts to achieve social change (aligned with social convention), were found to conflict with self-declared principles, below.

#### ***4.8 Dilemmas at Stake – Invisibility and ambiguity***

The lengths to which participants went to resist devaluing of the psychotic experience and defend against critical examination demonstrates a high level of commitment to the reality therein. Through discursive means, participants presented a credible and convincing account of the benefits and 'wisdoms' that accompany psychotic experiences. Holding a position, through an orientation of positivity in favour of the psychotic experience (even when they may have been hurtful) and a claim to expertise attached to a secure and impervious internalized space had consequences for participants. Even though attempts to normalize the PLE was made, an awareness prevailed of sustained social disapproval toward the psychotic experience. Difficulty in moving beyond stereotypes, and balancing accountability were also evident. Patterns of talk with regards consequences included covert performances, accountability, subversive enactments and self-doubt arose from the text. Discursive

accounts exposed compromises and contradictions in participant positioning through dilemmas at stake involving choice, acts of aversion and ambiguity.

#### **4.9 Dilemmas and choice**

Participants emphasised transitory/transformational processes involved in learning to live with psychotic experiences. Discourses consequently become subject to modification in accordance with social learning ie; how to adapt to (perceived) social and cultural responses to the psychotic experience. Discourses involve various challenges, requiring (often subtle) shifts and changes to linguistic performances according to the social environment (proximal and distal) with the intention to maintain a credible identity. Inconsistencies and variability that emerge from discourse led to dilemmas. Dictionary definitions of dilemmas comprise choices people are often faced with. By way of example: *“a situation which a difficult choice has to be made between two different things you could do”*

(Cambridge Dictionary, 2017;

<http://dictionary.cambridge.org/dictionary/english/dilemma> definition); *“A situation in which a difficult choice has to be made between two or more alternatives, especially ones that are equally undesirable.”* (Oxford Dictionary, 2017;

<https://en.oxforddictionaries.com/definition/dilemma>). Definitions imply conscious effort on behalf of those making difficult choices.

Positioning taken up by participants, through the creation of category entitlement, is achieved consciously. As described below participant positioning has conceivably led to consequences. The possibility that the consequences have unforeseen effects such as ending in exclusionary practices is explored.

#### **4.10 A discerning silence**

Below P8 describes how she feels judged, compelled to be discerning about her experiences and daily interaction with people who do not share the psychotic experience:

*“Spirituality and working with the vulnerable (.) other world experiences put the fear of god into people to use the term because its fear of the unknown(.) and if people fear the unknown they can abuse it or they can diss (1) it so there’s that aspect as well (1) I mean there is people in my family who I said are wonderful (.) older (.) old catholic people and they think, they’re worried for me because I’m not towing the party line (.) and they sense there’s something about me that they don’t understand (.) and again its fear of the unknown (.) and they’re good people (1) that’s why the discernment comes in” P8*

P8 begins with assigning spirituality and vulnerable people to “*other world experiences*”. The “*other world experiences*” cause fear and misunderstanding among the ill-informed because they belong to “*the unknown*”. These reactions can lead to ‘*abuse*’ of the experience and pressure to conform to traditional religion. P8 goes on to describe some people suspicious of the experience as “*wonderful*” and “*good people*”. They happen to be family members described as “*old catholic people*”. The people chosen and description provided to illustrate the level of suspicion of the experience enables P8 to shift the focus of vulnerability from those with PLEs (where she begins) to those who misunderstand, misrepresent and

potentially manipulate the experience. In describing the ill-informed in terms of “old”, “wonderful” “good” people, one is left assuming, they are naive, well-meaning in their actions. As P8 demonstrates tolerance and empathy toward people that are judgmental toward the world with which she operates she can elevate her position through the creation of a ‘moral order’ (Bergmann, 1998). In this instance, P8 has established personal ethical principles incumbent upon a standard of responsibility toward others (Tileaga, 2010). The discernment with which she ends is presented as a measure to protect those who struggle to accept the experience. This operates as a rhetorical device whereby P8 orientates the discourse - that she has little choice but to take up a position of social responsibility. The discernment with which she ends is presented as a measure to protect those who naively judge the experience.

Further, the experience (psychotic) does not resolve through organized religion (Catholicism) but through spirituality orientating P8 toward the “*spiritual but not religious*” camp described further by Kenneson (2015) as “*those who wear it as a badge of honor, that a deeper, more authentic form of spirituality is available apart from religious institutions.*” (p11). Kenneson points out that those who take up this position argue that their spirituality is more inclusive, individualised, personally meaningful and less restrictive than organized institutionalized religion. Declaring a spirituality that transcends institutionalized practice (beyond Catholic traditions) adds credence to P8’s moral order.

It is worth noting that she chooses to use family members to exemplify a moral dilemma she faces. The inclusion of family members as conspirators against the psychotic experience, combined with “*old Catholic*” traditions is particularly

significant here. Commitment to family cohesion and solidarity (through religious obligations etc) remains common throughout Irish Society (Gray et al, 2016). If P8 were to threaten family stability by challenging the status quo (becoming less discerning) she may be at risk of being judged a dissenter. The account therefore brings into focus a dilemma of stake for P8 where self-interest is sacrificed for the benefit of family cohesion.

Analysis of the above extract exalts those living with PLEs. However, it also demonstrates consequences of the position participants have taken up. This includes a social conscience leading to a moral position that allows the continuation of suspicion and social dissociation from the psychotic experience. P8 does not overtly defend the psychotic experience or confront those who are mistrustful and dismissive of it. The issue here is not one of P8's intentions, but the effect of her decision to take evasive action. She therefore accedes and corroborates, via social obligations, a covert social arrangement that acts to consciously 'regulate' the sharing of the psychotic experience. This puts at risk communicating any benefits the psychotic experience may offer fellow human beings. The consequences of P8's positioning and rhetorical devices deployed leads her to moderate the possibility or viability of dialogue at the cost of social arrangements with regards such things as the Irish family and religious traditions. If P8 were to openly declare her PLEs and challenge those who are mistrustful of the experiences she might be in danger of upsetting the status quo. The effects of her actions is that she acquiesces with the social conditions and communal settings. Other discursive accounts lead to additional concessions at the behest of a widening dialogue about psychotic experiences.

#### **4.11 Universalization and the aversion of collective action**

Text created at interview determined how participants are united in their commitment to an expertise secured to a unique, distinctive, deeply personal experience of PLEs; resistant to the meta/grand narratives that dominate cultural responses to psychotic experiences. There would appear, by virtue of the shared positions participants have taken up, that a collective identity is being formed and/or is already in existence. Au (2010) underlines three elements defining collective identities. I place in brackets alongside each element, corresponding features and positioning shared by participants. 1. Salience of a shared characteristic (PLEs), 2. Group consciousness of the same problem (social exclusion, inequality); 3. opposition to a dominant order (the meta/grand narratives). Matching each element with features and positioning as presented in text at interview, participants do appear to meet the criteria of a collective identity. That said, collective identities often involve calls to action, a desire for social change propelled by an ‘imagined’, or ‘figured world’:

*‘a realm of interpretation and action generated by the participants of a movement through their shared activities and commitments that imagines the terrain of struggle, the powers of opponents, and the possibilities of a changed world. (Holland et al, 2008, p97).*

Collective identities are naturally linked with social movements which have a ‘*Cultural-symbolic component*’ (Platt and Williams, 2002) in this case the lived experience and PLES attached to that which is understood as a democratic right to equality, inclusion, social participation. In order for a collective to achieve social change it would likely be required to ‘procure popular support’, gain public attention,

garner public sympathy. Given participants seek social acceptance of psychotic experiences the desire for social change is evident. The collective identity is attached to participant positioning through category entitlement (expert by experience), the desire for social change determined by democratic ideals.

Participants' motivation for social change involved an anticipated shift in culture based on a globalised, humanitarian, universal, at times celestial world view with which they are engaged. It is "*very encompassing*" and holistic; (*'that big spiritual thing'* involving "*every faith*", P8); it requires "*raised consciousness*" and "*raised awareness*" (P13) at individual and community levels leading to personal responsibility for health and healing. Corroboration for this shift in culture, for a raised awareness of the presence and need for an altered world view comes from an 'imagined' or 'figured' world found in participant discourse. Below P6 when prompted by the interviewer to expand on her use of the term spirituality describes how she believes (as did others) that there is an ongoing transformative shift bringing the immaterial and material together, the physical and spiritual domains.

*JW: 'I'm not sure if it's called a spiritual dimension (.) so it's just kind of interesting what you were saying?*

*P6: "so there's a sense of oneness that I'm a part of (.) so it's kind of like in terms of the chakra's, (1) it's a very higher chakra awareness but then there's also a transcendent experience (.) but there's also a descending that's really only happened over the last ten years of spirit coming into matter (.) you know (.) of coming more*

*fully into physical form and more fully on to planet earth (.) this physical reality (1) yeah (.) so it's like an energetic expansion upwards and downwards and vertically."*

Text generated by P6 above leaves open the prospect that she is part of a collective identity by locating a connectiveness through: *"a sense of oneness that I'm part of"*. The oneness involves energies that are situated in the body *"Chakras"* that go beyond (*'transcendent'*)/are conjoined with a multi-directional expansion of energy: *"upwards and downwards and vertically"*. The discourse marker *"you know"* is situated as a matter of fact (more below on its usage) to corroborate the assuredness that spirit is: *"coming into matter"*, *"coming more fully into physical form on to planet earth"*; *"over the last ten years"*. The discourse created by P6 engages metaphysical properties such as time, space, existence, cause and effect. These are representative of accounts offered by participants, conditional to the 'figured world' declared at interview. The collective identity is not attributed to identifiable groups, or socially mobilised collectives but through a consensual world view made up of universal properties; concepts that are debateable, for the most part formless, having a vagueness as to their direct interaction with the material world (metaphysical). This is corroborated through self-affirmed statements and experience (*"there's a sense of"* and *"transcendent"*). The collective identity goes beyond what unites participants in their opposition to the meta/grand narratives and subsequent social consequences as they see it, but engages realms, dominions, domains that make up an imagined world beyond materialism. Holland et al (2008) claim that collective identities are *'multifaceted and dynamic cultural productions which form and reform ... defy static description'* with the concept itself resisting definition (p97). The nature of collective identities is often messy; involving *'coalescing, splintering and reshaping of*

*movements*' engaged, responding to and influenced by '*shifting fields of power, politics and economy*' (Holland et al, 2008, p106). Perhaps it is a recognition of the messiness of collective identities that leads participants to avoid the creation of or involvement in a social movement involving identifiable groups, or socially mobilised collectives. Here, participant positioning allows for a collective identity to be declared but fails to engage or acknowledge necessary steps toward the creation of a social movement that would be required to achieve the social change they aspire - that of equality, inclusion, social participation for those who experience psychotic experiences. To put it another way, participant orientation (involving preference/choice?) toward a collective identity whilst precluding the possibility of involvement in collective action on behalf of/with those with psychotic experiences diminishes the prospect for appropriate and/or significant change in social responses to those living with said experiences. Once again social dialogue is averted, silencing the psychotic experience. This relates to another layer of participant discretion specifically creating a barrier between the private self (experience) and the public (the other) hindering further opportunity to transform social response to psychotic experiences.

#### ***4.12 Silencing through the creation of 'an-other'***

Regulating, moderating the sharing of the psychotic experience can corroborate circumstances whereby a 'them and us', an 'othering' between those living with psychotic experiences and those who do not arises and persists. The claim that the psychotic experience belongs to the individual, the insistence that it cannot be questioned because of the interiority involved, creates a privileged position for those who have experience of PLEs. However, the consequence of this positioning is the

maintenance (creation?) of social distance; of closing down opportunities for dialogue, of creating an 'us and them', an 'otherness' without naming it so.

The 'us and them', the otherness is created by exclusionary practices from the other. Otherness involves discourses that distinguishes moral and political judgments between/within groups emphasising effects of superiority and inferiority (Brons, 2015; Dervin, 2015). Superiority is usually portioned out by those who enforce the concept of 'abnormal' (Goggin, Steele and Cadwallader, 2017) through models, classifications and practices directed at groups who have been characterised as disabled, disadvantaged, deficit laden (Priya, 2015; Roberts and Schiavenato, 2017). The claim to specialness, to an expertise beyond reproach and the creation of a moral order arising from participant discourse positions those with PLEs in opposition to a disability/deficit model of psychosis (ie; disablism and the meta/grand narrative as per chapter 2). The traditional concept of otherness, is therefore challenged, reversed through a superiority constructed by participants, fashioned by those who are 'abnormalised' through cultural norms, and social arrangements. However, through acts of silencing the psychotic experience (averting public dialogue), deficit models of psychosis (ie; the meta/grand narratives) are allowed to dominate cultural norms and a direct challenge averted. P10 creates a layer of otherness and superiority attached to participant narratives. Below he shows the level of caution toward the meta/grand narratives of psychosis and how, through the lived experience he has learnt to embrace the psychotic experience.

At the outset of an interview with P10, an ex-psychiatric patient, he unequivocally dismissed the term psychotic or psychosis as defined by psychiatry, describing his

experiences as “*normal*” and with purpose (having the “*ability*” to hear voices). He later adds that while caught up in the psychiatric system he “*learned in many ways to adopt my belief system to fit in theirs*” but has since come to understand psychiatry as “*misguided on understanding of life experiences*”. He also couldn’t understand why there is a need to: “*run to counsellors (1) or get ourselves into this thing that we can’t run to counsellors (1) or get ourselves into this thing that we can’t do nothing unless we have actually counselling about it (.) or that we fit within this model.*”

Prior to the response below P10, was asked his opinion on the concepts of fear and coping and if they are ever applicable to psychotic experiences. He admitted that he was fearful when he initially began to hear voices. This was due to an uneasiness created by a lack of social reference from which to frame or understand the experience.

*“I have nothing to cope with because the voices are part of me (.) it’s not about coping with me (.) it’s about living with things that are part of me(.) that at times maybe confuse me or excite me (.) the same as any other things (.) so it wouldn’t be about coping (1) it would be about living with it (2) I suppose it’s primarily because I don’t see my experiences fitting anywhere within a psychological or psychiatric model(.) because their understanding and my experiences don’t make any sense to me (.) it actually makes me (2) when I started to try and make what I believe will fit within their model I actually believe then that the psychosis is actually within that framework (1) a psychiatric framework (.) they’ve created their own psychosis because for me that way of understanding is an insight (.) and it’s an insight into*

*human being (.) and psychiatry tries to deny the fact that people are human beings.”*

P10

P10 rejects the idea that he may be coping with voices declaring that they are a part of who he is. He is *“living with”* voices that can *“confuse or excite”* him. Psychiatric or psychological models do not match his understanding or experience of hearing voices. By trying to *“fit within their model”* P10 is positioning himself as someone who is reasonable, has tried to facilitate the models that he ended up rejecting. P10 shifts the site of psychosis, from those labelled psychotic, onto those who have developed treatment models of psychosis. Psychiatry, in particular denies: *“the fact that people are human beings”*. This would indicate a dehumanising aspect to psychiatric models of psychosis. The othering in this case does not involve individuals but expert, professional groups that are associated with these models; models that have created their own psychosis due to lack of insight which P10 has gained through ‘living with’ the experience. Living with vs the modelling, the conceptualising of the psychotic experience becomes the basis for the othering that is created here. To put it another way, there becomes the ‘(with)in’ crowd, and the ‘(with)out’ crowd.

Note also, a vagueness persists as no description, exploration or definition of these models is presented or discussed. The rejection of the term coping at the beginning of this extract requires further analysis.

#### **4.13 The divided or cohesive self**

Coping would bring with it the possibility of creating a distinction between a healthy unified self and an unhealthy divided self. In other words, through the initial rejection of the concept of psychosis, taking issue with the term coping and relocating personal failings (ie; lack of insight), PM is able to divert social discourses of personal deficit, concepts of illness, disability and personal failings onto ‘the other’ - psychiatric and psychological experts aligned with deficit (meta/grand narratives) models of psychosis. To accept the terms psychosis and coping would allow a weakening of privileges and/or declared expertise attached to a cohesive self-based on the lived experience. Further, a secondary consequence of this positioning is that the othering that is created through a generalised dismissal of these models opens up the potential for criticism – as being too crude, lacking detailed analysis.

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Indeed, the otherness created goes as far as closing off all possibility of ‘outsiders’ (in particular those aligned with the meta/grand narratives) being able to empathise or relate with the psychotic experience. Participant P13 is an individual who did not engage mainstream mental health services with regards his psychotic experiences. When asked how his psychotic experiences impacted his social relations; if he shares his experience with others who might have or have not experienced PLEs declared that there is *“no facility for it”*, that: *“if you went into the mental health services (.) what the fuck would they say to you if you start talking the way I am now?”* He continues by dismissing the possibility that the ‘other’ (those associated with the meta/grand narratives) have the capability to understand or help the individual living with the psychotic experience:

*“sure the person you’re talking to hasn’t a clue (.) what you’re on about (.) they’re not on that journey (1) they don’t understand you at all so they can’t help you (1) there’s no way they can help” P13*

P13 sates that there is no *“facility”* for psychotic experiences followed by a rhetorical question: *“what would they say if you start talking the way I am now?”*. This is answered in the statement directly above ending with an assertion that: *“there’s no way they can help”*. The impact of the rhetorical twist is the rejection of those who are associated with mainstream mental health services by shutting out the possibility of helping or understanding (*“hasn’t a clue”*) the person with psychotic experiences unless having gone through a similar ‘journey’. This creates a strict demarcation, a definitive line between those who are in a position to help and understand the psychotic person/experience, and those who are not.

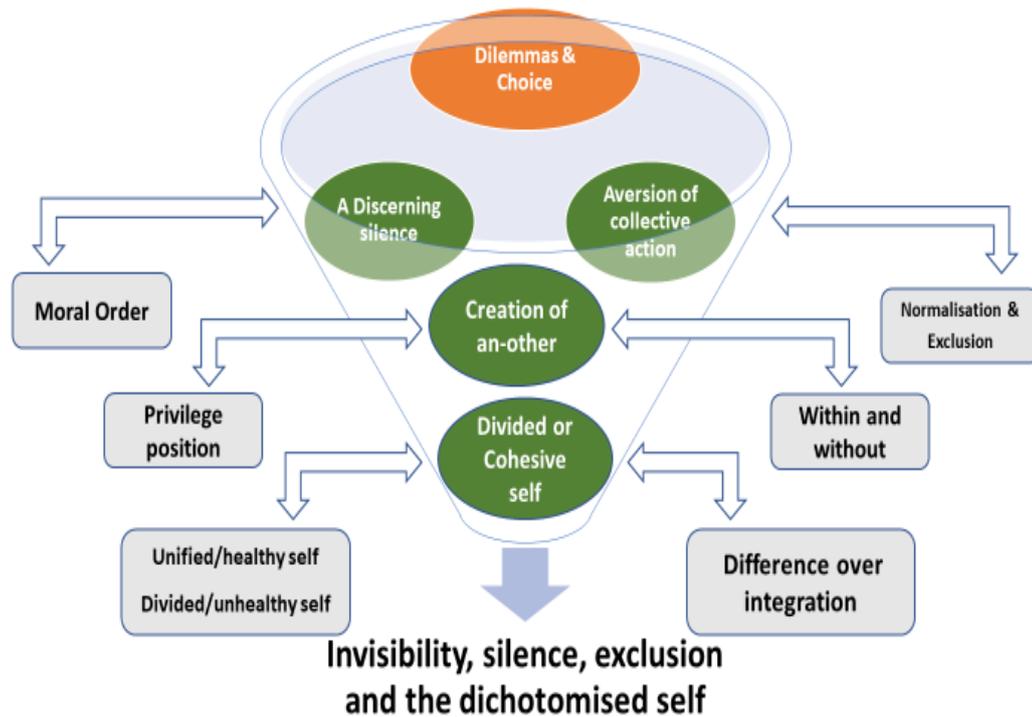
The exclusionary nature with which participants position themselves, morally and authoritatively; the enclosed space of an experience that can only be apprehended or understood through sharing, declaring and/or dialoguing (yet withheld); the acts of aversion leaves those without the experience (the other) little choice but to make assumptions or speculate about the experience. To put it another way, the ‘knowledge gap’ can therefore be conveniently bridged by cultural norms or socially informed conceptualisations such as that offered up by the meta/grand narratives of psychosis. This is the very thing participants are trying to avoid. The continuing dominance of cultural norms or/and socially informed conceptualisations of psychosis goes unchallenged, allowing various practices of social exclusion to persist.

Further, awareness of the impact of openly declaring psychotic experiences, vis a vis responsibility and commitment to social arrangements, is apparent. Participant discourses, including the latter extract from P10 when he dismisses psychiatric or psychological models of psychosis and the otherness created, implies awareness of the cultural dominance of said models. To reject these models in the manner with which it is done is to knowingly oppose the concept of ‘abnormal’ or ideas of personal deficit as informed by the meta/grand narratives. Participants are therefore conscious of the social dominance of these meta/grand narratives.

Consequences, as revealed to this point, permit a continued ignorance, disapproval and suspicion toward the psychotic experience. Under such conditions the opportunity to promote empathy is weakened and discriminating practices that disapprove the psychotic experience allowed to persist. Participants present the need to make psychotic experiences more visible, whilst ‘constructing’ the need for a measure of ‘hiddenness’ (Farrelly, 2015). At the heart of this hiddenness referred is risk – that mental health problems are associated with dangerousness - toward the self (eg; suicide) and toward the public – often rendering sufferers helpless at the whim of disease processes. Farrelly (2015), describes how the influence of media constructs a hiddenness, similar to a hidden epidemic, whereby mental health problems are often under-reported, concealed from public view, a situation explained and understood through the acknowledgement of the existence of stigma and discrimination compelling ‘sufferers’ to remain silent about their affliction.

The hiddenness presents as a dilemma at stake, were proclamations for the need to modify public responses to mental health (specifically psychotic experiences) consistently appears in text, yet, in order to divert claims of self-interest, maintain personal integrity and credibility to their accounts, participants are faced with, or on occasions choose to avert public dialogue presenting moral and social inhibitors that compel or oblige them to remain silent. Participant's discourse also reveals attempts to maintain images of a whole cohesive person (not divided), stable in their identity in order to divert disablism and the deficit model of psychosis (a divided self/incohesive self). Participants are choosing difference over integration whilst isolating the thing they represent. Another dilemma at stake arises from exposure of personal uncertainty destabilizing claims of an individualised, specialised expertise. At this stage, participant orientation is revealed, where disablism is rejected, as per the meta/grand narrative, normalisation and social acceptance of the psychotic experience is desired. However, dilemmas arise from this orientation when matched against core positioning as represented through Category Entitlement. Figure 3 below illustrates the dilemmas that arise for participants, the choices they make and their consequences.

