Learning to Dance in the Rain: Stories of Young People taking Antipsychotic Medication

by

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This thesis is dedicated in loving memory of my father

Chandra Ramdour

Abstract

Early intervention to promptly identify and treat psychosis limits the duration of untreated psychosis and improves patient outcome. Despite evidence to support efficacy, approximately 50% of young people do not take antipsychotic medication as prescribed. This research was designed to explore factors which may promote and deter teenage adherence with antipsychotic medication.

Initially intended as a quantitative study, the research pragmatically shifted to a qualitative design following recruitment difficulties. Narrative inquiry and auto-photography were used to obtain stories from ten young people prescribed antipsychotic medication as a teenager. Participants collected images illustrative of their medication journey, discussing these images and their medication stories at interview.

Analysis of data uncovered a metastory of a journey from darkness to brightness. In darkness, symptoms predominated bringing fear, isolation and unpredictability. As medication took effect, stories became brighter evidencing hope, happiness and productivity. Four stories linked to medication adherence emerged; namely endurance, motivation, control and resentment. Underpinning sub-stories included the endurance of resisting symptoms, taking medication long term and dealing with medication side effects. Sub-stories of motivations related to being well, being a ‘normal’ teenager and having a brighter future. Control was evident in the positive choices made, degree of openness and level of independence exerted. Young people often resented the fact that they were ill and were prescribed medication. They felt different from their peers. The main motivation for young people to take prescribed medication was to be well. Poor adherence was most commonly due to forgetfulness.

My findings suggest young people balance positive stories of motivation and control against negative stories of endurance and resentment when making decisions about medication. Adherence is dynamic as the balance of positive and negative stories constantly shifts. Staff should explore individual stories of motivation, control, resentment and endurance frequently, to better understand and promote medication adherence.

List of Figures

List of Tables

List of Images

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Abbreviations

ADHD	Attention Deficit Hyperactivity Disorder
APA	American Psychiatric Association
ANT	Attitudes to Neuroleptic Treatment Questionnaire
BEMIB	Brief Evaluation of Medication Influences and Beliefs
BPRS	Brief Psychiatric Rating Scale
CAMHS	Child and Adolescent Mental Health Services
CATIE	Clinical Antipsychotic Trials of Intervention Effectiveness
CINAHL	Cumulative Index of Nursing and Allied Health Literature
CMG	Continuous Measure of Medication Gaps
CMOS	Continuous Multiple Interval Measure of Oversupply
CRS	Compliance Rating Scale
CUtLASS	Cost Utility of the Latest Antipsychotic Drugs in Schizophrenia
DAI	Drug Attitude Inventory
DUP	Duration of Untreated Psychosis
EIS	Early Intervention Service/s
EPSE	Extrapyramidal Side Effects
EUFEST	European First Episode Schizophrenia Trial
FDA	Food and Drug Administration
FEP	First Episode Psychosis
FGA	First Generation Antipsychotic

HCPs	Healthcare Professionals
HIV	Human Immunodeficiency Virus
ITAQ	Insight and Treatment Attitudes Questionnaire
LCA	Latent Class Analysis
LCFT	Lancashire Care NHS Foundation Trust
LEO	Lambeth Early Onset study
MAQ	Medication Adherence Questionnaire
MARS	Medication Adherence Rating Scale
MEMS	Medication Event Monitoring System
MPR	Medication Possession Ratio
NHS	National Health Service
NRES	National Research Ethics Service
NICE	National Institute for Clinical Excellence
PANSS	Positive and Negative Syndrome Scale
PDC	Proportion of Days Covered
PEPP	Prevention and Early Intervention Programme for Psychoses
PETiT	Personal Evaluation of Transition in Treatment
PICU	Psychiatric Intensive Care Unit
QUATRO	Quality of Life following Adherence Therapy for People Disabled by Schizophrenia and their Carers
RCR	Refill Compliance Rate

ROMI	Rating of Medication Influences Scale
SAI	Schedule for the Assessment of Insight
SGA	Second Generation Antipsychotic
SUMD	Scale to Assess Unawareness of Mental Disorder
SWN	Subjective Wellbeing under Neuroleptic Treatment Scale
UCLan	University of Central Lancashire
UK	United Kingdom
USA	United States of America
WHO	World Health Organisation

CHAPTER ONE. INTRODUCTION

In presenting this narrative research of the medication stories of young people prescribed antipsychotic medication in their teenage years, I have chosen firstly to describe the journey which led to my interest in pharmacy, healthcare and more specifically mental health. I then describe my reasons for the research topic chosen, including further information about my PhD journey and how this progressed. Finally, I provide an outline of how my thesis is then presented. Throughout I have included reflective entries considering how my past experiences had the potential to influence my own position within the research undertaken.

1.1. The Start of My Journey

On reflection the start of my journey began in childhood, living with my parents and younger sister in Preston. My mother did not work whilst I was a young child but later went to teacher training college whilst I was at primary school. Post-qualification she worked teaching children who were mentally and physically disabled. My father moved to the United Kingdom from Mauritius at the age of 17 and subsequently trained as a nurse. He was both a registered general and mental health nurse. My father worked in a number of mental health specialties over the years, however, I only ever remember him working on older adult mental health wards.

I strongly believe that both parents having a background working with people with mental health and learning difficulties influenced my views and career choices. As a child, my sister and I would accompany my father to work during the school holidays when childcare was difficult to arrange. During our early childhood my father worked at the local mental health hospital, a large thriving community catering for hundreds of patients and my memories of visits to the hospital as a child are still vivid. One occasion springs to mind where my sister and I were particularly scared of an ‘old lady’ on the ward who was shouting and distressed. I remember us both sharing a big armchair and huddling into it thinking that she then would not notice us. Apart from that one occasion, I just remember being around the patients both on the wards and in the hospital grounds whilst we played and remember feeling comfortable rather than uneasy in this setting. My sister and I also used to regularly attend the social functions held at the school where my mother worked, including the school discos where we would dance with the students. I think that this exposure to those with mental health and learning difficulties at a young age gave me a greater appreciation of the difficulties some faced, but also meant that I felt comfortable with people who were diagnosed with mental health and physical or learning disabilities.

I decided whilst at high school that I wanted to become a pharmacist as I enjoyed science subjects, particularly chemistry. I ended up moving to Liverpool at the age of eighteen to start a pharmacy undergraduate degree course. Course content was limited in the area of mental health, however, we were lucky to receive exposure to the different fields of pharmacy during the course. I was clear having worked in these various fields, that a career as a hospital pharmacist would give me most job satisfaction as it provided greater opportunity to utilise my clinical training, influence patient care and outcomes and work alongside other healthcare professionals. I finished my degree in 1990, and started my pre-registration placement at a local hospital. During my pre-registration year I rotated through the various directorates and was lucky to spend four weeks on a mental health rotation. This mental health placement was back at the mental health hospital where my father had worked when I was at primary school and, given that it was in the days before the vast majority of long stay patients were discharged to community placements, there were still many wards located across the vast estate supporting large numbers of patients. The mental health pharmacist routinely attended consultant ward rounds and it was clear from the start that she was influencing and supporting decisions and choices around medication. She also spent a lot of time talking to patients and understanding their medication histories. It was immediately apparent to me that she was a valued and important member of the multidisciplinary team. This mental health placement sparked my interest in the field and this continues to this day. I see the impact, both positive and negative, that medication has on patients and am passionate about the important role a pharmacist plays in supporting patients and staff in making decisions about medication choices.

Following my pre-registration year I became a resident pharmacist, working shifts to ensure seven day cover and continuing to rotate through the various hospital specialities. Such was my love of mental health pharmacy, I always asked if I could cover the mental health wards when the mental health pharmacist was on annual leave.

After a couple of years, I then moved to another hospital where again I asked to cover the mental health wards on a permanent basis whilst also rotating through other areas. It was also at this stage in my working career that I completed a Postgraduate Diploma in Psychiatric Therapeutics wishing to further my knowledge in the field. My father by now was also working at the same hospital as senior nurse manager for the older adult mental health unit. We did not work routinely together, however I would on occasion bump into him on the wards when I was reviewing the prescription charts. Whilst we used to talk about work a lot, this tended to be very general. We never had lengthy discussions about medication adherence or mental illness. In 1996, an opportunity arose to specialise as a mental health pharmacist and I leapt at this opportunity. Since then I have worked on acute, adult, older adult, secure, rehabilitation and young people’s wards as well as providing services to all associated community teams. The majority of my clinical time has been spent on adult, older adult and secure mental health wards with less time spent on the young people’s wards or in the community teams.

1.2. Deciding Upon a Research Topic

Despite my limited exposure to young people with mental illness, I have always been aware that delays in effective treatment and poor medication adherence risk adverse outcomes. I was therefore keen to explore and understand this in more detail. This prompted my initial interest in undertaking research with young people in Early Intervention Services for mental health.

Colleagues spoke of the difficulties in undertaking research with young people as they are sometimes perceived as difficult to engage (Rhee et al., 2008, Nguyen et al., 2014). Whilst married, I have no children and so this also means that I do not spend considerable periods of time in the presence of young people. I have contact with teenagers through friends and family, however, this is much more different than living with young people and understanding things such as how they interact, behave and communicate. I was from the outset aware that I may not fully understand the terminology in common use and would need to clarify any points of understanding. However, I felt that this would not unduly disadvantage my undertaking this research as I would be able to ask staff routinely working with young people for any advice should this be needed.

Throughout my career in mental health I have always thought that medication adherence was important. On occasions, I have been prescribed courses of medication which I have not completed, or have missed doses of medication such as antibiotics and prophylactic antimalarial medication. Given this, some might question my statement that medication adherence is important, I would hope however that should I ever be prescribed medication for my mental health, I would fully adhere to this. This is because of my personal experiences of possible outcomes when medication adherence is poor and the subsequent distress it can cause to family members. Whilst there is no history of mental illness in my immediate family, I do have two more distant family members diagnosed with mental health problems in adulthood. I became more involved in the support of one family member whilst she was an inpatient, and have also provided support to her siblings in response to their distress that she was not taking her medication. When she was in hospital I went with my parents to visit her, and during the visit my father and I spent some time discussing how important it was to take medication to stay well. This was in response to concerns from staff and my father that she would not take medication post-discharge. From this conversation, I know that my father also shared my view that medication adherence was important.

I hope that my clinical experience working as a mental health pharmacist has afforded me some understanding of why people might not want to take medication. I have also extensively read the literature on this issue. I have seen the deleterious effects on physical health that has resulted from antipsychotic use in some people, and have on occasions recommended that particular medication is changed in response to side effects significantly impacting on a person’s physical health and wellbeing. I feel that whenever medication is proposed, comprehensive information needs to be provided. This needs to be appropriate so the recipient is able to understand and process this information to enable an informed choice about whether to take medication. I think that patients should be fully involved in discussions about medication so that they can be partners in the decision about which antipsychotic medication is prescribed. If they are unable to do this at the time due to their mental health, their involvement should be revisited at a later date. Whilst I appreciate that there are multi-modal approaches to treatment, my view is that medication is the cornerstone of treatment for psychosis complementing psychological and psychosocial interventions. Some would consider that I follow a ‘medical model’ in my role, and I accept this. I do, however, appreciate that other healthcare professionals would argue against adopting a medical model approach feeling that social and psychological factors are more important that the biological.

My passion for mental health and strong conviction that medication plays a vital role in the management of mental illness and improved outcomes for patients drove my desire to conduct research in this area to further enhance knowledge. Given my interest in medication adherence, and awareness that delays in instituting effective treatments for first episode psychosis (FEP) can have an adverse effect on patient outcome, I decided that this was the field in which I wanted to conduct my research. I felt that in undertaking this research, there was potential to strengthen the limited research literature base. The knowledge obtained could then influence medication interventions and approaches taken with young people who are being prescribed antipsychotic medication for the first time. Whilst my clinical experience has predominantly been with adults with chronic psychosis, I instinctively felt that different drivers to take or refuse antipsychotic medication may be present in this younger age group with first presentation psychosis. I wondered whether peer pressure from other teenagers may influence medication decisions given that teenagers are often easily swayed by the views of others. In a similar vein, I also wondered whether teenagers would be influenced by depictions of mental illness and antipsychotic medication in the media.

1.3. My PhD Journey

Having decided to research medication adherence in young people with psychosis, I then had to decide on my research questions. Initially I decided that I wanted to explore the factors staff, young people and their carers felt supported and detracted from adherence with antipsychotic medication. This would enable an assessment of whether the views across the three groups were similar or discrepant. The findings could then be compared with the published research outlining factors affecting adherence in children with chronic mental and physical health conditions.

I firstly considered whether focus groups would be a way of engaging staff, young people and their carers and gathering qualitative data on medication adherence. There was a facility within the University of Central Lancashire which specialised in running innovative and creative focus groups and I held some exploratory meetings to consider the different options available. Following these meetings I was interested in using Lego Serious Play©, a form of Lego bricks designed to be used by adults, to model more serious themes. To explore the feasibility of this, a meeting was held with the child and adolescent mental health (CAMHS) workers based in the early intervention service. Feedback received at this meeting was that some patients were reticent about being involved in a group and would prefer participation on an individual basis. The fact that their parents may also be involved in the study was seen as a drawback for some teenagers' participation in focus groups. During this stage, I also met with a professor at the University of Central Lancashire, whose particular research focus is with young people who are ill. She also indicated that sometimes young people just feel that they have little to contribute to a particular topic, are reluctant to travel to a place of unfamiliarity and speak in front of people they do not know. Based on this feedback I therefore decided to discount the use of focus groups and sought alternative means of engagement.

Having decided against using focus groups, I explored other avenues for engaging staff, young people and carers. I was keen to use technology as researchers working with children and young people suggested that this was an effective way of engaging this age group. I therefore chose to take a quantitative approach, developing and distributing a survey to obtain further information about medication adherence in this patient population. The intention was ultimately to develop and ratify a tool to assess medication adherence in children and young people, utilising the survey data obtained in the tool design. Despite numerous attempts to garner a sufficient response from suitable candidates, I received only a handful of responses from patients and their carers. This was disappointing as my predominant desire in undertaking this research was to understand the views of young people themselves. Without this, I felt that the research would have less utility in supporting clinical interventions to promote medication adherence. Given the poor survey response rate by carers and young people, I spent a long time considering why the survey had failed to garner sufficient interest from young people and their carers so I could contemplate other avenues by which to gather information. My explorations of research in young people then uncovered the possibility of using visual methodologies to effectively engage young people in qualitative research. I found references to the use of narrative research, where stories are used as source data. I felt that young people may be more interested in the research if they were asked to tell their story about taking medication using photographs, media images or drawings. In line with the requirements of my ethics approval, I was reliant on care co-ordinators to initially identify suitable participants. I therefore attended several meetings with staff working in Early Intervention Services, inpatient services for young people as well as several support groups for young people with psychosis. Posters advertising the research were also displayed in buildings where young people attended outpatient appointments. Despite all of these efforts recruitment was particularly slow. I feel that this was because there were several research projects being undertaken within the teams and so the young people were perhaps involved in other research projects. Additionally, care coordinators had lots of competing priorities and so advertising my research in their busy schedules was perhaps less of a priority. Thankfully there were several care coordinators and a couple of consultant psychiatrists who were particularly supportive, and due to the efforts of these people I managed to recruit 12 young people to the research with 10 young people completing data generation.

A further surprise and source of frustration was that despite allowing four weeks to complete the data collection phase this invariably took longer, and required numerous emails, phone calls and text messages on my part to ensure that the photographs were returned. In hindsight, I feel that I had been very naive in expecting teenagers who were busy at school and college, and who were at times mentally unsettled, to independently return the photographs without prompting.

Because of my concerns about getting sufficient numbers of participants, I decided to submit a substantial amendment to allow recruitment of people who were over 18, on the condition that they had taken medication at some point between the ages of 14 and 18. In the end, there were only two participants who fell into this category, both being twenty years of age. The other eight young people who completed the research were between the ages of 14 and 18.

Having completed the recruitment and analysed the data obtained, I then completed the writing of my PhD thesis, the structure of which will now be outlined.

1.4. The Structure of my PhD Thesis

Following on from this introductory chapter, Chapter Two provides an overview of psychosis in childhood before discussion the concept and relevance of duration of untreated psychosis (DUP). Information is also provided about the use of medication in psychosis describing psychosis in children and young people. Chapter Three then presents further detail on medication adherence and includes the search strategy supporting the integrative literature review of factors affecting medication adherence in FEP. Chapter Four is a stand-alone chapter dedicated to the survey research. Whilst initially debating whether the survey should be included in a thesis given the research is a qualitative exploration of young people’s stories of taking antipsychotic medication, the survey research with staff uncovered valuable information. This included, for example, the finding that nursing staff rate the impact of substance misuse, interference with goal attainment, fear of hospital admission and family views on medication adherence lower than prescribers. Whilst the survey research represented a detour in my qualitative research journey, I have dedicated Chapter Four to this detour, as the survey findings provide a means of contrasting staff and young people’s views within the discussion chapter. It also facilitates deliberation about whether staff views may impact on the effectiveness of clinical interventions to promote teenage adherence with antipsychotic medication. In Chapter Five, I outline the qualitative methodology used for my PhD study stating my research aim and questions, describing the underpinning research framework, before explaining in more detail how the research was undertaken. Chapter Six provides an overview of the participants, whilst Chapter Seven details the findings of the narrative research undertaken with young people. Chapter Eight is dedicated to a discussion about the research findings and how this augments current literature in the field. Finally, in Chapter Nine I outline my original contribution to research, strengths and limitations of the study, implications for clinical practice and suggest areas for further research.

CHAPTER TWO. BACKGROUND

2.1. Introduction

The purpose of this chapter is to give an overview of psychotic illness in children and adolescents before focusing on the role of medication in treatment. I start by presenting an overview of psychotic illness in children and young people considering prevalence rates, prodromal states and subsequent transition to psychosis. The concept of Duration of Untreated Psychosis (DUP) is outlined, with particular reference to factors affecting DUP and the impact this has on outcomes. Information is provided about medication prescribed to treat psychotic symptoms with consideration given to the effectiveness of antipsychotic medication in FEP. Finally, I discuss adherence to antipsychotic medication paying specific attention to the assessment of adherence, rates of adherence to antipsychotic medication in FEP and consequences of poor medication adherence.

Whilst recent guidance has suggested that Schizophrenia should be the preferred term for those fulfilling diagnostic criteria for the condition (Cantwell et al., 1999), I have opted to use the term psychosis throughout this thesis. This is because psychosis is the term I would most commonly use when speaking to young people about antipsychotic medication. I accept that some young people find it helpful to understand their experiences in the context of a particular diagnosis, however others find being labelled with schizophrenia stigmatising, confusing and distressing (Cantwell et al., 1999). For this reason I prefer to use the term psychosis, unless the person themselves refers to their illness as schizophrenia. This also mirrors the terminology used by colleagues working within the Early Intervention Service (EIS).

2.2. Psychosis in Childhood.

Before considering the topic of medication adherence in FEP, it is important to have an understanding of the prevalence and presentation of psychosis in childhood. Available information suggests prevalence rates of approximately 1.6 to 1.9 per 100,000 child population (Gillberg, 1984, Burd and Kerbeshian, 1987, Hellgren et al., 1987, Gillberg, 2000). Prevalence starts to increase sharply from the age of 14, with peak prevalence in the late teens and early 20s (Gillberg et al., 1986, Thomsen, 1996). Prior to the emergence of full blown psychotic symptoms in young people, prodromal symptoms are often evident. Defined as “early or premonitory symptoms of a disease or disorder” (Campbell, 1989), these symptoms may develop following a period of acute stress, distress or physical illness (Lincoln et al., 2011). Symptoms characteristic of a prodrome include marked withdrawal, impairment in role functioning, peculiar behaviour, impaired personal hygiene, blunted or inappropriate emotional response, speech disturbances, odd beliefs or magical thinking, unusual perceptual experiences and marked lack of initiative, interest or energy (American Psychiatric Association, 1987). Low mood, withdrawal, sleep disturbance and changes in appetite are most commonly reported (Herz and Melville, 1980, Birchwood et al., 1989). Following the emergence of non-psychotic prodromal symptoms, frequent and excessive emotional displays may precede the development of overt psychotic symptoms (Docherty et al., 1978). Psychotic symptoms include ‘positive symptoms’ such as thought disorder, paranoid delusions and hallucinations, as well as ‘negative symptoms’ such as marked apathy, blunted or incongruent emotions and social withdrawal (Wing and Brown, 1970). Progression of prodromal symptoms to frank psychosis usually occurs over a period of less than four weeks (Herz and Melville, 1980, Birchwood et al., 1989, Jorgensen, 1998), although the prodrome may last up to one year (Padmavathi et al., 1998).

Most of the disabling consequences of psychosis, in particular effects on social outcomes, develop before the onset of psychotic symptoms (Jones et al., 1993, Hafner et al., 1995, Yung et al., 1996). Early prodromal symptoms of mood, sleep and appetite disturbance as well as social withdrawal may spontaneously remit without intervention or, alternatively, develop into a disorder which may or may not be a psychotic episode (Gaebel et al., 1993). Thus, an emerging psychotic episode is extremely difficult to diagnose until the end of a pre-psychotic stage (Hafner et al., 1995, McGorry et al., 1995).

Studies have reported transition rates from prodromal to psychotic states of up to 50% (Klosterkotter et al., 2001, Miller et al., 2002, Yung et al., 2003, Haroun et al., 2006). A recent meta-analysis predicted transition in those at high risk of psychosis as 18% after 6 months, 22% after 12 months, 29% after 24 months, and 36% after 36 months of follow-up (Fusar-Poli et al., 2012). More recently, transition rates appear to be declining, with one centre in Victoria, Australia estimating a 20% year on year reduction (Yung et al., 2007). It has been suggested that these declining transition rates may be secondary to the benefits of early intervention treatment strategies, a greater likelihood of "false positives" because people are seeking help earlier, or benefits of adjunctive treatment with anxiolytics and antidepressants in the prodromal phase (Yung et al., 2007).

Whilst treatment of prodromal symptoms with antipsychotic medication may appear logical, ethically it causes some dilemmas. This is because it may result in unnecessary treatment of some patients whose prodrome would not have developed into a psychotic illness (Yung and McGorry, 1997, Rosen, 2000, Cornblatt et al., 2001, McGlashan, 2001, Corcoran et al., 2005). Randomised controlled trials have suggested potential benefits to treatment of medication in the prodrome (McGorry et al., 2002, McGorry et al., 2013), although positive benefits of medication did not always reach statistical significance (McGlashan et al., 2006). A recent meta-analysis concluded that preventive interventions, such as psychological and pharmacological treatment, in those at ultra-high risk of developing psychosis can reduce the risk of onset of the disorder by 52% to 54% after 12 months and by 35% to 37% in the longer term (van der Gaag et al., 2013). It was estimated that treatment of nine people in a prodromal state for 12 months would prevent conversion to FEP in one person (van der Gaag et al., 2013). What is clear, is that the early years following transition from prodrome to psychosis form a critical period, because of the likelihood of a rapid deterioration in functioning and poor recovery rates in the longer term, if psychosis is not adequately treated (Birchwood et al., 1998, Crumlish et al., 2009). EIS in the UK developed in recognition of the need to facilitate early detection of emerging psychotic symptoms, reduce delays to first treatment and provide consistent intervention during the critical period following initial diagnosis (Joseph and Birchwood, 2005). This strategy to support prompt and effective treatment is crucial to limit duration of untreated psychosis and maximise positive outcomes, as will now be outlined.

2.3. Duration of Untreated Psychosis (DUP)

DUP is defined as the time from manifestation of the first psychotic symptom to initiation of adequate antipsychotic drug treatment (Norman and Malla, 2001). Whilst estimation of DUP might seem straightforward on the basis of this definition, variations in how the onset of psychotic symptoms is defined, judgements as to when presentation switches from unusual or eccentric to psychotic, the degree of recall by patients (which in itself may be influenced by psychotic symptoms experienced), as well as recall of carers are all potential confounding variables (Häfner et al., 1993, Browne et al., 2000). The time at which DUP ends also varies in studies and can include the point at which antipsychotic medication is initiated, or the time at which adequate treatment according to particular criteria is reached (Larsen et al., 1996, Edwards et al., 1998, Haas et al., 1998, Craig et al., 2000). Despite these difficulties, it has been estimated that once psychotic symptoms appear the average DUP is between one (Loebel et al., 1992) and two (Larsen et al., 1996) years. A literature review was undertaken of factors affecting DUP. A number of themes emerged which will now be presented.

2.3.1. Factors Affecting Duration of Untreated Psychosis

Studies conducted in different countries have found variation in DUP across developed and developing countries. Studies have shown that prolonged DUP in developing countries is more likely where those with psychosis are living with extended families due to delays in seeking treatment (Padmavathi et al., 1998, Srinivasan et al., 2001). Cultural differences in familial recognition of illness can also delays access to treatment in developing countries (Srinivasan et al., 2001). Migration to another country has been linked to a prolonged DUP (Sterk et al., 2010, Boonstra et al., 2012b, Apeldoorn et al., 2014, Nerhus et al., 2015). Other factors associated with prolonged DUP include male gender (Loebel et al., 1992, Larsen et al., 1996, Larsen et al., 1998, Johannessen et al., 1999, Melle et al., 2004, Chang et al., 2011, Fridgen et al., 2013, Apeldoorn et al., 2014) and younger age at onset of psychotic symptoms (Johannessen et al., 1999, Craig et al., 2000, Bechard-Evans et al., 2007, Schimmelmann et al., 2008, Apeldoorn et al., 2014). Also of relevance is a family history of admission to a mental health ward (Verdoux et al., 1998), stigma (Corrigan, 2004, Tanskanen et al., 2011, Sadeghieh Ahari et al., 2014), insidious illness onset (Kalla et al., 2002, Chen et al., 2005a, Morgan et al., 2006, Compton et al., 2008) and greater severity of illness at the point of admission (Verdoux et al., 1998, Johannessen et al., 1999) which are all associated with a longer DUP. Lack of insight (Larsen et al., 1998, Drake et al., 2000), presence of negative symptoms (Larsen et al., 1996, Browne et al., 2000) and persecutory delusions (McGorry et al., 1996) also predict prolonged DUP. Poor educational attainment (Verdoux et al., 1998, Sadeghieh Ahari et al., 2014), pre-morbid functioning (Childers and Harding, 1990, Addington and Addington, 1993, Bailer et al., 1996, Fresán et al., 2003, Melle et al., 2004, Schimmelmann et al., 2008), neuropsychological and cognitive function (Kolakowska et al., 1985, Keshavan et al., 2003) and poor occupational, social and global functioning (Larsen et al., 1996, Verdoux et al., 1998, Johannessen et al., 1999, Kalla et al., 2002, Melle et al., 2004) also contribute adversley to DUP.

Some studies have failed to find links between DUP and age of onset (Haas and Sweeney, 1992, Loebel et al., 1992, Beiser et al., 1993, Häfner et al., 1993, Larsen et al., 1996, Haas et al., 1998, Drake et al., 2000, Morgan et al., 2006), age of first admission (Craig et al., 2000), ethnicity (Craig et al., 2000, Anderson et al., 2014), gender (Haas et al., 1998, Craig et al., 2000, Ho et al., 2000, Cascio et al., 2012) or marital status (Haas et al., 1998, Craig et al., 2000). Poor premorbid functioning (Ho et al., 2000, Chen et al., 2005a, Apeldoorn et al., 2014), socioeconomic status (Haas et al., 1998), educational or occupational attainment (Craig et al., 2000, Morgan et al., 2006, Bechard-Evans et al., 2007, Compton et al., 2008, Compton et al., 2011) or dose of antipsychotic on admission (Haas et al., 1998) have also been shown to be insignificant predictors of DUP.

It is clear from this review that there are many potential confounders of DUP. I will now outline why a prolonged DUP is of clinical relevance, and why EIS proactively tries to limit DUP.

2.4. Impact of Duration of Untreated Psychosis on Outcomes

Whatever the causes of a prolonged DUP, this is of clinical importance because of the potential link to poorer prognosis and outcomes (Larsen et al., 2000, Bottlender et al., 2003, Keshavan et al., 2003). There is however no clear consensus in the literature about whether prolonged DUP inevitably results in poor outcomes. Whilst many studies do highlight an association, some studies do not demonstrate significant links (Kolakowska et al., 1985, Linszen et al., 1998, Barnes et al., 2000, Craig et al., 2000).

2.4.1. Symptom Control

Studies have sought to assess the impact of DUP on global, positive, negative or affective symptoms. A randomised study known as the OPUS trial, named so in recognition of the intensive early treatment programme it provides, showed that participants with longer treatment free periods displayed more psychotic symptoms at both baseline and follow up (Jeppesen et al., 2008). In Drake et al.'s (2000) study DUP was the strongest predictor of symptom severity after 6-12 weeks treatment, even when controlling for severity of symptoms at baseline (Drake et al., 2000). This is in contrast to other studies which concluded that DUP had no effect on the course of psychotic symptoms (Linszen et al., 1998, Ho et al., 2000).

Focusing specifically on positive symptoms, these have been demonstrated as more enduring (McGorry et al., 1996, Szymanski et al., 1996, Bottlender et al., 2003, Jeppesen et al., 2008, Crumlish et al., 2009) and severe (Haas et al., 1998, Bottlender et al., 2000, Norman and Malla, 2001, Addington et al., 2004, Harris et al., 2005, Barnes et al., 2008, Hill et al., 2012, Wing Chung et al., 2012) in those with prolonged DUP. However, other studies have failed to confirm the association (Barnes et al., 2000, Browne et al., 2000, Craig et al., 2000, de Haan et al., 2000).

Studies have also shown a significant association between prolonged DUP and more severe negative symptoms at first presentation or admission (Larsen et al., 1996, Haas et al., 1998), at discharge (Haas et al., 1998, Bottlender et al., 2000) and at one year (McGorry et al., 1996, Larsen et al., 2000, Barnes et al., 2008, Galderisi et al., 2013), 10 year (Waddington et al., 1995), 12 year (Hill et al., 2012) and 15 year (Bottlender et al., 2003) follow up. One study found this association in women but not men (Scully et al., 1996). In contrast, other studies failed to find a significant association between prolonged DUP and severity of negative symptoms (Barnes et al., 2000, Browne et al., 2000, Craig et al., 2000, Addington et al., 2004, Harris et al., 2005, Jeppesen et al., 2008, Melle et al., 2008, Crumlish et al., 2009, Wing Chung et al., 2012).

Studies have also found a positive association between prolonged DUP and presence of affective symptoms (Binder et al., 1998), including depression (Edwards et al., 1998).

Whilst evidence is conflicting in relation to the impact of DUP on symptom control, the only systematic review conducted to date, which controlled for the impact of poor pre-morbid functioning, demonstrated a significant relationship at 12 months between longer DUP and all symptoms be they positive, negative or affective symptoms (Marshall et al., 2005). Another meta-analysis concluded that a prolonged DUP was associated with more severe negative symptoms, but not positive symptoms, at baseline (Perkins et al., 2005). This finding linking DUP to severity of negative symptoms has also been replicated in other meta-analyses (Boonstra et al., 2012a, Penttilä et al., 2014). The analysis by Penttilä et al. (2014) also found a significant effect of a prolonged DUP on severity of positive symptoms.

2.4.2. Remission

As well as an effect on symptom control, several studies have also shown an adverse association between prolonged DUP and recovery or remission rates. A longer DUP has been shown to lengthen the time to achieve remission (Loebel et al., 1992, Edwards et al., 1998, Díaz et al., 2013) and lower the rates of remission and recovery (McGorry et al., 1996, Barnes et al., 2000, Crumlish et al., 2009, Hill et al., 2012, Tang et al., 2014). Larsen et al.'s (2000) study of 43 patients with first episode psychosis found that those who were not in remission had a DUP three times greater than those in remission (Larsen et al., 2000). Other studies have however failed to confirm a link between DUP and likelihood of, or time to, remission (Wiersma et al., 1998, Robinson et al., 1999, Craig et al., 2000, Ho et al., 2000). The systematic review conducted by Marshall et al., (2005) showed a significant impact between prolonged DUP and lower rates of remission. This was replicated in a further meta-analysis (Penttilä et al., 2014).

2.4.3. Readmission

When considering the effect of prolonged DUP on readmission rates, a study of 228 patients with first-admission schizophrenia randomised to five different arms (psychotherapy, milieu therapy, ECT, drug alone or drug plus psychotherapy) demonstrated the advantages of early drug treatment. Those initially treated with medication or ECT had a better clinical, social and psychological outcome (May et al., 1981). Those who initially received non-drug treatments and stayed in hospital less than six months had subsequent higher readmission rates to hospital, indicating that an initial good response to non-drug treatments did not necessarily lead to better outcomes (Wyatt, 1991). Other studies have linked prolonged DUP to increased rates of re-admission in the subsequent two years (Wyatt et al., 1997, Qin et al., 2014) but fewer days spent in hospital over the next ten years (Penttilä et al., 2013). A retrospective study looking at readmissions over a 16 year to 33 year period also found that prolonged DUP significantly increased the number of readmissions in the very long term (Primavera et al., 2012). A recent meta-analysis concluded however that the association between prolonged DUP and hospital admission was insignificant (Penttilä et al., 2014).

2.4.4. Relapse

As well as increasing time spent in hospital, studies have shown that prolonged DUP increases relapse rates (Crow et al., 1986, Rabiner et al., 1986). Others have concluded that DUP has no effect on worsening of illness (Barnes et al., 2000) or risk of relapse at one year (Linszen et al., 1998), five year (Robinson et al., 1999) and 15 year follow up (Wiersma et al., 1998). The evidence is therefore contradictory as to whether DUP impacts on relapse rates.

2.4.5. Social Functioning

Other studies have shown that DUP can lead to poorer social functioning and attainment (Inoue et al., 1986, Larsen et al., 1996, Harris et al., 2005, Barnes et al., 2008, Crumlish et al., 2009, Hill et al., 2012, Qin et al., 2014) as well as poorer social integration (Drake et al., 2000) and limited social circles (Helgason, 1990, Tirupati et al., 2004, Jeppesen et al., 2008). A greater likelihood of homelessness and solitary living has also been demonstrated (Barnes et al., 2000). A systematic review and meta-analysis also evidenced the link between prolonged DUP and adverse social outcomes at months 6 and 12, but these ceased to be significant at month 24 (Marshall et al., 2005). The association between DUP and social functioning was also found in a later meta-analysis (Penttilä et al., 2014). Other studies however failed to show a significant association between prolonged DUP and social outcome (de Haan et al., 2000, Verdoux et al., 2001a) or independent living (Hill et al., 2012).

2.4.6. Occupational Functioning

Studies have also assessed the impact of a prolonged DUP on employment and occupational functioning. One meta-analysis concluded that a prolonged DUP did not impact on subsequent employment (Penttilä et al., 2014). Studies have however been mixed with some supporting an association between prolonged DUP and poorer employment prospects (Harris et al., 2005, Norman et al., 2007, Schimmelmann et al., 2008, Wing Chung et al., 2012), and others concluding that this was not significant (de Haan et al., 2003, Jeppesen et al., 2008, Hill et al., 2012). One study found that a prolonged DUP was associated with a significantly greater number of days spent at work over a ten year follow-up period (Penttilä et al., 2013).

2.4.7. Neurocognitive Functioning

Reviewing studies examining the effects of DUP on neurocognitive functioning, the majority have found no link (Binder et al., 1998, Barnes et al., 2000, Hoff et al., 2000, Norman et al., 2001, Ho et al., 2003, Addington et al., 2004, Rund et al., 2004, Rund et al., 2007, Barnes et al., 2008, Goldberg et al., 2009). A meta-analysis also failed to demonstrate an association between prolonged DUP and baseline neurocognitive function (Perkins et al., 2005). Two studies reported deficits in particular aspects of neurocognitive tests such as comprehension and executive functioning (Amminger et al., 2002, Joyce et al., 2002), whilst others evidenced poorer memory and attention in those with a longer DUP (Barnes et al., 2000, Cuesta et al., 2012). It has been suggested that DUP can affect specific executive functions of abstract thinking and perception and this may contribute to poorer social problem solving and adaptability within the community (Barnes et al., 2000).

2.4.8. Global Functioning

As well as considering the impact of DUP on social, occupational and neurocognitive functioning, it is important to reflect on how DUP affects global functioning. A prolonged DUP has been associated with poorer overall functioning in the pre-admission period (Larsen et al., 1996), during admission (Haas et al., 1998, Bottlender et al., 2002), at discharge (Bottlender et al., 2000) and in one year (McGorry et al., 1996, Larsen et al., 2000), two year (Wyatt et al., 1997, Keshavan et al., 2003, Fraguas et al., 2014) and 12 year (Hill et al., 2012) follow up studies. One study assessing 58 first episode patients, fifteen years after first admission found lower levels of global functioning even after controlling for potentially confounding variables (Bottlender et al., 2003). Another study retrospectively assessing global functioning over a minimum of sixteen years follow up also showed that longer DUP predicted poorer global functioning in the long term (Primavera et al., 2012). A systematic review (Marshall et al., 2005) and meta-analysis (Penttilä et al., 2014) have also confirmed the association between prolonged DUP and poor global functioning. However, global functioning was not significantly affected by DUP at two year follow up in a further study (Craig et al., 2000).

2.4.9. Quality of Life

As prolonged DUP has potentially adverse consequences across a number of different variables, it is not unreasonable to think that prolonged DUP may have an adverse effect on quality of life. Poorer scores on quality of life assessment tools have been evidenced at first presentation (Browne et al., 2000), one year (McGorry et al., 1996, Carbone et al., 1999), eight year (Harris et al., 2005), 12 year (Hill et al., 2012) and 20 year (Helgason, 1990) follow up. McGorry et al., (1996) found that DUP accounted for 15% of the variance in quality of life scores. This effect on quality of life is also supported by the findings of one systematic review (Marshall et al., 2005), but not in the other meta-analysis (Penttilä et al., 2014). One study assessing impact of early detection and reduced DUP on quality of life did not however find subjective or objective differences in quality of life assessed by living situation, activities of daily living, family relationships, social relationships, finances, occupational and educational factors, legal and safety issues or health (Melle et al., 2005).

2.4.10. Response to Medication

Other studies have looked specifically at the impact of DUP on response to antipsychotic treatment. It has been shown that limiting DUP shortens the time to medication response, and increases the likelihood of symptomatic response and remission (Larsen et al., 2000, Verdoux et al., 2001a, Malla et al., 2002b, Perkins et al., 2005, Barnes et al., 2008). A study to assess the impact of DUP on response to both delusions and hallucinations to medication found that whilst a prolonged DUP was associated with a longer time to improvements in delusional symptoms, this was not the case with hallucinations (Gunduz-Bruce et al., 2005). Another study found that after six months of treatment, impact on positive symptoms was lessened in those with a prolonged DUP, although this was not the case for negative symptoms (Szymanski et al., 1996).

Putting this into context, Lieberman et al. (2003) estimated that for every extra year of untreated psychosis, the odds of response were reduced by 15%. The Lieberman Study was a comparison of clozapine versus chlorpromazine in treatment-naive first episode patients, and as clozapine is only licensed for treatment resistant schizophrenia it could be argued that use of clozapine in this study was not reflective of clinical practice (Lieberman et al., 2003a). It has also been suggested that halving the duration of untreated psychosis would increase likelihood of medication response by 18% (Perkins et al., 2004). Evidence presented therefore suggests that prolonged periods without treatment leads to more severe symptoms, which subsequently prove more resistant to treatment with antipsychotic medication. A few studies have however failed to confirm a link between lengthy DUP and prolonged time to, and reduced rates of, treatment response (Kolakowska et al., 1985, Barnes et al., 2000, Craig et al., 2000, Ho et al., 2000).

2.4.11. Other Factors

For completeness, I have also included factors where single studies assessed the impact on antipsychotic medication adherence in FEP. A single study showed that a prolonged DUP was linked to greater behavioural disturbance, including potentially threatening behaviour to the life of self or others, inappropriate or bizarre sexual behaviour, damage to property or other behaviour deemed bizarre or inappropriate (Johnstone et al., 1986). A further study found that a prolonged duration of untreated psychotic symptoms was linked to a greater risk of suicide in the two years subsequent to first hospitalisation (Verdoux et al., 2001b). The only study assessing the impact of DUP on illicit substance use failed to find a link between DUP and substance misuse (Barnes et al., 2000). Another study concluded that prolonged DUP was associated with a longer initial admission to hospital (Penttilä et al., 2013).

In summary, evidence has been presented linking lengthy periods of untreated psychosis to poorer symptom control with medication. Delayed treatment also predicts a lengthier time to treatment response. Negative symptoms are likely to be more entrenched and remission rates lower, adversely impacting social and functional capabilities. Whilst many studies highlight an adverse effect of a prolonged DUP on clinical, social and vocational outcomes this is not a unanimous finding as some studies failed to demonstrate an association. Having presented background information about the presentation of a first episode psychosis, the focus of the literature review will now move to medication in the treatment of psychosis.

2.5. Medication in the Treatment of Psychosis

For reasons already outlined, one of the key aims of EIS is to proactively engage with young people and their carers, ideally in the prodromal phase, instituting effective treatments once a first episode psychosis is evident thereby minimising DUP and limiting adverse outcomes (Birchwood, 2002). Whilst holistic treatment involves psychosocial and psychological intervention, a key treatment intervention in psychosis is the prescribing of antipsychotic medication to target and treat psychotic symptoms. To achieve long term, full functional recovery it has been shown that early functional gains in response to symptomatic remission need to be demonstrated (Ãlvarez-Jimenez et al., 2012). Limiting DUP by prompt instigation of effective antipsychotic treatment provides a means of limiting adverse outcomes in respect of functioning, symptom control, quality of life and occupational or vocational attainment. Before considering the efficacy of antipsychotic medication, it is however important to briefly outline the history of antipsychotic medication and terminology in common use.

Antipsychotic medication has been available since the introduction of chlorpromazine in 1952 (Delay et al., 1952). Since then, numerous antipsychotic drugs have been developed and launched extending the pharmacological options for the management of psychosis. Chlorpromazine and antipsychotic medications with a similar mode of action and profile of receptor blockade have in the past been deemed ‘typical’ antipsychotics but are now classified as first generation antipsychotics (FGAs). More recently marketed antipsychotics were initially termed ‘atypical antipsychotics’, but are now referred to as second generation antipsychotics (SGAs). There is no consensus definition as to what constitutes a SGA, however, they are considered to be a group of drugs which are less likely to cause extrapyramidal side effects (NICE, 2002a, NICE, 2002b). The antipsychotic drugs amisulpride, aripiprazole, clozapine, olanzapine, paliperidone, quetiapine, sertindole, risperidone and zotepine comprise the group of SGAs.

The National Institute for Clinical Excellence (NICE) technology appraisal on the use of the atypical antipsychotics and the clinical guideline for the management of schizophrenia, first published in 2002, recommended the use of SGA medication for all those newly diagnosed with the psychotic illness schizophrenia (NICE, 2002a, NICE, 2002b). This was due to a lower incidence of extrapyramidal side effects and hyperprolactinaemia with the SGAs, and purported greater efficacy in treating negative symptoms. This advice subsequently changed in recognition of the potential for SGAs to induce weight gain and metabolic syndrome, with the latest guidance now requiring joint decision making by the healthcare professional and patient based on discussion and information about side effect profiles of the different antipsychotic medications (NICE, 2009a, NICE, 2014).

This change of direction was driven by two key studies comparing effectiveness of FGAs and SGAs. The Clinical Antipsychotic Trials of Intervention Effectiveness (CATIE) study was a large, long term study comparing effectiveness of the FGA perphenazine against four SGAs (olanzapine, risperidone, quetiapine and ziprasidone) in 1493 patients across 53 sites in the USA. It was a ground breaking study as it was the first such study to be conducted independently of pharmaceutical industry sponsorship. The conclusion reached was that perphenazine was as effective as, and comparatively tolerable to, the SGAs. (Lieberman et al., 2005). A further large, randomised, controlled, pragmatic study funded independently of pharmaceutical sponsorship was conducted in the United Kingdom. The Cost Utility of the Latest Antipsychotic Drugs in Schizophrenia Study (CUtLASS 1) drew similar conclusions to the CATIE study, in that SGAs did not markedly differ from FGAs when assessing quality of life, effectiveness and adherence rates (Jones et al., 2006).

A SGA which differs from the rest of the group is clozapine, as this is the only antipsychotic medication licensed for the management of treatment resistant schizophrenia. First marketed in the mid-1970s, it was subsequently withdrawn following a number of deaths in Finland. Further investigation uncovered that these deaths occurred secondary to development of the white blood cell disorders neutropenia and agranulocytosis (Amsler et al., 1977). Clozapine was subsequently re-launched with a requirement for mandatory full blood count monitoring in response to findings of a landmark study. This study showed superior efficacy of clozapine in treatment resistant schizophrenia (Kane et al., 1988). To this day, clozapine remains the gold standard for treatment resistant schizophrenia, where treatment resistance is defined as failure to respond to, or tolerate, a therapeutic trial of two antipsychotic medications one being a SGA (NICE, 2014). Clozapine was excluded as a treatment option in phase 1 CATIE and CUtLASS studies, but became the focus of investigation in the respective phase two trials. Phase two of the CATIE trial comprised recruits from phase one who had to discontinue the original study medication because of poor symptom control. In the study, participants entered one of two treatment arms, clozapine or an alternative SGA (olanzapine, quetiapine and risperidone). Those receiving clozapine were more likely to still be on the same treatment at the end of the trial, and to have benefitted from a greater reduction in symptoms (McEvoy et al., 2006b). In CUtLASS 2, a sample of 136 participants meeting criteria for treatment resistance were randomised to receive clozapine or an alternative SGA selected by the clinician. Symptomatic improvement in mental health was significantly associated with use of clozapine over the other SGAs (Lewis et al., 2006). There is therefore a strong evidence base for the use of clozapine in treatment resistant illness as this is more likely to result in an improvement in symptoms.

In those aged 15-17 years, a technology appraisal published by NICE recommended the initial use of risperidone for psychosis as risperidone is licensed for use in this age group. Use of aripiprazole was suggested in cases where risperidone was not appropriate for the individual patient (NICE, 2011a). In 2013, NICE published a clinical guideline for psychosis and schizophrenia in children and young people (NICE, 2013). Summarising recommendations around antipsychotic medication, the advice issued was that children and young people with FEP should be offered antipsychotic medication alongside psychological therapy. The guideline advocated that the choice of initial antipsychotic medication should be made jointly between healthcare professionals, the young person and their parents or carers, following a discussion about the likely benefits and propensity of individual drugs to cause metabolic, extrapyramidal, cardiovascular, hormonal and other side effects. The NICE clinical guideline suggested that the initial dose should be at the lower end of the recommended range for children if the medication was licensed in this population, otherwise a dose at the lower end of the range for adults should to be initiated before gradually increasing the dose. Once the optimum dose was reached, they recommended prescribing of a therapeutic dose of medication for 4-6 weeks before assessing efficacy. The use of multiple antipsychotics was to be avoided except for short periods when changing from one antipsychotic to another. The importance of baseline and ongoing monitoring for the emergence of adverse side effects, regular review of efficacy and comprehensive documentation of discussion and decisions around medication was also emphasised. In treatment resistant cases, the NICE guideline advised practitioners to review the diagnosis, establish that medication had been taken as prescribed and that psychological interventions had been provided and undertaken, and to consider whether other factors such as substance misuse, physical comorbidities or other prescribed medication could be contributing to poor response. Following such a review, clozapine was to be recommended for children and young people with treatment resistant illness, with subsequent consideration of clozapine augmentation with a second antipsychotic if required (NICE, 2013).

There are, therefore, a number of national guidelines supporting the use of antipsychotic medication as an effective treatment option in the management of a psychotic illness, with adherence to the same maximising the likelihood of symptomatic improvement.

When specifically considering antipsychotic treatment in those with first episode psychosis, short and long term studies have shown that introduction of antipsychotic medication will, in the majority of instances, bring about prompt improvement in psychotic symptoms (May et al., 1981, Emsley, 1999, Sanger et al., 1999, Malla et al., 2001, Lieberman et al., 2003a, Lieberman et al., 2003b, Schooler et al., 2005, Robinson et al., 2006, Zhang et al., 2013). Those in an initial phase of a psychotic illness are likely to be more responsive than those in chronic stages of the illness (Robinson et al., 1999), and such responses often result from use of much lower doses of medication (Oosthuizen et al., 2004, Robinson et al., 2005, Kahn et al., 2008, Josiassen et al., 2010). Meta-analyses of antipsychotic medication in children and young people also confirm efficacy of medication in this age group (Armenteros and Davies, 2006, Kennedy et al., 2007).

Whilst effective treatment of a first episode psychosis will hopefully lead to complete symptomatic and functional recovery, relapse risk remains high with more than 90% of patients relapsing within five years of recovery from a first episode illness (Wiersma et al., 1998, Robinson et al., 1999, Gitlin et al., 2001). Whilst the majority of studies highlight a protective effect of antipsychotic medication in reducing relapse risk (Szymanski et al., 1996, Robinson et al., 1999, Verdoux et al., 2000, Coldham et al., 2002, Üçok et al., 2004, Chen et al., 2010, Alvarez-Jiménez et al., 2011, Caseiro et al., 2012), this is not a universal finding (Craig et al., 2000, Harrigan et al., 2003).

In summary, antipsychotic medication is an effective intervention for symptoms of psychotic illness irrespective of the stage of illness. It is also an important strategy in reducing risk of relapse. Prompt and effective antipsychotic treatment is crucial, and inherent in this is ensuring the young person adheres to their antipsychotic medication.

2.6. Assessing Medication Adherence

Having considered the background for treatment with antipsychotic medication, the focus now moves to medication adherence in young people with FEP. This first requires consideration of the different ways in which adherence is defined and assessed in research literature.

2.6.1. Classification of Adherence

Three terms are routinely used in the study of patient acceptance of medication and treatment, namely compliance, concordance and adherence.

Compliance has been defined as:

> “*the extent to which a person’s behaviour coincides with the medical advice given”* (Haynes et al., 1979)

More recently, this term has fallen out of favour as it implies a degree of passivity in terms of obeying the advice given by a prescriber (Bebbington, 1995). Practitioners are now advised to use the terms concordance or adherence in preference to compliance.

Concordance has been defined as:

> “*an agreement reached after negotiation between a patient and health care professional that respects the beliefs and wishes of the patient in determining whether, when and how medicines are to be taken*” (RPSGB, 1997).

This definition is based around respect for the patient’s agenda and creates openness between the patient and the prescriber. There is recognition within this definition that concordance cannot be imposed upon a patient.

Adherence is the term most recently advocated and has been defined as:

> “*the extent to which patients follow the instructions they are given for prescribed treatments*” (Haynes et al., 2000)

This definition is intended to be non-judgemental without inferring blame on either the patient, prescriber or treatment and allows for flexibility in the level of adherence (Haynes et al., 2000). Thus, this term is intended to support ongoing dialogue about adherence between practitioner and patient, acknowledging that adherence may vary with time and circumstance.

Non-adherence has been further defined as:

> “*the failure to enter a treatment programme, premature termination of therapy and incomplete implementation of instructions, including prescriptions*” (Nose et al., 2003b)

The definitions quoted above are essential when examining the factors that affect adherence and interventions that are used to improve adherence. Adherence can be defined in terms of a quantitative measure of the percentage of prescribed doses taken. This approach is reasonable because in real life situations it is likely that most patients will either intentionally or unintentionally miss doses of medication, thereby requiring an element of pragmatism and flexibility by the practitioner when discussing medication adherence. Some studies have used an 80% cut-off to determine that a patient is adherent, some a 75% cut-off and others a 50% cut-off (Velligan et al., 2006). In effect, this means that the same patient could be categorised differently across two different studies depending on the operational definition of adherence employed. Some studies have used statistical measures such as the mean amount of medication taken over a specific time period, and it has been proposed that this measure should always be included to allow studies to be compared (Velligan et al., 2006). The problem with use of a mean percentage is that the time period over which adherence is measured can also vary across studies impacting on subsequent medication adherence. What is clear is that a lack of consensus about how to define medication adherence in research exists and impacts on the conclusions that can be drawn.

2.6.2. Measurement of Adherence

A further complication is that there are different quantitative or qualitative means of measuring adherence, each with its own advantages and draw backs.

Quantitative measures of adherence including pill counts, prescription refill rates, mechanical or electronic monitoring, chart reviews and measurement of blood or urine medication levels have all been shown to have limitations. Pill counts and prescription refill rates imply that a person has taken the medication collected when they may in fact be discarding it. Chart reviews for inpatients are also not 100% accurate as patients are adept at concealing medication should they not wish to take it. The measurement of blood and urine levels, whilst appearing to convey an accurate assessment, can be open to manipulation by the patient as adherence behaviour may change when patients know that a sample is due. The measurement methods can also bring bias as some laboratory tests are only effective at picking up very recent non-adherence. They will indicate the presence or absence of medication or metabolites but will not give any indication of partial adherence. There can also be significant inter-patient variation in rates of metabolism and volumes of distribution. These variations will affect the level of drug in either blood or urine and may affect the assessment of adherence.

