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A qualitative study using a constructivist grounded theory approach to investigate factors in Jordan that impact psychiatric medication-taking behaviour in schizophrenia and Bipolar I disorder

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1- Jordan University Hospital

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3- Our step Association

Publications and Conferences

I was a speaker at the first Jordanian mental health conference held in Amman-Jordan on 24th-26th May 2023. The findings of my study were presented to the audience from different subjects, such as psychiatrists, psychologists, nurses, and other organisations interested in mental health.

Abstract

Introduction:

Medication-taking behaviour remains a challenging issue in mental health settings. It is widely understood that most people with mental disorders do not take their medications as prescribed. This behaviour is moderated by many factors that influence the decision-making process regarding taking, giving, and prescribing psychiatric medications. Most studies on this topic in Jordan have used quantitative methods. However, these studies failed to explain the medication-taking behaviour toward psychiatric medication or address issues related to people with mental disorders and their families. To my knowledge, this is the first qualitative study in Jordan to investigate medication-taking behaviour among people with schizophrenia or bipolar I disorder from three different perspectives (service users, primary caregivers, and healthcare professionals).

Aim:

This study aimed to explore the factors that influence medication-taking behaviour among Jordanians diagnosed with schizophrenia or bipolar disorders and how these factors affect their decision to take their medications, with the specific objective of developing a theory that provides an understanding of the factors that impact taking psychiatric medications. The research question to be answered was “What are the factors that impact psychiatric medication-taking behaviour of service users, primary caregivers, and healthcare professionals' experiences and perspectives? How do these factors influence their taking behaviour?”

Methods:

A qualitative study used an adapted constructivist grounded theory approach supplemented by an analytical approach from the Straussian school. The study was conducted in three settings in Jordan: two mental health outpatient clinics and one community centre. Seventeen participants (n=17) were divided into three groups (six service users, four primary caregivers, and seven healthcare professionals -doctors and nurses) recruited for the study. Data were gathered through semi-structured interviews exploring participants’ views, experiences, knowledge, and beliefs about psychiatric medication taking, giving, and prescribing using online Zoom meetings and audiotape. These were transcribed and coded using constant comparative analysis.

Findings:

This study identified the factors that influence psychiatric medication-taking behaviour. Five categories emerged (experience with psychiatric medications, knowledge about psychiatric disorders and medications, beliefs about psychiatric disorders and medications, health care systems and policies, and financial insecurity). These categories highlight the major barriers and facilitators to taking, giving, or prescribing psychiatric medications in mental health settings in Jordan. This finding suggests that most service users and primary caregivers either took psychiatric medications as prescribed or stopped taking them. Experience with psychiatric medications highlights the most important factor that impacts psychiatric medication taking as well as the impact on their decision-making.

Discussion:

A key element is that service users and primary caregivers are willing to take their psychiatric medications as prescribed when they have a positive experience and good knowledge about mental disorders and medications in addition to family support, although negative beliefs about mental disorders spread in the community. The undeveloped healthcare system will meet their needs for mental health issues that impact their decision to visit the mental health setting because of the infrastructure of the psychiatric clinic, understaffing, crowded clinics, and medication not being available most of the time because the mental health service is free at the governmental clinic.

Conclusion:

These categories are facilitators or barriers for psychiatric medication-taking behaviour as well as internal and external factors because they interrelate and intersect with each other in many areas that impact the service user and primary caregivers' decision-making process to take psychiatric medication as prescribed or not based on these factors. This decision will later add to their motivation or barriers as well as internal and external factors. Additionally, these factors affect healthcare professionals when psychiatric medications are prescribed to service users. Therefore, service users, primary caregivers, and healthcare professionals should work together, considering the substantive theory developed to weigh the risks and benefits of psychiatric medications based on internal and external factors and build up their decisions.

Contribution of the findings:

Taking medications as prescribed in individuals with severe mental illness is influenced by various factors, which differ between the Middle Eastern and Western contexts. It is important to note that previous research has predominantly focused on the Western context. This study sheds light on Middle Eastern countries, especially Jordan, as this is the first qualitative study in Jordan that explores the factors that impact taking medications as prescribed from the perspective of service users and primary caregivers, which will help in developing interventions based on the cultural context which different from the western cultural context. Also, this study highlights an issue regarding Jordanian drugs versus international medications.

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Abbreviations Glossary

Wherever you find these Abbreviations, it stands for:

Table 1: Abbreviation glossary

AHPR	Al-Karama Hospital for Psychiatric Rehabilitation
APA	American Psychiatric Association
CDE	Center For Diabetes and Endocrine
DSMS	Diagnostic and Statistical Manual OF Mental Diseases -5th Edition
GDP	Cross Domestic Products
HCP/s	Healthcare Professional/s
IACS	Inter-Agency Standing Committee for Mental Health
ICD-10	International Classifications of Disease and Related Health Problems – 10th Revision
JNC	Jordan Nursing Council
JUH	Jordan University Hospital
KAUH	KING Abdullah University Hospital
KHCC	King Hussein Cancer Center
KHMC	King Hussein Medical City
MH GAP	Mental Health Gap Action Program
MH GAP-IG	Mental Health Gap Action Program –Intervention Guide
MHPSS	The Mental Health and Psychosocial Support Groups
MMAT	Mixed Method Appraisal Tool
MMH	Marka Military Hospital
MOH	Ministry of Health Jordan
NCDEG	National Centre for Diabetes, Endocrinology and Genetics

NCMH	National Center for Mental Health
NCRDA	National Centre For Rehabilitation of Drug Addicts
NHS	National Health Services
NGO’s	Non-Governmental Organizations
NICE	National Institution for Health and Care Excellence
PCG	Primary caregiver
REA	Rapid Evidence Assessment
RMS	Royal Medical Services
SU	Service user
Uhs	University Hospitals
UNRWA	United Nations OF Relief and Work Agency for Palestine Refugees in The Near East
WHO	World Health Organization

Chapter 1 : Cultural Background Related to Mental Health in Jordan

1.1 Introduction:

Mental health is a public health issue worldwide. Almost about one billion people worldwide are affected by mental health problems. This means that more than one in every 10 people is living with mental disorders (Datini et al., 2021; WHO, 2022a), and mental disorders contribute to 5% of the global disease burden and 31% of the non-fatal disease burden on the global disease chart (The World Bank Group & WHO, 2016; WHO, 2019a; Rehm & Shield, 2019; Datini et al., 2021).

In their report, The World Bank Group and World Health Organization (WHO) (2016) report that eighty per cent of those who are likely to encounter a mental health episode in their lives are from low- and middle-income nations. The global expenditure on mental disorders was about US $ 2.5 trillion in 2010, and this estimation is projected to increase in 2030 to US $ 6 trillion. Fifty-four per cent (54%) of the burden was found in low- and middle-income countries, estimated to increase by 4% by 2030 to reach 58%, combined with the loss of productivity and income due to disability, unemployment, or death. Consequently, psychiatric disorders are the world's leading contributors to disabilities, leading to missed economic productivity and imposing a considerable economic burden (The World Bank, 2019).

Despite these findings, less than 2% of worldwide government health spending is allocated to mental health (WHO, 2022a). The World Health Organization has constructed a comprehensive mental health action plan (2013-2030) to increase awareness of mental health issues and promote mental well-being, prevent psychiatric disorders, fight stigma, and provide care in low-middle income countries to reduce disabilities, morbidities, and mortalities of mental disorders (WHO, 2017b; WHO, 2021a).

Approximately 5%-10% of people with mental disorders are more likely to suffer from long-term disabilities (Mathers & Loncar, 2006; Datini et al., 2021). Despite the uncertainty of statistics regarding mental disorders because of a lack of data, particularly from low-income countries, mental disorders are among the leading causes of disabilities worldwide (Datini et al., 2021). However, the number of mental disorders is suspected to have increased due to the Covid-19 pandemic in 2020. Although support and prevention programs are provided to people, most cannot access mental health services (WHO, 2022a). Psychiatric disorders (bipolar and schizophrenia) are classified in the top five mental disorders prevalence after depression and anxiety; in 2019, the prevalence of bipolar was 0.3-1.2% with an average of 0.65 which about 46 million people diagnosed with bipolar disorder, and 24 million people with schizophrenia, the prevalence was 0.2-.04% with average about

0.3% cross the countries (Rehm & Shield, 2019; Dattani et al., 2021; WHO, 2022a). Mental disorders are associated with different factors, such as psychosocial stressors, cultural, individual factors, and environmental factors, which affect the functioning and productivity of individuals who need effective treatment and prevention programs (American Psychiatric Association, 2013; WHO, 2021a; WHO, 2022a). Despite the global awareness of mental disorders and their associated disabilities, a report by the WHO (2022b) on mental disorders stated the urgent need to reform mental health attitudes, actions, and treatment approaches in mental health care. For example, a small percentage of people with psychotic disorders who needed mental health services had access to it across the globe, while the majority (71 %) did not have access to these services, and about 12% of them were from low-income countries. However, the treatment of mental disorders is challenging across the globe because of stigma and discrimination, which impact medication-taking behaviour (WHO, 2022a).

Medication taking is essential in the treatment of major psychiatric disorders such as schizophrenia or bipolar disorder but challenging; nearly 50% around the world do not take their medicines as prescribed. This phenomenon is not new (WHO, 2003; Chapman & Horne, 2013). Likewise, in the Middle East, including Jordan, about 40%-60% of people diagnosed with severe mental illness, including bipolar disorder and schizophrenia, do not take their psychiatric medications as prescribed (Alhalaiqa et al., 2016; Mukattash et al., 2016; Mehralian et al., 2019; Al Maqbali et al., 2022).

1.2 Background (Jordanian context)

The geographical location of the Hashemite Kingdom of Jordan lies in the Middle Eastern countries to the northwest of Saudi Arabia, between the Palestinian territories and Israel to the west, Iraq to the northeast, and Syria to the north (World Atlas, 2015b; Central Intelligence Agency, 2020). According to the World Bank Income Group classifications, Jordan is considered an upper-middle-income country (World Bank, 2023b). With a total area of 89,318 square kilometres (Department of Statistics-Jordan, 2023), which is about three-quarters the size of Pennsylvania and smaller than Indiana [United States of America] (Central Intelligence Agency, 2020), Jordan has limited natural resources and is dependent on its ability to import refined goods, gas, and crude oil, the majority of which come from Saudi Arabia, Iraq, and Egypt (Jaber et al., 2004; World Bank, 2023a). Jordan's economy heavily depends on tourism, and the nation is home to several significant historical monuments, including Petra, Jerash, and Ajlun (Fischer et al., 2009). The Dead Sea, the lowest terrestrial region on earth, is unique to Jordan. Travellers from around the world visit these locations. Jordan’s climate mostly ranges between the Mediterranean and arid deserts, with its rainy seasons (November to April), as in Western countries. Temperatures in the northern and southern areas range from 9-13˚ C in winter, while in desert areas, this is 19-22˚ C in the summer, ranging between 26 and 29˚C (Central Intelligence Agency, 2020; World Bank, 2021).

From a total population estimated at 11.3 million at the end of 2022 (Department of Statistics-Jordan, 2023), Jordanian people are estimated to comprise around 8 million, with the remaining population being other nationalities (e.g., Syrian and Iraqi) (Department of Statistics-Jordan, 2016). In its report, Jordan's Department of Statistics-Jordan (2023) states that there has been a 5.3% increase in population based on assumptions of an increased flow of refugees because of unstable conditions in neighbouring countries. The Jordanian population is concentrated around the capital, Amman, which is located in the northwest of Jordan, and a smaller population is located in the southwest, along the shores of the Gulf of Aqaba (Central Intelligence Agency, 2020; Department of Statistics-Jordan, 2023). Jordan is divided into 12 governates, with the greatest population density in the capital, Amman, with about 42% of the population, followed by Irbid in the north, with about 18% of the population, and Az-Zarqa, with 14% of the population (Department of Statistics-Jordan, 2023).

The main religion in Jordan is Islam, and the majority of people there are Muslim, at 97.2% [official; predominantly Sunni], with 2.2% being Christian and other religions making up 0.6% (Central Intelligence Agency, 2020). The primary language is Arabic. Besides this, English is spoken as a second language and is widely understood among the upper and middle classes (The National Mental Health Team, 2010; Central Intelligence Agency, 2020). Mean life expectancy at birth is 75 years, and 74 and 77 for males and females, respectively (WHO, 2019; Central Intelligence Agency, 2020). The vast majority of the population is young, and the proportion of the population aged between 15 and 64 is 69%, and under 15 is 34%, while those 65 years old and above made up 3.7% of the total in 2018 (Department of Statistics, 2018; Central Intelligence Agency, 2020).

1.2.1 Values and Beliefs

The majority of Jordanians are literate adults over 15 years old who can read and write and carry out simple arithmetical calculations daily. The literacy rate (reading and writing) is 96% (WHO, 2017a; Central Intelligence Agency, 2020), divided into the following levels: 54% have less than secondary education, 15% have secondary education, 8% have a diploma (have studied for 2 years in college), and 19% have a bachelor's degree or above, having studied at university for 4 years or more (Department of Statistics, 2018). This reflects that Jordanians prioritise education, and the country is home to several reputable colleges. Jordan is home to a number of eminent academics and specialists in several disciplines (Zahran, 2010; Huneidi, 2014). However, while a large proportion of the population has been to school, college, or university, Jordanians seek health-related help from nonmedical personnel or try to find alternative and complementary medicines, or, as they are called, traditional therapies. Based on a belief in this approach and on heritage, Jordanians may ask advice from older people when they are ill and before they decide to obtain medical assistance, whatever the nature of their sickness. This is linked to the important role of extended families, who are expected to support each other, maintain their heritage, and stabilise the Jordanian culture. In the case of mental illness, patients and their families often prefer to seek traditional treatment rather than referral to psychiatric services because of a fear of social stigma and shame (Osman et al., 1993). There are two main aspects to complementary alternative medicine: herbal remedies and religious treatment.

1- Herbal remedies: Historically, plants were widely used to treat many diseases and are still used today (Wazaify et al., 2013; Mehta & Dhapte, 2015). In Jordan, 60% of the population uses plant-based therapies in a primary role in health and welfare (Afifi et al., 2010). Herbal remedies inherited from ancient ancestors in different areas of the world and Jordan are deeply bound to the beliefs and culture of the Jordanian population (Mehta & Dhapte, 2015). As with many other developing countries, plants are mainly used in Jordan as complementary or alternative medicines (Afifi et al., 2010; Wazaify et al., 2013; Mehta & Dhapte, 2015). Many Jordanians believe in the effectiveness of medicinal plants, which are used to treat a variety of chronic diseases such as cancer (Afifi et al., 2010), Diabetes mellitus (Wazaify et al., 2011), hypertension, chronic kidney disease, dyslipidaemia (Wazaify et al., 2013), mental health problems, and epilepsy (Alzweiri et al., 2011). Besides this, they depend on an herbalist who prescribes plant therapy- with experience in prescribing suitable herbs for their conditions (Alzweiri et al., 2011). People use herbal medicine alone or in combination with their conventional medications, and some revealed that the herbalist advises them to ask the pharmacist if herbal treatments conflict with their medical therapies because herbalists rely on knowledge gained from their ancestors and their work experience, which is not based on a scientific background (Issa & Basheti, 2017). Furthermore, in Jordan, most pharmacists and herbalists believe in herbal medicines, and they are widely used. However, these groups need more training and information from agencies specialising in herbal treatments to prescribe the right therapy and treatment to their customers Basheti et al., 2017). Pharmacies in Jordan are broadly distributed across country areas, and therefore, individuals seek help and medical advice from a pharmacist before they seek assistance from a medical specialist or physician after they seek traditional treatments. The pharmacist's role is to provide a variety of prescription and non-prescription medications, as well as cosmetic and medical equipment (Nazer & Tuffaha, 2017). However, there is a belief that the pharmacist's role is unclear and unsatisfying to individuals' expectations (Mukattash et al., 2018). This leads them to consult their religious healer in addition to the pharmacist.

2- Religious treatment: religious rituals and religious healers are common in Arabic world culture and used for the explanation of mental health problems by Muslims and Christians (Al-Sabaie, 1989; Al-Habeeb, 2003). Muslims strongly believe in Islam's teachings. However, Jordanian belief in supernatural powers such as jinn (spirits) and magic is strong for many reasons. Firstly, these are mentioned in the Quran. Secondly, beliefs are passed from the older generation (Al-Habeeb, 2003). Finally, 90% of followers of other religions across the world believe in the evil eye and the supernatural as causes of mental disorders (American Psychiatric Association, 2013).

Moreover, psychiatric symptoms depend on the cultural background of the individual and differ from culture to culture, in which symptoms considered to demonstrate mental disorders in one culture may be considered normal in another culture (American Psychiatric Association, 2013; Koelkebeck et al., 2017). Understanding the psychiatric symptoms from a cultural point of view is essential to help understand the sociocultural factors that impact psychiatric disorders and influence the onset and development of the disorders (Koelkebeck et al., 2017). This explains the delay in seeking help in some cultures.

However, a recent study in Jordan found that people with strong spirituality (faith, beliefs, and behaviours) have a lower prevalence of psychosomatic symptoms (Nawafleh et al., 2018). Similarly, studies conducted in the Middle Eastern countries of Iran and Kuwait found that religious activities relieve anxiety and depression and are considered the main factors of happiness and mental health well-being (Vasegh & Mohammadi, 2007; Abdel-Khalek, 2010). In Jordan, both Muslim and Christian individuals may visit a religious healer, and most males and females attribute the cause of their psychiatric illness to Allah's will, God's hands, the evil eye, or evil spirits. They use traditional terminology for some of these supernatural powers, such as *Darbah* (an attack of evil spirits) or *Hasad* (evil eyes). *Hasad* and *Darbah* are commonly used by women and less by men (Al-Krenawi et al., 2000). Muslims' use of *Dua'a* (praying and supplication to Allah) and reading of the Holy Quran by a sick person or healer (a person who reads the Holy Quran (Sheikh)) before or during medical treatment (Eltaiba & Harries, 2015). Also, Christians visit the tombs of saints to ask for help and relief for their symptoms (Al-Krenawi et al., 2000), andray (Koenig, 2009). However, women are less represented in seeking psychiatric assistance, and this is explained by fear of social stigma, which includes threats to their marriage (such as through divorce) or negative consequences for their family (with effects on their daughters and sons, such as the potential for them to remain unmarried). This leads them to seek other nonmedical modalities (Al-Krenawi et al., 2000; Okasha, 2003), irrespective of the availability of health services and mental health settings in the country and their catchment areas.

1.3 Health System in Jordan

Jordan is widely regarded throughout the Middle East for its high-standard medical facilities and medical tourism. Despite this, Jordan experiences a shortage of hospital infrastructure similar to that in other underdeveloped nations due to its low economic standing, despite having a solid medical reputation and an excellent healthcare system relative to other Middle Eastern countries (Sawalha, 2017). The regulatory body in Jordan is the Ministry of Health (MoH), managed through the High Health Council, which is responsible for law formulation and regulations headed by the Minster of Health (National Human Resources for Health Observatory & High Health Council, 2018)

The health system in Jordan has four major categories: public, military, private, and international charities.

- Public sector: Consists of the Ministry of Health (MoH), University Hospitals (UHs) such as Jordan University Hospital (JUH), King Abdullah University Hospital (KAUH), and the National Centre for Diabetes, Endocrinology and Genetics (NCDEG)
- Military Sector: Provided by the Royal Medical Services (RMS) and its branches nationwide.
- Private Sector: Includes all private hospitals and clinics.
- International and Charity sectors: Provide services via UNRWA (United Nations Relief and Works Agency for Palestine Refugees in the Near East), NGOs (Non-Governmental Organizations), and the King Hussein Cancer Centre (KHCC) (see Table 2: Main Health Sectors in Jordan) Adapted from (Higher Health Council & WHO, 2015; The National Mental Health Team, 2010).

Table 2: Main Health Sectors in Jordan

Jordan's Health Sectors			
Public	Military	Private	International and charity agencies
MoH UH NCDEG	RMS	All private hospitals and clinics	UNRWA NGOs KHCC

The total number of hospitals in Jordan is 120, distributed as followings: public hospitals account for 31 hospitals and many primary care centres, which provide health services for the majority of Jordanians, as well as Syrian refugees: two university hospitals, which support the public hospitals and provide services for Jordanian and non-Jordanian patients, and one the National Centre for Diabetes, Endocrinology and Genetics which is mainly concerned with diabetic patients. The military hospitals also support the public hospitals but are more concerned with officers and Jordanian armed and security personnel and their families. The largest contributor to the number of hospitals is the private sector, which includes 70 hospitals across the country (Department of Statistics-Jordan, 2023). These facilities provide a wide range of services for the Jordanian population based on health insurance, of which more than 80% are covered (National Human Resources for Health Observatory & High Health Council, 2018). For this study, mental health will be the main sector discussed next.

1.4 Mental Health System

The rising population in recent times, in addition to the continuous flow of refugees because of conflicts and instability in neighbouring countries, initially Iraq and, lately, Syria, have increased demand for health services, particularly in mental health. This is due to increased life stressors and psychosocial burden, in which war and psychological stressors have also increased the vulnerability of the population to mental health problems (WHO, 2017c; Ministry of Health, 2011; Higher Health Council & WHO, 2015). The sections which follow will detail the prevalence and incidence of mental disorders in Jordan, the chronological development of mental health services, community-based services for mental disorders, outpatient facilities, inpatient facilities, and day treatment units in Jordan.

1.4.1 Prevalence of the mental disorders:

The prevalence of Mental disorders is 13% of people worldwide. This means that one in five people have a mental disorder during a certain point in their lifecycle (Ritchie & Roser, 2018). A report by the WHO estimates that there are nearly one billion people in the world suffering from mental disorders (WHO, 2022), which contributes to 14% of the global disease burden and 31% of global disability from non-fatal diseases (The World Bank Group & WHO, 2016). In Jordan, scant data are available on the prevalence of mental illness. A study conducted in Irbid to the North of Amman in Northern Jordan looked back at patient records between 1984 and 1993 for those visiting the psychiatric clinic at Prince Basma Hospital aged 22-44 years. They found that the most common psychiatric diagnosis is schizophrenia (20%), which affects males more than females, followed by bipolar affective disorder (15%), which affects females more than males. However, in the last year, records showed that there was an increase in anxiety disorder, affecting most of the people visiting the clinic, and this could be because of the Gulf War in 1990-1991 (Zaidan et al., 2000).

Moreover, a previous study conducted in 1997 revealed that 60% of people in primary health care centres had mental disorders; this result is comparable with the highest result in developed countries, which is 63%. The study explained this based on the long-term psychological consequences of the Gulf War, which had lasted about one year at that time (Al-Jaddou & Malkawi, 1997). Additionally, psychiatric comorbidities among women in Irbid City were estimated at 26%, and psychological distress at about 39%, and this is associated with sociocultural factors such as family violence, marital status (divorced, widowed, or separated), lack of social support, or a violent marital relationship (Daradkeh et al., 2006). Recently, in their study, Ritchie and Roser (2018) found that the prevalence of mental health and substance use disorders across Middle Eastern countries was as follows: Jordan, Egypt, and Syria, 15 %; Saudi Arabia, Bahrain, Qatar, Kuwait, Oman, Iraq, Turkey, and Cyprus, 14 %; Lebanon and Yemen, 16%; The United Arab Emirate and Pakistan, 13%; and Iran, 18%. Regarding Jordan, this result is similar to a previous study in 2008, in which the Jordanian Psychiatric Team detailed that the prevalence of mental health problems in Jordan stood at around 15-20% of the general population (Hijiawi et al., 2013). Furthermore, the government indicates that there is a high prevalence of mental health problems, such as depression and developmental disorders, with no clear picture or precise information provided about this (Hijiawi et al., 2013).

1.4.2 Chronological events in the development of mental health services in Jordan

- In 1960, the first ward for mental health was established by the RMS (military hospitals which serve military personnel and their dependents) in Marka City, which is located to the North of the Capital, Amman). It had a total capacity of 30 beds, which were initial mental well-being assessments for new army personnel.
- In 1968, The Ministry of Health founded a specialized hospital, The National Centre for Mental Health (NCMH), at Al Fuheiss (North of the capital Amman), with a total of 60 beds (Hijiawi et al., 2013).
- In 1976, the psychiatric unit moved from Marka Military Hospital to King Hussein Medical Center (KHMC) in Amman, and the bed capacity increased by four to 34 beds.
- In 1988, NCMH began to provide mental health services for Jordanians and developed a mental health plan to improve significant areas, first, serving Jordanians with acute psychiatric problems in the inpatient unit and providing outpatient clinics for follow-up treatments and prescribing medications. Second, this formed a specialized area to train doctors, medical students, nurses, and other health professionals to be more skilled in dealing with mental health problems and patients.
- Later, in 1997, the psychiatric unit at KHMC moved to Marka Military Hospital (MMH) again, not as a unit but as a separate mental hospital to serve military personnel and their families. This was partly due to developments and the extra beds needed at KHMC to meet the needs of the growing population. This development formed the main mental health milestone from007 (Hijiawi et al., 2013; Higher Health Council & WHO, 2015).
- In 2007, when development had slowed in the mental health sector after the Iraq war, the burden in this area increased. Collaboration between United Nations (UN) agencies and NGOs was established (with more than 50 local and global agencies) to provide social support and train the staff, with the backing of the World Health Organization as technical advisors, which began in 2008 (The National Mental Health Team, 2010; Hijiawi et al., 2013).
- In 2012, the first psychiatric inpatient unit was established at a university hospital (KAUH), with a ten-bed capacity.
- In 2014, the second psychiatric inpatient unit at a university hospital (JUH) was opened, with a 12-bed capacity. This was supported by the WHO and aimed to decrease social stigma through integrating mental health services within general hospitals (Higher Health Council & WHO, 2015).

1.4.3 Community-based Mental Health Services

Community mental health services in Jordan are provided by the Ministry of Health, Royal Medical Services, University Hospitals, and the private sector (i.e., Al Rashid Hospital) as the main health sectors. These predominantly serve the capital (around 36% of Jordanians), and community services for the rural areas are still challenging. As discussed above, many people in these areas turn to alternative solutions, such as religious healers and herbalists. The further high cost of mental health services in the private sector and a lack of health insurance to cover this area exacerbates the problem (The National Mental Health Team, 2010; WHO,2011; Higher Health Council & WHO, 2015). Recently, the MoH, in collaboration with WHO, has developed community mental health centres to provide a multidisciplinary team (including psychoeducation, home visits, and awareness of community activities to reduce stigma). These centres serve approximately 5,500 individuals from all nationalities, including Jordanian, Syrian, and Iraqi, and about 150 children and adolescents monthly (WHO & MoH, 2018). Community-based mental health centres are distributed across Jordan.

1.4.4 Community Outpatient Clinics

There are 64 outpatient clinics to serve all patients in Jordan, including those in the private sector, while the majority are under the control of the Ministry of Health. Thirty-seven clinics integrate mental health services with other community hospitals: 7 are run by RMS, 8 are UHs, and 12 are private sector hospitals (The National Mental Health Team, 2010; WHO,2011; Higher Health Council & WHO, 2015).

However, while these entities are under the Ministry of Health, their diagnostic criteria are not unified. Alfar, National Professional Officer for Mental Health at the World Health Organization Office in the Jordan Country office (16/05/2019) [Personal communication via e-mail] states that diagnosis of mental disorders in Jordan is based on the Diagnostic and Statistical Manual of Mental Health (DSM-5) and the International Statistical Classification of Disease and Related Health Problems (ICD-10) as main handbooks, as well as the knowledge developed through observation in the field of mental health. DSM-5 is a handbook used by mental health professionals as a reliable source to guide them through the diagnostic process and includes diagnostic criteria for mental health problems, such as definitions, signs and symptoms, durations, and other measures. It is widely used across the world, and each disorder has a code (e.g., Schizophrenia is 295.90[F20.9], bipolar type disorders are 295.70 [F25.0]) (American Psychiatric Association, 2013). ICD-10 is a handbook that includes codes of diseases and diagnostic criteria for various health problems and contains mental health problems and classifications. Mental health and behavioural disorder codes run from F00-F99, Schizophrenia is coded F20, and bipolar affective disorder is F31 (WHO, 2016a).

These two handbooks are used based on the institution and person, or they could use both. However, the precise percentage prevalence of mental disorders remains unclear.

In Jordan, the WHO and MoH conducted a study in 2010 which showed the number of patients treated in outpatient clinics. This translated to 305 people per 100,000 Jordanians, with 39% female and more than half male, with an exact estimation of the number of children and adolescents unavailable. The diagnostic distribution of patients treated at outpatient facilities at MoH was as follows: 52% of individuals were diagnosed with schizophrenia and related disorders, followed by one-third (36%) with mood disorders (i.e., depression, bipolar disorder, and mania), and lastly, 12% with other mental disorders (stress-related disorders, somatoform disorders, substance abuse disorders, neurotic disorders, epilepsy, mental retardation, etc.). In comparison, across other service providers (RMS, UHs, and the private sector), 10-20% of patients treated in outpatient clinics were diagnosed with schizophrenia and related disorders, while 50% were diagnosed with mood disorders, including mania, depression, and bipolar disorders, and 20-25 % were diagnosed with anxiety disorders (WHO, 2011).

In the same year, 2010, the National Mental Health Team investigated the number of patients in mental health services and their diagnoses for Irbid City (located to the North of Amman). Outpatient clinics were randomly selected with a sample size of 350 patients over a week at seven outpatient clinics: two for MoH, one for RMS, one for KAUH, and three private clinics. The team found that around 49% of patients were diagnosed with schizophrenia and related disorders, followed by 29% with mood disorders, 10 % with anxiety disorders, 1.5% with substance abuse disorders, 2.5% with personality disorders, 4.5% organic disorders, and 4% with other mental illness.

Regarding adolescents and children, mental health services are provided by three outpatient clinics across the country, with two RMS-run clinics in Amman and Irbid and, for severe cases, one in JUH in Amman (Ministry of Health, 2011). The number of patients visiting outpatient facilities has recently increased from 280 (in 2011) to 827 (in 2017) individuals per 100,000 thousand Jordanians. This reflects population awareness and understanding of mental health problems and treatments, which contributes to decreasing the social stigma that delays treatment and raises the burden of mental disabilities, as well as the availability of mental health services across all of the country's regions (WHO, 2017d).

1.4.5 Community Inpatient Services

Inpatient mental health is provided through seven major hospitals, three operated by the Ministry of Health. The main lead and most significant mental hospitals are NCMH, in addition to Alkarama

Hospital for Psychiatric Rehabilitation (AHPR), and the National Centre for Rehabilitation of Drug Addicts (NCRDA). Two further centres are University Hospitals, which are JUH and KAUH. One hospital, a psychiatric unit in Marka Military Hospital, is under the supervision of RMS, and one mental health centre is supported by the private sector: AL Rashid Hospital (Higher Health Council & WHO, 2015).

The capacity for beds varies among these institutions, all located around the capital and urban areas (WHO,2011). For MoH, the beds are distributed as follows: 265 beds in NCMH, with a forensic section inside the centre; 150 beds at AHPR, mainly serving male patients for psychiatric rehabilitation purposes; and up to 40 beds for NCRDA WHO, 2015). Besides these, a mental health unit with a capacity of 15 beds is provided at Ma'an Government Hospital (located sth of the capital Amman) (WHO, 2016b). The MoH inpatient facility serves 45 patients per 100,000, and most diagnoses were for schizophrenia in both inpatient and outpatient facilities, with a 97% occupancy rate (Ministry of Health, 2011).

The military Sector provides mental health treatment through the psychiatric unit in Marka Hospital, with a total capacity of up to 43 beds, and the private hospital Al Rashid provides 120 beds for all Jordanians and other Arab nationalities (Higher Health Council & WHO, 2015). University hospitals (KAUH and JUH) provide inpatient psychiatric units with ten beds and 12 beds, respectively. These have no beds for children, but in JUH, inpatients treat adolescent patients of 15 years old and above. Fifty per cent of inpatient admissions were diagnosed with schizophrenia and related disorders, and thirty-five per cent were diagnosed with mood disorders (The National Mental Health Team, 2010; WHO,2011).

1.4.6 Community Day Treatment Facility

There is a one-day treatment facility under the care of NGOs which provides mental health services, as well as training staff and offering psychosocial services in other facilities it has. The facility treats 29 individuals at a time (approximately 0.52 per 100,000 Jordanians). However, this day unit has no treatment for children or adolescents. About 14% of patients are female (The National Mental Health Team, 2010; Ministry of Health, 2011).

1.4.7 Health Insurance Availability

Treatments and services are free of charge at Ministry of Health facilities for all Jordanians (WHO, 2011; Higher Health Council & WHO, 2015). In terms of the accessibility of psychotropic medications, 86% of Jordanians are covered by health insurance, whereas uninsured Jordanians are able to buy their psychotropic medication from the Ministry of Health and pay just one-third of the total cost of medicines because the government partly covers them, and therefore they are still cheaper than through private pharmacy (WHO, 2011; Higher Health Council & WHO, 2015). Moreover, non-Jordanians such as displaced Iraqis, Palestinian refugees, and Syrian refugees have no entitlement to free mental health care and medication services because contracts between the Ministry of Health and international agencies are not broken down with sufficient information about this (WHO, 2011).

MoH serves the general population at 44%, then RMS at 27%, while university hospitals, private hospitals and UNRWA serve 1.3%, 6.9%, and 6.8% of the general population in Jordan, respectively. The 14% of uninsured can access the private hospital or university hospital from their pocket or based on their company’s insurance coverage. It is common for Jordanian people to hold one or more health insurance policies, while patients who have MoH insurance cannot be treated in RMS facilities (WHO, 2016b).

1.4.8 Mental Health Workers

Mental health workers per population have remained unchanged globally since 2013, at 9 per 100,000 people (WHO, 2018). In Jordan, estimations of mental health workers are less than international estimates, at 7 per 100,000 people. In 2011, there were 1.09 psychiatrists, 0.54 medical doctors not specialized in psychiatry and 3.95 nurses (not dedicated to the mental health field) per 100,000 population, with just 0.27 psychologists and approximately 0.39 social workers and occupational therapists per 100,000 (MoH, 2011). However, in 2017, estimations of mental health workers were 5.91 per 100,000 Jordanians, with specializations in mental health broken down as follows and compared with 2011 estimates: 1.12 psychiatrists (compared to unspecialised medical doctors), 3.3 mental health nurses (compared with general nurses in 2011), 1.27 psychologists, and .22 social workers per 100,000 Jordanians, with other mental health workers not reported (WHO, 2017d).

1.4.9 Mental Health Expenditure

Jordan expects total health expenditures in 2011 to be 9.8% of the gross domestic product (GDP). (WHO, 2011). Financial support and budget for mental health are not identified (MoH, 2011; WHO, 2016b). However, while the central budgets for mental health come from the Ministry of Health, which is the leading supporter of mental health services in Jordan, noticeably, RMS expenditure on mental health is higher than the MoH because of the support of His Majesty King Abdullah II (WHO, 2011). However, for both sectors, most of these finances merely go to community health services and general hospitals, with a few going to mental health hospitals (WHO, 2011; WHO, 2017c). The

Higher Health Council and WHO (2015) identify the mental health budget as a barrier contributing to the slow development of mental health services. As well as a shortage of mental health workers this could be due to negative attitudes toward mental health such as social stigma, low incentives for mental health workers in comparison with other medical fields, and attractive offers in the Gulf States.

1.4.10 Mental Health Policy Developments

Until recently, no mental health policy unified the mental health stakeholders in Jordan. In addition, the public sector for mental health depends on biomedical treatments, with few focusing on psychosocial and community aspects (WHO, 2016b). General health policy is developed by the Higher Health Council, a body that promotes health policy nationwide and synchronises with other sub-sectors (i.e., RMS, UH, the private sector, etc.). The MoH is chosen by public law to be the legal authority for professional and health institutions in Jordan, working in collaboration with other national councils and health bodies (such as the Doctors' Union, Jordanian Nursing Council, Jordanian Medical Council, and Higher Health Council) to set, monitor, and implement health laws (The National Mental Health Team, 2010; Higher Health Council & WHO, 2015). Generally, until 2011, no general mental health policy unified all sectors, and each sector was considered a separate unit with its roles and policies (Hijiawi et al., 2013).

Mental health services in Jordan are restricted to mental health hospitals, not focusing on primary care services, which are more cost-effective (Ministry of Health, 2011). The Mental Health and Psychosocial Support Group (MHPSS) was established in 2007 as a result of the response to the arrival of Iraqi refugees in collaboration with NGOs and UN agencies, under the leadership of MoH, to coordinate and implement the Inter-Agency Standing Committee for Mental Health (IACS) in Jordan, to set minimum mental health standards (Hijiawi et al., 2013).

- In 2008, a collaboration between the Jordanian Ministry of Health and the World Health Organization, with the partnership of the Jordanian Nursing Council, led to the initiation and establishment of the National Steering Committee for Mental Health as a national institution to meet the mental health needs of Jordanians and refugees, and to reform mental health policy and systems (WHO & MoH, 2018). The main aims of this committee were:

1. Development and formation of a policy plan for mental health.
2. Organize and apply mental health services in the community.
3. Establishment of family-based interventions.

The committee members consist of those in the country's allied government and non-government entities (members of the Ministry of Health, Ministry of Social Development, Ministry of Higher Education, Royal Medical Services, University Hospitals, NGOs, and mental health professionals from the private sector). The committee was funded and supported by the World Health Organization Country Office (Hijiawi et al., 2013; WHO, 2011). In the same year, three outpatient departments were established (WHO, 2011). The National Steering Committee for Mental Health was concerned to achieve the following:

- In 2009, training for mental health workers, including a workshop on human rights and mental health, was held in Jordan as supported by the WHO, and the trainees were varied, including mental health professionals, family members, and service users (mentally ill patients). The Inpatient Model Unit was established in NCMH and supported by the Jordanian Nursing Council, MoH, and WHO (Hijiawi et al., 2013). The World Health Organization developed a Mental Health Action Plan at its first meeting in 2009, with the primary goal of providing guidelines for mental health during the upcoming years; the aims of this meeting were:
    1. Improve mental health care provided to the patient.
    2. Decrease stigma.
    3. Develop the role of the governorates to lead changes in mental health.
    4. Explore and implement a strategy to improve the mental health sector in developing countries.
    5. Collect reliable, giant-sca data regarding mental health around the globe (Hijiawi et al., 2013).
- Jordan was selected among six countries to implement the Mental Health Gap Program (mhGAP) as a pilot study in 2010. The same year saw the establishment of an association of individuals affected by mental health problems called "Our Step", which includes members from the MoH and WHO, mental health professionals and service users (patients) to encourage mental health in the community, decrease social stigma and raise insight into the importance of mental health (Hijiawi et al., 2013).
- In 2011, the first mental health policy was launched.
- Also, in 2011, new inpatient mental health units were opened, with the first unit in the university general hospital KAUH in North Jordan.
- Regular workshops for training mental health workers in implementing mhGAP to make it suitable for the social context (Hijiawi et al., 2013), and this includes training for general

health workers and social care staff within military, university, and MoH hospitals and centres (WHO, 2016b).

- In 2012, the first inpatient unit in a MoH hospital began its work in Ma'an, in the South of Jordan (Hijiawi et al., 2013). These units are established to improve access to mental health services for the community in rural areas. However, the occupancy rate for this unit is still low, at 35%-60% per month, and this is because of social stigma and discrimination in the South of Jordan toward mental illness, with the family preferring to send their patients out to Amman to avoid this discrimination within their society (WHO, 2016b).
- In 2014, new inpatient units were found in JUH, in Amman (Higher Health Council & WHO, 2015).

1.5 Mental Health Gap Program

The effort to improve and increase awareness in the mental health sector is occurring not only in Jordan but also in all countries around the globe. The World Health Organization, in its Health Assembly 66, adopted a holistic mental health plan for 2013-2020. This action plan contains global indicators to measure the implementation of the mental health plan across the members' countries, most of which have now developed policies and legislation depending on international human rights and further developed prevention programmes and training in mental health. Despite a growing focus on mental health across the world, the availability of mental health in low-middle-income countries is considered limited. Additionally, the ratio of mental health workers globally is still fixed at 9 per 100,000 population (World Health Assembly, 2018).

The Mental Health Gap Action Program was developed to:

- Improve mental health services in low-middle-income countries.
- Decrease the burden of psychological and neurological health problems.
- Focus on psychosocial interventions for both the mental health team and non-mental health team (general hospital) in further training.
- Assessment of and interventions for mental health and neurological problems. As a result, it will serve in early diagnosis and cost-effectiveness (Hijiawi et al., 2013).

The World Health Organization developed the Mental Health Gap Action Plan Intervention Guide (mhGAP-IG), and this includes a training programme for medical health workers who are not specialized in mental health and can be used in the community centre for early detection of mental neurological and substance abuse health problems through evidence-based guidance (WHO, 2017b).

The collaboration between the WHO, MoH, and other mental health streams in Jordan is to integrate a mhGAP programme to maintain an ongoing development process in the mental health sector. Moreover, there is a focus on the community care level rather than the psychiatric hospital, whereas, in the past, most of the mental health budget was focused on mental hospitals rather than community centres. As well as this, a collaboration between mental health professionals and other disciplines such as social work and physiotherapy is recommended, in addition to increasing the health promotion programme and psychosocial therapy, since most countries around the globe do not yet have such programmes functioning (WHO, 2017c). Activities for the mhGAP programme include training of trainers, supervisors, and identifying the role of nurses in primary health care centres and providing psychosocial training for them, besides encouraging collaboration between doctors and nurses (WHO, 2016b).

The World Health Organization maintained its role as the primary support for the MoH in developing the Mental Health Plan 2018-2020. The WHO Road Map, developed based on the Mental Health Gap Action Program 2013-2020 and the Eastern Mediterranean Regional Committee framework in 2015 (WHO, 2016b), contains recommendations summarised as follows:

- Continuing stakeholder efforts to support and strengthen governance development in mental health policy.
- Integrate mental health services into community-based centres rather than hospitals.
- Focus on involving and empowering service users (patients) and their families in the policy reform process.

The WHO (2016b) highlight six main points as a challenge in the policy reform process:

- Resistance to shifting from biomedical treatments to psychosocial and community-based approaches.
- Stigma toward mental health professionals.
- Lack of health care staff working in mental health services.
- Lack of financial support.
- High turnover of MoH nurses and doctors.
- Regional crises and conflicts in Jordan’s neighbouring countries affect the programme priorities and directions.

Leading solutions for these challenges are to:

- Focus on intensive investment in a multidisciplinary team at community-based centres.

- Identify other sources of support, such as donors.
- Find support from other ministries and the Royal Family.

Despite the WHO's efforts to improve mental health services in the country, these are still limited. Mental health services and psychosocial support remain needed in the area of interventions and support for both Jordanians and refugees. Refugees' children suffer from psychological problems such as a high level of anxiety and fear, while behavioural problems are noticed in boys and emotional difficulties in girls (WHO, 2016b). Moreover, notwithstanding the efforts of mental health stakeholders to improve health literacy in mental health across all areas in the country and to improve health-seeking behaviour for mental health problems, stigma is still one of the main challenges here, and people refuse to ask for or to be identified as beneficiaries of mental health services. As a result, mental health literacy[1] is still needed to raise awareness across all areas of the country and all different age groups, and education programmes such as psychosocial programmes are needed. Such a programme should be integrated into the school curriculum as regular material such as math, science, etc., by collaboration between the Ministry of Health and the Ministry of Education (WHO, 2016b).

The main points for mental health services from the service user's (patient’s) point of view identified by the World Health Organization (2016b) are:

- No definite diagnosis is provided in most cases.
- There is not enough time with patients.
- Treatments depend on medication without explaining its side effects or role in relation to the disease.
- Confidentiality is still needed (patient information is shared with doctors and people coming in and out of the room).
- Mental health rehabilitation.
- Lack of job opportunities for mentally ill patients
- Lack of quality of care in MoH centres.

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[1] It’s “Knowledge *and beliefs about mental disorders which aid their recognition, management or prevention*” (Jorm et al., 1997. 182)

- More support groups which focus on the psychoeducation and psychosocial support approaches are needed. Besides, training should be provided for patients and their families about coping strategies and mental disorders.

In conclusion, the mental health system in Jordan still needs support. In addition, misunderstandings of mental health illnesses in Jordan and the stigma attached to being identified as mentally ill leads to a worsening of the problem over time and results in delayed diagnosis as well as the treatment provided and in patients not taking their psychiatric drugs. The diagnosis criteria must be clearer and more relevant for all institutions and hospitals.

To the best of the researcher's knowledge, there is limited literature regarding the prevalence and incidence of mental illness in Jordan and scant literature that explores the reasons for not taking medication among people with schizophrenia and bipolar disorders. Medication-taking behaviour will be discussed next.

1.6 Medication-taking behaviour.

Various terms are used to describe medication-taking behaviour in the literature, and these terms have developed over time. These terms are compliance, adherence, concordance, and shared decision-making.

The terms “adherence” and “compliance” both refer to a patient's medication-taking behaviour and are used interchangeably or as a synonym with each other (Esposito, 1995; Crespo-Fierro, 1997; Bissonnette, 2008; Cramer et al., 2008; Barbosa et al., 2012). The term “concordance” is not related to medication-taking behaviour as with compliance or adherence but refers to the interaction between patients and health care providers. Concordance means that the patient has the right to negotiate with clinicians or healthcare providers about the treatment plan or medication and has the right to accept or refuse treatment (Bell et al., 2007). This term led to another term, which is “shared decision-making”. This focuses on the patient's understanding of the problem and right to discuss the risks and benefits of the treatment plan and to ask related questions to find out the best solution or choice with the healthcare provider(Ryan & Cunningham, 2014). The difference is that concordance gives patients the right to accept or refuse a treatment, while shared decision-making depends on sharing information between healthcare professionals and patients to provide a better understanding of the treatment process and regimen, which gives the power to the patient to make the decision. This section will discuss these terms, their historical background, definitions, and use in the literature.

1.6.1 Compliance:

Compliance was discussed from the nursing perspective in the early 1970s by Marston, a nurse author, who encouraged nurses to understand more about the term to enable them to educate people on how to take care of their health when a healthcare professional was not directly supervising them (Marston, 1970). After that, a variety of compliance definitions emerged in nursing literature. Nursing authors discussed compliance from other perspectives, as rather than referencing paternalism or coercion, they considered it as an active process of care in which the individual works to maintain his/ her health in close collaboration with health care personnel, who in turn encourage the active role of patients, who participate in their treatment plan (Baer, 1986; Brown & Grimes, 1995; Hentinen & Kyngäs, 1996).

In their literature review, Murphy and Canales (2001) showed that nursing authors discuss compliance in nursing from three perspectives: evaluative, rational, and acceptance. First, from an evaluative perspective, authors are concerned with the ethical consequences of compliance, and issues such as paternalism arise. They conclude that such a term does not include the nursing profession or reflect the nurse-patient relationship. Secondly, from the rational perspective, while the negative connotation of compliance is acknowledged and the term critiqued, these authors still use the term when appropriate. Third and finally is acceptance, in which nursing authors accept the term without offering critiques and, irrespective of the controversial debate, they go ahead with interventions that improve patient compliance and discuss the importance of the nursing contribution in improving patient compliance.

Compliance as a term in medical literature needs to be operationally defined to enable researchers to quantify it. Compliance is operationally defined as *“the extent to which a patient acts in accordance with the prescribed interval and dose of a dosing regimen*.” For example, a medication prescribed to be taken once daily or 12 hours apart for twice-daily doses (Cramer et al., 2008: 46). There are various methods to measure compliance, including 1) interview with the patient; 2) serum level of medication; and 3) pill count (Fletcher et al., 1979: 635). Fletcher, Pappius, and Harper (1979:635) state that an interview is the most common way of measuring medication compliance, in which the patient could be asked about their medication regimen (such as missing doses, forgetting doses, skipping doses, and frequency). Objective measurements include electronic pill count systems (Blalock & Patel, 2005; Biderman et al., 2009; Miasso et al., 2009; Dréno et al., 2010; Alikari & Zyga, 2014). A patient may be considered fully or acceptably compliant with the medication regimen when 80% of medications are taken. However, this percentage depends on the nature of the disease and the medication’s properties (Leslie et al., 2008). When this percentage falls below 80% to as low as

50%, the patient is considered partially compliant or non-compliant, based on the type of treatment (Leslie et al., 2008; Cramer et al., 2008).

Healthcare providers should consider the complexity of treatment regimens and the psychosocial traits of patients, such as social support and insight (Pijnenborg et al., 2013) [Insight is defined not only in terms of people's understanding of their illness but also in terms of understanding how the illness affects individuals' interactions with the world (Markova and Berrios, 1992)], and emotional states such as depression (Hardeman et al., 2010; Chakrabarti, 2014). On the other hand, some patients prefer that their doctor lead their decisions on treatments and medication. However, a growing body of literature has moved toward a partnership approach in making choices (Cushing & Metcalfe, 2007; De las Cuevas et al., 2012). Moreover, compliance is viewed as one-way communication between healthcare providers and patients, and this negatively affects the patient's autonomy and decision-making, thus leading patients to a maladaptive relationship with the treatment plan and non-compliance. Also, when patients fail to take prescribed medication as the physician orders or forget to take medications, this is considered non-compliant (Blalock & Patel, 2005; Bell et al., 2007; Miasso et al., 2009; Biderman et al., 2009; Dréno et al., 2010; Chakrabarti, 2014).

Jin and colleagues' (2008:274) qualitative literature review between 1970-2005 identified non-compliance factors that were categorised into six factors: Firstly, Patient-centred factors (age, ethnicity, gender, educational level, marital status, and beliefs). Patients underdeclared the use of complementary therapy, other forms of treatment, and alternative medicine (Benson & Britten, 2002; Elwyn et al., 2003). Second, therapy-related factors (e.g., route of administration, treatment complexity, duration of the treatment period, medication side effects, degree of behavioural change required, the taste of the medication, and requirement for drug storage), as well as patients' beliefs, motivations, and negative attitudes towards therapy. Third are social and economic factors, such as time commitment, cost of therapy, income, and social support. Fourth are healthcare factors (availability and accessibility). Fifth, Disease factors (dependent on the type of disease and whether chronic or acute), such as impaired insight, are associated with poor outcomes. For instance, people with mental illnesses, such as psychosis, suicidal ideation, and dementia, are at risk of impairment in their mental capacity and competence, affecting their decision-making (Felzmann, 2012; Pijnenborg et al., 2013). Finally, other factors (smoking, alcohol intake, and forgetfulness).

In conclusion, compliance is the oldest term used for behaviour in relation to taking prescribed medication, and although negative aspects of the term have been raised, it is still used in literature, with compliance defined as “the extent to which patients coincide with health care providers’ recommendations by following a diet, taking medication, and changing lifestyle”. Compliance is operationally defined as describing “to what extent patients take their medication as prescribed and can be measured by self-report, pills count, and electronic records”. However, many factors affect patient compliance, including patient-based factors, therapy/ medications, socio-economic factors, health care, and disease/condition factors.

1.6.2 Adherence:

During the 1990s, while compliance remained in the literature but under critique, the term adherence began to appear, and the use of the term compliance diminished as it was replaced by the newer term (National Council on Patient Information and Education, 2007; Hobden, 2006; Chakrabarti, 2014). Aronson (2007) (Editor-in-Chief of the *British Journal of Clinical Pharmacology*) prefers the term adherence, stating that it has a wide range of uses in the growing literature. The origin of this term comes from the Latin word *adhaerere,* which means to keep close or remain constant. However, in psychological and sociological literature, adherence has functioned as an alternative to compliance. Adherence develops the definition of compliance by focusing on the patient's active role in the decision-making process in terms of the therapeutic relationship between healthcare providers and patients. Adherence is "the extent to which patients' behaviour matches agreed-on recommendations from the prescriber" (Barofsky, 1978; Alikari & Zyga, 2014). Adherence is a multidimensional, multifaceted, and complex concept, affected by the patient's self-determination, self-efficacy, autonomy, and communication, impacting the patient’s behaviour and nursing practice (Gardner, 2015).

Adherence, as defined by the WHO, is “the extent to which a person's behaviour – taking medication, following a diet, and/or executing lifestyle changes, corresponds with agreed recommendations from a health care provider" (WHO, 2003: 18). This active role of patients can help them to follow their treatment regimen (Bell et al., 2007; Chakrabarti, 2014). This definition by the WHO is the most common definition of adherence and focuses on the patient-centred approach and not the clinician’s approach. In addition, it involves helping patients to decide what treatment is suitable but not blaming either the patient or healthcare provider for the failure of treatments (Horne et al., 2005; Bell et al., 2007; Bissonnette, 2008; Horne & Clatworthy, 2010; Fraser, 2010; Barbosa et al., 2012; Chakrabarti, 2014; Alikari & Zyga, 2014; American Pharmacist Association, 2020b).

Recently, adherence may be operationally defined as "taking medication concerning timing, dosage, and frequency, correspond with an agreed recommendation of health care provider" (American

Pharmacist Association, 2020a). There are two ways to measure medication adherence: direct and indirect (Horne et al., 2005; American Pharmacist Association, 2020b). It may be directly measured by checking the medication level in serum blood (Fletcher et al., 1979; Horne et al., 2005; American Pharmacist Association, 2020b). However, while this method is most accurate, indirect methods are the most used and measurement tools are varied, including the following. 1) An electronic device such as the Medication Event Electronic System MEMS. This is highly accurate, but the high cost of the device limits its use. 2) Refill rate and information technology depend on pharmacy databases and when fills and refills are done. This is useful for tracking patients electronically if they use the same pharmacy, but unfortunately, this method is unavailable in many countries, and many patients use more than one pharmacy. 3) Questionnaire or self-report, the most common tool for indirect measurement (WHO, 2003; Horne et al., 2005; Fraser, 2010; American Pharmacist Association, 2020b). 4) Pill count. 5) Patients' clinical response to medication (American Pharmacist Association, 2020b). These methods are available and easy to apply, but whatever tool is used, it should meet the basic requirements of psychometric measurements: reliability and validity (WHO, 2003; Fraser, 2010).

Adherence to treatment has different forms, such as full adherence, partial adherence, non-adherence, over-adherence, or selective adherence (Mutsatsa, 2017:27). Full adherence occurs when patients take all prescribed medications as prescribed, while non-adherence occurs when patients decide not to take medication at all or stop medication after an initial period of adherence (Masand et al., 2009; Mutsatsa, 2017:27). When the patient decides to be fully adherent to one type of medication and refuses to take another medication, this is called selective adherence, while partial adherence arises when patients decide to modify or change their dose without referring to the health care provider. Over-adherence occurs when patients overuse medication by taking more than prescribed, such as being advised to take one tablet per day and taking three with the perception that this will give a better outcome (Mutsatsa, 2017:27).

When the patient fails to follow the treatment plan, delays or fails to renew a prescription, skips doses, forgets doses, splits pills, and discontinues medication early: especially for patients who suffer from chronic illnesses (such as asthma, hypertension, diabetes, mental and neurological problems), non-adherence is the expected result, and this leads to poor health outcomes such as relapses, exacerbation of the signs and symptoms of disorders, toxicity and resistance to medication may occur, as well as increased treatment costs (WHO, 2003; Simpson et al., 2006; National Council on Patient Information and Education, 2007; Wong-Anuchit et al., 2019; American Pharmacist Association, 2020a).

Nonadherence can be intentional and unintentional. Intentional nonadherence is affected by patient beliefs, occurring when the patient decides to reject the treatment or modify the dose without clinicians' or healthcare providers' advice, based on their beliefs (for example, not taking medication because it is toxic). By contrast, unintentional nonadherence is affected by the patient's capacity and resources, such as memory deficiencies (e.g. forgetting to take medications and follow instructions), knowledge deficiencies about medication usage, renewing the prescription, or mechanical problems with opening or using medications (e.g. inhalers) (Horne et al., 2005; Atkins & Fallowfield, 2006; NICE, 2009; Biderman et al., 2009; Horne & Clatworthy, 2010; Mutsatsa, 2017:27). The World Health Organization lists factors affecting medication adherence, such as socioeconomic, medication and therapy factors, disease factors, health system factors, and patient factors (WHO, 2003). These factors, in combination or alone, lead to non-adherence behaviour (American Pharmacist Association, 2020a).

In conclusion, adherence is a multidimensional term. The World Health Organization defines adherence as "the extent to which a person's behaviour – taking medication, following a diet, and/or executing lifestyle changes, corresponds with agreed recommendations from a health care provider". Adherence may be measured by various methods such as serum level, questionnaire, self-report, pill count and prescription refill; however, the most common way to measure adherence is by questionnaire and self-report. Nonadherence could happen when the patient fails to follow the instructions for taking medication, forgets doses, or finishes the treatment early. However, adherence addresses the patient's active role in the therapeutic process but does not address this active role from a partnership perspective, such as in concordance.

1.6.3 Concordance:

Concordance is the agreement between the patient and health care provider about the suggested treatment plan and medication, with respect for the patient's beliefs and wishes (Haynes et al., 1979; Royal Pharmaceutical Society of Great Britain, 1997; Dickinson et al., 1999; Horne et al., 2005). The Royal Pharmaceutical Society of Great Britain (RPSGB) were the first body to discuss the term concordance and initiated the website www.cocnordnce.org, which describes the term, stating that concordance was a new approach to prescribing medication and that this approach aims to negotiate with the patient about the treatment and how to take their medication in a way that respects their values, beliefs, and wishes, in order to minimize medication wastage (Royal Pharmaceutical Society of Great Britain, 1997; Dickinson et al., 1999; Hobden, 2006).

Concordance has been defined as “an agreement reached after negotiation between a patient and a healthcare professional that respects the beliefs and wishes of the patient in determining whether and how medicines are taken” (Royal Pharmaceutical Society of Great Britain, 1997; Dickinson et al., 1999; Horne et al., 2005). This definition encourages the partnership between patients and health care providers, in which concordance is a process where health care providers and the patient discuss their views about the treatment and whether the patient will accept the treatment or not (Elwyn et al., 2003; Horne et al., 2005). Concordance reflects the patient's willingness and how far they care about the treatment, and the core of concordance is to improve health outcomes through discussion about treatment choices and their pros and cons, to allocate balanced options with the maximum benefits of medical care. However, the concordance process does not necessarily lead to behavioural changes. For example, after successful negotiation with the patient, the patient could decide not to take the medication or to change the treatment, and the outcome may not be as the healthcare provider expects (Dickinson et al., 1999; Elwyn et al., 2003; Horne et al., 2005; Lehane & McCarthy, 2009; Alikari & Zyga, 2014).

Horne et al. (2005) describe concordance as a term used to describe medication-taking behaviour, while adherence and compliance are used as scientific measurements. Also, they report that concordance is a complex term and a process to achieve a partnership with the patient and encourage decision-making, which refers to the extent to which patients are successfully supported in decision-making about their treatment and taking medication. However, the concordance process aims to identify patients’ views about having to take medication, discuss these views with the patient, inform patients about the pros and cons of taking and not taking the medication, and finally involve patients in treatment decisions over time (Elwyn et al., 2003; Horne et al., 2005). Besides this, the healthcare provider should be aware of factors that affect concordances, such as patients' beliefs, socioeconomic status, people around them, and previous experience (Anderson, Irene, 2013). Furthermore, the term concordance has increasingly been used in recent literature and has a wide range of usage in the European medical community and health science literature (Hobden, 2006; National Council on Patient Information and Education, 2007; Fraser, 2010; Felzmann, 2012; Anderson, 2013; Snowden et al., 2014; Taube, 2016; Ellis, 2018). On the other hand, concordance does not clearly address medication-taking behaviour as with adherence and compliance. Also, it does not consider the conflict that arises between evidence-based medicine and patients’ choices (e.g., when a patient refuses lifesaving measures) (Horne et al., 2005; Bissonnette, 2008; Alikari & Zyga, 2014).

The definition of concordance focuses on effective communication with patients (two-way communication), emphasises their role in the treatment process, respects their autonomy, and suggests discussion between patients and clinicians or health care providers on the goals of the treatment and the means of achieving these goals (Bell et al., 2007; Lehane & McCarthy, 2009; Vuckovich, 2010; Chakrabarti, 2014). When the interaction between the patient and health care provider has failed to establish a therapeutic relationship, non-concordance may occur. In addition, an ethical dilemma arises when healthcare providers introduce a choice that they think is best for the patient, but the patient thinks it is not and will not follow instructions (Bell et al., 2007; Ellis, 2018).

To overcome this dilemma, Fraser (2010), in an editorial article, suggests that patients who understood more about their medication would take it despite the number of medications prescribed or their side effects. In addition to this, concordance is concerned with prescribing medication upon agreement between two parties, appearing to form a bridge to medication-taking behaviour, through which, after the patient has gained more understanding about the diagnosis, medication, and outcome, they can find a decision as a partner (Segal, 2007; De las Cuevas, 2011; Felzmann, 2012; Chakrabarti, 2014; Taube, 2016). De Las Cuevas et al. (2012) report that concordance is a closed term for shared decision-making. Also, nurses and psychiatrists had a positive attitude toward the term. However, they conclude that patients still hold an idea of which healthcare providers own the decision, which is a limitation facing the concept. Concordance is used differently across the professions (medicine, psychiatry, nursing, and pharmacy), which leads to different usages of the term, but these disciplines agree to find a uniform scope for this partnership term (Snowden et al., 2014).

In conclusion, concordance as a term in medicine-taking is mainly concerned with partnership and consultation between patient and health care provider to initiate a therapeutic relationship based on equal parties, which results in more understanding about the diagnosis, medication, and therapeutic alliance which supports patient decisions, and this leads to the taking of medication. Both consultation and negotiation with patients lead to shared decision-making.

1.6.4 Shared decision-making:

The shared decision concept appeared for the first time in literature in 1972, put forward by Robert Veatch when he discussed ethical issues encountered in the medical field. Veatch reported that shared decision-making occurs when the trust relationship and confidence in the medical community are strong. Conversely, when this trust is broken, the decision-making process will discontinue (Veatch, 1972). The concept of shared decision-making became more popular in 1997 when this term was discussed by Charles et al. (1997) as an ideal model for the treatment of ethical dilemmas and sensitive situations that face the medical field, especially in chronic illnesses (Charles et al., 1997). Shared decision-making has four main components as suggested by Charles et al. (1997): 1) it involves at least two parties (patient and health care providers); 2) both have information to share; 3) both can take part in the treatment to build up an agreement about the preferred treatment; and 4) there is implementation of an agreed treatment plan. These characteristics facilitate a pathway to concordance (Hobden, 2006). Since then, the concept has come to be increasingly used in medical and mental health care (Charles et al., 1997; Hobden, 2006; Scholl et al., 2011; Bonfils et al., 2014; Ellis, 2018). Shared decision-making is defined as "*a process in which clinicians and patients work together to clarify treatment, management or self-management support goals, sharing information about options and preferred outcomes to reach mutual agreement on the best course of action*" (Charles et al., 1997:681).

Shared decision-making has become an essential issue in the medical field, and many developed countries have adopted this term and enacted legislation to broaden their role in healthcare settings. For example, in the United Kingdom, the National Health Services (NHS) has stated that the patient is the centre of health care, via including patients in the decision-making process and that shared decision-making would become the norm in the NHS (Department of Health, 2010; Coulter & Collins, 2011). They suggest that shared decision-making is important to involve the patient in the therapeutic process, and this will help achieve the expected outcomes because patients will then control their condition in collaboration with the healthcare provider (Coulter & Collins, 2011). Moreover, the United States of America's 2010 Patient Protection and Affordable Care Act supports the implementation of shared decision-making in the health system (Braddock, 2010). Shared decision-making may be used in many situations, such as when a patient undergoes surgical or medical interventions, takes medication, changes lifestyle habits, and diagnostic procedures or tests (Coulter & Collins, 2011). Shared decision-making appears simultaneously in medical ethics and health research because the medical field deals with patients and needs to protect these vulnerable groups and their dignity (Stiggelbout et al., 2015).

A few fundamental steps should be considered to achieve optimal benefit from shared decision-making: 1) define and explain the problem; 2) conduct a patient option discussion; 3) explain the pros and cons, considering the cost, either financial or health-based (relapses); 4) Discuss patient preferences and choices; 5) emphasise patient has the ability to choose; 6) evidence for the best choice; 7) discussion and recommendations from the health care provider; and 8) the decision is made (based on the discussion, the patient makes their his choice) (Makoul & Clayman, 2006; Ryan & Cunningham, 2014; Stiggelbout et al., 2015). These essential steps in shared decision-making improve patients' self-esteem, reduce anxiety, and increase patient information (Ryan & Cunningham, 2014). A systematic literature review showed the positive impact of shared decision-making on health outcomes (e.g., increased patient confidence and satisfaction) (Ryan & Cunningham, 2014; Shay & Lafata, 2015). At the same time, achieving the positive effects of shared decision-making through integration within the health system is still considered a challenge and is not always fully applied by the healthcare team (Légaré & Thompson-Leduc, 2014; Ryan & Cunningham, 2014). Various limitations and barriers affect the shared decision-making process (Elwyn et al., 1999; Ryan & Cunningham, 2014)

1- The patient refuses to share information or has a lack of knowledge.
2- The process is time-consuming.
3- Contextual factors such as age, educational level, and lack of training among healthcare providers affect the process.
4- The nature and type of decision have an impact (is it the best decision, and is it appropriate?).

In conclusion, shared decision-making is a process that has led to better outcomes and quality of care through collaboration between patients and healthcare providers. To achieve the maximum benefit from this process, essential steps should be considered before and during the shared decision-making process. Shared decision-making could lead to patients taking their medication and achieving the desired outcome.

Final Conclusion:

The terms adherence and compliance both refer to the patient's medication-taking behaviour and may be used interchangeably or as synonyms with each other to refer to patients taking the right medication at the right time and in the right dose. However, concordance is not related to medication-taking behaviour in the same way as compliance or adherence but refers to the interaction between patients and healthcare providers. Patients have the right to understand more about the problem and to discuss the risks and benefits of the treatment plan, and as a result, to ask questions and gain answers to find out with the health care provider the best solution/s or choice/s to achieve shared decision making.

In sum, three terms and approaches in medicine-taking behaviour seemingly seek to achieve the same outcome: improving patient medicine-taking behaviour but incorporating different views in different contexts. Concordance and shared decision-making are the processes needed to discuss the treatment options and positive and negative aspects of choices more deeply with the patient, to let the patient choose, which will improve their understanding of the health problem and improve their adherence to the treatment plan and medicine-taking behaviours. Concordance and shared decision-making are considered quality measures for communication improvement, patient participation in the treatment plan, and a positive relationship between patients and healthcare providers, which will be reflected in improved adherence to treatment regimens.

On the other hand, compliance and adherence are included under the general umbrella of medication-taking behaviour and are also used as measurement tools to identify the degree to which the patient follows the treatment plan and medication regimen agreed upon by the healthcare provider. Based on definitions from the World Health Organization (2003) for adherence, which reflect the patient's active role in following and taking the medication and the health care provider's responsibility to support them.

The concept of medicine-taking will be used for this thesis because it is the general term for adherence and compliance. Besides, it merges the essential characteristics of compliance, adherence, and concordance. Lehane and McCarthy (2009.29) report that "it is suggested, therefore, that the concept of adherence is suitably flexible to take account of patients' beliefs and attitudes, the ideological dynamics of patient-nurse interactions and the moral and practical concerns and responsibilities of the nursing profession in relation to patient medication-taking". The following table (3) summarises terms about medication-taking.

Table 3: Summary of medication-taking terms

Medication taking behaviour	medication-taking behaviour is the term used interchangeably or as a synonym with each other of adherence and compliance; both terminologies refer to patient's medication-taking (Esposito, 1995; Crespo-Fierro, 1997; Cramer et al., 2008; Bissonnette 2008; Barbosa et al., 2012). This thesis uses the term Medication taking behaviour because it is the general umbrella for adherence and compliance. Besides, it merges the essential characteristics of compliance, adherence, and concordance (Horne et al., 2005; Aronson, 2007; Lehane & McCarthy, 2009).
Compliance	The Latin word complire means to complete an action or fulfil promises (Aronson, 2007). The popular definition used in literature is the definition of Haynes, Taylor, and Sackett (1979:190) in their book "*The extent to which the patient's*

	behaviour (in term of taking medication, following a diet, and following other lifestyle changes) matches the prescriber's recommendations".
Adherence	The World Health Organization defines adherence as "*the extent to which a person's behaviour – taking medication, following a diet, and/or executing lifestyle changes, corresponds with agreed recommendations from a health care provider*" (WHO, 2003).
Concordance	Royal Pharmaceutical Society of Great Britain [RPSGB] (1997) defined concordance as "*an agreement reached after negotiation between a patient and a healthcare professional that respects the beliefs and wishes of the patient in determining whether and how medicines are taken*".
Shared decision making	Defined as *"a process in which clinicians and patients work together to clarify treatment, management or self-management support goals, sharing information about options and preferred outcomes to reach mutual agreement on the best course of action*" (Coulter & Collins, 2011. 2).

After exploring the main and common term of medication-taking behaviour, the Next section discussed the magnitude of medication not taken worldwide, in the Middle East, and Jordan, and what factors impact medication-taking behaviour.

1.7 Magnitude of non-taking of medication

The previous section discussed the terms used for medication-taking behaviour; this section will shed light on problems in medication-taking behaviour problem or non-taking of medication in mental health. Not taking medication as intended is a common problem in chronic illnesses and long-term therapy (WHO, 2003; Odegard & Capoccia, 2007; Gellad et al., 2011; Awwad et al., 2015; Alhaddad et al., 2016; Abbass et al., 2017; Gebeyehu et al., 2019; Mekonnen & Gelayee, 2020). Approximately 50% of people with chronic illnesses from the general population in developed countries did not take their medications as prescribed, while in developing countries, this was a higher percentage (Brown & Bussell, 2011). For example, in a systematic review and meta-analysis to assess medication taken as prescribed for osteoporosis in real settings, half of the patients failed to take their medication as prescribed (Kothawala et al., 2007). Forty per cent (40%) of patients with cardiac problems and heart failure do not take their medication as prescribed, which has a negative effect on their health (Leipzig et al., 1999; Alhaddad et al., 2016; Forsyth et al., 2019). Another study found that 39.6% of people with chronic kidney disease and diabetes did not take their medication as prescribed despite negative consequences (Balasubramaniam et al., 2019).

On the other hand, a prospective cohort study in Atlanta for patients with heart failure (n=308) with follow-up periods of two years showed that patients taking their medications regularly were associated with decreased hospitalization days, shorter hospitalization times, and better health status (Marti et al., 2013). Several studies have shown that up to half of patients with chronic illnesses did not take their medication as prescribed (Scheen & Giet, 2010; Painter et al., 2015). Nieuwlaat et al. (2014:2), in a systematic review which included 109 randomized control trials to answer the question "What are the findings of high-quality studies that tested ways to assist patients with adhering to their medicines?" state that although there are many current interventions (such as telephone counselling, diary checklists, pharmacist interventions such as educations, adherence manuals, and home telemonitoring), to improve medication taking in people with chronic health problems, these do not seem to be highly effective, and desired outcomes cannot be realized (for example, blood pressure remains high, uncontrolled blood sugar levels persist). These interventions did not improve medication taking as expected, and non-taking of medication remains high among people with chronic illnesses, forming a challenge for healthcare providers across the globe (Nieuwlaat et al., 2014; Kleinsinger, 2018).

Mental health problems affect approximately one billion people across the globe. The World Health Organization, in its report in 2022, highlighted that 301 million people were living with anxiety disorder, 280 million with depression, 40 million living with bipolar affective disorders, and 24 million people living with schizophrenia (WHO, 2022a). Mental disorders are one of the leading causes of disabilities worldwide (Mibei, 2013; James et al., 2018; Roser & Ritchie, 2020) and affect all socio-demographic groups and all age groups from 5 years to 90 years. However, the burden of disability is most impactful on the working-age group (15-70 years) (Institute for Health Metrics and Evaluation, (IHME), 2018). Medication not being taken is a common problem among people with mental illnesses (Rummel-Kluge et al., 2008; Hardeman & Narasimhan, 2010; Mibei, 2013; Semahegn et al., 2018). For example, in an RCT in Germany (n=135), people with chronic mental disorders reported that 54% of the participants did not take their medications as prescribed (Stentzel et al., 2018). Moreover, in a meta-analysis study which analysed 38 studies to explore the rate of medication taking in bipolar and schizophrenia disorders, the researchers found that the medication-taking rate for schizophrenia was about 42%, and 41% for bipolar, while around 58% did not take their medications as prescribed (Garcia et al., 2016). As a result, medication not taken as prescribed or which was stopped impacted outcomes and increased the rate of rehospitalization and relapses among people diagnosed with schizophrenia (McIntosh et al., 2006; Rummel-Kluge et al., 2008).

Medication not taken is still a challenge for the health care provider and health systems, resulting in patients' failure to achieve treatment goals, as well as negative outcomes and consequences (Xu et al., 2014; Awwad et al., 2015; Kleinsinger, 2018), relapses, comorbidities, deaths, increasing burden on the health system, individuals and families, and increased financial burden on public health services with the extra cost of treatment (National Institute for Health and Care Excellence, 2009; Hardeman & Narasimhan, 2010; Scheen & Giet, 2010; Chisholm-Burns & Spivey, 2012; Awwad et al., 2015).

The estimated cost per year of not taking prescribed medications in the United States is 100 billion dollars. As well as, the estimated deaths because of medication not taken are about 100,000 deaths per year (Kleinsinger, 2018). A previous study conducted in the United States by Chisholm-Burns and Spivey (2012) showed that medication not taken contributes to 100 billion dollars in rehospitalisation annually, with an estimated cost per person of $2000. Similarly, the worldwide cost of medication not taken among people with a chronic condition (cardiovascular, mental health, diabetes, osteoporosis, and gastrointestinal conditions) per person varies between $2741 and $43,404, and this evidence reflects the fact that non-taking of medication is a growing problem globally (Mikulic, 2018). In the United Kingdom, the NHS spent over £13 billion on medications in 2013/2014. However, 50% of medication was not taken as prescribed, and it was estimated that £300 million was spent on wasted or unused medications, and £500 million was the cost of medication not taken as prescribed. This places a huge burden on patient care and the NHS budget (Royal Pharmaceutical Society, 2020).

1.7.1 The Middle East and Jordan:

Not taking medication as intended is a common problem among patients with chronic illnesses in the Middle East and the Arab world, as with the rest of the world (Al Qasem et al., 2011; Yakeley, 2018; AlQarni et al., 2019). A systematic review was conducted in 2011 to identify medication-taking behaviour in the Middle East region among people with chronic illnesses such as hypertension, diabetes, chronic obstructive pulmonary disease, asthma, depression, schizophrenia, and epilepsy. The authors highlighted that the estimated rate of medication not taken as intended was from 1.4%-88%, and this varied depending on the disorder, the measurements used, as most of the studies used self-report combined with pill counts, and the definition of medication taking and non-taking, which varied between studies (Al Qasem et al., 2011). Furthermore, for example, a study in Saudi Arabia (n=212) found that one-third (36%) of patients with diabetes took their medication as prescribed, whereas patients who partially took or did not take their medication formed 64%, doubling the cost of treatment (AlQarni et al., 2019). Regarding psychiatric comorbidities in the Middle East region, these are similar to other parts of the world (Hamdan, 2009). As mentioned in previous sections (1.3, Mental Health System, and 1.3.1, Prevalence of mental disorders), the prevalence of mental disorders is about 13% of people worldwide (Ritchie & Roser, 2018), while its contribution to the global disease burden is around 5%, and it is considered the seventh leading cause of disabilities (Roser et al., 2021).

Non-taking of medication is common among people with mental illnesses (Rummel-Kluge et al., 2008; Bener et al., 2013; Awwad et al., 2015; Abbass et al., 2017). A study conducted in Qatar to investigate the extent to which people with mental illness take their antipsychotic medication found that about 28% of people diagnosed with schizophrenia did take their medication as prescribed, followed by depression at 14%, and bipolar affective disorder at 12% (Bener et al., 2013). In Jordan, a study to examine the prevalence and factors that decrease adherence to diabetic medication found that about 73% of patients who visited the UNRWA care setting in Amman did not take their diabetic drugs (Canali et al., 2018). Another study in Jordan showed that people with chronic illnesses such as diabetes and hypertension had a higher rate of medication-taking, estimated at 70%, and this was explained by having a home management programme as a follow-up (Al-Qudah et al., 2018). However, non-taking of medication is a major health problem in Jordan among people with mental disorders, affecting more than half of them (Alhalaiqa et al., 2016; Mukattash et al., 2018). A cross-sectional study to explore medication-taking behaviour prevalence among psychiatric patients in Jordan (n=243) found that medication not being taken as prescribed was estimated at 64%, with forgetfulness and polypharmacy being the main cause of medication not taken as intended (Mukattash et al., 2016). In the same year, another study was conducted to assess the level of medication taking among people with severe mental illnesses (schizophrenia and bipolar disorder n=108) in Jordan and reported that non-taking of medication was estimated at 83% (Alhalaiqa et al., 2016), which is considerably higher than the previous study explained by the different diagnoses included in the first study, such as depression, anxiety, schizophrenia, bipolar disorder, personality disorders, and autism), while the second included schizophrenia and bipolar disorders only.

1.7.2 Factors affecting medication-taking behaviour:

Medication-taking behaviour is complex and has many factors that affect the patient's medicine-taking, such as characteristics of the patient and disease, communication and attitudes of health care providers, and health system organizations (WHO, 2003; Jin et al., 2008; Scheen & Giet, 2010). There are five major interacting factors associated with the non-taking of medication among patients with chronic illnesses (hypertension, asthma, diabetes, and AIDS/HIV). These factors are grouped into several dimensions: socioeconomic factors, healthcare team and system factors, condition-related factors, therapy-related factors, and patient-related factors (WHO, 2003).

