

UNIVERSITY OF SOUTHAMPTON

FACULTY OF HEALTH SCIENCES

Volume 1 of 1

**STAKEHOLDER PERSPECTIVES TOWARDS SCHIZOPHRENIA CARE AT THE
SUB-DISTRICT LEVEL IN RURAL THAILAND**

by

Boonthan Kingsaiyhod

Thesis for the degree of Doctor of Philosophy

May 2016

UNIVERSITY OF SOUTHAMPTON

ABSTRACT

FACULTY OF HEALTH SCIENCES

Thesis for the degree of Doctor of Philosophy

STAKEHOLDER PERSPECTIVES TOWARDS SCHIZOPHRENIA CARE AT THE SUB-DISTRICT LEVEL IN RURAL THAILAND

Boonthan Kingsaiyhod

For the period 2012-2016, the Thai 11th National Health Development Plan focuses on the accessibility and equity of mental health care by using community collaborations in order to 'strengthen and empower the sub-district health system'. In reality, demands and supply should be balanced, based on available resources. Therefore, including the patients', caregivers' and health care providers' perspectives for schizophrenia care improvement is considered helpful to gain an in-depth understanding of the community mental health nursing care situation; this endeavour is aimed at improving mental health nursing practices, based on available resources.

There has been no previous research exploring stakeholders' perspectives of care at the primary level in the rural Thai community. This qualitative study aims to provide an in-depth understanding of both service users' and service providers' views. Semi-structured interviews were carried out with 40 participants within three groups, which involved patients with schizophrenia, their caregivers, the primary care staff in the community, and the supervisory teams in the community and psychiatric hospitals. Interviews were transcribed verbatim, translated into English and analysed using thematic analysis. Each group of participants was analysed individually to provide specific and integrated themes. Three key areas relating to all three groups are 1) the lived experience, 2) the importance of medication and 3) the service and support needs. The results illustrate the complexity of the Thai situation, due to poverty within a rural environment and conflicting views regarding the need to move away from a biomedical model of care. The results will be used to inform community mental health nursing practice and education in Thailand.

Contents

ABSTRACT	i
Contents	i
List of tables	ix
List of figures	xi
DECLARATION OF AUTHORSHIP	xv
Acknowledgements	xvii
Definitions and Abbreviations	xix
1. Chapter 1 Introduction	1
1.1 Schizophrenia care as the study focus.....	1
1.2 My interest and background.....	2
1.3 Conducting the study in rural Thai community settings.....	3
1.3.1 Rural definition.....	3
1.3.2 The importance of rural settings.....	4
1.3.3 Culture and the cultural impact on health.....	5
1.4 The current Thai health care system and schizophrenia care.....	6
1.5 Structure of the thesis.....	7
2. Chapter 2 Schizophrenia background	9
Introduction.....	9
2.1 Finding relevant evidence.....	9
2.2 A brief history of schizophrenia.....	11
2.3 Incidence and prevalence rates.....	12
2.4 The causes of schizophrenia.....	12
2.4.1 People’s general perspectives towards the causation of schizophrenia.....	12
2.4.2 Scientific perspectives towards schizophrenia causation.....	15
2.4.2.1 Genetic factors.....	15
2.4.2.2 Environmental factors.....	16
2.4.2.3 Brain and neurotransmitters.....	18
2.4.3 Psychosocial perspectives.....	19
2.4.3.1 Child development and family relationships.....	19
2.4.3.2 Life-events.....	20
2.4.3.3 Socio-cultural factors.....	21
2.4.4 Schizophrenia’s triggers and other risk factors.....	21

2.5	Diagnostic criteria.....	22
2.5.1	The International Classification of Diseases 10 (ICD 10)	22
2.5.2	Diagnostic and Statistical Manual of Mental Disorders 5 (DSM 5).....	22
2.5.3	Diagnostic criteria: ICD and DSM systems in Thailand	23
2.5.4	Limitations of ICD 10 and DSM 5	23
2.5.5	Accuracy of diagnosis: schizophrenia comorbidity.....	24
2.5.6	Current debates about schizophrenia around the world	25
2.5.6.1	Antipsychiatry movement	25
2.6	The impact of schizophrenia	26
2.6.1	Impacts on patients.....	26
2.6.1.1	Cognitive function.....	27
2.6.1.2	Social function	27
2.6.1.3	Occupational dysfunction	27
2.6.1.4	Physical health impacts	28
2.6.1.5	Social impacts	29
2.6.2	Impacts on health systems and countries	30
2.7	Schizophrenia treatments.....	31
2.7.1	Schizophrenia beliefs and its treatments	31
2.7.1.1	Neurobiological model (medical model).....	31
2.7.2	The bio-psychosocial model	33
2.7.3	Schizophrenia is a recurring and long term condition.....	34
2.7.4	Recovery from schizophrenia	34
2.8	Conclusion.....	35

3. Chapter 3 Literature review: stakeholder experiences and perspectives towards schizophrenia care in community settings
..... 37

Introduction	37
3.1 Finding relevant evidence.....	37
3.1.1 Developing the focal points for a literature review.....	37
3.1.2 Search strategies and article selection	38
3.1.1 Characteristics of selected articles	40
3.2 The experiences of patients with schizophrenia, their caregivers, and health personnel, regarding living with and caring for people with schizophrenia at the primary care level.....	42
3.2.1 The perspectives of patients with schizophrenia: community experiences regarding living with schizophrenia.....	42
3.2.2 Caregivers' perspectives: community experiences regarding caring for patients with schizophrenia.	43
3.2.2.1 Living with/ caring for schizophrenia causes difficulties	44

3.2.2.2	Caregivers' backgrounds.....	44
3.2.3	Caring and coping strategies	46
3.2.4	Care providers' perspectives	49
3.2.4.1	Knowledge and skills	49
3.2.4.2	Mental health policy and primary care staff beliefs	50
3.3	The needs of patients with schizophrenia, their caregivers and health personnel for schizophrenia care at the primary care level	52
3.3.1	Patients' needs	52
3.3.2	Sources of patient needs support.....	53
3.3.3	Caregivers' needs	54
3.3.4	Sources of caregiver need support	55
3.3.5	Health personnel needs	56
3.4	The recommendations for improving schizophrenia care at the primary care setting in rural areas	56
3.5	Service delivery in community settings.....	57
3.5.1	The treatment of schizophrenia in the community mental health care setting	57
3.5.2	Key issues for community care in rural Thailand	57
3.5.2.1	An overview of the Thai community mental health system....	57
3.5.3	The Thai national mental health policy for schizophrenia care in community settings.....	58
3.5.4	Thai community mental health care for schizophrenia	59
3.5.5	The way forward of caring for patients with schizophrenia in community settings.....	61
3.6	Gaps of knowledge	62
3.7	Research aims.....	63
3.8	Developing research questions	64
3.8.1	Research questions	64
3.9	Chapter summary	64
4.	Chapter 4 Methodology and method.....	67
	Introduction	67
4.1	Methodology.....	67
4.1.1	Ontology and epistemology underpinning this study.....	67
4.1.2	Research paradigm and design	68
4.1.3	Theoretical framework	70
4.1.3.1	The pragmatic approach	72
4.1.3.2	My epistemological/philosophical stance	73
4.1.4	Sampling strategy	74
4.1.5	Type of qualitative approach.....	78

4.1.5.1	The type of qualitative approach	78
4.1.6	The type of interview schedule	79
4.1.6.1	Semi-structured interviews	80
4.2	Method	81
4.2.1	Participants	81
4.2.2	Inclusion and exclusion criteria	82
4.2.3	Recruitment approach	86
4.2.3.1	Recruitment strategy 1	87
4.2.3.2	Recruitment strategy 2	88
4.3	Recruited research participants	88
4.3.1	Scheduling the interviews	89
4.4	Data collection	89
4.4.1	Recruited participants	89
4.4.2	Equipment	90
4.4.3	Pilot study	91
4.4.4	Health and safety	91
4.4.5	Ethical considerations	92
4.5	Interview transcription	95
4.6	The analytical approach	95
4.6.1	Trustworthiness of data	96
4.6.1.1	Credibility of data	96
4.6.1.2	Confirmability of data	97
4.6.1.3	Dependability of data	97
4.6.1.4	Transferability of data	97
4.6.2	Interview translation	97
4.6.3	Data analysis	98
4.7	Chapter summary	103
5.	Chapter 5 Findings	105
	Introduction	105
5.1	Overview of the participants	105
5.2	Summary of the themes from each participant group	108
5.3	Area 1: The lived experience	111
5.3.1	Theme 1: Fear of rehospitalisation	112
5.3.1.1	Sub-theme 1.1: Experience of compulsory care	112
5.3.1.2	Sub-theme 1.2: Support from health professionals	116
5.3.2	Theme 2: Living in the rural Thai community is good but	117
5.3.2.1	Sub-theme 2.1: Sympathetic culture and mental health support 117	

5.3.2.2	Sub-theme 2.2: Rebuilding relationships in the community	120
5.3.2.3	Sub-theme 2.3: Being an unwanted person.....	122
5.3.2.4	Sub-theme 2.4: Job opportunity and income.....	122
5.3.3	Theme 3: Seeking empathy.....	124
5.3.3.1	Sub-theme 3.1: Active listening.....	124
5.3.3.2	Sub-theme 3.2: Getting back to be one's pre-morbid self..	125
5.3.3.3	Sub-theme 3.3: Health education for the public.....	126
5.3.4	Theme 4: Caregiver's mix feelings towards schizophrenia care	129
5.3.4.1	Sub-theme 4.1: Unconditional love.....	129
5.3.4.2	Sub-theme 4.2: Ambivalent feelings.....	131
5.3.5	Theme 5: Using violence and punishment for management of schizophrenia.....	132
5.3.5.1	Sub-theme 5.1: Illegal punishment.....	133
5.3.5.2	Sub-theme 5.2: Compulsory hospitalisation.....	134
5.4	Area 2: The importance of medication.....	136
5.4.1	Theme 1: The role of monitoring medication.....	136
5.4.1.1	Sub-theme 1.2: Medication adherence leading to normality	136
5.4.1.2	Sub-theme 1.3: Medication as relapse prevention.....	137
5.4.2	Theme 2: Managing adherence to medication.....	140
5.4.2.1	Sub-theme 2.1: Community support for medication adherence management.....	141
5.4.2.2	Sub-theme 2.2: The importance of monitoring medication.	144
5.4.2.3	Sub-theme 2.3: Medication management as the heart of the care	145
5.4.2.4	Sub-theme 2.4: Compulsory treatment and detention.....	147
5.4.3	Theme 3: Recommendations for better medication management	149
5.4.3.1	Sub-theme 3.1: One-stop service at the primary care level is needed	149
5.4.3.2	Sub-theme 3.2: Community medication: medication delivery, medication reminder service.....	151
5.4.3.3	Sub-theme 3.3: Consultation is needed: medication, physical and sex life.....	153
5.4.3.4	Sub-theme 3.4: Enhancing medication adherence via a referral line and network.....	155
5.5	Area 3: Service and support needs.....	158
5.5.1	Theme 1: Experiences of current service.....	158
5.5.1.1	Sub-theme 1.1: Unmet needs.....	158
5.5.1.2	Sub-theme 1.2: Primary care staff role in medication concordance.....	159