Quantitative means of calculating a measure of adherence are also available using electronic systems and databases. Some of the more commonly used formulas employed in medication databases and clinical systems are the medication possession ratio (MPR), proportion of days covered (PDC), refill compliance rate (RCR), continuous measure of medication gaps (CMG) and the continuous multiple interval measure of oversupply (CMOS). Studies evaluating adherence rates in individuals using these measures have found that results differ for an individual depending on the measure used (Ahn et al., 2008, Karve et al., 2009, Martin et al., 2009).

As well as electronic data about prescription re-fills, electronic monitoring of the opening of containers holding medication provides another quantitative measure of adherence. One of the most common forms of electronic monitoring is the Medication Event Monitoring System (MEMS). This employs a specific medication bottle cap to generate records of the date and time the medication bottle is opened. Whilst seemingly more accurate than other objective measures of adherence such as pill counts and refill records, it could be argued that prior knowledge of the requirement to return electronic monitors for assessment purposes may lead to greater degrees of compliance than is usual, resulting in a degree of bias. Likewise, removal of an electronic cap from the medication bottle does not guarantee that the tablet or capsule has been swallowed (Velligan et al., 2006).

Recent advances have seen the first application for a digital medicine, filed in 2015 with the USA Food and Drug Administration (FDA). This digital medicine application relates to tablets of the SGA aripiprazole, each embedded with an ingestible sensor. The sensor communicates with a wearable sensor patch and a medical software application allowing for an estimation of adherence. The adherence data, with patient consent, can then be shared with healthcare professionals (Proteus Digital Health, 2016).

Qualitative measures including patient self-reports, health care professional and carer reports, patient interviews, clinical impressions and past medication taking have also been used to measure adherence. Evidence suggests that assessments by health care professionals are the least reliable of these measures, with one study concluding that physicians over-estimated adherence in 65% of patients whose blood sample analysis showed adherence to be poor (Borras et al., 2007). Another study found that clinicians failed to detect two thirds of patients who self-reported poor adherence (Hui et al., 2006a). The limitations of these measures are similar to those for the quantitative measures e.g. reliance on accurate recording and reporting (Farmer, 1999), and factors such as the time the reporter spends with the patient and their degree of involvement in the delivery of care, as well as a potential for poor response to medication to be misinterpreted as poor adherence (Velligan et al., 2006).

Patient self-report is the most common subjective, qualitative measure of adherence (Velligan et al., 2006). Whilst some have concluded that self-report may overestimate the extent of adherence (Jonsdottir et al., 2010, Lee et al., 2011), others have concluded that self-report provides an accurate reflection of medication adherence (Haukka et al., 2007). Byerly et al. (2007) sought to compare adherence rates using MEMS with self-reports of adherence by patient, clinician and research assistant. Prescriber and patient evaluations of non-adherence (7% and 5% respectively) were much lower than non-adherence estimates by the MEMS and research assistants (57% and 54% respectively) suggesting an overestimation of adherence by both prescribers and patients. (Byerly et al., 2007).

It is reasonable to conclude that whilst different measures of adherence exist, all have their limitations. A further means of assessing adherence is through the use of adherence tools and I now consider these tools in more detail.

2.6.3. Medication Adherence Tools

Adherence tools have been developed to assess self-reported attitudes to medication known to potentially impact on adherence. Such tools include the Drug Attitude Inventory [DAI] (Hogan et al., 1983), the Medication Adherence Questionnaire [MAQ] (Morisky et al., 1986), the Medication Adherence Rating Scale [MARS] (Thompson et al., 2000) and the Attitudes to Neuroleptic Treatment Questionnaire [ANT] (Kampman et al., 2000). Other tools available to support the assessment of adherence include the Rating of Medication Influences Scale [ROMI] (Weiden et al., 1994), the Personal Evaluation of Transition in Treatment [PETiT] (Voruganti and Awad, 2002), the Brief Evaluation of Medication Influences and Beliefs Scale [BEMIB] (Dolder et al., 2004) and the Subjective Well Being Under Neuroleptic Treatment Scale [SWN] (Naber et al., 2005). These tools measure a variety of different attitudes to, and effects of, medication including insight into illness and the need for treatment, positive and negative aspects of medication on mood, social and emotional wellbeing, experience of side effects and views of medication. Initial validation of these scales was undertaken predominantly in adults. Exceptions to this were the validation of the ROMI which included first presentation patients, and the ANT the youngest participant of whom was 16 years old. Townsend et al.'s (2009) study sought to evaluate whether the DAI would be suitable for use in an adolescent population experiencing a range of mental health disorders such as psychosis, attention deficit hyperactivity disorder and depression. This study found that the factor structure for the adolescent population only demonstrated a 'fair' correlation with that of the adult population, suggesting that adolescents' and adults' views, attitudes and experiences of taking psychotropic medication may differ (Townsend et al., 2009). Whilst there are numerous adherence tools available, some studies have also raised issues with consistency across tools, with the potential for adherence of the same individuals to be categorised differently depending on the scale used (Kikkert et al., 2008, Kikkert et al., 2011). This suggests that such tools should not be the sole basis for judgements about medication adherence.

2.6.4. Summary

In conclusion, there is no gold standard measure of adherence as all have particular limitations. It has therefore been proposed that all studies of medication adherence should incorporate at least two different measures, one of which should be an objective measure such as pill counts, electronic monitoring, prescription refill records or blood analysis (Velligan et al., 2006). Having presented a general overview of medication adherence and its assessment, I will not present information on rates of medication adherence in FEP.

2.7. Rates of Medication Adherence in First Episode Psychosis

Whilst acknowledging some of the difficulties in determining adherence with medication, studies have attempted to assess medication adherence rates in first episode psychosis. A systematic review, published in 2011, concluded that around 30% of first episode participants stop taking second generation antipsychotic medication in the first nine months of treatment (Miller et al., 2011). This review considered all cause discontinuation of medication including a deliberate decision by the patient or prescriber to change or stop antipsychotic medication, thereby over-estimating discontinuation due to poor adherence.

Considering studies which focus purely on non-adherence rather than all cause discontinuation rates, varying results have been obtained. Studies conducted over a 12 month period have demonstrated non-adherence rates of 45% (Rabinovitch et al., 2009), 49% (Le Quach et al., 2009), 59% (Coldham et al., 2002) and 70% (McEvoy et al., 2007). Longer studies conducted over a two year period demonstrated lower rates of non-adherence of 14.5% (Malla et al., 2008) and 25% (Gearing and Charach, 2009). These variations will in part be due to differences in methods for assessing adherence and adherence definitions however, depending on the reference source accessed, non-adherence with medication in first episode psychosis is estimated as anywhere between 14.5% (Malla et al., 2008) and 70% (McEvoy et al., 2007). This particularly wide reference range makes comparisons and generalisations problematic.

2.8. Consequences of Poor Adherence with Antipsychotic Medication

Thus far, it is evident that medication adherence can be problematic in first episode patients, although calculated rates of non-adherence vary depending on the research study examined. Poor antipsychotic medication adherence is currently the only consistent predictor of relapse with a high predictive power (Robinson et al., 1999, Chen et al., 2005b, Uçok et al., 2006, Caseiro et al., 2012). A systematic review and meta-analysis concluded that poor medication adherence increased the risk of psychotic relapse four-fold (Alvarez-Jimenez et al., 2012). Further studies have shown the negative impact of poor medication adherence on remission rates and time to remission (Strakowski et al., 1998, Malla et al., 2006, Malla et al., 2008, Petersen et al., 2008), psychopathology, social and vocational outcomes, hospitalisation and symptomatic remission (Verdoux et al., 2000, Coldham et al., 2002, Malla et al., 2002a, Petersen et al., 2008, Barbeito et al., 2013). One study found that dose reduction or discontinuation resulted in higher functional recovery, but not symptomatic recovery, when compared with maintenance antipsychotic treatment (Wunderink et al., 2013) suggesting some possible benefits to medication reduction. Other studies have also shown that discontinuation of medication may lead to increased cannabis use (Hides et al., 2006), poor insight (Lepage et al., 2010a) and disengagement with services (Chan et al., 2014b). Interestingly in the study by Lepage et al. (2010), positive symptoms of psychosis improved significantly with time for partially and poorly adherent groups as well as the fully adherent group, perhaps highlighting benefits of other treatment options and the possibility that some patients might not need to take medication consistently to achieve some benefit. Negative symptoms however deteriorated in those who were partially or non-adherent in this study (Lepage et al., 2010a).

It is therefore reasonable to conclude that poor adherence with antipsychotic medication has significant personal, social and economic sequelae with non-adherence increasing the risk of hospitalisation and use of other healthcare facilities, increasing lengths of hospital stay and likelihood of relapse, and reducing recovery rates. Evidence also suggests it may have indirect influences on quality of life and insight in a first episode population. These all contribute to increasing treatment costs, and come at personal cost to the service user and their carers. It is therefore important to consider factors that increase the likelihood of poor antipsychotic adherence in FEP, so we can identify those at potential risk and consider interventions which may promote adherence.

CHAPTER THREE. AN INTEGRATIVE REVIEW OF THE LITERATURE ON FACTORS AFFECTING ANTIPSYCHOTIC MEDICATION ADHERENCE IN FIRST EPISODE PSYCHOSIS

3.1. Introduction

Having outlined the importance of antipsychotic medication in reducing DUP and improving outcomes and presented initial information on medication adherence this chapter focuses specifically on factors affecting antipsychotic medication adherence in FEP. Firstly, I set out the details of the integrative literature review I undertook on medication adherence and present the approach used to identify and select relevant papers. I then present information on factors influencing antipsychotic medication adherence, as determined by the integrative review. Finally, views from healthcare professionals, carers and patients about influences on medication adherence in this cohort are provided.

3.2. The Literature Search

I started my PhD by conducting a literature search of adherence to antipsychotic medication. Having retrieved a large number of articles, I realised that I needed to take a more structured approach to ensure retrieval of high quality, relevant articles. There are different approaches to undertaking literature reviews and the choice depends on the topic area and the nature of knowledge and literature available. Careful decisions therefore needed to be taken about the choice of review undertaken. Due to the need to undertake a robust review that reviewed, critiqued and synthesised relevant literature of a limited but growing evidence base, I chose to undertake an integrative literature review (Torraco, 2005, Whittemore and Knafl, 2005).   Integrative literature reviews are the broadest type of literature review, of particular relevance to the science and delivery of healthcare, enabling inclusion of research grounded in diverse methodologies with the potential to play a substantial role in evidence based practice for nursing (Whittemore and Knafl, 2005). They are of relevance where the topic of investigation is a new and emerging concept (Torraco, 2005), as is the case with teenage antipsychotic medication adherence. Having previously looked into the evidence base around medication adherence as part of my clinical practice, I discovered that research around adherence with antipsychotic medication predominantly centres on an adult population with chronic psychoses such as schizophrenia. Research considering medication adherence issues in children focuses on study of physical health conditions such as asthma, diabetes and childhood human immunodeficiency virus (HIV). Where childhood mental health conditions are researched this usually involves attention deficit hyperactivity disorder (ADHD) or depression, with very little consideration of adherence issues pertinent to antipsychotic medication. This prompted my desire to conduct research into this area and conduct an integrative literature review to explore adherence with antipsychotic medication in young people with FEP. I felt that an integrative literature review was ideally suited to the topic being researched and the infancy of available research literature. It would strengthen my knowledge of relevant literature, thereby supporting an informed research study and conceptualisation of the parameters to be researched. An integrative review also provides a framework to deliver a literature review incorporating well-defined search parameters, explicit search terms, carefully chosen databases and clear criteria for assessment of the quality of the papers retrieved.

I conducted an integrative review of the literature using the computerised databases MEDLINE, Cumulative Index of Nursing and Allied Health Literature (CINAHL Complete) and PsycINFO to obtain key papers about medication adherence in young people with psychosis. These databases were chosen as collectively they provided the most comprehensive source of medicine, nursing, allied healthcare and mental health literature. The Boolean search terms (concordance OR adherence OR compliance) AND (“first episode psychosis” OR (psychosis AND (children OR adolescen*)) AND (medication OR medici*) in the abstract were used to access relevant references. Given the changing terminology in the field it was important to include the terms compliance, concordance and adherence as all have been preferred terms over different periods of time. I felt that use of broad search terms would capture most of the appropriate references in a limited field; however I also had to acknowledge that limitations exist in computerised searches such that inconsistent search terminology and indexing problems might yield only around 50% of eligible studies (Whittemore and Knafl, 2005). For this reason, I also analysed reference lists of retrieved reports to obtain additional articles of relevance not captured by the initial literature search (backward searching). I also looked at papers which had subsequently referenced the included paper to assess whether any of these met the inclusion criteria (forward searching).

The search was restricted to English Language, published, peer reviewed articles. I chose to limit the search to papers published from the year 1995 to current date. My reason for choosing articles from the year 1995 onwards was that the National Health Service (NHS) Plan, recognising the benefits of early intervention for FEP and requiring 50 early intervention teams to be established in the United Kingdom (UK), was published in 2000. Limiting my search from five years before this date would therefore also capture references from early implementers of EIS services. Clear inclusion and exclusion criteria were created to ensure that only relevant papers with sufficient quality were included in the review. Primary reference sources were obtained in preference to inclusion of review articles.

Inclusion criteria: articles were included

- If the article topic related to medication adherence in early psychosis, more specifically medication adherence rates, factors influencing medication adherence in children and adolescents, outcomes following both good and poor adherence with medication, measurement of adherence in children and adolescents or strategies to improve medication adherence in the population of interest.

Exclusion criteria: articles were excluded:

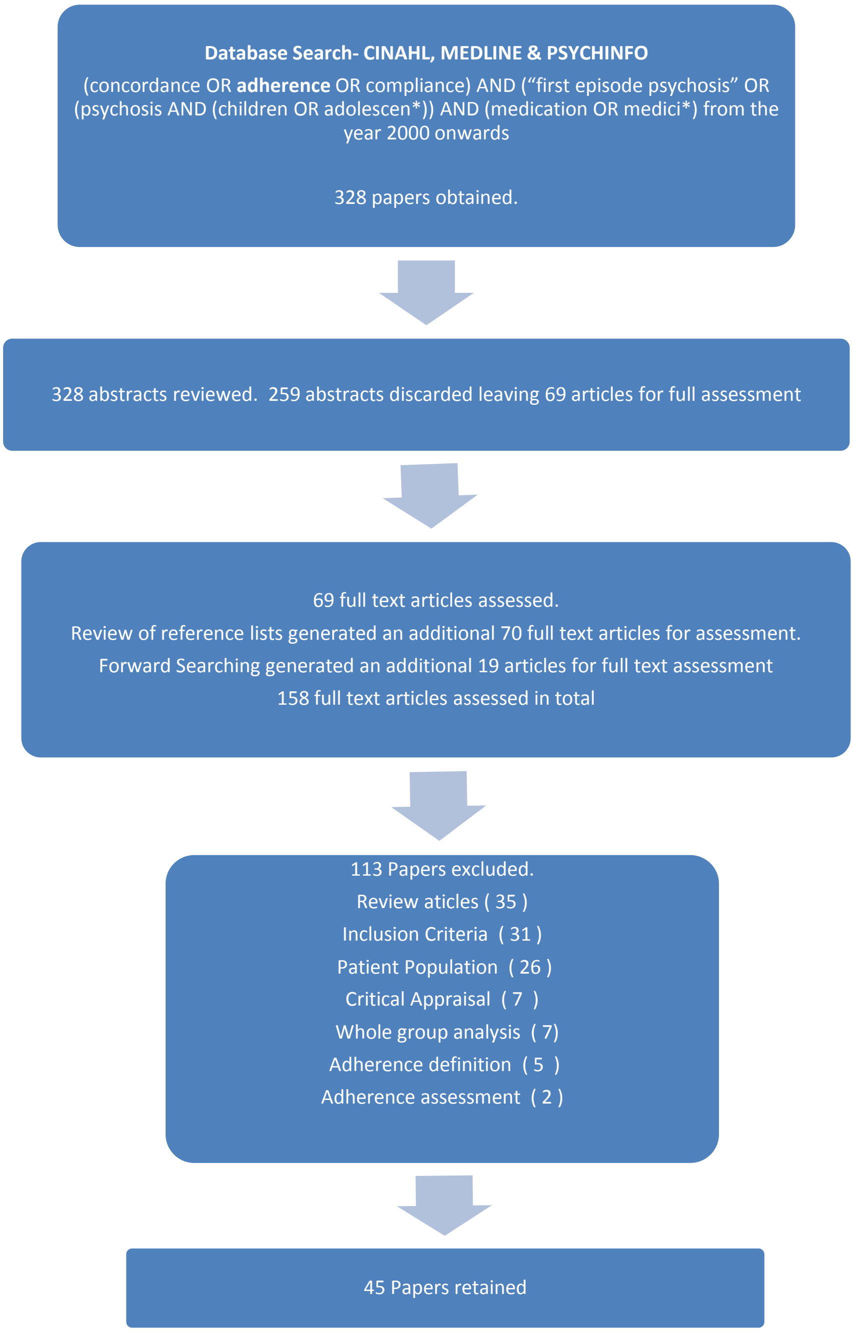
- If they did not meet the inclusion criteria described

- If they focused on other mental health disorders in children and adolescents where antipsychotic medication is not a mainstay of treatment e.g. ADHD or depression.
- If they centred on medication adherence in physical illness e.g. HIV, asthma or diabetes mellitus.
- Where articles incorporated a range of different psychotropic medications e.g. antipsychotics, antidepressant and stimulant medication, and presentation of results did not allow data for antipsychotic medication to be interrogated separately.
- Where a range of treatments e.g. medication and psychological interventions were considered and results were assessed as a whole.
- Where an assessment of medication adherence was undertaken, yet the article failed to clearly define how participants were assigned to the different medication adherence groups or to describe the means of measuring adherence.

A flowchart of the search strategy is included as Figure 3.1.

Initially 338 articles were obtained, 10 of which were duplicates. I then reviewed the 328 abstracts for relevance using the previously described inclusion and exclusion criteria. Following the abstract review, 69 full text articles were sourced. On reading these full text articles and critically appraising them using schedules from the Critical Appraisal Skills Programme (CASP, 2010) , 21 papers met the criteria for inclusion. Reference lists of these 21 full text articles were also reviewed and following a review of abstracts this revealed an additional 70 articles for full text assessment; of these, 17 were retained. Forward searching of references sourced a further 19 articles for full text assessment; of these 7 were retained. Thus, the final review included a total of 45 papers.

Figure 3.1. Flow Chart of Literature Search



For reference, a summary of included papers considering factors affecting medication adherence is included (Table 3.1) before presenting information about emerging themes from the integrative review.

Table 3.1. Factors Affecting Adherence with Antipsychotic Medication in Children, Adolescents and First Episode Psychosis

Reference	Study Design/duration	Participant Descriptors	Definition of adherence	Measurement of adherence	Results	Study Limitations
Barbeito et al. (2013)	Prospective, eight year cohort study.	92 consecutive admissions to a psychiatric ward in a general hospital in Victoria, Spain.	Good adherence: score of 4 on the Morisky-Green 4 item scale. Comparison of baseline and follow up scores classified patient adherence as always good, always bad, improving from bad to good or deteriorating from good to bad.	Self-report.	Poorer adherence associated with family history of psychosis, lower global functioning at baseline, fewer depressive symptoms, increased alcohol intake at baseline, involuntary first admission to hospital, cannabis use during follow up. Cannabis and tobacco use at baseline were not significant predictors of adherence.	Single site. No objective measure of adherence. Recruitment from a hospital ward only.
Chen et al. (2005b)	Prospective, three year follow up, cohort study.	93 patients consecutively diagnosed with FEP in Hong Kong.	Adherent : at least 75% compliance rate.	Self-report. Informant report.	Cognitive functioning not significant.	No objective measure of adherence. 30% lost to follow-up.
Coldham et al. (2002)	Prospective, follow up cohort study over 12 months.	186 patients in the Calgary Early Psychosis Programme.	Non-adherence: Stops medication for months at a time or doesn't take medication. Inadequate adherence: misses doses but never for longer than a few weeks at a time. Good adherence: Rarely or never misses doses.	Rating by primary rater from: Prescription chart review Case manager rating. Referred to a secondary rater where ratings differed.	Gender, substance misuse or diagnosis not significant. Non-adherent group were younger, had a younger age of onset and poorer pre-morbid functioning. At baseline and follow-up they had poorer insight and quality of life and were consuming more alcohol and cannabis. Family involvement was significantly associated with good adherence. Akathisia and extrapyramidal side effect (EPSEs) were not a significant predictor. Most significant predictors were younger age, poor pre-morbid functioning, low levels of family support and use of cannabis at follow up.	Retrospective analysis of adherence. Subjective measures only. Single site.
Faridi et al. (2012)	Prospective, follow up, cohort study over 12 months.	48 patients with FEP admitted to specialist EIS service in Montreal with concurrent active use of cannabis.	Adherent: Taking more than 75% of prescribed doses.	Self-report. Case manager report. Family report.	Those continuing and ceasing to take cannabis became less adherent in the first six months. By 12 months, 40% of those ceasing cannabis became adherent again, much lower than the 92% becoming adherent whilst continuing to consume cannabis .	Relatively small sample. Single site. No objective measure of adherence.

Reference	Study Design/duration	Participant Descriptors	Definition of adherence	Measurement of adherence	Results	Study Limitations
Gearing and Charach (2009)	Retrospective, follow-up, longitudinal, cohort study of patients discharged on antipsychotic medication between Jan 1999 and Oct 2003.	65 patients from six child and adolescent psychiatric inpatient units in Ontario, Canada.	Adherent: Following physicians instructions about medication.	Parental Report.	Ten times more likely to adhere if discharged on concurrent antidepressants or mood stabiliser. DUP showed trend towards statistical significance. Age, gender, family history of depression and decreased social support did not affect adherence.	Retrospective design. Information gathered from health records and parental report- relies on accurate and comprehensive records and parental memory over the preceding two years. All patients were discharged on one of three antipsychotic medications, olanzapine, risperidone or quetiapine. Single measure of adherence. No objective measure of adherence.
Hill et al. (2010)	Prospective, four year, follow up, cohort study.	171 patients in a region in Ireland.	Adherent: at least 75% compliance with prescribed doses.	Self-report.	Poor adherence linked to alcohol and drug misuse at baseline and at follow up, greater degree of symptoms, poor insight, poor global functioning, negative medication attitudes, longer DUP and more frequent hospital admissions over the four years.	Single measure of adherence. No objective measure of adherence. Adherence only assessed at baseline and four years and not at intervening periods. The study does not therefore capture changes in adherence with time.
Hon (2012)	Grounded Theory Study.	12 patients in an Early Intervention Service in Southern England.	This was a views study and it therefore relied on personal reflections about what affected adherence with antipsychotic medication.	Self-report.	Medication variance was driven by three factors: Quality of life (living a normal life, being in control, freedom to choose, independence social relationships. Health Status (impact of illness, efficacy and side effects of medication). Discernment (knowledge and information, self-assessment, personal experiences).	Single, inner city site. Researcher worked in the team so this might have introduced some bias. All patients in the study were prescribed aripiprazole. Results may have differed with other antipsychotic medications. Single measure of adherence. No objective measure of adherence.

Reference	Study Design/duration	Participant Descriptors	Definition of adherence	Measurement of adherence	Results	Study Limitations
Hui et al. (2006b)	Prospective, cohort study.	229 patients from two early psychosis clinics in Hong Kong.	Poorly adherent: if they indicated on the scale that they forgot to take medication or had stopped it of their own accord.	Self-report using an abridged version of the Medication Adherence Rating Scale. Clinician questionnaire based on the Medication Adherence Rating Scale.	Feeling embarrassed was significantly associated with stopping medication. Patient embarrassment was under-recognised by clinicians. Taking medication only when well was related to stopping but not forgetting to take medication. Feeling worse without medication was significantly linked to forgetting to take medication but not stopping medication. Feeling medication was beneficial was not associated with forgetting or stopping medication. In early psychosis the groups who forgot and stopped medication appeared distinct with few reporting both. 38% of patients reported forgetting their medication.	No objective measures of adherence. Partially funded by pharmaceutical company.
Kamali et al. (2006)	Prospective, six month, follow up, cohort study.	60 patients discharged from a psychiatric hospital in Dublin, Ireland.	Adherent: at least 75% compliance over preceding three months.	Self-report.	Poor adherence associated with greater positive symptom scores (grandiosity most predictive), alcohol misuse, substance misuse, poor insight (particularly if no substance misuse present). Insignificant factors: age, gender, admission status.	40% of the initial sample did not attend follow up. Insight assessed using the single item on the Positive and Negative Syndrome Scale (PANSS). Relatively small sample from a single service. Single measure of adherence. No objective measure of adherence.
Kampman et al. (2002)	Prospective, cohort study.	59 patients in a single site in Finland.	Self-report of adherence categorised as regular, irregular, occasional use or failure to use medication at all.	Medical record review which included: Self-report. Details of failure to collect a prescription at the expected time.	Increased risk of poor adherence with males, younger patients with limited social activities, greater total PANSS score and a low score in the positive symptom subscale.	Retrospective collection of adherence data from medical records only. Three month follow-up period. Weak definition of adherence. Single site. Relatively small sample.

Reference	Study Design/duration	Participant Descriptors	Definition of adherence	Measurement of adherence	Results	Study Limitations
Lecomte et al. (2008)	Cross sectional study.	118 patients with early psychosis from four sites in Canada.	Medication rating as follows: 1=Not taking medication as directed and no intention to. 2= Not taking medication as directed but considering doing so. 3= Not taking medication as directed but am going to start taking it. 4= Consistently taking medication as directed. Also asked on a scale of 1-100 how often they forgot to take medication, altered the dose, or intentionally missed a dose to suit need.	Self-report.	Predictors of poor adherence were being male, having a history of legal problems, presence of more positive symptoms, witnessing violence as a child and a personality trait of high agreeableness. No significant difference found for insight or substance misuse	91% reported always taking their medication as directed, they asked answers to the supplementary questions about forgetting, changing or altering dose and created three sub-groups i) perfect medication adherence with no changes in dose ii) medium adherence with less than 50% changes in dose iii) Poor adherence with no medication at all or changes in dose more than 50% of the time. This is a low delineator between good and medium adherence. Single measure of adherence. No objective measure of adherence.
Lepage et al. (2010b)	Six month, case control study.	160 patients in an EIS service in Montreal and 35 controls.	5 point Likert scale used: 4= fully adherent. 3= partially adherent. 2 or below= poorly adherent.	Case manager report based on: Patient interview Prescription review Pill count.	Age, gender, education and patient or parental socioeconomic status was insignificant. Type of antipsychotic medication was not significant. Verbal, performance or full scale IQ did not impact medication adherence.	Single site study. Environmental or motivational issues were not considered. Some participants were living with family which might have influenced adherence. Did not control for other factors which might have affected adherence e.g. substance misuse. Numbers of controls much lower than patients.

Reference	Study Design/duration	Participant Descriptors	Definition of adherence	Measurement of adherence	Results	Study Limitations
Le Quach et al. (2009)	Two year, randomised controlled trial.	547 patients in two sites in Denmark (Copenhagen and Aarhus).	Poor adherence: prescribed but not started, prescribed but discontinued, unregulated medication, symptomatic but poor motivation to take medication. Good adherence: medication taken as prescribed, not prescribed medication but not symptomatic.	Self-report. Staff report. Case note review. Prescription chart review.	Negative medication attitudes and lack of dual parental upbringing were the strongest predictors after two years of poor adherence. Poor insight at year 1, no vocational education and lack of a relative to interview at baseline were significant. After one year, negative medication attitudes, poor illness insight at baseline, substance abuse, no vocational education, young age and high global functioning predicted poor adherence.	Lack of clarity about some of the adherence categories e.g. unregulated medication. Assumptions made about adherence in those not prescribed medication, depending on whether they were symptomatic or not.
Malla et al. (2002a)	One year, prospective, cohort study.	66 patients in a programme to promote early recognition, comprehensive assessment and treatment. Urban population in Canada.	Compliance rated on a four point scale depending on whether 0-25%, 25-50%, 50-75% or 75-100% were taken in the previous month.	Consensus rating based on: Self-report Carer report Clinician report	Poor adherence associated with lower social relations and activities of daily living.	Approximately one-third of patients were excluded from analysis due to incomplete data. Single site.
McEvoy et al. (2006a)	Two year, randomised, double-blind, controlled trial.	251 patients over 14 study centres in North America and Western Europe.	Poor adherence: failure to take any medication over a seven day period.	Pill count. Self-report.	Higher levels of insight into psychiatric illness and need for medication predicted adherence.	Patients were prescribed either olanzapine or haloperidol. Patients had high baseline levels of insight which might have reflected in the results. Medication supplied free of charge which might have influenced adherence behaviours. Drug company sponsored.

Reference	Study Design/duration	Participant Descriptors	Definition of adherence	Measurement of adherence	Results	Study Limitations
Miller et al. (2009)	Prospective, one year, cohort study	112 patients from two services in New York enrolled in the Preventing Morbidity in First Episode Schizophrenia Study.	Adherent if medication was taken at least 50% of the time.	Self-report. Clinician report. Carer report. Plasma level monitoring.	Cannabis use associated with poor adherence.	Study was to compare effectiveness of two antipsychotics, this was therefore secondary analysis of study data. Study participants may not be representative of many patients with FEP. Low threshold for adherence. Study focused purely on cannabis and did not consider other illicit substances which may have been consumed.
Montreuil et al. (2012)	Prospective, six month, cohort study.	81 patients.	Adherent if more than 75% of full doses were taken for each month of the study.	Self-report. Clinician report. Carer report. Pill count.	Good case manager rated working alliance, but not patient-related alliance, was predictive of good adherence.	Single centre study. Study did not assess side effects of medication which may influence adherence and therapeutic alliance. Working alliance only rated by clinicians.
Mutsatsa et al. (2003)	Prospective, cohort study.	101 patients in West London.	Seven point Compliance Rating Scale (CRS). Good adherence: rating of 5 or above on the CRS. Poor adherence: rating of 4 or below on the CRS.	Clinician report. Carer report. Prescription chart review. Case note review.	Age, gender, substance or alcohol misuse, type of antipsychotic, ESPSEs or non-neurological side effects did not significantly affect adherence. Subjective wellbeing ratings were also not linked to adherence behaviours. Poor adherence was significantly linked to negative and disorganisation syndromes and poor total insight, illness awareness and recognition and need for treatment scores. Negative attitudes to medication (as measured by the Ratings of Medication Influences [ROMI] scale) were significantly associated with poorer adherence. Insight and negative attitudes to medication were most significant predictors of poor adherence accounting for 27% of the variance.	Single centre study.

Reference	Study Design/duration	Participant Descriptors	Definition of adherence	Measurement of adherence	Results	Study Limitations
Novak-Grubic and Tavcar (2002)	Prospective, naturalistic, one year, follow up, cohort study.	56 patients in a single site in Slovenia.	Adherent: Strict adherence to medication regimen.	Self-report. Carer report.	Socio-demographic variables e.g. age, living situation, marital, educational & occupational status, severity of EPSEs, type of medication, attitude to hospitalisation and length of stay were not significantly associated with adherence. Diagnosis of schizophrenia rather than schizophreniform or schizoaffective disorder, poor insight at discharge and more severe positive symptoms on admission were associated with poor adherence.	Sample all male. All initially admitted to a psychiatric intensive care unit which might reflect severity of illness or risk. Substance misuse was an exclusion criteria. Single site. Relatively small sample. Insight assessed from a single item in the PANSS questionnaire. Rigid definition of adherence. No objective measure of adherence.
Opjordsmoen et al. (2010)	Four year, cohort study.	217 consecutive admissions to three hospitals in Norway.	Adherent: taking prescribed medication.	Self-report.	Involuntary admission had no impact on treatment adherence.	Perceived coercion not assessed. Admission based on legislation in Norway. 23.1% refused consent. Definition of adherence not comprehensive. No objective measure of adherence.
Perkins et al. (2006)	Two year, randomised, double blind, clinical trial.	254 patients over 14 study centres in North America and Western Europe.	Non-adherent: refusal to continue taking any antipsychotic, start of the first seven day gap in medication (or the first four day gap if within the first 12 weeks of the study).	Pill count.	Age, gender, duration of illness, social support, diagnosis, ethnicity, alcohol, drug or cannabis use and negative aspects of treatment e.g. side effects, interference with life goals, embarrassment not associated with adherence. Belief in the need for treatment and benefits of medication was associated with adherence. Clinician rated akathisia, but not parkinsonian side effects, were associated with non-adherence. Increased BMI also significant for non-adherence over a seven day period. Non-adherence was 1.5 times greater with haloperidol than olanzapine but was mediated in part by other associations e.g. negative aspects of medication. Less improvement in positive symptoms and psychopathology linked to non-adherence.	Secondary analysis from a clinical trial to assess efficacy of olanzapine vs. haloperidol. Results obtained from a clinical trial rather than a naturalistic setting. Single measure of adherence. Social support was the perceived rather than actual level of social support.

Reference	Study Design/duration	Participant Descriptors	Definition of adherence	Measurement of adherence	Results	Study Limitations
Pogge et al. (2005)	Follow up, prospective, cohort study.	86 patients discharged from a private psychiatric hospital in New York on olanzapine or risperidone.	Adherent: currently (over the past week) taking medication as directed. Non-adherent: patient made the decision to stop medication on their own. Discontinued: medication stopped at the request of parent or prescriber	Self-report by patient through telephone interview. If patient was not a reliable historian a parent was approached.	Predictors of adherence were substance abuse, rapid weight gain during hospitalisation, failure to comply with individual therapy post discharge and being younger. Gender, ethnicity, diagnoses other than substance misuse, efficacy of medication, positive symptoms, side effects of EPSEs, memory changes, akathisia, sedation, anticholinergic side effects and perceived weight gain were not significant variables.	Risperidone or olanzapine not always prescribed for psychosis. Follow up adherence phone call occurred anytime between 3 and 18 months post-discharge. Patients were asked about current adherence so the design would not have picked up variable adherence patterns over time. Power calculation included but sample size was insufficient to detect differences between olanzapine and risperidone groups. Single site. No objective measure of adherence.
Rabinovitch et al. (2009)	Follow up, longitudinal, six month, cohort study.	102 consecutive admissions with FEP to the Prevention and Early Intervention Programme for Psychoses (PEPP) in Montreal, diagnosed with schizophrenia spectrum disorder or affective psychosis.	Adherent: Over 75% of prescribed doses were taken during the study period.	Formal interview with a trained rater. Adherence information obtained from the interview, case manager records of visits. Rated measure highly correlated with pill counts on a sample of 51 patients.	No significant difference for gender, age of admission, DUP, IQ, premorbid adjustment, diagnosis, substance misuse, level of baseline depressive symptoms, weight gain, EPSE's, disorganisation, psychomotor poverty or reality distortion syndrome. Level of social support and early medication acceptance were significant predictors of adherence.	Social support was case manager rated. In a smaller sample, social support was rated by the patient and the findings in terms of social support were not replicated. Poor records of weight acknowledged in first two months when most weight gain is likely to occur. Patients from a single service received intensive support and treatment programme.

Reference	Study Design/duration	Participant Descriptors	Definition of adherence	Measurement of adherence	Results	Study Limitations
Rabinovitch et al. (2013)	Follow up, longitudinal, cohort study.	81 FEP patients in the PEPP.	Good adherence: taking over 75% of prescribed doses over the previous month.	Patient Report. Clinician Report. Family Report. Pill counts used to determine a consensus measure of adherence.	Baseline social support was associated with initial adherence, but not with changes in adherence over time. Increased social support over time associated with a decrease in adherence, irrespective of insight and substance misuse. Significant correlation with mean insight scores. Trend with lifetime substance use disorder. No relationship with sex, marital status or level of psychopathology.	Patients subject to an intensive support and treatment programme. Might not be replicated in those receiving differing standards and means of care.
Robinson et al. (2002)	Prospective, one year, follow up, cohort study.	118 new admissions to an inpatient hospital in New York.	Poor adherence: failure to take medication for a period of at least one week.	Self-report. Carer report. Clinician report.	Poor adherence associated with poor premorbid, cognitive and executive functioning. Poor adherence associated with Parkinsonian side effects. Following first relapse, lower parental social class, poor education attainment, side effects and discontinuation of medication during the initial treatment phase were associated with poor adherence. Premorbid social functioning, DUP, diagnosis, symptom severity and family attitudes were not significant.	Early study. Data collection period was 1989-1996. No objective measure of adherence. Single site. Secondary study.
Segarra et al. (2012)	Prospective, one year cohort study.	577 patients recruited from 19 centres in Spain.	Good adherence: rating of 4 on the Morisky-Green scale with corroborative information from other sources .	Self-report. Carer report. Prescription review. Pill count.	Greater insight and higher levels of education were associated with better adherence at follow up. Treatment with a long acting injection was associated with higher rates of adherence.	10.3% were on long-acting antipsychotics and up to 47% were on a combination of long-acting and oral antipsychotics. The high proportion of patients on long-acting injections meant that adherence rates were high. This may not be representative of other samples. 22% drop out rate.

Reference	Study Design/duration	Participant Descriptors	Definition of adherence	Measurement of adherence	Results	Study Limitations
Sleath et al. (2010)	Retrospective, cohort study.	64,775 patients identified from a database detailing claims for prescription costs in Georgia and North Carolina in the United States of America (USA).	Adherent: at least one prescription was collected and the Proportion of Days Covered (PDC) by a prescription was 80%.	Proportion of days covered using prescription collection data.	Black children were less adherent than white children, or those of unknown race. Black children in North Carolina were more adherent than those in Georgia. Black boys were less adherent than black girls.	Single measure of adherence. No confirmation that medication was subsequently consumed. The database only records data from pharmacies receiving reimbursement via Medicaid.
Steger et al. (2012)	Follow up, six month, cohort study.	216 patients in the PEPP service in Montreal.	Adequate adherence: taking more than 75% of doses. Inadequate adherence: taking 75% or fewer prescribed doses.	Self-report. Case manager report.	Early resolution of negative, but not positive, symptoms associated with inadequate adherence. Those whose negative symptoms had resolved at 3 months were less likely to be adequately adherent at 6 months. Late resolution of positive and negative symptoms did not affect adherence rates. Baseline insight was significantly associated with later adherence. Diagnostic category was significant. Those with affective psychosis were more adherent than those with a schizophrenia spectrum disorder. Age, gender, marital status, DUP, diagnosis, substance misuse did not influence three month adherence in those with early resolution of negative symptoms.	Excluded patients with missing data were more likely to be inadequately adherent. Potential for sample bias. Single service study. No objective measure of adherence. Pharmaceutical company sponsored.

Reference	Study Design/duration	Participant Descriptors	Definition of adherence	Measurement of adherence	Results	Study Limitations
Tunis et al. (2007)	Naturalistic, randomised, open-label trial.	440 patients across 21 sites in the USA.	Adherent: Remaining on the initial antipsychotic for at least 180 days, with no treatment gaps greater than 14 days. Secondary analysis of antipsychotic persistence at 90 and 270 days was also undertaken.	ROMI Scale.	Antipsychotic persistence associated with initial prescription of olanzapine rather than risperidone, no comorbid substance misuse, positive relationships with staff and fulfilment of life goals. Patient persistence was on average 46 days longer when the initial prescription was olanzapine and 44 days longer when there was no misuse of substances. Patients were twice as likely to have persisted for 180 days if there was a strong therapeutic alliance or where medication was supporting fulfilment of life goals. Perceived daily benefit and fear of relapse were rated as the most influential factor for adherence, followed by side effect relief, fulfilment of life goals, deference to authority, positive relation with clinical staff, outside positive influence about medication, outside opinion that current medication is better and outside pressure by staff. Two most influentially rated factors, perceived daily benefit and fear of relapse did not mirror the most influential factors for persistence on actual assessment.	Only two antipsychotics were prescribed to patients. Higher level of monitoring within the study, even though it was conducted in a naturalistic setting, might have influenced responses and behaviours. Researchers were employed by the pharmaceutical company manufacturing olanzapine. Single measure of adherence.
Uçok et al. (2006)	Observational, one year, follow up, cohort study.	74 patients admitted with FEP in Turkey.	Non-adherent: less or no medication was taken for ten consecutive days.	Self-report. Carer report.	Higher ratings of suspiciousness on the Brief Psychiatric Rating Scale (BPRS) at discharge, was linked to poor adherence at follow-up.	All patients had been treated for their first episode in an inpatient clinic rather than the community which may have suggested more severe illness at commencement. No objective measure of adherence.
Verdoux et al. (2002)	Two year, follow up, cohort study.	35 consecutive admissions to a psychiatric hospital in Bordeaux fulfilling inclusion criteria.	Poor adherence: medication was stopped completely against medical advice for at least two weeks over a six month interval.	Self-report. Informant reports.	Poorer cognitive flexibility was associated with good adherence. No associations with verbal fluency, attention, visual-motor capabilities, verbal and visual memory.	Single site. No objective measure of adherence.

This summary of relevant papers highlights that the research studies have, in the main, been small scale and have utilised many different designs. Definitions of adherence are extremely inconsistent across published papers, and assessment of adherence has been via a number of different strategies although self-report appears most prevalent. All these variables make comparison of studies and conclusions about findings extremely difficult. The variability in approach also highlights a need to agree a gold standard for defining and assessing medication adherence in research. Despite these limitations, further information is now provided about factors affecting medication adherence. These factors are presented in six different subcategories; patient, social- and economic, health system or health team, condition, treatment and other factors affecting medication adherence. This mirrors five of the dimensions proposed by the World Health Organisation (WHO) for several physical health conditions such as hypertension, tuberculosis, asthma, cancer and HIV (World Health Organisation, 2003), however for psychosis I struggled to assign some research findings to the categories of patient, social- and economic, health system or health team, condition or treatment factors presented for physical illness, requiring addition of an ‘other’ category.

3.3. Patient Related Factors Affecting Adherence

Patient related factors which may impact on antipsychotic adherence in FEP include age, ethnicity, gender, insight, patient attitudes and personality traits.

3.3.1. Age

EIS caters for a wide age group, in recognition of the fact that first episode psychosis can present at any age in children and young adults. It is therefore important to consider whether age may influence adherence behaviours. Most studies concluded that age was not significant (Novak-Grubic and Tavcar, 2002, Mutsatsa et al., 2003, Kamali et al., 2006, Perkins et al., 2006, Gearing and Charach, 2009, Lepage et al., 2010a, Segarra et al., 2012, Steger et al., 2012, Chan et al., 2014a). A younger participant age was linked to poor adherence in a small number of studies (Coldham et al., 2002, Kampman et al., 2002, Pogge et al., 2005, Le Quach et al., 2009).

3.3.2. Ethnicity

The evidence base considering the effects of ethnicity on medication adherence in FEP is limited, however two studies have shown no impact on medication adherence (Pogge et al., 2005, Perkins et al., 2006). Sleath et al. (2010) found that black children in North Carolina and Georgia were significantly more likely to take their medication less than 80% of the time compared to white children or those classified as ‘unknown race’ (Sleath et al., 2010). Reviewing suicides within a year of first contact with mental health services, it was found that the incident of non-adherence with medication was higher amongst ethnic minority groups compared to a white population (Hunt et al., 2003). In another study greater adherence rates were found in white, rather than non-white, race in the twelve months following a first admission for affective psychosis (Strakowski et al., 1998). There is a suggestion therefore that in some ethnic minority groups rates of medication adherence are lower, but paucity of data prevents firm conclusions being drawn.

3.3.3. Gender

Another important demographic variable to consider is the effect of gender on medication adherence. The majority of studies have failed to find a link between gender and medication adherence (Coldham et al., 2002, Mutsatsa et al., 2003, Pogge et al., 2005, Kamali et al., 2006, Perkins et al., 2006, Gearing and Charach, 2009, Rabinovitch et al., 2009, Hill et al., 2010, Lepage et al., 2010a, Steger et al., 2012, Rabinovitch et al., 2013, Chan et al., 2014a). A few studies have concluded that males with FEP were less likely to take medication as prescribed (Kampman et al., 2002, Lecomte et al., 2008). In Sleath et al.’s (2010) study black girls were more likely to adhere with medication than black boys; however, considering the sample as a whole boys were more adherent (Sleath et al., 2010).

3.3.4. Insight

Another patient factor requiring consideration is insight. Insight in mental illness is a multifactorial phenomenon driven by psychological, neuropsychological and organic factors (Ouzir et al., 2012). Due to the nature of psychotic illness, insight is often lacking and is a common feature of the illness (McFarland et al., 2009). Differing definitions of insight have existed over the years and include the ability to perceive clearly or deeply; the faculty of seeing into inner character or underlying truth; intuitive understanding of the significance of an event or action; an understanding of relationships that sheds light on a problem; self-knowledge; and a sudden, penetrating understanding of a complex problem or situation (Silberman, 2014). Because of the negative impact poor insight has on patient outcome (Chan et al., 2014a), it is important to assess and measure this using available insight tools. The Insight and Treatment Attitudes Questionnaire (ITAQ) assesses the patient’s attitudes or beliefs about whether they are suffering from a mental illness, and subsequently whether this requires treatment (McEvoy et al., 1981). The Schedule for the Assessment of Insight (SAI) measures subjective recognition of mental illness, compliance with treatment and appropriate recognition of psychotic phenomena by the respondent (David et al., 1990). The Scale to Assess Unawareness of Mental Disorder (SUMD) considers awareness and attribution of illness, current and retrospective assessment of recognition of a mental disorder, the effects of medication and the consequences and specific signs of mental illness (Amador et al., 1993). Finally, the Birchwood self-report insight scale for psychosis focuses on general attributions about illness, specific attributions about symptoms and the perceived need for treatment (Birchwood et al., 1994).

The literature provides support for the fact that poor insight into illness and medication impacts negatively on medication adherence (Coldham et al., 2002, Novak-Grubic and Tavcar, 2002, Mutsatsa et al., 2003, Kamali et al., 2006, McEvoy et al., 2006a, Perkins et al., 2006, Le Quach et al., 2009, Hill et al., 2010, Segarra et al., 2012, Steger et al., 2012, Chan et al., 2014a). Isolated studies have failed to show an association between insight and adherence (de Haan et al., 2007, Lecomte et al., 2008), however this is outweighed by the amount of evidence supporting an association.

Having considered the effect of insight on medication adherence, it is also important to consider whether factors such as premorbid adjustment and personality features have a bearing on medication adherence.

3.3.5. Premorbid Adjustment

Initially I debated whether pre-morbid adjustment was a patient related or condition related factor. Premorbid adjustment is defined as “the degree to which a subject had fulfilled the appropriate expectations for his or her sex and age before the onset of the illness” (Phillips, 1953). On the basis of this definition, I decided premorbid adjustment was a patient-related, rather than an illness related factor as it related to a period preceding illness onset. Poor pre-morbid functioning has been associated with poor adherence in one study (Coldham et al., 2002), but not in another study (Rabinovitch et al., 2009).

3.3.6. Personality Traits

Studies have also found that personality traits may provide an indicator of medication adherence. Hostility and uncooperativeness (de Haan et al., 2007), high agreeableness (Lecomte et al., 2008) and suspiciousness (Uçok et al., 2006) have been linked to poor adherence. Embarrassment at the need to take medication was associated with poor adherence in one study (Hui et al., 2006a), but not in another study (Perkins et al., 2006).

3.3.7. Other Patient Related Factors

Finally, I will outline other patient related factors that have been suggested, in single studies, to be of relevance to medication adherence. Patient discernment as determined by knowledge and information, self-assessment and personal experience was one of three factors driving medication adherence in a grounded theory study conducted with patients prescribed the antipsychotic medication aripiprazole (Hon, 2012). Subjective wellbeing was also shown not to be important to medication adherence (Mutsatsa et al., 2003).

As well as patient factors, it is important to consider social and economic factors which may influence adherence in FEP.

3.4. Social and Economic Related Factors Affecting Adherence

In considering social and economic factors impacting on adherence, specific attention is drawn to the relevance of social support, including marital status, educational factors and socioeconomic situations.

3.4.1. Social Support

Given the relatively young age at which first episode psychosis can present, patients may still be living at home particularly if they are still of school age. It is therefore relevant to consider the impact family and social support has on medication adherence. Poor family involvement and social support has been shown to adversely affect medication adherence (Coldham et al., 2002, Le Quach et al., 2009, Rabinovitch et al., 2009), although other studies did not come to the same conclusions (Perkins et al., 2006, Gearing and Charach, 2009). In a later study conducted by Rabinovich et al. (2013), good social support networks were modestly associated with good medication adherence however increased levels of social support over time were associated with declining adherence rates (Rabinovitch et al., 2013). Whilst this initially appears counterintuitive, it may be that increased social support means that patients no longer feel that they need medication. Studies have also found that a lack of social activities can result in poorer adherence (Kampman et al., 2002, Malla et al., 2002a), however pre-morbid social functioning had no association with poor adherence in another study (Robinson et al., 2002).

It is important when considering these studies to acknowledge that the means of categorising family involvement varied across the studies. The methods utilised included involvement of family members in the early intervention programme, contact with family workers within the team, completion of required family assessments, availability for interview, lack of support or contact with a key relative and case manager rated support. Some of these could be considered weak proxy indicators of familial support and this may have influenced the findings.

Marital status might also be viewed as a proxy indicator of social support, however studies have not shown an association between marital status and medication adherence (Novak-Grubic and Tavcar, 2002, Steger et al., 2012, Rabinovitch et al., 2013).

3.4.2. Other Social and Economic Related Factors

Considering other studies which have included social and economic related factors, educational status (Novak-Grubic and Tavcar, 2002, Lepage et al., 2010a), intelligence scores (Rabinovitch et al., 2009, Lepage et al., 2010a), patient or parental socioeconomic status (Lepage et al., 2010a), living situation (Novak-Grubic and Tavcar, 2002), family history of depression (Gearing and Charach, 2009) and occupational status (Novak-Grubic and Tavcar, 2002) have been shown not to impact on medication adherence. One study found that lack of vocational education was associated with poor adherence (Le Quach et al., 2009). Other studies have suggested that poor education attainment predicts poor adherence after an initial relapse (Robinson et al., 2002, Segarra et al., 2012). It has also been suggested that lower parental social class (Robinson et al., 2002), family history of psychosis (Barbeito et al., 2013), a history of legal problems (Lecomte et al., 2008) and witnessing violence during childhood (Lecomte et al., 2008) can be predictive of poor adherence.

Having presented the evidence for social and economic-related mediators of adherence, the next dimension of health system- or health team- related factors will be addressed.

3.5. Health System or Health Team Related Factors Affecting Adherence

There are a number of health system- or health team- related factors which may affect medication adherence. These include healthcare systems, associated insurance policies, poor staff knowledge, ease of access to medication and relationships with healthcare professionals, staff (Whittemore and Knafl, 2005). There is limited information about heath team- or health system- related factors which impact antipsychotic medication adherence in FEP, which I will now present.

3.5.1. Therapeutic Alliance

When considering health team factors impacting on medication adherence, it is important to consider whether relationships between practitioners and patients influence subsequent adherence with antipsychotic medication. Studies have shown that poor therapeutic alliance (Tunis et al., 2007) and negative initial interactions with staff (de Haan et al., 2007) do adversely affect medication adherence. In one study case manager, but not patient, ratings of therapeutic alliance was found to be predictive of adherence (Montreuil et al., 2012).

3.5.2. Admission Status

Involuntary admission to hospital is another health system-related variable which has the potential to affect medication adherence. Although adherence to medication improved in the eight years following a first involuntary hospital admission (Barbeito et al., 2013), other studies have shown the opposite to be true (Kamali et al., 2006, Opjordsmoen et al., 2010). One study comparing adherence rates in an inpatient or outpatient setting concluded that the treatment setting at baseline had no impact on subsequent adherence (Hill et al., 2010).

3.5.3. Other Health Related Factors

Health system or team factors can also have an impact on the amount of information about both illness and medication a patient receives. Studies have shown that provision of information about illness and medication positively influences adherence with medication (Hon, 2012, Chan et al., 2014a).

Contrasting these findings, another study showed that admission length and the patients' feelings and attitudes to the admission were not a significant mediator of adherence (Novak-Grubic and Tavcar, 2002). Irrespective of the potential impact on adherence, national guidelines recognise the importance of patient-centred care and encourage healthcare professionals to involve patients in discussions about medication where this is appropriate (NICE, 2009a, NICE, 2009b, NICE, 2013, NICE, 2014).

3.6. Condition Related Factors Affecting Adherence

Whilst there is little literature addressing health system and health team related factors affecting antipsychotic adherence in FEP, the same cannot be said of condition-related factors as the evidence base is more expansive. Factors considered include diagnosis, DUP, symptoms, cognitive and global functioning and substance misuse.

3.6.1. Diagnosis

Antipsychotic medication may be used for a number of conditions such as first episode psychosis, schizophrenia, schizoaffective disorder or bipolar affective disorder. A study showed that adherence is higher in those with a diagnosis of schizophrenia rather than schizophreniform or schizoaffective disorder (Novak-Grubic and Tavcar, 2002), whilst another found that a diagnosis of schizophrenia as opposed to affective psychosis predicted poorer adherence rates (Steger et al., 2012). The majority of studies have however concluded that diagnosis has no bearing on medication adherence (Coldham et al., 2002, Robinson et al., 2002, Pogge et al., 2005, Perkins et al., 2006, Miller et al., 2009, Rabinovitch et al., 2009, Hill et al., 2010)

3.6.2. Duration of Untreated Psychosis

Given the negative outcomes already linked to a prolonged DUP, it is not unreasonable to question whether there is also an association between DUP and medication adherence. A prolonged DUP showed a trend to poor adherence in a study by Gearing and Charach (2009), and a significant association in another study (Hill et al., 2010). Other studies have shown that DUP (Robinson et al., 2002, Rabinovitch et al., 2009, Steger et al., 2012) and duration of illness (Perkins et al., 2006) are insignificant.