Similarly, in their qualitative literature review, Jin et al. (2008) explore factors impacting medication-taking behaviours (102 articles included). Many studies in the review were conducted in the United States, United Kingdom, Canada, and Australia with different populations and diseases (hypertension, chronic bronchitis, diabetes, and cancer) and found the same factors. However, the authors state that these factors are complex and interact with each other and would be better classified as "soft" and "hard" factors. Hard factors are factors that can be quantified and are amendable or controlled by healthcare professionals and through consultations, such as disease conditions, therapy-related factors, health systems and policies, whereas the soft factors' effects are challenging to measure. Failure in the soft factors (social, economic, and patient-centred factors) leads to failure in the hard factors. The review authors concluded that the effect of some of these factors on medication taking was not clear-cut, whilst the effect of other factors was unpredictable, and findings were contradictory. For example, some studies found that age increased medication taking, while other studies found no effect of age on medication taking (Jin et al., 2008). Medication not being taken as prescribed is pervasive in healthcare, and little has changed in this regard. Additionally, not enough research is being conducted systematically to determine the effects of medication not taken as prescribed on financial and health outcomes (Jin et al., 2008).

Medication-taking behaviour is challenging, as it necessitates interactions between many domains to improve it. Most problems with medication taking arise in people who have chronic illnesses and manage their medications at home (WHO, 2003). However, identifying the relevant factors will help refine or develop an intervention to improve medication-taking behaviour (WHO, 2003; Jin et al., 2008). Not taking medication as intended may either be intentional or non-intentional. For example, a conscious decision by patients to not take medication because it is costly is classed as intentional, but if patients forget to take medication because of diseases such as mental disorders, this is considered non-intentional (Gast & Mathes, 2019) (See section 1.6.2 Adherence).

In conclusion, not taking medication as prescribed or intended is a worldwide problem which affects more than half of people with chronic illnesses. Most of the studies in this area have been conducted in developed and Western countries, and few have been conducted in Asia and developing countries where a large proportion of people live. More studies are needed to formulate international guidelines and interventions to minimize this problem (Jin et al., 2008). Jordan has a similar problem to many other countries with respect to medication not taken as prescribed, involving about 73% of patients with chronic illnesses (hypertension, diabetes, rheumatoid arthritis, respiratory system diseases, and dyslipidaemia) (Awwad et al., 2015). A study in Jordan to evaluate medication taking as prescribed found that 64% of people with mental disorders (schizophrenia, bipolar disorder, depression, anxiety, personality disorders, and autism) did not take their medications as prescribed, whereas another study reports that 83% of people with psychiatric disorders (schizophrenia and bipolar disorders) did not take their medication as prescribed or did not take it at all (Alhalaiqa et al., 2016). The difference between the two studies' rates, although they used the same scale to measure medication-taking behaviour, comes from the nature of the diseases selected for the study, as schizophrenia and bipolar disorder are more chronic than other disorders. So, further studies are needed to explore what and how the factors affect medication-taking behaviour among people diagnosed with mental disorders, particularly schizophrenia or bipolar disorders, in Middle Eastern countries in general and Jordan in particular.

1.8 Schizophrenia and Bipolar

Schizophrenia and/or bipolar disorder were selected for the purpose of this study based on the following reasons: the prevalence of mental disorders is not clear (see section1.4.1Prevalence of mental disorders), schizophrenia and /or bipolar are the most cases noted by the current study author while he is working in the mental health settings in Jordan. The following section will discuss the schizophrenia and bipolar disorders criteria based on the two sources (DSM-5 and/or ICD-10) (see section 1.4.4 community outpatient clinics). This section clearly states that the diagnostic criteria in Jordan are not unified and depend on the institution and what diagnostic tool they can use. For the purpose of this study, the two diagnostic manuals [Diagnostic and Statistical Manual of Mental Disorders 5th edition (DSM-5)) which was developed by the American Psychiatric Association (APA), and the International Classification of the Disease 10th revision (ICD-10) developed by World Health Organization (WHO)] was used as diagnostic criteria to choose service users participants (See section 1.4.4 community outpatients' clinics)

1.8.1 Schizophrenia

Schizophrenia, as a medical term, was introduced by the Swiss psychiatrist Bleuler as a major mental disorder characterized by a group of signs and symptoms that affect social life, such as distortions in thinking, perception, and behaviour (WHO, 1998). Moreover, the APA's DSM-5 codes schizophrenia as 295,90 (F20.9) and defines it as "abnormalities in one or more of the following five domains: delusion, hallucination, disorganized thinking(speech), grossly disorganized or abnormal motor behaviour (including catatonia), and negative symptoms" (American Psychiatric Association, 2013.99). Schizophrenia is associated with impairment in emotional and cognitive states. Also, patients with schizophrenia have poor social function, which is reflected in their functional and occupational status and the economic burden for families and the government (Tarrier & Wykes, 2004). See Appendix-A

Schizophrenia is one of the most devastating mental disorders seen in psychiatric clinics in both developed and developing countries (Devaramane et al., 2011). Moreover, just 0.8% of people with schizophrenia in the United Kingdom have a job, while many more would like to work. Additionally, 14% of people with schizophrenia receive social care, in comparison with more than 40% of the general population receiving social care (Schizophrenia Commission, 2012). Side effects of medications and the severity of symptoms affect individuals' employment status. Moreover, people with schizophrenia often do not tell their employers about their illness as they fear discrimination during the process of employee selection (Marwaha & Johnson, 2005). Hakulinen et al. (2019) conducted a nationwide cohort study in Denmark (n= 9448) and found that people with schizophrenia have a low employment rate. However, people with a less chronic course of illness were more likely to get a job, with not gaining employment being explained by impairment in individuals' social function and by fear of discrimination. In the United Kingdom, psychotic disorders, including schizophrenia, affect 0.7% of the general population. In addition to this, schizophrenia and associated disorders affect around 15 per 1000 population (National Collaborating Centre for Mental Health, U K, 2014).

Schizophrenia is a chronic mental illness and affects 0.3%-0.7% of the general population or approximately 24 million people worldwide. It affects males more than females and starts from late adolescence to the early twenties in males and from the early twenties to early thirties in females. People with schizophrenia are 2-3 times more vulnerable to serious physical illness (such as cardiovascular, metabolic, and infectious diseases) than the general population, and 50% of patients die earlier than the general population. However, people with schizophrenia are less likely to seek or access medical help, as related to detachment from reality and stigma (American Psychiatric Association, 2013; National Collaborating Centre for Mental Health, UK, 2014; WHO,2018). Recent statistics show schizophrenia as one of the top fifteen disorders leading to disability worldwide (Vos et al., 2017).

1.8.2 Bipolar affective disorder (BAD)

The International Statistical Classification of Diseases and Related Health Problems ICD-10 (mental health and behavioural disorders) recognizes bipolar affective disorders as involving "repeated (i.e., at least two) episodes in which the patient's mood and activity levels are significantly disturbed. This disturbance consists of some occasions of an elevation of mood and increased energy and activity (mania or hypomania), and on others of a lowering of mood and decreased energy and activity (depression)" (WHO, 1992.300). In its definition, the American Psychiatric Association (2013) DSM-5 separates bipolar from depressive disorders and represents it under the separate title, "Bipolar and

Related Disorders", between schizophrenia and related disorders and depressive disorders. Because bipolar shares symptomology, family history, and genetic factors, when considering diagnosis, it is like a bridge between schizophrenia and depression. Bipolar disorder is a mental disorder that causes a period of depression known as a “depression episode” and a period of elevated mood known as a “manic episode” (Anderson et al., 2012; American Psychiatric Association, 2013). See Appendix B-1: Comparing diagnostic criteria for bipolar between DSM-5 and ICD-10.

The prevalence of bipolar affective disorder worldwide is approximately 0.6% of the general population. It occurs more in high-income and low-income countries (1.4% vs 0.7%, respectively) (American Psychiatric Association, 2013.130). Worldwide, bipolar disorder is the third largest cause of disability among mental disorders and contributes an average of 0.6% [0.3-1.2%] of the global disease burden. The number of people diagnosed with bipolar disorder was estimated at 46 million in 2017, of whom 48% were male and 52% were female, and in most countries, women were more likely to have bipolar than males. However, it affects all groups in the community at nearly the same percentage. In addition, it affects all age groups between 5 and 70+ years old; however, it generally starts at a younger age, with the onset likely lying between 15 and 49 (Dattani et al., 2021). It may be inherited and strongly correlates with genetic factors (Sullivan et al., 2012; American Psychiatric Association, 2013). Patients diagnosed with bipolar disorder have a risk of committing suicide, which is 15 times greater than in the general population, with one-quarter of this group completing suicide (American Psychiatric Association, 2013). Recently, bipolar disorder has been placed among the top thirty disorders which are the leading causes of disabilities worldwide (Vos et al., 2017).

In Jordan, as mentioned earlier in Chapter 1, there is no reliable data regarding specific diagnoses, but in general, there are 305 individuals per 100,000 who suffer from mental disorders. Half of this number is made up of schizophrenia patients. Moreover, 15%-20% of the general population suffer from mental disorders at some point in their lifetime. Based on the above, and for this paper, the ICD-10 classification for mental and behavioural disorders and DSM-5 will be used as diagnostic criteria to select the sample of schizophrenia and bipolar patients. See the above section (1.4.4 Community Outpatient Clinics).

1.8.3 Primary Caregiver and Family

With mental illness, families have the primary role of caring. In particular, sons, daughters, wives, or other relatives may help in this role (Huang et al., 2009; Chang et al., 2016). In Asian countries and due to cultural values, more than 70% of mentally ill patients live with their families (Chan, 2011). Additionally, all over the world, the most common primary caregivers are women (Chan, 2011). Usually, caregivers for mentally ill patients are called informal caregivers because they are not professional personnel in the health or medical field. These persons assist the patient in their daily activities, such as eating, taking medication and getting around. The most frequent caregivers for patients are their families or relatives (Tiegs et al., 2006; Ae-Ngibise et al., 2015).

Jordanian society is cohesive and characterised by strong relationships between family members, and the cultural background of Jordanian families involves the need to care about other family members (Abu-Ras, 2003). Since relationships are interrelated and complex (for instance, 30% of Jordanian marriages are between first cousins (Al-Gazali et al., 2006), it is common in Jordanian culture to care for ill family members regardless of the type of disease, and more attention is given to chronic disorders, mentally ill patients, diabetes, and heart disease. However, the culture has a negative impact on the families of mentally ill patients, such as through stigma, and the care of such patients is kept within the close family (Hasan & Musleh, 2017).

Conclusion

The inclusion criteria for schizophrenia and bipolar disorders will be based on ICD-10 mental and behavioural disorders (WHO, 1992) and DSM-5 criteria. The diagnosis will be taken from patients' records in outpatient clinics because the diagnostic criteria in Jordan depend on both ICD-10 and DSM-5, depending on the institution.

Exclusion criteria will include schizophrenia, bipolar patients who have learning disabilities, substance abuse, being aged under 18 years old, living alone or without a close primary caregiver, patients known to have an organic mental disorder, and/ or who are involved in a psychoeducation intervention.

Chapter 2 Literature Review

2.1 Introduction

The previous chapter highlights the problem of psychiatric medication-taking behaviour in the world, then sheds light on the Middle Eastern countries (see section 1.7 Magnitude of non-taking of medication), which shows the magnitude of the problem of not taking prescribed psychiatric medication. The purpose of this chapter is to critically review the research in Middle Eastern countries on the factors that impact psychiatric medication taking and then identify the areas which need further investigation and studies.

This chapter highlights the search strategy methodology and detailed Rapid Evidence Assessment review. This review did not aim to investigate every potential connection to the research region, nor was it intended to direct the study in a particular direction or anticipate the discoveries of the participants. Instead, this review aimed to guarantee that the chosen method and study area were adequate (Briner, 2017). This chapter aims to describe the search strategy using a wide range of databases to answer a specific research question identified in the previous section, critically appraise the selected or included articles, and analyse and discuss them. This review was designed to answer the following question:

What are the factors that affect medication-taking behaviour among people diagnosed with schizophrenia or bipolar disorder (Jordan and/or the Middle East)?

By answering this question, prior knowledge about the factors' impact on psychiatric medication-taking behaviour would be reinforced. The essential purpose of this review is to strengthen the theoretical sensitivity to important issues preceding data analysis.

Once this question was answered, the review continued throughout the investigation. It was continually and deliberately reviewed as the research progressed, with the help of published literature as a source of information that contrasted with field observations and shaped the final grounded theory (Strauss & Corbin, 1998). Reflecting frequently on how the review findings might have affected the study design is crucial. Before gathering primary data in the field, this reflexivity reduced the chance of prejudice (Dunne, 2011). The literature review search was re-run on 18-05-2023 to check if new articles or research were conducted after this review was completed.

This Rapid Evidence Assessment (RAE) presented the following:

- What is a Rapid Evidence Assessment review?

- Search method
- Results
- discussion

2.2 Rapid Evidence Assessment Review:

A systematic review of the literature employs a methodical and transparent approach to address targeted and specific research inquiries. This type of review entails identifying relevant studies, evaluating their quality, and synthesising their findings. Of utmost importance is the comprehensive delimitation of the research question (Armstrong et al., 2011). Systematic reviews of medical research are considered the most reliable evidence for experimental and quantitative studies, as well as qualitative studies (Jahan et al., 2016). A systematic review is defined as "a high-level overview of primary research on a particular research question that tries to identify, select, synthesize, and appraise all high-quality research evidence relevant to that question in order to answer it" (Cochrane Consumer Network, 2019).

Rapid Evidence Assessment (REA), a method that employs a systematic process and critical evaluation of the literature to give quick assessments of scientific research about interventions and clinical issues, serves as the foundation for this literature analysis (Barends et al., 2017). Rapid Evidence Assessment looks like a systematic review but is less rigorous, as it limits the grey literature and scope of searching specific areas or regions (Grant & Booth, 2009). However, it provides a deep understanding of existing literature, including gaps and uncertainties, clarifying definitions related to the research question, and understanding how these are conceptualised within the existing literature. REA provides a scientific method of reviewing literature within evidence-based management within a short period of 2-6 months (Grant & Booth, 2009; Department for International Development, 2015; Collins et al., 2015; Barends et al., 2017). Time constraints and narrowing search criteria could lead to selection bias and weaken the answers to the literature review question (Grant & Booth, 2009; Bianchi et al., 2016). This current study selected Rapid Evidence Assessment because the Author focused on identifying the factors that impact psychiatric medication taking in Middle Eastern countries with a brief background about the problem worldwide.

2.3 Search method:

2.3.1 Formulating the literature review question:

This review used a focused research question to guide the database search. This question was identified based on the acronym component of Khan et al. (2003), which helps in formulating a research question of two types: PICO and PEO. PICO [P- for the population. I–intervention or exposure. C- comparative intervention, and O- outcome measures or theme], used to formulate quantitative research questions, controlled trials, and intervention studies. The PEO [P- for population, E- for exposure, O- for outcome or theme] for qualitative research PEO acronym is used if the question does not look for intervention or comparison between interventions.

However, Rapid Evidence Assessment uses a different acronym, PICOC [P- for population, I- for intervention or management, C- for comparison, O- for the outcome, and C- for context; this reflects what kind of organisation or sector is relevant to contextual factors]. This helped the reviewer search for relevant studies. Although this review used REA, it did not look for an intervention to compare with other interventions. Therefore, a clinical question was formulated using the PEO (Bettany-Saltikov, 2012). The population was ‘people diagnosed with schizophrenia or bipolar’; the exposure was ‘prescribed psychiatric medication taking, and the outcome was ‘factors that impact their decision to take it as prescribed or not. The question for this literature using the PEO acronym was structured following a discussion with the study author and the supervisory team at the University of Hull. The literature review question is:

“What are the factors that affect medication-taking behaviour among people diagnosed with schizophrenia or bipolar disorder (Jordan and/or the Middle East)?”

Table 4: The PEO Acronym

Population	People diagnosed with schizophrenia and/or bipolar (Jordan, Middle East)
Exposure	Psychiatric medication
Outcome or theme	Factors that impact medication taking, Knowledge, attitude, behaviour toward taking medication, reasons, facilitators, and barriers

The initial search found that, in all countries, there is a paucity of studies conducted in mental health areas. It is not surprising that a few studies were conducted in Jordan; it was necessary to widen the search to include Jordan and Middle Eastern countries to identify the studies conducted outside Jordan that are relevant to the mental health topic, more specifically to psychiatric medication-taking behaviour.

2.3.2 Inclusion and exclusion criteria:

This section discusses the inclusion and exclusion criteria that helped select articles to be included in the literature review. The inclusion criteria were the Middle East. Jordan is in the Middle East region, which is located on the continent of Asia, and the majority of countries are Arab; however, Turkey has two parts, one located in Europe and the other in Asia (Middle East) (World Atlas, 2015a). Therefore, when searching the database, Turkey will be considered.

Table 5: Inclusion criteria

Inclusion
• All study types and primary resources are published in peer-reviewed journals, systematic reviews, and organizational reports.
• Studies outcome that investigate (taking behaviour measures, knowledge, attitude, and influences) that affect medication-taken behaviour among people with schizophrenia and/ or bipolar.
• Adult aged above 18 years. (under 18 is excluded because it does not reflect the sample characteristic of this current research, as the participants must be age 18 or above)
• Middle East and Turkey
• Published in the period 1980 until now [because the actual mental health services start beyond that date and are still developing until this time, as mentioned in Chapter 1, cultural background of the health system in Jordan]. Although mental health services in the Middle East region began in the early 19th century, modern psychiatry developed in the early 20th century. However, the early beginning of the work and prioritizing of mental health started in 2001 in Middle Eastern countries led by the World Health Organization in 2001 (Mohit, 2001). In addition, although mentions of mental well-being can be traced back in the English language before the 20th century, scholarly references to mental health as a domain or academic discipline were absent until 1946 (Bertolote, 2008).
• Published in English [in the Arab world, nursing and medical researchers publish in English]. There are Arabic Journals, and people who publish in Arabic are social sciences, but they translate their work to English for publication and H-index.

2.3.3 Database Search:

The current study employed a wide range of databases to identify relevant studies related to health, medicine, nursing, and mental health to answer the literature review-focused question. The search years were limited to January 1980-April to 2020. To identify relevant studies, the following databases were systematically searched in a manner that allows any other researcher to reveal the same result: CINAHL Complete [this database includes the most popular Journal in the Nursing and Medical Field with full text], MEDLINE [this database includes more reliable and specific data in medical fields such as nursing, medicine, the health care system, pre-clinical science, and many other health allied databases, which uses the Medical Subject heading index (MESH) which enables searching within more than 5400 citations in current Biomedical Journals]. PsycINFO [(American Psychological Association) is the largest database specialising in mental health and behavioural science and includes books, scholarly articles, and dissertations]. PsycARTICLES [from the American Psychological Association and provides a wide range of scholarly articles and peer reviews on psychology]. Academic Search Premier [this provides multidisciplinary scholarly articles and peer reviews].

The Cochrane Library [which covers healthcare interventions, including systematic literature review for randomised control trials (RCT) and meta-analysis]. Web of Science Core Collection [It covers general and multidisciplinary titles and is useful for looking for articles on specific topics or tracing citations and for conference papers]. The SCOPUS database provides research data through various articles, books, conferences, reviews, and systematic reviews. Using the University of Hull Library's electronic services. Open Grey literature will be used to search for Grey Literature [includes any information that is not produced for commercial purposes, such as data from unpublished work (thesis and dissertation), conference proceedings, reports, policy documents, working papers, newsletters, and any unpublished material] (Bettany-Saltikov, 2012:79). The Boolean operator was used to combine the search terms. In addition, a manual search of the retrieved articles was performed for relevant articles.

The search was conducted using combinations of different search terms after consultation with an information specialist [who is a member of the University of Hull library skills team) and a specialist in searching methods across a wide range of databases] on 14/04/2020 to check the searchability of the search term.

This REA review was conducted and reported in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses [PRISMA]. PRISMA is defined as "an evidence-based minimum set of items for reporting in systematic reviews and meta-analyses" (Moher et al., 2009). The search terms were developed in the selected databases and modified as necessary for the various databases using the following search terms:

Medicat*, treat*, therap*, drug*, adher*, concord*, complian*, taking or taken,"Mental disorder*","mental illness*", Schizoph*, Psychos*, "psychotic disorder*", Halluci*, Delusion*, Bipolar*, "Mania-Depression", "manic-depressive", Jordan*, "Middle East*", "Arab world", Bahrain*, Egypt*, Iran*, Iraq*, Yemen*, Qatar*, Syria*, Israel*, Palestin*, Kuwait*, Lebanon*, Oman*, Turkey*, "Saudi Arabia*", "United Arab Emirates".

The review question component served as the basis for the keywords. The author found synonyms to conduct a thorough search that included all the various ideas taken from the literature. Essential words were truncated by placing an asterisk (*). For instance, the query medicat* returns medication, medicated, and medicator. Additionally, a proximity search (N3 or near 3) to find the three words regardless of the order, for example (Medicat* or treat* or therap* or drug*) N3 (adher* OR concord* OR complian* OR taking or taken) would return the word medication, adherence, and taking in the same title regardless of the word order. OR and AND were used in combination to extend and narrow the search results, respectively.

The initially identified articles were screened by title against the selection criteria based on the focus of this review, and then the abstracts were read and checked against the inclusion and exclusion criteria. Duplicates were removed from all databases to narrow the results. Subsequently, the included articles were screened by full text for all records, considering relevant studies for the review against the inclusion and exclusion criteria. Finally, the included studies were critiqued and analysed. Subsequently, the reference list of the studies included a search for additional relevant publications. As the rapid evidence assessment process leads this literature review, it gives a liberty to decide which critical appraisal tool to select based on the included study types and to assess the methodological quality of the articles (Barends et al., 2017). In addition, the methodological appropriateness of the studies was based on their designs (Barends et al., 2017). This classification, alongside the critical appraisal tool, helped the researcher judge the article's quality and the literature review's overall quality. Barend et al. (2017.17) summarized the methodological appropriateness level as follows:

Table 6: Methodological Appropriateness Table

Study design	Level
Systematic review or meta-analysis for randomized control trials	AA
A systematic review of non-randomized control and/or before-after studies	A
Randomized Control Studies	
Systematic review or meta-analysis for controlled studies without a pretest or uncontrolled studies with a pretest.	
Non-randomised control before-after study	

Interrupted time series	B
Systematic review or meta-analysis of cross-sectional studies	C
Controlled studies without a pretest or uncontrolled studies with a pretest	
Cross-sectional study (survey)	D
Case studies, case reports, traditional literature review, theoretical paper	E

2.3.3.1 EBSCOhost Search:

The search was conducted on 14/04/2020, after search terms were entered into the search engine of EBSCOhost and selected the following entire databases (CINAHL Complete, MEDLINE, PsychINFO, PsycARTICLES, Academic Search Premier). The search terms used in the table are as follows:

Table 7: EBSCO databases search terms

A N D	(Medicat* or treat* or therap* or drug*) N3 (adher* OR concord* OR complian* OR taking or taken)
	“Mental disorder*” or “mental illness*” or Schizoph* or Psychos* or "psychotic disorder*" or Halluci* or Delusion* or Bipolar* or “Mania-Depression” or “manic-depressive”
	Jordan* or “Middle East*” or "Arab world" or Bahrain* or Egypt* or Iran* or Iraq* or Yemen* or Qatar* or Syria* or Israel* or Palestin* or Kuwait* or Lebanon* or Oman* or Turkey* or “Saudi Arabia*” or “United Arab Emirates”

N3 is the proximity search in the Boolean Operator, which means (near 3) to find the word within three words of one another regardless of the order in which they appear. Proximity search differs from one database to another. In addition, a proximity search was conducted to narrow the search and obtain relevant articles.

The search result *(See table 23)* revealed 1502 articles, then the search was limited to academic journals and the date between (1980-2020) the search result was (1476). Articles were removed after duplication (1056 articles). Articles were included after being scanned by title (148), and the remaining articles were excluded because they did not meet the inclusion criteria. The full list of excluded articles was documented (most of them discussed nonadherence for diabetes, antihypertensive, coronary artery disease, liver transplantation, thalassaemia, asthma, and HIV). Different age groups (children, school age, or less than 18 years) and duplication. Then 29 articles were selected for abstract screening. The final included articles were 10 articles. The excluded articles 19 because [2 was not English, just the abstract, 8 mixed populations not just bipolar or schizophrenia but major depression, anxiety, and other psychiatric disorders, 4 general psychiatric disorders not specific, and 5 different outcomes].

2.3.3.2 Cochrane Library:

The search for Cochrane Library terms is shown in table below. This search revealed (50) articles and classified them as follows [Cochrane Review (5), Trials (45)]. Included (4), after the duplication checked with other selected databases, the articles were excluded (50) *(See table: 26**Error! Reference source not found.**)*. Articles were excluded because they did not match the inclusion criteria and duplications found in other databases. This search covered the period between 1980-2020. The search term used the same searched term except the proximity and the way of searched combined [each term alternative entered in separate box and take number, and at the end combined these numbers with each other by using Boolean Operator and, or, not], MeSH terms not used, and this will help the consistency of search through the different databases, and this decision was made based on the information specialist [is a specialist Librarian in Literature review search strategy].

#1	(Medicat* or treat* or therap* or drug*) near/3 (adher* OR concord* OR complian* OR taking or taken)
#2	“Mental disorder*” or “mental illness*” or Schizoph* or Psychos* or "psychotic disorder*" or Halluci* or Delusion* or Bipolar* or “Mania-Depression” or “manic-depressive”
#3	Jordan* or “Middle East*” or "Arab world" or Bahrain* or Egypt* or Iran* or Iraq* or Yemen* or Qatar* or Syria* or Israel* or Palestin* or Kuwait* or Lebanon* or Oman* or Turkey* or “Saudi Arabia*” or “United Arab Emirates”

#4 Combine the search	#1 and #2 and #3 and #4

2.3.3.3 Web of Science Core Collection:

Searching this database as the same EBSCO search term, but the difference in searching was to use the basic search bar in Web of Science [see Table 8: Web of Science search terms], and there is no need for a proximity search here, the date covered 1980-2020, and limited to the conference proceeding index to cover Gray literature, the primary search hits (115), after duplicates removed, the articles is (106). Nine articles were included after title screening (9) articles. The remaining articles were excluded because they did not meet the inclusion criteria and were duplicates in other databases. After scanning the abstracts (five), articles were included. Finally, screening full articles, 1 article was included, excluded articles were 4 [2 different outcomes, 2 in Europe, Middle East, and Africa where data cannot be extracted based on the geographical area, all came together]. See table: 24).

Table 8: Web of Science search terms

A N D	(Medicat* or treat* or therap* or drug*) NEAR/3 (adher* OR concord* OR complian* OR taking or taken)
	“Mental disorder*” or “mental illness*” or Schizoph* or Psychos* or "psychotic disorder*" or Halluci* or Delusion* or Bipolar* or “Mania-Depression” or “manic-depressive”
	Jordan* or “Middle East*” or "Arab world" or Bahrain* or Egypt* or Iran* or Iraq* or Yemen* or Qatar* or Syria* or Israel* or Palestin* or Kuwait* or Lebanon* or Oman* or Turkey* or “Saudi Arabia*” or “United Arab Emirates”

2.3.3.4 SCOPUS Search:

SCOPUS is the world's largest abstract and indexing database, with over 33 million records. This database provides researchers with a wide range of articles, books, conference papers, reviews, and systematic reviews. The search was done as shown (table 9). When the search was performed, 189 articles were identified after duplicates were removed from the search and databases (170). Nine (9) articles were included by title scanning, and the remaining articles were excluded because they did not meet the inclusion criteria. Duplication was found with other databases after scanning the abstract (4). Finally, two articles were included after a full article screening. Two Articles were excluded because they have mixed populations.

Table 9: SCOPUS Search Terms

AND	(Medicat* or treat* or therap* or drug*) W/3 (adher* OR concord* OR complian* OR taking or taken)
	“Mental disorder*” or “mental illness*” or Schizoph* or Psychos* or "psychotic disorder*" or Halluci* or Delusion* or Bipolar* or “Mania-Depression” or “manic-depressive”
	Jordan* or “Middle East*” or "Arab world" or Bahrain* or Egypt* or Iran* or Iraq* or Yemen* or Qatar* or Syria* or Israel* or Palestin* or Kuwait* or Lebanon* or Oman* or Turkey* or “Saudi Arabia*” or “United Arab Emirates”

2.3.3.5 Open Grey:

This search was done to explore more about the medication-taking behaviour among schizophrenia and bipolar disorders in Europe. The search was done through their website, www.opengrey.eu. Grey literature will be searched for in Europe, specifically in Turkey, because all the Middle Eastern countries located in the Asian continent except Turkey have a part in Asia and Part in Europe. See [Table 10: Open Grey search box]. The search yielded no results, although many different terms were used.

Table 10: Open Grey search box

medication (non adherence or non compliance) among patients with (schizophrenia or bipolar) in Turkey.
(medication or drug or treatment or therapy) not taken among people diagnosed with schizophrenia and bipolar in Turkey.
(medication or drug or treatment or therapy) non (adherence or compliance or concordance) for people diagnosed with mental disorder in Turkey

medication non (adherence or compliance or concordance) for people diagnosed with mental disorder in Turkey

2.4 Results:

2.4.1 Search Summary:

Consultation with an information specialist was used to generate preliminary search terms to determine if this resulted in relevant articles being found, and this approach developed and refined the search terms. The search took place on 14/04/2020 and was limited to the years (1980-2020). Results relating to the search and selection of studies are summarised in the PRISMA Flow Diagram of the literature review [Figure 2 1: PRISMA Flow Diagram (Adapted from Moher et al., (2009)] Database searches yielded 1856 potentially relevant studies [1502 (CINAHL Complete, MEDLINE, PsychINFO, PsycARTICLES, Academic Search Premier), 115 Web of Science, 189 SCOPUS, Cochrane 50]. I try to look at possible search engines to cover all search areas and to find all possible articles published in the Middle East region that explain using various database platforms. Of these, 474 were duplicates, and 1217 were excluded because they did not meet the inclusion criteria and different populations such as (diabetes, HIV, and heart problems. A total of 166 articles were screened by title and abstract; 128 were excluded because they had (different populations and outcomes). The full texts of the 38 remaining papers were then independently screened, and at the end of this process, a total of 13 studies were included. Of the excluded studies were 25 because (2 were in Europe, the Middle East, and Africa for nurses and psychiatrists; data cannot be extracted for the Middle East only; 10 were mixed diagnoses not just schizophrenia or bipolar such as (major depression, anxiety, bipolar, schizophrenia, and personality), 2 full texts were other than English (articles found to be in Turkish language but the abstract in English, 7 does not investigate the reasons or barriers of not taking medication and other outcomes, and 4 general psychiatric conditions were no specific mental disorder.

The included studies were critically appraised and analyzed using a quality assessment tool, the Mixed Method Appraisal Tool (MMAT). The challenge of evaluating strength is crucial. Overall, the studies were generally strong despite the identified weaknesses.

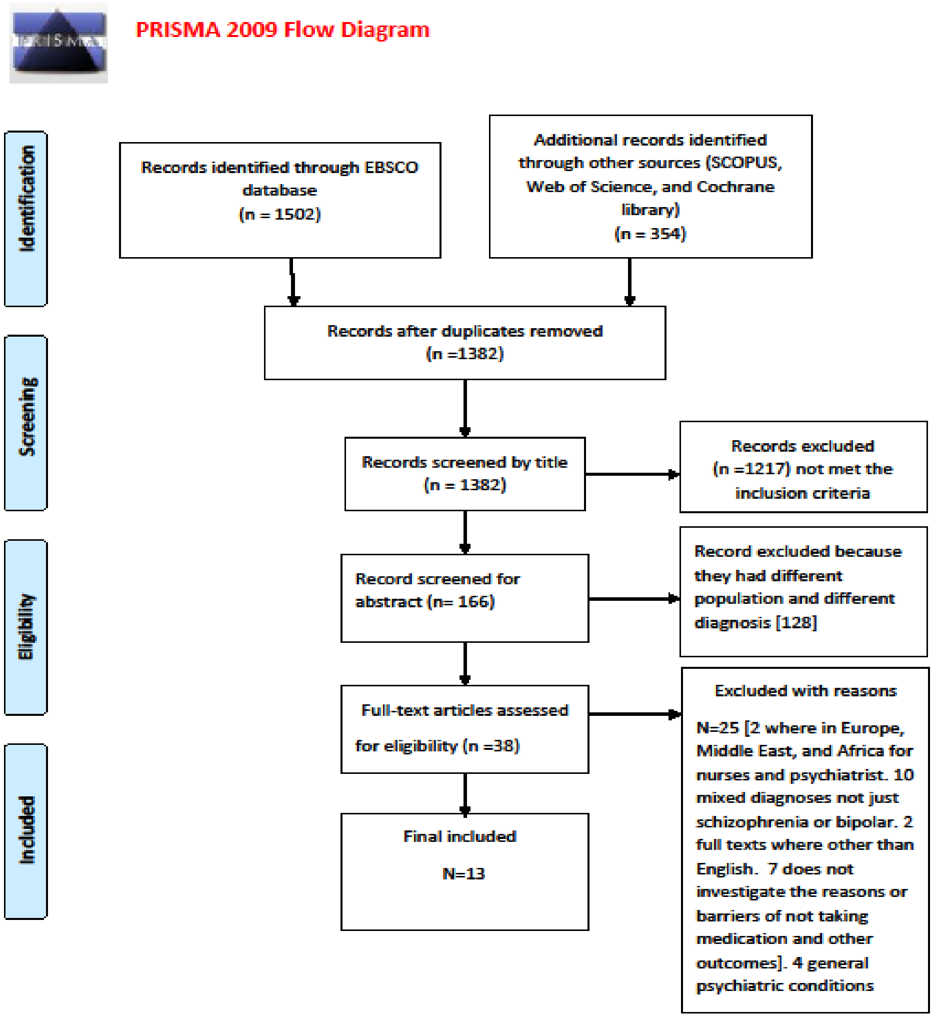

Figure 1: PRISMA Flow Diagram (Adapted from Moher et al., (2009))

2.4.2 Quality appraisal

Various validated appraisal tools were used to assess the quality of the studies included in the systematic literature review (Blank et al., 2012). Hong et al. (2018) mentioned that there are no general criteria for assessing the quality of studies because excluding articles based on quality assessment is discouraged. The rapid evidence assessment process includes a straightforward qualitative assessment (Grant & Booth, 2009), as mentioned in (2.3.3 database search). The Mixed Methods Appraisal tools (improved version 2018) were used to add more rigour to this review. MMAT was designed to facilitate a critical appraisal of different study designs, such as quantitative, qualitative, and mixed methods (Pace et al., 2012; Hong et al., 2018; Hong et al., 2019). The MMAT tool allows the researcher to appraise methodological quality for five categories [qualitative studies, randomised control trials, non-randomised trials, quantitative descriptive studies, and mixed methods studies)] (Hong et all., 2018). The availability of critical appraisal tools that include all research designs in one tool facilitates comparison between different methodologies (Crowe & Sheppard, 2011).

In the first version of the Mixed Methods Appraisal Tool launched in 2009, the reliability and efficiency were tested for the pilot version, which found that the agreement between reviewers or the inter-rater reliability was moderate to perfect (Pace et al., 2012). As well as the consistency of the global quality score is between 0.72 pre-discussion and 0.94 post-discussion (Pace et al., 2012). Crowe and Sheppard (2011), in their review, aimed to evaluate Critical Appraisal Tools (CAT), reviewed 44 Critical Appraisal Tools and found that 25 (57%) tools applied to more than one research design, 11 (25%) to True Experimental design, and 8 (18%) to individual research design. From the 25 tools, there were six tool measures: all research designs from these just one measure all research design and Mixed Methods, with high concurrent validity, including explanation and guidance to use which was the MMAT (Crowe & Sheppard, 2011). Additionally, the reliability and efficiency of MMAT were reported when used independently by more than one reviewer (Souto et al., 2015). Souto et al. (2015) stated that MMAT is widely used in many disciplines and countries such as [Canada, the UK, USA, Australia, Denmark, Belgium, Netherlands, China, New Zealand, and Switzerland]. However, it is recommended by the National Institute of Excellence of Health Services (NICE) in Quebec. This explains the wide use of this instrument in health research, and the average time to complete the checklist is 14 min (Hong et al., 2019).

The Mixed Methods Appraisal Tool has five categories, enabling one to choose the study's category. You will select the category based on the article design (Hong et al., 2018). The scoring of the MMAT is discouraged, and excluding articles based on their quality is not informative or recommended

(Hong et al., 2018). However, by contacting the author of the tool [Quan Nha Hong] by email on 07/05/2020 regarding scoring, she said, “You can use number and rating, but in the comments box, mention why this, and you can use the same rating used in the previous version. Count the number of yeses [without screening questions]. This will be your rating, but explain other answers (No, cannot tell). You can derive yours.” The new version has five categories, excluding screening questions. Each had five questions (yes, no, cannot tell). If yes, rate 1; if No or Cannot tell, the rate is 0. The rating was 20%-100%. The MMAT was used to appraise the included studies in this literature because most of the studies are cross-sectional surveys or descriptive, and based on the explanation above, it is valid for all research designs and to unify the appraisal tool for all included studies. See [table 28]. The data was extracted based on the REA process guidance (*See table 29:* Search outcomes)

This review identified 13 studies that were published between (2013-2020). All studies were quantitative: [9 were cross-sectional descriptive studies, three were prospective cohort studies, and one was a longitudinal prospective study]. The included studies were conducted in the following countries: Three in Jordan (Rababa’h & Alhmoud, 2013; Alhalaiqa et al., 2016; Issa et al., 2018), six in Egypt (El-Missiry et al., 2015; Elsheshtawy & Hussein, 2015; El Meguid et al., 2016; Sultan et al., 2016; Hassan et al., 2019; Radwan et al., 2020), and four in Turkey (Col et al., 2014; Karaytug et al., 2017; Karadağ et al., 2019; Ata et al., 2020). The studies included people diagnosed with schizophrenia or bipolar disorder, written in English, and reported the reasons, factors, or predictions for not taking medication.

Self-report was used in Twelve of thirteen articles to measure level of medication taking either alone in the study, or with other questionnaires to find correlation or relationships, such as five papers focused measures level of medication taking and potential reasons using different tools [such as Morisky Medication Rating Scale (MMRS), Brief Adherence Rating Scale (BARS), and Barnes Rating Scale (BRS) in people diagnosed with schizophrenia and bipolar (Col et al., 2014; Elsheshtawy & Hussein, 2015; Alhalaiqa et al., 2016; Karaytug et al., 2017; Karadağ et al., 2019), three were focused on the knowledge, and medication side effect in people diagnosed with schizophrenia and bipolar (Sultan et al., 2016; Issa et al., 2018; Ata et al., 2020), two measure the insight and psychiatric not taking medication in people diagnosed with schizophrenia (El Meguid et al., 2016; Hassan et al., 2019), one focused on cognitive function and medication taking behaviour in people diagnosed with schizophrenia (El-Missiry et al., 2015), one discussed the psycho-demographic characteristic and medication not taking in people diagnosed with bipolar I disorder (Radwan et al., 2020) , and one study explore medication not taking in people diagnosed with schizophrenia from psychiatrist and nurse perspective (Rababa'h & Alhmoud, 2013), for more details see *(table 29)*.

The quality of the included papers based on the MMAT rating varied between 40%-80% with a mean score of 71%, indicating that the included paper's quality is good. The included studies were considered to be at high risk for bias because they fall between levels B and D [9 cross-sectional descriptive were classified as level D and three prospective cohorts, one longitudinal study classified as level B] based on the REA process and methodological appropriateness (Barends et al., 2017). Papers with poor quality were not excluded, as it was still important to include their findings. Overall, the only aspect obtained was that the lower scores were related to the sampling methods. (*See table 29)*.

2.4.2.1 Sample Characteristic and sample size of included studies:

The sample size in all included studies was 1601 participants of people diagnosed with schizophrenia or bipolar disorder. Most participants in the included studies were diagnosed with schizophrenia (n = 1129, 71%) and bipolar disorder (n = 472, 29%). Most participants in the included studies were between 18 and 75 years old. Of the participants, 832 were male, and 590 were female. Studies that reported education level (Col et al., 2014; El-Missiry et al., 2015; Elsheshtawy & Hussein, 2015; Sultan et al., 2016; Alhalaiqa et al., 2016; Karaytug et al., 2017; Issa et al., 2018; Karadağ et al., 2019; Ata et al., 2020) showed that most of the participants were educated, and the education level for participants was categorised into three subsets: first more than primary education which included (secondary and university) 804. Lower than primary education (primary and elementary): 226. Third, illiterate 123. Studies report work status (El-Missiry et al., 2015; Elsheshtawy & Hussein, 2015; Sultan et al., 2016; Alhalaiqa et al., 2016; El Meguid et al., 2016; Karaytug et al., 2017; Issa et al., 2018; Radwan et al., 2020) the worker participants were 546, and 480 had no work. (For more details, see ***Error! Reference source not found.***).

2.4.2.2 **Rapid Evidence Assessment (REA) review:**

Based on the research question, the literature contained themes relevant to the research subject. The following discussion is organised around the themes highlighted in the literature. The REA review of articles to answer the review questions was organised into the following two themes:

1. Rate of medication taking and measures used.
2. Reasons for or predictors of medication not taking.

Theme one: Rate of medication taking and measures used.

Medication taking was measured in all (13) included studies using self-report questionnaires (Rababa'h & Alhmoud, 2013; Col et al., 2014; El-Missiry et al., 2015; Elsheshtawy & Hussein, 2015; Sultan et al., 2016; Alhalaiqa et al., 2016; El Meguid et al., 2016; Karaytug et al., 2017; Issa et al., 2018; Hassan et al., 2019; Karadağ et al., 2019; Radwan et al., 2020; Ata et al., 2020). One study used self-development questionnaires but did not mention reliability and validity or whether they used psychometric measures for the tool (Rababa'h & Alhmoud, 2013). Nine studies (Col et al., 2014; Elsheshtawy & Hussein, 2015; Alhalaiqa et al., 2016; Karaytug et al., 2017; Issa et al., 2018; Hassan et al., 2019; Karadağ et al., 2019; Radwan et al., 2020; Ata et al., 2020) used the Morisky Scale. The Morisky Medication Rating Scale-8 is a scale designed to measure the level of medication taking and to identify reasons why medication is underused; it measures medication taking at a three-level score below 6 are considered low or non-adherent, between 6-7 medium, and 8 with high adherence level; the most common factor measured is forgetfulness to take medication. This scale is reliable and valid (Morisky, 2008).

Two studies (El-Missiry et al., 2015; El Meguid et al., 2016) by Byerly et al. (2008) [Brief Adherence Rating Scale (BARS), a scale measuring antipsychotic medication adherence in schizophrenia, which is reliable and valid, rating between (0-100%), score below 70% considered as non-adherent or not taking medication as intended]. one study (Sultan et al., 2016) used Barnes Rating Scale (BRS), this scale developed to measure the side effects of antipsychotic medications, especially akathisia, and measure attitude of the patient toward the medication presents such side effects, this scale reliable and valid (Barnes, 1989). Elsheshtawy and Hussien (2015) used the MMRS_8 scale, but no details regarding the level of medication taken were mentioned in the study.

One study was conducted in Turkey (Karadağ et al., 2019), which used two methods to measure medication taking, which gave more accurate results: the MMRS-8 scale with another confirmation test, which is a blood test. A sample of 117 people was diagnosed with bipolar disorder, and they found that the majority of participants (98) were adherent, based on the scale and blood test results. However, 12 of 13 studies reported that the majority of participants (956) did not take their medication as intended (60%), 307 participants took medications as intended (19%), 248 participants partially took the medications as intended (15%), and one study (Elsheshtawy & Hussein, 2015) did not report any results, although it used the MMRS-8 questionnaire. For more details, (see table 28: critical Appraisal MMAT and table 29: data Extraction) in appendix.

Theme two: Reasons or predictors of medication not taking.

The patients provided a wide range of reasons, barriers, and predictions for medications not taken as intended. These reasons were derived by self-report questionnaires, which includes: medication side effects such as extrapyramidal, dyskinesia, and akathisia (Rababa'h & Alhmoud, 2013; Col et al., 2014; Alhalaiqa et al., 2016; Sultan et al., 2016; Issa et al., 2018; Ata et al., 2020; Qunaibi et al., 2021), forgetfulness (Rababa'h & Alhmoud, 2013; Alhalaiqa et al., 2016; Issa et al., 2018), lack of social support such as being single, lack of family support, living alone, has no siblings, brothers or sisters (Col et al., 2014; Elsheshtawy & Hussein, 2015; Karaytug et al., 2017; Hassan et al., 2019), lack of insight (Rababa'h & Alhmoud, 2013; Alhalaiqa et al., 2016; Hassan et al., 2019; Radwan et al., 2020), cognitive impairment (El-Missiry et al., 2015), lack of knowledge about medications and disorder (Rababa'h & Alhmoud, 2013; Issa et al., 2018), medication cost, and denial of illness, (Rababa'h & Alhmoud, 2013), complexity and severity of disorder (Rababa'h & Alhmoud, 2013; El Meguid et al., 2016) feeling worse after taking medications (Alhalaiqa et al., 2016). Age of onset, number of episodes (Col et al., 2014), low education level (Karadağ et al., 2019; Radwan et al., 2020), comorbid anxiety and stress, and duration of depression in bipolar disorder (Karadağ et al., 2019), and age (Radwan et al., 2020).

These reasons can be classified as intentional and unintentional [as mentioned earlier in 1.6.2 Adherence] the unintentional not taking medication, such as forgetfulness, lack of insight, cognitive impairments, lack of knowledge about medication and disorder, and lack of social support. Intentional not taking medications, such as medication cost, denial of illness, feeling worse after taking medication, and medication side effects.

Reasons for not taking medication could be classified into one of five categories as mentioned in (chapter 1.7.2 Factors affecting medication-taking behaviour). The reasons explored in this study can be classified based on that category as follows.

- Medication/therapy factors (such as side effects, cost of medication, worsening after medication, and lack of knowledge about medication and its side effects).
- Condition/disease factors (such as lack of insight, forgetfulness, denial of illness, severity of illness, duration and number of episodes, cognitive impairment, and age of onset).
- Socioeconomic factors (such as medication cost, low education level, lack of social support, being single, and living alone).
- Patient-related factors (lack of knowledge about disorders).

2.5 Discussion:

As mentioned in the previous section (Section 1.4, the magnitude of the problem), not taking medication as prescribed among people with mental disorders (schizophrenia or bipolar disorder) is a worldwide problem. The results of this review indicate that, elsewhere in the world, there is a problem with psychiatric medication taking as prescribed among people diagnosed with schizophrenia or bipolar I disorder in several Middle Eastern countries. However, caution must be taken before concluding the rate of not taking psychiatric medication because of the wide disparity in the estimates of medication not-taking rates between these studies, which varied from 16% to 87%. This variation could be due to differences in sample size, different definitions of not taking medication, taking medication between studies due to different questionnaires, all methods having advantages and disadvantages, and sociodemographic questionnaires used in the selected studies.

One study reported the lowest rate of not taking medication, which was 16%, conducted by Karadag et al. (2019) in Turkey, aimed to assess sociodemographic characteristics and their correlation with medication use. A sample of 117 people diagnosed with bipolar disorder used two methods to measure medication use: the MMRS-8 and a blood test. The selected sociodemographic characteristics were (age, sex, marital status, education level, social support, and number of episodes). After the data collection results, two groups arose: group medication taking as prescribed and medication not taking; most of the participants (84%, 98 participants) were taking their medication as prescribed, and (16% (19 participants) were not taking medication. The last group had a lower level of education. In addition, they reported that low educational level, duration of depression, and comorbid anxiety were predictors of not taking medication at a significance level of $p<0.05$. However, this result is not convincing because of the wide difference between the two groups and the small sample size.

One study reported that not taking medications from the perspectives of psychiatrists and nurses who dealt with patients. This study conducted by Rababa'h and Alhmoud (2013) in Jordan, the aim was to assess the frequency and factors associated with medication not taking among people diagnosed with schizophrenia. A self-development questionnaire measured the psychiatrists' and nurses' perceptions. They reported that denial and lack of information were the most important factors related to medication not taking, followed by medication side effects, forgetfulness, medication cost, and severity of illness. However, this result is valuable but might be invalid because of the lack of psychometric measures of validity and reliability of the tool developed by the authors. In addition, psychiatrists and nurses drew conclusions based on patients' records and did not form a meeting.

Another study mentioned that age was a reason for medication not taking; this is a longitudinal prospective study conducted in Egypt by Radwan et al. (2020). The study aimed to assess socio-demographic characteristics and their association with medication not taking among people diagnosed with bipolar I disorder. A Sample of 110 participants aged between 18-60 years, and the sociodemographic characteristics of the participants were (age, gender, education, marital status, and work). They reported that being male and having a single low education level were significantly associated with not taking medication ($p < 0.001$). Age and lack of insight were predictors of medication not being taken at a significance level of $p<0.05$. However, the authors did not mention which age group was a predictor or whether medication not taken was younger or older; further investigation is needed regarding age. Col et al. (2014) conducted a cross-sectional study to explore the factors that impact medication taking in bipolar 1 disorder in Turkey (78 participants). They found that at an early age at disease onset, social support and sufficient information about the disorder and treatment were predictors of medication taking.

The reasons reported by patients who did not take medication varied across the studies, but the most frequently reported reasons for not taking medication as prescribed were the side effects mentioned in five studies. Lack of insight was mentioned in the five studies. Lack of social support was reported in 4 studies, and forgetfulness was reported in 2. These reasons reported by patients in Middle Eastern countries are similar to those reported in the international literature (WHO, 2003; Jin et al., 2008; Naghavi et al., 2019) [see previously mentioned domains in 1.7.2 Factors affect medication-taking behaviour]. Where the five interactive domains are (socio-economic factors, therapy/medication-related factors, condition/disease factors, health system and professional factors, and patient factors); however, some common reasons reported by international literature were not reported here in these studies: health system/professional factors such as (trained professionals, mental health facilities, availability of mental health support team and facilities), and patient factors (beliefs, culture, perception, expectations, or experience). These studies were not designed to explore these aspects; therefore, there is a need for more qualitative studies to explore how these factors affect medication-taking behaviour in the Middle East in general and in Jordan.

One new study that met the inclusion criteria was identified in the re-run of the search on 18 May 2023 by Qunaibi et al. (2021), who conducted a study in Jordan/Jerash (rural area) to investigate the factors that impact medication-taking from patients' (schizophrenia, bipolar, and depression) perspective and to assess the role of the pharmacist in this process. Using a convenience sample, participants were recruited (n = 120) from a government hospital. They found that side effects were the main cause of medication failure. They concluded that positive attitudes, perspectives, and religious beliefs improve psychiatric medication use. This study did not affect the literature review, as it supports the abovementioned findings.

2.6 Conclusion:

This review confirmed the existence of not taking medications as a problem among people diagnosed with schizophrenia or bipolar I disorder in the Middle East in General and in Jordan in Particular. However, the variation in the rate of not taking medication is probably due to the different methods used in the studies. Some barriers to and predictors of not taking medication among this group of patients in this region were identified. However, these 13 studies highlight the need to expand this area of research, particularly in Jordan, and to improve the quality of such research. However, three studies conducted in Jordan were cross-sectional descriptive studies, which asked patients to complete the survey without other investigations. Therefore, there is a need for further research that explores barriers, reasons, and predictors of not taking medication to identify the type of intervention that may be needed to improve medication-taking behaviour.

2.7 Limitations:

The main limitation of this review was the small number of studies found to be relevant to the topics; the reasons could be the limitation of the search to the Middle East Region and Jordan, the population of the study of schizophrenia and bipolar, and the English language only. Furthermore, more studies have been conducted in different countries (Jordan, Egypt, and Turkey) with different cultures and professional backgrounds. The lack of experimental studies, small sample size, lack of descriptive sampling methods in some studies, and quality of the data analysis in some studies may bias their conclusions and raise doubts about the generalisability of the findings. Another limitation could be the Rapid Evidence Assessment review performed by one reviewer, which may have led to a selection bias in the studies. Moreover, The Quality appraisal tool, due to the way it is structured, misses some important aspects, such as the “risk of bias”, which helps reviewers to obtain a general judgment.

Chapter 3 : Study aim, Objective, Methodology, and Research method

3.1 Introduction

This chapter will outline the development of the research aim, objectives, questions, and research methodology, concentrating on the philosophical concepts that guided my decision to pursue this line of enquiry. Epistemological and ontological concepts and theoretical perspectives are also discussed. The rationale for using the constructivist grounded theory approach to direct my analysis and the theoretical foundations of grounded theory are discussed. Finally, grounded theory's key concepts and characteristics were defined and discussed, emphasising how I approached these characteristics in my methods. This chapter also discusses the research method (settings, gaining access, and recruitment process), data collection and analysis, and quality and trustworthiness.

3.2 Researcher role in the study (Positionality and reflexivity):

Positionality directs its focus towards the circumstances that give rise to the researcher's identity, a distinct identity that will inevitably influence the perspective from which the social world is perceived and comprehended. The principles of intersectionality and social standpoint theory serve as the fundamental basis for acknowledging and incorporating the concept of positionality within the realm of interpretivist research (Bukamal, 2022). In this current study, I consider my position as a mental health nurse and use a reflective note based on my cultural background. Lazard and McAvoy (2020:160) mentioned that reflexivity is a form of critical thinking that aims to articulate the contexts that shape the research processes and, subsequently, the knowledge produced. However, the researcher's positionality simultaneously interacts with reflexivity and is a fundamental aspect of data collection and analysis (Bukamal, 2022).

I am the primary researcher in this current study, which was conducted as part of my PhD research in nursing studies. All participants were aware of this aspect of the study. My positionality as an insider researcher in terms of culture is that I am Jordanian and live there, which lets me understand the cultural context of the participants in the study. However, there are some cultural boundaries; for example, when meeting female participants, you cannot ask her a sensitive question because of gender differences, such as asking her about sexual life or experience). Also, my position as a nurse in the early stage of my career adds another aspect of the positionality in terms of approaching the gatekeepers. I was aware of my position and experience while carrying out the data collection and analysis. The reflexive note was carried out throughout the research, and it focused on explaining the participants' emotional responses, such as crying or laughing during the interview.

The shifting in my position at the beginning of the study till the end of it was shaped by positionality and reflexivity, where my point of view changed from the positivist approach, which I held, to the interpretivist approach to understanding people's perspective about the phenomena. For example, I held a view that medication is very important in the treatment of severe mental illness, as I came from a medical background and belief in pharmacological treatment. After interacting with participants (service users and primary caregivers), my point of view began to change, especially when they told me that local medications are different from international medications and they prefer the international ones here. I started to write my reflection notes about why they believed that. What is different between them? I started to think differently and openly, which cannot be done with the positivist mentality of dealing with numbers.

[For example, the note was made for this point on 02/06/2021. This note is considered important because participants added new information to me, which was unexpected. When he talks about this point, his voice tone lets you feel how important it is and to what extent local vs international impact their medication taking] Service user 1.

Another example is when service users mentioned that antipsychotic medications increase their sexual desire, which is known to be the opposite, and already I have the idea that antipsychotic medications cause impotence. [note made here on 07/07/2021 with service user 4, This is a new thing to me, and I need to find the interpretation for this action and change in my thinking and position and to see things from the participant lens not just from a medical point of view, service user was influenced by this not also because hypersexuality but because of the culture as Muslims we are prohibited to sexual relation before marriage, this was a good reason for him to stop medications for instance.

My experience helped me in the construction of an understanding of how psychiatric medication-taking behaviour is deeply involved in the dynamics and interactions with each other during the interview. My career as a mental health nurse might grant me insider status as I am fully informed about the challenges that service users and healthcare professionals face working in Jordanian mental health settings. The methodological decisions were influenced by the research context and my positionality (Bukamal, 2022). Based on that, the research methodology was influenced by my insider positionality as a mental health nurse and gender when planning to collect data to choose a way culturally appropriate for the participants, and what kind of question should be asked if there is a sensitive question, what are the appropriate ways to ask them.

3.3 Research aim, objective, and questions developments

As mentioned above, my interest in “psychiatric medication-taking behaviour” began when I was in the clinical area as part of the master’s degree program in mental health. I was interested in exploring alternative medicines (herbal medicine) and how they could be effective in the treatment of mental disorders. After I obtained my master’s degree in nursing/mental health from a university in Jordan, I moved to the psychiatric unit as an in-charge nurse to learn and teach the new nurses and old nurses for three years. During that period in a psychiatric unit, I noticed that taking psychiatric medications faced a challenge from the service user, primary caregivers, community, and the best approach to finish the study. As the aims, objectives, and questions were explored, various methodologies were considered, affecting the formulation of the research questions. The initial decision was straightforward because the study aimed to explore social processes and behaviours (factors that impact psychiatric medication-taking behaviour) from different perspectives to gain an overall understanding.

A qualitative approach would be the most appropriate because it provides a comprehensive understanding of the phenomena under study (Creswell, 2012; Parahoo, 2014). Holloway and Galvin (2016) argued that a qualitative approach is most appropriate if the aim is to explore an area of a specific discipline rather than testing a hypothesis. However, the rationale for using qualitative study for my thesis is the lack of this type of study in Jordan, which explores these reasons in depth. To the best of my knowledge, this is the first qualitative study on this topic in Jordan. This decision was made based on the Rapid Evidence Assessment literature review, which informed that most of the studies in Jordan are quantitative and did not explore the perspectives of the participants (service users, primary caregivers, and healthcare professionals) on this topic.

Based on that, given information from certain qualitative methodologies were ruled out as viable choices. For example, ethnography examines individuals, groups, cultures, and community behaviour within a society or their setting and environment, focusing on how individuals interact and behave as members of these groups or cultures (Parahoo, 2014; Pope & Mays, 2020). As this design focuses on individual interactions within a certain group or culture, the researcher needs more than one approach to data collection, such as observation, interviews, and diaries, to understand the individual behaviour within a certain culture or group (Parahoo, 2014). This provides insight into a social process (psychiatric medication-taking behaviour), not a specific group or culture, given that the ethnography approach was not justified.

The phenomenological approach is another methodological and analytical choice that has proven to be more difficult and challenging during the developmental stage of the selected research methods.

Phenomenology examines how people perceive a phenomenon and focuses on their perception of their experiences. Phenomenological research aims to explain and analyse people's lived experiences (Polit & Beck, 2010; Creswell, 2012; Parahoo, 2014). In the current study, phenomenology was concerned with the sense of the lived experience of people taking and giving psychiatric medications. However, this research aims not to comprehend the experience per se but to explore factors that impact medication-taking behaviour and then to generate a conceptual or theoretical model to guide the practice. Therefore, the phenomenological approach is unsuitable for this study, as it would not enable the researcher to create or construct a conceptual or theoretical model. Besides, the phenomenological analysis is mainly narrative and descriptive (Starks & Brown, 2007), and this does not serve the aim of the study to extract factors or themes that influence medication-taking behaviour.

Given the difficulties of phenomenology, the possibility of using a grounded theory approach was assessed. Grounded theory and phenomenology have commonalities in that they both investigate phenomena from the perspective of individuals who have lived through them and often rely on the interpretation of interviews or focus group data to develop findings. These parallels can lead to ‘method slurring’, in which researchers mix terminology and research methodologies connected with the two approaches (Baker et al., 1992). Despite the similarities, the two approaches have different philosophical approaches, necessitating a different methodological process (Starks & Brown, 2007). Ethnography and phenomenology concentrate on studying a certain culture or the lived experience of the individual or group, neither of which allows us to describe a dynamic social mechanism. On the other hand, grounded theory will help describe and understand the participants’ processes, actions, and interactions toward certain phenomena to develop a theory or model from the collected data to explain the complex approach to certain phenomena.

Grounded theory is a method in which a researcher constructs a theory from data rather than testing it (Strauss & Corbin, 1998). Based on that, as the research aim is to explore a social process (psychiatric medication-taking behaviour from three different perspectives) and no theory will be tested, grounded theory is a viable choice. The selection of grounded theory impacted the aim and objective of the study, as outlined earlier. Therefore, the output of the grounded theory is related to the phenomena under study. Given that the initial aim and objective of the current study was to explore and determine how factors impact psychiatric medication-taking behaviour, the research aim was reviewed to reflect the desire to generate a theory from data. Grounded theory has two types of output: a formal theory, which generates a general insight into a broad concept, while substantive theory provides insight and focuses on a specific concept in a certain area of interest

(McCann & Clark, 2003). The narrow output defines the scope of this study; therefore, the most appropriate research objective is:

"To generate a substantive theory of what and how factors impact psychiatric medication taking for service users, primary caregivers, and HCP".

There are different schools of grounded theory, each with its own distinctive philosophical and procedural peculiarities but sharing the same fundamental methodological underpinnings, which is the creation of a theory from data (Morse, 2001). Grounded theory was selected, but there were three different schools, and choosing which school would serve the aim of the study depended on many factors such as the area of the study, beliefs and experience of the researcher, research aim, and question.

3.4 Grounded Theory

Glaser and Strauss developed grounded theory in the first half of the 1960s and described it as an inductive approach which generates theory or conceptual models from the collected data cyclically and iteratively (Glaser & Strauss, 1967; Charmaz, 2006). Grounded theory has recently become an important research method in nursing and medical fields (Creswell, 2012; Mertens, 2014; Parahoo, 2014; Pope & Mays, 2020). From a nursing perspective, grounded theory develops theory from collected data, which helps explain, understand, and predict the social process of the subject under investigation in healthcare settings (Maz, 2013). The main aim of grounded theory is to generate a theory or conceptual model (Glaser & Strauss, 1967; Charmaz, 2006). Moreover, grounded theory is not a theory per se but a process to develop a theory from the collected data in a systematic approach (Creswell, 2012; Parahoo, 2014).

Developing grounded theory includes the collection of primary data from interviews (data collection). Analyse these data locate and categorise themes (coding). Finally, illustrate and present the general explanations and the emergent themes (Charmaz, 2006; Creswell, 2012); this is then repeated from interview to interview in a process called constant comparison that is used to develop and construct the theoretical concept (Charmaz, 2006; Polit & Beck, 2010).

3.4.1 The version of grounded theory

There are three versions of the grounded theory: the classical or Glaserian grounded theory developed by Glaser and Strauss 1967, Strauss and Corbin 1990, and Charmaz 2006. According to some academics, Glaserian grounded theory is the method's "purest" branch since it still exhibits many of the traits initially listed in 1967. Despite the fact that Glaser has modified, enlarged, and clarified some of the ideas and concepts of the original method, the inductive approach to theory development's basic tenet has not changed (Heath & Cowley, 2004). Grounded theory was approached differently by Strauss. From a general viewpoint, Strauss and Corbin (1998) provided a method for developing theories that relied more on deduction and verification and less on induction (Heath & Cowley, 2004). Several analytical approaches have also been introduced as part of the shift away from Glaserian methodologies, providing a framework and procedure for creating theory from evidence. Theorists contend that this makes the methodology more transparent, repeatable, strong, and approachable for new scholars (Strauss & Corbin, 1998; Heath & Cowley, 2004).

Glaserian grounded theory continues to focus strongly on the theory being solely informed by data, with the researcher attempting to prevent preconceptions or prior knowledge of the subject matter from tainting the data or forcing the theory in a specific direction. A distinct perspective is taken by Straussian grounded theory, which contends that prior knowledge may be a helpful tool for researchers by improving theoretical sensitivity; that is, by promoting the formation of categories from the data and enabling a deliberate attempt to guard against bias (Hall & Callery, 2001).

However, the two dissimilar aspects discussed above (analytical methods and prior knowledge) suggest that a Straussian methodology would be more appropriate for a project carried out by a new grounded theorist with prior experience and subject-specific information.

Glaser and Strauss developed a grounded theory as the quantitative approach dominated social science in that period (Charmaz, 2006). They developed a grounded theory to generate a theoretical model which explains the social context (Glaser & Strauss, 1967). The differences in opinion between the founders of grounded theory led to the development of Strauss and Corbin’s approach, which led the literature to classify grounded theory into two main aspects: the Glaserian version based on the original work (Glaser, 1978) and the Straussian version based on the revision of Strauss (1987). Strauss and Corbin (1990; 1998). They modified the positivist approach adopted by Glaser and recommended a more systematic one (Creswell, 2012). Strauss and Corbin's work is an advancement of conventional grounded theory, eschewing some of Glaser's positivism in favour of a more interpretative paradigm (Mills et al., 2006).

However, Charmaz (2006) developed a new grounded theory approach, “constructivist grounded theory,” which was derived from the Straussian approach. Charmaz urges that the theories that emerge through this methodology are not fixed ideas waiting to be understood; rather, they are flexible, dynamic, and individualised constructions dependent on participant interactions, researcher viewpoints, and prior knowledge. (Charmaz, 2006). Moreover, Charmaz believes that Glaser and

Strauss adopted positivist epistemology and realist ontology, with some differences between their approaches (Charmaz, 2006).

Charmaz blended the earlier literature of symbolic interactionists into her writing while approaching grounded theory from an interpretative standpoint. It is not the researcher's sole responsibility to gather information, identify emergent themes, or develop theories. Instead, the researcher creates a reality influenced by those it contains by working with the participants. According to this worldview, there are as many realities created during research as there are participants. Participants share some aspects of these realities, but each is different and context-dependent (Mills et al., 2006). Many approaches to grounded theory fall within a spectrum between objectivist and constructivist perspectives (Charmaz, 2000). The constructivist approach did not look just at how individuals expressed their situations but also how interpreting this situation results in a theory. In addition, researchers should be aware of the differences between situations to understand how this arises and how it is maintained (Charmaz, 2006). Constructivist ground theorists claim that to develop a constructive approach, the researcher should be a part of the research, interactive process, and then active analysis rather than external prescriptions; analytic directions emerge from how researchers engage and interpret their similarities and emerging analyses (Charmaz, 2006). From a practical point of view, Charmaz acknowledged that researchers would bring their own experiences and expertise into any field of study, which is relevant to the methodology selected for this study. In fact, the researcher's involvement is crucial to developing grounded theory as they work with participants to pinpoint a realistic reality in their setting.

The final decision on where the study should proceed on the grounded theory continuum is personal, practical, and epistemological in nature. From an **epistemological** perspective, previous experience as a nurse in mental health settings and evaluating service users' and primary caregivers' psychiatric medication-taking behaviour suggested a range of views. These appeared to be affected by the clinical conditions and personal experiences of the service users and primary caregivers. This seems to reflect more interpretative and constructivist beliefs that no single reality exists and must be interpreted from different perspectives. In response to the study question, psychiatric medication-taking behaviour would vary depending on the individual participants' experience, knowledge, background about the disease and treatment, and beliefs. Thus, the goal is to develop a grounded theory that can recognise and accommodate the parallels and contrasts of these realities. These realities explore using coding as a tool which helps in forming the theory; Charmaz (2006) asserted that coding in grounded theory builds up a theory rather than testing a hypothesis;

therefore, analytical questions are needed by the researcher to understand more about the phenomena.

Charmaz (2000, 2006) provides clear instructions on developing grounded theory and explaining its epistemological foundations. Both Charmaz (2006) and Strauss and Corbin (1998) understand the researcher's position as a theoretically sensitive individual who brings foreknowledge to the field and whose interactions with participants can impact the ultimate product of any project. As a result, this study employed constructivist grounded theory supplemented by analytical tools from the Straussian version.

This study employed a constructivist grounded theory approach, which is an inductive approach distinguished by the use of a continuous comparison analysis of qualitative data, as explained by Strauss and Corbin (1990, 1998) and Charmaz (2006). This interpretive qualitative study is based on semi-structured interviews to explore the experience of the service user and primary caregivers to identify the factors and how these factors impact psychiatric medication-taking behaviour. Moreover, the healthcare professionals’ point of view about the psychiatric medication-taking behaviour and factors influencing it. This approach was used because it provides rich data and an in-depth analysis of the participants’ data (Creswell, 2012). Philosophical assumptions are required to understand and conduct rigorous research (Pope & Mays, 2020). Understanding philosophical assumptions directs research and reflects how researchers think as they bring their perspectives and beliefs into the research, whether they are aware of them or not (Creswell & Poth, 2016). Lastly, no studies have mentioned the factors that impact psychiatric medication-taking behaviour from three different perspectives and experiences (service users, primary caregivers, and healthcare professionals) in Jordan. Understanding psychiatric medication-taking behaviour is complex; however, there is a need to investigate the reasons or underlying factors and how psychiatric medication should be taken for better intervention in the future.

3.4.2 Why the constructivist approach?

To address a real issue in practice, this study was guided by an adapted version of constructivist grounded theory that reflected the nature of the research aim and questions, as well as the researcher's philosophical approach to relative ontology and constructivist epistemology; these adaptations relied on the researcher's above discussion. Constructivist grounded theory is a flexible approach to developing a theory based on data that uses principles and practices derived from traditional grounded theory guidelines (Charmaz, 2006). Constructivist grounded theory studies phenomena in their natural setting to understand what happens in real situations and how social interaction is integrated and constructed in the real world (Ghezeljeh & Emami, 2009).

This method was chosen because it was consistent with the researcher's current belief that a qualitative researcher cannot remain objective. It would be difficult for the researcher to play the role of an objective outsider because he had worked in a mental health setting and was familiar with the issues being discussed. The constructivist position employed here is that people diagnosed with mental disorders (schizophrenia or bipolar disorders) construct the meaning of psychiatric medication-taking behaviour through the interactive experience with the self (by trying the medications and testing the improvement) and others (projection from other experiences with the medications or people who try it). The employment of constructivist grounded theory can address the factors that impact medication-taking behaviour, which are poorly understood in the literature on Middle Eastern countries. In addition, this design helps describe the sense of reality regarding psychiatric medication use from the perspectives of service users and primary caregivers. There have been no studies on mental health settings in Jordan using this approach. Constructivist grounded theory provides a deeper understanding of the phenomena within the Jordanian context.

3.5 Research Method

The previous section outlined the decision to adopt the Constructivist grounded theory approach. There are basic aspects to which the researcher must adhere to a grounded theory method, regardless of the discrepancies between the various approaches that pertain to grounded theory. The researcher complies with the elements of grounded theory, including literature review, theoretical sensitivity, theoretical sampling, coding process, constant comparison analysis, and memoing. This increases the rigour of the study and adheres to grounded theory guidelines.

3.5.1 Literature review in grounded theory:

Grounded theory schools disagree on when and how to use the current literature. Glaser (2001) urges postponing the literature until after data collection and analysis to avoid contamination and influence from preconceived views on theory creation. However, Strauss and Corbin (1998) and Charmaz (2006) have another perspective, which acknowledges the value of reading the literature before beginning the study and claims that this approach is crucial to developing theoretical sensitivity.

This procedure helped the researcher create a variety of interview-prompting questions. Prior to starting data collection, the researcher completed a thorough literature analysis, which aided in streamlining ideas and facilitating the focus of the study. This review pointed out areas that already exist and assisted in determining areas that require additional study. Having reviewed the literature beforehand confirmed the originality of the work for the doctoral thesis and allowed the study to expand on previously published research in this field. During the data collection and analysis processes, access to literature was continuous. Using the literature to increase theoretical sensitivity involves comparing concepts with actual evidence.

3.5.2 Theoretical sensitivity

Strauss and Corbin (1998) urge that gaining an understanding and being sensitive to data is what theoretical sensitivity means. This enables the researcher to make sense of the data, comprehend them, and distinguish between relevant, significant, and irrelevant data. Reading the literature to familiarise with articles and acquire insight into the studied topic is also a source of theoretical sensitivity (Carpenter, 1999). However, as mentioned earlier, Glaser (1978) rejected the reading and contaminated the research ideas with the researcher's preconceived literature or professional experience regarding the phenomena under study. However, in the current study, my experience in mental health settings as a nurse and the literature review (Chapter 2) enhances theoretical sensitivity.

It is crucial to utilise in vivo coding to capture participants' "ordinary" language because it concentrates the analysis on what participants have to say about key concerns (Elliott & Jordan, 2010), which prevents data from being contaminated by the literature. Elliott and Jordan (2010) suggested that constant comparative analysis in the early stage will correct any pitfalls from previous knowledge or reading. The researcher was aware that due to his experience with some of the care settings and his position as the primary research tool, perfect impartiality and neutrality are difficult to accomplish; prior data about psychiatric medications and factors impact it. As a result of this self-awareness, the researcher was able to continually consider how important it was to be as transparent as possible with the participants, not to shape their impressions of the study and allow them to come to their conclusions and viewpoints.

3.5.3 Theoretical sampling

The use of theoretical sampling was a key component of Glaser and Strauss' original explanation of the grounded theory approach, and it has continued to be so throughout all the methodological and epistemological developments that have occurred in the years since. Evolving theory directs the researcher toward the data sources and categories they should look for next in theoretical sampling (Glaser & Strauss, 1967). Charmaz (2006.96) defined a theoretical sample as
“Seeking and collecting pertinent data to elaborate and refine categories in your emerging theory”. Charmaz (2006:100) describes the sampling in grounded theory as “initial sampling is where you start, while theoretical sampling directs you where to go”. Draucker et al. (2007) investigated "selective sampling”, which refers to the early phases of grounded theory investigations in which people and settings are specified before any data collection. A selective sample was first employed

to recruit three participants, one from each group. The initial semi-structured interviews were conducted using an interview guide and a preliminary analysis. Feedback from participants and supervisors was obtained, and minor modifications were made to the interview guidelines. One advantage of semi-structured interviews is the flexibility in which the researcher can modify the interview guide by adding or removing questions during data collection (Strauss & Corbin, 1998). Subsequently, the sampling strategy was changed to a theoretical sample to identify the key participants (service users, primary caregivers, and healthcare professionals) to answer the research question and provoke their perspectives and experiences. Recruitment continues until theoretical saturation is achieved based on Strauss and Corbin’s (1998) theoretical saturation, which is achieved when no more codes or themes appear or are added. Hence, this study employed constructivist grounded theory, and this sampling strategy was suitable for it. The selected clinical area and settings will provide the researcher with different levels of experience (psychiatric outpatient clinics and community centres). For more details about sampling, see (3.7.2 Sampling and sample size).

3.5.4 Coding

Using a coding paradigm in the Straussian approach is another divergence between Glaser and Strauss. The grounded theory became almost a "method" (rather than an "approach" to qualitative research) after Strauss and Corbin (1998) published a detailed, step-by-step guide to analysis. Three stages of analysis were used in structured coding and analysis: open, axial, and selective coding (Chen & Boore, 2009). This paradigm allows the researcher to search for specific patterns in the data, which adds deductive and validation elements to grounded theory (Woods et al., 2016). This coding system enabled the researcher to set the categories and dimensions of the initial phenomena for better explanations and understanding.

Coding is the main component of data analysis in grounded theory for all three versions. The coding starts by analysing the data line by line and word by word to initiate initial codes and concepts. Then, codes are organised and shaped to form categories, then categorised and compared with other categories (see Appendix 7). Connecting data to evolving theory and describing what appears and happens in the data, the coding process in grounded theory creates a framework for analysis (Charmaz, 2006). This method makes it easier to manage large data by breaking it into smaller, more manageable pieces (Charmaz, 2006). The main role of the researcher during the coding process was to interpret the data generated from the participants’ language, perspective, and experience. Hence, the researcher needs to immerse himself in the data to become familiar with it, facilitating the interpretation and understanding of phenomena (Mills et al., 2006).

The three different coding methods used in grounded theory schools have several characteristics. The original method presented by Glaser and Strauss (1967), the classic grounded theory Glaserian version, comprises substantive (open and selective) and theoretical coding to find a theory based on facts. The Straussian version uses a stricter coding scheme comprising open, axial, and selective coding to understand the data and create the theory (Straus & Corbin, 1990; Strauss & Corbin, 1998). While using a more pragmatic and flexible way to code the data, Charmaz (2006) makes it easier to create conceptual interpretations of occurrences.

In the current study, the researcher adheres to the coding framework specified by Strauss and Corbin (1990, 1998) while maintaining a constructivist mentality to focus on the data rather than strict processes to enable theory building (Charmaz, 2006).

Although the movement between coding steps is clear, the coding process is not sequential. For instance, the researcher frequently returned to the open coding stage during the axial coding stage and changed the codes and categories. Data analysis and coding were primarily focused on interview transcripts, with field notes and memoranda utilized throughout to assist the coding process and ensure consistency (see Appendix 7).

3.5.5 Constant Comparative analysis:

Charmaz (2006) mentioned that constant comparative analysis is a technique that uses inductive comparisons of data with data, data with category, a category with a concept, and category with category to produce ever more abstract concepts and hypotheses. The various stages of analytical progress were then compared.

To determine the link between ideas, perspectives, and experiences, the researcher examined them in the same interview and between the interviews. Data from the first three interview transcripts were analysed and compared to each other and within each other to provide and allocate codes, ideas, and categories that served as a guide for data gathering in subsequent interviews. Initially, the researcher identified code (open or initial coding see section 3.10.2, axial coding 10.3.3, and selective coding 10.3.4). The researcher employed this methodology throughout data collection and analysis. Each interview was transcribed and compared with other codes and categories.

3.5.6 Memo writing

Memoing allowed the researcher to jot down thoughts as they came to mind throughout the analytical process, allowing for later organisation, categorisation, and reflection. Also helps the researcher connect categories with each other and provide an in-depth understanding of the links between categories and subcategories (Straus & Corbin, 1990; 1998; Charmaz, 2006).

The construction of the final categories based on open, axial, and selective coding benefited from memo writing and thinking that followed. The researcher also utilised notes to update his supervisors regarding the analysis status.

The memo writing or field note-taking starts from the first interview. Although the interview was done using Zoom audio meeting and recorded certain note taking while participants were talking, crying and laughing, I can listen again to the recorder and an interpretation of this also written, for example, when a primary caregiver started crying while she was talking about her daughter, form my insider positionality understanding the cultural perspective about the people having a mental health problem, she worried about her daughter, and she will not marry if people knew that she has a mental problem.

In conclusion, this current study used a grounded theory approach for data analysis, as described by Strauss and Corbin (1998) and Charmaz (2006). The initial data analysis started from the beginning of data collection, so the concepts that emerged from the beginning were continuously compared with new concepts and categories.

3.6 COVID-19 Adaptation:

In light of the current COVID-19 pandemic, which affects the social life of people, the government needs to take extensive measures to stop the spread of this disease, such as banning flights, closing shops and restaurants, closing schools and universities, banning social gatherings, maintaining social distancing, and hand hygiene wherever you are. All these measures affected fieldwork in the research. This led the researchers to use remote methods to complete their work. Online methods and applications, such as Microsoft Teams and\ or Zoom, were the alternative methods to meet people instead of face-to-face interviews.

