‘It Levels You Out Again but You’re Not Dealing with the Trauma’: An Exploration into how People with a History of Interpersonal Childhood Trauma and Psychosis Subjectively Experience Antipsychotic Medications

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Submitted in total fulfilment of the requirements of the degree

Doctor of Philosophy

April 2020

Centre for Youth Mental Health

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Abstract

Among people diagnosed with psychotic disorders, those with a history of interpersonal childhood trauma (ICT) present with a more complex clinical profile. In addition to experiencing hallucinations/delusions, these individuals can experience a range of post-traumatic stress/trauma-related symptoms and, more specifically, the distress associated with remembering/re-experiencing traumatic events. There is also a high likelihood that people with trauma and psychosis will experience dissociation, depression, anxiety, suicidality, substance use and cognitive impairment. Irrespective of their symptomatic profile, these individuals are often prescribed an antipsychotic medication. Little is known about how these individuals experience the emotional, cognitive and physical effects of antipsychotics or how antipsychotics influence their trauma-related and other non-psychotic symptoms. Thus, this study aimed to explore how people with psychosis and a history of ICT subjectively experience the wide-ranging psychological and physical effects of antipsychotic medications.

An embedded mixed-methods research design with a qualitative phenomenological priority was implemented. Nineteen people who were diagnosed with psychosis and had experienced ICT participated in semi-structured interviews. Participants were specifically asked about how antipsychotics influenced their 1) general emotional, cognitive and physical states, 2) trauma-related thoughts, emotions and physical responses and 3) dissociative symptoms (depersonalisation and derealisation). Participants' interview transcripts were analysed using interpretative phenomenological analysis.

The results demonstrated that, for most participants, antipsychotic medications altered the way they experienced their memories of childhood trauma. There were

differences between participants in how antipsychotics altered their trauma memories. Some participants indicated that their medication alleviated the frequency and/or intensity of distressing trauma-related thoughts, emotions and/or physical symptoms, while others mentioned that their flashbacks and thoughts of past traumatic events intensified. Participants also reported that, by supressing trauma-related thoughts and emotions, antipsychotics prevented them from confronting or processing their childhood trauma. While participants considered this beneficial in the short term, they recognised that they would need to confront their trauma to heal. As such, having trauma memories supressed by the emotional and cognitive effects of antipsychotics was not considered beneficial in the long term by these participants. There was also a mixed response from participants about whether antipsychotic medications altered their dissociative symptoms.

Many participants reported that antipsychotics supressed their emotions and/or impaired their cognitive functioning, while a few mentioned that they were able to think more clearly and concentrate for longer. Many participants also described varying adverse physical effects of antipsychotic medications. The most common were weight gain and movement difficulties. Participants reported that they had tried many different antipsychotics before finding a medication that was somewhat effective in alleviating their psychotic symptoms.

This study's findings suggest that the cognitive, emotional and physiological effects of antipsychotic medications can be experienced as beneficial or detrimental depending, in part, on how they influence trauma-related thoughts/emotions/physical responses and dissociative symptoms. These findings highlight the need for intervention studies that evaluate the effect of antipsychotic medication on the trauma-related/post-traumatic stress and dissociative symptoms of people with a history of childhood trauma and psychosis.

Declaration of Originality

This is to certify that:

1. the thesis comprises only my original work towards the Doctor of Philosophy except where indicated in the preface
2. due acknowledgement has been made in the text to all other material used
3. the thesis is fewer than 100,000 words in length, exclusive of tables, figures, bibliographies and appendices.

Signed:

Ilias Kamitsis

Preface

This thesis includes a manuscript under review by the journal *European Psychiatry*. The manuscript presents a meta-synthesis that explored the subjective effects of antipsychotic medications by synthesising the findings of 24 qualitative studies. The primary author, Ilias Kamitsis, contributed 75% of the work required to complete this meta-synthesis. His contributions included: conceptualising the meta-synthesis, undertaking a systematic search for relevant articles, coding of textual findings from primary studies, developing descriptive and analytical themes, evaluating the methodologies of the included studies, writing the manuscript and incorporating suggestions made by co-authors. Assoc. Prof. Sarah Bendall and Prof. Louise Harms conceptualised the meta-synthesis, assisted in the development of analytical themes, and provided ongoing feedback on the paper. Ana M Garcia-Sanchez coded the textual findings (inter-rater coding), developed descriptive and analytical themes, and evaluated the methodologies of the included studies. Prof. Mario Alvarez-Jimenez provided feedback on the paper.

Capstone Editing provided copyediting and proofreading services, according to the guidelines laid out in the university-endorsed national 'Guidelines for Editing Research Theses'. The editor does not have expertise in the academic discipline of this thesis.

This research was supported by an Australian Postgraduate Award and Australian Government Research Training Program Scholarship.

Acknowledgements

Completing this PhD would not have been possible without the support and guidance of my supervisors, Assoc. Prof. Sarah Bendall and Prof. Louise Harms. Sarah and Lou, I am incredibly grateful for having you both as my supervisors. Thank you so much for believing in me during times of doubt and uncertainty, for encouraging me up until the very last days of writing my thesis, for all your feedback on my writing, and for providing a space where my ideas could be nurtured. Sarah, you believed in me from the very beginning, and always advocated for me at Orygen. Thank you for your tireless support, and for everything that you have taught me about trauma and psychosis. Lou, it has been a privilege to have had someone with your knowledge and experience guide me through the process of doing qualitative research. Thank you for all your kind words and invaluable advice.

A special thanks to all the participants for sharing their incredible insights into their experiences of taking antipsychotics, and for speaking so openly about their childhood trauma. Your stories of survival, resilience and healing are truly remarkable.

Thank you to all the case managers at Orygen who informed clients of this study. Thanks also to Prahran Mission, Blue Knot Foundation, the Victorian Mental Illness Awareness Council, and the Psychosis and Society group for supporting and promoting this study.

Many thanks to my advisory committee members, Assoc. Prof. Kelly Allott and Assoc. Prof. Bridget Hamilton, for all their advice and encouragement. Thank you to Prof. Patrick McGorry for his valuable feedback on the methodology of this study. Thanks also to Indigo Daya for her initial input into the direction of this study.

Thank you to Ana Garcia-Sanchez for doing such a fantastic job of analysing the findings of studies included in our systematic review and meta-synthesis. Thanks also to Prof. Mario Alvarez-Jimenez and Assoc. Prof. Brian O'Donoghue for all their feedback on this review.

I am very grateful for the ongoing support of my clinical supervisor, Tim Galbally, who has played an incredibly important role in my development as a psychologist. Tim, thank you for all your encouraging words, and for providing a space where I could openly speak about the many achievements and difficulties of my PhD journey.

To my friends and family, thank you so much for your unwavering belief in me, and for all your emotional support over the last few years. To my parents, there is nothing more that I could have asked from you. You have made every effort in helping me become the very best person I can be, and for that I will always be grateful. A most heartfelt thank you is extended to my grandparents – Ilias Kamitsis, Maria Kamitsis, Pantelis Germantis and Vasiliki Germantis, for their unconditional love and support.

Finally, I would like to acknowledge the ultimate sacrifice made by so many of my ancestors. The opportunities that I have had in my life were possible because of your enduring fight for freedom.

Dedication

This thesis is dedicated to *Konstantinos Katsifas*—a man who gave his life for his country and thus taken his place in the pantheon of Hellenic heroes.

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Chapter 1: Introduction and Thesis Overview

While we all want to move beyond trauma, the part of our brain that is devoted to ensuring our survival (deep below our rational brain) is not very good at denial. Long after a traumatic experience is over, it may be reactivated at the slightest hint of danger and mobilize disturbed brain circuits and secrete massive amounts of stress hormones. This precipitates unpleasant emotions intense physical sensations, and impulsive and aggressive actions. These posttraumatic reactions feel incomprehensible and overwhelming. Feeling out of control, survivors of trauma often begin to fear that they are damaged to the core and beyond redemption (van der Kulk, 2014, p. 2).

Traumatic events can be either interpersonal, whereby one individual intentionally commits a harmful act that threatens the life, safety or bodily integrity of another individual (e.g., childhood sexual abuse, physical assault or bullying), or non-interpersonal (e.g., an accident, illness or natural disaster) (Forbes et al., 2014; Spinazzola, van der Kolk & Ford, 2018). While all traumatic events can be damaging to the psyche, interpersonal trauma is perceived and encoded differently from non-interpersonal trauma (Keane, Magee & Kelly, 2018). In interpersonal trauma, or victimisation, 'the elements of malevolence, betrayal, injustice and immorality are more likely to be factors than in accidents, diseases and natural disasters' (Finkelhor, 2008, p. 23). Interpersonal trauma can also be cumulative and repetitive (Herman, 1992). This can occur when the victim is exposed to a situation from which they are unable to escape or are under the control of a perpetrator (Herman, 1992). This type of prolonged interpersonal trauma is often referred to as 'complex trauma' and typically occurs during

childhood when the individual is abused and/or neglected by caregivers who are expected to provide a safe environment (Ford & Courtois, 2013; Herman, 1992; Kezelman & Stavropoulos, 2012; Lawson, 2017). Thus, childhood abuse and neglect can involve a betrayal of the trust a child has in their primary relationships and can have a unique, pervasive effect on people's social, cognitive, emotional and biological development (Cook et al., 2005; D'Andrea, Ford, Stolbach, Spinazzola & van der Kolk, 2012; Spinazzola et al., 2005). As professor of clinical psychiatry and leading trauma researcher Judith Herman states, 'repeated trauma in adult life erodes the structure of the personality already formed, but repeated trauma in childhood forms and deforms the personality' (Herman, 1997, p. 96).

It is well-evidenced that interpersonal trauma in childhood is a significant risk factor for developing mental illness (Alvarez et al., 2011; McLaughlin et al., 2010; Wamser-Nanney & Cherry, 2018), including psychosis (Arseneault et al., 2011; Bell, Foulds, Horwood, Mulder & Boden, 2019; Cutajar et al., 2010; Daalman et al., 2012; Fisher et al., 2009; Sheffield, Williams, Blackford & Heckers, 2013; Shevlin, Dorahy & Adamson, 2007; Ucok & Bikmaz, 2007; van Nierop et al., 2014a; Wang et al., 2013). Studies have demonstrated that more than one-third of people who have experienced psychotic symptoms report a history of interpersonal childhood trauma (ICT) (Bonoldi et al., 2013). Childhood trauma has also been found to have a dose-response effect on psychosis, whereby the severity of trauma is associated with the severity of psychotic symptoms (Heins et al., 2011; Muenzenmaier et al., 2015). Recent systematic reviews have further noted that, among people diagnosed with psychotic disorders, those who reported a history of interpersonal trauma in childhood experienced hallucinations and delusions that were more severe and persistent (Bailey et al., 2018; Trotta, Murray & Fisher, 2015).

Other studies have shown that a history of childhood trauma increases the likelihood that people with psychosis will be diagnosed with post-traumatic stress disorder (PTSD) or experience particular PTSD- or trauma-related symptoms (Gearon, Kaltman, Brown & Bellack, 2003; Hardy et al., 2016). As such, these individuals often continue to have emotionally intense and vivid memories of past traumatic events. There is also a high likelihood that people with a history of childhood trauma and psychosis will experience dissociation (i.e., feeling detached or disconnected from themselves or their everyday environment) (Ross & Keyes, 2004; Sar et al., 2010; Varese, Barkus & Bentall, 2012), depression, anxiety (Agnew-Blais & Danese, 2016; van Neirop et al., 2015), increased substance use (Tomassi et al., 2017), suicidality (Mohammadzadeh, Azadi, King, Khosravani & Bastan, 2019) and cognitive impairment (Aas et al., 2011). Collectively, this research demonstrates that, among people diagnosed with psychotic disorders, those with a history of ICT are more likely to present with a number of wide-ranging psychopathological symptoms and, as a result, be diagnosed with more than one psychiatric disorder (Calhoun et al., 2007; Powers, Fani, Cross, Ressler & Bradley, 2016; Ross & Keyes, 2004). However, irrespective of their symptomatic presentations and diagnoses, the treatment of these individuals largely focuses on alleviating psychotic symptoms through the use of antipsychotic medications.

Antipsychotics have been consistently used as first-line pharmacological treatments for psychotic disorders, primarily because they can supress hallucinations and delusions (Leucht et al., 2013). However, antipsychotics have been increasingly prescribed to non-psychotic clinical cohorts over the past 20 years (Marston, Nazareth, Petersen, Walters & Osborn, 2014; Matone et al., 2012; Olfson, King & Schoenbaum, 2015; Sheehan et al., 2015), with studies demonstrating that these medications can alleviate mania, insomnia, anxiety, irritability and hyperactivity, among others

(Hershenberg, Gros & Brawman-Mintzer, 2014; Tohen et al., 2007; Vita, De Peri & Sacchetti, 2011). Antipsychotics can also cause a number of distressing adverse effects, including emotional flattening, cognitive dulling, sedation and excessive sleepiness (Bebbington et al., 2009; DiBonaventura, Gabriel, Dupclay, Gupta & Kim, 2012; Llorka et al., 2017; Moritz, Andreou, Klingberg, Thoering & Peters, 2013; Morrison, Meehan & Stomski, 2015; Waterreus et al., 2012). Further, a meta-synthesis of 24 qualitative studies exploring the subjective effects of antipsychotics (undertaken as part of this thesis and presented in Chapter 3) demonstrates that these medications do not exclusively alleviate psychosis but can also exert global psychological and physiological effects, including lowered arousal, induced sleep and alterations in cognition and emotion. Participants described these global effects as either beneficial (e.g., feeling calmer, thinking more clearly) or detrimental (e.g., lack of motivation, cognitive dulling, sedation, emotional flattening). Thus, the way in which the global psychological effects of antipsychotics interact with some non-psychotic symptoms may explain why these medications have been increasingly used to treat non-psychotic disorders. For example, the medications' ability to lower arousal may, consequently, alleviate symptoms of anxiety and hypervigilance in people diagnosed with PTSD.

Therefore, antipsychotics may alter the psychological state of people with a history of ICT and psychosis by influencing how they experience non-psychotic symptoms and exerting further emotional, cognitive and physical changes. As there is a high likelihood that these people will experience dissociative, PTSD and other non-psychotic symptoms, the way in which the global psychological effects of antipsychotics interact with non-psychotic symptoms may play a significant role in whether traumatised individuals consider these medications beneficial. The global psychological effects of antipsychotics may also influence how people experience their trauma memories. For

example, antipsychotic-induced emotional numbing may relieve the intensity of distressing emotions, such as anger, that an individual experiences when they are reminded of a particular traumatic event. Moreover, a few studies have demonstrated that people with psychotic disorders who reported a history of childhood trauma were more likely to respond poorly to antipsychotic medications (Hassan & De Luca, 2015; Misiak & Frydecka, 2016). Thus, a better understanding of how people with a history of ICT and psychosis experience the psychological and physical effects of antipsychotics is needed. This study aimed to explore how people with a history of ICT and a diagnosis of psychosis subjectively experience the wide-ranging psychological and physical effects of antipsychotic medications. The study addressed one primary research question and three subsidiary questions.

1.1 Primary Research Question

How do people with psychosis and a history of ICT subjectively experience the effects of antipsychotic medications?

1.2 Subsidiary Research Questions

1. How do people with psychosis and a history of ICT subjectively experience the effects that antipsychotics have on their emotional, cognitive and physical states?

2. How do people with psychosis and a history of ICT subjectively experience the effects that antipsychotics have on their 1) thoughts, images and/or memories, 2) emotions and 3) physical responses, related to their childhood abuse/neglect?

3. How do people with psychosis and a history of ICT subjectively experience the effects that antipsychotics have on any dissociative states (depersonalisation and derealisation)?

1.3 Personal Reflection

The initial ideas for this research project emerged while I was working as a psychologist at a drug and alcohol residential rehabilitation centre. After months of working at the centre, it became apparent that many of the people who entered our program had experienced some form of childhood abuse and/or neglect. For many of these people, using illicit drugs and alcohol had been a way of supressing their trauma memories. As such, when trying to remain abstinent, one of the main things that people struggled with was dealing with memories of childhood abuse and/or neglect. Therefore, while some people were not ready to discuss childhood trauma in counselling, it was something that surfaced and, thus, could not be avoided. If these people were to remain abstinent from drug and alcohol use, they needed strategies to help them manage the emotional distress that they experienced while in rehab.

I also noticed that many of these traumatised individuals had experienced psychotic symptoms and were prescribed an antipsychotic medication as a result. I started to think about the relationship between childhood trauma and psychosis. After preliminary research, I found that what I had observed in a clinical setting had been identified by many studies—that childhood trauma was a significant risk factor for developing psychotic symptoms.

Further, throughout this period, people often spoke to me about how they experienced the effects of antipsychotic medications and emphasised the associated side effects (or adverse effects). Specifically, they complained about the medications' sedative

and sleep-inducing effects. However, I noticed that some people were also much calmer and less anxious since starting the medication. Their sleep had also improved and they reported having fewer racing thoughts. They often mentioned that things were not bothering them as much as they had previously. Thus, I started to think about the effects of antipsychotic medications on people's mental state as a whole (not only on their psychotic symptoms) and how this differed from one person to the next. I also considered the effect of antipsychotics on the anxiety and distress levels of traumatised individuals who were currently in alcohol and drug rehab and whether it was valuable to have this distress alleviated with a psychotropic drug.

I approached Assoc. Prof. Sarah Bendall and spoke to her about these ideas. She mentioned that a few people had previously spoken to her about how the arousal-lowering effects of antipsychotics had effected the way they experienced their trauma memories. This led to a further discussion with Prof. Louise Harms about the need to obtain more in-depth information about how people with childhood trauma and psychosis subjectively experience antipsychotic drug treatment. As such, my personal experience in working with people with a history of childhood trauma and psychosis, and my subsequent conversations with Assoc. Prof. Bendall and Prof. Harms, formulated the basis of this research project.

1.4 Chapter Outline

This thesis comprises 10 chapters. Chapter 2 reviews the literature that explores the association between ICT and psychosis. Evidence pertaining to the prevalence of PTSD, dissociation and other non-psychotic symptoms in people with psychosis and a history of ICT is reviewed. A small number of studies investigating how people with psychosis and childhood trauma respond to antipsychotics is also evaluated.

Chapter 3 presents an article that is under peer review with *European Psychiatry*. The article explores the subjective effects of antipsychotic medications through a meta-synthesis of 24 systematically gathered qualitative studies. The data were analysed using thematic synthesis. This involved an initial line-by-line coding of textual findings from primary studies, followed by the development of descriptive and analytical themes. A detailed description of this methodology is offered in the review itself. All themes are described and discussed in reference to how people subjectively experienced the effects of antipsychotic medications.

In Chapter 4, the rationale of this research is outlined by integrating the literature that was evaluated in Chapters 2 and 3. The primary research question and three subsidiary research questions are also presented.

Chapter 5 provides an overview of the methodology of this research project. An embedded mixed-methods research design was implemented. This design included a predominantly qualitative approach, which was used to answer the research questions. Rating scales were used to measure trauma and psychosis. They served as the secondary quantitative strand of the research design, which is described in detail. The study's inclusion/exclusion criteria, rating scales, sampling and recruitment strategies, ethical considerations and data collection methods are outlined. Qualitative data were analysed using interpretative phenomenological analysis (IPA). A detailed description of IPA is also provided.

Chapter 6 provides a description of the study's sample, including an overview of the participants' demographic information, their psychosis diagnoses, the types of psychiatric medications they were prescribed and the severity and types of trauma they had experienced. This information was obtained via the quantitative strand of the research

design and has been presented in a separate chapter because it was fundamental to interpreting the qualitative findings.

Chapters 7, 8 and 9 present the study's qualitative findings. The superordinate themes presented in all three chapters provide information relating to how the participants subjectively experienced the effects of antipsychotic medications. The themes presented in Chapter 7 provide information about how antipsychotics specifically influenced the participants' trauma-related thoughts, emotions and physical responses. The themes presented in Chapter 8 relate to how antipsychotics influenced the participants' dissociative symptoms, while Chapter 9 outlines the participants' general experiences of taking antipsychotic medications. Some of the themes presented in Chapter 9 provide information about how the participants experienced the emotional, cognitive and physical effects of antipsychotics.

Chapter 10 provides a detailed discussion of the results from Chapters 7, 8 and 9, with an emphasis on answering the three subsidiary research questions. The findings are discussed in relation to the conclusions drawn in Chapter 3. Methodological strengths and limitations, conceptual and clinical implications and suggestions for future research are then proposed.

Chapter 2: Interpersonal Childhood Trauma and Psychosis

This chapter provides an outline of previous research that explored the relationship between psychosis and ICT. This outline is followed by a review of studies that evaluated the rates of PTSD, dissociation and other non-psychotic symptoms in people with psychosis and a history of ICT. Finally, this chapter provides an overview of a small sample of studies that explored the use of antipsychotic medications in people with psychosis and childhood trauma. The overview includes studies that evaluated how this cohort responds to antipsychotic drug treatment.

2.1 Interpersonal Childhood Trauma in People with Psychosis

To date, a number of extensive systematic reviews have demonstrated that ICT is a risk factor for psychosis (Bendall, Jackson, Hulbert & McGorry, 2008; Bonoldi et al., 2013; Cunningham, Hoy & Shannon, 2016; Matheson, Shepherd, Pinchbeeck, Laurens & Carr, 2012; Morgan & Fisher, 2007; Read, Van Os, Morrison & Ross, 2005; Varese et al., 2012). For example, Varese et al. (2012) undertook a meta-analysis of 18 case-control studies (n = 2048 psychotic patients; n = 1856 non-clinical controls), 10 prospective and quasi-prospective studies (n = 41,803) and eight population-based cross-sectional studies (n = 35,546). They demonstrated that childhood trauma increased the risk of psychosis with an odds ratio of 2.78. With the exception of parental death, all trauma types assessed (sexual abuse, physical abuse, emotional abuse, neglect and bullying) had statistically significant associations with psychosis. The researchers suggested (with the assumption of causality) that if childhood trauma were removed as a risk factor, the number of people with psychosis would reduce by 33%. Another review by Matheson et al. (2012) assessed the evidence pertaining to rates of childhood trauma in people with schizophrenia

compared with those in people with other psychiatric disorders and non-psychiatric controls. The researchers analysed 25 studies, including case-control, cohort and cross-sectional studies and found increased rates of childhood trauma among schizophrenia patients when compared to controls, with an odds ratio of 3.6. An increased risk of childhood trauma was also found in people with schizophrenia when compared to those with anxiety disorders. There were no differences in the rates of childhood trauma between schizophrenia and affective psychosis, depression or personality disorders. Higher rates of childhood trauma were found among people with dissociative disorders and PTSD when compared to those with schizophrenia.

In a meta-analysis of 23 retrospective studies, Bonoldi et al. (2013) demonstrated that people with psychosis (n = 2017) had a high self-report of childhood sexual abuse (26%), childhood physical abuse (39%) and childhood emotional abuse (34%). By comparing their findings to those of Kessler et al. (2010)—who demonstrated that, in a general population sample (n = 51,945), 8% experienced childhood physical abuse while 1.6% experienced childhood sexual abuse—Bonoldi et al. (2013) suggested that rates of childhood abuse are substantially greater among people with psychosis when compared with the those in the general population.

The association between ICT and psychosis has also been identified as having a dose–response effect, whereby the severity of childhood abuse is related to the severity of psychotic symptoms (Bentall, Wickham, Shevlin & Varese, 2012; Heins et al., 2011; Muenzenmaier et al., 2015). Trauelsen et al. (2015) demonstrated that, among 101 individuals with first-episode psychosis and 101 non-clinical controls, the risk of experiencing psychosis increased by 2.5 times for every additional adversity. More recently, Croft et al. (2019) examined a large population-based cohort (n = 4433) and found that exposure to three or more traumas during childhood or adolescence increased

the likelihood of a person developing psychotic symptoms (odds ratio = 4.74), which is significantly higher than if they were exposed to one or two traumas (odds ratio = 1.89 and 2.54 respectively). Additionally, the risk of experiencing psychosis was significantly higher after exposure to trauma at three different age periods (early childhood, middle childhood and adolescence) than exposure to trauma within one or two age periods.

Further, emerging evidence has suggested that ICT is predictive of psychotic experiences (De Loore et al., 2007; Janssen et al., 2004; Spauwen, Krabbendam, Lieb, Wittchen & van Os, 2006). In one longitudinal cohort study of 1112 adolescents (aged 13–16 years), Kelleher et al. (2013) demonstrated that having been a victim bullying and physical assault predicted psychotic experiences and that among traumatised individuals the cessation of trauma predicated a reduction in psychotic symptoms. Two systematic reviews have also demonstrated that ICT is associated with more severe and persistent hallucinations and delusions in people diagnosed with psychotic disorders (Bailey et al., 2018; Trotta et al., 2015). Trotta et al. (2015) aimed to assess the effect of childhood adversity on the course of psychotic symptoms by meta-analysing 20 prospective studies. The researchers demonstrated that childhood adverse events were associated with persistent psychotic symptoms. The odds ratios ranged from 1.8 to 3.26. Bailey et al. (2018) aimed to determine whether ICT was associated with the severity of psychotic symptoms by undertaking a meta-analysis of 29 cross-sectional and longitudinal studies (n = 4680). The concept ‘total childhood trauma’ was used to represent studies that reported a global measure of trauma or an integration of different types of abuse and neglect. Results revealed that total childhood trauma was associated with the severity of hallucinations and delusions. Negative symptoms severity was associated with childhood neglect, but not with total childhood trauma.

Studies have also found that the relationship between childhood trauma and psychosis remains significant when potential confounding variables are controlled (Fisher et al., 2014; Thompson et al., 2014). For example, using an epidemiological case-control sample (including 172 individuals with first-episode psychosis and 246 matched controls), Fisher et al. (2014) aimed to investigate the interaction between childhood physical abuse and family psychiatric history in the onset of psychotic illness. The results revealed that having at least one parent with a history of psychosis was more common among individuals with first-episode psychosis than in the community controls. However, controlling for a parental history of psychosis only had a small effect on the strength of the relationship between childhood physical abuse and psychosis. These results consolidated prior suggestions that ICT exerts at least a partially independent effect on psychosis (Bendall, Alvarez-Jimenez, Nelson & McGorry, 2013).

Specific types of childhood trauma have been related to particular psychotic symptoms (Bentall et al., 2012; Read, Agar, Argyle & Aderhold, 2003; Sheffield et al., 2013). One study demonstrated that among a sample of people diagnosed with a psychotic disorder (n = 114), those with a history of auditory hallucinations reported significantly more sexual, physical and emotional abuse than people who had never experienced auditory hallucinations (Sheffield et al., 2013). The researchers also found that in the absence of sexual abuse, physical and emotional abuse did not lead to a higher rate of auditory hallucinations, suggesting that sexual abuse is a specific risk factor for auditory hallucinations. Another study undertaken by Catone et al. (2015) explored the association between having experienced bullying and the risk of psychotic phenomena by analysing responses to the British Adult Psychiatric Morbidity Survey for the years 2000 (n = 8580) and 2007 (n = 7403). Having experienced bullying was positively associated with persecutory ideation (odds ratio = 2.99 in both years) and hallucinatory experiences (odds

ratio = 2.39 in 2000; odds ratio = 2.51 in 2007). These correlations remained significant even after controlling for other traumas and childhood sexual abuse. Having experienced bullying was also significantly related to a diagnosis of probable psychosis, with odds ratios of 3.91 for the year 2000 and 3.43 for 2007. Further, studies have reported similarities between the trauma experience and the content of psychotic symptoms (Hardy et al., 2005; Reiff, Castille, Muenzenmaier & Link, 2012; Romme, 2012). Thompson et al. (2010) investigated the prevalence of sub-threshold psychotic symptoms with sexual content in an ultra-high risk of psychosis sample (n = 92) and the relationship of these symptoms to previous sexual abuse. Of the 33 participants who reported a history of sexual abuse, 11 experienced at least one psychotic symptom with sexual content (e.g., delusions of being watched in the shower or undressing). The researchers concluded that there was a strong relationship between these symptoms and a history of sexual abuse.

Moreover, several studies have demonstrated that ICT is associated with the development of psychotic symptoms in people who are at ultra-high risk of psychosis (Addington et al., 2013; Loewy et al., 2019; Thompson et al., 2014). Specifically, two recent meta-analyses demonstrated that there was a high prevalence of childhood trauma among individuals who were considered at ultra-high risk of psychosis when compared to controls (Fusar-Poli et al., 2017; Peh, Rapisarda & Lee, 2019), while one review found that trauma was associated with more severe attenuated (or sub-threshold) psychotic symptoms (Brew, Doris, Shannon & Mulholland, 2018). In addition, Velinkonja and colleagues (2015) undertook a systematic review of 25 studies and demonstrated that childhood trauma was associated with schizotypy—a multidimensional construct that 'refers to a latent personality organisation that putatively harbors the liability for schizophrenia and can give rise to a variety of schizophrenia-related phenotypic outcomes' (Lenzenweger, 2018, p. 25).

It must be noted that the majority of studies evaluated in the reviews/meta-analyses exploring the relationship between ICT and psychosis have primarily used retrospective assessments to obtain data relating to past trauma (for example, Bendall et al., 2008; Matheson et al., 2012; Trotta et al., 2015). These designs have been criticised for potentially producing unreliable data as the recall of events that occurred many years ago may be impacted on by present deficits in psychological functioning (Fisher et al., 2011), and/or that people with psychosis may over report childhood adversity as an attempt to make sense of presenting symptoms (Susser & Widom, 2012). However, selected studies have suggested that rates of reporting childhood trauma between individuals with an ultra-high risk for psychosis (n = 41) and those with first episode schizophrenia (n = 83) do not differ from each other (Sahin et al., 2013). Furthermore, Fisher et al. (2011) demonstrated that in their sample 'histories of childhood adversity obtained retrospectively from psychosis patients showed evidence of reasonable reliability and comparability' (Fisher et al., 2011, pp. 550-551). The researchers specifically found that (i) among 30 individuals reports of adversity were fairly stable over a 7 year period, and (ii) among 157 individuals current psychopathology did not appear to have a measurable influence on the likelihood of childhood abuse self-reporting. Taken together the findings of Sahin et al. (2013) and Fisher et al. (2011) suggest that the association between trauma and psychosis is valid and not better explained by reporting bias.

Given the compelling evidence demonstrating that ICT is a risk factor for psychosis, many avenues of research are being pursued to further understand this relationship in greater depth. For example, several recent studies evaluated the explanatory role of potential mediating variables, including sensitisation, attachment style and social defeat. These studies found that among people diagnosed with a psychotic

disorder, those with a history of ICT were more emotionally reactive/sensitive to ongoing stress (Lordinois, Lataster, Mengelers, van Os & Myin-Germeys, 2011), had poorer (fearful/anxious and avoidant) attachment styles (Sheinbaum, Kwapil & Barrantes-Vidal, 2014; Sitko, Bentall, Shevlin, O'Sullivan & Sellwood, 2014; van Dam, Korver-Nieberg, Velthorst, Meijer & de Haan, 2014) and experienced feelings of outsider status and reduced self-value (van Nierop et al., 2014b). However, these studies went beyond the scope of this research and, thus, will not be evaluated in further detail. The remainder of this chapter will focus on examining the prevalence of PTSD in people with psychosis, the role of dissociation within the trauma–psychosis relationship (Pilton, Varese, Berry & Bucci, 2015) and the presence of other non-psychotic clinical characteristics among samples of people who have experienced ICT and psychosis.

2.2 Interpersonal Childhood Trauma, Post-Traumatic Stress Disorder and Psychosis

According to the fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5), the essential feature of PTSD 'is the development of characteristic symptoms following exposure to one or more traumatic events' (American Psychiatric Association [APA], 2013, p. 274). In the DSM-5, these 20 symptoms are presented across four symptom clusters: intrusions (e.g., involuntary distressing memories or flashbacks of a traumatic event), persistent avoidance (e.g., efforts to avoid reminders, such as people or places, that arouse thoughts or feelings related to a traumatic event), negative alteration in cognition and mood (e.g., an inability to remember specific aspects of the traumatic event, persistent distressing emotions such as fear or anger) and alteration in arousal or reactivity (e.g., hypervigilance, exaggerated startle response) (APA, 2013). In contrast to the DSM-5, the 11th version of the International Classification of Diseases (ICD-11) has

incorporated a diagnosis of PTSD that is characterised by six symptoms across three symptom clusters: re-experiencing in the here and now, deliberate avoidance and a sense of threat (Hyland, Shevlin, Fyvie & Karatzias, 2018). The ICD-11 also includes a new diagnostic category called 'complex PTSD' (CPTSD), which is a disorder 'that typically follows severe stressors of a prolonged nature or multiple or repeated adverse events from which separation is not possible (e.g., exposure to genocide campaigns, childhood sexual abuse, child soldiering, severe domestic violence, torture, or slavery)' (Maercker et al., 2013, p. 201). CPTSD includes all six PTSD symptoms as well as three additional symptom clusters that characterise disturbances in self-organisation: affective dysregulation, negative self-concept and disturbances in relationships (Hecker, Huber, Maier & Maercker, 2018). These additional symptom clusters aim to capture the pervasive psychological disturbances that occur after an individual is exposed to prolonged or repeated traumas—particularly those of an interpersonal nature that occurred during early development (Hyland et al., 2017). Several studies demonstrated that CPTSD has good construct validity among community and clinical populations, (reviewed by Brewin et al., 2017). However, there are currently no studies examining the prevalence of CPTSD among individuals diagnosed with psychotic disorders. Therefore, the research evaluated in this subsection focuses solely on PTSD.

A core feature of PTSD is that traumatic events are not remembered or relegated to the past in the same way as other life events (Rothschild, 2000). Memories of traumatic events, or trauma memories, are experienced with emotional intensity and distress (e.g., intense anger, overwhelming guilt or shame), contain greater sensory detail and are sometimes fragmented and disorganised (i.e., repetitious images or thoughts, disjointed thoughts that lack continuity) (Ashbaugh, Marinos & Bujaki, 2018; Bedard-Gilligan & Zoellner, 2012; Ford, 2018). Trauma memories can be experienced at random, or

triggered automatically when sensory input from the individual's current environment (e.g., loud yelling, specific odours) matches their sensory and emotional responses that were present when the traumatic event(s) occurred (Ozomoff, Pennington & Solomon, 2006; Rothschild, 2000). Thus, people can experience trauma memories that are intrusive or involuntary in nature (O'Kearney & Perrott, 2006) and, as a result, re-experience the traumatic event and their initial trauma response (i.e., how they reacted and what they were feeling when the traumatic event[s] occurred) (Ozomoff et al., 2006). This automatic and involuntary re-experiencing of traumatic events often takes the form of flashbacks, which, unlike other intrusive memories, are characterised by 'a phenomenological sense of reliving the event in the present—immediate and inescapable immersion in the situation or a resultant state of intense fear, horror, or helplessness' (Ford, 2018, p. 934). Flashbacks can involve disorientation and a confused awareness of the self and the circumstances surrounding one's current situation or environment—a state that may be accentuated by very high levels of arousal (Ford, 2018). Many traumatised people struggle to control the occurrence of flashbacks and thus, often avoid trauma-related cues to try to manipulate the chance of flashbacks being automatically triggered (Brewin, 2001).

Numerous studies have found that rates of PTSD are higher in people with psychosis than in the general population (Aakre, Brown, Benson, Drapalski & Gearson, 2014; Halasz, Levi-Gigi, Kelemen, Benedek & Keri, 2013; Neria, Bromet, Sievers, Lavelle & Fochtmann, 2002; Newman, Turnbull, Berman, Rodrigues & Serper, 2010; Resnick, Bond & Mueser, 2003). Seow et al. (2016) undertook a systematic review of 34 studies evaluating the rates of comorbid PTSD in samples of people diagnosed with schizophrenia spectrum disorders. The prevalence of comorbid PTSD across the included studies ranged widely from 0% to 57%, which the researchers suggested may have been

due to the inclusion of studies with different, incomparable populations (e.g., inpatients, outpatients, veterans). However, most of the studies reported prevalence rates of PTSD ranging from 20% to 30%, which were substantially higher than that of the general population (in which the prevalence of PTSD has been estimated at 2.2–8.8%) (Atwoli, Stein, Koenen & McLaughlin, 2015; Frans, Rimmo, Aberg & Fredrikson, 2005). The researchers emphasised that, because the studies in their review used a cross-sectional design, causal inferences between PTSD and schizophrenia could not be made. They also mentioned that it was difficult to make broad generalisations from their findings because the studies used different methodologies (e.g., different measures used for the same constructs).

Most of the studies in the review by Seow et al. (2016) measured lifetime trauma and did not differentiate between adult and childhood trauma. However, there are a few studies that evaluated the prevalence of ICT among individuals with PTSD and psychosis (Bendall et al., 2013; Calhoun et al., 2007; Gearon et al., 2003; Hardy et al., 2016). Calhoun et al. (2007) examined the prevalence of war exposure, interpersonal trauma and PTSD in a sample of 165 male veterans diagnosed with either schizophrenia or schizoaffective disorder. A total of 78 individuals (47.3%) met the diagnostic criteria for PTSD. Having experienced childhood physical abuse and physical assault in the past year increased the odds of a person having PTSD. Of the 78 individuals diagnosed with PTSD, 72% had experienced childhood physical abuse and 90% had experienced at least one recent physical assault. Sexual assault (in childhood and adulthood) was not associated with PTSD.

Another study by Gearon et al. (2003) assessed the prevalence of traumatic life events and PTSD among women diagnosed with either schizophrenia ($n = 33$) or schizoaffective disorder ($n = 21$), as well as those with comorbid substance abuse or

dependence. Of the 54 women, 25 (46%) were diagnosed with current PTSD. Childhood sexual and physical abuse as well as re-victimisation (i.e., experiencing both childhood and adult sexual or physical abuse) were significantly correlated with current PTSD. Of the 33 and 26 women who experienced childhood sexual abuse and childhood physical abuse, 61% and 65% met the criteria for current PTSD, respectively. The largest difference in PTSD severity scores was associated with both childhood and adult sexual abuse. Gearon et al. (2003) and Calhoun et al. (2007) explored the prevalence of PTSD in specific groups of people with psychosis: male inpatient veterans and female outpatients diagnosed with a comorbid substance use disorder (of which 92% were African American) respectively. The researchers of both studies mentioned that their findings had limited generalisability.

Further, Hardy et al. (2016) endeavoured to explore the involvement of specific psychological mechanisms (affect regulation, intrusive trauma memory, beliefs and depression) in the associations between trauma type and psychotic symptoms. The study comprised 228 individuals with psychosis who had experienced a recent relapse of positive symptoms. Forty-nine individuals (21.5%) met the symptom criteria for PTSD and eight of them (16.3%) had experienced childhood sexual abuse. Childhood sexual, physical and emotional abuse were all associated with more severe negative-other beliefs (i.e., an appraisal that others are, for example, threatening, hostile or untrustworthy) (Fowler et al., 2006). The association between childhood emotional abuse and persecutory delusions was mediated by negative-other beliefs. The results also revealed that the association between childhood sexual abuse and auditory hallucinations was mediated by post-traumatic avoidance, numbing and hyperarousal (but not intrusive memory or depression). The researchers indicated that intrusive memories were assessed in relation to the index event (i.e., the traumatic event that the participants indicated they

were most affected by), which in many cases was not sexual abuse. Therefore, intrusions related to sexual abuse may have been missed.

Two recent studies aimed to examine the associations between childhood trauma, PTSD symptoms and psychosis (Choi et al., 2015; Powers et al., 2016). Choi et al. (2015) examined a sample of 126 Korean psychiatric inpatients with psychosis (of whom 70 were female) and found high self-reporting of moderate to severe levels of childhood physical abuse (40.5%), childhood sexual abuse (37.3%) and childhood emotional abuse (31.7%). Their results also revealed that PTSD symptoms partially mediated the significant association between childhood abuse and psychotic symptoms. Powers et al. (2016) examined ICT and PTSD as predictors of a psychotic disorder diagnosis. The study comprised 328 individuals, of whom 85.4% were female and 96% were African American. Nineteen participants met the criteria for a current psychotic disorder diagnosis and 29 participants were diagnosed with a lifetime psychotic disorder. Higher rates of comorbid psychiatric conditions (major depression, substance dependence, lifetime suicide attempts, PTSD) were found in participants with a current psychotic disorder diagnosis than in those who did not meet the criteria for psychosis. Of the 19 participants with a current psychotic disorder diagnosis, 70.9% were diagnosed with either current or lifetime PTSD. Moderate to severe childhood abuse was more prevalent in participants diagnosed with a current psychotic disorder (72.7%) than in those who were not currently experiencing psychosis (41.7%). All three PTSD symptom clusters (i.e., re-experiencing, avoidance/numbing, hyperarousal) were independently associated with a current psychotic disorder diagnosis. It was also demonstrated that childhood trauma was predictive of psychosis and that PTSD mediated the significant association between childhood abuse and a current psychotic disorder diagnosis. As with other studies examining the prevalence of childhood trauma in people with PTSD and psychosis

(Calhoun et al., 2007; Gearon et al., 2003), Powers et al. (2016) indicated that the specificity of the examined population limits generalisability. Thus, further research is needed to make more conclusive generalisations regarding the causal link between childhood trauma, PTSD and psychosis. Nevertheless, the studies evaluated in this subsection do offer preliminary evidence that PTSD symptoms may help explain the relationship between childhood trauma and psychosis and the high prevalence of PTSD resulting from childhood trauma among individuals with psychosis.

2.3 Interpersonal Childhood Trauma, Dissociation and Psychosis

This subsection evaluates the role of dissociation within the trauma–psychosis relationship and the prevalence of dissociative symptoms among individuals who have experienced ICT and psychosis. The American Psychiatric Association (APA) has conceptualised dissociation as 'a disruption of and/or discontinuity in the normal integration of consciousness, memory, identity, emotion, perception, body representation, motor control, and behaviour' (APA 2013, p. 291). Researchers have argued that dissociation serves as a protective or coping mechanism that allows individuals to psychologically detach from events that are too overwhelming to process (Granieri, Guglielmucci, Costanzo, Caretti & Schimmenti, 2018; Kezelman & Stavropoulos, 2012; Longden, Madill & Waterman, 2012; Schimmenti, 2018; Schimmenti & Caretti, 2016). This can occur through such symptoms as depersonalisation (i.e., feeling detached, estranged or disconnected from one's own being) (Simeon & Hamilton, 2008) and derealisation (i.e., experiencing one's environment, including other people, as unreal, unfamiliar or unclear) (Boon, Steele & Van der Hart, 2011). Common descriptions of depersonalisation include: watching oneself from a distance (e.g., floating above oneself and observing one's own body), feeling disconnected from the body or from particular

body parts (Simeon, 2004), feeling unable to control physical movement (Sierra, Baker, Medford & David, 2005) and feeling a sense that particular events did not really happen (e.g., as if the event was a movie or a dream, or the feeling that someone else was involved in the event and/or it did not happen to oneself) (Boon et al., 2011). One survivor of severe ICT, Cathy Kezelman, describes her experience of depersonalisation while she was with her husband, Dan, and therapist, Kate:

> While I had a sense of him crying on some level of consciousness, at that point his tears flowed in a world which was far removed from mine. As I curled in on myself in a corner of a foreign chair, I was distanced from the drama unfolding in the room around me… 'Cathy! CATHY!' Kate used her business like voice to bring me back to the here and now. 'Cathy, what do you think about what Dan is saying?' I couldn't answer; I was so far away. As I battled my way through the layers of dissociative disconnection, I found recognition in my husband's distress, and his anguish yanked me right back (Kezelman, 2010, pp. 117-118).

Depersonalisation is often accompanied by derealisation (Simeon, 2004), of which common descriptions include: feeling as though one is living in a dream, robotically going through the motions of life while feeling dead inside (Hunter, Charlton & David, 2017), experiencing different parts of one's personal environment (e.g., one's own house) as strange or unfamiliar and experiencing one's surroundings as hazy, foggy or distant (Boon et al., 2011). In addition to the primary symptoms of detachment, disconnection and unreality, 'people with depersonalisation and derealisation can describe emotional numbing of positive and negative emotions' (Hunter et al., 2017, p. 1). Suggestions have also been made that dissociation activated by trauma can make individuals vulnerable to psychosis (Perona-Garcelan et al., 2012) and, more specifically, that voice-hearing experiences are best understood as dissociated aspects of self, resulting

from loss, trauma or interpersonal stress (Longden et al., 2012). However, the presence of intact reality testing differentiates symptoms of depersonalisation/derealisation from psychotic symptoms (APA, 2013).

To date, a number of studies have demonstrated associations between childhood trauma and dissociative symptoms among people diagnosed with psychotic disorders (Braehler et al., 2013; Holowka, King, Saheb, Pukall & Brunett, 2003; Perona-Garcelan et al., 2010; Renard et al., 2017; Ross & Keyes, 2004; Sar et al., 2010; Schafer et al., 2012). A study undertaken by Braehler et al. (2013) found that across three samples—people experiencing first-episode psychosis (n = 62), people with chronic psychosis (n = 43) and community controls (n = 66)—the severity of ICT was associated with the severity of dissociative symptoms (as measured using the Dissociative Experiences Scale [DES]). Of the five trauma types (physical, sexual and emotional abuse, physical and emotional neglect), emotional abuse had the strongest association with dissociation in the first-episode psychosis and chronic psychosis groups. Another study undertaken by Ross and Keyes (2004) demonstrated that 60 individuals with chronic schizophrenia fell into two subgroups: one group with high dissociation (a score of above 25 on the DES and/or a dissociative disorder diagnosis; n = 36) and another group with low dissociation (a score of below 10 on the DES and no dissociative disorder diagnosis; n = 24). The Dissociative Disorders Interview Schedule was used to determine whether participants met the diagnostic criteria for a dissociative disorder. Of the 36 high-dissociation participants, 16 were diagnosed with dissociative identity disorder (44%). The results revealed that 67% of the high-dissociation group experienced childhood physical and/or sexual abuse, whereas only 21% of the low-dissociation group reported physical and/or sexual abuse. The high-dissociation group also reported more comorbidity, including depression (83%) and borderline personality disorder (81%). It must be noted that the researchers did not

provide information about how many of the individuals who presented with these additional comorbidities experienced childhood physical and/or sexual abuse. However, given the high rates of both childhood trauma and comorbidity among the high-dissociation subgroup, it is likely that a substantial number of people with more severe dissociation and a history of childhood abuse also experienced depression and/or borderline personality disorder. The researchers concluded that among individuals with schizophrenia, there is a substantial subgroup of people with pathological dissociation, childhood trauma and other comorbidities.

Other studies have found that dissociation mediates the relationships between ICT and particular psychotic symptoms (Pearce et al., 2017; Perona-Garcelan et al., 2012; Sun et al., 2018; Varese et al., 2012; Yamasaki et al., 2016). Varese et al. (2012) aimed to investigate whether dissociative symptoms explained the relationship between ICT and hallucination-proneness. The study included a clinical sample of 45 individuals with schizophrenia spectrum disorders and 20 healthy controls with no reported history of hallucinations. To examine between-group differences, the clinical sample was divided into three subgroups: hallucinating individuals (n = 15), remitted hallucinators (n = 14) and non-hallucinating individuals (n = 16). Compared to the healthy controls, as well as the remitted and non-hallucinating clinical subgroups, the hallucinating individuals reported significantly higher dissociative tendencies and childhood sexual abuse. Dissociation mediated the association between childhood trauma and hallucination-proneness. The mediating role of dissociation was particularly strong for sexual abuse when compared to the other trauma types. It is clear from the research reviewed above that ICT is associated with dissociation and PTSD in people who have experienced psychotic symptoms. However, there is also evidence that ICT is associated with other

non-psychotic symptoms in people with psychosis. The following subsection will review these studies.

2.4 Other Comorbid Clinical Features and Cross-Diagnostic Associations

A number of studies have demonstrated high rates of other comorbidities (including depression, anxiety, suicidality, substance use and borderline personality disorder) among people presenting with psychotic symptoms and a history of ICT (Addington et al., 2013; Mohammadzadeh et al., 2019; Sar et al., 2010; Shannon et al., 2011; van Nierop et al., 2015; Vargas et al., 2019). One methodologically robust study by van Nierop et al. (2015) aimed to investigate the association between childhood trauma and depression, anxiety, mania and psychosis. The researchers used data from a general population sample (n = 6646, 1577 of whom were diagnosed with a mood disorder and 1120 had an anxiety disorder) and an additional sample of people diagnosed with schizophrenia (n = 825). The results indicated that for both the general population and schizophrenia samples, childhood trauma had a significantly stronger relationship with a combined admixture of symptom clusters (e.g., depression, anxiety, psychosis) than with specific isolated symptoms (e.g., psychosis alone). Interestingly, as the combination of symptom clusters increased (e.g., from three to four symptom clusters), so did the odds ratio of the relationship with childhood trauma. The researchers indicated that a limitation of their study was that they did not obtain data on the prevalence of other disorders that have been associated with childhood trauma, including PTSD, borderline personality disorder and dissociative disorders. They did mention that these disorders are known for their prominent mixture of affective, anxiety and psychotic symptoms. For example, as outlined in Subsection 2.3, Ross and Keyes (2004) demonstrated that of 36 participants

with schizophrenia and severe dissociation, 83% were also experiencing depression and 81% met the diagnostic criteria for borderline personality disorder. Thus, the researchers argued that their findings may extend to these disorders. In terms of methodological rigor, it is worth noting that the study used multiple samples that were large and representative, which increases generalisability (van Neirop et al., 2015).

Another study by Tomassi et al. (2017) evaluated the relationship between childhood trauma, affective psychosis and lifetime substance use in a large representative sample of 345 people with first-episode psychosis (mean age = 29.8 years). The results revealed that severe sexual abuse was significantly associated with affective psychosis. Specifically, 42% of the participants with a history of severe childhood sexual abuse experienced an affective psychosis compared with 22% of the participants who were not sexually abused. Individuals who experienced childhood abuse (60%) showed a significantly higher frequency of substance use (cannabis, cocaine and/or heroin) than individuals without an abuse history (39%).