3.6.3. Symptomatology

Ongoing positive and negative symptoms of psychosis may also affect whether somebody takes their medication as prescribed. Higher positive symptom scores have been linked to poor adherence (Novak-Grubic and Tavcar, 2002, Kamali et al., 2006, Perkins et al., 2006, Lecomte et al., 2008, Hill et al., 2010). In a study by Kampman et al. (2002), whilst a low positive subscale score on PANSS was linked to poor adherence, a high total score was also associated with poor adherence showing the adverse effect negative symptoms have on medication adherence. Early resolution of negative symptoms has also been linked to poor adherence (Steger et al., 2012). Other studies have shown that ongoing symptoms (Segarra et al., 2012) be that positive symptoms (Pogge et al., 2005), early or late resolution of positive symptoms (Steger et al., 2012), late resolution of negative symptoms (Steger et al., 2012), symptom severity (Robinson et al., 2002, de Haan et al., 2007), concurrent depressive symptoms (Barbeito et al., 2013), and ongoing psychopathology (Rabinovitch et al., 2013) have no influence on medication adherence.

3.6.4. Cognitive and Global Functioning

Other condition-related factors to consider include cognitive and global functioning. Cognition has been defined in the broadest term as ‘‘all processes by which… sensory input is transformed, reduced, elaborated, stored, recovered, and used’’ (Neisser, 2003). Evaluation of global functioning in mental health focuses on symptom severity or psychological, social, and occupational functioning (Gold, 2014). Global functioning is in itself affected by cognitive abilities. I decided to include cognitive and global functioning as a condition, rather than a patient related factor as they are both impacted so significantly by psychosis (Rasmussen et al., 2013). Chen et al. (2005) did not determine an association between cognitive function and medication adherence (Chen et al., 2005b). Mutsatsa et al. (2003) found that negative and disorganisation syndromes resulted in poorer adherence, although disorganisation and reality distortion syndrome were not associated with poor adherence in a study by Rabinovitch et al. (2009). Others have concluded that poor premorbid cognitive and executive functioning were significant factors for poor adherence (Robinson et al., 2002). In a two year prospective study good cognitive flexibility resulted in poorer rates of adherence, whilst verbal fluency, attention, visual-motor capabilities and verbal and visual memory had no influence (Verdoux et al., 2002). Poor global functioning has also been associated with both poor medication adherence (Hill et al., 2010) and good adherence (Le Quach et al., 2009). Evidence is therefore contradictory about the impact of cognitive and global functioning on medication adherence in FEP.

3.6.5. Alcohol Misuse

The literature also considers the impact of alcohol, cannabis and other illicit substances on medication adherence. Some of the articles include cannabis and alcohol in a general category of substance misuse whilst others separate them out. I have chosen to replicate the conventions used in the original articles. Initially, I debated whether these categories fit more closely in the section on patient related factors. My reasoning for including them as a condition related factor is because it has been estimated that approximately 40% of people with psychosis misuse substances at some point in their lifetime, at least double the rate seen in the general population (NICE, 2011b). There is therefore a strong association between substance misuse and the condition itself. The evidence base in relation to alcohol is split, with two studies showing that alcohol misuse negatively impacts on medication adherence (Coldham et al., 2002, Kamali et al., 2006) and another two studies highlighting no effect (Mutsatsa et al., 2003, Perkins et al., 2006)

3.6.6. Cannabis Misuse

Cannabis use has been shown to reduce adherence rates (Coldham et al., 2002, de Haan et al., 2007, Miller, 2007, Barbeito et al., 2013), although this was not replicated in a further study (Perkins et al., 2006). In a prospective 12 month study conducted by Faridi et al. (2012), those continuing to use and stopping cannabis became less adherent in the first six months of the study. By 12 months, 40% of those stopping cannabis became adherent with medication again compared with 92% who became adherent with medication whilst continuing to use cannabis (Faridi et al., 2012). Whilst this was a study with a relatively small sample size (n=48), it may be that those continuing to use cannabis may become more adherent with medication over time to reduce the risk of cannabis worsening psychotic symptoms. Cannabis is one of a number of substances liable to misuse, and some studies have assessed the impact of substance misuse more globally on medication adherence. These studies considering the impact of substance misuse on adherence in FEP will now be reviewed.

3.6.7. Substance Misuse

NICE identified that substance misuse is associated with poorer rates of medication adherence in those suffering a psychotic illness (NICE, 2011b). Whilst some studies in FEP support this (Pogge et al., 2005, Kamali et al., 2006, Tunis et al., 2007, Le Quach et al., 2009, Hill et al., 2010), others refute it (Coldham et al., 2002, Robinson et al., 2002, Mutsatsa et al., 2003, Perkins et al., 2006, Lecomte et al., 2008, Rabinovitch et al., 2009, Steger et al., 2012). One study linked poor adherence with a greater severity of substance misuse disorder, suggesting that adherence may also vary with the extent of substance misuse (Wade et al., 2007). The NICE guidance considers adults as well as young people, and given the evidence presented there may therefore be differences between cohorts of young adults with FEP and adults with chronic psychoses.

3.6.8. Other Condition Related Factors

Other condition-related factors may also affect adherence in FEP although the evidence is somewhat limited. Age of onset of illness (Segarra et al., 2012), age of admission, baseline depressive symptoms and psychomotor poverty (Rabinovitch et al., 2009), or memory changes (Pogge et al., 2005) have not been found to affect medication adherence in FEP. Failure to engage in individual therapy has however been shown to be influential (Pogge et al., 2005).

3.7. Treatment Factors affecting adherence

Having considered condition-related factors, treatment factors that may have a direct effect on adherence are now presented. These factors include patient attitudes, side effects, class of antipsychotic and concurrent medication.

3.7.1. Patient Attitude to Medication

One of the potential drivers of medication adherence is patient attitude to medication. A few studies have shown that negative medication attitudes result in lower adherence rates (Mutsatsa et al., 2003, Hill et al., 2010, Chan et al., 2014a), although this finding was not replicated by De Haan et al. (2007). Patients who felt that medication was beneficial were, surprisingly, no more likely to take it than those who found it less beneficial (Hui et al., 2006b). This finding was replicated by Pogge et al. (2005), who found that efficacy of medication was not significant when determining medication adherence. In contrast, a grounded theory study considered that efficacy of aripiprazole did impact on medication adherence (Hon, 2012). Failure to identify an association between adherence and medication efficacy in some published research may be due to the fact that adherence behaviour is multifactorial and decisions are influenced by more than one parameter. This may include, for example, an assessment of the relative merits of better symptom control versus the impact of side effects on daily living.

3.7.2. General Side Effects

Numerous studies have assessed the influence of side effects on antipsychotic medication adherence in FEP. Subjective experiences of medication (de Haan et al., 2007) and side effects (Perkins et al., 2006) were found not to have a bearing on medication adherence in the two identified studies. A qualitative study by Hon (2012) identified side effects as a potential modifier of medication adherence. Further studies have addressed the impact of differing side effects individually and these will now be described.

3.7.3. Extrapyramidal Side Effects

Extrapyramidal side effects is a term used for a group of side effects which include tremor, parkinsonian side effects, akathisia, dystonia, muscle rigidity and dyskinesia (Tandon and Jibson, 2002). Akathisia, but not parkinsonian side effects, were reported as having an adverse effect on antipsychotic medication adherence in one study (Perkins et al., 2006), however another found parkinsonian side effects to have a negative impact on adherence (Robinson et al., 2002). Other studies failed to shown a significant influence of akathisia (Coldham et al., 2002, Pogge et al., 2005), or extrapyramidal side effects (Coldham et al., 2002, Novak-Grubic and Tavcar, 2002, Mutsatsa et al., 2003, Pogge et al., 2005, Rabinovitch et al., 2009) on FEP medication adherence.

3.7.4. Weight Gain

Weight gain is another recognised side effect of some antipsychotic drugs (Robson and Gray, 2007), and some patients find it difficult to cope with the insatiable appetite and weight gain that may result (Usher et al., 2013). Studies have shown that weight gain can result in poor medication adherence (Pogge et al., 2005, Perkins et al., 2006), although this finding has not been consistent (Rabinovitch et al., 2009). In the study by Pogge et al. (2005) the findings varied depending on perceived and actual weight gain. Young people who rapidly gained weight gain were poorly adherent to medication. Perceived rather than actual weight gain had no effect on medication adherence.

3.7.5. Sedation

Another potential side effect which some patients find troublesome is sedation (Dibonaventura et al., 2012). The only study in FEP to consider the impact on adherence found there to be no association (Pogge et al., 2005) between adherence and sedation.

3.7.6. Anticholinergic Side Effects

Anticholinergic side effects that may be secondary to antipsychotic medication include dry mouth, blurred vision, urinary retention and particularly in the elderly confusion, disorientation and memory changes (Mintzer and Burns, 2000). Limited evidence suggests that anticholinergic side effects do not impact on medication adherence in FEP (Pogge et al., 2005)

3.7.7. Other Treatment Related Factors

As well as side effects of antipsychotic medication, the actual antipsychotic medication and the form prescribed is also of relevance to medication adherence. The particular medication prescribed was shown to have no influence on adherence in FEP in several studies (Novak-Grubic and Tavcar, 2002, Mutsatsa et al., 2003, Lepage et al., 2010a). Limited evidence suggests that FEP adherence may be better with injectable depot medication rather than oral medication (Segarra et al., 2012). Another study showed greater adherence rates with risperidone over olanzapine (Tunis et al., 2007).

Patients may also be prescribed other medication alongside their antipsychotic prescription. A concurrent prescription for an antidepressant or mood stabiliser has also been shown to be of no significance to adherence with antipsychotic medication in FEP (Gearing and Charach, 2009).

Studies also highlight that initial medication behaviours may mirror subsequent adherence patterns, with initial medication refusal being predictive of poor adherence longer term (Rabinovitch et al., 2009) and following an initial relapse (Robinson et al., 2002).

3.8. Other Factors Affecting Medication Adherence

On reviewing the evidence for factors affecting medication adherence I struggled to assign some findings to the five dimensions proposed by the World Health Organisation (WHO). This is because it is impossible to presume and make assumptions about what factors may have impacted on measures of a participant’s quality of life or goal attainment. I have therefore chosen to represent these factors of quality of life and goal attainment in a final ‘other factors’ category outwith the WHO classification (World Health Organisation, 2003) described in Section 3.2.

A poor quality of life at baseline and follow-up, as determined by use of quality of life scales, was shown to reduce medication adherence in FEP (Coldham et al., 2002). In a Grounded Theory study of FEP patients prescribed aripiprazole, quality of life as reflected by the parameters of living a ‘normal’ life, being in control, having the freedom to make choices, a good social circle and independence was one of three factors driving medication adherence (Hon, 2012).

Another aspect directly contributing to quality of life is goal attainment, which itself may predict adherence behaviour. The majority of patients presenting with FEP are young with many of their life goals yet to be achieved. Limited evidence suggest that the potential impact of medication interfering with attainment of life goals is not a significant predictor of adherence (Perkins et al., 2006).

Having outlined factors which may affect adherence with antipsychotic medication in FEP, it is also relevant to consider what strategies may improve adherence with medication.

3.9. Strategies to Improve Adherence

The WHO has proposed interventions that may support adherence across the five dimensions of patient, social and economic, health system or team, condition and treatment-related factors in several physical health conditions such as hypertension, tuberculosis, asthma, cancer and HIV (World Health Organisation, 2003). Patient related interventions for promoting adherence across the differing illnesses included setting mutually agreed goals, providing incentives, as well as use of memory aids and reminders. Socioeconomic interventions to support adherence included family support and preparedness as well as social support. Education on use of medicines is a useful condition-related intervention, and treatment interventions include simplification of medication regimens, education on the use of medication, education about adherence, prescriptions tailored to patient need alongside continual monitoring and re-assessment of medication and monitoring of adherence. Several health care and health team factors have been proposed to support adherence across different health conditions. These include good multidisciplinary care, training in educating patients about adherence, ready availability of information for patients, staff training in monitoring adherence, good therapeutic relationships, management of disease and treatment alongside patients, more intensive patient contact, adherence education and training in monitoring adherence (World Health Organisation, 2003). Unfortunately the WHO document did not include specific interventions to support adherence in psychotic illness, however other studies have considered this. One strategy commonly quoted as improving adherence in psychosis is adherence therapy. Adherence therapy centres around an observation that adherence is driven by a patient's beliefs and involves a patient centred approach that explores and tests patient beliefs about treatment, engages in structured medication problem-solving, explores ambivalence about taking medication and considers how medication might influence goal attainment (Brown et al., 2013). The evidence base for adherence therapy in psychosis is mixed with some studies supporting (Kemp et al., 1998, Gray et al., 2004, Maneesakorn et al., 2007), and others not supporting this approach (O'Donnell et al., 2003, Gray et al., 2006, Anderson et al., 2010). More recently, a study specifically considering the role of adherence therapy in early psychosis evidenced a significant reduction in relapse with the intervention (Brown et al., 2013). Whilst education strategies have been shown to increase knowledge about medication and illness, they have not been shown to significantly improve adherence in psychosis (Nose et al., 2003a, Brown and Gray, 2012). Such is the importance of the topic, NICE published a clinical guideline in 2009 to support medicines adherence and patient involvement in decisions about prescribed medication (NICE, 2009b). This guideline emphasised the importance of good communication between healthcare professionals and patients, provision of relevant information to facilitate increased patient involvement in the treatment decision making process and a patient centred approach depending on individual attitudes, motivations and drivers for good or poor adherence. This has more recently been reinforced in the NICE guideline for medicines optimisation, promoting the safe and effective use of medicines to enable the best possible outcomes (NICE, 2015). Despite this, studies have shown that patient and healthcare professional views about factors affecting medicines adherence do differ as will now be highlighted.

3.10. Patient, Carer and Staff Views on Medication Adherence

Whilst evidence exists about factors which may impact on antipsychotic medication adherence, there are very few studies comparing patient, carer and staff views. Where references exist these tend to focus on those with schizophrenia and do not consider FEP separately. Kikkert et al (2006) assessed views of patients, carers and professionals in respect of the importance of medication efficacy, side effects, self-management of side effects, positive and negative expectations and attitudes to medication, insight, information and involvement and professional and non-professional support in the promotion of medication adherence. Whilst there were similarities in the ratings between patients and carers, there were key differences between patients, carers and staff. Ratings of the importance to medication adherence were made against eighty two statements which could then be collated into ten clusters. Staff designated medication side effects as the second most important cluster determining medication adherence but this was rated much lower by patients (4th most important cluster) and carers (least important cluster). Efficacy of medication was the highest ranked cluster for patients and carers; however staff rated this as the fifth most important. Staff felt that insight was the most important cluster determining medication adherence, whereas carers rated this second and patients as the third most important cluster. Healthcare professionals also viewed negative medication attitudes and expectations more highly than patients and carers, and professional and non-professional support and side effects more highly than carers (Kikkert et al., 2006).

Another qualitative study comparing views of patients with schizophrenia, their carers and healthcare providers determined eight themes that influenced adherence. These themes were the environment (lack of support and cost), relationships between family and providers, insight and knowledge, symptoms and outcomes, side effects, substance misuse, stigma and dosing. Views of patients and their healthcare professionals on barriers, facilitators and motivators of adherence were assessed and agreement was found in less than two thirds of the groupings (Pyne et al., 2006). This provides further support for discrepant views between some patients and the staff supporting their care.

In a further study, reasons for medication continuation and discontinuation prior to and during a clinical trial were gathered from clinicians’ and patients’ perspectives. Both patients and clinicians ranked poor control of positive symptoms as the main reason for medication discontinuation before commencement on the study. During the study the most important reason for continuing treatment, as identified by both patients and staff, was that the study drug benefitted positive symptoms. Patients ranked side effects as the highest reason for discontinuation of the study drug, whilst staff continued to rank poor response of positive symptoms as the highest influence (Ascher-Svanum et al., 2010).

Finally, a more recent study compared the attitudes of staff and carers about schizophrenia, medication to treat schizophrenia and adherence to the medication. Three variances in opinion emerged between staff and carers. Firstly, carers felt that psychiatrists relied too much on information provided by patients when assessing adherence with medication. Carers, but not psychiatrists, felt that the condition itself affected adherence to medication. Finally, a higher proportion of carers (two-thirds) than staff felt that medication to treat schizophrenia was detrimental to health (Svettini et al., 2015)

None of the studies presented above considered views of healthcare professionals, patients and carers about adherence with medication in FEP, instead focusing on those with chronic psychoses.

3.11. Summary

Summarising the findings of my integrative review, it is clear that a large proportion of people prescribed antipsychotic medication for FEP do not take medication as prescribed by their doctor and this risks detrimental outcomes. Evidence shows that medication adherence rates in first episode psychosis range from 14.5% (Malla et al., 2008) to 70% (McEvoy et al., 2007, Miller et al., 2011). Where medication is not taken as prescribed adverse personal, social and economic consequences may result. Evidence suggests that poor adherence in FEP may be associated with longer time to, and poorer rates of, remission (Malla et al., 2006, Malla et al., 2008, Petersen et al., 2008). Poor adherence increases the likelihood of relapse (Robinson et al., 1999, Chen et al., 2005b, Uçok et al., 2006, Alvarez-Jimenez et al., 2012, Caseiro et al., 2012), and poorer clinical outcomes (Petersen et al., 2008, Barbeito et al., 2013). An increasing body of evidence is available considering factors which may affect adherence with medication in FEP. Much of the evidence is conflicting with regards to the patient, social and economic, health system and treatment related factors that drive medication adherence and this therefore warrants further study so the impact of poor medication adherence in FEP can be more fully understood. Limited evidence in chronic psychosis suggests differences in the views of patients, carers and healthcare professionals about influential factors impacting medication adherence. Published studies have not, thus far, sought to explore views of patients, carers and healthcare professionals about influential factors impacting medication adherence in FEP.

Upon recognising a lack of published literature comparing patient, carer and health professional views of factors affecting antipsychotic medication adherence in FEP, I initially decided to conduct focus groups to obtain qualitative information from young people, carers and staff. Lack of engagement with this proposal meant that I ended up taking a detour in my qualitative research journey by conducting quantitative survey research. This would provide evidence of whether views were similar or discrepant across the three groups and support an assessment of whether any differences may affect clinical intervention to support medication adherence. As described in Chapter One, this was a detour in my qualitative research journey due to recruitment difficulties. I have however decided to present the survey research in the next chapter as it produced some interesting results in the staff cohort.

CHAPTER FOUR. AN ELECTRONIC SURVEY AND A RE-ROUTING OF MY RESEARCH JOURNEY

4.1. Introduction

In this chapter, I present my initial plans for the study, my exploration of different philosophical worldviews and reflections about the most appropriate worldview underpinning the proposed research. I describe the electronic survey I undertook to gather data on factors influencing 14-18 year olds' adherence with antipsychotic medication. This chapter details the reasons why I undertook this survey, the research framework employed and some of the difficulties that had to be overcome. The research findings, which were subsequently published (Ramdour et al., 2015), are presented. A discussion of how the views of staff reflect and contradict conclusions in published literature are then presented, along with new findings not represented in similar survey studies of adherence in chronic psychoses. Finally, I outline the reasons why the research approach had to be revisited to engage young people in the study, and how this re-routing of my research journey subsequently directed the qualitative PhD research study.

4.2. Research Question

The objectives of this initial research were to explore factors affecting young people's adherence with antipsychotic medication with staff, young people prescribed antipsychotic medication between the ages of 14 to 18 and their carers. The research questions that underpinned the initial plans for the study were as follows:

- What factors are perceived by healthcare professionals (HCP), carers and young people to influence a young person's adherence to antipsychotic medication?
- Are there differences between HCP, carer and young people's views?

My initial thoughts were that there would be differences in opinions across the HCP, carer and service user groups about the factors affecting adherence. I also felt, based on the findings of a similar study in patients with schizophrenia (Kikkert et al., 2006), that staff would recognise the importance of insight and positive attitudes to medication in maintaining good adherence to medication and consider side effects to be one of the predominating determinants of poor adherence.

Having decided upon the research questions to be investigated, a four stage research framework was followed in designing the study (Creswell, 2014). The four components research approach, research design, philosophical worldview, and research methods will now be explored in more detail, however, a summary of the research framework chosen is presented in Table 4.1.

Table 4.1. Research Framework Summary

Research Approach	Quantitative
Research Design	Survey Research
Philosophical Worldview	Postpositivist
Research Method	Survey

4.3. Research Approach and Design

The research approach encompasses whether quantitative, qualitative or mixed methods research is selected, whilst the research design outlines the inquiry which sits beneath the research design.

The three research approaches, quantitative, qualitative or mixed methods research exist at different stages along a continuum (Newman and Benz, 1998). Whilst qualitative and quantitative research might be viewed at opposite ends of this continuum, the reality is that whilst a research study might veer towards either a qualitative or quantitative approach it can still incorporate aspects of the other approach (Crotty, 1998). As mixed methods research includes aspects of both qualitative and quantitative research this sits along the continuum between qualitative and quantitative research (Creswell, 2014).

Qualitative research is used for exploring and understanding meaning of social and human experience, seeking answers in relation to how social experience is shaped and given meaning (Denzin and Lincoln, 2008). In this way it can be viewed as subjectivist. Conversely, quantitative research tests objective theory by determining links and interdependencies across variables, tending to focus on numbers, statistics and analysis of specific variables (Denscombe, 2010). Mixed methods research involves the collation of both qualitative and quantitative data, to derive more comprehensive meaning than would have been obtained using either approach alone (Creswell, 2014). .

Initially I debated whether to take a qualitative approach and conduct focus groups for the purposes of data collection. Feedback from staff working with young people suggested that some patients would be reticent about being involved in a group preferring participation on an individual basis. I therefore decided not to use focus groups for the purposes of data collection. For this research study I wanted to measure the strength assigned to different factors which may affect adherence, comparing findings across three discrete groups. The research being proposed was therefore quantitative in approach.

Having decided to take a quantitative approach, I then had to consider the research design. It was suggested by a researcher in children's health that young people are more willing to contribute via electronic forums. This is because their participation is then at a time of their choosing. It does not require travel to places they may be unfamiliar with, or for them to interact with people they do not know. It was also suggested that other research studies in young people with FEP offered incentives to engagement. This feedback led me to decide upon a survey research design enabling electronic survey completion or completion of hard copy survey forms.

Differences between these three approaches also exist in the philosophical worldviews the researcher brings to the study and the research design and methods which translate the research approach into practice (Creswell, 2014).

4.4. Choosing a Philosophical Worldview

Worldviews are considered to be '*a basic set of beliefs that guide action'* (Guba, 1990). Thus, in research, they are the philosophical beliefs that a researcher brings to a study about the world itself and the nature of research. Philosophical beliefs will naturally be influenced by life experience, views of others and past research experience (Creswell, 2014). Other authors have coined different terms to detail such beliefs, namely paradigms, epistemologies and ontologies, or broadly conceived research methodologies. I will now describe features of the four worldviews most frequently described in research literature, with explanation of the thinking behind the worldview ultimately chosen being presented last.

4.4.1. The Transformative Worldview

A transformative worldview developed from a recognition by some that post-positivist assumptions developed theories that did not fit societal features of marginalisation, power, justice, oppression and discrimination (Creswell, 2014). This worldview is based on an ideal that research needs to confront social oppression through political change (Mertens, 2010). Whilst some young people with psychosis may be marginalised and suffer stigma based on the judgements and views of often ill-informed others, I do not approach this study with a strong argument to support a transformative worldview that young people with psychosis are oppressed or that there is a political agenda to be challenged which will subsequently impact on their approach to taking medication. On this basis my research cannot be considered to have its roots in a transformative worldview. I also do not instinctively operate or feel at my most comfortable working within a transformative worldview.

4.4.2. The Pragmatic Worldview

A pragmatic worldview is driven by actions, situations and consequences (Creswell, 2014). The aim is to outline the research problem, use all available approaches to uncover solutions to the research problem and find out what works (Patton, 1990). Pragmatists also recognise that research always takes place in particular contexts; these contexts include social, political, historical or other contexts. In order to maximise knowledge obtained and best understand the research problem, researchers working within a pragmatic worldview will employ numerous approaches often using both quantitative and qualitative design (Creswell, 2014).

In my personal life I tend to take a pragmatic view about many things and family and friends would say that one of my most common sayings is ‘What will be will be’. My professional background also lends itself to a pragmatic worldview as the world of psychiatry is rarely black and white or clear cut. Despite this, I still felt that a pragmatic worldview did not apply to this research as I felt it was, at heart, an exploratory study; it was neither based on an initial theory nor did the quantitative research aim to uncover solutions to the problem of medication adherence. The objective of my study was to better understand key influences in the hope that this might inform and direct clinical practice.

4.4.3. The Constructivist Worldview

Contrasting with a pragmatic worldview, constructivists believe that individuals seek understanding of the world in which they operate based on historical, cultural and social experience and in doing so develop varied and numerous subjective meanings to explain occurrences based on their background and experience (Crotty, 1998). Social constructivist researchers do not start with a theory but instead generate or inductively produce a theory or meaning based on open-ended questions and a focus on the contexts in which people live, work and interact in order to understand the historical and cultural perspectives. The researcher interprets the data obtained, but in doing so they accept that their interpretation will be influenced by their own personal, cultural and historical background (Creswell, 2013). The quantitative research was not intended to introduce open ended questions or inductively produce theory and so did not fit a social constructivist worldview.

4.4.4. The Post-positivist Worldview

Positivists hold the view that research is objective and what we know of the world can be understood by scientific measurement (Crotty, 1998). Addressing one of the criticisms made of positivism, post-positivists extend the thinking beyond positivism, acknowledging that we cannot always be certain about claims of knowledge when studying human behaviour (Phillips and Burbules, 2000). Thus, post-positivism recognises the reality that all methods of assessing objective accounts are flawed and so only a partially objective account of the world can be developed (Denzin and Lincoln, 2005). Knowledge is based on observation and measurement of the objective reality that exists in the world and therefore sits more comfortably within a quantitative research approach. A reductionist approach is often applied to reduce ideas into small, discrete sets to be further examined. The researcher begins with a theory, collects data to substantiate or refute the theory, and then makes any necessary revisions and conducts further tests (Creswell, 2014). I felt that this worldview sat most comfortably with my proposal to conduct a quantitative study intended to measure the importance assigned to medication adherence variables by young people, carers and healthcare professionals.

Having detailed the research approach, research design and underpinning philosophical worldview, I will now provide further information about the research method used to underpin the survey.

4.5. Methodology

In providing an overview of the survey methodology, I firstly detail the process employed to design the survey and obtain ethical approval before providing more information on the means of sampling the target population.

4.5.1. Survey Design

Separate surveys were designed and Survey Monkey$^{©}$ was used to obtain the views of staff working in EIS and CAMHS, carers and young people. Survey content was derived from conclusions in published literature of factors affecting antipsychotic medication adherence including insight, medication attitudes, side effects and substance misuse (Table 3.1). The content of existing tools such as the DAI (Hogan et al., 1983) and the MARS (Thompson et al., 2000) validated to assess medication adherence in adults were also considered. A consultant psychiatrist also outlined additional factors they felt were of relevance based on their observations from clinical practice.

Survey questions predominantly comprised Likert scales indicating respondent agreement with a range of statements. There was also an opportunity to provide additional information and comments via use of free text boxes in relation to the three most important factors influencing good and poor medication, and specific side effects impacting on adherence where this was indicated as promoting poor adherence by respondents.

The electronic surveys were firstly field tested by the researcher, members of the supervisory team and a member of staff well versed in the use of Survey Monkey within the School of Health at the University of Central Lancashire (UCLan). Content validity was explored with two school teachers, teaching staff working with current inpatients aged 14-16, three children aged 12, 16 and 18, a school governor and two inpatients aged 14-18 to ensure the young person's survey was relevant and would be easily understood by participants. Minor amendments to language used within the survey were made accordingly to ensure comprehension.

4.5.2. Ethical Approval

Ethical approval was obtained from the National Research Ethics Service, University of Central Lancashire and Lancashire Care NHS Foundation Trust Ethics Committees.

4.5.3. Survey Sample

Purposive sampling was utilised in this study. This is a method of non-probability sampling in which decisions concerning the sample recipients are taken by the researcher based upon a range of criteria which may include specialist knowledge of the research issue, or capacity and willingness to participate in the research (Alasuutari et al., 2009). Sampling was conducted in order to distribute the survey to staff with prior and/or current experience working with young people with psychosis. The survey was distributed to 184 multidisciplinary staff working in Lancashire EIS and CAMHS services via the staff email distribution lists. These teams were chosen as they both specifically target young people with mental health difficulties, including FEP. The online survey was also promoted through local team meetings, the hospital website and Facebook page and through the hospital Twitter account. Additionally, the mental health charity, Rethink, distributed the survey to its staff within the region. Members of the College of Mental Health Pharmacists and the Quality Network for Inpatient CAMHS email discussion groups were also invited to participate as further means of accessing staff working with the target patient population.

Posters and flyers were designed, advertising links to the surveys. Hard copies were also made available in reception areas, via care coordinators and service user and carer participation leads working in the CAMHS service. The surveys were also publicised via a number of other different forums (Table 4.2) to engage healthcare professionals, young people and their carers. These posters and flyers also referenced the opportunity to enter a draw for gift vouchers on completion of the survey. Whilst this might bring into question motives for involvement in the research study, I felt that participants would still engage fully and provide vital and robust data for the purposes of my analysis. Incentives were also being offered for the time required for participation in other studies of FEP being conducted at the time, and staff indicated that this had supported recruitment.

Table 4.2. Forums Used to Publicise the Survey

Mode	Forum
Meetings	CAMHS staff meetings EIS staff meetings Preston Mental Health Forum
Websites	Lancashire Care NHS Foundation Trust Young Minds Very Important Kids (VIK) website
Facebook	Lancashire Care NHS Foundation Trust Mental Health Foundation Young Peoples Mental Health Coalition
Twitter	Lancashire Care NHS Foundation Trust Mental Health Foundation Young People’s Mental Health Coalition
Press release	Press contacts of Lancashire Care NHS Foundation Trust
Email distribution	Rethink (North West England) College of Mental Health Pharmacists Staff distribution lists for EIS and CAMHS services in Lancashire Care NHS Foundation Trust

4.6. Results

Whilst it was not possible to estimate the number of people who received the survey, completed responses were received from 60 staff. Demographic information is provided in Table 4.3. Responses from young people and carers were much lower, with only five carers and four young people participating. This prevented any meaningful analysis in the patient and carer group and so I have chosen to focus purely on the findings from the staff responses.

Table 4.3. Staff Demographics

Characteristic	**n (%)**
Age of staff	
20- 29	8 (13.3%)
30- 39	21 (35.0%)
40- 49	21 (35.0%)
50- 59	9 (15.0%)
Not Stated	1 (1.7%)
Gender	
Male	22 (36.7%)
Female	37 (61.7%)
Not Stated	1 (1.7%)
Ethnicity	
White British	43 (71.7%)
White Irish	1 (1.7%)
Indian	5 (8.3%)
Pakistani	1 (1.7%)
Chinese	1 (1.7%)
Any other White background	3 (5.0%)
Any other Asian background	3 (5.0%)
Any other ethnic group	1 (1.7%)
Not stated	2 (3.4%)
Profession	
Registered Nurse/Registered Nurse and Manager	22 (36.6%)
Medical Doctor	12 (20.0%)

Pharmacist	6 (10.0%)
STaR*/Healthcare Support Worker	6 (10.0%)
Student Nurse	2 (3.3%)
Psychologist	2 (3.3%)
Occupational Therapist	1 (1.7%)
Other	4 (6.8%)
Not Stated	1 (1.7%)
Experience	
Less than 2 years	9 (15.0%)
2- 5 years	24 (40.0%)
6- 10 years	16 (26.7%)
Over 10 years	10 (16.7%)
Not Stated	1 (1.7%)

*STaR: Support, time and recovery

When analysing the data, factors were stratified according to how likely the individual factors would encourage both good and poor adherence with antipsychotic medication. The factors of most importance were those where at least 75% of staff ranked this as a very strong or strong influence on medication adherence or non-adherence. Important factors were those where 50- 74% of staff ranked this as a very strong or strong influence on medication adherence. Factors of lesser importance were the factors where 25-49% of staff ranked this as a very strong or strong influence on medication adherence. If less than 25% of staff ranked the factor as a very strong or strong influence, this was deemed to be not important.

Staff felt that the most important factors promoting good antipsychotic medication adherence in FEP were insight into the fact that medication would make them better and prevent relapse as well as rapport with and the views of staff (Table 4.4).

Table 4.4. Factors Promoting Good Medication Adherence (in descending order of importance)

Importance	Factor	Very Strong or Strong Influence (% respondents)
Most Important	Medication will make them better	93%
	Rapport with staff	85%
	Medication will prevent relapse	83%
	Views of Staff	78%
Important	To be in control of their life	70%
	To be in control of decisions about medication	68%
	Would be admitted to hospital if they did not take medication	68%
	Medication will help them achieve their goals	68%
	Pressure from family	67%
	Views of family	65%
	Medication will help them think more clearly	63%
	Pressure from staff	57%
Less Important	Views of friends	47%
	Views of other patients	40%
	Others will realise they are ill if they do not take medication	38%
	Pressure from friends	32%
	Pressure from other patients	30%

Not Important	Influence of television	18%
	Influence of newspapers of magazines	18%
	Influence of films	18%

The most important factors impacting on poor medication adherence were felt to be poor illness and medication insight, medication side effects and individuals exerting personal control (Table 4.5).

Table 4.5. Factors Encouraging Poor Medication Adherence (in descending order of importance)

Importance	Factor	Very Strong or Strong Influence (% respondents)
Most Important	They are not ill so do not need medication	92%
	Side effects of medication	87%
	Wanting to be in control of their own life	80%
	Medication decisions are up to them and nobody else	78%
	Thinking they only need to take medication when they are ill	78%
Important	Thinking medication may be bad for them	71%
	Thinking medication will not help them get better	71%
	Family have told them not to take medication	66%
	Thinking medication will not prevent relapse	66%
	Others knowing they are ill if they have to take medication	59%

	Feeling embarrassed at having to take medication	59%
	Their family do not think they are ill	58%
	Thinking it is unnatural to take medication	51%
Less Important	They would rather take illicit substances	49%
	They would rather drink alcohol	49%
	Other patients have told them not to take medication	47%
	Thinking medication will prevent attainment of goals	46%
	Influence of newspapers or magazines	44%
	Friends have told them not to take medication	42%
	Some staff think medication is not necessary	39%
	Their friends think they are not ill	36%
Not Important	Influence of films	24%
	They want to be admitted to hospital	22%
	Influence of television	21%

48 staff provided further information on the side effects they felt contributed to poor medication adherence (Table 4.6). Weight gain, sedation and extrapyramidal side effects were the most cited side effects mediating adherence with antipsychotic medication.

Staff were also given the opportunity to identify their views of the three most important factors promoting medication adherence in young people using free text options within SurveyMonkey©. Responses were collated, themed by response and counted. The three most important factors promoting adherence with medication were felt by staff to be symptom control, to get better and, thirdly, hope of a better quality of life. Staff were then asked to describe the three most important factors contributing to poor adherence with medication and these were again collated and themed. The three most important factors were side effects, failure to acknowledge the illness and lack of insight. This mirrors the feedback obtained through the targeted questions about medication adherence.

Table 4.6. Side Effects Influencing Adherence with Medication (n=48)

Side Effect	**Number of responses**
Weight gain/increased appetite	42
Sedation/tiredness/drowsiness/lethargy	31
Extrapyramidal Side Effects	19
Sexual dysfunction	14
Hypersalivation	10
Blunted emotions/affect/thinking/concentration	10
GI side effects	4
Neurological/headaches/dizziness	6
Metabolic	1
Need for regular blood tests	1
Reduced motivation	1
Sweating	1
Urinary incontinence	1
White count reduction with clozapine	1

Analysis of responses by doctors and registered nurses identified some variation in views. Doctors rated the views of family members much more highly in promoting adherence than nurses (92% rating it as a very strong or strong influence compared with 55% of nurses). Doctors also felt that fear of admission encouraged medicines adherence (92% rating it as a very strong or strong influence compared with 59% of nurses). Considering factors which are very strong or strong mediators of poor adherence, doctors also rated views of staff that medication is not necessary more highly than nurses (67% vs. 32%), ideas that it is not natural to take medication (75% vs. 41%), that taking medication will prevent goal attainment (75% vs.45%) and a preference for cannabis (83% vs. 23%) indicating differing views between these groups of healthcare professionals.

4.7. Discussion

The results presented highlight that from a staff perspective, a number of personal, social and treatment factors are influential in promoting adherence with antipsychotic medication in FEP. In a population of young people, patient insight into the need for medication, positive patient attitudes, relationships with staff and family are considered to be important in supporting adherence with medication. Side effects are considered a negative influence on medication adherence. Substance and alcohol misuse was perceived as having less of an impact than some published studies suggest, although doctors recognised that cannabis could deter medicines adherence. Media influences were also not considered to be strongly influential.

Published studies in FEP support staff views that patient insight into the need for medication is associated with greater rates of adherence (Coldham et al., 2002, Novak-Grubic and Tavcar, 2002, Mutsatsa et al., 2003, Kamali et al., 2006, McEvoy et al., 2006a, Perkins et al., 2006, Le Quach et al., 2009, Hill et al., 2010, Steger et al., 2012, Chan et al., 2014a). A couple of studies have failed to find a link between insight in FEP and medication adherence (de Haan et al., 2007, Lecomte et al., 2008). It seems reasonable to assume that when young people perceive the need for medication, and potential benefits this may produce they are more likely to take their medication (Perkins et al., 2006). If patients are embarrassed that they have to take medication that this can have an adverse impact on medication adherence (Hui et al., 2006b). Positive attitudes by young people to medication therefore seem to be important in determining whether medication is taken or not (Townsend et al., 2009) with studies confirming this association (Mutsatsa et al., 2003, Hill et al., 2010, Chan et al., 2014a). These findings therefore provide support for the initial hypothesis that staff would appreciate the importance of insight and positive medication attitudes.

Participating staff also felt that they themselves were a positive influence on medication adherence, suggesting that their role in reinforcing the positive benefits of medication and the rapport that they had with the young people affected the extent to which medication was subsequently taken. Limited published literature supports the importance of a good therapeutic alliance on medication adherence in first episode psychosis (De Haan et al., 2007, Tunis et al., 2007, Montreuil et al., 2012). One study comparing the views of first episode and multiple-episode patients with schizophrenia found that 74% of the FEP sample rated the doctor–patient relationship as a strong adherence influence compared with only 13% of the multiple episode sample, highlighting the importance of forging good therapeutic relationships in early psychosis and potentially different adherence drivers in first episode and chronic psychosis (Sapra et al., 2014). The doctor–patient relationship was the strongest influence on FEP adherence in the study by Sapra et al. (2014); however, only 18% of the FEP patients rated the influence of clinicians other than the doctor as highly influential. It is possible that this is linked to the fact that doctors prescribe medication in the majority of cases, and will as part of the consultation process have conversations about medication.

Staff indicated that family relationships and family perceptions of medication were also influential. While these influences were predominantly seen as beneficial, with children taking medication either because their parents wanted them to or because the young person did not want to worry their parents, there was also a view that this influence could be detrimental where family members did not see the need for medication and pressured their child not to take it. Published studies considering familial influences on adherence focus on the social support provided by families rather than the attitudes of family members to medication (Perkins et al., 2006, Rabinovitch et al., 2009, 2013.) This would therefore warrant further exploration. Influences of other patients and friends on adherence with medication were categorised by staff with lesser importance. This is perhaps surprising given the need of many young people to fit in with their peer group, and the potential for them to be swayed by their peer group to ensure acceptance and popularity.

Staff responding to the survey, in the main, did not feel as though media sources (television, newspapers, magazines or films) had a positive or negative influence on medication adherence. One study concluded that negative reports in the mass media significantly influenced public acceptability of psychotropic medication (Benkert et al., 1997). It is hypothesized that negative representations in the media may drive negative attitudes to medication, thereby influencing medication adherence, although no studies appear to have directly assessed this. My initial thoughts that media and peer pressure may have influenced adherence were not felt to be strong influences on medication adherence by staff working more closely with young people with FEP.

One of the strongest articulated influences on adherence was side effects, with 87% of respondents indicating that this was a very strong or strong determinant of poor adherence with antipsychotic medication. Lack of significant side effects was seen to promote adherence with medication, with side effects such as weight gain, sedation, sexual dysfunction, hypersalivation and extrapyramidal side effects increasing the risk of poor adherence. The highest rated side effect of concern was weight gain. The only papers to assess the impact of weight gain in first episode psychosis to date have produced conflicting results as to whether weight gain adversely affects medication adherence (Pogge et al., 2005, Perkins et al., 2006, Rabinovitch et al., 2009) and so further research would be beneficial. Interestingly, staff views that EPSEs significantly affect medication adherence are not supported in published literature (Coldham et al., 2002, Novak-Grubic & Tavcar 2002, Mutsatsa et al. 2003, Pogge et al. 2005, Perkins et al., 2006, Rabinovitch et al., 2009). The only study to date considering the effects of sedation also concluded that there was no effect on adherence with antipsychotic medication (Pogge et al., 2005). Survey responses received from staff therefore support my initial suggestion that, as is the case in schizophrenia, staff may overestimate the impact side effects have on medication adherence in FEP.

Published literature suggests medication adherence rates are lower in those who misuse alcohol (Coldham et al., 2002, Kamali et al., 2006), cannabis (Coldham et al., 2002, De Haan et al., 2007, Miller et al., 2009, Faridi et al., 2012, Barbeito et al., 2013) and other substances (Pogge et al., 2005, Kamali et al., 2006, Tunis et al., 2007, Hill et al., 2010), a conclusion endorsed by the NICE (2011). The evidence base is however mixed as some studies have failed to show a link with alcohol (Mutsatsa et al., 2003, Perkins et al., 2006), cannabis (Perkins et al., 2006) and substance misuse (Coldham et al., 2002, Mutsatsa et al., 2003, Perkins et al., 2006, Lecomte et al., 2008, Rabinovitch et al., 2009, Steger et al., 2012). Staff responding to the survey were less convinced that alcohol and substance misuse are associated with poor adherence to medication, although doctors felt that a preference for cannabis affected medication adherence. This may be secondary to differential gaps in the evidence base about the potential impact substance use may have on adherence across different professional groups.

The final concept emerging from the staff survey was the importance of personal control in determining adherence with medication. It has been suggested that young people are in a unique position of being under parental control while wanting to exert their independence and autonomy, and that this may subsequently influence the decisions they take about medication (Townsend et al., 2009). It is therefore postulated that at a time of uncertainty and worry when their life may appear to be escalating out of control, medication may be seen as one area where that young person can exert total control. There is limited evidence from a grounded theory study considering adherence with the antipsychotic drug, aripiprazole, that freedom to choose and being in control contributes to quality of life parameters that support medication adherence (Hon 2012). This provides support for one of the founding principles of the NICE guideline on medication adherence, namely patient involvement in choice and decisions around medication to promote medication adherence (NICE 2009).

4.8. Research Limitations

The research represents the views of a limited number of staff working with young people with a first episode psychosis. Analysis of the 18 respondents providing an address revealed that 12 were from Lancashire and so results from a more global sample may or may not differ. The initial intention was to compare staff views with those of young people and carers, however insufficient numbers of young people and carers were recruited representing a further limitation of the research.

4.9. Conclusion

Despite this being a detour in my qualitative research journey, this research represented the first attempt to gather views of patients, carers and staff about adherence with medication in FEP, although response rates only enabled analysis of staff responses.

Patient insight into illness and the benefits of medication, as well as positive therapeutic alliances, were seen as important determinants of antipsychotic adherence in first episode psychosis by staff. Unacceptable side effects were considered the strongest deterrent to adherence. The initial proposal that staff would recognise the importance of insight and positive medication attitudes and overestimate the importance of side effects was therefore proven. Staff also under-estimated the importance of forgetfulness in this age group when considering factors linked to poor medication adherence.

The research highlighted key differences in opinions of doctors and nursing staff about the importance of family member views and fear of admission in promoting adherence. Differences were also apparent in the importance attributed to patient views that medication is not necessary, and that it is not natural to take medication, in predicting medication adherence. Doctors were also more convinced than nursing staff that a perceived or actual detrimental effect on goal attainment and preference for cannabis negatively affected adherence with medication. Finally, this research suggests that staff do not consider that media influences, such as newspapers and television, affect adherence with antipsychotic medication in teenagers.

Acknowledging that these findings represent the views of only 60 staff, I felt that further exploration of this topic was warranted with young people experiencing a first episode psychosis. This would allow an examination of whether staff views are consonant or dissonant with the views of the young people themselves. I wanted to ensure the voices of young people with psychosis were heard, and this required consideration of the best methods to engage those who had taken medication as a teenager. Qualitative studies with this cohort of patients are extremely sparse (Charach et al., 2008). I therefore decided to conduct narrative research to support young people telling their medication stories. This narrative research with young people now provides the focus for the remainder of this thesis, and in the next chapter I provide an overview of narrative research and the approach taken in conducting this research.

CHAPTER FIVE. NARRATIVE RESEARCH

5.1. Introduction

In this chapter, I describe the aim of the narrative research and underpinning research questions. The research framework is then presented with emphasis on the research design and methods employed. Finally, details of how the research was approached and conducted are presented, addressing the research population, ethical approval, recruitment, data collection and assessment of data worthiness. Reflective entries are included throughout to highlight my deliberations about the best way to engage this patient population to effectively address the research aim and questions.

5.2. Research Aim and Questions

The aim of the research was to obtain stories from young people about their antipsychotic medication journey and their views about medication, with the intention of exploring what factors promote and discourage adherence with antipsychotic medication in a teenage population.

The specific research questions to be examined were:

- What influences adherence with medication in the young people studied?
- How do these influences compare with those affecting young people's adherence with medication for chronic physical illness?
- Do the young people's views about medication adherence concur or contradict the views of staff who participated in the survey research?

5.3. Research Framework

Having decided upon the research questions to be investigated, the research framework for the study then had to be agreed using the framework by Creswell (2014) previously described. A summary of the research framework is presented (Table 5.1). Background information was provided in Chapter Four about the different research approaches and philosophical worldviews, brief information is therefore given about the approach and worldview underpinning this research. In the following sections, I then explore in more detail the research design and method.

Table 5.1. Research Framework

Research approach	Qualitative
Philosophical Worldview	Social Constructivism
Research Design	Narrative Research
Research Method	Autophotography/ Auto Driven Photo Elicitation

For this research study I wanted to explore and understand what taking antipsychotic medication meant to young people, and whether there were particular influences on whether young people took their medication as prescribed or deviated from the prescriber's intentions. I was keen for this research to be rooted in the views of the participants themselves rather than my preconceived ideas or those derived from research literature. This therefore lent itself to a qualitative research approach.

I also felt that a social constructivist worldview was most relevant to this research as the intention was to seek subjective interpretation about what it is like to take medication as a teenager and what influences medication behaviours. Having conducted a literature review and worked clinically for numerous years with people prescribed antipsychotic medication the reasons for good or poor adherence appear to be subjective, complex and multifactorial. Historical, cultural and social views are also relevant when considering the topic of medication. Antipsychotic medication was first developed in the 1950s. Prior to this there would be no views about the value of antipsychotic medication and whether or not it was important to take this. Advances in medicine, knowledge about how antipsychotic medication works, increasing awareness of possible side effects and development of novel antipsychotic medicines also change people's perceptions. By way of an example, the first lobotomy was performed in 1935 and was seized upon by psychiatrists globally as a possible cure for certain psychiatric disorders. The number of procedures performed increased annually thereafter, started to decline in the 1950s and such procedures are now very rarely performed (Diefenbach et al., 1999). In the 1950s it is possible that a lobotomy was more acceptable to patients than taking the first available antipsychotic drug, chlorpromazine, as this was new and relatively untested. More recently there was a view that SGAs were more likely to act on negative symptoms and cause less EPSEs, leading to their preferential use over FGAs (NICE, 2002a, NICE, 2002b). Subsequently, it has been recognised that there is little difference in efficacy between FGA and SGA antipsychotics, with the exception of clozapine, and that SGAs are more likely to precipitate metabolic syndrome (Lieberman et al., 2005, Jones et al., 2006, NICE, 2014). There is also a social element as adherence rates may be improved through good therapeutic relationships (de Haan et al., 2007, Tunis et al., 2007). Thus there are historical, social and cultural influences to medication opinion which may subsequently impact on medication adherence. Given this historical, social and cultural context, the research was underpinned by a social constructivist worldview.

5.4. Research Design

Having decided upon a qualitative approach from a social constructivist worldview, the next step was to consider the research design. This involved consideration of the designs available and how they would best fit my research question, the particularities of my participants and other relevant factors. The research design is the type of inquiry to be used within a qualitative, quantitative or mixed methods approach. Creswell (2013) identifies five different qualitative research designs, namely phenomenology, grounded theory, ethnography, case studies and narrative research. An understanding of these different designs was therefore needed before a decision could be taken on the most appropriate design for my particular research study.

The age of research participants also needed to be considered when deciding on the research design. Undertaking research with young people poses particular challenges, especially in sensitive areas such as substance misuse, violence and sexual activities (Drew et al., 2010). For some young people adherence to medication may be a sensitive topic, as they may not want to admit to having to take medication or may not want significant others, such as their parents, to know that they are not taking medication prescribed for them. Historically, difficulties associated with undertaking research with young people were overcome by approaching proxies such as parents, teachers and healthcare professionals to provide accounts on behalf of young people (Santelli et al., 2003). However, more recently the shift has been towards research conducted in partnership with young people (Punch, 2002, Santelli et al., 2003). This requires consideration of different ways of gathering data, and tailoring of research methods to effectively engage with young people (Mauthner, 1997, Pole et al., 1999, Matthews, 2007). Research that involves young people at varying developmental stages needs to appeal to them, engage them and encourage discussion of ideas, views and perceptions that may not be easy to communicate (Drew et al., 2010). This led me to explore the five different research designs with a view to how they would fit with the principles of engaging and promoting young people to take part in the research. The approaches I discounted are presented first, with the research approach I selected described in more detail at the end.

5.4.1. Phenomenology

A phenomenological approach focuses on lived experience, by seeing things through the eyes of others who have experience of the particular phenomenon being researched (Denscombe, 2010). Typically between five and twenty five participants are included in a phenomenological research study (Polkinghorne, 1989). The findings are then condensed into an essence of ‘what’ they experienced, and ‘how’ they experienced it (Moustakas, 1994). Whilst data collection often consists of in-depth, multiple interviews with participants, other material can also be included such as taped conversations, poetry, music and art (Van Manen, 1990, Creswell, 2013).

Two questions form the basis for phenomenological explorations, ‘What have you experienced in terms of the phenomenon?’ and ‘What contexts or situations have typically influenced or affected your experiences of the phenomenon?’

(Moustakas, 1994). These questions are asked to gain a common understanding across participants. Researchers are encouraged to put their own views and experiences to one side, a process known as ‘bracketing’, so that past knowledge does not influence the data interpretation process (Van Manen, 1990). Data analysis is then conducted by highlighting significant portions of data (‘horizontalisation’) and developing ‘clusters of meaning’ from the statements (Moustakas, 1994).

Clearly, the research topic of ‘what influences adherence’ sits well with a phenomenological approach as there is potentially a common phenomenon of being asked to take prescribed medication then making decisions as to whether to take it or not. The numbers required would be achievable and there could be common features across participants. A phenomenological approach was taken in another study to explore experiences of young people prescribed antipsychotic medication (Murphy et al., 2015a). In this study ambivalence towards medication was evidenced, secondary to a lack of information about the illness and medication as well as stigma. Adherence was affected by this lack of knowledge, as well as a pressure to conform to their adolescent culture. Whilst a phenomenological approach has already been utilised to explore young people’s views about medication, the main concern in taking this approach was the need for multiple in-depth interviews with participants given the recruitment difficulties encountered in the preliminary research phase. I felt that young people might not want to meet repeatedly with a researcher given the commitments of school or college attendance, homework, work and social activities. I therefore needed to consider whether other approaches might engage young people more effectively and time-efficiently and so decided to explore other designs for my study.

5.4.2 Grounded Theory

In grounded theory the emphasis is on development of theory that emerges from the data obtained (Dawson, 2009). The aim is to discover or produce a theory from the data, a ‘unified theoretical explanation’ for an outcome (Corbin and Strauss, 2008). Prior knowledge and experience is put aside, in a similar way to the bracketing of phenomenology, and the theory is instead produced or ‘grounded’ in the data obtained from participants (Strauss and Corbin, 1998). Participants are interviewed and the researcher constantly compares data with that of previous participants to enable the researcher to formulate ideas and generate theory on an ongoing basis. This process continues until the researcher feels that no new information is being gleaned, a stage referred to as ‘saturation’ (Dawson, 2009). Data analysis commences with the identification of major categories of information (open coding), with each code then being subject to further analysis for sub-categories (axial coding). From this a theory is then developed to describe the interdependencies between the categories (selective coding) (Strauss and Corbin, 1990).

