Shared Decision Making in Secondary Mental Healthcare in Taiwan

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ABSTRACT

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Background

Although shared decision making has been widely advocated in mental health policies in western countries, there is limited evidence of shared decision making in South Asian cultures, particularly Taiwan. Thus, there is a need to explore shared decision making from the perspectives of Taiwanese health professionals and individuals experiencing mental health disorders. Such knowledge is of key importance to facilitate shared decision making in Taiwan's mental healthcare systems.

Aims

To explore/understand the process of decision making, from both health professional and patient perspectives, in secondary mental healthcare in Taiwan.

Methods

To address this aim, three separate but interrelated studies were conducted:

- **Study One:** A systematic review of previously published qualitative studies of patient perspectives of shared decision making.
- **Study Two:** Semi-structured qualitative interviews to explore patient perspectives of shared decision making in secondary mental healthcare in Taiwan.
- **Study Three:** Semi-structured qualitative interviews to explore health professional perspectives of shared decision making in secondary mental healthcare in Taiwan.

Results

The qualitative systematic review included 13 studies, and revealed a number of key barriers and facilitators to shared decision making. Barriers included: paternalistic attitudes of health professionals, poor quality interaction with health professionals, and

lack of professional knowledge and information. Factors enhancing shared decision making included a supportive attitude to patient involvement, sufficient information exchange, and other support resources.

Qualitative interviews with 20 patients found that they were not involved in the decision-making process due to: the professional status of health professionals in a submissive culture; negative perception of making decisions; and health professionals having limited time. However, patients showed a desire to be involved in decision making but required sufficient information exchange to enable them to do this.

Qualitative interviews with 24 health professionals revealed a number of barriers to and facilitators of shared decision making. Factors reducing shared decision making included: the powerful status of health professionals and families; a belief that patients had impaired decisional ability due to their mental illness; a lack of understanding of shared decision making; and insufficient time. Despite this, there was a view from a few health professionals that they understood the potential benefits of shared decision making.

The results of the above three studies were synthesised and revealed three mechanisms through which implementation of shared decision making could potentially be improved: capability/skill improvement; attitude/motivation modification; and sufficient time resource.

Conclusion

This study has provided an insight into implementing shared decision making in mental healthcare directly from patients’ and health professionals’ perspectives in Taiwan. The findings revealed that shared decision making was not yet understood or implemented in mental healthcare. Significant barriers and facilitators were identified and mechanisms were proposed to address the barriers to shared decision making. The findings of this study provided potential solutions to aid further training of staff and development of national policies on shared decision making.

DECLARATION

No portion of the work referred to in this thesis has been submitted in support of an application for another degree or qualification of this or any other university or other institute of learning.

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DEDICATIONS

This thesis is dedicated to my husband Tsen Lu (Nathan) and my son Ding-Lin Lu (Duke). It has been a very long journey, studying abroad, and they have loved me unconditionally throughout. In particular, my parents-in-law, who always love me and continually support me in pursuing my dream. Also, my parents who gave birth to me and raised me.

THE AUTHOR

I qualified as registered nurse in Taiwan in 2006. My first role was as a registered nurse at Tri-Service General Hospital (at the top level of health services in Taiwan). I was promoted to supervisor, with responsibility for managing acute wards, overseeing patient care, developing working guidelines such as physical restraint and de-escalation techniques, supporting and teaching student nurses, and handling administration.

In 2011, I completed my master’s degree at National Yang-Ming University (NYMU) and worked as a lecturer in two college-level institutions for teaching mental healthcare and the conducting of literature reviews.

INTRODUCTION

Overview of the study

This PhD study consists of three studies and a final synthesis of findings. The three studies comprise a systematic review of qualitative studies of patient perspectives of shared decision making (Study One), semi-structured qualitative interviews with patients in secondary mental healthcare in Taiwan (Study Two), and semi-structured qualitative interviews eliciting health professionals' perspectives of shared decision making in secondary mental healthcare in Taiwan (Study Three); a final synthesis draws the findings together and presents a conclusion and recommendations. The explanation of studies one, two and three are presented in the following chapters.

Aim of the PhD study

- to explore/understand the process of decision making, from both health professional and patient perspectives, in secondary mental healthcare in Taiwan.

Objectives

The objectives are:

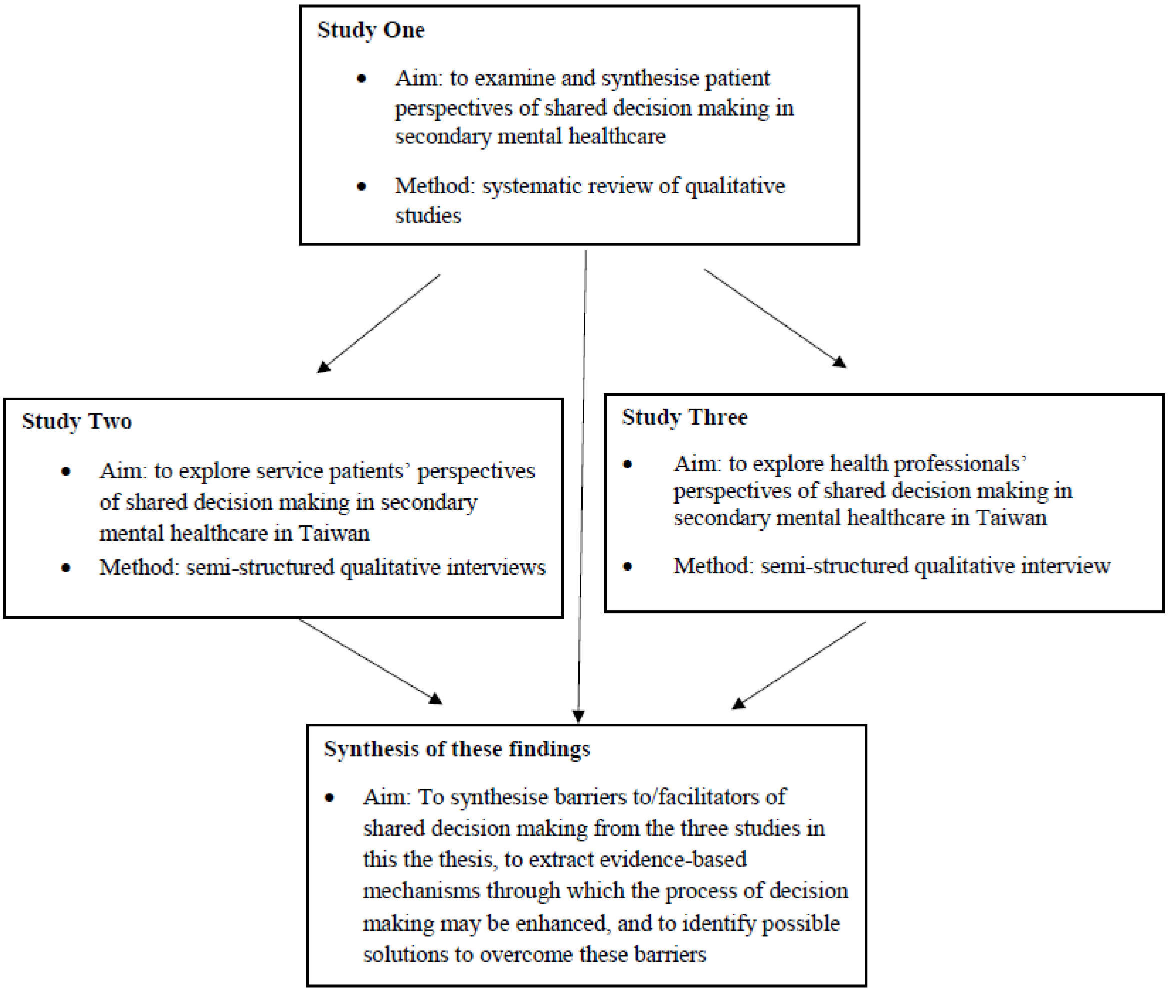
- to examine and synthesise patient perspectives of shared decision making in secondary mental healthcare using a systematic review of qualitative studies;
- to explore patient perspectives of shared decision making in secondary mental healthcare in Taiwan using semi-structured qualitative interviews;
- to explore health professional perspectives of shared decision making in secondary mental healthcare in Taiwan using semi-structured qualitative interviews.

Organisation of the thesis

This PhD comprises three separate, but interrelated, studies: a systematic review of qualitative studies (Study One), semi-structured qualitative interviews with patients in secondary mental healthcare in Taiwan (Study Two), and semi-structured qualitative interviews with health professionals in secondary mental healthcare in Taiwan (Study Three) (Figure 1).

Therefore, the thesis comprises eight chapters, of each of which an outline is presented here. Chapter One gives an overview of the topic and background information about the mental health system in Taiwan, and expands on the background by outlining the evidence regarding shared decision making. Chapter Two presents the aims and objectives, and a justification of the methodology, including its research paradigm. Chapter Three provides details of a qualitative systematic review of existing studies on shared decision making in secondary mental healthcare (Study One). Chapter Four presents the working methods which were used for the patient interviews (Study Two) and health professional interviews (Study Three). Chapters Five and Six provide details of the findings from Study Two and Study Three. Chapter Seven outlines the results of the synthesis of findings from the qualitative systematic review (Study One), patient interviews (Study Two), and health professional interviews (Study Three). Chapter Eight provides a discussion of the thesis, and recommendations for further studies.

Figure 1: Structure of the PhD



Study One

- Aim: to examine and synthesise patient perspectives of shared decision making in secondary mental healthcare
- Method: systematic review of qualitative studies

Study Two

- Aim: to explore service patients' perspectives of shared decision making in secondary mental healthcare in Taiwan
- Method: semi-structured qualitative interviews

Study Three

- Aim: to explore health professionals' perspectives of shared decision making in secondary mental healthcare in Taiwan
- Method: semi-structured qualitative interview

Synthesis of these findings

- Aim: To synthesise barriers to/facilitators of shared decision making from the three studies in this the thesis, to extract evidence-based mechanisms through which the process of decision making may be enhanced, and to identify possible solutions to overcome these barriers

Chapter One: Background

This chapter will be presented in four main sections. The first section will provide an introduction to the mental health system in Taiwan and the second section will present an overview of shared decision making. The third section will provide the rationale for the study. The final section will present a summary of this chapter.

1.1 Mental healthcare in Taiwan

Taiwan, located in East Asia, is a relatively small island (36,193 km^2) with a population of 23 million. With its rapidly growing economy, Taiwan is recognised as a developing country (United Nations, 2017). In Taiwan, the Ministry of Health and Welfare, which is part of the Executive Yuan (the department of the government in Taiwan), is responsible for formulating healthcare policies and managing the delivery of health services. In 1995, the government adopted a national health insurance system to underpin the Taiwanese healthcare system, including mental healthcare.

1.1.1 National Health Insurance (NHI)

Before nationwide health insurance was adopted, there were a range of insurance systems in Taiwan, such as government employee insurance, labour insurance, fishermens' health insurance, and farmers' health insurance. In 1995, the Taiwanese government consolidated all the insurance schemes into the single, nationwide system, the National Health Insurance (NHI) system.

The current healthcare system (including mental health) in Taiwan is based on National Health Insurance. This maintains that every citizen has an equal right to receive healthcare and treatment. It is compulsory for every citizen to register with the NHI to support their treatment and care (National Health Insurance Administration in Taiwan, 2016a). In 2016, it was estimated that 99% of the population was registered in the NHI (National Health Insurance Administration in Taiwan, 2016a).

The NHI is considered a successful health system with sufficient services because of high patient satisfaction, and high quality of care and treatment delivery (Wu et al., 2010). Results from a survey of client satisfaction with the NHI in 2014 indicated that about 80% of clients reported a high degree of satisfaction (Bureau of the National Health Insurance, 2015). Many features of the NHI contribute to high client satisfaction, including good accessibility of all levels of care, comprehensive coverage of different medical disciplines, short waiting times and low cost (Wu et al., 2010).

However, challenges that emerged included the quality of medical encounters, an unstructured referral system, and systemic financial problems (Wu et al., 2010). There are some barriers to the quality of medical encounters within the NHI system in Taiwan. In Taiwanese culture, people are used to seeking medical help even for minor medical conditions. People in Taiwan have an average of 13.4 patient visits per annum across healthcare services (Shih et al., 2010), compared with 5 for the United Kingdom (2009) (WHO Regional Office for Europe, 2018). Health professionals' (such as general practitioners and other doctors) income is based on the number of patients and level of treatment/care. It is usual for a health professional to see 50 to 100 patients in one day. The heavy workloads and resulting short duration of patient visits are significant features of the system (Chang et al., 2012). It could be difficult for health professionals and patients to explore their perspectives and to achieve sufficient information exchange in medical encounters. Therefore, these factors all negatively influence the quality of medical encounters.

Primary care does not act as an adequate gate-keeping system, even if this is directed by the government, as patients can bypass this system and directly access specialists services – this being the case, the gatekeeping system is not enforced. This means that individuals can select any level of medical services freely (Wu et al., 2010). Such a system is problematic as the majority of the population believe that higher level medical services provide better quality treatment and care, so they tend to use the higher-level services, and therefore these services, such as medical centres, are always over-subscribed.

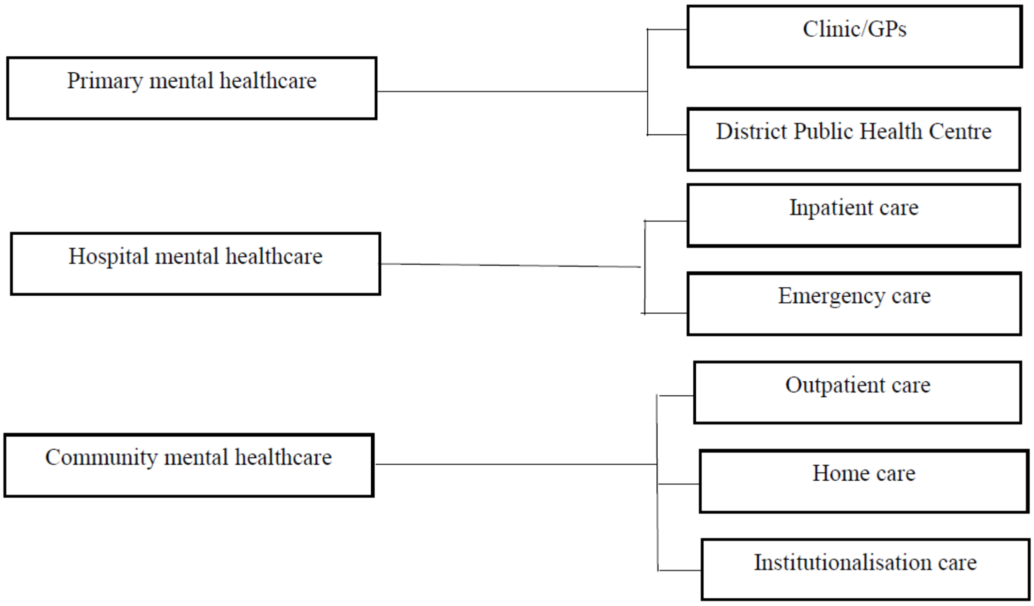
Furthermore, the availability of resource-intensive services in the NHI leads to high medical expenditure (Cheng, 2015; Wu et al., 2010). This has led the Taiwanese government to focus recently on the overuse and misuse of health resources. For example, the NHI introduced a new system of calculating premiums for insured people and companies to raise more funding from a variety of sources (Lan, 2017). The NHI is starting to be reformed but still requires significant work to bring it into a financially stable position (Cheng, 2015).

1.1.2 The mental healthcare structure in Taiwan

Almost one in four people in Taiwan suffer from common mental health disorders, including depression and anxiety disorders (Fu et al., 2013). The number of people who have a serious mental illness nationally was estimated to be about 203,587 in 2016 (almost 1% of Taiwan's population) (National Health Insurance Administration in Taiwan, 2016b). A 20-year repeated cross-sectional survey found an increasing trend in the prevalence of common mental disorders in Taiwan, which might be influenced by economic issues, such as the unemployment rate (Fu et al., 2013). Although it is difficult to draw any conclusions about the cause of this trend due to the complexity of mental illness, given the rapidly increasing prevalence of mental health problems, this sector of the population has started to receive more attention in the healthcare system in Taiwan.

The three levels of mental health services are primary mental healthcare, hospital mental healthcare, and community mental healthcare (see Figure 1.1). In Taiwan, primary mental healthcare refers to the general practitioners (GP) system; hospital mental healthcare focuses on the general hospital or specialised hospital systems; community mental healthcare refers to specialised and long-term rehabilitation systems.

Figure 1.1: The health care structure in Taiwan



The treatment and care team in mental healthcare comprises psychiatrists, mental health nurses, mental health nurse practitioners, clinical psychologists, occupational therapists, case managers, and social workers. Generally, mental health professionals are responsible for delivering mental healthcare and discussions with patients about their treatment and care. Each of the parts of mental healthcare is described below.

1.1.2.1 Primary mental health services

Primary care in Taiwan aims to provide comprehensive first contact and generally promote physical and mental health where people live or work. District public health centres and clinics/general practitioners (GPs), which mainly provide primary care, are mainly made up of general practitioners (GPs), community nurses, and pharmacists. The role of the healthcare professionals in primary care include preventing mental health issues and providing a psychiatric assessment. There are 372 district public health centres

(Health Promotion Administration, 2014) and 11,313 clinics (National Health Insurance Administration in Taiwan, 2016c) covering all regions in Taiwan.

1.1.2.2 Hospital mental health services

Hospital care aims to provide more specialised healthcare for people with mental illness. The core aim of the healthcare is to ensure patients have highly effective care and treatment, as well as to relieve symptoms when they experience a mental illness.

This level refers to hospital systems and mainly comprises inpatient mental healthcare. There are three sub-levels of hospital mental health services. These are medical centres (the highest level), regional hospitals, and district hospitals (the lowest level) across the geographical regions of the country. These facilities are provided by both the public and private sectors.

Unlike primary mental healthcare, hospital systems include most kinds of mental health professionals, including psychiatrists, mental health nurses, clinical psychologists, occupational therapists, and social workers.

1.1.2.3 Community mental health service

Community mental health services aim to provide services to people with long-term serious mental illness. Community rehabilitation institutions in Taiwan are defined as follows:

> *"The institutions provide rehabilitation therapy including occupational skills, attitude to work, social skills and activities of daily living in order to help patients with mental illness to re-integrate into family life and society."*
>
> (The Legislative Yuan of the Republic of China, 2007)

In Taiwan, the major institutions included in community mental services consist of community mental health centres, outpatient departments, day centres, day hospitals, rehabilitation services, halfway houses, and other support services. These different institutions include private and public providers.

The institutions provide professional services to assist the patient to rehabilitate and return to family and community life (The Legislative Yuan of the Republic of China, 2007). Within community mental healthcare facilities, there is at least one full-time mental health professional providing mental healthcare. As some community mental health services are attached to hospital systems, some health professionals may be responsible for both types of mental healthcare.

1.1.3 Psychiatric patient classification system

Overall, mental health treatment and care is provided in a variety of settings for people with mental illness. In Taiwan, the type of care people receive is dependent on how they have been classified by the psychiatric patient classification system. The core standard of psychiatric patient classification is designed to improve the efficiency and quality of care for people with mental illness. People with mental health problems are assigned to one of three types of mental healthcare (see Table 1.1).

However, there are still misgivings about the implementation of this system in practice (Hsieh and Shiau, 2006) and it has not been widely adopted by mental health professionals as a result. As mentioned earlier, due to the inadequacy of the referral system and the easy accessibility of mental health services, people are often not allocated the appropriate level of care.

Table 1.1: Psychiatric patient classification systems

Level	Criteria	Service
First	Psychotic symptoms needing acute treatment	Hospital care
Secondary	Remission; unstable condition needing active treatment	Hospital care or community care
Third	Continuing psychotic symptoms which influence social life; ineffective treatment outcome, needing long-term hospitalisation	Hospital care or community care
Fourth	Stable psychotic symptoms; partial deficits in functioning; potential for rehabilitation no need to be hospitalised all day	Community care
Fifth	Stable psychotic symptoms; chronic conditions; no need to be whole-day hospitalised needing assistance in daily life	
Sixth	Stable psychotic symptoms; chronic condition; no need to be whole-day hospitalised, including the elderly, those with dementia or mental retardation, or homeless people with mental health issues	

(Ministry of Health and Welfare, 1998)

1.1.4 Patients in halfway houses

In Taiwan’s health system, halfway houses are one of the community care services. According to the psychiatric patient classification system, patients at third and fourth level are considered to meet the criteria for halfway houses. Ideally, these halfway houses should offer temporary accommodation where patients with mental illness can stay and get support to reach their recovery goals, and learn to live independently (Shu et al., 2001). Although these patients have long-term mental health conditions and need continual medical support, they may have the potential for community rehabilitation. Based on this, psychiatrists from a psychiatric hospital or an outpatient department assess the patients’ conditions and then decide if referral to a halfway house is appropriate. Halfway houses set up regulations and ask patients to comply, and provide therapeutic programmes, such as pharmacotherapy, occupational therapy and vocational training (Shu et al., 2001). People residing in halfway houses are regularly followed up by mental health professionals in mental health outpatient departments in hospitals. Shu et al. (2001) stressed that the halfway houses aim to encourage patients with mental illness to take more responsibility for their own lives, rather than be passive recipients of medical care. However, her study also found that patients in halfway houses in Taiwan experienced a low level of autonomy (Shu et al., 2001).

The reality is that patients with mental illness in Taiwan are more likely to transit between inpatient wards and rehabilitative facilities rather than return to the community. Although these patients’ conditions are stable, they are more likely to be forced by health professionals and family to stay in halfway houses, and be absent from the decision-making process. A number of factors contribute to this situation.

Firstly, there is widespread stigma in Taiwanese society towards patients with mental illness, particularly those with schizophrenia (Zhuang et al., 2017). In traditional Chinese culture, these patients are commonly considered to be mad, unpredictable and dangerous (Wong and Xuesong, 2011), which limits their inclusion in society.

Secondly, in Taiwanese traditional culture, it is expected that family members should take responsibility for taking care of patients with mental illness, including financial support. It is likely to make more financial sense for family members to pay for care in a halfway house. National Health Insurance, costing somewhere between £100 and £250 per month, is substantially cheaper than the average cost of living in Taiwan. In some cases, this fee is waived with evidence from a psychiatrist of a diagnosed serious mental illness (National Health Insurance Administration in Taiwan, 2015).

Finally, recent legislation has also been drafted which prevents long admissions to acute inpatient facilities, due to the high cost (The Dispute of Committee in the National Health Insurance, 2008). Patients care is subsidised for 60-90 days, and if the admission extends beyond this period, that patient must pay higher fees and the hospital must justify the need for an admission that is longer than the average. If health professionals do not make a compelling argument for the need for the admission, any subsidies towards patient care from the government are withdrawn. Therefore, health professionals and families tend to find some mental health facilities, such as halfway houses to place these patients.

1.1.5 Taiwan Mental Health Act

One important development in mental healthcare was the evolution of mental health laws in Taiwan. In the early 1980s, two psychiatrists were assigned by the government to conduct a national survey to examine mental health facilities and staff resources in the country (Chuang et al., 1995). They found unpleasant and prison-like environments to be widespread across mental health facilities, and as a result the Taiwan Mental Health Act was established in 1990 (The Legislative Yuan of the Republic of China, 2007). However, the focus was still on reducing danger from patients with mental illness and protecting the public, rather than on patients' human rights (Tang, 1997).

At this stage, despite the efforts of the government and professionals, patients with mental illness were still compulsorily admitted to mental health facilities where there were no mental health professionals. There was a series of criminal cases related to mental health patients and the abuse of mental patients in a religious institution, which accelerated the enactment of the Mental Health Act in Taiwan. One significant abuse scandal (Long Far Temple) emerged concerning patients with mental illness (Wu and Cheng, 2017). The director of Long Far Temple used metal chains to "help" people with mental illness. This Buddhist temple chained patients with stable mental conditions to patients with more serious conditions, in an attempt to transfer healthy behaviour/thought processes from the stable patient to the unstable one. The pictures of these patients shocked the Taiwanese people and the government started to pay more attention to the patients' human rights.

Accordingly, the Taiwan Mental Health Act was amended several times to ensure patients' rights in cases of compulsory admission. In the most recent version, the act aims to protect patients from discrimination or stigma, to help patients and their families with recovery, to ensure that the final decision on the compulsory admission of patients with serious mental health illness is approved by the authorised review committee, to encourage patients to return to and stay in the community, and to promote and prevent mental health issues (Chou, 2015).

The next section considers the evidence base for patient involvement in shared decision making and the rationale for the thesis.

1.2 Shared decision making

Shared decision making is a two-way communication process between patients and healthcare professionals, where both collaborate in making healthcare decisions. (Charavel et al., 2001; Edwards and Elwyn, 2009; Entwistle, 2009). Charles et al. (1999) conceptualised decision making as a dynamic process and identified a typology of actions that come under this heading including information exchange, deliberation and decision making. In theory, both patients and healthcare professionals follow a series of actions, including sharing information, identifying the task of making a decision, understanding the best evidence about risks, and identifying the benefits of different types of therapy (Légaré and Witteman, 2013; Mead and Bower, 2000). Based on this information, both parties deliberate, culminating in patients and healthcare professionals reaching a consensus (Charles et al., 1997; Charles et al., 1999).

This model assumes that both health professionals and patients can contribute relevant information during the decision-making process. Adams and Drake (2006) note that healthcare professionals have the newest evidence-based information on diagnosis, the course of illnesses, and treatment options. Although patients may have limited knowledge of medical issues, they are the experts on their treatment preference, their own values, and their treatment goals (Charles et al., 1997). Taking into account the voices of both of these parties together, can, therefore, make for better decisions for patients (Slade, 2017).

1.2.1 History of shared decision making

It is acknowledged that the relationship between healthcare professionals and patients is one of the most complicated interpersonal relationships (Edwards and Elwyn, 2009). Prior to the development of the biopsychosocial model, healthcare professionals, as biomedical experts, generally adopted a paternalistic attitude toward patients (Adams and Drake, 2006).

In the mid-1900s, some clinicians focusing on the doctor-patient relationship started to develop an increasing interest in patients' perspectives of their illnesses and clinician-client relationships (Balint, 1957). Following this, others directly advocated that patients' experiences of illness and psychosocial factors should be considered during decision making, rather than only professional knowledge (Ellwood, 1988).

The term "shared decision making" was first adopted in 1982 in the USA (President's Commission for the Study of Ethical Problems in Medicine and Behavioral Research, 1982, p.44). The report states that:

> *"Shared decision making requires that a practitioner seek not only to understand each patient's needs and develop reasonable alternatives to meet those needs but also to present the alternatives in a way that enables patients to choose one they prefer. To participate in this process, patients must engage in a dialogue with the practitioner and make their views on well-being clear."*

It is recognised that shared decision making is designed to shift healthcare to a system where patients are well informed and collaborate with their health professionals (Delbanco et al., 2001). One famous phrase, "nothing about me without me", succinctly expresses the essence of shared decision making (Delbanco et al., 2001). Shared decision making has been widely accepted by experts in evidence-based medicine and widely recommended in general medical encounters (Charles et al., 1999; Slade, 2017).

Shared decision making has gradually become the principal mechanism for ensuring patient involvement. In many countries, shared decision making is promoted and integrated into healthcare policy for its potential to improve the health outcome of patients (Coulter et al., 2011; Légaré and Witteman, 2013). For example, in 2011 the Salzburg Global Seminar, which aims to formulate core goals of shared decision making, suggested that policymakers adopt a policy to encourage implementation of shared decision making in healthcare (Salzburg Global Seminar, 2011).

Most recently, an increasing body of theoretical and empirical literature has examined the issue of shared decision making in healthcare. A review in the early 1990s found that only 10 publications per year were indexed with the key word "shared decision making", increasing to 75 in 2003 (Makoul and Clayman, 2006). From 2004 to 2014 this rose to 34,378 (Koster, 2014).

1.2.2 Definition of shared decision making

Shared decision making has been defined as:

> *"An approach where clinicians and patients share the best available evidence when faced with the task of making decisions, and where patients are supported to consider options, to achieve informed preferences."*
>
> (Elwyn et al., 2010)

Although an agreement on a definition of shared decision making has not been reached, some key attributes have been widely accepted. For example, it is recognised as a dynamic process. As part of this process, at least two people, including a patient and a health professional, are involved and act as partners in decision making. Both parties share information and keep well informed about the benefits and risks of the treatment and expected outcomes, and their preferences, values and circumstances. Based on these, both partners try to reach a mutual agreement regarding preferred treatment options (Hoffmann et al., 2014; Légaré and Stacey, 2009; Sheridan et al., 2004).

1.2.3 Different interpretations of shared decision making

Many interpretations of the concept of shared decision making in healthcare have been described in the literature (Makoul and Clayman, 2006; Stacey et al., 2010). Originally, Emanuel and Emanuel (1992) were concerned with the physician-patient relationship in decision making and argued that a mutualistic relationship is the best way to allow both healthcare professionals and patients to take active roles in decision making. According to this model, both patient and physician hold equal power, and responsibility and deliberation are needed on the part of both; patient values are considered, and healthcare professionals give advice based on these values (Emanuel and Emanuel, 1992). After this, Charles et al. (1997) provided a framework of shared decision making which had been described in the previous section, and has frequently been used in shared decision making intervention studies (Makoul and Clayman, 2006).

Nonetheless, there remains much debate among researchers and clinicians about the interpretations of shared decision making. For example, Elwyn et al. (2000) stated that healthcare professionals should take more responsibility for extracting or responding to patients' preferences during shared decision making. Charles et al. (1997) assumed that healthcare professionals and patients should eventually agree on the decisions being made. However, others have suggested that 'agreeing to disagree' about a course of action is also possible in shared decision making (Joseph-Williams et al., 2017).

While there is no common conceptual interpretation of shared decision making, elements of shared decision making have been widely accepted by many researchers. Makoul's systematic review synthesised 161 conceptual models of shared decision making and identified nine characteristics of health professionals' behaviour in shared decision making, including:

- define/explain the problem
- provide treatment options
- discuss pros/cons (benefits/risks/costs)
- understand the patients' values/preferences
- discuss the patient's ability/self-efficacy
- present professional knowledge/recommendations
- check/clarify the patient's understanding
- make or explicitly defer decisions
- arrange follow-up

(Makoul and Clayman, 2006)

Makoul's framework is applicable across many health service settings. However, his model is limited in that it only focuses on the interaction between patients and health professionals, rather than including patients' families and the wider multi-disciplinary team (Slade, 2017).

1.2.4 Shared decision making is recommended in mental healthcare

Shared decision making is emphasised in policies in many Western countries (Coulter et al., 2011; Del Piccolo and Goss, 2012). In traditional mental healthcare, the main goal was described as helping patients "comply with their treatment plan" rather than involving them in deciding it (known as the paternalistic model) (Deegan, 2007). By implementing shared decision making, the traditional power imbalance between health professionals and patients can be reduced (Capers, 2010). Meanwhile, it is evident that involving both health professionals with expertise in clinical knowledge and patients with expertise in personal beliefs and values produces better decisions, which could bring more benefits to patient recovery (Slade, 2017).

1.2.4.1 Ethical perspective

From an ethical perspective, shared decision making is a basic human right (Drake and Deegan, 2009; Nelson et al., 2001). The right to liberty and self-determination should involve full engagement in the decision-making process and the communication of understandable and unbiased information about treatment and care (Coulter and Collins, 2011). The ethical imperative for shared decision making should build on the principles of good practice, respecting patients' right to know (Elwyn et al., 2013a). In this case, shared decision making which safeguards the autonomy of patients by encouraging their involvement in making decisions about their treatment and care is recommended.

1.2.4.2 Clinical evidence

Research evidence has identified improved outcomes from implementing shared decision making in mental healthcare (Hauser et al., 2015; Joosten et al., 2009; Joosten et al., 2008; Malm et al., 2003). Active patient involvement leads to better engagement, better quality decisions, and improved adherence, which are recognised as indicators of better outcomes (Slade, 2017). The evidence supporting this is as follows.

One systematic review included 11 randomized controlled trials across different health settings (two directly focused on mental healthcare) which aimed to examine the effectiveness of intervention to improve shared decision making in practice (Joosten et al., 2008). The review found that five studies (two of which were focused on mental healthcare) reported that shared decision making had a positive effect on outcome measures including treatment adherence, and depression levels were improved by implementing shared decision making (Joosten et al., 2008). However due to methodological limitations of the included studies (e.g. small sample size), only limited conclusions can be drawn.

A later systematic review aimed to examine the effects of shared decision making on patient-related outcomes, and included 22 studies (Hauser et al., 2015). Five of the included studies involved decision making in mental healthcare, one focusing on people with substance-misuse (Joosten et al., 2009), three on patients with schizophrenia (Hamann et al., 2007; Hamann et al., 2011; Malm et al., 2003), and one on patients with depression (Loh et al., 2007). They found that ten of the included studies indicated positive effects of shared decision making, including two which were focused on mental healthcare. For example, in Sweden, a randomised controlled trial with a two-year follow-up, involving 53 patients with schizophrenia, found that shared decision making led to improved social functioning and higher satisfaction with treatment (Malm et al., 2003). Another follow-up study with 220 substance-dependent patients in the Netherlands showed that shared decision making significantly improved patient-related outcomes, including reduction in primary substance use and addiction severity (Joosten et al., 2009).

A Cochrane review (Duncan et al., 2010) found only two randomised controlled trials. One study conducted in Germany with 405 patients with depression found that the level of patient participation in treatment decision making and patient satisfaction improved without increasing consultation time (Loh et al., 2007). The second randomized controlled trial (also conducted in Germany) involved 107 patients with schizophrenia, with results showing no difference in the health outcome between intervention and control groups (Hamann et al., 2007). A more recent systematic review which explored patients’ experience of clinical assessment involved twelve studies (ten quantitative studies, one qualitative, and one mixed methods) of patients with bipolar disorder (Fisher et al., 2016). In this review, the one qualitative study included took place in the UK and involved 28 patients with mental illness (Bilderbeck et al., 2014). The review found that patients desired more active roles in decision making, and that the advantages of implementing shared decision making included improved treatment adherence, increased patient satisfaction, and reduced suicidal ideation. Whilst the reviews findings are informative, the scarcity of qualitative studies raises concerns of the absence of the patient voice. The most recent systematic review aimed to examine a rationale for shared decision making in mental healthcare (James and Quirk, 2017). The results suggested that shared decision making was widely acceptable and was considered to bring benefits to mental healthcare. Although some positive effects of implementing shared decision making were identified, the reviewers concluded that they were not able to draw any firm conclusions about the strength of the evidence.

The existing quantitative studies have produced some valuable evidence about the benefits and effectiveness of shared decision making, but as yet there has not been adequate critical appraisal of the possible qualitative evidence, particularly in mental healthcare. There is a lack of qualitative systematic reviews which directly examine how patients view shared decision making in mental healthcare. Further reviews are needed to understand this field comprehensively.

In the next section, a discussion of the challenges involved in implementing shared decision making will be presented.

1.2.5 Challenges to implementation of shared decision making

Despite these developments in shared decision making, studies show that patients are often not included in decisions about treatment, and shared decision making is not widely implemented in mental healthcare (Bee et al., 2015; Beitinger et al., 2014; Joseph-Williams et al., 2014a; Patel et al., 2008).

Two narrative reviews (Beitinger et al., 2014; Patel et al., 2008) and one systematic review (Bee et al., 2015) formed similar conclusions about shared decision making. A narrative review including 24 studies revealed that patients desired a more active role during decision making, but patient involvement did not occur (Patel et al., 2008). However, it is evident that implementation of shared decision making bring benefits to patients (Patel et al., 2008). A recent narrative review (Beitinger et al., 2014) which focused on patients with schizophrenia and included 18 articles found that the outcome of shared decision making is positive but implementation of shared decision making in mental health needs further work. In addition, a recent systematic review aimed to examine how patient-involved care planning is operationalised within mental healthcare (Bee et al., 2015). This review included 117 studies and concluded that there is a lack of patient involvement in mental healthcare (Bee et al., 2015).

This lack of patient involvement is illustrated by the 2017 Community Mental Health Survey in England which found only 52 % of the responders fully agreed that they were involved in decision making about the “medication” they received, and 55% fully agreed that they were involved in decision making about “treatment or therapies” to be used as much as they wanted (N=8,944) (Care Quality Commission, 2017). Of the responders who received new medication, only 54% reported that they were definitely given information about the medication in a way they could understand (Care Quality Commission, 2017). The evidence suggest that efforts to implement shared decision making in mental healthcare have met with resistance. Some of the key challenges are summarised below.

1.2.5.1 Professional paternalistic attitude

Professionals’ attitudes could be a key to influencing the level of patient involvement in decision making (Charles et al., 1999; Cribb and Entwistle, 2011; Kon, 2010). Patients have also acknowledged that their ability to participate depends on their healthcare professionals (Frosch et al., 2012). To facilitate shared decision making, healthcare professionals need to actively encourage patients to engage in the shared decision making process (Edwards and Elwyn, 2009; Mead and Bower, 2000). Therefore, the role of health professionals is vital for patient involvement in making decisions.

However, one study which analysed eighty transcripts in Italy found that health professionals only made limited attempts to involve patients with mental illness in decision making (Goss et al., 2008). In the UK, Quirk et al. (2012) analysed audiotapes of 92 outpatient consultations and examined health professionals' attitudes during consultations. The results revealed that health professionals often adopted a paternalistic attitude in the decision-making process.

1.2.5.2 Concerns about patients' impaired decisional capacity

While many studies generally support the positive impact of shared decision making, health professionals are concerned about the decisional abilities of patients with mental illness. Two qualitative studies have explored barriers to shared decision making from psychiatrists' perspectives. Both studies took place in the UK, one involving 21 general adult psychiatrists (Seale et al., 2006) and the other 26 consultant psychiatrists (Shepherd et al., 2014). Both studies showed that healthcare professionals considered mental health patients to have impaired abilities or poor insight into mental illness, leading to unwillingness to involve them in decision making. In such cases, psychiatrists were afraid that patients would make risky decisions which would worsen patient outcomes.

Despite evidence to the contrary, Auerbach (2000) argued that some healthcare professionals distrust the ability of people with mental illness to make competent decisions. It is challenging for many patients with mental health problems to believe that health professionals are willing to share with them the right to make decisions together (Happell et al., 2004). Thus, some decisions about treatment or care are related to a complex risk-benefit trade-off which is not just about treatment outcome but also about patients' personal lives (Drake and Deegan, 2009).

This view has been contested: for example, a study in the United States which aimed to examine decisional capacity for informed consent in schizophrenic research subjects found that patients with schizophrenia had the same decisional ability (after training) as those without schizophrenia (Carpenter et al., 2000). Similar studies have concluded that patients with mental health problems are able to understand treatment information and make rational decisions (Bunn et al., 1997; Carpenter et al., 2000; Hamann et al., 2006; Stroup et al., 2005).

1.2.5.3 Passive patient preference

Another consideration is patient preference in decision making. Patient preferences about being involved in shared decision making vary in healthcare. Some patients may prefer to make informed decisions, but others may want to leave the final decision to their health professionals (Légaré and Witteman, 2013). It is potentially challenging for health professionals to involve patients with low motivation in decision making. Thus, patient preference about participation in decision making exists on a continuum from passive to highly active, but those who are actively involved reported greater satisfaction or better outcomes (Kessler et al., 2001).

It is argued that patients' role preferences should be discussed and accepted, even if patients prefer a passive role (Elwyn et al., 2000). As this debate has emerged, an increasing majority of patients have indicated that they prefer active involvement in deciding their treatment and care (Chewning et al., 2012). A systematic review which explored the involvement preference of patients with substance use disorder concluded that the patients desire a more active role in decision making (Friedrichs et al., 2016).

Patients' role preferences in decision making have received increasing attention in practice (Clarke et al., 2015). Despite the extended discussion between health professionals and patients in general practice, preference discussion is still limited in mental healthcare. For example, in the USA, researchers who analysed 191 mental health visits found that more time was spent on scientific discussion (about pros and cons, nature of decision, uncertainties, goal/context, and understanding) than on discussing preferences (about the patient's role, alternatives, and preferences) in these medical encounters (Fukui et al., 2015). It could be important for making decisions to encourage the patients to express their views about their preferences, and gain an insight into what factors influence these opinions.

1.2.5.4 Time-consuming issue

A common argument proposed by some health professionals is that the process of involving patients in the decision-making process is time-consuming (Ford et al., 2002; Légaré et al., 2008). Health professionals cite the difficulty of looking up evidence about certain conditions during a busy working day and bringing this evidence into consultations with patients (Ford et al., 2002). Given the relatively short consultation times, health professionals have argued that they do not have sufficient time to implement shared decision making (Charles et al., 1999; Coulter, 2010; Towle et al., 2006).

Although health professionals struggle with their busy timetables, a variety of approaches could be employed to improve the process of shared decision making. For example, many health professionals are concerned about providing patients with sufficient information on treatment and care in a short consultation time. Thus, verbal explanations, which were viewed as the time-consuming part, may be optimised in the following ways: audiotapes, videos, booklets, computer programs, and interactive websites could be used to provide the information more efficiently to help patients to understand.

In addition, there is substantial evidence to the contrary: a Cochrane systematic review which aimed to assess the effects of decision aids for people facing treatment or screening decisions yielded inconsistent results regarding consultation length where shared decision making was practised (Stacey et al., 2014). Nine of the included studies related to consultation length of shared decision making found mixed results. Six studies found there was no difference in consultation lengths between a shared decision-making group and a control group. Two studies showed that the shared decision making group took longer than the comparison group. One indicated that the shared decision making group took less time in consultation. In particular, one study in the USA focused on shared decision making in primary care for depression, and found that the consultation time did not differ between those with and without shared decision making. Therefore, it is difficult to conclude whether shared decision making is a time-consuming procedure.

Overall, although implementation of shared decision making in mental healthcare is challenging in some ways and some concerns have been discussed, there is a clear desire for patient involvement in decision making and various benefits have been recognised. Further efforts are needed to enhance active patient involvement in decision making in mental healthcare.

1.2.6 Decision aids

It is clear that, world-wide policy makers welcome the integration of shared decision making into healthcare (Harter et al., 2011). Shared decision making is now part of patient-centred care policies in some western countries, such as the UK (Coulter et al., 2011; Elwyn et al., 2010). While governments have recently promoted shared decision making in healthcare, its implementation still needs further work, as described in the earlier sections, due to various barriers, such as health professionals' attitudinal issues, limited time resources, and concerns about mental conditions (Coulter et al., 2011). Hence, the use of decision-support tools and resources is fundamental to facilitating shared decision making in practice.

The International Patient Decision Aid Standards Collaboration, which is a world-wide group of researchers, health professionals, patients, and carers who are interested in the design and use of decision aids (DAs), defines them as follows:

> *"Patient decision aids are tools designed to help people participate in decision making about healthcare options, with the goal of promoting deliberation between patients, healthcare providers, and others about those options."*
>
> (Volk et al., 2013)

Despite there being no agreement on the definition, some studies have suggested that implementation of shared decision making requires both skill and awareness on the part of health professionals (Makoul and Clayman, 2006) and the involvement of patients (who are experts on their own values and preferences) (Slade, 2017). A study which included 212 participants (researchers, practitioners, patients, and policy makers) produced a quality criteria framework for Decision Aids, and identified a number of key requirements (Elwyn et al., 2006) including:

- systematic development process
- providing information about options
- presenting probabilities
- clarifying and expressing values
- using patient stories
- guiding/coaching
- disclosing conflicts of interest
- providing internet access
- balanced presentation of options
- using plain language
- basing information on up to date evidence
- establishing effectiveness.

A number of decision support tools have been developed to overcome the challenges and facilitate shared decision making in healthcare, but there is no consensus about the definition of decision aids. Decision aids are often employed in the context of shared decision making to support patients to make medical decisions (Coulter and Collins, 2011). To ensure that patients are able to actively engage in decision making, decision aids are utilised to support them with clear and understandable information about their conditions and treatment options (Drug and Therapeutics Bulletin, 2013). By promoting active patient involvement, decision aids differ from merely educational materials such as passive informed consent materials (O'Connor, 2001).

A variety of forms of decision aids have been used, including a simple one-page sheet, a script of option outcomes, education and counselling about option outcomes, audiotapes, videos, booklets, computer programmes, decision boards, and interactive websites (Coulter and Collins, 2011; Ng et al., 2013). Some are designed to be completed by patients prior to their medical encounters and others are designed to be completed during the consultation (Substance Abuse and Mental Health Service Administraction, 2010).

1.3 Rationale for the study

In general, positive effects of shared decision making have been identified and some efforts have been made to support its implementation in practice. Although most patients seem to desire a more active role in decision making, from the evidence, shared decision making does not take place routinely in mental healthcare. Many barriers or challenges have been identified in the literature.

Furthermore, current research on shared decision making has primarily been conducted in western countries (Coulter et al., 2011; Elwyn et al., 2010), but is less visible in other parts of the world (Capers, 2010). Although some policy makers in Taiwan have started to promote shared decision making in healthcare since 2016, further work is still needed both in studies and in practice (Liao et al., 2017).

In more submissive cultures, shared decision making could face more challenges. In such cultures, people expect a paternalistic model in decision making and assume that health professionals should take on the responsibility of being decision makers (Coulter and Jenkinson, 2005). Similarly, in a typical East Asian family, such as in Taiwan, authoritative family members are more likely play a decision-maker role and patients are more likely to play a silent role during decision making, due to the traditional cultural pressure (Gilbar and Miola, 2015).

The issues for shared decision making in mental healthcare are likely to be compounded and challenging because of societal perceptions of patients with mental illness, and it is implied that the mental health professionals, particularly psychiatrists, should hold the most power and decide for patients with mental illness based on their best interests (Shepherd et al., 2014). Also, in the view of health professionals, patients with mental illness have a lack of insight, which renders them unable to make reasonable decisions (Shepherd et al., 2014).

There is still very little evidence about the process of decision making in Asia, and specifically in Taiwan. Therefore, there is a need to explore and address the use and perspectives of shared decision making in mental healthcare and in other cultures. This study starts to address this gap in evidence.

1.4 Summary

This chapter has provided an overview of mental healthcare in Taiwan and shared decision making in current practice, together with explanations of the various benefits but also challenges of implementing shared decision making in mental healthcare. The next chapter will provide a discussion of the methodology used for this thesis.

Chapter Two: Methodology

This chapter will present a discussion of the methodological foundations for this thesis. An overview of research paradigms and a rationale for adopting the approach taken will be provided. Following this, the aims and objectives of the study will be outlined. Specific details of how the author ensured trustworthiness and methodological quality will be given. Finally, details of ethical considerations and obtaining ethical approval for this research will be presented.

2.1 Research paradigms

The term "research paradigm" is defined as an interpretative framework, which is underpinned by a set of beliefs and views about the world and how it should be understood (Guba, 1990; Kuhn, 1970). A research paradigm creates an integrated view of how knowledge is perceived and how researchers can see themselves in relation to this knowledge when formulating and developing a research proposal. Meanwhile, it is not only imperative to consider what methodological strategies will be used to answer a research question, but also important to understand the justification for the methodological strategies (research design) and the researchers' own philosophical assumptions (Guba, 1990).

There are highly abstract principles guiding researchers in their exploration of the universal aspects of human beings (Denzin and Lincoln, 2005). Beliefs regarding ontology, epistemology and methodology are involved in these principles, which guide researchers in acting in and seeing the world (Denzin and Lincoln, 2003b; Weaver and Olson, 2006).

Ontology refers to the kind of being the human individual is, and what the nature of reality is; epistemology is about the relationship between the enquirer and the known, and the methodology sets out to explore how we gain knowledge about or know the world (Weaver and Olson, 2006). In other words, ontology is about understanding what reality is, epistemology is about how people know something, and methodology is how people find it out. Researchers can apply a variety of fundamental strategies to develop new knowledge.

Selecting a suitable choice of research paradigm is based, therefore, on the nature of the research questions which the researcher intends to ask (Denzin and Lincoln, 2005). Many research paradigms are applied for the purposes of health research (Creswell, 2007; Green and Thorogood, 2009; Teddlie and Tashakkori, 2009). The two most common research paradigms have significantly influenced researchers for decades: positivism and interpretivism, which lead to the different research methodologies (Tuli, 2010). The positivist paradigm is commonly aligned to a quantitative methodology, whilst interpretivism refers to a qualitative methodology (Rahman, 2016). Both qualitative and quantitative approaches are based on philosophical traditions and have different ontological and epistemological assumptions. The section below provides a more detailed overview of each paradigm.