5.5.1.3	Sub-theme 1.3: The impacts of attitudes, knowledge and skill	161
5.5.1.4	Sub-theme 1.4: Improving service users' faith in the primary care staff	164
5.5.2	Theme 2: Thai cultures and beliefs.....	165
5.5.2.1	Sub-theme 2.1: Caregivers' beliefs inform the care and coping patterns	165
5.5.3	Theme 3: Humanised and holistic care	169
5.5.3.1	Sub-theme 3.1: Poverty as a huge obstacle.....	170
5.5.3.2	Sub-theme 2.2: Workforce limitation, Boon and holistic care.	172
5.5.3.3	Sub-theme 3.2: Dehumanised human care: 'scheduling timetable like feeding a dog'	175
5.5.3.4	Sub-theme 3.3: Devaluing and labelling.....	177
5.5.4	Theme 4: Recommendations	180
5.5.4.1	Sub-theme 4.1: Recommendations for service improvement	180
5.5.4.2	Sub-theme 4.2: Community mental health care governance	183
5.5.4.3	Sub-theme 4.3: The need to have an effective referral system	185
5.5.4.4	Sub-theme 4.4: Support for service users: medication delivery, financial help and rehabilitation	186
5.6	Chapter summary.....	189
6.	Chapter 6 Discussion	191
	Introduction	191
6.1	Area 1: Lived experiences.....	191
6.1.1	The patients' perspectives towards the psychiatric hospital.....	191
6.1.2	Stigma, social isolation and being dependent.....	192
6.1.3	Violence	195
6.1.4	Schizophrenia care burden	197
6.2	Area 2: Importance of medication	199
6.2.1	Improving medication adherence in order to reduce violence ..	200
6.2.2	Factors related to non-medication adherence and discontinuity of care	202
6.2.3	Comparing views about the importance of medication	205
6.2.4	Fragmented health care service	207
7.	Chapter 7 Recommendations and conclusions.....	208
	Introduction	208
7.1	Area 3: Recommendations.....	208
7.1.1	Structure of mental health services.....	208

7.1.2	Key recommendations	209
7.1.2.1	Public health policy for mental health service	209
7.1.2.2	THPH staff improvement: attitudes, knowledge and practice 211	
7.1.2.3	Culture/ beliefs and community mental health care	214
7.1.2.4	The need of an emergency service for community mental health care	216
7.2	Discussion of the limitations and potential biases	217
7.2.1	Limitations and potential biases.....	217
7.3	Reflections and suggestions for future research.....	218
7.3.1	Reflections.....	218
7.3.1.1	Researcher: me as an outsider and in a researcher's shoes.	219
7.3.1.2	Research data collection in Thailand	220
	1) Distributing research packs in the Thai context	220
	2) Travelling to rural Thai communities	222
	3) Interview places	223
	4) Interviewing patients with schizophrenia	223
	5) Interview methods	224
	6) Transcribing interviews and translating transcripts	224
	7) Impact of media	225
	8) The data analysis process	226
7.4	Contribution of knowledge	226
7.4.1	The gap between the Thai public mental health policy and community mental health care practice	227
7.4.2	Needs and unmet needs for mental health care at the rural Thai primary care level.....	228
7.4.3	The impacts of cultural beliefs towards community mental health care. 229	
7.4.4	Suggestion for future research.....	230
7.5	Final conclusion.....	230
Appendices		233
Appendix 1: Definition of Rural area in Thailand, England and United States of America.....		235
Appendix 2: Keywords for database searching		236
Appendix 3: Inclusion and exclusion criteria		237
Appendix 4: Database search 3 Databases from EBSCO host		239
Appendix5: The example of selected articles for schizophrenia causes ...		245
Appendix 6: The example of using Critical Appraisal Skills Programme (CASP) for critiquing article		246

Appendix 7: Comparison between ICD10 and DSM5 criteria for schizophrenia diagnosis.....	249
Appendix 8: Search terms.....	251
Appendix 9: Inclusion and exclusion criteria.....	255
Appendix 10: Example of selected literature for experiences of living with/ caring for schizophrenia	256
Appendix 11: The example of using Critical appraisal using Critical Appraisal Skills Programme (CASP) for critiquing article.....	257
Appendix 12: Ethical approval in the UK	259
Appendix 13: Ethical approval in Thailand	261
Appendix 14: Poster advertising the study.....	265
Appendix 15: Participant information sheet (for patients with schizophrenia)	266
Appendix 16: Participant information sheet (the caregiver of patients with schizophrenia)	271
Appendix 17: Participant information sheet (for the Health Promotion Hospital staff)	276
Appendix 18: Participant information sheet (the community mental health supervisory team).....	281
Appendix 19: Participant invitation letter.....	286
Appendix 20: Reply slip.....	287
Appendix 21: Consent form	289
Appendix 22: Document sheet for participants' information	291
Appendix 23: Interview schedule	295
Appendix 24: Example of probes, prompts and cues	299
Glossary.....	301
List of References.....	303

List of tables

Table 1 Advantages and limitations of purposive sampling and convenience sampling	75
Table 2 Inclusion and exclusion criteria for patient with schizophrenia group	83
Table 3 Inclusion and exclusion criteria for caregivers of a patient with schizophrenia	84
Table 4 Inclusion and exclusion criteria for Tambon Health Promotion Hospital (THPH) Staff (primary care staff)	85
Table 5 Inclusion and exclusion criteria for THPH supervisory team.....	85
Table 6 Characteristics of the patient group	105
Table 7 Characteristics of the caregiver group.....	106
Table 8 Characteristics of the health professional group	106
Table 9 Outline of themes for the patient group.....	108
Table 10 Outline of themes for the caregiver group.....	109
Table 11 Outline of themes for the health professional group	110
Table 12 Comparison between advantages and disadvantages of each participant recruitment strategy.....	221

List of figures

Figure 1 Database search and literature selection	10
Figure 2 Database search and study identification	39
Figure 3 Hierarchy of evidence: ranking of research evidence evaluating health care interventions (Evans 2003 p.79)	41
Figure 4 Conceptual framework of re-hospitalisation of patients with schizophrenia in Thailand (developed by the author).....	60
Figure 5 The relationships of ontology, paradigm and methodology adapted from Guba (1990), Denzin and Lincoln (2005) and Parahoo (2014)	68
Figure 6 Thailand map illustrating the five provinces from which participants were selected, namely: Khampaeng phet, Uthai thani, Nakhon Sawan, Chinat and Pichit (source: http://divezone.net/travel/thailand).	77
Figure 7 Conceptual framework for stakeholder perspectives towards community mental health service at the sub-district level in rural Thailand	82
Figure 8 Purposive sampling strategies for participant selection.....	87
Figure 9 Open coding using NVivo software package.....	100
Figure 10 An example of displaying potential themes, codes and quotes.....	101
Figure 11 The three areas of findings	111

DECLARATION OF AUTHORSHIP

I, Boonthan Kingsaiyhod declare that the thesis entitled:

Stakeholder perspectives towards schizophrenia care at the sub-district level in rural Thailand.

and the work presented in the thesis are both my own, and have been generated by me as the result of my own original research. I confirm that:

- this work was done wholly or mainly while in candidature for a research degree at this University;
- where any part of this thesis has previously been submitted for a degree or any other qualification at this University or any other institution, this has been clearly stated;
- where I have consulted the published work of others, this is always clearly attributed;
- where I have quoted from the work of others, the source is always given. With the exception of such quotations, this thesis is entirely my own work;
- I have acknowledged all main sources of help;
- where the thesis is based on work done by myself jointly with others, I have made clear exactly what was done by others and what I have contributed myself;
- none of this work has been published before submission, or [delete as appropriate] parts of this work have been published as: [please list references]

Signed:

Date:.....

Acknowledgements

I would like to thank the Praboromarajchanok Institute for Health workforce development for funding my PhD.

I would like to express my gratitude to the psychiatric hospital, the research project collaborators, my research participants, and all who were involved in my data collection process in Thailand. Without such wonderful support, especially from Ms Thongjen, I do not know how I would have accomplished this hard work within the limited time.

Without the excellent and supportive supervisory team, I would not have reached this point. My sincere thanks go to Dr. Maggie Donovan-Hall, my main supervisor, who has devoted her time and effort to supervise me to reach the standard of doctoral level. I also would like to express my gratitude to Dr. Diane Carpenter and Professor Mary Gobbi, my co-supervisors, for their guidance, enthusiastic encouragement and useful suggestions regarding my work.

I felt honoured to have Dr. David Boorer to spend his time to proofread and recheck my thesis, to Dr. Sukhumaphorn Sriwisit and Dr. Buppha Raksanam for providing their valuable time to check the transcripts back translations, as well as Mr. Adam T.W. Marley, who rechecked the translated transcripts.

I would also like to express my appreciation to my family, friends, peer reviewers and the Buddhist monks who all helped and encouraged me to get through my PhD journey. I am also most grateful to the Faculty of Health Sciences, University of Southampton, for giving me chance to pursue my MSc and PhD programmes. I considered studying here has been one of the best chapters in my life.

Definitions and Abbreviations

Ch.	Chapter
CN	Chinat
DoMH	Department of Mental Health
DOT	Directly observed treatment
EE	Expressed emotion
KP	Khampaeng phet
NW	Nakhon Sawan
PC	Pichit
PCU	Primary Care Unit
SAO	Sub-district Administrative Organisation
THPH	Tambon Health Promotion Hospital
UT	Uthai thani
VHV	Village Health Volunteer
WHO	World Health Organization

1. Chapter 1 Introduction

This chapter illustrates my interest and background in this clinical area, which influenced my decision to carry out this research project.

1.1 Schizophrenia care as the study focus

I experienced caring for a female patient with chronic schizophrenia in a government psychiatric hospital in Thailand during my undergraduate nursing programme. I had mixed feelings at the time because I was new to psychiatric nursing. I was worried and afraid because she was a very strange and challenging patient for me to deal with; I saw her hit another patient once, and she also talked to herself most of the time. For the duration of my two-month placement I never saw anyone visit her. I wondered, amongst other things, how she could survive if she was discharged to live at home. Unfortunately, my questions were never answered.

Whilst completing my MSc in Advanced Clinical Practice, I researched information, documentaries, campaigns, videos and films related to schizophrenia; particularly regarding patients' experiences, stigma and caring for patients at home. One film that I personally found inspiring was *A Beautiful Mind*, based on the life of Professor John Nash, who was awarded the Nobel Prize in Economic Sciences, despite suffering from severe schizophrenia throughout his life. Although the issue of schizophrenia diagnosis is the subject of an on-going debate, this film has inspired me to consider cultural differences between Western countries and Thailand, concerning mental health. For example the hope, love and support from family and friends, as portrayed in this film, reduced Professor Nash's suffering to the extent that he eventually managed to live with schizophrenia and pursue an illustrious academic career. However, it is likely that that this is an exceptional case that has been exaggerated for a Hollywood film and is unlikely to reflect reality and real-life patients, few of whom enjoy such life trajectories. However, family support is something that is likely to be important, and can reasonably be expected in all cultures. This led me to consider whether such caring environments exist in rural Thailand, where cultures and religious beliefs potentially affect schizophrenia care.