Initially, I had thought about conducting semi-structured interviews as part of a grounded theory approach, similar to the method employed in another qualitative study of medication adherence in FEP (Hon, 2012). This study explored factors affecting adherence in FEP with a single antipsychotic drug, but originality within the context of my PhD would be ensured by exploring young people’s views of taking a range of antipsychotic medication. My reasons for discounting this approach centred on the fact that my research aim was not about generating theory. As it is suggested that grounded theory studies typically involve around 20 participants (Creswell, 2013), I also felt that this would be difficult given that my research involved teenagers who have many competing interests and demands. The survey used in the preliminary research phase had failed to gain sufficient interest and I questioned whether the same would be true if participants were required to engage purely in an interview. I was concerned that I might not reach a stage of data saturation if participant numbers were limited. Additionally, in Hon’s (2012) grounded theory study, the researcher worked in the EIS service, had developed working relationships with some of the participants and this would naturally have aided recruitment. Such relationships would not be present in my case and I would again need to rely on care coordinators identifying potential candidates for interview, a strategy which had not been too successful previously. I therefore continued to explore other designs to find one which most suited the proposed study

5.4.3. Ethnography

Whilst grounded theory approaches are based on the assessment of many participants who share the same characteristics which make them suitable for the study, they may not be based in the same place or interact so often that they develop shared patterns of behaviour. Ethnographic studies are founded on the observation of particular cultural or sub-cultural groups. The researchers often immerse themselves within that cultural group in order to explore and understand shared behaviours, values, beliefs and languages thereby enabling in-depth observation and interaction (Silverman, 2010).

When considering ethnography for my study I acknowledged that the participants would all be members of the EIS or CAMHS services and accepted that this could be deemed a specific cultural group. However, the young people would potentially be from different teams across Lancashire and interaction between participants would not have been present to the extent required for an ethnographic study. Not being a full-time member of the EIS or CAMHS teams, I also felt that I would not have enough contact time with the young people to do justice to this design. Ethnographic studies typically involve the whole of a particular group, at least at the outset, and so again this would limit data collection as there is no single forum through which all of the young people linked to a team meet together. Observation of interactions would therefore not be easily facilitated. Whilst I was interested in relevant cultural influences, this was not the driving force being the research. This therefore led me to then think about whether a case study design would be appropriate.

5.4.4. Case Studies

Whilst ethnography seeks to understand how a particular culture might function, case study research involves exploration of a phenomenon in a single or few cases via extensive, in-depth data collection using a number of different mediums e.g. interviews, observation, reports (Denscombe, 2010). This design was not felt to be suitable given the need for extensive data collection via different means. Experience in the exploratory stage of my study highlighted the difficulties in getting young people to engage. This would potentially prove more problematic if the young people needed to provide data in a number of different formats. I also questioned how I would choose the participants as this design usually involves no more than four or five cases given that analysis becomes more dilute with an increasing number of participants (Creswell, 2013). I would be relying on care coordinators to identify participants for me based on particular criteria, however with such a small number of participants I was concerned that the data obtained might not be rich enough to present an in-depth picture of the pertinent issues with taking antipsychotic medication. I therefore discounted this approach and moved on to consider the final qualitative approach of narrative research.

5.4.5. Narrative Research

Despite the words ‘story’ and ‘narrative’ having different meaning they are often used interchangeably (Waziri et al., 1993). A simple definition of a story is something told by someone, with a simple definition of a narrative being the resulting product after the story has been analysed (Frank, 2010). Polkinghorne (1996) considers narrative as a story within a wider story, with each part linking and connecting to each other to impart meaning and understanding. Within this research I was interested in the stories young people tell about medication and interpreted these stories using narrative techniques.

The focus of narrative research is the interpretation of stories obtained in research, particularly on the meanings people make of what happened (Chase, 2007). On this basis, I felt that a narrative research design lent itself to understanding motivations for medication acceptance or refusal. This design also sits well with a social constructivist worldview, as stories aid people to construct, articulate and understand their social world (Bold, 2011). Young people have stories to tell about their experiences of taking medication, and how these experiences affect decisions about whether they take prescribed medication or not. I felt very strongly that these stories needed to be heard and understood, so this naturally progressed to a view that narrative research was the design of choice.

Further reading of the topic led me to realise that proponents of narrative research view it in a number of different ways, employing different approaches to analysis (Bold, 2011). Common elements exist in that stories of personal experience are gathered, retold based on defined narrative elements and rewritten into chronological sequence incorporating the place or setting of the storytellers experience (Creswell, 2013). Through my deliberations of the subject, I uncovered a number of different approaches to analysis of narratives which can broadly be termed structural, temporal, sociolinguistic and content analysis.

Structural Analysis

Labov and Waletzky (1997) assess narratives as building blocks of information that come together to form a temporal sequence of events. These individual blocks of information provide referential meaning of personal interest, or evaluative meaning which links to social context. Analysis is based on a formal approach of linguistic structure whereby parts of sentences are related to what happens in the story (Bold, 2011). Labov and Waletzky contend that a 'fully-formed' narrative displays six core features which form the basis of their framework for analysis. The 'abstract' provides information on what the story is about and the 'orientation' on the context of the story. The 'complicating action' serves to provide readers with an insight into what happened next, whilst the 'evaluation' highlights the significance of this. The 'resolution' offers information on the outcome, and finally the 'coda' is a statement returning perspective to the here and now (Labov and Waletzky, 1997). The framework presented by Labov and Waletzky provides a means by which the researcher can identify, unpick and compare narratives about particular events whilst presenting the information from the viewpoint of the storyteller (Andrews et al., 2008). Critics of this approach argue that not all narratives will fit into this framework as they do not contain all six core elements, that the framework does not take into account current use of English language or cultural and gender influences on storytelling, nor does it allow for use of other means of storytelling such as photographs and poetry (Andrews et al., 2008). Core features may be presented in a different order, and stories may intertwine with each other making the narrative structure more complex than described by the framework (Frank, 2010).

In a similar vein, Burke's (1945) approach to analyzing narrative is to consider five aspects, some of which overlap with those presented by Labov and Waletzky. These five components are the act, scene, agent, agency and purpose, or put more simply the What?, When or Where?, Who?, How? and Why? (Burke, 1945)

During the process of data analysis, I did utilise the framework by Labov and Waletszky as an introduction to narrative analysis (Appendix 1). I sometimes struggled to identify all aspects outlined in the framework, but was not particularly concerned about this as I knew from prior reading that this was one of the criticisms of the framework. Whilst feeling that I was taking a more narrative approach, I did not feel that I was critically considering the transcripts. This resulted in my exploring other avenues for narrative analysis.

Temporal Analysis

Other authors deviate from a structural approach and consider narratives from a perspective of the natural passage of time and sequencing of events. I have classified these approaches as temporal analyses. All of the approaches I will describe contain a temporal aspect, although other aspects of narrative are also featured. Clandinin and Connelly (2000), propose that events have a past, present and potential future (Clandinin and Connelly, 2000). Data are analysed according to three different categories, continuity (past, present and future) but also by interaction (personal and social), and places (physical places or the story-tellers places). Similarly, Cortazzi (1993) proposes three features of a narrative which brought together form a plot structure. Temporality describes a sequence of events in time. Causation considers how one event causes another, as assessed by those listening or reading the information. Finally there is the element of human interest, without which there is no narrative (Cortazzi, 1993). Considering the transcripts obtained from the interviews, I could clearly see temporal aspects to the stories told and could identify the elements of causation and human interest.

Sociolinguistic Analysis

In contrast to all of these viewpoints, a sociolinguistic approach is advocated by Gee (1991) who pays more attention to how something is said, analysing pauses and other aspects of interrupting speech which serves to present information to those listening in distinct segments (Gee, 1991). Sociolinguists may also focus on aspects of conversation such as turn-taking or sequencing (Bold, 2011). I questioned the value of such an approach based on the research questions being explored, as I did not feel that the outputs would be particularly engaging or have the potential to influence clinical practice. I also do not have a sociolinguistic background so felt I could not do this approach justice. I therefore moved on to consider analysis of the content of stories.

Content Analysis

When classifying narrative analysis as a form of content analysis, I understand this to mean where the focus of analysis is on the content and meaning of the story told. Some authors argue that meaning is more important than the structure of a narrative (Clough, 2002, Bolton, 2006) and conduct thematic analysis of the data obtained (Bold, 2011). The key difference between thematic analysis and narrative analysis is that narrative analysis starts from the perspective of the story teller rather than the analyst, and centres on the analysis of events over time with the intention of producing new meanings (Waziri et al., 1993). Other approaches which could be classed as content analysis are those which are based on the plot and genres within stories.

Having explored the different approaches to narrative analysis, I decided that I wanted to concentrate my analysis on the content of the stories, as I felt that this would result in richer outputs than a purely structural approach.

5.5. Research Method

Having chosen to use a narrative research design as a means of aiding understanding and gaining some insight into potential ways of transforming approaches to medication adherence, I still had to decide on the research method for gathering, analysing and interpreting the data. Throughout the research project, I had been keen to try and capture young people's interest by using methods which would harness their imagination and creativity. This led me to explore the role of visual methods of data collection to support this research, before finally agreeing on autophotography (auto-driven photoelicitation) as a means of gathering data. My reasons for these decisions are now detailed along with supporting literature.

5.5.1. Visual Research

A literature review evaluating the choice and use of visual methods of research proposes a number of benefits in using this methodology (Pain, 2012). Participants often feel more comfortable and communicative when they are able to use visual images as prompts (Banks, 2001, Clark-Ibáñez, 2007, Keller et al., 2007). Visual methods also facilitate rapport between researcher and participant (Gold, 2004, Drew et al., 2010), enhance engagement with the research itself (Rhodes and Fitzgerald, 2006) and provide the researcher with insight into someone else's world (Chalfen, 1998, Gold, 2004). Visual methods are also considered a good way of engaging children and young people as they often find it easier to express themselves visually (Clark, 2005, Kinney, 2005). Visual methods are seen as a way of redressing the power imbalance between adult researchers and children because research is conducted in partnership with the children (Clark, 2010, Drew et al., 2010). Others have concluded that use of photographs as a research methodology serves to empower young people and helps them articulate sensitive, complicated or difficult topics (Rose, 2001, Pink, 2006, Thomas, 2009). Visual data provides a means of including those who may find it difficult to contribute because of language difficulties or other contextual issues, and can therefore be an important in providing a medium by which minority and disadvantaged groups can express their views and feelings (Bold, 2011). Given all of these purported benefits, I therefore decided that a visual method of data collection was ideally suited to this research. This then required a decision to be taken about the visual medium which would best suit data collection considering the study participants and research questions being examined.

5.5.2. Photographic Research

Visual research comprises a wide range of data be that drawings, advertisements, collages, diagrams, signs or video-recordings, however photographs are by far the most common visual aid used (Emmison, 2012).

Photographs are employed in a number of different ways within research. Photographs can be used as a stimulus for interviewing, systematic recording of a particular topic such as facial expressions, content analysis of naïve photographs whereby additional information is obtained other than that intended by the photographer, native image making where indigenous groups take photographs and then assess the outputs and documentary photography, or narrative visual theory where the visual coefficients of a social organisation are explore through photography (Wagner, 1979).

In contrast, Douglas Harper provides an alternative framework for photographic research comprising four categories. The scientific category is where photographs are viewed as storage devices for depicting data for further analysis. In the narrative category, photographs are used to study the process of social interaction and life as it unfolds. When using a reflexive category the subject is involved in uncovering meaning of the images. Finally the phenomenological category focuses on eliciting personal knowledge though photographs which have a personal meaning (Harper, 1988). Considering Harper’s viewpoint and how it applies to this research, whilst the proposed research project might initially be viewed as reflexive this is not the case as reflexive approaches still involve the researcher taking the images. The most common approach within this category is that of ‘Photo-elicitation’ whereby images taken or gathered by the researcher are used as prompts in subsequent interviews with participants (Emmison, 2012). I felt that it was important for the young people to take photographs themselves rather than be provided with images to then use as a basis for interviews. By asking young people to generate their own images, this would ensure that the personal stories of the young people were accurately and comprehensively represented. The young people would present their views about medication, rather than this information being based on my thoughts from past experiences and knowledge of the literature. Considering the framework of Harper presented above, I considered that asking young people to take their own photographs would represent both a useful scientific and phenomenological approach.

Autophotography

The research methodology described, whereby participants take their own photographs is referred to as ‘auto-driving’ (Heisley and Levy, 1991) ‘auto-photography’ (Noland, 2006) or ‘autodriven photo-elicitation’ (Jenkings et al., 2008). First used in 1966, when cameras were given to Navajo Native Americans to analyse ways in which they viewed and experienced the world (Ziller and Rorer, 1985), auto-photography has become more prevalent since the advent of affordable, disposable cameras in the 1980s (Thomas, 2009) and the availability of cameras on devices such as mobile phones. This approach assumes that photographs have a role and purpose in ‘promoting reflections that words alone cannot’ (Clark-Ibáñez, 2007). The photographs are a means of obtaining rich verbal data which then takes priority over the images themselves (Drew et al., 2010). It is suggested that auto-photography may more readily allow exploration of personal subject areas (Ziller, 1990). In young people, it has been argued that photographs can provide visual narratives that both represent and facilitate further reflection (Olney and Farber, 1995). It also can be a valuable and fun method to use when working with teenagers who lack self-esteem (Noland, 2006). Others argue that use of pictures allows understanding of ‘self’ to be better represented, as the person taking the photographs has the freedom to choose scenes and subjects which best represents their opinions on a particular topic (Combs and Ziller, 1977, Ziller and Lewis, 1981). Given all these arguments, I felt that the ideal methodology to explore this sensitive topic was auto-photography as an approach to in-depth interviewing (Drew et al., 2010). This sits with Harper’s methodology of using photographs as interview stimuli (Harper, 1986). Many young people already have mobile phones with cameras and take photographs to post on social media sites. I therefore felt that they would be comfortable with the prospect of taking photographs to articulate their views about medication. I hoped that the young people would more readily engage in the research because of the artistic element of the photography stage, but I also needed to cater for those situations where taking a photograph might be particularly difficult or for situations where young people might not be comfortable taking photographs themselves. For this reason, participants were also able to include existing photographs or images from sources such as magazines and the internet if they felt they readily depicted their feelings about medication. It was felt that combining these two approaches would ensure a richness of data that might not otherwise be captured and help ensure the safety of the young people in the study.

Photographs as Data

Having decided to use photographs as a means of illustrating medication stories and informing subsequent discussions at interview, I was then left to debate whether the photographs themselves would be analysed separately and be included in the thesis as another form of data. Within anthropological fields, inclusion of images within texts has been more prevalent than within the social sciences (Emmison, 2012). It is suggested that this is because anthropology articles are usually describing cultures which may be alien to readers, that differences in culture, race and geography allow the reader to more readily accept photographs which might otherwise be seen as offensive, and that subjects within the photographs are unlikely to protest at being photographed because of power imbalance with the photographer (Emmison, 2012). In sociology it is proposed that photographs are less likely to be included in texts because a greater emphasis is placed on words to understand or interpret social action (Fyfe and Law, 1988), indeed it has been argued that:

> "*a photograph depends on caption and textualisation to give it authentic and precise social scientific meaning. In this way it loses its autonomy as a photograph, and thus any claim to make a contribution 'in its own right'. In social science, as in most other discipline areas, images need words, whilst words do not necessarily need images*" (Chaplin, 1994).

Others have argued that a reluctance to include photographs within sociology research texts is based on a concern about the observation, regulation and control of subjects within the photographs (Tagg, 1993).

Having considered these two opposing viewpoints, I felt that whilst inclusion of photographs was not vital, it might at times aid understanding of the concepts being articulated and be more engaging to the reader. Conversely, there would be no need to include all of the photographs as this might dilute meaning and visual impact. From my reading of the use of visual research, I did however recognise a need to avoid self-censorship and be able to provide a reasoned argument for inclusion or exclusion of particular photographs within the thesis (Emmison, 2012).

Having articulated the reasons for choosing the different elements of my research, and summarised the research framework in Table 5.1, I will now go on to describe the research in more detail outlining the target population for the study, ethical issues which required consideration and the process by which data was collected.

5.6. Research Population.

As already outlined the population being researched was teenagers prescribed medication for a psychotic illness. The inclusion and exclusion criteria are now presented to further detail the target population

5.6.1. Inclusion Criteria

To be accepted into the study, participants had to be between 14 and 18 years old, have contact with EIS or CAMHS services, and have had experience of taking antipsychotic medication. Alternatively they could be accepted into the study if they were over the age of 18 but had been prescribed antipsychotic medication at some point between the ages of 14 and 18.

5.6.2. Exclusion Criteria

Participants were excluded if their current mental or physical state precluded them from being able to actively participate or give informed consent for involvement in the study.

5.7. Ethical Issues

The nature of the research being conducted, and the intended research population, all contributed to the need to explore numerous and complex ethical issues. This section is therefore sub-divided to provide more detailed information on research ethics approval, informed consent, mental capacity, data management, confidentiality and other ethical issues.

5.7.1. Ethics Approval

As the research was being conducted within the National Health Service, ethical approval from the National Research Ethics Service (NRES), Lancashire Care NHS Foundation Trust (LCFT) Ethics Committee and the University of Central Lancashire (BuSH) Ethics Committee was a pre-requisite to progressing the research. Approval was obtained from NRES and LCFT ethics committees in February 2010, with chair’s approval from BuSH in March 2010 based on the approval already obtained from NRES and LCFT ethics committees. The NRES and LCFT ethics committees made several requests for amendments to submissions and supporting paperwork and these will be outlined in the relevant sections below.

5.7.2. Informed Consent

This research study involved participants who were potentially vulnerable on two counts, namely their age and the presence of a mental illness. To safeguard the wellbeing of these young people, a number of requirements were included through all stages of the research to ensure that it was appropriate for that young person to engage in the research, their wellbeing was ensured and informed consent to participation obtained.

When first submitting the paperwork for ethics committee approval, LCFT asked that I expand the description regarding assessing capacity to consent. They also wanted further information on what would happen if service users were unable to consent, and whether parental consent would be sought. In response to these questions, a decision was taken that assessment of capacity would first be undertaken by the care coordinators of potential research participants. Care-coordinators only approached me if the young person was able to give informed consent. The advantage of this initial assessment was that it was undertaken by a healthcare professional who knew the young person, their history and current mental state.

I then went with the care coordinator to discuss the research project with the potential participant. This had the advantage that the young person was more relaxed at the initial introduction as there was a familiar member of staff present. The young people were given a research information sheet at this stage incorporating an expression of interest form (Appendix 2).

Parental consent was also obtained from parents or guardians of those aged 14 or 15 through use of a parental research information sheet incorporating a parental consent form (Appendix 3). At the NRES ethics committee meeting, the issue of parental consent was also raised and the committee asked that the process be revised so that young people aged 14 or 15 consented in writing to the researcher approaching their parents or guardian. The initial intention had been to get verbal consent to approach the parents or guardian. The requirement to obtain written parental consent for those aged 14 and 15 was included in the patient consent to fulfill the requirements of the ethics committee.

Written consent was gained from the young person at this stage for the photography and interview stage (Appendix 4). Verbal consent was reaffirmed at the start of the interview stage. If at any stage informed consent could not be assured, the researcher would withdraw the young person from the study.

At the end of the interview it was made clear that consent for inclusion of some or all of the photographs could be withdrawn during the interview or within the four week period thereafter. A photography permission form was also used to obtain consent to store the photographs electronically for five years, to include the photographs in this thesis, other presentation or academic publications (Appendix 5).

As well as considering the consent of that young person to participate in the research, it was also necessary to consider consent of any other person whose photograph might be taken. If the young person took photographs of other people, they had to get those people to sign a model release form (Appendix 6). Photographs were then only included in the thesis, publications or any presentations if a completed model release form was available.

5.7.3. Mental Capacity

As well as assessing the young person's ability to provide informed consent, consideration also had to be given to mental capacity and whether this would impact on any decisions taken about involvement and participation in the study. Again care coordinators were only asked to recommend those young people who were mentally and physically well enough to actively engage and progress the study. During the interview participants could take a break whenever they wished and also terminate the interview at any stage if they felt in any way uncomfortable or unwell. The NRES ethics committee also insisted that I contact the care coordinator if concerns about the person's physical or mental wellbeing became evident at any point during the research. This was made clear to participants via the research participant information sheet.

5.7.4. Data Management

Another ethical issue I had to address was that of data management. To ensure data security a number of steps were taken. Firstly, all manual data containing personal details (including photographs) were stored in a locked filing cabinet in my work office. All audio files were transferred to a secure password protected computer and then deleted from the audio recorder. These files were password protected. Any hard copies of transcripts were kept in a locked cabinet when not in use, and all electronic copies were password protected on a password protected laptop. This was the case for all electronic data which was stored on a password protected computer. A password protected encrypted memory stick was used to backup data. When not in use this was kept in a locked cabinet in my work office. The CD-Roms containing participant photographs were kept in this locked cabinet when not in use. If there were occasions where I returned home after an interview and was unable to immediately place the recorder/paperwork in my work office, I stored the data in a sealed envelope within a locked desk draw in my home office. Finally, all personal data (excluding photographs) were to be securely destroyed once it was no longer needed.

5.7.5. Confidentiality

Whilst effective data management is one means of ensuring confidentiality, there were other aspects of confidentiality to consider as part of the research. When detailing narratives obtained from participant stories within the thesis, pseudonyms were used to protect identity. Whilst this goes someway to protecting confidentiality it cannot guarantee it (Elliott, 2005), as it is possible that close friends and family would still be able to recognise the participant stories if they were aware that the young person was participating in the study.

5.7.6. Other Ethical Issues

In conducting this research there were other ethical issues I had to consider. The age of the participants required particular consideration and, as already described, parental consent was obtained for participation of those under 16. I also sent all of the research literature for participants and parents to the safeguarding lead for their consideration and comments as part of the development process. They asked that the following statement be included at the end of the research protocol in a section on ‘Safeguarding Children’ (Appendix 7):

> “*Lancashire Care Trust (LCFT) staff have a duty of care to safeguard and protect children at risk of harm and neglect from the subsequent negative outcomes and enable all children to reach their full potential. Every child has the right to be protected from potential significant harm. If at any time staff identify concerns for a child/ young persons welfare or believe a child is suffering, is at risk of suffering abuse or neglect or has suffered abuse or neglect a referral must be made to Children’s Integrated Services (CIS) in line with LCFT and Local Safeguarding Children Board*

> *Procedures. The child/ young person's welfare should remain the central concept in any assessment*".

There was also the potential that participants might disclose sensitive information to me, knowing that I was a healthcare professional rather than a family member or friend (Rice and Ezzy, 1999). This was a particular concern of the NRES ethics committee, who were keen to understand how I would respond if young people disclosed that they were not taking their medication at interview. The committee subsequently required that I inform their doctor or care coordinator in the event of such a disclosure. This requirement was therefore added to the participant research information sheet. I also reinforced this verbally with the young person when consenting them to the study so they were clear about this responsibility. Given the requirement to inform the care coordinator or consultant if I was concerned about the young person's mental health during any meeting, I did initially wonder whether this would cause the young person to deliberately hide such information from me. Following the interviews I was left with the impression that this had not been the case, as young people seemed comfortable relaying the negatives as well as the positive aspects of taking medication. One young girl disclosed that she wanted to reduce her medication during the interview and had a meeting with the consultant the following week to discuss this. Whilst her father administered medication, she was in midst of taking her GCSEs and so I was concerned that she might try to secrete the medication. I was relieved that the research protocol fully supported my contacting the care coordinator to confirm that she was aware of the patient's wish to reduce the dose and had indeed arranged a meeting with the consultant to discuss this. By requiring me to disclose non-adherence to the team, the ethics committee ensured that I was not in a position described by Duncan et al. (2009) where disclosure of poor adherence to medication led to an ethical dilemma because assurances had been given to participants that information would not be disclosed to health professionals responsible for delivering care.

Once ethical approval was obtained, I then moved onto the recruitment phase of the research.

5.8. Recruitment

Participants were recruited from EIS and CAMHS tier 3 and 4 services at Lancashire Care NHS Foundation Trust (LCFT). Potential participants were informed of the study through posters displayed in reception areas, by care coordinators within the community teams, provision of information on discharge from an inpatient ward, or through attendance at a young person's support group, 'The Crew'. Participant information sheets incorporating expression of interest forms (Appendix 2) were provided, along with a parental information sheet and consent form (Appendix 3) if the young person was under the age of 16.

5.9. Data Collection

Return of expression of interest forms and any associated parental consent forms marked the start of the data collection phase. Data collection progressed through a number of sequential phases, namely the introductory meeting, photography phase, interview and transcribing stages.

5.9.1. Introductory Meeting

For those who returned an expression of interest form and fulfilled the criteria for participation in the study, an introductory meeting was arranged. At this meeting the care coordinator was present to facilitate introduction to the researcher and make the young person feel more at ease when meeting somebody they had not met before. During this meeting the study was discussed in more detail and the young person was asked to take photographs depicting 'What medication means to me'. Participants were told that they could include both positive and negative aspects of taking their medication. They were informed that the focus was on their personal views and experiences, as opposed to that of the wider public, and that the information could be based on experiences and hopes in the past, present and/or future. It was made clear that up to twenty photographs could be taken, and that other images e.g. from magazines, photograph albums or the internet could also be included. In the event of the latter being provided, the researcher sought permission to take a digital photograph of the images submitted if they were not subject to copyright. The purpose of the Model Release Form (Appendix 6) was also explained as a means of ensuring the consent of all involved. During the initial meeting, participants were given the opportunity to ask any questions and seek further clarification. A consent form was completed for the photography and interview phase of the project (Appendix 4). Participants were informed that their care coordinator would be advised of their involvement in the study. A time frame for taking the photographs was agreed between the researcher and the participant, usually around four weeks, and if not taking photographs via a personal mobile phone, a disposable camera was provided. The cameras were labeled with sequential letters of the alphabet so I could identify which research participant had taken the photographs when the disposable cameras were returned. Information discussed during the meeting was reinforced through provision of a photography guidance sheet (Appendix 8).

5.9.2. Photography Stage

After the initial meeting the young person was left to their own devices to take their photographs. Once the photographs had been taken, participants emailed the photographs to a university, password protected, email account or posted the camera back to the researcher in a pre-paid padded envelope provided. If photographs were not returned in the timeframe agreed, I made contact with the young person to check that the data collection was progressing, answer any further questions and then agree a new timescale for the photographs to be returned.

On receipt of the camera or emailed photographs, I then obtained (a) a set of prints for participants, and (b) a CD-ROM of these prints. The participants were already aware, and had consented to the fact, that I would look at the photographs before sending them back. This was purely to check that they had been developed correctly. Participants had also given consent to the researcher having a copy of all photographs on CD-ROM.

Having checked that the photographs had been developed properly, the photographs were returned to the participant on a mounted card. Participants had to select photographs for discussion, giving the photograph a title. They then had to indicate, through use of adhesive labels provided, whether the photograph represented a positive or negative aspect of medication and whether the photograph was relevant to the past, present and/or future. To support this stage a photograph selection form was provided (Appendix 9). That said, not all of the young people titled and labeled the photographs. However, this did not prevent the research from progressing.

On return of the photographs to the participant, the researcher agreed a convenient time and date for an in-depth interview to hear their story about taking antipsychotic medication.

5.9.3. Interview Stage

Interviews were conducted at a time and place suggested by the young person. If the researcher was going to interview the young person alone, at a site which was not trust premises, the Lone Worker Policy for the Trust was followed.

At the start of the interview, verbal consent was obtained. I clarified whether there were any time constraints to the interview, and the participant was advised that they could take a break whenever they wished. Participants also completed a form identifying which photographs they gave permission to be stored, and/or used in a thesis, and/or used in presentations or exhibitions, and/or used in academic publications (Appendix 5).

During the interview, participants were given the choice of selecting the photographs and talking about what the photograph meant, or alternatively telling me their medication story and referring to the photographs throughout as an illustration of that part of the story. All but one of the participants chose to go through the photographs and tell me what aspect of their journey the photograph depicted. This one participant wrote out her story prior to the interview and then arranged her photographs sequentially in the order in which they appeared in her story.

Open questions were used to encourage participants to respond in a manner they found meaningful (Grace, 1991). If the young person was struggling to articulate their views and thoughts, flash cards were available to support discussion about particular factors which might promote or interfere with adherence. These flashcards were derived from the outputs of the preliminary research phase which involved staff surveys of factors affecting adherence with medication. During the interviews these flashcards were not used as I felt that the young people were depicting their views clearly enough. Whilst a couple of young people were not particularly forthcoming at interview, they did respond to additional probing questions and I felt that they would not welcome or appreciate use of the flashcards. Any points of uncertainty during the interview were clarified with the participant for the purpose of clarity. To support this process an interview prompts sheet was designed (Appendix 10). This prompt sheet was used during the initial interview more as a prompt to the process and I did not methodically ask the questions that had not been covered during the interview. This is because I felt it was important for the content of the interview to be driven by the young person. I considered that it may put particular ideas in the young person's mind if I asked targeted questions related to adherence factors identified in published literature as being important.

At the end of the interview participants were given a £10 gift voucher in recognition of the time taken to participate in the study. They were also advised that they had a 'cooling off' period of one month during which time they could contact the researcher and ask for some or all of their data to be removed from the study. The audio-recordings of the interviews were then sent for transcription soon after completion of the interview to support data analysis.

5.9.4. Transcribing Stage

Interviews from all participants were transcribed verbatim by an external transcriber, with the content then checked by myself for accuracy. Transcripts were anonymised and pseudonyms applied to each young person to support anonymity. As transcription is such a crucial part of the analytical process, this was conducted by a skilled transcriber recommended by a member of my supervisory team. Even with use of an experienced transcriber, there are some recognised limitations such that it has been suggested that:

> *"It is now widely accepted that it is all but impossible to produce a transcript of a research interview, or any other type of conversation, which completely captures all of the meaning that was communicated in the encounter itself. Any transcription of speech must therefore be understood as a compromise" (Elliott, 2005).*

On receipt of each transcript, the digital recording was analysed alongside the transcript repeatedly to confirm data accuracy. Other safeguards to enhance data worthiness were also considered as part of the process.

5.10. Data Worthiness

When undertaking narrative analysis, it is vital that the researcher understands the different ways that data might become distorted. Within this research project, there was the potential for this to happen with the images themselves, other media images presented, during the interview process and then when undertaking data analysis for presentation within the thesis. I now describe how I guarded against this when undertaking the research.

5.10.1. Photographs

When the research participant used the photographs to articulate their story about medication, it was essential that I understood as far as possible what was being depicted within the photograph, capturing information not just related to medication but exploring issues such as the relationships between the photographer and other subjects in the photograph and how this might have affected the image produced. This is because when using photographs in research, they must be assessed giving due consideration to the key criteria of authenticity, credibility, representativeness and meaning (Scott, 1990).

Authenticity cannot really be questioned when using photography, however credibility requires more attention given changes that can be made to photographs with technology and advances in photographic development. That said, the young person had been involved in the production of the end product, and so even if changes have been made the photograph could still be viewed as representing a selective account of reality. One young person, a keen photographer, had planned to make changes to her photographs to make the image more visually captivating and to better illustrate the points she was making in taking the photographs. Unfortunately her camera broke during the research project and she was therefore unable to produce any photographs for inclusion in the research. All photographs included in the research were therefore in their original format and had not been altered in any way.

In using photographs as a prompt for further exploration the researcher is also required to consider criteria of representativeness and meaning, considering the historical content in which the photograph was taken, any additional data which can be used for triangulation purposes, evidence of themes across different photographs and scrutiny of individual photographs to understand texture and nuance (Dowdall and Golden, 1989). This seemed to be a useful approach to ensure that the photographs were represented faithfully by the written information they generated. It was important that I clarified the meaning of the photographs during the interview rather than making assumptions based on the scene being depicted. Encouraging the young people to title their images also supported some basic understanding about what the image was representing. In asking further questions about the photographs when their meaning was unclear, steps were being taken to ensure the research was robust and faithfully represented the young people’s stories of taking antipsychotic medication.

5.10.2. The Interview

The interview also required consideration of data worthiness. The story told at interview will be influenced by the subjective process of reminiscing and recreating the story, as well as the memory of those events (Reissman, 1993, Bold, 2011). This is highlighted by Webster, who argues that:

> ‘*narrative is not an objective reconstruction of life- it is a rendition of how life is perceived’ (Webster, 2007).*

It was therefore crucial that I understood the context in which information was being supplied, or the context in which events took place, to fully appreciate the stories (Clandinin and Connelly, 2000). During the interview this was achieved by asking for points of clarification where there was ambiguity about the information being presented.

Dynamics between the researcher and participant also influence the story being told (Bleakley, 2004), as do other factors such as participant motive and the intended audience (Wertz, 2011). I wondered whether my professional background as a pharmacist might encourage the young person to talk openly about their medication, or whether the young person might say what they presumed I wanted to her. I therefore made it explicit at interview that I wanted to know about the bad as well as good things about medication. To encourage reflexivity I kept a research diary so I could record relevant information and observations which might affect the information being obtained. I also decided to use some of the suggestions made by Valerie Yow to ensure I kept an open mind during the interview period, asking myself the following questions and documenting thoughts in my research diary:

- What am I feeling about this young person?
- What similarities and differences between me and the young person impinge on this situation?
- What are the effects on me as I conduct the research and how might my reactions be affecting the young person? (Yow, 1997)

My reflections on these questions are included in the next chapter where I provide an overview of each young person who participated in this research.

Following data collection, I then moved to analysis of the data which also required consideration of data worthiness.

5.10.3. Data Analysis

It is suggested that in the process of retelling a story told by a participant, the researcher will pass through at least five levels of representation all of which have the potential to distort information (Reissman, 1993). Firstly, in attending to the experience the researcher may focus on selected aspects of the experience to make the account meaningful. Secondly, when recounting the experience, this will be influenced by factors such as personal memory, things the storyteller perceives as important, what the storyteller thinks their audience will want to hear and the cultural background and influences of the storyteller. Different genres may be employed which will have different effects on the reader depending on how successfully they attune the reader to the storytellers' perspective. Thirdly, transforming accounts into a script requires interpretation thereby lending itself to the possibility of incomplete or selective information being presented. Speech uses features such as inflection, volume, and repetition to convey meaning and it is important to report such features as part of the transcription process to present a complete picture to the reader. Fourthly, when analysing experiences to create a metastory to capture accounts of all participants, there is a process of determining the significance of all the information presented, editing the information and then re-presenting this as a story in itself. Once again, this process has the potential to distort the final product and must be considered as part of the research process to ensure a fair representation of data. Finally, those reading the research will themselves bring their own background, personal experiences, values and perceptions into the reading of experience and this will influence their own interpretation of the information presented (Reissman, 1993).

It was important to consider all these different aspects of potential data distortion and misrepresentation when conducting and analysing the research. I also investigated other ways of evaluating the results of any analysis and robustness of the research methodology. Whatever the focus of analysis, Sikes and Gale (2006) have listed several qualities of a good story, namely liminality where gaps in the text are introduced so readers can use their own experiences to fill in any missing or ambiguous information, transgression when the ensuing emotional response, future possibilities and dreams are attended to, evocation where readers are emotionally moved by the story presented, complexity, creativity and audience engagement (Sikes and Gale, 2006). Stories are not just heard by verbal and written word but by other media such as photographs, videos, music, drawings provide as was the case in this research study. Common features of all of these methods of narration are that they aid humans to make sense of things, represent the experience rather than providing that experience itself, and seek to transform those involved (Andrews et al., 2008). Whilst all of the qualities may not be present in the stories as data, they may be more likely to be present in visual data and in the metastory produced by the researcher (Bold, 2011).

Given these common themes of a good story, I decided to evaluate content against measures proposed by Sikes and Gale (2006) as I felt that these succinctly captured these themes and enabled an assessment as to the authenticity of the information presented. The first measure 'substantive contribution' considers how the story informs understanding of social and cultural life. 'Aesthetic merit' assesses ability of a story to open senses, encourage interpretative responses and obtain reactions from the reader. 'Reflexivity and participatory ethics' questions the reflexivity of the researcher undertaking the narrative research by exploring aspects such as how the narrative was obtained, what could have influenced the text obtained, how this was addressed and whether the way in which participants are represented was fair and accurate. 'Impact' simply assesses the impact of the narrative on those involved. Finally, 'near experience' involves a judgement on whether the information presented rings true and offers a fair representation of the events described (Sikes and Gale, 2006).

My reflections on all of these aspects formed part of my research diary and contributed in part to my understanding of my position within the research project presented in the introductory chapter. Having presented the means in which data can be distorted, and the means of guarding against this, I will now detail my approach to the data analysis itself.

5.11. Dialogical Narrative Analysis

My initial approach to data analysis was to read the stories repeatedly, then organise the content into codes and sub codes in Excel. I soon abandoned this approach as I found it cumbersome and unwieldy. I also felt that, rather than engaging with the story, I was formulaically going through a process rather than considering the underlying meanings to what was being said. Thus the outputs felt more like thematic rather than narrative analysis. I also struggled to engage with the framework for narrative analysis proposed by Labov and Waletsky (1997) (Appendix 1) as I felt that this was also not supporting my engagement with the stories as I was focusing on uncovering the different aspects to a story, such as the abstract, coda, complicating action rather than engaging with the content of the story. An example of how I attempted to use the framework by Labov and Waletsky (1997) is included as Appendix 1. I then began to wonder whether the stories from young people about their medication experiences would uncover different genres depending on, for example, attitudes to medication, insight, internal and external influences on medication and subsequent medication taking behaviour. In my wider reading of the topic, I came across the concept of dialogical narrative analysis outlined in the book 'Letting Stores Breathe: A socio-narratology' (Frank, 2010). An outline framework is provided as a means of supporting critical analysis of the content of the story and its resultant effects. Dialogical narrative analysis requires respect for the initial and obvious understanding of a story, whilst requiring the listener to dig more deeply for unspoken meaning. Questions are proposed to support discovering of hidden meaning such as what is as stake for whom?; what is narratable?; how do characters hold their own in the story?; what effect does the story have on these characters?; what are the elements of fear and desire in the story?; and how does the story do the work of memory? (Frank, 2010). Having discovered this approach, I decided that dialogical narrative analysis would ensure that I did justice to the stories being told, uncovering both hidden as well as obvious meaning. I also felt that it might ultimately support identification of different sub-stories and genres. In taking a dialogical stance, I not only focused on the aspects outlined above, but considered the different capacities of stories present in transcripts as outlined by Frank (2010). I was therefore looking at whether the stories made trouble for characters, how the story tested and showcased individual characters, what points of view were articulated, whether there was suspense within the story, were there any unexpected twists and turns or morals to the story, whether aspects of the story resonated with other stories told by participants, were symbiotic relationships evident, did plots and characters change as the story unfolded, what truths were told and how my imagination was fired by the story. I started out by handwriting features of the different stories under the headings described above. In my analysis of the first transcript for example, I felt that the stakes for Ameeta were being defined as a carer, a nurse, somebody who is ill. Also at stake was Ameeta never being able to get past the dark times. This stake was redefined as her story progressed with Ameeta redefining herself as her own, independent person and asserting her right to a brighter future. Medication changed possibilities for Ameeta as by controlling symptoms medication enabled her to re-engage with her hobbies, attend college and undertake college courses. This consequently made her feel like a valued member of society with a bright future. She described her life as a ‘life worth living’. I continued to write down by interpretation of the questions posed and the capacities outlined by Frank (2010). Having completed this for the first transcript, I then checked my interpretations with my supervisory team to confirm that I was taking a sensible and reasonable approach and had not missed any major concepts. I continued analysing in this way until my confidence with dialogical narrative analysis increased. Recognising the advantages of having a system to organise data more efficiently, I then started to code using the quantitative analysis software package MaxQDA 11. Within MaxQDA 11, I structured the codes so that they mirrored the initial narrative questions and capacities of stories articulated by Frank (2010). I also introduced additional codes to focus on themes which seemed to be prevalent during the interviews held. Additional codes included emotions linked to medication such as happiness, resentment, anger as well as specific themes related to medication adherence, including factors promoting or deterring adherence, specific side effects and prescribed dose. When new concepts emerged from interviews I went back to previous interviews to check that I had not missed similar concepts within the transcripts of earlier participants. For the purpose of illustration, when considering the interview transcript for one of the participants, Allison, I recognised a new code about doing more things on medication. I realised that I had missed this in earlier transcripts so went back to recode these. Allison had also taken an overdose, a new stake to acknowledge in the coding system, and I had missed this when considering

Katey's interview transcript. In undertaking a process, similar to the constant comparison conducted in grounded theory approaches, I ensured robustness of the data analysis process.

Before embarking on an outline of my findings from the data analysis process, I will in the next chapter give a brief outline of the young people who participated in this research. Incorporated into this information are relevant aspects taken from my research diary to evidence the process by which data worthiness was considered.

CHAPTER SIX. AN OVERVIEW OF THE YOUNG PEOPLE

Whilst undertaking this research, I was extremely privileged to meet with and hear stories from young people who had met with varying degrees of adversity during their teenage years yet had responded to this with courage and determination. I was humbled and inspired when talking to them and therefore felt it was important to present an overview of their background, situation and stories so others could benefit from this same appreciation of the personal circumstances forming the backdrop to their stories. I have included demographic information using pseudonyms about their age, gender, ethnicity (Table 6.1), as well as information about the number of photographs/images/drawings presented and the length of our interviews (Table 6.2). Far more interesting to me, however, is the background information which provides an insight into these remarkable young people. Reflexive entries have also been included of my impression of these initial meetings, based on the entries in my research diary .

Table 6.1. Demographic Information of Young People

Pseudonym	**Age**	**Gender**	**Ethnicity**
Ameeta	17	Female	Asian-Pakistani
Victoria	16	Female	White-British
Katey	16	Female	White-British
Allison	20	Female	White-British
Christina	16	Female	White-British
Samantha	18	Female	White-British
Gabriella	17	Female	White-British
Michelle	20	Female	White-British
Stephen	15	Male	White-British
Jonathan	17	Male	White-British

Table 6.2. Summary of Data Received

Pseudonym	Interview Duration	Number of Images
Ameeta	25 minutes 43 seconds	8
Victoria	28 minutes 0 seconds	6
Katey	45 minutes 45 seconds	13
Allison	49 minutes 14 seconds	17
Christina	38 minutes 48 seconds	10
Samantha	Approximately 27 minutes	8
Gabriella	10 minutes 48 seconds	3 (described)
Michelle	46 minutes 44 seconds	10
Stephen	14 minutes 32 seconds	0
Jonathan	22 minutes 23 seconds	20 (described)

Ameeta

I was first introduced to Ameeta by her care coordinator at the children’s home where she lived. When we arrived for the morning appointment Ameeta was still in bed, and so I spoke to her about the research whilst she was dressed in pyjamas and dressing gown and obviously still sleepy. Quietly spoken and appearing quite timid, I wondered whether she was clear about what she needed to do and so repeated this a few times in different ways. During this initial meeting I found out that she was doing a European Driving Licence Computer course at college; when I next met her she was part way through a twelve week programme with the Prince’s Trust and was about to start a placement at a nursery school. Her ambition was to start a Health and Social Care Level 3 course.

When I turned up to interview Ameeta, the staff at the home took me into the office and explained that Ameeta had had a particularly difficult week. This was because another resident, who she had known for some time, had killed themself. I suggested re-arranging, however staff told me that preparing for our meeting had been a distraction for her and she had spent a lot of time preparing for our discussion. This included rehearsing with staff what she wanted to say at interview as she was worried she had not done the right thing and may not be providing relevant information. I was a little apprehensive about how Ameeta would be given the enormity of what she had experienced that week, but was extremely thankful that staff had thought to speak to me about this before I saw her. When I went into the lounge, Ameeta had already arranged all the photographs on the table and had printed images from the internet as further illustrations. She had also gone to the trouble of writing out her story in an exercise book.

During the interview it became apparent that Ameeta had found things difficult during her childhood. She spoke about being the main carer for her family, including two uncles with bipolar disorder, and the stress this caring role placed her under. She spoke of the ‘trauma’ she experienced, how her day to day life was very hectic and busy. Whilst she would previously put a smile on her face, deep down she was very low in mood. When she first started to experience psychotic symptoms she did not realise or appreciate what was going on and was unable to see a future. This ultimately culminated in a hospital admission.

Ameeta was the first person I interviewed as part of this research and I was incredibly moved by the efforts she had gone to, particularly in light of the recent suicide of a friend. I was however conscious that my concerns about the recent death of a friend prevented my exploration of the ‘trauma’ she repeatedly referred to during her childhood. I took from the discussion that this was in relation to family pressures and the caring role she had to assume, however the trauma could have extended beyond the information she volunteered at interview. Ameeta was obviously looking forwards and doing everything she could to make a brighter future for herself. She seemed surprised when I told her what a fantastic job she had done supporting this research, shyly accepting this praise. She impressed upon me how determined she was to move forward and not look back, doing everything she possibly could to achieve her goals. I came away from the interview desperately wanting her to succeed and achieve the goals she had set herself.

Victoria

My first introduction to Victoria was at home alongside her care co-ordinator. Her sister and grandmother were also present when we visited. Victoria has an autism spectrum disorder and Asperger's syndrome as well as bipolar affective disorder. She needed help from the care co-ordinator to complete the paperwork and this is an aspect I had not considered when preparing for the interview. I was glad that the care coordinator was present as this could otherwise have been awkward as I had not realised that she would struggle to complete the documentation. Despite this, I was clear that she was able to understand information presented, weigh up the pros and cons of participation and provide informed consent. She also asked why I had put a letter 'C' on the disposable camera and I had to explain that this was so I could identify who the camera was from when it was returned to me. Again, I was surprised to be asked this question as it had not occurred to me that people may question this. Victoria has a keen interest in gardening and was really pleased that her father had fixed the greenhouse as she had been able to plant some seeds. She took me out to the garden with her care co-ordinator, keen to show us what she had been doing in the garden. She had been busy since the greenhouse had been mended planting vegetables, herbs and flowers and was really proud of her achievements. She was well versed in what had been planted telling us the names of all the different flowers she was growing. Not in any way being an avid gardener, I was impressed by her knowledge of the different plants and flowers in the garden as she was able to name many of them.

When I next turned up to interview Victoria, I was introduced to her father. Victoria was particularly upset that only two of the photographs she had taken had turned out, and asked me to take some more photographs on my mobile phone to include in the study. She chose to take photographs of a baby anteater in a book, the contents of the kitchen cupboard and some of the plants and vegetables in her garden, explaining that these replicated the photographs that had not turned out. I was having a difficult day as I had learned that morning that a family member battling terminal cancer had died. I had therefore spent the morning comforting my mother. At times during the interview, Victoria's eyes welled up and it looked as though she were fighting not to let the tears fall. This was particularly true when talking about her five month stay in hospital and how she thought she would never go home. I tried to steer the conversation back to more positive things when she appeared so upset; this may therefore have stilted the interview. The discomfort I felt at her obvious distress may have been due in part to my family bereavement and a wish to avoid upsetting topics.

When I saw Victoria she was also part way through GCSEs and this was placing additional stresses on her. I was pleased that her father was at home, making sure he knew I was leaving in case she wanted to talk things through after the interview. I also contacted her care coordinator to explain she had been upset during our meeting as I was concerned about her.

My impression of Victoria was somebody who was struggling to come to terms with her numerous conditions. She was unsure how she really felt about having to take medication, but wanted to ultimately stop her medication as she saw little benefit in taking it. She saw herself as somebody who was not 'normal' and desperately wanted this to change; indeed normality was a recurring theme throughout our discussion. I was left with the overall impression that she was struggling to find and assert her identity and had no clear sense of self.

Katey

My first meeting with Katey was a little stressful as I turned up to college only to find I was at the wrong campus. I rushed over to the correct site and was directed to a meeting room where the care coordinator and Katey were talking. Both were incredibly understanding about the mix up but I was very flustered. Katey was doing a health and social care course at college, a busy course with lots of college hours in the week for lectures. Katey was an active member of a support group consisting of young people and parents who have used inpatient services in the past. This group work in partnership with inpatient staff and managers to develop services, and Katey had been an integral part of the project to change the ward catering arrangements to self-catering. Through her involvement with this group, Katey also sat on interview panels for recruitment of new inpatient staff.

Katey lives with her mum, stepfather and two half-siblings. She has no contact with her father, but sees her two brothers at weekend when they come to stay at the house.

Katey had been admitted to hospital on three different occasions due to her mental health. The first admission was because of her eating disorder, with subsequent admissions due to depression and anxiety. Previously prescribed antidepressants, at the time of the interview she was prescribed the antipsychotic medication risperidone and had been taking this for four months. When we met for the interview, Katey was still having days when her mood was low and a dose increase of risperidone was being considered because of ongoing psychotic symptoms. Despite this, she was doing well with her college course and was thinking about applying to University to start a mental health nursing course.

My impression of Katey was that of a sociable young lady; striving towards a career as a nurse. Despite seeing a lot of positive aspects to her medication, she also showed some ambivalence to it and had concerns about her weight increasing with an increasing antipsychotic dose. With her history of an eating disorder I felt that this concern was completely understandable. She was taking a mature approach by discussing her concerns, monitoring her actions and deciding what was and was not acceptable to her.

Allison

I first met Allison at a meeting of a local patient and carer support group. She wanted to get involved in the study but was unsure whether she had been on antipsychotic medication until another member of the group informed her that she had taken this before. We subsequently met at the shared accommodation where she was living. Whilst discussing the study and what was required, I was struck by the extensive scarring on both her arms due to self-harm. Her eyes were constantly moving from side to side making me wonder whether she had a form of epilepsy. She explained that she would soon be moving to alternative accommodation as her current placement was dominated by male tenants and she wanted to move somewhere with more women. I subsequently visited her at her new house, a converted barn in a rural setting with fabulous views over the surrounding countryside. The house had only opened six weeks previously and there was still building work ongoing. The interior was very luxurious with an indoor swimming pool, a huge modern kitchen where all the residents seemed to congregate and a large dining table at which the interview was conducted. Allison seemed much happier in the new accommodation and whilst making tea in the kitchen it was evident that she had bonded with some of the other girls who were staying there and enjoyed talking to the other residents.

During the course of the discussion it became apparent that Allison had been in hospital for a prolonged period, including a stay on the psychiatric intensive care unit (PICU) having absconded from the open ward. She was discharged to her community placement straight from the PICU and found the transition from hospital to home particularly difficult. This culminated in a large, serious overdose requiring paramedic intervention and a hospital stay. Her account of the overdose was particularly vivid and she had clearly been frightened by this.

Subsequent to the overdose, medication had been stopped by the prescriber but was being reconsidered due to re-emergent symptoms. She was very selective about who she discussed symptoms and medication with, and did not appear to have a relationship with her father or fiancé that allowed her to comfortably talk about such topics. I wondered what was driving the secrecy with family members, perhaps a wish to not worry them or concerns about how they would react to the information.

Christina

My first meeting with Christina was at the school she attended, her care coordinator was present. Before the meeting, I was given an overview of the school and it's ethos as it is so unique. Catering for students with social, emotional and behavioural difficulties, the school focus is on vocational training in areas such as hair and beauty, construction and expressive arts as well as teaching more traditional subjects such as Maths, English and Information Technology. I was told that the majority of students were vulnerable, disaffected, disengaged or at risk of exclusion from other schools. On admission to the school, an emotional screening tool routinely utilised showed that Samantha had high levels of anxiety, depression, explosive anger and over-dependence on adults. Despite this, her school attendance is good and she was described as very open, artistic and articulate. She uses art to express her thoughts and feelings about her mental illness and I was encouraged to look at her portfolio. Christina was studying health and beauty and so I was shown the salon where they undertook the different treatments. Medication was stored at the school in case her mother forgot to give it to her. Her mother was diagnosed with bipolar affective disorder, and this led to her at times forgetting to give Christina her medication.

When I spoke to Christina she was very keen to use her artwork for the project. She appeared a little sedated, and her hands and legs were bouncing up and down whilst we were speaking. I wondered whether this was secondary to anxiety or side effects of medication. I left the school anticipating the art work she might complete for the research given all of the very positive feedback about her outstanding artistic ability. When the photographs of her artwork were subsequently returned, the images leapt out and were very dramatic showcasing her amazing talent

Samantha

My first impression of Samantha was somebody who was extremely shy. I joined a planned meeting with her care coordinator who had briefly explained beforehand the purpose of my visit. Quietly spoken, Samantha indicated that she was happy to take part in the study on the understanding that she did not have to include photographs of herself as part of the study. She also appeared a little startled when I disclosed that the interview would be taped. I had to explain that the interview would not be played back to her as she told me she did not like hearing her voice on recordings.

When I interviewed Samantha she had recently got the results of her health and social care course and was beaming when she told me that she had got a distinction star, double distinction. Following this achievement, she was debating whether her next step would be to undertake an apprenticeship or go to university. She had managed to secure work in the administration department of a local school and this was swaying her towards an apprenticeship.

