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**EXPERIENCING ANTIPSYCHOTIC MEDICATION:
FROM FIRST PRESCRIPTIONS TO ATTEMPTED DISCONTINUATION**

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List of Abbreviations

ACT: Acceptance and Commitment Therapy

AD: Antidepressant medication

AM: Antipsychotic medication (oral unless otherwise specified)

BC: Brief Cope

BC-Active: Brief Cope composite score for all Active Coping items

BC-Avoidant: Brief Cope composite score for all Avoidant Coping items

BMLSS: Brief Multidimensional Life Satisfaction Scale

CAMS: Current Antipsychotic Medication Status

CBT: Cognitive Behavioural Therapy

FEP: First Episode Psychosis

FGA: First Generation Antipsychotic (typical AM – oral unless otherwise stated)

MS: Mood stabiliser medication

MSPSS: Multidimensional Scale of Perceived Social Support

NAA: Number of Additional Approaches used

OSE: Overall Subjective Experience (of taking AMs)

PRN: Pro Re Nata meaning 'as needed'

RCT: Randomised Controlled Trial

QOL: Quality of Life

SGA: Second Generation Antipsychotic (atypical AM – oral unless otherwise stated)

TEAMS: The Experiences of Antipsychotic Medication Study

WRAP: Wellness Recovery Action Plan

ABSTRACT

Antipsychotic medications (AM) are the designated first-line intervention for psychosis in international best-practice guidelines and are prescribed for a range of other mental-health problems. Relatively little is known about how people subjectively experience AMs and attempted discontinuation or about the role psycho-social factors play in recovery outcomes. This research explores how people experience AMs, use psycho-social strategies and, where relevant, manage discontinuation.

An anonymous online survey was completed by 144 New Zealand adults who had ever taken oral AMs for any reason for more than 3 months. Seven in-depth interviews were conducted to explore experiences of people who had discontinued AMs for over one year.

In Study One, survey participants reported a range of diagnoses including schizophrenia spectrum disorders, bipolar disorder, and depression. Half described a primarily negative first prescription experience. Other treatment options were rarely offered at first prescription but were nevertheless used by many. Few people reported being well-informed of the potential benefits and risks. Descriptions of taking AMs ranged from “life-saver” and “useful tool” to “mixed bag” and “hell”. Most experienced both benefits and adverse effects. Most (79%) had contemplated stopping AMs, and 73% reported making at least one attempt, with variable preparations, methods and outcomes described. Hierarchical multiple regression suggested social support, active coping and avoidant coping were independently predictive of quality of life but current use of AMs was not.

In Study Two, the interviewees revealed that maintaining wellbeing during and after withdrawal from AMs was primarily a function of coming to understand themselves and their needs, connecting with supports, and finding strategies that worked for them, which included accepting symptoms and signs of distress.

Conclusions include that AMs can be experienced as crucial lifesavers, useful tools with drawbacks and/or destructive forces to endure or escape. Attempted discontinuation is common and some people succeed in their efforts to stop, although withdrawal can be risky and is often poorly supported. Multiple psycho-social strategies are helpful additions or alternatives to AMs. Since quality of life is associated with coping and social support, treatment systems cannot rely solely on medication to produce positive outcomes for those who take AMs.

**CHAPTER ONE:
INTRODUCTION**

Antipsychotic medication (AM) is used by most people who experience psychosis and many people who experience mania, often under involuntary conditions. The Experiences of Antipsychotic Medication Study (TEAMS) set out to explore what it is like to take AMs from the perspective of the people taking them, with the ultimate aim of strengthening their contribution to the discourse surrounding AMs and their use. I conducted two separate studies. First, an anonymous survey explored the experiences of people who currently take or have previously taken AMs. Second, a small number of interviews were carried out with a sub-group of survey participants who had stopped taking AMs long-term.

The current introductory chapter presents the rationale for this research in the context of the history of AMs. Chapter Two presents a more detailed review of the literature regarding the effects of AMs and attempted discontinuation. The methodology and results of the two separate studies are presented in two parts. Part One presents and discusses the results of the survey study. First, in Chapter Three the methodology for the survey study is presented. In Chapter Four, experiences of prescribing, AM effects and use of additional approaches are presented for the whole sample of 144. In Chapter Five, experiences of attempted discontinuation are presented for the sub-sample of 105 who had made at least one attempt to stop. Chapter Six presents the results of a hierarchical multiple regression testing for predictors of quality of life (QOL) among the whole sample of 144. Part Two consists of Chapter Seven in which the methodology and findings are presented of the interview study investigating what enabled a subgroup of people who maintained discontinuation long-term to manage their wellbeing during withdrawal from AMs and beyond. Finally in Chapter Eight, the findings of both studies are brought together in a concluding discussion.

My interest in this area began over a decade ago when engaged as a residential support worker on the night shift, where I was charged with making sure people took their evening medication. They would line up, I would hand out their medication and sign that I had sighted them taking it. Some seemed happy with this arrangement. Others said the medication was unwanted and associated with negative effects. I would typically find myself sitting up late with people when they were distressed by visual or auditory hallucinations. We would discuss their lives and there always seemed to be something meaningful beneath these unusual experiences, which were continuing to unfold even among those who took the most medication. Everyone was assigned Pro Re Nata (PRN) medication to take as needed. This was often not needed after we had talked. I went home when the day-staff arrived to administer the morning medication routine. During the day no-one

participated in therapy and all of the personal development programmes focused on daily living skills or occupational activities that seemed unlikely to address the issues I heard about in our informal late-night support sessions. I began researching psycho-social adjuncts to AMs in my spare time and went on to conduct my Master's research exploring the impact of group-based anxiety information and support on the recovery outcomes of people diagnosed with schizophrenia spectrum conditions and bipolar disorder who identified having difficulties with anxiety (Barr, 2009). My research interest at this time was on exploring whether psycho-social factors thought to be common across different diagnostic categories might serve as efficient treatment targets. This was a small study but I noticed that at three months follow-up only the two participants who were not taking any psychiatric medications had maintained their improvements (Larsen-Barr & Owens, 2013). For the first time, I found myself immersed in the medication research as I attempted to explain this unexpected result.

Following this, and prior to undertaking my training as a clinical psychologist, I spent several years employed within the service-user workforce as part of a national stigma reduction initiative. I have not had direct experience with AMs or the conditions they are typically used for, but in the course of my life and my work with the service-user movement, I have had wide-ranging indirect experiences through contact with friends, family members and colleagues who have taken or continue to take AMs. Several colleagues in the service-user workforce managed experiences of mania or psychosis long-term without medication and a number of people in my social circle have made frequent attempts to stop taking AMs that have always resulted in relapse and a return to AMs. Others found AMs invaluable. Holding a psychological perspective and viewing people as autonomous beings who act on their own experiences in a way that affects those experiences, I began to wonder whether psycho-social processes and the use of adjunctive approaches might be involved in the variation I observed in the experiences and outcomes of people taking AMs and those attempting to stop. I became motivated to explore what these factors might be and how it was that people might be able to use them to their advantage. I considered that detailed descriptions of how people experience AMs and manage during and after withdrawal would be of use in clinical practice and would also be of relevance to many of my own friends and family members. It might also contribute to the research literature, where the voices of people who take AMs appear to be lacking.

Background and Rationale

Within the research literature, the discourse about AMs has largely involved clinicians and researchers, with few opportunities for the people using these medications to contribute to the conversation. Thousands of articles have explored the issues of symptom reduction, adverse effects, discontinuation rates, and the impact of medication factors including agent, dose and timing (see

Chapter Two for detail). In comparison, relatively few studies explore the experiential nature of taking AMs or the impact of the psycho-social approaches people might combine with them. The result is a body of knowledge that largely frames AMs as the dominant factor involved in the recovery outcomes of those who take them. An extensive literature base demonstrates the value of psycho-social approaches to recovery, but this is rarely incorporated into the AM research. It is common to read of psycho-social studies controlling for medication use, but much less common to read of AM studies controlling for psycho-social factors with the exception of demographic variables of age, occupational status and education. Furthermore, much of the literature assumes AMs are necessary life-long treatments for biologically-based conditions. This stance may affect the conclusions drawn from results as researchers may overlook data that is inconsistent with their underlying assumptions or priorities. Literature produced by the service-user movement reveals people who take AMs have different assumptions and priorities that emphasise the psycho-social aspects of their lives and daily functioning. A growing body of research suggests AM outcomes might improve when combined with additional psycho-social approaches and highlights a sub-group who may do better without AMs. TEAMS was designed to emphasise the service-user voice in the discourse about AMs by exploring their subjective experiences within the wider psycho-social context of their use.

The Introduction of Antipsychotic Medication

Understanding the history of AMs helps explain why subjective experiences and psycho-social measures have been poorly represented in the AM research literature, and the cultural significance of efforts to incorporate service-user voices. AMs brought about a major shift in the treatment of people with severe psychological problems. Their introduction both coincided with and reinforced faith in a biomedical explanation of psychosis and mania. Furthermore, many people who take AMs have historically been deprived of their human rights, and only in the last few decades has there been some redress to this through legislation.

The first AM, chlorpromazine, was initially trialled in Birmingham, England, in 1953 with the results published in 1954 (Kendall, 2011). Chlorpromazine had been discovered in France in 1951, when Simone Courvoisier was exploring the use of a chlorinated antihistamine in surgery and discovered the rats she was using as test subjects became “indifferent” to food rewards and aversive shocks (Runciman, 2013). A group of 27 people in an inpatient psychiatric ward were given chlorpromazine in a multiple-baseline, reversal-design trial in which each person served as their own control (Elkes & Elkes, 1954). Participants and clinicians were masked as to whether they were receiving a placebo or chlorpromazine in each period. At the end of the trial, a quarter of participants, seven people, were reported to have “definitely improved,” 11 were classified as

slightly improved and nine remained behaviourally unchanged (Elkes & Elkes, 1954). When participants were reversed from chlorpromazine to placebo, psychotic symptoms reappeared, with the same content as previously reported (Kendall, 2011). Chlorpromazine, also known as Thorazine or Largactil (after its 'large action'), received government approval for use in the USA in March of 1954, was in almost universal use across the USA before the turn of the next decade (Mosher, Gosden, & Beder, 2004), and had reached New Zealand by 1955 (Brunton, 2012).

After the introduction of chlorpromazine, came an array of pharmaceutical options claiming to 'treat' psychosis. In 1971, the first of a new type of AM, clozapine was released in Europe but withdrawn four years later (Wenthur & Lindsley, 2013) following high mortality rates related to a serious adverse effect called agranulosis that causes susceptibility to infection (Kendall, 2011). A 1988 study showed the risk of agranulosis could be monitored via regular blood tests (Kane, Honigfeld, Singer, & Meltzer, 1988) and clozapine was approved for use in the USA and the UK by 1990, with the condition that anyone prescribed clozapine receive routine blood tests (Kendall, 2011). A range of new antipsychotics appeared in the following two decades, with risperidone being approved for use in America in 1994, olanzapine in 1996, quetiapine in 1997, and more beyond this (Shen, 1999). All medications first approved after 1989 came to be referred to as atypical antipsychotics or Second Generation Antipsychotics (SGA) and all those first approved prior to this came to be referred to as typical or First Generation Antipsychotics (FGA).

Mechanisms of Action and the Chemical Imbalance Theory

Initial observations regarding the effects of AMs and their mechanisms of action changed social constructions regarding the cause of psychosis and spurred the rise of a biomedical theory that has dominated the literature and superseded service-user voices ever since. Early researchers showed that AMs inhibit dopamine systems and theorised that these same neurotransmitters must be responsible for causing the symptoms of psychosis in the first place (Whitaker, 2005). Working backwards from the observed effect of the medication on behaviour, the biomedical theories posited that mental-health problems were caused by a neurochemical imbalance. Symptoms of psychosis consistently re-emerged when the medications were withdrawn and this was interpreted as evidence that the medications were required to correct a theorised underlying neurochemical dysfunction with dopamine (Moncrieff, 2013). However, the re-emergence of symptoms is now thought to be the result of a biochemical rebound effect caused by withdrawing from AMs (see p13) rather than an underlying tendency of the people taking them (Breggin, 2013; Chouinard, Jones, & Annable, 1978; Moncrieff, 2006). The early faith in AMs was quickly met with evidence that AMs were neither a "cure" nor harm-free. It did not take long for researchers to identify that the same mechanisms responsible for reducing symptoms, also caused a wide range of adverse effects

including increased risk of future relapse, and unpleasant subjective responses (de Haan et al., 2004). These mechanisms are rarely accounted for in discussions about the effectiveness of AMs, the outcomes of discontinuation, or what these things mean for the people who take them. Where AMs were once considered a biological treatment for an underlying chemical imbalance, research has been accumulating since the 1950s to suggest they achieve their effect by suppressing symptoms rather than addressing their cause (Carlsson, 1978; Chouinard & Jones, 1980; Elkes & Elkes, 1954), which appears to be strongly tied to adverse life experiences rather than being a simple by-product of biology (Read, 2014). AMs may not have quite the long-term outcomes that the early treatment literature might have predicted (Moncrieff, 2013); see Chapter Two.

AMs were initially referred to as ‘major tranquilisers’ due to a wide-spread suppressive effect on emotions, cognition and behaviour; the term neuroleptics was first used in 1955 due to observed effects on the motor system and they have been referred to as antipsychotic medications from as early as 1969 (King & Voruganti, 2002). The earliest descriptions in English described how they “produce a state of motor retardation, emotional indifference, and somnolence, and the dose must be increased accordingly as tolerance develops,” and that “some patients dislike their treatment and complain of their drowsiness and weakness. Some say they feel ‘washed out,’ as after an exhausting illness, a complaint which is indeed in keeping with their appearance” (Lehmann & Hanrahan, 1954, p229-230). Even in the first trial of chlorpromazine, the authors note that participants “continued to be subject to delusions and hallucinations though they appeared to be less disturbed by them” and conclude that “The relief afforded by chlorpromazine thus appears to be principally symptomatic” (Elkes & Elkes, 1954, p564). When non-clinical subjects take AMs they tend to report only adverse reactions to the ensuing state of sedation and demotivation (Healy & Farquhar, 1998), and some of the newer AMs are reportedly used as recreational drugs due to that same effect (Hanley & Kenna, 2008).

The same mechanisms of action are thought to cause the symptom reductions and adverse effects that accompany AMs (Carlsson, 1978). AMs predominantly inhibit dopamine and act variously on histamine, acetylcholine, noradrenalin, and serotonin at different receptor sites (Anden, 1974; Roth, Hamblin, Sibley, & Meltzer, 1996; Shen, 1999; Wenthur & Lindsley, 2013). Each of these neurotransmitters has been implicated in a range of functions, from metabolic functioning to emotional arousal, which correspond to the range of effects associated with AMs and their withdrawal (Anden, 1974; Carlsson, 1978; Chouinard et al., 1978; Shirazi-Southall, Rodriguez, & Nomikos, 2002; Steiner, Laporta, & Chouinard, 1990). Researchers theorise that inhibiting dopamine systems causes the brain to respond by accelerating the production of dopamine to regain baseline status and then increasing the density of synaptic receptors to maintain that status (Chouinard et al.,

1978; Chouinard & Jones, 1980; Steiner et al., 1990). This neurological adjustment is thought to produce a tolerance to the medication over time and a surge or rebound in dopamine levels when the medication is withdrawn, due to the proliferation of the associated receptors, and an associated re-emergence of somatic and psychotic symptoms upon discontinuation of AMs (Chouinard et al., 1978; Steiner et al., 1990). This is often referred to as a rebound phenomenon (Moncrieff, 2006) or “supersensitivity psychosis” in an attempt to distinguish this from relapse that is unrelated to medication factors (Chouinard & Jones, 1980; Chouinard, 1991; Steiner et al., 1990).

The rebound phenomenon may account for a proportion of the relapses observed proximal to the reduction or discontinuation of AMs (Moncrieff, 2006). Reinstating AM in these instances may constitute treating the withdrawal syndrome with the agent that caused it and potentially increase the risk of future rebound (Breggin, 2013). Recent research has suggested that since AMs were first introduced rates of chronicity have increased among people who experience mental-health problems (Whitaker, 2005). Early studies found people diagnosed with schizophrenia who had never been treated with AMs showed significantly lower rates of hospitalisation than those treated with AMs (National Institute of Mental Health Psychopharmacology Service Center Collaborative Study Group (NIMH), 1964; Rappaport, Hopkins, Hall, Belleza, & Silverman, 1978; Schooler, Goldberg, Boothe, & Cole, 1967). Treatment with AMs appeared to have a short-term benefit that came at the cost of increased vulnerability to relapse over time. From 1955 to 2000 there was a four-fold per-capita increase in the number of people seeking treatment for mental-health problems in a year, and the number of people receiving disability for mental-health problems underwent similar per-capita inflation (Whitaker, 2005). Rather than correcting an existing neurochemical imbalance, it has been argued that AMs create one (Breggin, 2013; Chouinard et al., 1978; Moncrieff, 2013; Whitaker, 2005). The rebound phenomenon makes interpreting the results of RCTs of AMs difficult, particularly when relapse and symptom exacerbation or remission are used as outcome measures; very few studies are based on results obtained from participants who have never taken AMs before, most placebo groups and many active treatment groups are recently withdrawn from a previous AM during baseline data collection and the results may be skewed by these points of comparison (Whitaker, 2005).

There have always been dissenting voices among the research community arguing for an alternative view to the chemical imbalance theory of psychosis and advocating psycho-social perspectives and modes of treatment (Chouinard et al., 1978; Elkes & Elkes, 1954; Foucault, 1992; Laing, 1970; Rappaport et al., 1978; Szasz, 1962) but they have represented a minority amid the surge of opinion and AM research espousing the biomedical belief. It is only relatively recently that the literature has come to more commonly share an alternative narrative that reframes experiences

of psychosis as meaningful responses to adversity and argues against a narrow biomedical approach (Bentall & Morrison, 2002; British Psychological Society Division of Clinical Psychology (BPSDCP), 2014; Healy & Farquhar, 1998; Morrison, Hutton, Shiers, & Turkington, 2012; Read, 2014; Runciman, 2013), in much the same way that service-users have framed them since the 1970s. However, in reviewing the literature, the psycho-social research appears to remain overshadowed by the volume of studies with a narrow biomedical focus, which often fail to control for the potential contribution psycho-social processes might make to their results.

Deinstitutionalisation and the Service-user Movement

There has been a long history of service-user activism with respect to AMs and the treatment systems they are used within. Reliance on hospital-based treatment began to reduce in the 1930s and psychiatric institutions started closing from the early 1960s (Ross & Read, 2004). In line with international policy developments (Cosman, 2001; Grob, 2005; Hale, 2007), New Zealand introduced legislation in 1969 that “simplified the process of committing patients to mental hospitals and recognised new trends in community care” (Brunton, 2012, p4). In New Zealand the last hospital closed in 1989 (Brunton, 2012). This process of deinstitutionalisation has been previously attributed to the introduction of AMs, but was more likely the result of economic factors (Warner, 1997), and was consistent with the growingly active service-users who had begun to organise their own community recovery groups and instigate letter-writing campaigns for more humane treatment from the hospitals where they were detained, often indefinitely (Ross & Read, 2004; Survivors History Group, 2016; Whitaker, 2010).

However, the shift towards community-based services also meant the closure of institutions that had come to serve as therapeutic communities, this clashed with service-user priorities leading to the formation of one of the first, organised service-user activist groups, the Mental Patients Union, in London (Irwin, Mitchell, Durkin, & Douieb, 1972). From 1968-71, service-user activist groups formed in Norway, England and in Scotland, where a group in a locked ward coined the term Mental Patients Union for the first time (Campbell & Roberts, 2009; Survivors History Group, 2016). These groups did not appear to have been aware of each other’s actions. When the closure of London’s Paddington Day Hospital was announced in 1971, a group of service-users organised a series of successful protest actions (Survivors History Group, 2016) that served as an “example of realised patient power” and brought about further recognition that service-users needed unions to protect their human rights (Irwin et al., 1972). Drawing on the principles of Marx and Foucault the London-based group of service-users and like-minded clinicians published a proposal outlining the need for a Mental Patients Union and began to organise their first meeting (Roberts, 2008). The Fish

Pamphlet, as it came to be called, featured on the cover a picture of a fish struggling on a hook together with a statement inspired by the work of American psychiatrist Karl Menninger that read,

An individual having unusual difficulties in coping with his environment struggles and kicks up the dust, as it were. I have used the figure of a fish caught on a hook: his gyrations must look peculiar to other fish that don't understand the circumstances; but his splashes are not his affliction, they are his effort to get rid of his affliction and as every fisherman knows these efforts may succeed, (Irwin et al., 1972).

Over a hundred people came to the first public meeting of the Mental Patients Union in March 1973 (Jackson, 2008; Roberts, 2008) where it became apparent that other similar groups already existed. New MPUs emerged over the next year and in 1974 they held a conference and formed The Federation of Mental Patients Unions (Campbell & Roberts, 2009; Survivors History Group, 2016). Service-user activism grew in New Zealand from 1974 with the formation of The Mental Health Foundation, which set out to reduce stigma and champion service-user rights through a series of community initiatives and media activities, such as a 1977 Telethon and later a series of television commercials (Gawith & Abrams, 2006). The movement started to organise in the USA in 1978 with an initiative called On Our Own: Patient Controlled Alternatives to the Mental Health System (Survivors History Group, 2016).

As The Fish Pamphlet illustrates, the early service-user groups argued that their mental-health problems were meaningful signs of a struggle to cope with difficult life circumstances, and that mental-health treatments such as psychiatric medications represented an effort to suppress or control that struggle (Irwin et al., 1972). “The union was about the dignity of mental patients, about being able to speak for ourselves” says one of the founding members, Andrew Roberts, (Jackson, 2008). They made a case for freedom of choice, access to psycho-social therapeutic options, and the right to refuse treatments including psychiatric medications (Irwin et al., 1972). But it would take decades for the requests of the service-user movement to be reflected in relevant legislation or treatment policies, and these voices continue to appear rarely in the research literature relative to clinical perspectives.

Contemporary Use of AMs and Best Practice Guidelines

Best practice guidelines and legislation. Antipsychotic medication is currently considered best practice intervention in psychiatric guidelines for managing mental-health problems involving psychotic features internationally (Buchanan et al., 2009) and in New Zealand (Royal Australian and New Zealand College of Psychiatrists (RANZCP), 2004b). AMs are also included among the

recommended pharmacological interventions for bipolar disorder (RANZCP, 2004a). Best practice guidelines should be read in the context of the relevant human rights legislation. In New Zealand, the introduction of such legislation was motivated by a 1988 public health scandal that emphasised the need for protections of patient rights (Gawith & Abrams, 2006). The subsequent inquiry, published in 1996, revealed that mental-health services were grossly under-resourced and service-users faced considerable stigma and rights violations that required addressing (Gawith & Abrams, 2006). In 1992 the early legislation governing mental health treatment in New Zealand was superseded by The Mental Health (Compulsory Assessment and Treatment) Act, which required that an individual be judged to be a safety risk to self or others before compulsory treatment could be justified (Ministry of Health, 1992). The Human Rights Act made it illegal to discriminate on the basis of a person's mental-health status in 1993 (Gawith & Abrams, 2006). Shortly after this, the New Zealand government established a Health and Disability Commissioner (Ministry of Health, 1994) and in 1996 a Code of Health and Disability Consumer Rights was established in law, requiring all services and professionals to "take reasonable actions in the circumstances to give effect to the rights" of service-users (The Health and Disability Commissioner, 1996). These rights included the right to be 1) treated with respect, 2) to be free of coercion, 3) to be allowed independence, 4) to receive services of an appropriate standard, 5) to effective communication, 6) to be fully informed, 7) to make an informed choice and give informed consent, and 8) to have support people with them when they access services, (The Health and Disability Commissioner, 1996). More recently both the British Psychological Society and the National Centre for Health and Care Excellence (NICE) have published best practice guidelines that emphasise alternatives to AMs, combined approaches and more prudent use of AMs as a first option (BPSDCP, 2014; NICE, 2014).

Consumer rights legislation introduced in most Western countries across the 1980s and 1990s requires that people receiving AMs be provided with information about the benefits and risks of AMs and an opportunity to give informed consent or assent to treatment (Cosman, 2001; Grob, 2005; Hale, 2007), yet it may be that few people actually receive such information or opportunities. Studies of clinician perspectives suggest they may believe seeking informed consent is unnecessary among people with psychosis and that sharing AM information with them will increase their level of anxiety (Schachter, Kleinman, & Williams, 1999). However, people experiencing psychosis, and any other mental-health problem, are competent to voluntarily choose or refuse to consent to taking AMs "if he or she is aware of having a mental disorder; has sufficient knowledge about medication and mental disorder; and does not base the refusal on delusional beliefs" (Beck, 1987, p369). Information sharing is therefore a critical component of informed choice. An analysis of 4,500 calls to Schizophrenia Ireland's helpline in the two years from 1999-2000 found that 60% of calls were

related to seeking information about medication and a cross-sectional survey of 461 people within their wider service network (88% of whom were taking AMs), found that 32% had not received verbal information about the benefits or risks from their prescribing clinician, 42% did not receive a written record of their medications, and 65% did not receive written information about the benefits or risks (Farrelly, 2002). Similar results were reported in an analysis of calls to England's SANE Line (Wallace, 1994).

Prevalence of AM use. In New Zealand, AMs may presently be prescribed to approximately 50% of people using community mental-health services (Humberstone, Wheeler, & Lambert, 2004), may be used by 1.2-2.2% of the general population at any given time (McKean & Vella-Brincat, 2010), and are predominantly prescribed to people diagnosed with schizophrenia spectrum disorders and to a lesser degree, bipolar disorder (Wheeler, Humberstone, & Robinson, 2006), although psychiatrists report routinely prescribing AMs for 'off-label' conditions including anxiety, post-traumatic stress disorder, sedation and the adverse effects of other medications (Monasterio & McKean, 2011), despite evidence suggesting there is limited benefit to this practice (Maher et al., 2011). Prevalence of AM use in New Zealand seems consistent with the United States of America (USA) where 50% of people are prescribed AMs at discharge from hospital (Centorrino et al., 2002) and with Australia where 77% of community mental-health service-users receive at least one AM (Keks et al., 1999). Research from Australia and the USA suggests AMs are used by the majority of people who experience psychosis (81.6% - Waterreus et al., 2012) and a substantial portion of people with bipolar disorder (45% - Rascati et al., 2011). In contrast, services in Western Lapland employ a delayed, short-term approach to AM use and as a result only 33% of people with psychosis receive AMs (Seikkula, Alakare, & Aaltonen, 2011). Similar delayed-use approaches have been used at selected services in America's Soteria Project and Sweden's Parachute Project, where many people reach remission of symptoms without AMs (Bola & Mosher, 2002; Bola, Lehtinen, Cullberg, & Ciompi, 2009; Cullberg, Levander, Holmqvist, Mattsson, & Wieselgren, 2002).

Polypharmacy. Polypharmacy refers to the concurrent prescription of multiple psychiatric medications, often in situations of comorbidity or presence of residual symptoms that still require treatment. Concurrent use can be of multiple AMs and/or concurrent use of antidepressants (AD), mood stabilisers (MS), anxiolytics or sleep agents. Despite this being common practice, evidence to support either prescribing practice is lacking (Buchanan et al., 2009). Best practice guidelines for AM treatment recommend the use of the lowest possible doses, and accordingly the use of multiple concurrent AM agents is advised against (Buchanan et al., 2009). Polypharmacy has been independently associated with increased adverse effects in exchange for no improvement over those receiving one medication alone (Brooks et al., 2011). In New Zealand most people (85.4%) are

prescribed only one antipsychotic medication, 17.9% are prescribed two antipsychotics and 1% prescribed three or more AM agents, (Wheeler et al., 2006). This is similar to the prescribing patterns found in Italy at the same time (Tomasi et al., 2006) though American studies have reported concurrent use of multiple AMs at higher rates of 40%-57.7% (Covell, Jackson, Evans, & Essock, 2002; Faries, Ascher-Svanum, Zhu, Correll, & Kane, 2005). In the Australian Study of High Impact Psychosis, 28.1% of people with schizophrenia diagnoses were taking multiple AMs concurrently and 63.4% were taking psychiatric medications of different classes, (Waterreus et al., 2012), similar to the rates found in earlier outpatient studies (Keks et al., 1999).

Combined approaches. Best practice guidelines also recommend that treatment with AMs be combined with psycho-social interventions, particularly talking therapies such as Cognitive Behaviour Therapy (CBT), (BPSDCP, 2014; Buchanan et al., 2009; McGorry, Alvarez-Jimenez, & Killackey, 2013; RANZCP, 2004a; RANZCP, 2004b). Research has demonstrated that psycho-social approaches including mindfulness (Khoury, Lecomte, Gaudiano, & Paquin, 2013), talking therapies like CBT (Álvarez-Jiménez, Parker, Hetrick, McGorry, & Gleeson, 2011; Morrison et al., 2013; Nelson, 2005), psychoanalytic therapy (Garfield & Mackler, 2009) and ACT (Smout, Hayes, Atkins, Klausen, & Duguid, 2012), peer support (Castelein et al., 2008; Dillon & Hornstein, 2013), and family-based approaches like open dialogue (Seikkula et al., 2011) can improve recovery outcomes for people who experience psychosis. The strongest evidence is for CBT, which in some cases has been superior to AMs in preventing relapse (Álvarez-Jiménez et al., 2011) and may serve as an appropriate alternative to AMs for some people (Morrison et al., 2015a; Morrison et al., 2013).

Recovery outcomes may improve when psycho-social adjuncts are added to AM treatment (Bustillo, Lauriello, & Horan, 2001; Guo et al., 2010; Hogarty & Ulrich, 1998), but it seems the majority may not have access to these (Morgan et al., 2012). In a national Australian study, most were taking antipsychotics and had visited a GP recently, a fifth had participated in CBT, and about a third in other forms of counselling, psychotherapy or group therapy (Morgan et al., 2012). Almost a quarter said they needed services but could not access them due to financial limitations or lack of availability (Morgan et al., 2012). Other studies have suggested many people taking AMs may use additional non-medication approaches. A cross-sectional survey of service-user practices within Schizophrenia Ireland's network showed 56% of people (the majority of whom were using AMs) accessed talking therapy or counselling, 61% employment support, 51% creative approaches including art therapy, and 51% peer support, and that on average 75% of people reported these adjuncts to be helpful (Farrelly, 2002).

Combined approaches also likely include physical strategies. Exercise and nutritional approaches have been recommended as strategies to assist with the management of adverse effects

such as weight-gain and sedation (Meehan, Stedman, & Wallace, 2011), while research from other fields suggests physical activity has positive effects on mood (Kanning & Schlicht, 2010) and sexual functioning (Lorenz & Meston, 2014), that nutritional supplements can improve moods (Kaplan et al., 2001), and that herbal medicines with psycho-active properties can be useful as alternative aides to sleep and relaxation, when they are prescribed safely with consideration for their respective adverse effects and contraindications (Ernst, 2004; Spinella, 2001). Relatively little is known about how people combine AMs with additional approaches or what impact that has on their outcomes.

Tolerability and Acceptability of AMs

While AMs are widely prescribed a large proportion of people who initiate antipsychotic treatment only partially adhere to the medication regime and/or attempt to discontinue the regime altogether (see page 20). Rates of partial adherence and persistence of use often form proxy measures of treatment tolerability. The Health Belief Model posits that people's health behaviour is the result of an interaction between four main factors: (1) individual goals and priorities; (2) an evaluation of the perceived adverse effects of the health problem and the personal risk of suffering these effects; (3) the individual's perception of the likely effectiveness, benefits and costs of the target health behaviour (i.e. taking AMs), including physical, psychological, and practical disadvantages and barriers to action; and (4) the availability of internal or external cues to action that trigger health behaviour (Bebbington, 1995; Becker & Maiman, 1975). The research regarding AMs suggests these same factors apply to the choices people make about taking AMs.

In a qualitative analysis, Gibson and colleagues (Gibson et al., 2013) identified two central reasons for taking (and not taking) AMs, each with several sub-themes or variations. The first theme, "Living well for self and others," related to persisting with AMs as part of ongoing efforts to stay well and avoid negative consequences. Living well for self and others was also a reason for intentional partial or non-adherence. People reported taking more medication to manage symptoms, less medication to manage side-effects, and smaller amounts due to "feeling well". The second theme, "Obstacles to adherence," described reasons for unintentional partial or full non-adherence and included forgetting due to feeling well or being busy and forgetting because of medication side-effects or the intensity of symptoms. The third theme, 'Therapeutic support,' related to enabling/disabling communication, willingness to discuss medication with clinicians and accessibility of supportive others/clinicians. People make decisions about their medication by considering practical issues and QOL and attempting to choose a course of action that maximises the potential benefit to them and reduces the potential harm (Carrick, Mitchell, Powell, & Lloyd, 2004; Gibson, et al., 2013). It appears people often make adjustments to their medication regime in order to improve its tolerability on a day-to-day basis.

Rates of partial adherence. Partial adherence refers to an incomplete or independently adapted observance of a prescribed AM regime; definitions in the literature include accidentally missed doses, deliberately missed or smaller doses, or deliberately larger or more frequent doses, but only deliberately missed or small doses inherently denote poor tolerability. Partial adherence may be common to between 16% (Gilmer et al., 2004) and 77% (Gibson et al., 2013) of people taking antipsychotic medications; this can be intentional or unintentional, and involve taking more or less of the medication. A small mixed-methods questionnaire study in America recently asked people with schizophrenia about their adherence to current antipsychotic medication regimes (Gibson et al., 2013). Of the 35 participants, 46% reported following treatment recommendations exactly, and 54% reported intentional partial non-adherence, but when questioned further 71% of the sample reported unintentional non-adherence, with a total of 77% reporting some kind of intentional or unintentional adherence. Of those who reported intentional non-adherence, 47% reported being non-adherent two or more times a month, 63% intentionally took more medication and 63% intentionally took less (Gibson, et al., 2013). These results are similar to the results found thirty years ago (Hogan, Awad, & Eastwood, 1983), in another questionnaire-based, self-report study of adherence in outpatients with schizophrenia, (n=150; 54% “noncompliant” to some degree). Research comparing adherence rates of those with different diagnoses found no significant difference between those with affective and non-affective conditions (Dolder, Lacro, Dunn, & Jeste, 2002).

Rates of discontinuation. Discontinuation refers to non-adherence or full termination of a prescribed AM, and this can be periodic (e.g. a three month period of discontinuation followed by regular adherence) or continuous (e.g. complete and ongoing abstinence). It seems at least 25%-30% of people discontinue AMs at least once (Crespo-Facorro et al., 2011; Glick & Berg, 2002) and at most 60%-82% of people taking AMs do so (Cooper, Moisan, Gaudet, Abdous, & Gregoire, 2005; Lieberman et al., 2005; Rascati et al., 2011). Several studies report discontinuation rates around 50%-60% (Bitter et al., 2008; Buchanan, 1992; Dolder et al., 2002; Peuskens, Gillain, De Graeve, Van Vleymen, & Albert, 2009). A 15-year follow-up study of 145 people with remitted schizophrenia diagnoses found a relatively stable rate of medication-use across time and suggested people who chose not to take medication at 2-years post-discharge (36%) had not changed their minds at the 15-year assessment point (39%). Other studies have also suggested that people stick by their decisions regarding discontinuation and persistence of use (Buchanan, 1992; Gibson et al., 2013; Glick & Berg, 2002).

In 1983, Hogan and colleagues identified seven factors that predicted medication adherence and discontinuation among people with schizophrenia diagnoses: Subjective positive response,

Subjective negative response, Health/illness, Physician, Control, Prevention, and Harm. They found that a 'subjective positive response' to antipsychotics accounted for 59.8% of variance in adherence and persistence of use, while 'subjective negative response' accounted for 11.7% (Hogan et al., 1983). Buchanan's (1992) study showed that individual perceptions that drug treatment helps are significantly associated with persistence at 2-year follow-up and that compulsory treatment had negative association with persistence. Perceptions of a potential positive future outcome may be associated with persistence of use, but this effect has been shown to diminish over time (Buchanan, 1992) in favour of more immediate considerations such as the impact of side effects on the demands of daily life (Gibson, et al., 2013).

Subjective Experiences

To fully understand the effects of AMs and the decisions people make about their use, it is important to ask people directly for their own subjective experiences. Details about adverse effects and possible benefits are helpful but they do not tell us what it is actually like to experience those things in daily life. Clinician and service-user priorities and perspectives regarding the objectives of recovery may differ, with service-users placing a greater emphasis on their psycho-social functioning and QOL (Byrne, Davies, & Morrison, 2010). Subjective studies provide an opportunity to give prominence to the priorities and perspectives of the people who take AMs in a field that has historically excluded or minimised them. Studies of the subjective experience of taking AMs suggest there are additional cognitive, emotional and psycho-social effects associated with taking AMs that are not captured by the RCT literature (N=80, Angermeyer, Löffler, Müller, Schulze, & Priebe, 2001; N=44, Browne et al., 1998; N=25, Carrick, Mitchell, Powell, & Lloyd, 2004; N=150, Hogan, Awad, & Eastwood, 1983; N=1478, Lako et al., 2013; N=439 internet comments, Moncrieff, Cohen, & Mason, 2009; N=95, Moritz, Andreou, Klingberg, Thoering, & Peters, 2013; N=10, Morrison, Meehan, & Stomski, 2015; N=285, Naber, 1998; N=80, Rofail, Heelis, & Gournay, 2009; N=7, Runciman, 2013; N=16, Titelman, 2001). These experiences tend to be stable over time (see review by Hellewell, 2002), though some report more favourable experiences with short-term use (Titelman, 2001). Subjective experiences make significant contributions to predictions of QOL (Browne et al., 1998), symptom severity (Naber, 1998) and decisions about adherence and persistence of use (Hogan et al., 1983).

Taking AMs can involve a combination of different positive and negative experiences (Lako et al., 2013) but people often frame them in global terms (Carrick et al., 2004; Runciman, 2013). Multiple qualitative studies have included descriptions of "hell" and becoming a "zombie" (Angermeyer, Löffler, Müller, Schulze, & Priebe, 2001; Moncrieff et al., 2009; Rogers et al., 1998; Wallace, 1994; Waterreus et al., 2012) and point to subjective experiences of social withdrawal or

disconnection, self-doubt (Moritz et al., 2013), interference with identity and understanding of self (Titelman, 2001), difficulty with daily functioning (Gibson et al., 2013; Naber, 1998; Rofail et al., 2009), and distress regarding adverse effects (Chiang, Klainin-Yobas, Ignacio, & Chng, 2011; Morrison et al., 2015b). Some may be ambivalent towards AMs or view them as a form of punishment and describe experiences of accepting or becoming resigned to taking them (Morrison et al., 2015b; Titelman, 2001). The qualitative research also supports the presence of people who have favourable subjective responses to AMs and describe “life-savers” and “relief” from distressing symptoms (Angermeyer et al., 2001; Moncrieff et al., 2009; Rofail et al., 2009; Wallace, 1994).

A number of studies have included subjective ratings of perceived helpfulness and found most people rate AMs to be somewhat to very helpful and a small group experience them as unhelpful (Castle, Morgan, & Jablensky, 2002; Waterreus et al., 2012). Several researchers have concluded that subjective experiences of AMs and the decisions people make about their use are based on interplay between the beneficial and adverse effects of AMs and the impact they have on daily functioning and the lives of their significant others (Awad & Hogan, 1994; Carrick et al., 2004; Geyt, Awenat, Tai, & Haddock, 2016; Gibson et al., 2013; Roe, Goldblatt, Baloush-Klienman, Swarbrick, & Davidson, 2009; Salomon & Hamilton, 2013). It has been concluded a number of times that taking AMs may involve a potentially painful awareness of a trade-off between adverse effects, including reduced life expectancy, and the management of disruptive symptoms (Carrick et al., 2004; Gibson et al., 2013; Rogers et al., 1998; Titelman, 2001; Wallace, 1994). One model proposes subjective experiences are a by-product of an interaction between psycho-social adjustment, premorbid characteristics, psycho-social performance, personality characteristics, social resources and the ability to use social networks, in addition to the impact on symptoms and side effects (Awad & Hogan, 1994).

Neuroleptic Dysphoria. Neuroleptic Dysphoria is a term often used to describe a family of subjective effects that include a sense of apathy, increased effortfulness, clouded thinking/poor concentration, lethargy and emotional flatness often associated with being unhappy (Moncrieff et al., 2009; Moncrieff, Cohen, & Porter, 2013) and closely related to the high rates of sedation noted in the adverse effects literature (Jones, 2012). A systematic review of adherence studies in the late 1990s found that the subjective experience of dysphoria was significantly associated with low rates of adherence (Fenton, Blyler, & Heinssen, 1997), suggesting this is one of the least tolerable aspects of taking antipsychotic medication. Neuroleptic dysphoria is commonly described by people who take AMs but have no mental-health problems (Healy & Farquhar, 1998), suggesting this is unlikely to be a product of the negative symptoms associated with schizophrenia spectrum disorders or the

anhedonia associated with depression. In 1977, the Israeli researchers Belmaker and Wald recorded their personal experiences after the injection of 5 mg of haloperidol, reporting that, “Each [of us] complained of a paralysis of volition, a lack of physical and psychic energy. [We] felt unable to read, telephone, or perform household tasks of [our] own will, but could perform these tasks if demanded to do so,” (cited in Jones, 2012, 292).

Unaddressed needs. People who take AMs also commonly report having unaddressed information and support needs, which likely also affects their subjective experience of AMs. Respondents of a self-report survey exploring antipsychotic medication adherence recently shared a desire to be better informed about alternative treatments, the long term effects of medication and the effects of taking medication while pregnant (Gibson et al., 2013). They also noted a need for improved access to talking therapies (Gibson et al., 2013). Other studies have also suggested that subjective experiences may entail a lack of information, and subsequent confusion and restricted access to non-medication approaches (Cleary, Freeman, Hunt, & Walter, 2005; Farrelly, 2002; Rofail et al., 2009; Runciman, 2013; Wallace, 1994; Waterreus et al., 2012).

Power dynamics. The subjective experience of taking AMs may be affected by the power dynamics within people’s relationships with their prescribing clinicians and wider support networks. People taking medication commonly describe making their medication choices with an awareness of the actions that could be taken by significant others and mental-health professionals if they refuse, the obligation they feel towards their significant others and the stigma attached to their mental-health problem (Carrick et al., 2004; Farrelly, 2002; Gibson et al., 2013; Read, 2005; Rogers et al., 1998; Runciman, 2013). Taking AMs, or wanting to stop taking them, may also affect the power dynamics within those same relationships. People may receive frequent reminders and checks from their spouse or a parent or have to take their medication in front of a spouse or family to prove their adherence with the regime (Rogers et al., 1998). While family support may increase persistence of use (Gilmer et al., 2004) subjective descriptions suggest this can be experienced as coercive and controlling (Rogers et al., 1998). Family members may lack a full appreciation of the subjective adverse effects experienced by people who take AMs, but have a keen awareness of physical health consequences and the risks associated with withdrawal (Angermeyer et al., 2001). An analysis of family-member calls to England’s SANE Line suggests that family members may experience “despair and frustration” in response to withdrawal-associated relapses (Wallace, 1994) and this may partially motivate their efforts to encourage persistence of use, even in the context of significant adverse effects. People taking AMs similarly describe a cycle of recurrent relapses and dysphoria that has an air of hopelessness to it and some people may wish to discontinue medication but feel unable to

because of the “perceived power that other people [have] over their lives and medication taking” (Rogers et al., 1998, 1319).