In this current study, the main area affected was the fieldwork, which was the interview with participants, and this led to consequences of changes; for example, the researcher now needs a gatekeeper to help him recruit his sample from abroad as the study intended to be done in Jordan and needs to look at what online application allowed them to interview participants with respect to their data privacy and confidentiality (see Appendix 5-E letter to the gatekeepers).

Since the study design was qualitative interview-based and because of the COVID-19 pandemic and the social distancing rule, the probability of collecting the data as a face-to-face interview is very low, and online meetings or telephone interviews are alternatives to face-to-face interviews. Based on this situation, the supervisory team agreed to consult professors from outside the team to give their opinions about the best interview applications[2], particularly in Jordan. During this period of the environmental issues and the pandemic because of (COVID-19). The online meeting method saves time and money, minimising the cost of travel for the researcher and participant from and to the site of the interview, which may encourage participants to participate in the study.

As the interview with the participants was held online, the various options allowed us to choose one of these programs to collect the data. Zoom application video or audio is recommended because of its familiarity with the participants, as recommended by the scholars in Jordan, and the ability to record the interview with participants, allowing us to return to the recording for transcribing the data. In addition, the Community Centre is a supportive environment for service users. It will encourage them to express their experience and the signal, be robust and more reliable, patients (the service users) use the centre facility, and the community centre leads to welcome participation in research. They helped and supported them as they could, as they said when contacted by email.

As the online interview is employed as an alternative data collection method, the consent checklist and information sheets are sent to potential participants via email for them to read; if there are any questions, they will contact the researcher. If participants accepted participation, this was confirmed by their replies (yes, I agree). The researcher will go through the consent checklist point-by-point at the beginning of the interview to ensure that participants read and agree. Before recording the interviews with the participants, verbal consent will be recorded; the researcher will sign the consent checklist, and a copy will be sent to the participant via email. The email and contact details were saved in an encrypted file on the University of Hull server. The researcher asked the participants who agreed to participate to state that their participation was voluntary and they understood that they had the right to withdraw at any point before the interview ended and wanted to proceed.

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[2] For more information about JW and TB (PhD supervisors), Professor MH (from the University of Hull, Faculty of Health Science) and I suggested Professor AM a PhD (Professor, Psychiatric Nursing, School of Nursing, The University of Jordan). Professor AM is the same professor recommended by Professor MH for contact in Jordan). In addition to the two others from the fieldwork, YA (Psychiatric Mental Health Nursing- Registered Nurse PMH-RN. Works as a psychotherapist at Kalema Centre for Cognitive and Behavioural Therapy at this Centre in Amman), and AK (PhD, RN, MSN; Department of Nursing, Prince Hamzah Hospital, Ministry of Health). Amman-Jordan). Professor AM recommended using Zoom application video or audio in Jordan. YA and AK Indicate using Zoom, messenger, or telegraph applications were perfect in audio call meetings because they were tried with their patients.

3.7 Settings

This study was conducted in two outpatient psychiatric clinics and one community centre where selective and theoretical recruitment was employed. Seventeen participants were recruited from the three groups. An interview guide was developed based on the literature, feedback, and comments from supervisors and peers. The probing questions were changed based on a continuous analysis of the interviews to saturate the emerging themes using theoretical sampling. Interviews were transcribed verbatim. A preliminary analysis was performed before conducting the interviews. Using NVivo 12, analysis was completed using the upgraded version of NVivo R 1.5 software. Data from 17 interviews were] analysed using a constant comparative analysis technique. Interviewees were provided with transcripts of their interviews for review and discussion (the peer debriefing technique). Academic supervisors evaluated some transcripts and the progress of the analysis.

Before data collection took place, I took several steps to reach this point. First, filling out the application form is a requirement for PhD students to get ethical approval from the university. After several edits and adding information, especially after the COVID-19 pandemic, -I need to rewrite the data collection plan to fit the new situation and to decide what I need for this and what application I need to conduct the interview- the university granted me the ethical approval letter, then I found that I may use another application for contacting patient so I made an amendment which also approved by the university. Then I started to contact the selected hospitals in Jordan, and because of my positionality as an insider, I got the ethical approval as I knew the rules of application and what I needed exactly there. Data collection took place in mental health outpatient departments and community centres in Jordan after permission was granted by the Faculty of Health Science Ethics Committee at the University of Hull and then from selected organisations in Jordan.

1- Jordan University Hospital (one of the largest teaching hospitals in Jordan located in Amman city) as mentioned in (1.3 Health System in Jordan).

2- Ministry of Health Outpatient Departments for Mental Health. These outpatient departments cover different geographical areas in the Kingdom, serving most people diagnosed with mental illnesses, as mentioned in (1.3 Health System in Jordan).

3- Community Centre (Our Step Association): This national non-profit association run by service users (people with mental illness), established in 2010. The main goal is to support service users and participate in developing mental health policies and legislation that promotes the rights of people with mental disabilities to sustain them within the community (Mental Health Innovation Network, 2014; Our Step Association, 2017).

The researcher selected these outpatient departments and community centres for several reasons. First, using various mental health outpatient departments between general hospitals and hospitals for mental health will provide different perspectives and views that will enrich the study and facilitate the recruitment process. Second, most of the population in Jordan is concentrated in Amman City. Third, people who came to Amman from different regions and areas in Jordan sought good medical care. Fourth, the Ministry of Health's outpatient departments will provide a rich and diverse area for recruiting the sample. Ministry of Health has the largest body of health in Jordan and provides mental health facilities. Thus, because the Ministry of Health is in the public sector, most Jordanians are free, as mentioned in Chapter 1 (1.4.7 Health Insurance Availability). Finally, the community centre (our step association) was selected because people with mental illnesses run it. Thus, it provides a rich data collection environment and a variety of experiences.

Jordan's healthcare system has four sectors: public, educational, private, and military. The Ministry of Health is the regulatory body of these sectors that follows the general health policies and principles provided by the Ministry of Health. In addition, it has policies and rules which regulate daily work, as mentioned in Chapter 1. However, the Ministry of Health, Jordan University Hospital, and the community centre have an ethics committee. Therefore, permission and ethical approval were sought. Because of the COVID-19 pandemic (2020/2021), permission was requested via an online application through the website of these organisations after permission was granted by the Ethics Committee of the Faculty of Health Science at the University of Hull as a copy needed to be attached to the application for these organisations.

The Ministry of Health Outpatient's Mental Health Department has 37 outpatient departments (See Chapter 1.4.4 Community Outpatient Clinics). These clinics work daily from 8 am-4 pm except for Friday and Saturday. At Jordan University Hospital, there is one outpatient clinic for mental health, and psychiatry runs four days a week: 9 am-2 pm Sunday, Tuesday, and Thursday. On Mondays, from 11 am-4 pm.

3.7.1 Gaining Accesses

Initially, the researcher gained ethical approval from the ethics committee of the following institutions (See Appendix D: Ethical approval forms). The ethical approval form was submitted to the ethics committee at the Faculty of Health Science, University of Hull after all forms were completed and signed off by the supervisory team. After that, approval was granted. Then, this letter was sent to the ethics committees of the selected institutions in Jordan. Every institution has its special requirements; all forms and requirements were submitted online or sent by email because of COVID-19 restrictions on travel. Then, ethical approval was granted from the selected institutions. The next step was to send the approval letter to the gatekeeper to start the recruitment process.

1- Faculty of Health Science (FHS), University of Hull. Then

2- Ministry of Health, Jordan.

3- The ethics committee for each hospital.

4- Community Centre (Our-Step Association).

Jordan has no national ethical approval system, and most hospitals have an ethics committee. For example, to gain ethical approval from a public hospital in Jordan, the researcher must apply to the Ministry of Health Ethics Committee to apply to each hospital separately. Teaching hospitals have ethics committees, and community centres have separate entities and ethics committees. Therefore, researchers have applied these directly.

After ethical approval is obtained from the Faculty of Health Science at the University of Hull, UK, a moral application will be submitted to the ethics and research committee of the Ministry of Health, Jordan University Hospital, and the community centre (our step association). In light of the COVID-19 (2020) pandemic, an application form will be filled out online on the official site for these organisations, including (a brief description of the study and the purpose of the study) and a copy of the ethical approval from the University of Hull, interview questions, and Good Clinical Practice certificate.

First, Jordan University Hospital is a teaching hospital under the Ministry of Health and the University of Jordan Care. However, the Hospital has an ethics committee for submission of the application will be submitted. The committee gathered monthly to decide on the Institutional Review Board (IRB) and other issues.

The second is the Outpatient Department of Mental Health. These departments are under the Ministry of Health, where the application will be submitted to the ethics committee, and they gather for decisions and other issues every month after these departments grant the IRB, the community centre (has its ethics committee).

The suggested data collection period may take up to three months (this period has been given based on the participant's response rate estimated as 20% /day from outpatient departments, as these clinics deal with more than 200 patients and their primary caregivers per day). The hospital outpatient mental health clinic was chosen to allocate the study sample. Participants will be selected according to their availability in the clinic and will meet the study inclusion criteria mentioned in the sample section. No extra cost is needed because the study will be conducted online and based on the participants' schedules.

3.7.2 Sampling and sample size

The theoretical sample in grounded theory starts with selective sampling, and the rest is open, depending on concept development (Charmaz, 2006; Corbin & Strauss, 2015) (see Section 3.5.3). The researcher cannot predict the number of participants while constructing a theory because it is a crucial step in maintaining the flexibility of the sample and setting depending on concept development (Corbin & Strauss, 2015). Holloway and Galvin (2017: 151) “There are no rigid rules; 6-8 data units are seen as sufficient when the sample consists of a homogeneous group, while between 14-20 might be needed for a heterogenous sample”. Moreover, Mason (2017: 72) urged that in qualitative studies, “the sample size may be small or large depending on the type of research question, material, and time resources”.

Charmaz (2006.114) suggests that 25 participants are sufficient to reach data saturation. Similarly, Creswell (2012.210) suggests that the sample size for qualitative research typically varies from 1-40 participants. Charmaz (2006.113) mentioned that “*Categories are saturated when gathering fresh data no longer sparks new theoretical insight, nor reveal new properties of these core theoretical categories*”. However, when to stop sample recruitment depends on the research decision as the data analysis develops indicators of whether or not the categories are saturated. Based on that, the researcher can decide whether to stop or continue sampling; however, the researcher will stop sampling at some point in the study (Morse, 2007). In qualitative research, the author emphasizes that the primary consideration regarding sample size pertains to the ability to produce an adequate amount of data, which enables the investigator to explore the research inquiry effectively (Mason, 2017).

In the current study using selective sampling strategies, I recruited 17 participants who met the inclusion criteria and decided to stop recruitment after conducting seventeen interviews with fourteen participants. I felt I had generated enough and sufficient data to answer my research question, and data saturation was met, which occurred when no new themes emerged from the interview from each study group, as discussed above.

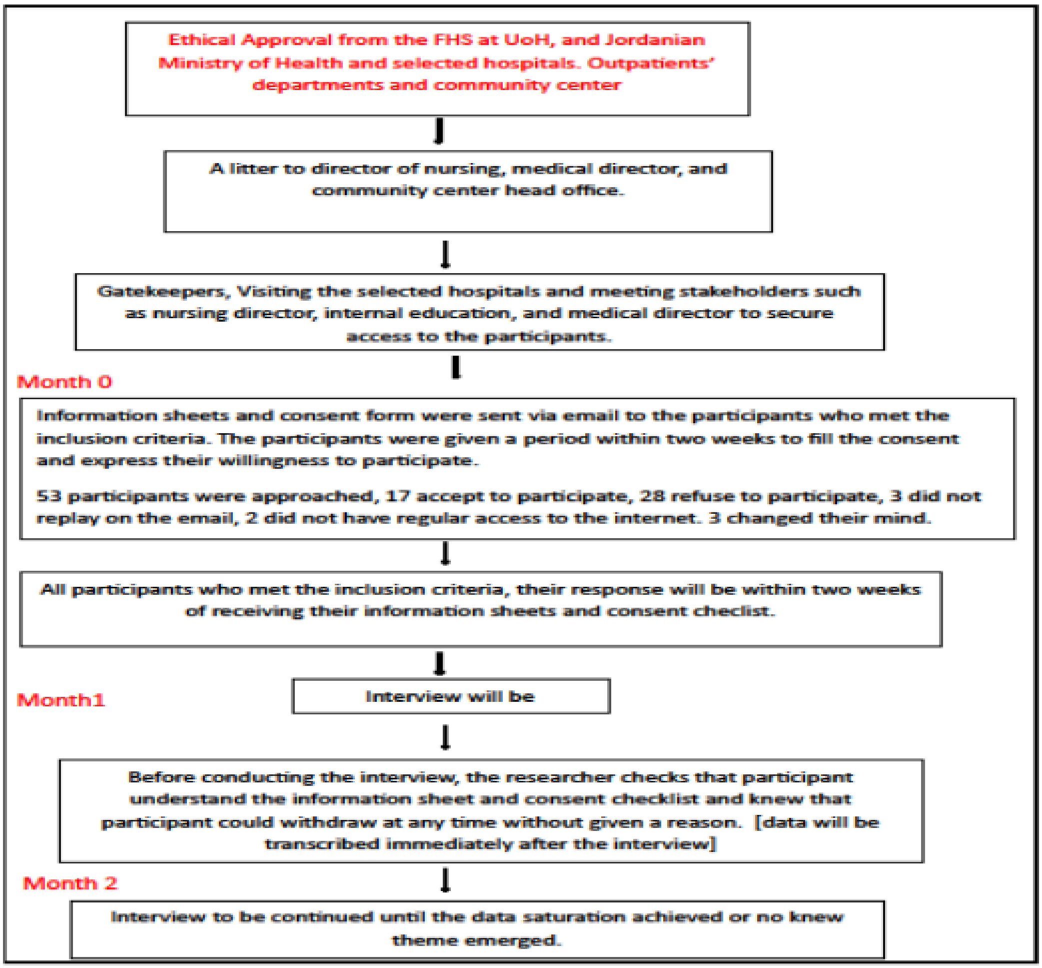
The study participants were recruited from outpatient mental health settings and community centres (Our-Step Association). As patients who attend these clinics are generally stable, able to decide on their health (Townsend & Morgan, 2017), and manage their medication at home by themselves or by their primary caregiver, the reasons for being in the outpatient department are to follow up or renew their prescriptions. Participants were people diagnosed with schizophrenia or bipolar disorder, primary caregivers, and healthcare professionals in an outpatient mental health department. Therefore, a selective sample was used. A selective sample is a type of non-probability sampling that is part of a selective sample, popular in qualitative research (Mertens, 2014). It is used to develop in-depth details about a phenomenon and help the researcher select participants or sites rich in information to help researchers explore the phenomenon (Creswell, 2012). The selective sample allowed for data collection from the available participants in the clinic at that time and met the inclusion criteria. Therefore, at the beginning of the study, a selective sample was used to choose the sample in the beginning, and after the interviews with participants from the three groups, data were transcribed and preliminarily analysed after each interview directly to check for further questions that may be needed to add to the interview question guide based on the participants and supervisor feedback few modifications and prompts added to the interview guide based on the emergent themes to explore more about the phenomena. Thus, the study began with selective sampling and ended with theoretical sampling. One of the advantages of semi-structured interviews is the possibility of modifying the interview prompts and questions by adding or removing them during the data collection phase, depending on the emerging theme (Corbin & Morse, 2003).

3.7.3 Sample recruitment

Participants were selected from the outpatient departments (because I need to understand the factors from the outpatient department who are able to communicate and take their medication at home, not in the acute phase and their medication is controlled by nurses) of Jordan University Hospital, outpatient mental health clinic department under the Ministry of Health, and community centre (Our-Step Association). The study was conducted online owing to the COVID-19 pandemic. The gatekeeper (the person who will help the researcher with sample recruitment; this could be a psychiatrist, nurse, or manager) asked to help the main researcher identify the participants (health care professionals from the selected hospitals and the community centre) (See Figure 14: Appendix E- 5. Letter to the gatekeeper-Senior Nurse and Figure 15: Appendix E- 6. Letter to the gatekeeper-community centre) by approaching the participants and post flyer in the clinical and community centre (see Figure 18: Appendix E- 9. Flyer to Service user and primary caregiver and Figure 17: Appendix E- 8. Flyer to HCP). In addition, the researcher sent email invitations to the healthcare professionals' participants (See Figure 16: Appendix E- 7. Email Invitation to HCP). Contacting the gatekeeper was important, and it was an easy step for me because of my job as a nurse in the past.

They were provided with the inclusion and exclusion criteria. The potential participants were asked to contact the researcher by email for further information about the study; some participants preferred to use their smartphone to be contacted via “what’s app”, but the sheet and consent checklist to be sent to their emails, so an ethical approval from the University of Hull obtained (see Figure 6: Appendix D- 2. University of Hull approval letter -amended).

The sample was divided into three groups: patients (service users), primary caregivers, and healthcare providers. The recruitment depends on the inclusion and exclusion criteria. See Table 11: Participant inclusion and exclusion criteria.



Ethical Approval from the FHS at UoH, and Jordanian Ministry of Health and selected hospitals. Outpatients' departments and community center

A litter to director of nursing, medical director, and community center head office.

Gatekeepers, Visiting the selected hospitals and meeting stakeholders such as nursing director, internal education, and medical director to secure access to the participants.

Month 0

Information sheets and consent form were sent via email to the participants who met the inclusion criteria. The participants were given a period within two weeks to fill the consent and express their willingness to participate.

53 participants were approached, 17 accept to participate, 28 refuse to participate, 3 did not replay on the email, 2 did not have regular access to the internet. 3 changed their mind.

All participants who met the inclusion criteria, their response will be within two weeks of receiving their information sheets and consent checlist.

Month1

Interview will be

Before conducting the interview, the researcher checks that participant understand the information sheet and consent checklist and knew that participant could withdraw at any time without given a reason. [data will be transcribed immediately after the interview]

Month 2

Interview to be continued until the data saturation achieved or no knew theme emerged.

Figure 2: Process of ethical approval and recruitment process

3.7.4 Inclusion and exclusion criteria for participants:

See the table below for inclusion and exclusion criteria for the participants.

Table 11: Participant inclusion and exclusion criteria

Inclusion criteria	Exclusion criteria
patients	
1- People with schizophrenia or bipolar disorder aged 18 years or older. (because I need to meet the patient alone, not with family, The policy in Jordan is that people under age 18 must be accompanied by an older family member (mother, father, older brother or sister), as the legal age in Jordan is 18 years and above (International Centre for Missing & Exploited Children, 2019, national child protection legislation, Art 2, as the presence of family member will impact on the participant's point of view.	Age less than 18 years.
2- Primary diagnoses with schizophrenia or bipolar disorder are based on the ICD-10 criteria and DSM-5 (see Chapter 1.4.1 Prevalence)	Other psychiatric disorders have a dual diagnosis or involve alcohol consumption.
3- Receiving at least one prescribed psychiatric medication.	Not receiving psychiatric medications.
4- Able to read, understand, and write Arabic (psychiatrist, then the author KO will assess that)	Unable to read or write
5- Cognitive function to give verbal consent (the researcher will assess cognitive mental ability on the day of the interview by discussing the consent checklist with participants. Participants who can recall, summarise the main purpose of the study and understand that will be selected)	Participants were unable to recall or understand the main aim of the study.
Family member	
6- Family or primary caregivers, age above 18 years, lived with patients for one or more years.	Not live with patients or care with patients occasionally.
7- Who can write and read Arabic	Who are illiterate or unable to write and read.
Health care professionals	
8- For health care professionals, if registered qualified nurses (a nurse holding a bachelor's degree in nursing who completed four years at university) or an Associated nurse (with a nursing	For nurses who work with patients for less than one year, resident doctors in psychiatric departments do not start third-year residency—nurses or

assistant degree completed two years at college) work with patients for more than one year. Psychiatrists or third-year resident doctors in the psychiatric department	doctors who take a prolonged leave, such as unpaid leave.

In addition, the participants needed to be:

- Willing to participate.
- Able to participate.
- Willing to discuss their perception, attitude, knowledge and share information about their experience with the phenomenon under study.

3.7.5 Mental Capacity

The cognitive mental ability of people diagnosed with schizophrenia or bipolar disorder will be assessed based on the Mental Capacity Act of 2005 in the UK. The UK Mental Capacity Act (2005) was chosen because there is no such act in Jordan. However, researchers in Jordan depend on the Jordan Food and Drug Agency (Jordan Food and Drug Administration, 2003) and the Ministry of Health law to guide their research. These laws are based on the Declaration of Helsinki (Ramahi & Silverman, 2009). The Declaration of Helsinki is a set of principles that drives healthcare providers to conduct research involving humans. Therefore, the researcher will rely on these principles to select participants (people with schizophrenia or bipolar disorder). The National Health Services (NHS) mentioned that if a person can understand the given information, retain it, and use it as part of the decision-making process, they can give a consent form (National Health Services, 2018). Based on this, the information sheets will be explained to the patients, and they will be asked to summarise the most important points and what they understand. If patients cannot do that, they will be excluded.

3.7.6 Participant’s recruitment

Participants in this study were not paid for their time; they were told that explicitly and stated that clearly in the information sheet. As this study was not funded by any institution, participants were thanked at the end of the interview and told that their participation was priceless and valuable, which will help improve medication-taking behaviour for people with mental disorders. They were happy to participate as they wanted to express their feelings and emotions.

Patients (Service Users)

Service users were recruited from outpatient departments, which are known to be a rich environment for people diagnosed with schizophrenia or bipolar disorder and their primary caregivers. The participants were selected based on the inclusion criteria provided to the gatekeeper. Participants were asked to provide their email them, and gatekeepers sent the emails to the researcher (one of the gatekeepers was a patient diagnosed with schizophrenia, and she now led the community centre. She helped me a lot in recruiting participants from the community centre and advised me in some areas of interview questions). The researcher sent the information sheets and consent checklist to them and answered any questions they had about the study. After they replied (in the email, yes, I agree to participate), they asked which communication method they preferred: video or audio. The interview was scheduled via the Zoom application audio. At the beginning of the interview, participants were asked again if they were happy to proceed with the study using Zoom and digital recording, and their verbal consent was confirmed. The participants were asked before the beginning of the interview recording and after the recording started to provide their consent). At the beginning of the interview, the researcher ensured that the participant had the mental capacity to provide the consent checklist by understanding the given information, retaining it, and using it as part of the decision-making process. This is a mental capacity assessment. As the researcher went through the consent checklist point by point, he signed on behalf of the participants and resented it back to them by email, which was kept in a secure encrypted file at the University of Hull server.

Similarly, the Community centre participants (Our-Step Association) can make their own decisions, as they depend entirely on themselves. As mentioned earlier, Our Step Association is run by service users. As mentioned above, mental capacity was checked by asking them questions about the information sheets. The inclusion and exclusion criteria will be given to the head of the Association (Mrs A A), who helped in the participants' recruitment process (*See Figure 10: Appendix E- 1: Service User Information sheet).*

Primary caregiver

The gatekeeper person (a health care professional, a psychiatrist from the outpatient department, and the head of the Our Step Association) posted a flyer on the clinic announcement board and community centre. The interested participants contacted the researcher directly, and the gatekeeper asked the service user's family if they wanted to participate in the study. If they agreed, they were required to provide their emails to them or email the researcher directly, who sent further details about the study by email. The information sheet and consent checklist answer any questions about the study (their emails were provided voluntarily after the gatekeeper told them about the study). After sending their responses by email (yes, I agree to participate), in the same email, they asked which communication method they preferred, zoom audio or video. The interview was scheduled via Zoom's audio application.

At the beginning of the interview, participants were asked again if they were happy to proceed with Zoom to confirm their verbal consent checklist and check their mental capacity. The researcher will go through the consent checklist point-by-point, then he will be signed by the participant's name and resent it back to them by email, which will be kept in a secure encrypted file at the University of Hull server. as mentioned earlier. However, if the service user and the primary caregiver are from the same family, they will be asked to interview separately, as the community centre's people are entirely independent. The hospital participants' gatekeeper (HCP) will ask the service user and the primary caregiver if they can meet separately or not; if not, the gatekeeper will ask them to meet (dyad) *(See Figure 11: Appendix E- 2: Primary caregiver Information sheet).*

Health care professional (HCP)

The gatekeeper (HCP) provided the author with an email from healthcare professionals or psychiatrists who were interested in the study. This was given voluntarily; the gatekeeper posted a flyer in the outpatient mental health department, and interested participants contacted the author directly. Emails were sent to them to participate in the study; if they agreed, an information sheet and consent checklist were sent to them. The researcher answered all questions before the beginning of the interview. Once they accept participation, interviews will be scheduled. Healthcare professionals were the same as other participants. Verbal consent was obtained at the beginning of the interview. The researcher went through the consent checklist point by point, then signed it on behalf of the participant's name and resent it back to them by email. This consent checklist was kept in a secure encrypted file at the University of Hull server (See Figure 12: Appendix E- 3: Healthcare professionals Information sheet).

Table 12: The timeline for participant recruitment.

Period	Process
Month 0	The participants were allocated to outpatient clinics. Information sheets and consent checklists were delivered to participants via email.
Month 0- Month 1	Participants who were willing to participate responded within two weeks of the email.

Month 1	Participants who agreed to participate were interviewed using the Zoom online application.
Month 2	The interviews continued until data saturation was achieved.

Excluded participants.

As mentioned earlier, the excluded participants did not meet the inclusion criteria and were under 18. The study focused on people diagnosed with schizophrenia or bipolar disorder to understand their behaviour toward psychiatric medication. Therefore, the researcher must follow the inclusion and exclusion criteria to answer the research questions. At the hospital, diagnoses can be found in the patient's records, so the gatekeeper (psychiatrists) can identify their diagnoses. However, the gatekeeper (head of the community centre) needs to check the participants' discharge reports to confirm the diagnosis in the community centre.

Participants who could not read and write Arabic were excluded because there was an information sheet and consent checklist. They needed to understand independently and not be influenced by the gatekeeper or the researcher. The participants should be able to make their own decisions about participation in the study. The gatekeeper asked the potential participants to read and write Arabic and to read a small paragraph as well. This was reassessed during the interview when the consent checklist and information sheets were discussed. While the primary caregiver can read and write as he reads the poster and contacts the researcher, this is considered an assessment of their ability to read and write Arabic and when the consent checklist was discussed in the interview. The study also focused on people diagnosed with schizophrenia or bipolar disorder as the primary diagnosis, so any other psychiatric disorders were excluded.

3.8 Ethical considerations:

The present study was conducted in Jordan. Ethical approval was obtained from the Faculty of Health Science Ethics Committee of the University of Hull, and the Institutional Review Board (IRB) was obtained from the institutions allocated for data collection in Jordan (Jordan University Hospital, Ministry of Health, and Community Centre) before data collection. As the topic is sensitive to Jordanians, close attention will be paid to the confidentiality of the participants' information, autonomy and voluntary participation, beneficence, non-maleficence, and justice.

3.8.1 Confidentiality:

The interviews were conducted online using the Zoom application, in addition to a digital recorder to record the interviews. A cover letter containing information about the study's general purpose was emailed to the potential participants. A clear statement indicates that no data, such as names, are requested on the information sheet, and they are replaced by code. The information is confidential unless there is information that will help with the medical treatment or threaten the service user's life or others; this is explained in the information sheet and consent checklist. The disclosures may indicate risk from the patient [service users], primary caregiver, or misconduct/unprofessional behaviour from healthcare professional participants. This disclosure will be delivered to doctors, healthcare professionals, and primary caregivers. The researcher will inform the responsible manager of the threat from a healthcare professional to the patients. This is clearly stated in the information sheet and consent checklist (see the attached forms). The same was true at the Community Centre: any behaviour or talk indicating risk for the participants or other people in the community centre will be delivered to the head of this community centre. In this study, no risky behaviour or misconduct was noted or reported by the participants.

The researcher ensured the data were stored according to the Data Protection Act (2018) in the UK and at the University of Hull Data Protection Policy. Interview transcripts and records (MP4 and/or M4A) were saved on a University of Hull secure drive for backup (such as one drive platform or the University of Hull servers). The digital recorder MP3 was downloaded to the University of Hull server via a USB or memory stick. After the transcription and analysis of the interview ended, the recordings (MP4, M4A, and MP3) were destroyed.

In contrast, the participant's personal information and contact details (emails) were coded and saved in encrypted Microsoft Word on the University of Hull server for destruction 10 years after the study ended or based on the University of Hull guidelines. Personal information or contact details will not be shared with anyone because it has sensitive information about vulnerable populations who have a mental disorder, except the principal supervisor, as the custody will be transferred to him after I finish my PhD at the University of Hull. Any information other than personal information and contact details, such as the research method protocol, could be available. The transcript was destroyed after the data analysis and finding chapter was finished based on the University of Hull protocol.

In Jordan, no acts or laws inform the researcher to protect the participants' data, but they rely on the research's general principles to do good and do no harm. However, the researcher stated a clear statement in the consent checklist, telling the participants that their confidentiality would be a top priority and protected unless there was an issue that would expose them to any potential risk, such as (suicide or psychological harm) as mentioned earlier.

The participants did not track the interview quotations displayed in the research. Recording was done using two methods: digital recording and zoom recording. During the recording, the researcher asked the participants not to mention their names. The digital recorder provided a code number rather than a name. MP4 and/or M4A and MP3 of the interview were destroyed, and the interview transcript was saved securely on the University of Hull server.

The personal data of the participants was recorded during the interview as interview questions, and it was anonymised and securely saved. These personal data are used for descriptive statistics to describe the sample and in the discussion section.

The researcher ensured that the data were stored in accordance with the UK's Data Protection Act (2018). The study was conducted online in the UK (interview host). However, the interviews were transcribed after the meeting. The transcript is then saved on the University of Hull secure drive for backup. Ten years after the completion of this thesis, the data were destroyed.

However, the online application and recording may breach the patient’s privacy (not with Zoom as it has GDPR-compliant principles (lawfulness, fairness, transparency, purpose limitation, data minimisation, accuracy, storage limitation, integrity and confidentiality, and accountability)). However, the researcher may not have met with the patients alone. The family may be anywhere around the patients where the researcher cannot see them, which may affect their views. To overcome this, the service user and the primary caregiver were asked to attend the interview together; however, most participants were alone.

Service users and their primary caregivers were asked to be alone in the room with nobody else. Gatekeepers were asked to recruit service users who could meet the researcher alone. The researcher used reflective field notes completed immediately after each interview to ensure that any important observations were linked to the time of each recording and transcript. If the primary caregiver's interference interrupts the interview with the service user, the researcher may cancel this participation and dismiss the interview. However, the convenience to the participants of this method is for the same or similar reasons (reduced travel, saving money for buying food while waiting in the clinic, etc.) and being in friendly surroundings.

However, the researcher stated a clear statement in the consent checklist to tell the participants that their confidentiality would be a top priority and protected unless there was an issue that would expose them to any potential risk, such as (suicide) or physical harm). However, the researcher informs the responsible manager if there is a threat from a healthcare professional toward patients, such as poor practice.

3.8.2 Autonomy and voluntary participation

Participant autonomy is another ethical concern in health research. The information sheet stated that participation in this study was voluntary. The participant had the right to withdraw at any point until the end of the interview, after which withdrawal of your data would no longer be possible because the data would have been anonymised or committed to the final report. If you choose to withdraw from the study, the information given will not be able to give it to you, as it is anonymised. The interview participants will give their consent and verbalise that they will participate voluntarily. During the online interview, participants had the right to pause the interview for a break, which will also be explained on the information sheet.

However, the participants were people diagnosed with mental disorders, and this group was considered vulnerable. British Psychology Society (2014.31) mentioned that vulnerable groups include "children under the age of 16 years, people with learning or communication disabilities, patients in care, people with lack of mental capacity, people engaged in illegal activities, or drug abuse". This population requires further attention to understand the nature and purpose of the study (British Psychological Society, 2014). As this study had three groups, the vulnerable group was patients (people diagnosed with schizophrenia or bipolar disorder). The researcher ensured that all participants fully understood the information sheet and answered their questions about the study; significantly more time was needed for the patient [service user] participants. Also, there is no relationship between the participants and me prior to the study, so there is no embarrassment in forcing them to participate.

3.8.3 Beneficence and non-maleficence

The researcher always attempts to ensure that the study will not harm the participants and society. However, the researcher ensured that the study results were beneficial for the participants and the whole community, as the study aimed to identify the factors that influence psychiatric medication-taking behaviour. The researcher hoped that this would help develop interventions to improve medication-taking behaviour in the future. On the information sheet, the researcher explained that there is no direct benefit from participation in this study, such as payment for participation.

The benefit of this study is that the participants were actively involved. This will help generate learning materials for the future, and the study's findings will be shared with them to show how the results could help other people improve their mental health. The possible risks from this study to the research participants may have been stress or anxiety. Through discussion, they may become more aware of what they do not know or understand regarding their diagnosis and treatment.

To minimise risks, the purpose of the study was explained to the participants to help them understand why their participation is important, how their participation will be protected, and how their data will be protected. The participants had the right to withdraw from the study without mentioning any reason. They will be able to withdraw their data from the study until they are transcribed, after which their withdrawal will no longer be possible because the data are anonymised or committed to the final report. Their data would not be retained if they chose to withdraw from the study before transcription. As mentioned earlier, considering COVID-19, this study was conducted online to consider all previous measures. This online method saved more time for participants and researchers and was more convenient for all study participants, as the interview was scheduled based on their time and preferred place.

3.8.4 Justice

The study sample was selected based on the selective sampling technique; the sample was recruited from outpatient departments in two hospitals and one community centre, as mentioned earlier. All participants provided the same information about the study; in the interviews, the participants were asked based on the interview guide.

3.9 Data Collection

3.9.1 The Consent checklist

The consent process is an essential part of the data-collection phase. None of the participants continued the study unless the verbal consent checklist was recorded. Participants were given an information sheet and consent checklist (by email) to read thoroughly before the interview to be able to share their verbal consent.

The consent checklist included details on voluntary participation in the study and data protection. However, the researcher will go through the consent checklist point-by-point, then sign it on behalf of the participants by their names and return it to them by email, which was kept in a secure encrypted file at the University of Hull Server.

Additional time is needed for patients (service users) to explain the information sheet and consent checklist. This helped them decide whether they would take part in the study. Service users are recruited as they can depend on themselves and make their own decisions. They went through the consent checklist independently during the interviews with the researcher.

See Appendix 6 for research documents (patient Information Sheet, primary caregiver information sheet, healthcare professional information sheet, and consent form checklist).

3.9.2 Qualitative interview

Interviews are an important data-collection method in qualitative research (Creswell, 2012; Mertens, 2014). For example, people diagnosed with schizophrenia or bipolar disorders and primary caregivers who can report their beliefs and attitudes and talk about their behaviour and knowledge will provide rich information about this phenomenon. Healthcare professionals may also discuss their experiences with patients and their families about medication-taking behaviour and give their impressions and responses.

The most common qualitative research method for producing knowledge is interviews (Mertens, 2014; Denzin Lincoln, 2018). Postmodern age interviews have many different shapes than traditional face-to-face interviews, such as by telephone or using the Internet for online applications such as Zoom and Skype (Denzin & Lincoln, 2018). An important feature of grounded theory interviews is that they must be adaptable and receptive to new ideas. In practice, this implies that each interview will be unique because it will be impacted by the themes shown in prior interviews (Strauss & Corbin, 1998). This distinguished grounded theory interview from other interviews used in different qualitative studies had the same question set for all participants (Denzin & Lincoln, 2018). The interview was considered a good opportunity to build a trusting relationship with the interviewees to describe their experiences, feelings, beliefs, and knowledge; furthermore, the participants understood the research problem more through discussion.

3.9.3 Semi-structured interviews and rational

In qualitative research, three types of interviews are structured, semi-structured, and in-depth. First, structured questions with limited answers lead to structured interviews, and the interviewer needs to be trained. Second, semi-structured interviews provide an in-depth description of the phenomenon under study using open-ended questions, which enable participants to express their experiences, beliefs, and attitudes in words. Third, the in-depth interview is less structured than the two types above; it explores one or two themes with more important details (Pope & Mays, 2020).

In the current study, semi-structured interviews with open-ended questions were used to enable the researcher to investigate and probe more meaningful details about the topic. This approach was chosen to explore the beliefs, behaviour, knowledge, and experience of people diagnosed with schizophrenia or bipolar disorder and primary caregivers toward psychiatric medication and factors that influence medication taking, as well as to explore healthcare professionals' views regarding this issue. An interview guide was based on the research questions to build up the prompts to structure the interview to focus on the research problem (Pope & Mays, 2020). The length of the interview ranged from 30 minutes to an hour to develop an in-depth understanding (DiCicco ‐ Bloom & Crabtree, 2006). The interview was 45-60 min because the participants were service users, primary caregivers, and healthcare professionals who have other responsibilities, so the interview was adjusted to suit them.

Semi-structured interviews included an interview guide that involved pre-planned prompts that guided the researcher to cover the area of interest in the interviews with all participants. Using this approach, the researcher could use probing questions to enrich the interview information; the researcher could eliminate irrelevant data and save time (Holloway & Wheeler, 2010).

3.9.4 Interview Guide

Before conducting the interviews, prompts were designed to ensure the focus of the study. These prompts are derived based on a gap in the literature in Jordan regarding medication-taking behaviour among people with mental disorders, such as schizophrenia or bipolar disorders, as mentioned in Chapter 2 (literature review). This literature reported that several factors influencing medication-taking behaviour among people diagnosed with schizophrenia or bipolar disorder need further investigation in Jordan. Another advantage of the semi-structured interview is that it enables the researcher to modify questions during data collection in response to the collected data (Holloway & Wheeler, 2010; Denzin & Lincoln, 2018).

Different types of questions can be asked in qualitative research, such as experience, knowledge, beliefs, attitudes, feelings, perspectives, and behaviours (Patton, 2002). The following prompts will guide the interview to underpin these prompts further, and a subset of questions will be included under each, as shown in the table below. Some differences in the prompt questions for the groups depended on the emergent themes from the previous interview, which made it flexible and adapted to the emergent theme and ideas. Charmaz (2006) suggested that the questions should not be judgmental, and this allows the interviewee to give more details about the study subject. I was interested in and enthusiastic about conducting the interview.

Main interview general prompts:

1. Participants' beliefs and attitudes regarding taking psychiatric medications.

2. Participants' knowledge of psychiatric medications.

3. The participants understood the factors that influenced their medication taking.

4. The participants were taking psychiatric medication.

Table 13: Interview topic guide

Prompts	Service users (Figure 21: appendix E-12. Service user interview guide)	Primary caregivers (Appendix E- 1. Primary caregiver interview guide	Health Care Professionals (Appendix E- 10. healthcare professionals' interview guide)
	Demographic data: Age, gender, smoking, drinking alcohol (how much, how many years), medications name, dose, route, frequency, marital status, average income, work, study, and how many years being diagnosed].	age, gender, smoking, patient medication name, dose, route, and frequency, relationship to the patient, marital status, average income, work, study, how many years taking care of the patient, connection to the patient)	age, gender, years of experience, study level, how many years treating or dealing with psychiatric patients.
Q1 Prompts: Participants' knowledge about their psychiatric medications.	Tell me about your medication. What do you think about (X medications? What is it for? What is the most important thing to know about this medication?	Could you tell me about the medications of the person you are caring for? What do you think about (X medications? What is it for? What is the most important thing you should know about this medication?	To what extent do you think that patients and their primary caregivers have any knowledge about their medications? What is the important thing they know about their medication?
Q2 Prompts: Participants' beliefs about psychiatric medication.	Do you think that X medication helps you? Could you talk more about that?	Do you think that psychiatric medication is helping the person you care for? Tell me more about that.	Do you think that psychiatric medication is helping patients? Tell me more about that.

Q3 Participants' experience with psychiatric medication taking.	Can you tell me more about your experience with your psychiatric medication? Is there anything else you want to tell me about your medication? How do you manage?	While you are caring for the person, they take psychiatric medication. Can you tell me about your experience with that? Is there anything else you want to tell me about your medication? How do you manage that?	From your experience as a healthcare professional dealing with patients and families, could you tell me more about the psychiatric medication among these groups? Is there anything else you want to add?
Q4 Prompts: Understand what helps/barriers to taking medications.	Can you tell me what you think about when you are deciding if you want to take your medication or not?	Can you tell me what you think about when you are deciding if you want to give the person you care for the medication or not?	What do you think are (helping or preventing) patients or primary caregivers from taking the psychiatric medication as intended?
Q5 Prompts: Participants' experience and knowledge.	If you need more information about your medication, what do you do?	If you need more information about the medication of the person you care for, what do you do?	How do we ensure patients/caregivers have all the medication information? Can you give some examples?
Q6 explore knowledge about the medications.	Are there times when you do not take your medication? No, why not? Yes, tell me more about that.	Do you (as a primary caregiver for the person), to the best of your knowledge, ever miss taking a dose? No, why not? Yes, please, could you tell me more?	How often do patients or their primary caregivers tell you that they miss some medication doses? What do you do in such a case?

3.9.5 Conducting an interview and practical issues:

Before the interview by the principal researcher (Khaldoon), it was arranged based on the participants' schedule and held online using the Zoom application. The researcher reminds the participants about the purpose of the study and the confidentiality of the data provided unless there are any issues regarding the participants safeguarding that will be disclosed to third parties (primary caregiver, healthcare professionals, healthcare professionals managers, community centre gatekeeper). Otherwise, everything would be confidential. According to Mertens (2014), conducting a successful interview requires preparation, and she suggested six steps to conduct the interview:

1- Hold an introductory meeting to build trust and remind patients of the purpose of the study.

2- Interviews in a local language enable the researcher to explore the phenomena more and the questions to be clearer.

3- Make an interview schedule; this will help the researcher set up the time and days and who are the participants. This will help save time for the researcher.

4- Create an interview guide to help the researcher outline the interviews.

5- The interview guide should be open-ended, not yes or no, to provide more information.

6- Pilot the interview, checking the suitability of the question and any modifications needed to serve the study's main aim. Please note that no interview was repeated.

3.9.6 Zoom Application (audio):

As mentioned earlier in this chapter (3.6 COVID-19 Adaptation), this study was conducted abroad. Therefore, academics and healthcare professionals recommend using the Zoom application video or audio in Jordan's mental health area. Many studies in different domains have used the Zoom application in Jordan, such as teaching and health studies (e.g., (Akour et al., 2020; Al-Balas et al., 2020). Full registration was completed by buying the application for the data collection period between 3-6 months. The Zoom version is the latest version at the time of full registration. This enabled the researcher to save the record of the interview on the Zoom cloud, which allows recording and saving up to 30 days; the recording was available after the interview ended (it may take up to about two times your meeting lengths to process, as the Zoom technical support explained that entirely). This enabled the researcher to access and listen to the recording again, download it, and transcribe it after the interview. The recording was then deleted from the Zoom cloud after downloading to the University of Hull servers. Deletion of the recording from the cloud adds more room for further recording. As for data protection, the cloud's omission is permanently impossible to bring back, as the Zoom team said when contacted about privacy and data deletion. In addition, they stated that the Zoom application complies with the GDPR. They did not record or use the registered people’s data or their interviews or recordings.

Zoom video and audio communication is a General Data Protection Regulation (GDPR) and Data Protection Impact Assessment (DPIA) compliance as its–encryption. Data are secured and protected against damage, loss, and unauthorised alterations (ZOOM, 2020; Zoom Privacy Statement, 2020). The estimated cost of full Zoom registration for the year is approximately £200-400. Zoom is known to comply with GDPR data protection and personal information privacy, both locally and internationally. These principles are (lawfulness, fairness, transparency, purpose limitation, data minimisation, accuracy, storage limitation, integrity and confidentiality, and accountability), and will be protected by end-to-end encryption by Zoom (Zoom Privacy Statement, 2020; ZOOM, 2020).

Full licence Zoom provides more security and data protection via end-to-end encryption and backup files in case of damage; data are protected against lawful and unauthorised persons' access. The interview was saved on the Zoom cloud, and the researcher transcribed and downloaded the recording to the University of Hull server within four working days. Once the interview format MP4 and/or M4A format was downloaded from Zoom cloud, it was deleted immediately, and once deleted from the cloud, there was no way to bring them back again (securely deleted) (Zoom Privacy Statement, 2020; ZOOM, 2020).

The interviews were transcribed and cleaned of all personally identified data into a password-protected Microsoft Word document and saved on the researcher's cloud storage at the University of Hull servers that are encrypted and password protected. The themes that emerged for the data analysis were transferred to Microsoft Word, saved on the researcher's cloud storage, and backed up on university secure drives. Interview data were collected and stored at the University of Hull server. This data protection process was similar for the three groups of the study (patients (service users), primary caregivers, and healthcare professionals).

Zoom is globally well-known and operated, so the data can be stored in any country where the service provider has the facility. Data storage depends on the host's geographical location (Zoom Privacy Statement 2020). Thus, it will be in the UK using the University of Hull server, which complies with the UK GDPR. See Table 14: How to join Zoom meeting (practical guide)(This information will be included in the email and the information sheet).

Table 14: How to join Zoom meeting (practical guide)

How to join Zoom (practical guide)
To Join a Zoom Meeting, the link is sent to you. Click on it, and it will direct you to the meeting screen. If you are using a laptop to access the session, you will be prompted to download the Zoom plugin after clicking on the meeting link (provided to you via email). If you have headphones or earplugs, please use them because they help eliminate background noise. Please follow your screen instructions to download the plugin, which is easily accessible, safe, and secure. Please click Open Zoom Meetings if you see the system dialogue. If nothing prompts from the browser, go to Zoom.US to download and run Zoom. To be able to join a virtual session by mobile phone or tablet device, use the free Zoom app. Must be downloaded from the application store. The meeting room will be opened 10 minutes before, so please sign early, overcome any obstacles before the meeting starts, and then feel free to switch off video and audio and carry on with your day until the session starts.

3.9.7 Interview stages

I conducted interviews every two to four days based on the participants' schedules and availability, which made it easier to immerse myself in the data throughout the interviews and gave me more time to listen to and transcribe them. There was no matter what the time interview was conducted as it was already scheduled based on the participant's availability and free time, given that some interviews were conducted in the morning and evening (no limitation for this as it is best to fit for the participants), taking into consideration the time differences between the UK and Jordan which were two hours ahead in Jordan.

Charmaz (2006) advise using open-ended questions, not leading questions, to avoid directing participants to a narrow theme. To establish rapport with the interviewee, the researcher introduced himself at the start of the conversation and requested permission to record the conversation. As explained in the information sheet, the application of Zoom recording and digital voice recording was described. Reiterating that there were no correct or incorrect responses and that the conversation would represent their viewpoints and experiences about psychiatric medication use, the interviewer outlined the study's objectives.

The researcher told the participants that they could stop the recording for a break or if they wanted to withdraw from the study at any time, with no explanation. None of the participants asked for a break or withdrawal; however, the meeting was in a friendly environment at their home using Zoom, and the time ranged between 45-60 minutes. The researcher began the meeting with an open question as an ice-breaking technique and then went through the interview guide.

The participants were thanked for their thoughtful cooperation at the end of the interview, and the researcher obtained their consent to contact them in the future for participant verification or to acquire additional data if needed. Interviewees received the researcher's contact details, including their name and email address, if they required further information. The study will be presented at national and international conferences and published in peer-reviewed journal papers, where their details will be anonymised. Study data were provided to the participants and participating hospitals.

3.9.8 Transcription

All the interviews were digitally recorded and transcribed verbatim. Strauss and Corbin (1998) and Charmaz (2006) did not warn against using audio recordings to transcribe the interview verbatim as they are used as an analytical tool. Many researchers and supervisors advise that PhD students or researcher transcribe their study interviews themselves, giving the researcher more experience, immersing themselves in the study data, and becoming more familiar with the theme (Poland, 1995). Three interviews were conducted to begin the process, and verbatim transcripts were used. One of the interviews was then translated into English and forwarded to supervisors for their comments and feedback, and the Arabic version was returned to participants for feedback or corrections. The remaining interviews were transcribed throughout the data-gathering phase. Memos and reflective diaries were used to promote reflection.

To ensure the transcription was accurate, each recording was listened to a second time and compared to the transcripts. Seventeen transcripts were provided back to the participants via email for review to ensure that they accurately reflected the conversations that took place during the interviews. After the interview, the researcher transcribed it manually on paper and then printed it in Microsoft Word in a certain format so that it could be imported into NVivo easily. The transcript contains 9-15 pages, and the researcher conducted 17 interviews, which required considerable time for transcription and analysis. The transcript interview was imported into NVivo to be all in one place, protected by usernames and passwords. Data was analysed and transcribed by the author of the study.

3.9.9 Translation

In addition to Arabic, Jordanians use English as a second language. They study English in secondary and postsecondary institutions, and several higher education specialities teach their students in English (see 1.2 Background (Jordanian context]). However, the interviews were conducted in Arabic, as not all participants (service users and primary caregivers) could speak English and maintain the same criteria and prompts of the interview guide. The interview guide was translated into Arabic and back-translated into English to check the accuracy and consistency of the concept.

Translation from other languages to English is based on the researcher's desire to publish work in English-language journals in the future (Nurjannah et al., 2014). I intended to disseminate the results in English, as most good-quality journals are in English; the selected quotes were translated into English throughout the analysis, and all codes and categories were written in English. A back translation from Arabic to English was performed to verify the translation's accuracy, and the text's coherence was checked. The translation accurately captured the intended meaning. The researchers were able to familiarise themselves with the data using this method. The translation made it easier to analyse the data and improved the researcher's understanding of certain expressions, such as laughter, stillness, and pause. As the researcher did the back-translation by himself and checked by peer-review who are professionally using bilanguage (Arabic and English), the researcher had finished a master’s degree, and now he is a PhD student at the University of Hull, so he is able to do the job (See Appendix E-13 Example of translation).

3.10 Data Analysis

According to Corbin and Strauss (2014), it is imperative that qualitative researchers have strong analytical and creative skills to understand the data and build theoretical conceptions and theories. Thus, the trustworthiness of this study was driven by the researcher's previous experience, skills, and competence. The researcher completed several workshops on qualitative data analysis and attended several appointments with the Library Skills Team at the University of Hull. In addition, the researcher stayed connected with supervisors to obtain their help, advice, and feedback on the data analysis process. This provided him with the skills and training he needed to analyse the interviews thoroughly.

Data analysis is a continuous process in qualitative research, where interviews are constantly re-evaluated to generate codes and categories that reflect the data. As part of the data collection process, the researcher recorded and transcribed all interviews verbatim during and after the data collection phase so that the participants' words could be preserved. Primarily, the researcher listened to and reviewed the transcripts of the interviews in the early stages to get a sense of what was being discussed and familiarised themselves with the codes, ideas, and emerging themes (Glaser, 1978; Charmaz, 2006). The first round of interviews was conducted, followed by the initial round of analysis. Seventeen interviews were conducted using the constant comparative analysis method.

The semi-structured interviews used in this study were part of an adapted version of the grounded theory design, which also included an approach for the analysis given by Strauss and Corbin (1998) and Charmaz (2006). A constant comparative approach was used in this strategy, which involved systematic data collection, coding, and analysis using theoretical sampling. However, the researcher did not strictly adhere to the protocols established by Strauss and Corbin (1998), instead adopting a constructivist methodology that used a flexible approach to allow theory building (Charmaz, 2006). The coding procedure was not sequentially performed. Example: The researcher returned to the first stage of the process (initial coding) multiple times during his axial coding work and modified the codes. Data analysis and coding were primarily centred on the interview transcripts, with the field notes being used to assist in the coding process and to ensure consistency throughout the study.

The analysis was conducted in accordance with the common elements of grounded theory, which include theoretical sensitivity, theoretical sampling, coding process (initial coding, axial coding, and selective coding), constant comparative analysis, and field notes. These components are critical in providing a coordinated, systematic, and adaptable research approach.

3.10.1 Qualitative Data Analysis software

When conducting this study, NVivo software was utilised, which helped streamline the process of handling and organising a huge amount of data. The researcher must read and engage with the text in qualitative research before coding it; qualitative analysis tools make this process easier. Seventeen interviews were imported into NVivo R (Release 1.5.1 QRS), the newest version of the software. This software is available from the University of Hull at the Information Centre for Technology. NVivo provides a toolkit for rapid coding and thoroughly exploring qualitative research methods (Creswell, 2012.243).

The researcher thoroughly read and examined the transcripts and translated any English terms used by healthcare professionals or participants to Arabic terms, resulting in final transcripts that comprised only Arabic text. Using this software, on the other hand, presented numerous difficulties.

The researcher was required to learn how to practice using the software, which he accomplished through three training sessions with the Library Skills Team at the University of Hull and then by consulting the official NVivo website for assistance. The researcher cleared the formatting of the Word document transcripts as NVivo does not support Arabic and functions properly only when transcripts are in plain format. When I opened NVivo for the first time, I selected to create a new project. After that, I started importing the interview to NVivo and then started to initiate codes. These codes were allocated to categories, which allowed me to contrast codes with each other just by clicking on and checking the specific code or category for all participants on one page, so I could make judgments whether code\ codes fit in a specific category, or I can move it to another category and so on.

Moreover, searching for specific words in the text, viewing and printing selected passages with their given codes, comparing codes with other codes, comparing new transcripts with prior transcripts, and finding the relationship between themes were all possible for the researcher during this study. The researcher's burden was reduced by this method, and the power of the qualitative analysis increased. Keeping all the data in NVivo increased the credibility of the project and made it easier to create an audit trail. Field notes were loaded into the software and used with data analysis to assist with the coding process.

3.10.2 Initial Coding

First, the transcripts were read thoroughly while the researcher listened to the audio recordings to familiarise themselves with the material and associated concepts. This is critical for cultivating theoretical sensitivity and awareness of evidence (Glaser, 1978). The researcher began the analysis with the first interview, followed by the other interviews. At this stage, the researcher analysed each interview separately before conducting the next interview to adhere to grounded theory guidance and theoretical sampling. See (Table 3-6: Example of initial coding) which was exported from NVivo R software.

Table 15: Example of initial coding

Fear of Addiction
crowded clinic
the community does not support
culture believe
religion support

Fear of people what they think
Did not accept the diagnosis
disease affect my life
distance affect me
doctor shifting and changing
doctor communication
doctors do not listen to you
doctors told me to stop
educated people help me
My experience with medication-taking
experience with a psychology counsellor
family believe
family not supporting me
Father helped me
The doctor did not help me.
doctors did not explain
doctors’ point of view
government clinic experience
no privacy
Not all medication is available at the clinic.
trust doctors
Diagnosis was late
problem appears
Know about mental illness.
did not know more details about the medication
I know my dose.

I know what this medication used for
I know medications name
lack of service
increase or decrease dose based by himself
medication is free in the government clinic
medication did not help me to overcome the disorder
Medication did not treat the symptoms but controlled the mood.
medication different international and local
medication from other sources
Medications helped me
not taking as prescribed
not taking based on myself
not taking because of family
side effect
Some medication useless
taking medication
Think about changing medication by myself.
treatment costly
mental health neglected
Never stop medication
Never take it based on me.
not a specialist on YouTube
other support treatment
other treatment costly
pandemic COVID-19
patients’ exploitation

feel frustrated
friendship with doctor
I did not know what happened.
I do not have money.
I suggest
patients believe
The psychiatric visit is costly.
seeking help
source of information
Internet
Read from leaflet
work help me
type of information
Use other people's experience.

As part of the open/initial coding process, researchers combed through the data, word-by-word or sentence-by-sentence, in search of recurring themes and beginning codes and ideas. This method helped identify the attributes and dimensions of the initial categories (see Section 3.5.4).

The codes that emerged were produced by the researcher and represented his knowledge of the data, for example, the favourable influence of religious beliefs, or they were the participants' actual words, called in vivo codes. Using the actual words of the participants as codes demonstrates that the findings are based on facts grounded in the data (Glaser & Strauss, 1967). Generally, the researcher assigned codes to words, phrases, and expressions that stood out as interesting, noteworthy, and intriguing. During this stage, in which discussions produced certain categories, it became apparent that the initial interviews did not adequately explain some issues. Therefore, in subsequent interviews, the researcher inserted prompts for these questions to better understand the participants' experiences. The researcher asked follow-up questions based on the participants' answers to the initial interview questions.

The texts were analysed to extract the main ideas and themes using questions like, "What do these data reveal?" and "What do these data represent? They were posed to the texts to extract the major themes. The researcher questioned the data to explore and facilitate comparisons between different processes, actions, interactions, and emotional responses noted in the context (Corbin & Strauss, 2014). With a wide range of questions, researchers can classify data into all manifestations. For example, the researcher asked questions about cultural beliefs and knowledge about medication (In Vivo codes), such as what you think about psychiatric medication? What do you know about your psychiatric medication? The answers to the questions varied between texts, whether different or similar, indicating data saturation, especially when more similar answers were repeated.

The researcher worked through the transcripts one at a time, comparing and challenging data. Initial codes were extracted from the data and grouped into larger abstract codes. Subsequently, the codes were divided into distinct categories and subcategories based on their similarities and differences, which were aggregated into conceptual codes. Many conceptual codes remained, but they were reduced by grouping together comparable codes and reflecting on the meanings that emerged from this process (Graneheim & Lundman, 2004; Elo & Kyngäs, 2008; Corbin & Strauss, 2014).

Codes from the NVivo program were exported to a spreadsheet and printed to aid further refinement efforts. Repeated codes of comparable meaning were then integrated or removed by the researchers. He also renamed a few of the initial codes. The number of stems or main (parent nodes in NVivo) was lowered, and the initial codes were also reduced due to this procedure. The researcher was able to better understand the relationships between concepts and categories after integrating and improving the codes. Therefore, the next step of the data analysis (axial coding) was to code the primary categories at a higher level of abstraction and establish their link with subcategories.

3.10.3 Axial coding

Axial coding was defined by Strauss and Corbin (1998.123) as a process for reassembling disparate data into a cohesive whole, which helps connect categories to subcategories. Axial and initial coding was used in this study. Axial coding began after the seventh interview to relate the codes to fragmented categories in the initial coding stage. The connections between categories and subcategories through their properties and dimensions provide a deep understanding of the phenomena under study (Strauss & Corbin, 1998). Axial coding resulted in the development of subcategories that addressed numerous concerns regarding the category, including when, where, and why the phenomena occurred; who took activities in reaction to the occurrence and how; and what the implications of these actions (See Appendix F).

The researcher used these questions for the analysis. For example, participants from the service user (patient) group mentioned that psychiatric medication is different, which affects their adherence to the treatment. Therefore, the researcher asked questions about the data during analysis, such as how the medication differs and whether this relates to its side effects or manufacturing issues, as mentioned by other service users. Subsequently, the participants were asked what they did regarding the medication differences and where the differences were. These questions also asked healthcare professional groups to identify beliefs and observations for this category and what actions they took. As revealed in the data, the service user who really cares about their medication asked the physicians to prescribe the same medication they used to take, as the new or alternative medication usually manufactured locally is not helpful.

On the other hand, service users who did not care about medication or were not convinced about it did not take it as prescribed or did not take it at all to prove that medication was not helpful. This explains why service users behave differently toward psychiatric medications. However, healthcare professionals noted that some service users did not take their medication as intended because the medication name was different, and they claimed that the new medication (alternative) was not as effective as the old one. Doctors try to explain the differences between medications based on their experiences and observations. They confirmed that the local medication differed from the international medication, but they did not know what happened or where these differences emerged. Finally, the researcher considered the consequences and outcomes that result in changing their medication-taking behaviour, such as not taking at all or not taking medication as prescribed. This explains a new problem that requires further investigation, as healthcare professionals suggest, besides focusing on service users and primary caregiver education.

Axial coding used a constant comparison analysis to compare the categories. This process made the refinement easier and confirmed that each category was mutually exclusive. The constant comparison analysis supported the researcher in verifying and rechecking the primary categories that emerged from the data to ensure they were all consistent.

Finally, this study aimed to develop a new understanding of the factors that impact medication-taking behaviours. At this point, the researcher needed to connect several subcategories of a category to develop an overall theory that could explain the phenomenon. Data analysis in the grounded theory concludes with selective coding, which builds on the work done in initial and axial coding before it.

3.10.4 Selective coding

According to this coding process, the major categories were refined and integrated to generate a new theory or theory of the whole. A set of central categories is identified, each corresponding to the data (Charmaz, 1990; Strauss & Corbin, 1998). The central category drags other categories together to comprehensively understand and explain the phenomenon (Strauss & Corbin, 1998).

Core categories were conceptualisations that fit the data well and appeared in all the interviews to varying degrees. This allowed for a reasonable and coherent interpretation of the factors that impact psychiatric medication-taking behaviour. It explains the service user and primary caregiver's beliefs and knowledge of psychiatric medication and why they sometimes fail to adhere to their medications. To obtain theoretical saturation, the researcher used theoretical sampling and data analysis to determine the theoretical scheme (Strauss & Corbin, 1998). Theoretical saturation was achieved when all categories became saturated, data did not yield any new theoretical insights, and the theory became well-developed (Charmaz, 2006). In this study, researchers were able to identify differences in the data inside and across categories by selective coding. This process continued until the completion of the thesis writing period. (See appendix F).

3.11 Quality and trustworthiness

The term "trustworthiness" or "rigour" relates to the degree of confidence in the data, their interpretation, and the techniques utilised to verify the study's quality (Polit & Beck, 2010; Creswell, 2014). Charmaz (2006) Identified the characteristics that help achieve trustworthiness and quality in grounded theory studies: credibility, dependability, confirmability, and transferability.

3.11.1 Credibility

Credibility refers to trust in the accuracy and interpretation of data. The researcher must build trust in the accuracy of the findings for specific participants and situations in the study, such as internal validity in quantitative research (Polit & Beck, 2014). The researcher adopted several techniques in this study to develop and achieve credibility, based on Charmaz (2006). 182) criteria, that credibility will be achieved if the researcher “achieved familiarity with the setting or topic, complete systematic comparisons between categories, Are there strong logical links between the gathered data and your argument and analysis? Did your research provide enough evidence for your claims to allow the reader to form an independent assessment and agree with your claims?” To answer this question, credibility was achieved.

As the data collection was done online, the researcher spent sufficient time learning how to use the Zoom application, which was used to interview the participants. The researcher attended several workshops on conducting research online during the COVID-19 era, enabling him to develop his research skills, especially online ones. In addition, the researcher carefully selected the online meeting program as remote data collection was in Jordan, and most people were familiar with this program; this familiarity helped the researcher and saved time instead of learning participants to use the new program. However, the researcher built trusting relationships with participants by using other means of communication, such as WhatsApp, to contact participants and send them the information sheets and consent checklist. Furthermore, they answered any questions that they had about the study. This process enabled the researcher to deal with different circumstances and facilitated communication and interviewing of the participants.

Another strategy for increasing trust is regularly comparing emerging data from participants' interviews. This aided the researcher in double-checking and rechecking the primary categories and subcategories for consistency (Guba & Lincoln, 1989). Additionally, the sampling strategy contributes to credibility (Stenfors et al., 2020). Therefore, this study's selective and theoretical sample contributes to credibility. The participants selected for this study were divided into three groups: service users (patients), primary caregivers, and healthcare professionals. Service users were participants diagnosed with bipolar I disorder or schizophrenia for one year or more, taking or prescribed psychiatric medication, and able to read and write in Arabic. Primary caregivers were family members who cared for service users in the first instance, could read and write Arabic, and lived with participants in the same house. Healthcare professionals were psychiatrists, resident doctors in psychiatry, or mental health nurses (registered or practical nurses) dealing with patients diagnosed with schizophrenia or bipolar disorder for more than one year. Therefore, all three groups had the required information about the phenomenon under study and were willing to share their experiences, knowledge, and beliefs regarding psychiatric medication-taking behaviour.

The credibility of this study was impacted by the researcher's previous experience, abilities, and competency. The researcher had a master’s degree in mental health nursing during this course. He had training in different psychiatric units and three years of experience as a qualified in-charge nurse at the psychiatric unit. He also qualified as a Clinical Nurse Specialist from the Jordanian Nursing Council, which facilitated the recruitment process. The interviews were conducted in the mid-third year of his PhD. Before this time, the researcher attended several workshops on qualitative research, online data collection, research during COVID-19, and interview skills. In addition, the researcher maintained touch with the study supervisors to obtain advice and criticism and resolve any issues that arose. This gave him the tools and training to conduct credible interviews.

The study's accuracy was verified using peer review and debriefing groups through supervisory team meetings and consultations. The study supervisors monitored every step of the research process, gave the researcher critical feedback and critiqued their work. They aided me in collecting, analysing, and interpreting the data. The debriefing procedure improved the researcher's ability to organise and clarify the study results.

3.11.2 Dependability

Dependability refers to the consistency and stability of data over time (Polit & Beck, 2014). This suggests that the outcomes will be the same if the study is replicated. The researcher used the same interview guide to conduct all the interviews to achieve dependability. Then, the researcher transcribed all 17 interviews and analysed them using NVivo R 1.5 software. Data collection and analysis were easier for the researcher because he had acquired the necessary skills and expertise during his doctoral study, enhancing data consistency and reliability.

3.11.3 Confirmability

When conducting research, it is important to ensure that participants' experiences and views accurately reflect the findings rather than the researcher's preferences. This can be accomplished through an audit trail, which allows outside organisations to track the research process step-by-step using the defined methods. The audit trail records the researcher's decisions on acquiring access to the field, recruiting subjects, and performing analyses; in other words, it explains in detail what you have done (Holloway & Wheeler, 2010; Hollway & Galvin, 2016).

In this dissertation, I have presented comprehensive information regarding the narratives of the individuals involved, which have been captured in meticulous field notes, transcripts, and a diary reflecting upon my biases and perspectives. This extensive documentation serves the purpose of elucidating my decision-making process and ensuring the study's reliability and trustworthiness. Also, this study employed a digital recorder, Zoom Cloud recording, and transcribed the interviews, which would make future audits easier to conduct. The quotes cited in the results section include the participant code and interview number. NVivo R 1.5 software was used to record the researcher's data analysis and interpretation, making it easier to conduct an audit of the work.

Another strategy employed in this study to increase confirmability was reflexivity. The researcher knew that achieving perfect objectivity and neutrality would be difficult because of his familiarity with several care settings and function as the primary research tool. As a result, the researcher was aware of monitoring his actions and relationships with the participants, which fostered sensitivity and objectivity (Holloway & Wheeler, 2010).

The first crucial step in my personal reflexivity shaped my study to understand this dynamic and explore the factors that impact their taking behaviour. During the data analysis, I began to uncover the issues involved in psychiatric medication-taking behaviour. I see myself trying out new ways to understand psychiatric medication-taking behaviour from the service users' and primary caregivers' points of view as a result of producing new tools to adapt to their preferences and situations.

3.11.4 Transferability

Transferability in qualitative research reflects the generalisability of quantitative research (Polit & Beck, 2010). When examining the potential relevance and practicality of research results, it is crucial to consider the concept of transferability, as described by Lincoln and Guba (1985) (Holloway and Galvin, 2016). Transferability, in this context, refers to the extent to which the findings of a particular study can be applied to other settings or populations. It is a criterion that assists researchers in determining the extent to which my findings can be transferred and utilized in different contexts, thereby enhancing my research's overall usefulness and value. By considering transferability, researchers are able to assess the external validity of their findings (Creswell, 2014). This can be accomplished by developing a suitable interpretation of phenomena that can be applied to comparable situations or settings, for example, in a psychiatric or outpatient clinic.

The study was undertaken in Jordan because the researcher prefers the findings to be transferable there. This study recruited three large bodies, which reflect the mental health setting and account for more than 80% of the sample population. The study participants were divided into three groups to cover all the areas and perspectives (service users who reflect the patients, primary caregivers who reflect the family, and health care professionals), representing a member of this setting. The emergent themes from participants’ views were related to other outpatient mental health settings in Jordan. For example, beliefs about taking psychiatric medication.

3.12 Chapter Summary

This qualitative study employed an adapted form of constructivist grounded theory designed to investigate the factors impacting psychiatric medication-taking behaviour from three perspectives: service users, primary caregivers, and healthcare professionals, to understand more about the knowledge, experience, and attitudes toward psychiatric medications. Ethical approval was obtained from the Faculty of Health Science Ethics Committees at the University of Hull, Jordan’s Ministry of Health, Jordan University Hospital, and the Our-Step Association. The study was conducted in three settings (one government, one teaching hospital, and one community centre for people with mental disorders).

The sample consisted of 17 participants for all three groups of the study (six service users, four primary caregivers, and seven healthcare professionals). Data were collected through online semi-structured interviews using the Zoom application and digital recorder. This provided rich data regarding the phenomena under study from the participants. All interviews were recorded via the Zoom application, and a digital recorder was transcribed verbatim after that. Seventeen interviews were imported to NVivo R to extract the emerging theme, which was then analysed using constant comparison. Data were kept confidential and secure and met the ethical standards for data protection. The analysis adheres to Strauss's three stages of coding (initial, axial, and selective) while retaining Charmaz's constructivist flexibility to allow for theory growth. The following measures were used to ensure the study's credibility and quality: academic supervisors read and followed the study methodology, reflexivity, and peer debriefing, as well as academic supervisors' advice.

Chapter 4 Findings

4.1 Introduction

The previous chapters outlined the methods and methodology of data collection and discussed the constant comparative analysis, which led to the interview analysis process presenting the study findings. This chapter presents the study findings generated from online semi-structured interviews; the average time was 47 minutes. Data were collected from 17 participants (six service users, four primary caregivers, and seven healthcare professionals) in three mental health settings in Jordan (two outpatient mental health clinics and a community centre). Please note that service users and primary caregivers are not dyads or have relationships with each other. Seventeen interviews were analysed using constant comparative analysis during the data-gathering phase, as outlined by Strauss and Corbin (1998) and Charmaz (2006); the concepts and categories that emerged from each data analysis phase were compared to concepts that emerged from any subsequent new context. The researcher performed a constant comparison until the data were saturated. The researcher immerses himself in the interviews by refining and reading the transcripts; this reflects the essential role of the researcher in analysing and interpreting the data within the Jordanian context and from his background as a mental health specialist. During data analysis, it was evident that medication-taking behaviour was influenced by different factors mentioned by participants. Also, participants discussed unexpected factors that may impact their taking behaviour, such as international and Jordanian local medications.

4.2 Role of the researcher in constructing theory:

In Charmaz's constructivist grounded theory, the researcher is viewed as an integral element of the data collection and analysis processes rather than separate from the data or reality (Charmaz, 2006). Categories and models evolve based on participants' and researchers' interpretations (Charmaz, 2006). This study extracted five interrelated categories from the participants' interviews (service users, primary caregivers, and health care professionals). Using my principal position as the researcher and my background as a nurse working in a mental health setting and working with people diagnosed with mental disorders assisted me in gaining a deeper contextual understanding of the participants' data. In addition, the findings' interpretation, determination, and organisation are shaped by my clinical experience in mental healthcare in the Jordanian context. My clinical experience also helped me become theoretically sensitive to psychiatric medication-taking behaviour from the participant's perspective. It also helped me write memos and notes, extending my ability to understand, refine, and define the data and develop categories and themes to become a model.

4.3 Participants in the study:

This section presents the data of the (17) participants in the study table (16) below, showing the sample characteristics. The participants' ages ranged from 23 to 62 years for all three groups. The youngest age group was the service user group, followed by HCPs and then primary caregivers. All the study participants were Muslims. Nine males (52%) and eight females (48%) were interviewed.

The characteristics of each study group were as follows: service user group ages ranged from 23- 38 years, 67% of the participants were male, and 33% were female. Five out of six were single, and one was divorced. Five out of six patients were diagnosed with schizophrenia (83% of the sample), and one out of six (17%) was diagnosed with bipolar I disorder. Three out of six (50%) were employed, and 50% did not work because of the disorder. Most service users were educated (two high schools, three bachelor's degrees, and one master's degree), and the family income ranged from high to medium.

The primary caregiver group aged 45-62 (4 out of 4) was female and educated. It should be noted that most of the primary caregivers in Jordan are female (sisters or mothers) (see Chapter 1.8.3, Primary Caregiver and Family). Their experience in caring ranged from 4-20 years of caring. Furthermore, family income ranged from low to medium (See Chapter 1.2 Background (Jordanian context)).

Finally, the healthcare professionals' group was aged between 28-44 years old, and their length of experience working with people diagnosed with mental disorders was between 3-14 years. The healthcare professionals included two psychiatrists, two resident doctors, and three registered nurses. See table below. **Error! Reference source not found.**

Table 16: Demographic characteristics of the study participant.

Participants	**Age**	**Gender**	**Family Income**	**Diagnosis**
Service users 1- service user 6	23-38	4 males 2 females	Medium-high	5 schizophrenias 1 bipolar I disorder
Primary caregiver 1- primary care giver4	45-62	4 females	Low-medium	
Healthcare professional 1- healthcare professionals7	28-44	5 males 2 females		3 nurses, 2 psychiatrists, 2 resident doctors

4.4 Categories derived from data for each group:

This section of the chapter presents in detail each category, subcategories, and elements for each group (service user (SU), primary caregiver (PCG), and health care professionals (HCP)) that were identified through the analysis of the interview, and then discusses the relationships within them and between them using the extract from the interview transcripts. The codes and categories generated from the interviews were continually refined until the following categories of the study groups emerged:

Five major general categories were generated from three groups of studies which influence medication taking, giving, and prescribing, as follows:

1- Experience with psychiatric medication.
2- Knowledge of psychiatric disorders and medications.
3- Beliefs about psychiatric disorders and medications.
4- Health care system and policies.
5- Financial insecurity.

However, the three groups almost have the same main categories; this difference comes from the different positions of the participants (service users who take the medications, primary caregivers who gave the medications, and health care professionals who prescribed the psychiatric medications). Each one expresses his/her point. For example, the experience with psychiatric medications reflects the service user's experience of taking it and the primary caregiver’s experience of giving it to their service user, while the health care professionals' experience reflects the health care professionals experience communicating with service users and their primary caregiver and how they are taking and giving it. Each category, subcategory, and element is discussed in detail, along with related quotes from the interviews. See table 17 below for more details), which are discussed separately.

Table 17: Main categories for each group

Categories	Service User (SU)	Primary caregiver (PCG)	Healthcare professionals (HCPs)
Category 1	Experience with taking psychiatric medication.	Experience of giving medications: Experience of the primary caregiver giving psychiatric medications.	Healthcare professional's experience prescribing psychiatric medication
Category 2	Knowledge about psychiatric disorders and medications.	Knowledge of what the primary caregivers know about psychiatric medication and source of knowledge.	Healthcare professionals' observation of service users and primary caregivers' knowledge about medication
Category 3	Beliefs about psychiatric disorders and medications and how that influence medication taking.	Beliefs: primary caregivers' beliefs about psychiatric medications and how this influences given it.	Healthcare professionals' observation of service users and primary caregivers' beliefs about medication and mental illness
Category 4	Health care system and policies: influence psychiatric medication taking.	Health care system and policies: the influence of health care system on psychiatric medication taking.	Health system and policies: impact on medication taking and giving.
Category 5	Financial insecurity: impacts medication taking.	Financial status: impact medication giving.	Financial status: impact medication taking.

4.5 Main Categories from interviews after merging

The main categories for the three groups are presented together to discuss the commonalities and differences in each category from different points of view. However, this study has three groups, but the focus will be on the service user to be presented first because of my experience, and as I discussed above in methodology (Chapter 3), most of the studies in Jordan are concerned or conducted using quantitative methods and the voices of the service users are not heard. Therefore, I will pay attention to them first, as they reflect on the heart of the problem, and their perspective about psychiatric medication is the most important, as I need their voice to be heard. The participants (service users) in this study were well-functioning in the community and were able to reflect on their medication-taking behaviour over time. [Table 19: Main categories of the study] summarises the main categories with the number of times participants mentioned in the text. The second table summarises the main categories, subcategories, and elements. [See table 19 below].

Table 18: Main categories of the study

#	Categories	# Of time mentioned by Participants			# Of times mentioned in the transcribed text		
		SU	PCG	HCP	SU	PCG	HCP
1	Experience with psychiatric medication.	6/6	4/4	7/7	283	259	264
2	Knowledge about psychiatric disorders and medications	6/6	4/4	7/7	151	86	148
3	Beliefs about psychiatric disorders and medications	6/6	4/4	7/7	106	30	240
4	Healthcare system and policies	6/6	4/4	7/7	90	38	70
5	Financial insecurity impacts medication taking.	6/6	4/4	7/7	21	17	61

Table 19: Main categories, subcategories, and elements of the three groups after merging

Main categories	**Subcategories**	**Elements of subcategories**
1: Experience with psychiatric medications	Experience with medication:	• side effect • local medications vs international medications • motivation to take or give. • Discourage to take or give
	Experience with support system:	• Family support • Community support • Self-support
	Experience with disease	• not aware of my condition • disease affect my life
	other treatments	
	Healthcare professional's experience prescribing medication	• Experience with prescribing psychiatric medications • Missed dose. • Service users decide to take the medications.
	Consequences	• change in taking behaviour. • relapse
2: knowledge about psychiatric disorders and medications	Lack of knowledge	• Knowledge about the disorder • Knowledge about the medications.
	Source of information	• Using Internet • Ask HCP • Learn from other experiences. • Reading from leaflet
3: Beliefs about psychiatric disorders and medications	Beliefs of SU, family, and healthcare professionals Stigma Religion Treatment journey	
4: Healthcare system and policies	health care professionals	• The doctor did not explain. • Doctor's attitude and communication • Doctor rotations

		- Doctor trading's - healthcare professionals role at the clinic
	settings	- Crowded clinic - Mental health neglected. - Bad experience - Distance from the service
5: Financial insecurity impacts medication taking.	Cost	- Psychiatric visit expensive - Medications expensive
	environmental factors	COVID -19 pandemic

For more details about how the categories were drawn from the data (see Table 31: Appendix F- 1. Example of how category 1 (Experience) was drawn from the data), which described category 1 experience, this example was applied to all other categories.

4.5.1 Category 1: Experience with psychiatric medications

Experience with psychiatric medication was a clear finding from the participant's data -three groups. This category includes varied experiences in taking, giving, and prescribing psychiatric medications, reflecting the analysis of the three groups. Participants from the service user group and primary caregivers expressed their experiences with psychiatric medications and how these experiences affected their decision-making for taking and giving medications. Healthcare professionals provide another perspective on psychiatric medication-taking behaviour through observations and talking with service users and their families. Healthcare professionals' experiences either aligned with or contradicted the points made by service users and primary caregiver participants about medication taking or added a completely different view. Presenting three different views of the same category provides a comprehensive overview. All participants mentioned their experience with psychiatric medications, either as a barrier or driver toward psychiatric medication-taking behaviour. This category overlaps with the above-mentioned categories, as the experience formed via interaction with the surrounding environment includes relatives, neighbours, community, and the healthcare setting. This interaction was influenced by beliefs, knowledge of mental disorders and their medications, healthcare settings, and financial status. Additionally, this experience constructed their decisions regarding medication-taking behaviour or giving it.