Samantha's story about the impact of her illness was particularly moving and I struggled with how difficult it must have been for her when symptoms were particularly troublesome. The voices she heard meant that she found it difficult to leave home, always wanting to ensure that doors and windows were locked and family members were safe. Samantha had also self-harmed in response to the voices and taken overdoses of prescribed medication. Despite this she had achieved outstanding course results, showing fierce determination and courage, and was thinking about what her next career steps.

Michelle

When I met Michelle, with her psychologist at a local GP surgery, she was immaculately dressed and made up obviously taking a lot of pride in her appearance. She was bubbly, enthusiastic and really keen to get involved in the research. She was an undergraduate at Leeds University but came home regularly so she did not foresee any problems with arranging to be interviewed at home. There was a delay between the initial and follow up meeting as she was in her final year and under pressure to complete her dissertation. Once her dissertation was handed in, she became unwell and so again this delayed the interview. When we met she was ecstatic as she had been for an interview the day before and been offered a job. She was working as a youth worker when we met, but had also successfully undertaken numerous placements as part of her university course.

Michelle was very forthcoming during the interview and again I was struck by the adversity and tragedy she had overcome during her childhood. The trauma she disclosed included the murder of a relative when she was still at high school. The interview progressed very well and was helped by the fact that Michelle herself had interviewed people as part of her dissertation transcribing the interviews herself.

Gabriella

Gabriella was the participant I most struggled to engage. The interview seemed particularly difficult and felt a little stilted as Gabriella's answers were brief and not particularly expansive. I was also nervous around her dogs as one kept jumping up at me, and I think this affected my abilities to garner more information from Gabriella. I sensed that she was picking up on my discomfort around her pets which could also have made her feel less at ease. She struck me as somebody who was very shy with limited social support excepting her family. She clearly loved the menagerie of animals that joined the interview at varying stages. Gabriella was clearly very imaginative and had put a lot of thought into the composition of the photographs taken. Unfortunately her camera broke before she had chance to send them so she instead described the photographs at interview. Even when described verbally I could visualise how the photographs would have looked as Gabriella described her intentions so clearly.

Stephen

I first met Stephen at his school, along with his care coordinator. One of the teachers was waiting in reception, keen to speak to the care coordinator about her concerns with regards to Stephen's presentation. I knew beforehand that Stephen struggled at school, for the past nine months he had been at home or at a 'medical school'. It subsequently transpired that this was the first week back at this school and the week had not gone particularly well. When I subsequently spoke to Stephen, he appeared fairly quiet but pulled faces when he learnt he would have to take photos and then have an interview that was recorded. He also did not know what a disposable camera was so I had to explain this to him. He agreed to participate, however his interest seemed superficial and I wondered whether he would complete the photographs and interview given his obvious unease about this. A long time passed between the initial and final interview as he broke his leg and injured his back in a gardening accident. Because of his injuries the discussion about medication went ahead without photographs as he was struggling to take photographs following the accident. His mother joined the interview part way through with Stephen's consent. She did contribute to the interview, however I did not feel that this detracted from the information Stephen provided. Prior to her involvement, I was struggling to get Stephen to engage and the interview was feeling particularly stilted. This improved when his mother joined the interview. I was conscious however that his mother disclosed some information that Stephen himself would not have provided. This was particularly evident from Stephen's facial expression as his mother spoke of the weight gain he experienced with medication.

Jonathan

I first met Jonathan in a coffee shop with his care coordinator; he had already started to take photographs on his mobile phone as he was on holiday from college. At college he was doing a fine art and photography course and the photographs he showed me were excellent and thoughtful images which fired my imagination. He highlighted from the start that he was ambiguous about his medication likening it to a 'mist'. It was clear from information disclosed that Jonathan had ongoing psychotic symptoms. Jonathan mentioned that this was affecting his ability to engage in and progress his fine art as he was struggling to find inspiration; this was clearly troubling him. The time between the initial and final interview was also prolonged for Jonathan. When I first turned up to interview him he was suffering from pleurisy and was too unwell to proceed. His mother suggested I arrange subsequent meetings through her as Jonathan forgot a lot of things. Jonathan was also unable to send me the photographs he took on his mobile phone as he could not load them onto a computer to send via email.

A Brief Overview of Those who Withdrew from the Study.

Paul

Paul was the first person I recruited to the study and he lived in the same children's home as Ameeta. A few weeks later he was admitted to hospital and then on discharge relocated to Scotland which prevented on-going participation.

Jackie

Jackie seemed very keen to be involved in the study and had asked to take photographs on her own camera as photography was one of her hobbies. She subsequently withdrew from the study as she had to undergo surgery and felt unable to continue.

CHAPTER SEVEN. RESULTS

7.1. Introducing the Results

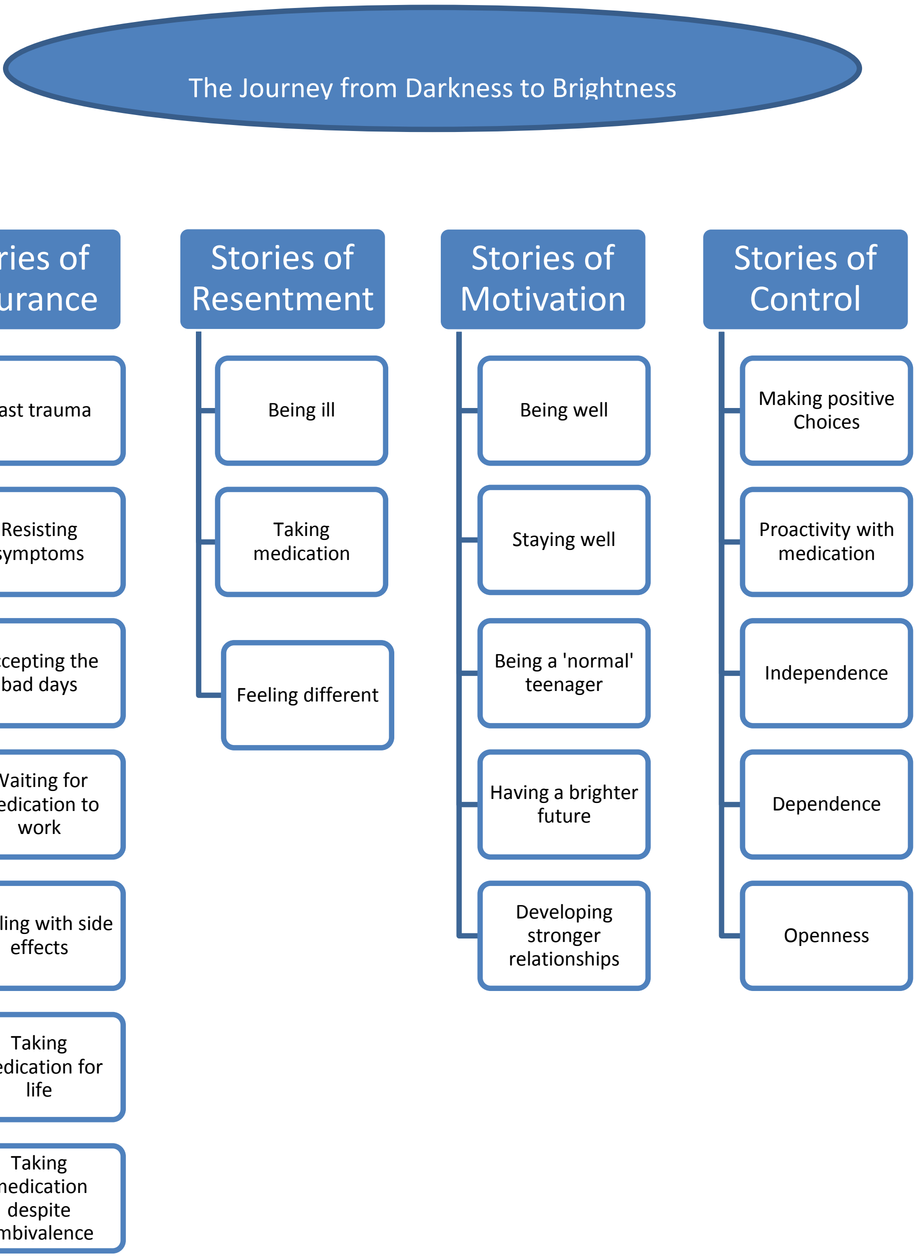
Having described the methodology employed during this research, I will now outline the results of the narrative analysis. When coding the interview transcripts using Frank's (2010) outline framework, a metastory of moving from darkness to brightness emerged in both the stories told and the photographs and drawings used to illustrate the young people's medication journeys. Four stories were also evident, namely stories of endurance, motivation, control and resentment. Underneath all of these stories were different sub-stories which together combined to emphasise the importance of the overarching story to the young people involved (see Figure 7.1).

In presenting the results, I will first discuss the metastory before concentrating on the individual stories and their underlying sub-stories. In presenting the results I have deliberately chosen to include illustrative quotes from the young people as well as some of the images presented given the time, effort and imagination employed to create and/or generate the pictures and the powerful responses some of these images and their association stories provoked. Permission was sought from the young people to include any of the images of themselves within this thesis.

7.2. The Journey from Darkness to Brightness

The metastory that emerged from all the stories narrated by the young people, albeit to different degrees, was a move from 'dark times' where symptoms predominated bringing fear, isolation and unpredictability to brighter times of happiness, friendships, productivity and hope as medication started to take effect and symptoms lessened. Whilst there was acknowledgement by Ameeta and Michelle that other interventions also supported this improvement and a degree of doubt by Jonathan and Victoria that these changes were in fact due to medication, the other young people directly attributed these positive developments to the effects of medication.

Figure 7.1. A Summary of the Overarching Metastory, Stories and their Associated Sub-Stories



Before effective medication regimens were prescribed, many of the young people experienced auditory hallucinations of such a negative nature that they were worried that harm would come to themselves or their families. Allison, Katey and Michelle were concerned that they would instigate harm with Allison explaining:

> *"…it was getting to the point they [the voices] were telling me to hurt my family as well" (Allison).*

Ameeta on the other hand was concerned about harm coming to her family even though she was not hearing voices instructing her to harm them. As Ameeta described:

> *"I thought someone close to me would get hurt. There was a lot of paranoia and stuff like that, so they were dark times" (Ameeta).*

The paranoia and associated fear for her family still resonated with Ameeta, leading her to take two pictures that she self-titled 'Trauma and Dark Times' (see Image 7.1). In doing so, Ameeta directly referenced the darkness of her past in both the illustrative quote and self-titled photographs.

Image 7.1. Photographs by Ameeta "Trauma and Dark Times"

Psychotic symptoms and the associated fear and darkness this produced contributed to the social isolation experienced by the young people.

Christina, an extremely talented artist, also spoke about how her drawing style was influenced by her emotions and symptoms. Using light pencil when she was feeling good and heavy, dark ink when she was not well, she produced a very visual representation of her journey between darkness and brightness (see Images 7.2 and 7.3). It should be noted that the titles on all of Christina's drawings were included by Christina herself.

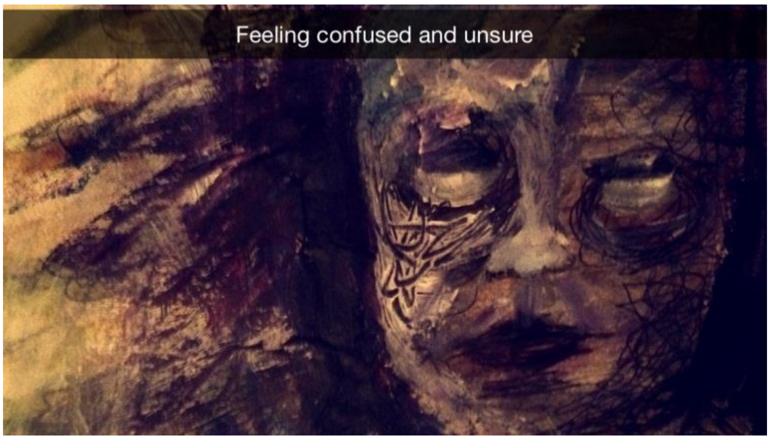


Image 7.2. A Dark Ink Drawing by Christina "Feeling Confused and Unsure"

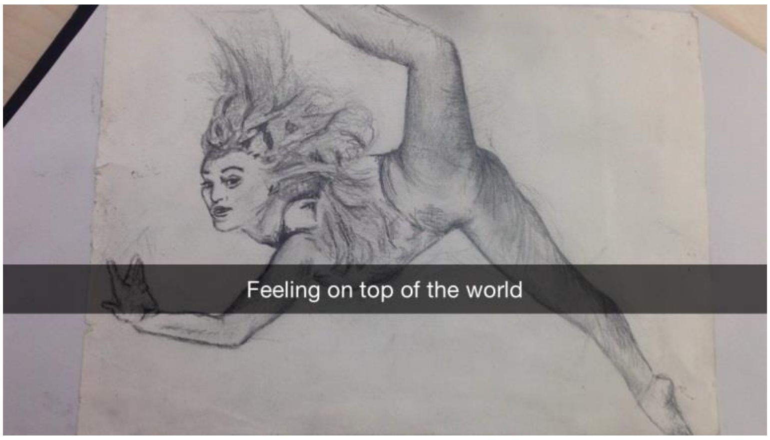


Image 7.3. A Light Pencil Drawing by Christina "Feeling on Top of the World"

Christina's use of dark ink to illustrate 'feeling confused and unsure' (see Image 7.2), mirrors Michelle's very strong imagery of darkness (likened to living in a cave) to describe aspects of her life before medication. Michelle outlined this saying:

> “…*before being on medication and I was in a really dark place you don’t really see the world as a positive place or a nice place at all. You really kind of – it’s quite a dark place to be in and you don’t appreciate things and you don’t want to go out of the house, you don’t want to see people, you know. You just want to kind of stay in your cave or in your bed and not interact or see anyone, you know, and it’s really difficult because you kind of isolate yourself. One thing that the medication has done has made me realise how to appreciate things and be able to get up in the morning and go out and do things and last summer it was my first year – it was four years since I was on medication and I remember taking this picture and just appreciating the view and being out in the sun, in the air, and in the sun and on the beach. When I was little my mum used to always take me to – [place]- and it always used to do me the world of good because I’ve always been quite an anxious person. I’ve always preferred the sun, I’ve always preferred things like that and my mum has always taken me to places like this to make me feel better. And it was actually the first time I looked up and I was kind of like – ‘I’m starting to appreciate the world again” (Michelle).*

Michelle, in the same vein as Ameeta, spoke specifically of darkness when illustrating life before taking medication. Michelle, however, moves on to speak of her current enjoyment of life using the illustration of being out in the fresh air and sun (see Image 7.4). The sun also represents brightness and so again Michelle’s story contrasts dark and brightness to reflect life before and after medication.

Gabriella was unable to send photographs as her camera broke after she had taken them. She did, however, describe her plans to edit the photographs to illustrate her feelings, one photograph being an arm with a capsule resting on it. Gabriella explained why she had taken this particular photograph, saying:

> *“…the arm is black and white in the background and then the pill is quite vibrant colours so it stood out. That was kind of to*

> *represent like colour in black and white symbolising hope (the medication) in darkness really" (Gabriella).*

Thus, Gabriella contrasts darkness and brightness through use of the colour black to represent darkness, and white to symbolise the hope that medication may lighten the darkness.

Image 7.4. A Photograph by Michelle about Appreciating Life Again.

Both Ameeta and Jonathan used the metaphor of 'light at the end of the tunnel' to signify the importance of medication in symptom control and recovery, with Jonathan describing the photo taken on his mobile phone as follows:

> *"I was sat in the back seat of the car and I just kind of saw this mist and the whole thing was just very, it was kind of a light at the end of the tunnel kind of thing because you see the light shining on to it, and that was kind of how I was hoping the medication was going to go. I was eventually going to reach the end of this kind of period of darkness. You can see the trees covering up most of the ground and then just that (the light) at the end" (Jonathan).*

Jonathan, like Gabriella, is also talking about the hope that medication will end the darkness in his life. He acknowledges that he has not reached that stage yet, and is indeed doubting that he ever will, saying:

> "*I think I am just going to have to deal with this forever or at least for a while more, but I will be able to cope with it a lot better" (Jonathan).*

Hope that medication would also improve symptoms was also a strong motivating factor for young people starting to take medication. Katey spoke about her reasons for taking medication when it was first prescribed despite her fears about side effects, saying:

> "*The hope that it would get better, yes, because I didn't really speak to my family about what was going on and when they did find out they were like quite shocked and they wanted it all to stop. So I thought the medication is there to help me really if I take it then it will stop and then I could help and then they won't be worried. So I carried on taking it in the hope that it would get better" (Katey).*

Whilst Jonathan does not feel that medication has been strongly instrumental in helping his illness, stating early on in his interview that medication has neither helped nor hindered him, he goes on to acknowledge the possibility that medication may have been one of the strategies that has helped reduce the intensity of his auditory hallucinations when he talks about:

> "*…this strange submerged world which was just voices in my head and spending time on my own and drugs and all the strange things. I don't know if I got out of that on my own or if aripiprazole helped. But these days they [the voices] are at a more manageable level, just a very low background noise most of the time. Although I still get episodes where I freak out and become very loud and I see things and get paranoid and suffer from delusions" (Jonathan).*

Jonathan continues to take medication because he is not experiencing side effects that concern him. I think there is also an element of his continuing to take medication in the hope that the darkness ends and the light starts shining brightly. This is evidenced when Jonathan describes a picture of the light shining through his bedroom curtains, as he says:

> "*It's like it is a bit hopeful, it's like a very hopeful thing to be on medication, you are just hoping at the end of the day, there's nothing sure and that's what this is about, it's a very dark room where you get a bit of light. It's like the meds are trying to break through. The light trying to get through curtains is like the meds trying to get through to my head I suppose, just hopeful, wishful thinking" (Jonathan).*

Jonathan also referred to his visual hallucinations as having a different quality to real images. He explained that his hallucinations were very dark and not fully formed, contrasting with real and actual images that he could see more clearly than the hallucinations. In doing this he highlighted another aspect to the imagery of darkness.

All of the young people spoke of the positive difference medication made to their symptom control and how this positively impacted on their vocational, educational, social or emotional quality of life. This may not have been immediately obvious to Jonathan, Victoria and Christina, who at times expressed ambivalence about medication, however they all highlighted positive aspects to medication at varying points in their stories. Victoria and Christina highlighted the role medication had in facilitating discharge from hospital, and Jonathan wondered whether medication had played a role in reducing the intensity of his voices whilst recognising that medication had played a part in bringing a focus to his life. Jonathan, whilst expressing ambivalence about medication on several occasions at both the initial meeting and interview, was obviously still hoping that medication would reduce the intensity of his voices further. Whilst Gabriella's symptoms had lessened on medication she did not talk about how this had subsequently impacted on her quality of life, other than to express her happiness that the voices were less intense and intrusive. This is perhaps more indicative of the difficulties I had engaging Gabriella in discussion and getting her to expand on information beyond what her photographs were illustrating. Ameeta, Victoria, Allison, Christina, Samantha and Michelle all acknowledged that medication had supported them to get out of the house more. For Ameeta (see image 7.5) and Victoria this had enabled them to participate in their respective hobbies of baking and gardening.

Image 7.5. A Photograph by Ameeta about Enjoying Baking

Being able to leave the house more often also facilitated increased social activities and contact with friends for Ameeta, Allison, Christina, Samantha and Michelle. This social contact brought brightness and happiness to their lives, contrasting with the dark times of social isolation.

As well as positive impacts socially, medication had also resulted in positive educational and vocational journeys. For Katey, Victoria, Christina, Samantha the medication had helped them through the stress of exams. Whilst Victoria and Christina felt that they would have managed as well without the medication, the other young people clearly felt that the medication had been instrumental in their exam success and subsequent ability to progress to college, university or a career. These young people were certainly experiencing brighter times and the prospect of brighter futures with the positive impacts of the medication. Samantha clearly stated that she would not have finished her health and social care course without the antipsychotic medication. She could not concentrate at college because of the voices and so had to study in a separate room with support staff to keep her focused on the work at hand. She also missed some college having to attend the accident and emergency department because she frequently cut her arms in response to the voices. Samantha ended up getting distinction star and double distinction on the course, an achievement she felt would have been unattainable before being prescribed medication. These outstanding results have enabled her to consider whether to go to university or do an apprenticeship, and she is currently working in the administration department at a local primary school to have a taster of an apprenticeship. For Ameeta, the medication had been beneficial in supporting her to undertake vocational qualifications and start a placement with the Prince's Trust. She was very positive about the direction her life had taken and was very much looking to a brighter future, explaining:

> *"I managed to see a bright future for me moving forward and pictured myself, pictured a life worth living" (Ameeta).*

This quote by Ameeta captures the journey she sees herself on, moving forwards towards the brightness of a life worth living.

Medication had also had a positive emotional impact, with Ameeta, Allison, Katey, Michelle and Samantha speaking of how much happier they were on medication. This was particularly evident when Katey said:

> *"I'm happy that I'm on it [medication], I'm happy that it makes me happy and I can carry on and do whatever and – I don't know, I'm just happy" (Katey).*

Samantha also spoke of being happy now that she was in control of the voices rather than the voices being in control of her, taking a photograph of nature and a blue sky to illustrate her happiness and contentment (see Image 7.6)

Whilst the participants were predominantly in a bright and happy phase of their lives when I met them, they were however realistic in recognising that there would always be good and bad days. Whilst these bad days may resemble a brief journey back to the dark times, there appeared to be an acknowledgment that the bad days would be more manageable and not of the magnitude or duration of the darkest times when the illness was at its most severe. This view was crystallised in the heartfelt words of Ameeta when she pronounced that 'the stress-free fairytale just doesn't exist'. Christina felt that medication was not helping her voices to the extent that she wanted, and she continued to have intermittent dark days when she struggled to ignore the numerous voices inside her head. Whilst Victoria recognised that medication had helped in her discharge from hospital, she still wanted to stop her medication and resented the fact that she was being told to remain on it whilst she finished her GCSE exams. She was struggling to embark on the journey towards her idea of a brighter time when she would no longer need to take medication. She was also helpless in her ability to control the pace of that journey as decisions were being taken for her. Thus, there was still an edge of darkness to Victoria's story that prevailed more obviously than in the stories told by the other young people.

Image 7.6. A Photograph by Samantha to Illustrate Happiness

Although reducing components of stories down into factors in a table could be seen as reductionist, summaries of the dark and bright aspects to the stories told by participants are provided in Tables 7.1 and 7.2 and will be outlined in more detail throughout the chapter.

Table 7.1. Elements of Darkness in Individual Stories

Element of Darkness	Ameeta	Allison	Christina	Gabriella	Jonathan	Katey	Michelle	Samantha	Stephen	Victoria
Being a carer	✓									
Being like family members	✓									
Being on medication			✓							✓
Childhood trauma	✓						✓			
Dependence on medication		✓	✓			✓	✓	✓		✓
Dependence on others			✓							
Eating disorder		✓				✓				
Feeling alone	✓	✓	✓		✓	✓	✓	✓		✓
Feeling different			✓	✓		✓		✓		✓
Harm coming to others	✓	✓	✓				✓	✓		
Helplessness	✓	✓	✓							✓
Hospital admission	✓	✓	✓			✓				✓
Medication ineffective			✓		✓					✓
Recklessness		✓			✓	✓	✓			
Secretiveness		✓		✓			✓			

Element of Darkness	Ameeta	Allison	Christina	Gabriella	Jonathan	Katey	Michelle	Samantha	Stephen	Victoria
Self-harm		✓				✓		✓		
Side effects		✓	✓	✓	✓	✓	✓	✓	✓	✓
Stigma		✓				✓	✓			
Struggling with identity										✓
Symptoms	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓

In considering the socio-narratological components of the young people's stories, the elements of darkness (see Table 7.1) equate with the forces of fear within individual stories, whilst the elements of light (see Table 7.2) could be viewed as the forces of desire. This metastory of darkness and brightness also fired my imagination as I thought and reflected upon how it must be living with psychotic symptoms, fearful of how you might respond to the symptoms or being terrified of leaving the house. To me the young people's descriptions made it feel like it was an awful experience.

The four stories that underpin the young people's journey from darkness to brightness can also be categorised according to dark and light, with stories of endurance and resentment representing darker stories than the brighter stories of motivations and taking control. These stories will now be discussed in more depth.

Table 7.2. Elements of Brightness in Individual Stories

Element of Brightness	Ameeta	Allison	Christina	Gabriella	Jonathan	Katey	Michelle	Samantha	Stephen	Victoria
Being a ‘normal’ teenager	✓					✓		✓		
Being happy		✓		✓		✓	✓	✓		
Career ambitions	✓	✓				✓	✓	✓		
Discharge from hospital	✓		✓			✓				✓
Engaging in education	✓		✓			✓	✓	✓		✓
Engaging in hobbies	✓		✓			✓	✓			✓
Healthier lifestyle		✓					✓			
Improved relationships		✓			✓	✓	✓	✓	✓	
Independence	✓					✓	✓	✓		
Looking to a brighter future	✓	✓				✓	✓	✓		
Openness			✓		✓			✓	✓	
Socialising	✓	✓	✓			✓	✓	✓		
Support networks	✓	✓	✓		✓	✓	✓	✓	✓	
Taking control	✓					✓	✓	✓		
Volunteering						✓				

7.3. Stories of Endurance

The stories told by the young people evidenced different aspects of endurance related to past experiences, illness and medication. Endurance evident in past experiences predominantly involved having to deal with trauma and illness.

There was also endurance in managing symptoms and the bad days that inevitably formed a feature of the young people's lives. Once medication was initiated there was then the endurance of waiting for medication to help symptoms, managing side effects, taking medication for life and taking medication despite ambivalence about the same. These stories of endurance outline some of the features of the capacity for stories to make trouble or deal with trouble for those involved. They highlight some of the stakes such as fears of not being able to participate in teenage activities, loss of independence, readmission and worries about relapse that these young people had to deal with. In some cases the stories also describe how these stakes were overcome.

7.3.1. Stories about Dealing with Past Trauma

Several young people spoke about past traumas experienced in their formative years. Ameeta did not go into specific detail about her traumatic experiences, and given her fragility when interviewed I consciously chose not to explore this in more detail. My impression from what she did say at interview was that the trauma was related to her home life and the associated caring responsibilities for her family, as well as her own symptoms of psychosis, low mood and suicidal ideation prior to her receiving input from mental health services. Ameeta spoke of the impact this trauma had on her when she said:.

> *"I experienced a lot of trauma. My day to day life was very hectic and busy. I would put a smile on my face but deep down I was very low in mood. I had a lot of emotions inside me that I couldn't explain. I had reached the point where I no longer saw a purpose for me in life which was when I first began to experience psychosis without realising or fully understanding what was truly going on" (Ameeta)*

Michelle also talked about trauma, particularly in relation to a family member who was murdered when she was fourteen years old. She spoke about how medication, along with cognitive behavioural therapy, had helped her to overcome the ongoing difficulties this was creating and to respond differently to bereavement, she explained:

> *“In my life I’ve suffered with a lot of trauma and trauma which at twenty years old, the trauma that I’ve gone through is not what normal people at twenty-one would go through. It’s things that you see on the TV and you’d go – that would never happen to my family, and you’d kind of not think about it but it does happen. And one thing that I struggled with before my medication is overcoming those traumas and I took bereavement really bad, I found it very hard. I find attachment very hard, you know letting someone go. I used to have thoughts of, because I’d so many traumas, I was pushing my mum away because I was so scared that she might die that I did not want to be close to her. And one thing that I feel being on medication has done is I was on medication when my grandad died last year and I felt like I was a lot calmer when it came to the death” (Michelle).*

Michelle chose a photograph of herself as a baby with her grandfather as the image to support this part of her interview (see Image 7.7).

Image 7.7. A Photograph of Michelle with her Grandfather

Some of the young people's vivid accounts of their psychotic symptoms could also be considered traumatic. I present these as a separate substory of endurance because of the ongoing efforts required in resisting and managing symptoms.

7.3.2. Stories about Resisting Symptoms

Having already detailed some of the difficulties young people faced resisting voices that told them to harm family members, there are also other stories related to enduring ongoing symptoms which merit consideration.

Christina still hears three voices and when they are all speaking at once she finds this hard to manage, becoming in her own words "spaced out", feeling as though everything is rushing past her, that she is not part of the world, that everything is "blurry" and there is too much going on in her head (see Image 7.8).

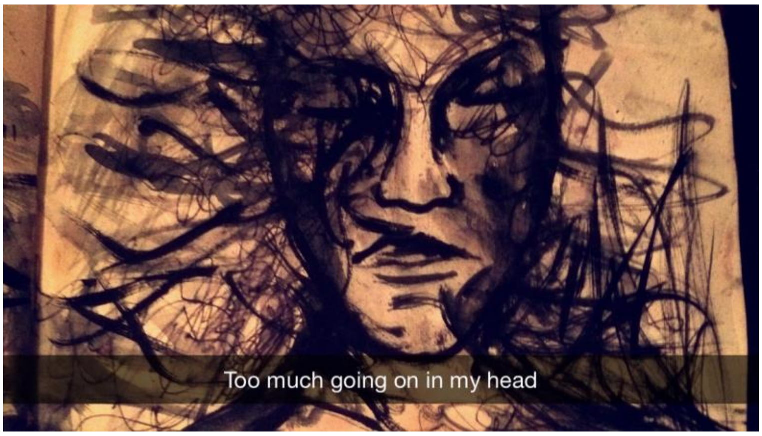


Image 7.8. A Drawing by Christina "Too Much Going on in my Head"

Katey had periods of low and high mood which she found particularly difficult to deal with, and Victoria also found the mania a particularly troublesome feeling that she worried would never be controlled and she would therefore never be able to leave hospital. Katey described the impact her variable mood had on her willingness to take medication when she said:

> *"it was just becoming really overwhelming and I was just struggling with everything and it was getting worse every day so*

> *whenever they said – "Oh we can give you medication to try and make this stop", I was willing to do it". (Katey)*

At the time I interviewed Allison, she was not prescribed any medication as it had been previously withdrawn by her doctor following an overdose. More recently, symptoms had returned and an appointment had been arranged to discuss medication being restarted. Whilst the voices had not got to the stage of instructing her to harm her family, they were instructing her to harm herself; she was managing, with effort, to resist.

Other young people were also managing with ongoing symptoms, their goal being to have manageable symptoms rather than being symptom free. For Samantha she was content that the voices were quieter and she could ignore them as they no longer called out her name. Michelle, Ameeta and Allison also spoke of being able to cope with the voices better since being prescribed medication. Michelle told of a particular trip to the beach with her mum on a sunny day when she was able to resist symptoms, saying :

> *"I would not eat, I would not do anything you know, and people would not want to be in my company because it was very negative. I was not a very positive person to be around. I remember this day and thinking: 'I'm up and I'm not listening to those voices and I'm having a good day'. (Michelle)*

When I spoke to Jonathan, his views of his ongoing symptoms were slightly different in that he viewed them very much as part of himself and contributed to who he was as a person. He therefore did not direct his efforts towards resisting symptoms. He was pleased that the voices and visions were more manageable, but was unsure how much medication was responsible for this. When describing a photograph he had taken of a sky to depict his ongoing symptoms, Jonathan captured how he viewed his symptoms and the illness as the cloudy part of himself, explaining:

> *"This is on a good day, this is just the sun and the clouds and the clouds are like my illness. They are still there but they kind of*

> *make me whole as like a person as well as it being a nice day. You've got to have some clouds haven't you?"(Jonathan).*

Jonathan was not alone in still experiencing bad days and this was another element of endurance the young people had to manage.

7.3.3. Stories about Accepting the Bad Days

Even accounting for the fact that some young people have to live with ongoing symptoms, most of the people were realistic and recognised that there would be good as well as bad days, irrespective of whether this was linked to their illness. There was therefore an element in most stories of enduring the bad days and employing coping mechanisms to get through them.

Ameeta, Christina and Michelle all focused on thinking about the good days to get them through the bad. For Ameeta, she looked at her memories book when she needed to focus on positive aspects of her life proclaiming a need to "*live in the present and create new ones [memories] for the future because it's the good times that get you through the worst*". Michelle had kept all of the thank you cards received from her university placements to remind herself of how far she had come and how much she could achieve (see Image 7.9), whilst Christina tried to remember all of the positive aspects to her life including her family and friends who were always there to help her through difficult times.

Image 7.9. A Photograph of Michelle's Thank You Cards

Allison had a wall in her bedroom covered in inspirational quotes that she could read when she was having a bad day. She also had one of her favourite quotes tattooed on her arm so she could glance down and remind herself that there would always be bad days and life was about learning to embrace these. Allison's tattoo proclaimed:

> *"It's not about waiting for a storm to pass it's about learning to dance in the rain". (Allison).*

I had not heard this quote before, but for me this captured the essence of how many of the young people interviewed were approaching and accepting their illness with bravery, courage and determination to move forwards. It also captured how the young people continued with their lives whilst waiting for medication to control symptoms. For this reason, I incorporated part of this quote into the title of this thesis as it seemed to eloquently represent the essence of a successful journey towards a brighter and happier future.

7.3.4. Stories about Waiting for Medication to Work

Another endurance story central to the stories told was about how the young people had to wait until medication started to work. Ameeta, Allison, Samantha and Stephen felt that medication took longer to work than they expected. Staff had explained the delayed response to Ameeta and Samantha so they were aware that the effects would not be immediate, however Stephen clearly lacked awareness about this as his mother explained:

> "*Right at the beginning because I think they weren't instant, I think he expected to take a tablet and to like instantly feel happy. And because he was not getting that and because his mood was so low as well we went through a bit of a bad time where – that's it, there's no point taking it because it's not doing any good for me, so what's the point of taking it and he did not take it. Everybody else could tell a difference except for Stephen. So you had a very firm talking to did not you, by [the care coordinator] and a few others at school and you know, various other people, who said –*

> *“Look, you know, you can’t tell a difference but everybody else can and it does take some time”. So you’re pretty good now aren’t you. It’s not very often that he forgets because I have to take it out for him you know and leave it on the side. But right at the beginning he was a bit of a devil for not taking it” (Stephen’s mother).*

Allison also spoke of the time it took for medication to get into her system and start to improve symptom control, saying:

> *“…it takes time to get into your system because obviously you can’t just take it one night and then, you know, and obviously you feel better and everything. I think it took about three or four months to get into my system”. (Allison)*

Four of Samantha’s photographs were imaginatively taken to display the time it takes for medication to take effect, showcasing a series of photographs of a daffodil blooming from bud to fully opened flower with time (see Image 7.10).

Image 7.10. Photographic Series by Samantha about Waiting for Medication to Work

For some young people, the medication they were initially prescribed did not effect the desired improvement of symptoms. This led to alternative antipsychotic medications being tried. This requirement to switch antipsychotic medication introduced a longer delay as the young people concerned endured ongoing symptoms whilst waiting to be prescribed medication that would control their symptoms. Ameeta was prescribed Olanzapine and Risperidone before finally improving with aripiprazole. Katey spoke of being prescribed lots of different medications that did not help and Christina also did not respond positively to Olanzapine, saying:

> *"I used to have a bad day pretty much every day with Olanzapine. I did not really have many good days". (Christina)*

Gabriella also had to endure a lot of different antipsychotics before finally going back to the first antipsychotic prescribed, risperidone. This seemed to result in fewer side effects the second time around. She outlined her journey through these different medication trials, explaining:

> *"I was put on risperidone which gave me a few side-effects so they put me onto aripiprazole then the aripiprazole was not really doing anything and things had really got worse so they put me on amisulpide and then when that was not doing anything either they put me back on risperidone, because that was the one that seemed to do a lot more than the others". (Gabriella)*

For others, medication was changed because of side effects, and side effects represented another story of endurance that I will now consider.

7.3.5. Stories about Dealing with Side Effects

Once medication was prescribed and starting to take effect, many of the young people then had to endure a range of side effects due to their antipsychotic medication.

For every young person except Ameeta and Jonathan, weight gain was something that they had found particularly troublesome. Victoria spoke about how she was always hungry when she was first prescribed medication and would "*eat and eat and eat"* resulting in weight gain and Michelle also indicated how unhappy she was with the amount of weight she gained when she first started on medication. Michelle included a photograph of numerous chocolate bars to illustrate this aspect of her medication journey (see image 7.11). Katey also felt more hungry and gained weight when she was first prescribed risperidone. This was directly responsible for her stopping taking medication for about a month. Katey had previously been admitted with an eating disorder and so she was particularly conscious about her weight and body image. Her eating disorder had been of such a concerning magnitude that she described at interview being at “death’s door” because of this, and so she like all of the other young people experiencing weight gain worked hard to counteract this side effect. Despite stopping medication because of the weight gain Katey resumed taking the risperidone as she was terrified that the symptoms would return.

Image 7.11. A Photograph by Michelle about Weight Gain

Ongoing symptoms were an issue when I saw Katey at interview and a dose increase of risperidone was being considered. When discussing her feelings about the plan to increase the dose, her attitude was that she was going to try the higher dose and assess the impact on her weight, explaining:

> *“I am going to try it (medication) and then if I do put on weight I’m going to stop because it’s – I’d rather not put on weight and struggle a little bit than put it on and maybe not see a benefit at all”. (Katey)*

Allison spoke of how she gained weight very quickly on olanzapine and this was the reason medication was subsequently changed to quetiapine. Allison also had a history of eating disorder and spoke about how she felt like a completely different person because she had gained so much weight on medication. Olanzapine was deliberately commenced because she was underweight but Allison spoke of how resisting feelings of hunger at this stage in her life made her proud. She did however start to eat when she felt hungry as staff in the hospital told her ‘she would be admitted to an eating disorders unit if she failed to gain weight’. Allison therefore had to endure the weight gain so she could avoid transfer to an eating disorders unit. Allison included two photographs of herself before and after she had gained weight to illustrate the difference, and a before and after photograph was also included by Michelle who was also very conscious of her image and how she looked to other people (see Image 7.12).

Image 7.12. A Photograph by Michelle to Illustrate Weight Gain

Gabriella and Christina also had to endure weight gain on antipsychotic medication with Christina bemoaning:

> *“it’s a lot of weight, I was a size six and now I’ve gone up to a size fourteen” (Christina)*

When interviewing the participants, the last two interviews were with the only two young men who completed the study. Prior to these interviews, I did wonder whether weight gain would be a concern for these men as it had been such a striking feature in the stories of all the young women except Ameeta. Stephen initially spoke of how he had no side effects with his risperidone. However, after his mother joined the interview she spoke of how he had gained weight on medication and did not like this. Stephen looked at his mother in embarrassment when this was mentioned with his expression questioning why she had brought this up. I was therefore left with the impression that this was a sensitive subject for Stephen. The only side effect Jonathan mentioned was a hand tremor with aripiprazole. It is however notable that the side effect profile for aripiprazole is very appealing to those concerned about weight gain as it is less likely than other antipsychotics to cause this.

Sedation was the second most prevalent side effect discussed at interview. Victoria was particularly concerned about the impact that this had on her daily activities describing how sometimes she went out for a long walk but was too tired to finish it, having to return home sooner that she wanted (see Image 7.13).

Michelle was also worried about how she would get up for her new job each morning when she confided:

> *“This has been the biggest problem with having my medication, sleeping. Before medication I had insomnia really bad, would not sleep, would not go to bed, it was awful. My medication makes me sleep straight away [she gives a little laugh] knocks me out completely but I can’t get up in the morning anymore without having six alarms across my room”. (Michelle)*

Image 7.13. A Photograph by Victoria Representing Sedation

Christina spoke of wanting to stay in bed all day at times, and whilst this did not particularly concern her it meant that her mother had to constantly shout at her to get up for school. Some of this was related to medication, however, she also recognised that if she was having a bad day this also impacted as she would think that there was no point getting up as nothing would make her feel better (see Image 7.14).

Image 7.14. A Drawing by Christina "Feel Like Staying in Bed"

Allison also noted the effects sedation had, enduring this at the start of treatment but eventually recognising that the sedation was lessening as her body adapted to the new medication. Allison explained:

> *"…when I first started taking it I felt tired constantly, all the time, proper like lethargic like where you can't be bothered doing anything because you are that tired. But as time went on it lessened quite a lot, it was not as bad. It still made me a little bit tired but not as much as it did at first". (Allison)*

Other side effects were also mentioned at interview albeit less frequently. Katey, Christina and Jonathan all mentioned having tremors with their medication. Samantha experienced galactorrhoea and did not at first realise that fluid expression from the nipples could be secondary to medication. She managed this initially by always wearing jackets to hide the problem, however on reading the patient information leaflet and recognising this was because of the amisulpride she spoke to her psychiatrist and the medication was changed. Gabriella had a photosensitivity reaction to risperidone and developed a rash on her hands. When Christina took her aripiprazole at night it caused insomnia but this was easily managed by taking the dose earlier in the day. Allison experienced cold sweats, headaches and also felt that a return of her seizures could have been related to medication. The young people in the study therefore experienced and endured a wide range of side effects related to their antipsychotic medication but employed different strategies to manage these, displaying high levels of agency.

As well as young people having to endure the side effects of medication there was also another medication aspect to endurance because of the length of time antipsychotic medication has to be taken for which will now be explored.

7.3.6. Stories about Taking Medication for Life

During the interviews with young people discussions arose at times about the length of time they might have to take their antipsychotic medication. Most did not want to contemplate the possibility that they might have to take this long term or for life. Michelle was one of the oldest participants at 20, and when asked what key messages she would have for teenagers about to start taking antipsychotic medication for the first time her response was:

> *"I just think that if I could give advice to anyone, which I'd love to, it's like not being scared about going onto things like antipsychotics because they are not forever and they will help". (Michelle)*

Both Allison and Samantha did not like to think that they would be on antipsychotic medication for life, but indicated that if this was the case then they would accept this because the alternative of living with psychotic symptoms was too hard to imagine. This was explained by Allison who said:

> *"I don't want to be someone who takes medication for the rest of their life, then I think to myself, if it's going to help then it's worth it". (Allison)*

Gabriella also highlighted this as an issue when describing another photo she had taken prior to her camera breaking, detailing:

> *"…one of them [the photographs] was a dinner plate with a pile of pills on it and a knife and fork and it was quite a simple picture. Well they are all quite simple pictures really, and it was to symbolise like having to take the pills every day and how it's something that we have to do and people don't really realise that. It's like a regular thing. It affects how we live really because like you've got to eat to survive so like eating the pills is what I was going for". (Gabriella)*

As well as the possibility of having to take medication for life, Allison, Katey and Michelle also spoke of their fears of becoming physically and/or psychologically dependent on medication with Allison saying:

> *"I think to myself I don't want to end up getting addicted to it if you know what I mean. Some people get addicted to prescribed drugs*

> *don't they to the point where they need to keep taking them?" (Allison)*

There is therefore an element of endurance about continuing to take medication despite fears of dependence, however, this again is driven by a wish to have manageable symptoms. Some young people also continued to take medication despite their ambivalence as will now be discussed.

7.3.7. Stories about Taking Medication Despite Ambivalence

Another aspect of endurance in the stories was highlighted by Victoria, Christina and Jonathan who continued to take medication despite a view that it was not particularly benefitting their symptom control and illness. All three young people were unclear whether medication was helping with their illness. For Christina and Jonathan this opinion was driven by the fact that they had ongoing and seemingly frequent symptoms. Jonathan in particular spoke about being "ambiguous" about medication representing his view that whilst he was not finding medication particularly troublesome to take, he still had ongoing symptoms. Jonathan was not sure whether medication had been in anyway helpful in reducing the intensity of the symptoms, or whether this was because he was spending less time on his own and had stopped using illicit drugs. He was particularly vocal about this saying:

> "*All of them [the photos] have this ambiguous kind of nature I would say because that's how I feel about my medicine, I just feel ambiguous. This is just like your average day in quite a serene place. I suppose that's how I feel about the meds, not here or there, just, you know" (Jonathan).*

Christina also continued to endure taking medication despite ongoing symptoms and views that it was not helping, she explained:

> "*I can see their lips moving but I'm hearing the voices in my head but the voices just overwhelm me so I can't really hear what they are saying……I just – [pause] I feel as if it's – [pauses again – longer this time] I don't know – like just why me, why do I have to*

> *take it, why? Because in my eyes I don't feel like it's making that much of a difference so I think like - why should I still be taking this when it's not making that much of a difference?" (Christina).*

Christina also presented how disaffected she feels about taking medication in one of her drawings (see Image 7.15).

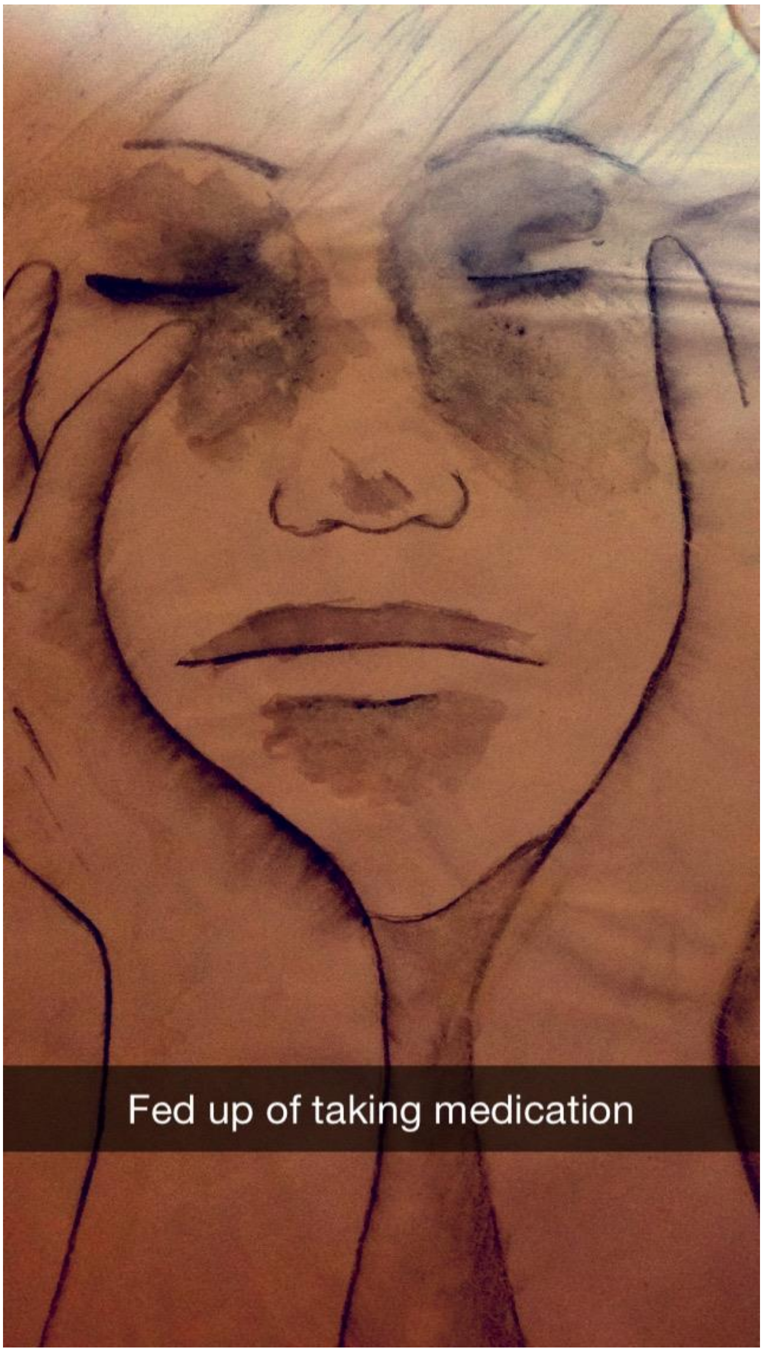


Image 7.15. A Drawing by Christina "Fed Up of Taking Medication"

Victoria's ambivalence and resentment towards her medication appeared not to be driven by ongoing symptoms. Whilst she seemed to acknowledge that she was manic when admitted to hospital and takes medication to prevent mood swings, she did not feel that she was ill anymore and was therefore struggling to understand why she should continue to take the medication. At times, Victoria also attributed her admission to a breakdown and mood swings to normal teenage behaviour, proclaiming:

> "*I don't think that there's anything wrong with me. I might have mood swings and I might be autistic but there's nothing wrong with that. I mean before I had my breakdown I was perfectly fine" (Victoria).*

Victoria was very clear during the interview that she did not think medication was natural and did not agree with taking it. Whilst in hospital she felt that medication was a poison but put this down at interview to her paranoid symptoms. However, she still does not want to take medication explaining:

> "*I don't agree with taking medication, I don't think it's natural really and I shouldn't have to so as soon as possible I want to be off it" (Victoria).*

Her endurance is particularly evident throughout all of the stories as she is continuing to take medication despite these strongly held opinions. This may be because her father gives her the medication as he was annoyed when she forgot a dose soon after her discharge from hospital. Victoria is very close to her father and depends on his support and help, so perhaps her motivation to continue taking medication is related to a wish to avoid worrying her father.

These substories of endurance represent some of the darker stories told. However, the young people also told brighter medication stories, including stories of motivation which will now be considered.

7.4. Stories of Motivation

Throughout individual stories there were also a number of different motivating factors to continue taking prescribed medication. Whilst these may not have been apparent to the young person at initiation of treatment, the positive outcomes resulting from improved symptom control in each individual case became motivating factors for ongoing adherence with antipsychotic medication. These positive outcomes secondary to improved symptom control with medication incorporated stories of being well, stories of staying well, stories about being a ‘normal’ teenager, and stories about having a bright future. These components again reflect the forces of desire that emerged from individual stories. Whilst the young people may not always have been able to foresee the positive impact that medication would make in their lives when starting to take it, recognising how medication had enhanced their quality of life was a strong motivating factor in their continuing to take the medication.

7.4.1. Stories of Being Well

Fundamental to young people’s views about medication was the extent to which they recognised that medication had played a part in improving symptoms and assisting their journey to recovery. Christina and Jonathan were more ambivalent about medication because they were still symptomatic, however, most young people had noticed a marked improvement in symptoms with medication and this was their primary motivation for continuing to take it. Whilst Joanthan still had hope that medication would support recovery, Ameeta and Gabriella recognised that medication had been instrumental in their recovery. One of Ameeta’s photographs depicted how her recovery was achieved by taking small steps and a mindset that there was no going back (see Image 7.16.).

Ameeta and Katey were apprehensive about going on medication at first. For Ameeta her apprehension revolved around the fact that she had previously cared for relatives who were on medication for mental illness, and was worried medication would make her feel empty; devoid of emotion or feeling. Because of her paranoid ideation, Ameeta was also concerned that harm would come to family members if she took medication. It was seeing other people in hospital progressing that made Ameeta want to improve her own situation by taking medication. As Ameeta herself explained:

> "…*when I went into hospital I saw other people and they were progressing really well, and I wanted to become like that" (Ameeta).*

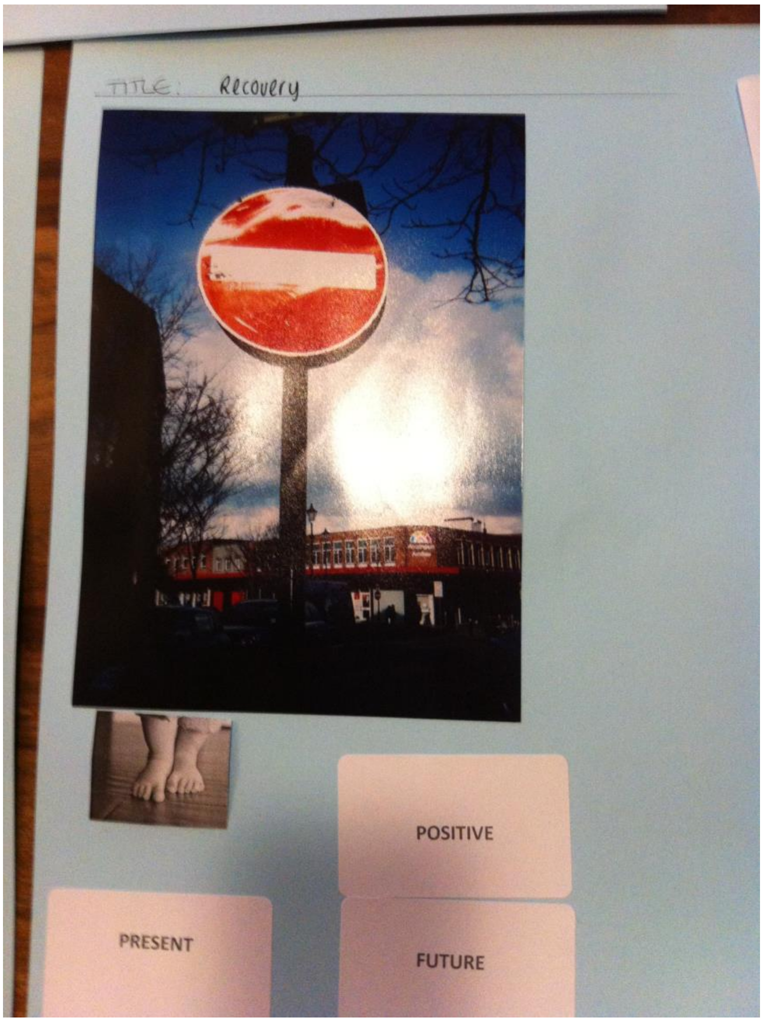


Image 7.16. A Picture by Ameeta "Recovery"

For Katey, her reluctance was understandable because she had never taken medication before and it was something new. Ultimately it was a wish to be well that motivated her to take the medication.