2.1.1 Positivism versus interpretivism

2.1.1.1 Positivism

A positivist view focuses only on factual knowledge which is gained through observation and measurement, and positivists believe that there is a single reality (Crotty, 1998). Positivism holds the ontological principle that an external objective reality exists for any situation or research phenomenon, which is independent of the researchers, and the epistemological principle that this reality is free from any time and context and can be generalised to all human knowledge (Denzin and Lincoln, 2005). The basis of positivism is that researchers can be totally objective and reality exists independent of the observer (Pring, 2000; Scotland, 2012). In other words, when adopting positivism, researchers are independent of the research and the research can be purely objective. Furthermore, positivist researchers believe that this reality can be found through scientific experiments which are quantitative methods, such as nomothetic experiments, laboratory experiments, and quantitative analysis (Denzin and Lincoln, 2005; Neuman, 2011). Thus, a positivist study is purely objective and trustworthy with a rigorously structured research method.

However, beyond these features of this research paradigm, one disadvantage is obvious. The epistemological disadvantages of positivism give rise to reservations about its appropriateness for the field of nursing studies (Clark, 1998). Positivism refers to the idea that researchers need to concentrate on facts rather than on the meaning of human behaviours and human interests (Aliyu et al., 2014; Rahman, 2016). Researchers adopting positivism are limited to using an objective approach to collect data and interpret the meaning of data (Aliyu et al., 2014). For social science, a positivist approach is significantly lacking in its ability to capture the complexity and meaning of human behaviours and social phenomena (Denzin and Lincoln, 1998).

2.1.1.2 Interpretivism

Conversely, interpretivism holds the view that reality is constructed by social phenomena created by humans, and exists in multiple, context-specific situations (Green and Thorogood, 2009; Guba and Lincoln, 1994). Interpretivist studies aim to generate descriptions of and insights into social phenomena and unveil the meanings of social behaviours (Jacox et al., 1999).

The ontological assumption of interpretivism is relativism (Guba and Lincoln, 1994). Reality is subjective and socially constructed by individual interpretation and cannot be separated from the “person” (Mack, 2010). Interpretivists believe that there is no single reality, and therefore those multiple realities need to be interpreted (Guba and Lincoln, 1994). The reality is mediated by individual senses and the world is pointless without consciousness (Scotland, 2012).

The epistemological assumption of interpretivism is one of subjectivism based on real world phenomena, and the belief that knowledge is inductively gained through individual experience. Only if meaning is constructed though the interaction between consciousness and an individual world can it be discovered and transmitted in a social context (Crotty, 1998). Interpretivists believe that even individuals in the same population can create their own meanings for an event and interpret the same event differently. The way to experience a world is to participate in it, which is both to encounter and to mould (Heron and Reason, 1997). Therefore, through the position of individuals who are participating in it, the social world can be understood (Cohen et al., 2007). Also, individual social constructs that can be understood are extracted through interaction between participants and researchers (Guba and Lincoln, 1994).

Some argue that the interpretivist approach is advanced and more scientific for understanding social science (Travers, 2008). The paradigm presents researchers with the chance to understand individual experiences and meanings in some depth, and has been widely recognised as appropriate for use in qualitative studies (Creswell, 2007). Furthermore, researchers in interpretivist studies should treat participants as human rather than objects of natural science, to capture the subjective meaning of social phenomena (Mack, 2010).

Despite the features of interpretivism, some researchers consider that there are some disadvantages to interpretivist studies due to the subjective nature of this approach. Data, therefore, is heavily influenced by individuals’ perspectives and values. In these cases, it could be difficult to generalise the findings from these studies to other situations (Mack, 2010). However, as interpretivist studies do not aim to be generalisable, such studies can provide thick descriptions of data and a high level of validity (Mack, 2010).

2.1.2 Applying the interpretivist paradigms

Overall, from a philosophical perspective, positivists aim to formulate laws based on prediction and generalisation, and propagate the application of empirical methods to answer a research question (Scotland, 2012). Positivists attempt to identify what factors affect the outcomes which researchers are interested in (Creswell, 2007). Interpretivists aim to understand social phenomena from an individual's perspective, probing interaction between people and the cultural and social contexts where they live (Creswell, 2007). Also, the interpretivist paradigm has proved the best way for researchers to understand and interpret participants' perspectives of the phenomena being studied (Guba and Lincoln, 1994), so these statements support the choice of interpretation for health researchers who propose to investigate a phenomenon in a group of patients or particular health settings.

Furthermore, in health studies, human beings are subjects who can help researchers understand their social behaviours. Adopting the interpretivist paradigms assists researchers to observe the phenomena from the inside, rather than objectively observe it from outside (Mack, 2010). Unlike positivism, it is impossible to separate the researchers from the research participants, especially in social sciences, due to the interactions between humans (Mack, 2010). In other words, from interpretivists' viewpoint, the idea is that pure objectivity on human behaviour is difficult. Therefore, the interpretivist paradigm is beneficial to gain insight and understanding of behaviour, in order to explain the meanings of actions from the perspective of participants (Scotland, 2012).

It is still unclear how patients and healthcare professionals engage with each other around decisions for the care and treatment of the patients in the Taiwanese context. This paradigm could significantly help health researchers when they require in-depth and insightful information about a dynamic process. As the aim of this study was to explore and understand patient and health professional perspectives of shared decision making in secondary mental healthcare, and their social and historical constructions of the context in Taiwan, an interpretive paradigm is the most judicious choice to explore patients' and health professionals' perspectives.

2.2 Research aim and objectives

2.2.1 Aim

- to explore/understand the process of decision making, from both health professional and patient perspectives, in secondary mental healthcare in Taiwan.

2.2.2 Objectives

Key objectives included:

- to examine and synthesise patient perspectives of shared decision making in secondary mental healthcare using a systematic review of qualitative studies;
- to explore patient perspectives of shared decision making in secondary mental healthcare in Taiwan using semi-structured qualitative interviews;
- to explore health professional perspectives of shared decision making in secondary mental healthcare in Taiwan using semi-structured qualitative interviews.

A detailed discussion of methodologies for each objective will be presented, including qualitative systematic review methodology and qualitative research methodology.

2.3 Qualitative systematic review methodology

2.3.1 Types of systematic reviews

A literature review is a summary of a subject field which can be used to support the identification of specific review questions (Rowley and Slack, 2004). Although all review types are required be systematic at some level, the extent could vary between different types of reviews depending on the methods used (search, appraisal, synthesis, and analysis) (Booth et al., 2012). There are two main types of literature review: systematic, and traditional narrative reviews (Cook et al., 1997; Greenhalgh, 2010).

A narrative review is a summary which applies informal or subjective methods to collect and interpret evidence (Grant and Booth, 2009). Narrative reviews are used to summarise the evidence and are mainly descriptive, without involving systematic evidence-based criteria (Greenhalgh, 2010). They often include searches and selections based on the reviewer’s personal interests and subjective judgments, potentially leading to bias (Cook et al., 1997). The extraction of information from findings is subjective and lacks explicit criteria for inclusion (Green et al., 2006). Using this approach, the data is described rather than interpreted and it is therefore less rigorous (Paré and Kitsiou, 2017).

A systematic review is a summary of the literature that uses systematic, reproducible, explicit methods to search, critically appraise, and synthesise literature on a specific topic (Gopalakrishnan and Ganeshkumar, 2013). The main purpose of a systematic review is to identify key scientific contributions to a particular field, or to answer a specific question based on pre-identified criteria (Higgins and Green, 2011). The use of systematic methods helps minimise bias and provide impartial conclusions (Cipriani and Geddes, 2003; Cook et al., 1997; Higgins and Green, 2011). Systematic reviews can help researchers to understand inconsistencies between various studies, and produce more precise recommendations than those from narrative reviews (Cook et al., 1997).

While quantitative systematic reviews are well established through the Cochrane Collaboration's work, qualitative systematic reviews have been developed more recently and are still evolving (Seers, 2015). Most systematic reviews involve a meta-analysis which requires statistical techniques to synthesise the quantitative data for included studies (Petticrew and Roberts, 2005). The Cochrane Collaboration has raised awareness of qualitative systematic reviews in health and now has a Qualitative and Implementation Methods Group (Gulmezoglu et al., 2013).

2.3.2 Selecting qualitative systematic review methodology

Qualitative systematic review methodology was selected to be consistent with the review aims and on the bases of the research questions. These were: to identify qualitative evidence of patient perspectives of shared decision making in secondary mental healthcare, and its barriers and facilitators. This review aims to systematically identify, extract and synthesise evidence about patient perspectives of shared decision making.

A qualitative systematic review systematically searches for studies on a topic, extracts the findings from each study, and synthesises the evidence together to explore a review question (Grant and Booth, 2009; Higgins and Green, 2011; Seers, 2012). Stern et al. (2014) stated that the questions used in qualitative systematic reviews emphasise the perspective of the participants involved in and experiencing the phenomena with which the researchers are concerned.

Noblit and Hare, who are pioneers in the area of qualitative synthesis, describe qualitative reviews as interpretative (Noblit and Hare, 1988). Interpretative approaches aim to interpret the data, and from that interpretation to develop a theory which is helpful for understanding or predicting human behaviour (Seers, 2015). Furthermore, the value of generating qualitative evidence as thick descriptions has been recognised (Denzin, 1989).

Thick descriptions, which are often extracted from qualitative studies, are “deep, dense and detailed accounts of problematic experience”. This means that thick descriptions focus on deeper aspects of phenomena, such as feelings and the meaning of human actions (Holloway and Wheeler, 2010). Consistent with interpretivist paradigms, in this review, the author therefore focused on thick descriptions from qualitative evidence to explore the interpretations in depth.

For complex interventions, the need for rigorous evidence must come from multi-method evaluation and high-quality reports which focus on both the effectiveness of interventions and efforts to implement the interventions more widely (Thomson, 2009). Dixon-Woods et al. (2006) argue that qualitative systematic reviews would not be limited to studying the effectiveness of the interventions but would also be able to make unique contributions to in-depth understanding of the intervention, such as identifying particular patterns and contexts. In other words, qualitative systematic reviews could contribute to determining what interventions work or do not work, and to understanding when, how, or why an intervention could be effective. In this way, evidence-based interventions and practices can be reviewed through a broader, culturally rich and contextual lens.

Because of complex and numerous issues related to providing services and support to patients with mental illness, qualitative approaches that explore experiences, perspectives, relationships, and phenomena are required. Meanwhile, detailed portrayals of aspects of shared decision making, including the mechanisms whereby shared decision making functions, in-depth interpretations of how patients view the implementation of shared decision making in mental healthcare, and facilitators of/barriers to shared decision making, could be extracted from thick descriptions in qualitative studies. These features of qualitative systematic reviews could meet the research question of this review: to systematically explore patients’ perspectives of shared decision making within the existing literature.

2.3.2.1 Search tool

A search tool is a technique to identify focused research questions and to improve the comprehensiveness of systematic reviews in various ways, including determining inclusion/exclusion criteria, searching studies, extracting data from studies, and reporting findings (Aslam and Emmanuel, 2010; Higgins and Green, 2011). In this review, the SPIDER tool was used to organise the process of the review.

In the search stage, a search tool standardises systematic search strategies and assists researchers to identify possible search concepts and increases rigour in research (Cooke et al., 2012). The majority of search tools emphasise quantitative studies more, such as PICO (Population, Intervention, Comparison and Outcome), which is designed to identify and particularise quantitative enquiries (Richardson et al., 1995). Thus, Cooke et al. (2012) argue that this tool is inappropriate for a qualitative systematic review.

The SPIDER tool, developed by Cooke et al. (2012), is a five-concept tool which supports incorporating the synthesis of qualitative research into systematic reviews; the concepts include sample (S), phenomenon of interest (PI), design (D), evaluation (E), and research type (R) (Cooke et al., 2012). Based on this tool, one research question of this review is, 'What perspectives of shared decision making prevail amongst patients with mental illness in secondary mental healthcare?'

It might be not necessary to use each concept of the tool to the same extent (Higgins and Green, 2011). For example, if researchers applied the concept, "research type (R)" in the SPIDER tool to narrow down the number of included studies, they could miss out some mixed-methods studies, and meaningful qualitative parts of mixed-methods studies could be ignored by searches. In order to include more potentially relevant studies at the search stage, the researcher only used three of the SPIDER tool's search term concepts to identify studies, namely "sample", "phenomenon of interest", and "evaluation".

2.3.2.2 Data extraction

Data extraction is the process of selecting and recording relevant data from the studies included in the review (Heyvaert et al., 2016). The extraction procedure typically involves summarising all relevant data in the included studies which meet the criteria of the review. This relevant data often includes pertinent contextual issues, characteristics of the population, phenomena of interest, research design, methodology, and the outcome (Heyvaert et al., 2016; White and Schmidt, 2005).

While extracting findings from qualitative studies, it might be difficult to ascertain what counts as relevant findings and to identify the key concepts and succinct summaries of findings (Thomas and Harden, 2008). Therefore, extracting all eligible data could avoid omitting potential findings related to review questions (Noyes and Lewin, 2011). Furthermore, Thomas and Harden (2008) recommend taking all of the eligible texts labelled as results or findings as data to be processed in a thematic synthesis. This approach therefore guided data extraction in order to extract all relevant findings and results from each included article.

2.3.2.3 Quality of the review

Critical appraisal is the process of systematically assessing and judging the quality of research in a specific field (Higgins and Green, 2011). The critical appraisal of the quality of studies is an essential component in evidence-based practice (Clarke and Oxman, 2003; Mhaskar et al., 2009). The level of quality of a qualitative systematic review can determine whether the review can discover new understandings, often helping to clarify "why", and bringing the potential to establish a new theory (Seers, 2015).

Although a range of critical appraisal tools is available for the assessment of the quality of qualitative studies, there is no significant consensus on the best tool (Dixon-Woods et al., 2006). In this review, the consolidated criteria for reporting qualitative research (COREQ) were applied.

The COREQ, developed by Tong et al. (2007), comprises a 32-item checklist. It helps researchers to understand important aspects of the research team, study methods, context of the study, findings, analysis and interpretations (Tong et al., 2007). The COREQ is recognised as a suitable tool for researchers conducting systematic reviews of qualitative studies (Booth et al., 2014).

2.3.2.4 Synthesis/Analysis of qualitative studies

Qualitative synthesis has been defined as "a methodology whereby study findings are systematically interpreted through a series of expert judgements to represent the meaning of the collected work" (Bearman and Dawson, 2013). By involving qualitative evidence, researchers can interpret social phenomena including the mechanisms of acceptance, feasibility, the meaningfulness of an intervention, and related barriers to and facilitators of an intervention (Booth, 2016). Qualitative synthesis also has the potential to identify omissions and gaps in existing research, and can add interpretation and depth to qualitative evidence (Major and Savin-Baden, 2010).

A variety of methods have been developed to use with these approaches, including narrative synthesis, critical interpretive synthesis, grounded theory synthesis, meta-ethnography, meta-study, and thematic synthesis (Bearman and Dawson, 2013; Dixon-Woods et al., 2007). There are some descriptions of different approaches in Table 2.1 below. It should be noted that the development of qualitative synthesis is still not complete and there are still relatively few examples of some approaches being applied (Tacconelli, 2010).

Table 2.1: Methods proposed for the synthesis of qualitative evidence

Synthesis method	Description
Meta-ethnography	A set of techniques for synthesising qualitative studies. It involves the selection, comparison and analysis of studies to create new interpretations or concepts.
Thematic synthesis	The identification of recurrent or important themes. Findings of included studies are summarised under thematic headings. Information is tabulated, allowing identification of prominent themes and offering structured ways of dealing with the data in each theme.
Grounded theory	Originally, grounded theory was developed for use with primary studies and describes methods for sampling, data collection and data analysis. Recently, its potential application to the synthesis of multiple qualitative studies has been explored.
Content analysis	A systematic technique for categorising data into themes and counting the frequency of the themes.
Case survey	A formal process for coding data from qualitative cases into a quantitative form
Qualitative research synthesis: qualitative meta-synthesis	A set of techniques for the interpretive integration of qualitative findings.
Qualitative research synthesis: qualitative meta-summary	A set of techniques for the quantitative aggregation of qualitative research findings.
Narrative synthesis	A general framework and specific tools and techniques that help to increase transparency and trustworthiness. It can be applied to reviews of quantitative or qualitative research, as individual tools and techniques can be selected according to the type of study design and the type of data included in the review.

(Tacconelli, 2010)

Thematic synthesis was selected for the qualitative systematic review in this study. Originally, the aim of thematic synthesis was to explore these approaches to see “what works” (Ring et al., 2011). Thematic synthesis involves the clear identification of prominent or recurrent themes, and organises and summarises the findings of different studies according to specified thematic headings (Dixon-Woods et al., 2005; Thomas and Harden, 2008). Thematic synthesis is widely applied in qualitative synthesis to explore participants’ experiences and views (Garcia et al., 2002; Mcinnes and Chambers, 2008;

Morton et al., 2010). Thomas and Harden (2008) have also detailed each step of thematic synthesis and provide a clear example process for health studies. Accordingly, thematic synthesis was selected for this study.

Thomas and Harden (2008) proposed three steps in thematic synthesis (see Figure 2.1):

- Free line-by-line coding of textual findings from primary studies;
- Organisation of these free codes into descriptive themes;
- Development of analytical themes.

Figure 2.1: The steps of thematic synthesis

For free coding line-by-line, researchers code a text one line at a time to identify some meaningful codes. Each piece of data in turn could be annotated using a set of pre-existing codes, or new codes could be added if necessary.

Next, researchers start to review similarities and differences among the codes assigned in the first step to group them into a parallel structure. In some cases, new codes may be applied to capture the meanings of a group of initial codes. Thus, in this step descriptive themes are generated from an inductive analysis of the findings of the included studies.

Finally, based on the above steps, the findings of the included studies are integrated into a complete picture. By using descriptive themes from the above inductive analysis, “going beyond” the content of the original studies and interpreting the relationships between descriptive themes using a hierarchical tree structure leads researchers to answer their review questions. Thus, analytical themes are generated in this step.

The author sought an approach to summarise and analyse evidence from qualitative studies exploring how patients viewed shared decision making in secondary mental healthcare. It was expected that this approach would also help the author to recognise appropriate themes to meet the aims and objectives of the study.

2.4 Qualitative research methodology

An increasing body of literature has emphasised the value of qualitative studies (Denzin and Lincoln, 2005; Flick, 2009). Qualitative approaches are important in helping researchers to determine the nature of a phenomenon and the meaning of an experience (Fitzpatrick and Boulton, 1994; Lobiondo-Wood and Haber, 2013). The data and findings of qualitative studies provide an in-depth understanding of insights into research problems (Creswell, 2007; Denzin and Lincoln, 2003b). Specific cultural and social factors can be identified through qualitative works, and such factors can be helpful to improve quality of care (Pope et al., 2002). For the development of qualitative research, many methodologies are discussed in the literature (Flick, 2009). Based on the interpretivist paradigm, the qualitative methodology for primary studies (patient interviews and health professional interviews) was selected.

2.4.1 Qualitative approaches

Generally, different qualitative approaches share a similar goal: to reach an understanding of a specific phenomenon from the perspective of people experiencing it (Vaismoradi et al., 2013). Therefore, a considerable overlap can exist between different qualitative approaches in terms of methods, process and techniques (Vaismoradi et al., 2013). Many types of theoretical methodologies for qualitative research are employed in studies: these include: grounded theory, phenomenology, ethnography, case study, action research, and a generic qualitative approach. The approaches will be discussed further in the following sections.

2.4.1.1 Grounded theory

The main purpose of grounded theory is to construct a theory that can help to integrate human behaviours, experiences, and actions (Lobiondo-Wood and Haber, 2013). In a grounded theory approach the research questions focus on a problem that is associated with the complexities and processes of human actions and interactions. The core of grounded theory includes using systematically inductive principles of data collection and data analysis to establish theoretical frameworks (Denzin and Lincoln, 2003b).

2.4.1.2 Phenomenology

Phenomenology aims to investigate or inquire into the meanings of experiences as people live with them, and to reveal an insight into the essence of the lived experience (Flick, 2007; Van Manen, 2007). Therefore, phenomenological research is applied to describe, explain and understand the meaning of human experiences.

2.4.1.3 Ethnography

Ethnography is identified as a study approach to understand behaviours, social interactions, and perceptions that happen within groups, teams, organisations, and communities (Reeves et al., 2008). This approach is designed to describe, understand and interpret a specific social circumstance with a complete range of opinions and cultural diversity (Gerrish et al., 2010). The findings of ethnographic studies can help researchers to explore how cultural beliefs, knowledge and values affect the experiences of a specific population in a particular setting (Lobiondo-Wood and Haber, 2013; Patton, 2002).

2.4.1.4 Action research

Action research involves doing research with and for people in the context of its application, and has been recognised as a facilitator and evaluator of change (Gerrish et al., 2010). In the healthcare field, action researchers work closely with health providers to systematically observe the issues of changing practice, and then develop potential solutions to practical problems (Meyer, 2000). Engaging in action research is an empowering experience for researchers (Gerrish et al., 2010; Meyer, 2000). This approach requires that participants recognise the need to change and are also willing to actively take part in the change process (Meyer, 2000).

2.4.1.5 Generic qualitative approach

A generic qualitative approach is described as “an approach to seek to explore and understand a phenomenon, a process, or the perspectives and worldviews of the people involved” (Merriam, 1998). Generic qualitative approaches offer an opportunity for researchers not to be limited by a single established methodology but to utilise the tools that established methodologies provide, and to formulate research designs which fit their epistemological positions and specific research questions (Kahlke, 2014). Researchers who employ a generic qualitative approach need to make their theoretical position explicit (Caelli et al., 2003; Merriam, 1998). Caelli et al. (2003) argue that although a generic qualitative approach is not guided by a definitive or traditional set of philosophic assumptions, as in one of the qualitative methodologies above, a growing trend of generic studies has appeared, particularly in applied disciplines (such as nursing).

Although other approaches above, such as grounded theory, phenomenology and ethnography, help researchers to frame methodological strategies, in some ways they also limit their applicability (Percy et al., 2015). Also, there is a broader public debate around research genres and studies which do not fit with any established methodologies (Caelli et al., 2003). In some cases, the study questions might fit more than one established methodology (Cooper and Endacott, 2007; Kahlke, 2014) and researchers need to consider a more generic qualitative approach.

To meet the main aims of this study, to explore patient and health professional perspectives of shared decision making in secondary mental healthcare in Taiwan, a generic qualitative approach was selected. A generic qualitative approach using thematic analysis could identify both study participants' beliefs, experiences, preferences, and views about how decision making has been processed or shared. Meanwhile, this study simply seeks to explore the perspectives of those involved in a specific decision-making process, with no requirement to build a theory (grounded theory) or examine cultural diversity (ethnography). Therefore, a generic qualitative approach was applied to gather the information from patients and health professionals.

2.4.2 Qualitative data collection methods

Within qualitative research, three kinds of data collection are used: interviews, observation, and focus groups (Creswell, 2007; Ellis, 2013; Mack et al., 2005).

Observation is a data collection approach in which researchers directly observe participants in natural settings or occurring events (Creswell, 2007). A focus group is a group discussion on a specific topic designed to answer a research question (Creswell, 2007). The discussion is processed, guided and recorded by a researcher. Interviews share many common features with a focus group, but there is only one participant, who is individually interviewed (Mack et al., 2005). Each method has different strengths and weaknesses, as detailed in Table 2.2.

Table 2.2: Strengths and weaknesses of different types of data collection

Type	Strengths	Weaknesses
Observation	• Allows insight into contexts, relationships, behaviours	• Time-consuming • Ethical dilemma of consent of participants
Interview	• Elicits in-depth responses, with nuances and contradictions • Gets at an interpretive perspective i.e. the connections and relationships a person sees between particular events, phenomena and beliefs • Addresses sensitive topics	• Lack of professional interviewing experience • Long time needed for preparation and management • Subjective bias of the interviewer
Focus group	• Elicits information on a range of norms and opinions in a short time • Group dynamic stimulates conversation and reactions	• Difficult to motivate and involve all participants • Difficult to address sensitive topics

(Ellis, 2013; Mack et al., 2005)

2.4.2.1 Selecting an interview approach

In this study, interviews were used to generate data from both patients and health professionals. An interview has been defined as a conversation between two persons which is instituted by interviewers for the specific purpose of gathering information on specific topics, and focuses on research objectives, description or explanation (Cohen et al., 2007). In-depth interviews are integral to an interpretive approach and the decision to interview people about research topics is derived from the epistemological and ontological positions that knowledge about people's subjective reality can only be obtained from the people themselves (Crotty, 1998). Some scholars (Kvale and Brinkmann, 2009; Patton, 2002) have argued that in-depth interviews aim to directly draw out perspectives, feelings, opinions, views and experiences from participants. Similarly, Miller and Classner (2011) suggested that the in-depth interview could clarify the nature of the specific phenomena of interest, such as the culture framing the subjects' experiences and social world.

Furthermore, qualitative interviewing approaches are suitable for investigating sensitive topics (Elam and Fenton, 2003). It is evident that participants may be more comfortable discussing sensitive perspectives or topics of experience in an individual one-to-one interview rather than through other approaches (Ellis, 2013; Mack et al., 2005). Certain research topics in nursing and health have the potential to involve sensitive topics which cause participants distress and discomfort (Enosh and Buchbinder, 2005). Therefore, in this study interviews were used to explore the perspectives of patients and health professionals.

2.4.2.2 Semi-structured interviews

There are various types of interview, including structured, semi-structured and unstructured (Flick, 2009; Kvale and Brinkmann, 2009).

A structured interview is an interview in which both the questions and the answer categories have been fully developed before the interview (Floyd and Fowler, 2004). By contrast, an unstructured interview has no specific set of pre-determined questions and allows participants to explore their own experience and develop their own directions in the interviews (Fontana, 2004). A semi-structured interview asks a series of preset open-ended questions (Ayres, 2012). The topic guide is developed for semi-structured interviews, which is a series of topics to discuss with participants (Fitzpatrick and Boulton, 1994).

The semi-structured interview is known for its flexibility, enabling researchers to follow up new ideas and produce richer data (Al-Busaidi, 2008). Unlike structured interviews, which have been criticised for their inflexibility and leave little room for unanticipated exploration (Murphy et al., 1998), semi-structured interviews allow the researcher to be more open to exploring the participants' point of view (Flick, 2009). Compared with an unstructured interview, a semi-structured interview is an efficient approach which assists participants to focus more on the topics in which the researcher is interested (Kvale and Brinkmann, 2009). Furthermore, the semi-structured interview is commonly used in health-related qualitative studies (Al-Busaidi, 2008). Therefore, this study applied semi-structured interviews to collect data from both patients and health professionals.

2.4.3 Sampling

A sample has been identified as "a finite part or subset of participants drawn from the target population" (Martínez-Mesa et al., 2016). Two main techniques of sampling are probability and non-probability.

Probability sampling aims to randomly select the smallest population which can be considered as representative of the whole population or wider society (Marshall, 1996). In other words, every subject has an equal chance of being selected to be a part of the study. Typically, probability sampling techniques are commonly employed for quantitative studies but are rarely appropriate for conducting qualitative research (Marshall, 1996).

However, non-probability sampling is a sampling technique where not all participants are given an equal chance of being included (Etikan et al., 2016). In other word, non-probability sampling is where researchers select participants based on the subjective judgment of the researchers rather than on a random basis. However, non-probability does not aim to meet the criterion of randomness. Instead, subjective methods based on researcher interest are used to select which criteria are used to select the sample (Etikan et al., 2016; Flick, 2009).

Denzin and Lincoln (2003a) state that the aim of sampling in qualitative studies is to understand a specific topic and generate information-rich data. This means that the findings of qualitative studies are intended to be applied to the specific population which has possibly the richest source of information to answer the study questions, rather than the whole population. In fact, non-probability sampling is more typically employed in qualitative enquiries (Creswell, 2007). For these reasons, non-probability sampling was used to explore the topic in this study.

There are many different types of non-probability sampling in qualitative research, including purposive, snowballing, convenience, and theoretical sampling (Creswell, 2007; Flick, 2009; Marshall, 1996). Purposive sampling is a non-probability sampling technique in which the researcher chooses from a large population subjects who are available to give an account of their experiences. Therefore, the goal of purposive sampling is to select participants with specific characteristics which are of interest, which will best enable researchers to answer their research questions (Flick, 2009). Unlike convenience sampling, which selects participants only based on convenient accessibility, purposive sampling is used where subject characteristics are purposely chosen to achieve population diversity, which may identify essential differences between participant viewpoints (Teddlie and Yu, 2007).

This sampling approach can provide researchers with the justification for making generalisations from the target sample in which the researcher is interested, whether such generalisations are theoretical, analytic and/or logical in nature (Polit and Tatano Beck, 2004). For these reasons, purposive sampling, which is often widely used in social sciences, was applied in this study for both the patient and the health professional interviews.

2.4.3.1 Sample size

Sample size is the number of participants in a sample for an experiment, a survey, or other study type (Kadam and Bhalerao, 2010). Qualitative researchers are more concerned with the richness and depth of data than the number of participants (Patton, 2002). In a qualitative study, sample size is based on including participants who are capable of providing rich descriptions of particular phenomena (Denzin and Lincoln, 2003a). Therefore, researchers in qualitative studies generally discuss reaching data saturation when deciding the size of sample.

Data saturation has been defined as the point at which additional data do not generate any new codes or themes, i.e. the researcher finds that no new codes occur in the data (Given, 2016; Urquhart, 2013). In this study, data collection continued until the data saturation point was reached, which was when further sampled data did not lead to any new themes emerging (Given, 2016). Sample size in this study therefore reflects the number of participants who were able to provide new and relevant information for describing and interpreting the phenomenon adequately.

Although data saturation is the guiding principle, an estimated sample size for this study was provided. There are no definite rules for sample size in qualitative studies (Patton, 2002) and a wide range of different sample sizes in qualitative research are reported in the literature. For example, Thomson (2011) reviewed 100 qualitative studies related to grounded theory and found the average sample size was 25, but the suggested sample size should be 30 to fully develop all aspects of the given phenomena (Thomson, 2011). Similarly, another review (Mason, 2010) included 560 PhD studies and the result shows that, although there is no consensus on the size of sample for qualitative studies, the common sample sizes were 20 and 30 (median was 28 and mean was 31). Others have stated that, according to the experience of most qualitative researchers, few new themes come out of transcripts, and data saturation is reached, after researchers have interviewed 20 participants (Green and Thorogood, 2009).

In this study, approximately 20-25 eligible patients in halfway houses and approximately 20-25 eligible registered mental health professionals in secondary mental healthcare in Taiwan were to be recruited to participate in semi-structured interviews, to ensure data was not lost and to achieve richness of information. Nevertheless, the sample size could have decreased or increased depending on when data saturation was achieved.

2.4.4 Data analysis

Qualitative data analysis methods should be planned prior to data collection as part of the research design process and should fit the theoretical position of the selected research methodology (Creswell, 2007). In qualitative studies, the data analysis process generally involves preparing and managing the data, reducing the data into codes and then themes, and finally producing a report in the form of figures, tables, or a discussion (Creswell, 2007). This process is crucial to provide a high-quality qualitative report. Researchers should be aware that the qualitative data analysis process is circular, not linear, and researchers need to interact closely with the data (Maxwell, 2009). Dey (1993) also mentioned that it is better for qualitative researchers to learn data analysis by actually doing it, to foster analytical skills.

Before the discussion on the data analysis approaches, researchers should identify the types of qualitative data sources in their studies. Some researchers might focus on a single data resource but others might involve more than one data resource in the same study (Sutton and Austin, 2015). There are some common ways to generate qualitative data, such as interviews, observations, documents, and audiovisual material (Creswell, 2007). Qualitative data, which is generally non-numerical, comes in a variety of forms, including:

- audio recordings
- video recordings
- written notes, transcripts
- images (e.g. pictures, photos, drawings or diagrams)
- documents (e.g. diaries, newspapers, magazines, or reports)

(Ellis, 2013; Mack et al., 2005)

There are a number of approaches to qualitative data analysis with different analytical methods, and focusing on different aspects of the data (Thorne, 2000). While there are numerous guidelines for qualitative data analysis, applying these guidelines involves judgment and creativity due to the uniqueness of each qualitative study (Patton, 2002). Some common types of data analysis have been used in health studies:

- narrative analysis
- discourse analysis
- constant comparative analysis
- content analysis
- thematic analysis

2.4.4.1 Narrative analysis

Narrative analysis is an approach for understanding how and why people talk about their lives as a story, which is influenced by self-identity and social interaction between the narrator and audience (Earthy and Cronin, 2008). The main narrative themes within the accounts which people provide about their lives can be detected by analytic processes, and this information can explain how people understand and make sense of their lives (Thorne, 2000). Narrative analysis strongly emphasises how people present their accounts of themselves and the stories that people tell provide insights into their lived experiences, the complexity of human lives, cultures, and people's behaviours (Sandelowski, 1994).

2.4.4.2 Discourse analysis

Discourse analysis is an analysis strategy for exploring texts within the sociocultural practice (Wetherell et al., 2001). The nature of discourse analysis is hermeneutic and phenomenological, focusing on the lifeworld and the meaning people make through the application of language (Miles, 2010). It assumes that there are multiple constructed realities, and researchers working within this assumption aim to understand the interplay between social contexts and language.

Typically, this method involves an analytical process including deconstructing and critiquing language use and the social context of language use (Miles, 2010). In discourse analysis, speech is not just a direct representation of human experience, but an explicit linguistic tool constructed by many social or ideological impacts. The focus of discourse analysis is to develop theories in sociolinguistics and cognitive psychology in order to understand what is represented by the variety of ways in which people communicate ideas (Thorne, 2000).

2.4.4.3 Constant comparative analysis

Constant comparative analysis is an approach for analysing data to develop a grounded theory. In the analysis process, newly gathered data are continually compared with previously collected data to develop conceptualisations of the possible relationships between the data (Glaser and Strauss, 1967). This process aims to examine emerging ideas which might take the research in new and insightful directions. In constant comparison, the properties and dimensions of the categories are generated and patterns are developed that improve the interpretive power of these categories (Holloway and Todres, 2007). Glaser and Strauss (1967) also argue that the comparative analytical method can be suitable for social units of any size to generate theory. This process involves four stages:

- comparing incidents applicable to each category
- integrating categories and their properties
- delimiting the theory
- writing the theory

(Glaser and Strauss, 1967)

2.4.4.4 Content analysis

Content analysis is an approach for analysing large volumes of textual data and different data sources to corroborate evidence and make replicable and valid interpretations from the data to its context (Elo and Kyngas, 2008). As Elo and Kyngas (2008) also explained, this approach can be employed with either qualitative or quantitative data. The approach aims to offer an insight into specific phenomena in which the researcher is interested. Furthermore, Cavanagh (1997) described content analysis as a flexible method for analysing textual data, and content analysis has been widely applied in health studies in recent years (Hsieh and Shannon, 2005). However, this approach emphasises quantification of data, so the frequency of different categories and themes in a qualitative study is recognised as a proxy for significance (Vaismoradi et al., 2013).

2.4.4.5 Selecting thematic analysis as a study approach

In this study, thematic analysis was employed to explore patient and health professional perspectives of shared decision making in secondary mental healthcare in Taiwan. Thematic analysis is based on the identification of themes from the data, identified by a coding scheme, often from pre-determined themes. The approach is widely used in qualitative analysis, generally treating accounts as a rich resource to uncover the reality or experiences to which they refer. It is evident that this approach is widely used across various epistemologies and qualitative research questions (Braun and Clarke, 2006; Nowell et al., 2017). In a generic qualitative research approach, thematic analysis is recommended (Percy et al., 2015).

Braun and Clarke (2006) assert that thematic analysis should be the foundation for qualitative analysis due to core skills being developed through thematic analysis for conducting other forms of data analysis. Thematic analysis emphasises ascertaining, examining, and recording themes within data (Braun and Clarke, 2006) and aims to present the key components of each participant's account (Braun and Clarke, 2006; Green and Thorogood, 2009). This approach also helps researchers to recognise typical responses and identify the salient responses of particular groups of participants (Green and Thorogood, 2009). It is used to analyse qualitative data systematically. Braun and Clarke (2006) argue that qualitative studies can produce trustworthy and insightful findings through a rigorous thematic analysis (Braun and Clarke, 2006).

In addition, due to its theoretical freedom, it is highly flexible and can be modified to meet the needs of many studies, and to provide an information-rich and detailed account of the data (Braun and Clarke, 2006; King, 2004). As the use of this approach does not require technological or theoretical knowledge of other qualitative research methodologies, thematic analysis is more usable for researchers who have little experience of conducting qualitative studies or are not familiar with qualitative analysis (Braun and Clarke, 2006).

There are several key steps related to thematic analysis:

- familiarisation with the data
- generating initial codes
- searching for themes
- reviewing themes
- defining and naming themes
- producing the report

(Braun and Clarke, 2006)

Firstly, researchers read the transcribed data several times and make notes of initial ideas during this process (Braun and Clarke, 2006; Green and Thorogood, 2009). Repeated reading can help researchers to grasp the whole picture of the raw data. Braun and Clarke (2006) indicated that taking notes could ensure researchers are well prepared to carry out coding.

Coding is the next phase, and categorising meaningful data into groups facilitates the development of a logical set of themes. Patton (2002) argued that pattern recognition is a key competency in applying thematic analysis. Initial codes are produced as part of this process. A long list of codes will be generated and then the next step is to codify these into categories in order to search for potential themes. Following this, exploration of the relationship between codes and themes could be facilitated by reviewing themes and generating a thematic map of the analysis (Braun and Clarke, 2006). Coding schemes can be applied to define and name themes. In this part of the analysis, it is essential to clarify the concept of each theme and discuss it with research colleagues (Green and Thorogood, 2009). Producing the report involves a final analysis of selected extracts and aims to produce a scholarly report of the findings (Braun and Clarke, 2006).

2.5 Ensuring quality and trustworthiness

Confirming trustworthiness is a way to ensure that the findings of qualitative research are worthy of attention (Lincoln and Guba, 1985). To achieve rigour and trustworthiness, researchers must be consistent and strict in employing sampling and analysis methods in a logical flow to ensure quality in qualitative studies (Flick, 2007; Patton, 2002).

Lincoln and Guba (1985) proposed four strategies for establishing the quality of qualitative research:

- credibility
- transferability
- dependability
- confirmability

Strategies for these criteria can be employed throughout the study process to enhance the quality and trustworthiness of qualitative research. Some need to be addressed prior to the study, but others are used during the data collection process and after the data are interpreted (Krefting, 1991). Detailed discussion will be presented in the following sections.

2.5.1 Credibility

Credibility refers to how believable each part of a qualitative study is, comparing the actual findings with the original questions for the study. However, the credibility of qualitative studies is often discredited as the finding of qualitative analysis is judgment dependent (Mays and Pope, 2000).

Thus, peer debriefing has proved to be a key technique to achieve credibility in qualitative studies (Patton, 1999). Peer debriefing is a strategy where researchers, during the research process, seek scholarly guidance and support from other professionals, such as supervisors in the case of postgraduate students (Anney, 2014). This strategy requires academic supervisors to engage in discussion and questioning of the study in a consistent and systematic manner, and all these discussions should be recorded in notes that will be useful in data analysis (Barusch et al., 2011). Through this strategy, researchers can also explore their perspectives, reactions, and analyses as they go through the research process (Barusch et al., 2011). Also, constructive feedback from academic supervisors can help improve the quality of the qualitative study and ensure credibility (Shenton, 2004). Therefore, peer debriefing was used to ensure credibility in this study.

2.5.2 Transferability

Transferability is the generalisability of the findings of the research from a section of the research sample to the general population of individuals in a similar condition (Lincoln and Guba, 1985). While qualitative studies are traditionally not considered to be generalisable, it is still worth drawing attention to representational generalisation to ensure the quality of the research (Brett, 2018). The researcher should provide a thick description of the participants and the research process for the readers to decide if the results are transferable to other settings or contexts (Korstjens and Moser, 2018). Although the researcher cannot know every site to which a reader may wish to transfer the findings, providing thick descriptions helps other readers to judge transferability (Lincoln and Guba, 1985).

Anney (2014) also argued that thick description involves the researcher clarifying every detail of the research processes, from data collection to production of the final report. Therefore, researchers should provide sufficient contextual information about the field (Korstjens and Moser, 2018) and clearly illustrate that the sample is an accurate reflection of the population studied (Krefting, 1991). During data collection, collecting participants' demographic data and comparing it with the information about the target population will help readers judge the potential of its application in their own settings (Krefting, 1991; Shenton, 2004). For this study, thick descriptions of these aspects were provided to support transferability.

2.5.3 Dependability

The notion of dependability refers to consistency in collecting data, which has implications for the stability of a study's findings over time (Lincoln and Guba, 1985). To ensure dependability, researchers should confirm that the process of the research is logical and explicitly documented (Tobin and Begley, 2004). Korstjens and Moser (2018) also argue that researchers should check whether the analysis process is consistent with the defined standards for a research design. Some strategies can be employed to ensure dependability, including an audit trail, dense description of research methods, step-wise replication and peer examination (Krefting, 1991). In this study, an audit trail was employed to ensure dependability.

An audit trail is kept to document the methodological and theoretical decisions made and how the data were gathered, recorded and analysed throughout the study process (Bowen, 2009). In addressing this, researchers should describe their research design and its application clearly, along with details of how they carried out data collection and reflective appraisal during the study (Shenton, 2004).

2.5.4 Confirmability

Seeking confirmability means that researchers strive to ensure the objectivity of the whole study process (Lincoln and Guba, 1985). Steps should be taken to ensure that the neutrality of the findings is based on the experiences and ideas emerging from the information rather than being based on the preferences and characteristics of the researchers (Mays and Pope, 2000). Sufficient explanation of the study needs to be given, enabling the reader to judge the validity of the research. Studies recommended an audit trail, reflexive journal and triangulation to strengthen the confirmability of a qualitative inquiry (Bowen, 2009; Krefting, 1991; Lincoln and Guba, 1985).

In this study, an audit trail and reflexive journal were used to enhance confirmability. An audit trail was kept to ensure dependability, and was then also useful for confirmability. An audit trail helps other reviewers to trace the whole study through the decision making and the rest of the process as described.

In addition, reflexivity refers to how researchers consider the sensitivity of data collection during the study (Mays and Pope, 2000). A reflexive journal has been recognised as reflexive documents which are held by the researchers in order to reflect on, interpret, and plan data collection (Wallendorf and Belk, 1989). Also, it helps to assess the influence of the researchers' background, perceptions and interests throughout the qualitative study process (Krefting, 1991). Anney (2014) suggest that researchers should document all events that occurred in the field, as well as personal reflections in relation to the study. Similarly, Korstjens and Moser (2018) also argue that this process should review researchers' own biases, preferences, preconceptions, and relationships to the respondents, and how these relationships influence participants' responses.

2.6 Ethical principles

Beneficence, non-maleficence, autonomy and justice are issues addressed by the principles of biomedical ethics (Beauchamp and Childress, 2013). In this study, the potential ethical issues were considered and taken into account; the study had to be approved by the University of Manchester and local research committees in Taiwan. Further details of each principle will be presented in the following sections.

2.6.1 Autonomy

The notion of autonomy encompasses showing respect for the subjects' choices, and this often refers to the protection of a participant's ability to make his or her own decisions. One important component associated with respect for autonomy is disclosure. In order to ensure the participant's participation in the study is fully voluntary, the researchers must share the understanding of what has been agreed (Beauchamp and Childress, 2013). The researchers must provide all relevant information about the research and what will happen as a result of participants being involved to help them make informed decisions (Faden and Beauchamp, 1986). This information should include the purpose and method of the study, the risks and benefits of participation, and the right to withdraw from the study at any point without any questions (Beauchamp and Childress, 2013).

In a qualitative research study, informed consent has been recognised to ensure this principle, which means participants are able to gain sufficient information about the study by this means (Greaney et al., 2012). The importance of informed consent has been identified by Orb et al. (2001) to ensure that patient have sufficient information and to provide an opportunity for participants to refuse to take part in the study. Therefore, every participant should give written informed consent to participate in the study (Creswell, 2007; Munhall, 1993).

In particular, informed consent plays an essential role in protecting the autonomy and dignity of patients with mental illness (Carpenter and Conley, 1999). For such patients, all possible ethical principles need to be given careful consideration by those involved in the research. Meanwhile, the requirement of informed consent has been added in law to ensure patients' rights in both practice and research (Doyal, 2002). For these reasons, this study used informed consent to ensure autonomy.

2.6.2 Beneficence and non-maleficence

The principle of beneficence indicates wanting to do what is good for others: the doing of good, the active promotion of good (Beauchamp, 1984). Munyaradzi (2012) argues that the principle is expressive of humanity, altruism, unconditional love, and optionally moral ideals. In the biomedical field, beneficence requires that, to the best of their ability, health professionals try to bring positive benefits for patients, such as good health, or to prevent and eliminate harmful conditions (Munyaradzi, 2012). It is not just the possible benefits for the participants of taking part in the research but also the potential costs and risks that need to be considered.

On the other hand, non-maleficence is the principle of not inflicting evil or causing any harm to others. (Paavilainen et al., 2014). The principle of non-maleficence refers to the obligation not to inflict harm intentionally (Beauchamp and Childress, 2013). Further examples of non-maleficence include avoiding different forms of harm in medical care, such as medical error, inequitable treatment, or negative influence on participants' benefits (Beauchamp and Childress, 2013). These are associated with either exposing participants to a risk or causing actual harm to participants. This involves avoiding even the risk of harm. Munson (2004) states that if a researcher has purposely or accidentally subjected a participant to needless risk, then he or she has violated this principle.

A risk-benefit assessment can be used to scrutinise the potential risks and benefits of participating in the study and strike a balance between all aspects, including financial, physical, mental and social (Polit and Beck, 2014). Interestingly, the researchers commonly pay attention only to financial and physical risk, but not mental or social risk (Greaney et al., 2012). For example, in qualitative interview studies, the time sacrificed to take part is commonly mentioned as the cost of participating in the research (Beauchamp and Childress, 2013). However, Greaney et al. (2012) recommend that a risk assessment should also consider psychological distress, and any factors which could cause discomfort or uncomfortable feelings to participants. Also, support mechanisms such as a distress management plan and a complaints process should be in place for participants (Polit and Beck, 2014). These potential risks and benefits were discussed in applying ethical considerations.

2.6.3 Justice

The principle of justice is that all participants have equal rights (Gillon, 1994). This is the right to be treated equally and should not be compromised for any kind of reason. All people should be provided with fair opportunities to be involved in studies (Emanuel et al., 2000).

In addition, the implementation of justice aims to recognise the vulnerability of the participants, and their possible contributions to the study (Orb et al., 2001). The same publication asserts that listening to the voices of minority and vulnerable groups and protecting those who are most vulnerable, such as children, prisoners, and the mentally ill, are further approaches to implementing justice. For example, prejudice and discrimination may be a reflection of the stigmatisation of patients with mental illness, who often experience injustice or are treated differently. It is important to provide an opportunity for this sensitive group to have their voices heard.

Therefore, Greaney et al. (2012) argue that researchers should carefully consider their criteria for including and excluding certain groups from a study. Detailed explanation of why specific groups are excluded or included should be given, and a rationale should be provided for this decision within the research protocol (Greaney et al., 2012). In order to understand patients and professionals' perspectives of shared decision making, these two participant groups were recruited in this study. All details of inclusion and exclusion criteria will be presented in the working methods chapter (see Chapter Four).

2.7 Summary

In summary, this chapter has detailed both the qualitative systematic review and the primary qualitative studies (patient interviews and professional interviews) used in exploring the aims and objectives of this doctoral study. The epistemological, ontological and methodological decisions relevant to the study were made according to all the principles described in depth above. The following chapter will present the working methods and the findings of the qualitative systematic review.

Chapter Three: Systematic review of qualitative studies (Study One)

This chapter will present working methods and findings for a qualitative systematic review which explored patient perspectives of shared decision making in secondary mental healthcare. The rationale for selecting a qualitative systematic review was presented in Chapter Two. This chapter will present in four sections: the first section will provide details of the working methods of the review and the second will describe the review findings. The third section will present the discussion of the strengths and the limitations of this review. The final section will provide a summary of this chapter.

3.1 Review methods

3.1.1 Review aims and objectives

3.1.1.1 Review aim

- to examine and synthesise patient perspectives of shared decision making in secondary mental healthcare.

3.1.1.2 Review objectives

- to explore the decision-making experiences of patients in secondary mental healthcare;
- to examine the facilitators of and barriers to shared decision making from the perspective of patients in secondary mental healthcare.

3.1.2 Literature search strategy

In this review, the SPIDER tool was utilised to organise the review process. As outlined previously, the SPIDER tool is a search tool used to synthesise qualitative research in systematic reviews through five concepts: sample(S), phenomenon of interest (PI), design (D), evaluation (E), and research type (R) (Cooke et al., 2012). In order to include more potentially relevant studies, the author only used three of the SPIDER tool's search term concepts to search studies at this stage, namely "sample", "phenomenon of interest", and "evaluation".