A number of other studies found that ICT is strongly associated with a history of suicide attempts and suicide ideation in people with psychotic disorders (Conus, Cotton, Shimmelmann, McGorry & Lambert, 2010; Hassan, Stuart & De Luca, 2016; Mohammadzadeh et al., 2019; Ucok & Bikmaz, 2007). One recent study aimed to determine whether ICT predicted suicidal risk (as determined by current suicide ideation and lifetime suicide attempts) in 82 individuals with schizophrenia (Mohammadzadeh et al., 2019). People with high levels of ICT (39%) were found to be at a significantly higher risk of suicide and reported more severe symptoms (depression, as well as positive and negative symptoms) than did people with low levels of trauma. The findings also showed that people with lifetime suicide attempts reported more severe depression. However, after controlling for depression severity, it was revealed that 1) people who reported

higher levels of sexual abuse had also made more lifetime suicide attempts and 2) people with higher levels of physical neglect continued to experience more severe suicide ideation. Thus, depression, sexual abuse and physical neglect served as independent predictors of suicidality. The researchers concluded that people with schizophrenia who had severe depression and a history of sexual abuse or physical neglect in childhood were at the greatest risk of suicide. These conclusions further consolidated the findings of van Neirop et al. (2015) that people with a history of ICT (including those with psychosis) were more likely to experience an admixture of psychopathological symptoms.

ICT has also been found to increase the risk of aggressive and/or violent behaviour among individuals who have experienced psychosis (Bosqui et al., 2014; Khalid, Ford & Maughan, 2012; Spidel, Lecomte, Greaves, Sahlstrom & Yuille, 2010). One meta-analysis of 11 cross-sectional and case-control studies (n = 2215) found that people with psychotic disorders who experienced childhood maltreatment were at approximately twice the risk of being violent than people with no reported abuse in childhood (odds ratio = 2.46) (Green, Browne & Chou, 2019).

Two other systematic reviews aimed to explore the relationship between childhood trauma and cognitive functioning in people who had experienced psychosis (Dauvermann & Donohue, 2019; Vargas et al., 2019). Vargas et al. (2019) meta-analysed 24 studies (n = 3315) and found a small negative association between ICT and overall cognitive ability in people diagnosed with psychotic disorders. Regarding specific cognitive domains, a modest negative relationship was found between ICT and working memory. A case-control comparison using seven studies comprising 1193 healthy controls was also undertaken. The association between ICT and cognitive functioning was significantly stronger in healthy individuals compared to that in people with psychosis. The researchers suggested that the effect of trauma may have been masked by

other factors related to a psychotic disorder diagnosis, such as current difficulties, medication use and genetic influences. In most of the 21 studies reviewed by Dauvermann and Donohue (2019), participants with psychosis and a history of childhood trauma experienced cognitive deficits that were more severe than those without a trauma history. There was greater inconsistency in the relationship between childhood trauma and cognitive functioning among people with chronic schizophrenia than in non-clinical cohorts, as well as in people who were at ultra-high risk of psychosis, had experienced first-episode psychosis and were diagnosed with chronic bipolar disorder. The researchers indicated that this inconsistency may be due to the variability of trauma measures used across the included studies. They also mentioned that, in the chronic schizophrenia group, the effect of trauma may have been influenced by other factors, such as a general variability in cognitive performance in people with schizophrenia. While more methodologically robust studies are needed to determine how much of an effect ICT has on the cognition functioning of people with psychosis (in particular those with chronic schizophrenia), these reviews offer preliminary evidence that an association does exist between trauma and particular cognitive deficits (e.g., working memory).

Moreover, a number of studies have shown that the relationship between ICT and psychosis exists cross-diagnostically – that is, within samples of individuals diagnosed with non-psychotic disorders, those with a trauma history are more likely to also experience psychotic symptoms (Hamersley et al., 2003; Upthegrove et al., 2015). For example, among a sample of people diagnosed with major depressive disorder (n = 623), Gaudiano and Zimmerman (2010) demonstrated that there was a greater possibility that individuals had experienced sexual abuse (odds ratio = 2.75) or physical abuse (odds ratio = 2.81) if they had been diagnosed with the psychotic subtype of major depressive disorder as opposed to the non-psychotic subtype. This difference remained significant

even after controlling for depression severity and demographic factors. Interestingly, when compared to participants with the non-psychotic subtype of major depressive disorder, those with the psychotic subtype were more likely to be diagnosed with PTSD. Additionally, the strength of the association between ICT and psychosis in major depressive disorder appears similar to that observed among individuals diagnosed with a psychotic disorder (e.g., Varese et al., 2012), suggesting that the strength of this relationship also exists on a cross-diagnostic level.

Further, one recent systematic review and meta-analysis of 30 studies aimed to explore the association between childhood maltreatment and 12 negative outcomes in people with bipolar disorder (Agnew-Blais & Danese, 2016). Each clinical outcome was meta-analysed independently. All 12 meta-analyses revealed that people who had experienced childhood maltreatment had additional and more severe clinical features (including a higher risk of comorbid PTSD, depression and psychosis severity) than people without a history of maltreatment. These findings demonstrated that, in bipolar disorder, ICT is associated with psychosis as well as an increased likelihood of comorbidity.

The studies evaluated in this subsection clearly demonstrated that, in addition to experiencing dissociative and PTSD-related symptoms, there is a high likelihood that people with ICT and psychosis will present with other non-psychotic symptoms. This suggests that among people with psychosis, those with a history of childhood trauma are likely to have a more complex clinical profile. The following subsection will review a small sample of studies that examined the use of antipsychotics among people with a history of childhood trauma and psychosis.

2.5 Interpersonal Childhood Trauma, Psychosis and Antipsychotic Medication

The research evaluated thus far has suggested that among people who have experienced psychosis, those with a history of ICT are more likely to exhibit additional non-psychotic symptoms and, as a result, be diagnosed with more than one psychiatric disorder. However, irrespective of the diagnosis, a core component in the treatment of these individuals focuses on the alleviation of hallucinations and delusions—mainly with the use of antipsychotic medication. There are currently a few studies that have endeavoured to examine the use of antipsychotics in people with childhood trauma and psychosis or have provided information on how this cohort responded to antipsychotic treatment (Hassan & De Luca, 2015; Lecomte et al., 2008; Misiak & Frydecka, 2016; Schneeberger, Muenzenmaier, Castille, Bataglia & Link, 2014). One cross-sectional study aimed to determine the profiles of individuals with early psychosis who did not adhere to antipsychotic treatment or adequately engage with relevant mental health services (Lecomte et al., 2008). All participants (n = 118; mean age = 25) were prescribed a second-generation antipsychotic (SGA), with many receiving a combination of both antipsychotics and mood stabilisers. Witnessing violence during childhood was a significant predictor of poor medication adherence. Childhood physical abuse was also the strongest predictor of poor service engagement.

Two studies evaluated how people with trauma and psychosis responded to antipsychotics. The first study specifically explored the association between the accumulation of life adversities (including ICTs) and resistance to antipsychotic treatment in people diagnosed with either schizophrenia or schizoaffective disorder (Hassan & De Luca, 2015). The participants' treatment-resistance statuses were determined using the APA's criteria for refractory schizophrenia. The sample comprised 78 treatment-resistant

participants (41.9%) and 108 non-treatment-resistant participants (58.1%). Treatment-resistant status was positively correlated with the accumulation of lifetime adversities. Participants with four or more lifetime traumatic experiences were four times more likely to be resistant to antipsychotic medications. Regarding ICT, treatment-resistant participants reported significantly more severe sexual abuse, emotional abuse and emotional neglect. The second study aimed to investigate whether childhood trauma influenced how people with first-episode schizophrenia respond to antipsychotics (Misiak & Frydecka, 2016). The sample comprised 64 inpatients, of whom 32 were men (mean age = 24.1 years) and 32 were women (mean age = 28.9 years). All participants were treated with an SGA and monitored for 12 weeks. The one additional psychiatric medication type that participants may have received was benzodiazepines. The Early Trauma Inventory Self-Report – Short Form (ETISR-SF) was used to assess four trauma types: general trauma, physical punishment and emotional and sexual abuse (Bremner, Bolus & Mayer, 2007). General trauma included both interpersonal (e.g., witnessing violence) and non-interpersonal traumatic events (e.g., experiencing a natural disaster). Participants were considered to respond to treatment if they had a final severity score of mild or less on eight Positive and Negative Syndrome Scale items. The study's results revealed that childhood trauma was significantly associated with a poor response to antipsychotic treatment after 12 weeks. General trauma, emotional abuse and negative symptoms served as independent predictors of a poor treatment response.

Moreover, another study explored the use of psychotropic medications (including antipsychotics) in 183 people with severe mental illness and a history of stressful childhood experiences (SCEs) (Schneeberger et al., 2014). The sample was diagnostically distributed as follows: schizophrenia (n = 73; 39.9%), schizoaffective disorder (n = 59; 32.2%), bipolar disorder (n = 34; 18.6%), major depressive disorder (n = 13; 7.1%) and

other (*n* = 4; 2.2%). Participants endorsed the following types of childhood trauma: emotional abuse (*n* = 76; 48.6%), physical abuse (*n* = 115; 73.2%), sexual abuse (n = 39; 24.6%), witnessing domestic violence (*n* = 58; 37.2%) and the reported arrest of an immediate family member (*n* = 57; 36.4%). Several participants also reported having a caregiver with a substance abuse problem (*n* = 74; 47%) and/or a mental illness (*n* = 45; 29%). The participants were divided into two subgroups: high-SCE (having experienced 4 to 7 SCEs) and low-SCE (having experienced 0 to 3 SCEs). More than two-thirds of the sample were taking an SGA and almost one-third was prescribed a first-generation antipsychotic (FGA). The results revealed that participants in the high-SCE subgroup were prescribed a significantly higher Olanzapine equivalent dosage (13.1 mg) than those in the low-SCE subgroup (10.4 mg). The high-SCE subgroup was also taking a significantly higher Olanzapine equivalent dosage of FGAs (11.1 mg) than the low-SCE subgroup (7.6 mg). With regard to generalising these findings to people with psychosis and a history of ICT, it must be noted that the study likely comprised participants who did not experience psychotic symptoms. However, almost three-quarters of the sample were diagnosed with a psychotic disorder. Individuals diagnosed with either bipolar disorder or major depressive disorder may have also experienced hallucinations or delusions. Further, the researchers suggested that participants with a history of ICT may have been prescribed higher doses of antipsychotics to control their more intense psychotic symptoms, which implied that most of the sample had experienced psychosis.

The small sample of studies evaluated in this subsection demonstrate that among people who have experienced psychotic symptoms, those with a trauma history are more likely to respond poorly to antipsychotic drug treatment. While additional studies incorporating larger sample sizes are needed, it is likely that this poor treatment response

is due to traumatised individuals experiencing psychotic symptoms that are more severe and persistent.

2.6 Summary

The research evaluated in this chapter demonstrates that ICT is a major risk factor for psychosis. It is also evident that among people diagnosed with psychotic disorders, those with a history of trauma in childhood experience more severe and persistent hallucinations and delusions. Childhood trauma has been found to have a dose–response effect, whereby the severity of trauma is associated with the severity of psychotic symptoms. Further, studies have found that a substantial number of people with childhood trauma and psychosis are diagnosed with PTSD and experience dissociative symptoms (with some people also meeting the diagnostic criteria for dissociative disorders such as dissociative identity disorder). A number of studies also demonstrated that, when compared to non-traumatised individuals, people with a history of childhood trauma are more likely to experience depression, anxiety, increased substance use, suicidality (including ideation and an increased number of lifetime suicide attempts) and cognitive impairment. Collectively, this research suggested that among people with psychosis, those with a history of ICT are likely to experience more severe positive symptoms and comorbid non-psychotic symptoms. They are also more likely to be diagnosed with more than one psychiatric disorder, such as PTSD, dissociative identity disorder, bipolar disorder and major depressive disorder. Regarding pharmacological treatment for psychosis, a small number of emerging studies have found that in people with psychotic disorders, those who reported experiencing trauma in childhood were more likely to respond poorly to antipsychotic medications.

Chapter 3: The Subjective Effects of Antipsychotic Medications: A Systematic Review and Meta-Synthesis of Qualitative Findings

3.1 Preamble to Manuscript

This chapter presents a manuscript that is under review by the journal *European Psychiatry*. Consistent with the requirements of *European Psychiatry*, a Vancouver referencing style has been used. The paper includes one figure and four tables, all of which are presented within the manuscript.

The meta-synthesis aimed to explore the subjective effects of antipsychotic medications by synthesising the findings of 24 systematically gathered qualitative studies. Meta-synthesis is an emerging technique that uses a range of data analysis methods to integrate the findings of numerous qualitative studies (Lachal, Revah-Levy, Orri & Moro, 2017). The purpose of undertaking this meta-synthesis was to obtain a better understanding of the benefits and harms of antipsychotic medications. It was demonstrated that the emotional, cognitive and arousal-lowering effects of antipsychotic medications can be subjectively experienced by people as beneficial (e.g., feeling calmer, having improved sleep, thinking more clearly) or detrimental (e.g., experiencing lethargy, excessive sleepiness, mental clouding). As outlined in Chapter 4 of this thesis, the review's conclusions played a key role in forming the rationale of this research project.

3.2 Manuscript

The Subjective Effects of Antipsychotic Medications: A Systematic Review and Meta-Synthesis of Qualitative Findings

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Abstract

Objective: Antipsychotics, while effective in alleviating psychotic symptoms, have been associated with a variety of adverse effects. Moreover, antipsychotics have been increasingly prescribed to people diagnosed with nonpsychotic disorders. As such, a better understanding of their subjective therapeutic value and adverse effects is essential. We therefore aimed to explore the subjective effects of antipsychotics by synthesising relevant qualitative findings. *Methods:* Studies (published between 1990 and 2014) were retrieved from PsycINFO, PsycARTICLES, MEDLINE, and Health Source: Nursing/Academic Edition. Data were analysed using thematic synthesis. This involved the free line-by-line coding of textual findings from primary studies, and the development of descriptive and analytical themes.

Results: Twenty-four studies that reported the experiences of 1609 individuals were included. Six analytical themes emerged: disorder related changes (general effect on mental condition, unspecified symptomatic change, alteration in psychotic experiences), alteration in cognitive functioning (changes in thought process, impact on concentration and memory), emotional changes (mood changes, emotional flattening and numbing), alters arousal (calmness, sedation, motivational change, alteration in levels of anxiety, altered sleep, tiredness and fatigue), physical responses (dizziness, weight gain and increased appetite, sexual difficulties, drooling, other physical complaints), and movement difficulties (inability to sit still, sporadic and uncontrollable physical movements, physical rigidity).

Conclusion: Different people experienced many of the same antipsychotic effects (e.g., lowered arousal, induced sleep) as either beneficial or unpleasant. With regard to the impact that antipsychotics have on cognition and emotion, people subjectively

experienced both negative effects (e.g., emotional flattening, concentration difficulties) and positive effects (e.g., improved mood, better concentration).

Key words: antipsychotic drugs; neuroleptic drugs; subjective health; qualitative evaluation

1. Introduction

Since the advent of Chlorpromazine in the 1950s antipsychotics have served as a first line treatment for psychotic disorders (1). Over the past twenty years, however, antipsychotics have been increasingly prescribed to a more diverse clinical population (2-6), with less than half of primary care prescriptions of antipsychotics issued for the treatment of psychosis and bipolar disorder (7). Common diagnoses for which antipsychotics are prescribed included: anxiety, depression, dementia, sleep and personality disorders.

Antipsychotics, while effective in alleviating the positive symptoms of psychosis (8), have been associated with a variety of adverse effects, such as weight gain and sexual dysfunction (9, 10). Furthermore, despite that antipsychotics are frequently used as a prophylactic maintenance treatment for psychotic disorders, one randomised trial demonstrated that at seven-year follow-ups people who discontinue or significantly reduce the dose of their medication are more likely to recover from psychosis than those people who remain on an antipsychotic (11). Researchers have thus suggested that the use of antipsychotic maintenance treatment as a default intervention for psychotic disorders needs to be reconsidered (12, 13), with the evaluation of the potential long-term benefits and risks serving as a measure of success of drug maintenance versus discontinuation (14).

A better understanding of the benefits and harms of antipsychotics is thus needed. This may be obtained by evaluating their subjective effects. The majority of quantitative studies (including randomised controlled trials) use structured rating scales to identify symptomatic change and adverse effects. These psychometric instruments however, are bound by particular conceptual parameters, and, as such, are constrained in their ability

to elicit novel data relating to peoples' subjective experiences. Qualitative studies are less subject to such restraints, as they incorporate methods of data collection (e.g. semi-structured interviews) that allow people to describe, in their own words, changes to their physical and psychological state. Furthermore, a synthesis of findings from numerous qualitative studies exploring subjective antipsychotic effects can achieve a greater conceptual understanding of the topic than any single empirical study (15), and can subsequently allow for the emergence of fresh insights (16). We thus aimed to explore the subjective effects of antipsychotic medications by synthesising relevant qualitative findings.

2. Methods

We analysed the findings of multiple studies using thematic synthesis, a method that draws on the process of thematic analysis – a technique used to analyse primary qualitative data (17). Recent meta-syntheses have commonly used thematic synthesis as a method of data analysis (18-20). Thematic synthesis aims to identify the recurring themes in the primary studies, analyse these themes and draw conclusions that can answer particular review questions (21). This is achieved through three overlapping phases: the free line-by-line coding of textual findings from primary studies, the organisation of these free codes into related areas allowing for the construction of descriptive themes, and the development of analytical themes. The first step, line-by-line coding, allows for a subsequent cross study descriptive analysis whereby codes from all studies are used to develop descriptive themes. These descriptive themes are then used to develop analytical themes, or a new interpretation which goes beyond the original studies.

This methodology was chosen for two reasons. First, it allowed for relevant findings to be extracted from qualitative studies with a scope that expands beyond the exploration of antipsychotic effects. Second, the development of both descriptive and analytical themes allowed for an investigation into the subjective effects of antipsychotics that is not bound by pre-existing conceptualisations of how these drugs work.

2.1. Literature search

Articles were initially identified by searching the databases: PsycINFO, PsycARTICLES, MEDLINE, and Health Source: Nursing/Academic Edition. The searchable period was between January 1990 and June 2014. We searched for articles published from 1990 onwards because the early 1990s saw the advent of the second

generation antipsychotics (SGAs), and we wanted to include studies that measured the experiences of people taking different types of antipsychotic medications, including first-generation antipsychotics (FGAs) and SGAs. The search process involved using the terms: [qualitative OR patients view OR experience OR meaning OR patient centred OR consumer] AND [antipsychotic medication OR neuroleptic medication OR antipsychotics OR clozapine OR olanzapine OR risperidone OR quetiapine OR aripiprazole]. Studies were included if they:

1. Investigated and/or reported on any aspect of participants' direct subjective physical and/or psychological experience of taking antipsychotics. The phrase direct subjective experience relates to primary medication effects (e.g., "my mind became clearer"), and was used to differentiate these experiential changes from patients attitudes/evaluations of specific drugs (e.g., "I don't like it because it reminds me that I have schizophrenia"). No attempt was made to verify any subjective descriptions of potentially objective effects. Many direct medication effects can be measured subjectively and objectively (e.g., weight gain). As such, there must be some focus on subjective experience, which is determined by the method of data collection, inclusion criterion (ii).
2. Implemented a qualitative method of data collection; including interviews, focus groups, open ended questionnaires, and/or online self-report commentary.
3. Were published in English.
4. Included a clinical sample.

2.2. Comprehensiveness of reporting

Reviewers IK and AMG-S independently evaluated the information reported on by each study using the consolidated criteria for reporting qualitative research (COREQ), a 32-item checklist with three domains – research team and reflexivity, study design, and data analysis and findings (22). The COREQ offers a framework that reviewers can use to explicitly report important aspects of qualitative research methodologies (interviews and focus groups), from which the trustworthiness/validity of primary study findings can be assessed. The COREQ was not used to exclude any studies.

2.3. Synthesis of findings

Two reviewers (IK and AMG-S) independently identified the text body of the results section from each article that specifically related to participants' direct subjective experience of taking antipsychotics. This included relevant findings provided in table format. Participant quotations, which in qualitative research are considered raw data, were not coded and only used in the review to illustrate descriptive themes. Both reviewers then independently coded each line of relevant text using a 'free code' structure. This process of line-by-line coding allowed for the transition of concepts from one study to another. Contradictions in coding were resolved by consensus. The same two reviewers then independently conceptualised descriptive themes by mapping interconnections between codes. Discrepancies in the phrases used to identify descriptive themes were resolved by re-examining the interconnections between codes. Both reviewers subsequently grouped these themes into clusters so as to develop analytical themes. This interpretation was further examined during a group discussion with reviewers SB and LH. In order to develop analytical themes that most accurately characterised clusters of descriptive themes, where necessary, reviewers referred back to the literature to identify

how a particular concept was understood. For example, the concept of arousal – defined as a state of being alert, attentive and awake – seemed to most accurately characterise one cluster of descriptive themes.

3. Results

The search yielded 2877 citations (Fig 1). Twenty-four studies with a total of 1609 participants were included in the review.

3.1. Study characteristics

A description of each study is provided in Table 1 (23-46). The studies were published between 1998 and 2014. In 22 studies data from 690 participants taking antipsychotics were collected through interviews (n = 18), a combinations of both interviews and focus groups (n = 3), or the naturalistic observation of psychiatric consultations (n = 1). These 22 studies were carried out in 12 countries: Germany, England, Wales, Scotland, the United Kingdom, Canada, Australia, Norway, Sweden, Ghana, Ethiopia, and the United States. Two studies qualitatively analysed the online medication reviews of 919 individuals from consumer generated and health websites (29, 35).

Fourteen of the 24 studies incorporated a sample comprised entirely of individuals with psychosis, while in eight studies participants were diagnosed with a range of mental disorders. Of those eight studies, in two studies a psychotic disorder diagnosis was reported in more than 80% of participants. In the two studies that analysed online medication reviews, people self-reported why they were prescribed an antipsychotic. Of the 24 studies, all the participants in seven studies and the majority (>80%) in two studies (25, 35) reported taking an SGA. In three studies it was reported that participants were taking an FGA or SGA. Eight studies did not specify the type of antipsychotic taken by participants. Of these eight studies, three evaluated the subjective effects of depot antipsychotics.

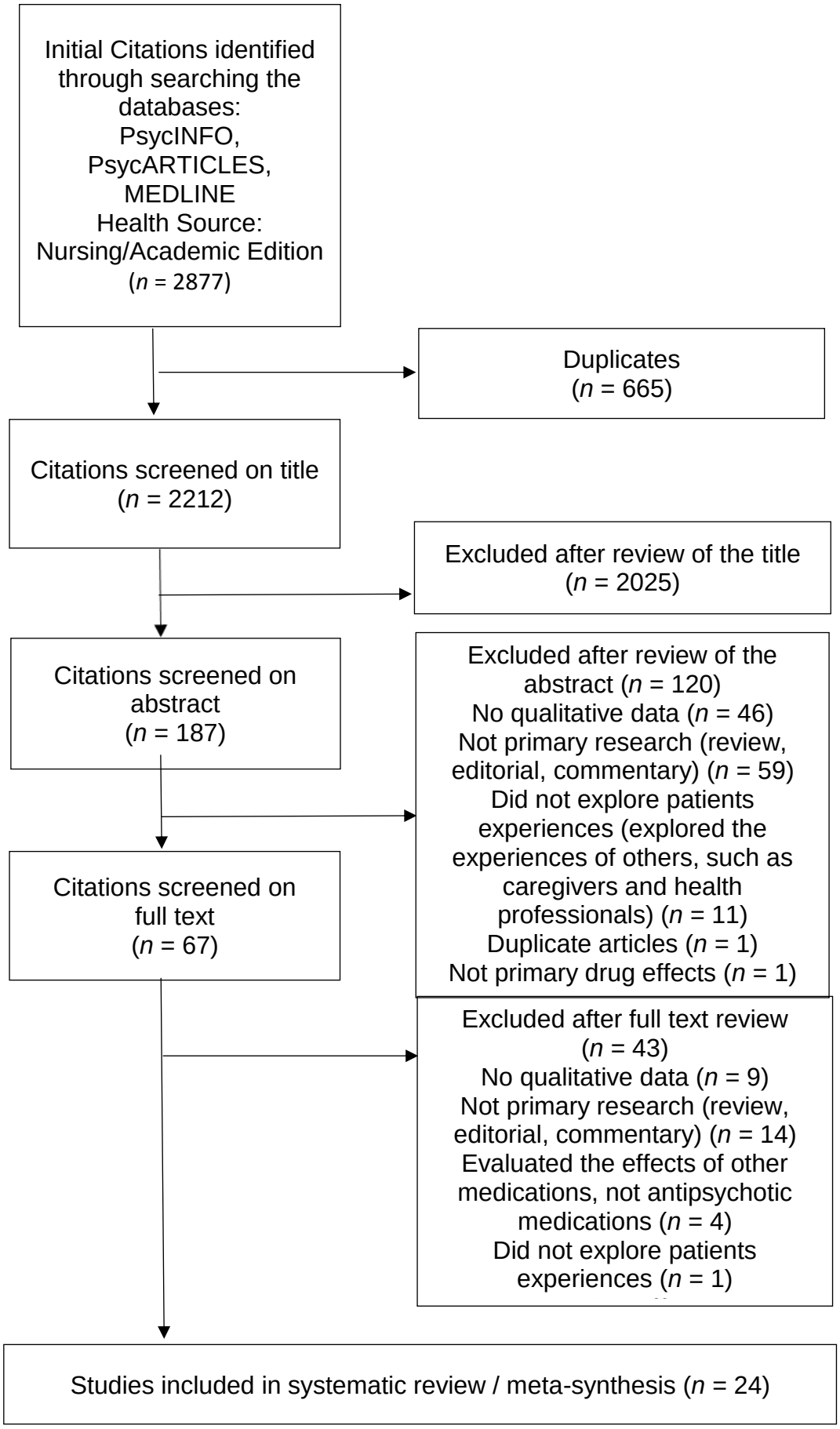

Fig. 1. Flow diagram of search strategy.

Table 1

Characteristics of Included Studies

Study	Country	Aims / research questions	Sample characteristics	Data collection	Data analysis	Antipsychotic type
Angermeyer et al. 2001** (23)	*Germany*	To explore what people suffering from schizophrenia thought about neuroleptic treatment, and especially how they perceived treatment with Clozapine For a subsample of patients, to investigate their relatives' view on Clozapine	80 patients diagnosed with schizophrenia (age range 18-60) who were being treated with Clozapine during their in-patient or acute day hospital treatment 46 patient relatives	Semi-structured interviews	Content analysis	Clozapine
Carrick et al. 2004 (24)	England	To gain a person-centered account of the experience of taking antipsychotics	24 adults diagnosed with a psychotic disorder or borderline personality disorder (age range	In-depth interviews	Grounded theory	Not specified

Study	Country	Aims / research questions	Sample characteristics	Data collection	Data analysis	Antipsychotic type
		To determine not only whether a certain side-effect was experienced, but also how disturbing the person found it to be	24-70) who were currently taking antipsychotics			
Crossley and Withers 2009 (25)	England	To discover how informed the participants were about their medication, including the main effects, side effects and contraindications To explore how people with an intellectual disability feel about taking long-term antipsychotic medication	8 adults with a mild to moderate intellectual disability (age range 31-66) who were currently taking antipsychotics	Semi-structured interviews	Grounded theory	Varied. Some participants were taking two of: Clozapine (n = 4) Olanzapine (n = 2) Zuclopenthixol (n = 3) Haloperidol (n = 1) Risperidone (n = 3)

Study	Country	Aims / research questions	Sample characteristics	Data collection	Data analysis	Antipsychotic type
		To develop a model to capture and reflect how participants with intellectual disabilities experience medication and identify key factors relating to their experiences and understanding				Chlorpromazine (n = 4)
Forchuk et al. 2003 (26)	Canada	To understand the experience of recovery from psychosis from the consumer/client perspective	10 adults starting a new atypical neuroleptic who had ongoing problems related to symptoms of psychosis (age range 26-51)	Semi-structured interviews	Ethnographic method	Clozapine (n = 7) Risperidone (n = 3)
Goldbeck et al. 1999 (27)	Scotland	To investigate further psychiatric patients' knowledge	59 patients (age range 22-75) diagnosed with a psychotic	Semi-structured interviews	Not stated	Depot neuroleptic medication.

Study	Country	Aims / research questions	Sample characteristics	Data collection	Data analysis	Antipsychotic type
		of their depot neuroleptic medication	disorder (n = 50), bipolar affective disorder (n = 6), depressive disorder (n = 2) or borderline personality disorder (n = 1)			Specific type not stated
Hodge and Jesperson 2008* (28)	Australia	To clarify the presence of various side-effects experienced by consumers taking Clozapine, and to elucidate the impact these side-effects and blood tests have on their quality of life To highlight any discrepancies between the views of consumers	27 consumers with a diagnosis of either schizophrenia (n = 25 or schizoaffective disorder (n = 2) who were currently taking Clozapine (age range 23-49)	Semi-structured interviews	Not stated	Clozapine

Study	Country	Aims / research questions	Sample characteristics	Data collection	Data analysis	Antipsychotic type
		and those of their treating clinicians				
Hughes and Cohen 2011* (29)	No specific country	To describe the most frequently reported effects of Escitalopram and Quetiapine in online consumer reviews, to compare them with effects described in professionally controlled commercial health websites, and to gauge the usability of online consumer medication reviews	480 individuals taking Quetiapine	Online search for consumer reviews	Coding strategy	Quetiapine
Jenkins et al. 2005* (30)	United States	To investigate the subjective experience of the process of	90 adults diagnosed with either schizophrenia (n = 73) or	Semi-structured interviews	Systematic analysis via	Clozapine (n = 51)

Study	Country	Aims / research questions	Sample characteristics	Data collection	Data analysis	Antipsychotic type
		improvement and recovery from the point of views of persons diagnosed with either schizophrenia or schizoaffective disorder	schizoaffective disorder (n = 17). Mean age = 40.7 years		software program, Atlas.ti	Risperidone (n = 16) Olanzapine (n = 15) Other atypical antipsychotics (n = 8)
Kinter et al. 2009 (31)	Germany	To elicit endpoints directly from patients with schizophrenia, ascertain whether patients are sufficiently cognoscente to express what endpoints are and are not important to them, and to rank relevant endpoints	30 patients with schizophrenia (age range 18-65)	Focus groups / Semi structured interviews	IPA	Typical or atypical antipsychotics

Study	Country	Aims / research questions	Sample characteristics	Data collection	Data analysis	Antipsychotic type
Lorem et al. 2013 (32)	Norway	To illuminate the patient perspective on drug treatment and user involvement To increase knowledge about how different experiences with user involvement influence the satisfaction and recovery of people with psychotic disorders	9 patients with a psychotic disorder (age range early 20s-50s)	Interviews driven by a narrative approach	Narrative thematic analysis	Not specified
McCann et al. 2004 (33)	Australia	To explore how young people with schizophrenia experience their illness as an embodies phenomenon and find meaning in the illness	9 young adults with schizophrenia	Unstructured interviews	Descriptive phenomenology Approach by Giorgi (1985)	Not specified

Study	Country	Aims / research questions	Sample characteristics	Data collection	Data analysis	Antipsychotic type
Mills et al. 2011* (34)	UK	To investigate prisoners subjective experiences of antipsychotic medication and how such experiences and aspects of the prison environment and regime might affect medication adherence and satisfaction	44 prisoners (age range 19-61) diagnosed with a psychotic disorder (n = 38) or personality disorder (n = 6)	Semi-structured interviews	Content analysis	Typical or atypical antipsychotics 64% prescribed atypical drugs
Moncrieff et al. 2009* (35)	No specific country	To describe and compare the subjective effects produced by taking different sorts of antipsychotic drugs. To focus on the subjective mental alterations produced by	439 individuals diagnosed with psychosis/schizophrenia bipolar disorder, depression or anxiety	Online search for consumer reviews	Content analysis	Older/typical antipsychotics (n = 46) Risperidone (n = 223)

Study	Country	Aims / research questions	Sample characteristics	Data collection	Data analysis	Antipsychotic type
		the drugs, and look for evidence of both positive and negative drug-induced effects To explore how these mental effects related to the drugs physical effects	46 were taking typical drugs (mean age = 36.3), and 393 atypicals (mean age = 32.2)			Olanzapine (n = 170)
Murphy et al. 2013** (36)	Canada	To explore the lived experience of youth, caregivers, and prescribers with antipsychotic medications To focus on the experience of weight gain for youth taking antipsychotics, their caregivers, and the prescribers	18 youths (age range = 13-26) with a range of psychiatric conditions (psychosis, bipolar disorder, depression, anxiety, sleep disorder, OCD, ADHD, autism, anger problems/violent behavior, borderline personality disorder)	Interviews	Interpretive phenomenology	Varied. Some participants had reported taking more than one of: Quetiapine (n = 5) Olanzapine (n = 4) Risperidone (n = 8) Ziprasidone (n = 2)

Study	Country	Aims / research questions	Sample characteristics	Data collection	Data analysis	Antipsychotic type
			10 caregivers; 11 prescribers			
Read 2012** (37)	Ghana	To provide a qualitative perspective on the limitations of antipsychotic medication as experienced by people with mental illness and their families in rural communities in Kintapo, Ghana	25 people with mental illness 31 family members 11 traditional/other healers	Interviews and focus groups	Ethnography	Not specified
Rogers et al. 1998 (38)	UK	To explore patients reasons for taking neuroleptics and the ways in which patients self-regulate their medication	34 patients diagnosed with schizophrenia or schizoaffective disorder (age range 18-56)	In-depth interviews	Not stated	Type not specified All were taking an oral neuroleptic 14 patients were also taking depot

Study	Country	Aims / research questions	Sample characteristics	Data collection	Data analysis	Antipsychotic type
						neuroleptic medication
Seale 2007 (39)	UK	To explore the ways in which sedation and mental clouding are presented and engaged with during outpatient psychiatric consultations in which antipsychotics are reviewed	92 outpatients with a mean age of 42 years	Naturalistic observation of psychiatric consultations	Coding strategy via qualitative data management software, NVIVO	Single atypical antipsychotic (n = 60) Single typical antipsychotic (n = 20) Two different types of antipsychotics (n = 11) Unknown (n = 1)

Study	Country	Aims / research questions	Sample characteristics	Data collection	Data analysis	Antipsychotic type
Smith et al. 1999 (40)	Wales	To examine whether sufferers decisions to comply with depot neuroleptic medication reflect their expectations about the consequences of taking such medication	40 adults with a diagnosis of schizophrenia (age range 20-65)	Interviews	Content analysis	Depot neuroleptic Type not specified
Svedberg et al. 2003 (41)	Sweden	To explore how patients experience living with long-acting depot antipsychotics	11 patients (age range 34-55) receiving depot antipsychotics for 2 years 8 diagnosed with schizophrenia	Open ended interviews	Content analysis	Depot neuroleptic Type not specified
Teferra et al. 2013** (42)	Ethiopia	To explore the reasons for low adherence to medication in rural Ethiopia from the perspectives	24 patients with schizophrenia 19 caregivers 7 field workers	In-depth interviews and focus groups	Thematic analysis	Not specified

Study	Country	Aims / research questions	Sample characteristics	Data collection	Data analysis	Antipsychotic type
		of people with schizophrenia, their caregivers, research field workers, and health workers	1 health worker			
Thomson 2014* (43)	Australia	To better understand the nature of caffeine use and its effects among individuals with schizophrenia	20 patients with schizophrenia (age range 29-61)	Semi-structured interviews	Thematic analysis	Not specified
Usher 2001 (44)	Australia	To explore the experience of taking neuroleptic medications from the individual's perspective	10 patients with schizophrenia	In-depth interviews	Interpretative phenomenology	Not specified

Study	Country	Aims / research questions	Sample characteristics	Data collection	Data analysis	Antipsychotic type
Usher et al. 2013 (45)	Australia	To describe the experience of weight gain associated with second generation antipsychotics from the perspective of the consumer taking the medication	8 individuals with schizophrenia who gained weight as a result of taking atypical antipsychotics (ag range 18-60)	Semi structured interviews	Phenomenological analysis	Atypical antipsychotics
Vandyk and Baker 2012 (46)	Canada	To investigate the subjective experience of weight and lifestyle from the perspective of persons with schizophrenia	18 adults (age range 31-64) diagnosed with schizophrenia (n = 10) or schizoaffective disorder	Conversational interviews	Grounded theory	Atypical antipsychotics 10 participants also prescribed typical antipsychotics (concurrently or in the past)

**Implemented a mixed methods research design which also included a quantitate data collection method*
***Also explored the experiences of significant other and/or health professional which have not been evaluated in the current review*

3.2. Comprehensiveness of reporting of included studies

The comprehensiveness of reporting varied across the studies, with between 10 and 22 of the 32 COREQ items being clearly documented (STable 1). Ten studies met 18 items or more, while six studies reported on 12 or less items. Two studies did not implement interviews or focus groups as methods of data collection, thus many items across the first and second domains of the COREQ were not applicable. All 24 studies specified the sample size and appeared to present data that was consistent with their findings. Twenty-three studies clearly presented major themes, stipulated how those themes were derived and included quotations from participants in their results. The methodological orientation, sampling technique and major characteristics of the sample were described in 21 studies. None of the studies reported on the type of information about the researcher that was given to participants, nor on whether participants received a copy of their transcript.

3.3. Synthesis

Six analytical themes were identified as being central to participants' direct subjective experience of taking antipsychotics: disorder related changes, alteration in cognitive functioning, emotional changes, alters arousal, physical responses, and movement difficulties. Table 2 lists the studies from which each theme was elicited. Table 3 provides quotations from participants to illustrate each theme.

STable 1

Comprehensiveness of Reporting of Included Studies (Consolidated Criteria for Reporting Qualitative Research, COREQ – 32 Item)

		Study reference																							
Reporting Criteria	No (%)	23	24	25	26	27	28	29*	30	31	32	33	34	35*	36	37	38	39	40	41	42	43	44	45	46
Personal Characteristics																									
Interviewer / facilitator	9(37.5)		●													●		●	●	●	●	●	●		●
Credentials	11(45.8)		●		●	●	●	●		●				●				●			●	●	●		
Occupation	8(33.3)		●		●	●				●		●				●							●	●	
Gender	20(83.3)		●	●	●		●	●	●	●	●	●	●		●	●	●	●	●	●	●	●	●		●
Experience and training	4(16.6)		●													●				●	●				
Relationship with participants																									
Relationship established	5(20.8)		●	●			●															●			●
Participant knowledge of the interviewer	0(0)																								
Interviewer characteristics	2(8.3)		●																				●		
Theoretical framework																									
Methodological orientation and theory	21(87.5)	●	●	●	●			●	●	●	●	●	●	●	●	●		●	●	●	●	●	●	●	●
Participant selection																									
Sampling	21(87.5)	●	●	●	●	●	●	●	●	●			●	●	●		●	●	●	●	●	●	●	●	●
Method of approach	13(54.2)	●	●	●			●		●	●					●					●	●	●	●	●	●
Sample size	24(100)	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●
Non-participation	10(41.7)	●	●	●	●	●			●				●						●			●			●

Reporting Criteria	No (%)	Study reference																							
		23	24	25	26	27	28	29*	30	31	32	33	34	35*	36	37	38	39	40	41	42	43	44	45	46
Setting																									
Setting of data collection	11(45.8)	●	●		●	●					●		●			●		●		●		●			●
Presence of non-participants	3(12.5)			●						●						●									
Description of sample	21(87.5)	●	●	●	●	●	●	●	●	●	●		●	●	●	●	●	●	●	●		●		●	●
Data collection																									
Interview guide	18(75)	●	●	●	●	●	●		●	●	●		●				●		●	●	●	●	●	●	●
Repeat interviews	8(33.3)	●		●	●					●						●				●			●		●
Audio/visual recording	18(75)	●		●	●				●	●		●	●		●	●	●	●	●	●	●	●	●	●	●
Field notes	5(20.8)			●						●					●						●				●
Duration	12(50)	●		●					●			●	●				●	●		●	●		●	●	●
Data saturation	5(20.8)		●	●	●																	●		●	
Transcripts returned	0(0)																								
Data analysis																									
Number of data coders	11(45.8)	●		●				●	●			●		●	●				●		●	●	●		
Description of coding tree	1(4.2)									●															
Derivation of themes	23(95.8)	●	●	●	●	●		●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●
Software	8(33.3)	●		●	●				●		●				●			●				●			
Participant checking	1(4.2)																						●		
Reporting																									
Quotations presented	23(95.8)	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●		●	●	●	●	●	●
Data and findings consistent	24(100)	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●
Clarity of major themes	23(95.8)	●	●	●	●	●		●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●
Clarity of minor themes	20(83.3)	●	●	●	●	●		●		●		●	●	●	●		●	●	●	●	●	●	●	●	●

*In these studies interviews and focus groups were not utilised as methods of data collection, thus many COREQ items did not apply.

Table 2

Themes Identified in Each Study

	Study reference																							
Themes	23	24	25	26	27	28	29	30	31	32	33	34	35	36	37	38	39	40	41	42	43	44	45	46
Disorder related changes																								
General effect on mental condition	Y	–	–	Y	Y	–	–	–	–	–	–	–	Y	–	–	Y	–	Y	Y	–	–	Y	–	–
Unspecified symptomatic change	–	Y	–	–	–	–	Y	Y	Y	Y	–	Y	–	–	–	Y	–	–	–	Y	–	–	–	–
Alteration in psychotic experiences	Y	–	–	Y	Y	Y	Y	–	–	–	–	–	Y	–	Y	Y	–	Y	–	–	–	–	–	–
Alteration in cognitive functioning																								
Changes in thought process	Y	Y	–	Y	Y	–	Y	–	Y	Y	–	–	Y	–	–	Y	Y	Y	Y	–	–	Y	–	–
Impact on concentration and memory	Y	–	–	Y	–	Y	–	–	–	–	–	–	Y	–	–	Y	–	–	Y	–	–	–	–	–
Emotional changes																								
Mood changes	Y	Y	–	Y	Y	Y	Y	–	Y	–	–	Y	Y	–	–	–	–	Y	–	–	–	–	–	–
Emotional flattening and numbing	–	–	–	–	–	–	–	–	Y	Y	–	–	Y	–	–	–	–	–	Y	–	–	–	–	–
Alters arousal																								
Calmness	Y	–	–	Y	Y	–	–	–	–	–	–	Y	Y	–	Y	Y	–	Y	–	–	–	–	–	–
Sedation	Y	–	Y	Y	Y	Y	Y	Y	–	–	Y	–	Y	Y	Y	Y	Y	Y	Y	–	Y	–	–	–
Motivational change	Y	–	–	Y	–	Y	–	–	–	–	–	–	Y	–	–	Y	–	–	–	–	–	–	–	–
Alteration in levels of anxiety	Y	–	–	Y	–	Y	Y	Y	–	–	–	Y	Y	–	–	Y	–	Y	–	–	–	–	–	–
Altered sleep	Y	Y	Y	–	Y	–	Y	–	Y	–	Y	–	Y	–	Y	Y	Y	Y	–	Y	–	–	–	–
Tiredness and fatigue	Y	Y	Y	–	Y	–	Y	Y	Y	Y	–	–	Y	–	Y	Y	Y	Y	Y	Y	–	–	–	–

	Study reference																							
Themes	23	24	25	26	27	28	29	30	31	32	33	34	35	36	37	38	39	40	41	42	43	44	45	46
Physical responses																								
Dizziness	Y	Y	–	–	Y	Y	–	–	–	–	–	–	–	–	–	Y	–	–	–	–	–	–	–	–
Weight gain and increased appetite	Y	Y	–	–	Y	Y	Y	Y	Y	–	Y	–	Y	Y	Y	Y	–	–	Y	Y	–	–	Y	Y
Sexual difficulties	Y	–	–	–	Y	–	–	Y	Y	–	Y	–	Y	–	–	–	Y	–	Y	–	–	–	–	–
Drooling	Y	–	–	Y	–	Y	–	Y	Y	–	–	–	–	–	–	–	–	–	–	Y	–	–	–	–
Other physical complaints	Y	Y	Y	Y	Y	Y	Y	Y	–	–	Y	–	Y	–	Y	Y	–	Y	Y	–	–	–	–	–
Movement difficulties																								
Inability to sit still	Y	Y	–	Y	Y	Y	–	–	–	–	–	–	Y	–	–	Y	–	Y	Y	–	–	Y	–	–
Sporadic and uncontrollable physical movements	Y	–	–	–	Y	–	–	Y	Y	Y	–	Y	Y	–	–	Y	–	Y	Y	Y	–	Y	–	–
Physical rigidity	Y	–	–	–	Y	–	–	Y	–	Y	–	–	Y	–	Y	–	Y	Y	Y	Y	–	–	–	–

Y - Yes

Table 3

Quotations from Participants of Primary Studies

Themes	Participant quotations
Disorder related change	
General effect on mental condition	I mean, in retrospect, I feel better, so I guess it must have been the right treatment (23)
	I realise I need the medication to maintain my equilibrium and to maintain my mental health and my saneness and that without it I have seen the effects of mental illness on my life (44)
	They give me poison, that's what I get, "poison". I've always taken them, when they've given me them, but I've never wished to take them. I don't think they do me any good (38)
Unspecified symptomatic change	I don't like the symptoms I suffer when I'm not on the medication… (34)
Alteration in psychotic experiences	I still hear the voices but their nicer and I can control them (38)

Themes	Participant quotations
	Some of them are really funny voices but er sometimes I get the shits up, you know the telly and er, you know you get frightened but if you take your drugs you cope and dismiss it … (38) numbed my brain from paranoid thoughts… (35)
Alteration in cognitive functioning	
Changes in thought process	It's as if there's this clamp over your head… (24). Can't think straight (24) …another feeling is like a screw being tightened in your brain and that is from the medication… it feels like a pressure point being turned on in your brain and it feels pretty awful… (44) … these drugs can alter everything… you can't really trust what they do… you have to be careful because your mind changes and you

Themes	Participant quotations
	think differently… you lose control of your thinking (44)
Impact on concentration and memory	…yes, it's very difficult to concentrate, to focus on something… (23)
	My comprehension's better, my concentration's better. I feel like I'm getting better but I still hear the voices. (26)
Emotional changes	
Mood changes	…I'm feeling pretty depressed at this point, suicidal, so I'd say it's negative (26)
	When I'm rather down and then take these tablets… well, that helps me all right (23)
Emotional flattening and numbing	I know from my previous life how I should behave… when I should smile to show happiness… but my gut feelings are completely gone (31)

Themes	Participant quotations
	I feel absolutely nothing!!No sadness, no joy, NOTHING (35)
Alters arousal	
Calmness	The tablets they calm me down quite a lot (38)
	I have trouble with mixing with people and things like that, so it helps me to stay calm (34)
	It just calms me down and gets me on a level (34)
	Well, I'm calmer and I'm playing it cool and I'm not phoning everyone up all the time (26)
Sedation	Well you just sort of, you're walking around like a zombie and you're like you can't join with things… you're just sat there saying yes and no… (38)
	After medication, it feels like I've slowed down, everything is going a lot slower (33)

Themes	Participant quotations
Motivational change	I felt as if I had absolutely nothing to talk about. I kept wondering about whatever [it] was that had been so interesting during most of my life that I had suddenly lost... (35)
	I'm unmotivated… before I got ill I read a lot and dealt with intellectual things, and today I don't do these things anymore… (23)
Alteration in levels of anxiety	The anxieties are less present (23)
	Feeling of anxiety that sort of leaves a cloud over my head (26)
Altered sleep	They all thought that it was doing me good, but that was because I was asleep nearly 18 hours a day (33)
	I would stand there and I couldn't do anything without falling asleep (37)

Themes	Participant quotations
	I sleep 10-12 hours a day and still have periods where I have to nap (or could fall asleep standing up) (29)
	…while it does provide me sleep…it's the kind of sleep that wouldn't allow me to be woken, even if my house is on fire. I am not able to be woken from this coma-like sleep for hours. That scares me (29)
	I just literary slept for six months–or it felt like it (24)
	Well, I would say it's a bit of a sleeping pill, perhaps, 'cause I always sleep through the night" (23)
	…very effective with sleep: 30 minutes max after taking 125-150 mg at night. I'm out for good (29)
Tiredness and fatigue	…so lethargic, not wanting to do anything (24)

Themes	Participant quotations
	As for farming, if I had the strength, I would have done some if I could. But I don't have the strength (37)
Physical responses	
Dizziness	It was getting absolutely ridiculous. Every time I stood up I fell over. That just seemed an awful lot worse than the symptoms… (24)
	Under that Clazaril, that I was given, I simply couldn't work… I stood on the ladder and then I got dizzy (23)
Weight gain and increased appetite	Instantly I noticed I started eating more… probably in the first week… I just kept eating, never stopped… I used to sneak food… come out and sneak food out of the cupboard and hoard in my room… (45)
	Well I had taken a particular med, clozapine, for a short bit, couple of weeks or so, and it just made my appetite increase a lot and I put on

Themes	Participant quotations
	about 40 pounds. I'd never been that weight in my whole life (46)
	I've never been able to eat as much as I did when I was on Zyprexa. I gained 40lbs in no time… (35)
	And I was exercising, eating the same way. I find taking weight off is impossible… Big time on the weight gain on this pill (36)
Sexual difficulties	…a decreased libido is not a nice side-effect to deal with (31)
	…can't get excited about things, libido and drive have been obliterated (35)
	Sexually, my medication effects my ability to ejaculate… (33)
	I lost my libido, I lost my drives, I lost my ability to get an erection (35)

Themes	Participant quotations
Drooling	When I wake up, there's always this stain in my bed from slobbering (23)
Other physical complaints	you have to take laxatives with this stuff (23)
	I really couldn't cope with it, mentally… I'd get up in the morning and the milk was just dripping on my feet (24)
	I am getting more and more thirsty. I don't know why but it's true (26)
Movement difficulties	
Inability to sit still	I couldn't sit down, and I couldn't stand up and I was jumping up and down all the time and it was a real nightmare. (24)
	restlessness, the kind where you wanna kill yourself (35)
Sporadic and uncontrollable physical movements	I had serious unrest in my legs and could not hold them still (31)

Themes	Participant quotations
	I just couldn't coordinate my muscles… I would try to brush my teeth and… I couldn't get my hand to move properly to brush my teeth or brush my hair… (44)
Physical rigidity	I felt like I was in slow motion (35)

3.3.1. Disorder related change

Seventeen of the 24 studies reported on whether antipsychotics affected the way participants' subjectively experienced their mental disorder. Three themes were identified: general effect on mental condition, unspecified symptomatic change, and alteration in psychotic experiences.

3.3.1.1. General effect on mental condition (8 Studies)

Many participants' reported that their mental condition improved and/or was stabilised after taking antipsychotics. Participants within four studies mentioned that antipsychotics prevented relapse (27, 38, 41, 44). Some participants within four studies stated that they experienced no beneficial effect from antipsychotics (23, 26, 38, 40).