Allison, Ameeta, Christina, Jonathan, Michelle and Samantha all continued to experience symptoms although they spoke of medication making the symptoms less frequent, quieter or more manageable. This in itself was a sufficient motivator to continue the medication, as Michelle says:

> "…*and, you know, medication has made these voices a lot more quieter and it's made me want to get up in the morning, get changed, have a shower, you know, where I would not have a shower, I would not, I'd stay in bed" (Michelle).*

For those young people who recognised the positive impact of medication on their symptom control, a further motivation to take medication was to remain well.

7.4.2. Stories of Staying Well

In Ameeta's, Katey's and Samantha's stories it was evident that they dreaded the possibility that the dark times (when they were previously unwell) may return.

Whilst Victoria spoke at length of how she no longer felt the need to take medication she did, at times, say things which supported the role of medication in relapse prevention, saying '*if they take it off me now then I might go manic again*'.

Allison spoke of how she and other friends had in the past stopped medication as they felt better and did not need it, highlighting a lack of awareness of the role of medication in preventing relapse. They eventually resumed medication when their illness worsened as the positive aspects of medication at this stage then outweighed the negative aspects, highlighting the dynamic nature of medication adherence. Allison described:

> "…*when I first got put in hospital when I was seventeen and I was taking meds then but that was only antidepressants, but when I got out of hospital I thought – 'Oh no I'm fine now, I don't have to take them'. Then obviously because you think that you are better you don't need them when obviously it's the medication that's making you feel better. I think quite a lot of friends that I've got*

> *like when I was younger, quite a lot of them said that to me, they'd stopped taking them when they felt better but then about three or four, no about two or three weeks later, they'd start to feel worse again. But that's why I stopped taking mine" (Allison).*

For Ameeta, Allison, Christina, Katey and Victoria another important aspect of remaining well was avoiding the need to go back into hospital. Allison had absconded during her admission because of a wish to get out of hospital resulting in her being placed in a Psychiatric Intensive Care Unit. Ameeta and Victoria also spoke of how uncomfortable they felt being observed by staff on the ward, with Ameeta likening this to the television show – 'The Cube'- where the television audience are peering into a glass box where the contestant is sitting (see Image 7.17). This image also represents the loneliness Ameeta felt whilst an inpatient, mirroring the emotions expressed by Christina when she was also admitted to hospital. Katey summed up the motivation of staying well and avoiding readmission when she explained that going back into hospital is her "worst fear".

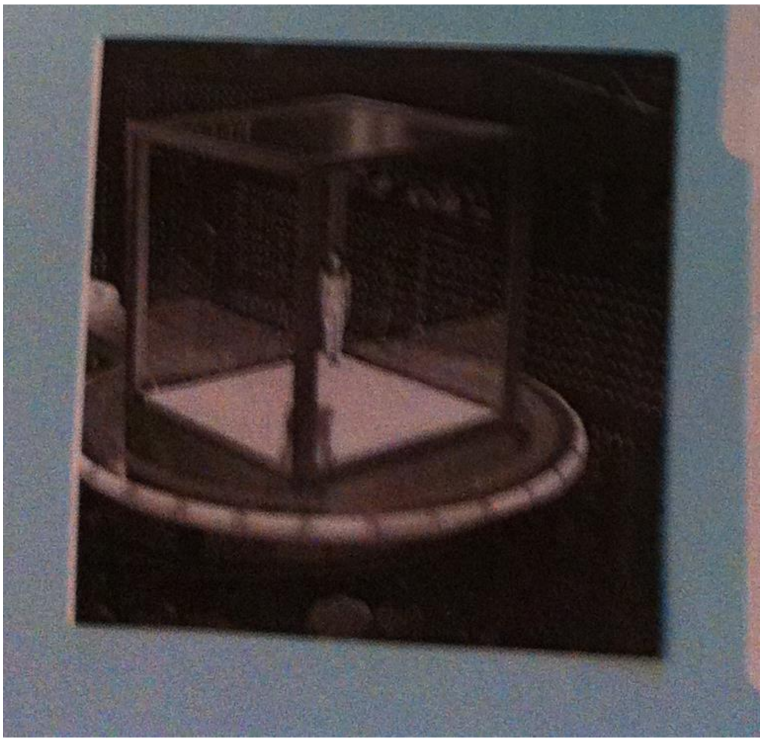


Image 7.17. A Photograph by Ameeta to Represent "Feeling Alone"

Being admitted to hospital because of poor mental health sets teenagers apart from their peers, and another motivation evident in the stories was a stated wish to be a ‘normal’ teenager.

7.4.3. Stories of Being a ‘Normal’ Teenager

Accepting that people’s views of what a ‘normal’ teenager is vary, the word ‘normal’ was still commonly used during the interviews with the young people. This was in a variety of contexts from doing normal teenage activities, wanting to be free of symptoms to wanting to be like their peers who were not mental ill engaging in usual teenage activities. This appeared to be driven by a wish to feel and be viewed like other teenagers without mental health difficulties. Whilst not all of the young people interviewed felt that they had experienced stigma because of their mental illness, for Michelle and Katey this had been a ‘source of trouble’ within their individual stories. This was reflected in a drawing Katey included which was her way of making a statement about not being crazy (see Image 7.18).

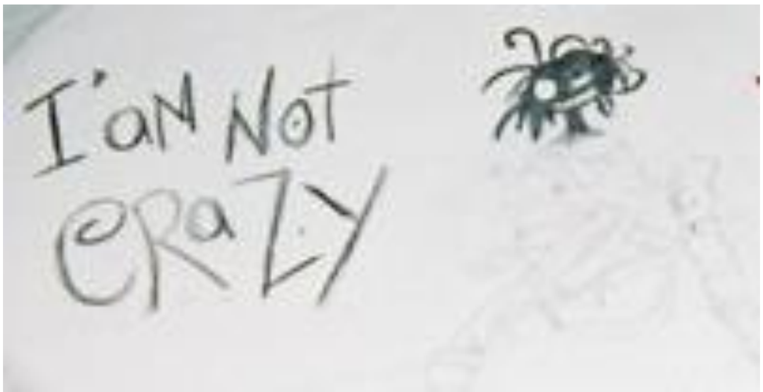


Image 7.18. A Drawing by Katey “I Am Not Crazy”.

Michelle also spoke of the stigma still associated with mental illness saying:

> “*I think stigma is a big thing which is still around with mental health, you know, if you tell someone, if you say the word ‘psychosis’ to someone they will always think, maybe - oh you might go and kill someone or you might be a bit crazy - you know,*

> *and they don't understand the underlying issues and the ins and out of it, you know" (Michelle).*

Taking medication had supported this wish to be 'normal' in a number of ways, by allowing the young people to go out and spend more time with friends, to strengthen and develop friendships and be accepted by their friends, to remain at school or college and to become more independent. Medication had enabled Ameeta, Michelle and Samantha to leave the house more and this had meant that they were able to spend more time with family and friends. Katey and Allison had become closer to family members having previously deliberately distanced themselves from family because of the content of their auditory hallucinations. Allison's fiancé had told her of the positive difference medication had made to Allison's personality and consequently their relationship. Stephen's relationships with his friends had also strengthened as he was kinder to them.

Improvement in symptoms had also enabled Katey, Michelle and Samantha to remain at university and college. When the voices were at their worst, Samantha had to study in a separate room with support staff to keep her focused on the work at hand. As the symptoms improved with medication, concentration abilities increased and this resulted in Samantha re-integrating into lessons with other classmates. Similarly, Katey had also not attended school but an education centre. Katey described the impact this had when saying:

> *"Before I went to college I did not go to school. I went to an education centre for a couple of hours a day and I did not do a lot there, I did not get on with the people there really. So by going to college I've been able to like talk to people my own age and just laugh and just do normal things and go out and that's helped a lot as well" (Katey).*

Michelle also spoke of how she could have left university after her first year because her mood was so low and she was struggling to concentrate and attend lectures. Medication had been instrumental in her remaining at university, increasing her attendance at lectures, obtaining positive feedback from her work placements and ultimately in facilitating her completion of the degree course.

Whilst accepting the role of medication in making the young people feel ‘normal’ for Christina, Katey, Samantha, Gabriella and Victoria the fact that they had to take medication was stigmatising and set them apart from their peers. This was highlighted by Gabriella who explained:

> “…*it [medication] helps, but obviously it makes you feel a bit different from everybody else but it’s alright taking it I think” (Gabriella).*

Despite this, these young people continued to take medication with the majority of them believing it to be instrumental in ensuring a brighter future for them.

7.4.4. Stories of a Brighter Future

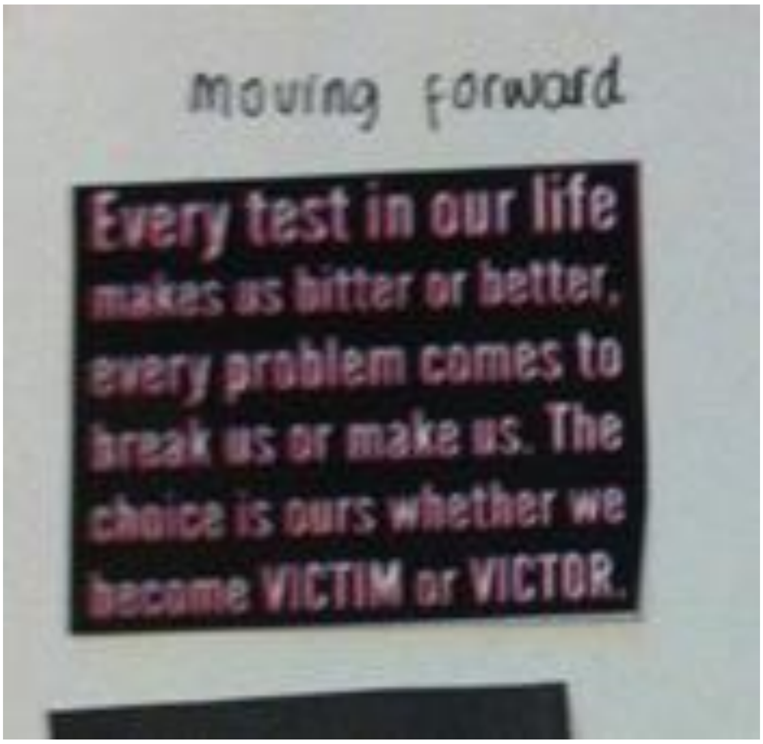
As well as the motivation of being a ‘’normal’ teenager, there was also the motivation of a brighter future which many teenagers naturally aspire to. For Ameeta, Allison, Katey, Michelle, Samantha, this brighter future was very much centred around educational and vocational achievements. A brighter future was not just measured however by educational and vocational attainment, but socially and emotionally through a desire to be happy and to have strong relationships.

When I saw Ameeta, she had written her medication story out in advance and was the only young person to use the story rather than the photographs as the starting point for the discussion about medication. The opening line of her story was very poignant with Ameeta saying:

> “*In life you have a choice being the victim or being the survivor but sometimes it’s not as easy as that” (Ameeta).*

The plot of Ameeta’s story was therefore very focused upon survival against the odds and claiming victory over her illness. Ameeta also used a saying (see

Image 7.19) she obtained from the internet to illustrate her opinion of how best to move forwards towards a brighter future further emphasising a ‘plotline’ of victory over illness.



moving forward

Every test in our life makes us bitter or better, every problem comes to break us or make us. The choice is ours whether we become VICTIM or VICTOR.

Image 7.19. A Photograph by Ameeta “Moving Forwards”

Ameeta’s notion of victory and a brighter future was focused on always looking forwards, making something of herself, seeing a brighter future, having a life worth living and being independent. Samantha’s story also had a similar plot of claiming victory over her illness when she expressed her happiness that she now controlled the voices rather than the voices controlling her. Samantha was deliberating about whether the next phase of her life would involve university or completing an apprenticeship, whilst Katey was very clear that her goal was to go to University saying:

> “*I’m planning to go to university soon and I can do that now that I’m on my medication and everything’s under control. Without it I don’t think I’d be able to think about that” (Katey).*

Christina was very excited about starting A-levels at college the following year so she could continue her art work. Allison’s ambition was to have a career, whilst Michelle had just obtained her first job having finished her degree course at University. A brighter future for many of the young people involved was dependent on educational and vocational attainment which is to be expected in young people of school and college age. There was a sense that for many they were on the start of an exciting journey, as summed up with Katey saying:

> *“I was curious about what was going to happen and now I’m more curious as to what is going to happen in the future. Since I’ve been taking medication I’m more able to do things” (Katey).*

Another ‘force of desire’ evident in the stories of the majority of young people interviewed was about being happy, and this formed another subjective measure of a bright future. Allison specifically linked happiness and a brighter future in the same sentence saying:

> “*I was more happy in myself and stuff, I was actually looking forward to the future” (Allison).*

For Allison, Katey and Samantha it was evident that their idea of happiness was also measured in strong personal relationships and wide social circles. Allison was looking forward to her future with her fiancé, Samantha was very happy in the company of her siblings and Katey was enjoying a better relationship with friends, family and her boyfriend. Whilst Stephen and Jonathan both noted improved relationships with family and friends, it was less evident from their interviews how they subjectively measured happiness and so assumptions cannot be made that these positive relationships influenced their level of happiness. This may be because the interviews with Jonathan and Stephen were shorter and they were more centred around the medication itself rather than the emotions and feelings taking medication engendered in them.

Gabriella’s measure of happiness was that her symptoms were getting better, and this was mirrored by all of the young women except Victoria and Christina. Gabriella was planning to draw a smiley face on a Paracetamol tablet to illustrate her happiness that she was moving towards recovery, whilst Katey also used one of her photographs to visually represent how happy she was (see Image 7.20).

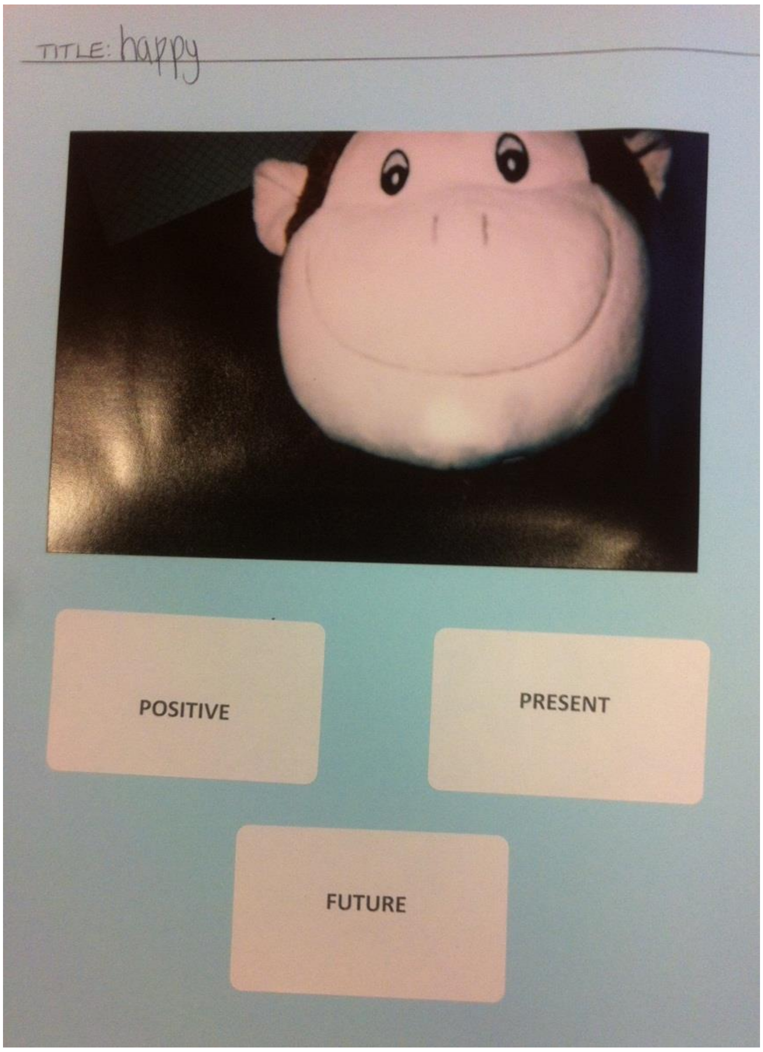


Image 7.20. A Photograph by Katey "Happy"

Happiness was also attributed to stronger relationships that developed as symptoms improved secondary to antipsychotic medication.

7.4.5. Stories of Strong Relationships

Many young people also directly attributed medication to improving their social circle and strengthening their relationship. In response to thoughts of harming family members, Katey and Allison withdrew from family members. Smantha, Katey and Michelle spent most of their time isolated in their bedrooms as this is where they felt most safe. As medication began to take effect and symptoms lessened young people became more sociable with others and were able to go out of the house more. This resulted in stronger relationships with family and friends. Samantha was particularly happy that she now had her first boyfriend and talked of how this would not have been possible before medication. Samantha explained that she would not have been able to leave the house to meet up for a date during the dark days when the voices were controlling her and limiting her ability to leave the house. Michelle and Stephen also both commented on how friends were more willing to spend time with them because of the positive impact medication had made on their demeanour, with Stephen explaining:

> "*Yes like when I was not on them [the tablets] I'd be very annoyed and mean with them [his friends] but now that I'm on them people just think I'm just a right nice person" (Stephen).*

As well as improving relationships with friends, Katey, Allison, Samantha and Michelle also highlighted that it had resulted in a journey towards better familial relationships. They were increasingly able to interact and engage more with their family members and this closer contact had subsequently brought brightness to their lives. For Katey this had resulted in a closer relationship with her younger brothers, with her outlining:

> *"I was really, really close to my two brothers, I spent all my time with them when we were younger, then whenever I got poorly I spent less and less time with them. My mum and dad are divorced so they live with my dad during the week and then with my mum at the weekend and I live with my mum full-time. I don't have any contact with my dad so I don't get to spend a lot of time with them either. But now I'm more confident around them and I spend more time with them and to go out and just to wind each other up… I enjoy spending time with them now… it's fun" (Katey).*

The positive impact medication effected on social relationships and the young peoples' subsequent levels of happiness was a motivation to continuing adhering to the antipsychotic medication.

All of these stories of motivation reflect particular forces of desire within the young people's stories. They also introduce an element of suspense with the hope that these individual goals are attained and highlight the individual stakes that are central to the stories should they not be reached. Other elements which could have been presented in this section include independence, confidence and involvement. I have however decided to explore these under a separate heading of control, as the stories highlighted young people who were both in control and lacked control of their life and destiny and this seemed to merit its own story.

7.5. Stories of Control

When hearing the young people's stories it was evident that whilst most were taking control of their individual story, some seemed powerless to effect change. In narrative terms, this was illustrative of the degree of agency within each story. Within this section I will consider subsets of control in relation to making positive choices, asserting independence, being dependent and being open about mental health.

7.5.1. Stories about Making Positive Choices

Stories about making positive choices are evident in many of the individual accounts already recited. One of the key positive choices the young people made was to actually take their prescribed antipsychotic medication, and the young people showed high levels of agency with regards to this. Poor adherence was most commonly unintentional adherence with Christina, Jonathan, Samantha, Victoria and Stephen admitting to having forgotten to take the occasional dose of medication.

In addition to taking medication, the young people actively welcomed and utilised the support mechanisms available to them. All remained in contact with their mental health team and gained support from their family, friends or children's home staff. Others sought help and support elsewhere. For Ameeta this support was provided by the crisis team and charities such as Mind and the Samaritans, whilst Christina gained a lot of support from her youth worker and the youth club she attended. Katey was a dynamic member of a patient and carer support group, petitioning for healthier meals for young inpatients and subsequently supporting the introduction of self-catering on the inpatient wards. Katey also interviewed people applying for mental health jobs on the young person's inpatient unit, positively utilising her previous experiences as an inpatient. With support, Ameeta was becoming more assertive in taking control of her life, being driven by a wish to have a positive future, make something of herself and not having to rely on others to care for her. Support was also helping the other young people interviewed continue their daily activities and work towards their amibitions for their future.

Other young people also spoke of the positive coping mechanisms they employed when they were having a bad day. Many of these have previously been described; time spent doing hobbies, reading memory books or favourite quotes, focusing on good times or seeking out support from friends and family. A couple of the young people were also undertaking additional treatments with Christina actively engaged in art therapy and Michelle receiving ongoing support and treatment through Cognitive Behavioural Therapy sessions.

Another feature of making positive choices was shown by Katey, Michelle and Jonathan in their renouncement of previously reckless behaviour. Michelle in particular spoke of how she put herself in danger by going out, spending lots of money on alcohol and not thinking about her personal safety when she first went to University. This had impacted negatively on her attendance at lectures. However, with the introduction of medication things changed for the better with Michelle saying:

> "*Before I was on medication my lifestyle was very reckless. I'd drink a lot, I'd go out a lot with my friends, I did not really have a care, I was quite, safety was not a thing that I'd thought about really, you know. I would not care really, like I would not think about my own safety. I'd do stuff and not think of the consequences doing it and one thing that medication did do was settle me down a lot in that sense" (Michelle).*

Following the introduction of medication, Michelle described how she became calmer. This led to her making positive choices to spend her money on other things she enjoyed such as shopping, and to take care of her body by adopting a healthier lifestyle.

One of the other young people leading a reckless lifestyle was Jonathan, who admitted putting people who wanted to buy illicit drugs in contact with drug dealers in a nearby city. He spoke of doing this as his head was instructing him to do it, but this all stopped after the police came to his house to speak to him and his parents about it. Jonathan spoke of how it was this visit by the police that made his parents realise he was unwell, prompting them to seek support from mental health services.

Allison and Katey also displayed features of reckless behaviour when they took large overdoses. Katey repeatedly stopped taking antidepressant medication to store it up for an overdose, saying:

> "*I'm not very reliable whenever it comes to medication. When I was first put on medication, anti-depressants, I was on them for about six months and I decided to take a lot of them and overdose on them. So my medication was locked away from me for about two years and in that time I stopped taking my medication three times and started building them up to take another overdose but I was always being found out about it" (Katey).*

Whilst Katey had repeatedly stopped taking antidepressants to self-harm, she had not overdosed on antipsychotic medication. Allison was not prescribed medication when I saw her as this had been stopped following a large and serious overdose when she was feeling low and felt that life was no longer worth living. Allison took an overdose of twenty quetiapine 200mg tablets mixed with fluoxetine but someone walked in whilst she was taking the overdose and called an ambulance. She described the subsequent events disclosing:

> "*I was that out of it, I did not even know, because I remember sitting in my bedroom and the ambulance people came up and I*

> *said to her – 'Can I go to bed?'. She [ambulance staff] said ' – [participant] if you go to sleep you are not going to wake up'. Because I think my pulse was at a hundred and sixty I think it was, and then I thought if I go to sleep, because I did not want to be here anyway. Then she said to me – 'Just let me search online what these tablets can do to you', and then she searched it and her face just dropped, and I was like – is it a bad thing? Because I was really confused, because I think she was waiting for someone else to come up, another colleague of hers or something, and I started to get really drowsy to the point where I couldn't even dress myself or anything. Anyway I went to go into the ambulance and I nearly fell but then I felt, you know like I did in hospital when I was about to have a fit, so then I thought I was going to have a fit again but I did not, and we got to A&E and I stood up to walk in and she says 'It's alright love, I'll push you in', you know in the bed. But then I don't remember even going into A&E, the next minute they were shining like a light on my eyes going – 'Wake up Michelle' you know in resus, and then I ended up conking out again and then the next minute when I woke up I was on a ward at about three o'clock in the morning thinking, 'Where?' (Allison).*

Allison was adamant that she would never take another overdose again as it had been such a dreadful experience. She did however also explain that staff at her supported accommodation would administer medication and observe her talking it so she could not secrete medication and take a further overdose. This left me wondering whether she herself was acknowledging the possibility that she could overdose again.

Whilst Allison, Katey, Jonathan and Michelle had all displayed reckless behaviour, they had also all been proactive in making positive choices to renounce these harmful activities.

7.5.2. Stories of Proactivity with Medication

Another way young people were proactive and positively exerted control was by becoming more informed about medication, taking a more active role in decision making in relation to medication and side effects, and accepting responsibility for taking medication.

Samantha became very proactive having previously forgotten doses of medication, and subsequently placed her medication into a dosette box each week which she could then leave on her bedside cabinet. The dosette box meant that her siblings and the dog could not accidentally take the medication from the bedside cabinet and allowed her to see at a glance whether she had taken her medication (see Image 7.21). She had also established a routine around taking medication after her breakfast.

Image 7.21. A Photograph by Samantha of her Medication Dosette Box

Side effects to medication were a major stake that some young people had to manage and overcome. These experiences were also linked to fears that side effects may return with planned dose changes and changes to prescribed medication.

The most common side effect highlighted was weight gain. It was, however, most prevalent in the Katey's and Allison's stories. Katey and Allison both had a history of an eating disorder requiring admission to an eating disorders unit or intervention to prevent admission to an eating disorders unit. For these two young women they were particularly concerned about experiencing a relapse of their eating disorder as this would then potentially result in one of their fears being realised, namely admission to an eating disorder unit and being tube fed. This was evident with Allison saying:

> "*I think they knew that I had issues with eating because it was on my notes as well that I'd been to eating disorder services and places, but, I don't know, all they kept saying to me was, 'Oh you've got to eat, you've got to eat or you are going to get put into an eating disorder unit'. So then I think I thought to myself - I've got to start eating to get better because that's the last place I want to be, because I don't want to be tube fed or anything. But then as time went on, especially when I got out was when, you know, I felt the worst because of how much weight I'd put on" (Allison).*

The side effects were proactively managed and overcome in a number of different ways by the people who took part. For Allison, Katey and Michelle weight gain was limited by adopting a healthier lifestyle where they were conscious about what they ate. Katey, Michelle, Stephen and Victoria increased their physical activity by gardening, walking and exercising as Katey explained:

> "*I've started to be a lot more conscious about what I'm eating and how much and starting to exercise a little bit more now" (Katey)*.

Another side effect caused by medication was sedation. This was invariably managed by wake up calls from parents, although Michelle had employed a more practical solution by having numerous alarm clocks across her bedroom so she has to get out of bed to turn them off (see Image 7.22).

Image 7.22. A Photograph by Michelle of Managing Sedation

The medication regimen was changed due to the side effects experienced by Allison, Christina, Samantha and Gabriella. Their willingness to discuss side effects with the care team is evidence of high levels of agency and resulted in their side effects lessening or disappearing. Katey spoke of how delighted she was when staff listened about her weight gain and changed her medication, perhaps reflective of previous experiences of being coerced by staff into eating to avoid admission to an eating disorders unit alongside a lack of understanding about her fears of gaining weight.

Despite the wide range of side effects experienced by the young people studied, it is noteworthy that side effects rarely resulted in intentional nonadherence. It was evident in the stories told that the young people dynamically balanced the impact of side effects against the impact medication was having on symptoms and as a result of this continued to take their medication. There was only one instance where side effects did directly affect medication adherence; Katey stopped risperidone because of weight gain. She did then make a conscious decision to restart the medication as she was terrified about what would happen, explaining:

> "*I have always gone back to doing it because of the fear of what's going to happen if I don't take it….just losing control completely and ending up back in hospital" (Katey).*

Another way young people took control of their medication was by becoming more informed about it. When Samantha first started to experience galactorrhoea she did not realise this was due to medication. It was only when she read the medication information leaflet that she recognised this and was then able to discuss the problem with her psychiatrist and switch to an alternative antipsychotic. She had not read the information leaflet when initially prescribed the medication and took responsibility for this herself. She indicated that she would not normally read the medication information leaflets as it can put you off taking medication. Samantha also had not taken much notice when information about her medication was provided by the healthcare team. Christina asked me during the interview how her medication worked and what it was supposed to do, and Allison spoke of how a lack of information about medication resulted in her not wanting to take it, saying:

> "*I got put back in hospital for taking an overdose because they'd changed it again (the medication) to something else which I did not know what it was. Then I found it was for people that were psychotic but then I did not believe I was psychotic so I did not want to take it" (Allison).*

Ameeta appeared the most informed about her illness and medication, talking about the impact of stress on symptoms, medication working to correct chemical imbalances as well as environmental and genetic contributors to illness. Interestingly, Christina and Victoria seemed least informed about their medication and they were the young people who displayed the greatest degree of ambivalence towards their medication. During the interview Christina explained:

> "*This is like feeling confused and unsure about my medication like why? Confused about what it's actually meant to do and stuff like that. I'm unsure about what it's meant to do because I don't really, no-one's really explained to me what it's meant to do. My mum said it's supposed to like calm me down and control the voices but no-one has really told me, like the doctors or owt like that, they've not really explained what it's meant to do so I don't really know. So I couldn't really say whether it's working or it's not working because I don't know what it's meant to do, if you know what I mean. I don't – [slight pause, hesitancy as if searching for right words] I feel like it's affecting me a little bit like I can control it [the psychosis] more but I don't know if that's myself or the medication because I don't know what it's meant to do" (Christina).*

Despite feeling that she did not have enough information about how medication worked and what it was supposed to do, Christina had not been proactive in seeking out this information perhaps highlighting a lack of independence relying instead on others to provide this information contrasting with some of the other young people who were demonstrating increasing levels of independence.

7.5.3. Stories of Independence

Medication facilitating increasing levels of independence was another story of control that emerged. Ameeta, Katey, Michelle and Samantha all attributed their levels of independence in part to medication as they were able to socialise and attend further education courses. Ameeta proclaimed during the interview that she was going to continue to be assertive in making her life her own, whilst

Katey spoke of the impact medication had on her ability to undertake her Health and Social Care college course saying:

> "*It's made me a lot more independent, I'm able to go to college by myself and oversee my work and manage my time, and able to work as well, and without my medication I would not be able to do any of that" (Katey).*

Katey also used a photograph of a cat to depict her independence, given that cats are often perceived as independent animals (see Image 7.23).

Image 7.23. A Photograph by Katey of Independence

Contrasting with these stories of independence, there were however features of dependence prevalent in other stories.

7.5.4. Stories of Dependence

Whilst medication for some young people brought about an increased level of independence, for Allison, Christina, Stephen and Victoria medication reinforced their dependence on others. All four young people were given medication by a parent or carer because they had previously forgotten to take their medication. Christina also had a back up supply of medication at school so teachers could give medication if her mother also forgot. The fact that a parent administered medication did not seem to bother Stephen and for Allison this was a condition of her placement in supported accommodation. However, this was a source of irritation for Christina and Victoria, Christina said:

> "*I've got like a little routine going, my mum's got me in a routine, she gets up and wakes me up and makes me go down for breakfast and makes me have my tablets and get ready for school. I think I want to learn – get a chalkboard or something like that though, so I can have more independence to remind me to take my tablets or something like that because I'm going to college this year and I just think I should. I don't know why – I feel like I should, it's my, like not decision, like it's my – what do you call it?.....my responsibility" (Christina).*

The language used by Christina was particularly interesting as there was a strong sense of her being made to take her tablets against her wishes. I therefore wondered whether she would take medication if this was her responsibility, or whether she would stop the medication as she also did not feel it was helping her symptoms. Victoria also felt she was being disadvantaged by taking medication as she wanted to go on a particular residential course and could not go as there was nobody able to administer her medication. Victoria therefore had no control over this situation which was a source of frustration for her.

7.5.5. Stories of Openness

Another way in which young people seized control was by being more open about their illness and the fact that they had to take medication. Initially there appeared to be a reluctance to disclose this information because of fears about stigma and how others would then perceive them. This was very articulately expressed by Michelle saying:

> "*it's quite a secretive world I think because you don't like people knowing what's going on and why you are taking tablets. You don't really tell people about these tablets because, you know, they could look up the name online and see what it is" (Michelle).*

Whilst nobody other than Gabriella's mother knew that she took medication for a mental illness, Jonathan and Samantha had always been very open about this. Jonathan had never experienced stigma and held the view that if people responded negatively this was not worth worrying about, saying:

> "*No I never minded it I never cared what people thought. I suppose it just was not important to me, if someone did not like it then I would not be friends with them you know" (Jonathan).*

Samantha also felt a responsibility to talk about mental illness and her medication and actively encouraged people to ask questions so they could be more informed about mental health issues.

Contrasting with this high degree of openness, Allison, Christina, Katey and Michelle were more selective about who was aware that they took medication. Whilst initially more secretive about this, they had chosen to disclose to close friends that they took medication as their mental health improved. In the case of Christina this was driven in part by external factors given side effects that were apparent to others and she also had to decline sleepovers at friends' houses as she needed her mother to administer medication and get her ready in the morning. Allison had spoken to a close friend she met in hospital about her illness and medication, but was reluctant to confide in her fiancé and family. I was surprised about this and wondered whether this was driven by a fear of how they would react if they knew the full extent of her symptoms, whether it was through a desire to prevent them worrying, or a view that they would not be able to understand what she was going through. Allison also refused to go sleepovers as other people would then realise that she was prescribed medication and she was concerned about what people would think if they knew she heard voices. Whilst Katey had disclosed to other people at college that she took medication, this appeared to have had negative consequences as she talked of having few friends at college as people did not understand what was wrong, felt that she was 'crazy' and that they needed to be wary of her. She seemed to be the young person most affected by stigma from others.

7.6. Stories of Resentment

The final story that emerged was that of resentment. The young people felt different from their peers because they had to take medication, they felt that this set them apart and singled them out as being different to other young people.

7.6.1. Stories of Resentment at Being Ill and Taking Medication

Whilst most young people interviewed had noticed some positive difference with medication there was understandably an element of frustration that they had to deal with the symptoms and subsequent impact on their lives that the illness brought. Victoria appeared to lack insight into the fact that she was unwell, however this varied throughout the interview when she at times acknowledged her illness and at other times attributed her difficulties to normal teenage issues. There was however an underlying current of resentment from Allison, Christina, Gabriella, Jonathan, Michelle, Samantha and Stephen about their mental illness although they had learnt to accept this. This resentment was not overtly expressed but was felt as an undercurrent to their stories.

Whilst acknowledging the role medication had played in controlling symptoms and therefore supporting an outward appearance of ‘normality’ to others, there was also resentment for some about having to take medication to be able to do things their friends could do without medication. Allison, Katey, Michelle, Samantha and Victoria all felt this way, with Christina saying:

> “*One time I forgot, well a few times I forgot then one time – I’m fed up of taking it! So I just thought to myself – I don’t need to take it anymore, because when I’m having a good day you don’t, you think to yourself – I don’t need it anymore, when you’re not hearing voices and things like that. Sometimes I’ll just stop and then I’ll wake up in the morning and they won’t be there and I’ll be like – I don’t need to take it today so I’ll not take it for a few days and then have a big come-down a few days later and they’ll come back and it will all come back ten times worse. But sometimes I get fed up with taking medication because none of my friends take*

> *anything and it's like – why? Why me? You know what I mean, why does it have to happen to me" (Christina).*

For most young people one of their goals was to be able to reduce and ultimately stop medication. The dose prescribed was also in the cases of Michelle and Katey linked to their assessment of how dependent they were on the medication with Katey saying:

> "*I felt more that I had to rely on the medication because I had to take such a high dose, I did not like being dependent on it. I don't like being dependent on medication. I hate taking medication and it just broke me up a bit it's like – 'why have I got to depend on medication to get through like day to day tasks?" (Katey)*

The sense of resentment about having to take medication was most strongly expressed by Victoria and appeared to be driven by a couple of factors. Firstly, Victoria had little ability to influence her position and this was the basis of some of her resentment. Despite wanting to come off her medication because of a view that it was not benefiting her and was unnecessary, she kept being told by staff that she had to maintain her current medication regimen until after her exams. Secondly, her father administered her medication and so she had no ability to exert her wish not to take medication unless she directly defied her father. Victoria's close relationship with her father meant she did not wish to worry or upset him, thus she seemed helpless to be able to exert her independence and desire to stop taking the medication. This all contributed to a difficult interview where I was concerned that she may start crying at any moment, such was the level of her distress at having to continue taking medication.

7.6.2. Stories of Resentment about Feeling Different

The final resentment factor that Allison, Christina, Katey, Michelle, Samantha and Victoria expressed was feeling different because of their illness and the fact that they had to take medication. Victoria, a keen gardener, illustrated this difference by taking a photograph of two different plants, a heather and a phlox, that stood side by side outside her greenhouse (see Image 7.24). Whilst initially appearing to be a single plant, closer examination reveals two different, adjacent plants of similar size. The heather has purple flowers whilst the phlox has more distinctive white flowers.

Image 7.24. A Photograph by Victoria about Feeling Different

When speaking about her friends Katey said:

> “*I think they’ve got more of an understanding now. I am the same as everybody else, I just have different coping mechanisms and I respond to stress in different ways” (Katey).*

This highlights the way Katey is trying to normalise her situation as no two people can be the same. This desire to feel normal had also been the basis for Christina and Katey to have missed doses of antipsychotic medication. Doses had been missed on days where symptoms had not been evident, however, fear of symptoms returning or deterioration in mental state invariably led to medication being resumed. As Katey explained:

> "*There have been times when I've not wanted to take it because I don't – I've been – 'oh I really don't want to take my medication today, I just want to be normal for a day', and I have gone a couple of days without taking it but I have always gone back to doing it because of the fear of what's going to happen if I don't take it" (Katey).*

Whilst a lot of stories represented a move from darkness to brightness these resentments still brought an element of darkness to the happiness displayed by most of the young people.

7.7. Conclusion

In outlining the findings from my research I have described how the main stories emerging from the young people in relation to medication were of endurance, motivation, control and resentment. Descriptions, quotes and images have been used to reinforce aspects of these four stories to give the reader a feel for the traumas, struggles, strength, determination and achievements within the individual stories. Many of the stories told contributed to a metastory of a journey from darkness to brightness, and the words within this metastory were supplemented by supporting visual images of light and dark. An element of darkness still remained with some resentment evident about the need to take medication to stay well and be able to do 'normal' teenage activities. Even where young people accepted their illness and the need for medication there was still a frequent refrain running through the stories, namely 'Why'? Christina summed up the views of many when she said '*Why me, why do I have to take it, why?'*. It became evident that young people were consciously or subconsciously balance the positive and negative aspects of medication when making decisions about whether to take medication as prescribed. In balancing stories of motivation and control against stories of endurance and resentment, the young people were making dynamic decisions about medication adherence in response to their current situation and personal opinions.

CHAPTER EIGHT. DISCUSSION

8.1. Introduction

In this chapter, I will start by reflecting upon how the stories of endurance, motivation, control and resentment contribute to the concept of dynamic medication adherence. The young people involved in this research balanced the positive and negative aspects of medication when making decisions about whether to take medication as prescribed. The relative balance of these different aspects varied with time and circumstance, meaning that adherence was dynamic rather than static. These medication decisions were driven by the balance of brighter stories of motivation and control against darker stories of endurance and resentment. Examples of the way young people balanced these aspects is provided throughout the chapter. This shifting and responsive approach to adherence reflects many aspects of dynamic medication adherence (de Haan et al., 2007, Le Quach et al., 2009), however my interpretation is more complex bringing into the equation specific stories of motivation and control versus endurance and resentment. At its most simple, the balance of these four stories and their dynamic impact on medication adherence can be represented pictorially (see Figure 8.1). In doing so, I acknowledge that this is a simple illustration of a complex relationship. Therefore, the complexity of these relationships will be further explored in the rest of the chapter under the broad headings exploring motivation and control and then exploring endurance and resentment. Within these sections I will provide evidence to support my deliberations from stories presented in the previous chapter, whilst weaving in capacities of stories that were deeply tied up with the factors that promoted and/or prevented the young people's medication adherence. Capacities are the narrative equipment of stories, they are the core features which make the stories breathe, work and act (Frank, 2010). The capacities that will be considered are *trouble, character, points of view, suspense* and *imagination* (Frank, 2010); when these capacities are presented in the discussion, they are presented in italicized text. A capacity for *trouble* is the way in which a story may deal with *trouble,* or make *trouble,* for those involved in the story. Stories showcase, probe and challenge peoples' *character*. Individuals may embrace, resist or fail to recognise the *character* in which they are cast within the story. Stories also present *points of view* which make particular viewpoints more compelling and credible to the audience. Within stories aspects of *suspense* make the stories exciting, dramatic and engaging. Endings of stories are never assured so there is always an element of drama as the story unfolds and draws to a conclusion. Even when the told or written story has concluded, the story continues to breathe as it lives on in the continuing retelling of the story. Finally stories have the capacity to arouse *imagination* and emotions. Stories can make the unseen visible to others who have not been cast in similar stories (Frank, 2010). All of these capacities combine to make stories a powerful tool in the engagement and education of others.

Figure 8.1. Pictorial Representation of Dynamic Adherence (with stories of motivation and control in balance with stories of resentment and endurance)

Narrative elements of *tone, temporality* and *agency* will also be highlighted throughout the chapter. I will link the stories to research and evidence underpinning from the literature on young people with both mental and chronic physical illness. Studies of adherence in chronic physical illness are introduced where published research in adolescents with mental health is limited or absent. My discussion examines where the findings from extant literature reflect or contradict my findings about antipsychotic medication adherence in adolescents. As part of this element of the discussion, I also compare the views of young people in the study and the opinions of health professionals from my survey research. This will all evidence how young people actively balance the positive and negative aspects of medication; in doing so they are, in the words of one young person, ‘Learning to Dance in the Rain’.

8.2. Stories of Brightness

Stories of motivation and control represented the brighter aspects of young people’s medication journeys. All of the sub-stories of motivation (being well, staying well, being a ‘normal’ teenager, having a brighter future and stronger relationships), and all but one of the sub-stories of control (making positive choices, proactivity with medication, independence and openness) represented positive consequences of taking medication. Narratively the *tone* of these stories was therefore positive and presence of these stories was more likely to dynamically shift medication behaviour towards good adherence. The one exception was dependence, a sub-story of control with a more negative *tone* which in some circumstances, such as fear of being addicted to medication, could dynamically result in poorer adherence with medication. These sub-stories will now be explored in more detail.

8.2.1. Becoming and Staying Well

A wish to reach a stage in their medication journey where the young person was well, and then remained well, represented the most significant driver to take prescribed medication and was an important contributor to dynamic medication adherence. This is because the most dominant capacity for *trouble* within all of the stories told was the illness and associated symptoms. Symptoms such as hallucinations and paranoid delusions resulted in some of the darkest times for the young people and were typified by fear, isolation and admission to hospital.

In some cases the young people talked of recklessness and found this behaviour to be *trouble*some. The young people frequently made reference to darkness when describing this stage of their medication journey leading me to try and imagine the difficulties of living with the darkness of psychosis. In exploring the literature on darkness and light, I found two particular articles were of real value. The first was a study exploring women's experiences during the first few days of a postpartum psychosis (Engqvist and Nilsson, 2013). I found this article interesting as the emergent theme of 'Shades of Black with a Ray of Light' had some resonance with the young people interviewed as part of my study and the metastory of a journey from darkness to brightness. The mother's darkness centred on themes of lack of sleep, no longer wanting the baby, thoughts of harming themselves and/or their child and being in an 'unreal' world. This unreal world was described variously as being in a vacuum, having strange feelings in their heads, feeling part of a mystery where everything rolled around without making sense, being in total turmoil and feeling confused, insecure and fearful. One woman described how things seemed so unreal she felt that she must be dead. Family member accounts were of their loved one being lost in the world and totally absent (Engqvist and Nilsson, 2013). The feelings of confusion, fear and turmoil described by these women were also evident in the stories of young people in my study, with a descriptor of darkness also applied. The ray of light in the mother's stories was not overly apparent within the journal article, however the ray of light for the young people participating in my research was 'hope'. Hope of recovery, hope of a brighter future and a good quality of life. Further context to the darkness of psychosis was evidenced in a second article, a personal account of schizophrenia. This account described the empty spaces of blocked thoughts, a tortured mind and fear of a brain which "torments me in times of psychosis, always threatens me, and seems to always be laughing at me, scorning my vulnerability…. I am alone with my darkness" (Ruocchio, 1991). Many young people also described the fear and torment of psychotic symptoms and it is therefore unsurprising that the young people's predominant reason for taking medication was in the hope that symptoms would reduce and hopefully disappear.

Seven participants noted a dramatic improvement in symptoms with medication and their lives became brighter as a result; this became a key motivating factor to continue to adhere to medication as they dynamically balanced their quality of life before medication when symptomatic, against their quality of life once medication started to take effect and symptoms reduced. This resonates with staff opinion in my earlier published survey research. Ninety three percent of the 60 survey respondents highlighted a wish to get better as the strongest motivator for medication adherence, with relapse prevention the third strongest motivator to take medication (Ramdour et al., 2015). A wish to be well and remain well is also evidenced in the literature as positively influencing medication adherence. Evidence from four studies in EIS concluded that perceived medication efficacy is positively associated with medication adherence (Hui et al., 2006a, Perkins et al., 2006, Le Quach et al., 2009, Hon, 2012) mirroring the views of most young people in this study. In the study by Le Quach et al. (2009), perceived benefit of medication and a desire to avoid relapse of illness were the predominating subjective reasons for good adherence to antipsychotic treatment at two year follow up, showing the importance young people assign to medication efficacy. This reflects my research findings as a positive influence of medication on symptom control, leading to an improved and sustained benefit on mental wellbeing, was the strongest subjective reason for young people continuing to adhere to antipsychotic medication (Ramdour et al., 2015). However, the published evidence base is not overwhelmingly supportive. There is one published study which failed to replicate an association between subjective experiences of medication, including perceived benefits of medication, and subsequent adherence (de Haan et al., 2007). The authors questioned whether inclusion of research participants dependent on cannabis had influenced their findings. In my study nobody disclosed cannabis use although participants were not directly questioned about this as part of the research. It could be that young people misusing cannabis may perceive benefits of medication differently to those not using cannabis. Improvement in mood, reduction in daily stresses and ease in socialisation are cited as a reason for using cannabis by some people experiencing psychosis (Dekker et al., 2009, Archie et al., 2013). It could therefore be argued that people prescribed medication who also use cannabis may struggle to attribute improvement in symptoms to either medication or cannabis.

Whilst seven young people clearly recognised the positive difference resulting from antipsychotic medication, there were three young people who more obviously struggled to perceive benefits of medication. The *tone* to their stories was more negative. These three young people still continued to take antipsychotic medication, albeit forgetting to take the occasional dose. Negative perceptions of efficacy did not consistently affect medication adherence. Subjective efficacy of medication was not ultimately a strong determinant of these three young people's medication adherence, contradicting the findings of other published literature (Hui et al., 2006b, Perkins et al., 2006, Tunis et al., 2007, Hon, 2012) This could be because in two of the three cases, young people were given medication by a parent or school teacher limiting their abilities to influence adherence. In the other case the young person dynamically balanced any inconvenience cause by the medication against positive benefits, and as he was not finding the medication *trouble*some he continued to take it. This young person was still hopeful that medication would improve symptoms, however he was arguably showing low levels of *agency* in continuing to take the prescribed medication when he felt it was not helping his mental state. There was no indication that he was proactively seeking alternative medication or different treatment options.

8.2.2. Being a 'Normal' Teenager

Another story of motivation that was prevalent within many of the young people's stories was a wish to be a 'normal teenager'. When examining this in more detail, it became apparent that the young people's views of normality were very much linked to their stories of a brighter future; going to college or university, getting a job, having a good social life, having positive and sustaining relationships with family and friends. Considering published literature, living a normal life was one of the factors linked to poor medication adherence in another study of FEP (Hon, 2012). This has also been demonstrated to influence adherence in other chronic health conditions such as chronic kidney disease (Johnson et al., 2008), cystic fibrosis (Dziuban et al., 2010), diabetes

(Auslander et al., 2010), epilepsy (Kyngäs, 2000b) and organ transplants (Simons et al., 2010, Taylor et al., 2010), with young people expressing a yearning to forget that they have an illness (Rhee et al., 2009). Whilst my study provides evidence that a desire to feel normal may lead to intermittent poor adherence, further evidence from a larger population sample is needed to support or refute this. The fact that most young people spoke of their desire to feel 'normal' but continued to consistently take medication, despite in some cases a degree of ambivalence towards medication, was an unexpected finding. This is because ambivalence is usually associated with poor medication adherence (Laakso, 2012) and taking medication is often seen as something that sets young people with FEP apart from their peers (Ng et al., 2011). This provides another example of the way in which the young people in my study balanced the positive and negative aspects of taking prescribed medication, namely their desire to feel 'normal' or 'recovered' against their ambivalence towards medication. The concept of recovery in psychosis is measured across dimensions of clinical and social recovery as well as from subjective accounts of personal and existential recovery (Lam et al., 2011). From a psychiatric perspective, recovery means that symptoms are well managed, cognition is preserved and adherence to medication is assured (Link and Phelan, 2001, Brown et al., 2008, Ng and Klimidis, 2008). From a patient perspective recovery from FEP is achieved when there is no longer a need to be prescribed antipsychotic medication and when the young person feels 'normal' (Ng et al., 2011). This therefore introduces a complex dynamic for young people with FEP who may measure recovery by not being prescribed medication, or alternatively by feeling normal because symptoms of the illness have been effectively controlled by medication. It is probable that antipsychotic medication supports and enhances a young person's sense of normality if their medication results in a reduction in symptoms such as hallucinations, delusions and social withdrawal. This was particularly highlighted by one young person in my study who spoke about being noticeable different to other people because of the way she behaved and the content of her conversation, and spoke of the social isolation that resulted from this obvious sign of difference. The ultimate goal for most young people in the study was for antipsychotic medication to be withdrawn, possibly seeing this as a sign of recovery as proposed by Ng et al

(2011). Another sign of recovery could also be optimism about, or achievement of, a brighter future.

8.2.3. Having a Brighter Future

One story of motivation that was constant throughout all stories was goal attainment. This was fundamental to the young people's desire to have a bright future and feel 'normal'. Adolescence is naturally a time of forming close friends and romantic relationships, focusing on school achievement and future career goals, establishing autonomy, developing a sense of personal identity and setting and pursuing goals (Holmbeck, 2002, Schwartz and Drotar, 2006, Modi et al., 2009, Schwartz and Parisi, 2013). Goals have been shown to not only facilitate wellbeing and purpose in life but direct human actions (Pervin, 1989, Emmons et al., 1998, Little, 1998). It is therefore unsurprising that in an adolescent age group, goal attainment may direct actions in relation to young people's adherence with medication. The young people in this study had shown tenacity and fight under difficult circumstances in their pursuit of these goals, demonstrating personal qualities of ambition. Many had already been victorious in achieving some of their goals such as completing exams and attending college and university. Medication for mental illness has been shown to positively impact on success and acceptance into the college community, empowering the students (Kranke et al., 2013). Several young people in my study specifically mentioned that they would never have been able to go to college or university had it not been for their medication, supporting the findings of Kranke et al. (2013). Young people were also attaining goals in other non-academic domains by engaging in hobbies, overcoming eating disorders and increasing their levels of independence. They were striving forwards on a journey towards the brightness of a career, sustained romantic relationships and other incremental personal goals displaying high levels of *agency* in their pursuit of these goals. This was another maintaining factor promoting medication adherence and introduced a further element of *suspense* wondering whether the young people would attain all of the goals they had set themselves. Interference with life goals has been shown not to affect medication adherence in one study in FEP (Perkins et al., 2006), however, patients were twice as likely to have persisted with treatment for six months if the medication was facilitating fulfillment of life goals in another study in FEP (Tunis et al., 2007). The findings from my study support the suggestion that where antipsychotic medication is seen to support goal attainment, this becomes a motivating factor to persist with antipsychotic medication.

Whilst personal goals were a motivating factor for adherence in the young people studied, it is also important that illness and treatment goals are set by those suffering chronic illness as this is beneficial in promoting disease management and maintaining and enhancing well-being and quality of life (Barlow, 1996, Altemeier, 1997, Bradley et al., 1999). Goal setting in children and adolescents is particularly important given the prevalence and challenges of managing a chronic illness at a young age (Schwartz and Drotar, 2006). As already described the prevalent illness goal for the young people involved in my study was recovery. A further illness goal for some young people was avoidance of hospital admission. Treatment goals were also apparent with the young people expressing a desire for manageable side effects. They also wanted to be prescribed as low a dose of medication as possible to control their symptoms, with their ultimate treatment goal being to reduce and stop medication.