Within this category were six subcategories from the three groups (experience with medications, experience with support systems, experience with the disease, experience with other treatments, Healthcare professionals prescribing medications, and consequences).

4.5.1.1 Experience with Medications:

The first significant subcategory in category 1 (experience with psychiatric medication). This subcategory discusses the factors related to medications that impact psychiatric medication-taking behaviour based on participants' experiences. All service users and primary caregivers discussed this as a motivation or discouragement that helped them to decide about medication-taking behaviour; another perspective added by the healthcare professionals' experience. This subcategory has four elements, as shown in the figure above, which include side effects, local vs. International medications, motivations to take or give medications, and discouragement to take or give medications.

Side effects:

Side effects were the main element in the experience with medication subcategory, which shows how side effects impact psychiatric medication-taking behaviour. All participants (17/17) mentioned side effects, with (168) references (time mentioned during interviews) and were identified as a barrier.

Service users were thinking of stopping, or already stopping, or changing the dose of the medications because of their side effects.

> *"Solian causes me cramps, but not very bad…. For example, I remember my mother used to have very strong complications, a strong shaking until the doctor changed her medication, and she became better" (Service user 1, male 38 years old).*

> *"…I didn't take it regularly because of the side effects" (Service user 2, male 37 years old).*

Similarly, the primary caregivers mentioned that they were concerned not about the medication but the side effects. Therefore, primary caregivers refuse to give the medications because it has strong side effects such as cramps or convulsions, and emotionally, they do not like to see their son or daughter suffering from them.

> *"The experience was difficult with him, not easy, but I need to bear with him to make him get better……I mean, he is a young man of thirty-seven years of age. I want him to recover, marry, and return to his normal life. Medicines make him sleepy, so you know I am a mother, so I will be sad when I see my son suffer" (Primary caregiver 2, Female, 62 years old).*

Correspondingly, through their observations, experience, and communication with service users and primary caregivers who visited the clinics, healthcare professionals found that side effects were the most common reason mentioned by service users and their families who visited the clinic that influenced medication-taking behaviour. Service users and primary caregivers were afraid of the side effects, and they said that medications did not help them, but worsened the case because of the side effects.

> *"Of course, side effects are the most important thing, so they do not take the medicine" (Healthcare professional 1, male, 34 years old).*

There are Similarities and differences in the side effects related to age, gender, work, and study, besides individual perspectives variation. Some side effects were not mentioned by all participants and varied among service users, primary caregivers, and healthcare professionals. An example of similarities mentioned by all the participants from three groups (service users, primary caregivers, and healthcare professionals) as follows: cramps (6)[3], insomnia, nightmares, and high mood (3)[4].

> *"As the disease affects my life, things that prevent me from taking the medication are the side effects like insomnia……. Sometimes medications cause nightmare" (Service user 3, male 31 years old).*

Some side effects were mentioned by all participants, but they differed according to age, gender, work, or study. Such as the following side effects: sleep or sleepy (14)[5], weight gain & increased appetite (10)[6], sexual problems (7)[7], hair loss (3)[8], and affect her period (2)[9]. Sleeping and weight gain it was the main concern among participants (service users and primary caregivers).

> *"The medicine, yes, I have my job, and the medicine is making me sleepy and dizzy, and I went to the doctor. I told him that the medicine was making me sleep, and I had a job and that I needed a solution. I am a teacher and teach children, so I need a light medicine or reduce the dose" (Service user 6, female, 38 years old).*

Primary caregivers are afraid of the side effects as they may cause injury to the service users and risk for falls because of the sedative effect of the medications.

> *"Means the medications have a hypnotic or I would tell you something that I don't want him to work as I am afraid that he will fall" (Primary caregiver 2, Female, 62 years old).*

Similarly, from the healthcare professionals' experience, they report that sleeping impacts their ability to work and late arrival to their work.

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[3] Causing cramps mentioned by: SU 1,4. PRIMARY CAREGIVER1,3. HCP 1,7.

[4] Insomnia, nightmare, and high mood mentioned by: SU 3, PCG 4, HCP 2.

[5] Sleeping mentioned by: SU 1,2,3,4,5,6. PCG 1,2,3,4. HCP 1,2,6,7.

[6] Weight gain mentioned by: SU 2,3,4,6. PCG 3,4. HCP 2,4,6,7.

[7] Sexual problem mentioned by: SU 1,4. HCP 1,2,4,5,6.

[8] Hair loss mentioned by: HCP 1,2,4.

[9] Affect period mentioned by: HCP 1,4.

> *“Also, most people do not stick to the medication because most of their time is asleep, and medications make them unfocused at work and arrive late most of the time” (Healthcare professional 2, female, 29 years old).*

The same concern regarding sleeping from the healthcare professionals' point of view that service users and their families who are concerned about sleeping are people who have work or study, and those who do not have work have no matter with that.

> *“Medications have sedative effects, so the people who work medication will cause a problem for them as he needs to wake up early to go to work, but who don’t work has no matters with that!” (Healthcare professional 6, female, 30 years old).*

Some side effects impact males more than females and younger people than older people, and vice versa. For example, sexual problems concern for men as weight gain concern for younger women. Weight gain and increased appetite were the second causes mentioned by the participants to skip the medications. One HCP[10] urged that age made a difference; weight gain is not a matter for older women versus younger women or girls who always want to look good. However, weight gain is a concern for males and females.

> *“…Also, it differs by age. For example, young women differ in the issue of weight gain than older women. Younger more concern about weight” (Healthcare professional 6, female, 30 years old).*

Sexual problems were mentioned by seven out of seventeen participants from two groups: male service users and healthcare professionals. Three service users said that medications affected their sexual status and that they were not married. Similarly, the healthcare professionals mentioned that sexual problems were the main concern of men. This caused them to stop taking the medication or ask the doctor to change it. Service users did not mention more details about this as they felt embarrassed, and primary caregivers were female, and they did not mention this because of cultural barriers to this sensitive topic. However, more exploration was performed using healthcare professionals.

> *“I mean, the side effects of Zoloft, for example, I felt sexually active, and I am not married. I mean Zoloft is not comfortable physically and psychologically” (Service user 1, Male 38 years old).*

> *“I mean, anti-psychotics, especially with young people, affect sexual desire, and this is a very important thing for young people, especially males. When he feels that he has a deficit or*

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[10] urged by HCP 6.

> *defect in his sexual desire, things become catastrophic, and he abandons all medicines" (Healthcare professional 5, male, 35 years old).*

Memo: female service users or primary caregivers cannot talk about sexual problems or a sensitive female issue, such as periods with males, because of cultural issues, so more exploration is done with HCP.

Additionally, there was a side effect that influenced females only, as mentioned by the HCP: hair loss and period issues. These side effects are mentioned by people who experience this problem; however, no service users or primary caregivers mentioned that, as healthcare professionals noted in the clinic, females who experience hair loss or problems in their period intend to change the dose or stop taking the medications.

> *"I mean, for example, it can affect you, for example, and cause hair loss. For women, it can also affect the menstrual cycle" (Healthcare professional 1, male, 34 years old).*

Other side effects impact medication-taking behaviour, such as anxiety and stress (2)[11], increased heart rate, elevated blood sugar, and thyroid problems[12]. This side effect is mentioned once either by the service user or the primary caregiver.

> *"….. medication cause increasing in the heart rate…. I mean, now I was bothered by the medicine because I read that it stimulates appetite and raises blood sugar" (Service user 6, female, 38 years old).*

> *"She had a problem with her thyroid and began to take thyroxin; this problem happened after she was admitted to the psychiatric unit and took psychiatric medication, especially injections, as she before not suffered from any thyroid problem" (Primary caregiver 3, female, 54 years old).*

The healthcare professionals did not mention these side effects when they asked if this complaint was noted in the clinic, but they urged that not all side effects should occur with service users. However, one healthcare professional urged[13] that the doctor should do a good assessment for the service user to avoid some of these problems by prescribing a medication that had a few side effects or did not impact their physical health, and he encouraged the service user to tell his healthcare professional about any psychical side effects appearing after he started on psychiatric medication immediately and not to wait until the next visit.

> *"…. very important, why does the patient not adhere to the treatment or stop it, it will be a flaw of the doctor assessment, how, for example, do you see the patient weighing one hundred*

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[11] Anxiety and stress mentioned by: SU 1,3.

[12] These side effect mentioned by: SU 6. PCG 3.

[13] HCP 7.

> *and thirty kilos? Why do you prescribe him medicine? One of its side effects is an increase the appetite, an increase in his weight…. For another patient, for example, who has other problems, diabetes and high blood pressure, why do you prescribe medications that impact his blood sugar …. I mean, some medications affect diabetes, and blood pressure doctors should be careful with their assessment" (Healthcare professional 7, male, 44 years old).*

Local medications VS international medications[14]:

This is the second element in the experience with medication subcategory 15 out of 17 mentioned that the difference between medications produced locally and internationally affects medication-taking behaviour. This is a very important element mentioned by the service user at first, then explored broadly by other participants.

Fifteen out of seventeen[15] mentioned that local medications are free at the governmental clinics because they are produced locally; however, old-generation antipsychotics, which have a negative side effect, are not as ~~foreign~~ international, although they have the same active materials. In addition, it has many brand names where the service users and primary caregivers try to stay with the same name as they believe [16]. In addition, the dose must be adjusted to meet the international medication dose[17]. Comparably, international medication had fewer side effects, as they contain new-generation antipsychotics, which control the symptoms because of the accurate dosage and active materials. However, it is expensive, and not all service users or primary caregivers can buy it. Therefore, they are referred to government clinics and try to adapt to the side effects or change the dose until they feel comfortable[18]. The reasons mentioned discouraged the service user and primary caregiver from taking their medications as prescribed, either by changing the dose, stopping taking the medications or swapping to international ones, but not the opposite as they will relapse [19] if they swap from international to local. Not only is the name different also differences in the shape and size of the bills[20] (This element overlaps with the health care system and policies, which are discussed later in category 4, and financial insecurity category 5).

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[14] See Appendix H: Medication brand name (which report the medication names mentioned by the participants in the study)
[15] SU1-6. PCG3,4. HCP1-7.
[16] SU2. HCP3,4,5,6.
[17] SU1, HCP5, HCP 6.
[18] SU1-6. PCG 3,4. HCP1-7.
[19] SU3, 4. PCG 3,4, HCP 5,6.
[20] HCP 5.

> *"It depends on the medication. If not the same that I used to take, I did not take it……. By God, I do not know, but I got used to a certain name, so I am trying to stay with him. I did not like to keep changing" (Service user 2, male 37 years old).*

> *"Some medications had strong side effects which affected me. I told the doctor about that, and he said that there were no other medications in the clinic. Take this one, and you will adapt to it with time……….For five months, I suffered from side effects, and then I got used to them, and because of the lack of money, I had to stay with the government clinics. However, I would like to go to a private doctor" (Service user 4, male, 27 years old).*

> *"Yes, by God, we have noticed a difference…… We noticed that international medicine does not increase the appetite like the local one, and the side effects are lighter" (Primary caregiver 4, female, 61 years old).*

Their experience working with service users and primary caregivers in the clinic and prescribing medications varies from international and local based on the availability of the medications healthcare professionals also noted at the clinic.

> *"The patient says that the international drug is more effective, based on the fact that he tried the international drug and the local drug, and he says that he was more comfortable with the international drug, and the symptoms eased. There are a few side effects; for example, in terms of sleep, the patient says when I take the local medicine takes a long time for me to fall asleep, but when I took the international, I sleep quickly" (Healthcare professional 2, female, 29 years old).*

> *"The names of the medicines are different; for example, we have a patient who was taking international Seroquel, and the hospital stopped prescribing it. We swapped him to the local Seroquel(equeal) he relapsed. The reason for the setback was that he switched from the expensive international drug to the local drug; why is it possible because the drug concentrations differ from one company to another? I do not know" (Healthcare professional 3, male, 33 years old).*

However, the data show a different point of view about the local medication; one service user did not take the international medication they started on the local as they followed up in the government clinic and did not try any other brand, and he was doing well. This difference between them may depend on which medications he starts on and the cost of medications; healthcare professionals noted that some service users at the clinic swap between local and international and were good[21].

> *"I tried the local brands only. I tried Risperdal, which is the (Ablifay), and others, but I cannot remember the names" (Service user 4, male, 27 years old).*

> *"On the other hand, people because of its cost. The international is expensive to refer to the alternative. He asks that it is the same scientific name as you give it. Oh, I say, there are no*

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[21] SU 4, HCP4

> *problems, and they change from one trade name to another without problems" (Healthcare professional 4, male, 28 years old).*

Local medications were much cheaper than international ones. This has led service users to use it. It is free at governmental clinics and cheap. Besides the limited source of income, they thought to buy international medications from the pharmacy from their pocket, as they did not trust the local medications (here overlap with categories 4 and 5). The financial capacity of the Ministry of Health does not enable it to buy new antipsychotic medications, so it still prescribes older generations, which had more side effects than the new generations, as the only available local medications[22].

> *The new generation of antipsychotics is not available at the governmental clinic because it is expensive and has few side effects, and at the governmental clinic they gave us medications for free, that is why there are no new generations medications there" (Service user 1, Male 38 years old).*

> *"Also, the Ministry of Health does not have the financial capacity to buy new generations of antipsychotic medications at an expensive price and distribute them to the people at a low or no price" (Healthcare professional 4, male, 28 years old).*

> *"It is, unfortunately, ah. Here we have the term any Jordanian medicine or a manufacturer in Jordan that is a failed medicine. This is the culture of our society, and its effectiveness is ineffective" (Healthcare professional 5, male, 35 years old).*

However, Local medication needs to be adjusted to meet the dose of the international medication; two healthcare professionals[23] mentioned that they increased the dose of local medication to double or triple the international medication dose to achieve the same effect, or the service user will relapse.

> *"From their personal experience, some doctors said that what medicine is manufactured in international countries has the best effect, and this is a point that I touched on with many doctors. I mean, even in our hospital (***), for example, international Seroquel that the bipolar patient takes 400 milligrams he improved, and things become excellent, and he reaches recovery quickly, and when we change to the local brand name, the same dose 400 mg, supposed to be the same composition and the same effect, but he has a relapse" (Healthcare professional 4, male, 28 years old).*

Motivation to take or give medications:

The third element of the experience with the medication subcategory is what encourages service users to take medications and primary caregivers to give the medications. In addition, the healthcare professionals' observations, experience, and perspectives on that. All participants mentioned various motivations, which

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[22] SU 1, PCG 4, HCP 4, HCP 6.

[23] HCP 5,6.

catalysed psychiatric medication taking as prescribed. These motivations differed from each group's perspective (service users, primary caregivers, and healthcare professionals). However, there is a common factor between them. Medications helped service users in different areas of their lives, such as continuing their education[24], controlling symptoms[25], fearing relapse[26], maintaining improvement[27], and hoping to stop medications in the future[28]. These motivations are driven by positive attitudes toward medications[29]and normalization[30].

> *“Frankly, medications helped me to continue my education” (Service user 3, male, 31 years old).*
>
> *One of the things that helped them to take the medications is that the symptoms decreased or subsided” (Healthcare professional 1, male, 34 years old).*
>
> *“I mean, for example, if I want to leave the medication, it will increase my visual and auditory hallucinations, as I will not be able to live my normal life so that I will suffer and I feel tired” (Service user 4, male, 27 years old).*
>
> *"There were many of them who continued to take medicine, and their condition improved with family support and work. Complete their studies, and at least they practice their social life normally and merge with the community too" (Healthcare professional 7, male, 44 years old).*

However, in terms of schizophrenia and bipolar disorders, all healthcare professionals suggested that people with bipolar I disorder have a better response than those with schizophrenia disorder. A service user diagnosed with bipolar disorder can go ahead in their life, while people who have schizophrenia can control their symptoms and perform their daily living activities if they are taking their medications as prescribed. Seven out of seven mentioned that.

> *"We can say that bipolar is a little better in terms of responding to the treatment; for them, it was better, and they reach recovery, control the disease, continue their lives, graduate from university, adapt to the disease, and get married, which means they are almost back active in society. But schizophrenia here in Jordan is almost very similar to the world, which means that no medications lead to a full recovery, but it can lead to reducing symptoms, controlling his disorders, and controlling daily life in terms of behaviour" (Healthcare professional 4, male, 28 years old).*

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[24] SU1,3. HCP 2,6,7.

[25] SU1-6. PCG 1-4. HCP 1,4,6.

[26] SU 1,2,4. PCG 2,

[27] SU 5,6. PCG 3,4. HCP 1,4,7.

[28] SU 4. HCP 1.

[29] SU 1,4,6. PCG 4. HCP 2.

[30] SU 2, HCP 4,5.

> *“Parents, of course, always have hope that we will leave the medicines and the patient will live his normal life” (Healthcare professional 1, male, 34 years old).*

The drivers that move these motivations are the positive attitude and experience with psychiatric medication, which made that difference in their life; they should feel that taking medications is a normal thing as other diseases.

> *"I used to give her medicines on time, exactly at 10:00 in the morning and 10:00 in the evening, four pills. I gave her the medications, and after her status improved and she responded to the medications, she realized that the medication was good, and she told me that I wanted to take the medication myself…. Even if I will try not to give her the medications, she asked me for it" Primary caregiver 4, female, 61 years old).*

> *"But when you go to the doctors and discuss the problem with them, they do not discuss the matter with you, and tell you, my brother, a diabetic patient takes diabetes medicine does he cured. I told him no; the doctor told me that the medicine would help me control the disease and this medicine would keep me from controlling the situation. If you do not take medicine, your condition will be very bad. It was really a convincing idea. It is possible that I can control the situation, although I feel that these medicines have not worked as a final solution except that I am in control of the symptoms" (Service user 2, male, 37 years old).*

> *“Increasing information, lectures, and awareness-raising on the subject of medicines and their importance, and what is expected to happen to him, do not let him feel that what is happening to him is strange, but we explain what is expected (I mean, we do normalization, meaning that it is a normal thing)” (Healthcare professional 4, male, 28 years old).*

Discouragement to take or give medications as prescribed:

This is the fourth element of the subcategory experience with medication. All participants mentioned different reasons which discouraged them from taking and giving the medications as prescribed or stopping taking them other than side effects and local vs. international medications, as mentioned earlier. However, there was a common reason among the three groups, and the factors mentioned by one or two groups are as follows: medication useless[31], feeling frustrated[32], stopping when improved[33], taking it for a long time[34], life stressors and family problems[35] , and forgetting or being busy[36].

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[31] SU1-5, PCG 1,4.

[32] Su2,4,5.

[33] SU2, PCG 3, HCP 1-7.

[34] SU 2. PCG 2, HCP 5.

[35] SU 1,2,3. PCG 1,2. HCP 1.

[36] SU 2, PCG 1,2,3,4. HCP 1,5.

Medication useless:

Medication did not help them work, and there were no signs of improvement after taking the medication. Service users urged that medication did not cure the disease but only controlled the mood, not all symptoms. Besides, the medication they took to relieve the side effects was not helping them to control the medication side effects, so they decided to change or stop taking it.

> *"I mean, how much have I changed medicines! I changed many, many medicines, and it did not work for me, and I did not get out of the condition or disease and symptoms as they were. There are medicines that I have been on for a long time, meaning six, seven or eight months or for a year, and I am not getting better" (Service user 5, female, 23 years old).*

Feel frustrated:

Medication is useless, leaving the participants (3/6 service users and 2/4 primary caregivers) in a state of frustration as there is no result from it, which is reflected negatively in their experience. Therefore, they decided not to take medications as prescribed, such as decreasing the dose, increasing the dose for a better effect, and stopping taking it at least once during their treatment.

> *"Well, maybe. I mean, how do I tell you that? Its medicine makes you feel empty. It is possible for someone to leave the medicine to get rid of this feeling. Because medicine sometimes causes depression. It is possible for one to think of leaving in order to improve himself better than this" (Service user 4, male, 27 years old).*

In contrast, healthcare professionals mentioned that their experience at the clinic found that medications are helpful, but the family and service users were not convinced to take them because of the negative experience they had.

> *"It depends on the patient himself and his family. There are people who tell you that they take the medicines and they do not improve completely; here we go back to a very important point because you want them to understand that it does not necessarily improve 100% if it improves from 60 to 70%, it will be a very good thing. Even if it has some side effects (Healthcare professional 7, male, 44 years old).*

The negative experience with medications, as there is no result, could lead the service user to commit life-threatening conditions, such as suicide, as they feel depressed and frustrated by the medications.

> *"Then I despaired because I did not see the result of what, so I tried to commit suicide by self-harm, and I said, I am done. I want to die. Quite frankly, it was a stupid decision. Then, I tried to commit suicide another time in 2019. I took 25 lithium pills, but, unfortunately, I mean, at that time, I mean, physically nothing happened to me; my family took me quickly to the hospital and did a gastric lavage. But after that, the situation was very bad for me psychologically" (Service user 5).*

MEMO: This participant attempted suicide two years ago; nowadays, she is good and has improved, but it is worth mentioning this situation to reflect the extent to which service users are emotionally impacted by the treatment when there is no result.

Stop when improvement:

However, the service user could stop taking the medication when he improved and felt good but relapsed after that.

> *"My symptoms eased, and I continued to adhere to the medication for three months when I felt my condition improved, I cut the medications, and the symptoms returned" (Service user 2, male 37 years old).*

On the contrary, primary caregivers keep giving psychiatric medications, although they have a negative experience with it, and they are emotionally impacted when they see their loved ones suffer from the medication's adverse side effects. It is difficult for them, but they want their service users to improve and return to their lives.

> *"I wanted the girl to recover so that she would serve herself and manage her life because I will not live forever. I did not want the disease to stay with her for a long time. No one cared about her. She was good when she was taking the medication, but because of the side effects, she is the one who did not like it and the one who bothered her" (Primary caregiver 3, female, 54 years old).*

Take it for a long time.

The duration of taking psychiatric medications was a concern for service users and their primary caregivers, which impacted their medication-taking behaviour.

> *"Oh, God, it was a difficult experience, and for a start, I felt that he had to stick to the treatment. But it should not last for a lifetime, especially young people like him" (Primary caregiver 2, Female, 62 years old).*

In contrast, other service users mentioned that they were willing to take medications for a long time if they could control the disease. Additionally, the healthcare professionals mentioned that the service users and their families accept taking the medications for a long time when they realise the importance of medications.

> *“I cut the medications based on myself. However, the doctor told me that I should take the medication for the rest of my life………. For me, I do not leave the medicines because my nerves cannot stand it. I mean, if I leave it, I will relapse” (Service user 1, Male 38 years old).*

Life stressor.

Life stressors and family problems cannot be ignored. People suffering from mental disorders have more pressure on them, in addition to work pressure and lack of financial resources.

> *" One suffers from psychological pressure and fatigue. He has the pressures of life such as finances, study, work, money, and life matters" (Healthcare professional 1, male, 34 years old).*

Forgot or being busy:

Healthcare professionals urge that there is nothing called I forgot to take the medication or that there is no forgetting, but many service users intentionally reduce the dose. Alternatively, take it not as prescribed because of being busy or waking up late, which happened unintentionally. However, they take it when they can or remember it. Service users or primary caregivers could change or skip one dose or one day because they were busy with their work and forgot to take the medication or take it later in the day, or they decrease the dose as the medication makes them sleepy, which affects their ability to work, and they are hurt (may fall).

> *"Now I have another problem when I am late to take the prixal dose because of my work pressure, or I do not take it for a day or two or a day and a half. I forget because I am tired from work, and the same is with fluoxetine. Nothing happens to me; I take it as normal; there is no problem" (Service user 2, male, 37 years old).*

Primary caregivers and healthcare professionals added other reasons: age[37], difficulty dealing with service users[38], and pregnancy[39].

The age of the primary caregiver affects the prescription of medications, especially when they renew the prescription.

> *"I am old age and do not bear public transportation to the hospital; it is far from us, so we have a problem with renewing prescriptions" (Primary caregiver 2, Female, 62 years old).*

Dealing with service users:

The primary caregiver mentioned that dealing with service users is hard, and they are frightened to be hurt, as noted by the HCP.

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[37] PCG 2. HCP 6.

[38] PCG1,2,3,4. HCP 3,7.

[39] Being pregnant PCG 3. HCP 1,3,4,7.

> *"When the situation worsens, we call the police, and they come and take him to the hospital; he is admitted for a week, and then they discharge him when his condition stabilizes" (Primary caregiver 1, female, 45 years old).*

Being pregnant is one factor that drives the female to stop taking psychiatric medications because of the side effect that influences their baby or foetus. This is mentioned by two groups: primary caregiver and HCP.

> *"Currently, a girl has been married for four months and is newly pregnant. I went to the gynaecologist's doctor to ask her about antipsychotic medications. She told me that it is forbidden because it affects the foetus, at least until the first four months are over; she is currently in the second month" (Primary caregiver 3, female, 54 years old).*

> *"Pregnant women tend to stop taking medication during pregnancy because they want to protect the foetus, and taking medication during pregnancy may make me want to have a child with a mental illness……Some of them tell you that the medicine can cause you to abort, so do not take any medication." (Healthcare professional 3, male, 33 years old).*

Additionally, other points were added by healthcare professionals and service users, which are a number of medications[40], pharmacists[41], also healthcare professionals mentioned severe cases vs mild cases[42]and lack of insight[43].

Number of medications

The healthcare professionals observe that more medication to take is less to follow. Some service users and their families complain about the number of medications that they need to take and the difficult schedule they need to follow. They believed that taking a smaller number of medications or doses was better for them.

> *"The issue of polypharmacy, I mean, when you write to the patient medication, two or three, he does not stick too much" (Healthcare professional 5, male, 35 years old).*

On the contrary, one service user mentioned that taking too many medications did not matter, while I felt improvement.

> *"No, it makes no difference to me. I have reached to take thirteen (13) pills together, but I have control over the matter and live my life" (Service user 5, female, 23 years old).*

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[40] SU5, HCP 4,5,6.
[41] SU3, HCP5,6.
[42] HCP5,6,7.
[43] HCP 1,2,4,7.

As a solution, healthcare professionals suggest, from the beginning, not to prescribe many medications for them.

> *"The fewer medications, the better. This thing is useful because when we increase the medicine, patients respond to it. We do not give him many medicines; we start with two or three medicines at most, and you can convince the patient of them" (Healthcare professional 6, female, 30 years old).*

Pharmacists:

This finding reflects how other healthcare professionals (pharmacists) impact medication-taking behaviours). First, this was an observation from one of the service users' primary caregivers (his sister), who was a pharmacist, and she prevented him from taking psychiatric medications because of their side effects.

> *"My sister is a pharmacist. She prevented me because of side effects were strong and caused addiction" (Service user 3, male, 31 years old).*

More details from the healthcare professionals about that finding healthcare professionals explained that the pharmacist teased the service user who came to the pharmacy with a prescription containing psychiatric medication or told him that this medication would hurt him. One healthcare professional mentioned that the situation happened to him, and he was shocked by the pharmacist's behaviour.

> *Yes, I mean, when the patient comes with a prescription containing psychiatric drugs, he is insulted by the pharmacist, and he becomes mocked. Service users told me such things, but I did not believe it. Unfortunately, the situation has happened to me. I went to bring the prescription because the pharmacist did not believe the service user and told him the prescription was fake. When I went to the pharmacist and gave him the prescription, he began to look at me from toe to head. I felt this a humiliation, and I felt it was a devaluation. Many people refuse to go to the pharmacy to dispense the treatment because of this. The important thing is that the pharmacist put the prescription in my face and told me, "To go outside before I call the police" This is why people were avoiding embarrassment and refused the medication" (Healthcare professional 5, male, 35 years old).*

Severe cases vs mild cases:

Healthcare professionals mentioned that taking medications depends on the case; for example, the service user who has an acute case accepts taking the treatment faster than mild cases because they want to finish their suffering.

> *"In very severe cases, I notice that the patient and his family accept the medicine more than patients who are at the beginning of the disease because they have suffered a lot and want to*

> *rest, and want a solution regardless of the side effects" (Healthcare professional 5, male, 35 years old).*

Lack of insight.

This overlaps with disease-related, but here reflects the insight that medications are helpful. Healthcare professionals mentioned that people do not believe in mental illness to convince them of psychiatric medications.

> *"Some of them refuse the drug itself, I do not want to be treated. I do not need to take medication, and this case depends on the diagnosis" (Healthcare professional 4, male, 28 years old).*

4.5.1.2 Experience with support system:

The second subcategory is supporting systems. This explains how the support system affects medication-taking behaviour. All participants mentioned that the support system could be considered a motivation or discouragement to take or give, even prescribing medications; besides, this plays a role in the decision-making process for medication-taking behaviour. A support system is essential for mental health, especially for the family. This subcategory includes three elements: family support, community support, and self-support.

Family support:

The role of the family is essential, especially when the disorder is in its initial state, as the service user needs care and support with medications and daily living activities. As it is important to help service users overcome the stigma, positive family support is considered a motivation to continue treatment and take medications.

> *"Yes, in the beginning, my father was the one who was caring for me from the first dose and followed with me dose by dose, and I was really comfortable with medicines" (Service user 1, male, 38 years old).*

> *"Neither supportive parents nor supportive society, unfortunately, I started suffering from secondary school. The second semester, my marks were getting worse and psychologically, were very bad. I felt like I was in a sea, and every time I tried to stop on my feet. I relapsed until I reached the end of secondary school. The first semester, I tried to keep the momentum and hard work to finish, but my mood was bad, and I felt physical pain. I did not know how to sleep at night, and in the morning, I felt like a stupor. I was telling my family, and they did not respond to me. They told me you were spoiled" (Service user 3, male, 31 years old).*

However, the absence or inactive family role will impact the treatment progress, and the service user may not follow up with the clinic or even come to the psychiatric clinic (this subcategory overlaps with category 3, beliefs).

Community support:

Family support is important and the surrounding community where the family lives because this community impacts the family’s behaviour; however, there is a lack of knowledge in the community about mental illness (this overlaps with category 2, knowledge). This poverty led the family to keep the issue of mental illness in the family and not share it, as they fear social stigma (this overlaps with Category 3 beliefs).

> *"In addition, the family has social relations; their social status is changed when they become afraid of the side effects, they become afraid of people noticing this thing, and they fear society’s view of the stigma attached to mental illness. Stigma mainly impacts medication taking" (Healthcare professional 4, male, 28 years old).*

> *“The people who understand me are the educated people at the university, and they supported me a lot. They supported me with the report that this student has a special health concern. They were psychologically supportive. Educated people helped me by making the subject easier. The support of the community and the educated people at the university helped me to adhere to medication greatly. I hope our society becomes more aware of the issue of mental health” (Service user 3, male, 31 years old).*

Because the community had poor knowledge, this would be a barrier and delay the treatment process. On the other hand, one service user mentioned that the educated people at the university supported him in overcoming his problem, reflecting the importance of knowledge**.**

Self-support:

Despite the difficulties with mental disorders and taking psychiatric medications, when participants feel that there is no support, but they are controlling the disorder by medication, they try to support themselves by themselves. This keeps them taking their medication and following up with their doctors. Two out of the six service users said that they supported themselves because they wanted to control the disorder and were afraid of relapse.

> *“But most of the time, I take the medication on my own, even if I have been patient for a day, but I take medications back because I don't want to relapse and think about the past” (Service user 1, Male 38 years old).*

> *“If I stop the medications, my condition will be very bad. So, I said to myself that it is true that it does not solve the problem, but the medications keep symptoms under control” (Service user 2, male 37 years old).*

4.5.1.3 Experience with disease:

The third subcategory of experience was disease related. This subcategory discusses how the disease impacted medication-taking behaviour. The most important thing mentioned by all the participants was that disease impacts awareness. Healthcare professionals mentioned it as a lack of insight. The experience with diseases subcategory has elements which are unaware of their condition and how the disease affects their life (work[44], study[45], forgetting the medication[46]). The disease is considered a barrier because it impacts insight, and this impacts the taking behaviour.

Unaware of their condition:

Participants mentioned that the disease impacts their taking of the medications as they refuse the treatment because service users and primary caregivers are unaware of what is happening with them or with their son or daughter at the beginning of the disease. Similarly, all healthcare professionals mentioned a lack of insight as an important factor impacting service users and their families taking the medications when they were prescribed them. Unaware or lack of insight for family and service users delays the treatment because the family or primary caregivers did not accept the idea of mental illness, or they thought that the child was acting for attention, and they spoilt him, or they believed in Jinn, eye, and envy (see category 3 beliefs for more details and category 2 knowledge).

> *"The lack of awareness, I mean, during a period that passed me, and I said that it is over, I said that I do not need treatment or medicine, I was not aware of what I was talking about" (Service user 5, female, 23 years old).*

> *"Parents do not know about mental illnesses because they do not recognize mental illnesses. But they tell you what eye, envy, jinn, and such are stories, and they say that mental illness does not exist, and we do not want our son or daughter to take such medicines, what do people say about our son" (Healthcare professional 2, female, 29 years old).*

Awareness is important to continue the treatment, so at the beginning, family and service users are not convinced of it, but after a while of the treatment, they know more about mental disorders and how medication helped them.

> *" She understanding and conscious of what happen. but at first was not convinced that she was sick" (Primary caregiver 3, female, 54 years old).*

> *"One of the most important reasons, he is not convinced that he is mentally ill. I mean lack of awareness or insight" (Healthcare professional 1, male, 34 years old).*

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[44] SU 1,2,3,6. PCG 1-4. HCP 1.

[45] SU 2,3,5

[46] SU 5,6

The disease affects my life (work and study).

All participants mentioned that the disease affects work and study; service users cannot work because of signs and symptoms, or the medication's side effects, as they sleep most of the time or make them drowsy. In addition, they could not complete their study because of disease signs and symptoms such as obsession, depression, and phobias, and they forgot to take the medication because of the disease itself (signs and symptoms such as hallucinations and delusions). However, the primary caregivers mentioned that their work was impacted as they needed to combine the service users and follow them; they also mentioned that they prevented their patients from working because of their disease.

> *"I want to continue my study, but I cannot complete it due to special circumstances of the psychological problem………… But it began to appear and affect my life, for example, almost daily, from secondary school, but I did not understand what happened, then affected my work. I cannot find a job" (Service user 2, male 37 years old).*
>
> *"…I forgot the medication because of the disease, but I took it when I remember" (Service user 5, female, 23 years old).*
>
> *"The parents do not follow, and they tell you that they also want to catch up with work. I go out from 7:00 in the morning until 7:00 in the evening. I do not follow up with him, especially if the financial situation is weak, so they did more than one job and have no time" (Healthcare professional 1, male, 34 years old).*

Healthcare professionals argue that the diagnosis itself affects medication taking, and they say that people diagnosed with bipolar disease progress better than those diagnosed with schizophrenia. Healthcare professionals stated that people diagnosed with Bipolar I disorder adapt to the disease, and this helped them to work and return to their normal life patterns, and they were aware of their medications. On the other hand, people with schizophrenia are unable to return to their normal life but may control their symptoms; they are also unable to work, are not aware of their medications, and need someone with them to follow. One healthcare professionals describe schizophrenia as the "cancer of the mental disorder" because it is difficult to cure and deal with.

> *"We can say that bipolar is a little better in terms of responding to treatment for them it was better, and they reach recovery, control the disease, continue their lives, graduate from university, coexist with the disease, and get married, which means they are almost back active in society2 (Healthcare professional 4, male, 28 years old).*
>
> *"As for schizophrenia, it is a little more complicated, which means that the diagnosis is worse than other diagnoses, and the treatment journey takes longer. A percentage of them can practice their lives somewhat, and some of them are saying that our life is over. I mean, it looks like cancer" (Healthcare professional 6, female, 30 years old).*

4.5.1.4 Experience with other treatments:

The fourth subcategory is using other treatment modalities. All participants mentioned other treatment modalities which helped in addition to medications, such as (psycho-behavioural therapy, electroconvulsive therapy (ECT), and traditional treatment (herbal medicine and religious healers to be discussed in more detail in category 3, beliefs). Although behavioural therapy is useful, it is expensive and not available in all government clinics. Healthcare professionals mentioned that some families and service users come to the clinic and ask for behavioural therapy as they do not want to take medications. However, others have found that behavioural therapy is neither helpful nor expensive.

> *"Here in Jordan, most focus only on pharmacotherapy. Psycho-behavioural therapy, very little and this field still needs work, and it is also very expensive" (Healthcare professional 5, male, 35 years old).*

> *"The doctor said I will do a behavioural treatment, but he does not work or do anything. I mean, she goes and sits with him for a quarter of an hour with her, but (15 minutes) I mean, he listens to her" Primary caregiver 4, female, 61 years old).*

In addition, service users and primary caregivers believe behavioural therapy or other treatment modalities will provide good results and progress if combined with medications[47]. However, medications alone are ineffective, and other modalities will not be effective alone. Similarly, healthcare professionals mentioned that medication alone would not help. It should be combined with other treatment modalities such as psychotherapy, behavioural therapy, and cognitive behavioural therapy. We need to incorporate these in the treatment plan.

> *"See, doctor, frankly, medicines are not everything. I mean, for example, Behavioral therapy is important, and medicines are important. I mean, for example, that medicines will not cure 100%, and neither, for example, behavioural therapy, will cure me 100%, nor will I be able to do anything on my own. I mean I need all three together to get better. But at some point, I will not be able to enter behavioural and cognitive therapy before I start taking antidepressants because I feel that I must improve first in order to be able to complete the session, and if I am not getting better and will not receive anything" (Service user 5, female, 23 years old).*

However, Primary caregivers and service users believe in traditional and herbal medicines, which they tried before psychiatric medicine, such as religious healers and traditional treatment (see Category 3 belief/treatment journey).

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[47] SU 4,5. PCG 3,4. HCP 5,6,7.

“I thought that it was a disease from the jinn and touch and so on because I used to see things that people did not see, and then my family took us to the religious healer, but it was useless. Then we went to the general practitioner and referred us to the psychiatrist” (Service user 4, male, 27 years old).

4.5.1.5 Healthcare experience prescribing psychiatric medications:

This is the fifth subcategory in experience related to healthcare professionals' experience while prescribing psychiatric medications. This subcategory includes three elements: experience of prescribing, missed dose, and service users deciding to take or not.

Experience with prescribing:

Here, the healthcare professionals discussed the factors that affected the prescription of medications, which they noted and observed at the clinic. Healthcare professionals found that family and service users are concerned about the duration of taking the medications, and if it is for a long time, they may not take it. The people who ask about the medication they find helpful to prescribe and explain more about that, and they are sure that those people will take the medication as prescribed.

> *"There are parents who said our son or daughter, when he took medicine, his condition became perfect. We almost forgot that he was sick and started going ahead in his life normally. So, they asked us now, do we want to continue the medication, or do we want to reduce it or stop it" (Healthcare professional 7, male, 44 years old).*

In addition, healthcare professionals found that some people come to the clinic for psychiatric medications, but they are not sick; they have an addiction. This kind of person was hard to know from the first time as they came to the clinic and acted as patients well.

> *"There are patients who want a specific medicine, especially those who are addicted, and they know the symptoms of illness and reading about them. They asked for a specific medicine, which is usually for the mood or things like that. Of course, you cannot know until the doctor sees him and reviews more than once at the clinic, and it is possible to know them from the assessment of the patient's mental state and through the interview. However, most read about the case very well" (Healthcare professional 3, male, 33 years old).*

For example:

> *"Yes, there is a patient who has come, and you feel that he wants to behave as if he knew about mental illnesses. I got a case where he was sick with (an antisocial personality), and he told me that he was tired and ashamed of this behaviour and that he needed medicine to help him, and his life was stopped, so he asked me for something we did not prescribe them for his condition (Rivotril and Tramadol), and when we asked him why you want them, he said that these medicines helped him. He wanted to plan to get rid of the situation he was in. In light of these words, and he would like to be treated, we gave him a prescription, but in the second session, and after examination and interview, it was found that this person was not right, and*

> *he was addicted to these medicines. We did not prescribe these medications for them again and referred him to the addiction centre " (Healthcare professional 5, male, 35 years old).*

Another problem that healthcare professionals face while prescribing medications is when they are prescribed a controlled drug. These prescriptions face a problem at pharmacies because pharmacists refuse to prepare them for service users as they experience a huge number of fake prescriptions (see previous section barrier to taking psychiatric medications/ pharmacist).

> *"The other problem is prescribing medications (controls) such as benzodiazepines or gabapentin. Many people face a problem in pharmacies that they do not accept to give them the prescription because in many cases have fake prescriptions or the prescription is incorrect. Many pharmacies toughed their instructions on these things" (Healthcare professional 4, male, 28 years old).*

> *" Service users told me that there are pharmacies that sold psychiatric medications for them, as not all drugs are controlled, only addictive drugs are controlled and checked by the pharmacist" (Healthcare professional 2, female, 29 years old).*

The healthcare professionals found that the education level of the service user and their family plays an important role when prescribed medications, as this helps them adhere to the treatment if they have a good understanding and education level.

> *"I mean, the parents impact medication taking, especially if they are not educated; frankly, the educated are easier than the one who is not educated, you can discuss and talk with him. Those who do not know or are not educated, unfortunately, cannot talk to them and cannot discuss them at all; even if I explain and discuss them, he will tell you that they are convinced that psychotropic drugs cause addiction (my son will run in the streets and talk to himself, let us not be without medicine)" (Healthcare professional 5, male, 35 years old).*

On the other hand, other healthcare professionals mentioned that educated people is a negative thing as they read, but they did not understand, so they changed medications without talking to us.

> *"Of course, if the educational level is acceptable, that is, talking about a university or secondary school is different from the patient who is not educated, they keep asking, but these have advantages and disadvantages. Sometimes educated people go to read on the internet, and they tell you this medicine does not affect the patient and such, and they want to change based on what they read on the internet. However, those who are not educated listen to the doctor's words and are interested to listen from us, take the clinic's phone, and it starts ringing and asking us if they have an inquiry, and his commitment is better. But not with everyone, meaning there is a difference between those who are interested and those who are not" (Healthcare professional 2, female, 29 years old).*

1.5.3 Missed dose and check-taking:

The healthcare professionals (7 of 7) mentioned that it is important to check taking to ensure that service users and their families adhere to the treatment plan. However, mistakes occurred, such as taking medications not as prescribed, for example, increasing the dose to get better soon or decreasing the dose as the symptom improved. These happened intentionally, while some unintentionally forgot to take it because they were busy or working, as mentioned earlier (see barrier to take medication/ forgot or being busy).

> *"They stopped taking the medications when symptoms disappeared, and the feeling of improvement, or reducing medications, I mean, he does not take them as the doctor writes them. I mean, instead of two pills, it will take one pill for a case. This thing we know when they were at the clinic for follow up, some of them tell us, and some of them do not, and some of them told you that I took more medicine to get better soon" (Healthcare professional 1, male, 34 years old).*

Healthcare professionals check for missed doses through interviews with service users and their families; however, some told them about missed doses, and some did not. Here, the healthcare professionals depend on the signs and symptoms of relapse to check if the patients take the medications as prescribed. In addition, the service user repeatedly visits the clinic.

> *"Of course, when does he come to us after he relapsed a second time, and when we asked him, he told us that I became good and stopped the medication. This is clearer with the parents than the many reviews because every time that he stopped the medication will relapse and they must be taken to the hospital" (Healthcare professional 6, female, 30 years old).*

It is worth mentioning that primary caregivers noted that the service user did not take their medications as prescribed when he behaved weirdly.

> *"I mean, what do we see when he released? The first thing he shaves his hair to zero, and then he puts on the clothes of my brother who is fifteen years younger than him (15 years old)" (Primary caregiver 1, female, 45 years old).*

Also, primary caregivers depend on the direct observation and medication counts to ensure that he took the medications 4 out of 4 mentioned that.

> *“I was watching her while she was taking the treatment, and she was very committed to it” Primary caregiver 4, female, 61 years old).*

However, some medications must be stopped as they have a high blood level, which is checked monthly at the clinic.

> *"Of course, it was explained to them that a level of medication needs to be checked, such as lithium and depakine. We must do a blood level check every month, and when he returns to the clinic, they keep following them" (Healthcare professional 1, male, 34 years old).*

One service user mentioned that he stopped taking his medications because of the high level.

> *"The first thing, because of the side effects, is that it makes me very tired. The second and most important reason is that the drug level in the blood was high" (Service user 5, female, 223 years old).*

When a missed dose occurs, the healthcare professionals respond to this, not as a crime or something big done by the service user. They try to show that this is normal and could happen to anyone; the most important thing is that the service user is honest and tells them the truth to give him the right advice. Additionally, they clarified to them the importance of taking medications and suggested some useful tips which could help them not to do this again, such as (a medication box or setting reminders on the phone, letting someone remind them).

> *"Oh yes, but most of the medicines, if he does not take a dose, it is not a problem. The most important is that you told me" (Healthcare professional 3, male, 33 years old).*

Service users decide to take or not:

The healthcare professionals mentioned giving the service user the choice to take the medications after they explained to them. It is important to be convinced that they take them on their own. This depends on the status of the service user, which is fully aware of what happens. In some cases, doctors decide to give the medication by force if there is any danger or if it could threaten the lives of others. Here, there is a protocol to bring him to the hospital against his wishes via the police.

> *"No, no, absolutely not forcing him, but if the patient has bipolar or schizophrenia and not taking treatment leads to a relapse, and this relapse will lead to that he poses a danger to himself such as suicidal thoughts, or hallucinations of voices and orders to harm, or hits, destroys and harms the people around him, and the expenses become a lot like bipolar patients, I mean, in a patient who sold her apartment very cheap, she posed a danger to herself and others. Then there is an official way how the parents or carer to bring them to the hospital, which, through the civil defines and, he is admitted against his will. In these cases, we give the medicine, and he does not agree to it. Of course, every case has its circumstances" (Healthcare professional 4, male, 28 years old).*

4.5.1.6 Consequences:

This is the sixth subcategory of Category 1: Experience with psychiatric medication. The decision of taking or not taking medications as prescribed will result in positive or negative consequences which encourage the service users whether to take the medications or not. Positive consequences such as they able to work, study, and go back to their normal life, as mentioned earlier (4.5.1.1 Experience with psychiatric medications/motivations to take medications). However, negative consequences impact their medication taking, resulting in changes in medication-taking behaviour, such as increasing, decreasing, or not taking the dose, and relapses which impact their lives. All participants mentioned these consequences and how they impacted their decisions regarding the medication taken.

Change in taking behaviour.

Here, we mainly focused on service users and primary caregivers. All mentioned that they decreased, increased, or stopped medication based on themselves without asking for healthcare professionals at some point in their treatment journey. This decision was based on the reasons mentioned above, such as side effects, no improvement, or family support. However, some service users and primary caregivers did not change their medications until they consulted the healthcare professionals. The result of taking or not taking leads the service user and their primary caregivers to draw their decision to continue or to leave the medications based on the motivations or discouragement to take the medications.

> *"Oh, I thought and quit the medication once, but I noticed that my situation worsened, so I said that one must take the medication. I stopped the medication without knowing anyone, based on myself" (Service user 3, male, 31 years old).*

> *“I completed my bachelor's and master's education and had high grades” (Service user 1, Male 38 years old).*

> *“No, we don’t change based on ourselves, but after asking the doctor about that” (Primary caregiver 3, female, 54 years old).*

Healthcare professionals noted that people tend to decrease the dose; however, in some circumstances, they increase the dose because some medications have a tolerance level, so they need to increase the dose to overcome this without telling us.

> *"Now, the medicines that reach tolerance level in the body, the patient may increase doses, instead of taking a pill, he is taking two or three pills because one tablet is not enough. So, he starts to raise the dose. Usually, this is what we see" (Healthcare professional 6, female, 30 years old).*

Some try medications from other sources or buy them from the pharmacy without referring them to the doctor. (two out of six service users mentioned and four out of seven healthcare professionals.

> *"I tried to take psychiatric drugs that my friend brought from Egypt, and it was useless" (Service user 2, male 37 years old).*

> *"Up to my knowledge, the medicines that have the most control are only the gabapentin and the benzodiazepine. As for the rest of the medicines, oh yes, the patient can read on the internet and treat case by case" (Healthcare professional 5, male, 35 years old).*

However, in some cases, some medications are stopped by a doctor because they need to be carefully taken and regularly monitored because of the toxic level; at this stage, the doctor may stop it. One service user mentioned this.

> *“Doctor stopped lithium because of high level in blood” (Service user 5, female, 23 years old).*

Relapses:

However, these changes in behaviour will lead to relapse, which impacts the service user's life and lets him think of stopping the medications, as he believes that the medication ruined them. All participants mentioned relapses as a barrier to taking the medications, as well as the result of not taking the prescribed medications. However, after the relapse, the patient reconsidered taking the medications as it was good and controlled his life. Relapses are the indicators for the participants which indicate whether medication is useful or not. Four out of six service users mentioned that they relapsed after stopping taking the medications then they realized how important it is.

> *"When I leave the medicine for two or three days released and think of people and problems from the past, then I became nervous, So, I learned not to leave the medicine" (Service user 1, Male 38 y).*

Seven out of seven healthcare professionals mentioned that service users come to the clinic after they stopped taking the medications and relapsed.

> *"When symptoms reappear, and he relapsed after stopping the medication, he comes back to us and starts asking. Then he thinks that he will take the treatment so that he does not relapse" (Healthcare professional 2, female, 29 years old).*

4.5.2 Category 2: Knowledge about psychiatric disorders and medications:

Knowledge was the second major category of knowledge identified in the data. Knowledge gives the service user and the primary caregivers information about the medications and helps them to draw their decisions about psychiatric medications. This depends on different factors, such as what they know about the disease and medications, from where they got their information, and who they asked. This category includes two subcategories: knowledge of mental disorders, medications, and sources of information. (*Please see* Table 32: Appendix F- 2. Example of how Knowledge category is drawn from data).

Service user's and primary caregivers' knowledge affects their decision to take psychiatric medications. Service users and primary caregivers use this process to draw their decision about medication taking based on their knowledge and source of information. Knowledge about psychiatric medications and disorders is considered a barrier or facilitator to taking medication and could be considered an external or internal factor if the service user learns by himself or from others.

4.5.2.1 Lack of Knowledge:

This subcategory discussed lack of knowledge as a barrier to taking, giving, and prescribing medications. Data from interviews showed that community and service users have few details about psychiatric disorders and their medications. It also shows what people know and do not know about mental illness and psychiatric medications, what type of information they have, what the community knows about it, and how this affects their taking. The element of this subcategory includes knowing a few details about the disorders and knowing a few details about the medications.

Knew a few details about the disorder:

All participants mentioned that the community and people surrounding them did not know or knew very little about psychiatric disorders, which came from their backgrounds and beliefs that psychiatric disorders come from a supernatural power, vitamin deficiency, frustration, and divorce. This domain overlaps with beliefs discussed later (see Category 3: beliefs). Participants had previous knowledge about mental illness from their ancestors and beliefs (see1.2.1 Values and Beliefs). This previous knowledge is based on their life experience and influences their decisions about seeking help from a specialist, which delays their treatment and improvement.

Lack of information about the disorder included lack of information about the signs and symptoms of the disorder; service users and primary caregivers experienced symptoms of a mental disorder, but they did not know that these were symptoms of psychiatric problems at that time, such as fear of people gathering, feeling defeated, isolating themselves, and not knowing what happened to them. However, the family believes this is a sign of supernatural power, such as Jinn's touch or evil eyes.

> *“The problem with us is that there is no information about mental illnesses, and the parents are ignorant of this subject and are convinced of envy and jinn. Unfortunately, there is not enough knowledge about mental illness in Jordan in this field” (Service user 3, male, 31 years old).*

> *"At first, we suspected with the eye and envy that the girl was envied, as they told relatives and neighbours, and we took her to the religious healers to read on her and tried herbs, which were all useless. Ultimately, the general doctor advised us to see a psychiatrist" (Primary caregiver 3, female, 54 years old).*

The study showed that all (six) service users knew their diagnosis and no other information about the disorder. All (4) primary caregivers knew that this was a brain disease. Similarly, the healthcare professionals found that service users and their families who came to the clinic did not know anything about mental disorders unless they had previous cases in the family or read about them.

> *"I know that it's a brain disease, so the patient begins to see things that are not present" (Primary caregiver 1, female, 45 years old).*

> *"Because it is the society itself and the psychological culture in it is few. So, I suppose that they know nothing about mental illness and medications" (Healthcare professional 6, female, 30 years old).*

The healthcare professionals urge that there is awareness in the community about mental disorders and medications, but not that much. People knew that there was a mental problem, but to what extent it impacted our lives, they did not know.

> *"Recently, there has been a significant improvement in mental health. Many patients accept that they have a mental illness. Let us say that they acknowledge that the symptoms they have are due to mental illness, but they do not understand psychiatric medications. Their understanding is limited. They know it is a mental illness, but to what degree it affects our lives, they still do not know" (Healthcare professional 6, female, 30 years old).*

On the other hand, the awareness of the community was misunderstood. Healthcare professionals [48] noted that some people who came to the clinic diagnosed themselves by reading the signs and symptoms that they experienced.

> *"Ah, you can say that there are people diagnosed themselves, uh, maybe we have people diagnosed themselves with obsessive-compulsive disorder, for example, who has disorder, anxiety, social phobia and a spectrum of depression, and when asking them by whom you diagnosed, they said read on the internet" (Healthcare professional 4, male, 28 years old).*

Know a few details about medications:

Participants (all service users and primary caregivers) had few details about their medication, such as name, dose, time, and some side effects. They were familiar with the Internet and self-reading, as I will discuss later in the next section. They did not know the important details and significant side effects impacting their medication-taking behaviour. Additionally, this was confirmed by healthcare professionals' observation that service user and their families who came to the clinic did not know details about their medications, such as names and some side effects. However, they depend on the tablet's colour [49]and the shape of the box[50].

> *"I take a medicine called Seroquel and another one called Jorex for depression. I know that Seroquel is an antipsychotic that helps eliminate hallucinations, delusions, and psychotic thoughts. I take two pills in the morning and two in the evening, 200 mg of Seroquel. And I take a Zolex pill, six 6 mg in the morning. I kept continuing the treatment even when the symptoms subsided because I knew that one should not interrupt the treatment" (Service user 4, male, 27 years old).*

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[48] HCP 4,5,6.

[49] PCG 2,3. HCP 5

[50] HCP 5.

> *"Frankly, I do not know much about medicines, but I know that it is for schizophrenia. I know some of the side effects that the doctors told us about" (Primary caregiver 1, female, 45 years old).*

> *"Frankly, not many patients and their families know about their psychiatric medications. They do have no information, but when they come to us, we explain to them" (Healthcare professional 2, female, 29 years old).*

However, it is important to keep the box of medications and the leaflet back to it when needed to know more about them.

> *"I do not remember the names of the medicines. I have to read from the box, let me see the box, stay with me for a while so that I can show them to you......I am taking Seroquel 100 mg three times a day. Only this drug is the one I knew. Also, I took Zoloft 200mg twice and kemadrin one tab a day…. Give me a minute to go back, and I will answer the rest of them. Now I took Lamictal 200 mg, and Sirubin 200 mg three times the dose" (Service user 6, female, 38 years old).*

However, knowing more about medication encourages them to take it. Participants mentioned this during the interviews. More information allows the service user and primary caregivers to know what and how to use medications. Healthcare professionals stated that the more they knew, the more they took their medications.

> *"But if they are convinced and take the necessary education, the outcomes will be excellent. Some of them took the medications and adhered to them. The results were wonderful because they knew the mechanism of the disease, the mechanism of how the drug works on the disease" (Healthcare professional 5, male, 35 years old).*

4.5.2.2 Source of information:

Seeking information and knowledge about mental disorders and medications to obtain more information. This subcategory discussed the source of information that the participants used to obtain more information about their diagnoses and medications. Based on that, they decide to take or not take the medications. For example, they used the web and other websites to find information about psychiatric disorders and some medications. Alternatively, some service users ask healthcare professionals (doctors or pharmacists) about medications. Another source of information is the experience of using different medications and reading the leaflet. The Source of information includes four elements: using the Internet, asking healthcare professionals, learning from other experiences, and self-readings, which all participants mention; at least the service user or primary caregiver uses one or more of these ways.

Using internet:

Currently, the Internet is widely used to find different types of information. One is information about the medication’s usage and side effects, mentioned by 15 out of 17 participants. Service users and primary caregivers used websites to check their medication dose, side effects, and diagnosis; these websites were obtained by asking healthcare professionals or searching the Internet.

However, they said that some websites are not trusted or authorised, and their content does not mention scientific information about mental illness. They mentioned that envy and evil eyes are causes of mental disorders. Besides, there is a site which is not official, or you cannot depend on to build up your knowledge about the medications or disorders as people use it to gain money. Service users used these websites because there was no explanation for them.

> *"I read on the internet. I mean, can I use Google to search about some medications and read what it does, what are its side effects, what are the doses one can take, and what are the highest and lowest doses……I prefer to use the internet, as it has a trusted official site which you can depend on to take your information from it. but the diagnosis is from the doctor, not by these sites …. For example, I did not know what my diagnosis was until I read about the medications that I took and what is used for. Doctors did not tell me what my diagnosis was. I knew by myself from the Internet. The doctor did not explain to me that" (Service user 1, Male 38 years old).*

Participants urged that the Arabic content on the Internet is very poor regarding mental health and mental disorders; besides the YouTube channel, which has Arabic content, it has non-scientific content.

> *"I mean, the Arabic content is very poor with regard to the issue of mental health, so those who work at mental health discover that the knowledge in society is zero because people tell us that you work with crazy people, this is the simplest thing, and this is rather than there is no culture about mental health" (Healthcare professional 3, male, 33 years old).*

Searching for more information on the Internet helps service users and primary caregivers know more about medications, which will improve their medication-taking behaviour. However, some service users and primary caregivers use this information to control their dose without asking the HCP[51], so they increase or decrease the dose by themselves.

> *"I am not improving until I searched for the information in the English content because there is a lack of Arabic content and awareness on the subject of mental health and psychotropic drugs" (Service user 5, female, 23 years old).*

> *"However, 20% of patients read online; they increase and decrease the dose based on what they read. The last time we had a patient who changed medications every day because he reads on the internet, whether psychiatric or other medications" (Healthcare professional 1, male, 34 years old).*

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[51] SU 1,2,3. PCG 3. HCP 1,4,5,6.

Ask HCP

Participants (service users and primary caregivers) asked healthcare professionals or pharmacists to understand or to get more information about the disease and medications, and they asked them about a trusted website if they needed to use the Internet to get more information. As mentioned above, sometimes doctors did not explain enough to them, so they returned to use the Internet. However, this affects their medication-taking behaviour when they have less information. Some explained to pharmacists what happened to them, and they described medications for them without any official diagnosis[52]. It is worth mentioning that pharmacists could give medication to the people, as this is a norm in Jordan (see 1.2.1 Values and Beliefs). Some psychiatric medications are controlled, but some are not. Category 4 health systems and policies will discuss this in more detail. However, most service users and primary caregivers prefer that psychiatrist prescribe their medications.

> *"I went to the pharmacy, and I told the pharmacist what happened with me and prescribed me a medication" (Service user 2, male 37 years old).*

> *"It is possible to use the internet, but I have never done this. I mean, I like to take from trusted places and people, such as the medical staff" (Service user 4, male, 27 years old).*

Service users and primary caregivers urged that they were using the Internet because healthcare professionals at the governmental clinic did not explain to them about medications or disorders.

> *"I asked more than one doctor in Jordan about the diagnosis, each telling a figure. Even the doctors did not explain anything to you, neither about the disease nor about medicines, even the private doctor who diagnosed me for the first time. I returned to him after a period of time, and I did not find my file with him. Same complaint" (Service user 1, Male 38 years old).*

The healthcare professionals defended this point and stated that we could explain, but not from the first session, be the fourth or the third. We need service users and their families to accept the treatment, but first need to convince them of the treatment, which did not happen from the first session. In addition, the healthcare professionals check the service user and primary caregiver's information about medication and check if they understand what they explain before leaving the clinic by telling it back; if there is any misunderstanding, they explain more than once.

> *"The problem begins with the issue of education, and we must focus on the disease. Now, the patient will be convinced and adhere to the medicine if he understands what exactly the mechanism is in which the medicine works and how it affects the disease, and this is not from*

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[52] SU 2.

> *the first possible session from the third or fourth he begins to be convinced to take the treatment" (Healthcare professional 5, male, 35 years old).*

> *"I sit with him and explain to him about the medicines and told him to say them back to me so that I can make sure that they understand correctly and repeat the topic with the parents" (Healthcare professional 1, male, 34 years old).*

Additionally, the healthcare professionals stated that the level of education for the service user and primary caregiver is an important factor when they explain the medications, as this helps them understand medication side effects and medication regimen[53]. In addition, the healthcare professionals mentioned that younger people are more interested and know more about technology, so they read and discuss medication more than older people[54]. One healthcare professional urges that the level of education is irrelevant. Service users and their families accept mental illness.

> *"Ah, being educated (medical laboratory), this helped me to contact social workers on Facebook, that they do not help us with medicines, but of course they help me behaviourally, eh, but medicines in general, I remain afraid of them because when I read about their side effects, I remain hesitant whether to give them or not" (Primary caregiver 3, female, 54 years old).*

> *"Yes, a lot, especially the young generation who is conscious of technology, they discuss more and search on the Internet, and they will see some medicines and read about them, and they discuss us more than elderly" (Healthcare professional 4, male, 28 years old).*

> *"The educational level of the parents is a factor in the commitment to treatment, but unfortunately, it is not as you think. You are saying that if the parents are educated or the level of education is high, it will affect them, but unfortunately not. Some of them are educated, and they go to the religious healer before they go to the psychiatrist, and some of them are doctors" (Healthcare professional 7, male, 44 years old).*

Learn from other experiences:

The third element of Category 2 (knowledge) is learning from other experiences, which overlaps with the Category 1 experience of taking psychiatric medications. I considered this source of information as people developed their knowledge from their experience in dealing with psychiatric medications. Participants mentioned that they used other experiences to control their disease and took the medications as they learned from others, such as the previous case in the family or his neighbour or from his trial's different medications. This impacts medication-taking behaviour, so they may decide whether to take medication or

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[53] SU 1-6. PCG 3, HCP 1-6.

[54] HCP 4,6.

not based on the knowledge formed by this experience. They found an actual example to see this medication's effect and reflected on their case.

> *“We, as a family, believe in the existence of mental illness, and we have also gone through previous experiences, such as my uncle, aunt, and my sister are suffering from mental disorder. We are an educated family” (Service user 6, female, 38 years old)***.**

Reading from leaflet

Self-reading is the fourth element of the source of the information subcategory, the most common way to obtain information about medications. Despite various resources to gain information, reading from leaflets was used by the vast majority of participants (service users and primary caregivers), and all of them used these methods. However, Leaflets that come with the medication box give them more information about medication and usage, but some information needs more explanation from a specialist in mental health, especially if the leaflet is in English and there are no Arabic translations.

> *"I mean, we are educated, so we read the leaflet to get more information about the medications" (Primary caregiver 1, female, 45 years old).*

4.5.3 Category 3: Beliefs about psychiatric disorders and medications:

Beliefs about psychiatric medications and disorders were viewed as important factors influencing medication-taking behaviour. All participants identified beliefs as facilitators or barriers that influence medication taking, which overlaps with community knowledge about psychiatric disorders and treatment because this knowledge in the community was built up through their beliefs and experiences. These beliefs originated from culture and religion, so they are a common factor among participants, as they are in the same surroundings. However, this where different from family to family; this depends on what extent they know about mental disorders and what they believe about them. Beliefs affect the treatment process and help.

Beliefs are perceived as internal factors, facilitators, or barriers to medication use. Besides, service users and their families start their treatment journey by visiting religious healers and other traditional treatments before thinking about seeking help from the medical team because they believe that mental disorders are caused by supernatural powers. Through the analysis of the interviews, four subcategories related to this category emerged: service user, family, community, and healthcare professionals’ beliefs, stigma, religion, and treatment journey.

Subcategory relates to beliefs regarding psychiatric disorders, medications, and treatments. As mentioned above, beliefs impact medication uses either as a facilitator or a barrier. Their surroundings affected participants (service users and primary caregivers) and their beliefs. In Jordan, they believe that mental disorders are caused by supernatural powers such as envy, eye, and Jinn touch [55] , as in many other countries (See 1.2.1 Values and Beliefs). In addition, they believe that psychiatric medication will hurt them because of side effects, such as fear of addiction, and there is no improvement[56]. This belief impacts medication taking, as they refuse to take the medication when prescribed to them.

> *"Family do not know about mental illnesses because they do not accept mental illnesses. But they tell you that eye, envy and Jinn and such stories. They say that mental illness does not exist, and we do not want our son or daughter to take such medicines" (Healthcare professional 2, female, 29 years old).*

> *"But I feel like he has become addicted as if the drug is in a narcotic substance that causes addiction. As I feel my son has become addicted on medications because he keeps asking about it" (Primary caregiver 2, Female, 62 years old).*

> *“When I took the medicine, my family wouldn't let me take it so I could follow up because my parents don't belief in psychiatric disorders” (Service user 4, male, 27 years old).*

Beliefs about marriage allow people to think of stopping medications and keeping them secret. Participants mentioned that marriage was one of the factors that led service users and their families to stop taking and giving medication [57]. However, healthcare professionals argue that this worsens the situation because after marriage and stopping medication, relapses occur when the partner discovers that his/her partner takes psychiatric medication, and then divorce occurs. On the other hand, if the service user stopped their medications and got married, and the other party knew that and supported them to continue treatment, this would encourage them to take their medications. As an example of this, a primary caregiver mentioned that.

> *"How do I want to get married while I am taking psychiatric medications?" (Service user 3, male, 31 years old).*

> *"When service users get married and stop taking the drugs, they will have a relapse after a while, as the other party does not know about psychiatric drugs, but when they know. They will go the court and divorce happened as there is a deception, and they did not talk or hide the issue" (Healthcare professional 7, male, 44 years old).*

> *"When the right husband came and got engaged, she reminded me of the medicine, even when I forgot, she would say where the Prixal pill is" (Primary caregiver 3, female, 54 years old).*

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[55] Su1,3,4,5,6. PCG 3,4. HCP 1-7.

[56] SU 1,2,3,6. PCG 2,3. HCP 1-7.

[57] SU 2,3,4,6. PCG 3,4. HCP 2,4,7.

Building a trusting relationship is essential in the mental health setting between service users and HCPs; when this is missed, dealing with service users will be difficult as they will not trust the doctors and will not trust the treatment they prescribe. Service users mentioned that they did not believe in mental health doctors, as they did not listen to them and answer their questions. However, healthcare professionals stated that a trust relationship should be there to let them accept the treatment [58].

> *"I cannot find a solution in Jordan, and this is the problem of taking medication and changing it. Each doctor does it his way. This is a problem with the doctors" (S U 1).*
>
> *"As the doctor says, I did not see an improvement, but I controlled the disease" (Service user 2, male 37 y).*
>
> *"Now, the first and most important thing is that he should be comfortable with the doctor and trust him so that he can accept what the doctor tells him. But when the doctor told him to take this medication as I told you and you will be fine, he will not trust us and stop taking treatment" (Healthcare professional 6, female, 30 years old).*

4.5.3.1 Stigma

All participants mentioned stigma as a barrier to taking medication. They think about people and how they will look at them if they know that they have a mental illness or have a psychiatric disorder. The cultural beliefs surrounding the service user and primary caregivers impact the beliefs of the family and neighbours, which impacts the service user's medication-taking behaviour.

> *"But the reasons why I left medications, in the beginning, was the stigma that I am mentally ill, what people will say about me, and so on, I was embarrassed about the subject" (Service user 1, Male 38 y).*
>
> *"There is also no privacy in clinics, and this is a girl. I mean, we try to keep the matter secret so that you know what people and society are saying" (Primary caregiver 4, female, 61 years old).*

The healthcare professionals said that fear of social stigma prevents them from visiting the psychiatric clinic, as they refuse to be diagnosed with mental disorders, which is reflected in prescribing medications.

> *"Your diagnosis is wrong. All of this is due to the stigma of the people in Jordan, the rate of which is very high. besides, the negative society's view of mental illness, psychiatric medications" (Healthcare professional 5, male, 35 years old).*

These beliefs delay seeking help as well as delaying the treatment plan because they fear embarrassment from society and refuse to visit a psychiatrist if they try to keep this secret, as they are afraid of the stigma.

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[58] SU 1,2,3,5. HCP 4,6.

4.5.3.2 Religion:

Religion is the third subcategory and is considered to be a factor that motivates or discourages medication-taking behaviour 10 out of 17 said that the vast majority of people in Jordan are Muslims (see 1.2.1 Values and Beliefs). Religious healers are considered first-line treatment for mental illness because they believe that the cause of mental disorders is supernatural[59]. On the other hand, Participants mentioned that religion is a support factor with medication, which helps them to overcome the problem [60].

> *“Also, I recited the Qur'an a lot to comfort me, with medicines, and things are good” (Service user 6, female, 23 years old).*

> *“People did not beliefs in doctors, and they told me to go to a religious healer better for you” (Service user 3, male, 31 years old).*

4.5.3.3 Treatment Journey:

Beliefs of the family or primary caregivers play an essential role in seeking help, especially when their children complain. However, this is different because of the complaint related to mental disorders, so they think that the boy or the girl was spoilt and acting like he/she was mentally ill, so they did not take it seriously and left them for a long time not treated. Alternatively, the family refuses the idea when the doctor tells them that their child has a mental illness, so they try to find out with traditional treatment.

This kind of traditional treatment led us to consider the treatment journey for mental illness in Jordan. As mentioned above, participants mentioned this as the journey because they tried different traditional treatments before finding their way to the psychiatrist. This delay is based on their beliefs and is affected by the surrounding community, which makes the problem more complicated (see 1.2.1 Values and Beliefs).

> *“I thought that it was a disease from the jinn and evil eyes, and so on, because I used to see things that people did not see, and then my family took me to the traditional healer and religious healer. But it was useless, and then they took me to the general practitioner, and he referred us to the psychiatrist” (Service user 5, female, 23 years old).*

> *"Therefore, we discovered that the Jordanian people when they get sick. Our treatment journey for them is different from that of other societies. For example, the first way to search for a cure from the disease is abnormal; for example, they are the first thing that begins to ask neighbours, relatives, and friends afterwards if he feel that this does not work. He thinks of visiting a religious healer to read the Quran to them later if it does not work, he tries another religious healer. Then he uses a second, third, and so on after that, but he ends up failing with*

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[59] SU 3,4,6. PCG 3, HCP 1-7.

[60] SU 4,6. PCG 3.

> *them. Then, they can turn to the general practitioner now, the general doctor, but they see that you need a psychiatrist. This is the sequence" (Healthcare professional 5, male, 35 years old).*

All participants mentioned that traditional treatments such as (religious healers, herbal treatments, and old people's experiences) were used before they thought to visit the psychiatrist because they did not believe in mental illness at first. This delay impacts progress and recovery.

4.5.4 Category 4: Health system and policies

All participants' interviews viewed the health system and policies as a significant category; 17 out of the 17 mentioned that the health care system for mental health had impacted their medication-taking behaviour for many reasons. These reasons included two subcategories: healthcare professionals and healthcare settings (psychiatric clinics). These were identified as barriers or facilitators of taking psychiatric medication or thinking about visiting a mental health clinic. In addition, they are perceived as external factors which cannot be easily changed.

This subcategory relates to healthcare professionals, including all healthcare workers in psychiatric clinics (psychiatrists, resident doctors, nurses, and assistant nurses). Participants (service users and primary caregivers) viewed this as a significant concern because the doctor did not explain or give them details about the diagnosis and medication. This would impact their taking behaviour if they did not have sufficient information about the disorders and the treatment plan. This is interrelated with knowledge, as it will lead them to search for information from other resources that may not be helpful and direct them incorrectly. This subcategory has five elements: doctor does not explain, doctors' attitude and communication, doctors' rotation, doctor trading, and healthcare professional's role in the clinic.

The doctor does not explain.

All participants, from service users (6/6), primary caregivers (4/4), and healthcare professionals (1/7), mentioned that the doctor at the government clinic did not explain because it was crowded and had no time to explain. Lack of information impacts medication-taking behaviour, as the service user and primary caregivers need to know more about their conditions. However, they try to visit a private psychiatrist, and he explains to them a few details about the disease and medications. On the contrary, other healthcare professionals claimed that they explained to the service user and their families or the primary caregivers about side effects, what they used for, the dose, when to take, and how to take, and they checked their understanding by letting the service user family tell it back as mentioned above (category 2 knowledge about the psychiatric disorder and medication/source of information/ask healthcare professionals).

> *"No one explained anything to me. They just told me to take this medication and go home. I mean, the doctor in the government clinic did not explain anything even they did not ask you*

> *anything, just they prescribed the medication and went home" (Service user 4, male, 27 years old).*

> *"When I saw that the hospital (*****) did not give me information, and they did not help me, we said we would go and try the private. Yes, a private doctor in a hospital (***) explained to us but not that much" (Primary caregiver 3, female, 54 years old).*

> *"They do not know much. I mean, the patient and his family must know about these side effects, the medical staff must tell each patient about the medicine and why it is prescribed to the patient, its symptoms and how to take the medicine, and what the most important things that he should know" (Healthcare professional 3, male, 33 years old).*

Doctor attitude and communication:

Another factor is the doctor's attitude and communication with patients, which affect their medication behaviour. The most respectful doctor or psychiatrist is the one looked for by service users and primary caregivers. Three of the six service users viewed attitudes and communication as barriers to taking their medications, changing their doctor, or moving from the government to a private clinic.

> *"Frankly, there are psychiatrists in the government. It is possible that this job does not fit them. I mean, the doctor may scold you for something you have done or may cause a problem for you. He cannot believe that this medicine is not suitable for you and causes fatigue, for example. There is a doctor whose way is not comfortable for me. I will stop taking the medication and follow up with him. I mean, as you tell him, this medicine is not suitable for me; its side effects are very strong and do not respond to you. The doctor will not respond to you, and he will do nothing. Instead, he told you there is no medication except this; take it, and you will adapt to side effects after a while. This happened with me and other people" (Service user 4, male, 27 years old).*

Four out of the six service users said that doctors did not care when they discussed with them or did not listen to their complaints. One in four said that doctors treated mentally ill people as stupid or did not understand them.

> *"Another thing is that many doctors treat psychiatric patients as idiots. The doctor has the magic solution or the magic cure. I mean, this medication will make you strong like a horse. Doctors think the patient is insane, stupid, and not conscious" (Service user 3, male, 31 years old).*

On the contrary, if the healthcare professionals could communicate in a good manner and professionally, the service provider and primary caregiver would trust him and accept his treatment plan.

> *"Now, of course, if you are able to communicate with the patient in a good, understanding and sympathetic manner and know that he is not happy while he is taking these medicines, but he needs you to be kind to him and feel that he has a problem that he is taking psychiatric drugs and you treat with him in a fair way like other patients, this encourages him to take medicine" (Healthcare professional 6, female, 30 years old).*

Doctors' rotation[61]*:*

Another factor that impacts medication-taking behaviour is the health policy of doctor rotation. This policy informed doctors to rotate in the government clinic every 4 months. This rotation influences service users as they build a trusting relationship with a doctor; surprisingly, they are not their next time. It is difficult for a service user to build a trusting relationship. Each doctor has a treatment plan and its way. However, doctors' rotation affects the trust relationship between doctors and patients, and the ratio between doctors and patients is very low in Jordan, which does not give them enough time to explain to the service user.

> *Every time you meet a doctor who is not the same one you follow, there is a problem in government clinics and turning over doctors. Because you, as a patient, get used to a doctor who is comfortable with him. He knows your case. Suddenly, you will find a second doctor in a bad manner, all of which influences taking the medicine" (Service user 4, male, 27 years old).*

Doctor trading[62]*:*

Service users mentioned other reasons affecting their medication-taking, such as patient exploitation. These elements reflect how the private sector did not care about the service user but about the money, which impacted medication-taking behaviour. However, some decide to use private clinics, as there is more time for them to ask and take information, although it is expensive. However, some private doctors take this as a trade to gain more money.

> *"He is a private doctor; I think he wants money. I do not feel like he is treating her. He just gives her medicine" (Primary caregiver 4, female, 61 years old)*

Similarly, one healthcare professional mentioned that medication trading is there in a private setting. This is reflected in his experience.

> *"I will tell you from my own experience. I opened a private clinic for five years and closed it about nine months ago because of what I saw in the private sector, which is one of the reasons for the issue of medicines and trafficking in them by some doctors and pharmaceutical companies" (Healthcare professional 7, male, 44 years old).*

Healthcare professional's role at the clinic:

The role of healthcare professionals at the clinic is important; nurses and doctors are teams, and the main important role is increasing awareness about mental disorders and medication taking, besides their main

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[61] SU 1,4. HCP 5,7.

[62] SU 3. PCG 4. HCP 1,4,7.

role in treating the service user. All healthcare professionals mentioned that they explained the medications and side effects to the service user and the primary caregivers who attended the clinic. The main role is for doctors; however, nurses can share with them by teaching service users about medications, but unfortunately, their role is in arranging appointments and calling for the next one to see the doctor more than caring. The role of healthcare professionals impacts medication taking and prescribing by convincing service users and primary caregivers to take the medication by increasing their knowledge.

> *"The subject of medicines and the increase of information, lectures and awareness on the medicines and their importance, and what is expected to happen to him, but we explain what is expected (meaning we do normalization, meaning that it is a normal thing)" (Healthcare professional 4, male, 28 years old).*

> *"Our role at the clinic is organizational. The whole issue is with the doctor. I mean, we can sit with the patient, and the doctor is in the room. Our role is administrative rather than awareness. I mean, we are here in the clinic. I mean, we are just working as we receive the patient, and we stop him at the turn in order more than the awareness role. But I mean, frankly, if we have time, and so we try to explain to the patient they stay in the clinic, of course, according to the patients who are interested and who are not interested" (Healthcare professional 2, female, 29 years old).*

However, other healthcare professionals see that the role of nurses is important as we work together as a team.