A long-list of potential search terms was developed during a broader search, again conducted by the author, based on the scoping review, reading of individual studies and browsing medical subject headings (MeSH). The search strategies were also built up from a series of test searches and discussions of the results of those searches with the supervisory team. These search terms were revised and modified in subsequent meetings with the supervisory team. Any differences of opinion were discussed with the supervisory team to make final decisions. All search terms are presented in Table 3.1.

The search terms for each concept were combined via the Boolean operators AND, OR and NOT.

Table 3.1: Search concepts and terms

Group A: Sample		**Group B: Phenomenon of Interest**		**Group C: Evaluation**
schizophrenia schizoaffective psychosis* psychoses* psychotic* psychiatric* "severe mental" "chronic mental" "serious mental" SMI bipolar depress* "delusional disorder" “mental health service*”	**AND**	"shared decision*" "shared decision making" "information sharing" "mutual decision*" "participatory decision making" "client participation" involvement	**AND**	view* experience* opinion* attitude* perspective* feeling* belief value
“ ”= When a word or phrase is in quotes the results include only articles with the same words in the same order. ***=Truncation symbol; for instance, decision* retrieves ‘decisions’ as well as ‘decision’.**				

This search strategy was applied to eleven databases, namely:

- CINAHL Plus (Cumulative Index to Nursing and Allied Health Literature) (1937-present)
- Medline (1946-present)
- PsycINFO (1806-present)
- Embase (1974-present)
- Health Management Information Consortium, HMIC (1979 to March 2016)
- EBM review - Cochrane Database of Systematic Reviews, CDSR (2005-present)
- EBM review - Database of Abstracts of Reviews of Effects, DARE (accessed via Ovid)
- British Nursing Index (1994-present)
- Applied Social Sciences Index and Abstracts, ASSIA (1987-present)
- International Bibliography of the Social Sciences, IBSS (1951-present)
- Social Services Abstracts (accessed via ProQuest) (1979-present)

Searches were limited to studies published in English because no financial resources were available for translation or for accessing databases in other languages. All databases were searched from inception to September 5, 2016. After initial searches via these databases, key studies were also hand-searched via databases.

3.1.3 Selection criteria

The process of selecting the relevant articles, i.e. defining eligibility criteria, is one of the essential principles of systematic reviews (Petticrew, 2001). Unlike the search stage, which aimed to include all possible existing studies, this stage aimed to filter the studies to include only relevant ones in the synthesis. Therefore, the all concepts of the SPIDER tool (sample/setting, phenomena of interest, design, evaluation, and research type) were used to develop the inclusion/exclusion criteria. These criteria are detailed in Table 3.2.

Table 3.2: Inclusion criteria and exclusion criteria

Concepts	Inclusion criteria	Exclusion criteria
Sample/setting	• Adults (18 and over) in secondary mental healthcare • Population mixed • At least 75% of the sample in above settings • Or if the study results present patient perspectives separately	• Children or youths (aged under 18) • Adults in any acute psychiatric wards of hospitals
Phenomena of interest	• Patient experiences/perspectives of involvement in decision making about their treatment and care • Facilitators of or barriers to involvement in decision making from patient views or perspectives	Experiences/perspectives of only carers and/or professionals of their involvement in shared decision making about patients' treatment and care
Design	• Primary data from published articles or dissertations • Qualitative methodology • Interview, focus group, observation • Data analysed by (as a minimum) thematic analysis	• Case reports or one participant studies • Using questionnaires to collect data • Not primary data • Grey literature
Evaluation	Views, experiences, opinions, attitudes, perspectives, beliefs or feelings of patients in secondary mental healthcare	Understanding and knowledge about shared decision making
Research type	• Qualitative data exploring patients' experiences and perspectives of shared decision making about their treatment and care • Only English articles	• Quantitative studies • Systematic review • Meta-analysis

3.1.3.1 Sample/settings

Serious mental illness (SMI) was defined as schizophrenia, schizoaffective disorder, affective disorder (including bipolar disorder and depression), and other psychoses. This is based on how serious mental illness is defined in the Quality and Outcomes Framework in the UK (Health and Social Care Information Centre, 2015) and prevalence surveys (Kessler et al., 2001; Steadman et al., 2009). In some studies, populations labelled as "serious/severe mental illness" were also included in this review where no specific diagnosis was provided.

Services offering secondary mental healthcare included: community mental health centres, outpatient clinics, outpatient department, clubhouses, day centres, day hospitals, rehabilitation services, group homes, halfway houses, and other support services. Studies solely focused on patients in acute wards of hospitals were excluded. It is likely that there would be differences between the experience of patients with serious mental illness in acute inpatient wards and those with serious mental illness in other units, due to the nature and severity of symptoms (Marshall et al., 2001).

3.1.3.2 Phenomena of interest

The inclusion criteria were intended to select any qualitative studies with a primary data focus on the process of shared decision making about treatment and care, or possible facilitators and/or barriers to shared decision making, for patients in secondary mental healthcare. Studies focused on engagement with or involvement in other activities, such as research, were excluded as these are not related to the aims of this review.

3.1.3.3 Design, evaluation, and research type

Qualitative studies that were published in English and which used individual interviews, focus groups or observations to explore the perspectives of shared decision making about treatment and care amongst patients in secondary mental healthcare were included in this review. In addition, research using mixed methods or involving data from participants other than the patients themselves was included only if the results had been reported separately.

All types of qualitative empirical studies were considered to meet criteria of this review, including grounded theory, phenomenology, ethnography, case studies, action research and thematic analysis. Abstracts and other grey literature such as conference papers were excluded as they did not provide enough detailed information to extract and analyse critically (Autorino et al., 2007).

3.1.4 Eligibility screening

Each article was initially screened, by title and abstract, by two reviewers separately (the author & Dr Laoise Renwick). The reviewers rated each article as either 'relevant', 'maybe' or 'irrelevant'. If there was any conflict, the paper was discussed and if agreement was not reached the paper was sent to a third reviewer (Professor Karina Lovell).

Full-text copies of potentially relevant articles were read by the author, using the inclusion and exclusion criteria. The third reviewer (Professor Karina Lovell) checked inclusion and exclusion reasons for the first eleven articles, to enhance rigour.

3.1.5 Data extraction

An extraction sheet was developed by the author after discussion with the supervisory team (see Appendix 1). In this study, study characteristics, demographics, methodology and outcomes were extracted from eligible studies.

3.1.6 Quality appraisal

To determine the quality of the included papers, the Consolidated Criteria for Reporting Qualitative Research (COREQ) proposed by Tong et al. (2007) was employed. The COREQ is presented in Part B of the extraction sheet (Appendix 1). The COREQ consists of a 32-item checklist and was designed for appraising qualitative studies across three domains, namely research team and reflexivity, study design, and data analysis and reporting. Detailed discussion of the quality of the included studies is presented in Section 3.2.3.

3.1.7 Synthesis of qualitative studies

Thematic synthesis was used in this review, based on the work of Thomas and Harden (2008), who proposed three steps:

- Free line-by-line coding of textual findings from primary studies;
- Organisation of these free codes into descriptive themes;
- Development of analytical themes.

3.1.7.1 Step one: Free line-by-line coding of textual findings from primary studies

The first step is to code texts line by line. The use of line-by-line coding aims to inductively create free codes to explain each sentence extracted from the findings of primary studies with a parallel structure (Thomas and Harden, 2008). All extracted data were coded by the author and a long list of codes, along with the extracted data, was created. An example of the studies included in this review is detailed below (Table 3.3).

Table 3.3: An example of use of line-by-line coding

Data extraction	Code
"I also felt I could be more honest with GH because of the case manager's support, and that perhaps GH would take my concerns more seriously in the future." (Delman et al., 2015)	• Importance of support from other professionals
"I think sometimes the doctors have too much power, especially psychiatrists, they make decisions about where you're going to live. I mean, Dr M basically made a decision on my life. She decided that I was under her care, she decided what medication I was going to have, and she decided where I was going to work. Now, isn't that power?" (Laugharne et al., 2012)	• Professionals have great power • Potential coercion

3.1.7.2 Step two: Organisation of free codes into descriptive themes

The purpose of the second step was to develop descriptive themes from included studies. Based on the similarities and differences between the themes, ten main descriptive themes were identified (see details in Table 3.4).

Table 3.4: Summary of descriptive themes

No	Descriptive themes
1	Lack of information about treatment and/or care
2	Lack of interaction with health professionals
3	Robotic care
4	Mental illness
5	Health professionals with paternalistic attitude
6	Health professionals are qualified to decide
8	Good relationship between patients and health professionals
9	Patient believing self to be an expert on his/her own mental illness
10	Sufficient information and resources

3.1.7.3 Step three: Development of analytical themes

The final step in thematic synthesis aims to interpret the findings of the included studies (Thomas and Harden, 2008). This step often includes collapsing some themes and grouping them into new or existing themes. Also, in order to ensure the themes are well represented, it is important to re-check the data used in the included studies. The descriptive themes (see above) were restructured in this stage.

After re-examination of the themes, the sub-theme "robotic care" was combined with "lack of interaction with health professionals" and renamed "poor quality of interaction with health professionals", based on similarity. In addition, the theme "lack of information about treatment and/or care" was renamed "lack of professional knowledge and information". Furthermore, two sub-themes, "mental illness" and "health professionals are qualified to decide", were collapsed into "health professionals with paternalistic attitude". Based on similarity, three descriptive themes ("professionals with paternalistic attitude", "poor quality of interaction with health professionals, "lack of professional knowledge and information") were grouped into a single main theme: "barriers to shared decision making".

Conversely, in the included studies, patients mentioned not just barriers to shared decision making but also how some facilitators improved levels of patient involvement and shared decision making. A good relationship between patients and health professionals was renamed "supportive attitude to patient involvement". After reviewing the theme, "patient believing self to be an expert on his/her mental illness" was collapsed into the descriptive theme "supportive attitude to patient involvement". After this, "sufficient information and resources" was restructured into two different themes: "sufficient information exchange" and "other support resources".

The author grouped three descriptive themes, namely "supportive attitude to patient involvement", "sufficient information exchange", and "other support resources" into one main theme and named this main theme "facilitators of shared decision making". (For an overview of analytic themes, see Table 3.5).

Table 3.5: Two primary analytical themes from the synthesis of included studies

Main themes	Sub-themes
Barriers to shared decision making	• Professionals with paternalistic attitude • Poor quality of interaction with health professionals • Lack of professional knowledge and information
Facilitators of shared decision making	• Supportive attitude to patient involvement • Sufficient information exchange • Other support resources

3.2 Findings

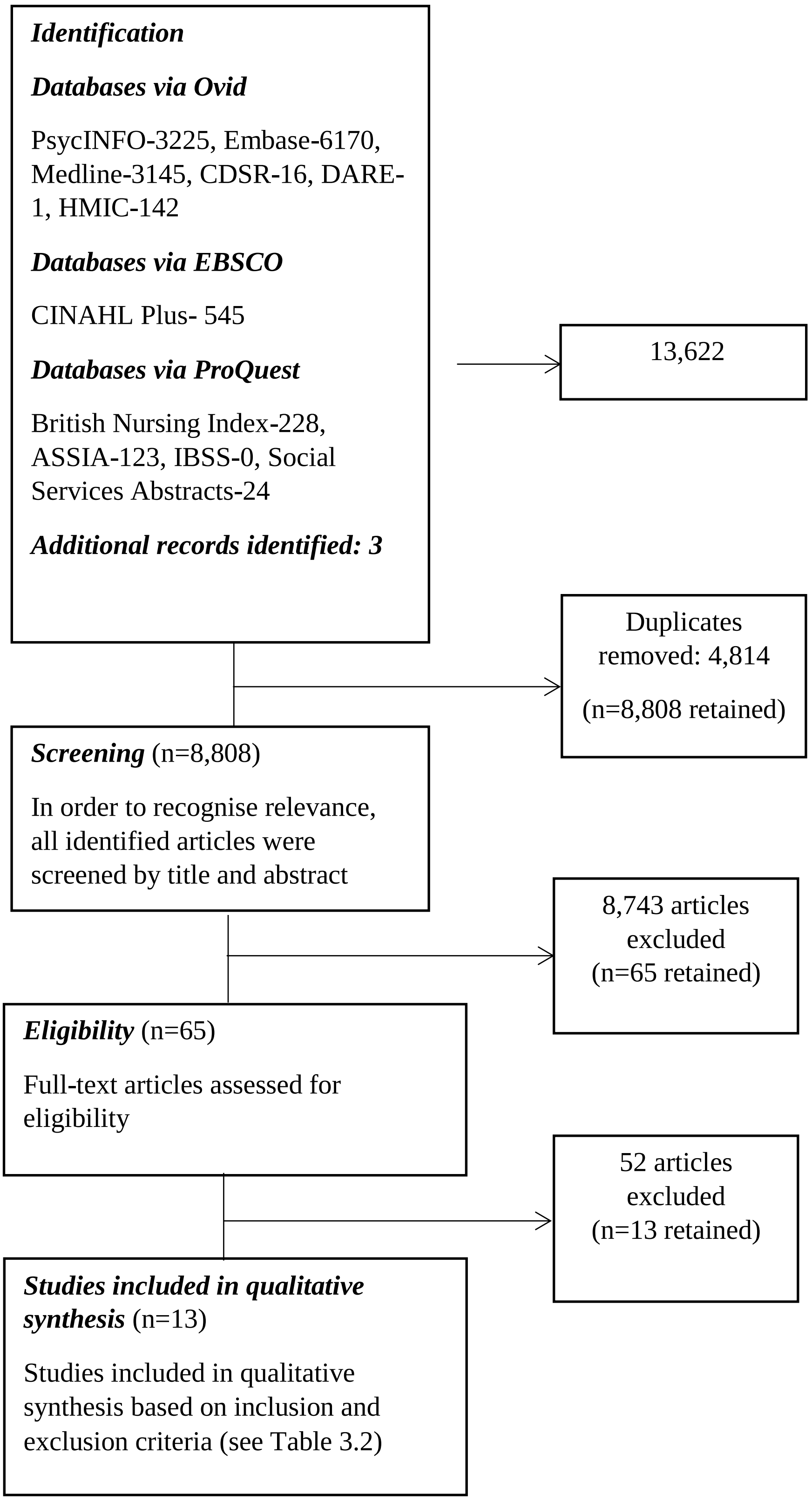
3.2.1 Search results

The search identified 8,808 publications and dissertations (Figure 3.1). The title and abstract screening excluded 8,743 studies. Full text screening of the remaining 65 articles eliminated a further 52 studies. The remaining 13 studies were included in the review. A summary of this process and the reasons for exclusion are presented in Figure 3.1 and Table 3.6.

Table 3.6: Studies on shared decision making excluded from the review

Reasons for exclusion	Number of studies excluded	Number of studies retained (from 65 studies)
Sample/setting	14 studies	51
Phenomena of interest	4 studies	47
Design	20 studies	27
Evaluation	0 studies	27
Research type	14 studies	13
	Total: 52 excluded	**Total: 13 retained**

Figure 3.1: Flow of the review



3.2.2 Characteristics of the included studies

The key characteristics of each study are summarised in Table 3.7. The review included 13 studies. The included studies were predominantly conducted in the United States (n=8) or the United Kingdom (n=4). All included studies were published in a ten-year period between 2006 and 2015 (Table 3.7).

3.2.2.1 Methodological design

All included studies used a qualitative design. The studies used various data collection processes: six used in-depth interviews (Delman et al., 2015; Gioia et al., 2014; Goscha and Rapp, 2015; Laugharne et al., 2012; Wharne et al., 2012; Woltmann and Whitley, 2010), four conducted focus groups (Connor and Wilson, 2006; Jones et al., 2013; Tanenbaum, 2008; Velligan et al., 2016), two incorporated both focus groups and in-depth interviews (Dahlqvist et al., 2015; Farrelly et al., 2016), and one used observation (Matthias et al., 2012).

Five of the studies adopted grounded theory (Connor and Wilson, 2006; Dahlqvist et al., 2015; Farrelly et al., 2016; Goscha and Rapp, 2015; Jones et al., 2013). Velligan et al. (2016) employed the constant comparative methods approach to their analysis. The remaining seven studies used thematic analysis (Delman et al., 2015; Gioia et al., 2014; Laugharne et al., 2012; Matthias et al., 2012; Tanenbaum, 2008; Wharne et al., 2012; Woltmann and Whitley, 2010).

3.2.2.2 Characteristics of participants

In total, 397 participants were included in studies, of which 341 were patients, 48 were health professionals, and eight were carers. Health professionals' and carers' views were not included in this synthesis.

Sample sizes ranged from 3 to 80 participants. Of the included studies, 9 were patient-only samples (Connor and Wilson, 2006; Dahlqvist et al., 2015; Delman et al., 2015; Gioia et al., 2014; Jones et al., 2013; Laugharne et al., 2012; Tanenbaum, 2008; Wharne et al., 2012; Woltmann and Whitley, 2010), and the remaining four used mixed samples comprising patients and carers (n=1) (Velligan et al., 2016) or patients and professionals (n=3) (Farrelly et al., 2016; Goscha and Rapp, 2015; Matthias et al., 2012).

Although all included studies reported that the participants were recruited from secondary mental healthcare settings, only 10 studies reported participants' diagnoses. Three studies did not report discrete diagnoses but used "patients with mental illness" or "serious mental illness" to describe their samples (Connor and Wilson, 2006; Farrelly et al., 2016; Jones et al., 2013). The majority of patient participants were recruited from outpatient clinics, community and other secondary mental healthcare (Table 3.7).

Table 3.7: Summary of the included studies on perspectives of shared decision making amongst patients

Study details				Sample Characteristics			Methodology	
No	**Authors**	**year**	**Country**	**Patient number**	**Sample characteristics**	**Setting**	**Data collection**	**Analysis**
1	Connor & Wilson	2006	UK	31	• people with serious mental illness, including schizophrenia, depression and bipolar disorder	User groups and community residential settings	Focus groups	Grounded theory methodology
2	Dahlqvist_ Jönsson	2015	Sweden	20	• Psychosis - 3, schizophrenia - 3, bipolar disorder - 4, depression - 4, and others - 6 • Mean age =52 (range 26-64) 6 men and 14 women	User-organised clubhouses and drop-in centres	Five focus groups and two individual interviews	Constructivist grounded theory methodology
3	Delman	2015	USA	24	• schizophrenia - 2, schizoaffective - 8, bipolar - 9, depression - 3, and personality disorder - 2 • Mean age =24 (range = 19–30) • 67% were female and 33% were male	outpatient services	Semi-structured interviews	Thematic analysis
4	Farrelly et al	2015	UK	51	• Diagnosis: not stated • Mean age=39 years old • 52 % were female	Generic and specialist community mental health teams in four English Mental Health Trusts	Focus groups and individual interviews	Grounded theory methodology
5	Gioia et al	2014	USA	20	• bipolar disorder - 10, schizophrenia - 6, and other (schizoaffective or depression) - 4 • Mean age=52.9 (SD: 6.8) • 18 men and 2 women	Outpatient program	Semi-structured interviews	Thematic analysis (Template analysis)

6	Goscha	2015	USA	12	• all clients with a severe and persistent chronic mental illness, including schizophrenia and other psychotic disorder • Mean age =45 • 7 men and 5 women	A community mental health centre	Semi-structured interviews	Grounded theory methodology
7	Jones et al	2013	USA	54	• Diagnosis: not stated • Mean age = 48 (range 39-57) • 17 men and 34 women	Secondary mental health services	Focus groups	Grounded theory approach
8	Laugharne et al	2011	UK	22	• Schizophrenia/ schizoaffective - 6, bipolar disorder - 7, and psychosis - 7 • Median Age = 51 (range 38- 62) in Cornwall • Age range 21-40 in London • 12 men and 10 women	Secondary mental health services	in-depth interviews	Components of grounded theory and thematic analysis
9	Matthias, et al	2012	USA	40	• Schizophrenia/schizoaffective disorder-25, major depression -8, bipolar disorder -4, or other -3. • Mean age = 43.5 (SD ±15.2) • 19 men 21women	A community mental health centre with a recovery-oriented focus	Direct observation	Thematic analysis
10	Tanenbaum	2008	USA	38	• people with serious mood, anxiety or thought disorder • Age (range 20’s to 60’s) and most were in their 30’s and 40’s. • 16 men and 22 women	An urban clubhouse and two at a consumer-operated centre in a suburban/rural county	Four focus groups	Thematic analysis
11	Velligan et al	2016	USA	10	• Schizophrenia - 3, affective disorder -5, and anxiety disorder - 2 • age: not stated • 5 men and 5 women	Outpatient Transitional Care Clinic	Two focus groups	Open coding framework and constant comparative method

12	Wharne, et al	2012	UK	3	Psychosis - 3 aged from late 30s to early 50s three men	Not stated	Semi-structured interviews	Thematic analysis
13	Woltmann & Whitley	2010	USA	16	Schizophrenia - 8, bipolar disorder - 4, major depression - 2 and other - 2 Mean age = 45 (SD: 8.2; range 33-58) 9 men and 7 women	Three sites of a large, urban community mental health agency	Semi-structured interviews	Thematic analyses

3.2.3 Quality of included studies

The COREQ quality appraisal tool was used to assess quality (see Part B, Appendix 1). There is no official scoring system for the tool. Therefore, the author used the number of items which had been well presented in the studies to indicate their level of quality. The possible range of numbers was from 0 to 32 items (Booth et al., 2014). Furthermore, there was no cut-off for the COREQ tool (Tong et al., 2007), but for the purposes of this review, three levels of quality were applied: low (0-10 items present), medium (11-21 items present), and high (22-32 items present). To help the reader to understand how these quality levels were arrived at, the author considered that if only one third of the items were explained then the quality level was low; more than one third but not two thirds represented medium quality; more than two thirds was high quality. Detailed discussion of the assessment outcomes of each study is presented below and in Table 3.8.

Among the 13 studies assessed, no study met all of COREQ's quality criteria. Quality scores ranged between 9 and 23. One study was assessed as high quality in this review (met 23 of the criteria): the one carried out by Farrelly et al. (2016). Most of the included studies (n=11) were recognised as medium quality. The most frequently occurring COREQ score (mode) was 17 out of 32, meaning that more than half of the criteria had been properly explained (median score was also 17 and the mean score was 15.62). One was low quality and only met 9 of the criteria.

The studies were recognised as medium quality and provided some details in the "study design" (15 criteria) and "analysis and findings" domains (9 criteria). However, compared with the high-quality study, these studies only met 50% of the criteria (12 out of 24 criteria) in these domains. Also, there was a significant lack of information in the "research team and reflexivity" domain. In some cases, none or only one of 8 criteria were reported.

The lowest score was 9 for the study conducted by Jones et al. (2013) and was characterised as low quality in the assessment. Similarly, a lack of detail in the "research team and reflexivity" domain was identified. Beyond this, discussion of "research design" and "analysis and findings" in this study was unclear and met less than 50% of the criteria. The inadequacy of reporting in these two domains made it impossible for the reader to judge the research process properly.

Table 3.8: Quality appraisal outcomes

Included studies the COREQ	Connor et al (2006)	Dahlqvist et al (2015)	Delman et al. (2015)	Farrelly et al. (2016)	Gioia et al. (2014)	Goscha et al (2015)	Jones et al. (2013)	Laugharne et al. (2012)	Matthias et al. (2012)	Tanenbaum (2008)	Velligan et al. (2016)	Wharne et al. (2012)	Woltmann et al (2010)
Research team and reflexivity													
1. Interviewer/facilitator	✘	✓	✓	✘	✓	✘	✘	✘	✘	✓	✘	✓	✘
2. Credentials	✘	✓	✓	✓	✘	✘	✘	✘	✓	✘	✓	✘	✘
3. Occupation	✓	✓	✘	✓	✘	✘	✘	✓	✓	✘	✘	✓	✘
4. Gender	✘	✘	✘	✘	✘	✘	✘	✘	✘	✘	✘	✘	✘
5. Experience and training	✘	✓	✘	✘	✘	✘	✘	✘	✘	✘	✘	✓	✓
6. Relationship established	✘	✓	✘	✓	✘	✘	✘	✘	✘	✘	✘	✓	✘
7. Participant knowledge of the interviewer	✘	✘	✘	✓	✘	✘	✘	✘	✘	✘	✘	✘	✘
8. Interviewer characteristics	✘	✘	✘	✓	✘	✘	✘	✓	✘	✘	✘	✘	✘
Study design													
9. Methodological orientation and Theory	✓	✓	✘	✓	✓	✓	✓	✘	✘	✘	✘	✓	✘
10. Sampling	✓	✘	✓	✓	✓	✓	✘	✓	✘	✓	✓	✘	✓
11. Method of approach	✓	✓	✓	✓	✓	✘	✘	✓	✘	✓	✓	✘	✘
12. Sample size	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
13. Non-participation	✘	✓	✓	✘	✓	✘	✘	✘	✓	✘	✘	✘	✘
14. Setting of data collection	✓	✘	✓	✓	✘	✘	✘	✓	✘	✓	✓	✘	✘
15. Presence of non-participants	✘	✘	✘	✘	✘	✘	✘	✘	✓	✘	✓	✘	✘
16. Description of sample	✘	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
17. Interview guide	✓	✘	✓	✓	✓	✓	✘	✓	✘	✘	✓	✘	✓

18. Repeat interviews	✘	✘	✘	✘	✘	✓	✘	✘	✘	✘	✘	✘	✘
19. Audio/visual recording	✓	✓	✓	✓	✓	✓	✘	✓	✓	✓	✓	✘	✓
20. Field notes	✓	✓	✓	✓	✓	✘	✘	✘	✘	✘	✓	✘	✘
21. Duration	✓	✓	✓	✓	✓	✓	✘	✓	✘	✓	✘	✘	✘
22. Data saturation	✓	✘	✓	✓	✘	✘	✘	✓	✘	✘	✘	✘	✘
23. Transcripts returned	✘	✘	✘	✘	✘	✓	✘	✘	✘	✘	✘	✘	✘
Analysis and findings													
24. Number of data coders	✘	✘	✓	✓	✘	✘	✓	✓	✓	✓	✓	✘	✓
25. Description of the coding tree	✓	✘	✘	✘	✘	✘	✘	✘	✘	✘	✘	✘	✘
26. Derivation of themes	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✘
27. Software	✘	✘	✓	✓	✓	✓	✘	✘	✓	✘	✓	✘	✓
28. Participant checking	✘	✓	✘	✓	✘	✓	✘	✘	✘	✘	✘	✘	✘
29. Quotations presented	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
30. Data and findings consistent	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
31. Clarity of major themes	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
32. Clarity of minor themes	✓	✓	✓	✘	✓	✘	✓	✓	✘	✘	✓	✓	✓
Total	**17/32**	**19/32**	**20/32**	**23/32**	**17/32**	**15/32**	**9/32**	**17/32**	**13/32**	**13/32**	**17/32**	**12/32**	**12/32**
Outcome of the assessment	**Medium**	**Medium**	**Medium**	**High**	**Medium**	**Medium**	**Low**	**Medium**	**Medium**	**Medium**	**Medium**	**Medium**	**Medium**

3.2.4 Analytical themes

Key descriptive themes were grouped into two broad analytical themes, namely “barriers to shared decision making” and “facilitators of shared decision making”. A summary of the findings of the included studies is presented in Table 3.9. The number of studies where each theme and sub-theme was identified as a barrier/facilitator influencing patient involvement is presented in Table 3.10.

Table 3.9: Summary of findings of the included studies on perspectives of shared decision making from patients

No	Authors (year)	Summary of findings/results
1	Connor & Wilson (2006)	**Barriers to shared decision making** • Disempowerment due to stigma of mental illness not only from society but also professionals • Imbalanced power between patients and professionals • Negative attitude of professionals **Facilitators of shared decision making** • Reliable professional-patient relationship (good communication and sufficient time) • Professionals having good supportive skills (empathy, respect, listening, common sense, humanity, sufficient time, reassurance, caring, understanding, patience, trust, compassion and practical organisational skills) • Individual support for patients (personal life, medication, care, and occupational therapy) • Peer support between patients • Sufficient information for patients
2	Dahlqvist_Jönsson (2015)	**Barriers to shared decision making** • Powerful role of professionals due to inequality in access to knowledge • Insufficient information • Untrusting professional-patient relationship **Facilitators of shared decision making** • Patients feeling respected • Flexible mental health care • Alliance between patients and professionals (listening, accepting different opinions, understand needs and expectations of both sides, equal power, willingness to get involved in decision making) • Active involvement in decision making • Trust in patients' decision making abilities • Other professionals providing advice without criticising • Sufficient professional information from video or someone with similar experience • Positive attitude of professionals • Sufficient time • Equal rights and equal responsibility
3	Delman (2015)	**Barriers to shared decision making** • Health professionals with negative attitudes • Lack of time for consultations

		• Limited patient self-efficacy **Facilitators of shared decision making** • Health professionals with positive attitudes • The psychiatrist's flexibility • Other support resources • Self-confidence
4	Farrelly et al (2015)	**Shared decision making is not widely implemented in mental healthcare** **Barrier to shared decision making** • Patients distrusting their health professionals • Powerful role of professionals due to professional knowledge • Patients' low self-confidence in their abilities to make decisions
5	Gioia et al (2014)	**Facilitators** • Support resources • Individual information about illness • Reliable relationship with professionals
6	Goscha (2015)	**Barriers to shared decision making** • Patients do not receive relevant information about their medication **Facilitators of shared decision making** • Patients having a positive working relationship with professionals • Patients having positive motivation for life • Patients having disclosed personal information and preferences • Professional advisors (case managers)
7	Jones et al (2013)	**Factors in shared decision making** • Patients experienced being controlled during any decision making • Powerful roles of professionals • Peer support amongst patients helps improve self-determined motivation, self-confidence/self-efficacy, and behavioural education • Patients feel empowerment/self-confidence when making decisions by themselves • Patients have increasing understanding of triggers, warning signs, behaviour patterns, medication use and the role of professionals • Improvement of professional-patient relationship via WRAP (Wellness Recovery Action Plan, which help patients to make decisions)
8	Laugharne et al (2011)	<u>**Trust**</u> **Facilitators**

		• Trusting therapeutic relationship ○ building trust by disclosing personal information ○ time ○ positive attitude and behaviour of professionals ○ professional image **Barriers** • undermining trust due to nature of illness • coercive/negative experience of treatment **<u>Choice</u>** **Facilitators** • Enough knowledge of patients • Sufficient time with professionals **Barriers** • Lack of information/knowledge about their treatment options • Impaired decision making capability; serious illnesses • Powerful roles of professionals • Burden of decision making • Negative experience of decisions they made previously
9	Matthias et al (2012)	**The process of shared decision making required:** • Sharing opinions, concerns, and/or preferences • Giving information about medication • Deliberation of a decision • Mostly reaching an agreement **What happened during decision making:** • Health professionals initiated most decisions • Decisions about follow-up appointments normally by agreement
10	Tanenbaum (2008)	**Factors which influence decision making:** • Doctor-patient relationship • Self-knowledge • Personal meaning • Recovery-related values • Need for information from multiple sources (professionals, carers, other resources) • Professionals' positive attitude toward sharing information • Accuracy of delivering professional knowledge

11	Velligan et al (2016)	**Barriers to shared decision making** • Negative attitudes of health professionals toward patients • Limited access to mental health system **Facilitators of shared decision making** • Respect for therapeutic relationship • Sufficient information • Easy access to services
12	Wharne, et al (2012)	**Barriers to shared decision making** **Being Excluded or withdrawing from decision making** • Losing valued social positions • Being left unsupported • Not being consulted about treatment • Seeking isolation **Being in the wrong place at the wrong time** • Lives that are broken up by periods of detention in hospital, leading to problems with, e.g. relationships with others, employment or somewhere to live. • Prone to wandering and random occurrences **Struggling to make experiences meaningful** • Not being able to share unusual beliefs and experiences • Adapting to being different
13	Woltmann & Whitley (2010)	**Patients desire autonomous/shared decision making** **Factors in shared decision making** • Relationship and interaction with health professionals

Table 3.10: Overview of analytical themes

Themes	**Barriers to shared decision making**			**Facilitators of shared decision making**		
Sub-themes Studies	Professionals with paternalistic attitude	Poor quality of interaction with health professionals	Lack of professional knowledge/information	Supportive attitude to patient involvement	Sufficient information exchange	Other support resources
Connor et al. (2006)	**V**	**V**	**V**	**V**	**V**	**V**
Dahlqvist et al. (2015)	**V**		**V**	**V**		**V**
Delman et al. (2015)	**V**	**V**	**V**	**V**	**V**	**V**
Farrelly et al. (2016)	**V**	**V**				
Gioia et al. (2014)			**V**		**V**	**V**
Goscha and Rapp (2015)		**V**	**V**	**V**	**V**	**V**
Jones et al. (2013)	**V**	**V**		**V**	**V**	**V**
Laugharne et al. (2012)	**V**		**V**	**V**	**V**	
Matthias et al. (2012)					**V**	
Tanenbaum (2008)	**V**			**V**	**V**	**V**
Velligan et al. (2016)	**V**	**V**	**V**	**V**	**V**	
Wharne et al. (2012)	**V**	**V**	**V**			
Woltmann et al. (2010)			**V**	**V**	**V**	**V**

3.2.4.1 Theme 1: Barriers to shared decision making

This theme describes the factors patients perceived as barriers to involvement or inclusion in shared decision making in mental healthcare, consistently linked with "professionals with paternalistic attitude", "poor quality of interaction with health professionals", and "lack of professional knowledge and information".

3.2.4.1.1 Sub-theme: Health professionals with paternalistic attitude

When patients experienced paternalism from health professionals, they perceived that they would be unable to actively participate in decision making and tended to adopt a silent role. Although there was alternative evidence in some individual cases, the accounts indicated prevailing negative assumptions and paternalistic attitudes from health professionals about patient involvement in decision making. Patients often felt prohibited from speaking up in clinical encounters. For example:

> *"...It was just to do what they said, for they were always right, even if you felt that this can't be correct, that this is not right for me, they were right in all cases and that was not good at all."* (Dahlqvist et al., 2015)

Similarly, even if patients desired or preferred a more active role in decision making, they perceived that their health professionals were unwilling to share decision making with them. This is illustrated in the example below:

> *"They* (health professionals) *are taught that they are the ones that provide the healthcare and so they see us agitators from their perspective."* (Connor and Wilson, 2006)

The data showed that seeing health professionals as authority figures led to patients being reluctant to become involved in decision making. In this case, patients perceived that health professionals held a more powerful role in the decision-making process. This was highlighted by a patient in the following example:

> *"They're (health professionals) the authority, and I don't know anything – that's how they think."* (Jones et al., 2013)

Such statements were perceived to demonstrate the health professionals' need to be the key decision makers. Patients felt health professionals considered themselves superior. Patients also stressed living in fear of further coercive treatment or care, and of decisions usually made by others. One patient described how health professionals acted when they wanted to refuse treatment, and then how health professionals considered themselves authorities:

> *"Um, the very first time I was sectioned* (sic), *what really give* (sic) *you ECT against your will, and that's when I tried to run for the door."…"There was nothing nice or doctoring speciality or loving or caring – you know he thought he was he was a glorified police* (sic) *"* (referring to a psychiatrist). (Wharne et al., 2012)

Furthermore, a few patients perceived existence of a power imbalance between health professionals and themselves. Patients felt powerless about the situation and that they were being lost in the decision-making process in all areas of their life. This is demonstrated in the following example:

> *"I think sometimes the doctors have too much power, especially psychiatrists, they make decisions about where you're going to live. I mean, Dr M basically made a decision about my life. She decided that I was under her care, she decided what medication I was going to have, and she decided where I was going to work. Now, isn't that power?"* (Laugharne et al., 2012)

3.2.4.1.2 Sub-theme: Poor quality of interaction with health professionals

A number of studies highlighted that the lack of – or poor-quality – communication was a significant challenge for patients. Patients' descriptions of interactions with health professionals were generally negative. Barriers to communication and interaction between patients and health professionals could cause patients to become less able to be involved in decision making. These could involve the use of inappropriate language and responses in communication, or lack of time to communicate with health professionals during decision making.

Disrespectful language was often reported, and was perceived to reduce the level of patient involvement in decision making. Health professionals dominated decision making encounters. Patients felt that health professionals did not respect patients and provided examples of negative verbal or non-verbal behaviour, thereby creating barriers to shared decision making. There were more subtle forms which manifested themselves in professionals using challenging responses to patients, characterised by statements such as "*no, we can't do that*" or "*you should*".

Many patients commonly reported that health professionals unconsciously treated them like children, and it was also perceived by the patients that health professionals saw themselves as parents who should take the role of proxy to make decisions for patients (as for children). Patients explained this by the use of disrespectful responses to patient involvement from health professionals, for example:

> *"The need to be a good boy. Don't be a naughty boy. Get us to behave like children, manage us."* (Connor and Wilson, 2006)

Similarly, from the patients' point of view, other people seem to think of people with a mental illness as being "child-like" and hence having impaired decisional capability, as illustrated below:

> *"There was nothing that stimulated me intellectually. And they automatically assume that if you have got a mental illness you are not intellectually capable*." (Connor and Wilson, 2006)

Patients also felt that professionals used inappropriate language, and certain problematic behaviour, when interacting with patients. Not listening was widely reported by patients. One patient described a situation where he felt completely ignored by his health professionals:

> *"He wouldn't listen to anything. He didn't do anything. With Depakote, when I needed my blood test, he never got my blood test. He never rescheduled my appointments, he just didn't do ANYTHING for me."* (Delman et al., 2015)

In some cases, health professionals were described as "rude", as illustrated below:

> *"I wanted a joint crisis plan 'cause I thought it might make a difference* (…) *with regard to how the psychiatrist would approach things if I got sick. 'Cause I've been sectioned so many times. But I remember, on the day that* (the facilitator) *came* (the psychiatrist) *was on the* (computer), *he was so rude* (...) *and he was on his* (computer) *most of the time when* (the facilitator) *was talking. He had his back turned."* (Farrelly et al., 2016)

Health professionals' failure to respond to patients' questions were commonly reported by the patients. It was perceived that health professionals paid more attention to addressing their own concerns and just asking questions they thought were important to them. Of central concern to patients was being listened to, not just about their symptoms but their stories too. They felt that health professionals often paid attention only to the nature of their illness rather than their personal experience and preference, and this often resulted in failure to listen to patients as patients expected, for example:

> *"And they just dealt with symptoms of what was wrong with me: they never asked me about my father's death, they never asked me about the break up with my long-term girlfriend. There was never any reference made to that, not once, I was just pumped full of drugs."* (Connor and Wilson, 2006)

Furthermore, some patients characterised health professionals as robot-like, fixated on standard procedure and unable to provide care at a human level. Health professionals failed to demonstrate an understanding of patients' suffering and were described as having "become desensitised" and treating patients "like cattle". For example:

> *"...didn't say hello, how are you, how are you feeling today, he just walked to the next person... and he did not speak to one patient, he didn't say, they were like cattle..."* (Connor and Wilson, 2006)

In addition, patients particularly emphasised the lack of time they spent with health professionals. Some patients perceived that the limited time allocated for consultations with their health professionals was insufficient for patient involvement in decision making**.** This prevented patients from talking about any difficulties they might be experiencing, asking questions, or expressing their concerns or preferences. Accordingly, this influenced their willingness to engage in treatment or care, for example:

> *"Sitting for hours, waiting, and only seen for five minutes. As soon as I walk in, he's already writing (a prescription), not talking to me."* (Velligan et al., 2016)

3.4.2.1.3 Sub-theme: Lack of professional knowledge and information

Patients repeatedly emphasised that knowledge gaps were a barrier to being able to participate in the decision-making process with their health professionals. For example, one patient commented that he/she saw his/her role as being very limited in making decisions about the treatment because he/she did not have the professional knowledge/information that the health professionals did.

> *"To be involved in decisions... well... of course, it's probably hard to participate in care when you have no education, and the others are sitting there with professional training and knowledge."* (Dahlqvist et al., 2015)

Beyond the nature of the knowledge gap between health professionals and patients, it was perceived that the patients did not receive sufficient information about their treatment and care. Patients commonly perceived that they were not given sufficient information and knowledge about their treatment. Patients said that they did not gain relevant information or knowledge about their treatment and care in medical encounters. From their perspective, the level of information about treatment plans provided by the healthcare professionals was insufficient. Therefore, they were not able to contribute more during the decision-making process. One patient explained how they accepted treatment but were not told the reasons for it:

> *"It feels like the ball is always in their court; they're making decisions and they're not explaining anything."* (Velligan et al., 2016)

Furthermore, patients with mental illness judged their decisional capacity negatively because of their lack of professional knowledge. The sense of being negatively judged by others served to undermine their confidence in being involved in decision making. Patients frequently said that they were not qualified to express their views and then lost confidence. One patient explained:

> *"I don't make many decisions because I'm frightened of making the wrong one."* (Laugharne et al., 2012)

Although there was a lack of receiving information and knowledge, the patients emphasised the desire for more information/knowledge. Patients stated that they particularly wanted information about medication, including the benefits and unwanted effects. This is illustrated in the quote below:

> *"...What I can sense when talking medicine / is / that you may only know what the idea is and how it should work, but then nothing is said about side effects."* (Dahlqvist et al., 2015)

Less commonly, but importantly, the sense of having a right to be involved in decision making and ask for more information was not widespread. Without this, patients became accustomed to the traditional silent role in decision making. For example, one patient described that he/she was not aware of the application of shared decision making in healthcare. Therefore, he/she did not realise his/her right to take or refuse the medication given by the health professionals, so he/she was more likely to accept it submissively, as the following quote illustrates:

> *"I just didn't know I could choose which medications I could be on or that I could refuse at all."* (Delman et al., 2015)

3.2.4.2 Theme 2: Facilitators of shared decision making

Although mostly it was barriers that patients reported, all of the studies found factors that facilitate shared decision making. Three major facilitators were found: supportive attitude to patient involvement, sufficient information exchange, and other support resources.

3.2.4.2.1 Sub-theme: Supportive attitude to patient involvement

Nine studies found that a supportive attitude to patient involvement was important in shared decision making. Patients believed that health professionals with supportive attitudes enabled them to ask questions, express their concerns or preferences, and share personal information. For example, one patient commented:

> *"In recent times, we have more or less the same ideas, but before that some of the ideas weren't the same. Because we weren't familiar with each other: they being a professional and me being a consumer, and learning to be more receptive to me being a consumer…we see more eye to eye on a lot of issues."* (Woltmann and Whitley, 2010)

Patients emphasised positive/supportive attitudes from health professionals, such as kindness, empathy and friendliness. These helped health professionals and patients to build trusting relationships. Patients perceived that health professionals who displayed human qualities and treated them as independent people had been most helpful.

> *"They believed in my ability, and they did so I grew... The more you see and show that you can do, the more chances you get. So it has meant that I have grown and, yes, I feel a thousand times better now."* (Dahlqvist et al., 2015)

Less commonly mentioned, but important, was how health professionals reacted when a disagreement emerged between them and the patients. Sometimes health professionals disagreed with what patients really wanted, such as reducing psychiatric medication, but still they both worked together to make a final decision. Even where health professionals were concerned about patients' decisions, they still tried to provide support to help patients work through their decisions. One patient shared a situation where he/she wanted to change medication and how the health professionals supported him/her in changing it:

> *"I wanted to go off meds. She said she didn't want me to do it but it was my decision and she'd help me do it in a way that would be most effective, and we can catch anything if I have an issue. She told me to call if I was having any delusions - to call the crisis line here; she wanted to make sure that nothing bad happens, or something, we can stop."* (Delman et al., 2015)

3.2.4.2.2 Sub-theme: Sufficient information exchange

In order to reach a mutually agreed-upon decision, openly sharing opinions and/or concerns was recognised as an important facilitator by patients. From the patient views, both professional knowledge and information, and personal preference and concerns, were important in making a shared decision about treatment and care. Therefore, having their medical knowledge and information needs met in an appropriate way was an essential facilitator for many patients. However, if patients did not acknowledge their condition, and they did not understand their available options, they were not able to participate in decision making.

Unsurprisingly, several patients reported there was a need for, in particular, pharmacological information. The patients in the included studies most frequently paid attention to medical information and spoke of medication discussions, such as the side effects of medication, changes of medication, or reduced dosage. The following example illustrates this shared process:

> *"Consultants have looked at me and they have considered that I've got enough knowledge and experience to be able to have an input into what the medication is."* (Laugharne et al., 2012)

Many patients believed information about treatment alternatives should be provided by health professionals, for example:

> *"Explain what it is and then give you an option between different medications"* and *"This one is for this, this one works really well with this, this one works really well with this."* (Velligan et al., 2016)

Conversely, patients with their unique expertise believed they could offer more information about their treatment preferences and facilitate a process of sharing the information. The importance of patient knowledge about themselves and their own conditions was repeatedly pointed out by the patients. In particular, one patient stressed the importance of health professionals taking what patients say into account to ensure a more accurate clinical diagnosis. Some even mentioned that personal expertise and medical expertise were equally important in the decision-making process. Therefore, patients felt that their voice should be heard by health professionals, for example:

> *"The people who are trying to decide how to give the right kind of help need to hear from the people who need the help."* (Gioia et al., 2014)

Similarly, some patients highlighted the importance of the professionals listening to patients rather than just adhering to theory or textbook facts about mental illness. They perceived that their first-hand accounts and research evidence were equally important in decision making. A patient who was diagnosed with depression asserted that health professionals should integrate what they heard from patients with what they learned from textbooks:

> *"Theory is good, it is good to understand theory but there has got to be a practical side too. You have got to get someone to say well I haven't read such and such a book on depression but I have suffered from depression and this is what I have gone though* (sic) *on a day to day basis."* (Connor and Wilson, 2006)

From the patient views, one way that health professionals gained mutual understanding in decision making was to know the patient's personal details and social circumstances. Patients' personal preferences about treatment options, and their goals and beliefs could have an impact on what kind of decision they would like to make. One patient commented that it is important that health professionals understood them as a person and not just the mental illness:

> *"I've got a very good CPN… she knows a lot about my personal circumstances, she knows I've got two daughters and knows I want to be part of their lives… She's got a nice personal touch to her, she tells me about her family and things."* (Laugharne et al., 2012)

3.2.4.2.3 Sub-theme: Other support resources

A prominent theme in people's experience of shared decision making in eight of the studies related to other supportive resources. The importance of multiple resources which could help them through decision making was identified by the patients in the included studies. They felt that it was very important that support resources were provided at any time they needed them. One patient mentioned:

> *"The resources have to be there. You could have the best heart in the world but the resources have to be there."* (Connor and Wilson, 2006)

Consistent with the previous themes detailed above, some patients felt that the flow of communication could be difficult because of a knowledge gap or personal communication skills. The help offered by these supporting people was varied, and included professional skills and communication strategies, which could give patients more confidence to express themselves. It was also thought helpful if what was likely to be discussed with health professionals in the medical encounter was also discussed in advance by patients. Access to a person or tool that has professional knowledge or sufficient information about mental health decisions was needed before, during and after decision meetings with their health professionals. These support resources varied from people to tools, such as family involvement, other professionals, patients with similar mental illness, and decision aid tools.

The patients expressed the importance of feeling that a supportive person was on their side. A supportive person could help them to express their preferences and ask questions without feeling criticised. The encouragement of a support person in decision making might reduce negative experiences and enhance the level of involvement in decision making.