1.2 My interest and background

My intention of studying abroad is to improve the quality of community mental health care for patients with schizophrenia in Thailand. My background is that of a Registered Nurse (RN) and I have a masters' degree in Advanced Clinical Practice (focusing on mental health) from the University of Southampton, UK. My mental health nurse's perspective influences me to consider providing community mental health care at the primary care service level, as a first priority. My masters' dissertation was about the effectiveness of using adherence therapy for patients with schizophrenia, with the aim of preventing their relapse and rehospitalisation.

I have been working for the Sirindhorn College of Public Health as a nursing lecturer for several years. It is interesting that the Public Health graduates, who are not specially trained to care for those with mental illness, need to be a part of a community mental health care team for discharged patients. It seems that patients with schizophrenia may need special care when living outside the psychiatric hospital, due to several influencing factors, such as non-medication adherence, stigmatisation and the nature of the disease itself. Hence, primary care is the most important level of care for preventing the re-hospitalisation of such schizophrenia patients; a home-based regimen which can cause patient and family burdens and increased health care expenses. A lack of mental health personnel may be considered as a limitation of the Thai health care system. Therefore, to resolve this problem, the idea of enabling and supporting community mental health services is considered to be the most efficient option to meet mental health care needs in the country.

Due to the current staffing structure, and the lack of health professionals with expertise in mental health care, at the moment the Thai government is unable to provide intervention care for patients with schizophrenia within community settings. Furthermore, there is currently a lack of understanding and insight into the stakeholders' needs regarding the delivery of further interventions and support in this area.

It therefore appears that it would be worthwhile to undertake a cross-cultural comparison between a developed country, the UK, where I pursued my MSc and PhD and a developing one, such as Thailand. This decision is based on the

thought that, without adjusting knowledge to be appropriate for specific cultural and health care contexts, new knowledge ‘imported’ from the UK, may be rejected by, and therefore not benefit, stakeholders in Thailand. In addition, it is considered that the UK has made significant progress in moving from the biomedical model of mental health care to a bio-psychosocial model more focused on client-centred care; while Thailand seems to retain the traditional biomedical paradigm of health care. Therefore, the UK mental health care experience could be used as a model for future improvement when adapted to the Thai context.

1.3 Conducting the study in rural Thai community settings

Thailand is a developing upper-middle income country located in South East Asia (World Bank 2014). In 2012 the Thai population was 66,785,000 people (World Bank 2014). 5.4 million are below the official poverty line, 88% of whom were living in rural areas (Thai National Statistical Office 2010; World Bank 2014). The prevailing culture is that of a relatively conservative Asian kingdom imbued with Buddhist ethics; 93.4% of the population are Buddhist, 5.2% are Muslim and 1.4% are Christian and other religions. The majority of the population (67.5%) is of working age (15- 59 years old) (Thai National Statistical Office 2010).

1.3.1 Rural definition

Defining the concept of ‘rural’ before starting this research project is crucial, because this definition will be used to exclude potential research participants who do not meet the inclusion criteria. Therefore, this definition procedure can help the researcher to achieve valid research results from real rural areas and participants, instead of urban or a mixture from both areas. Defining ‘rural areas’ is crucial for the government’s strategic planning, regarding the fair improvement of health care for real rural people (Hart et al. 2005b; Hart et al. 2005a). Generally, the definition of ‘rural’ varies because there are many criteria to categorise and define the meaning of the term, depending on the use to which it is put and the specific context of each country. For this chapter,

Chapter 1 Introduction

classification of rural definitions between Thailand, the UK and the US are illustrated briefly in appendix 1.

In conclusion, there is no international consensus on a definition of 'rural area' (Hart et al. 2005b; Hart et al. 2005a). Hence, the Thai definition of 'rural' is applied to this research as follows: 'the countryside or the regions that are far away from the capital city'. This will be suitable for the Thai context of this research, allowing the author to interpret the meaning of 'far away'. The uniqueness of the Thai rural areas is the researcher's concern; hence, city centre zones and major cities in Thailand are avoided. Therefore, the results of this study will be considered for mental health care improvement, particularly at the sub-district level in rural Thailand.

1.3.2 The importance of rural settings

Although the Thai public health department launched a service plan aiming to promote collaborative community mental health care within the community, and with different levels of care, there is a lack evidence to support whether people with schizophrenia in rural areas have received, or are receiving, the care they need. There are four interesting factors that may affect schizophrenia at the primary care level in rural Thailand: i) namely low-income, ii) unavailability of public transportation, iii) traditional culture/ belief systems, and iv) no full-time mental health specialists available for community mental health care. Therefore, these factors may affect mental health care at the primary care setting regarding accessibility and discontinuation of care.

Moreover, low income and limited transportation form substantial economic barriers to accessing care and continuing to receive it. However, from the Thai minimum wage (Trading economic.com 2015), it is can be assumed that people who live in the rural Thai community may have lower incomes because of their types of jobs; conversely, rural Thais are rich in cultural heritage and beliefs, which may affect mental health care.

1.3.3 Culture and the cultural impact on health

Culture is defined as “the collective programming of the mind” (Hofstede 1980 p13) which comprises four key components: ‘set of belief’, ‘behaviour’, ‘value’ and ‘lifeway’ (Bonder and Martin 2013 p3). Culture can shape an individual’s perceptions, which are not only about gender roles in society, socio-economic factors and social norms, but also health and illness (Helman 2007 p5; Hofstede 2011). It could be argued that culture and health perception is complicated; concepts about which there are many different perspectives. For example, health professionals and laypeople are likely to view disease and sickness differently (Conrad and Barker 2010); also laypeople and health professionals in different cultures may perceive and define health and illness differently (Bonder and Martin 2013). As a result, this may cause discrepancies between health care plans and treatment compliance (Bonder and Martin 2013).

Interestingly, Hofstede (2011) indicates that there are two distinct types of cultures in this model: namely, individualism and collectivism. An individualist is more self-centred, if compared to a collectivist, because an individualist lives a life by using their own values, beliefs and judgments. Alternatively, collectivists are more reliant on society’s norms and culture (Biddle 2012). It could be implied that an individualist (idiocentric) tends to be less concerned about social norms than a collectivist (allocentric) (Triandis et al. 1988).

Asian countries as a whole have been categorised as collectivist (Rhee et al. 1996; Hofstede 2011). However, in Thailand, peoples’ lifestyles in the capital city tend to reflect individualistic lifestyles, whereas people in rural areas could be considered to be more collectivist. Therefore, it could be seen that the Thai people in rural areas are potentially compliant with social norms, cultures and beliefs. At this point, it is considered that social support is essential for community mental health care, particularly in rural settings, because rural people tend to more concern about culture than urban dwellers. Hence, considering the patient’s culture is not only beneficial to their health, but also to their sense of self in their society (Conrad and Barker 2010; Gallagher et al. 2015). The rural Thai community is considered as collectivist because of the distinct characteristics regarding *Kreng Jai*, epitomised by sympathetic and supportive behaviour. In addition, there is not only the Thai culture which

could influence community mental health care but also the Buddhist beliefs. For example 'Boon' and 'Karma' could influence peoples' ways of thinking, which may relate to health perception, help seeking and health care provision. It could be summarised that culture and social norms not only shape an individual's perspective towards health and illness, but also their recovery; a point which will be expanded in Chapter 2 (topic 2.7.4).

1.4 The current Thai health care system and schizophrenia care

To enhance the health care services in the country, the *Thirty Baht Universal Health Care Coverage Policy* was inaugurated to provide free health care services from April 2001, in order to improve accessibility to care services (Suraratdecha et al. 2005 p227; Hughes and Leethongdee 2007 p1001; Bureau of Policy and Strategy Ministry of Public Health 2009). The policy is intended to enhance health care accessibility at different levels of care by using the referral system. This means that, if necessary, service users need to be referred to specialists by their general practitioners (GPs) or other health authority staff. For example, in the psychiatric hospital in this research, the ratio of psychiatrists and trained mental health specialists seems low relative to the Thai population. For every 100,000 population there are only 0.4 psychiatrists, and 3.02 postgraduate registered nurses (The Thai Ministry of Public Health 2013). Therefore, it is questionable whether the Thai mental health care system has the basic resources to provide the necessary care to meet patients' and caregivers' needs and maintain, and/ or improve the quality of care due to this chronic manpower shortage.

Furthermore, although the free health care scheme also covers the care of schizophrenia sufferers in community settings, who seem to be gaining greater accessibility of care, the Thai primary care level has faced problems of staff collaboration at different levels of health care provision and resource allocation (Hughes and Leethongdee 2007 p1006). Hence, it would be helpful to explore and understand the current situation regarding schizophrenia care provision from different perspectives.

1.5 Structure of the thesis

This PhD thesis comprises of seven chapters. Chapter one is the introduction, which reflects on why this research topic was of interest to the author and to nursing studies. The literature review in this study is divided into two separate chapters: two and three. This is because it is crucial to provide the discussion of ongoing schizophrenia debates, as well as literature reviews, which reveals gaps of knowledge and justifies the importance of conducting this research. Therefore, chapter two presents a review of literature concerning the definition and diagnosis of schizophrenia, its impacts, treatments, on-going schizophrenia debates and schizophrenia care in Thailand. Chapter three presents a literature review focusing on stakeholders' experiences and perspectives towards schizophrenia care in community settings. Furthermore, Chapter three also presents the rationale for conducting this research to fill the identified knowledge gap, as well as the research aims and research questions, are explained and discussed. Chapter four expounds the ontological and epistemological stance underpinning the study, justifying the methodology and approaches used in this research project. Chapter five illustrates research findings from the forty research participants comprising patients, caregivers and health care professionals. The data are categorised into three areas: i) the lived experience, ii) the importance of medication, and iii) the service and support needs. Chapter six presents the discussion of research findings in the two main findings' areas, namely, i) the lived experience, and ii) the importance of medication. Chapter seven expounds schizophrenia care recommendations. The researcher's experiences of conducting research in rural Thai settings are also reflected upon and discussed in this chapter. Moreover, the contribution of the research to community mental health nursing knowledge and the final conclusion are summarised in order to highlight the importance of schizophrenia research in primary care settings in rural Thailand.

The next chapter provides a detailed background on schizophrenia, as sourced from relevant literature, together with its allied controversies which have been debated for over a century.

2. Chapter 2 Schizophrenia background

Introduction

This chapter aims to contextualise the background of schizophrenia by providing a literature review focusing on a brief history of schizophrenia, including causation, impact, diagnostic criteria, debates, treatments and recovery. Schizophrenia is known as the most severe and chronic mental disorder; however, it is also considered to be a potentially treatable disorder (WHO 2014). The symptoms related to a diagnosis of schizophrenia are viewed as positive (e.g. delusions and hallucinations) and negative symptoms (e.g. apathy and social withdrawal) (WHO 1992; NHS Choice 2012; American Psychiatric Association 2013). Currently, debates about schizophrenia diagnostic systems are probably unresolved. It should also be stressed that this review is based on standard diagnostic criteria regarding the ICD and DSM systems, which are used around the world in order to reduce diagnostic errors. A systematic search was used to find relevant evidence regarding the aetiology, diagnosis, debates, impact of and treatments for schizophrenia.