3.3.1.2. Unspecified symptomatic change (8 Studies)

Participants mentioned that as a result of antipsychotics they experienced some symptomatic improvement. However, the nature of these symptoms was not described.

Many participants stated that antipsychotics controlled or reduced their symptoms. Some participants within one study indicated that Quetiapine worsened their symptoms (29).

3.3.1.3. Alteration in psychotic experiences (9 Studies)

Participants reported that antipsychotics alleviated their psychotic symptoms. In five studies participants specifically mentioned that antipsychotics caused their auditory hallucinations to become fainter and/or less frequent (23, 26-28, 38). Two studies specifically reported on a variety of ways in which antipsychotics influence participants' experience of psychosis (35, 38). In one study it was emphasised that antipsychotics did not remove hallucinations/delusions altogether but rather helped participants cope with their symptoms (38). The other study suggested that medication decreased the intensity and emotional impact of hallucinations/delusions (35). A few participants within two studies indicated that antipsychotics exacerbated or caused hallucinations (27, 29), while a few participants within another study stated that the medications inadequately controlled their psychosis (26).

3.3.2. Alteration in cognitive functioning

Fourteen of the 24 studies reported that participants subjectively experienced an antipsychotic exerted change in their cognitive functioning, as characterised by two themes: changes in thought process, and impact on concentration and memory.

3.3.2.1. Changes in thought process (13 Studies)

Many participants within seven studies mentioned that due to their medication they were unable to think clearly (24, 26, 29, 31, 35, 39, 41). This lack of clarity of thought

was often described by participants as a state of mental "fogginess" or "dullness." Some participants indicated that antipsychotics caused their thinking to become a lot slower or more delayed, while others stated that they had "a blank mind" or "no thoughts." Participants in the study by Usher (44) specified that antipsychotics exerted unpredictable changes to the way they think. Some participants within two studies experienced a loss or reduction in creativity (35, 41). Participants within three studies indicated that the antipsychotics helped them think clearer (26, 27, 31), while a small number of participants within one study reported that their medication reduced cognitive deficits (23). A few participants within three studies emphasised that the medication helped control troublesome thoughts (26, 27, 38).

3.3.2.2. Impact on concentration and memory (6 Studies)

Participants within five studies reported that antipsychotics worsened their concentration (23, 26, 28, 35, 38). A few participants from three studies indicated that their concentration improved while taking antipsychotics (26, 28, 41). Some participants within two studies mentioned that antipsychotics caused them memory problems (35, 41), while a few other participants within one study stated that their memory improved (26). In one study some participants suggested that memory deficits can be helpful in forgetting bad things (41).

3.3.3. Emotional changes

Twelve of the 24 studies reported that participants' subjectively experienced an antipsychotic related alteration in their emotional state. These alterations included: mood changes, and emotional flattening and numbing.

3.3.3.1. Mood changes (10 Studies)

Many participants talked about the effect antipsychotics had on their mood, and within the study cohorts there were conflicting accounts about how antipsychotics can effect mood. Some participants within seven studies indicated that their medication induced depression (24, 26, 28, 29, 34, 35, 40), while others from within five studies experienced an antidepressant effect from their medication (23, 26, 28, 29, 40). Participants in one study mentioned that antipsychotics helped stabilise their mood (27), while a few in another study indicated that the drug caused them mood swings (31). A few participants within another study were uncertain whether their depressed mood was a symptom of their illness or an effect of the medication (24).

3.3.3.2. Emotional flattening and numbing (4 Studies)

Numerous participants indicated that antipsychotics flattened and/or numbed their emotions. Respondents in one study stated that this emotional numbing left them feeling "weird", "empty", "dead inside", and "shut down" (35). A few participants in another study reported that the drugs helped appease distressing feelings (41).

3.3.4. Alters arousal

Twenty-one of the 24 studies reported that participants' subjectively experienced antipsychotic exerted changes in their levels of arousal, which was evidenced in six different ways: calmness, sedation, motivational change, alteration in levels of anxiety, altered sleep, and tiredness and fatigue.

3.3.4.1. Calmness (8 Studies)

Many participants reported that antipsychotics exerted a calming effect. Many participants in one study emphasised the calming and relaxing effects of Clozapine (23). Similarly, in another study participants mostly portrayed their medication as a calming agent (38). Some participants within two studies mentioned that this sense of calmness alleviated their restlessness, irritation and/or hostility (23, 34).

3.3.4.2. Sedation (16 Studies)

Participants spoke of the medication's sedative effect. Numerous participants described this unpleasant sedative state using words/phrases such as: "zonked out", "drowsy", "doped" and "slowed down." Many other participants used the word "zombie" to describe themselves and the way in which they engaged with their environment.

3.3.4.3. Motivational change (5 Studies)

Some participants stated that while on their medication they lacked the motivation to get up in the morning and/or to undertake activities that they previously enjoyed. Participants within four studies indicated that as a result of their medication they experienced a suppression of interest (23, 28, 35, 38). A few participants within two studies reported improved motivation (26, 28).

3.3.4.4. Alteration in levels of anxiety (9 Studies)

Within some of the study cohorts there were conflicting accounts on how antipsychotics can effect anxiety. Many participants within six studies reported a reduction in anxiety levels (23, 26, 28, 29, 34, 35), while some participants within seven

studies indicated that when on antipsychotics they experienced “nervousness” and “higher anxiety” (26, 28-30, 35, 38, 40).

3.3.4.5. Altered sleep (13 Studies)

Many participants within eleven studies complained of excessive antipsychotic-induced sleepiness (23-25, 27, 29, 33, 35, 37-39, 42). Participants mentioned that despite getting enough sleep in the evening they still struggled to stay awake during the day. Some participants indicated that they experienced a deep sleep induced state from which it would be extremely difficult to be woken. Many participants within seven studies spoke of a favourable antipsychotic influence on their sleeping patterns (23, 27, 29, 35, 37, 39, 40). Specifically, participants in one study commented on Clozapine’s ability to help them sleep “well”, “calmly” and “deeply” (23).

3.3.4.6. Tiredness and fatigue (15 Studies)

Participants mentioned that antipsychotics made them feel increasingly tired and fatigued. Many participants described feeling lethargic and lacking in energy. Others indicated that they felt weak or worn-out.

3.3.5. Physical responses

Nineteen of the 24 studies highlighted that antipsychotics caused participants to subjectively experience varying physical responses. Five themes were identified: dizziness, weight gain and increased appetite, sexual difficulties, drooling, and other physical complaints.

3.3.5.1. Dizziness (5 Studies)

Participants indicated that antipsychotics made them feel dizzy or faint. Some participants stated that this experience impeded their ability to work.

3.3.5.2. Weight gain and increased appetite (16 Studies)

Many participants indicated that their appetite and weight increased within weeks of commencing their medication regimen. Others mentioned that they gained an excessive amount of weight. Some participants emphasised that despite trying different methods they struggled to lose weight while taking their medication.

3.3.5.3. Sexual difficulties (8 Studies)

Many participants mentioned that while on their medication they experienced a loss of libido. Participants in one study suggested that a decreased libido is good when lacking a partner (41). Some participants mentioned that as a result of their medication they were impotent or unable to ejaculate.

3.3.5.4. Drooling (6 Studies)

While taking antipsychotics participants experienced drooling. Some participants specifically complained of involuntary drooling or a dribbling mouth at night.

3.3.5.5. Other physical complaints (14 Studies)

Several other antipsychotic-induced physical effects were reported by participants. Each of these physical effects was mentioned by a few participants in four studies or less, so they have been clustered together and characterised by the theme *other*

physical complaints. Participants most often reported experiencing a dry mouth (24, 25, 27, 38), increased perspiration (23, 26, 28), slurred speech (38, 41), blurred vision (27, 38), headaches (23, 40), constipation (23, 27, 28, 40), and galactorrhea/lactation (24, 35). Other medication related physiological effects that were reported on less often included: irregular heartbeat/heart problems (27, 28), vomiting (27), increased frequency of urination (28), gastrointestinal discomfiture (30), eyes rolling back (37), blood draws (30), swelling of the tongue (37), tingling in the arms and legs (41), sensitivity to sharp light (41), excessive thirst (26), and amenorrhea (33).

3.3.6. Movement difficulties

Seventeen articles in our sample reported that participants subjectively experienced antipsychotic-induced movement difficulties. Three themes were identified: inability to sit still, sporadic and uncontrollable physical movements, and physical rigidity.

3.3.6.1. Inability to sit still (10 Studies)

Participants indicated that as a result of their medication they struggled to remain physically still. In one study it was demonstrated that of those respondents who reported akathisia some also experienced suicidal thoughts (35).

3.3.6.2. Sporadic and uncontrollable physical movements (12 Studies)

Many participants subjectively experienced antipsychotic induced tremors and uncontrollable physical movements. Participants in one study mentioned that this

uncontrollability would result in a lack of physical coordination or a disjunction between themselves and their body (44).

3.3.6.3. Physical rigidity (10 Studies)

While taking antipsychotics participants subjectively experienced physical rigidity. Participants often mentioned that they felt physically “stiff”, “slow”, “heavy”, “paralysed”, and “stagnant.”

4. Discussion

This study is the first to explore the subjective effects of antipsychotics by synthesising the findings of 24 systematically gathered qualitative studies. In accord with the findings of single qualitative and quantitative studies, some participants mentioned that as a result of taking antipsychotics they experienced a general improvement in their mental health, while many participants complained of antipsychotic-related weight gain, sexual problems, and movement difficulties. One key finding of this meta-synthesis is that different people experience many of the same medication effects as either beneficial or unpleasant. This diversity of experience was most strongly evidenced in the way in which participants from the majority of studies described antipsychotic-induced states of low arousal. Many participants assessed this drug related decrease in arousal as a helpful calming effect, while others described it as an undesirable state of disinterest and fatigue. The term sedation, while rarely used by participants to describe their experiences, was often used by researchers to characterise distressing states, such as drowsiness and lethargy. The difference in how decreased arousal can be experienced as either desirable or unfavourable was also evidenced when evaluating how participants described the medication's sleep inducing effects. While a large number of participants complained of excessive antipsychotic related sleepiness, others indicated that their medication helped improve their sleep. In accord with our findings, a recent review confirmed that SGAs may ameliorate insomnia in patients with schizophrenia (47), while other studies have demonstrated that patients often reported excessive daytime sleepiness as a common adverse effect of antipsychotics (48-50). This discrepancy in how people experience the arousal-lowering effects of antipsychotics may be due to a number of factors, including

individual clinical differences and medication dose. For example, an individual without major sleep difficulties who is taking a higher dose of the drug may complain of excessive sleepiness. The subjective experience of individuals taking antipsychotics is thus complex. Therefore, more in-depth information is needed about the specific effects (e.g. induced sleep) that are reported on by participants in randomised trials. This may involve the inclusion of open ended questions to existing rating scales, whereby participants are asked to describe their experiences of specific effects, and whether those effects were detrimental or beneficial. This may offer further insight into whether (and if so how) specific medication effects, such as sedation, interact with symptoms in a helpful or unhelpful way.

Another key finding of our study was that people described contrasting subjective antipsychotic effects on emotion and cognition. While many participants from fourteen studies complained of flattened emotional responses, a depressed mood, impaired concentration and an inability to think clearly, others across eight studies commented on the medication's antidepressant effect and its ability to help them think clearer and concentrate better. These differences may be due to a number of factors, including participants' broad symptomatic profile and how the antipsychotic might interact with mood symptoms, additional medications, the effects of psychosis on their cognitive functioning, the degree of cognitive impairment and medication dose. While quantitative studies have demonstrated that antipsychotics can impair cognitive abilities in patients diagnosed with a psychotic disorder (51-54), this impairment has been associated with higher doses of the drug (55). Studies have also found that a dose reduction or guided discontinuation of antipsychotics improves neurocognitive functioning in this cohort (56-58). Moreover, randomised placebo-controlled studies have found that antipsychotics

impair information processing speed, attention and learning in young healthy volunteers (59, 60).

Our meta-synthesis approach also provided insights into the potential mechanisms by which the drugs may act to relieve psychotic symptoms from the perspective of subjective experience. Two studies from our sample suggested ways in which antipsychotics alter the subjective experience of psychosis. One study suggested that antipsychotics didn't remove positive symptoms altogether, but rather helped people cope with their symptoms (38). These conclusions align with those drawn from two other quantitative studies (61, 62). The first study found that patients predominantly experienced a detachment from symptoms rather than an elimination of symptoms (61). In the second study the researchers demonstrated that antipsychotics rapidly reduced the behavioural impact of the primary psychotic symptom, and decreased individuals' cognitive preoccupation and emotional involvement with that symptom (62). In another study from our sample it was found that, for some respondents, the medications decreased the intensity, intrusiveness or emotional impact of psychotic symptoms (35). Similar conclusions were drawn by Moritz and colleagues (63), who used a quantitative approach to demonstrate that while taking antipsychotics people reported negative subjective effects on cognition and emotion. The researchers concluded that the dampening of emotion and the deficit of cognition may explain why antipsychotics reduce psychotic symptoms. Further research is required to more conclusively determine nuance effect of antipsychotics on positive symptoms. This may be achieved through a mediation model whereby, for example, emotional flattening and cognitive slowing are measured as mechanisms through which antipsychotics alter psychotic experiences. Incorporating a qualitative component through the use of a mixed-methods design whereby specific open-

ended questions are asked about the kinds of medication related changes people experienced in their positive symptoms, may add further substance to the results obtained from a mediation analysis.

4.1. Strengths and limitations of the review

This meta-synthesis explored the subjective effects of antipsychotics using a substantially larger sample than any one individual qualitative study. Two reviewers independently coded the data and conceptualised themes, minimising the possibility of interpretation bias. Despite the inclusion of studies with a scope that expanded beyond the exploration of subjective antipsychotic effects, our descriptive themes indicated considerable overlap from each of the primary studies. The descriptive and analytical themes offer a higher level of conceptual thinking regarding the subjective effects of antipsychotics, in that medication exerted psychological and physical changes can be perceived in a way that is not bound by the dichotomous categorisation of specific drug related therapeutic effects and side-effects.

The review did not include unpublished findings, and underrepresented people from non-English speaking backgrounds. None of the studies in our sample specifically investigated the experiences of people who were given medication involuntarily, while only one study explored the experiences of individuals with an intellectual disability. As such, our findings may not be generalizable to specific populations. Furthermore, our review included 10 studies with participants diagnosed with disorders other than psychosis. This may add to bias when making inferences about how people diagnosed with psychotic disorders experience the subjective effects of antipsychotics.

While many important COREQ items were met by the majority of studies in our sample, there was considerable variability in how many items were reported across the included studies. No studies reported on whether participants were given a copy of their transcript, nor on whether they were provided with information about the researchers. Offering interviewees the opportunity to review their transcripts is important as it intends to validate the transcripts (64). The relationship between the interviewer and participants – which is, in part, based on what the participants know about the researcher – can influence participants' responses, and thus should be described (22, 65).

We did not exclude studies based on the type of antipsychotic taken by participants. While focusing solely on the subjective effects of SGAs may have allowed for more specific conclusions, it would have also resulted in the exclusion of many valuable studies because they either: (a) did not report on the type of antipsychotic taken by participants (even though many were most likely taking an SGA), or (b) included participants who reported taking an FGA. Moreover, recent meta-analyses have demonstrated that the effectiveness and side-effect profile of SGAs is similar to that of the FGAs (66-69).

4.2. Implications for the conceptualisation of antipsychotic drug action

Our results suggest that the therapeutic value of antipsychotic medications can be wide ranging and not distinct to the alleviation of psychotic symptoms. Moreover, it seems that many effects that are often deemed side-effects to the drug's antipsychotic actions, such as its sleep inducing effects, are often perceived by individuals as primary effects. Our results thus offer some support to Moncrieff and Cohen's drug centred model, which purports that psychiatric medications act as psychoactive substances that induce

complex, varied and unpredictable mental and physical effects which people may experience as global (e.g., cognitive slowing), rather than distinct therapeutic effects and side-effects (70, 71).

4.3. Implications for clinical practice

As a result of this synthesis, several strategies could be implemented by clinicians to more effectively assess the therapeutic value of antipsychotic medications. The global physiological and psychological effects of antipsychotics (e.g., lowered arousal) can have a positive or negative impact on nonpsychotic symptoms. As such, the likely effects of medication should be described to the individual in a nuanced way, whereby they are not simply informed of the medication's side-effects, but rather given a more detailed explanation of how specific effects can be experienced as either helpful or undesirable. Additionally, by identifying how a patient's subjective experience of their psychotic symptoms is being influenced by the medication's more global psychological effects, clinicians may be able to more accurately determine whether the drug will be helpful or unhelpful in the longer term for that patient, and whether an alternative psycho-social intervention can offer a similar benefit. Furthermore, many of the medication's adverse effects reported on in the review resemble symptoms of mental disorders. Caution thus needs to be taken before characterising these experiences as symptoms.

5. Conclusions

This meta-synthesis demonstrates that many of the same antipsychotic effects, such as the drug's sleep inducing effects, can be subjectively experienced by people as valuable or unpleasant. With regard to the impact that antipsychotics have on cognition and emotion, people reported both negative effects (e.g., emotional flattening, concentration difficulties) and positive effects (e.g., improved mood, better concentration). Many people also experienced a number of other medication related adverse effects, including weight gain, sexual dysfunction and movement difficulties. Our results therefore suggest that antipsychotics exert global physiological and psychological effects that can be subjectively experienced as beneficial or detrimental depending, in part, on how they influence specific psychopathological symptoms.

Funding

A. M. Garcia-Sanchez was supported by a fellowship from Alicia Koplowitz Foundation, Spain. S. Bendall and M. Alvarez-Jimenez were supported by fellowships from the National Health and Medical Research Council (Australia).

Declaration of interest

None of the authors reported any conflict of interest.

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3.3 Summary

This meta-synthesis explored the subjective effects of antipsychotic medications by synthesising the findings of 24 qualitative studies with a combined total of 1609 participants. The results demonstrated that antipsychotics exert global psychological and physiological effects (e.g., lowered arousal, altered cognition and emotion) that can be subjectively experienced by people as either beneficial or unpleasant. Therefore, it was suggested that the therapeutic value of antipsychotic medications can be wide-ranging and not distinct to the alleviation of psychotic symptoms. These conclusions played a key role in forming the rationale of this research project.

In Chapter 2 of this thesis it was demonstrated that among people with psychosis, those who report a history of childhood trauma are more likely to experience additional non-psychotic symptoms, such as dissociation and cognitive impairment. There is also a high likelihood for these traumatised individuals to experience the distress that is associated with the remembering of past traumatic events. As such, the global psychological effects of antipsychotic medications may influence how people with childhood trauma and psychosis experience non-psychotic symptoms. Antipsychotics may also alter the ways in which traumatised individuals experience their trauma memories. For example, antipsychotic induced emotional numbing may alleviate the intensity of trauma-related emotions. Therefore, a better understanding of how people with childhood trauma and psychosis subjectively experience the psychological and physical effects of antipsychotics is needed. A more detailed outline of the research project's rationale is presented in Chapter 4 of this thesis.

Chapter 4: Rationale and Research Questions

In this chapter, the rationale of this research project is conceptualised by collating the literature that was evaluated in Chapters 2 and 3. Chapter 2 of this thesis demonstrated that among people with psychosis, those who have experienced ICT are likely to present with a more complex clinical profile. In addition to being diagnosed with a psychotic disorder (or a mood disorder with psychotic features), many of these individuals meet the diagnostic criteria for PTSD (or experience particular PTSD-related symptoms). Therefore, in addition to experiencing hallucinations/delusions, people with trauma and psychosis may also experience the distress associated with various symptoms of PTSD—and more specifically, the re-experiencing of traumatic events and their initial trauma response. This may include the experience of trauma-related thoughts, images, emotions and/or particular physical responses (e.g., an increase in heart rate, difficulty breathing, physical tension, tremors). It was also evidenced in Chapter 2 that there is a high likelihood that people with childhood trauma and psychosis will experience dissociation (depersonalisation and derealisation), depression (low mood, lack of interest in pleasurable activities), suicidality (suicide ideation, lifetime suicide attempts), anxiety, increased substance use and cognitive impairment. As such, these individuals are likely to experience a number of wide-ranging psychopathological symptoms and as a result are often diagnosed with more than one psychiatric disorder, such as schizophrenia (or some other psychotic disorder, such as schizoaffective disorder), PTSD, depersonalisation/derealisation or dissociative identity disorder, substance use, bipolar disorder and/or major depressive disorder.

Chapter 2 also reviewed a small number of studies that have examined the use of antipsychotics in people with childhood trauma and psychosis. These studies have found that among people with psychotic disorders, those who reported experiencing childhood trauma are less likely to adhere to antipsychotic treatment and more likely to respond poorly to antipsychotic medications. Another study found that among people with psychosis, traumatised individuals are prescribed higher doses of antipsychotics. Collectively, these studies offer some preliminary evidence that antipsychotics may be less effective in treating individuals with psychosis who report a history of childhood trauma.

In Chapter 3 of this thesis, the subjective effects of antipsychotic medications were explored through a meta-synthesis of 24 systematically gathered qualitative studies. This meta-synthesis demonstrated that antipsychotics do not exclusively alleviate psychosis, but rather exert global psychological and physiological effects (e.g., lowered arousal, induced sleep, alteration in emotion, mood and cognitive functioning), which people may experience as beneficial (e.g., feeling calmer, thinking more clearly, having improved mood or sleep) or detrimental (e.g., experiencing disinterest or a lack of motivation, cognitive dulling, emotional flattening or numbing, depression, excessive sleepiness). It was suggested that the way individuals subjectively experience particular antipsychotic effects depends, in part, on how these effects interact with particular psychopathological symptoms. For example, a medication's arousal-lowering effects may make an individual with PTSD less hypervigilant or less overly sensitive to potential threats that may be related to past traumatic experiences. Thus, the global psychological effects of antipsychotics may be one reason why these medications have been helpful in better managing manic bipolar episodes (Chwieduk & Scott, 2011; Findling et al., 2009;

Tohen et al., 2007), alleviating severe anxiety (Hershenberg et al., 2014; Maher et al., 2011), improving sleep and reducing the intensity of nightmares among people with PTSD (Wang, Woo & Bahk, 2013), reducing symptoms of impulsivity, anger and irritability in people with borderline personality disorder (Vita et al., 2011) as well as controlling disruptive and aggressive behaviours in children with autism (McCracken et al., 2002; Pandina, Bossie, Youssef, Zhu & Dunbar, 2007), attention-deficit hyperactivity disorder and oppositional defiant/conduct disorder (Armenteros, Lewis & Davalos, 2007; Findling et al., 2004; Reyes, Buitelaar, Toren, Augustyns & Eerdekens, 2006). Alternatively, the global psychological effects of antipsychotics may worsen particular symptoms. For example, an individual with a history of dissociation may experience their surroundings as unclear or foggy. These symptoms of derealisation may be exacerbated by the induced cognitive dulling caused by antipsychotic medications.

As such, antipsychotic medications may exert a global effect on the psychological state of people with childhood trauma and psychosis by, among other means, influencing how they experience non-psychotic symptoms and exerting further emotional, cognitive and physical changes, which are often referred to as drug-related side effects (e.g., emotional flattening, sedation, apathy, cognitive dulling). Given that these individuals are likely to experience dissociative and other non-psychotic symptoms, the way in which the medication's global effects interact with these symptoms may play a significant role in whether these individuals consider antipsychotics to be helpful and, if so, in what ways. Furthermore, these drug-induced global psychological effects may also influence people's trauma-related symptoms—more specifically, their current experiences of prior trauma. For example, emotional numbing can potentially reduce the intensity of an individual's re-experiencing of their initial affective response (e.g., intense anger) to

specific traumatic events. As demonstrated in Chapter 2, there is also a greater likelihood that traumatised individuals will experience psychotic symptoms that are more severe and persistent than individuals without a trauma history. This may be one reason why some studies found that these individuals responded poorly to antipsychotic treatment. Therefore, individuals who have experienced psychosis and ICT can have very different experiences with antipsychotic medications compared with individuals without a trauma history.

Taking these factors into consideration, it seems that further understanding is needed about how antipsychotics influence the psychological and physical state of people who have experienced ICT and psychosis. The first step in gaining this understanding is to ask people with childhood trauma and psychosis directly about their subjective or lived experience of taking antipsychotics and, more specifically, whether these medications have influenced the way they experience their prior trauma. To achieve this, a qualitative methodology is considered most suitable. Qualitative data collection methods, such as open and semi-structured interviews, give research participants the opportunity to describe a phenomenon in their own words and, as a result, allow for a rich description and analysis of their lived experience. A detailed description of the study's methodology is provided in Chapter 5.

4.1 Research Aim and Questions

The overall aim of this study was to gain a better understanding of how people with psychosis and a history of ICT experience the wide-ranging subjective psychological and physical effects of antipsychotic medications. To achieve this, the study addressed one primary research question and three subsidiary questions.

4.1.1 Primary Research Question

How do people with psychosis and a history of ICT subjectively experience the effects of antipsychotic medications?

4.1.2 Subsidiary Research Questions

1. How do people with psychosis and a history of ICT subjectively experience the effects that antipsychotics have on their emotional, cognitive and physical states?

2. How do people with psychosis and a history of ICT subjectively experience the effects that antipsychotics have on their 1) thoughts, images and/or memories, 2) emotions and 3) physical responses, related to their childhood abuse/neglect?

3. How do people with psychosis and a history of ICT subjectively experience the effects that antipsychotics have on any dissociative states (depersonalisation and derealisation)?

Chapter 5: Methodology

This chapter provides an overview of the methodology of this research project. It outlines the embedded mixed-methods research design that was implemented, and explains why this design incorporated a predominantly qualitative phenomenological approach. It also describes the purpose of the secondary quantitative strand of the design. The chapter then outlines the study's inclusion/exclusion criteria, rating scales, sampling and recruitment strategy, ethical considerations and the methods of data collection and analysis.

5.1 Research Design

This study implemented an embedded mixed-methods research design with a qualitative phenomenological priority (see Figure 5.1). This approach incorporates either a quantitative strand within a traditional qualitative research design (e.g., a phenomenological study) or a qualitative strand within a quantitative design (e.g., a randomised controlled trial; Creswell & Plano Clark, 2011). The collection and analysis of the second data set (the second strand) can occur before, during or after the application of the data collection and analysis procedures associated with the predominant design (Creswell & Plano Clark, 2011). The second strand is used to enhance, develop, inform and/or support the predominant design (Bryman, 2006; Creswell & Plano Clark, 2011).

With regards to answering the research questions, a qualitative phenomenological approach using semi-structured interviews was considered the most suitable methodology. Qualitative research aims to gain an in-depth understanding of people's

experiences, perceptions and behaviours, as well as the meanings they attach to them (Moser & Korstjens, 2017).

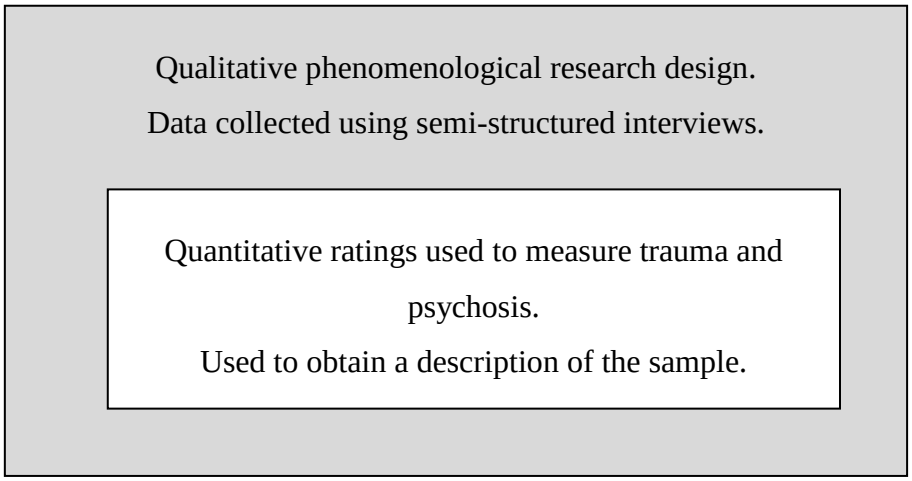

Figure 5.1. Embedded mixed-methods research design whereby a quantitative strand (unshaded area) has been incorporated within a qualitative phenomenological study (shaded area).

Qualitative research is not concerned with finding an objective truth, but rather aims to obtain an understanding of subjective experience and process by giving voice to research participants (Moser & Korstjens, 2017). Phenomenology, as an approach to qualitative research, aims to understand how meaning is created through a rich description and close analysis of peoples' lived experience (Harper, 2012; Starks & Trinidad, 2007). This is fundamentally achieved by asking the broad question: 'What is it like?' (Englander, 2012). Phenomenological research endeavours to describe what several individuals have in common as they experience a specific phenomenon (Creswell, 2007; Wertz, 2005). Therefore, while phenomenology initially captures, as close as possible, how each research participant experiences a phenomenon (Davidsen, 2013), individual

experiences are reduced to a description of the phenomenon's universal nature (Creswell, 2007).

The open or semi-structured interview is considered the most appropriate data collection method for a phenomenological study (Padilla-Diaz, 2015; Smith & Osborn, 2008). Both open and semi-structured interviews offer participants the opportunity to describe their experience of a specific phenomenon in their own words. This allows for the discovery of data that expands beyond the restricted conceptual parameters of existing quantitative instruments. As such, a more powerful explanation of subjective experience can be obtained (Barrantes-Vidal, 2014). This is evidenced in studies examining a number of phenomena, including: what is 'therapeutic' about the therapeutic relationship for mental health care recipients (Shattell, Starr & Thomas, 2007), the experience of having and/or recovering from a mental illness (Johnson, 1998; Kang & Kim, 2014; Nielson & Cairns, 2009; Sutton, Hocking & Smythe, 2012), such as schizophrenia (Knight, Wykes & Hayward, 2003; McCann & Clark, 2004), living with a mentally ill family member (Van Parys, Smith & Rober, 2014; Wankiiri, Drake & Meyer, 2013) and having an emotionally abusive spouse/partner (Queen, Nurse, Brackley & Williams, 2009). Moreover, by asking individuals with a trauma history to describe their experiences with antipsychotics, the study draws on consumer expertise—a practice recommended and endorsed by exponents of the hearing voices movement, an emerging network of mental health service users/survivors who aim to promote the needs and views of 'experts by experience' in the realm of voice hearing (Corstens, Longden, McCarthy-Jones, Waddingham & Thomas, 2014).

Quantitative ratings were used to measure trauma and psychosis. This served as the quantitative strand of the research design. These ratings were used to obtain a

description of the sample—that is, obtaining more systematic information about how severely traumatised people were in relation to other previously researched groups, the types of trauma that they had experienced and the nature of their psychosis. In some contexts, this can allow for a more specific interpretation of the study's findings. For example, upon extensive review of qualitative studies exploring people's experiences of mental illness, it was found that many studies incorporated objective assessments of participants' symptoms even within a qualitative framework (see e.g., Ben-David et al., 2014; Byrne & Morrison, 2010; Harris, Fallot & Berley, 2005; Jenkins & Carpenter-Song, 2009; Lim, Nathan, O'Brien-Malone & Williams, 2004). However, quantitative assessments of trauma and psychosis were conducted at the end of the qualitative interview to reduce the chance of the structured questioning in these measures influencing the qualitative accounts. As such, these quantitative assessments were not used to determine whether people met the study's eligibility criteria.

All participants were given the opportunity to participate in follow-up semi-structured interviews. These involved reading a summary of the study's initial findings and sharing any further insights that they may have about their experience of taking antipsychotics. Within a phenomenological study, it is considered important to undertake additional or follow-up interviews, as they offer participants the opportunity to expand on the information that was initially offered (Padilla-Diaz, 2015).

5.1.1 Interpretative Phenomenological Analysis

IPA was specifically selected as the method of qualitative inquiry. IPA is an approach to conducting qualitative research that aims to capture the principal ideas of participants, and offer a subsequent interpretation of this material that is grounded in their

emerging accounts (Larkin & Thomson, 2012). IPA draws on ideography in that it focuses on the particular (the unique experience of the individual) rather than the general (the individual as an exemplar of a group) (Larkin & Thomson, 2012) and thus, is concerned with participants' subjective reports rather than the conception of objective accounts (Brocki & Wearden, 2006). IPA is characterised by a movement from the descriptive to the interpretive (Smith, Flowers & Larkin, 2009) and, in this regard, adds an analytical component to the general descriptive nature of a phenomenological research approach. Therefore, IPA is epistemologically influenced by hermeneutic phenomenology, which asserts that the understanding of any phenomenon can only ever be interpretive in nature (Larkin & Thomson, 2012). While IPA is concerned with trying to understand what something is like from the participants' point of view, it can also involve an exploration into whether something is emerging that participants themselves may not be aware of—that is, it asks the question: what is the person trying to achieve here? (Smith & Osborn, 2008). Thus, within IPA, the degree of interpretation can vary; however, this study endeavoured to privilege the participants' perspectives on what it is like taking antipsychotics. As such, the analysis remained as close as possible to the participants descriptions of their lived experience.

5.1.2 Sample Size

The fundamental purpose of phenomenological qualitative research is not to generalise to a wider population but rather, to obtain in-depth knowledge about a specific phenomenon (Onwuegbuzie & Collins, 2007)—in this instance, the experience of taking antipsychotic medications. Therefore, qualitative studies incorporate relatively small sample sizes primarily because less detail is generally obtained from each individual

participant when there is a large number of people (Creswell & Plano Clark, 2011). However, the sample size does vary according to the research question(s) and specific approach implemented (Onwuegbuzie & Leech, 2007). It is typically suggested that a phenomenological design should incorporate a sample size that ranges between 5 and 25 individuals (Creswell, 2007). Thus, the researcher endeavoured to obtain between 15 and 20 participants. The exact sample size was predominantly influenced by a recruitment endpoint.

5.1.3 Sampling

Participants were purposefully recruited from the Early Psychosis Prevention and Intervention Centre of the Orygen Youth Health Clinical Program (OYHCP), Prahran Mission and the general community (for details of the recruitment process, see Subsection 5.3.1). The general community encapsulates all people in the wider Australian community who have publicly indicated (e.g., through published material, public speaking engagements or on their individual and/or specific organisation-based websites) that they have experienced psychosis and ICT. Recruiting from these two services, as well as the general community, was done to obtain a sample comprised of a broader range of consumers, including those who may: (1) have recently commenced and are currently engaged in and/or receiving treatment from a mental health service; (2) have been engaged in and/or receiving treatment from a mental health service for a longer period of time and (3) may have at some point in the past but are not currently engaged in and/or received treatment from a mental health service.

5.2 Ethics Approval

Ethics approval to recruit participants from the OYHCP was initially obtained from the Orygen Research Review committee (ref: F15-188; see Appendix A) and the Melbourne Health Human Research Ethics Committee (HREC ref: HREC/15/MH/251/MH Project Number: 2015.117; see Appendix B). An ethics amendment was approved by the Melbourne Health Human Research Ethics Committee (see Appendix C). This allowed for the recruitment of participants from Prahran Mission and the general community. Ethics approval was also obtained from NEAMI's Research and Evaluation Committee (see Appendix D). However, this approval was obtained well into the recruitment process and due to time constraints, participants were not recruited from NEAMI National.

5.3 Procedure

Prior to obtaining ethics approval, a meeting was held with Ms Indigo Daya, a consumer advocate and general manager of consumer and career advice and leadership at the Mental Illness Fellowship. As this study aimed to draw on the expertise of mental health consumers, it was deemed valuable to have an initial discussion about its rationale and feasibility with a consumer advocate who had disclosed in the public domain (e.g., on her personal website and in public talks) that she had experienced childhood trauma and psychosis, and had taken antipsychotic medication. Ms Daya gave input into the direction of the study. Generally, the recruitment strategy involved distributing flyers outlining the study's scope, asking relevant health professionals, case managers, support workers and/or consumer advocates if they would be willing to inform suitable patients/clients of the study, placing information on the websites of relevant organisations

and, where possible, presenting the study to consumer groups and asking for expressions of interest to participate. However, the recruitment strategy varied across each of the two organisations and the general community.

5.3.1 Recruitment

5.3.1.1 Early Psychosis Prevention and Intervention Centre

From the OYHCP, participants were specifically recruited from the Early Psychosis Prevention and Intervention Centre (EPPIC). EPPIC is a service located in the Western region of metropolitan Melbourne that provides specialised treatment and support for young people aged between 15 and 25 years who have experienced a first episode of psychosis. The services provided by EPPIC include an inpatient unit, medical care and intensive outpatient case management. The researcher attended EPPIC clinical meetings to introduce the study to case managers. During these clinical meetings, the researcher verbally described what participation involved, the study's inclusion/exclusion criteria and how participant distress/safety would be managed. Case managers were given two different versions of a study flyer, both of which outlined the study's scope and provided the researcher's contact details. One version of the study flyer was for case managers themselves (see Appendix E), while the other version was to be given to potential participants (see Appendix F).

Three different strategies were used to recruit participants from EPPIC. The first strategy involved making contact with new EPPIC clients who were allocated to a recruitment pool. As a number of studies were simultaneously recruiting participants from the OYHCP, a recruitment process was introduced whereby every new client would be allocated to a specific study. Therefore, a client (and their case manager) could only be

approached by the researcher of the study to which they had been allocated. If the client did not wish to participant in that particular study, or if they were deemed ineligible for participation, they were allocated to another study that was also recruiting participants from the OYHCP. All studies were placed on a research wheel whereby clients were sequentially referred from one study to the next. A spreadsheet was developed that included the name of every client and the study to which they had been allocated. Changes on the spreadsheet regarding the study allocation of each client were made accordingly. Thus, the researcher contacted the case managers of clients allocated to this study to determine if they were eligible for participation.

The second recruitment strategy involved directly approaching case managers and asking whether they were aware of any other pre-existing clients (not allocated to a particular study) who may meet the study's eligibility criteria. If the case manager thought that a client may be eligible, they would then inform that client of the study and ask whether they were interested in participating. The contact details of eligible clients who were interested in participating were forwarded to the researcher.

The third strategy involved obtaining the names and contact details of clients with a trauma history who participated in another study. The researcher was initially informed by Associate Professor Sarah Bendall of a prior study that was conducted at OYHCP and included participants with a trauma history. The research team of that prior study were contacted and asked if they were aware of any participants who may have met the current study's eligibility criteria. A short list of participants was emailed to the researcher, who then liaised with the case managers to ensure that it was appropriate for their clients to be contacted.

All prospective participants (recruited through each of the three strategies) were telephoned and provided with a full verbal explanation of the purpose and procedure of the study. A telephone script was used as a guide (see Appendix G). Once they received this information, if prospective participants were still interested in participating a, screening process was undertaken to confirm whether they met the study's eligibility criteria. Those participants who were under the age of 18 required parental or guardian consent in addition to their own written consent. Parents or guardians were initially contacted via telephone and provided with a full verbal explanation of what participation in the study involved. A parental/guardian participant information sheet/consent form (PICF-PR; see Appendix H) was then sent to parents/guardians via email or post. The PICF-PR had to be completed and dated prior to the scheduled first interview. If the young person was estranged from their parents, had no guardian or was geographically removed from their parents in such a way as to make obtaining their parental or guardian consent impractical, the concept of the mature minor would have been used to determine the ability of the young person to consent themselves. However, this was not required. All interviews were undertaken by the researcher in consulting rooms at EPPIC. The researcher ensured that each case manager was informed of the time and date of their client's interview and available to offer further support (if needed) to their client after the completion of the interview.

As the researcher was liaising with multiple case managers and clients, a document was developed to record: (1) when contact had been made with each case manager and client, (2) whether the client met the study's eligibility criteria and (3) any reasons why they did not participate in the study. This document included the client's

name, date of birth, contact details (mobile number and/or email address), case manager and the EPPIC region from which they were receiving treatment.

5.3.1.2 Prahran Mission

Prahran Mission is community based not-for-profit organisation offering services for people experiencing mental illness and/or social disadvantage in Melbourne. Prior to obtaining ethics approval, the researcher and Associate Professor Sarah Bendall attended a case management meeting where they introduced the study to team leaders. The researcher was informed that Prahran Mission required prior ethics approval before committing to the study. Therefore, the researcher obtained initial ethics approval for EPPIC participants and provided Prahran Mission's management with the approval documentation. An ethics amendment was then approved by the Melbourne Health Human Research Ethics Committee, allowing for the recruitment of participants from Prahran Mission. The researcher attended site meetings to inform support workers about the study. During these meetings, the researcher verbally described what participation involved, the study's inclusion/exclusion criteria and how participant distress/safety would be managed. Support workers were given a study flyer that outlined the study's scope and provided the researcher's contact details. Support workers were invited to refer consumers to the study and provide them with a study flyer. The researcher also attended two consumer-based hearing voices support groups organised by Prahran Mission's Voices Vic initiative. Voices Vic is a specialist program in Victoria, led by people with a lived experience, which aims to improve the lives of people who hear voices. During these groups, the researcher informed consumers of the study and provided copies of the project flyer to those who showed interest in participating. All prospective participants

were provided with a full verbal explanation of the purpose and procedure of the study. Once they obtained this information and if they were interested in participating, a screening process was undertaken to confirm whether they met the study's eligibility criteria. All interviews were undertaken by the researcher in consulting rooms at Prahran Mission sites.

5.3.1.3 General community

The researcher made contact with a number of community mental health and trauma-based organisations. A research invitation email and study flyer were sent to all members of the online Google group, Psychosis and Society. This group comprised both consumers with lived experience of mental illness and mental health professionals who have an interest in psychosis and its treatment. The invitation email outlined the study's aims and briefly described what participation involved. The researcher also contacted the Victorian Mental Illness Awareness Council (VMIAC), a non-government organisation for people with lived experience of mental illness. The invitation email and study flyer were sent to all VMIAC members who were on their email list. Further, contact was made with the Blue Knot Foundation, an organisation that aims to empower recovery for adult Australians who have experienced childhood trauma—complex trauma. Information about the study and the researcher's contact details were placed on their blog and online newsletter, *Breaking Free*.

The researcher also contacted individuals who have indicated in the public domain (e.g., through published material, public speaking engagements or on their individual and/or specific organisation-based websites) that they have experienced psychosis and ICT, and invited them to participate in the study. Individuals were informed of the study

and invited to participate via email, phone and/or through in-person contact. Individuals were contacted via telephone or email if (1) their contact details were available in the public domain (e.g., on their individual and/or a specific organisation-based website), (2) upon being informed of the study, they made some initial contact with the researcher or (3) they offered their contact details to members of the research team (e.g., during a public speaking engagement).

Individuals informed the researcher via email or telephone contact that they were interested in participating. A follow-up telephone conversation then took place between the researcher and each individual. During this conversation, the researcher undertook a screening process to determine whether the individual met the study's eligibility criteria, provided them with full verbal explanation of the purpose and procedure of the study, and arranged a mutually convenient time and date for the interview to be undertaken. Each interview was undertaken in a safe location of each participant's choice. Consulting rooms at Orygen Youth Health were made available. For logistical purposes, some participants who were interstate were interviewed via telephone. A copy of the participant information sheet/consent form (PICF-GC; see Appendix I) was either mailed or emailed to those participants who undertook a telephone interview. Upon reading the PICF-GC, these participants were asked to sign the consent form and either mail or email it back to the researcher. Those who received a hard copy were also given a prepaid self-addressed envelope.

5.3.2 Inclusion and Exclusion Criteria

To be eligible for participation, individuals had to:

- have taken an antipsychotic medication (typical or atypical, administered through oral or intravenous means) for the treatment of psychosis.
- currently be taking this medication (minimum of six continuous weeks), or if medication had been ceased, have taken this mediation for no less than three continuous months in the last 10 years.
- be aged between 16 and 65 years (inclusive). Participants recruited from EPPIC were to be aged between 16 and 25 years. Participants recruited from Prahran Mission and the general community were to be aged between 18 and 65 years.
- have an adequate comprehension of the English language.
- be clinically stabilised (i.e., engaged with the service, have some insight into their illness and have made improvement in symptoms and functioning).
- not have an intellectual disability.
- have a history of ICT. With regard to this criterion, the researcher asked participants during the initial screening process, whether, during childhood, they experienced abuse (physical, sexual, emotional) or neglect (physical, emotional). This aligns closely with the phenomenological approach in that the focus is not on proving whether a person's report of the past is factually accurate but is rather on understanding what happened from their perspective (Harper, 2012).

5.3.3 Data Collection

At the scheduled time of their interview, those participants who were aged 18 years or over were initially required to read the relevant version of the participant

information sheet/consent form (PICF; see Appendices I–K). The PICF outlined the study's purpose, provided information regarding participants' right to confidentiality and outlined their general right to withdraw at any time. Participants under the age of 18 were required to have a parent or guardian complete the PICF-PR prior to the day of their interview. The information provided on the PICF was also reinforced verbally to all participants. Sufficient opportunity was provided for all participants to ask the researcher questions related to the study. Only when these questions had been addressed to the satisfaction of the participants were they asked to sign and personally date the informed consent form.

Upon signing the consent form, participants provided demographic information and engaged in semi-structured interviews where they were questioned about how they experienced the effects of antipsychotic medications (for details regarding the interview process, see Section 5.4). An interview schedule was used. The semi-structured interviews were audio recorded using two recorders. Quantitative ratings of trauma and psychosis were completed at the end of the interview. Childhood trauma was measured using the Childhood Trauma Questionnaire (CTQ; see Appendix L) and general exposure to potentially traumatic events was measured using the Life Events Checklist (LEC; see Appendix M). Questions on the CTQ and LEC were asked verbally by the researcher to each participant who was interviewed via telephone. These participants were emailed copies of these measures so that they could visually follow along while they were being questioned. The diagnosis of a psychotic disorder, or mood disorder with psychotic features, was made via the administration of Modules A (Mood Episodes), B (Psychotic and Associated Symptoms), C (Psychotic Disorders) and D (Mood Disorders) of the Structured Clinical Interview for DSM-5 Disorders – Research Version (SCID-5-RV).

Additional information regarding the CTQ, LEC and SCID-5-RV modules is provided in Section 5.5. The total interview time varied from 1.5 to 2.5 hours. Participants were asked if a summary of their interview could be sent to their case manager/support worker and whether they wanted a copy of their transcript. Depending on what they preferred, participants were sent a copy of their transcript via email or post. The participants were also asked if they would like to attend a second reflective interview (of no longer than one hour) whereby, upon reading a summary of the study's initial findings, they could share any further insights about their experience of taking antipsychotics. Participants were reimbursed $60 for their time. This included traveling costs (e.g., $15 for the purchase and daily full-fare top-up of a Myki card). One participant who was interviewed via telephone indicated that he preferred to receive a Coles voucher. Participants were asked to sign a receipt indicating that they had received this monetary reimbursement.

Those participants who indicated that they would like to participate in a second follow-up interview were contacted by the researcher after the initial data had been analysed. The researcher telephoned interested participants to provide a full verbal explanation of the purpose of this follow-up interview and arrange a mutually convenient time for the interview to be undertaken. Approximately one week prior to the follow-up interview, participants were provided with a document that included the interview questions and a summary of the study's initial findings (see Appendix N). This was sent via email or post. The participants were encouraged to read the study's findings and spend time reflecting on the questions prior to attending the interview. All follow-up interviews were undertaken via telephone. Participants were put on loud speaker and the interviews were audio reordered using two recorders. Participants were asked if they would prefer

to read the findings again, or whether they would like the researcher to read the findings to them. These participants were reimbursed $30 for their time.

5.3.3.1 Semi-structured interview process

Participants were asked three primary questions and, depending on their answers, up to five follow-up questions. Each follow-up question was only asked if relevant information had not been elicited by the primary question or the previously asked follow-up question with which it was associated. This process is outlined in Figure 5.2. An interview schedule that included the primary and follow-up questions was used as a guide. The first primary question aimed to elicit information on, and open a dialogue about, participants' subjective experience of taking antipsychotics. As such, participants were asked: What is it/was it like taking antipsychotic medication? Three follow-up questions (1a, 1b and 1c of Figure 5.2) followed the response of each participant to obtain data relevant to the first subsidiary research question. The second primary question endeavoured to obtain information on whether antipsychotic medication altered how participants experience thoughts, images and/or memories related to their childhood abuse/neglect. Two follow-up questions (2a and 2b of Figure 5.2) proceeded the participant's response to obtain data relevant to the second subsidiary research question. These follow-up questions were only asked if information relating to the second subsidiary research question had not been obtained through questions (1), (1a) and/or (1c). The third primary question aimed to obtain information on whether antipsychotics altered participants' dissociative experiences (depersonalisation and derealisation).

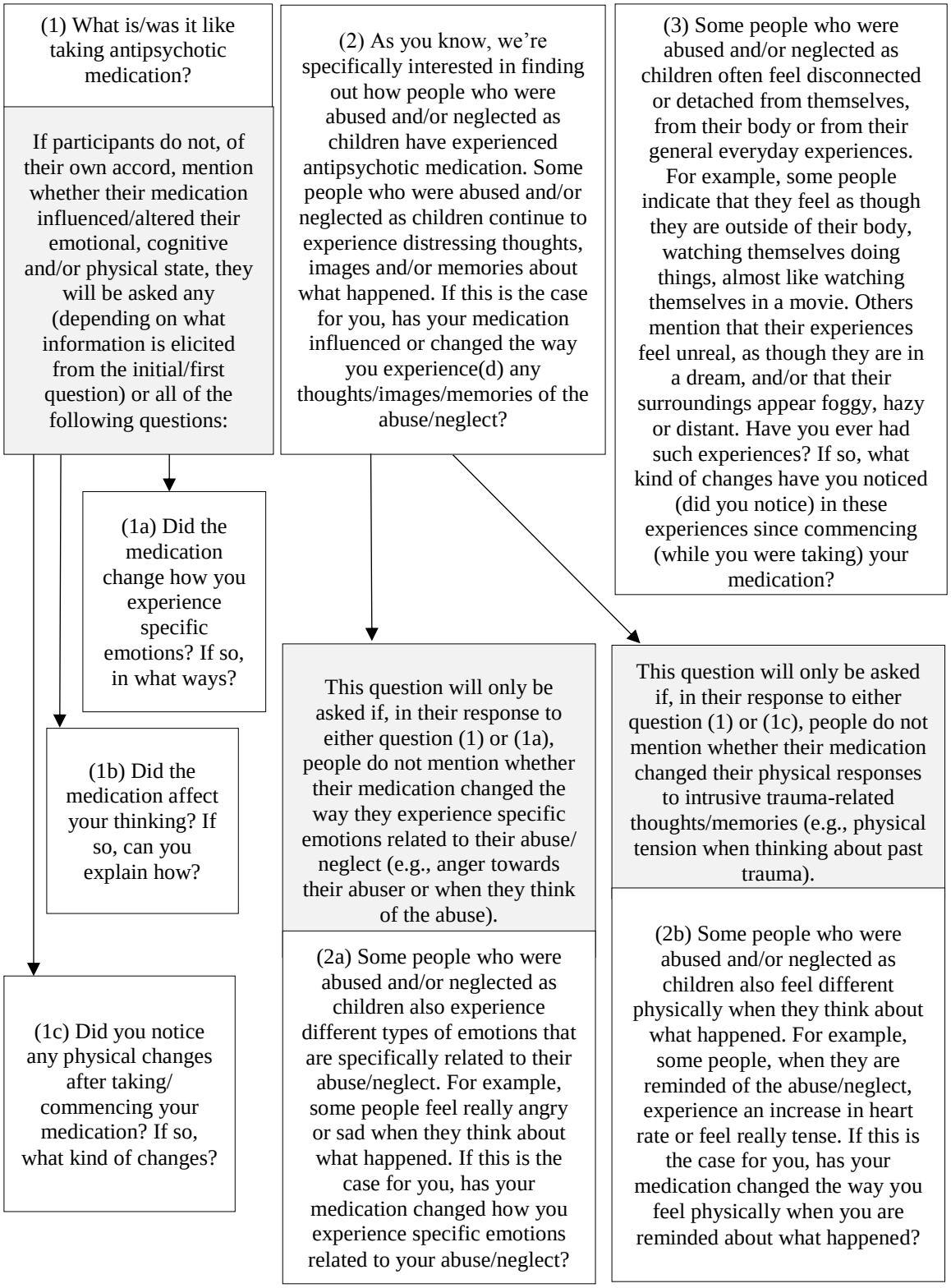

Figure 5.2. Interview structure.