Because many people appear to be aware of the relevant legislation that could lead them to being admitted to an inpatient unit under compulsory treatment, they report following instructions or remaining silent about alternative strategies they use to avoid doing anything that might cause mental-health professionals to have them “sectioned” or increase their medication (Rogers et al., 1998; Wallace, 1994). When clinicians are faced with descriptions of negative subjective experiences, they are seen by service-users as tending to “symptomize or downplay” them and may misinterpret adverse effects and lack of efficacy as signs of illness requiring increased doses and additional medication agents (Runciman, 2013, p66). These invalidating and pathologising responses from others may prevent people from sharing their experiences with their prescribing physicians and can have a lasting impact on people. There is a relationship between how people with mental-health problems are perceived and labelled by others, how they perceive themselves and how they think others perceive them (Markowitz, Angell, & Greenberg, 2011). Furthermore, stigmatised self-perceptions are associated with poorer recovery outcomes (Markowitz et al., 2011). The stigma of having a mental-health condition may make it more difficult for people taking AMs to assert their autonomy or preferences. Any attempt to understand the subjective effects of taking AMs would likely be incomplete without an exploration of the prescribing process and the power dynamics that can surround them.

Summary

AMs have a sixty year history of use. They have been the focus of considerable debate within the literature, and between people who prescribe them and those who use them. One of the major points of debate has been whether people should have the choice to refuse AMs or discontinue AMs. Mechanisms of action suggest discontinuation may be a difficult experience and high rates of relapse are often used to justify ongoing maintenance treatment over many years. However, combined or alternative approaches may have better or equivalent results. The subjective experience research to date suggests AMs can be a relief but they can also make life more difficult. Where there are thousands of AM studies with a clinical focus there are relatively few that emphasise service-user voices or consider the other approaches and strategies that people may use.

The Experiences of Antipsychotic Medication Study

TEAMS is a mixed-method, exploratory study of experiences of taking AMs, guided by five broad research questions that allow an in-depth systematic investigation into the range of experiences involved in taking AM. First, what is it like to take AMs? This was conceived of as

including experiences with prescribing, medication effects, QOL impacts, and global perception of AMs. Second, what other approaches do people use and how helpful are they? Third, what is it like to attempt to stop AMs and how do people manage the process? Fourth, does the use of AMs and psycho-social factors predict current recovery outcomes, defined as satisfaction with QOL? And fifth, how do people who successfully discontinue AMs maintain their wellbeing during and after withdrawal? This study sought to understand AM experiences within a wider bio-psycho-social framework of recovery. The research questions rest on assumptions that mental health is dynamic rather than a static state and that people are active in the processes within which it unfolds.

Data collection was conducted across two separate studies. In Study One an anonymous online survey was used to collect information about the experience of taking AMs, use of additional approaches, current coping and social support, and if applicable, experiences of attempting to discontinue AMs. The survey focused on issues of what happened for participants in the course of taking AMs, what qualities the participants attributed to the experiences of taking (or stopping) AMs, and what they did to influence their experiences and recovery outcomes. Content analysis was used to explore subjective experiences and a hierarchical multiple regression was used to explore predictors of current satisfaction with QOL. In Study Two a small number of semi-structured interviews were conducted with survey participants who indicated they had attempted to stop taking antipsychotic medication and had remained medication-free for at least 12 months. Thematic analysis was used to explore how people maintained their mental health during and after withdrawal from AMs, in greater depth than was possible with the survey. The methodology and results of these studies will be presented in two parts, following a review of the AM research literature.

CHAPTER TWO: REVIEW OF THE ANTIPSYCHOTIC MEDICATION LITERATURE

In this chapter I review the literature regarding the beneficial and adverse effects of taking AMs, and their impact on QOL, followed by a review of the literature regarding the benefits and adverse effects of withdrawing from AMs and the outcomes of those who discontinue. In order to explore psycho-social factors of relevance to the issue of understanding the effect of combined approaches, throughout this review attention is given to identifying psycho-social processes and adjuncts shown to have relationships with the outcome measures in question.

The Effects of Antipsychotic Medication

Understanding the effects of AMs requires a consideration of their impact on symptoms, the nature of any associated adverse effects and the ultimate outcome for people's QOL. Methodological issues make it difficult to interpret the results of the research exploring AM effects, particularly in the context of the rebound phenomenon. Much of the research explores whether taking AMs is associated with symptomatic reduction, relapse prevention or improvement in QOL compared to baseline, but does not speak to the issue of whether taking AMs is associated with better outcomes than not taking them. Many of these studies include in their designs preliminary 'acute treatment phases' and then preferentially select people who respond to treatment for further follow-up and analysis, or exclude people who discontinue AMs, which may mean those with favourable responses to AMs are over-represented (e.g., Hamilton, Revicki, Genduso, & Beasley, 1998; Haro, Novick, Perrin, Bertsch, & Knapp, 2014). Inconsistencies in operational definitions also make comparisons between studies difficult (Bobes, Garcia-Portilla, Bascaran, Saiz, & Bouzoño, 2007). Studies with positive findings for AM use tend to adopt lower thresholds for defining symptomatic remission that include people who are still symptomatic (Haro et al., 2014), while studies with negative or equivalent findings adopt higher thresholds that would exclude anyone still experiencing the positive or negative symptoms of psychosis (Harrow & Jobe, 2007; Wunderink, Nieboer, Wiersma, Sytema, & Nienhuis, 2013).

Most RCT studies include in both active and control conditions participants who have previously taken AMs and have to be switched to the trial drug before the study begins. This means baseline data collection takes place either while they are treated with another AM or shortly following a period of withdrawal. A 2007 review (Bobes et al., 2007) identified 20 studies reporting positive relationships between AMs and QOL. Few of the studies reviewed described the method for managing withdrawal, and all that did include this information described collecting baseline measures shortly after gradual or abrupt withdrawal from a previous AM (e.g., Naber et al., 2005).

Such a practice likely skews the amount of improvement observed at follow-up or in comparison to placebo groups who may be experiencing withdrawal-related rebound effects. Furthermore, follow-up periods vary widely but remain relatively short-term in nature, and large drop-out rates may mean people with negative outcomes or whose outcomes might change over time will be under-represented. For example in one study concluding a positive relationship between QOL and AM use, 57% of an clozapine group and 28% of a haloperidol group completed the trial and were available to follow-up (Rosenheck et al., 1997) and in another study 35% of those assigned to olanzapine completed the 26-week trial and were included in the analysis (Naber et al., 2005). Finally, a possible publication bias in the RCT literature means that studies showing smaller effect sizes and studies with negative findings are often not published (Turner, Knoepflmacher, & Shapley, 2012).

Symptom Reduction and Relapse

AMs are typically used in the management of psychosis and mania, and recent research suggests the associated symptom reduction tends to be small to moderate. Meta-analysis shows atypical AMs are more effective than placebo, can produce modest reductions in the acute symptoms of psychosis in comparison to placebo and prevent relapses in a majority of study participants (Leucht, Arbter, Engel, Kissling, & Davis, 2009). Using Hedge's *g* the pooled effect-sizes for antipsychotic medications on change in overall symptoms sat at 0.51, where an effect size of 0.50 is typically considered representative of a moderately observable effect. The combined effect size was -0.48 for positive symptoms (range -0.36 aripiprazole to -0.83 risperidone), -0.38 for negative symptoms (range -33 aripiprazole to -56 amisulpride) and -0.29 for depression (range -0.06 risperidone to -0.50 amisulpride) (Leucht et al., 2009). Studies using the Brief Psychiatric Rating Scale as a measure of symptom-change had a combined improvement of just one point on the Clinical Global Impression (CGI) scale. Studies using the Positive and Negative Symptom Scale (PANSS) showed a combined improvement of 10 points, where a difference of 15 is usually considered representative of a minimal clinical improvement according to the CGI scale (Leucht et al., 2009). These results have been supported by two later meta-analyses with equivalent findings (Lepping, Sambhi, Whittington, Lane, & Poole, 2011; Leucht et al., 2013).

Meta-analyses and systematic reviews of RCTs comparing FGAs to SGAs show there is no significant difference in the efficacy of the two classes of antipsychotics when equivalent doses are used (Geddes, Freemantle, Harrison, & Bebbington, 2000; Girgis et al., 2011; Leucht et al., 2009b; Zhang et al., 2013). People taking different agents spend the same proportion of time in remission and relapse states (Girgis et al., 2011). The results appear comparable when AMs are used to treat bipolar disorder. A 2005 systematic review identified eight RCTs that explored the effects of SGAs on bipolar disorder symptoms and also found effect sizes of no more than moderate magnitude (Jones,

Thompson, & Bitter, 2006), though even modest improvements in symptom severity may produce a substantial change in the individual's subjective experience.

Although the research reports symptom reductions for a substantial proportion and often a majority of people taking AMs, they consistently report a portion of participants whose symptoms do not respond to AMs. For example studies show 43.8% - 65% of participants' symptoms respond to AMs (combined mean 41%) and that 20% of study participants relapsed while receiving medication (Leucht et al., 2009). Similarly, a naturalistic follow-up study of people with schizophrenia diagnoses reported that not taking AMs was predictive of relapse after two years: 53% had at least one period of relapse, 45.6% of whom were taking AMs, while 38.9% of the no-relapse group was taking AMs and the majority were not (Boyer et al., 2013). Finally, while short-term studies suggest AMs reduce symptoms more than placebo, the differences may reduce over time (Harrow, Jobe, & Faull, 2012; Leucht et al., 2012). Therefore, it appears there may be sub-groups of people who experience complete or partial remission of the symptoms of psychosis and/or no periods of relapse, and a further sub-group for whom AMs produce no noticeable change in symptom severity over placebo and who continue to experience relapses while taking AMs.

A recent study found that those in remission or functional recovery at one year follow-up were no more likely to be taking AMs but were significantly more likely to be without any psychiatric medications at all when compared to those who did not achieve remission or recovery status, contrary to the expectations of the authors (Schennach et al., 2012). A number of longitudinal observational studies have compared the rates of symptomatic remission of those maintained on AMs to those who discontinue and have also suggested more favourable results for those who stop, consistent with the early research regarding relapse rates (NIMH, 1964; Rappaport, Hopkins, Hall, Belleza, & Silverman, 1978; Schooler, Goldberg, Boothe, & Cole, 1967). The longest of these compared symptom reduction and global psycho-social outcomes among people with schizophrenia (n=64) and those with other psychosis experiences (n=81) who were randomised to continuous AM use or discontinuation (Harrow & Jobe, 2007; Harrow et al., 2012). The initially young group of people was assessed over 20 years at multiple different points in time following discharge from hospital. The researchers found significantly better rates of symptomatic remission among those who discontinued in both diagnostic groups, at all time periods except the two-year point where there was no difference (Harrow & Jobe, 2007; Harrow et al., 2012). The more favourable outcomes for the discontinuation group emerged at four and a half years following discontinuation (Harrow et al., 2012). At the 15-year follow-up, 64% of the schizophrenia patients taking AMs had psychotic activity, while 28% of those not on any medications had signs of psychotic activity ($p = 0.01$). Of those with the poorest 15-year outcome profiles, 83% were taking AM. Those who had discontinued

at the 15-year follow-up had significantly more periods of recovery across the study period than those who persisted (Harrow & Jobe, 2007) and this remained the case at the 20-year time-point (Harrow et al., 2012).

A second study explored symptomatic remission as one measure of recovery after seven years among people with first episode psychosis (FEP) who had participated in a previous trial comparing a discontinuation and dose reduction programme to maintenance treatment over a two year period (N=103). At seven years follow-up, they compared those who discontinued to those who continued on maintenance doses, and reported equivalent levels of symptomatic remission but significantly better functional outcomes among those who had stopped for the two years preceding the seven-year follow-up (Wunderink et al., 2013). Notably, relapse rates reduced among those who stopped after the three-year assessment point, which may explain the disparate results in studies with shorter follow-up periods. Those who stopped AMs earlier in the course of treatment formed a sub-group who had the most favourable outcomes (Wunderink et al., 2013). An earlier study with a 7.5 year follow-up period reported that not taking AMs was associated with increased odds of full functional recovery (61.1% full recovery vs 16.8% no full recovery discontinued AMs, OR=7.79, $p=0.000$), but did not include this in a subsequent exploration of independent predictors or their discussion of results (Álvarez-Jiménez et al., 2012). The results of a more recent study testing for predictors of discontinuation concurs with the findings of Wunderink and colleagues regarding relapse and remission, but suggests the presence of a sub-group who stop and show more favourable outcomes (Landolt et al., 2016). These studies suggest taking AMs cannot be guaranteed to produce better outcomes in the long term than not taking AMs and that there is a subgroup of people who do well without them.

Symptom reduction and psycho-social processes. Internal psycho-social resources may affect the recovery outcomes of those who take AMs and stop taking them, but are not often considered in most study designs. One qualitative study asked people taking AMs about their alternative strategies for coping with symptoms of schizophrenia and reported the most common coping strategies included listening to music or the radio, talking to other people, exercise, praying or religion, alternative medication including herbal and homeopathic remedies, massage, yoga or relaxation classes, walking, alcohol and cigarettes, and reading. Self-medication with other drugs, particularly non-prescription drugs was also reported to be common, as was using sleeping pills or exceeding the recommended dose of sedating medications to sleep (Rogers et al., 1998). These strategies could have a range of different effects on the severity of symptoms experienced by people taking AMs and may represent unmeasured variables that could influence the results of AM research. People who use combined approaches may show more favourable outcomes than those receiving treatment

AMs alone (Guo et al., 2010; Hogarty & Ulrich, 1998). For example, one study found participation in standardised psychological treatment was one of only two significant predictors of remission among those using AMs, along with fewer negative symptoms (Gaebel et al., 2014).

Furthermore, research exploring the outcomes of alternatives to AMs has suggested that those who participate in CBT instead of using AMs may show greater symptom reduction than those maintained on AMs (Morrison et al., 2015a; Morrison et al., 2013). A 1998 study analysing the ten-year outcomes of Open Dialogue in Finland showed a 63% reduction in long-stay hospitalisations for people with schizophrenia in comparison to historic treatment as usual (Tuori et al., 1998). A 2009 review of medication-postponement approaches including the Soteria research found a modest improvement in long-term outcomes and small to medium composite effect sizes in comparison to treatment-as-usual (Bola et al., 2009). This is consistent with a hypothesis that there are sub-groups of people who do well and sometimes better without AMs in addition to those who experience clinically significant but modest improvements in symptom severity and reduced relapse while taking AMs. This suggests a one-size-fits-all approach to treatment with AMs is unlikely to produce the best outcomes for everyone.

Adverse Effects

AMs are commonly associated with a range of adverse cardio-metabolic, neuro-cognitive, anticholinergic, and hormonal effects that impact both physical and psycho-social functioning. AMs have been associated with increased mortality rates (Weinmann, Read, & Aderhold, 2009), type two diabetes, metabolic syndrome, weight-gain, hyperlipidemia, and hypertension, life-threatening cardiac problems and immunological dysfunction, heightened cholesterol, and movement disorders including a sense of inner restlessness and agitation called akathisia and the irreversible parkinsonian condition tardive dyskinesia (Hansen, Maciejewski, Yu-Isenberg, & Farley, 2012; Haro, Novick, Suarez, & Roca, 2009; Kane, 2001; Lieberman et al., 2005; Morgan et al., 2012). The list of adverse effects continues into sedation, hypersomnia, difficulty concentrating, sexual dysfunction, the absence of menstruation in women, galactorrhoea/lactation in men and women, osteoporosis (Chiang et al., 2011; Hamer & Haddad, 2007; Leucht et al., 2013), cognitive impairments (Cuesta et al., 2015), reductions in the volume of several brain structures (Crespo-Facorro et al., 2008) and changes in the organisation of receptors that produce withdrawal symptoms when AMs are discontinued or reduced (Chouinard et al., 1978).

Additional anticholinergic effects commonly reported include dry mouth, constipation, urinary retention, bowel obstruction, dilated pupils, blurred vision, increased heart rate, and decreased sweating AMs where the rate of Type II diabetes is reported to be double that of the general population (Cimo, Stergiopoulos, Cheng, Bonato, & Dewa, 2012). Perhaps the most extreme

adverse effect, Neuro-Malignant Syndrome is characterised by fever, muscle rigidity, autonomic nervous system instability and reduced consciousness, which occurs in approximately 0.02-1.9% of people treated with AM; between 4% -25% of people who develop the condition die (Nielsen, Wallenstein Jensen, & Nielsen, 2012). Where most adverse effects tend to resolve following withdrawal of the AM agent and can be monitored via routine medication reviews and blood-work, some are permanent, like diabetes, and may appear only after withdrawal such as the extrapyramidal disorders of tardive dyskinesia and tardive psychosis (Breggin, 2013).

Results from the Second Australian Study of High Impact Psychosis revealed 80.5% of people taking AMs experienced adverse effects in the previous four weeks (Morgan et al., 2012). A 2006 meta-analysis of SGA outcomes among people who have bipolar disorder (Jones, et al., 2006) showed the most commonly reported adverse effects were somnolence/sedation (21-80% range in prevalence reported by 8/9 studies) and headache (9-47% range reported by 6/9 studies). Much of the research regarding adverse effects excludes people who discontinue AMs early in the study, meaning they reflect the experiences of those who persist with AMs, without capturing the experiences of those who stop.

Meta-analyses consistently find more similarities than differences between the adverse effects of different agents but suggest a more positive profile for SGAs over FGAs due to reduced rates of extra-pyramidal symptoms (Leucht et al., 2009; Zhang et al., 2013). A meta-analysis of over 200 clinical trials with a combined sample size of 43 049 participants recently found that with a few exceptions all SGA drugs included in the analysis and the FGA haloperidol were associated with sedation and weight gain though Olanzapine was associated with significantly more weight gain than the other agents (Leucht et al., 2013). Both FGAs and SGAs have been linked with extra-pyramidal symptoms though they occur at greater rates among those taking FGAs (Leucht et al., 2009; Leucht et al., 2013; Peuskens et al., 2009). The Australian Study of High Impact Psychosis concluded that the adverse effects profile for people taking SGAs was on average better than those taking FGAs though the difference was small; 86.1% of the FGA group reported one or more adverse effect compared to 80.7% of the SGA group (Waterreus et al., 2012). Adverse effects are clearly common to the experiences of people taking either class of AM agent.

Impact of adverse effects. In the second Australian Study of High Impact Psychosis, 69.7% of people reported a slight to severe impairment to their daily lives due to the adverse effects of AMs (Waterreus et al., 2012). Adverse effects may impact attitudes towards AMs (Chiang et al., 2011), and the tolerability of AMs, although the research is not conclusive in this regard (Ascher-Svanum et al., 2010; Hogan et al., 1983; Lieberman et al., 2005). Studies of partial adherence to prescribed medication regimes show people frequently adjust the timings and amounts of their doses according

to the changing demands of their daily life and the impact side effects have on their functioning (Gibson et al., 2013). The subjective studies suggest many people experience a dysphoric reaction to the emotional and cognitive adverse effects of AMs (see Chapter One). Adverse effects may both directly and indirectly increase suicidality among some people (Mihanović et al., 2010). The severity and impact of adverse effects may be associated with medication factors such as greater doses, (Chiang et al., 2011; McEvoy, Hogarty, & Steingard, 1991), longer periods of continuous treatment (Hansen et al., 2012), concurrent polypharmacy (Brooks et al., 2011), treatment system factors like dismissive prescriber responses to reported adverse effects (Jones, 2012; Seale, Chaplin, Lelliott, & Quirk, 2007), and the impact they have on daily life. Many adverse effects such as sexual dysfunction, weight gain and diabetes are multi-factorial and potentially influenced by the way in which people cope with or adjust to them and the reduced activity often associated with mood problems and negative symptoms.

Adverse effects can require treatments and interventions of their own, with a range of exercise and diet strategies suggested to address weight gain and medications for cardiometabolic effects (Heald, 2010). People may find a large part of their recovery plan involves engaging themselves in efforts to manage the adverse effects of taking the medication (Meehan et al., 2011). Different coping strategies are needed for different adverse effects and commonly include the maintenance of a balanced lifestyle, staying active, healthy eating and sleeping routines, self-soothing, and “fostering a positive outlook on life” (Meehan et al., 2011). Regularly using strategies such as these could have an ameliorative effect on both the impact of many adverse effects and the severity of symptoms experienced by people taking AMs. The high rate of adverse effects observed across all AM agents has led many researchers to question the wisdom behind best practice guidelines recommending AMs as the first-line intervention for psychosis and the adoption of long-term maintained use as a routine practice (Morrison et al., 2012; Tyrer, Jul 2008).

Quality of Life

AM outcomes have conventionally been defined in terms of symptomatic reduction and side effect profiles. Researchers in the early 1990s called for QOL to be included as an outcome measure in studies exploring the impact of AMs and set out a theoretical model for doing this (Awad & Hogan, 1994). Awad and Hogan’s conceptual model for QOL and subjective experiences of neuroleptics (Awad & Hogan, 1994, p29) proposed an interaction between psycho-social and medication factors, including personality characteristics, educational/vocational factors, values and attitudes, resources, ability to use social networks, and psycho-social adjustment, in addition to side effects, symptoms and the individual’s subjective interpretation of them.

Results of studies exploring the QOL outcomes of AM are inconsistent with respect to the positive or negative valence of the relationships observed between QOL and persistence of AM use. Most QOL studies with follow-up periods of three years or less report positive associations between QOL and taking AMs when compared to placebo groups (Hamilton et al., 1998), baseline (Bobes et al., 1998; Colonna, Saleem, Dondey-Nouvel, & Rein, 2000; Essock, Hargreaves, Covell, & Goethe, 1996; Giner et al., 2004; Gureje et al., 2003; Hertling et al., 2003; Ho, Miller, Nopoulos, & Andreasen, 1999; Kilian et al., 2011; Meltzer, Burnett, Bastani, & Ramirez, 1990; Montes, Ciudad, Gascón, & Gómez, 2003; Naber et al., 2005; Revicki, Genduso, Hamilton, Ganoczy, & Beasley, 1999; Ritchie et al., 2003; Rosenheck et al., 1997; Strakowski et al., 2005; Tran et al., 1997; Velligan et al., 2003; Voruganti et al., 2002), and those who discontinue (Alonso et al., 2009; Haro et al., 2014). Again, differences across AM agents tend to be small to non-existent (Alonso et al., 2009; Bobes et al., 2007).

A close reading of the detail within these results reveals improvements in QOL are by no means universal to all who take AMs; for example in a 1-year follow-up, 53% of those taking Olanzapine and 42% of those taking Haloperidol met criteria for improved QOL (Revicki et al., 1999). A group of researchers recently conducted a post-hoc analysis of the three-year remission rates in the results of the Schizophrenia Outpatient Health Outcome (SOHO) study, which tracked people (N=6516) with schizophrenia who showed an early favourable response to AMs, (Haro et al., 2014). They found a positive predictive relationship between remission of symptoms and QOL, and that having “good compliance” with AMs made a positive independent contribution to QOL as opposed to being “never compliant” (Haro et al., 2014). This study had the longest follow-up period of all the QOL studies showing positive relationships with persistence of use; however, the outcomes of those who stop may improve after three years.

A number of studies have compared the QOL outcomes of those who take AMs to those who stop taking AMs, and report equivocal results or find in favour of those who discontinue. A longitudinal follow-up study of people with psychosis found those who had discontinued AMs at the 15-year follow-up were more likely to reach recovered status, assessed with the Levenstein-Klein-Pollack scale for QOL, compared to those who continued with AMs (Harrow & Jobe, 2007). Another study compared the QOL outcomes (using an idiographic questionnaire) and Global Assessment of Functioning (GAF) scores of those who continued AMs and those who discontinued AMs and reported that “only small differences could be found” in GAF scores between groups, without reporting on the specifics of these differences in any detail (Laengle et al., 2010). Gaebel and colleagues discovered a group of people who discontinued and then took AMs intermittently had higher rates of relapse but that QOL was comparable to those who persisted (Gaebel et al., 2011).

Another longitudinal study found those who discontinued AMs had significantly better global psycho-social functioning at the seven-year follow-up point when compared to those who continued on maintenance AMs, but there was no significant difference in QOL (Wunderink et al., 2013). A Nigerian study of 313 consecutively referred outpatients with schizophrenia diagnoses performed a hierarchical multiple regression to test for predictors of current QOL and found medication adherence was an independent negative predictor of QOL ($\beta = -.184$; $p = .001$) and that AM dose was an independent negative predictor of specific QOL sub-scales of physical health, psychological health and environment (Adelufosi, Ogunwale, Abayomi, & Mosanya, 2013). Taken together the research on QOL outcomes of AMs suggests there may be subgroups of people with positive and negative QOL outcomes, both among those who persist and those who discontinue. In the Nigerian study (Adelufosi et al., 2013), symptom severity, medication-related variables and a range of external psycho-social factors were included in a predictive model and found to account for 24% of the variation in QOL. Several studies have suggested symptomatic severity and QOL share a predictive relationship among people with schizophrenia diagnoses who take AMs (Bobes et al., 1998; Haro et al., 2014; Hertling et al., 2003; Hofer et al., 2004; Meltzer et al., 1990; Montemagni et al., 2014) and among those who stop (Adelufosi et al., 2013; Harrow & Jobe, 2007; Wunderink et al., 2013). However, these factors alone cannot account for all of the variation observed in the QOL outcomes of those who take AMs or those who do not.

Quality of life and psycho-social processes. Internal and external psycho-social factors may play an influential role in QOL outcomes (Van Rheenen, Murray, & Rossell, 2015), but they are more rarely discussed in the AM literature. There is far more consistency in the results regarding the influence of psycho-social factors on QOL than there is for persistence of AM use. External psycho-social factors have received the greatest attention with remarkable consistency in the findings of different studies. External psycho-social factors found to be predictive of QOL among people who persist or discontinue AMs include occupational status, social support measures, educational status, family status, and living situation (Adelufosi et al., 2013; Alonso et al., 2009; Haro et al., 2014; Harrow & Jobe, 2007; Hofer et al., 2004).

Internal psycho-social factors have been rarely investigated but a small number of studies have suggested that coping via active social diversion (Montemagni et al., 2014) and a negative subjective response to AMs (Browne et al., 1998; Hofer et al., 2004) make predictive contributions to the QOL of people taking AMs and those who stop taking them. Early research among people with schizophrenia emphasised internal psycho-social dimensions and suggested those who were able to cognitively integrate their experiences of mental-health problems showed better recovery outcomes than those who cognitively avoided or 'sealed over' the experiences (Levy 1975; McGlashan 1975).

The wider QOL literature has identified a plethora of dimensions sharing predictive relationships with QOL outcomes among both clinical and non-clinical groups. These include active and avoidant coping styles (e.g., among older adults with schizophrenia - Cohen, Hassamal, & Begum, 2011), flexible coping (e.g., among people with cancer - Cheng et al., 2012; among people with depression and anxiety - Fresco, Williams, & Nugent, 2006), perceived coping capacity (e.g., among people with psychosis - Broyd, Jolley, & Johns, 2016), but not the number of coping strategies used (e.g., among people with schizophrenia – moty El Sheshtawy, 2011). Other studies highlight self-efficacy (e.g., among people with schizophrenia - Jansen, Gispen-Dewied, & Kahn, 1999; Ventura, Neuchterlein, Subotnik, Gitlin, & Sharou, 1999), the related dimension of empowerment (e.g. among people with psychosis - Wciórka, Świtaj, & Anczewska, 2015), autonomy (e.g., among people who take psychiatric medications - del Barrio, Cyr, Benisty, & Richard, 2013), hope (e.g., among people with schizophrenia - Rudnick & Martins, 2009), and experiential acceptance (e.g., among people with psychosis - Vilardaga, Hayes, Atkins, Bresee, & Kambiz, 2013). Little of the AM research controls for or considers the impact these internal dimensions might have on the outcomes observed.

Summary of Medication Effects

In summary, AMs are associated with moderate rates of symptom reduction, relapse-prevention and improved QOL but it is unclear whether they produce better long-term outcomes over not taking them. Variation within the results of most studies suggests there are sub-groups with different subjective experiences and different outcomes both while taking AMs and after stopping them. A range of medication, clinical, and psycho-social factors are thought to influence these outcomes. Much less is known about the role psycho-social factors play, though research outside of the AM literature has much to add. The addition of psycho-social interventions may improve outcomes and some forms of therapy can serve as appropriate alternatives. This chapter will close with a consideration of the literature regarding withdrawal from AMs and the factors affecting discontinuation outcomes.

Attempted Discontinuation

Experiences of attempting to discontinue AMs appear to be common to many people who initiate treatment with them. Understanding these experiences entails an understanding of the effects of withdrawal, the process people followed, the outcomes of their attempt and how they manage without AMs. The literature seems incomplete in this regard, though substantial information is available to suggest that despite the difficulties involved, there is a sub-group of people who are able to discontinue AMs and manage well. I have identified only three studies that specifically explore the subjective experience of attempting AM discontinuation (N=12, Geyt et al.,

2016; Read, 2005; N=7, Roe et al., 2009; N=98, Salomon & Hamilton, 2013). They all focus on the personal decision to take or not take AMs alongside withdrawal effects, treatment systems, social support, and information gathering, without exploring people's personal efforts to cope in detail.

Withdrawal Effects

AMs have a range of withdrawal effects that can mimic the experience of mania, psychosis and physical illness, producing difficulty sleeping, nausea, loss of appetite, diarrhoea, sweating, tremors and withdrawal-related dyskinesia, difficulty concentrating, disorganised thinking, impaired reasoning, mood disturbances such as anxiety, and potentially hallucinations and florid psychosis (Breggin, 2013; Gardos, Cole, & Tarsy, 1978; Lehman, 2002; Moncrieff, 2013; Moncrieff, 2006; Moser et al., 2005). These can appear from days to months after the first reduction or full discontinuation and withdrawal-related "psychotic decompensation" has been reported up to twelve months later (Breggin, 2013; Gardos et al., 1978).

The most commonly studied withdrawal effect is the phenomenon of withdrawal-related relapse. Relapse rates reported in the literature vary depending on the way in which it is defined, for example, whether hospitalisation is required or what degree of symptomatic exacerbation is set as the threshold for relapse (Boyer et al., 2013; Gitlin et al., 2001). Relapse rates during withdrawal and shortly following discontinuation are likely strongly influenced by the Rebound Phenomenon associated with withdrawing from AM. For example, a systemic review conducted in 1995 reviewed 66 withdrawal studies involving 4365 patients with schizophrenia and reported a mean cumulative relapse rate of 53% in patients withdrawn from AMs compared to 16% in those maintained on AMs with a mean follow-up period of 9.7 months (Gilbert, Harris, McAdams, & Jeste, 1995). However, a reanalysis of this data suggested the risk of relapse was substantially lower in studies employing a gradual withdrawal procedure (Baldessarini & Viguera, 1995).

Withdrawal-related rebound can be easily confused for the original symptoms AMs were prescribed for (Breggin, 2013) and the few qualitative studies available suggest these experiences are common, and can engender fear, distress, confusion about how to manage and what the experience means, and risks to personal safety (Geyt et al., 2016; Roe et al., 2009; Salomon & Hamilton, 2013). They also highlight that people become less fearful of distressing symptoms as they become more experienced in their efforts to cope with them (Geyt et al., 2016). Other qualitative AM studies have included an exploration of withdrawal experiences (Carrick et al., 2004; Narendorf et al., 2015; Titelman, 2001) and they concur with the discontinuation studies to suggest people may use periods of discontinuation to help them assess their ability to cope and the place that continuous or intermittent AM use might have for them in future (Geyt et al., 2016; Roe et al., 2009; Salomon & Hamilton, 2013). Therefore, experiencing difficulty managing withdrawal effects may

change the way people view both themselves and AMs. This underscores the importance of exploring how people cope during their attempts to stop.

Withdrawal Methods

Withdrawal methods are differentiated in the literature based on whether they follow an abrupt or gradual course, though there is substantial inconsistency in the length of time taken and the magnitude of each reduction. An analysis of the self-help literature available for AM withdrawal (Breggin, 2013; Cassani, 2016; Darton, 2013; Hall, 2012; Lee, 2010; Lehman, 2002; May, Jhugroo, & Thomas, 2016), suggests that unless people are hospitalised for supervised withdrawal, the duration of the withdrawal period and the time between each reduction should be flexibly determined in response to the withdrawal effects that appear, how long it takes to stabilise following each reduction, and whether a temporary resumption of prior doses is required, rather than following a strict time schedule. When reduction is not possible without intolerable withdrawal effects, one source recommends first switching to AMs that act on fewer receptor sites (Lee, 2010). When multiple medications need to be withdrawn, it has been suggested this be done sequentially not simultaneously, beginning with the agent that was most recently initiated or is most toxic, and withdrawing any sleeping agents last, though this should be guided by the preference of the person themselves (Breggin, 2013). The literature suggests even miniscule reductions can produce noticeable withdrawal effects for people who have been taking AMs long-term and the recommended magnitude of each reduction is usually 10% of the current dose, with the proviso that this be adjusted if it proves to be poorly tolerated (Breggin, 2013; Hall, 2012; May et al., 2016). Specialised pill-cutters and pill-shavers are available to assist people to reduce tablets more precisely and the literature also refers to the advantages of liquid formulations in allowing reductions of small magnitude (Breggin, 2013).

Managing discontinuation can be an intricate balancing act and in the context of rebound psychosis and mania which may impair self-reflective capacity, there is more to a safely managed withdrawal method than the rate of reduction. The person-centred approach to psychiatric drug withdrawal set out by psychiatrist Peter Breggin (2013) suggests that the active involvement of at least one additional person, being informed about the possible withdrawal effects, open communication about the effects of each reduction, a variety of pleasurable and self-soothing activities, and a strong sense of personal responsibility are also crucial to the safety and success of any discontinuation attempt. Psychiatrist Alice Lee emphasises the importance of establishing optimal nutrition to support neurotransmitter functioning and an adequate sleep cycle prior to undergoing withdrawal (Lee, 2010). The Coming Off website created by clinicians and people who have withdrawn from psychiatric medications concurs with these recommendations and further

emphasises the importance of developing alternative strategies for managing moods and thoughts and finding ways to understand and process experiences of distress prior to, during and following withdrawal (May et al., 2016). An e-book focused on harm-reduction during withdrawal also promotes the use of other strategies, further suggests that timing may be an important issue and prompts people to reflect upon the stability of their living situation, difficult anniversaries that may be nearing, and the presence of other stressors before deciding whether it is a good time to stop a medication (Hall, 2012, p29). This all suggests that internal and external psycho-social processes and non-medication physical processes may affect the outcomes of those who discontinue. However, none of the discontinuation outcome studies specifically report on how people prepared for or coped during the process or moving forward.

Discontinuation Outcomes

Discontinuation outcomes can refer to rates of symptomatic relapse, functional recovery or symptomatic remission, or duration of maintained discontinuation. As outlined above, research comparing the symptom reduction, relapse rates and QOL outcomes of those who continue AMs to those who discontinue has suggested the possibility that there may be a sub-group of people who do well without AMs, particularly in the long-term (Harrow & Jobe, 2007; Harrow, Jobe, & Faull, 2012; NIMH, 1964; Rappaport, Hopkins, Hall, Belleza, & Silverman, 1978; Schennach et al., 2012; Schooler, Goldberg, Boothe, & Cole, 1967; Wunderink, Nieboer, Wiersma, Sytema, & Nienhuis, 2013). Most recently, Landolt and colleagues (2016) found no significant difference in remission, or relapse scores between those who persisted and those who discontinued AMs one year after participating in an RCT comparing atypical agents for FEP. Additionally, they identified a subgroup among those who discontinued that did not relapse ($n=39/74$) and a further subgroup among those who discontinued ($n=18/74$) that did not relapse and experienced symptomatic remission (Landolt et al., 2016).

A small number of graded discontinuation studies also suggest a sub-group of people who take AMs are able to maintain long-term discontinuation. Faber and colleagues found 54.5% of their 'Graded Discontinuation' group ($n=22$) were able to completely discontinue medication and showed significant improvements in cognitive functioning, noting the initial low-doses used in the Netherlands, where the study was completed, as a possible contributing factor (Faber, Smid, Van Gool, Wiersma, & Van Den Bosch, 2012). Another group (Nishikawa, Hayashi, Koga, & Uchida, 2007) conducted a naturalistic follow-up study to a stepped withdrawal programme and found 26.7% of their sample with remitted schizophrenia ($n=30$) was able to successfully discontinue medication and maintain their results during a two year follow up period. While half of these people required multiple attempts, all were able to maintain healthy functioning (Nishikawa et al., 2007). Another

study reports on the successful discontinuation of all but two of 15 people with non-psychotic depression who were identified in a prior study to have been taking redundant AMs for a range of 1-30 years (Mortimer, Martin, Wheeler Vega, & Tyson, 2003). The study notes a further 25 who withdrew independently prior to being contacted about the gradual withdrawal study and showed significantly reduced chronicity (duration of illness) in comparison to the prior study participants who continued AMs (Mortimer et al., 2003), similar to results reported elsewhere (Rothschild & Duval, 2003). This is consistent with other studies that have additionally suggested matters of chronicity, duration of treatment with AMs, and dose affect discontinuation outcomes (Chouinard & Jones, 1980; Crow, Macmillan, Johnson, & Johnstone, 1986; Nishikawa et al., 2007; Rothschild & Duval, 2003; Wunderink et al., 2013) and the outcomes of people who use CBT as an alternative to AMs (Morrison et al., 2012). Medication factors like dose and duration of treatment with AMs have been shown to affect withdrawal effects in some studies (Crow et al., 1986; Gardos et al., 1978; Gilbert et al., 1995; Read, 2005).

High rates of symptom exacerbation and relapse may be common following guided discontinuation, but not inevitable. Four RCTs assessing oral AM discontinuation reported 19%-91% of people who discontinued had relapsed by nine to twelve months follow-up when this was defined as substantial symptom exacerbation, while 16%-57% of people experienced hospitalisation (Boonstra, Burger, Grobbee, & Kahn, 2011; Chen et al., 2010; Gaebel et al., 2011; McCreadie et al., 1989). Studies employed various graded withdrawal methods carried out over periods ranging from four weeks to three months, which is a relatively short period of time and may contribute to the high rates of relapse they observed. Other studies have shown a similar distribution of results (Crow et al., 1986; Kane, Rifkin, Quitkin, Nayak, & Ramos-Lorenzi, 1982). It is unclear how the withdrawal procedures differed across studies and what effect internal psycho-social processes and external resources may have had in the variable rates of relapse reported. Taken together these studies add to evidence suggesting that there is a subgroup of people who stop AMs without experiencing symptomatic relapse or hospitalisation. Other writers have come to similar conclusions (Bentall & Morrison, 2002; Breggin, 2013; Harrow & Jobe, 2007; Landolt et al., 2016; Moncrieff, 2013; Morrison et al., 2012; Morrison et al., 2013; Rappaport et al., 1978; Wunderink et al., 2013).

Psycho-Social Factors and Discontinuation

Relapse rates during withdrawal and the outcomes observed following discontinuation may be a product of the interplay between the personality characteristics, resources and learned skills needed to manage mental-health experiences and the withdrawal effects that accompany discontinuation. In one study successful discontinuation was significantly predicted by greater baseline social integration, better clinician-judged prognosis, and a higher level of education (Landolt

et al., 2016), while other researchers have found those who successfully stop taking AMs and have good outcomes may have significantly more developmental achievements and internal locus of control prior to stopping (Harrow & Jobe, 2007). People who have made previous attempts to discontinue medication may be more likely to successfully stop (Nishikawa et al., 2007). Each attempt may represent an additional opportunity to develop the coping skills and support systems needed to prevent relapse during and after withdrawal. There are no studies reporting on how people cope during or after withdrawal. However, a study exploring the use of CBT instead of AMs showed a person's appraisal of their own symptoms was significantly predictive of symptom severity (Morrison et al., 2012), supporting the hypothesis that the way people respond to their experiences is an important area for future research considering discontinuation outcomes.

Unfortunately, little is known about the subjective experience of managing the withdrawal effects discontinuation can entail. Such information is likely to be of strong relevance to people who take AMs, given discontinuation occurs at high rates and the risks associated with discontinuation can be great. The three existing experiential studies of AM discontinuation have highlighted the challenges involved in becoming an expert in managing symptoms, building a support network, finding responsive clinicians, and accessing information for discontinuation, alongside the risks, distress and frustration that can be associated with an unsuccessful attempt (Geyt et al., 2016; Roe et al., 2009; Salomon & Hamilton, 2013). These results are supported by other subjective AM studies explored in Chapter One. In the course of seven interviews, Olga Runciman identified two people with schizophrenia diagnoses who stopped taking AMs (Runciman, 2013). They described the importance of being able to meaningfully understand and recognise their symptoms and develop ways of managing them – they noted achieving this through experiencing those symptoms and learning from them (Runciman, 2013), suggesting symptoms may not necessarily be something to avoid. A study published outside of the peer-reviewed literature by MIND UK explored the experiences and outcomes of 248 people who had attempted to stop taking any psychiatric medication including an unspecified number of people who had attempted to stop an AM agent alongside other psychiatric medications and 21 people who had attempted to stop a single AM, among whom over half attempted to stop without the support of a doctor (Read, 2005). Those who sought and gained doctor's support for their attempt were no more likely to succeed in stopping than those who proceeded without or against doctor's advice due to the impoverished nature of the information and support people received (Read, 2005).

People who discontinue AMs or express a desire to do so may be perceived as 'noncompliant' by clinicians. One study found that approximately half of a group of people taking AMs involuntarily had lost their right to choose as a result of an attempt to discontinue due to adverse effects they

found intolerable (Naber, Kircher, & Hessel, 1996). Clinicians encountering people who choose not to follow their treatment recommendations, may experience countertransference responses including hopelessness and frustration, “a desire to see the patient taught a lesson by suffering a relapse” and/or “the urge to abandon or humiliate” them (Fenton et al., 1997, p645). Another study showed that when professionals are aware a person is reducing their medication they often misinterpret normal behaviour as symptomatic and inflate their estimations of the person’s clinical severity (Thomas, Katsabouris, & Bouras, 1997), likely changing the way they respond to that behaviour and the social feedback available to the person who is reducing. Thus attempting to discontinue AMs may have the consequence of inspiring unhelpful responses in the clinicians involved in providing support during antipsychotic withdrawal, affecting both the therapeutic alliance and potentially also the outcomes of attempted discontinuation.

Summary

Observational studies show that many people take AMs and among them many people seem to attempt to stop. Much of the research frames stopping as a negative outcome to prevent, but that outcome would likely be perceived quite differently by the people who set out to achieve it. Both those who persist with AMs and those who discontinue can have positive outcomes with respect to the severity of psychosis and mania, relapse, and QOL. Adverse effects are experienced by most people while they take AMs to some degree and withdrawing from AMs carries its own set of adversities for people to bear. AM mechanisms of action introduce a neurological propensity to relapse that is not present prior to taking AMs in addition to cognitive difficulties and serious physical health problems, some of which are irreversible. Subjective experiences can vary similarly, but it seems common for people to have a dysphoric response to AMs that can interfere with their daily life as opposed to improving it. These sub-groups with different outcomes and experiences may not appear for some years following the onset of primary symptoms and may be missed by studies employing short data collection periods. Relatively little research has explored the role that psychosocial factors play in AM outcomes and what research has been conducted suggests they may be particularly salient to the way in which AMs are experienced and the outcomes observed. AMs are taken by people within the context of their daily lives and the treatment systems they are engaged with. Other people may also play a role in determining AM effects, outcomes and subjective experiences. There is a need for further research that gives special consideration to coping, social support, and the additional approaches people use to maintain their wellbeing while they are taking AMs, during their attempts to withdraw, and after discontinuation.