**Figure 3. The silencing effects and consequences of commitment to orientation**



To begin, *Dilemmas* entail difficult *Choices* involving compromises and/or contradictions. Moving from the top to bottom, from left to right, participants established a *Moral Order* by declaring social responsibility toward others who are ill prepared to accept the psychotic experience (a Discerning Silence, Participant 8). The moral order established a reasoned silence surrounding the experience. Participant's desire (orientation) to *Normalise* the psychotic experience, involved declarations that it is a natural human experience, open to all. This had *Exclusionary* consequences as participants' call to universalise the psychotic experience through a sense of oneness and social acceptance (Participant 6 and Participant 8) failed to

initiate the practicalities (eg; engaging public dialogue) and collective action required to create the desired social change. Further acts of exclusion appeared when participants maintained a position of *Privilege* through the lived experience creating a demarcation, a definitive boundary based on criteria of superiority/inferiority ‘shutting out’ the ‘without’ group (Participant 10) diminishing the possibility to be understood. The creation of an ‘*Us*’ and ‘*Them*’ made up of those who have or continue to live with the psychotic experience and those who do not (the ‘within’ and ‘without’ groups respectively) created another layer of exclusion. This contradicted the desire to universalise the psychotic experience, as participant’s determinations to remain within established social convention and expectation involving democratic ideals eg; inclusion and equality were compromised. Finally, participants were faced with a dilemma involving a dichotomy that is reflective of everyday social conditions. Conscious effort was made to maintain a *Unified/healthy self* against a backdrop where a *Divided/unhealthy self* is associated with the psychotic experience. This led participants into a situation where they chose difference over integration compromising efforts to achieve social approval of the psychotic experience. All of the above feature’s participant orientation toward social acceptance of the psychotic experience yet presents a number of challenges and problematic consequences - that of a continuing silence toward the psychotic experience. Below I present findings that widen these issues further considering their effects and consequences against prevailing social conditions.

#### ***4.14 Diminishing claims to expertise through the need for***

##### ***Order and presence of Ambiguity***

The use of metaphors analogically and figuratively applied has already been discussed above. The purpose of the metaphor has been established, however questions as to

usefulness in accordance with participant's wanting to avoid or counter the meta/grand narratives of psychosis need to be considered further, specifically those that might undermine their claim to an independent individualised expertise based on a cohesive, stable identity leading to dilemmas at stake.

#### **4.14.1 Parallel use of language**

Participants often used metaphors of a technical or mechanical nature (physical phenomena) to describe processes involving their psychotic experiences. Skelton et al (2002) found similar use of metaphors within medical practice interpreted as attempts *“to repack the psychological as the mechanical. That is, the doctor’s metaphorical system may be regarded as an appropriate way of imposing ordered calm on a disparate mass of expressive data”*. (p117) Rosenman (2008) observes that psychiatric (diagnostic) concepts *“are built on embedded metaphors now treated as literal facts”*, (p391) creating a bridge *“between literal and metaphorical knowledge”* (p395). The above points to a disconnect between everyday use of metaphors involving psychological and emotional problems and clinical interpretation. However, if participants applied metaphors that are of a mechanical nature or/and encourage comparable order in their usage they may be reflective of the same clinical systems, or at least demonstrate inconsistency or incompatibility with the direction of linguistic travel so desired ie; separate their discourse from descriptions and interpretations as applied by the meta/grand narratives.

Below, P1, originally diagnosed with Bi-Polar disorder describes one of his first encounters with psychiatry whilst an inpatient in a psychiatric hospital where his professional background influenced his thinking around his ‘psychotic breakdown’.

Prior to this his psychiatrist offered to “repair” P1 stating: “ *if the fuse blew (1) I’d investigate the circuit*” to which P1 replied: *‘you’re not investigating my circuit the way you’re talking here’*”

He goes on to describe his experience with psychiatry:

*“the consultant came around again and he said he recommend ECT because of my severe depression (.) and being an electrician I thought maybe it might jog the electronics in my body (.) in my brain at the time (.) which I believed it was (.) you know electrical impulses going to wherever(1) so I agreed to have it”*

P1 describes his initial rejection of his psychiatrist’s analogy to treat his condition. However, it is apparent that he is not resistant to the analogy per say, but to the description of the (intrusive?) intervention – “*to investigate his fuse*”. Later, he considers ECT as a worthwhile treatment for his depression. This is based on an analogised comparison between symptoms of depression and faulty electronics in his brain. He confirms his commitment to this analogy by agreeing to accept ECT which “*might jog the electronics*” in his body or/and his brain. The cause has been established (analogically), the treatment recommended and accepted.

Further on, P1 describes how ECT left him feeling like a “*Zombie*” not knowing where he was; experiencing headaches, left feeling disillusioned with psychiatry.

Mechanistic analogies did not appear again in the text generated at interview.

However, when the following question was put to P1 by the interviewer: *‘What would you say to someone who would say that we are biological (.) so is there not a*

*biological part of it (.) what would you say to that?* P1 began to describe “*biological*” and “*chemical*” influences (eg; serotonin) on emotional health paraphrasing his psychotherapist who described how: “*the further back the diaphragm goes back (.) the more happy chemicals go through*”. The question put to P1 likely prompted this response. However as described earlier, this does not constitute interference but acts as an activation to provoke a response, invoking participant positioning by creating a confrontative arena (as per methodology chapter, 3.10). I was a bit apprehensive putting this question to participants. My concern was that it would be perceived as a cynical ploy, placed during conversation as an overt challenge, querying participant’s interpretation and motivation in constructing their reality. There was a potential for participants to be suspicious toward my intentions, to withdraw or ‘close down’ the conversation, no longer accepting me as an insider. Although this trepidation existed, participant responses to this question did not lead to withdrawal or reluctance to continue. There was no perceived suspicion or closing down of the conversation, nor could I find evidence in the text of any shift in levels of openness and positioning from participants. This was also found to be the case with the response from P7 below, p201 when I again created a confrontative arena.

P1 believed that spirit, mind, body, soul, and that a balance in life style comprising nutrition, exercise, meditation are necessary in maintaining good mental health and that (as referenced earlier under the theme above (Validation, through the intrapersonal) his mental health issues do not constitute “*a chemical imbalance*”. Nevertheless, there was ambiguity with regards biological influences and personal responsibility in maintaining good mental health: “*we cause the chemical imbalance*

*in ourselves (1) it's not inherent in us (.) but we cause it through our ups and downs*

*(1) now I don't know would you agree with that?"*

Above, P1 asks the interviewer/researcher for his opinion - if he agrees with his analysis that chemical imbalance is: “*not inherent in us (.) but we cause it through our ups and downs.*” This indicates uncertainty on P1’s behalf. Secondly, it is a statement that is unclear; contradictory. Something inherent suggests permanency, something essential, or a characteristic attribute; of nature or habit

(<https://en.oxforddictionaries.com/definition/inherent>;  
<https://www.merriamwebster.com/dictionary/inherent> 1/08/2017).

P1 questions if the chemical imbalance is something that occurs naturally, subject to natural or inherited characteristics or attributes; or if we cause it through our actions (eg; life choices?). It is difficult to know if the “*ups and downs*” he refers to are casual in terms of choices made or inherent, subject to natural idiosyncratic processes. The lack of clarification brings with it ambiguity. However, the main issue at stake here is not one of clarity, but emotional burden, a sign of uncertainty and need for assurance, which is contrary to the position of assuredness attached to the specialism and expertise (as per Category Entitlement) declared by participants. The exposure of ambiguity can be explained through positioning, again pointing to a dilemma at stake with particular effects and consequences.

#### **4.14.2 Ambiguity and positioning**

According to Hong (2015) the presence of ambiguity and uncertainty during conversation indicates position-taking involving personal affect and subjectivity –

visa-vis *“my style of being in the world”* (p201) In other words, position-taking in the context of P1 above is akin to an admission that he is struggling with words to describe his mental health struggles (*“I don’t know”*) and contradictions thereof. The question put to the interviewer/researcher (*“would you agree with that?”*) is an appeal, to understand or respond to his predicament. There were other examples of appeals directed at the interviewer/researcher seeking corroboration, empathy or/and sympathy signifying participant’s dilemmatic challenges involving personal affect and positioning. These present a dilemma at stake where statements of fatality and causality conflicts assertions of sureness, competency, personal responsibility toward the psychotic experience. In one hand he is saying he is sure that there is no chemical imbalance involved, on the other he is questioning whether there is personal responsibility or seeks clarification for same. Similar examples of this uncertainty are revealed in the discursive practice as illustrated through the act of petitioning.

#### **4.14.3 Petitioning**

The use of the term ‘You know’ commonly appeared throughout texts. This was specifically directed at the interviewer in order to elicit empathy or sympathy toward the interviewee. ‘You know’ appeared as 1) assumptive remarks (taking for granted that the interviewer understood the participant’s experiences or beliefs or knew what the participant was referring to 2); as matters of fact (that there was no other way of understanding or interpreting an event or experience). In line with the author’s interpretation of the use of the term ‘you know’, Laserna et al (2014) found, as a discourse marker, it is applied when the speaker is seeking and/or inferring agreement from the listener of a state of affairs or an account during conversation.

P6 speaks of her childhood experiences and how this might have influenced the appearance of some of her PLEs (later described in terms of high levels of suspiciousness):

*"I grew up in an area (.) a very rough working class area (.) it was very aggressive and very violent (1) I was quite afraid of other people and other kids you know (.) and I wanted to withdraw"*

P6 gives an account of her childhood where she experienced social/environmental impositions (aggression and violence) on her emotional welfare. *"You know"* is situated post description of these impositions and just prior to a description of conceivable adverse impact (wanting to withdraw). This is delivered to reinforce a matter of fact whilst encouraging sympathy (based on the fact that P6 could not assume that the interviewer would share this specific experience), positioning P6 as a casualty of social/environmental circumstances. Moreover, *"You know"* inviting a sympathetic response, signifies a request for affirmation, indicating diffidence and personal uncertainty.

An associative use of language appears in the application of the question: *"do you understand me?"* usually found at the end of a participant's sentence. This was used for similar purposes (P11 above) ie; to encourage an empathetic, sympathetic response (in the above example, to the participant's beliefs and experiences). Below, P11 appeals to the interviewer to understand and agree with his analyses of social conditions:

*"I seen something recently where 40% of society thought mental health patients weren't trustworthy(.) and 60% wouldn't employ them (1) I thought they were talking about politicians (1) I thought they\_were talking about bankers (.) I thought they were talking about developers do you understand me? (1) and they do things on a vast scale*

*(2) they had a responsibility (.) they abdicated that responsibility as soon as the thing fell apart (1) they paid themselves big money because they were so talented (.) I'm not completely mad (.) they're not talented (1) bitter stream begets bitter water (.) a crystal stream begets crystal (1) it's as simple as that (1) a German can't beget a Yugoslavian (.) do you understand me? (.) in that sense (.) Unless they emigrate there and sign up for citizenship (.) do you understand me? (.) How do I say it to make you understand (.) eh?"*

P11 compares the treatment of people with mental health problems to those who are questionably corrupt yet thought to be 'talented'. Metaphors are put to good use comparing pure water with water that has been contaminated and a race, Yugoslavian's, that suffered at the hands of unwanted forces during World War 2. One is left to suppose that mental health patients are the pure and the innocent; not corrupt, the oppressed at the hands of an aggressive force. He implores the interviewer to agree with his observations of people with major mental health problems being judged and by association being subjected to social injustice. He is asking approval from the interviewer through understanding and accepting how

society, according to his analyses, really operates. The repeated use of “*do you understand?*” gives rise to his need to be understood, an appeal for corroboration through empathy. The extract ends with an appeal, a pronouncement, an avowal that he is uncertain if he has got his message across and/or is struggling to find the right words or find clear descriptions to illustrate his point – “*How do I say it to make you understand (.) eh?*”

The above extracts demonstrate a desire, expressed by participants, to be understood; for a sympathetic/empathetic response to the linguistic challenges, social, institutional and environmental impositions raised and endured ie; social injustices and emotional burden. This exposes a level of ambiguity and uncertainty, a desire for affirmation of ‘being in the world’ that involves problematic personal affect that gives an impression of susceptibility, compromising self-assuredness of an independent and competent expertise secured to the subjective, that is self-experience. This illustrates self-doubt, potentially displacing self-experience from a secure position of certitude and personal responsibility to one of vulnerability. A dilemma at stake arises from this dual positioning whereby the authoritative knowledge base, staked by participants, is diminished through a reliance on others to affirm and respond to a state of emotional (or psychological) ambiguity; the latter being part of the meta/grand narratives ie; persons with psychosis predisposed to vulnerability and dependency. Further, returning to the beginning of this section, in particular P1’s contradictory positioning and use of metaphors (technological and/or mechanical), it would appear that this has been applied serving similar functions to that which reflects clinical need and interpretation ie; the need for assuredness, or/and order. This may inadvertently serve to bridge the gap between literal knowledge as per the meta/grand narratives and

metaphorical knowledge that becomes culturally acceptable. Similar use of metaphors appeared at various junctures in text generated by participants. Examples included: “Energetic blockage”, “energetic field”, “downloading”, “being plugged in”. Their usage potentially influenced by the functions of technical language, erring toward cognitive processing models developed by the meta/grand narratives where order is required or/and desired.

This is perhaps to be expected where culturally: “discourses are overshadowed by 'other' dominant discourses, and therefore derive from and feed back into existing prevalent discourses” (Talbot, 1996, p226). However, the appearance of existing, prevalent discourses attaches a vulnerability to participants, creating doubt as to social independence and expert opinion as asserted at interview through Category Entitlement. •

To conclude this section, text generated by participants revealed efforts to defend an identity attached to the PLE, whilst exposing a number of dilemmas at stake. The dilemmas at stake, the effects and consequences of these repertoires are revealed in terms of discursive performances that are contrary to original positioning taken up by participants; vis-à-vis expert by experience and the need for social change laying forth a number of challenges for participants.

Summarily they are: 1. Remaining silent and averting public dialogue about psychotic experiences whilst proclaiming a need for modifications in public response to said experiences. 2. Whilst the expert positioning is confidently asserted by participants, uncertainty, ambiguity, efforts to resist notions of a divided self, maintaining a cohesive self and a need for order was exposed running contrary to the

assuredness declared. An added dilemmatic dimension appeared in the form of Lived Ideological Dilemmas. The ideologies referred to are the principles and practices imparted by participants (eg; the creation of a moral order (p8, A Discerning Silence); the claim to expertise); the dilemmas arise from the inconsistencies and variability that appear in the text contrary to the aforementioned. These are presented below.

#### **4.15 Ideological dilemmas**

In choosing difference over integration, rejecting normalization associated with the meta/grand narratives of psychosis, participants are trying to avoid assimilation whilst remaining hidden. Simultaneously, they are promoting moral principles of inclusivity and equality.

A principle of morality can only exist in competition with or in opposition to practices that conflict it. In discourse terms Billig (1991) puts it: “*we cannot understand the meaning of a piece of reasoned discourse, unless we know what counter positions are being implicitly or explicitly rejected*” (p44). Counter positions to the meta/grand narratives of psychosis is apparent throughout participant interviews. However, taking up a counter position comprises choices that may not have the desired effect such as consequences above. Below, choices will be explored, and rhetorical devices deployed as appears in text. This will help appreciate the ideological dilemmas arising from interview.

#### **4.15.1 The appropriateness of Lived Ideological Dilemmas**

Discourse theory on ideological dilemmas contrast ideology with common sense notions, culturally established social ‘truths’, conventions and realities. This includes tensions between such things as individual autonomy and social obligations; sources of authority and implementing/promoting equality (Billig et al, 1988; Condor and Gibson, 2007). In other words, it is commonplace to declare, claim or align oneself with an established principled position such as the right to vote, yet carry out practices that contradict these revealed through, for instance, speech acts. Social actors operate under these conditions; often faced with ideological challenges on a daily basis – they are therefore lived ideological dilemmas. Here, there is a widening social context to be considered beyond personal identity; where effects and consequences of positioning through discursive performances is matched against discourses of morality, socially and culturally determined eg; those of democracy, equality, inclusivity.

#### **4.15.2 Democratic ideals and the attenuation of claims to truth**

Principles aligned with common sense notions, culturally established social ‘truths’ and realities such as acceptance and diversity; autonomy and egalitarianism were present in participant discourses (ie; their lived ideologies). Given the aforementioned; manifestations of exclusivity found within text (the Otherness) it would appear incompatible with prevailing moral positioning taken up by participants. Inclusivity, equality; principles of diversity and autonomy bring with them notions of liberality and democratic ideals ie; promoting freedoms to choose, define and create personal meaning around experiences. There is an acknowledgment and an acceptance here that experiences can be open to a number of interpretations, up for

public debate, subject to personal opinion, including ones informed by the meta/grand narratives. The following question was put to P2 who replied in accordance with the above principles:

JW: *“What would you say to people who say they have psychosis (.) that’s how they describe themselves (.) they’ve gone to see a doctor and they’ve got a diagnosis for instance and they medicate (.) and they say that’s where I’m at (.) and that’s what I understand (.) and I’m happy with that (1) what would you say?”*

P2: *“I’d say (.) then stay where you are (1) if you’re happy that’s fine (.) I have no problem with where you’re at and the only person I can deal with in my life is me”*

P2 states that she has no issue with someone with psychotic experiences who finds ‘happiness’ in medicine. Her focus is on personal responsibility: *“the only person I can deal with in my life is me.”* Prior to this statement P2 (as did most other participants) warned of the debilitating effects of psychiatric medicine; how it hinders the natural process living and dealing with problematic psychotic experiences. In extended unbroken text to the initial question P2 describes how she doesn’t *“need anyone outside”* herself, having *“reached a connection with a higher power that has guided me this whole way”*. She ends this extended response reiterating her commitment to democratic ideals: *“But (.) if somebody else needs to (1) and the medication works and going to the doctor (.) and they’re ok doing that (.) I say they should be free to do that”*. That the person may be ill informed, that P2 may have a better solution or that social or environmental influences may have a bearing on the

individual's appreciation of their psychotic experiences (for example beyond medicine) is secondary to the democratic ideals of choice and autonomy.

There are several critical elements that arise from this moral positioning leading to a lived ideological dilemma for participants:

1. That systems of institutional or political authority that participants are critical of ie; those associated with the meta/grand narratives, go unchallenged and/or indiscriminately accepted.
2. The truth; personal beliefs of psychotic experiences that participants hold to (eg; spiritual framing/'higher power') is in danger of becoming undermined as other versions of truth are just as legitimate and worthy of consideration.

Participants are left appeasing established 'every day/common sense' vis-a-vis embedded democratic ideals, whilst simultaneously holding to a personal truth that may not satisfy the analytic systems that dominate democratic societies, yet allow circumstances where the thing they resist (meta/grand narratives) continues to be facilitated/legitimised. The risk for participants becomes one of being exposed as being exclusive; dogmatic and anti-democratic forcefully asserting their truth onto others. In order to avoid such exposure, they are obliged to dislocate the certitude of their 'truth'.

#### **4.16 Unique, deeply personal experience yet ordinary/every day**

The need to dislocate truths attached to personal experience of PLEs incites another dilemmatic challenge for participants. Participants claim stake to an expertise secured to a unique, distinctive, deeply personal experience of PLEs. However, this is set against an assertion that psychotic experiences are universal, within the reach of all, its ordinariness and everydayness emphasised. Tension arises from these competing positions involving social acceptability, normalisation and individualisation. The proposition that everyone has the ability to ‘realise’ the gift of psychosis; that it is within their reach, commitment and personal effort, necessitates personal effort and commitment. The level of commitment, as above, leads to conflicts with democratic ideals participants espouse.

P 3 has never engaged mental health services but has experienced hallucinations which he links with life events (eg; death and bereavement). He intuitively interprets these psychotic events finding corroboration from various sources - from reading, research and talking to people with similar experiences. He describes psychotic events as: *“normal (.) ordinary (.) quite common”*. His journey led to contact with *“people who are distressed”*, his engagement with same becoming ‘a form of vocation’; adding that he uses ‘the word [vocation] advisably’. Following these assertions, taking into account descriptions and affirmations made by participants from previous interviews, the interviewer/researcher put the following question to P 3 which was interjected before completion. The interjection was indicative of the eagerness of participants to respond and take charge of the direction of linguistic travel during interview.

JW: *“So it sounds as if you’re (.) I’m not saying you’re gifted but there’s a sense of...”*

P 3: *“Well I think we, everybody is gifted (.) just in different ways and some people never wake up to their gift because the wakening up process can be (1) as in my case (.) I woke up to some gifts that I realized I have but I believe that everybody else has the same kind of gift (.) but they haven’t woken up to them because if you’ve wakened up to some of these gifts they become responsibilities (.) and that can be (.) not demanding but they can be (.) literally a responsibility to respond to them or else to be irresponsible and step back from them (1) if you step back from them I think you diminish yourself (.) if you try to live up to them I think you can enhance yourself (.) enhance your life and make your life much more meaningful.”*

Interjections in conversation indicates emotional intentions of a speaker interrupting the flow of another. This can include perceived conditions of dominance (eg; men dominating women; see Zimmerman and West, 1975) or *“high involvement”* (Tannen, 1994) an eagerness to engage, indicating that the subject matter is of particular significance or importance to the ‘interjector’. Given earlier claims that participants are found to be an empowered and willing cohort regards participation, it is likely that it is eagerness (‘high involvement’) that motivated P 3’s intervention when the question was put to him by the interviewer/researcher. Moreover, the issue of self-interest was evident in the discourse above, involving ‘self-initiated self-repair’ - a speech act that is initiated and performed by a speaker in order to correct any

ambiguity surrounding a potential trouble source (Hutchby and Wooffitt, 2008). The act of self-initiated self-repair requires conscious effort, is often applied to maximise clarity and rectify any potential misunderstanding of a word or phrase through self-interruption and/or editing (Schiffrin, 2006).

In the case of P 3 above he brings attention to the use of the word “*vocation*” as it applies to his self-found “*gifts*” cautioning that it is used “*advisably*”. The cautioning operates as self-initiated self-repair. Vocation is commonly linked with acts of occupation, career or profession, but can also have religious connotations eg: a calling into priesthood. As P 3’s cautioning toward the word vocation is not explored it would be presumptive as to what, in the given context, his specific issue(s) with the word is. However, following his cautioning of the appropriateness/applicability of the word vocation the words gift and responsibility appear.

A gift is something understood as something given, received and/or something that a person may be endowed with eg; a skill, competency or intuitive ability. The word responsibility implies something we become/are expected/obliged to be accountable to/for. P 3 describes the realisation of his gift of PLEs as enabling him to help those in distress. This orientates his PLE in the direction of personal endowment as described above. The added dimension of responsibility that he refers to resonates choice with regards to realising or developing personal endowment. In order to ‘wake up’ to the gift(s) of psychosis; to utilise and “*enhance your life and make your life much more meaningful*” the benefactor has: “*a responsibility to respond to them or else to be irresponsible and step back from them*”. The consequences of stepping

back is that you *“diminish yourself”*. It follows that the ‘specialness’, the expertise that participants declare can only be obtained if the individual becomes responsible for/toward the psychotic experience.