Depending on how participants responded to all primary and follow-up questions, the researcher would ask additional probing and/or clarifying questions, such as: (a) Can you tell me more about how [name of medication] slowed your thoughts? (b) Are there any other ways in which the medication changed how you felt? and (c) You indicated that [name of medication] helped you gain control of your thoughts. What exactly is it like to 'gain control' of your thoughts? Throughout the interview, when using these probing and/or clarifying questions, the researcher ensured that they used each participant's language (i.e., metaphors, analogies, descriptive words). For example, if a participant indicated that antipsychotics made them feel 'like a zombie', then the researcher would ask: Can you describe for me this experience of feeling 'like a zombie?' Throughout the interview, the researcher also summarised participant responses and engaged in reflective listening. This allowed participants to further elaborate on what they had discussed. Moreover, when participants were asked a particular question (either a primary, follow-up or probing question), they would often speak about a number of different experiences. For example, when asked about the effect of the medication on their thoughts, some participants also mentioned physical changes that they experienced. Therefore, the researcher also took notes during the interview process. This allowed the researcher to ask further questions about a particular experience that a participant had previously mentioned. At the end of the interview, participants were asked if there was anything further that they wanted to mention about their experience of taking antipsychotics, which they deemed important but had not had the opportunity to speak about. In every interview, this elicited either new information or additional information regarding matters that had already been discussed.

5.3.3.2 Participant safety and distress management

Procedures were put in place to ensure that any distress experienced by participants would be appropriately managed. If at any stage throughout the interview process participants become distressed, the interview would be temporarily stopped and an assessment of their level of distress would be undertaken by the researcher. This assessment involved the researcher asking the participant how distressed they were feeling and whether they were experiencing an exacerbation of any other symptoms (e.g., anxiety). One participant experienced low levels of distress. After taking a short break, she was able to continue with the interview.

Moreover, upon completion of each interview, the researcher, who is a qualified psychologist with clinical experience (more than five years) in working with people experiencing mental illness, ensured that he was available for an additional hour if further debriefing and/or support was needed. If the researcher had any concern about the safety of the participant, a risk assessment (including suicide) was to be conducted. A safety plan would be implemented whereby, as a means of providing further assessment and support, distressed participants would, if applicable, be referred back to the service from which they were recruited and, if necessary, to the nearest crisis assessment team. Participants would also be given the number to Lifeline and those recruited from EPPIC would be referred to their case manager. The researcher ensured that each case manager was informed of the time of their client's interview and available to offer further support (if needed) after completion of the interview. With regard to participants from Prahran Mission, it was ensured that a support worker would be available to offer support if needed. Prior to the interview, a discussion was had with participants recruited from the general community about what, if any, additional support they may need to assist them if

they experienced any distress. Participants from the general community who were interviewed via telephone were required to provide the researcher with the contact details of either a support person or medical/health service from whom they were currently receiving treatment. They were informed that this support person or medical/health service would be contacted if the researcher was concerned for their safety. If participants were not currently engaged with a mental health service and they required counselling, this would have been undertaken either with the student researcher immediately after the interview, or as soon as could be arranged through one of the services listed in Appendix O. However, this was not required. Participants who were aware that they may have experienced some discomfort from participating in the study booked appointments with their private psychologists a few days after the interview.

5.4 Sample

Case managers from EPPIC were approached regarding the recruitment of 105 clients. Of those, 20 had either been discharged or were not engaging with the service. Sixteen clients indicated that they were not interested in participating in research, while six others were considered (by their case managers) unsuitable for research due to the complexity of their mental health conditions or current life circumstances. The case managers of eight clients were unable to either (a) be contacted (despite multiple attempts via telephone and email over a period of 4–6 months) or (b) provide information about whether those clients would be eligible to participate (or interested in participating) before the recruitment endpoint. Forty-eight clients were considered ineligible for participation because they either: had not experienced or reported ICT (n = 32), had never taken a antipsychotic medication (n = 2), had not taken an antipsychotic for a long enough period

(*n* = 4), were considered clinically unstable (*n* = 8), were under 16 years of age (*n* = 1) or had been diagnosed with an intellectual disability (*n* = 1). Two clients indicated that they were interested in participating; however, after multiple attempts, the researcher was unable to make contact with them. Consequently, five EPPIC clients participated in the study.

Two individuals who were obtaining support from Prahran Mission contacted the researcher. Both were eligible and participated in the study. Fifteen people who were engaged with other community mental health or trauma-based organisations/groups enquired about participating in the study. One woman was considered ineligible because she had not taken an antipsychotic, while another was living oversees (she was informed that ethics had been obtained to recruit participants from Australia only). One woman was considered eligible and agreed to participate. However, when the researcher attempted to schedule an interview time, she could not be contacted. Another woman also agreed to participate, but experienced a major family problem and withdrew from the study prior to being interviewed. The researcher further contacted three individuals who had publicly disclosed that they had experienced ICT and psychosis. One woman did not respond to the researcher's emails. Another stated that she would consider participating, but made no further contact with the researcher. Twelve individuals recruited from the general community participated in the study and four of these were interviewed via telephone. In total, the study comprised 19 participants. Details regarding participant demographics will be outlined in Chapter 6 of this thesis.

The researcher emailed and/or telephoned all participants to ask if they were interested in participating in a follow-up interview. Nine participants could not be contacted. One participant indicated that she would like to participate in a follow-up

interview, though upon receiving a copy of the follow-up questions and summary of the study's findings, she stated that she was no longer interested. Two other participants were unable to participate due to a decline in their mental health. The researcher and one other participant were unable to arrange a mutually convenient time to undertake the interview prior to the cut-off date. One participant stated that she was happy to be interviewed again; however, she did not have anything further to add to what she mentioned during her initial interview. Follow-up interviews were undertaken via telephone with five participants.

5.5 Materials

Demographic, Treatment and Illness Information (see Appendix P)

Non-identifiable demographic questions were asked regarding age, gender, income source, highest level of completed education and marital status. Participants were asked additional questions regarding: (1) the type of antipsychotic(s) they had taken, including the dosage and frequency, (2) whether they were simultaneously prescribed other psychotropic drugs (e.g., antidepressants, anxiolytics, etc.) and (3) the names of any organisations from which they were currently receiving mental health support/treatment. Participants were also asked if they had ever received psychological treatment for their trauma.

Interview Schedule

The interview schedule (see Figure 5.2) was developed by the researcher in consultation with the research supervisors. This included three primary questions and five follow-up questions. Details regarding how these questions were asked are outlined in Section 5.3.3.1.

Childhood Trauma Questionnaire (CTQ) (see Appendix L)

The CTQ is a 28-item self-report questionnaire that retrospectively assesses the frequency and severity of childhood trauma across five factors: physical, sexual and emotional abuse, as well as physical and emotional neglect (Bernstein et al., 1994). Each item (e.g., 'I didn't have enough to eat') is rated on a five-point scale (1 = never true, 2 = rarely true, 3 = sometimes true, 4 = often true and 5 = very often true). The CTQ has four severity classifications across each of the five factors: none or minimal, low to moderate, moderate to severe and severe to extreme (Bernstein & Fink, 1998). High internal consistency is indicated by a Cronbach's α cross-factor range of .79 to .94, while good test-retest reliability is demonstrated by an interclass correlation of .88 (Bernstein et al., 1994). Studies have demonstrated that the CTQ has good criterion validity across multiple samples, including: a community sample from the United States (*n* = 579), adolescent psychiatric inpatients (*n* = 396), people who were abusing illicit substances (*n* = 1,003; Bernstein et al., 2003), and people diagnosed with schizophrenia (*n* = 100; Kim, Bae, Han, Oh, & MacDonald, 2013). The CTQ has been widely used in research exploring the relationship between childhood trauma and adult psychopathology (Gaudiano & Zimmerman, 2010; Sar et al., 2010; Schafer et al., 2012; Sheffield et al., 2013).

Life Events Checklist (LEC) (see Appendix M)

The LEC is a 17-item self-report questionnaire that was developed concurrently and is often administered with the Clinician Administered PTSD Scale (Blake et al., 1995). The LEC aims to assess a respondent's exposure to potentially traumatic events (e.g., life-threatening illness or injury) through the use of a 5-point nominal scale (1 = happened to me, 2 = witnessed it, 3 = learned about it, 4 = not sure and 5 = doesn't apply) (Gray, Litz, Hsu & Lombardo, 2004). The LEC allows individuals to endorse exposure

to multiple trauma, and has good overall test-retest reliability (r = .82) and convergent validity (Gray et al., 2004).

Structured Clinical Interview for DSM-5 Disorders Research Version (SCID-5-RV)

The SCID-5 is a semi-structured interview guide for making the major DSM-5 diagnoses (First, Williams, Karg & Spitzer 2015). SCID-5-RV includes all of the disorder subtypes and severity and course specifiers. Four modules were administered: modules A (Mood Episodes), B (Psychotic and Associated Symptoms), C (Psychotic Disorders) and D (Mood Disorders).

Follow-up Questions and Summary of Findings (see Appendix N)

Prior to attending their follow-up interviews, participants were given a document outlining the four questions that they would be asked and a summary of the study's initial findings. Each question related to a subset of themes. All themes were placed directly below the question to which they were related. Except for the first theme (which related to question 1), the themes were grouped into four topic areas. The number of participants who spoke about each theme was placed in brackets next to each theme. Topic 3 included a number of themes that were not directly related to the study's research questions. Therefore, these themes have not been presented or discussed further in this thesis.

Audio Recorders

Two audio recorders were used: the Phillips Voice Tracer DVT2700 and the Olympus VN-711PC Digital Voice Recorder. Both audio recorders allow for digital audio recordings that can be uploaded onto a computer as MP3 files.

5.6 Data Analysis

All interviews (including follow-up interviews) were professionally transcribed by Pacific Transcription, an Australian transcription company that specialises in legal and medical transcription services, radiology typing, medico-legal work, typing of research interviews and focus groups ('About Pacific Transcription', 2018). To ensure accuracy in transcription, the researcher read all the transcripts while simultaneously listening to the interview recordings. Minor corrections were made. One participant sent a letter to the researcher one week after her interview with additional information regarding her experience of taking antipsychotics. The participant mentioned that she wanted this additional information included in the analysis. This letter was attached to her transcript and analysed accordingly.

The analysis of the qualitative data followed the IPA guidelines outlined by Smith and colleagues (2009). This involved a number of key steps. The researcher commenced the analysis with the interview that he found most detailed and engaging. Initially, the researcher immersed himself in the data by reading each transcript multiple times. This ensured that the participant became the focus of attention. A manual process of coding, or a line-by-line annotation of each participant's transcript, was then undertaken. A two-column table was established whereby the transcript was copied into the left column and explanatory comments (or codes) regarding evidenced content were made in the right column. There were no rules dictating what should be commented upon; the aim was to produce a comprehensive set of notes on the similarities, differences, elaborations and contradictions in the participant's statements (Smith et al., 2009). Thus, attention was paid to descriptions of what was experienced and how it was experienced (Starks & Trinidad, 2007).

The transcripts and associated explanatory comments/codes of four interviewees were checked by the researcher's supervisors, Associate Professor Sarah Bendall and Professor Louise Harms. This was done to ensure that the researcher was coding appropriately—that is, ensuring that the codes reflected what participants were saying. In some instances throughout the interviews, the researcher repeated what participants had described and asked them to confirm whether this was an accurate summation of their experience. If the participant confirmed that the researcher's reflective comment accurately captured their experience, then this comment was also coded. In the four interviews that were checked by the researcher's supervisors, these particular codes were highlighted in yellow. This allowed them to specifically check whether these codes accurately captured the participants' lived experience.

When the ideas of each individual participant were identified, emerging descriptive themes for each case were conceptualised. This was achieved by mapping interconnections and patterns between codes, and producing a concise statement that represented what was important in the various codes. Descriptive themes were then grouped into clusters to form superordinate themes. This process was informed by two methods: abstraction, which involves grouping similar themes together under a new name that characterises that group, and subsumption, whereby one of the themes becomes the superordinate theme because it connects many related themes (Smith et al., 2009). An example of this analytical process is provided in Table 5.1. Upon its completion, the researcher then searched for patterns across the entire data set. This involved identifying connections between the superordinate themes of different cases. When these themes appeared to have a strong connection with one another, some were relabelled so that one label (or theme) represented an obvious higher-order quality that appeared to emerge in

the sample data. This allowed the analysis to have a dual quality, ‘pointing to ways in which participants represent unique idiosyncratic instances but also shared higher order qualities’ (Smith et al., 2009, p. 101). Throughout this process, the researcher had regular

Table 5.1.

Example of IPA

Original transcript	Explanatory comments/codes	Descriptive themes	Superordinate theme
Probably my anxiety and ability to deal with stress, has helped. Also the way I process - which I think is in conjunction with the counselling that I had to have - the way I feel about the childhood trauma, so that now I'm more able to divorce myself from the situation rather than having to relive it all the time. Now I just step back - take a step back from it and see it in a more objective light.	Antipsychotics have helped with her anxiety. Antipsychotics have helped her deal with stress. In conjunction with the counselling, antipsychotics have helped her divorce herself from the memory of her childhood trauma, rather than having to relive it all the time.	Both medication and counselling have helped her distance herself from trauma.	Medication and counselling help equally in dealing with trauma.

Original transcript	Explanatory comments/codes	Descriptive themes	Superordinate theme
My further thoughts are that as you aware that the joint use of counselling and drugs to help me overcome my voices and childhood trauma were useful. However, I reflect that when I was being tried on a variety of antipsychotics I was also receiving counselling. I was unable to get the most out of my counselling due to the drugs not working and so I was still experiencing voices and anxiety over past experiences. It was only when I got Solian, a drug that worked to help	It was the joint use of counselling and drugs that helped her overcome her voices. It was the joint use of counselling and drugs that helped her overcome her childhood trauma. While she was taking a variety of different antipsychotics, she was not able to get the most out of her counselling because the drugs were not working.	Unable to get the most out of counselling when the drugs were not working. Drugs diminished the voices and she was able to get the most out of counselling.	

Original transcript	Explanatory comments/codes	Descriptive themes	Superordinate theme
diminish my voices that I was able to get the most out of my counselling. I also know that it was only through counselling that I was able to confront and approach my childhood trauma effectively. This was made possible due to the drugs letting me have a clearer mind with fewer voices. However, with the drugs alone I would not have been able to confront my past and as a result present ideas and feelings. It was therefore the equal use of counselling and drugs	It was only when she got Solian, a drug that actually helped diminish her voices, that she was able to get the most out of her counselling. It was only through her counselling that she was able to confront and approach her childhood trauma effectively. The drugs gave her a clear mind with fewer voices, thus, allowing her to appropriately engage in counselling	Drugs and counselling work equally.	

Original transcript	Explanatory comments/codes	Descriptive themes	Superordinate theme
that worked for me and still does to this day. I still have both on a regular basis.	and confront her childhood trauma effectively. With the drugs alone, she would not have been able to confront the past and, as a result, her present ideas and feelings. It was an equal use of counselling and drugs that worked for her. She still has both counselling and drugs on a regular basis.		

meetings with his supervisors to discuss the appropriateness of superordinate themes. The follow-up interview transcripts were analysed using the same method. In Chapters 7, 8 and 9 of the manuscript, data—as represented by direct participant quotations—are used to support the emergence of specific superordinate themes. Participants are differentiated by a number. Quotations are thus referenced using participants' assigned numbers.

An evaluation of the prevalence of superordinate themes across the entire dataset was also undertaken. The primary objective of qualitative research is to obtain an in-depth understanding of a particular phenomenon. However, demonstrating that a few, some or many participants reported an experience can make patterns within the data emerge with greater clarity and potentially generate new research questions (Dey, 1993; Sandelowski, 2001). With regards to IPA, many recent studies have specifically reported the prevalence of descriptive and/or superordinate themes (see e.g., Kaspar & Kroese, 2017; Palmieri, 2018; Pateraki, Vance & Morris, 2018; Rhodes, O'Neill & Nel, 2018; Smethurst & Kuss, 2018). While there is no precise method for reporting prevalence in qualitative research, it is important to ensure that there is consistency in how this is done (Braun & Clarke, 2006). Therefore, the terms/phrases used to describe the prevalence of a particular theme (or experience) were allocated a specific numerical range. These terms/phrases (and their associated numerical ranges) are: a few (2–4 participants), some (5–9 participants), many (10–14 participants) and most (15–18 participants). If a theme was evidenced in the data of only one or all of the participants, this was explicitly stated (e.g., 'All of the participants reported').

All superordinate themes were grouped under three research topics. Each topic is presented as an individual chapter within this thesis. In addition to answering the primary research question, each chapter also provides information that aims to specifically answer the relevant subsidiary research questions. The themes that are presented in Chapter 7 aim to answer the first and second subsidiary research questions while those presented in Chapter 8

focus on the third subsidiary research question. Some of the themes that are presented in Chapter 9 aim to answer the first subsidiary research question. New themes were not identified from the analysis of participants' follow-up interview transcripts. Therefore, the description of each theme includes any relevant information that emerged from the follow-up interviews.

5.7 Summary

This study implemented an embedded mixed-methods research design with a qualitative priority. IPA was specifically selected as the method of qualitative inquiry. Semi-structured interviews were used to obtain data that answered the research questions. The CTQ, LEC and SCID-5-RV were used to obtain systematic information about the severity of participants' traumas, the types of trauma that they had experienced and the nature of their psychotic symptoms (presented in Chapter 6 of this thesis). This served as the secondary quantitative strand of the research design. Participants were purposefully recruited from EPPIC, Prahran Mission and the general community. All qualitative data were analysed using the IPA guidelines outlined by Smith and colleagues (2009).

Chapter 6: Description of the Sample

This study explored how people with a history of ICT and psychosis subjectively experience the effects of antipsychotic medications. As such, it was important to gain a thorough understanding of participants' trauma histories, their psychosis diagnoses and the types of antipsychotics that they had taken. This information would also support a more specific interpretation of the study's qualitative findings. Thus, this chapter provides a thorough description of the study's sample by outlining participant demographics, their psychosis diagnoses and the types of psychiatric medications that they have taken. Information about the severity of participants' childhood trauma and the different types of the trauma that they experienced throughout their lives is also presented.

6.1 Participant Characteristics

The sample comprised 19 participants (14 females and 5 males) aged between 16 and 59 years (Mean age = 36.5 years). Participant demographics are outlined in Table 6.1. At the time of their interviews, none of the participants were psychiatric inpatients. Only one participant reported that they had no prior psychiatric impatient admissions. Seven participants were receiving treatment or support from one or more public mental health services. Four participants were receiving support from both a public mental health service and a private psychologist/psychiatrist. Eight participants were receiving support solely from a private psychologist and/or psychiatrist. Of the five participants recruited from EPPIC, four were engaged with the service for six months or less, while one had been receiving treatment for one year.

Table 6.1

Participant Demographics (N = 19)

Variable	*n* (%)
Sex	
Male	5 (26.3%)
Female	14 (73.7%)
Age range	
16–17 years1 (5.3%)	
18–24 years	5 (26.3%)
25–34 years	3 (15.8%)
35–44 years	5 (26.3%)
45–54 years	2 (10.5%)
55–64 years	3 (15.8%)
Marital status	
Married	5 (26.3%)
In a relationship	2 (10.5%)
Divorced/separated	3 (15.8%)
Single/never married	9 (47.4%)
Highest level of completed secondary education	
Year 7	0 (0%)
Year 8	1 (5.3%)
Year 9	1 (5.3%)
Year 10	2 (10.5%)
Year 11	3 (15.8%)
Year 12/VCE	14 (63.1%)
Additional qualifications*	
None	1 (5.3%)
Trade/technical training	4 (21.1%)
Certificate	6 (31.6%)
Tertiary diploma	7 (36.8%)
Tertiary degree	3 (15.8%)
Currently secondary school	1 (5.3%)
Currently tertiary education	3 (15.8%)
Employment status*	
Unemployed	2 (10.5%)
Full-time work	1 (5.3%)
Part-time/casual work	5 (26.3%)
Student	8 (42.1%)
Volunteer work	4 (21.1%)
Self-employed	1 (5.3%)

Variable	*n* (%)
Disability support pension	1 (5.3%)
Country of birth	
Australia	13 (68.4%)
England	1 (5.3%)
New Zealand	1 (5.3%)
Tonga	1 (5.3%)
Philippines	1 (5.3%)
South Africa	1 (5.3%)
Egypt	1 (5.3%)
Number of lifetime psychiatric impatient admissions	
No impatient admissions	1 (5.3%)
1 impatient admission	6 (31.6%)
2 impatient admissions	1 (5.3%)
3 impatient admissions	2 (10.5%)
4 impatient admissions	0 (0%)
5 or more impatient admissions	9 (47.4%)

Note. *Participants were able to choose multiple options.

Participants' diagnoses and the type of psychiatric medications taken are outlined in Tables 6.2 and 6.3. Seventeen participants reported that they were currently taking an SGA. One participant was taking a depot antipsychotic, while another was only taking an antipsychotic when required (*pro re nata*; PRN). Six participants were currently taking two different antipsychotics. Of those six, four participants were taking their additional antipsychotic as a PRN. Of the 17 participants currently taking an antipsychotic, eight were taking one additional psychiatric medication (an antidepressant, mood stabiliser, benzodiazepine or anti-side effect medication). Two participants were taking an additional antidepressant and mood stabiliser, while another participant was taking an additional antidepressant and benzodiazepine. One participant was taking an additional mood stabiliser and anti-side effect medication. Another participant was taking an additional antidepressant, mood stabiliser and benzodiazepine. Two participants mentioned that they had stopped taking antipsychotic medication approximately three years ago. Of those two, one participant had

taken an antipsychotic for seven years, while the other had taken the drug for four years. Both participants were currently taking an antidepressant. Across the entire sample, the most commonly taken antipsychotic medications were Olanzapine (n = 10), Quetiapine (n = 9), Aripiprazole (n = 7) and Risperidone (n = 6).

Table 6.2

Psychosis Diagnosis (N = 19)

Variable	*n* (%)
Psychosis Diagnosis*	
Schizophrenia	10 (52.6%)
Schizoaffective disorder, depressive type	3 (15.8%)
Schizoaffective disorder, bipolar type	2 (10.5%)
Unspecified psychotic disorder	1 (5.3%)
Bipolar disorder, with psychotic features	3 (15.8%)
Age of onset of frank psychotic symptoms	
0–9 years	2 (10.5%)
10–19 years	11 (57.9%)
20–29 years	5 (26.3%)
30–39 years	0 (0%)
40–49 years	1 (5.3%)

Note. *DSM-5 diagnosis of a psychotic disorder or mood disorder with psychotic features made using the SCID-5-RV.

Table 6.3

Types of Psychiatric Medications Taken (N = 19)

Variable	*n* (%)
Currently taking antipsychotic medication	
Yes	17 (89.5%)
No	2 (10.5%)
Type of antipsychotic medication(s) currently taking	
Clozapine (Clozaril)	1 (5.3%)
Olanzapine (Zyprexa)	2 (10.5%)
Quetiapine (Seroquel)	2 (10.5%)

Variable	*n* (%)
Aripiprazole (Abilify)	3 (15.8%)
Asenapine (Saphris)	2 (10.5%)
Paliperidone (Invega)	1 (5.3%)
Quetiapine (Seroquel) & Aripiprazole (Abilify)	1 (5.3%)
Quetiapine (Seroquel) & Lurasidone (Latuda)	1 (5.3%)
Aripiprazole (Abilify) & Chlorpromazine (Largactil)	1 (5.3%)
Aripiprazole (Abilify) & Lurasidone (Latuda)	1 (5.3%)
Aripiprazole (Abilify) & Amisulpride (Solian)	1 (5.3%)
Asenapine (Saphris) & Amisulpride (Solian)	1 (5.3%)
Number of different antipsychotic medications tried/taken	
2 types	10 (52.6%)
3 types	1 (5.3%)
4 types	2 (10.5%)
5 or more types	6 (31.6%)
Type of antipsychotic medication previously taken	
Olanzapine (Zyprexa)	8 (42.1%)
Quetiapine (Seroquel)	5 (26.3%)
Risperidone (Risperdal)	6 (31.6%)
Chlorpromazine (Largactil)	1 (5.3%)
Trifluoperazine (Stelazine)	1 (5.3%)
Flupentixol (Depixol)	1 (5.3%)
Zuclopenthixol (Clopixol)	1 (5.3%)
Other/type unknown	6 (31.6%)
Other psychiatric medications prescribed	
Antidepressant	9 (47.4%)
Benzodiazepine	6 (31.6%)
Mood stabiliser	4 (21.1%)
Anti-side-effect	2 (10.5%)

Ten participants indicated that they had previously been diagnosed with PTSD, while 14 had previously received, or were currently receiving, psychological treatment for trauma. Of those 14 participants, two mentioned that this treatment was ongoing for a period of over 20 years, while one participant stated that she was receiving this treatment ‘when required’ for five years. For the other 11 participants, the duration of the psychological treatment they received (or were receiving) for their trauma ranged from six months to three years.

6.2 Trauma Type and Severity

As measured using the CTQ, the number of participants who experienced different levels of trauma severity for five different types of childhood trauma (emotional, physical and/or sexual abuse, as well as emotional and/or physical neglect) is outlined in Table 6.4. Twelve of the 19 participants experienced severe to extreme levels of trauma severity for at least one trauma type. Three other participants experienced moderate to severe levels for at least one trauma type. One participant reported that he either did not experience childhood trauma or that the severity of this trauma was minimal. Eight participants reported experiencing (to some degree) all trauma types. Of those eight participants, two experienced severe to extreme levels of trauma severity for all trauma types, while two other participants reported severe to extreme levels of trauma severity for four trauma types. Three participants reported experiencing (to some degree) four of the five trauma types.

Table 6.4

Frequency of Severity Categories Across the Five Scales of the Childhood Trauma Questionnaire (N = 19)

	Classification			
Scale	None (or minimal) *n* (%)	Low (to moderate) *n* (%)	Moderate (to severe) *n* (%)	Severe (to extreme) *n* (%)
Emotional abuse	2 (10.5%)	7 (36.8%)	2 (10.5%)	8 (42.1%)
Physical abuse	9 (47.4%)	2 (10.5%)	2 (10.5%)	6 (31.6%)
Sexual abuse	6 (31.6%)	2 (10.5%)	4 (21.1%)	7 (36.8%)
Emotional neglect	5 (26.3%)	2 (10.5%)	4 (21.1%)	8 (42.1%)
Physical neglect	6 (31.6%)	3 (15.8%)	4 (21.1%)	6 (31.6%)

The number of participants who reported exposure to each of the 17 potentially traumatic events outlined on the LEC is presented in Table 6.5. The majority of participants reported that they themselves experienced ('happened to me'): a physical assault (n = 16), an unwanted or uncomfortable sexual experience (n = 15), some other stressful event or experience (n = 15), a sexual assault (n = 13) and/or severe human suffering (n = 9).

Table 6.5

Frequency of Categories Across the Seventeen Events Outlined on the Life Events Checklist (N =19)

Event	Happened to me *n* (%)	Witnessed it *n* (%)	Learned about it *n* (%)	Not sure *n* (%)	Does not apply *n* (%)
Natural disaster (e.g., flood, hurricane, tornado, earthquake)	6 (31.6%)	3 (15.8%)	6 (31.6%)	0 (0%)	7 (36.8%)
Fire or explosion	4 (21.1%)	4 (21.1%)	5 (26.3%)	1 (5.3%)	8 (42.1%)
Transportation accident (e.g., car or boat accident, train wreck, plane crash)	6 (31.6%)	4 (21.1%)	5 (26.3%)	1 (5.3%)	7 (36.8%)
Serious accident at work, at home or during recreational activity	6 (31.6%)	4 (21.1%)	4 (21.1%)	1 (5.3%)	9 (47.4%)
Exposure to toxic substance (e.g., dangerous chemicals, radiation)	3 (15.8%)	0 (0%)	1 (5.3%)	2 (10.5%)	14 (63.1%)

Event	Happened to me *n* (%)	Witnessed it *n* (%)	Learned about it *n* (%)	Not sure *n* (%)	Does not apply *n* (%)
Physical assault (e.g., being attacked, hit, slapped, kicked, beaten up)	16 (84.2%)	5 (26.3%)	4 (21.1%)	1 (5.3%)	1 (5.3%)
Assault with a weapon (e.g., being shot, stabbed, threatened with a knife, gun, bomb)	8 (42.1%)	5 (26.3%)	4 (21.1%)	0 (0%)	5 (26.3%)
Sexual assault (rape, attempted rape, made to perform any type of sexual act through force or threat of harm)	13 (68.4%)	2 (10.5%)	5 (26.3%)	0 (0%)	2 (10.5%)
Other unwanted or uncomfortable sexual experience	15 (78.9%)	2 (10.5%)	2 (10.5%)	0 (0%)	3 (15.8%)
Combat or exposure to a war zone (in the military or as a civilian)	0 (0%)	0 (0%)	1 (5.3%)	0 (0%)	18 (94.7%)
Captivity (e.g., being kidnapped, abducted, held hostage, prisoner of war)	3 (15.8%)	0 (0%)	0 (0%)	0 (0%)	16 (84.2%)
Life-threatening illness or injury	7 (36.8%)	3 (15.8%)	3 (15.8%)	1 (5.3%)	7 (36.8%)
Severe human suffering	9 (47.4%)	5 (26.3%)	2 (10.5%)	1 (5.3%)	4 (21.1%)

Event	Happened to me *n* (%)	Witnessed it *n* (%)	Learned about it *n* (%)	Not sure *n* (%)	Does not apply *n* (%)
Sudden, violent death (e.g., homicide, suicide)	3 (15.8%)	1 (5.3%)	11 (57.9%)	0 (0%)	5 (26.3%)
Sudden, unexpected death of someone close to you	6 (31.6%)	3 (15.8%)	3 (15.8%)	0 (0%)	7 (36.8%)
Serious injury, harm or death you caused to someone else	3 (15.8%)	0 (0%)	1 (5.3%)	2 (10.5%)	13 (68.4%)
Any other very stressful event or experience	15 (78.9%)	2 (10.5%)	2 (10.5%)	0 (0%)	4 (21.1%)

The potentially traumatic events that were most often witnessed by participants included: a physical assault (*n* = 5), an assault with a weapon (*n* = 5) and severe human suffering (*n* = 5). The majority of participants reported that they had not personally experienced, witnessed or learned about the following events: combat or exposure to a war zone (n = 18), captivity (n = 16), exposure to a toxic substance (n = 14) and causing serious injury, harm or death to someone else (n = 13). With regard to item 17 (‘any other very stressful event or experience’), four participants stated what this event/experience was. These occurrences included: bullying, immigration, a medical condition and helplessly watching one’s mother experience a stroke. The participant who reported on the CTQ that he either did not experience childhood trauma or that the severity of this trauma was minimal was the individual who reported that he helplessly watched his mother have a stroke when he was five years old. This participant also stated on the LEC that he experienced physical assaults. He verbally informed the researcher that these assaults occurred during his teenage years. Three

participants reported that they themselves experienced (‘happened to me’) a sudden, violent death (e.g., homicide, suicide). It is possible that these participants interpreted the phrase ‘happened to me’ as having someone close to them die, experiencing suicidal thoughts and/or attempting suicide.

6.3 Summary

The study comprised 14 females and five males. Seventeen participants reported that they were currently taking at least one SGA. Two participants had discontinued their medication approximately three years ago. Ten participants met the diagnostic criteria for schizophrenia. Eight participants had experienced at least one depressive and/or manic episode and thus, were diagnosed with either schizoaffective disorder or a mood disorder with psychotic features. The data obtained via the CTQ demonstrates that many participants had experienced severe levels of childhood trauma. Many participants also reported experiencing multiple types of childhood trauma (e.g., sexual, physical and emotional abuse). The information obtained via the LEC indicates that the majority of participants had experienced a physical assault, sexual assault and/or some other unwanted sexual experience. The LEC also provided more specific information about the types of trauma experienced by participants (e.g., assault with a weapon or captivity).

Chapter 7: Effect of Antipsychotics on Trauma-Related Experiences

This chapter outlines whether antipsychotic medications altered participants' trauma-related thoughts, images/flashbacks, emotions and physical responses. It provides a detailed description of the effects that antipsychotics had on how participants experienced their trauma memories. The chapter also provides information on how participants conceptualised the role of antipsychotics in the process of healing from childhood trauma. It further details participants' descriptions of the specific benefits of trauma-focused psychological therapy and how this differed from antipsychotic drug treatment. Participants' experiences are conveyed through the development of six superordinate themes.

7.1 Altering Trauma-Related Experiences

Many participants reported that antipsychotic medications altered how they experienced trauma-related memories. Some specifically indicated that antipsychotics alleviated the intensity and/or frequency of trauma-related thoughts, emotions and/or physical symptoms. One participant reported that she did not experience any thoughts or emotions while taking a high dose of an antipsychotic. She described how she did not linger on past traumatic events or experience intrusive trauma-related thoughts. She stated:

> *While I was taking the maximum dose, I honestly don't think I had any emotion. I definitely didn't linger on any of those things. I don't even—I don't remember them coming to my mind at all, but I definitely didn't spend any long time pondering on them or thinking about them. Yeah, I really don't think they were there [12].*

Another participant mentioned that while taking antipsychotic medication, even if she did think about her past trauma, the thought would not stay in her mind. However, she stated that if she does not take her medication, 'those thoughts get in there [into her mind] and they don't go away' [16]. This participant further reported that when she thinks about what happened, she feels very sad and angry. She also stated that the trauma-related thoughts were often the cause of physical tension; she described her hands and fingers feeling like playdough. Therefore, because the antipsychotics prevent her thoughts from being 'generated properly' [16], the emotional and physical responses occur less often. She did mention that the physical tension can be triggered by visual stimuli (e.g., seeing something on television) and thus, it still does occur while on the medication, though it is less often. Another participant spoke about how antipsychotic medication prevents her from ruminating over traumatic memories. She emphasised that when she stops taking her medication, trauma-related thoughts flood her mind. She also described how antipsychotics subdue emotions, such as anger, that are related to specific traumatic memories:

> *The antipsychotics help me deal a lot with my trauma because I often—I have a problem with ruminating over the memories I have that are traumatic…I take my medication and all of a sudden it's like it's fine; I don't think about it. I'm at peace with it. But when I get off my medication there's a bit of a backlash, particularly in the first few days that I get off my medication where I just can't stop thinking about it and I'm constantly crying and I'm constantly pacing and constantly just getting really, really mad at my mother and at the people who've hurt me. It's just it kind of subdues my emotions a little bit more…So the medication definitely helps me kind of subdue my traumatic memories and not be so angry at my parents for neglecting me and not raising me well [19]*.

This participant indicated that when she takes her medication, she has a significantly different perspective about how she was treated by her family, particularly her mother. She stated that, while taking antipsychotics, she is able to establish a rationale for why her mother treated her badly. She is able to recognise that her mother had a terrible childhood and that this influenced her ability to be a good parent. In contrast, when she does not take her medication, she is unable to follow this process of rationalisation. She is quick to conclude that there is no excuse for the abusive treatment that she received from her mother. This participant also mentioned that while she still continues to feel angry about what happened, the anger is less intense when she is taking her medication. She reported:

> *It makes me just not—like more at peace with it to be honest. So, I've got more perspective on it…Like for example, with my mother I put into perspective, okay, so she had a very abusive childhood; she had a very narcissistic mother. She is dealing with all these issues when she's having children. I'm still pissed at her, but at the same time I kind of understand where she's coming from. She should have done better, but you know, she has her reasons for what she did. But when I'm off my medications sometimes I slip into—occasionally I slip into the thought where it's just like: this is absolutely ridiculous; there is no excuse for what she did and the way she treated me. I get very emotional about it…Yeah, that's when I'm off my meds. But honestly, I still remain angry to my mother even when I'm on my medication. It's just that it becomes less intense when I'm on my medication [19].*

Another participant described how antipsychotics helped her contain the intense emotions that she experienced while doing trauma therapy. She reported that her emotions would intensify rapidly during therapy and that her psychologist suggested that a low dose of

antipsychotics could relieve this emotional intensity. She stated: ‘My psychologist was recommending a lower dose because she felt that I flooded really easily in trauma therapy with emotion, and that a low dose would just keep a bit of a lid on it’ [5]. This participant further mentioned that by subduing emotion, antipsychotics can give a person rest from the intensity of trauma therapy. She stated that antipsychotics are like a cocoon that protects a person from the ‘extreme emotions’ that they may experience during trauma therapy:

> *The drugs are a cocoon, right, they provide this little cocoon that you can sit in. Because you’re not exposed to the extreme emotions that you might be otherwise, and if you need a rest from the intensity of the trauma work, you get the rest through the drugs [5].*

A few participants described how antipsychotics have been valuable in alleviating trauma-related stress and anxiety. These participants mentioned that their anxiety levels can rise rapidly when they are not taking antipsychotics. They mentioned that while they still continue to experience some anxiety, it is less severe than when they were not taking antipsychotics. For example:

> *Antipsychotics have been for me a killer for anxiety…If I’m not on antipsychotics I can get very, very anxious, very, very, very quickly [15].*

> *I know that the medication does help me with my anxiety and my stress levels. If I relive my—or something causes me to relive my trauma from my childhood, then I instantly get stressed, whereas in the past it would be like going up like a volcano, whereas now it rises, but it doesn’t rise as much [11].*

In contrast, a few other participants reported that, while taking antipsychotic medication, their trauma-related flashbacks, thoughts and physical symptoms were intensified or occurred more frequently. One participant described how particular flashbacks became more vivid when he was taking antipsychotics. He stated that the flashbacks were so intense that he actually believed that the perpetrator was in the room with him. He reported:

> *I would have to say that it heightened the flashbacks. As I said, the—what I call the visitations that I would totally believe that one of the Christian Brothers was actually in the room with me. I could sense him, I could smell him, even though he wasn't there. The flashbacks at night were becoming far more frequent, far more vivid...whether it was just coincidental, and I'm just being honest and fair, but during that period of Seroquel that's when it literally came out, it became a much more intensified, much more heightened [10].*

Another participant described how the medication's side effects were similar to some of her trauma-related physiological symptoms. She said: 'It's like the medications they give you the feelings just from the side effects, just the racing heart, the sweating' [7]. Thus, she stated that these experiences were 'happening all the time, even when you don't ask for it' [7] while taking antipsychotics.

Another participant described how antipsychotics changed how he viewed his trauma, stating that it was like viewing it through 'one of those tinted glass bottles, rather than a clear glass bottle' [14]. He said that by viewing it through a tinted glass bottle 'you can add things in. It can be a stronger effect on you' [14]. He further described how the trauma is 'amplified a bit' and that it is like examining it through 'a magnifying glass' [14].

7.2 Antipsychotics Prevent You From Confronting Trauma

A few participants reported that antipsychotics prevented them from confronting their trauma by subduing traumatic memories. These participants stated that this can be beneficial in the short term, in that it can give them relief from distressing trauma-related thoughts and emotions. They reported that by not constantly thinking about past traumatic events, their daily lives become easier. However, participants also mentioned that this may not necessarily be beneficial in the long term, and that they do need to confront their traumatic pasts in order to deal with them. The following three quotations illustrate this point:

> *The medication helps me not have to deal with that so I can go about my day-to-day life, you know what I mean. Otherwise, I'll be stopping at least once a day to cry, even though I kind of do need to cry and I do need to confront these emotions and I do need to deal with these issues [19].*

> *I don't think that subduing or hiding my trauma from myself in the long term is going to do me any good. But in the short term, I think it's a great thing that I get to give my brain a rest from the trauma [16].*

> *I feel what it does, it puts you in a state where you can, where it levels you out again but you're not dealing with the trauma [9].*

One participant stated that she was unable to meaningfully engage in trauma therapy while taking a high dose of Seroquel. She said that antipsychotics prevented her from experiencing certain emotions, which was a fundamental part of her psychotherapeutic work. This participant emphasised that, for much of her life, she had been emotionally repressed and

that her feelings ‘didn’t feel safe’ [5]. Therefore, she had to learn how to feel her emotions by fully experiencing them. She stated:

> *But it was too tight a cocoon, let’s put it that way. It was smothering me, you know. I couldn’t—yeah, I think to do trauma work, the point of this trauma work that I was doing anyway was to learn to feel your feelings, and I had been emotionally repressed for the majority of my life because of my childhood trauma…So I wasn’t taught how to feel my feelings, and my feelings didn’t feel safe. So, I had to learn to do that and on 800 milligrams of Seroquel, I couldn’t feel my feelings [5].*

This participant described how she had to lower the dose of her medication to a point where she could experience her emotions, while also not being overwhelmed by the intensity of trauma therapy (see Section 7.1). Thus, while a higher dose of the medication did not allow her to confront and address her trauma, a lower dose served as a valuable initial strategy to contain the intense emotions that she experienced during therapy. This participant also stated that when medications supress trauma-related emotions and flashbacks, they prevent those experiences from be integrated. She stated: ‘So when you are getting a strong feeling or a trauma flashback and you take some medication to push it away, you are not integrating the experience. You are just pushing the experience away’ [5].

7.3 No Change in Trauma-Related Experiences

Some participants indicated that antipsychotics did not change their experiences of trauma-related thoughts, emotions and/or physical responses. Participants described how they continued to experience specific physical symptoms (e.g., an increase in heart rate, physical tension, tremors) when exposed to particular triggers. For some participants these triggers were

external (e.g., being touched in a particular way), while for others they were internal (e.g., a specific thought or emotion). This is evidenced in the following quotations:

> *It's like sometimes the most normal things could trigger it, could trigger those memories. It's like someone could touch—brush by me or touch my shoulder or something, and I could react to it. Touching my hair is a trigger…It sounds really bad, but talking to my mum is a trigger, and whenever I talk—not whenever; sometimes when I talk to her I remember because she's directly linked to what, to one of the incidents [1].*

> *I'm real cautious of my—of people. Especially when they come near me, real—I keep my guards up with people. When someone just comes at me, I sort of like flinch [4].*

> *No, because, I guess, the emotion that I feel is anxiety more than anything…so that hasn't changed…Yeah, shaky and tense and yeah, heart rate goes up and everything [18].*

> *I literally—when I start thinking about what she did, my hands turn to fists. Like I start standing up and I just kind of charge at her as if I'm going to like punch her, as if she's in front of me and I'm going to punch her or something. I get really mad that I just do have an increased heart rate and I do get very psychical…All I know is that it happens when I'm on my medication and when I'm off my medication [19].*

One participant reported that while very high doses of antipsychotics stopped all trauma-related thoughts, emotions and dreams, these experiences continued when she took

moderate doses of the drug. She stated: ‘It was like an every night dream probably from when I was three really until I was on the maximum dosage’ [12]. Another participant reported that antipsychotics have not changed how she experiences trauma-related thoughts, primarily because she has ‘blocked out’ her trauma: ‘I say not really because I’ve blocked them out. If I were—if I had to talk about them, I could, but for the most part, everyday life, I don’t spend my time thinking about it’ [1]. However, she did mention that she can still be triggered and reminded of what happened by different environmental stimuli. Another participant described how she has continued to question why she had to experience particular traumatic events in her life, which then makes her feel sad. She reported:

> *I kind of question it, like why did it happen? Then I get sad as well, sometimes. If something happens to me, then I get in this sad mood because I feel like everything’s just happening to me, and that it’s just been so wrong. Everything wrong just keeps happening, and if something happens then I get really sad about it [4].*

7.4 Uncertain About What’s Altered Trauma-Related Experiences

Some participants stated that they were unsure whether the antipsychotic medication altered particular trauma-related thoughts, emotions and/or physical responses; for example:

> *I’d just get really angry at what happened and stuff. I haven’t been feeling like that for a long time…It just went away. I never actually tried to make it go away, it just went away itself…It’s probably been the medication maybe; I’m not quite sure. Yeah [4].*

Participants described how specific trauma-related experiences may have been altered by a number of different factors, including: antipsychotics, counselling or psychological

interventions, other medications or an attitude change. The participants emphasised that it is difficult for them to determine exactly what altered their trauma-related thoughts and emotions. This point is clearly illustrated in the following four quotations:

> *I haven't kept the bad, negative memories. I've forgotten it, I don't know whether it's the medication that's done that…It could be the attitude, or way I've thought about things. Or the way that the professionals talk to me about things. It could be numerous factors come into it, yeah [6].*

> *I don't know if that's again, through medication or therapy, that sort of thing…Also, being on the Epilim as well…that sort of thing, so you don't know if it's the Saphris or you don't know if it's the Epilim [9].*

> *Even though I didn't really talk about the trauma with any of my people at the time or afterwards or ever actually, the pills helped me with sadness. Whether that was the antidepressants I'm not sure or antipsychotics even I'm not sure but it definitely helped me feel less sad [15].*

> *They haven't changed but they've since the years have gone on, they've become less and less…Probably the counselling, yeah. Maybe the medication as well [18].*

One participant mentioned that she thought about her trauma more often since commencing antipsychotic medication. She stated: 'It's more difficult to repress it' [13] but was unsure whether 'this was because of the medication or not' [13]. She reported that prior to

her psychotic episode she would ‘repress’ as much as she could; thus, it may be that she is now remembering (and no longer repressing) the trauma.

7.5 Processing and Addressing Trauma Through Psychotherapy

A few participants spoke about how psychotherapy helped them process and address their childhood trauma. One participant indicated that therapy involved learning how to ‘integrate’ particular experiences and memories, and tolerate emotions. She stated: ‘You have to basically sit with that emotion; you’ve got to accept those memories’ [5]. This participant mentioned that she did not know that she had experienced childhood trauma prior to experiencing a major psychotic episode. However, she understood that the psychotic episode happened for a reason, and while antipsychotic medication alleviated her initial distress, she ‘wanted healing’ and ‘healing wasn’t going to come from a pill’ [5]. She described how therapy was ‘intense’ and noted that ‘stuff started coming up real fast’ [5]. At that point, medication did help her contain her emotions (see Section 7.1) until she was able to develop nonpharmacological coping strategies. She stated: ‘I still get those triggers but I have hugely improved coping strategies. So, I can actually deal with and integrate that stuff’ [5].

Another participant indicated that she has experienced stiffness and tension in her neck as a result of childhood trauma. She attributed the alleviation of this physical tension to psychotherapy: ‘No, it’s definitely therapy and just me having an awareness of my trauma and how it’s impacted on me’ [9]. In terms of how therapy has helped, she stated: ‘I’m a lot more confident in seeing my trauma for what it is, basically, yeah’, and ‘I’ve been able to estrange myself from my perpetrators as well’ [9]. Another participant described how he was required to confront his past in therapy and, as a result, was able to admit that he had been abused. He indicated that he has been able to heal by gradually moving through different stages:

I started to work with psychologists and psychiatrists and I can actually admit that I was sexually and physically abused. I call that period my victim period. I'm now into the sort of survivor mode and hoping to get into the thriver mode…it's like anything in life, you know, you've got to avoid avoidance. That's what I'd done for so long. So, it was confronting my demons…So confronting allowed me to move into the victim stage [10].

Another participant stated that upon disclosing her childhood trauma, her therapist informed her that many other people had similar experiences, which made her feel less isolated. In therapy, she was also able to examine each component of her trauma individually. She mentioned that her childhood trauma was a 'big mass of things' [11] before she commenced therapy. She described these as valuable aspects of therapy:

It's always been kept in the family, so I never talked about it. Actually, being able to disclose it has made a lot of difference, and it has really helped me to feel as if I was not isolated, because I wasn't aware—I didn't think about the fact that other people go through these sort of experiences as well. So, through the counselling they were able to say to me look, other people in this situation have reacted in this way, and it has helped if you can do this…You feel like you're not the only oddball on the street. Also, with the counselling they were able to help me dissect all the trauma that went on and then look at each individual component to the dissection rather than having it just as one big mass of things. That has really helped as well [11].