PART ONE

SURVEY STUDY:

EXPERIENCES OF ANTIPSYCHOTIC MEDICATION

CHAPTER THREE:

SURVEY STUDY METHODOLOGY

This chapter describes the methodology used in the survey research exploring experiences of taking AMs, attempting to discontinue AMs, and current QOL outcomes. Three separate investigations were carried out. Results are presented and discussed in Chapters Four, Five and Six.

Ethics Approval

Ethics approval was granted for a period of three years by the University of Auckland Human Participants Ethics Committee.

Participants and Recruitment

Criteria for participation in the survey were kept deliberately broad to allow recruitment of a sample that would include people who discontinue (a group often excluded from other studies), people prescribed AMs for psychosis, people prescribed AMs for other reasons, and people taking different AM agents. People were eligible to take part in the survey if they were at least 18 years old, a New Zealand citizen or resident, living in the community (i.e. not currently in hospital), judged themselves to be well enough to reflect on their experiences without undue distress (according to their own judgement) and had taken or were currently taking an oral AM continuously for at least three months for any reason. Participants were recruited via service-user and professional mental-health networks across New Zealand, with efforts to publicise the study among the general population via mainstream radio media and word of mouth. See Chapter Four for a full description of the participants comprising the whole sample (n=144) and Chapter Five for details regarding a sub-sample (n=105) who had made at least one attempt to stop.

Survey Construction and Content

An anonymous, online survey was constructed to explore experiences of taking AMs. The experience of taking AMs was conceptualised as involving prescription experiences, medication experiences, use of additional approaches, and given the high rates of discontinuation reported in the literature, experiences of attempting to stop AMs. Within each of these four main areas of inquiry, supplementary measures using multiple-choice and check-list questions were alternated with open-ended questions designed to elicit personal evaluations of the experiences involved in taking AMs (examples are described below). There was no limit to how much or how little each person could write in response to open questions. The bulk of the survey questions were adapted with permission from the Experiences of Antidepressants Survey (Read, 2013; Read, Cartwright, & Gibson, 2014) and others were reproduced with permission from the interview schedule used by the

second national Australian Study of High Impact Psychosis (SHIP, Waterreus, 2013; Waterreus et al., 2012). Standardised scales were included to evaluate current outcomes and the potential role of coping and social support. These were the Brief Multidimensional Life Satisfaction Scale (BMLSS - Büsing et al., 2009) as a measure of current QOL satisfaction, the Brief Cope (BC - Carver, 1997) for current coping behaviours, and the Multidimensional Scale of Perceived Social Support (MSPSS - Zimet, Dahlem, Zimet, & Farley, 1988) as a measure of social support (see Measures for further detail). The survey was piloted with a convenience sample of people who had experience with AMs and were known to the researcher, and changes were made accordingly. The survey is presented in full in Appendix One.

The survey comprised four parts exploring (1) socio-demographic information, current outcomes (BMLSS), coping (BC), social support (MSPSS) and additional strategies; (2) the prescription process; (3) most recent use of AMs and subjective experiences of the medication(s); and (4) attempts to discontinue taking AMs. All participants were presented with the first three parts of the survey. A question at the end of part three asked participants to indicate whether they had ever tried to stop taking AMs. Participants who indicated they had previously attempted to stop taking AMs were presented with part four of the survey. Prescribing experiences, medication experiences and use of additional approaches are reported in Chapter Four. The results for the smaller sub-sample who had discontinued use of AMs are reported in Chapter Five. The analysis of current recovery outcome (QOL/BMLSS), internal and external psycho-social resources (coping and social support) and CAMS is reported in Chapter Six.

Demographic Variables

Current age in years, gender, and ethnicity, highest level of education, income band, and occupational status were included as demographic variables. See Chapter Four for results and Appendix One for response options. Occupational status (employed full-time, employed part-time, student, unemployed or specified other) was later dichotomised based on whether time was spent involved contributing to community or educational activities regardless of whether this was paid. Those who indicated paid full-time or part-time work and/or study or specified self-employed or volunteer roles were coded as employed and those who selected unemployed or specified other responses referring to beneficiary status, being retired or to family roles such as parenting were coded as unemployed. Participants were also asked to indicate the primary symptoms they experienced when they started AMs, age of symptom onset, whether they had ever received a formal diagnosis, if so, what that was, and the age they first started AMs.

Current Antipsychotic Medication Status

Current AM Status (CAMS) was a dichotomous variable based on participants' yes/no responses to a survey item asking "Are you currently taking an oral Antipsychotic Medication?" For the purposes of the regression analysis, a CAMS score of 0 represented No Current AM Use at the time of survey completion and a CAMS score of 1 represented Current AM Use at the time of survey completion.

Current Quality of Life

QOL represents a measure of subjective wellbeing, health and psycho-social functioning. Current QOL was chosen as the primary measure of current recovery outcomes because satisfaction with social and daily functioning is a top recovery-priority for people with experience of mental-health problems (Byrne, Davies, & Morrison, 2010). Current satisfaction with QOL was assessed using the Brief Multidimensional Scale of Life Satisfaction (BMLSS - Büssing et al., 2009). The BMLSS is an adaptation of the longer and more widely used Brief Multidimensional Student's Life Satisfaction Scale. The BMLSS rates satisfaction with family, friends, work, self, living situation, financial situation, future prospects, health situation, ability to cope with life, and overall life. It yields a single score expressed as a percentage of the maximum possible score, where 100 is representative of total satisfaction with every area of life. The BMLSS has been shown to have strong internal consistency (Cronbach's $\alpha = 0.869$) and good external validity with respect to subjective measures of depression symptoms (Beck's Depression Inventory), physical and mental health-related QOL as measured by the Medical Outcomes Study Short-Form Health Survey (SF-12), as well as objective measures of relationship status and the presence and duration of medical problems such as cancer and chronic pain (Büssing et al., 2009). The BMLSS was thought to represent an efficient means of assessing subjective recovery outcomes that incorporated satisfaction with internal dimensions of QOL in addition to physical health and the external dimensions of social, occupational, and living situation.

Internal and External Psycho-Social Resources

Psycho-social resources were defined as the psychological, behavioural, interpersonal, and non-medication processes, strategies, and sources of support that people used to manage their mental health. Measures included use of additional approaches, current social support and current coping style. Satisfaction with social support and ability to cope both represent dimensions of QOL outcome assessed by the BMLSS. Several studies have suggested social support dimensions such as number of supports, level of social integration and coping via social diversion are predictive of QOL among people taking AMs, in addition to the demographic variable of occupational status. Few

studies have explored how the quality or adequacy of one's social supports might contribute to predictions and no studies have explored whether active or avoidant coping play a role in QOL among those who discontinue or persist with AMs, though research from other fields suggests this is likely.

Use of additional approaches. Participants were shown a list of common additional approaches to recovery and asked to indicate which options they had used at any time in their recovery and rate how helpful they found each approach used (see Table 3.1 in Chapter Four for a summary of approaches and their helpfulness ratings). The list was adapted from the list of alternative approaches used in the Experiences of Antidepressants Survey (Read et al., 2014), with the guidance of my service-user advisors. The thirteen options included several psycho-social and physical non-medication approaches. The number of additional approaches (NAA) used by each person was summed to provide a single measure of how many non-medication approaches to recovery each person had currently employed, at any stage in their history, expressed on a scale from 0 – 13.

Current social support. Current social support was assessed using the Multidimensional Scale of Perceived Social Support (MSPSS – see Appendix One). The MSPSS is a 12-item measure of the perceived adequacy of social support (Zimet et al., 1988; Zimet, Powell, Farley, Werkman, & Berkoff, 1990). Adequacy refers to how well the person's social support needs are met and items query the presence or absence of specific social support characteristics or qualities, rather than representing objective frequency of interactions or number of social contacts, or the subjective satisfaction with social support, which is assessed as part of the BMLSS. For example, item one asks respondents how much they agree or disagree with the statement, "there is a special person with whom I can share my joys and sorrows." In this sense, the MSPSS may reflect a measure of a person's opportunities for accessing instrumental support as part of their efforts to cope. Each item reflects one aspect of the quality of the respondent's social support within the domains of family, friends and significant others. Participants rate their agreement with each item from one (strongly disagree) to seven (strongly agree).

The scale yields a single score of total perceived social support (the mean of all 12-items) which ranges from one (worst possible score) to seven (best possible score) and sub-scores for satisfaction with three sources of social support, namely family, friends and significant others, each assessed with four items (Canty-Mitchell & Zimet, 2000); the total score was used as a measure of each participant's perception of the adequacy of their current social support. The MSPSS has been shown to have strong construct validity and good internal reliability among people with schizophrenia (Vaingankar, Abidin, & Chong, 2012) in addition to having good external reliability

among adolescents (Canty-Mitchell & Zimet, 2000; Duru, 2007), and outpatients with schizophrenia and bipolar disorder (Cecil, Stanley, Carrion, & Swann, 1995). It has been used to assess relationships between social support and a wide range of variables including AM adherence among people with FEP (Rabinovitch, Cassidy, Schmitz, Joobar, & Malla, 2013), symptoms of depression and anxiety (Hefner & Eisenberg, 2009; Zimet et al., 1988) and QOL (Chung, Yoon, Park, Yang, & Oh, 2013).

Current coping style. Current coping style was assessed using the Brief Cope (BC), a 28-item scale that assesses the frequency with which people use different coping behaviours (Carver, 1997). The scale yields 14 sub-domain scores which comprise active coping, instrumental support, emotional support, venting, religion (includes meditation), positive reframing, acceptance, planning, denial, self-distraction, substance abuse, behavioural disengagement, humour, and self-blame subscales, which have been validated as dispositional measures that predict both trait anxiety and perceived stress (Doron et al., 2014). There is no total score, as it would not be meaningful, nor is there a standardised way of collapsing these subscales further. Other researchers have demonstrated the Brief Cope can be collapsed on a theoretical basis into composite scales, although methods for doing so vary with the theoretical orientation of the researchers. Some researchers have found support for the use of an approach-avoidance framework (Roth & Cohen, 1986) to create composite scales for avoidant and active coping (e.g., Amoyal et al., 2011), others have used the problem-focused/emotion-focused model (Folkman, Lazarus, & Hogan, 1985) to further distinguish problem-focused coping from active emotion-focused coping and avoidant emotion-focused coping (e.g., Schnider, Elhai, & Gray, 2007), and others have found support for five composites regarding problem-solving, support-seeking, cognitive restructuring, distraction, and avoidance (Doron et al., 2014).

For the purposes of the current investigation, the 14 sub-domains were collapsed into two composite scales for avoidant coping and active coping on the basis of transdiagnostic research suggesting experiential avoidance may be a common vulnerability factor across diagnostic categories including depression, anxiety and psychosis (Hayes et al., 2004; Smout et al., 2012). Active coping was defined as the use of approach-focused strategies that involve thinking about or acting on, approaching or moving towards the stress or distress. The active coping score (BC-Active) comprised the average score of all items for the sub-domains active coping, instrumental support, emotional support, venting, religion, positive reframing, acceptance, humour and planning subscales. Avoidant coping was defined as cognitively or physically moving away from contact with stressors or distress, and the avoidant coping score (BC-Avoidant) comprised the average score of all items for the sub-domains of denial, self-distraction, substance abuse, behavioural disengagement, and self-blame. Whereas other researchers have included the self-distraction and humour sub-domains in their

composite scores for active coping, in the current investigation self-distraction was conceived of as a strategy that involved deliberately not thinking about or attending to the stressor or distress and was included with the avoidant coping strategies. Humour could be conceived of as an attempt to mask the expression of certain emotional elements of an experience. However, because the mask of humour provides a means for talking about difficult subjects it was included with the approach-based strategies. Higher BC-Active and BC-Avoidant scores represented more frequent use of those strategies. Hierarchical multiple regression was used to test whether BC-Active and/or BC-Avoidant contribute to prediction of satisfaction with QOL.

Prescription Experiences

Prescription experiences were explored in two parts with a primary focus on the first prescribing experience and a single open-ended question about the nature of the ongoing prescribing experience. Subjective Prescription Experiences were defined as descriptive evaluations of the external and internal qualities and characteristics of the situation(s) involved in accessing AMs (1) for the first time and (2) ongoing thereafter. Subjective initial prescription experiences were queried by providing participants with a starter-phrase and asked them to continue it: “For me, the experience of first being prescribed antipsychotic medication was...” Supplementary measures of the initial prescription experience included questions about age at first prescription, compulsory status, information about benefits and risks, information about when and how to stop, other options offered, predicted duration of treatment, and satisfaction with the first prescribing experience. The ongoing prescribing experience was queried in an open question asking, “What was the ongoing prescribing process like for you?”

Subjective Experiences of AMs

The subjective experience of taking AMs was defined as the self-assessed quality and characteristics of the effect of AMs themselves. This was queried through an open-ended question designed to elicit an evaluation of the overall subjective experience of taking AMs together with a series of supplementary measures of the experience of taking AMs all focused on the participants’ most recent or current medication regime. These were benefits, adverse effects and their impact, partial adherence and reasons for it, perceived helpfulness, and perceived impact on QOL, along with thoughts of stopping and whether any attempts had been made.

Overall subjective experience. The overall subjective experience of taking AMs (OSE) was defined as the global, qualitative evaluation of the effect of taking AMs and was queried by asking participants to complete the starter phrase “In my life, antipsychotic medications have been...” Content analysis yielded a measure of the valence of each participant’s OSE, expressed as Positive,

Negative or Mixed, and a range of sub-categories revealing the detail of the specific positive and negative elements of the experiences. OSE was intended to provide a measure of what it is like to take AMs overall.

Most recent or current medication regime. Participants were asked when they were most recently taking AMs (most recent regular use: taking at the current time; In the last year; 2 years ago; 3 – 5 years ago; more than 5 years ago). They were then asked for the name(s) of their most recent AM(s). Participants responded in open-ended comments and their responses categorised into specific agent groups (e.g. olanzapine, risperidone), and then into agent types, typical/FGA or atypical/SGA. As a measure of polypharmacy, participants were also asked whether they were taking any other medications (tablets or injections) for their mental health at the same time, and if so what the names of those concurrent medications were. The same process was followed to categorise their use of concurrent psychiatric medications. Participants who were coded into multiple AM agent categories or one or more other medication category, were further categorised as either receiving a single AM alone or receiving polypharmacy.

Benefits. Benefits of most recent or current AMs were measured via content analysis of participant responses to an open-ended question asking simply, “What were the benefits of taking antipsychotic medication for you?” Supplementary questions included the impact on QOL scale used in the Experiences of Antidepressants Study (Read et al., 2014) and the Helpfulness rating scale used in the SHIP study with a slight re-wording of the neutral point on the scale from ‘neither’ to ‘unsure’ (Waterreus et al., 2012).

Adverse effects and their impact. Adverse effects were measured by providing participants with a list of commonly reported associated difficulties and asking them to select all that applied. The impact of these adverse effects was assessed via a follow-up rating-scale reproduced with permission from the SHIP interview schedule (Waterreus et al., 2012), which asked people “How much is your everyday life affected by the problems you experience as a result of the antipsychotic medication you take?” Response options are presented in Appendix One and results in Table 4.1 in Chapter Four.

Partial adherence. Adherence was defined as following a prescribed regime and could be classified as Full or Partial, and is distinguished from discontinuing completely. Participants were asked whether they took their current or most recent AM(s) exactly as they were prescribed, with all yes responses indicating Full Adherence and all no responses indicating Partial Adherence. Those with partial adherence were asked to select from a list the kinds of changes they made (Taking medication less often or in smaller doses than prescribed; Taking medication more often or in larger doses than prescribed; Taking the same amount but at a different time than prescribed; I don’t

remember). They were also asked about their reasons for partial adherence with an open-ended question that was subject to content-analysis.

Persistence and discontinuation rate. ‘Persistence’ and ‘discontinuation’ are my preferred terms for what other researchers might refer to as compliance and non-compliance. Persistence was defined as continuing to take AMs, with or without full adherence. Discontinuation was defined as stopping AMs completely. The central measure of persistence and discontinuation was Current AM Use, assessed by asking participants whether they were currently taking oral AMs on a regular basis. All who said yes were defined as persisting or being current users of AMs and all who said no were defined as discontinued or not currently using/taking AMs. Supplementary measures included an item designed to assess the desire for persistence or discontinuation, by asking whether participant’s had ever thought of stopping AMs, and an item designed to assess previous discontinuation, by asking all who indicated thinking about stopping, whether they had ever made an attempt to do so. Participants who responded yes to this final question were directed to the final section of the survey to query the nature of their experience with stopping.

Experiences of Attempted Discontinuation

Participants were asked to focus on their most recent attempt to stop taking AMs when responding to questions about their experiences with AM discontinuation. A series of open-ended questions explored withdrawal effects, withdrawal coping efforts, unhelpful and helpful aspects of the attempt, support received during the process, and finally, the outcome of the attempt. These are defined in greater detail below. Supplementary measures included reasons for discontinuation, number of attempts, age at most recent attempt, most recent withdrawal method, consulting a doctor, any preparations, types of preparation (for those who made any preparations) and time off AMs. CAMS, most recent regular use, and time off AMs were used as measures of discontinuation outcome alongside participant description of whether they were ultimately able to stop.

Withdrawal methods. Withdrawal methods were differentiated on the basis of whether the reduction was gradual (i.e., a slow taper or stepped reduction) or abrupt (i.e., sudden reduction to zero medication without preparatory reductions). Participants were asked to indicate via multiple-choice whether their most recent attempt employed an abrupt withdrawal method (e.g., I stopped taking the medication abruptly all in one go) or a gradual withdrawal method (e.g., I slowly reduced my dose over a period of time before stopping entirely). Those who indicated following a gradual reduction were asked how long they had taken to make the reduction, and their responses were sorted into time to reduce sub-groups.

Withdrawal effects. Withdrawal effects were defined as the physical, cognitive, emotional or psychological features and functional changes that follow reduction or discontinuation of AMs, as

per the participant's own subjective assessment. Withdrawal effects were queried by asking "What were the effects of withdrawing from the medication?" Responses were subject to content analysis and categorised in positive, negative, mixed and zero/none groups.

Withdrawal relapse. Withdrawal related relapse was operationalised as the re-emergence or exacerbation of primary symptoms, or the emergence of new emotional or psychological symptoms that cause disrupted functioning and begin proximal to the cessation or reduction of AMs. References to relapse that occurred years following discontinuation were defined as taking place outside of the withdrawal period and were excluded. Because the sample includes people with a range of primary symptoms, withdrawal-related relapse was not limited to the rebound of psychosis or mania alone. The definition was designed to have a low-threshold and capture those who became hospitalised as well as those who considered themselves to have 'become unwell' but remained out of hospital. This definition includes references to getting unwell, relapse, rebound, hospitalisation or compulsory treatment, general indications of substantial deterioration (e.g. "*a disaster*"), specific symptoms of psychosis or mania, and other alterations in sleep, mood, thinking and behaviour that disrupt functioning such as agitation, suicidal ideation, obsessions, uncharacteristic behaviour, an insufficient standard of self-care and/or uncontrollable racing thoughts. Participant responses to questions about the effects of withdrawal, coping experiences and the outcome of their attempt were reviewed and each participant categorised as having a withdrawal-related relapse or not.

Withdrawal coping and support. Participants' subjective experiences of coping and support during the withdrawal process were queried with four related open-ended questions regarding how participants coped with the unwanted effects of withdrawal, what support they had available, and what strategies and supports they found helpful and unhelpful.

Subjective discontinuation outcome. Subjective discontinuation outcome was the participants' self-assessment of whether they reached their target goal of stopping regular use of AMs, regardless of symptomatic remission, relapse or current use of AMs. Participant responses to the survey question, "What was the outcome of your attempt to stop taking medication?" were explored and the full range of outcomes identified and coded, these were then categorised broadly according to content referencing (1) Stopped Discontinuation Outcomes (defined as achieving the target goal of stopping AMs), (2) Resumed Discontinuation Outcomes (defined as not achieving the target goal and returning to regular use of AMs), (3) Attempt In Progress/Uncertain Discontinuation Outcomes (defined as an attempt that is underway and has an undetermined outcome) and (4) Other Cannot be Coded outcome statements (defined as off-topic or ambiguous statements). Stopped and Resumed outcomes were then further analysed for specific content elements regarding the subjective nature of either experience (see Chapter Five).

Data Analysis

In addition to summarising the descriptive statistics, two separate methods of data analysis were employed and are described below. Content analysis was used to explore the whole sample's subjective descriptions of their experiences of taking AMs (see Chapter Four for results) and the sub-sample describing the experience of attempted discontinuation (see Chapter Five for results). A hierarchical multiple regression was used to explore predictive relationships between QOL, CAMS, coping, social support and number of additional approaches used (NAA; see Chapter Six for results).

Content Analysis

Content analysis was used to summarise the range of experiences described in participants' responses to open-ended questions regarding their subjective experiences. A data-driven, inductive process was used to identify content categories within each section of the qualitative data set, based on the explicit semantic content within participant descriptions. Participant data was then coded accordingly in SPSS to generate totals for further analysis. Responses to each qualitative survey item were explored in detail and every unique content item was labelled and defined. Similar and related content elements were collapsed into content categories. Content categories with three or more references were retained and those with single references were grouped into 'other' categories. Where appropriate, the content categories were then classified as positive or negative elements of the subjective experience in question.

Finally, responses were grouped into higher-order categories such as the positive, negative or mixed quality of the subjective experience. Categorisation of the positive or negative valence of a content category followed a deductive process based on the assumption that symptoms, hospitalisation, relapse, distressing thoughts and emotions, medication side effects, disruptions to functioning and resuming AMs following an attempt to discontinue, represent unwanted, disadvantageous components of experience. Symptom reduction, pleasant thoughts and emotions, improved or facilitated functioning and stopping AMs following an attempt to discontinue, were assumed to represent wanted, advantageous components of experience. Accordingly, no distinction was made between the positive and negative valence of discontinuation outcomes, the benefits of AMs, withdrawal-related relapse, withdrawal coping methods, helpful strategies and supports, or unhelpful strategies and supports. Participants who referenced only positive content categories were classified as having wholly positive subjective experiences of the subject in question. Participants who referenced only negative content categories were classified as having wholly negative subjective experiences of the domain in question. Those who referred to both positive and negative content categories were classified as having mixed subjective experiences. Most content analyses were limited to responses to a single question, regardless of whether the participant

mentioned this elsewhere in the survey. However, for withdrawal-related relapse all open-ended responses within the discontinuation section of the survey were explored for references to relapse as defined above.

Coding reliability was checked by two people with experience in the mental-health field, but outside of the field of clinical psychology. Both had previously used AMs themselves. One worked as a counsellor and the other as a consumer advisor to mental health services. Each person was assigned a section of data and independently coded a randomly selected 20% of responses. Definitions were first discussed and clarified with each reliability checker prior to coding. Inter-rater reliability was then calculated by comparing their ratings to researcher classifications. Items with coding disagreements were discussed with each person to further clarify definitions and a second reliability check carried out on the same items. The results of the reliability calculations are presented in Chapter Four.

Hierarchical Multiple Regression

Statistical analyses were carried out using SPSS version 23. Prior to analyses, and to test the assumptions of parametric tests, data was screened for normality using the Kolmogorov-Smirnov Test. Linearity between BMLSS and the continuous predictor variables (age, MPSS, BC-Active, BC-Avoidant, and NAA) was assessed using Pearson's Two-Tailed T-Test and linearity between BMLSS scores and the categorical predictor variables (occupational status, gender and CAMS) was assessed using Spearman's Rho.

A three-step hierarchical multiple regression was conducted to explore whether current use of oral AMs (CAMS), active and avoidant coping (BC-Active and BC-Avoidant), perceived adequacy of social support (MSPSS) and NAA were predictive of participant recovery outcomes, defined as current QOL satisfaction and evaluated via total BMLSS score. Given satisfaction with social support, coping capacity and work-life each represent dimensions of QOL, I hypothesised that involvement in occupational activities, social support adequacy, and coping would be predictive of QOL. The regression analysis was designed to test the relative, independent contributions of social support adequacy, coping and NAA, over and above CAMS, and explore the direction of any predictive relationships observed. In step one, age, gender and occupational status were included as control variables given existing literature suggesting possible positive correlations between QOL and age (e.g., Boyer et al., 2013), occupational status and gender (e.g., Alonso et al., 2009; Boyer et al., 2013). I then tested the independent contributions of CAMS (step two), and the psycho-social factors (step three) to BMLSS over and above these demographic factors. Results are presented in Chapter Six.

CHAPTER FOUR: EXPERIENCES OF TAKING ANTIPSYCHOTIC MEDICATION

This chapter describes the variety of experiences involved in taking AMs. The descriptive data for participant demographics is presented first, followed by prescription experiences, use of additional approaches, most recent experiences of AMs, and overall subjective experiences of AMs (OSE). Results present a combination of summed participant responses to multiple-choice, rating scale and check-list questions together with content analysis results showing the unique units of content identified within participants' open-ended comments and the frequency of references made to each. The reliability checking process resulted in an overall agreement rate of 96.7% (first prescription experiences 100%; OSEs 100%; withdrawal effects 100%; withdrawal coping strategies 95.5%; helpful approaches 100%; unhelpful approaches 90.9%; discontinuation outcomes 100%; withdrawal related relapse 100%).

Participants

In total, 202 people began the survey and 158 people completed it. Of the 44 people who did not complete, 18 dropped out after the first two questions regarding consent and eligibility; the remaining 26 closed the survey at various points throughout. Completed survey responses were explored for validity by checking that participant responses to questions about AM agents named a typical or atypical neuroleptic and were internally consistent across questions regarding current medication status. Of the 158 participants with complete response-sets, eight discussed medications that were not AMs and were excluded from the sample. Further analysis led to the identification of an additional six participants with contradictory answers to multiple-choice questions about their current use that prevented reliable interpretation of their responses; these participants noted they were (a) not currently taking AMs *and* (b) had never tried to stop. It is possible these participants considered themselves to have stopped without *trying* or employing effort, however it was impossible to interpret the responses this way with any certainty. In the interest of reliability and erring on the side of caution, these participants were excluded from further analysis, yielding a final sample size of 144.

The final sample was predominantly female, of New Zealand-European ethnicity, educated beyond high-school and employed in part-time or full-time work and study (see Table 1.1). The exclusion group was predominantly female, of New Zealand-European ethnicity, with an average age of 49 years.

Table 1.1. Participant Demographic Information

Gender	Count (%)	Highest Education	Count (%)
Female	104 (72.2%)	High School Incomplete	8 (5.6%)
Male	37 (25.7%)	High School Complete	15 (10.4%)
Other	3 (2.1%)	Diploma or Certificate	50 (34.7%)
Ethnicity		University Degree	71 (49.3%)
NZ European	120 (83.3%)	Approx. Annual Income	
Maori or Part Maori	13 (9.1%)	Under \$10 000	24 (16.7%)
Other Ethnicity	11 (7.6%)	\$10 001 to \$20 000	37 (25.7%)
Current Age		\$20 001 to \$30 000	31 (21.5%)
Range	18-70 Years	\$30 001 to \$50 000	22 (15.3%)
Mean	41.1 Years	\$50 001 and Over	30 (20.8%)
18 to 29 Years	33 (22.9%)	Occupational Status	
30 to 39 Years	38 (26.4%)	Employed Part Time	39 (27.1%)
40 to 49 Years	28 (19.4%)	Employed Full Time	42 (29.2%)
50 to 59 Years	34 (23.6%)	Student	13 (9.0%)
60 Years or Over	11 (7.6%)	Unemployed	17 (11.8%)
		Other	33 (22.9%)

This table summarises the demographic data for the whole sample of N=144. All percentages are expressed as a portion of the whole sample and rounded to 1 DP.

A summary of clinical and medication factors can be found in Table 1.2. Approximately two thirds of the participants were currently taking AMs at the time they completed the survey. Most reported starting AMs between 18 and 29 years of age (inclusive).

Table 1.2 Participant Mental Health History and Medication Information

Initial Primary Symptoms ^a	Total n (%)	Most Recent AM Types ^c	Total n (%)
Hallucinations	51 (35.4%)	SGA Only	127 (88.2%)
Delusions	66 (45.8%)	FGA Only	11 (7.6%)
Mania	70 (48.6%)	Both SGA and FGA	3 (2.1%)
Depression	101 (70.1%)	Most Recent Polypharmacy	
Other	61 (42.4%)	Concurrent Use of Multiple Meds	104 (72.2%)
Age of Onset^{b,c} (range: 4-63 yrs)		Single Oral AM Only	30 (20.8%)
Onset Under 18 Years	53 (36.8%)	Don't Know Other Meds	10 (6.9%)
Onset 18 to 29 Years	43 (30.0%)	- Multiple Oral SGAs	8 (5.6%)
Onset 30 to 39 Years	18 (12.5%)	- Multiple Oral FGAs	2 (1.4%)
Onset 40 to 49 Years	6 (4.2%)	- Both Oral SGAs and FGAs	3 (2.1%)
Onset 50 to 65 Years	4 (2.8%)	- Concurrent Antidepressants	65 (45.1%)
Diagnoses Received^a	127 (88.2%)	- Concurrent Mood Stabiliser	39 (27.1%)
Bipolar Disorder	60 (41.7%)	- Concurrent Benzodiazepines	22 (15.3%)
Schizophrenia Spectrum Disorders	46 (31.9%)	- Concurrent Sleeping Pills	21 (14.6%)
Depressive Disorder	46 (31.9%)	- Concurrent Other (e.g. stimulants)	8 (5.6%)
Anxiety Disorder	36 (25.0%)	- Concurrent Depot AMs	3 (2.1%)
Personality Disorder	21 (14.6%)	Full Adherence to AM Prescription	
Eating Disorder	7 (4.9%)	Yes	99 (68.8%)
Autism Spectrum Disorder	4 (2.8%)	No	42 (29.2%)
Others	7 (4.9%)	I Don't Remember	3 (2.1%)
Age Started AMs^b (range: 12-63 yrs)		Persistence of Oral AM Use	
Before 18 Years	18 (12.7%)	Thought of Stopping	114 (79.2%)
18 to 29 Years	68 (47.2%)	Attempted Stopping	105 (72.9%)
30 to 39 Years	31 (21.5%)	Current AM Status (CAMS)	
40 to 49 Years	17 (11.8%)	Yes Current Use of Oral AMs	91 (63.2%)
50 to 65 Years	8 (5.6%)	No Current Use of Oral AMs	53 (36.8%)

N = 144; All percentages rounded to 1 dp. (a) Participants were able to select/describe more than one primary symptom or diagnosis and they frequently reported multiple differential diagnoses without distinguishing a primary or current diagnosis. (b) Age of Onset of the primary symptoms that led to AM prescription. (c) Excludes those who selected 'do not remember'. Totals do not sum to 100%.

The majority were most recently or currently taking SGAs (three people could not recall their most recent AM agent). The specific break-down of SGAs currently or most recently in use was as follows: Quetiapine 52.1% (n=75); Olanzapine 17.4% (n=25); Risperidone 16.7% (n=24); Clozapine 3.5% (n=5); Aripiprazole 6.9% (n=10) and Amisulpride 0.7% (n=1). FGAs in use were as follows: Haloperidol 3.5% (n=5); Stelazine 2.8% (n=4); Chlorpromazine 2.1% (n=3); and Mellaril, Neulactil and Thiothixene used by one participant each (0.7%). Regarding polypharmacy, a minority reported taking multiple AMs of the same or different class concurrently and nearly three quarters reported taking additional medications for their mental health at the same time as taking their most recent AMs.

Participants selected from a list the symptom-sets they were experiencing when first prescribed AMs and were invited to specify others not included in the list. Content analysis of 'other' responses to the question regarding primary symptoms revealed 18.1% of participants described experiences of Anxiety and Trauma Responses such as "*dissociation*", "*panic attacks*", "*anxiety*" and "*OCD*", while 9.0% described Insomnia and Sleeplessness, 6.3% described Emotional Distress such as "*torment*", "*intense sadness*", "*anger*", "*fury*" and "*distress*" and 6.3% referred to Intrusive Thoughts such as "*racing thoughts*", "*rumination*" and "*paranoia*" that could go with any mental-health condition. Additional hypomania or other mania descriptions were given by 4.2% of participants, while 4.9% referred to Further Symptoms of Psychosis such as "*voices*" or "*drug psychosis*" in their other comments. Finally, 2.8% reported Destructive or Self-Destructive Behaviour such as "*I tried to kill myself*", three people (2.1%) made general references to the Side-Effects of Antidepressants requiring treatment with AMs, and 3.5% made reports of other primary symptoms including a single mention of "*spiritual experiences*" and two references to eating issues. Age of onset for these experiences ranged from approximately four to 63 years old.

Most (88.2%) reported receiving a diagnosis, with bipolar disorder, schizophrenia spectrum disorders, and depression being the most common (see Table 1.2). Among the other diagnoses were two reports of substance use disorder and single reports of brain cancer, ADHD and cerebral lupus. Many participants described multiple diagnoses without clarifying whether these were differential or comorbid labels and where this was not apparent, every reported label was coded into a diagnostic content category (e.g. where schizoaffective disorder and bipolar disorder were described together). Given the unreliability of reported diagnoses, a dimensional approach was adopted and reports of primary symptom-sets were used for further analysis. Grouping those who selected hallucinations, delusions and/or mania from the primary symptoms check-list together with those who selected depression and/or other and specified additional, associated symptom-sets in their comments (3.5% hypomania or mania, 2.1% other psychosis), showed 80.6% of the sample experienced the hallmark

symptoms of psychosis or bipolar disorder (n=116/144) and 19.4% of the total sample did not (n=28/144).

Prescription Experiences

Initial Prescription Experiences

As shown in Table 2.1, a quarter of participants were under a compulsory treatment order (CTO) at the time of their first AM prescription. It was not uncommon to be told to take AMs for the “rest of your life” or to receive no discussion about how long to take AMs. Few participants reported feeling well-informed of the benefits and risks of AMs at first prescription, being offered other options to consider, or being told how to stop taking AMs. Approximately one third reported being at least somewhat satisfied with the first prescription experience.

Table 2.1 *Initial Prescription Experiences*

Compulsory Status^a at First Prescription count (%)		Initial Predicted Duration of Use^a count (%)	
Compulsory Initial Script	36 (25.0%)	Specified Time Up to 1 Year	17 (11.8%)
Non-Compulsory Initial Script	101 (70.1%)	Over a year	14 (9.7%)
Initially Informed of Benefits and Risks		The Rest of Your Life	37 (25.7%)
Not at all informed	48 (33.3%)	Until You Feel Better	22 (15.3%)
Slightly informed	38 (26.4%)	Not Told / Not Discussed	29 (20.1%)
Moderately informed	24 (16.7%)	Satisfaction with Initial Prescribing	
Well informed	19 (13.2%)	Very satisfactory	12 (8.3%)
I Don't Remember	15 (10.4%)	Satisfactory	35 (24.3%)
Initially Informed of when to stop^a		Not sure	37 (25.7%)
Yes	9 (6.3%)	Not satisfactory	25 (17.4%)
No	110 (76.4%)	Not at all satisfactory	35 (24.3%)
Initially Offered Additional or Alternative Options^a		Subjective Initial Prescription Exp.^b	
Yes	39 (27.1%)	Negative First Prescription	73 (50.7%)
No	88 (61.1%)	Positive First Prescription	33 (22.9%)
		Mixed First Prescription	24 (16.7%)

Results of supplementary multiple-choice measures and content analysis regarding the initial prescribing experience (exp). All percentages expressed as a proportion of N=144. (a) Excludes don't know/remember responses; (b) Excludes participants with responses that could not be coded into positive/negative/mixed content categories. Totals do not equal 100%.

Results of the content analysis for Initial Prescribing Experiences are summarised in Table 2.2. Approximately one fifth of the sample gave wholly positive descriptions of the first prescribing experience, approximately one half gave wholly negative descriptions, and a sixth gave mixed positive and negative descriptions. In total, nearly two thirds had negative elements in their descriptions of the initial prescribing experience and approximately one third included positive elements. Several participants who used negative terms, referred to the negative side-effects of AMs when describing what the initial prescribing experience was like and several participants who used positive terms referred to the positive effect of AMs. These comments were deemed to refer to medication effects rather than the prescribing process and will not be described any further here.

However, because multiple participants gave such descriptions they were coded here as part of the prescribing experience, indicating that some people find it difficult to separate the prescribing experience from the impact the medication has. A small number of comments were not coded due to ambiguity, references to topics other than the first prescription or descriptions of not being able to remember this information, for example *“I was completely crazy”* (#28), and *“due to lots of ECT my long term memory is poor and I don’t recall my first experience”* (#47).

Table 2.2 *Subjective Experiences of the Initial Prescription*

Content Categories	Total (%)
Subjective Initial Prescription Experience	
Only Positive	33 (22.9%)
Only Negative	73 (50.7%)
Only Mixed	24 (16.7%)
Uncoded	14 (9.7%)
Positive Elements of Initial Prescription	57 (36.6%)
Relief or Hope for Relief	34 (23.6%)
Positive Initial Medication Effects	13 (9.0%)
General Positive Description Only	7 (4.9%)
Improved Understanding of Self	3 (2.1%)
Other: Supportive Clinician, My Choice	2 (1.4%)
Negative Elements of Initial Prescription	94 (65.3%)
Experienced Anxiety, Fear, Trauma	39 (27.1%)
Confusing	18 (12.5%)
Confronting Own Attitudes about Mental Health and Medication	16 (11.1%)
Negative Initial Medication Effects	13 (9.0%)
General Negative Description Only	11 (7.6%)
Loss of Autonomy	10 (6.9%)
Depressing, Demoralising or Producing Hopelessness	3 (2.1%)
Desperation	3 (2.1%)
Other: Lonely or Isolated, Negative Episode Effects	3 (2.1%)

This table presents results of a content analysis of responses to the question asking people to complete the sentence *“For me, the experience of first being prescribed AMs was...”* All percentages out of N=144.

Positive elements of initial prescription. There was little variation in the content shared by those who included positive elements in their descriptions of the initial prescribing experience. The most frequently used terms referred to a sense of relief at discovering an option available to them or hope for relief from distress, for example, *“A relief, a sign of hope”* (#11), and *“A bit of hope that things may get better, maybe they are taking me seriously”* (#126). A relief was also related to an Improved Understanding of Self, gained through a diagnosis made as part of the prescribing process, for example, *“A relief because I had a diagnosis and finally knew what was wrong with me”* (#67).

Negative elements of initial prescription. Among the negative elements of the first prescription experience, Anxiety, Fear and Trauma were referenced most frequently. A number of participants within this category used descriptions such as *“scary,” “terrifying,” “horrifying,” “a nightmare,” “HELL,” “traumatic”* and *“worrying”*, without providing further detail. Others shared longer comments referencing other content categories as the source of the fear or anxiety, or

referring to the experience as a traumatic event in reference to other content categories of Confusion, Loss of Autonomy, Confronting Own Attitudes of Mental-Health and Medication, and/or the Negative Initial Effects of AMs. For example, a number of people referencing fear connected this to a sense of uncertainty produced by being confronted with a diagnosis or medication that called their perception of reality into question or implied some form of mental deficiency, for example *“Scary, overwhelming, felt like an admission of being defective, unable to trust myself”* (#49). Others linked the frightening experience to being confronted with an approach that was inconsistent with their own beliefs and attitudes, for example, *“horrific I had not even taken a pain killer for 20 years it was against my belief system felt like a death sentence”* (#60). Some comments connected anxiety and fear with the experience of Confusion produced by lacking information about AMs, for example, *“Terrifying as I did not fully understand at that point how and why they worked, that they could be prescribed for different conditions”* (#55). Comments describing trauma appeared to consistently refer to Loss of Autonomy, for example, *“Disempowering, like being abused or raped with all your power taken from you”* (#94).

Comments referring to Confusion described a lack of information about what AMs were, what they could be used for, and why they were being prescribed, for example, *“Very confusing because I didn't entirely understand what it was or why I was taking it or for how long or what I was taking it for specifically, like how it would help”* (#59). Others connected their confusion to a perceived Loss of Autonomy that prevented them from seeking clarifications, for example, *“Confusing, and I felt I was unable to speak on my own behalf to find out more”* (#2).

Among those who referred to a Loss of Autonomy, some described a subjective sense of disempowerment and implied loss of choice while others described coercive, forced aspects of the first prescription, for example, *“Frightening, disorientating. Felt loss of control over life”* (#123), *“Terrifying (held down and injected), disabling, disempowering and a life changing experience”* (#26), *“Horrible, I was forced to take them against my will”* (#15) and *“the most disempowering experience of my life. I had made it very clear from my first contact with mental health services that I did not consent to any psychotropic drugs as I held strong opinions surrounding their use”* (#53).

Ongoing Prescription Experiences

As shown in Table 2.3, similar proportions of the sample gave positive and negative descriptions of the ongoing prescribing process with a small group who gave mixed reports and another group whose comments could not be coded in this way due to ambiguous, missing, or off-topic responses (e.g., referring to medication effects instead of prescribing factors) or descriptions of forgetting, for example, *“I got used to it after some time”* (#106), and *“it helps me get to sleep”* (#135).

Table 2.3. *Subjective Experiences of the Ongoing Prescribing Process*

Content category	Count (%)
Subjective Experiences of Ongoing Prescribing	
Positive Descriptions	42 (29.2%)
Negative Descriptions	48 (33.3%)
Mixed Descriptions	25 (17.4%)
Uncoded Descriptions	29 (20.1%)
Positive Elements of Ongoing Prescribing	
General Positive Description	37 (25.7%)
Consultation and Reviews	13 (9%)
Clinician Support or Rapport	10 (6.9%)
Corrected Medication Regime	8 (5.6%)
Becoming Informed	7 (4.9%)
Easy to Organise and Finance	5 (3.5%)
Other: Correct Diagnosis	2 (1.4%)
Negative Elements of Ongoing Prescribing	
Narrow Focus on Meds Only	19 (13.2%)
Battle to be Heard	15 (10.4%)
General Negative Description	14 (9.7%)
Lack of Information	12 (8.3%)
Difficult Emotional Responses	12 (8.3%)
Many Different Clinicians or Agents	11 (7.6%)
Loss of Autonomy	9 (6.3%)
Lack of Supportive Consultation or Review	8 (5.6%)
Stressful to Organise and Finance	4 (2.8%)

This table presents the frequency of participant references to elements of the ongoing prescribing experience. Percentages are expressed as a proportion of the whole sample of 144.

Positive elements of ongoing prescribing. Among those with positive or neutral elements in their descriptions, most gave brief general descriptions such as *“ok”* (n=10/144) and *“fine”* (n=2/144), *“no problems”* (n=3/144), and *“excellent”* (n=1/144), without providing further information. Nearly 10% of the sample and 19.4% of those with positive elements referred to Consultation and Reviews that were responsive to their needs and self-reports, for example *“I was transferred from a registrar to a permanent psychiatrist. She correctly diagnosed me and changed my medication. Since then I have been v happy with the process, consultation and reviews,”* (#1). One person with a mixed experience compared encounters with reviews that were and were not responsive to their self-reported needs, explaining the ongoing prescribing process was *“Horrific until I was listened to. I begged the psychiatrist not to give me any more of this drug, that they were giving me too much, that it was beginning to knock me around. Later after moving back to my home town I went under the care of another psychiatrist. For the first time in six weeks someone listened and immediately began working with me to assist me to withdraw from [the AM]”* (#53).

The few referring to Clinician Support or Rapport generally referred to supportive and collaborative working relationships, for example, *“very supportive and helpful”* (#99) or described in more detail the various roles of trust, listening and autonomy, for example, *“Pretty cruisy, I am open*

about my mental health with my GP so I trust him to make good decisions about my medication” (#67), “Depends on the doctor. First one bad, second very good - worked with me on diagnosis and best medication” (#90) and “I have a very good relationship with my current psychiatrist and he listens to me and I am in control at every stage” (#50).