The principle of choice in engaging the psychotic experience is also emphasised by P13. Prior to the statement below, and similar to P3, he extolled the virtues of the psychotic experience, believing it had a healing dimension that everyone can learn from:

*“so you either have to be willing to go through that or you don’t go through that (1)  
that’s a choice you make” P 13*

The individual has to be *“willing* and choose to engage the PLE in order to ‘discover’ its healing powers and wisdoms therein. Here, the everyday principles of choice and autonomy, reflective of socially and culturally established discourses of morality determined by democratic ideals are being promoted by participants. However, even though these culturally established principles are endorsed and promoted by participants, contradictory positions exist, whereby alignment with democratic ideals becomes conflicted through the creation of a social hierarchy, expanded below.

#### ***4.17 An unintended hierarchy?***

Common to ‘democratised’ societies is the liberalisation of the individual, of the right to social participation, of being recognised as an individual with unique opinions, beliefs, practices and needs (Thelan, 2014). Choice and autonomy lie at the heart of the aforementioned. P3 uses the principle of autonomy to distinguish between those

who indulge the psychotic experience for the benefits of their own personal development and for social good ie; to help people who are distressed and those who do not. <sup>8</sup> According to participants there are a number of routes to encounter the psychotic experience, some of which merge or co-occur - 1) inducement through human intervention, often in group settings (eg; hylotropic breathing) 2) experiences inherited/handed down via previous lives lived (eg; reincarnation) 3) traumatic life events. Choice may be involved in any or all of these routes eg; choosing to engage human intervention (1) to induce the psychotic experience which may become associated with previous lives (2) or/and traumatic life events (3).

However, choice to enter the psychotic experience was not always explicitly stated by participants and in some cases the psychotic experience appeared without warning, beyond their control.

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<sup>8</sup>-By way of demonstrating the interrelatedness of the discursive nature of participant's positioning, evidence of a social hierarchy as appears in text has already been constructed through the 'other', the creation of an us and them. However, the distinction here is that 'the other' serves as a measure of resistance to dominant ideals and cultural norms (meta-grand narratives) constructing a superiority serving to protect personal identity (dilemma at stake with exclusionary consequences); the hierarchy above is constructed in a way that participants are claiming to live out, assume dominant ideals and cultural norms assimilating and acquiescing to social practices and expectations yet perform contradictory practices.

Psychotic Like Experiences have been shown to be relatively common throughout populations (see chapter 2). However, this information also leaves us with a current fact that the great majority of individuals throughout general populations do not share the psychotic experience. The potential for any-one to experience PLEs has also been alluded, however the proviso would be that an element of choice would be required of the person who does not share the experience, in order to engage it and reap its personal and social benefits. Here, the dilemma (challenge) lies at two levels.

Firstly, there is an insistence to normalise, through the encouragement and promotion of the psychotic experience thereby initiating social acceptability, whilst claiming stake to an expertise secured to a unique, distinctive, deeply personal experience.

Participant positioning of personalised expertise becomes diluted through the universalisation of the experience. Under these conditions being endowed with a gift, maintaining a level of 'specialness' attached to personalised expertise becomes standardised, mundane, everyday even banal. Any claim to expertise (or specialism), as culturally understood, is undermined through the commonality of the experience.

Secondly, responsibility for/toward the psychotic experience becomes dependent upon the willingness of the benefactor to utilise and 'harvest' the experience. This creates a distinction between those who engage the psychotic experience and those who refuse, are unwilling, are afraid to or remain 'stuck' in their psychotic world. This orientates toward judgemental and exclusionary practices. The former diminishes and negates participant claims to an individualised, specialised expertise; the latter creates an exclusivity, a social hierarchy that inhibits the social flatness endorsed by democratised and liberalised societies that participants consent to ie; through their

universalization all psychotic experiences are of equal value and that people should be judged according to their willingness to accept and/or engage the psychotic experience.

There is a dichotomisation at work here splitting categories of people.

Dichotomisations commonly occur in everyday discourse, appearing in discursive accounts generated by participants, below.

#### **4.18 Embodied text**

Participant positioning relies heavily on the internalisation of the PLE placing emphasises on public/private worlds extending into a mind/body dichotomy. Their resistance to the meta/grand narratives, reliance on non-material, alternative frames of psychotic experiences (mind, soul, spirituality) yet reference to the material (physiological, biological) influences is present. Problems of ‘dualistic conceptions of mind-body’ arise. Willig (2000) suggests problems of mind-body dualism can be overcome by understanding the generation of text through the process of embodiment. The extent with which participants overcome this culturally imbedded dichotomy of mind/body dualism, the consequences and effects and where this leads them is explored below.

##### **4.18.1 Dichotomisations. The mind body problem and embodied discourse**

People tend to believe that their bodies are occupied as opposed to their existence stops at their body.

*“we do not feel as if we are our bodies; we feel as if we occupy them.”*

(Bloom, 2004, as cited in White, 2015)

This points to a dualism, involving dichotomous thinking (Wilson, 2010) eg; Globalization or Internationalisation; Science or Mysticism; Mental illness or Social phenomena. A mind-body dualism ie; a division between the material and the nonmaterial; a belief that a soul, a spirituality, a mind, a consciousness exists outside/beyond the everyday materiality that is our physical bodies continues to *“circulate through Western culture”* (Alexandra, 2015, p41). By way of example, Singleton (2012) refers to national surveys involving teenagers (US, Great Britain and Canada) where it was found approximately half believe in an afterlife. In his own study of 13 –29-year-olds (combining data from national census of Australia, interviews and survey) he found that participants harboured a spirituality that hinges on the belief that there is an afterlife; therefore, once the body dies and decomposes, the soul, spirit; some form of consciousness, life or presence prevails. This allows religious or spiritual convictions to endure as our existence beyond our bodies remains a possibility. The secularisation of nations, where traditional religious institutions and practices have declined, have tended not to diminish the belief in the existence of the immaterial as part of human existence; where a spirituality is increasingly individualised: *“Idiosyncratic”, “self-directed”* and *“eclectic” “reflecting prevailing cultural trends and trajectories”* (Singleton, 2012, p466). Dualism in broad terms subordinates one ideology over another (either/or) often disregarding contexts, the fluidity and potential for *“relational dialogism”* (Wilson, 2010). Where mind-body dualism is particularly challenged, is how the immaterial (mind) and material

(brain/body) interact. To put it another way, what are the casual relations between both, what is/are the mechanism(s) through which they influence one another?

•  
P7, someone who had a long history of using psychiatric services, at one stage being hospitalised for approximately 12 years, created a dualism through rhetorical means when asked by the interviewer/researcher the following:

JW: *“what would you say to somebody who would come along and say (.) you’ve been through the system (.) it’s obvious that you’ve had a mental illness and (.) you know it’s all biological (.) so therefore you’re in remission and you know (.) what would you say to somebody like that?”*

P7: *“Did you ever have the flu?”*

•  
JW: *“Ok (.) yeah.”*

•  
P7: *“And are you in remission from the flu?”*

JW: *“Ok”*

P7 does not address the question put to her head on; but diverts via a rhetorical device. She firstly addresses the question, with a question: *“Did you ever have the flu?”*. The interviewer is subsequently drawn into a sequence of talk led by the interviewee. Given the question *“Did you ever have the flu?”* is one with high probability of receiving an affirmative response (which happened: *“Ok (.) yeah”*) P7 is prospecting that she would be able to follow up with another question completing the rhetorical

sequence whereby the interviewer does not contest the account; where synchronisation between the interviewer and interviewee is complete. Further, an added dynamic may have arisen where, as noted earlier, the interviewer is highly likely to be perceived as an ‘insider’, a collaborator; the interview taken as facilitative and non-confrontative. P7 may reasonably have taken for granted that her rhetorical questions would be met with a corroborative and agreeable response. Not only does this sequence of talk end in an inclination toward corroboration to P7’s denunciation of a medical interpretation of her (continued) psychotic experiences, it also establishes a dichotomy that separates illness (physiology) from psychotic experiences. There is an implicitness, a subtlety (ie; it is not immediately obvious) to this rhetorical process that ends in this dichotomy. However, some participant accounts were more explicit in their established beliefs and positioning regards dichotomies, specifically mind/body dualism. This involved causality.

#### **4.18.2 Mind/Body dichotomy, causality and discourse**

##### **connectives**

Inferences to causal relations can be found in discourse markers. Specifically, these are termed Discourse Connectives-: “*generally understood as explicit indicators of discourse relations within a text*” (Rysová and Rysová, 2014, p452). The presence of discourse connectives has been shown to be universal (Rysová. 2017). Discourse connectives can appear in single word format: ‘because’, ‘therefore’, ‘however’, ‘so’, ‘when’, ‘and’, ‘is’; or appear in multi-word formations: ‘and due to’, ‘what naturally follows is’, ‘the result is’ (Rysová. 2017). When applied, discourse connectives can stimulate casual interpretation (Sanders and Mulder, 2009), highlight or raise awareness of casual interactions between entities (Ramesh and Yu, 2010). In a world

where: *“Humans see causality everywhere and in everything ... encoded in the grammar of various languages”* (Le Guen et al, 2015, p2) discourse connectives can help underline casual relations. The appearance of discourse connectives reveals performances of a discursive nature enabling speakers to highlight preferred causalities complimentary to their world view. Discourse connectives were occasionally used by participants. However, given participant positioning, claiming an expertise attached to an enclosed internalised intrapersonal space, particular attention is paid to discourse connectives that reveal lived ideological dilemmas of a dualistic nature involving the public/private; mind/body dichotomies offered up during interview. Some discursive accounts offered by participants, involving mind/body dichotomies were sustained and methodical; an example of which follows.

P5, who had limited experience of mental health services, stated he was *“clear”* that:

*“what happened to me wasn’t an illness”; “you’re feelings and your thoughts are coming from you’re physiology (.) they’re nothing to do with anyone else”; “your body’s there before your mind (.) and your mind makes sense of your body”; “I think I’m fairly clear that the brain and the body are the same thing”.*

P5 is constructing a dichotomy common to dualism; dividing mind and body. He utilises the single word connective ‘*and*’ to combine thoughts and feelings which are fastened (“*coming from*”) to the ‘mechanics’ of the body – “*physiology*”. He also secures the brain to the body believing they are ‘*the same thing*’. It might appear that he ranks the body over the mind “*there before*” but ends in determining that the mind has a higher-level function: “*your mind makes sense of your body*”. This dualism,

where the immaterial and the material; the mind and body become dichotomised was present throughout participant's discourse with a distinct predilection for the immaterial to subordinate the material. Further, P5, similar to other discursive accounts, places self-experience in terms of privacy (my business) and/or out of reach of others: *"feelings and your thoughts ... they're nothing to do with anyone else"*. This adds another dichotomous layer of disconnect vis a vis; between the internal experience and communal life.

P5 presents this dichotomy to justify his belief that his PLEs were not illness related ie; physiologically determined. However, if the *"mind makes sense of your body"* a logical conclusion, based on common sense notions made up of social 'truths' and realities would be that processing of information is taking place ie; thinking and rationalising as an activity is involved. If P5 chooses a dualism that subordinates the material body for the immaterial (mind) he is at risk of emulating cognitive theory that "assumes that cognition is the property of individual minds. The body and the social context are conceptually separate" (Alexandra, 2015, p542). However, contrary to this P5 believes thinking takes place in the body: *"thoughts are coming from your physiology"*.

The discursive nature of his discourse (found throughout other participant's discourse<sup>9</sup>) is contradictory and ambiguous and fails to resolve his rejection of illness or cognitive deficits (vis a vis meta/grand narratives) being related to his PLEs. Moreover, in contrast, to the above-dichotomies, there were attempts to construct a mind-body holism (Hamilton and Hamilton, 2015) in the form of an embodied sense

of self, fashioned by the generation, influence and distribution of knowledge through history and culture.

**JW:** *“So there’s the spiritual (.) there’s the body thing(.) and you did use the term you know (1) the thoughts and feelings (.) what would you say or what would you say to people who say this is all just kind of fuzzy stuff (.) really you can’t have a mind without a brain and your body can’t exist (.) we’re biological beings and our thoughts and feelings (.) surely there’s a connection to the brain and all that stuff (.) how would you respond to people like that?”*

**P5:** *“I think my mind is much bigger than that (1) my mind to me is social (.) ideas aren’t just in brains, they’re in books (.) they’ve come down through the centuries (.)*

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<sup>9</sup> Here I refer back to P1 above and return to the interrelatedness of the discursive nature of participants positioning demonstrated through the degree with which mind/body dualism creates problems for participants. P1 believes the origin of psychotic experiences is ‘*not a chemical imbalance*’ but holistic, involving spirit, mind, body, soul. In contrast he later describes biological and chemical influences on mood: ‘*...the further back the diaphragm goes back, the more happy chemicals go through ...*’ applying metaphors that are of a mechanical nature (similar to that found in medical practice) and assumes an ambiguous position as to personal responsibility in creating a chemical imbalance: ‘*...we cause the chemical imbalance in ourselves, it’s not inherent in us... I don’t know would you agree with that?*’ The level of ambiguity reveals the extent of the problem participants are trying to address in detaching their experiences from a material determinism from which the meta/grand narratives depend.

*through culture (1) my mind isn't just the brain and the brain isn't only in the head (.)  
it's all the way through your body."*

Above, P5 responds to a problematic view, as presented by the interviewer, of his attempt to separate psychotic experiences from illness through mind-body dualism. The interviewer alludes to a reliance on the body and brain in order to exist, highlighting the significance of biology, its relation to thoughts and feelings, connecting mind and brain. P5 does not explicitly deny this, declaring that what follows is based on his own belief about the view presented to him: *"I think"*. He continues utilising discourse connectives that make causative connections between mind, society and ideas. These are insistent, applied in certain terms; the mind *"is"* social, *"ideas aren't just in brains, they're in books"*. He then goes on to apply some multi-word connectives specific to ideas which seem to flow: *"come down through"* historically, and *"through culture"*, ending *"all the way through your body"*. P5 is offering a holistic dualism (Hamilton and Hamilton, 2015) where *"knowledge is understood as a product of an interaction between human society and its world"* (Jungert, 2013, p2), the embodied sense of self being shaped *through* social forces with casual consequences that end up impacting the material body which the brain is part of. Describing the mind as *"social"* may imply that it is a mere concept constructed for social/metaphorical purposes and/or is the 'vessel' through which information, knowledge and historical/cultural influences and experiences flow. It is hard to know which or perhaps it is both? This attempt at dualistic holism is however in contrast to the previous statements P5 made where a distinct dualism between body and mind is carved, where a disconnect between the internalised self-experience (made up of thoughts and feelings) and communal life is expressed. He later admits:

*“god it’s very hard to define these things isn’t it?”* indicating an awareness of a lived ideological dilemma. This problem, I argue below, is common to Western society, a discourse that may not have the desired effect for participants.

#### **4.19 A common problem**

It is easy to draw attention to the lack of consistency, the ambiguity that exists here. The level of discursiveness is reflective of the mind/body dualism that has *“plagued Western philosophy since the Enlightenment”* (Hamilton and Hamilton, 2015, p3); found in every day social, scientific and medical discourse (Demertzi et al, 2009; Mehta, 2011; Riekkii et al, 2013). Hamilton and Hamilton (2015) go on to claim that resolving the problem of dualism is *“a complex and gargantuan philosophical and scientific task”* (p3), one that might never be resolved. The lived ideological dilemma for participants is not so much the contradictions and ambiguities that accompany their usage of mind/body dualism in defending their position regards the meta/grand narratives (indeed they are replaying the mind-body dualism that already exists in greater society), but their ability and likelihood of transforming, revolutionizing, converting public discourses on psychotic experiences through mind/body dualism. Dualism, as Bordo (2004, p8) argues *“cannot be deconstructed in culture the way it can be on paper”*. Similarly, Wilson (2010) contests that dualism *“has led to the privileging of theory over experience”* (p 734). Bordo and Wilson maintain that consequences of dualism on groups that are socially misrepresented and/or devalued cannot be addressed at an intellectual or academic level but through social (inter)action (where *“the “margins” are brought to the “center”*”; Bordo, 2004, p28). In referring to, appealing to, or relying on mind-body dualism to counter the meta/grand narratives of psychotic experiences, participants may be preventing, as referenced earlier, ‘relational dialogism’ to take place at

communal and societal levels where facilitation, perceptions and responses to the psychotic experience can improve. This is one of participants' primary concerns, yet regardless of accounts of dualistic holism their positioning commits them to a dualism subordinating the material for the immaterial; or to put it another way 'mind' (spirit, soul) over 'matter'. The end product, I argue, is that discourses that subordinate one element of existence (the material body) for another (the immaterial mind, spirit, soul), specifically those that replay culturally imbedded dichotomies, may only serve to distract from the material world where political authority and structural power operates - elements of Western society that cannot be ignored if the social transformations participants aspire is to occur. This I expand in the discussion. However, before bringing findings to a conclusion, I present Figure 4 below illustrating the consequences of participant orientation to achieve the social acceptance of the psychotic experience so desired.

**Figure 4. The ever-widening context of participant Orientation, unintended consequence and effects**

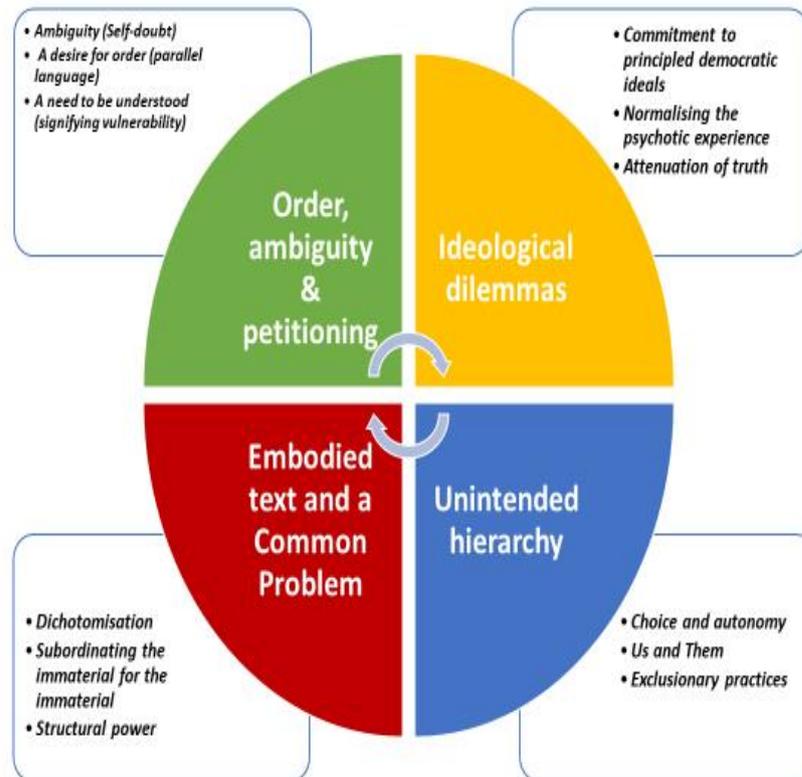


Figure 4 illustrates the consequences and effects of participant’s discursive performances taking into consideration the orientation of their discourse drawing it into an ever-widening context. Working clockwise from the category, top left. The presence of *Ambiguity* in participant’s discursive performances, the desire to stabilise the psychotic experience through a discourse of *Order* (similarly found in a meaning making system allied with the meta/grand narratives) and the extent of *Petitioning* to establish corroboration and certainty to their accounts destabilised participant’s claim to a self-assured expertise. This highlighted levels of self-doubt and vulnerability

contrasting with the self-assured position of expert by experience. *Ideological Dilemmas* contrasted participant awareness and subsequent commitment to every-day social convention (ie; Lived Ideological Dilemmas vis-a-vis democratic ideals) against the surety of their ‘truth’ that is anchored to the subjective, lived experience. Conforming to democratic principles of choice involving the right of others to hold various accounts of psychotic experiences, allows indiscriminate acceptance of competing interpretations conceding the legitimisation of the meta/grand narrative. Here, attempts to *Normalising* the psychotic experience, translated through the non-material is less likely to find social acceptance where a knowledge gap can be easily filled by the meta/grand narrative. Therefore, the democratic ideals participants expressed led to conditions where attenuation of their self-assured truth through a specialism (Expert by Experience) resulted. Personal responsibility aligned with social convention, that is democracy, where persons need to take responsibility and embrace the psychotic experience, otherwise they will be “diminished” as a human being created a *Non-intended hierarchy*. An *Us* and *Them* was established through this act of exclusivity, once again contradicting democratic ideals vis-à-vis social inclusion and equality. Finally, participants discursive performances reveal a lived ideological dilemma played out in everyday discourse, yet to be concluded in Western society – that of a mind/body, material/immaterial dichotomies. I put it that the *Embodied text* where participants subordinate the material for the immaterial fails to conclude this dichotomy (as they believe they have), presented as a route to normalise the psychotic experience and does not address the structural material power that maintains the meta/grand narratives. In summarising Figure 4, the orientation of discourse as revealed through participant discursive acts ultimately leads to attenuation of their self-declared/self-assured expertise and truth, a silencing of the

psychotic experience and presents dilemmas involving contradictory practices (exclusion and formation of social hierarchy) failing to address the structural power that maintains the meta/grand narratives challenged throughout their interviews. I provide an overall summary of findings below.

## **4.20 Summary/concluding findings**

Text generated from one-one interviews were analysed to reveal the existence of repertoires and the discursive manner with which participants relate their identity and achieve positioning when accounting for their PLEs. Attention was paid to the effect and consequences (compromises and dilemmas) that their positioning has on their day to day interactions with the social world, through their desire for change through the orientation of their discourse. The positioning reached through discursive means and subsequent consequences and effects of their orientation is summarised in the remaining part of this chapter.

### **4.20.1 Summary findings**

Participants, defended their identity through repertoires evoking Category Entitlement - laying claim to an expertise that can only be achieved having 'journeyed through' the psychotic experience, coming to a realisation of the positivity offered by the experience, normalising, naturalising and universalising the experience. The end point was a 'specialism', an expertise that is believed to be overlooked and undervalued requiring public attention and recognition; the authentication of this expertise claimed through the discursiveness of corroboration, rhetoric, consensus and competent application of metaphors bringing meaning and life to the world of PLEs. Participants called upon scholarly and professional experts as corroborators, applied

rhetoric and consensus to close off challenges to their accounts to achieve a positive identity and establish credibility to their accounts. The level of effort and commitment to the psychotic experience revealed participant awareness of prevailing attitudes and public perceptions toward the psychotic experience dominated by the meta/grand narratives - which they denounced. The final discursive effort in creating and maintaining a credible identity; the subsequent positive account of psychotic experiences was to establish 'beyond doubt' the truth therein through 'fact construction', in accordance with an expertise (expert by experience) attached to the lived experience, internalised, individualised beyond reproach – sacrosanct. Participants in defending the psychotic experience opposed a normalisation founded on conformity choosing difference above integration. However, a number of consequences and effects to this positioning, contrary to the desires as revealed through participant's primary orientation arose – that of normalisation and social acceptance of the psychotic experience.