7.6 Medication and Counselling Help Equally in Dealing with Trauma

One participant specifically described how she was able to address her childhood trauma through the combined use of antipsychotic medication and counselling. She reported that, for some time, the medications she took did not alleviate her auditory hallucinations, which prevented her from meaningfully engaging in counselling. She eventually tried a drug that alleviated these hallucinations and gave her a clearer mind, which then allowed her to adequately confront her trauma in counselling. To illustrate:

> *It was only when I got Solian, a drug that worked to help diminish my voices that I was able to get the most out of my counselling. I also know that it was only through counselling that I was able to confront and approach my childhood trauma effectively. This was made possible due to the drugs letting me have a clearer mind with fewer voices. However, with the drugs alone, I would not have been able to confront my past and as a result present ideas and feelings. It was, therefore, the equal use of counselling and drugs that worked for me and still does to this day. I still have both on a regular basis [11].*

7.7 Summary

This chapter has outlined six superordinate themes that describe the effect of antipsychotics on how participants remembered and re-experienced past traumatic events. Some participants reported that antipsychotic medication alleviated the frequency and/or intensity of distressing trauma-related thoughts, emotions and/or physical symptoms. In contrast, other participants indicated that they experienced more intense or frequent flashbacks, thoughts of childhood trauma and/or physiological symptoms of anxiety while taking

antipsychotics. Participants further indicated that, by supressing trauma-related thoughts and emotions, antipsychotics prevented them from confronting their childhood trauma. Participants mentioned that this did offer relief from the distress caused by specific trauma-related thoughts and emotions and was, thus, considered beneficial in the short-term. Participants reported that their daily lives became easier when they were not thinking about past traumatic events and/or experiencing trauma-related emotions. One participant further mentioned that a degree of antipsychotic induced emotional blunting helped her engage in trauma-focused psychotherapy. However, the participants also recognised the need to confront trauma to heal. As such, having their trauma memories supressed by antipsychotic medications was not considered beneficial in the long term. A few participants also described the benefits of trauma-focused psychotherapy and how this differed from antipsychotic drug treatment. These participants reported that it was through psychotherapy that they were able to process or address their trauma. Some participants reported that they were uncertain about whether it was antipsychotics, psychotherapy or some other psychiatric medication that altered how they experienced specific trauma-related thoughts, emotions or physical symptoms.

Chapter 8: Effect of Antipsychotics on Dissociative Experiences

During their interviews, the participants were given a verbal description of what it may be like to experience dissociative symptoms (depersonalisation and derealisation). They were asked whether they had ever experienced such symptoms and, if so, whether antipsychotics changed how they experienced these symptoms. Thirteen participants indicated that they did at some point in their lives experience dissociative symptoms. This chapter thus describes the effect that antipsychotics had on participants' dissociative symptoms. Their experiences are conveyed through the development of four superordinate themes.

8.1 Altering Dissociative Experiences

Some participants reported that antipsychotic medications altered their dissociative experiences. A few indicated that antipsychotics alleviated specific dissociative symptoms, such as feeling detached from one's body and disconnected from the environment. For example:

> *It's like going to sleep, but you're awake, but then at the same time you're aware of what you're doing; not aware, but you can see yourself doing things. It's like you're just watching yourself and you're just floating… I just know that when I started to take the medication and taking it for quite a while, it lessened [1].*

> *I used to get a vague sort of dissociation where I would sort of zone out for a while…With the Latuda it doesn't happen at all, with the Latuda. With the Zyprexa,*

with the Risperdal, with the Abilify, it tended to happen anyway but with Latuda, Latuda has seemed to have killed it off [15].

One participant stated that her dissociative experiences had ceased while taking an antipsychotic; however, she was unaware that she had stopped dissociating because she was on very high doses of the drug. Throughout her interview, this participant described how high doses of antipsychotics prevented her from being aware of what she was (or was not) experiencing, including any dissociative symptoms. It was only upon retrospective reflection that she was able to determine that she had stopped dissociating while taking high doses of antipsychotics. She reported:

Yeah, quite often I've had the—like the dissociation and looking down, like I call it like the cornice of the ceiling, looking down that was and has been very common. It wasn't, that wasn't there, the dissociation wasn't there while I was taking the antipsychotics…I don't even think I was aware it wasn't happening to be honest. I mean I guess it was one less thing to cope with. From that point of view, it was good, but I wasn't aware that it had stopped happening [12].

Another participant described how she continued to change identities while taking antipsychotic medication. However, she mentioned that antipsychotics alleviated the severe distress that she experienced while in some of those altered states:

The last diagnosis I received was dissociative identity disorder. So, when I am dissociated, I switch into altered identities, states of consciousness. Sometimes, in those states, I will be extremely distressed and the drugs will help relieve that intensity. So,

in those states, I might self-harm, I might—one of my altered states is extremely regressed child-type alter who just cannot be helped. She's in a state of total terror. So, the drugs help with that [5].

This participant reported that by alleviating the distress that she experienced while in an altered state of consciousness, antipsychotics assisted her in returning to her own identity. She stated: 'it'll maybe switch me back as well so I can come back to my—I can relax and come back to my body and my identity' [5]. She mentioned that by supressing dissociative experiences, antipsychotics prevent a person from integrating those experiences. In this regard, she emphasised that antipsychotics influence dissociative experiences in the same way that they influence trauma-related thoughts and emotions. She reported: 'But again it's the same issue I was talking about before of, they suppress the stuff but they don't help integrate it. So that's where I've been able now to learn to do that for myself' [5]. In contrast, another participant reported that his dissociative experiences intensified while taking antipsychotics. While taking Seroquel, this participant reported that his experience of depersonalisation was so intense that he believed he could fly. He stated:

I used to describe when I was being abused that I would be looking down at this poor kid being raped, and then I'd realise that it was me…But that—that feeling of hovering, that feeling of flying intensified during those—that period of the Seroquel, to the point where I would wake up and literally believe that I could go and fly [10].

8.2 The Drug-Induced State is Like Dissociation

A few participants described subjective antipsychotic effects that were similar to particular dissociative experiences. One participant reported that antipsychotics 'nulled' his

'sense of reality' [14] and changed how he perceived his environment and past experiences, such as his trauma (see Section 7.1). He likened the sensation to seeing through 'tinted glass bottles, rather than a clear glass bottle' and stated that things appear altered because of the 'different colours and different magnification or distortions on the glass, dimples on the glass' [14]. In his follow-up interview, this participant reported that because antipsychotics alter how life is experienced, they can allow dissociative experiences to continue. He emphasised that it can, therefore, be dangerous to prescribe antipsychotics to people who dissociate:

> *I think in general its dangerous giving antipsychotics to people with dissociative experiences, if they're experiencing it already. The altering of the experience of life through these antipsychotics is only going to continue those thoughts and those actions and that way of thinking [14].*

Another participant mentioned that antipsychotics made her feel 'more detached' [19] from herself and her emotions. She further stated that she felt 'a little bit not in this world' while taking her medication because her 'reactions aren't quite as in the here and now' [19]. Another participant mentioned that the effects of antipsychotics and the experience of dissociation prevent a person from fully experiencing their emotions. She stated that, in this sense, antipsychotics 'support dissociation' and 'encourage people to avoid the extreme feelings' [5]. This participant reported that she was able to deal with her dissociation by learning to confront her feelings, which was the opposite of the antipsychotics were doing. She said: 'I've found that the best way to deal with dissociation is actually the opposite, is to go to the feelings, feel the feelings and learn a lot of techniques to help me do that' [5]. She described how she was previously unable to feel her anger and thus, she 'would completely switch to this

other personality that can get very angry' [5]. She reported that by learning how to own her experience and feel her anger, she is able to stay in her body.

8.3 No Change in Dissociative Experiences

A few participants reported that antipsychotic medications did not change alter how they experienced specific dissociative symptoms. Participants described a number of different dissociative symptoms that they continued to experience while taking antipsychotics, such as, feeling detached from themselves, perceiving their environment as unclear or unreal and switching to alternate identities. They emphasised that these dissociative experiences were distressing and unhelpful. A few participants mentioned that their dissociative symptoms occurred when they were in specific situations or environments, such as being around large crowds, while others indicated that they would dissociate at random times. To illustrate:

> *Yep I still do. I've had the one where it feels like it's not clear. I still get it now, when I'm walking around. It's mainly when I'm around a lot of people…Yeah, that still happens a lot of the time [4].*

> *Yes, so I actually named it without even realising I'd named it. I said to my doctor one day: I've got this depersonalisation feeling that keeps freaking me out. I said it just feels like I'm standing and all of a sudden, my whole essence goes out of me…But that feeling of being outside of my body happened a lot, a lot in my 20s, it was an awful feeling, just shocking [7].*

One participant specifically mentioned that antipsychotics have not changed how she experiences dissociation, primarily because she willingly changes personas. Unlike the other

participants, this individual emphasised that she has control over her dissociative experiences, as she willingly allows other personas to take control of her body. She reported that she shares her body with these other personas. Thus, changing personas is a choice that has remained uninfluenced by the effects of antipsychotics. She stated: 'Well I, how do I, yeah, I do feel dissociated at times but that's because I willingly swap personas…So, sometimes I do let other personas take control of this body, so we share' [2].

8.4 Uncertain About What's Influenced Dissociation

A few participants stated that they were unsure whether antipsychotic medication altered their dissociative experiences. One participant mentioned that she had not had an out of body experience for some time. She stated that she was not sure whether her medication had prevented these dissociative experiences because she also implemented boundaries and developed other self-management skills. These boundaries have prevented her from being exposed to triggers that might cause her increased distress and, in turn, the need to dissociate. She said:

> *I'm boundaried at the moment; I've set my boundaries. So even just not having a boyfriend is a great thing. They're the kind of triggers that get you to the point where you could do something disastrous and I haven't been that wound up. I've used self-management skills to—yeah, so I can't answer that at the moment [16].*

Another participant stated that she does not think that antipsychotics have prevented the dissociation from occurring, primarily because she did not dissociate and was more present when she ceased her medication. She reported:

It's entirely possible that my medication has helped me with that. I admit I never really thought about that, but I don't really think that it did, to be honest. I think the main reason—because when I spent around a week off my medication I didn't dissociate in the slightest; in fact, if anything, I was more present [19].

8.5 Summary

This chapter has outlined four superordinate themes that describe the effects of antipsychotics on participants' dissociative symptoms. While a few participants reported that antipsychotic medications alleviated their symptoms of depersonalisation and derealisation, others indicated that they experienced no change in their dissociative symptoms while taking antipsychotics. A few participants described mind-altering antipsychotic effects that were similar to their dissociative symptoms, while others indicated that they were uncertain if antipsychotic medications changed their dissociative symptoms.

Chapter 9: General Experiences of Taking Antipsychotics

This chapter outlines participants' general experiences of taking antipsychotic medications. Participants described how they subjectively experienced the emotional, cognitive and physical effects of antipsychotics. They also spoke about the impact that antipsychotics had on their psychotic symptoms. They further described the sleep inducing and lethargic effects of these medications. Participants also shared their ideas about the function of antipsychotics and reported on their experiences of switching between multiple medication types and doses. These experiences and ideas were conveyed through the development of 11 superordinate themes.

9.1 Subdued Emotion

Some participants reported that antipsychotic medication subdued their emotions. Participants reported that they felt emotionally numb and/or were on a constant emotional plateau while taking antipsychotics. They emphasised that antipsychotics prevented them from fully experiencing many positive emotions, such as joy and happiness, and from outwardly expressing emotion. They also mentioned that the suppression of emotion was one aspect of a general mental 'dulling' that they experienced while taking antipsychotics. To illustrate:

> *I felt that the drugs were possibly suppressing the good feelings. So, your spark, that thing that makes you fill with joy…I suspect that the drugs had something to do with that, that they were dulling that as well. I guess they dull everything, so they're going to have that effect on the positive emotions as well as the negative [5].*

I don't know what the word is. I don't know if it's the compassion anymore. I'm not—I don't have that excitement, I don't have that emotion like I used to have, yeah…The medication definitely leaves you on a plateau [9].

I don't think I displayed any emotion. I really don't. I think I was quite—I wasn't negative or nasty to my daughters but I just displayed no emotion good or bad. It was like just an autopilot sort of. I've—in the reaction with the doctor, there was no outward emotion, but it did quite upset me [12].

Yeah, probably a little bit. Numb's probably the right word. Not numb to the point where I can't feel anything, but numb as in emotionally numb a little bit [17].

Some participants indicated that they did not experience specific emotions in the same way that they did prior to commencing their medication. One participant spoke about how the mind-altering effects of antipsychotics changed how he experienced happiness and stated that it was often difficult to recognise when he was feeling happy. He reported:

To be happy, it's hard to feel happy when something is altering it and it doesn't feel like happy was. So, it's a different type of happy and you don't think it's right. So, it's hard to believe it's happy or if it is happy you don't recognise it [14].

Participant 5 mentioned that, while antipsychotics initially helped her by subduing the intensity of distressing emotions, such as fear, she perceived the drugs as a 'temporary solution' because she eventually wanted to fully experience her emotions. She stated: 'I wanted to feel fully my joy especially…I don't think it's possible to feel true authentic joy and bliss on these

medications' [5]. Another participant specifically discussed how antipsychotics prevented her from emotionally connecting with other people and noted that it has become difficult for her to 'access the right emotion at the right time for the right reasons' [16]. She stated, for example, that if she was with her brother, it would be difficult for her to emotionally connect with him as a brother:

> *Your body doesn't have the ability to naturally connect whereas in a normal sense when you're in the room with your brother, you're comfortable in that room because it's your brother, for instance. But you can be in a room with your brother, and I've used brother, I don't know why, but my body doesn't pick up that it's my brother so I might have a sense of fear around someone who I'm normally very safe around. So, yeah [16]*.

This participant also reported that it has become difficult for her to assess the emotions of others and emphasised how she struggles to detect emotional cues when communicating with others. For example, she mentioned that she would often struggle to recognise whether somebody was comfortable talking to her about a specific issue. She stated:

> *Whereas normally your emotions pick up on it—oh, that person is not comfortable, whereas I haven't got that ability to really assess what another person is feeling or if they're unhappy or happy or what have you. Yeah, in fact, I'm a bit subdued to it [16]*.

9.2 An Altered Mind

Many participants reported that antipsychotic medications altered their cognitive functioning. A few participants stated that antipsychotics dulled their thinking, reduced their mental sharpness and/or impaired their ability to think analytically and creatively. As a result

of the impairment in their creative thinking, participants reported that they struggled to find solutions to daily life problems, such as how to pay their bills when experiencing financial difficulty. Further, participants mentioned that they often struggled to comprehend the severity of certain problems while taking antipsychotics. To illustrate:

> *Yeah, there was clarity in contrast to the psychosis. Because things had slowed down, and that was nice for a while. But then I started to notice that it was, yeah, foggy. So initially it was welcomed, and then I—when I felt ready I guess to expand myself again and start to engage in life, that was when I started to notice that I was just not sharp. I lost my sharpness. Nowadays, having been off antipsychotics for two years even though I take PRN occasionally, my mind is so sharp. I can really see the difference when I think back [5].*

> *When I was on a high dose, there was no creative thought, none. It was only when I started to lower it, that I was able to start experiencing creative thought. Creative thought isn't just creative art, it's also creative thinking around living. I can't pay this bill; how can I pay this bill. If you don't have creative thought, you can't pay your bills, because you don't have money. But then you don't have the ability to think ideas, it stops all of that [7].*

> *I really don't think I actually thought at all, I really think the autopilot was, I had absolutely no, no concept of my financial situation. Not a clue on earth…I was doing the autopilot thing and I didn't—just couldn't do very—look into or comprehend or, I guess, have the energy to look into very specific things that took a lot of very precise, analytical thinking [12].*

One participant indicated that—as a result of antipsychotics—it takes him longer to process what the other person is saying in conversations. He also reported that he needs more time to think about what he wants to say to avoid 'talking in circles' [14]. He stated: 'I'm not saying what I mean. I start telling you about something and then get lost in what I'm trying to tell you and I've got to be brought back to what I started with. Yeah, it's confusing me' [14]. In attempting to describe how antipsychotics have made it more difficult for him to cognitively process things, this participant mentioned that it is as if there is a cloud in front of his mind that everything from the environment must pass through before it entering his brain. He said: 'What's happening in front of my eyes and my body it's got to go through the cloud before it goes to the brain and get processed and then it's got to come out of the cloud to react' [14].

Some other participants reported that antipsychotics made it increasingly difficult to concentrate on specific tasks, such as doing a crossword. They mentioned that it was difficult to focus on a specific tasks while taking antipsychotics, primarily because they were constantly distracted by other things and ideas. They described this mental process as something that they had little or no control over. To illustrate:

> *I found it very hard to concentrate. So, it was one of the biggest things that I still suffer from now is my ability to concentrate…So, I'd sit down and think 'okay, well I'll do a crossword', but I just couldn't concentrate, there was just no focus there [10].*

> *Another side effect was that I wasn't able to focus—I wasn't able to focus my mind on things. I was always going off on tangents and things like that. Another one was that I wasn't able to string sentences together properly in my head and verbally then dish it out [11].*

> *I remember the Olanzapine taking control from me. I was—the best I could describe it was a distracted mind where I would have to be really careful tasking myself because I wouldn't complete tasks, and would finish—be halfway through this task and that task and that task all at once. So, I felt that was as a result of the medication doing something with my concentration levels [16]*.

Participant 16 also mentioned that (while taking antipsychotics) specific thoughts enter and exit her mind rapidly; when she considers a particular task, she easily forgets what she was supposed to be doing. She said: 'I might sit down to write an email. Before I even open my emails, I've forgotten what email I'm meant to be doing. Or I'll go into the emails, and…I instantly get lost in them' [16]. She further reported that she can 'lose track in conversation' and that she may not realise whether the other person has finished speaking. She stated: 'I don't warrant or validate it. It's almost like I'm staring at the stars whilst they're talking to me. But I am actually thinking that I'm listening to them but I'm not' [16]. She indicated that it is for these reasons that her 'world needs to be more defined or more grouped or more categorised' [16].

A few participants stated that their current antipsychotic medication has helped them think more clearly and/or maintain concentration on specific tasks for longer periods. These participants also reported that they had more control of their thinking while taking antipsychotics and that their thinking was more organised and less chaotic. To illustrate:

> *Whereas when I'm on antipsychotics things are clearer. My thoughts are clearer and everything's clearer…On antipsychotics for me I'm back in control of my thinking and my life [15]*.

It does help me ruminate less and it helps me kind of slow down my thinking, like so I end up—I'm able to focus on tasks for quite a lot longer...But generally, it's just like my thoughts are just more organised and in a straight line and what I mean by straight line is that one thought leads to another, rather than a whole lot of different thoughts kind of meshing into one that don't really have to do with one another [19].

Participant 19 mentioned that her thinking is also significantly influenced by her environment. If her environment is untidy, dirty and chaotic, then she is more likely to experience disorganised and chaotic thinking. She reported that she is currently in a 'safe environment' and thus, when she is off her medication, her 'thoughts aren't quite as disorganised and aren't as chaotic' [19].

9.3 Impact on Psychosis

All the participants spoke about the effect of antipsychotics on their psychotic symptoms. Some participants noted that their symptoms diminished completely while taking the medication. For example:

I also feel that people were following me. I thought my thoughts were being broadcasted by the general public all the time. I never had something I could call myself in my thinking…The medication did a great job in removing these symptoms [6].

One of those participants stated that while her medication worked well in eliminating her symptoms, they worsened when she took more than the prescribed dose. She reported:

But the Seroquel increased the schizophrenia and the demon things and all that stuff. I thought it would help me sleep peacefully, and that's why I was taking more of it, trying to get rid of the demons and stuff. But it was making it worse [15].

Many participants reported that antipsychotic medications played some role in reducing the frequency, intensity and/or psychological impact of psychotic symptoms. However, these participants did mention that antipsychotics have not completely eliminated their psychotic symptoms, or that they alleviated some but not all of their symptoms. For example, some participants noted that, while their auditory hallucinations diminished, they continued to experience visual hallucinations and/or delusions. To illustrate:

The voices—I haven't experienced the voices, but I've had visual hallucinations since the medication [1].

It's—it hasn't completely gotten rid of the voices but it's reduced it and I can distract myself…Before, it was constant, constant, one second, second, second. Like, say I hear them about 10 times in one minute. Now it's about one time every half hour [3].

No, still pops up here and there, my psychosis is still there, but it's helped me a lot. It's made it—it gets better every time, so it's getting better every day sort of thing…That, I don't really hear anymore. The only thing that I do still go through is when people are talking; I feel like it's about me [4].

They're still there a little bit at the moment even with Solian. Sort of like you go to bed and you're laying down and your mind is drifting trying to go to sleep. Then you hear

a voice going sort of like, not exactly like this, but it's like come and think with me come and talk to me in your mind. Enticing you away. It's like fishing for you [14].

A few participants specifically indicated that antipsychotics stop the initial thought that may lead to psychosis. These participants stated that when they do not take their medication, one thought can easily transform into a series of spiralling thoughts. As a result, they may then experience a psychotic episode. The participants described how antipsychotics prevent the initial obsessive or delusional thought from transforming into a series of spiralling thoughts. They reported:

I don't keep the thought. It's gone straightaway. Whereas when I'm not on the medication, those thoughts get in there and they don't go away. So, my voices in the head start, all that sort of start and that thought could lead into an action which leads into a consequence which can go for a week, a month, a year [16].

I have thoughts that come in but I can—it's like I put a brick wall up and they hit the brick wall and they just bounce back, they just go. If I wasn't on the meds they'd come in, I'd think about them…and they'd be going around and around like a treadmill. But with the Olanzapine like I said it's like there's that brick wall up and it's just bang they hit the brick wall and then their gone. That's probably been the biggest change that I've been able to make and probably one of the main reasons why I take the meds, because it feels so good to have that brick wall up [17].

I get obsessive thoughts, say if it's triggered by seeing a light in the sky, just a light going across the sky. That's the trigger thought. When you're not on antipsychotics,

> *that thought will go - I always call it the steam train of thoughts, so whoo-whoo all aboard, two hours later, you're raving manically psychotic, because of that trigger thought, has just had no time to stop. It just leads in to one thing in to another…The antipsychotics do put a full stop in that thought process, definitely [7]*.

Participant 17 further indicated that he may sporadically experience an invasive thought that goes 'around and around' in his mind like a 'treadmill' while taking antipsychotic medication. However, this participant emphasised that if he does experience a thought that is 'more invasive and gets on the treadmill', he can 'kick it off' and more easily rationalise what he is experiencing. He stated: 'I can rationalise it and say right that's not right, okay we'll assess the situation, what is the appropriate response to this situation' [17].

In her follow-up interview, Participant 16 reported that since the dose of her medication increased, she slept more heavily and heard more intense voices upon waking in the morning. She attributed the increased intensity of her voices to the changes in her sleeping patterns:

> *I just find that too much sleep is not a good thing. You know the voices in my head become—it's like they're rested…Well that's what's happened since they've increased it. So I'm falling asleep, and I'm probably sleeping heavier and I'm waking up pretty early, but with intense voices [16]*.

Participants 11 and 15 reported that while their current medications have been effective in alleviating their hallucinations and delusions, an increase in stress can still exacerbate particular psychotic symptoms. For example, Participant 11 stated: 'Often the day after I've been to see Dad, I'll have a bad day, so the voices become more prominent, and can be debilitating' [11]. With regard to how her current medication influences her psychotic

symptoms, Participant 11 indicated that while she still continues to hear voices, the voices are quieter:

> *For example, when I hear voices, and if I'm not taking medication, it will be like I've got a person sitting opposite me having a conversation. Sometimes they get loud. They shout and scream. With the Solian, it means that they tend to fade into the background as if they're just like a radio going on in the background [11].*

During her follow-up interview, Participant 11 reported that when she becomes unwell and her doctor increases the dose of her medication, the hallucinations (and a number of other side effects) occur more frequently. She stated: 'I get restless hands, restless feet. My lower jaw pulsates. I tend to hallucinate more than what I usually do' [11].

A few participants mentioned that they had previously tried various antipsychotics that were ineffective in supressing their psychotic symptoms. Participants indicated that they did not notice any change in the frequency and intensity of their psychotic symptoms but did experience the side effects of the medication. They reported:

> *Well, when I first started taking the antipsychotic medication it wasn't good at all because it didn't affect me in the way it was supposed to, intended to. It didn't affect my voices. All I got was just the side effects. It wasn't a very pleasant experience. It wasn't until I got on to the Solian that I actually got some relief from the voices, with the Solian, naturally affected them, so in a positive way [11].*

> *Not at all, no. The voices got bad if anything…Didn't really work, no. It was just another altered state of reality I think [14].*

It was that I just kept getting sick. The doctor couldn't figure out what the problem was and so she tried me on different drugs and more different drugs and I still ended up back in hospital. So, they tried a different drug. It just didn't seem to work until the Latuda I just was really unstable, terribly unstable. I was always in hospital. It wasn't working that's all that really happened [15].

A few participants reported that confronting and challenging the irrationality of their psychotic symptoms has been more effective in alleviating these symptoms than their antipsychotic medication. One participant described how he began to resist and 'push his voices away', while another mentioned that she would identify how illogical her delusions were. To illustrate:

Voices changed. It probably just made it—that's when I started to come into a recovery journey and I started to realise that the voices weren't there to help me, that they were negative for so many years. I started to turn my back on the voices. I started to fight them. I started to sort of resist them and push them away in my mind [14].

I found what was more effective was people telling me that what I was believing wasn't true. So, confronting it and just finding how illogical it was or how much it didn't make sense…No, definitely confronting them is like 80 per cent of it and then the medication is like 20 per cent of it…But anyway, it was—it doesn't seem to matter if I'm on medication or not, I still end up experiencing delusions; it's only when I confront them that they seem to go away [19].

Participant 19 reported that her delusions are ‘highly symbolic’ and that they usually represent something occurring in her life. She further described that her delusions are strongly connected to her emotional experience and that she may become so emotional that her ‘emotions kind of manifest themselves into delusions’ [19]. This participant mentioned that antipsychotics can, therefore, influence her delusions by helping her control her emotions. She stated:

> *So, I think what the antipsychotic does, what I feel it does for me is just kind of helps me control my emotions a bit more. But every now and then it comes across a delusion that it’s like too strong that it just doesn’t subdue [19]*.

A few participants reported that antipsychotics alleviated the distress and panic that was associated with the experience of psychosis and generally reduced the effects of specific symptoms. These participants mentioned that antipsychotic medications made their psychotic symptoms less worrying and minimised the priority of specific symptoms. The following two quotations illustrate this point:

> *Yeah, but it’s like with voices, I mean the drugs don’t really stop the voices. I don’t know anyone that that—they just suppress things. They provide some cotton wool, the cocoon again. They provide some insulation from the intensity of it all...It just makes them a little bit less. Not as intense, or not as worrying I suppose, not as distressing. Yeah, but they’re still there [5]*.

The medication does reduce the panic around those things, I will give it that, that's why I'm still on it, because it reduces the panic around it…It lessened their impact and it lessened their priority [7].

Participant 7 further reported that antipsychotics prevent her from being consumed by particular hallucinations. She often heard an orchestra playing beautiful music and if she had not taken medication, her 'creative brain would take it to new realms' [7]. While taking antipsychotic medication, the music was broken into segments and thus, she did not focus entirely on the music. She said: 'But when you're on meds, it puts a full stop on it; so I hear the music and stop. Then it's like it's cut in to segments, rather than steam train all the way to whacky land' [7].

One other participant mentioned that she continued to hear voices while she was taking antipsychotic medication. She mentioned that the only time that her voices may have decapitated was when she was on extremely high doses of the drug. She indicated that while taking 'mega high dosages' [12] of antipsychotics she wasn't able to comprehend whether she was or wasn't hearing voices. She said, 'I just didn't have the comprehension to know if they were there or not. I wasn't aware of them' [12]. This participant reported that she had heard voices since she was a toddler and that hearing voices was a part of who she was and how she understood her environment—which is likely why the medication did not eliminate the voices fully. She stated:

No, and I think part of that was because I always had that. From a little kid…It was like a thing. It was always part of my knowledge of the world. It was part of my every day experience of life [12].

This participant reported that antipsychotics prevented her from harming herself and others. For example, she mentioned that, at one stage, she believed that a building was calling her and telling her to climb it and jump off with someone else. She reported that she did not have the energy and urge to act on these thoughts while taking antipsychotics:

> *Well, I didn't have the energy to do it. It didn't—yeah I just didn't—I guess the urge to do that was gone and even if the urge hadn't gone, I just did not have the energy to do that. That's what I saw the purpose for me of the drugs were, not so much to protect myself but to protect other people [12]*.

Another participant mentioned that medication has worked intermittently during recent years. She reported that her hallucinations sporadically either subsided or intensified. She indicated that this was frustrating and difficult, as she is sometimes distressed by the hallucinations. She stated:

> *At the start, it didn't work for about two months, so it took about two months to kick in. So, I was hearing voices and seeing things that weren't there. Then, after that it started working...The voices and hallucinations kind of subsided, but not completely. After about a year or so, it stopped working. But they didn't increase the dose. Then, for some reason it started working again and it worked for a few years and then just before I saw [name of case manager], it had stopped working [18]*.

One participant reported that despite trying four different second-generation antipsychotics, she has continued to experience visual hallucinations. She stated: 'My hallucinations, one of them has, because I have two different types, one of them has lessened

but the other one hasn't; it's a new one that just appeared afterwards' [2]. Another participant mentioned that, while he was informed by medical professionals that antipsychotics would alleviate his psychotic symptoms, his symptoms actually worsened when he commenced medication. He reported:

> *I—yes, as I was saying, that emotionally and mentally it was a heightened sense of it all, rather than what I was led to believe that it would sort of—not necessarily nullify, but reduce and manage those symptoms, that it actually increased them [10].*

9.4 Induce Sleep

Many participants discussed how antipsychotic medications induced sleep. Some participants specifically reported that antipsychotics helped improve their sleep, and indicated that sleep was crucial in maintaining their mental health. Participants described a number of different ways in which antipsychotics were used to specifically assist them in improving their sleep, such as taking a delayed-release tablet a few hours before going to sleep or an immediate-release tablet just before going to bed. The following three quotations illustrate this point:

> *So, I was put on quite a mild dose and I would say it alleviated some of the anxiety and helped me sleep. So, I've definitely experienced some of the advantages of it. I think sleep is so critical when you're going through psychosis. You have to sleep. That is one of the gifts of antipsychotics, they help you get to sleep, they calm everything down [5].*

> *I've been struggling a bit with sleep. Like being really—I'm getting enough sleep, but I've been really restless and waking up and that throughout the night, and waking up really early before the sun rises and not being able to go back to sleep and stuff…That's*

why he increased my Seroquel. It's a fast release one. I had my first dose of it last night, and I slept heaps better [8].

Because it's slow release it goes over a couple of hours or whatever so by the time I actually go to bed, I'm actually ready for bed. I tend to sleep better if I have that eight o'clock dose. I tend to sleep better. Obviously if I don't sleep then there's a bigger chance of mania and stuff happening so I definitely try to sleep [15].

One participant mentioned that while her medication helped her to fall sleep, it made it increasingly difficult to get up early in the morning. She stated:

It definitely helps with sleep, yeah, definitely. It almost helps me sleep a little bit too much, I often find it hard to get up in the morning a little bit. When I'm off my meds and I've watched my diet, I usually get up around 7:00 AM. When I'm on my meds I get up around 10:00 AM, 10:00 AM, 9:00 AM, depending on the environment that I'm in. So yeah, I find it a lot harder to get out of bed [19].

Some participants complained of excessive antipsychotic-induced sleepiness. One participant stated: 'I remember just sort of pacing, walking a circle around the mental ward for hours on end. Then I'd just get exhausted, and then I'd just sleep for 24 hours' [10]. A few participants described how the excessive sleepiness caused by antipsychotics prevented them from doing basic daily activities and/or effectively communicating with other people. This point is clearly illustrated by the following four quotations:

The first medication I took made me sleep quite a lot, and I - that wasn't helpful because I was still going to school then. It made me—I wasn't as productive as I could be, and it made me really tired also…Yeah, it was really hard because I'd be asleep. I'd sleep throughout the day and then wake up, and sometimes I wouldn't even have a day because I would go to sleep at night and wake up at night; that's how long it would make me sleep [1].

Just sleeping, so sleeping day in day out, day in day out. I had a dog and I had to put a doggy door in the back door, so my dog could actually go out to the toilet, because I wasn't able to actually stand up [7].

I mean the minute I sat down I was asleep. I would fall asleep talking to people…if I wasn't standing up I was asleep. Even, you know, and it was really rude. Someone would be talking to me and I was asleep. It wasn't—yeah it just kind of—it happened [12].

Yeah, well at first—well, when I was discharged from hospital, I think it made me really drowsy, so I couldn't stay awake and do things [13].

Participant 7 further reported that her long-term antipsychotic use had left her unable to sleep without them; she was now dependant on antipsychotics. She stated: 'Yeah, so I can't sleep without Seroquel now, because once you're on Seroquel you can't sleep if you don't take it' [7]. Participant 13 mentioned that she initially took her medication in the morning. As a result, she experienced the excessive sleepiness throughout the day, which prevented her from completing tasks. This participant indicated that she now takes her medication at night and has

noticed an improvement in her ability to function during the day. She said: ‘Yeah, like I’m not—I take it at night now so then I don’t fall asleep during the day because before I took it in the morning, yeah’ [13].

Another participant mentioned that, while her current oral medication has improved her sleep, she previously experienced excessive sleepiness on a higher dose of a depot antipsychotic. This participant indicated that the excessive sleepiness impeded her ability to maintain and form meaningful relationships: when people visited her, she was always sleepy and unresponsive. Therefore, her friends found her different from her normal talkative self. She reported:

> *Because the way I’d come across and the way I would be and my presence, it would just put a damper on it, and people would see me as different and stuff…and I was always sleepy and so, the quality of the relationship wasn’t there [13]*.

Participant 16 indicated that since the dose of her medication increased, she began sleeping ‘heavier’. She stated that this is ‘not a good thing’ [16], as she is now hearing more intense voices, which she attributes to the change in her sleeping patterns (see Section 9.3).

Participant 17 stated that he sometimes oversleeps while taking antipsychotics. However, he does value his sleep and has accepted this as a side effect of the medication. It is for these reasons that he did not complain of excessive sleepiness and said: ‘I can sleep 14 hours if need be or longer perhaps. But they’re just the side effects of the medication. I’ve got to live with it…I’m the type of person who enjoys sleep anyway’ [17].

9.5 Lethargic and Unmotivated

Some participants indicated they felt lethargic and lacked energy while taking antipsychotic medications. Participants reported that they were 'knocked out' by antipsychotics and that their medication induced a lethargic state that was like being 'stoned'. The term 'zombie' was often used by participants to describe an extreme state of lethargy that made it increasingly difficult for them to engage in meaningful activities. This point is clearly evidenced by the following three quotations:

> *So, I came into hospital; it was for the first time given high doses of antipsychotics, and I remember being wiped out for a couple of weeks. My husband was freaking out because I turned into a zombie [5].*

> *So, for the last 12 months I've been on the depot and it knocked me out and I was really, like really stoned all the time and slow…I was like a zombie on it [8].*

> *You know, they'd force me up, but I was just so lethargic…My general recollection was that it basically turned me into a bit of a zombie, if you like [10].*

Participant 12 emphasised that she was barely able to function while taking high doses of antipsychotics and that this was because her medication had virtually turned her into 'a living zombie'. She described herself as being on 'autopilot', whereby, out of core necessity, she completed only the most basic daily tasks. She said: 'I went to work, sat at my desk, when the time came went to pick the kids up. It was truly an autopilot' [12]. This participant further indicated that she did not 'have the energy to look into very specific things that took a lot of very precise, analytical thinking' [12] and that it took her hours to complete everyday tasks.

She stated, for example, that washing a few dishes was like ‘running a marathon’ and described how she could only wash a few dishes at time and had to take constant breaks:

> *I had to do the dishes and I just had no energy, none. What I would do, and that’s really sad but it was the only way I could do the dishes, like I would do—wash two dishes, put them on the drainer, and doing those two dishes…was just so, so hard. Then I couldn’t do the next dish and I had a chair in the kitchen and I sat down and I timed that I only sat down for five minutes and although I couldn’t and I didn’t have the energy I got up and I did the next two dishes and then do my five minutes sitting down. You can imagine how long the bloody dishes took [12]*.

A few participants emphasised that when they were extremely unwell, they needed to be sedated by antipsychotics. One participant stated that she had ‘a big psychosis about a year ago’ and that she ‘needed to be really sedated’ [8] as a result. Another participant indicated that, when she was experiencing a psychotic episode, ‘everything was happening rapidly’ and she was ‘out of control and very frightened’ [5]. Consequently, she was prescribed high doses of antipsychotics to calm her. She said: ‘I was knocked out. I don’t even really remember that time myself, yeah. Because they had to put me on very high doses to calm me down from that state’ [5].

Participants further reported that they have not felt motivated to engage in specific activities while taking antipsychotics. One mentioned that while the medications have helped her ‘relax and just kind of let things flow’ [19], they have also decreased her motivation to study. She said: ‘When I’m off my medication, I feel more motivated to study and I feel kind of more productive in a way because I feel more of a drive to do homework’ [19].

9.6 Adverse Physical Effects

The participants all reported experiencing varying adverse physical effects of antipsychotic medications. Many stated that they gained a significant amount of weight since commencing their medication; their 'appetite increased' and they were 'hungry all the time'. They mentioned that this weight gain was difficult to control and had a negative effect on their self-worth. Participants specifically reported that Olanzapine [Zyprexa] caused severe weight gain. These points are evidenced by the following four quotations:

> *Weight gain, so I went from about 60 kilograms to 120 kilograms within a year…Yeah and going through a 60-kilo female with a little bit of self-worth and trying to find your way in the world, to an absolute overweight, non-gendered blob, is what I used to call myself. Just completely destroying, soul destroying [7].*

> *I was on Zyprexa for a long time and I was quite thin and then I put on 30 kilos in two months on that medication. I will never touch that again. That's so bad for weight gain [8].*

> *The previous ones like Olanzapine I put on a lot of weight. Like about 20 or 30 kilos. It's got a side effect of eating a lot. I don't think it really helped me that mentally [14].*

> *Killer weight gain. Absolutely killer. I put on more weight on Olanzapine than with any other drug. Like about 30 kilos [15].*

Some participants on antipsychotics indicated that they experienced movement difficulties, such as: 'restlessness' [4], 'muscle stiffness' [5], 'twitches' in the arms and eyes

[10], ‘twitching in the face’ [14] and ‘a pulsating jaw’ [11]. One participant stated that her muscles would ‘turn to concrete’ and ‘shut down’ [7]. She mentioned that she was in ‘extreme agony’ and thus, would struggle to get up and do basic everyday tasks. She said: ‘If I did go up to go to the toilet, I’d actually collapse or just walk in to the wall. In the end, I just went in the toilet in my bed and dealt with it later’ [7]. Many participants also reported experiencing other adverse physical effects of antipsychotics. These included: drooling, eyesight problems, tachycardia, involuntary upward deviation of the eyes (oculogyric crisis), loss of libido, excessive perspiration and a dry mouth.

9.7 Perceived Function and Usefulness of Antipsychotics

During their interviews, many participants spoke about the general function of antipsychotics within the context of their lives. Participants reported that while taking antipsychotics was ‘helpful’, they also had to tolerate some distressing side effects. They described how antipsychotic treatment is ‘never going to be perfect’ [15] and that the adverse effects of antipsychotics go ‘hand-in-hand’ [17] with their beneficial effects. Participants mentioned that when they experienced a severe deterioration in their mental health, taking antipsychotics was ‘necessary’ as they had no other option. Therefore, they made the choice to continue taking their medication despite experiencing distressing side effects. These points are illustrated by the following four quotations:

> *Helpful—been helpful, but it’s also been very—I would say annoying, because of the side effects that I get from it. It makes me irritable; I get a bit drowsy, I can’t stand still, I guess I get restless as well. Yeah, just those side effects mainly [4].*

That was probably about five or six years of hell as well, with the side effects of the Seroquel, but I persevered, because if I didn't take it, I would be dead. It's bittersweet…But the main thing why I stayed on it, was because it didn't cause the oculogyric crisis, that's the main reason why I stayed on it. Because I was absolutely petrified of that happening [7].

You might need to rely on the fact that you are going to be slightly impaired in some ways or it's going to have slight side effects and whatever and that's just sort of the price you pay. [11].

No, I mean it was the only way that I could survive. The point at which like, you know, do I take them and walk around as a vegetable, but at least I can feed my kids [12].

A few participants reported that while antipsychotic medications may assist them in managing their illness by supressing acute symptoms, they cannot help them heal from certain experiences, such as childhood trauma. They emphasised that illness management is something different from healing and reported that an individual must address the underlying cause of their illness to heal. One participant stated, for example, that while antipsychotics were 'muffling' her 'suicidal depression', they did not address the 'underlying causes of what was going on' [7]. She mentioned that many of her mental health issues were the result of certain experiences and that 'you can't cure experience, but you can heal from it' [7]. Another participant reported that, during the acute phase of her psychotic illness, antipsychotics did play 'an important role' [5] in that they alleviated her severe anxiety and helped calm her. However, she indicated that once she felt stable and 'a bit more normal' [5], her 'intuition was demanding healing' and she knew that 'healing wasn't going to come from a pill' [5]. This participant

realised that her psychosis had happened for a reason and that she needed to ‘pay attention to it’ [5] and explore what it meant by doing the relevant psychotherapeutic work. She further mentioned that, even while taking antipsychotics, many people continue to experience specific symptoms, primarily because their psyche is demanding healing. She reported:

> *But unless I think you’re taking the 800 milligrams or the very high doses, which did seem to stop everything, the psyche has its own way of just busting through all of the stuff and going, ‘I want healing and I want your attention’. So, that’s why I believe that there’s a persistence of symptoms for anyone who’s on these things for long term [5]*.

Participant 5 further mentioned that learning how to successfully manage her distress without the use of antipsychotics has been ‘empowering’. She stated that ‘not having to look for external things’, such as antipsychotics, to deal with certain distressing experiences has made her feel as though she is ‘not a helpless victim’ and reinforced a ‘sense of sovereignty’ [5]. She also mentioned that ‘there’s a connotation that comes with meds as well of, oh, you’re broken now and you need a pill to fix you’ [5]. She described how this originates ‘from the medical model, the pathology model, of physical disease’, whereby a person is perceived as having a disease that requires treatment with a specific medication. She indicated that this is ‘disempowering’, as it does not allow the patient to ‘make the leap of, oh well, I can do this without the meds’ [5]. This participant discussed a particular situation wherein her doctor stated that his intention to ‘poison those voices’ [5], implying that he would prescribe an antipsychotic that would eliminate her auditory hallucinations. She mentioned that, while he had good intentions because her voices were distressing, he was unable to ‘interpret the voices’ as messages of her ‘internal distress’ and help her ‘sit with that pain’ [5].

Some participants reported that antipsychotics relieve the distress that is associated with specific experience and thus, can be a good short-term intervention. Participants stated that antipsychotics are like a 'Band-Aid' in that they temporarily alleviate acute symptoms but do not cure mental illness or address its underlying causes. They emphasised that, while antipsychotics are not a long-term solution to presenting mental health problems, they can, for some people, be a valuable tool in their 'mental health toolkit' [12]. To illustrate:

> *I feel medication is a bit of a Band-Aid. I think it's needed in short term situations, but I feel people need to address their trauma, that sort of thing, to really move on [9].*

> *Sometimes you have to have the Band-Aid before you can deal with what's under it, if that makes sense…To me it's like they give you the opportunity to get better in the short term if the side effects aren't too bad…Yeah, it's not the long-term solution, but for some people like, you need like a mental health toolkit, and there's lots of things in that [12].*

> *Definitely numbing is the word I'd use and, yes, not really dealing with the root of the problem which is different for everyone you know [14].*

> *I would probably just say that medications, they're like a Band-Aid. I suppose my journey and what I'd like to work on more in the future is my own baggage. Medications are great because they're the antiseptic cream or the Band-Aid…but the healing has to come from inside doesn't it. When you cut yourself, you put a Band-Aid on but it's not the Band-Aid that heals the cut is it; it's the body that heals it [17].*

Some participants emphasised that mental health is not achieved through medication alone but rather, through a combination of equally important factors that include: antipsychotic medication, counselling or psychological therapy, community engagement, the 'right' attitude, a desire to find help, faith (religion or spirituality), exercise, no illicit drugs, time with pets and distraction strategies. This is evidenced in the following four quotations:

> *You can't expect antipsychotics to remove psychosis completely. You've got to also be able to be active in the community. You've got to be able to connect to the community, and you've got to make yourself be a valuable source of the community. Doing something meaningful that can be meaning to you, and productive…Yeah, and also being able to participate in some of the aspects of religion that they do. The confession, communion...That's been therapeutic for me [6]*.

> *For me, what it comes down to is my faith and my attitude and being obedient with medication and preserving with it. They're the three things that have made me be able to move forward and not let it get in the way. I'm a big one for no excuses. There's always some help and there's always support and there's always things you can do [8]*.

> *I do think that it is just—well, regardless of what type of illness it is, that you have to have a holistic approach…good social involvement is really important and things like having pets and all of that [12]*.

> *The way the medication works, that I'm going to need to take medication for the rest of my life, that's just the way it's going to be. But I think I can do things, like the CBT and emotional intelligence and rationalising my thoughts and things like that, I think I can*

do things like that that will help. So for me it's a compounding sort of thing. The medications and my own way of working, when I mix the two together things are really good [17].

9.8 Injection Medication is Horrible and Invasive

One participant spoke in detail about how depot injection medication was 'horrible', 'painful' and 'embarrassing' [17]. This participant described how 'the initial side effects of injection medication are more intense…than oral meds' [17]. He said: 'So on oral meds, I might be five or 10 kilograms overweight and a little bit tired. On injection medication I'd be 10 to 15 kilos overweight and tired all the time' [17]. He mentioned that it was extremely 'invasive' to have 'a bloody needle shoved in your butt once a fortnight' [17]. He also indicated that 'things are up and down like a bloody roller coaster' [17] while taking injected medication. He reported:

So, the first two or three days after the injection, I'd be blue, like the medication would spike but my mood would go down. Then it would be five or six or seven or more days of picking myself up and getting going, then four or five days of 'yeah okay this is reasonable' [17].

This participant further mentioned that throughout the first 10 years of his illness, receiving a depot antipsychotic was often 'married' with his experience of numerous 'brutal' involuntary hospitalisations that 'are still hard to talk about' [17]. He reported that once every six months there would be an instance where he would be pinned down in the isolation ward by numerous 'heavy psych nurses' [17] and injected in the buttocks with a 'tranquiliser' [17].

9.9 Changing Medication Type and Dose

Most of the participants discussed their experiences of changing their medication type and/or dose. Many participants tried multiple antipsychotics before finding a medication that worked, and/or that did not cause severely distressing side effects. This is evidenced in the following four quotations:

> *I have a lot of side effects from medication, so I've had to swap a lot…I went from Quetiapine to Aripiprazole and that was the one that gave me a lot of muscle spasms, bedridden me. Then I swapped to Risperidone and that gave me a lot of the embarrassing ones [embarrassing side effects] and now I'm on Asenapine [2].*

> *I was on some awful, awful medications with some awful side effects. They pretty much ruined my life for about 10 years, the side effects themselves. It wasn't until I got on to the Seroquel trial in 2000, that things started to improve, in terms of medication. Not just the symptoms but the actual medication itself [7].*

> *Well, when I first started taking the antipsychotic medication it wasn't good at all because it didn't affect me in the way it was supposed to, intended to. It didn't affect my voices. All I got was just the side effects. It wasn't a very pleasant experience. It wasn't until I got on to the Solian that I actually got some relief from the voices [11].*

> *The doctor couldn't figure out what the problem was and so, she tried me on different drugs and more different drugs and I still ended up back in hospital…It just didn't seem to work until the Latuda I just was really unstable, terribly unstable. I was always in hospital [15].*

Many participants mentioned that they have often altered the dose of their antipsychotic medication, some against medical advice and others with the support of their doctor. Participants indicated that they experienced an illness relapse or an exacerbation of particular symptoms when they reduced their medication dose. For some, these relapses were reminders that they needed to continuously take their antipsychotic medication. One participant said: 'I've trialled coming off it and then I've relapsed. Through this experience of relapsing, it's made me realise the need to remain on the medication and its importance and its significance to my health, yeah' [6]. Participants indicated that they were prescribed higher doses of antipsychotics when experiencing a crisis that might exacerbate their symptoms or an event that could cause prolonged distress. One participant indicated that she was currently 'a direct witness to the royal commission' into institutional responses to child sexual abuse and, as a result, has 'rehashed trauma' [16]. She emphasised that this has caused her distress and thus, the dose of her antipsychotic medication has been increased.

Some participants mentioned that they were able to significantly lower their medication dose or discontinue antipsychotic maintenance treatment without relapsing. One participant reported successfully discontinuing her antipsychotic maintenance treatment by learning non-pharmacological 'coping strategies' and 'distress tolerance' [5]. Another participant indicated that she was able to reduce the dose of her medication within three to four years by 'learning the patterns' of both her illness and 'the pills' [7]. However, this participant mentioned that it was her dog that initially made her question whether she 'was on too much medication' [7]. She described how she came to realise that the dog required care and that she could not be 'sleeping day in day out' [7] as she was while on extremely high doses of antipsychotics. She also reported that the sedative and sleep-inducing effects of Seroquel made it difficult for her to get up and take the dog for a walk. This made her question whether she should be trusting the doctors who prescribed high doses of antipsychotics and she began to consider the

possibility ‘that actually things could be different’ [7]. At that point, she began to gradually reduce the dosage of her medication without the support of her doctors, who considered her ‘non-compliant’ [7].

A few participants reported that they have been prescribed two or more different antipsychotic medications, of which at least one is used as a form of maintenance treatment, while the other is a PRN medication. The participants indicated that they use the latter when, for example, they experience ‘strange thoughts’ [16] or ‘when the voices start to get out of control’ [11]. Participants also mentioned that they take an additional pill before and/or after a stressful event, as this can prevent or alleviate symptoms that may be exacerbated by situational stress. One participant stated that while her ‘father caused all the trauma’ in her childhood, they still ‘visit him on a regular basis’ [11]. She reported that she feels ‘anxious prior to’ visiting him and her ‘anger and anxiety levels go up’ [11] when she is with him. She also stated that she is ‘very vulnerable to having more voices and anxiety’ [11] immediately following the visit. In an attempt to alleviate her anxiety and the frequency of her voices, this participant reported that she takes an additional antipsychotic before and after visiting her father. However, she mentioned that this ‘doesn’t always work’ and described how the day after the visit will often be a ‘bad day’ when the ‘voices become more prominent’ and ‘debilitating’ [11].

Another participant who was able to successfully discontinue her antipsychotic maintenance treatment reported that she now only takes an antipsychotic when she goes ‘through periods of crisis’ [5]. She mentioned, for example, that she took Zyprexa for a period of seven days after a recent hospital admission to ‘have a smooth landing at home’ [5] before going ‘off it again’ [5]. This participant further explained that because she may ‘end up relying on Valium too much’ and is ‘worried about addiction’ to benzodiazepines, she is ‘using Zyprexa instead’ [5]. This participant also reported that tries hard to ‘just go to sleep naturally’ [5] even though she has been ‘told to use it [Zyprexa] for sleep’. She indicated that using

Zyprexa to deal with her insomnia ‘has a price’, as she ‘can’t wake up very easily the next day’ [5].