Corrected Medication Regimes involved descriptions of adjustments being made to their medications to address adverse effects, for example, *“Ok, I told my GP (post discharge from CMHC) that I was sedated and having break through symptoms so he re-referred me and the medication was changed” (#19).* A small group of participants discussed the value gained from Becoming Informed about the medication and their options, either through independent learning that could be brought into clinical reviews or through information sought from and shared by the prescribing clinician. For example, *“Since then it's been a bit better. It's good now. My current psychiatrist is very good at keeping me informed and giving me options” (#3) and “Better - I was able to ask my community psychiatrist(s) questions about treatment and anti-psychotics and get more information” (#76).* Finally, there was a group of references to it being Easy to Organise or Finance. This was sometimes because it was easy to contact the prescribing clinician directly or through a support-worker, when needs changed or a repeat prescription was required. For example, *“I see my psychiatrist ever three months and we review my meds then. In between times I see my psych nurse every fortnight and bring any medication issues up with him (or text him in between times). He then gets my psychiatrist to make changes as needed” (#109), and “Easy - just call my doc for a repeat!” (#115).* There were also two other references to receiving a Correct Diagnosis.

Consultation and Reviews were frequently referred to together with Clinician Support or Rapport, Corrected Medication Regimes and Becoming Informed. For example, *“I have a very good relationship with my current psychiatrist. I do lots of research and also know a lot more about my illness now, sometimes we can reduce sometimes up the medication depending on symptoms” (#50).*

Negative elements of ongoing prescriptions. Within the negative descriptions of the ongoing prescribing experiences a portion of respondents gave brief general descriptions that could not be coded any further than their negative valence; for example, *“not great”, “shit”, “stressful”, “poor” and “pretty dreadful”.* Many of the negative content elements appeared to be reverse reflections of the positive elements. References to a Narrow Focus on Medication Only described how the prescribing process appeared to focus solely on AM options and increasing doses, neglected to address the option of stopping AMs, and/or did not provide information about alternative or additional options. Respondents referring to this content element said *“they just keep telling me to take the pills” (#86), “It was passed on to GP who made no attempt to change or stop it. He made no assessments when I asked for repeat prescriptions. Just continued to write them out” (#32), “the*

ongoing prescribing process was a nightmare. I wanted to please my psychiatrist but believed the med was bad for me and had trouble making myself take it. Most of the time with my psychiatrist was focused on him persuading me to be compliant” (#71), and “The whole focus is on me being compliant to take meds and not the context of my over-all recovery. So long as the voices are gone, that is all they look at” (#66). One participant reflected on the impact this narrow focus on medication might have had on their development, commenting “I wish I had different options explored when I first entered the system, and I don't know what kind of effect having been on this kind of medication over such a long time through an important developmental phase would have had” (#31).

Comments referring to a Battle to be Heard described struggling to have their self-report taken seriously by their prescribing clinicians. Participants made statements such as “[It was a] battle. With one particular drug prescribed whilst inpatient I informed staff of negative side-effects, was told “that is not a side-effect of that medicine, you are being treatment resistant, take it” (#2). A number of participants referring to this difficulty being heard, also made reference to an actual or perceived Loss of Autonomy.

References to Loss of Autonomy described a reduced sense of being able to choose freely for themselves or an actual loss of the right to choose due to being “under The Act” (#56). They described “terrible, enforced treatment” (#82), “Pressure from my doctor, my family and my husband because they were afraid” (#43), “I felt a bit like it was all “happening TO me” (#112), “It was assumed. There was never any discussion about reducing medication even with the undesirable side effects, simply a check on whether I am not suicidal, how things have been and another prescription. It felt like I was locked in” (#25), “Scary. Felt like doctors had total control over my life/body” (#123), and “Imposed on me. Although I was always a voluntary patient, I was told that if I did not comply with meds I would be committed and lose any choice and then be given ECT as well. To the best of my memory, by the time I was discharged I had more “insight” and had been convinced that it was best to keep taking the medication, and I did” (#92).

Those describing a Lack of Information Sharing explained that “I also remember the Doctor talking with my mother a lot. Instead of me” (#35), “I felt like my doctors really didn't know the drug very well. They prescribed it but I ended up doing my own research when they weren't able to answer/dismissed questions about side effects I was experiencing” (#37), and “Maybe they could tell me more about risks they always gloss over that” (#52). References to Many Different Clinicians or Agents described “Constant changing of medications with no real consistency with seeing different Psychiatrists frequently” (#17), and “changed doctors often so each doctor had a different approach” (#126).

Participants describing a Lack of Supportive Consultation and Review referred to a lack of regular monitoring or follow-up of the medication effects and their personal recovery outcomes, such that the prescribing experience could engender a sense of being unsupported or uncared for. *“Ongoing - generally never got reviewed until I needed medical intervention (hospitalisation). At those times it was just increased with little monitoring,”* (#105).

Several participants referred to Difficult Emotional Responses of confusion, fear and embarrassment, commenting that it was *“Very, very humiliating, intimidating and frightening, losing all respect and dignity”* (#92), *“Confusing, fearful”* (#28), *“Variable. I found that each medical professional had different views on prescribing antipsychotics which was confusing and upsetting”* (#55), and *“confusing, they kept adjusting the dosages and then changed the brand of antipsychotic medication completely. I got a print out of the side effects during the ongoing prescribing process though, which was super scary”* (#38).

Finally, a number of people said it was Stressful to Organise and/or Finance. Participants commented it was *“Hard financially, needing to go to the doctor so often and scared of the withdrawal if I accidentally run out of pills before my appointment”* (#5), that it was *“Good. But the lack of emergency prescriptions from pharmacy is disheartening. When I've forgotten to get repeat on say a Friday and can't get to doctor until Monday that throws me out as I have no medication for 3 days”* (#127), and that it was *“a hassle going to get them”* (#34) or *“irritating in that I have to go into my psych's office every 3 months even when I am well”* (#100).

Use of Other Approaches

All 144 participants were asked to select from a list the other recovery approaches they had used in addition to AMs and, if used, to rate how helpful they were (see Table 3.1). The majority of this sample (96.5%) had used at least one other approach in addition to AMs. The majority of the group had used two or more approaches (range 0 – 13). The most commonly reported additional approach used was individual therapy or counselling followed by support groups. Summing the frequency of helpfulness ratings in the slightly to extremely helpful range revealed most found the additional approaches they used helpful to some degree (range 66.0% – 93.9%).

Table 3.1 *Use and Perceived Helpfulness of Additional Approaches*

Approaches Used ^a		Helpfulness Ratings ^b					No. Approaches ^a	
Options	Total Used	Not Helpful	Slightly Helpful	Mod. Helpful	Very Helpful	Extremely Helpful	No. Used	Total
1-1 therapy ^c	132 (91.7%)	8 (6.1%)	16 (12.1%)	21 (15.9%)	55 (41.7%)	32 (24.2%)	Zero	5 (3.5%)
Support group	89 (61.8%)	12 (13.5%)	14 (15.7%)	20 (22.5%)	27 (30.3%)	16 (18.0%)	1 Only	1 (1.0%)
Supplements ^c	87 (60.4%)	16 (18.4%)	22 (25.3%)	24 (27.6%)	14 (16.1%)	11 (12.6%)	2 to 3	22 (15.3%)
Meditation	86 (59.7%)	12 (14.0%)	22 (25.6%)	14 (16.3%)	21 (24.4%)	17 (19.8%)	4 to 5	28 (19.4%)
Nutrition advice ^c	78 (54.2%)	14 (17.9%)	19 (24.4%)	19 (24.4%)	18 (23.1%)	8 (10.3%)	6 to 7	45 (31.3%)
CSW ^c	73 (50.7%)	9 (12.3%)	25 (34.2%)	13 (17.8%)	12 (16.4%)	14 (19.2%)	8 to 9	27 (18.8%)
Exercise options	70 (48.6%)	5 (7.1%)	16 (22.9%)	16 (22.9%)	20 (28.6%)	13 (18.6%)	10 +	16 (11.1%)
Herbal remedies	64 (44.4%)	17 (26.6%)	19 (29.7%)	16 (25.0%)	6 (9.4%)	6 (9.4%)		
Respite service	55 (38.2%)	7 (12.7%)	9 (16.4%)	11 (20.0%)	12 (21.8%)	16 (29.1%)		
Rel/fam therapy ^c	53 (36.8%)	18 (34.0%)	13 (24.5%)	13 (24.5%)	6 (11.3%)	3 (5.7%)		
PSW ^c	45 (31.3%)	3 (6.7%)	13 (28.9%)	8 (17.8%)	15 (33.3%)	6 (13.3%)		
AOD counselling	26 (18.1%)	4 (15.4%)	5 (19.2%)	5 (19.2%)	3 (11.5%)	9 (34.6%)		
Cultural support	20 (13.9%)	4 (20.0%)	4 (20.0%)	2 (10.0%)	6 (30.0%)	4 (20.0%)		

Participants (n=144) selected from a list all other approaches they had tried at any stage and rated how helpful they were. All percentages are rounded to 1 dp. Total Used = total number of participants who used an approach. No. of Approaches = the total number of additional approaches participants used. Helpfulness = frequency of self-reported helpfulness ratings for each approach. (a) Percentage expressed as proportion of total sample (n=144) (b) percentages are expressed as a proportion of Total Used; n varies for each approach, see Total Used. (c) Approach labels have been abbreviated: 1-1 Therapy = Individual Therapy or Counselling; Supplements = Vitamins and Supplements; CSW = Community Support Worker; Exercise Options = Green Prescription or Exercise options. Rel/fam Therapy = relationship or family therapy; PSW = Peer Support Worker; Nutrition advice = Nutrition and Diet Advice.

The approaches most frequently rated slightly to extremely helpful by those who had used them were individual therapy or counselling (93.9%), peer support workers (93.3%), 'Green Prescription' or exercise options (93.0%), community support workers (87.6%), respite services (87.3%) and support groups (86.5%). Most participants who tried individual therapy or counselling rated it very or extremely helpful (65.9%). With the exception of individual therapy, the approaches most frequently rated as helpful were each used by less than two thirds of the sample. Every approach was rated Not Helpful by at least some of the people who tried it. The approaches most frequently rated Not Helpful were relationship or family therapy, herbal remedies, cultural support, vitamins and supplements, and nutrition and dietary advice.

Grouping additional approaches into those utilising physical health methods (vitamins, nutritional advice, herbal remedies, exercise options) and those utilising psycho-social methods (the three talking therapy approaches, support groups, peer support workers, community support workers, meditation, and cultural support) revealed that most people in the current sample used both physical and psycho-social additional approaches (n=126/144; 87.5%). A minority reported using only psycho-social additional approaches (n=13/144; 9.0%). The only people who did not use psycho-social approaches were those who did not use any additional approaches at all.

Persistence, Partial Adherence and Perceptions of AM Effects

Participants were asked to focus on their most recent or current experiences with AMs when answering questions about their perception of benefits and adverse effects, the impact of adverse

effects, adherence, helpfulness, and the impact on their QOL. Results are summarised in Table 4.1. Of the whole sample, 66% reported finding AMs somewhat to very helpful while 70.1% thought AMs had slightly or greatly improved their QOL and 22.9% thought AMs had made their QOL slightly or greatly worse. A separate cross-tabulation showed that of those who were currently taking AMs (n=91) 80.2% reported finding AMs helpful (n=73/91) and 83.5% perceived an improvement in their QOL (n=70/91). Among those who had stopped (n=53), 41.5% rated them as helpful (n=22/53) and 47.2% reported a perceived improvement in QOL (n=25/53). In turn, 47.2% of those who had stopped reported AMs to have been unhelpful (n=25/53; 47.2%) and 43.3% reported a perception AMs had worsened their QOL (n=23/53). Among those who continued to take AMs 5.5% found them unhelpful (n=5/91) and 11.1% perceived a deterioration in their QOL (n=10/91).

Table 4.1. *Adherence, Persistence and Perceptions of AM Effects*

Perceived Helpfulness	Count (%)	Adverse Effects	Count (%)
Very helpful	47 (32.6%)	Drowsiness, sedation	116 (80.6%)
Somewhat helpful	48 (33.3%)	Weight gain	98 (68.1%)
Unsure	19 (13.2%)	Emotional numbing	77 (53.5%)
Somewhat unhelpful	8 (5.6%)	Loss of motivation	73 (50.7%)
Very unhelpful	22 (15.3%)	Feeling not like myself	71 (49.3%)
Perceived Impact on QOL^a		Increased appetite	71 (49.3%)
Greatly improved	51 (35.4%)	Dry mouth	66 (45.8%)
Slightly improved	50 (34.7%)	Loss of sex drive	65 (45.1%)
Unchanged	10 (6.9%)	Tremors	45 (31.3%)
Slightly worse	12 (8.3%)	Dizziness	36 (25.0%)
A lot worse	21 (14.6%)	Suicidality	24 (16.7%)
Benefits^b		Hypertension	14 (9.7%)
Stopped/Reduced Psychosis or Mania	67 (46.5%)	Diabetes	10 (6.9%)
Increased Sleep	27 (18.8%)	No Adverse Effects	4 (2.8%)
Stable Moods	26 (18.1%)	Impact of Adverse Effects	
Reduced Anxiety	23 (16.0%)	Not at all	26 (18.1%)
Improved Functioning	18 (12.5%)	Mildly	53 (36.8%)
Improved Thinking	11 (7.6%)	Moderately	41 (28.5%)
Less Destructive Behav.	9 (6.3%)	Severely	24 (16.7%)
Sedation	3 (2.1%)	Full Adherence to Regime	
No Benefits	11 (7.6%)	Yes	99 (68.8%)
Other	8 (5.6%)	No	42 (29.2%)
Don't Know / Not Sure	4 (2.8%)	I Don't Remember	3 (2.1%)
Persistence and Discontinuation			
Has Thought of Stopping	114 (79.2%)	Yes Current Oral AMs	91 (63.2%)
Has Tried to Stop	105 (72.9%)	No Current Oral AMs	53 (36.8%)

Percentages are reported as a proportion of the whole sample n=144. (a) Perceived impact on QOL in comparison to the time leading up to first prescription. (b) Reported benefits are the result of a content analysis of participant responses to an open-ended question about the benefits they experienced as a result of their current or most recent AM regime.

Most respondents indicated full adherence to the prescribed medication regime when they were taking AMs with around a third indicating partial adherence. Responses to a multiple-choice question asking what kinds of changes people made, showed 20.1% of the whole sample, or 69.0% of those who were partially adherent, reported taking medication less often or in smaller doses than prescribed (n=29); 14.6% of the sample and 50% of those who were partially adherent reported

taking AMs more often or in larger doses than prescribed (n=21); and 9.7% of the sample and 33.3% of those who were partially adherent reported taking the same amount but at a different time than prescribed (n=14).

Participants who indicated partial adherence were asked an open question about their reasons for making changes to their medication regimes (n=42). Among those who made changes to their medication regimes, 50% described doing so in order to Manage the Intensity or Timing of Unwanted Side Effects (n=21/42), for example *“If I took the prescribed dose I would have been so sedated I wouldn't have been able to get up and do anything”* (#139), and 31.0% said they did so in Response to Fluctuating Needs and Symptoms (n=13/42), for example *“Because I am not a robot or a test tube. My body needs more or less at different times”* (#44). Participants in these two groups repeatedly commented that they saw themselves as the best experts in judging how much medication they needed to take and when. The following two comments provide representative examples: *“I believe I know my body and mind (most of the time) better than others and hence my 'charting and scripting' of anti-psychotics to suit my ever changing needs”* (#118), and *“I felt like it knocked me round too much and know I am more sensitive to meds than doctors who don't know me so I trust my own judgement”* (#144).

Forgetting was given as a reason for partial adherence by 16.7% of those who made changes (n=7/42), while 9.5% reported partial adherence to Prepare For or Test My Ability to Discontinue (n=4/42), 7.1% said they took less medication in order to Stockpile AMs for Suicide by Over Dose (n=3/42), and 7.1% indicated taking more medication for the reason of Overdosing to Sleep for Extended Periods (n=3/42). A selection of sub-threshold comments (19.0%; n=8/42) referenced such things as asserting autonomy, for example *“because no one was forcing me anymore”* (#26), limited capacity to self-monitor, for example, *“I have autism, I didn't understand why I needed to take it, had no support to remind me to take it”* (#93), and stigma, for example *“don't like taking 'psych' meds because of the label it gives i.e. confirms I'm a psych patient”* (#47) and *“I couldn't come to terms with the fact that it was me who was crazy not everyone else”* (#76).

Perceptions of Benefits and Adverse Effects

The majority of participants reported experiencing both benefits and adverse effects associated with their current or most recent use of AMs (n=123/144; 85.1%). Zero benefit was accompanied by one or more adverse effect for 9.7% of participants (n=14/144), while one or more benefits came with zero adverse effects for 2.1% of the group (n=3/144). Some described what it was like to experience limited to no benefit and highlighted difficulties they faced, making such comments as *“It was like being in a straitjacket I was unable even to walk to the letter box. I had no feelings at all felt like a zombie”* (#88) and *“It allowed me some degree of functioning from a place of*

none. Although I felt very disconnected/spaced/ drugged/robotic/wiped out” (#1). One participant referred to the numbing of emotions as a benefit, where others described them in negative terms “I guess the inability to feel emotions. Allowed me to disconnect from myself and become something foreign” (#101).

Perceived benefits. Among the whole sample, 89.6% reported at least one benefit as a result of their current or most recent AM regime. The most common benefits were Stopped or Reduced Positive Symptoms of Psychosis or Mania, followed by Increased Sleep, Stabilised Moods, Reduced Anxiety, and Improved Functioning in terms of relationships, coping with stress and/or occupational activities, for example *“I have been able to get married, get to my 10th wedding anniversary, have 2 dogs and 2 cats and be godfather to one of my friends children and best-man at another friend’s wedding” (#33).* It was more common for people to comment that symptoms reduced (n=53) than stopped (n=18). People who referred to the cessation of symptoms commented as follows, *“100% removal of all symptoms” (#7), and “My head noise stopped” (#21)* while those who referred to reduced symptoms described how *“The bizarre intrusive thoughts were under control and that enabled me to investigate what they were, why they happened and how to manage them in the future” (#65), “[...] I describe it like [the voices] stay at the back of my head now instead of occupying me for most of the day” (#78) and “Hallucinations are not so vivid and don’t last long” (#113).* Benefits were often linked together, for example, *“Calmed the voices and paranoia down so that I could manage to keep my job as able to concentrate better” (#17).*

Perceived adverse effects. Adverse effects were reported by 97.2% of the sample. As shown in Table 4.1 the majority reported sedation, more than two thirds reported weight gain, and around half of the sample reported emotional numbing, loss of motivation, a changed sense of self, dry mouth, and loss of libido. One in six reported an increase in suicidality. Additional disadvantages not listed in Table 4.1 included Impaired Cognitive Functioning (n=7), Akathisia or Restlessness (n=5), a Negative Impact on Identity and Sense of Self (n=5), Stigma, (n=4), Constipation (n=3), Deteriorated Appearance (n=3), Increased Saliva (n=3) and New Psychotic Symptoms (n=3) where psychosis had been absent before. The remaining additional disadvantages were referred to by one or two people each and included agranulosis, lactation, hypotension, oculogyric crisis, priapism, hair-loss, nausea, increased anger, and concerns about child-bearing and fertility (reported by one female and one male participant). Adverse effects had at least a slight impact on daily life for the majority of the participants, and one in six reported a severe impact.

Overall Subjective Experiences of Taking Antipsychotic Medication

As a measure of the overall subjective experience of taking AMs (OSE), participants were asked to complete the sentence ‘In my life, Antipsychotic Medications have been...’ As shown in

Table 5.1, broadly similar numbers reported wholly positive, negative and mixed OSEs. An additional cross-tabulation (see Table 5.2 in Appendix Three) showed that people from each of the three OSE groups reported thinking about stopping (n=33/53, 62.3% positive OSE; n=39/42, 92.2% negative OSE; n=38/45, 84.4% mixed OSE), trying to stop (n=31/53, 58.5% positive OSE; 35/42, 83.3% negative OSE; n=37/45, 82.2% mixed OSE) and having currently discontinued oral AMs (n=9/53, 17% positive OSE; 24/42, 57.1% negative OSE; 19/45, 42.2% mixed OSE). People among both positive and negative OSE subgroups described wholly positive first prescription experiences (n=20/53, 37.7% positive OSE; n=5/42, 11.9% negative OSE), and wholly positive ongoing prescription experiences (n=24/53, 45.3% positive OSE; n=7/42, 16.7% negative OSE), received at least a moderate level of information about what benefits and risks to expect (n=23/53, 43.4% positive OSE; n=10/42, 23.8% negative OSE), perceived improvement in their QOL (n=52/53, 98.1% positive OSE; n=10/42, 23.8% negative OSE) and to find AMs slightly to greatly helpful (n=51/53, 96.2% positive OSE; n=13/42, 31% negative OSE), but these appeared to be more commonly reported among those with positive OSEs. People in both positive and negative OSE subgroups reported receiving no information about the benefits and risks when first prescribed AMs (n=14/53, 26.4% positive OSE; n=20/42, 47.6% negative OSE) and being severely impacted by the adverse effects of AMs (n=3/53, 5.7% positive OSE; n=17/42, 40.5% negative OSE), but these experiences appeared more common among those with negative OSEs.

Table 5.1. Overall Subjective Experiences of Taking AMs

Overall Subjective Experience	Count (%)
Positive	53 (36.8%)
Negative	42 (29.9%)
Mixed	45 (31.3%)
Uncoded	4 (2.8%)
Specific Positive Elements of Experience	
1: General Positive Helpful Description	33 (22.9%)
2: Helpful for Certain Things	26 (18.1%)
3: Helpful When Needed	16 (11.1%)
4: Helpful Once Find the Right Regime	13 (9.0%)
5: A Life-saver	12 (8.3%)
6: Essential or Necessary	7 (4.9%)
Specific Negative Elements of Experience	
1: Increased Difficulty Living My Life	45 (31.3%)
2: General Negative Description	15 (10.4%)
3: A Significant Negative Life Event	10 (6.9%)
4: Difficult Period of Trial and Error	11 (7.6%)
5: Ineffective or Insufficient	9 (6.3%)
6: The Harm Outweighed the Help	5 (3.5%)
7: Disempowering or Against My Will	4 (2.8%)
8: Prescribed Too Long or Too Heavily	3 (2.1%)
9: Stigma, Shame and Embarrassment	3 (2.1%)

This table shows Positive and Negative Elements of Overall Subjective Experiences. Percentages are expressed as a proportion of the total sample (N=144). Four 'overall experience' responses could not be coded and were excluded from this analysis. Single participants referred to multiple content elements and totals do not equal 100%.

Positive Elements of Overall Experience

Positive elements of the OSE were reported by 68.1% of the sample, comprising those with positive and mixed OSEs (n=98). Positive elements were defined as statements that described AMs as overall a beneficial, desirable or advantageous part of life or served a function, with or without qualifying statements regarding type, degree or duration of benefit and are summarised in Table 5.1.

Most comments referring to positive elements of the OSE used generalised positive descriptions such as *“helpful”*, *“useful”*, *“effective”*, or *“beneficial”*, without qualifying statements. A second group used qualifying statements that described AMs as being overall Helpful for Specific Things, including Stabilising Moods (n=11/144; 7.6%), Sleep (n=7/144; 4.9%), Reducing Anxiety, Fear and Agitation (n=6/144; 4.2%), Reducing Symptoms of Psychosis (n=5/144; 3.5%), Reducing self-harm urges (n=4/144; 2.8%) and Enabling Daily Functioning (n=4/144; 2.8%). For example *“useful to stabilise my mood”* (#79), *“at least it helped me get to sleep and stay asleep”* (#115), *“they allow me to be calm, less anxious, less suspicious”* (#101), *“a miracle when it is got right as it seems to tweak the brain and bang the voices leave you alone on the whole”* (#82), *“they take away [...] most of the violent and suicidal thoughts”* (#89) and *“They make me able to get through the day (mostly) and allow me to leave my home to go outside and on a good day out and about the local neighbourhood”* (#58).

The group who noted AMs were Helpful When Needed comprised those who described AMs as Helpful to Get Through Difficult Times (n=10/144; 6.9%), for example, *“helped me get through an unstable period of my life”* (#63), and those who emphasised AMs were Helpful in the Short Term (n=6/144; 4.2%), for example *“A short term help [...] then a burden”* (#26) and *“A temporary solution”* (#110). A fourth group specified that AMs were helpful for them once they had identified the “right” agent (n=9/144; 6.3%) or dosage (n=5/144; 3.5%), most often a lower dose. Of those who referenced Finding the ‘Right’ Regime, all but two described a *“frustrating”* or *“trying”* journey of trial and error and were categorised as having mixed OSEs.

Participants who used the words “life saver” or an equivalent description, made comments like *“[AMs provide] a major relief from the monsters. [...] For me they have saved my life,”* (#58) and *“A lifesaver. When I was in breakdown, I seriously considered suicide,”* (#76). Of those who described AMs as Essential or Necessary, most provided no further qualification, but two people described AMs as Necessary but Unwanted, one as Necessary and Useful, and one person emphasised AMs were Essential to Ongoing Wellbeing.

Negative Elements of Overall Subjective Experiences

Negative elements of the OSE were reported by 60.4% of the sample, comprising those with wholly negative and mixed OSEs (n=87/144) and are summarised in Table 5.1. Negative elements

were defined as statements that describe AMs overall as an unhelpful, costly, unwanted, disadvantageous or ineffective part of life, with or without qualifying statements regarding type, degree or duration of the negative element.

Approximately a third of the total sample referred to Difficulty Living Life, which included reports that AMs Disrupted Psycho-social Functioning (n=17/144; 11.8%), Disrupted Physical Health (n=15/144; 10.4%), caused Unwanted Emotional Effects (n=9/144; 6.3%) and Exacerbated Mental Health Problems (n=6/144; 4.2%), which referred to the Worsening of Existing Problems (n=3/144; 2.1%), the Initiation of First Hallucinations and Delusions (n=2/144; 1.4%) and one other comment. The sub-category of Disrupted Psycho-Social Functioning included references to General Disruption and Limitation (n=7/144; 4.9%), Difficulties from Cognitive Effects (n=5/144; 3.5%) and Diminished QOL (n=5/144; 3.5%), with a single other comment referring to Looking like a Mental Patient. Most participants reported multiple negative elements in a linked manner, for example, *“[In my life AMs have been...] shit always side effects that far out-weigh the pros, lost all creativity, lost my computer designing hobbies as I lost all ability to want to do anything even though I would like to, pretty much ruined a lot of work I had done to better myself in my life,”* (#34). Another person commented *“While I was taking them I felt suicidal because of the impact of the antipsychotics. They made me lethargic, killed my sex-drive and destroyed my creativity. They robbed me of everything I value in myself as a person,”* (#71).

Participants describing Disrupted Physical Health reported Managing Weight Gain (n=10/144; 6.9%) and Being Unhealthy (n=8/144; 5.6%), which included descriptions of Major or Permanent Physical Damage (n=4/144; 2.8%) and Developing Diabetes (n=2/144; 1.4%). For example, *“[In my life AMs have been...] bad for me; have given me diabetes”* (#45), *“I had a goitre as a result of taking these drugs and had to have surgery. I now only have half a thyroid gland, and my singing voice has been damaged”* (#71), and, *“have caused major or immense physical health damage”* (#128).

Unwanted Emotional Effects included Lack of Emotion and Motivation (n=4/144; 2.8%), Feeling Depressed and Distressed (n=3/144; 2.1%) and Others (n=2/144; 1.4%). Unwanted Emotional Effects can be represented by comments such as *“[In my life AMs have been...] a double edged sword. They help me with my bad experiences but they also take away the wind in my sails”* (#15), *“made me feel emotionless and like I'm a zombie”* (#142), and *“depressing”* (#4).

Those who described the OSE as A Significant Negative Life Event used phrases like *“One of the worst things to ever happen to me”* (#11), *“the ruin of my life”* (#92), *“A disastrous mistake”* (#20) or emotive words like *“hell”* (#6, #60), *“torture”* (#2) and *“curse”* (#124). Comments that reported A Difficult Journey of Trial and Error all came from participants with Mixed OSEs, who gave

descriptions such as *“Frustrating as it took a long time to get the one that suited me”* (#91). These are the same participants who referred to the positive content category, Helpful Once Find the Right Regime.

People describing AMs as Ineffective or Insufficient noted AMs Did Not Help (n=7/144; 4.9%) or were Insufficient Alone (n=2/144; 1.4%); One person described how a narrow focus on medication left them feeling unsupported, *“[In my life AMs have been...] unhelpful, it didn't feel like I was being supported and instead more of a here you go take these pills and be on your way situation”* (#59). The content category of The Harm Outweighed the Help, is represented by comments such as *“[In my life AMs have been...] helpful up to a point, but the harm they caused was very much worse than the help they gave”* (#71).

Those within the Disempowering or Forced category commented *“[In my life, AMs have been...] forced, pointless, disruptive, dangerous, frightening and disempowering”* (#26). One person named the source of this disempowerment, commenting, *“The horrific and debilitating side effects of this drug combined with the disempowering experience of losing my right to decline treatment was the most traumatic experience of my life”* (#55). Although it did not meet threshold for a content category of its own, two participants highlighted that it was Difficult to Stop. Results from the discontinuation section of the survey suggest a large part of the sample may share this experience of difficulty.

Discussion

This investigation was concerned with answering two simple questions, what is it like to take AMs, and what other approaches do people use? Results will be discussed in light of these questions in turn. The results of this mixed methods survey shows most people experienced benefits and adverse effects, contemplated stopping and had made at least one attempt to stop. Content analysis led to the identification of sub-groups of people who report wholly positive, wholly negative and mixed OSEs, determined by the number, degree and direction of effects on psychological wellbeing, physical health, social-occupational functioning, and the impact of environmental and prescribing factors. Contemplating and attempting to stop AMs was common among all three OSE subgroups and was also described by the sub-group who reported benefits to their QOL and perceiving AMs to be helpful. Where most people described at least some benefit to taking AMs, a sub-group reported experiencing deterioration in their QOL, found AMs unhelpful and faced difficulty living their lives as a result. Both initial and ongoing prescribing experiences were frequently marked by a lack of information and a narrow focus on AMs, and could produce a range of fearful and confusing reactions. Collaborative and responsive consultation and prescriber willingness to adjust medications when this was indicated were major features of positive prescribing experiences and

the journey towards finding a medication regime with the least possible adverse effects. Most participants reported using multiple additional options at some point, with the majority reporting use of psycho-social options like individual therapy, support groups and peer support workers, alongside non-medication physical approaches like exercise, and nutritional advice. AMs appear to be rarely used in isolation.

What is it Like to Take AMs?

This study demonstrates that overall the subjective experience of taking AMs is highly variable and extends beyond medication factors, the effect on symptom severity, and the simple presence or absence of adverse effects. AMs were described as affecting “*every aspect of my life*” by one participant and though others did not use these same words, they frequently listed multiple areas of their life that had been affected by taking AMs, either in positive or negative terms. In this sample, OSEs involved psychological factors such as emotional responses, coping capacity, goals, sense of self-efficacy and control, identity, and personal belief systems, social-occupational factors such as engagement with meaningful life activities and interpersonal relationships, physical health factors pertaining to appearance, diet, exercise, and long-term health conditions, prescribing factors such as choice, responsive monitoring, information sharing, clarity of communication, and clinician listening, and environmental factors such as the fluctuating demands of everyday life and the limitations of the available treatment systems. This is consistent with other research suggesting subjective experiences of AMs are influenced by psycho-social adjustment, premorbid characteristics, psycho-social performance, personality characteristics, social resources and the ability to use social networks, in addition to the impact on symptoms and side effects (Awad & Hogan, 1994) and are ultimately judged based on their overall ability to “maximise wellbeing” (Carrick et al., 2004).

The positives and negatives of AM experiences. Results show AMs can be experienced positively and negatively, often in profound and wide-reaching ways. Both the prescribing process and the effects of the medications themselves can be experienced as “*a nightmare*” and “*hell*” or as “*life-savers*” and sources of “*relief*”, and variations in between. These exact descriptions have been given by people taking AMs in multiple other studies (Moncrieff et al., 2009; Wallace, 1994) and do not appear to be unique to this particular sample. Positive experiences of the AMs included relief from symptoms, improved ability to function in self-care, social and occupational activities, enhanced capacity for coping with stress and adverse effects that were more manageable. In comparison, the negative experiences included limited impact on symptoms, reduced ability to function in self-care, social and occupational activities, greater difficulty coping, and adverse effects that were difficult to manage against the demands of daily living or had caused long-term or serious

health conditions. In some cases AMs were associated with suicidality and some people tied this to the psycho-social impacts of the adverse effects they experienced, as other studies have also revealed (Mihanović et al., 2010). A small group reported experiencing their first psychotic or manic symptoms following the initiation of AMs, in support of previous research demonstrating the questionable value of prescribing AMs for off-label purposes (Maher et al., 2011; Monasterio & McKean, 2011).

More of the participants saw AMs as having improved their QOL and been helpful to them than not, similar to other studies (Waterreus et al., 2012). Perceptions of helpfulness were distributed almost identically to perceptions of the impact of QOL, suggesting that evaluations of helpfulness might be based on the perceived impact of AMs upon QOL. Those who were no longer taking AMs, rarely described positive OSEs, or rated AMs as helpful or responsible for improvements in their QOL, and frequently reported negative experiences. These are precisely the people who are excluded from other studies of AM experiences, which also appear to find higher rates of perceived helpfulness than reported by this sample, (e.g., 82.2% helpful in Waterreus et al., 2012). The implication is that studies of the perceived impact of AMs may be positively skewed when those who have discontinued are excluded from the analysis. Nonetheless, the current results support a conclusion that AMs can be perceived as both helpful and improving QOL as well as being experienced as unhelpful and having a deleterious effect.

There was a clear subset who reported AMs had made their QOL worse and had not been helpful to them, and this suggests it cannot be assumed that taking AMs always results in subjective improvements for people. Results regarding the participants' overall subjective experiences of taking AMs indicate this is likely due to the wide-ranging negative effects AMs could have on the domains of psycho-social functioning, emotional wellbeing and physical health in the context of relatively little symptom reduction. Consistent with prior research, the results suggest a dysphoric subjective response to AMs is relatively common, involving difficulties with sedation, emotional numbing, lost motivation, and increased difficulty living life (Angermeyer et al., 2001; Browne et al., 1998; Moncrieff et al., 2009; Wallace, 1994; Waterreus et al., 2012). Alongside related descriptions of disconnection and loss of the emotional qualities of life, two people used the traditional description of becoming a zombie (Moncrieff et al., 2009; Wallace, 1994).

Other researchers suggest that neuroleptic dysphoria may be difficult to distinguish from the negative symptoms of psychosis or depression, (Wallace, 1994) but in this sample participants clearly attributed the medication as the cause of these effects. Where a sense of disconnection was already present, this was described as worsening. The current results qualitatively expand on other studies demonstrating a predictive relationship between dysphoric responses and QOL (Browne et

al., 1998) by showing that living with neuroleptic dysphoria can subjectively feel like “hell” or “torture” and makes it more difficult for people to function in life. These experiences are also shared by people in non-clinical samples, who after one day of treatment described experiencing anxiety about whether the experience would end (Healy & Farquhar, 1998).

The vast majority of the sample reported experiencing benefits and adverse effects together. The positive or negative valence of participants’ overall subjective experience of taking AMs reflected the perceived impact on their QOL and ability to function on a daily basis. This supports previous studies showing that subjective experiences extend beyond the simple matter of symptom reduction and adverse effects (Tranulis, Goff, Henderson, & Freudenreich, 2011) and that people make decisions about whether to continue taking AMs based on “a reasoned evaluation” of the costs and benefits in regards to their capacity to “live well for self and others” (Carrick et al., 2004; Gibson et al., 2013). An examination of the adverse effects most commonly reported reveals a list of experiences with a strong potential to impact the psycho-social nature of daily life. Accordingly, around two thirds reported that the adverse effects mildly-severely impacted their daily functioning similar to the rate reported elsewhere (Waterreus et al., 2012).

The benefits reported were similar to those described in other qualitative studies (Angermeyer et al., 2001; Moncrieff et al., 2009). More people reported reduced psychosis or mania symptoms than full remission of symptoms, and together half the group reported the ‘antipsychotic’ effect the medications are named for. Nearly ten percent of the current sample reported experiencing zero benefits and at least one adverse effect. This is consistent with AM outcome studies suggesting small-to-moderate effect sizes (Leucht et al., 2009) and studies of subjective experiences that indicate a high level of individual variation (Moncrieff et al., 2009).

These results suggest a group of people experience limited benefit alongside great costs and may be poorly served by a narrow focus on AM treatment, while at the same time others experience great benefit and manageable costs. Individual variation appears to rule the day, and what is one person’s life-saving relief or useful tool, is another’s personal burden, nightmare or hell. The experience can change with shifting medication regimes, but participants referred to a wide range of factors when making their subjective assessment of the positive and negative elements of taking AMs. It appears crucial that people taking AMs are asked what effect it is having on their individual attempts to make the most of their lives. Research identifying predictors and correlates are useful ways of highlighting areas of potential importance, but the results of this study suggest there is little better substitute for assessing outcome than providing the space for the individual’s voice to be heard.

The subjective role of AMs in recovery. The current results show some people experienced AMs as essential to their ongoing wellbeing, while others described them as a “useful tool” for certain purposes and short-term periods of difficulty, and yet others found no place for them at all. For some, they were more of a curse or a burden than a blessing and for others the adverse effects were seen to be worth the benefits gained and/or bearable. There is evidently a group of people for whom AMs are invaluable during acute periods and who are happy to use AMs to control unwanted symptoms long-term. However there is also clearly a group of participants who experience increased difficulty living their lives, and are in need of a more holistic approach and alternative options. While some people were able to stop taking AMs and/or had found their way to a range of additional options, there was in this sample, a subset of people with wholly negative OSEs who continued to take them, and had made multiple attempts to discontinue, without success. For this group, AMs appeared to be experienced as something to escape from or endure without subjective benefit.

The issues of withdrawal and discontinuation appear to be important considerations for many people who use AMs, consistent with the findings of other studies (Cooper et al., 2005; Lieberman et al., 2005; Rascati et al., 2011). Around three quarters of the whole sample had contemplated stopping, the vast majority of people who thought about stopping, made at least one attempt to do so, and a substantial group described ultimately discontinuing AMs. The majority of people with negative and mixed experiences reported thinking about and attempting to stop taking AMs. However, a smaller subset of people with positive OSEs also reported thinking about, attempting and discontinuing AMs. Similar to the findings of other researchers (Carrick et al., 2004; Gibson et al., 2013; Runciman, 2013), these results suggest that persistence of use is not a compliance or insight issue but a choice based on the place AMs have in a particular person’s life alongside their current priorities, values, daily demands, and personal goals. Further analyses presented in Chapters Five to Seven explore the experiences involved in discontinuation, how people manage these experiences, whether persistence of use and/or psycho-social factors predict current QOL, and how the subgroup who successfully discontinue maintain their wellbeing long-term.

The impact of prescribing experiences. The current results support prior studies suggesting prescribing factors such as clinical relationship factors (Gibson et al., 2013; Tranulis et al., 2011) and human rights issues regarding informed choice and consent (Carrick et al., 2004; Farrelly, 2002; Waterreus et al., 2012) are also influential parts of the subjective experience of taking AMs. In this study, people with negative OSEs appeared to be more likely to report wholly negative first prescription experiences than those who reported positive OSEs (69% compared to 39% respectively). Consistent with prior research, the current investigation suggests that prescribing

experiences can engender fear responses (Gibson et al., 2013) and that compulsory treatment can contribute a source of trauma to the experience of taking AMs, even though some respondents also see it as necessary (Naber et al., 1996). Positive prescribing experiences were marked by regular and responsive consultation and reviews, supportive clinician behaviours like listening, communication, attending to self-reported subjective experiences, information-sharing and system factors enabling ease of access. Negative experiences were marked by the reverse in addition to experiences of confusion, emotional distress, and lost autonomy.

Notably, the conditions of informed consent were infrequently met among the current sample. Few people said they were well-informed of the benefits and risks or offered any other option at first prescription. Some described being too unwell to process this at the time, but most people received very little information prior to starting AMs. Other studies suggest a lack of information-sharing is a relatively common situation and has been for some time (Wallace, 1994; Waterreus et al., 2012). In the current study, people with negative OSEs appeared to more often report having received no information about what to expect from AMs compared to those with positive or mixed OSEs (48% compared to 26% and 27% respectively). Those with positive OSEs appeared more likely to report being moderately to well informed, compared to those with wholly negative or mixed experiences (43% compared to 24% and 20% respectively). These results suggest receiving more information about the benefits and risks during the prescribing experience may be associated with more positive OSEs. Some participants shed light on how lacking information meant they found adverse effects “unexpected” and “scary” when they experienced them.

Beyond the first prescription, there were numerous reports of ongoing confusion, a continuing lack of information provision and a narrow focus on AMs as the only options. Furthermore, it appears that even without a compulsory treatment order, the power imbalance inherent in the clinical relationship produced a loss of autonomy and agency that prevented some people from voicing their concerns, requesting other options, or discussing a desire to stop. Furthermore, some described how prescribing clinicians did not seriously consider their experiences when they did voice them or gave invalidating responses. Other researchers have also concluded that restricted autonomy and agency are frequent aspects of the prescribing experiences people who take AMs (Carrick et al., 2004; Gibson et al., 2013). Participants in this study attributed lost autonomy to differing clinician priorities, a narrow system focus on AMs alone, and clinician preconceptions about their capacity for reliable self-report. It was also recognised that personal characteristics such as a lack of assertiveness could play a role.

Lost autonomy, restricted information and lack of choice were described in terms of great distress by participants in this study, affecting their relationships with prescribing clinicians and the

medication itself, but also their sense of themselves as citizens with the ability to safely express their opinions and make choices about the things that affect their lives. It appears that where there is an actual or perceived loss of autonomy and choice, AMs are transformed from potentially useful tools to try, into an imposed form of control to struggle against or submit to. Repeated experiences of disempowerment likely produce reductions in self-efficacy, increased distress, and hopelessness that undermine personal recovery goals. On the other hand, collaborative decision-making in terms of a choice to take AMs, finding the 'right dose', analysing the costs and benefits, and having the option to stop appear likely to improve subjective experiences, as other researchers and clinicians have recommended (Breggin, 2013; BPSDCP, 2014; del Barrio et al., 2013; Moncrieff, 2013; Morrison et al., 2012).

What Other Approaches Do People Use?

This study demonstrates that AMs are unlikely to be used in isolation but rather form part of a wide array of additional and alternative options. Very few people had not tried any of the thirteen listed options. The majority used four or more additional approaches and reported finding them helpful at rates similar to or greater than AMs. Most participants used both psycho-social approaches and physical health approaches, with a minority reporting a sole focus on psycho-social approaches. It appears that where prescribers were described as having a narrow focus on AMs only, those taking AMs may have a much more holistic approach to their recovery and seek out additional approaches to support their psycho-social functioning and their physical wellbeing. Other research has concluded people taking AMs employ non-medication strategies for improving their life experiences (Carrick et al., 2004; Farrelly, 2002) and show improved recovery outcomes when psycho-social options are used as adjuncts (Chung et al., 2013; Guo et al., 2010; Hogarty & Ulrich, 1998) or alternatives (Álvarez-Jiménez et al., 2011; Morrison et al., 2013). In other studies people taking AMs highlight the value of seeking information, making life-style changes, building coping capacity, and finding practical solutions (Carrick et al., 2004), employment support and creative approaches like art therapy as well as counselling, and peer support (Farrelly, 2002). Though it has often been argued in the literature that there is no consensus regarding the efficacy of non-medication adjuncts or alternatives to AMs, the 144 people in the current sample express loud and clear that they find additional approaches helpful. For example, therapy, peer support, and exercise options were perceived to be helpful by more than 90% of people who had tried the approach. Every approach was helpful to many and no approach was helpful for everyone.