In terms of support from other professionals, the patients suggested that supportive professionals could provide their knowledge to offer guidance in making decisions, for example:

> *"You might have a support person or a counsellor or PSR* (psychosocial rehabilitation) *facilitators or even a psychiatrist. That person has the education level to help you determine what you need to do, also friends and family."* (Jones et al., 2013)

Meanwhile, it was perceived that support was also to communication strategy. Some patients found they were more confident if they had support with communication skills before actually interacting with their health professionals. For example, one patient described a situation where one member of staff in a group home encouraged him/her to actively communicate with his/her health professional:

> *"The* (group home staff member) *encouraged me to write down what I wanted to say, or the questions I had. That way I didn't have to verbalize it. Having that*

> *paper in front of me, I was able to bring up medication problems right when we first sat down."* (Delman et al., 2015)

Similarly, some patients pointed out that other patients who have similar conditions or experience could provide an insight into their mental health conditions. Advice from these people could help the patients focus on their points of concern and promote discussion with their health professionals. Two examples follow:

> *"I think it's good to hear what others are doing and what's working for them…"* (Tanenbaum, 2008)

> *"It's better if someone who has had experience of it can describe it. Someone you feel understands and then you may feel oh well this might be something for me... or maybe you feel, no, this was not what I thought."* (Dahlqvist et al., 2015)

Less commonly mentioned in studies but important to note were the views of family involvement in decision making. Some believed that active family involvement could help patients to gain more understanding of their conditions and provide someone to keep an eye on the warning signs of relapse. For example, one patient described how they gained more understanding of their medication plan and mental health conditions with their spouse's support:

> *"I had more of an understanding* (when my spouse was involved) *of my mental health, and my medication, and the effectiveness of both," declared one married veteran.* (Gioia et al., 2014)

In addition, the importance of decision aids and interventions has been stressed in these data. A few patients felt that they were able to be involved in decision making because they used some decision aids or participated in shared decision making interventions, which could improve the implementation of shared decision making in mental healthcare. The intervention promoted participation by helping patients to gain sufficient knowledge/information, and asking questions during decision-making meetings. Therefore, some patients believed that decision support could potentially help them to be actively involved in decision making; for example:

> *"WRAP gave me the idea of taking my list of wellness tools to the psychiatrist's office and using it to discuss [things]... [It] made me bring up and talk about a lot of things that I wouldn't have otherwise."* (Jones et al., 2013)

3.3 Strengths and limitations

To the author's knowledge, this review is the first qualitative systematic review to provide a thorough meta-synthesis of the experience of shared decision making and possible barriers and facilitators for patients of secondary mental healthcare. The reported findings should be carefully considered in the context of the strengths and limitations of the synthesis which was carried out.

First, the review incorporated the experiences of patients with mental illness from diverse backgrounds and circumstances. Also, the reported findings given are comprehensive, sourced from qualitative investigations undertaken in various regions of the world. However, all the studies were conducted in western countries, such as the US, the UK, Canada, and Sweden. Meanwhile, none of these studies was carried out in Asian countries, including Taiwan, the specific context of the author. Therefore, the implications cannot be translated to other non-western high- or low-income countries.

There is a lack of studies on decision making in Asian counties, particularly in Taiwan, suggesting that shared decision making has only recently been conceptualised and has not been widely introduced in practice, including in mental healthcare (Hou, 2015; Hsu et al., 2015; Yen and Hsu, 2007). To date, there are no relevant studies on decision making for patients with mental illness in Taiwan. This is a significant gap between western and Asian countries.

Second, only few published studies of perspectives on shared decision making concentrate the majority of their research on both patients and health professionals, despite evidence that in this context mental health patients' views can be lost. Therefore, it is possible for some studies to not reach saturation point to adequately address all potential issues that may have arisen from the patients' perspectives.

Third, some limitations of qualitative synthesis should be considered. Researchers have argued that qualitative data is not suitable for synthesis as every researcher could produce very different results from the same data, which leads to concerns about rigour in systematic reviews (Jensen and Allen, 1996). Despite this, in the interpretive paradigm, it is argued that reality is constructed by social phenomena created by humans, and exists in context-specific situations which are multiple rather than singular (Green and Thorogood, 2009; Guba and Lincoln, 1994). Synthesis of qualitative studies could help people to understand the essences of specific phenomena and advance knowledge (Sandelowski, 1993). Also, qualitative meta-synthesis relies on interpretation of narrative inferences rather than statistical inferences (Jensen and Allen, 1996). Therefore, the validity of qualitative synthesis should be carefully considered when conducting reviews. To reach valid interpretations, this review strictly followed the recommended set of procedures to achieve credibility.

Finally, although all the studies were carefully considered by the author when deciding to include or exclude them, the quality of each study could vary. Overall, the quality of the studies was categorised as high, medium or low, and thus it is difficult to be confident of the overall findings as representative of patients' views. Furthermore, due to resource limitations, this review excluded non-English publications, which raises the possibility of missing relevant studies.

Hence, further studies could collect data directly from not only health professionals but also patients in other contexts. Moreover, it could address the methodological constraints of the studies, such as data analysis, in a rigorous way.

3.4 Summary

To summarise, this systematic review has produced important findings regarding patients' views about their experience of shared decision making, and possible barriers to and facilitators of shared decision making in mental healthcare. The findings of this review strongly supported the idea that patients in mental healthcare still played passive roles in the decision-making process. The findings of this review introduced two important themes: barriers to and facilitators of shared decision making.

There were three significant barriers to shared decision making in mental healthcare. The health professionals commonly adopted a paternalistic attitude to stop patients being actively involved in the decision-making process. Meanwhile, the poor quality of interaction with health professionals was also recognised as a major barrier to shared decision making, from the patients' accounts. Additionally, patients did not have the confidence to be actively involved due to their limited professional knowledge.

By contrast, some facilitators were also identified in the interviews. Health professionals with a supportive attitude could be the key to facilitating the implementation of shared decision making. Also, patients pointed out that sufficient information exchange could also be of benefit in implementing shared decision making. Moreover, some patients also realised the importance of other support resources, such as other health professionals and decision aids, which helped them to actively engage in decision making.

This chapter has provided an insight into the patient perspective of shared decision making in secondary mental healthcare, as described in the existing literature. However, there is a lack of direct evidence about the perspectives of either patients or mental health professionals about shared decision making in Asian countries, including Taiwan. Increased emphasis needs to be placed on how their views can change mental healthcare practice or services. In addition, the limitations of some methodologies, as described in Section 3.3, could be improved in some ways. Therefore, this chapter has established that, whilst the review highlighted some evidence that patients are being consulted in some contexts, there was a definite need to undertake studies of patients' and health professionals' views directly in this area in other cultural contexts.

Chapter Four: Working methods for patient and health professional interviews

The research design of this study was presented in Chapter Two, which described the underpinning methodology. This chapter will present the working methods for the two qualitative studies exploring patients' and health professionals' perspectives on how decision making was shared in secondary mental healthcare.

4.1 Participant selection

4.1.1 Patient interviews

The aim of using purposive sampling (described in Chapter Two) was to ensure the selection of information-rich participants for the most effective use of limited resources. The sampling strategy sought to recruit patients with a diagnosis of mental illness who were using halfway houses (for inclusion and exclusion details see Table 4.1).

Table 4.1: Patients – inclusion and exclusion criteria

Inclusion criteria	Exclusion criteria
• Adults aged 20 or over who have mental illness • Using halfway houses • Able to read and understand traditional Chinese or English, and speak Taiwanese, Mandarin, or English	• Less than 20 years old • Unwilling to participate; not able to communicate in Taiwanese, Mandarin, or English • Refusing audio-recording

The reason patient participants were recruited from half-way houses was to involve patients with experience across numerous mental health secondary services, such as inpatient settings, outpatient departments, and other secondary mental health settings. Typically, patients in halfway houses have been referred from inpatient units and continue to attend out-patient services, so they are likely to have experience across the range of services provided in mental healthcare in Taiwan. In addition, according to the National Health Insurance system, patients who are referred for treatment in community rehabilitation centres and halfway houses typically have stable psychotic symptoms and long-term support needs, but they are considered to have the potential for rehabilitation to return to the community to live independently (Hsieh and Shiau, 2006). In other words, these patients now have a stable psychiatric condition but have broad experiences across secondary mental healthcare. Therefore, patients in halfway house were selected for conducting this study.

Adults aged 20 or over were included because in Taiwan, research participants are legally required to be adults, i.e. over 20 years old (The Legislative Yuan of the Republic of China, 1929). This criterion also applied to the health professional group.

4.1.2 Health professional interviews

The sampling of health professionals aimed to capture a wide range of mental health settings with a range of clinical roles in secondary mental health service (see Table 4.2 for details). The rationale for including professionals with a minimum of one year's experience is that professionals need to have experience of the phenomenon of interest and trainees may not have direct experience.

Table 4.2: Health professionals – inclusion and exclusion criteria

Inclusion criteria	Exclusion criteria
• Registered mental health professionals including psychiatrists, mental health nurses, nurse practitioners, clinical psychologists, occupational therapists, case managers, and social workers • Aged 20 or over • Working in secondary mental healthcare, including community mental health centres, outpatient departments, outpatient clinics, day centres, day hospitals, rehabilitation services, group homes, halfway houses, or other support services • With at least one year's experience of working in mental healthcare • Able to read and understand traditional Chinese or English, and speak Taiwanese, Mandarin or English	• Under 20 years old • Less than one year's working experience • Unwilling to participate • Not able to communicate in Taiwanese, Mandarin, or English • Refusing audio-recording

4.2 Recruitment

Following confirmation of ethical approval from the University of Manchester (Ref: 2017-2009-3358) and Chang-Gung Medical Foundation Institutional Review Board

(Ref: 201700879B0) in Taiwan, the author visited the five settings (one outpatient department, one day care centre and three halfway houses) to explore recruitment for both studies. The department managers and mental health professionals were approached in their workplaces, either individually or at team meetings, in order to explain the purpose of the studies and data collection procedures, and to identify participants meeting the study criteria. There were individual meetings with managers in the various settings. The author also made ten presentations to health professionals in their workplaces to help them to gain more understanding of the purpose of the studies and the data collection procedures. After this, the managers and health professionals contacted three halfway houses to facilitate this study. Three halfway houses agreed to facilitate study and three health professionals in the halfway houses were willing to be the author's main contact person to facilitate data collection.

4.2.1 Patients

For the patient group, patients were identified through the managers and healthcare professionals in three halfway houses in Taiwan.

Two methods were used to recruit potential patient participants in the halfway houses:

- information packs (10/07/2017)
- posters (10/07/2017-01/09/2017)

The study information pack was distributed to each resident. The healthcare professionals were asked if there were any concerns about risks that may present to the patient or the author in conducting an individual interview before distributing packs, and no concerns were raised, thus no resident was excluded for reasons of safety. To promote recruitment, posters were displayed in the public areas of halfway houses.

Patients were given at least 48 hours to read the information sheet, and think about taking part in the research. If any patient was interested in taking part or wished to ask any further questions about the research, they could contact the author via phone or email. A contact number and email address were given in the invitation letter and the information sheet so that, if the potential patient participants required more information, they could contact the author directly. Also, in order to provide flexibility, potential patient participants could leave a message using the contact form to indicate they were interested (either giving it to their health professionals or leaving it in message boxes in the reception of the halfway houses). The author regularly checked with the health professionals and the message box at least weekly.

4.2.2 Health professionals

The author used two stages to maximise recruitment and ensure variation in the types of healthcare professionals sampled.

- **stage one:**
    - posters in staff offices in the five selected settings (one outpatient department, one day care centre and three halfway houses) (10/07/2017-01/09/2017)
    - information pack allocated for the five selected settings (10/07/2017)
    - adverts on social media (10/07/2017-01/09/2017)
- **stage two:**
    - adverts on social media (01/11/2017-15/11/2017)

First, the author identified potential professional participants through the managers of one outpatient department, one day-care centre, and three halfway houses. During the initial stage of recruitment, research information had been presented by the author to managers of the settings through either one-to-one or group meetings. The author asked the managers of these five settings to send the information sheet, the non-named invitation letter, and the contact form to all registered mental health professionals there, to invite them to take part in the study. In addition, posters advertising the study were placed in staff offices of the five selected settings (one outpatient department, one day-care centre, and three halfway houses) to identify more mental health professionals. To maximise health professional recruitment the study was advertised via social media including Facebook, Twitter, and PTT Bulletin Board System (which is the largest terminal-based bulletin board system (BBS) based in Taiwan) from 10th July 2017 to 1st September 2017. The author's contact details (phone number and email address for work) were provided in the advert. Potential professional participants could contact the author via phone and email to gain further information. Information sheets were then provided via post or email to explain the details of the study. In this stage, the author explained further details of the study to potential professional participants via phone and email to clarify any questions they had. Then the health professionals were given at least 48 hours to consider whether they were willing to participate in the study. Professionals were then asked to sign the consent form. In order to take part, they could contact the author via phone or email to arrange an interview.

Although this first stage was fruitful for recruiting health professionals (such as psychiatrists), no mental health nurses were recruited. To ensure the diversity of the health professional sample, a second stage of recruitment was implemented. The authors contacted other health professionals to spread the information about the study, and then re-posted the advert in some nurses' groups (professional nurses' groups on social media). One nurse colleague supported the study by spreading this information to relevant groups on social media.

4.3 Data collection – Qualitative interviews

The author conducted individual face-to-face, semi-structured interviews.

4.3.1 Topic guide

Topic guides for each of the patients and health professional groups (Appendix 2 and Appendix 3) were devised from the results of the qualitative systematic review and modified after discussion with supervisors. In order to become familiar with the topic guides and to ensure flow of the interview the author practiced with a supervisor and colleagues. Further minor modifications were made following this process.

4.3.1.1 Patient interviews

Patients were asked to discuss their experience of decision making in mental healthcare. Here, clarification was provided around the term "decision making": "making decisions about treatment and/or care in mental healthcare" because it was felt that patients may not be familiar with the concept of shared decision making. Patients were asked about their preferred level of involvement in treatment and care decisions and to identify facilitators or barriers influencing patient involvement in decision making.

The patient interview questions focused on the following issues:

- their experience of decision making in secondary mental healthcare
- their preference about decision making in secondary mental healthcare
- their expectation of decision making in secondary mental healthcare
- barriers to/facilitators of their involvement in decision making

4.3.1.2 Health professional interviews

Health professional interview questions focused on the following issues:

- their experience of decision making in secondary mental healthcare
- their attitude toward patient involvement in decision making
- their understanding of shared decision making
- barriers to/facilitators of patient involvement in decision making

4.3.2 Demographic data collection

To ensure the sample could be described, demographic data were gathered on both patients and health professionals using a brief questionnaire (Appendices 4 and 5).

4.4 Data analysis

All interviews were digitally recorded and transcribed verbatim by the author.

4.4.1 Qualitative data analysis software

Computer assisted qualitative data analysis software was employed to assist in the analysis of the data. Qualitative data analysis software was used because it supports several analytical styles (Fielding and Lee, 1991), helps portray data transparently and provides an audit of the data analysis process (Carcary, 2009; Welsh, 2002). Therefore, computer-based methods have been recognised as valuable means of improving the rigour of qualitative research (Alhojailan, 2012; Welsh, 2002).

NVivo software was used to manage and analyse the data in this study. NVivo (QSR International Pty Ltd. Version 11, 2015) is a qualitative data analysis software package consistent with thematic analysis. It can help analyse qualitative data at various stages: gathering all the evidence, subsequently organising it into codes and grouping it into similar themes (Alhojailan, 2012). Welsh (2002) also points out some features which make this software easy to use. For example, using this program, documents can be imported directly from a word processing package and coded. This helped the author to easily see the details of the data. Another strength is the model explorer tool in Nvivo, which is useful to map out diagrammatically how these themes relate to each other, in order to make sense of them (Welsh, 2002). Also, NVivo has been recognised as one of the most popular qualitative data management programs in the field of health (Zamawe, 2015). Therefore, in this study the information was entered in Microsoft Word and then transferred to NVivo.

4.4.2 Thematic analysis

During the data analysis process, thematic analysis as proposed by Braun and Clarke (2006) was applied. There are several steps that guided the author when interpreting the data:

- familiarisation with the data
- generating initial codes
- searching for themes
- reviewing themes
- defining and naming themes
- producing the report

4.4.2.1 Familiarisation with the data

All interviews were transcribed by the author herself. Following the completion of the transcriptions, the first three interviews in each group (patients and health professionals) were transcribed into English and read by the author and supervisory team to ensure they gathered in-depth information around each topic, and also to ensure completeness of the interviews. The first step was to gain familiarity with the data by listening to the recordings of the interviews and rapidly reading the transcripts of the interviews and field notes (Braun and Clarke, 2006). As part of the qualitative data analysis, all recordings were carefully listened to and transcribed in Chinese by the author using Microsoft Office Word 2010 software. Recordings were listened to repeatedly.

4.4.2.2 Generating initial codes

The next step after familiarisation is generating initial codes. This is an analytic process which involves a conceptual and semantic reading to generate the codes (Clarke and Braun, 2013) in NVivo. This second stage involves making concise notes about important features of the data related to the research. After reading all the transcripts of the interviews, the author coded the transcripts. Using NVivo software, extracts across transcripts that were related to each other were grouped together into codes (known as ‘nodes’ in the software). All the interviews were coded using this approach, and a final reading was undertaken to identify any possible missing codes. At this stage, long lists of codes were generated from both patient interviews and health professional interviews. Table 4.3 below provides an example of how initial codes were added to the data extraction.

Table 4.3: Data extraction with initial codes applied

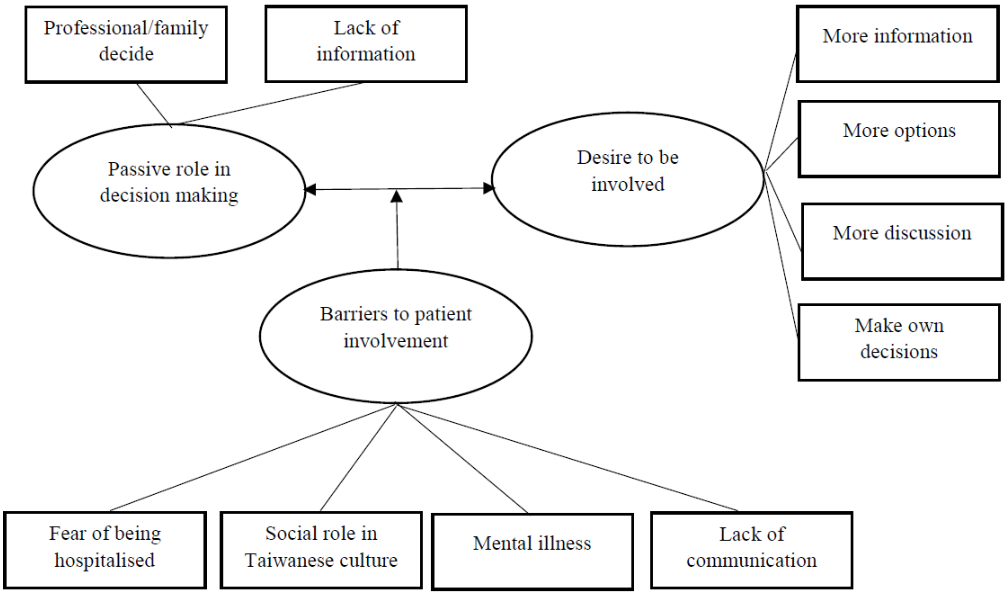
Studies	Data extraction	Initial code
Patient interviews	*I told them: I don't want to take this medication… But the staff told me I must take it… or they will take me to be hospitalised. So… so… I took it…* **(09 Patient)**	• Patient cannot decide treatment or care • Verbal threat about re-hospitalisation from professionals
Professional interviews	*I don't think it is a great idea to give them many treatment options. They feel panic when they get this disease. If they are given a lot of information at one time… they can't make a decision. You know the patients still ask the professionals to decide for them. They don't want to decide. So… isn't it pointless to provide options at the beginning?* **(01 Psychiatrist)**	• Felt a lot of information would be overwhelming • Patients prefer a passive role • Professionals have negative attitude to shared decision making

4.4.2.3 Developing themes

Following coding, a long list of potential themes and sub-themes was identified. (Appendix 6). Clarke and Braun (2013) describe this stage as being more like coding your initial codes to search for a pattern within your initial codes, or nodes. A theme is an interpretive concept which explains the characteristics of the data and identifies meaningful patterns within the data. Importantly, researchers should actively construct their themes rather than discover themes hidden in the data (Clarke and Braun, 2013). Further, the aim of this step is to understand the relationships between codes rather than identify an overarching theme structure.

Figure 4.1 presents an example of an initial thematic map for patient interviews. To ensure the themes were appropriate for analysis, all these themes were descriptive and were easy to allocate or assign at this stage.

Figure 4.1: Initial thematic map for patients



4.4.2.4 Reviewing themes

Following this process, the author checked that the themes represented the full data-set (Clarke and Braun, 2013). It is important to ensure the themes tell a compelling and conclusive story from the data (Clarke and Braun, 2013; Spencer et al., 2014). The author started to consider the essence of and relationships between the themes and discuss the emerging themes with the supervisory team. Although this is a time-consuming process it provides a greater level of interpretation across the data. This often involves collapsing or combining themes to explain the data comprehensively (Braun and Clarke, 2006).

By continued discussion with the supervisory team, the main themes and sub-themes were structured for both patient interviews and professional interviews.

Using NVivo, the author constantly reviewed the content of the nodes at this stage. Node classifications containing recognised characteristics from all sources were created. Memos were also used for documenting the author's questions, ideas, and thoughts during data analysis.

For the patient interviews, all potential themes were reviewed and two main themes were identified, namely "barriers to patient involvement in decision making" and benefits of shared decision making".

For the professional interviews, the author also reviewed all the themes based on the codes generated earlier, during step two and three, and identified two main themes, namely “barriers to shared decision making” and “facilitators of shared decision making”.

4.4.2.5 Defining and naming themes

This step involves conducting and writing up detailed analyses of individual themes, and researchers should ask themselves what story was told in any given theme, and how each theme represents a particular part of the whole story (Clarke and Braun, 2013). To ensure the themes were named appropriately, the author identified the nature of each theme and constructed an informative and convincing name for each. For example, at this stage, the theme “benefits of shared decision making” was renamed as “facilitators of shared decision making”. All details of each developed theme will be presented in Chapters Five and Six. The interpretation of the result was agreed with the supervisory team.

4.4.2.6 Producing the report

In this stage it is essential to write the analytic narrative and data extracts all together, to explain the whole story in a coherent and persuasive way (Braun and Clarke, 2006). As the data analysis process reached an advanced level, a broader picture or visual interpretation of the data became necessary for producing reports and models. This also involved contextualising all the findings within the existing literature. These strategies were used at this stage to present the results from the data. A detailed discussion of the findings will be presented in subsequent chapters. At each stage of the data generation and analysis process, regular meetings were held with the supervisory team to review sampling strategies, transcripts, coding, memos and field-notes, and to identify categories and explain the relationships between codes.

4.5 Rigour

To ensure that the quality of this study was maintained throughout the research process, the principles of credibility, transferability, dependability, and confirmability were considered (Lincoln and Guba, 1985).

4.5.1 Credibility

Peer debriefing is a strategy where the author seeks scholarly guidance and support from professionals, such as supervisors, to improve credibility. The supervisory team, whose perspective of this study was more neutral, examined and provided feedback to support the development of this study and enhanced the quality and credibility of this thesis. Throughout the research process, regular meetings were held with the supervisory team to discuss general methodology, working methods (such as interview topic guides and interview transcripts), and the final report.

4.5.2 Transferability

Transferability refers to the extent to which the results of qualitative studies can be transferred or generalised to different contexts or settings. A rich description of the research process and details of the participants should be provided to ensure transferability. In this thesis, detailed discussion of how the study was conducted are presented in Chapter Two (Methodology) and this chapter (Working methods). Data collection was conducted to substantiate the interpretation produced and the diversity of the population studied. Also, thick description of the participants will be presented in Chapters Five (Findings from patient interviews) and Six (Findings from professional interviews). Therefore, readers will be able to use the information to establish whether the findings of this study are applicable to their own settings or services.

4.5.3 Dependability

Dependability, regarded as reliability in qualitative studies, draws attention to the need for researchers to explain the changing context where the research was conducted (Korstjens and Moser, 2018; Lincoln and Guba, 1985). The criterion of replicability or repeatability, which forms part of a traditional quantitative view of reliability, could be challenging to meet in qualitative studies.

In this study, to ensure dependability, an audit trail was used and details of features of the study design, such as data collection and sampling, are presented within the thesis. Methodological and theoretical decisions were discussed in Chapter Two (Methodology). This chapter also provided all the details of the processes of data collection and data analysis. The research design and its application are presented in the thesis to ensure dependability.

4.5.4 Confirmability

Confirmability aims to ensure the results could be confirmed or corroborated by others to minimise potential misinterpretation. As in qualitative studies it is assumed that researchers bring their own perceptions to the studies, it was vital to ensure the objectivity of the whole study process. The strategies of an audit trail and a reflexive journal were used in this study. The audit trail was discussed above. In this section, the author therefore focuses on reflexivity.

4.5.4.1 Reflexivity

In order to enhance confirmability, a reflective journal was employed throughout data collection and analysis to help the author to assess incorrect assumptions, personal influence, and possible misinterpretations of the data. Reflexivity is a process of introspection for researchers into their subjectivity in the research process. In interpretivism, reflexivity, which is the appraisal of the influence of the author on the participants studied, is needed (Horsfall, 1995).

This is a dynamic process while the study is being conducted of recognising, examining, and understanding how researchers' social background and assumptions influence their research practice (Hesse-Biber, 2007). The principles of reflexivity are to ensure methodological cohesion, work inductively, be responsive as a researcher, recruit an appropriate and accurate sample, and attend to ethics (Morse et al., 2002). It will be discussed in detail in the following sections, including the positionality of the author, the use of field notes, and ethical approval.

4.5.4.1.1 The author

All aspects of the study, including participant recruitment (patients and health professionals), data collection (qualitative semi-structured interviews), and data analysis (thematic analysis and using the supervisory team for data analysis) were conducted by the author.

The author has long-term practice and interest in shared decision making, quality of life, evidence-based practice, long term mental ill health, and mental healthcare research, and has been involved in several research projects relating to patients in mental healthcare, such as a patient quality of life project and a stigma in mental healthcare project. The author has previously worked as a registered nurse in mental healthcare and as a lecturer in nursing colleges in Taiwan.

The author has spent a significant amount of time reading, understanding, and writing about decision making, so previous knowledge could have had a significant impact on the interpretation of the data. This background has its advantages but has some disadvantages the author was also aware of: for example, loyalty to mental health professional groups could have compromised objectivity. Due to the nature of qualitative studies, it is impossible to separate the author from the qualitative data collection (Patton, 2002). To minimise these potential problems, self-reflexivity and regular meetings with supervisors were used.

During the interviews, participants were aware that the author was a nurse in mental healthcare in Taiwan and a PhD student at the University of Manchester. However, these roles could have influenced patients' involvement or responses to the interviews in some ways. Some participants may have felt that it was difficult or unsafe to disclose their true feelings and behaviour about decision making in mental healthcare. This might have been exacerbated by a social desirability bias, where participants will often reply to questions on sensitive topics inaccurately to manage the impression they are giving, or for ego-defensive reasons (Fisher, 1993). In this case, participants are more likely to provide an answer which is socially acceptable rather than disclose his or her true perspective or behaviour. In order to mitigate this, the author therefore explained to the participants that the aim of study was to explore their perspectives, but not to judge them, and that there were no right or wrong answers to the interview questions.

At the same time, due to the author's circumstances and professional position, additional concerns might be raised about confidentiality. A full explanation of confidentiality and how this was maintained was provided to the participants prior to the interviews. Further details of how confidentiality was managed will be discussed in the autonomy section.

4.5.4.1.2 Field notes

The use of field notes is regarded as one of the core tools for qualitative studies (Tong et al., 2007). Field notes serve many functions, such as documenting valuable contextual data, constructing thick descriptions of the data, and encouraging the author to be reflective (Phillippi and Lauderdale, 2018). Most qualitative research methods suggest taking field notes to enhance rigour and trustworthiness (Creswell, 2007; Patton, 2002).

In this study, both descriptive information, including interview dates, settings, behaviours, and conversations which the author observed, and reflective information, such as personal thoughts, questions, ideas, and concerns during the interviews, were systematically taken down for each interview. Field notes were taken for all interviews to:

- encourage the author's reflection and identification
- document any social behaviour or environmental stimulus in which the author was interested
- provide valuable context to inform data analysis and facilitate the initial coding

Descriptive information in field notes (such as interview dates and settings) was used to provide thick description of the research process and details of the participants. Also, reflective information including the author's thoughts, ideas, questions, and concerns were reviewed by the author during data collection in order to maintain consistency in conducting this study. Meanwhile, field notes do not just foster self-reflection, but also are crucial for understanding and interpreting in a research study. Through the field notes, some ideas, initial codes and potential themes were identified, which fostered a more developed interpretation. During data analysis, a set of field notes helped the author recall the interviews and then distinguish relevant information and accurately code the data.

4.6 Ethical considerations

Through undertaking training in ethics and data collection prior to applying for ethical approval, the author felt comfortable with both the participants' rights during the study and the requirements of the health services. These courses included:

- Research Ethics Application: University & NHS
- Lone Worker Training for Field Researchers
- Data Protection
- Good Clinical Practice (number: 2017043)

Ethical considerations were taken into account and the application was submitted to:

- the University of Manchester Research Ethics Committee (ref: 2017-2009-3358) (see Appendix 7)
- the Chang-Gung Medical Foundation Institutional Review Board (ref: 201700879B0) (see Appendix 8) in Taiwan.

All the study procedures were approved by these bodies.

The procedures proposed by Beauchamp and Childress (2013) were applied to ensure that the four ethical principles of conducting health research were followed: autonomy, beneficence, non-maleficence, and justice. These are discussed below.

4.6.1 Autonomy

Potential participants were provided with an information sheet detailing the process of the study and potential benefits and risks of taking part, which was favourably reviewed by the relevant ethical committees. Both patients and health professionals had to provide informed written consent to participate in the study. Each participant's signature was obtained on an informed consent form. Details of informed consent are presented in Appendix 9 and Appendix 10. All participants were reminded by the author that their involvement was totally voluntary and not influenced by any other external pressure or discrimination.

The author ensured that participants fully understood the purposes and the process of this study by asking them to read an information sheet which the author provided prior to the interviews. They could decide if they were willing to take part or not without any pressure. Potential participants were given at least 48 hours to consider whether they wanted to participate or not. The whole process was confidential and the participants were fully informed.

Participants could withdraw from the study at any point during the interview without giving any reason, and up until the data was anonymised and analysed (approximately one month after the interview). If participants refused to take part in the study, there was no effect on their treatment and care/professional career and legal rights, and this was made clear in the study documentation.

A digital voice recorder was used during each interview, with the agreement of participants. Even if they either refused permission to use direct quotes in any report or declined to receive the summary of findings, they still could take part in this study. They could indicate via the consent form if they agreed to these two aspects.

4.6.1.1 Confidentiality

For both groups, the participants were informed that the discussion would be confidential unless they provided information that suggested suicide or risk of harm to themselves or others. Participants were informed that the author would inform their healthcare professionals or GPs if risk to self or others was identified. For the professional group, the participants were informed that confidentiality would only be broken if evidence of practice which was inappropriate or harmful to patients emerged during the interview. The author would in such circumstances inform their managers. Each participant was given a reference number and their data was coded with these IDs without linking to their names. After the interviews, written consents and any documents containing the participants' personal details were securely locked in a cabinet in Chang-Gung Medical Hospital. After data collection finished, these documents were transported securely by the author in her hand luggage to the University of Manchester, where they were locked in a locked cabinet. The codes were linked to the relevant consent forms, which were stored separately.

During transcription, personal details of the participants were removed by the author. Audio-files were uploaded onto an encrypted server at the University of Manchester and then accessed only via a password protected computer and deleted from the digital recorder as soon as possible. All digital recording files on the encrypted server at the University of Manchester were deleted after transcription was completed. Information stored on the University of Manchester computer or the encrypted server at the University of Manchester is protected with passwords and the passwords are held by the author. Only the supervisory team (Professor Karina Lovell and Dr Laoise Renwick) in the UK and the principal investigator have access to identifiable data. Furthermore, when the study was completed, the results of the study were documented and a summary provided to all participants. The data generated is to be stored for 10 years after completion of the study. Following completion of the study, all participant contact information was destroyed. During the interview process, the privacy of the interview environment was managed carefully. Those who decided to proceed arranged a preferred date, time and place for a face-to face interview. For the patient group, the interviews were conducted in a private room located in one of the three halfway houses. For the health professional group, the interviews were conducted in a private room at their workplace or in the hospital as they preferred.

4.6.2 Beneficence and non-maleficence

The author clearly discussed the individual and practical benefits with the participants. In this study, although there was no obvious benefit from taking part, participants had an opportunity to express themselves. Furthermore, there was a possibility of patients’ care being changed, or for health professionals to receive training based on the findings of this study. By publishing the results of this study, these might be used to improve the level of care for patients and provide health professionals with insight into how patient feel about the decision-making process. In order to facilitate this, the summary of findings of this study will be sent to the participants who indicated on their forms that they wished to receive it. During the ethics committee application, the potential risks and benefits of participating in this study were assessed by the author, the supervisory team, the external committee at the school, the University of Manchester Research Ethics Committee, and the Chang-Gung Medical Foundation Institutional Review Board.

4.6.2.1 Potential benefits of participation

As for benefits, the individual and practical benefits of taking part were discussed with the participants. Although there would be no direct benefit to research participants, understanding patients' and health professionals' experiences of decision making will help understand what kind of decision-making model is experienced by patients in mental healthcare. In addition, facilitators and barriers which influence this process might be identified from this study. Most importantly, this could provide an insight into the preference of patients with mental illness during decision making.

4.6.2.2 Potential risks of participation

In terms of potential risk, the two most significant risks of harm posed to the participants were breaching confidentiality and causing distress. The issue of confidentiality was discussed above. In this following section, the research will present how the risk of participant distress was managed.

- **Distress management**

Due to the potentially sensitive nature of the topics related to negative experiences of decision making, participants might have felt overwhelmed or become upset during interviews. During the interview, the author was careful and used words with no subjective judgment, and time was taken to end interviews well by asking participants about their experience of the interview, to check whether the interview had unsettled them in any way and to discuss any issues that had arisen. Some personal questions about the process of decision making in mental healthcare might have caused distress. A distress policy was written and was adhered to (Appendix 11).

4.6.3 Justice

To ensure justice, significant efforts were made, including equal opportunities for both patients and health professionals to participate in this study. Information packs were allocated for both patients and health professionals, and inclusion criteria were widely distributed for both groups (within the selected settings for both groups, and on social media for the professional group). In order to ensure that patients were not discriminated against, assessment of eligibility for participation should focus on the ability to understand and voluntarily participate without any external pressure. In addition, the length of interviews was kept to the minimum possible. Participants (patients and health professionals) were compensated for their time and effort when participating in the study with everyday supplies such as toiletries or a pre-paid gift card for no more than £10.

4.7 Summary

Overall, this chapter has discussed the working methods for studies based on interviews with patients and health professionals. These two studies aimed to explore their perspectives of how decision making was shared in mental healthcare. A qualitative method was used to generate data to provide a comprehensive and informative interpretation of the doctoral study. The qualitative studies incorporated thematic analysis and were underpinned by the philosophical position of interpretivism.

Chapter Five: Findings from patient interviews (Study Two)

This chapter will present the findings of the qualitative interview study which comprised in-depth semi-structured interviews with 20 patients in secondary mental healthcare (Study Two).

5.1 Characteristics of patient participants

Patients were purposively selected from three halfway houses between July 2017 and August 2017. A total of 92 information packs were distributed in the three halfway houses; 23 returned the contact form (20 contact forms through health professionals and three contact forms through the message boxes) indicating patients were interested in participating in the study. Of these, 20 patients agreed to be interviewed, and three felt they did not have enough available time to be interviewed and refused to take part. All interviews were held in interview rooms in the halfway houses. Interview duration ranged from 40 minutes to 79 minutes (average of 43 minutes).

The characteristics of the interviewed patients are presented in Table 5.1.The patients comprised 13 males and 7 females with an average age of 38 years. Most patients had been staying in halfway houses from a few months to 3 years (n=14). Five had been in halfway houses from 4 to 6 years and one for more than 10 years. Most (n=17) patients identified or reported that they had a diagnosis of schizophrenia, and three as having bipolar disorder, major depression, and schizoaffective disorder respectively.

Table 5.1: Characteristics of patient participants by reference number

Reference no.	Gender	Age	Self-Diagnosis	Duration of accommodation
1	Male	52	Schizophrenia	0 years 6 months
2	Female	55	Schizophrenia	1 year 1 month
3	Male	54	Schizophrenia	10 years 0 months
4	Female	39	Schizophrenia	3 years 0 months
5	Male	35	Schizophrenia	2 years 0 months
6	Male	46	Schizophrenia	1 years 9 months
7	Male	32	Schizophrenia	5 years 0 months
8	Female	57	Schizophrenia	4 year 0 months
9	Male	52	Schizophrenia	1 year 6 months
10	Male	52	Schizophrenia	6 years 1 month
11	Female	61	Bipolar disorder	3 years 0 months
12	Male	48	Schizophrenia	4 years 0 months
13	Male	32	Schizophrenia	2 years 0 months
14	Female	53	Schizophrenia	0 years 3 months
15	Female	28	Schizophrenia	1 year 0 months
16	Female	28	Major depression	0 years 1 month
17	Male	47	Schizophrenia	1 year 6 months
18	Male	39	Schizophrenia	1 year 2 months
19	Male	46	Schizophrenia	2 years 0 months
20	Male	35	Schizoaffective	4 years 0 months

5.2 Themes developed from the patient interviews

Details of the working methods and analysis of Study Two were given in Chapter Four. Data were managed in NVivo 11 (QSR International Pty Ltd., Australia) and analysed using Thematic Analysis encompassing six stages: familiarisation, generating initial codes, searching for themes, reviewing themes, defining and naming themes, and producing the report (Braun and Clarke, 2006).

Using the principles of thematic analysis, two main themes were identified and several sub-themes were identified (Table 5.2).

- **Theme 1** focused on barriers to shared decision making
- **Theme 2** focused on facilitators of shared decision making

A discussion of these main themes and their sub-themes will be presented below. Example thematic frameworks can be viewed in Appendix 12 (Themes 1) and Appendix 13 (Theme 2).

Table 5.2: Themes identified from patient interviews

Main themes	Sub-themes
1. Barriers to shared decision making	• Professional status of health professionals in submissive culture • Negative perception of making decisions • Limited time resource
2. Facilitators of shared decision making	• Sufficient information exchange • Desire to make decisions

5.2.1 Theme 1: Barriers to shared decision making

From the patients' accounts, shared decision making generally did not occur in mental health settings. Overwhelmingly, all patients described how the majority of decisions about treatment and care were made by health professionals and/or the families. A strong sense of powerlessness was widespread among patients, a feeling derived from the "professional status of health professionals in a submissive culture", "negative perception of making decisions", and "limited time resources" in their mental healthcare. These three issues will be explored in the sub-themes below.

5.2.1.1 Sub-theme: Professional status of health professionals in a submissive culture

One of the major causes of reluctance to be involved in decision making was the professional status of health professionals, leading to patients conforming to the socially sanctioned role of "patient". Fundamental beliefs in a submissive culture, such as that "health professionals know better", and a fear of being labelled as a "difficult patient", strongly influenced how patients viewed the role of health professionals in the decision-making process. Meanwhile the power to decide that patients should be hospitalised was held by mental health professionals and therefore this reinforced the sense of power imbalance in the relationship.

Patients believed that both patients and health professionals in mental healthcare held different levels of power, based on the Taiwanese submissiveness culture. Patients viewed health professionals as authority figures and felt they should obey what mental health professionals said. Patients were relatively passive, did not assess their own conditions, and dependent on the health professionals' advice. This culture and obedience to authority are revealed in the following two examples:

> *"They are doctors. Doctors are qualified to control your treatment and care. Doctors are able to prescribe your medication. No one else can. They control… that's* (making decisions) *their responsibility."* (08 F)
>
> *"There is no reason why… they should… They* (professionals) *are born to decide. They are professional. Yeah… that's why I should obey them."* (04 F)

This not only referred to the individual roles of health professionals and patients, but was also related to how cultural beliefs influence patients when seeking medical help. The majority of the patients in the interviews shared a relatively similar pattern of treatment-seeking behaviours across mental health settings. The patients frequently perceived that there was a golden rule for how to interact with health professionals in Taiwan. The main role of patients was simply to provide medical symptoms to health professionals, and then let the health professionals decide for them. Patients perceived their role in relationships with their health professionals to be as "receivers" rather than "providers". The patients believed this – it is what they had been taught since they were children. This feeling therefore led to it becoming conventional wisdom to accept health professionals' advice. In this culture, it seemed to be unreasonable or unfamiliar for the patients to speak up or make their own decisions during the process. For example:

> *"It's just like seeing a doctor for a cold. I go to see a doctor for a cold and a doctor asks me my symptoms. And then does some examinations. And then you get some medication. It is a standard procedure. Like me. I told him* (a doctor)*: 'I have cough, a runny nose, sore throat, and headache.' And then the doctor*

> *gave me some medication to take. And then I took them… That's what happened to me. Never have I ever questioned this before. That's what I was told when I was a kid. I got used to this procedure. I think this is it. This is how the health system works."* (05 M)

Furthermore, the sense that health professionals knew better was widely described in the patients' accounts. Throughout the interviews, more explanations referred to the fact that health professionals knew best due to their professional knowledge. Formal professional training and qualifications in medicine created a sense of correctness, authority, and superiority where "the doctor knows best". The view that health professionals all were experienced enough to recognise what was the best for patients could cause the latter to be reluctant to take an active role in decision making. The data showed that the feeling of deference to health professionals was considered socially appropriate, for example:

> *"As doctors, they have professional knowledge to make judgements. They are psychiatrists. Professional knowledge and professional staff. They went to medical school for seven years. They are experts on mental health. They definitely know how to cure patients and what to do."* (16 F)

In these cases where the patients did not understand their disease or the available treatment/care options they cannot participate in decision making. Therefore, they tended to leave the decisions to the health professionals, who are "qualified". In secondary mental healthcare settings, this was mentioned by those patients who believed that a passive role was socially appropriate for them, for example:

> *"I don't know about medicine… don't understand. I just do what they say and take what they give me."* (01 M).

Less commonly mentioned, but nevertheless prominent, was a fear of being labelled as a "difficult patient". There was considerable pressure on patients to conform to social roles and the social expectations of others, particularly of health professionals. For example, the health professionals gave positive feedback when the patients played their passive roles well but gave negative feedback when the patients played their roles badly, which normally meant including some behaviour the health professional did not agree with. Therefore, patients acted submissively during decision making to avoid displeasing their health professionals. For example, asking too many questions or refusing the health professionals' recommendations were not allowed, in the patients' view.

> *"If they* (health professionals) *ask you to participate some activities* (such as exercise)*, you should go and be well behaved. You should comply with it. Or if you refuse to take part or turn them down, they will shout at you… you know their faces… They don't like patients who ask a lot of questions or are not well behaved. I don't know how to describe it, but I should comply with them."* (07 M)

Alongside this problem were the covert contracts that a few patients developed with their health professionals, where they felt coerced into adopting the role of a "good patient". This role was regarded as one of passivity and compliance. Patients described their sense of needing to be respectful of what health professionals suggested and expressed the negative implications of being a "difficult patient" if they did not. Many patients believed that they should not be involved in decision making, often due to fear of annoying the health professionals and the potential repercussions. The potential retribution prevented patients from actively engaging in decision making discussions. For example:

> *"You can't deny their professional status… Because they are doctors. They help us, but they don't require any input from you. If you refuse to take their advice… that means you are not respectful to them. You are too difficult to please."* (20 M)

In addition, patients often perceived that patient hospitalisation and discharge schemes were all decided by the health professionals. Therefore, patients believed that health professionals were superior to them. The fear/threat was expressed by every patient, without probing, that unless they complied with the treatment and care decisions they would be re-hospitalised.

The threat of being sent to hospital, which resulted in a loss of liberty, indicated that patients felt controlled, rather than involved in decisions about treatment or care. This was strongly driven by a fear of mental hospitals: a sense that mental hospitals are effectively a restricted environment for people suffering from mental illness. In particular, the use of involuntary and coercive interventions in the hospitals was a major threat for the patients. They commonly reported that they were being physically restricted without their consent, leading to them adopting silent roles during decision making.

> *"In hospitals, we* (patients) *are nuts and they are health professionals. What can you do against them? If you don't follow their instructions, then they lock you up*

> *without asking you. Nothing you can say about it. They tie you up and even tell you: "anything you say is useless". "We are health professionals in a hospital" and "I can decide what to do to you* (referring to coercive interventions)*."* (06 M)

Of central concern to the patients, the threat of greater use of involuntary interventions and coercive measures, such as physical restraint and enforced medication and injections, were widespread, and the patients often described these interventions and measures as traumatic and unnecessary.

> *"They felt I spoke loudly and got emotional. They wanted to tie me up. I said I was fine and no need to be tied up. The problem was they still thought I was not stable and did not take my medication regularly. But I did not want to…. I hated it* (physical restraint)*. They just forced me."* (20 M)

They explained how such measures and interventions were given in mental hospitals without their consent if judged by health professionals to be in their best interests. Most patients reported how such practices violated their sense of dignity.

> *"I am so scared* (of physical restraint)*. So afraid of it! So I messed up. Like a dog, you know, you were tied by these belts. Really tight* (around both hands and legs) *and not able to go to the bathroom by myself... So devastated. I should listen to them."* (18 M)

They also described having been hurt or injured by such coercive procedures. Therefore, the great fear/threat that patients lived with was that of being sent to the hospitals. For example:

> *"If you don't listen to the nurses, they tie you up. Even if you improve your behaviour, they still tie you up. They must tie you up for an hour. Some* (nurses) *even give you an injection. Even if you are yelling in the room, they won't listen to you. Like this. You must do what they* (nurses) *ask you to do."* (10 M)

In addition, there were not just coercive measures or involuntary interventions, but also restrictions on patients' daily lives. From the patient views, hospitalisation caused disruption to their daily routine, such as social activities and working. Patients felt that health professionals had huge powers in that they decided if they were permitted to go outside, visit someone, have a meal with their friends or families, or go shopping. Patients mentioned that the health professionals employed these "god-like" rules to force them to adhere to treatment regimens in the hospitals; for example:

> *"As the nurse said….if I lay on the bed in my room…they* (nurses) *would say: 'If you lie in like that, you will not sleep at night.' In the end, they* (nurses) *said: 'if you still lie on your bed, we will restrain you. Or not allow you go outside and go shopping'. Can't go outside or anywhere. So I don't really like going to hospitals"* (15 F)

As part of the negative experience of being hospitalised, verbal threats of hospitalisation from health professionals were widely reported by patients. They reported that demanding language was used to force the patients to comply with instructions, such as *"you must"* and *"you should"*. They expressed such threats as frightening and perceived them as way of gaining power and control over their lives, for example:

> *"I told them: I don't want to take this medication… But the staff told me I must take it… or they will take me to be hospitalised. So… so… I took it… and after this, I told my doctor what happened to me… You know what?… My doctor just kept silent… Like nothing had happened… He said: 'Adjust… it is just fine… to adjust.'"* (09 M)

Patients described many of the characteristic statements used to them, including *"take your medication or go to hospital"*, *"if you are* well-behaved, you won't need to go to hospital", *"listen to me, and nothing bad will happen to you again"*, and *"you have to take medication"*. Patients complied and tolerated such threats but were clear that they were an effective "weapon" used by health professionals to force patients to comply with instructions.

Patients acknowledged that they were powerless, in that it was impossible to discharge themselves from services, particularly acute wards. It was perceived that there was no exit for them to escape. Patients said they were locked in wards and told they could not leave even if they wanted to. Some patients compared being detained to imprisonment and even described themselves as "prisoners" locked up in the hospitals, as illustrated by the example below:

> *"Because… because… this belongs… this is same as* (being a) *'prisoner'…because they are locked up as well. We have to accept assessment. This is all decided by health professionals… same as prisoners. Many prisoners*

> *are locked up as a big group. I certainly felt uncomfortable. But what can I do about it?"* (07 M)

More interestingly, in some cases, the patients described a feeling of culpability when they did not fulfil the health professionals' or families' expectations, behaved unacceptably, or were forced to comply with the professionals' instructions more than usual. As a result, the patients tended to submissively follow the rules to earn "privileges". One patient described it as follows:

> *"If you are well-behaved, you can go outside and you can be discharged from here soon. Just follow the instructions. This is good for you."* (08 F)

Some family members also treated the patients the same way to force them to comply with instructions. For example, one patient described how his brother asked him to take medication regularly and told him what would happen if he refused to do so. He explained:

> *"My brother said: 'If you are taken there* (the hospital)*... we will lock you up for more than a year.'... No doubt... You can't say no... In the hospital, your family has to agree or you can't be discharged from the hospital. You know my friend has been locked up for a year... He is not allowed to discharge himself from the hospital. Can you imagine that? I told a nurse: 'I don't want to stay here'... But I got no reply... I had been locked up for one year... You know my friend... he is still locked up... Not like here* (the halfway house)*... you have more freedom."* (18 M)

5.2.1.2 Sub-theme: Negative perception of making decisions

In patients' accounts, there was a concern about their decisional capability due to their mental illness. A variety of negative perceptions of their decisional ability led patients to have no confidence in expressing their perspectives or asking to be involved in decision making. It was generally more acceptable for the patients to keep silent in the decision-making process. Some patients believed that it was appropriate that mental health professionals did not actively engage with them, due to their mental conditions.

