Middlesex University and Metanoia Institute

Factors that help or hinder personal recovery in people with a schizophrenia diagnosis: a different sort of "therapeutic" relationship

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1. Abstract

This collaborative study grew out of the lived, learned experience of the primary inquirer and co-inquirer, a diagnosed paranoid schizophrenic. Embracing a phenomenological (Heidegger, 1927/1962) participatory action attitude (Reason & Bradbury, 2001) using research as a tool to offer a practical alternative, the study aimed to generate knowledge to empower persons with a schizophrenia diagnosis by raising conscious awareness of what either helps or hinders personal recovery. A total of eight credible exemplars with experiences synonymous with a schizophrenia diagnosis participated in open dialogical interviews. An a priori open coding framework derived from my selective, guided interrogation of the personal recovery oriented literature was applied to and iteratively integrated with the inductively driven data which emerged from the interviews. Nine organising themes emerged which converged around three interdependent global themes: Context, Meaning Making and Identity Formation, Interpersonal Relationships and Organisational Culture – Systems. Figural to this intersubjective, contested and co-created multiversal space is a different sort of therapeutic relationship built on pragmatism, authenticity and a tolerant understanding and willingness to embrace and make meaning of disconcerting subjective experiences. The study generates knowledge to challenge and de-construct the essentially contested construct of schizophrenia along with the myths, misconceptions and negative stereotypes which maintain "it", by raising conscious awareness of and redressing the inherent power imbalance in staff-client relationships and by privileging and validating the voices of the people who own the experience. These hitherto largely unheard voices support the call for an empowering "paradigm shift in relation to the experience that these [schizophrenia] diagnoses refer to" (BPS, 2014). The originality and challenge of this approach resides with fellow mental health and allied professionals willingly embracing incongruent disconcerting worlds, surrendering the privilege of professional disciplinary power and taking "on board that there is no us and them, there are only people trying to make the best of our situation" (Understanding Psychosis and Schizophrenia, 2014, p. 113).

2. The "subject" matter and the subjects: The conundrum of schizophrenia, a biological disease of the brain or an essentially contested concept?

2.1 Collaborative inquiry

Embracing the over-arching principles of participatory action research (PAR; Reason & Bradbury, 2001) the study was conducted in collaboration and in regular consultation with my colleague, co-participant and expert by experience Mr Paddy McGowan henceforth, referred to as Paddy.

2.1.1 Collaborative inquirer

Paddy, Service User Consultant and Senior Lecturer with Dublin City University School of Nursing, speaks humanely and sometimes painfully from the first person perspective of someone diagnosed with paranoid schizophrenia, experiences which saw him involuntarily detained (off and on) in hospital for some 15-years. Paddy, therefore, speaks authoritatively and authentically from the *inside out*, relying not on the presuppositions of dubious and largely unproven scientific theories (Mosher, 2001) but from reflecting sensitively and honestly on the internal and external trauma and distress he experienced and the subsequent psychiatric treatment he received. Thankfully, with gritty self-determination, hard-earned endeavour and the support of fellow survivors and professionals, Paddy recovered from schizophrenia and from the psychiatric system charged with treating him. Admirably, he does not look back on these experiences with either bitterness or anger, but instead has devoted his working life to relentlessly, but constructively, challenging what he sees as the inadequacies of a 'maintenance' medically-oriented psychiatric system which he considered to have unwittingly hindered his personal recovery by focusing on and privileging clinical recovery. Henceforth, driven by a dignified compassion, Paddy embarked on a one-man crusade across Ireland, literally living out of a suitcase, telling his remarkable and liberating story to convince and persuade professionals, service-users, policy makers, politicians and health ministers of the need to get into the so-called 'recovery position' (Slade et al., 2014). Tireless efforts and passionate conviction culminated in Paddy setting up and becoming the founding Director (CEO) of the Irish Advocacy Network, a user-led organisation, which advocates on behalf of persons and their families experiencing or recovering from severe mental health difficulties.

With the Advocacy Network well established and flourishing, Paddy took up and maintains a strategic developmental post with the Health Service Executive and Dublin City University combining teaching with developing creative, pragmatic and collaborative alternatives to the so-called medical or maintenance model. He is a longstanding and prominent member of the International Network of Treatment Alternatives for Recovery (INTAR) and is respected by the mental health community locally, nationally and internationally as a leading and inspirational authority in the field.

2.1.2 Principle inquirer

My beliefs about the phenomenon of the inquiry, schizophrenia, are shaped by my upwards of thirty years working as a research practitioner in child, adolescent, adult and forensic mental health settings.

2.1.2.1 Broadmoor Special Hospital

My first brush with unbridled madness dates back to 1990 when I spent a year working in the psychology – neurophysiology department of Broadmoor Special Hospital for the criminally insane. In this "Mansion for Monsters" (Walsh, 2013), which housed such notorious inmates as Peter Sutcliffe, alias Jack the Ripper and Ronnie and Reggie Kray I did indeed come face to face with unimaginably disturbed and disturbing states of mind which left a dark and indelible imprint on my psyche. In Broadmoor, however, I also met "Mad Mary" an elderly frail female patient who was unceremoniously prised, screaming, from around my neck during a venture onto the all-female ward to conduct a psychological assessment with another non-compliant but seemingly terrified patient who was refusing to leave the ward. Brushing myself down from the contemptuous and humiliating looks of the nursing staff, I found myself curiously disturbed by my intense and intimate interaction with Mary. This led me to look at Mary's file which surprisingly held very little social, demographic or clinical information given she had seemingly been admitted to Broadmoor from a psychiatric hospital aged fourteen. My request for her archived file was subsequently denied under statute of the Official Secrets Act. This prompted me to quiz some of the older nursing staff about Mary's incarceration. They advised me that at the turn of the century it was not uncommon for "morally insane" young woman like Mary to be involuntarily incarcerated in asylums to protect the morally righteous and powerful, but helpless, landed gentry from the insatiable, promiscuous behaviour of these morally delinquent sexual

predators - "Mad Mary's". Family members, either through shame or having been paid off for their silence, lost contact with their hapless, morally insane children, while any children conceived from their perceived sexually depraved behaviour were either forcibly aborted or taken off them prior to their being incarcerated and forgotten. Reflecting on my intimate encounter with Mad Mary, I wondered, given how she had gazed longingly, despairingly into my eyes screaming "Stephen", whether she believed me to be her long-lost child who had been forcibly prised from around her neck. Mary's tangible torment infused me with an intense despair, but also rage with the unthinkable thought that she and many like her had been condemned to insanity and life-long imprisonment by a perverse and oppressive psychiatric system complicit in protecting predatory paedophiles. Sadly, shortly after my encounter with Mary she died, alone and unknown in Broadmoor. This left me with the question "who is morally insane?"

2.1.2.2 Residential therapeutic community psychiatric alternatives

My experiences in Broadmoor convinced me that I did not want to pursue a career in forensics and I returned to Northern Ireland in 1991, which coincided with the de-institutionalisation of the psychiatric hospitals under the auspices of the so called 'People First' policy. This saw me work for some ten years in residential democratic, therapeutic community psychiatric alternatives with people who would previously have been hospitalised and whose experiences and associated internal and external distress were synonymous with a diagnosis of schizophrenia. Notable, amongst my numerous housemates were Joe and Gemma.

Joe, aged forty seven, had been diagnosed with paranoid schizophrenia aged seventeen. Thereafter, he spent most of his adult life detained in hospital because of his apparent propensity for violence, fuelled by gratuitous violent phantasies, persecutory auditory as well as visual hallucinatory experiences and an intense dislike of people with "blue eyes".

Several community-based placements had broken down because of unsolicited "actual" violent outbursts where Joe would indiscriminately and without provocation "strike out". His Charley Chaplin gangster-like gait, unnerving grimace and stony stare, the extrapyramidal side effects of decades of maintenance neuroleptic medication confirmed his dangerous reputation. It was unanimously decided that because I had brown eyes I should work with Joe who, on entering the

community, remained extremely withdrawn, self-isolating and suspicious. Compliant, but unable to tolerate physical or emotional closeness, he avoided all social interaction and remained virtually mute. This saw him goaded by and unpopular with the other residents in the community and to a greater or lesser degree feared by and frightened of the staff. Over time Joe gradually began to disclose that for much of his young life he had been exposed to extreme violence. Notably, as a seventeen year old he witnessed a neighbour having his "brains blown out", one of the then all-too-routine atrocities of the Northern Ireland "Troubles".

His father was also routinely physically violent. Joe recalled as a young child desperately wanting to "get close" to his father who would literally call him to heel when out walking in the nearby Cavehill park. However, when he got indiscriminately "too close", his father would "strike out" with the back of his clenched fist, goading and mocking Joe as he went tumbling backwards to the ground. On several occasions during his late adolescence the police were called to the house. Joe, who was trying to protect himself from his increasingly violent and controlling father, was forcibly removed to psychiatric hospital, handcuffed, terrified and brutally beaten in the back of a police Land Rover. A disproportionate use of violence seemingly justified because he was a paranoid schizophrenic with a perceived, inherent propensity for violence.

With this context to his violent behaviours, we worked out and agreed a routine in which he took on the dirtiest and most unpopular chore in the house, emptying the bins early each morning. This enabled him to participate but also to feel safe by keeping interactions to a minimum, while winning him the popularity of the community who in turn he gradually started to trust. This saw his social interaction increase through regular participation in several therapeutic groups and he developed socially, nurturing a keen interest in poetry, in particular Heaney. He also began to trust me, the "brown eyed boy", enough to empty and contain the contents of his chaotic - psychotic mind during weekly one-to-one key-work sessions. Over the course of his tenancy there were no violent outbursts and only one psychiatric hospital admission to trial him on Clozaril, the latest atypical neuroleptic "wonder" drug, which required routine taking of bloods to monitor for toxic, and potentially fatal adverse reactions. Joe became understandably concerned by and fearful of hospitalisation, but reluctantly complied with this, psychiatry's last ditch attempt to "cure" him of his "treatment resistant schizophrenia". Some seven days into Joe's hospitalisation I visited him on the ward. He is sitting up in bed relaxed with the

knowledge that he is soon to be released back to the community. We make small talk and he tells me some of the residents visited him earlier in the week. I ask if he has had any other visitors to which he replies "yes, every day, three times a day". Joe pauses and then elaborates "he's here now", quizzing, "can't you see him, the little red devil sitting at the bottom of the bed". Joe grins, grimaces, his blue eyes meet my brown and as I leave the ward I reflect on my relief that he has neither been cured by, nor perhaps lost to psychiatry.

Gemma was a thirty five year old diagnosed paranoid schizophrenic taken into care aged fourteen and thereafter detained in psychiatric hospital for most of her adult life. Gemma is preoccupied with terrifying persecutory delusions centred on the belief that the world is full of "evil forces, witch-craft" and "black-magic", accentuated by olfactory and auditory hallucinations, bad-smells and self-denigrating voices. Gemma protects herself and me with prayers and religious pendants which she ritualistically gives me before I retire for the night during my routine weekly sleep-overs. In the middle of the night Gemma frequently climbs out of her bedroom window and walks to her sister's house some ten miles away. Because she is deemed a vulnerable adult with no "insight", this behaviour results in frequent detentions in hospital.

One night on a community holiday, following a barbeque Gemma is sitting outside starring at the stars, we get talking, and she tells me how she feels "safe, free outside" and goes on to tell me how as a seven year old child one morning she came downstairs to find her father had "painted all the windows over with black paint, pitch black, to stop evil eyes from peering in". Gemma elaborates that her father regularly locked her and her sister in a dark room for days at a time to protect them from this "evil world" while systematically sexually abusing them. At night, Gemma and her sister would stay out for as long as they could and or climb out the living room window of their ground floor apartment building. Gemma's mother was an alcoholic, which meant she was frequently hospitalised and unavailable.

2.1.3 The subjectivity of the inquirer

My challenging and at times harrowing experiences of being with, tolerating and bearing witness to human "madness" as described above motivated me to challenge and de-construct, with Paddy, the medicalization of "schizophrenia" and the de-humanisation of the "schizophrenic''. We have reviewed the emerging scientific evidence (or the lack of it) alongside powerful personal testimonies and lived, learned experience of others who like Paddy have recovered from schizophrenia (Chadwick, 2006; Chandler & Hayward, 2009; Cohen, 2005; Deegan, 1994, 1996, 2001, 2005; Ridgway, 2002; Romme et al., 2009). We concur with more eminent colleagues, that "part theories whether psychoanalytic, cognitive behavioural, neurotransmitter, genetic, traumatic etc. are unlikely to unravel [either] the conundrum of schizophrenia [or the schizophrenic conundrum]" (Mosher, 2001, p. 14). In the context of the current inquiry schizophrenia, therefore, is viewed as an essentially contested concept (Geekie, 2004) and hereafter unless stated otherwise schizophrenia (schizophrenic) or psychosis (psychotic) is used to refer to persons whose experiences are synonymous with the diagnosis as opposed to "it" being considered indicative of a "disease"-based scientific disorder. It is envisaged that an open declaration of these presuppositions will militate against bias by broadening inquirers' as well as readers' understanding of multiple ways of viewing the phenomenon of the "subject" of schizophrenia (Morrow, 2005).

2.2 Historical overview – cultural context

Notwithstanding the continued debate and controversy surrounding aetiology, treatment and prognosis (British Psychological Society, 2014a) schizophrenia is considered the lynchpin of models of mental illness around which Western perspectives, principles and practices of medically-modelled mental health care revolve (Geekie, 2004). Schizophrenia is frequently seen as the lost cause of psychiatry, and schizophrenics as the 'un-recoverables' and in Western culture the term schizophrenia and the many myths surrounding it (Boyle, 2013) extend far beyond the scope of mental health professionals and in layman's terms "it" is often equated with "mad" and or "bad" (The Sun Newspaper, 2013). From this perspective the relentless but predominantly bio-medically-oriented search for the Holy (or un- Holy) Grail of schizophrenia by mental health and allied professionals including, but not limited to psychiatrists may reflect the uneasy efforts of our culture to come to grips with our primarily "ill" defined relationship to the terrifying and age-old human condition of madness.

2.2.1 The construction of the concept of schizophrenia

As a concept schizophrenia owes its origin to the writings of Pinel and Haslam, who over one hundred years ago described signs and symptoms amongst individuals that today map onto contemporary psychiatry's conceptualisation of the symptomatology of schizophrenia as operationally defined in widely used diagnostic classification systems (DSM-5, APA, 2013; ICD-10, 1992). In 1896 Emile Kraepelin was the first to formally conceptualise these subjective experiences and their behavioural correlates as "dementia praecox", a psychiatric disorder characterised by early onset *praecox* and inevitable progressive deterioration, *dementia*. In 1911 Kraepelin's contemporary Eugen Bleuler expanded the classification system to capture what he perceived were the "group of the schizophrenias", inferring not a unitary disease, but a syndrome with possible different aetiology, pathogenesis and clinical presentation.

Kraepelin and Bleuler (considered the grandfathers of modern psychiatry) consistent with scientists from other fields of medicine at the turn of the 19th Century were attempting to create a nosology of "disease" in the hope that eventually this would shed some light on physical pathology, which at the time Kraepelin wrote was "wrapped in impenetrable darkness" (Kraepelin, 1913: 224). Henceforth, throughout the 20th century and thereafter, a full spectrum of paradigmatic (bio-psycho-social) lights have optimistically penetrated and illuminated this aetiological darkness, only to flicker and fuse in the absence of well replicated evidence from scientifically robust studies (Laurelle, 2000; Read et al., 2004; Zipursky et al., 2013). From this perspective the construction of schizophrenia remains open to being de-constructed and re-constructed in the light of ever-emerging evidence (British Psychological Society, 2014a).

2.2.2 Schizophrenia as an essentially contested concept

In light of the above and because, there is no pathophysiological test that can reliably distinguish between someone who has and someone who does not have a diagnosis of schizophrenia (BPS, 2014a; Szasz, 1967) diagnosis continues to rely on classifying and interpreting certain phenomenological subjective experiences and associated behaviours as the psychopathological signs and symptoms of madness. This "I name, therefore, I know" mentality is however fundamentally flawed (Cancro, 2004, p. 242) in that creating a name does not a nosological entity make, let alone identify a category of a real disease (Bentall, 1990, 2003, 2004, 2009; Bentall et al., 1988; Boyle, 1999, 2002, 2013; BPS, 2014a). Indeed, unlike most physical

diseases, which have specific symptoms, the symptoms of schizophrenia are heterogeneous, spanning not only other psychiatric disorders, but also apparent amongst individuals in the non-psychiatric "normal" population and where differences are quantitative rather than qualitative (Linscott & van Os, 2013; Romme et al., 2009; Tien, 1991; Van Os et al., 2009). Neither does diagnosis predict the variable course (either individual or cross-cultural) of the so-called "illness" (Zipursky et al., 2013) or the subsequent variable responses to treatment (Boyle, 1999; Goldner et al., 2002; Torrey, 1987). It is these anomalies which have led many including myself to conclude that schizophrenia is best viewed as an "essentially contested concept.... the proper use of which inevitably involves endless disputes about [its] proper use on the part of their users" (Gallie, 1955/56, p. 169). From this perspective and in keeping with the view that meaning is determined by usage (Wittgenstein, 1953) the disagreement and controversy surrounding schizophrenia is not considered incidental, accidental or temporary, but is an essential defining aspect of the concept itself (Geekie, 2004).

2.2.3 The medical model – the psychiatric signs and symptoms

Notwithstanding the diagnostic anomalies outlined above, foremost amongst the core phenomenological-perceptual experiences that define and characterise schizophrenia are (i) auditory hallucinations, that is voices which often issue commands or comment on the individual's actions, but distinct from the persons own thoughts and non-consensual in that they are inaudible to anyone other than the recipient and (ii) delusions, defined as "erroneous beliefs that usually involve a misinterpretation of perceptions or experiences".

Auditory hallucinations - hearing voices.

"People have always heard voices. Hearing voices was what spiritual and artistic people did and it was perfectly normal. But now, people who hear voices are simply labelled as "mad". What has happened to inner voices: have they changed or is it society that has undergone a transformation" (Inter-voice press release, 2006).

Auditory hallucinations are one of the most common experiences amongst people with a diagnosis of schizophrenia (Bentall, 2004) where upwards of half report hearing "voices" (Landmark et al., 1990). However, it is estimated that between 4 - 5 percent of the general population also hear voices at any given time (Shevlin et al., 2007; Tien, 1991). Of these the vast majority will never be in contact with psychiatric services (Bentall, 2004) while two thirds do not find the experience unduly distressing and can use it to their benefit (Romme et al., 2009). It is

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estimated, therefore, that hearing voices is synonymous with the questionable diagnosis of schizophrenia in only one out of every six people. In other words, 84% of voice hearers are needlessly discriminated against because of the 16% whose experiences are possibly indicative of a genuine illness (Romme, & Escher, 2011). The term "psychiatric voice hearer" therefore, as used in the present context, is not meant to demean or denigrate the experience, but to distinguish between those who hear voices and those whose voice hearing experience is synonymous with being labelled mentally-ill.

Passive listeners

While I unequivocally accept and respect the right of psychiatric voice hearers to listen to their voices through psychiatry's traditional subjective interpretation of their experience, by doing so they risk becoming passive recipients of professional wisdom or disciplinary power (Stevenson & Cutcliffe, 2006). If this asymmetrical relational dynamic is internalized to critically self-scrutinise it can produce a specific style of subjectivity or "governmentality" (Foucault, 1979) that creates compliant subjects or in this instance "good schizophrenics" (Roberts & Wolfson, 2004). This "once a schizophrenic always a schizophrenic" mantra although not supported by long-term follow-up studies (Calabrese and Corrigan, 2005; Harrison et al., 2001; Zipursky et al., 2013), results in negative stereotyping, discrimination (Thornicroft et al., 2009), social exclusion and self-stigmatisation (Flanagan et al., 2012) which are aberrant and synergistic precursors for a career of dependency and chronic psychiatric disability that effectively destroys any real hope of personal recovery (Harding et al., 1987; Slade et al., 2014).

Active voice hearers

Alternatively, psychiatric voice hearers who reject the native language of biological psychiatry and resist having their "voices" subjugated as the incomprehensible ramblings of a broken brain, risk being accused of lacking insight, which paradoxically is often taken as further evidence that they are suffering from a "treatment resistant" mental illness (Thomas & Bracken, 2004). For these voice hearers the language of psychiatry is experienced as a powerful, oppressive and a malevolent voice which, paradoxically, can compound and accentuate the distress of the non-consensual "voice" psychiatry is charged with silencing (Chandler & Hayward, 2009; Walsh & Boyle, 2009).

The context and quality of voices

Common to all voice hearers is the different influence that each voice has on their emotions and behaviour and the influence the voice hearer feels they have on each of their voices (Birchwood & Chadwick, 1997; Leff, et al., 2013, 2014; Romme, 1998; Romme et al., 2009; Waddington, 2016). The context, content, volume and tone of each voice and the extent to which the listener feels able to control these auditory and contextual qualities will determine whether the voice is experienced as (i) omnipotent good-benevolent (a positive, comforting experience) (ii) omnipotent bad-malevolent (a negative, persecutory experience) or (iii) benign-indifferent (neither positive or negative) (Birchwood et al., 2000; Romme et al., 2009; Vaughn & Fowler, 2004).

Irrespective of the attributions psychiatric voice hearers make for their experiences, many are frustrated that psychiatrists, counselling/clinical psychologists, mental health social workers, and allied professionals are not willing to listen to or help them understand and make meaning of their experiences in terms of social, cultural and relational contexts (Birchwood et al 2000; Faulkner & Layzell, 2000; Longden et al., 2011; Rose, 2001; Vaughn & Fowler, 2004; Walsh et al., 2015). I share the view that personal meaning-making is an inherently empowering experience (Dilks, et al., 2010; Longden et al., 2011) which in contrast with reductionist "biomedical [or other psycho-technological] interpretations are experienced as limited, at best unhelpful and at worst harmful" (Thomas and Bracken, 2004, p. 361).

Delusions

The content of delusions may include a variety of themes, although persecutory delusions characterised by the person believing others are plotting against them or that they are being followed, spied on etc. are notably common (DSM-5, 2013, APA). So-called delusions of reference are also widespread where the individual attributes personal significance to seemingly innocuous gestures or comments, passages from books-newspapers, the lyrics of songs or other environmental stimuli in the belief that they are directed specifically towards *referencing* them. *Bizarre* delusions or beliefs that are "clearly implausible and not understandable [incomprehensible] and do not derive from ordinary life experiences" (p. 275, DSM-IV, 1994) are considered to be especially characteristic of schizophrenia. Examples of bizarre delusions (considered amongst the Schneiderian first-rank symptoms) include "thought insertion", the

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belief that alien thoughts have been put into the person's head, "thought withdrawal" the belief that the person's thoughts have been taken away by an outside power or "delusions of control" where the person feels that their thoughts / actions are being controlled and influenced by an external force.

However, it is often difficult to distinguish between what is a delusional belief and that of a strongly held idea, while the degree of "bizarreness" is generally determined by cultural orientation (Johnson & Friedman, 2008). It is estimated, therefore, that upwards of 70% of the general, non-psychiatric population endorse beliefs that could be considered delusional (Verdoux et al., 1998) confirmed by a recent meta-analysis of epidemiological studies which found widespread evidence for psychotic experiences in children and adults (Linscott & van Os, 2013).

The medicalisation of madness

Over a century on since Kraepelin's original formulation and despite the absence of unequivocal scientific evidence (BPS, 2014; Jay, 2003; Read et al. 2004; Zipursky et al., 2013) and the most comprehensive genetic association study of genes previously reported to contribute to the susceptibility to schizophrenia having drawn a "blank" (Hamilton, 2008), many biogenetic psychiatrists cling to the belief that schizophrenia is a chronic, severe and disabling brain disease (National Institute for Mental Health, 2003). Equally non-believers like me and Paddy are often branded as irresponsible heretics, where for Szasz (1997) modern man's "unbelief in mental illness" equates with medieval man's "unbelief in God…. requir[ing] so extreme an estrangement from obvious reality as to be if not strictly impossible practically so". This omnipotent and omniscient biological reductionist approach is premised on the belief that the phenomenological experiences that have come to define schizophrenia, primarily hallucinations and delusions, are epiphenomenal - that is, understandable only as meaningless and incomprehensible expressions of a genetically predisposed, biochemically dysfunctional, or "broken" brain; so-called "empty speech acts, whose informational content refers to neither world or self" (Berrios, 1991). From this perspective the focus of treatment is on the classification and elimination of symptoms and "the arrivals of the neuroleptics [the treatment of choice for schizophrenia] seemed to have spurred a reductionist belief in the possibility of physical explanations being not only necessary but sufficient" (Martindale et al., 2000, p. 3).

The treatment of choice

Undoubtedly, many people find the generalised, drug-induced sedating effect of major tranquillisers (Moncrieff, 2008) a helpful way of regulating otherwise dysregulated, often terrifying, emotions (Karon, 2001). As such, so-called neuroleptic medication will remain an essential and indispensable element in the treatment of schizophrenia. Nonetheless, it is important to stop short of inferring that what are now cleverly marketed as "anti-psychotics" provide a magic bullet, disease-based cure (British Psychological Society, 2000; Moncrieff, 2008), and to recognise that they do not help everyone and rarely alleviate problems completely (BPS, 2014a; Brown & Herz, 1989; Warner, 1985). Moreover, neuroleptics in and of themselves can cause adverse, distressing and sometimes irreversible extrapyramidal side effects (Jeste & Wyatt, 1979; Liberman et al., 2005; Swett, 1975; Van Putten et al., 1984; Whitaker, 2005) as well as Neuroleptic Induced Deficit Syndrome (NIDS) characterised by motivational difficulties (Schooler, 1994; Sullivan & Lukoff, 1990) or more serious malignant-toxic and potentially fatal reactions (Caroff, 1980; Dukes, 1992; Heald, 2010; Whitaker, 2005). These unpleasant and or "toxic", potentially lethal side effects lead to difficulties with compliance where a study of the efficacy of neuroleptics (that included older-typical as well as newer-atypical agents) found 74% of participants stopped taking their medication within 18-months because of "inefficacy or intolerable side effects or for other reasons" Liberman et al., 2005, p. 1209).

2.2.4 A psychosocial trauma based model.

Juxtaposed with the conceptualisation of the disease based construction of schizophrenia, Rieger (1896) noted that many schizophrenics have talked about incest, sexual abuse and physical abuse: but astutely qualified that such talk was nearly always dismissed as the ravings of lunatics. Over 100 years on and consistent with my own lived experiences already referenced, emerging empirical evidence from recent reviews of the literature is highlighting a well-replicated and robust relationship between early trauma-based, or adverse victimisation experiences, not least childhood sexual and childhood physical abuse (CSA-CPA), impoverished physical or emotional environments, and a later diagnosis of schizophrenia (Bentall et al., 2012; Campbell & Morrison, 2007; Cutajar et al., 2010; Davies & Burdett, 2004; Morrison et al., 2003; Murphy et al., 2015; Verese et al., 2012). For example, at the hard end of the trauma spectrum, Read et al. (2004) found that 60% of male and 69% of female psychiatric inpatients and

outpatients, at least half of whom were diagnosed psychotic, had been physically or sexually abused as children.

In a population survey of 8580 adults Bebbington et al. (2004) found that individuals diagnosed with schizophrenia were 15 times more likely to have been abused as children than members of the "normal" population. Likewise, a prospective population study of 4045 individuals found that those subjected to CA before age-16 were 9.3 times more likely than those not exposed to CA to develop positive psychotic symptoms of a severity requiring mental health care and for those suffering the most severe abuse the risk rose to 48 times (Janssen et al., 2004). Similarly, Shevlin et al. (2007) found people exposed cumulatively to CSA, CPA and bullying were 18 times more likely to develop psychosis increasing to 193 times for those exposed to five or more cumulative traumatic events. The link with psychotic symptoms, therefore, appears to be dose dependent with the severity (Spauwen et al., 2006), frequency (Shevlin et al., 2007) and cumulative types (Scott et al., 2007) of early adverse traumatic experiences.

Strong statistically significant relationships have also been found between CSA-CPA and the symptoms of schizophrenia (Bentall et al., 2012; Cutajar et al., 2010), most notably hallucinations (Read & Ross, 2003; Whitfield et al., 2005) and to a lesser degree persecutory-paranoid and grandiose delusions (Read & Ross., 2003). For example, Read and Argyle (1999) and Read & Ross (2003) found that the content of upwards of half schizophrenic symptoms of abused adult inpatients was obviously related to the abuse, (i.e. hearing the voice of the perpetrator) while several studies found that visual hallucinations and delusional material of survivors of CSA contain both flashback as well as more symbolic elements of the actual traumatic experience (Ensink 1992; Geekie, 2004). In these instances the signs and symptoms indicative of schizophrenia are not the inchoate, incomprehensible ramblings of a "lunatic", but are comprehensible as intrusive re-experiencing of actual or symbolic representations of or dissociative defences against trauma based experiences heavily imbued with meaning (Dillon et al., 2012; Karon, 2003; Longden et al., 2011, 2012).

From this perspective and concurring with my own lived experience the neurobiology of schizophrenia becomes the neurobiology of traumatic stress, terror and existential anxiety (Karon, 2003; Koehler, 2005; Read et al., 2001) and the hypothesised (dopaminergic) abnormalities (Gainetdinov et al., 2001; Laurelle, 2000) heavily implicated in the

aforementioned disease model and which justify the "therapeutic" mechanism of action of the "anti-psychotics" become epiphenomenal. As such, Morrison et al., (2003) suggest "that at least a significant proportion of psychotic disorders do arise as a response to [consensual] trauma and that posttraumatic stress disorder, PTSD- like symptoms can be developed in response to people's [non-consensual traumatic] experience of psychotic episodes" (p. 347). In a similar vein, informed by a systematic review of 180 studies, including the aforementioned large-scale population studies (and subsequently supported by two more recent meta-analyses (Beards et al., 2013; Varese et al., 2012), Read et al., (2005) believes that the "symptoms considered indicative of psychosis and schizophrenia, particularly hallucinations, are at least as strongly related to childhood abuse and neglect as many other mental health problems [concluding] that recent large scale, general population studies indicate the relationship is a causal one, with a dose effect" (p.1). Likewise, Johnstone (2007) argues "that the [symptomatic] experiences service users report are, in many cases, a natural reaction to the abuses they have been subjected to. There is abuse and there are the effects of abuse. There is no additional 'psychosis' that needs explaining" (2007, p. 217). This hypothesis is further substantiated by the relationship found between childhood recollection of threat and subordination and later psychotic experiences in clinical as well as non-clinical populations (Murphy et al., 2012). Finally, in a landmark case in New Zealand the judge from synthesising and weighing up the best available scientific evidence concurred with a previous UK judge's decision to uphold the appeal of a sexual abuse survivor and overturned the lower court's decision that there was no causal link between early trauma and schizophrenia (LS v Accident Compensation Corporation NZACC 385, 22 November 2013)

2.2.5 The mask of psychotic diagnosis

I believe that by ignoring what is "scientifically" unknown (which greatly outweighs what is "scientifically" known) about the essentially contested concept of schizophrenia (Geekie, 2004), there is an increased risk that "it", and those who suffer from "it" become reduced to a medically meaningless (Bentall, 1990, 2004, 2009; Boyle, 1999, 2002, 2013; Bracken & Thomas, 2005; Romme et al, 2009), de-humanising and alienating set of symptoms (WHO, 2015). Garfield (2003) refers to this as the "mask" of psychotic diagnosis and recounts, (concurring with my own and Paddy's lived experience) noting that many service users who feel forced to wear it and or powerless to remove it, testify that the diagnosis together with prejudices, discrimination and

fear of others is more disfiguring, disabling and disempowering than the deficits supposedly inherent to the "schizophrenic" disorder (Longden et., al., 2011; Read & Baker, 1996; Walsh et al., 2015; Walsh, 2016).

2.2.6 The unheard "voice" of madness

Amidst a cacophony of claims and counterclaims (scientific or otherwise) about the nature of schizophrenia, the consensual voice of the so-called "schizophrenic" goes largely unheard. For me it is difficult to reconcile this selective but perhaps self-serving professional-scientific deafness with *The National Service Framework for Mental Health's* insistence that the interests of people in recovery must lead services (Department of Health 1999). Likewise, where research does not indicate a clear treatment of choice (differential efficacy), Department of Health clinical practice guidelines clearly state, "patient preference should inform patient choice" (DoH, 2001, p.36). It is worth noting, therefore, that people with severe psychiatric disabilities (including schizophrenia) are not campaigning merely for scientific rigour and the "objective" medicalisation of their "illness" into a less than reliable diagnostic category (Bentall et al., 1988; Bentall, 1990, 2004, 2009; Boyle, 1999, 2013) that ignores individual human differences and experiences (Bentall, 2003; Slade & Priebe, 2001; Slade et al., 2014). In marked contrast service-users

"Value research into the different aspects of human suffering and survival. But we want this research to be from the perspective of people who experienced the turmoil. Our testimonies and our suggestions as to what would really help have been recorded for many years now. It is time for our perspectives and ideas to be taken seriously"

(User/Survivor Advisory Group 1999, p. 7)

From this perspective, if mental health services are to become truly evidence-based as well as values-based they must move beyond tokenism by "integrating individual clinical experience of authorities [experts by and with lived experience] with the best available external clinical evidence from systematic research" (Sackett et al., 1996, p72.).

2.2.7 Different subjectivities and the co-construction of meaning

I believe, therefore, that experts with lived experience can shine a new light which may help to penetrate the hitherto impenetrable darkness. Contrasting these first person perspectives and

subjectivities with the subjectivity of the counselling psychologist- psychological therapist and allied mental health worker can open up a dialogue that potentially leads to shared meaning and new understanding (BPS, 2014a; Chadwick, 2006; Davidson & Stayner, 1997).

For example, the so-called pathological "breaking of associative threads" which, for Bleuler and for modern psychiatry remains one of the core-defining features of schizophrenia, is described from a first-hand perspective like this:

"Feeling that they are giving in to death and becoming separated from themselves by a wall of glass… the horror and powerlessness of becoming inaccessible to themselves as well as to others and feeling pushed out to the margins of their own awareness where they can be only passive and distant spectators of the chaos that rages in their minds. Perceiving themselves to be at the mercy and whims of the storms of illness, people may have little choice but to act and appear to others as they themselves feel internally: like a nobody nowhere" (Weingarten, 1994, p. 374).

This encapsulates the difficult-to-grasp phenomenological paradox expressed time and time again by the person diagnosed with schizophrenia;

"Someone who is no one, someone who is and who expresses his or her being in words of non-being… when being is not to be, that of a "nobody nowhere" (Sandin, 1993).

2.2.8 Aims and objectives

Using a participatory action (Reason & Bradbury, 2001) existential phenomenological framework (Halling &Nill, 1995; Heidegger, 1962), the current collaborative inquiry privileged the subjectivity of experiences synonymous with the "essentially contested" (Geekie, 2004) phenomenon of schizophrenia. This challenges and transcends traditional bio-medical psychiatry's axiomatic view that it is a degenerative, disabling and irreversible disease of the brain (Panskepp, 2004). The study also started from the assumption that a key aspect of establishing a relationship that is therapeutic is first to acknowledge the inherent difficulty of engaging (Walsh, 2016) this disengaged and often feared client group (McCabe et al., 2003; Thurston, 2003; Walsh et al., 2015). Addressing a notable gap in the psychiatric therapeutic relationship literature, the collaborative inquiry explored the interpersonal attributes in context with mental health professionals as well as with key significant others, including family members, peers and friends, which acted as a precursor to developing a relationship (Prouty, 1994) that either helped or hindered their personal recovery (Bola & Mosher, 2003; Calton et al., 2007; Kanter, 2000). It was hoped the participatory action collaborative method of inquiry would

also actively raise consciousness, challenge myths, negative stereotypes, stigma and exclusion which, as already noted compound a sense of isolation, alienation, disempowerment and disablement which act as barriers to personal recovery (Slade et al., 2014; Thornicroft et al., 2009).

3. The Therapeutic Relationship in psychotherapy and the non-relational schizophrenic

3.1 The Therapeutic relationship

The concept of the therapeutic relationship owes its origins to Freud (1895) who referred to the patient being a "collaborator" with the doctor, highlighting the importance of the development of "the [patient]..attach[ing] himself to the doctor and linking [him] with the images of people by whom he was accustomed to be treated with affections" (Freud, 1913, p.124). Henceforth, operationalised and referred to inter-changeably as the "therapeutic alliance", "therapeutic relationship" or "working alliance" (Catty, 2004), the nature and quality of the relationship between the psychological therapist and client has occupied a central pan-theoretical position to examine the therapeutic process, psychotherapy outcome and the relationship between the two (Bordin, 1976, 1994; Botella et al., 2008; Horvath, 2005; Luborsky, 1976; Norcross & Wampold, 2011). For Freud (1913) the so-called positive transference as described above became "the vehicle of success in psychoanalysis exactly as it is in other methods of treatment" (Freud 1913, p. 7). However, subsequent definitions of the therapeutic relationship are grounded in and influenced by the philosophical underpinnings and presuppositions of particular theoretical models (Hewitt & Coffey, 2005; McCabe & Priebe, 2004).

3.1.1. Psychodynamic-analytically oriented perspectives

Not unexpectedly because the psychodynamic perspective of the therapeutic relationship stems from Freudian concepts, it can be seen to co-exist in the interplay of the immediacy of the real person-to-person relationship and the representational transference and counter-transference or phantasy elements which, belong to significant past relationships (Howgego et al., 2003). In contrast and challenging Freud's classical objective authoritarian stance, a more contemporary Jungian oriented approach views the therapeutic relationship as a much more dialogical egalitarian process which transforms both the client and the therapist (Shattell et al., 2007). In a similar vein, contemporary inter-subjective perspectives highlight the triadic and co-created nature of the therapeutic relationship (Mitchell, 2000; Ogden, 1996; Stolorow, 2013) which, comprises as well as contrasts the subjective "real" relationship and the therapeutic "working" alliance (Meissner, 2006) between the therapist and the client which "exists apart from but

parallel to the [representational] transference - countertransference relationship and the assigned [rigid psychotherapeutic] roles" (Stern et al., 1998, p. 916). From this perspective the relational dynamics (explicit and implicit) and co-regulation of affect (Beebe & Lachman, 1998) within the therapeutic relationship (and by implication any relationship) not only mediates, but of itself creates a curative potential (Della-Badia, 1999; Richardson, 2001; Schore, 2003, 2008 Greenwood, 2014; Walsh, 2016).

3.1.2 Humanistic - person centred and existential perspectives

The humanistically derived person-centred definition of the therapeutic relationship is grounded in the work of Carl Rogers (1902 – 1987). It posits that non-specific factors or the three "core" conditions of empathy, unconditional positive regard and congruence are of themselves essential and sufficient elements for therapeutic change. This approach to the therapeutic relationship is described as a non-prescriptive way of being with the patient, which facilitates the optimum conditions for growth and change through the therapeutic use of self (Watkins, 2001).

In contrast the existential arm is founded on assisting the client to deal with the four universal and inescapable concerns of human existence: freedom, isolation, meaninglessness and death (Yalom, 1980). From this perspective the therapeutic relationship provides a "dress rehearsal" for novel and authentic ways of relating with an indestructible other (Yalom, 1980). However, as with the aforementioned person-centred approach, importance is attributed to "being with" the patient, while equally stressing that authenticity gets lost if and when technique [psycho-technological correctness] is privileged over "turning towards another with one's whole being" (Yalom, 1980, p. 410).

3.1.3 The cognitive behavioural perspective

The CBT approach to the therapeutic relationship is grounded in the constructs of self-concept defined primarily as a structural representation of self which evolves out of interactions between significant others (Murran et al., 2001) and causal schemas - that is, beliefs and assumptions regarding cause-and-effect relationships (Kelly, 1955/1991; Leahy, 2003). The behavioural element focuses on reinforcing behavioural and relational patterns which may facilitate or inhibit the development of a good therapeutic relationship however, this is primarily regarded as a means to an end rather than an end in and of itself.

3.1.4 Contextual or pan – theoretical models

Contextual or pan-theoretical models of the therapeutic relationship focus on general or overarching factors that span different therapeutic modalities (Stiles et al., 1998). For Barkham (2002) these elements include an emotionally charged, confiding relationship which takes place in a healing setting mediated by the expectation that the therapist can and will help. Likewise Clarkson (1990) believes that distinctive relational types (working alliance, representational, reparative, subjective – I /you and transpersonal) are to a greater or lesser degree present in all psychotherapies arguing for the "integration of a multiplicity of different therapeutic relationship modalities". For me these pan-theoretical models have pragmatic multi-disciplinary/modality relevance and appeal because they provide a generic yet flexible framework which is not purely defined by or confined to the presuppositions, values and attitudes of particular theoretical models as with those already described (Hewitt & Coffey, 2005). On this same point Jaspers as early as 1959 stated that "the ultimate thing in the doctor-patient relationship is *existential communication*, which goes far beyond anything that can be planned or methodologically staged [or manualised]. The whole treatment is… defined within a community of two selves who live out the possibilities of existence itself, as reasonable beings" (Jaspers, 1959).

3.1.5 The evidence-base

Evidence derived from meta-analytic review alongside recent post-hoc analyses of several methodologically robust randomised controlled trials (Castonguay et al., 1996; DuRubeis & Freely, 1990; Elkin, 1994; Gaston, 1990; Hollon et al., 1991; Horvath & Symonds, 1991; Horvath et al., 1993; Krupnick, 1996; Shapiro et al., 1994; Stiles et al., 1998) indicates that the strength of the therapeutic relationship is the most meaningful if moderate predictor of a positive outcome in all forms of psychotherapy (Botella et al., 2008; Department of Health, 2001; Horvath, 2005).