> *"Yes, yes, of course, their role is important. It is no less important than the role of the psychiatrist. Nursing is very important because it is the first person to see patients and talk to them, and I frankly like to work within the presence of a certain team" (Healthcare professional 7, male, 44 years old).*

4.5.4.1 Health setting: psychiatric clinic experience

Mental health clinic settings were identified as barriers to taking psychiatric medications; all participants mentioned several factors that led them to say that. This subcategory has four elements: crowded clinic, mental health neglect, bad experience with the clinic, and distance from the service. All of these are considered barriers and external factors which affect medication-taking behaviour. This belief was formed based on their experiences at a mental health clinic. It is worth mentioning that the overlap between categories cannot be separated. In the mental health setting, these beliefs intersected with Category 4 healthcare settings and experience (Category 1).

Crowded clinic:

The main factor mentioned above is a crowded clinic (mentioned by all the participants). There is a huge number of patients in the clinic, and this affects many areas, such as the privacy of the service user[63]and the time for each patient with the doctor, so the doctor will not be able to explain details to the service user or family[64], long time for follow up and pharmacy queue[65], and medication is not available all the time[66], Service users refuse to visit the clinic because of these factors, mainly because there is no privacy. However, one of the reasons that most people visit the government clinic is that all Jordanian people are treated free of charge, and the medication is free[67] because it is expensive outside (private sector).

No Privacy:

Privacy is an essential issue for service users and their primary caregivers, and because the clinic is crowded, there is no privacy, leading the patient not to visit it. Five of the 17 participants mentioned this.

> *"There is also no privacy in clinics, and this girl means we want to keep the matter confidential so that you know what people and society are saying" Primary caregiver 4, female, 61 years old).*

No privacy will impact the service user and the primary caregivers' understanding of the medication, resulting in a lack of information, which will impact their participation in medication-taking and giving behaviour.

Not enough time with the doctor:

Lack of information about the medication led the service user to stop taking it. In particular if they had no answers from their healthcare professionals or had no time to discuss it with them. The overlap between experience, knowledge, and healthcare settings is clear at this point.

> *"Oh, of course, when I do not have any information on medicines, and I am not convinced of it, and I did not take my time with the doctor explaining to me about it. I will give up one or two pills, or I think to leave the medicine" (Service user 1, Male 38 years old).*

Additionally, some clinics renew prescriptions without talking to the service user or primary caregivers.

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[63] SU 1,2. PCG 3. HCP 4,7.
[64] SU 1,2. HCP 4,6,7.
[65] SU 3,4. PCG 1,2,3.
[66] SU 2,4,5. PCG 2,3. HCP 1,2,5,6.
[67] SU 3,4,5,6. PCG 1,2,3. HCP 4,5,6,7.

> *"But in the government, they wrote the prescription and goodbye. I take it from the pharmacy, and I go back every four months, and the doctor sees him every four months" (Primary caregiver 1, female, 45 years old).*

Long-time follow-up:

A long time to follow up because of the vast number of visitors to the clinic is a barrier to renewing the medications or following up with doctors. They said this was because of the number of clinic visitors and the long pharmacy queue.

> *“The service is free at the governmental clinic, but the follow-up is very long every 4 months because there are many patients. This is one hospital, and all patients come to it. Besides, there is a very long line at the clinic and pharmacy” (Service user 3, male, 31 years old).*

As the clinic visit is time-consuming for some service users and their primary caregivers, this leads them sometimes not to attend the clinic.

***Not all medications are available*.**

The crowded clinic results in a lack of medications or not all medications being available. The unavailability of medications depends on the budget of the Ministry of Health, which is related to the policies and regulations of the Ministry of Health.

> *"Yes, yes, the financial means cannot enable the Ministry of Health to buy new medicines such as the third and fourth generation, so we give the first and second generation, and the side effects are many compared to the new generations of antipsychotics" (Healthcare professional 6, female, 30 years old).*
>
> *“According to what is available every time in (***), they give us a form of medicine, but the scientific name is present" (Primary caregiver 3, female, 54 years old).*

This will not allow them to buy a new generation of antipsychotics which have fewer side effects, so they depend on old ones besides the alternative medications available with different names every time they renew the prescription, and this impacts their taking as mentioned in Category 1, experience with psychiatric medication local vs. international.

Medication is free.

All Jordanian people are insured for mental health issues for free at governmental clinics, and they can take medications for free. This encourages them to visit clinics because psychiatric treatments and medications are expensive in the private sector.

"The government, the number of visitors is large because the medicines are free, so you will be prescribed from the available medicine as not all medications are available" (Service user 5, female, 23 years old).

Another point raised by the healthcare professionals which improves their medication-taking behaviour, is that governmental or educational hospitals are better than mental health hospitals[68]. This is because service users and their primary caregivers encourage visits to the hospital if the psychiatric clinic in the governmental hospital, rather than in the mental hospital, reduces social stigma.

> *"The one who encourages them to go to the hospital (***) is a general hospital and has all specialities. He will not be embarrassed. If they ask him, where are you going by saying them to the hospital (***), he does not have to say that it is in psychiatric clinics" (Healthcare professional 2, female, 29 years old).*

Mental health neglected:

Mental health was neglected (6/17 patients). Participants found that during their clinic visit, they identified that it was a factor which allowed them to leave medication or follow up with a private doctor. They also affect their medication-taking and follow-up.

> *"In Jordan, the care is very poor, and they do not care about the patient. I mean, the government does not care much because of the number of people using the service" (Primary caregiver 1, female, 45 years old).*

Based on the above, the service users described their experience with the mental health clinic as a bad experience. Nevertheless, they still follow up because the medication is free, and they cannot buy it from outside. Four out of the six mentioned that their experience was bad with the psychiatrist.

> *“My experience with the Ministry of Health, psychiatric hospitals and psychiatric clinics was very bad. I said, “It is impossible for me to go to them, but my diagnosis was schizophrenia, and my treatment was Prixal, and it was expensive. Its price was 70 dinars for the box.” So, I had to go to the clinics of the Ministry of Health” (Service user 2, male 37 years old).*

Distance from the services:

The participants viewed this during the interview as a factor affecting medication prescription, follow-up, and taking. As a result, some patients were forced to visit the nearest psychiatrist, which was private and costly.

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[68] HCP 2,3,5.

> *“Wallah (I swear) that the distance impact on medication taking, because you need to use more than one transportation to arrive to the clinic and the same when you go back, and if you were tired you may think not to go” (Service user 4, male, 27 years old).*

As well as, healthcare professionals mentioned that services not available in all areas impact medication prescribing and taking.

> *"Ah, there are patients who say that this is the problem because they live so far away that they cannot go to get their prescription" (Healthcare professional 6, female, 30 years old).*

On the other hand, other healthcare professionals mentioned that distance does not matter.

> *"The distance is not an excuse to stop treatment because the medicines are given for a month, so if the patient or his family don't care about the medicine, they will take the distance as an excuse to stop the medicine. I mean, all of them are once a month when he will come to renew the medicine. I mean, he or someone from the family should dispense the medicine and be finished" (Healthcare professional 3, male, 33 years old).*

Similarly, one service user mentioned that distance does not matter if the doctor is good. If I get a cure for my disease or symptoms, I will go if it is in another country.

> *“The distance was not an obstacle in particular with the symptoms that I had with me. I will go to another governorate, as long as this doctor has a good reputation” (Service user 6, female, 38 years old).*

4.5.5 Category 5: Financial Insecurity

All participants mentioned financial status, which not only impacted medication taking but also a psychiatrist visit. Service users have delayed their visits to a psychiatrist and keep suffering from signs and symptoms of mental problems until they can save money to visit the psychiatrist. As mentioned above, the government clinic is free but has many visitors, so some prefer to visit the private clinic and wait until they have the money for it. This delay affects their treatment plan and the recovery process from mental disorders. There are two elements: the cost of psychiatric visits and medications and natural disasters.

4.5.5.1 Cost:

Psychiatrists visit expensive:

Participants mentioned this as a barrier to seeking help because they do not have work or cannot work because of the disorder (see category 1 experience with psychiatric medications/discouragement to take or give medication). However, the government offers free treatment for mental disorders, but as mentioned before, in the Category 4 health system and policies, the clinic is crowded, and extended follow-up time allows the service user to seek an alternative with the private sector, which is expensive.

> *“I did not visit the psychiatrist at the beginning because I don’t have money” (Service user 2, male, 37 years old).*

> *“It was costly at the beginning because I was following up with a private doctor, but while I am improved, it's ok” (Service user 4, male, 27 years old).*

Psychiatric medication expensive:

Participants identified the medication cost as a factor that affected their choice because they preferred to buy it from their pocket. As discussed above, they do this because of the brand in Category 1 experience with psychiatric medication/local vs. international medications. However, the service users went to the government clinic because they had insufficient money.

> *“Psychiatric medications are expensive as well as the psychiatric treatment, so the service user prefers to go to the governmental clinic” (Service user 5, female, 23 years old).*

~~However,~~ they reduce the medication dose or cut off the treatment to reduce the treatment expenses if this is not the main medication.

> *"If the main medicine is not the one prescribed, they think to reduce medicine or cut it for a week until they reduce the treatment costs. I mean, instead of taking the box of medicine for a month, divided it for two months" (Healthcare professional 1, male, 34 years old).*

Some service users were buying medication from their pocket to continue the same medications they used to take, as some medications were not available in the government clinic or other brands. A service user with a good financial status buys their medication; at this point, buying medication is considered a driver to adhere to medications and an external factor that cannot be controlled.

> *“When I have money, I buy the medication that I used from the pharmacy. When I have no money, I split the medication into several parts. Now I have money so I can buy it from the pharmacy” (Service user 2, male 37 years old)**.***

> *“My financial status is good, so I was buying medications from the pharmacy. The important thing is that my health improves” (Service user 5, female, 23 years old).*

Healthcare professionals urge that as the medications are expensive, the service user can accept an alternative cheaper than international medications unless they are not convinced, so they go private.

> *"I mean, the patients have a right. In the end, there will be some savings because international medicine is very expensive, and he needs to pay, so we can have a dialogue with him and convince him that we can raise the dose of the local medicine or find an alternative that matches your financial capabilities" (Healthcare professional 6, female, 30 years old).*

4.5.5.2 Environmental factors

This category originates from the interviews as a barrier to taking medication because of the COVID-19 pandemic which impacts the world's financial status from 2020-March 2022. Like other medical fields, the lockdown affected the psychiatric clinic. People with mental disorders were more influenced because they were afraid of the virus and thought that the world would end. This influences their medication taking. Some of them did not take the medication as the world was going to end and there was no need for medication; other service users decided to decrease the dose or split it to stay for a long time until they could prescribe the medication or buy it from the pharmacy. COVID-19 also impacts the financial status of the world in general and on psychiatric patients, particularly because they are already unable to work and depend on their families, which increases the financial burden on their families and is reflected in their treatment because psychiatric medications are expensive, and the family prefers not to buy them at that time. However, COVID-19 was identified as a barrier, but the service users adapted to the situation to keep their condition under control. Service users 4 out of 6 buy the medications during COVID-19 to keep themselves controlling the disease.

> *"Corona, Wallah (God)! has affected a lot; frankly, as I told you, the government clinics were far from us, and lockdown applied. Some of these medicines I had to buy them at my expense during this period. I mean, it was a problem, frankly, but I cannot leave or stop the medicine; I went to buy it from the pharmacy" (Service user 4, male, 27 years old).*

Another primary caregiver mentioned that they were not able to buy it, so they stopped taking it because COVID-19 affected the prescription.

> *"The problem has affected us a lot, and by God, we have been overwhelmed for a long time for medicines that we are not able to prescribe until we are allowed to review and dispense medicines" (Primary caregiver 2, Female, 62 years old).*

The healthcare professionals (7/7) mentioned that COVID-19 impacts medication taking, so the people who can buy medication buy it, while others either cut the medications or decrease the dose to be enough for them to return to normal; some of them relapse and go to emergency.

> *"Corona has affected me greatly and negatively. I mean, in many patients who have relapsed during this period. Because patients are unable to come to the hospital and receive treatment due to quarantine, patients who are in good financial condition bought the medicine at their expense" (Healthcare professional 1, male, 34 years old).*

One service user developed a fear of mixing with others or going out because of infection. Her mother obtained the medications for her from the pharmacy. Similarly, the healthcare professionals (2/7) noted that fear of COVID-19 affected people with mental disorders, and the problem worsened.

> *"Frankly, I was very afraid that I would go outside because of the Coronavirus. People have problems adhering to health laws and procedures, so Mama used to go to buy medicine from the pharmacy because I did not go to the government, so I had no problem, meaning the important thing was that I bought medicine and stayed in control of the disease" (Service user 6, female, 38 years old).*

4.6 Conclusion

The main categories were drawn from the Service users, primary caregivers, and healthcare professionals who build their experiences through interactions with people, family, and the healthcare system. This interaction provides them with more information and an understanding of the disease, medications, and beliefs in the community. Participants' (service user and primary caregivers) knowledge developed through communication with the surrounding community, health care professionals, and self-reading from the Internet, as well as their knowledge impacted by their beliefs and experiences. This helps them decide whether to take or not take their medications. Service users' and primary caregivers' beliefs about mental health delay their seeking behaviour for help and treatment from healthcare professionals and mental health settings because they seek traditional treatment first.

In addition, psychiatric visits and medications are costly. Therefore, financial incapacity limits psychiatric visits and medication purchases, which are already influenced by the health system and policies for mental health in Jordan (1.3Health System in Jordan). As the treatment in the government sector is free, it is crowded, so people either wait for their turn or look for the private sector, which is expensive. Some special circumstances, such as environmental issues (COVID-19 2020-2022), impacted the financial status of people (some of them lost their jobs and saved money for their basic needs). For healthcare settings, COVID-19 limited access to healthcare settings and minimised or limited people's sources of income. This new experience will add to their experience and help them learn how to cope with these situations in the future. All these categories communicate, interrelate, and intersect and are influenced by each other. However, these relationships led service users to decide whether to take their medications or not.

These intersecting circles overlap, and all categories are impacted by each other. Thus, when the service user and primary caregiver enter these circles, their knowledge, experience, and beliefs will continue to develop in a way which impacts their behaviour toward taking and giving psychiatric medications.

4.7 Summary:

Five significant categories emerged from the interviews: the first category is experience with psychiatric medications, which has six subcategories (medication-related factors, disease-related factors, experience with support system, other treatment modalities, healthcare professionals prescribing medications, and consequences). The second category is knowledge about psychiatric disorders and medications, which includes two subcategories (knowledge about psychiatric disorders and treatment and source of information). The third category is beliefs about mental disorders and treatment, which contains 4 subcategories (family, service users, and healthcare professionals’ beliefs, stigma, religion, and treatment journey). The fourth category is healthcare systems and policies, which includes two subcategories (healthcare professionals and healthcare settings). Finally, is financial insecurity category includes two sub-categories, which are (costs and environmental factors). All of these categories are interrelated, considered in both ways as facilitators or barriers to taking the medications, as discussed above. Before service users decide to take or not take the medications, they go through this cycle of interrelations to develop their decision; whatever the decision is, it follows with consequences which support either the facilitator or barriers and back to the cycle (see Figure 3: Substantive grounded theory psychiatric medication-taking behaviour process and decision in Jordan.).

Chapter 5 Discussion

5.1 Introduction

This study aimed to identify the factors that impact medication-taking behaviour among Jordanian people diagnosed with mental disorders (schizophrenia and/ or bipolar I disorder) from three different perspectives (service users, primary caregivers, and healthcare professionals). This chapter represents a reorganization of the findings chapter (chapter 4), using a substantive grounded theory generated from the data. The central argument in this chapter is the factors that impact medication-taking behaviour from service users' and primary caregivers’ lens and their experience toward taking or giving psychiatric medications.

The key finding of this study was summarised in the previous chapter (chapter 4) and is considered in relation to barriers or facilitators for medication-taking behaviour. These five categories are experience with psychiatric medications, knowledge about psychiatric disorders and treatment, beliefs about psychiatric disorders, healthcare settings and policies, and financial insecurity).

5.2 Substantive grounded theory:

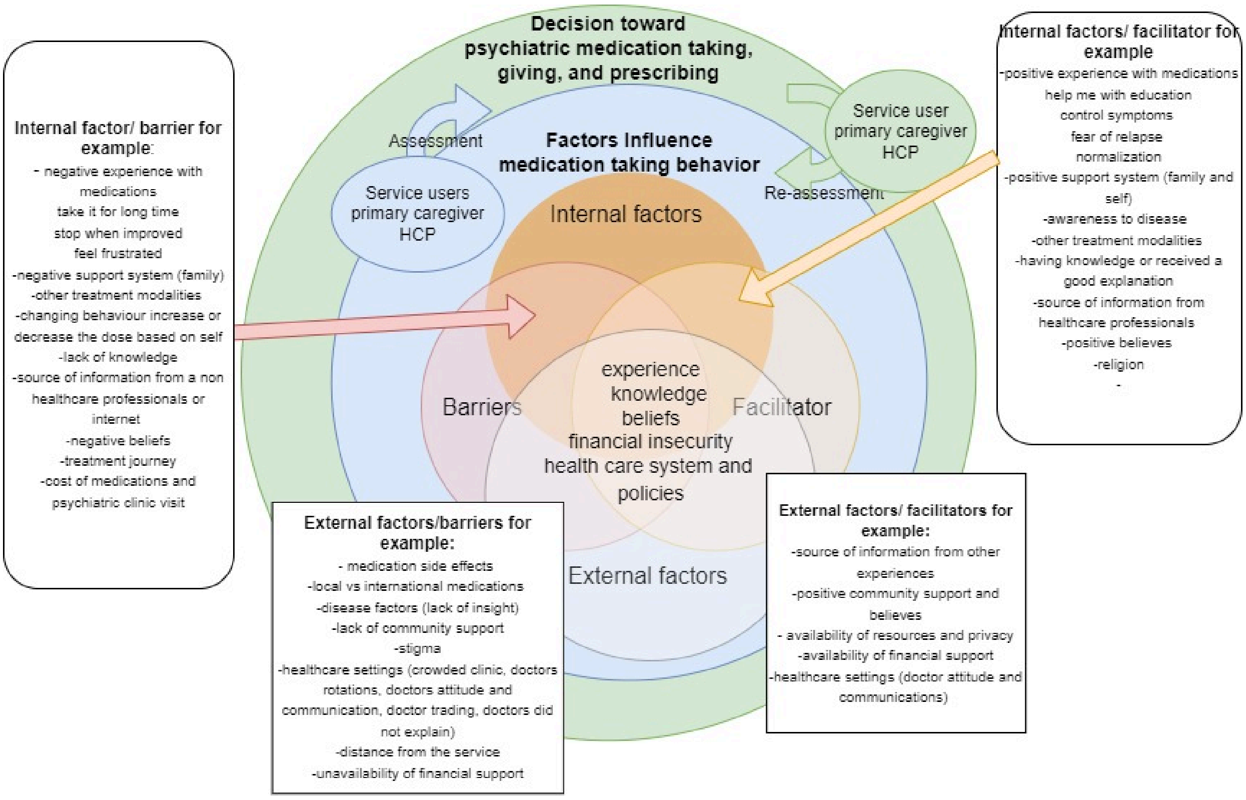

Figure 3: Substantive grounded theory psychiatric medication-taking behaviour process and decision in Jordan.

The preceding chapters described the approach used to build Jordan's grounded theory of medication-taking behaviour. The theory evolved from a constant comparative analysis of data from participants' responses and interviews and information from previous research.

Theory development began with a literature review (Rapid Evidence Assessment Review) related to factors impacting medication-taking behaviour in Jordan and the Middle East. This literature review (Chapter 2: literature review) provides a sensitivity about the phenomena and develops prior information about some initial areas which need exploration, notably the settings where data were collected, the type of people who participated in the study, ~~and~~ medication-taking behaviour, and reasons for medication not taking as prescribed. Following this review, selective sampling identified the criteria of the participants and then theoretical sampling to explore the topic of psychiatric medication-taking behaviours in Jordan.

The substantive grounded theory (figure 3 above) illustrates the key findings of this study. The findings highlight five major categories which intersect and interrelate with each other, impact each other, and form the decision toward psychiatric medication-taking behaviour. Experience with psychiatric medications develops through the knowledge that service users and primary caregivers have about mental disorders and psychiatric medications, from where they get information about them. Their beliefs about mental disorders and medications are deeply rooted in their cultural and religious beliefs, which impact their knowledge and experiences. Healthcare settings and financial difficulties also affect knowledge and experience.

The outer circle indicates the decision about taking psychiatric medication and how difficult it is to draw the decision, as you need to go through the inner circles, which indicate the factors that impact the decision to take medication. The inner circle has four intersected circles. These circles reflect internal and external factors, which are divided into internal barriers and facilitators. These factors can be controlled by service users or primary caregivers. External barriers and facilitator are beyond their control. For example, negative experiences and attitudes (medication is not helpful) toward medications from the service users and primary caregivers are considered internal factors and barriers to taking medications, while positive experiences and attitudes (medication helped me to complete my study) reflect internal factors and facilitator to take the medications. On the other hand, service users and primary caregivers who had a bad experience with health care settings such as (crowded clinics, medication side effects, and local vs international medications) are external factors and barriers to taking the medications, whereas good doctor attitude and communication, availability of resources, and community support considered as external and facilitator factors to take their medications.

According to the Health Belief Model (HBM), people are more likely to take health-related actions if they perceive themselves as vulnerable to a condition (perceived susceptibility), if the condition could have serious implications (perceived severity) if they perceive a particular course of action as having the potential to lessen susceptibility or severity or result in other positive outcomes (perceived benefits), and if they perceive few negative aspects of the health action (perceived barriers) (Rosenstock, 1974; Rosenstock et al., 1988). This model focuses on people's attitudes and beliefs (Rosenstock et al., 1988; LaMorte, 2022) that might impact medication taking and seeking help to explain and predict health behaviours. Two behaviours are crucial for medication acceptance: service users and primary caregivers must be aware of their conditions, benefits, outcomes, and advantages of the treatment. This reflects shared decision-making process dimensions and health literacy.

In accordance with the integrated conceptual health literacy model developed by Sorensen et al. (2012), people need to access health information, understand this information related to their health, assess their ability to understand their choices, and finally communicate with their healthcare professionals to make their decisions. This model reflects the domain in which people use health knowledge to make decisions; however, their beliefs affect their knowledge and the decision to seek help from healthcare professionals. In this study, participants' service users and their families -perceived susceptibility- to their mental health problems and psychiatric medications from their culture and beliefs as they connected their mental problem to supernatural power, so the action taken to overcome this problem is to use traditional treatment such as religious healers (Sheikh) and herbal medicine (See chapter 1.2.1 Values and Beliefs), before using general healthcare system services which then refer them to mental health settings. This journey provides them with negative or positive experiences regarding mental disorders and their treatment. Mental health settings and healthcare professionals reinforced their knowledge and experience as well as their decisions about psychiatric medication-taking behaviour. Financial status, which reflects the ability to visit a psychiatrist, follow up with a private clinic, or buy psychiatric medications, also plays an important role in the decision-making process. Additionally, financial issues were more affected by COVID-19. See the case scenario below for further clarification.

Case 1*: A 23 year old female service user diagnosed with bipolar I disorder tells the story of how their family dealt with her disease, as they believe that the cause of the mental disorder is supernatural power and must be treated by traditional means of treatment such as religious healer and herbal treatment; this idea was reinforced by their neighbours, but at the end, they found it useless and went to the hospital.*

> *"My family was trying to find me a solution. People were telling them that the girl was bewitched and had evil eyes. The religious healers come to the house; one who shouts at me once attacked me with my big toe in order to get the bad blood out. It is something you cannot imagine out of nature. For example, once, I went to a popular religious healer whose name is (***), who is, of course, living in a villa. You literally have nowhere to sit in the men's room or the women's room. She told me that you have polycystic ovaries and you have a stomach germ. I did not believe it and went to the hospital and checked, I did all the tests, and nothing came out as she said" (Service user 5, female, 23 years old).*

Healthcare professionals mentioned the experience, knowledge, and beliefs of service users and primary caregivers as factors that impact prescribed psychiatric medication taking (facilitator or barrier). The service users who visited the clinic already had previous experience and knowledge and held a belief about psychiatric disorders and medications, which allowed them to accept or refuse to prescribe psychiatric medication. This perspective from healthcare professionals is formed from their experience of treating people with mental disorders, as they are part of the community and know the community's points of view about the treatment of mental disorders.

> *" We have many service users who see that the last one in the treatment journey to visit is a psychiatrist after they went to the religious healer and priests and found them useless" (Healthcare professional 7, male, 44 years old).*

Deciding to visit a psychiatrist or taking psychiatric medications is a hard and complex process because it depends on several factors which decide on taking hard such as social stigma, side effects, fear of addiction, other experiences, and poverty (Deegan, 2007). The decisional conflict in taking psychiatric medications could also be related to a difficult regimen and long-term use of psychiatric medications, where the prescriber should consider the shared decision process and ensure that the service users have sufficient information and positive attitudes toward the treatments will help them take their psychiatric medications (Jawad et al., 2018).

As shown in the substantive theory figure 3 above, many factors affect medication-taking decisions. The factors that fall in the intersected area could be related to one or more sections or cycles. The current study found that experience with psychiatric medication is reinforced by service users' and primary caregivers' knowledge and beliefs about mental illness and medications, the healthcare system, and their financial status. Service users and primary caregivers entered the cycle of decisions regarding taking psychiatric medications. The cycle of decisions and factors comprises an iterative process. Every time a decision is made, it is reassessed, and the cycles are entered again. Therefore, the decision is subject to change; for example, people may decide to stop taking medications (decision made) because of the negative experience from side effects (factors/barrier); after the situation worsens and relapses impact their life or no changes happen (a consequence of decision)–as mentioned in (Chapter 4: Findings) decisions lead to consequence either positive or negative–they rethink using the medications (reassessment) despite the negative experience, but they still control the disorder and their life (decision), and so on (see the case in the box below). The fluidity of this process makes the decision process dynamic and impacts the factors either by changing the barriers or improving the facilitators, for example.

Case 2*: A 37-year-old male service user diagnosed with schizophrenia was not convinced to take medications because of his belief about the medications, but his decision changed as he experienced controlling the diseases and then controlling his life.*

> *"I have an idea that medication is hurting me instead of treating me. I believe that this medication is not helpful at all as it doesn't offer a final solution to the problem…but when I took Prixal and fluoxetine for a while, I became convinced that the medicines, despite their bad side effects and not relieving symptoms significantly, but I controlled my mood" (Service user 2, male 37 years old).*

Case 3*: A 31-year-old male service user diagnosed with schizophrenia disorder took psychiatric medications for 14 years; at some point, he thought many times to stop the medications, but when his condition worsened, he thought back to take the medications, as the medications helped him to continue his education and finish his study.*

> *"Sometimes, I stopped the medications, but my condition worsened, then I said, I must adhere to medication" (Service user 3, male, 31 years old).*

Healthcare professionals' decisions about prescribing psychiatric medications for service users are impacted by these factors because healthcare professionals are part of Jordanian society and understand why people refuse or are reluctant to be prescribed psychiatric medications; as a result, these factors could be facilitators or barriers to prescribing psychiatric medications for their service users. It is considered an external factor related to the health system itself, not healthcare professionals' personnel. A shared decision will help them to formulate a better understanding of psychiatric medications and factors that impact taking behaviour (Morant et al., 2016). Shared decision-making helps service users and healthcare professionals communicate and share information (Coulter & Collins, 2011) (see Chapter 1 (1.6.4 Shared decision-making).

Elwyn et al. (2012) developed a model for shared decision-making and how it can be applied in clinical settings. They described that the model had three main steps: introducing choices, describing choices, and helping patients explore preferences. However, they mentioned that healthcare professionals need training to lead a shared decision-making process. The Agency for Healthcare Research and Quality (2020) developed a SHARE approach to train healthcare professionals about shared decision-making and how to apply it during their practice, which aligns with the Elwyn model. SHARE acronym stands for (Seek, Help, Assess, Reach, and Evaluate), where the clinician or healthcare professionals seek agreement for patients' participation in the process, help them explore the available choices, assess the patient's preferences and values, and reach the decision with an agreement between both parties, at the end evaluation of the decision made by the patients, which helps the patients to participate in their treatment plan and options which will then be reflected in their commitment to the plan (Central Intelligence Agency, 2020).

In Jordan, few studies have explored the shared decision-making approach among cancer patients (Obeidat, 2013; Obeidat, 2015), and one study has explored shared decision-making from a physician's perspective (Zisman-Ilani et al., 2020). Obeidat (2013), in her narrative review to examine the shared decision-making in non-western countries regarding informing people about the diagnosis and treatment of cancer, noted that shared decision-making is new in non-western societies, so assessment, education, training, and support were needed to help patients with chronic illnesses explore their preferences for diagnosis and treatment. Zisman-Ilani et al. (2020), in their study, which aimed to explore and develop more understanding of the shared decision-making process and patient-centred care using a survey of 36 healthcare professionals (Jordan, Israel, and the United States), found that a lack of patient's education and time impact the shared decision process. Moreover, Jordan and Israel found that staff shortages and a lack of resources were barriers to the implementation of the shared decision process. Due to deeply ingrained cultural ideas and traditions, Jordan, like other Arab nations, has historically placed less weight on the patient's perspective in the patient-physician relationship (Obeidat, 2015). These findings are concurrent with the substantive theory above, which shows that the knowledge and experience of service users and healthcare professionals impact the decision to take medication. However, Studies on Jordanian people diagnosed with mental disorders' preferences for decision-making about their treatment are lacking.

The suggested substantive theory explains the processes and factors that influence medication-taking behaviour. The next section will discuss the factors separately, although there is some area of interrelation between them that will be difficult to separate.

5.3 Experience, knowledge, and belief toward psychiatric disorders and medications:

The categories of psychiatric medications in this study were internal, external, facilitator, or barrier toward psychiatric disorders and medication-taking behaviour. Experience, knowledge, and beliefs are considered internal when they come from the service users' or primary caregivers' experience, knowledge, and beliefs about the medications, such as *'bad or strong side effects'*, where medications are produced, what encourages people to take or give, what prevents them from taking, or giving psychiatric medications as prescribed. The internals could be facilitators of medication-taking or barriers. These factors are influenced by service users' knowledge and beliefs about mental disorders and medications. Additionally, more experience is formed when they use healthcare settings and communicate with healthcare professionals in mental health clinics. This category highlights two main points: side effects (antipsychotic differences based on age and gender and hypersexual behaviour) and international medication versus local ones. The following section examines these points.

5.3.1 Side effects and medication-taking behaviour.

There have been a variety of reported experiences with psychiatric medications and the decision to take prescribed medications. One of these experiences was the side effect. This finding is not unexpected, and they concur with a study conducted in New Jersey and the United States by Swarbrick and Roe (2011) through their qualitative study of factors that impact psychiatric medication taking and the process of choosing to take or not from the perspectives of people with mental illness (n=19 schizophrenia, bipolar, and depression disorders) recruited by convenience sampling from the community-based peer-operated self-help centre. They found that the decision to take, stop, or decrease the dose of psychiatric medications was influenced by a negative attitude toward the medications because of side effects. Similarly, in Africa, Ghana, Kretchy et al. (2021) conducted a cross-sectional study at a public psychiatric hospital (n=121 people with schizophrenia and their caregivers) to investigate beliefs about psychotropic medication taking, side effects, and medication taking from a dyad perspective. They reported that side effects impacted psychotropic taking among people diagnosed with schizophrenia and the views of their caregivers. However, in their study, McCann and colleagues investigated the factors that impact antipsychotic medication taking among Australian people diagnosed with schizophrenia, recruited by convenience sampling (n=81) from the western region of Melbourne (rural area). They reported that side effects impact medication-taking behaviour by decreasing or changing the dose but do not lead them to stop taking it (McCann et al., 2008). Likewise, other scholars have reported that side effects per se are not the leading cause of not taking psychiatric medications but are a moderator (e.g., Jónsdóttir et al., 2013; Vassileva et al., 2014; Ostrow et al., 2017).

From the perspective of healthcare professionals, severe side effects is the main cause of service users' decision to stop taking psychiatric medication (Öhlund et al., 2018; Cooper et al., 2019). In Jordan, a cross-sectional survey-based study was conducted in outpatient psychiatric clinics in four different hospitals with a convenience sample of (n-243) people diagnosed with mental disorders (schizophrenia, bipolar disorders, depression, anxiety, and autism) to explore the prevalence and factors of not taking medications and found that side effects are the second cause of not taking antipsychotic medications after forgetting (Alhalaiqa et al., 2016). In 2021, another cross-sectional survey-based study with a convenience sample of (n=120) people with schizophrenia, depression, bipolar, and obsessive-compulsive disorders) to investigate their awareness of psychiatric disorders and treatments conducted in an urban area in Jordan at a governmental hospital in Jerash governate, stated that side effects are the main reason for not taking psychiatric medications (Qunaibi et al., 2021). These studies support the findings of the present study reported in this thesis.

5.3.1.1 Side effects based on Age and gender

The current study found that some side effect differs based on age and gender, such as weight gain and sexual problems (see section 5.2.1.2).

Weight gain has been found to have an impact on medication-taking behaviour in many studies (Zimmermann et al., 2003; Helbling et al., 2006; Swarbrick & Roe, 2011; Ostrow et al., 2017; Öhlund et al., 2018). Haack et al. (2009), in their narrative review, which includes (24 articles) about the differences in antipsychotic side effects related to sex differences (gender) among psychotic disorders bipolar I and schizophrenia, reported that gender (male or female) had a different response to side effects, such as an increase in body weight which is a concern for young female. Similarly, Seeman (2020) reviewed quantitative and qualitative studies for the last ten years and reported that there is a difference in the side effects of antipsychotics (used for bipolar I and schizophrenia disorder) based on gender, such as weight gain occurring in women more than men for both disorders. Correspondingly, a 1-year longitudinal prospective study conducted at a university hospital in Egypt with a convenience sample (n=110 bipolar I disorder) aimed to identify the sociodemographic factors that impact medication taking in bipolar I disorder revealed that being younger age and male barrier toward taking antipsychotic medications as prescribed, whereas older service users, being female, and as factors motivate medication-taking as prescribed regardless of the side effects (Radwan et al., 2020). Similarly, younger age is a moderator for medication not taken as prescribed for treatment for people with schizophrenia or bipolar I disorder (Coldham et al., 2002; McCann et al., 2008; Garcia et al., 2016). However, old age is a barrier related to comorbidities such as hypertension and diabetes (Eticha et al., 2015). This contradicts the healthcare professional perspective of this current study finding, which reported that older patients were willing to take their medications regardless of the side effects and considering their comorbidities, while younger patients were vulnerable to not taking them.

Bak et al. (2021), in their meta-analysis, which includes (404 articles) to assess the impact of antipsychotics on weight gain, report that most of the antipsychotic medications (Clozapine, olanzapine, haloperidol, risperidone, amisulpride, aripiprazole, Asenapine, Quetiapine, and chlorpromazine) increased the body weight and disturbed the metabolism process. Women gain more weight than men because of hormonal considerations and other factors if they receive the same dose of antipsychotics as men (Haack et al., 2009). Zimmermann (2003) conducted a literature review of the epidemiological studies that assessed weight gain with a range of antidepressants and antipsychotics. They reported that the weight gain could be due to the lack of activities and an increase the food intake, as the psychiatric medications increased the body weight gradually. However, these studies support the findings of the current study, but the decision-making process is complicated, as other studies have shown that other factors impact weight gain, such as lack of activity and hormonal changes in women.

5.3.1.2 Sexual problems and medication-taking behaviour

Many studies have reported sexual dysfunction and decreased libido as antipsychotic side effects that impact medication-taking behaviour (Smith et al., 2002; Cooper et al., 2019). Healthcare professionals in the current study mentioned that the common problems were sexual dysfunction, erectile dysfunction, and desire for male service users, which is consistent with the literature.

Unexpectedly, two service users reported hypersexual behaviour (the medication increased their libido, one of them taking aripiprazole and the other sertraline HCL). This is an issue in Jordan, as many Jordanians are Muslims (it is forbidden–Haram–to engage in sexual relations before marriage), and they are upset because they are not married, which impacts their taking. This finding was consistent with that of Hacck et al. (2009), who reported that male service users reported sexual problems more than females. A case study In Germany reported a 42-year-old female patient (schizophrenia) increased her libido and sexual desire after being treated with aripiprazole. However, they recommend that Aripiprazole could be used in cases experiencing a decrease in libido and sexual problems due to other antipsychotics (Schmid et al., 2011). Das et al. (2012) report one case study (Minnesota/United States) for a (55-year-old) man who had hypersexuality after taking sertraline HCL (Zoloft) while he was taking Bupropion (antidepressant) who was treated for post-traumatic stress disorder and major depressive disorder, this behaviour decreases gradually after he stopped it.

However, a report by Pfizer (2016), approved by the USA Food and Drug Administration, showed that Sertraline HCl impacts the sexual and reproductive health of men and women (sample n=3066 participants in a randomised, double-blind control study) by decreasing their libido by 7% and 4%, respectively. For men, erectile dysfunction, ejaculation disorder, and male sexual dysfunction accounted for 4 %, 11%, and 2 %, respectively. In a single randomised control study in Iran with a convenience sample with randomisation (n=195 patients with a major depressive disorder) to assess sexual dysfunction induced by antidepressants, they reported that sertraline is the least common medication that causes a sexual problem and less than fluoxetine and trazodone (Khazaie et al., 2015). However, the above study showed that sertraline could induce hypersexuality when combined with bupropion, but not alone. The randomised trial supports the manufacturer; in the current study, the case is different: it is a bipolar I disorder treated with sertraline, which had another scenario; further investigation is needed as the service user's medication did not have bupropion, and he did not have previous hypersexual behaviour.

Another study by Cheon et al. (2013) reported two case studies in Korea of females diagnosed with schizophrenia who had hypersexuality after taking the antipsychotic aripiprazole (Abilify), although it is expected that antipsychotic-induced sexual dysfunction occurs. They referred to the different compounds of the medication and types of antipsychotics. In France, a study reported that aripiprazole increased libido and sexual desire for females and males, and a case study of a 35-year-old female patient with schizophrenia treated with aripiprazole reported increased sexual desire and libido (Vrignaud et al., 2014). Das et al. (2017) reported a case study of a 33-year-old male with paranoid schizophrenia experiencing hypersexuality and increased intercourse frequency. Another two cases in India of male patients taking aripiprazole (Reddy et al., 2018). This was reported by the Food and Drug Administration (FDA) drug safety report in 2016 when raising a warning because any compulsive behaviour that occurs in service users who start on aripiprazole within days to a week, such as (hypersexual behaviour in three cases) was not known to be hypersexual before taking this medication, and this behaviour decreased after stopping this medication (FDA Drug Safety Communication, 2016). This finding may explain the hypersexuality observed in the current study.

For females, this topic is considered sensitive to Jordanian culture and cannot be explored further, as other Arabic cultures find talking about this topic of being unmarried or married sensitive and difficult to discuss because of religious and cultural barriers (Kingori et al., 2018; Alomair et al., 2020; Alomair et al., 2022). However, this study did not explore more sexual problems from female service users as they were single and due to religious and cultural barriers. Based on the previous literature, healthcare professionals found this topic is complex and hard to discuss with female service users; even females attending the family planning clinic reluctant to disclose this topic (Alomair et al., 2020). However, in this current study, service users did not mention anything to the male researcher about the female problem, even hair loss, but health care professionals mentioned some female problems such as hair loss and menstrual problems, nothing more than that, further investigation needed in the future research.

5.3.2 Medication origin and manufacturers:

Unexpectedly, the participants reported that Jordanian drug manufacturers are supervised by The Jordan Food and Drug Administration (JFDA). It observes and follows up on the medication from the first time that it is manufactured as a raw material through all its manufacturing stages until it is obtained as a ready-to-use product. The principal goal of the Drug Directorate is to ensure that all medications, whether imported or locally produced, are safe, effective, and inexpensive for the public. To stay updated with the most recent scientific and international advancements, the Directorate periodically evaluates foundations and legislation(Jordan Food and Drug Administration, 2014).

In their study, Haqaish and colleagues described the JFDA as the only regulating body in Jordan which licenced pharmaceutical industries and pharmacies in Jordan and conducted a survey-based study to compare JFDA as a regulating body with other global regulating systems in Australia, Canada, Saudi Arabia, and Singapore. They revealed that the JFDA has had great success in its capacity as a regulatory body by creating and implementing precise rules that are in accordance with global best practices (Haqaish et al., 2017). However, the JFDA has controlled medications all over Jordan and achieved good results compared to the global body regulations and protocol review. Medication differences between local and international medications are present, and further investigation is needed.

The controversy between originator and generic brands found in many studies reported that antipsychotic medication bioequivalent[69] is different between branded brands, which differ in their adverse effects and tolerability; therefore, doctors should take care when switching and considering dose adjustment. The

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[69] [Is the absence of a significant difference in the rate and extent to which the active ingredient or active moiety in pharmaceutical equivalents or pharmaceutical alternatives becomes available at the site of drug action when administered at the same molar dose under similar conditions in an appropriately designed study, (Chapter 21. CFR (eCode of Federal Regulations) part 314.3 (CFR, 2023)].

reason for switching between brands is likely to be economic, as they need to take it for a long time. However, switching could impact medication taking (Carbon & Correll, 2013; Dunne et al., 2013; Polić-ViŽintin et al., 2014). Howland (2010) reported that generic and branded medications (antipsychotics, antidepressants, and anticonvulsants) had no consistent evidence of differences in their effectiveness and safety; however, there are some differences related to adverse effects and people's beliefs about the treatment, which are raised by their experience and expectations about the outcome or relapses.

In the United States, Manigault et al. (2016) in their review reported that the swap of medications from brand name to generic name is cost-effective (generic cheaper than the brand name), decreases healthcare costs, and encourages patients to use governmental healthcare settings. However, generic drugs are cheap, but they differ in their bioequivalence, bioavailability[70], and therapeutic index, so healthcare professionals should consider this point while swapping the medications and adequate education for the service users and their families required.

Drug bioavailability affects drug effectiveness, and it may be necessary to adjust the dose to reach the minimum concentration of the drug for the desired effect (Price & Patel, 2022). In this current study, doctors need to double or triple the dose of some local drugs to meet the international one (for example, international Seroquel XR 400 mg two times daily. For Local equeal (Quetiapine), this needs to be increased to 800 mg or 1000mg two times a day to get the equivalent effect) which exceeds the limit of the daily dose, which is 800 mg/day for schizophrenia or bipolar disorder (Pharmaceutical Product News, 2010). For more clarification, see the example.

> *“There is something else on the Seroquel, and these I noted in a hospital (***). Uh, the international Seroquel was more effective, and the patients were on 600 milligrams and stable when he switched to the alternative. Of course, the alternative (Local medicine called equeal) is cheaper than international medicine. The effect of the drug differed, and the service user relapsed, so I decided to raise the dose of the local drug to 800 milligrams and 1000 milligrams to adjust the international level and the equivalent of 600 milligrams, which means that the permissible dose has been exceeded because the equeal is weak. Most of the patients told me our situation was better when we were on international medication.” (Healthcare professional 5, male, 35 years old).*

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[70] [Is the rate and extent to which the active ingredient or active moiety is absorbed from a drug product and becomes available at the site of drug action (Chapter 21. CFR (eCode of Federal Regulations) part 314.3 (CFR, 2023)],

However, healthcare professionals urge some service users to switch between local and international due to financial difficulties with no relapses, which may arise from the idea or belief that the service users or primary caregivers hold about the treatment and mistrust local medicine and healthcare teams.

Medication bioavailability differs according to gender; this is based on many factors such as hormonal changes (period), pregnancy, and slower gastric emptying in women than in men, which impacts psychotropic medication absorption and effect; therefore, healthcare providers should consider this point while prescribing psychotropic medications for female service users (Bergiannaki & Kostaras, 2016). The metabolism and elimination of antipsychotics in women are affected by the female hormone oestrogen; for example, drug absorption in women is slower than the male because hormonal changes influence the stomach in women, while the stomach in men is more acidic, which increases the rate of drug dissolution. Drug distribution is based on many factors, one of which is fatty body nature, which is more common in women than in men, allowing the drug to be stored in the body of women more than in men, which increases the half-life of medication. Another pharmacodynamic property affected by sex is the elimination process of the medication, which is faster in men than in women due to the glomerular filtration rate being faster in men (Haack et al., 2009; Seeman, 2020). This could explain the findings of the current study and the differences in the severity of side effects between men and women.

5.3.3 Other factors are facilitators and barriers to taking medications.

In the current study, participants reported that there were motivator or facilitator factors that improved their taking while the barrier discouraged their taking (see previous chapter 4: Findings).

These findings are comparable to several studies which reported these factors as facilitators or barriers. Pyne et al. (2006) conducted an in-depth qualitative interview study at an outpatient mental health clinic in a veteran hospital in the United States (n=26) with service users diagnosed with schizophrenia and schizoaffective disorder and care providers. They found that decreased symptoms, spiritual activity, stress reduction, and being active in the community and family factors that improve medication-taking behaviours while increasing symptoms and less engagement in the community are barriers. Likewise, Bressington et al. (2013), in their cross-sectional survey study in Hong Kong (n=584), explored the factors that impact antipsychotic medication-taking. They reported that positive attitudes and fewer side effects improved medication taking. In Ethiopia, a cross-sectional survey-based study by Eticha et al. (2015) (n=393) found that positive attitudes, fewer side effects, and awareness facilitate antipsychotic medication-taking among people with schizophrenia. Negative experiences and side effects are barriers (Swarbrick & Roe, 2011).

Ostrow et al. (2017), in their study (n=250) of US people with mental disorders, found that taking psychiatric medications for a long time is a factor leading to discontinuation of medications. Similar findings were reported in Oman, in which cultural beliefs about mental disorders were the same as those in Jordan.

A cross-sectional study included (n=251) service users diagnosed with schizophrenia, bipolar disorder, depression, and anxiety disorders and found that taking medication for a long time had an impact on their taking behaviour (Al Maqbali et al., 2022). These findings are in line with those of the current study, in which service users and their families refuse to take psychiatric medications if they take them for a long time.

In another study in Jordan, in line with the current study findings, which reported barriers toward antipsychotic medication taking, Mukattash et al. (2016) conducted a cross-sectional study to identify prevalence and factors that impact medication taking (n=243) people with mental disorders (schizophrenia, bipolar, depression, anxiety, and personality disorders), they reported that side effect and polypharmacy as factors impact medication taking. A similar result was found in Oman, another Arab and Muslim country, a study reported that therapeutic regimen complexity is the main factor impacting participants' medication taking (Al Maqbali et al., 2022). These findings were in line with this study's findings, where service users and their families failed to refill the medications or go to the follow-up visit because of side effects (sleep) and changing their taking because of polypharmacy and regimen complexity (see Chapter 4 findings/ Experience with Medications:.

5.3.4 Support system and medication-taking behaviour.

Families in Arab countries are considered the major support and care units for ill people (Ciftci et al., 2013). Therefore, it is unusual for a family member to attend a psychiatric or general clinic alone, as there is always a family member (parents, siblings, or relatives) who shows concern and helps with treatment (Fakhr El-Islam, 2008). On the other hand, negative attitudes and low family and community support toward antipsychotics impact taking behaviour and lead to refusal or stop-taking (Colom et al., 2005; Helbling et al., 2006; Garcia et al., 2016; Karaytug et al., 2017; Jawad et al., 2018). The current study reported that family and community surroundings are considered facilitators or barriers, which is supported by the literature which identified family and social support as factors that impact medication taking (Colom and Lam, 2005; Stentzel et al., 2018; & Marrero, 2020). Colom and Lam (2005), in their literature review to identify factors that impact medication taking in bipolar patients, found that family and community support could be a facilitator or barrier to antipsychotic medication taking depending on the knowledge they have about the disorder and the treatment.

Similarly, Stentzel et al. (2018) conducted a randomized controlled study in Germany to explore factors that impact medication taking and reported that social support and being employed facilitate antipsychotic medication taking. Employment helps participants engage in social activities and receive more social support, which improves their understanding and insight. Likewise, in their systematic review, Marrero et al. (2020) found that family support by providing interpersonal communication facilitated medication taking. Family support could improve medication taking if considering the health beliefs and surrounding culture as a modifiable factor and can be changed to improve health. In Spain, a prospective cohort study (epidemiological multicentre non-interventional) was conducted to assess the factors leading to relapse in schizophrenia (n=1646) and reported that low family support is a predictive factor for not taking medications (San et al., 2013). This finding supports the findings of the current study on positive family and community attitudes toward psychiatric disorders and medications, which improve medication taking.

The current study found that self-support is important when family and community are barriers, and service users need to support and encourage themselves to overcome the disorder (see Chapter 4/ Experience with support system). Archiopoli et al. (2016) conducted a cross-sectional survey to explore interpersonal communication and self-efficacy on medication taking (n=344 people with depression) in the southwestern state of the US, finding that self-efficacy and support is important to achieve your goals. Sefl-efficacy reflects the personal traits which help them learn social skills and problem-solving to achieve their goals (Bandura, 2006). Self-efficacy is a dimension in the health belief model which reflects people's level of confidence in drawing their decisions based on their knowledge, which helps them integrate themselves with health-promoting behaviour (LaMorte, 2022). This is in line with the current study, where service users and their primary caregivers, as shown in the substantive theory above, were considered factors that impacted their decision to take psychiatric medications, where self-efficacy helped them to assess the benefits and barriers to continuing or discontinuing medication.

5.3.5 Schizophrenia/ ~~or~~ bipolar and medication-taking behaviour decision.

In the current study, HCPs indicated that patients with bipolar I disorder who were treated showed better progress than those with schizophrenia. This is in line with Harvey's (2006) review paper, which aimed to define the functional recovery for bipolar disorder and schizophrenia, the comparison between the two disorders, as both disorders nearly have the same management at the beginning and the same short goal which minimises hospitalisation and prevents serious harm to self or other, whereas the long-term goal for both disorders is to promote recovery. They reported that a significant difference in recovery between schizophrenia and bipolar disorder, which arises from the functional recovery of bipolar disorder, is better than that of schizophrenia in terms of social activities and back activity in the community. Similarly, in their longitudinal study with 1 year and 10 years follow-up for bipolar disorder and schizophrenia recovery and remission in Norway, Åsbø and colleagues found that the recovery rate in bipolar disorder was twice that of schizophrenia. Service users with bipolar back to an adequate level of function, such as part-time work or study (Åsbø et al., 2022).

The healthcare professionals in the current study reported that people with severe cases of schizophrenia or bipolar I disorder accepted the treatment more than service users with mild to moderate symptoms.

> *"But this depends on the disease in relation to the other, meaning some diseases are easier to treat than others, in diseases of severe cases and patients with more chronic conditions" (Healthcare professional 6, female, 30 years old).*

This contradicts a cross-sectional web survey study in the United States by Johnson et al. (2007) (n=469 bipolar I disorder), which reported that the severity of symptoms impacts medication taking because of its impact on cognitive functions and impaired service user preference for the treatment. A similar result was reported in Bulgaria in a cross-sectional survey-based study by Vassileva et al. (2014), who found that symptom severity was a barrier to medication taking (n=226 patients with schizophrenia). In China, Hui et al. (2015) reported that patients at the first onset of the disease did not take their medications because of denial or lack of insight. The same results were found in Egypt by Al-Meguid et al. (2016) and Radwan et al. (2020), who revealed that severely ill patients did not take their medications as prescribed. This contradiction may come from the fact that most of these studies were cross-sectional survey-based designs that did not explore in depth the medication taking, cultural differences, and beliefs; the current study mentioned that from their experience while treating service users (as mentioned in Chapter 1.2.1; value and beliefs, Chapter 4 findings), where service users and their families used the traditional treatment which was not helpful before they visited the psychiatrist and because of that they accepted the treatment to control the situation. People with middle-to-moderate cases are still in the traditional treatment cycle.

Mental disorders impact service users’ study and work, as well as primary caregiver work, because they need to stay and take care of their son, daughter, or family member. Lack of work or recurrent absences add a burden on the family's economic status, which impacts their care. This is consistent with a study in the UK, which reported that mental disorders are associated with long-term disability and loss of productivity, poverty, and social isolation (Henderson et al., 2011). Its impact on service users' school achievement is due to the absence of or dropping out of school due to mental disorders (Esch et al., 2014). These findings correspond with current findings where the service user's school and work absence because of their signs, symptoms, and fear of social stigma impact their medication taking.

5.3.6 Other treatment modalities, beliefs, and medication-taking behaviour decisions.

In the current study, participants mentioned other treatment modalities which helped them and could be used separately or in combination with medications, such as psychotherapy and traditional therapy (herbal treatment and religious healers). Healthcare professionals try to connect psychotherapy and medications, as medications alone are not enough for people with mental disorders to recover and become active in the community, although this service is limited in Jordan.

This is consistent with a recent metanalysis of randomised controlled studies to evaluate the effectiveness of psychopharmacology and psychotherapies in the treatment of mental disorders such as (schizophrenia, bipolar, obsession-compulsive disorders, depression, and other disorders), they reported that although the vast number of research and trials about psychopharmacology combined with psychotherapies it's still limited in its effectiveness in treating mental disorders (Leichsenring et al., 2022). Pietrabissa et al. (2022), in their editorial on the research topic of the effectiveness of psychotherapy in the treatment of mental disorders, report that individualised psychotherapy is effective in treating mental disorders in youth where psychological symptoms and distress have decreased. These are factors that provoke mental problems, as shown in this study (e.g., family problems) (chapter 4 findings), where individualized psychotherapy may be helpful.

Other treatment modalities are impacted by service user experience, beliefs, and cultural factors; participants visit a psychiatric clinic and try treatment, which includes herbal treatment and religious healer visiting, which is widely used in Jordan (see chapter 1.2.1 Values and Beliefs). This consistency with the literature, patients' and family members' perceptions of external control by supernatural beings are reinforced by religious healers, as advised by friends and family, which delayed their psychiatrist visits (Fakhr El-Islam, 2015). On the other hand, when they believe that this is from Allah (God), and they must deal with it, they accept it by taking medications and using other treatments prescribed by their doctors besides reciting the Quran and praying (spiritual activities). A psychiatrist and religious healers should treat mental disorders to provide the expected outcomes of the treatment (Khalifa et al., 2011; Dein, 2020). Spiritual activities in the Arab region need to be considered as supportive treatment with psychiatric medications (Al-Krenawi, 2005; Fakhr El-Islam, 2008; Nolan, 2011; Fakhr El-Islam, 2015).

In the United Arab Emirate (one of the GULF countries in the Middle East Region), a qualitative study (n=10 religious healers) conducted by Thomas et al. (2015) reported that the integration of traditional religious healers within the healthcare system would provide a valuable contribution to mental healthcare services, and based on the religious healer perspective in many cases, traditional treatment and medical interventions improve the patient experience using mental health services and could improve outcomes; however, further investigation and quantitative studies are needed to provide a precise picture of the results of integration between medical and traditional treatment for mental illnesses.

The use of herbs as treatment for different kinds of illness is part of the culture in Jordan, so religious healers or herbalists prescribe herbs to treat service users, as described in Chapter 1 (1.2.1 Values and Beliefs). The knowledge and experience they learned from their predecessors is not education or training, and the regulation is unclear for herbalist practice in Jordan (Abu-Irmaileh & Afifi, 2003; Afifi et al., 2010; Jordan Food and Drug Administration, 2014). Afifi and Abu-irmaileh (2000) listed herbs less commonly used in Jordan, which were used to treat disorders based on the herbalist perspective and experience and listed that *Boraginaceae-Echium Judaeum*-local name O'Od Hawa was used for nervosity and hyperactivity. *Rhamnaceae-Zizyphus sprina Christi*- the local name is Sider, to treat nightmares, and *Fagaceae-Quercus coccifera*- The local name is Sindyan, to treat the post-partum syndrome. Another study in Jordan focused on the pharmacological activities of *Echium judaeum*, which grows wild in Jordan, showing that these remedies are used as antidepressants and antioxidants (Al-Hamaideh et al., 2017) and are also used in Iran to treat stress and anxiety (Saki, 2018). Soh and Walter (2012) reported that herbal medicine is widely used in treating mental health problems in different parts of the world as a part of their traditions and culture before they visit the psychiatrist. However, there is insufficient evidence that this is helpful either alone or in the treatment of mental disorders.

Herbs differ according to the culture of each region. Herbal medicine should be used with caution, as it has been used for centuries, which does not mean that it is safe. Herbals and other treatment modalities used in collaboration with others may help treat mental disorders (Soh & Walter, 2012; Gureje et al., 2015). Gureje et al. (2015) mentioned that traditional and herbal medicines are rooted in the community, culture, beliefs, and experiences. Most people use this alternative medicine to treat illnesses, including mental disorders. Religious healers and herbalists in low- and middle-income countries provide mental health treatment and services due to a lack of mental health services and literacy among the population and healers as inherited by ancestors. Collaboration between traditional treatment providers and mental health teams needs to be conserved to improve mental health services and reduce stigma (Gureje et al., 2015). This is consistent with the current study's findings that other treatment modalities do not stand alone to treat mental disorders. Similar findings were found in China by Deng et al. (2022), who reported that service users hold beliefs about the reasons for mental disorders related to supernatural power; therefore, they used another traditional Chinese treatment.

5.3.7 Pharmacist and medication-taking behaviour decision.

Pharmacists play an active role in taking medications. In their narrative review of the role of pharmacists in mental health settings in Spain, Rubio-Valera (2014) found that pharmacists play an important role in a multidisciplinary team in mental health settings and community centres, as they reviewed the medications and reported side effects which impact service users' behaviour. Similarly, Bingham et al. (2020), in their retrospective review, found that there is a crucial role for pharmacist consultation and improvement in the use of psychotropic medication. In the current study, unexpectedly, two HCPs mentioned that pharmacists negatively impact medication-taking because of the social stigma and lack of health literacy about mental disorders. This finding contradicts the literature. However, this current study did not explore the pharmacist's perspective toward mental disorders or medications. The findings reflect three participants' views about that. This difference came from the social stigma toward mental illness in Jordan. Healthcare professionals clearly stated that.

This could be related to insufficient mental health literacy among HCPs, not only pharmacists but, in general, primary care and community centres. Dalky and colleagues conducted a cross-sectional descriptive study to investigate the stigma perception, knowledge, and attitude of (541 HCPs) in primary care centres in northern and central cities in Jordan, reporting that HCPs working in primary or general settings had a negative attitude toward mental illness and treatment (Dalky et al., 2020). A cross-sectional correlational survey in Jordan to study the knowledge, attitudes, and beliefs of nurses working in mental health settings in Jordan (n= 157 nurses) reported that nurses in Jordan believe in many cultural misconceptions and preconceptions about mental illness; for example, about 40% of the participants believed that the cause of the mental disorders was related to the evil eye, black magic, or jinn, and 20% of their belief that mental disorders are punishment from God (Allah). However, the majority of them think that mental disorders could be treated by traditional treatment, such as religious healers to remove dark magic and evil eyes (Rayan, 2022). This reflects the current study substantive theory that cultural beliefs affect service users, primary caregivers, and healthcare professionals' beliefs and knowledge regarding mental disorders and treatments.

5.3.8 Problem with prescribing psychiatric medications

Healthcare professionals face the problem of prescribing psychiatric medications because service users and their families prefer non-pharmacological treatment (see section 5.2.6) and lack mental health literacy in the population, as mentioned earlier. This is consistent with Helbing et al. (2006), who reported that general practitioners have more understanding than the general population about the importance of antipsychotic medications and urge doctors to consider this while prescribing antipsychotic medications as the service user will face pressure to stop it from community-related to lack of knowledge and side effects.

Ostrow et al. (2017), in their cross-sectional web survey aimed to explore the experience and support system during the discontinuation process and what factors impact it to support their decision, a web-based survey for 250 people with severe mental disorders (schizophrenia disorders, bipolar I disorder, and depressive disorder) and taking psychiatric medications in the United States (this study was the first study examine this approach), reported that prescribing and discontinuing the antipsychotic medications should be done with the agreement of both prescriber and service users. This encourages shared decision-making, as mentioned earlier in the substantive grounded theory model and medication optimisation, where the service users and healthcare professionals reach the point agreed on the treatment and accept to take the medication as prescribed to optimise the medication effect and outcome (McFarland et al., 2021). However, psychiatrists urge that taking psychiatric medications for a long time improves medication-taking behaviour, outcomes, and recovery (Cooper et al., 2019; Kretchy et al., 2021).

Through their prescription, healthcare professionals assessed missed doses and taking behaviour, as well as intentional and unintentional medication not taking. Intentional not-taking happens when service users or primary caregivers do not take or give medications purposively, such as (missing a dose or changing it to meet their needs). On the other hand, not taking medications because of being busy or forgetting the dose is unintentional and considered a passive process (Wroe, 2002; WHO, 2003; Lowry et al., 2005; Gadkari & McHorney, 2012), in their systematic review Fahrni (2022: 2) reported that forgetfulness remains the main problem facing medication taking. Moreover, they used the term “medication-taking conduct”, which is defined as

“Whether or not a patient is capable of taking medication in a manner judged to be congruent with the governing norms”.

Based on the above definition, healthcare professionals identified missed doses during the interview by self-reporting from the service users and primary caregivers, and their response was not to blame the service user but to encourage them to express more to help them explore the factors that led to this behaviour. This enables healthcare professionals to reassess the medication list and improve prescriptions and medication taking through the shared decision process, which is an active part of this process to improve medication taking. As indicated by the World Health Organization report, service users should have an active role in the treatment and not blame the service users if they do not take their medications as prescribed will improve medication taking in the future (WHO, 2003).

To improve medication taking and deal with missed doses, three healthcare professionals in this study reported normalisation as a factor that improves medication taking. Normalisation means, in psychiatry, an individual with disabilities lives as normal people and merge them into a culture which allows the culture to be normative (Wolfensberger, 1970; Law, 2021). Normalisation is used in cognitive behavioural therapy to treat psychotic disorders and obsessive-compulsive disorders and to destigmatise the disorders and what happens with them as normal (Kingdon et al., 1994). Healthcare professionals (three doctors) used this principle to improve medication adherence, with the aim of taking psychiatric medications as other medications for hypertension and diabetes, so that the service user feels that taking medications is a normal thing, and they found it works and improves medication adherence. However, further investigations are required.

> *"One of the important points is normalization. It means that when the patient comes to take the medicine, do not let him feel that this is a strange thing. On the contrary, show him that it is normal to take medications, and we all take medicines, and medicines do not decrease your value. On the contrary, you improve your condition and control your life. I mean, these are the most important things that I noticed and touched, from my experience, and it affected the course of treatment and taking medicines" (Healthcare professional 5, male, 35 years old).*

Good communication and shared decisions about antipsychotic medication taking entirely by the service users; however, it is a shared process between service users and health care professionals, which influences medication-taking decisions and behaviour, as doctors or prescribers do not control the decision (Reich et al., 2018; Vitger et al., 2022).

5.3.9 Insight, mental health literacy, and medication-taking behaviour.

Previous studies have reported that lack of insight or poor insight is the factor that drives service users and primary caregivers not to take their medications or to follow up with psychiatric visits (Alasmee, 2020; Deng et al., 2022; Al Maqbali et al., 2022). Similarly, studies have reported that lack of insight was the main cause of not taking medications as prescribed for people diagnosed with schizophrenia and bipolar disorder (Garcia et al., 2016; Jawad et al., 2018). Poor insight impairs the ability to recognise the need for treatment (Al Maqbali et al., 2022) and affects their decision to visit a psychiatrist and take psychiatric medications, which delay their treatment progress and recovery (Nolan, 2011; Fakhr El-Islam, 2015). On the other hand, awareness and insight into bipolar and schizophrenia disorders are important to the treatment, which helps service users and primary caregivers gain more information about mental disorders and treatment (Myin‐Germeys et al., 2018; Lysaker et al., 2018). Studies have identified insight as an important mediator to help improve medication-taking behaviour in people diagnosed with schizophrenia and bipolar disorder (Yen et al., 2005; Medina et al., 2012). This corresponds with the findings of the current study:

Knowledge positively or negatively affects taking. This is consistent with studies identifying lack of awareness as a barrier to psychiatric medication taking while having sufficient information about medication regimen and mental illness improves medication taking and follow-up visits (Rababa'h & Alhmoud, 2013; Col et al., 2014; Issa, 2018). Lack of knowledge and mental health literacy about mental disorders and treatments in the Arab region is linked to a lack of mental health literacy in the general community and healthcare professionals working in general hospitals and mental health settings (Al-Yateem et al., 2017; Dalky et al., 2020; Elyamani & Hammoud, 2020; Khatib & Abo-Rass, 2022). A study conducted in Jordan reported that the majority of healthcare professionals have a stigma toward people working in mental health settings because of a lack of knowledge about the causes and treatment of mental disorders (Dalky et al., 2020). This study was conducted in the general population, but it reflects mental health literacy among the Jordanian population, which is consistent with the current study findings that the lack of knowledge about mental disorders impacts psychiatric visits as well, delays help-seeking, and causes mental disorders. Knowledge of mental disorders constructed by beliefs and the surrounding environment. This is supported by another study in Jordan, which showed that nurses working in mental health settings lack knowledge about the causes of mental disorders, as most of them believe in supernatural powers as a cause of mental illness (Rayan, 2022). Rayan recommended that education and mental health literacy among nurses working in mental health settings improve the quality of nursing care provided to the service users and help them overcome misconceptions about the mental disorders causes. Lack of knowledge influences their ability to identify the signs and symptoms of mental disorders; therefore, they relate it to other reasons, as mentioned above.

5.3.10 Level of education, knowledge, and medication-taking behaviour decision

The level of education was found to motivate to take psychiatric medications in many studies; for example, a study in Jordan and another in Egypt found that a high level of education (bachelor’s degree and above) impacted medication and had a better understanding (Issa et al., 2018; Radwan et al., 2020). On the other hand, Ethiopia is illiterate or has a low level of education impact medication taking (Eticha et al., 2015; Öhlund et al., 2018). A cross-sectional correlational study in Jordan reported that the level of education has an impact on antipsychotic medication taking. They found that those higher educated (bachelor’s degree and above) have a greater tendency to take their antipsychotic medications and understand more about their illness. In contrast, a low level of education (primary and secondary) showed a low level of taking antipsychotics, and knowledge, which impacted their taking because of the lack of mental health literacy and a lack of understanding about the treatment regimen and the side effects of medications (Issa et al., 2018). Similarly, numerous studies have reported that people with a low level of education have shown that medication not taken as prescribed rate is higher than among highly educated people (Garcia et al., 2016; Karadağ et al., 2019; Radwan et al., 2020).

Another HCP perspective in the current study opposed this idea, stating that low or high levels of education did not make a difference, as the shame culture is dominant in the community because of social stigma and lack of mental health literacy (Issa et al., 2018; Dalky et al., 2020; Rayan, 2022). In this current study, other healthcare professionals urged that the level of education is an area of controversy between healthcare professionals views, as they described in (Chapter 4, Lack of Knowledge), educated people discussed more than low educated or illiterate because they need to know more about the medications, sometimes a lot of reading leading to stop taking the medications, although they are educated, but they still do not understand the medical term of medications and usage. On the other hand, less educated or older people did not discuss or ask them to take the medication because the doctors knew what was best for them, which could be related to the lack of mental health literacy, as discussed above. These variations in the views of HCP participants come from the different experiences they have while treating people with mental disorders.

In the current study, service users and primary caregivers knew the basics about their diagnosis (name) and no more than that unless they read from the internet or other resources (e.g. other experience -friends or previous family member); healthcare professionals urge that service users and their families had poor mental health literacy so they tried traditional treatment before they decided to visit a psychiatric clinic, similar to studies conducted in Jordan by Al-Krenawi et al. (2000) and Nolan (2011), who reported that

Jordanian people seek help from non-medical personnel at first (see 1.2.1.Values and Beliefs). Likewise, a study in Oman reported that people with mental disorders such as schizophrenia or bipolar disorder look for other explanations for their conditions and treatment from nonprofessional personnel (Al Maqbali et al., 2022).

Lack of knowledge and mental health literacy about mental illness in the community will influence the knowledge of service users and their primary caregivers.

This impacts their medication taking as they try medications based on their knowledge and experience, leading them to end up not taking their medications as prescribed or stop taking them, which will reinforce their negative attitude toward psychiatric medications. Similar studies found that people using other resources or online for self-diagnosis are helpful in drawing a possible explanation about what they have if there is a specialist in mental health, but not prescribing medications; however, they used these resources to support more than diagnosis and to increase their knowledge about mental disorders causes and treatment (Horgan & Sweeney, 2010; Giles & Newbold, 2011; Andersson & Titov, 2014).

Lack of Knowledge about the disorder drove to lack of information about the medications and regimens. However, some service user and primary caregivers in current study service users and primary caregivers pointed out that they knew about their medications, but the analysis found that their information is basic about the medication name, dose, time, and some side effects; few of them identified the indication or what used for, and some of them missed up with names of medications. Some of these depend on the colour, shape, and size of the pill.

> *“I tried the local brands only. I tried Risperdal, which is the (Ablifay), and others, but I cannot remember the names” (Service user 4, male, 27 years old).*
>
> *"According to the colour of the carton and the shape of the pill"(Primary caregiver 2, Female, 62 years old).*

The example above shows how service users and primary caregivers identify their medications. Although service user 4 knew the names, those names were different medications not the same (Risperdal are not the same Abilify (aripiprazole); however, both are used to treat psychosis. These findings indicate that service users and primary caregivers have little information about their psychiatric medications. This indicated that they misunderstood the medications and were confused. This is consistent with other studies which identified that people who lack knowledge about medications and side effects influence medication-taking behaviour (Gibson et al., 2013; Issa et al., 2018). HCPs mentioned that the level of education has an impact on gaining knowledge and understanding more about mental disorders and medication regimens, indications, and side effects. However, a better understanding of service users and primary caregivers can help them make decisions about taking their medications (Öhlund et al., 2018; Issa et al., 2018; Karadağ et al., 2019; Radwan et al., 2020; Lindenmyer et al., 2020).

Knowledge of psychiatric disorders and medications is required to improve medication-taking behaviour, as discussed above. Not all sources were trusted for gaining information. Dan and colleagues found in their study that service users and primary caregivers obtained their information from different resources such as media, including television, books, and magazines, as well as from healthcare professionals and their relative experience (Dan et al., 2014). Using different resources improves mental health knowledge and minimises stress and stigma (see above normalisation).

People widely use the Internet to obtain more information about their medications, disorders, and other health problems, and they are looking for interventions and procedures (Gray et al., 2005; Horgan & Sweeney, 2010; Giles & Newbold, 2011; Andersson & Titov, 2014; Seven et al., 2021). Using the Internet was the most common source mentioned by the participants. However, they reported that not all websites can be trusted, as many websites provide non-scientific knowledge about mental disorders and medications, which reflects the poor level of mental health literacy in the community. Educated service users and primary caregivers are looking for English websites for more information related to disorders and medications because there is a poverty in Arabic content about mental disorders and medications, as some websites run for profit purposes and have non-scientific information such as the cause of mental illnesses is from evil. This is consistent with studies exploring the use of the Internet in the Arab world, which found that most of the websites were about general health and few of them were specialised or discussed a specific disorder; however, some of the information was inaccurate or misleading, and most of them were designed for healthcare professionals rather than general audiences (Alnemary et al., 2017; Alkhateeb & Alhadidi, 2018). In the current study, HCPs urged that the website should be trusted and present scientific information, especially about mental disorders, and Giles and Newbold (2011) reported that mental health professionals are unable to decide the extent to which the Internet is trusted as there is much nonsense information. Misleading information or untrusted websites impact service user information and change their taking behaviour; some service users in this study changed their medications based on what they read on the Internet.

> *"The dose is not enough, and I read on the internet that these medicines cause anxiety, so I increased the dose by half a pill out of curiosity. I said if I increased the dose, these symptoms would disappear. These symptoms are fear and anxiety, and it subsided" (Service user 1, Male 38 y).*

Horgan and colleagues mentioned that although the Internet is the most reliable source of information, it is not as reliable as healthcare professionals. They reported that people prefer to use the Internet for consultation because it is faster, but the most reliable source is direct meetings with mental health professionals (Horgan & Sweeney, 2010). Unfortunately, the infrastructure of the psychiatric clinic impacts healthcare professionals and service users because of the lack of privacy and time for doctor-service user meetings (this will be discussed later in the next section: healthcare system and policies), which is consistent with the findings of the current study. Gibson et al. (2013) conducted a mixed-method study to understand the treatment choice and support services needed to maximize the benefits of the treatment for people diagnosed with schizophrenia or bipolar I disorder in England (n=35). They report that service users need more information about the disorders and medication, and emotional support by healthcare professionals could help them formulate their choices and understand more about their treatment and medication-taking behaviour, which will improve their health and living.

Another source is to ask pharmacists (see Section 5.2.7) about the medication or ask other people from relatives or friends who have tried the medications before and learned from them (Dan et al., 2014). This depends on different factors. First, the level of education was discussed. The second level of awareness about the treatment and they are convinced of the disease, as discussed above.

The current study found that reading from the leaflet of medication was the most common after using the Internet and asking healthcare professionals, especially if there was an Arabic translation of the content about the medications. Reading from the leaflet provides service users with information about side effects, which may be reduced psychologically as they know about it, which impacts their taking (Webster et al., 2018). Reading leaflets and asking healthcare professionals about unknown or unfamiliar information provides a positive attitude toward medication taking (Patel et al., 2018; Karuniawati et al., 2019). Conversely, the level of education interferes with medication taking, where the more educated people cannot understand the different uses of the medications, so they may stop the medications until they discuss them with psychiatrists or healthcare professionals.

Education level is important, as discussed above. The suggested difference is related to the nature of the disease and service users' concerns. People with a high level of education need to ask for healthcare professionals in mental health with regard to their medications to subside the misunderstanding about the medication name, indications, and side effects.

5.3.11 Stigma and medication-taking behaviour decision.

Stigma is a domain in the Muslim communities as in other communities. Although Muslims generally have positive views on mental health care, they still hide the problem because of stigma (Ciftci et al., 2013). This is consistent with the findings of the current study, which revealed that service users or primary caregivers conceal the mental problem of fear of shame and stigma and that they will not get married. In their study in Ethiopian community rural areas, Shibre and colleagues surveyed 178 mostly Muslim families of individuals with schizophrenia and reported that 64 per cent of the participants experienced stigma related to a relative with mental problems and fear of not being married (Shibre et al., 2001). Similar results were found after 13 years. In their review to understand stigma in the Muslim community, Ciftci (2013) reported that in the Muslim community, they would not consider marriage with an individual or family having an individual suffering from mental illness, but they could socialize with them. In Jordan, mental disorders remain hidden from others, as they fear that this will impact their daughter and son's marriage in the future (Nolan, 2011; Alasmee, 2020).

Stigma is not only associated with the Muslim community but also has a cross-cultural impact; for example, Marrow and Luhrmann compared the perspective of United state families with Indian families regarding family honour, moral responsibilities, shame, cultural acceptance of approaching psychiatric clinics, and accepting psychiatric treatment, and found that the Indian family intended to conceal the family member who was diagnosed with mental disorders in their home and provided care, while the American families sent the ill family member to home care or specialised governmental institutions (Marrow & Luhrmann, 2012). Likewise, in Iran, a qualitative study included (n=37) people diagnosed with bipolar disorder to explore the factors that delay their seeking help and treatments and found that people try not to share their mental problems with others as they fear social stigma and impact other family members' relationships, friends, and marriage, because they decided to visit general practitioners and use traditional treatments such as religious healers, not because of stigma only but also due to lack of mental health service. This process delays their seeking help and their prognosis (Mianji & Kirmayer, 2022). Similarly, Chinese families try to keep it secret because of social stigma and cultural factors (Mak & Cheung, 2008). The findings of these studies reflect that stigma is a cross-cultural problem and its impact on seeking help behaviour as well as on medication-taking behaviour.

Many studies in the Arab region have reported stigma as a major factor in medication not taking and seeking mental health treatment because of culture and beliefs about mental disorders (Okasha, 2003; Abu-Ras, 2003; Fakhr El-Islam, 2008; Okasha et al., 2012; Hassan et al., 2019; Khatib & Abo-Rass, 2022), which is impacted by the lack of mental health literacy, as mentioned above. The Arab world is both culturally and religiously homogeneous. The majority of the Arab world consists of Muslims who speak Arabic. Many Arabs believe that mental illness is a divine punishment or the result of demonic possession (Pridmore & Pasha, 2004; Ciftci et al., 2013) (See 1.2.1 Values and Beliefs). The impact of stigma on medication taking, delay seeking help, using different treatment methods before visiting a psychiatrist, and impacting their lives (Ciftci et al., 2013; Rayan & Obiedate, 2017). These findings are comparable to the current study’s finding that service users delay treatment when help is sought and lead them to try alternatives to psychiatric medication treatment before they visit a psychiatrist.

Stigma, as mentioned earlier, impacts on family life, friends, and marriage. In the Current study, one healthcare professional reported that marriage should be clear and straightforward with no deceptions or hidden information, and the partner must know about mental disorders or any other medical conditions before marriage, as partner (husband or wife) support is important. Al Maqbali et al. (2022) reports the same result in their cross-sectional study with a convenience sample of (n=151 patients with schizophrenia) to understand the factors that influence not taking medications, where they found that married service users were taking their medication as prescribed compared to the non-married or single service user, this because of the husband or spouse support. In the current study, service users mentioned that they should conceal their mental problems to be able to marry this community culture.

As marriage could lead to pregnancy, one primary caregiver mentioned that they stopped psychiatric medication because they were afraid of the side effects of the medication on the foetus. This is concurrent with Reinstein et al. (2020), who reported that pregnant women who have schizophrenia or bipolar disorder intended to stop antipsychotics while they are pregnant more than non-pregnant as they fear the side effects on their foetus. However, extra care should be given to pregnant women who receive antipsychotic medications, and healthcare providers must pay attention to the teratogenic side effects which may impact the foetus, which is the reason for the discontinuation of medications during pregnancy (Jawad et al., 2018).