These negative perceptions originated from various sources, including the patients themselves, health professionals, and the public. Surprisingly, the strongest sense of impaired decisional ability was reported by the patients themselves. In this regard, a number of patients reported that they were afraid of making unwise or irrational decisions. For example:

> *"I am ill* (mental illness). *How could I make decisions? I feel great if they decide for me."* (12 M)

From the patient views, the patients with a first or recurrent psychotic episode tended to have experienced being out of control of their actions and movements, and being a risk to the public and themselves. Owing to these negative experiences in the past, the patients found it was difficult to believe that they were still capable of making any decisions about their treatment and care. In particular, patients who experienced intolerable symptoms (delusions or auditory hallucination) often felt very afraid that they were losing control again. Therefore, patients believed they were not qualified to make any decision because of having mental illness. For example:

> *"I was losing control. I don't know what disease I have. I could not sleep at night. Every day there were a lot of voices* (auditory hallucination). *I was sick. Not clear… There were a variety of treatments. If you are sick, this* (treatment option) *should be decided by doctors."* (10 M)

There were further examples in the data of patients who "lost control" and deemed themselves incapable of making reasoned medical decisions.

> *"Yeah… if I don't take medication, I get out of control. Because… I have mental illness, I lose control. I couldn't make my own decisions. How can I make my own decisions? You must take medication. That's it. Because you are hospitalised… you lose control. You are not able to make decisions."* (07 M)

Furthermore, patients also felt that the public's negative judgement aggravated the situation. One patient gave an example of a murderer, who the television news implied was suffering from mental illness. It appeared that the awareness of this trend shaped patients' attitudes towards themselves and reinforced a sense that patients were not qualified or not able to be involved in decision making.

> *"I think any patient with mental illness is not able to make their own decisions. Some of them may lose control and then kill someone. For example, XXX, he lost control and killed someone. Can someone like me make their own decisions?"* (03 M)

In addition, patients felt that health professionals also negatively judged them and viewed them as "patients without the ability to make decisions". The sense that the patients who were admitted to "mental health hospital" were viewed negatively also influenced the level of patient involvement in decision making. One patient described how he tried to ask more questions about his condition when he was first admitted, but the health professionals refused to answer. He perceived that the health professionals believed that he (the patient) was now suffering from mental illness and had been sent to the hospital, so he was no longer capable of making his own decisions. Therefore, the health professional refused to provide any information to him (the patient). The patient used the term "psychiatric hospital" to imply his decisional capability was impaired in the other people's view:

> *"I went to XXX hospital. I wanted to ask some questions about my condition. But they* (health professionals) *told me this is a psychiatric hospital and I am a person with mental illness. I had a headache and auditory hallucination. Someone* (auditory hallucination) *was talking to me. And then I was admitted* (to the hospital). *32 years old. I wonder if anyone still wants to discuss anything with me."* (06 M)

Although most of patients paid attention to decisions about treatment and care, such as medication and recovery plans, a few patients also mentioned how these judgements negatively influenced decisions about their daily life. For example, one patient gave an impassioned explanation about how she could not decide to live with her own son. Her health professionals perceived that she was suffering with her mental health and made risky decisions. She reported the feelings of powerlessness as follows:

> *"For example, they aren't willing for me to take my baby along. This is a clear rule. I don't think I need to stay in the halfway house. I am able to find a job and live on my own. Why do I need to stay here? They think I am ill, that I am not able to take care of myself or my baby and decide. So they decide everything for me."* (04 F)

5.2.1.3 Sub-theme: Limited time resources

Most patients felt that health professionals, even if they agreed to shared decision making, were under too much time pressure and/or had limited resources available to give patients as much information or support in making decisions as they wanted. Patients felt that health professionals were required to see a lot of patients every day. The ideas that “health professionals are busy”, “there are a lot of patients waiting” and they “do not have sufficient time” were frequently reported in the data. Because they were not given adequate time to ask questions or respond, the patients often felt unable to be involved in the decision-making process. Also, this feeling put pressure on the patients to shorten their time with the health professionals. One patient described it as follows:

> *“I don’t know. Every appointment with him* (the health professional) *finished very quickly. Because there are always other patients who are waiting. He needed to see a lot of patients in one day. So we did not talk too long. I hoped we could talk for a longer time. You know.”* (04 M)

Similarly, feelings of a lack of available time, along with the number of patient contacts, led patients to hesitate to ask more questions or express their expectations. This limited time could result in less detailed explanations to patients about treatment and care. Even if the patients were deeply concerned about their condition, there was not enough time for them to be actively involved in decision making. For example:

> *“If some professionals are able to give me some information that will be great. How to use the medication and what side effects I might notice. I want to know… but, probably, the doctors don’t have much time. Like me, I am going to see my doctor tomorrow. I am number 130. I bet the doctor won’t have time for me.”* (05 M)

Due to limited time being available, the patients noticed the health professionals tried to make more efficient use of what time there was. This caused some problems in health professional-patient interaction across the mental healthcare settings, such as no privacy, no proper attention, and inefficient communication in medical consultations.

Patients described their appointments with health professionals as having a lack of privacy during their consultations. It was relatively common practice in Taiwan to see a number of patients together in one appointment. Owing to the limited available time, the health professionals tended to see as many patients as they could in as short a time as possible. In some situations, health professionals asked more than one patient into the room at once. For example, one patient discussed his/her case with a health professional while other people (other patients) were in the same room to wait for their appointments. Even if the patients would have liked to discuss something with the professionals, it was difficult for them to express deep feelings in front of others:

> *"Three were in the same room. How could you say something sensitive to the doctor? How could you discuss anything with the doctor? How could I react to this? Three of us… say something…. The doctor gave us medication. That's all. And then I got medication. The end."* (09 M)

A few patients believed that the performance of the mental healthcare professionals needed to be improved in some ways. It was perceived that the health professionals did not pay proper attention in the consultation. It seemed that the patients were not the primary focus of attention and a large of amount of the health professionals' time was spent interacting with a "computer" rather than "patients". Health professionals interacted with their patients for only a small part of the time; for example:

> *"He* (the health professional) *did not say much. He just typed into his computer. How can I express anything to him?"* (18 M)

In addition, there was no opportunity to have direct conversation with health professionals, particularly psychiatrists, which was also pointed out by a few patients. An unsatisfactory amount of communication often caused the patients to be frustrated and limited their active involvement in decision making. A patient described the situation when he refused to take medication and intended to discuss it with his psychiatrist, and how the health professionals responded to him, as follows:

> *"We didn't really discuss it directly… He didn't come. But my nurse told him… He replied and the nurse told me what he said. He said: "Take it or leave it"."* (03 M)

5.2.2 Theme 2: Facilitators of shared decision making

In the accounts, patients placed more emphasis on barriers to shared decision making as opposed to facilitators. Yet it was clear from the data that patients also saw examples of how shared decision making could be facilitated. Although the levels of involvement in decision making desired varied, many patients said that they wanted a more active role in the decision-making process. Almost every patient desired more information, but not everyone wanted to make final decisions. This clear desire motivated them to consider the possibility of their involvement in decision making and the potential of implementing shared decision making.

Active involvement in decision making was conceptualised by patients as a process whereby they could be engaged in their treatment and care, making it more likely to empower their decisional control. To this end, the two notions of shared decision making which were consistent with these principles are explored in the following two sub-themes. These are: sufficient information exchange and desire to make decisions.

5.2.2.1 Sub-theme: Sufficient information exchange

Patients felt adequate information exchange was essential for them to gain a comprehensive understanding of what they should expect to happen next, and what conditions they might experience. Some patients directly mentioned that patient involvement could bring some benefits for treatment and care. Moreover, their knowledge about their bodies could also improve health professionals' understanding of their health conditions. Their unique expertise was recognised as important. The patients believed that long-term illness made them good doctors, and they were experts on their own diseases and bodies. They perceived that it was worth listening to people who actually required this help. For example, one patient explained that he had suffered from mental illness for a long time, which meant that prolonged illness had made him an expert on his condition:

> *"Long illness makes the patient a good doctor."* (01 M)

Furthermore, active patient involvement could facilitate mutual understanding between health professionals and patients. In particular, from patients' points of view, they emphasised more the importance of how their voice could be heard by health professionals and others. This active involvement gave the patients the unique opportunity to express their views on their medical condition and treatment. One patient said:

> *"Because doctors should discuss with us to see how this medication works for us. They* (doctors) *prescribed medications to us. They should show respect for my choices. To see if I am cured, they should observe how I react to the medications."* (19 M)

Similarly, patients believed that providing information on treatment and care could help alleviate concerns and reduce the uncertainty of the patients. The patients would perceive that their expectations and concerns about their treatment and care for their mental illness had been considered in the process. The patients would take part as information-givers and not just passive recipients of medical information; for example:

> *"Based on this (active involvement), I could be cured quickly. I could understand if I am ok or not. I could explain my feelings about medication to them. They don't need to spend much time conducting experiments on me."* (03 M)

In the process of exchanging information, it was not just that health professionals could gain the most effective understanding of patients' conditions and their expectations, but also that patients could have an insight into their mental illness and recovery plan. By making sure that patients understood their recovery goals, their conditions, symptoms, and the choice of treatment, patient perceived that they could be engaged in their prevention plan. One patient explained:

> *"If…*(I can be actively involved in decision making)*…. Because I can understand my symptoms and conditions. I could understand how to prevent a relapse, to understand better if my condition is worse or better."* (05 M)

Numerous patients recognised the desirability of gaining more information about their treatment/care. Unsurprisingly, most of the patients frequently paid attention to information/knowledge about medication, such as its effects and side-effects, changes of medication, or dosages. For example:

> *"I want to… I want to know the effects of the medication. In fact, I really want to ask the doctors."* (19 M)

Patients rarely mentioned their desire to be given information about relevant treatment options rather than being presented with a single treatment plan decided by the health professionals. For example, one patient stated:

> *"I think I do… I do want to know about other treatment options. For example, treatment one, treatment two, and treatment three. This would be really great. I don't know why the health professionals don't implement that. I don't know how they think."* (08 F)

5.2.2.2 Sub-theme: Desire to make decisions

Although almost all patients desired more information about their treatment and care, they had different views of the right to make final decisions. One of the key notions of shared decision making, as described by a few patients, was making their own decisions. The desired levels of involvement in decision making varied from making their own decisions to tending to leave it to health professionals to make decisions about their treatment and care. Some patients directly mentioned they would prefer to make their own decisions about treatment and care, for example:

> *"I certainly do* (want to make my own decisions)*. But no way… The only thing I can do is live here* (in the halfway house)*".* (14 F)

More than sharing information on treatment and care, the patients would like to have opportunities to deliberate with health professionals about their expectations, based on their preferences and personal values. The view that patients and health professionals should jointly engage in the decision-making process and come to a negotiated agreement about which treatment is chosen and implemented was widely identified by the patients. Here are two examples:

> *"I want to discuss with my doctors that I don't want to take medication… yeah. 'Cause I took medication for many years. I don't think I need to take this… I think I will be fine even if I don't take any medication."* (04 F)
>
> *"I think… if… medication… I want to discuss with him* (the professional) *whether I could adjust my medication. Now what he gave me… I can't get out my bed in the morning, I feel drowsy. I can't get out of my bed. I would like to tell him this is not right for me. I would like to change it."* (12 M)

From some patient perspectives, patients should have the right to speak up and make their own decisions because the decisions on treatment or care would have consequences for their everyday lives. The patients believed they were more comfortable making these kinds of decisions and taking responsibility. For example, some patients directly mentioned they would prefer to make their own decisions on treatment and care;

> *"He* (professional) *never discussed it with me* (treatment options). *If possible, we could discuss it… and then I could decide myself. If you can decide, you feel better in your mind. This is all decided by me! No matter if it results in good or bad. I feel more comfortable about this. It wasn't decided by anyone else but me. Although I am a little slow on the draw and have a bad memory. But I believe I am able to make my own decisions."* (06 M)

Another patient who suffered medication side effects explained why it would have been better for him to make his own decision in the first place:

> *"It is better they tell me* (more about treatment options). *It is better to have choices. You could find a treatment that is more perfectly suitable for you. That would be really great… After I took medication, I didn't know about its side effects. I gained weight - from 70 kg to 90 kg. I didn't know about it at the beginning. I hope I have other options."* (05 M)

In the interviews, the patients also recognised that deliberation involves two-way communication between patients and health professionals. The patients should provide their views on treatment and care. Meanwhile, the professionals also were experts providing medical facts and experience. Therefore, from patient perspectives, suggestions about treatment and care offered by professionals could be equally important to patients to make more considered decisions about their treatment and care. One patient mentioned:

> *"I also would like to hear some professional advice from the professionals. I think if you got many professional suggestions, you could compare other treatments from different angles. You could hear different solutions."* (05 M)

Some patients recognised the importance of professional recommendations in making informed decisions. Even though the patients would like to make their own decisions, they believed they still needed the advice of health professionals. One patient explained this in the following quotation:

> *"It will be great if I have medication options. But I would love to hear some advice from my health professionals. And then I can choose the best one for myself."* (17 M)

In their accounts, patients focused more on the decisions about their treatment and care. However, a few patients also reported the importance of making their own decisions about their daily routine. For example, one patient explained her preference for making decisions, and that she desired to make not only medical decisions but also daily life decisions. She said:

> *I hope I can decide where I want to live and…if I am stable. The doctor can reduce the dosage of my medication.* (07 M)

Patients had different preferences about the level of their involvement in decision making. Although some said they wanted to be involved in the decision-making process, in fact some often preferred the health professionals to make the final decision for them. Despite some patients not wishing to make their own final decisions, most still would like to have more information about their treatment and care. For example:

> *"Actually, I just want to understand what my medication is for… I don't need to know what choices I have… For example, what treatment I take… particularly what medication is for… Effects or side-effects. That's all I want."* (02 F)

> *"Just information about my medication. Just let me know what medication they give me and why. What the medication is. Other things… that's fine. I don't need to decide."* (16 F)

5.3 Strengths and limitations

To the author's knowledge, this is the first study exploring patients' perspectives of decision making in mental health in Taiwan. This study has provided an insight into how patients view the decision-making process and what they need. The importance of patients' suggestions has been identified by previous research and by the findings of this study. It is evident that patients should be involved in developing any new healthcare delivery and care approaches, such as shared decision making. Therefore, the findings of this study provide a unique opportunity for health professionals and policy makers to explore how to improve levels of patient involvement in decision making and the quality of healthcare.

There are limitations to this study. The findings should be treated cautiously because of the small number of respondents (n=20). Although qualitative studies are not intended to be generalisable, their strength depends on transferability: whether the results are transferable to other settings or contexts (Korstjens and Moser, 2018). However, the sample in this study comprised patients only from halfway houses and therefore were not transferable to other mental health settings. The largest number of patients were diagnosed with schizophrenia (n=17) and thus this limits the findings to this group. In addition, patients in the halfway houses could have more complex long-term mental health conditions and support needs in terms of shared decision making than other patients in secondary mental health settings. Yet, these patients also have rich experience of making decisions across different settings (inpatient and outpatient departments).

Moreover, some studies also found that even amongst patients with different forms of mental illness, most of them wanted a more collaborative role in decision making than they usually experienced (De Las Cuevas et al., 2014; Hill and Laugharne, 2006). Meanwhile, there is a significant knowledge gap about patient perspectives of decision making in Taiwan. Exploring the desires of patients with different psychiatric diagnoses or in various mental healthcare settings might be valuable, and would be imporaant to explore in future studies.

5.4 Summary

Overall, two main themes were identified: barriers to and facilitators of shared decision making. Evidence from this study suggested that patients in mental healthcare in Taiwan were not involved in the decision-making process, and paternalistic and coercive decision making was commonly reported. Three main barriers to shared decision making were identified, which included the idea that the powerful status of health professionals led patients to believe that the health professionals were more qualified to be the decision makers than the patients themselves. Also, patients had negative perceptions of their ability to make right decisions and therefore did not have the confidence to be involved in the decision-making process. Furthermore, a lack of sufficient and quality time with health professionals prevented patients expressing their deeper feelings, and therefore had a negative impact on patient involvement in decision making.

Despite these barriers, the patients in this study still desired a more active role in the decision-making process. These desires drove patients to engage more in the decision-making process and therefore facilitated shared decision making. Currently, opinions from the patients in Taiwan were divided about what level of more active involvement in decision making they desire. Generally, all patients looked forward to more information about treatment and care, such as the effects and side effects of medications. Interestingly, not everyone would like to make final decisions about their treatment and care. Some directly expressed that they desired not just to gain information but also to deliberate with mental health professionals and then to make a final decision about their treatment and care. However, a few patients would like to avoid making their own decisions and chose to leave the final decisions to the health professionals alone. Although there were differences in desired levels of patient involvement, all patients expected a more active role than now.

The next chapter will provide a detailed discussion of the interviews conducted with mental health professionals.

Chapter Six: Findings from health professional interviews (Study Three)

This chapter will present the findings of the qualitative study which consisted of in-depth semi-structured interviews with 24 health professionals in secondary mental healthcare in Taiwan.

6.1 Characteristics of professional participants

Professionals were purposively selected from the five chosen settings between July 2017 and November 2017. A two-stage recruitment strategy was implemented as detailed in the working methods chapter (Chapter Four):

- **stage one**: of the 95 packs distributed, 23 returned consent to contact forms; of these 20 agreed to interviews. (Three refused to participate due not having time to undertake an interview.)
- **stage two**: of the 20 packs distributed, ten returned consent to contact forms; of these six agreed to interview. The four who did not consent did not have time to take part in an interview. During stage one, professionals were identified through the managers of one mental health outpatient department, one day-care centre, and three half-way houses. 20 study information packs were distributed, reflecting the number of qualified health professionals in the settings. Furthermore, recruitment adverts were posted in health professional groups on social media. 75 information packs were distributed, reflecting the number of potential professional participants who responded. Therefore, 95 information packs in total were distributed in stage one. Following this, 23 potential professional participants returned the contact form, but three refused to participate in an interview due to the long duration of the interviews. Therefore, 20 professional participants agreed to interview at this stage.

In stage two, due to the initial lack of response from nurses, a second stage of recruitment was carried out. Adverts were posted in particular nurses' groups on social media. 20 study information packs were sent out when potential professional participants contacted the author and then 10 returned the contact forms. However, four refused to take part in interviews for two reasons, including no mutually suitable time and long duration of interviews. In the end, there were six professionals who agreed to interviews in the second stage.

26 interviews were conducted with health professionals. However, as two professionals withdrew their consent following the interview, only 24 interviews were retained for data

analysis. Interview duration ranged from 38 minutes to 1 hour and 32 minutes (average of 55 minutes). The characteristics of the interviewed professionals are presented in Table 6.1. Professionals comprised 13 males and 11 females, aged between 28 and 54 (average of 37.8 years); there were 13 psychiatrists, 6 mental health nurses, 3 occupational therapists, one psychologist, and one social worker, and their durations of clinical experience ranged from 1 year and 8 months to 28 years (average of 12 years and 11 months).

Table 6.1: Characteristics of professional participants by reference number

Reference no.	Gender	Age	Professional role	Working experience
1	Male	40	Psychiatrist	11 years 0 months
2	Female	35	Psychiatrist	3 years 2 months
3	Male	33	Psychiatrist	4 years 1 month
4	Male	39	Psychiatrist	7 years 3 months
5	Male	43	Psychiatrist	16 years 1 month
6	Male	54	Psychiatrist	28 years 0 months
7	Male	44	Psychiatrist	16 years 8 months
8	Male	38	Psychiatrist	12 years 0 months
9	Male	42	Psychiatrist	16 years 1 month
10	Male	35	Psychiatrist	3 years 4 months
11	Female	41	Occupational Therapist	15 years 0 months
12	Female	45	Occupational Therapist	20 years 1 month
13	Male	40	Psychiatrist	10 years 0 months
14	Male	41	Psychiatrist	11 years 2 months
15	Female	49	Psychologist	15 years 0 months
16	Male	28	Occupational Therapist	3 years 2 months
17	Female	43	Social worker	7 years 0 months
18	Male	39	Psychiatrist	3 years 9 months
19	Female	34	Registered Nurse	13 years 0 months
20	Female	36	Registered Nurse	12 years 7 months
21	Female	39	Registered Nurse	17 years 4 months
22	Female	31	Registered Nurse	4 years 5 months
23	Female	40	Registered Nurse	14 years 0 months
24	Female	37	Registered Nurse	1 year 8 months

6.2 Themes from the health professional interviews

The data were managed in NVivo 11 (QSR International Pty Ltd., Australia) and analysed using Thematic Analysis encompassing six stages: familiarisation, generating initial codes, searching for themes, reviewing themes, defining and naming themes, and producing the report (Braun and Clarke, 2006). The analysis process was described in full in the working methods chapter (Chapter Four). In brief, a long-list of codes was gathered in the initial stage of data analysis. Based on the similarities and differences, the codes were combined or collapsed into themes. Example thematic frameworks can be viewed in Appendix 14 and Appendix 15. Two main themes and sub-themes were identified from the data (see Figure 6.1 and Table 6.2).

- **Theme 1: barriers to shared decision making** provides a discussion about barriers negatively affecting the implementation of shared decision making, and is divided into four sub-themes.
- **Theme 2: facilitators of shared decision making** focuses on to what extent health professionals are aware of patient autonomy in mental healthcare and understand the benefits of implementing shared decision making, and its potential positive impacts on patient outcomes. It is divided into two sub-themes.

Table 6.2: Themes identified from health professional interviews

Main themes	Sub-themes
1. Barriers to shared decision making	• Powerful status of health professionals and families • Patients with impaired decisional ability due to mental illness • Health professionals lack understanding of shared decision making • Insufficient time
2. Facilitators of shared decision making	• Awareness of patients' right to autonomy • Understanding of potential benefits of shared decision making

6.2.1 Theme 1: Barriers to shared decision making

Overall the data showed that professionals failed to practice or embrace the concept of shared decision making. The majority of professionals thought there were significant challenges to implementing shared decision making. Key barriers were identified from the professionals' statements, and included "the powerful status of health professionals and families”, “patients with impaired decisional ability due to mental illness”, “health professionals lacking understanding of shared decision making”, and “insufficient time”. Further discussion of each theme will be presented in the following sections.

6.2.1.1 Sub-theme: Powerful status of health professionals and families

This sub-theme revealed that professionals often had a powerful status in their relationships with patients, and indicated that they and family members were considered superior to patients. From the health professionals’ perspective, it was socially acceptable that health professionals and family members took a proxy role and decided for patients in mental healthcare. This idea had a negative impact on active patient involvement and the implementation of shared decision making. In the following sections, the powerful status of health professionals and family members will be presented.

6.2.1.1.1 Professional-patient relationship

All professionals held strong beliefs that health professionals should have more power than patients and perceived that such power was justified as it was their duty to make the best decision for patients. The professionals articulated that there were different social roles for patients and professionals. They considered themselves to be “providers” who should provide treatment and care for patients, and that patients should be “receivers” of their decisions. The professionals asserted that the traditional allocation of responsibility meant decision-making mainly belonged to the health professionals, particularly psychiatrists. This belief strongly drove how health professionals viewed their role in decision making. Two professionals explained:

> *“We are more like ‘a provider’ to provide resources and to solve problems.”* (06 M, Psychiatrist)
>
> *“I don’t know, this is kind of a tradition of healthcare? They (patients) are more like a receiver rather than a provider. They don’t speak up for themselves.”* (11 F, Occupational Therapist)

Some professionals explained this situation by citing the cultural perspective that “health professionals know better” or “doctors know better”. A fundamental virtue in Taiwanese culture was respect for one's parents, elders, and ancestors, and this extended to some professions, such as teachers, doctors, and lawyers. One professional explained this idea and linked it to how the culture meant that they were reluctant to actively involve patients in decision making. For example:

> *"I think in Chinese society, people are supposed to listen to the elderly and authorities. I think people get used to this… You should listen to people with professional ability. I guess they* (patients) *get used to putting doctors or nurses into positions of power. Therefore, doctors and nurses think they are in the position* (to decide)*".* (14 M, Psychiatrist)

Similarly, there was broad agreement that the best approach to making decisions about treatment and care was based on professional knowledge. It was perceived that health professionals were justified in making treatment and care decisions for patients as they had superior levels of knowledge. Professionals described how their beliefs about the superiority or authority of health professionals had been reinforced since childhood, i.e. that doctors' and other health professionals' orders and advice should be adhered too. One professional reported:

> *"This is traditional eastern culture. It is kind of authoritative. A doctor is more…*(qualified). *When people were children, they were told to comply with doctors. We should completely obey them and do what they ask. That's what people have been taught since they were children."* (12 F, Occupational Therapist)

In health professionals' accounts, knowledge was believed to require professional training and education programmes to prepare health professionals for a continuous process of learning how to make clinical decisions, which patients did not have. Because of biomedical and practical expertise, professional training, and experience, health professionals were in the best position to assess trade-offs between different treatment options and to make the best decisions for patients. For example:

> *"I think [shared decision making] could be difficult in mental healthcare. It could be challenging. For example, we* (health professionals) *assess [patients' conditions] according to the standard assessment. After professional assessment, there is the best* (treatment) *option and then I make a* (treatment) *plan. This is what we do."* (16 M, Occupational Therapist)

Furthermore, some health professionals also proposed that they would be well versed in the newest and most valid clinical thinking. Health professionals would not only know the best treatment option available, but also they would consistently apply the updated knowledge when selecting treatments for the patients. For example:

> *"Because psychiatrists have practical expertise in mental healthcare. There are psychiatrists for mental healthcare and physicians for general medicine. You don't ask physicians for information about general surgery. And they have a lot experience of taking care of patients every day. They are very familiar with this. They know how to deal with this and make adequate medication decisions."* (19 F, Registered Nurse)

The professionals discussed clinical guidelines which allowed them to correctly decide about appropriate care for specific clinical circumstances. This is illustrated in the quote below:

> *"For example, I would tell them that if you get mental illness, you need to take medication. We would let them know what their medication is, but what kinds of medication they need to take is decided by you* (professionals) *based on the clinical guidelines."* (03 M, Psychiatrist)

Interestingly, some professionals emphasised the legitimacy of their right to prescribe medication for patients. Based on this legal right, they felt empowered to be the decision maker. One professional reported:

> *"I believe the right to prescribe medication belongs to doctors. Although this is doctors' right, we all hope the patients take their medication regularly."* (10 M, Psychiatrist)

The importance of the duty of prescribing medication and control of the hospital discharge scheme were reported to reinforce the power of health professionals. The right to hospitalise and discharge patients was mainly held by the health professionals and this again reinforced their power to exert control over patients. Health professionals felt that patients themselves had a similar perception of health professionals' powerful roles. In order to avoid staying in hospital longer, patients tended to ingratiate themselves with health professionals by following their instructions. This led to health professionals clearly feeling their powerful status of being health professionals. Furthermore, this sense of enhanced knowledge legitimated health professionals' use of control and coercion. For example,

> *"Because patients have an expectation: I need to be discharged from the hospital first. I feel, in this situation, they will follow the orders of doctors. And they would try to figure out what doctors think or want. Based on this, they would do what*

> *they think the doctor has asked them to do. And then they could leave hospital."* (14 M, Psychiatrist)

An interesting issue reported by a few health professionals was that by offering options to a patient or embracing the principles of shared decision making might make them look indecisive to patients. They felt that by embracing shared decision making this would show 'weaknesses and professional incompetence' to the patient. Hence this might go some ways to explain why health professionals perceived a paternalistic or authoritative attitude to be correct and why they found it difficult to embrace the concept of shared decision making. They articulated that if they invited patients to participate in decision making, this may give rise to confusion or a sense of insecurity. The perception that "the professionals are not sure what they are doing" was identified from the interviews. One professional mentioned concern about disclosing uncertainty about treatment, which would adversely affect the relationship:

> *"If you* (professionals) *provide more decision options… no matter how you explain it… they would think you are not 100% sure about this… You tell them too much and this means you're not doing your job, you know. This could bring unnecessary trouble* (medical malpractice) *for yourself."* (02 F, Psychiatrist)

Professionals also described the hierarchy within the health profession, with doctors at the top of the pyramid. Many of the health professionals discussed this authoritative/paternalistic view as coming between psychiatrists and patients, and that they themselves (i.e. other health professionals) followed the psychiatrists' instructions as they were top of the hierarchy and therefore had the most power and control. Health professionals themselves perceived that it was the psychiatrist who should make the decisions. The perception that there was no room for an inter-professional healthcare team was commonly reported by professionals (except psychiatrists). One mental health nurse described this as follows:

> *"They* (psychiatrists) *don't offer options. They just… explain. Nurses just explain what choices the psychiatrists made, such as dose or frequency. Actually these medication treatments were mainly explained by the doctors rather than us* (nurses)*. But so far, we've never seen any doctors offering options to patients. It is all decided by the doctors."* (22 F, Registered Nurse)

The roles of doctors and other professionals, such as nurses, were inherently different, which was reflected in their education and responsibilities. These differences had led to power stereotypes in each profession and influenced how they recognised their role in decision making. Interestingly, even other professionals believed medication was only managed by "doctors."

> *"This is a doctor's job. Doctors are responsible for deciding what medication they should take. Because patients don't have any medical background. They haven't studied in a specialist medical educational system. Even me* (nurse), *I have some basic knowledge but I am still not a doctor to know which medication will be effective for patients."* (24 F, Registered Nurse)

6.2.1.1.2 Family-patient relationship

From health professionals' perspectives, the family structure exerted significant influence on the level of patient involvement in medical decisions. Although it was clear that health professionals were seen as – and felt justified as acting as – authority figures, this also extended to some degree to family members. Therefore, the negative influence of the powerful status of family members was also reported in health professionals' accounts.

Health professionals discussed the traditional patriarchal family structure in Chinese society and its impact on patients' decision-making authority regarding mental health treatment options. The professionals reported that there was normally one family member who held the most entitlement to make all decisions in family. In traditional families, decision making was mainly vested in the father or older family members. These family members commonly played authoritative roles in decision making in healthcare. A complex interplay of cultural factors related to family could deprive patients of all their rights and thus reduced their levels of involvement in decision making in mental healthcare. For example:

> *"This is the power structure in a patient's family. If the family power type is an authoritative one, the father takes more power. And then he* (a patient) *can only listen to his father. This is possible. In this situation, no matter what he does, or tries to do against it, or how he tries to communicate* (with his father), *it is useless. Eventually, he can only listen to the decision maker in his family and follow his instructions."* (23 F, Registered Nurse)

There were factors which drove this idea in the culture, including family responsibility for patients' behaviour and the need for family support. It was perceived that these family members should prevent the patient with mental illness from misbehaving. Also, family members were not able to simply abandon their responsibilities for the patients' behaviour. The strong sense of moral responsibility for patients with mental illness reinforced the power of family members. It was perceived that "whoever takes the responsibility makes the decisions." One specific example was given by a nurse, who explained that family members of one patient needed to respond in public to the murder committed by the patient.

> *"The family is too closed. Right, you should read the current news. XX* (the killer on TV news and indicated as a patient with mental illness) *is in his 20s. He is a legal adult in law. In the West, if someone commits a murder like that, his parents do not need to show up or do anything else. But in Chinese society, his parents needed to kneel in front of the public. At the beginning, they* (the parents) *did not do anything. They were attacked in the newspaper or community. It appeared that they have responsibility for this* (behaviour). *This* (patient involvement) *is really challenging."* (21 F, Registered Nurse)

In particular, health professionals considered there was an obvious need for patients with mental illness to gain family support. They pointed out the importance of family involvement in decision making in order to be able to count on family support. There was widespread concern that if family members were not the main decision makers, the patients would lose all aspects of family support. Therefore, the health professionals believed it was important to take the family's voice into account during decision making. In most situations, from the health professionals' perspective, the family's voice was much more important than patient's. One example:

> *"In Taiwan, we* (professionals) *need to take a family as a unit. Without family intervention, in fact it is difficult for you to do anything* (about patients). *For example, we* (decide) *to transfer a patient to a halfway house. But the family does not support this… don't agree with this. They will take a patient out within one or two weeks."* (09 M, Psychiatrist)

Similarly, health professionals were fearful of being criticised by family members, which might also explain their reluctance to engage in shared decision making. It was perceived that any conflict could bring a lack of family support, which could be detrimental to patient recovery. One professional explained that there were consequences, such as poor treatment or care adherence, if families did not support patients. For example:

> *"Family members will question you in the end. Or they will criticise you: 'Why did you let the patient decide alone?' In order to protect ourselves* (professionals)*, we need family permission. You know even if patients feel they do not need to stay here* (in mental healthcare)*, but their family disagree, I think we wouldn't take the patient's opinion to discharge him. This must be agreed by family members, or the services or nurses won't be able to take their* (patients') *opinion."* (22 F, Registered Nurse)

A few health professionals also noted that for patients to survive in the community their financial needs must be met. From their observation, family members provided financial support to patients. One professional explained that therefore, if there was any disagreement between patients and family members, the preference of the family members was more vital than the patients' as family members were the ones who paid the fees. This situation therefore enhanced the power status of family members; for example:

> *"It* (patient involvement) *is difficult in mental healthcare. First, this disease is a long-term condition. Maybe 40 or 50 years. Sometimes even 50 or 60 years. For example, some family members don't agree to patients being discharged from the hospital. If we* (professionals) *insist on doing so based on patients' wishes, their family members may say: 'How can they live without financial support from us? They don't have a home.' What can we do about this? Let them live on streets? You see what I mean."* (21 F, Registered Nurse)

6.2.1.2 Sub-theme: Patients with impaired decisional ability due to mental illness

A clear sub-theme that was generated from the data was that health professionals fundamentally believed that patients had impaired decisional ability due to their mental illness. Health professionals were concerned about this impaired decisional capacity and therefore recognised it as a major barrier to shared decision making. As health professionals saw it, patients normally made unwise or irrational decisions which worsen their outcomes, such as refusing to take medication.

> *"Let patients decide?… If you ask me to do something I believe could worsen his/her outcome, I will definitely refuse. Some patients with mental illness don't have the ability to make decisions."* (08 M, Psychiatrist)

Frequently professionals recognised cognitive deficits as a general problem for all patients with mental illness, but particularly patients with schizophrenia. From the professionals' perspective, cognitive impairments were critically associated with functional disability, particularly decisional functioning, which was a core characteristic of the illness. Cognitive impairment was reported frequently by patients in practice and therefore brought concerns to the health professionals' minds: *"whether patients are able to make the "right" decision"*. One professional mentioned:

> *"For example, patients with schizophrenia, because their cognitive function and understanding facility are really poor, it is really hard…*(to involve them).*"* (14 M, Psychiatrist)

Due to their concerns about cognitive deficits, the health professionals felt that patient involvement could have serious consequences. It appeared that involving patients in these medical decisions could be problematic if their preferred course of treatment contradicted a professional recommendation. For example:

> *"Because they normally ask to stop major medication. For example, one depressed patient doesn't want to take anti-depressive medication but asks for sleeping pills. Basically, I think the request is against the treatment guidelines and will lead to a depressive episode. I would turn them down."* (09 M, Psychiatrist)

The health professionals believed that the more severe the symptoms an individual experienced the more decisional capacity was impaired. Many interviewees mentioned that shared decision making in acutely ill patients was nearly impossible. This might be even more complicated to implement as fears that the patients had limited ability were justified. One example:

> *"One of my patients, he has delusions and auditory hallucinations. In this situation, his opinion cannot be involved."* (05 M, Psychiatrist)

These challenges focused on the patients' capacity for decision making, which could be adversely affected by psychosis. The concern was that decisions were made without taking adequate account of possible factors such as their ability to cooperate with a plan, the outcomes and risks associated with the decisions, or their social circumstances. One health professional described his experience of patient involvement and how the patient made a harmful decision due to psychiatric symptoms:

> *"Say one schizophrenia patient breaks his leg, and he refuses to accept treatment. And then the professionals follow his wishes as we need to respect his wishes? Don't treat him and let it be out of shape? In this case, he has delusions about surgery. Due to this illness, he cannot make this decision."* (07 M, Psychiatrist)

By contrast, a few professionals considered that patients in stable remission were easier to involve in the process. They believed that those patients deemed "mentally stable" were more likely to be competent to choose from a variety of care plans or treatment options. Therefore, even if shared decision making was carried out, in practice the feasibility might depend on the severity of psychiatric symptoms or the phase of the illness. One professional addressed how different levels of psychiatric symptoms influenced patient involvement in decision making.

> *"For our patients, this* (shared decision making) *helps them to make autonomous decisions and* (professionals) *to respect their autonomous decisions. I think this idea is quite nice. For people in a stable condition, this is suitable. But acutely ill patients may refuse to take treatment. You still need to respect the wishes of this kind of patient? This is not suitable for them."* (06 M, Psychiatrist)

The health professionals indicated that as a patient was mentally unwell then this clearly meant that they had no or limited decision making capacity. Poor insight was recognised by health professionals to be a standard indicator of patients' lack of awareness of their conditions. In this situation, health professionals felt that shared decision making might be diminished or absent entirely. From the professional views, these patients did not believe that they are suffering from mental illness and easily refused to take the recommended treatment and care. The health professionals described the patients as "having lack of insight" or "having poor insight", for example:

> *"On the other hand, some patients don't accept their mental illness. They don't understand their mental illness. It would probably be difficult to involve them in the decision-making process."* (01 M, Psychiatrist)

Consistent with above, lack of insight was believed by health professionals to lead to a high rate of medication non-adherence for patients in mental healthcare. In the interviews they often correlated lack of insight with poor medication adherence. They considered that there were various negative consequences of non-adherence for patients, including symptom exacerbation, worse functional performance, and re-hospitalisation, which damages patient outcomes. This resulted in a reduced desire on the part of professionals to engage patients in the decision-making process. One professional directly linked these factors and said:

> "(Why patients are not involved)*... because they have poor insight.* (Patients think)*: "I don't have a disease. Why do I need to take medication". They* (the patients) *are discharged from hospitals but then don't get followed up in the outpatients department. And then they have an acute episode and call an ambulance. Because they experience repeat onsets and this brings really bad outcomes for them."* (19 F, Registered Nurse)

6.2.1.3 Sub-theme: Health professionals lack understanding of shared decision making

Another key barrier to health professionals' willingness to engage in shared decision making was their lack of knowledge of shared decision making. Although there were various levels of understanding of shared decision making, most had low levels of understanding. More than half of the professionals had heard of shared decision making but were unable to correctly describe its principles and implementation. Some professionals had heard of the term but had forgotten the interpretation. For example:

> *"I can't remember... It was kind of a long time ago when I heard this term* (shared decision making). *It might be four or five years ago. I also read some related books or articles... I remember I read this term somewhere. But you ask me to explain this right now. I don't think I am able to explain it clearly."* (05 M, Psychiatrist)

However, some professionals had not heard of shared decision making. One professional showed his lack of information and knowledge of shared decision making by repeatedly asking the author to define it:

> *"So… I think I don't know much more about the shared decision making tool. Or could you explain it to me in one minute. I don't really have the relevant information. I can only imagine what this would look like."* (04 M, Psychiatrist)

A few professionals were able to understand and interpret the term, for example:

> *"I feel shared decision making is a way to meet patient needs. Based on their wishes, I believe it is kind of application of shared decision making. You* (health professionals) *provide some treatment options. And then patients to decide which one it is they prefer. Of course you have to explain the pros and cons of the options.* (03 M, Psychiatrist)

From the professional views, the importance of understanding of all aspects of shared decision making was a key step for implementing it in healthcare. Although casual awareness did not guarantee familiarity with shared decision making and, critically, the ability to apply it correctly in practice, this was definitely the first step towards implementing shared decision making by health professionals. Conversely, if there was a lack of knowledge, it could be challenging to facilitate or implement it. One professional said that they must gain the relevant knowledge about shared decision making as the first step.

> *"I don't know what SDM is… I have to have some knowledge first. And then I can decide if I need this kind of training or not. If this model… could bring some benefits to patients and to me, I may want to understand. But first I should know what it is."* (01 M, Psychiatrist)

Commonly, health professionals recognised training programmes were useful for collecting and organising information about shared decision making contexts. Although some professionals did not understand shared decision making well, they had still noticed that a few government activities had been developed to support patient involvement in decision making. Despite this, insufficient materials or training to put shared decision making into practice were widely reported by the health professionals. Lack of learning resources limited their desire to adopt shared decision making; for example:

> *"There might be some courses* (about shared decision making)*, but I don't get the information. Perhaps there are some, but they're not really advocated… It is difficult for us* (to adopt it)*."* (13 M, Psychiatrist)

In addition, during the interviews, interestingly, some professionals agreed there was a lack of understanding of shared decision making but reported no motivation to learn more about it. Some health professionals seemed to believe that shared decision making was occurring in mental healthcare in Taiwan. In the minds of some healthcare professionals, it appeared that shared decision making had already been integrated into patient care, so there was no need to know more about it. One participant described how he thought about shared decision making, which he believed had been implemented already.

> *"In mental healthcare, I think we have already done this for such things as discharge planning. I do believe we* (health professionals) *are doing this. We just don't use data based evidence to do so."* (12 F, Occupational therapist)

6.2.1.4 Sub-theme: Insufficient time

A further barrier which related to health professionals was insufficient time to put shared decision making into practice for patients. Commonly, health professionals believed that a clinical practice was a very busy place and there was a variety of knowledge which needed to be transferred. Given the time-poor environments of many healthcare settings, this was a valid concern. The working conditions for healthcare professionals were becoming increasingly stressful.

Although health professionals desired a more manageable workload, they felt the National Health Insurance made this impossible. Across the interviews, professionals, particularly doctors, told the interviewer that they had up to 100 patient contacts per day (and sometimes more than 100). They felt the number of patients they saw was excessive, with just 5-10 minutes for each appointment in some settings. It was perceived that this normally resulted in a lack of time in their working day to offer high quality communication with their patients. Consequently, health professionals perceived that time limitations were key factors in not implementing shared decision making.

> *"If you are working in an outpatient department, it could be difficult due to our National Health Insurance. Like me, you can only spend three hours finishing morning or afternoon appointments. You need to see 30 or 40 patients in one morning or afternoon session. That means you only can spend 5 minutes for per patient. 5 minutes! You know in this situation, we* (professionals) *don't have any opportunity to do it* (shared decision making). *So it is more efficient if we decide for them* (patients)*."* (08 M, Psychiatrist)

To address this in more detail, within the National Health Insurance, some even mentioned the strongest influence on professional income was the number of patient visits, for which health professionals were paid on a piecework basis. This meant the high earners needed to see a large number of patients every day. Some hospitals set up "sales targets" for the health professionals and expected to increase the "sales figures". As a higher level of service would need more money from the National Health Insurance, health professionals in higher-level practices would be required to see more patients.

> *"For example, the hospitals expect you have good sales figures. So you are not allowed to only see 3 or 4 patients. Or just 10 patients. No quantity means no profit, which is related to your income. Some professionals are even criticised by the hospitals. Maybe some new doctors do not have many patients. They may spend 40 minutes or 1 hour seeing a patient. But this is difficult.* (04 M, Psychiatrist)

Due to high workloads the professionals felt there was no time for training or to implement shared decision making. For example:

> *"I think this* (shared decision making) *will only bring a burden and extra workload to mental healthcare. Because you have to have comprehensive knowledge about mental health resources. I have a lot of experience of many different settings, so I know. But others don't. If you want to implement it, they would have to undertake a lot of training. We are already too busy."* (06 M, Psychiatrist)

Furthermore, the time-consuming shared decision making also added to the heavy workload of health professionals. Although most of them had little understanding of shared decision making, they recognised that it could be very time-consuming. Those professionals placed primary emphasis on providing sufficient information for patients, which should be the first step in shared decision making. In the professionals' view, the most time-consuming course regarding shared decision making was to enable patients to understand possible treatment options. One psychiatrist explained:

> *"Because it* (shared decision making) *needs a long time to explain. To be honest, this will take a long time to implement. Also there is a lot of work I need to do in the outpatient department. This is time-consuming."* (09 M, Psychiatrist)

Similarly, a few professionals believed that shared decision making might require the involvement of multiple internal professionals, which could be a big barrier in a busy health service context. One professional explained they therefore needed to set up group meetings which involved other mental health professionals such as nurses, psychologists, and social workers. There was a strong and widespread sense that shared decision making would inevitably take more time, which the health professionals did not have, and would stop health professionals implementing it. For example:

> *"I believe it* (shared decision making) *would be difficult to implement in practice. I suppose… Say you want to apply it in every case, getting different professions to work as a team. All the professionals come to discuss everything with the patients. I think time management would be really difficult. For example, doctors could not come as they have a lot of meetings, outpatient appointments and so on."* (11 F, Occupational Therapist)

One interesting issue referred to the inappropriateness of adopting shared decision making in mental healthcare from the health professionals' perspectives. It was more likely that health professionals had concerns that more shared decision making across the mental healthcare continuum increased the demand for unnecessary interventions. This led some professionals to perceive that their workload would be significantly increased by implementing shared decision making and they would not be able to use their time in an efficient way. One professional explained:

> *"I think the medical environment in Taiwan is relatively special. So sometimes you want to introduce some new intervention into our society and this needs time to reshape the intervention. And you should be sure this is beneficial for health professionals. Because I think this is a mutual thing. This should be beneficial for both* (patients and professionals) *and then you adopt it. But if this is only beneficial for patients it is not necessary to implement it. It will bring a huge workload for health professionals."* (10 M, Psychiatrist)

6.2.2 Theme 2: Facilitators of shared decision making

The interviews showed that shared decision making was not the norm in mental healthcare in Taiwan. In their accounts, the health professionals paid far more attention to the barriers to shared decision making than to possible facilitators: not every professional seemed to have the desire or the necessary understanding to improve or implement shared decision making.

Despite this, more than half of the professionals were aware that the implementation of shared decision making could be facilitated in some ways. Professionals noted that the lack of patient involvement in decision making might be problematic, and patient involvement might be positive for the health outcomes of some patients with mental illness. This awareness motivated health professionals to reflect on how decisions are shared in the current health system and to consider the possibility of shared decision making in mental healthcare. Therefore, two sub-themes were identified in the data: “awareness of patients’ right to autonomy” and “understanding of the potential benefits of shared decision making”.

6.2.2.1 Sub-theme: Awareness of patients’ right to autonomy

The idea of patient autonomy was valued by some of the professionals. It was perceived that the principle of patient autonomy was usually associated with allowing or enabling patients to make their own decisions about which treatment or care interventions they will or will not receive.

Some professionals recognised the importance of patient autonomy and believed that patient involvement in decision making was needed in mental healthcare. With this awareness, health professionals were more likely to facilitate the implementation of shared decision making. There were two notions driving this motivation, including human rights over one’s own body and uncertainty about treatment and care.

A few professionals reported that active patient involvement was a basic human right, and a key concern in biomedical ethics. With this perception, the professionals believed that patients were able to control their own bodies and lives rather than live under the control of others (health professionals or family members). The sense that patients should be offered options and allowed to make informed decisions about treatment or care interventions was crucial. Two examples:

> *“Because you own your body. You* (patients) *can decide how you want to use your body in the next decades. This body is mine. You should understand what will happen in the next decades if you decide to take this intervention or treatment. I believe this is the right thing to do.”* (12 F, Occupational Therapist)
>
> *“I hope they* (patients) *can be involved in decision making, because they should have the right to decide what treatment they want to receive.”* (17 F, Social Worker)

In order to protect patient autonomy, one professional felt that health professionals should discourage inappropriate paternalism and protect patients from undesired intervention. The idea that patients should be enabled to make informed decisions rather than be forced was explained in the following example:

> *"It is not right to violate their human rights. It is just not right. Because they don't meet the criteria for compulsory admission. They have the right* (to refuse to be admitted). *You cannot do this."* (18 M, Psychiatrist)

It was notable that some showed empathy with patients and experienced concern for them. One professional put herself in the 'patient role' to understand and address their patients' suffering. It appeared that empathy supported patients' autonomy and it also allowed the health professionals to self-reflect about patients participating in decision making. For example:

> *"If I was a patient* (with mental illness)*, I suppose I wouldn't like someone else deciding for me. I would think I had been deprived of my liberty and dignity. Besides I could only follow the instructions of other people, including doctors or family members. It is just* (better) *decided by me. If I was a patient, I would think like that."* (23 F, Registered Nurse)

Another driver of patient autonomy was uncertainty about health treatment and care. The idea there was uncertain or unknown evidence about the risks and benefit of treatment options and no clear standards of care was commonly reported by the health professionals to support the idea of shared decision making. Apparently, there was no exact right course or best medical choice for patients in practice from the professionals' perspectives. Although health professionals could easily access up-to-date knowledge about medication, a psychiatrist said that there is still no "perfect answer" in treatment options and patient preference could be a key in this. One specific example of the clinical uncertainty of medication was given by another health professional. He said:

> *"For example, he felt bad about Seroquel* (Quetiapine). *And he wants to change to Risperidone* (Risperdal)*. That's fine. Just change it. Because to be honest with you - this is my personal view - even now the newest research cannot predict which medication is the most effective for patients. So why not* (implement shared decision making)*?"* (09 M, Psychiatrist)

Similarly, some therefore perceived that there was no perfect treatment and therefore the duty of health professionals was to communicate this uncertainty to patients rather just guiding them in clinical decisions. This led health professionals to see the potential of shared decision making in mental healthcare. Actively involving patients in the decision-making process was seen as more sensible in this situation. For example,

> *"There is no 100% correct answer for medicine. This is probably why it* (shared decision making) *might be implemented. Doctors might have better knowledge. But not all decisions are suitable for everyone. There might have been some* (medical) *mistakes, so a new policy* (shared decision making) *came out."* (10 M, Psychiatrist)

6.2.2.2 Sub-theme: Understanding of potential benefits of shared decision making

Despite the findings described above, i.e. that most professionals did not involve patients in decision making; some professionals felt that there were potential benefits of shared decision making, including improving responsibility, motivation, and understanding of patients' conditions.