The empirical paradigm - alliance as predictor of outcome

Therapeutic relationship research has tended to fall into two broad categories (Horvath, 2005). The first type has focused largely on the association between the therapeutic relationship and therapy outcome across various therapeutic contexts. This has included the aforementioned different types of treatments (e.g., cognitive behavioural therapy, supportive psychotherapy, etc.)

and or diagnostic groups (e.g., depression, anxiety etc.) while also exploring the effect of such variables as therapist gender or levels of training and experience. A focus within these studies has been the comparative magnitude of the relationship between outcome and the perceptually distinct *client* and *psychological therapist* perspectives of the therapeutic relationship, as well as the magnitude of the association between the therapeutic relationship and outcome at different stages of therapy (Horvath & Bedi, 2002; Martin et al., 2000).

Summarising the above lines of inquiry, the therapeutic relationship outcome relationship has remained comparatively consistent across reviews with correlations ranging between 0.22 – 0.29 (Horvath & Greenberg, 1994; Horvath & Symonds, 1991; Norcross & Wampold, 2011). Generally the client's assessment of the therapeutic relationship is a better predictor than the psychological therapist's assessment. Initial or early therapeutic relationship is an equally good or better predictor of outcome than subsequent or later assessments and therapeutic relationship gains are generally incremental but not identical to therapeutic gains.

Establishing and maintaining the therapeutic relationship
The second, albeit interconnected, line of research has concentrated less on the association between the therapeutic relationship and outcome and more on the role, development and maintenance of the therapeutic relationship across the course of therapy itself. Common areas of inquiry have included examining so-called "tears [ruptures] and repairs" in the therapeutic relationship as opportunities for therapeutic progress (Safran & Murran, 2000) alongside identifying differences between divergent (largely diagnostic) client groups in relation to the behavioural and relational, professional as well as personal attributes of psychological therapists which are associated with a positive therapeutic relationship experience.

Notable gaps in the knowledge base
Notably absent from both lines of research inquiry (Hersoug et al., 2001) is an investigation of the therapeutic relationship with clients in psychiatric settings with a diagnosis of psychosis (Johansson & Eklund, 2004; McCabe, Heath et al., 2003; McGuire et al., 2001) where based on a systematic review of the relevant psychiatric literature McCabe & Priebe (2004) concluded that the therapeutic relationship with the seriously mentally ill has not been widely investigated.

This apparent absence or lack of interest in therapeutic relationships for these diagnostic groups may be both a cause and effect of the perceived difficulty or fear (Karon, 2001) of engaging with and relating to these clients. For persons diagnosed with schizophrenia this is compounded by the belief that psychopharmacological interventions are sufficient and psychotherapeutic interventions potentially harmful, further fuelling and fuelled by the myth that "patients" with schizophrenia are non-relational and do not recover (Calabrese and Corrigan, 2005; Harding et al., 1987; Harrison et al., 2001; Slade et al., 2014). These negative misconceived stereotypes, prejudice, stigmatisation (Thornicroft et al 2009; WHO, 2015) and concomitant relational exclusion (explicit-implicit) compounds a sense of alienation, helplessness and hopelessness (Flanagan et al., 2012). Paradoxically, this highlights the need to establish and maintain a relationship that is therapeutic (Hewitt & Coffey, 2005; Walsh, 2016) with this often maligned, feared and largely misunderstood client group (Karon, 2001).

4. The therapeutic relationship – in "anti-therapeutic" psychiatric environments

Many service users and professionals alike report being extremely dissatisfied with acute psychiatric hospital care (Quirk & Lelliot, 2001; Rose, 2001; Schizophrenia Commission 2012; Walsh et al., 2015) which continues to be viewed as a problematic and largely "anti- therapeutic" component of the UK mental health system (Berry et al., 2016; Johnson et al., 2009; Perkins & Slade, 2012; Walsh & Boyle, 2009). Paradoxically, however, in these psychiatric systems patients have consistently reported that establishing a relationship is one of the most crucial "therapeutic" factors in their care (Hewitt & Coffey, 2005; Johansson & Eklund, 2004; Rogers & Pilgrim, 1994), as this can be a pivotal interpersonal medium through which diagnoses are made, treatment plans are negotiated and the majority of interventions delivered (Priebe & McCabe, 2006). Notably, however, there is a relative paucity of research on the therapeutic relationship in these psychiatric settings (Johansson & Eklund, 2006; McCabe & Priebe, 2004; McGuire et al., 2001) and what research there is has primarily been imported from psychotherapy theory and practice. Likewise and consistent with the general therapeutic relationship literature, in the psychiatric therapeutic relationship literature, persons whose experiences are synonymous with a schizophrenia diagnosis are greatly under-represented ((Martin et al., 2000; Hewitt & Coffey, 2005; Walsh, 2016) and or misrepresented (Chandler & Hayward, 2009).

The perceived difficulty of engaging with and relating to these so-called "psychotic" clients (Walsh, 2016) may be both a cause and effect of the apparent lack of interest in the therapeutic relationship for the SMI. The assumption that they cannot form a collaborative relationship (Repper & Perkins, 2003) either real or representational (Karon, 2001; Malmberg & Fenton, 2001) is compounded by the aforementioned if misconceived belief that psychopharmacological interventions are sufficient and psychotherapeutic interventions potentially harmful (Lehman & Steinwachs, 1998; Malmberg & Fenton, 2001). There are no financial incentives for pharmaceutical companies to challenge either of these misconceptions (Priebe & McCabe, 2008) while the myth persists that patients with schizophrenia cannot and do not recover (Harding et al., 1987; Calabrese and Corrigan, 2005; Harding & Zahniser, 1994; Harrison et al., 2001; Schizophrenia Commission, 2012; Zipursky et al., 2013).

Consequently, mental health-psychiatric practice is dominated by an anti-emotional, bio-medical maintenance model (Hewitt & Coffey, 2005) which under-values the therapeutic relationship (including the nurse patient relationship) and the possibility that SMI can be successfully treated by so-called talking therapies (Repper & Perkins, 2003). This effectively forecloses on an exploration of the unique lived experience of the person which is indisputably pathologised (Boyle, 2013). This is corroborated by the first person lived experience of Paddy. Equally from a psychological perspective, if rigid and prescriptive "psycho-technolog[ically]" correct approaches are privileged over establishing a relationship, (Jung et al., 2015) the client is left feeling that the psychological therapist/counselling psychologist does not care about them as a person, exacerbating their sense of hopelessness and alienation (Collins & Cutcliffe, 2003; Flanagan et al., 2012).

4.1 The therapeutic relationship in psychiatry

As already noted in chapter two, operational definitions of the therapeutic relationship vary across the different schools of psychotherapy. Moreover, conceptualisations of what constitutes a relationship that is therapeutic in psychiatric settings with the SMI is primarily imported from psychotherapy and remains largely "ill"-defined (Chandler & Hayward, 2009; McCabe & Priebe, 2004). It is not clear, therefore, if or to what extent the interpersonal elements can meaningfully generalise to psychiatry or get lost in translation. For example, McGuire et al. (2001) examining six theoretical models of the therapeutic relationship (psychoanalytic, role theory, social constructionist, systems theory, social psychological and cognitive behaviourist) concluded that while each has relevance, none has been "fully specified and comprehensively investigated in psychiatric settings" and there has been a distinct lack of focus on the universally recognised collaborative affective bond elements (Catty, 2004).

Consequently, a comparison of the therapeutic relationship across the main modalities of psychotherapy in psychiatric settings reveals several important intrinsic as well as contextual differences. Firstly, to a greater or lesser degree the therapeutic relationship is unavoidably affected by the hierarchical, statutory and regulatory nature of psychiatric services where patients are potentially the subjects of compulsory or coercive treatment measures (Priebe & McCabe, 2008). Secondly, treatment is primarily open-ended, initiated by multidisciplinary professionals and increasingly in recovery-oriented services by peer mentors and advocates. This means that

the therapeutic relationship is much more loosely defined and less likely to constitute a scheduled dyadic meeting in a regular location for a time limited or specified period. Thirdly, in psychiatric settings treatment goals are generally more fluid, focused primarily on medically - oriented maintenance interventions, alongside providing pragmatic support with housing and employment and with markedly less emphasis on emotional or cognitive processes and change. Because of this professionals often work in multidisciplinary teams which, means that patients have relationships with a variety of professionals and increasingly also advocates and peer mentors at any one time. Finally, in psychiatric settings care is much more eclectic in nature, integrating various therapeutically-oriented interventions at a physical, psychological and social level.

These distinctive differences between formal psychotherapy and eclectic psychiatric care (Priebe & McCabe, 2006, 2008) has meant that in the latter the therapeutic relationship has become confused and conflated with the concept of "engagement" (Catty, 2004). Equally in psychiatry the term engagement is often used interchangeably to refer to such things as medication compliance, maintaining contact with services by attending appointments, or being involved in a collaborative relationship. Although each of these definitions involves collaboration, the third is perhaps more closely related to establishing a more in-depth interpersonal relationship incorporating an affective bond. As such, while I share the view that the therapeutic relationship does differ in conceptualisation and context, I believe that it has the potential to transfer to a psychiatric setting where it is equally if not more relevant, not least from the perspective of the patient (Berry et al., 2016; Karon, 2003; Shattell et al., 2007; Walsh, 2016).

The therapeutic relationship and *outcome* in psychiatry
Notwithstanding the aforementioned nuances and regardless of treatment orientation, alliance or outcome measure, a consistent association has been found between a good therapeutic relationship and improved outcome across an array of mental health conditions (Fluckiger et al., 2012; Horvath et al., 2011). This includes depression (Arnow et al., 2013; Krupnick et al., 1996) complex PTSD (Cloitre et al, 2004) addictive disorders (Meier et al., 2005) and of particular relevance to this inquiry, schizophrenia (Frank & Gunderson, 1990; Jung et al., 2015; Rogers et al.' 1967). For patients diagnosed with psychosis, associations have been found between the

patient rated quality of the therapeutic relationship and the severity of symptoms (Barrowclough et al., 2010; Jung et al., 2014) admissions to hospital and adherence to treatment (Weiss et al., 2002).

Notably and in contrast to psychotherapy research where typically the client's ratings of the therapeutic relationship have greater predictive power (Horvath & Symonds, 1991), in the treatment of depression and psychosis, including schizophrenia, the therapist's rating of the therapeutic relationship has been shown to have a stronger association with outcome (Gehrs & Goering, 1994; Neale & Rosenheck, 1995). Interestingly, however, the association found between the therapeutic relationship and a positive outcome is not always a function of either psychopathology or mediated by adherence to the prescribed intervention (McCabe & Priebe, 2003; Priebe & Gruyters, 1993). In an inpatient setting several studies have shown that therapist characteristics explain a high proportion of the variance in therapeutic relationship ratings (Dinger et al., 2008). For example, in a group of patients with psychosis treated with client centred therapy Rogers et al. (1967) found that the patients' perceptions of the therapists' unconditional positive regard, genuineness and empathic understanding were associated with a better outcome. Likewise, Esther et al. (2015) found that the effectiveness of CBTp for psychosis was mediated by the patient's perception of the genuineness of the therapist. Finally, in a psychiatric out-patient setting Johansson & Jansson (2010) found that therapist or relational variables and not patient variables explained most of the variance in the relationship between the therapeutic relationship and outcome. Foremost amongst these relational attributes was the perceived sensitivity and responsiveness of the therapist towards these "difficult to engage" clients.

4.1.1 The nurse-patient relationship

In psychiatry because mental health nurses form the largest professional discipline providing care on an everyday basis for sustained periods, they are in a pivotal position to establish relationships that are therapeutic (Cameron et al., 2005). The therapeutic relationship in nursing is founded on the interpersonal relations theory of Peplau (Horsfall, Stuhlmiller, et al., 2001) which draws on Sullivan's (1953) concepts of security operations and parataxic distortions where the "general principle is to struggle with the problem and not with the patient" (Peplau, 1997, p. 164) and establish "empathic linkages" to facilitate feeling the emotions experienced by the

patient (Peplau, 1997, p. 163). Similarly, Travelbee (1969) challenged the unwritten, but time-honoured law of emotional distancing from the patient by arguing that nurse patient interactions should be both planned and emotionally involved (Shatell, et al., 2007).

In a secondary analysis of 20 qualitative interviews with patients experiencing severe mental illness, Shattell et al. (2007) examined the perceived therapeutic elements of interpersonal interactions with mental health professionals, primarily (though not exclusively) psychiatric and general or dialysis nurses. Contextualised against the perceived challenge, stigma and prejudice of living with mental illness (Flanagan et al., 2012) compounded in this instance by frequent reports of domestic violence, substance abuse/dependency and homelessness, three figural themes were identified by the patients. The first theme "relate to me" reflected the nurse practitioner being perceived as reliable, patient, authentic, non-judgemental and optimistic, underpinned by genuine attempts to make meaning of and validate the lived experience of the patient, while connecting at an emotional level. Related sub – themes included "feeling special", seeing each individual as unique and mediated by "touch" which, included reaching out physically as well as emotionally through "self – disclosure", getting to know and connecting with the personal – subjective (Stolorow, 2013) as well as the professional selves of the nurse practitioner.

The second related theme, "know me as a person" involved the nurse practitioner taking the time and investing energy in getting to know and understand the *person*, characterised as a "way of being" with the *patient*. The third and final theme, "get to the solution" incorporated a more pragmatic approach, which focused on giving practical advice on how and where the patient could source and access necessary life-sustaining resources alongside providing support to achieve an explicit or implied goal. Although at times this meant not only "doing with" but also "doing for" the patient, it was founded on working collaboratively and at sufficient depth to identify relational-behavioural patterns, connect them meaningfully with emotions and life events "to get down to the real problem not just the symptoms" (Shattell et al., 2007).

Comparing a psychiatric outpatient and a psychotic in-patient cohort
Consistent with the findings of the above study in Johansson & Eklund's (2003) qualitative inquiry of the patient's experience of receiving psychiatric care, the main category which

emerged was the "quality of the helping encounter". However, in contrast to Shattell et al's inquiry which, focused primarily on the nurse-patient relationship and included only one client diagnosed with schizophrenia, Johansson & Eklund adopted a sampling strategy to ensure maximum variation. As such, they deliberately selected a cross section of *outpatients* who met ICD-10 diagnostic criteria for affective, neurotic and personality disorders, as well as an *in-patient* sub sample being treated in a specialised rehabilitation unit for young people with psychosis, primarily schizophrenia.

While the quality of the helping encounter emerged as the most important common factor across the out-patient and in-patient samples, notable differences in the perceived therapeutic elements of these encounters emerged between the two diagnostically and contextually distinguishable cohorts. For the out-patients (and irrespective of whether they reported being satisfied or dissatisfied with their care) feeling understood was pivotal to the quality of the helping encounter as well as the quality of the care they experienced. Of the four patients who reported being satisfied with their care, key therapeutic elements which emerged were warmth, empathy, taking sufficient time to understand the unique situational context alongside entering into and communicating with the emotional world of each individual client. In contrast, the three patients who were dissatisfied with their care felt misunderstood in interactions which were typically experienced as affectively disengaged from and disinterested in their unique lived and situational experience.

Foremost amongst the sub-categories which emerged amongst the out-patients was the therapist taking sufficient time to sensitively "open up" and listen attentively to their "inner world" as opposed to listening for and acting haphazardly on preconceived, but often "ill" conceived and generalised solutions, whether psychotherapeutic or psychopharmacological. Clients favoured a reflective and collaborative approach to making meaning of their problems.

As with the outpatient sample, for the young psychotic in-patient sample the existence of a therapeutic relationship, along with feeling understood, emerged as the two dominant central themes. However, distinctive to the inpatient group was a clearly expressed relational ambivalence manifesting as a longing for closeness and authentic engagement that co-existed with a fear of closeness and a need for emotional distancing. A further ambivalence emerged in the domains of activity and passivity. Participants reported feeling frustrated and bored by the

slowness of the mundane routine, but equally at times feeling pressured by the demands of the treatment programme - a simultaneous desire for "rest and peace" and "speed and action" (Johansson & Eklund, 2003, p. 343). Another important sub category for the inpatient psychotic group was that of "meaningfulness", wanting to be seen as personally meaningful along with feeling that their communications were being taken seriously and were understandable. Patients also reported the need to feel respected, "to be met and understood" as whole subjects as opposed to being "assessed and interpreted" as objects (Johansson & Eklund, 2003, p. 343).

Finally, a more tangible and practical aspect of meaning in the inpatient setting was having a clear understanding of the rules and regulations of the ward regime as well as the purpose, rationale and function of the programme of treatment. Patients highlighted the fundamental importance of stability and structure, the prerequisite of which was continuity of staff and a reliable, predictable external environment which they reported relieved the pressure of their often unpredictable and overwhelming internal subjective experiences.

4.1.2 Community based psychiatric alternatives and the keyworker – client relationship

Also notably absent from the therapeutic relationship literature is any systematic application to either generic acute and or community based psychiatric alternatives to care. In this context the Care Plan/Management Approach (CPA) dictates that the primary relationship is often between the client and a named worker or so-called "keyworker" a role which I fulfilled while working in residential democratic therapeutic community care. In both an acute and community based supported housing settings the named worker is often a multidisciplinary mental health professional (CPN, social worker, etc.) with little or no formal training in the psychological therapies and with a multiplicity of roles, which combine a practical co-ordinating function with a more interpersonal supportive one. The community care of the severely mentally ill therefore extends far beyond the walls of the consulting room and the formal psychotherapeutic relationship (Kanter, 2000). From this perspective Kanter (2000) sees the keyworker-client relationship with the SMI, as analogous to the relationship between the social care worker and the child, drawing and elaborating on the noted difference between formal psychotherapy and social care as espoused in the later writing of Clare Winnicott (1964) where;

"The social [care] worker.... starts off as a real person concerned with the external events and people in the [client's] life. In the course of her work with him, she will attempt to bridge the gap between the

external world and his feelings about it and in so doing will enter his inner world too. As a person who can move from one world to another the [care-worker] can have a special value all her own for the [client], and a special kind of relationship to him which is quite different in kind from the value and relationship that a psychotherapist has. The [care-worker] can never become entirely the subjective object which the psychotherapist becomes; she is bound to external reality because she is part and parcel of the [client's] real world, and often is responsible for maintaining that world. The [care-worker] is therefore in a strategic position in their lives because she is in touch with a total situation representing a totality of experience (Winnicott, 1964, p. 45).

Interestingly, what Winnicott describes as the characteristic features of the care-worker-client relationship is remarkably synchronous with a contemporary inter-subjective perspective of the totality of the psychotherapeutic relationship (Orange et al., 1997; Stolorow, 2013), in other words a relationship comprising the subjective "real" relationship and the therapeutic or working alliance (Meissner, 2006) which, "exists apart from but parallel to the transference countertransference relationship and the assigned [rigid psychotherapeutic] roles" (Stern et al., 1998). In a related vein Mosher (2001) outlines an evidence-based interpersonal phenomenological framework for establishing and maintaining meaningful contact with these "non-relational" or more accurately difficult-to-engage clients. This community based, de-medicalised psychiatric alternative has been shown to be equally clinically as well as more cost-effective in promoting recovery than traditional psychiatric care (Bola & Mosher, 2003; Calton et al., 2007). Consistent with the findings of the qualitative inquiries already reviewed the focus of this interpersonal phenomenological approach is less about theoretical technique or prescriptively doing to and more about relationally "being with" (Mosher, 1999), embracing the experiences synonymous with a diagnosis of schizophrenia as valid and understandable within the historical context of each individual's life (Chandler & Hayward, 2009; Longden et al., 2011, 2012; Thomas & Bracken, 2004). The importance of this way of "being with" or alongside someone, is corroborated by the personal testimonies of persons who have recovered from serious mental ill-health who consistently highlight the therapeutic potential of having someone believe in them and their experiences whether construed as consensual or non-consensual (Allot et al., 2003; Chandler & Hayward, 2009; Deegan, 1996; Gottstein, 2003; Onken et al., 2006, 2007; Ridgway, 2002; Roberts & Wolfson, 2004; Romme et al., 2009).

The ego-supportive function of the TR for the psychotic patient

In the now well established Care "Management" framework, Kanter (2000) builds on Winnicott's conceptualisation of "management" to highlight the life-sustaining ego-supportive function of the therapeutic relationship for the SMI. For Winnicott this is of central importance in the treatment of psychotic patients and extends beyond the verbal to include the practical provision of basic physical needs (food, shelter – housing) alongside co-regulating hitherto overwhelming dysregulated affect and intolerable frustration, which for Schore (1996, 1997) reflects a pan-developmental deficiency that mediates all Axis – I (personality) and Axis – II (mental health) disorders as conceptualised in the then (DSM – IV- TR; APA, 2001). Taking a similar developmental perspective Winnicott posits that the "individual introjects the ego-supportive mother" and as "de-adaptation" occurs in "graduated doses" this provides the impetus for increased autonomy and independence (Winnicott, 1965). Analogously, in the realm of the care "management" system the keyworker becomes a functional role model or surrogate mother, bridging and integrating the reciprocally determined disparate dissociative threads of the social, interpersonal and subjective emotional environments of their clients (Harris & Bergman, 1987). As these ego supportive functions are gradually internalised and integrated the client can begin to recover or for the first time discover autonomy and independence.

A transitional "participant"

For Kanter this ego-supportive "management" function is at the "heart and soul" of community care for the severely mentally ill. From this perspective the keyworker is a "transitional participant" dynamically linking as well as creating clear boundaries between past and present, fantasy and reality and self-other (Kanter, 2000). In a community care setting and paralleling my own experience of working as a keyworker, the transitional participant has literally nowhere to hide and the priority is one of survival.

"If you survive, then and only then you may find yourself used in a quite natural way by the client who is becoming a person and who is newly able to make a gesture of a rather simplified loving nature…….
[management] can be a very deliberate act of therapy done by professionals in a professional setting. It may be a kind of loving but often it has to be a kind of hating, and the key word is not treatment or cure, but rather it is survival" (Winnicott, 1971, pp 227 – 228).

In my bid to survive, a capacity for playful engagement (alongside taking the work seriously) was both vital and life-sustaining. The work of building a sustainable therapeutic relationship with a more psychotically organised patient cannot begin until they develop a similar capacity to "play" (Winnicott, 1970). However, for the psychotic client, it is especially difficult to differentiate the boundary between fantasy and reality which is at the heart of being able to engage in and enjoy playful activity. As such, "schizophrenic patients as a group give the impression of being less interested, or successful, in pursuing pleasure than any other group of patients" (Hill, 1955, p. 60). Moreover, this capacity to play cannot be learnt surreptitiously through sophistic efforts, it is learned simply by playing. In the keyworker or carer-client relationship playing can involve social and recreational activities which, combined with a genuine and a sublime capacity to laugh heartily "with the patient" at each of our own shortcomings is critical as well as curative. From this pragmatic yet playful vantage point the keyworker, carer or significant other is the "vehicle for a more personal [co-created] attachment" (Thurston, 2003, p. 196).

4.1.3 The therapeutic relationship as therapy

As already reviewed in Chapter Two (2. 2. 4.) and concurring with my own practice based lived experience already referenced there is a substantial and growing body of empirically derived evidence, which indicates that early trauma based victimisation experiences not least CPA and CSA, emotional and physical neglect are linked to symptoms indicative of psychosis in general (Beards et al., 2013; Bentall et al., 2012; Cutajar et al., 2010; Geekie, 2004; Janssen et al., 2004; Read & Argyle, 1999; Read & Ross, 2003; Read et al., 2004; Shevlin et al., 2007; Spauwen et al., 2006; Whitfield et al., 2005; Verese et al., 2012) and a diagnosis of schizophrenia in particular (Cutajar et al., 2010; Read & Hammersley, 2005; Read et al., 2005). Overwhelming interpersonal developmental traumas and disruptive or disrupted attachments greatly impact on the developing brain, the capacity to regulate affect (Fonagy et al., 2002; Schore, 2000, 2008; Wilson & Houart, 2004) and the co-determined capacity to establish and maintain trusting, mutually dependent and satisfying relationships (Fonagy et al., 2002). In what is an emotionally charged, as well as vacuous, potentially persecutory and often trauma laden inter-subjective field (Aron, 1991; Stolorow, 2013) the prompt appearance of a relationship cannot and should not be taken for granted (Atwood, 2012; Greenson, 1967; Stolorow et al., 1987). As such, convincing

these so-called "disembodied spirits and de-animated bodies" (Stanghellini, 2004) alongside the equally at times disembodied and de-animated psychological therapist of the safety and value of relationship is fraught with difficulty (Karon, 2003; Thurston, 2003; Walsh, 2016). From this perspective the therapeutic relationship is not simply a means to an end, but an end in itself and where crucially, what is therapeutic is the relationship (Calton et al., 2007; Della-Badia, 1999; Hewitt & Coffey, 2005).

Conclusion

In synthesising clients' lived experiences of what constitutes a relationship that is therapeutic in a psychiatric setting, prime importance is awarded to a person centred, genuine and individualised relationship built on reliability, trust, respect and empathy (Rogers, 1942). Equally, and consistent with an interpersonal approach (Yalom, 1980) authenticity is regarded as a pivotal personal attribute characterised by a special yet "down to earth" (Falk – Rafael, 2001, p. 7) and ordinary way of relating where the central and interrelated figural "relate to me" and "know me as a person" themes share certain similarities with contemporary relational and inter-subjective formulations (Mitchell, 2000; Orange et al., 1997; Stolorow, 2013; Stolorow et al., 1987). From this perspective clients want to be seen and known as unique individuals mediated by a spirit of open minded and nonintrusive curiosity (Karon, 2003) which avoids diagnostic-illness saturated stereotypes, prejudice and stigma (Munhall, 2004). Finally, over and above talking, clients want a pragmatic and ego-supportive, solution focused approach which involves providing relevant information, credible explanations and hands-on practical support.

For the psychotic client the therapeutic relationship is marked by an extreme relational ambivalence which most likely reflects the inherent subjective quality of the "schizophrenic" disorder (Gonzalez de Chavez et al., 2000), not least because subjective and often trauma based persecutory experiences get objectively enacted and potentially either amplified or transformed in the therapeutic relationship (Dilks et al., 2010). A key component of building authentic relationships with persons whose experiences are psychotic therefore involves taking time and energy to interact fully with the lived experience or "historicity" (Kanter, p. 17) of each individual client (Chandler & Hayward, 2009; Longden et al., 2011, 2012). For me this is necessarily founded on a radical and authentic "willingness to collaborate with [and tolerate]

experiential [non-consensual] worlds that may disconcert" those of the psychological therapist

(Chandler & Hayward, 2009, p. 8).

5. Method

5.1 Design

5.1.1 Collaborative inquiry

Embracing the over-arching principles of participatory research (PAR; Reason & Bradbury, 2001) the study was conducted in collaboration and in regular consultation with Paddy co-participant and diagnosed "Paranoid Schizophrenic". This collaborative partnership enabled a rich relational-dialectical, pragmatic and credible framework to reflexively interrogate my theoretical presuppositions and preconceived ideas in an attempt to get at the essence of the complex and essentially contested phenomenon of schizophrenia (Geekie, 2004). However, equally, because this was necessarily "my" doctorate, the collaboration created a counterintuitive hierarchical and uncomfortable tension between my role as the principle inquirer (doctoral candidate) and Paddy's role as the "patient". This mirrored and parodied the power imbalance inherent in the doctor – patient relationship in the psychiatric system which privileges, values the knowledge of the "doctor".

5.1.2 Mixed Method

The use of multiple data collection or so-called mixed methods originates in the earliest of social science research (Hanson et al., 2005). However, Campbell and Fiske (1959) are generally attributed as the first investigators to systematically collect multiple *quantitative* data within a single study (Sieber, 1973). This became the precursor for the process of triangulation which posits that divergent *quantitative* and or *qualitative* data can provide multiple reference points to better identify the exact or relative position of an object or phenomenon by "uncover[ing] some unique variance which, otherwise would have been neglected by a single method" (Jick, 1979). In my original mixed method design the hypothetico-deductive quantitative arm would have involved administering several standardised questionnaires to a sufficiently powered sample to generate quantitative data, which would have been analysed using univariate and multivariate inferential statistical tests.

5.2 Ethical approval

Ethical approval of the mixed methods (*quantitative-qualitative*) design was granted by Metanoia Institute and Middlesex University. Participants for the quantitative arm would have been recruited from a homogenous population of persons whose experiences were synonymous with a schizophrenia diagnosis. In line with research governance requirements (DoH, 2001) because this population were considered NHS "patients" (either past or present) the research proposal would have to be submitted to and ethical approval granted by the Office of Research Ethics Committee for Northern Ireland. Historically, these now regional committees are grounded in the field of bioethics predicated on the Nuremburg experience (Ramcharan & Cutcliffe, 2001), which found that researchers cannot always be trusted to prioritise and privilege the interests of the research subjects. Henceforth, ethics committees are to a greater or lesser degree tied to the health/medical model of ethical decision making, gauged primarily by judiciously considering the perceived *risk* to *benefit* ratio for the subjects of the inquiry. However, post-modern qualitative paradigms challenge these traditional notions of absolute scientific truths (Ponterotto, 2005) and post-modern researchers like me "challenge the epistemological relevance of professional ethics codes on the basis of [purely] positivist notions of value free science and individual autonomy" (Morrow, 2005, p. 147) wherein "respondents' values are systematically disregarded as mere opinions with no foundation in scientific knowledge" (Lincoln & Guba, 1985, p. 225).

This traditional bioethical framework, therefore, created particular problems for my democratic PAR approach where the research design is fluid and emergent, and the precise balance between risks and benefits is more difficult to determine in advance and can change during the inquiry (Ramcharan & Cutcliffe, 2001). From a positivist ethical perspective, it is these very factors which are regarded as evidence of poor research design, which is considered inherently "unethical", making it extremely unlikely that ethical approval would be granted.

5.2.1. Ethically important moment

The debate and discourse between these divergent medical and social health care research ethics is ongoing but, remains largely unresolved. This created an "ethically important moment [dilemma]" (Guillemin & Gillam, 2004, p. 262) for myself and Paddy because in our PAR

collaborative design the researcher and subject were interchangeably considered one and the same. This forced a choice. I could either submit the (quantitative- qualitative) mixed methods proposal for ethical approval in its participatory-social phenomenological entirety, which might well elicit either an outright rejection or a request for revisions for the reasons already outlined. I felt this would have ethically compromised and betrayed the core principles of the inquiry by disempowering the participants and preventing us from better understanding the schizophrenia phenomenon. The second option involved me "playing the game" - that is, adjusting the proposal to fit the conventional medically oriented, positivistic ethical framework, which would equally betray the participatory action democratic principles, disempowering the participants and denying true access to the schizophrenia phenomenon.

As the method continued to form and evolve around this problem, it stimulated open and honest debate between myself and Paddy which involved interrogating our own and the other's pre-suppositions, ethical and otherwise. Paddy questioned the rationale behind the quantitative arm and the concomitant need to access an NHS "controlled" population, which, he argued, would be compromised by their "patient" status and for him decreased the likelihood of authentic genuine engagement with the subjects and the subject matter. In a similar vein, he believed the medically oriented "scientifically" bound bioethics committee would explicitly-implicitly dismiss our conceptualisation of schizophrenia as an essentially contested concept as "unscientifically absurd". The latter argument is weighted persuasively by Paddy's ongoing challenge to his diagnosis of paranoid schizophrenia. Although everyone agrees that he has personally, if not clinically, recovered (he still hears voices), his recovery is considered attributable to having been misdiagnosed, as "real schizophrenics" don't recover, a tragic "error", however, which saw Paddy detained in psychiatric care for some 14 – years. Paddy therefore believed that staying outside the conventional medically oriented scientific system would create a healthy tension which would add to the weight and the truth value of the findings.

At this stage I was reluctant to let go of the/my positivist arm and put forward the counter argument that multiple methods can be usefully deployed in a single study by taking advantage of the best of both worlds that is the representativeness and generalisability of quantitative findings and the richness and real world nature of qualitative findings (Greene & Caracelli,

2003). However, interrogating my academic–scientific status revealed an intellectualised defence against trusting the legitimacy of the subjective experience of the person who owns the experience. This, alongside requiring objective absolutistic proof through quantification that these experiences exist in my reality represented an absurd, but clear "crisis of representation" (Denzin & Lincoln, 2000) which defeated the very essence of the inquiry. On this basis, I decided to forego the quantitative (my positivist) arm in favour of a more in-depth inquiry using an integration of the qualitative methods-procedures described below. The revised methodology along with a clear and detailed rationale for changing it was re-submitted to Metanoia and Middlesex who subsequently granted ethical approval.

5.3. Philosophical assumptions

5.3.1 Paradigm – method fit

Despite claims of complementarity, considerable and ongoing controversy exists regarding the underlying philosophical assumptions of integrating methods (whether quantitative or qualitative) centring primarily on the issues of (i) paradigm-method fit and (ii) the best paradigm (Madill & Gough, 2008). The paradigm-method fit debate centres on whether meta-philosophical paradigms (e.g., post-positivism, constructivism etc.) and research methods *have* to fit together? For example, Guba and Lincoln (1988) identified distinctive paradigmatic differences between conventional post-positivist philosophical assumptions and naturalistic assumptions not in terms of what we know, but how we know what we know (epistemology), the nature of reality (ontology), values (axiology) and methodological process (Ponterotto, 2005). This debate has created a notable schism between traditional inquiry paradigms and naturalistic paradigms which argue that because of the meta-philosophical miss-match between these world views and certain methods, mixed methods are incompatible or untenable (Smith, 1983). In contrast, Reichardt and Cook (1979) argue that paradigms and methods need not be inherently linked, pointing out that quantitative measures are not purely objective or qualitative measures only subjective. For example, assessment of psychopathology and diagnosis in the field of mental health relies primarily on the pseudo-objective quantification of criterion symptoms open to subjective interpretation and independent of aetiology, prognosis or response to treatment (Bentall, 2009; BPS, 2014a).

5.3.2 The best paradigm

The best paradigm issue centres on the more general question of "What philosophical paradigm is the *best* foundation for mixed methods research?" (Hanson et al., 2005, p. 225). Creswell et al. (2003) argue that purposely using competing paradigms creates a healthy dialectical tension between contradictory viewpoints which should be honoured not reconciled. From this perspective mixed methods research is regarded as a credible and valid method which allows the investigator(s) to utilise and justify a diversity of philosophical foundations which are not determined by the method but by the investigators and the research question. Equally and distinct from a methodological purist approach which argues that the foundational epistemological and ontological assumptions of methods are mutually exclusive and contradictory, pragmatists believe different methods can be usefully deployed in a single study and unlike situationalists regardless of circumstance. Pragmatism, therefore, is a broad church which embraces a diversity of ideas, equally values objective and subjective knowledge and privileges "what works" (Tashakkori & Teddlie, 2003).

5.4 Phenomenological inquiry

Phenomenological methods of inquiry evolved primarily out of the work of the philosopher Edmund Husserl (Husserl, 1954). As a philosophy of science that emerged during the 20th century, one of its greatest impacts has been in the field of mental health (Spiegelberg, 1972). These inquiries emphasising, "experience, process, freedom, the importance of the client-therapist relationship, and viewing the client's problems from his or her perspective" (Halling & Nill, 1995, p. 28) challenge de-humanisation in psychology and psychiatry (Wertz, 2005).

5.4.1. Heidegger and the double hermeneutic

A Heideggerian existential phenomenological perspective (Heidegger, 1962) moves beyond pure description, arguing that all extant mental life is dependent on a relation to something, an "object" outside of itself that "means something to me" (Wertz, 2005, p. 169). The mental life of the "schizophrenic" therefore, is dependent on the relationship with and the meaning they and others attribute to the concept of schizophrenia, which extends beyond the objective diagnostic nomenclatures outlined in DSM-5. To ensure that the reality and action of the participants were not replaced or subjugated by a fictional or pseudo-scientific world constructed by me in the

service of either achieving my doctorate or the dominant medical conceptualisation of schizophrenia and the "schizophrenic" (Horsfall et al., 2001; Schutz, 1967) I started with and privileged the concrete lived experience while reflectively explicating the experiential process through which the experience was lived to enable new ways of knowing to emerge (Wertz, 2005). This approach was thought to be appropriate because of the inherent subjective non-consensual quality of psychotic experiences (Gonzalez de Chavez et al., 2000).

5.5 Participatory action research

As the name implies participatory action research (PAR) is founded on the principles of *participation* "sharing [collaboratively] in something" and *action* - offering a practical alternative using research as a tool (Merrian – Webster Incorporation, 2004). From this perspective the method formed and evolved around the problem (Bakan, 1967) with the primary objectives of producing "knowledge and action directly useful to a community and empowerment through consciousness raising" (Reason, 1994, p. 48). PAR has been successfully applied in psychiatric settings to facilitate mutual, reciprocal understanding, inform service provision and enhance co-operative relationships between service providers and consumers/survivors (Camardese & Youngman, 1996; Nelson et al., 1998; Park et al., 2014; Rogers and Palmer-Erbs, 1994; Walsh & Boyle, 2009).

5.5.1 The participatory attitude

PAR is not, therefore, a macro method per se (McTaggart, 1997) but an attitude or mind-set (Kidd & Kral, 2005) where my values, Paddy's and the participants' were considered equally valid. This dynamic, dialogical and reflective inquiry evolves out of the self-identified needs, challenges and lived experiences of a group. However, this can be difficult alongside a more conventional "hierarchy of evidence" (NICE, 2006) which claims exclusive ownership of methods of knowledge gathering (UKCP, 2011) which undervalues the knowledge of marginalised and stigmatised peoples (Fals-Borda, 1991, 1997).

PAR is founded on "a commitment to full democratisation of both content and method" (Chataway, 2001, p. 240). I was genuinely respectful of as well as hopefully respected by and open to the experience of the participants, creating an inter-subjective catalyst "for a dynamic

and [co]-evolving experience of understanding, growth and action" (Kidd & Kral, 2005, p.188). I had also to negotiate and re-negotiate the delicate balance between sharing rather than prescriptively imposing knowledge. This open and comparatively equitable or at least flattened hierarchical stance to learning was based on respecting the legitimacy of the participants' knowledge as well as methods of generating knowledge to inform practice/action (Rahman, 1991).

5.5.2 Critical inquiry

Critical inquiry or conscientisation is a reflective process by a group about the nature of their disenfranchisement, the mechanisms by which inequalities are maintained or perpetuated, and the action needed to change their circumstances (Fals-Borda, 1991, 1997). Since the subjective truth of persons with a schizophrenia diagnosis are often dismissed as "lack of insight" and taken as proof of the existence of illness, it was vital that I maintained an open and critical attitude to multiple, often dialectical perspectives, while being equally committed to an overarching shared vision. Herein for me lay the greatest challenge as well as the potential benefit of my active participation. This was further compounded by me holding and demonstrating sufficient authority and disciplinary power to convince the examiners that this was my doctorate, while managing the tension that Paddy, my collaborative inquirer, would remain doctor-less, a antithetical position to the PAR principle that our epistemologies hold the same currency.

5.5.3 Evenly suspended attention – authentic participation

To avoid silencing or subjugating the very voices I was attempting to liberate, I systematically interrogated my own epistemological, ontological and axiological assumptions. This involved constantly monitoring my use or potential abuse of my disciplinary power (Stevenson & Cutcliffe, 2006), "willing[ly] collaborat[ing] with experiential worlds that disconcert[ed] [my] own" (Chandler & Hayward, 2009, p. 8), and tolerating the uncertainty of "not knowing", all of which are considered essential features for working clinically with a psychotic population (Karon, 2003). However, with this came the risk that I would either over-identify with or forego my critical awareness of the knowledge and perspective of the subjects. It was equally important, therefore, not to devalue or lose track of my own perspective, knowledge and lived experience which was respected and valued by Paddy and the research subjects by virtue of their

willingness to participate. However, because of possible negative experiences with the psychiatric system, it was important not to mistake participation with trust and be aware of the implicit pressure to either, comply with, resist, or be suspicious of, the uncharacteristic benevolent sharing of power offered by me the (pseudo-doctor) inquirer. It was essential therefore that my critical awareness and attention remained "evenly suspended" - "be [ing] open minded, but knowing [my] commitments" (Bruner, 1990) as "it is in the critical meeting place between these two sets of knowledge" (Kidd & Kral, 2005, p. 190) that the synergistic potential for truly transformative action would emerge (Reason & Bradbury, 2001). This, integrated with embracing a democratic PAR attitude embedded in "authentic participation" (Kidd & Kral, 2005, p. 192) between myself, Paddy and the participants generated a rich, hitherto largely untapped synthesis of "living knowledge" (Friere, 1982) to better understand and make more visible the self-defined, self-directed and largely unmet needs of this group (Johansson & Eklund, 2006; McCabe & Priebe, 2003; McGuire et al., 2001; Schizophrenia Commission, 2012; Thornicroft et al., 2009).

5.6 Validity

In the comparatively contemporaneous and ever-evolving post-positivist field of qualitative methods the issue of quality referred to variously and interchangeably as *validity*, *credibility*, *rigour* or *trustworthiness* is regarded as both paradigmatically universal as well as paradigm bound or specific (Morrow, 2005). In terms of the former, and while neither exhaustive nor rigidly inflexible, general areas of concern include *social validity*, *subjectivity* or *reflexivity*, *adequacy of data* and *adequacy of interpretation.*

5.6.1 Social validity

As already stated in detail in Chapter Two schizophrenia was conceptualised as an essentially contested concept, and the subjects considered largely misunderstood. My own and Paddy's personal and professional *commitment* through engagement with the subjects and subject matter (schizophrenia) added to the *social validity* for understanding schizophrenia, as well as empowering the person(s) who owns these experiences (Yardley, 2000).