A second conclusion is that there is no single 'right' approach for everyone and people likely require information about a variety of options to select the combination that might best suit their particular collection of needs. It appears the search for the most helpful additional options might be

marked by a process of trial and error similar to the experience of taking AMs. It is unknown how long it took the current sample to discover and access the options they used or what other options they were aware of when they made their treatment choices. The specifics of how each approach was used by participants in this study are also unknown and may influence how helpful they were seen to be. For example, there are many different kinds of vitamins and supplements, a variety of ways to receive nutrition and dietary advice, different models for implementing peer support, and individual therapy or counselling might involve seeing different professionals for variable lengths of time, using different modalities. Person-specific factors such as personal goals and values also likely play a role in the kinds of approaches sought out and found to be helpful, in much the same way as the appear to be involved in AM experiences.

The current study has demonstrated that people who take AMs are a heterogeneous group, with a variety of different psycho-social and physical health needs, some of which are a direct response to the AMs. The number, type and helpfulness of additional options used may reflect the range of AM-related difficulties requiring management, and the level of support required to cope with mental-health experiences like hallucinations, delusions, mania, which can be markedly disruptive. The discovery that so many people found most of the additional approaches they tried helpful in some way supports the recommendations made in several books and reports, stating that AM use should be supplemented with psycho-social approaches such as talking therapy, self-help resources, mutual support groups, and practical support (BPSDCP, 2014; Garfield & Mackler, 2009; RANZCP, 2004a; RANZCP, 2004b).

Unfortunately, many people are not offered these additional options, either at the first prescription or thereafter, and must discover them independently of their prescribing clinician. However, providing information about the available alternative or additional options is a core criterion for informed choice, particularly among people who express a desire to refuse AMs (Beck, 1987). It is not possible to make a choice when only one option is presented, or when the options are to take the AMs voluntarily or be committed to hospital and forced to take them, as one participant described, *“Although I was always a voluntary patient, I was told that if I did not comply with meds I would be committed and lose any choice.”* Providing people taking AMs with multiple additional options to consider alongside or as alternatives to AMs would appear likely to improve their overall subjective experiences, their capacity for coping with eventual attempts to stop, and their ultimate recovery outcomes.

CHAPTER FIVE:
EXPERIENCES OF ATTEMPTED DISCONTINUATION

Survey participants who reported previous attempts to stop taking AMs were presented with a selection of questions concerning their experience with attempted discontinuation. Participants were asked about their reasons for stopping, number of attempts, and, focusing on their most recent attempt, their withdrawal methods, doctor's input, preparations, withdrawal effects, support, coping strategies, time off AMs, and the outcome of their attempt (i.e. whether they stopped or resumed AMs).

Participants

Participants were the 105 survey participants who indicated they had previously thought about stopping AMs and had made an attempt to stop. The characteristics of this sub-sample are presented in Table 6.1.

Table 6.1. *Characteristics of the Subsample who had Attempted to Stop Taking AMs*

Participant characteristics	Count	(%)	Participant characteristics	Count	(%)
Gender			Age of Primary Symptom Onset		
Female	78	(74.3%)	Under 18 Years	45	(48.9%)
Male	25	(23.8%)	18-29 Years	28	(30.4%)
Gender Diverse	2	(1.9%)	30-39 Years	11	(12.0%)
Ethnicity			40-49 Years	4	(4.3%)
NZ-European	88	(83.8%)	50-65 Years	4	(4.3%)
Maori or Part Maori	9	(8.6%)	Age First Started AMs (mean 29 yrs; range 12-63 yrs)		
Other	8	(7.6%)	Under 18 Years	15	(14.4%)
Current age (mean 41 yrs; range 18-70 yrs)			18-29 Years	47	(45.2%)
18-29 years	25	(23.8%)	30-39 Years	23	(22.1%)
30-39 years	25	(23.8%)	40-49 Years	12	(11.5%)
40-49 years	22	(21.0%)	50-65 Years	7	(6.7%)
50-59 years	23	(21.9%)	Most recent or current AM type(s)		
60-70 years	10	(9.5%)	Typical AM Only	9	(8.8%)
Occupational Status			Atypical AM Only	90	(88.2%)
Not Employed	21	(20.0%)	Both Typical and Atypical AM	3	(2.9%)
Yes Employed	84	(80.0%)	Polypharmacy – multiple concurrent psych meds		
Highest level of education			No polypharmacy single oral AM only	22	(21.0%)
Did not complete high school	6	(5.7%)	Yes Polypharmacy	76	(72.4%)
Completed high school	10	(9.5%)	Age at Last Attempt to Stop (mean 36 yrs; range 16-70 yrs)		
Diploma/cert. after high school	37	(35.2%)	Under 18 years	1	(1.0%)
University degree	52	(49.5%)	18-29 years	35	(34.3%)
Hallmark Symptoms of Bipolar or Psychosis			30-39 years	27	(26.5%)
Yes	84	(80.0%)	40-49 years	22	(21.6%)
No	21	(20.0%)	50-70 years	17	(16.7%)

This table presents the demographic and clinical characteristics of the subsample of survey participants who indicated making an attempt to stop taking AMs. Percentages are expressed as a proportion of the whole sub-sample of 105.

Most participants (63.8%) had made multiple attempts to discontinue (n=67/105); 35.2% made one attempt (n=37/105); 32.4% made two-three attempts (n=33/105); 16.2% reported four-

five attempts (n=18/105), 4.8% reported six-seven attempts (n=5/105); 4.8% reported eight-nine attempts (n=5/105); 5.7% reported ten or more attempts (n=6/105). One response was missing (range = 1-100).

Respondents were asked to focus on their most recent attempt when answering questions about discontinuation. Details of their attempts and current AM use are presented in Table 6.2. Among those who had made a discontinuation attempt approximately one half were taking AMs at the time they completed the survey.

Table 6.2. *Details of Most Recent Attempt to Discontinue AMs*

Response Option	Total (n=105)	Response Option	Total (n=105)
Main Reasons to Stop^a		Consulted a Dr	51 (48.6%)
Felt better and did not think was needed	46 (43.8%)	Made Preparations	64 (61.0%)
The medication was not helping	40 (38.1%)	Had Support ^c	52 (49.5%)
Wanted to solve the problem without medication	50 (47.6%)	AM Use to Cope	34 (32.4%)
Medication caused unpleasant side effects	76 (72.4%)	Time off AMs	
Afraid would get dependent	25 (23.8%)	< 1 month	28 (26.8%)
Worried about long-term physical health effects	47 (44.8%)	1 – 6 months	16 (15.2%)
Self-Reported Withdrawal Method^a		6 – 12 months	7 (6.7%)
Gradual withdrawal ^b	55 (52.4%)	More than a year	54 (51.4%)
Abrupt withdrawal	44 (41.9%)	Current AM Use	
			52 (49.5%)

This table presents results of multiple-choice and check-list questions regarding reasons for wanting to stop, withdrawal method, consulting a doctor, temporarily using AMs to cope during withdrawal, time off AMs, and rate of current AM use for the sub-sample who had made attempts to stop (n=105). (a) Excludes those who selected Do Not Remember; (b) Self-reported gradual withdrawal method – actual time-to-reduce varied from one week to several years; (c) Had Support refers to the number of participants who qualitatively described at least one form of support from others during the withdrawal process.

Withdrawal Methods

Although Table 6.2 shows approximately half the group followed a gradual withdrawal method, the time taken to reduce was highly variable, ranging from one week to three years. Among those who indicated using a gradual withdrawal method (n=55), 5.5% described being In Progress (n=3/55), 18.2% reported reducing to zero medication in under one month (n=10/55), 27.3% described reducing over a period of one to two months (n=15/55), 23.6% in three to six months (n=13/55), 16.4% in a period exceeding six months (n=9/55) and 9.1% of those who reported a gradual reduction were uncertain of their time-frame or did not specify one (n=5/55). Almost two thirds of the whole sub-sample reported making advanced preparations for their attempt, just under half consulted a doctor before starting their attempt, and a third reported temporarily using AMs to cope during the withdrawal process, which included 25% of participants who withdrew abruptly (n=11/44) and 40% of participants who reported withdrawing gradually (n=22/55).

The most frequently reported advanced preparation methods (selected from a check-list) were attempts to gather information about AM withdrawal (n=33/105; 31.4%), informing family,

partner or spouse of plans and preferences for support (n=33/105; 31.4%) and making a gradual withdrawal plan before making any changes (n=32/105; 30.4%). The remaining preparation methods were establishing a stable, regular routine (n=25/105; 23.8%), reducing environmental stress (n=24/105; 22.9%), establishing a regular sleeping pattern (n=19/105; 18.1%), seeing a counsellor or therapist to help manage during withdrawal (n=18/105; 17.1%), informing friends of plans and what to expect (n=17/105; 16.2%), creating a formal advanced directive (n=14/105; 13.3%), stopping or reducing drug-use (n=13/105; 8.6%), arranging a safe place to go should the need arise (n=7/105; 6.7%), learning meditation (n=7/105; 6.7%), stopping or reducing alcohol-use (n=5/105; 4.8%) and joining a support group (n=3/105; 2.9%).

Support for Attempted Discontinuation

Approximately half of the group described having support during their attempt in the form of material, practical or emotional assistance, help or care from others. Further analysis of the level of support described revealed that 13.3% (n=14/105) of those who made attempts reported having multiple forms of support available from multiple sources, such as multiple professionals, family members and peers and could be further categorised as describing a High Level of Support, for example *“Family support, GP and counsellor”* (#22), and *“Support from GP, support from family and friends, options of call the CATT team, and having PRN available”* (#20). Within this category, one participant noted *“I have always received help with the best intentions. Sometimes I feel smothered or monitored - so sometimes maybe I have had too much support”* (#41). A classification of Moderate Support was given to 21.9% (n=23/105) and was defined as multiple forms of support from one or two sources of support, such as individual family members and a counsellor, or vice versa, for example *“I had emotional support from my partner, family and friends”* (#124), and *“Support from wife to encourage walking, breathing, healthy eating, re-framing negative experiences and visualising a positive future”* (#25).

Low support, defined as having at most, one form of support available from one source of support, was reported by 14.3% (n=15/105), for example, *“I joined an internet support group which gave me confidence that there were others like me, and that my desire to not take drugs was not just a symptom of illness as my psychiatrist had told me.”* (#71), and *“My family didn't know much about what to do. I was seeing one counsellor at the time who was mildly helpful, although cautious”* (#75). Among the participants who described having no support (n=53/105; 50.5%) during their attempt, most simply stated “None” or expanded on this briefly to say *“No support, just decided to do it on my own. Thought others would advise against this”* (#130) and *“People in my life knew that it was my plan, but I was too proud to ask for help when I needed it”* (#31).

The Effects of Withdrawal

For the purposes of this study, withdrawal effects were defined as the physical or psychological features that follow reduction or discontinuation of AMs. Content analysis was conducted first to identify the presence or absence of withdrawal effects and the positive, negative or mixed subjective valence of the overall experience of withdrawal effects, second, to identify the specific elements of these experiences and third, to investigate rates of withdrawal-related relapse. Participants were asked to focus on their most recent attempt to discontinue and references to withdrawal effects of previous attempts were disregarded. Participants who described experiencing Zero or Minimal Side Effects uniformly offered one-two word responses such as “none” or “not huge” and no further analysis of content was carried out. Results are presented in Table 6.3.

Table 6.3. *Subjective Withdrawal Effects and Rates of Withdrawal-Related Relapse*

Content category	Count (%)	Content category	Count (%)
Subjective Withdrawal Effects		Positive Withdrawal Effect Elements ^a	20 (19.0%)
Negative Effects Only	59 (56.2%)	General positive description	7 (6.7%)
Zero Withdrawal Effects	19 (18.1%)	Emotional Benefits	6 (5.7%)
Positive Effects Only	14 (13.3%)	Clearer Thinking More Alert	5 (4.8%)
Mixed Positive and Negative	6 (5.7%)	More Energy	3 (2.9%)
Other (Do Not Remember)	7 (6.7%)	Short Lived Positive Effects	2 (1.9%)
Negative Withdrawal Effect Elements ^a	65 (61.9%)	Withdrawal Related Relapse	
Physical Withdrawal Effects	36 (34.3%)	Yes Withdrawal Related Relapse	55 (52.4%)
Emotional Withdrawal Effects	32 (30.5%)	No Withdrawal Related Relapse	38 (36.2%)
Psychosis/Mania/Getting Unwell	24 (22.9%)	Unknown Withdrawal Related Relapse	12 (11.4%)
Confusion, Dissociation, Disorientation	6 (5.7%)		
Difficulty with Functioning and Rels	3 (2.9%)		
Short Lived Negative Effects	3 (2.9%)		

This table presents the content analysis results for responses to the question, “what were the effects of withdrawing from the medication?” compared to self-reported withdrawal method. Withdrawal-related relapse was defined as the re-emergence or exacerbation of primary symptoms or emergence of new symptoms during the process of reducing AM use or the six month period following total abstinence. All percentages rounded to 1 dp and are expressed as a proportion of n=105. (a) Most content elements contain several sub-categories, see text for detail.

Positive Withdrawal Effects

Positive withdrawal effects were defined as statements describing benefits or advantages experienced during the process of reducing AMs or within the period of six months post-discontinuation. Most participants sharing positive withdrawal effects used general positive descriptions such as “*feeling better*” and “*positive*” without any qualifying statements. Those who referenced Emotional Benefits reported Being Able to Feel Again (n=4/105; 3.8%) and other sub-threshold reports of reduced suicidal urges and depression, restored motivation, the return of hope and a return to self. One participant described experiencing the first four of these Emotional Benefits together, “*I began to have hope, my suicidal feelings reduced. I began to feel again, and had the urge to create again. My sexual functioning did return, but it took years.*” (#71).

Comments referring to Clearer, More Alert Thinking described *“Increased cognitive ability actually was like a fog slowly lifting from my mind. I could understand things at work that had been unfathomable before”* (#71). Participants who described experiencing More Energy used descriptions such as *“Started feeling less tired and got more energy”* (#115). Two participants reported Short Lived Positive Effects, describing similar emotional and cognitive benefits, but specifying that these quickly transformed into unwanted symptoms, for example, *“Able to associate ideas better, not as drowsy, more alert, feel better, then after a few days not able to sleep, libido increased begin to associate ideas of paranoid, stay awake”* (#40).

Negative Withdrawal Effects

The most commonly reported withdrawal effects were in the physical domain and comprised Insomnia or Disturbed Sleep (n=22/105; 21.0%), Feelings of Physical Illness like nausea, diarrhoea, vomiting and headaches (n=9/105; 8.6%), Unpleasant Physical Sensations (n=7/105; 6.7%), Appetite and Rapid Weight Loss (n=6/105; 5.7%), Shaking (n=3/105; 2.9%), Sweating (n=3/105; 2.9%), and one single reference to Seizures. Unpleasant Physical Sensations included Restless Legs, Jitters or Restlessness (n=4/105; 3.8%), Aches and Pains (n=3/105; 2.9%), Electric Shock Sensations (n=2/105; 1.9%) and Itchiness (n=1/105; 1.0%). Descriptions of physical withdrawal effects included, statements such as *“Couldn't eat or sleep. Felt nauseous all the time. General feelings of illness”* (#14), *“Shakes, sweats, aches, restless legs”* (#32); *“Terrible. I have come down off illegal drugs before and the withdrawals were worse than that. Diarrhoea, nausea, electric shocks going through your body, wrestles [restless] among others”* (#36); and *“bad cramps, headaches, diarrhoea, sluggishness. Generally poor health. About 8 weeks”* (#50).

Participants described eight forms of Emotional Withdrawal Effects comprising increased Anxiety and Fear (n=15/105; 14.3%), Low Mood, Sadness and Depression (n=13/105; 12.4%), Irritability and Agitation (n=7/105; 6.7%), Suicidality (n=5/105; 4.8%) and, within the ‘other’ category, Mood Swings (n=2/105; 1.9%). Comments described *“Irritability increased. Increased episodes of despair”* (#58), *“[I] was a lot less regulated, a lot more anxious,”* (#77); and *“More anxiety, more intensity of OCD and depression,”* (#118). Single participants each described increased Violent Urges and A Sense of Regret for making the withdrawal attempt. Those who reported symptoms of psychosis/mania or ‘getting unwell’ reported experiences such as *“Extreme paranoia and voices and hallucinations,”* (#52) and *“I'd become manic and paranoid,”* (#126).

Comments within the Confusion Disorientation and Dissociation content category described *“felt as though everything was a blur”* (#11), *“loss of cognitive clarity”* (#41), and *“felt like it was [an] out of body experience”* (#78). Difficulty with Functioning and Relationships referred to difficulty relating to others (n=2/105; 1.90%), performing daily activities and working during withdrawal

(n=2/105; 1.90%). Comments within this content category stated that withdrawal, *“decreased my ability to function and cope with relationships”* (#77). One participant *“Ended up losing my job and had to relocate where I lived”* (#33).

Finally, three participants (2.9%) noted that for them the negative effects of withdrawal were short-lived and resolved after days (*“72 hours”*) or weeks (*“8 weeks”*). One commented, *“Extreme panic, dissociative episodes, hallucinations, delusions, lasting 24-72 hours per dose reduction, then resolving completely at the end of that period”* (#20). For another, the short-lived negative effects were less severe, *“Did feel initially more anxious and slightly suicidal as the medication came out of my system, then it was fine”* (#25).

Withdrawal-Related Relapse

Using a low-threshold definition for relapse (see Chapter Three), around half of the participants were deemed to have experienced some level of withdrawal-related rebound as a result of their discontinuation attempt (see Table 6.2). Among those who relapsed, 43.6% specifically mentioned symptoms of psychosis or mania, hospitalisation or used words similar to “relapse” when describing the withdrawal effects (n=24/55). The remaining 56.4% of people classified as experiencing Withdrawal-Related Relapse (n=31/55) reported other disruptive and distressing alterations in sleep, mood, thinking and behaviour such as agitation, suicidal ideation, obsessions, uncharacteristic behaviour, failure to meet a sufficient standard of self-care and/or racing thoughts. Relapse was reported by 37.1% (n=43/84) of those who experienced the Hallmark Symptoms of Bipolar or Psychosis and 42.8% (n=12/21) of those who did not experience the Hallmarks of Bipolar or Psychosis. Finally, withdrawal-related relapse was reported by 32.1% of those who attempted discontinuation and were not currently taking AMs at the time they completed the survey (n=17/53), and by 73.1% (n=38/52) of those who were currently taking AMs.

Coping with the Effects of Withdrawal

Withdrawal coping methods were defined as statements describing behavioural, cognitive, social, environmental or physical attempts to manage the challenges and stressors involved in withdrawal from AMs. Statements that described giving up on the attempt and resuming AMs were considered discontinuation outcome statements and were not coded as coping attempts. Using this definition, 79% of responses could be coded into at least one coping method content category (see Table 6.4).

Table 6.4 Coping During withdrawal

Content category	Count (%) n=105
1: Personal Strategies	38 (36.2%)
2: Nothing or No Coping Strategies*	18 (17.1%)
3: Support Strategies	13 (12.4%)
4: Medication Strategies	9 (8.6%)
5: Environmental Strategies	8 (7.6%)
6: Substance Use Strategies	8 (7.6%)
7: Other	4 (3.8%)
8: Do Not Remember	4 (3.8%)
9: Uncoded	22 (21.0%)

Content categories for (a) coping during withdrawal, (b) helpful supports and strategies (c) unhelpful supports and strategies. *Nothing or No Coping Strategies includes 6 participants who reported experiencing only negative withdrawal effects, 1 who reported both negative and positive withdrawal effects, 3 who reported only positive withdrawal effects, 7 who reported experiencing zero withdrawal effects, and 1 who could not recall.

Coping Strategies Used

As shown in Table 6.4 participants described managing withdrawal effects using a range of methods, the most common being Personal Strategies. While not meeting the threshold for a content category, it is worthwhile noting that within the ‘other’ content category, two participants reported coping with AM withdrawal effects via Self-Harm and Suicidal Behaviour. Although about a sixth described using No Coping Strategies, most of these people did not appear to need them; only seven people or 6.7% of the sample reported having no strategies and experiencing negative withdrawal effects that would require coping efforts. In addition, 30.5% (n=32/105) named one coping strategy, 17.1% (n=18/105) named two to three strategies, and 4.8% (n=5/105) named four or more (range 0-7) coping efforts together, for example, “*Had lots of baths. Cried. Created. Prayed. Psychology appts. Ate well. Held on for dear life*” (#58).

Personal Strategies were defined as the use of thought-based and/or behaviour-based activities for managing withdrawal experiences. These included Health Behaviours (n=12/105; 11.4%) involving diet and exercise, and a range of Psychological Strategies (n=37/105; 35.2%) aimed at curbing the difficult aspects of the process including (e.g., self-care, meditation and prayer, distraction, self-expression, routine, therapy techniques and attitudinal factors relating to determination and perseverance). Health Behaviours comprised Exercise and Walking (n=8/105; 7.6%), Eating Well and Drinking Water (n=4/105; 3.8%), and one reference to Taking Supplements, for example, “*changed diet, daily exercise*” (#4), “*Went for long walks*” (#41), and “*upping my supplements*” (#43). Psychological Strategies included references to Activities for Self-Care and Comfort (n=14/105; 13.33%), Determination, Willpower and Perseverance (n=9/105; 8.57%), Distraction (n=7/105; 6.67%), Meditation, Mindful Breathing and Prayer (n=6/105; 5.71%), Routine

and Living Life (n=5/105; 4.76%), Therapy Techniques (n=3/105; 2.9%), and Self-Expression (n=3/105; 2.9%).

Activities for Self-Care and Comfort comprised Getting Extra Rest (n=9/105; 8.6%), Showers and Baths (n=3/105; 2.86%), and sub-threshold mentions of Herbal Teas (n=2/105; 1.90%), Heat Bags (n=1/105; .95%), Personal Grooming (n=1/105; .95%) and Sleep Hygiene (n=1/105; .95%), for example, *“Kept life very simple and allowed for plenty of rest”* (#130), and *“Showers”* (#91). References to Determination, Willpower and Perseverance described how an attitude of persistence and motivation assisted people to cope, for example, *“stayed focused on what I wanted to achieve”* (#17), *“Holding on to the hope that things will get better and these are only side effects from the medication withdrawal”* (#25), *“Just went through it and hoped to reach the other end”* (#78). References to Routine and Living Life can be represented by comments stating *“[I] continued with my life”* (#14), *“I had fun every day, I talked to people, I lived and loved etc.”* (#71), and *“Walking more and exercising more, grooming more, cleaning more and more in a routine for myself”* (#92). References to Self-Expression described venting emotion via crying or yelling in addition to writing and being creative.

Medication strategies were defined as the use of a medicine, pill or tablet to curb unwanted withdrawal effects; this could include temporary or Pro Re Nata (PRN) use of the AM agent that was the target of the withdrawal attempt; giving up on the attempt and resuming the AM was considered an outcome statement about stopping and was not coded as a coping attempt. A few participants described PRN Benzodiazepine Use (n=3/105; 2.9%) and Pain Relief (n=3/105; 2.9%). One participant noted using Antihistamines for itches (1%), two people reported the use of Sleeping Pills (1.9%), and two described using low-dose AMs on an as-needed basis (1.9%). Examples included comments stating *“Took narcotic painkillers I had been prescribed previously for back pain as well as antihistamines for itchiness”* (#37), *“Painkillers (prescribed) for headaches”* (#17), *“Temporarily used small amounts of benzodiazepines”* (#16) and *“yo yo'd on and off, and went to 'nibbling' on the side of the meds as there were no dose low enough at the end to come off it”* (#66). The entire sub-sample answered a closed question about the use of temporary or 'PRN' AMs as a withdrawal coping method: here, a third of those who attempted discontinuation reported using low-dose or temporary AMs to manage the withdrawal effects.

Environmental strategies were defined as the use of environmental-modification or stimulus control as a method for managing the effects of withdrawal. Participants described Creating a Safe, Low-Stress Environment (n=5/105; 4.8%), for example, *“[I] made sure I was in a safe place with people who loved me”*(#55) or *“Took some time out, stayed with my family through this process”* (#105), and Avoiding Stressful Environments (n=4/105; 3.8%), for example, *“avoided going into*

public places" (#55) and *"I would barricade myself in my flat"* (#130). For some, environmental strategies rested on the support of others, such as family members who provided a place to stay.

Support strategies were defined as the use of help, advice, connection, resource-sharing or care from other people. Participants described using support from Therapists and Counsellors (n=6/105; 5.7%), Psychiatrists or Doctors (n=3/105; 2.9%), Family or Spouse (n=3/105; 2.9%) and Other Supports (n=2/105; 1.9%) including one reference to Support Groups (1%) and one nonspecific report of 'others' (1%). Family or Spouse support strategies referred to *"talking to my wife"* (#25), staying with family and being with loved ones.

Substance-Use Strategies were defined as the use of non-prescription, illicit or legal substances to cope with withdrawal effects. Participants reported Drinking Alcohol (n=3/105; 2.9%), Taking Drugs (n=3/105; 2.9%) and Smoking Cigarettes (n=3/105; 2.9%). Examples included *"Ended up drinking in the evenings to get to sleep, went to see a counsellor to help with the emotional changes (didn't help), didn't really cope at all"* (#31), and *"whatever I felt was needed, smoked a bit of weed"* (#51).

Perceptions of What Helps and Hinders the Withdrawal Process

Helpful Strategies and Supports for Withdrawal

As shown in Table 6.5, when asked what they had found most helpful during withdrawal, participants described a similar array of strategies and approaches, with the addition of Information Strategies and a group of comments emphasising Tapering Slowly. Though a sixth reported that Nothing Helped, 9.5% reported experiencing negative withdrawal effects and that Nothing Helped them with this and the remainder of those who reported that nothing helped did not report any unwanted withdrawal effects.

Table 6.5. *Helpful and Unhelpful Strategies and Supports During Withdrawal*

Helpful Withdrawal Approaches ^a		Unhelpful Withdrawal Approaches ^b	
1: Personal Strategies	40 (38.1%)	1: Unhelpful Perspectives	22 (21.0%)
2: Nothing Helped ^c	18 (17.1%)	2: Nothing Unhelpful	17 (16.2%)
3: Supportive Others	17 (16.2%)	3: Unhelpful Professionals / Systems	17 (16.8%)
4: Information Approaches	11 (10.5%)	4: Lack of Information	8 (7.6%)
5: Tapering Very Slowly	7 (6.7%)	5: Unhelpful Personal Coping Methods	8 (7.6%)
6: Medication Strategies	5 (4.8%)	6: Reducing Too Quickly	3 (2.9%)
7: Other Helpful (Substances/Enviro)	3 (2.9%)	7: Environmental Demands	3 (2.9%)
8: Do Not Remember	3 (2.9%)	8: Uncoded	37 (35.2%)
9: Uncoded	14 (13.3%)		

This table presents the results of the content analysis regarding (a) helpful supports and strategies (b) unhelpful supports and strategies. (c) Nothing helped includes 10 who reported negative withdrawal effects and 8 who reported zero or positive withdrawal effects. Percentages are expressed as a proportion of 105.

The most commonly expressed helpful approach within the Personal Strategies category was the attitudinal factor of Determination, Willpower and Motivation (n=17/105; 16.2%), for example, *“deciding to do it and sticking to that choice. Otherwise I would have become stuck in a fear of whether I would be able to cope without it”* (#30) and *“me and my wilful personality”* (#64). Psychological Strategies were referenced by 13.3% of the sample (n=14/105) and comprised descriptions of Taking Control (n=7/105; 6.7%) and Cognitive Therapy Techniques (n=3/105; 2.9%) with sub-threshold references to meditation, self-compassion, and addressing personal issues. Those who referenced Taking Control described *“[A] feeling of empowerment about managing my own wellness because it was about taking back responsibility for myself”* (#17) and *“I no longer had antipsychotic staring me in the face so I pretty much forgot I was supposed to be crazy and remembered/relearned how to be myself as I had no excuse”* (#39). Within Cognitive Therapy Techniques participants described *“Doing cognitive work. Being aware of thought processes and metacognitive analysis”* (#44) and *“I believe I could handle the psychosis as I had developed a watcher in me which [sort] of kept me grounded”* (#62).

Most references to Supportive Others described Supportive Professionals (n=8/105; 7.6%) such as *“being able to work with my team of doctor, therapist etc. as a person whose input was listened to, not just told what to do as though I was not even a part of the process”* (#2), *“GP - very supportive and prepared to think beyond simply taking medication”* (#22). One participant described how a specialised supplements company *“held a positive attitude for me”* (#45). A further four participants referenced Supportive Family, Friends or Spouses (3.8%), with one participant specifying *“Discussing what I wanted them to do in the event of rebound effects”* (#20). The group of Other Helpful Support Strategy comments included a single reference to Support When it Went Badly, two references to Holistic Support (1.9%) and two references to Peer Support (1.9%) *“from others who had stopped taking it because they knew what I was going through,”* (#135). One commented of Peer Support, *“It gave me validation at a time when I desperately needed it”* (#75).

Information strategies were defined as acquiring or possessing certain information that was helpful or beneficial during withdrawal. Participants described the helpfulness of Knowing what to Expect from withdrawal (i.e., information about what might happen and what it means: n= 9/105; 8.6%) and Having a Plan (i.e., information about what to do: n=3/105; 2.9%). Information was described as allowing participants to *“[recognise] it was withdrawal, not thinking my mind was going insane again”* (#82). The majority did not specify the sources of their information, but two participants noted finding this information through online reading.

The small group who described Tapering Slowly highlighted the value of a gradual withdrawal method, for example, *“Reducing the intake in very small amounts was the most helpful*

thing in coming off the medication” (#101). Helpful Medication Strategies included Sleeping Agents (n=3/105; 2.9%), for example, “sleeping pills for rebound insomnia initially” (#81) and sub-threshold references to Having an Alternative AM to Take and Adding or Adjusting Other Medications. Within the Other Helpful Strategies category, two participants described Substance Use as helpful during withdrawal and one highlighted the Environmental Strategy of connecting with nature, “Walking in nature - was calming, refreshing, distracting and was great for my self-esteem” (#26). The two Substance Use comments described “smoking weed and why because it’s the only thing that keeps me on a stable keel so far” (#35) and “I sometimes smoked a little grass or drank moderately, both for the symptoms of schizophrenia AND for the unpleasant effects of the medication” (#47).

Unhelpful Strategies and Supports for Withdrawal

Participants were asked “What did you find unhelpful in your attempt to stop taking antipsychotic medication and why?” As shown in Table 6.5, a number of participants who had attempted stopping reported that Nothing Was Unhelpful or gave comments that could not be coded, most often by describing withdrawal effects instead of unhelpful strategies or supports. This meant that 48.57% of the sample reported strategies and supports they had found unhelpful in their attempt to stop AMs (n=51/105).

Responses referencing Unhelpful Perspectives, most frequently described Unhelpful Perspectives from Others (n=20/105; 19.0%), which included descriptions of Others Worrying and Second-Guessing Ability to Manage (n=11/105; 10.5%) and Medical Perspectives that AMs are Necessary (n=7/105; 6.7%) along with two Other comments referencing Judgement in general terms (1.9%). Participants described “*feeling second-guessed by some people as to my ability to manage*” (#2), “*People over analysing my every mood and suggesting that I was becoming unwell*” (#17), “*family fear because they believed that I would fall over/ fail and burden them again*” (#45), “*the clinical paradigm that you will always need medication*” (#10), “*people saying you will get worse, the getting worse is only a withdrawal. If that killed me I didn't care I didn't want them anymore*” (#60), and “*judgement about the fact that no one thought I was ready and tried to force me to take it instead of letting me make my own mistakes and learn from them*” (#135). Three participants described how the worries of others made it Unhelpful to Talk About Discontinuation with Others (2.9%). Unhelpful Perspectives also included a group of references to participants’ Own Expectations, Fears and Judgements (n=4/105; 3.8%) such as “*my own anxiety about [withdrawal effects]*” (#44) and “*the risk of being put under the Act and forced to take drugs*” (#73).

Responses referring to Unhelpful Professionals and Systems, most often described a Lack of Professional Support and Guidance (n=13/105; 12.4%), along with an Other category (n=2/105; 1.9%) comprising sub-threshold references to Being Discharged without Follow-up when

appointments were missed and Lack of Information Handover Between Clinicians. Within a Lack of Professional Support and Guidance, most described an absence of support from their primary clinicians, for example *“Opposition from doctors instead of support”* (#57), and three specified Barriers to Accessing Support (2.9%), two referred to Not Being Listened To (1.9%), for example, *“The psychiatrist who thought they knew everything and did not listen to me. It’s my body and they did not believe the way I was feeling”* (#52), two referred to Being Given No Alternatives (1.9%), for example, *“Being given little to no alternative options”* (#77), and two referred to Withholding Information (1.9%) for *“the doctor giving no information”* (#54). Barriers to Accessing Support included single references to financial, service-criteria and availability restrictions, for example *“not having the finances to see the doctor whenever I needed”* (#127) and *“Having not been in mental health services for over a year after being discharged from youth services, I didn’t have access to that level of support and clinical oversight, or access to referrals to services which would have been immensely helpful - respite, community support worker, peer support, domestic support etc.”* (#32).

Participants who described an unhelpful Lack of Information, most commonly referred to Lacking Information About What to Expect from Withdrawal (n=5/105; 6.7%) with sub-threshold references to Lacking Information about Alternatives and Support Options (n=2/105; 1.9%) and Lacking Information to Plan Effectively (n=1/105; 1%). Comments described *“not knowing how severe [the withdrawal effects] would be”* (#33), *“not planning it properly - not understanding the effect it would have on me, needing to go easy on myself etc.”* (#81) and *“Wishing I could look for supports to do this correctly but knowing there weren’t any”* (#82).

Unhelpful Personal Coping Methods included references to Isolation and Being Unable to Reach Out (n=3/105; 2.9%) and the sub-threshold content categories Substance Use (n=2/105; 1.9%), Ignoring Professional Advice (n=1/105; 1.0%), Persisting (n=1/105; 1.9%) and Positive Thinking and Mindfulness (n=1/105; 1.9%). Those referencing Isolation and Not Reaching Out noted, *“Not feeling like I could talk to anyone and be listened to”* (#39), *“Isolation. Because I needed love. And only very rarely I had it in me to reach out”* (#60) and *“[having to] keep away from all health services including my GP because of the risk of being put under the Act and forced to take drugs”* (#73). References to Substance Use described how *“Caffeine exacerbated the akathisia”* (#11), in addition to the use of alcohol and illicit drugs.

References to Environmental Demands described the difficulty of withdrawing while managing daily responsibilities like work, study and childcare, for example, *“life at that time was also full of change, moving out of home, leaving university, starting a course and new job... It was an unhelpful time to try and stop taking meds”* (#32); and *“having to cope with 2 under 2 year olds”*

(#91). Reducing Too Quickly included references to tapering too quickly (n=2/105; 1.9%), stopping suddenly (n=1/105; 1.0%) and stopping more than one medication simultaneously (n=1/105; 1.0%).

Attempted Discontinuation Outcomes

Results presented in Table 6.2 showed approximately half of those who made attempts were not currently using AMs and had remained off AMs for over a year. A further break-down revealed that among the current users 53.8% reported staying off AMs for less than one month (n=28/52), 26.9% from one to six months (n=14/52), 5.8% reported staying off AMs for six months to a year (n=3/52), and 13.5% reported staying off AMs for more than a year (n=7/52). Among those who were not currently taking AMs, no one reported staying off for under a month, 3.8% had been off AMs for one to six months (n=2/53), 7.5% had been off AMs for six months to a year (n=4/53), and 88.7% reported staying off AMs for over a year (n=47/53). Both those who stopped and those who resumed AMs made their most recent discontinuation attempts around seven years after they first started. Additionally, current users made their most recent discontinuation attempt on average around 9.7 years after they first initiated AMs. Those who were not currently using AMs made their most recent attempt 6.6 years after they initiated AMs.

Table 6.6 shows most participants described a Stopped Discontinuation Outcome. The majority of those who described successfully stopping AMs, reported they had remained off AMs for over one year, and were Not Currently Taking AMs, and none reported current use of Depot AMs. In addition, 37.9% (n=22/58) of those who reported stopped outcomes indicated they had last regularly used AMs two-five years ago, and 34.5% (n=20/58) had last used AMs regularly over five years ago. Among those who described resuming AMs following their most recent discontinuation attempt, all indicated they currently used oral or depot AMs, most remained off AMs for under one month. About half of each discontinuation outcome group had consulted a doctor and followed a gradual withdrawal method. Over half of the people who stopped and around a third of those who resumed had support for their attempt. In addition, the majority of people who described using Personal strategies for coping with withdrawal appeared to stay off AMs for over a year (n=25/38; 65.79%). Most people describing support strategies for coping during withdrawal (n=8/13; 61.59%), Medication strategies (n=7/9; 77.78%) and Environmental strategies (n=5/8; 62.50%) also stayed off for over a year. By comparison, 25% of those who used substances to cope remained off AMs for over a year (n=2/8). Specific elements of Stopped and Resumed Subjective Discontinuation Outcomes are presented in Table 6.7.

Table 6.6. *Attempted Discontinuation Outcomes*

Subj. Discontinuation Outcome^a	Total (n=105)	
Stopped	58 (55.2%)	
Resumed	37 (35.2%)	
Uncertain: Attempt In Progress	5 (4.8%)	
Other Cannot Be Coded	5 (4.8%)	
	Composition of Subjective Discontinuation Outcome Groups^b	
Discontinuation Variables	Stopped (n=58)	Resumed (n=37)
Mean Years Since Started AMs ^c	7.0 years	7.3 years
Gradual Reduction ^d	31 (53.4%)	17 (45.9%)
Consulted Doctor	32 (55.1%)	15 (40.5%)
Had Support for Attempt	34 (58.6%)	12 (32.4%)
Withdrawal Relapse	16 (27.6%)	35 (94.6%)
	Time Off AMs	
< 1 Month Off AMs	1 (1.7%)	24 (64.9%)
1-6 Months Off AMs	2 (3.4%)	11 (29.7%)
6-12 Months Off AMs	4 (6.8%)	1 (2.7%)
> 1 Year Off AMs	51 (87.9%)	1 (2.7%)
Yes Current Oral AM Use	10 (17.2%)	36 (97.3%)
Yes Current Depot AMs	0 (0.0%)	5 (13.5%)

This table presents (a) the content analysis of participant's qualitative responses to the question "What was the outcome of your attempt to stop taking antipsychotic medication?" (n=105) and (b) shows the supplementary outcome measures for those with Stopped Outcomes (n=58) and those who Resumed (n=37), but excludes those with Uncoded or In Progress subjective discontinuation outcomes. (c) Mean years since started AMs is based on the number of years between age started and age at most recent attempt to stop. (d) Self-reported gradual withdrawal method, range 1 week to 3 years.

Table 6.7. *Subjective Discontinuation Outcome Elements*

Content category	Count (%)	
Stopped Outcome Elements	58	(55.2%)
Stopped - No Qualifiers	36	(34.3%)
Stopped and Have Not Taken Since	12	(11.4%)
Stopped and Take When Needed	5	(4.8%)
Stopped for Extended Time then Returned to AMs	4	(3.8%)
Other: Stopped and Switched to Different Class of Meds	1	(1.0%)
Effect on Health and Wellbeing	29	(27.6%)
- Improved Health and Wellbeing	23	(21.9%)
- Ongoing Difficulties to Manage	9	(8.6%)
Resumed Outcome Elements	37	(35.2%)
Resumed AMs - No Qualifiers	26	(24.8%)
Resumed AMs with Changes	6	(5.7%)
Compulsory Treatment Order or Hospitalisation	8	(7.6%)
New Realisations and Understanding	7	(6.7%)
Other: E.G, health, sense of failure	3	(2.9%)

This table presents the specific content elements referenced by participants who described Stopped Subjective Discontinuation Outcomes and those who described Resumed Subjective Discontinuation Outcomes. All percentages are expressed out of 105.

Stopped Discontinuation Outcomes

Participants who described Stopped Discontinuation Outcomes used words like "successful" (#27), phrases like "I stopped the medication" (#5) and "I have never taken antipsychotic medication since" (#14) and/or referred to living with the impact of having stopped AMs, such as "Life went on as usual - I felt like a human being again" (#74), "Eventually learned to understand recognise and manage my warning signs, stress, sleep etc." (#98), and "It was positive in continuing towards

wellness" (#134). Most provided brief indications of stopping or living with the effects of stopping without additional qualifying statements (see Table 6.6), but some specified they had not taken AMs again and others reported that they Stopped and Take AMs When Needed, or Stopped for an Extended Time then Returned to AMs or Stopped. Only one reported that they stopped and Switched to a Different Class of Medication.

Half of those who indicated Stopped Discontinuation Outcomes also referred to Effects on Health and Wellbeing. Most described living with Improved Mental Health and Wellbeing, which comprised Improved Psycho-Social Wellbeing (n=19/105; 18.1%), for example *"I experience no psychosis and only occasional anxiety [...] I am (reasonably) physically healthy, extremely mentally healthy, working and enjoying life"* (#20), The Resolution of Side Effects (n=5/105; 4.8%), for example *"I felt less sedated"* (#19) and *"lost 50kgs and am now within the normal weight range"* (#26), and Coping Well with Other Strategies (n=4/105; 3.8%), for example, *"I manage my mental health well. I have occasionally visited counsellor since stopping medication, but mostly use my support network for help now. I would not describe myself as having a mental illness [...] I am now a thriving individual with a great job; lots of future prospects; and wonderful people around me"* (#14). A minority referred to Ongoing Difficulties to Deal With, including Ongoing Mental-Health Problems (n=7/105; 6.7%) and the subthreshold category of Unresolved Adverse Effects of AMs (n=2/105; 1.9%).

Those who referred to Ongoing Mental-Health Problems, predominantly described the Persistence of Primary Symptoms (n=6/105; 5.7%) at varying levels of manageability with one sub-threshold reference to Ongoing Insomnia. Participants commented *"I wasn't better but at least I wasn't taking it anymore unnecessarily"* (#61), *"I [had] highed psychiatric experiences [but] I knew I was and could live with that. after 6 month I was very tired thought I couldn't go on but health supplement helped that"* (#62), *"I still have mental health issues, but I cope in other ways"* (#77) and *"the depression and anxiety have never gone away. Any decent sort of stress brings it back. Have had a few mild episodes of paranoia. Can recognise it to some degree"* (#91). Both references to Unresolved Adverse Effects of AMs described a lasting cognitive impact; *"several years later I still think that my ability to think has been seriously compromised"* (#31), and *"I'm not creative much anymore and haven't gone back to designing art and all the stuff I loved"* (#35).

Resumed Discontinuation Outcomes

Participants who indicated they had resumed AMs following their most recent attempt to discontinue, used words like *"hospital"* (#15), *"failure"* (#43) and *"restarted"* (#89), phrases like *"got sick and went back on them"* (#49), *"stay on prescribed dose"* (#50), *"forced to take it"* (#59) or *"relapse followed by subsequent compulsory increases in my medication"* (#80). The majority

referred to having resumed AMs without qualification, but ten participants provided additional qualifying comments noting they Resumed AMs with Changes to their mental-health team or medication regime (n=6/105; 5.7%) or Resumed AMs with a Compulsory Treatment Order (CTO) or Hospitalisation (n=8/105; 7.6%). Among those who described Resuming AMs with Changes, two reported changing to a different AM (1.9%), two reported changing to lower doses (1.9%), one reported changing psychiatrists (1%) and one reported resuming AMs and stopping another medication in their regime instead (1%). Those who Resumed AMs with a CTO or Hospitalisation gave descriptions such as, *“Failure. I am still on the meds and on a CTO as I relapsed,”* (#49) and *“ended up back in hospital very very unwell,”* (#54).