A few participants reported that being mentally healthy is largely dependent upon taking the correct combination of psychiatric medications, which may include an antipsychotic, an antidepressant and a mood stabiliser. Participants indicated that finding the right combination of psychiatric medications has been a challenging process, primarily because they would continue to become unwell and/or experience severe side effects. One participant said: ‘It’s been hell actually to be honest. It’s been hell trying to get the right combinations, that’s what we’ve been trying to get and we seem to finally have it now, which is amazing’ [15].

9.10 Uncertain About What Caused Change

Many participants reported that they were uncertain about whether antipsychotics altered or caused particular symptoms. One participant described feeling ‘more anxious’, gaining ‘a bit of weight’ and being ‘a lot more scared to do things’; however, she is unsure whether ‘that’s because of the medication’ [13] because she was ‘disorganised for a long time’ and cannot ‘remember a lot’ [13]. She indicated that it is difficult to remember when she ‘was in hospital’, ‘what the symptoms were’ and when she ‘started taking the…antipsychotic medication’ [13].

A few participants reported that a combination of different psychiatric medications, including antipsychotics, may have caused certain adverse physical and psychological effects. They further reported that it was difficult for them to determine whether particular experiences were symptoms of their illness or side effects of their antipsychotic medication. This point is evidenced in the following four quotations:

So, it kind of confuses you; it makes you feel, is it my medication or is it my psychosis sort of thing. It's really hard to—if you're trying to understand what's going on, it's really hard because you don't know what it is: medication making you agitated and irritable, or the—your psychosis [4].

So, it's hard to know whether it was the antipsychotic drugs that were making me depressed, or if it was just the natural cycle of psychosis...I really had a lot of trouble multitasking on the medication...Memory was pretty bad as well. But again, I attribute both of those things—trouble multitasking, and also memory—to partly the psychosis. So, it's hard to untangle which is which [5].

I don't retain things as well as what I can…but I don't know if that was through just being unwell, but I don't know if that is a side effect of the antipsychotic medication [9].

Sometimes I go from one sentence to another sentence very quickly. It does—sometimes, what I say doesn't make sense...I'm not sure if it's from the medication or from what I'm going through [18].

Another participant mentioned that while her general recollection of her experience with Olanzapine was 'really bad', she was 'unsure how bad the drug was due to other things happening' [16]. She stated that, while taking Olanzapine, she had a 'marriage breakdown' that would have been 'very traumatic for anyone' [16]. She also reported that she was 'very young' and that her life consisted of some 'very intense aspects' [16]; therefore, she stated that it could have 'been all of that put together that caused' her 'bad experience' [16].

9.11 Use of Metaphors

During their interviews, many participants used metaphors to describe the subjective effects of antipsychotic medications. A more detailed description of these subjective effects is provided within the subsections of the relevant themes. Participants often used metaphors to describe the extreme lethargy that they experienced while taking antipsychotics. For example, they stated that this lethargic state was like being ‘high’, ‘stoned’ or a ‘zombie’. One participant specifically mentioned that she was on ‘autopilot’ [12], inferring that she effectively had no awareness of her environment and was mechanically completing only the most basic daily tasks. Another participant used the phrase ‘chemically restrained’ [16] to describe how antipsychotics had prevented her from being physically active and mentally astute.

Some participants used metaphors to describe the function of antipsychotics and how these medications are helpful. They reported that antipsychotics were like a ‘Band-Aid’ in that they may temporarily alleviate acute symptoms but do not address the underlying causes of mental illness. Participants emphasised that antipsychotics can be a valuable ‘tool’ in their ‘tool box’ [14].

Participants also used metaphors to describe how antipsychotic medications influenced their psychotic symptoms. For example, one participant stated that antipsychotics put a ‘full stop’ [7] to the initial thought that may lead into a series of spiralling psychotic thoughts.

A few participants also used metaphors to describe how antipsychotics influenced their trauma-related experiences. One person reported that antipsychotics have changed the way he viewed his trauma, and that this is like viewing it through ‘one of those tinted glass bottles’ [14]. He also mentioned that his trauma is ‘amplified’ while taking antipsychotics and that this akin to examining it through ‘a magnifying glass’ [14]. Another participant who mentioned that antipsychotics subdued her emotions, stated that her medication served as a ‘cocoon’ that

offered her rest from the ‘extreme emotions’ that she experienced while doing trauma therapy [5].

9.12 Summary

This chapter has outlined 11 superordinate themes that describe participants’ general subjective experiences of taking antipsychotic medications. Many participants mentioned that antipsychotics subdued their emotions and/or impaired their cognitive functioning. Participants reported that they were unable to think analytically and concentrate on specific tasks. In contrast, other participants indicated that their current medication helped them think more clearly and concentrate for longer. All study participants experienced at least one adverse physical effect of antipsychotic medications; the most common were weight gain and movement difficulties (restlessness, physical stiffness and tremors). Nevertheless, many participants reported that antipsychotics reduced the frequency and/or intensity of their psychotic symptoms. Participants indicate that they had tried many different antipsychotics before identifying a drug that was effective in alleviating these symptoms and/or did not cause intolerable adverse effects. Some participants reported that antipsychotics improved their sleep, while others complained of excessive sleepiness. Further, some also reported feeling lethargic, unmotivated and lacking energy. Participants discussed the general function of antipsychotics and mentioned that, while antipsychotics were helpful, they induced distressing adverse effects. Further, the participants emphasised that while antipsychotics can help a person manage their illness by reducing symptoms, they cannot help them to heal from difficult experiences, such as trauma. Thus, the participants differentiated between illness management and healing. Many participants reported that they were unsure about whether their medication changed or caused specific symptoms. Participants often used metaphors to describe the effects of antipsychotics.

Chapter 10: Discussion

This chapter discusses this study's findings in relation to the primary research question: How do people with psychosis and a history of ICT subjectively experience the effects of antipsychotic medications? In the first section, participants' trauma severity and clinical complexity are evaluated in relation to the research presented in Chapter 2. The second section discusses the qualitative findings presented in Chapters 7–9. Some of these findings relate to subjective antipsychotic effects that have already been extensively researched and/or discussed in Chapter 3. Therefore, these generally well-known findings are only briefly discussed or are not mentioned in this chapter. The discussion within this chapter focuses on the most innovative findings that specifically relate to how traumatised individuals experience the effects of antipsychotics. This is achieved through an exploration of the following subsidiary research questions:

1. How do people with psychosis and a history of ICT subjectively experience the effects that antipsychotics have on their emotional, cognitive and physical states?

2. How do people with psychosis and a history of ICT subjectively experience the effects that antipsychotics have on their 1) thoughts, images and/or memories, 2) emotions and 3) physical responses, related to their childhood abuse/neglect?

3. How do people with psychosis and a history of ICT subjectively experience the effects that antipsychotics have on any dissociative states (depersonalisation and derealisation)?

10.1 Participants' Clinical Complexities and Trauma Experiences

The majority of participants in this study appeared to have experienced complex trauma, in that their abuse and neglect was ongoing and committed by parents, guardians and/or family members. With regard to trauma severity, information obtained via the CTQ, LEC and semi-structured interviews demonstrated that the study included a sample of highly traumatised participants. Interestingly, a greater number of participants reported experiencing a physical assault or unwanted sexual contact on the LEC than on the CTQ. This may be because some participants only experienced particular traumas during adulthood. Throughout their semi-structured interviews, participants also described (or made some reference to) different traumatic events that they experienced during adulthood. For example, one participant described how she was held hostage, while a few others mentioned that they experienced extremely distressing involuntary hospitalisations. Thus, it is evident that many participants in the study experienced some degree of re-victimisation. This finding is consistent with prior research demonstrating that childhood trauma is a significant risk factor for experiencing subsequent traumatic events (Anderson, Howard, Dean, Moran & Khalifeh, 2016; Coid et al., 2001; Noll, Horowitz, Bonanno, Trickett & Putnam, 2003; Widom, Czaja & Dutton, 2008). While a formal diagnosis was not made by the researcher, 10 participants reported that they had previously been diagnosed with PTSD. Further, during their semi-structured interviews, participants provided detailed descriptions of how they continued to relive past traumatic events by experiencing trauma-related thoughts, flashbacks and dreams. According to the DSM-5, these trauma-related memories would be considered intrusive symptoms of PTSD (APA, 2013). In this regard, participants' qualitative accounts further consolidate, to some degree, their self-reported diagnosis of PTSD.

This study found that participants experienced a multitude of nonpsychotic symptoms, including: depressed mood, anxiety, insomnia, suicidal ideation, depersonalisation and/or

derealisation. This finding is consistent with the evidence evaluated in Chapter 2, which showed that, among people who have experienced psychosis, those with a history of ICT present with a more complex clinical profile. Many of the quantitative studies reviewed demonstrated that, in addition to being diagnosed with a psychotic disorder, there is an increased likelihood for these individuals to experience PTSD, dissociation, depression, mania, suicidal ideation, increased substance use and cognitive impairment (Braehler et al., 2013; Calhoun et al., 2007; Mohammadzadeh et al., 2019; Tomassi et al., 2017; van Nierop et al., 2015; Vargas et al., 2019). A number of participants also reported that they had experienced five or more psychiatric impatient admissions. This may be due to them experiencing more severe or persistent psychotic symptoms and other comorbid mental disorders. This premise is supported by research demonstrating that the risk of rehospitalisation increases in people diagnosed with psychotic disorders when they have experienced: previous psychiatric hospital admission, co-occurring substance use disorder, more severe positive symptoms and/or illness exacerbation (Doering et al., 1998; Lieberman et al., 2005; Olfson et al., 1999; Olfson, Ascher-Svanum, Faries & Marcus, 2011).

Therefore, it is evident that participants in this study had highly complex clinical profiles (a multitude of nonpsychotic symptoms, including dissociation, severe hallucinations or delusions, severe ICTs and possible re-victimisation or additional traumas throughout adulthood). As will be demonstrated in the following section, this clinical complexity played an important role in how the participants subjectively experienced the wide-ranging psychological effects of antipsychotic medications.

10.2 Participants' Subjective Experiences of Antipsychotic Medications

10.2.1 Effect on Trauma Memory

A subsidiary research question of this study was to explore how people with psychosis and a history of childhood trauma experience the effects of antipsychotics on their trauma-related thoughts, emotions and physical responses. That is:

> Subsidiary research question: How do people with psychosis and a history of ICT subjectively experience the effects that antipsychotics have on 1) thoughts, images and/or memories, 2) emotions and 3) physical responses, related to their childhood abuse/neglect?

A key finding of this study was that antipsychotic medications did alter how the majority of participants experienced memories of childhood trauma. However, there were substantial differences between how antipsychotics altered participants' trauma memories. Some participants indicated that their medication alleviated the frequency and/or intensity of distressing trauma-related thoughts, emotions and/or physical symptoms—and considered this helpful. In contrast, while taking antipsychotics, other participants experienced more intense or frequent flashbacks, thoughts of past traumatic events and/or physiological symptoms of anxiety. These experiences were described as distressing and unhelpful. Some participants emphasised that while their medication may have altered one particular aspect of their trauma memory, they did not experience meaningful positive change in other symptoms or experiences. For example, a few participants reported that, while antipsychotics alleviated the intensity of trauma-related emotions, they continued to experience physical symptoms, such as tremors or a rapid heart rate, when exposed to specific triggers. With regard to emotion, participants most often reported a reduction in emotional intensity. When questioned about physical responses, the participants often described changes in the frequency and intensity of

their anxiety symptoms (e.g., rapid heart rate, tremors). For a few participants, these anxiety symptoms continued to be triggered by external cues (e.g., speaking with an abuser or discussing childhood trauma), even while taking their medication. The participants frequently described the connections between trauma-related thoughts, emotions and physical symptoms. For example, some participants reported that thinking about their childhood trauma served as an internal trigger of subsequent emotional distress, anxiety and related physical responses. As such, when their medication alleviated the frequency of these thoughts, participants also experienced a reduction in the intensity or frequency of particular emotional and physiological responses.

These differences can be explained by a number of interrelated factors. Participants remembered and re-experienced past traumatic events in various ways. This is consistent with prior research demonstrating that, after being exposed to a traumatic event, people may experience different types of PTSD-related symptoms (McMillen, North & Smith, 2000; Runyon, Faust & Orvaschel, 2002). For example, while some people may meet the full criteria for a diagnosis of PTSD, others may only experience specific arousal and intrusive symptoms (McMillen et al., 2000). In this study, some participants reported experiencing intense trauma-related emotions when thinking about their abuse or neglect. Others did not experience specific emotions as intensely, but continued to experience intrusive thoughts, physiological anxiety symptoms and/or other physical symptoms (tension, numbness) triggered by external cues. Thus, each participant reported antipsychotic-induced changes to the predominant ways in which they remembered or re-experienced childhood trauma, which varied across the sample.

The influence of antipsychotics on how participants remembered and re-experienced past traumatic events depended on the medication's general effect on their emotional and cognitive state. Those participants who generally experienced antipsychotic-induced emotional flattening or numbing also reported the suppression of trauma-related emotions. As mentioned

above, this depended on whether (and to what degree) they experienced distressing emotions related to childhood trauma. In this regard, one of the drugs' most common adverse effects, emotional flattening, was beneficial in addressing distressing trauma-related emotions. While participants considered being unable to fully experience emotions unpleasant (and even distressing), they found relief in subduing particular trauma-related emotions. There also appeared to be a connection between the ways in which antipsychotics altered participants' general cognitive functioning and how they experienced thoughts or memories of past traumatic events. For example, participants who reported ruminating less or not having a continuity in thought also mentioned that they tended to think less about their childhood trauma or did not experience a continuous spiralling of trauma-related thoughts. A few participants who experienced specific antipsychotic-induced cognitive deficits, such as brain fog, confusion and racing thoughts, also mentioned that their trauma memories were amplified (e.g., adding parts to the trauma narrative and being unsure of whether these events actually occurred, more vivid flashbacks and intrusive thoughts). Therefore, the adverse emotional and cognitive effects of antipsychotics can influence how people remember their trauma. This influence can be either helpful (not thinking about past traumatic events) or detrimental (an amplified view of childhood trauma).

Many participants specifically reported being on significantly high doses of antipsychotics during certain periods. This affected how they experienced their trauma memories and, thus, what they reported during their interviews. Higher doses were generally associated with severe sedation, cognitive dulling and emotional flattening, which subsequently resulted in the suppression of trauma memories. Further, different participants appeared to respond differently to the same SGAs. This also influenced how they experienced changes to their trauma memories. For example, a few participants reported that Quetiapine alleviated their trauma-related symptoms of anxiety, the same drug exacerbated these

symptoms in others. As outlined in Section 10.1, many participants had tried multiple antipsychotic medications. As such, what participants reported in terms of how they experienced the subjective effects of antipsychotics was dependant on which medications they had tried before their interviews and how they specifically responded to those particular medications. This demonstrates that particular antipsychotics can have an unpredictable effect on how individuals experience their trauma memories.

10.2.1.1 Confronting and processing trauma

A second key finding of this study was that by subduing participants' trauma memories, antipsychotics prevented them from confronting their childhood trauma. Participants mentioned that this was beneficial in the short term in that it alleviated the distress associated with the constant remembering and re-experiencing of past traumatic events. However, they also recognised that confronting trauma was an important therapeutic step towards healing. Therefore, having their trauma memories supressed by the mind-altering effects of antipsychotic drugs was not considered beneficial in the longer term. Thus, these participants appeared to face an internal conflict between the short-term benefits of suppressing trauma-related thoughts and emotions and the potential longer-term detriment of not allowing themselves the opportunity to address their childhood trauma.

These findings reveal that people's beliefs about the relationship between their childhood trauma and presenting mental illness, as well as how trauma should be addressed, influence their views on the value of antipsychotic maintenance treatment. The participants in this study indicated that they have considered discontinuing or reducing the dose of their medication at some point in the future to process their trauma. One participant also spoke in detail about how she had to lower the dose of her medication to meaningfully engage in trauma-focused psychological therapy. She reported that antipsychotics prevented her from fully

experiencing particular emotions, which was a core aspect of therapy. Trauma-focused psychological therapies include in vivo exposure, which involves a gradual increase in physical or sensory contact with situations, locations and objects that trigger distressing symptoms, and/or imaginal exposure, whereby the individual voluntarily recalls traumatic events in vivid detail (Perrin, 2013). The successful implementation of these techniques requires the individual to reach an optimal level of arousal—that is, a state in which they can experience and tolerate emotion without becoming overwhelmed (whereby re-traumatisation may occur) or 'shut-down' and emotionally numb (Rothschild, 2011; Kezelman & Stavropoulos, 2012). The ability of antipsychotics to lower arousal and subdue emotion may, therefore, prevent an individual from adequately activating their trauma memory and, in turn, engaging in meaningful trauma-focused psychological therapy. This may explain why current Australian guidelines for the treatment of posttraumatic-stress reactions suggest that some drugs may interfere with the effectiveness of psychological treatment (Phoenix Australia – Centre for Posttraumatic Mental Health, 2013).

A few participants also discussed what they gained from trauma-focused psychological therapy and how this differed from antipsychotic drug treatment. Participants mentioned that, as a result of psychological therapy, they became more aware of the psychological effect of trauma, learned how to tolerate or self-regulate emotions and integrate memories, dissected the different aspects of trauma, and acknowledged a history of childhood abuse. These various aspects of therapy had a positive effect on participants' mental health. They reported feeling less overwhelmed and distressed by trauma memories. Researchers have suggested that trauma-based psychological therapies, such as trauma-focused cognitive behaviour therapy (TF-CBT) and prolonged exposure therapy (PET)—both of which have strong empirical support for the treatment of PTSD (Ehlers et al., 2010; Foa, McLean, Capaldi, Rosenfield, 2013; Mills et al., 2012; Powers, Halpern, Ferenschak, Gillihan & Foa, 2010)—may also be

safe and effective treatments for traumatised individuals presenting with psychosis (Bendall, Alvarez-Jimenez, Killackeya & Jackson, 2017; Bendall, Jackson, Hulbert & McGorry, 2011; van den Berg et al., 2018). A recent systematic review of 15 studies demonstrated that psychological therapies (CBT, PET, eye movement desensitisation and reprocessing, and written emotional disclosure) were effective in alleviating the post-traumatic stress symptoms of 585 people diagnosed with a psychotic disorder (Swan, Keen, Reynolds & Onwumere, 2017). However, as mentioned, the effectiveness of these psychological therapies in both research and clinical settings may be influenced (positively or negatively) by the emotional, cognitive and physiological effects of antipsychotic medications.

10.2.1.2 Conceptual and clinical implications related to trauma memory

A number of important conceptual and clinical implications can be drawn from the specific findings discussed in this subsection. The broader implications drawn from the study's cumulative findings will be outlined later in this thesis (Section 10.4). It has been demonstrated that antipsychotic medications do alter how people with a history of childhood trauma and psychosis experience their trauma memories. As discussed, these alterations can be beneficial or detrimental and thus, play a significant role in whether people consider their medication helpful. Therefore, it is important for clinicians to (1) have a sound initial understanding of how each individual remembers and re-experiences past traumatic events, and (2) engage in ongoing assessment of how this remembering/re-experiencing of trauma is influenced by the effects of antipsychotic drugs. Further, clinicians should enquire whether and, if so, how people prefer to manage their trauma and the role of antipsychotics in this process. While some people may believe that they must confront their trauma to heal, possibly through psychological therapy, others may be content in having particular trauma-related experiences or symptoms supressed by antipsychotics. Those individuals who do wish to confront their trauma may

request to have their medication dose lowered. Clinicians should, thus, collaborate with these individuals to determine a medication dosage that would allow them to confront or process their trauma, while also ensuring the effective management or alleviation of their psychosis and/or other symptoms. It is also valuable for clinicians to recognise that traumatised individuals may change their beliefs about the connection between their childhood trauma and mental illness over time, and may reconsider whether they need to confront their trauma. As such, despite being content with a particular medication dose for some time, people may eventually decide to have this dose lowered to meaningfully engage in trauma-focused psychological therapy (or another approach to confront their trauma). Clinicians should engage in an open dialogue with these clients about how lowering their medication dose may affect their experiences in therapy (e.g., emotions may be experienced more intensely) and any other symptoms for which medication was initially prescribed.

As mentioned, trauma-focused therapies require people to discuss past traumatic events and can, therefore, cause increased emotional distress and/or initial symptom exacerbation in some people (Foa, Zoellner, Feeny, Hembree & Alvarez-Conrad, 2002; Tong, Simpson, Alvarez-Jimenez & Bendall, 2017; Tong, Simpson, Alvarez-Jimenez & Bendall, 2019). As described in detail by one participant in this study, a low to moderate dose of antipsychotics may help people contain the distressing emotions experienced during psychotherapy. Therefore, when adjusting an individual's medication dose, it may be valuable for clinicians to also consider whether and, if so, how antipsychotics assist them to manage any emotional distress experienced during therapy. As such, an optimal medication dose may be one that allows the client to adequately experience their emotions during therapy, while also preventing extreme levels of emotional distress. However, as psychotherapy progresses and people learn how to regulate their emotions using non-pharmacological strategies, the use of antipsychotic medications as a means to contain emotion should be re-evaluated. This may require further

adjustments to a person's medication dose. As mentioned, it is important for clinicians to consider and assess how any adjustments in medication dose may influence other symptoms (e.g., psychosis, anxiety, mania, etc.).

Moreover, current theories of PTSD suggest that avoidance of trauma-related sensations, thoughts and emotions maintains PTSD symptoms by preventing people from adequately processing their trauma memories and learning new and more helpful patterns of responding to trauma-related cures (Ehlers & Clark, 2000; Fleurkens, Rinck & van Minnen, 2014; Foa & Rothbaum, 1998; Kumpula, Orcutt, Bardeen & Varkovitzky, 2011; Pineles et al., 2011). Therefore, when conceptualising antipsychotics from the perspective of theories of PTSD maintenance, the ability of these medications to suppress participants' trauma memories may be a form of indirect post-traumatic avoidance. Prior studies have demonstrated that people with a history of ICT are likely to use avoidance as a coping strategy (Phanichrat & Townshend, 2010; Reddy, Pickett, Orcutt, 2006; Sigmon, Greene, Rohan & Nichols, 1996; Simons, Ducette, Kirby, Stahler & Shipley, 2003). It has also been consistently evidenced that, in adults with a history of childhood trauma, avoidant coping strategies are associated with current psychopathological symptoms and increased psychological distress (Bal, Van Oost, Bourdeaudhuij & Crombez, 2003; Canton-Cortes & Canton, 2010; Johnson, Sheahan & Chard, 2003; Min, Farkas, Minnes & Singer, 2007; Reddy, et al., 2006; Steel, Sanna, Hammond, Whipple & Cross, 2004). As demonstrated in this study, some traumatised individuals may experience short-term benefits by having their trauma memories supressed by antipsychotics. For example, not having to constantly experience the distress associated with trauma-related thoughts may improve peoples' daily functioning (e.g., improved ability to work or study). However, clinicians should be mindful that this can also be a form of avoidant coping, which may be less adaptive and detrimental in the longer term. Thus, clinicians should be aware of theoretical models of PTSD maintenance and provide clients with psych-education about the

potential long-term negative effects of avoidant coping. Clinicians may also consider encouraging clients to use more adaptive and healthy strategies to cope with their trauma memories. This may include strategies such as cognitive reframing, expressing emotion and actively seeking change and social support, all of which have been associated with decreased symptomatology and improved psychological functioning in people with a history of childhood trauma (O'Leary, 2009; Merrill, Thomsen, Sinclair, Gold & Milner, 2001; Runtz & Schallow, 1997).

10.2.2 Effect on Dissociation

Another subsidiary research question of this study explored how people with psychosis and a history of childhood trauma experience the effect of antipsychotic medications on their dissociative symptoms.

> Subsidiary research question: How do people with psychosis and a history of ICT subjectively experience the effects that antipsychotics have on any dissociative states (depersonalisation and derealisation)?

This study found that there was a mixed response from participants about whether antipsychotic medications altered their dissociative symptoms. A few participants reported that antipsychotics alleviated their symptoms of depersonalisation/derealisation, while others mentioned that they experienced no change in dissociative symptoms. One participant emphasised that his symptoms worsened while taking Quetiapine. The reason for these mixed results may be related to theories of the relationship between dissociation and PTSD/trauma-related symptoms. As described in Chapter 2, dissociation allows individuals experiencing current trauma to detach themselves from traumatic experiences. This is a normal

psychological process during acute trauma but in the face of ongoing traumas becomes habitual and generalised. This detachment can then become an automatic (or unconscious) means of coping with overwhelming emotions (Schimmenti, 2018; Schimmenti & Caretti, 2016) and is often associated with emotional suppression or numbing (Monde, Ketay, Giesbrecht, Braun & Simeon, 2013; Tibubos et al., 2018). Paradoxically, it has also been evidenced that people with clinical levels of depersonalisation also experience more emotional reactivity and distress than healthy individuals (Medford, 2012; Thomson & Jaque, 2018). Further, studies have demonstrated that post-traumatic stress and emotion dysregulation were predictive of dissociative symptoms among traumatised individuals (Briere, 2006; Hetzel-Riggin &Wilber, 2010). In accord with these findings, many participants in the current study who had experienced dissociative symptoms also reported distressing post-traumatic intrusions, trauma-related emotions and/or anxiety. Some individuals also experienced the alleviation of both dissociative and trauma-related or PTSD symptoms. As such, this relief from dissociation may have been an indirect effect of the medication's ability to supress these trauma-related thoughts, emotions and/or physiological symptoms. For example, one participant who reported fewer dissociative symptoms while taking antipsychotics also emphasised how useful her medication was in alleviating trauma-related anxiety. Another participant who reported an exacerbation in dissociative symptoms while taking Quetiapine also mentioned that he began to experience more vivid flashbacks and intense trauma-related emotions. Thus, it is possible that antipsychotics can influence symptoms of depersonalisation/derealisation by altering how people remember and re-experience past traumatic events.

A number of other factors need to be taken into consideration when interpreting the findings regarding the effects of antipsychotics on participants' symptoms of depersonalisation and derealisation. As discussed in section 10.1, many participants experienced additional traumatic events during adulthood (e.g. being held hostage, rape, physical assault, etc.). When

considering that dissociation serves as a protective mechanism during acute trauma, it is possible that re-traumatisation caused an exacerbation of dissociative symptoms in some participants while they were taking an antipsychotic. Furthermore, information obtained via the semi-structured interviews suggests that the severity and frequency of dissociative symptoms did appear to vary among participants. While some participants described vivid out of body experiences, others stated that at times their environment appeared somewhat unclear or hazy. Also, many participants reported that they were previously on very high doses of antipsychotics, while some participants mentioned that they had engaged in trauma-focused therapy and/or implemented other nonpharmacological grounding strategies while taking antipsychotic medication. As such, the effect of antipsychotics on participants' dissociative symptoms may have been further influenced by: (1) the severity and frequency of symptoms, (2) medication dose, and (3) the use and effectiveness of nonpharmacological approaches. For example, one participant stated that while her dissociative symptoms had ceased, she was unaware that she had stopped dissociating because she was on a very high dose of antipsychotic medication.

There are currently no recommended evidenced-based pharmacological treatments for depersonalisation/derealisation (Gentile, Snyder & Gillig, 2014; Hunter et al., 2017). There are a few case reports demonstrating an improvement in these symptoms with the use of Quetiapine (n = 1; Mancini-Marïe, Fahim, Potvin, Beauregard & Stip, 2006) and Aripiprazole (n = 3; Uguz & Sahingoz, 2014). In contrast, another case report demonstrated that one male patient with schizophrenia developed symptoms of depersonalisation/derealisation after being prescribed Quetiapine (Sarkar, Jones & Sullivan, 2001). While these mixed findings do align with what was reported by participants in the current study, none of the case reports stated whether the participants had a trauma history or diagnosis of PTSD. Further research is needed to determine whether antipsychotics are an effective treatment for depersonalisation and, more

specifically, whether the effect of these medications on trauma memory is related to how they influence dissociative symptoms.

This study also demonstrated that a few participants described antipsychotic effects that were similar to dissociative experiences. Two participants specifically mentioned that the mind-altering effects of antipsychotics can support and maintain dissociation. As such, the altered mental state produced by antipsychotics may serve a similar purpose to dissociation—a form of avoidant coping that allows the individual to detach from distressing or overwhelming emotions and memories. In subsection 10.2.1.2 it was mentioned that the antipsychotic induced suppression of trauma-related thoughts and emotion can, for some people, be a form of posttraumatic avoidance. However, in traumatised individuals who are also experiencing dissociative symptoms, antipsychotics may further prolong avoidance by creating a drug induced mental state that is subjectively experienced as something similar to the individual's pre-existing dissociative state. Therefore, from this perspective, the mind altering effects of antipsychotics can cause avoidant coping by supressing people's trauma memories, and/or maintaining (and even exacerbating) their dissociative symptoms. While a direct inquiry was not made by the researcher, two participants [2 and 5] specifically reported that they continued to alter identities or personas while taking antipsychotics. This form of dissociation is referred to as 'identity disruption' and is characterised by a dissociative organisation of the personality that is composed of two or more parts, with each part experiencing different feelings, thoughts, perceptions, physical sensations and behaviours (Boon et al., 2011). The divided parts can be known or unknown to the individual (the central personality), who may refer to them as parts, states, personas or alters (Parry, Lloyd & Simpson, 2018). Identity disruption (or the presence of two or more distinct personality states) is the defining diagnostic feature of dissociative identity disorder (DID; APA, 2013). Current theories suggest that DID develops when a child is exposed to severe abuse (most often

physical or sexual abuse) with a disorganised attachment to parents or guardians (Dorahy et al., 2014). The child must have the biological capacity for dissociation, which leads to the development of multiple unintegrated personality states (Dorahy et al., 2014; International Society for the Study of Trauma and Dissociation, 2011). These personality states are often fixed in trauma-time (the developmental time periods during which the individual experienced traumatic events) and can hold traumatic memories, painful or overwhelming emotions, sensations and experiences (Boon, et al., 2011). As a result, the individual is unable to develop an integrated sense of self across varying behavioural and emotional states (Putnam, 2006).

The diagnosis of DID (previously known as multiple personality disorder) has been associated with controversy (Dorahy et al., 2014). Some clinicians and researchers have affirmed that DID is a distinct disorder with a unique set of core symptoms (Dorahy et al., 2014), while others have suggested that few differences exist between the symptoms of DID and those of other disorders, such as borderline personality disorder (Lauer, Black, & Keen, 1993). It has also been suggested that DID can be partly explained by iatrogenisis—the creation of symptoms that don't really exist by some clinicians (Gillig, 2009; Piper & Merskey, 2004). However, studies have consistently demonstrated that 'DID can be distinguished accurately from other psychiatric disorders and non-patients using structured interviews and self-report measures of dissociation' (Dorahy et al., 2014, p. 405). In this study, only Participant 5 reported that she had been diagnosed with DID. However, the participants were not asked specific questions about this form of dissociation, so it is possible that Participant 2 also met the diagnostic criteria for DID. As mentioned, both participants reported that antipsychotics did not alleviate their dissociative symptoms; that is, they continued to experience multiple identities while taking their medication. Participant 5 did report that her medication alleviated the extreme emotional distress that she experienced while in particular altered states. This allowed her to return to herself (the central personality) sooner than she otherwise would have.

Thus, in this case, antipsychotics had an indirect effect on dissociation: they alleviated the participant's emotional distress and, as a result, she remained in an altered or dissociative state for a shorter duration. This participant did mention that, by alleviating the distress experienced by particular alters, antipsychotics prevented integration, which she considered an important therapeutic step towards overcoming dissociation. Therefore, similar to what was mentioned by participants about the effect of antipsychotics on trauma memory, in this instance, the alleviation of emotional distress was considered a short-term benefit that prevented longer-term healing.

At the time of writing this thesis, there were no intervention trials evaluating antipsychotic medications as treatments for DID; however, case reports demonstrate that the multiple personality states of two adolescents and one adult with DID diminished while taking an antipsychotic (Lai, 2012; Okugawa, Nobuhara, Kitashiro & Kinoshita, 2005; Perales-Blum, Ibarra-Yruegas & Cuellar-Barboza, 2015). Nevertheless, current treatment guidelines state that 'medications for DID are usually best conceptualized as "shock absorbers" rather than as curative interventions' (International Society for the Study of Trauma and Dissociation, 2011, p. 151), and that antipsychotics 'may help with overall hyperarousal, panic, terror, and thought disorganization' (International Society for the Study of Trauma and Dissociation, 2011, p. 153). These suggestions align with the reports of Participants 2 and 5: antipsychotics do not alleviate dissociation but can reduce the emotional distress experienced while in an altered state.

Moreover, Participants 2 and 5 reported that antipsychotic medications did not alleviate their auditory and visual hallucinations. This finding aligns with the current guidelines for the treatment of DID that state: 'hallucinatory phenomena in DID, even when alternate identities engage in command hallucinations mandating danger to self or others, are usually unaffected by even high-dose neuroleptics' (International Society for the Study of Trauma and

Dissociation, 2011, p. 153). The hallucinatory experiences of people diagnosed with DID may have unique aspects, which may explain why antipsychotics are not considered an effective treatment for these symptoms. Researchers have suggested that, among people with DID, those with psychotic symptoms may experience more than two voices, both child and adult voices, and/or a combination of auditory, visual, olfactory, tactile and gustatory hallucinations (Dorahy et al., 2009; International Society for the Study of Trauma and Dissociation, 2011). People may also experience inner voices that represent some form of communication between different identities, as opposed to external auditory hallucinations (International Society for the Study of Trauma and Dissociation, 2011). Other researchers have suggested that individuals with DID may experience dissociative psychosis, a syndrome that involves one or more personality states that appear to be characterised by psychotic experiences and heavily intrude upon, or obtain control of, the central personality (van der Hart & Witztum, 2009). It is important to note that, with regard to the two participants in this study, minimal information was obtained regarding the nature of their psychotic symptoms and the connection between their hallucinations and alternate identities. Further research is needed to explore the efficacy of antipsychotics in alleviating the psychotic symptoms of people diagnosed with DID.

10.2.3 Emotional, Cognitive and Physical Effects of Antipsychotics

A third subsidiary research question of this study explored how people with psychosis and a history of childhood trauma experience the emotional, cognitive and physical effects of antipsychotic medications.

> Subsidiary research question: How do people with psychosis and a history of ICT subjectively experience the effects that antipsychotics have on their emotional, cognitive and physical states?

Many participants reported that antipsychotic medications supressed their emotions and/or impaired their cognitive functioning. This was also demonstrated by the meta-synthesis of prior qualitative studies exploring the subjective effects of antipsychotics (presented in Chapter 3). More recently a systematic review of 35 qualitative studies found that users of antipsychotics 'consistently described a distinctive experience characterised by sedation, cognitive impairment, emotional blunting and reduced motivation' (Thomson et al., 2020, p. 161). In this study there were subtle differences between participants in how antipsychotics altered their emotional states. Some reported being unable to express or display emotion while taking antipsychotics, while others mentioned that they did not experience emotions in the same way. Participants indicated that they were unable to experience any emotion while on higher doses of antipsychotics, suggesting that medication dose affected the degree to which emotions could be experienced. A few participants who reported that antipsychotics supressed their emotions also experienced a general mental dulling that was characterised by particular cognitive deficits. For example, one participant, who stated that she displayed no emotion while on antipsychotics, also mentioned that she was on autopilot, that is, performing daily tasks automatically without thinking and being unable to think analytically. With regard to cognitive functioning, many participants reported that antipsychotics impaired their analytical and creative thinking, as well as their ability to concentrate on specific tasks. In contrast, a few participants mentioned that they were able to think clearer and concentrate for longer as a result of their medication. These differences appeared to be the result of a multitude of interrelated factors, including the degree of participants' cognitive impairment, medication dose, the effects of psychosis and other nonpsychotic symptoms on cognitive functioning, and symptomatic change over time. For example, one participant stated that she experienced racing anxiety-arousing thoughts during a psychotic episode. She mentioned that antipsychotics slowed her

thinking, which resulted in mental clarity. However, this participant also reported that antipsychotics substantially reduced her mental sharpness as she exited periods of crisis and started to feel calmer. In accord with prior findings (Husa et al., 2014), participants described more severe cognitive deficits while taking higher doses of antipsychotics (e.g., no creative thought, brain fog, inability to solve problems). Further, as discussed in Subsection 10.2.1, some participants mentioned that having particular trauma-related thoughts and emotions supressed was helpful. These findings demonstrate that the emotional and cognitive effects of antipsychotics can be subjectively experienced in a positive or negative way depending, in part, on how they interact with trauma-related experiences or symptoms.

Moreover, many participants described a multitude of adverse physical effects, of which the most common were weight gain and movement difficulties (physical rigidity, restlessness and tremors). This was also a key finding of the meta-synthesis presented in Chapter 2. These adverse physical effects have also been extensively evaluated in the literature (Allison et al., 1999; Bak, Fransen, Janssen, van Os & Drukker, 2014; Dayabandara et al., 2017; DiBonaventura et al., 2012; Kane et al., 2009; Leucht et al., 2013; Lieberman et al., 2005; Panagiotopoulos, Ronsley & Davidson, 2009; Stroup & Gray, 2018; Waterreus et al., 2012; Wonodi et al., 2007; Woods et al., 2010). As such, they will not be discussed in detail.

10.2.4 Effect on Psychosis

Many participants in this study reported that antipsychotics reduced the frequency and/or intensity of their psychotic symptoms. However, participants reported trying multiple antipsychotics before finding a medication that was somewhat effective in alleviating their hallucinations or delusions, and/or didn’t cause severe adverse effects. Other participants mentioned that they did not experience any meaningful or consistent change in the frequency or intensity of their symptoms despite having tried two or more different medications. As such,

there were substantial differences in how participants responded to particular antipsychotic medications and, more specifically, SGAs. For example, while a few participants reported that Quetiapine reduced the frequency or intensity of their hallucinations, others noticed minimal symptomatic change or an exacerbation of symptoms while taking this drug. To date, multiple meta-analyses have demonstrated that, at best, only small efficacy differences exist between antipsychotic medications (including FGAs and SGAs; Leucht et al., 2009; Leucht et al., 2013; Lieberman et al., 2005; Samara, Cao, Helfer, Davis & Leucht, 2014; Samara et al., 2016). Thus, researchers have concluded that each antipsychotic has a unique risk-to-benefit profile (Correll & De Hert, 2013; Leucht et al., 2013), which may partially explain why the study participants responded differently to particular antipsychotic medications. In addition to the specific antipsychotic taken, medication dose also appeared to influence how participants experienced psychotic symptoms. Many participants reported being prescribed very high doses of antipsychotics at some point in their lives, with a few participants reporting that they were put on the maximum recommended dose. While high doses were generally associated with a suppression of symptoms (along with other distressing adverse effects), a few participants reported that their auditory and visual hallucinations intensified when their dose increased.

Consistent with prior findings (Misiak & Frydecka, 2016), it is possible that participants had tried various medications and were prescribed high doses because they generally responded poorly to antipsychotics. There are a number of possible reasons that can explain this poor response. Considering that many participants experienced multiple psychiatric impatient admissions, it is probable that they generally experienced more severe and persistent psychotic symptoms. A few participants also reported that their symptoms were exacerbated by an increase in stress and/or re-experiencing childhood trauma. As participants were not specifically asked about the connections between their trauma and psychosis, it is possible that a greater number of participants experienced an exacerbation of symptoms when their trauma

memories were triggered by particular cues. Further, as mentioned in Subsection 10.2.2, some participants may have experienced dissociative psychotic symptoms, which are considered resistant to antipsychotics (International Society for the Study of Trauma and Dissociation, 2011).

This study's findings also revealed that the nature and development of participants' psychotic symptoms varied substantially. This also appeared to influence how each participant responded to their medication, and the different ways in which antipsychotics altered their psychotic experiences. For example, a few participants reported that antipsychotic medications prevent an initial obsessive or delusional thought from transforming into a series of spiralling thoughts that subsequently manifest in a psychotic episode. Another participant mentioned that her delusions develop when she becomes highly emotional about a particular situation that is often connected to childhood trauma. She reported that antipsychotics prevent her delusions from fully developing by subduing her emotions. These examples also demonstrate that the cognitive and emotional effects of antipsychotics can influence how people subjectively experience psychotic symptoms.

A few participants reported that antipsychotic medications did not alleviate their hallucinations or delusions, but rather minimised the priority and psychological impact of these symptoms. They specifically mentioned that antipsychotics relieved the distress and anxiety that was associated with psychosis and generally made symptoms less worrying. This offers further support to the findings of Mizrahi and colleagues (2005, 2006), who found that antipsychotics do not eliminate hallucinations or delusions but rather create a detachment from these symptoms (i.e., not thinking about, taking notice of or preoccupying oneself with psychotic symptoms). However, as discussed in Chapter 3, further research is needed to determine precisely how antipsychotic medications influence psychotic symptoms.

10.2.5 Illness Management, Healing and the Role of Antipsychotics

Another key finding of this study was that illness management through the use of antipsychotics was considered different from healing by a few participants. These participants reported that while antipsychotics can supress symptoms, they do not address the cause of mental illness. They emphasised that their mental health problems were the result of difficult life experiences, such as childhood trauma. They also reported that antipsychotics did not eliminate their hallucinations or delusions but rather, reduced the distress that was associated with these symptoms. Interestingly, these participants had successfully discontinued or significantly reduced the dose of their medication. They also described clear reasons for wanting to reduce their doses, such as improving their general functioning and needing to confront childhood trauma through psychotherapy (see Subsection 10.2.1.1). As such, there appears to be a connection between participants' beliefs about the cause of their mental illness and their decisions to discontinue or reduce the dose of their medication. Similarly, another qualitative study demonstrated that among 11 voice hearers, those who had a 'turning towards recovery' narrative (normalising and engaging voices or trying to understand what the experience meant) generally reported that antipsychotics were ineffective and had lowered the dose of their medication over time (de Jager et al., 2016). In contrast, individuals who had a 'turning away' narrative (using all resources to survive the experience of voice hearing) were more accepting of the medical model of psychosis (that voices are symptoms of an illness) and emphasised the value and efficacy of antipsychotics (de Jager et al., 2016).

10.3 Methodological Strengths and Limitations

A major strength of this qualitative phenomenological study was the recruitment of 19 participants with a history of childhood trauma and psychosis (many of whom also experienced dissociative symptoms). Participant recruitment for this study was extremely difficult. Many

willing and/or eligible people were often mentally unwell or experienced social crises that prevented them from participating. Additionally, when initial contact was made with many of these individuals, there was often uncertainty about whether they would be able to participate in the future. Therefore, the researcher was consistently following-up with people and/or their case managers for periods of up to six months. Other eligible young people from EPPIC were considered by their case managers to be unsuitable for research due to their clinical complexities. Despite these difficulties, the researcher was able to achieve the objective of recruiting between 15 and 20 participants.

Another strength of the study was that IPA allowed for a rich description of how participants experienced the effects of antipsychotic medications. Thus, IPA was proven to be an effective method of qualitative inquiry for this study. Further, the researcher's clinical and core counselling skills enabled him to build rapport with participants. This appeared to make it easier for participants to discuss difficult experiences during their interviews.

This study had a number of methodological limitations. As a result of the recruitment difficulties mentioned in this subsection, only five young people were recruited from EPPIC. It was initially expected that the sample would comprise a greater number of young people who had experienced first-episode psychosis (EPPIC clients). The sample was also predominantly composed of females. However, there was an even spread of participants across the different age ranges. Further, the study included participants who had been receiving support and/or treatment from both the public and private mental health sectors. As such, when considering the clinical complexity of this cohort, the sample appeared to comprise a diverse group of people.

A few participants reported that they were uncertain about whether antipsychotics altered how they experienced their trauma-related thoughts/emotions/physical responses and/or other symptoms. This was because they were also taking other psychiatric medications and/or

engaging in psychotherapy. As such, it was difficult for them to distinguish which medication was altering or causing particular symptoms and/or whether certain improvements were the result of specific psychological interventions. However, this uncertainty only related to certain specific symptoms; most of the study participants appeared certain about whether antipsychotics altered how they experienced their trauma memories and/or other symptoms/experiences.

The participants were not asked if they experienced multiple personas, a major diagnostic feature of DID. In retrospect, a more thorough exploration of how antipsychotics affected dissociation would have been achieved if participants were also asked about whether they had experienced multiple personas and whether antipsychotics altered these specific dissociative experiences. As such, the conclusions drawn about how antipsychotics altered participants' dissociative symptoms are limited. Further, participants were not asked about whether antipsychotics influenced their mood symptoms. The meta-synthesis presented in Chapter 3 found that antipsychotics had a contrasting subjective effect on mood; some people reported that antipsychotics induced depression while others stated that their medication improved their mood. Further, at least eight study participants had experienced a depressive and/or manic episode in the past. As such, it is possible that antipsychotics altered participants' depressive or manic symptoms, which may have influenced how they subjectively experienced the effects of these medications.

Moreover, an important methodological consideration was the length of time that people needed to take their medication to be eligible for participation in the study. Six weeks continuous of antipsychotic use was required or, if medication had been ceased, potential participants would need to have taken this medication for three continuous months within the past 10 years. Thus, four clients from EPPIC were considered ineligible because they had not taken an antipsychotic for a sufficient period. The rationale for this exclusion criterion was that

people may experience a delayed response to antipsychotic medications. While some studies have shown that people can experience symptomatic improvements within two weeks of commencing an antipsychotic (Agid, Seeman & Kapur, 2006; Leucht, Busch, Hamann, Kissling & Kane, 2005), it may take longer to identify the most effective and tolerable antipsychotic dose for each person in clinical settings (Haddad & Correll, 2018). As such, taking an antipsychotic for a period of six weeks, or three months if medication had been ceased, was considered ideal.

10.4 Conceptual and Clinical Implications

This study's findings have a number of important conceptual and clinical implications. It was demonstrated that the emotional and cognitive effects of antipsychotics altered the way in which many participants remembered and/or re-experienced past traumatic events. It was further evidenced that the specific ways in which antipsychotics altered participants' trauma memories influenced, in part, whether they considered their medication helpful. There was also a mixed response from participants about whether antipsychotics alleviated their dissociative symptoms. As such, for participants in this study, the subjective therapeutic value of antipsychotic medications was not limited to the alleviation of psychotic symptoms. These findings demonstrate that a more accurate means to understand how these people subjectively experience the effects of antipsychotics would be through a drug-centred model, which purports that psychiatric medications, including antipsychotics, are fundamentally psychoactive drugs that alter people's physical and mental states (Moncrieff & Cohen, 2005; 2009). The drug centred model suggests that there is no essential distinction between 'drugs used for psychiatric treatment and recreational psychoactive drugs like alcohol and cocaine. All psychoactive drugs produce altered physical and mental states, which can influence the way people think, feel and act, with different sorts of substances having different sorts of

effects' (Moncrieff, 2018, p. 134). From this perspective, the drug-induced physiological and mental alterations of psychiatric and recreational drugs may be helpful because they supress the manifestation of psychopathological symptoms (Moncrieff, 2013; Moncrief & Cohen, 2009; Moncrieff, Cohen, & Porter, 2013). For example, alcohol can reduce arousal and weaken social inhibition, effects which may be experienced as helpful by people who suffer from social anxiety (Moncrieff, 2009; Moncrieff, 2018; Moncrieff, Cohen & Mason, 2015). Antipsychotics are considered to work in a similar way, whereby particular effects (e.g., sedation, emotional numbing, cognitive dulling) may alleviate symptoms, such as racing thoughts, agitation and mania. With regard to traumatised individuals, this may involve the suppression of trauma-related emotions, post-traumatic intrusions and the physiological symptoms of anxiety. As mentioned in subsection 10.2.1.2, the antipsychotic induced suppression of people's trauma memories can be a form of avoidant coping. It has also been demonstrated that after experiencing a traumatic event people will often use recreational drugs, such as alcohol, to alleviate their emotional distress and/or possible symptoms of PTSD (Ertl, Saile, Neuner, & Catani, 2016; Volpicelli, Balaraman, Hahn, Wallace, & Bux, 1999). Therefore, for traumatised individuals, the psychoactive effects of antipsychotic medications and some recreational drugs can have one similar function, the suppression (and possible avoidance) of trauma-related thoughts and emotions.

It is thus suggested that clinicians may find value in adopting a drug-centred approach when prescribing antipsychotics to people with a history of childhood trauma and psychosis. This offers clinicians the opportunity to engage in a discussion with people about how the altered mental states produced by antipsychotics may influence trauma-related experiences or symptoms and allow the patient to decide which drug-induced effects they might find beneficial (Moncrief & Cohen, 2009).

Further, it is suggested that clinicians should tailor antipsychotic drug treatment to each person's individual needs when treating those with a history of childhood trauma. Consequently, when prescribing antipsychotics and/or altering dosage, it may be valuable for clinicians to consider the following: (1) the effect of these medications on PTSD- or trauma-related and dissociative symptoms, (2) how the person would prefer to address their trauma (or how antipsychotics may prevent or help them to address trauma) and (3) how the medication's global psychological effects (e.g., effect on arousal, emotion and cognition) influence a person's general mental health and specific symptoms. A detailed discussion of the first two points is provided in Subsection 10.2.1.2.

10.5 Directions for Further Research

A number of potential avenues for further research have emerged from this study. It was demonstrated that antipsychotics altered how participants experienced their trauma memories, which influenced whether they considered their medication helpful. While these findings were exploratory only, they suggest that the effect of antipsychotics on trauma memories can influence mental health and general functioning. As such, there is a need for intervention studies to evaluate the effect of antipsychotics on the trauma-related/post-traumatic stress symptoms of people with a history of childhood trauma and psychosis. As mentioned, a limitation of this study was that participants were also taking other psychiatric medications, which may have influenced how they experienced their trauma memories. Thus, future studies may aim to recruit participants who are not prescribed an additional psychiatric medication. However, this may be difficult when considering that traumatised individuals are likely to experience other nonpsychotic symptoms that are being treated with additional medications.

Further, additional information is needed on whether the emotional and cognitive effects of antipsychotics influence how people with psychosis experience trauma-focused psychological therapy. Studies evaluating these psychological interventions could incorporate a qualitative component whereby people are asked about how antipsychotics have influenced their ability to engage in therapy.

A few study participants reported that antipsychotics alleviated their symptoms of depersonalisation and/or derealisation. However, others mentioned that they continued to dissociate while taking their medication. While participants in this study were asked if they experienced symptoms of depersonalisation and derealisation, they were not asked whether they experienced multiple personality states. Thus, more information is needed to determine whether and, if so, how antipsychotics influence the dissociative symptoms of traumatised individuals. Future studies may also implement a mediation model to assess whether the effect of antipsychotics on trauma-related experiences/symptoms indirectly influences dissociation.