5.6.2 Reflexivity

Qualitative methods openly acknowledge the inherent subjectivity of gathering, analysing and making meaning of the data. In the current phenomenological, PAR framework, understanding and meaning-making, therefore, were purposely co-constructed. To "avoid an alienated mode of consciousness" (Heshusius, 1994, p. 15) that would separate the knower from the known, my primary focus, therefore, was on "connected knowing" (Belenky et al., 1986) to increase an "awareness of a deeper level of kinship between the knower and the known" (Heshusius, p. 16). This depended on me establishing an empathic human relationship with the research participants where emotionally "being with" or present superseded mere observation, creating a "holistic apprehension of reality as mutually co-evolving" (Heshusius, 1994, p. 20).

5.6.3 Adequacy of data

Erickson (1986) outlines five major types of evidentiary adequacy, including: (i) adequate amounts of evidence (ii) adequate variety in the types of evidence (iii) interpretative status of evidence (iv) adequate disconfirming evidence and (v) adequate discrepant case analysis.

5.6.3.1 Adequate amounts of evidence - rigour

In qualitative inquiry the actual number of participants is important, but not sufficient in assessing the adequacy of the evidence. Although no hard and fast rules exist "the situational diversity necessary for identifying thematic patterns is often provided by three to four interview transcripts" (Pollio et al., 1997, p. 51). Ultimately, however, the "validity, meaningfulness and insight generated...... have more to do with the information – richness and the observational/analytical capabilities of the researcher than with sample size" (Patton, 1990, p. 185). From this perspective the *rigour* of sampling procedures; quality, length and depth of interview data; and variety of evidence took precedence over the sample size (Yardley, 2000). The sample, therefore, was purposeful and criterion based selected by Paddy from the informal but close-knit service user/survivor movement/fraternity in Ireland. Respecting and foregrounding the study in the culture and context of the participants alongside identifying what were considered credible exemplars or "information rich cases" (Morrow, 2005, p. 255) maximised the descriptive richness and depth of the emerging data which was grounded in lived experience. Selection of participants by an "insider", Paddy, who endorsed the purpose and value

of the inquiry, instilled trust in the legitimacy and credibility of me as the "outside" investigator, "optimising the trustworthiness and truth value" of the data which emerged from the interviews (Morrow, 2005).

5.6.3.2 Adequate variety in types of evidence

To ensure a sufficient range of types of evidence, data was deliberately obtained from a variety of sources which included:

(i)   a selective, guided interrogation of the extant "grey literature" directed by Paddy (conducted by me) grounded in and focused on narrative accounts and personal testimonies of those either living with or recovering from a schizophrenia diagnosis. Contrary to the assertion that an *a priori* awareness or interrogation of the literature may narrow or cloud the inquiring lens and introduce bias (Glaser & Strauss, 1967), from a Heidegerrian perspective and in agreement with Morrow (2005) I believe "that investigators *always* believe something about the [thing] phenomenon in question and that a greater grounding in the literature mitigates bias by expanding the researcher's understanding of multiple ways of viewing the phenomenon" (p. 254)

(ii)   the respective "outsider" and "insider" perspectives of my own and Paddy's experiences

(iii)   the focused, in depth discourse between myself and Paddy

(iv)   the semi-structured interviews with the seven "credible exemplars"

It is considered that triangulation of these interrelated sources was sufficiently focused yet broad enough to provide an adequate range of data that enhanced the rigour, truth value, credibility and trustworthiness of the emergent evidence to challenge myths and raise consciousness.

5.6.3.3 Interpretative status of evidence

As with the adequacy of the data collected, the subsequent analysis depended on the transparency and trustworthiness of the interpretation and presentation of the data in a coherent way. The dialogical interviews included the preliminary in depth discourse between myself and Paddy juxtaposed with broad brushed themes which emerged from my interrogation of the extant narrative literature and personal testimonies of persons either living with or who had recovered from a schizophrenia diagnosis. This combination was used to construct an *a priori* deductive

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but open coding framework (Crabtree and Miller, 1999). The interpretation of the findings, balanced as well as highlighted the possible tension between the respective and divergent "outsider" and "insider" discourses of myself and Paddy, while equally balancing participants' "thick descriptions" of their context-bound interactional interpersonal experiences (Geertz, 1973, 1978) which either helped or hindered them in their personal recovery.

5.6.3.4 Adequate disconfirming evidence/discrepant cases

My own lived, learned experience and prolonged immersion of upwards of ten years in the "field" of the inquiry (Residential Therapeutic Community Alternatives) facilitated an affinity with the schizophrenia phenomenon which, it is argued, potentially adds to the coherence and interpretive status of the emergent evidence. However, this affinity could also have restricted my capacity to see possible disconfirming evidence or discrepant cases which could provide valuable information regarding interpretation of the evidence. To avoid this I used the emergent evidence to judiciously interrogate and where necessary revise my perceptions until they accurately reflected the lived experiences of the participants in a comprehensive, credible and meaningful way.

5.7 Paradigm specific validity

As well as the paradigmatically universal quality criterion framework outlined above, rigour was bound by the epistemological, ontological and axiological underpinnings specific to the prescribed discipline-method(s) of the inquiry (Morrow, 2005). The participatory action social phenomenological method falls between a post-positivist constructivist/interpretivist and postmodern critical ideology.

5.7.1 Constructivism

Guba and Lincoln (1994) argue that "the issue of quality criteria in constructivism is.... not well resolved and a further critique is needed" (p. 114). This prompted Morrow (2005) to expand interpretivist/constructivist criteria to include (i) the depth at which the meaning-making of participants is understood (*verstehen*; Ponterotto, 2005) and (ii) the degree to which meanings are co-constructed between collaborative inquirers and or participants. To a greater or lesser degree the former is related to Guba and Lincoln's (1989) *ontological authenticity* and the latter

to *educative authenticity*. However, in the context of an interpretivist/constructivist ideological framework, Morrow (2005) believes these criteria must go deeper to consider "*context*, *culture* and *rapport*" (p. 253). Notwithstanding the risk of blurring, confusing the boundaries between research and therapy (Haverkamp, 2005) for me as a research practitioner/inquirer *rapport*-building was a comparatively natural process. However, with this came the risk that I would focus blindly, exclusively on intra-psychic and interpersonal factors at the expense of the *context* and *culture*. In the current inquiry I protected "this sensitivity to context" (Yardley, 2000) by ensuring that the emergent data was "recontextualised" while considering the dual perspectives of the dominant "disease" bound psychiatric model and a post-psychiatry recovery oriented alternative grounded in the service user-survivor movement (Bracken & Thomas, 2005; Slade et al., 2014).

5.7.2 Postmodern critical inquiry

Postmodern, ideological and critical research purposely foregrounds the historical situatedness of the inquiry, highlighting the centrality of issues of power and oppression - and of particular importance to critical perspectives, the potential to create change – *catalytic authenticity* (Patton, 2002). In the current inquiry, increasing consciousness involved my identifying sources of inequality by representing the perspectives, "voices", of those who have been silenced or disempowered, while identifying who benefits from and how this power is exercised (Morrow, 2005). This seemingly altruistic act of representation would clearly benefit me which meant paying close attention to the power dynamics between myself, Paddy and the participants challenging a more formulaic approach to validity (Lather, 1994). As such the PAR framework was "neither anti-method nor antipositivism [but] a continuing conversation" (Kidd & Kral, 2005, p 190) between myself and the participants.

5.8 Ethical procedures

Ethical procedures around recruitment, sampling, collection of information, analysis of the data and writing up the findings adhered to the traditional ethical principles and values of the British Psychological Society (BPS; 2009, 2014b). Each potential participant received summary information outlining the rationale, aims and objectives of the research in an easy-to-read, user-friendly format (Appendix I). Consent was informed and written (Appendix II) with the proviso

that there was no obligation to participate and where refusal would not prejudice subsequent uptake of or right to services or future treatment. The identity of participants and information remained strictly confidential, subject to the legal requirements of the Data Protection Act 1998. The research procedure was considered non-invasive and the risk to prospective participants was considered low or minimal. However, if by participating in the study any of the participants became unduly distressed I was available to discuss and resolve any concerns that arose.

5.8.1 Ethics as process

An ethics as process model moves beyond bureaucratic regulation and the structures of conventional ethics committees (Ramcharan & Cutcliffe, 2001) to purposely consider how my individual decisions, actions, relationships and commitments as the research inquirer influenced the "trustworthiness" of the relationships with the participants which, evolved throughout the process of the inquiry (Haverkamp, 2005). In this fluid and dynamic process I remained open and reflexively attentive to "ethically important moments [events]" (Guillemin & Gillam, 2004, p. 262).

Relationality was primarily concerned with ensuring that the interests, rights and characteristics of the participants were self-defined and self-directed, alongside considering the context and system in which an ethical dilemma arose. *Subjectivity*, meant considering how my own personal biases or self-interests, not least my doctorate candidature could influence my decision making process or choice of action. Finally, *accountability* involved me taking ownership of and responsibility for the consequences of my actions, alongside correcting the potential adverse consequences of action/inaction and subsequent re-engagement with the decision making process should the ethical dilemma remain unresolved. From this perspective "ethically important moments" were pragmatically founded on so-called "virtue ethics" (Fisher, 2000; Kitchener, 1984, 2000) which, expanding on Aristotelian principles, argues that my ethical character as a researcher is gauged by the ethical choices I have made throughout my career (Meara et al., 1996). In other words, my "virtuous character is marked by the choice of virtuous actions" (Almond, 1998, p. 11) which, in turn underlies my readiness to and the likelihood of identifying "ethically important moments".

5.8.2 My ethical character

Subscribing to this ethics as process, participatory action framework created another inherent ethical dilemma. As a doctorate candidate it was imperative that I took ownership and clearly demonstrated the work was mine, while equally honouring the invaluable, unique and lived learned experience and knowledge of Paddy. This tension was easily resolved by awarding axiological equivalence, value and validity to each of our respective epistemological and ontological positions/assumptions. However, the truth was that I would be awarded a doctorate, advancing my professional status and credibility. In marked contrast Paddy would remain doctor-less, a diagnosed schizophrenic relentlessly challenging his diagnosis. It is hard to determine, therefore, to what extent my subjectivity as an aspiring doctoral candidate influenced how I may have protected or subjugated the interests, rights and characteristics of the participants,.

5.9 Procedure

5.9.1 *A priori* deductive framework

A theoretically-driven deductive, but open coding framework was developed from my selective, guided interrogation of the personal recovery oriented literature. The review was informed by the research objectives, purposely guided by Paddy and conducted by me to focus on and privilege the personal perspective and narrative accounts of credible exemplars, persons whose experiences were synonymous with either living with or recovering from a schizophrenia diagnosis. Articles, personal accounts and testimonies reviewed included; Allot et al. (2003), Chandler & Hayward (2009), Cohen (2005), Deegan (1994, 1996, 2001), Dilks (2010), Geekie (2004), Gottstein, (2003), Onken et al. (2006), Ridgway (2002), Romme et al. (2009).

5.9.2 Discursive dialogue between myself and Paddy

As a precursor to conducting individual interviews with the participants (see below) I and Paddy engaged in a 90 minute in-depth discursive dialogue, drawing on each of our experiences of living and working with schizophrenia. In an attempt to "bracket off", suspend or at least interrogate our preconceived ideas about the phenomenon, we focused on identifying concrete and thick descriptions grounded in each of our lived situational experiences (Wertz, 2005). We, focused on pinpointing and describing interpersonal and context bound situational experiences

with significant others which we felt had either helped or hindered Paddy and others to live with or recover from a schizophrenia diagnosis. The discourse was digitally recorded and transcribed by me.

5.9.3 Credible exemplars

The participants were purposely recruited from a cohort of "credible exemplars" whose lived, learned experiences provided a unique, revelatory and authentic relationship with the subject matter of "schizophrenia". These included me, Paddy and seven credible exemplars from the service-user survivor community in Ireland who were either living with or who had recovered from a schizophrenia diagnosis. Prospective participants for the inquiry were purposely identified by Paddy who had an open and unrestricted gateway into the diverse, obscure and somewhat clandestine network of user-led survivor organisations throughout Ireland, predicated on the idea that the research should and would directly benefit and empower the participants (Fuente, 2004). This notion of beneficence – non maleficence challenges the conventional wisdom of objectivity and neutrality, which is ensconced in traditional positivist methods (Haverkamp, 2005). In this process relationality was actively encouraged and I did not see the participants as examples of "universal categories", that is schizophrenics who needed to be paternalistically over-protected by applying rigid universal risk-averse principles ethical or otherwise. However, I did remain sensitive and responsive to the context (Haverkamp, 2005) of interviewing the participants about their experiences to mitigate the potential for re-traumatisation, a so-called ethics of care (Fisher, 2000). Participants were invited to talk openly and at depth illuminating the rich relationality and emotionality of their lived experiences. However, this was done and contained within a window of tolerance (Ogden et al., 2006) mindfully attending to and co-regulating vehement emotions in context to enable participants to meaningfully recall their experiences but without intrusively, vividly re-living them and where necessary grounding them in the here and now relationship with me. Notwithstanding the latter when reflecting on and checking in with each participant at the end of the interview all but one reported they found talking about their experiences helpful-beneficial. For the one exception who was especially guarded and difficult to engage I followed up with their key-worker who was in attendance on the day of the interview. All of the participants were also given my telephone

number with instruction to contact me if subsequently they became distressed following the interview.

Prospective participants were sent a letter (Appendix I) explaining the rationale, aims and objectives of the collaborative inquiry in everyday language and inviting them to participate in a semi-structured interview with me.

The discursive dialogical exchange between me and Paddy, along with one of the interviews with Sean took place in Paddy's home. The remaining six interviews were conducted over the course of two days in a Mental Health Recovery Resource Centre in Castleblaney, Ireland.

Participants – credible exemplars
With the exception of Paddy to protect the anonymity of the participants pseudonyms are used.

Paddy
Collaborative inquirer and co-participant, diagnosed paranoid schizophrenic (see section 2.1.1)

Sean
Sean was a single white Male of Irish origin in his early forties. He reported prodromal symptoms for some seven years leading up to what he described as his "first break" aged 24 – 25 manifest by hearing derogatory, persecutory "voices" commenting, eliciting fear and paranoia and precipitating his being detained in hospital for 6 months. Thereafter he was diagnosed with schizophrenia and experienced several subsequent psychotic episodes, admissions to hospital, where the primary treatment of choice was maintenance neuroleptic medication.

Aedan
Aedan was a single thirty-nine year old white Irish male. He reported his first "breakdown" aged twenty-one while studying at University in the UK. Following a fracas with his housemates the police were called to the scene, whereupon they handcuffed and took him into custody. Subsequently, he was detained in a UK psychiatric hospital before being transferred to hospital in Ireland. He was diagnosed with schizophrenia where indicative symptoms included

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suspiciousness, paranoia and hearing voices which he attributed to a religious experience of "channelling" or "conversing" with the dead. The primary treatment of choice was maintenance neuroleptic medication.

Aisling

Aisling was a thirty one year old white married female of Irish origin. She reported the sudden onset of her first "psychotic break" aged nineteen following the acrimonious breakdown of a relationship. This precipitated involuntary admission to psychiatric hospital and a preliminary diagnosis of schizophrenia – schizoaffective disorder manifest by extreme "highs and lows, fear, paranoia" and hearing voices co-existing with what she described as an intensely terrifying and exhilarating depersonalisation – derealisation experience of "being joined to the sky" which she attributed to a "spiritual experience of grieving for the world". She reported several subsequent episodes, including one in Thailand necessitating voluntary and involuntary admissions to a psychiatric hospital. The primary treatment of choice was maintenance neuroleptic medication.

Gerard

Gerard was a single white male of Irish origin. He reported the onset of his "schizophrenia" aged twenty two while studying at University in the UK, manifest by hearing derogatory, defamatory voices through the walls, compounded by self- loathing and paranoia which precipitated an involuntary admission to a psychiatric hospital for some 5 weeks. He also reported several subsequent "breakdowns" manifested primarily as anxiety, depression and suicidal ideation, intent which precipitated further voluntary as well as involuntary admissions to hospital. On reflection, he attributes his psychotic experiences to sustained bullying and one particularly violent and humiliating assault during his adolescence where the voices were a representation of these childhood "bullies" and the later abrasive and "aggressive" housemates at University. Primary treatment was "aggressive" psychopharmacological medication which included various combinations of antidepressants, anxiolytics and maintenance neuroleptics alongside ECT which he experienced as ineffectual and unhelpful. At the time of the interview he had successfully completed a program to withdraw from medication and he was currently medication free.

Odran

Odran was a white, single Irish male in his mid-twenties. He reported the sudden onset of hearing persecutory voices aged 18, commenting and telling him "people [were] out to harm – kill him" because he was "wrong to people". He was hospitalised aged 18 and detained for some two years and remains under the care of statutory psychiatric services residing in supported flatlet accommodation adjacent to and part of the local psychiatric hospital, returning to the family home most week-ends. His persecutory voices and paranoia remain resistant to neuroleptic medication of which he says "if they were helping me, I'd be well by now." Because of his "sickness" he reported being "terrified that he will be harmed by or harm someone". He shows an extreme suspiciousness and social withdrawal, avoidance where even "think[ing] about people [makes] him terrified", compounded by the fear that his intentions will be misunderstood because he "can't get over with the mind, speaking to people. That people don't know what [he's] talking about" while equally feeling "people [like me are intrusively] making [him] talk". In the interview with myself this led to especially guarded, monosyllabic responses "yes, no, I don't know", eliciting an ill-fated interrogatory response which led to further defensive withdrawal and precipitated an unplanned, premature ending. An enactment, in this instance, of my insensitivity towards the sensitive or so-called difficult-to-engage client.

Ciara

Ciara was a thirty-year-old white female of Irish origin. She reported a perceived "normal" family upbringing, but elaborated stating her father was physically abusive, and her mother and father had a co-dependent dependency on alcohol. She also reported being "sexually molested" aged eleven by a female team leader, which precipitated the onset of deliberate self-harming behaviours cutting, alcohol substance abuse, and hitherto uncharacteristic risk-taking behaviour as a way of "get [ting] out of [her] head". This disrupting-disruptive behaviour continued into adolescence where she reported being "drug raped" aged fourteen, which precipitated an overdose aged fifteen. Subsequently, between the ages of seventeen and eighteen she became enmeshed in a sexually violent abusive relationship. She was hospitalised aged eighteen, the first of several subsequent voluntary and involuntary admissions throughout her twenties. Finally she reported being "forced to have an abortion" aged twenty one. She attributes the onset of her difficulties to age eleven when she noted a change in the way she felt following being sexually

molested. Subsequently, she was diagnosed with depression, obsessive compulsive disorder, schizo-affective disorder and more recently bi-polar disorder. She reports hearing negative, derogatory and persecutory voices, "internal and external dialogue" commenting, "conversing…. You're fucking bullshit, you're full of shit"… You're fucking disgusting." She was previously involved with Child and Adolescent Psychological Therapy Services and also attended adult statutory as well as private psychotherapy/psychology services often adjunctively with psychopharmacological treatment which has included minor (anxiolytic) as well as major tranquillisers (neuroleptics) and anti-depressants. At the time of the interview she reported being medication free.

Maeve

Maeve was a forty two year old white female brought up in and of South African Origin. She experienced an acrimonious "traumatic" breakdown of her marriage of some thirteen years, and reflected that while her spouse who disclosed he was gay was not physically aggressive he was verbally threatening, emotionally abusive and controlling. Following the break-up and in advance of her breakdown, she became "estranged from [her] eleven year old son" who did not want to see her and who was staying with her then husband. This saw her temporarily homeless and without finance. She reported being unable to sleep or eat for several days leading into what was described as a "psychotic moment", manifest by hearing command auditory hallucinations, voices from the radio, offering conflicted messages, do/don't do this, and instructing her to follow her "three legged cat" otherwise the "Garda would come and get her". Dressed in night attire she followed the cat to an adjacent third floor apartment where the voices told her a couple were abusing children, whereupon she retrieved plates from a nearby bin which she threw, smashed against the door of the apartment. Upon opening the door, she confronted a bemused elderly couple "screaming and shouting" at them and demanded entry to the apartment. The Garda were called and she was taken to and detained in hospital in a "padded cell" where she remained for ten days before being released to a day hospital which she attended for three days a week as an outpatient. The primary treatment of choice was neuroleptic medication. There were no episodes either before or after this so-called psychotic moment, which she believes was stress- induced and retrospectively believes the accusatory command voices and delusional ideas

where a representation of her context bound situation, a husband who constantly threatened to call the Garda when she tried to gain access and demanded to see her estranged son.

6. Data analysis

6.1. The analytic method

The method of analysis was grounded in a hybrid approach of qualitative methods of thematic analysis (Fereday & Muir – Cochrane, 2006) which assimilated and accommodated an a priori open and fluid deductive framework (Crabtree & Miller, 1999) with a data driven inductive approach (Boyatzis, 1998). This enabled the principles of the participatory action phenomenological framework to be integral to the process of deductive thematic analysis, while allowing themes to emerge from the interview data using inductive coding. This reflexive and iterative process involved making meaning of the way the participant made meaning of their world alongside generating second or higher order interpretive understanding of the phenomenon of the inquiry (Schutz, 1967).

Figure 1. Sequential steps of data collection and analysis
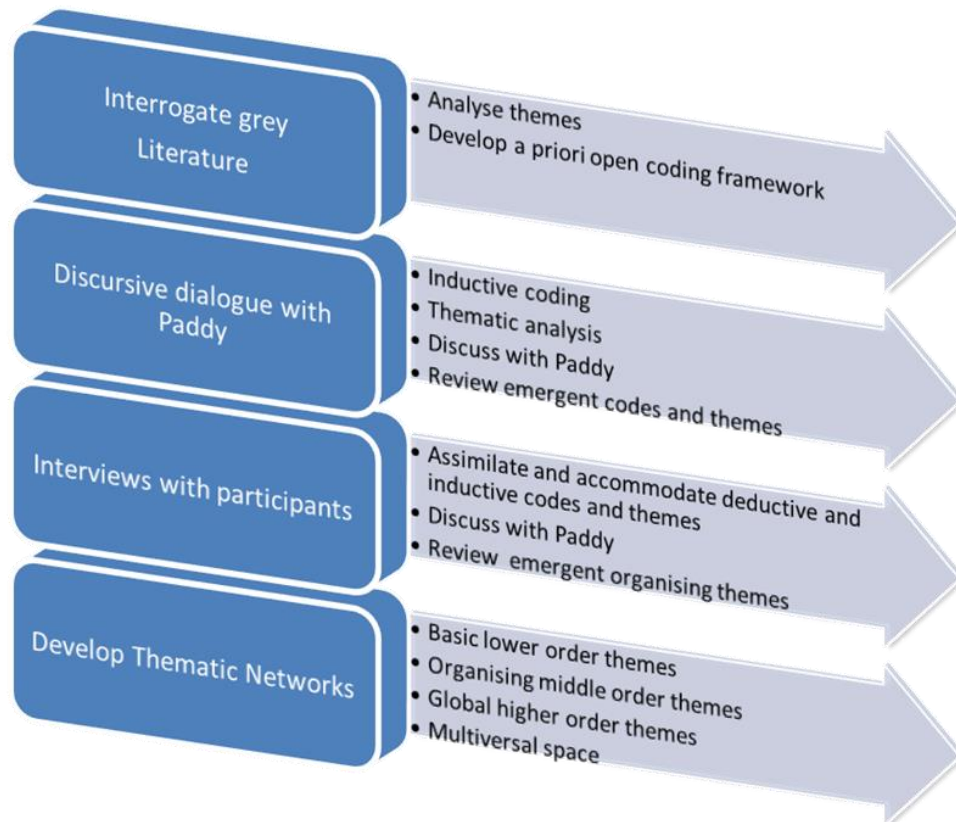
6.1.1. Stage 1: The *a priori* coding framework

Overarching themes were drawn from my interrogation of the selected extant "grey" [recovery] literature already referenced. The analytic method, macro thematic analysis was conducted within the theoretical parameters of the research question, aims and objectives sufficiently specific to identify broad and loosely defined categories which either helped or hindered living with or recovering from a schizophrenia diagnosis but open and semi-permeable to allow new or salient categories to emerge.

I wrote the codes for the open coding framework according to the procedure outlined by Boyatzis (1998) and identified by:

1. A code label or name which incorporated a keyword or short phrase that held implicit meaning, but which did not necessarily reflect the specific features of the overall category.
2. A broad definition of what the category concerned, and
3. A thick description of the meaning of the code which outlined defining characteristics and parameters that specified the scope, limitations and how to know when the category occurred.

I developed the a priori coding framework independently and in advance of my in depth discourse with Paddy and each of the seven research participants.

6.1.2 Thematic analysis

6.1.2.1 Discursive dialogue between myself and Paddy

Firstly Paddy and I listened to the 90 minute digital recording of our in-depth discursive dialogue independently to familiarise ourselves with the contours of the raw data and as far as possible suspend a distinctive research focus to gather and grasp our own and each other's language, expressions and meaning (Giorgi & Giorgi, 2003).The interview-dialogue was subsequently transcribed by myself. Henceforth, we both read and re-read the transcript independently in an iterative way empathically coperforming involvement in each of our respective "inside-out" and "outside-in" lived situations with the phenomenon of schizophrenia.

Henceforth I read, re-read the transcript at depth applying my a priori framework to organise the text while writing newly emergent key words/codes in the margins to open up the framework, "horizontally" grouping segments of texts by basic themes using first person contextual descriptions to extract and demarcate (cutting and pasting) organising themes or "meaning units" and eliminating redundant information which did not contribute to the meaning of the description (Wertz, 2005). This reflective, intuitive process involved moving dynamically, recursively from basic theme to organising theme and from organising theme to whole narrative in an attempt to both verify and identify counter-instances of the structural organisation as well as the possible interdependence of the themes as they emerged (Wertz, 2005). At this point I came together with Paddy to discuss and reflect on the emergent basic themes and organising themes.

6.1.2.2 Discourse with credible exemplars

I listened to each of the digital recordings, read and re-read the transcripts of each of the seven interviews immersing myself in the data "unconscious[ly] as well as consciously process[ing] the information" (Boyatzis, 1998, p. 45). I summarised each transcript separately, making notes in the margins of each page to tentatively identify preliminary codes as they emerged. Henceforth, I systematically applied the hybrid inductive-deductive process to manage, dissect and organise the text from each of the interview transcripts to reflect salient themes based on "description thick" relational, context bound experiences (Giorgi & Giorgi, 2003) which participants felt had consistently "helped "or "hindered" them in living with or recovering from a schizophrenia diagnosis. My analysis of each of the transcribed texts was fluid, open to and opening up further interpretation, guided, but not confined by the emergent basic themes, organising and global themes. I assigned newly emerging inductively driven codes to segments of the text which described a new theme not already in and distinctive from the thematic framework (Boyatzis, 1998). These additional basic themes either expanded or elaborated on the existing organising themes or remained distinct and generated a separate and unique inductive data driven theme which was assimilated into the refined organising themes and thematic network(s) which I subsequently applied to the text. This osmotic process involved me moving from the individualised yet perceptually distinct personal experiences and micro meaning making "truths" of myself, Paddy and each of the seven participants while reflecting on and against the macro meaning levels of general "truths" and global themes as they emerged. This helped me identify,

integrate and synthesise truths which were neither completely idiosyncratic nor universal regarded as the most meaningful and credible typologies of knowledge (Wertz, 2005).

6.1.2.3 Verification

At this advanced stage of the analysis I came together with Paddy to reflect on and consider if the themes generated from the data driven inductive process accessed and adequately "grasped" the implicit dimensions of the totality of our respective relational and context bound experience of living/working with (and in Paddy's case recovering from) schizophrenia. Inevitably, because myself and Paddy would "adopt different perspectives and pose different questions to the same text [phenomenon] we would come up with different interpretations" (Kvale, 1996, p. 212). The purpose was not, therefore, to establish inter-rater reliability between our respective outside – in and inside out perspectives, but to open up a reflexive dialogue which would elaborate meaning privileging "perspectival subjectivity" over "biased subjectivity" to avoid (as in the Dr – patient dyad) selective interpretation (Haverkamp, 2005) of the schizophrenic subject and subject matter of schizophrenia.

6.1.3 Thematic networks

At this stage of the thematic analysis the themes were gathered to discover patterns in the data (Crabtree & Millar, 1999) aided and illustrated by the use of thematic networks, which organised the data around and depicted the relationships between (i) the lower order text driven *basic themes* (ii) categories of themes clustered to summarise more abstract or *organising themes* and (iii) higher order global or overarching themes which captured the main metaphorical tenets of the text as a whole. Each of the thematic networks were dichotomised by central or global themes which had either *helped* or *hindered* the participants personal recovery.

Finally, I returned to and re-read the original transcribed text (interview material) through the lens of the global, organising and basic themes of each of the respective thematic networks, systematically (i) describing the content, grounded in and supported by description thick text exerts, quotes and (ii) exploring and explicating emergent patterns which elaborated meaning, illustrated and contextualised by specific examples. Each of the previous stages were critically scrutinised to ensure that the basic, organising and global themes accurately represented the

initial raw data, iteratively moving between text and each of the thematic networks. Finally, principal themes and distinctive patterns were abstracted, summarised and synthesised to formulate an overarching and coherent explanatory framework with reference to the research question, interrelated underlying theoretical interests as well my own and Paddy's engagement with the schizophrenia phenomenon.

7. Findings

7.1 A *priori* deductive framework

My initial interrogation of the selective testimonies and narrative accounts of individuals who had lived with and personally recovered from a diagnosis of schizophrenia (as with Paddy) identified four generic superordinate categories. These included (i) attitude towards illness (ii) authenticity (iii) inter-subjectivity and (iv) interpersonal relational ambivalence each discriminated by what had *helped* and what had *hindered* them in their personal recovery. The templates for each of the four broad categories are represented in Tables 1a. – 4a. What *helped*, and Tables 1b. – 4b. What *hindered*.

7.1.1 First category - attitude towards "illness"

Table 1a. Coding framework for attitude towards illness – what helped?

Code 1	
Label	Conceptual framework
Definition	The primary threat to relationship building is the therapists beliefs and assumptions about and attitude towards the "illness"
Description	Schizophrenia is regarded as an essentially contested concept and experiences synonymous with the diagnosis are understandable and personally meaningful in the context of the idiosyncratic life experience of the person owning and living with the experience.
Code 2	
Label	Needs adapted treatment
Definition	Treat the person, not the illness
Description	A non-prescriptive/non paternalistic, person centred collaborative approach which adapts to the self-identified needs of the client.
Code 3	
Label	Prognosis
Definition	Recovery oriented, focused on capacity to function, enablement and quality of life.
Description	Challenges negative, illness saturated stereotypes and misconceived myths recovery is personal, self-defined and self-directed.

Table 1b. Coding framework for attitude towards illness – what hindered?

Code 1

Label	De-contextualised conceptual framework
Definition	A reductionist medicalization of "symptoms" and behaviours.
Description	Experiences are de-contextualised, viewed as pathological, disease bound, illness saturated and personally meaningless and with little regard for or interest in the unique lived experience of the client.

Code 2

Label	Prescriptive treatment, medical or otherwise.
Definition	Paternalistic, professionally directed, impersonal and inflexible.
Description	Maintenance based, primarily focused on symptom management and compliance, noncompliance/responsiveness is indicative of treatment resistance, overly risk adverse (unsafe certainty) which inhibits autonomy and independence.

Code 3

Label	Prognosis poor, unrecoverable
Definition	Negative and misconceived stereotypes and myths about recovery.
Description	Overly and unduly pessimistic attitude to "it" schizophrenia, which is viewed as a lifelong chronic and debilitating illness.

7.1.2 Second category authenticity

Table 2a. Coding framework for authenticity– what helped?

Code 1

Label	Authentic
Definition	Validates and takes seriously the unique lived experience of the client.
Description	An ordinary way of relating, being emotionally present and involved "with" and conveying an understanding of the emotional and relational impact of the subjective experiences of the client.

Code 2

Label	Meaning - making
Definition	Making meaning of the way the client makes meaning of and constructs their world.
Description	Open minded and genuine engagement with and tolerance for non-consensual experiences which may disconcert those of the listener.

Code 1	
Label	Inauthentic
Definition	Patronising and haphazardly ridicules or contemptuously dismissive of the subjective lived experience of the client.
Description	Authoritarian, emotionally uninvolved and detached, conveys no interest in or genuine understanding of the subjective lived experience of the client, relates to the "it" illness.
Code 2	
Label	De-meaning making
Definition	No interest in metaphor or making meaning of the way the client makes meaning of or constructs their world.
Description	Disconcerted by non-consensual experiences, coercively imposes a rigid preconceived conceptual framework on experiences synonymous with a diagnosis of schizophrenia.

7.1.3 Third category - inter-subjectivity

Table 3a. Coding framework for inter-subjectivity – what helped?

Code 1	
Label	Real, ego - supportive
Definition	A dependable, non-paternalistic relationship focused on finding solutions to everyday life situations as they emerge.
Description	A reliable, unambiguous, pragmatic, reality based and solution focused relationship with built in flexibility to agree on and take measured calculated risks, which promote independence.
Code 2	
Label	Working alliance.
Definition	A collaborative and co-created affective interpersonal bond.
Description	A robust person centred relationship founded on empathic, co-created engagement and a reasonable willingness to work purposefully towards self-defined treatment goals and tasks.
Code 3	
Label	Representational subject – subject.
Definition	Tolerating the uncertainty of not knowing, validating and openly collaborating with experiential worlds that may disconcert your own.
Description	Convey an understanding of the terror of traumatic existential experiences, whether real or non-consensual/imagined and be aware of and accept what you represent in the mind of the other. Survive deadness, tolerate hating and terror and don't be afraid to get it wrong.

Table 3b. Coding framework for inter-subjectivity – what hindered?

Code 1

Label	Ego – suppressive.
Definition	An unreliable, "ill" defined and ambiguous relational style with the primary focus on identifying problems.
Description	An unpredictable, inflexible and impractical attitude to over-coming problems manifest by overprotective intrusiveness and extreme risk adverse guardedness which restricts independence and autonomy.

Code 2

Label	Unhealthy, dysfunctional alliance.
Definition	Anti-collaborative, problem centred and de-personalised.
Description	A fragile, asymmetrical depersonalised relationship founded on disciplinary – professional power and a resistance to work purposefully towards mutually agreed goals.

Code 3

Label	Object- subject.
Definition	Intolerant of not knowing and being known.
Description	Unwillingness to validate and openly collaborate with representational – disconcerting experiential worlds. Unable to convey a genuine understanding of the existential terror of overwhelming traumatic experiences. Risk adverse fear of making mistakes, compounding and compounded by a defensive over reliance on rigid theoretical or psycho-technological presuppositions.

7.1.4 Fourth category - relational ambivalence

Table 4a. Coding framework for interpersonal relational ambivalence– what helped?

Code 1

Label	Relational ambivalence.
Definition	Sensitivity and responsiveness to a powerful conflicted ambivalence for establishing trustworthy relationships.
Description	Awareness of the latent longing for authentic emotional engagement co-existing with emotional distancing manifest by an incapacity for and fear of closeness-merger, but equally co-existing with a desire to be fully understood through a meeting of minds.

Table 4b. Coding framework for interpersonal relational ambivalence– what hindered?

Code 1	
Label	Relational rigidity.
Definition	Insensitive and unresponsive to the conflicted ambivalence of establishing and maintaining adaptive mutually dependent interpersonal relationships.
Description	Unable to adapt to dialectical relationship patterns-styles manifest by a paradoxical and confusing longing for, but avoidance of closeness, juxtaposed with an explicit-implicit fear of either merger and or rejection, abandonment.

7.2 Hybrid thematic analysis and global themes

The integration of the *a priori* deductive coding frameworks outlined above with the data induced themes which emerged from the thematic analysis of 367 pages of transcribed text derived from my exchange with Paddy and the subsequent interviews with the seven participants generated a total of sixty three codes or basic themes. These basic themes, twenty eight and thirty five respectively, for what *helped* and *hindered* converged and were clustered around the issues discussed to formulate basic lower order themes ten of which *helped* (Appendix IIIA, Table 1a.) and eleven, which *hindered* (Appendix IIIb, Table 1b.). These lower order themes became the building blocks or meaning units for middle order or organising themes which summarised the principal assumptions of distinctive groups of basic themes while abstracting and revealing a deeper level of meaning from the discursive text.

Subsequently, these middle order organising themes became the foundation for a total of three Global super-ordinate themes, Context, Meaning Making and Identity Formation, Interpersonal Relationships and Organisational Culture. Together, these three themes encompassed the principal metaphors in the data as a whole, discriminated by what *helped* (Appendix IVa, Table 2a.) and *hindered* (Appendix IVb, Table 2b.) in living with and recovering from a schizophrenia diagnosis. The basic themes, grouped by organising themes and each of the overarching global themes are configured and illustrated using thematic networks to emphasise the dynamic interrelatedness of the respective constituent elements of each.

7.3 Overall multiversal space

This meta-perspectival space reflected the interdependency between the three global themes Context, Meaning Making and Identity Formation, Interpersonal Relationships and Organisational Culture - Systems which together represent an intersubjective, contested and co-created contextual, relational and organisational space which can either help (Figure 2a.) or hinder (Figure 2b.) personal recovery.

Figure 2a. Multiversal intersubjective space which helped personal recovery
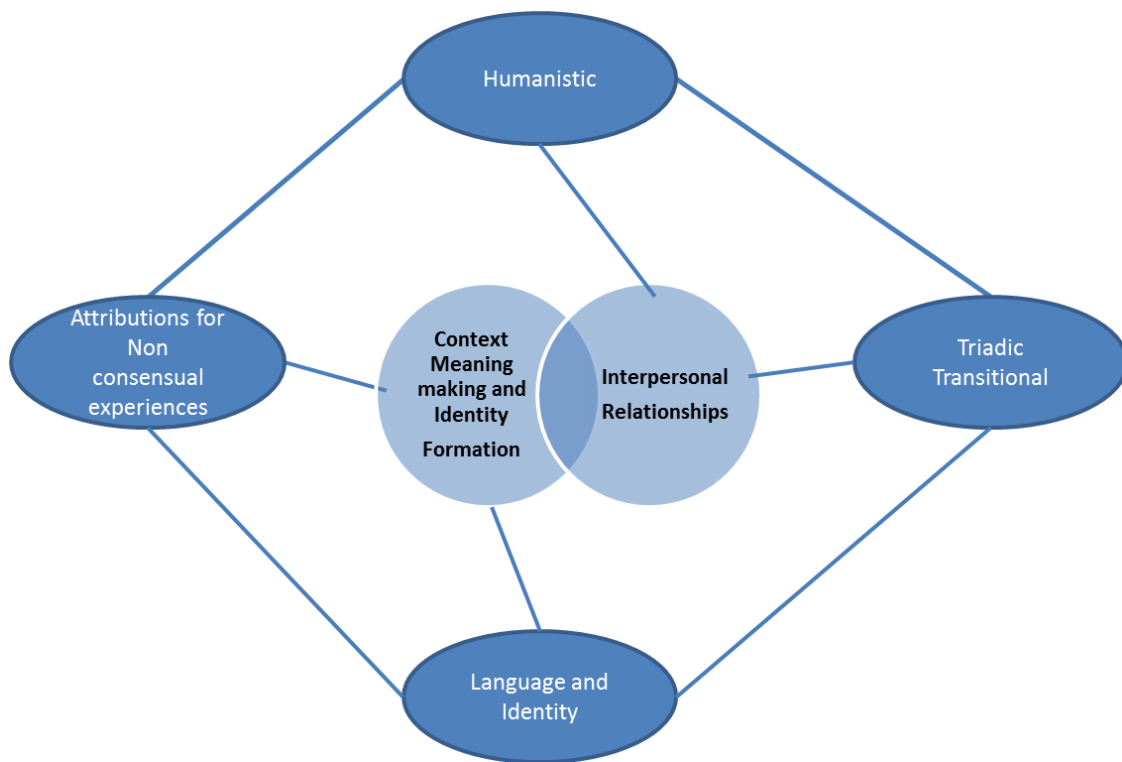
Figure 2b. Multiversal intersubjective space which hindered personal recovery
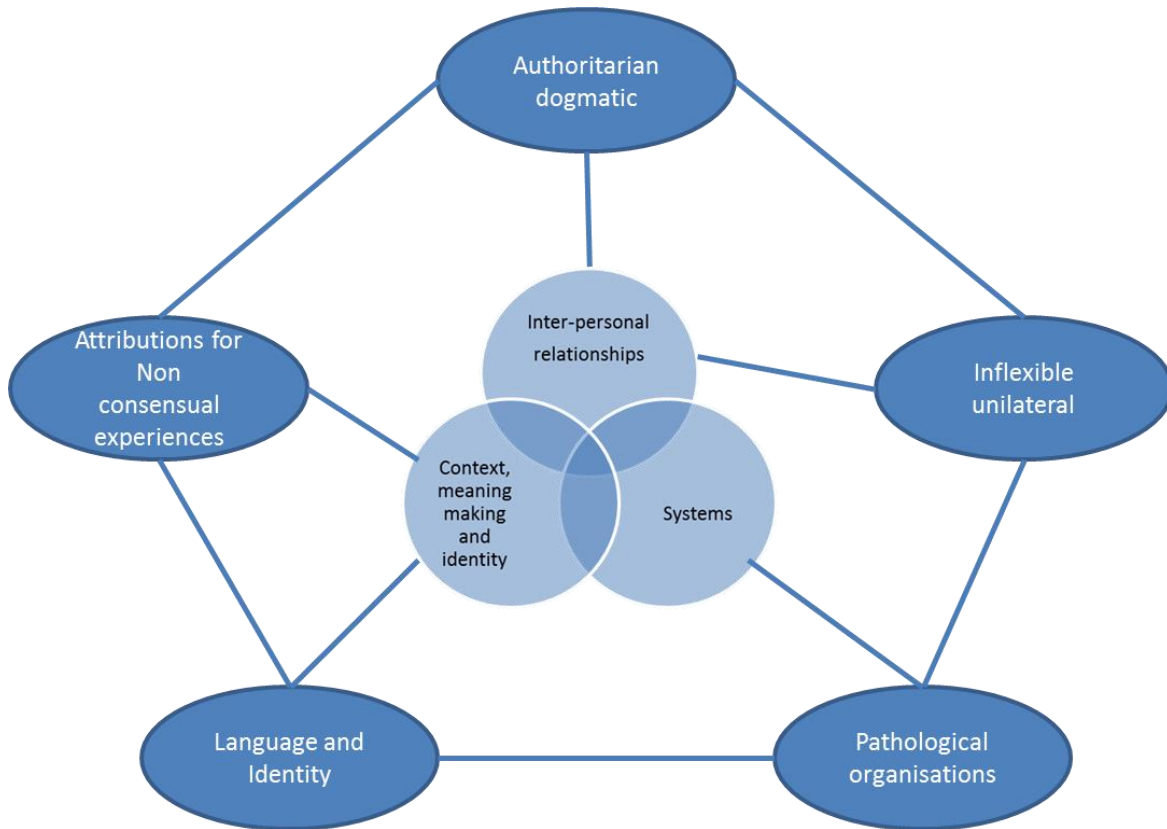
7.4 Theme one - Context, meaning making and identity formation (Helped)

The first global theme *context*, *meaning making* and *identity formation* assimilated and expanded on the a priori deductively derived category of attitude towards illness. It describes how the context in which in particular "voice" hearing and other non-consensual experiences occur, the subsequent meaning attributed to and self-other identification with these experiences synergistically interact through language to forge or coperform identity. Descriptions of what participants found helped were structured according to two organising themes, attributions for non-consensual illness experiences and language and identity (Figure 3a.)