Seven participants referred to developing New Realisations and Understandings following their return to AMs, including Accepting AMs (n=5/105; 4.8%) and Improved Self Knowledge (n=2/105; 1.9%), for example, *“ultimately better compliance with taking my medication”* (#80) and *“Greater self-knowledge. Gratitude that I have the medication to keep stable,”* (#56). The majority of participants did not comment on how their wellbeing was affected following their discontinuation attempt; among those in the other category, one participant noted that resuming was something they *“had to recover”* from (#102), another noted they *“felt very deflated”* (#32) and one described an improvement in their health following a subsequent change in prescribing clinician and medication regime, commenting, *“I got a new psychiatrist that works with me, to help me. No more strokes or ill health”* (#52).

Discussion

This cross-sectional survey of 105 people’s most recent attempts to stop taking AMs represents one of the largest studies of AM withdrawal experiences to date and is the second to explore the way people cope. Results reveal discontinuation is commonly associated with difficult withdrawal effects and withdrawal-related relapse, though these are not inevitable. Optimal conditions for withdrawal were rarely met among the current sample, with wide variation in the practical implementation of ‘gradual’ withdrawal, a lack of information provision and low rates of support from others. Nonetheless, for many people a great deal of forethought, preparation and active coping is involved in attempting to stop AMs. There is a sub-group of people who are successful in their attempts and remain off AMs long-term, and a sub-group who resume AMs within a short time of stopping or who do not manage to stop at all. The current study also reveals a sub-group who stop and never take AMs again and a sub-group who stop for long periods and later return to using AMs when they feel that it is needed. Withdrawal-related relapse may be common among both those who ultimately stop and those who resume AMs. Among those who stop, some

describe ongoing remission of symptoms and others describe being able to manage symptoms in other ways and engage with the activities of a meaningful life, whatever that might mean for them. Some people who stop continue to struggle with their mental health, and appear to prefer this to resuming AMs. People who make unsuccessful attempts and resume taking AMs may face unwanted outcomes such as hospitalisation, compulsory treatment and a switch to depot formulations that preclude them from making choices about their AM use and can produce further distress and demoralisation.

Withdrawal Methods

Although the research literature recommends that people withdraw gradually from AMs (Gilbert et al., 1995) at a maximum rate of 10% per step (Breggin, 2013), this study suggests many people stop abruptly or reduce in a short space of time, and may lack adequate information about how to implement gradual reductions. There was substantial variation in the time-frames people used for gradual withdrawal, with some people reporting they reduced 'gradually' across as little as one week and others describing a reduction that took place over a number of years. Among those who sought their doctor's advice before they began to withdraw, much of the advice received was focused on discouraging discontinuation or recommended the person withdraw gradually without providing detail about what 'gradually' meant. This apparent lack of useful guidance may help explain the results of other studies that have found seeking doctors' advice is not associated with improved discontinuation outcomes (Read, 2005). Despite having little support from their doctors, most made some preparations for their attempt and a third attempted to gather their own information about withdrawal, recruit family or spouse support, or create a plan for how to withdraw gradually, suggesting people could put considerable forethought and effort into their attempt.

The person-centred approach to psychiatric drug withdrawal set out by Breggin (2013) underscores the importance of being well-informed about the possible withdrawal effects prior to making a discontinuation attempt, in order to better recognise them should they occur and adjust the tapering schedule in response. Similar to the descriptions in the literature, some participants in this sample commented that withdrawal effects could take days to weeks to dissipate following a reduction in AM dose (Dilsaver & Alessi, 1988) and described waiting until they had stabilised on one dose, before reducing further, similar to the approaches recommended in the literature (Breggin, 2013; Hall, 2012). However, these appeared to be a minority of cases here, and the current study shows many people proceed with a withdrawal method that is poorly informed by the available evidence.

Withdrawal Effects

This study demonstrates AM withdrawal can involve a range of aversive experiences that can be difficult to cope with and manage, particularly without support. Results are consistent with previous research suggesting that withdrawing from AMs can involve experiencing psychosis or mania, alongside a range of physical and emotional effects, and a subsequent impact on self-care and occupational activities, and are often particularly challenging to cope with (Breggin, 2013; Dilsaver & Alessi, 1988; Geyt et al., 2016; Lehman, 2002; Moncrieff, 2013; Roe et al., 2009; Salomon & Hamilton, 2013). These results also suggest that withdrawal does not have to be a negative, distressing experience, consistent with the only other survey of discontinuation experiences conducted to date (Salomon & Hamilton, 2013). Importantly, a small group of participants reported zero negative withdrawal effects, suggesting it is possible for some people to withdraw without major disruption. It was more common to experience some degree of withdrawal-related difficulty and distress, particularly with regard to somatic complaints and emotional distress. Results suggest that a lack of information about what to expect and how to manage it may add to the distress caused by withdrawal effects and reduce peoples' ability to recognise and cope with them.

A 'rebound' or withdrawal-related relapse rate of around 50% is similar to the rate found in a meta-analysis of over 60 RCTs comparing maintenance to discontinuation (Gilbert et al., 1995) and the largest existing qualitative study of discontinuation to date (N=98, Salomon & Hamilton, 2013), though higher (Zipursky, Menezes, & Streiner, 2014) and lower rates (Landolt et al., 2016) have been reported by individual studies using different definitions. Importantly, these results highlight that withdrawal-related relapse and successfully stopping AMs are not necessarily mutually exclusive. Though most people who relapsed were currently using AMs, some were not and had remained off AMs for over a year, with many reporting their most recent use was over five years ago. It may be here that the additional approaches described in Chapter Four become particularly useful to those who stop AMs.

Similar to other studies (Salomon & Hamilton, 2013; Titelman, 2001; Tranulis et al., 2011), for some people psychosis-related and emotional withdrawal symptoms, particularly in the context of an unsuccessful attempt, were attributed to internal factors like their own inherent mental health status rather than the effects of the medication leaving their system. When the attempt was unsuccessful, some people seemed to re-evaluate AMs as essential for them, despite sometimes continuing to face significant side effects. Given the proximity these negative withdrawal experiences had to the discontinuation of AMs, it is highly likely that for many people the distressing symptoms they considered to be signs of a returning disorder "requiring more medication was in

reality a withdrawal reaction requiring patience, understanding and perhaps a temporary resumption of a previous dose” (Breggin, 2013, p 133).

Coping with the Effects of Withdrawal

This is the largest study to date that specifically explores how people cope with the difficult aspects of withdrawing from AMs. In this sample, people who described successfully stopping appeared to be more likely to report having strategies to cope. A wide range of strategies were often used in concert. It seems discontinuation outcomes are not a simple by-product of medication-factors and withdrawal method, but are also associated with the individual’s capacity to cope with the effects of withdrawal. This implies people with improved capacity to cope during withdrawal could have better discontinuation outcomes. Even those who eventually resume taking AMs could have a more positive experience if they were equipped with tools to cope with the effects of withdrawal safely. A further implication is that studies regarding discontinuation from AMs would benefit by including measures of their participants’ coping behaviours.

The current results suggest a range of active coping strategies involved in self-care, self-soothing, expression, physical health, support and practical problem-solving such as environmental modification might be helpful. Participants also described using a range of avoidant coping strategies such as distraction, isolation and to a lesser-extent substance-use. Only a third indicated temporary resumption of the AM during withdrawal, suggesting many people may have had an inflexible approach to adjusting their rate of reduction that potentially increased the likelihood of experiencing withdrawal effects and withdrawal-related relapse (Breggin, 2013; May et al., 2016). Future research is needed to assess what coping methods are associated with improved capacity to prevent and manage difficult emotions, reduced functioning, feelings of physical illness and potentially a relapse of primary symptoms.

Experiences of Support from Others

Attempts to stop are often poorly supported and some people attempt discontinuation without any support at all. Half of this group had support for their attempts, few had a high level of support, and only half consulted a doctor, similar to other studies (Read, 2005). Very few people who reported no support also reported no need for it, suggesting it was relatively common for people to struggle with the effects of withdrawal alone. A number of people described deliberately withholding information about their attempt from prescribers and family members due to fear of discouragement, being seen as “non-compliant” and/or being placed on a compulsory treatment order as a result. Other research also suggests a fear of discouraging, invalidating or coercive responses from others might not be entirely unfounded and appear to be a reality for many people

who attempt to stop (Gibson et al., 2013; Runciman, 2013; Salomon & Hamilton, 2013; Thomas et al., 1997). For this group of people, attempted discontinuation likely involves isolation from others that potentially adds to the distress they face during withdrawal. While some lack support, results of the current study suggest contact with supportive others is experienced as helpful in many people's attempts to cope with the effects of withdrawal, consistent with other qualitative studies (Geyt et al., 2016; Roe et al., 2009; Salomon & Hamilton, 2013), and a recent outcome study suggesting social integration is an independent predictor for successful discontinuation (Landolt et al., 2016).

Friends and family members may often step in to fill the gap left by an absence of support from treatment systems, or provide support alongside clinicians. Other research has highlighted that family members may experience "frustration and utter desperation" in the context of attempts to discontinue (Wallace, 1994) along with fear and guilt that provide a good recipe for increased conflict on top of the withdrawal effects themselves (Breggin, 2013). Family-member responses to discontinuation attempts may influence the context within which the attempt takes place, the likelihood of help-seeking behaviour, and the outcomes obtained. The experience of attempting to discontinue can, therefore, be said to affect the individual and their natural support systems. It has been suggested the entire family needs support to cope with withdrawal (Breggin, 2013; Wallace, 1994). Future research in this area is warranted.

Repeated Attempts and Issues of Consent

This study demonstrates that even though attempted discontinuation is often associated with difficult withdrawal effects and tends to be poorly supported, many people make multiple attempts to stop; in this sample around two thirds did so. Other studies have found it often takes multiple attempts to develop the strategies to successfully withdraw from AMs (Nishikawa et al., 2007). It can be concluded that some people are dedicated to a desire to stop taking AMs and that discouraging them from attempting to fulfil this recovery goal does not act as a deterrent. This discouragement may engender a sense of disempowerment, isolation and added distress during the attempt to stop. Given the potential risks and benefits of attempting discontinuation are so great, there is a great need to provide support and guidance to help people make these attempts safely and with the minimum possible amount of distress.

The first prescription often takes place at a time of high distress when people may not be able to give full consideration to information shared, and the variable outcomes associated with AMs mean it is very difficult for any clinician to accurately predict how someone will respond. The absence of support to stop AMs in the face of a strong desire to do so renders ongoing consent to treatment impossible. This study suggests the only sure way to chart a course is with responsive collaboration that ensures those across the spectrum of subjective experience are able to choose

the options that are best for them, and be free to change their mind and stop AMs should things not work out as they expected. Quite simply, in the words of those who take AMs themselves, *“I know my body and mind”* and *“people need to be listened to.”*

Discontinuation Outcomes

Results are consistent with other research revealing a subgroup who are able to stop taking AMs (Baldessarini & Viguera, 1995; Nishikawa et al., 2007) and may go on to have equal or better recovery outcomes compared to those who continue to take AMs (Faber et al., 2012; Gaebel et al., 2011; Harrow & Jobe, 2007; Landolt et al., 2016; Wunderink et al., 2013). Medication factors like duration of continuous use, dose and age at treatment initiation are all thought to be involved in differential rates of relapse following discontinuation (Gilbert et al., 1995; Nishikawa et al., 2007). Internal coping resources and social support opportunities also play a likely mediating role in determining the severity of withdrawal symptoms, and the impact withdrawal-related relapses have on discontinuation outcomes. Results suggest many people struggle to interpret and cope with the effects of withdrawal and most often lack adequate information and support to make discontinuation attempts safely. Nonetheless, even within these less than ideal conditions, some people are able to stop taking AMs for long periods of time and manage their mental-health well using alternative strategies (see Chapter Seven).

CHAPTER SIX:
CURRENT RECOVERY OUTCOMES (QUALITY OF LIFE)

This investigation explores whether use of oral AMs (Current AM Status; CAMS), coping style, social support adequacy and use of additional approaches were predictive of current QOL recovery outcomes. See Chapter Three for a description of the methodology. A hierarchical multiple regression was used to test whether demographic variables (age, gender and occupational status), current AM status (CAMS), and the psycho-social variables social support (MSPSS), active coping (BC-Active), avoidant coping (BC-Avoidant) and number of additional approaches used (NAA) were independently predictive of current QOL satisfaction, assessed via total score on the BMLSS. Results are presented in two sections. First a description is given of the data-screening procedures evaluating the assumptions of normality, linearity and homoscedasticity. Second, the results of the regression testing are presented, beginning with evaluations of multicollinearity and the selection of predictor variables for further analysis, and finally the results of a hierarchical multiple regression testing whether BMLSS was predicted by CAMS and the psycho-social factors of interest. To conclude, results are discussed against the existing literature.

Participants

Participants were the 144 New Zealand adults who completed the survey, and were taking or had previously taken any typical or atypical oral AM regularly for at least three months, for any reason. See Tables 1.1-1.2 in Chapter Four for participants' demographic, medication and diagnostic information.

Data Screening

The data-set was screened for normality, linearity, and homoscedasticity prior to selecting predictor variables for further analysis. Descriptive data showed wide variation in BMLSS scores across the sample (range 8.33-100; M=63.18; SD=18.79; Median=65.00), both among those who continued to take AMs (range 15.00 – 95.00; M=60.4; SD 18.56; Median=61.67) and those who had discontinued (range of 8.33 – 100; M=67.1; SD=18.71; Median=70.00). Of those who had discontinued AMs 81.13% had high BMLSS scores (50 or more), and 18.89% had low BMLSS scores (under 50) compared to those in the continued use group where 71.43% had high BMLSS scores and 28.7% had low BMLSS. BC-Active scores ranged from 2.44 to 7.67 (M=4.95; SD=1.04; Median=5.00) and BC-Avoidant scores ranged from 2.20 to 7.61 (M=4.10; SD=1.12; Median=4.00) across the data-set. Total MSPSS scores ranged from 1.58 to 7.00 (M=5.08; SD=1.23; Median=5.08) where 1 was the worst possible score and 7 was the best possible score.

Normality

The normality characteristics of the dependent and independent variables were tested using the one-sample Kolmogorov-Smirnov Test and are summarised in Table 7.1 below. Kolmogorov-Smirnov test statistics fell in the significant range for BC-Avoidant and NAA suggesting a non-normal distribution for these variables. However, the test statistics for BMLSS, Age, MSPSS and BC-Active did not reach significance, suggesting they did follow a normal distribution. I note for the reader that the CAMS score and Occupational Status are dichotomous and cannot be expected to be normally distributed. They were therefore not included in these analyses.

Table 7.1 Normality Characteristics of BMLSS, Current AM Status (CAMS) and Psycho-Social Factors.

Variables	Normal Parameters		Most Extreme Differences			Kolmogorov-Smirnov Test Statistic*	Asymp. Sig. (2-tailed)
	Mean	SD	Absolute	Pos.	Neg.		
BMLSS	63.183	18.794	.067	.043	-.067	.067	.200
MSPSS	5.078	1.229	.059	.059	-.059	.059	.200
BC-Active	4.955	1.039	.066	.054	-.066	.066	.200
BC-Avoidant	4.104	1.121	.111	.111	-.069	.111	.000
NAA	6.097	2.731	.097	.091	-.097	.097	.002

Normality characteristics of BMLSS, MSPSS, BC-Active, BC-Avoidant, and NAA. SD=Standard Deviations; Pos.=Positive; Neg.=Negative. * One sample Kolmogorov-Smirnov Test indicating BC-Avoidant and Additional Approaches deviate from normality.

Linearity

Bivariate correlation coefficients for all IV and DV pairs are presented in Table 7.2. Results of the Pearson's correlations suggested linear relationships between BMLSS and Age, MSPSS, BC-Active, and BC-Avoidant, but no linear relationship between BMLSS and NAA. Results of the Spearman's Rho suggested a linear relationship between BMLSS and the categorical variables of Occupational Status and CAMS but not gender. Variables that failed to show a linear relationship with BMLSS were dropped from the regression analysis (i.e., NAA, Gender).

Homoscedasticity

Examination of the homogeneity of variance of the dependent variable using Levene's Test revealed BMLSS variance to be homoscedastic when grouped by CAMS (Levene's=.065, $p=802$) but heteroscedastic when grouped by Occupational Status (Levene's=3.998, $p=.047$), possibly due to the disproportionate number of people in the Employed ($n=109$) and Unemployed ($n=35$) groups.

Regression Analysis

A regression analysis was performed to determine if QOL assessed with the BMLSS could be predicted by CAMS and the psycho-social variables of interest (e.g., MSPSS, BC-Active, BC-Avoidant and NAA), over and above prediction of known related demographic factors (e.g., age).

Selection of Predictor Variables

Gender and NAA failed to show significant linear correlations with BMLSS (see Table 7.2 below). These were not included in the final model. Preliminary examination suggested the following predictor variables had significant correlations with BMLSS: Age, Occupational Status, CAMS, MSPSS, BC-Active and BC-Avoidant. All but two of these variables met the assumptions required for regression; due to heteroscedasticity of the data within Occupational Status and non-normal distribution of BC-Avoidant scores, results will need to be read with caution. As dichotomous variables, CAMS and Occupational Status were not included in the test of normality.

Table 7.2. *Bivariate Correlations Between BMLSS, Current AM Status (CAMS) and Psycho-Social Factors.*

		BMLSS	Gen. ^a	Age	Occ. ^a	CAMS ^a	MSPSS	BC-Active	BC-Avoidant
Gender ^a	r	.120							
	Sig.	.151							
Age	r	.252	-.038						
	Sig.	.002	.648						
Occ. Status ^a	r	.347	.118	-.056					
	Sig.	.000	.158	.503					
CAMS ^a	r	-.170	-.118	-.130	-.231				
	Sig.	.042	.160	.120	.005				
MSPSS	r	.540	.151	-.050	.132	-.087			
	Sig.	.000	.071	.549	.113	.301			
BC-Active	r	.247	-.039	.072	.165	-.131	.210		
	Sig.	.003	.642	.390	.048	.116	.012		
BC-Avoidant	r	-.391	-.061	-.245	-.032	.044	-.189	.168	
	Sig.	.000	.470	.003	.702	.604	.024	.045	
NAA	r	-.004	-.008	.032	-.075	-.006	.021	.230	.013
	Sig.	.966	.921	.701	.373	.942	.799	.006	.880

Bivariate correlations between the BMLSS and candidate predictor variables Gender (Gen), Age, Occupational Status (Occ), CAMS, MSPSS, BC-Active, BC-Avoidant and NAA. (a) Spearman's Rho Correlations presented for all pairs with one or more categorical variable (Gender, Occupational Status, CAMS). In all other cases, Pearson's Correlations are presented.

Multicollinearity

Multicollinearity of the potential predictor variables was then examined to determine if any pair of these variables measured the same construct. As shown in Table 7.2, results of the Pearson Correlations and the Spearman's Rho showed no correlations between predictors above the $r=.6$

threshold for multicollinearity, suggesting each predictor measured distinct constructs. Small but statistically significant positive correlations were observed between MSPSS and BC-Active, between BC-Active and BC-Avoidant, and between BC-Active and the NAA. Small but statistically significant negative correlations were observed between BC-Avoidant and MSPSS, and between BC-Avoidant and age. Results of the Spearman's Rho suggested a statistically significant but small negative correlation between CAMS and Occupational Status that remained well below the threshold for multicollinearity.

Predictors of Current QOL Outcomes

In step one, Age and Occupational Status were entered. This equation was significantly predictive of BMLSS outcomes, $R^2=.220$, $F(2, 141)=19.853$, $p=.000$, and both Age ($\beta=.277$, $t=3.714$, $p=.000$) and Occupational Status ($\beta=.396$, $t=5.312$, $p=.000$) showed significant, independent contributions to prediction of variance in BMLSS outcomes.

In step two, CAMS was added to the equation and did not contribute significantly to improving prediction of BMLSS, $R^2=.221$, $R^2_{\text{change}}=.001$, $F_{\text{change}}(1, 140)=.179$, $p=.673$. Age ($\beta=.272$, $t=3.596$, $p=.000$) and Occupational Status ($\beta=.388$, $t=5.037$, $p=.000$) continued to show independent prediction of BMLSS. CAMS did not contribute independently to prediction of BMLSS ($\beta=-.033$, $t=-.423$, $p=.637$).

In step three, the psycho-social variables social support (MSPSS), active coping (BC-Active) and avoidant coping (BC-Avoidant) were added into the equation. Addition of these factors significantly improved prediction of BMLSS scores, $R^2=.544$, $R^2_{\text{change}}=.323$, $F_{\text{change}}(3, 137)=32.302$, $p=.000$. The final model predicted 54.4% of the variation in BMLSS scores. Psycho-social variables made the strongest unique contribution to the final model and significantly predicted 32.3% additional variance in BMLSS scores.

Each of the demographic and psycho-social variables was independently predictive of BMLSS scores when all other variables were held constant. Age ($B=.320$, $\beta=.214$, $t=3.495$, $p=.001$) and Occupational Status ($B=13.277$, $\beta=.304$, $t=5.033$, $p=.000$) continued to positively predict variance in BMLSS scores. Of the psycho-social factors, higher MSPSS scores ($B=6.539$, $\beta=.428$, $t=6.948$, $p=.000$) and BC-Active scores ($B=2.622$, $\beta=.145$, $t=2.347$, $p=.020$) were significantly predictive of better BMLSS scores, while higher BC-Avoidant scores ($B=-4.563$, $\beta=-.272$, $t=-4.328$, $p=.000$) were significantly predictive of poorer BMLSS scores. CAMS continued to show no independent prediction of BMLSS scores ($B=-.279$, $\beta=-.007$, $t=-.119$, $p=.905$). The full model summary and coefficients for the hierarchical multiple regression are presented in Tables 7.3-7.4 in Appendix Three.

Discussion

Quality of Life has been emphasised as an important dimension for assessing AM outcomes. The current investigation aimed to explore whether continuing to take AMs was predictive of higher QOL satisfaction among a cross-sectional group of 144 adults. A second aim was to explore whether coping, social support and number of additional approaches used made independent contributions to current QOL scores among those who continued with AMs and those who had discontinued. The central finding of the current investigation is that social support and the active/avoidant dimensions of coping make independent contributions to the prediction of QOL for those who had stopped taking AMs and those who continued. Consistent with other research, occupational status and age also made independent contributions to prediction. The main implication is that efforts to increase the QOL of people who take or stop taking AMs, should attend to the adequacy of their social support networks, engagement in occupational activities, and coping capacity rather than focusing on persistence of use or medication-factors alone. This has relevance for future research, clinical practice and for people seeking to enhance their own recovery outcomes independently. Models put forward by other researchers (Bobes et al., 2007, p 217) have previously hypothesised that AMs affect QOL in a linear process from reduced symptoms and side effects, leading to a subjective response to AMs, eventual treatment adherence, and improved QOL. The current results suggest relationships between AM use and QOL may not be as direct as these previous models suggest and further research is needed to explore the impact of psycho-social variables, particularly with respect to adequate social support and dimensions of coping, alongside medication factors. To follow, these results will be discussed with respect to the existing research and the two parts of the research question guiding this investigation.

Does Taking AMs Predict QOL?

Bivariate correlations revealed that taking AMs had a small though significant negative correlation with BMLSS but did not make an independent contribution to prediction of BMLSS over and above age and occupational status when entered into the regression. There were no significant bivariate correlations between current AM use and any of the psycho-social variables included in the preliminary analysis, apart from a modest but significant negative correlation with employment. This additionally suggests that AM use may not be directly related to improved capacity for coping, satisfying social relationships, or occupational status as much of the current literature seems to assume (e.g., Bobes et al., 2007). These results accord with other studies that find no significant predictive relationship between persistence of use and QOL (Gaebel et al., 2011; Wunderink et al., 2013). Furthermore, they are inconsistent with prior research demonstrating positive predictive relationships between QOL and AM use (Alonso et al., 2009; Giner et al., 2004; Hamilton et al., 1998;

Haro et al., 2014; Hertling et al., 2003; Meltzer et al., 1990), and those showing independent negative predictive relationships between AM use and QOL (Adelufosi et al., 2013; Harrow & Jobe, 2007). Subgroups with favourable outcomes following discontinuation have been identified in other studies (Landolt et al., 2016; Wunderink et al., 2013). A recent study identified a sub-group among those who discontinued, did not relapse and experienced symptomatic remission; membership in this group of 'successful discontinuers' was positively predicted by a higher level of education and baseline social integration than those who continued or those who stopped but had poor recovery outcomes (Landolt et al., 2016). It is unclear what the finding regarding education might mean for people taking AMs who have poor educational achievements, as is common among people with developmental disorders such as autism, which was reported by four people in the current sample.

There are several indicators of the possible presence of sub-groups in the current data-set. The descriptive data show people in the group who continued AMs and the group who discontinued had BMLSS scores in the low and high ranges. Additionally, as described in Chapter Four, among the current sample, 70.14% perceived their QOL to have been improved by taking AMs, 22.92% perceived their QOL to have worsened, and 8.3% perceived their QOL to have remained unchanged by taking AMs. These subjective reports suggest most people perceived AMs to affect their QOL. It is possible that those who perceived a QOL impact from taking AMs, attributed changes in their functioning caused by other factors to their use of AMs and that there really are no differences in the QOL outcomes of those who take AMs and those who don't. However, it seems likely that there are sub-groups who experience positive and negative QOL outcomes when they take AMs and sub-groups who experience positive and negative QOL outcomes after stopping. If there is a sub-group of people who do better without AMs and a sub-group who respond better with them, the current results suggest these sub-groups may be differentiated by factors other than current use of AMs.

It seems possible that other medication or clinical factors may be more predictive of QOL outcomes, or more positively associated with occupational status, social support, and coping than whether it is taken or not. Untested medication and clinical factors such as higher dose (Adelufosi et al., 2013; Gaebel et al., 2011), side effect profiles involving neuroleptic dysphoria, akathisia and/or sexual dysfunction (Browne et al., 1998; Hofer et al., 2004), symptom reduction (Haro et al., 2014; Hertling et al., 2003), symptom profile and severity (Hofer et al., 2004; Montemagni et al., 2014; Norlelawati et al., 2015) and age at treatment initiation (Alonso et al., 2009; Haro et al., 2009), may be more directly predictive of current QOL than the simple fact of whether a person is taking AMs or not. Current use of other mental-health medications (Brooks et al., 2011), duration of continuous use (Chouinard & Jones, 1980) and for those who stop, time since discontinuation (Wunderink et al., 2013) are also likely to be involved and were not controlled for in this investigation.

Do Psycho-Social Processes Predict QOL?

Of the four psycho-social dimensions explored in the current model all but the NAA showed significant bivariate correlations with BMLSS, and were included as possible predictors in the regression model. MSPSS score, BC-Active and BC-Avoidant were each independently predictive of BMLSS and in the final model they together predicted 32% of the variance in BMLSS, though their respective contributions were modest. Psycho-social factors did make an independent contribution to BMLSS over and above age, occupational status, and CAMS. The strongest predictors of BMLSS were social support ($\beta=.428$; $p=0.000$) and occupational status ($\beta=.302$; $p=.000$), followed by avoidant coping ($\beta=-.272$; $p=.000$), which made a negative contribution. Several prior studies of people taking AMs have also found positive relationships between QOL, social support and occupational status (Adelufosi et al., 2013; Alonso et al., 2009; Montemagni et al., 2014). One recent QOL study has explored the role of coping strategies in predicting QOL outcomes among people maintained on AMs, (Montemagni et al., 2014) and another has explored coping in QOL among older adults with schizophrenia but did not comment on use of AMs (Cohen et al., 2011). An exploration of QOL outcomes in a sample of 92 people diagnosed with schizophrenia who were all stable on AMs, tested whether coping, and symptom severity predicted current QOL and found coping via active social diversion made a positive independent contribution to predicted QOL and partially mediated a negative relationship between increased negative symptoms and QOL (Montemagni et al., 2014). Cohen and colleagues found both active and avoidant coping mediated the relationship between symptom severity and QOL (Cohen et al., 2011). This is potentially the first AM study to show that active and avoidant coping make independent contributions to QOL, over and above AM use.

Given that data collection took place at a single point in time, it is not possible to reliably comment on the direction of the observed relationships on the basis of the current model alone; social support, occupational status and coping may be products of QOL rather than or in addition to being producers of QOL. The relationship probably moves in both directions. For example, people with lower QOL likely have more aversive daily experiences to avoid and fewer opportunities for social support adequacy and active coping, while coping capacity and social support may serve to maintain or shift QOL over time. Though the psycho-social variables each made independent contributions to prediction, the bivariate correlations suggested they also shared a small amount of overlap. More adequate social support was associated with reduced avoidant coping and increased active coping, while avoidant coping reduced with age, and active coping increased with the number of additional approaches people used. Increased social support adequacy may provide the individual with greater opportunities to use active coping methods such as venting and help-seeking, and a reduced need for avoidant coping. Again, bidirectional relationships are likely and the reverse

scenario could also be true based on these results – active coping could create increased contact with social support networks, while increased avoidant coping may reduce contact with social support. Using additional non-medication approaches may help people learn active coping skills, and active coping skills may help people use more additional approaches. Other contextual factors like life stressors and access to resources, and additional psycho-social factors such as education (Landolt et al., 2016), and locus of control (Harrow & Jobe, 2007) are also likely involved and were not tested in this model.

While this study showed NAA may not be predictive of QOL, most people subjectively reported finding additional approaches helpful. Treatment outcome studies have previously demonstrated that adding psycho-social interventions aimed at employment, social activities, and coping skills to treatment with AMs produces more favourable outcomes than treatment with AMs alone (Bustillo et al., 2001; Gaebel et al., 2014; Guo et al., 2010), and that CBT can serve as an alternative to AMs with equivalent or better outcomes (Morrison et al., 2013). This supports the conclusion that certain types of additional approach may improve QOL outcomes and the proposition that coping and social support can affect QOL outcomes in AM use in addition to being affected by those QOL outcomes. Future research exploring relationships between AM use and QOL may need to control for the possible effects of these psycho-social variables on their chosen outcome measures, in addition to demographic variables like occupational status and age.

The final model implies that people who use AMs or have stopped using them, might independently improve their outcomes by actively building satisfying support relationships with friends, family and significant others, reducing reliance on avoidant coping strategies like distraction or alcohol-use, increasing their use of active coping strategies, and occupying at least part of their time with some form of community activity (whether that is paid, voluntary, or study-based). Personal history, stressful circumstance, adverse events, resource restrictions, and the symptoms of mental-health problems can make these things difficult to do. The descriptive data presented in Chapter Four reveals adverse effects may also represent barriers to the forms of coping, occupational activities and social support that the current investigation suggests contribute to positive QOL outcomes. In this study, avoidant coping reduced and QOL satisfaction increased with age, suggesting that things might improve as people become more experienced and develop a wider range of internal and external resources for living well. Additional non-medication approaches may help people address the barriers to high QOL and improve their recovery outcomes. This study provides support for clinical practice focused on enhancing active coping and social support, and reducing habitual avoidant coping. Improving the adequacy of social supports is likely to require attention to both opportunities for satisfying connections and the personal capacity to take

advantage of those opportunities and resources. Similarly efforts aimed at increasing active coping and reducing avoidant coping, are likely to be most effective when they attend to the adverse contextual factors people are likely responding to, as well as their personal repertoire of coping strategies.

These results call into question the clinical practice of relying on AM use as the primary or only intervention for psychosis or mania. The descriptive data presented in Chapter Four reveals that, at least for the participants of this study, AMs are only one of multiple strategies people employ to improve their experiences. While much of the research literature frames AMs as the central intervention for psychosis, this study suggests that for the people who use them they are a small piece of a much larger puzzle. A holistic model of QOL outcomes for people who take or stop taking AMs is likely to comprise medication and clinical factors alongside treatment system (e.g., types of additional approaches used), and contextual factors, together with psycho-social processes. These psycho-social processes likely include subjective experiences of AMs, locus of control, self-efficacy, flexibility, occupational status, social support, education, and as this study demonstrates, active and avoidant coping. This is consistent with the earlier conceptual model proposed by Awad and Hogan in the 1990s (Awad, 1992), adds to a small body of literature suggesting some people who stop AMs may do better or just as well as those who persist with them, and extends this literature by suggesting that the way people cope with their life experiences makes an independent contribution to their ultimate recovery outcomes both on and off AMs.

PART TWO

INTERVIEW STUDY:

EXPERIENCES OF SUCCESSFUL DISCONTINUATION

CHAPTER SEVEN:
MAINTAINING WELLBEING DURING AND AFTER
WITHDRAWAL FROM ANTIPSYCHOTIC MEDICATION

This chapter presents the methodology and results of Study Two, which comprises a thematic analysis of seven interviews with a sub-group of survey participants who self-identified as successfully stopping AMs for at least one year. Interviews established the details of each participant's mental-health and medication history, their withdrawal method, withdrawal effects, the additional approaches and coping strategies they used, current use of AMs and other medications, and their self-defined recovery outcome. Once each participant's discontinuation experiences and coping methods were clear, interviews turned towards exploring how participants were able to achieve their outcomes and maintain their wellbeing during the process of withdrawal and beyond.

Methodology

Participants and Recruitment

Interview participants were recruited through the Study One survey (see Chapter Three). Survey participants who had attempted discontinuation and indicated remaining off AMs for one year or more were presented with an invitation to take part in an interview about what had enabled them to maintain their wellbeing during and after withdrawal. Participants who expressed an interest in being interviewed completed a confidential screening questionnaire to establish eligibility and had an opportunity to ask questions before consenting to participate. Study two participation criteria mirrored Study One, with the amendment that people were not currently taking oral or depot AMs, and had not taken them on a daily basis for at least one year. Ethics approval was granted by the University of Auckland Human Participants Ethics Committee together with Study One.

Data Collection

Participants were interviewed in a single, two-hour interview conducted over the phone or face-to-face in a place most comfortable for the participant, depending on their location. All interviews were audio recorded. Participants were informed that they could take a break and/or request the tape be turned off at any time. Interview recordings were transcribed by a professional transcriber who signed a confidentiality agreement, before being de-identified by the researcher, and provided to the participant to check for accuracy. All information regarding people, places and services that could allow participants or others to be identified was removed from the transcripts.

Measures

A semi-structured interview schedule was constructed to establish participant demographics and medication factors (including medication regimes, time on and time off AMs), and then explore their withdrawal preparations, methods and effects, coping strategies, medication strategies, social support, clinical support, and current recovery outcomes (see Appendix Two). During the first participant's interview, an additional item regarding personal attributes was added to the schedule. Each interview item was used as a prompt to explore how participants had maintained their wellbeing during and after withdrawal. For example, a question regarding what people did to cope, would be followed-up with a question about how they were able to employ those strategies and how those strategies helped them.

The primary measure of interest in this investigation was maintaining wellbeing. I define maintained wellbeing as a state "in which every individual realises his or her own potential, can cope with the normal stresses of life, can work productively and fruitfully, and is able to make a contribution to her or his community" (World Health Organization, 2016). Participants were asked within the interviews to share how they defined recovery for themselves. Each participant was then asked to rate on a scale of 0-5, their satisfaction with their current wellbeing against their definition, where a rating of five represented 100% satisfaction.

Data Analysis

In Study Two a thematic analysis was used to identify semantic patterns within participant descriptions of maintaining their wellbeing during and after withdrawal from AMs. I followed the six-step process outlined by Braun and Clarke (Braun & Clarke, 2006). I familiarised myself with the transcripts through repeated readings and noted down items of interest. This began with checking the typed transcripts against the audio recordings, a second reading to remove identifying information, a third reading to identify participant characteristics, and a fourth reading to identify withdrawal methods and select relevant text for thematic analysis. The aim was to provide a detailed account of the processes involved in participants' efforts to manage their experiences during and after withdrawal. Participant demographic, background and current outcome information were collated for sample characteristics, all references to the process of maintaining mental health during or after withdrawal were selected for coding and thematic analysis, and other subjects discussed in the transcript were excluded from further analysis.

Codes were generated on the basis of explicit semantic content and the relevant transcript data was collated to each code. Themes were constructed by analysing patterns in the initial codes and grouping meaningfully similar codes together into themes and sub-themes that represented the data. An inductive, data-driven process of interpretation was used to generate codes and a degree of

deductive reasoning was incorporated to identify the thematic patterns expressed across them. Themes and the relevant text were then reviewed with my primary supervisor who was asked to assess whether the themes and sub-themes faithfully represented the data and addressed the research question. This resulted in a number of clarifications and adjustments, before the themes were finalised, defined and named. Exemplar quotes were selected for each theme and are reported verbatim. Quotes were carefully edited to preserve participant confidentiality, including the removal of names, services, and locations. When needed, quotes were edited for ease of reading, by removing repeated words and fillers, or joining related comments together. At times, I have added words in square brackets to aid flow. Great care was taken not to alter the meaning of what was said.

Prevalence was defined as the number of participants who referred to a theme, regardless of how often the theme was raised. Frequencies are reported to give an indication of the pervasiveness of the themes across the data-set. However prevalence does not automatically imply significance (Braun & Clarke, 2006); a single theme referred to by one person could be of equal significance to one referred to a multitude of times.

The data was interpreted according to a critical realist framework, which acknowledges “the ways individuals make meaning of their experience, and, in turn, the ways the broader social context impinges on those meanings, while retaining focus on the material” (Braun & Clarke, 2006, p81). As with any interpretive approach, the assumptions and priorities of the researcher have bearing on which elements of the material are given focus. I have a clinical psychology background and assumed the symptoms of mental-health problems were something participants would be motivated to reduce or avoid. A lack of direct experience may have left me prone to neglecting areas of relevance.

I managed the limitations of my clinical background and lack of direct experience by attending to and using the participants’ terminology. In advance I read a number of personal stories of withdrawal from AMs to become familiar with what might be involved (Lehman, 2002). Seeking participants’ own definitions of recovery during the interviews provided a framework against which I could interpret their transcripts, rather than relying solely on my clinical assumptions about what maintaining wellbeing meant. Each interview involved clarifying my understanding of participant descriptions to ensure a shared understanding of the phenomena we were discussing. Several times in each interview, participants corrected my interpretation of the meaning they intended to convey, allowing me to adjust my line of inquiry and understanding of their responses to more closely match the participant’s constructions and assumptions rather than my own. At the end of each interview, I offered a summary of my interpretation of how they had maintained their wellbeing during and after withdrawal, and requested participants to add anything that was missing or correct anything I

had misinterpreted. During the interpretation of results, I was able to return to these sections of conversation to guide me towards the participants' values and assumptions, in addition to validating the themes with my primary supervisor, as described above.

Findings

In the subsequent sections I present the interview participant characteristics, followed by a brief description of each participant's withdrawal method and self-defined recovery outcome, and the findings of the thematic analysis exploring how they maintained their wellbeing.

Participants

Seven women recruited through the discontinuation section of the survey volunteered to take part in a semi-structured interview regarding their experiences of maintaining their mental health during and after withdrawal. Participant characteristics are summarised in Table 8.1.

Table 8.1. *Interview Participant Characteristics*

Participants							
Characteristics	Sarah	Joanne	Carley	Jan	Karen	Rebecca	Theresa
Age	35	49	53	52	63	48	52
Employment	Employed	Employed	Student	Employed	Employed	Student	Employed
Education	Tertiary	Tertiary	Tertiary	Tertiary	Tertiary	Tertiary	Tertiary
Gender identity	Female	Female	Female	Female	Female	Female	Female
Sexuality	Lesbian	Hetero	Hetero	Bisexual	Hetero	Hetero	Hetero
Rel Status	Partner	Married	Partner	Single	Married	Married	Married
Hallmark symptoms	Psychosis, mania, dep	Mania, psychosis	Psychosis, mania, dep	Mania, dep	OCD, dep	Mania, dep	Mania, dep
Age of onset	17	23	31	15	10	16	17
Age First AMs	17	23	31	43	18	41	47
Time on AMs ^a	17 yrs	1 yr	4 yrs	9 yrs	9 yrs	2 yrs	8 mo
Most recent AM	Quet.	Halo.	Quet.	Quet. ^b	Quet.	Risp	Olanz.
Polypharmacy	MS, AD		Sleep aide	AD, MS, Benzo	AD, MS, Benzo	MS	MS, Benzo
Current meds	Zero	Zero	Zero	Zero	AD	MS ^c	MS
Time off AMs	1 yr 3 mo	25 yrs	2 yrs 6 mo	5 yrs	4 yrs	2 yrs	3 yrs
Recovery rating ^d	5	5	4.75	4.8	4	5	4

This table presents the characteristics of the sample of seven interviewees. Names have been changed. Quet = Quetiapine; Halo = Haloperidol; Risp = Risperidone; Olanz = Olanzapine. (a) Time on AMs represents longest duration of continuous use based on medication history obtained during interview. (b) Jan's continuous use of AMs took the form of alternating 1-2 week periods of daily AM use separated by 1-2 week gaps over 9 years. (c) Karen reports current daily MS is taken at a low dose that does not show up in her blood-tests. (d) Self-rated satisfaction with current recovery outcome on a scale of 0-5 where 5=100% satisfaction.

Each participant was given a pseudonym for the purposes of presenting results. As shown in Table 8.1 they all had previous tertiary qualifications, were currently employed in some form of paid

and/or voluntary work or study, and six were married or involved in intimate relationships. In addition, five were New Zealand European, two were Part Maori, and six were mothers of teenage or adult children. A diagnosis of bipolar disorder was reported by six participants, all of whom described psychotic elements to their experiences; two also noted differential diagnoses, including dissociative disorders and schizophrenia, and were not sure which best fit for them. Two participants disagreed with their diagnoses of bipolar disorder, although they recognised experiences of mania and psychosis. Six had received compulsory treatment in hospital at least once. Jan had never received compulsory treatment or been hospitalised, but she described a prescribing situation initiated by the occupational health service at her place of work and reported a conflict of interest that left her feeling unable to freely choose.

All but one was most recently taking an atypical agent and all but one reported concurrent polypharmacy at that time. Most participants had taken AMs continuously over several years and several had changed agents during that time. Three exceptions are worth noting. Carley reported initial continuous use of a typical AM for seven months, followed by a medication-free period of 15 years and then continuous AM use for four years. Jan's continuous use of AMs took the form of alternating 1-2 week periods of daily AM use separated by 1-2 week gaps over nine years. Karen had a brief experience with chlorpromazine in hospital during late adolescence and later took AMs continuously for nine years. All seven participants used additional non-medication approaches and six had participated in talking therapy for several years. Other non-medication approaches included personal development workshops, support groups, exercise, diet, nutritional supplements, creative activities, yoga, meditation and mindfulness, cultural workshops, self-help books and online research, conference attendance, and church activities.

Withdrawal Methods and Current Recovery Outcomes

Most participants reported a gradual reduction across a period of months or years, and for all but one this was undertaken with the support of their prescribing clinician. Table 8.1 highlights that the participants were highly satisfied with their current recovery outcomes and had remained off AMs for periods ranging 1.25 to 25 years. Definitions of recovery most often described a constantly unfolding process rather than a static outcome and referred to emotional satisfaction or contentment, capacity to cope with or manage daily experiences, personal growth, and QOL dimensions such as engagement with meaningful activity. Individual withdrawal methods and recovery definitions are given below.