The level of participant awareness of social disapproval toward the psychotic experience became more apparent when consequences of their positioning was shown, revealed through a number of dilemmas at stake. Participants positioning had a number of (unintended?) consequences, revealed through dilemmas at stake. Participants positioned themselves in opposition to deficit models of psychotic experiences (vis a vis; as perceived through the meta/grand narratives). However, they also provided examples when they felt obliged to withhold the psychotic experience from social interaction through a commitment to the status quo leading to the creation of a moral order. Rhetoric and corroboration were applied to promote and uphold social status of persons with PLEs by creating a niche, an exclusivity for said persons. This niche was particularly noticeable, set against persons who aligned

themselves with the meta/grand narratives of psychosis. Denunciation of the meta/grand narratives also included declarations of a ‘completeness’ to psychotic experiences that entails a unified self, obviating links or associations with illness and an unhealthy divided self. Participants also constructed a collective identity that diminished the possibility of collective corroborative action to achieve to social change to improve responses to psychotic experiences. The rejection of those aligned with the meta/grand narratives created a demarcation, a dividing line between those who have entered the psychotic experience, and those who have not. The consequence of an exclusivity, an ‘otherness’, of the other discursive categories under the repertoire Dilemma at Stake was social distance, a barrier to empathy, a declined potential for dialogue to take place between social actors and those living with PLEs, ultimately silencing the psychotic experience. Participant orientation, the desire for social acceptance toward the psychotic experience was found to have other consequences and effects that compromised their positioning involving practices and principles declared at interview.

The discursive acts to protect the site of the psychotic experience (ultimately personal identity of the person living with PLEs) from negative assessment from others had a contrasting effect against participant’s principles and practices found throughout their discourses. These appeared in the final repertoire Lived Ideological Dilemmas.

Lived Ideological Dilemmas played out in a widening social and political context where declared practices and principles toward democracy, inclusiveness and social responsibility conflicted with discursive acts that created an exclusiveness (a social hierarchy), allowing the deficit models of psychotic experiences to go unchallenged

displacing social responsibility toward the psychotic experience, closing off potential for public dialogue to take place. Participants claiming stake to a specialness, an expertise, a gift that is universally accessible, personalised and unique at the individual level ultimately becomes standardised, mundane, everyday even banal. The expert by experience claiming stake to a unique gift becomes mainstream putting at risk their exclusivity. Other contradictions and ambiguities (emotional uncertainty) arise from participant discourses. Acts of petitioning revealed a level of participant self-doubt. References to metaphorical systems with a function to establish order were found to be similar to those within/throughout the meta/grand narratives. The 'expert by experience' constructed by participants contrasted against the traditional conceptualisations of expert opinion and professionalism, publicly and culturally established. The contradictions and self-doubt served to undermine participant claims to an assured expertise based on the concept of 'expert by experience'.

Additional, an intervention in the guise of a problematic view, a 'challenge' to participant's orientation toward a material/immaterial dualism was met with a holistic dualism applying discourse connectives ie; melding mind, body and social context. However, such efforts are compromised, limited and, I argue, counterproductive dislocated from the practicalities required to achieve social change. Holistic dualism as an alternative system of understanding, apprehending and assessing psychotic experiences is limited as a means to address dominant cultural conceptions and established dualistic practices common to public life. I put it that there is a requirement to address structural and political power if the social change participants are aspiring, as revealed through their orientation, is to occur. This discourse and

potential for action is missing from their discursive accounts. I discuss the significance of this below.

## Chapter 5 – Discussion

Before presenting this chapter and in order to link the preceding chapters with the remainder of this thesis a brief re-visitation of the overall theoretical framework that has focused the study, ‘steered’ the aims and objectives is warranted – that of Social Constructionism and Discourse Analysis.

Social Constructionism maintains that there are no conclusive facts about the world; that multiple versions of reality are anticipated and legitimate (White, 2004). In real terms this means that there are competing realities, where ‘criteria for truth’ are contested and various ways to describe the world available. The social world we inhabit is primarily constructed through language where choice of words and descriptions become embroiled in performative acts in order to achieve and validate an opinion, a moral position, a world view. This leads us into a world where the study of language becomes central to understanding the means by which we construct the world around us, allowing competing versions of truth, in turn able to reveal issues of social power. Discourse analysis was chosen as a research method to reveal the construction of language and subsequent power struggles that exist in relation to a social object – psychotic experiences.

Discourse analysis was chosen to facilitate the process of meaning making with regards the psychotic experience, understand the construction of identity and positioning taken up, and discursive challenges that arise in maintaining and defending both from the first person, lived experience perspective. Repertoires were taken as the main unit of text for analysis with ‘secondary’ units of text (eg; rhetorical devices, discourse markers etc), considered as part of the discursive performances

enacted at time of interview. During analysis, particular attention was paid to levels of consistency, variability and compromises that appeared in text and how these discursive performances are related to/influenced by larger meta-narratives, demands and general expectations from the social environment. The discursive performances and subsequent challenges that arise acknowledges the nuanced manner with which we are impelled to construct and defend our identity, take up a particular position with regards a social object – again the psychotic experience.

Having presented findings where variabilities, inconsistencies and compromises were revealed I now bring these together and connect their interactions and implications within a wider social context. This will help understand issues of power and influence on discourse created by participants and allow me to make suggestions as to how this discourse might evolve and gain social purchase under social conditions, at a point in human history. I firstly present personal benefits of the discourse created by participants, then turn my attention toward wider social conditions that bring about possibilities for a social movement to influence the direction of discourse and public response as desired by participants, revealed through their orientation <sup>10</sup>.

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<sup>10</sup>Here I refer back to chapter 3 ‘Research orientation during analyses and presence of researcher’ where the research supervisor was referred as a reflexive source to create necessary tension through questioning and probing as part of an intersubjective process during analyses. Whilst the primary aims of this thesis was consciousness raising among the participant cohort demanding critical examination identifying compromises, contradictions etc within discourse generated at interview, my research supervisors suggested I also look for positive aspects of the discourse ie; personalised gains. This was useful and prompted the perspective taken below.

Before proceeding. I would like to take this opportunity to acknowledge the narratives, the stories of realization, of the personal feats and individual effort made by participants living with psychotic experiences, particularly given the hostile social environment that refuses to accept the psychotic experience as a human experience of value. However, I must note that the focus of this study was not to highlight these 'success stories' as might appear in other literature, through other methodologies, but to seek a way forward through consciousness raising in order to change public responses in favour of the psychotic experience. Seeking a way forward requires a certain method or form of critical analysis described above. I have decided to add a 'reflexive narrative' in an Epilogue at the end of the thesis to describe personal struggles in coming to terms with some of my findings as demanded of the methodology and leave some unanswered questions that I believe requires attention and may led to further research into the area of psychotic experiences.

Further, it is common that available research evidence relevant to the topic of the thesis be considered and presented throughout relevant chapters - with particular emphasis on the literature review and the discussion, below (Uncles, 1998). Here I return to the end of Chapter 1, pages 27-29 where I introduced the relevance of conducting an integrative literature review 'sketching prevailing ideas around a subject matter' in order to locate rhetorical functions, socially constructed discourses on psychotic experiences. This, I argue, is in keeping with the parameters of what is to be achieved through discourse analytic studies. In the remaining chapters I will continue to use this approach precluding the depth of research evaluation as required of other methodologies, locating discourses that influence and inform participant

accounts establishing their wider effects and consequences in accordance with prevailing social conditions.

### **5.1 From personalised gains to collective possibilities**

Findings established participants had a high level of commitment to claims of a subjective, personalised, experience-based expertise featuring independence and individuality. Text generated at interview revealed a persistence of this claim to expertise and individuality even though a number of challenges for participants emerged. Participants were by and large aware of these challenges - such as dilemmas faced in resolving the mind-body dichotomy relied upon to counter the meta/grand narratives, an awareness of the silencing that their moral positioning leads to (choosing to remain silent) and the revelation that ambiguity and self-doubt existed alongside the aforementioned certainty to expertise. Remaining committed to positioning that is knowingly problematic leads one to believe that there are benefits thereof. Below I present what I believe these benefits to be, broadening out the consequences of findings as they relate to the effects of discourse created by participants at interview, in the context of public discourses according to the social conditions with which they operate.

### **5.2 Positioning and self-esteem**

In keeping with social constructionism all human experiences, such as mood and emotional responses, are “*socially molded*” (Aranguren, 2017) interpreted and influenced by social and cultural normativism at a given time (Hewitt, 2002). Self-esteem as “*an object of cultural discourse*” (Hewitt, 2002) is indicative of a socially accepted normativism at work whereby a form of individualism is played out

influencing how we interpret and manage our emotional responses to social challenges. Examining the concept 'self-esteem' through a social constructionist lens Hewitt (2002) concludes that it is representative of "*mood*" interpreted through culture, subject to social conditions where 'social comparisons' and personal evaluations are promoted. Similarly, Gergen (2011) notes: "*once an emotion is performed the relational scenario also prescribes what follows.*" (p114). In 'Western' terms people are encouraged to find self-acceptance, seek acceptance from others; uphold standards of efficacy with regards to individual actions and measured performance in order to find or maintain emotional equilibrium. Aranguren's (2017) analysis of the interplay between culture and coping (emotional responses to environmental/social challenges) leads him to conclude there is a "*non-reductive biology of emotions*" (p259). He determines that the demands of coping as a necessary part of 'survival', brings into play self-preservation as a primary function of emotions, itself associated with identity threat, or to put it another way to preserve, "*self-integrity*" (Sherman and Cohen, 2006). Participant positioning involving discursive performances where an expertise through Category Entitlement (Figure 2), the creation of a Moral Order and privileged position (Figure 3) is achieved involved determinants of identity threat where self-efficacy, feeling valued and the creation of positive meaning around personal experiences was at play. These determinants reflect a form of individualism common in Westernised, industrialised societies related to a need for social validation (Petriglieri and Stein, 2012).

- Discursive performance during interview provided evidence of a perceived hostility toward the psychotic experience. This hostility is evidenced else-where (eg; as presented in the Chapter 3, literature review), impacting the type of actions

(responses) made possible for those living with PLEs, or as Foucault (1980, p93) puts it; ‘*a certain economy of discourses of truth*’ that is made available. I argue below that responses available to participants have an emotional basis (coping) prompted by an awareness of an unsympathetic environment toward the psychotic experience, in turn influenced by a modern emphasis of comparative evaluation.

I present that the requirement to respond to this environment understandably led to personalised gains for the individual in order to achieve emotional equilibrium. A form of individualism comes to light from these personal benefits.

Here I refer to theories and concepts that have impacted and shaped identity in modern times, in particular that which encourages/favours or discourages/disapproves certain behaviours, attributes or characteristics. This involves normalisation encouraging self-assessment and comparative evaluations wrapped up in constructs such as self-esteem, as ‘an object of cultural discourse’ where particular expectations and demands upon individuals are compelled, leading to self-regulatory behaviours; or as Foucault (1982) put it “*self-governance*” - the conduct of conduct:

*“This form of power applies itself to immediate everyday life that categorizes the individual, marks him by his own individuality, attaches him to his own identity, imposes a law of truth on him which he must recognise, and which others recognise in him.”*

(Foucault 1982, 212)

I contend below that acts of aversion (ie; silencing, Figures 3 and 4, Chapter 4); of pitching one's knowledge and abilities against socially sanctioned expertise and authority (the Other, Figure 4), are potential indicators of social anxiety, driven by fear of being judged and publicly shamed. I argue that participants have committed to an identity centred on the creation of positive narratives around their psychotic experiences made possible through discursive performances (Category Entitlement) that appeal to public notions of morality, individual freedoms, normalization ie; their orientation.

### **5.3 Feeling valued**

#### **5.3.1 By others**

The need for validation from others is a common experience for people. It has potential to confirm "*the worldview*" and build "*self-esteem components of the individual's anxiety-buffering system*", through reduction in uncertainty as to one's place in the world (Pyszczynski et al, 2004, p464). The positive experience of feeling valued by others is traced from 'cradle to grave', such as affirmative experiences during childhood, to old age where recognition for contribution to communal and family life is related to wellbeing. Data revealed a number of discursive categories that highlighted the need for participants to feel accepted by others (acts of Petitioning), yet for the majority superior to others (Figure 4), in other words affirmation from personal, communal and social worlds.

#### **5.3.2 Social comparison**

Social comparison theory, as initiated by Festinger (1954) proposed that individuals are inclined to evaluate their own abilities, views and opinions by comparing

themselves to others. According to Festinger, the tendency for social comparison serves to establish certainty within evaluative domains. An added dimension is the functionary purpose of social comparison that of “*self-esteem enhancement/protection*” (Kruglanski et al, 2012). There are a number of directions with which individuals can move when comparing themselves as a function to enhance their self-esteem.-These involve vertical (comparing social status) and horizontal dimensions (contrastive/connective comparisons, of doing better or worse).

### **5.3.3 Social Comparison and Othering**

As Foucault points out, power is not simply a physical force, an unsophisticated, static top down authoritative source, constantly bearing down on helpless servile persons (Foucault, 1975). It is all pervasive, something that people desire in their own lives (yet cannot be possessed), something that is often resisted, redefined and reshaped. What Foucault refers is that power is also available to those who are/may be judged relatively powerless; who actuate their own will to power eg; defiance against unwanted status or identities. This leaves open possibilities and opportunities to resist or defy categorisations that impact one’s social image, reputation and sense of self. Options open to those who resist power includes the power not to believe (for instance in mental illness, Walsh et al, 2008) the power to define oneself in accordance to a preferred identity (Philbin, 2009). Positioning oneself as superior to groups or institutions recognised as having authoritative expert knowledge is a form of resistance, one that people with major mental health problems are willing and able to deploy (Crossley, 2006; Walsh et al, 2008). This is not to say that superiority can ever be fully achieved or unequivocally staked, but that participants have positioned themselves as having expert knowledge through Category Entitlement and have used

this to enhance their (self) identity. This can involve an appeal to high ranking, culturally appropriate standards of conduct, of rightness or wrongness (ie; Moral Order, Figure 3 and democratic principles, Figure 4). Below I present resistance as will to power in relation to moral/ethical positioning taken up by participants, commonly practiced in Westernised, industrialised nations, present in public discourse. The acts of positioning, I present, serves to relieve and avert emotional burden for persons living with psychotic experiences who, as already shown through levels of awareness of the social power, of the negative consequences of the meta/grand narratives, are socially tainted. I begin with describing how participants have implicated the horizontal dimension of social comparison.

### **5.3.4 Horizontal dimension - Social Comparison as applied to peers and the general public**

A social comparison was enacted by participants implicating the Horizontal dimension, (contrastive/connective comparisons, of doing better or worse). This involved, at one level responsibility toward the psychotic experience where you would “diminish yourself” (participant 3, 4.15.2), comparing those who somehow lost their sense of independency or/and remain within the mental health system, to those (participants) who have successfully navigated their way out of the mental health system or averted/never required support from statutory mental health services. Here choice, as part of democratic reality is factored regards accepting or rejecting psychiatric treatments, accepting or resisting diagnoses, remaining within or without statutory mental health services. That said, in this case, the contrastive nature of these circumstances, of participants being in a better or more fortunate situation than others who share the psychotic experience does not necessarily constitute a downward

oriented social comparison toward mental health service users. There was evidence of sympathy directed at such persons, of suggestions as to what might better serve them where reference to 'survivors of the system' was made (eg; Chapter 4 'A neglected source of knowledge'; Validation of the Intrapersonal); Universalization and the aversion of collectivisation where a dehumanising aspect of psychiatric services was highlighted, and a more hopeful and holistic world view was offered. The horizontal social (connective) comparison enacted by participants toward others with similar experiences is one of doing worse. However, given sympathy expressed toward this comparative/connective cohort, reasons for their circumstances focus on misfortune and/or the weight of authority of services dominated and guided by the meta/grand narratives. This allows participants to establish a connective relationship with less fortunate peers(?), experts by experience, and continuation of their moral positioning vis a vis; not to be seen to be judgemental, elitist or exclusive by demonstrating a sympathetic response to those caught up in the mental health system.

The primary differentiation created through horizontal social comparison was of moral character/fortitude between themselves (participants), others who share the psychotic experience (those caught up in the psychiatric system) against those who have never 'entered' the experience yet refuse it (ie; Othering). People who belong to the former group, who have embraced responsibility toward the psychotic experience, are better off than those belonging to the latter two groups. However, given evidence of a sympathetic assessment of the circumstances mental health service users find themselves in, it is those who have not encountered, entered into or refuse to engage the psychotic experience who are the primary target in a horizontal social comparison. Here, the horizontal dimension is directed at the public on grounds of the universalisation of the psychotic experience as accounted for through democratic

ideals. In other words, positioning emphasised equality as a universal human principle with no hierarchy applied. It follows that we are all equal through shared human experience; connected. The latter group (the public) are ‘missing out’ of personal benefits (deep wisdoms and enhanced wellbeing) derived from the psychotic experience, due to fear and/or ignorance, therefore worse off. The contrastive nature of acts engaging the horizontal dimension allows a nonthreatening, non-confrontational, benign posture toward those with equal significance and importance (Experts by Experience caught up in the mental health system) and just as importantly the public. The Discerning Silence (Participant 8; Chapter 4) operates (whether intended or not) as a ‘moral buffer’ where participants do not contest, upset or antagonise the public through actions that may appear ‘inconsiderate’ or result in social distance or disconnection. This allows for the cultivation and maintenance of a strategy, as per an ‘interpretative community’ (more on the significance interpretative communities below) - that of collective action targeting civic opinion, challenging cultural practices that are stereotypically represented in public discourses. Potential for collective action remains, reducing the likelihood of hostility or/and division which would endanger or threaten the prospect of gaining public sympathy. A strategy (when/if activated), of gaining public sympathy, of instilling empathy toward marked individuals perceived as ‘suspiciously’ different – those living with the psychotic experiences – can remain a possibility. The enactment of the horizontal (and vertical dimensions below) of social comparison sustains moral positioning maintaining potential for social action, which in turn has personal benefits for participants - below.

This horizontal social comparison can help “*maintain positive self-perceptions and emotional wellbeing ... particularly in low-control circumstances*” (Rahimi et al,

2017, p3). Low control circumstances can include situations where a meta/grand narrative has ‘power over’ distinguished individuals (participants) who are aware of its influence over public perceptions and responses to that which marks them disapprovingly different from others – those living with psychotic experiences. An awareness that the authority bestowed to the meta/grand narratives cannot be easily dismissed or dismantled; that the language that it instils has an alienating (Byrne et al, 2016) and dehumanising effect (Perkins and Repper, 2001; Sewell, 2018) creates circumstances where options to counter such effects are limited. Those who operate under the auspices of the meta/grand narrative are themselves an interpretative community, their authoritative position as: *“embedded practitioner whose standards of judgment, canons of evidence, or normative measures are extensions”* of the community itself (Fish, 1989, as cited by Scher and Kozłowska, 2018, p89). One community (participants) interprets psychotic experience through the subjective, as part of their discursive strategy calling upon public sensibilities – that of normative, virtuous, ethics, and rights (or to put it another way ‘moral norms’, Scher and Kozłowska, 2018); the other (under the meta/grand narratives) through an objective lens justifying its actions that are risk averse, reverting to responsibility and obligations to public safety. Given awareness of the authoritative position bestowed to those operating under the meta/grand narratives, yet the potential for participants to execute a number of strategies including confrontation, discussion, dialogue, it would appear that the social comparison as an act that elevates their status is consolidatory (Philbin, 2015). In this case, the consolation does not end in accepting an ‘unwanted identity’ (Philbin, 2015) but from an inverted silence that satisfies each individual implicated in their interpretative community. The inverted silence helps maintain emotional equilibrium, self-integrity and self-worth – that of self-esteem. They have

chosen silence involving certain ‘complicities’ toward an elite with claims to specialist knowledge, charged with anti-democratic and human rights breaches, whilst themselves maintaining a distinctive referential, privileged position made up of embodied knowledge through Category Entitlement vis-à-vis Expert by Experience. This presents a dilemma where tensions: “*between words and deeds*” exists; “*between representational acts and redistributive actions*” (Thurlow and Jaworski, 2017, p251). The horizontal dimension as applied by participants allows prospects to gaining public sympathy to continue, maintaining social union whilst enabling a claim to expert knowledge. A question arises from this dilemma - has this declared source of knowledge and wisdom potential for social change at the collective level as expressed through participant orientation?

### **5.3.5 Vertical social comparison and the call to normative ethics**

Through Category Entitlement where psychotic experiences are presented as significations of underlying social discordance, as being particularly undervalued (Neglected Source of Knowledge); where the Universalisation of the psychotic experience (4.10) is asserted alongside principles of democratic ideals (4.14.2) participants have raised morals and normative ethics centred on human rights that are socially sanctioned; generally accepted, recognisable, embedded throughout Western society- individual autonomy, equality, inclusion, community participation. In appealing to these commonly understood, generally accepted, established ethics they are setting them-selves up as lived examples of high moral standing against an ethics that is presented as dogmatic, often callous, lacking ‘moral imagination’ (Thomas and Longden, 2013). Lewis and Callard (2017) in assessing a Bill of Rights developed by the World Psychiatric Association, designed to align psychiatric practice with the Convention of Rights for People with Disability, found the tone and content wanting.

Efforts by the WPA lack: “*engagement with the complex challenges of coercion, institutionalisation, consent, and community inclusion*” according to these authors, allowing continued contravention of Human rights and remaining silent on social justice issues encountered by ‘psychiatric populations’. Thomas and Longden (2013) describe how mental health practitioners would be better served if they were to discard the technological model of mental health (effectively the meta/grand narratives) by engaging the moral imagination. In order to resolve ethical challenges that arise when supporting someone with a major mental health problem, the process would involve the exploration of an extensive range of possibilities in a given situation or circumstances combining creativity and an empathetic response. Thomas and Longden (2013), specific to mental health practice, describe the moral imagination as a process where interpersonal facilitates meaningful engagement with the individual’s narrative (the storying and re-storying required to maintain/gain emotional wellbeing) enabling the creation of dignified identities; recognising and engaging the existential nature of experiences that are estranged due to lack of pre-established reference points and lose of communal interaction.