Figure 3a. Thematic network for context, meaning making and identity formation- *helped*

Getting my own interpretation, non reductionist , idiosyncratic frame work to understand experiences.

It happened for a reason experiences are personally meaningful and understandable in the context of lived experience.

Attribution for Non consensual "illness" experience

CONTEXT MEANING MAKING AND IDENTITY FORMATION

Language and identity

More than the diagnosis the diagnosis is "ill" defined and doesn't define the person, misconceived illness saturated stereotypes are challenged

No sort of gooble de gook Identity is forged in iterative interaction using normal everyday language.

7.4.1 Attributions for non-consensual illness experience (helped)

This theme reflected the benefit participants attributed to mental health professionals, family and friends being open to seeing and exploring their voice hearing and other non-consensual experiences as personally meaningful in the context of their unique lived experience.

7.4.1.1 It happened for a reason

Paddy attributed the sudden onset of his first voice hearing experience aged fourteen to the sudden death, loss of what for him was a significant and foundational attachment figure, his grandmother.

It was just bang (claps hands together) one minute there is nothing there everything is going along as if it was the way it's supposed to be and all of a sudden this addition, this thing arrives and it happened to be a voice

The context was that it was of grief so that was the first time I heard the voice but and that…. So that voice carried on

The voice that I heard was definitely hers and still is hers, initially I didn't know it to be hers because I thought she was dead, buried, gone…. so therefore it couldn't be her, but it makes sense that it's her

All but one of the participants identified one or more significant adverse life experiences as having contributed to the onset of their difficulties. Aisling alluded to the grief bound nature of her "psychotic" episodes.

For me it happened for a reason, I see my psychosis as a spiritual enlightening or emergency. Maybe I was grieving for the world, that's what it felt like

Gerard related the onset of his aggressive voices to being bullied, which provoked and was provoked by earlier traumatic memories of being severely bullied as a child.

I moved into a house and I had a lot of bullying there, really, and obviously a traumatic memory, which sort of, provoked me internally and I was very afraid of what people thought about me…

I'd be afraid my mind was crazy. After a while I woke up one morning and I started hearing voices through the walls, so it was an aggressive guy and then a less aggressive guy and then a girl who was trying to hold them back.

Finally, Ciara noted a direct relationship between being sexually molested during and through early adolescence and the onset of her symptoms.

The main problem for me. When I was eleven, I went through a traumatic experience of being molested sexually.

7.4.1.2 Getting my own interpretation

For Paddy and each of the seven participants, there was a context which made sense of their non-consensual, hitherto nonsensical symptomatic voice hearing and other experiences. Likewise, all of the participants noted how this reframing of their experiences helped to normalise what hitherto were regarded as unfalsifiable evidence of an illness which in turn lessened the confusion, fear and distress associated with the thought that they were mad. For Paddy the voice of his grandmother became and continues as a lifelong, consoling companion which brought and brings him comfort not persecution.

When she speaks it's her in every sense of, the way, ah… the tone everything is exactly the sort of conversations, the advice that is exactly how she was when she was alive, that end of it……. that end of it hasn't changed,

Aisling viewed her experiences as a spiritual and enlightening process of working through and letting go, something which she believes was a pivotal, huge aspect of her personal recovery.

The way I was grieving and the way I was letting go of things in my episodes, like smoking a cigarette after something big had just happened… I think that's a huge aspect of me moving on, is seeing it differently than other people, getting my own interpretation and my own meaning out of it.

Gerard noted how by identifying and making meaning of the context of his voices ultimately helped them to go away.

I identified the voice as one of the people I live with, G, I'd met two of his friends another time, so it looks like two or three of the others [voices] were there, but for me I'd say that [context] helped the voices to go away.

Likewise, Maeve reported how retrospectively she viewed her experiences as a normal reaction to an abnormal situation, the acrimonious breakdown of an emotionally abusive marriage

I am calling it a reaction, a normal reaction to an abnormal situation

Finally, Sean commented on how his Shaman friend helped him to reframe his experience as normal and creative which brought a more acquiescent, peaceful state of mind.

Put a creative label on it or put a different aspect on to what happened. I wanted to put some framework on this. I knew it wasn't this bipolar or schizoaffective disorder, or whatever they're calling it lately. I knew it wasn't that, it's normal, whatever normal is, but peaceful maybe.

7.4.2 Language and identity (helped)

7.4.2.1 More than the diagnosis

This theme reflects how significant others in challenging the misconceived illness saturated de-meaning "schizophrenic" identity using ordinary, destigmatising and empowering language helped to affirm their personhood to promote resilience, wellbeing and recovery.

Paddy commented on how his interactions with Edna a peer advocate with lived experience helped him to challenge his schizophrenic identity

When I would refer to myself as being schizophrenic, she would say that I wasn't, in many ways she was arrogantly ah saying that the label of schizophrenia doesn't exist and for me to accept and allow myself to be classified as a schizophrenic was demeaning myself and for me…. she always said that you are more than the diagnosis you know.

She was almost saying to me was well you have the choice you can either stay and hold onto that fucking label that you cherish or you can say to yourself fuck maybe there is something else and start to disband and dismantle the label that's there and start to look for something else.

Sean spoke to how his therapist challenged his diagnosis, which for him created an impetus to get well, instilling hope and a sense that recovery was possible, while also highlighting the importance of his brother creating an alternative normal identity which challenged his negative illness stereotype.

My therapist said, "I never believed you had schizophrenia. It's a bullshit diagnosis." I don't know how much longer I could have kept going on, you know, I said, I'm going to beat this fully.

Stephen. just didn't say the negatives. He wasn't focused on what you're not.

7.4.2.2 No sort of gobbledegook

Paddy and other participants commented on the pivotal role normal language played in helping them to communicate, construct, deconstruct and reconstruct what at times was a conflicted and confused identity.

She spoke to me in very normal language, there was no sort of gobbledegook for want of a better way of describing it ah, she seemed no she knew where I was coming from, the difference with her was that I could talk the way I wanted to talk, communicate and articulate the way I needed to articulate and she understood and if she didn't understand she asked me.

Sean described a helpful interaction with his GP who demystified the diagnosis using normal language.

"Look, it is just terminology, it is just a word." That really helped me a lot.

Likewise, Maeve spoke about the benefit of professionals simply listening and communicating using ordinary, normal language.

I just spoke and she just listened really. It probably helped me normalise things in my own head.

Finally, several participants noted how peer advocates, by understanding the language, could act as interpreters between professionals and service users.

Advocates, they understand the language, they understand where it goes, where it's been.

Theme one - context, meaning making and identity formation (hindered)

7.4.3 Attributions of non-consensual illness experience

In contrast, when non-consensual voice hearing and other experiences were decontextualized, detached from participants' lived experience and labelled by others as pathologically meaningless using diagnostic language, participants were left feeling detached, demeaned and demoralised. Descriptions of what hindered were structured according to two organising themes (Figure 3b.)

Figure 3b. Thematic network for context, meaning making and identity formation - *hindered*

Your fucking sick – experiences are illness saturated

What was going on?
experiences are de-contextualised, divorced from lived experience and meaningless.

Attributions for non consensual "illness" experience

CONTEXT MEANING MAKING AND IDENTITY FORMATION

Language and identity

My trade was to be mad
The diagnosis of schizophrenia defines the totality of the "schizophrenic"

Code word and mumbo jumbo
Schizophrenic identity is forged in iterative interaction using pathological language.

7.4.3.1 What was going on?

Paddy and several participants described how the decontextualized, misconceived and typically hostile abreaction of family members and significant others accentuated their fear, paranoia and confusion

Paddy recalled the brutal and frightening reaction of his schoolteacher to disclosing he was hearing a "voice".

Nobody had given me any context other than this was not a normal experience, people do not normally experience hearing voices or seeing things or anything like that so this was an illness, the teacher he wasn't laughing…. like it was only his reaction to me that actually scared me and made me start to think that there was something wrong.

Ciara spoke about the disconcerting hostile and fear inducing reaction of her sister to her becoming "ill".

When I first became ill, she roared at me in the hospital, "You're fucking sick". I was like, "I'm not". I was 19 years of age going what was she on about? I was scared from hearing that.

Aisling recalled being equally traumatised and frightened by the suddenness and confusion of her experience, confined in a hospital room without any explanation as to what was happening.

It was initially just a bang, really. It just happened. I didn't know what was going on at all. I suppose I was hospitalised pretty quickly, had a couple of really low days and a lot of paranoia with it. Yes, I was in hospital for two weeks, but very much shell shocked from it all and kept in a room.

Sean reiterated the terror inducing reaction from both not knowing what "schizophrenia" was compounding and compounded by having no one explain the context of what he was going through.

I was, I was absolutely terrified. I did not know what it [schizophrenia] was. There was no real consciousness about mental illness. Nobody sat down and tried to explain it to me. Like "This is what you are going through" Nobody at all.

Maeve also spoke of her confusion being accentuated by professionals not taking the time to explain what was going on.

I said to them, "Look, what happened to me?" They couldn't tell me. They put me on schizophrenic medication and they told me I had a psychotic moment.

7.4.3.2 You're fucking sick
This reflected how, in the absence of any tangible, easily identifiable context, participants' confusing experiences and behaviours were pathologised and used as irrefutable evidence that they were sick.

Ciara noted how her sister forcibly insisted she was "sick" which of itself accounted for her behaviour and explained why she was in hospital:

When I first became ill, she [sister] roared at me in the hospital, "You're fucking sick". I was like, "I'm not". I was 19 years of age going what was she on about?

Sean recalled his first bewildering interaction with a psychiatrist telling him he had schizophrenia and his mother being devastated by the news of his diagnosis.

The first time I went to a psychiatrist, when I was in hospital, phoned my mum and told her that I had schizophrenia she nearly died.

Paddy, along with Sean and Maeve noted how polypharmacy that is the use of multiple "anti"-psychotic prescribing patterns was of itself used and taken as evidence that they were sick – "psychotic".

They just put you and pumped you full of medication. Gave me shock therapy.

They just kept saying, "Take this medication. Take it, take it." They wouldn't listen to what I said.

Finally, Sean described a more implicit demeaning pejorative interaction with allied mental health support workers which subtly but powerfully communicated and reinforced his "illness" identity.

They said something like, "You are the best person we've seen with this illness"… I know it's derogatory.

7.4.4 Language and identity (hindered)
This theme reflected how a schizophrenic identity gets forged in unilateral, autocratic, hierarchical and primarily staff-patient relationships using diagnostic language, "labels" and "mumbo jumbo" which is used to validate and is validated by "scientific", medicalised treatments and professional disciplinary power.

7.4.4.1. Code words - mumbo jumbo
Paddy and other participants spoke to how the dominant language, "mumbo jumbo" of psychiatry spoken primarily, but not exclusively, by mental health professionals was used to construct and enforce a schizophrenic illness identity as well as communicate and explicitly or implicitly enforce compliance with a confusing, non-consensual reality.

Paddy described how the schoolteacher's language brutally enforced his illness stereotype.

He was beating me with a leather strap, I remember that and he kept telling me I was a lunatic it was the first time that ah, that someone actually equated the word lunatic to what was actually happening.

Paddy and other participants also spoke about having to learn and communicate in a "foreign language" telling professionals what they wanted to hear, not what they wanted to say.

To me this was all fucking mumbo jumbo, but it was mumbo jumbo that these people knew and seemed to understand so I didn't question it. For them to make sense of what I was saying not that I made sense of it, I created a set of language and a way of describing and a way of articulating so that people would understand, but it bore no resemblance of what I was trying to say. I knew it was the language I needed to use to play out any given circumstance that was around me.

Similarly, Aisling spoke about just saying and doing whatever her psychiatrist wanted and expected her to say.

Sometimes I go into see the psychiatrist and I am like you know, "Okay, you win. I will say whatever the hell you want me to say…… You just go along and do what they say.

Aisling also spoke about the use of code words and the disparate language used by professionals, and service users with respective implied or perceived threats.

Everyone has code words, you have to do this or else you're going to do this, or this is going to happen. .....we're coming from that and they're coming from that, but completely separate, completely different ways of looking at it.

Finally, Aisling recalled how she was given another diagnostic label:

Putting things into boxes, labelled or whatever, bipolar they added that extra label on top and I think it's just stupid. I just don't get it.

7.4.4.2 My trade was to be mad

For Paddy his schizophrenic identity was validated through the explicit and implicit abuse of professional disciplinary power, beginning with the brutal reaction of his school teacher to his first disclosure that he was hearing voices and subsequent interactions with mental health professionals. Paddy and other participants described how these sustained iterative interactions with multi-disciplinary mental health and allied professionals who they perceived as knowledgeable created a so-called "respectable" identity which ultimately maintained an unhealthy co-dependent relationship with schizophrenia and an investment in being mentally ill.

The people that gave me that identity were actually people that we in society or I would have been brought up to look up to so they were doctors, doctors, nurses were all telling me this is who you are.

consultant psychiatrists, psychologists that I'd ever come into contact with I'd have looked at them as being up there experienced…… they were…. they were people that knew what they were talking about I had come to accept this label, to accept this diagnosis of schizophrenia, I bought totally into the idea that I was mad …..My trade was to be mad and their trade [mental health professionals] was to be the keeper of the mad.

Fucking doctors told me I'm schizophrenic I've spent years in a hospital because I was one, I'm on fucking medication….. err all these fucking treatments and …it was almost respectable to have that covering identity of being a lunatic or being mentally ill.

7.5 Second global theme interpersonal relationships (helped)

The second global super ordinate theme, interpersonal relationships, assimilated and expanded on the *a priori* deductively derived categories of authenticity, interpersonal relational ambivalence and inter-subjectivity. The global theme was organised around two organising themes for what *helped* - Humanistic and Triadic Transitional (Figure 4a.) and two sub-themes for what *hindered* – inflexible-unilateral and authoritarian-dogmatic (Figure 4b.).

7.5.1 Overarching style humanistic (helped)

A humanistic style of relating was characterised by an open minded, ordinary, collaborative, authentic, empathic and non-judgmental way of being with or standing alongside.

7.5.1.1 Just being there

All the participants spoke about how the felt experience of someone just being there, present and accepting of them in the moment, receptive without expectation made them feel safe and encouraged them to engage. For example, Aisling talking of her partner, noted

He was just really gentle, receptive, but just present. Just being there I think was the biggest thing… this is where we are and this is where we are today, it was just being there with somebody until maybe they did open up about things.

He was safe and I knew he wasn't part of the hospital. He was just there on the level of I'm just here.

7.5.1.2 Preaching what she spoke - congruent

Paddy and other participants spoke to the importance of significant others (for Paddy his grandmother, grandmother's "voice" and his peer mentor who picked up where his grandmother left off) being congruent in their thoughts and actions, a personification of an ethical, virtuous character who lived their actions.

By watching her [Edna peer mentor] and seeing her…… without her trying to coerce…… was just observing her, I started to realise there was something else that she was actually living and preaching what she spoke.

That comfort was there and that understanding was there, and that acceptance was there [deceased Grandmother and Grandmothers "voice"]. Ah, I felt understood.

Aisling talked about feeling congruent in the presence of and being with her archetypal loyal and trustworthy friend, her dog.

The two of us [dog] will go off into the woods and just even sitting there, I'm having a shit fucking day, I don't want to move anywhere, he's just there equally pissed off, just the sensitivity of it… having an avenue for sensitivity.

7.5.1.3 To be listened to not to be judged – unconditional positive regard

Paddy and _all_ the participants highlighted the importance of a person centred relationship characterised by having someone listen to them with compassionate understanding and without judgement which instilled a sense of hope in the face of adversity.

What she focused on was me, to be listened to, not to be judged she Edna probably in her own way picked up from where my grandmother left off (laughs).

Aisling talking about her dog noted

He's not passing judgement on it, connecting in with an animal. They don't talk back!

Gerard talking about his meditation teacher recalled

Buddhist, [Meditation Teacher] you know a lot of love and compassion… he was a very warm personality. There was understanding and compassion and I found it genuinely positive. I was getting that message of compassion and kindness off him regularly. That's what I'm getting – to love and be loved is the most important thing in my life, maybe even just to love others.

Gerard also noted the benefit of someone believing in him, holding and instilling realistic hope that he could and would recover.

The most important thing is to believe in the other person and to see where they can go. He said to me, "You have to go from victim to being victor".

When he [therapist] said that he believed in me, he had hope for me as well. I learnt they all held hope for me.

Figure 4a. Thematic network for Interpersonal Relationships - *helped*

Listened to not to be judged unconditional positive regard

Just being there an ordinary way of being and being with

Peaching what she spoke authentic beliefs and actions are congruent

Humanistic

INTERPERSONAL RELATIONSHIPS

Triadic Transitional

Walking the walk – Ego–supportive, pragmatic, practical, meets basic needs for food, safety and shelter

A different sort of relationship affective, reliable, resilient and robust alliance , goals are agreed collaboratively

Stepping into the fire - open and attuned to subjective reality and a capacity to feel the fear without being frightened

7.5.2 Triadic transitional (helped)

7.5.2.1 Walking the walk, ego – supportive

Almost without exception, participants highlighted the vital and literally life-sustaining importance of a so called ego-supportive relationship grounded in being dependable, unambiguous, pragmatic, reality-based and focused on ensuring their basic needs were met alongside helping them find solutions to everyday life situations. Participants also highlighted the value of engaging in meaningful activity, whether occupational, vocational, educational or recreational.

Paddy noted and valued the pivotal role Edna played in his recovery by ensuring his basic everyday needs were met, while also adapting her level of input and support to meet his changing level of functioning and maximise independence.

Edna showed me things, you know it wasn't just about sitting in ah, ah, ah in a sort of a therapeutic environment and sitting down and waiting, practically how you do it, help with the basic human things of how do we get food, how do we pay for this, you know the basic fucking things of how we live.

Days when I just couldn't have risen out of the bed, within the psychiatric system their job would have been to get me out of bed, whereas with Edna's part was well you need to rest now, you know so there wasn't, wasn't this conflict.

Likewise, Aisling reported the value of her partner co-ordinating daily practical support while Gerard noted the importance of compassionate support which encouraged autonomy while also avoiding hostile confrontation.

My partner, he would be the one coordinating with my family who was to come in today.

Some people are very compassionate, but they also push you…… Yes, they push without hate.

Several participants noted the value of engaging in meaningful activity which over and above the positive social, vocational and educational aspect instilled a sense of purpose, routine and self-worth. For example, Sean and Gerard highlighted the importance of work

I joined up to an employability service that helps get those with, quote, 'disabilities'…
that got me into a job. So suddenly I was in a job, I was grounded and I was earning money and I had started a Buddhist class so I was learning about my emotions. I learned a lot about anger and self-hate and stuff.

I got into work and I worked successfully in primary schools, like in education. I see other people and I play music and I have a fairly full life and a fairly active life now.

7.5.2.2 A different sort of relationship - healthy working alliance – (helped)

This reflected a collaborative, thought provoking and co-created affective interpersonal relationship that is resilient, persevering, sensitive and responsive to the noted relational ambivalence, mistrust and disconcerting subjective experiences.

Paddy spoke of how he gradually established a healthy working relationship with Edna who was sufficiently sensitive and resilient to withstand his intense ambivalence and mistrust of engaging, often manifest by either and or withdrawal and hostility.

It was a <u>different sort of relationship</u> completely and that was what built the faith in it. I realised this wasn't a relationship that was built out of, out of fear or domination or neediness.

The majority of the voices were vehemently against her, (Edna) they hated her with a passion. Initially there was there was suspicion ah, ah, they [voices] still had a very negative approach towards her.

Gerard also spoke about the resilience, patience, perseverance and belief of his therapist when thwarted by his intermittent lack of motivation and reluctance to engage which eventually saw him set and move purposefully towards and achieve his goals.

My therapist was very proactive, she never gave up on me there was a time, you didn't want to do anything you put in the effort, you kept coming back. You could have given up, she never said, Gerard you can't do it go and get that degree, don't give up the most important thing is to believe in the other person and to see where they can go.

Finally, Odran spoke of the fragile, transient nature of being able/unable to trust and engage with hospital staff, which was contingent on and fluctuated with his mood. However, with patience and perseverance he gradually established a collaborative working alliance towards achieving his goals.

I do, I trust him. Sometimes, when I'm feeling good. Then when my mind is thinking of doing bad, then I think he's lying to me. Then, I do think he's talking about me and that. Talking to the nurses and doctors. Asking them what can I do? What can I do to put myself right? I ask the nurses and doctors how I'm going to deal with it.

7.5.2.3 Stepping into the [subjective] fire (helped)

This reflected a sense of being emotionally attuned, known and held, mediated by a meeting of minds, calmly tolerating the uncertainty of not knowing (Karon, 2001, 2003) alongside validating, collaborating and conveying an understanding of the indescribable terror of the client's subjective, non-consensual experiences (Volkan, 1995).

Paddy captured this less tangible and difficult-to-grasp, but nonetheless powerful implicit relational style as a sense of being seen, known and knowing that she Edna knew and understood him which, made him feel connected.

She Edna was one of those people who didn't have to speak to you... knew by the look of her you knew by the way she was ..... she was a remarkable being now a remarkable woman ..she knew where I was coming from,... I knew when I spoke to her, she knew what I meant, when I spoke to her and she spoke to me there was a connection.

Paddy elaborated on this value of having someone attuned to and willing to embrace his subjective, terrifying reality.

Being able to be aware of the subjective reality of the person that's with them. And how each of them reacts to each other without putting the pressure of having to fit or conform, its' going to take maybe another set of skilled people that's going to be able to be comfortable enough to step into the fire with them.

In a similar vein, Gerard spoke poignantly about how his brother validated and was attuned to the threatening, persecutory aspect of his voice hearing experiences.

I was hearing voices, so it was an aggressive guy and then a less aggressive guy. I was saying to my brother, "I'm afraid they'll come in and fight me." He put his arm around my shoulders and he said, "If he comes in we'll fight them" and that's the nicest thing anyone ever did for me, a perfect example of how to help someone with schizophrenia"... to say, "Gerard I accept you where you are".

Equally, Aisling spoke about how her partner "naturally" intuitively just sat with and literally "held" her for several hours until her inexplicable, unnameable dread and terror simply subsided.

It was about eight hours, J just literally held me here and I just screamed and screamed. It's just hard to explain to people who'd never understand. It's just the way it was. It wasn't like we have to do it this way..... It just came naturally... I knew he was safe. He was just there on the level of I'm just here.

Aisling also recalled her sense of implicitly knowing and being known, trusting the intention of the other, conveyed by the reflection of how she was seen in their eyes in this instance, as gentle, real and receptive, an embodied experience of being emotionally present in the moment.

When you're in this deep sponge of stuff and somebody comes into the house, it's like you can feel their energy and the intention of what they're coming in for... people's eyes was always a good thing for me, being able to see whether they had souls in them, behind them or not picking up messages from people intuitively through whatever they're feeling in their body, or whatever. He was just really gentle, receptive but just present, you knew he was just being very real about who you were right there and then.

Finally, Aisling alluded to her partner's tolerance and her dog's sensitivity for calm acceptance of not knowing, but simply just listening and being there for her.

He's able to just say that's the way it is and I'd be going why? He just says, "That's it". They might not understand how it goes, but like J, that sort of person who will always just listen.

That's been a turning point for me, I think having – connecting in with something else. If you can't connect with a human, connecting in with an animal, they don't talk back. Just the sensitivity of it. Having an avenue for sensitivity, whatever way it is.

7.5.3 Second global theme interpersonal relationships (Hindered)

This global category was organised around two organising themes for what *hindered* inflexible unilateral and authoritarian dogmatic (Figure 4b.).

Figure 4b. Thematic network for Interpersonal Relationships- *hindered*

A robot an element –
Domineering , cold, closed minded and impersonal

No empathy no compassion
dispassionate, dogmatic and un-empathic
.

Authoritarian
Dogmatic

**INTERPERSONAL
RELATIONSHIPS**

Inflexible
unilateral

Expected to get along with life - ego
suppressive, impractical, over-
protective and demoralising

Fear from the unknown - enforces
objective reality and is fearful and
intolerant of disconcerting subjective
experiences.

You can't do this you have to do that
asymmetrical, detached, prescriptive and problem
centred

7.5.3 Overarching style authoritarian dogmatic (hindered)

In contrast to a collaborative and compassionate, humanistic style this reflected a rigid, closed minded, cold, coercive, dispassionate and hierarchical way of relating, grounded in the abuse of power, control and compliance.

Paddy recalled the violent, abusive and inhumane reaction of his schoolteacher to first disclosing he was hearing a "voice".

He [schoolteacher] was beating me with a leather strap, I remember that and he kept telling me I was a lunatic.

Henceforth, he talked about feeling helplessly trapped by the propensity of his subsequent hostile, persecutory "voices" which if communicated elicited an equally hostile, dismissive or coercive reaction.

[Voices] really…… really pushed the whole sense of paranoia deeper into me the negative voices were pushing into me so, so you're caught in this whole sort of rabbit in the headlights sort of scenario.

Equally, Gerard spoke about feeling caught between and destroyed by his relentless and inescapable cacophony of derogatory evil voices which only he could hear compounding and compounded by the incessant hostility and the equally inescapable verbal abuse he experienced from his family.

So for seven or eight years after that I got constant abuse, my mother coming down into the room and screaming her head off at me, my father came in shouting at me. I was hearing voices so it was an aggressive guy….. an enemy [voices] saying, "You're a cunt," or, "You're worthless," or, "You're a wanker," or whatever a really evil voice talking in your ear the voices were wearing me down….it was just wearing the shit out of me so I would be actually destroyed.

Similarly, Aisling spoke about the hostile and dispassionate reaction of her sibling

When I first became ill, she [sister] roared at me in the hospital, "You're fucking sick".

Several of the participants talked about experiencing mental health staff as cold, domineering and dispassionate, noting the inherent power imbalance while Ciara in particular felt enraged by the passive-aggressive, controlling and inhumane interactions under the perceived threat of being detained.

"Do you [psychiatrist] talk to people like this normally? Are you that inhuman?" Because the way he was speaking was just I'm not here, I'm a robot and an element, No, humanity. How could they let people like him be dealing with people?

There was one [psychiatrist] who had no empathy so I just avoided her a few bad memories.

Gerard, highlighting the power imbalance, commented

I hated the nurse, she had no compassion, she was only concerned about herself, there was this terrible power imbalance.

"This is here to help you" and I said, yes, but you're threatening me that I could be here for 30 days this sort of stuff.

7.5.4 Inflexible unilateral

7.5.4.1 Expected to get along with life, ego – suppressive
This sub-theme reflected an unreliable, "ill" defined and ambiguous relational style. The primary focus was on identifying problems - psychopathological deficits - alongside imposing an inflexible, prescriptive and impractical approach to either overcome these problems or manage symptoms. This led to an overprotective intrusiveness and extreme risk-averse guardedness creating unhealthy dependency, restricting autonomy and leading to learned helplessness.

Paddy highlighted the inflexibility of the care plan approach which for him was typically tokenistic, prescriptive and didn't change to meet his changing needs.

You've a fucking care plan in place that doesn't change, but it's not about actually how and what the person needs at any given time to help them to get through whatever it is they're getting through at that point in time.

Gerard noted the absence of any reliable, practical, structured support when transitioning from hospital back to the community

I was put in hospital, jettisoned back out into society, I changed or transmogrified or transformed depression, transmogrified maybe a better word... expected to get along with life or something, to get on and be a 9:00 am to 5:00 pm person or whatever. But without any support, I had one lady called up maybe once every few months. I don't know if there was any sort of routine to it, It was supposed to support me, but I don't know what she was doing or anything or how she was supporting me.

Gerard also talked about the lack of support with regards helping him to secure and maintain employment and the negative impact this had on his self-worth.

I was losing the jobs. I was not doing the jobs right, I was a mess back then. If someone at work had been able to understand those sorts of things, then they would change a lot of things... I felt very belittled by the whole experience.

Finally, Aisling and Ciara spoke about the ego-suppressing nature of their interactions with mental health and allied professionals and the risk-averse, fear-inducing response to their contemplating having a baby.

I understand where they're [mental health workers] coming from, but it's really patronising, They're limiting your core belief system, really fearful if I want to have a baby and she [psychiatrist] goes, "It is fearful. It's all about fear". I thought, I just don't get this. Is anyone going to help me?

7.5.4.2 You can't do this you have to do that -unhealthy "working" alliance
This was reflected by a fragile, asymmetrical and impersonal relationship founded on professional disciplinary power and aloofness, interventions are prescriptive and problem centred. Several participants talked about the patronising, prescriptive, one-sided and at times threatening nature of their interactions with hospital staff, which left them wanting to disengage, disempowered and angry but with little choice but to comply. For example, Ciara noted

You can't do this, you have to do that... I didn't want to be a part of the how things work around here We're [patients's] coming from that and they're [staff] coming from that, but completely separate, completely different ways of looking at it.... you have to do this or else we're going to do this, or this is

going to happen. I was so angry coming out of that place. Well, I complied obviously at the time. I really didn't want to.

Ciara also recalled feeling enraged with the impersonal, insensitive and dismissive nature of her exchange with her psychiatrist where the primary focus was on symptoms and problems.

"Have you got any signs of harming yourself or anything like that? Are you hearing any voices or anything?" But the way he said it the most arrogant, arrogant person I've ever come across in my whole life.

Gerard talked about the inherent power imbalance and hierarchical, asymmetrical, egocentric and dismissive nature of his relationship with nursing staff and his psychiatrist

The nurses – there was a power imbalance. It wasn't nice she was only concerned about herself. The psychiatrists had all the power so they could see you if they wanted to see you, so they might see you once every two weeks, sort of thing.

In a similar vein Maeve recalled the literally prescriptive, condescending and problem focused nature of an exchange with her psychiatrist

She just used to say to me, keep taking the tablets and do what the nurses and doctors tell me. I'll get well then if I do that; "If you take the medication."

Several participants also talked about the anti-collaborative, hostile and problem focused exchanges with family members, recalling frequent tirades of one-sided verbal abuse which left them feeling inadequate and unaccepted. For example, Gerard noted

I got constant abuse for sleeping in, my mother coming down into the room and screaming her head off at me and every day, "Why aren't you getting up?..."My sister was all the time, "Lose weight," I felt not accepted after that. My mother was like, "Lose weight," or shouting stuff like, "You have to get a girlfriend".

7.5.4.3 Pushed onto me object – object - fear from the unknown

This sub-theme was reflected by significant others, primarily mental health professionals, explicitly or implicitly imposing a singular objective reality, being intolerant and fearful of either not knowing or being known, alongside an unwillingness to embrace or validate disconcerting and terrifying subjective realities.

Paddy talked about how the schoolmaster, the psychiatric system and society were equally intolerant of and disconcerted by his subjective voice hearing experiences, eliciting an especially brutal or hostile reaction.

The school master reacted in exactly the same way as the vast majority of society around me reacted and ah the psychiatric system reacted in exactly the same way they didn't beat me with the leather, but so the sort of belief systems and treatments that they pushed onto me were exactly the same as what the teacher done you know they were a mirror image of each other, they were exactly the same response.

Paddy and other participants commented on how the scientific-objective eye of the well-trained diagnostician, psychiatric nurse [as well as other mental health professionals] obscured any attempts at understanding or embracing their subjective lived experience.

Student nurses there… they can tell you everything about a diagnosis of schizophrenia. But they can't tell you how to actually sit down with somebody and how to understand their experiences…. They don't understand, but they understand the science, whatever the science is?

Aisling talked about the reluctance and perceived fear of mental health staff to know or be known, applying objective and objectifying diagnostic labels to box her in and prevent any subjective understanding of how *she* felt.

This is my interpretation. But they added that extra label on top and I think it's just stupid. I just don't' get it. It's just fear, fear of the unknown, not putting people in boxes, but being able to feel what's going on with them.

Aisling also talked about the absence of any empathic connection with her psychiatrist and the agonising pain of feeling no one could or wanted to understand the subjectivity of her experiences.

There was one [psychiatrist] who had no empathy so I just avoided her. I'd feel like I was kicked in the stomach from the people not understanding what was going on in my own head.

Finally, Odran and Gerard talked about feeling guarded and conflicted about what they said to mental health professionals about their subjective experiences because they were frightened they would disagree or possibly lock them up.

If I wasn't thinking the right things, [to mental health professionals] I wasn't smart or cute or anything to help myself that they might lock me up or something.

Meaning is relative really, isn't it? So I suppose, maybe limited relativity to the outside world, but just to feel comfortable for me and for my world. But then everybody else [mental health professionals] does not agree with that, you see? That is the whole problem with people being in an alternate state, sort of being psychotic or whatever.

7.6 Theme three pathological organisations

This global theme (Figure 5.) emerged independent of the deductively derived codes, from the discursive interviews with the credible exemplars all of whom had been admitted to inpatient psychiatric care on at least one occasion both on a voluntary and involuntary basis. The theme reflects how the psychiatric system has a personality structure or organisation (Steiner, 1993) over and above the sum of the personalities of the staff and patients who inhabit it.

7.6.1 A police state

This reflected what was perceived as an egocentric and self-serving "system" which is coercive, closed, faceless, autocratic, oppressive, ever-changing and inflexible - a so-called pathological organisation (Rosenfeld, 1988). The structure and everyone inside it is tasked to ensure the system runs smoothly. This means "it" is intolerant of "disorder", and demands and where necessary enforces subservience by establishing unhealthy symbiotic co-dependent relationships between staff and patients.

Figure 5. Thematic network pathological organisations
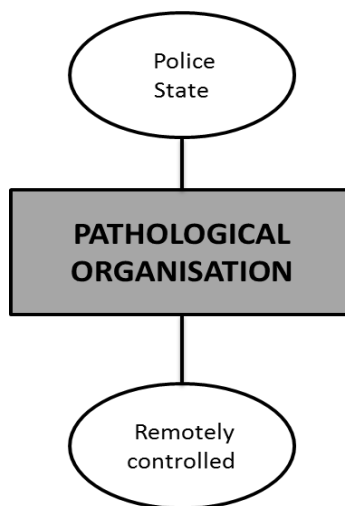
Paddy talked about the system "itself" as being totally mentally ill, comprised of multiple paranoid personalities which mirror, compound and are compounded by the paranoid negative personalities that make up the system leaving Paddy and others feeling entrapped.

The system has several (negative) personalities, part of the personality is paranoid, totally delusional and insane, the system itself is fucking totally mentally ill. I experienced negative personalities so they were, they almost imitated how I was in the sense of there, there's part of the personality is paranoid, is

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paranoid, so therefore, the compliance piece and all that end of it sits into it, you are stuck within that system, it's like a mirror image of each other.

For Paddy the survival of the system is dependent on unhealthy co-dependent relationships between staff and patients and where to survive in or get out of the system "patients" have no choice but to comply and play the "power" game of being and accepting they are mad!

It's not helpful, but it's helpful for the system, it's helpful to keep that system alive, we live and feed off each other you know one can't survive without the other we have these models of ideas of what we need to do but we only have them because they suit what we need to have in place professionally for ourselves.

I was forcibly compliant ah, we played this game of who wins, who loses you learn how to play these games how to create and keep the system going we actually teach people, train them and teach them, give them white coats, maybe not white coats now, but collectively we give them a white coat they also gained authority ah, they also gave me authority they also gave me the authority to be mad they wanted me to comply but they gave me the authority to be mad!

Likewise, Aisling noted

It's a weird place in there when you're at the beginning of coming into that place, people have a lot of game playing, patients playing games and playing the system. I didn't want to be a part of the how things work around here, well, I complied obviously at the time. I really didn't want to.

Sean commenting on his hospital experience noted

This is bullshit what is happening here [hospital], you know, with the nurses, they are not helping anyone, the nurses – there was a power imbalance, It wasn't nice sucking up to the nurse…, I hated the nurse… I just remembered that memory, I have to get out of this place.

Finally, Gerard equated the hospital system to a police state staffed by the Gestapo and with the inhumanity of a concentration camp instilling both rage and terror:

The thing about hospital, it just fucking crushes you. It is just there is no talking, it is just all this monolith of medication, standing over you like a police state. It has made me very angry, it made me agitated and frustrated. It is not nice to be agitated and frustrated. I would rather not be agitated and frustrated, the whole scary thing about the whole mental asylums is that, if you lose the plot or if you get angry or mad then they will dope you up. They will shock you or whatever. Like the One Flew Over The Cuckoo's Nest sort of thing.

This entire thing, the lunatic asylum, where they do all these horrible things to you, it is worse than the Gestapo. Basically, it is like a concentration camp. But that sort of fear is always there, that fear of mental health….. I felt lucky that I actually got out of there. I resolved never to go back and I never did go back to the hospital.

7.6.2 Remotely controlled

This reflects a system where coercion is considered synonymous with cure. The establishment mind, misconceptions, stigma and shame pervades the four walls of the psychiatric institution distorting the perceptions of outside others (family, friends) who take on its eyes and ears instilling paranoia and enforcing control (not to be confused with *delusions* of control) which leads to entrapment and demoralisation.

Paddy who spent a total of some fourteen years of his life in hospital, talked about being literally locked up and metaphorically locked in:

You're detained within that psychiatric system, whether it be within the walls or outside of it because you're totally detained into the way it works the way you're treated and everything So there's no escape, there's absolutely no escape, imprisoned within their own minds as you've said and within the system, like people are remotely controlled they're totally fucking controlled within that system, without being aware of it.

Your neighbours and everybody else outside your family and everybody else become the fucking eyes and ears of the psychiatric system so you have no escape from it and that's why a lot of people commit suicide because there ain't, there ain't an escape from it and those that are intuitively, realise themselves that they can never escape from this are those that end up taking their own lives because they…. they realise that this is going to be their lives for the rest of their life cause they don't have the sense of knowing how to get out of it.

Ciara talked about how her "folder of mental health history" was metaphorically filed in and shared with others:

The fact that you have a folder of mental health history and them knowing about it, That whole thing, people talk about it.

Finally, Gerard talked about the stigma and discrimination he experienced not least in the workplace.

That is why you don't bring it [diagnosis] up really, because once you bring it up, something in the air has changed. Like you have killed a baby or something like that, if you have brought up anything mental health or something like that. You have done something terrible.

Life might not be fair sometimes. If you have a mental illness, you may not get parity or might not get fair play in terms of job interviews. I found that I do not think you do get fair play in terms of job interviews and stuff.

8. Discussion

8.1 Deductive coding categories

From my initial interrogation of the selective testimonies and narrative accounts of persons' whose experiences were synonymous with a diagnosis of schizophrenia four generic superordinate categories emerged, dichotomised by what either helped or hindered personal recovery.

8.1.1 First category - attitude towards illness

The first category was constructed around a conceptual framework which, posited that the biggest threat to establishing and maintaining a meaningful relationship are the attitudes of psychological therapists – allied mental health workers, relatives, family caregivers and friends towards the schizophrenic illness (Chadwick, 2006).

Reports of - *what helped* (Table 1a.) centred on maintaining an open-minded attitude, foregrounding the person and their personhood and viewing experiences synonymous with the diagnosis as meaningful and understandable in context (Dillon et al., 2012; Longden et al., 2011, 2012). This reflected a flexible, non-prescriptive"[inter] personal medicine" approach (Deegan, 2005) which privileged self-defined above clinical recovery (Slade et al., 2014) founded on collaborative endeavour and perseverance from both the client and key significant others. These included mental health practitioners/allied professionals, peers, mentors, family caregivers and friends.