It is also important to ensure that young people understand the nature and implications of their illness and goals, and the impact this has on illness management (Bauman, 2000). Treatment or illness related goals may need to be modified as the young person grows and matures (Madsen et al., 2002), and the presence of the illness itself may in itself compromise attainment of identified goals (Seiffge-Krenke, 1998). One young person in my study initially failed to get a placement to study A-level art because she did not have the pre-requisite number of GCSEs. This is because the pressure of exams made the tremors caused by medication much worse, making it physically more difficult to complete work in the exam. The voices she continued to hear also proved a distraction when sitting exams. Accessing educational and vocational training can be more difficult for those diagnosed with a mental illness (Russell and Lloyd, 2004) but with support from her family and care coordinator, she had successfully challenged this and obtained a college placement. In doing so, she had to accept that she would have to progress her art A-level differently to other students with more individual support provided by college staff outside of the usual classes. Whilst this decision would enable this young person to continue her studies, it was also in some ways fostering social exclusion. Social exclusion occurs when someone wants to participate in key activities of the society in which they live but are unable to do so for reasons beyond their control (Burchardt et al., 2002). This young person already struggled with her identity and felt different to her peers because of her illness and need for medication. In accepting this college placement she had to accept that she would be treated differently to most other students at college because of her ongoing psychotic symptoms. She would be socially excluded by being taught individually away from her peers when she would prefer to progress her studies as other students on the course. Another young person had attended an education centre as a younger teenager because of her illness and the difficulties this caused her at school. She eventually started college, which in itself was a huge personal achievement. This young person was also singled out for individual study away from the wider college class because of florid psychotic symptoms, however, as medication improved symptom control she was subsequently able to reintegrate into college classes to be taught alongside her peers. There was therefore a degree of flexibility in the approach used depending on the young person’s presentation and this flexibility in approach has been identified as key to supporting academic attainment in those with mental illness (Weiner, 1998). The illness in both cases had the potential to compromise attainment of personal goals however the young people were showing themselves to be resilient *characters* in responding to the presenting barriers.

Goal attainment was identified in my study as a significant motivation for good medication adherence in young people prescribed antipsychotic medication. This is supported by limited published research. One study has argued that medication adherence is an outcome of desire in adolescents with mental illness (Longhofer and Floersch, 2010). If young people have no desires then they are less likely to adhere to medication. There is also a complex dynamic between desire and disappointment when children and adolescents have to additionally factor in the desire of their parents or guardians and others with authority to promote medication adherence. Longhofer and Floersch (2010) identified three types of desire and disappointment relevant to adolescent adherence with medication for mental illness, namely instrumental desire, concordant desire and conditional desire. Instrumental desire relates to the immediate effects produced by medication adherence; disappointment results if medication does not produce the desired results leading to alternative strategies such as psychotherapy or relaxation classes being sought (Longhofer and Floersch, 2010). Examples of instrumental desire were evident in my research in several ways, in the way medication reduced exam stresses for some of the young people involved, the way taking medication reassured family members and the way medication enabled discharged from hospital. Concordant desire is where individuals taking medication actively desire the expected outcomes. If the desired outcome is not achieved then the individual seeks a change in dose or a switch to alternative medication rather than an alternative treatment strategy as is the case in instrumental desire (Longhofer and Floersch, 2010). In my research, all of the young people wanted their symptoms to improve after being prescribed medication so they felt less anxious, confused and fearful. Some young people were using additional treatment interventions such as psychological therapy, but such therapies were never in place of medication. Even where medication had not produced the intended response, doses had been increased or alternative antipsychotic medications tried. The young people were all evidencing concordant desire. Finally, conditional desire is where medication fails, the desire for the medication disappears and the individual gives up on medication (Longhofer and Floersch, 2010). Whilst three young people felt to a certain extent failed by their medication, as it had not resulted in the desired effect, none had completely abandoned their medication. Hence, there were no examples of conditional desire in my study.

Given the limited evidence base about the importance of goal attainment to medication adherence in adolescents with mental illness (Perkins et al., 2006, Tunis et al., 2007), I sought to assess the evidence base in adolescents with chronic physical illness and adults. Research on the impact of goal setting in adolescents with a chronic health condition is limited (Schwartz and Drotar, 2006), with one study of adolescents with cancer reporting that those with future-orientated goals were more likely to be perfectly adherent to medication regimens (Hullmann et al., 2015). Goal setting in adults has been shown to promote health-related changes in behaviour (Strecher et al., 1995), management of chronic illness (Bradley et al., 1999) and wellbeing (Echteld et al., 2001, Pinquart et al., 2005, Schwartz and Drotar, 2006). There is therefore some supporting literature in chronic physical illness to evidence the benefit of goal setting not only with medication adherence but across wider domains.

8.2.4. Developing Stronger Relationships

As well as considering attainment of personal goals, normality was also assessed in the strength of the young person's social relationships and abilities to socialise with others with young people consistently reporting improved relationships as a result of their antipsychotic medication. Social isolation is common in those experiencing psychosis (Judge et al., 2008). Some young people lose friends in the early years of psychosis, preferring to spend time with those in mental health services who are more likely to understand what they are going through, or fearing rejection because of their psychosis (MacDonald et al., 2005). Developing relationships takes courage particularly for those with psychosis; one recent study highlighted that 70% of participants avoided close personal relationships because they anticipated discrimination (Brain et al., 2014). As already detailed, this fear of discrimination was evident in the stories of some of the young people who took part in my study. Despite these fears, it is evident that young people at risk of or experiencing psychosis desire relationships, be those relationships friendly or intimate (Ben-David et al., 2014). The majority of young people in the study had overcome fears of stigmatisation and discrimination, disclosing to close friends details of their illness and developing new relationships. One young person was delighted that she had recently started seeing her first boyfriend, and another also spoke about the support received from his girlfriend. Seven participants spoke about becoming more sociable and developing stronger relationships as medication took effect and symptoms receded. This reflects findings from other studies evidencing a beneficial effect of medication adherence on social relationships (Kane, 2013, Svettini et al., 2015). The young people with strong relationships and an active social life spoke of how happy this made them feel; this represented another motivating story for medication adherence. Their stories were much brighter than the young people with limited social contact with their peers.

In contrast to those young people who had good and varied social support, two of the young people involved in my study appeared to be loners, reliant on family members or pets for companionship. These two young people both struck me as being particularly despondent with their current situation; loneliness was a dark aspect of their current circumstances. It is however known that those suffering a first episode psychosis can report loneliness particularly where they lack a confidant (Sündermann et al., 2013) and are more likely than those without psychosis to have a smaller social circle and fewer friends (Macdonald et al., 2000). There was an element of *suspense* within these young people's stories as I wondered whether their social circle would expand or whether this loneliness would remain.

As well as improving relationships with friends and peers, many young people participating in the research also held a positive point of view that taking medication had improved their relationships with family members. This was directly linked to the receding of hallucinations telling them to harm family members, but was also a consequence of their increased ease socialising and spending time with family members. Key literature considering medication adherence in adolescents with long term physical or mental illness considers the impact that family and friends can have on rates of adherence, either by supporting the young person or if necessary prompting and administering medication. Some literature suggests that familial involvement supports adherence (Kyngäs, 2000a, Kyngäs, 2000b, Coldham et al., 2002, Rabinovitch et al., 2009, Rhee et al., 2009). In my study, three young people's adherence was associated with the support provided to take their medication by family members or teachers providing confirmatory evidence that social support can improve medication adherence. In contrast, other studies provide evidence that family dynamics may also be the basis for poor adherence if the home environment is troubled or adolescents rebel against their parents by not taking medication (Mulvaney et al., 2008, Hommel and Baldassano, 2010, Taylor et al., 2010, Wamboldt et al., 2011). There was no evidence that the adherence of young people in my study was negatively affected by family dynamics. In a recent study considering schizophrenia from the point of view of the carer, 46% of carers indicated that their family member taking medication had greatly improved their relationships with the carer (Svettini et al., 2015) . This research provides original, confirmatory evidence from the perspective of the young person that medication improves the quality of relationships, not only with family members but with friends and peers. This in turn provides young people with strong motivation to adhere to medication and maintain these relationships.

8.2.5. Making Positive Proactive Choices

In taking medication, the young people were making a positive choice in attempting to control their symptoms so they could move to a brighter phase in their lives. Two young people independently chose to use medication reminder aids as a prompt to taking medication; in doing so they were again making positive choices, demonstrating proactivity with medication and high levels of *agency*. Whilst this study has predominantly focused on the contribution medication made to the management of their illness, the young people also stated that medication was not the only reason why their illness had improved. The importance of psychological and psychosocial intervention was highlighted, as well as their personal determination in resisting and managing the dark symptoms of their illness. Psychological and psychosocial intervention have been demonstrated as effective treatment modalities and are recommended in national guidelines as components of a gold standard approach to the management of FEP and schizophrenia (NICE, 2009a, NICE, 2011a). In FEP it is recommended that antipsychotic medication is used alongside psychological therapy such as cognitive behavioural and family therapy; antipsychotic medication can enhance effectiveness of the psychological intervention (NICE, 2013). In accessing and engaging with psychological therapies as well as prescribed medication, these young people were doing all they could to increase their chance of recovery. Positive choices and proactivity were evidenced in the way young people also used positive coping strategies such as memory books, distraction, meaningful activity and support from staff, family and friends to manage the dark days when ongoing symptoms were more intrusive or they felt more stressed or upset. The young people were using many different strategies, including adhering to medication, to maximise and maintain health and wellbeing and avoid relapse. They were displaying high levels of *agency* in the different approaches used to manage and control symptoms. Strength, courage, determination and resourcefulness were evidenced in the way these young people approached and managed their illness. Given this there was naturally an element of *suspense* in the stories they told with a sense of hoping they would remain well and wondering whether they would relapse in the future.

8.2.6. Independence and Dependence

As many young people's symptoms lessened and social functioning improved, their medication journey naturally led them towards brighter times of increasing independence. Young people explicitly stated that without medication they would not have been able to go to college or university, complete exams or think about future career ambitions. Taking effective medication shortens DUP which is itself linked to better social and vocational outcomes in measures such as occupational and social functioning and attainment (Inoue et al., 1986, Larsen et al., 1996, Barnes et al., 2000). This was evidenced in my study by independence resulting from exam success, vocational learning and the undertaking of work based placements. The reported benefits of social integration (Drake et al., 2000), social functioning (Barnes et al., 2008) and social networks (Helgason, 1990, Tirupati et al., 2004, Jeppesen et al., 2008). were apparent in the developing social relationships of most young people and the increased time spent socialising with friends. This introduced further levels of independence from their families as the young people spent more time away from their home environment. Medication adherence was directly associated with an increased level of independence, evidenced by improved occupational, vocational and social functioning. This independence presented a motivating factor to take medication.

Whilst independence was a brighter story of control, at the opposite end of the spectrum dependence presented *trouble* for some young people. Dependence was referenced in two ways, through reliance on other people to administer medication or physical and psychological dependence on antipsychotic medication. This represented a darker aspect of medication for the young people involved and the *tone* of these stories was therefore negative. Five of the ten young people interviewed admitted to forgetting doses of medication. Published research shows that forgetfulness is one of the most common factors for poor adherence in adolescents with chronic illness. One systematic review concluded that unintentionally forgetting medication was the second highest reported reason for poor adherence across a number of different illness and studies (Hanghøj and Boisen, 2014). With five young people forgetting to take their medication, this was the highest single reported reason for poor adherence in my study. Studies in asthma (Buston and Wood, 2000, Velsor-Friedrich et al., 2004, Naimi et al., 2009, Rhee et al., 2009, Wamboldt et al., 2011), cystic fibrosis (Rosina et al., 2003, Gray et al., 2012) and type 2 diabetes (Mulvaney et al., 2008, Rothman et al., 2008) highlight that patients with these conditions frequently forget doses of medication, with some studies suggesting that this happens in 53% of adolescents diagnosed with these conditions (Rothman et al., 2008, Rhee et al., 2009, Dziuban et al., 2010). Medication forgetfulness was also found in 84.8% of patients with inflammatory bowel disease (Gray et al., 2012), more than 55% of patients with severe hemophilia (De Moerloose et al., 2008) and by between 30% and 56% of patients with kidney, heart or liver transplants (Simons and Blount, 2007, Zelikovsky et al., 2008, Simons et al., 2009, Simons et al., 2010). My finding that five of the ten young people admitted to forgetting occasional doses of medication is therefore broadly similar to the findings in young people with chronic physical illness.

For three young people in my study, medication forgetfulness resulted in medication oversight by a parent or teacher increasing their dependence on others and limiting the opportunity for these young people to stop taking their medication. Published research in physical illness suggests that parents may have difficulties passing the responsibility for taking medication over to their children, and that this impacts negatively on the adolescents strive for autonomy and self-management of their illness (De Moerloose et al., 2008, Mulvaney et al., 2008, Taylor et al., 2010, Mulvaney et al., 2011, Wamboldt et al., 2011). It has however also been suggested that whilst young people may feel uncomfortable being given medication by a parent, that not being monitored can also be viewed as a sign of parents who ‘do not care’ (Wamboldt et al., 2011). Some young people with chronic health conditions have reported not receiving adequate support from parents (Kyngäs, 2000a, Kyngäs, 2000b, Mulvaney et al., 2008), with some young people expressing a fear of asking parents for help with their medication regimen (Bullington et al., 2007). One young person in my study wanted to exert her autonomy by stopping her medication, but did not want to worry her father by doing so. The fact that her father was insistent on administering medication introduced an element of resentment as all she wanted to do was exert her independence and make her own decisions about taking medication (Taylor et al., 2010). Contrasting with this viewpoint, another young person who had medication administered welcomed this support, seeing it as a sign of caring by a mother who herself struggled with mental illness (Wamboldt et al., 2011).

Considering the fact that young people cited forgetfulness as the most common reason for poor adherence with antipsychotic medication, I was interested in assessing staff opinion of the importance of medication forgetfulness. Only four people responding to the staff survey highlighted forgetfulness as a reason for poor adherence, showing some discrepancy with the young people’s accounts. Staff were not directly questioned about forgetfulness in the survey, and so staff had to indicate this as a potential adherence factor through free text boxes; results may have been different had a specific question about forgetfulness been included. Whilst five young people reported that they just forgot to take their medication at times, they gave no further reasons for this. With hindsight, this is something I wish that I had explored further as there are many contributory factors as to why adolescents with chronic illness may forget their medication. These include unexpected changes to the young person’s schedule (Hommel and Baldassano, 2010, Taylor et al., 2010, Wamboldt et al., 2011), distractions due to other activities (Rothman et al., 2008), not being at home to take the medication (Zelikovsky et al., 2008, Gray et al., 2012) and social commitments such as parties (Mulvaney et al., 2011).

Another feature of dependence was in the fact that the young people had to take medication to get better and remain well. Whilst medication had been instrumental in improving symptoms for most young people, the goal for all was to be able to reduce and stop medication. Current guidance suggests that medication should be continued for one to two years following remission from a first episode of psychosis (NICE, 2013). A recent study of 174 experienced healthcare professionals working in early psychosis indicated that over 75% of clinicians felt that a plan of antipsychotic withdrawal would be considered in more than 60% of patients whose symptoms had remitted. This medication discontinuation could take place within 12 months of symptom remission as only 31% of respondents felt that medication should continue for at least 12 months following recovery (Thompson et al., 2015). This suggests that there is potential for the young people to achieve their goal of discontinuing medication. One young person said she would continue to take medication for life if needed, as she never wanted to return to the dark times when she was being controlled by voices, however she still hoped that she would be able to manage without medication in the longer term. The possibility of medication discontinuation in itself introduces a further element of *suspense* in their stories due to the potential for relapse.

One young person interviewed was concerned about the possibility of physical dependence on the antipsychotics. Whilst antipsychotics are generally not considered addictive, it is recommended that they are withdrawn gradually over several weeks to prevent discontinuation syndromes (Goudie, 2000). The possibility of addiction was however of real concern to this young person and so she was encouraged to have an open discussion with her care team about her concerns.

8.2.7. Stories of Openness

As these young people became better, achieved their goals and started to socialise more, many became more open with close friends about the fact that they had a mental illness and were prescribed medication. At the darkest points of their journey they would have feared such disclosure, concerned that friends would label them ‘crazy’. This is a natural reaction to the stigma still present in relation to mental illness (Murphy et al., 2015a). A stigmatised person has been defined as someone who expects to be rejected as a friend, employee, neighbor, or intimate partner, and to be devalued as less trustworthy, intelligent and competent by most people owing to his or her mental illness (Link and Phelan, 2001). Self-stigma is evident when a person accepts these prejudicial views and internalises these negative perceptions which then impacts on their self-esteem (Corrigan and Watson, 2002). Psychosis and schizophrenia remain the most stigmatised mental health conditions, with those diagnosed with the illness often labeled unfairly as dangerous and unpredictable (Thornicroft et al., 2009). Stigmatising attitudes towards people with mental illness are also common in adolescents (Reavley and Jorm, 2011). When young people’s attitudes to a range of mental health disorders were explored through case studies, adolescents indicated a higher degree of unpredictability in the case study of psychosis and a greater likelihood of the adolescents distancing themselves socially from somebody who presented in this manner (Reavley and Jorm, 2011). It is therefore not unexpected that young people in this study were initially careful about disclosure of their psychosis to their peer group, fearing the negative responses, stereotyping and discriminatory actions that may result (Hinshaw, 2005, Moses, 2010). Other studies have also shown that the general public and mental health staff prefer to maintain social distance from those with psychosis (Corrigan et al., 2002), contributing to the sense of social isolation felt by young people with psychosis and impacting on their willingness to seek support. One-fifth of college students failing to seek treatment for their mental health needs cited worries about what others would think as a major reason for this reluctance to seek support from services (Pedersen and Paves, 2014). Other studies would, however, suggest the majority of young adults think it acceptable for care from mental health services to be sought, and would not think any less of the person for doing so (Eisenberg et al., 2009, Lally et al., 2013, Pedersen and Paves, 2014). In my study one young person was incredibly open with friends, colleagues and the general public encouraging them to ask questions about her illness and the medication she took. When this was explored further she indicated a personal role in reducing stigma by encouraging debate and discussion with others about mental illness. In doing so, she was displaying herself as a courageous, trail blazing *character* within her own story.

In exploring these stories of motivation and control, other illustrations are also provided about how the young people's *characters* are both tested and displayed. The first young person I interviewed spoke about how everybody has a choice whether they become bitter or better, broken or made, victim or victor; these aspects of *character* were evident in other young people's stories. The idea of people with illness being a victim, being bitter or broken fits with Frank's (1995) description of a wounded storyteller (Frank, 1995). Frank himself is a wounded storyteller having recovered from a heart attack and cancer (Frank, 2002) and sought to obtain illness narratives from others, ultimately proposing three different narrative types of chaos, restitution and quest associated with illness (Frank, 1995). Chaos narratives are evidenced in stories of people overwhelmed by their illness, unable to remove themselves from it. One bad thing after another happens within chaos narratives, and the storyteller is stuck in an unrelenting present. Restitution narratives are apparent where storytellers identify with the illness as a disruption to their happy, healthy lives. Storytellers feel that will get better quickly, soon reverting back to their pre-illness self. Finally, quest narratives are illustrated in stories where the person who is ill seeks to use their experiences for the benefit of themselves and others (Frank, 1995). The young person who spoke about having a choice of becoming a victim or victor had clearly made a choice to become victorious. Previously seeing herself as a victim because of her caring responsibilities, the pressures at home and her illness, the earlier illness narrative was one of chaos. She subsequently re-engaged with hobbies, spent more time going out with friends, felt comfortable seeking help when needed from staff and services and was undertaking college and vocational courses to support a future career and to help others. Her illness narrative had moved from one of chaos to quest. Other young people had also been victorious overcoming the chaos of serious eating disorders and/or episodes of self-harm to move to a position of stability and brightness. Whilst the majority of young people were still symptomatic, they were managing these symptoms without resorting to the previous darkness of self-harm and social isolation. Other young people were doing well at college or university having previously isolated themselves because of symptoms; some had achieved excellent exam results despite missing some of their education through illness whilst others were considering career paths actively seeking out a brighter future. Many young people were interested in pursuing a career with young people or a career in health and social care, feeling that their personal experiences could be used positively for the benefit of others. This also provides examples of quest narratives described by Frank (1995) within the young people's stories. These stories show personal *characteristics* of determination, resilience and courage in pursuit of personal goals.

Literature evidences that those vulnerable to psychosis vary in their ability to cope with everyday life stressors (Goh and Agius, 2010), with psychiatric symptoms emerging or worsening when the individual's vulnerability threshold to cope with stressors is exceeded (Pruessner et al., 2011). Individuals vulnerable to psychosis also vary in their degree of resilience to stressors (Drvaric et al., 2015). Resiliency may be influenced by individual ability to cope with emotions and difficult situations (Johnson et al., 2010), self-esteem and coping skills (Pruessner et al., 2011). It has been suggested that positive coping skills and resiliency protect against high levels of psychosocial stress (Drvaric et al., 2015). Many of the young people with brighter stories of motivation and control evidenced personal *character*istics of resilience and positive coping strategies. Several young people spoke of the trauma and dark times experienced in their past. One young person in particular presented an excellent account of how she had overcome this trauma and darkness, moving away from the family environment she found so difficult, seeking help from healthcare professionals and staff at the children's home, using positive coping strategies such as memory books and meaningful activity and taking small steps towards a brighter future. I also propose that medication had a role in increasing these young people’s resilience, although it has been suggested that medication does not impact on levels of stress (Pruessner et al., 2011). My reasoning for this is that many young people spoke about being more able to cope with ongoing voices when prescribed medication. Some young people also recognised that medication had made them calmer and better able to respond to difficult situations.

Whilst the majority of young people could be considered victors in overcoming the darkness in their lives, Victoria seemed to have cast herself as a victim within her own story. People with illness may often present themselves as victims, reflecting a dominant cultural perception of people with illness as ‘victims’ requiring care and often resulting in a passive response to illness (Frank, 1995). Resenting the fact that she was prescribed medication and could not reduce this until after her exams, questioning her illness and portraying a sense of annoyance and anger at her personal circumstances, this young person came across as a young woman struggling with her identity and actively resisting being cast in her story as a *character* who was ill. There was considerable conflict within her story as she debated with herself whether she was ill or not and whether she was ‘normal’ or not. She appeared to have little capacity to influence her own situation, displaying low levels of *agency*. Her *character* appeared broken when I saw her, and recounting her story caused her to become upset and almost tearful. There was however a sense that this desolation could change in the future as she attempted to move forward on her medication journey, exerting more personal control of her destiny by actively seeking agreement from healthcare professionals to reduce her medication.

This young person’s story also evidences the concept of dynamic adherence. Whilst she spoke about certain positive aspects to medication, these were related to her time in hospital when she actively recognised symptoms of mania and could see the impact medication had on controlling manic symptoms and, ultimately, facilitating discharge. The balance of positive and negative aspects of medication was very much in favour of her taking medication. Following discharge home and return to college, the balance had shifted towards more negative stories of medication endurance and resentment manifesting in her desire to withdraw medication. As is the case in dynamic medication adherence, this young person’s decisions were being driven by life circumstance and personal beliefs (Krummenacher et al., 2014). Her willingness to take medication had altered because she no longer saw a role for medication in reducing the threat of illness and relapse. This attitudinal change is captured in one of the most commonly used models to explain variance in adherence behaviour, a modification of the Health Beliefs Model (Becker, 1979). This model focuses on three dimensions. The first dimension is the individual’s readiness to undertaken the recommended sick-role behaviour i.e. to take prescribed medication. This first dimension comprises a number of factors namely, motivations such as willingness to seek help and accept medical intervention, value of illness threat reduction such as perceived susceptibility of relapse and the probability that medication adherence will reduce the threat of illness (Becker, 1979). Changes in this dimension were apparent between the young person’s admission to hospital and the young person’s current position of having spent time living back at home without needing hospital admission. This young person was less willing to undertake the recommended sick-role behaviour. The second dimension involves psychosocial variables which may alter beliefs and attitudes in the first dimension. This second dimension includes variables such as cultural influences, therapeutic relationships, social support and previous experiences of healthcare environments (Becker, 1979). This dimension had remained static for the young person between the time of hospital admission to the time she participated in the study. The final dimension of the model, sick role behaviours, include those behaviours associated with the individual’s acceptance of his or her illness, including adherence to medication (Becker, 1979). This young person had become less accepting of her illness with time and circumstance. An individual’s medication adherence is directly linked to the patient’s readiness to take prescribed medication as well as psychosocial factors (Rickles, 2010) as outlined in the Health Beliefs Model. Psychosocial influences and readiness to take medication vary with time and circumstance, and so this model also supports the concept of dynamic medication adherence.

As well as stories of motivation and control, such as being well, staying well, being a normal teenager and being open about both illness and medication, darker stories of endurance and resentment were also evidenced in other young people’s stories. These will now be explored further.

8.3. Stories of Darkness

Stories of endurance and resentment represented stories of darkness in the young people’s medication journeys. All of the sub-stories of endurance (dealing with trauma, resisting symptoms, accepting the bad days, waiting for medication to work, dealing with side effects, taking medication for life and despite ambivalence), and all of the sub-stories of resentment (being ill, taking medication and feeling different) represented more negative consequences of both the illness itself and taking medication. The *tone* of these stories was therefore negative and they represented the darker sources of *trouble* evident in the young people’s journeys. Whilst presence of these stories may instinctively be considered to dynamically influence behaviour towards poor medication adherence, this rarely proved to be the case in the young person undertaking this research as bright stories of motivation and control outweighed the darker stories of endurance and resentment.

8.3.1. Trauma

Two young people specifically spoke of the trauma they endured in their earlier life and attributed medication, in part, to helping them overcome this. Psychological and psychosocial intervention had also been instrumental in helping these young people move beyond the trauma and develop coping strategies for the future should they find themselves in similar situations, as recommended in national guidance (NICE, 2013). They were displaying high levels of self-efficacy in coping with these stresses, as evidenced in other studies (Macdonald et al., 1998, Schmidt et al., 2014). The young people had shown great strength of *character* in dealing with these traumas, moving forwards to a brighter point in their lives. Whilst not every young person spoke specifically of past trauma, all of the young people talked about the nature of the symptoms of their illness necessitating prescribing of antipsychotic medication. This represented another story of endurance.

8.3.2. Symptoms and 'Bad Days'

For six young people in this study, their psychotic symptoms were such that they had to endure voices telling them to harm other people and/or themselves. They were fearful of these voices and their abilities to resist them; when the voices were at their darkest and strongest the young people isolated themselves to avoid acting on these instructions to harm others. This safety behaviour has been suggested by other authors as a component of a cognitive model for hallucinations (Beck and Rector, 2003). Individuals are less likely to respond to command hallucinations to harm others than they are to respond to hallucinations to harm themselves (Beck-Sander et al., 1997). This was evidenced in my study with some young people unable to resist command hallucinations to harm themselves but never acting on instructions to harm others. This self-harm manifested in either self-mutilation or medication overdoses. The young people who did self-herm aligned these behaviours to the darker aspects of their journey. That some young people participating in this research had resorted to self-harm is not surprising. One study conducted in the UK found that 11% of those diagnosed with FEP self-harmed in the period between symptom onset and engagement with services (Harvey et al., 2008). Other studies have suggested that the incident of self-harm may be even higher (Proctor et al., 2004, Falcone et al., 2008). One can only imagine the difficulties these young people faced enduring and resisting these symptoms; all displayed great courage and determination in doing so. The introduction of medication had in most cases resulted in a quieting of the voices but they rarely disappeared completely. The young people did report finding their voices more manageable and easier to resist. This finding is in keeping with published literature which suggests that a significant number of people have persistent psychotic symptoms (Livingstone and Wykes, 2010). Some authors have suggested that up to 50% of people with psychosis can have ongoing symptoms despite taking medication (Fowler et al., 1999). The young people were realistic in their opinion that there would always be bad days but had been proactive in the way they approached these dark days, using coping strategies and interventions which reminded them of brighter times.

8.3.3. Waiting for Medication to Work

When medication was first prescribed, four young people found that it took longer to take effect than they had anticipated. Two had been informed about the delayed effect of medication, however for one young person this lack of information resulted in poor adherence as he was expecting an immediate response and stopped taking medication because he felt it was not working. This highlights the importance of providing information such as how long medication will take to work (up to six weeks), as highlighted in NICE guidance (NICE, 2009b). The narrative aspect of *temporality* is also reflected in the stories of the young people waiting for medication to take effect. They all unanimously stated that medication had taken longer to work than they have anticipated, even when this delayed response had been highlighted by healthcare professionals. As well as wondering whether any positive effects of medication would be apparent, the young people also had to consider the possibility that they may experience side effects of medication.

8.3.4. Medication Burden

Medication burden is a term used to capture a number of inconveniences in relation to medication, including the number and size of tablets, side effects and palatability of medication to be taken. It has the potential to interfere with patients' daily lives, affect wellbeing and risk medication-related difficulties (Mohammed et al., 2016). In my study, side effects were the most prominent feature of medication burden. Once medication was prescribed, all but one of the young people had to endure side effects of medication. This is not unexpected given that children and adolescents are more sensitive to the effects, including side effects, of antipsychotic medication (Correll, 2011). Reviewing published literature, side effects have been demonstrated as impacting adversely on medication adherence in FEP in some studies (Robinson et al., 2002, Pogge et al., 2005, Tunis et al., 2007, Opjordsmoen et al., 2010, Hon, 2012). Other studies in FEP have concluded that side effects do not influence medication adherence (Coldham et al., 2002, Novak-Grubic and Tavcar, 2002, Mutsatsa et al., 2003, Perkins et al., 2006). Side effects of medication have also been associated with poor medication adherence in 4% of patients with cancer (Hullmann et al., 2015), 7% of adolescents with cystic fibrosis (Dziuban et al., 2010), 14% of patients with inflammatory bowel disease (Greenley et al., 2010), 18% of young people with asthma (Rhee et al., 2009), and 16% and 27% of adolescents with transplants (Simons and Blount, 2007, Simons et al., 2010). These studies in physical illness provide evidence to support the fact that side effects of medication can at times result in poor adherence with medication, although the relative importance of this may vary across different chronic physical health conditions.

The most common side effect highlighted by the young people in my study was weight gain, followed by sedation and EPSEs. Weight gain is a recognised side effect in children and adolescents treated with antipsychotic medication, as evidenced by a recent systematic review (Almandil et al., 2013). Published literature about the impact of weight gain on antipsychotic medication adherence is mixed, with one study in FEP suggesting an adverse association (Pogge et al., 2005) and a further study concluding there is no association between weight gain and antipsychotic medication adherence (Rabinovitch et al., 2009). In my study, seven young people mentioned that they had gained weight due to prescribed medication. In my earlier published survey research, staff identified weight gain as the side effect most likely to affect medication adherence, with 42 respondents specifically highlighting this as a factor for poor medication adherence (Ramdour et al., 2015). Despite this, there was only one occasion where this resulted in poor adherence with medication. In this instance the young person, who had a history of eating disorder, stopped medication because of weight gain; she later resumed taking it, fearful that symptoms would worsen, she would end up in hospital, unable to attend college and achieve her goal of becoming a mental health nurse. This provides another example of dynamic adherence, in that whilst taking medication the weight gain dominated her thoughts tipping the balance towards poor adherence. Once she stopped taking medication, the fears of relapse and the impact this would have on her future goals overtook the concerns about weight gain, swinging the balance in the opposite direction towards better adherence. This reflects the findings of Tunis et al. (2007), that young people with psychosis are more likely to persist with treatment where this is viewed as supporting goal fulfillment (Tunis et al., 2007). The young people also spoke about strategies they had adopted to manage the weight gain, largely exercise and healthy eating. Pharmacological strategies such as a change or dose reduction of medication had also been employed in some instances. Several systematic reviews and meta-analyses support pharmacological (Fiedorowicz et al., 2012, Mizuno et al., 2014, Zheng et al., 2015) and/or non-pharmacological strategies (Álvarez-Jiménez et al., 2008, Das et al., 2012) such as lifestyle and behavioural interventions, to manage antipsychotic-induced weight gain. The interventions being utilised to manage antipsychotic weight-gain by the young people and their care team were therefore appropriate.

Sedation was another side effect cited as problematic by five young people in my study. Thirty one staff responding to the survey research felt that sedation adversely affected medication adherence (Ramdour et al., 2015). Despite these views, none of the young people in this study were poorly adherent to medication as a consequence of sedation. This mirrors findings in published research of FEP (Pogge et al., 2005). Once again, the young people complaining of sedation employed proactive interventions to manage this side effect, using numerous alarm clocks set around the bedroom so they would have to get out of bed to switch them off or ensuring wake-up calls from a parent who persisted until the young person arose from their bed.

Extrapyramidal side effects were the third most frequent side effect, reported by three young people in the study and listed as a potential modifier of adherence by 19 staff responding to the survey research (Ramdour et al., 2015). The EPSEs took the form of tremors, however again young people continued to take medication despite the inconvenience resulting from the tremors. My finding that EPSEs had no effect on medication adherence reflects the conclusions of most published studies in FEP (Coldham et al., 2002, Novak-Grubic and Tavcar, 2002, Mutsatsa et al., 2003, Pogge et al., 2005, Rabinovitch et al., 2009), although one study (Robinson et al., 2002) did suggest an association between EPSEs and poor medication adherence.

In my study, other aspects of medication burden such as tablet size, number of medications and their taste was not reported to have any impact on adherence in young people taking antipsychotic medication. This conflicts with published literature in chronic physical health conditions where there is a suggestion that medication burden, other than side effects, also negatively impact medication adherence. It has been suggested that adolescents may not adhere to medication because of complicated regimens (Rosina et al., 2003, Bullington et al., 2007, Rhee et al., 2009, Dziuban et al., 2010, Hommel and Baldassano, 2010), the taste of the medicine (Bullington et al., 2007, Simons and Blount, 2007, Zelikovsky et al., 2008, Modi et al., 2009, Simons et al., 2009, Dziuban et al., 2010, Simons et al., 2010, Gray et al., 2012) and the size of the tablets (Simons and Blount, 2007, Simons et al., 2009, Simons et al., 2010). This did not feature as a concern in this research study. The greatest number of medications taken by a young person for their mental illness was two medications, once or twice daily, via the oral route. When compared with regimens for some physical health conditions such as organ transplants and type 2 diabetes, the prescribed regimens for young people in this study could therefore be considered relatively straightforward. This has likely influenced the lack of impact the medication regimen had on medication adherence. It could however be a further example of balancing symptom control against aspects of medication burden such as the complexity of the regimen or the number of medications or doses prescribed.

In summary, despite experiencing significant side effects, all of the young people were proactive in their management of medication burdens employing lifestyle, behavioural and practical strategies such as exercise, healthy eating, alarm clocks and wake up calls to overcome side effects; they were also willing to discuss treatment options with health professionals when other strategies did not have the required impact on side effects. The young people displayed high levels of *agency* in their management of side effects; by employing different strategies to manage these side effects the young people were indeed

‘Learning to Dance in the Rain’. My research findings complement published studies in FEP that weight gain, sedation and EPSEs are not significant factors for poor adherence with medication. Had the young people’s responses to these side effects been passive, rather than proactive, then the findings may have differed as the balance between the positive effects of medication and the negative impact of side effects would have differed. When comparing the findings about side effects from the young people’s stories with the survey responses from health professionals, health professionals appeared to over-estimate the impact of medication side effects on adherence emulating the findings of another published study (Kikkert et al., 2006). Side effects of medication, particularly weight gain, sedation and EPSEs were cited by staff as the second most common reason for poor adherence (Ramdour et al., 2015). This was not reflected in the young people’s stories highlighting a need for further staff awareness in this area.

8.3.5. Taking Medication for Life

Despite various stories of endurance related to medication, the young people in my study continued to take it. They also had to contemplate the possibility that they may have to endure taking medication long term. Whilst most young people held a point of view that they would only be on medication in the short term, and the ultimate aim in all cases was to be able to reduce and stop medication, there was recognition by most young people that medication was still needed at the current time. Only one young person was adamant that she could manage without medication and resented the fact that she could not stop it. It also has to be acknowledged that at various times in the young people’s journeys they held more negative points of view reflecting the dynamic perspective to medication attitudes. At times the young people felt that they were not ill and did not need medication, or were better and therefore no longer needed to take medication. Three young people all narrated this as a feature of their individual stories, although with two young people this was associated with previous experiences of being prescribed antidepressant medication rather than currently prescribed antipsychotic medication. My findings did indicate that whilst poor insight into illness and the need for medication may be a factor in adolescent medication adherence, this was more commonly associated with adherence to previously prescribed antidepressant medication. Only one young person admitted not taking antipsychotic medication because she felt well, was having a good day and thought she could manage without the medication, displaying a lack of insight. Insight has been shown to be a significant determinant of medication adherence in studies of FEP, be that in domains of illness awareness (Mutsatsa et al., 2003, Segarra et al., 2012, Chan et al., 2014a), need for treatment (Mutsatsa et al., 2003, Perkins et al., 2006) or overall insight (Coldham et al., 2002, Mutsatsa et al., 2003, Kamali et al., 2006, McEvoy et al., 2006a, Segarra et al., 2012). Results from the staff survey also highlighted staff awareness of the potentially negative impact of poor insight on medication adherence. Ninety two percent of staff indicated that young people thinking they were not ill resulted in poor adherence, making this the most important factor for poor adherence in the views of staff. Whilst there is evidence in published literature to support these health professional views (Coldham et al., 2002, Mutsatsa et al., 2003, Kamali et al., 2006, McEvoy et al., 2006a, Le Quach et al., 2009, Hill et al., 2010, Segarra et al., 2012, Steger et al., 2012, Rabinovitch et al., 2013), the fact that poor insight contributed to poor adherence in only one young person in my study cannot be viewed as strong evidence to support the link between insight and medication adherence. This lack of association reflects findings from one other published study (Lecomte et al., 2008). In recognising that my finding contradicts the majority of literature in relation to the negative impact of poor insight on medication adherence in FEP, it must be acknowledged that this research was conducted in a small sample of young people who had been selected by care coordinators; this may have influenced the results with care coordinators unwittingly or preferentially selecting those with more insight.

Another factor which may have influenced levels of insight was the extent to which health professionals had discussed illness and prescribed medication with the young people. One young person did not initially feel that she needed quetiapine as nobody had explained that her experiences were secondary to psychotic symptoms. Upon realising that it was an antipsychotic medication, her first reaction was to say that she did not need it as she was not psychotic.

Another young person felt that she was taken more seriously in adult services than in CAMHS and was helped to understand her illness more. Published literature has shown that where young people feel they are being treated like a child who cannot take care of themselves this can impact negatively on their self-management of illness (Rhee et al., 2009). When Michelle was treated like an adult and was given information about her illness and why staff felt medication was necessary she accepted medication, providing support to this argument. The importance of provision of information about medication and patient involvement in medication decisions is given in NICE guidelines relating to psychosis (NICE, 2013, NICE, 2014), medicines adherence (NICE, 2009b) and medicines optimisation (NICE, 2015). Studies show that lack of information from, or inadequate communication with doctors, has in particular been perceived as a lack of support by adolescents with chronic physical illness (Kyngäs, 2000a, Kyngäs, 2000b, Rosina et al., 2003, Swarztrauber et al., 2003, Mulvaney et al., 2008, van Dellen et al., 2008, Taylor et al., 2010, Wamboldt et al., 2011), with a frequent refrain from mothers and children in one study being that doctors were cold and impersonal communicating more with their computer than their patient (van Dellen et al., 2008). A recent qualitative study of young people's experiences of taking medication also highlighted that a lack of knowledge about antipsychotic medication affected decisions about commencing, taking and continuing medication (Murphy et al., 2015a). It is therefore important that prescribers and other healthcare professionals provide adequate information in a suitable format to support adherence with medication (NICE, 2009b).

Lack of awareness about how medication worked and its function was evident in another young person, and may have been implicated in her ambivalence to medication. A couple more young people continued to endure taking medication despite a degree of ambivalence towards it. One young person had not noticed dramatic improvement in symptom control and was therefore ambivalent about benefits, however side effects were not troublesome so he was happy to continue taking it. Had side effects been of more concern to him, it is likely that this would have swung the balance between positive and negatives towards poorer adherence.

Another young man admitted to not taking the occasional dose of medication purely because he was in a dark, bad mood. Some studies in physical illness suggest that teenage defiance can be a root cause of poor adherence with medication (Mulvaney et al., 2008, Rhee et al., 2009, Hommel and Baldassano, 2010, Taylor et al., 2010, Wamboldt et al., 2011, Gray et al., 2012). This refusal to take medication because of a bad mood could be viewed as an act of defiance, a way of exerting personal control or indeed as a symptom of his illness. Adolescence is a time of developing a clearer sense of self, gaining increasing levels of independence and taking control of personal, emotional and financial matters, however it also introduces some challenges such as exerting authority, taking risks and demanding rights (Christie and Viner, 2005). Staff responding to the preliminary research questionnaire felt that personal control was an important mediator of medication adherence, reflecting limited findings in published literature of young people experiencing a mental illness (Townsend et al., 2009). Eighty percent of staff felt that a wish to be in control of their own life was a very strong or strong influence on poor adherence, with 78% similarly highlighting a view that all medication decisions are solely up to them (the young person) as having a very strong or strong influence on poor adherence with antipsychotic medication. Adolescents may exert their authority by refusing to take medication long term, however further research is warranted to explore this within the specific topic area of psychosis in young people.

8.3.6. Being Ill, Taking Medication and Feeling Different

Finally, another prevailing capacity of *trouble* within the young people's stories was their feeling different from their peers because they were ill and had to take medication. Considering the evidence base in adolescents taking antipsychotic medication, there appears to be no published literature to date directly considering whether feeling different directly impacts on medication adherence in young people prescribed antipsychotics. In one published qualitative study of medication adherence in FEP, 'living a normal life' was identified as being an influential measure of quality of life. Quality of life was then shown to affect adherence with the antipsychotic medication aripiprazole. It is probable that feelings of difference may impact on 'living a normal life' thereby influencing antipsychotic medication adherence in FEP (Hon, 2012). In a further qualitative study, pressure to conform to their peer group was highlighted to affect young people's decisions about medication adherence (Murphy et al., 2015a). It is possible that this pressure to satisfy their peer group may be linked to a requirement or desire to be like their peers rather than standing out as different.

The young people in my study most often storied resentment to both the illness and medication. Coming to terms with psychosis has been identified as an important stage in recovery (Waite et al., 2015). It has been argued that grief and mourning for losses engendered by the illness, and hopelessness about having a bright and viable future with the illness, are an important part of coming to terms with a diagnosis of psychosis (Wittmann and Keshavan, 2007). It is therefore not unexpected that such stories of resentment were evident in six young people's stories. One point of view expressed on several occasions was 'Why Me?', as young people struggled to come to terms with their illness. They compared their situation to friends who were not mentally ill and who did not need medication to be able to undertake usual teenage activities. The illness and requirement to take medication set them apart from their peers and made them feel different; these aspects of their stories not only outlined their resentment but were narrated in negative, dark *tone*s.

Studies in HIV (Veinot et al., 2006), cystic fibrosis (Dziuban et al., 2010) and sickle cell disease (Modi et al., 2009) highlight that feeling different can directly contribute to poor adherence with medication regimens. This finding has also been replicated in type 2 diabetes (Mulvaney et al., 2008, Auslander et al., 2010), chronic kidney disease (Kemp et al., 1998, Johnson et al., 2008) and liver transplants (Taylor et al., 2010). Whilst there is a reasonable evidence base to support the positive association of feeling different on poor adherence across a range of different physical health conditions, this association was not apparent in my study. Whilst six young people spoke of feeling different because they were prescribed medication, only one young person stopped taking medication for a few days because of her 'desire to be normal'. They did not speak of any pressure from their peers to stop medication, although other published literature suggests that pressure to conform to peers can affect medication adherence (Murphy et al., 2015a). Young people appeared to balance how taking medication set them apart from their peers against how improved symptoms secondary to medication supported an outward appearance of ‘normality’ to their peer group. This supposition is evident in the example of one young person who was, by her own admission, noticeably different to peers because of her topics of conversation and behaviour. Being on medication brought some normality and brightness into her life as she was able to move to college from an education centre and was better able to interact with other college students. She stopped medication on occasion because it made her feel different to others but then resumed it because of her wish to remain at college and retain her independence. This story again provides evidence that adherence with antipsychotic medication is dynamic.

As feeling different contributed to intermittent adherence in only one young person, there is no strong evidence from my research that feeling different results in poor adherence with medication. The consequences of feelings of difference or ‘wishes to be normal’ are worth further exploration in future studies.

Young people can also feel different to their peers because of hospital admissions. For five young people this represented another aspect of *trouble* within their stories. Although one young person who had been admitted to hospital on three separate occasions recounted two admissions in a positive light, she also had an admission that she found particularly difficult. All of the other young people admitted to hospital spoke about how difficult they found this experience and how desperate they were to be discharged back home. The troubles associated with hospital admission were linked to the young people being away from their usual home environment, feeling isolated from family and friends, feeling under constant observation from staff on the ward and also a genuine fear and dislike about hospitalisation. Studies in children have identified fears of hospital admission linked to familial separation and feeling alone (Coyne, 2006, Wilson et al., 2010). As well as the loneliness resulting from a hospital admission, children also miss school, the loss of independence and limited abilities to undertake activities (Bossert, 1994, Coyne, 2006, Lindeke et al., 2006). Children have also expressed a dislike of hospital admission because of unfamiliarity of the environment (Coyne, 2006). The reasons the young people in this study found hospital admission dark and *trouble*some are therefore corroborated by published research. Whilst some young people highlighted that their worst fear was readmission, none of the young people concerned directly attributed a fear of readmission to their continued adherence with medication. I propose that this is another subconscious motivator for medication adherence linked to young people taking medication to stay well. This is not something that is readily evidenced in published studies and could be explored in future research.

Finally, as already briefly discussed, a particular source of resentment was the illness itself and need for the young people to have to take medication. Studies have found that teenagers with asthma (Buston and Wood, 2000, Rhee et al., 2009, Wamboldt et al., 2011), diabetes (Mulvaney et al., 2008, Auslander et al., 2010, Mulvaney et al., 2011) and cystic fibrosis (Dziuban et al., 2010) are often embarrassed about disclosing their illness to friends and peers. Other studies in diabetes (Mulvaney et al., 2011), solid organ transplants (Bullington et al., 2007, Simons and Blount, 2007, Simons et al., 2010), chronic kidney disease (Johnson et al., 2008) and asthma (Naimi et al., 2009) have found that teenagers are reluctant to take medication in front of their friends. Whilst the majority of evidence suggests that people with chronic health conditions dislike feeling different from their friends and want to be able to undertake usual teenage activities, there is also some evidence that adolescents may feel special and unique because of their illness, poorly adhering to medication fearing rejection if they were to become well (Bullington et al., 2007). Comparing these findings in chronic physical illness with the young people in my study, all of the young wanted to recover and so there was no evidence that people were intentionally non-adherent to remain ill. Young people with psychosis have similar concerns to adolescents with chronic physical illness about friends being aware of their illness, or knowing that they take medication. I propose that these concerns may be even more challenging for young people with psychosis due to the ongoing stigma about mental illness (Kranke et al., 2010, Gerlinger et al., 2013). It was clear from the young people's stories that they were fearful of the reactions they would get following such disclosure. They were worried that people would consider them ‘crazy’ or dangerous; they were fearful of being stigmatised because of their mental illness. This concern about stigma is also evidenced in a qualitative study of other young people prescribed antipsychotic medication (Murphy et al., 2015a). A systematic review concluded that fears of dangerousness due to mental illness is the most significant reason why the public maintain social distance from those with a mental illness (Mertika et al., 2006). A recent narrative study identified that young children who had a parent with a mental illness were aware of social stigma and therefore avoided disclosure about their parent’s mental illness, (Murphy et al., 2015b) providing further support for childhood awareness of stigma. Given this awareness of social stigma around mental illness at such a young age, and the link with rejection and personal devaluation, it is not surprising that the young people in this study were not always willing to disclose details of their illness and medication to close friends. They were even more reluctant to discuss this openly with peers. Two young people were more willing to discuss their illness and medication openly, with one young girl in particular seeing it as a personal responsibility to encourage questions with the aim of reducing the stigma around mental illness. She showed great bravery and courage in being so willing to discuss her illness, reflecting how far she had come in her journey from the dark past of isolating herself at home, fearful of leaving the house or interacting with others.

8.4. Summary

In conclusion, the young people were balancing individual stories of motivation and control against stories of resentment and endurance when making decisions about medication. Medication adherence was dynamic, with the relative balance of these positive and negative aspects of medication influencing subsequent adherence behaviour. All were displaying high levels of *agency* in overcoming the symptoms of their illness, journeying away from the dark times of uncontrollable, distressing symptoms, social isolation and fear towards a brighter future of independence, happiness and success.

CHAPTER NINE. CONCLUSION

Having presented my findings and discussion, this final chapter provides details of my original contribution to knowledge, strengths and limitations of the research, implications for practice and suggestions for further research. I conclude by summarising what these young people’s stories can teach us as health professionals and people.

9.1. Original Contribution

When embarking on this research, I felt that there was a need to hear stories from young people about their medication journeys in order to understand their perspectives of what it was like to take antipsychotic medication. In undertaking this research, I have made an original contribution in a number of different ways. Firstly, this is the only study to my knowledge to use auto-photography to explore medication adherence in any form of mental illness within published literature. It is also the only study which uses narrative research methodology to obtain views about medication adherence in mental illness that I have been able to find in published literature. Focusing specifically on adolescents, there are limited published qualitative studies addressing antipsychotic medication (Hon, 2012, Murphy et al., 2015a). One study used a grounded theory approach with FEP patients prescribed the antipsychotic medication, aripiprazole (Hon, 2012). A further study took a phenomenological approach to explore antipsychotic medication experiences of young people (Murphy et al., 2015a). The research undertaken in my study used a narrative, rather than a grounded theory or phenomenological, research approach and participants could be prescribed any antipsychotic medication between the ages of 14 and 18 to meet the inclusion criteria.

The findings also represent an original contribution to knowledge. On analysing the young people’s individual stories, a metastory emerged whereby the young people journeyed from a place of darkness to brightness as medication took effect and psychotic symptoms lessened. Such a metastory has not been referenced in published literature of young people with psychosis prescribed antipsychotic medication. Four key stories became apparent; stories of endurance, stories of motivation, stories of control and stories of resentment. Adherence behaviour depended upon the relative balance of motivation and control (promoting adherence) versus endurance and resentment (potentially deterring adherence). Where young people could appreciate that medication was helping to control symptoms, improve quality of life, contribute to goal attainment and facilitate independence they were willing to endure more of the negative aspects of medication such as side effects and feeling different. This was because the perceived benefits of medication outweighed the drawbacks of medication. Where this balance swung the other way, and drawbacks outweighed the perceived benefits, resentment increased towards the medication. Medication efficacy was the predominating aspect promoting adherence with medication as this was fundamental to stories of motivation and control such as being well, staying well, feeling ‘normal’, having a bright future and being independent. Forgetfulness was the most common reason for poor adherence, mirroring findings in adolescents with chronic physical illness. The research findings also suggest that medication burden including complicated medication regimens or unpalatable medicines were not a feature of poor adherence in adolescents prescribed antipsychotic medication, contrasting with findings in research of adolescents with chronic physical illness. Finally, the research provides original evidence that strengthening relationships with family, partners and friends as a consequence of taking prescribed medication is a motivator to continued use of antipsychotic medication in adolescents. Other studies consider the impact social support has on medication adherence in FEP (Malla et al., 2002a, Perkins et al., 2006, Gearing and Charach, 2009, Rabinovitch et al., 2009, Rabinovitch et al., 2013) and this usually reflects whether somebody is available to provide support or prompt and administer medication. Some literature also suggests that antipsychotic medication can adversely affect young people’s relationships (Murphy et al., 2015a). My study provides new evidence that indirect effects of medication on social support through strengthening relationships and widened social circles encourages future adherence with antipsychotic medication.

9.2. Strengths and Limitations

In conducting this research, I sought at all times to approach it in a way which ensured rigour and would promote confidence in the research findings. As with all research, there were strengths and limitations in the research design and methodology which will now be outlined.

Strengths

One of the key strengths of this research is the use of a novel qualitative approach to explore antipsychotic medication adherence in adolescents. Many medication adherence studies take a quantitative approach, measuring adherence and then comparing with demographic data and results of tools to assess features such as insight and attitudes to medication. Thus, there is an element of limiting results according to the measures being assessed. In asking young people to tell their story of their medication journey, I was trying to capture all of the information they themselves found relevant. The information they provided was in no way restricted through use of semi-structured interviews, rating scales or tools. I also feel that the young people were more willing to participate as they were controlling the information provided at interview and felt more comfortable and at ease telling their story rather than answering lots of questions in an interview schedule.

The involvement of care coordinators in electing young people who were able and willing to take part and give informed consent and in introducing me to the young person was a further strength of the research. This is because the young people felt more relaxed being introduced to me by somebody they knew. I also feel that involvement of the care coordinators ultimately led to high quality information being provided by the young people concerned, as the care coordinators selected those who would understand and engage well with the research design and method. Only two young people dropped out of the research and this was due to factors outwith their control, namely relocation to another country and the need for an operation.