Some professionals described that active involvement in shared decision making could help patients with mental illness to understand their responsibility regarding important recovery goals in healthcare. They felt that encouraging patients to be involved in treatment decisions would allow patients to take responsibility for their treatment and care. They felt that greater patient control over their care and treatment would lead patients to feel empowered and relate positively to taking responsibility. Some professionals believed this effort could help to improve health outcomes, such as medication adherence. One professional described this as below:

> *"If today we have a child, he asks for something. And then we discuss with him and then decide together. It is better, isn't it? OR would he like to let the parents decide everything for him? I believe this is the same with the patients. Now we hope patients will decide to take their medication regularly and this is decided by us* (health professionals) *and the patients together. In this situation, responsibility plays a very important role. If you do it that way, the patients will take responsibility, you know?* (05 M, Psychiatrist)

Conversely, as a health professional explained, sometimes health professionals purposely ignored the fact that patients were able to make decisions about their medical care, particularly hospitalised patients or those who were seriously ill. This could bring a sense of who the main decision maker was, and thus who took all the responsibility. Both health professionals and patients wondered if they were capable of achieving any recovery goals or had no confidence in it. One professional mentioned what happened if health professionals tended to decide everything for patients.

> *"If I ignore their ability to make decisions about treatment and care, they could think: 'These* (decisions) *are all decided by doctors or other professionals'. It was like they didn't need to take any responsibility… Even if he is a psychosis patient, he could still decide. These things should be not decided by doctors… I should have noticed this* (that the decisions were all made by professionals) *but I didn't. It's as though the patient sees me as some sort of barrier to stop him recovering. I just see him as a child. And then this means he never ever takes responsibility."* (14 M, Psychiatrist)

The importance of motivation was also pointed out by the professionals as having the potential to improve the health outcomes of patients with mental illness. Along with more engagement in decision making, the theme of patient motivation was identified as being frequently reported in the interviews. From the professionals' point of view, motivated patients could have more desire and energy to be continually committed to a treatment plan and their conditions were more inclined to improve. This was also described as an important determinant of rehabilitation outcome for mental healthcare. In more detail, motivation directly contributed to patient outcomes in terms of their demeanour and their compliance with a long-term rehabilitation plan. Two instances follow; one refers to accommodation and another is about medication treatment:

> *"I believe patients all want to have options, because they don't just go the place* (possible accommodation) *for one or two days. Sometimes it is more likely to be about their future - the rest of their life. If they can decide on their own and they like it, they could stay longer."* (06 M, Psychiatrist)

> *"You let him decide about his medication. He has more motivation. He is more willing to take the medication."* (03 M, Psychiatrist)

Furthermore, some of the health professionals had found that it was meaningless to force patients to follow instructions. If patients experienced compulsion, it appeared they had no motivation to take more positive action in terms of their treatment or care. One occupational therapist reported:

> *"If he was forced or pushed, he didn't like* (the intervention). *We* (health professionals) *didn't really want this. For example, for occupational training, this is invalid and not effective. Patients without any motivation were forced. This is meaningless. They didn't want to stay."* (11 F, Occupational Therapist)

A few professionals explained that there was an opportunity for health professionals to gain insight into exactly what happened to patients when they actively engaged in decision making. In this process, patients were supported in articulating their understanding of their medical conditions and also what they hoped treatment would achieve. Some professionals reported more generally that it could help them to gain a more precise understanding of the patients' conditions. Therefore, health professionals felt more confident in supporting patients in treatment or care plans. One professional mentioned:

> *"If patients have a full discussion with me, I feel more confident in the treatment. For example, the patient discussed all the details about how he took Lithium before. And then we decided he would take Lithium next. I did not really have to worry about side effects. I could have more information about the patient. And this helps me to have more confidence. And therefore in the decision-making process, I think patient involvement is positive."* (02 F, Psychiatrist)

6.3 Strengths and limitations

The findings of this study have provided insight into how mental health professionals perceive shared decision making in Taiwan. To the author's knowledge, this is the first study that has explored health professional perceptions on shared decision making in Taiwan. Therefore, this study could have the potential to support and build further knowledge to provide in-depth descriptions of specific shared decision making interventions and relevant training, as well as the facilitators of and barriers to implementing shared decision making in healthcare, particularly in mental healthcare.

However, a number of limitations of this study are identified: for example, the study involved only healthcare professionals in Taiwan. There could be some differences in healthcare across different countries and this may influence how health professionals perceive the decision-making process in practice. A further limitation is that there is a strong possibility of sample selection and recruitment biases as it may be that the professionals who participate in studies are more interested or enthusiastic about shared decision making and therefore not representative of health professionals in general. In particular, the number of mental health nurses recruited was lower than expected. Data on who refused to participate and who withdrew from the study was not collected, thus not allowing comparison between the sample and the general population of mental health professionals meeting the including criteria.

Also, this study only collected perspectives about healthcare professionals' attitudes and self-reported behaviours; objective observation of healthcare professionals actually interacting with patients was not used in this study. Thus, it may be difficult to draw a firm conclusion about whether the situations described were a true reflection of reality. In order to fully explore the dynamics of decision making, observation research would be useful to examine the decision-making process in mental healthcare in real time. In spite of these limitations, the findings have provided a unique opportunity for health professionals to offer some insight towards re-evaluating shared decision making in mental healthcare.

6.4 Summary

This chapter has provided the findings of how health professionals perceive shared decision making in mental healthcare. The findings indicated that paternalism was still widespread in mental healthcare and the absence of patient involvement in decision making was acceptable to the mental health professionals. Two main themes were generated from the mental health professionals' accounts: barriers to shared decision making and facilitators of shared decision making.

Although health professionals' opinions varied based on their experiences of decision making in mental healthcare, most health professionals felt there were various difficulties related to implementing shared decision making. Numerous concerns about patients taking a more active role in decision making were identified from the data. The health professionals perceived that decision making was their duty as health professionals, and that they were more qualified to make decisions about treatment and care. Interestingly, the importance of family involvement was also pointed out by the health professionals. Due to the moral responsibility to take care of patients with mental illness, families held higher status than patients. Therefore, it was perceived that the family should be the proxy for patients in decision making. Also, concerns about patients' impaired decisional ability were recognised to have negative impacts on active patient involvement in the decision-making process. Additionally, health professionals had limited knowledge about shared decision making and therefore they were unable to implement it. Finally, the negative perception of limited time resources also stopped the implementation of shared decision making.

Conversely, some health professionals realised the importance of patient involvement in decision making and believed that shared decision making could bring benefits to patient outcome and recovery goals. These could motivate health professionals to implement shared decision making in mental healthcare. Some health professionals believed patient involvement contributes to autonomy and is a basic right for patients. As a matter of ethical principle, the health professionals felt that every patient should have rights over their own bodies and make decisions about their bodies. Shared decision making was seen as a way to make this possible. Additionally, it was highlighted by health professionals that shared decision making could help patients to engage in their treatment and care and therefore have potential benefits for patient outcomes.

Chapter Seven: Synthesis

This chapter will provide details of the process and outcome of the synthesis of research related to patients' and health professionals' perspectives of shared decision making. It aims to synthesise barriers to and facilitators of shared decision making from the three studies in this thesis, to extract evidence-based mechanisms through which the process of decision making may be enhanced, and to identify possible solutions to overcome these barriers.

7.1 Synthesis methods

7.1.1 Evidence resources

There were three sources of data from which evidence was synthesised:

- a systematic review of qualitative studies of patient perspectives of shared decision making in secondary mental healthcare (detailed in Chapter Three)
- qualitative interviews with patients to explore their perspectives of how decision making is shared in secondary mental healthcare in Taiwan (detailed in Chapter Five)
- qualitative interviews with health professionals to explore their perspectives of shared decision making in secondary mental healthcare in Taiwan (detailed in Chapter Six).

7.1.2 Synthesis process

Firstly, the author reviewed all transcriptions of both health professional interviews and patient interviews to become familiar with the data again. Following this, a summary table of background information and the findings from each evidence source was created (Appendix 16). All findings of each study were extracted in the summary table and re-read to identify all potential mechanisms through which patients' and health professionals' attitudes and actions could improve patient involvement in decision making. All three evidence sources were equally weighted by the author and all potential improvement mechanisms found were taken into account. The mechanisms initially identified are presented in Table 7.1.

Next, the author re-read all the evidence and the table of extracted improvement mechanisms. The visualisation of these data helped the author to gain an overview of the findings and to review the applicability of the improvement mechanisms. Initial synthesis outcomes and solutions identified from the data were collapsed or combined into a final list of improvement mechanisms. Following completion of data extraction, a narrative summary of each improvement mechanism was produced, which included the barriers, facilitators and potential solutions (Table 7.2).

Table 7.1 Summary of initial synthesis outcomes and possible solutions

	Qualitative review	Patient interviews	Professional interviews	Synthesis	Possible Solutions
Misuse of restrictive/involuntary interventions to force patients to follow instructions	**Barriers** Professionals paternalistic attitude towards decision-making **Facilitators** The importance of professionals adopting a supportive attitude	**Barriers** Powerful status of health professionals and paternalist relationship between health professionals and patients Clear evidence of misuse of compulsory and involuntary interventions Seeing restrictive/involuntary interventions as a consequence of not following instructions of health professionals Verbal threats of being hospitalised from health professionals and families	**Barriers** Belief that health professionals are more qualified to be the main decision-makers was widely reported Failure to use involuntary interventions as the last resort **Facilitators** Sense of patient autonomy enhances patient involvement	Both health professionals and patients confirm that health professional hold paternalistic attitude toward patients in decision making Patients consistently reported health professionals used restrictive/involuntary interventions to force them to comply with instructions Patients and health professionals realised the importance of positive attitude of patients and health professionals	Approaches which are supportive of shared decision making should be applied in mental healthcare. Training could include • Emphasis on promoting patients' rights to autonomy • Emphasis on methods to promote active patient involvement in decision-making • Opportunities to reflect on attitudes and behaviour not consistent with sharing decisions Providing a working definition of restrictive/involuntary interventions could provide greater clarity for health professionals around when it is acceptable to use these interventions, in order to avoid their misuse as punishments/sanctions. Health professionals and patients should be given opportunity to discuss causes of power imbalance in decision making and influence of each parties.
Health professionals and patients do not	**Barriers**	**Barriers**	**Barriers**	Both patients and health professionals confirm that they have	Training for incorporating evidence individualised to patients' unique

promote patient decisional capability	Patients with a limited professional knowledge levels	Widespread reporting of having no confidence to make decisions about their treatment and care due to their mental illness Negative perception of decisional capability due to their mental illness Clear evidence of sense of “health professional knows better”	Belief that patients with impaired decisional capability were not able to make decisions Information asymmetry between health professionals and patients was identify by mental health professionals	no confidence in the decisional capability of patients. Patients and health professionals identify patients with limited professional knowledge, which could prevent them being involved.	circumstances and presented in a format they can understand. Optimising means of delivering professional information, such as decision aids, flyers and websites developed by health professionals.
Limited knowledge of shared decision making-Professionals	N/A	N/A	**Barriers** Limited knowledge of implementation of shared decision making from health professionals. **Facilitators** The importance of understanding of benefit of shared decision making had been identified	Health professionals identified limited knowledge about shared decision making as a barrier to implementation of it.	Increased understanding of potential benefits of patient involvement and shared decision making. Training in the knowledge and principles of shared decision making • definition • evidence • implementation • effectiveness/outcome Increased flexibility for training of shared decision making through • case study • workshop • seminars • online courses
Health professionals are unable to provide sufficient time	**Barriers** Poor quality of communication due to	**Barriers** Clear evidence that health professionals provided	**Barriers** Widespread reporting of heavy workloads which	Both health professional and patients confirm that environment in mental	Optimising work flow for and demands on health professionals

	limited time was reported by patients.	limited time with patients: no privacy, no attention, and not enough time.	left no room for health professionals to have time to involve patients in decision making. Due to the NHI system, health professionals need to see a lot patients every day	healthcare is time-poor.	• simplify health records and working systems • in-depth discussion about the pressure from health insurers to keep patient visits short and the increasing number of patients Support tools and resources • shared decision making tools

Table 7.2 Synthesis summary of improvement mechanisms

Improvement mechanism	Barriers	Facilitators	Possible solutions
Capability/skill improvement			
Increasing patient decisional capability	Both patients and health professional confirm that they have no confidence in the decisional capability of patients **(patient interviews and health professional interviews)** Patients and health professionals say that patients' limited professional knowledge could prevent them being involved **(systematic review, patient interviews, and health professional interviews)**	Clear evidence of sufficient information exchange, including professional knowledge and personal preference facilitate patient involvement **(systematic review and patient interviews)**	Step one: understanding patients' information need • Training for health professionals reflecting that they are essential sources of health advice that patients access Step two: Offering information in the way patients can understand • Optimising means of delivering professional information, such as decision aids, flyers and websites developed by health professionals. • Training for incorporating evidence individualised to patients' unique circumstances and presented in a format they can understand. Step three: offering opportunity for patients to reflect on their understanding of the information.
Improving professional knowledge levels of shared decision making	Health professionals identified limited knowledge about shared decision making as a barrier to implementing it **(health professional interviews)**	The importance of understanding the benefit of shared decision making was identified **(health professional interviews)**	Increased understanding of potential benefits of patient involvement in shared decision making

			Training about the principles of shared decision making: • definition • evidence • implementation • effectiveness/outcome Increased flexibility for training in shared decision making through • case studies • workshops • seminars • online courses
Attitude/motivation modification and improvement			
Attitude modification of health professionals about patient involvement	Both health professionals and patients confirm that health professionals hold paternalistic attitudes toward patients in decision making **(systematic review, patient interviews, and health professional interviews)** Patients consistently reported health professionals used restrictive/involuntary interventions to force them to comply with instructions **(patient interviews)**	Patients and health professionals realised the importance of positive attitude of patients and health professionals **(systematic review, patient interviews, and health professional interviews)**	Approaches which are supportive of shared decision making should be applied in mental healthcare. Training should encourage health professionals to reflect on their paternalist attitude and behaviour Awareness of patients’ right to autonomy should be stressed in mental health education program or professional training Training should help health professionals to understand how to encourage patients to actively engage in decision making Health professionals and patients should be given the opportunity to discuss the causes of power imbalance

			in decision making and the influence of each party
Attitudinal modification of use of involuntary intervention	Clear evidence of misuse of compulsory and involuntary interventions **(patient interview)** Seeing restrictive/involuntary interventions as a consequence of not following the instructions of health professionals **(patient interviews and health professional interviews)** Verbal threats of being hospitalised from health professionals and families **(patient interviews)**	N/A	The purposes and working definition of applying restrictive/involuntary interventions should be clearly identified as being to help patients to regain control rather than consequences or punishment for patients. Mental health professionals should understand the negative impacts of restrictive/involuntary interventions on patients Respectful communication strategies during the interventions
Limited time resources improvement			
Using limited time efficiently	Both health professionals and patients confirm that the environment in mental healthcare is time-poor **(patient interview and health professional interviews)**	Clear evidence that sufficient information exchange improves patient involvement levels **(systematic review and patient interviews)**	Optimising work flow of and demands on health professionals • simplify health records and working systems • in-depth discussion about the pressure from health insurers to keep patient visits short and the increasing number of patients Support tools and resources • shared decision making tools

7.2 Synthesis outcomes

Three improvement mechanisms were identified across the three evidence sources (Table 7.2). Based on these, implementation of shared decision making could be improved through: capability/skill improvement, attitude/motivation modification and improvement, and limited time resources improvement. The following sections will present an in-depth discussion of the synthesis outcomes and possible solutions for overcoming barriers to the improvement mechanisms.

7.2.1 Capability/skill improvement

7.2.1.1 Increasing patient decisional capability

Synthesis outcome

It was evident in both patient and professional interviews that there was little confidence in patients' decisional capacity. Most participants (both health professionals and patients) felt that patients with mental illness suffered from impaired decisional capacity and difficulty in absorbing knowledge about their treatment and care in order to make rational decisions.

Health professionals were concerned that patients with mental illness, who generally lacked insight and were suffering from psychotic symptoms, would make unreasonable or unwise decisions which might worsen their health outcomes or jeopardise their recovery goals, such as refusing to take medication and thus causing relapse. It was assumed by health professionals that patients did not have the capability to take an active role in decision making. Therefore, health professionals, whose reason was not impaired, took responsibility to decide for patients with mental illness.

Patients who were interviewed and the patients' views in the systematic review expressed that they had no confidence to participate in the decision-making process due to limited knowledge levels and long-term mental health conditions, such as hallucination and delusion. Therefore, there was clear evidence that patients had negative perceptions of their capability to understand the information provided by others and underestimated their knowledge gain relative to that of health professionals. Thus, it was perceived that the decisions should be left to the experts who own the knowledge.

Possible solutions

The synthesised data indicated that efforts to promote mutual communication and sufficient information exchange during decision making may enhance the implementation of shared decision making. Patients could gain more understanding of their treatment and care and therefore enhance their confidence to participate in decision making (Clarke et al., 2016; Joseph-Williams et al., 2014a). There are three steps to improve patient knowledge levels. Step one: understanding patients’ information needs; step two: offering information in a way patients can understand; step three: offering an opportunity for patients to reflect on their understanding of the information (Clarke et al., 2016). Detailed discussions of each step will be presented in the following sections.

Step one: Understanding patient information needs

It was evident that the patients often reported that they desired more information than they received. While health professional participants felt that they spent a substantial proportion of time providing information and education to patients, the patient data contradicted this as they described not receiving information, or receiving unclear information and knowledge about their illness or treatment.

Because of the perception among patients that seeking more information about their health was critical, and that the information should be tailored to their specific clinical conditions, it may be essential to promote an ethos consistent with the exploration of patient information needs. Understanding what information patients really need could therefore provide greater clarity for health professionals about what information and knowledge should be delivered in order to increase patients’ limited knowledge levels and meet their information needs.

Step two: Offering information in a way patients can understand

Sharing information appropriately was recognised as essential to providing effective care for patients in both the patient interviews and the systematic review. Although the health professionals agreed with the importance of patient education, most patients – by their accounts – had difficulties in understanding the information given to them. Specifically, both health professionals and patients had some concerns about patients’ capability to absorb professional knowledge. Therefore, it seems essential to find an appropriate approach to delivering medical information to improve patient knowledge levels.

It was evident that patients' perception of the ways health professionals deliver information and knowledge was negative. The information was often partly understood, misunderstood, or misinterpreted. It could be important to look at knowledge delivery through the patients' eyes. Assessment of patients' capacity to understand specific healthcare information could be important for health professionals in deciding how to provide the information. A large amount of knowledge needs to be covered in order to present integrated clinical information in diverse health settings, and the use of 'bite size chunks' or a 'lay' written leaflet or website would be appropriate options to ensure patients receive understandable, accurate and evidence-based information. Patient education is effective when patients receive accurate, timely, and unambiguous information from health professionals in a way they are able to understand (Marcus, 2014) and then patients are enabled to participate responsibly in decision making.

Step three: Offering opportunities for patients to reflect on their understanding of the information received

The patient data was replete with evidence of health professionals' inability to provide opportunities for patients and health professionals to communicate fully in medical encounters. Examples were given of professionals persistently failing to ask or to understand what information patients needed and whether patients had gained sufficient knowledge to take part in decision making. Furthermore, after being provided with a little knowledge or information about their treatment and care, patients felt that health professionals then attempted to ignore their further requirements or questions. This was particularly true for patients who had not been professionally trained, and only partially understood – and quickly forgot – the information they had received. As they pay more attention to processing the information they are given about a new diagnosis, a new treatment, or a new medication, patients may need an opportunity to review all the details with their health professionals and then clarify where they require further information from them.

In addition, although the health professionals believed they had spent time during the encounters verbally providing medical education, the patients' perception was that health professionals, particularly psychiatrists, did not spend sufficient time with them. In the interviews, both health professionals and patients agreed that there was a large amount of medical information which needed time to be thoroughly explored and understood. As the patients described it, the quality of the medical encounters is often seen as time-poor:

patients rarely had sufficient time to formulate their questions in the outpatient appointments. For these reasons, consideration must be given to how to improve the time-poor environment, which is also discussed in Section 7.2.3, and then the effectiveness of the educational process might be significantly enhanced.

7.2.1.2 Improving professionals' knowledge of shared decision making

Synthesis outcome

The health professionals recognised that a potential barrier to implementing shared decision making was their limited knowledge about it. Although health professionals' knowledge levels about shared decision making ranged from 'never heard of it' to 'fully understand it', most did not have a clear understanding of shared decision making. Even for those health professionals who felt that there were benefits to shared decision making, their overall knowledge, conceptualisation and practical implementation were limited.

Factors identified by the health professionals as contributing to this included a lack of learning materials or training, no motivation to understand, and limited time resources. Although the government had made some efforts to promote the implementation of shared decision making, limited learning materials and training for health professionals was recognised as a major barrier. Furthermore, because of limited knowledge about it, a few health professionals felt that shared decision making had already been implemented in mental healthcare, or was not suitable for patients with mental illness. Therefore, they were unable to be motivated to learn about the new idea.

Possible solutions

As described earlier, the health professionals strongly indicated that even if shared decision making could bring benefit to their practice, as a first step they needed to gain knowledge about shared decision making. Some barriers should be taken into account in developing the education programmes and training for health professionals.

The importance of learning materials and training was identified by all the health professionals. As some health professionals mistrusted shared decision making as a norm in mental healthcare, they felt there was no need to learn more about it. However, a few essentials that the health professionals mentioned in the interviews should be covered in this training, including what shared decision making is, how to implement it and what its benefits are. These could help health professionals to clarify the real situation of making decisions in mental healthcare. Meanwhile, because of health professionals' busy programmes, it may be important to consider the flexibility of training for mental health professionals. In order to enhance accessibility of this training, some other forms of training should be also considered, such as online courses.

In addition, it may be worth considering that a few health professionals indicated that decision making would be a process of communication between health professionals and patients. Knowledge of effective communication is important when exploring what type of relationship with clinicians could maximise patient involvement in their own health and care, and how this might be reflected in medical education and training. This training and these learning materials would support health professionals in adopting shared decision making and information giving. Some communication skills training may be needed to make shared decision making possible in mental healthcare.

7.2.2 Attitude/motivation modification and improvement

7.2.2.1 Modification of health professionals' paternalistic attitude to patient involvement

Synthesis outcome

Across the evidence sources, both health professionals and patients confirmed a widespread paternalistic attitude to patients amongst health professionals. It was widely practised because health professionals were usually expected to make the best decision for the patient. Power imbalance between health professionals and patients was significant in the decision-making process and has existed for a long time in all healthcare fields (Joseph-Williams et al., 2014a).

There was good evidence that these attitudinal barriers were delaying progress in implementing shared decision making. There were natural duties and roles for health professionals and patients; health professionals should be the ones to make decisions and patients should submissively accept a silent role during the process. It was more rational that decisions should be left to health professionals, who were more qualified to decide. Therefore, the dominance of health professionals and the passivity of patients were commonly adopted roles in healthcare.

Another potential barrier that exacerbated the power imbalance between health professionals and patients was that the power to order hospitalisation and other involuntary and restraint interventions was held only by the health professionals. Patients, therefore, were afraid of speaking up and felt there would be consequences if they refused to follow instructions. These barriers will be discussed in depth in Section 7.2.2.2.

Interestingly, the importance of family involvement was also recognised in both patient and health professional interviews. Both groups also believed that elderly, male family members had a dominant role in decision making, usually more than patients. Meanwhile, as families had a moral responsibility for patients, the family held much more power in mental healthcare. Thus, many participants argued that the dominance and decision-making authority of families in society in general was reflected in mental healthcare.

Possible solutions

Unsurprisingly, having sufficient knowledge and information is key for patient involvement in decision making. There was a natural knowledge gap between health professionals and patients. Therefore, improvement of patient knowledge levels could be helpful to improve the power imbalance in the health professional-patient relationship. Some possible solutions for the knowledge gap have been discussed in the previous sections.

However, knowledge alone may be insufficient to change this trend of paternalistic relationships between health professionals and patients. Attitudinal barriers from health professionals were widely reported in the studies as preventing patients being involved in decision making. There was a persistent belief amongst the professionals that they were more qualified to make decisions, and their failure to involve patients in decision making, such as refusing to explain the rationale for treatment and intervention, not responding to patients' requirements, or when they expressed their preference about treatment and care, could be a barrier to shared decision making: not only could it cause increased patient passivity, it could also erode health professional-patient relationships.

For these reasons, the importance of supportive approaches in decision making should be stressed in professional (medical and nursing) education and training. Meanwhile, implementation of shared decision making training for health professionals should consider focusing on communication skills training in decision making, including sharing information, deliberation and making final decisions (The Health Foundation, 2012b). Training options to meet these needs are explored by discussion; a series of meetings would need to be held in order to thoroughly explore their incorporation in implementing shared decision making (The Health Foundation, 2012a).

In order to reduce the dominance of close family and other relatives, respecting patient autonomy could be important for health professionals to consider. Understanding patients' cultural and family backgrounds could also be a key to developing proper communication strategies with patients and family members. Also, careful observation of family interaction is critical to ensure patients make decisions based on their personal preference and desire rather than coercion by the family.

7.2.2.2 Attitudinal modification regarding use of involuntary intervention

Synthesis outcome

The misuse of involuntary interventions, such as restraint, seclusion, and injected medication, was evident in both the patient and the health professional studies. All patients in the studies had experienced being hospitalised or other involuntary interventions. They often felt powerless and hopeless during these experiences and some of them saw the experience as traumatic. Therefore, patients tended to submissively accept requests from health professionals and act in the way they thought health professionals would like.

Although both groups believed that health professionals' power was reinforced in this way, patients strongly perceived this power as a threat in the decision-making process. Across all the patients, during hospitalisation and involuntary intervention their voice was often ignored by the health professionals. In order to keep patients passive in decision making, both health professionals and patients described that health professionals tended to use involuntary intervention as a threat to force patients to follow their instructions. In some examples, patients described how health professionals used involuntary intervention as "punishment" if they did not listen. Intense fear and feelings of being threatened were consistently widespread in the patients' accounts.

Possible solutions

The purpose of involuntary interventions and hospitalisation should be clearly stressed as a way to help people to regain control rather than as a tool for forcing them to follow instructions. The use of these interventions should only be adopted when other preventive strategies, such as de-escalation techniques, have failed (NICE, 2017). Owing to the perception among health professionals that coercion is an effective way to control patients, an ethos consistent with the development of a definition may be needed, to provide an alternative way of offering less coercive methods and routines on which to depend to manage patients in the various settings. Therefore, a clear working definition of these interventions and criteria for hospitalisation should be developed for health professionals in practice. With these clear definitions, health professionals could clarify the proper situations in which to apply these interventions and how to use them (Horsburgh, 2004). Furthermore, promotion of rapid deployment of other possible interventions and the minimisation of coercion could also be helpful to ensure equality of patient and health professional roles.

Even if, in some situations, involuntary interventions or hospitalisation are inevitable, health professionals should use more respectful communication strategies during intervention. It may be useful for health professionals to explore patients' views on the situation and discuss their needs and their concerns, offering sufficient time for patients to respond and have the opportunity to speak up. Seeing patients as the central focus of care is key to communicating with patients. Some training in communication skills may help health professionals to provide higher quality care.

7.2.3 Limited time resources improvement

7.2.3.1 Using limited time efficiently

Synthesis outcome

The issue that health professionals had limited time with patients was recognised to prevent effective communication between health professionals and patients. The patient data strongly indicated the poor quality of medical encounters with mental health professionals. For example, some patients complained that there was no privacy in the clinical room at all, as the health professional asked more than two patients to wait in the same room, in order to see as many patients as possible. Similarly, both health professional and patient groups confirmed that patients normally had only five to ten minutes with their health professionals in each medical encounter. The issue of limited time resources was identified by both parties as impeding shared decision making.

Furthermore, the causes of professionals failing to provide enough time for patients were discussed in both studies. Patients paid attention only to the numbers of patients that health professionals needed to see each day, which they used to explain why the health professionals were always busy, whereas health professionals provided more insight into the reasons why they needed to see a large number of patients in one day. The health professionals said that the National Health Insurance system required them to increase their "sales figures" in the practice. The numbers of patients they saw therefore had significant influence on the hospitals' and clinics' revenues from the National Health Insurance, as well as their personal incomes. Accordingly, they must complete patient visits efficiently and quickly.

Another barrier to shared decision making was concern about its time-consuming nature. Although health professionals did not have a full understanding of shared decision making, the data showed a widespread belief that it was time-consuming. Concern that implementing shared decision making would bring increased workloads was a potential barrier for health professionals. For these reasons, they were reluctant to expedite shared decision making.

Possible solutions

The importance of how to use limited time could be a key to improving and facilitating shared decision making in mental healthcare. However, in the data, the health professionals often struggled with high workloads. Therefore, optimising work flow for and demands on health professionals may be a key to help health professionals to use their limited time efficiently. For example, complicated medical records and working systems could be made simpler and more flexible. Thus, increasing the availability of health professionals for patients may improve the quality of medical encounters.

It also worth clarifying the belief that shared decision making is time consuming. Although some studies believe that shared decision making needs time to perform in practice (Ford et al., 2002; Légaré et al., 2008), there is also evidence that implementation of shared decision making does not need extra time (Stacey et al., 2014). Therefore, it may be important to gain more evidence to decide if shared decision making requires more time in practice.

While it could be challenging, some system-level efforts could be needed to improve the often time-poor environment. The significant stressor that health professionals need to see a large numbers of patients each day needs to be improved. Therefore, an in-depth discussion is needed within the health system about the pressure from health insurers to keep patient visits short in order to increase the number of patients seen. Striking a balance between demand and workloads could be a key to dealing with this challenge.

Therefore, the authorities should carefully consider the negative impacts of this pressure and review the work flow for health professionals.

In addition, due to the concern about the time-consuming nature of shared decision making, it may be worth introducing some support tools and resources for shared decision making. For instance, information in a variety of formats, such as flyers and booklets, could be used to help patients to gain the knowledge to participate in decision making (Drug and Therapeutics Bulletin, 2013). However, some patients might still prefer to receive material about their specific circumstances that health professionals recommend (Clarke et al., 2016). Thus, the process of knowledge delivery could be carried out using alternative means such as online services or the telephone. Additionally, information from support groups or internet-based discussion groups could be also helpful, to enable patients to learn from others with similar medical conditions. These resources would give patients more flexible ways to exchange information and increase knowledge levels about treatment and care.

7.3 Summary

This chapter has presented a synthesis of one qualitative systematic review and two qualitative interview studies (patient interviews and health professional interviews). The findings of the synthesis have provided a detailed discussion on the decision-making process in secondary mental healthcare in Taiwan, and how health professionals and patients felt about the process. Three main improvement mechanisms were identified: capability/skill improvement, attitude/motivation modification improvement, and limited time resources improvement. First, the knowledge levels of both health professionals and patients should be improved to ensure they are able to undertake shared decision making. Second, attitudinal modification regarding paternalism could also be a key to facilitate shared decision making. It could be important for health professionals to critically review and reflect on their part in the decision-making process and then provide proper support to enable patients with mental illness to actively participate in decision making. Finally, the importance of improving the time-poor environment was identified by both groups. Although some systemic efforts need to be made, optimising work flows and introducing support tools may also help health professionals use their limited time more efficiently. With these three improvement mechanisms, the implementation of shared decision making could progress in mental healthcare. The next chapter will discuss the findings of the synthesis, its implications, and the direction of further studies.

Chapter Eight: Discussion

This chapter will provide a detailed discussion of this thesis. The first section of this chapter will present a summary of the main findings in relation to the aims and objectives of the thesis. The second section will provide a discussion of the strengths and weaknesses of the synthesis. The third section will review the findings and compares them with the current literature. Following this, the fourth section will discuss possible further studies in this area. Finally, the conclusion will be presented.

8.1 Summary of key findings

8.1.1 Qualitative systematic review (Study One, Chapter Three, pg. 65)

Aim: To examine and synthesise perspectives of shared decision making amongst patients in secondary mental healthcare.

Methods: Using a systematic search strategy, the meta-synthesis identified qualitative studies exploring patient perspectives of shared decision making in secondary mental healthcare. The review followed the principle of thematic synthesis, as outlined by Thomas and Harden (2008).

Findings: 13 studies were included in the synthesis. Patients in mental healthcare played passive roles in the decision-making process. There were two main themes: "barriers to shared decision making" and "facilitators of shared decision making".

Barriers

- professionals with a paternalistic attitude
- poor quality of interaction with health professionals
- patients lacking professional information and knowledge

Mental health professionals' paternalistic attitudes prevented patients being actively involved in the decision-making process. Another barrier to shared decision making recognised by patients was the poor quality of interaction with health professionals Furthermore, patients were concerned about their limited professional knowledge preventing them from participating in decision making.

Facilitators

- supportive attitude to patient involvement
- sufficient information exchange
- other support resources

A supportive attitude from mental health professionals could facilitate the implementation of shared decision making. Sufficient information exchange was also reported by the patients as being a significant benefit to implementing shared decision making. Furthermore, some patients also felt that support resources, including decision aids, could help them to actively engage in decision making.

8.1.2 Patient interviews (Study Two, Chapter Five, pg. 120)

Aim: To explore patient perspectives of shared decision making in secondary mental healthcare in Taiwan.

Methods: Semi-structured qualitative interviews were used. Interviews were conducted with 20 patients sampled purposively and recruited from three halfway houses in Taiwan. The interviews were analysed using thematic analysis (Braun and Clarke, 2006).

Findings: 20 patients were included in this study. Patients in mental healthcare in Taiwan were not involved in the decision-making process. Two main themes were identified: barriers to and facilitators of shared decision making.

Barriers

- the professional status of health professionals in a submissive culture
- a negative perception of making decisions
- limited time resources

As the health professionals had power and status, patients perceived that decision making should be left to those who were more qualified, i.e. the health professionals. Patients had negative perceptions of their ability to make decisions and therefore did not have the confidence to be involved in the decision-making process. Furthermore, a lack of sufficient and quality time with health professionals, particularly psychiatrists, prevented patients expressing their deeper feelings, and therefore had a negative impact on patient involvement in decision making.

Facilitators

- sufficient information exchange
- desire to make decisions

Patient participants wanted to gain sufficient information to improve their level of involvement in the process. One interesting finding regarding the need to make final decisions was that some patients preferred to make the decisions themselves, but some tended to leave final decisions to the health professionals alone. Although not everyone attempted to make their own final decisions, all patients reported a clear need for more active patient involvement in decision making.

8.1.3 Health professional interviews (Study Three, Chapter Six, pg. 140)

Aim: To explore health professionals' perspectives of shared decision making in secondary mental healthcare in Taiwan.

Methods: Semi-structured qualitative interviews were employed. The semi-structured interviews were analysed using thematic analysis (Braun and Clarke, 2006).

Findings: 24 mental health professionals, purposively sampled from secondary mental healthcare in Taiwan, were individually interviewed. Overall, paternalism was still widespread in mental healthcare and the absence of patient involvement in decision making was common, according to the mental health professionals. Two main themes were generated: "barriers to shared decision making" and "facilitators of shared decision making".

Barriers

- powerful status of health professionals and families
- patients with impaired decisional ability due to mental illness
- health professionals lack understanding of shared decision making
- insufficient time

From the health professionals' perspective, decision making about treatment and care was a natural responsibility of being a health professional. Interestingly, the powerful status of not just health professionals but also families negatively influenced active patient involvement. Additionally, patients' impaired decisional ability also brought some concerns to health professionals. Meanwhile, there was a significant lack of knowledge about shared decision making amongst health professionals, leading to them being unable to implement it. Another barrier was that health professionals perceived that they struggled to spend sufficient time with patients, and therefore felt that shared decision making would be impossible to implement.

Facilitators

- awareness of patients' right to autonomy
- understanding of potential benefits of shared decision making

Although health professionals focused more on the barriers, some were aware of significant potential benefits of patient involvement in decision making, and were more motivated to facilitate shared decision making in practice. It was perceived that active patient involvement is an approach to ensure patient autonomy. Furthermore, the health professionals also discussed the importance of shared decisions in enabling patients to engage more in their treatment and care, which would then bring potential benefits to patient outcomes. Therefore, they were more willing to adopt shared decision making in practice.

8.1.4 Synthesis of the studies (Chapter Seven, pg. 164)

Aim: To synthesise barriers to/facilitators of shared decision making from the three studies in this the thesis, to extract evidence-based mechanisms through which the process of decision making may be enhanced, and to identify possible solutions to overcome these barriers.

Methods: A synthesis of the findings from the qualitative systematic review, patient interviews, and health professional interviews was presented in Chapter Seven.

Findings: Although patients desired shared decision making, it has not yet been implemented in mental healthcare in Taiwan. Three types of barriers were identified: capability/skills barriers, attitude/motivation barriers, and limited time resources. Three improvement mechanisms were identified:

Capability/skill improvement

- increasing patients' decisional capability
- improving professionals' knowledge of shared decision making

Concerns that patients with mental illness might have impaired decisional capacity were widespread in the synthesis. Therefore, it was perceived by all the groups that patients had difficulty absorbing knowledge about their treatment and care in order to make rational decisions. To overcome this, increasing professional knowledge levels could be a key to increasing patients' decisional capability so that they may participate in decision making. Patients could gain professional knowledge from their health professionals and other resources such as literature and the internet, and then could build enough confidence to be actively involved.

Another barrier to shared decision making was that health professionals had a significant lack of understanding of shared decision making. Although their knowledge levels varied, most did not have a clear understanding of the subject and felt it could be difficult to implement. Before they were able to implement shared decision making, the first step was that they must have knowledge about it. Thus, the importance of improving professionals’ level of knowledge of shared decision making was also identified in the study.

Attitude/motivation modification and improvement

- modification of health professionals’ paternalistic attitude to patient involvement
- attitudinal modification regarding use of involuntary interventions

It was evident that a widespread paternalistic attitude to patients existed amongst health professionals. Therefore, modifying health professionals’ attitudinal barriers to patient involvement could be a key to facilitating shared decision making in mental healthcare. Importantly, the power imbalance between health professionals and patients could also be improved by continued reflection on paternalism in the patient-health professional relationship. Health professionals should, therefore, understand how to take a supportive approach to encourage patients to explore their preferences, and then form an alliance with patients during decision making. Furthermore, the purpose and working definition of involuntary interventions should clearly emphasise helping patients to regain control, rather than being a punishment imposed by health professionals.

Limited time resources improvement

- using limited time efficiently

Health professionals and patients recognised that the issue of health professionals having limited time prevented effective communication between health professionals and patients. Therefore, using limited time resources efficiently may facilitate the application of shared decision making. The work flow and demands on health professionals may need optimising to make sure health professionals have sufficient time with patients. Also, some tools and resources to support shared decision making, such as decision aids, could potentially be used to reduce the time it takes to exchange information, and then shared decision making could be used more efficiently in a limited time.

8.2 Strengths and limitations

The strengths and limitations of each study (one systematic review and two qualitative studies) were presented in depth earlier in this thesis. Only a brief summary will be therefore presented in the following sections. Following this, discussion on strengths and limitations for the final synthesis will also be provided.

8.2.1 Qualitative systematic review (Study One)

The systematic review (Chapter Three) provided an in-depth discussion directly from patients' perspectives of shared decision making. A key limitation of the review was that it only included studies from western countries, which made it difficult to adapt the findings to other cultural contexts. In addition, there were the limitations of qualitative synthesis to be considered. As this synthesis only focused on qualitative evidence, objectivity should be carefully taken into account.

8.2.2 Patient interviews (Study Two)

This was the first study directly exploring patient perspectives of decision making in mental healthcare in Taiwan (Chapter Five). Therefore, the study provided a unique opportunity for patients to speak up about their views of this process and for health professionals and policy makers to explore how to improve levels of patient involvement. However, there were limitations to consider: although generalisability is not the main purpose of qualitative studies, the small population should be taken into account. Furthermore, the patients in this study were only recruited from the halfway houses. This could lead to the conclusion that the findings may not be transferable to other mental health settings. Although the patient participants were recruited only from halfway houses, they had long-term and rich experience of mental healthcare.

8.2.3 Health professional interviews (Study Three)

In terms of health professional interviews (Chapter Six), this study was the first to provide an insight into how mental health professionals perceive shared decision making in Taiwan. However, there were limitations which included the potential threat of sample selection and recruitment biases. It may be that professionals were more engaged in the topic, shared decision making, and therefore not representative of health professionals in general. One major factor in this was that the number of mental health nurses recruited was lower than expected. Also, two professional participants asked to be withdrawn from the analysis. Although they did not provide reasons for withdrawing, sensitive topics about decision making for patients with mental illness could have negatively influenced how the health professionals viewed their own behaviour in practice, leading them to refuse to continue to participate. Therefore, this could influence how well the study represents the general population from which the professionals were drawn (Sica, 2006; Smith and Noble, 2014). Furthermore, the data were only collected from self-reported behaviours, which may be difficult to be totally objective about (Rosenman et al., 2011). Therefore, it might be difficult to draw any firm conclusions.

8.2.4 Synthesis

All details of the strengths and limitations of each study have been presented in the previous chapters. This section now focuses on the overall synthesis of this doctoral study. Its main strength is that it has addressed a gap in knowledge relating to patients' perspectives of shared decision making, by both examining the existing literature and obtaining new evidence obtained directly from patients and health professionals in secondary mental healthcare in Taiwan. There have been no published studies exploring decision making in mental healthcare in Asia generally or in Taiwan in particular. Therefore, this study could provide an initial insight into shared decision making in a different context, rather than only a western one.

Furthermore, the study captured the phenomena of the decision-making process comprehensively. It was not just limited to understanding how decision making is shared in mental healthcare, and barriers to and facilitators of it, but also explored improvement mechanisms to overcome the barriers to shared decision making. Meanwhile, both health professionals' and patients' voices were taken into account at the same time, in order to provide a more representative account and a more in-depth discussion of shared decision making through a different lens than other qualitative research in this area.

However, there are some limitations which should be considered while examining the findings of this doctoral study. Although this synthesis did not aim to achieve quantitative generalisability, only the findings from three data resources, including one qualitative systematic review and two qualitative studies (patient and health professional groups), were included in the synthesis. However, the data was recognised by the author, with the agreement of the supervisory team, to have indeed achieved saturation. Therefore, the quality of the data would be able to provide an in-depth insight into the phenomena in which the author was interested. Furthermore, although there are various approaches to qualitative syntheses, this overall synthesis only focuses on improvement mechanisms. In order to pay attention not just to themes which were generated from the data but also to possible improvement, and to develop strategies for overcoming these barriers to shared decision making, the main emphasis was recognised before the synthesis was conducted.

8.3 Current literature

There has been increasing scholarly attention paid to shared decision making in mental healthcare since the author commenced this doctoral study. This section will therefore provide a discussion of the findings of this study and compare them with the most recent literature.

The participants' (both patients' and health professionals') accounts in this study presented a widespread view that there has been a failure to actively involve patients in decision making, and it is evident in recent literature that patients are still commonly excluded from the decision-making process (Care Quality Commission, 2017). Equally common is the belief that patients with mental illness should not be involved in decision making, and widespread use of potential coercive interventions was widely reported by both health professionals and patients in this study; this, too, is echoed in the most recent literature (Saya et al., 2019; Shepherd et al., 2014). These practices are inconsistent with patients' legal right to be involved in their treatment and care, which has in recent years been enhanced and added to in law by lawmakers world-wide, including in Taiwan (Liao et al., 2017). The practices also violate ethical principles of health practice, such as autonomy, which encompasses showing respect for the patients' choices, and often refers to the protection of a patient's ability to make his or her own decisions (Beauchamp and Childress, 2013). Despite some advances, this remains an area of concern (Slade, 2017).

It is worth noting that some policies have been created and efforts made to improve shared decision making in healthcare internationally (Slade, 2017). Furthermore, some countries have been integrating shared decision making into their standard principles in mental healthcare to ensure patients have the right to make their own informed decisions (Hem et al., 2016). Despite this, one recent cross-national mixed-method comparative case study in the UK found that patients in mental healthcare were not really involved in the decision making process (Coffey et al., 2019) and one systematic review also supported the suggestion that shared decision making has failed in mental healthcare (Bee et al., 2015). It is clear that patient passivity is still common in the decision-making process around the world (Care Quality Commission, 2017) and specifically in Taiwan (Liao et al., 2017), and the use of potential coercion is still widespread in mental healthcare (Care Quality Commission, 2019).

In Taiwan, some relevant laws, such as the Patient Self-Determination Act, have been enacted to ensure patients' right to make decisions (Liao et al., 2017). Although a nationwide shared decision making programme has been in place since 2016, shared decision making is still seen as a new concept (Liao et al., 2017). Consistent with the findings of this study, however, there is still a significant lack of understanding of shared decision making and it is still not applied in practice in Taiwan (Liao et al., 2017). Therefore, it is clear that implementation of shared decision making still needs further work to make it possible in mental healthcare, particularly in Taiwan.

From patients' views in this study, there was a strong perception that patients had a clear desire to be involved in decision making, which was also frequently reported in the literature (Chewning et al., 2012; Kiesler and Auerbach, 2006). One systematic review aimed to explore the preference-match strategy in physician-service user communication. This review included 69 studies and revealed that patients expected more active roles in decision making than they experienced (Kiesler and Auerbach, 2006). One more recent Cochrane systematic review, including 115 studies, also concluded that most patients desired shared decision making in medical encounters (Chewning et al., 2012). These findings are consistent with this study showing patients are largely positive about patient involvement.

However, the finding of this study showed some divergence in patients' desire for active involvement in some ways. Similarly, some previous studies have suggested that patient preferences about involvement in decision making could vary (Levinson et al., 2005). Although the patients studied were clear in their desire for more active involvement in decision making, their desired involvement levels varied from more information to making their own decisions in this study. Despite not every patient wanting to make their own decisions, all patient participants still desired more information about their treatment and care. These findings converge with current literature: many would prefer not to remain passive, and to receive more information about their health conditions (Bowling and Ebrahim, 2001; Dahlqvist et al., 2015; James and Quirk, 2017). According to NICE, some patients may not want to take an active role during decision making, but they should always have an opportunity to decide what level of involvment they want (NICE, 2019).

Substantial evidence suggests that patients in mental healthcare are motivated to be actively involved, both in this study and in the literature (Bowling and Ebrahim, 2001; Dahlqvist et al., 2015; Fisher et al., 2016; James and Quirk, 2017; Woltmann and

Whitley, 2010), but this study found that numerous barriers are created through insufficient information exchange and a lack of opportunities for deliberation. Significantly, a variety of challenges to embedding shared decision making in routine services have been highlighted in this study and in the literature (Bee et al., 2015; Joseph-Williams et al., 2014a; Joseph-Williams et al., 2014b; Joseph-Williams et al., 2017; Slade, 2017; Stovell et al., 2016), including in Taiwan (Liao et al., 2017). Other research has found that because of these barriers, integrating shared decision making into routine practice has been surprisingly impeded (Joseph-Williams et al., 2017). Comparison and consideration of the findings from these patient and health professional interviews expose some barriers to shared decision making where greater attention may be required.

The importance of providing sufficient information for patients has been identified in the literature (Faller et al., 2016; Joseph-Williams et al., 2014b), as in this study. It could be difficult for patients to participate in decision making without any knowledge about their illness, health conditions and available options (Joseph-Williams et al., 2014a). The findings of this study and in the literature point out the importance to the decision-making process of patients and health professionals having sufficient knowledge (Légaré et al., 2018; Stiggelbout et al., 2015). As education initiatives that enhance health professionals' ability to integrate shared decision making into their practice are significant, a variety of training programmes have identified to support health professionals in this process (Diouf et al., 2016; Légaré et al., 2018). However, Joseph-Williams et al. (2014b) also stated that although providing information is important to shared decision making, it is not enough to facilitate it in practice and they believed more actions needed to be taken to deal with attitudinal barriers.