In contrast, reports of an attitude towards the perceived illness which *hindered* recovery (Table 1b.) were grounded in a de-contextualised and psychopathological conceptual framework where "schizophrenia" and the "schizophrenic" are viewed as synonymous. The focus is on managing symptoms and arresting what is perceived as a chronic, debilitating and degenerative disease (Slade et al., 2014).

8.1.2 Second category - authenticity

The second category authenticity as related to what *helped* (Table 2a.) reflected key significant others taking seriously and validating the idiosyncratic lived experience of the person (Atwood, 2012). This authentic way of being and engaging with the client's world was grounded in openly embracing and consensually validating (Sullivan, 1953) their oftentimes frightening and confusing experiences to convey an empathic understanding of the disconcerting, and disorienting emotional and relational impact on self and other (Chandler & Hayward, 2009).

In contrast, a so-called inauthentic attitude (Table 2b.) was characterised by an authoritarian, emotionally uninvolved, detached and disinterested relational style to the "it" illness. Disconcerting subjective experiences, symptoms are construed as evidence of an "illness", and either sealed over (McGlashan, et al., 1975) or coercively corrected by imposing and enforcing a medicalisation of experience which is considered devoid of either, meaning, substance or impact (Berrios, 1991; Boyle, 2002, 2013; BPS, 2014a).

8.1.3 Third category - inter-subjectivity

The third category labelled interpersonal ambivalence referenced a relational style which acknowledged and was sensitive to the intense and overwhelming phobia of attachment – attachment loss (van der Hart et al., 2006; Walsh, 2016). Reports of what helped (Table 3a.) negotiate this dialectical, emotionally imbued relational dilemma around intimacy included responsivity. This revolved around a capacity to compassionately and intuitively move towards, between and away from an emotional meeting of minds (Bacal, 2005; Mallinckrodt et al., 2005) gauged by and contingent on the co-existing longing for authentic, emotional connection and the conflicted terror of loss of self-identity through complete merger (Mahler et al., 1975).

In contrast a rigid relational style manifest by an inability to respond sensitively to this equidistant relational ambivalence between and fear of closeness and distance was viewed as a threat to the relationship which hindered recovery (Table 3b.).

8.1.4 Fourth category - interpersonal relational ambivalence

The fourth and final deductively driven superordinate category which emerged labelled inter-subjectivity reflected a co-created capacity to relate in the moment, moment by moment in and between a three dimensional relational space (Atwood, 2012; Orange et al., 1997; Stolorow, 2013) which included (i) an ego oriented, practical function (ii) a collaborative working relationship and (iii) a subjective, implicit meeting of minds (Schore, 2003; Stern et al., 1998) in the context of an overall embodied experience (Ogden, et al., 2006).

In terms of what helped (Table 4a.) and considering each of the three relational reference points, first was an ego supportive relationship (Kanter, 2000; Walsh, 2016) founded on dependability and pragmatism. The focus was on solving real everyday problems by ensuring basic needs were met. Second was a collaborative working alliance grounded in a co-created and co-regulated affective interpersonal bond, sufficiently resilient to withstand challenge and rupture and promote repair, encouraging a reasonable reciprocal willingness to work purposefully towards self-defined and realistic goals. Third, was a subject – subject representational relationship characterised by an open implicit willingness to know and be known by and in the mind of the other (Atwood, 2012; Stern et al., 1998), tolerate the uncertainty of not knowing (Karon, 2001; Stonier, 2015), embrace disconcerting incongruent experiential worlds and convey an understanding of the existential terror and impact of inhabiting this world (Karon, 2003).

Turning to reports of what *hindered* (Table 4b.) while considering each of the three relational reference points, first was an ego-suppressive relational style characterised by an unreliable, "ill" defined, impractical problem focused approach which, alongside a marked guardedness and intrusive overprotectiveness created an unhealthy co-dependence which restricted autonomy and personal development. Second was an unhealthy, impersonal asymmetrical alliance founded tenuously on professional disciplinary power (Stevenson & Cutcliffe, 2006) and intolerant of challenge or negative affect. Third and finally, was an object – object way of relating. This was characterised by an unwillingness to know or be known (Bolas, 1987) alongside an intolerance for the uncertainty of not knowing (Karon, 2001; Stonier, 2015), eliciting either a refusal or fear of embracing incongruent, disconcerting experiential worlds and a defensive over reliance on cold, rigid theoretical pre-suppositions (Walsh, 2016).

8.1.5 Divergent truths

Overarching, converging similarities were apparent between the *a priori* deductively driven categories outlined above and the data induced – driven themes which emerged from my in depth dialogical exchange with Paddy and the interviews with the seven participants. However, notable differences also emerged in the language I used to create or construct these respective truths as well as the dimensionality of the space in which they were constructed. Despite my intention to purposefully privilege the subjective lived experiences and language of the participants, this privilege was somehow if unintentionally lost in my translation.

From a social constructivist viewpoint, therefore, I acted out of awareness (Gergen, 1994) to create a unidimensional deductive framework which supported and made meaning of my preferred, established construction of reality, itself a function of and subject to my dominant professional language and privilege; enforced by my cross professional disciplinary power (Stevenson & Cutcliffe, 2006) as the primary investigator and psychological therapist. The hidden power of this process resides in the subterfuge of a so called absent standard (Sampson, 1993) which, reflects the unseen and unspoken imbalance of power that exists in psychotherapeutic contexts (Green & Stiers, 2002). While this position is often confused for or defended as "objectivity" by those who practice it (Green & Stiers, 2002) for Sampson it amounts to *viewlessness* which, blinds us to the truth of the other. This effectively shuts down open dialogical exchange and in this instance generated unidimensional, static and emotionless coding categories devoid of relational shared meaning or understanding of either the subject (schizophrenia) or subjects (schizophrenics) of the inquiry. Remarkably, or perhaps not so remarkably my deductively derived and categorical closed coding system shares certain similarities with the dialogically and diagnostically closed coding systems (e.g., DSM – 5, APA, 2013) which are constructed around and serve the prescribed and unfalsifiable truth of the dominant privileged others in the mental health system and which equally are relatively devoid of relational shared meaning or mutual understanding (Boyle, 2013; BPS, 2014a; Dillon et al., 2012).

A social constructivist view of psychotherapy posits that reality is a function of the language used to create the therapeutic dialogue (Gergen, 1994). From this perspective and in stark contrast to my static interrogation of the literature; my interactive dialogue with Paddy and each of the seven participants was negotiated in a three dimensional inter-subjective relational space (Aron, 1991; Orange et al., 1997; Stolorow, 2013) using ordinary language. This created a healthy tension where each of our truths were constructed as well as interrogated by our respective languages uncovering absent standards if and when they emerged, such that no one or single truth was privileged over and above the other (Sampson, 1993). This interwoven with the spontaneous affect laden dialogue opened up a potentiating and dynamic space where all truths were entertained without privilege. Henceforth, these truths assimilated with the subsequent truths which emerged out of each of the interviews with each of the other participants generated a three dimensional relational space (thematic framework) grounded in a shared, reciprocal meaning and understanding.

At the outset, it was considered that my preliminary interrogation of the literature to construct an *a priori* deductive, but open coding framework (Crabtree and Miller, 1999) would expand my understanding [lived, learned experiences] of multiple ways of viewing the phenomenon" (Jick, 1979, p. 254). In principle this process of triangulation by including another alternative reference point should have added to the evidentiary adequacy of the data by increasing the variety in the types of evidence (Erickson, 1986). However, in practice this was offset by the questionable transparency and trustworthiness of my interpretation and analysis of this particular evidentiary arm. In the absence of any interactive dialogue with these so-called paper participants the/my a priori framework was constructed using my first person "psychological" language which unwittingly privileged my construction of the truth and potentially silenced or misrepresented the voices I was trying to access and liberate. Although I can defend this as "objectivity" (Green & Steirs, 2002) cleverly masquerading as evidentiary adequacy, equally it can be considered tantamount to viewlessness (Sampson, 1993). My only true, credible defence, therefore, is to openly acknowledge that throughout the inquiry I have evidently struggled with my so-called postpositivist socialisation (Ponterotto, 2005) a limitation which increased the risk of postpostivising the constructivist – interpretivist methodology which is "akin to forcing a round

peg into a square hole" (Ponterotto, (2005, p. 127), and *vis a vis* forcing schizophrenia into the schizophrenic.

8.2 Overall findings

Thematic analysis and global themes

Notwithstanding my post-positivistic bias described above, the osmotic integration of the *a priori* deductively derived categories with the data induced themes generated a total of three higher order global themes discriminated by what helped and what hindered personal recovery. These reflected Context, Meaning Making and Identity Formation, Interpersonal Relationships and Organisational Culture which together represent an intersubjective contested and co-created contextual, relational and organisational space which can either help (Figure 2a.) or hinder (Figure 2b.) personal recovery.

8.3 First global theme context, meaning making and identity formation (helped)

The first global theme *context*, *meaning making* and *identity* (Figure 3a – 3b.) was structured around two organising themes (i) attributions for non-consensual illness experience and (ii) language and identity.

8.3.1 Attributions for non-consensual "illness" experience

8.3.1.1 It happened for a reason

As already outlined many individuals whose experiences are synonymous with a schizophrenia diagnosis, including voice hearing, report early adverse victimisation experiences ranging from sexual violence - abuse, neglect, broken disrupted attachments, loss, bullying, racism, poverty, social deprivation and inequality (Bentall et al., 2012; Campbell & Morrison, 2007; Cutajar et al., 2010; Davies & Burdett, 2004; Dillon et al., 2012; Morrison et al., 2003; Murphy et al., 2015; Verese et al., 2012). Ciara reported several severe and cumulative developmental childhood traumas. All of the participants reported non-consensual experiences synonymous with a schizophrenia diagnosis, all of them reported hearing voices either dialoguing, conversing, commenting or commanding and all of them recalled and attributed a context to the onset of these experiences. The context to the onset of Paddy's first voice was grief, a voice which he later attributed to be that of his dead grandmother. Aisling also described the grief imbued

context to her psychotic episodes, feeling she was "grieving for the world" while also noting she had not grieved for the loss of an earlier and significant long-term relationship. Likewise, Maeve attributed the onset of her commentary of voices and referential ideas to the sudden acrimonious breakdown of her marriage to an aggressive spouse, which left her homeless, economically deprived and involuntarily estranged from her young son. Aedan and Gerard broke down while away from home studying and experiencing conflict with housemates. Paddy and other participants also reported hearing, especially negative, persecutory and derogatory voices.

8.3.1.2 Getting my own interpretation

Attributing meaning and getting their own interpretation for non-consensual voice hearing and other experiences lessened the distress and fear associated with these experiences. When Paddy attributed and listened to his voice as that of his dead grandmother, it became a source of compassion which consoled and comforted him when faced with adversity, including the adversity of being diagnosed with schizophrenia. Likewise, Sean believed his voice hearing experiences were spiritual in origin a way of "channelling, conversing" with the dead, while for Aisling finding her own interpretation of what was an intensely "spiritual enlightening and meaningful experience" was "a huge aspect of moving on". Gerard on hearing his first voice like Paddy was fearful he was going crazy, however, when he later identified, contextualised the aggressive voice along with the other two more benign voices as representations of his housemates it "helped the voices go away". Likewise, Maeve and Ciara on reflection saw their voice hearing experience and the voices they heard as a meaningful representation of what was going on in their life at the time.

Taken together the above findings concur with Johansson and Eklund's (2003) qualitative inquiry where psychotic inpatients reported that what helped was the "quality of the helping encounter" mediated by wanting to be seen as personally meaningful along with their communications, voices being taken seriously in the context of their lived experience (Beavan, 2010). This theme of "it happened for a reason" is also corroborated by the testimonies and narrative accounts of persons with lived experience (Chadwick, 2006; Chandler & Hayward, 2009; Longden et al., 2011, 2012; Walsh et al.., 2015). A foundational element of establishing authentic relationships with psychotic patients therefore involves investing the time and energy

to understand the "historicity" of each individual's unique, lived experience (BPS, 2014a; Dillon et al., 2012; Kanter, 2000; Longden et al., 2011, 2012). From this perspective, mental health, counselling psychologists and allied professionals must not "insist that service users accept one framework of understanding" (BPS, 2014a, p. 102) but work within and validate a framework of understanding which makes sense in the context of the unique lived experience of each individual client (Atwood, 2012; Johnstone & Dallos, 2013; Longden et al. 2011, 2012; Walsh et al., 2015). Identifying with and tolerating the vulnerability and uncertainty of not knowing either what schizophrenia is or how best to treat it (Karon, 2003) opens up an avenue to grasp and empathise with (Stonier, 2015) the phenomenologically unbounded vulnerability of the schizophrenic experience of not or nonbeing (Chadwick, 2006; Sandin, 1993).

Given the robust and well replicated relationship found between early adverse developmental and victimisation experiences and psychosis "service users and their families [must] look forward to finally being asked about adverse life-events and offered self-defined and self-directed support that address the social [or inter-personal] causes of their difficulties" (Read et al., 2005, p. 17). Services, therefore, should be trauma informed (Bloom & Farragher, 2010) and people with a schizophrenia diagnosis should be routinely screened and assessed as well as treated for trauma based experiences (Dilks et al.,2010; Dillon et al., 2012; Read & Ross, 2003).

8.3.2 Language and identity

8.3.2.1 More than the diagnosis - no sort of Gobbledegook
At illness onset, participants were typically confused, frightened and disorientated, desperately trying to make sense of their emotionally overwhelming dysregulated experiences. This made them particularly sensitised and susceptible to the reactions and meaning-making framework of authoritative professional others, where identity was constructed according to an "I name therefore I know" logicality (Cancro, 2004) which privileged the dominant, first language of the knower. Paddy described how Edna (a peer advocate) speaking in the ordinary language of her own lived experience, challenged the totality of the label of schizophrenia as demeaning, forging a space where he could begin to slowly "disband and dismantle" his schizophrenic identity. Albeit initially this was a frightening thought it nonetheless created the possibility that there was "something else" (Walsh et al., 2015). Likewise, Eoin recalled that his therapist by challenging

his schizophrenia diagnosis opened up a space for an alternative identity to emerge which instilled realistic hope and became the impetus for his personal recovery. Finally, several participants noted how peer advocates with lived experience by understanding the language could act as interpreters between mental health professionals and service users. This highlights the importance of communicating using ordinary language while distinguishing between (i) clinical recovery focused either on getting rid of symptoms (non-consensual experiences) or in the "schizophrenic" gaining sufficient insight into the medicalised fact that these experiences are indicative of an illness and (ii) "self"-defined and dynamic personal recovery (Deegan, 2005) which focuses on enablement towards living a fulfilling and meaningful life (Slade et al., 2014).

8.3.3 Attributions for non-consensual "illness" experience (hindered)
8.3.3.1 What was going on – you're fucking sick

Attributions for voice hearing and other non-consensual experiences that were either de-contextualised as meaningless or contextualised as unequivocal evidence of an illness accentuated confusion, fear and anger. For Paddy it was not the voice of his grandmother per se, but, the adverse and abusive abreaction of his schoolteacher that scared and led him to believe "there was something wrong". Aisling described how she was equally scared by her sister's hostile reaction, roaring at her that she was "f----- sick" while Maeve described her fear surrounding the suddenness with which she found herself in a psychiatric hospital confined to a room and without any explanation to why she was there or rationale for her psychopharmacological treatment. This left her feeling "shell shocked", literally traumatised and paranoid, intensified by her experience of the psychiatrist as cold dismissive and disinterested. Finally, Aedan described his experience of being first diagnosed with schizophrenia as terrifying not "know[ing] what it was" and with no one taking the time "to explain what [he was] going through" or offer any rationale as to why he was being heavily medicated or administered ECT which elicited an uncharacteristic but justifiably angry reaction.

Johansson and Eklund's (2003) qualitative study found that patients felt disorientated and confused if they did not have a clear understanding of either the hospital or treatment regime whether psychopharmacological or otherwise (Johansson and Eklund, 2003). It is important, therefore, that we move beyond an unfalsifiable medical model and the misconception that non-

consensual experiences are unequivocal evidence of a dysfunctional, bio-chemical imbalance of the brain (BPS, 2014a) and the reductionist belief that psychopharmacological treatments of choice are both necessary and sufficient (Martindale, et al., 2000; Moncrief, 2008).

In addition, because this same reductionist conceptualisation is implicitly embedded in mental health legislation it has become the overly simplified and far reaching justification for involuntary, unlimited detention and coercive treatments which alarmingly are on the increase (Schizophrenia Commission, 2012). As professionals, we often appeal to and defend this risk-adverse practice with our duty of care, asserting that anyone who refuses psychopharmacological treatment, often because they find it ineffective or the side effects intolerable (Moncrief, 2008; Leucht et al., 2012; Liberman et al., 2005) either lacks insight or is treatment resistant. While priority must always be awarded to doing everything we can to keep people safe, it is important that we understand the full complexity and context of each individual's lived experience and where ever possible accept and help them get their own interpretation of it (BPS, 2014a; Dillon et al., 2012). This means foregrounding, respecting and working collaboratively with each person's individual frame of reference to generate mutual understanding that will promote meaningful and personal recovery (BPS, 2014a; Longden, 2011, 2012).

8.3.4 Language and identity (hindered)

8.3.4.1 My trade was to be mad - code words and mumbo jumbo

When initially prescribed by authoritative and highly respected mental health and allied professionals, diagnostic labels were typically perceived by participants as compelling, persuasive and objective scientific descriptors of a real illness. However, for Paddy and the other participants with the growing realisation that their diagnosis was independent of either "cause or cure" (Boyle, 2013; BPS; 2014a) at a subjective human level these same labels were construed as pejorative, demeaning and objectifying which if internalised created an absolutistic and shame based schizophrenic identity (Flanagan et al., 2012), unhealthy co-dependency, disablement and entrapment (Slade et al., 2014).

From this perspective dominant, credible others, not least mental health and allied professionals are both given and enforce explicit and implicit disciplinary power (Stevenson & Cuttcliffe, 2006). Paddy felt strangely obliged to accept a label because it was conferred by an authority

figure, first the school teacher and later doctors and nurses, people who were "up there, experienced, people that knew what they were talking about". Thus he began his apprenticeship towards madness necessarily learning and speaking the language, "mumbo jumbo" of the mad as well as using the "code words" of the professional "keepers of the mad". Bilingually proficient and having mastered his trade created a co-dependent tautological relationship (Cancro, 2004) between the professional disciplinary power of the "Fucking doctors [who] told [him he was] schizophrenic [because he] spent years in a hospital [and] was on fucking medication" *and* a "respectable… covering identity of being a lunatic or being mentally ill", which meant he invested in and eventually "bought totally into the idea that [he] was mad". This is reminiscent of the surreal discourse between the gregarious and bewitching Cheshire cat and young Alice in her Adventures in Wonderland (Lewis Carroll, 1965). Alice objects that she doesn't "want to go among mad people" only to be told patronisingly yet notionally sympathetically by the grinning larger than life creature "Oh, you can't help that, we're all mad here. I'm mad. You're mad". When Alice questions the validity of his diagnosis by asking "How do you know I'm mad"? He retorts laughing manically "You must be or you wouldn't have come here".

From a constructivist perspective, these demarcated, stereotypical roles between staff and patient, sanity and insanity were constructed and maintained by language (Gergen, 1994). For Paddy these "completely separate, completely different ways of looking at it" effectively shut down any opportunity for collaborative dialogical exchange between staff and patients. This left the latter feeling not listened to or understood (BPS, 2104a; Chadwick, 2006; Walsh et al 2015).

Notwithstanding the questionable scientific validity (Bentall, 2004; Boyle, 2013) of standardised diagnostic coding systems (e.g., DSM –5, APA, 2013) it is important to highlight and be aware that language by itself, "add [ing] that extra label on top" can alienate and entrap. This effectively shuts down open dialogue and mutual understanding towards establishing a collaborative relationship, not to be confused with compliance and forced insight which by contrast creates a divisive "them" and "us". This concurs with one of the key, most important messages of a major evidence based report by the BPS division of Clinical Psychology which argues that "the main way that we all need to change is by taking on board that there is no "us" and "them", there are only people trying to make the best of our situation" (BPS, 2014a, p. 113). Crucially, upwards of a quarter of the contributors to this report (as with all the participants

excluding myself, of this inquiry, though perhaps the difference with me is one of volume, intensity and sensitivity) were experts with lived experience, people, including professionals (psychologists) who have themselves experienced symptoms (voices, paranoia) synonymous with and or received a schizophrenia diagnoses.

If counselling psychologists/psychotherapists, mental health and allied professionals are to see the method in and make meaning out of what is defined as madness, we must listen more attentively to the voices indicative of madness which we cannot or choose not to hear (Dillon et al., 2012: Longden et al., 2011, 2012). This will mean foregoing a prescriptive paternalistic approach, whether psychopharmacological or psycho-technological which creates and maintains division. Not telling someone how to proceed, but supporting them in proceeding (Geekie, 2004), not coercively "doing to" but "being with", not treating the "it" illness (Mosher, 1999, 2001) but, engaging compassionately and humanely in a radical, yet ordinary meaningful relationship characterised by an open "willingness to collaborate with experiential worlds that may disconcert [our] own" (Chandler & Hayward, 2009, p. 8) the sine qua non of building an authentic relationship.

8.4 Second global theme interpersonal relationships

The second global theme interpersonal relationships was organised around two relational themes for what *helped* (Figure 4a.) triadic transitional and Humanistic and two themes for what hindered (Figure 4b.) unilateral inflexible and authoritarian dogmatic.

8.4.1 Triadic transitional (helped)

This interpersonal relational style is characterised by significant others being able to adapt to and transition between a three cornered relational space which is action oriented, practical and pragmatic (ego- supportive – *walking the walk*), reliable and resilient (collaborative alliance – *a different sort of relationship*) and open, emotionally attuned and regulating (subject-subject *stepping into the fire*).

8.4.1.1 Walking the walk, ego – supportive (helped)

In a desperate measure to escape from the system while on weekend leave, Paddy absconded from the local psychiatric hospital where he was detained, hitched a ride to London with a lorry driver friend which found him free, but literally down and out on the streets of London. At this point a peer advocate ensured he had food, shelter and money and clearly communicated she was trustworthy and cared. While the other participants did not find themselves in such extreme or desperate circumstances, Aisling highlighted the importance of her partner taking on an auxiliary ego function by organising and co-ordinating daily practical support to enable her to live outside of the hospital. Paddy also noted how Edna quietly adapted her response to meet his changing level of functioning by allowing him to rest when tired. Each of the participants stressed the importance of positive affirmation and being gently encouraged to engage in meaningful activity and social interaction. However, this did not happen in a relational vacuum where notably key people (auxiliary egos) were typically not part of the mental health system, but included peer mentors/advocates, with lived experience, relatives (spouse, partner, brother) and a meditation teacher. These relationships and interactions did not involve actual therapy, but were nonetheless therapeutic, pragmatic and dynamic. They included helping deal with voices, fear and self-hate, compassionately "push[ing] without hate" to set goals and engage in peer support groups, education, vocational activities and employment. For all the participants this led to improved social skills and confidence, which instilled self-worth and realistic hope that moved them beyond maintenance and their disability (Slade et al., 2014). Finally, and interestingly Paddy attributed the voice of his dead grandmother as a dependable, stabilising and ego-supportive influence, a voice of sanity which brought solace and comfort exactly as she did when alive.

The above findings are consistent with Maslow's hierarchy of need (Maslow, 1954) and the view that when people are coping with overwhelming experiences (whether internally or externally driven and in interaction) priority should be given to looking after their basic needs for food, shelter and money (Mental Health Foundation, 2014). From this perspective services must be able to adapt to and be built around actively supporting people in whatever way they find most helpful, what is referred to as "services on tap not top" (Shepherd et al., 2008). This recognises that practical help alongside ego-supportive relationships which "get to the solution" by providing practical advice about how and where to access life sustaining resources (Shattell, et al., 2007; Walsh et al., 2015) are often as or even more important than actual, traditional

therapeutic interventions which target clinical symptoms (BPS, 2014a; Kanter, 2001). Likewise, engaging in meaningful activity such as work and education were considered of central importance, providing a sense of well-being, self-worth and positive identity. A key task, therefore, for mental health and allied professionals is to help people find and maintain employment or access and engage with education or meaningful activity (Grove et al., 2005; Walsh et al., 2015), focusing on strengths, not deficits to "push without hate" towards achieving their self-identified goals. This "management" or auxiliary ego function (Kanter, 2000) means that the mental health professional must become a surrogate mother (Winnicott, 1965) gently supporting the psychotic client to recover or for the first time discover autonomy and independence (Kanter, 2000).

8.4.1.2 Expected to get along with life ego suppressive – (hindered)

In contrast to a flexible ego-supportive approach an ego suppressive relational style was marked by an inflexible and patronising attitude which for Aisling completely undermined her "core belief system". Paddy remarked on how he was expected to adapt his behaviour and level of functioning to what was prescribed in a fixed care plan. Gerard spoke about being "jettisoned [from the hospital] back out into society" without a clearly defined support plan or reliable support worker. Ciara noted how she was unable to gain any respite while in hospital because of the anxiety elicited by having nowhere to live. Likewise, Maeve noted that when she was issued with a hospital bill she panicked because on top of her marriage breaking up and reduced work hours she was unable to afford the rent for her apartment. A recovery or well-being approach highlights the importance of enabling people to live as independent, meaningful and fulfilling lives as possible. However, recovery and enablement must not be mistaken for the idea that people should be able to fully function without ongoing practical support (Slade et al., 2014) and or be used as an excuse to withdraw support to those with ongoing disabilities (Harper & Speed, 2012). For one participant in particular the absence of employment based support or understanding in the workplace meant he was unable to secure or hold down a job which left him feeling belittled and demoralised. The majority of people with psychosis want to remain productive yet approximately 90 percent of those engaged with specialist mental health services are either unemployed (Schizophrenia Commission, 2012) or experience discrimination in the workplace (Walsh et al., 2015). Meaningful employment or purposeful activity provides a sense

of positive identity and can have a more valuable impact than any treatment (NICE, 2014; Psychosis and Schizophrenia in Adults) where the most effective approach is to first support someone to find suitable employment and then support them to stay in work (Sainsbury Centre for Mental Health, 2009, 2013).

Finally, both Aisling and Ciara noted how their psychiatrist wanted them to seemingly abandon aspirations of motherhood and adopted a scaremongering risk-adverse position which accentuated their fear and helplessness and elicited anger.

8.4.1.3 A different sort of relationship (helped)

Notably, all of the participants acknowledged that a necessary pre-requisite for establishing a collaborative relationship involved working hard at establishing a relationship (Harder et al., 2014; McCabe et al., 2003; Thurston, 2003; Walsh et al., 2015). Foremost amongst the indicative relational attributes of significant others which participants found helpful was a sensitivity and *optimal responsiveness* (Bacal, 2003) to their at times extreme relational ambivalence alongside a quiet resilience and perseverance in the face of their suspicion, mistrust and lack of motivation (Walsh, 2016). For Paddy and others this tolerance and permissiveness gave way to a "different sort of relationship… [not] built out of fear or domination or neediness and which promoted recovery through "having someone believe in, persevere and gently push without hate" towards gradually attaining self-defined and self-directed goals. Interestingly, outside of Paddy with whom I had an already well-established collaborative relationship, the relative difficulty of evidencing clear examples of a positive relationship can in of itself be taken as evidence of the difficulty of either establishing a relationship or the relative little importance awarded to it by mental health staff (McCabe et al., 2003; Thurston, 2003; Walsh et al., 2015). Interestingly, for Eoin and Odran this difficulty was to a greater or lesser degree enacted in our dialogical exchange, manifest by guardedness and for Odran in particular a paranoid persecutory fear that he "will be harmed by or harm someone" (including me). Reflecting on the transcriptions I reflected that I was not optimally sensitive and responsive, but was more intent and desperate to engage or more accurately intrude to get what "I" wanted. In turn, my unsolicited intrusiveness elicited further withdrawal and to some degree a passive-aggressive compliance, which precipitated eventual premature disengagement; a lived example of relational insensitivity contributing to disengagement (Johansson & Jansson, 2010).

8.4.1.4 You can't do this you have to do that unhealthy working alliance (hindered)

Each of the participants spoke to the unhealthy and the disempowering impact of typically one-sided hierarchical exchanges where oftentimes mental health professionals and primary family caregivers were not experienced as allies standing alongside, but protagonists standing above, aloof, impersonal and overly critical. This inherent power imbalance and perceived superiority complex or arrogance was maintained by focusing on problems or deficits, alongside making what were perceived as unrealistic demands. These belittling put-downs accentuated by what were experienced as veiled threats of "you have to do this or else we're [staff] going to do this, or this is going to happen", forced compliance which elicited resentment and anger and created an antithetical "them and us" (BPS, 2014a). This effectively shut down collaborative open dialogue. As already noted it is essential to progress beyond an "us and them [mentality] and recognise there are only people trying to make the best of [their] situation" (BPS, 2014, p. 113). Only then is it possible to self-identify and move forward towards attaining self-directed goals that promote personal growth, independence, inclusion and citizenship (Slade et al, 2014).

8.4.1.5 Stepping into the fire subject – subject (helped)

Each of the participants spoke of and valued feeling connected to someone or something. For Aisling this was her loyal and trusted dog. For each of the participants this reflected an implicit, embodied and intuitive "avenue for sensitivity" of knowing and being known (Aron, 1991; Atwood, 2012; Stern et al., 1998; Stolorow, 2013) which as with the dog was oftentimes conveyed non or pre-verbally. This concurs with the view that therapeutic relationships should be built on "empathic linkages" (Peplau, 1997, p. 163) mediated by an embodied experience of reaching out physically as well as emotionally to "touch" the subjective world of the patient, similar to the theme of "feeling special" in Shattell et al's (2007) qualitative analysis of interviews with SMI clients. Likewise, in Johansson & Eklund's (2003) qualitative inquiry of patients receiving outpatient and inpatient psychiatric care, priority was awarded to the psychological therapist taking time to gently "open up", listen attentively to and communicate with their inner world. In the current inquiry this interpersonal phenomenological way of "being with" clients (Mosher, 2001) was especially valued during emotional crisis when abusive and threatening voices and other non-consensual persecutory experiences were driving or being driven by an indescribable fear experienced by Aedan as "worse than terror". Here, Paddy also

noted the importance of having someone consensually validate (Sullivan, 1953) his unfathomable fear or fear of the fear, Aedan described a similar scenario where his brother literally stood alongside him, while for Aisling her partner literally just calmly held her while she "screamed and screamed".

Many people with severe and complex mental health needs are "almost by definition vulnerable to experiencing emotional crisis" (Slade et al., 2014, p. 15). This combines with hypervigilant sensitivity for emotions associated with these crises and increases their vulnerability (Gumley et al., 2015). More resources, therefore, must be targeted at preventative and early intervention services to mitigate crisis (Schizophrenia Commission, 2012). When people become emotionally overwhelmed less intrusive alternatives to being admitted to or being threatened with coercion or involuntary admission to inpatient psychiatric care should be readily available (Calton et al., 2007; Gale et al., 2008; Schizophrenia Commission, 2012).

Interestingly, for each of the participants in the current inquiry it was not a mental health professional who "stepped into the fire". Rather, for Paddy and other participants it was peer mentors or advocates with lived experience while for others it was their siblings or spouse and for Aisling her dog who knew intuitively what to do.

Altogether, this highlights the need for more so-called crisis recovery or safe houses (Calton, 2007; Slade et al., 2014) staffed by peer mentors with lived experience (Mosher, 1999, 2001) who know implicitly what to do and without the fear of getting it wrong (Karon, 2001). Likewise, hearing voices groups for people who hear voices co-facilitated by a counselling psychologist/mental health practitioner and a voice hearer is a good avenue to sensitively tune into and understand the subjectivity of these experiences. There is also a need to train mental health staff and counselling psychologists/psychotherapists in the skill of "being with" that is to connect with, validate and embrace non-consensual voice hearing and other intersubjective disconcerting experiences (Atwood, 2012; Chandler & Hayward, 2009; Orange et al., 1997). This means being able to tolerate not knowing (Stonier, 2015) as well as tolerate the uncertainty and fear which comes with the knowledge of either not knowing what to do or doing the wrong thing (Karon, 2001). Only then is it possible to reflectively "be with" hold (sometimes literally), co-regulate and de-escalate the subjective emotional experiences of the client through a right hemisphere – right hemisphere connection which enables implicit knowing and conveys non-

verbally that you understand (Schore, 2003). This radical engagement (Atwood, 2012) involves an astute moment by moment awareness of the totality of our own (psychologists/psychotherapists) and the others' (clients) inter-related internal and external mental and physical experiences. A useful avenue to hone and modulate these qualities, therefore, is mindfulness training (Jung et al., 2015). Another innovative development is Avatar therapy which uses a computerised software program to create an image human or otherwise, which caricatures the entity of the "voice(s)" of the voice hearer including content and tone. Subsequently the therapist facilitates a dialogue between the Avatar and the voice hearer. Henceforth, the therapist encourages the voice hearer to stand up to and challenge the validity and power of the personification of the dialogued voice such that they move from being helplessly controlled to being in control. Over and above preliminary findings demonstrating the positive therapeutic effect of Avatar therapy with voice hearers (Leff et al., 2013, 2014) the program could be usefully deployed as a training tool for non-voice hearing psychological therapists. This would enable them to more fully appreciate and understand the internal and external relational impact of living with and listening to what for several participants was a relentless commentary, a cacophony of derogatory and defamatory persecutory voices constantly berating and bullying and leaving Gerard feeling completely "destroyed".

Finally, advance directives, popular and effective with clients (Slade et al., 2014) where they agree in advance what action to be taken and by who in a particular circumstance/eventuality could also be put to good use. In this instance the client could identify a trusted and safe individual(s) of their choice to "be with" them in their crisis, whether human or animal. Interestingly, innovatively as related to the latter the Burgholzni Hospital in Zurich (of Eugen Bleuler fame) has a therapeutic dog in each unit to "be with" and effectively co- regulate, relieve the tension of the psychotic inpatients.

8.4.1.6 Pushed onto me object – object - fear from the unknown
Strikingly of those individuals that participants experienced as being willing and able to turn up (Bollas, 1987) and embrace their disconcerting subjective- experiential worlds (subject – subject) all of them had lived experience. Ciara elicited a visceral sense of being "kicked in the stomach from people not understanding what was going on in [her] head". Aedan attributed this tendency towards objectification to mental health professionals being unable to tolerate the uncertainty of

the "fear of the unknown" which for Karon (2001) along with not being frightened of getting it wrong is the cornerstone for working therapeutically with psychotic patients. Ironically, Odran spoke about his fear of talking about what he was really thinking for fear mental health professionals would think he was "not thinking the right [or disconcerting] things", leaving him naturally guarded (not to be mistaken for paranoia) and frightened he would be locked up. Similarly, Aisling revealed she never told anyone in the hospital what she was thinking for fear she would not be released. Likewise, Gerard spoke about the "problem with people being in an alternate [psychotic] state" and the "relativity" of and conflict between what for him was a "comfortable" and potentially "creative" subjective experience and the uncomfortable disconcerting impact disclosing these experiences had on the objective reality of mental health professionals, primary caregivers, family and friends. Equally Paddy's first disclosure of his voice hearing experience to the schoolmaster elicited a brutal reaction of being beaten with the leather, for Paddy a "mirror image" of how the psychiatric system subsequently responded "push[ing] belief systems and treatments onto [him]" and in both instances seemingly confusing coercion with cure (Szasz, 2010).

8.4.1.7 Overarching style humanistic (helped)

A humanistic "presence" was in many ways personified by Paddy's grandmother. Paddy reflected on how this humanistic voice was subsequently embodied by Edna. Several participants talked about the value of someone "just being there on a level" communicating using ordinary language simply knowing "where it goes" and being fully accepted "where you are" in the moment. Aisling spoke about the unconditional companionship of her dog. Others felt a similar connectedness with their human companions who conveyed a genuine warmth, compassion and understanding enabling them "to love and be loved".

This humanistic presence of simply being and staying with the person is remarkably similar to what emerged from Shattel et al's (2007) qualitative inquiry with patients experiencing severe mental illness where the key emergent theme, regarding what helped "relate to me" was characterised by the nurse practitioner being reliable, patient, non-judgmental, authentic and realistically optimistic. Furthermore the second and related theme to emerge "know me as a person" was characterised like the current inquiry as a "way of being with" the patient, present to and openly, genuinely accepting them fully as they are in the moment. Johansson & Eklund's

(2003) qualitative inquiry of patient's receiving psychiatric care found that of the four out-patients' who reported being most satisfied with their care the therapeutic relationship was characterised by warmth and the therapist taking time to get to know and empathise with their emotional world. The inpatient sample also reported the need to feel respected and in particular "to be met and understood" as whole subjects.

Taken together, these findings, which concur with those from the current inquiry are consistent with the long held empirically established and now well replicated finding that the patients' perception of the therapist's unconditional positive regard, genuineness and empathic understanding are preconditions for a positive alliance (Norcross, 2011) which predicts a better outcome and including for patients with psychosis (Rogers et al., 1967). Likewise, Evans-Jones et al. (2009) found that patients with psychosis who experienced their therapist as trustworthy and empathic rated the alliance more positively, while Jung et al. (2015) found perceived "genuineness" was the most meaningful predictor of a positive alliance for patients receiving CBTp for psychosis.

8.4.1.8 Authoritarian dogmatic

In contrast to a grandmotherly humanistic presence a dogmatic, authoritarian relational style was personified by Paddy's abusive and enraged schoolteacher who enforced his rigid beliefs by brutally beating him, presumably either as punishment for being a "lunatic" or in an attempt to beat the lunacy, demons out of him (not unlike the barbaric psychiatric "treatments" and exorcisms administered in the past). For Paddy and other participants these cold, coercive and antagonistic voices of the enraged school teacher, family members relentlessly screaming and shouting abuse or dispassionate, passive-aggressive mental health professionals, enforcing perceived unrealistic demands, mirrored and accentuated the equally callous, unrelenting and inescapable "enemy" of "evil" internally driven persecutory voices. For Paddy this pushed the "paranoia deeper into" and left him feeling paralysed by an unfathomable fear. Likewise, Gerard reported feeling altogether disempowered, worthless and totally destroyed. Several of the participants also spoke about experiencing mental health staff as distant, disdainful and dispassionate, "inhuman" and "without empathy" being related to like a "robot" an "element" reflective of a de-animated and disembodied part object (Stanghellini, 2004) a no-body, nowhere

(Sandin, 1993). For many of the participants these negative interactions elicited both anger and fear and left them with especially traumatic memories of being hospitalised.

Paddy spoke to his sense that professionals drawn into the world of mental health and more implicitly the internal subjective world of psychosis could be "taught how to do the thing in a more humanistic fashion". Rogerian factors are considered as basic therapeutic skills, the *sine qua non* to establish and build rapport. However, as noted an over identification with a reductionist medicalisation of madness and objectification of the mad means we can become blinded by science, whatever the science is? (Alanen, 2009; Dillon et al., 2012). As such oftentimes we can fail to see the person while inadvertently relying overly on either "heavy duty" polypharmacy or psycho-technological and manualised interventions (Jung et al., 2015; Martindale, et al., 2000; Walsh et al., 2015). This compounded by and compounding being unable to tolerate the uncertainty of not knowing what to do or frightened of doing the wrong thing (Karon, 2001) creates a division between a disengaged, depersonalised and disenfranchised "them" and an impersonal, dispassionate and inhuman "us" (BPS, 2014a).

To the extent that these divisions hide healthy parts of the self, it is only by removing diagnostic and theoretical masks and defences that the humaneness will be put back into schizophrenia and the person back into the schizophrenic (Alanen, 2009). Undoubtedly personalising and humanising madness in this way, may reactivate the evocative feelings that either the lunatics are taking over the asylum or conversely, that the keepers of the asylum-sanity have finally gone or been driven insane, so to speak joined the unbelievers (Szasz, 1967). Many counselling psychologists, mental health and allied professionals protest, therefore, that this is tantamount to irresponsibly colluding with or reinforcing so-called delusional thinking. However, for me there is a clear line between collaborating and colluding and it is pretentious and inauthentic to equate authentically listening to and exploring other worlds (Atwood, 2012) and entertaining an idea (delusional or otherwise) with co-habitation (Chandler, & Hayward, 2009).

A more explicit focus on these issues in training, clinical supervision and continued professional development programs, therefore, could help counselling psychologists/psychotherapists develop or re-discover these Rogerian qualities. Another useful and related avenue of inquiry is mindfulness based training for counselling psychologists/psychotherapists as well as primary caregivers/family members to encourage them to purposely pay attention to their own feelings

and reactions in their interaction with the feelings and reactions of their clients/relatives non-judgementally, towards establishing an optimally responsive, genuine, embodied and human focused relationship (Ryan et al, 2012; Siegel, 2010).

8.5 Global Theme three pathological organisations

8.5.1 Police state
Paddy spoke about the multiple, negative pathological personalities or selves of the perceived "mentally ill" psychiatric hospital system built on unhealthy co-dependent relationships that instilled as well as accentuated paranoia and fear. Collectively the system both held and was given the "white coat" authority to confer madness, earned by resentfully complying with "playing the game and playing the system" viewed as the only realistic, viable way to "get out". Alternatively, for those perceived non-compliers the system was seen to enforce its' power under the coercion of what was equated to a Gestapo run totalitarian "Police state". Gerard recalled his experience of the hospital system as especially traumatic and oppressive noting how they "threw the [psychopharmacological] book" at him, administering a monolith of medication alongside what for him were draconian and dangerous treatments such as ECT. Administered against his will and without any therapeutic gain left him feeling angry and agitated, which resulted in being administered ever more aggressive treatments. This confusion between perceived "treatment resistant" aggression and an understandable resistance to ineffectual and aggressive treatment, coercion and or as cure (Szasz, 2010) created a treatment effect which, for many toughened their resolve to stay well for fear of being forcibly readmitted to hospital, likened by Gerard to a "concentration camp" that just "fucking crushes you".