5.4 Health system and policies and financial difficulties

Participants identified health systems and policies as barriers which impact medication-taking behaviour. This finding is consistent with Alasmee (2020), in a qualitative study (n=21) of primary caregivers in Saudi Arabia, who reported that healthcare professionals’ poor communication negatively impacts the experience of primary caregivers who form a negative attitude toward psychiatric medications and impacts service users’ understanding of the treatment and medications. Lack of experience among healthcare providers dealing with psychiatric disorders and lack of knowledge is reflected in their way of communication and negative attitudes toward working with people with mental disorders (Dalky et al., 2020). However, good communication is important for facilitating understanding and providing a positive attitude and experience with mental disorders (Reich et al., 2018). Izugbara et al. (2010) reported that using medical terms during communication with patients is the reason for misunderstanding and confusion.

Good communication enables service users to interact with their mental health professionals more actively and assists professionals in understanding the challenges that patients face throughout the treatment. Service users and their families' views toward mental illness and treatment would improve as a result of this therapeutic teamwork, and stigma may also be mitigated and improve the shared decision-making process, which impacts medication taking (Morant et al., 2016). The service users in the current study mentioned that doctor attitude and communication impact their understanding, as well as doctors providing them with insufficient information about their disorders, so they use different methods such as the Internet and reading the leaflet, as mentioned earlier, to improve their understanding. This overlaps between the health system and knowledge and experience categories. Insufficient information reflects a lack of mental health literacy among healthcare providers, as mentioned earlier. This finding is consistent with a qualitative study in Canada by Wojtowicz et al. (2014) (n=7), which reported that psychiatrists provide insufficient information to their service users about their medication side effects and disorders, which has an impact on service user knowledge and decisions about treatment.

Communication helps build a trusting relationship between service users and healthcare providers. However, service users in the current study report that this trust is missed because of doctor rotation every four months (policy of Ministry of Health).

> *"For example, in the government clinic in a certain period, doctors changed, and from one specialist to another, he told you something different. The last one I saw, he told me all my medication was not needed, like this way, and there was a problem with my medication. I was taking kemadrin for side effects, and he stopped it, and other medications also stopped it" (Service user 1, Male 38 y).*

The above quote explains the importance of the trusting relationship between doctors and service users and how doctor rotation impacts their treatment, their decisions about medication taking, and why they mistrust healthcare professionals. The relationship between service users and healthcare professionals is important. Day et al. (2005) studied the relationship between healthcare professionals, services, and attitudes in terms of medication taking among people diagnosed with schizophrenia and schizoaffective disorder (n=228 participants in North Wales and Northwest England in cities and rural catchment areas) using a structural equation modelling, they found that good relationship between service user and the healthcare professionals since the beginning improve the service user attitude toward the treatment. The level of satisfaction between healthcare professionals and service users positively affects medication taking (McCann et al., 2008). Trust relationships are an important factor in dealing with people diagnosed with mental disorders because the continuity of care and follow-up help them in their treatment (Green et al., 2008; Soh & Walter, 2012), which are missed in the current study because of the Ministry of Health rules and regulations for doctor rotation.

In Jordan, service users are seen by resident doctors while they follow up and, in some instances, by a psychiatrist (first-time visit). This could be another reason for the lack of trust among healthcare providers and the lack of experience of resident doctors in the communication process (Dalky et al., 2020). The power of doctors affects this relationship (Wojtowicz et al., 2014). This is consistent with the current study findings that the service users mentioned that the doctor did not discuss the disorder or medications with them.

> *"I mean, for example, he doesn't tell you what your illness is, what your diagnosis is, why? They do this so that you do not go to another doctor and tell him that I suffer from this" (Service user 3, male, 31 years old).*

Healthcare professionals in the current study disagree with this point raised by service users, and they reported that HCPs explain and discuss the issue with service users and their families. However, because of crowded clinics, long queues waiting for turns, and time constraints impact healthcare professionals' communication and explanations with service users. This finding is in line with AlGhurair et al. (2012) systematic review that healthcare systems and providers could impact medication-taking behaviour in different ways, such as poor communication between healthcare providers, lack of information provided to the patients, and medications not available in the clinic.

Healthcare professionals and service users mentioned that crowded clinics impact service user privacy, negative experiences of using government clinics, and limited time with doctors to obtain more information. These findings are consistent with those of Semahegn et al. (2020), who reported in their systematic review and meta-analysis (which included 46 studies, n= 4504) that the health system and health care team were a barrier to medication-taking behaviour for the following reasons: lack of mental health literacy, long follow-up visits, mistrust with HCP, health care provider negative attitude and poor communication, complexity of medication regimen and prescribing medications, and poor clinical structure. Similarly, Rayan (2022), in a recent study (n= 157 mental health nurses), reported that negative attitudes toward mental disorders impact their communication and dealing with people with mental disorders, although nurses play an important role in providing mental health services. Likewise, Deng et al. (2022) reported a lack of knowledge and non-scientific understanding of the impact of mental illness and treatment on medication taking.

The current study reported that the role of nurses in outpatient mental health clinics is unclear compared to that of the organiser, despite their crucial roles in inpatient settings. Thus, this role must be expanded. However, mental health in Jordan is under development, and mental health teams are planned to be trained within the mental health gap program of the World Health Organization. However, this has not yet been achieved (WHO, 2017b, WHO, 2020). In the current study, service users mentioned that mental health services in Jordan were poor due to many factors, such as medication unavailability and lack of privacy. Healthcare professionals reported that a lack of mental healthcare providers and a huge number of service users in the clinic for follow-up impact their communication, attitude, and lack of time spent with service users, leading to an impact on medication-taking behaviour. However, the Ministry of Health and World Health Organization (2020) provides a program to train healthcare professionals working in mental health settings and healthcare professionals working in primary care to provide mental health care for people in primary care and community centres in order to minimise the shortage of mental health personnel (WHO, 2020a; Dalky et al., 2020). Similarly, in China, a qualitative study (n= 31 mental health care professionals) reported that service users could stop taking their medications due to resource shortages, such as lack of mental health care providers and training, lack of financial resources, and lack of social support (Deng et al., 2022).

Poor mental health clinic structure minimises the privacy of the service user, which affects their ability to understand more about their case and their medication regimen (see Chapter 4 Findings/ No privacy).

These findings were consistent with Bondre et al. (2021) in their commentary paper, which reported the importance of privacy, especially with stigmatising disorders such as mental disorders; protecting their privacy and their record is a priority for health system stakeholders. Similarly, a qualitative study in Iran (37 service users) reported that the infrastructure of the mental health setting and limitations of the system impact help-seeking behaviour as well as treatment, and healthcare professionals need training as they do not listen to the service user. However, service users are dissatisfied with psychotherapy because of its high cost and lack of benefits (Mianji & Kirmayer, 2022). However, more information is needed about medications and disorders, with better access to services and healthcare professionals, besides social and emotional support, promoting positive attitudes toward treatment and taking medications (Gibson et al., 2013).

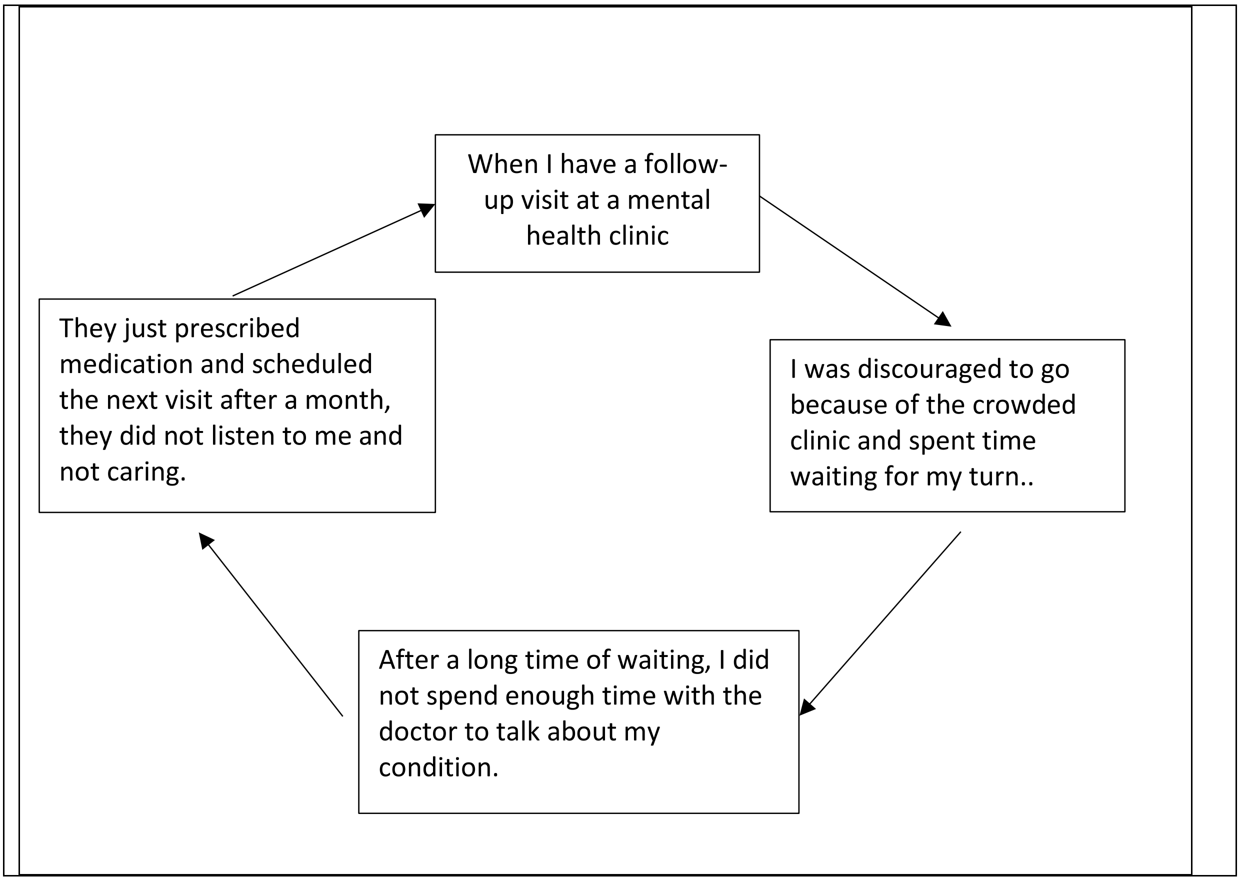
On the other hand, the Ministry of Health provides psychiatric medication free for Jordanian service users and at a very low cost for non-Jordanians (WHO, 2020), which helps them to prescribe and take their medication, but due to the vast number of service user who visits the government clinic some medication or most of it not available at the time they renew their prescription, alternative medication was prescribed for them as discussed earlier in section (5.3.2 Medication origin and manufactures) the impact of alternative medication on medication-taking behaviour. As a result, service users need to buy it from private pharmacies, which is expensive and has an impact on their medication taking either by stopping it or minimising the dose (Semahegn et al., 2020). This study reported although the medication is free, it is the old generation antipsychotic which had severe side effects which impacted their taking due to the side effects. Healthcare professionals in this study also reported that, but the reason beyond that is that the mental health budget is limited, as new generations of medications are costly to buy and sell at a very low price or free in the governmental mental health sector. However, the alternative is sometimes available, but the service users prefer the international one (5.3.2 Medication origin and manufacturers). This is consistent with the WHO report and Nolan study report in Jordan about mental health status, which reported that the mental health budget is limited, which impacts mental health services such as medication availability and the infrastructure of the outpatient departments (Nolan, 2011; WHO, 2020).

Participants mentioned that their bad experiences with mental health settings, such as crowded clinics, long time to follow, and medication unavailability, led them to visit private doctors despite the financial burdens and constraints.

A similar result was reported by Nolan (2011), who found that the private sector provides the same services as mental health governmental clinics, but it is too expensive because the main aim is profit and gain money, as mental health treatment is expensive in Jordan. In Ethiopia, a review by Davari et al. (2018) reported that physicians got a promotional benefited from pharmaceutical industries or companies by prescribing certain medications for the service user, which impacted their prescribing medication decisions. This is consistent with the findings of the present study.

In the current study, participants mentioned that the distance from the service impacts their medication taking. Likewise, lack of access and long distances from the service are considered barriers to treatment (McCann et al., 2008; Semahegn et al., 2020). Lack of service, lack of mental health knowledge, beliefs, and lack of mental health professionals allow service users to use other means of treatment, such as traditional treatment and religious healers (WHO, 2020a; Semahegn et al., 2020; Mianji & Kirmayer, 2022) which affects their medication-taking behaviour and delays their visit to mental health clinics. This reflects on their experience because lack of money will force them to use the governmental clinic where not all medications are available, and the service for mental health is below their expectations as they described it as ignored because of many factors mentioned, such as mental health settings being crowded, lack of time spent with doctors, some medications being unavailable, poor communication with healthcare professionals, and lack of privacy because this topic is considered sensitive because of social stigma related to it.

"The problem here in Jordan is the mental health is neglected, there is no caring about people's mental health. The people are psychologically destroyed" (Service user 3, male, 31 years old).



Mental health clinics in Jordan lack expertise and resources such as specialised mental health personnel, and some medication is not available (Nolan, 2011), as it provides basic mental health needs such as consultation and prescribed medications; however, mental health services are limited in community centres because of stigma, lack of knowledge, and negative attitudes of healthcare professionals toward mental illnesses, which explains the shortage of healthcare workers in mental health settings (Dalky et al., 2020). This is consistent with this study, which reported that there is a shortage of healthcare professionals working in mental health settings, and the services provided are just prescribing and renewing prescriptions; however, these services in some areas are not available every week but one day a week.

Financial constraints, lack of money for transportation, and buying basic needs of their living impact medication-taking behaviour. One of the undesirable side effects of antipsychotic medications is increased appetite, which adds another burden to their economic status (Semahegn et al., 2020). This is in line with the findings of the current study, as shown in the findings section, that people’s financial difficulties impact their ability to buy medications, especially when they have other responsibilities toward other members of the family.

Participants in this study mentioned that financial difficulties impact their medication-taking behaviour in different ways, such as the inability to buy medication or visiting a private psychiatrist because it is too expensive; however, financially capable service users or primary caregivers are willing to buy medications produced outside of Jordan as it is better from Jordanians (see section 5.3.2). This finding is comparable to that of a cross-sectional study in Iran (n=429 service users), which reported that lack of financial support led service users to minimise the number of prescribed medications to cover other expenses (Mehralian et al., 2019). In line with the previous section, people who hold beliefs about mental disorders caused by sorcery or black magic may use related treatment besides their medication treatment if there is no harm from it, which adds more financial constraints (Soh & Walter, 2012). Financial difficulties impact people's decisions to take or buy medications and act as barriers to treatment (Bressington et al., 2013; Mianji & Kirmayer, 2022). Garcia et al. (2016) in their systematic review, found that financial incapability impacts negatively on medication-taking behaviour. Another study in Egypt showed that financial capability improves medication adherence (Jawad et al., 2018).

The current study was conducted while the COVID-19 pandemic invaded the world, and its effects impact several aspects of life, such as financial, social, and mental health. Participants in this study reported that the COVID-19 pandemic negatively impacted medication-taking behaviour, where some of the primary caregivers and service users lost their jobs, which impacted their medication prescriptions and increased levels of stress and anxiety.

The findings of this study are in line with an Australian study conducted during the peak of the COVID-19 pandemic period, March-April 2020, which included 5070 Australians using an online survey. They reported that COVID-19 affected mental health during the outbreak and that the levels of stress and anxiety were very high (60%). Financial difficulties and worries were high because of global financial crises and unemployment problems, which negatively impacted mental health (Newby et al., 2020). Likewise, COVID-19 exacerbates mental health problems among people who do not work, women, and have limited financial resources or low incomes (Pieh et al., 2020). Regarding the financial incapability impact on service users' medication-taking behaviour, participants in this study revealed that service users and primary caregivers minimised using the medication to save money for their living, and some of them stopped taking it for the same reasons.

Similar findings in Jordan have reported that families of individuals with chronic illnesses (cancer and diabetes) decide to minimise healthcare expenditure because it is a chronic problem and does not need urgent management to minimise costs (Doocy et al., 2016). This clears the picture about mental disorders and shows that the people in Jordan prioritise their needs based on their financial status, even if this affects their health. Bassiony et al. (2022) conducted a retrospective study (n=90 service users with schizophrenia) in Egypt and reported that the COVID-19 pandemic impacted service users and their families in different aspects of life; COVID-19 increased their worries about getting infected, fear of death, and lack of family support, are the most factors impact on service users medication, as a result, increase the relapse rate. The lack of family support during the COVID-19 period impacts social relations and increases social isolation and loneliness (Pieh et al., 2020).

This study showed that environmental factors such as COVID-19 impact on medication taking and relapses increased due to a lack of family support, and service users did not renew their prescriptions. COVID-19 has had a negative impact on service users' experiences during the pandemic and has impacted medication-taking decisions and follow-up visits. Lockdown policies and procedures prevent people from moving out of their houses with a lack of supportive services to provide them with their prescriptions, as the policy of lockdown was difficult in Jordan, and the availability of medication was limited.

These findings were consistent with the literature in Jordan. There is an effort to maintain control over CPVID-19, so the government has implemented public health infection prevention and control measures, such as social distancing, minimizing or stopping all inbound, outbound, and international travel, and appointing the Minister of Defines as an authorized body to issue the necessary orders (Alqutob et al., 2020). The COVID-19 pandemic affects not only people with mental illness but also the general population, where mental disorders, such as obsessive-compulsive disorder (OCD), anxiety, stress, fear of death, depression, somatisation, and sleep disorders, affect most people (Lu et al., 2020; Zhang et al., 2020; Seetan et al., 2021).

Based on the above discussion of the factors that impact medication taking among service users diagnosed with schizophrenia or bipolar I disorder, the decision to take psychiatric medications resulted in positive consequences and effectiveness of the treatment, with a positive attitude toward taking psychiatric medications. However, the negative consequences of not taking psychiatric medications affect service users' health by inducing relapse, losing work, and delaying their studies and daily activities. Changing in taking behaviour: increasing or decreasing the dose or trying other medications from other sources, such as trying medications from friends or based on other experiences.

Colom and Lam (2005) mentioned that not taking medications led to consequences such as relapse, which impacted the decision to take medication. Discontinuation often occurs without informing psychiatrists or healthcare professionals (Endale Gurmu et al., 2014; Cooper et al., 2019). Changing medication-taking behaviour led to relapses, which impacted their life, work, and study. However, relapse is a negative experience, but it could be a motive to change their decision based on insight and awareness after experience not taking consequences. Similarly, in their study, Swarbrick and Roe (2011) reported that although it is difficult to take psychiatric medications, the positive aspect is better than the negative aspect and relapses.

5.5 Summary:

Experience, knowledge, beliefs, healthcare systems, and financial insecurity are important determinants of psychiatric medication taking and giving. Participants construct their experiences through interactions with the surrounding environment. Experience is considered a facilitator of taking psychiatric medications if the service user finds the right support system and advice to seek help as soon as possible from a specialist. However, the experience was considered negative and a barrier when they experienced negative outcomes and side effects of medications reported by all participants.

New findings were added to the current study in Jordan. Which is local medication versus international medications; participants described this topic and highlighted it as an important factor that impacts their medication taking. However, this requires further investigation in Jordan.

Social and family support are important factors in the use of psychiatric medications. On the other hand, the negative idea about mental disorders is still dominant in the community and culture because of people’s beliefs about the cause of mental illness from supernatural powers such as evil eyes (hasad) and evil spirits (Jinn), which impact medication taking, giving, prescribing, and visiting mental health settings. Service users and primary caregivers experience different treatment modalities, such as (psychotherapy alone, herbal treatment, and religious healers) before deciding to visit a psychiatrist, which delays their treatment and recovery process.

Motivations such as positive outcomes (continuing education, work, and going ahead in their lives) were a driver to continue psychiatric medications despite the side effects. On the other hand, negative experiences with psychiatric medications, such as (medication not being helpful, adverse side effects, forgetfulness, mild cases, and pharmacists) were barriers; however, the last was shockable since the pharmacists should be providing a positive role, as discussed above, but the opposite was here the pharmacist was a barrier toward psychiatric medication taking.

Knowledge, beliefs, health systems, and financial insecurity are facilitators or barriers that impact medication-taking behaviour in Jordan. Lack of knowledge as an internal factor related to lack of health information about disorders can be modified by increasing knowledge and teaching service users and primary caregivers. False information about disorders and treatments is considered an external factor which may negatively impact medication taking. Knowledge is important for developing more information about psychiatric medications and disorders using scientific methods, and reliable resources will motivate service users and their primary caregivers to take their medications.

Healthcare systems and infrastructure also play a crucial role in influencing mediation-taking behaviour, as they are associated with stigma, and expensive psychiatric medications and psychiatric visits limit the usage of these facilities.

The substantive theory presented by the current study highlights the factors that impact medication-taking behaviour either positively or negatively on service users and primary caregivers' decisions about taking or not taking psychiatric medications. Service users' and primary caregivers' levels of education and the culture surrounding them affect their acceptance of taking psychiatric medications because of a lack of mental health literacy in the community. Service users' and primary caregivers' awareness and insight into the problem are halfway to the treatment. There are consequences for taking or not taking the medications, which could be good or bad depending on the service user and primary caregiver's decision. Consequences could change the decision about taking psychiatric medications as the decision process is dynamic and subjective to change based on the consequences and reassessment of the decision, as explained in the substantive theory.

Chapter 6 Reflection, implications, and conclusion

6.1 Introduction:

This chapter concludes the thesis by examining substantive grounded theory in accordance with Charmaz's framework (2006, 2014) criteria for quality in grounded theory. This will also reflect the theory's possible future contribution. This has implications for mental health clinical practice in Jordan, education, management, and future research. This current study will highlight how the theory provides value for mental health settings and clinical practice by offering a theoretical model of decisions regarding psychiatric medication taking in Jordan. Furthermore, there is a suggestion on how this framework could be used in other areas of health practice. The acknowledgement of the study limitations and how they could be addressed in future studies. This chapter ends with a conclusion which highlights the main outcomes of this study.

6.2 Evaluation of substantive theory:

Chapter Three : Study aim, Objective, Methodology, and Research method) has already discussed and detailed the steps used to ensure the trustworthiness of the qualitative research. Now is the time to evaluate the theory as a finished research result of sufficient quality in the table below using Charmaz's (2006; 2014) criteria for evaluation of the grounded theory using the main principles (credibility, originality resonance, and usefulness). These criteria were chosen to ensure that the constructivist approach was used while developing the substantive theory. Also, the Qualitative guideline COREQ (COnsolidated criteria for REporting Qualitative research) was checked against the thesis. Please see Appendix I, page 322.

Table 20: The evaluation criteria for the theoretical model

Criteria for evaluation	Criteria properties and evidence from the thesis based on the Charmaz criteria (Charmaz, 2006; 2014) are applied to substantive theory.
Credibility	• The grounded theory research approach was thorough, and the methodology and procedures were consistent (Chapter 3 Methodology). • Through methodical comparisons between observations and categories, a constant comparison analysis was performed (Chapters 3 Methodology and Chapter 4 Findings). • The amount of relevant information was sufficient for the proposed theory to be supported, and its development from the data was transparent and unforced (Chapter 3 Methodology, and Chapter 4 Findings)

	• The reader of the thesis may establish their own opinion of the notions that arose to build the theory since there was adequate depth in the presentation of the data and analysis (Chapter 4 Findings and Chapter 5 Discussion).
Originality	• To provide a new perspective on categories that were fresh and distinct into psychiatric medication-taking behaviour and decision process (Chapter 2, literature review; Chapter 4, Findings; Chapter 5, discussion). • The theoretical and social implications of this theory are discussed (Chapter 5 Discussion).
Resonance	• The individuals associated with the conditions of the topic area helped to co-construct meanings that made sense to them (Chapter 4: Findings and Chapter 5: Discussion). • Conceptual, individual, and social process links were developed when data analysis suggested causal links (Chapter 3 Methodology and Chapter 4 Findings). • An analysis led to a theory which offered deeper insight into psychiatric medication-taking behaviour problems in mental health settings and communities (Chapter 4 Findings and Chapter 5 Discussion).
Usefulness	• The central phenomena and main categories were abstract and essential social processes with functional applications across mental health care settings and at the community centre (Chapter 4 Findings and Chapter 6 Discussion). • The theory offers an interpretation of the data that people can use while taking, giving, or prescribing psychiatric medications (Chapter 4 Findings and Chapter 6 Discussion). • The theory presents useful guidance for enhancing psychiatric medication-taking behaviour in outpatient mental health settings and the community (Chapter 5 Discussion and Chapter 6 Conclusion). • The theory can be used and tested in areas other than mental health settings (Chapter 6 Conclusion).

6.3 Disseminating the findings:

Sharing research results with colleagues and inviting feedback and discussion are the first steps in improving them. From this current study, the researcher wants to publish at least two publications following the completion of PhD studies. One is a literature review. The other will be centred on the study findings, which will be published and viewed by Jordanian healthcare professionals and decision-makers. Also, a copy of the findings will be translated into Arabic for the service users and their families to encourage them to participate in future research; their perspective is important. The last will be ready after the completion of the PhD. Additionally, an effort will be made to submit this paper to a high-impact journal.

The abstract of the current study's findings was presented at the 1st Jordanian conference for mental health, which was held in Amman between 24th -26th May 2023. The researcher plans to publish the first written paper in the Journal of Clinical Nursing (impact factor:4.423), where it will introduce substantive grounded theory for medication-taking behaviour to a wider nursing audience. Second, the Literature Review described in (Chapter 2: Literature Review) was developed and systematised to provide a thorough overview of the most recent data on psychiatric mediation-taking behaviour. This work will be submitted to the Journal of Transcultural Psychiatry (impact factor:2.390). Finally, a paper will be submitted to the Journals of the American Psychiatric Nurses Association (impact factor:2.056) to provide a philosophical view on the implication of substantive grounded theory for psychiatric medication-taking behaviour on wider nurses specialised or interested in mental health nursing. In addition, this thesis is available through Hydra, the University of Hull’s Digital Repository (https://hydra.hull.ac.uk).

6.4 Contribution to the knowledge:

In this current study, most studies identified in the literature review on psychiatric medication-taking behaviour for schizophrenia or bipolar disorders in the Middle East and Jordan were quantitative and identified some barriers which impact psychiatric medication-taking behaviour (Rababa’h & Alhmoud, 2013; El-Missiry et al., 2015; Elsheshtawy & Hussein, 2015; Alhalaiqa et al., 2016; Karaytug et al., 2017; Ata et al., 2020). However, these studies did not explain how these factors impact psychiatric medication-taking behaviour or the decision to take medication.

This current study has examined and analysed Jordanian service users, primary caregivers, and healthcare professionals’ perspectives on psychiatric medication-taking behaviour. Few studies in Jordan (Rababa’h & Alhmoud, 2013; Alhalaiqa et al., 2016; Issa et al., 2018) and (Qunaibi et al., 2021) have been conducted in mental health settings in relation to psychiatric medication not taken for schizophrenia or bipolar I disorder. However, these studies did not include service users' or primary caregivers’ views in relation to psychiatric medication taking, nor did they provide a rationale about the factors that impact psychiatric medication-taking behaviour. Furthermore, these studies used quantitative approaches and questionnaires mainly to explore whether psychiatric medication was taken or not and mentioned some barriers which prevented them from taking it, with the most common being forgetfulness, as mentioned in (Chapter 2: Literature Review). As a result, the use of quantitative methods in these studies did not explore the perspectives and experiences of service users and primary caregivers about taking psychiatric medication or why they decided not to take or give psychiatric medications. In addition, the objectivist character of quantitative research restricts the collection of deeper, more detailed data on the subject. Consequently, a qualitative methodology was applied to obtain information to address these issues. Understanding these factors and how they influence psychiatric medication-taking will help in developing an educational program to mitigate these factors and improve the medication-taking experience.

The contribution of this study is that factors impacting adherence in people with severe mental illness a different in a Middle Eastern compared to a Western context (where previous research has predominated). Psychiatric medication taking will not improve until service users and primary caregivers feel empowered to initiate the change toward psychiatric medication and overcome the stigma and cultural context associated with mental disorders. They need to take medication as their priority to go ahead in their lives and if they feel control over their situation. Service users, primary caregivers, and healthcare professionals need to go through substantive grounded theory to investigate the factors that impact their medication taking, giving, and prescribing. This will be new in a mental health setting, as using substantive grounded theory will help in the shared decision process about psychiatric medication taking and achieve a holistic and comprehensive view of the factors, whether to overcome the identified barrier or to improve the facilitator toward taking the medications. The following derived diagram (see figure 4 below) from the substantive theory may help them to go and understand the theory.

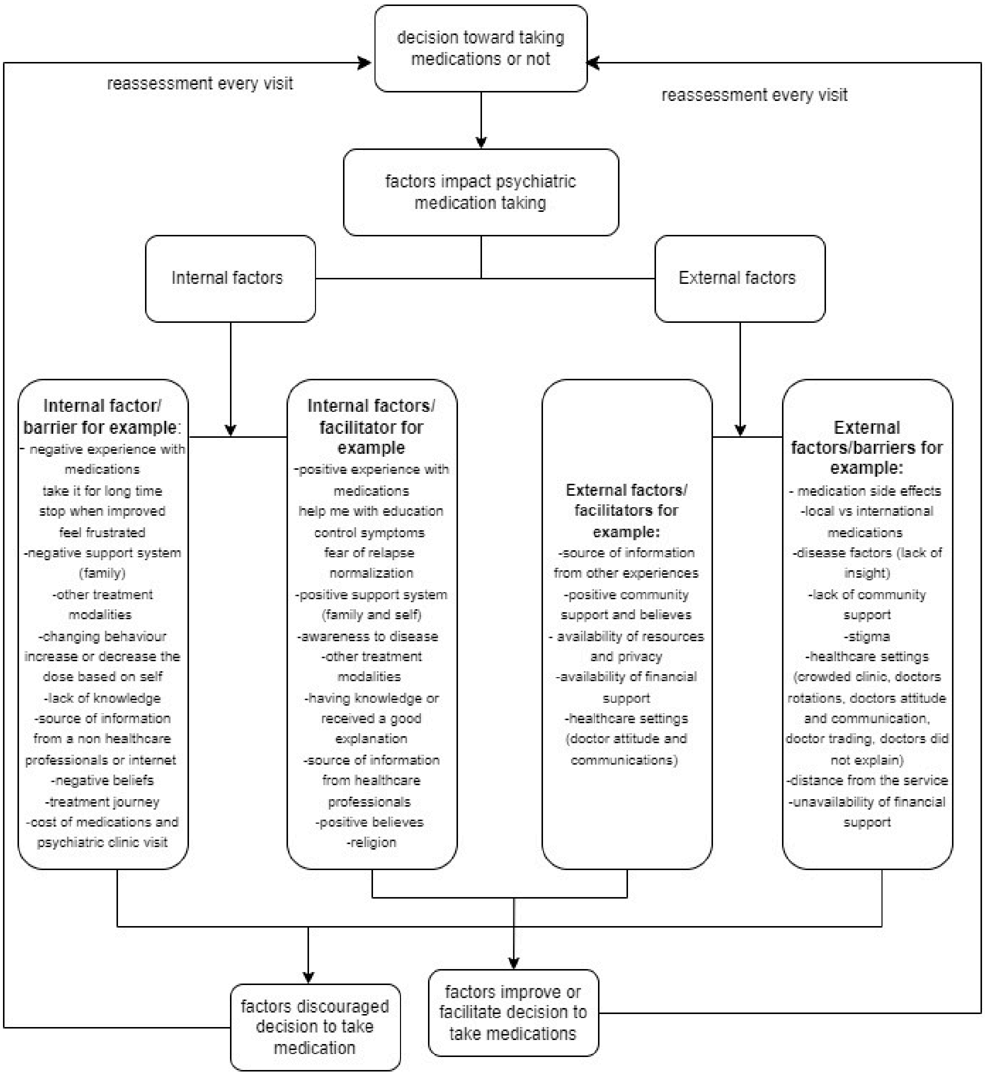


Figure 4: Flow diagram shows the process of identifying factors that impact medication decisions in clinical settings

It is clear from the findings that service users and primary caregivers lack knowledge about mental disorders and psychiatric medications, which are rooted negatively in the culture, which influences their taking and before their help-seeking behaviour, so their experience with the psychiatric problem and medications are all formulated by culture, family belief, and myths about mental disorder causes and traditional treatment.

The current study is also useful because it explains why psychiatric medication-taking behaviour remains a problem. The findings are relevant to Jordan as well as to other Middle Eastern countries such as Oman, the United Arab Emirates, Egypt, and Turkey.

The current study provides service users and primary caregivers with a chance for their voices to be heard. The current study sheds light on Jordanian service users' and primary caregivers' perspectives and experiences in relation to taking and giving psychiatric medication. This is the first qualitative study to address service users' and primary caregivers' experiences and perspectives on psychiatric medication-taking behaviour in Jordan.

Another main finding the current study sheds light on is the “medication is different”; this refers to the medication produced locally and internationally or outside Jordan. Further investigation is required in this area.

6.5 Limitations of the study:

Nonetheless, this study contributes substantially to this knowledge base despite certain limitations. The Literature Review included a small number of articles on the phenomena under study. One explanation might be that the search was restricted to the Middle East and Jordan, the study population had schizophrenia or bipolar disorder, and English was the only language used. Several studies may have biased conclusions and cast doubt on the generalisability of the findings because of a lack of experimental trials, small sample sizes, a lack of proper sampling techniques, and poor data processing. Another drawback is that the literature review of the current study used the Rapid Evidence Assessment (REA) technique, article screening for abstract and full text, and the search process done by one researcher, which might skew the research selection, limit the search area, and introduce potential bias.

Also, I think there is sampling bias because of selecting outpatients only, as I need to understand the factors from the outpatient department who are able to communicate and take their medication at home, not in the acute phase and their medication is controlled by nurses.

Grounded theory has inherent limitations. The technique is centred on the construction of a theory based on evidence from a small, defined sample of people. This limits the generalisability of this study. Earlier chapters detailed the actions taken throughout this research to improve the rigour of the final theory. They include a clear and transparent method for selective theoretical sampling and the use of primary data to support emergent theories and findings.

However, semi-structured interviews provided a deep understanding of the phenomenon and rich data on what happened in the mental health settings and the community about psychiatric medication-taking behaviour. The researcher finds a source of disagreement or new knowledge that needs to be explored more between the participants of three groups or participants of the same group. This prompted the researcher to conduct further interviews in order to achieve data saturation. The researcher attempted to explore the reasons for disagreement and new information from the participants, which added more questions to the proposed interview guide to ensure more in-depth and meaningful data from the participants.

The use of face-to-face interviews was considered in the planning of this study but was amended due to the COVID-19 pandemic (2020-2021) to be an online interview, which added a new burden to the researcher's shoulder as he needed to ensure the data protection of using the Zoom application as the platform for conducting the interview. A gatekeeper needed to allocate the participants for this study, which required more time and privacy considerations to meet the University of Hull guidelines. However, face-to-face interviews provide the researcher with more social cues, such as voice, intonation, body gestures, and body language, which add additional information and depth to the verbal context. This part is missed when online audio or telephone meetings are used. Online audio interviews have advantages over face-to-face interviews because of the wide geographical area which could be included in online interviews, and social cues such as voice and intonation could still be used as an extra source of information (Opdenakker, 2006). Online interviews could be carried out when there is no possibility of conducting face-to-face interviews because, for many reasons, such as the spread of infectious diseases or war zones, the online audio interview minimises the body language and non-verbal communication, which adds more information to the interview, but the voice could be used as social cues (Saarijärvi & Bratt, 2021).

In the current study, we planned to use video calls for the interviewee, but the participants preferred using Zoom audio without video. Video calls have the characteristics of face-to-face interviews, except for geographical locations (Saarijärvi & Bratt, 2021). The reason for this is the nature of the participants as two groups: people diagnosed with mental disorders (schizophrenia or bipolar disorder) and the other group primary caregiver for people diagnosed with mental disorders. Another reason is that the Internet signal is not good when using video and audio calls at the same time; the voice is unclear, and the quality of the picture is bad, which depends on the quality of the Internet connection. Two participants were willing to participate but had no internet connection.

A preliminary analysis of the interviews guided the data-collection plan. However, Practical reasons prevented the researcher from conducting a full theoretical sample because there was only a three-month window of opportunity for data gathering in Jordan, and the primary caregivers were all female. Therefore, the point of view that was not explored in this instance was that two primary caregivers were approached, but they did not accept participation. A slight change in the interview questions generated responses to data problems and helped the researcher identify important people to fill in codes and categories to support theory development.

Moreover, translation from Arabic to English could be limited as some terms in Arabic hard to find an expression in English.

The researcher conducted the study in Jordan because he wanted the findings to be relevant. Despite this last point, it should be interesting and helpful in other contexts with comparable circumstances. Here, it is stated that the current study's outcomes also relate to other Middle Eastern countries, such as China and India. However, the cultural and social contexts may differ between countries. Jordan, as a developing country, has limited resources and has a different cultural and societal heritage in relation to mental disorders and treatment. Therefore, a recommendation for future research will be to conduct the same study in different countries, such as the UK or USA to compare the results and explore if the cultural context makes any differences.

The four primary caregivers in the current study were female because the main role in caring for sick people in Jordan was female (sister, mother, and daughter), so the data were not enough to understand the perspective of male primary caregivers to see if there were any differences between male and female primary caregivers.

The purpose of the current study was to explore the perspectives and experiences of service users and primary caregivers about psychiatric medication-taking behaviour and to understand the factors which work as facilitators or barriers to taking or giving psychiatric medications and healthcare professionals (psychiatrists, nurses, and psychiatric resident doctors). Therefore, future studies could involve other healthcare professionals, such as pharmacists' social workers, psychologists, and community centres, to obtain different and holistic views of psychiatric medication-taking behaviour.

The current study did not include all psychiatric disorders, which were important for exploring additional factors related to taking psychiatric medication. Also, it did not include people less than 18 years old. However, some caregiver service users were underage of 18 years old. Therefore, it would be beneficial to include other service users and primary caregivers for other mental disorders to explore their perspectives on psychiatric medication-taking behaviour.

Also, the study excluded the people who cannot read and write Arabic; this may limit the number of participants which would be considered in future studies.

The three interview transcripts were translated from Arabic to English. In addition, the quotes used in the current study were translated into English, which increased the study time and load. The translation of contexts between the two languages is regarded as a constraint. Nonetheless, the researcher undertook translation and back-translation to ensure that the translations accurately reflected the Arabic language spoken by the participants.

Although the NVivo program was useful for managing the vast volume of data, the researcher encountered several issues during data analysis. For example, at the start of the study, NVivo 12 was used, and then the university upgraded it to Nvivo R 1.5, with the data and codes where corrupted efforts were made to recover the data by contacting the Nvivo main office because the university team was unable to solve it. In addition, the program did not support Arabic, and the researcher employed a variety of methods to import Arabic transcripts into NVivo. Nevertheless, employing NVivo posed far too many challenges to be entirely functional, particularly if Arabic was utilised. In addition, the change from box drive to one-drive storage platforms is another limitation for data storage and synchronisation. I found Box more reliable than One Drive because Microsoft Word stops working and saves data several times while activating autosave, which corrupts the discussion chapter several times, as there are many versions saved in the chapter, which adds more workload and time to the researcher.

6.6 Recommendations Implications for future research:

Grounded theory was used to develop an explanation generated from the data for a particular phenomenon, in this case, psychiatric mediation-taking behaviour. The development of grounded theory in the Jordanian context provides new insights into this area of mental health. Thus, it may only be considered a starting point for a more thorough study. The two key components of the present study that determine the direction, scope, and methods of the research program are the limitations of the study itself and the questions generated by the study findings.

Patient public involvement (PPI) is a feature of health research in the UK, where it is seen as good practice to bring in members of the target population during the design and development stages of a project, sometimes all the way through. This could be a recommendation to be a new ground in Jordanian mental health research with such an approach to research methodology. Perhaps we can suggest this as a future development for projects of this type.

As the researcher is a lecturer at the university, this is a chance to implement these findings and knowledge for better practice for future nursing students and better practices for nurses and calls for more study in mental health practice and settings in Jordan. It also provides valuable information about psychiatric medication-taking behaviour and factors that impact the decision to take from the perspectives of service users, primary caregivers, and healthcare professionals.

This study adds another essential finding in relation to mental health settings and healthcare professionals, which needs more investigation and policy by the policymaker agencies in the Ministry of Health, as the change in this area should be through them, such as crowded clinics to provide a policy to visit the mental health clinic in general or specialised hospitals to reduce the huge number of visitors and to provide more training for healthcare professionals in general and mental health settings to be more professionals and improve their communication skills with service users and primary caregivers.

Medication is influenced by environmental disasters such as COVID-19, which impact their beliefs, financial status, and ways of thinking about the basic needs of life versus psychiatric medication taking. This point needs more effort by the policy maker for further investigation and improvement to mitigate or eliminate this barrier in the future and plan for other environmental issues which may impact psychiatric or other medication taking, such as earthquakes.

In Jordan, studies are needed to explore the differences between Jordanian and international brands, as participants indicated that Jordanian medications have no effect but have negative side effects.

The researcher intended to plan a qualitative study to explore the role and perspective of pharmacists toward people taking psychiatric medications, as the findings of the current study show that they negatively impact medication-taking behaviour. Moreover, studies are needed to understand the role of religious healers or traditional treatment means regarding mental health areas and the types of herbs or remedies used.

The researcher intends to plan for a focused group study to explore different views of service users, primary caregivers, healthcare professionals (nurses, psychiatrists, and pharmacists), religious healers, and herbalists. Then, based on the emerging data, modifications may be made for the current substantive grounded theory model to be more holistic and comprehensive. This will help in developing instruments in the future to precisely identify the factors that impact psychiatric medication-taking behaviour within the Jordanian context, which could then be used broadly.

Suppose there is any opportunity for the researcher to conduct a focused group in developing countries such as the UK. In that case, this will help provide a comparison between the group’s findings within different contexts in relation to people, country, culture, and non-scientific means of treating mental disorders, such as schizophrenia or bipolar disorder.

6.7 Conclusion:

In conclusion, the current study reviewed service users, primary caregivers, and healthcare professionals' perspectives on the factors that influence psychiatric medication-taking behaviour. This goal was justified because of the small number of studies in the Middle East Region and Jordan on this topic, and this is the first qualitative study in Jordan using a grounded theory approach for this phenomenon. The previous chapters highlight the study methods and main findings and outline the emergent theory categories of factors that impact the decision-making process for medication taking, giving, and prescribing psychiatric medications. The theory emerged from analysing the data from interviews using a constant comparative analysis paired with evidence from previous literature.

Five major categories emerged from the data which explained the psychiatric medication-taking behaviour facilitator and barriers, which outlined the process of decision-making regarding medication-taking behaviour: experience with psychiatric medications, knowledge of psychiatric disorders and medications, beliefs about psychiatric disorders and medications, healthcare systems and policies, and financial insecurity. A detailed discussion examined how constructivist grounded theory and its categories that arose from this data fit with other works and literature.

A key finding of this study is that the factors that impact psychiatric medication-taking behaviour are dynamic and interconnected. The change in one factor will be reflected in the other factors, either facilitator, barrier, internal, or external, which will influence the decision to take, give, and prescribe medications. The decision about psychiatric medication-taking behaviour and its factors will remain in this cycle.

For practice, this study offers insight into the real situations of psychiatric medication taking, giving, and prescribing facilitators and barriers. Developing a substantive grounded theory model will help healthcare professionals, service users, and primary caregivers in Jordan work together to construct their decisions about psychiatric medications in light of the factors that impact their taking.

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Appendix A: Schizophrenia diagnostic criteria

Table 21: Appendix A. Comparison of the diagnostic criteria for schizophrenia (Adapted from DSM-5 and ICD-10 manuals).

Features	ICD-10	DSM-5
Name of the disorder	Schizophrenia	Schizophrenia
Psychotic symptoms	A minimum of one obvious symptom of the first rank symptoms: - Delusional perception - Auditory hallucination - delusion of thought interference - delusion of control and negative symptoms or symptoms, usually two or more if less clear cut from at least two of the groups listed.	At least one of these must be (1), (2), or (3) of (criterion A): - Delusion. - Hallucinations. - Disorganized speech (e.g., frequent derailment or incoherent) - Grossly disorganized or catatonic behaviour. - Negative symptoms (i.e., diminished emotional expression or avolition).
Duration of psychotic symptoms	Should have been clearly present for most of the time during a period of 1 month or more. Symptoms duration for less than one month, whether treated or not, should be diagnosed as acute schizophrenia.	Tow (or more) of criterion A for at least one month if treated successfully, or Continuous signs of the disturbance persist for at least 6 months and may include periods of negative symptoms.
Social and functional criteria	Not focused on social and functional aspects as a main criterion of diagnosis. A significant and consistent change in the overall quality of some aspect of personal behaviour manifests as loss of interest, aimlessness, idealness, a self-absorbed attitude, and social withdrawal.	Social or occupational dysfunction: For a significant portion of time since the onset of the disturbance, the level of functioning in one or more significant areas, such as work, interpersonal relations, or self-care, is markedly below the level achieved prior to the onset (or when the onset is in childhood or adolescence, there is failure to achieve the expected level of interpersonal, academic, or occupational; functioning).
Subtypes	Paranoid Hebephrenic (disorganized)	Does not include subtypes.

	Catatonic Undifferentiated Post-schizophrenic depression Residual Simple schizophrenia Other	
Cognitive impairment	Does not include cognitive impairment as a symptom	Which included in criterion B functional and social aspect
Course specifier	With no duration defined, symptoms appear. Continuous Episodic progressive or stable deficit More episodes with complete or incomplete remission	To be considered after one year of diagnosis with no contradiction with the diagnostic criteria: The first episode is currently an acute episode. The first episode, is currently in partial remission. First episode, currently in full remission. Multiple episodes, currently in acute episode. Multiple episodes, currently in partial remission. Multiple episodes, currently in full remission. Continuous episode. Unspecified with catatonia

Appendix B: Bipolar diagnostic criteria

Table 22: Appendix B. Comparing diagnostic criteria for bipolar between DSM-5 and ICD-10

Aspects	ICD-10	DSM-5
Diagnosis name	Under Mood disorders umbrella which subdivided into 7 categories: F 30 Manic episode F31 Bipolar affective disorder F32 Depressive episode F33 Recurrent depressive disorder F34 Persistent mood disorders F38 Other mood disorders F39 Unspecified mood disorder	Bipolar and related disorders Separated from depressive disorders and located between the Schizophrenia spectrum and other psychotic disorders and depressive disorders
Diagnostic criteria	Bipolar guideline, there must have been at least one other episode (hypomanic, manic, depressive, or mixed) in the past.	The manic episode may have been preceded by and may be followed by hypomanic or major depressive episodes.
	Manic episodes usually begin abruptly and last for between 2 weeks and 4 - 5 months (median duration about 4 months). Depressions tend to last longer (median length about 6 months), though rarely for more than a year, except in the elderly. The first episode may occur at any age, from childhood to old age. Elevated mood, increased energy and activity or decrease energy and activity, and low mood.	Manic Episodes: A distinct period of abnormally and persistently elevated, expansive, or irritable mood and abnormally and persistently increased goal-directed activity or energy, lasting at least 1 week and present most of the day, nearly every day (or any duration if hospitalization is necessary). During the period of mood disturbance and increased energy or activity, three (or more) of the following symptoms (four if the mood is only irritable) are present to a significant degree and represent a noticeable change from usual behaviour: Inflated self-esteem or grandiosity. Decreased need for sleep (e.g., feels rested after only 3 hours of sleep). More talkative than usual or pressure to keep talking. Flight of ideas or subjective experience that thoughts are racing. Distractibility (i.e., attention too easily drawn to unimportant or irrelevant external stimuli), as reported or observed. Increase in goal-directed activity (either socially, at work or school, or sexually) or psychomotor agitation (i.e., purposeless non-goal-directed activity). Excessive involvement in activities that have a high potential for painful consequences (e.g., engaging in unrestrained buying sprees, sexual indiscretions, or foolish business investments).

		The mood disturbance is sufficiently severe to cause marked impairment in social or occupational functioning or to necessitate hospitalization to prevent harm to self or others, or there are psychotic features. The episode is not attributable to the physiological effects of a substance (e.g., a drug of abuse, a medication, other treatment) or another medical condition. Note: A full manic episode that emerges during antidepressant treatment (e.g., medication, electroconvulsive therapy) but persists at a fully syndrome level beyond the physiological effect of that treatment is sufficient evidence for a manic episode and, therefore, a bipolar I diagnosis.
	hypomanic: The current episode must fulfil the criteria for hypomania F30.0 [There is a persistent mild elevation of mood (for at least several days on end), increased energy and activity, and usually marked feelings of well-being and both physical and mental efficiency. Increased sociability, talkativeness, overfamiliarity, increased sexual energy, and a decreased need for sleep are often present but not to the extent that they lead to severe disruption of work or result in social rejection. Irritability, conceit, and boorish behaviour may take the place of the more usual euphoric sociability].	Hypomanic Episodes: 1. A distinct period of abnormally and persistently elevated, expansive, or irritable mood and abnormally and persistently increased activity or energy, lasting at least 4 consecutive days and present most of the day, nearly every day. 2. During the period of mood disturbance and increased energy and activity, three (or more) of the Manic Episode symptoms above but less in severity (four if the mood is only irritable) have persisted, represent a noticeable change from usual behaviour, and have been present to a significant degree. 3. The episode is associated with an unequivocal change in functioning that is uncharacteristic of the individual when not symptomatic. 4. The disturbance in mood and the change in functioning are observable by others. 5. The episode is not severe enough to cause marked impairment in social or occupational functioning or to necessitate hospitalization. If there are psychotic features, the episode is, by definition, manic. 6. The episode is not attributable to the physiological effects of a substance (e.g., a drug of abuse, a medication, other treatment).

	F31.3 Bipolar affective disorder, current episode mild or moderate depression. the current episode must fulfil the criteria for a depressive episode [characterized by depressed mood, loos of interest and fatiguability, with following symptoms: (a) reduce concentration (b) reduce of self-esteem (c) idea of guilt (d) bleak and pessimistic views of the future (e) idea of self-harm or suicide (f) disturbed sleep (g) diminished appetite] of either mild [F32.0] or moderate [f32.1] severity. Moreover, there must have been at least one hypomanic, manic, or mixed affective episode in the past. F31.4 Bipolar affective disorder, current episode severe depression without psychotic symptoms. the current episode must fulfil the criteria for a severe depressive episode [F32.2] as above without psychotic symptoms. Also, there must have been at least one hypomanic, manic, or mixed affective episode in the past. F31.5 Bipolar affective disorder, current episode severe depression with psychotic symptoms. The current episode must fulfil the criteria for a severe depressive episode [32.3] with psychotic symptoms. Also, there must have been at least one hypomanic, manic, or mixed affective episode in the past. F31.6 Bipolar affective disorder, current episode mixed. Depressive symptoms and symptoms of hypomania or mania may also alternate rapidly, from day to day or even from hour to hour. A diagnosis of mixed bipolar affective disorder should be made only if the two sets of symptoms are both prominent for the greater part of the current episode of illness, and if that episode has lasted for at least 2 weeks.	Major Depressive Episode: Five (or more) of the following symptoms have been present during the same 2-week period and represent a change from previous functioning; at least one of the symptoms is either (1) depressed mood or (2) loss of interest or pleasure. 1. Depressed mood most of the day, nearly every day, as indicated by either subjective report (e.g., feels sad, empty, or hopeless) or observation made by others (e.g., appears tearful). 2. Markedly diminished interest or pleasure in all, or almost all, activities most of the day, nearly every day. 3. Significant weight loss when not dieting or weight gain. 4. Insomnia or hypersomnia nearly every day. 5. Psychomotor agitation or retardation nearly every day. 6. Fatigue or loss of energy nearly every day. 7. Feelings of worthlessness or excessive or inappropriate guilt (which may be delusional) nearly every day (not merely self-reproach or guilt about being sick). 8. Diminished ability to think or concentrate, or indecisiveness, nearly every day. 9. Recurrent thoughts of death (not just fear of dying), recurrent suicidal ideation without a specific plan, or a suicide attempt or a specific plan for committing suicide. The symptoms cause clinically significant distress or impairment in social, occupational, or other important areas of functioning. The episode is not attributable to the physiological effects of a substance or another medical condition.
	F31.1 Bipolar affective disorder, current episode manic without psychotic symptoms. The current episode must fulfil the criteria for mania without psychotic symptoms F30.1 [The episode should last for at least 1 week and should be severe enough to disrupt ordinary work and social activities more or less completely. The mood change should be accompanied by increased energy and several of the symptoms referred to	Other specifier found under separate category which is unspecified bipolar and related disorders [296.80 (F31.9)]. -With anxious distress (mild, moderate, moderate-severe, and severe). -Manic, hypomanic episodes with mixed features. -Depressive episodes with mixed features.

	above (particularly pressure of speech, decreased need for sleep, grandiosity, and excessive optimism).	-With melancholic features (e.g., lack of pleasure in all activities) -With atypical features (e.g., long standing pattern). -With psychotic features. -With catatonia. -With peripartum onset. -With Seasonal pattern. -In partial remission. -In full remission.
	F31.2 Bipolar affective disorder, current episode manic with psychotic symptoms. the current episode must fulfil the criteria for mania with psychotic symptoms (F30.2); [The clinical picture is that of a more severe form of mania as described in F30.1. Inflated self-esteem and grandiose ideas may develop into delusions, and irritability and suspiciousness into delusions of persecution. In severe cases, grandiose or religious delusions of identity or role may be prominent, and flight of ideas and pressure of speech may result in the individual becoming incomprehensible. Severe and sustained physical activity and excitement may result in aggression or violence, and neglect of eating, drinking, and personal hygiene may result in dangerous states of dehydration and self-neglect].	
	F31.7 Bipolar affective disorder, currently in remission. The patient has had at least one manic, hypomanic, or mixed affective episode in the past and in addition at least one other. affective episode of hypomanic, manic, depressive, or mixed type, but is not currently suffering from any significant mood disturbance and has not done so for several months. The patient may, however, be receiving treatment to reduce the risk of future episodes.	

Appendix C: Literature review tables

Table 23: Appendix C-1. EBSCO search Summary

Database	Number of articles	Articles after duplication were removed from all selected databases and screened by title.	Includes by title scanning	Includes by abstract scanning	Included after full article scanning
CINHAL Complete	213	1056	148	29	10
MEDLINE	344				
PsychINFO	449				
PsychARTILCES	5				
Academic Research Premier	491				
Total	1502	1056	148	29	10

Table 24: Appendix C- 2. Web of Science summary

Database	Number of articles	Articles after duplication were removed from all selected databases and screened by title	Includes by title scanning	Includes by abstract scanning	Included after full article scanning
Web of Science Core Collection	115	106	9	5	1
total	115	106	9	5	1

Table 25: Appendix C- 3. SCOPUS search summary

Databases	Number of articles	Articles after duplication were removed from all selected databases and screened by title	Includes by title scanning	Includes by abstract scanning	Included after full article scanning
SCOPUS database	189	170	9	4	2
Total	189	170	9	4	2

Table 26: Appendix C- 4. Cochrane Library summary

Databases	Number of articles	Articles after duplication were removed from all selected databases and screened by title	Includes by title scanning	Includes by abstract scanning	Included after full article scanning
Cochrane Library Cochrane review Cochrane trials	50 (5) (45)	50	0	0	0

Table 27: Appendix C- 5. Database Summary table

Database	Number of articles	Articles after duplication were removed from all selected databases and screened by title	Includes after title scanning	Includes after abstract scanning	Included after full article scanning
EBSCOhost Search	1502	1056	148	29	10
Web of Science Core Collection	115	106	9	5	1
SCOPUS Database	189	170	9	4	2
Cochrane Library	50	50	0	---	
Total	1856	1382	166	38	13

Table 28: Appendix C- 6. Critical Appraisal MMAT

Categories of study design	**Screening questions**		**3. Quantitative Non-randomized**					**4. Quntitative descriptive**					**Rate**	**Comments**
Studies of bibliographic and country	**S1**	**S2**	**Q 3.1**	**Q 3.2**	**Q 3.3**	**Q 3.4**	**Q 3.5**	**Q 4.1**	**Q 4.2**	**Q 4.3**	**Q 4.4**	**Q 4.5**	**Total**	
1-Alhalaiqa et al., (2016)- Adherence to antipsychotic drug measured by an Arabic version of Morisky Scale (Jordan)	Yes	Yes						Yes	Yes	Yes	Yes	Cannot tell	80%	Analysis plan not clear, significant level not mentioned. Just percentage and frequencies.
2-Issa et al., (2019)- Knowledge of and adherence to antipsychotic medications among individuals diagnosed with schizophrenia (Jordan)	Yes	Yes						Yes	Yes	Yes	No	Yes	80%	Nonresponse rate 27%, the response rate is below 80%.
3-Rababa'h & Alhmoud (2013)- partial adherence with antipsychotic medications and factors related to medication relapse in Jordanian patients with schizophrenia (Jordan)	Yes	Yes						No	Yes	No	Yes	No	40%	Sample does not represent the target population more information needed about sampling. Statistical analysis does not clear more details needed. Methods is described but no validity or reliability provided
4- Eman Elsheshtawy and Ramadan A. Hussein (2015)- Determinants of long duration of untreated psychosis and medication adherence in Egyptian schizophrenic patient: role of social support. (Egypt)	Yes	Yes						No	Cannot tell	Yes	Yes	Cannot tell	40%	The sample at the beginning was 107, then 90 was selected, in result section 105 was recruited and 90 was selected, nor further explanation about the difference of the reporting 107, then 105 more information needed. Researcher mentioned medication adherence level and mentioned the scale used but there is no table or narrative explain that it just used percentage to correlate with social support
5- Hasan et al., (2019)- Assessment of Impact of Insight on Medication	Yes	Yes						No	Yes	Yes	Yes	Yes	80%	How sample recruited, sampling process not mentioned.

Categories of study design	Screening questions		3. Quantitative Non-randomized					4. Quntitative descriptive					Rate	Comments
Studies of bibliographic and country	**S1**	**S2**	**Q 3.1**	**Q 3.2**	**Q 3.3**	**Q 3.4**	**Q 3.5**	**Q 4.1**	**Q 4.2**	**Q 4.3**	**Q 4.4**	**Q 4.5**	**Total**	
Adherence in Schizophrenic Patients (Egypt).														
6- Karaytug et al., (2017)- Assessment of Treatment Adherence in Patients with Bipolar Disorder (Turkey).	Yes	Yes						No	Yes	Yes	Yes	Yes	80%	Not clear how sample selection take place. Type of sampling methods.
7-Esra col et al., (2014)- Factors affecting treatment compliance in patients with bipolar I disorder during prophylaxis: a study from Turkey (Turkey)	Yes	Yes						Cannot tell	Cannot tell	Yes	Yes	Yes	60%	Sample and sampling were not clear, inclusion and exclusion not mentioned.
8-Karadag et al., (2019)- Assessing the treatment adherence and clinical correlates of low adherence among bipolar disorder outpatients: a cross-sectional study (Turkey)	Yes	Yes						Cannot tell	Cannot tell	Yes	Yes	Yes	60%	Sampling and sample selection not mentioned, beside inclusion and exclusion criteria were not clear.
9- El-Missiry et al., (2015)- Comparing cognitive functions in medication adherent and non-adherent patients with schizophrenia (Egypt)	Yes	Yes	Cannot tell	Yes	Yes	Yes	Yes						80%	Sample selection does not clear more information needed.
10-El Meguid et al., (2016)- Understanding medication nonadherence in a sample of Egyptian patients with schizophrenia in relation to illness severity and insight (Egypt)	Yes	Yes	Cannot tell	Yes	Yes	Yes	Yes						80%	Sample selection and methods do not clear the researcher did not mention how the sample recruited, cannot judge if sample is representative

Categories of study design	**Screening questions**		**3. Quantitative Non-randomized**					**4. Quntitative descriptive**					**Rate**	**Comments**
Studies of bibliographic and country	**S1**	**S2**	**Q 3.1**	**Q 3.2**	**Q 3.3**	**Q 3.4**	**Q 3.5**	**Q 4.1**	**Q 4.2**	**Q 4.3**	**Q 4.4**	**Q 4.5**	**Total**	
11- Sultan et al., (2016)- Studying medication adherence in patients with schizophrenia: focus on antipsychotic-related factors. (Egypt)	Yes	Yes	Cannot tell	Yes	Yes	Yes	Yes						80%	Sample selection does not clear more information needed.
12-Radwan et al., (2020)- Psycho-demographic and clinical predictors of medication adherence in patients with bipolar I disorder in a university hospital in Egypt (Egypt)	Yes	Yes	Cannot tell	Yes	Yes	Yes	Yes						80%	Sample selection does not clear more information needed.
13- Ata et al., (2020)- The impact of side effects on schizophrenia and bipolar disorder patients' adherence to prescribed medical therapy (Turkey)	Yes	Yes	Cannot tell	Yes	Yes	Yes	Yes						80%	Sample selection and method do not clear the researcher did not mention how the sample recruited, cannot judge if sample is representative
14- Qunaibi et al., 2021- Perspectives of psychiatric patients in rural areas of Jordan: Barriers to compliance and pharmacist role. (Jordan)	Yes	Yes						Yes	Yes	No	Yes	Yes	80%	The measurement scale measure face validity only no psychometric measurement done as it is a self-development scale.

Table 29: Appendix C- 7. Data Extraction

Author, Year & Place	**Aim of the study**	**Population, sample, and sampling**	**Design**	**outcomes**	**Data collection**	**Analysis**	**Limitation**	**Quality rating**	**Methodological Appropriateness** **level**
1- **Alhalaiqa et al., (2016)- Adherence to antipsychotic drug measured by an Arabic version of Morisky Scale** **Jordan**	was to assess medication adherence levels among people with mental illness	1)Mental illness (schizophrenia, and bipolar). 2)Convenience sample 108 participant of outpatient mental health clinic at the National Centre of Mental Health. Schizophrenia 73, Bipolar 35. 3)Age 21-75 year (m=49), Gender (F=21 (19%), M=87 (80%)), educated 77 (72%), not educated=31 (28%). Working 20 (19%), not 88 (81%). Married 42 (39%), single 62 (57%), others 4 (4%)	Cross-sectional study.	1)90 participants about (83%) shown low adherence level. 56% of patient's belief that increased number of prescribed medications decrease adherence. 2)The major reason for adherence based on MMRS was medication side effect (55%, feeling worse after taking medication (52%), and forgotten to take medication (50%). 3) 50% of patients mentioned that having barrier to attend follow up appointment, the barrier to follow up as following (distance 7%, transportation 10%,	By questionnaire Morisky Medication Rating Scale (MMRS). And Demographic questionnaire.	Descriptive statistics [frequencies and percentage). Difference means, Pearson correlation, and power calculation for sampling.	Subjective recorded of adherence level by patient and this led to personal or recall bias. Convince sample from one hospital led to selection bias, and lack of generalizability.	**80%** **Analysis plan not clear, significant level not mentioned. Just percentage and frequencies**	**D**

Author, Year & Place	**Aim of the study**	**Population, sample, and sampling**	**Design**	**outcomes**	**Data collection**	**Analysis**	**Limitation**	**Quality rating**	**Methodological Appropriateness level**
				Money 3%, and ALL of them 30%). More studies needed for further explorations. 4) number of Admission and follow up appointment were negatively correlating with adherence level (r= -0.3, p=0.002 and r= -0.32, p=0.001 respectively).					
2- **Issa et al., (2019)- Knowledge of and adherence to antipsychotic medications among individuals diagnosed with schizophrenia.** **Jordan**	was to identify the knowledge and its correlation with level of adherence to antipsychotic medication.	1)People diagnosed with schizophrenia 2)A convenience sample of 365 participants of outpatient's clinic at the National Centre of Mental Health. 3)Age 21-67 (m=42.9). gender M=198 (54%), F=167 946%), Worker 256 (70%) not 109 (17%). Educated 304 (83%), illiterate 61 (17%). Married 243	Cross-sectional correlational study.	1)Lack of knowledge about antipsychotic medications was found among patients diagnosed with schizophrenia. 2)Most patients (87%) reported low levels of adherence to their antipsychotic medications (13% were adhere). 3)The majority of participant (more than 88%) know the name and dose of their medication. However more than 80% of them has lack of knowledge	By questionnaires: Understanding of Medication Questionnaire and Morisky Medication Adherence Scale. And Demographic questionnaire.	Significance level was set at p< 0.05. Descriptive statistics. Pearson r correlation coefficients, independent t-test, ANOVA and Post hoc (Tukey test).	Data collected from patients. The subjectivity of measuring scale (MMAS) which is not giving accurate measures of medication like serum level.	**80%** **Nonresponse rate 27%, the response rate is below 80%.**	**D**

Author, Year & Place	Aim of the study	Population, sample, and sampling	Design	outcomes	Data collection	Analysis	Limitation	Quality rating	Methodological Appropriateness level
		(67%), single 66 (18%), others 56 (15%).		about symptoms of disorders and side effect of medication such as (tardive dyskinesia). 4) forgetfulness was the most common reasons based on MMRS scale (67%) unintentionally. 5) positive relationship between medication adherence and knowledge scale (r=0.37, p<0.001)					
3- **Rababa'h & Alhmoud (2013)- partial adherence with antipsychotic medications and factors related to medication relapse in Jordanian patients with schizophrenia.** **(Jordan)**	was assessed the frequency of and factors contributing to partial adherence.	1)Psychiatrists and nurses work with patient diagnosed with schizophrenia 2) 47 participants (12 psychiatrists, and 35 nurses). Assessed records of 179 patients diagnosed with schizophrenia	Cross-sectional study.	The psychiatrists regarded (74%) of the evaluated patients as unintentionally partially adherent, (40%) of the patients were intentionally partially adherent with medication. throughout the study period. The most frequently assessed patient-related factors contributing to partial adherence were denial of illness (80%), lack of or insufficient information about their disease and	Sociodemographic questionnaire, and self-development questionnaire, to measure psychiatrists and nurses' perceptions	t-test, arithmetic means (measures mean and average), At significant level of p<0.05	Small sample size nor representative from one psychiatric clinic at Royal Media Services. Some data may have not been recorded in the patients report.	**40%** **Sample does not represent the target population more information needed. Statistical analysis does not clear more details needed. Methods is described but no validity or reliability provided**	**D**

Author, Year & Place	**Aim of the study**	**Population, sample, and sampling**	**Design**	**outcomes**	**Data collection**	**Analysis**	**Limitation**	**Quality rating**	**Methodological Appropriateness level**
				medication (74.9%/73.7%). need someone to remind them to take their medication (74.3%). side-effects related causes (64.8%). the cost of medication (63.1%). and long duration and complexity of regimen (60.9%).					
4- **El-Missiry et al., (2015)- Comparing cognitive functions in medication adherent and non-adherent patients with schizophrenia.** **(Egypt)**	Was explore the relationship between cognitive dysfunction and non-adherence to antipsychotic medication	1)People with schizophrenia (outpatients109 participants. 2)Age:18-57years (M=32 years). Gender M=77 (71%), F=32 (29%). Educated 96 (88%), illiterate 13 (12%). Work 62 (57%), not 47 (43%).	Prospective cohort study.	Approximately 69% of participant were nonadherent. Cognitive deficit a factor associated with non-adherence. Patients who have good cognitive tests have good adherence. At significant level of p=0.006.	By questionnaires: Wechsler Adult Intelligence Scale (WAIS), Wechsler Memory Scale-Revised (WMS-R) and Wisconsin Card Sorting Test (WCST) and six months later by the Brief Adherence Rating Scale (BARS).	t-test for difference mean, and chi-square, at significant level of p<0.005	Small sample size. Not including type of antipsychotic and did not take into consideration the sedative effect of antipsychotic on participant. Researcher did not investigate other possible factors could affect adherence such as (stigma, patients' attitude toward medication, and socio-cultural barriers). They did not consider socio-economic cost of medication which	**80%** **Sample selection does not clear more information needed.**	**B**

Author, Year & Place	Aim of the study	Population, sample, and sampling	Design	outcomes	Data collection	Analysis	Limitation	Quality rating	Methodological Appropriateness level
							considered a predictor of medication taking.		
5- **Eman Elsheshtawy and Ramadan A. Hussein (2015)- Determinants of long duration of untreated psychosis and medication adherence in Egyptian schizophrenic patient: role of social support.** **Egypt**	Was to evaluate the role of social support in medication taking.	1)Muslim People diagnosed with Schizophrenia. 2)Convenience sample Outpatients 90 participants. 3)Mean age [20-65 years, Mean=32 years]. gender M=58 (54%), F=32 (37%). Work 24 (27%), not work 66 (73%). Married 52 (58%), single 38 (42%). Education 12 years of less 65 (72%), 12 years or more 25 (28%).	Cross-sectional study.	Social support was the only predictor and was highly correlated with medication adherence scale (beta= .388, p<0.01).	By questionnaires: Scales for the Assessment of Positive Symptoms and Negative Symptoms (SAPS and SANS), Global Assessment of Functioning (GAF), Morisky Medication Adherence Scale (MMAS), Schedule for the Assessment of Insight (SAI-E), and Multi-Dimensional Scale of Perceived Social Support	Differences between means, t-test, and chi-square, stepwise regression at Significant level of p<0.05.	cross-sectional has limitations to draw causal relationship. Small sample size limit generalization. Assessing medication adherence by self-report	**40%** ***The sample at the beginning was 107, then 90 was selected, in result section 105 was recruited and 90 was selected, nor further explanation about the difference of the reporting 107, then 105 more information needed. Researcher mentioned medication adherence level and mentioned the scale used but there is no table or narrative explain that it just used percentage to correlate with social support.***	**D**
6- **El Meguid et al. (2016)- Understanding medication nonadherence in**	was to identify the clinical features of schizophrenia that correlate with nonadherence to medication.	Patients diagnosed with schizophrenia were 109 participants in the outpatient clinic. Mean age 32 years.	Prospective cohort study.	Two-thirds (68.8%) of the studied patients were nonadherent, and only one-third. (31.2%) were adherent.	Patient assessed twice at the beginning of the study then after 6 months then data verified through collateral	Mean differences, independent t-test, chi-square Pearson correlation, and logistic regression. at	Small sample sizes may limit the generalizability of the study. There is a lack of objective adherence	**80%** **Sample selection and methods do not clear the researcher did not mention how the sample recruited, cannot judge if**	**B**

Author, Year & Place	**Aim of the study**	**Population, sample, and sampling**	**Design**	**outcomes**	**Data collection**	**Analysis**	**Limitation**	**Quality rating**	**Methodological Appropriateness level**
a sample of Egyptians. **patients with schizophrenia in relation to illness severity and insight** **(Egypt)**		M=68, F=41. Work 47, no work 62.		The major predictive factor of non-adherence is among nonadherent group is insight less and severity of illness at significant level (p<0.05. 94% of non-adherent were insight less.	information form family. By questionnaires: Positive and Negative Syndrome Scale (PANSS). Six months later, the patients were reassessed. with PANSS, the Brief Adherence Rating scale, and the Scale to Assess unawareness of medical disorder.	significant level of p<0.05	measures – for example, plasma drug concentration. The present study may not generalize to the general patient population as it is. based on a convenience sample.	**sample is representative**	
7- **Sultan et al., (2016)- Studying medication adherence in patients with schizophrenia: focus on antipsychotic-related factors.** **(Egypt)**	was to estimate the rate of nonadherence and to assess medication-related extrapyramidal and weight-gain side effects influencing adherence to antipsychotic drugs.	1)Patients diagnosed with schizophrenia. Outpatients 109 participants. 2)M=77, F=32. Age 18-65 (M=32 years). Educated 95 (87%), illiterate 14 (13%). Work 62 (57%), No work 47 (47%).	Prospective Cohort study.	Overall, 68.8% of the patients were nonadherent to their antipsychotic medications. Experiencing motor side effects had significant relation to adherence as the presence of dyskinesia, akathisia, and extrapyramidal symptoms lead to nonadherence (P= 0.014, 0.017, 0.00, respectively). But not significant as	Data was collected at 2 points at the beginning and after 6 months to ensure not miss any side effects appears. By questionnaires: Side effects of antipsychotics were assessed using. the Simpson Angus Scale (for extrapyramidal symptoms), Barnes Rating Scale (for akathisia), and Abnormal	Descriptive statistic, paired t-test for compare means, Pearson r correlation test, logistic regression, at significant level p<0.05	Small sample size. Cross-sectional design cannot draw causal relationships. They did not examine the patients' belief and attitude to medication and the impact of stigma on drug. compliance. Beside the duration of illness as predictor of nonadherence.	**80%** **Sample selection does not clear more information needed.**	**B**

Author, Year & Place	Aim of the study	Population, sample, and sampling	Design	outcomes	Data collection	Analysis	Limitation	Quality rating	Methodological Appropriateness level
		Married 27 (25%), single 75(69%), other 7 (6%).		predictive factors on logistic regression. Across two group adherent and nonadherent males were more nonadherent at a significant level of p=0.002.	Involuntary Movement Scale (for dyskinesia). Brief Adherence Rating Scale. Finally, patients' weights were again measured.				
8- **Hasan et al., (2019)- Assessment of Impact of Insight on Medication Adherence in Schizophrenic Patients** **(Egypt)**	Was to assess the impact of insight on psychotic medication adherence.	1)People diagnosed with schizophrenia Outpatients 50 participants. 2)Sampling not mentioned 3)age 22-57 years (M=40) gender M=32 (46%), F=18 (36%).	Cross-sectional non-interventional study.	1)Family support has significant relation with medication adherence (p=0.028). 2) medication adherence has strong positive relation with insight (p<0.0001). 3) Lack of Insight and social support have strong positive relation with medication adherence.	By questionnaires: Schedule for Assessment of Insight-Expanded Version (SAI–E) translated into Arabic by Marwa Abdelgawad. The degree of medication adherence was measured by using Medication Adherence Rating Scale (MARS).	Data were analysed by independent sample, paired t test linear regression, P-value was considered significant if < 0.05	Small sample size limit generalizability. Cross-sectional design did not provide a causal relationship.	**80%** **How sample recruited, sampling process not mentioned**	**D**

Author, Year & Place	**Aim of the study**	**Population, sample, and sampling**	**Design**	**outcomes**	**Data collection**	**Analysis**	**Limitation**	**Quality rating**	**Methodological Appropriateness** **level**
9- **Radwan et al., (2020)- Psycho-demographic and clinical predictors of medication adherence in patients with bipolar I disorder in a university hospital in Egypt.** **(Egypt)**	Was to assess the socio-demographic and clinical factors associated with medication nonadherence in patients with BD	1)People diagnosed with bipolar I disorder outpatients 110 participants. 2)Age 18-60 years. Gender (M=74, F=36). Majority of participants were single 50 (46%). Married 42 (39%), other 18 (16%). No work 65, work 45.	Longitudinal prospective study.	Age and impaired insight were found to be significant predictive factors for non-adherence at significant level of (p<0.05, p<0.001 respectively). Being female, married, older people, and high educational level noticed to have high adherence. Being male, unmarried, low educational level associated with low adherence (not taking) at significant level of p<0.001. 58% (64) of participants has not taking their medication as intended. 21 (19%) medium adherent, 25 (23%) participants high adherence.	By questionnaires: Young Mania Rating Scale, Clinical Global Impression, Global Assessment of Functioning, Sheehan Disability Scale and Insight and Treatment Attitude Questionnaire	ANOVA, analysis of variance; Chi-square, and logistic regression. At p < 0.05 statistically significant.	Self-reporting. Objective assessments could have decreased any variance because of error. Small sample limited generalization.	**80%** **Sample selection does not clear more information needed.**	**B**
10- **Esra Col et al., (2014)- Factors affecting treatment compliance in**	Was to identify factors affecting treatment adherence among people with bipolar	1)People with bipolar I disorder Outpatients 78 participants.	Cross-sectional descriptive.	57% of participants are complaints, whereas 43% are non-complaints. 39% of complaint participants report	By questionnaires: Sociodemographic questionnaire.	Parametric and non-parametric measures. Independent t-test, chi-square (fisher, Mantel-	Small sample size and no scale was used to determine side effect	**60%** **Sample and sampling were not clear, inclusion and exclusion are too limited, age between**	**D**

Author, Year & Place	Aim of the study	Population, sample, and sampling	Design	outcomes	Data collection	Analysis	Limitation	Quality rating	Methodological Appropriateness level
patients with bipolar I disorder during **prophylaxis: a study from Turkey** **(Turkey)**		2)Age 18-65 years. Gender M=28 (28%), F=50 (64%). Married 49, single 25, other 4. Education elementary 32, high school and university 46.		good social support, and 22 participants of noncompliance report poor social support at a significant level (p=0.035). The lack of social support, lack of knowledge provided by physicians about illness and treatment, and number of rehospitalizations are factors associated with non-compliance. Age of onset, total number of episodes, and medication side effects are predictors of non-compliance.	Mediation Adherence Rating Scale (MARS). Hamilton Depression Rating Scale (HDRS) and Young Mani Rating Scale (YMRS).	Haenszel). Logistic regression (Backward LR). at significant level p<.05		**18-65 years, and take mood stabilizers medications.**	
11- **Karaytug et al., (2017)- Assessment of Treatment Adherence in Patients with Bipolar Disorder** **(Turkey)**	was to identify demographic characteristics that predict medication not taking.	1)Patient diagnosed with bipolar disorder 85 participants Outpatients 2)gender M=41 (48%), F44 (52%). Married 41 (48%), single 44 (52%). Education elementary 30 (35%), high school	Cross-sectional analytical.	Approximately 70% of patients were not taking their medication as intended. Factor that predicting not taking medication were being single and lack of social support at significant level of p<0.05.	By questionnaires: Morisky Medication Adherence Rating Scale. And semi structured interview based on DSM 4 criteria	Descriptive statistics, Chi square (fisher's exact test, student t-test, ANOVA. statistical significance was set as p<0.05.	Small sample size limit generalization.	**80%** Not clear how sample selection take place. Type of sampling methods.	**D**

Author, Year & Place	**Aim of the study**	**Population, sample, and sampling**	**Design**	**outcomes**	**Data collection**	**Analysis**	**Limitation**	**Quality rating**	**Methodological Appropriateness** **level**
		55 (65%). Works 30 (35%), no work 55 (65%).							
12- **Karadag et al., (2019)- Assessing the treatment adherence and clinical correlates of low adherence among bipolar disorder outpatients: a cross-sectional study.** **(Turkey)**	was to assess sociodemographic and clinical correlates of poor treatment adherence.	1)People diagnosed with bipolar. 117 participants of outpatient's psychiatric clinic. 2)mean age 41 years. Gender F=69 (59%), M=48 (41%). Married 52, Unmarried 65. Educated primary 35, high school and university 82.	Cross-sectional study.	1)Adherent 98 (84%), non-adherent 19 (16%). Non-adherent. 2)participants were low educated, were more likely to be not married, and had a greater prevalence of anxiety disorder comorbidity. Logistic regression analyses revealed that comorbid anxiety disorder, lower education level, and duration of depression period were the main predictors of poor adherence at significant level of ($p=0.016$, $p=0.026$, $p=0.000$).	By questionnaires: sociodemographic form, the SCID-I, the Morisky 8-item Medication Adherence Questionnaire, the Hamilton Depression Scale, the Young Mania Rating Scale, Schedule for Assessing the three components of insight, and Global Assessment of Functioning Scale Blood sample	Descriptive statistics, chi square, t-test, logistic regression. At $p<0.05$	a cross-sectional study cannot permit drawing causal associations. between the factors studied. Patient's knowledge level or awareness of features of the disorder was not evaluated. Standard questionnaires targeting understanding of the disorder itself should be applied to support a direct relationship with the treatment adherence.	**60%** **Sampling and sample selection not mentioned, beside inclusion and exclusion criteria were not clear.**	**D**
13- **Ata et al., (2020)- The impact of side effects on schizophrenia and bipolar**	Was to investigate the impact of side effect of antipsychotic on medication taking behaviour.	1)People diagnosed with bipolar and schizophrenia Inpatients 92 participants 47 bipolar, 45 schizophrenia.	Cross-sectional descriptive analytical design.	Most of participants were poor adherent mean score 86% [bipolar= 92%, schizophrenia 80%]. Most of bipolar patients had side	By questionnaires: Medication Adherence Rating Scale (MARS) and Liverpool University Neuroleptic Side	Mean difference between scales, chi square, independent sample t-test, and Pearson	Restricted nature of sample group. Medication adherence via self-report.	**80%** **Sample selection and methods not clear the researcher did not mentioned how the sample recruited, cannot judge if**	**D**

Author, Year & Place	Aim of the study	Population, sample, and sampling	Design	outcomes	Data collection	Analysis	Limitation	Quality rating	Methodological Appropriateness level
disorder patients' adherence to prescribed medical therapy. **(Turkey)**		2) Mean age 44 years, gender (M= 44 (48%), F=48 (52%), Married 33 (36%), single 39 (42%), others 20 (22%). No work= 18 (20%), works 74 (80%). Illiterate 4 (4%) educated primary 64 (70%), university and highs school 24 (26%). Not educated (44%)		effect to medication more than schizophrenia [15%, and 6% respectively]. Side effects were correlated with medication not taking behaviour among bipolar (at significant level of [p=0.025] and not significant with schizophrenia (p=0.53). High side effect low adherence	Effect Rating Scale (LUNSERS).	correlation. at significant level of p<0.05	The small size of psychiatric clinic limited the calculation of power analysis.	**sample is representative**	
14) Qunaibi et al., 2021- Perspectives of psychiatric patients in rural areas of Jordan: Barriers to compliance and pharmacist role **(Jordan).**	The aim of this study was to investigate perspectives of patients diagnosed with psychiatric disorders, living in rural areas in Jerash, Jordan, regarding their awareness about their conditions, including religious and cultural factors, adherence to their treatment and related barriers, with special focus on pharmacist's role.	Convenience sampling 120 participants (depression, schizophrenia, and bipolar)	Cross-sectional survey design	Barriers affecting adherence included mainly suffering from adverse effects (31.9%) and being unconvinced that they needed a medication (23.3%). Only 14.2% of patients reported that they refer to the pharmacist to get information about their medications.	Two final year pharmacy student with interview the patients and fill the survey	standard deviation (SD), frequency and percentages. Pearson's correlation test was used to determine the relationship between adherence level to treatment. A probability value of <.05 was considered to be statistically significant for all analysis tests.	Adherence measure by self-report Questionnaire validated with (face validity only) Convenience sample limited the generalizability as the sample recruited from one setting.	**80%** **The measure scale is self-developed with no reliability or validity measure.** **Just face validity**	**D**

Table 30: Appendix C- 8. Common feature of participants in included studies

articles	Sample	Age	Schizophrenia	Bipolar	Gender		Medication taken level			Education			Work status	
					Male	**Female**	**High**	**Low (non)**	**Medium**	**>primary education**	**<primary education**	**Illiterates**	**worker**	**Not worker**
(Alhalaiqa et al., 2016)	108	21-75 years	73	35	87	21	3	90(83%)	15	77		31	20	88
(Issa, E., Hamdan-Mansour, & Hamaideh, 2018)	365	21-67 years	365	----	198	167	1	317 (78%)	47	304		61	256	109
(Rababa'h & Alhmoud, 2013)	179	-----	179					72 (40%)	107					
(El-Missiry et al., 2015)	109	18-57 years	109	----	77	32	34	75 (69%)		96		13	62	47
(Elsheshtawy	90	20-65 years	90	-----	58	32				25	65		24	66

& Hussein, 2015)														
(El Meguid et al., 2016)	109	Mean age 32 years	109	------	68	41	34	75 (69%)					47	62
(Sultan et al., 2016)	109	18-65 years	109	-----	77	32	34	75 (69%)		95		14	62	47
(Hassan et al., 2019)	50	22-57 years	50	----	32	18		25 (50%)	25					
(Radwan et al., 2020)	110	18-60 years	----	110	74	36	21	64 (59%)	25				45	65
(Col et al., 2014)	78	18-65 years	-----	78	28	50	45	33 (42%)		46	32			
(Karaytug et al., 2017)	85	Mean age 36 years	---------	85	41	44	25	31 (36%)	29	55	30		30	55

(Karadağ et al., 2019)	117	Mean age 40 years	----	117	48	69	98 (84%)	19 (16%)		82	35			
(Ata et al., 2020)	92	Mean age 44years	45	47	44	48	12	80 (87%)		24	64	4		
Total	1601		1129	472	832	590	307	956	248	804	226	123	546	480

Appendix D: Ethica approval letters

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PRIVATE AND CONFIDENTIAL
Khaldoon Obiedate
Faculty of Health Sciences
University of Hull
Via email

12th May 2021

Dear Khaldoon

REF FHS328 - A Qualitative study to understand factors that influence psychiatric medication taking among people diagnosed with schizophrenia or bipolar disorders, their primary caregiver, and health care professionals in Jordan

Thank you for your responses to the points raised by the Faculty of Health Sciences Research Ethics Committee.