2.1 Finding relevant evidence

Several resources were searched for evidence relating to the relevant topics: namely, book chapters, websites, journal articles, unpublished MSc dissertations and PhD theses, government documents and electronic databases. Electronic databases were searched: specifically CINAHL, MEDLINE, PsycINFO, Web of knowledge, EMBASE, AMED and ThaiLIS (a Thai database). References, citations and other relevant literature from 'Google scholar' were manually searched, seeking seminal works as well as a broader range of key papers in the field. The numbers of final selected articles are illustrated in Figure 1. The systematic search, article selection and critical appraisal processes are outlined in appendices 2-5.

Chapter 2 Schizophrenia background

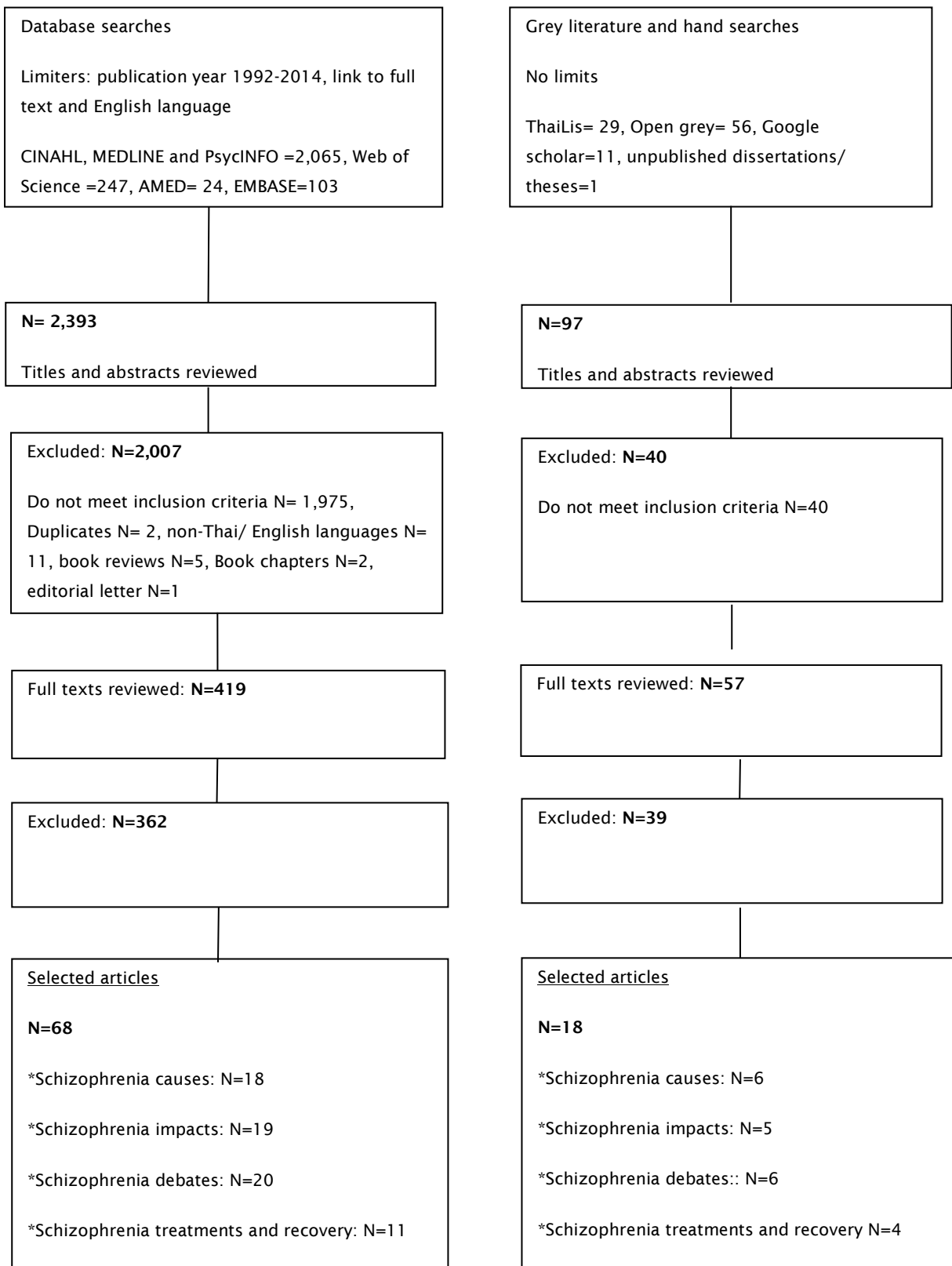


Figure 1 Database search and literature selection

2.2 A brief history of schizophrenia

Schizophrenia comes from Greek rooted words which are *schizein* (split) and *phren* (mind); a name based on the belief that the illness is caused by evil or a spirit (Fusar-Poli and Politi 2008). Schizophrenia is a severe and long term condition which is normally recurrent within one, two or five years after the prodromal stage: the stage of emerging social withdrawal and lack of interest with self and the environment (Kongsakorn et al. 2005; NICE 2010; Centre for Addiction and Mental Health 2012; Department of Mental Health 2012). Before the term schizophrenia emerged, there was no concept of this type of mental disorder. Dr. Emile Kraepelin, a German physician, used 'dementia praecox' to name this group of symptoms but the criteria used to categorise this disorder were not fully accepted because they were unclear and came from unreliable retrospective data collection (Read 2004d; Jablensky 2010). Later, Sigmund Freud indicated the concepts of mental functioning and symptom formation, which has been used by Eugen Bleuler to further develop the concept of schizophrenia (Rosenthal 1968; Ashok 2012). Bleuler was a Swiss psychiatrist who rejected Kraepelin's dementia praecox concept and constructed a broader concept of schizophrenia (Jablensky 2010; Ashok 2012; Black and Grant 2014). Following this, the concept of schizophrenia was modified by Schneider, thereby influencing the starting point of development of the schizophrenia diagnostic criteria; the DSM criteria (Black and Grant 2014). These criteria are helpful for psychiatrists, particularly in investigating and diagnosing schizophrenia. Categorising schizophrenia by using standardised criteria helps to estimate its incidence and prevalence rate, which will be discussed below. It is argued that the term schizophrenia may not explicitly characterise this mental disorder, because schizophrenia is no longer regarded as a fragmented mind or personality (Kim and Berrios 2001; Silveira et al. 2012; Living with schizophrenia 2014). This may be because the term 'split-mind' is not a precise concept to define the characteristics of schizophrenia (van Os 2009). Moreover, some of the symptoms of schizophrenia overlap with other physical and psychological diseases, such as catatonic behaviour (American Psychiatric Association 2014).

2.3 Incidence and prevalence rates

For global incidence and prevalence rates, the incidence rate (new cases) of patients with schizophrenia is around 3 per 10,000; the prevalence rate (all patients with schizophrenia) is approximately 1% of the world's population (WHO 2014). It is argued that the discrepancies and biases in the criteria used to diagnose schizophrenia will impact on the global incidence data and prevalence rates, as a result of using unreliable diagnostic criteria and 'biased assessment' (Barbato 1998 p6; Read 2004a p44). For example, prevalence rates in Spain and the UK are quite similar, with the prevalence rate in Spain around 3 per 1,000 (age between 18-54 years) and 5 of 1,000 persons in the UK (age between 16-75 years) (Ayuso-Mateos et al. 2006; NICE 2010). In the Thai community setting, the prevalence of schizophrenia among the adult group is around 8.8 per 1,000 (Phanthunane et al. 2010); in this research the adult survey group is aged between 15- 59 years. There are some hidden reasons, including legislation, culture and belief systems, which may stop people from seeking formal help which, in turn, can result in hiding cases or delaying treatments (Swartz et al. 2003; Wang 2011). Thus, this may affect the number of people who have been officially diagnosed with schizophrenia in some countries. For example, Taiwanese patients with schizophrenia tend to use informal mental health services, such as Buddhists and folk healers to treat psychotic symptoms (Wang 2011). Therefore, knowing the potential causes of the illness can help to prevent the harm associated with schizophrenia.

2.4 The causes of schizophrenia

The actual causes of schizophrenia are unknown. There are several belief models which underpin schizophrenia's aetiology, which can be broadly categorised as lay and scientific perspectives.

2.4.1 People's general perspectives towards the causation of schizophrenia

Six studies (Furnham and Chan 2004; Godoy-Izquierdo et al. 2007; Saravanan et al. 2007; Sanseeha et al. 2009; Sanders et al. 2012; Chakraborty et al. 2013) met the inclusion criteria and were chosen in order to discuss the lay perspective of the aetiology of schizophrenia; across the world in general and

Thailand in particular. There are five cross-sectional studies, of which two are from India, one from Spain, one from Australia and one from Hong Kong. There is only one phenomenological study from Thailand. These studies focus on understanding the perception of schizophrenia, in which clinical implications could refer to seeking help and establishing a mental illness perception model. The studies have shown that lay people have various perceptions of schizophrenia's causes, which depend on their belief systems, as well as information they have received. This section will discuss the lay perspective of the causes of schizophrenia, compared with lay Thai people. It appears that supernatural beliefs regarding schizophrenia are likely to occur in developing countries; beliefs which may be informed by religious values. The evidence shows that lay people who believe in different religions have different views towards the diagnosis of schizophrenia. The southern and eastern Indian population, many of whom have little or no education, who live in rural areas, and whose faith is Hindu or Islam, believed in non-physiological causes of schizophrenia (Saravanan et al. 2007; Chakraborty et al. 2013). People in southern India and north-eastern Thailand have similar views towards schizophrenia's causation. Such views consider 'black magic, evil spirits and previous deeds' can cause schizophrenia, which may be similar to the views of traditional Hong Kong Chinese people (Furnham and Chan 2004; Sanseeha et al. 2009; Chakraborty et al. 2013). The phenomenological study reveals that Thai people believe in 'bad karma' based on the Buddhist belief which perhaps influences them if they suffer from schizophrenia as a patient, family member or caregiver (Burnard et al. 2006; Sanseeha et al. 2009). 'Bad karma' in Buddhism means doing something wrong, either from a past life or this life, so schizophrenia is seen as punishment. However, it should be noted that both studies focused upon patients with schizophrenia and their family members with low incomes and education and, therefore only explored a small group. The study by Chakraborty et al. (2013) recruited four groups of patients, with schizophrenia, depressive disorder, obsessive compulsive disorder (OCD) and other anxiety disorders, and somatisation and dissociative disorder; so recruiting patients with more than one diagnosis can cause heterogeneity. The authors did not discuss the issue of ethical approval. Additionally, the recruited participants were from outpatient departments only; focused on the working group with an age range between 32.82 ± 12.82 years old (maximum is 45.64 and minimum is 20 years old). For Sanseeha et al. (2009) their study cannot

Chapter 2 Schizophrenia background

easily be generalised as the eighteen Buddhist participants were from the north-east of Thailand. However, in Thailand there are mixtures of different local cultures which allow local lay people to view the causes of schizophrenia differently. For example, the family of patients with schizophrenia in the south of Thailand tend to perceive that schizophrenia is a test from Allah (the Muslim's God), so it is believed that people with schizophrenia have undergone the expiation of sin, and both they and their caregivers obtain merit (Vanaleesin et al. 2007). However, Vanaleesin et al. (2007) and Chakraborty et al. (2013), who focussed on the Muslim culture, present different points of view.