It was demonstrated that there were differences between participants in how particular antipsychotic medications influenced their hallucinations and/or delusions. Participants had also experienced multiple impatient hospital admissions and were often on very high doses of antipsychotics. While these findings were exploratory only, they suggest that participants continued to experience distressing psychotic symptoms while taking antipsychotic medications. Thus, further research is needed to determine whether antipsychotics are less effective in alleviating the hallucinations or delusions of people with a history of childhood trauma (or complex trauma) and dissociation. There is also a need for more information from larger samples about whether and, if so, why those with a history of childhood trauma and psychosis are prescribed higher doses of antipsychotics.

10.6 Conclusion

This is the first Australian study to explore how people with psychosis and a history of ICT subjectively experience the effects of antipsychotic medications. The findings demonstrate that the emotional, cognitive and physiological effects of antipsychotics altered the ways in which participants remembered and re-experienced past traumatic events. However, there were differences in how these medications altered the ways in which individual participants experienced their trauma memories. Some participants mentioned that antipsychotics alleviated the frequency and/or intensity of trauma-related thoughts, emotions or physical responses, while others reported that their flashbacks and thoughts of childhood trauma intensified. Participants also reported that, by supressing trauma-related thoughts and emotions, antipsychotics prevented them from confronting their trauma. While this was considered beneficial in the short term, the participants recognised that confronting childhood trauma was an important therapeutic step towards healing. As such, the suppression of trauma memories by the mind-altering effects of antipsychotics was not considered beneficial in the long term. It was further demonstrated that there was a mixed response from participants about whether antipsychotics altered their dissociative symptoms. These findings suggest that the wide-ranging psychological effects of antipsychotics can be subjectively experienced as beneficial or detrimental depending, in part, on how they influence trauma-related thoughts, emotions and physical responses, as well as dissociative symptoms. Further intervention studies are needed to determine how people with childhood trauma and psychosis respond to antipsychotic drug treatment.

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Appendix A: Orygen Research Review Committee Ethics Approval (RRC Ref: F15-188)

Orygen
The National Centre of Excellence in Youth Mental Health

RESEARCH REVIEW COMMITTEE

Approval of Research Project Form

This form is to be submitted with the Research Governance Application, as the Site Specific Approval form, to Melbourne Health Office for Research for all research projects conducted at OYHCP.

Project Title:	The Subjective Experience of Taking Neuroleptic Medication: A Qualitative Study of People with Psychotic Illness and a History of Childhood Trauma
RRC reference number:	F15-188
HREC Reference number:	2015.117
Chief Investigators:	Dr Sarah Bendall

I, A/Prof Frances Kay-Lambkin Chair, Orygen Research Review Committee, do certify that the above research project has been reviewed and approved by the Orygen Research Review Committee, to be conducted by the aforementioned Chief Investigators at Orygen.

Signed:

Date: 23/07/2015

Please direct any inquires to Tia Berry, RRC Secretariat research@orygen.org.au ph: 9342 2965

35 Poplar Road
Parkville VIC 3052
1300 679 436

ABN 85 098 918 686
orygen.org.au

An initiative of The University of Melbourne, Melbourne Health and The Colonial Foundation

Appendix B: Melbourne Health Human Research Ethics Committee ethics approval (MH Project Number: 2015.117)

PO Royal Melbourne Hospital
Parkville Victoria 3050
Telephone 61 3 9342 8530
Facsimile 61 3 9342 8548
Email: research@mh.org.au
Website: https://www.thermh.org.au/research/researchers
ABN 73 802 706 972

OFFICE FOR RESEARCH

T1

MELBOURNE HEALTH HUMAN RESEARCH ETHICS COMMITTEE

ETHICAL APPROVAL

Dr. Sarah Bendall
Centre for Youth Mental Health
Orygen Youth Health Research Centre
35 Poplar Road
Parkville, VIC, 3052

23 November 2015

Dear Dr. Sarah Bendall,

AU RED HREC Reference Number: HREC/15/MH/251

MH Project Number: 2015.117

Project Title: The Subjective Experience of Taking Neuroleptic Medication: A Qualitative Study of People with Psychosis and a History of Childhood Trauma

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I am pleased to advise that the above project has **received ethical approval** from the Melbourne Health Human Research Ethics Committee (HREC). The HREC confirms that your proposal meets the requirements of the National Statement on Ethical Conduct in Human Research (2007). This HREC is organised and operates in accordance with the National Health and Medical Research Council's (NHRMC) National Statement on Ethical Conduct in Human Research (2007), and all subsequent updates, and in accordance with the Note for Guidance on Good Clinical Practice (CPMP/ICH/135/95), the Health Privacy Principles described in the Health Records Act 2001 (Vic) and Section 95A of the Privacy Act 1988 (and subsequent Guidelines).

HREC Approval Date: 23 November 2015

Ethical approval for this project applies at the following sites:

Site
Orygen Youth Health Clinical Program
Orygen: The National Centre for Excellence in Youth Mental Health

Approved Documents:

The following documents have been reviewed and approved:

Document	Version	Date
Protocol	2	07 November 2015
Protocol Appendix A – Structure of Interview		
Master Participant Information Sheet/Consent Form - Self	2	07 November 2015

Master Participant Information Sheet/Consent Form - Parent/Guardian	2	07 November 2015
Demographic, Treatment and Illness Information Sheet	2	07 November 2015
Telephone Script	1	07 November 2015
Advertisement for Participants		
Advertisement for Case Managers		
Childhood Trauma Questionnaire (CTQ)		
Life Events Checklist (LEC)		1995

Site Specific Assessment:

SSA Authorisation is required at all sites participating in the study. SSA must be authorised at a site before the research project can commence.

The completed Site-Specific Assessment Form and a copy of this ethics approval must be submitted to the Research Governance Office in order to obtain authorisation to commence your project. It is recommended that you check details of governance application submission requirements with each participating site.

Conditions of Ethics Approval:

- You are required to submit to the HREC:
    - An Annual Progress Report (that covers all sites listed on approval) for the duration of the project. This report is due on the anniversary of HREC approval. Continuation of ethics approval is contingent on submission of an annual report, due within one month of the approval anniversary. Failure to comply with this requirement may result in suspension of the project by the HREC.
    - A comprehensive Final Report upon completion of the project.
- Submit to the reviewing HREC for approval any proposed amendments to the project including any proposed changes to the Protocol, Participant Information and Consent Form/s and the Investigator Brochure.
- Notify the reviewing HREC of any adverse events that have a material impact on the conduct of the research in accordance with the NHMRC Position Statement: *Monitoring and reporting of safety for clinical trials involving therapeutic products May 2009*.
- Notify the reviewing HREC of your inability to continue as Coordinating Principal Investigator.
- Notify the reviewing HREC of the failure to commence the study within 12 months of the HREC approval date or if a decision is taken to end the study at any of the sites prior to the expected date of completion.
- Notify the reviewing HREC of any matters which may impact the conduct of the project.
- If your project involves radiation, you are legally obliged to conduct your research in accordance with the Australian Radiation Protection and Nuclear Safety Agency Code of Practice 'Exposure of Humans to Ionizing Radiation for Research Purposes' Radiation Protection series Publication No.8 (May 2005)(ARPANSA Code).

The HREC may conduct an audit of the project at any time.

Yours sincerely

Ms Jessica Turner
Manager - Human Research Ethics Committee

Appendix C: Melbourne Health Human Research Ethics Committee Ethics Amendment Approval (MH Project Number: 2015.117)

MELBOURNE HEALTH

Office for Research
The Royal Melbourne Hospital
Level 2 South West
300 Grattan Street
Parkville VIC 3050
Australia

Telephone: +61 3 9342 8530
Facsimile: +61 3 9342 8548
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MELBOURNE HEALTH HUMAN RESEARCH ETHICS COMMITTEE

ETHICAL APPROVAL OF A RESEARCH PROJECT

Dr Sarah Bendall
Orygen Youth Health Research Centre
Locked Bag 10, VIC 3052
Australia

22 September 2016

Dear Dr Sarah Bendall,

AU RED HREC Reference Number: HREC/15/MH/251
Melbourne Health Site Reference Number: 2015.117

Project Title: The Subjective Experience of Taking Neuroleptic Medication: A Qualitative Study of People with Psychosis and a History of Childhood Trauma

I am pleased to advise that the Melbourne Health HREC has approved an amendment to the above project to include additional participating sites. The Melbourne Health HREC is accredited by the Consultative Council for Human Research Ethics under the single ethical review system.

HREC Approval Date: 22 September 2016

Additional Participating Sites:

- Prahran Mission

Approved Documents:

- Protocol, Version 3, dated 19 July 2016
- Protocol Appendix A – Structure of Interview, undated
- Protocol Appendix B – List of Counselling Services, undated
- Master Participant Information Sheet/Consent Form, Version 4, dated 23 August 2016
- Advertisement, Version 2, dated 07 September 2016

Site Specific Assessment:

Site

You are now required to submit this HREC Approval letter with an electronic copy of the approved documents named above as part of the Site Specific Assessment application to the Research Governance Officer at each additional site, as listed above, to obtain approval to commence the project at that site(s).

Conditions of Ethics Approval:

In order to comply with the National Statement on Ethical Conduct in Human Research 2007, Guidelines for Good Clinical Research Practice and Melbourne Health Research Policies and Guidelines you are required to:

- Submit a copy of this letter (via the principal investigator at each site) to the person responsible for radiation safety at each participating site – ***do this if*** the project involves exposure to ionising radiation and the Radiation Safety Officer (RSO) / Medical Physicist for that site has advised that the project needs to be added to the site's Licence for Research Involving Human Volunteers issued by the Department of Health Radiation Safety Section. (See information re radiation requirements at www.health.vic.gov.au/cchre). *Note:* A project cannot commence at a site until the Principal Investigator at that site has received notification from his/her RSO that the project has been added to that site's licence;
- Notify the HREC of the actual start date of the project at each Victorian site;
- Submit to the HREC for approval any proposed amendments to the project including any proposed changes to the Protocol, Participant Information and Consent Form/s and the Investigator Brochure;
- Notify the reviewing HREC of any adverse events that have a material impact on the conduct of the research in accordance with the NHMRC Position Statement: *Monitoring and reporting of safety for clinical trials involving therapeutic products May 2009*;
- Notify the HREC of any unforseen events;
- Notify the HREC of your inability to continue as Principal Investigator or any other change in research personnel involved in the project;
- Notify the HREC if a decision is taken to end the study at any of the Victorian sites prior to the expected date of completion or failure to commence the study within 12 months of the HREC approval date at any of the Victorian sites;
- Notify the HREC of any other matters which may impact the conduct of the project.

Reporting

You are required to submit to the HREC:

- An Annual Progress Report every 12 months (or more frequently as requested by the reviewing HREC) for the duration of the project. This report is due on the anniversary of HREC approval. Continuation of ethics approval is contingent on submission of an annual report in a timely manner; and
- A comprehensive Final Report upon completion of the project.

The HREC may conduct an audit of the project at any time.

Please Note: Templates for reporting Amendments, Adverse Events, Annual Report/Final Reports, etc. can be accessed from: www.health.vic.gov.au/cchre

Please refer to the Melbourne Health Office for Research website to access guidelines and other information and news concerning research at Melbourne Health: https://www.thermh.org.au/research/researchers

A list of those HREC members present at the review of this project can be obtained from the above website.

Yours sincerely

Ms. Jessica Turner
Manager - Human Research Ethics Committee

Appendix D: Neami National Ethics Approval

Neami National
Improving Mental Health and Wellbeing

Neami National Head Office · 4-8 Water Road, Preston VIC
P 03 8691 5300 · admin@neaminational.org.au

The Subjective Experience of Taking Neuroleptic Medication: A Qualitative Study of People with Psychosis and a History of Childhood Trauma

9th August, 2017

Mr Leo Kamitsis
Centre for Youth Mental Health
University of Melbourne

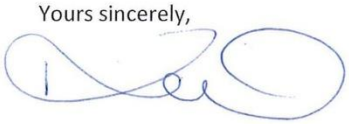
Email: elanios@bigpond.net.au

Dear Leo,

Neami National's Research and Evaluation committee have reviewed and understood the project proposal details regarding the 'The Subjective Experience of Taking Neuroleptic Medication: A Qualitative Study of People with Psychosis and a History of Childhood Trauma' and provided approval that this project aligns with Neami's strategy and values for research and evaluation projects. I hereby give permission for yourself and the researchers involved in this project to undertake research activities as outlined in the Neami Research Approval Checklist.

We thank you for submitting your proposal to Neami's Research and Evaluation Committee for Neami to support recruitment and participation in this project.

Yours sincerely,



Keren Wolstencroft
Research Coordinator – Research and Evaluations
Neami National
4-8 Water Road, Preston VIC
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Appendix E: Project Flyer for Case Managers

Orygen
The National Centre of Excellence in Youth Mental Health

INTERESTED PEOPLE WANTED FOR LOCAL RESEARCH ON THE SUBJECTIVE EFFECTS OF ANTIPSYCHOTIC MEDICATIONS!

Do you have any clients who have…

- Been diagnosed with a psychotic disorder, such as Schizophrenia?
- Experienced childhood abuse or neglect?
- Taken, or are currently taking, antipsychotic medication?
- Understand and communicate well in English?

If so, you are invited to ask them if they would like to participate in a study undertaken by Orygen: The National Centre for Excellence in Youth Mental Health, and the University of Melbourne.

What is the study about?
The purpose of this study is to explore how people with psychosis and a history of childhood trauma experience antipsychotic medications, and whether these medications have affected their cognitive, emotional and physical state. We also wish to investigate whether antipsychotics influence the way these people experience thoughts, images and/or memories of past trauma, and whether they alter any experiences of dissociation.

What does participation involve?
If your client chooses to take part, he/she will be involved in one initial interview of approximately two hours, and if he/she likes, a second follow-up interview of approximately one hour. During the initial interview your client will be asked to complete two questionnaires relating to their past trauma. The session will also involve being asked questions by the researcher about their experience of taking antipsychotic medication. During the second optional interview, which will occur a few months after the first interview, your client will be asked to offer their opinion about the study's initial findings.

Who to contact?
If you have any clients who you think may be interested in taking part in this study, or would simply like more information, you are welcome to contact Leo Kamitsis on 0411 448 276, or via email: leo.kamitsis@orygen.org.au.

Appendix F: Project Flyer for Participants

Orygen
The National Centre of Excellence in Youth Mental Health

INTERESTED PEOPLE WANTED FOR LOCAL RESEARCH ON THE SUBJECTIVE EFFECTS OF ANTIPSYCHOTIC MEDICATIONS!

Have you….

- Been diagnosed with a psychotic disorder, such as Schizophrenia?
- Experienced childhood abuse or neglect?
- Taken, or are currently taking, antipsychotic medication?
- Understand and communicate well in English?

If so, you are invited to participate in a study undertaken by Orygen: The National Centre for Excellence in Youth Mental, and the University of Melbourne.

What is the study about?
The purpose of this study is to explore how people with psychosis and a history of childhood trauma experience antipsychotic medications.

What does participation involve?
If you chose to take part, you will be involved in one initial interview of approximately two hours, and if you like, a second follow-up interview of approximately one hour. During the initial interview you will be asked to complete two questionnaires relating to your past trauma. The session will also involve being asked questions by the researcher about your experience of taking antipsychotic medication. During the second optional interview, which will most likely occur a few months after the first interview, you will be asked to offer your opinion about the study's initial findings.

Who to contact?
If you think that you may be interested in taking part in this study, or would simply like more information, you are welcome to contact Leo Kamitsis on 0411 448 276, or via email: leo.kamitsis@orygen.org.au.

Appendix G: Telephone Script

Telephone script – Initial contact with participants

Preamble

"Hi (***participant's first name***), my name is Leo Kamitsis. I'm a research student at Orygen. I was given your contact number by (***case manager's full name***), your Orygen case manager. I'm doing a research project which aims to explore what it feels like for people who have experienced psychosis and childhood trauma to take antipsychotic medications.

I believe (***case manager's first name***) spoke to you about our project and you mentioned that you'd be interested in talking a little more about our project. ***At this point it is anticipated that the prospective participant may indicate whether they are or are not interested in participating. If not, then the student researcher will ask him/her:*** So I wanted to ask you whether you would be interested in participating in this study, and if so whether this is a good time for me to tell you more about what our project is about and what is involved. This should take about 10 or 15 minutes. If this isn't a good time for us to have a chat I'm happy to call you back at a time that is more convenient for you."

Agenda points

- A more detailed explanation of the study's purpose and aims.
- Discussion about what participation involves. During this discussion participants will be informed that participation will involve one initial interview of approximately two hours, and if they like, a second follow-up interview of approximately one hour.

Appendix H: Participant Information Sheet/Consent Form—Parent/Guardian

Participant Information Sheet/Consent Form – Parent/Guardian

Health/Social Science Research– *Parent/Guardian consenting on behalf of participant*

Orygen – The National Centre of Excellence in Youth Mental Health

Title	The Subjective Experience of Taking Antipsychotic Medication: A Qualitative Study of People with Psychosis and a History of Childhood Trauma
HREC Number	HREC# 2015.117
Project Sponsor	Orygen, The National Centre of Excellence in Youth Mental Health
Principal Investigator	Dr Sarah Bendall
Associate Investigator(s)	A/Prof Lou Harms and Leo Kamitsis

Part 1 What does the child's participation involve?

1 Introduction

This is an invitation for the child in your care to take part in this research project, which is called The Subjective Experience of Taking Neuroleptic Medication: A Qualitative Study of People with Psychosis and a history of Childhood Trauma. They have been invited because they are taking, or have taken antipsychotic medication, and they have talked with their case manager about having experienced childhood trauma (such as physical abuse or neglect).

This Participant Information Sheet/Consent Form tells you about the research project. It explains the processes involved with taking part. Knowing what is involved will help you decide if you want the child to take part in the research.

Please read this information carefully. Ask questions about anything that you don't understand or want to know more about. Before deciding whether or not the child can take part, you might want to talk about it with a relative, friend or local health worker.

Participation in this research is voluntary. If you do not wish the child in your care to take part, they do not have to.

If you decide you want the child to take part in the research project, you will be asked to sign the consent section. By signing it you are telling us that you:

- Understand what you have read
- Consent to the child taking part in the research project
- Consent to the child being involved in the research described
- Consent to the use of the child's personal and health information as described.

You will be given a copy of this Participant Information and Consent Form to keep.

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2 What is the purpose of this research?

Some people with psychosis have had traumatic childhood experiences, such as emotional, sexual or physical abuse. As part of their treatment, many of these people have taken an antipsychotic medication. The purpose of this project is to explore what it feels like for people with psychosis and a history of childhood trauma to take antipsychotics, and whether these medications have affected their thinking, as well as their emotional and physical state. We also wish to investigate whether antipsychotics influence the way these people experience thoughts, images and/or memories of past trauma, or their emotional and physical responses to it, and whether they alter any experiences of feeling disconnected from themselves or their environment. As far as we are aware, a specific exploration into how people with psychosis and a history of childhood trauma subjectively experience antipsychotic medications has yet to be undertaken. By undertaking such an exploration, we hope to learn more about the effect that these medications have on the individual as a whole, and on the way they currently experience their trauma memory.

The results of this research will be used by the researcher Leo Kamitsis to obtain a PhD (Youth Mental Health) degree.

This research has been initiated by the researcher, Dr Sarah Bendall.

This research has been funded by the University of Melbourne.

3 What does participation in this research involve?

If you decide that the child may take part in the research project, after signing this participant Consent Form, participation will involve the child completing one initial interview of approximately two hours, and if your child choses, a second follow-up interview of approximately one hour and fifteen minutes. Both interviews will be undertaken with the same researcher, Leo Kamitsis.

During the initial interview your child will be asked to complete two questionnaires relating to their past trauma. These will include questions about whether your child has experienced physical, sexual and emotional abuse. In order to further confirm your child's psychosis diagnosis, your will also be asked a series of questions about their psychotic symptoms." Your child will further be asked questions by the researcher about their experience of taking antipsychotic medication, and whether these medications have influenced their thinking, as well as their emotional and physical experience. The researcher will also ask your child some questions about whether their medication has influenced the way they experience any thoughts, images and memories of their trauma, , their emotional and physical responses to their trauma,and whether the medication has altered any experiences of feeling disconnected from themselves or their environment. Your child can choose to not answer these questions if they wish.

Your child will also be asked if they would like to participate in a second interview which will occur a few months after the first interview. During this session your child will be asked to read a short summary of the whole study's findings obtained from the initial interview process, or if they prefer, have the researcher describe these findings to them. Your child will then be asked to offer their opinion about these findings.

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Both interviews will be audio recorded and produced in exact written form. Each interview will be typewritten professionally by an independent service. The service which will undertake the writing of each interview will keep the information they receive confidential. Your child's responses to the two questionnaires and their personal details, such as their full name and address, will not be given to this service. Once your child's interview is typewritten copy will be emailed to them.

As part of the interview process, we would also like your permission to look at your child's clinical file to get information about any medication they are taking and how long they have been at the service.

There are no costs associated with participating in this research project. However, your child will be reimbursed $60 for participating in the first interview, and an additional $30 if they chose to participate in a second interview. The reimbursement should cover any expenses associated with the research project visit.

4 Other relevant information about the research project

It is estimated that 25 participants will take part in this project. Participants will be recruited from the Early Psychosis Prevention and Intervention Centre (EPPIC) of the Orygen Youth Health Clinical Program, the Mental Illness Fellowship (MIF), and Prahran Mission's Voice Vic program.

5 Does the child have to take part in this research project?

Participation in any research project is voluntary. If you do not wish for the child to take part, they do not have to. If you decide that they can take part and later change your mind, you are free to withdraw the child from the project at any stage.

If you do decide that the child can take part, you will be given this Participant Information and Consent Form to sign and you will be given a copy to keep.

Your decision that the child can or cannot take part, or that they can take part and then be withdrawn, will not affect their routine care, relationship with professional staff or relationship with those treating your child or Orygen Youth Health.

6 What are the possible benefits of taking part?

We cannot guarantee or promise that the child will receive any benefits from this research; however, possible benefits may include having the opportunity to reflect on how antipsychotic medication has affected them psychologically and physically. Information obtained through the research interview may assist with your child's treatment and care and may be fed back to the treating team with their permission. The results of this study may enrich our understanding of how people with psychosis and a history of childhood trauma experience antipsychotics.

7 What are the possible risks and disadvantages of taking part?

You should be aware that talking about their experience with antipsychotic medications or their childhood trauma may cause your child distress. Your child may feel that some of the questions we ask are stressful or upsetting. If they do not wish to answer a question, they may skip it and

go to the next question, or they may stop immediately. If the participant becomes upset or distressed as a result of their participation in the research project, the research team will be able to arrange for the participant to talk to their case manager. If your child requires counselling, the researchers will arrange counselling for them either with Leo Kamitsis (immediately after the interview) or their EPPIC case manager. They may prefer to suspend or end their participation in this research if distress occurs. If your child discloses any current trauma the research team can assist them in informing their case manager.

8 What if I withdraw the child from this research project?

If you do consent for your child to participate, they are free to withdraw or be withdrawn by you from this research project at any point during the study, either verbally or by completing the "Withdrawal of Consent" form which the research team will provide. If you decide to withdraw your child from the project, please notify a member of the research team before withdrawal. A member of the research team will inform you if there are any special requirements linked to withdrawing. If you do withdraw your child, you will be asked to complete and sign a 'Withdrawal of Consent' form; this will be provided to you by the research team.

If you decide that your child is to leave the research project, the researchers will not collect additional personal information, although personal information already collected will be retained to ensure that the results of the research project can be measured properly and to comply with law. You should be aware that data collected up to the time of withdrawal will form part of the research project results. If your child's data has not yet been processed and you do not want it to be included, you must tell the researchers when withdrawing from the research project.

9 Could this research project be stopped unexpectedly?

This research project may be stopped unexpectedly for a variety of reasons. These may include reasons such as:

- if an undue amount of distress is experienced by participants of the study.
- the student researcher discontinuing with his respective course of study.

However, many studies of a similar nature to this current study have been conducted in the past through Orygen, The National Centre of Excellence in Youth Mental Health without any incident or cause to end the study. Therefore the likelihood that the study will be stopped is low.

10 What happens when the research project ends?

If you or your child would like feedback on their individual results from the interview process, you or your child may ask a member of the research team. Feedback can be provided to you or your child in either a verbal or written format. Your child will be invited to attend the second interview, where they will be provided with their choice of a written or verbal summary of the study findings and given the chance to comment on those findings. Even if your child does not wish to attend a second interview, we will provide you or your child with a summary of the results of the project when the project is concluded if requested. If you or your child would like this summary we will ask you or your child for some contact details so that we can post or email it to you or your child. This is expected to be available in June 2016. We will also publish results

of the study in publicly available scientific journals. **Part 2 How is the research project being conducted?**

11 What will happen to information about the child?

By signing the consent form you consent to the research team collecting and using personal information about the child for the research project. The personal information that the research team collects and uses is from the interview(s) and questionnaires they complete. Any information obtained in connection with this research project that can identify your child will remain confidential and will only be used for the purposes stated in this document. It will only be disclosed with your permission, except as required by law.

Information about your child may be obtained from their health records held at this and other health organisations for the purpose of this research. For example, information relating to the type of medications your child has taken in the past and the date in which they commenced their treatment at Orygen may be obtained from your health records. By signing the consent form you agree to the research team accessing health records if they are relevant to your child's participation in this research project.

Information from the interviews conducted for this study (including electronic or digital information kept on storage media or recording equipment) will be kept in a locked filing cabinet at Orygen, The National Centre of Excellence in Youth Mental Health. This information can only be accessed by the principal researcher, Dr Sarah Bendall, and the associate investigators Associate Professor Lou Harms and Mr Leo Kamitsis. Your child's questionnaire responses will be entered without any identifying information into a computer database, which will be password-protected and only accessed by Dr Bendall, A/Prof Harms and Mr Kamitsis. Electronic copies of your child's interview recordings and transcripts will also be password protected and accessed only by the researchers involved in this project. Your child's data will have a unique code, which will be linked to their contact details, which is kept in a separate password-protected file (printed copy stored in a locked filing cabinet), for the purpose of contacting them for further information or, with your consent, contacting them for future research projects at Orygen. Only Dr Bendall, A/Prof Harms and Mr Kamitsis will have access to the link between the unique code and your child's contact details.

Upon completion of the study, your child's information will be kept for a minimum of 5 years from the date of final publication. After that it will all be destroyed.

We will endeavour to keep all the information that we collect in the interview process strictly confidential. There are some exceptions to this: 1) information from the assessments may be communicated with your child's case manager to ensure that they receive the best care possible; 2) if we are concerned about your child, we may need to discuss this with their case manager and doctor at Orygen; 3) if as a result of the information your child discloses in the interview relating to their past trauma or abuse we believe that someone else may be at risk. In some cases we may contact The Department of Human Services (DHS) about risk to children under the age of 17 years. Mandatory reporting laws require clinicians to report to Child Protective Services any suspected cases of child abuse and neglect (Children, Youth and Families Act 2005 (Vic.). In cases where abuse is reported, information gathered by researchers is passed on to the clinical team and the appropriate clinical procedures normally used within the mental health service are implemented. This may involve reporting abuse to DHS or other support services. In all cases we will discuss this with your child first.

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Your child's medical record and any information obtained during the study are subject to inspection, for the purpose of verifying study procedures and the data, by the relevant authorities and authorised representatives of the Orygen, the Melbourne Health Human Research Ethics Committee, the Melbourne Health Office for Research or as required by law. By signing the consent section, you authorise release of, or access to, this confidential information to the relevant study personnel and regulatory authorities as noted above.

Information about your child's participation in this research project will be recorded in your medical record.

We plan to publish group results, for example, in scientific journals, to present them in scientific conferences and talk about them to other people who work in mental health industries in order to help them improve the service they provide to people with psychosis who are currently taking, or contemplating on taking, antipsychotic medication.

In any publication and/or presentation, information will be provided in such a way that the child cannot be identified, except with your express permission. As this is an exploratory study, which aims to obtain an in-depth understanding of peoples' experience of taking antipsychotics, if the results are published, direct quotations may be taken from your child's transcript to illustrate a certain aspect of the findings. In such articles, another name will be used so that your child cannot be identified.

In accordance with relevant Australian and/or Victorian privacy and other relevant laws, you have the right to request access to the information about the participant that is collected and stored by the research team. Your child also has the right to correct any information with which they disagree. Please inform the research team member named at the end of this document if you would like to access the participant's information.

We are also seeking your consent to store and use information we gather during this interview(s) with your child in any future research projects that might be conducted. By providing your contact details on the consent form below you are consenting to the possibility of being contacted in the future and asked if you or your child would like to participate in any follow-up research.

12 Complaints and compensation

If your child suffers any distress or psychological injury as a result of this research project, you should contact the research team as soon as possible. You will be assisted with arranging appropriate treatment and support for the participant.

If you or your child have a complaint about the research team, OR any serious event that occurs following your child's participation in this project, you or your child should talk with their case manager and/or contact the complaints person listed on this form.

13 Who is organising and funding the research?

This research is being conducted by Orygen, The National Centre of Excellence in Youth Mental Health. It is being funded by the University of Melbourne.

Orygen
The National Centre of Excellence in Youth Mental Health

14 Who has reviewed the research project?

All research in Australia involving humans is reviewed by an independent group of people called a Human Research Ethics Committee (HREC).

The ethical aspects of this research project have been approved by the HREC of Melbourne Health.

This project will be carried out according to the National Statement on Ethical Conduct in Human Research (2007). This statement has been developed to protect the interests of people who agree to participate in human research studies.

15 Further information and who to contact

The person you may need to contact will depend on the nature of your query. If you want any further information concerning this project or if you have any problems which may be related to your involvement in the project, you can contact

Research contact person

Name	Dr Sarah Bendall
Position	Principal Researcher
Telephone	(03) 9342 2986
Email	sarah.bendall@orygen.org.au

If you have any complaints about any aspect of the project, the way it is being conducted or any questions about being a research participant in general, then you may contact:

Complaints contact/HREC Executive Officer details

Reviewing HREC name	Ms Jessica Turner
HREC Executive Officer	Manager, Melbourne Health Human Research Ethics Committee
Telephone	(03) 9342 7602
Email	Jessica.Turner@mh.org.au

Consent Form – Parent/Guardian

Title	The Subjective Experience of Taking Antipsychotic Medication: A Qualitative Study of People with Psychosis and a History of Childhood Trauma
HREC Number	HREC# 2015.117
Project Sponsor	Orygen, The National Centre of Excellence in Youth Mental Health
Principal Investigator	Dr Sarah Bendall
Associate Investigator(s)	A/Prof Lou Harms and Leo Kamitsis
Location	Orygen Youth Health Clinical Program

Declaration by Parent/Guardian

I have read the Participant Information Sheet or someone has read it to me in a language that I understand.

I understand the purposes, procedures and risks of the research described in the project.

I have had an opportunity to ask questions and I am satisfied with the answers I have received.

I freely agree to the child participating in this research project as described and understand that I am free to withdraw them at any time during the project without affecting their future care.

I understand that I will be given a signed copy of this document to keep.

☐ I understand that information my child provides for this research may be disclosed to their case manager, and that mandatory reporting laws require that clinicians report any case of suspected child abuse or neglect to Child Protective Services.

Name of Child (please print) _____

Signature of Child _____ Date _____

Name of Parent/Guardian (please print) _____

Signature of Parent/Guardian _____ Date _____

Name of Witness* to Child and Parent/Guardian Signature (please print) _____

Signature _____ Date _____

* Witness is not to be the investigator, a member of the study team or their delegate. In the event that an interpreter is used, the interpreter may not act as a witness to the consent process. Witness must be 18 years or older. Witness is required when the participant cannot read the document for him/herself.

Declaration by Researcher†

I have given a verbal explanation of the research project, its procedures and risks and I believe that the child and parent/guardian have understood that explanation.

Name of Researcher† (please print) _____

Signature _____ Date _____

† An appropriately qualified member of the research team must provide the explanation of, and information concerning, the research project.

Note: All parties signing the consent section must date their own signature.

Form for Withdrawal of Participation – Parent/Guardian

Title	The Subjective Experience of Taking Antipsychotic Medication: A Qualitative Study of People with Psychosis and a History of Childhood Trauma
HREC Number	HREC# 2015.1 17
Project Sponsor	
Principal Investigator	Dr Sarah Bendall
Associate Investigator(s)	A/Prof Lou Harms and Leo Kamitsis
Location	Orygen Youth Health Clinical Program

Declaration by Parent/Guardian

I wish to withdraw the child from participation in the above research project and understand that such withdrawal will not affect their routine care, or their relationships with the researchers or Orygen Youth Health.

Name of Child (please print) _____

Signature of Child _____ Date_____

Name of Parent/Guardian (please print) _____

Signature of Parent/Guardian _____ Date_____

In the event that the parent's/guardian's decision to withdraw is communicated verbally, the Senior Researcher must provide a description of the circumstances below.

Declaration by Researcher†

I have given a verbal explanation of the implications of withdrawal from the research project and I believe that the child and parent/guardian have understood that explanation.

Name of Researcher (please print) _____

Signature _____ Date _____

† An appropriately qualified member of the research team must provide information concerning withdrawal from the research project.

Note: All parties signing the consent section must date their own signature.

Appendix I: Participant Information Sheet/Consent Form—General Community

Participant Information Sheet/Consent Form

Health/Social Science Research - *Adult providing own consent*

Orygen – The National Centre of Excellence in Youth Mental Health

Title	The Subjective Experience of Taking Antipsychotic Medication: A Qualitative Study of People with Psychosis and a History of Childhood Trauma
HREC Number	HREC# 2015.117
Project Sponsor	Orygen, The National Centre of Excellence in Youth Mental Health
Principal Investigator	Dr Sarah Bendall
Associate Investigator(s)	Prof Lou Harms and Leo Kamitsis

Part 1 What does my participation involve?

1 Introduction

You are invited to take part in this research project, which is called The Subjective Experience of Taking Neuroleptic Medication: A Qualitative Study of People with Psychosis and a history of Childhood Trauma. You have been invited because we understand that you are taking, or have taken antipsychotic medication, and you have experienced childhood trauma. We have gained this information either a) because you have publically disclosed it (on a website, during a public talk, in a book); b) previously told us about it; or c) you have contacted us and talked to us after having been told about the study by others.

This Participant Information Sheet/Consent Form tells you about the research project. It explains the processes involved with taking part. Knowing what is involved will help you decide if you want to take part in the research.

Please read this information carefully. Ask questions about anything that you don't understand or want to know more about. Before deciding whether or not to take part, you might want to talk about it with a relative, friend or local health worker.

Participation in this research is voluntary. If you don't wish to take part, you don't have to.

If you decide you want to take part in the research project, you will be asked to sign the consent section. By signing it you are telling us that you:

- Understand what you have read
- Consent to take part in the research project
- Consent to be involved in the research described
- Consent to the use of your personal and health information as described.

You will be given a copy of this Participant Information and Consent Form to keep.

Orygen
The National Centre of Excellence in Youth Mental Health

2 What is the purpose of this research?

Some people with psychosis have had traumatic childhood experiences, such as emotional, sexual or physical abuse. As part of their treatment, many of these people have taken an antipsychotic medication. The purpose of this project is to explore what it feels like for people with psychosis and a history of childhood trauma to take antipsychotics, and whether these medications have affected their thinking, as well as their emotional and physical state. We also wish to investigate whether antipsychotics influence the way these people experience thoughts, images and/or memories of past trauma, or their emotions and physical responses to it, and whether they alter any experiences of feeling disconnected from themselves or their environment. As far as we are aware, a specific exploration into how people with psychosis and a history of childhood trauma subjectively experience antipsychotic medications has yet to be undertaken. By undertaking such an exploration, we hope to learn more about the effect that these medications have on the individual as a whole, and on the way they currently experience their trauma memory.

The results of this research will be used by the researcher Leo Kamitsis to obtain a PhD (Youth Mental Health) degree.

This research has been initiated by the researcher, Dr Sarah Bendall.

This research has been funded by the University of Melbourne.

3 What does participation in this research involve?

If you consent to being in the study, after signing this participant Consent Form, participation will involve one initial interview of approximately two hours, and if you like, a second follow-up interview of approximately one hour and fifteen minutes. Both interviews will be undertaken with the same researcher, Leo Kamitsis.

During the initial interview you will be asked to complete two questionnaires relating to your past trauma. These will include questions about whether you have experienced physical, sexual and emotional abuse. In order to further confirm your psychosis diagnosis, you will also be asked a series of questions about your psychotic symptoms." The session will further involve being asked questions by the researcher about your experience of taking antipsychotic medication, and whether these medications have influenced your thinking, as well as your emotional and physical experience. The researcher will also ask you some questions about whether your medication has influenced the way you experience any thoughts, images and memories of your trauma, your emotional and physical responses to your trauma, and whether the medication has altered any experiences of feeling disconnected from yourself or your environment. You can choose to not answer these questions if you wish.

You are also welcome to participate in a second interview that will occur a few months after the first interview. During this session you will be asked to read a short summary of the whole study's findings obtained from the initial interview process, or if you prefer, have the researcher describe these findings to you. You will then be asked to offer your opinion about these findings.

Both interviews will be audio recorded and produced in exact written form. Each interview will be typewritten professionally by an independent service. The service which will undertake the writing of each interview will keep the information they receive confidential. Your responses to

the two questionnaires and your personal details, such as your full name and address, will not be given to this service. Once your interview is typewritten a copy will be emailed to you.

There are no costs associated with participating in this research project. However, you will be reimbursed $60 for participating in the first interview, and an additional $30 if you chose to participate in a second interview. The reimbursement should cover any expenses associated with the research project visit.

4 Other relevant information about the research project

It is estimated that 25 participants will take part in this project. Participants will be recruited from the Early Psychosis Prevention and Intervention Centre (EPPIC) of the Orygen Youth Health Clinical Program, Prahran Mission, and the wider community.

5 Do I have to take part in this research project?

Participation in any research project is voluntary. If you do not wish to take part, you do not have to. If you decide to take part and later change your mind, you are free to withdraw from the project at any stage.

If you do decide to take part, you will be given this Participant Information and Consent Form to sign and you will be given a copy to keep.

6 What are the possible benefits of taking part?

We cannot guarantee or promise that you will receive any benefits from this research; however, possible benefits may include having the opportunity to reflect on how antipsychotic medication has affected you psychologically and physically. If you were informed of this study by a health professional from whom you are currently receiving treatment, information obtained through the research interview may assist with your treatment and may be fed back to that health professional with your permission. The results of this study may enrich our understanding of how people with psychosis and a history of childhood trauma experience antipsychotics.

7 What are the possible risks and disadvantages of taking part?

You should be aware that talking about your experience with antipsychotic medications or your childhood trauma may cause you distress. You may feel that some of the questions we ask are stressful or upsetting. If you do not wish to answer a question, you may skip it and go to the next question, or you may stop immediately. If you become upset or distressed as a result of your participation in the research project, and have chosen to provide the research team with the contact details of an additional support person, the research team will be able to arrange for you to talk to that support person. If you require counselling, the researchers will arrange counselling for you either with Leo Kamitsis (immediately after the interview) or as soon as can be arranged through one of the services outlined on a list that will be given to you. You may prefer to suspend or end your participation in this research if distress occurs. If you disclose any current trauma the research team can assist you in informing your case manager.

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8 What if I withdraw from this research project?

If you do consent to participate, you are free to withdraw from this research project at any point during the study, either verbally or by completing the "Withdrawal of Consent" form which the research team will provide to you. If you decide to withdraw from the project, please notify a member of the research team before you withdraw. -

If you decide to leave the research project, the researchers will not collect additional personal information from you, although personal information already collected will be retained to ensure that the results of the research project can be measured properly and to comply with law. You should be aware that data collected up to the time you withdraw will form part of the research project results. If your data has not yet been processed and you do not want it to be included, you must tell the researchers when you withdraw from the research project.

9 Could this research project be stopped unexpectedly?

This research project may be stopped unexpectedly for a variety of reasons. These may include reasons such as:

- if an undue amount of distress is experienced by participants of the study;
- the student researcher discontinuing with his respective course of study.

However, many studies of a similar nature to this current study have been conducted in the past through Orygen, The National Centre of Excellence in Youth Mental Health without any incident or cause to end the study. Therefore the likelihood that the study will be stopped is low.

The student researcher will be co-supervised by Dr Sarah Bendall and Prof Lou Harms. Throughout the recruitment process the student researcher will engage in fortnightly supervision sessions with both or either of Dr Bendall and Prof Harms. During these sessions any issues relating to the safety of participants will be discussed and evaluated. If the student researcher is concerned for the safety of a participant during or after their interview he will contact both or either of Dr Bendall and Prof Harms. Dr Bendall is a registered clinical psychologist with over 15 years of clinical experience in treating people with post-traumatic stress disorder (PTSD), and 10 years of experience researching and treating people with first episode psychosis. Prof Harms has over 10 years of clinical experience in working with people with mental health issues, and 13 years of experience in researching trauma, loss, and posttraumatic growth.

10 What happens when the research project ends?

If you would like feedback on your individual results from the interview process, you may ask a member of the research team. Feedback can be provided to you in either a verbal or written format. You will be invited to attend the second interview, where you will be provided with your choice of a written or verbal summary of the study findings and given the chance to comment on those findings. Even if you do not wish to attend a second interview, we will provide you with a summary of the results of the project when the project is concluded if requested. If you would like this summary we will ask you for some contact details so that we can post or email it to you. This is expected to be available in March 2017. We will also publish results of the study in publicly available scientific journals.

Orygen
The National Centre of Excellence in Youth Mental Health

Part 2 How is the research project being conducted?

11 What will happen to information about me?

By signing the consent form you consent to the research team collecting and using personal information about you for the research project. The personal information that the research team collects and uses is from the interview(s) and questionnaires you complete. Any information obtained in connection with this research project that can identify you will remain confidential and will only be used for the purposes stated in this document. It will only be disclosed with your permission, except as required by law.

Information from the interviews conducted for this study (including electronic or digital information kept on storage media or recording equipment) will be kept in a locked filing cabinet at Orygen, The National Centre of Excellence in Youth Mental Health. This information can only be accessed by the principal researcher, Dr Sarah Bendall, and the associate investigators Professor Lou Harms and Mr Leo Kamitsis. Your questionnaire responses will be entered without any identifying information into a computer database, which will be password-protected and only accessed by Dr Bendall, Prof Harms and Mr Kamitsis. Electronic copies of your interview recordings and transcripts will also be password protected and accessed only by the researchers involved in this project. Your data will have a unique code, which will be linked to your contact details, which is kept in a separate password-protected file (printed copy stored in a locked filing cabinet), for the purpose of contacting you for further information or, with your consent, contacting you for future research projects at Orygen. Only Dr Bendall, Prof Harms and Mr Kamitsis will have access to the link between the unique code and your contact details.

Upon completion of the study, your information will be kept for a minimum of 5 years from the date of final publication. After that it will all be destroyed.

We will endeavour to keep all the information that we collect in the assessments strictly confidential. There are some exceptions to this: 1) if we are concerned about risk to yourself or someone else, we may need to discuss this with the nearest crisis assessment team; 2) if as a result of the information you disclose in the interview relating to your past trauma or abuse we believe that someone else may be at risk. In some cases we may contact The Department of Human Services about risk to children under the age of 17 years. Mandatory reporting laws require clinicians to report to Child Protective Services any suspected cases of child abuse and neglect (Children, Youth and Families Act 2005 (Vic.)). In cases where abuse is reported, information gathered by researchers is passed on to the clinical team and the appropriate clinical procedures normally used within the mental health service are implemented. This may involve reporting abuse to DHS or other support services. We will try to the best of our ability to discuss this with you first.

Information obtained during the study are subject to inspection, for the purpose of verifying study procedures and the data, by the relevant authorities and authorised representatives of the Orygen, the Melbourne Health Human Research Ethics Committee, the Melbourne Health Office for Research or as required by law. By signing the consent section, you authorise release of, or access to, this confidential information to the relevant study personnel and regulatory authorities as noted above.

We plan to publish group results, for example in scientific journals, to present them at scientific conferences and talk about them to other people who work in mental health industries in order

to help them improve the service they provide to people with psychosis who are currently taking, or contemplating on taking, antipsychotic medication.

In any publication and/or presentation, information will be provided in such a way that you cannot be identified, except with your express permission. As this is an exploratory study, which aims to obtain an in-depth understanding of peoples' experience of taking antipsychotics, if the results are published, direct quotations may be taken from your transcript to illustrate a certain aspect of the findings. In such articles, another name will be used so that you cannot be identified.

We are also seeking your consent to store and use information we gather during this interview(s) with you in any future research projects that might be conducted. By providing your contact details on the consent form below you are consenting to the possibility of being contacted in the future and asked if you would like to participate in any follow-up research.

In accordance with relevant Australian and/or Victorian privacy and other relevant laws, you have the right to request access to the information about you that is collected and stored by the researchers about you. You also have the right to request that any information with which you disagree be corrected. Please inform the research team member named at the end of this document if you would like to access your information.

12 Complaints and compensation

If you suffer any distress or psychological injury as a result of this research project, you should contact the research team as soon as possible. You will be assisted with arranging appropriate treatment and support.

If you have a complaint about the research team, OR any serious event that occurs following your participation in this project, you should contact the complaints person listed on this form.

13 Who is organising and funding the research?

This research is being conducted by Orygen, The National Centre of Excellence in Youth Mental Health. It is being funded by the University of Melbourne.

14 Who has reviewed the research project?

All research in Australia involving humans is reviewed by an independent group of people called a Human Research Ethics Committee (HREC).

The ethical aspects of this research project have been approved by the HREC of Melbourne Health.

This project will be carried out according to the *National Statement on Ethical Conduct in Human Research (2007)*. This statement has been developed to protect the interests of people who agree to participate in human research studies.

15 Further information and who to contact

The National Centre of Excellence in Youth Mental Health

The person you may need to contact will depend on the nature of your query. If you want any further information concerning this project or if you have any problems which may be related to your involvement in the project, you can contact

Research contact person

Name	Dr Sarah Bendall
Position	Principal Researcher
Telephone	(03) 9342 2986
Email	sarah.bendall@orygen.org.au

If you have any complaints about any aspect of the project, the way it is being conducted or any questions about being a research participant in general, then you may contact:

Complaints contact/Reviewing HREC approving this research and HREC Executive

Reviewing HREC name	Ms Jessica Turner
HREC Executive Officer	Manager, Melbourne Health Human Research Ethics Committee
Telephone	(03) 9342 7602
Email	Jessica.Turner@mh.org.au

Consent Form - *Adult providing own consent*

Title	The Subjective Experience of Taking Antipsychotic Medication: A Qualitative Study of People with Psychosis and a History of Childhood Trauma
HREC Number	HREC# 2015.117
Project Sponsor	Orygen, The National Centre of Excellence in Youth Mental Health
Principal Investigator	Dr Sarah Bendall
Associate Investigator(s)	Prof Lou Harms and Leo Kamitsis
Location	Orygen Youth Health Clinical Program

Declaration by Participant

I have read the Participant Information Sheet or someone has read it to me in a language that I understand.

I understand the purposes, procedures and risks of the research described in the project.

I have had an opportunity to ask questions and I am satisfied with the answers I have received.

I freely agree to participate in this research project as described and understand that I am free to withdraw at any time during the project without affecting my future care.

I understand that I will be given a signed copy of this document to keep.

☐ I understand that mandatory reporting laws require that clinicians report any case of suspected child abuse or neglect to Child Protective Services.

Name of Participant (please print) _____

Signature _____ Date _____

Name of Witness* (please print) _____

Signature _____ Date _____

* Witness is not to be the investigator, a member of the study team or their delegate. In the event that an interpreter is used, the interpreter may not act as a witness to the consent process. Witness must be 18 years or older. Witness is required when the participant cannot read the document for him/herself.

Declaration by Researcher†

I have given a verbal explanation of the research project, its procedures and risks and I believe that the participant has understood that explanation.

Name of Researcher† (please print) _____

Signature _____ Date _____

† An appropriately qualified member of the research team must provide the explanation of, and information concerning, the research project.

Note: All parties signing the consent section must date their own signature.

Form for Withdrawal of Participation - *Adult providing own consent*

Title	The Subjective Experience of Taking Antipsychotic Medication: A Qualitative Study of People with Psychosis and a History of Childhood Trauma
HREC Number	HREC# 2015.117
Project Sponsor	Orygen, The National Centre of Excellence in Youth Mental Health
Principal Investigator	Dr Sarah Bendall
Associate Investigator(s)	Prof Lou Harms and Leo Kamitsis
Location	Orygen Youth Health Clinical Program

Declaration by Participant

I wish to withdraw from participation in the above research project and understand that such withdrawal will not affect my relationships with the researchers, those from whom I may be receiving mental health support / treatment.

Name of Participant (please print) _____

Signature _____ Date _____

In the event that the participant's decision to withdraw is communicated verbally, the Senior Researcher must provide a description of the circumstances below.

Declaration by Researcher†

I have given a verbal explanation of the implications of withdrawal from the research project and I believe that the participant has understood that explanation.

Name of Researcher (please print) _____

Signature _____ Date _____

† An appropriately qualified member of the research team must provide information concerning withdrawal from the research project.

Note: All parties signing the consent section must date their own signature.

Appendix J: Participant Information Sheet/Consent Form—EPPIC

Participant Information Sheet/Consent Form

Health/Social Science Research - *Adult providing own consent*

Orygen – The National Centre of Excellence in Youth Mental Health

Title	The Subjective Experience of Taking Antipsychotic Medication: A Qualitative Study of People with Psychosis and a History of Childhood Trauma
HREC Number	HREC# 2015.117
Project Sponsor	Orygen, The National Centre of Excellence in Youth Mental Health
Principal Investigator	Dr Sarah Bendall
Associate Investigator(s)	A/Prof Lou Harms and Leo Kamitsis

Part 1 What does my participation involve?

1 Introduction

You are invited to take part in this research project, which is called The Subjective Experience of Taking Neuroleptic Medication: A Qualitative Study of People with Psychosis and a history of Childhood Trauma. You have been invited because you are taking, or have taken antipsychotic medication, and you have talked with your case manager about having experienced childhood trauma (such as physical abuse or neglect).

Your contact details were obtained from your case manager at the EPPIC clinic.

This Participant Information Sheet/Consent Form tells you about the research project. It explains the processes involved with taking part. Knowing what is involved will help you decide if you want to take part in the research.