Given the information you have provided I confirm approval by Chair's action.

Please refer to the Research Ethics Committee web page for reporting requirements in the event of any amendments to your study.

Should an Adverse Event need to be reported, please complete the Adverse Event Form and send it to the Research Ethics Committee FHS-ethicssubmissions@hull.ac.uk within 15 days of the Chief Investigator becoming aware of the event.

I wish you every success with your study.

Yours sincerely

Professor Liz Walker
Chair, FHS Research Ethics Committee

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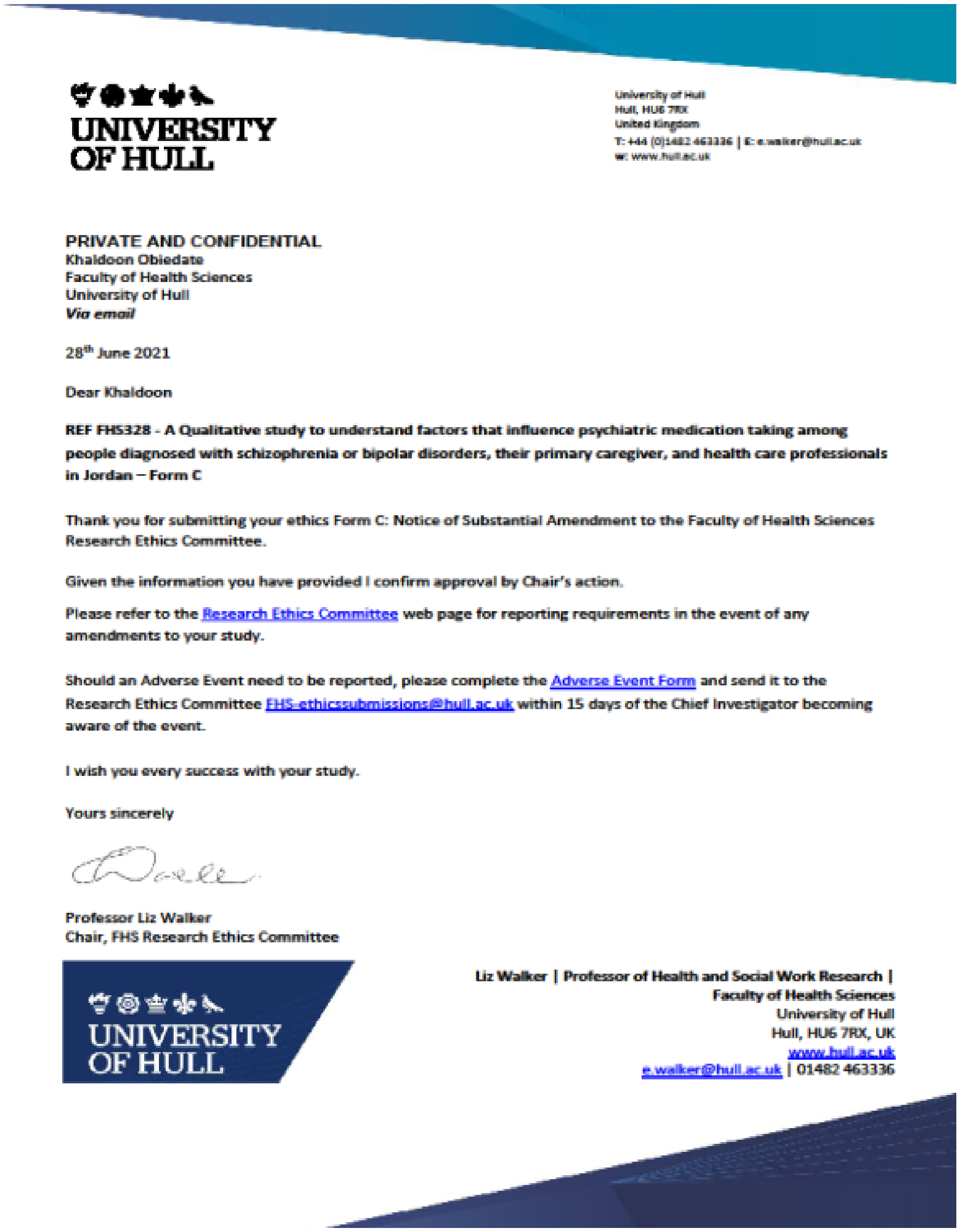
Figure 5: Appendix D- 1. University of Hull approval letter



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PRIVATE AND CONFIDENTIAL
Khaldoon Obiedate
Faculty of Health Sciences
University of Hull
Via email

28th June 2021

Dear Khaldoon

REF FHS328 - A Qualitative study to understand factors that influence psychiatric medication taking among people diagnosed with schizophrenia or bipolar disorders, their primary caregiver, and health care professionals in Jordan – Form C

Thank you for submitting your ethics Form C: Notice of Substantial Amendment to the Faculty of Health Sciences Research Ethics Committee.

Given the information you have provided I confirm approval by Chair's action.

Please refer to the Research Ethics Committee web page for reporting requirements in the event of any amendments to your study.

Should an Adverse Event need to be reported, please complete the Adverse Event Form and send it to the Research Ethics Committee FHS-ethicssubmissions@hull.ac.uk within 15 days of the Chief Investigator becoming aware of the event.

I wish you every success with your study.

Yours sincerely

Professor Liz Walker
Chair, FHS Research Ethics Committee

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Figure 6: Appendix D- 2. University of Hull approval letter -amended

جمعية خطوتنا

الرقم: ج خ / 1087 / ص 2021/18

التاريخ: 2021/6/14

الدكتور خلدون عبيدات المعايطة

كلية العلوم الصحية / جامعة هل البريطانية

تحية طيبة وبعد

تتقدم جمعية خطوتنا لدعم حقوق الأشخاص ذوي الإعاقة النفسية واسرهم بالأردن بجزيل الشكر لك بإشراك أعضائها بالدراسة التوعوية بفهم العوامل التي تؤثر على تداول الأدوية النفسية لدى الأشخاص الذين يعانون من اضطرابي الفصام وثنائي القطب ومقدمي الرعاية الأساسيين لهم، والكادر الطبي المختص في الأردن.

بالنظر إلى المعلومات التي قدمتها عن الدراسة وموافقة جامعة هل البريطانية بإجراء البحث، نؤكد لكم موافقة الهيئة الإدارية لجمعية خطوتنا على إجراء البحث وتقديم أقصى تعاونها للمساعدة في نجاح البحث.

كما نرجو من حضرتكم تزويدنا بنتائج البحث بعد الانتهاء منه واعتماده رسميا.

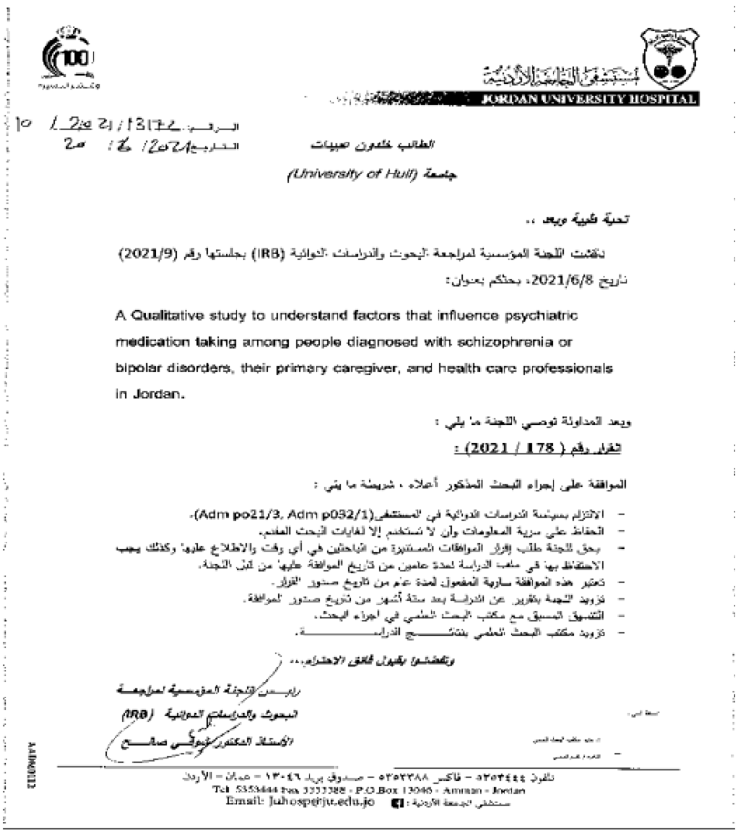
مع أمنياتنا لك بالتوفيق والنجاح

رئيسة جمعية خطوتنا

أميرة علي الجمل

الرصيفة – حديقة فرح / هاتف ٠٧٩٧٩٤٢٢٠٤١
Email : ourstep_ 2010@hotmail.com

Figure 7: Figure 6: Appendix D- 3. Our Step Association Approval Letter



مستشفى الجامعة الأردنية
JORDAN UNIVERSITY HOSPITAL

الرقم: 10 /2021/13172
التاريخ: 20 /6 /2021

الطالب خلدون صبيات
جامعة (University of Hull)

تحية طيبة وبعد ..

ناقشت اللجنة المؤسسية لمراجعة البحوث والدراسات الدوائية (IRB) بجلستها رقم (2021/9) تاريخ 2021/6/8، بحثكم بعنوان:

A Qualitative study to understand factors that influence psychiatric medication taking among people diagnosed with schizophrenia or bipolar disorders, their primary caregiver, and health care professionals in Jordan.

وبعد المداولة توصي اللجنة ما يلي :

القرار رقم (178 / 2021) :

الموافقة على إجراء البحث المذكور أعلاه ، شريطة ما يلي :

- الالتزام بسياسة الدراسات الدوائية في المستشفى(Adm po21/3, Adm p032/1).
- الحفاظ على سرية المعلومات وأن لا تستخدم إلا لغايات البحث العلمي.
- يحق للجنة طلب إقرار الموافقات المستنيرة من الباحثين في أي وقت والاطلاع عليها وكذلك يجب الاحتفاظ بها في ملف الدراسة لمدة عامين من تاريخ الموافقة عليها من قبل اللجنة.
- تعتبر هذه الموافقة سارية المفعول لمدة عام من تاريخ صدور القرار.
- تزويد اللجنة بتقرير عن الدراسة بعد ستة أشهر من تاريخ صدور الموافقة.
- التنسيق المسبق مع مكتب البحث العلمي في اجراء البحث.
- تزويد مكتب البحث العلمي بنتائج الدراسة.

وتفضلوا بقبول فائق الاحترام...

رئيس اللجنة المؤسسية لمراجعة
البحوث والدراسات الدوائية (IRB)
الأستاذ الدكتور شوقي صالح

نسخة إلى :

تلفون ٥٣٥٣٤٤٤ – فاكس ٥٣٥٣٣٨٨ – صندوق بريد ١٣٠٤٦ – عمان – الأردن
Tel. 5353444 Fax 5353388 - P.O.Box 13046 - Amman - Jordan
Email: Juhosp@ju.edu.jo مستشفى الجامعة الأردنية

Figure 8: Appendix D- 4. Jordan University Hospital approval letter

وزارة الصحة

الرقم: تطوير/معلومات/ ٥٢٧٣
التاريخ:
الموافق: ٢٠٢١/٧/٥

مدير مستشفى المركز الوطني للصحة النفسية

تحية طيبة وبعد ...

أرفق طياً صورة عن كتاب مدير ادارة مستشفيات البشير / رئيس لجنة اخلاقيات البحث العلمي رقم م ب ١ / لجنة أخلاقيات/٢٠٥٩٢ تاريخ ٢٠٢١/٧/١ بخصوص الموافقة لطالب الدكتوراة خلدون محمد علي عبيدات من جامعة هال البريطانية إجراء بحث بعنوان:

(A Qualitative study to Understand Factors that Influence Psychiatric Medication Taking among People Diagnosed with Schizophrenia of Bipolar Disorders, Their Primary Caregiver, and Health Care Professionals in Jordan)

(دراسة نوعية لفهم الأسباب التي تؤثر على تناول الأدوية النفسية لدى الأشخاص الذين يعانون من الفصام واضطراب ثنائي القطب ، ومقدمي الرعاية الاساسية لهم ، والعاملين في القطاع الصحي من ممرضين وأطباء نفسيين في الأردن)

وذلك عن طريق اجراء مقابلات فردية عن طريق تطبيق زووم مع متلقي الخدمة المصابين بالفصام او اضطراب ثنائي القطب ، وكذلك مع مقدمي الرعاية الرئيسية له من العائلة ، وايضا مع الممرض او الطبيب النفسي العامل في العيادات النفسية في العيادات الخارجية لمستشفى المركز الوطني للصحة النفسية

أرجو التكرم بالإيعاز لمن يلزم لتسهيل مهمة إجراء الدراسة اعلاه ، على ان يتم موافاة لجنة اخلاقيات البحث العلمي بنتائج الدراسة العائدة للبحث اعلاه .

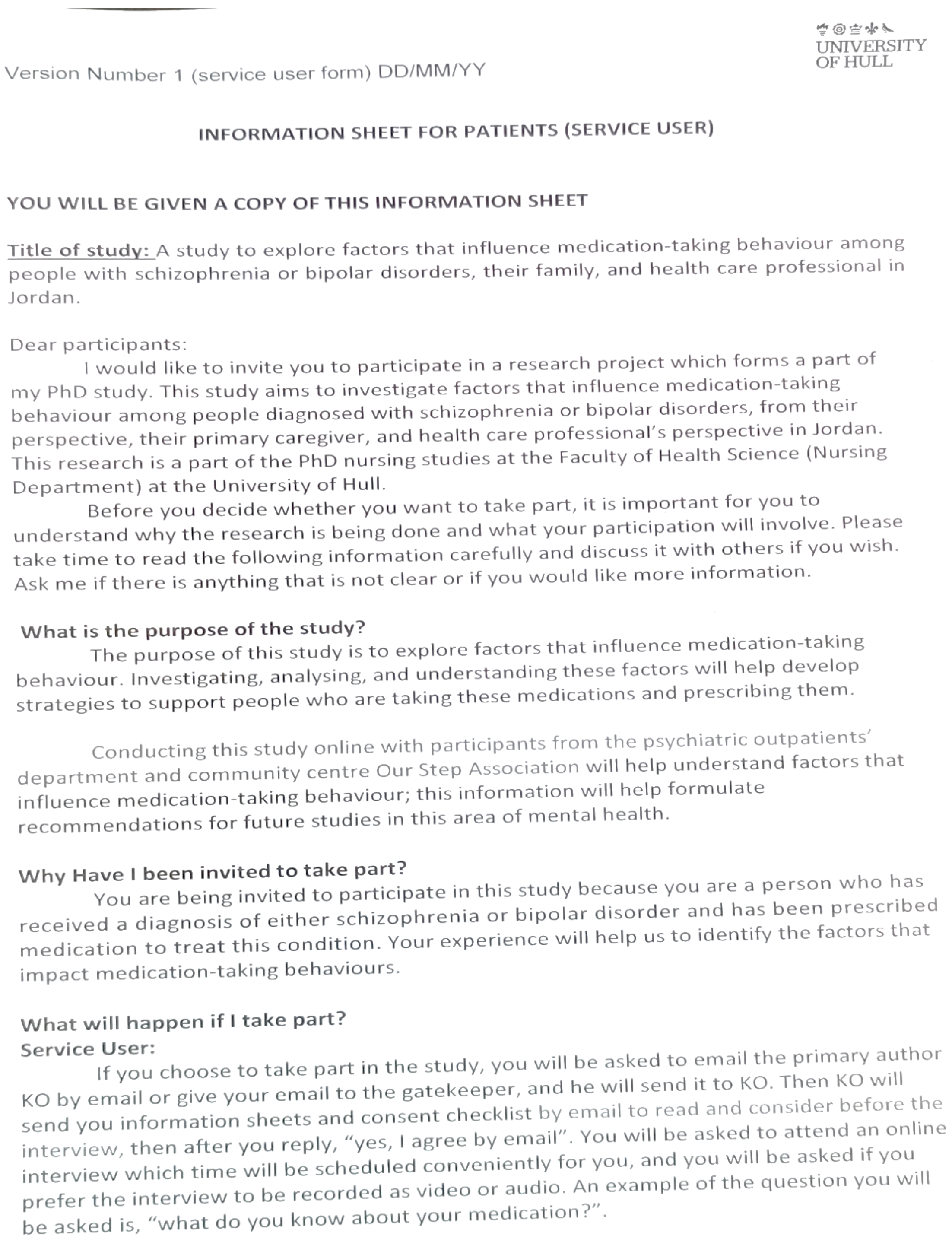
وتفضلوا بقبول فائق الاحترام ...

مدير مديرية التعليم وتطوير الموارد البشرية

الدكتورة رهام الحمود

Figure 9: Appendix D- 5. Ministry of Health (to National Centre for Mental Health) Approval letter

Appendix E: Research Documents



Version Number 1 (service user form) DD/MM/YY

UNIVERSITY
OF HULL

INFORMATION SHEET FOR PATIENTS (SERVICE USER)

YOU WILL BE GIVEN A COPY OF THIS INFORMATION SHEET

Title of study: A study to explore factors that influence medication-taking behaviour among people with schizophrenia or bipolar disorders, their family, and health care professional in Jordan.

Dear participants:

I would like to invite you to participate in a research project which forms a part of my PhD study. This study aims to investigate factors that influence medication-taking behaviour among people diagnosed with schizophrenia or bipolar disorders, from their perspective, their primary caregiver, and health care professional's perspective in Jordan. This research is a part of the PhD nursing studies at the Faculty of Health Science (Nursing Department) at the University of Hull.

Before you decide whether you want to take part, it is important for you to understand why the research is being done and what your participation will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask me if there is anything that is not clear or if you would like more information.

What is the purpose of the study?

The purpose of this study is to explore factors that influence medication-taking behaviour. Investigating, analysing, and understanding these factors will help develop strategies to support people who are taking these medications and prescribing them.

Conducting this study online with participants from the psychiatric outpatients' department and community centre Our Step Association will help understand factors that influence medication-taking behaviour; this information will help formulate recommendations for future studies in this area of mental health.

Why Have I been invited to take part?

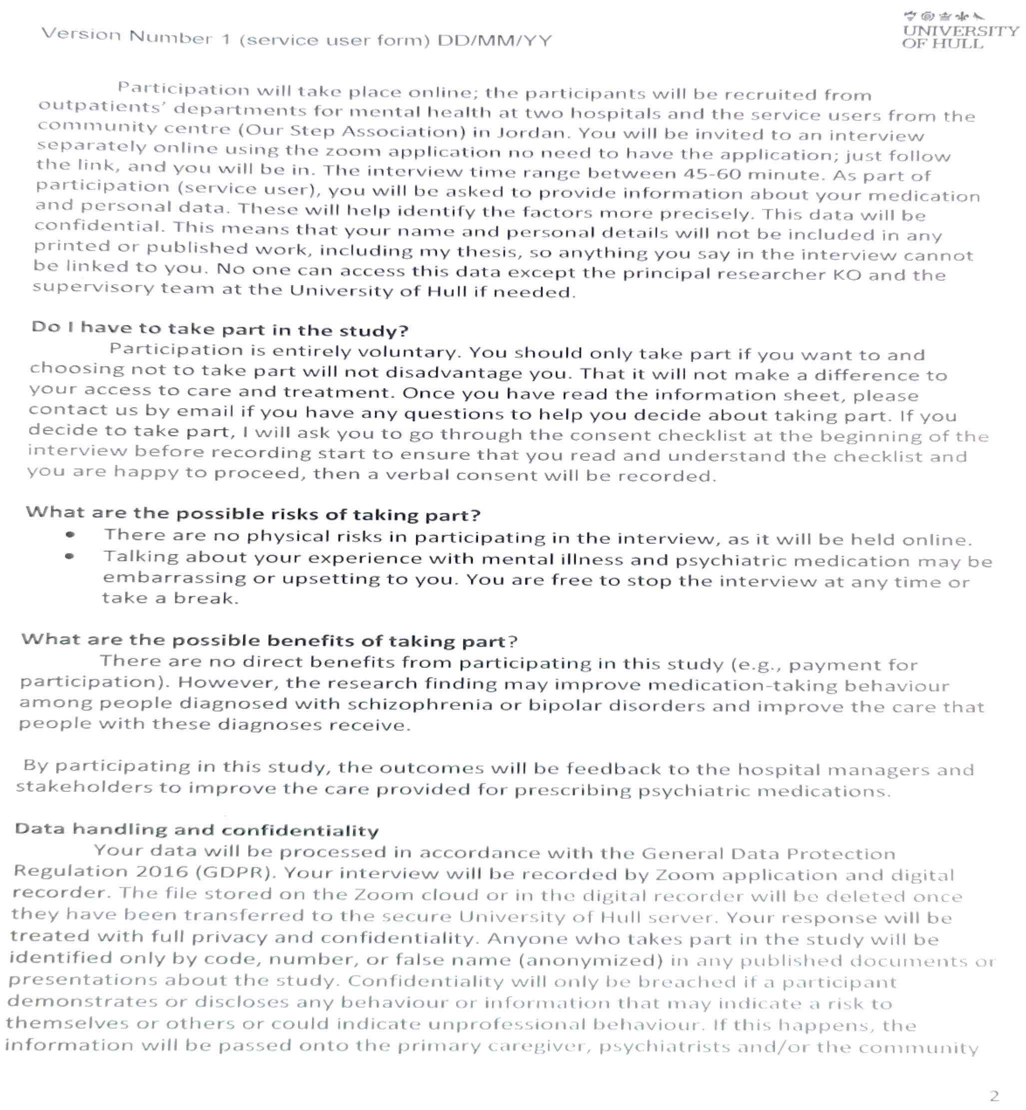
You are being invited to participate in this study because you are a person who has received a diagnosis of either schizophrenia or bipolar disorder and has been prescribed medication to treat this condition. Your experience will help us to identify the factors that impact medication-taking behaviours.

What will happen if I take part?

Service User:

If you choose to take part in the study, you will be asked to email the primary author KO by email or give your email to the gatekeeper, and he will send it to KO. Then KO will send you information sheets and consent checklist by email to read and consider before the interview, then after you reply, "yes, I agree by email". You will be asked to attend an online interview which time will be scheduled conveniently for you, and you will be asked if you prefer the interview to be recorded as video or audio. An example of the question you will be asked is, "what do you know about your medication?".

Figure 10: Appendix E- 1. Service User Information sheet



Participation will take place online; the participants will be recruited from outpatients' departments for mental health at two hospitals and the service users from the community centre (Our Step Association) in Jordan. You will be invited to an interview separately online using the zoom application no need to have the application; just follow the link, and you will be in. The interview time range between 45-60 minute. As part of participation (service user), you will be asked to provide information about your medication and personal data. These will help identify the factors more precisely. This data will be confidential. This means that your name and personal details will not be included in any printed or published work, including my thesis, so anything you say in the interview cannot be linked to you. No one can access this data except the principal researcher KO and the supervisory team at the University of Hull if needed.

Do I have to take part in the study?

Participation is entirely voluntary. You should only take part if you want to and choosing not to take part will not disadvantage you. That it will not make a difference to your access to care and treatment. Once you have read the information sheet, please contact us by email if you have any questions to help you decide about taking part. If you decide to take part, I will ask you to go through the consent checklist at the beginning of the interview before recording start to ensure that you read and understand the checklist and you are happy to proceed, then a verbal consent will be recorded.

What are the possible risks of taking part?

- There are no physical risks in participating in the interview, as it will be held online.
- Talking about your experience with mental illness and psychiatric medication may be embarrassing or upsetting to you. You are free to stop the interview at any time or take a break.

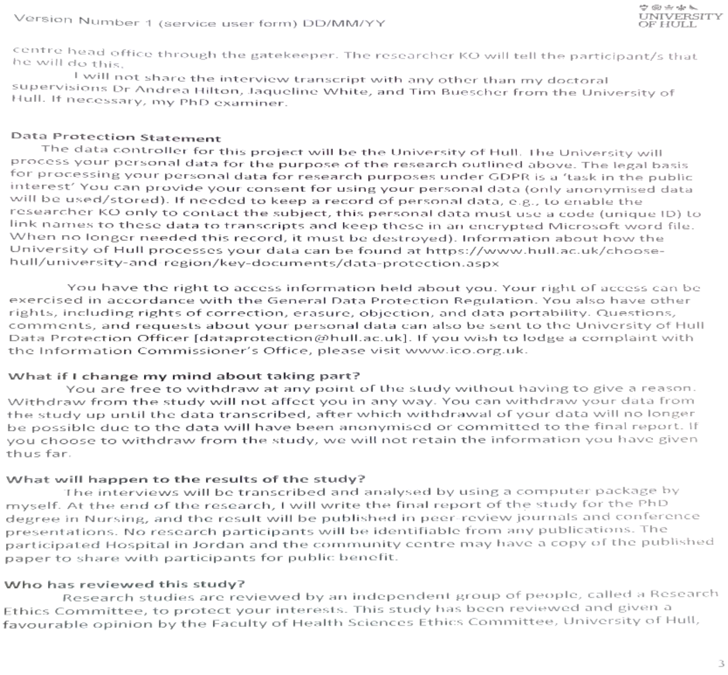
What are the possible benefits of taking part?

There are no direct benefits from participating in this study (e.g., payment for participation). However, the research finding may improve medication-taking behaviour among people diagnosed with schizophrenia or bipolar disorders and improve the care that people with these diagnoses receive.

By participating in this study, the outcomes will be feedback to the hospital managers and stakeholders to improve the care provided for prescribing psychiatric medications.

Data handling and confidentiality

Your data will be processed in accordance with the General Data Protection Regulation 2016 (GDPR). Your interview will be recorded by Zoom application and digital recorder. The file stored on the Zoom cloud or in the digital recorder will be deleted once they have been transferred to the secure University of Hull server. Your response will be treated with full privacy and confidentiality. Anyone who takes part in the study will be identified only by code, number, or false name (anonymized) in any published documents or presentations about the study. Confidentiality will only be breached if a participant demonstrates or discloses any behaviour or information that may indicate a risk to themselves or others or could indicate unprofessional behaviour. If this happens, the information will be passed onto the primary caregiver, psychiatrists and/or the community



centre head office through the gatekeeper. The researcher KO will tell the participant/s that he will do this.

I will not share the interview transcript with any other than my doctoral supervisions Dr Andrea Hilton, Jaqueline White, and Tim Buescher from the University of Hull. If necessary, my PhD examiner.

Data Protection Statement

The data controller for this project will be the University of Hull. The University will process your personal data for the purpose of the research outlined above. The legal basis for processing your personal data for research purposes under GDPR is a 'task in the public interest' You can provide your consent for using your personal data (only anonymised data will be used/stored). If needed to keep a record of personal data, e.g., to enable the researcher KO only to contact the subject, this personal data must use a code (unique ID) to link names to these data to transcripts and keep these in an encrypted Microsoft word file. When no longer needed this record, it must be destroyed). Information about how the University of Hull processes your data can be found at https://www.hull.ac.uk/choose-hull/university-and-region/key-documents/data-protection.aspx

You have the right to access information held about you. Your right of access can be exercised in accordance with the General Data Protection Regulation. You also have other rights, including rights of correction, erasure, objection, and data portability. Questions, comments, and requests about your personal data can also be sent to the University of Hull Data Protection Officer [dataprotection@hull.ac.uk]. If you wish to lodge a complaint with the Information Commissioner's Office, please visit www.ico.org.uk.

What if I change my mind about taking part?

You are free to withdraw at any point of the study without having to give a reason. Withdraw from the study will not affect you in any way. You can withdraw your data from the study up until the data transcribed, after which withdrawal of your data will no longer be possible due to the data will have been anonymised or committed to the final report. If you choose to withdraw from the study, we will not retain the information you have given thus far.

What will happen to the results of the study?

The interviews will be transcribed and analysed by using a computer package by myself. At the end of the research, I will write the final report of the study for the PhD degree in Nursing, and the result will be published in peer-review journals and conference presentations. No research participants will be identifiable from any publications. The participated Hospital in Jordan and the community centre may have a copy of the published paper to share with participants for public benefit.

Who has reviewed this study?

Research studies are reviewed by an independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given a favourable opinion by the Faculty of Health Sciences Ethics Committee, University of Hull, the ethics committee of the Jordan University Hospital, the ethics committee of the Ministry of Health, and the Community centre.

Who should I contact for further information?

If you have any questions or require more information about this study, please contact me using the following contact details:

Name: Khaldoon M. Obiedate
Email: K.M.Obiedate-2018@hull.ac.uk

What if I have further questions, or if something goes wrong?

If you wish to make a complaint about the conduct of the study, you can contact the University of Hull using the details below for further advice and information:

[A study to explore factors that influence medication-taking behaviour among people with schizophrenia or bipolar disorders, their family, and health care professional in Jordan]
By Khaldoon Obiedate.
University of Hull, United Kingdom
Upon Kingston Hull,
Cottingham Road, HU6 7RX
Supervisor Andrea Hilton Office: 0044-01482-463347
OR
By email: A.Hilton@hull.ac.uk

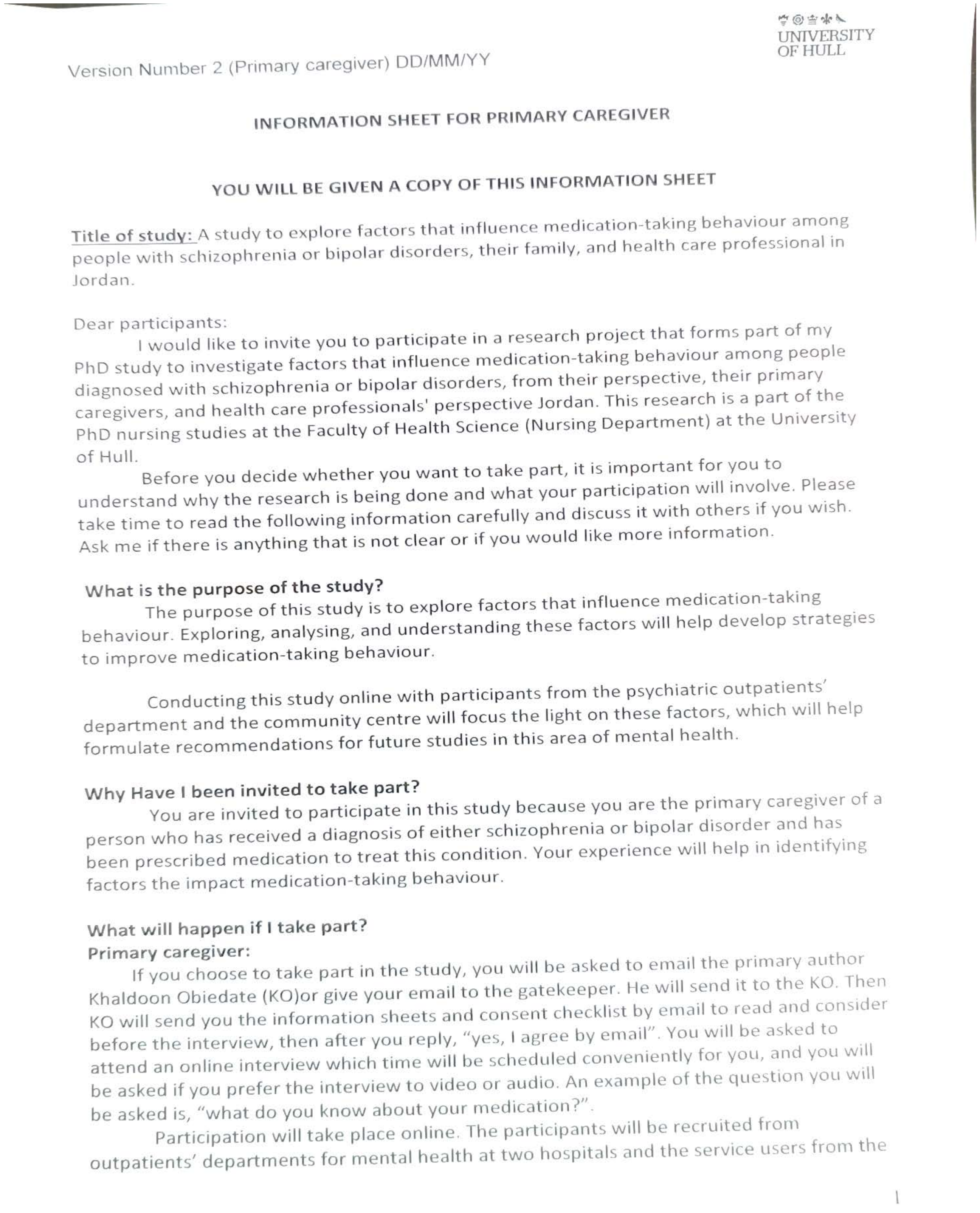
Thank you for reading this information sheet and for considering taking part in this research.

How to join Zoom:

(This information will be included in the email and the information sheet)

The link will be sent to you; what you need is to click on it, it will direct you to the meeting screen. If you are using a laptop to access the session, after clicking on the meeting link (provided to you via email), you will be prompted to download the Zoom plugin. If you have

headphones or earplugs, please use them as they will help eliminate background noise. Please follow the instructions on your screen to download the plugin, which is easily accessible, safe, and secure:
Then please click Open Zoom Meetings if you see the system dialogue. If nothing prompts from the browser, go to Zoom.US to download and run Zoom.
To be able to join a virtual session by mobile phone or tablet device, the free Zoom app must be downloaded from the applications store.
The meeting room will be open from 10 minutes before, so please sign in early, overcome any obstacles before the meeting start, and then feel free to switch off video and audio and carry on with your day until the session starts.



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OF HULL

Version Number 2 (Primary caregiver) DD/MM/YY

INFORMATION SHEET FOR PRIMARY CAREGIVER

YOU WILL BE GIVEN A COPY OF THIS INFORMATION SHEET

Title of study: A study to explore factors that influence medication-taking behaviour among people with schizophrenia or bipolar disorders, their family, and health care professional in Jordan.

Dear participants:

I would like to invite you to participate in a research project that forms part of my PhD study to investigate factors that influence medication-taking behaviour among people diagnosed with schizophrenia or bipolar disorders, from their perspective, their primary caregivers, and health care professionals' perspective Jordan. This research is a part of the PhD nursing studies at the Faculty of Health Science (Nursing Department) at the University of Hull.

Before you decide whether you want to take part, it is important for you to understand why the research is being done and what your participation will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask me if there is anything that is not clear or if you would like more information.

What is the purpose of the study?

The purpose of this study is to explore factors that influence medication-taking behaviour. Exploring, analysing, and understanding these factors will help develop strategies to improve medication-taking behaviour.

Conducting this study online with participants from the psychiatric outpatients' department and the community centre will focus the light on these factors, which will help formulate recommendations for future studies in this area of mental health.

Why Have I been invited to take part?

You are invited to participate in this study because you are the primary caregiver of a person who has received a diagnosis of either schizophrenia or bipolar disorder and has been prescribed medication to treat this condition. Your experience will help in identifying factors the impact medication-taking behaviour.

What will happen if I take part?

Primary caregiver:

If you choose to take part in the study, you will be asked to email the primary author Khaldoon Obiedate (KO)or give your email to the gatekeeper. He will send it to the KO. Then KO will send you the information sheets and consent checklist by email to read and consider before the interview, then after you reply, "yes, I agree by email". You will be asked to attend an online interview which time will be scheduled conveniently for you, and you will be asked if you prefer the interview to video or audio. An example of the question you will be asked is, "what do you know about your medication?".

Participation will take place online. The participants will be recruited from outpatients' departments for mental health at two hospitals and the service users from the

1

Figure 11: Appendix E- 2. Primary caregiver information sheet

community centre (Our Step Association) in Jordan. You will be invited to an interview separately online using the Zoom application no need to have the application; just follow the link, and you will be in. The interview time range between 45-60 minute. As part of participation (as a primary caregiver), you will be asked to provide information about (the person you care for) medications and your personal data. These will help identify the factors more precisely. This data will be confidential. Your name and personal details will not be included in any printed or published work, including my thesis, so anything you say in the interview cannot be linked to you. No one can access this data except the principal researcher KO and the supervisory team at the University of Hull if needed.

Do I have to take part in the study?

Participation is entirely voluntary. You should only take part if you want to and choosing not to take part will not disadvantage you in any way. Once you have read the information sheet, please contact us if you have any questions to help you decide about taking part. If you decide to take part, I will ask you to go through the consent checklist at the beginning of the interview before recording start to ensure that you read and understand the checklist and you are happy to proceed, then a verbal consent will be recorded.

What are the possible risks of taking part?

- There are no physical risks in participating in the interview, as it will be held online.
- Talking about your experience in relation to mental illness and psychiatric medication may be embarrassing or upsetting to you. You are free to stop the interview at any time or take a break.

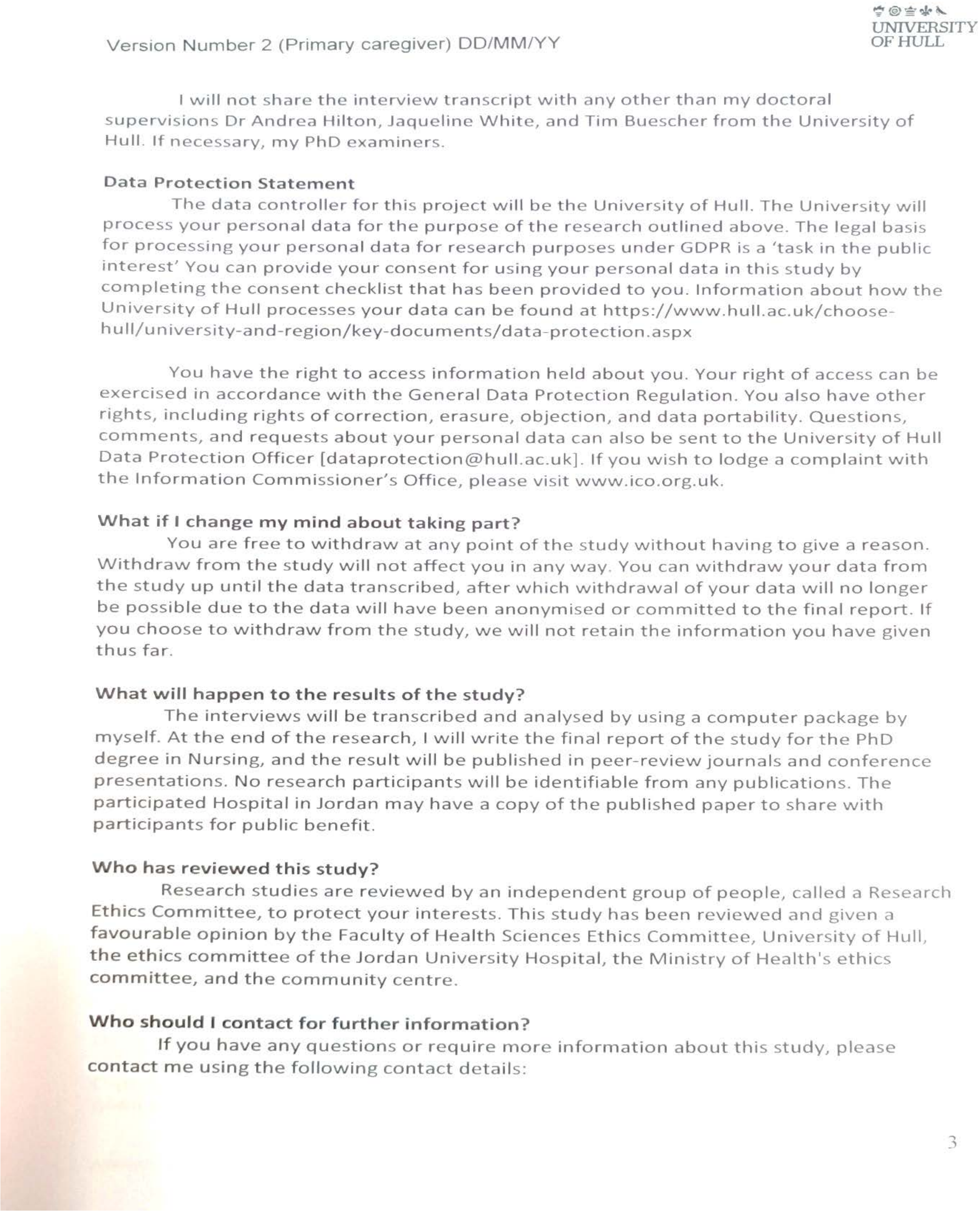
What are the possible benefits of taking part?

There are no direct benefits from participating in this study (e.g., payment for participation). However, the research finding may improve medication-taking behaviour among people diagnosed with schizophrenia or bipolar and improve health care professionals' practice.

By participating in this study, your voice will be heard by hospital managers and stakeholders to improve the care provided for prescribing psychiatric medications.

Data handling and confidentiality

Your data will be processed in accordance with the General Data Protection Regulation 2016 (GDPR). Your interview will be recorded by Zoom application and digital recorder. The file stored on the Zoom cloud or in the digital recorder will be deleted once they have been transferred to the secure University of Hull server. Your response will be treated with full privacy and confidentiality. Anyone who takes part in the study will be identified only by code number or false name (anonymised) in any published documents or presentations about the study. Confidentiality will only be breached if a participant demonstrates or discloses any behaviour or information that may indicate a risk to themselves or others. If this happens, the information will be passed onto the direct manager through the gatekeeper, and the researcher KO will tell the participant/s that he will do this.



I will not share the interview transcript with any other than my doctoral supervisions Dr Andrea Hilton, Jaqueline White, and Tim Buescher from the University of Hull. If necessary, my PhD examiners.

Data Protection Statement

The data controller for this project will be the University of Hull. The University will process your personal data for the purpose of the research outlined above. The legal basis for processing your personal data for research purposes under GDPR is a 'task in the public interest' You can provide your consent for using your personal data in this study by completing the consent checklist that has been provided to you. Information about how the University of Hull processes your data can be found at https://www.hull.ac.uk/choose-hull/university-and-region/key-documents/data-protection.aspx

You have the right to access information held about you. Your right of access can be exercised in accordance with the General Data Protection Regulation. You also have other rights, including rights of correction, erasure, objection, and data portability. Questions, comments, and requests about your personal data can also be sent to the University of Hull Data Protection Officer [dataprotection@hull.ac.uk]. If you wish to lodge a complaint with the Information Commissioner's Office, please visit www.ico.org.uk.

What if I change my mind about taking part?

You are free to withdraw at any point of the study without having to give a reason. Withdraw from the study will not affect you in any way. You can withdraw your data from the study up until the data transcribed, after which withdrawal of your data will no longer be possible due to the data will have been anonymised or committed to the final report. If you choose to withdraw from the study, we will not retain the information you have given thus far.

What will happen to the results of the study?

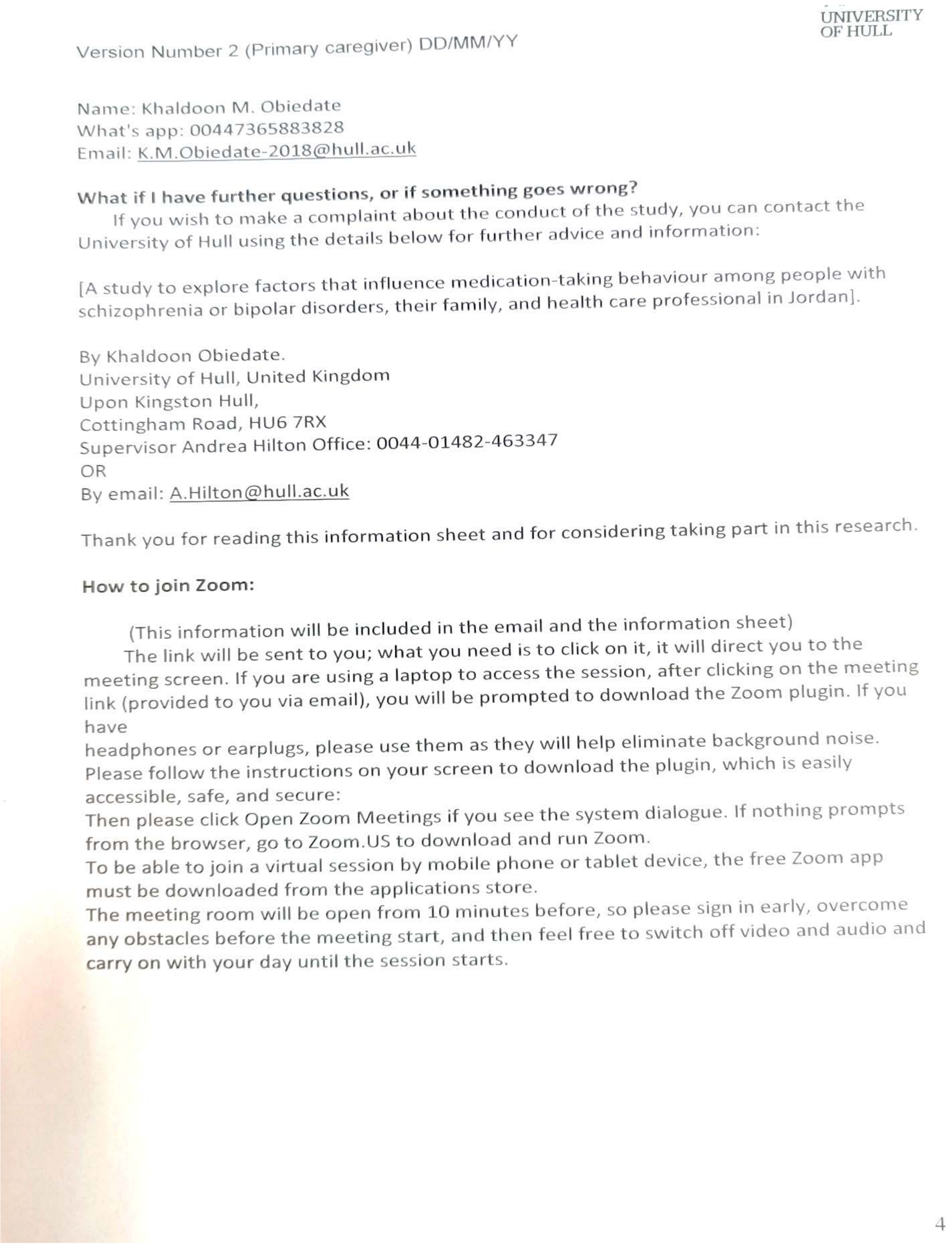
The interviews will be transcribed and analysed by using a computer package by myself. At the end of the research, I will write the final report of the study for the PhD degree in Nursing, and the result will be published in peer-review journals and conference presentations. No research participants will be identifiable from any publications. The participated Hospital in Jordan may have a copy of the published paper to share with participants for public benefit.

Who has reviewed this study?

Research studies are reviewed by an independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given a favourable opinion by the Faculty of Health Sciences Ethics Committee, University of Hull, the ethics committee of the Jordan University Hospital, the Ministry of Health's ethics committee, and the community centre.

Who should I contact for further information?

If you have any questions or require more information about this study, please contact me using the following contact details:



Version Number 2 (Primary caregiver) DD/MM/YY

Name: Khaldoon M. Obiedate
What's app: 00447365883828
Email: K.M.Obiedate-2018@hull.ac.uk

What if I have further questions, or if something goes wrong?

If you wish to make a complaint about the conduct of the study, you can contact the University of Hull using the details below for further advice and information:

[A study to explore factors that influence medication-taking behaviour among people with schizophrenia or bipolar disorders, their family, and health care professional in Jordan].

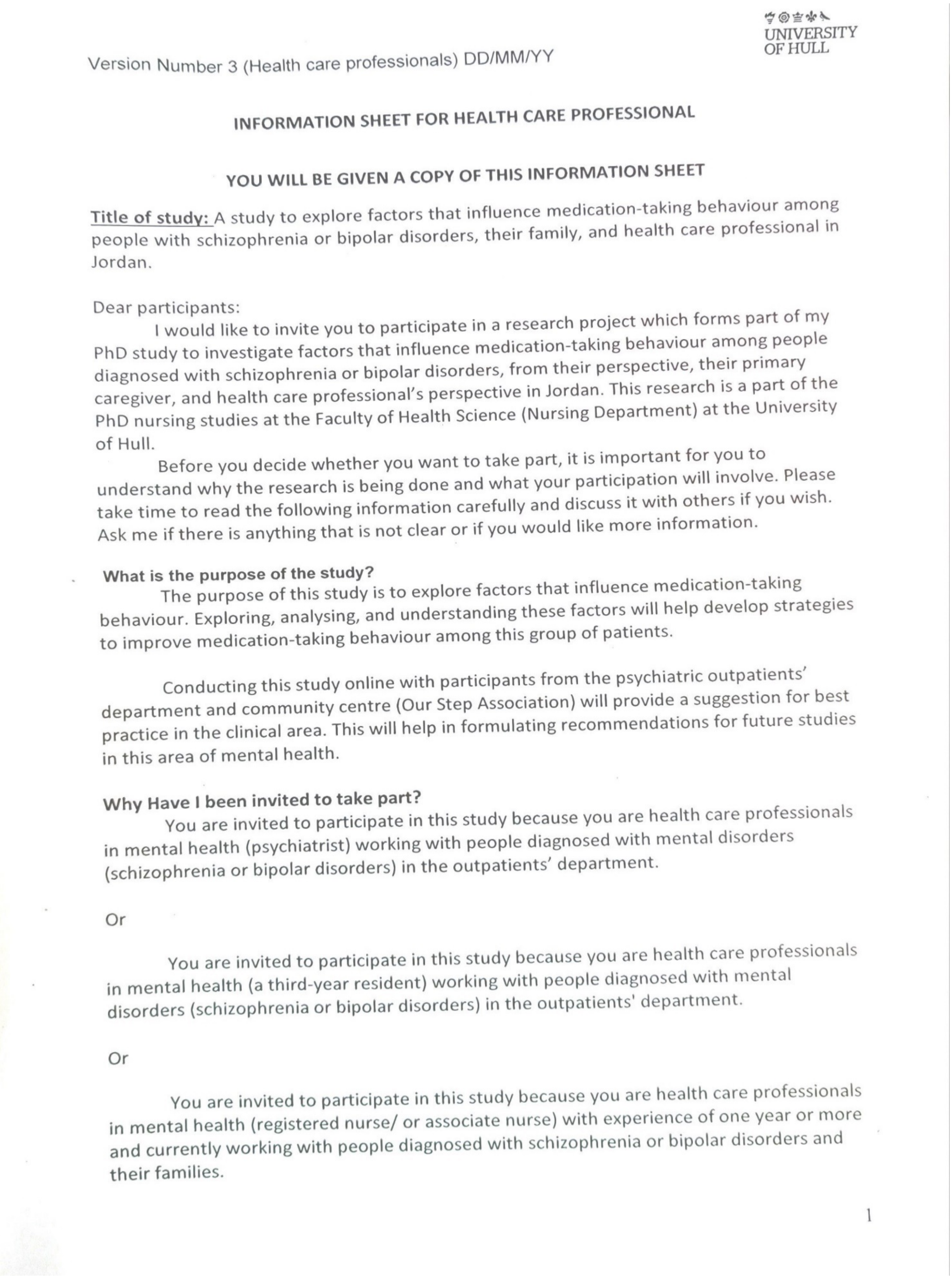
By Khaldoon Obiedate.
University of Hull, United Kingdom
Upon Kingston Hull,
Cottingham Road, HU6 7RX
Supervisor Andrea Hilton Office: 0044-01482-463347
OR
By email: A.Hilton@hull.ac.uk

Thank you for reading this information sheet and for considering taking part in this research.

How to join Zoom:

(This information will be included in the email and the information sheet)

The link will be sent to you; what you need is to click on it, it will direct you to the meeting screen. If you are using a laptop to access the session, after clicking on the meeting link (provided to you via email), you will be prompted to download the Zoom plugin. If you have
headphones or earplugs, please use them as they will help eliminate background noise.
Please follow the instructions on your screen to download the plugin, which is easily accessible, safe, and secure:
Then please click Open Zoom Meetings if you see the system dialogue. If nothing prompts from the browser, go to Zoom.US to download and run Zoom.
To be able to join a virtual session by mobile phone or tablet device, the free Zoom app must be downloaded from the applications store.
The meeting room will be open from 10 minutes before, so please sign in early, overcome any obstacles before the meeting start, and then feel free to switch off video and audio and carry on with your day until the session starts.



UNIVERSITY
OF HULL

Version Number 3 (Health care professionals) DD/MM/YY

INFORMATION SHEET FOR HEALTH CARE PROFESSIONAL

YOU WILL BE GIVEN A COPY OF THIS INFORMATION SHEET

Title of study: A study to explore factors that influence medication-taking behaviour among people with schizophrenia or bipolar disorders, their family, and health care professional in Jordan.

Dear participants:

I would like to invite you to participate in a research project which forms part of my PhD study to investigate factors that influence medication-taking behaviour among people diagnosed with schizophrenia or bipolar disorders, from their perspective, their primary caregiver, and health care professional's perspective in Jordan. This research is a part of the PhD nursing studies at the Faculty of Health Science (Nursing Department) at the University of Hull.

Before you decide whether you want to take part, it is important for you to understand why the research is being done and what your participation will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask me if there is anything that is not clear or if you would like more information.

What is the purpose of the study?

The purpose of this study is to explore factors that influence medication-taking behaviour. Exploring, analysing, and understanding these factors will help develop strategies to improve medication-taking behaviour among this group of patients.

Conducting this study online with participants from the psychiatric outpatients' department and community centre (Our Step Association) will provide a suggestion for best practice in the clinical area. This will help in formulating recommendations for future studies in this area of mental health.

Why Have I been invited to take part?

You are invited to participate in this study because you are health care professionals in mental health (psychiatrist) working with people diagnosed with mental disorders (schizophrenia or bipolar disorders) in the outpatients' department.

Or

You are invited to participate in this study because you are health care professionals in mental health (a third-year resident) working with people diagnosed with mental disorders (schizophrenia or bipolar disorders) in the outpatients' department.

Or

You are invited to participate in this study because you are health care professionals in mental health (registered nurse/ or associate nurse) with experience of one year or more and currently working with people diagnosed with schizophrenia or bipolar disorders and their families.

1

Figure 12: Appendix E- 3. healthcare professionals information sheet

What will happen if I take part?
Health care professionals:

If you choose to take part in the study, you will be asked to email the primary author Khaldoon Obiedate (KO), by email or give your email to the gatekeeper, and he will send it to the KO. Then the researcher will send the information sheets and consent checklist by email, then after you reply, "yes, I agree by email". You will be asked to attend an online interview which time will be scheduled conveniently for you. An example of the question you will be asked is, "what do you know about your patient's medication?".

Participation will take place online. You will be interviewed separately. The interview time range between 45-60 minute. As part of participation (as health care professionals), you will be asked to provide information about your role and personal data. These will help identify the factors more precisely. This data will be confidential. Your name and personal details will not be included in any printed or published work, including my thesis, so anything you say in the interview cannot be linked to you. No one can access this data except the principal researcher KO and the supervisory team at the University of Hull if needed.

Do I have to take part in the study?

Participation is entirely voluntary. You should only take part if you want to. Choosing not to take part will not disadvantage you in any way. Once you have read the information sheet, please contact KO if you have any questions to help you decide about taking part. If you decide to take part, I will ask you to go through the consent checklist at the beginning of the interview before recording start to ensure that you read and understand the checklist and you are happy to proceed, then a verbal consent will be recorded.

What are the possible risks of taking part?

- There are no physical risks in participating in the interview, as it will be held online.
- Talking about your experience in relation to mental illness and psychiatric medication may be embarrassing or upsetting to you. You are free to stop the interview at any time or take a break.

What are the possible benefits of taking part?

There are no direct benefits from participating in this study (e.g., payment for participation). However, the research finding may improve medication-taking behaviour among people diagnosed with schizophrenia or bipolar and improve health care professionals' practice.

Data handling and confidentiality

Your data will be processed in accordance with the General Data Protection Regulation 2016 (GDPR) at the University of Hull. Your interview will be recorded by Zoom application and digital recorder. The file stored on the Zoom cloud or in the digital recorder will be deleted once they have been transferred to the secure University of Hull server. Your response will be treated with full privacy and confidentiality. Anyone who takes part in the study will be identified only by code number or false name (anonymised) in any published documents or presentations about the study. Confidentiality will only be breached if a participant demonstrates or discloses any behaviour or information that may indicate a risk to themselves or others or could indicate unprofessional behaviour. If this happens, the information will be passed onto the direct manager through the gatekeeper, and the researcher KO will tell the participant/s that he will do this.

I will not share the interview transcription with any other than my doctoral supervisions Dr Andrea Hilton, Jaqueline White, and Tim Buescher from the University of Hull. If necessary, my PhD examiners.

Data Protection Statement

The data controller for this project will be the University of Hull. The University will process your personal data for the purpose of the research outlined above. The legal basis for processing your personal data for research purposes under GDPR is a 'task in the public interest' You can provide your consent for the use of your personal data in this study by completing the consent form that has been provided to you. Information about how the University of Hull processes your data can be found at https://www.hull.ac.uk/choose-hull/university-and-region/key-documents/data-protection.aspx

You have the right to access information held about you. Your right of access can be exercised in accordance with the General Data Protection Regulation. You also have other rights, including rights of correction, erasure, objection, and data portability. Questions, comments, and requests about your personal data can also be sent to the University of Hull Data Protection Officer [dataprotection@hull.ac.uk]. If you wish to lodge a complaint with the Information Commissioner's Office, please visit www.ico.org.uk.

What if I change my mind about taking part?

You are free to withdraw at any point of the study without having to give a reason. Withdraw from the study will not affect you in any way. You are able to withdraw your data from the study up until the data anonymised and transcribed, after which withdrawal of your data will no longer be possible due to the data will have been anonymised or committed to the final report. If you choose to withdraw from the study, we will not retain the information you have given thus far.

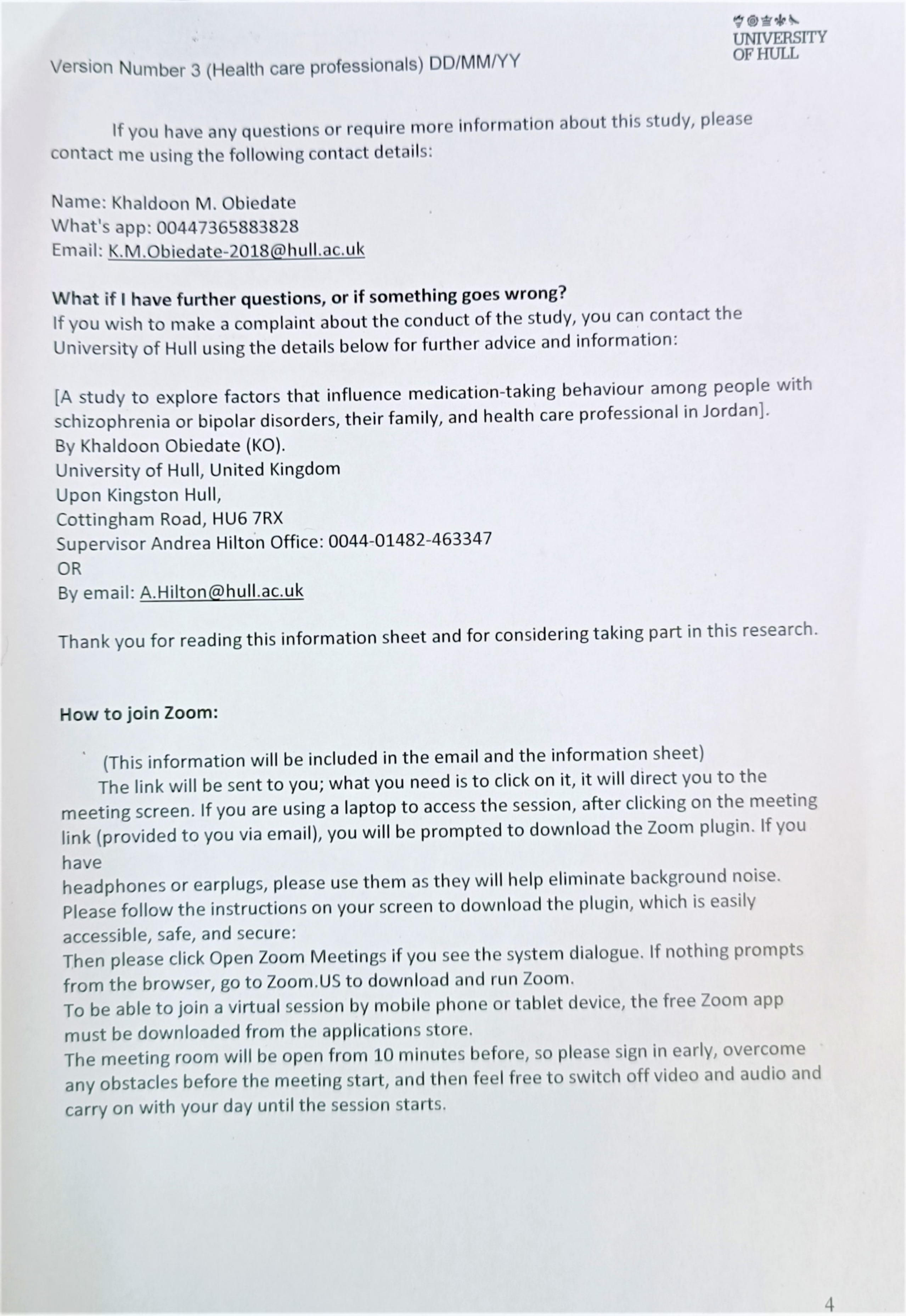
What will happen to the results of the study?

The interviews will be transcribed and analysed by using a computer package by myself. At the end of the research, I will write the final report of the study for the PhD degree in Nursing, and the result will be published in peer-review journals and conference presentations. No research participants will be identifiable from any publications. The participating Hospital in Jordan may have a copy of the published paper to share with participants for public benefit.

Who has reviewed this study?

Research studies are reviewed by an independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given a favourable opinion by the Faculty of Health Sciences Ethics Committee, University of Hull, the Jordan University Hospital's ethics committee, the Ministry of Health ethics committee, and the community centre.

Who should I contact for further information?



If you have any questions or require more information about this study, please contact me using the following contact details:

Name: Khaldoon M. Obiedate
What's app: 00447365883828
Email: K.M.Obiedate-2018@hull.ac.uk

What if I have further questions, or if something goes wrong?

If you wish to make a complaint about the conduct of the study, you can contact the University of Hull using the details below for further advice and information:

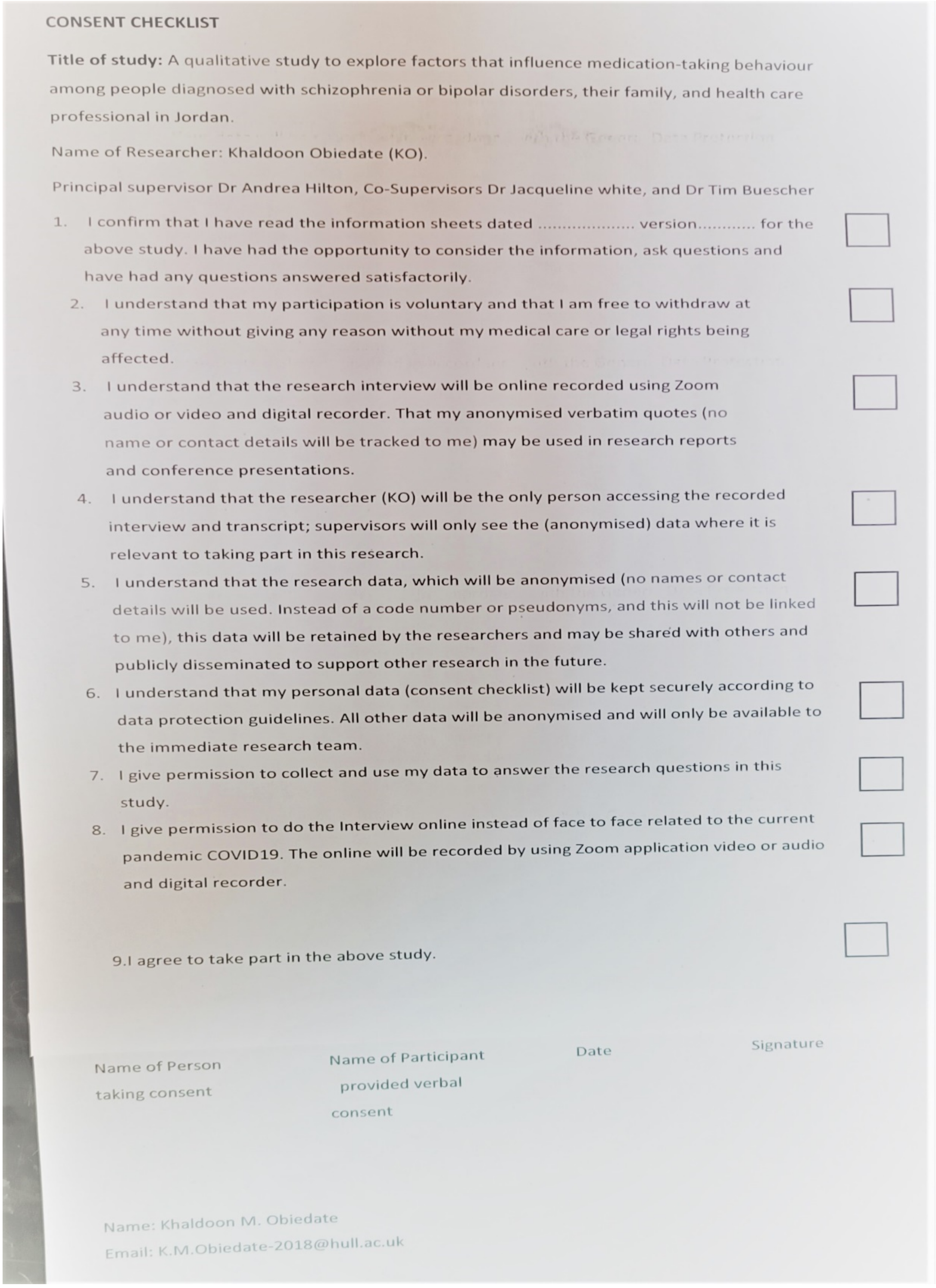
[A study to explore factors that influence medication-taking behaviour among people with schizophrenia or bipolar disorders, their family, and health care professional in Jordan].
By Khaldoon Obiedate (KO).
University of Hull, United Kingdom
Upon Kingston Hull,
Cottingham Road, HU6 7RX
Supervisor Andrea Hilton Office: 0044-01482-463347
OR
By email: A.Hilton@hull.ac.uk

Thank you for reading this information sheet and for considering taking part in this research.

How to join Zoom:

(This information will be included in the email and the information sheet)

The link will be sent to you; what you need is to click on it, it will direct you to the meeting screen. If you are using a laptop to access the session, after clicking on the meeting link (provided to you via email), you will be prompted to download the Zoom plugin. If you have
headphones or earplugs, please use them as they will help eliminate background noise.
Please follow the instructions on your screen to download the plugin, which is easily accessible, safe, and secure:
Then please click Open Zoom Meetings if you see the system dialogue. If nothing prompts from the browser, go to Zoom.US to download and run Zoom.
To be able to join a virtual session by mobile phone or tablet device, the free Zoom app must be downloaded from the applications store.
The meeting room will be open from 10 minutes before, so please sign in early, overcome any obstacles before the meeting start, and then feel free to switch off video and audio and carry on with your day until the session starts.



CONSENT CHECKLIST

Title of study: A qualitative study to explore factors that influence medication-taking behaviour among people diagnosed with schizophrenia or bipolar disorders, their family, and health care professional in Jordan.

Name of Researcher: Khaldoon Obiedate (KO).

Principal supervisor Dr Andrea Hilton, Co-Supervisors Dr Jacqueline white, and Dr Tim Buescher

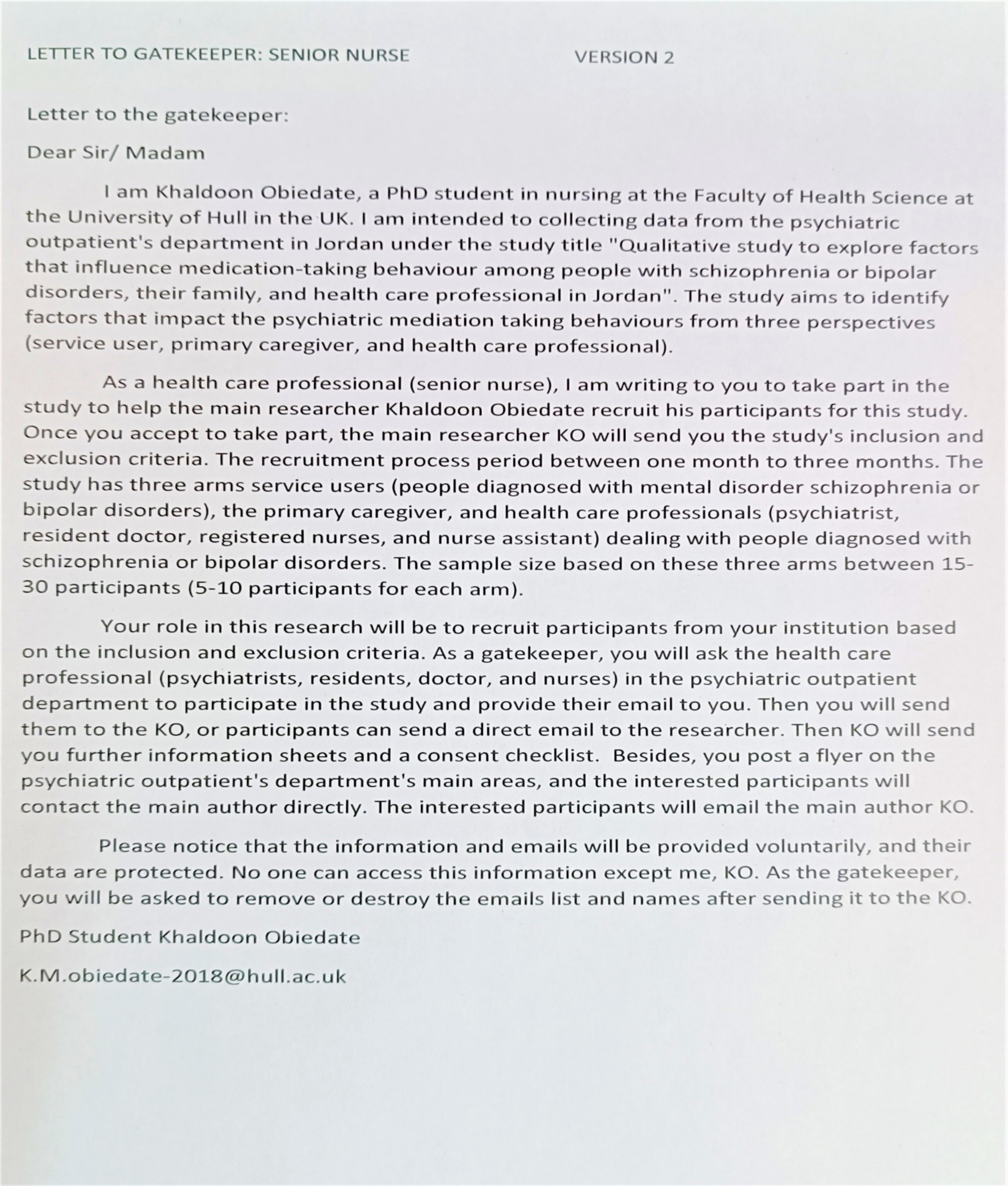
1. I confirm that I have read the information sheets dated .... version............ for the above study. I have had the opportunity to consider the information, ask questions and have had any questions answered satisfactorily. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason without my medical care or legal rights being affected. ☐
3. I understand that the research interview will be online recorded using Zoom audio or video and digital recorder. That my anonymised verbatim quotes (no name or contact details will be tracked to me) may be used in research reports and conference presentations. ☐
4. I understand that the researcher (KO) will be the only person accessing the recorded interview and transcript; supervisors will only see the (anonymised) data where it is relevant to taking part in this research. ☐
5. I understand that the research data, which will be anonymised (no names or contact details will be used. Instead of a code number or pseudonyms, and this will not be linked to me), this data will be retained by the researchers and may be shared with others and publicly disseminated to support other research in the future. ☐
6. I understand that my personal data (consent checklist) will be kept securely according to data protection guidelines. All other data will be anonymised and will only be available to the immediate research team. ☐
7. I give permission to collect and use my data to answer the research questions in this study. ☐
8. I give permission to do the Interview online instead of face to face related to the current pandemic COVID19. The online will be recorded by using Zoom application video or audio and digital recorder. ☐

9.I agree to take part in the above study. ☐

Name of Person taking consent	Name of Participant provided verbal consent	Date	Signature

Name: Khaldoon M. Obiedate
Email: K.M.Obiedate-2018@hull.ac.uk

Figure 13: Appendix E- 4. Consent Checklist



LETTER TO GATEKEEPER: SENIOR NURSE VERSION 2

Letter to the gatekeeper:

Dear Sir/ Madam

I am Khaldoon Obiedate, a PhD student in nursing at the Faculty of Health Science at the University of Hull in the UK. I am intended to collecting data from the psychiatric outpatient's department in Jordan under the study title "Qualitative study to explore factors that influence medication-taking behaviour among people with schizophrenia or bipolar disorders, their family, and health care professional in Jordan". The study aims to identify factors that impact the psychiatric mediation taking behaviours from three perspectives (service user, primary caregiver, and health care professional).