In Australia, Maori people are a minority group who believe that supernatural power can cause schizophrenia (Sanders et al. 2011). This is completely different from Hong Kong (a small developed Asian country) and the UK where, in general, people believe that bio-psychosocial factors cause schizophrenia. However Hong Kong Chinese people appear to have a more negative attitude towards schizophrenia (Furnham and Chan 2004). Australians tended to believe that drugs, alcohol and bio-psychosocial factors can cause schizophrenia, whereas the Spanish believe that emotions can cause schizophrenia (Godoy-Izquierdo et al. 2007; Sanders et al. 2011).

It can be seen that the instruments used to gather data for the five cross-sectional studies were different, and some researchers appear to have used inappropriate tools. For example, Sanders et al. (2011) used the Drug Attitude Inventory (DAI-10) and Brief Illness Perception Questionnaire (B-IPQ) to measure schizophrenic illness perception. The nature of the DAI-10 instrument focuses on how a person perceives themselves when taking medication, which obviously is not relating to mental illness perception. The B-IPQ, which was used by Saravanan et al. (2007), is too general and fails to give any details about how one perceives his/her mental illness, if compared with the expanded version of the Schedule of Assessment of Insight (SAI-E).

The perspectives towards the causes of schizophrenia in Thailand are limited in the north-east and the south of Thailand, where the cultures and beliefs are different from the other parts of Thailand. Hence, the generalisations of the study results need to be addressed with caution, particularly using the evidence relating to local mental health care anywhere else.

In summary, religions and belief systems can influence people to perceive schizophrenia's causes differently. Lay people, with low education and economic status in developing countries, tend to believe in supernatural, rather than scientific, factors to explain schizophrenia and its causes. People who have the same religious beliefs, such as Muslims in India and Thailand, perceived schizophrenia's causes distinctively. Science and technology are growing gradually around the world, including in Thailand. Hence, the next section will provide the scientific perspectives towards schizophrenia's causation in the world, compared to Thailand.

2.4.2 Scientific perspectives towards schizophrenia causation

The scientific beliefs of schizophrenia's causation can be divided into three groups: genetic factors, environmental factors or abnormalities of brain and neurotransmitters (Tsuang 2000; Tsuang et al. 2001; Os and McGuffin 2003; Van Haren et al. 2013; Poels et al. 2014). The medical model focuses on biological causes and their impacts. However, there are similarities between Thailand and other countries regarding the medical model's explanation of the causes of schizophrenia. Ten academic articles (three systematic meta-analyses, three reviews of literature, three case control studies and an editorial) were reviewed. The selected papers will be used to discuss the aetiology of schizophrenia, according to the bio-psychosocial model. This section will be divided into two parts: early and late life factors.

2.4.2.1 Genetic factors

In early life, there are several factors that can cause schizophrenia; namely genetic factors – with evidence from studies of both identical and non-identical twins, maternal factors, birth complications and environmental factors. The evidence shows that fathers aged 50 years and older may be at an increased risk of having children with schizophrenia, particularly when compared with fathers aged 25 years or younger, because of sperm mutations (Mark and Opler 2008; Matheson et al. 2011). This may imply that defects of genes can cause schizophrenia, which may happen before embryo fertilisation. There are several research projects working on finding specific genes that influence schizophrenia, based on the belief that a specific gene may cause the illness and that it can transfer from parents to children (Govitrapong et al.

Chapter 2 Schizophrenia background

2002; Wong and Van Tol 2003; Lichtenstein et al. 2009; Fleming and Martin 2011; Matheson et al. 2011; Owens et al. 2011; Panichareon et al. 2012a; Panichareon et al. 2012b). There are certain gene locations that may cause schizophrenia and psychosis, such as 22q11-13, 5q, 11q, 18q, 19p and 22q (Wong and Van Tol 2003 p286). The locations, namely OPCML, CTXN and SLC12A2 genes, were claimed as risk factors for schizophrenia in Thai populations (Panichareon et al. 2012a; Panichareon et al. 2012b). However, these studies have not been replicated worldwide (Fleming and Martin 2011).

A systematic review and meta-analysis claimed that genes play an important role in predicting schizophrenia. The chance to have schizophrenia among twins depends on their origins; whether they are monozygotic or dizygotic. For example, there is an 81% chance for another identical twin to have a diagnosis of schizophrenia if the first twin is so affected (95% Confident Interval, 73-90%) (Sullivan et al. 2003). Furthermore, monozygotic twins (the twins that have shared genes) have a 50-70% greater chance of being diagnosed with schizophrenia, than the general population (Tandon et al. 2008). If one of the dizygotic twins has schizophrenia, the other twin will have approximately a 14% chance of also having schizophrenia, whereas the general population will have only a 1% chance (NHS Choice 2012). However, Owens et al. (2011) suggests there is no significant specific gene that causes schizophrenia in twins.

It is argued that although there are several studies which report links between genes and schizophrenia, there are no specific genes that are a schizophrenic marker (National Alliance on Mental illness 2014). Moreover, heterogeneity of the empirical studies may mislead conclusions from meta-analysis data due to no common standard of participant recruitment, regarding the use of diagnostic criteria (Sullivan et al. 2003).

2.4.2.2 Environmental factors

In later life, environmental factors can influence schizophrenia (Johannessen 2002). There are several potential environmental factors that may cause or influence schizophrenia; these can be separated into two phases, namely prenatal and postnatal periods.

In the prenatal period, hazardous chemical exposures, infections and birth complications are risk factors relating to having children with schizophrenia (Mark and Opler 2008; Khandaker et al. 2013a; University of Maryland Medical Center 2014). Additionally, a systematic review suggested maternal respiratory or reproductive infections as possible causes of schizophrenia (Khandaker et al. 2013b). On the other hand, a cohort study showed that there is no relationship between the herpes simplex virus type 2 and the development of schizophrenia (Brown et al. 2006). There are low effect sizes for maternal factors, such as having a diagnosis with diabetes mellitus, stress and nutrition that may cause schizophrenia (Matheson et al. 2011).

Birth complications, such as emergency Caesarean section, have a medium effect size for having a child with schizophrenia (Matheson et al. 2011). After the birth of a baby, it is found that those who have had a traumatic birth and asphyxia have a higher chance of developing schizophrenia in the future than children who did not experience such trauma (Dalman et al. 2001; Braehler et al. 2013; University of Maryland Medical Center 2014). Although a meta-analysis was conducted with regard to obstetric complications inducing schizophrenia (pooled estimated 1.3, 95% CI 0.87 to 1.98), recruitment biases are of concern regarding the authors being limited to a specific tool, unclear criteria and severity of obstetric complications (Geddes and Lawrie 1995 p 421; Crow 2001). Furthermore, the season of the birth has been shown to be linked to the development of schizophrenia, with higher incidence accompanying a winter birth; however, the incidence is quite low at around 1.1% (Tandon et al. 2008; Matheson et al. 2011; Cheng et al. 2013). There are several hypotheses on season of birth causing schizophrenia, such as influenza and measles infection, extreme cold temperature exposure, genetic causes and malnutrition in winter time (Battle et al. 1999). This means that people who were born in the winter season may have other risk factors that cause them to have a diagnosis of schizophrenia. Hence, it is argued that there are some unknown causes for schizophrenia, rather than merely a winter birth (Tochigi et al. 2004).

Moreover, people who were born and/or live in urban areas may have a higher chance of being diagnosed with schizophrenia, as compared to those living in rural areas, although there is only a small effect size for this factor (Matheson et al. 2011). For example, a meta analysis indicated that the effect size, calculated from the Netherlands, Sweden and Denmark, is 2.37 (95%

Chapter 2 Schizophrenia background

confidence interval [CI] = 2.01–2.81) (Vassos et al. 2012 p 1121). From the Israeli perspective, men who are living in urban cities with high population density areas (0.10%, 95% CI; 0.019–0.18, P=0.015) are at risk of having schizophrenia (Weiser et al. 2007). Weiser et al. (2007) suggested that although living in urban areas itself exerts only a small impact on having a schizophrenia diagnosis (0.0098), it will be greater if this is combined with having low cognitive and social functioning. Stress in urban living seems to be a major issue which influences schizophrenia (Lederbogen et al. 2013). Additionally, urban areas offer increased chances to get infections and exposure to chemical substances (as in air-borne pollutants), but the incidence is inconsistent (McGrath 2006). It is argued that little is actually known about the environmental factors that can cause schizophrenia (Tandon et al. 2008).

2.4.2.3 Brain and neurotransmitters

It is considered possible that brain and neurotransmitter abnormalities can cause schizophrenia. Abnormal brain anatomy has been associated with schizophrenia (Alvarez-Jiménez et al. 2009; NHS Choice 2012; Moran et al. 2013; Van Haren et al. 2013; Roman-Urrestarazu et al. 2014). Although larger brain ventricles have been linked with schizophrenia, this factor can also be found in other mental disorders, such as bipolar disorder (Strasser et al. 2005).

Brain lesions have also been implicated as a potential cause of schizophrenia. In addition, brain lesions at the orbitofrontal cortex can also negatively affect a patient's decision making (Larquet et al. 2010). In such a case, this may include trauma patients who did not have schizophrenia before. For example, having a brain trauma injury may bring schizophrenia later (see cases involving other schizophrenia risk factors) (Lederbogen et al. 2013). Hence, careful differential diagnosis is crucial.

It is not only brain defects which have been associated with schizophrenia, but also abnormalities of neurotransmitters. For neurotransmitter abnormalities, a study indicated that abnormality of glutamate metabolism is one hypothesised cause of schizophrenia (Poletti et al. 2013; Poels et al. 2014). The neurotransmitter dopamine is also believed to be associated with schizophrenia; hence neuroleptic drugs have been developed to block dopamine transmission (Remington et al. 2013; Seeman 2013; Kimura et al. 2014). However, such blocking may influence the dopamine system to become

over-active (Read 2004a). Moreover, one neurotransmitter that is believed to be a positive symptom stimulant is serotonin (Eggers 2013). It is arguable that although brain lesion and metabolism may cause schizophrenia, the evidence for this is unclear (Gainetdinov and Mohn 2001; Abi-Dargham 2004; Howes and Kapur 2009; Onitsuka et al. 2013).

Traumatic brain injury (TBI) may cause schizophrenia but it is only a small effect size (Matheson et al. 2011). On the other hand, Molloy et al. (2011) found that there is a significance between TBI and diagnosis of schizophrenia; however, there is no evidence available about the levels of TBI.