Sarah. Sarah reduced from 600mg in 25 mg intervals over a period of years and then reduced from 25 mg to zero because there were no smaller tablets available. She had the support of a private psychiatrist, key-worker and therapist during withdrawal, and they were in communication

with each other. Sarah had a loose plan for reducing, set with her psychiatrist, with the expectation this would be adjusted if “it wasn’t working.” She kept a written mood and sleep journal to keep track of her experiences prior to, during and after withdrawal. Sarah experienced difficulty sleeping and a manic episode approximately 3 months after she stopped, for which she briefly resumed a prior dose and then reduced across a further six weeks. Her definition of recovery follows.

I don't think zero symptoms is either expected or kind of reasonable. I think it's, it's how much that distresses or prevents me doing what I need or want to do. It's a fine balancing act of managing the severity of that symptom to make sure that it isn't majorly impacting on, on life in a way that prevents [me] doing what I need to do, or want to do. I think at the moment it's mostly working and yeah. And like anything sometimes life gets in the way of that but it's about working with that rather than fighting it. (Sarah, 17 years on AMs, 1.25 years off AMs, recovery rating 5/5)

Joanne. Joanne described an abrupt withdrawal from AMs, “flushing them down the toilet” after one year’s continuous use, without any input from professional support or family. During her initial withdrawal she was living with another person who was also experiencing psychosis and did not respond to her “strange behaviour”. She described experiencing florid psychosis and mania for a period of approximately three months and identifying a service-user collective that allowed her to use their back room as a safe space to “move through” her experiences. She reported experiencing residual symptoms with two further full episodes across the following 25 years, managed without any psychiatric medication, and noted that these had become a thing of the past at the time of the interview. Her definition of recovery follows.

Moving through those experiences allowed me to achieve what I've achieved, which is why I can't really call it recovery. Because what would I be recovering from? I mean they were a tool and a mechanism for me to move through to get to where I needed. I haven't really got [a word for recovery]. Evolution. Life. It's just life, yeah. Well I suppose, okay, so you asked about an end point in the recovery process or a measure of your recovery process. Peace is a kind of measure I think. And freedom I suppose, both mental, physical freedom yeah. Not feeling like I have limitations. (Joanne, 1 year on AMs, 25 years off AMs, recovery rating 5/5)

Carley. Carley withdrew across three months with the support of her GP and a specialised nutritional supplement that came with an online diary for self-monitoring her progress, and phone

support from the company that created them. This was her fifth attempt to stop and all prior attempts had been abrupt and resulted in relapse and resumption of daily AMs. Using a special pill-cutter, Carley quartered all her pills, and worked down from the biggest to the smallest pieces before reducing to eighths and repeating the process. She described difficulty sleeping and a four-day relapse of mania six months after stopping, which she managed at home with the support of a friend and without medication. She now manages with daily supplements and a range of psychosocial strategies. Her definition of recovery follows.

Personally my definition of recovery is awareness of where I'm at, how I'm doing and preparedness to take steps if I'm not walking down the right path. If I get on the wrong path just being able to get back on the right path again. (Carley, 4 years on AMs, 2.5 years off AMs, recovery rating 4.75/5)

Jan. Jan described continuing to take a MS during withdrawal from AMs and later discontinued this. Jan changed prescribing clinicians to a GP who knew her well and agreed to support her to independently discontinue provided she checked in regularly and did not drink alcohol. Jan first withdrew from an AD suspected of precipitating her frequent manic states, and used AMs only for insomnia for a few weeks; she then increased her exercise to the point that she started sleeping at night and “just stopped” using AMs as she needed them less. She wasn't sure how long this had taken. She did not notice much beyond occasional difficulty sleeping. Jan was not currently taking daily medication of any kind but had a “stack” of MSs and ADs in the cupboard in case she experienced a relapse. Her definition of recovery follows.

It's contentment. Yeah and for me it's acceptance of things. (Jan, 9 years on AMs, 5 years off AMs, recovery rating, 4.8/5)

Karen. Karen discontinued several medications with the support of a private psychiatrist who provided written information and sometimes drawings to help Karen plan her reductions. She withdrew from daily benzodiazepines prior to stopping AMs; she continued to take a MS and an AD during withdrawal from AMs, later discontinued the MS and carried on taking the AD. Karen withdrew AMs across six months using a pill-cutter and later by shaving small amounts off her pills using a special pill shaver. She described noticing no withdrawal effects when she stopped taking AMs and emphasised how she “backed off” from a reduction if she felt “unstable” for any reason. Her definition of recovery follows.

[Recovery is] being determined to have a so-called normal good quality of life. I think that's been the driving force. It's being able to have a partner, be married or whatever. Have children. Raise those children Yeah having a nice house and a garden, I mean I like to garden. All those sorts of things. Ordinary things. (Karen, 9 years on AMs, 4 years off AMs, daily AD, recovery rating 4/5)

Rebecca. Rebecca continued to take a MS during and after withdrawal from AMs. Rebecca tapered swiftly with the support of her GP by switching to alternate days for two weeks, then using AMs on a PRN basis to cope with increased anxiety for two months before stopping entirely without relapse. Rebecca was taking a MS at the time she withdrew and continued to take this at the time of the interview. She noted that a recent blood-test had failed to register a therapeutic dose in her system and her doctor had discussed discontinuing it in the near future, when the time felt right. Rebecca had not participated in talking therapy but described learning about CBT through her education and own independent learning. Her definition of recovery follows.

[Recovery is] living well. Yep. Just you know living well and being able to make sense of stuff. It's about recognising what [symptoms] are and managing them to the best of my ability. And regardless of whether you're living really well or still struggling with it there should be no shame attached to it. (Rebecca, 2 years on AMs, 2 years off AMs, daily MS, recovery rating 5/5)

Theresa. Theresa continued to take a MS during and after a gradual withdrawal from AMs across six months, supported by her psychiatrist and a written Wellness Recovery Action Plan (WRAP) that included a number of personal supporters. Theresa experienced difficulty sleeping during withdrawal which she was able to manage in other ways. She went through a relapse over a year later during which she returned to the full dose of her original AM for two weeks and then tapered down again over four weeks.

To me recovery is living a life where I am happy to live each day. I think recovery is happening at lots and lots of different levels. Recovery is like the soil in the earth. If you took a slice of earth and you looked at that you would find all these different layers. And I feel like recovery is like this, but it doesn't happen on one day at the same time. It happens on all these different layers and all different times. Your environment influences your life and your

life influences your mental health. They're not alone standing. (Theresa, 8 months on AMs, 3 years off AMs, daily MS, recovery rating 4/5)

Thematic Findings

Three central themes were constructed from the participant narratives about maintaining their mental health during and after withdrawal. The analysis aimed to explore important themes, regardless of whether they were shared or not. However, the three central themes were shared by all participants, with some variation across the sub-themes within each major thematic stream (see Table 8.2). All participants discussed the importance of understanding themselves and I named this theme 'Coming to Understand Myself and My Needs.' All participants discussed finding, learning and using a range of strategies and tools for their wellbeing, referring to a theme I have named 'Finding What Works for Me.' All participants described a role for the professional and natural support systems they had available to them and the way in which they used those supports, referring to a third major theme of 'Connecting with Supports'.

Table 8.2 *Themes of Maintaining Wellbeing During and After Withdrawal from AMs*

Theme	Count
Coming to understand myself and my needs	7
Being aware of my risk factors and early warning signs	7
Discovering meaningful frames of reference	6
Understanding my identity and purpose	5
Healing and resolution	3
Finding what works for me	7
Building a tool-box of strategies to support myself and flexibly meet my needs	7
Acceptance over resistance	7
Drawing on my personal qualities to reach my recovery goals	6
Creating positive life experiences	4
Connecting with support	7
Trusting others so I don't have to it alone	7
Making connections with other people who have similar experiences	7

This table presents the themes constructed from interviews with seven women regarding the experience of successfully discontinuing AMs and what enabled them to maintain their wellbeing during and after withdrawal from oral AMs. Four currently used zero daily psychiatric medications and three continued to use other psychiatric medications such as ADs and MSs.

Coming to Understand Myself and My Needs

The whole group described 'Coming to Understand Myself and My Needs' as a crucial to their efforts to maintain wellbeing during and after withdrawal. Four sub-themes were constructed and are presented in Table 8.2. This was a process of developing self-knowledge that involved an understanding and awareness of their personal risk factors and the early signs of symptom exacerbation or re-emergence, discovering meaningful frames of reference, and understanding their

purpose and identity. For some there had been a process of healing and resolution through understanding their underlying issues.

Being aware of my risk factors and early warning signs. Participants understood what becoming unwell looked like for them, how they might notice this at its earliest stage and how they might be triggered by different stressors, health conditions, or times of year. Understanding the potential withdrawal effects they might expect helped people to become aware of the particular risk factors and early warning signs to attend to during reduction and how to respond to them. Employing a process of self-reflection and self-observation, participants were able to be aware of how they were responding to things and identify when difficulties were starting to arise. They described learning to 'check-in' and 'self-monitor' what was happening for them and be mindfully aware of their internal responses. This was likened to carrying out 'self-therapy' through dialogue with a kind of internalised counsellor. Recognising the limitations of their own awareness, some kept a written journal to aide their reflective process and memory of their observations over time.

It's really important to be aware of your triggers and know what signs of un-wellness look like. And even now, if I've been really busy, feeling a bit stressed, have had not a good night's sleep, I will actually reality-check. I will check in, like, I know the kinds of thinking that go with being unwell. And so I'll run through like a tick-list, in my head. And go, well, how do I feel about this? And how do I feel about that? (Rebecca)

[I learned to keep] checking in with where I'm at and being able to kind of internally communicate, as well as externally, figuring out actually this is what's going on, this is where I'm at. I think [keeping a journal] partly helps because my memory is not good. It's kind of an external memory bank, a reality check really. It is one tool that has helped me to stay well (Sarah)

Each time [I attempted to stop and relapsed] it became less severe, and it frightened me less. It felt like a bicycle I was learning to ride, and that the wobbles were less wobbly. I've been fascinated by the process and watching it, and asking what's happening here, why is this happening. For me it's more just having that bigger picture going on all the time, and seeing yourself as an actor on a stage. And if you were the director, you know, is it going well or is it going badly. It's that self-observation. You can actually be your own counsellor. (Carley)

Discovering meaningful frames of reference. The majority of this group described a process of discovering new ways of understanding and labelling their mental-health problems that fitted with their systems of belief, humanised their responses, and gave them a framework for making meaning out of their experiences. Viewing symptoms through an illness framework was unhelpful and sometimes distressing. Finding alternative frames of reference settled distress responses to experiences of difficulty and helped people direct their efforts to cope. Discovering meaningful frames of reference allowed participants to make sense of symptoms and early warning signs as human responses informing them they had unmet needs to attend to and inviting them to reflect and act on this. These could be physical needs for nutrition and exercise, or psycho-social needs for self-care, safety and connection, and these two domains were frequently linked together. Frames of reference were discovered through reading, attending conferences, personal development workshops, professional development, talking therapy, other service-users, chance encounters with knowledgeable people, and online research.

For me, if I can really pinpoint what the source of my anxiety is, [I can] actually deal with that directly. I feel like I've got a framework, which enables me to make sense of the world and a plan in place for staying healthy. (Rebecca)

If you see yourself in the light of illness and disease then time is not going to be your friend. But if you see yourself as someone on a journey you will get better. I think I take any symptom as an invitation to dig deeper. If you have a symptom you need to look around and be with it for a while, and see if you can pick up what the cause might be. I mean it's like when you get a headache. I mean people just reach for a Panadol instead of saying am I thirsty, have I been in front of my computer too long, is my neck okay, do I need to just go for a walk. There's a few key things which I think we sort of need. So I'm going to go through what we need. Safety and acceptance, and peace and quiet. Emotional support, healthy food and sunshine. I've got it written down here. Clean water, nature, baths, warm baths, gentle distraction and purpose. Depression doesn't cause depression, it's a symptom you know. And mania is a symptom. (Carley)

The first thing I ever read or came across that made any sense whatsoever was a book that framed those mental health experiences in something other than illness or a medicalised approach. Because I'd never, I'd never come across any other frame of reference for it. So as soon as I read that, this kind of world opened up, that there are different ways of thinking

about these experiences that actually fitted how I felt and what I felt about what had happened. (Joanne)

Three mentioned they found meaningful frames of reference in coming to understand different medication effects or learning their diagnosis. Understanding medication effects and diagnostic labels allowed some people to separate their identity from things that affected them, such as a mental-health problem or medication side-effects. This was often the result of self-directed learning combined with seeking information from clinicians.

I consider myself incredibly fortunate to have had a few things happen. I got a diagnosis for a start. And that makes you go back through your whole way of being and examine what's you, what's your illness, what's your childhood shit if you like. And I guess that that was the journey to developing self-awareness. For me, the label enabled me to make sense of a whole bunch of stuff. I mean, before getting a diagnosis I can remember saying to people, I have always felt like I'm on a path in life where I'm not always in the steering wheel. You know, I'm not always in control and sometimes things just happen. And I'd always explained it away like that. But actually in hindsight with the benefit of a label, it's like, well actually, I wasn't in the driver's seat because I was unwell at the time. (Rebecca)

Understanding my purpose and identity. Another dimension of self-understanding involved developing and holding an awareness or vision of one's purpose and identity, outside of being someone who experienced a mental-health problem or took AMs. Participants described an awareness of what was important to them, what they wanted in their life and who they were. This awareness of identity was described as allowing people to direct their behaviour in a way that had congruence with their values. Awareness of identity was used to help them know what they needed and inform their efforts to understand the meaning behind their symptoms. For some, understanding their identity and vision for the future was grounded in an awareness of what they did not want to become.

I think if you've got, you've got to have a strong sense of identity. I think if somebody asks you who you are, what do you believe in, what do you think is the purpose of life, if you can't answer all that, you're not going to be able to do any of this other stuff. I think a lot of my adult life has been about developing my identity or I guess redeveloping my identity. (Rebecca)

So I have this picture in my mind of me sitting in my rocking chair on my porch saying do you know when I was old, rocking backwards and forwards, and talking to my grandchildren. And if things get tough then that is the picture that I pull forwards. Yeah, well hopefully I live that long, but I want to see what this world is like when I'm old. And it's like if I don't keep myself well I won't get there. (Theresa).

Understanding identity also referred to an appreciation for the stigma attached to being 'a mental patient' and the ability to construct an alternative narrative for self that opened space for different possibilities.

Self-stigma in mental health is the worst. You wake up in the morning and almost every day you've got this who am I, where am I, what am I doing, where am I going? Just for a second, 'but you're a mental health patient' just comes slamming in and destroys the day. It's like you drown in the stigma. Yeah, I kind of just lost myself completely and I had to re-find myself. I guess part of my identity now is that I'm educated in mental health, I'm a researcher in mental health, I've had my own experiences and I'm a survivor. So it's kind of like, it's a better story. (Carley)

Healing and resolution through understanding underlying issues. Three participants described coming to understand their underlying issues as part of their ability to maintain their wellbeing. Understanding their underlying issues allowed them to heal emotional wounds from past trauma, grief, difficult experiences with their family of origin or the experience of a mental-health problem. Two participants included descriptions of forgiveness.

I think fundamentally, I know the origins of my mental illnesses. I know why they occurred. I am very clear about that. Whereas before I was just managing symptoms. Dealing with symptoms you know and not ever really dealing with the origin. So when I was able to deal with the origin, it took a long time, like four years. Four years of psychotherapy. My God. And I figured it all out. And I'm at peace with it. I've put it to bed. That's a huge resolution. (Karen)

So part of the process of a manic episode is almost like repressed psychological garbage gets released and is coming up for healing and resolution. Time to heal is so important. I'm not so

scared about myself anymore, but it's taken a long time. Because when you have a breakdown everybody gets scared for you, and you get scared for yourself. And it takes a long time to know that actually you're okay. So just finding myself again and not seeing myself as damaged goods. [Recognising] I've actually got something worthwhile to bring into a relationship. That's taken time. I thought can I forgive myself for having had a mental health problem? Is it okay that I've been psychotic seven times? And it's like yes. (Carley)

Finding What Works For Me

Alongside coming to understand themselves, all participants described finding strategies that worked to help them insert the ingredients of wellbeing into their daily life and cope with symptoms, stressors, and distress. 'Finding What Works' involved building a tool-box of strategies for flexibly meeting different needs, adopting an approach of acceptance over resistance, drawing on personal qualities to persist until they find what helps them manage and creating positive life experiences.

Building a tool-box of strategies to support myself and flexibly meet my needs. Building a "tool-box" of strategies to cope with stress and distress was seen as a critical component of maintaining wellbeing during and after withdrawal. Participants emphasised having multiple options available to them in any given situation. This was seen as particularly important in the context of withdrawal, where something else would be needed to fulfil the function previously met by AMs, but it was also framed as an important part of their wider journey to generally support themselves to live well. Knowing one had strategies to cope provided people with a sense of control and choice that reduced their general stress and distress. Participants highlighted they had a range of different physical, emotional, psychological, and social needs and required a holistic set of strategies that addressed each area.

I guess, when you're taking away one of the things that's holding you, making sure that those gaps are filled. Whether that's with the supportive others around you, whether it's the mindfulness, whether it's the creative stuff, but making sure that you're not falling through a gap that you're knowingly creating for yourself. It's not one piece of yourself in isolation, it's supporting yourself in all of those aspects that help. I think for me it's keeping a balance of all the strands really. (Sarah)

So we [the therapist and I] talked about a lot of strategies. So by having all those strategies I could use those strategies and found that they actually worked. And I felt much more in

control and much more able to set boundaries and that sort of thing. So things settled down. So by getting control of that then the OCD wasn't in control. (Karen)

People emphasised this was a self-directed journey to find what worked and to do what was necessary for self-care and wellbeing. They were aware others could support their process, but only they could take the necessary actions to maintain their wellbeing. Three participants specifically mentioned how having responsibility to others, including children and partners, helped to motivate them to hold responsibility for taking care of themselves. The whole group universally described a flexible quality to their use of strategies; this could involve using multiple approaches in sequence, "experimenting" with what worked in that given situation. Flexibility allowed people to adjust their strategies depending on their context and their understanding of their needs. Where prescribing clinicians had been involved in supporting the creation of a reduction plan, these plans were adjusted when withdrawal symptoms appeared, and if stressful situations arose.

I think when it all clicked into place, was sort of when I did that journey myself. Very self-directed. You know, your own decision to try and find things that work for you. (Rebecca)

The group described developing strategies for relaxation and sleep, self-soothing and self-care, distracting themselves, expressing distress, directing or expending energy, resolving interpersonal conflict, and asserting themselves, alongside nutritional and exercise strategies for building their physical resilience or addressing other health problems that affected their mental health. Where distraction was used, this was done with a purpose in mind rather than being a habitual response. Several participants had written plans to prompt them to remember their strategies in times of distress; one had an actual box filled with physical reminders and resources for self-soothing. The group described using many approaches to find the strategies that worked for them, including personal development groups, consultation with psychiatrists, talking therapy, key workers, exercise groups, support groups, peers, websites, social media networks, meditation centres, spiritual groups, reading self-help books and memoirs, and through formal education in the fields of mental health and community development.

So you've just got to chip at all sides. Diet, sleep, exercise, who you spend your time with, what you spend your time doing. I've tried lots of modalities. I would glean just a few things from each one. Mental health is like all these different things keep your head above the water, and mental health [problems] is like you drown. And then things get your head above

the water again. And what I've sort of learnt is that it's okay to drown, you can actually breathe down there too. Well you've got a choice, you've either got to cope or not cope. And whatever helps you cope is good. So I think I've never really got to the place of not coping. It is flexibility isn't it. It's emotional and physical flexibility. (Carley)

PRN use of AMs or other medications like sleeping aides represented one strategy in the 'tool-box' of five participants, framed as a strategy for use at times when none of their other options were working. In this manner, they also adjusted their use of medication strategies depending on their understanding of the situation and their needs, the degree of their distress, and the results of their efforts, until they found what worked to return them to a state of wellbeing.

There is a reluctance [to use medications now] but it's not a, hell no, it's a, I must be really at a point where it's gonna be not having other options to manage. I guess knowing that above all I want to stay well and to be able to do all the things I want to do that, sometimes that's counterproductive, just that blanket no to medication. So taking a kind of overall picture to maintaining it [my wellbeing]. And medication can be one of the tools that I use to do that. (Sarah)

Acceptance over resistance. All participants in this sample described the importance of their own willingness to accept and allow symptoms in order to find what works. Acceptance was frequently paired with the concept of channelling or redirecting energy in healthy, helpful or at least harm-free ways. This was contrasted with an attitude of shame, judgement, fear, suppression or denial that tended to escalate distress and prevented people from being aware of their responses, finding ways to maintain their wellbeing or being able to trust others sufficiently to seek support. Acceptance over resistance appeared to create space for understanding self, connecting with supports and ultimately finding what works.

It's like you can sink to the bottom and then kick start off the bottom. You know, people drown in shallow water just fighting it the whole time, rather than just go I'm going to be depressed for a few days, I'm just going to let it be. When you're bursting with adrenalin, to be contained is just the worst thing. If I'm buzzing with adrenalin I'll try and use it. I'll go to the beach and have a big walk, or go out in the garden, or I'll clean the house. So I don't try and suppress adrenalin, I use it. It's there to be used. [It's] acceptance. It is a few simple words, you know. Like close your eyes, where in your body do you feel this emotion, is it

okay for it to be there. It's just so easy. Fighting something is so hard, accepting something is so much easier. (Carley)

Drawing on my personal qualities to reach my recovery goals. Participants described drawing on personal characteristics like persistence and curiosity to remain on the journey to find what works for them in the pursuit of their own self-defined recovery goals, no matter what. They persisted through "hideous" experiences with therapists until they found people that were supportive. They "fought" prescribing clinicians until they supported their decisions to withdraw from AMs. They "searched" online for information they needed to understand their experiences and the different things that affected them. When asked what it was that enabled them to do these things, participants referred to being a strong, determined and persistent person, and having a questioning and curious nature. Two also referred to being educated and intelligent, and reaching a level of maturity that allowed them to know who they are and what they wanted for themselves.

I think one of my sometimes positive traits is that I'm stubborn and if I start something I'm going to keep going to see it to completion if it's at all possible. Sometimes that gets you into trouble. But I think, without a doubt that's probably been a contributor, the fact that I'm determined. At one point I was so dumbed down in terms of being able to interact with the world. And somehow I still managed to do some part time University study through that fog of antipsychotics and whatever else I was on. So it wasn't like I was somebody that didn't have the research behind them, I was not an unintelligent person that didn't know. (Sarah)

I'm a free thinker. And I've just been stubborn enough to try and find my own solutions. So I follow certain writers around the world, and researchers. I want to know for myself, I don't like second hand information. And even when I've been really manic and unwell a part of me is always observing myself. And even though it has felt way off in the distance and it's just become a tiny little part of me, and it can no longer regulate my behaviour through it, it's always observed and thought this is interesting. (Carley)

In my mother's line there is a kind of long line of rebels. I always have been like that right from when I was little. There's just something that's like, I am my own person and I'll fit your school system and I'll fit your whatever but something deep down will always forge my own way, you know. (Joanne)

I'm actually a very strong person I think. Because you know, my mental illnesses started when I was ten. The events in my life, like being in a big mental hospital at the age of 18 or 19, you grow up pretty quickly. I think I'm quite tough like that. Well, I've had to be. Because you see I've had a burning desire to live a normal life. (Karen)

Creating positive life experiences. Participants also emphasised that finding what worked for them extended beyond coping with stress and distress into strategies focused on engaging with activities that created positive life experiences. This involved establishing healthy daily routines, engaging in occupational and leisure activities, and participating in family and community life. Being able to manage symptoms and withdrawal effects was necessary, but insufficient. Maintaining wellbeing also necessitated finding what worked to create a meaningful life that met their self-care needs, stimulated positive emotions and reinforced positive perceptions of the self. Some spoke of how this became easier for them to do following withdrawal as the adverse effects of taking AMs resolved.

Having something meaningful, whether that's paid or voluntary work, something that feels like it's useful to the world. One of the things that really I like about [the creative arts space] is, you walk in the door there and it's really about what's going right. It's about the art, the creative stuff, rather than about the wrong stuff that's too hard, or that's kind of making things not good. When you walked in the door nobody asked you about diagnoses or what was wrong specifically. But you were an artist, you were a musician, you were whatever you were there for, rather than what was wrong in your life. (Sarah)

All of those things that I had experienced including the things [symptoms] that were still popping up every now and then gradually diminished as my engagement in my life and my busy-ness and my kids and stuff gradually grew. And then that kind of took over. (Joanne)

I didn't take [PRN medication] an awful lot. Because I got energy, I started walking. Because I was walking I was tired. Because I was tired I then could sleep. I was going to do things, I started playing sports. I was with people again; I was talking to people again. The normal stuff started happening again. I started making a point of getting up first thing in the morning, having a shower. I walked to school with my son. The routine part is my most important part in life. Even when I wasn't formally working, then I was doing something every day, having something to look forward to, going out of the house. (Theresa)

Connecting with Supports

A major theme weaving across all participant narratives was the importance of connecting with support to maintain their wellbeing. 'Connecting with Supports' included the special value of being connected to people with similar experiences and trusting others so they didn't have to manage alone. Trusting others also involved being trusted by others and having access to people who were trustworthy in regards to their ability to provide the support that was needed.

Participants described using trusted and trusting supporters as external self-checks, being selective about who they trusted to be involved in their recovery, finding supporters who empowered them to help themselves, and having the resources to access the supports they needed. The majority had support from their prescriber for their withdrawal and described their guidance as useful to them.

Making connections with other people with similar experiences. Participants in this study were recruited primarily via service-user networks across New Zealand. The entire sample discussed the particular value of being connected with other people with personal experience of mental-health problems, whom they felt truly understood what they were going through. In these relationships the support and understanding flowed in two directions. These connections came through participation in support groups and service-user networks, employment in the service-user workforce, and engagement with peer-led services. Participants described learning new information, frames of reference, and coping strategies that aided their understanding of themselves and their journey to find what works for them. They emphasised these connections allowed them to discover stories of recovery that gave them hope. Humour was a strong element of these relationships which tended to be described as missing from professional support relationships. Participants described laughing together about their experiences and being able to talk about them in light-hearted terms that lifted their mood and enabled them to talk about things that were often difficult to express. Other people with mental-health problems were described as understanding without judging, enabling people to be open about their experiences of struggling. Where family and friends were described as often becoming distressed themselves by participant expressions of distress, other people with personal experience were described as being able to accept them in these moments, talk them through what was happening, and in some cases, help make the adjustments they needed.

The team [of consumer advisors] I worked with were all either starting on meds or coming off meds, or had had similar experiences. So it was wonderful. You'd sit around and talk about it. That was very important. In fact, that was much more supportive than my actual personal friends outside of work. Yeah, that was a godsend. Most of my personal friends had

never had any kind of mental illness. But my workplace is where you could all just kind of talk about it. And it was hugely helpful. There was a lot of humour. Whereas there was hardly any humour in the [mental-health service]. It's all terribly serious. And I could see that you could laugh about some awful things with respect. You had to laugh. (Karen).

Social support was just not even a factor (during withdrawal). I don't know that I would have even considered mentioning it to friends. I don't think it would have meant anything to them. I think I've got some very good friends who are very Pollyanna-ish and their solution is just to make everything okay. And that's not how things work. I've got some newer friends that I've made recently who have had experience of mental health [problems] and probably would be in a far better decision to pick if things were going wrong and say, hey, you need to do something here. (Rebecca)

[At the WRAP group] I realised there were other people going through exactly the same thing I was going through. The facilitators were my peers. They weren't some people that had studied forever. They were people that had been in hospital themselves. They spoke from their personal experience. It gave me major, major hope because I thought if they can do it then I will be able to go back to school next year. And maybe it is possible [to recover] because there's so many of us who have done it and there are so many people who are doing it. And different people would say I do this when this happens, when I have a panic attack I do this. It's like oh, I can try that. So I then stole their ideas. (Theresa)

Trusting others so I don't have to do it alone. Most narratives about what enabled people to maintain their wellbeing during and after withdrawal highlighted the importance of not being alone in their efforts and referred to the use of multiple forms of professional support and natural support. This required people to trust others to have their best interests at heart, to be open about their experiences and to reach out for the knowledge, guidance, and compassion others had to share. This also rested on being trusted by their supporters to know and describe what they were experiencing and do what they needed to take care of themselves.

Actually there's a thing that comes in there that I think is really important. And that's the ability to trust that there are other people that have got your best interests at heart. And I think if you can't trust other people then this is a very hard process to do alone. (Rebecca)

I've always had that support. My husband, my sons and my step-son, they're the reason that made the difference why I'm here. In my WRAP plan I've got 5 supporters. Some of them don't know each other; some of them do know each other. And all of them have very different roles. (Theresa)

A number of participants described limitations in their self-awareness of manic states and had supporters who knew them well and were trusted to help them observe their early warning signs. This could be a difficult thing to do; fears about resuming AMs and internalised stigma about what it means to become unwell were associated with finding others' feedback about early warning signs distressing.

I have a whole lot of [supporters] in my personal life and I have a long term psychotherapist and a few others in a team that have worked with me for many years that also kind of, they know me well and are able to say, do you think you need to slow down or whatever the prior agreed course of action might be. (Sarah)

Some people also described being selective about who they trusted to be involved in their withdrawal process and ongoing efforts to cope, excluding people who might not be able to contain their own anxiety, who might discourage their preferred means of coping or who were not able to understand their frames of reference. Family members and friends without personal experience were often described as grounding influences and sources of general connection, communication and practical help rather than directly being involved in managing mental-health experiences or the withdrawal experience.

I chose to let people support me and I also chose to support myself a lot more. Family see you when you're at your worst. The thing is you're only at your worst for a day or two, a few hours here and there, but it makes such a dramatic impression. And then they are so scared of that happening again because they felt so uncomfortable that they'll go to great lengths to suppress it. And they start to get wound up, and they start either avoiding you or crowding in on you, because your spontaneity is seen as being sort of a danger signal or something like that. (Carley)

A number of participants described the particular value of selecting professional supporters, especially talking therapists, who had an empowering approach focused on equipping them with

what they needed to autonomously manage their wellbeing, and encouraging self-responsibility and self-directed action.

One of the first things [the most helpful psychologist] said to me was, my job is to make myself redundant. My job is to give you the skills to work through this and to live your life. And I remember feeling really incensed. I didn't know what she was talking about. It took me a month to figure that out. But I think that's the fault of some of the clinicians too. Coz they say, well, I'm here to help you. Most of them have said that to me. Hello, how are you, I'm here to help you. And it's never been, together we're going to do this, she was the only one that actually said, look, you know, we're going to work at this together. And I'm going to make myself redundant. (Karen)

Two participants referred to the importance of seeking support from people who were willing to accept and allow symptoms as opposed to those who might react to them and highlighted the role accepting others could have on their own self-acceptance and ability to manage or move through experiences of distress safely.

[The last time] I went way up a friend came and stayed and looked after me at home for four days. I just ate well. I thought I was making homeopathy but he just let me play around with my water and my drips, my little bottles. It was a bit out there but it wasn't doing anyone any harm. He didn't try and impose on me at all. If I wanted to talk about a topic he just listened. He would just light the fire and prompt me for when it was time to cook. And look he didn't question me when I put a teddy bear in a nightie and tucked it up into bed. He just let me do it, he didn't even ask why. It felt like experiences in my past come up to be healed rather than suppressed. And I just came right. I was back at university a week later and nobody knew any difference. So I now know I can go through a manic episode without medication, as long as I make sure I'm in a safe space with a safe person. (Carley)

There were no specialised supports for withdrawing from AMs available in NZ aside from the participants' prescribing physicians who were frequently viewed as being reluctant to provide support for withdrawal and participants described creating their own network of trusted supports. Only one person undertook the withdrawal process without the support of their prescribing clinician and for most this involved support to plan and adjust the tapering process. Having prescriber support for withdrawal was framed as allowing people to feel safer in making their attempt. Most

described additional supporters such as therapists, key-workers, friends who came to stay and take care of them, or took the children for a day, family who filled in when they could not function at their usual level, and having people to talk to. Psychologists, friends and colleagues could serve as advocates to help gain the support of prescribing clinicians. Professional supporters were described as more willing to trust people to attempt discontinuation when they had other natural supports involved and vice versa.

For some, it was a journey of trial and error through multiple different prescribing clinicians until they found someone to support their withdrawal process or through multiple different therapists until they found someone they could build a therapeutic alliance with. Carley described “fighting” with her GP until they agreed to support her withdrawal in conjunction with phone monitoring from a specialised nutritional supplement company she had found online; Rebecca with her psychiatrist until her therapist stepped in to advocate for a medication review. Karen described several distressing and unhelpful attempts to seek therapy before she found a therapist with an approach and style that fitted for her. A number of participants described having access to private psychiatrists and therapists. Two participants explicitly highlighted the importance of having the financial resources available to allow them the opportunity to choose who they worked with.

Discussion

This qualitative investigation into the experience of successful withdrawal from AM demonstrates that the domains of self-knowledge and understanding, psycho-social skill development and practical strategies for daily living, and support and connection work together to help enable people to maintain their wellbeing during and after discontinuation. Acceptance of distress, flexibility, self-direction, trust, information gathering, and determination were central to these processes. Though other researchers have explored subjective experiences of withdrawal effects, different outcomes, and how people arrive at their decision to resume or discontinue AMs (Geyt et al., 2016; Roe et al., 2009; Salomon & Hamilton, 2013), this represents the first qualitative study exploring how people manage during and after withdrawal.

Participants in this small sample of women defined recovery and wellbeing in terms of their ability to live a meaningful “ordinary life” and manage both their internal experiences of distress and the external stressors they encountered. Mental-health problems, symptoms, early warning signs, distress and life stress were framed as experiences to accept, learn from and move through rather than being mutually exclusive with recovery and wellbeing. This is consistent with other research suggesting service-user priorities extend beyond symptom severity and relapse prevention (Byrne et al., 2010) and the World Health Organisation’s definition of mental health as “a state of wellbeing in

which every individual realises his or her own potential, can cope with the normal stresses of life, can work productively and fruitfully, and is able to make a contribution to her or his community” (World Health Organization, 2016).

The participants in the current sample experienced severe mental-health problems that are often described as requiring life-long maintenance treatment with AMs or other medications (Miller, 2013). In this sample of people who had maintained their wellbeing without AMs for over a year, four used no medications at all for periods ranging 1.25 – 25 years, consistent with the results of prior studies demonstrating some people do well without medication (Harrow & Jobe, 2007). Similar to the results of other discontinuation studies, all participants described periods of symptom exacerbation and many experienced relapses in the years following withdrawal (Zipursky et al., 2014); this appeared to reduce over time as they learned how to understand and cope with their experiences, consistent with the findings of longitudinal research (Harrow et al., 2012). Learning what worked to maintain their wellbeing appeared to require experiencing some symptoms to experiment with. One participant described how she felt like she was learning to “ride” herself and this got easier as she became more experienced with managing. Most of the current group shared this sentiment and described feeling less frightened in response to symptoms when they arose, consistent with other studies showing that reducing the negative appraisals people make about their symptoms correlates with reduced symptom severity (Morrison et al., 2012). As time progressed, people gained more understanding of their needs, and how to meet them and their experiences of distress became less frequent, less frightening and much shorter. Therefore it appears that maintaining wellbeing is a process that unfolds over time as people become more experienced with their responses to the stressors of withdrawal and life beyond, similar to the conclusions made in other studies (e.g., Carrick et al., 2004; Geyt et al., 2016).

For some, AMs remained an option they temporarily turned to when nothing else was working for them. Others have also highlighted that some people willingly return to AMs should they be needed (Geyt et al., 2016; Roe et al., 2009), and have suggested a low threshold for temporarily resuming AMs may assist people in resolving withdrawal-related relapses without hospitalisation (Gitlin et al., 2001). This was a useful strategy for some people in the current investigation. The current results show that additionally, some people were able to resolve relapse and prevent hospitalisation with other strategies alone, supporting the results of other studies (Bola et al., 2009; Morrison et al., 2013). At times resolving relapse and preventing hospitalisation seemed to rest on having a safe space within which people could accept and direct their symptoms and contact with others who could allow them to do this. The responses of others could either exacerbate or reduce the distress people were experiencing as a result of their symptoms. Developing connections with

others who had personal experience of mental-health problems and/or shared their frames of reference appeared to enable participants to fill a gap when their friends, family or clinicians were not able to allow them the space they needed to accept and safely direct symptoms and signs of distress. Recent research has also highlighted the importance of supportive others as a 'safety net' for discontinuation (Geyt et al., 2016).

A complex layering of self-understanding was necessary to maintain wellbeing during and after withdrawal, moving from more objective phenomena such as medication effects, symptoms, behaviours, and triggering events towards more subjective and philosophical dimensions of meaning, interpretation, identity, underlying physical and emotional issues, forgiveness, and meta-cognitive processes of self-reflection. Discovering meaningful frames of reference for making sense of mental-health problems opened space for people to understand what they needed and direct their efforts to cope. Self-understanding could be facilitated by others but also involved self-directed learning and research. Being able to understand withdrawal effects and symptoms of distress, plan how to recognise them, and identify what to do when they appeared helped people to maintain their wellbeing during withdrawal.

While understanding was framed as a necessary facet of maintaining wellbeing, it was insufficient on its own. Participants emphasised the importance of finding alternative strategies to replace AMs. Some had done this deliberately to help themselves discontinue AMs and others had developed them as part of their general aim to "live well." Having strategies to cope with difficult experiences and a flexible approach to using them lent people a sense of being in control of their experiences and capable of coping with any challenge they might face. Other studies have shown that cognitive and coping flexibility are associated with each other and rates of anxiety and depression (Fresco et al., 2006). The current study suggests these dimensions of flexibility are also relevant to people experiencing psychosis and mania. In addition the current group appeared to gain a more internalised locus of control and greater sense of self-efficacy through this process of developing a multitude of coping strategies and supports, and the knowledge that they would be able to use them. This is consistent with other studies demonstrating that poor self-efficacy and past performance contribute to habitual avoidance (Feltz, 1982), among people with psychosis (Ventura et al., 1999), increased experiences of distress and poorer QOL (Hayes et al., 2004). The related dimension of internal locus of control has been shown to make an independent contribution to the long-term recovery outcomes of those who stop taking AMs (Harrow & Jobe, 2007), but the role of self-efficacy and use of coping strategies in maintaining wellbeing during and after withdrawal from AMs has yet to be explored. This investigation indicates future research in this area is warranted.

The current results strongly suggest that being able to accept and direct symptoms of distress rather than suppressing, fighting, denying or avoiding them facilitates the understanding, strategy development and supportive connections that enable people to maintain their wellbeing during and after withdrawal. I argue that coming to self-understanding and developing strategies that work, which were vital to maintaining wellbeing for the participants in this group, would be precluded by an approach to coping focused on suppression, denial or avoidance of symptoms or distress. Similarly, one could not seek and accept support without acknowledging that something was happening. Earlier research has demonstrated the exacerbating effects of suppression and habitual avoidance on the arousal of physical stress responses, attentional vigilance for self-relevant threats (Wegner, Schneider, Carter, White, & Sherman, 1987), associations with mania (Van Rheenen, Murray, & Rossell, 2015) and psychosis (Jansen et al., 1999), reduced interpersonal functioning and emotional wellbeing (Gross & John, 2003). Where poor self-efficacy, suppression and avoidance pose great barriers to wellbeing, the current results show acceptance plays a core role in maintaining wellbeing, in line with the notion that “one cannot leave a place until one has arrived at it” (Greenberg, 2004, p3).

It has been suggested elsewhere that a “strong sense of personal responsibility is the single most important indicator for successful withdrawal” from psychiatric medications (Breggin, 2013, p 138). Consistent with this, the current sample explicitly referenced self-responsibility and self-direction when describing what enabled them to maintain their wellbeing. This did not mean that they managed on their own or saw themselves as responsible for everything. However each person had a commitment to doing what was necessary to take care of their needs, including their need for connection and help. Taking responsibility and seeking support required trust and it also required being trusted by others. When support-seeking was met with worry and discouragement, people described being less likely to reach out to those people. At times it was seen as helpful to be selective about who was involved in providing support for mental-health concerns and withdrawal, given the added distress that unhelpful responses from others could cause. A personal attitude of determination enabled people to persevere through unhelpful support experiences and continue help-seeking until they found what they needed.

The service-user movement has a long history of using the metaphor of a fish struggling on a hook to communicate the idea that experiences of mental-health problems are meaningful when seen in context (Irwin et al., 1972). The behaviour of a fish caught on a hook might appear strange to those who are unaware of the situation, but to those who understand it is clear the struggle is an attempt to escape something painful (Menninger, 1937). Consistent with this, the current investigation suggests accepting and acknowledging the symptoms of one’s struggle, understanding

the context, and developing skills to cope enables people to maintain their wellbeing both during and after withdrawal from AMs. Results further suggest that sometimes people need supportive others to help them understand what is wounding them and discover the tools to 'unhook' themselves from the struggle.

PART THREE
CONCLUSIONS

**CHAPTER EIGHT:
CONCLUDING DISCUSSION**

Summary of Key Findings

This is among the largest of only a few studies to explore the subjective experience of attempted discontinuation in addition to experiences of taking AMs, and is the largest to explore the way in which people cope during and after withdrawal. A survey of 144 people and a small series of in-depth interviews were used to explore experiences of taking AMs and attempts to discontinue them. Consistent with previous research, results show AMs have a wide-range of subjective effects on physical, emotional and psycho-social functioning beyond symptom reduction and adverse effects, and can be experienced overall as a life-saving relief, a useful tool with specific purposes, and/or a disruptive influence, nightmare or form of hell (Carrick et al., 2004; Moncrieff et al., 2009).

The adverse effects and subjective descriptions associated with neuroleptic dysphoria were common among this group, as they are among others (Browne et al., 1998; Moncrieff et al., 2009; Wallace, 1994). The current study supports existing research showing the prescribing process can also be experienced in both positive and negative terms, but often appears to involve a lack of information about the benefits and risks, lack of ongoing responsive consultation, narrow focus on AMs alone and/or an actual or perceived loss of autonomy (Carrick et al., 2004; Cleary et al., 2005; Gibson et al., 2013; Rofail et al., 2009). Lacking information and lost autonomy appear to be more common among those who describe negative OSEs and is associated with experiences of confusion, fear and frustration.

Similar to the conclusions made in other studies, the current investigation suggested that for those who take AMs, recovery is seen in terms of one's ability to function in daily life and AMs are judged in terms of how much they facilitate or inhibit their ability to do that (Carrick et al., 2004; Gibson et al., 2013). While people are rarely offered other options during the prescribing process, for most people AMs are but one of many approaches they use to maintain their wellbeing, in line with the findings of studies conducted in other countries (Carrick et al., 2004; Farrelly, 2002). Study one and Study Two showed many people use non-medication physical-health approaches such as nutrition and exercise alongside additional psycho-social approaches such as therapy, peer support and their own internal coping strategies, while taking AMs, during withdrawal, and following discontinuation.