8.5.2 Remotely controlled
Paddy and other participants talked about the stigma and discrimination they experienced because of the myths and misconceptions which surround their diagnosis (Thornicroft et al., 2009; Walsh et al., 2015). Paddy spent a total of approximately 14 years, literally locked up and metaphorically locked in, institutionally "imprisoned" by the perceived establishment mind. For Paddy this brainwashing and big brother presence of eyes and ears constantly watching their every move, listening to and hanging on their every word represents a life which for some "for the rest of their life" is considered not worth living. These words taken out of context, either de-

contextualised or taken literally, could be seen to be indicative of extreme paranoia or so called delusions of control. However, for Paddy the tragic reality is that for some the only escape to what is perceived as their otherwise inescapable, intractable and intolerable entrapment is to take control by committing suicide.

Aisling talked about how her "folder of mental health history" was metaphorically filed in, shared between and influenced the perceptions of others beyond the walls of the psychiatric hospital. Similarly, Aedan talked about the stigma and discrimination he experienced not least in the workplace because of the perception and misconceptions regarding "anything mental health". This meant he didn't bring "it" up because it changed the "air", a metaphorical bad smell constantly hanging over him, which meant others related to him as if he had committed a terrible, heinous crime like "kill[ing] a baby or something".

These harrowing narrative accounts of admissions to and of being in the psychiatric hospital system are consistent with the finding that acute psychiatric inpatient care is one of the most problematic elements of the UK mental health system (Berry et al.., 2016; Muijen, 1999, 2002; Quirk & Lelliott, 2001; Schizophrenia Commission, 2012), with notable divisions between the perspectives of patients and professionals and an over emphasis on the importance of clinical practice over humane patient care (Alanen, 2009; Dowds & Fontana, 1977; Mayer & Rosenblatt, 1974).

Correcting this perspectival and practice based bias Gilburt et al. (2008) using a participatory action research approach (like the current inquiry) designed and led by service users with experience of admission to a psychiatric hospital (also like each of the participants of the current inquiry) explored service users' experience of psychiatric hospital admission in the UK. Making explicit and addressing the inherent power imbalance involved in the research process, (paralleling the noted power imbalance between staff and patient in the psychiatric system) alongside purposeful efforts to empower the nineteen research participants they found the quality of the emotional, interpersonal environment over and above the role and structural aspects of the hospital were the most meaningful predictors of their hospital experience. This supports the view that the hospital is a living system – organisation (Rapoport, 1960) with multiple selves that contribute to a culture which is greater than the sum of its patient – staff parts (Bloom, 1997). Concurring with the current inquiry "coercion" emerged as a dominant relational theme

experienced objectively as restrictions to freedom, restraint and compulsory treatment. This highlights the inherently coercive nature of the English Mental Health Act (Kaltiala-Heino, 1999) and while particularly relevant to detained patients it is not necessarily a function of the Act itself but of the relationships with and the attitude of the staff who enforce it. Equally for voluntary patients in Gilburt et al's (2008) study as in the current inquiry, perceived or subjective coercion manifest itself as veiled threats from staff regarding the consequences of non-compliance. For Szasz (1972) this institutional imbalance of power amounts to "an acknowledged practice of medical fraud" because "a person is forced to sign in…. as a voluntary patient under the threat of commitment". For service users in both inquiries this created understandable mistrust, fear and lack of safety (not to be mistaken for paranoia, aggression or treatment resistance). This led to service users in both inquiries "playing the game" and "following the rules" to survive and get out of the perceived custodial system which merely masquerades as a place of asylum. Finally, negative experiences surrounding types of treatment included being over medicated or "doped up" and having insufficient capacity to consent to in particular ECT, both of which service user participants in both studies also related to perceived coercion.

For many participants an iatrogenic side effect of the psychiatric system was a deeply held fear which for many acted as the primary motivation for staying well. For people experiencing overwhelming distress which overrides their capacity to function and leaving them especially vulnerable, the hospital should be seen as a sanctuary (Bloom, 1997) a place of safety where they would willingly choose to go to recover. Safety, however, is built on trust which can and must exist between individuals and also in a system or institution (Mechanic, 1998). The system is made up of the staff and patients who inhabit it who in turn are inhabited and influenced by the culture of the system. The therapeutic potential of the system, therefore, does not itself reside in the structure, but in the quality of the interpersonal relationships inside the social structure (Gale et al., 2008; Mosher, 2001; Rapoport, 1960). To break down the noted inherent power imbalance which breeds paranoia, fear and contempt, staff – patient relationships, therefore, should differ in function not status (Rapoport, 1960). However, the primary function must not be focused on the survival of the system built on mistrust and unhealthy coercive co-dependency which inhibits personal recovery, but on the enablement of the client built on collaborative inquiry, compassion and trust.

For those touched by psychosis it remains a perplexing, terrifying and invariably traumatic experience (Walsh et al., 2015). The "keepers" of the asylum, therefore, amongst them counselling psychologists/psychotherapists may be reluctant to hand over the keys and or the "lunatics" may be reluctant to take them (Bracken & Thomas, 2005). However, it is only when allied mental health professionals and service-users feel safe enough to explore each other's world view that real learning and sustainable change can take place. In contrast, when professionals (like me) and service-users (like Paddy) feel threatened by each of our respective incongruent world views this co-creates a toxic combination that results in unchallenged paternalism, disciplinary power (Stevenson & Cutcliffe, 2006), high use of coercion and the prescriptive imposition of misconceived explanatory models whether recovery oriented or otherwise (Schizophrenia Commission, 2012; Slade et al., 2014).

8.6 Implications for and application to practice

The PAR inquiry (Reason & Bradbury, 2001) founded on the principles of democratic *participation* (including participation between myself and Paddy) aimed to generate knowledge from within and directly useful to the service user survivor community by raising conscious awareness and understanding of the subjective challenge and subjectivity of living with a schizophrenia diagnosis (Atwood, 2012); alongside taking *action* which would facilitate mutual, reciprocal understanding between mental health service providers, primary caregivers, family, friends and consumers/survivors to challenge myths, misconceptions, negative stereotypes and stigma (Flanagan et al., 2012; Thornicroft et al., 2009) to promote enablement and personal recovery (Slade et al., 2014).

Empowerment through consciousness raising

The study supports the view that psychologists/psychotherapists should accept as well as proactively raise conscious awareness amongst fellow mental health and allied professionals, primary caregivers, families and friends that schizophrenia is an essentially contested concept (Geekie, 2004) answering the call for "a paradigm shift in relation to the experience that these diagnosis refer to" (BPS, 2014a). This would be a huge first step towards stopping service users being either explicitly or implicitly coerced to accept any one framework of understanding (BPS, 2014a; Schizophrenia Commission, 2012), opening up a meaningful dialogue towards

"collaborative formulation" (Division of Clinical Psychology, 2011) which by privileging and validating the unique lived experience of each individual client (BPS, 2014a; Longden et al., 2012) promotes mutual understanding, empowerment and enablement (Slade et al., 2014). Counselling psychologists/psychotherapists should also be aware of and raise conscious awareness of the empirically robust, well replicated and proposed causal relationship (Read et al., 2005) between early developmental adverse life and victimisation experiences and psychosis to ensure routine standardised assessment alongside evidence based and trauma informed, focused treatment (Bloom & Farragher, 2010; Longden et al., 2012; Read & Ross, 2003).

Action

The inquiry, therefore, contributes and adds to counselling psychology's 'demand for rigorous empirical enquiry with a firm primacy of the counselling or psychotherapeutic relationship' (Professional Practice Guidelines, 2005, p.1) in this instance specific to working with clients with a schizophrenia diagnosis, illuminating the interpersonal attributes and communication style they should adopt to establish a relationship that is therapeutic (Walsh, 2016).

Professional development training program

It emerged that mental health and allied professionals over-identify with the science of schizophrenia, privileging assessment and de-meaning diagnostic objectification (Cancro, 2004) wherein coercion becomes synonymous with cure (Szasz, 2010). This highlights a skills deficit which could be usefully addressed by a bespoke, tailored training program focused on educating mental health professionals how to, in the words of Paddy "do the thing in a more humanistic fashion" (Alanen, 2009).

Strikingly, in the current inquiry, none of the individuals experienced as having humanistic attributes were mental health professionals while equally all of those willing to embrace non-consensual subjective experiences were peer mentors or advocates with lived experience. The training program, therefore, would be designed and delivered collaboratively by a mental health professional/psychologist and an expert by and of lived experience, standing alongside and giving equal privilege to the axiological, epistemological and ontological assumptions of each (Mosher, 1999, 2001).

The professional development program, therefore, would be grounded in supporting the aforementioned paradigm shift that does not coerce service users into "accepting one framework of understanding" (BPS, 2014a, p102) enabling open dialogical exchange towards "collaborative formulation" and taking on board that there is no "us" and "them" there are only people trying to make the best of their situation (BPS, 2014a). Indicative key syllabus and content would include:

- Increasing awareness of the relationship paradox, phobia and fear of this population.

- Raising conscious awareness of the oppressive and demoralising impact of absent standards, professional privilege, disciplinary power and psycho-technological jargon.

- Distinguishing between coercion and compliance, which disables and disempowers *and* collaborative therapeutic endeavour which empowers and enables.

- Distinguishing between clinical and personal recovery.

- Understanding the often traumatic context of the onset of non – consensual experiences while highlighting the now well established and empirically based proposed causal relationship between adverse childhood and victimisation experiences and a schizophrenia diagnosis.

- Understanding the importance and therapeutic potential of a congruent, dependable, auxiliary ego – supportive, solution focused and strengths based supportive relationship.

- Developing mindful awareness and optimal emotional responsivity to embrace and co-regulate the experiential world of the client as well as self-manage, regulate emotions, thoughts and behaviours in interaction with the client.

The training could be delivered as either a standalone continued professional development workshop to multidisciplinary mental health and allied professional or be embedded in cross disciplinary clinical training programmes for counselling/clinical psychology/psychotherapy, mental health nursing, social work and psychiatry.

Therapeutic supervision

A key implicit factor towards establishing a relationship with persons with a schizophrenia diagnosis is accepting the inherent subjectivity and terrifying reality of their lived experience (Atwood, 2012) which gets objectified and enacted in interpersonal relationships (Dilks et al., 2010). Counselling psychologists/psychotherapists therefore must have the pre-requisite skills

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and training to willingly "collaborate with experiential worlds that may disconcert their own" (Chandler & Hayward, 2009, p. 8). This means being able to tolerate the uncertainty and fear which comes with the knowledge of either not knowing what to do and or the fear of doing the wrong thing (Karon, 2001; Stonier, 2015). To mitigate burnout and compassion fatigue (Figley, 2002) mental health and allied professionals working in the field of psychosis would benefit from routine specialist supervision to "survive" the occupational hazard (Winnicott, 1971) which comes from the radical engagement (Atwood, 2012) of stepping into the so called subjective fire pf psychosis.

Family support

Several participants reported especially strained family relationships which often evolved out of negative transactions with primary caregivers characterised by their being experienced as protagonists, overly critical, intrusive and making unrealistic demands, indicative of a so-called high expressed emotion (EE) environment (Brown, 1959; Brown & Rutter, 1966) which has a well-established and robust relationship with relapse (Bebbington & Kuipers, 1994; Kavanagh, 1992). Kavanagh's (1992) transactional model of EE argues that the behaviour of both the relative caregiver and the patient are adaptive reactions to cope with and manage the emotional stress and shock of a schizophrenia diagnosis, moderated by (i) the interpretation that the "patient" and caregiver attributes to the attitudes and behaviour of each other and (ii) the coping strategies that each has available to deal with them. Cozolino et al. (1988) found that low-EE relatives have a greater awareness and knowledge of the subjective impact of a schizophrenia diagnosis while Greenley (1986) found that any relationship between increased emotional distress and EE was dependent on whether or not the family viewed the patient as genuinely ill. This is consistent with one of the key findings of the current inquiry where the response of relatives was mediated by the attributions they made for non-consensual illness experiences.

The psychoeducational family intervention program, therefore, would focus on supporting relatives and primary caregivers to understand the context and subjectivity of symptomatic or de-compensatory behaviour (Atwood, 2012) helping manage their emotional reaction to the dysregulated emotions of their relative to enable a sensitive and compassionate or low – EE response to mitigate relapse. The psychoeducational training program would be delivered

collaboratively by a mental health professional and a peer mentor or advocate with lived experience. This would provide an open dialogical framework to (i) challenge myths and misconceptions surrounding the diagnosis as well as the attributions for and attitudes towards behaviours synonymous with the diagnosis and (ii) emotionally support, resource and build resilience towards creating a low – EE environment which promotes enablement and personal recovery.

Systems change

Participants' perceptions of acute inpatient care remain one of the most problematic elements of the UK mental health system (Muijen, 1999, 2002; Quirk & Lelliott, 2001; Schizophrenia Commission, 2012) with notable divisions between the perspectives of professionals "them" and patients "us" and where clinical practice overrides humane care (Alanen, 2009) which is often synonymous with coercion (Szasz, 2010). To break down this inherent power imbalance staff – patient relationships should differ in function not status (Rapoport, 1960). The primary function, however, must not be one of survival of the system founded on unhealthy coercive co-dependent relationships which inhibit recovery (Slade, et al., 2014) but on the enablement, wellness and resilience of the client built on compassionate and collaborative democratic dialogue. Outside of challenging and changing the establishment mind-set there is also a need for more recovery houses and psychiatric therapeutic community alternatives (Calton et al., 2007; Gale & Sánchez España, 2008; Slade et al., 2014; Swinburne, 2000; Tucker, 2001) staffed by those with lived experience (Mosher, 2001) which have been shown to be equally effective as traditional, medically oriented and perceived custodial models of care (Calton et al., 2007).

8.7 Limitations

Notwithstanding the collaborative nature of the inquiry it was restricted by the confines of it being a single person study, which relied on the good will and commitment of Paddy who enabled access to a difficult-to-access population of credible exemplars from the service user survivor movement in Ireland. More resources would have increased access to a larger group with greater diversity and who were at different stages of their recovery, not least those currently disengaged, in acute remission or hospitalised. Congruent with the PAR approach the study would have been strengthened by recruiting and embedding service users with lived experience

in the operationalisation stage. For example, conducting semi-structured interviews would have increased the sample size and tapped an otherwise untapped deep and rich vein of information which is not easily mined by professionals (like myself) without lived experience who are often perceived as part of the system as well as part of the problem. This highlights the tension between the methodologically collaborative PAR line of inquiry and my single person doctorate line of inquiry, an absent standard, which to a greater or lesser degree compromised the subjects and subject matter by creating an antithetical power imbalance which in turn potentially contributed to and influenced ethically important moments. A further limitation was my struggle with my postpositivist socialisation which undoubtedly increased the risk of postpostivising the constructivist – interpretivist methodology. On reflection, therefore, it is questionable if my initial interrogation of the literature to construct an *a priori* deductive "open" coding framework, putting my doctoral stamp on the inquiry expanded understanding by a process of triangulation or alternatively closed down and distorted understanding.

The purposeful sampling strategy alongside the limited resources surrounding the selection and recruitment also meant an absence of ethnic or cultural diversity in the sample. With the exception of one white female of South African origin, all the participants were white Irish. Although three of the participants had experienced psychiatric treatment under the UK mental health system a more culturally diverse sample could have usefully explored and compared the experiences of those from Black and ethnic minority backgrounds who are a notably disenfranchised, marginalised and oppressed group within the UK psychiatric system (Schizophrenia Commission, 2012). A further cross cultural study, therefore, would help to shed light on the contextual and cultural idiosyncrasies of this group which either help or hinder their personal recovery

Finally, while the participants were purposefully selected as credible exemplars by Paddy, equally because they were known to Paddy who as the collaborative inquirer and co-participant they knew was known to me, there may have been an explicit or implicit pressure to comply, that is to tell me what they thought Paddy wanted them to say. Equally, notwithstanding Paddy's depth, breadth, richness and reflexivity of and on his lifelong, hard earned lived experience there may have been an explicit or implicit pressure for me to comply and privilege his perspective over that of the other participants – a hierarchy of evidence of a different qualitative typology.

8.8. Conclusion

This PAR inquiry was founded on the principles of participation, "sharing [collaboratively] in something" and action, offering a practical alternative using research as a tool. Therein, therefore, lay the primary objective of producing "knowledge and action directly useful to a community [of persons whose experiences were synonymous with a schizophrenia diagnosis] and empowerment through consciousness raising" (Reason, 1994, p. 48). The inquiry produces knowledge to challenge and de-construct what is the essentially contested construct of schizophrenia along with the myths, misconceptions and negative stereotypes which maintain "it", raising conscious awareness of the inherent power imbalance in staff - client relationships maintained by "ill" conceived disciplinary power and absent standards. The inquiry acts to redress this power imbalance by privileging and giving free voice to the people who own the experience, supporting the call for an empowering "paradigm shift in relation to the experience that these [schizophrenia] diagnosis refer to" (BPS, 2014), breaking down divisions and taking "on board that there is no us and them", there are only people trying to make the best of our situation" (Understanding Psychosis and Schizophrenia, 2014, p. 113).

To support this paradigm shift mental health and allied professionals must first act to change their attitude to the person owning these experiences, tolerate the uncertainty of not knowing and openly embrace disconcerting incongruent experiential worlds. Second, they must engage in a meaningful and democratic dialogue towards "collaborative formulation" (Division of Clinical Psychology, 2011) and meaning-making which privileges and validates the unique lived experience of each individual client, promoting personal recovery through mutual, compassionate understanding, empowerment and enablement (Slade et al., 2014). Finally, they must routinely ask about adverse life-events and ensure services are trauma informed (Bloom & Farragher, 2010) and trauma based (Dillon et al., 2012).

Interpersonal as well as organisational relational dynamics formed the core of participants' experiences of what helped and what hindered them living with or recovering from a schizophrenia diagnosis. This reinforces and adds to counselling psychology's – "demand for rigorous empirical enquiry with a firm primacy of the counselling or psychotherapeutic relationship" (Professional Practice Guidelines, 2005, p.1), illuminating the interpersonal

attributes, attitudes, optimal role responsiveness and communication style specific to establishing and maintaining a relationship that is therapeutic with clients with a schizophrenia diagnosis. It is not, therefore, that these so-called difficult-to-engage clients do not want or cannot commit to establishing relationships, but rather they want and value "a different sort of relationship" which they can commit to.

Finally, in relation to institutional relational dynamics the inquiry challenges the establishment mind where coercion and clinical practice have become, albeit inadvertently, confused with cure or override humane care. It is clear, therefore, that the therapeutic potential of the psychiatric system does not and must not reside in the structure, but in the quality of the human relationships inside the social structure (Rapoport, 1960) where staff – patient relationships must differ in function not status. Moreover, the primary function of these systemic relationships must not be the survival of the system built on unhealthy, coercive co-dependency (Slade, et al., 2014), but on the survival and enablement of the client, built on open, collaborative, democratic dialogue and compassionate, reciprocal understanding where there is no "us" and "them", there are only people trying to make the best of our situation" (Understanding Psychosis and Schizophrenia, 2014, p. 113).

9. Epilogue – personal reflections

Several years have passed since I enthusiastically presented my research proposal to my then fellow Metanoia candidates who, along with my supervisor, received it with enthusiasm and encouragement, providing the impetus for me to submit and subsequently receive ethical approval from Middlesex.

In the intervening years the collaborative inquiry has in the words of one participant "transmogrified" in response to the inevitable challenges which emerged out of and in response to the PAR process. However, two near experience events related to both the "subjects" and "subject" matter of the inquiry deserve painful reflection, while equally respecting the sensitivity and integrity of those concerned.

I can't go on

Some two years into the inquiry on May Bank holiday I received a phone call from my then eighty-four year old mother (hitherto fully functional and independent) who calmly told me "I can't take anymore son, I can't go on I'm going to fill the bath and drown myself". Living nearby I intervened to prevent her acting on her intent to kill herself. However, this, her death wish saw a rapid and unstoppable downward spiral into a subjective non-consensual world either to escape from or being drawn into something terrible. Whatever tenuous contact she had with me and "my" reality involved telling me how much she wanted and deserved to die, but didn't deserve or want to suffer the torment she was experiencing by living – and knew I would understand. Ashamedly, I didn't. Psychopharmacological interventions proved ineffective. I took time off work to "be with" my mother 24/7 with the support of my wife, maternal aunt and sister. She refused to eat, drink or attend to her personal care, moving between extreme agitation and catatonia, muttering incomprehensibly and on one occasion tried strangling herself with the light cord in the bathroom, terrified, tormented and seemingly unreachable. Having worked in psychiatric therapeutic community alternatives this mindless torment was well known yet paradoxically unknown, while I had seen "it" before I had never seen my mother like this before, which terrified and tormented me. I desperately needed a context and was hopeful the ongoing physiological tests would reveal something organic, a medicalisation for my mothers' madness. Nothing.

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She continued to deteriorate, which saw the family pressurise me to have her admitted to psychiatric care where she would get "the specialist medical care" she needed. One evening I arrived at the house to witness her being interrogated by the crisis response team. She was worse than terrified. I persuaded all parties that hospitalisation was not necessary and advised I would speak to the consultant psychiatrist who luckily I knew.

This saw my family (maternal aunt /sister) turn on me, accusing me of neglect by refusing to have her hospitalised – she was "f------ sick". Thankfully the consultant was supportive as was the GP and both agreed psychiatric hospitalisation would not be in my mother's best interests and they mobilised admission to general hospital to treat her for dehydration and run further physical tests. A drip balanced her salt-potassium levels, which, alongside her being encouraged to eat, saw an improvement in her physical and mental state - hope. Some three weeks later I arrived at the hospital to find her confined to the bed shaking, eyes rolling and muttering, semi-or unconscious and seemingly oblivious to my "being present". The nursing staff informed me she had become extremely agitated through the night, they had called the duty psychiatrist who had administered depot "heavy duty" neuroleptic medication. I was demoralised, defeated, "fucking crushed".

Sufficiently recovered physically and subsequent tests revealing no underlying organic physiological abnormalities or conditions, she was released from hospital with a day "ego-support" program to ensure basic needs were met while attending psychiatry on an out- patient basis maintained on various combinations and doses of psycho-active medication. I visited daily. After two weeks she refused day-support and despite support from myself, my wife, relatives and neighbours she disengaged, refusing to eat or drink and unable to either leave or settle in the house because of debilitating anxiety, agitation, paranoia, fear and shame, praying for death and unreachable. A minor fall and fractured metatarsal saw her admitted to respite residential nursing care for the elderly infirm – which evolved into her home.

My emotional and evocative reflections on my mother are interspersed with comments – themes which emerged from and are true and relevant to the inquiry which equally could have been influenced by my near experience of caring for my mother whose experiences are to a greater or lesser degree synonymous with the "subjects" and "subject" of the inquiry. As such for me many questions remain unanswered. Would admission to psychiatric hospital - the "system" - and

perceived specialist medical treatment have killed or cured? Was I a neglectful son? Did I walk the walk and talk the talk, practice what I preach? Did I have the willingness or right skill set to step into the fire and "be with" or was I burnt out from being unable to tolerate the unbearable uncertainty of not knowing what to do or terrified and ashamed that I did the wrong thing. Why am I even including these reflections - am I authentic, genuine congruent? Am I unashamedly shaming, betraying her, playing the victim or martyr? Finally dependent on the answers to the questions posed, is my virtuous ethical character intact or destroyed and in tatters?

There ain't an escape

On July Bank Holiday 2013 I picked up a voice mail message from Paddy's eldest son asking that I contact his father urgently. On contacting Paddy he advised me that his wife L was missing. L had a diagnosis of bi-polar disorder, but had remained comparatively stable with no admissions to hospital for some 10 years as from meeting Paddy. I knew L well and like Paddy, she was a well-known, quietly active and popular member of the Irish and International survivor movement. I also knew that over the past six months she had been experiencing difficulties manifest by and cycling between paranoid guardedness and withdrawal and equally paranoid agitation, confusion and disorientation. Despite Paddy taking time off work to provide 24/7 care and "heavy duty" major tranquillising medication her manic state escalated to the point where against Paddy's better judgement and the pressure of him having to return to work she was hospitalised. Some weeks later a visit to hospital revealed extensive bruising, the result of being forcibly "held down" and administered depot neuroleptic medication. This persuaded Paddy and her family (mother and sisters) to mobilise discharge where between them they took up an auxiliary ego supportive function which saw slow but steady improvement.

Over this same period I met socially with L and Paddy on several occasions during what were routine overnight stays in their home, a welcoming and relaxed atmosphere where in front of a peat burning fire we discussed the progress of the current inquiry and engaged in general and typically light-hearted chit – chat. Subsequently Paddy asked if I would consider talking, engaging with L on a professional basis as there were "things", traumatic in her past, she had never spoken but wanted and was ready to speak about. An ethical dilemma? Fearful and resistant I gently pushed back, voicing my concerns regarding how my relationship with Paddy

and L would influence the impartiality of the therapeutic space, thereby potentially inhibiting open dialogue and disclosure. Paddy advised that she trusted and felt safe with me because I was not part of the "system".

Tragically, I never spoke to L either personally or professionally. Three torturous weeks from her going missing her body was found. She had taken her own life. The funeral saw the service-user, survivor community, mental health and allied professionals, families and friends come together to pay their respects to support and stand alongside Paddy to honour her life and memory. Burdened by his intense grief and the nature of her death as an icon of the "survivor" movement Paddy felt a deep sense of shame, guilt and betrayal. She had not survived under his watch. He was devastated, demoralised, "fucking crushed".

Yet another ethical, moral dilemma: would I/we bin the inquiry out of respect or perhaps more accurately for me from a felt sense of helpless defeat, despair, anger, demoralisation and perceived injustice? Alternatively, should I/we complete the inquiry in memory of and respect for L, my mother and others like her to raise conscious awareness, challenge myths, stigma and misconceptions?

In what has become a haunting hiatus, my mind continues to revisit Paddy's tragic but prophetic words;

You have no escape from it and that's why a lot of people commit suicide because there ain't, there ain't an escape from it and those that are intuitively, realise themselves that they can never escape from this are those that end up taking their own lives because they…. they realise that this is going to be their lives for the rest of their life cause they don't have the sense of knowing how to get out of it

L showed a courage and willingness to engage with and felt safe, trusted me. Did my hypocritical reluctance to engage convey, confirm there was no way out? Was I scared to walk the walk and "step into the fire" subject – subject, or am I simply feeding a false omnipotence and or martyrdom to think it would have changed the tragic outcome? Or are my meanderings nothing more than a hollow double-jeopardy for being unable to engage and bring my mother back to emotional life - reality.

Some months after L's death while driving home, I took a call on Bluetooth. It was Prof C of Dublin City University, where Paddy is employed as a senior Lecturer. She and another lecturer from the institution along with his sons and in-laws were in ego-auxiliary 24/7 attendance at

Paddy's home. She told me bemusedly that Paddy had taken to and was refusing to get out of bed for upwards of a week now. They were very concerned for his wellbeing and his sons and she wondered if I would be good enough to speak to him. I replied that I was willing to engage contingent on Paddy's willingness to talk to me. After some shuffling about they came back to say he would like to talk to me privately and they took the phone to the bedroom and closed the door. I apologised for not being in touch explaining that I was selfishly avoiding the pain of being unable to say or do anything to take away his unavoidable, perhaps unbearable grief and simply "didn't know what to say"? Paddy replied quietly there is nothing to do or say, but asked if I would kindly convey that he was far from "suicidal", just exhausted.

On reflection I found myself echoing the words of Edna his long time peer advocate and relayed to Prof C he's just exhausted let him sleep. At the same time I found myself feeling less burdened with the sense that Paddy could see and would find a way out which unlike my mother or L did not involve death.

Tolerating uncertainty

The fact that there are no correct answers to the questions asked and some questions remain unasked leaves me with the dilemma of having to tolerate the uncertainty of not knowing if what I did or didn't do (for my mother or L) was the right thing or did I get it horribly wrong? Wrestling with these painful near experience dilemmas has raised and sharply focused my conscious awareness of the subject and the subject matter and given me an extra layer of sensitivity which hones an implicit skinless relational responsivity which at times exposes and overwhelms me. As I write, exposed and vulnerable, Searle's words soar into my stream of consciousness "it is folly to set out to rescue the patient from the dragon of schizophrenia: the patient is both the maiden in the dragon's grip, and the dragon itself". (p. 75).

My mother subsequently contracted cancer and died in October, 2015. In the three months leading into and including her death, I was able to simply "be present, be with". As I witnessed her struggle with the physicality of dying, I also witnessed her come back to life emotionally and in death we reconnected and let each other go with an immense sadness but in peace. I decided to complete and submit the thesis and Paddy told me he trusts and will endorse what I have written post the chaos in each of our personal lives. However, I find myself ashamedly avoiding him to

avoid the pain I feel by being present in his presence while wondering if equally he is avoiding me for the same reason. For different reasons both of us are drawn to the subjective world of psychosis and have a lifelong passion for the work. I desperately want to reconnect in an inter-subjective space where we can reflect on and share our personal and professional experiences and hope the work can act as a catalyst to revitalise our conscious awareness and provide an impetus for both of us to emotionally reconnect and get back into the belly of the work.

When submitting an early first draft my supervisor commented that I needed to "big it up", that is the contribution to the field. A challenging and daunting thought given much of what we know is what we don't know about the perplexing and essentially contested concept of schizophrenia. This compounded by a deep shame based response to each of our near experience tragedies where terror, torment and enlightenment painfully coexists perhaps caused us, certainly me, to dumb it down. As such I hope we have struck a realistic optimism where the work will make a small but valuable contribution to raise conscious awareness with the establishment [psychological] mind, address myths, misconceptions and open a space where democratic collaborative dialogue can lead to therapeutic action that empowers, enables and promotes personal recovery.

I will end this my embattled and at times embittered journey of discovery with an ironic but an enlightening twist in the tail of the Searlian dragon. For Searles the dragon represents the patient's resistance to becoming "sane" enacted in a fierce battle with the therapist's relentless and heroic efforts to rescue them from the demon, which is perhaps also an equally savage fight to the death with our own (therapist) "insane" demonic parts. Searle's recalls discovering with wry amusement that Uccello's painting of St. George and the Dragon has an absurd but an illuminating feature. The dragon from which he is rescuing the maiden is actually a pet on a chain, apparently under her control.

Throughout this project and perhaps for much of my personal and professional life I have wrestled with my demons, like Searle's dragon, un-leashed, but on closer examination more under my control and implicitly known to me in my relationship with my mother than I ever realised. It is this knowingness that now makes painfully explicit my hitherto unfathomable and irresistible draw towards and easiness I felt with these essentially contested psychotic states of mind. In my relentless quest to rescue psychotic maidens and slay psychotic dragons, my

unwieldly near experience, double edged sword has served me well, at times both beguiling and tormenting me. With this project and the life of my mother having finally drawn to a close it seems the time is right for me to lay down my sword, wherein by surrendering to my fear of both knowing and not knowing what schizophrenia is will hopefully through time free me from its grip.

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APPENDIX I

<u>**INFORMATION LEAFLET**</u>

<u>An exploration of what helps and what hinders the person in living with or recovering from experiences synonymous with a psychiatric diagnosis.</u>

<u>Invitation to participate in a participatory action research project</u>

You are being invited to participate in a collaborative research study, which, we think is important to people whose experiences are synonymous with a diagnosis of "schizophrenia" (or related disorders), a diagnosis which you may or may not agree with. The following information tells you what is involved so that you can decide whether or not you want to participate. Please understand that this is entirely your choice and feel free to ask questions about anything which is unclear to you.

Many people with a psychiatric diagnosis report feeling stigmatised, isolated from and or by family and friends, which, makes it especially difficult to talk to and trust people. This means that the relationship with a mental health or allied professional is often the primary and most frequent point of human contact. This relationship, therefore, can either help or hinder the process of living with or recovering from the distressing experiences synonymous with a psychiatric diagnosis.

The research is collaborative in nature being conducted with my colleague and co-participant, Mr Paddy McGowan, who recovered from schizophrenia for which he was previously hospitalised. The research design gives great importance to the subjective experience of living with experiences synonymous with a psychiatric diagnosis and we are inviting you to participate in an interview with myself. The interview (arranged at a mutually convenient time, place) will last for approximately 60 - 90 minutes with an emphasis on exploring the interpersonal attributes of a significant person that you consider has either helped or hindered you in the process of living with or recovering from your distressing experiences. The interview will be digitally recorded and subsequently key themes-attributes will be identified.

You have been personally identified as it is considered that your lived experiences would be an invaluable source of information which will help to raise awareness, dispel myths and contribute to an increased understanding of how best to establish and maintain helpful and meaningful relationships with people who experience mental-health difficulties.

Confidentiality is assured and all interview responses-material will be made anonymous and only distinguishable by code-number. My collaborative inquirer (Paddy) and my supervisor from the Metanoia Institute in London will have access to this coded information to help with analysing the data but they will not be able to identify you personally.

What happens if you are worried: It is considered, there is little risk to you in taking part. However, if for whatever reason you experience any distress or become worried after the interview you can contact me in person to discuss any concerns you may have.

Name: David Cameron contact number: #######5445.

APPENDIX II

WRITTEN CONSENT FORM

Title of research proposal: An exploration of what helps and what hinders the person in living with or recovering from experiences synonymous with a psychiatric diagnosis.

REC Number:

Name of participant (Block Capitals):
Address:

The study organisers have invited me to take part in this research. ☐

I have read and understand what is in the information leaflet about the research. ☐

I have a copy of the leaflet to keep. ☐

I have had the chance to talk and ask questions about the study. ☐

I know what my part will be in the study and I know how long it will take. ☐

I know how the study may affect me. I have been told if there are possible risks. ☐

I understand that personal information is strictly confidential: I know the ☐
only people who may see information about my part in the study are the research team.

I willingly consent to be a participant in the study. No-one has put pressure on me. ☐

I know that I can withdraw from the study at any time. ☐

I know if I do not take part it will not influence my treatment in the future. ☐

I know that the interview will be audio-taped and kept only as long as necessary. ☐

☐

I know that if there are any problems, I can contact: David Cameron ☐

   Telephone no:……… #######5445…………………………….

Participant's Signature: ....

Date: ....

The following should be signed by the investigator responsible for obtaining consent

As the Investigator responsible for this research or a designated deputy, I confirm that I have explained to the participant named above, the nature and purpose of the research to be undertaken.

Investigator's Name: ....Signature: ....
Date: ....

APPENDIX IIIa
Table 1a. From codes to themes – *helped*

Table 1a. From codes to themes helped		
Codes (step 1)	*(Issues discussed)*	*Themes Identified (Step 2)*
-Self-affirming -De-medicalisation	Diagnosis Self-affirmation Holistic Embodied Lived experience Attributions Context Affect Relationships Lived experience	1. **More than the Diagnosis** is "ill" defined and doesn't define the person, misconceived illness saturated stereotypes are challenged.
-Destigmatising -Empowerment -Enablement -Collaborative -Normalisation	Independence Healthy protest Critical inquiry Resilience Normalisation Language Listening Relationships Flexibility Lived experience Personal identity Humanness Stereotypes Lived experience Power	2. **No sort of gobbledegook** identity is forged in iterative interaction using normal everyday language.
-Recovery -Wellness	Growth Aspirations Resilience Hope Endeavour Spirituality Relationships Diagnosis	3. **Getting my own interpretation** - non reductionist, idiosyncratic framework to understand experiences.
- Contextualised - Meaning making	Metaphor Narrative Symbolism Comprehensible Adverse experiences Relationships	4. **It happened for a reason** experiences are personally meaningful and understandable in the context of lived experience.
-Re-moralisation -Needs based	Pragmatism Flexibility	5. **Walking the walk** – ego-supportive, pragmatic, practical

-Solution focused	Shelter Support Doing with Achievements Unambiguous Safety Creativity Relationships	meets basic needs for food safety and shelter.
-Resilient -Goal oriented -Collaborative - Interpersonal	Collaboration Dependability Purposeful Goals Robustness Engagement Relationships Trust Safety Affect	6. **A different sort of relationship** - Affective, reliable, resilient and robust alliance, goals are agreed collaboratively.
- Attuned -Reflexive -Validating -Containing	Authenticity Openness Tolerance Reflexivity Self-awareness Empathy Humility Immediacy Steadfastness Mindfulness Terror Subjectivity Relationships Sensitivity	7. **Stepping into the fire** - open and attuned to subjective reality and a capacity to feel the fear without being frightened.
-Person centred -Being there	Empathy Trust Warmth Compassion Openness Humility Relationships	8. **Just being there** - person centred, collaborative, open minded, and ordinary way of being and being.
-Congruent -Authentic	Flexibility Tolerance Validating Patient Attuned	9. **Preaching what she spoke** - Authentic and accepting, beliefs and actions are congruent.
-Accepted -Non judgemental	Attributions Values	**10. Listened to not to be judged –** unconditional positive

	Relationships	regard

TABLE 1b. *From Codes to themes - hindered*

Codes (step 1)	(Issues discussed)	Themes Identified (Step 2)
- Illness saturated -Them and us	• Diagnosis • Symptoms • Aetiology • Stigma • Relationships • Identity • Doctor patient	1. **My trade was to be mad -** the diagnosis of schizophrenia defines the totality of the schizophrenic
- Labelling - Disciplinary power - Psychopathology	• Power – Authority • Dependency • Compliance • Psychopathology • Dogma • Language – jargon • Identity • Stereotypes	2. **Code words and mumbo jumbo** – Schizophrenic identity is forged in a unilateral relationship using pathological language and "disciplinary" power
- Medicalisation - Disempowering - Disabling	• Psychopathology • Deficits • Maintenance • Hopelessness • Despondency • Poor prognosis • Medication • Polypharmacy • Chronicity	3. **You're fucking sick** - experiences are "illness" saturated
-De-contextualised -De-meaning -Disembodied -Hostility	• Meaninglessness • Reductionist - biochemical • Concrete - Literal • Incomprehensible • Confusion • Fear	4. **What was going on?** Experiences are de-contextualised, divorced from lived experience and meaningless
-Demoralisation -Overprotective -Impractical	• Problems • Symptoms • Intrusiveness • Control • Ambiguity • Risk adverse • Basic needs • Dependency	5. **Expected to get along with life** - ego suppressive, impractical, over-protective and demoralising
-Problem focused -Prescriptive	• Aloofness • Arrogance	6. **You can't do this you have**

-Hierarchical	• Insensitive • Domineering • Detached	**to do that** Asymmetrical, detached, prescriptive and problem centred
-Impersonal -Objectifying -Disconnected -De-animated -Intolerant	• Guardedness • Insincere • Omnipotence • Omniscient • Distant • Detached • Fear • Persecution • Non-consensual experiences	7. **Fear from the unknown** - enforces objective reality and is fearful and intolerant of disconcerting subjective experiences.
-Authoritarian -Sanctimonious -Contemptuous	• Hostility • Condescending • Judgemental • Cynicism • Oppression • Callous	8. **A robot an element** – Domineering, cold, closed minded and impersonal.
-Dogmatic -Dispassionate -Incongruent	• Inflexibility • Intolerance • Impatience • Depersonalisation • Detached • Avoidant • Disingenuous	9. **No empathy, no compassion** dispassionate, dogmatic and un-empathic.
-Compliance -Regimented -Coercion	• Control • Rules and regulations • Procedural • Passive aggressive • Indignant • Inflexible • Powerless • Detained • Imprisoned • Co- dependency • Oppression	10. **Police state** the system is intolerant of disorder, survival relies on unhealthy co-dependent relationships
-Detained -Indoctrinated -Stigma	• Diagnosis • Power • Control • Psychiatric system	11. **Remotely controlled** the system is pervasive and its influence and insidious power extend beyond the walls of the

	- Fear - Paranoia - Entrapment - Shame - Indoctrination - Stereotypes	institution

Table 2a. From Basic to Organising to Global Themes – *Helped*

TABLE 2a. *From Basic to Organising to Global Themes – Helped*		
Themes as Basic Themes	*Organising Themes*	*Global Themes*
1. **More than the Diagnosis** is "ill" defined and doesn't define the person, misconceived illness saturated stereotypes are challenged	Language and identity	**Context Meaning making and Identity**
2. **No sort of gobbledegook** identity is forged in iterative interaction using normal everyday language		
3**. Getting my own interpretation** - non reductionist, idiosyncratic framework to understand experiences.	Attributions for non-consensual illness experience	
4. **It happened for a reason** experiences are personally meaningful and understandable in the context of lived experience.		
5. **Walking the walk** – ego-supportive, pragmatic, practical meets basic needs for food safety and shelter	Triadic Transitional	**Interpersonal relationships**
6. **A different sort of relationship** - Affective, reliable, resilient and robust alliance, goals are agreed collaboratively		
7. **Stepping into the fire** - open and attuned to subjective reality and a capacity to feel the fear without being frightened		
8. **Just being there** - person centred, collaborative, open minded, and ordinary way of being and being with	Humanistic	
9. **Preaching what she spoke** - Authentic and accepting, beliefs and actions are congruent.		
10. **Listened to not to be**		

judged – unconditional positive regard		

APPENDIX IVb

Table 2b. From Basic to Organising to Global Themes – *Hindered*

TABLE 2b. *From Basic to Organising to Global Themes – Hindered*		
Themes as Basic Themes	*Organising Themes*	*Global Themes*
1. **My trade was to be mad -** the diagnosis of schizophrenia defines the totality of the schizophrenic	Language and identity	**Context Meaning making and Identity**
2. **Code words and mumbo jumbo** – Schizophrenic identity is forged in a unilateral relationship using pathological language and "disciplinary" power		
3. **You're fucking sick** - experiences are "illness" saturated	Attributions for non-consensual illness experience	
4. **What was going on?** Experiences are de-contextualised, divorced from lived experience and meaningless		
5. **Expected to get along with life** - ego suppressive, impractical, over-protective and demoralising	Inflexible unilateral	**Interpersonal relationships**
6. **You can't do this you have to do that** Asymmetrical, detached, prescriptive and problem centred		
7. **Fear from the unknown** - enforces objective reality and is fearful and intolerant of disconcerting subjective experiences.		
8. **A robot an element-** Domineering, cold, closed minded and impersonal.	Authoritarian dogmatic	
9. **No empathy, no compassion** dispassionate, dogmatic and un-empathic.		
10. **Police state** the system is intolerant of disorder, survival	Psychiatric system	**Pathological Organisations**

relies on unhealthy co-dependent relationships and equates coercion with cure		
11. **Remotely controlled** the system is pervasive and its influence and insidious power extend beyond the walls of the institution		