2.4.3 Psychosocial perspectives

Read and Haslam (2004) point out that most people generally consider that psychosocial factors, such as child development problems, family issues, stress from life events, and socio-cultural issues can cause schizophrenia more than biological causes such as, brain chemical or genetic abnormalities. There is evidence that psychosocial factors, such as unhappy or dysfunctional families, childhood trauma, loss and stress are identified as possible causes of schizophrenia (Os and McGuffin 2003; Read et al. 2004a; NHS Choice 2012). However, Matheson et al. (2011) found no significance for childhood sexual and/or physical abuse as causative. It is argued that although psychosocial factors may not be a significant cause of schizophrenia, they may influence the recurrence of psychotic symptoms (Os and McGuffin 2003). For example, after having a diagnosis of schizophrenia there are associations with low family support, unemployment and cultural factors regarding emotional expression, which can cause relapse (San et al. 2013; Singh et al. 2013). The three main psychosocial factors identified in the literature: child development and family relationships, life-events and socio-cultural factors, are discussed below.

2.4.3.1 Child development and family relationships

Family background and family relationships appear to be associated with schizophrenia. Poor communications between family members, particularly between a mother and child are especially noteworthy. This perspective is associated with psychodynamic, family transaction and double bind theory. Psychodynamic theory hypothesises that children who have been over-protected from their mothers will be at risk of contracting schizophrenia, if

Chapter 2 Schizophrenia background

compared with mothers who rejected their children (Meyer 1999). The psychodynamic model outlines the concept of miscommunication in the family, which can cause stress and 'disassociation'. Likewise, the double bind model indicates that a 'schizophrenogenic mother' produces unclear messages to the child, which causes frustration and fixation (Bateson et al. 1976; Weakland 1976). The transaction theory highlights the importance of the way that the family communicate, which may put the child in 'can never win' situation, whereas the family transaction theory focuses on characteristics, such as, rigid, loose and ambiguous communication (Ferriter 1999 p81). Stress in an unhappy family, which may come from poverty, low social class and poor family communication, could cause emotional breakdown and possibly trigger schizophrenia (Read 2004e; Read et al. 2004b). Interestingly, immigrants and ethnic minorities who have low socio-economic background tend to be more likely to be diagnosed with schizophrenia when compared with wealthy people. It could be hypothesised that having a low income could cause conflicts and arguments among parents which, in turn, could cause stress in the family (Read et al. 2004b). Communicating by negative emotional expression is also correlated with the onset of schizophrenia (Phillips et al. 2007). It is worth noting that expressed emotion (EE) may cause stress between patients and their relatives (Bachmann et al. 2002); family arguments and high emotional expression may cause relapses in schizophrenia sufferers (Bebbington and Kuipers 2008).

2.4.3.2 Life-events

The stress-vulnerability model is considered as one possible explanation of schizophrenia's cause (Zubin and Spring 1977). Phillips et al. (2007) argued that although stress could potentially be associated with the onset of schizophrenia, it is still unclear how stress causes psychosis. Stress could come from serious life events, such as divorce, losing a loved one and other traumatic family issues. This may create a higher risk of having a diagnosis of schizophrenia. For example, Read et al. (2004b) maintain that higher expressed emotion (EE) increases a relapse risk in patients with schizophrenia. This can be seen in some cultures where there is significant negativity towards this group. A study by Hultman et al. (1997) found that patients with schizophrenia who sought social support, could cope better with their negative life-events which, in turn, could help to delay any relapses.

2.4.3.3 **Socio-cultural factors**

The individual's social network appears to be an important factor associated with the causation of schizophrenia, which could be linked to labelling theory. There are negative and positive sides of social networks in relation to coping with stress. Fewer social networks and less support may be a schizophrenia influencing factor (Hammer et al. 1978; Bebbington and Kuipers 2008). However, unhelpful and critical social networks could be particularly stressful. Labelling theory suggests that when a person stands out from the social norm, for example by being a member of an ethnic minority group, they feel that they are discriminated against, which may increase stress (Bryant-Davis and Ocampo 2005).

In summary, psychosocial factors can be a potential schizophrenia cause. All three main psychosocial factors: child development and family relationships, life-events and socio-cultural factors appear to be associated with the diagnosis of schizophrenia; however, substantial evidence regarding these psychosocial factors as causative remains debatable.

2.4.4 **Schizophrenia's triggers and other risk factors**

There are some special characteristics that may be risk factors for schizophrenia, such as gender, age, drug abuse, urban living and immigration (Matheson et al. 2011; NHS Choice 2012; University of Maryland Medical Center 2014). In addition, males tend to be diagnosed with schizophrenia more frequently than females, at a ratio of 1.4:1 (McGrath 2006). Schizophrenia is a mental disorder that usually first occurs during late adolescence and young adulthood (16-30 years) (University of Maryland Medical Center 2014). However, another risk factor, late-onset schizophrenia (having schizophrenia at the age of 40 or over) is more commonly diagnosed in woman rather than men (American Psychiatric Association 2013).

In summary, schizophrenia's causation is various and demonstrates no absolute pattern. It can be noted that psychosocial factors are similar to the other potential causes of schizophrenia, in that they are unlikely to be a single cause but constitute influencing factors. The existing evidence can be used,

Chapter 2 Schizophrenia background

albeit cautiously, because the studies are of low quality. Although there are several studies about the aetiology of schizophrenia, they are limited in terms of replication (Fleming and Martin 2011). This may be difficult for lay people to understand, as well as opposing lay people's beliefs towards schizophrenia's causation. Although the causes of schizophrenia are unclear, the disease affects not only patients, but also people who are involved with caring for someone with the diagnosis. A nation's human resource pool and economic well-being will also be negatively affected.

2.5 Diagnostic criteria

There is no laboratory test to confirm a diagnosis of schizophrenia but it is usually based upon the evidence from presented symptoms and storytelling from patients, their relatives and caregivers (Sanders et al. 2012). Currently, there are two international classification systems for the diagnosis of schizophrenia: the International Classification of Diseases 10 (ICD 10) and the Diagnostic and Statistical Manual of Mental Disorders 5 (DSM 5) (WHO 1992; American Psychiatric Association 2013). Both ICD 10 and DSM 5 will now be described and compared.

2.5.1 The International Classification of Diseases 10 (ICD 10)

In general, the ICD 10 provides disease classification criteria, including those for schizophrenia. The ICD 10 has been developed and improved by the World Health Organization (WHO), and now comprises clinical and research versions (WHO 2014). Its intention is to minimise cultural bias, as well as improve generalisability of the diagnostic criteria. The ICD 10 was developed by multicultural mental health professionals who are experts in the field (Alarcón 2009). ICD 10 is not only beneficial in clinical practice, but also in health policy, research and statistics regarding mortality and morbidity rates.

2.5.2 Diagnostic and Statistical Manual of Mental Disorders 5 (DSM 5)

DSM 5 was developed by the American Psychiatric Association (APA), and launched in May 2013 (American Psychiatric Association 2013). There are some changes to the diagnosis, such as cancelling schizophrenia sub types in order to improve validity of diagnosis, as well as clarifying characteristics of

catatonia (American Psychiatric Association 2014). However, both ICD 10 and DSM 5 aim to assist their users to unite schizophrenia diagnoses, as well as improving the reliability and validity of diagnostic criteria (Michael et al. 2004).

2.5.3 Diagnostic criteria: ICD and DSM systems in Thailand

ICD 10 was introduced in Thailand in 1993 and was piloted in 15 hospitals (Wansa 2006). In Thailand, it is accepted that both ICD and DSM have been used for clinical diagnosis and research (Leelanuntakit and Udomratn 1999). Currently, ICD 10 TM is being developed in order to adjust the coding system and criteria to suit the Thai health system (Nitsuwat and Paoin 2012). For example the addition of treatment-resistant schizophrenia would be more inclusive and thereby help to develop a more specific treatment plan (Udomratn 2009). It is arguable that ICD-10 may not perfectly match with the Thai context. There are some debates around schizophrenia, the discrepancies and limitations of the diagnostic criteria, and accuracy of diagnosis, which will be discussed below.

2.5.4 Limitations of ICD 10 and DSM 5

Although ICD 10 and DSM 5 have been developed and improved, it appears there are also some limitations, such as code recording, details of the diagnostic criteria, language and cultural differences. Moreover, ICD10 and DSM 5 only provide short explanations for schizophrenia diagnosis (Frances and Widiger 2012; Frances and Nardo 2013). It is indicated in the DSM 5 that language and culture may lead to a misdiagnosis regarding delusional experiences and alogia (American Psychiatric Association 2013). Hence, cautious assessment is required regarding immigrants who speak different languages and have different cultural backgrounds from those of the mental health assessors (WHO 1992; American Psychiatric Association 2013). ICD 10 and DSM 5 are the most popular classification systems for the diagnosis of schizophrenia and are available for international application (see appendix 7). ICD 10 and DSM 5 are similar in terms of defining schizophrenia and recognising it as a cognitive deficit disorder. Both ICD 10 and DSM 5 define schizophrenia based on abnormalities of moods, emotions, cognition and behaviour. However, the definitions are not unequivocally clear (Frances and Widiger 2012); hence schizophrenia may be redefined in ICD 11 (Frances and

Chapter 2 Schizophrenia background

Nardo 2013). It is arguable that schizophrenia itself is an unclear mental disorder for which there is no study which could clarify actual causes and/or the relationships between potential causes and dysfunctions (Keukens 2006). Thus, the definition of schizophrenia will continue to be a contentious issue due to limitations of scientific evidence to clarify its causes, symptoms and associated dysfunctions (Frances and Widiger 2012).

The APA decided to cancel schizophrenic subtypes and catatonic behaviour because they intended to maintain validity of the criteria (American Psychiatric Association 2014). However, the appearance of schizophrenia subtypes may affect morbidity rates, because this will not be compatible with ICD 10. Furthermore, DSM 5 only provides a one month period for confirming a diagnosis of schizophrenia after having positive signs and it is possible that some patients may have another mental disorder or organic brain disorder instead, or as well. Hence, this may affect prevalence rates, treatments and stigma afterward.

2.5.5 Accuracy of diagnosis: schizophrenia comorbidity

Read (2004b) and Keshavan et al. (2013) argue that using schizophrenia as a current term does not show diagnostic accuracy. Although ICD 10 and DSM 5 provided differential diagnoses for schizophrenia, some authors state that it is doubtful whether schizophrenia does actually exist, or if there is a group of psychotic symptoms clearly denoting the existence of schizophrenia. This uncertainty is because schizophrenia itself consists of psychotic symptoms shared with other mental disorders, such as bipolar disorder and post-traumatic stress disorder (PTSD) (Gearon et al. 2003; Bottas et al. 2005; NHS Choice 2012).

On the other hand, a confirmed diagnosis of schizophrenia can negatively affect individuals with this mental illness. It is argued that schizophrenia cannot be used for describing, and therefore labelling, patients (Desapriya and Nobutada 2003; Sato 2003; Takahashi et al. 2009; van Os 2009; Brabban et al. 2013; Keshavan et al. 2013; Lasalvia and Tansella 2013; Lee et al. 2013; Sugihara and Takei 2013; Maruta et al. 2014).