It is evident that attitudinal barriers to shared decision making are more significant than other barriers in this study. This study showed that health professionals reported that they ignored patients' desire for active involvement, and a similar conclusion was drawn in the literature (Dahlqvist et al., 2015). The issue of attitudinal change in health professionals has been pointed out in recent years (Joseph-Williams et al., 2017). This study's negative findings are consistent with the existing literature, which is replete with examples of professionals adopting paternalistic attitudes to patient involvement in decision making, particularly in mental healthcare (Hem et al., 2016; Quirk et al., 2012). Health professionals' attitudes were identified as a significant barrier, with the implication that patients should not be involved in decision making (Bae, 2017). To explain this, health professionals believed they should take responsibility as the main decision makers, as they act in the patients' best interest based on their biomedical ethical codes (Slade, 2017).

This sense of power imbalance between health professionals and patients was widespread across health settings around the world (Joseph-Williams et al., 2014a; Ljungberg et al., 2016). Also, Taiwan has a long tradition of paternalism in the therapeutic relationship (Tai and Tsai, 2003), as is seen in many other countries (Hu et al., 2014; Murgic et al., 2015). This could also explain why patients feel they cannot participate in shared decision making, rather than not wanting to (Joseph-Williams et al., 2014a; Ljungberg et al., 2016). Furthermore, the use of involuntary interventions exacerbates the power imbalance between health professionals and patients (Ljungberg et al., 2016). In mental healthcare, there is a rising trend in the use of coercion and involuntary interventions (Sashidharan and Saraceno, 2017). Patients with mental illness who were subjected to coercive psychiatric interventions had negative experiences and views of the experience, such as trauma/retraumatisation, distress, fear, feeling ignored, and being dehumanised, both in this study and literature (Cusack et al., 2018). These experiences of being restrained in hospitals create trauma and fear regarding future treatment and care (Brophy et al., 2016). In most patient accounts, the overwhelming majority of patients had experienced the use of coercion in mental healthcare, such as taking medication, physical restraint and rapid tranquilisation in hospitals. In patient accounts, the power to use coercive interventions is generally held by health professionals rather than patients. Therefore, patients and health professionals believed the powerful status of health professionals. Patients with mental illness are therefore constrained from expressing their perspectives openly and honestly to health professionals because of fear of the "consequences" (National Mental Health Consumer and Carer Forum, 2009). This sense of health professionals having the more powerful role could explain why shared decision making is severely lacking in mental healthcare.

Meanwhile, both this study and the literature found that the sense that patients with mental illness often suffer from a lack of insight into their mental health conditions leads health professionals to believe they might refuse to accept any treatment, which could create a conflict with the biomedical ethical principles and worsen patient health outcomes. (Shepherd et al., 2014; Slade, 2017). Concerns about patients having impaired decisional ability were also found in other studies, and are highlighted in the literature as barriers to involvement (Scholl and Barr, 2017; Slade, 2017). The consistency of this finding across our patient and health professional interviews can be seen in a number of ways. For example, health professionals believed that patients commonly refused to take medications. Impaired decisional capability of patients with mental illness has been frequently argued in this study and in the literature (Seale et al., 2006; Shepherd et al., 2014). This may be explained by concerns that patients would make risky and irresponsible decisions leading to worse health outcomes (Shepherd et al., 2014). Therefore, these concerns led to health professionals not attempting to involve patients with mental illness. This may also explain why the patients in Taiwan also undervalue their ability to understand professional information about treatment and care, and their lack of confidence in asking questions. However, only if patients acknowledge that their unique expertise on their own bodies is valuable in the decision making process and they are capable of understanding information will they be able to actively enage in decision making (Joseph-Williams et al., 2014a).

In addition, as described in this study, lack of knowledge of shared decision making among health professionals was a major barrier to implementing it. Only a few health professionals articulated clear values and understanding reflecting components of shared decision making and the potential benefits of shared decision making which have been promoted to improve healthcare in Taiwan. From this study, there is a significant knowledge gap amongst health professionals in terms of how to practise shared decision making. Lack of awareness of and familiarity with the intervention could negatively affect health professionals' knowledge about implementing it (Cabana et al., 1999). A prerequisite for implementing shared decision making is that mental healthcare professionals are not just willing but also have the ability to involve patients in decisions (Grim et al., 2016).

One more concern, about limited time resources, is also widespread among health professionals in many current studies (Joseph-Williams et al., 2017; Liao et al., 2017; Terry and Coffey, 2019). Health professionals perceive that they struggle to provide additional time for patients in order to implement shared decision making (Liao et al., 2017). As found in this study, patient participants also consider health professionals' limited time as a significant barrier to patient involvement in decision making. However, a number of decision aids have been developed to overcome the challenges of limited time resources (Légaré et al., 2018). These helpful tools could overcome this barrier effectively.

8.4 Clinical implications

Attention should be paid to these suggestions for facilitating the implementation of shared decision making in mental healthcare. Although patients in mental healthcare reported a clear desire for a more active role during decision making, shared decision making is not actually the norm in mental healthcare. The findings of this study could be an important resource for patients to have this unique opportunity to explain their perspectives on shared decisions making to the public. Also, health professionals have specific insights into their interactions with patients and what it is important for them to explain to the public.

Furthermore, to develop and implement shared decision making in practice, various barriers and facilitators which were identified by this doctoral study should also be taken into account. First, as earlier described, some training is required for both health professionals and patients to increase their knowledge levels to enable them to participate. Second, attitudinal barriers evidently influence health professionals' and patients' beliefs about patient involvement. Therefore, the need for modification of these negative perceptions has been pointed out in the study. Finally, the issues of a time-poor environment in practice were also identified and need to be improved.

In addition, the significance of family involvement in decision making was identified in the study. The complicated structure of the patient-family relationship and implicit moral responsibility could be a key to successfully implementing shared decision making in mental healthcare. It is worth mentioning that health professionals should consider how to handle disclosure and understand the family dynamic process to improve patient involvement.

Meanwhile, training for health professionals to facilitate shared decision making is also essential to make this possible in practice. However, there are few education programmes on shared decision making available for health professionals to improve their knowledge and develop their skills. While patients indicated in the interviews that they needed more understandable knowledge delivery, health professionals admitted they have limited knowledge and skills to provide it. Therefore, the findings of this study could be used to develop medical education programmes for health professionals to improve these.

8.5 Further research

The findings of this synthesis serve as relevant evidence of what is available and what patients desire from mental healthcare, and how health professionals view patient involvement in decision making. However, the importance of family involvement is also recognised in the study. Given the limitations of this study, it would be worth strengthening the evidence through similar qualitative research reaching out to other groups, such as family caregivers.

Furthermore, the study suggested three improvement mechanisms to overcome patient passivity and barriers to shared decision making. However, these potential improvements and levels of involvement were only expressed in qualitative evidence in this synthesis. Further studies may need more objective and quantitative measurements of the effectiveness of these improvements, such as randomised controlled trials, to justify these suggestions.

Meanwhile, the effectiveness of these shared decision making interventions still remains unclear in a wide range of health settings (Légaré et al., 2018). In order to embed shared decision making into routine practice in mental healthcare, it may be important to establish an understanding of the effectiveness of these interventions through a future study. Also, as there is a lack of intervention studies in Taiwan, it may be difficult to determine which of these interventions will work in the different cultural context, or how.

8.6 Conclusion

The study aimed to explore the decision-making process in secondary mental healthcare in Taiwan from the perspective of patients and health professionals. It consists of three studies: 1) a systematic review of qualitative studies of patients' perspectives of shared decision making in secondary mental healthcare; 2) qualitative interviews with patients in secondary mental healthcare in Taiwan; 3) qualitative interviews with health professionals in secondary mental healthcare in Taiwan.

The exploration resulted in the identification of patient passivity and health professional dominance, and other barriers to and facilitators of shared decision making. Despite the limitations of this study, it would be valuable to consider the findings to facilitate evidence-based implementation of shared decision making.

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Appendix 1: Extraction sheet for qualitative systematic review

To be extracted: information refers to perspectives of shared decision making from health users

Part A: Demographic information

General information

Title:

Year:

Name of authors:

Nation of data collection:

Aim:

Methodology

Study design:

Theoretical framework for the study

Data collection

Data analysis

Participant selection

Target population:

Number of participants:

Setting/context:

Sampling:

Recruitment method:

Inclusion criteria/Exclusion criteria:

Characteristics of study population

Gender:

Age:

Diagnosis:

Part B: Consolidated criteria for reporting qualitative studies (COREQ) Checklist

Domain 1 Research team and reflexivity			
	Characteristics		Comments
1.	Interviewer/facilitator Which author/s conducted the interview or focus group?	☐Yes ☐No	
2.	Credentials What were the author's credentials? E.g. PhD, MD	☐Yes ☐No	
3.	Occupation What was their occupation at the time of the study?	☐Yes ☐No	
4.	Gender Was the author male or female?	☐Yes ☐No	
5.	Experience and training What experience or training did the author have?	☐Yes ☐No	
	Relationship with participants		
6.	Relationship established Was a relationship established prior to study commencement?	☐Yes ☐No	
7.	Participant knowledge of the interviewer What did the participants know about the author? e.g. personal goals, reasons for doing the research	☐Yes ☐No	
8.	Interviewer characteristics What characteristics were reported about the interviewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	☐Yes ☐No	
Domain 2: study design			
	Theoretical framework		
9.	Methodological orientation and Theory What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	☐Yes ☐No	
	Participant selection		
10.	Sampling How were participants selected? e.g. purposive, convenience, consecutive, snowball	☐Yes ☐No	
11.	Method of approach How were participants approached? e.g. face-to-face, telephone, mail, email	☐Yes ☐No	
12.	Sample size How many participants were in the study?	☐Yes ☐No	
13.	Non-participation How many people refused to participate or dropped out? Reasons?	☐Yes ☐No	
	Setting		
14.	Setting of data collection Where was the data collected? e.g. home, clinic, workplace	☐Yes ☐No	
15.	Presence of non-participants Was anyone else present besides the participants and researchers?	☐Yes ☐No	

16.	Description of sample What are the important characteristics of the sample? e.g. demographic data, date	☐Yes ☐No	
	Data collection		
17.	Interview guide Were questions, prompts, guides provided by the authors? Was it pilot tested?	☐Yes ☐No	
18.	Repeat interviews Were repeat interviews carried out? If yes, how many?	☐Yes ☐No	
19.	Audio/visual recording Did the research use audio or visual recording to collect the data?	☐Yes ☐No	
20.	Field notes Were field notes made during and/or after the interview or focus group?	☐Yes ☐No	
21.	Duration What was the duration of the interviews or focus group?	☐Yes ☐No	
22.	Data saturation Was data saturation discussed?	☐Yes ☐No	
23.	Transcripts returned Were transcripts returned to participants for comment and/or correction?	☐Yes ☐No	
Domain 3: analysis and findings			
	Data analysis		
24.	Number of data coders How many data coders coded the data?	☐Yes ☐No	
25.	Description of the coding tree Did authors provide a description of the coding tree?	☐Yes ☐No	
26.	Derivation of themes Were themes identified in advance or derived from the data?	☐Yes ☐No	
27.	Software What software, if applicable, was used to manage the data?	☐Yes ☐No	
28.	Participant checking Did participants provide feedback on the findings?	☐Yes ☐No	
	Reporting		
29.	Quotations presented Were participant quotations presented to illustrate the themes / findings? Was each quotation identified? e.g. participant number	☐Yes ☐No	
30.	Data and findings consistent Was there consistency between the data presented and the findings?	☐Yes ☐No	
31.	Clarity of major themes Were major themes clearly presented in the findings?	☐Yes ☐No	
32.	Clarity of minor themes Is there a description of diverse cases or discussion of minor themes?	☐Yes ☐No	

Part C: Finding from the paper

Appendix 2: Topic guide for patients

Detailed interview topic guide

Health services user perspectives of decision making in secondary mental health services in Taiwan

Introduction:

Go through the information sheet to introduce the details of the study, including purpose, method, process of the study, confidentiality, and the right to withdraw from the study at any time during the interview without giving any reason and up until the data is anonymised and analysed (approximately one month after the interview).

Ensure informed written consent is obtained.

Even if they refuse the use of direct quotes in any report or decline to receive the summary of findings of this study, they still can take part in this study.

The role of the author

Background information

Warm-up question

Could you please tell me your name?

Could you please tell me what shared decision making means to you?

Experience of the process of decision making

Can you tell me about your experience of how decisions are made in mental healthcare?

Prompts:

You take medication everyday could you please tell me how and who made this decision?

Could you please describe how you decide to move in the halfway house?

What exactly happened when decisions were being made about your treatment or care?

What was it like for you?

How did you feel about this? Why?

Do you receive the information you needed during decision making?

What was this?

How did you receive this?

Was anything missing?

How satisfied were you with the health professional during this process?

Probe (attitudes, behaviours and outcomes)

Preference

What level of involvement do service users want in decisions about their treatment and care?

Prompts:

When decisions arise in relation to your medication or your care plan, would you like to be involved in these decisions? Why?

What are potential benefits? What are the potential difficulties?

Are there any decisions you would not want to be involved in? (Probe specific examples)

Barriers to and facilitators of shared decision making

What barriers are there to involving patients in decision making in mental healthcare? (probe individual and cultural barriers)

What would help you be involved in decision making?

Prompts:

What are the challenges you encounter when faced with making decisions about your mental healthcare?

What specific things might help you be involved in decision making in mental healthcare?

How do you think you might influence the process of making decisions?

What role do mental health professionals currently have in decision making about treatment or care?

Any support? What kind of support?

What are mental health professionals/providers' attitudes towards involving patients in decision making in mental health care? Do you think this could have an impact on how involved patients are in the decision making process?

Is there anything else you think of which may be helpful or challenging when decision are made in relation to your treatment or care?

Is there anything you would like to add or share with me about your perspectives?

Additional probes will be used during interviews to encourage participants to explore, such as:

Can you say something more about….

Then what happened?

Do you have further examples of this?

Can you give me more detailed descriptions of what happened?

You said… What do you mean by that?

Conclusion

Is there anything you would like to add?

Thank you very much for participating.

Appendix 3: Topic guide for health professionals
Detailed interview topic guide

Mental health professionals' perspectives of decision making in secondary mental health services in Taiwan

Introduction:

Go through the information sheet to introduce the details of the study, including purpose, method, process, confidentiality, and the right to withdraw from the study at any time during the interview without giving any reason and up until the data is anonymised and analysed (approximately one month after the interview).

Ensuring written informed consent is obtained.

Even if they refuse the use of direct quotes in any report or decline to receive the summary of findings of this study, they still can take part in this study.

Clarify the role of the author

Background information

Warm-up question

Could you please tell me about your role in secondary mental health services?

Attitude toward shared decision making

How do you feel about shared decision making in mental healthcare?

Prompts:

Do you have any experience of involving patients with mental illnesses in decision making? What happened? How do you feel about this?

When do you think it is acceptable to involve patients with mental illness in decision making on their treatment or care? Why?

Has involving patients in decision making been a negative or positive experience? Why?

Should patients and their carers be involved in making decisions on their treatment and care? Why/why not?

Advantages/disadvantages

Supports for professionals

What support would professionals need to undertake shared decision making successfully within mental health services?

Prompts:

What knowledge would you need to enable you to involve patients with mental illness in decision making?

What resources might be helpful during shared decision making in mental healthcare?

What kind of training might be helpful for staff to improve patient involvement in the decision making process?

Barriers to and facilitators of implementing shared decision making

Prompts:

What makes it most difficult for you to involve patients in making decisions about their treatment and care? Any there any other difficulties? (Probe individual and cultural factors).

What is your role in the decision making process? How do you think you might influence the process of making decisions? Why?

How does patient attitudes/behaviours influence your willingness and ability to involve them in decision making about their care/treatment?

What factors may have a negative effect on shared decision making in mental healthcare?

What factors may have a positive effect on shared decision making in mental healthcare?

Is there anything that could make it better or worse? Could you give examples?

Is there anything you would like to add or share with me about your perspectives?

Additional probes will be used during interviews to encourage participants to explore, such as:

Can you say something more about…

Then what happened?

Do you have further examples of this?

Can you give me more detailed descriptions of what happened?

You said… What do you mean by that?

Conclusion

Is there anything you would like to add?

Thank you very much for participating.

Appendix 4: Background of mental health patients

The University of Manchester

Background of mental health service users

Date:

Reference number:

Date of birth: ________________

Gender:

☐ Male ☐ Female

Psychiatric diagnosis: ________________

Onset age of mental illness: ______ years old

Duration of stay in the mental health service: _______ month(s) _______ year(s)

Appendix 5: Background of mental health professionals

MANCHESTER
1824
The University of Manchester

Background of mental health professionals

Date:

Reference number:

Date of birth: _________________

Gender:

☐ Male ☐ Female

Occupation

☐ Psychiatrists ☐Mental health nurses ☐Nurse practitioners

☐Clinical Psychologists ☐Occupational Therapists

☐Case Managers ☐Social Workers

What type of mental health service you work at: ________________

Duration of working in mental health service: _______ month(s) _______ year(s)

Appendix 6: Initial themes

1. Patient Interviews

Passive role for patient

Main themes	Sub-themes
Professionals decide/Family decides (power imbalance)	Decision about treatment and care Decision about daily life
Lack of information	Professional knowledge about treatment Sense of patient involvement

Barriers to patient involvement

Main themes	Sub-themes
Power of professional/Consequence of resisting professionals or families/Fear of being hospitalised	Staying in hospital for a long time Changing of medication treatment Involuntary treatment Relapsing Negative experience of making own decision
Social role of being patients in Taiwanese culture	Well behaviour Family pressure
Mental illness/doubtful ability to make right decisions	Psychiatric symptoms Loss control Not able to make right decision
A lack of communication between professionals and patients	Limited time resources No privacy

Patient desires different level of patient involvement

Main themes	Sub-themes
More information	Treatment and care Side effects of medication
More treatment options	Medication options Other treatment options
More discussion	Patient preference Professional recommendation Reasons for suggesting the treatment option Further plans
Make own decision	make own decision based on own preference

2. **Professional Interviews**

Passive motivation to implement shared decision making

Main themes	Sub-themes
Concern about impaired decisional ability	Serious mental illness Psychiatric symptoms Medication adherence Lack of insight Impaired cognitive function Lack of professional knowledge
Taiwanese submissive culture	Lack of motivation for involvement Powerful role of professional/discomfort of power exchange Family's negative attitude to patient involvement
A lack of information about shared decision making	Never heard about shared decision making Heard about shared decision making but does not fully understand all aspects of shared decision making No relevant learning resource
Mental health system problems	Staff shortage Limited time resources

Lack of patient involvement in mental healthcare

Main themes	Sub-themes
Decided by others	Professional decides treatment Family decides daily life
Limited information	No information Wrong information
Limited options	No options Accepted options

Moral sense of patient involvement

Main themes	Sub-themes
Basic human right	Respect to patient Well informed Autonomy
Uncertainty of treatment	Risk of treatment There is no 100% right answer
Empathy	Role play (if I were a patient)

Benefit to shared decision making/active patient involvement

Main themes	Sub-themes
Mutual understanding	Patient preference Patient condition

	Professional recommendation
The therapeutic alliance	collaborative relationship between patient and professionals taking Responsibility Setting recovery goal together
Motivation	Engagement in treatment

Appendix 7: Ethical approval from the University of Manchester

Research Governance, Ethics and Integrity
2nd Floor Christie Building
The University of Manchester
Oxford Road
Manchester
M13 9PL
Tel: 0161 275 2206/2674
Email: research.ethics@manchester.ac.uk

Ref 2017-2009-3358
26/06/2017

Dear Ms Chia-Yi Lin, , Prof Karina Lovell, Dr Louise Renwick

Study Title: The decision-making process in secondary mental healthcare in Taiwan

University Research Ethics Committee 3

I write to thank you for submitting the final version of your documents for your project to the Committee on 21/06/2017 20:49. I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form and supporting documentation as submitted and approved by the Committee.

Please see below for a table of the title, version numbers and dates of all the final approved documents for your project:

Document Type	File Name	Date	Version
Advertisement	Appendix 13 contact form	27/04/2017	1.1
Distress Protocol/Debrief Sheet	01062017-V2-distress policy	01/06/2017	2
Lone Worker Policy/Procedure	01062017-V2-Appendix 25-lone worker assessment	01/06/2017	2
Lone Worker Policy/Procedure	01062017-lone worker	01/06/2017	2
Additional docs	01062017-V2-Appendix 25-lone worker assessment	01/06/2017	2
Questionnaire	Appendix 7&8 Background questionnaire-	01/06/2017	1
Additional docs	The letter from the committee	01/06/2017	1
Topic Guide	08062017-Appendix 1&2-topic guide	08/06/2017	2
Additional docs	12062017-V2-Social media recruitment text	12/06/2017	2
Additional docs	a letter from a gatekeeper	12/06/2017	1
Additional docs	12062017-V2-response letter	12/06/2017	2
Advertisement	21062017-V3-Appendix 9-12 letter and advert	21/06/2017	3
Participant Information Sheet	21062017-V4-Appendix 3&4 information sheet-2	21/06/2017	4
Consent Form	21062017-V4-Appendix 5&6 consent forms-2	21/06/2017	4
Additional docs	21062017-Traditional Chinese version (Appendix 14-24)	21/06/2017	3
Additional docs	21062017-response letter-Chiayi, Lin	21/06/2017	1

This approval is effective for a period of five years however please note that it is only valid for the specifications of the research project as outlined in the approved documentation set. If the project continues beyond the 5 year period or if you wish to propose any changes to the methodology or any other specifics within the project, an application to seek an amendment must be submitted for review. Failure to do so could invalidate the insurance and constitute research misconduct.

You are reminded that, in accordance with University policy, any data carrying personal identifiers must be encrypted when not held on a secure university computer or kept securely as a hard copy in a location which is accessible only to those involved with the research.

Reporting Requirements:

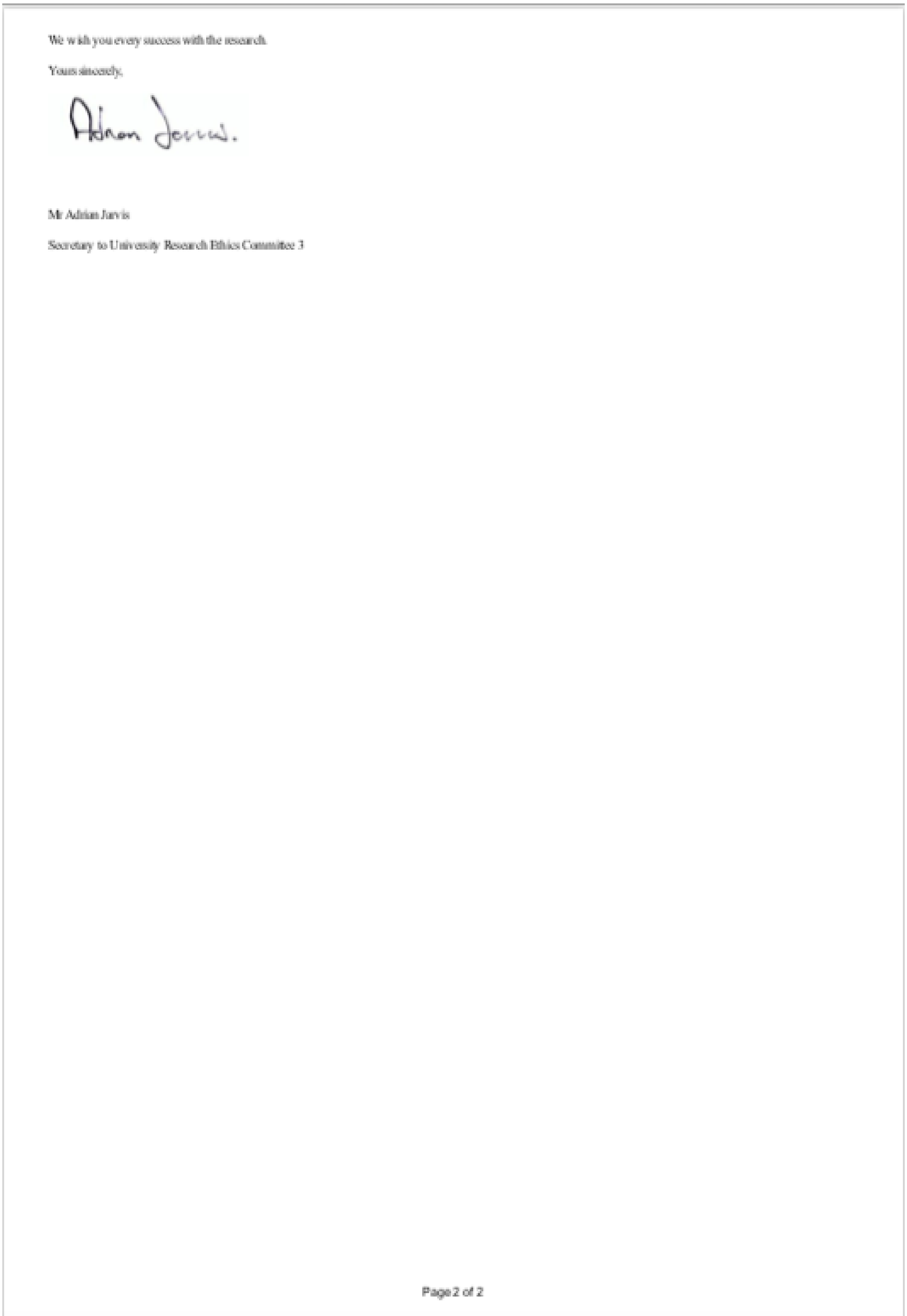
You are required to report to us the following:

1. Amendments
2. Breaches and adverse events
3. Notification of progress/end of the study

Feedback

It is our aim to provide a timely and efficient service that ensures transparent, professional and proportionate ethical review of research with consistent outcomes, which is supported by clear, accessible guidance and training for applicants and committees. In order to assist us with our aim, we would be grateful if you would give your view of the service that you have received from us by completing a **UREC Feedback Form**. Instructions for completing this can be found in your approval email.

Page 1 of 2



We wish you every success with the research.

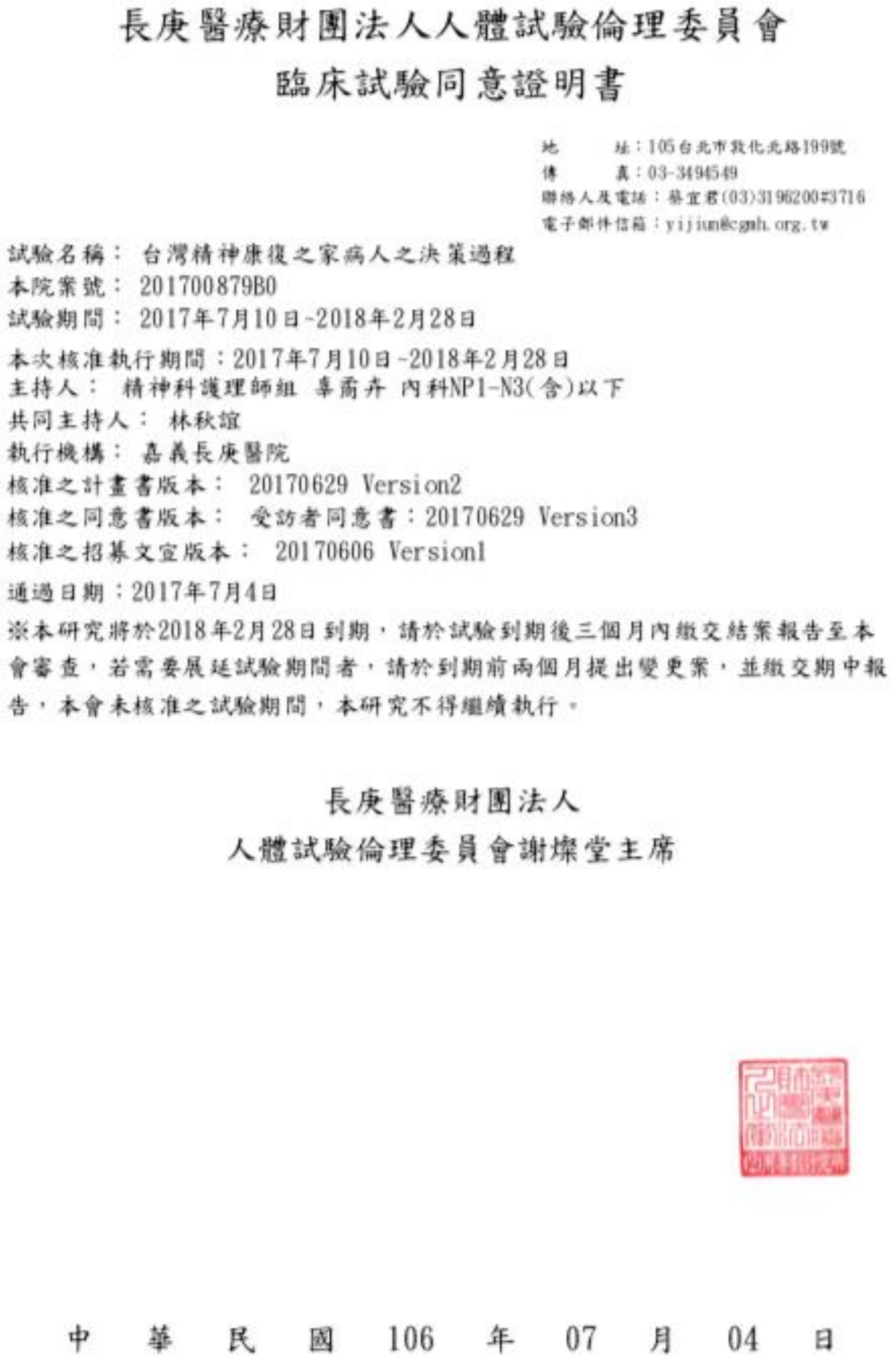
Yours sincerely,

Adrian Jarvis.

Mr Adrian Jarvis

Secretary to University Research Ethics Committee 3

Appendix 8: Ethical approval from the local committee in Taiwan



長庚醫療財團法人人體試驗倫理委員會
臨床試驗同意證明書

地　　址：105台北市敦化北路199號
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聯絡人及電話：蔡宜君(03)3196200#3716
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試驗名稱：台灣精神康復之家病人之決策過程
本院案號：201700879B0
試驗期間：2017年7月10日-2018年2月28日

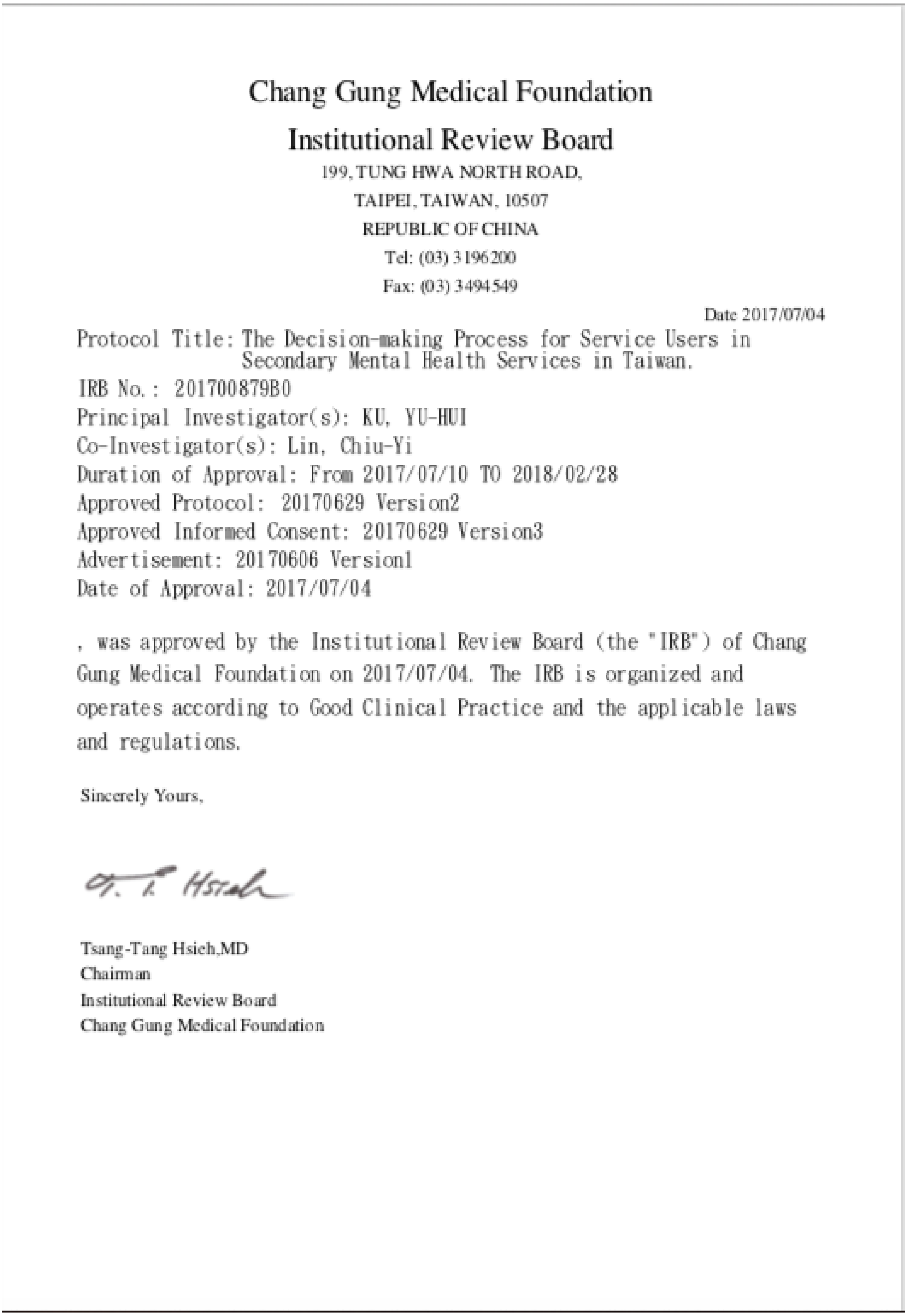
本次核准執行期間：2017年7月10日-2018年2月28日
主持人：精神科護理師組 辜喬卉 內科NP1-N3(含)以下
共同主持人：林秋誼
執行機構：嘉義長庚醫院
核准之計畫書版本：20170629 Version2
核准之同意書版本：受訪者同意書：20170629 Version3
核准之招募文宣版本：20170606 Version1

通過日期：2017年7月4日

※本研究將於2018年2月28日到期，請於試驗到期後三個月內繳交結案報告至本會審查，若需要展延試驗期間者，請於到期前兩個月提出變更案，並繳交期中報告，本會未核准之試驗期間，本研究不得繼續執行。

長庚醫療財團法人
人體試驗倫理委員會謝燦堂主席

中　華　民　國　106　年　07　月　04　日



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Institutional Review Board
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Date 2017/07/04

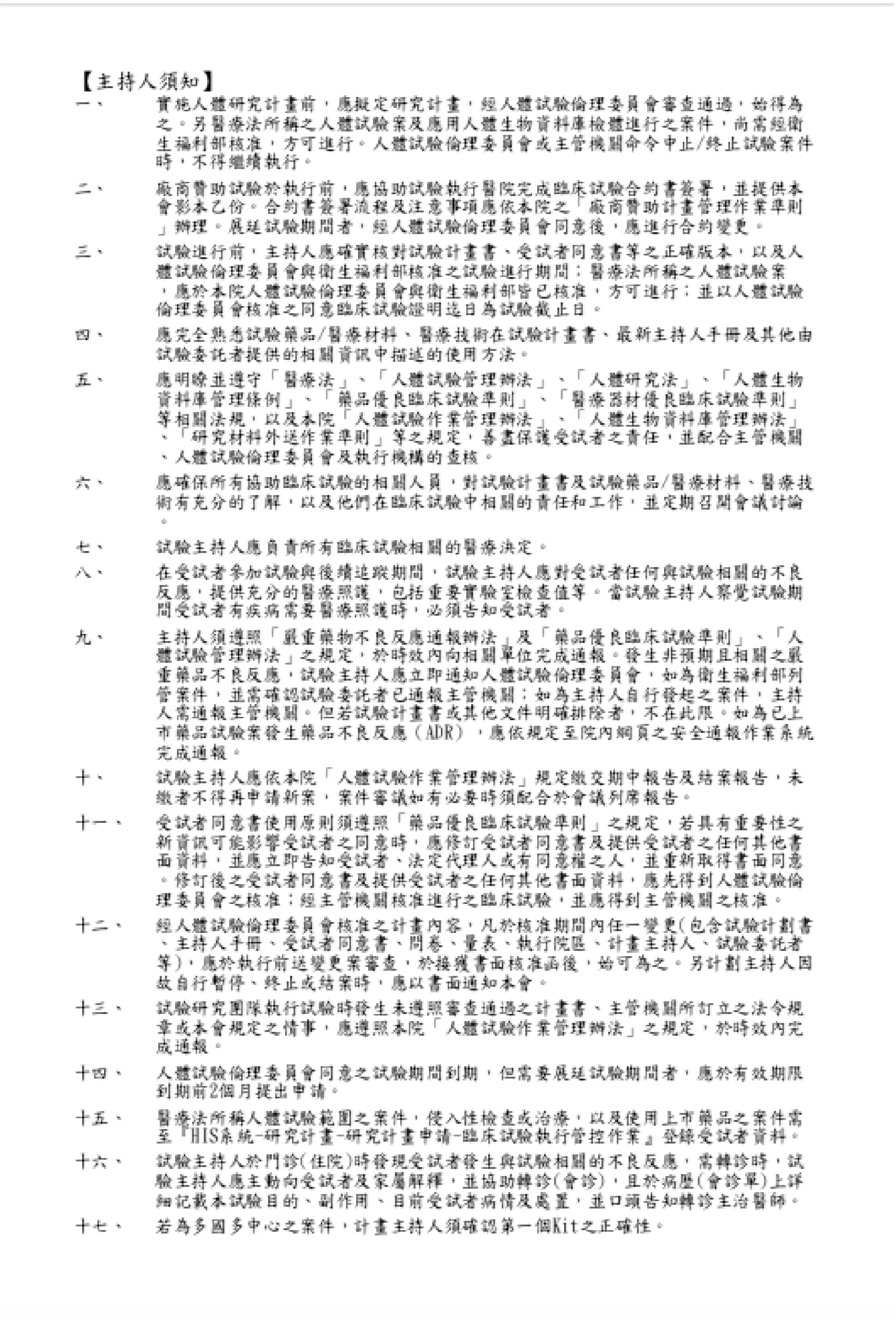
Protocol Title: The Decision-making Process for Service Users in Secondary Mental Health Services in Taiwan.
IRB No.: 201700879B0
Principal Investigator(s): KU, YU-HUI
Co-Investigator(s): Lin, Chiu-Yi
Duration of Approval: From 2017/07/10 TO 2018/02/28
Approved Protocol: 20170629 Version2
Approved Informed Consent: 20170629 Version3
Advertisement: 20170606 Version1
Date of Approval: 2017/07/04

, was approved by the Institutional Review Board (the "IRB") of Chang Gung Medical Foundation on 2017/07/04. The IRB is organized and operates according to Good Clinical Practice and the applicable laws and regulations.

Sincerely Yours,

T. T. Hsieh

Tsang-Tang Hsieh,MD
Chairman
Institutional Review Board
Chang Gung Medical Foundation



【主持人須知】

一、 實施人體研究計畫前，應擬定研究計畫，經人體試驗倫理委員會審查通過，始得為之。另醫療法所稱之人體試驗案及應用人體生物資料庫檢體進行之案件，尚需經衛生福利部核准，方可進行。人體試驗倫理委員會或主管機關命令中止/終止試驗案件時，不得繼續執行。

二、 廠商贊助試驗於執行前，應協助試驗執行醫院完成臨床試驗合約書簽署，並提供本會影本乙份。合約書簽署流程及注意事項應依本院之「廠商贊助計畫管理作業準則」辦理。展延試驗期間者，經人體試驗倫理委員會同意後，應進行合約變更。

三、 試驗進行前，主持人應確實核對試驗計畫書、受試者同意書等之正確版本，以及人體試驗倫理委員會與衛生福利部核准之試驗進行期間；醫療法所稱之人體試驗案，應於本院人體試驗倫理委員會與衛生福利部皆已核准，方可進行；並以人體試驗倫理委員會核准之同意臨床試驗證明迄日為試驗截止日。

四、 應完全熟悉試驗藥品/醫療材料、醫療技術在試驗計畫書、最新主持人手冊及其他由試驗委託者提供的相關資訊中描述的使用方法。

五、 應明瞭並遵守「醫療法」、「人體試驗管理辦法」、「人體研究法」、「人體生物資料庫管理條例」、「藥品優良臨床試驗準則」、「醫療器材優良臨床試驗準則」等相關法規，以及本院「人體試驗作業管理辦法」、「人體生物資料庫管理辦法」、「研究材料外送作業準則」等之規定，善盡保護受試者之責任，並配合主管機關、人體試驗倫理委員會及執行機構的查核。

六、 應確保所有協助臨床試驗的相關人員，對試驗計畫書及試驗藥品/醫療材料、醫療技術有充分的了解，以及他們在臨床試驗中相關的責任和工作，並定期召開會議討論。

七、 試驗主持人應負責所有臨床試驗相關的醫療決定。

八、 在受試者參加試驗與後續追蹤期間，試驗主持人應對受試者任何與試驗相關的不良反應，提供充分的醫療照護，包括重要實驗室檢查值等。當試驗主持人察覺試驗期間受試者有疾病需要醫療照護時，必須告知受試者。

九、 主持人須遵照「嚴重藥物不良反應通報辦法」及「藥品優良臨床試驗準則」、「人體試驗管理辦法」之規定，於時效內向相關單位完成通報。發生非預期且相關之嚴重藥品不良反應，試驗主持人應立即通知人體試驗倫理委員會，如為衛生福利部列管案件，並需確認試驗委託者已通報主管機關；如為主持人自行發起之案件，主持人需通報主管機關。但若試驗計畫書或其他文件明確排除者，不在此限。如為已上市藥品試驗案發生藥品不良反應（ADR），應依規定至院內網頁之安全通報作業系統完成通報。

十、 試驗主持人應依本院「人體試驗作業管理辦法」規定繳交期中報告及結案報告，未繳者不得再申請新案，案件審議如有必要時須配合於會議列席報告。

十一、 受試者同意書使用原則須遵照「藥品優良臨床試驗準則」之規定，若具有重要性之新資訊可能影響受試者之同意時，應修訂受試者同意書及提供受試者之任何其他書面資料，並應立即告知受試者、法定代理人或有同意權之人，並重新取得書面同意。修訂後之受試者同意書及提供受試者之任何其他書面資料，應先得到人體試驗倫理委員會之核准；經主管機關核准進行之臨床試驗，並應得到主管機關之核准。

十二、 經人體試驗倫理委員會核准之計畫內容，凡於核准期間內任一變更(包含試驗計劃書、主持人手冊、受試者同意書、問卷、量表、執行院區、計畫主持人、試驗委託者等)，應於執行前送變更案審查，於接獲書面核准函後，始可為之。另計劃主持人因故自行暫停、終止或結案時，應以書面通知本會。

十三、 試驗研究團隊執行試驗時發生未遵照審查通過之計畫書、主管機關所訂立之法令規章或本會規定之情事，應遵照本院「人體試驗作業管理辦法」之規定，於時效內完成通報。

十四、 人體試驗倫理委員會同意之試驗期間到期，但需要展延試驗期間者，應於有效期限到期前2個月提出申請。

十五、 醫療法所稱人體試驗範圍之案件，侵入性檢查或治療，以及使用上市藥品之案件需至『HIS系統-研究計畫-研究計畫申請-臨床試驗執行管控作業』登錄受試者資料。

十六、 試驗主持人於門診(住院)時發現受試者發生與試驗相關的不良反應，需轉診時，試驗主持人應主動向受試者及家屬解釋，並協助轉診(會診)，且於病歷(會診單)上詳細記載本試驗目的、副作用、目前受試者病情及處置，並口頭告知轉診主治醫師。

十七、 若為多國多中心之案件，計畫主持人須確認第一個Kit之正確性。

十八、 應遵照「人體試驗管理辦法」、「醫療機構及醫事人員發布醫學新知或研究報告倫理守則」及本院「研究成果發表於報章媒體作業準則」規定，醫療法所稱人體試驗之研究成果須經衛生福利部審核通過後，試驗主持人始得發表。

十九、 因試驗計畫主持人過失造成醫院或他人受損害時，須由計畫主持人負法律責任。

二十、 免除受試者同意後仍會適時提供受試者試驗相關訊息。

二十一、 當受試者在納入研究後成為受刑人，主持人得知後應以非預期問題通報本會及試驗委託者。

二十二、 其餘未盡事宜，請參照本院「人體試驗作業管理辦法」辦理。

CHANG GUNG MEDICAL FOUNDATION

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Institutional Review Board A

2017 January - 2017 June

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黃英霓 Ying-Ni Huang	Female 女性	Law 法律	None 無
鄭欽明 Kenny Cheng	Male 男性	Business Management 企業管理	Children's Hearing Foundation 雅文兒童聽語文教基金會
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Chairman：T. T. Hsieh

Tsang-Tang Hsieh, M.D.

Appendix 9: Consent form (patient version)

MANCHESTER
1824
The University of Manchester

Consent Form (service user version)

(Date: June 2017, Version: 4)

Study Title: The Decision making Process for Service users in Secondary Mental Health Services in Taiwan.

Name of Researcher: Chiu-Yi, Lin		Please initial all boxes
1	I confirm that I have read the attached information sheet dated June, 2017 (version 4) on the above project and have had the opportunity to consider the information and ask questions, and had these answered satisfactorily.	☐
2	I understand that my participation in the study is voluntary and that I am free to withdraw at any time during the interview and up until the data is anonymised and analysed (approximately one month after the interview) without giving any reason and without my medical care or legal rights being affected and this will be made clear in study documentation.	☐
3	I understand that data collected during the study may be looked at by individuals from the University of Manchester, from regulatory authorities or from the Chang-Gung Medical Foundation Institutional Review Board in Taiwan, where it is relevant to my taking part in this research. I agree to these individuals having access to this information.	☐
4	I agree to the use of digital recording	☐
5	I agree to the possible use of anonymised quotations.	☐
6	I agree to take part in the above study.	☐
7	I would like to be informed of the findings of this research and agree to my name and email / address being added to a mailing list that will be used solely for the purposes of disseminating the findings of this research.	☐

Name of participant:…………………… Name of researcher:……………………

Date:…………………………………… Date:…………………………………….

Signature: ……………………………... Signature: ………………………………

Appendix 10: Consent form (health professional version)

MANCHESTER
1824
The University of Manchester

Consent Form (health professional version)

<u>(Date: June 2017, Version: 4)</u>

Study Title: The Decision making Process for Service users in Secondary Mental Health Services in Taiwan.

Name of Researcher: Chiu-Yi, Lin		Please initial all boxes
1	I confirm that I have read the attached information dated June, 2017 (version 4) on the above project and have had the opportunity to consider the information and ask questions, and had these answered satisfactorily.	☐
2	I understand that my participation in the study is voluntary and that I am free to withdraw at any time during the interview without giving any reason and up until the data is anonymised and analysed (approximately one month after the interview) without giving a reason and without my professional career or legal rights being affected and this will be made clear in study documentation.	☐
3	I understand that data collected during the study may be looked at by individuals from the University of Manchester, from regulatory authorities or from the Chang-Gung Medical Foundation Institutional Review Board in Taiwan, where it is relevant to my taking part in this research. I agree to these individuals having access to this information.	☐
4	I agree to the use of digital recording, with possible use of anonymised quotations.	☐
5	I agree to the possible use of anonymised quotations.	☐
6	I agree to take part in the above study.	☐
7	I would like to be informed of the findings of this research and agree to my name and email / address being added to a mailing list that will be used solely for the purposes of disseminating the findings of this research.	☐

Name of participant:…………………… Name of researcher:……………………

Date:…………………………………… Date:…………………………………….

Signature: ……………………………... Signature: ………………………………

Appendix 11: Distress policy

If this happened, there were steps to manage distress:

The author would ask whether she/he needs to stop the interview immediately or needs a short break.

If service users had any questions, the author would address them immediately. The author would provide some support to the participants and reiterate that they have the right to refuse to answer some question if they did not want to.

The author would ask them if they were willing to continue the interview and assess whether the participant was still able to continue the interview based on the author's professional knowledge (the author is a mental health nurse who is trained and experienced at identifying and managing distress).