- The application of normative ethics enables participants to apply upward social comparison, levelling themselves with those afforded high social status, who proclaim specialist knowledge, who are sanctioned to enforce laws that according to various mental health service users, academic and professional commentators (Crossely, 2006; Spandler and Calton, 2009; Lewis and Callard, 2017) impede various democratic rights - equality, citizenship, social participation - the aforementioned professional groups. This allows for raised self-esteem for those who deploy this ‘strategy’ by creating a morally inferior ‘Other’ and enable vertical social comparison.

The change in dynamics, the relationships between health professionals and persons presenting with mental health problems has shifted significantly over the last few decades (Svavarsdóttir et al, 2018). There is a growing emphasis, reflected in the production of numerous policies and guidelines developed by statutory services and professional groups, where the patient through their lived experience is recognised as an expert in their own right. In accordance, the need to create a milieu where power sharing and shared decision making becomes embedded in practice has arrived (Beyene et al, 2018). However, scepticism remains regards the ability or willingness of traditional systems and professional groups to adapt and fully embrace this democratic process (Rogers et al, 2009; Davidson, 2009). Davidson (2009) observes that self-management programmes, some service user-led, some generic, others condition specific have tended to be rolled out as part of an overall agenda to address the need to acknowledge and exploit the individual abilities of the expert patient. Davidson notes however that these programmes tend to be ‘complimentary rather than alternative’, ‘lending responsibility rather than sharing it’. The tendency to be relatively prescriptive in approach indicates the continued dominance of a paternalistic mental health system. This somewhat conflicts with participant discourses, whose orientation is fixed on democratic processes, where equal rights to self-determination and recognition of the psychotic experience as a normal, universal experience should be facilitated, not managed. The segregation of persons, as occurs under systems of categorisations, is replaced by a democratic process where the will to power, interpretative and meaning making processes is in the hands of those with lived experience of psychotic experiences. Participant discourse dismantles expert status as traditionally conceived. The journey to personal wellbeing involves living

through an experience, making life choices, personal morals and access to interpretative power. The need to be ‘fixed’ or cured by professional experts is turned on its head as expert status is defended through the lived experience (‘I know what is best for me’), staked through democratic ideals (‘I have the right to choose, to be equal’); where alternative meaning making systems address people’s need to become and not perform in accordance with social norms and expectations. The meaning making process as advocated by participants, is becoming more influential (Noorani, 2013), challenges traditional ideas on expertise, where professionalism becomes foregrounded by the real expert found in their presence – the expert by experience. However, as I relate later, there may be challenges and limitations to this idealistic notion of self-determination, some of which come from a wider social context.

#### ***5.4 A new (public) order. The rise of the new expert and the identification of an interpretative community***

Discourse studies of morals provides evidence that as Western societies have transformed over time, morals have become more individualised and diverse, increasingly used for purposes of supremacy, dominance and (personal) advantage (Bergman, 1998; Tosi and Warmke, 2016). With such high stakes to personal integrity I argue that people with psychotic experiences (participants), are benefitting from moral positioning, as per the construction of a morally inferior Other (4.12), with compensatory benefits. In other words, common to groups/persons living with experiences that are socially tarnished, publicly discredited, alienated, isolated, shunned - the psychotic experience (see for example Thornicroft, 2006; Philbin, 2009; Farrelly, 2015) the creation or construction of moral supremacy over the Other

functions as a mechanism to maintain/enable raised self-esteem and self-integrity, above.

The creation of the Other as discursively performed by participants was achieved multidirectional, levelled at various interactions and observations of others. Firstly, and most prominently, a comparison was constructed, a distinction between those living with psychotic experiences and those associated with the meta/grand narratives. The insistence that it is only through the lived experience (Emergence of Expertise, Category Entitlement - chapter 4) that you can truly understand, appreciate or meaningfully support someone with psychotic experiences places those with said experiences, peers, in an expert role permitting the application of a Comparison Class whereby:

*“an expert’ is a triadic predicate... a three-part relationship between a knower, a subject and a comparison class. To say that a subject S is an expert on a subject O is to say that s has an ability and/or level of knowledge concerning O that is significantly greater than a comparison class K.”*

(Ben and Smit, 2017, p640).

Ben and Smit make this observation under the umbrella of Social Constructionism:

*“This indelible reference to a comparison class implies that there is an essentially social dimension to expertise”. (p640).*

Therefore, Subject O’, in line with constructed identity, becomes the unique, individualised, internal world of the knower, the ultimate source of truth and knowledge. This is reminiscent of Socrates dictum; ‘Know thyself’ a principle that remains socially influential, commonly regarded in people’s lives (Green, 2018). It is

applicable to personal development, self-improvement (morally and spiritually) “*an early sign of the individual breaking away from his full participation and absorption in the divine order*” (Reiss, 1985, p355). The expertise that is being offered by participants, constructed on the basis of self-knowledge, responsibility toward oneself involving choice and diversity, is an expertise frequently applied, pitched against expertise afforded to traditionally held, authoritative powers.

Examples of changes that have taken place over the last few decades, ones which have refocused the concept of expertise (at least at the discursive level) within/throughout traditional professional groups can be found in the worlds of journalism and medicine. Journalism has been observed to have made a significant ‘move away’ from one of its essential criteria of reporting – that of objectivity - described by Bolger et al (2016) as: “(1) *relying on external sources and (2) excluding personal views and values by avoiding the use of subjective language.*” (p6) Participatory journalism, whereby personal experience and first hand witnessing is increasingly relied upon; where “*a true account of reality can be presented*” on the bases of objectivity, is now overridden by an assumption: “*that the audience would, for instance, have a preference for personal, trivial or sensational topics and take up a subjective, emotional style*” brings into focus public discourses that are considered incompatible with a ‘journalism’ that was ideally “*depersonalized and rationalized*” (Bolger et al, 2016, p2) There is also growing recognition of the ‘expert patient’ whose subjective experience of illness, distress, discomfort and reporting of symptoms is acknowledged as a major factor in clinical decision making and self-management of various health conditions (Xiao, 2015). The rise of the expert patient has provided impetus for self-experience - the subjective - to influence, orientate, direct what was once dominated

by a unidirectional decision-making process when a clinician and/or allied health professional would prescribe, advise, instruct the patient in ‘health behaviours.’

The change in journalist and health professional practices demonstrates standardised recognition of various forms of expertise and knowledge, found in participant discourses, reflecting a culture that now legitimises personalised, individualised (lay) discourse that often challenges and is at variance with traditional authoritative expertise (Koschack et al, 2015). That is not to say that ‘professionally qualified’ scientific based expertise has minimalised its influence or become irrelevant (in fact Cook et al 2004 and Kerr et al, 2007 make a case that the status quo remains) but that there is evidence of public re-evaluation of competing sources of expertise based on trustworthiness (see for example scientific evidence vs experiential knowledge; Koschack et al, 2015). An emergence of public mistrust and scepticism toward professionally qualified accounts and witness to events constitute discourses that amalgamate meta-discursive features (Ribeiro, 2010). For example, Kerr et al (2007) present that a hybridisation of lay person (lived experience) and expert (rationalised, science based) knowledge is now established providing opportunities to construct corroborative statements (blending both sources of knowledge) that lend more credibility to accounts or narratives advantageous to a cause or world view, shaped to gain maximum influence on public discourse and by extension public responses to psychotic experiences. Knowledge sources involving hybridisation appeared in participant discourse eg; acts of corroboration (Figure 2, Chapter 4) and Petitioning (4.13.3). However, the central point to be made here is that variances that transpire with this hybridisation of knowledge lie with emphasises on either side of the expert continuum, within/throughout interpretative communities (Johnstone, 2004; Scher and

Kozłowska, 2018). It is this hybridisation as an impetus to address the structural power that maintains the meta/grand narrative that participant's overlook or neglect.

It is obvious that participant orientation toward normalisation and universal acceptance of the psychotic experience reflects wider social trends where defence of the individual at political and communal levels has become centre stage (O'Flynn, 2013; Queiroz, 2018). Defence of the individual fits hand in glove with 'modern day' social movements. By way of example, Fuchs (2006) identifies several dynamics during the emergence of a social movement, one of which is 'internalism'. Here, under the guise of individualism, agency, autonomy, and, as presented in participant discourse, the right to choose one's own pathway toward wellbeing and meaning making is asserted. Though participant positioning is fixed to the individual (Expert by Experience), discursive acts indicate 'collective intentionality' (Fitzpatrick, 2003) as specified in their orientated discourse, vis-a-vis desire for social change. The necessary steps (as I have already alluded), to create social change such as direct-action involving protest and verbal interaction with the general public is lacking. However, that is not to say that a social movement cannot be identified among the participant cohort, but rather their discursive acts indicate wider social trends where collective intentionality exists in the absence of direct action (Fitzpatrick, 2003). Social movement theory takes account of collective intentionality broadening possibilities and consequences of interpretative strategies. Interpretative strategies are found within and throughout participant discourse and as I present below reveal an interpretative community with potential for affirmative acts to achieve the social change in favour of the psychotic experience that participants aspire.

Below I present conditions where affirmative acts may be realised, and the social change participants orientate toward/desire might take hold.

#### **5.4.1 The interpretative community and potential for collective action**

Fish, (1989) describes an interpretative community as: *“not so much a group of individuals who shared a point of view, but a point of view or way of organizing experience”* (as cited by Scher and Kozłowska, 2018; p88) An interpretative community is ‘marked’ not by a specific meaning attached to a stable, consensual, harmonized, consolidated world view but in its interpretative strategy which is *“not natural or universal, but learned”* (Fish, 1976, p484). The strategy adopted (learned) by an interpretative community involves a particular way of reading (and shaping/reshaping) text consisting of cultural assumptions where *“opposing positions (are) made possible”* (Fish, 2010, p. Inserted italics in brackets mine.). A claim to expertise premised on the subjective, first person narrative creates a distinction (opposition) to an objectified version or representation of behaviours and experience. The territory staked by research participants (and others with psychotic experiences – see for example Thornhill et al, 2004; Jacob, 2015); the strategy employed, is one of ownership (through Category Entitlement), where the personal narrative, first-hand, lived experience is believed to trump other versions or accounts; in particular sources that judge ‘from a distance’. Ownership involves the authentication of individualised, personalised knowledge centred on the internal experience where *“meaning is in the eye of the beholder”* where *“interpretation must achieve not reference”* (Díaz, 2001) ie; those who ‘possess’, live with the psychotic experience are in the most advantageous position to judge and place value upon it. An example

of the individualised, internalised expert narratives as staked by participants in a broader, public discourse comes from the recent referendum on abortion in Ireland where the ‘successful’ camp won public opinion with a discourse of ownership and personal trust in the subjective through an appeal to women ‘knowing their own bodies’. This, in contrast to the ‘Right to Life’ of the unborn, whose subjective experience could not be directly expressed or represented.

For an interpretative community to achieve public sympathy, to gain maximum traction over public narratives, a strategy to gain legitimacy for truth(s) over another is required. Participants are aware of the objective power of the meta/grand narratives. A major part of their strategy is to appeal through an ‘experience-oriented’ society (Groot, 2017) where subjectivity is crossed with ownership of named experiences creating a higher truth claim. Ownership, of an experience(s), as in the case of this study lends legitimacy; authenticates a version of truth enabling a strategy involving moral positioning which participants have taken up in order to mark themselves distinctive (superior) from those allied with the meta/grand narratives.

The strategy deployed by the interpretative community constituting research participant’s positioning is achieved through the subjective, engaging the vertical dimension implicating status of expert persons or professional groups (Locke, 2003) upsetting a balance of power, achieving a sense of superiority through morals and (normative) ethics that are established, publicly agreeable. Unlike ethics applicable to professional groups constituting a set of standards to guide decision making and practices (see for example Keohn, 1994; Knapp and VandeCreek, 2012), morals are contingent upon personal beliefs, principles influenced by culture, personal history;

reflective of ongoing social appraisal of behaviours, conduct and character (Cohen and Morse, 2014). The Social Comparison constructed by participants is made through an appeal to the right of the individual involving morals that are steeped in a rights-based approach, commonly deliberated and aspired throughout Western, industrialised societies such as member states of the EU, including Ireland, the site of this study (Manners, 2008). These included the individual right to religious (spiritual) beliefs, expression and opinion (expert by experience, self-knowledge and alternate realities); the right to autonomy, to equality, inclusion, community participation. This is in contrast with those practicing under the meta/grand narratives who are often positioned as ill-informed, aggressive in their opinion of/over others, as inhumane, unable or unwilling to consider the effects of the treatment models they apply to people living with psychotic experiences. There are strong, substantive confirmations that the primary focus of those working under the meta/grand narratives is to compel treatments and interventions at the behest of individual rights, participation and social justice (Thomas and Longden, 2013; Sweeny et al, 2015; Lewis, 2009; Lewis and Callard, 2017). There is certainly evidence that this is the case where social control remains a primary concern and consequence of public mental health services, where:

*“Anticipated discrimination influencing patients’ views of their experiences, negative experienced discrimination in many domains of life might be related to prior coercive mental health service intervention.”*

(Thornicroft et al, 2009)

This demotes ethics that are applied in justifying practices under the auspices of the meta/grand narratives. Due to the social status afforded to professionally qualified

groups associated with the meta/grand narratives (in particular psychology and psychiatry) participants have constructed a moral superiority through a normative, virtuous ethics. Virtuous/normative ethics focus on personal choice, behaviours, emotions, motivations to action that reflect individual character (Gardiner, 2003). These are often embodied throughout social, communal settings, culturally established. This is in contrast to a formalised ethics that is deliberated/decided by an elite group of ‘qualified’ experts, establishing standards of conduct involving ‘duties and rules’ (Manners, 2008) rationalised through projected probabilities of the consequence of interventions. Such ethics are risk averse, closing off opportunities to explore interventions beyond traditional practice, regularly denying psychiatric populations rights enjoyed by normal populations such as autonomy, social justice and freedom of thought (Thomas and Longden, 2013). ‘Alternative practices’ to mental health such as shamanism do not factor in an objective, scientific, evidence based world as idealised by the meta/grand narratives (see chapter 3); elevated projections of risk inhibit, rationalise, attach a reasonableness to practices that may be seen by others to threaten human rights. A question arises however: can this claim to moral authority and claimed expertise that participants and similar others stake be transferred or benefit others who share the psychotic experience? This is significant given participant’s orientation toward social change (ie; universal acceptance of the psychotic experience) and the obvious need for social action if this is to be achieved.

### **5.5 *Can self-knowledge benefit others?***

The privileged position that self-knowledge creates enables those with lived experience to subvert, substitute or emulate that which is staked by groups of mental

health professionals described above, yet is there any social advantage to this ‘staked expertise?’ ie; can this transfer onto similar others, or to put it another way peers?

Although participants described events and accounts of ‘alternative practices’ (Shamanism; Holotropic Breathwork etc) they did not expand into the context where peer support could/should be readily offered, easily accessed. Studies into the efficacy of peer support delivered within statutory mental health systems may help point to the potential to develop systems, services or communities where this source of knowledge may benefit others who find themselves faced with similar life experiences. Such studies have had mixed results.

A systemic review of research on peer support conducted by Repper and Carter (2011) found that mental health service users benefited from this service with regards declined social isolation and stigmatisation. The primary impact was observed to be a reduction in hospital admissions - similar to that found by Valenstein and Pfeiffer (2018) in a randomised control trial involving 441 mental health service users engaged in six Crisis Resolution Teams across the UK. Although findings were favourable in the Valenstein and Pfeiffer (2018) study the authors highlighted the need for clarity as to the specific components, active or crucial elements, that led to the success of the intervention. Studies on peer support, specifically delivered as part of statutory mental health services, indicate the complexity involved in peer support services, particularly interpersonal processes.

Applying Theory Construct and Content Analysis methodology to the concept of peer support within (general) health care settings Dennis (2003) raises a number of adverse outcomes that have been found in a number of studies, namely: “*incorporate conflict,*

*criticism, failed social attempts, emotional over-involvement resulting in contagion stress, reinforcement of poor behaviors, diminished feelings of self-efficacy, lack of stability”* (p328) Whilst these findings may appear to have no bearing on this particular study, I argue that potential negative consequences to providing or offering peer support (as outlined) may threaten willingness for those claiming or positioning themselves as experts by experience to come forward and transfer knowledge, act as a guide or mentor to others who find themselves distressed and in similar circumstances to that which they experienced themselves. Secondly, in constructing an identity through positioning as an expert based on unique, individualised, internalised experiences (*vis-à-vis* expert-by-experience) solely based on the lived experience leaving others to recognise, nurture, take responsibility for their own expertise (or you will “diminish yourself”, participant 3, 4.13), falls into the category of an expertise that is socially constructed and not one that is based on realism (knowledge that is out there, theoretical or practical, Ben and Smit, 2017). To put it another way, practices such as shamanism and holotropic breathing have not been tested in accordance with the same standards of scientific enquiry to ascertain its efficacy as the public might expect. It is therefore not knowledge that is transferable, but a philosophy, a way of living in the world that is encouraged, enabled, through choice and personal responsibility. This ‘philosophy of living’ harks back to the Greek proverb: ‘Physician heal thyself’, where self-regulatory behaviours, projected by a self-authoritative and self-knowing conscience for the purposes of achieving self-healing is encouraged; where one should tend to one's own personal challenges rather than criticizing or advising how others address theirs (Hirsch et al, 2002). However, the issue of averting communal/social dialogue around the psychotic experience (the aversion of collective action, 4.11) is amplified here and remains problematic,

somewhat disenfranchising claims to high moral/ethical standards as publicly warranted. Transfer of knowledge, experience and moral fortitude in order to support others in similar times of need also becomes problematic as it cannot be achieved.

To summarise this section, responsibility, as directed at/expected of professional groups associated with the meta/grand narratives; in particular those with public responsibility for mental health, does not apply to this interpretative community who might offer their expertise for the benefit of others, yet through discursive means, by referencing certain cultural 'normativisms', (democratic practices eg; choice and personal agency) detract responsibility toward others. This echoes elements of personal responsibility or self-determination seen as a cornerstone of 'Recovery' from mental health problems, evidenced in numbers of accounts written by persons who have declared 'recovered' from psychosis (eg; Deegan, 1993; Bassman, 2007). Problems as to how, why and in what circumstances this expertise can be applied for the benefit of others struggling with challenges that arise from psychotic experiences remains.

### ***5.6 Within or without a social movement for those with psychotic experiences?***

The issue at stake here is the claim to an expertise that aims to dislocate traditionally established professionalism, standards of knowledge, authoritative power whilst remaining silent on the issue at stake (the latter three sources charged with side stepping, ignoring or dislodging democratic ideals and human rights). Participant orientation toward social acceptance of, normalising/humanising the psychotic experience while maintaining public silence confounds features of responsibility

attached to offering knowledge, expertise, supports that similar others could benefit from - specifically reaching out to those with the psychotic experience and creating meaningful social change.

Taylor and Whittier (1992) in assessing how informal networks and collective identities lead to collective action, emphasise the significance of “*strong bonds as the basic building blocks of social movements*” (p169). Van Dyke et al (2004) identify two primary strategies/routes in pursuing social change, activated by social movements - 1. targeting government, the state and its institutions or 2. changing public opinion, identities and cultural practices. They note that all of the movements they studied (4,654 in total over an eight-year period) involved, to a lesser or greater degree strategy number 1. Those with a Civil Rights agenda (eg; gay/lesbian and Women’s groups) focused strategy number 2 targeting public opinion, challenging cultural practices, enhancing identities stereotypically represented in public discourses. Given participant positioning that appealed to civic, commonly held criterion of morals/ethics; the linguistic efforts in defending the subjective world that is the psychotic experience, of maintaining a universalism and positivity toward the psychotic experience, it would appear that participants primarily orientate toward strategy number 2 with linguistic efforts levelled at public opinion and cultural practices through an activation of Civil and democratic Rights based on individual entitlements. However, they do not take the practical steps to address structural power that maintains social perceptions and responses toward the psychotic experience. I explore below why this might be so.

## **5.7 A New Age or maintenance of old structures of power?**

Data revealed participant beliefs that their unique experiences and world views were of universal importance. There is a comparison here to a counterculture of spiritual or religious dimensions, akin to a post traditional or secular 'revolution' described by Houtman and Aupers (2008) as: *“an offshoot of the tradition of Western esotericism”* (p101). Houtman and Aupers (2008) add that spirituality has become increasingly privatised, individualised involving *“processes of socialisation through which people come to adopt a spiritual discourse about the self and the role played by problems of meaning and identity in making people amenable to such a discourse.”* (p117). The problems of meaning and identity *“the declining grip of external and authoritative sources of meaning and identity robs late-modern individuals of the protective cloak of ‘pre-given’ meaning and identity and throws them back upon themselves in dealing with their ‘precarious freedoms”* (Beck and Beck-Gernsheim, 1992: 16; as cited by Houtman and Aupers, 2008, p112). Because it is ultimately only one’s internal experiences made up of feelings, cognitions, imaginings and intuitions that remain sources to conjure answers to those questions, *“a shift of authority: from “without” to “within”*” (Heelas, 1995: 2, as cited by Houtman and Aupers, 2008, p112) *“the loss of the protective cloak of ‘pre-given’ meaning and identity creates tensions and anxieties”* (p113). With a growing scepticism, rejection, diminishing faith in institutional religion and with it a void created due to declining external interpretative and explanatory sources of meaning and authority it is understandable that people with experiences (the psychotic experience), particularly those when first encountered lack social reference and would turn to the very source where the experience itself takes place. Under conditions where the psychotic experience remains an internalised

event because of stigma, discrimination and public ignorance, explanation and any (psychological or emotional) resolution required or sought is difficult to achieve because disclosure becomes risky, disjointed and dislocated. To achieve resolutions to alienation, shame or bewilderment encountered, there would be a requirement to attach the psychotic experience to an external source, one that the public can relate to, accepts as part of social and cultural reality. Groot (2017) points to the current social environment where the exceptional, the distinguished is embraced:

*“this rational climate does favour the experience of the extraordinary, the attribution of special gifts and the feeling of being lifted up from everyday life. The appreciation of special experiences responds perfectly to the discontent with the dominant Western worldview.”* (p3).