Thirdly, I feel that the young people concerned engaged well with the autophotography aspect of the research. Whilst I did not always end up receiving hard copies of photographs taken, the images and illustrations and even the would-be images employed by the young people were incredibly imaginative. These images introduced an additional layer by which to understand the young person and their story. The images also increased the impact of the stories told by offering a visual representation. All but one of the young people chose to go through the photographs one by one at interview and tell me why they had taken the photograph and what it represented. This allowed them to easily structure the information provided; the photographs provided prompts to the information they wanted to give. Only one young person presented the information as a story from beginning to end of her medication journey, and she had written this down beforehand so as not to forget and to make things easier at interview. The young people, in the main, seemed at ease talking about their photographs and could spend most of the interview looking at the photographs rather than me if this made them feel more at ease. I think this all contributed to the young people being more open and talkative at interview than they may otherwise have been. Focusing discussions around what the photographs meant made it easier for young people to discuss their views and feelings; the original intentions of using a visual methodology to engage young people in the research was incredibly effective. Despite struggling at times to engage one young person in discussion about her illness and medication, she became much more animated when describing the photographs she had taken. She had been very creative in capturing these images and was keen to edit the images so they became an even stronger representation of her story. Unfortunately her camera broke and she was unable to share these pictures. She was however able to describe the photographs in considerable detail incorporating her ideas about how she had planned to edit the photographs using different colours and photographic effects. This highlights the strength of the methodology chosen as this young person was still able to engage in discussions about her medication despite the photographs being physically absent. She still chose to focus her discussion around the images taken rather than just recount her medication story to me.

Finally, I think that the narrative approach combined with use of visual imagery enabled a more meaningful appreciation of what taking antipsychotic medication meant to the young people involved. Without the combination of both narrative analysis and autophotography, it is possible that the metastory of a journey from darkness to brightness may not have been as readily apparent. The images themselves provided evidence of the contrast between darkness and brightness and this enabled this concept to naturally emerge during discussions about the images.

Limitations

As well as significant strengths to the research, there were also a number of limitations. Whilst previously arguing that involvement of care coordinators was a strength of the research, some might also say that their involvement led to a degree of participant selection that otherwise would not have occurred. This may have introduced a degree of bias, as it is possible that those young people agreeing to participate may have been those who had more insight or were more adherent due to positive experiences of taking medication. To defend against this, it was made clear through written and verbal information that I wanted to hear the good and bad stories around medication. If the information was overwhelming positive at interview, I directly asked whether they had ever experienced any negative things in relation to medication. In the images presented, and verbal information provided, the young people were willing to disclose negative features of medication and so I do not think that this concern was realised.

It was also a requirement of the ethics committee that young people be informed that their care coordinator or doctor would be contacted if they disclosed at interview that they were not currently taking prescribed medication. I was required to disclose any concerns about mental state should they be evident during my interactions with the young people. I was initially concerned that this may encourage people not to speak openly about poor adherence, but again this did not materialise with the young people still disclosing past reasons for not taking medication. Nobody disclosed that they were not currently taking medication, however, I felt that this was probably a reflection of current adherence behaviour. I was concerned that one young person may not take medication as she was so disaffected by it, however her father was administering medication and so I was reassured that this was being monitored and she was taking it. In the end I was relieved that the ethics committee had required these additions to the research proposal, as I did on one occasion approach a care coordinator when somebody became upset at interview talking about past and current experiences.

It could also be argued that some young people may not have been willing to engage in the research as they felt that this required a degree of artistic ability. I propose however that the advantages of using visual research approaches outweighed this. Some young people did at times find it difficult to take photographs to explain certain concepts, however in these instances they resorted to the internet and obtained relevant images online. One young person did struggle to imagine the pictures he could take to illustrate his medication journey. I therefore had to explain and give examples during further telephone conversations. This young person did not take any photographs in the end, as he sustained significant injuries in a gardening accident and so was housebound for a long period. In hindsight, I think this also provided him with a feasible excuse to cover up the fact that he did not really understand what was required, however he was still able to participate in the research without providing photographs.

On reflection, I was also unrealistic in my expectation that the young people would return their photographs within the agreed timescale without prompting. Numerous follow up telephone calls, emails and text messages were required before photographs were returned, and during some of these conversations it became apparent that the young person had not started to take photographs. The need to devote time and energy to taking the photographs may have put some off engaging with the research. Other factors which may have also detracted from participation include the need to be interviewed, for the interview to be recorded and to speak to somebody about medication who they had only met during a brief interview. That said, I think the fact that I was not working in any of the teams the young people attended meant that they may have seen me as more independent and therefore been more open during interview.

Finally, there are limitations in the sample recruited as all young people were in contact with services in Lancashire. Findings may therefore have differed had the sample been more geographically spread. The sample was predominantly female (80%) and Caucasian (90%). The stories may differ to stories told by young people from a different population. However, it should also be acknowledged that the young people's stories are bound by context, time and memory.

9.3. Implications for Practice

Having considered both the strengths and limitations of the research, I will now consider implications for practice based on the research findings. I propose that it is important for healthcare professionals to explore and understand young people's individual medication stories, not only to effectively engage them in ongoing discussion but to monitor and promote medication adherence. I also suggest that there are advantages to using narrative research approaches as an innovative means of providing a person-centred approach to medication adherence. Recent national drivers encourage and promote medicines optimisation, 'a person-centred approach to safe and effective medicines use, to ensure people obtain the best possible outcomes from their medicines' (NICE, 2015). A key principle in medicines optimisation is seeking to understand the patient's experience (RPSGB, 2013). Medical narrative is shifting away from the physician's narrative towards greater emphasis on the patient narrative (Morris, 2000), with narratives now being perceived as a helpful means of understanding the individual, person-specific meaning, context and perspective of illness (Greenhalgh and Hurwitz, 1999). Narrative medicine has been defined as "medicine practiced with… narrative skills of recognising, absorbing, interpreting, and being moved by the stories of illness" (Charon, 2006). In telling these stories, the patient describes the life of their own illness in their own words (thus providing insight into past and current experiences), their sense of suffering, how this feels to the patient and those close to them, their experience of symptoms, indeed anything that is of relevant to their own particular story (Kalitzkus and Matthiessen, 2009, Frank, 2010). The cathartic experience of telling stories and having healthcare professionals actively listen and absorb what is being said has the potential for the patient to find healing (Rian and Hammer, 2013). It has also been demonstrated to reduce anxiety (Freeman, 1991) and increase general wellbeing (Brooker and Duce, 2000). For the healthcare professional, narrative medicine has also demonstrated improvements in team unity and perception of other people's perspectives, whilst reducing stress and compassion fatigue (DasGupta et al., 2006, Sands et al., 2008). Thus narrative medicine has the potential to enhance the experience of patient and professional alike, and may influence outcomes through co-creation of illness stories, the mutual understanding developed through the story-telling process and the resultant improved patient-professional relationship. Whilst acknowledging that not all patients will feel comfortable or ready to recount their individual illness stories, I consider that the practice of narrative medicine, and more specifically narrative pharmacy, has the potential to ensure healthcare professionals become truly patient-centred in their response to illness for the benefit of both self and patient, thereby improving outcomes including adherence with medication. Asking young people to describe their medication journey is an effective way of exploring relevant motivators and detractors of medication adherence.

Staff should also explore relevant features of endurance, motivation, control and resentment with young people to promote open discussion about the positive and negative aspects of taking medication. Staff should not make assumptions, for example that significant side effects will naturally equate with poor adherence. In exploring stories of endurance, motivation, control and resentment, healthcare professionals need to consider the relative balance of positive and negative aspects of medication with the young people themselves. In doing so healthcare professionals will gain an appreciation of individual motivations and goals which may promote and deter medication adherence.

Finally, adherence needs to be frequently explored with young people as adherence behaviour is rarely static, instead varying dynamically with time, circumstance and attitude.

9.4. Proposals for Future Research

In undertaking this research it became apparent that published qualitative research in this topic and with this patient population is scarce. This therefore warrants further attention and qualitative studies with participants from a wider geographical footprint should be undertaken.

Future research in young people with mental illness, and healthcare professionals supporting them, could seek to determine whether narrative evidence based medicine approaches result in improved outcomes compared with treatment as usual. Such research could take the form of two patient groups whose baseline medication adherence is assessed using both subjective and objective measures of adherence. Additional assessment scales of other factors which may affect medication adherence, such as attitudes to medication and insight, would also be prudent. One group would then receive treatment as usual, whilst the other group would also be the recipient of narrative evidence based medicine approaches. Repeat measures of adherence and assessment scales could then be undertaken to assess for any changes in adherence, insight and attitudes across the two patient groups. Research with staff could also assess whether narrative evidence based medicine approaches increase job satisfaction, reduce stress and improve team cohesiveness in those working with young people experiencing psychosis.

Research could also explore whether goal-setting could improve adherence to medication in those with FEP. One patient group would receive treatment as usual. The other group would additionally set goals and measure progress against these goals over time. Baseline and repeat measures of adherence could then determine whether goal setting provided any benefit in terms of improved adherence with medication.

Having provided suggestions for future research, I conclude this thesis with my reflections on what the young people’s stories can teach us both as healthcare professionals and people.

9.5. What These Stories Teach Us as Healthcare Professionals and People

In undertaking this research using visual and narrative approaches, young people felt comfortable recounting their individual stories. Findings from these stories have already been presented and discussed. I would however like to suggest that the most encouraging and life-affirming moral learning evident throughout the young people’s stories is that they can succeed, despite the utmost stress, trauma and adversity, attaining their individual goals. Their success and determination should provide encouragement to everybody, whether they are suffering a mental illness or not. One young person highlighted that you can start with nothing and make something of yourself; that it is all about taking small steps in the right direction to get to your goal. Positive journeys from darkness to brightness were evidenced through the young people’s stories, despite set-backs along the way. These amazing young people were all ‘Learning to Dance in the Rain’.

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APPENDICES.

Appendix 1. Labov and Waletsky framework

This is outlined by using an excerpt from Ameeta’s story.

Feature	Example	Reflections
Orientation	From a young age I was piling things on top of me, living at home which is very difficult for me, and I felt I was the primary person responsible for my family	Pressure being placed on an individual at such a young age. Cultural expectations of a caring role for females.
Complicating action	I experienced a lot of trauma. My day to day life was very hectic and busy	Ameeta didn’t fully expand on the trauma. I did not delve further as she had just lost a friend to suicide.
Evaluation	I would put a smile on my face but deep down I was very low in mood	How Ameeta was feeling had gone unrecognised partly due to her determination not to outwardly display how she was feeling.
Evaluation	I had reached the point where I no longer saw a purpose in life	The anxiety, stress and fear that must be present when you are experiencing psychotic symptoms but don’t understand or recognise them for what they are.
Evaluation	which was when I first started to experience psychosis, without realising or fully understanding what was truly going on	

Resolution	It was then, when I reached the point when I was unable to see a future, which led to my admission to hospital	What it must be like to be admitted to an inpatient mental health unit at such a young age
Coda	It was at that point I started to take medication and antipsychotic medication	Medication was only commenced in hospital presenting a delay in treatment of psychosis.

Appendix 2. Research information sheet

Research Information Sheet for Service Users.

‘What taking medication means to me’

January 2013

Thank you for taking an interest in our project. My name is Sonia Ramdour and I am a pharmacist with the Lancashire Care NHS Foundation Trust. I am currently carrying out a research project with the early intervention service, child and adolescent mental health service and the University of Central Lancashire and I am looking for volunteers to help me with this. This study is wanting to hear stories from young people who have taken medication at some time between the ages of 14 and 18. We want to find out more about what taking medication means to people when they are teenagers.

You are being invited to take part in this study. Before you decide, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear, or if you would like more information. Take time to decide whether or not you wish to take part. Thank you for reading this.

What is the purpose of the study?

I am wanting to explore what taking medication for psychosis means to young people. It is hoped that by understanding more about this we will be able to provide more suitable information and help for young people prescribed this medication and their families

Why have I been chosen?

There is very little information on this topic particularly in the 14 to 18 year old age group. We are therefore concentrating on patients in this age group who have current contact with early intervention or CAMHS (child and adolescent mental health) services.

Who is organising and funding the study?

This study is funded by the Pharmacy Department of the Lancashire Care NHS Foundation Trust and has been organised by the Pharmacy Department, the Early Intervention Service and researchers from the University of Central Lancashire.

Do I have to take part?

You are free to agree or refuse to take part in this study and your decision will not in any way affect your relationship with your doctors or nurses or your subsequent treatment. If you did decide to take part you would be free to withdraw at any time without giving a reason or your care being affected

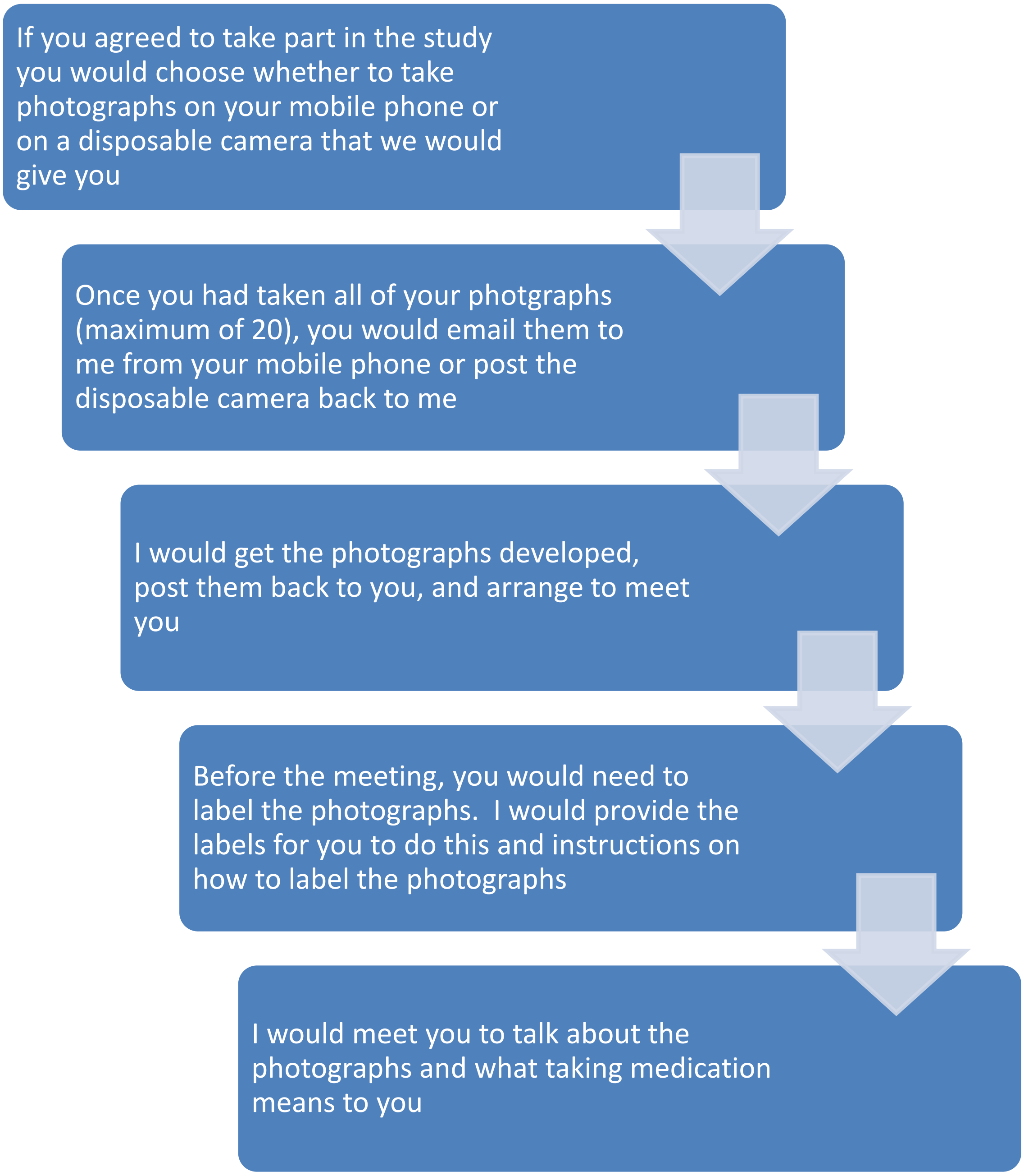
What would I have to do?

If you took part in this study you would be asked to take some photographs representing what taking medication for your mental wellbeing means to you. You would take these photographs on a disposable camera we would give you or on your mobile phone. If you took photographs of other people you would also need to ask them to complete a form giving permission for the photograph to be used in the study. We would not use photographs with people in them unless we had their permission to do so.

You would then email the photographs to me or send the disposable camera back in the prepaid envelope provided. Any mobile phone charges incurred sending the photographs straight from your phone will not be reimbursed, however there would be no cost to you if you are using a disposable camera or sending them as attachments to an email from a computer.

Once I have had the photographs developed I would then send them back to you.

I would then contact you and arrange a meeting to discuss the photographs in more detail. Please see the diagram below for further information about how this would happen.



If you agreed to take part in the study you would choose whether to take photographs on your mobile phone or on a disposable camera that we would give you

Once you had taken all of your photgraphs (maximum of 20), you would email them to me from your mobile phone or post the disposable camera back to me

I would get the photographs developed, post them back to you, and arrange to meet you

Before the meeting, you would need to label the photographs. I would provide the labels for you to do this and instructions on how to label the photographs

I would meet you to talk about the photographs and what taking medication means to you

What are the risks or benefits to me?

There are no risks but it would involve you giving up some of your time and may cause you to think about unpleasant experiences you have had in the past with medication.

There may be no immediate direct benefit to you, although you may find it helpful to share your experiences and find out what others think about taking medication. We hope that your feedback will help us examine and evaluate our services for the future

Is the study confidential?

Yes, anything you say or write would remain confidential. Any information we hold about you pertaining to this study will be held securely and destroyed at the end of the research study.

Would anyone else know I was taking part?

Staff from the Early Intervention or CAMHS service may talk to you about the research study so you know about it. You do not have to take part in it if you do not want to, and this will not affect the service you receive from them. If you are 14 or 15, then we will have to contact your parents or guardians before you can take part in the study. We will ask you to complete a form giving the phone number of your parents/guardian so that we can call them and confirm that they are happy for you to take part. They will also need to complete a parental consent form.

What will happen if I don’t want to carry on with the study?

You are free to withdraw from the study completely at any time or withdraw particular photographs or information you have provided up to four weeks after the meeting to discuss them.

What will happen to the results of this study?

It is intended that the results of this study will guide further research on different ways to provide information on medication to encourage and support people in the 14 to 18 year age group to take their prescribed medication. It is anticipated that the anonymised results will be published as a journal paper and be presented at conferences. The research will also form part of my PhD thesis. You will not be personally identified in these documents although direct quotes from the information obtained may be used. The results will be discussed within the early intervention service and a summary of the main findings will be sent to those participants who request feedback**.**

Who has reviewed the study?

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by North West 12 Research Ethics Committee (Lancaster). It has also been reviewed by the Lancashire Care NHS Foundation Trust Ethics Committee and the Ethics Committee at the University of Central Lancashire.

What if there is a problem?

If you have worries about any aspect of this study, you should ask to speak to Professor Joy Duxbury who is leading this study [telephone number 01772 895110]. She will do her best to answer your questions and address any concerns. If you are still unhappy and want to complain formally, you can do this using the Lancashire Care NHS Foundation Trust Complaints Procedure Details can be obtained from the Complaints Manager, Sceptre Point, Sceptre Way, Walton Summit, Bamber Bridge, Preston PR5 6AW. Telephone 01772 695316)

Further information

If you have any further questions please feel free to ask and if you think of anything later on, you can contact me at:
Sonia Ramdour, Guild Lodge, Guild Park Hospital, Whittingham, Preston PR3 2AZ or by telephoning 01772 406640.

If I am not in the office please leave a message on the answer phone and I will contact you as soon as I am able

You should keep a copy of this information for future reference.

Thank you for considering whether you want to be involved in the study**.**

Expression of Interest Form

Study about ‘What taking antipsychotic means to me’.

Name:

Age:

Address:

Telephone number:

Email:

Please tick which of the following statement/s applies:

I am currently a patient with the early intervention or CAMHS service ☐

I attend the support group ‘The Crew’ ☐

I am aged 14-18 and currently taking antipsychotic medication ☐

I am over 18 and was prescribed antipsychotic medication at some point between the ages of 14-18 ☐

I am aged 14 or 15, and know that my parents/guardian will have to agree to me taking part in the study. Their contact details are as follows: ☐

Name of Parent/Guardian…………………………………………….

Telephone number of Parent/Guardian……………………………

I have read the information leaflet and am interesting in being involved in the study

Signed________________________________**Date** _______________________

Please return this form using the following FREEPOST address:

Sonia Ramdour
Medication study (Pharmacy)
Clinical Governance Network Team
FREEPOST RSAK-2BJS-JJCE
Po Box 592
Preston
PR5 6XT

Appendix 3. Parental information and consent form

Research Information Sheet for Parents/Guardians of 14 and 15 year olds

'What taking antipsychotic medication means to me'

January 2013

Thank you for taking an interest in our project. My name is Sonia Ramdour and I am a pharmacist with the Lancashire Care NHS Foundation Trust. I am carrying out a research project with the Early Intervention, Child and Adolescent Mental Health (CAMHS) services and the University of Central Lancashire and I am looking for volunteers to help me with this. This study is looking at what young people think about antipsychotic medication.

Your child is interested in taking part in this study but we need your permission for them to do this. Before you decide, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear, or if you would like more information. Take time to decide whether or not you wish them to take part. Thank you for reading this.

What is the purpose of the study?

I want to hear stories from young people about what taking medication means for them. By doing this, I hope to have a greater understanding about the decisions young people make in deciding whether or not to take medication for their mental health difficulties. It is hoped that by understanding more about what young people think, and by hearing their stories, we will be able to provide more suitable information for patients and carers about medication

Why have they been chosen?

There is very little information on this topic particularly in the 14 to 18 year old age group. We are therefore concentrating on patients in this age group who have current contact with the Early Intervention or CAMHS service.

Who is organising and funding the study?

This study is funded by the Pharmacy Department of the Lancashire Care NHS Foundation Trust and has been organised by the Pharmacy Department, the Early Intervention service and researchers from the University of Central Lancashire.

Do they have to take part?

You and your child are free to agree or refuse to take part in this study and this decision will not in any way affect your relationships with the doctors or nurses or your childs subsequent treatment. If you did decide they could take part they would be free to withdraw at any time without giving a reason or your care being affected. You can also withdraw them at any time without giving a reason or their care being affected

What would they have to do?

In the first part of this study we conducted a medication survey to get some information on what influences whether people choose to take or not take medication prescribed for psychosis. We now want to get more in-depth information about this from young people, and plan to do so by asking them to take photographs about what taking antipsychotic means to them. We will then arrange a meeting with your child so they can tell us what the photographs mean, and tell us their story about taking antipsychotic medication.

We have given you this leaflet as your child has indicated a wish to take part in the study. If you agree to them taking part, you will then need to complete the form at the end of this leaflet and return it using the freepost address provided.

What are the risks or benefits to them?

There are no risks but it would involve them giving up some of their time and may cause them to think about unpleasant experiences they have had in the past with medication.

There may be no immediate direct benefit to your child, although they may find it helpful to share their experiences and find out what others think about taking medication. We hope that their feedback will help us examine and evaluate our services for the future

Is the study confidential?

Yes, anything your child says or writes would remain confidential. Nobody will be able to identify your child from any information we include in publications, presentations or the research thesis. Any information we hold about your child will be destroyed at the end of the research study.

Would anyone else know they were taking part in the study?

Staff from the Early Intervention or CAMHS service may talk to your child about the research study so they know about it. Your child does not have to take part in it if they do not want to, and this will not affect the services received from the Early Intervention or CAMHS service. If you do not wish them to take part then this will also in no way affect the service received by the team. Their care coordinator and consultant will be informed that they are taking part in this study.

What will happen if they don’t want to carry on with the study?

They are free to withdraw from the study at any time. If they withdraw from the study, we will use the data collected up to the point that they withdraw unless we are told otherwise.

What will happen to the results of this study?

It is intended that the results of this study will guide further research on different ways to provide information on medication to encourage and support people in the 14 to 18 year age group to take their prescribed medication. It is anticipated that the results will be published as a journal paper and included in a research thesis, but your child will not be personally identified although direct quotes from the information obtained may be used. The results will be discussed within the Early Intervention Service and a summary of the main findings will be sent to those participants who have asked for feedback.

Who has reviewed the study?

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee, to protect participants' interests. This study has been reviewed and given favourable opinion by North West 12 Research Ethics Committee (Lancaster). It has also been reviewed by the Lancashire Care NHS Foundation Trust ethics committee and the ethics committee at the University of Central Lancashire.

What if there is a problem?

If you or your child have a concern about any aspect of this study, you should ask to speak to the Principal Investigator for this study, Professor Joy Duxbury [telephone number 01772 895110]. Any concerns will be looked at by Professor Duxbury, however If you remain unhappy and wish to complain formally, you can do this using the Lancashire Care NHS Foundation Trust Complaints Procedure Details can be obtained from the Complaints Manager, Sceptre Point, Sceptre Way, Walton Summit, Bamber Bridge, Preston PR5 6AW. Telephone 01772 695316)

Further information

If you have any further questions please feel free to ask and if you think of anything later on, you can contact me at Sonia Ramdour, Guild Lodge, Guild Park Hospital, Whittingham, Preston PR3 2AZ or by telephoning 01772 406640.

If I am not in the office please leave a message on the answer phone and I will contact you as soon as I am able. You should keep a copy of this information for future reference. Thank you for considering whether you want your child be involved in the study

uclan School of Health
University of Central Lancashire

Lancashire Care NHS
NHS Foundation Trust

Study Number: 09/H1015/77

Parental Consent Form for Service Users Aged 14 and 15

Factors influencing teenage adherence with antipsychotic medication

Please initial box

I confirm that I have read and understand the information sheet dated January 2013 (version 3) for the above study and have had the opportunity to ask questions. ☐

I understand that my child's participation is voluntary and that they are free to withdraw at any time, without giving any reason and without their medical care being affected. ☐

I understand that my child will be asked to take photographs for this study. ☐

I consent to use of digital audio-recording during the interview ☐

I give consent to the use of direct quotes my child may make during the interview and understand that their name will not be included alongside these quote ☐

I understand that their care coordinator and consultant will be informed of their involvement in the study ☐

I agree to them taking part in the above study. ☐

I understand that relevant sections of data collected during the study may be looked at by individuals from the University of Central Lancashire, from regulatory authorities or from the Lancashire Care NHS Foundation Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to this data. ☐

Name of child (Please Print) ……………………………………………

Name of parent (Please Print)………………………………Date……

Signature of Parent …………………………………………………

Please return in the FREEPOST ENVELOPE provided

Appendix 4. Consent form

uclan School of Health
University of Central Lancashire

Lancashire Care NHS
NHS Foundation Trust

CONSENT FORM

'What taking antipsychotic medication means to me'

Please initial below only if you agree with the statements. Please ask if you are unclear or have any questions. Please also print your name, sign and date the form below.

Initials

1.	I have read and understood the information sheet for this study	
2.	I have had the opportunity to ask questions about the study and these have been answered to my satisfaction	
3.	I understand that my participation is entirely voluntary and that I am free to withdraw at any time	
4.	I understand that if there are concerns about my mental health during any meetings with the researcher, that they may have to contact my care coordinator or a member of my mental health team	
5.	I understand that if I disclose that I am not currently taking my medication, the researcher will be obliged to discuss this with my care coordinator.	
	PHOTOGRAPHY PHASE	
6.	I agree to comply with the guidelines given in the 'Photograph guidance sheet for participants' document	
7.	I agree for the researcher to view these photographs after development and for a CD-Rom to be produced so the researcher can view these on her computer	

8.	I agree to a selection of these photographs being used in the PhD thesis/ subsequent publications and/or presentations as stated in the ‘Photograph Use Permission Form’. I also understand that I can request for certain photographs NOT to be used.	
	INTERVIEW PHASE	
9.	I agree to the interview being audio recorded	
10.	I understand that quotes of what I have said in the interview may be used in the thesis and in presentations and publications. I understand that my name will not be used and the quotes will be anonymised	
11.	I agree to take part in the above study	

______________________________ ______________________________

Participant’s name Researcher’s name

______________________________ ______________________________

Participant’s signature Researcher’s signature

Date __________________ Date __________________

Appendix 5. Photography permission form

Photograph Use Permission Form

‘What taking antipsychotic medication means to me’

Photograph number	Stored electronically for 5 years	Thesis publication	Presentations/ exhibition	Academic publications
1				
2				
3				
4				
5				
6				
7				
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16				
17				
18				
19				
20				

I consent to the following photographs being used for the stated purpose.

Participant Name

Researcher Name

Participant signature

Researcher Signature

Date

Date

Appendix 6. Model release form

uclan School of Health
University of Central Lancashire

Lancashire Care NHS
NHS Foundation Trust

Model Release Form

'A research project'

Your photograph has been taken by ___________________ as part of a research project they are participating in. This project is being undertaken jointly by the Lancashire Care NHS Foundation Trust and the University of Central Lancashire, Preston.

Please sign below to state that you are happy for the following:

- **I consent to this photograph being used as part of the research study and thesis about the study.**
- **I consent to this photograph being used in a range of academic publications.**
- **I consent to this photograph being use in an exhibition or oral presentation**
- **I consent to this photograph being stored on a secure computer at the University of Central Lancashire or Lancashire Care NHS Foundation Trust for up to 5 years.**
- **I understand that I will not be identified by name in any of the above.**

Name ____________________________________

Date ____________________________________

Signature ____________________________________

Appendix 7. Research protocol

Research Protocol

An Exploration of Perceptions affecting medication adherence in young people in early intervention services with a diagnosis of psychosis.

Protocol Author: Sonia Ramdour, Lead Pharmacist Central Lancashire.
Protocol date: March 2014.

Introduction.

Medication is an important intervention in the management of mental health illness and has significant mental health benefits for the individual. If a service user does not take medication as prescribed, this may adversely impact in the short and long-term through ongoing symptoms, and poorer response to medication the longer the duration of untreated illness.

Antipsychotic medication has been shown to be effective in the treatment of schizophrenia but the importance of medication in the prevention of relapse has been reviewed by a number of authors (Davis et al. 1993; Gilbert et al.1995; Hogarty 1993). Hogarty in 1993 reviewed the effectiveness of antipsychotic medication in preventing relapse and showed that relapse rates in the first year following hospitalisation can be reduced from 70% to 40% by the use of antipsychotic medication (Hogarty 1993). Davis et al carried out a meta-analysis of 35 double blind studies comparing maintenance treatment with placebo in 3,720 chronic schizophrenic patients. The results showed that patients who do not receive antipsychotics are more likely to relapse within three years with relapse rates of 55% in those patients randomized to placebo treatment as compared to 21% in the antipsychotic treatment group (Davis et al. 1993). Gilbert et al reviewed the effect of antipsychotic withdrawal from an analysis of 66 studies involving the withdrawal of medication, which included 4365 patients. The mean cumulative relapse rate was 53% in those patients withdrawn from medication over a period of 9.7 months compared to 16% in those maintained on antipsychotic treatment (Gilbert et al. 1995). Whilst there are several factors which impact on the validity of these types of reviews e.g. lack of diagnostic details, the absence of a standardised definition of “relapse”, the inclusion of conditions that would not be diagnosed as schizophrenia using contemporary criteria and lack of clarity around duration and dose of medication in the preceding episode, it is clear that there are significant risks to individuals who choose not to take their antipsychotic medication.

Gilbert el al. in their review examined factors that may predict relapse but rejected them however Baldessarini et al. further analysed the evidence reviewed by Gilbert et al and provide a list of predictive risk factors with antipsychotic withdrawal e.g. gradual discontinuation of treatment, lower prescribed dose of antipsychotic.

The issue of whether maintenance treatment is required by all patients with a diagnosis of schizophrenia has been reviewed by the NICE schizophrenia guidelines. It is reported that around 20% of patients will only experience a single episode. Identifying this patient group is however not possible and therefore the NICE guidelines have concluded that pharmacological relapse prevention should be considered for every patient who is diagnosed with schizophrenia (NICE 2002).

Whilst many clinicians would consider medication efficacy with regards to the balance of improved symptoms vs. adverse effects, a broader concept has been suggested which also takes into consideration factors important to the individual prescribed the medication. Such factors may relate to issues of tolerability, ability to live independently, physical health and other quality of life measures (Thomas 2007). It has been suggested that effectiveness of medication is characterised by four different outcome categories: symptoms of the disease, burden of treatment, burden of illness and health and wellness (Nasrallah et al, 2005). In isolating the individual factors that may impact upon treatment adherence it is therefore important to consider that these should not be viewed in isolation but as part of a complex interdependence which overall improves the quality of life for individual patients with a diagnosis of schizophrenia.

Services users, carers and healthcare professionals within early intervention services may have a variety of views, or personal experience, of why there is often a reluctance to take prescribed medication for mental illness and these views need to be sought in a systematic, evidenced based way to inform discussion about future interventions and information provision. It has been suggested in existing research that people need to recognise a benefit from taking medication and that side effects can influence decisions around whether or not to take medication as prescribed. It is anticipated that research focused on views of this younger age group, their carers and professionals working with them may guide interventions which would hope to positively impact on adherence rates with medication in the future. The 14 to 18 year age group has been neglected in research of this type to date, and therefore it is important to consider their views as they may differ from those individuals who are older.

PHASE ONE

Objectives.

The objectives of phase one of this study are as follows:

1. To explore factors that are perceived as influencing service user’s adherence to medication
2. To assess whether there are differences in the views of healthcare professional (HCP's), carers and service users
3. To consider whether the three groups have different perceptions of what constitutes a benefit from medication
4. To inform discussion about future interventions and provision of information that may positively impact on adherence rates with medication in this 14 to 18 year old age group.

Participants.

Inclusion Criteria.

1. Service users aged 14 to 18 who have been referred to the early intervention service or child and adolescent mental health (CAMHS) services for assessment and/or treatment
2. Carers of a 14−18 year old who has current contact with the early intervention or CAMHS service
3. Staff currently working within early intervention or CAMHS services

Exclusion Criteria.

1. Those unable to participate and/or give valid consent due to physical or mental health problems
2. Service users under the age of 14 or over the age of 18
3. Those caring for someone who is under 14 or over 18
4. Staff not currently working within early intervention or CAMHS services

Sample and recruitment.

Participants will be recruited from early intervention and child and adolescent mental health services (CAMHS) tier 3 and 4 services within Lancashire Care NHS Foundation Trust as follows:

Phase One

- Posters advertising the initial study questionnaire will be displayed in key areas e.g. clinic waiting areas.
- Flyers will be given to care coordinators so they can pass them on to patients and carers on their case load who fulfill the inclusion criteria for the study.
- Likewise, reception staff will give flyers to those fulfilling the criteria who attend outpatient clinics.
- Staff will receive a flyer via staff email distribution lists.
- The questionnaire will also be publicised on the trust website, twitter and facebook pages

The questionnaire may also be publicised via links from mental health charities to the trust website page, and also via ‘retweets’ from mental health charities who are signed up to receive tweets from the trust twitter page.

Participation will be optional.

Design of the study.

Participants will be asked to complete an anonymous questionnaire designed to assess perceptions of and influences on medication adherence. Separate questionnaires will be completed by staff, service users and carers although content will be broadly similar excepting demographic information (further information is detailed below). These questionnaires have been designed using ‘Survey Monkey’ and will be accessible to participants online via weblinks to the Survey Monkey website or as a hard copy.

An overview of the research, including objectives and information on what will happen with the data collected, will be included at the start of the questionnaire

Limited demographic information will be obtained as follows:

- Age (completion of this question is optional)
- Sex (completion of this question is optional)
- Ethnicity (completion of this question is optional)
- Whether the participant has ever been prescribed medication for psychosis
- Whether they are a patient aged 14 to 18 who has had contact with EIS or CAMHS services.
- Whether they are a carer of someone aged 14-18 in contact with the EIS or CAMHS service, If so they will be asked whether their child/guardian has ever been prescribed antipsychotic medication
- Whether they are a healthcare professional currently working with EIS or CAMHS services. Is so they will be asked their profession and the length of time they have worked in CAMHS or EIS

Once the questionnaire has been completed all participants will have the option of entering into a draw for one of five £15 vouchers per participant group (HMV, Waterstones or iTunes). Contact details will need to be provided if the participant wants to be entered into the draw so winners can be sent the vouchers. Participants will also be given the following options:

- To take no further part in the research
- To become a member of an electronic focus group
- To meet the researcher on an individual basis to discuss their views in more detail
- To invite the researcher to a support group they are involved with to discuss issues with the group

Those expressing an interest in the focus groups, e-forum or meeting with the researcher will have to provide information so the researcher can contact them. A participant information sheet and consent form will then be provided electronically or by post. If they want to proceed they will be asked to return a hard copy of the consent form using the freepost address specified. Those aged 14 and 15 will also be required to provide a phone number for their parent/guardian. The researcher will then phone to validate that the parent/guardian is aware of their child's wish to become involved in the study and provide a parental consent form for completion.

Once all consent forms have been received the participants expressing an interest in the electronic focus group (e-forum) will be registered on the secure, private, password protected UCLAN community website which is maintained and supported by UCLAN and is endorsed by their ethics committee in the faculty of health. Registration will enable access to the relevant medication adherence e-forum depending on whether they are a service user aged 14 or 15, a service user aged 16-18, a carer or healthcare professional. A code of conduct for users of the site is already established and enforced. The researcher will pose questions about medication adherence on the site and participants will then have the opportunity to respond. The administrator and researcher will have editing rights to the forum in the event of inappropriate content being posted e.g. excessive swearing. The forum will be closed at a time when the researcher feels that no new information is being obtained.

Once consent forms have been received for those wanting to participate in a one to one interview, the participant will be contacted and a time and place to meet arranged. The Lancashire Care NHS Foundation Trust lone worker policy will be followed by the researcher. The interview will take the form of a semi-structured interview recorded to allow transcription. The recording will be stored securely in a locked cabinet within a locked room and deleted at the point that the research study ends.

Additionally, focus groups may be conducted with attendees of current patient and carer forums across Lancashire. Members will be provided with details of the study and focus group in advance and have the option to participate in the focus group or not attend. Consent forms will be completed by any attendees.

Respondents to the questionnaire can also invite the researcher to attend existing service user and carer groups in North West England to conduct a focus group. These will be conducted as described above.

Those participating in the focus groups, e-forum or discussions with the researcher will be entered into a draw for the opportunity to win one iPad should they so wish.

Proposed method of analysis.

This mixed methods study will explore the factors perceived as influencing willingness to take medication in this population of service users using the following:

1. Results of the questionnaire
2. Focus group outputs (electronic and face to face)
3. Transcripts of semi-structured interviews

Ethical Issues and potential risks of participation in the study.

In designing this study, the very young age of the service user group has required particular attention. Where participants are aged 14 or 15, parental consent for involvement in any one to one interviews or focus groups (including those which will be conducted electronically) will be a pre-requisite. Any interviews and focus groups will take place outside of school hours so that involvement in the study will not mean patients missing school.

It is hoped that potential participants will be keen to complete the questionnaire either electronically or as a paper copy, as this can be done quickly in a convenient location e.g. home. Youngsters may be more willing to engage in electronic focus groups as they in the main embrace such technology. Electronic forums will support those youngsters who are not confident in face to face interactions with others. A reminder of the need for confidentiality will be issued at the start of any focus group and if required during any focus group discussions by the facilitator. There will be the option to leave at any point during the focus group or interview if the participant does not feel able to continue their involvement. Care coordinators will be informed in the event that there are concerns about a service users or carer's mental state at interview or during a face to face focus group. If healthcare professionals need additional support, this will be provided by existing mechanisms in place in the trust.

Participation is entirely voluntary and no-one will be disadvantaged if they choose not to participate. No participant will be financially disadvantaged by their involvement.

PHASE TWO

Objectives.

The objectives of this study are as follows:

1. To further explore factors that are perceived by young people as influencing service user's adherence to medication using autophography

2. To inform discussion about future interventions and provision of information that may positively impact on adherence rates with medication in this 14 to 18 year old age group.

Participants.

Inclusion Criteria.

1. Service users of the early intervention service or child and adolescent mental health (CAMHS) services, or service users who attend the support group ‘The Crew’ who have taken antipsychotic medication at some point between the ages of 14 and 18 inclusive

Exclusion Criteria.

1. Those unable to participate and/or give valid consent due to physical or mental health problems
2. Service users who were not prescribed antisychotic medication at some point between the ages of 14 and 18 inclusive

Sample and recruitment.

Participants will be recruited from early intervention and child and adolescent mental health services (CAMHS) tier 3 and 4 services within Lancashire Care NHS Foundation Trust or from the support group ‘The Crew’ initially.

Posters will be displayed in reception areas advertising the second phase of the research, which will require young people to take photographs about what taking medication means to them and then discuss this topic with the researcher. Care coordinators in CAMHS and early intervention services will identify young people aged 14-18 who are likely to participate and then arrange a joint visit with the researcher to discuss the research, provide an information sheet and expression of interest form to be returned to the researcher at the meeting or in a freepost envelope provided. Staff in younger persons inpatient units will also be asked to identify those young people approaching discharge who may wish to be contacted about the research after discharge. The researcher will meet these young people on the ward before discharge and ask their permission to contact them about possible participation in the research three months post-discharge. The researcher will also attend any relevant patient forums in the community with the approval of the forum facilitator. The research will be discussed at a meeting in the presence of the forum facilitator and information sheets and expression of interest forms provided as above. The expression of interest form will require provision of contact details for parents and guardians for those aged 14 and 15. The parent/guardian will be contacted by the researcher, the study discussed and a parental information sheet incorporating a parental consent form provided. The research study will only progress in those aged 14 and 15 on receipt of the parental consent form.

Design of the study.

In the second phase of the study, the first twelve young people returning expressions of interest forms will be contacted and a meeting arranged to discuss the study in more detail. They will be asked to take photographs depicting ‘what medication means to me’. Participants will be told that this can include both positive and negative aspects of medication. Participants will be reminded that the focus is on their own personal views and experiences, as opposed to that of the wider public, and will be informed that they can focus on experiences and hopes in the past, present and/or future. Participants will be told that they can take ‘real life’ photographs, or collect other images, for example, from photo albums, magazines etc. If such images are presented then the researcher will seek permission to take a digital photograph of those images.

During this meeting participants will be given the chance to ask any questions, be asked to sign a consent form for the photography and interview phase of the project and if not taking photographs via a personal mobile phone they will be provided with a disposable camera. They will also be made aware of the importance of getting written permission before taking photographs of other individuals and will be provided with copies of the Model Release Form to facilitate this.

A time frame for this stage will be agreed between the researcher and the participant but it is anticipated to be approximately 4 weeks. Once the photographs have been taken participants will email the photographs to a university email account or post the camera back to the researcher in a pre-paid padded envelope provided. The researcher will obtain (a) a set of prints for participants, and (b) a CD-Rom copy of these prints for the researcher. The participant will have been made aware and consented to the fact that the researcher will look at these photographs before sending them back to check that they have developed correctly. Participants will also consent to the researcher having a copy of all photographs on CD. In addition participants will be sent instructions alongside their photographs regarding the next stage of the process which will outline the need to select and label those photographs they wish to discuss.

Once the photographs have been returned to the participant the researcher will call and arrange a convenient time and date for an in-depth interview where participants will be asked to talk about their experiences of taking medication. Before the interview, participants will be asked to verbally reaffirm their consent to the interview phase of the project. Participants will also complete a form identifying which photographs they give permission to be stored for 5 years, and/or used in a thesis, and/or used in presentations or exhibitions and/or used in academic publications. During the interview, participants will be asked to talk about their experiences of taking medication, before being asked to talk specifically about the photographs they have taken. They will be asked questions to explore whether any of the information provided promotes medication adherence or interferes with it. They will also be asked specific questions based on findings of the staff survey to enable any concurring or discrepant views to be discussed. At the end of the interview they will have a final opportunity to add anything else they consider appropriate.

It is anticipated that the interview could take up to one hour, although participants will be made aware that they can take a break whenever they wish and/or finish earlier than expected. At the start of each interview the interviewer will negotiate how much time the participant has available for the interview and tailor the process accordingly. All recordings will be transcribed verbatim for later analysis. After the interview, participants will be thanked for their time and be presented with a £10 gift voucher in recognition of their input. They will also be advised that they have a ‘cooling off’ period of one month during which time they can contact the researcher and ask for some or all of their data to be removed from the study.

Summary of the process.

Potential participants are approached by researcher and a member of staff who knows them. Information sheet and expression of interest form is provided

On receipt of expression of interest form, the researcher contacts the parent/guardian of those aged 14 and 15. The young person will not be contacted again until written parental consent is received

The young person is contacted and a meeting with the researcher arranged. At this meeting the photography stage is explained in detail. A photography guidance sheet is provided along with a model release form for completion by anyone they photograph. Consent is assessed and the consent form completed. A disposable camera is provided where this is the preferred method to take photographs. The consultant and care coordinator are informed of their involvement in the study.

The young person takes up to 20 photographs and then returns them to the researcher

The researcher arranges for the photographs to be developed along with a CD-Rom of the photographs

The researcher returns the developed photographs to the young person mounted on cards. Printed labels are included so they can give the photographs a title, identify whether the image represents a positive or negative aspect of taking medication, and indicate whether the photograph is relevant to the past, present and/or future before the interview. A photograph selection form is provided so they are clear about what they need to do with the photographs before the interview.

The researcher contacts the participant and arranges a date, time and venue for the interview

At the start of the interview, verbal consent is reaffirmed. Permission is obtained to audio-record the interview. The interview is then conducted in line with the interview prompts sheet. At the end of the interview the photograph use permission form is completed. If the person has disclosed that they are currently not taking medication the care coordinator will be informed. The young person will be made aware of this disclosure

Proposed method of analysis.

Narrative analysis of in-depth interviews conducted with young people participating in the auto-photography part of the study

Ethical Issues and potential risks of participation in the study.

In designing this study, the very young age of the service user group has required particular attention. Where participants are aged 14 or 15, parental consent for involvement in this phase of the study will be a pre-requisite. Any interviews will take place outside of school hours so that involvement in the study will not mean patients missing school, college or work.

Young people participating in the auto-photography part of the study will in the main have been identified by their care team as being able to participate in the study and give the necessary informed consent. Alternatively, they will be community patients attending a patient forum facilitated by a member of staff. They will be given clear instruction about what images they can use e.g. from magazine or the internet, and be told that they can only include images of other people with their written consent on the model release form. If this is not available then the images will not be included in the research. Additionally, any images deemed by the researcher to be inappropriate will be excluded from the research and the young person informed of the reasons for this. Young people will provide written consent at the start of the study to the photography and subsequent interview and will provide further verbal consent at the interview stage. They will be able to withdraw at any point during the study and also withdraw all or part of their images during and up to four weeks after their interview.

Participation is entirely voluntary and no-one will be disadvantaged if they choose not to participate.

Safeguarding Children

Lancashire Care Trust (LCFT) staff have a duty of care to safeguard and protect children at risk of harm and neglect from the subsequent negative outcomes and enable all children to reach their full potential. Every child has the right to be protected from potential significant harm. If at any time staff identify concerns for a child/ young persons welfare or believe a child is suffering, is at risk of suffering abuse or neglect or has suffered abuse or neglect a referral must be made to Children's Integrated Services (CIS) in line with LCFT and Local Safeguarding Children Board Procedures. The child/ young person's welfare should remain the central concept in any assessment

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Appendix 8. Photography guidance sheet

Photograph Guidance Sheet for Participants

‘What taking antipsychotic medication means to me’

This sheet will provide you with further details regarding the steps you need to take in this stage of your participation in my study. Please don’t let this guidance sheet put you off taking part. It just gives you some useful information. If you have any further questions, or experience any difficulties in undertaking this task, please contact me (Sonia Ramdour) on 01772 406640 or SJRamdour@uclan.ac.uk

What should I take photographs of?

I would like you to think about what taking antipsychotic medication means to you, both the good and bad things. I would like you to take *up to 20 photographs* which you believe represent your views about antipsychotic medication. You can focus on what this means in the present, past and/or future. There is no right or wrong way to do this and everyone who takes part in the study will take different pictures. When taking these photographs please remember that some might be used in my thesis, in articles, or at conferences. You have the right to tell me that I cannot use certain photographs in this way.

Do I need to obtain permission before taking photographs of people?

It is important that when you take your photographs that you respect the privacy of other people. Please do not take a picture of someone who does not wish to be photographed. If you are taking a photograph of an individual, please ask them to sign a Model Release Form (or their parent/guardian if they are under the age of 16) – included in this pack

If you are taking a picture of a group of people who could be identified, it would be good to let them know that this photograph may be used in a range of academic publications/conference presentations.

Can I use old photographs?

Yes it is fine to use some old photographs if you want to. You may already have some photographs which you think represent your views on taking medication. I will request permission from you to take a photograph of these pictures using a digital camera. Please do take at least some new photographs, and then you can talk about both the old and new photographs in the interview stage of this project.

Can I use other resources?

Again it is fine to use resources such as pictures of things you would struggle to photograph yourself. A picture of this from a magazine or the internet would be fine. Again I will ask permission to take a photograph of these using a digital camera.

How long do I have to take these photographs?

I will give you four weeks to take the photographs and either email the photographs or post the camera back to me. However, if you feel you need a longer period of time then that is also fine – we can discuss this after the initial four week period.

What do I do once I have taken my photographs?

Once you have taken up to 20 photographs please email them to me at SJRamdour@uclan.ac.uk if you have taken them on your mobile phone. If you have taken photographs on the disposable camera then return the camera to me in the pre-paid padded enveloped I have provided for you marked ‘Private and Confidential’. The camera will have your participation number on the front so I am able to identity whom the photographs belong to.

What happens next?

Once I have received the camera or email, I will get the photographs developed. I will check the photographs to ensure they have developed properly and I will post the photographs to you with additional instructions. I will also keep a copy of your photographs (on CD-Rom) so I can use them in my study.

Please look through the photographs and remind yourself why you took each one. I will telephone you a few days after sending the photographs to arrange a time for us to meet again and for you to talk to me about the photographs you have selected.

Appendix 9. Photography Selection Form

Lancashire Care NHS
NHS Foundation Trust

uclan School of Health
University of Central Lancashire

Photography Selection Form

‘What taking antipsychotic medication means to me’

Dear

Please find enclosed the photographs you recently took as part of my research study. You will notice that these have been mounted onto card ready for the next step of the process.

I will be in touch shortly to organise a time/date for us to explore these photographs in detail. However, in preparation for this meeting it would be really helpful if you could take a short amount of time to do the following:

1. Remove any photographs which you do not wish to include in the discussion.
2. Add any additional photographs/images to the spare cards (use a paperclip if you do not wish to stick these down)
3. For each photograph write a title which briefly explains what this is.
4. Please also use the stickers I have include in the pack to help label the photograph. You will find the following labels
    a. Positive aspects (of taking antipsychotic medication)
    b. Negative aspects (of taking antipsychotic medication)
    c. Past (i.e. this relates to the past)
    d. Present (i.e. this relates to the present)
    e. Future (i.e. this is relevant to the future)
    f. Some blank labels for if you need more

Please attach all labels that apply to the photograph.

I have included an example to illustrate this titled ‘Sleepiness’. If this is not clear or you have any questions, please do not hesitate to contact me on 01772 406640 or SJRamdour@uclan.ac.uk (Monday – Friday 9am – 5pm please). I will be in contact within the next week to arrange a time/date for my interview with you.

Best wishes,

Sonia Ramdour

Pharmacist and Research student

Title: Sleepiness……………………………

PAST

PRESENT

NEGATIVE

Appendix 10. Interview Prompts

Before the interview begins I need to check a few things with you.

1. Have you read and understood the information sheet? Do you have any questions?
2. Briefly explain the format of the interview – what they can expect.
3. Ask if they are happy to verbally reaffirm consent taken at photograph stage
4. How long do you have for this interview? Any time constraints? Explain that we will have a break half way through and that they may pause or stop at any point.
5. Ask permission to audio-record the interview
6. Check if there are any last minute questions.
7. Ask the participant to sort the photographs in order of importance.

Now we can get started on the interview.

1. Can you start by telling me little bit about yourself
2. As you know I am wanting to hear your story about taking antipsychotic medication. Please can you tell me your story about taking this medication using the photographs you have taken. When you do this it would be great if you could also include the title you have given the photograph. I would like you to tell me your story in as much detail as you can. I will not interrupt you but I may take some notes in order to ask you some questions later.
3. Wait until the participant appears to have finished speaking and prompt them if there is anything else they would like you add.
4. Ask about any shifts in views about antipsychotic medication
5. If prompts are needed to obtain more information then consider the following:

- Ask participants to expand on why they chose the particular titles for any photographs where it has not been explained/is not self evident.
- Consider past/present/ future pictures and explore any shifts in view

6. Probe more in relation to what motivates them to take their medication and if there is anything that makes them think about not taking medication.
7. Ask them to pick out three sort cards which for them are really important in terms of taking medication. Ask them to tell a story about the particular cards chosen.

- What other people think about medication
- Pressure to take or not take medication
- Wanting to be in control
- Media e.g. internet, tv, magazines, newspapers
- Wanting to be well
- Achieving my goals
- Side effects
- Admission to hospital
- I'm not ill
- I'm embarrassed
- Medication won't help
- Medication is bad for you
- I'm better now

8. I would just like to give you a final opportunity to say anything else you feel may be relevant to taking antipsychotic medication

Thank them for their time. Give voucher. Complete photography use permission form if not already completed. Remind them that they can withdraw any photographs over the next four weeks by contacting me. Ask whether they would want written feedback on key findings from the study