The survey results support existing research showing it is common for people to attempt to discontinue AMs (Cooper et al., 2005; Lieberman et al., 2005; Rascati et al., 2011), make multiple attempts to do so (Wallace, 1994) and to maintain discontinuation over time (Harrow & Jobe, 2007). This is not the first study to show that people contemplate and attempt discontinuation often. The

current study extends these conclusions to suggest the desire to stop taking AMs is not limited to those with negative experiences alone – people who find AMs beneficial also contemplate and attempt to stop AMs. Decisions about persistence of use are based on evaluations of one's ability to manage wellbeing, not simple reflections of negative attitudes towards medication in general, a lack of insight, or intolerance of side effects. Study one and Study Two demonstrated that it is possible to successfully discontinue for extended periods, sometimes indefinitely. A third of the whole survey sample had discontinued at the time of the study, similar to the stable discontinuation rate reported in a longitudinal study with a cross-sectional design and comparable sample size (Harrow & Jobe, 2007). Half of the 105 survey participants who attempted to stop remained AM-free for a year or more and some people last used AMs over five years ago. Among the interview participants in Study Two, one had remained off AMs for 25 years without using any psychiatric medications. The two studies show withdrawal often entails a lack of information, poor support, and a range of physical, emotional, cognitive, social and functional disruptions that can be difficult to cope with, and which may include exacerbation of symptoms to the point of relapse.

In Study One, a hierarchical multiple regression demonstrated the psycho-social variables of active and avoidant coping, together with social support adequacy independently contributed substantially to prediction of a subjective measure of current QOL, over and above known demographic predictors (i.e., age and occupational status), whereas current AM status did not. Furthermore, content analysis and interview results both showed it is possible for some people to stop AMs long-term and maintain their mental health using only psycho-social and non-medication physical approaches, or a combined approach that includes other psychiatric medications and/or temporary 'PRN' use of AMs on an as-needed basis, when other options are not available or effective. People who successfully discontinue AMs emphasise that maintaining wellbeing during and after the process of withdrawal is a function of coming to understand one's experiences and needs, finding a multitude of strategies and routines that work, connecting with supports, accepting symptoms of distress, and using personal qualities of determination and curiosity to persist through obstacles encountered. This supports the conclusion that active coping makes a positive contribution to QOL and avoidant coping makes a negative contribution. This accords with other studies that have found associations between both objective and subjective measures of QOL and internal and external psycho-social factors among people who take AMs and people who discontinue (Adelufosi et al., 2013; Alonso et al., 2009; Haro et al., 2009; Harrow & Jobe, 2007; Montemagni et al., 2014; Norlelawati et al., 2015; Wunderink et al., 2013).

While the existing literature appears to be in general agreement that occupational status, and social support are positively associated with QOL outcomes for people who take AMs and those

who stop, studies are inconsistent in the conclusions drawn about relationships between persistence of use and QOL. The current results are consistent with studies demonstrating people who stop AMs generally have no better or worse recovery outcomes than those who continue to take AMs (Landolt et al., 2016; Rappaport et al., 1978; Wunderink et al., 2013). There may be sub-groups with better outcomes (Landolt et al., 2016) and accordingly in the current study, the range of QOL outcomes varied from low to high, both among those taking and not taking AMs. This appears consistent with the presence of sub-groups among those who stop who have significantly better and worse subjective QOL outcomes than those who continue. The presence of sub-groups would also help explain why some studies with different sampling methods demonstrate positive relationships between stopping AMs and QOL-related measures of recovery (Adelufosi et al., 2013; Harrow & Jobe, 2007), while others find the opposite (Alonso et al., 2009; Bobes et al., 1998; Giner et al., 2004; Strakowski et al., 2005). However, this study suggests persistence of use does not distinguish those with favourable QOL outcomes from those with poor QOL outcomes. Other more specific medication factors such as dose and polypharmacy, and clinical factors such as symptom severity likely play a role predicting QOL outcomes alongside the psycho-social factors highlighted in this study.

The current results suggest the variation in findings regarding QOL, symptomatic remission, and relapse rates may be a reflection of individual differences rather than solely sampling or measurement error, or differences in medication and clinical factors alone. Other studies also suggest individual differences in internal and external psycho-social resources affect the recovery outcomes of people who take AMs (Haro et al., 2014) and stop taking AMs (Harrow & Jobe, 2007; Landolt et al., 2016; Wunderink et al., 2013), alongside the medication factors that have traditionally been the area of interest. Study one and two together highlight the importance of attending to psycho-social factors, self-reported subjective experiences of AMs, and individual preferences regarding persistence of use and the additional approaches that might be helpful. This is consistent with the existing evidence showing psycho-social approaches to treatment may be associated with improved outcomes when used in addition to AMs (Guo et al., 2010) or as alternatives (Morrison et al., 2013). A synthesis of the available research regarding the impact of premorbid characteristics (Harrow & Jobe, 2007; Landolt et al., 2016) and psycho-social treatments (Guo et al., 2010; Morrison et al., 2013) suggests it is most likely that QOL outcomes and subjective experiences of AMs both influence and are influenced by psycho-social factors alongside physical health, and the medication factors and dimensions of symptom severity that are the usual focus of research regarding AM use and discontinuation.

Implications for Clinical Practice

Given the high rates of AM prescription, it is likely that anyone working in a mental-health setting works with people who take AMs. These results imply it is insufficient for prescribing clinicians to monitor symptoms and adverse effects alone when reviewing the impact of AMs. There is a need to emphasise psycho-social factors and QOL during medication reviews, that is, to consider the person as a whole and in context. People who take AMs also use a range of other approaches and the current study suggests it is important for all clinicians involved in the wider treatment system to explore how their clients experience AMs, beyond the prescribing clinician. AMs can have wide-reaching disruptive effects on people's experience of being able to think clearly, wake up in the morning, get motivated, connect to others and generally function on a day-to-day basis. Even among those who experience benefits most also appear to be managing adverse effects that have at least a slight impact on their daily life. A therapist or key-worker, who understands their clients' subjective experiences of taking AMs and their related long-term goals regarding AMs, will be better able to adapt their approach to resolve any barriers posed.

The current results also strongly support the arguments made by other researchers (Bentall & Morrison, 2002; Breggin, 2013; del Barrio et al., 2013; Moncrieff et al., 2009; Morrison et al., 2012; Tyrer, Jul 2008; Whitaker, 2010), consumer rights legislation (The Health and Disability Commissioner, 1996), and the service-user movement (Campbell & Roberts, 2009; Gawith & Abrams, 2006; Irwin et al., 1972; Survivors History Group, 2016), that people should have the choice to take AMs or not take them, the choice to change their minds later, and all the information required to make choices that are safe and have the best possible outcome for their quality of life. The finding that most people attempt to stop taking AMs implies most people taking AMs would be unlikely to have their needs met by a treatment system focused solely on medication, supporting the recommendations made in the British Psychological Society's recent guidelines for promoting recovery from psychosis (BPSDCP, 2014). This study also found that many people view AMs as at least slightly helpful and some experience them entirely positively, which in turn implies that most people would be unlikely to have their needs met by a treatment system focused solely on non-medication approaches. While those who are happy to take AMs appear to have their needs met in that regard, those who would like to stop taking AMs or who would prefer not to start them at all, appear to be less well-served. Expanding on other research regarding the impact of adverse effects (Mihanović et al., 2010), Study One showed both taking AMs and attempting discontinuation can be associated with suicidality for a small group, which further underscores the importance of providing other options and support to stop safely.

Interview results highlight prescribing clinicians can be important sources of information about what to expect from withdrawal, how to plan and adjust the taper over time, and what might be needed to cope. They could also serve as a check-point during the process to address any limitations in self-awareness that might occur during withdrawal-related relapse. However, survey results suggest this rarely takes place. Many people proceed with their attempts without their doctor's support or despite active discouragement, and rely on their own information-seeking and additional supports alone, with variable outcomes. Given it was possible to stop long-term and maintain wellbeing without AMs this study suggests it is warranted and necessary for treatment systems to support people to discontinue AMs if they choose and to make that choice safely and with the least amount of distress possible. The results of the interviews suggest that such support should extend to dimensions of understanding self and identifying needs, strategies for coping and building resilience, strengthening social connections, acceptance of distress, and developing persistence and curiosity. Again, the results imply a role for clinicians from wider treatment systems in sharing information and strategies to empower people to develop the capacities to maintain their wellbeing.

Where the body of literature appears to frequently become stuck in a debate for or against the use of AMs, the conclusions of the present research imply the reality is far less black-and-white and much more complex for those who actually take AMs. While some people do stop taking AMs without any intention of returning to use them again, many people who stop find a place for taking AMs when none of their own internal or external strategies are working to keep them feeling in control of their experiences and able to function in life. Other qualitative studies suggest the psycho-social and physical-health strategies that were reported to be helpful during and after withdrawal, may also help people cope with the adverse effects of taking AMs (Meehan et al., 2011) and the symptoms for which they are prescribed (Rogers et al., 1998). This supports the implication that empowering people to strengthen their internal and external psycho-social resources would potentially improve the overall recovery outcomes of those who take AMs as well as those who wish to stop taking them.

The results also suggest that where clinicians are not willing to provide this support, many people construct it for themselves in the self-directed pursuit of their personal recovery goals. This highlights the ongoing agency of people who take AMs and the need for clinicians to adopt a person-centred approach guided by the individual's recovery goals rather than systems focused purely on monitoring symptoms and promoting persistence of use. This study concurs with other research to show that simply directing people back to their prescribing doctor is often insufficient in either discouraging discontinuation or ensuring a safely managed withdrawal method (Read, 2005).

Results also suggest the need for services specifically set up with the aim of supporting safe withdrawal, particularly in circumstances where the individual's wider social environment acts as a barrier. Such services are available elsewhere (Arizona Alternative to Meds Centre, 2016). In lieu of this, several books (Breggin, 2013; Hall, 2012; Lehman, 2002) and electronic resources (Cassani, 2016; Darton, 2013; Lee, 2010; Mackler, 2013; May et al., 2016; The Icarus Project, 2015) are now available, which may assist clinicians and clients to plan a safe withdrawal method and prepare to manage the process. All clinicians who work with people who take AMs are in a position to share these sources of information with people considering discontinuation.

Limitations

The survey and interviews involved relatively small samples, with different characteristics than those reported elsewhere. People residing within inpatient units and those without internet access were unable to participate. The sample was predominantly educated and employed, which suggests those with favourable objective outcomes and/or premorbid characteristics may have been over-represented in this study, in comparison to population-based studies of AM use among people with psychosis (Morgan et al., 2012). Furthermore, an over-representation of women and people of NZ-European ethnicity means results may neglect areas of specific relevance to men, people with other gender identities, and those from other ethnic groups.

The cross-sectional design may additionally limit the generalisability of results regarding prescription experiences to current populations. However, those who were currently taking AMs and those who stopped reported a similar range of initial and ongoing prescribing experiences suggesting that the historic nature of some reports was not a major factor influencing the findings. The current results were consistent with much of the existing research but this sample reported discontinuation rates towards the higher end of the range published in the literature (Lieberman et al., 2005; Peuskens et al., 2009; Rascati et al., 2011), and higher rates of polypharmacy (Waterreus et al., 2012; Wheeler et al., 2006). The former is likely a reflection of the inclusion of people who were no longer currently taking AMs and are usually excluded from other studies; the latter may be related to the inclusion of people who were taking AMs a long time ago; studies of prescription patterns suggest rates of polypharmacy may change over time (Edlinger et al., 2005; Gilmer, Dolder, Folsom, Mastin, & Jeste, 2007; Nielsen, Le Quach, Emborg, Foldager, & Correll, 2010). In the current study polypharmacy was just as common among those who were currently taking AMs, as those who had previously taken them. An imbalance in the number of people in each of the CAMS and occupational status sub-groups and heteroscedasticity within the BMLSS scores of the occupational status sub-groups used in the Study One regression and this may have exerted an influence on the results.

This study used self-report measures to explore the experience of taking AMs and attempting to stop them, in context with the other approaches people use. The regression presented in Chapter Six, therefore relies on participants' subjective self-assessments, and it is unknown whether wholly objective clinician-rated measures would yield the same results. The model did not test which components of QOL were predicted by occupational status, perceived adequacy of social support, or coping; their impact may be limited to satisfaction with the relevant domain of QOL or extend across multiple domains. The current results were largely consistent with the existing research with the primary difference being conclusions regarding the presence of a predictive relationship between AM use and QOL measures, and the positive or negative direction of that relationship. Other studies have used a similar approach and found similar results to those found here, including evidence to support the conclusion that there are sub-groups who have different experiences and outcomes (Harrow & Jobe, 2007; Landolt et al., 2016).

However, the use of different QOL measures limits the confidence with which we can meaningfully interpret the similarities and differences observed between study results. The BMLSS used in the current study explores satisfaction with family, friends, work, self, living situation, financial situation, health situation, future prospects, and life in general, but does not include items for symptoms, relapse and rehospitalisation, or objective dimensions of QOL as do the measures used by other studies with potentially comparable results (European QOL Questionnaire - Haro et al., 2014; Levenstein-Klein-Pollack scale - Harrow & Jobe, 2007; Manchester Short Assessment of QOL - Landolt et al., 2016; WHOQOL-BREF - Wunderink et al., 2013). Similar limitations and considerations apply to comparisons of measures of coping and social support, particularly given the novel manner of arriving at composite scores for active and avoidant coping in the current investigation. A previously established predictive relationship between BMLSS scores and relationship status, symptoms of depression, physical health conditions, and health-related QOL (Büssing et al., 2009), lends some cautious confidence to comparisons with the existing literature and the conclusion that the results are a reliable reflection of the relationship between the participants' outcomes and their psycho-social resources.

A final major limitation of the current study is the lack of measures for symptom severity and a range of medication factors known to play a role in both subjective experiences and QOL outcomes. AM dose, duration of continuous treatment, concurrent polypharmacy and continuing use of other medications after stopping AMs may affect subjective experiences and QOL outcomes (Adelufosi et al., 2013; Hamilton et al., 1998; Haro et al., 2014), and were not included as possible predictors in the regression model. Furthermore, some research suggests the QOL improvements associated with taking AMs may peak at six months and then plateau (Alonso et al), and that initial

increases in symptomatic relapse among those who stop reduce over time to match the relapse rates of those who persist, (Wunderink et al., 2013), and continue to improve over the long-term (Harrow & Jobe, 2007; Harrow et al., 2012). Thus the timing of data collection in respect to participant's duration of use and time off AMs may also play a role in the outcomes observed. The current sample includes people who had variously taken and stopped taking AMs for different lengths of times. These missing variables may account for some of the variation observed in subjective experiences and QOL satisfaction of those who take and those who stop taking AMs. The predictive model presented here showed that in the current sample, age, occupational status, coping, and social support accounted for just over half of the variance in subjective QOL, independent of current AM status. The non-representational nature of the current study can only suggest possibilities in the range of experiences and the relationships observed between variables among this group of people. The observational nature of the study further means any claims about the direction of the relationships observed are purely hypothetical.

Future Research

Future research is needed to replicate these results with a larger, representative sample and explore how issues of symptom severity, dose, timing, and polypharmacy influence relationships between QOL outcomes and psycho-social variables like coping, social support and occupational status, both among those who take AMs and those who stop taking them. The use of subjective measures of QOL means future research is required to explore whether the results hold when objective measures are included such as number of social supports, relationship status, and life achievements. Further research is also needed to investigate whether the contributions of these psycho-social variables are limited to specific QOL domains or extend beyond this.

Results regarding attempted discontinuation highlight a need for future research exploring whether discontinuation outcomes are significantly predicted by instrumental support for withdrawal, personal coping efforts, the duration of AM treatment, the time taken to withdraw, and the use of temporary medication strategies to manage rebound symptoms. There is scarce research available on the effectiveness of non-medication physical approaches to recovery such as nutrition and exercise, but a substantial number of people in the current sample used these approaches and they also seem to warrant further research alongside the use of psycho-social approaches. Among the additional approaches explored in this study, all were helpful to most and unhelpful to some; interview results suggested issues of timing, trust, and autonomy may affect how additional approaches are experienced. Further research is needed to help tease out what internal and external factors influence the helpfulness of the potential additions and alternatives to AMs.

Few studies exploring AM outcomes have accounted for a possible influence of the individual's own internal resources, the perceived adequacy of their social supports or use of other approaches, and much of the research has limited its assessment of the outcomes to measures of symptom severity and relapse rates without addressing the psycho-social dimensions of daily functioning and a meaningful life, or the individuals' personal definition of recovery. The current results show these are important to people who take AMs and have modest, independent relationships with their recovery outcomes. This implies future research into AM outcomes should account for the influence of internal and external psycho-social factors on symptom severity, relapse and QOL outcomes, in addition to exploring the effect AMs have on those dimensions. Because RCTs do not control for the influence of psycho-social variables such as coping, there is no way to know that the results previously reported are directly related to the AM being trialled, or the effect of these unmeasured and potentially confounding factors. The current study suggests recovery is an interconnected bio-psycho-social process enacted by autonomous people seeking to enhance their experience of life within the constraints of their circumstances, and that AMs are almost always only one part of the bio-part of that equation. Future research regarding AMs should consider them against the wider context within which they are used and extend this context to the internal characteristics of the people involved.

Final Remarks

Much of the existing research regarding the subjective experiences and QOL outcomes associated with taking AMs and attempting discontinuation focuses on medication factors over psycho-social variables and external over internal dimensions. This mixed-methods study revealed a range of subjective experiences consistent with other studies showing high rates of dysphoria, experiences of AMs as life savers and hell, and suggesting dimensions of autonomy and informed choice have a substantial effect. A major conclusion is that AMs have both positive and negative subjective effects on almost every facet of daily life from physical health to emotional and psycho-social functioning. The descriptive data revealed a subgroup of people who manage well with AMs and a subgroup who manage well without AMs. The results also revealed subgroups of people who experience difficulty and distress when taking AMs and attempting to stop. These are not always mutually exclusive groups. Furthermore, current use of AMs does not appear to be independently predictive of QOL outcomes and it appears other factors may differentiate sub-groups better than persistence of use. For most people AMs are one of many strategies used to maintain wellbeing, and this was true for those who continue and those who stop. Developing the psycho-social and physical-health capacity to maintain wellbeing is important to the recovery outcomes of those who take and stop taking AMs. Active coping, avoidant coping, and social support make modest,

independent contributions to satisfaction with QOL and may represent important ways in which people can influence their outcomes while taking AMs and after they stop. These dimensions may also represent important ways in which other people can facilitate the outcomes of people who take AMs and those who would prefer to stop.

Finally, contemplating and attempting to stop taking AMs were among the most commonly reported experiences in this study. Much of the existing research regarding discontinuation regards this as “non-compliance” and focuses on identifying who is non-compliant, and how to increase compliance. This has created a body of literature interwoven with unspoken assumptions that those who stop are lacking insight or self-awareness, have a negative attitude to medications, and are predetermined to experience poorer outcomes. Sharing results and approaching treatment using a deterministic framework of compliance obscures the wider context within which AMs are used and upon which they have an effect along with the agency and actions of the people who use them. It is often argued that symptoms of mental-health problems are meaningful signs of struggle when seen in context (BPSDCP, 2014). Nearly eighty years ago Karl Menninger, who inspired the opening statement in the MPU’s famous Fish Pamphlet (Irwin et al., 1972), emphasised how a person’s “struggles are all that the world sees and it usually misunderstands them. It is hard for a free fish to understand what is happening to a hooked one,” (Menninger, 1937, p3). This particularly applies to experiences with taking and stopping AMs, where the individual’s situation may be complicated by the unseen effects of the medication and its withdrawal, which can be wide-reaching.

Understanding subjective experiences reveals the wider context within which AMs have their effect and the meaningful reasoning behind the treatment decisions of those who use them and those who attempt stop. The current study joins a small but growing body of research supporting a shift towards vocabularies of informed choice and treatment systems that approach people who take (and stop taking) AMs as autonomous agents operating in the bio-psycho-social nature of their experiences. The participants I met through these two studies were not simply passive recipients of biologically determined symptoms, relapses or periods of recovery. AMs and the systems that surround them could both help and hinder people in their journey towards recovery. As with any journey, allies and contextual conditions were important and could at times be found wanting. But people were the protagonists and the narrators of their own stories.

My motivations for this research trace back to experiences of sitting up late in a residential facility with service-users who were distressed by hallucinations despite being on large doses of AMs. My passage through the literature suggests it is possible those large doses contributed to the chronicity of their symptoms. I wish I had done more to advocate for reductions and alternative options. People seeking to recover from severe mental-health problems like psychosis “need the

encouragement and support of an ally and an advocate, rather than the distanced and dispassionate insights of a neutral observer” (Davidson, 2011, p108). This is especially true for people taking AMs. The results suggest something important was unfolding in those informal, late-night support sessions, where expressions of extreme distress were met with an attitude of acceptance, encouragement to talk, and a shared activity of comfort. In those moments, initial help-seeking attempts evolved into further experiences of active coping and connection, rather than being immediately suppressed with an additional dose of medication. In that sense perhaps the most important work I did there took place with the simple act of making people a cup of tea and creating space for them to give voice to their internal worlds and the stories that sit behind them. I believe we can learn a great deal from the 144 AM stories shared by the participants in this research. Their over-riding collective message seems to be that AMs are only ever part of the recovery tool-box and treatment systems must look beyond symptom management to the areas of life that matter most to the person walking the journey.

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APPENDIX ONE: THE EXPERIENCES OF ANTIPSYCHOTIC MEDICATION SURVEY

THE EXPERIENCES OF ANTIPSYCHOTIC MEDICATION SURVEY

(Please note: This survey was placed on Survey Monkey)



Welcome to *The Experiences of Antipsychotic Medication Survey*. This survey is in 4 parts and usually takes 30 – 45 minutes to complete. Not all questions will be relevant to you, so the time taken to complete the survey will be different for each person. Some questions may seem repetitive. Please answer these questions anyway. If you do not remember something, you can select or write 'I don't remember' and carry on to the next question.

1. I confirm that I fit all of the criteria in the following list:

- a. I have been taking or have previously taken an oral antipsychotic medication continuously for at least three months for any reason (such as Olanzapine, Risperidone, Clozapine, Quetiapine, Haloperidol etc).
- b. I am aged 18 or older
- c. I live in New Zealand
- d. I am not currently experiencing acute symptoms
- e. I am living in the community: i.e. you are not staying in an inpatient unit at the current time

Yes / No

Part 1. CURRENT INFORMATION

The first part of this survey is about your current situation.

2. Gender _____

3. Age _____

4. Ethnicity _____

5. Level of Education (please check one):

- Did not complete high school
- Completed high school
- Diploma/certificate after high school
- University degree

6. Approximate Annual Personal Income

- Under \$10,000
- \$10,001 - \$20,000
- \$20,001 - \$30,000
- \$30,001 - \$50,000
- \$50,001 or more

7. Occupational Status

- Employed part time
- Employed full time
- Student
- Unemployed
- Other:

8. What is your occupation?

9.								
<p>The following questions ask about your current satisfaction with different areas of your life. Circle the best answer for each.</p> <p>I would describe my satisfaction with ...</p>		very dissatisfied	dissatisfied	mostly dissatisfied	(equally satisfied and dissatisfied)	mostly satisfied	satisfied	very satisfied
H1	... my family life as...	0	1	2	3	4	5	6
H2	... my friendships as...	0	1	2	3	4	5	6
H3	... my work life as...	0	1	2	3	4	5	6
H4	... myself as ...	0	1	2	3	4	5	6
H5	... where I live as...	0	1	2	3	4	5	6
H6	... my overall life as...	0	1	2	3	4	5	6
H7	... my financial situation as...	0	1	2	3	4	5	6
H8	... my future prospects as ...	0	1	2	3	4	5	6
G1	...my health situation as ...	0	1	2	3	4	5	6
G3	...my abilities to cope with everyday life as ...	0	1	2	3	4	5	6

10. We are interested in how you feel about the following statements. Read each statement carefully. Indicate how you feel about each statement.

Select "1" if you Very Strongly Disagree

Select "2" if you Strongly Disagree

Select "3" if you Mildly Disagree

Select "4" if you are Neutral

Select "5" if you Mildly Agree

Select "6" if you Strongly Agree

Select "7" if you Very Strongly Agree

1. There is a special person who is around when I am in need. 1 2 3 4 5 6 7
2. There is a special person with whom I can share my joys and sorrows. 1 2 3 4 5 6 7
3. My family really tries to help me. 1 2 3 4 5 6 7
4. I get the emotional help and support I need from my family. 1 2 3 4 5 6 7
5. I have a special person who is a real source of comfort to me. 1 2 3 4 5 6 7
6. My friends really try to help me. 1 2 3 4 5 6 7
7. I can count on my friends when things go wrong. 1 2 3 4 5 6 7
8. I can talk about my problems with my family. 1 2 3 4 5 6 7
9. I have friends with whom I can share my joys and sorrows. 1 2 3 4 5 6 7
10. There is a special person in my life who cares about my feelings. 1 2 3 4 5 6 7
11. My family is willing to help me make decisions. 1 2 3 4 5 6 7
12. I can talk about my problems with my friends. 1 2 3 4 5 6 7

11. These items deal with ways you currently cope with things that are stressful, distressing or challenging. There are many ways to try to deal with problems. These items ask what you do to cope with things at the current time. Obviously, different people deal with things in different ways, but we are interested in how you try to deal with things. Each item says something about a particular way of coping. We want to know how much or how frequently you did what the item says in the previous two weeks. Don't answer on the basis of whether it seemed to be working or not—just whether or not you were doing it in the previous two weeks. Try to rate each item separately in your mind from the others. Make your answers as true FOR YOU as you can.

Please use these response choices.

1 = I didn't do this at all

2 = I did this a little bit

3 = I did this a medium amount

4 = I did this a lot

1. I turned to work or other activities to take my mind off things. 1 – 2 – 3 – 4
2. I concentrated my efforts on doing something about the situation I'm in. 1 – 2 – 3 – 4
3. I said to myself "this isn't real". 1 – 2 – 3 – 4
4. I used alcohol or other drugs to make myself feel better. 1 – 2 – 3 – 4
5. I got emotional support from others. 1 – 2 – 3 – 4
6. I gave up trying to deal with it. 1 – 2 – 3 – 4
7. I took action to try to make the situation better. 1 – 2 – 3 – 4
8. I refused to believe that the difficulty was happening. 1 – 2 – 3 – 4
9. I said things to let my unpleasant feelings escape. 1 – 2 – 3 – 4
10. I got help and advice from other people. 1 – 2 – 3 – 4
11. I used alcohol or other drugs to help me get through it. 1 – 2 – 3 – 4
12. I tried to see it in a different light, to make it seem more positive. 1 – 2 – 3 – 4
13. I criticised myself. 1 – 2 – 3 – 4
14. I tried to come up with a strategy about what to do. 1 – 2 – 3 – 4
15. I got comfort and understanding from someone. 1 – 2 – 3 – 4
16. I gave up the attempt to cope. 1 – 2 – 3 – 4
17. I looked for something good in what was happening. 1 – 2 – 3 – 4
18. I made jokes about it. 1 – 2 – 3 – 4

- 19. I did something to think about it less, such as going to movies, watching TV, reading, daydreaming, sleeping, or shopping. 1 – 2 – 3 – 4
- 20. I accepted the reality of the fact that the difficulties were happening. 1 – 2 – 3 – 4
- 21. I expressed my negative feelings. 1 – 2 – 3 – 4
- 22. I found comfort in religion or spiritual beliefs. 1 – 2 – 3 – 4
- 23. I tried to get advice or help from other people about what to do. 1 – 2 – 3 – 4
- 24. I practiced learning to live with it. 1 – 2 – 3 – 4
- 25. I thought hard about what steps to take. 1 – 2 – 3 – 4
- 26. I blamed myself for what I was experiencing. 1 – 2 – 3 – 4
- 27. I prayed or meditated. 1 – 2 – 3 – 4
- 28. I made fun of the situation. 1 – 2 – 3 – 4

12. What additional approaches have you used and how helpful have you found them?

	1. Not Used	2. Used and Not Helpful	3. Used and Slightly Helpful	4. Used and Moderately Helpful	5. Used and Very Helpful	6. Used and Extremely Helpful
Individual therapy or counseling						
Relationship/family therapy						
Drug and/or alcohol counseling						
Support group						
Community support worker						
Cultural support						
Peer Support Worker						
'Green Prescription' / exercise options						
Nutrition and dietary changes						
Vitamins/nutritional supplements						
Herbal remedies						
Meditation practices						
Respite service						
Other (please state)						

13. There are many theories, and lots of debate, about what causes mental-health problems.

What do you think caused the experiences for which you received antipsychotic medication?

Part 2. THE PRESCRIBING PROCESS

1. Have you ever taken an oral antipsychotic medication continuously for longer than 3 months?

Yes/No (No = exit screen)

2. Are you still taking oral antipsychotic medication? Yes/No

3. What experiences were you having that led you to being prescribed antipsychotic medication:

- Hallucinations
- Delusions
- Mania
- Depression
- Other: Please describe:

4. Approximately when did you first start experiencing these things?

Year: _____ or Don't Remember

5. Were you ever given any formal diagnoses? Yes/No

If yes, Q6, if No, Q8

6. What were the diagnoses you were given?

7. In what year did you *first* begin taking anti-psychotic medication? _____

If you were first prescribed antipsychotic medication a long time ago, you might not remember all of the finer details about the initial prescription process, but you might still remember some of your main experiences. If you don't remember, please select or write 'I don't remember' and move on to the next question.

8. Were you under a compulsory treatment order at the time that you were first prescribed antipsychotic medication? Yes/No/Don't Remember
9. Please finish this sentence. For me, the experience of first being prescribed antipsychotic medication was...
10. How well informed of the benefits and risks of antipsychotic medication do you remember being when you were first prescribed them?
- Not at all informed
 - Slightly informed
 - Moderately informed
 - Well informed
11. What possible positive effects or benefits do you remember being told about?
12. What possible side effects or risks do you remember being told about?
13. Were you offered any other treatment options to consider as alternatives or additions to antipsychotic medication? Yes/No/Don't Remember
If yes, Q14, what options; If No/Don't Remember, Q15, expected duration
14. What other options were you offered?
15. When you started taking antipsychotic medication, how long were you told you could expect to take it for?
- A. About a month
 - B. 1 – 3 months
 - C. 4 - 6 months
 - D. 7 - 12 months
 - E. more than a year
 - F. the rest of your life
 - G. until you felt better
 - H. other

16. Were you informed of how you would know when to stop taking antipsychotics medication?

Yes/No/Don't Remember

17. If yes, what were you told?

18. Overall, how satisfactory was the *initial* prescribing process for you?

1. Not at all satisfactory
2. Not satisfactory
3. Not sure
4. Satisfactory
5. Very satisfactory

19. What was the *ongoing* prescribing process like for you?

20. Have you ever received an antipsychotic medication *injection* on a regular basis? Yes/No

If No, go to Part 3, Experiences of Taking Antipsychotic Medication.

21. Do you currently receive an antipsychotic medication *injection* on a regular basis?

Yes/No

22. Did you receive the antipsychotic injection *at the same time* as taking an oral antipsychotic medication? Yes/No

23. In your experience, was the antipsychotic injection more or less helpful than the pills?

- More helpful than the pills
- No more or less helpful than the pills
- Less helpful than the pills

Part 3. YOUR EXPERIENCE OF ANTIPSYCHOTIC MEDICATION

The following section is interested in your most recent or current experiences of taking antipsychotic medication.

1. When were you most recently taking oral antipsychotic medication on a regular basis?

- Taking at the current time
- In the last year
- 2 years ago
- 3 – 5 years ago
- More than 5 years ago

When answering the questions in this section, please think about your most recent experiences of taking the medication. If you were taking antipsychotic medication a long time ago, you might not remember all of the finer details, but you might still remember some of your main experiences. If you don't remember, please select or write 'I don't remember' and move on to the next question.

2. What is the name of your current or most recent anti-psychotic medication (if you know)

_____ | I Don't Know | I Don't Remember

3. What dose were you / are you on? _____ | I Don't Know | I Don't Remember**4. What other medications for mental health (tablets and injections) were you or are you taking at the same time? _____ | I Don't Know | I Don't Remember****5. Please complete this sentence or paragraph. In my life, antipsychotics have been ...****6. How helpful would you say the antipsychotic medication was?**

- 1. Very unhelpful
- 2. Somewhat unhelpful
- 3. Unsure
- 4. Somewhat helpful
- 5. Very helpful

7. While taking anti-psychotic medication my quality of life was/is:

1. A lot worse
2. Slightly worse
3. Unchanged
4. Slightly improved
5. Greatly improved

8. What were the benefits of taking antipsychotic medication for you?**9. What were the disadvantages of taking antipsychotic medication for you?** Please use the 'other' option to describe any disadvantages that are not included in the list of options.

- Drowsiness, feeling tired, sedation
- Dizziness
- Loss of motivation
- Feeling not like myself
- Emotional numbing
- Hypertension
- Increased appetite
- Weight gain
- Dry mouth
- Tremors
- Loss of sex drive
- Diabetes
- Suicidality
- Withdrawal effects
- Health problems: Please state
- Other: (please state)

10. How much is your everyday life affected by the problems you experience as a result of the antipsychotic medication you take?

0. Not at all
1. Mildly
2. Moderately
3. Severely

11. When taking antipsychotic medication do you or did you always take the antipsychotic medication exactly as prescribed? Yes/No/ I Don't Remember

If yes, or don't remember, please go to Q14 other comments. If No, go to Q12, type of changes.

12. What kinds of changes do/did you make? Select as many as apply.

- Taking medication less often or in smaller doses than prescribed
- Taking medication more often or in larger doses than prescribed
- Taking the same amount but at a different time than prescribed
- I don't remember

13. What are the main reasons why you don't/didn't always take the medication exactly as prescribed?

14. Is there anything else you would like to say, or emphasise, about your experiences with antipsychotics?

15. Have you ever thought about stopping your antipsychotic medication altogether?

Yes/No

If yes, go to Q16, if No, go to completion screen.

16. Have you ever tried to stop taking antipsychotic medication?

Yes/No

If Yes, go to Part 4. If No, go to completion screen.

Part 4. YOUR EXPERIENCE OF ATTEMPTED DISCONTINUATION

Part 4 of The Experiences of Antipsychotic Medication Survey is for people who have previously tried to stop taking antipsychotic medication. There are 20 questions in this section.

1. How many times have you tried to stop taking antipsychotic medication altogether?

2. Approximately how old were you when you FIRST attempted to stop taking medication?

3. Approximately how old were you when you MOST RECENTLY attempted to stop taking medication?

If you have made more than one attempt to stop taking antipsychotic medication, please think about your most recent attempt when answering the following questions. If your most recent discontinuation experience was a long time ago, you might not remember the finer details. Just do your best and if you don't remember, select 'I Don't Remember' and move on to the next question.

4. What were your main reasons for wanting to stop taking antipsychotic medication? Select all that apply. Please use the 'other' option to describe any of your main reasons that are not included in the list of options.

- Felt better and thought I didn't need it
- The medication was not helping
- Wanted to solve the problem without medication
- Medication caused unpleasant side effects
- Afraid that would get dependent on the medication
- I worried about the long-term effect on my physical health
- I don't remember
- Other reasons; please describe

5. What else do you have to say about your reasons for wanting to stop taking antipsychotic medication?

6. How did you go about withdrawing from antipsychotic medication?

- A: I slowly reduced my dose over a period of time before stopping entirely*
- B: I stopped taking the medication abruptly all in one go
- C: I don't remember
- D: Other

If A, go to Q7, if B/C/D, go to Q8.

7. Approximately how long did it take you to reduce to no medication?

8. Did you make any preparations for your attempt to stop taking antipsychotic medication?

Yes/No

If yes, go to Q9, if No, go to Q10

9. What, if any, preparations did you make for your attempt to stop taking antipsychotic medication? Please select all that apply.

- I tried to gather information about coming off antipsychotic medication
- I made a plan for gradual withdrawal before making any changes
- I informed friends of my plans and what to expect
- I informed my family, partner or spouse of my intentions and/or how I wanted them to support me.
- I stopped or reduced taking drugs
- I stopped or reduced drinking alcohol
- I arranged a safe, quiet place to go in case the need arose
- I got into a regular sleeping pattern
- I reduced the stress in my environment
- I took time off work or away from study
- I created an advanced directive with a plan for how I wanted to handle relapse if it happened
- I learned meditation
- I started seeing a counsellor, psychologist or psychotherapist to help me manage my experiences during withdrawal
- I joined a support group
- I made sure I had a stable, regular routine
- I don't remember
- Other...

10. Did you consult with a doctor before stopping your medication regime?

Yes/No/I Don't Remember

11. What advice or information do you remember finding or being given about coming off antipsychotic medication? _____ | I Don't Remember**12. What were the effects of withdrawing from the medication?**

- 13. What did you do to cope with the unwanted effects of withdrawing from the medication?**
- 14. Did you ever briefly resume taking the antipsychotic medication or increase the dose again to control the side effects of coming off the medication? Yes/No**
- 15. What support did you have for your attempt to stop taking antipsychotic medication?**
- 16. What strategies and supports did you find most helpful in your attempt to stop taking antipsychotic medication and why?**
- 17. What strategies and supports did you find unhelpful in your attempt to stop taking antipsychotic medication and why?**
- 18. What was the outcome of your attempt to stop taking antipsychotic medication?**
- 19. What else would you like to share about the experience of coming off antipsychotics?**
- 20. How long did you stay off antipsychotic medication for, the last time you attempted to discontinue?**
- A: Less than a month
 - B: 1 – 6 months
 - C: 6 – 12 months
 - D: More than a year*

ENDS

Completion Message

*Respondents who select option D on Question 20 are shown the alternate completion message inviting expressions of interest in Study Two.

APPENDIX TWO: STUDY TWO INTERVIEW SCHEDULE

1. GENERAL INFORMATION

Gender identity _____ Age _____

Ethnicity _____ Sexual Orientation _____

Occupation _____ Diagnosis _____

Primary Symptoms _____

Age of onset _____

Age started AMs _____

Age stopped AMs _____

2. Medication Factors

What was your medication regime before you decided to stop taking antipsychotic medication?

3. Specific Preparations

What preparations did you make to discontinue antipsychotic medication?

How did you know to do that? What enabled you to do that?

4. Withdrawal Method and Withdrawal Effects

How did you go about withdrawing the AM?

What effects did you notice as you started to withdraw from the medication?

5. Coping Strategies

How did you cope with the effects of withdrawing from the medication?

How did you know to do that? What enabled you to do that?

6. Medication Strategies

How did you use medication to help you manage the effects of withdrawing?

How did you know to do that? What enabled you to do that?

7. Social Support

What sources of social support did you have available during your discontinuation attempt?

How did you use them? What enabled you to do that?

8. Clinical Support

What kinds of clinical support did you have during your discontinuation attempt?

How did you use them? What enabled you to do that?

9. Outcomes

What were the outcomes of stopping antipsychotic medication for you?

How do you manage things now? What enables you to do that?

How do you define recovery for yourself?

How would you rate your current recovery outcome on a scale from 1-5, where 1 is the worst it could be and 5 is the best it could be?

APPENDIX THREE: ADDITIONAL TABLES

Table 5.2. Composition of the Overall Subjective Experience Sub-Groups

Supplementary measures	Overall Subjective Experiences of AMs ^a		
	Positive (n 53) Count (%)	Mixed (n 45) Count (%)	Negative (n 42) Count (%)
Primary initial symptoms			
Hallmark symptoms of mania and/or psychosis	42 (79.2%)	34 (75.6%)	37 (88.1%)
No hallmark symptoms of mania or psychosis	11 (20.8%)	11 (24.4%)	5 (11.9%)
Age Started AMs ^c			
Under 18 Years	4 (7.6%)	7 (15.6%)	5 (11.9%)
18-29 Years	22 (41.5%)	22 (48.9%)	22 (52.4%)
30-39 Years	11 (20.8%)	11 (24.4%)	9 (21.4%)
40-49 Years	9 (17.0%)	3 (6.7%)	5 (11.9%)
50-65 Years	7 (13.2%)	1 (2.2%)	0 (0%)
Compulsory Status			
Yes Compulsory First Script	11 (20.8%)	10 (22.2%)	14 (33.3%)
Level of Information about Benefits and Risks ^c			
Not At All Informed	14 (26.4%)	12 (26.7%)	20 (47.6%)
Slightly Informed	10 (18.9%)	18 (40.0%)	10 (23.8%)
Moderately - Well Informed	23 (43.4%)	9 (20.0%)	10 (23.8%)
Offered Additional Options	17 (32.1%)	16(35.6%)	6 (14.3%)
Subjective First Prescription Experiences ^b			
Positive First Script	20 (37.7%)	7 (15.6%)	5 (11.9%)
Negative First Script	17 (32.1%)	26 (57.8%)	29 (69.0%)
Mixed Script	11 (20.8%)	8 (17.8%)	5 (11.9%)
Subjective Ongoing Prescription Experiences ^b			
Positive Ongoing Prescription	24 (45.3%)	11 (24.4%)	7 (16.7%)
Negative Ongoing Prescription	12 (22.6%)	18 (40.0%)	18 (42.9%)
Mixed Ongoing Prescription	8 (15.1%)	10 (22.2%)	7 (16.7%)
Perception of Effects			
Perceived Slightly – Greatly Helpful	51 (96.2%)	32 (71.1%)	10 (23.8%)
Perceived Slightly – Greatly Improved QOL	52 (98.1%)	33 (73.3%)	13 (31.0%)
Impact of Adverse Effects on Daily Life			
Not At All	11 (20.8%)	6 (13.3%)	7 (16.7%)
Mild-Moderate	39 (73.6%)	36 (80.0%)	18 (42.9%)
Severe	3 (5.7%)	4 (8.9%)	17 (40.5%)
Persistence of use			
Thought of Stopping	33 (62.3%)	38 (84.4%)	39 (92.9%)
Tried to Stop	31 (58.5%)	37(82.2%)	35 (83.3%)
Currently Discontinued	9 (17.0%)	19 (42.2%)	24 (57.1%)

A cross-tabulation showing the composition of the OSE sub-groups. Tests for statistically significant differences between OSE sub-groups were not carried out. (a) Four participant comments could not be coded into positive, negative and mixed OSE categories, and (b) comments that could not be coded into positive, negative and mixed prescription categories are excluded from this table. (c) Don't Know and Don't Remember responses are excluded from the table. 16 people did not remember the level of information they received. Totals do not equal 100%.

Table 7.3. Summary of the Hierarchical Multiple Regression Model for Predicting QOL^d

Model	R	R ²	Adjusted R ²	Std. Error of the Estimate	Change Statistics				
					R ² _{Change}	F _{Change}	df1	df2	Sig. F _{Change}
1	.469 ^a	.220	.209	16.719	.220	19.853	2	141	.000
2	.470 ^b	.221	.204	16.768	.001	.179	1	140	.673
3	.737 ^c	.544	.524	12.972	.323	32.302	3	137	.000

(a) Predictors: Occupational Status, Current Age. (b) Predictors: Occupational Status, Current Age, CAMS.

(c) Predictors: Occupational Status, Current Age, CAMS, MSPSS, BC-Active, BC-Avoidant.

(d) Dependent Variable: BMLSS

Table 7.4. Coefficients for Predictors of Variance in QOL^a

Model	Predictors	Unstandardised Coefficients		Standardised Coefficients	T	Sig.
		B	Std. Error	Beta (β)		
1	Current Age	.413	.111	.277	5.312	.000
	Occupational Status	17.288	3.254	.396		
2	Current Age	.405	.113	.272	3.596	.000
	Occupational Status	16.943	3.364	.388	5.037	.000
	Current AM Status	-1.275	3.013	-.033	-.423	.673
3	Current Age	.320	.091	.214	3.495	.001
	Occupational Status	13.277	2.638	.304	5.033	.000
	Current AM Status	-.279	2.338	-.007	-.119	.905
	MSPSS Score	6.539	.941	.428	6.948	.000
	BC-Active Score	2.622	1.117	.145	2.347	.020
	BC-Avoidant Score	-4.563	1.054	-.272	-4.328	.000

(a) Dependent Variable: Total BMLSS score.