Please read this information carefully. Ask questions about anything that you don't understand or want to know more about. Before deciding whether or not to take part, you might want to talk about it with a relative, friend or local health worker.

Participation in this research is voluntary. If you don't wish to take part, you don't have to.

If you decide you want to take part in the research project, you will be asked to sign the consent section. By signing it you are telling us that you:

- Understand what you have read
- Consent to take part in the research project
- Consent to be involved in the research described
- Consent to the use of your personal and health information as described.

You will be given a copy of this Participant Information and Consent Form to keep.

Orygen
The National Centre of Excellence in Youth Mental Health

2 What is the purpose of this research?

Some people with psychosis have had traumatic childhood experiences, such as emotional, sexual or physical abuse. As part of their treatment, many of these people have taken an antipsychotic medication. The purpose of this project is to explore what it feels like for people with psychosis and a history of childhood trauma to take antipsychotics, and whether these medications have affected their thinking, as well as their emotional and physical state. We also wish to investigate whether antipsychotics influence the way these people experience thoughts, images and/or memories of past trauma, or their emotions and physical responses to it, and whether they alter any experiences of feeling disconnected from themselves or their environment. As far as we are aware, a specific exploration into how people with psychosis and a history of childhood trauma subjectively experience antipsychotic medications has yet to be undertaken. By undertaking such an exploration, we hope to learn more about the effect that these medications have on the individual as a whole, and on the way they currently experience their trauma memory.

The results of this research will be used by the researcher Leo Kamitsis to obtain a PhD (Youth Mental Health) degree.

This research has been initiated by the researcher, Dr Sarah Bendall.

This research has been funded by the University of Melbourne.

3 What does participation in this research involve?

If you consent to being in the study, after signing this participant Consent Form, participation will involve one initial interview of approximately two hours, and if you like, a second follow-up interview of approximately one hour and fifteen minutes. Both interviews will be undertaken with the same researcher, Leo Kamitsis.

During the initial interview you will be asked to complete two questionnaires relating to your past trauma. These will include questions about whether you have experienced physical, sexual and emotional abuse. In order to further confirm your psychosis diagnosis, you will also be asked a series of questions about your psychotic symptoms." The session will further involve being asked questions by the researcher about your experience of taking antipsychotic medication, and whether these medications have influenced your thinking, as well as your emotional and physical experience. The researcher will also ask you some questions about whether your medication has influenced the way you experience any thoughts, images and memories of your trauma, your emotional and physical responses to your trauma, and whether the medication has altered any experiences of feeling disconnected from yourself or your environment. You can choose to not answer these questions if you wish.

You are also welcome to participate in a second interview that will occur a few months after the first interview. During this session you will be asked to read a short summary of the whole study's findings obtained from the initial interview process, or if you prefer, have the researcher describe these findings to you. You will then be asked to offer your opinion about these findings.

Both interviews will be audio recorded and produced in exact written form. Each interview will be typewritten professionally by an independent service. The service which will undertake the writing of each interview will keep the information they receive confidential. Your responses to

the two questionnaires and your personal details, such as your full name and address, will not be given to this service. Once your interview is typewritten a copy will be emailed to you.

As part of the interview process, we would also like your permission to look at your clinical file to get information about any medication you are taking and how long you have been at the service.

There are no costs associated with participating in this research project. However, you will be reimbursed $60 for participating in the first interview, and an additional $30 if you chose to participate in a second interview. The reimbursement should cover any expenses associated with the research project visit.

4 Other relevant information about the research project

It is estimated that 25 participants will take part in this project. Participants will be recruited from the Early Psychosis Prevention and Intervention Centre (EPPIC) of the Orygen Youth Health Clinical Program, the Mental Illness Fellowship (MIF), and Prahran Mission's Voice Vic program.

5 Do I have to take part in this research project?

Participation in any research project is voluntary. If you do not wish to take part, you do not have to. If you decide to take part and later change your mind, you are free to withdraw from the project at any stage.

If you do decide to take part, you will be given this Participant Information and Consent Form to sign and you will be given a copy to keep.

Your decision whether to take part or not to take part, or to take part and then withdraw, will not affect your routine care, your relationship with professional staff or your relationship with those treating you or with Orygen Youth Health.

6 What are the possible benefits of taking part?

We cannot guarantee or promise that you will receive any benefits from this research; however, possible benefits may include having the opportunity to reflect on how antipsychotic medication has affected you psychologically and physically. Information obtained through the research interview may assist with your treatment and care and may be fed back to the treating team with your permission. The results of this study may enrich our understanding of how people with psychosis and a history of childhood trauma experience antipsychotics.

7 What are the possible risks and disadvantages of taking part?

You should be aware that talking about your experience with antipsychotic medications or your childhood trauma may cause you distress. You may feel that some of the questions we ask are stressful or upsetting. If you do not wish to answer a question, you may skip it and go to the next question, or you may stop immediately. If you become upset or distressed as a result of your participation in the research project, the research team will be able to arrange for you to talk to your case manager. If you require counselling, the researchers will arrange counselling for you either with Leo Kamitsis (immediately after the interview) or your EPPIC case manager. You

may prefer to suspend or end your participation in this research if distress occurs. If you disclose any current trauma the research team can assist you in informing your case manager.

8 What if I withdraw from this research project?

If you do consent to participate, you are free to withdraw from this research project at any point during the study, either verbally or by completing the "Withdrawal of Consent" form which the research team will provide to you. If you decide to withdraw from the project, please notify a member of the research team before you withdraw. -

If you decide to leave the research project, the researchers will not collect additional personal information from you, although personal information already collected will be retained to ensure that the results of the research project can be measured properly and to comply with law. You should be aware that data collected up to the time you withdraw will form part of the research project results. If your data has not yet been processed and you do not want it to be included, you must tell the researchers when you withdraw from the research project.

9 Could this research project be stopped unexpectedly?

This research project may be stopped unexpectedly for a variety of reasons. These may include reasons such as:

- if an undue amount of distress is experienced by participants of the study;
- the student researcher discontinuing with his respective course of study.

However, many studies of a similar nature to this current study have been conducted in the past through Orygen, The National Centre of Excellence in Youth Mental Health without any incident or cause to end the study. Therefore the likelihood that the study will be stopped is low.

10 What happens when the research project ends?

If you would like feedback on your individual results from the interview process, you may ask a member of the research team. Feedback can be provided to you in either a verbal or written format. You will be invited to attend the second interview, where you will be provided with your choice of a written or verbal summary of the study findings and given the chance to comment on those findings. Even if you do not wish to attend a second interview, we will provide you with a summary of the results of the project when the project is concluded if requested. If you would like this summary we will ask you for some contact details so that we can post or email it to you. This is expected to be available in June 2016. We will also publish results of the study in publicly available scientific journals.

Part 2 How is the research project being conducted?

11 What will happen to information about me?

By signing the consent form you consent to the research team collecting and using personal information about you for the research project. The personal information that the research team collects and uses is from the interview(s) and questionnaires you complete. Any information

The National Centre of Excellence in Youth Mental Health

obtained in connection with this research project that can identify you will remain confidential and will only be used for the purposes stated in this document. It will only be disclosed with your permission, except as required by law.

Information about you may be obtained from your health records held at this and other health organisations for the purpose of this research. For example, information relating to the type of medications you have taken in the past and the date in which you commenced your treatment at Orygen may be obtained from your health records. By signing the consent form you agree to the research team accessing health records if they are relevant to your participation in this research project.

Information from the interviews conducted for this study (including electronic or digital information kept on storage media or recording equipment) will be kept in a locked filing cabinet at Orygen, The National Centre of Excellence in Youth Mental Health. This information can only be accessed by the principal researcher, Dr Sarah Bendall, and the associate investigators Associate Professor Lou Harms and Mr Leo Kamitsis. Your questionnaire responses will be entered without any identifying information into a computer database, which will be password-protected and only accessed by Dr Bendall, A/Prof Harms and Mr Kamitsis. Electronic copies of your interview recordings and transcripts will also be password protected and accessed only by the researchers involved in this project. Your data will have a unique code, which will be linked to your contact details, which is kept in a separate password-protected file (printed copy stored in a locked filing cabinet), for the purpose of contacting you for further information or, with your consent, contacting you for future research projects at Orygen. Only Dr Bendall, A/Prof Harms and Mr Kamitsis will have access to the link between the unique code and your contact details.

Upon completion of the study, your information will be kept for a minimum of 5 years from the date of final publication. After that it will all be destroyed.

We will endeavour to keep all the information that we collect in the assessments strictly confidential. There are some exceptions to this: 1) information from the assessments may be communicated with your case manager to ensure that you receive the best care possible; 2) if we are concerned about risk to yourself or someone else, we may need to discuss this with your case manager and doctor at Orygen; 3) if as a result of the information you disclose in the interview relating to your past trauma or abuse we believe that someone else may be at risk. In some cases we may contact The Department of Human Services about risk to children under the age of 17 years. Mandatory reporting laws require clinicians to report to Child Protective Services any suspected cases of child abuse and neglect (Children, Youth and Families Act 2005 (Vic.)). In cases where abuse is reported, information gathered by researchers is passed on to the clinical team and the appropriate clinical procedures normally used within the mental health service are implemented. This may involve reporting abuse to DHS or other support services. We will try to the best of our ability to discuss this with you first.

Your medical record and any information obtained during the study are subject to inspection, for the purpose of verifying study procedures and the data, by the relevant authorities and authorised representatives of the Orygen, the Melbourne Health Human Research Ethics Committee, the Melbourne Health Office for Research or as required by law. By signing the consent section, you authorise release of, or access to, this confidential information to the relevant study personnel and regulatory authorities as noted above.

Information about your participation in this research project will be recorded in your medical record.

We plan to publish group results, for example in scientific journals, to present them at scientific conferences and talk about them to other people who work in mental health industries in order

to help them improve the service they provide to people with psychosis who are currently taking, or contemplating on taking, antipsychotic medication.

In any publication and/or presentation, information will be provided in such a way that you cannot be identified, except with your express permission. As this is an exploratory study, which aims to obtain an in-depth understanding of peoples' experience of taking antipsychotics, if the results are published, direct quotations may be taken from your transcript to illustrate a certain aspect of the findings. In such articles, another name will be used so that you cannot be identified.

We are also seeking your consent to store and use information we gather during this interview(s) with you in any future research projects that might be conducted. By providing your contact details on the consent form below you are consenting to the possibility of being contacted in the future and asked if you would like to participate in any follow-up research.

In accordance with relevant Australian and/or Victorian privacy and other relevant laws, you have the right to request access to the information about you that is collected and stored by the researchers about you. You also have the right to request that any information with which you disagree be corrected. Please inform the research team member named at the end of this document if you would like to access your information.

12 Complaints and compensation

If you suffer any distress or psychological injury as a result of this research project, you should contact the research team as soon as possible. You will be assisted with arranging appropriate treatment and support.

If you have a complaint about the research team, OR any serious event that occurs following your participation in this project, you should talk with your case manager and/or contact the complaints person listed on this form.

13 Who is organising and funding the research?

This research is being conducted by Orygen, The National Centre of Excellence in Youth Mental Health. It is being funded by the University of Melbourne.

14 Who has reviewed the research project?

All research in Australia involving humans is reviewed by an independent group of people called a Human Research Ethics Committee (HREC).

The ethical aspects of this research project have been approved by the HREC of Melbourne Health.

This project will be carried out according to the *National Statement on Ethical Conduct in Human Research (2007)*. This statement has been developed to protect the interests of people who agree to participate in human research studies.

15 Further information and who to contact

The National Centre of Excellence in Youth Mental Health

The person you may need to contact will depend on the nature of your query. If you want any further information concerning this project or if you have any problems which may be related to your involvement in the project, you can contact

Research contact person

Name	Dr Sarah Bendall
Position	Principal Researcher
Telephone	(03) 9342 2986
Email	sarah.bendall@orygen.org.au

If you have any complaints about any aspect of the project, the way it is being conducted or any questions about being a research participant in general, then you may contact:

Complaints contact/Reviewing HREC approving this research and HREC Executive

Reviewing HREC name	Ms Jessica Turner
HREC Executive Officer	Manager, Melbourne Health Human Research Ethics Committee
Telephone	(03) 9342 7602
Email	Jessica.Turner@mh.org.au

Consent Form - *Adult providing own consent*

Title	The Subjective Experience of Taking Antipsychotic Medication: A Qualitative Study of People with Psychosis and a History of Childhood Trauma
HREC Number	HREC# 2015.117
Project Sponsor	Orygen, The National Centre of Excellence in Youth Mental Health
Principal Investigator	Dr Sarah Bendall
Associate Investigator(s)	A/Prof Lou Harms and Leo Kamitsis
Location	Orygen Youth Health Clinical Program

Declaration by Participant

I have read the Participant Information Sheet or someone has read it to me in a language that I understand.

I understand the purposes, procedures and risks of the research described in the project.

I have had an opportunity to ask questions and I am satisfied with the answers I have received.

I freely agree to participate in this research project as described and understand that I am free to withdraw at any time during the project without affecting my future care.

I understand that I will be given a signed copy of this document to keep.

☐ I understand that information I provide for this research may be disclosed to my case manager, and that mandatory reporting laws require that clinicians report any case of suspected child abuse or neglect to Child Protective Services.

Name of Participant (please print) _____

Signature _____ Date _____

Name of Witness* (please print) _____

Signature _____ Date _____

* Witness is not to be the investigator, a member of the study team or their delegate. In the event that an interpreter is used, the interpreter may not act as a witness to the consent process. Witness must be 18 years or older. Witness is required when the participant cannot read the document for him/herself.

Declaration by Researcher†

I have given a verbal explanation of the research project, its procedures and risks and I believe that the participant has understood that explanation.

Name of Researcher† (please print) _____

Signature _____ Date _____

† An appropriately qualified member of the research team must provide the explanation of, and information concerning, the research project.

Note: All parties signing the consent section must date their own signature.

Form for Withdrawal of Participation - *Adult providing own consent*

Title	The Subjective Experience of Taking Antipsychotic Medication: A Qualitative Study of People with Psychosis and a History of Childhood Trauma
HREC Number	HREC# 2015.117
Project Sponsor	Orygen, The National Centre of Excellence in Youth Mental Health
Principal Investigator	Dr Sarah Bendall
Associate Investigator(s)	A/Prof Lou Harms and Leo Kamitsis
Location	Orygen Youth Health Clinical Program

Declaration by Participant

I wish to withdraw from participation in the above research project and understand that such withdrawal will not affect my routine care, or my relationships with the researchers, those treating me or Orygen Youth Health.

Name of Participant (please print) _____

Signature _____ Date _____

In the event that the participant's decision to withdraw is communicated verbally, the Senior Researcher must provide a description of the circumstances below.

Declaration by Researcher†

I have given a verbal explanation of the implications of withdrawal from the research project and I believe that the participant has understood that explanation.

Name of Researcher (please print) _____

Signature _____ Date _____

† An appropriately qualified member of the research team must provide information concerning withdrawal from the research project.

Note: All parties signing the consent section must date their own signature.

Appendix K: Participant Information Sheet/Consent Form—Prahran Mission

The National Centre of Excellence in Youth Mental Health

Participant Information Sheet/Consent Form

Health/Social Science Research - *Adult providing own consent*

Orygen – The National Centre of Excellence in Youth Mental Health

Title	The Subjective Experience of Taking Antipsychotic Medication: A Qualitative Study of People with Psychosis and a History of Childhood Trauma
HREC Number	HREC# 2015.117
Project Sponsor	Orygen, The National Centre of Excellence in Youth Mental Health
Principal Investigator	Dr Sarah Bendall
Associate Investigator(s)	Prof Lou Harms and Leo Kamitsis

Part 1 What does my participation involve?

1 Introduction

You are invited to take part in this research project, which is called The Subjective Experience of Taking Neuroleptic Medication: A Qualitative Study of People with Psychosis and a history of Childhood Trauma. You have been invited because you are taking, or have taken antipsychotic medication, and you have either talked with your support worker about having experienced childhood trauma (such as physical abuse or neglect), or upon being informed of the study by the researchers' during an educational group, have contacted the researchers' and indicated that you have experienced childhood trauma.

If your support worker at Prahran Mission was the one who informed you of the study, your contact details were obtained from that support worker.
This Participant Information Sheet/Consent Form tells you about the research project. It explains the processes involved with taking part. Knowing what is involved will help you decide if you want to take part in the research.

Please read this information carefully. Ask questions about anything that you don't understand or want to know more about. Before deciding whether or not to take part, you might want to talk about it with a relative, friend or local health worker.

Participation in this research is voluntary. If you don't wish to take part, you don't have to.

If you decide you want to take part in the research project, you will be asked to sign the consent section. By signing it you are telling us that you:

- Understand what you have read
- Consent to take part in the research project
- Consent to be involved in the research described
- Consent to the use of your personal and health information as described.

You will be given a copy of this Participant Information and Consent Form to keep.

Orygen
The National Centre of Excellence in Youth Mental Health

2 What is the purpose of this research?

Some people with psychosis have had traumatic childhood experiences, such as emotional, sexual or physical abuse. As part of their treatment, many of these people have taken an antipsychotic medication. The purpose of this project is to explore what it feels like for people with psychosis and a history of childhood trauma to take antipsychotics, and whether these medications have affected their thinking, as well as their emotional and physical state. We also wish to investigate whether antipsychotics influence the way these people experience thoughts, images and/or memories of past trauma, or their emotions and physical responses to it, and whether they alter any experiences of feeling disconnected from themselves or their environment. As far as we are aware, a specific exploration into how people with psychosis and a history of childhood trauma subjectively experience antipsychotic medications has yet to be undertaken. By undertaking such an exploration, we hope to learn more about the effect that these medications have on the individual as a whole, and on the way they currently experience their trauma memory.

The results of this research will be used by the researcher Leo Kamitsis to obtain a PhD (Youth Mental Health) degree.

This research has been initiated by the researcher, Dr Sarah Bendall.

This research has been funded by the University of Melbourne.

3 What does participation in this research involve?

If you consent to being in the study, after signing this participant Consent Form, participation will involve one initial interview of approximately two hours, and if you like, a second follow-up interview of approximately one hour and fifteen minutes. Both interviews will be undertaken with the same researcher, Leo Kamitsis.

During the initial interview you will be asked to complete two questionnaires relating to your past trauma. These will include questions about whether you have experienced physical, sexual and emotional abuse. In order to further confirm your psychosis diagnosis, you will also be asked a series of questions about your psychotic symptoms." The session will further involve being asked questions by the researcher about your experience of taking antipsychotic medication, and whether these medications have influenced your thinking, as well as your emotional and physical experience. The researcher will also ask you some questions about whether your medication has influenced the way you experience any thoughts, images and memories of your trauma, your emotional and physical responses to your trauma, and whether the medication has altered any experiences of feeling disconnected from yourself or your environment. You can choose to not answer these questions if you wish.

You are also welcome to participate in a second interview that will occur a few months after the first interview. During this session you will be asked to read a short summary of the whole study's findings obtained from the initial interview process, or if you prefer, have the researcher describe these findings to you. You will then be asked to offer your opinion about these findings.

Both interviews will be audio recorded and produced in exact written form. Each interview will be typewritten professionally by an independent service. The service which will undertake the

writing of each interview will keep the information they receive confidential. Your responses to the two questionnaires and your personal details, such as your full name and address, will not be given to this service. Once your interview is typewritten a copy will be emailed to you.

There are no costs associated with participating in this research project. However, you will be reimbursed $60 for participating in the first interview, and an additional $30 if you chose to participate in a second interview. The reimbursement should cover any expenses associated with the research project visit.

4 Other relevant information about the research project

It is estimated that 25 participants will take part in this project. Participants will be recruited from the Early Psychosis Prevention and Intervention Centre (EPPIC) of the Orygen Youth Health Clinical Program, Prahran Mission, and the wider community.

5 Do I have to take part in this research project?

Participation in any research project is voluntary. If you do not wish to take part, you do not have to. If you decide to take part and later change your mind, you are free to withdraw from the project at any stage.

If you do decide to take part, you will be given this Participant Information and Consent Form to sign and you will be given a copy to keep.

Your decision whether to take part or not to take part, or to take part and then withdraw, will not affect your routine care, your relationship with professional staff or your relationship with those supporting you or with Prahran Mission.

6 What are the possible benefits of taking part?

We cannot guarantee or promise that you will receive any benefits from this research; however, possible benefits may include having the opportunity to reflect on how antipsychotic medication has affected you psychologically and physically. Information obtained through the research interview may assist with your care and may be fed back to the supporting team with your permission. The results of this study may enrich our understanding of how people with psychosis and a history of childhood trauma experience antipsychotics.

7 What are the possible risks and disadvantages of taking part?

You should be aware that talking about your experience with antipsychotic medications or your childhood trauma may cause you distress. You may feel that some of the questions we ask are stressful or upsetting. If you do not wish to answer a question, you may skip it and go to the next question, or you may stop immediately. If you become upset or distressed as a result of your participation in the research project, and you have a support worker at Prahran Mission, the research team will be able to arrange for you to talk to your support worker.. If you require counselling, the researchers will arrange counselling for you either with Leo Kamitsis (immediately after the interview) or, with a support worker at Prahran Mission (as soon as can be arranged). You may prefer to suspend or end your participation in this research if distress

occurs. If you disclose any current trauma the research team can assist you in informing your support worker.

8 What if I withdraw from this research project?

If you do consent to participate, you are free to withdraw from this research project at any point during the study, either verbally or by completing the "Withdrawal of Consent" form which the research team will provide to you. If you decide to withdraw from the project, please notify a member of the research team before you withdraw. -

If you decide to leave the research project, the researchers will not collect additional personal information from you, although personal information already collected will be retained to ensure that the results of the research project can be measured properly and to comply with law. You should be aware that data collected up to the time you withdraw will form part of the research project results. If your data has not yet been processed and you do not want it to be included, you must tell the researchers when you withdraw from the research project.

9 Could this research project be stopped unexpectedly?

This research project may be stopped unexpectedly for a variety of reasons. These may include reasons such as:

- if an undue amount of distress is experienced by participants of the study;
- the student researcher discontinuing with his respective course of study.

However, many studies of a similar nature to this current study have been conducted in the past through Orygen, The National Centre of Excellence in Youth Mental Health without any incident or cause to end the study. Therefore the likelihood that the study will be stopped is low.

The student researcher will be co-supervised by Dr Sarah Bendall and Prof Lou Harms. Throughout the recruitment process the student researcher will engage in fortnightly supervision sessions with both or either of Dr Bendall and Prof Harms. During these sessions any issues relating to the safety of participants will be discussed and evaluated. If the student researcher is concerned for the safety of a participant during or after their interview he will contact both or either of Dr Bendall and Prof Harms. Dr Bendall is a registered clinical psychologist with over 15 years of clinical experience in treating people with post-traumatic stress disorder (PTSD), and 10 years of experience researching and treating people with first episode psychosis. Prof Harms has over 10 years of clinical experience in working with people with mental health issues, and 13 years of experience in researching trauma, loss, and posttraumatic growth.

10 What happens when the research project ends?

If you would like feedback on your individual results from the interview process, you may ask a member of the research team. Feedback can be provided to you in either a verbal or written format. You will be invited to attend the second interview, where you will be provided with your choice of a written or verbal summary of the study findings and given the chance to comment on those findings. Even if you do not wish to attend a second interview, we will provide you with a summary of the results of the project when the project is concluded if requested. If you would like this summary we will ask you for some contact details so that we can post or email it to you.

Orygen
The National Centre of Excellence in Youth Mental Health

This is expected to be available in March 2017. We will also publish results of the study in publicly available scientific journals.

Part 2 How is the research project being conducted?

11 What will happen to information about me?

By signing the consent form you consent to the research team collecting and using personal information about you for the research project. The personal information that the research team collects and uses is from the interview(s) and questionnaires you complete. Any information obtained in connection with this research project that can identify you will remain confidential and will only be used for the purposes stated in this document. It will only be disclosed with your permission, except as required by law.

Information from the interviews conducted for this study (including electronic or digital information kept on storage media or recording equipment) will be kept in a locked filing cabinet at Orygen, The National Centre of Excellence in Youth Mental Health. This information can only be accessed by the principal researcher, Dr Sarah Bendall, and the associate investigators Professor Lou Harms and Mr Leo Kamitsis. Your questionnaire responses will be entered without any identifying information into a computer database, which will be password-protected and only accessed by Dr Bendall, Prof Harms and Mr Kamitsis. Electronic copies of your interview recordings and transcripts will also be password protected and accessed only by the researchers involved in this project. Your data will have a unique code, which will be linked to your contact details, which is kept in a separate password-protected file (printed copy stored in a locked filing cabinet), for the purpose of contacting you for further information or, with your consent, contacting you for future research projects at Orygen. Only Dr Bendall, Prof Harms and Mr Kamitsis will have access to the link between the unique code and your contact details.

Upon completion of the study, your information will be kept for a minimum of 5 years from the date of final publication. After that it will all be destroyed.

We will endeavour to keep all the information that we collect in the assessments strictly confidential. There are some exceptions to this: 1) information from the assessments may be communicated with your support worker to ensure that you receive the best care possible; 2) if we are concerned about risk to yourself or someone else, we may need to discuss this with your support worker at Prahran Mission and/or the nearest crisis assessment team (CAT); 3) if as a result of the information you disclose in the interview relating to your past trauma or abuse we believe that someone else may be at risk. In some cases we may contact The Department of Human Services about risk to children under the age of 17 years. Mandatory reporting laws require clinicians to report to Child Protective Services any suspected cases of child abuse and neglect (Children, Youth and Families Act 2005 (Vic.)). In cases where abuse is reported, information gathered by researchers is passed on to the clinical team and the appropriate clinical procedures normally used within the mental health service are implemented. This may involve reporting abuse to DHS or other support services. We will try to the best of our ability to discuss this with you first.

Information obtained during the study are subject to inspection, for the purpose of verifying study procedures and the data, by the relevant authorities and authorised representatives of the Orygen, the Melbourne Health Human Research Ethics Committee, the Melbourne Health Office for Research or as required by law. By signing the consent section, you authorise release of, or access to, this confidential information to the relevant study personnel and regulatory

authorities as noted above.

We plan to publish group results, for example in scientific journals, to present them at scientific conferences and talk about them to other people who work in mental health industries in order to help them improve the service they provide to people with psychosis who are currently taking, or contemplating on taking, antipsychotic medication.

In any publication and/or presentation, information will be provided in such a way that you cannot be identified, except with your express permission. As this is an exploratory study, which aims to obtain an in-depth understanding of peoples' experience of taking antipsychotics, if the results are published, direct quotations may be taken from your transcript to illustrate a certain aspect of the findings. In such articles, another name will be used so that you cannot be identified.

We are also seeking your consent to store and use information we gather during this interview(s) with you in any future research projects that might be conducted. By providing your contact details on the consent form below you are consenting to the possibility of being contacted in the future and asked if you would like to participate in any follow-up research.

In accordance with relevant Australian and/or Victorian privacy and other relevant laws, you have the right to request access to the information about you that is collected and stored by the researchers about you. You also have the right to request that any information with which you disagree be corrected. Please inform the research team member named at the end of this document if you would like to access your information.

12 Complaints and compensation

If you suffer any distress or psychological injury as a result of this research project, you should contact the research team as soon as possible. You will be assisted with arranging appropriate treatment and support.

If you have a complaint about the research team, OR any serious event that occurs following your participation in this project, you should talk with your support worker and/or contact the complaints person listed on this form.

13 Who is organising and funding the research?

This research is being conducted by Orygen, The National Centre of Excellence in Youth Mental Health. It is being funded by the University of Melbourne.

14 Who has reviewed the research project?

All research in Australia involving humans is reviewed by an independent group of people called a Human Research Ethics Committee (HREC).

The ethical aspects of this research project have been approved by the HREC of Melbourne Health.

The National Centre of Excellence in Youth Mental Health

This project will be carried out according to the *National Statement on Ethical Conduct in Human Research (2007)*. This statement has been developed to protect the interests of people who agree to participate in human research studies.

15 Further information and who to contact

The person you may need to contact will depend on the nature of your query. If you want any further information concerning this project or if you have any problems which may be related to your involvement in the project, you can contact

Research contact person

Name	Dr Sarah Bendall
Position	Principal Researcher
Telephone	(03) 9342 2986
Email	sarah.bendall@orygen.org.au

If you have any complaints about any aspect of the project, the way it is being conducted or any questions about being a research participant in general, then you may contact:

Complaints contact/Reviewing HREC approving this research and HREC Executive

Reviewing HREC name	Ms Jessica Turner
HREC Executive Officer	Manager, Melbourne Health Human Research Ethics Committee
Telephone	(03) 9342 7602
Email	Jessica.Turner@mh.org.au

Consent Form - *Adult providing own consent*

Title	The Subjective Experience of Taking Antipsychotic Medication: A Qualitative Study of People with Psychosis and a History of Childhood Trauma
HREC Number	HREC# 2015.117
Project Sponsor	Orygen, The National Centre of Excellence in Youth Mental Health
Principal Investigator	Dr Sarah Bendall
Associate Investigator(s)	Prof Lou Harms and Leo Kamitsis
Location	Orygen Youth Health Clinical Program

Declaration by Participant

I have read the Participant Information Sheet or someone has read it to me in a language that I understand.

I understand the purposes, procedures and risks of the research described in the project.

I have had an opportunity to ask questions and I am satisfied with the answers I have received.

I freely agree to participate in this research project as described and understand that I am free to withdraw at any time during the project without affecting my future care.

I understand that I will be given a signed copy of this document to keep.

☐ I understand that information I provide for this research may be disclosed to my support worker, and that mandatory reporting laws require that clinicians report any case of suspected child abuse or neglect to Child Protective Services.

Name of Participant (please print) _____

Signature _____ Date _____

Name of Witness* (please print) _____

Signature _____ Date _____

* Witness is not to be the investigator, a member of the study team or their delegate. In the event that an interpreter is used, the interpreter may not act as a witness to the consent process. Witness must be 18 years or older. Witness is required when the participant cannot read the document for him/herself.

Declaration by Researcher†

I have given a verbal explanation of the research project, its procedures and risks and I believe that the participant has understood that explanation.

Name of Researcher† (please print) _____

Signature _____ Date _____

† An appropriately qualified member of the research team must provide the explanation of, and information concerning, the research project.

Note: All parties signing the consent section must date their own signature.

Form for Withdrawal of Participation - *Adult providing own consent*

Title	The Subjective Experience of Taking Antipsychotic Medication: A Qualitative Study of People with Psychosis and a History of Childhood Trauma
HREC Number	HREC# 2015.117
Project Sponsor	Orygen, The National Centre of Excellence in Youth Mental Health
Principal Investigator	Dr Sarah Bendall
Associate Investigator(s)	Prof Lou Harms and Leo Kamitsis
Location	Orygen Youth Health Clinical Program

Declaration by Participant

I wish to withdraw from participation in the above research project and understand that such withdrawal will not affect my routine care, or my relationships with the researchers, those supporting me or Prahran Mission.

Name of Participant (please print) _____

Signature _____ Date _____

In the event that the participant's decision to withdraw is communicated verbally, the Senior Researcher must provide a description of the circumstances below.

Declaration by Researcher†

I have given a verbal explanation of the implications of withdrawal from the research project and I believe that the participant has understood that explanation.

Name of Researcher (please print) _____

Signature _____ Date _____

† An appropriately qualified member of the research team must provide information concerning withdrawal from the research project.

Note: All parties signing the consent section must date their own signature.

Appendix L: Childhood Trauma Questionnaire

Childhood Trauma Questionnaire

When I was growing up ...	Never	Rarely	Sometimes	Often	Very Often
1. I didn't have enough to eat.					
2. I knew that there was someone to take care of me and protect me.					
3. People in my family called me things like "stupid," "lazy," or "ugly."					
4. My parents were too drunk or high to take care of the family.					
5. There was someone in my family who helped me feel that I was important or special.					
6. I had to wear dirty clothes.					
7. I felt loved.					
8. I thought that my parents wished I had never been born.					
9. I got hit so hard by someone in my family that I had see a doctor or go to the hospital.					
10. There was nothing I wanted to change about my family.					
11. People in my family hit me so hard that it left me with bruises or marks.					
12. I was punished with a belt, a board, a cord, or some other hard object.					
13. People in my family looked out for each other.					
14. People in my family said hurtful or insulting things to me.					
15. I believe that I was physically abused.					
16. I had the perfect childhood.					
17. I got hit or beaten so badly that it was noticed by someone like a teacher, a neighbour or doctor.					
18. I felt that someone in my family hated me.					

19. People in my family felt close to each other					
20. Someone tried to touch me in a sexual way, or tried to make me touch them.					
21. Someone threatened to hurt me or tell lies about me unless I did something sexual with them.					
22. I had the best family in the world.					
23. Someone tried to make me do sexual things or watch sexual things.					
24. Someone molested me.					
25. I believe that I was emotionally abused.					
26. There was someone to take me to the doctor if I needed it.					
27. I believe that I was sexually abused.					
28. My family was a source of strength and support.					

Appendix M: Life Events Checklist

LIFE EVENTS CHECKLIST (LEC)

Listed below are a number of difficult or stressful things that sometimes happen to people. For each event check one or more of the boxes to the right to indicate that: (a) it *happened to you* personally, (b) you *witnessed it* happen to someone else, (c) you *learned about it* happening to someone close to you, (d) you're *not sure* if it fits, or (e) it *doesn't apply* to you.

Be sure to consider your *entire life* (growing up as well as adulthood) as you go through the list of events.

Event	Happened to me	Witnessed it	Learned about it	Not Sure	Doesn't apply
1. Natural disaster (for example, flood, hurricane, tornado, earthquake)					
2. Fire or explosion					
3. Transportation accident (for example, car accident, boat accident, train wreck, plane crash)					
4. Serious accident at work, home, or during recreational activity					
5. Exposure to toxic substance (for example, dangerous chemicals, radiation)					
6. Physical assault (for example, being attacked, hit, slapped, kicked, beaten up)					
7. Assault with a weapon (for example, being shot, stabbed, threatened with a knife, gun, bomb)					
8. Sexual assault (rape, attempted rape, made to perform any type of sexual act through force or threat of harm)					
9. Other unwanted or uncomfortable sexual experience					
10. Combat or exposure to a war-zone (in the military or as a civilian)					
11. Captivity (for example, being kidnapped, abducted, held hostage, prisoner of war)					
12. Life-threatening illness or injury					
13. Severe human suffering					
14. Sudden, violent death (for example, homicide, suicide)					
15. Sudden, unexpected death of someone close to you					
16. Serious injury, harm, or death you caused to someone else					
17. Any other very stressful event or experience					

Appendix N: Follow-up Questions and Results Summary for Participants

Follow-up questions and Summary of Findings

Between October 2016 and September 2017 we interviewed 19 people who experienced childhood trauma and psychosis about their experiences of taking antipsychotic medications. The interviews were then typed up and analysed. During your follow-up interview you will be asked four questions. These questions are listed in red. Below each question you will find key themes relating to what people spoke about in their initial interviews (the study's preliminary findings). The majority of themes are grouped into four topic areas. The number of participants who spoke about each theme is placed in brackets next to each theme. From now until the day of your follow-up interview, we would like you to spend some time reading the theme descriptions and reflecting on the questions. This may help you identify any further insights that you would like to share during your follow-up interview.

Question 1
We found that people had a lot to say about the function of antipsychotics within the context of their lives. Upon reading the description of this theme, have you got any further insights about your experience of the function and usefulness of antipsychotic medications?

Perceived function and usefulness of antipsychotics. (13 participants).
Some of the main things mentioned by participants were:

- Taking antipsychotics is bittersweet. The medications are important in maintaining mental health, though a person has to tolerate some distressing side-effects. The medication needs to be taken despite the side-effects.
- Being mentally healthy isn't achieved through medication alone, but through a combination of equally important things which include: antipsychotic medication, counselling, community engagement, having the right attitude (wanting to get help), faith (religion / spirituality), exercise and use of distraction strategies.
- Antipsychotics are like a Band Aid, they can calm a person down and level them out, though they don't help them deal with the underlying problem.
- Healing is different from illness management. Antipsychotics help a person manage their illness, though they don't help them heal from certain experiences. Healing comes from within oneself.
- Being fixed by drugs reinforces to that person that they are sick and broken.

Question 2
Upon reading the theme descriptions outlined under topic 1, have you got any further insights about how antipsychotic medications have influenced any trauma-related thoughts emotions, and/or physical symptoms that you may have experienced?

Topic 1 – Impact of antipsychotics on trauma-related experiences (thoughts, emotions, and physical responses / symptoms).

Antipsychotics prevent you from confronting trauma. (4 participants).

By stopping trauma related thoughts and supressing trauma related emotions, antipsychotics prevent a person from confronting and addressing trauma.

Uncertain about what's altered trauma related experiences. (7 participants).
Uncertainty about what changed the trauma related thoughts, emotions and/or physical symptoms. Change could have occurred because of the antipsychotics, other medications, counselling or some other factor.

No change in trauma-related experiences. (6 participants).
Antipsychotics didn't change the way people experienced trauma related thoughts, emotions, and/or physical symptoms.

Altering trauma related experiences. (10 participants).
People spoke about how antipsychotics altered their trauma related experiences. Antipsychotics prevented people from ruminating about traumatic experiences, and subdued trauma-related emotions. When doing trauma therapy, antipsychotics are like a safe cacoon that gives a person rest from experiencing the intense emotions. Medication also relieves trauma-related anxiety. While taking antipsychotics, trauma-related experiences occur more often. Trauma-related experiences are intensified or amplified.

Processing and addressing trauma through psychotherapy. (4 participants).
Healing form trauma involves addressing the abuse / neglect, a person needs to avoid avoidance. This occurs through psychotherapy as the drugs alone don't allow a person to confront the past. It is through psychotherapy and not medication that a person is able to make sense of what happened and estrange themselves from their perpetrators. Awareness of trauma also helps you deal with the physical effects of trauma. Furthermore, healing from trauma occurs through the reactivation of emotion and the integration of experience. Antipsychotics prevent the integration of experience.

Medication and counselling help equally in dealing with trauma. (1 participant).
Antipsychotics give a person a clear mind with fewer voices, which allows them to appropriately engage in counselling and confront childhood trauma effectively.

Question 3
Upon reading the theme descriptions outlined under topic 2, have you got any further insights about how antipsychotic medications have influenced any dissociative symptoms[2] which you may have experienced?

Topic 2 – Impact of antipsychotics on dissociative experiences.

Altering dissociative experiences. (5 participants).
People indicated that antipsychotics altered their dissociative experiences. People mentioned that antipsychotics reduced dissociation. Antipsychotics relieve the distress that a person may experience while in an altered state or identity. Other people indicated that while taking antipsychotics their dissociation was intensified.

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[2] People with dissociative symptoms may describe feeling disconnected or detached from themselves, from their body, or from their general everyday experiences. For example, some people indicate that they feel as though they are outside of their body, watching themselves doing things, almost like watching themselves in a movie. Others mention that their experiences feel unreal, as though they are in a dream, and/or that their surroundings appear foggy, hazy or distant.

No change in dissociation. (4 participants).
People stated that antipsychotics didn't change the way they experienced dissociation.

Uncertain about what's influenced dissociation. (5 participants).
Uncertain about what it is that's changed dissociative experiences. It may have been the antipsychotics, though it may also have been something else.

The drug induced state is like dissociation. (3 participants).
Antipsychotics and dissociation are both means through which a person avoids experiencing feelings / emotions. Antipsychotics thus support dissociation, in that they exert a state that serves the same purpose as dissociation. Antipsychotics make a person feel more detached from themselves and from the world around them. When a person is off their medication they are more present. Antipsychotics exert a numbed altered state whereby a person is out phase with reality.

Question 4
Upon reading the remaining theme descriptions under topics 3 and 4 bellow, have you got any further insights about your experience of taking antipsychotic medications?

Topic 3 – Other important themes that aren't directly related to the subjective effects of antipsychotics.

The public health system is unhelpful. (5 participants).
People spoke about how the public health system is unhelpful. It was mentioned that in the public health system people are judged by the diagnostic labels that they are given. In the public health system people are often allocated a different counsellor, and they have to retell their story many times which isn't helpful. People indicated that involuntary treatment is traumatic.

Therapeutic relationship. (7 participant).
People spoke about the importance and nature of the relationships they had with medical / health professionals. It was mentioned that a trusting and supportive therapeutic relationship with one's doctor, psychiatrist and psychologist is essential for people with mental illness. People indicated that they experiencing a lack of understanding and support from medical professionals.

Understanding psychosis. (13 participants).
People described their psychosis, spoke about what they thought caused their psychosis, and expressed their general view about psychosis. Some of the main things mentioned were:

- Psychosis happens for a reason and it needs to be understood. Psychosis is a spiritual crisis.
- Hearing voices is a part of who a person is, like eye colour, hence why people hear voices even while taking antipsychotics.
- Some voices are pleasant.
- Becoming so emotional that the emotions manifest into delusions.
- Thoughts spiral out of control and transform into psychosis.

- Fighting the voices changes the way they speak to a person. Challenging the delusions by questioning whether they are real alleviates their importance.
- Voices are connected to childhood trauma. The voices are those of the perpetrators. Trauma related triggers increases a person's vulnerability to hearing the voices.
- Psychosis is caused by illicit drugs.
- Psychosis is related to mania.

Physical problems attributed to childhood trauma. (3 participants).
People believe that childhood trauma has caused them physical health problems, such as a deterioration in eyesight and osteoarthritis.

Other suggestions. (7 participants).
People made suggestions about how to improve antipsychotic treatment and mental health treatment in general. Some suggestions were:

- Gaining more awareness about the effects of antipsychotics. Educating employers about antipsychotics, and how people taking antipsychotics can still function and be good at their job.
- Development of formal records of antipsychotic related adverse effects reported on by patients that all doctors can see.
- Testing antipsychotics on more diverse populations.
- Organisations and practitioners need to be trauma informed.
- Highlighting peoples' positive experiences with antipsychotics.
- Providing more drug and alcohol rehabilitation services for people.
- Doctors need to be spending more time with people and asking the right questions, not just pushing medications onto people.

Topic 4 – General experience of taking antipsychotics.

Induce sleep. (11 participants).
It was mentioned that antipsychotics induce sleep. People indicated that antipsychotics helped them sleep. People also stated that antipsychotics cause excessive sleepiness, in that they would sleep too much at night, or end up falling asleep at inappropriate times during the day. High doses of the drug seem to cause excessive sleepiness.

Lethargic and unmotivated. (8 participants).
People indicated that antipsychotics turned them into a zombie, especially when on higher doses. People mentioned that while taking antipsychotics they felt tired and lethargic, and they lacked the motivation and energy to do things.

Subdued emotion. (7 participants).
Not experiencing emotions at the same intensity, or in the same way, while on antipsychotics. Feeling emotionally numb or detached. Antipsychotics make a person less sensitive to the environment, as they are not as bothered by what's happening around them.

Impact on psychosis. (19 participants).
People mentioned whether and how their psychosis has been influenced by antipsychotics. People indicated that antipsychotics alleviated their hallucinations and delusions. People also reported that they continued experiencing psychotic symptoms while on medication. With regard to how antipsychotics influence psychosis, people reported the following:

- Antipsychotics relieve psychosis by slowing down the mind, or by putting a stop to the thought process that leads to psychosis.

- Antipsychotics relieve the panic that occurs when experiencing psychosis.
- While on antipsychotics voices fade into the background, like hearing a radio, rather than being loud and overwhelming.
- Antipsychotics relieve the intensity of delusions by subduing the emotions that are connected to specific delusions.

An altered mind. (11 participants).
People spoke about the way in which antipsychotics altered their mind. It was mentioned that antipsychotics dull or slow a person's thinking. It's hard to concentrate on individual tasks and engage in analytical thinking. It's difficult to do everyday things due to lack of creativity, as the drugs stop the creative thought. While on antipsychotics a person's thinking is clearer and less chaotic.

Adverse physical effects. (19 participants).
People described a number of drug related adverse physical effects, of which the most prominent were: significant weight gain, muscle stiffness, tremors and restlessness. Other adverse effects that people reported were: a dry mouth, loss of libido, nausea and bad skin.
Injection medication is horrible and invasive. (1 participant).
With injection medication there are many ups and downs, whereas with oral medications there is consistency. The process of getting the injection is invasive and demeaning.

Use of metaphors. (12 participants).
Metaphors were often used to describe the effects of antipsychotics, or what it has been like to take antipsychotics.

Changing medication type and dose. (17 participants).
People spoke about their experiences of needing to change their medication type and dose. Some of the main things that were mentioned were:

- Taking an antipsychotic when needed, as a PRN. For example, taking an additional pill when experiencing increased levels of anxiety.
- Needing to try multiple antipsychotics before finding a medication that works.
- Stopping the medication results in illness relapse.
- Needing to alter the dose of the medication throughout your life. For example, when going through a crisis you may need to be on a higher dose.
- Becoming aware that you don't need to constantly be on such a high dose of the drug.
- Being mentally healthy is about getting the right combination of psychiatric medications.

Uncertain about what caused change. (10 participants).
People were uncertain about what caused or changed certain experiences (or symptoms). It may be one or a combination of the following: the antipsychotics, other psychiatric drugs, the illness itself, lifestyle changes or other psychological interventions / strategies.

Appendix O: List of Counselling Services

Service: Swinburne University of Technology Psychology Clinic
Address: The George Swinburne Bldg. 34 Wakefield St, Hawthorn, VIC, 3122
Phone: (03) 9214 8653

Service: The University of Melbourne Psychology Clinic
Address: Level 7, 14-20 Blackwood Street, North Melbourne, Vic, 3051
Phone: (03) 9035 5180

Service: The Salvation Army's Melbourne Counselling Service
Address: 69 Bourke St, Melbourne, Vic, 3000
Phone: (03) 9653 3250

Service: Primary Care Psychology
Address: 601 Dandenong Rd, Armadale, Vic, 3143
Phone: (03) 9553 8838

Service: Mingary Counselling Service
Address: Level 2, St Michael's Place, 120 Collins Street, Melbourne, Vic, 3000
Phone: (03) 9654 5120

Service: The Talk Shop Counselling & Psychology
Address: Suite 3, Ground Floor, 2 Brandon Park Drive, Wheelers Hill, Vic, 3150
Kew Junction Tower, Level 1, 89 High Street South, Kew, Vic, 3101
60 Gertz Avenue, Reservoir, Vic, 3073
HWT Tower, Level 23, 40 City Road, Southbank, Vic, 3006
Phone: 1300 224 665

Appendix P: Demographics Treatment and Illness Information Sheet

Demographic, Treatment and Illness Information

Date: _____

SECTION 1 – BASIC INFORMATION

1. **ID number**

2. UR: _____

3. Rater: _____

4. Sources of information: (mark all relevant sources)
a. Patient
b. Clinical file
c. Staff

5. Sex: 1 = M 2 = F

6. Marital status:
1 Married/De Facto
2 Separated
3 Divorced
4 Widowed
5 Never Married

7. **a.** Current main work status:
0 Unemployed
1 Full-time Work
2 Part-time/Casual Work
3 Student
4 Home Duties/House Work
5 Volunteer Work
6 Other (specify)
_____

8. Educational level:
a. Highest year completed at school:
6 (or below)
7
8
9
10
11
12
VCE

b. Additional qualifications:
0 Nil
1 Trade or Technical Training
2 Tertiary Diploma
3 Tertiary Degree
4 Currently Secondary School
5 Currently Tertiary Education
6 Incomplete Tertiary/Technical Training

9. Country of birth (please specify): _____

10. Year of first arrival in Australia: _____

11. Ethnic self-identification: _____

12. Main language spoken as a child: _____

13. Command of English:
1 None
2 Poor
3 Fair
4 Good
5 Native Language

14. Type of psychotic disorder diagnosis: _____

15. Diagnosis of Post-traumatic Stress Disorder (PTSD): 0 No 1 Yes

SECTION 2 – IMPORTANT DATES

16. Date of birth: _____ / _____ / _____

17. Date of onset of frank psychotic symptoms: _____ / _____ / _____

18. Date of admission/registration: _____ / _____ / _____

SECTION 3 – TREATMENT INFORMATION

19. Admission at time of assessment: 0 Outpatient 1 Inpatient

20. Daily dose of any antipsychotic prescribed:
NOTE: You may record more than one drug. Also record CPZ equivalents.

Drug	Prescribed?		Daily Dose	CPZ Equivalent
a) Chlorpromazine (Largactil)	Yes	No		
b) Risperidone (Risperdal)	Yes	No		
c) Clozapine (Clozaril)	Yes	No		
d) Olanzapine (Zyprexa)	Yes	No		
e) Quetiapine (Seroquel)	Yes	No		
f) Droperidol (Droleptan)	Yes	No		
g) Haloperidol (Haldol/Serenace)	Yes	No		
h) Pimozide (Orap)	Yes	No		
i) Thioridazine (Aldazine/Melleril)	Yes	No		
j) Fluphenazine (Anatensol/Modecate)	Yes	No		
k) Trifluoperazine (Stelazine)	Yes	No		
l) Flupenthixol (Fluanxol)	Yes	No		
m) Thiothixene (Novane)	Yes	No		
n) Pericyazine (Neulactil)	Yes	No		
o) Zuclopenthizol (Clopixol)	Yes	No		
p) Lithium/Sodium Valporate	Yes	No		
q) Other _____	Yes	No		

21. Antipsychotic medication compliance:

0 Not Applicable
1 Complete Non Compliance
2 Irregular to Very Irregular Compliance
3 Reasonable Compliance
4 Full Compliance
-9 Unknown/Missing

22. Daily dose of any <u>other psychotropic medication</u> prescribed (including antidepressant, anxyiolitic, benzodiazepine, stimulant and anti-side effect medications):
NOTE: You may record more than one drug.

Drug	Prescribed?		Maximum Daily Dose
a) Antidepressant	Yes	No	
b) Anti-anxiety/Anxyiolitic	Yes	No	
c) Benzodiazepine	Yes	No	
d) Stimulant	Yes	No	
e) Anti-side effect	Yes	No	
f) Other _____	Yes	No	

23. Medication compliance:

0 Not Applicable
1 Complete Non Compliance
2 Irregular to Very Irregular Compliance
3 Reasonable Compliance
4 Full Compliance
-9 Unknown/Missing

24. Alcohol and Drug use today

0 No
1 Yes
what kind?

How much?

25. Organisations from which currently receiving mental health care.

1. _____
2. _____
3. _____
4. _____
5. _____

26. Have received in the past, or currently receiving psychological treatment for trauma:

0 No
1 Yes

27. Duration of treatment: _____