Appendix 5 Table of categories

Table of Global Themes - Helped

Global Theme 1: Context, Meaning making and Identity; P= Paddy; P1 = Sean; P2 = Aedan; P3 = Aisling; P4 = Gerard; P5 = Odran; P6 = Ciara; P7 = Maeve

Organising Themes	Participants contributing to the theme	Dimensions to Themes	Cross References with line numbers of transcribed text	Indicative quotes with line numbers
Attribution for non-consensual illness experiences	P, P1, P2, P3, P4, P6, P7	**"It happened for a reason"** - spiritual enlightenment Traumatic – CSA - sexual violence/abuse, violence, grief, loss, estranged acrimonious relationship, friction, bullying, pressure, stress, escape, survival mechanism, drugs, genetic Meaning making **"Getting my own interpretation on it"**, creative, working through, letting go, shared experience, grieving, Karma, emotional	P/ P1/82, 420, 513, 889 P2/24, 26,107,150, 790 P3/17, 110,160, 220, 381, 478, 481, 564, 585, 592, 603 P4/46, 163, 858, 900, 908, 1018 P6/12, 51, 59, 120, 149, 174, 240, 271, 278, 284, 333, 378, 412, 509, 522, 527, 593, 605,1312, 1417, 1431 P7/18,22, 203, 221, 228, 400, 419 , 612, 634 , 720, 876, 1159	The context was that it was of grief so that was the first time I heard the voice P For me it happened for a reason, I see my psychosis as a spiritual enlightening or emergency P3/742 Maybe I was grieving for the world, that's what it felt like I had a lot of bullying there, really, and obviously a traumatic memory, which sort of, provoked me internally P4/54 But that wasn't really the main problem for me. When I was 11 I went through a traumatic experience of being molested sexually P5/12 A huge aspect of me moving on, is seeing it differently than other people, getting my own interpretation and my own meaning out of it P3/450 "Okay, well, that's where that's come from." And would trace everything back. P5/240 I am calling it a reaction, a normal reaction to an abnormal situation P5/522 I figured everything out for myself. Okay. What had happened is my marriage had broken up and it got really nasty. It was quite abusive, mentally abusive P7/18 That's how I can look at it now, by putting everything together as to the traumatic experience I had. P7/410 The voices made sense, yes. That's why I wasn't scared of the

		intelligence, diagnosis		voices. P7/1159
Language and identity		"**More than the diagnosis**" is "ill" defined and doesn't define the person Misconceived illness saturated stereotypes are challenged "**No sort of gobbledegook**" – normal, ordinary language	P6/333, 347, 353, 362, 543, 1062, 1089, 1177, 1186, 1247, 1508, 1172 P7/919, 991, 1055, 1145	Because I always knew it was more than just big bouts of depression P5/333, Just talk to me like I am normal P5/1642 Helped me normalise things in my own head. P7/698

Global Theme 2: **Interpersonal relationships**

Organising Themes	Participants contributing to the theme	Dimensions to Themes	Cross References with line numbers	Indicative quotes with line numbers
Humanistic	P, P1, P2, P3, P4, P6, P7	**"Just being there"** Person centred, present, accepting, gentle, alongside,	P/133,271, 687, 959 P1/, 432, 675, 696, 864, 885, 1049,1384 P2/511 P3/285, 291, 900, 913, 931, 939, 1012, 1110 P4/269, 292, 400, 579, 840, 992 P6/636, 824, 1628 P7/572, 1027	That comfort was there and that understanding was there and that acceptance was there P/271 It is down to the basic friendliness, that basic compassion. That should be what medicine is about in the first place, that kind of helpfulness. P1/1384 I have humanised them in my head. P6/1628 He was just really gentle, receptive but just present. Just being there I think was the biggest thing… this is where we are and this is where we are today, it was just being there with somebody until maybe they did open up about things P/ 133 He was just there on the level of I'm just here P3/291
				By watching her and seeing her, without her trying to coerce, was just observing her I started to realise there was something else that she was actually living and preaching what she spoke (P/756)
		"Preaching what she spoke" Congruent, genuineness, integrity, empathic, attuned, sensitive,	P/ 139, 352, 361, 377, 403, 587, 621, 636, 645, 756, 760, 763, 835,	

172

		respectful	960, 1285, 1300, 1051 P1/ 383, 420, 515, 528, 1204	Period of discovery, about this all what I had been through and these are people that, everyone had been through it themselves. It was great. P1/515 What she focused on was me, to be listened to, not to be judged P/ 152
		"To be listened to not to be judged" non- judgmental, tolerant permissive, unconditional, compassionate, understanding	P/152, 219, 229,239, 271, 376, 396, 470, 480, 494, 545, 842, 904, 969, 1051, 1384 P1/ 398, 596, 635, 973, 1083, 1094 P3/303, 308, 711, 1027 484,741, 840, 1034, P4/ 165, 218, 256, 277, 330, 348, 392, 411, 421, 473, 490, 618, 633, 635, 683,	People who are sympathetic towards you, definitely. It is the sympathy, and the sympathy it boils down to where ever you go P1/596 He was just being very real about who you were right there and then P3/303 I've come across one nice psychiatrist, but in that terms he's a lot more compassionate P3/711 A lot of love and compassion. P4/165

			751, 800, 805, 856, 873, 882, 886, 889, 930, 935, 949, 958, 975, 981, 1002, 1016, 1074	
			P6/274 689, 696, 709, 719, 968, 1062, 1089, 1100, 1274, 1368, 1642, 1688	
			P7/698, 869, 873, 877, 911, 919, 938, 956, 973, 1056, 1066, 1126, 1138, 1145	I think that just being able to talk to someone who understands things that you've been through, symptoms, and doesn't judge you. P7/919
Triadic Transitional	P, P1, P2, P3, P4, P5, P6, P7	**Ego – supportive "walking the walk"** - pragmatic,	P/132, 443, 637,645,	It was the basic things, the basic thing was, you know, how do we get food, how do we pay for this you know the basic fucking things about how we live P/882

| | | practical, meets basic needs, vocational, educational, occupational | 756, 760, 763, 867, 873, 882, 893, P1/ 211, 398, 513, 535, 906 , 962, 973. 995, 1016, 1083, 1092, 1024, 1295, 1384 P2/70, 79, 117, 590, 1051 P3/ 285, 292, 474, 506, 931, 1041, 1063, 1108, 1131 P4/246, 256, 266, 291, 297, 337, 350, 371, 381, 400, 410, 433, 473, 481, 485, 507, 521, 579, 587, | What actual therapy means is, something like playing a banjo, talking, having the crack or whatever, and just like talking to people, going out for a walk, stuff like that. P1/1092

I had a peer, someone I could talk to. One of the guys, a friend- P4/371
the peer support work also helped me recover. There was a weekly meeting there and people could ring and talk P4/880
I suppose with the peers and people around you then like you kind of almost make a joke of it P6/825 |

			602, 618, 626, 640, 648, 751, 792, 840, 856, 880, 931, 945, 976, 991 P5/369, 402,407, 570, 699 P6/ 825, 858, 1062, 1089, 1186, 1274, 1437	
		Therapeutic Alliance – "a different sort of relationship" robust, reliable, collaborative, affective, goal oriented	P/395,448, 469, 480, 490, 497, 556,570, 596, 621, 928, 958, P1/583, 588, 594, 1099 P4/130, 136, 220, 589, 688, 707, 864, 886, 890, 957, 1014 P5/199. 203, 554,	It was a different sort of relationship completely in the that sense and I think that was what built the faith in it that I realised this wasn't a relationship that was built out of, out of fear or domination or on neediness P/490

			597 P6/230, 450, 630, 1697	
		Subject – subject – "stepping into the fire" open and affectively attuned to subjective reality, embodied experiences, co-regulate affect	P/138, 377, 587, 864,874, 966, 969 P1/329, 419, 516, 889 P3/160, 171, 187, 192, 198, 217, 484, 511, 900, 1026, 1034 P4/422, 805, 1018, 1066, 1074	Being able to be aware of the subjective reality of the person that's with them P/966 The experience of illness or whatever you want to call it, the alternate reality P1/329 You can feel their energy and the intention of what they're coming in for P3/511 Just the sensitivity of it. Having an avenue for sensitivity P3/1034

Table of Global Themes – Hindered

Global Theme 1: Context, Meaning making and Identity

Organising Themes	Participants contributing to the theme	Dimensions to Themes	Cross References with line numbers	Indicative quotes with line numbers
Attribution for non-consensual illness experiences	P, P1, P2, P3, P4, P5, P6, P7	**What was going on?** **You're fucking sick** De-contextualised, depersonalised medicalised, illness, signs and symptoms, mad, schizophrenic, diagnosis, heritability, fear, stigma, confusion, hostility, projection, patronising	P/15, 18,45, 57, 61, 69, 166, 185, 193, 222, 245, 251, 255, 258, 276, 298, 459, 504, 528, 542, 624, 678, 694, 735, 812, 855, 981, 986, 1012, 1069 P1/ 76, 90, 119, 171, 198, 239, 261, 266, 429, 446, 461, 467, 760, 801, 816, 1332, 1349 P3/ 53, 269, 441, 502, 602, 637, 672, 775, 784, 789, 806, P4/ 194, 570, 612, 922 P5/ 41, 278, 433, P6/ 114, 127, 152, 170, 210,	Nobody had given me any context other than this was not a normal experience people do not normally experience hearing voices or seeing things or anything like that so this was an illness (P/2). But they used shock therapy and a lot of medication like Mellaril and heavy medication and stuff, the old style medication, Haloperidol and stuff P1/121 That is seen as your mental illness. That is like the anger or even grief these days, you know it is getting even worse in some respects P1/467 They just kept saying, "Take this medication. Take it, take it." They wouldn't listen to what I said P7/146 When I did speak to the doctors and I said to them, "Look, what happened to me?" They couldn't tell me. They put me on schizophrenic medication and they told me I had a psychotic moment. P7/187

Language and identity		My trade was to be mad Code words and mumbo jumbo Schizophrenic, illness identity, polarised, compliance, jargon, them and us, power, stigma, negative stereotypes, prejudice, discrimination, dogma	305, 325, 362, 480, 697, 805, 868, 907, 936, 988, 1397, 1657, 1673, 1705 P7/ 17, 26, 129, 141,146, 154, 166, 187, 416, 446, 542, 547, 609, 1008, 1058, 1175	
Language and identity		**My trade was to be mad** **Code words and mumbo jumbo** Schizophrenic, illness identity, polarised, compliance, jargon, them and us, power, stigma, negative stereotypes, prejudice, discrimination, dogma	P/51, 60, 218, 224, 248, 254, 258, 278, 288, 310, 384, 393, 458, 503, 507, 511, 522, 532, 536, 540, 577, 620, 624, 649, 672, 693, 724, 727, 735, 738, 741, 776, 803, 812, 856, 918, 981, 997, P1/40, 76, 119, 165, 171, 198, 261, 285, 323, 349, 363, 446, 462, 467, 718, 734, 751, 759, 774, 780, 800, 815, 875, 890, 898, 909, 1024, 1080, 1089,	He was beating me with a leather strap, I remember that and he kept telling me I was a lunatic it was the first time that ah, that someone actually equated the word lunatic to what was actually happening P/51 To me this was all fucking mumbo jumbo, but it was mumbo jumbo that these people knew and seemed to understand so I didn't question it. For them to make sense of what I was saying not that I made sense of it, I created a set of language and a way of describing and a way of articulating so that people would understand but it bore no resemblance of what I was trying to say. I knew it was the language I needed to use to play out any given circumstance that was around me (P/11) My trade was to be mad and their trade was to be the keeper of the mad and we played this game of who wins, who loses you know hide and seek P/727 Living with my mum as a schizophrenic was very difficult. P1/40 When you're in there everyone has code words, you have to do this or else you're going to do this, or this is going to happen P3/646 Yes, because I could see how she could change from when she thought she was talking to a professional to when she thought she was talking to a simpleton. P6/1611

			1142, 1162, 1231, 1242, 1332, P2/ 252, 318, 355, 1046, 1062 P3/ 308, 314, 608, 610, 646, 661, 665, 673, 755, 775, 777, 785, 791, 807, P4/ 194, 243, 293, 309, 364, 614, 924 P5/ 612 P6/35, 113, 115, 126, 152, 169, 231, 255, 281, 284, 305, 323, 336, 353, 362, 480, 522, 642, 697, 805, 899, 907, 928, 936, 973, 989, 1159, 1359, 1363, 1397, 1576, 1605, 1611, 1671, 1688, 1704 P7/ 132, 141, 166, 188, 416, 488, 531, 542, 551, 555, 560, 610, 1175	

Global Theme 2: Interpersonal Relationships Hindered

Organising Themes	Participants contributing to the theme	Dimensions to Themes	Cross References with line numbers	Indicative quotes with line numbers
Authoritarian dogmatic	P, P1, P2, P3, P4, P6, P7	"**A robot an element**" Domineering, cold, closed minded, impersonal, stigmatising, prejudice, discrimination, stereotypes, shaming, denigrating, condescending, involuntary detention	P/171, 190, 193, 243, 525, 527, 572, 693, 811, 854, 979, 985, P1/40, 70, 170, 198, 261, 266, 323, 332, 338, 341, 349, 354, 359, 365, 410, 426, 430, 436, 467, 557, 567, 717, 728, 742, 752, 759, 775, 759, 800, 807, 815, 896, 1026, 1132, 1142, 1151, 1231, 1242, 1280, 1297, 1311, 1319 P2/263, 329, 364, 369, 1046, 1062 P3/398, 441, 503, 603, 628, 644, 661, 665, 673, 678, 716 , 731, 733, 755, 775, 780, 785, 791, 807	To be shunned P/171 To be someone who carries a mark of shame or stigmatised or oppressed P/176 Living with my mum as a schizophrenic was very difficult P1/40 People laugh at, and they see mental people like retards, it is always a joke thing. Like, retards, spas, you know. "You are a spa, you are a retard, and you are off your head P1/349 "The men in white coats are going to come and get you." This entire thing, the lunatic asylum, P1/752 Yes, there is a stigma P2/1062 The way he was speaking was just I'm not here, I'm a robot and an element, I don't give a fuck. He was really arrogant, P3/665 Just the fact that you have a folder of mental health history and them knowing about it P3/731 It was like, "Oh God, not a bipolar person having a baby." P6/299 She really has been so overpowering, so put me down, put me down, put me down, P6/444 So I have to feel it like I have a contagious disease, P6/899 Oh yes, my mother would be ashamed too P6/914 "This woman is totally mad." I thought that if I had told them my story they would lock me up and I wouldn't get out P7/167 They would drag me off. A couple of times they had thrown me in the padded room, P7/511

			P4/39, 244, 293, 306, 318, 320, 491, 556, 614, 711, 843, 925, 964, 1010 P6/108, 121, 299, 302, 305, 323, 432, 442, 444, 642, 697, 866, 868, 880, 882, 899, 907, 914, 916, 921, 932, 936, 968, 973, 988, 1354, 1358, 1397, 1404, 1494, 1576, 1577, 1604, 1611, 1642, 1653, 1688, 1705, P7/129, 132, 141, 167, 187, 416, 511, 515, 543, 547, 555, 561, 632, 932, 1011, 1025, 1175, 1178,	
		"**No empathy, no compassion**" Dispassionate, dogmatic, un-empathic, intolerant, punitive, critical, hostile	P/44, 52, 57, 61, 84, 195, 219, 225, 1067 P1/ 129, 165, 220, 225, 446, 239, 462, 737, 754, 816, 870, 883, 1137, P2/143, 160, 463,	He [school-teacher] was beating me with a leather strap, I remember that and he kept telling me I was a lunatic P/ 52 The way base simple things of compassion, empathy…. Acceptance are way of the benchmark, they didn't have that P/219 There was one [Psychiatrist] who had no empathy so I just avoided her a few bad memories (P) I hated the nurse, she had no compassion, she was only

| | | | P3/513, 663, 678, 695
P4/ 370, 450, 452, 457, 542, 581, 763`
P6/144, 174, 198, 236, 463, 478, 486, 594, 620, 689, 695, 740, 744, 747, 788, 794, 811, 829, 852, 1470,
P7/142, 733, 735, 740, 753, 804, 807, 811, 859, 921, 996, 1046, 1052, 1058 | concerned about herself, there was this terrible power imbalance (P)
"Do you [Psychiatrist] talk to people like this normally? Are you that inhuman?"
When I first became ill, she [sister] roared at me in the hospital, "You're fucking sick" (P/3WS116172
In my case, I was not tolerated so I had to go the hospital route P1/220
It is worse than the Gestapo P1/754
They took me away in fucking handcuffs. Sorry, for swearing. P1/143
No, humanity. How could they let people like him be dealing with – people P3/694
Just the fact that you have a folder of mental health history and them knowing about it P4/ 314
For seven or eight years after that I got constant abuse for sleeping in P4/450
There was one who had no empathy so I just avoided her P4/681
There was never such a thing as, "Come here and we will give you a hug," or anything like that, P6/695 |
| | | | | |

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| Inflexible unilateral | P, P1, P2, P3, P4, P5, P6, P7 | "**Expected to get along with life**" Ego – suppressive, impractical, overprotective, unsupportive, and demoralising, self-defeating | P/ 534, 638, 706, 707, 725, 734, 809, 889, 893, 896,
 P1/ 38, 287, 295, 306, 425, 427, 442, 505, 530, 735, 795, 808, 815, 822, 870, 932, 981, 991, 985, 994, 1016, 1026, 1212, 1241, 1251, 1260, 1276, 1298, 1307, 1319,
 P2/143, 148, 463, 558, 837, 932, 1045
 P3/ 108, 723, 774, 1005,
 P4/458, 576, 588, 598, 613, 693, 736, 739, 769, 771, 781, 785, 896,
 P5/453
 P6/202, 433, 788, 795, 797, 816, 826, 849, 854, 861, 1434, 1444, 1451
 P7/449, 585, 593, 605, 657 | All the very things you should have.. or wanted to be in your life that you couldn't achieve was because of this new identity and it was almost respectable to have that covering identity of being a lunatic or being mentally ill and meant you couldn't achieve anything else P/534
 There was nothing really productive in it… in the sense of of learning a trade, P/725
 Nothing to do in there at all apart from smoke and play cards and get fat. Basically, to put it rather bluntly P/269
 I felt lucky that I actually got out of there. I resolved never to go back and I never did go back to hospital P/287
 I basically had to cure myself over the next 10 to 12 years and find myself out of that, the whole hospitalisation thing and the aftermath of it, and try to get back on the tracks again P/306
 But there was no sign posting back then P/505
 The hardest thing is that when you get back out of hospital you lose contact with everyone else. There is no real forum for us service users, of contacting service users or being in touch with other service users, or people like you P/530
 Jettisoned back out into society, I changed or transmogrified or transformed depression, transmogrified maybe a better word. I just expected to get along with life P/981
 Trying to get back into society, not thinking about it, but then it would happen again P3/108
 I wasn't great working on the farm so I was in the – cleaning the shed and my father came in shouting at me. I had no interest. My energy was sapped from the illness P4/456
 I'd go into work and for the first maybe half an hour I'd be asleep. I'd have to stand up straight, take off my jumper P4/781
 I lost everything I had. I had a house, I had friends; I had everything. I think I wanted to do the same like those days. I kept trying and trying it. But I wasn't getting anywhere P5/453 |

				And nobody to talk about it after coming out of the hospital until you have an appointment two weeks later and then one then and a month later, P6/202
				"Sure, you wouldn't be able to go for that. You haven't got your qualifications. You didn't finish your nursing P6/433
				Fuck can you throw me out in the fucking street, that I had no money. P6/795
				I went up to Galway, got a flat and stuff, but I wasn't well then. I wasn't well, everything got on top of me P6/797
				"This is fucking shite." And just putting down the bag and crying and it is like, "This isn't fair. I should have some better support then this shite." P6/816
				My first week hospital was like, "Oh God no I'm going to be going home. I am going to go out homeless. Sure, I have to do this and I have to do like." There was no rest at all P6/1444
				My head was still spinning. I had to drive, I had to work, I had to fill in forms, and it was the most difficult thing to do because I couldn't concentrate P7/449
				On top of my marriage breaking up, my hours got cut down at work. I couldn't afford my apartment anymore P7/461
				I panicked. I didn't know what to do. I had this bill. "I've got to pay this bill, I've got to pay this bill. I've got to pay my rent. What do I do? What I do?"P7/465
			P/243, 250, 254, 257, 277, 285, 341, 375, 662, 666, 672, 677, 686, 854, 911 P1/63, 70, 76, 119, 129, 239, 261, 266, 444, 447, 467, 563, 780, 800, 882,	I could question some of the treatments, I could question the use of ECT and the use of anti-psychotic medication, I could question all of that P/243
				They were just wrong, they were biologically or biochemically wrong, my brain was wrong, so therefore I was mentally ill P/250
				My experience was that nobody wanted to deal with you. Everybody was trying to put you in the direction of the psychiatrist, P70
				They basically threw the book at me as far as treatments

| | | "**You can't do this you have to do that**" Asymmetrical, detached, dismissive, defensive, condescending, impersonal, prescriptive and problem centred, refer on | 1092, 1132, 1137, 1142, 1151, 1163, 1332, 1349, P2/319, 364, 369, 830, P3/54, 441, 503, 624, 638, 644, 646, 654, 661, 665, 673, 681, 694 , 710 , 716, 752, 780, 785, 790, 803, 807, 1057 P4/193, 243,287, 293, 299, 305, 308, 314, 318, 320, 364, 497, 690, 925, 954, 1054 P5/278, 433 P6/120, 126, 138, 145, 148, 152, 259, 323, 444, 479, 486, 522, 620, 636, 642, 659, 689, 747, 925, 933, 958, 970, 1394, 1571, 1586, 1597, 1608, 1650, 1662, 1668, 1678, 169, 1702 P7/ 129, 141, 188, 416, 542, | P1/119 A lot of people that want to put you in hospital straight away P/198 I still feel angry about the fact they gave me shock therapy. I do not think that achieved anything at all P/239 They were trying to treat the illness, yes, but they basically just had their idea. P/261 Too much reliance on medication and shock therapy and stuff like that. Over reliance on medication, P/266 Then there was no talk about anything, there was no talking. They did not talk about anything P/436 There is no talking, it is just all this monolith of medication, P/447 Most of them are very brisk, they are like doctors, writing away at their scripts P/1132 Too formal and too cut and dried, very cut and dried. Not people you can loosen up to P/1137 Very much shell shocked from it all and kept in a room. I never associated with the fact that it was in hospital, it was a complete blur P3/54 It opened my eyes – I was taking medication so I said, "Why am I taking this?"P4/193 The psychiatrists had all the power so they could see you if they wanted to see you P4/243 Nurses just stayed in the kitchen so they didn't interact P4/293 305 People aren't ready, killing the voices, or they might be institutionalised. P4/1054 I was getting injections and the tablets were making me sick. They wouldn't let me out P5/433 They put me on antidepressants and they tried to blame the hormones and stuff like that. But they put me on antidepressants, I would say about 15 years of age P6/126 Plenty of tranquillisers and antidepressants and stuff P6/170 |

				554, 566, 1176, 1178	So I have never had any of this normalised for me; only what I have been constantly throwing around in my head P6/210
					I really had to drag it out of them because they wouldn't tell me anything P6/259
					You know bipolar people don't really have normal relationships P6/305
					She noticed it wasn't normal behaviour for somebody my age, but she brought me to the doctor, they told me I was a bully and they put me on antidepressants, P6/479
					"Look at me, look at me, look at me. Ask me, ask me what's wrong." P6/689
					They have all those expectations of you and expect you to be a certain way. P6/958
					Yes, because I could see how she could change from when she thought she was talking to a professional to when she thought she was talking to a simpleton, P6/1608
					Every time I went to see the psychiatrist in the past two years. Every time I went in, you are going in now to be told I am so pretty and I can do anything. I was like, "If I fucking hear it one more time I'll slap her in the face." That is not going to help me, stop patronising me. P6/1650
					You have two or three minutes to give them two or three months P6/1662
					I never felt understood, I was never given time. Time what the psychiatrist need. And you never will. I never felt that they took any time to really talk to me so everything was always very rushed P6/1678
					Yes, to really to get an idea of who EK is because you are the next customer, check stamp, out you go, here is your thing, out you go. P6/1685
					He said, "Look, take her to hospital." I tried to run away, out of the police station. They grabbed me and they forced me into the car P7/129
					They just kept saying, "Take this medication. Take it, take it."

		Pushed onto me Fear from the unknown" Enforces objective reality and is fearful and intolerant of disconcerting subjective experiences, disembodied,		They wouldn't listen to what I said P7/141 They couldn't tell me. They put me on schizophrenic medication and they told me I had a psychotic moment. P7/188 I refused to take it. They would stand screaming at me, so I did take it. P7/542 "Swallow your medication, swallow your medication. Swallow it, swallow it, swallow, swallow it, swallow it." P7/547 I'd put it in my mouth and they'd go, "Swallow." I go (Makes swallowing noise) and they'd say, "Good girl" and I'd walk off, throw it away. P7/554 The doctor I saw would only release me if I agreed to go there P7/566
			P/ 163, 168, 190, 193, 224, 868, 980, 985 P1/165, 171, 185, 193, 322, 329, 444, 575, 583, 742, 897, 1021, P4/103, 136, 449, 1010 P5/474, 480, 518, 525, 829, 860, P6/110, 865, 879, 891, 904, 1350, 1355 P7/166, 827, 839, 922, 925, 932, 1011, 1025, 1058, 1139	Fears the first thing P/163 Discomfort that everyone around me has created or correction a lot of people that I've come into contact.. been around have been uncomfortable P/190 They have projected their... their discomfort onto me and I think others have become a victim of that P/193 Totally against me, my my experience because the problem.. So there was no validation, but it was, it was my experience was the proof (laughs) that I was mentally ill in their eyes P/221 Putting the pressure of having to fit or conform. P/968 Everybody else does not agree with that, you see? That is the whole problem with people being in an alternate state, sort of being psychotic or whatever P/165 What I needed was people to explore with me what I had been through, rather than just, you know, he is there, we are here, this kind of thing. It is almost, people did not talk anything about it at all. It was never talked about P/322 It is my world, but it is like, people cannot tell that what is going on with you. P/575

				People are afraid of losing their minds big time. It is one of the biggest fears of people P/722
				How the fuck are they ever going to know what this feels like? They're never going to have a clue to know P3/329
				I just don't' get it. It's just fear, fear from the unknown. We're coming from that and they're coming from that, but completely separate, completely different ways of looking at it, 609/P3
				They didn't know exactly what was going on P4/103
				I had a therapist, but he wasn't really sure what was happening. He was a very good guy, but you know P4/136
				Now you're hitting it – they thought they understood, but they never understood P4/449
				I'd feel like I was kicked in the stomach from the people not understanding what was going on in my own head P4/1010
				I found it hard. I'm never going to be right. That's why people are at me because I'm I'm, no good to people; I'm useless. It's hard to get on well with people P5/474
				If I wasn't thinking the right things, I wasn't smart or cute or anything to help myself that they might lock me up or something P5/518
				She wasn't aware of what was going on in my head, P6/110
				So we will avoid that, avoid the fact that we are sitting in a psychiatric unit and we will talk shite about everything else." The pink elephant, they will go "Can't see it." P6/865
				They are all very good in theory like, the slightest sign of anything wrong, then I thought I could handle the bipolar thing but I can't P6/1350
				I could see just that they thought, "This woman is totally mad." I thought that if I had told them my story they would lock me up P7/166
				I could see it in his face, he didn't believe me. P7/922
				"Don't tell him anymore because he's going to think you're nuts. He doesn't believe you anyway." P7/932

| | | | | She was interviewing me. I felt like I was being interrogated. That's what I felt like P7/1011 |
| | | | | Everybody was looking at me and didn't know where I was coming from. They didn't understand P7/1058 |

Global Theme 3. Pathological Organisations Hindered

Organising Themes	Participants contributing to the theme	Dimensions to Themes	Cross References with line numbers	Indicative quotes with line numbers
Police state	P, P1, P2, P3, P4, P5, P6, P7	Intolerant of disorder, control, rules and regulations, procedures, passive aggressive, indignant, inflexible, detained, disempowered, imprisoned, unhealthy co-dependency, oppressive	P/177, 226, 244, 251, 258, 304, 328, 378, 426, 463, 706, 718, 721,728, 735, 741, 824, 835, 892, 894, 900, 912, 916, 976, 981, 986, 996, 1082, 1090 P1/114, 119, 120, 122, 129, 239, 240, 248, 261, 261, 285, 287, 446, 460, 475, 831, 882 P2/329, 364 P3/53, 314, 626, 632, 638, 644, 647, 710, 780, 785 P4/ 243, 293, 305, 320, 322 P5/ 412, 433, 519 P6/170, 556, 765, 772, 1310, 1573, 1602,	The system has several (negative) personalities, part of the personality is paranoid, totally delusional and insane, the system itself is fucking totally mentally ill. I experienced negative personalities P/935 The compliance piece and all that end of it sits into it, you are stuck within that system P/ 948 It's not helpful, but it's helpful for the system, it's helpful to keep that system alive P/741 I was forcibly compliant ah, we played this game of who wins, who loses you learn how to play these games how to create and keep the system going P/728 They wanted me to comply, but they gave me the authority to be mad P/! I got hospitalised and that was quite traumatic P1/114 Threw the book at me as far as treatments are concerned P1/120 They used shock therapy and a lot of medication like Mellaril and heavy medication and stuff, the old style medication, Haloperidol and stuff P1/122 I still feel angry about the fact they gave me shock therapy. I do not think that achieved anything at all P1/239 I felt lucky that I actually got out of there. I resolved never to go back and I never did go back to hospital P1/287 The thing about hospital, it just fucking crushes you It is just there is no talking, it is just all this monolith of medication, standing over you like a police state P1/446. The whole scary thing about the whole mental asylums is that, if you lose the plot or if you get angry or mad then they will

| | | | 1608, 1685
P7/132, 140,
166, 178, 229,
416, 481, 486,
509, 525, 542,
547, 550, 566 | dope you up. They will shock you or whatever. Like the One Flew Over The Cuckoo's Nest sort of thing P1/460
The nurses – there was a power imbalance, It wasn't nice 'sucking up' to the nurse…, I hated the nurse… I just remembered that memory, "I have to get out of this place P/
I felt lucky that I actually got out of there. I resolved never to go back and I never did go back to hospital P1/287
This entire thing, the lunatic asylum, where they do all these horrible things to you, it is worse than the Gestapo. Basically, it is like a concentration camp P1/753
But the medical hospital was - at first it was hard because the cell - the room you're in was very cold P2/364
Yes, I was in hospital for two weeks, but very much shell shocked from it all and kept in a room P3/53 It's a weird place in there when you're at the beginning of coming into that place, people have a lot of game playing, patients playing games and playing the system P3/308
In hospital, maybe two weeks. The threatening aspect of that P3/632
I didn't want to be a part of the how things work around here, well, I complied obviously at the time. I really didn't want to P3/654
It does feel like that. It is archaic. It's really old fashioned. P3/710
The psychiatrists had all the power P4/243
This is bullshit what is happening here [hospital], you know, with the nurses, they are not helping anyone" P4/299
There was a power imbalance P4/305
I just remembered that memory, "I have to get out of this place." P4/322
It was frightening P5/412
I was getting injections and the tablets were making me sick. They wouldn't let me out P5/433
I wasn't smart or cute or anything to help myself that they |

				might lock me up or something P5/519
				Sitting up in a bed smoking cigarettes and given plenty of tranquillisers and antidepressants and stuff P6/170
				So where have the 10 years gone, in and out of hospital like I have achieved fucking nothing because of the services P6/556
				Often they were all talking shit and that wasn't it and I don't want to kill myself. I got my way out of it, I said, "I have to get out of here"P6/765
				No, not I was only 18, I was fucking terrified P6/772
				Even hospitalisation a couple of times; that they would have sucked the energy out of me P6/1310
				Sending you for therapy that you didn't ask for. And suggesting, like I actually didn't want to do cognitive analytical therapy, but just because they told me I needed I did P6/1573
				I'm not going to see that OT. That patronising fucking bitch. How dare she use that tone of voice with me. Am I stupid?"P6/1602
				I could see how she could change from when she thought she was talking to a professional to when she thought she was talking to a simpleton P6/1608
				They took me into- it was a padded cell P7/132
				We were arguing whether I should take this medication. They just kept saying, "Take this medication. Take it, take it." They wouldn't listen to what I said. Eventually, I put it in my mouth and they said, "Swallow" and I pretended to swallow P7/140
				I could see just that they thought, "This woman is totally mad." I thought that if I had told them my story they would lock me up and I wouldn't get out P7/166
				It was terrible P7/178
				I was in there involuntarily. I wouldn't have gone voluntarily P7/229
				They put me on schizophrenic medication and it didn't help at all. It just spaced me out completely and I was confused P7/416
				When I was in the hospital all I wanted to do was get out of

				there. My whole aim was to get out P7/481 To get out of hospital, yes, yes. That's what drove me P7/486 I remember the door opening up and I would make a run for it, but I was really trying to get out and they would drag me off. A couple of times they had thrown me in the padded room. P7/509 I started to cop on, "Sylvia, look, if you carry on like this they're going to throw you in here and throw away the key and you're not going to get out."P7/515 I refused to take it. They would stand screaming at me, so I did take it P7/542 "Swallow your medication, swallow your medication. Swallow it, swallow it, swallow, swallow it, swallow it." P7/547 I would line up waiting for the medication, "Where's my medication?" It was an act. "Where's my medication? I want my medication. I want it." P7/550 It was like it took four days to suss out what was going on. Then, once they thought they had me under control I obviously played ball and eventually I got out P7/560 The day hospital, yes. What that was, the doctor I saw would only release me if I agreed to go there, so I agreed to go there. P7/566
Remotely controlled			P/177, 511, 524, 530, 531, 532, 640, 749, 752, 776, 782, 786, 792, 813, 1005, 1092 P1/307, 332, 349, 359, 360, 365, 368, 409, 467, 717, 737, 742, 752, 896,	Carries a mark of shame or stigmatised or oppressed or whatever way you want to describe it P/177 They have projected their… their discomfort onto me and I think others have become a victim of that P/194 My own identity had been taken from me P/511 They're fucking lost cause they still refer to the, the asylum, they still refer to how things work in, within the asylum P/749 Taken totally out with them P/752 Once you're given the diagnosis. Whether you spend all of your time in hospital or hospital ward or whether you spend it at home in your own community or a hostel or anything else

			932, 1024, 1033, 1141, 1151, 1165, 1204, 1217, 1241, 1251, 1332 P2/1062 P3/731, 739, 756, 1052, 1057 P4/557, 613, 756, 924 P5/495, P6/298, 302, 560, 896, 904, 911, 918, 933, 1355, 1420 P7/632, 802, 827, 833, 842, 921, 932	you're detained P/776 You're detained within that psychiatric system, whether it be within the walls or outside of it because you're totally detained into the way it works the way you're treated and everything else around it P/782 People are remotely controlled now from within the four walls, they don't even have to be there you know they're totally fucking controlled within that system P/1092 The whole hospitalisation thing and the aftermath of it, and try to get back on the tracks again P1/307 The experience of being in hospital, the experience of illness or whatever you want to call it, the alternate reality P1/329 A lot of people, most people, everyone has a kind of a prejudice. There is that inbuilt P1/340 They see mental people like retards, it is always a joke thing. Like, retards, spas, you know. "You are a spa, you are a retard, and you are off your head." P1/349things to be in the way of my happiness are things like my involvement as a service user with the mental health service P1/409 That is seen as your mental illness. That is like the anger or even grief these days, P1/467 They were never let out of the room, people were kept in rooms in this country and never let out of the rooms. They were just kept prisoners in their own homes P1/727 There was shame and really a morbid fear P1/742 They would say, "The men in white coats are going to come and get you." P1/752 The whole society, the locality at home knows about it, but I have to just keep your head P1/1033 Yes, there is a stigma around there P2/1062 Just the fact that you have a folder of mental health history and them knowing P3/731 It's just that sense of just me and them and the separation P3/1052

				I'd have a few bad memories where I wasn't being accepted so P4/557
				So normal people would say, like in our work someone would start hearing voices so they might say, "Oh, we had better bring you into the hospital," when they could manage at home P4/613
				My parents went to the Shine group and they said something like, "You are the best person we've seen with this illness." P4/924
				Yes and people won't leave me alone. The town people won't leave me alone P5/495
				Her face was terrified as if I was her daughter and I was 14, going to have a baby. It was like, "Oh God, not a bipolar person having a baby." P6/298
				Other people's not actually saying it, but I get the impression people like you can't really now have kids; and you will never be in a normal relationship really, you know bipolar people don't really have normal relationships P6/302
				15 years of my life are stolen from me that I didn't get to live without being cornered or feeling watched, analysed and blamed." I just hadn't been free to just be for 15 years, so that is annoying P6/560
				So I have to feel it like I have a contagious disease P6/896
				The stigma of it, like you know padded cells and people chained to the walls and the lunatic asylum P6/904
				Oh yes, my mother would be ashamed too P6/911
				She was so ashamed, you know. It was like, "What are you ashamed about, it's not you it's me." reflection on her P6/918
				So they have stuck me in the box now without me realising. That is what they have done to me and they treat me like that. So I can't be normal, everything I do is something to do with P6/933
				One tear that came out of my eye, "Oh, it's the bipolar." Gone P6/1355

				I am using the word 'normal' a lot, but what I mean is what society thinks P6/1401
				He tried to get sole custody of my son, saying I was in hospital and I was unstable P7/632
				In my head at the time, it was almost like brainwashing and I was petrified of him, absolutely petrified P7/802
				I didn't really tell anybody the whole story because I was scared what they would think of me and how they would relate to me P7/827
				The guy I was with for just over a year, I tried telling him part of my story, but I could see it in his face he didn't believe me. P7/921
				Yes. I shut down then. I completely shut down and like, "Don't tell him anymore because he's going to think you're nuts P7/932

APPENDIX 6 Examples of Transcripts

Paddy

DC: I don't know where you want to start in terms of going back to when you first felt there was a problem, or has it changed… even if you think if someone had related to you at that point in time other than they did, because you, from what you have told me before were much in the dark about what was going on so you were much more I don't know accepting of what people were telling you.

PMc: See for me….. well for me if you go back to the earliest point… the earliest point for me is 14 years of age.

DC: 14 years of age.

PMc: Ah… that was…. I remember, I can actually remember exactly the first time I first heard voices… I can remember it…..it was ten past two on a Friday in a history class at school and I remember hearing a woman's voice at the back of my head (indicates with hand and looks round behind him) but I had no understanding of what was going on other than I heard a woman's voice.

DC: So you had no sense or way of making meaning of that experience.

PMc: There was absolutely no, absolutely nothing there was no context as such you know even to this day I've often asked myself…

DC: No context.

PMc: Well there was a context but there wasn't a context, there is a context but then there was absolutely no understanding of where… why or what it was about.

DC: At that point in time.

PMc: Not… not…not when it first…… the thing that has always played about with me.. why was it ten past two, why was it a Friday evening, why was it a history class at school, why did this start…. you know….you know why was it not nine minutes past two or ten past five in the evening, why was it bang.. ten past two this woman's voice starts at the back of the head that's how quick it was, it wasn't something that gradually happened it was just bang (claps hands together) one minute there is nothing there everything is going along as if it was the way it's supposed to be and all of a sudden this addition, this thing arrives and it happened to be a voice and as we.. the context of it went on that the voice actually turned out to be that of my grandmother and you know.. so the context of that was now for me to understand now was that two weeks before the voice started my grandmother had died I'd seen her die, seen her buried, seen her wake and seen her buried……… so as far as I was concerned she was gone, at the time I didn't know that's what the voice was about… but.

DC: There was no link between the experience and the voice.

PMc: Well there was no link…. No not in the sense.. no obviously I was traumatised in the sense that I was grieving but there was no well… it wasn't a traumatised state I wasn't experiencing a traumatised state other than the fact of it being grief, I don't know whether you can equate grief as being trauma or as trauma being grief… but you know what I'm saying it wasn't…..ah…. the context was that it was of grief so that was the first time I heard the voice but and that…. So that voice carried on.

DC: I mean what was your experience of that experience.. was it frightening… was it bizarre.

PMc: There was no fear with it.

DC: No fear.

PMc: Absolutely no fear with it because well when it started I seen it as a joke as a laugh when I started to tell everybody about hearing this voice everybody was laughing except the teacher he wasn't laughing…. like it was only his reaction to me that actually scared me and made me start to think that there was something wrong.