It may appear that the social environment favours the performative acts, the discursive objectives of participants, their orientation as presented in chapter 4 as per normalising the psychotic experience, yet, the desired consequences as aspired by those belonging to this interpretative community identified vis a vis; attempts to establish counter discourses, may have the converse effect and work to satisfy and maintain a materialism and rationality that they are trying to unravel. Even though a world of holistic dimensions was accounted for - spirituality, mind, body (eg; Embodied text, 4.17), – put forward to bring about changes to how the psychotic experience is interpreted, spoken about, responded to, facilitated; reconciling these worlds is incredibly difficult in Western Societies where an *“instrumental rationality”* (O’Neill et al., 2014), an objectively reasoned version of reality securely attached to a materialism that requires quantifiable accounts of social life dominates. Groot (2017)

describes one of the major obstacles facing communities that offer counter discourses to a culture dominated by materialism – that of assimilation: •

*“During the 1960s, beatniks and hippies embraced spirituality, nature and authenticity in what seemed like a rebellious response to mainstream culture. At the end of the twentieth century, their notions became a crucial part of consumerism. The discomfort with rational Western culture is now supplemented with a romantic counterculture that has gone mainstream”* (p3)

What Groot refers to is the ease at which a rational, materialist, consumer driven society can draw upon/adapt counter discourses as part of its overall governance and command structures: *“This is why advertisements for commercial products, such as beer and shampoo, sometimes refer to magic and the mystical, why foods and lifestyles promise access to nature and the authentic self and why celebrities are popular”*. (Groot, 2017, p3). This points to a culture dominated by a materialism that is parasitic upon discourses that begin at the periphery, becomes fashionable, that appeals to a new way of seeing or experiencing the world, that has the potential to reshape the individual, yet taken up by other forces and used for its own purpose – consumerism. Individual profiling required to satisfy market forces becomes part of the process of identity formation; part of an *“All-integrating and unchallenged coherence”* (Blühdorn, 2006, p29). This brings us to the problem of mind-body dualism as per chapter 4 where a common dichotomy may play into the hands of the world view the interpretative community is resisting.

As pointed out, referring Mind body dualism to resist, question or elude the meta/grand narratives may be futile, and merely replay discursive dichotomies that

have persisted for centuries. Mind body dualism remains unresolved in Western society and according to various scholars may never be resolved (Qazi, 2018); its significance playing out in spiritual, religious and scientific realms where levels of influence, of material and non-material worlds are differentiated to various degrees depending on one's epistemological and ontological positioning. As stated in Chapter 4 (4.18) dualism may become a distraction as the interpretative community engages levels of ontological and epistemological depths; the complex nature of which makes the holism constructed by participants; the reconciliation of the material and the immaterial unresolvable allowing those operating under the meta/grand narratives dominion over public discourse by having the last say, reminding the public of the 'hard facts' of the private impact and social cost of psychosis and the need for intervention (Farrellyb, 2015; Bilić and Georgaca, 2007; Henderson, 2018). How society frames connections between psychotic events, interpretations and appropriate responses is heavily influenced by this discourse melding risk and health enabling associated practices to persist. Even though the interpretative community recognises the authoritative power of the meta/grand narratives, their insistence (reliance?) on dualism to undermine said narratives, not to mention the inverted silence, indicates limited awareness or lack of alternative ways of creating text about psychotic events beyond discursive performances that are already available. Blühdorn (2006) citing Roth, (1994) observes if:

*“Their ‘self-perception as radically different . . . is self-deceptive if it does not take into account the narrow limits of its alternative components and the wide range of characteristics it shares with its [societal environment]’. Social movements ‘therefore, never act outside of the imagined logic of the system’” (p27).*

The interpretative community referred here may require an enhanced reflexivity if it is to step outside/beyond the ‘imagined logic’; that which repeatedly returns to quantifiable, objectifiable measurements of human performance, essentially justifying the continuation of the meta/grand narratives and overall materialism and rationality that dominates Western society. Further to this, Blühdorn (2006) describes social movements as having a stabilizing effect on current social systems:

*“by reproducing ‘the belief in the autonomous subject’ where: ‘the only societal movements that are possible today are movements that defend the personal Subject ... that construct or defend ... the personal rather the collective ... that no longer present a ‘political alternative, but alterity, i.e. the desire of individuals to be different from the system and experience themselves as autonomous subjects.’” (p35/36)*

There is a paradox here, where ‘the system’ that is associated, promotes and participates with democracy - where health, wellbeing and prosperity; choice, inclusivity, individual rights, is promoted, taken up by social actors - becomes the very thing that regurgitates, adapts, restricts and ultimately shuts down alternative discourses that may lead to improved circumstances for the dispossessed (Farrelly<sub>b</sub>, 2015). Springer (2012) links this to the rise of neo-liberalism where *“a discourse that encompasses material forms in state formation through policy and program, and via the subjectivation of individuals on the ground”* is enabled; where *“the potential for democracy emerges from pre-existing circumstances of social relations”* (Farrelly<sub>b</sub>, 2015, p13-14) – the status quo. As Gershon (2011) notes accepting diversity, promoting self-experience on an individual basis can play into the hands of neoliberal ideals where: *“Difference is not neoliberalism’s enemy, especially not when these*

*differences can so easily be figured as homogeneous heterogeneities*” (p545). The interpretative community in emphasising the deeply personal/individualised yet universal nature of the psychotic experience (Ideological Dilemma, 4.14, chapter 4); the autonomous-self as per choice and personal responsibility and self-determination; self-healing where personal fortitude becomes a central characteristic to achieve recovery could be accused of corroborating neo-liberal ideals where a form of materialism dictated by ‘the Market’ is confirmed, restated and replayed. Here: “*A seeker is therefore marked by the exercise of self-authority: It is up to the seeker to pick and choose, combine and synthesize, his or her own journey*” (Wood, 2016, p3). This leaves the interpretative community found here open to public criticism - of thoughtless, reckless and unrealistic approaches to supporting people experiencing ‘psychotic crisis’ (publicly marked as vulnerable and at risk) allowing them to flounder in a complex, inconsistent and incoherent world where guidance and advice as per traditional conceptions of expertise is inhibited and no obvious system of support is put forward, tested, made readily available. I would like to state that this is not my personal criticism, but one that exists, that the interpretative community would likely be accused of given existing systems and public concerns.

In orienting a strategy of changing public opinion, identities and cultural practices the interpretative community identified here, implicates itself in a struggle for recognition of the psychotic experience; as being part of the human condition and with it raised awareness of various breaches of civic and human rights. However, the very structures, knowledge and power base constituted by the meta/grand narratives, allowing associated institutions and practices to persist is not addressed. This leaves those who potentially, or who are currently being ‘treated’ by the mental health

system (peers) vulnerable to the rights breaches as highlighted by participants. Yet participants, demonstrated through the Horizontal Dimension of Social Comparison (5.3.4), strategically remained sympathetic toward such persons. Cunningham and Savage (2015) present that:

*“Construct[ing] a narrative solely around the characteristics and problems of the most disadvantaged people and places ... does not address how the power and privileges of the advantaged are organized.”* (p332)

Beresford (2016), highly acclaimed academic, self-proclaimed user of mental health services and personal experience of the welfare system, notes the failures of deinstitutionalisation under neoliberalism where reduction in public expenditure was the primary rationale; to recent times where a constant with ‘recovery, as part of UK government mental health program, is diminution in long term support; to reduce service user dependency on state benefits moving them into employment. Regardless of this social reality; *“we are encouraged to be ‘aspirational’, denying who we actually are and creating alternative fantasies, as well as to distance ourselves from our peers as ‘other’*”. (Beresford, 2016, p346). If discourse is to change in the direction advocated by this interpretative community, programmes of care and appropriate structural arrangements may be required to avoid lessons of the past, ensure appropriate supports are made available to those struggling with ‘psychotic crisis’. This would also be required if they are to win over a ‘concerned public’ (Smith-Merry, 2018).

Taking up a moral position based on individual character and fortitude (‘I am doing better’ 5.3.4; ‘I have higher ethical standards than identified others’, 5.3.5) in line with

commonly understood moral norms and human decency may avert from distress that accompanies ‘problematic’ psychotic experiences. Psychotic Like Experiences may appear benign, but the structures, the knowledge base that sustains the public perception of all that is associated with psychotic experiences; the level of influence and authoritative knowledge on public discourse, institutions and practices emanating from the meta/grand narratives remains intact. I therefore contend that the discursive performances conducted by the interpretative community is reflective of a discourse, driven by an ‘economy of truth’, where the individual as an exploitative resource (Groot, 2017, p3) as per autonomy and agency contrived by neo-liberal ideals maintaining the status quo.

To conclude this section, the above may appear to have drawn a negative, futile and pessimistic view of the strategy adapted by this interpretative community. However, there is a larger picture to be drawn here, one that may help participant orientation toward the normalisation and public acceptance of the psychotic experience, leading to the fruitfulness urged by Potter and Wetherell (2007) when applying discourse analysis. The fruitfulness may lie with opportunities already identified above currently existing in current ‘trends’ of social discourse, found in the discursive performances as achieved by participants. This would involve a corroborative approach which I will turn to below.

## **5.8 Social movements as Early warning systems**

I argue that participants for this study are part of an interpretative community, constituting a social movement through collective intentionality. Strategies deployed by the interpretative community have been noted preserving a sense of self that maintains self-integrity, positioning aligned with moral norms, civic and communal

ideologies pertaining to principles of democracy and human rights to achieve public sympathy. The strategies chosen are constituted by and reflective of a social system compelled by a materialism that promotes self-enhancement through neoliberal ideals; parasitic toward discourses that might threaten the status quo. Through strategies such as opportunistic marketing, personal profiling, adapting democratic principles - choice, autonomy, prosperity and diversity - alternative or counter discourses are enveloped shaped and reshaped to satisfy these neoliberal ideals.

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Habermas (1981) observed social movements to be analogous to “*early warning systems*” of an established order; Luhmann (1995) as “*indicators of societies condition*”. There are a number of frustrations, and displeasures that appear in the discursive performances by participants that reflect public disquiet toward the materialism allied with neoliberal ideals dominating society today; a level of dissatisfaction and discontent that provides a window into the social disconnection and ‘dehumanising’ effects of neoliberalism as enacted by the meta/grand narratives. Current conditions, as noted by Beresford (2016), encourages neoliberal governments forming alliances with a prevailing, expanding psychiatry and a broad public acceptance of ‘psych-thinking’. Combined; “*Both neoliberalism and mainstream psychiatry individualise responsibility and frame understanding in terms of individual rather than social causes and analysis.*” (Beresford, 2016, p346). The interpretative community identified here emphasise ownership over the psychotic experience, as an internal, personalised event leaving them open to similar critique ie; that they have limited concern of social causes and social analysis of psychotic experiences. I have presented that the interpretative community have taken the responsibility of the individual toward their psychotic experience, their journey toward ‘recovery’ as an

event that should be marked with autonomy, agency, self-determination, social and communal acceptance. However, against this desire for change, as highlighted through participant orientation, lies the meta/grand narratives through its alliance with neoliberal forces that act in opposition to this liberal position on psychotic experience - where experience is “*reduced to silence by positivism*” (Foucault, 1965, p198), a positivism that can act in favour of social elites based on an economy of truth (Tesler, 2018). I describe below how those working within the meta/grand narratives can enhance a ‘truth’ that participants espouse and help address the structural power and knowledge base avoiding the inhibitions to change as outlined above.

### **5.9 Science, elitism and societal forces**

Tesler (2018) refers to two major historical events swayed by scientific appraisal that changed public opinion of groups judged deficient; socially deviant - that of race and sexuality. During the 1930s scientific consensus presented that there was no discerning biological or genetic difference between races, and in 1974 the American Psychiatric Association relinquished its position that homosexuality and lesbianism were mental illness. These events changed public opinion, but the impact of expert knowledge in the guise of the scientific community has somewhat waned since then. Fast forward today, Tesler (2018) analysing the impact of scientific consensus on climate change on public policy observes that:

*“science-minded elites are not the principal initiators of new partisan policies; interest groups, political intellectuals, and perhaps even ambitious politicians are more important actors.... The dynamics of public opinion formation may still be top down, but science-minded elites are not the top.” P323*

Scientific ‘truths’ can therefore become truths of convenience where elite groups with vested interests, such as those identified by Tesler, can regulate public opinion in turn initiating policies that ultimately influence and justify state responses and institutions. The convenience for an elite operating under the meta/grand narratives is that public policy on mental health, including Mental Health Legislation, and ensuing institutional arrangements fit hand in glove with neoliberal ideals confirming and maintaining ‘economies of truth’. A circularity exists where mental health legislation places ultimate responsibility on a ‘psych community’ in managing crisis pertaining to risk of/to psychotic persons (Smith-Merry, 2018); neoliberal governments have at their disposal an array of experts and professionals to carry out this public duty which the public have to a large extent accepted and ‘learnt’ to expect. Somewhat obscured within the circle is the vested interest of pharmaceuticals and its relationship with medicine. For decades major concerns about the efficacy of psychiatric medications, in particular risk to physical health and exacerbation of mental health problems has been raised by various academics, scholars and health practitioners (see for example Whitaker, 2010; Davies and Read, 2018, Stockman et al 2018, on the addictive properties of anti-depressants and effects of withdrawal; of anti-psychotics; brain atrophy as a consequence of long-term usage of anti-psychotic medications - Breggin, 1990; Ho et al, 2011). Despite strong evidence that serious risks with psychiatric medications exists, continued reliance on and increase in prescribing persists (Whitaker, 2010; Ilyas and Moncrieff, 2012; Moncrieff 2010; specific to Ireland see thejournal.ie: ‘HSE prescriptions for antidepressants and anxiety medications up by two thirds since 2009’). Worth noting is that a significant number of the various practitioners, scholars and academics critical of the over reliance on psychiatric

medications to treat psychotic ‘symptoms’ are found within the ‘psych community’ – namely psychiatry and to a lesser extent psychology. This implies that a schism exists within the ‘psych’ groups operating under the meta/grand narratives. Given the level of divergence and contradictory evidence made available by these groups, questions on the presentation of evidence, the weight each source is given in influencing national policies and guidelines (in turn having direct impact on practice and institutions), requires highlighting. In reviewing NICE guidelines on the diagnoses and management of Depression (NICE, 2009) and ADHD (NICE, 2008) Moncrieff and Timimi (2010) highlight lack of critical analysis of the validity of both diagnoses and recommended treatment. Taylor and Perera (2015) highlight issues regards evidence and recommended interventions as appears in NICE guidelines (2014) for the treatment and management of psychosis. They make the point that CBT is over promoted; “*as a panacea*”; “*beyond the evidence*” and that recommendations on prescribing anti-psychotic medications are “*nonspecific and vague*”. Moncrieff and Timimi (2013); Taylor and Perera (2015) for different reasons are concerned about the political implications of these national guidelines. Specifically, Moncrieff and Timimi describe guideline formations involving selection and interpretation of data as a process that favours, “*the symbiosis between power and knowledge*”; that is convenient, technologically driven vis-à-vis governed by medicine and diagnoses. The process ignored opposing evidence, closed down alternative solutions, whilst giving the impression of consensus in reaching conclusions and recommendations. Moncrieff and Timimi (2013) determine that “*The medical profession and the pharmaceutical industry obviously benefit, but patients and parents have also been instrumental in the medicalisation of ADHD in particular*” adding that: “*Some of the authors of both guidelines considered here have declared financial conflicts of*

*interest involving various drug companies, in common with authors of other clinical guidelines”* (p69). This points to privileged knowledge, adapted and applied by select individuals to maintain a narrative to their advantage, knowledge as noted by Moncrieff and Timimi that permeates public conscience and behaviours – their example, family and patients. Moncrieff et al (2005) comment that the relationship between Psychiatry and the pharmaceutical industry meets: *“commercial rather than clinical or scientific demands’ leading to ‘the popularity of developing cheaper ‘me too’ options”* (p84). Marcia Angell, former Editor in Chief of one of the most prestigious internationally renowned medical journals for over 20 years - *The New England Journal of Medicine* - is more specific when she writes:

*“Breaking the dependence of the medical profession on the pharmaceutical industry will take more than appointing committees and other gestures. It will take a sharp break from an extremely lucrative pattern of behaviour. But if the medical profession does not put an end to this corruption voluntarily, it will lose the confidence of the public, and the government”* (Angell, 2009).

From the comments, observations, concerns made above there may arise potential to develop a ‘counter narrative’ to the meta/grand narratives; one that supports participant orientation of humanising the psychotic experience, addressing some of the structural power, part of an overarching governance structure within neo-liberal ideology. Firstly, professional groups operating under the meta/grand narratives are themselves divided on the validity and value of scientific evidence, of the merits of the technological model of mental health it represents and spawns. Main concerns from the various scholars, practitioners, researchers referred to above centre around

practices and institutional care that threaten and inhibit civic and human rights of persons identified as ‘having’ psychosis; concerns (buoyed up by mounting evidence and rational argument), about the threat to health in prescribing psychiatric medications. Those who provide the knowledge and language of critique disturb the status-quo; opening up possibilities for a holistic rights-based approach to mental health, an approach that challenges the monopoly commanded by a ‘psych-elite’, in particular those with vested interests (Koppl, 2010). The message put forward by critics, the discursive acts applied correspond the same standards of logic and rational argument, employing the same ‘scientific apparatus’ essential for the continued dominance of the meta/grand narratives. In other words, strategies toward economies of truth, the tools of science and rational argument organised to maintain the meta/grand narratives are now inverted. The growing number of ‘expert’ critics of the meta/grand narrative points to a model under threat (Kuhn, 1962); one that may no longer find indiscriminate acceptance in a society whose values are shifting, where the traditional concept of expertise is being challenged (above).

Secondly, there is growing evidence of a cynical public increasingly questioning/challenging the credibility and value of scientific enquiry, in particular scientific knowledge utilised to steer individual morals (Cho and Relman, 2010) and lifestyle choices (Hobson, 2002). These are increasingly “*viewed as a bureaucratic tool*” (Seale and Fulkerson, 2015) implying a “*society-science distance*” (Bauer, 2009; Moran, 2013). Additional, according to Coleman (2013) is a growing “*distaste for fundamentalist certainty*” (as cited by Doona, 2016) that has developed alongside modernity pointing to a public erring in the direction of pluralism. This illustrates a civic disposition, reflected in participant discourses, toward the protection of individual rights and diversity; valued and defended with minimum interference from

authoritative sources. The level of public cynicism toward science and resistance against efforts to impose certainty or conclude an individual's identity (labelling and categorising) brings us back to Habermas and Luhmann above who describe social movements in terms of 'early warning systems'; 'indicators of societies condition'. I put it that the interpretative community identified here, their positioning through Category Entitlement, their orientation (or collective intentionality) toward acceptance of the psychotic experience, (primarily though democratic principles) is reflective of wider social trends constituting attitudes toward traditional expertise and authoritative sources.

### ***5.10 From disclosure to social action***

Similar to the above, I contend that the discourse generated by the interpretative community as represented in the findings reflects a broader, social condition of underlying discontentment toward authoritative sources that threaten an individual's right to define and redefine oneself, to express oneself, make lifestyle choices and determine moral imperatives. Even though a personalised, individualised expertise based on internalised first-person experience is itself a form of resistance, of preserving a preferred sense of self inhibiting others to question, define or claim to represent the reality therein the social distance created may itself inhibit necessary shifting of discourse into an advantageous communal space. Considering concerns raised by the 'expert' critics operating within the meta/grand narratives above, issues that have arisen from discourses created by participants (identified as part of an interpretative community) and an underlying public disquiet and discontentment with authoritative sources that infringe upon individual freedoms, conditions for 'communicative action' (Habermas, 1987), may have arisen.

Communicative action involves dialogue between persons/groups strategically invested in life worlds that can be morally and ethically challenging, of relational importance requiring contemplation, reflection and resolution at communal level. The lifeworld referred extends beyond the lived experience expressed through a wholly internalised, enclosed subjectivity (as expressed by participants, reflective of a general social disposition illustrated by for example participatory journalism above), to an intersubjective arena where the context of lives lived takes centre stage. In this communal space the otherness created is dissolved through communicative action initiating a deliberative process where individuals interact and coordinate action seeking consensus in interpretation and shared rationality of the situation. Although the interpretative community identified in this thesis resists rational objective scientific enquiry, particularly that which interferes in areas of human endeavour such as autonomy, morality and personal identity, a corresponding rationality appears in their discourse. Their rationality shows up in their discursive performances, consciously and deliberately acted out with purposive intent ie; to protect individual integrity by referring to normative values. Moving the enclosed subjectivity into a dialogical space may for participants risk exposure to scrutiny questioning the integrity of a truth claim, but subjectivity in and of itself may not be able to make a significant shift in the way the public interprets, responds and talks about psychotic experiences. I contend that in order to shift the direction of discourse in favour of the psychotic experience as desired through participant discourse orientation, the interpretative community is required to find a way of 'letting the public in', forestalling the silence that participants enact in their discursive accounts, whilst

making allowances for a rationality and objectivity that engages civic concerns such as health and safety.

An added dimension of Communicative Action, Reflective disclosure, is proposed by Kompridis (2005). Reflective disclosure consummates social criticism initiating practices and circumstances where imagination and articulation of meaningful alternatives to current social and political conditions, by “*acting back on their conditions of intelligibility*”. The intelligibility and acting back referred to here requires a reflexivity of openness, transparency and acceptance of the challenges, limitations and drawbacks to the positioning taken up by the interpretative community (in this instance participants with PLES). The interpretative community implicates a measurement, a standard of (moral and social) truth, hinged upon an internalised, personalised reality (Expert by Experience). Moran (2013) argues that Truth has social capital, whereas Wrenn (2017) shows that Truth has no actual intrinsic value described as: “*the value something has in itself and apart from its relationship to anything else.*” (p108). In effect Truth is ‘intrinsically neutral’, something the interpretative community needs to be aware of, its significance discussed below.

### **5.11 The truth is ‘out there’**

Wrenn, is particularly cynical toward Truths attached to personal beliefs. Truth is what we make it, is often convenient and what-ever ‘the Truth’ really is, a claim to truth often depends on what is acceptable, for whom and for what purpose. Presenting truth through the application/reliance upon autobiographical realities, as defended by the interpretative community, is in danger of ending in a number of ‘Truth

inversions'. As I see it, there are two challenges to the source and standard of achieving truth claims as applied by the interpretative community. Firstly, a truth that necessitates, is heavily dependent on personalised subjectivities, confirmed through the source itself, becomes a mere reflection of the individual, with limited vision beyond itself, potentially having little social consequence. Neoliberalism as already presented is invested in and parasitic toward such autobiographies. The source of truth in the case of an over reliance of the subjective world initiating self-seeking; self-affirming beliefs and behaviours is the very thing that feeds a rational, neoliberal system which the interpretative community is trying to avoid. Secondly, truth centred on personalised subjectivity allows others to present alternative or counter truths about personal experience of psychotic experiences by applying the same standard of truth. For example, those who claim through their lived experience to have positive experiences of mental health services and/or of anti-psychotic medications, corroborating the meta/grand narrative (see for example, First Person Account, 2018). The existence of truth inversions is nothing new and probably not surprising given social conditions where the march of individualism, the right to hold personal beliefs and increased opportunity for self-expression has expanded. However, if the interpretative community continue with a strategy that orientates toward changing public discourse, associated interpretations and responses toward psychotic experiences, the ambiguity and inconsistency that arises from their positioning, culminating in truth inversions would leave a noticeable knowledge gap and scupper their strategic intentions.