2.5.6 Current debates about schizophrenia around the world

There are issues concerning schizophrenia which have not been completely resolved. This is because schizophrenia itself may not be viewed as one single mental disorder, but a group of psychotic symptoms (Bentall 1990; Bentall 1993; Knoll et al. 1998). Additionally, schizophrenia's diagnosis is considered an unreliable procedure due to the low standardisation of clinical diagnosis around the world (Read 2004b). Unfortunately, the evidence regarding debates about schizophrenia in Thailand is unavailable. Hence, only evidence from western and eastern countries will be discussed below.

2.5.6.1 Antipsychiatry movement

In the early 1930s, Laing criticised and opposed the idea of mental health diagnosis and treatment. This was later termed the 'anti-psychiatry' movement by Cooper (Szasz 2008). The anti-psychiatry movement was initiated mainly by Laing, Szasz and Cooper, a group of psychiatrists who intended to reform both mental health diagnosis and treatment (Coppock and Hopton. 2000; Szasz 2008). Interestingly, Laing and Cooper were trained in the communist system (Szasz 2008). This may have influenced their philosophy regarding the concern of equality of humanity in every single person. Anti-psychiatry was initially introduced in the USA and came to the UK in late 1970s (Coppock and Hopton. 2000).

The key points of the anti-psychiatry movement are the 'myth of mental health causation', the ineffectiveness of antipsychotic medication and that ECT was considered a dehumanising treatment. 'Schizophrenia' is criticised as a myth because the actual cause is still unknown; therefore a diagnosis of mental illness only serves to label a person (Coppock and Hopton. 2000; Szasz 2008; Whitley 2012). The antipsychiatry group viewed mental health problems as a phenomenon, instead of as a disease, which could happen to everybody (Szasz 2008). Furthermore, the antipsychiatry group believed that antipsychotic medication only benefitted drug companies (Szasz 2008). They argued that if the actual cause was still unknown, how could it be treated? As an example, they argued that antidepressant medication and placebos are equally effective for patients (Whitley 2012). In addition, ECT was considered a dehumanising treatment and both physical and ethical dilemmas surrounded it (Szasz 2008; Adams 2015).

Chapter 2 Schizophrenia background

Currently, the antipsychiatry movement allows people with mental health problems to talk about their experiences and need for care (Crossley and Crossley 2001). Interestingly, there is an example of non-medication compliance in India, where the authors appeared to oppose the antipsychiatry movement and suggested health education for the wider public regarding the effectiveness of treatment compliance (Arun and Chavan 2004). It could be deduced that perspectives towards mental health disease could lead to patterns of mental health care. This suggests that once people with mental health problems believe that neuro-chemicals are causative, they would be more likely to seek for medication treatment.

Thailand seems to have no formal antipsychiatry movement. This may be because of the specific Thai belief system regarding fear of labelling and being afraid to oppose health professionals. The fear of labelling could be expanded in that, generally, Thai people avoid seeking help from mental health services (Lotrakul and Saipanish 2009). In the rural Thai community, people do not normally criticise or oppose the health professionals' opinions, which may be because they believe that the health professionals know more than they do. Hence, these two main beliefs may inhibit the formation of an anti-psychiatrist movement in Thailand.

2.6 The impact of schizophrenia

The impact of schizophrenia is varied and severe. It is not only patients themselves who are affected, but also health systems, national economies, family members and communities. This topic will illustrate schizophrenia's impacts regarding patients, caregivers, health systems and national economies and will be discussed below.

2.6.1 Impacts on patients

Schizophrenia affects patients cognitively, physically and socially. Unfortunately, there is no Thai study available in this topic area; thus only evidence from western countries will be discussed.

2.6.1.1 Cognitive function

Schizophrenia affects a patient's cognition, perception, behaviour and communication (NICE 2010; WHO 2011; Joseph et al. 2013). Cognitive functioning impairment among patients with schizophrenia can affect occupational, social and economic functioning, which may be unrelated to the severity of the psychotic symptoms (Keefe and Harvey 2012). Patients experience a decline in their capability of doing everyday life activities, such as shopping, as well as in their communication skills (Harvey and Bowie 2012). This may link to problems with their ability to memorise. Additionally, abstract thinking and conceptual organisation are also negatively correlated with psychotic symptoms (Urbach et al. 2013). Most patients with schizophrenia have memory impairment regarding learning new information, reasoning and problem solving, speed of processing and thinking (Keefe and Harvey 2012). These issues can affect social skills in patients with schizophrenia.

2.6.1.2 Social function

Although some patients with schizophrenia are free from cognitive impairment, social withdrawal may still occur. From the psychological perspective, the Theory of Mind (ToM) is an individual's capability to understand other people's mind or body language, based on one's own information perception (Brüne 2005). Urbach et al. (2013) found no correlation between social skills regarding ToM with positive symptoms among patients with schizophrenia. 'False beliefs', which are influenced by positive symptoms, affect social dysfunction in patients with schizophrenia (Strauss 1993 p215; Brüne 2005 p23). Patients with schizophrenia have low ability to concentrate on social communication, which may affect socialising (Keefe and Harvey 2012).

2.6.1.3 Occupational dysfunction

The impacts of cognitive and social dysfunctions can deter patients with schizophrenia from working. For example, reading impairments can disrupt a patient's thought processes which may affect their study or career (Keefe and Harvey 2012; Whitford et al. 2013). Social withdrawal is usually found in males with schizophrenia (American Psychiatric Association 2013). This may be because of the pathology of schizophrenia itself, experiencing low self-esteem

Chapter 2 Schizophrenia background

after having cognitive deficits and social impairments. Schizophrenia causes occupational dysfunction (American Psychiatric Association 2013).

2.6.1.4 Physical health impacts

It appears that patients with schizophrenia have shorter life expectancies than the general population (Jeste et al. 2011). Five studies were selected as the basis for discussing schizophrenia-related premature deaths.

Premature death is potentially higher in patients with schizophrenia, compared to other groups of people. Causes of death can be both natural and unnatural. Natural deaths in patients with schizophrenia are various, depending on country and place of living. A five year cohort study found that 12.4% of patients with schizophrenia in a rural community in Ethiopia died because of infections, other natural cause of deaths, and accidents; however, the researchers did not compare the death rates of patients with schizophrenia to those of the general population (Teferra et al. 2011). Conversely, cohort studies from developed countries, such as the UK, Sweden and Germany, found a broad range of natural and unnatural causes of death. Natural causes of death in those developed countries were cardiovascular diseases, metabolic syndrome, non-compliance and unhealthy lifestyle: unnatural death includes suicide (Brown et al. 2000; Fors et al. 2007; Schoepf et al. 2012). Patients with schizophrenia might die because of committing suicide, accident, unhealthy lifestyle, non-compliance, comorbid diseases and/ or their medications' side effects. Some of these causes of death can be prevented by improving health care services, as well as considering more effective medications.

Using this evidence to make recommendations for clinical practice and policy will be dependent upon the quality of evidence. Overall, standards of schizophrenia diagnosis, and death follow up, in each cohort study may be different. For example, Teferra et al. (2011) seriously screened its population to ensure that patients have a diagnosis of schizophrenia, by using the ICD-10 criteria, but the causes of death were not defined by ICD-10 criteria. Brown et al. (2000) followed DSM IV criteria according to the psychiatrist diagnosis; however, this study has explicit follow up criteria regarding causes of death. It is also argued that each cohort study has limitations regarding participant numbers, with small settings which cannot be generalised to other populations. Moreover, different countries have different health and welfare

state systems, as well as socio-cultural and environmental contexts, which may affect a patient's death in some way. However, these issues are not discussed in the reviewed studies.

2.6.1.5 Social impacts

Living with schizophrenia in society may affect patients and their caregivers regarding stigmatisation and help-seeking. Patients with schizophrenia can be stigmatised by themselves, their caregivers, society and health personnel (Ananthawat 2008; Khumhom 2009; Luethaisong 2009; Doungkaew 2010; Pengtee 2010; Bhikha et al. 2012; Thirthalli and Kumar 2012). Having a diagnosis of schizophrenia may serve to stigmatise patients and their family members, which may stop them from seeking help and socialising (Thirthalli and Kumar 2012). Feelings of being ashamed may be influenced by religious or other belief systems; a situation which is usually found in Buddhists in Asian developing countries, such as India and Thailand (Sanseeha et al. 2009; Thirthalli and Kumar 2012).

The systematic review by Thirthalli and Kumar (2012) found that different groups of people view schizophrenia differently, depending on their experiences and relationships with patients with schizophrenia. For example, doctors who have more clinical experiences than medical students tend to have more positive attitudes towards patients with schizophrenia. However, the patient's relatives perceived stigma more than the patient's caregivers. The systematic review by Bhikha et al. (2012) stated that 85% of the research population believe in non-scientific causes of schizophrenia and such persons tend to seek for help from traditional healers.

Unpublished evidence in Thailand reveals that the Thai rural society can, perhaps, be characterised as a blaming society located in non-empathetic community settings (Khumhom 2009; Luethaisong 2009; Doungkaew 2010; Pengtee 2010). This causes 51.1% of patients with schizophrenia to have low self-esteem (Ananthawat 2008). Self-stigmatisation causes the patients to withdraw from society (Khumhom 2009). Caregivers and relatives of patients with schizophrenia 'feel ashamed, stressed, fed up and burdened', as well as labelling the patient as an abnormal person (Khumhom 2009; Luethaisong 2009). People in the community, as well as health personnel, perceive that the caregivers can cause schizophrenia and, perhaps, the caregivers may have the

Chapter 2 Schizophrenia background

same mental disorder as the patients (Pengtee 2010). The recommendations for reducing stigma within the rural Thai community setting rest upon having a mobile team to provide more information about schizophrenia. Also, it is suggested the caregivers should seek for help from community mental health leaders (Pengtee 2010). However, evidence reviewed may contain biases regarding generalisation of findings.

In summary, patients with schizophrenia and their caregivers can be stigmatised by themselves, people in their community and health personnel. The evidence reveals that religions and/ or belief systems can cause stigma and negatively influence help-seeking patterns. A traditional healer is the first support for many rural patients with schizophrenia and their caregivers. This may delay 'proper' treatment; a delay that may cause the development of severe and chronic schizophrenia. Thus, providing information about schizophrenia, and involving the community in caring for patients, may have positive clinical implications.