DC: So that was the first point then… it was somebody else's reaction to what you were experiencing.

PMc: Yeah.. yeah he well… he obviously thought I was taking the piss that I was fooling about or whatever it was …… and when in fact when I think back on it now its only when you ask me that question well…… I haven't, I haven't really ever thought of it I remember he was… he was beating me with a leather strap, I remember that and he kept telling me I was a lunatic.

DC: Whenever you disclosed.

PMc: Yeah …… well I started telling him about hearing this woman's voice…. well I suppose I was half-jokingly laughing when I was telling him about hearing this woman's voice and his reaction was he just lost it.

DC: His reaction was he punished you in a very brutal way.

PMc: Well…. Ah….. that's the way it was then, the point, the point for me I hadn't thought about it, its only now that I'm thinking about it, it was the first time that ah……..that someone actually equated the word lunatic to what was actually happening without me understanding….. obviously I heard the word before but I'd never made any connection with it, never made any sense…. never you know…. didn't internalise it to be anything to do with me, it was just a word, just a way of talking……but I suppose his reaction and I don't know for I never spoke to him about it, but his reaction was probably two things, probably one of frustration in the sense that I was acting the lag and this thing was going on and talking about hearing woman's voices and him sort of picking up on the sense that I was talking about hearing voices and telling him and everybody else that I was hearing this voice and his reaction to that was probably only fucking lunatics hear voices you know…. So there was probably part of it.

DC: So what was that like……something which was very unhelpful which you internalised.

PMc: Ah totally…..well to some degree I must have internalised it but its only as time progressed on that it…….the first voice never became a problem as such, it was only later on

with the addition of the other voices that it became a problem that the……..because for many ways for me when I first started to hear that voice it was as I say it was nothing of fear…..but for me it was like a progression…………………………..of a…..it was like an addition to puberty it was actually….. internally I thought like.. I thought this is what happens whenever everything else is changing and all those other things are happening that this must be…..this must be what happens so it wasn't a problem it was only later that…

DC: So whenever he responded in that way did you think differently of the experience.

PMc: I don't think….I don't think I did and I probably did sub-consciously but then I suppose his response to me seemed a natural response because that's how he responded to everything that annoyed him so therefore that's what….. you know that's what we were used to, that's the way schools were, that's the way punishments were dealt out so therefore that end of it didn't……there was a bigger fear about being punished, but it wasn't about being punished for hearing the voices it was about the punishment so probably one part of me internalised it and one part of me normalised it if that makes sense in the sense of this is what happens at this place at this time and that's how things are dealt with…….but as I say its only as years went on and different things happened and the addition of the other voices that I started…..well the context of them changed in the sense that the first voice has never been…..never been problematic in the sense of…..sense of being negative….it has always been a positive ah…. the other voices…

DC: But the response to your disclosing it was negative but I mean… you think then you thought well I'm not going to tell anybody about what I'm experiencing.

PMc: Well you see I didn't tell anybody…….I didn't tell anybody for years after that I was experiencing or hearing voices.

DC: As from the fourteen year old who told the school teacher.

PMc:Yeah……told nobody nothing….. right up until I was in psychiatric services for a period of time… before I actually disclosed to anybody and I would have been in for a fair period of time before I disclosed to anybody that I was hearing voices so I had entered the psychiatric system without disclosing that I was a voice hearer it was only as time changed that I happened to tell that I was hearing voices so that end of it has never…you know that end of it has never really changed you know in that sense… but I suppose but it has been…it has been… I haven't really thought….I never really thought about it in any great depth about the initial.. the first time to be honest its only now that I've sort of …when you ask the question and go back that far to think about it… it must have been internalised there must have been some part of an internal…an internal fear and maybe that built from there within me.

DC: And then as well you're saying that the context was whenever you think back the context was at that time you were….. also at that time grieving for your grandmother.

PMc: Well yeah and that was…..that is the context of it ….ah the context of it was… the context was her death but the voice that I heard was definitely hers and still is hers, initially I didn't know it to be hers because I thought she was dead, buried, gone….so therefore it couldn't be her, but it makes sense that it's her because even to this day……..when she speaks it's her in every sense of the way ah……mannerisms, the tone everything is exactly the sort of conversations, the

advice that is exactly how she was when she was alive, that end of it…….that end of it hasn't changed.

DC:I mean … you get comfort from that.

PMc: Ah immense comfort.

DC: All the time.

PMc: All the time, I never, I never…..her voice is the constant… the constant that keeps things positive if it wasn't there probably, well I would hazard a guess to say that if her voice hadn't have stayed and hadn't stayed constant I probably wouldn't…probably wouldn't be here to-day because there would have been many times when I would have attempted or tried to take my own life, I definitely would have succeeded if her voice hadn't been there probably still would….. times, times when real depth of trouble or bother or problems it was her voice that sort of always brings the level back into it.. brings the sort of well…opens ..ah presents you with the questions that makes you start to think in a deeper sense about what it is that's really bothering…bothering you in the first place.

DC: Do you think that kind of defined the relationship you had with your grandmother.

PMc: Ah yeah, ah yeah she was…as I have said several times she was my education… she was you know sense of history, sense of being, sense of knowledge came from her I would say my education stopped the day that she died…ah because I never…I never picked it up at school or never understood much at school or stuff like that but whatever I do….whatever the little I do know I know from her.

DC: So you had a sense of feeling really understood by her.

PMc: Ah totally and she….there was no question about that…..ah yeah she was one of those people who didn't have to speak to you knew by the look of her you knew by the way she was ….. she was a remarkable being now a remarkable woman (Pause).

DC: Whenever you think back about that because in many ways what you're saying is what you got from your grandmother was something which sustained you…… from that relationship from that real relationship that whenever you heard the voice of what you now recognise as your grand-mum's - grandmother what do you think you would have needed at that particular time from someone not from grand-mum she almost provided something for you even though she was gone but what do you think you could have gotten from the real world from say….. say from the teacher what sort of a response would have been helpful for you if you disclosed that have you any idea now or is that just impossible… impossible to think about.

PMc: No to be understood.

DC: To be understood.

PMc: Yeah I suppose in many ways to be listened to…….not to be judged.

DC: Pretty normal ordinary things.

PMc: Yeah well you see that's….that's the funny thing about it in the sense that those are the normal things that you think should be………seen as givens or taken as givens but they're not they're the very things that the majority of outsiders or the majority of people don't give or don't accept or don't follow or won't ah…….. feel comfortable to facilitate.

DC: Why do you think because it's not an unreasonable thing to ask for but from what you're saying as soon as you behave in a way which is seemingly indicative of madness or whatever you want to call it people don't give that….. what stops them from giving you that then.

PMc: Ah…… I think it's fear.

DC: Fear.

PMc: Fears the first thing…….but it's also…it's also…..it's also historic in the sense that if how…………..people with different…………understandings of life or experiences of life are viewed by larger society but it's also a lot to do with how……. society in general has developed this misconceived idea of what it is to be mad I think it's partly that and the equation of mad equals bad so there's a whole variety of things that are.. that are all sort of pitted and tied together and that actually makes it very uncomfortable or very fearful for people to asked to be part of something which is not the normal experience for them so I suppose it's understandable that society has this idea that……..madness…………..is something to be afraid of ……something to be shunned away or to ah…. deny, I suppose it's acceptable that it's understandable why people respond the way they do……..plus there is probably another part of them somewhere within their own being or own experiences of life comes very close to that point of being mad themselves and ah……have the insight and understanding to realise that if they divulge it they'll end up being the very thing they don't want to be or to be ah…..to be…. or to experience what it is to be someone who carries a mark of shame or stigmatised or oppressed or whatever way you want to describe it, all of the things that…..that sit on the shoulders of people deemed to be different (pause).

DC: As you move forward then because the paradox it would seem from what I'm understanding from what you're saying that you were getting what you needed from your grandmother but the very point you disclose that you were hearing her voice was when all the problems started because people couldn't make sense of that other than you must be mad.

PMc: Yeah and I suppose in one sense if I had been able to say it's my grandmother that's speaking to me well I suppose people would have probably thought or anyone that would have been close to me would have thought he is fucking nuts cause she'd dead or what kind of lunacy is going on in his mind listening to people that's dead hearing voices that aren't there so in many ways it is paradoxical in the sense that the very thing… the very thing that brings me comfort has been the biggest discomfort of my life ah……. (laughing) that for me…that for me that discomfort piece of it is… isn't discomfort that I have created but discomfort that everyone around me has created or correction a lot of people that I've come into contact.. been around have been uncomfortable with so…………….

DC: They're reaction.

PMc: They have projected their … their discomfort onto me and I think others have become a victim of that… in that sense, but as I say the very thing that brings me comfort has been always the thing that has caused me the biggest oppression so it is… so it's a catch twenty two.

DC: Do you regret having disclosed.

PMc: I do.

DC: You do.

PMc: I do in many ways I do ah….. in many ways I do and in many ways I don't. I do in the sense that had I not have disclosed life probably could have been a lot different and then equally the very fact that I did disclose life has been very different… you see again (laughs) it's that paradox between you know in an ideal perfect world would I .. probably would have been… I probably would have been…I probably would have been better not disclosing ah…… had I been able to keep it in such a way that I wouldn't have… I wouldn't have..

DC: Or if you had have disclosed what you're saying is you would want actually a response which equated to what grand-mother was already doing.

PMc: Yeah.

DC: Which was someone to treat you in a comforting way in a way where you felt understood, thought about or listened to compassionately, authentically.

PMc: Yeah and paradoxically again that's exactly… if you bring it into the professional world that's exactly what I expected to find when I went first of all to psychiatric services that's what I went looking for……. unfortunately it wasn't the response I got but that's what I went looking for.

DC: But you thought they would have an understanding of it or a framework.

PMc: Totally, totally I thought this is something these people are professionals, they're experienced, they know… what they're at, they're trained in this they world they understand it when you listened to them they seemed to make sense of what they're talking about they seemed to have the knowledge but the way base simple things of compassion, empathy…. Acceptance are way of the benchmark, they didn't have that.

DC: So they didn't equally validate the experience but used it almost against you..

PMc: Totally against me, my…. my experience because the problem.. so there was no validation but it was… it was my experience was the proof (laughs) that I was mentally ill in their eyes……. So, so again………. My world and the world that I was experiencing and living within was in… in.. disharmony with the world that they were working so therefore they….. the two couldn't meet together and compassionately understand each other.

DC: I mean was there anybody in particular within that.. I mean I don't mean personally.

PMc: There was.. there was a few people yeah… but there was one nurse in particular who understood where I was coming from and didn't judge me….. in many ways, but was the

protector in many ways of a lot of things, a lot of things could have been worse had she not have been about … and in many ways…. she probably in her own way picked up from where my grand-mother left of (laughs)… in many ways… not totally but in many ways she did ah…. probably a lot of the time didn't even realise she was doing it… in fairness when I start when I think through it as years have gone on but instinctively knew that's what I needed… ah so in many ways yeah but then the question always comes back to that… in that system and all the people that I met don't get me wrong they were good people…. But I can honestly say that there was only one that really made……. Well there were……. Wait till we see one……………………… There was probably a total of about four in those very early years that made any……. Consecutive years through it…… that ever made any real sort of………… attempt at understanding………. Not that anybody else done me any harm….. but they just… (Pause).

DC: Did, did anybody else do you harm albeit inadvertently… when you think back.

PMc:Ah….. ah they done a lot of harm, they never done, they never…. They never you know never done me any physical harm as such except I could question some of the treatments, I could question the use of ECT and the use of anti-psychotic medication…….. I could question all of that.

DC: But at the time did you accept it.

PMc: I did accept it because at the time I bought totally into the idea that I was mad…..that I was different… there was things going on in my life that shouldn't have been happening.. for example the voices shouldn't have been happening nobody took the time to ever try to explore what they were about….. they were just wrong, they were biologically or biochemically wrong, my brain was wrong so therefore I was mentally ill.

DC: Did you accept that.

PMc: I totally accepted it yeah because that.. ah that's.. that nobody ah made any….nobody had given me any context other than this was not a normal experience people do not normally experience hearing voices or seeing things or anything like that so this was an illness.

DC: That equals madness.

PMc: An illness that equals madness and madness has to be treated in a certain way to try and alleviate the suffering or ameliorate the suffering was the word.. if that's the right word that… that was used it was certainly used by a few people that they were going to ameliorate the suffering you know and I suppose in many ways…. In many ways I was glad of that….. because I wanted to be normal…. I wanted to be back to who I was again… ah.. so yeah I bought into it.

DC: I mean at that time… at that time did you feel you didn't belong or fit in.

PMc: Oh yeah……. I knew my world was falling apart there was no question about that because the more I started……. The more I started to…… well…….. I'll tell you what happened I started to disconnect from the external world and spent more tome connecting with the internal worlD and what I mean by that is I spent more time connecting with my grandmother's voice (Pause).

DC: But in a comforting way.

PMc: Totally in a comforting way and ………… because that comfort was there and that understanding was there………… and that acceptance was there I didn't need the external world…… ah…..so I'd become quite happy……… within my own internal world……. But that become problematic for the external world……. Because they're………. the external world viewing of me was that I was withdrawn totally within myself and I was……moving away from that and that was another symptom of my mental illness…….. so everything was…. Everything was and when they explained these things…. I suppose well I can understand where you're coming from and these things and…… they had all these great ideas you know there was psychologists would tell me…. And Jungians would say this……..different ones would say that and we can make sense of this….. and to me this was all fucking mumbo jumbo but it was mumbo jumbo that these people knew and seemed to understand so I didn't question it.

DC: Made sense to them within their framework.

PMc: Yeah.

DC: But for you it didn't really fit.

PMc: Didn't fit for me in any sense but then who was I …. You know how…… how was I going to change that whole world of learning and of knowledge…. You know for…. therefore I bought into it I accepted that's what it was but and at no time… at no time with all this knowledge and this experience and this expertise were they able to stop the voices…. You know regardless of what they used or how they done it or what they done they didn't stop the voices.

DC: How did you make sense of that because they were telling you that they were going to do whatever they were going to do with their tool kit whether it was biological or it was psychological.

PMc: Ah.. see that's a good question in the sense…… I'll tell you exactly what it was…… it scared the shit out of me.. I'll tell you why it scared the shit out of me I had an external set of voices that were telling me this is what's going to happen and this is why this is happening because it was within my brain and all the rest of it and then I had an internal set of voices that erer totally arguing…. Against what was happening in the external world the internal voices were telling me at tomes these people are trying to kill me.. ah that these people were trying to take the voices away from me and so I was struggling with this internal set of voices that were telling me one thing and the external set on the outside that were telling me something else and both of those worlds were colliding and I was caught totally in the middle of that collision…. Not being able to control it and having no control over what was happening internally or externally.

DC: And then the conflict was that there was part of you that was wanting to relate to the external world and there was another part that was terrified.

PMc: Yeah… terrified but there was a part of me that wanted to relate to the internal world as well…. But was terrified of the consequences of relating to that as well so therefore you become caught within this completely artificial world….. that…. that you have really no part in other than as an observer.

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DC: Do you think then that dilemma got played out gets played out in your relationships, actual relationships where there is part of you wants to trust the person but there is another part of you is terrified that you can't trust people.

PMc: Totally and it's the same with the internal voices it's the same with the voices you hear……… its exactly the same thing and it's….. the way I've explained it at times or tried to explain it… its as if you're inside your own body looking out at this world that's… that's in conflict between the.. the internal voices and the external voices its almost like you know there you hear people saying about dying and the out of body experience (laughs) its almost bloody like that you're…….. out of your own body watching this sort of film that's going on around you, this drama that's going on around you and you have no control in it you want to reach in… its like you know… you ever watch the TV ah….. ah… a football match and you're watching your favourite football team playing their opponents on the field and you can see what's going to happen and you're roaring at the TV not to do this…. Watch this and watch the other but it's still happening and you can do nothing, you roar as long as you want to roar and shout as much as you want to shout but you ain't going to change what's going to happen….. and that's exactly what it's like when you're observing this conflict between………. the psychiatric system for want of a better way of describing it trying to create a war with the voices that you're hearing creating their own survival mechanisms against this oppressing sort of an army that go at…. and all you're doing is observing it from the outside (phone rings… interrupts discourse pause recording).

CONTD

DC:I think where we left off you were talking about that …… that conflict between the system or the internal or the external world and how that then gets played out in relationships where part of you wants to relate seemingly but there is another part of you telling you not… not to trust anybody internally or externally worlds…. How does that do you deal with that.

PMc: You see…….. see I don't think….

DC: How do you need someone then to relate to you when you're in that place that's what I'm thinking ……. What will….. what's helpful….. how does… how does someone engage with you in a way which you will engage.

PMc: You see for me…… for me it was just luck in the sense of finding some one person that wasn't prepared ……. to look at this in a very technical sort of way for want of a better way of describing it so, therefore,….. she had no interest …… in what…….. the psychiatric system had to say was going on she had no interest really in many ways of what internally the voices where ….. while she had regard for them ……. she knew that they were part of a wider picture as well but what she focused on was me…… how…. can you get ….. me to …… start to accept and trust people again because I…… that was where my biggest problem was it wasn't that there was a system on one side and there was voices on the other side was actually trusting people again, trusting what was happening around me and then trusting myself to understand what the voices were about.

DC: What was it about her you think that in my head…. that you took the leap of faith…..

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PMc: Well the biggest thing was she had come through it herself that was the first thing she had experienced it herself and she had found her own way through it.

DC: And you knew that.

PMc: I didn't …….. I knew that she had……………… no I didn't know she had, I knew that she had been in the system and I knew that she had the same sort of diagnosis…… and she seemed to be …… in many ways the same as the people that I'd spent the same time with in hospital………. You know so……….. I didn't know that she was any different other than the fact……… you know what I mean…….. in the sense that (sigh) ……… she didn't appear with no halo around her head, she didn't appear with no sort of … ah a badge or expertise other than the fact of having come through the…. the experience herself and listening to her saying that she had recovered…………. I couldn't make sense of that.

DC: What……. What can you give me an example…… in your mind at that pont did that mean.

PMc: I had no…… no idea what she meant … ever I had absolutely no idea.

DC: You had been told that before in a sense that if you do this and you do that the.. the suffering will be ameliorated …. and you took that as an article of faith so someone else comes along and tells you……. You mean what was the difference with her do you think where again you were prepared to trust her take a risk of relating to her.

PMc: Well the first… the first question……. the first thing was……… that she spoke to me in very normal language….. there was no sort of gooble de gook for want of a better way of describing it………. ah she seemed……….. no she knew where I was coming from.

DC: She knew……. you felt that.

PMc: Ah I knew and knew… I knew when I spoke to her she knew what I meant.

DC: So you felt understood.

PMc: Ah I felt understood………. Ah ……… she didn't take my mind over in the sense that what……….. what…….. when I spoke to her and she spoke to me there was a connection the difference between how we related and how I related within the system when I spoke for arguments sake to the psychiatric nurse.

DC: Or the school – teacher.

PMc: Or the school – teacher or anybody else it was…….. I needed to speak in a different language for them to make sense.

DC: For them to make sense.

PMc: For them to make sense of what I was saying……… not that I made sense of it I created a set of language and a way of describing and a way of articulating so that people would understand but it bore no resemblance of what I was trying to say……. Does that make any sense?

DC: It does.

PMc: And so therefore……… with Edna.

DC: Basically what you're saying is you learnt another language.

PMc: Totally.

DC: To…. such that somebody else could understand, but you didn't understand the language.

PMc: Totally …… no but I knew it was the language I needed to use to play out any given circumstance that was around me the difference with E was that I didn't need to do that the difference with her was that I could talk the way I wanted to talk communicate and articulate the way I needed to articulate and she understood and if she didn't understand she asked me (laughs).

DC: Which in a sense… as well validated you're experiences.

PMc: She never questioned……. she never questioned what was happening she never questioned….. why it was happening the only thing that she ever questioned was…. when I would refer to myself as being schizophrenic…. she would say that I wasn't and that caused me conflict because I had come to accept this label, to accept this diagnosis of schizophrenia and here was someone who had spent time in hospital….. was living… pretty much by

Example of excerpts from transcript - Aisling

DC: But do you think that's hard in the context, again in the society in which we live or do you think there's space for you to do that?

Aisling: I suppose I've seeked out an awful lot of areas in which way I could – how this has been interpreted. I would use them to my advantage in the sense – an example, I have a really good Shaman friend in Galway and he would go off and do iboga, all these plants. My last time I was hospitalised, after I came out it was like go see Paul.

I went to see him and I sat down, we were watching the football and my husband, my partner at the time, was sitting down there talking about football. Then we had the tea out and we started talking, and biscuits. I was like, "I want to know about your iboga, what were you experiencing?" Because I was experiencing getting out of my bed and looking at a skull in the mirror, grieving for the world, grieving for very isolated events that had happened.

The way I was grieving and the way I was letting go of things in my episodes, like smoking a cigarette after something big had just happened. It was just these methods. He was basically interpreting what he was saying what happened to him. I was like that seems so exactly like letting go of the demons and letting go of these things. Is it a bad thing that I go through this excessive way of it? It's different but...

DC: When you use the word demons, is it demonic? Is it terrifying?

Aisling: Well it is when you're in it.

DC: It is when you're in it?

Aisling: It is when you're in it.

DC: Do you think anybody can reach you in that state or help you at that point? What would be...?

Aisling: The prime thing this – another example of my sister Sharon. When I first became ill she roared at me in the hospital, "You're fucking sick". I was like, "I'm not". I was 19 years of age going what was she on about? I was scared from hearing that. But when I did the house thing with my partner, he would be the one coordinating with my family who was to come in today.

Because when you're in this deep sponge of stuff and somebody comes into the house, it's like you can feel their energy and the intention of what they're coming in for. Sometimes my elder sister was always that provoker of you are sick. But I locked myself into the bedroom upstairs for some particular reason, I can't remember why. She came up the stairs

and she was talking through the door at me. There's a part of you that's always there and you know who this is, this is your sister. She's like, "I'm not here to tell you anything", joking about the fact that, "Please don't tell me to fuck off" and all this.

I'd be roaring at her, laughing, telling her to fuck off. Just being there I think was the biggest thing. I would think back and I can remember talking to the kids next door and singing away. My family would be sitting in the back garden with me, hanging out, roaring and laughing at the stuff that comes out of my mouth and stuff like that. But their eyes would be like my God is this right? But that's the way it happened I suppose.

DC: Now you say that at times do you want your own space?

Aisling: Yes.

DC: You don't want people around when you're like that and other times you do want people around? You need to decide that?

Aisling: Yes. It's interesting. James, my partner – I'd wake up in the morning and feel completely alive and altogether, having the most amazing shower in my whole life. He'd have breakfast for me downstairs and I was totally in that garden of Eden feeling, twinkly lights and everything feels amazing, never feeling so connected in my life before. He'd head off for the day and he said, "Why don't you bring Toby the dog out down to the park and play tennis with it?" I'd go down with music in my ears in this park – music is very powerful for me anyway.

DC: Music?

Aisling: Yes. But I think it encapsulated how I was feeling. Music was the closest thing to the awe that I was feeling at that time.

DC: So you get connected to music then?

Aisling   Yes, I think you do. It's safety – whenever I hear the live version of the Jeff Buckley concert, it brings me back to Thailand. It brings me back to being in that hut and that feeling of sheer and utter connection to heaven. But hallucinating at the same time, hallucinating that the roof was coming off and I was part of the sky. I still believe actually the fishes were calling me when I was waving at them over the pond. I really believed that there was a huge energy that came out of all of this. But yes, I don't know.

DC: Can we just go back? I'm taking you all over the place, I'm sorry.

Aisling: No, you're grand.

DC   The whole part – what was the critical example from there, because you said in your mid 20s there was a part when you thought...?

Aisling:	After this house thing, after being in the house, which you would imagine probably wouldn't have happened, but I became very dark. I think it was the realisation is this going to happen all the time? Am I this fucking sensitive? Oh my God, what am I going to do? Nobody understands me. Would they ever understand that I feel spiritual? How would anybody understand that? That's the deep rooted – I knew then. I knew it wasn't like this flippant thing that happened. For me it happened for a reason. It happened for me to see things.
DC:	So you see it as an enlightenment experience, a terrifying one?
Aisling:	Yes, even though it is really terrifying in it. I don't know. I have loads of theories on it, but I know what I felt when I was in it that it couldn't possibly be all my imagination and what not. This felt so real, parts of it. Maybe I was grieving for the world, that's what it felt like. But then I just became really, really dark and just didn't know what to do. So that's why I always searched for people like Shamans.
DC:	You sought people out, you think?
Aisling:	Yes, I did because I wanted to put some framework on this. I knew it wasn't this bipolar and schizoaffective disorder, or whatever they're calling it lately. I knew it wasn't that. It was only - because the last time I actually said I was talking to God. I do believe we are artefacts of Jesus and Mary and the child.
	This is my interpretation. But they added that extra label on top and I think it's just stupid. I just don't' get it. It's just fear, fear from the unknown. We're coming from that and they're coming from that, but completely separate, completely different ways of looking at it.
DC:	When you said that whenever there was the first break, it was this particular individual, there was something about him. You felt he gave off – by doing nothing, he was doing a lot almost just by being there. Equally can you think of a particular individual who was very unhelpful and what was it with them?
Aisling:	We were talking about psychiatry and going in. I was explaining about a couple of years ago when I came out of hospital. I kind of go in for 10 days really, that seems to be the cycle. They drug me so quickly as well. I remember I had to go through this process because I was admitted by a doctor. I was sectioned in or whatever you call it.
	I'd never experienced that in Galway before because the Mental Health Act, this whole system of solicitors and tribunals and all this kind of stuff, which I was caught in the middle of, because I was in this period where I never really lasted any longer than 10 days in hospital, maybe two weeks. The threatening aspect of that.

DC: Threatening?

Aisling: Of me being in longer than I should be. Even though they were, "This is here to help you" and I said, "Yes, but you're threatening me that I could be here for 30 days" this sort of stuff. I think there's a little loop hole there that needs to be ironed out. I never had that aspect before when I was in before. It was more like when you're done you get out.

                       But then this process was completely different, by talking to a solicitor and talking very differently about this tribunal stuff. When you're in there everyone has code words, you have to do this or else you're going to do this, or this is going to happen. I was so angry coming out of that place. But I went to a day hospital, as you had to do to follow up...

DC: You had to do it? You were happy to comply?

Aisling: Well I complied obviously at the time. I really didn't want to do it but it was a part of starting back into managing your meds. I knew I couldn't just come off my meds. I was never that type of person anyway, just to go recklessly off the medication, because I knew how critical that would be. But I remember going and sitting in - there was a young, he was obviously a trainee doctor, clearly.

                       He had the sheets of questions like you've always got, going through them. I've always experienced those with other doctors, but he was ticking all the boxes. I said, "Do you talk to people like this normally? Are you that inhuman?" Because the way he was speaking was just I'm not here, I'm a robot and an element, I don't give a fuck. He was really arrogant.

                       Yes, completely. But then he walked out the door to get a pen. He walked out the door and I was sitting here, walked in through, he came back and he was, "Have you got any signs of harming yourself or anything like that? Are you hearing any voices or anything?" But the way he said it and the fact that he was so flippantly coming in and out of the door, I swear to God, I would have shot him in the face if I'd had a gun. He was just the most arrogant, arrogant person I've ever come across in my whole life.

                       I said, "If this is the training that you're getting and if this is how you're told to talk to people like me," I said "I fucking pity the people who are in worse conditions than I am coming in to see you". I said, "It's such a shame". So it's shit like that, that should not happen. That's just appalling. So it's the training, the complete lack of anything ever happening in his life clearly.

DC: Maybe he just treated you as the schizoaffective patient?

Aisling: Oh yes, clearly.

DC: There was nothing else...?

Aisling: No, humanity. How could they let people like him be dealing with –
             people should be rated on how they are humanly in this system.

DC: Ticking the box.

Aisling: Yes.

Example of excerpts from transcript - Gerard

Gerard: I was doing a computer course, and I made a mistake. One of the things I did was – this is going to sound awful, but someone had a really good CV. This was before the internet so I made a copy of it and I stole it, and he saw the copy and I had rancour and then I fell out with an awful lot of my college friends and other stuff.

I remember one night in a part of my memory I was in my bed and they were talking about me from the sitting room and it went up through the thing and I was in my bed and I was, you know, shaking away, physically fairly stronger than the guy. So I had for a few months – and then a rumour was spread about me, a nasty rumour. So for a few months there I was just very paranoid about what people thought about me.

At that stage I didn't want to get up in the morning and I went to the doctor and he said – I was shaking – that was one traumatic memory. Then after that I said I'd get out of Castlebar and I went to Sligo to study computing there. After a traumatic incident and those people in the house – a good-looking woman and I liked her and there was another guy and the three of them didn't get along with me. I didn't get anything wrong at that time.

They'd, sort of, head to the pub without me and I made a bit of a mistake, and then a traumatic memory, it took me years to find the memory. I had memories, like, I'm not too sure, but were the neighbours talking about me through the walls? Probably not. So then I moved into a house and I had a lot of bullying there, really, and obviously a traumatic memory, which sort of provoked me internally and I was very afraid of what people thought about me.

Then – how would I put it? So then I was working in a computer company at the time doing work experience from the college course and then I was worried that the people around me didn't like me so that was – I'd failed my college because I'd got into the work experience before the results. So I got that so I was coming off and, how do I put it? So there were staff there and one of them was kick-boxing and I was afraid, "This guy doesn't like me, and such and such."

Then it's debatable, but I could have been – maybe you could confirm if you have heard other people's stories that I got more and more afraid and let's say, I thought I was muddling up my thoughts, and maybe I was. The literature on hearing voices said sometimes that happens so I'd be afraid my mind was crazy. So you can imagine any thoughts about women, any thoughts, my mind was going a bit crazy.

So I was afraid I was muddling up these thoughts, which is a very scary experience for anyone. So I was sitting in there I kept my mouth closed because I was afraid I was doing that and that started getting on top of me and I must have been getting paranoid and here is a walk out where I was working. I remember

found the literature for a counsellor, a therapist in the thing and I walked out – so I was in the woods and I was afraid people were following me.

I was afraid, anyway, so I called from the woods and I phoned the best therapist I could ever hope to meet and I rang him up and he said, "Where are you?" I said, "I'm in the middle of the woods." (Laughs). So that was okay, and the guy I was living with, his name was Gary, he had a strong personality and I was later to meet a few of his friends, So, you know, he was maybe a little aggressive, or I felt judged by him and, you know, how do I put it? After a while I woke up one morning and I started hearing voices through the walls so my

DC: What age were you then? Can you remember?

Gerard: I was around 22.

DC: 22.

Gerard: 22, so I started hearing voices through the walls. I went into work and I'd be walking to work and then I thought people were following me. So I walked to work and I'd be walking faster and looking behind me, and this was nagging at me and so I went to work and I could hardly get any work done. My concentration was gone and they were afraid, but no one put their arm around me or could say something. They didn't know exactly what was going on.

DC: Do you think whenever you say that – sorry for pausing - do you think it would have been good at that point for someone to put their arm around you?

Gerard: It would have meant a lot.

DC: It would have meant a lot.

Gerard: In hindsight because I was so afraid.

DC: So that was the primary feeling, fear?

Gerard: It was fear and self-hate and so I was afraid and for me, I don't know if it's true, but for me it was like I had broken or I felt judged or bullied and then I started to bully myself instead of standing up to society and realising that everyone isn't perfect, that they should accept people where they are at. So it was fear, an awful lot of fear. Because of that fear – I come from a farming background, and I liked boxing so for a while I could have – I remember I was walking, I walked to – yes, so I was afraid, and I was afraid of women. You know, the people who were out to get me writing stuff on the internet and stuff like that.

But I could still acknowledge the people – you could still spot love, and so that would have been one thing if someone had put their arm around me and said, "Thomas are you okay? You could do with talking to someone"

DC: At that point in time?

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Gerard: At that point in time. Now I had a therapist, but he wasn't really sure what was happening. He was a very good guy, but you know, it was coming to a head. So one story, I don't know if helps, I walked to the lake where, you know, before when I was walking in the woods and I started crying, "I'm sick of these people following me," and then I was walking – I thought I'd just get out the house and start walking.

            There was an elderly couple walking behind me and I thought they were the two people who were following me so I nearly turned back and I came very close to actually hitting somebody, you know, which I would have really regretted. I never hurt anyone. That was the dangerous period. Also there was other stuff. I'd be going to sleep at night and because there would be voices all the time, I'd start praying.

            I couldn't sleep for a lot of the time so I'd start praying. It was the first time I had started praying in a long while and then I was, sort of didn't believe in God, you know, I was doing computers, you know, more logical? Then I was actually – I was later to learn that the person that - I identified the voice to meeting Paddy. One of the people I live with, Gary, I'd met two of his friends another time so it looks like two or three of the others were there, but for me, let's say, I was actually living in the wrong place at the wrong time.

DC: Now you've got that insight, do you think that has helped you make sense of your experiences?

Gerard: Hugely, because with Paddy I'd say that it helped the voices to go away. So I knew the guy, because I knew Gary, I later went onto become Buddhist, you know a lot of love and compassion.

DC: Is that what you are saying you needed?

Gerard: I need it, so when I'd seen Gary, I sort of – the voices would be going, I had, like, a little image of Gary in my stomach so how do I put it? So if he was saying something negative then I'd say something positive back and when I'd say something positive he'd say something positive about me. Then I'd pray for a good thing for him and then I also loved and accepted him so if I had known this years earlier I would have worked on that part.

DC: So do you think that would have helped, if you'd been able at that point to make sense of the voices?

Gerard: Hugely and to tell them to go away, so let's say there was for maybe about a month or six weeks I knew there was something wrong, so someone had told me, you know, in the psychiatric place, "Tell the voices to go away, talk to them later," there would have been a month of horrendous pain gone.

DC: How did you make sense of them or how did people around you in the psychiatric system make sense of the experiences at that time?

Gerard:	I went into the small psychiatric hospital in Swinford, and it opened my eyes – I was taking medication so I said, "Why am I taking this?" Then I was in there I could see other people that were maybe bipolar and they were saying – you don't want them controlling the thoughts or the television or are they reading my mind or something like that? So that gave me subconsciously – then I was in a rooming with another guy, an elderly guy and he used to do boxing when he was younger and he was afraid of the voices coming in.

So I was sort of clicking there and then I was rooming with someone who was suicidal and they had to hide the razors from him. That maybe subconsciously would have been ticking away at the same time. Then I was in the psychiatric hospital and then it suddenly occurred to me, how can three people be outside my house – outside this thing, constantly be following me day and night? Do they not have to go to the toilet or go someone else?

Then I went from there to the shower and you'd, sort of, have to run around the whole building to hear the voices and how would I put it? That someone was in the shower – I said, how can someone so quickly have run around the building? Obviously the voices would be telling me answers to that, you know, so for me I don't think however clever it is in your own head, obviously you need to be a bit cleverer. But sometimes the mind can trick itself as well.

Maybe emotional intelligence is a lot more or maybe it's just some people realise stuff, maybe it's Karma, you know, or something like that. So then I went down to the therapist and I said, "Do you know what? These voices aren't real." Then I went out with my mother and we were having tea and we were laughing, "Oh they're not real at all."

In fact at that time I had met a voice hearer who had told me how to deal with my voices and let's say there was scientific evidence to show that that would have worked, if I had gone back in a travelling machine, I probably would have taken that advice, but you know

DC:	So you would have taken any advice at that time?
Gerard:	Yes.
Interviewer:	So you were quite naïve and susceptible?
Respondent:	Yes, but I took the tablets and the voices went away and actually it's a psychiatric hospital and I was in there only five weeks, and it was a very positive experience.
Interviewer:	So that helped?
Gerard:	Yes, but I got a bit of a shock. There were no counsellors. There were no psychological therapists. The psychiatrists had all the power so they could see you if they wanted to see you, so they might see you once every two weeks, sort of thing. There was no therapy. There were no talking groups. There was a good creative writer, so he really helped me in my own recovery.

DC: Did you creative write?

Gerard: Yes. We became friends.

DC: What was it about him, which you found was helpful?

Gerard: I suppose he was a very warm personality. He was American and so he was a good storyteller and he wanted to write, so he picked up, okay, "This fellow is good at-" so he actually spent extra time with me on my own doing the writing

DC: So he was taking an interest in you then?

Gerard: He did. The nurses in the psychiatrist hospital were fairly good. There was a room in the psychiatric hospital where no one was so I was looking up self-help books like the Power of Now and other stuff and there were nice people in the group who were talking about stuff like the twelve steps. I hate to use the word 'normal' or 'more recovered', but I felt, "Okay, these people," there was a bit of friendship.

DC: So there was some understanding as well?

Gerard: Yes.

DC: And compassion?

Gerard: Yes. There was understanding and compassion and I found it genuinely positive and then I went to the day centre in Clamars and that was a nightmarish experience.

DC: Nightmarish, so this was a completely different experience?

Gerard: Completely different.

DC: What was it about it?

Gerard: It was that I'd go in and there was no one, really, my own age that I could connect with. Maybe more recovered or more normal, so I'd come off a breakdown, so you'd need a year to recover from that. I was low and I was getting grief from my family and I went in there and there was one nice nurse and he had a game of pool with me and that was really – the other nurses just stayed in the kitchen so they didn't interact.

           But the creative writing class was on so I went into that and he was going through a divorce, my friend, and you know, so he wanted to stay away from the house, the kids. So we became friends so I'd visit his house and we were chatting away and he was, sort of, showing me, "This is bullshit what is happening here, you know, with the nurses, they are not helping anyone."

           This is going to sound horrible, but some of the women, they'd maybe given up on living, let's say, the good life, you know, having a job, being fit or whatever. Some of them were overweight and the nurses – there was a power imbalance so I remember, one memory, the nurse was weighing this woman that she was very

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overweight and the woman started saying how, "I was doing the exercise and eating such and such." It wasn't nice, I don't know, I'll use a bad word – 'sucking up' to the nurse. I hated the nurse.

DC: So what did you hate about the nurse?

Gerard: She had no compassion.

DC: No compassion.

Respondent: No compassion, she was only concerned about herself, so she was actually weighing the other person and holding it up against her. So there was this terrible power imbalance and then there was another woman who was maybe, a bit different, so they might not have had good social skills so I just remembered that memory, "I have to get out of this place."

DC: So that's what motivated you to get better, to get out?

Gerard: To get out of there, so I kept the writer friend as a friend, so we'd be visiting each other and I helped him through his divorce. His wife was actually quite violent. She was mad and so I helped him. We both helped each other and I joined up to an employability service that helps get those with, quote, 'disabilities'.

DC: So that was a practical level of support, which you think was necessary as well?

Gerard: Yes, so that got me into a job. So suddenly I was in a job, I was grounded and I was earning money and I had started a Buddhist class, so I was learning about my emotions. I learned a lot about anger and self-hate and stuff, so I remember walking in and the teacher – he actually mentored businesses, like Kingspan and all of the self-hate he was mentoring people as well. He was doing the Buddhist class for free. I have a picture of him on my phone.

            So he met me the first day, I shook his hands and I remember one of the courses was that selfishness is the cause of all mental suffering because you are thinking about yourself, when if you think about others you will be happy. So I was getting that message of compassion and kindness off him regularly. Also he started me on a leadership plan, where you'd have your three year goal and fifteen year goal, your three month goal and your strategy for that.

            So I went to a course and then I started setting my goals. So I brought that into work so I worked really hard and so I was kept on after the Christmas period. You know, obviously the staff went off a lot and then obviously I went in at the right time because of the sort of people working, and then after Christmas I was kept, so I felt really good and was on Solian, but I was so fucking tired, you know.

            The one thing I would have is a person would keep a diary or maybe a folder to keep what medication they are taking, because in the early stages they switched from medication to medication and I wasn't sure what was happening. When I

first broke I was depressed, but I didn't even know what the word 'depressed' was, or wasn't connecting with my feelings.

DC: You didn't know what that state of mind was?

Gerard: No, and I was getting grief, because I was feeling low, I was eating a lot of sugary food. So if I had a peer, someone I could talk to. One of the guys, a friend-

DC: So at that point you think you needed a peer?

Gerard: I needed a peer.

DC: What do you see as the qualities of a good peer? What do they need to have to rate someone?

Gerard: I would see a bit of information on the voices on mental health so when the courses are going up, stuff on helping people get jobs that would be critical.

DC: To get that educational part of information, but what about the personal qualities again which you needed?

Gerard: Wisdom.

DC: Wisdom?

Gerard: Yes, because you need someone to accept you fully. So, someone to say, "Thomas, I accept you where you are."

DC: Accept your framework of how you were making sense of the world?

Gerard: Yes, there is also a story with that, maybe a typical story. Like, before I went into this mental hospital, my brother had helped me. He went to the psychiatrist with me and my family were getting angry because they didn't know what to do.

DC: Your family were getting angry?

Gerard: Yes.

DC: You think because they didn't know what to do?

Gerard: They didn't know what to do and still no one has talked to them, but my brother had a really good heart. He had a leadership quality and he had a kindness quality and he also could see outside of, "You're not what you earn." You know, that standard. So he had a really good heart. So I was hearing voices, so it was an aggressive guy and then a less aggressive guy and then a girl who was trying to hold them back.

So I thought I had really good hearing, so they were down the road, in the countryside, and I was in the bedroom and there was a bed each side, you know. I was saying to my brother, "I'm afraid they'll come in and fight me." So I went in and I got into, you know – my brother said, "Thomas, come into bed with me."

He put his arm around my shoulders and he said, "If he comes in we'll fight them," and that's the nicest thing anyone ever did for me, a perfect example of how to help someone with schizophrenia.