Wrenn (2004) presents that in order for a belief (version of truth) to become accepted, it would need to become a "*candidate for knowledge*" based on a hypothetical and

categorial “*Epistemic Normativity*”. Wrenn describes Epistemic Normativity in terms of that which: “*arises from the causal connections between cognitive means and epistemic ends*”. In context of this study, internal representation of reality, privileged and defended by this interpretative community, reflective of a wider social disposition (epistemological internalism) would be required at some level to match or reflect external representation (epistemological externalism) if it is to become a candidate for credible knowledge (Wrenn, 2004). Moran (2000) shows that experience “*presents itself as the experience of engaging directly with the world*” and that “*Subjectivity must be understood as inextricably involved in the process of constituting objectivity ... objectivity for subjectivity*” (p15). In other words, subjectivity has its eye on a rational objectivity, is able to influence and shape objective measures (and presumably its outcomes) by referencing subjectivity through feedback derived from social reality - that is the lived experience, the life world. In order for a truth (ie; that psychotic experiences is part of the human condition) to be accepted as socially valuable and achieve social purchase a level of correspondence between the subjective and objective material world would be required.

### **5.11.1 From truth to a responsible communal response**

Here, it is worth pointing out that it is not the psychotic experience that is questioned, confirmed/reconfirmed as a form of reality, but the belief (corroborated above) that the psychotic experience is excluded from what is deemed normal human experience and therefore those who live with/or have lived with the experience are subject to (or at least risk of being subject to) misuse and neglect of human and civic rights as raised by the interpretative community. For the interpretative community to elevate its truth claim the social reality as described could be confirmed and corroborated through

rational argument and reporting as presented by the 'expert critical voices' working under the meta/grand narratives as referenced above. The risk, as the interpretative community may be conscious of, is that the current preference for personal, trivial or sensationalism, of a subjective, emotional style of reporting may lead to an inquisitive, intrusive public leading to questions as per health and safety concerns, of biological and genetic influences over their psychotic experiences pertaining to urges and behaviours. I suggest the interpretative community would prefer to avoid such questions, hence their tendency to remain silent. Worth noting though is that social movements such as feminism, of gay and lesbianism, of the black movement have tended to maintain a public discourse that has focused on issues of equality and social inclusion. The public are to an extent deterred or discouraged from asking such questions around genetic and biological influences on being a woman, to being gay or lesbian, to being born black. These questions have become somewhat obsolete or irrelevant as issues of inequality and social exclusion take precedence. The interpretative community would do well to learn from any advances made by such groups (though I acknowledge continuing struggles experienced by these groups). That said, issues of health and safety, of the ability of managing psychotic experiences and potential for intervention will most likely remain. This is perhaps where the greatest risk to allowing a public in to the 'privatised/hidden' lives of the interpretative community, but one I contend worth taking. •

I would add that the interpretative community may consider the likelihood that there will always be some people with psychotic experiences of such a severe and complex nature that they require intervention from state bodies, facilitated by legislation. The case for this likelihood is amplified as part of modernisation. The potential for such interventions requires dialogue at various levels, within and beyond groups involved

in communicative action and reflective disclosure. Communication and communal engagement is essential, led by authentic and genuine communal concern for the individual where a risk discourse that expresses: “*outrage at behavior deemed socially unacceptable, thereby exerting control over the body politic as well as the body corporeal.*” (Lupton, 1993, p425) is resisted. Where state sanctioned intervention may be warranted Open Dialogue (2.21, Chapter 3) as facilitating the necessary communicative space during ‘psychotic crisis’ may provide some of the answers. The caring process should also consider a Moral Imagination that can facilitate the shared subjectivity and life world of all involved. The level of reflexivity put forward requires recognition of forces of socialization and amendments to certain social structures that impede a humane and compassionate response to psychotic experiences. One that enables shared responsibility in creating meaning that is of universal importance.●

## 6. Chapter 6 – Conclusion

### 6.1 *Implications for individuals*

At a personal level, participants, through deployment of repertoires and acts of positioning - specifically othering and social comparison -elevated and maintained self-integrity and a preferred self. Othering created a superiority between those with psychotic experiences and professional groups operating under the meta/grand narratives by claiming an expertise through category entitlement based solely on self-experience and an appeal to normative ethics. The expertise staked through an individualised, personalised reality where the ‘beholder’ becomes the ultimate judge and arbitrator of psychotic experiences formed a layer of protectionism for the individual. Under these conditions self-experience becomes sacrosanct, never to be questioned. Normative ethics is described in terms of public understandings of right and wrong, in this case commonly understood morals pertaining to civic and human rights. Participants aligned themselves with the aforementioned normative ethics pitching themselves against an ethics created by an exclusive, elite group of professionals (the psych community) operating under the meta/grand narratives. The call to normative ethics allowed participants to claim superiority against an ‘expert group’ through an appeal to higher ethical standards, ones that the public can relate to. By way of example, participants valued and upheld autonomy, equality and social inclusion as part of their individual moral frame when interacting with others, a moral frame that should apply to those with psychotic experiences. Conversely, those operating under the meta/grand narratives were charged with imposing interventions, practices and identities upon people labelled psychotic therefore threatening and contravening their human and civic rights - specifically rights to inclusion, equality

and autonomy. The participant group could position themselves as superior to a group of recognised experts (who are sanctioned to carry out ‘dehumanising’ acts) through higher ethical standards publicly and commonly understood and shared. This positioning enabled the vertical dimension - social comparison (comparing social status) enhancing a sense of self through virtuous claims.

A horizontal dimension was enabled (doing better or worse) through ‘subtle’ acts of positioning that allowed participants to maintain self-integrity and a preferred self, whilst avoiding social distance that would threaten their moral positioning. Across the horizontal dimension reference was made to those ‘caught up in the mental health system’ labelled psychotic (peers?) and comparisons made between participants with all others who have not lived with the ‘psychotic experience’ (the general public).

These comparisons factored another layer of othering. Although participants claimed strength of character central to learning to accept and live independently with the psychotic experience, therefore doing better than those caught up in the mental health system, they were at odds to ensure they were seen to remain sympathetic toward this group of ‘peers’ ie; to avoid claiming superiority, looking down, judging them.

Othering directed at the general public emphasised social and individual benefits of living with psychotic experiences (an overall positivity), the need to accept it as part of the human condition (universalisation) the wisdoms and richness therein, and how they were missing out because of fear or ignorance. However, as with the comparison made with peers, participants were careful not to denounce those whom they need a continued relationship with - the general public. To maintain a narrative of acceptance and universalisation of the psychotic experience, participants remained silent in their everyday social circle, in their condemnation of the public, not wanting to be seen to be detached from peers averting speech acts that would contradict their

moral positioning and orientation – that of equality and inclusivity. To outrightly condemn the public or to claim superiority toward peers through a comparison of total exclusivity would risk a strategy whose aim is to gain public interest and sympathy in order to create a discourse in favour of the psychotic experience.

## **6.2 *Implications for a social movement***

Discourse created by participants indicated they were mindful of public interpretations, beliefs and perceptions of psychotic experiences via their desire, or more succinctly their discourse orientation toward inclusivity and equality (eg; horizontal dimension above) inferring a requirement for social action. This pointed toward a social movement. Given participants were diverse in their beliefs and interpretations of psychotic experiences, with geography also separating them, it was apparent they did not come from or belong to a coherent whole, an identifiable group or organisation. However, discursive performances corroborated an interpretative community through shared discursive strategies. The primary strategy oriented toward holism, individualism and normalisation claiming civic and human rights, constructing a positive message about psychotic experiences appealing for public sympathy and a desire to challenge and change the public narrative as informed by the meta/grand narratives. The strategy chosen did not target political, institutional or structural power, but highlighted suspect mental health practices that contravened individual rights pertaining to autonomy and agency appealing to democratic ideology and a shared normative ethics.

However, the strategy chosen represents neoliberal ideals where counter narratives are often replayed, adapted and reassembled to preserve a liberalism built on a materiality that maintains social hierarchies and inequalities - the status quo and elitism.

Neoliberal ideals encourage self-serving behaviours, an individualism, a marketplace where self-enhancement is encouraged/realized through the exercise of choice and individual fortitude; vis-à-vis autonomy and agency as per strategies applied by the interpretative community. Moreover, a strategy of the interpretative community is to create a division of morality between those who live with psychotic experiences and those who operate under the meta/grand narratives charged with judging, misrepresenting and imposing practices upon those with self-experience. Given the interpretative community adapt a strategy of 'educating' the public about the reality of psychotic experiences yet choose to remain silent; that they replay neo-liberal ideals and distance themselves from all 'experts' as traditionally conceived operating under the meta/grand narratives it is improbable that they would be successful in their intentions. Firstly, replaying neo-liberal ideals will only serve a system where standards of normalisation occurs through the quantification of human performance; pitching one individual against another in a competitive environment, highlighting risk behaviours that threaten social stability. Secondly, remaining silent communally or publicly will not achieve the social change they aspire. Thirdly, in distancing themselves from all experts operating under the meta/grand narrative's, assurances to the public - that of health and safety associated with psychotic events - may not materialise in a world where autonomy and agency can be overridden by a 'perceived' need for intervention. It is health and safety concerns that sustains the public perception of psychotic experiences and these I argue cannot be ignored. Notably, a significant number of experts - scholars and practitioners - operating under the meta/grand narratives have similar concerns raised by the interpretative community identified here, concerns that point to a potential to develop a symbiosis of knowledge

and expert opinion from a number of sources creating space to construct a culturally acceptable narrative sympathetic and accepting of the psychotic experience.

### **6.3 *Blending expertise***

Observed in today's society are challenges to traditional expertise and professionalism. It is common to find experts involved in all fields of natural phenomena referring to the lived experience, the life world of individuals, no longer seeking to observe effects, describe impact and provide explanation without consultation and facilitating public and/or communal dialogue. The location of knowledge, specifically that directly impacting on health and wellbeing has shifted from an aggregated reliance on categorisation and symptomology, based on generalised observation imposing explanation and advice, to facilitation of self-reporting, whilst considering social context of the individual. This has changed the nature of interactions and relationships between a client/patient; public and private self, leading to calls for a holistic response to individuals in need. Deciding symptomatology is increasingly augmented by self-reporting where the individual can help the practitioner understand the nature of any discomfort and personal meaning attached to their experiences.

In the context of mental health, current expertise is challenged, critics pointing to a mismatch between self-knowledge, decision making apparatus and interventions that are available. Decision making apparatus has been shown to be anti-democratic in favour of vested interests and a 'psych-elite', interventions shown to be damaging to health, contravening civic and human rights. A number of scholars and practitioners operating under the meta/grand narratives (the other as categorised by the

interpretative community) have consistently raised these concerns seeking a holistic response and an agenda of social justice to mental health. Given concerns similarly raised by the interpretative community and a growing number of practitioners and allied scholars, it may be fruitful to open up spaces for dialogue where these sources of knowledge can be combined, synthesised in order to construct a public narrative that addresses the issues of wellbeing, health and safety concerning psychotic experiences. A starting point would be to turn to communicative action where a willingness to communicate and learn with others is undertaken without resorting to power as a means of persuasion. Here, communicative action is preferred over a systems approach and instrumental action, human performance as defined by neoliberalism no longer becomes the yard stick with which we should aspire; a culture of being is preferred over one of doing. Finally, even though a reconstructed narrative may improve public response to psychotic experiences, it may always be the case that the complexity and depth of some individual's distress is so unmanageable that they require 'caring for' or 'caring with'. Again, communicative action involving 'communities of interest' may be central to a process whereby state sanctioned intervention is humanely practiced, redeveloped and warranted. Here as alluded in the literature review Open Dialogue may provide some of the answers including the encouragement of Moral Imagination as part of the caring process.

#### ***6.4 The rise and fall of new wave social movements***

Considering tensions between individual positioning and collective action, findings and discussion as interpreted and presented in this thesis signifies challenges increasing numbers of interpretative communities seeking recognition and social

change encounter, specifically where: “the increasing importance of individual autonomy within networks is centred on the empowered individual’s role in enhancing democratic control over the direction that society is taking” (Gillan, 2018, p.16 ). As presented above, the general trajectory society is on is very much in the direction of liberalism, diversity, the promotion of individual autonomy and personal responsibility (as found in participant discourse). This presents an ever-changing world where individuality raises new levels of social complexity and interpersonal demands, where: “The politics of lived spaces” are played out in “Alternative spatialities” (Keith and Pile, 2013, p27). Alternative spatialities can materialise in a variety of spaces (eg; virtual or actual) where subjectivities are facilitated, where action can be expressed through and/or restricted to collective intent as revealed through the orientation of participant discourse where the desire for social change toward the psychotic experience was expressed, not actioned. Kraus (2012) observes that “Social phenomena are not simply constituted by the subjective meanings agents assign to them. They are also objective facts in the sense they are constituents of social reality which can coerce agents into adapting their behaviour”, (Kraus, 2012, p347). Spatialities, where intentionality occurs, in particular that which involves an increasing need for subjective interpretation and the facilitation of personalised meaning making, motivates individuals to believe that social change is possible, even imminent. It is this belief that I think participants of this thesis hold on to, with their behaviours adapted to wider democratic ideals and principles through which they assert their rights and protect their identity. Added to this social reality is temporality, where protest becomes progressively fluid, rising and falling, coming and going, appearing and reappearing; periodic (McDonald, 2002; McDonald, 2004; Gillan, 2018; Poell, 2019). The collective identity, the extent of ‘we-ness’ traditionally

associated with social movements has been transformed by a “new order of life movements” (Blumer, 1995), where “experiences of oneself” becomes the focal point and social movements become “experience movements” accentuating “experiences of difference” (McDonald, 2004). The difficulty for modern social movements in accentuating experiences of difference, highlighted through discourses created by the interpretative community identified here, is the difficulty in establishing representation (what, who?) and agreeing a strategy (why, how, where?) resulting in collective action. I argue that these constituent parts are required to achieve structural transformation of mental health systems for the benefit of those within and without the institutions dominated by the meta/grand narratives.

The silence chosen(?) by participants serves to protect the subjective from an overly inquisitive public, but also from intrusive forces that maintains a disapproving message about the psychotic experience. MacClure et al, (2010) describe such silence as: “an impediment to analysis or the emergence of an authentic voice” (p492). Similarly, Scambler and Kelleher (2007); Kaun and Treré (2018) point out that silence can be a form of resistance creating a layer of protectionism from “excessive intrusions” where decolonization through silent ownership over life worlds can be achieved. Barranquero (2013) and Pink (2008) describe comparable acts of resistance involving ‘disconnection’ from a rapidly changing temporal capitalism, where alternative platforms of ubiquitous communication and connectivity are being created. Silence and disconnection can therefore operate as a form of power and resistance ie; strategies of indifference, disengagement and denunciation of meta/grand narratives potentially enabling the individual to live outside/beyond the gaze of what is perceived as systems of control. In considering these observations though, I remain of

the opinion that participant's orientation is compromised and found wanting if social change, as revealed through their orientation, is to be achieved. That said, there may be hope for these 'new wave' social movements.

In 'modern times' social movements may appear to be more erratic or episodic; driven by an individualism struggling to achieve collective transformations lacking representation and strategic direction. People that find themselves socially oppressed or persecuted through systems of classification typically have a consistent narrative, repeated throughout their history. The 'survivor movement', the 'anti-psychiatry movement', groups opposed to a biological reductionism and deficit models that threatens the dignity and identity of those judged inferior (the psychiatrically unwell) has maintained a message of liberalism and human rights, highlighting inhumane practices and a paternalistic view of persons living with extreme states of mind, body, spirit. Perhaps the interpretative community, through its collective intentions will eventually locate a moment in history when spatialities and temporality collide; an optimum time when they will find a public receptive to the psychotic experience accepting its rightful place in human experience. I maintain though that the spatialities and temporality found, created, discovered should welcome in and engage the practitioners and allied scholars equally critical of the meta/grand narratives, associated practices and representations that belie the psychotic experience. As things stand though, relying solely on "experiences of difference" as a basis for interpretation and representation risks fragmentation where the modelling of a "democratic way of self-organisation and action" is arduous and difficult to achieve (Sapouna and Gijbels, 2016, p401). Explicit, visible acts of resistance and activism is wanting, as is a consensual message that might shift public discourse and institutional

response from one of rejection and social isolation to one that accepts the psychotic experience as a humanly shared event.

## **6.5 *Limitations and ‘Real-world Contribution***

Limitations, including shortcomings in design and ‘real-world’ impact are common in research. Below I comment on a number of limitations of this study hoping they may help others interested in taking a similar route in researching discourses on psychotic experiences and mental health in general.

Firstly, discourse analysis as a research methodology errs toward deconstruction of language where alternative knowledges can be drawn out potentially influencing associated practices (Georgaca, 2014). Correspondently, Harper (2006) puts it that discourse analysis is pretty much ineffective in transforming established interventions with Breeze (2011) pointing out that discourse analysis has been described as an “intellectual orthodoxy”. The outcome of this thesis could be framed in similar terms where discourses presented by participants could be perceived as being subject to an overly critical methodology with no benefit for persons living with psychotic experiences, or indeed other stakeholders interested in psychotic experiences and mental health in general. I would acknowledge anyone coming to this conclusion. However, equally I would point out that this thesis was necessarily exploratory in nature. I did not start out with a hypothetical or theoretical question to be answered or to find resolution or solution to a specific problem. I have however, successfully linked findings with real-world implications that can influence common responses and practices toward the psychotic experience.

As already stated throughout this thesis, discourse, contrary to what others might believe, is never complete, fixed or secure in its totality. Discourses are full of contradictions, compromises, inconsistencies, nuanced and fluid. By revealing limitations, found in participant discourse, revealed through their ideological dilemmas, positioning and orientation I have opened windows of consciousness to distal forces, that work against their desire through their orientation to find universal acceptance of the psychotic experience. In revealing these limitations, I am able to bring real-world structural challenges to this interpretative community encouraging collective reflexivity and synthesis of knowledge that I believe would find social purchase at the level they are pitching their discourse. Further, struggles of identity at the discourse level encourages practitioners to consider the impact of categorisation on persons subjected to labels and to appreciate their psychological, emotional and behavioural impact. It should be no surprise then that resistance to categorisations and associated deficit models of psychosis exists (the meta/grand narrative), present in certain speech acts and response behaviours such as resistance to and avoidance of services (Brett et al, 2014). It is the experience of identity threat, as revealed in participant discourse, that those working within the meta/grand narratives need to acknowledge, accept and understand if they want to develop and maintain meaningful working relationships. Brett et al (2014) recommend that approaches toward ‘troubled’ populations with psychotic experiences include “normalizing and validating contexts in which psychotic experiences can be accepted ... rather than attempting to control them ... less stigmatising” (p213)

In summary, contrary to criticisms from Harper (2006) and Breeze (2011) above I argue that given the real-world impact of meta- discourses on person’s identity and

subsequent behavioural responses discourse analysis and in particular this thesis has real-world value raising awareness of direct consequences and conflictual relations influencing associated practices (public and institutional), toward psychotic experiences (Georgaca, 2014). In drawing attention toward real-world impact and effects of discourse produced by the meta/grand narratives on persons living with psychotic experiences, it is possible to influence and change the way the public and authoritative forces frame their understanding of psychotic experiences, in turn respond more positively to individuals living with these experiences. The real-world impact of these discourses and potential to generate conditions where responses are affirmative and accepting toward the psychotic experience highlights the distinct contribution of this thesis. Lastly, referring back to the introduction of this thesis, there has to date been few qualitative studies carried out on people living with psychotic experiences outside/beyond statutory mental health systems. This particularly applies to Ireland as a potential site for further research in this area. This is a gap in knowledge, potentially lucrative in forming a deeper understanding of how people with what is understood as a troubling or troubled experience can and do live successfully with them. The direct impact of this thesis emanating from its unique contribution to knowledge pertaining to psychotic experiences is presented below in the list of recommendations.

## **6.6 Recommendations**

A common response to recommendations arising from discourse analysis studies is to approach with “extreme caution” (eg; Farrelly, 2015). Renkl (2013), whilst acknowledging such reservations refers to discourse analysis studies that are practically grounded - “use inspired”. Renkl warns against discourse studies that

present general sweeping recommendations proposing that they should be modest and legitimate. I believe that the recommendations below are both realistic and legitimate, applicable to practices and social responses to psychotic experiences. I put it that this transcends criticisms that discourse analysis is merely an intellectual orthodoxy with little inference toward established structures of power. The recommendations speak to social dimensions, of dialogue, culture and education with research implications.

### **6.6.1 Finding a common language through dialogue**

As a provocative and deliberative social object, it is difficult to find a common language on psychotic experiences that enables the creation of an interpretative framework that captures, reflects and satisfies the myriad of groups and persons that have a direct interest in the lives who live with this experience. As noted at various junctures of this thesis there is ample evidence that one of the most notable sources of discomfort, disquiet and mistrust among persons with psychotic experiences is the interpretative power bequeathed to established groups of mental health experts, taken up and reflected back at micro and macro levels.

The need for a common language involving all ‘stakeholders’ may never satisfy all interested parties but space to enter into dialogue where the interpretative power of the meta/grand narrative, its direct impact on the people it captures and defines is openly discussed, deliberated, and confronted is a worthy exercise. Finding a universal language where an agreed humanity is attached to psychotic experiences becomes familiar, established and socially accepted is possible to achieve. There are dialogue groups established in Ireland that take place in community settings primarily made up of persons with self-experience, carers/family members and mental health

professionals. These Trialogue meetings address issues of concern, chosen for discussion and deliberated on (see Mental Health Trialogue Network Ireland: [www.trialogue.co](http://www.trialogue.co); <https://www.facebook.com/pages/category/Community/Mental-Health-Trialogue-Network-Ireland-107425315996430/>). Studying differences and any shift in language that takes place at these informal settings can be captured and its underlying meaning analysed through linguistic methodologies. Here it is possible to identify avenues where institutional and by default public response to psychotic experiences can be transformed as a direct consequence of the function of dialogue groups. Where formal decision making is removed, as occurs in the Trialogue groups, Schiffman (2001) suggests “informal consensus” can be achieved where “people are making adjustments in their habits and tailoring their linguistic production to their perceptions of what their hearers/interlocutors want to hear”. Adjustments at the linguistic level and newly formed habits in response formation are often made unconsciously with a naturalisation of a new ‘spoken norm’ being established, “retrospectively, after it happens”. Studying the development of discourses that occur through a collective and naturalising linguistic process could potentially lead to the identification of an underlying consensus as to a ‘spoken norm’ toward the psychotic experience. The establishment of a spoken norm through corroboration and consensus could ultimately determine better ways of describing and framing psychotic experiences, enable and improve practices and public responses.