As a health care professional (senior nurse), I am writing to you to take part in the study to help the main researcher Khaldoon Obiedate recruit his participants for this study. Once you accept to take part, the main researcher KO will send you the study's inclusion and exclusion criteria. The recruitment process period between one month to three months. The study has three arms service users (people diagnosed with mental disorder schizophrenia or bipolar disorders), the primary caregiver, and health care professionals (psychiatrist, resident doctor, registered nurses, and nurse assistant) dealing with people diagnosed with schizophrenia or bipolar disorders. The sample size based on these three arms between 15-30 participants (5-10 participants for each arm).

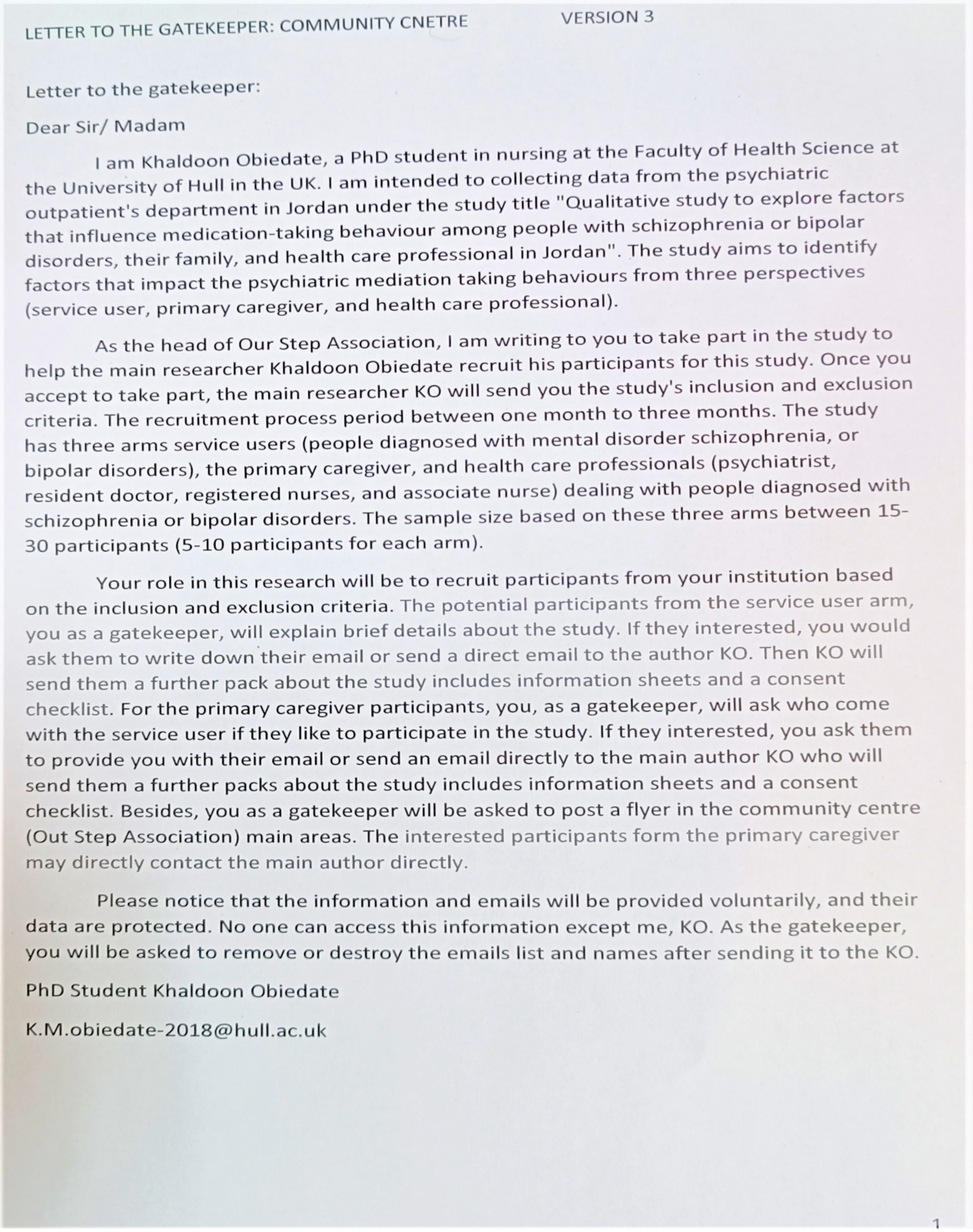
Your role in this research will be to recruit participants from your institution based on the inclusion and exclusion criteria. As a gatekeeper, you will ask the health care professional (psychiatrists, residents, doctor, and nurses) in the psychiatric outpatient department to participate in the study and provide their email to you. Then you will send them to the KO, or participants can send a direct email to the researcher. Then KO will send you further information sheets and a consent checklist. Besides, you post a flyer on the psychiatric outpatient's department's main areas, and the interested participants will contact the main author directly. The interested participants will email the main author KO.

Please notice that the information and emails will be provided voluntarily, and their data are protected. No one can access this information except me, KO. As the gatekeeper, you will be asked to remove or destroy the emails list and names after sending it to the KO.

PhD Student Khaldoon Obiedate

K.M.obiedate-2018@hull.ac.uk

Figure 14: Appendix E- 5. Letter to the gatekeeper-Senior Nurse



LETTER TO THE GATEKEEPER: COMMUNITY CNETRE VERSION 3

Letter to the gatekeeper:

Dear Sir/ Madam

I am Khaldoon Obiedate, a PhD student in nursing at the Faculty of Health Science at the University of Hull in the UK. I am intended to collecting data from the psychiatric outpatient's department in Jordan under the study title "Qualitative study to explore factors that influence medication-taking behaviour among people with schizophrenia or bipolar disorders, their family, and health care professional in Jordan". The study aims to identify factors that impact the psychiatric mediation taking behaviours from three perspectives (service user, primary caregiver, and health care professional).

As the head of Our Step Association, I am writing to you to take part in the study to help the main researcher Khaldoon Obiedate recruit his participants for this study. Once you accept to take part, the main researcher KO will send you the study's inclusion and exclusion criteria. The recruitment process period between one month to three months. The study has three arms service users (people diagnosed with mental disorder schizophrenia, or bipolar disorders), the primary caregiver, and health care professionals (psychiatrist, resident doctor, registered nurses, and associate nurse) dealing with people diagnosed with schizophrenia or bipolar disorders. The sample size based on these three arms between 15-30 participants (5-10 participants for each arm).

Your role in this research will be to recruit participants from your institution based on the inclusion and exclusion criteria. The potential participants from the service user arm, you as a gatekeeper, will explain brief details about the study. If they interested, you would ask them to write down their email or send a direct email to the author KO. Then KO will send them a further pack about the study includes information sheets and a consent checklist. For the primary caregiver participants, you, as a gatekeeper, will ask who come with the service user if they like to participate in the study. If they interested, you ask them to provide you with their email or send an email directly to the main author KO who will send them a further packs about the study includes information sheets and a consent checklist. Besides, you as a gatekeeper will be asked to post a flyer in the community centre (Out Step Association) main areas. The interested participants form the primary caregiver may directly contact the main author directly.

Please notice that the information and emails will be provided voluntarily, and their data are protected. No one can access this information except me, KO. As the gatekeeper, you will be asked to remove or destroy the emails list and names after sending it to the KO.

PhD Student Khaldoon Obiedate

K.M.obiedate-2018@hull.ac.uk

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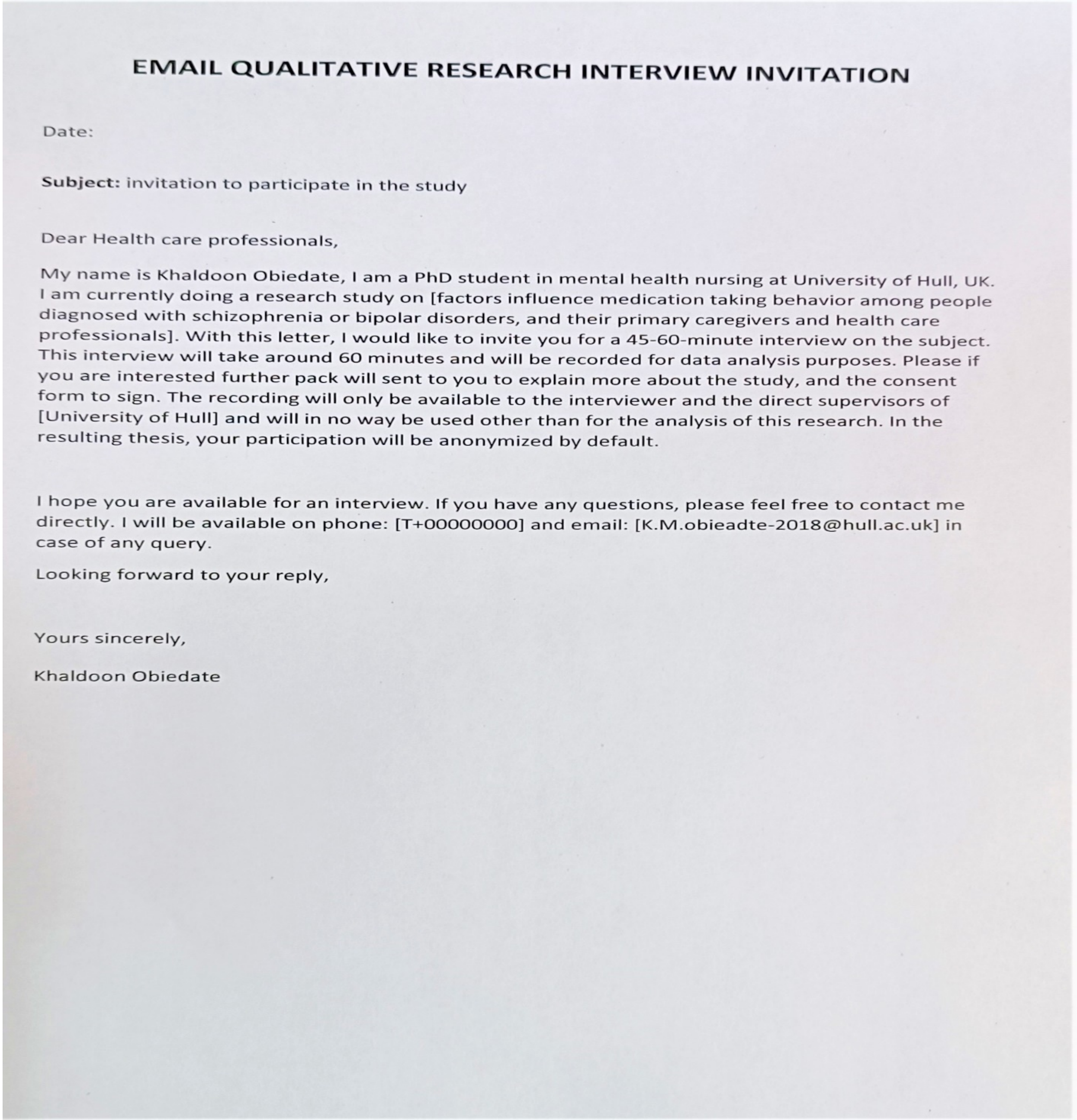
Figure 15: Appendix E- 6. Letter to the gatekeeper-community centre



EMAIL QUALITATIVE RESEARCH INTERVIEW INVITATION

Date:

Subject: invitation to participate in the study

Dear Health care professionals,

My name is Khaldoon Obiedate, I am a PhD student in mental health nursing at University of Hull, UK. I am currently doing a research study on [factors influence medication taking behavior among people diagnosed with schizophrenia or bipolar disorders, and their primary caregivers and health care professionals]. With this letter, I would like to invite you for a 45-60-minute interview on the subject. This interview will take around 60 minutes and will be recorded for data analysis purposes. Please if you are interested further pack will sent to you to explain more about the study, and the consent form to sign. The recording will only be available to the interviewer and the direct supervisors of [University of Hull] and will in no way be used other than for the analysis of this research. In the resulting thesis, your participation will be anonymized by default.

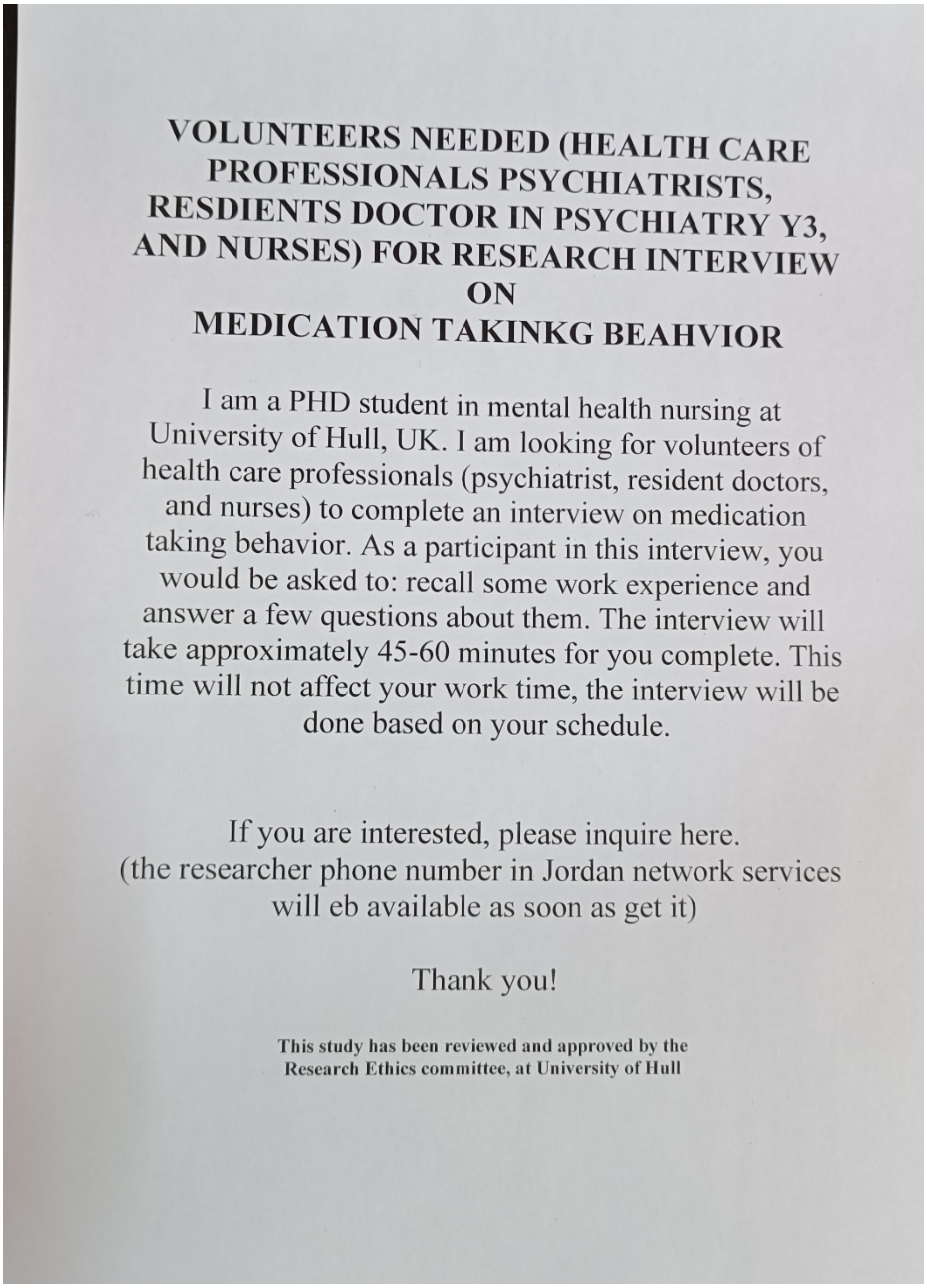
I hope you are available for an interview. If you have any questions, please feel free to contact me directly. I will be available on phone: [T+00000000] and email: [K.M.obieadte-2018@hull.ac.uk] in case of any query.

Looking forward to your reply,

Yours sincerely,

Khaldoon Obiedate

Figure 16: Appendix E- 7. Email Invitation to HCP



VOLUNTEERS NEEDED (HEALTH CARE PROFESSIONALS PSYCHIATRISTS, RESDIENTS DOCTOR IN PSYCHIATRY Y3, AND NURSES) FOR RESEARCH INTERVIEW ON MEDICATION TAKINKG BEAHVIOR

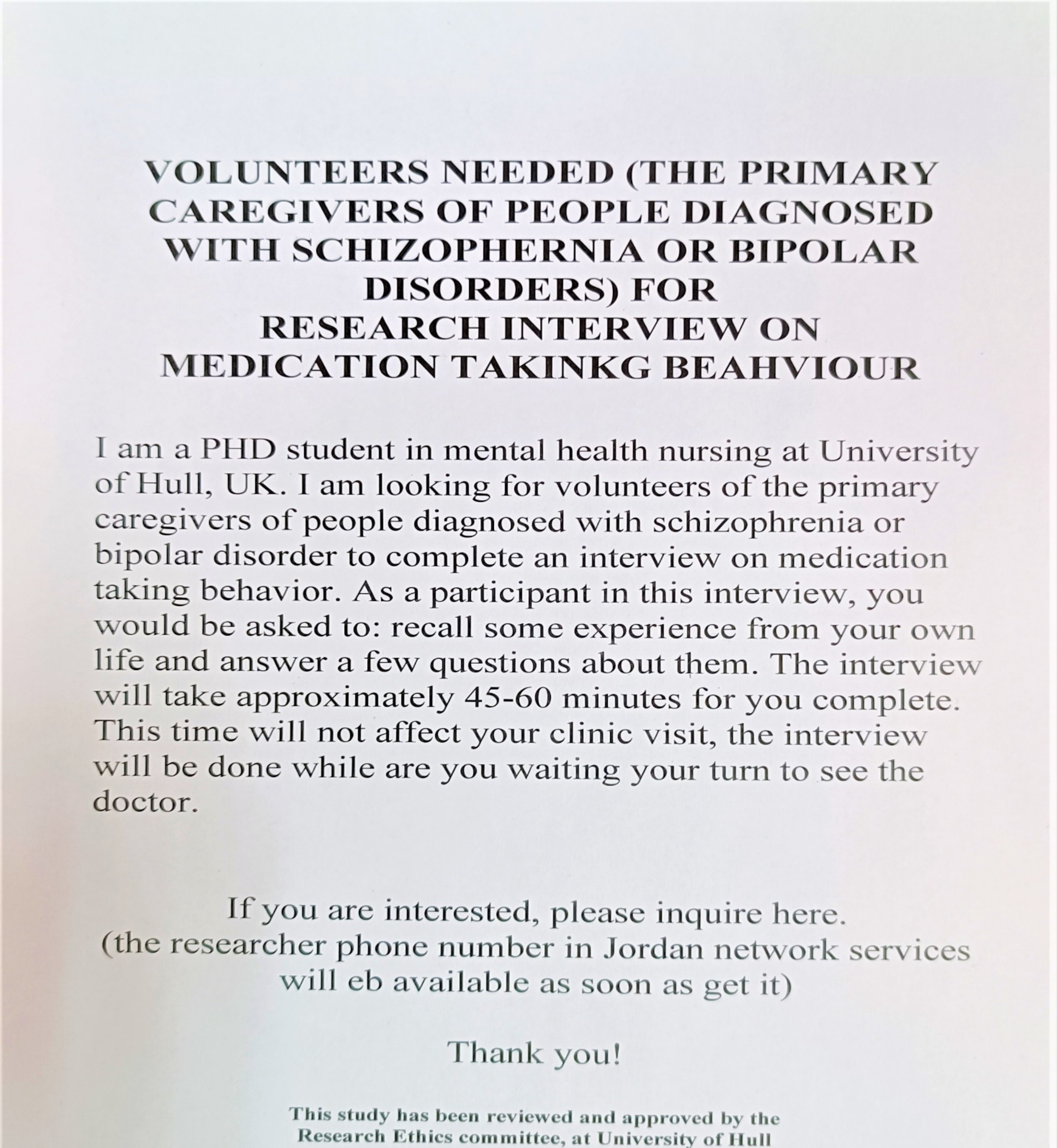
I am a PHD student in mental health nursing at University of Hull, UK. I am looking for volunteers of health care professionals (psychiatrist, resident doctors, and nurses) to complete an interview on medication taking behavior. As a participant in this interview, you would be asked to: recall some work experience and answer a few questions about them. The interview will take approximately 45-60 minutes for you complete. This time will not affect your work time, the interview will be done based on your schedule.

If you are interested, please inquire here.
(the researcher phone number in Jordan network services will eb available as soon as get it)

Thank you!

This study has been reviewed and approved by the Research Ethics committee, at University of Hull

Figure 17: Appendix E- 8. Flyer to HCP



VOLUNTEERS NEEDED (THE PRIMARY CAREGIVERS OF PEOPLE DIAGNOSED WITH SCHIZOPHERNIA OR BIPOLAR DISORDERS) FOR
RESEARCH INTERVIEW ON MEDICATION TAKINKG BEAHVIOUR

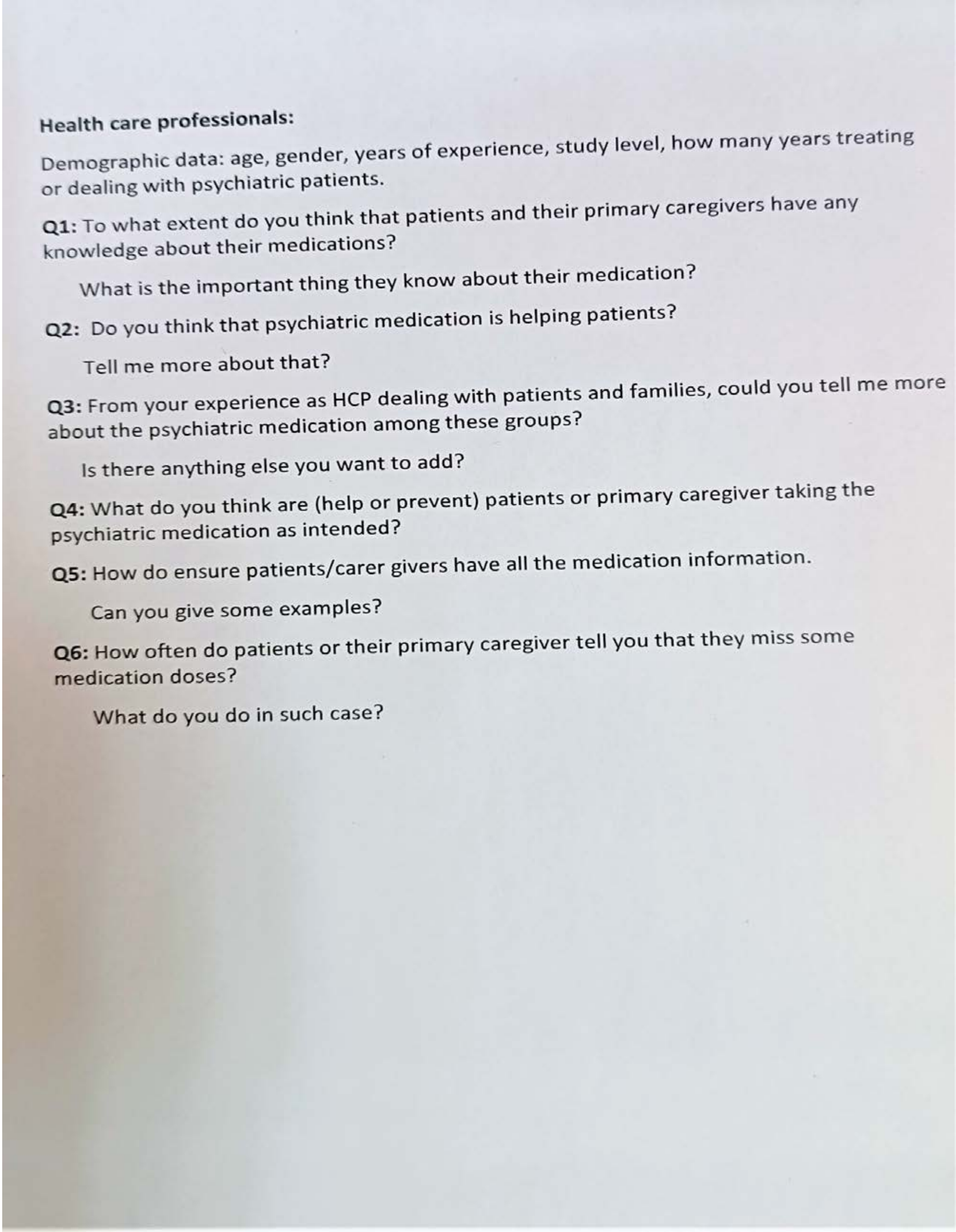
I am a PHD student in mental health nursing at University of Hull, UK. I am looking for volunteers of the primary caregivers of people diagnosed with schizophrenia or bipolar disorder to complete an interview on medication taking behavior. As a participant in this interview, you would be asked to: recall some experience from your own life and answer a few questions about them. The interview will take approximately 45-60 minutes for you complete. This time will not affect your clinic visit, the interview will be done while are you waiting your turn to see the doctor.

If you are interested, please inquire here.
(the researcher phone number in Jordan network services will eb available as soon as get it)

Thank you!

This study has been reviewed and approved by the Research Ethics committee, at University of Hull

Figure 18: Appendix E- 9. Flyer to Service user and primary caregiver



Health care professionals:

Demographic data: age, gender, years of experience, study level, how many years treating or dealing with psychiatric patients.

Q1: To what extent do you think that patients and their primary caregivers have any knowledge about their medications?

What is the important thing they know about their medication?

Q2: Do you think that psychiatric medication is helping patients?

Tell me more about that?

Q3: From your experience as HCP dealing with patients and families, could you tell me more about the psychiatric medication among these groups?

Is there anything else you want to add?

Q4: What do you think are (help or prevent) patients or primary caregiver taking the psychiatric medication as intended?

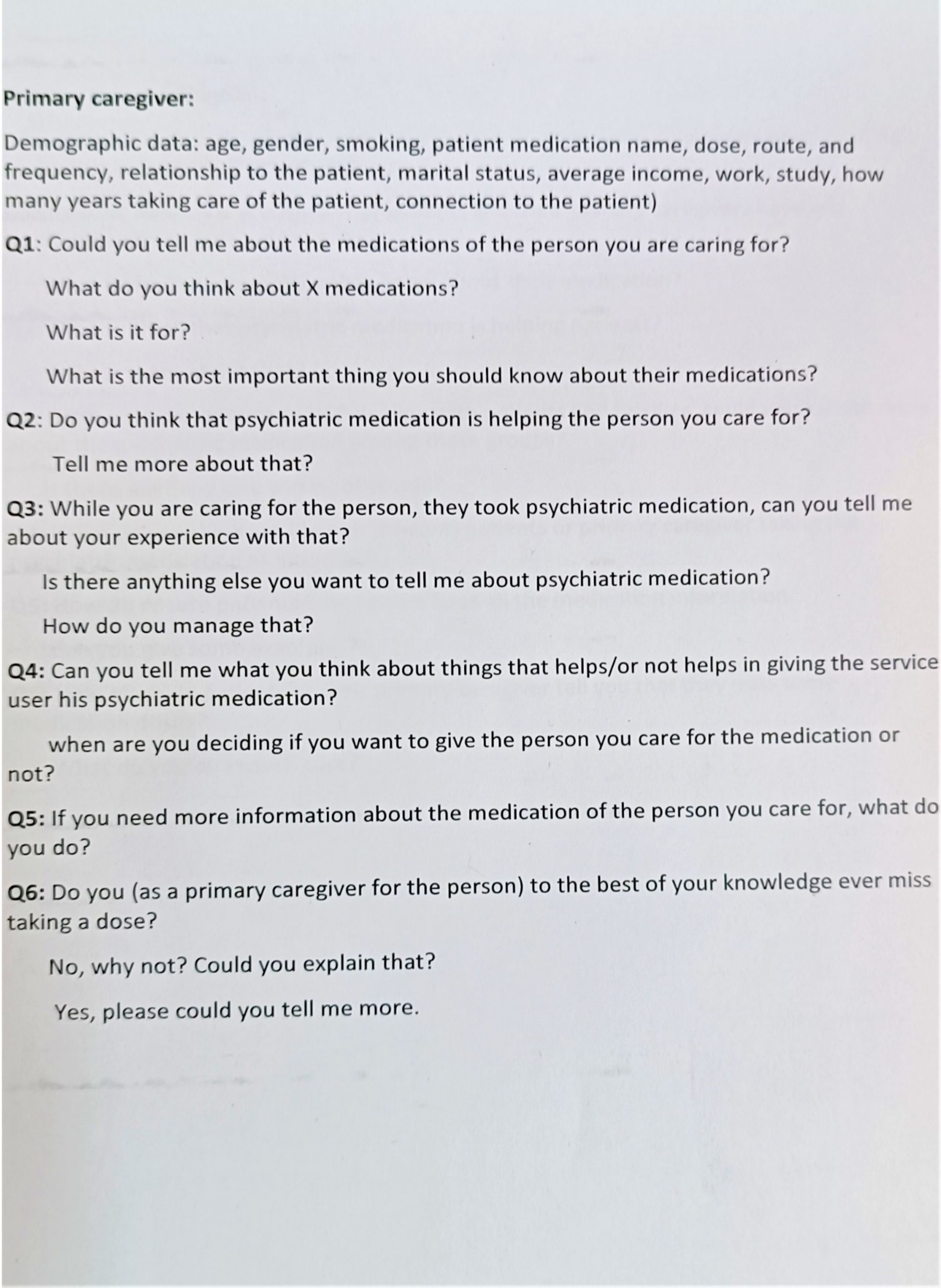
Q5: How do ensure patients/carer givers have all the medication information.

Can you give some examples?

Q6: How often do patients or their primary caregiver tell you that they miss some medication doses?

What do you do in such case?

Figure 19: Appendix E- 10. healthcare professionals' interview guide



Primary caregiver:

Demographic data: age, gender, smoking, patient medication name, dose, route, and frequency, relationship to the patient, marital status, average income, work, study, how many years taking care of the patient, connection to the patient)

Q1: Could you tell me about the medications of the person you are caring for?

What do you think about X medications?

What is it for?

What is the most important thing you should know about their medications?

Q2: Do you think that psychiatric medication is helping the person you care for?

Tell me more about that?

Q3: While you are caring for the person, they took psychiatric medication, can you tell me about your experience with that?

Is there anything else you want to tell me about psychiatric medication?

How do you manage that?

Q4: Can you tell me what you think about things that helps/or not helps in giving the service user his psychiatric medication?

when are you deciding if you want to give the person you care for the medication or not?

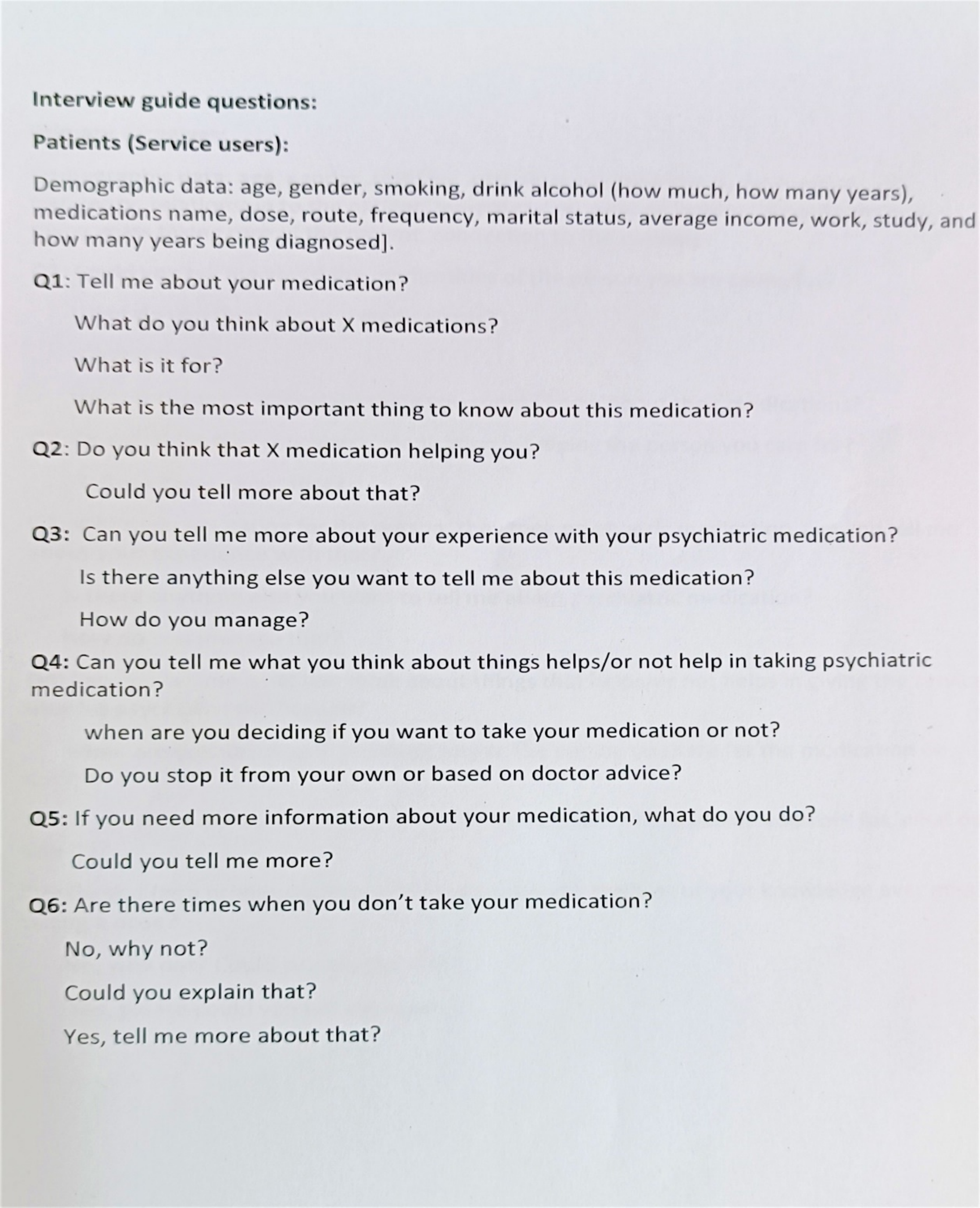
Q5: If you need more information about the medication of the person you care for, what do you do?

Q6: Do you (as a primary caregiver for the person) to the best of your knowledge ever miss taking a dose?

No, why not? Could you explain that?

Yes, please could you tell me more.

Figure 20: Appendix E- 1. Primary caregiver interview guide



Interview guide questions:

Patients (Service users):

Demographic data: age, gender, smoking, drink alcohol (how much, how many years), medications name, dose, route, frequency, marital status, average income, work, study, and how many years being diagnosed].

Q1: Tell me about your medication?

What do you think about X medications?

What is it for?

What is the most important thing to know about this medication?

Q2: Do you think that X medication helping you?

Could you tell more about that?

Q3: Can you tell me more about your experience with your psychiatric medication?

Is there anything else you want to tell me about this medication?

How do you manage?

Q4: Can you tell me what you think about things helps/or not help in taking psychiatric medication?

when are you deciding if you want to take your medication or not?

Do you stop it from your own or based on doctor advice?

Q5: If you need more information about your medication, what do you do?

Could you tell me more?

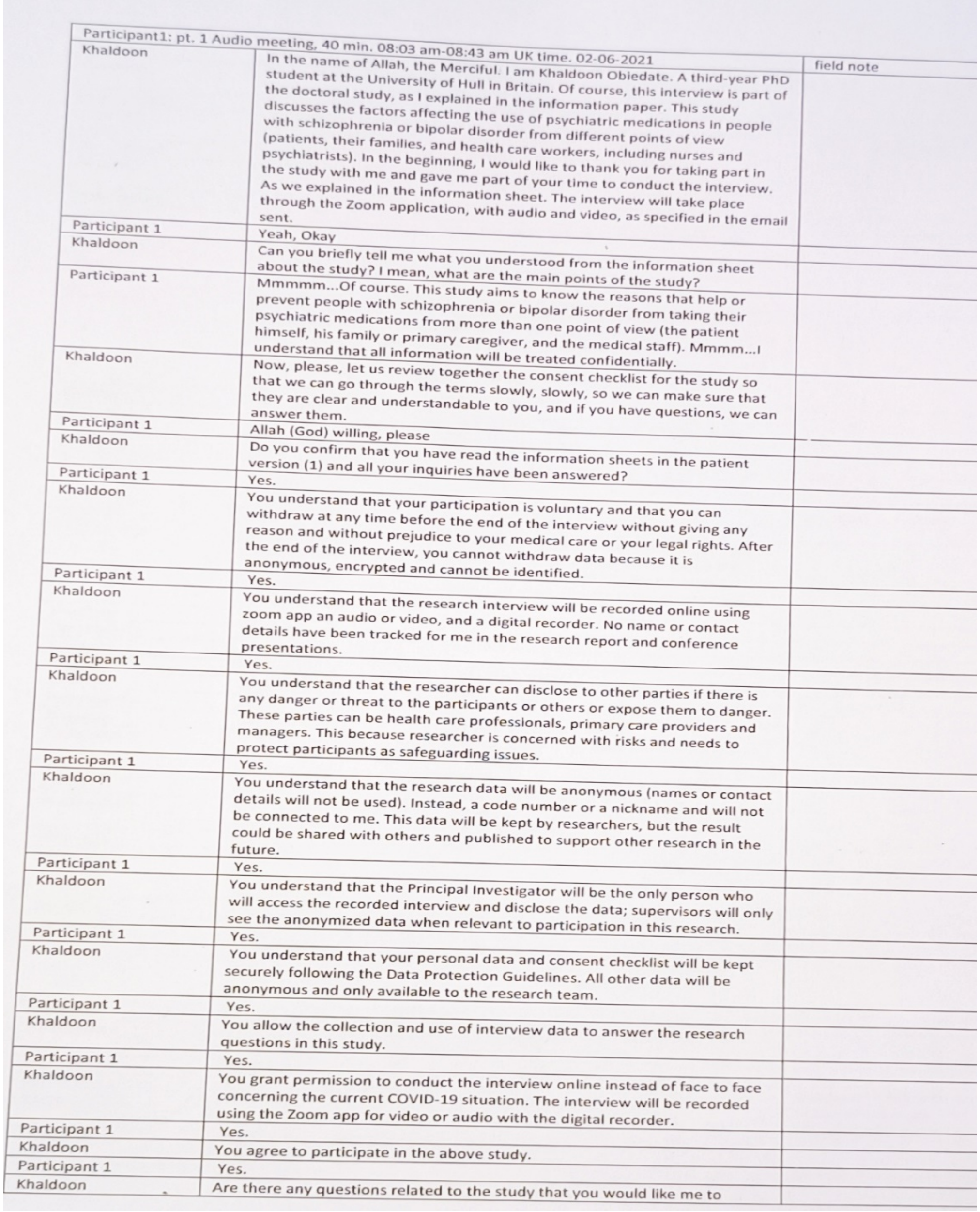
Q6: Are there times when you don't take your medication?

No, why not?

Could you explain that?

Yes, tell me more about that?

Figure 21: Appendix E- 12. Service user interview guide



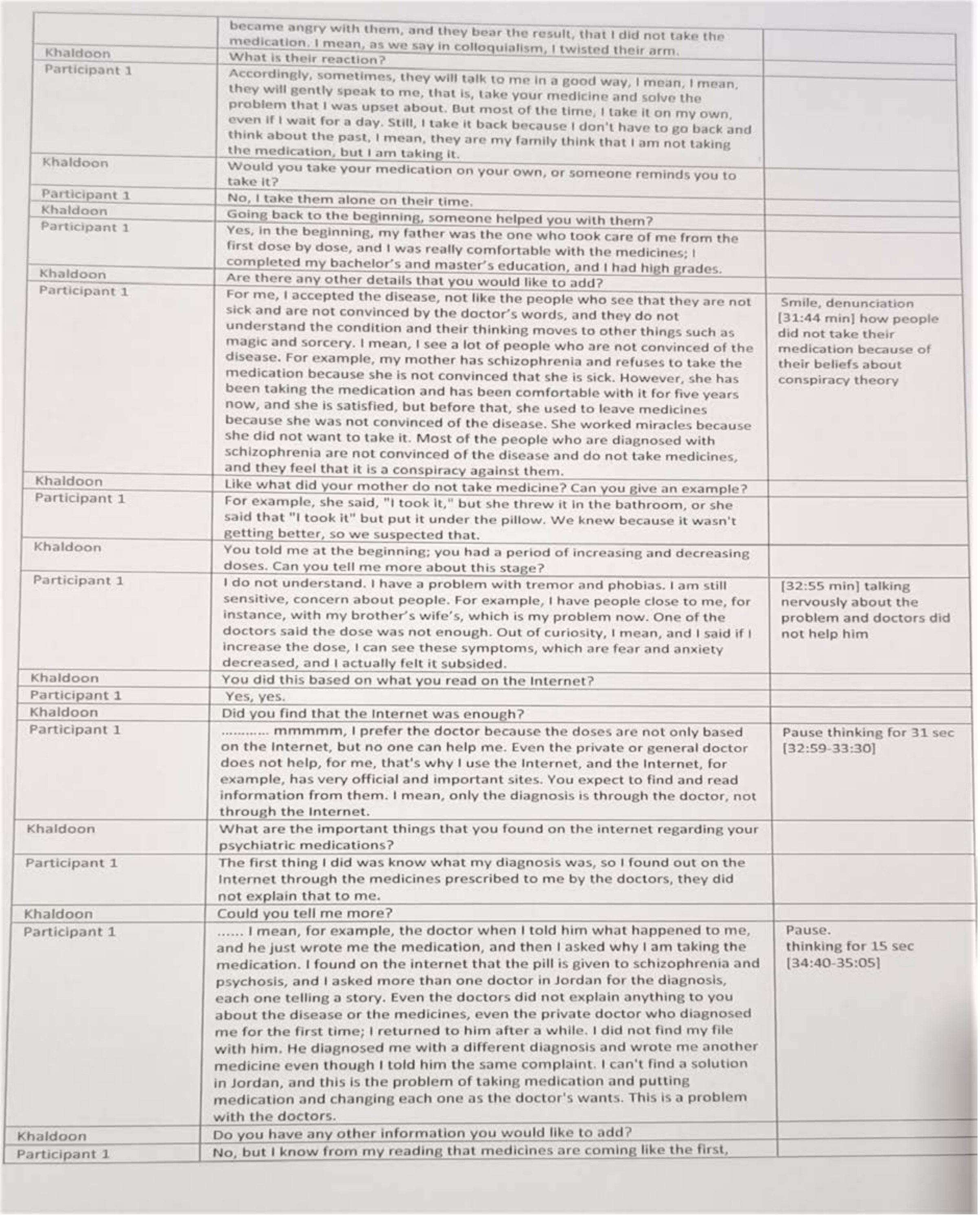
Participant1: pt. 1 Audio meeting, 40 min. 08:03 am-08:43 am UK time. 02-06-2021		field note
Khaldoon	In the name of Allah, the Merciful. I am Khaldoon Obiedate. A third-year PhD student at the University of Hull in Britain. Of course, this interview is part of the doctoral study, as I explained in the information paper. This study discusses the factors affecting the use of psychiatric medications in people with schizophrenia or bipolar disorder from different points of view (patients, their families, and health care workers, including nurses and psychiatrists). In the beginning, I would like to thank you for taking part in the study with me and gave me part of your time to conduct the interview. As we explained in the information sheet. The interview will take place through the Zoom application, with audio and video, as specified in the email sent.	
Participant 1	Yeah, Okay	
Khaldoon	Can you briefly tell me what you understood from the information sheet about the study? I mean, what are the main points of the study?	
Participant 1	Mmmmm...Of course. This study aims to know the reasons that help or prevent people with schizophrenia or bipolar disorder from taking their psychiatric medications from more than one point of view (the patient himself, his family or primary caregiver, and the medical staff). Mmmm...I understand that all information will be treated confidentially.	
Khaldoon	Now, please, let us review together the consent checklist for the study so that we can go through the terms slowly, slowly, so we can make sure that they are clear and understandable to you, and if you have questions, we can answer them.	
Participant 1	Allah (God) willing, please	
Khaldoon	Do you confirm that you have read the information sheets in the patient version (1) and all your inquiries have been answered?	
Participant 1	Yes.	
Khaldoon	You understand that your participation is voluntary and that you can withdraw at any time before the end of the interview without giving any reason and without prejudice to your medical care or your legal rights. After the end of the interview, you cannot withdraw data because it is anonymous, encrypted and cannot be identified.	
Participant 1	Yes.	
Khaldoon	You understand that the research interview will be recorded online using zoom app an audio or video, and a digital recorder. No name or contact details have been tracked for me in the research report and conference presentations.	
Participant 1	Yes.	
Khaldoon	You understand that the researcher can disclose to other parties if there is any danger or threat to the participants or others or expose them to danger. These parties can be health care professionals, primary care providers and managers. This because researcher is concerned with risks and needs to protect participants as safeguarding issues.	
Participant 1	Yes.	
Khaldoon	You understand that the research data will be anonymous (names or contact details will not be used). Instead, a code number or a nickname and will not be connected to me. This data will be kept by researchers, but the result could be shared with others and published to support other research in the future.	
Participant 1	Yes.	
Khaldoon	You understand that the Principal Investigator will be the only person who will access the recorded interview and disclose the data; supervisors will only see the anonymized data when relevant to participation in this research.	
Participant 1	Yes.	
Khaldoon	You understand that your personal data and consent checklist will be kept securely following the Data Protection Guidelines. All other data will be anonymous and only available to the research team.	
Participant 1	Yes.	
Khaldoon	You allow the collection and use of interview data to answer the research questions in this study.	
Participant 1	Yes.	
Khaldoon	You grant permission to conduct the interview online instead of face to face concerning the current COVID-19 situation. The interview will be recorded using the Zoom app for video or audio with the digital recorder.	
Participant 1	Yes.	
Khaldoon	You agree to participate in the above study.	
Participant 1	Yes.	
Khaldoon	Are there any questions related to the study that you would like me to	

Figure 22: Appendix E- 13. Example of translation

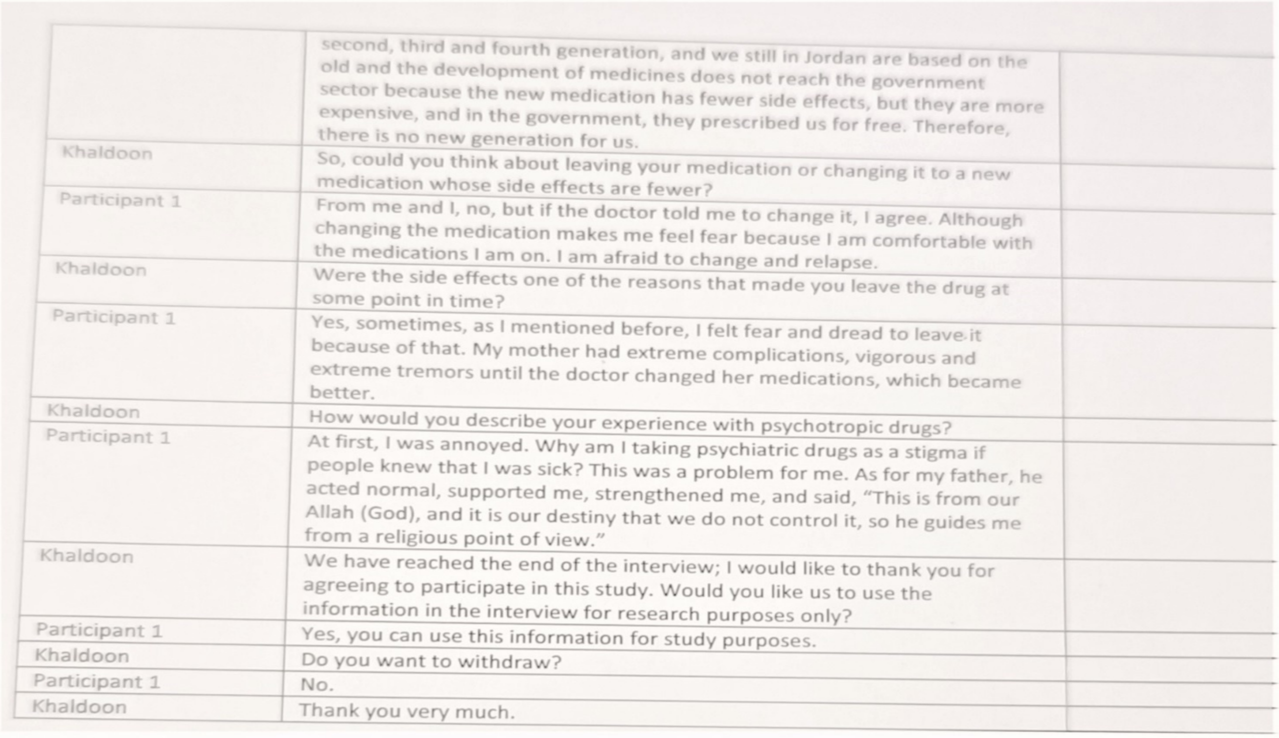
	answer before we start?	
Participant 1	There is no question. Please let's start the interview.	
Khaldoon	Now, when I start recording, I will ask your consent again to record your agreement to participate in the above study.	
Participant 1	Yes, no problem.	
Khaldoon 10:22	Allah (God) willing, we will start recording now (peep, peep meeting recording start). Do you agree to use Zoom in this interview?	Recording start 10:22
Participant 1	Yes. I agree.	
Khaldoon	Do you agree with the items and points in the study consent checklist?	
Participant 1	Yes, I agree with that list.	
Khaldoon	Are there any questions about the study before starting the interview?	
Participant 1	No, everything is clear.	
Khaldoon	Mr. (Participant 1) Can you tell me about yourself briefly, please?	
Participant 1	Yes, mmm, my name is (xxx); I had a master's degree in marketing, uh, at the outset; I want to tell you about the disease. I have schizophrenia. This is what I have been diagnosed with so far. I have taken treatment and am relieved (Alhamdullilah), thanking God. I am relieved and feeling very well. There have been no setbacks or relapses for many years. What would you like to know too?	
Khaldoon	How old are you?	
Participant 1	I am 38 years old, unmarried, not working; I do not work; I mean due to illness. Of course, I have not been working since 2014.	
Khaldoon	Yes	
Participant 1	I have, I have, of course, my hobbies, of course, computers and programming.	(Change the topic at minute12:00) but this did not affect the answer
Khaldoon	Ah.	
Participant 1	I studied marketing, but I did not work in this field. I wanna say, I did two research studies. The first research was on the quality of services in the health sector in Amman city, and the second study was for a master's degree. It was social responsibility and mental health in the government sector, too. It was in Amman.	
Khaldoon	Do you smoke?	
Participant 1	uh, yes, I am a smoker, a heavy smoker.	
Khaldoon	How many cigarettes per day?	
Participant 1	Wallah (I swear) 40 cigarettes mean two packs.	
Khaldoon	What about alcohol, do you drink?	
Participant 1	No, no, no, I don't drink alcohol.	
Khaldoon	Okay, do you know the names of your psychiatric drugs?	
Participant 1	I mean, of course, I know. Of course, Solian is my main medication and Amex. Of course, I take Zoloft with them, which is for depression. It is for the small thing. But the main is Solian; this is my psychiatric medication.	
Khaldoon	Do you know how to take it in terms of method and frequency?	
Participant 1	Ahh, I take Solian, the dose of 200 milligrams three times a day, and I take Zoloft 100 milligrams twice, in the morning and at night.	
Khaldoon	You told me that you did not work; what is the average family income?	
Participant 1	Ahha, the family income, my father is a merchant of apartments, and he did not have a monthly payment, I mean, but, Alhamdulillah (thank God), the income is good.	
Khaldoon	How many years have you been diagnosed with schizophrenia?	
Participant 1	Approximately from 2009, I was not diagnosed before. However, in1999, in my teenage years, there was no proper treatment for me. I was not... sorry, I mean, no precise diagnosis; nothing was clear until 2009 with a private doctor. I was diagnosed with schizophrenia and took Solian, and from that day, I feel good.	
Khaldoon	What do you know about Solian?	
Participant 1	I only know that it's for schizophrenia and psychosis, I took it. I have not tried any other medication.	
Khaldoon	What is the most important thing you need to know about it?	
Participant 1 14:35	I know mmm... it's American that what I know.	[laughing 14:35] as he did not know too much about his medication
Khaldoon	What is your doctor's advice? What do you need to know about it, about its side effects?	
Participant 1	Unfortunately, doctors here in Jordan did not tell us anything. They do not tell us anything. Like this, they do not even say what your diagnosis is; I knew	

	about my diagnosis by myself and began reading about it from the drug's leaflet and the internet.	
Khaldoon	What about the other medications, Amex and Zoloft? What did you say about them?	
Participant 1	No, no, no, they didn't tell me anything, but when I told them about stress and anxiety, they described me the Zoloft, and I was the one who suggested it to them because I read about it, and Dr said to me, okay, okay, I'm done with it I will prescribe it for you.	Nervousness, denunciation and dissatisfied with the way that doctors behave with them (15:00)
Khaldoon	Do you think these medicines helped you and how?	
Participant 1	No. I mean, for example, that it is okay for me to stop feeling wrong, or it means sympathy from others. Bs (but) frankly, helped me from the first tab. Of course, it relieved me a lot. I was taking the highest dose, and according to my reading about Zoloft, I did not have to continue it for more than six months to a year, but does uh, I mean, I mean, I have taken it for more than 5 years now. I asked the doctor once if he could stop it, he told me that there is no need to stop it if you are comfortable with it. However, I read about the medication the patient does not need for a long time.	
Khaldoon	Can you tell me about the drugs, explain to me more about them, please?	
Participant 1	The Solian was at the beginning, of course, but I got used to it. It caused me drowsiness. The Solian's cause me tremor, but not severe, and even the Kemadrin didn't work with it while I was taking a pill a day, and then I stopped taking Kemadrin because it was useless. Now, mmmm, the side effects of Zoloft, I mean, for example, increase the sexual desire, I feel sexually active, and I am not married. This makes me uncomfortable emotionally and psychologically.	
Khaldoon	Do you think that these drugs helped you to overcome the disease barrier?	
Participant 1	No. I mean, all those medications did make me mentally healthy and comfortable. Ah, however, I cannot work, I don't try to work under pressure or responsibility, so I can't know if I can work or not. No, these drugs did not help me. I think besides, the treatment must also have behavioural therapy. I did not find this type of treatment in the country (Jordan) in a way that would make me overcome this barrier, although I did use any behavioural therapy I heard about. Unfortunately, that I went to it, was very expensive and it was useless.	
Khaldoon	What do you think is the problem with these medications, and why did they not help you?	
Participant 1	In my opinion, I mean, these medicines like the ones that contain a kind of anaesthesia. I mean, they are supposed just to relieve you and ease your relapses. But in your life, you cannot do anything, I mean, unless accompanied with behavioural treatment to help you get out of what you are in, and with the medications, of course.	
Khaldoon	Can you describe your experience with psychiatric medications during this period and the past period?	
Participant 1	Of course, I take medicines constantly, unless I forgot the time of the medicine or missed it by mistake, but I have been taking it constantly from 2009 to today. I used to have anger, and so on, and I didn't want to take medicine, then I relapsed, and it would be difficult for my family to convince me back to take medications because I was in relapse, and I didn't see that I had a problem. When I come back and take medicine, I feel comfortable. I mean, many situations like this, but in the end, I was taking the medication. I mean, my experience with medicines, frankly, was not bad.	
Khaldoon	Can you tell me more about the reasons that made you leave the medicine or not take it according to the doctor's prescription?	
Participant 1	.... Mmmmmmmm, as for me when I took medicine, Solian. I have anxiety and tension, and I call it a phobia. I don't know, from the time I took the Solian till today; I have a phobia of people around me, I mean, I have problems, I don't like gatherings, because of problem may happen from that sometimes. Therefore, I don't want to take the medication, so this fear and phobia will disappear. I can live my life, but I relapse when I leave the medicine for two or three days.	Silent, thinking for about 30 sec [20:00-20:30]
Khaldoon	You left the medication based on your decision, or was it from the doctor?	
Participant 1	No, no, never, based on me. My doctor told me that I need to take medicines for life.	
Khaldoon	How did you manage your psychiatric medications on your own, or someone takes care of you?	
Participant 1	No, in the beginning, I was taking medicine on my own, and I took treatment from when I went to the doctor in 2009. I was diagnosed and took the Solian. This was due to a significant problem, meaning I broke the house and was in a very nervous state that could be called psychotic features. In what	

	happened that day, the police entered, and my family, unfortunately, locked me up for a night in the police station. On the second day, my family took me upon my request to the psychiatrist, and I took the Solian, and I feel better after a few days. Since that day, I know that it is always good, and I take it, and it comforts me, which does not make me angry and nervous.	
Khaldoon	What are the reasons that make you decide to leave the drug from your point of view?	
Participant 1	.... Mmmmm. I mean, I take medicine, not I don't take it. But the reasons why I left it sometimes. In the beginning, was the stigma that I am mentally ill, what people will say about me, and so on. I was embarrassed from that. But this is the stage that I skipped because of the father's support. Now, for me, I do not leave the medicine because my nerves cannot bear. I mean, if I leave it, I think about people from the past, old problems, and then get nervous when I remember these things and go back to the past. So, that's why I don't leave the medicine.	Pause thinking for about 5 sec [22:49-22:54]
Khaldoon	Is there a desire to withdraw?	
Participant 1	No. There is no desire to withdraw.	
Khaldoon	Still want to complete the interview using the Zoom app.	
Participant 1	Yes, we continue.	
Khaldoon	Where do you get information about medicines?	
	Mmmmm, I read on the internet. I mean, I can open Google and do search on the medicine and read what it does, what are its side effects, what doses you can take, and what is the lowest or high dose.	
Khaldoon	Can you increase and decrease the dose on your own?	
Participant 1	Frankly, frankly, I did this, I did this, I mean, for example, when I first took the drug in 2009, the dose was 200 milligrams in the morning and 200 milligrams in the evening. For instance, after a while, every time I go to the doctor -I go back to the government consulting clinic-. Every time the specialist doctor tells me, mmmmmm, he increases the dose. I mean, I tell him, for example, that I am afraid, I am nervous; I have a fear of the problems that are happening around me, so he increases it for me. Then, I took Amex -which is produced locally in Jordan-I read on the internet that there are still different medicines. I mean, it is true that it is the same scientific formula, but it differs from company to company or from country to country in terms of the strength of the drug. I bought the foreign drug -produced internationally, not locally- Solian. I took the dose one pill by myself, and then I increased half a pill, which now is 300 in the morning and 300 in the evening, and I increased them by myself, and I am comfortable with it without returning to the doctors, the doctors did not help me at all, they do not help at all.	
Khaldoon	From which side do the doctors do not help you?	
Participant 1	I mean, they don't listen to me, this is the first problem, for example, I want to tell them about my medications, and I have new things, the doctor said no, no, let's not play with medicines, and stay as you are. Another thing every doctor says something different. From specialist to specialist- at government clinics, they change doctors every time. Hence, every visit, I found a different doctor-He saw my medications and said that all my medications had no need. He told me there was a problem with the medicines. I mean, by the way, I mean, I mean, a kind of sedative medication would come with it, and a Kemadrin also stopped it. Mmmmm, I do not feel that they treat the patient in a correct way, and at the same time, they do not listen to you, and they do not help. they never discuss with you the doses you take. I mean, they did not discuss medications, but they will write you medications and prescribe them every month. They prescribed the medicines you have already taken in the last visit.	
Khaldoon	Do you mean that they do not explain the side effects; do you ask them about that?	
Participant 1	Well, at first, I'm telling you, I'm following up from 1999 in the government clinic, I mean, I was asking at first, and they wouldn't discuss with me. I mean, in the first place, I mean, the door kept open, and the staff entered and go out while we are sitting with the doctor. There is no privacy, and there is no way that you discuss with the doctor in government centres.	nervously talking about privacy and confidentiality when he visits the doctor at the governmental clinic [28:00 min]
Khaldoon	Do you think that these things affect you in terms of taking medications?	
Participant 1	Uh, of course, sure. When I have no information on the medication and I am not convinced of it, and I have not taken enough time with the doctor to discuss with him and to explain to me, I will leave one or two pills.	
Khaldoon	Are there days when you did not take the medication?	
Participant 1	Yes, it happened to me. One day, I had a problem with my family. I did not take the medication I want to make them feel afraid of me and relapsed and	



	became angry with them, and they bear the result, that I did not take the medication. I mean, as we say in colloquialism, I twisted their arm.	
Khaldoon	What is their reaction?	
Participant 1	Accordingly, sometimes, they will talk to me in a good way, I mean, I mean, they will gently speak to me, that is, take your medicine and solve the problem that I was upset about. But most of the time, I take it on my own, even if I wait for a day. Still, I take it back because I don't have to go back and think about the past, I mean, they are my family think that I am not taking the medication, but I am taking it.	
Khaldoon	Would you take your medication on your own, or someone reminds you to take it?	
Participant 1	No, I take them alone on their time.	
Khaldoon	Going back to the beginning, someone helped you with them?	
Participant 1	Yes, in the beginning, my father was the one who took care of me from the first dose by dose, and I was really comfortable with the medicines; I completed my bachelor's and master's education, and I had high grades.	
Khaldoon	Are there any other details that you would like to add?	
Participant 1	For me, I accepted the disease, not like the people who see that they are not sick and are not convinced by the doctor's words, and they do not understand the condition and their thinking moves to other things such as magic and sorcery. I mean, I see a lot of people who are not convinced of the disease. For example, my mother has schizophrenia and refuses to take the medication because she is not convinced that she is sick. However, she has been taking the medication and has been comfortable with it for five years now, and she is satisfied, but before that, she used to leave medicines because she was not convinced of the disease. She worked miracles because she did not want to take it. Most of the people who are diagnosed with schizophrenia are not convinced of the disease and do not take medicines, and they feel that it is a conspiracy against them.	Smile, denunciation [31:44 min] how people did not take their medication because of their beliefs about conspiracy theory
Khaldoon	Like what did your mother do not take medicine? Can you give an example?	
Participant 1	For example, she said, "I took it," but she threw it in the bathroom, or she said that "I took it" but put it under the pillow. We knew because it wasn't getting better, so we suspected that.	
Khaldoon	You told me at the beginning; you had a period of increasing and decreasing doses. Can you tell me more about this stage?	
Participant 1	I do not understand. I have a problem with tremor and phobias. I am still sensitive, concern about people. For example, I have people close to me, for instance, with my brother's wife's, which is my problem now. One of the doctors said the dose was not enough. Out of curiosity, I mean, and I said if I increase the dose, I can see these symptoms, which are fear and anxiety decreased, and I actually felt it subsided.	[32:55 min] talking nervously about the problem and doctors did not help him
Khaldoon	You did this based on what you read on the Internet?	
Participant 1	Yes, yes.	
Khaldoon	Did you find that the Internet was enough?	
Participant 1	.... mmmmm, I prefer the doctor because the doses are not only based on the Internet, but no one can help me. Even the private or general doctor does not help, for me, that's why I use the Internet, and the Internet, for example, has very official and important sites. You expect to find and read information from them. I mean, only the diagnosis is through the doctor, not through the Internet.	Pause thinking for 31 sec [32:59-33:30]
Khaldoon	What are the important things that you found on the internet regarding your psychiatric medications?	
Participant 1	The first thing I did was know what my diagnosis was, so I found out on the Internet through the medicines prescribed to me by the doctors, they did not explain that to me.	
Khaldoon	Could you tell me more?	
Participant 1	...... I mean, for example, the doctor when I told him what happened to me, and he just wrote me the medication, and then I asked why I am taking the medication. I found on the internet that the pill is given to schizophrenia and psychosis, and I asked more than one doctor in Jordan for the diagnosis, each one telling a story. Even the doctors did not explain anything to you about the disease or the medicines, even the private doctor who diagnosed me for the first time; I returned to him after a while. I did not find my file with him. He diagnosed me with a different diagnosis and wrote me another medicine even though I told him the same complaint. I can't find a solution in Jordan, and this is the problem of taking medication and putting medication and changing each one as the doctor's wants. This is a problem with the doctors.	Pause. thinking for 15 sec [34:40-35:05]
Khaldoon	Do you have any other information you would like to add?	
Participant 1	No, but I know from my reading that medicines are coming like the first,	



	second, third and fourth generation, and we still in Jordan are based on the old and the development of medicines does not reach the government sector because the new medication has fewer side effects, but they are more expensive, and in the government, they prescribed us for free. Therefore, there is no new generation for us.	
Khaldoon	So, could you think about leaving your medication or changing it to a new medication whose side effects are fewer?	
Participant 1	From me and I, no, but if the doctor told me to change it, I agree. Although changing the medication makes me feel fear because I am comfortable with the medications I am on. I am afraid to change and relapse.	
Khaldoon	Were the side effects one of the reasons that made you leave the drug at some point in time?	
Participant 1	Yes, sometimes, as I mentioned before, I felt fear and dread to leave it because of that. My mother had extreme complications, vigorous and extreme tremors until the doctor changed her medications, which became better.	
Khaldoon	How would you describe your experience with psychotropic drugs?	
Participant 1	At first, I was annoyed. Why am I taking psychiatric drugs as a stigma if people knew that I was sick? This was a problem for me. As for my father, he acted normal, supported me, strengthened me, and said, "This is from our Allah (God), and it is our destiny that we do not control it, so he guides me from a religious point of view."	
Khaldoon	We have reached the end of the interview; I would like to thank you for agreeing to participate in this study. Would you like us to use the information in the interview for research purposes only?	
Participant 1	Yes, you can use this information for study purposes.	
Khaldoon	Do you want to withdraw?	
Participant 1	No.	
Khaldoon	Thank you very much.	

Appendix F: Findings Tables

Table 31: Appendix F- 1. Example of how category 1 (Experience) was drawn from the data

Initial (open) coding	Axial coding		Focused (Selective) coding	
Weight gain & increased appetite. sleep tiredness and laziness causing cramps sexual problem medication has sedation. medication cause insomnia problem at work cause anxiety and stress feel empty. Increase heart rate. Elevate blood sugar.	bad side effect	side effect	Medication related	Experience with taking psychiatric medications
Adapted to side effects.	adapted to side effect			
Use the old generation. The new medication has fewer side effects.	Old vs new			
Medication different local medications use international medication.	local vs international			
medication useless Feel depressed. Not taking because lack of information experience with his mother not taking. change taking because of work. life stress affect taking not taking because of anger not take because of family problem. if not the same did not take it stop taking because I need to take it for long time. stop when improvement. unless forgot or missed dose by mistake	Taking barriers			

help control symptoms. psychologically relaxed decreased feeling of fear and stress maintain improvement. fear of relapse decrease feeling of sympathy from others. from the first use decrease relapse. cannot live without medication. decrease feeling unfair stop anger stop thinking in the past continue my education help to sleep good experience no relapse not to change medication by my self-based on doctor take medication regularly I cannot stop medication used to use one name hate to change	Drive to take medication		
family support family not support self-support	Experience with the support system		
not aware does not work because of disease disease affect my study disease affect my life forgot to take because of disease no work experiences not take because of hallucination and delusion	Experience with disease		
ketamine iv behavioural therapy expensive behavioural therapy not available ETC behavioural therapy not useful	Experience with other treatments		

Table 32: Appendix F- 2. Example of how Knowledge category is drawn from data

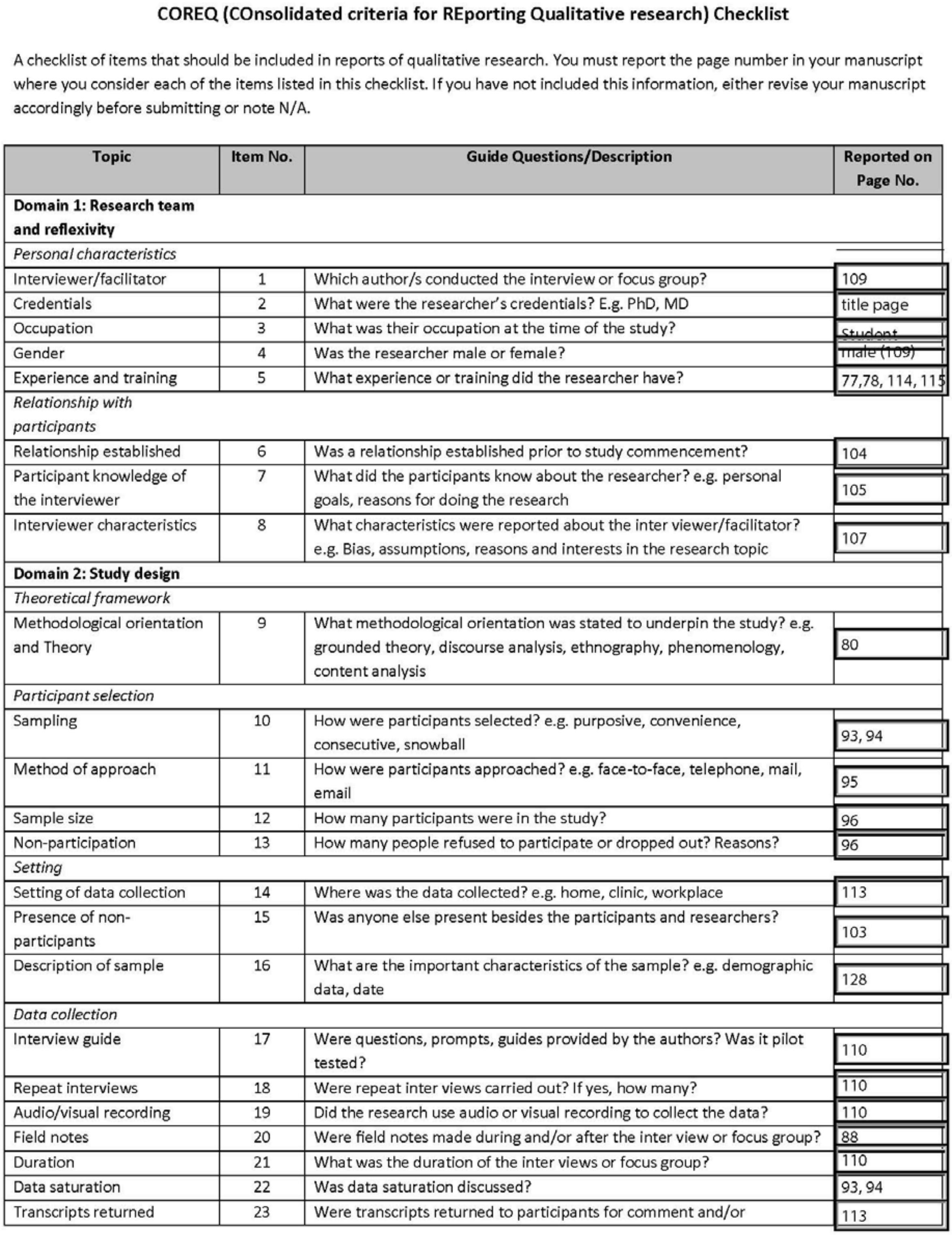
Initial code	Focus coding		Axial coding
community has no details about mental illness know his diagnosis fear from people I did not know what happen start to isolate myself I feel defeated I am sick as my father	Few details about the disease	Lack of knowledge	Knowledge about psychiatric disease and medication
knowing his medication not taking because lack of information forgot names	Few details about medications		
know diagnosis not authorized people looking for dose and side effects	Using Internet	Source of information	
ask doctors ask pharmacist	Ask HCP		
learn from other experience	Other experience		
reading from leaflet	Self-reading		

Appendix H: Medication brand name

Table 33: Appendix H- 1. Medications Name (Brand and Generic)

#	Brand name	Generic name
1	Solian, Amex	Amisulpride
2	Zoloft	Sertaline HCL
3	Kemadrin	Procyclidine Hydrochloride
4	Seroquel, Solitek, Serolex, equeal	Quetiapine Fumarate
5	Prexal	Olanzapine
6	Zylax	Hydroxyzine
7	Lithium	Lithium Carbonate
8	Indicardin	Propranolol
9	Ablifiy	Aripiprazole
10	fluoxetine	Fluoxetine
11	Faverin	Fluvoxamine maleate
12	Effexor	Venlafaxine
13	Depakine	Depakine Chrono
14	Zolex	Pantoprazole

Appendix I: COREQ checklist

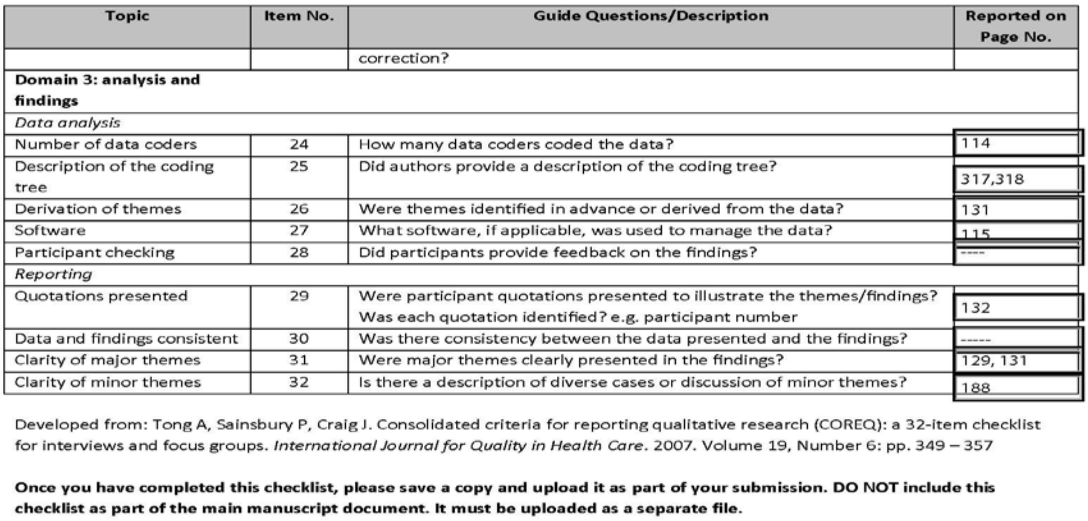


COREQ (COnsolidated criteria for REporting Qualitative research) Checklist

A checklist of items that should be included in reports of qualitative research. You must report the page number in your manuscript where you consider each of the items listed in this checklist. If you have not included this information, either revise your manuscript accordingly before submitting or note N/A.

Topic	Item No.	Guide Questions/Description	Reported on Page No.
Domain 1: Research team and reflexivity			
Personal characteristics			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	109
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	title page
Occupation	3	What was their occupation at the time of the study?	Student
Gender	4	Was the researcher male or female?	male (109)
Experience and training	5	What experience or training did the researcher have?	77,78, 114, 115
Relationship with participants			
Relationship established	6	Was a relationship established prior to study commencement?	104
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	105
Interviewer characteristics	8	What characteristics were reported about the inter viewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	107
Domain 2: Study design			
Theoretical framework			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	80
Participant selection			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	93, 94
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	95
Sample size	12	How many participants were in the study?	96
Non-participation	13	How many people refused to participate or dropped out? Reasons?	96
Setting			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	113
Presence of non-participants	15	Was anyone else present besides the participants and researchers?	103
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	128
Data collection			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	110
Repeat interviews	18	Were repeat inter views carried out? If yes, how many?	110
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	110
Field notes	20	Were field notes made during and/or after the inter view or focus group?	88
Duration	21	What was the duration of the inter views or focus group?	110
Data saturation	22	Was data saturation discussed?	93, 94
Transcripts returned	23	Were transcripts returned to participants for comment and/or	113

Figure 23: Appendix I. COREQ checklist



Topic	Item No.	Guide Questions/Description	Reported on Page No.
		correction?	
Domain 3: analysis and findings			
Data analysis			
Number of data coders	24	How many data coders coded the data?	114
Description of the coding tree	25	Did authors provide a description of the coding tree?	317,318
Derivation of themes	26	Were themes identified in advance or derived from the data?	131
Software	27	What software, if applicable, was used to manage the data?	115
Participant checking	28	Did participants provide feedback on the findings?	----
Reporting			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	132
Data and findings consistent	30	Was there consistency between the data presented and the findings?	-----
Clarity of major themes	31	Were major themes clearly presented in the findings?	129, 131
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	188

Developed from: Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

Once you have completed this checklist, please save a copy and upload it as part of your submission. DO NOT include this checklist as part of the main manuscript document. It must be uploaded as a separate file.