If not, the interview would stop immediately, and there were sources of support which would be provided (see 6-9 below). The author would ask the participants if they would like their data to be removed from the study.

If the participant continued the interview, there were some further steps that would be followed during and after the interview:

During the interviews

The author would continue to observe the participants' non-verbal and verbal cues.

Participants would be asked to share their experiences, as far as they were comfortable with doing so.

At the end of the interview, the participants would be given time to express their emotions about the interview and reflect on the experience of being part of this project.

Some support resources would be provided:

For the service user group, relevant support resources would be provided to participants, such as the consultant's phone number or/and appointments with their GPs or mental healthcare providers:

For the health professional group, the authors would provide the consultant's phone number and ask participants to contact their close family or friends for continued emotional support.

Contact details for the author were provided to each participant in both groups.

After the interview

The author would inform mental healthcare providers or GPs if necessary (including suicide or risk of harm to themselves or others).

If they were concerned about the information they have provided, participants could contact the author to withdraw at any time during the interview and up until the data was anonymised and analysed (approximately one month after the interview), and their data would be destroyed upon request.

Appendix 12: Example of thematic frameworks for the patient interviews (Theme 1)

Theme 1: Barriers to shared decision making			
Themes	**Professional status of health professionals in a submissive culture**	**Negative perception of making decisions**	**Limited time resources**
Number of reports	20/20	9/20	10/20
1	*I believed him. I have been seeing him (the doctor) for a long time. I have never changed my doctor.* *I don't know about medicine… don't understand. I just do what they say and take what they give me*	N/A	N/A
2	*He said he is able to cure my auditory hallucinations… only if I follow the instructions… It is not really bad for me… I don't know how other people feel about this… but it is fine for me.* *Anyway… he told me not to ask too many questions… I am afraid to ask… you know… like my roommate…(to be hospitalised)*	N/A	*I felt it was not great. The most important thing was the three patients' conditions. I wanted to discuss my condition with the doctor but it was very difficult.* *But… you know, he (the doctor) had to see more than one hundred patients in one day. He did not have much time for me.*
3	*I do believe psychiatrists are professional. We should respect to them… This is why our behaviour should be controlled by professionals.* *Sometimes I don't really want to take medication. But they (health professionals) said if don't want to take medications, just go to hospital. I don't think I need it but I still take it.*	*I think any patient with mental illness is not able to make their own decisions. Some of them may lose control and then kill someone. For example, XXX, he lost control and killed someone. Can someone like me make their own decisions?*	*We didn't really discuss it directly… He didn't come. But my nurse told him… He replied and the nurse told me what he said. He said: "Take it or leave it".*
4	*There is no reason why… they should… They (professionals) are born to decide. They are professional. Yeah… that's why I should obey them.*	*For example, they aren't willing for me to take my baby along. This is a clear rule. I don't think I need to stay in the halfway house. I am able to find a job and live on my own. Why do I need to stay here? They think I am ill; that I am not able to take care of*	*I don't know. Every appointment with him (the health professional) finished very quickly. Because there is always another patient who is waiting. He needed to see a lot of patients in one day. So we did not talk too long. I hope we could talk for longer. You know.*

		myself or my baby and decide. So they decide everything for me.	
5	*It's just like seeing a doctor for a cold. I go to see a doctor for a cold and a doctor asks me my symptoms. And then does some examinations. And then you get some medication. It is a standard procedure. Like me. I told him (a doctor): 'I have cough, a runny nose, sore throat, and headache.' And then the doctor gave me some medication to take. And then I took them… That's what happened to me. Never have I ever questioned this before. That's what I was told when I was a kid. I got used to this procedure. I think this is it. This is how the health system works.*		*If some professionals are able to give me some information, that will be great. How to use the medication and what side effects I might notice. I want to know… but, probably, the doctors don't have much time. Like me, I am going to see my doctor tomorrow. I am number 130. I bet the doctor won't have time for me.*
6	*I have not discussed it with him (the health professional) yet. But…I was trying to discuss it with him before, he was just staring at me. He looked not happy about it. So… I am not sure I should say something about it.* *Because you say more and you take more medication or you get sent to hospital. You ask more questions and this is what happens next.*	*I went to XXX hospital. I wanted to ask some questions about my conditions. But they (health professionals) told me this is a psychiatric hospital. I am a person with mental illness. I had a headache and auditory hallucination. Someone was taking to me. And then I was admitted. 32 years old. I wonder if anyone still wants to discuss anything with me.*	*I would love to know (the treatment options) but the doctor won't tell us this. They are too busy. My doctor needs to see at least 38 patients a day. Don't have time to discuss with every patient for this.*
7	*The right of making decisions belongs to them (health professionals). The only thing we should do is to tell them your condition.* *Because… because… this belongs… this is same as (being a) 'prisoner'…because they are locked up as well. We have to accept assessment. This is all decided by health professionals… same with prisoners. Many prisoners are locked up as a big group. I certainly felt uncomfortable. But what can I do about it?*	*Yeah… if I don't take medication, I get out of control. Because… I have mental illness, I lose control. I couldn't make my own decisions. How can I make my own decisions? You must take medication. That's it. Because you are hospitalised… you lose control. You are not able to make decisions.*	N/A
8	*They are doctors. Doctors are qualified to control your treatment and care. Doctors are able to prescribe your*	N/A	*I feel it was very quick (the appointment). It is not allowed to prolong the time. If you delay… all patients are delayed.*

	medication. No one else can. They control… that's (making decisions) their responsibility. *They are authority. You just a patient. This is the rule you must follow the instructions.* *If you are well-behaved, you can go outside and you can be discharged from here soon. Just follow the instructions. This is good for you.* *This is why I don't want to take medication but I still do. XXX hospital you know. Yeah, here (the halfway house) is more open. But the hospital is locked. Living here has more freedom but if you had been sent to the hospital…you know it is different….just follow the instructions and listen to them (health professionals).*		
9	*Yes, this is a doctor's duty. He (the doctor) sent me to the psychiatric hospital. I cannot say anything. I told him I don't want to. But it is their job to decide.* *If you don't listen to the nurses, they tie you up. Even if you improve your behaviour, they still tie you up. They must tie you up for an hour. Some (nurses) even give you an injection. Even if you are yelling in the room, they won't listen to you. Like this. You must do what they (nurses) ask you to do.* *I told them: I don't want to take this medication… But the staff told me I must take it… or they will take me to be hospitalised. So… so… I took it… and after this, I told my doctor what happened to me… You know what?… My doctor just kept silent… Like nothing had happened… He said: 'Adjust… it is just fine… to adjust*	N/A	*Doctors nowadays need to see a lot of patients in one day. Sometimes, you know, more than 100 patients. Perhaps they don't really remember who they met today.* *Three were in the same room. How could you say something sensitive to the doctor? How could you discuss anything with the doctor? How could I react to this? Three of us… say something…. The doctor gave us medication. That's all. And then I got medication. The end.*
10	*If you didn't listen to the nurses, they tied you up. Even you improved your behaviours, they still tied you up.*	*I was losing control. I don't know what disease I have. I could not sleep at night. Every day there were*	N/A

	They must tie you up for an hour. Someone (nurse) even gave you an injection. Like this. You must do what they (nurses) ask you to do.	*a lot of voices (auditory hallucination). I was sick. Not clear… There were a variety of treatments. If you are sick, this (treatment option) should be decided by doctors.*	
11	*I must respect doctors. Or why do we go to see them? They give us medication and we take it. They are professional….. What they said should be right.*		N/A
12	*They are doctors! They are doctors. We are patients. They asked: how are you lately? They ask some questions. And then they prescribe some medications for you. They are doctors. Or you think you can decide? You decide? And they follow? No way… They are professional, but you are not.* *The manager (in the halfway house) said if I don't take medications, I will be sent to the hospital. This is what they say.*	*I am ill (mental illness). How could I to make decisions? I feel great they decide for me.*	
13	*They are doctors. They are trying to help you rather than hurting you. You should believe this. This is what they do.* *There is no other way. They (health professionals) are the most powerful in the ward. There is no way to discuss with them. Just do what they ask and don't make any trouble.*	*My aunt said we are psychiatric patients. Just do what they (health professionals) say. No arguing with anyone. No choice.*	N/A
14	*This is their job (health professionals). They are helping me. They are taking care of me.*	N/A	*Four patients once in the same appointment. There were many patient waiting outside. We (the four patients) were seeing the same doctor. We took turns to talk with our doctor. Only little time for each of us.*
15	*Because he is my doctor. They can decide for me. They can fix it for me.* *The doctor told me: if you don't take medication, you will be taken to hospital. I felt really upset… really upset. And then I went to see the doctor and I said: I*	N/A	N/A

	will take the medication and cooperate with you. But you please don't give me too strong a drug. I don't want to be like a scarecrow… feeling stiff in my whole body. *As the nurse said….if I lay on the bed in my room…they (nurses) would say: 'If you lie in like that, you will not sleep at night.' In the end, they (nurses) said: 'if you still lie on your bed, we will restrain you. Or not allow you go outside and go shopping'. Can't go outside or anywhere. So I don't really like going to hospitals.*		
16	*As doctors, they have professional knowledge to make judgements. They are psychiatrists. Professional knowledge and professional staff. They went to medical school for seven years. They are experts on mental health. They definitely know how to cure patients and what to do.* *If you keep asking…that means you are not stable. I don't want to go to the hospital. This is the rule here. The only thing I can do is to accept it.*	N/A	*Sometime you waited for so long and did not want to talk a lot. I just want to leave there as soon as possible. I was no. 91.*
17	*Based on their profession (health professionals), they know what is suitable for me. They are mental health professionals. They know patients' needs. I told them my symptoms.* *(I) just follow my mum's instruction. Take medication regularly. No hallucinations. No self-taking. Or if you don't. You must to go to the hospital.*	*I just follow the health professionals' instructions. They told me I am permanently disabled because of mental illness. This means I am really serious. So I just follow what they decide and take medication.*	N/A
18	*My brother said: 'If you are taken there (the hospital)… we will lock you up for more than a year.'… No doubt… You can't say no… In the hospital, your family has to agree or you can't be discharged from the hospital. You know my friend has been locked up for a year… He is not allowed to discharge himself from the hospital. Can you imagine that? I told a nurse: 'I don't want to stay*	*I never read these prescription. Doctors read. I don't know what it says. Because it is too difficult for me. I haven't liked to read since I was a little. Life passes. My brain is not clear (because of mental illness). You know (the patient used the finger to point himself head)*	*He (the health professional) did not say much. He just typed in his computer. How can I express anything with him?*

	here'… But I got no reply… I had been locked up for one year… You know my friend… he is still locked up… Not like here (the halfway house)… you have more freedom. *One staff member was really aggressive…..he made all the patients so afraid of him…. nervous. I am not going to hospital… no way….I was terrified of him … He said: "why you are there…don't know what to do? Hurry up!" He kept saying… kept saying: "Why do you do nothing but just lay down?" Very, very aggressive. Kept swearing. If you talk back… you will be pinned to the ground and the nurses will give you a shot. They are really aggressive.*		
19	*I want to ask but I am afraid to ask. I think patients should have right to understand their conditions. Sometime you should ask. But… maybe you should not. This might cause an argument with your health professionals. This is not necessary.* *It is difficult to say no to them (health professionals). They are the boss. If they send you to hospital, you must stay there.*	N/A	N/A
20	*You can't deny their professional status… Because they are doctors. They help us, but they don't require any input from you. If you refuse to take their advice… that means you are not respectful to them. You are too difficult to please.* *If you were not well-behaved, you were "tied up"… Yeah, some doctors did this…*	N/A	N/A

Appendix 13: Example of thematic frameworks for the patient interviews (Theme 2)

Theme 2: Facilitators of shared decision making		
Themes	**Sufficient Information exchange**	**Desire to make decisions**
Number of reports	17/20	16/20
1	*Long illness makes the patient a good doctor.*	N/A
2	*To my mind, I do want the doctor explain it to me. But he didn't have enough time.* *The medications you take don't suit you. They [professionals] can't understand your symptoms very quickly. Right? If they know a lot about you… you will get better in a fortnight.*	*Actually, I just want to understand what my medication is for… I don't need to know what choices I have… For example, what treatment I take… particularly what medication is for… Effects or side-effects. That's all I want.*
3	*Based on this (active involvement), I could be cured quickly. I could understand if I am ok or not. I could explain my feelings about medication to them. They don't need to spend much time conducting experiments on me.* *…um… in fact… I would like to take part… Because I am back to normal. Of course I want to know what happened to me…. For example, I want know why I need to use each psychiatric medication.*	N/A
4	*I want to discuss with my doctors that I don't want to take medication… yeah. 'Cause I took medication for many years. I don't think I need to take this… I think I will be fine even if I don't take any medication.*	*I want to discuss with my doctors that I don't want to take medication… yeah. 'Cause I took medication for many years. I don't think I need to take this… I think I will be fine even if I don't take any medication.*
5	*If…(I can be actively involved in decision making)…. Because I can understand my symptoms and conditions. I could understand how to prevent a relapse, to understand better if my condition is worse or better.*	*I hope I have other treatment choices. I can find which one is the best for me. This is good for me… I don't want this side effect (gaining weight). I want to be skinny. It is better for my health. Look healthy. This is also good for job*

		interview you know. So I hope the doctor gives me a list of treatment options and I can make my own decision. *It is better they tell me (more about treatment options). It is better to have choices. You could find a treatment that is more perfectly suitable for you. That would be really great… After I took medication, I didn't know about its side effects. I gained weight - from 70 kg to 90 kg. I didn't know about it at the beginning. I hope I have other options.* *I also would like to hear some professional advice from the professionals. I think if you got many professional suggestions, you could compare other treatments from different angles. You could hear different solutions.*
6	*And I want to know more about the medication I take now. Because I'm having injections right now. I wonder if there is another option but the same type of the medication. I'm kind of allergic to this medication. I want them to understand my condition.* *They (the health professionals) can understand me and give me the right medication based on my condition. This would be more comfortable.*	*He (professional) never discussed it with me (treatment options). If possible, we could discuss it… and then I could decide myself. If you can decide, you feel better in your mind. This is all decided by me! No matter if it results in good or bad. I feel more comfortable about this. It wasn't decided by anyone else but me. Although I am a little slow on the draw and have a bad memory. But I believe I am able to make my own decisions.*
7	*I hope to understand the reason why I need to stay in the halfway house and why I need to take this medication. This is what I hope. I want to know. But they (health professionals) never discuss it with me.*	*I hope I can decide where I want to live and…if I am stable. The doctor can reduce the dosage of my medication.*
8	*I think I do… I do want to know about other treatment options. For example, treatment one, treatment two, and treatment three. This would be really great. I don't know why the health professionals don't implement that. I don't know how they think*	*I want to make my own decisions too.*
9		*Of course I want to (make decisions). I want to move out (the halfway house). But they say this is not allowed.*
10	*I want to ask them about my medication treatment but I am afraid of them (health professionals).*	*I don't want to make medication decisions. I don't know much about medication. Just two pills. Should be fine.*

11	*I don't know, I just took what they gave to me. I am not sure. Perhaps I want know more. I am not sure.*	N/A
12	*I think… if… medication… I want to discuss with him (the professional) whether I could adjust my medication. Now what he gave me… I can't get out my bed in the morning, I feel drowsy. I can't get out of my bed. I would like to tell him this is not right for me. I would like to change it.*	*I think… if… medication… I want to discuss with him (the professional) whether I could adjust my medication. Now what he gave me… I can't get out my bed in the morning, I feel drowsy. I can't get out of my bed. I would like to tell him this is not right for me. I would like to change it.*
13	*I never thought about this. I just took medication you know. Or I should ask them (the health professionals). Are you sure I can ask them? I should…right…. I want to ask them what this medication for. I should ask them next time.*	N/A
14	*Of course, I love to know more about my treatment. But I am not sure I can…*	*I certainly do (want to make my own decisions). But no way… The only thing I can do is live here (in the halfway house).*
15	*I want to discuss with the health professionals. I want to tell them I feel the medication is fine for me. But I feel I want to eat more food. I wonder if there is another way to strike a balance.*	*I want to decide, you know, about my medication. I want to manage my medication.*
16	*I want know what medication they gave to me. Why they chose this and why I need to adjust the medication this time.* *It is right they are professional. But some medication is not just suitable for me. Last time, I wanted them to prescribe FM2 (Flunitrazepam), but they refused. And gave me another medication. I could not sleep that night. This is not helpful at all.*	*Just information about my medication. Just let me know what medication they give me and why. What the medication is. Other things… that's fine. I don't need to decide.*
17	*I hope I will be told about other choices (about medication treatment). They will tell me the advantages and disadvantages of treatment.*	*It will be great if I have medication options. But I would love to hear some advice from my health professionals. And then I can choose the best one for myself.*

18	N/A	*Doctors… I would like to know what I can't eat or drink. I want them to tell me what medication I can take. Some information about how to take medications.*
19	*Because doctors should discuss with us to see how this medication works for us. They (doctors) prescribed medications to us. They should respect to my choices. To see if I am cured, they should observe how I react to the medication.* *I want to… I want to know the effects of the medication. In fact, I really want to ask the doctors.*	*I want to… I want to know the effects of the medication. In fact, I really want to ask the doctors.*
20	N/A	*Because I don't know what medication they are prescribing for me. I don't know if this medication is right for me. I want to ask them what medication they give to me. What the effects or side effects of this medication are. I want to know this.*

Appendix 14: Example of thematic frameworks for the health professional interviews (Theme 1)

Theme 1: Barriers to shared decision making

Themes	**Powerful status of health professionals and families**	**Patients with impaired decisional ability due to mental illness**	**Health professionals have lack of understanding of shared decision making**	**Insufficient time**
Number of reports	23/24	24/24	24/24	15/24
1	*In addition, in Taiwan, I think this is the culture… If you get sick… you go to see a doctor… and you get medicine. All they need to do is just go to see a doctor. And a doctor tells them what to do.*	*On the other hand, some patients don't accept their mental illness. They don't understand their mental illness. It would probably be difficult to involve them in the decision making process.*	*I don't know what SDM is… I have to have some knowledge first. And then I can decide if I need this kind of training or not. If this model… could bring some benefits to patients and to me, I may want to understand. But first I should know what it is.*	*For example, some professionals are really busy. They might just tell patients to take the medication they give them, without any discussion. We just decide for them.*
2	*If you (professionals) provide more decision options… no matter how you explain it… they would think you are not 100% sure about this… You tell them too much and this means you're not doing your job, you know. This could bring unnecessary trouble (medical malpractice) for yourself. Patients in Taiwan don't have this kind of thought about patient involvement in medical decisions or relevant information about this. For example, some of my friends or family, if doctors offered treatment options for them, they would probably feel odd, you know.* *Because we are in Taiwan, we (health professionals) should respect their families. They (patients) will be taken*	*Because patients don't accept their mental illness. I am afraid they can't comply with medication if they know much about their treatment. This also causes conflict between patients and their families. He/she (patient) may feel he/she doesn't have mental illness, complains about side effects and eventually refuse to take any medication.*	*As far as I know, but I have only had a look at two PPTs (Power-point slideshows). It seems that they include professionals and patients. And they discuss the case together. And then they decide together? But I am not sure.*	*I feel the big problem is we (health professionals) don't have much time to discuss with patients in this medical environment. Maybe patients also feel they don't have time to have an opportunity to ask more questions.*

	care of by their family. I think if we don't respect the families during making decision, patients will lose the support of their families. This would make their healthcare difficult. So I think I need to involve the family to make decisions for patients.			
3	*For example, I would tell them that if you get mental illness, you need to take medication. We would let them know what their medication is, but what kinds of medication they need to take is decided by you (professionals) based on the clinical guidelines.* *We have the professional knowledge to judge (treatment options). This is what doctors should do.*	*Because some cases insisted on making bad choices for themselves. So we have a responsibility to talk with them… Some have really poor judgement… you know… We discussed this (in some lectures). The lecturers didn't have any answers for that. From my perspective, those patients lose their ability to make a judgement. Their will can't be seen as will, you know? This is important. He has poor judgement. He is a seriously ill patient and out of touch with reality. You talk about sharing decision making with this kind of patient. That's strange.* *Patients with psychosis or patients without any insight into their mental illness, of course, are less involved (in decision making).* *I think it (patient involvement) is difficult for them (patients with psychosis) because they have low motivation. So they don't ask questions. And all this because they have poor cognitive function and negative symptoms. Patients with avolition or patients who don't care about their*	*"I feel shared decision making is a way to meet patient needs. Based on their wishes, I believe it is kind of application of shared decision making. You (health professionals) provide some treatment options. And then patients to decide which one it is they prefer. Of course you have to explain the pros and cons of the options. But I wonder if this is suitable for patients with mental illness. For example, today, if a patient intended to commit suicide, it would be impossible for me to agree with his/her decision. This is odd. You know, if shared decision making is implemented in mental healthcare.*	*You (health professionals) are not able to explain all the information for every patient. Because there are 118 beds in the acute wards and almost 100 patients in the day care centre.*

		disease… I think there is no way to involve patients like that. *I believe the level of insight is really important to determine if patients are able to be involved. If you don't know you have mental illness, how can you be involved?*		
4	*The role of doctors is naturally to have responsibility (to decide). We would guide him or take a dominant role. Because we know well his disease and support resources. This is an unavoidable responsibility.*	*Another example is his symptoms. Sometimes he is really depressed; often he could hesitate or wouldn't be able to decide. In this case, we (professionals) would make most of the decisions. Because you ought to be more dominant, to guide him. I suppose this is a better way.*	*So… I think I don't know much more about the shared decision making tool. Or could you explain it to me in one minute. I don't really have the relevant information. I can only imagine what this would look like.*	*For example, the hospitals expect you have good sales figures. So you are not allowed to only see 3 or 4 patients. Or just 10 patients. No quantity means no profit, which is related to your income. Some professionals are even criticised by the hospitals. Maybe some new doctors do not have many patients. They may spend 40 minutes or 1 hour seeing a patient. But this is difficult.*
5	*From my perspective of being a health professional, we should choose the best treatment for patients. Help them to get better and use some ways to help them, to let them stay (in hospitals). This is what we should do.* *During decision making, you will find that sometimes, particularly for some young adults, the right of making the decision belongs to their significant family member rather than themselves. For example, their father.*	*One of my patients, he has delusions and auditory hallucinations. In this situation, his opinion cannot be involved.* *They are not stable. We can't follow their instructions and let them discharge themselves from the hospitals, right?* *For example, patients with poor medication adherence cannot take responsibility for their decisions. This could influence how much they can be involved.* *For example, one of my patients had delusions about how Satan is coming to our world. If he died he could save all people in the world. So he refused to*	*I can't remember… It was kind of a long time ago when I heard this term (shared decision making). It might be four or five years ago. I also read some related books or articles… I remember I read this term somewhere. But you ask me to explain this right now. I don't think I am able to explain it clearly.*	N/A

		take any food. In this case, he was not able to take responsibility for his life. So we should take responsibility to help him, to give him some involuntary intervention.		
6	*We are more like ‘a provider’ to provide resources and to solve problems.*	*For our patients, this (shared decision making) helps them to make autonomous decisions and (professionals) to respect their autonomous decisions. I think this idea is quite nice. For people in a stable condition, this is suitable. But acutely ill patients may refuse to take treatment. You still need to respect the wishes of this kind of patient? This is not suitable for them.* *If patients say they don’t have mental illness – why do they need to take medication – “these medications are poison” – you are psychiatrist, should you respect his/her decisions? If they are in an acute episode, they have delusions, they have wrong ideas about their mental condition. It would be wrong if I still respected these decisions. It could hurt them.*	*I know shared decision making. Our institution also wants to implement shared decision making. We hope patients will have autonomy. I tell them (patients) the pros and cons of each option.* *Eventually they decide. I know now it is widely acceptable in end-of-life care. But if this is implemented in mental healthcare, it will only increase our workload.*	*I think this (shared decision making) will only bring a burden and extra workload to mental healthcare. Because you have to have comprehensive knowledge about mental health resources. I have a lot of experience of many different settings, so I know. But others don’t. If you want to implement it, they would have to undertake a lot of training. We are already too busy.*
7	*Because this is a pattern in Taiwan, how you see the health professionals. We need to comply with this principle. So you normally take medication provided by the health professionals. We had been taught when we are kids. You get used to this.* *In term of types of medication, this decided by me (health professional)*	*Say one schizophrenia patient breaks his leg, and he refuses to accept treatment. And then the professionals follow his wishes as we need to respect his wishes? Don’t treat him and let it be out of shape? In this case, he has delusions about surgery. Due to this illness, he cannot make this decision. Another possibility is that patients with serious conditions or psychosis don’t*	*I seems to have heard this (shared decision making) before. But I don’t really understand what it means, exactly. I suppose that we (health professionals) should sit down with patients and discuss all medical decisions. And then we should respect his/her decision. And also explain more details of the treatment? I wonder if informed*	*It is difficult for you (health professionals) to provide a variety of treatment options for patients like a vending machine. In this case, in the NHI, the effectiveness of your outpatient clinic is very poor.*

	based on your condition and my profession. This because I could choose the treatment that is in the best interest of the patients.	*have any sense of reality. Or they don't have insight. Or even worse, they might have some risk of violence or suicidal. They are not able to take part in medical decision making.* *We (health professionals) are worried that they are not able to accept treatment, so we don't let them be involved. Because they have no insight, they refuse to take medication.*	*consent is a kind of shared decision making. Is it? I would like to know. I don't know the definition of shared decision making.*	
8	*Many patients get used to decision making being the doctors' responsibility. Or they would wonder why they need to see a doctor and spend money on an outpatient appointment.* *Not every patient wants to make decisions. They believe you are doctors. You are professionals, you decide.*	*Let patients to decide…..If you ask me to do something I believe could worsen his/her outcome, I will definitely refuse it. Some patients with mental illness don't have the ability to make decisions.*	*I have heard this term (shared decision making) before, but I don't really understand it. Maybe this should involve patients, doctors, and other professionals? For example, some patients suffer from both mental and psychical problems. Not just psychiatrists but also physicians discuss together? I am not sure.*	*If you are working in an outpatient department, it could be difficult due to our National Health Insurance. Like me, you can only spend three hours finishing morning or afternoon appointments. You need to see 30 or 40 patients in one morning or afternoon session. That means you only can spend 5 minutes for per patient. 5 minutes! You know in this situation, we (professionals) don't have any opportunity to do it (shared decision making). So it is more efficient if we decide for them (patients).*
9	*In Taiwan, we (professionals) need to take a family as a unit. Without family intervention, in fact it is difficult for you to do anything (about patients). For example, we (decide) to transfer a patient to a halfway house. But the family does not support this… don't agree with this. They will take a patient out within one or two weeks.*	*Because they normally ask to stop major medication. For example, one depressed patient doesn't want to take anti-depressive medication but asks for sleeping pills. Basically, I think the request is against the treatment guidelines and will lead to a depressive episode. I would turn them down.*	*If my memory is correct, I seem to have heard this term (shared decision making) in some workshops or from one of my colleagues.* *I think what you need to do is: first we (professionals) need to know what benefit it (shared decision making) brings for health professionals. And then I might like to know, or have some interest in learning about it. If there are*	*Because (shared decision making) needs a long time to explain. To be honest, this will take a long time to implement. Also there is a lot of work I need to do in the outpatient department. This is time-consuming.*

			benefits (to professionals), I will have more motivation.	
10	*I believe the right of prescribing medication belongs to doctors. Although this is doctors' right, we all hope the patients take their medication regularly.*	*But for some patients with serious mental illness or with long-term conditions, decisions should be made by us or their family. They (patients) follow our decisions.* *For example, some patients with schizophrenia and bipolar disorder, because they need treatment. These kinds of patients need long-term treatment. Normally they are not able to make their own decisions.* *Or they don't have the ability to research information or gain correct knowledge about medication.*	*I have heard this term (shared decision making) recently. As I understand, it was as if there are many treatment options. Health professionals could provide their understanding of different options. And then patients make the final decisions.* *I think the medical environment in Taiwan is relatively special. So sometimes you want to introduce some new intervention into our society and this needs time to reshape the intervention. And you should be sure this is beneficial for health professionals. Because I think this is a mutual thing. This should be beneficial for both (patients and professionals) and then you adopt it. But if this is only beneficial for patients it is not necessary to implement it. It will bring a huge workload for health professionals.*	*From a psychiatrist's point of view, if there are many patients in one day, it could be difficult if I spend too much time on one patient – particularly for patients with minor conditions.* *Because we (health professionals) don't have enough time. But it (shared decision making) needs to take a lot of time. And maybe it isn't really very effective. Overall, it is difficult to implement it for all patients.* *I think the medical environment in Taiwan is relatively special. So sometimes you want to introduce some new intervention into our society and this needs time to reshape the intervention. And you should be sure this is beneficial for health professionals. Because I think this is a mutual thing. This should be beneficial for both (patients and professionals) and then you adopt it. But if this is only beneficial for patients it is not necessary to implement it. It will bring a huge workload for health professionals.*
11	*I think they (patients) can comply with our orders well. It is a doctor's role to be an authority figure.* *I don't know, this is kind of a tradition of healthcare? They (patients) are more like a receiver rather than a provider. They don't speak up for themselves.*	*I believe this (patient involvement) should depend on the severity of their mental illness. I mean sometimes patients have been influenced by their psychosis symptoms. Then it would be unreasonable to accept their decisions.*	*I've never heard of this (shared decision making). I know about some ideas of patient involvement. But I never heard this term.*	*I believe it (shared decision making) would be difficult to implement in practice. I suppose… Say you want to apply it in every case, getting different professions to work as a team. All the professionals come to discuss everything with the patients. I think time management would be really difficult. For example, doctors could not come as they*

	This is our healthcare system. Like my parents: they said, "I believe what doctors say, but I don't believe what our daughter (the health professional) says. This is kind of our tradition. Everyone think doctors are very intelligent. *For example, the patients and family in the wards took the right position when they see the doctors. So you say don't doctors have authority status?*			*have a lot of meetings, outpatient appointments and so on.*
12	*This is traditional eastern culture. It is kind of authoritative. A doctor is more…(qualified). When people were children, they were told to comply with doctors. We should completely obey them and do what they ask. That's what people have been taught since they were children.* *We (health professionals) can provide some information. But I think it is up to their family to decide. The family takes over you know. We are not the ones who need to take care of them (patients) forever. But their family do.*	*I believe their decisional capability and motivation are impacted by mental illness. They are suffering from negative symptoms. So they don't engage in decision making and have no motivation.*	*I know about this (shared decision making). My hospital wants to implement this. I believe that shared decision making means that we (health professionals) provide some treatment decisions. For example, option A, option B, and option C. and then some evidence for each option. For example, breast cancer. Survivability of each surgery option. Patients could make their own decisions based on this evidence.* *In mental healthcare, I think we have already done this for such things as discharge planning. I do believe we (health professionals) are doing this. Just we don't use data based evidence to do so.*	*I think we (health professionals) now facing a shortage of human resources in practice. There are a lot of patients but only few professional staff. It is a difficult time right now.*
13	*No (we don't provide treatment options), because we (professionals) know best.*	*Some patients have conditions such as psychosis, schizophrenia, or bipolar disorder. Their decisional function is not good enough.*	*There might be some courses (about shared decision making), but I don't get the information. Perhaps there are some, but they're not*	N/A

	No! No! (Providing treatment options) we are the ones who know which one is the best. They don't understand. *Like some older doctors, such as Dr. XXX, they have strong authority. They believe patient should follow the instructions. Until now, some patients still believe this is what doctors should do. They are powerful, and we (patients) should listen to it.* *Beside, taking care of patients is family's responsibility. I think patients can go home but family don't. I think we need to respect family. And family should make decision for them (patients).*	*Some people with bipolar or schizophrenia, or depression. They have to take medication so they can control their symptoms. But if they refuse, they are more like a loose cannon. This kind of person will cause difficulty in the community. For example, if there is a person with schizophrenia living downstairs, he might make a lot of noise or yell in his home every single night. Or he might put a lot of rubbish in the public area and make it dirty. In fact, we feel scared. One day he may start a fire and burn down the whole building. How can we accept their decisions (to refuse to take medication)?*	*really advocated… It is difficult for us (to adopt it).*	
14	*I think in Chinese society, people are supposed to listen to the elderly and authorities. I think people get used to this… You should listen to people with professional ability. I guess they (patients) get used to putting doctors or nurses into positions of power. Therefore, doctors and nurses think they are in the position (to decide).* *Because patients have an expectation: I need to be discharged from the hospital first. I feel, in this situation, they will follow the orders of doctors. And they would try to figure out what doctors think or want. Based on this, they would do what they think the doctor*	*For example, patients with schizophrenia, because their cognitive function and understanding facility are really poor. It is really hard… (To involve them).* *If he decides not to take medication and I believe he will hospitalised again soon, I will not compromise with this. If he says directly that he will not take any medication after being discharged from the hospital, I will actively engage him. I mean he has to take medication. He cannot to refuse it. He will therefore be sent to the hospital soon.*	*I heard some policy makers want to implement this (shared decision making). As far as I know, put simply, most of the time doctors make almost every decision for patients. But when the outcome of the decision is not good, there is an argument. Because this is all decided by doctors, it is more likely that the doctors should take all the responsibility. Shared decision making aims to help health professionals to understand patient preference and expectations. And then they combine that with evidence and find the best option for patients.*	N/A

	has asked them to do. And then they could leave hospital.			
15	N/A	*It is different. Let me think. Because it is really hard to talk with or involve patients with psychosis.*	*Yes, I heard about this (shared decision making) recently. I think shared decision making is making an informed decision. For example there are treatment A and treatment B. health professionals discuss the advantages and disadvantages of these treatments with patients. And then support the patients to make decisions.*	N/A
16	*I think (shared decision making) could be difficult in mental healthcare. It could be challenging. For example, we (health professionals) assess (patients' conditions) according to the standard assessment. After professional assessment, there is the best (treatment) option and then I make a (treatment) plan. This is what we do.*	*I think this (the level of patient involvement) depends on cognitive function. For example, some patients in chronic wards – they are not able to have a discussion with you.*	*Shared decision making? There seem be some workshops. But I personally don't know about this.*	N/A
17	*If you have been to hospitals, you should know doctors are the most powerful in hospitals. They are the boss.*	*Some patients are not able to go into the group you know. They keep talking about their delusions. How can you interact with them?*	*Shared decision making….I think I saw this in an article. But I don't know any details of it.*	*It (shared decision making) is difficult to take it further in practice because of time limitations. There are many tasks which I need to finish. For example, groups for patients, groups for sexual victims, outpatient appointments, and so on.*
18	*This is natural… there is a knowledge gap. We are professionals (to decide).*	*When they need hospitalisation, we need to have a conversation with the family and patients. This is an art…. Because patients are ill. They don't have an insight into their mental illness. How can we discuss treatment with patients in this condition?*	*I have heard of shared decision making. I think it could have been difficult before we had the Mental Health Act. Although I don't really understand it, I would say the aim of it is that we (health professionals and patients) all discuss everything together and then make decisions.*	N/A

19	*Because psychiatrists have practical expertise in mental healthcare. There are psychiatrists for mental healthcare and physicians for general medicine. You don't ask physicians for information about general surgery. And they have a lot experience of taking care of patients every day. They are very familiar with this. They know how to deal with this and make adequate medication decisions.* *The decision about whether patients are able to be discharged from hospital is down to their family. Because their family are the people who will take care of them after a period of hospitalisation*	*"(Why patients are not involved)… because they have poor insight. (Patients think): "I don't have a disease. Why do I need to take medication". They (the patients) are discharged from hospitals but then don't get followed up in the outpatients department. And then they have an acute episode and call an ambulance. Because they experience repeat onsets and this brings really bad outcomes for them.*	*I seem to have heard of shared decision making before. It involves nurses, doctors, and patients? I cannot remember. But as I understand this literally, all parties discuss it together? I am not sure, really.* *To be honest, I am not sure this is really helpful. Even if it could bring some benefits, I still think it is difficult, you know. How to do it… and I believe there is a gap with reality. And there are many challenges.*	*Time. Because health professionals are busy. Their families have jobs. It is difficult to arrange time for all the people.*
20	*Why aren't patients with mental illness able to take part (in decision making)? Because they don't have professional knowledge. Unless we (health professionals) explain to them what this medication for… they don't know.* *The doctor would not normally agree that a patient can be discharged from the service. There is no reason. They (patients) still have family. Their family will be worried about their safety. For example, if they (a patient) discharge themselves from the services on their own; they are hit by a car on their way home. And then the family will criticise us (health professionals) for letting them discharge themselves.*	*They (patients) may say they don't have psychiatric symptoms and why do they need to take this medication. They are not able to make right decisions.*	*I've never heard of this (shared decision making) before.*	N/A

21	*The family is too closed. Right, you should read the current news. XX (the killer on TV news and indicated as a patient with mental illness) is in his 20s. He is a legal adult in law. In the West, if someone commits a murder like that, his parents do not need to show up or do anything else. But in Chinese society, his parents needed to kneel in front of the public. At the beginning, they (the parents) did not do anything. They were attacked in the newspaper or community. It appeared that they have responsibility for this (behaviour). This (patient involvement) is really challenging.* *It (patient involvement) is difficult in mental healthcare. First, this disease is a long-term condition. Maybe 40 or 50 years. Sometimes even 50 or 60 years. For example, some family members don't agree to patients being discharged from the hospital. If we (professionals) insist on doing so based on patients' wishes, their family members may say: how can they live without financial support from us? They don't have a home." What we can do about this? Let them live on streets? You see what I mean*	*I think we label patients with mental illness as not able to make their own decisions. This may be influenced by the news or movies. We believe they are crazy and are not able to judge. Even I have been influenced by these reports.* *I believe it (shared decision making) is difficult. In particular, our patients don't like to take medication and have some bizarre behaviour.* *For example, one of our cases was suffering from a hernia and a doctor suggested he had surgery. But he said no. We tried to communicate with his family. But the patient still refused. We encouraged the family to talk with him. His sister-in-law came by…because his brother was ill. So only his sister-in-law. His sister-in-law talked to him and suggested he had surgery. The doctor thought it was better for him to have surgery as soon as possible. But the patient still said no. So surgery was delayed. The patient thought he was not ill at all. [He thought]: "No hernia. Why do I need to have surgery? Yeah… I haven't got a hernia. Why do I need to?" And then the doctor explained it to him. He said to us: "The doctor is lying to me. I don't have a hernia."*	*Yeah, I heard about it (shared decision making). It is quite popular recently. I know the XXX emergency department is now working on it. So that's why I heard about this. It seems to involve patients and their family… and doctors provide some information? And then decide together? Is that correct?*	*Shared decision making takes a lot of time which we (health professionals) don't have. It is challenging.*
22	*For now, doctors don't provide any treatment options for patients. This is all decided by doctors. This is*	*if you are a patient with psychosis and disorganised behaviour, you are not able to make a good decision. We or*	*Someone mentioned this (shared decision making) recently. In mental healthcare, patient, family,*	N/A

	professional. The right of prescribing belongs to the doctors. *I believe this is related to Taiwan's traditions. Everything is decided by the family.* *Family members will question you in the end. Or they will criticise you: "Why did you let the patient decide alone?" In order to protect ourselves (professionals), we need family permission. You know even if patients feel they do not need to stay here (in mental health services), but their family disagree, I think we wouldn't take the patient's opinion to discharge him. This must be agreed by family members, or the services or nurses won't be able to take their (patients') opinion.* *They (psychiatrists) don't offer options. They just… explain. Nurses just explain what choices the psychiatrists made, such as dose or frequency. Actually these medication treatments were mainly explained by the doctors rather than us (nurses). But so far, we've never seen any doctors offering options to patients. It is all decided by the doctors.*	*the family should decide. This is the pattern. There are rare families that will take patients with mental illness seriously. This is what I think. I believe they (patients) have been labelled as incompetent.*	*psychiatrist, nurse, social worker, occupation therapist, and psychologist work together when making decisions. When there is a problem, they all work together to sort it out.*	
23	*This is how health professionals foster their profession. For example, only doctors can prescribe medication. This is how people were educated. We have seen this a lot. You can get any Chinese*	*I wonder if patients in a psychotic condition really make the right choice. Or if it is decided by his/her symptoms.*	*I've heard of this (shared decision making) before. But… I don't really know about the content of it. There are some workshops in the*	*Normally it (shared decision making) does not happen in mental healthcare. It takes too much time in the outpatient department. But doctors only have a little time. For example, one doctor needs to see 100 patients in one*

	medication. You can make a tea with any Chinese herb. But in healthcare, this is the rule. Only doctors have the right to prescribe. *This is their power structure in a patient's family. If the family power type is an authoritative one, the father takes more power. And then he (a patient) can only listen to his father. This is possible. In this situation, no matter what he does, or tries to do against it, or how he tries to communicate (with his father), it is useless. Eventually, he can only listen to the decision maker in his family and follow his instructions.*		*hospitals. But I am too busy to take the class. So I am not clear about it.*	*morning, within 3.5 hours. You want to have a discussion with them in only a few minutes? It is impossible. If we do (implement shared decision making), doctors may need to spend one or two hours seeing one patient.*
24	*This is a doctor's job. Doctors are responsible for deciding what medication they should take. Because patients don't have any medical background. They haven't studied in a specialist medical educational system. Even me (nurse), I have some basic knowledge but I am still not a doctor to know which medication will be effective for patients.*	*I believe that patients with mental illness have been seen as being not able to judge stuff correctly. From my perspective, I may feel they are not able to make the right decision. But I believe they are of relative low status.*	*Share decision making…..sorry, I have never heard of this before.*	N/A

Appendix 15: Example of thematic frameworks for the health professional interviews (Theme 2)

Theme 2: Facilitators of shared decision making		
Themes	**Awareness of patients' right to autonomy**	**Understanding of the potential benefits of shared decision making.**
Number of reports	14/24	16/24
1	N/A	N/A
2	N/A	*If patients have a full discussion with me, I feel more confident in the treatment. For example, the patient discussed all the details about how he took Lithium before. And then we decided he would take Lithium next. I did not really have to worry about side effects. I could have more information about the patient. And this helps me to have more confidence. And therefore in the decision making process, I think patient involvement is positive.*
3	N/A	*You let him decide about his medication. He has more motivation. He is more willing to take the medication.*
4	N/A	N/A
5	*If today we have a child, he asks for something. And then we discuss it with him and then decide together. It is better, isn't it? OR would he like to let the parents decide everything for him? I believe it is the same with the patients. At least he has right to decide who should decide it.*	*If today we have a child, he asks for something. And then we discuss with him and then decide together. It is better, isn't it? OR would he like to let the parents decide everything for him? I believe this is the same with the patients. Now we hope patients will decide to take their medication regularly and this is decided by us (health professionals) and the patients together. In this situation, responsibility plays a very important role. If you do it that way, the patients will take responsibility, you know.*
6	*For our patients, this (shared decision making) helps them to make autonomous decisions and (professionals) to respect their autonomous decisions. I think this idea is quite nice.*	*I believe patients all want to have options, because they don't just go the place (possible accommodation) for one or two days. Sometimes it is more likely to be about their future - the rest of their life. If they can decide on their own and they like it, they could stay longer.*

7	*We should implement patient-centred care and discuss their case with them. It depends on them. They have the right to know what treatment they are taking now.*	*Because the future of mental illness is becoming a long-term condition for patients. They should improve their insight. If they are involved, they are more willing to fight for this mental illness.*
8	*(Why do you think patients should take part in decision making?)Because this medication will be taken by patients. They can ask questions about it.*	
9	*For example, he felt bad about Seroquel (Quetiapine). And he wants to change to Risperidone (Risperdal). That's fine. Just change it. Because to be honest with you - this is my personal view - even now the newest research cannot predict which medication is the most effective for patients. So why not (implement shared decision making)?*	*I think this (shared decision making) could improve the therapeutic relationship and the quality of care. I'm guessing. I don't really know.*
10	*There is no 100% correct answer for medicine. This is probably why it (shared decision making) might be implemented. Doctors might have better knowledge. But not all decisions are suitable for everyone. There might have been some (medical) mistakes, so a new policy (shared decision making) came out.*	*Basically, I personally believe that this (patient active involvement) is better. Because they discuss it with us and they have some ideas about their treatment and care. They can engage in the process. This is not only about health professionals.*
11	N/A	*If he was forced or pushed, he didn't like (the intervention). We (health professionals) didn't really want this. For example, for occupational training, this is invalid and not effective. Patients without any motivation were forced. This is meaningless. They didn't want to stay.*
12	*Because you own your body. You (patients) can decide how you want to use your body in the next decades. This body is mine. You should understand what will happen in the next decades if you decide to take this intervention or treatment. I believe this is the right thing to do.*	*In fact, I have been a patient (with a long-term condition) since I was little. I actually have a thought. For me, because I had serious surgery in my mouth, I don't want to talk with others close up, because I easily spit on them. So when I recalled that time. I thought: if I hadn't accepted surgery, I wouldn't have needed to experience this side effect. But there was no choice. No one told me. I thought you (the health professional) were supposed to tell me all the options, or you should tell me what will happen next. It is a better way. For patients here it should be the same (12 Occupational Therapist)*
13	N/A	N/A
14	*For example one of my patients who was suffering with nasopharyngeal carcinoma was recommended by one doctor to take surgery and then radiotherapy and chemo therapy. My patient complied with the doctor. Based on the evidence base, the doctor didn't do anything wrong, but he*	*If I ignore their ability to make decisions about treatment and care, they could think: 'These (decisions) are all decided by doctors or other professionals'. It was like they didn't need to take any responsibility… Even if he is a psychosis patient, he could still decide. These things should*

	didn't pay attention to how the patient think about this. The truth is, my patient was worried about side effects of this treatment. He had been diagnosed with bladder cancer a long time before. He had been through this treatment once. He didn't want to undergo all these processes again. He has the right to say something about his treatment. I think this is important to think about.	*be not decided by doctors… I should have noticed this (that the decisions were all made by professionals) but I didn't. It's as though the patient sees me as some sort of barrier to stop him recovering. I just see him as a child. And then this means he never ever takes responsibility.*
15	*Let me think… this (patient involvement) may be a great idea. I've never thought about this. In this way, I can show respect to their rights (to decide).*	*Maybe this (shared decision making) is right. They can decide which therapy they need. I can respect all their decisions. There is no argument between us (the health professional and patients). We could work together.*
16	N/A	*Patient involvement also influences their motivation. For example, if they are involved and have some discussion with us… For example, they choose one occupation therapy. For example he/she decides to help sell happy meals on the wards (one type of occupation therapy in the setting). This is decided by him/her. When he/she faces some challenge, they are more likely have the motivation to continue. This helps them to reach the goal.*
17	*I hope they (patients) can be involved in decision making, because they should have the right to decide what treatment they want to receive.*	*But this is their life, long life. We need to let them know how to take responsibility for their own life. If their decisions are decided by others, they refuse to take any responsibility. They cannot engage in their treatment. It is impossible for them to recover.*
18	*"It is not right to violate their human rights. It is just not right. Because they don't meet the criteria for compulsory admission. They have the right (to refuse to be admitted). You cannot do this.*	N/A
19	N/A	*To be honest, I am not sure this is really helpful. Even if it could bring some benefits, I still think it is difficult, you know. How to do it. And I believe there is a gap with the reality. And there are many challenges.*
20	N/A	N/A
21	*To be honest, I believe that if they (patients) are stable, you know, they should have right to say they want to be discharged from the hospital or something (treatment).*	N/A
22		N/A

23	*If I was a patient (with mental illness), I suppose I wouldn't like someone else deciding for me. I would think I had had been deprived of my liberty and dignity. Besides I could only follow the instructions of other people, including doctors or family members. It is just (better) decided by me. If I was a patient, I would think like that.*	*I believe their (patients') views should be involved. I mean, if I'm setting a goal with them... Not just "We (health professionals) think this is best for you (patients)". "We (health professionals) are on your (patients') side. We are working together. You (patients) will have more motivation to reach the goal."*
24	*I believe they have rights, because they are independent people. They have a right to decide (treatment or care).*	*If we have a recovery plan which he/she doesn't have any motivation for, for example, you deliver a plan which he doesn't agree with, he doesn't want to do it. It is useless. But if he has the motivation, I believe he can implement his plan successfully.*

Appendix 16: Extraction sheet for synthesis

To be extracted: information refers to perspectives of shared decision making in secondary mental healthcare (one systematic review and two qualitative studies)

Part A: Demographic information

General information

Title:

Year:

Aim:

Methodology

Study design:

Data collection:

Data analysis:

Participant selection

Target population:

Number of participants:

Setting/context:

Sampling:

Recruitment method:

Inclusion criteria/Exclusion criteria:

Characteristics of study population

Gender:

Age:

Diagnosis/profession:

Part B: Findings from the studies