### **6.6.2 The role of Culture**

Cultural environments can influence social responses to psychotic experiences, as presented in Chapter 2 (2.17 and 2.18) where some are found to be more inviting and facilitative than others. As pointed out culture has a bearing on those with self-

experience, specifically their ability to cope and relate with psychotic experiences. This includes the availability of social reference points from which persons living with psychotic experiences who live outside/beyond state services or institutional care attach their experiences to, such as cultural symbols and spiritual outlets. Cultural comparison research into non-clinical populations living with psychotic experiences tends to focus on frequencies, variances and outcomes as accounted through categorisations and epidemiological measures (see for example Vermeiden et al, 2019). Findings from these studies seem to result in pessimistic outcomes for those who satisfy thresholds of inadequacy and distress as judged by the chosen measurements. This perpetuates the deficit models, vis-à-vis meta/grand narrative, with little or no room for optimism for those who live with considerable and enduring psychotic experiences. Narratives involving positive meaning making systems are worth studying where successful coping is captured from a first-person perspective linked with cultural symbols and spiritual conduits (ie; the availability of environments where non-material explanations can be facilitated). Cultural backdrops, symbols and non-material interpretations may have a role in helping people who first encounter psychotic experiences. An overly rationalised interpretation of psychotic experiences fixed to a material world leaves those with first time experience of psychotic events in a vacuum, deprived of a social reference point from which they can initially make sense of and/or anchor their experiences to, leaving feelings of mistrust and abandonment. Exploring the availability and effects of symbols and cultural conduits may help people find meaningful reference points to their psychotic experiences at first point of experience allowing for a more positive and socially beneficial narrative to expand into various social and communal settings. Lessons derived from studying the potential impact of symbols and non-material

representations and interpretations across cultures, found in participant narratives could expand into the practices directly and indirectly involved with the meta/grand narratives.

### **6.6.3 Education for mental health professionals and services**

In order to maximise the likelihood of achieving an empathetic response to those they seek to help and support, health professionals should be committed to life-long learning and open to new ways of 'seeing'. One of the areas specific to mental health, highlighted in this thesis, where practitioners are particularly challenged, is understanding and appreciating the position taken up by persons with significant mental health problems who refuse or decide not to engage with services (Henshaw and Freedman-Doan, 2009; Dixon, Holoshnitz and Nossei, 2016). Disengagement, refusal and service avoidance is often taken by practitioners as part of an underlying pathology such as lack of insight and elevated suspicion/paranoia (see for example Smith et al, 2013). Stigma surrounding mental health, service use and prescribing of psychiatric medications is understood as a factor in disengagement, refusal and service avoidance (Wagstaff, Graham and Salkeld, 2018). However, the level of identity threat experienced by mental health service users and potential users of services goes underappreciated. For many, receiving a psychiatric diagnosis implies a major flaw in character, receiving psychiatric medications taken as further confirmation - an attempt to correct their personality. Additional to generalised experience of stigma and complexities of experiencing psychotic events as highlighted by Wagstaff, Graham and Salkeld (2018); Smith et al, (2013), disengagement, refusal and service avoidance needs to be taken as reasonable acts of resistance in order to protect identity. This needs to be understood, acknowledged and

acted on if services are to be more effective and ‘successful’ when offering their support to those who may need it. The response from services to disengagement or refusal often involves coercion or force which leads to increased distance and mistrust between service user, or potential service user, and practitioner. Considering the depths of disenfranchisement experienced by service users and potential users of mental health services highlighted here it is recommended that practices and strategies of engagement address the impact of diagnoses and medical intervention at the level of identity. Improvements in practices, engagement and offering of services could be developed through consensus applying methods of research, facilitation of dialogue groups or both.

Finally, what this study demonstrates is the extent of social influence, the level of authority bequeathed to the meta/grand narrative and its direct effects on the lives of persons living with psychotic experiences. The history of the meta/grand narrative and how it came to establish itself involves the construction of a reality through a discourse of public concern, attached to health and safety removing psychotic experiences from rational human activity. The words, descriptions and interpretations as presented by the meta/grand narrative filters down into a broad social conscience, influences public response and institutional practices toward the psychotic experience. This has led to social shaming, the effects of which has been shown to silence the people it purports to represent. Nevertheless, there are a number of factors that might have worked in favour of this cohort helping them move beyond the shaming effects of the meta/grand narrative.

On pages 151 and 152 I describe the age range of this cohort of research participants as significant (middle to old age) indicating depth and breadth of lived experience over significant lengths of time. To add to their depth and breadth of lived experience I combine the extent of knowledge specific to psychotic experiences and mental health in general. The extent of this knowledge is borne out of discourses created at interview, particularly in relation to the meta/grand narrative with, having reflected on conversations once each interview concluded, the level of education and professional qualifications that a number of participants had achieved. Although not part of data collection, I learnt that at least close to two thirds of participants were highly educated with a minimum of two completing PhDs, three up to master's degree (with one of those conducting their own PhD study) and several up to bachelor's degree level. Several had professional qualifications, including paediatric nursing and qualifications derived from psychotherapy training programmes. Add to this persuasive levels of self-belief that participants are successfully living with psychotic experiences (evidence endorsing this belief can be found page 140, Participant Criteria), that they belong to the general population (p12) and appear to have found social spaces and other dimensions (eg; spiritual) to attach their experience to it is easy to conclude that this is a group of people who feel empowered and are not affected by the shaming effects of the meta/grand narrative. However, even among a group of persons who present as articulate, vocal, well informed, empowered and socially active (research participants), silence becomes the primary response and means of resistance toward the meta/grand narrative highlighting the level of influence and authoritative effect on social convention.

All is not lost though. If history has taught us anything, social transformation including changes to public response and cultural arrangements can occur through the creation of an evolving narrative and/or shift in discourse. Equally then, the findings and recommendations as presented above can translate into the world of human response to social objects leading to social change including acceptance and facilitation of the psychotic experience at a public level in turn transforming institutional and practice arrangements as conventionally consummated. Discourse analysis does tend to separate language from practice but it also “tries to find causal relations in the use of language and the influence on practice” (Metze and Brink, 2006, p1). I therefore hold that the recommendations as presented above and discourse studies in general can create meaningful change to a culturally formed response to a commonly shared human experience.

## **6.7 Epilogue**

I am taking the opportunity as part of overall reflexivity to state some of my anxieties and personal struggles whilst carrying out this thesis. I am also taking this opportunity to express some observations that may be interpreted as additional recommendations which I think best put in a personally reflexive manner.

Conducting this thesis has affected my own world view and created certain challenges and discomforts over the journey. There has been a genuine emotional and physical impact, pushing me back against personal inclinations and support I feel toward the positioning, orientations and intentions of the interpretative community identified herewith. I still concur with the interpretative community’s call for universal validation, positive and optimistic narratives in favour of the psychotic experience in

order to transform public response and discourse, yet have been left with several questions, conundrums, dilemmas.

As stated in chapter 3, I identify with what is sometimes called the ‘survivor movement’, a movement of persons who claim that psychiatric services and psychiatric practices have damaged individuals who require or seek support during, for want of words, ‘emotional and psychological crisis’; a movement that seeks an appropriate societal response including justice for such persons. The support that many believe is required for persons experiencing such a crisis is at the most basic human level, of kindness; genuine authentic listening, non-judgmental empathetic responses with a holistic, accepting corroborative programme of care implemented to dispose of non-consensual interventions. This has been and remains my principled, values base position; one that I believe aligns with text created by participants of this study.

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For many, psychiatric services threaten individual autonomy, the right to choose and meaningfully participate in care and treatment by denying informed consent, misinform service users and withhold or misuse essential information on many, if not all psychiatric treatments. Paternalistic, non-consensual and alienating practices erodes self-belief, isolating the individual from meaningful human interaction, estrangement and deference where they become strangers to their own narrative. It is not so much the individuals working within the mental health system that is the target for change, but the system with which they work under. Stories of maltreatment are well documented, and I have certainly heard enough of them to believe that things should and can change with determination and the presentation of an ‘obvious truth’

that takes hold of the public imagination altering opinions and responses. I am therefore sympathetic toward the 'cause' and remain committed, though have stepped back over the years whilst completing this thesis where personal reflection and challenges to my world view has taken place.

During analysis, I was particularly anxious that what I was uncovering was incorrect, over critical, even unacceptable; 'letting the side down'. I have never questioned the positive storying of how people have managed to successfully live with, integrate, create confident and constructive meaning about their psychotic experiences and that this occurs on a daily basis. Perhaps though, given the methodology chosen, this thesis was never going to enforce this positive message and allow positive storying to unfold as appears in various forums, in other literature. It took a while to accept the fact that the main issue being addressed through the methodology chosen for this study is to critically examine the ability of such narratives, 'alternative truths', certain ways to talk about psychotic experiences to change public discourse under social conditions they currently exist. In hindsight, it should have come as no surprise that given the endurance and longevity of the meta/grand narratives, replacing or overthrowing its 'hold' on public discourse would be more complex and more difficult than imagined. Certainly. I never fully appreciated the wider public conditions that allow the meta/grand narrative to continue to dominate. I believe that allowing the positive narratives of psychotic experiences to flourish, to ascertain their usefulness, their potential to constructively guide or inspire others, their utility in transforming mental health systems is for another methodology, for another day. Perhaps the interpretative community could consider conducting a study that would represent the specific lessons derived from these life journeys (in particular the life

worlds and alternate meaning created) for the benefit of peers or service providers, or indeed join forces with academic institutions to co-produce such an endeavour?

Given the level of diversity and disposition toward inclusivity expressed in today's society (at least at the surface), the individual nature with which participants presented their stories should be expected. The diversity of life stories however became problematic in identifying a pattern of talk that achieved consistent levels to enable a coherent discourse of 'coping'/living with the psychotic experience that could represent a new or alternative way of talking about this human state. I was left feeling frustrated as my desire to find this pattern of talk was consistently confounded by the chosen methodology.

My discomfort was most intense whilst analysing text and preparing findings. I was particularly uncomfortable noting and highlighting compromises, even contradictions, of the struggle's participants were experiencing in creating a holistic view of psychotic experiences, squaring the world of mind, body, spirit. Given the revolutionary nature of discussions I have participated in with peers over the years, the tendency of participants to resort to silence was a phenomenon that stood out for me. Indeed, this was exemplified in narratives that dissolved at a point where causal links with their psychotic experiences might have been confirmed. For instance, a number of participants shared experiences of trauma and neglect at which point they shifted focus talking about previous lives at different points of history, of spiritual and cosmic dimensions to their experiences. I could theorize or hypothesise that they were defensive, avoiding talking about such deeply embedded experiences, that this was 'proof' that there is an underlying link between past traumas and hardships leading to the existence of psychotic experiences. However, that would be looking

beyond the text, potentially leading to the inclusion of psychodynamic measures to the methodology (eg; unconscious conflicts, ego defence etc). Perhaps allowing the world of ‘observable’ causative effects to creep in was to be avoided as this would be too close to the objective measures directly linked with the material world applied by the meta/grand narratives in confirming diagnoses, cognitive defects? I am unable to confirm.

That said, the discourse created during interview appears to me to err toward anti-establishment. This has left me with another conundrum that could only be answered by the interpretative community. Is there a suggestion for a total disentanglement of state led services for persons with (problematic) psychotic experiences, pushing for a total overhaul, an alternative through communal led responses where funding is given over to independent community driven services? Or is there a suggestion for more input or control over state-led services? Indeed, is this the wrong choice of questions in the first place? This is not entirely clear.

Related to this final question is the context of my employment over the duration of this thesis. I work full time as a ‘training officer’ often delivering peer-led courses on self-advocacy to groups of mental health service users. Their lives as I see it are wrapped up in the meta/grand narratives, dependent upon statutory services. Some have complex needs, including an assortment of psychotic experiences, intellectual difficulties, brain trauma, drug and alcohol addiction. This has left me with another conundrum that could only be answered through dialogue with the interpretative community. If the current mental health establishment is to be replaced, how do we (the interpretative community) constructively and empathetically deliver and inspire a new service, a new discourse to this group? How do we inspire local communities to

embrace and become meaningfully involved in these services? One thing constantly on my mind is that the cohort of people who continue with statutory mental health services cannot be left behind as we strive to drive forward. I remain ambiguous to addressing their needs but remain optimistic to meeting the challenges.

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# Appendix A

## *Interview Schedule*

1. *Could you tell me about your psychotic like experiences (you may use other terminology or words to describe these eg; extraordinary experiences; unusual beliefs etc).*
2. *Can you remember when you began to have these experiences?*
3. *What sense of/what meaning do you attach to these experiences?*
4. *(How) has your understanding of these experiences changed over time?*
5. *What would you say are the most significant influences on any change in understanding of these experiences were/are?*
6. *To summarise - you have described your experiences in spiritual terms; explained beyond the material body? What would you say to someone who has similar (psychotic like) experiences to yourself, but their explanation is biological, and genetic and that they are happy to take medications?*

*\*The above(question 6) is an example of an 'alternative' or*

*'problematic' view on participants representation presented nearing the end of the interview creating a "Confrontative arena" (as per Interviews, Chapter 3).*

7. *Have you anything else to add or ask?*

# **Appendix B**

## ***Ethics approval, Dublin City University (2011)***

Dublin City University

Ollscoil Chathair Bhaie Ätha Cliath



Dr. Liam MacGabhann, School of Nursing

16<sup>th</sup> March 2012

REC Reference: DCUREC/2012/060

Proposal Title: A discourse analyses of people living with Psychotic like  
Experiences in Ireland. Coping and relating.

Applicants: Dr. Liam MacGabhann, Prof. Chris Stevenson, Mr. Jim  
Walsh

Dear Liam,

Further to review, the DCU Research Ethics Committee approves the changes made to this research proposal. Materials used to recruit participants should note that ethical approval for this project has been obtained from the Dublin City University Research Ethics Committee. Should further substantial modifications to the research protocol be required at a later stage, a further submission should be made to the REC.

Yours sincerely,

A handwritten signature in cursive script, appearing to read "Dr. Donal re'Mathuna", written over a horizontal line.

Dr. Donal re'Mathuna  
Chair  
DCU Research Ethics Committee

Office  
of  
the  
Vice  
-  
President  
for  
Research  
Dublin  
City  
University,  
Dublin 9,  
Ireland

# Appendix C

## ***Recruitment Flier***

### **A discourse analyses of people living with Psychotic like Experiences in Ireland. Coping and relating.**

Do you see, hear or feel things that no-one else does? Hold personal beliefs that others might judge as unusual; find hard to believe or hard to accept? Experience levels of suspicion of living things (including people) or objects in the world, so much so that it impacts on your relationship with others? If so, you are invited to engage in a study designed to increase understanding of these experiences - sometimes labelled psychosis or psychotic like experiences.

The research is part of PhD study conducted by the School of Nursing and Human Sciences, Dublin City University. The questions below will help you decide if you can take part in the study.

- 1. *Are you aged 18 to 65 years old?***
- 2. *Would you be willing to share some examples of your psychotic like experiences with the researcher?***
- 3. *Have you experienced something similar to the above occurrences and live with these without professional support from statutory psychiatric services?***
- 4. *Do you feel confident that you have lived successfully with these experiences?***

**If you answer yes to each of the above would you be willing to engage with this study?**

#### **How do I volunteer to take part?**

Use the contact details below where you will be expected to leave a phone number and date/time when you are available to discuss the study. The researcher, who has a lived history of mental health problems and has learnt to deal with these, will then get back to you as soon as possible. During the telephone conversation he will ask some questions to help decide who can take part in the first stage of the research.

**Anonymity and confidentiality assured.**

**Ethical approval has been granted by Dublin City University Ethics committee**

**Tel: 0851526581**

**Email: [james.walsh49@mail.dcu.ie](mailto:james.walsh49@mail.dcu.ie)**

## Appendix D

### *List of organisations and networks for recruitment*

Organisational and individual networks that the researcher approached and has formal relationships

<b>Organisation</b>	<b>Website</b>	<b>Business</b>
1. Irish Advocacy Network	<a href="http://www.irishadvocacynetwork.com/">http://www.irishadvocacynetwork.com/</a>	An advocacy service providing peer advocacy to people with mental health problems throughout Ireland.
2. SHINE	<a href="http://www.shineonline.ie/">http://www.shineonline.ie/</a>	A nation wide voluntary organisation providing support and advice primarily to people with 'enduring mental illness'.
3. GROW Ireland	<a href="http://www.grow.ie/">http://www.grow.ie/</a>	A mutual help organisation supporting people with mental health

		problems on their journey toward recovery.
4. Hearing Voices Ireland	<a href="http://www.voicesireland.com/Home.htm">http://www.voicesireland.com/Home.htm</a> Hearing Voices Ireland also has an active Facebook Page linked to their main webpage.	A peer-led self-help organisation for anyone who hears voices and feels isolated with this experience.
5. National Service User Executive	<a href="http://www.nsue.ie/">http://www.nsue.ie/</a>	A representative organisation funded by the HSE, established to act as a conduit for mental health service users and carers driving change to services at a national level.

<p>6. Expert by Experience Advisory Committee; Amnesty International, Irish Division</p>	<p><a href="http://www.amnesty.ie/content/workingpartnership">http://www.amnesty.ie/content/workingpartnership</a></p>	<p>A group of 10 people with experience of mental health problems working in partnership with Amnesty Ireland to advise and support their human rights campaign for people with mental health problems in Ireland.</p>
<p>7. Critical Voices Network</p>	<p><a href="http://www.cvn.ie">www.cvn.ie</a> CVN also has an active Facebook Page linked to their main webpage.</p>	<p>Established as an online forum to allow space for critical voices of mental health services to be heard and shared.</p>

# Appendix E

## Telephone interview schedule

1. Age?
2. Gender?
3. Approximately how long and roughly how often have you/do you experience Psychotic Like Experiences?

4. Have you ever discussed these experiences with a health professional?

If no, go to question 7

5. If yes please explain:

- a) How long did you engage with these services?

- b) When was the last time you engaged these services?

7. Have you ever been treated for drug or alcohol problems?

8. Have you ever experienced head injury, brain trauma or been treated for a brain tumour?

9. Have you been diagnosed with any disease that may cause Psychotic Like Experiences?

For example: Epilepsy, malaria, hypoglycaemia, etc...

Thank you for participating in this questionnaire

# Appendix F

1.



Jim Walsh

School of Nursing

Dublin City University

Whitehall

Dublin 9

28<sup>th</sup> April 2012.

Dear Jim,

*Re: A discourse analyses of people living  
with psychotic like experiences in Ireland.  
Coping and Relating.*

Thank you for your email regarding support for individuals taking part in your Phd. I am happy to confirm that Claire Hawkes and Susan McFeely are available to provide this. If you would like to discuss the detail please give Claire or Susan a ring. We currently have no waiting list so individuals will have good access should they need it.

Please note that since January 1st we have placed a charge on counselling.

Very best of luck with the work.

Yours sincerely

---

Patricia Seager,

**Assistant Director**

## 2.

**The HSE National Counselling Service welcomes calls from adults who have experienced abuse in childhood. Contact details are as follows:**

The HSE National Counselling Service welcomes calls from adults who have experienced abuse and trauma in childhood. Contact details are as follows:

### **HSE Area Freephone Number**

HSE Dublin North East (North Dublin & Meath) 1800 234 110

HSE Dublin North East (Navan, Cavan, Louth & Monaghan) 1800 234 117

HSE Dublin Mid-Leinster (South Dublin, East Wicklow) 1800 234 111

HSE Dublin Mid-Leinster (West Dublin, West Wicklow & Kildare) 1800 234 112

HSE Dublin Mid-Leinster (Laois, Offaly, Longford & Westmeath) 1800 234 113

HSE West (Galway, Mayo & Roscommon) 1800 234 114

HSE West (Limerick, Clare & North Tipperary) 1800 234 115

HSE West (Donegal, Leitrim, Sligo) 1800 234 119

HSE South (Waterford, Wexford, Kilkenny, Carlow and South Tipperary) 1800  
234 118

HSE South (Cork & Kerry) 1800 234 116

### **3. Misc supports**

**Samaritans** 1850 609090

**AKOS** (Healthy Living Centre) School of Nursing, Dublin City University - 01  
700 7171

**SHINE** counselling service - 01 860 1620 (note; there is a small cost to this service)

**Aware Defeat Depression Help Line** - 1890 303 302 (10am – 7pm)

**GROW help line** - 1890 474 474

**HeadsUp** text service is (run by RehabCare) Text the word HeadsUp to  
50424

**1Life Suicide Prevention** Help Line - 1800 247100

# Appendix G

## Consent form

### Consent form - questionnaires

Dear participant, in order to ensure you consent to taking part in this study you are asked to complete and sign this consent form and will be invited to partake in completing two questionnaires. This should last between 30 – 40 minutes. If you choose to withdraw at any time in the study process you will be supported in this decision and will be given equal access to information and support services. The researcher may ask to meet you for a follow up interview to clarify information that you have shared.

#### Participant Confirmation:

(Please answer each question)

Have you read or had read to you the Information Sheet?

Yes/No

Do you understand the information provided to you?

Yes/No

Have you had any opportunity to ask questions and discuss the study?

Yes/No

Have you received satisfactory answers to your questions?

Yes/No

Are you agreeable to having your interview recorded?

Yes/No

#### Participant Signature:

I have read and understood the information in this form and the attached information sheet. My questions have been adequately answered by the researcher and I have a copy of the consent form. Therefore, I consent to participate in this research project.

Participants Signature:

---

Name in Block Capitals:

---

Witness:

---

Date: \_\_\_\_\_

# Appendix H

## Example of analysis

Below I present three abstracts from three separate participants. These have particular functions leading to consequences, indicating overall participant orientation of their discourse. The below also demonstrates the interrelatedness of text constructed at interview colour coded to illustrate 'themed' textual strategies. helping when taking context into question.

- P 8 - I really believe we're moving into a place in the world (.) where we all have to claim our own power and (.) it's not enough to go through the priest (10, the pastor (1), the rabbi (1), the minister(1), we need to take our own responsibility for our own holistic health which includes the spiritual health
- P 7 – So you're not getting the information from outside (1), you get the information from your own inner wisdom (.) but I don't believe your own inner wisdom just lands here.
- P9 - I think that everybody can heal themselves and everybody knows what to do in situations (.) and anybody who judges what somebody does in a situation has never been in it. Because you have no idea (1) don't need anyone outside myself. Because I feel I have reached a connection with a higher power that has guided me this whole way

Demonstrates strong commitment, assertion of beliefs through thoughts, feelings and inclinations. Responsibility for own wellbeing  
The subjective as a source of 'wisdom' beyond other sources, not to be questioned.  
Questions sources that relate to convention.

Overall orientation denotes non-material/non-physical aspects to health and wellbeing and by association psychotic experiences?