2.6.2 Impacts on health systems and countries

Schizophrenia is chronic and recurring, so the expenditure for treating and caring for its patients is high. Chisholm and Knapp (2002) found that the direct cost of community care for patients with schizophrenia in Denmark was nearly twenty-fold cheaper when compared to inpatient care; whereas it was nine-fold in Spain, four-fold in England and Italy, and one-and-a-half fold in the Netherlands. These differences are because of the relationships between higher costs of care and higher demands, duration and severity of mental illness (Knapp et al. 2002). In 2004-2005, English society spent 6.7 billion pounds on the direct cost of [providing care for people with schizophrenia and nearly 4 billion pounds for indirect costs, such as unemployment among both patients and their caregivers. In 2008, overall schizophrenia expenditure in Thailand was 563 million pounds (1 pound = 55 Baht). In 2002, the US spent nearly 70 billion US dollar for both direct and indirect costs (1 pound = 1.5 US dollars) (Wu et al. 2005). However, direct cost per patient with schizophrenia in Australia was 140- 383 Australian dollars, with an average of 14,000 Australian dollars per annum for indirect cost (1 pound = 2 Australian dollars) (Fitzgerald et al. 2007). In 2008, Taiwan spent 16,576 US dollars caring for a patient with schizophrenia (Lee et al. 2008), whereas 23.8 billion US dollars were spent for

patient care in Japan (Sado et al. 2013). It is argued that the cost estimation data from different countries are not comparable because those expenditures are based on individual country living standards. However, the cost analysis of schizophrenia care clearly illustrates significant economic burdens around the world.

In summary, schizophrenia not only affects patients with schizophrenia but also their caregivers, their health systems, as well as broader society. The expenditure will increase or vary with needs, hospitalisation, severity and duration of the illness. However, schizophrenia's costs can be decreased by providing community care instead of inpatient care. This means that a good community mental health service can provide initial care for managing any recurrence of the disease.

2.7 Schizophrenia treatments

2.7.1 Schizophrenia beliefs and its treatments

Currently, there are two main theoretical positions regarding the causation of schizophrenia: the neurobiological model (medical model) and the bio-psychosocial model. Both schools of thought provide different treatments which will be discussed further.

2.7.1.1 Neurobiological model (medical model)

In the neurobiological model perspective, schizophrenia can be treated by choosing from a range of options: antipsychotic medication, psychosocial interventions and / or electroconvulsive therapy (ECT); all depending upon the individual patient's conditions (NICE 2010). However, treating patients who have schizophrenia is different around European countries in terms of drugs of choice, because psychiatrists in different countries were taught differently, and different health systems provide different antipsychotic drug for their patients (Papageorgiou et al. 2011). There are first and second generation neuroleptic drugs available for schizophrenia, which aim to reduce positive symptoms (Kurtz and Marcopulos 2012). Patients with schizophrenia in Thailand are rarely prescribed second generation antipsychotics, due to their high cost to the patient (Udomratn and Vasiknanonte 2009). Hence, patients in Thailand will have more chance to have side effects from first generation antipsychotics.

Chapter 2 Schizophrenia background

Although various papers were published stating that antipsychotic drugs are effective for treating patients with schizophrenia, 'conflicts of interest' should be considered regarding the drug companies involvement in funding the studies and publishing the work (Mosher et al. 2004; Read 2010). For example, in the Chaichan (2004) study a randomised control trial study was supported by the medical company. This means that the evidence for the effectiveness of neuroleptic drugs may well be biased, tainted by vested interests. However, patients are more likely to suffer side effects from pharmacotherapy and other complications, including obesity, cardiovascular disease and diabetes (Hert et al. 2011).

Electro convulsive therapy (ECT) has been used for the treatment of schizophrenia since the early 20th century, based on a belief that inducing grand mal seizures will improve (that is reduce) psychotic symptoms (Read 2004c; Tandon et al. 2010). The key debates about using ECT for patients with schizophrenia can be grouped into four main points: the origin and mechanism of ECT, a lack of a guideline consensus, a lack of concern about patient's rights regarding compulsory treatment and ECT causing memory loss (Cyrzyk, 2013). Cyrzyk (2013) compared using ECT to treat serious mental illness, such as, schizophrenia, major depression and bipolar disorder in Australia and the UK. The use of ECT has however, been declining due to its side effects regarding brain damage, which is considered a permanent side effect (Read 2004c). It is argued that the evidence that Read (2004c) referred to is based on patients with depression, rather than patients with schizophrenia. Therefore, the evidence of ECT's side effects is still unclear.

In contrast, although evidence of the effectiveness of ECT for patients with schizophrenia, since the 1940s, is still weak, ECT is considered to be a relatively safe treatment (Ministry of Health NSW 2011). However, it needs a global ECT guideline, especially for pregnant patients, in order to improve patient outcomes (Leiknes et al. 2013). Moreover, randomised control trials (RCTs) are needed to improve knowledge about the cost-effectiveness of ECT (Greenhalgh and Peacock 2005). It is argued that although there is no evidence of an ECT mechanism regarding reducing psychotic symptoms, harm and cost-effectiveness, ECT is still deemed necessary for patients who do not respond to antipsychotic drugs (Greenhalgh and Peacock 2005). It is recommended that sufficient ECT information should be provided for service users, health

professional education and training, as well as offering rehabilitation programmes for patients (Cyrzyk 2013). The Royal College of Psychiatrists (2014) noted that ECT is still used for patients who have severe depression, considering this symptom may be harmful to the patient's life (e.g. antipsychotic drug resistant, not eating and/ or having suicidal ideas); however ECT is no longer used for the treatment of schizophrenia in the UK.

It should be noted that one of the most important treatments is antipsychotic medication, which can help to control psychotic symptoms (NICE 2010). Prescribed antipsychotic medication is currently the best available treatment option for outpatients with schizophrenia, particularly for patients in Thailand who live in rural areas, because it is convenient to access and administer (Department of Mental Health 2012). Adherence to prescribed antipsychotic medication is the fundamental principle of relapse prevention and recovery from psychotic symptoms, in terms of a patient gaining insight into their illness (NICE 2010; Kingsaiyod 2011). Hence, facilitating medication adherence is one of the most important duties for the community health care providers who are looking after discharged patients with schizophrenia.

2.7.2 The bio-psychosocial model

The bio-psychosocial model (or holism) comes from a school of thought which considers every dimension of an individual's life: the physical, psychological and spiritual dimensions (Dogar 2007 p12). The idea of holistic care in clinical practice is increasing, which may be as a result of the WHO campaign. The WHO promotes the idea of holism because, currently, there are increasing concerns about only using the bio-psychosocial model in clinical practice. In the UK, the NICE guidelines (2010) suggested that both anti-psychiatric medication and psychosocial therapy (e.g. cognitive behavioural therapy, adherence therapy and family intervention) reduces the severity of psychotic symptoms in patients with schizophrenia in both inpatient and outpatient settings. For inpatient care, psychiatric clinicians should assess patients' backgrounds; not only their physical or mental health but also other allied relevant circumstances, ethnic and cultural/belief system (Waltzer 1982; NICE 2010). This could assist health professionals to find out more about the related factors that may affect illness and prognosis, as well as patients' health-related behaviours (Waltzer 1982; Dogar 2007). Furthermore, Dogar (2007) suggests

Chapter 2 Schizophrenia background

that providing mental health care should demonstrate concern about service user's religions and cultures, because these can change health behaviour in the positive way. Mohr and Huguelet (2004) indicate that religions and community affect patients with schizophrenia regarding 'reconstructing a sense of self and recovery'. This means that, in general, patients with schizophrenia need spiritual and social, as well as medical, support. This idea relates to the previous sections on aetiology, illness perception and help-seeking behaviour. Unfortunately, there is no guideline for providing psychosocial interventions from the Thai Department of Mental Health (DoMH) regarding community mental health day to day practice. Therefore, providing psychosocial interventions in the Thai community setting, at primary care level, seems unusual. It is arguable that although it appears that the bio-psychosocial model influences the recovery process in care, the effectiveness of bio-psychosocial interventions in the community is not widely tested. Therefore, it is doubtful whether such a model is effective and appropriate in day to day practice, in the Thai community settings.

2.7.3 Schizophrenia is a recurring and long term condition

Living with a chronic mental health condition is difficult. After having a diagnosis of schizophrenia, patients have a 50% higher risk of premature death and 10% higher suicide rate than the general population (NICE 2010). Although psychotic symptoms of discharged patients with schizophrenia are controllable, medication and other support are still necessary (NICE 2010; Department of Mental Health 2012). This is because good community mental health care can prevent the recurrence of schizophrenia, as well as reduce mortality rates due to physical problems. However these patient outcomes depend upon the availability of the service and staff (Patel et al. 2007). It is crucial for community mental health care teams to provide care based on the service user's needs, particularly by aiming to reduce any unmet needs.

2.7.4 Recovery from schizophrenia

Recovery from schizophrenia comprises several aspects and can be categorised into three groups: complete recovery, social recovery and hospitalisation (Warner 2004). However, only 14-20% of global patients with schizophrenia are described as having fully recovered (NICE 2010), which means that patients

with schizophrenia suffer from long term mental health conditions throughout their lives (Varcarolis 2004). Grant (2015) argues that recovery concepts may be different between individuals with mental illness and health professionals. Moreover, the criteria of 'normal and abnormal belief' is still unclear (Bentall 2003 p132). Hence, this could affect communication between health professionals and patients regarding treatment management. Deegan (1988 p11) found that recovery is more about the process of recovering and improving sense of self, and regaining life purpose, instead of highlighting the rehabilitation process. Full recovery seems remote for many such patients; however, it is important to help patients with regard to their social recovery, because this benefits them in terms of being independent and gaining self-control (Warner 2004). Hence, good self-management has been combined with other caring initiatives in western countries, particularly in the UK and U.S.A. (Davidson 2005b). However, this scenario may differ from the Thai perspective in terms of expectations towards those who are mentally ill. It is acceptable in the Thai society that individuals who are mentally ill and/ or have disabilities can be dependent, which means they are partially or fully cared for by caregivers and perhaps do not need to work. However, this can cause burdens in certain areas, such as families, and will be discussed in the next chapter.

2.8 Conclusion

Schizophrenia is currently an unclear psychiatric disorder, regardless of the time and effort clinicians and researchers have spent on it. The potential causes appear to involve genetic, environmental and psychosocial factors. It is argued that some people believe that schizophrenia is a 'genetic time bomb' mental disorder which means that schizophrenia hides in a person's gene and waits for the time to show its symptoms (Read 2004b). However, without exact knowledge of the root cause(s) of the illness, schizophrenia is difficult either to prevent or treat. Although there are international diagnostic criteria available, heterogeneity of clinical features of schizophrenia is a problem inhibiting confirmation of diagnosis. Moreover, patients with schizophrenia are likely to have lower life expectancy, if compared with the general population. This is because of suicide attempts, negative effects of medication related to schizophrenia treatment, substance misuse and other complications. Treating schizophrenia is based on medical and bio-psychosocial models, which are

Chapter 2 Schizophrenia background

distinct, but each does appear to help to improve the prognosis of schizophrenia. Hence, although schizophrenia is rarely in full remission, providing good service delivery may reduce its burden. In Thailand, provision of schizophrenia treatments and care, based upon neurobiological and bio-psychosocial models, may be different from other countries. However, availability and accessibility of services are limited.

In the next chapter, current evidence of service delivery for care, at the primary care level, will be reviewed and appraised.

3. Chapter 3 Literature review: stakeholder experiences and perspectives towards schizophrenia care in community settings

Introduction

This chapter aims to provide a review of literature regarding experiences and perspectives towards schizophrenia and its patients' care in community settings, from 1992 to 2014. Evidence is based on updated versions of ICD and DSM in order to ensure that research participants featured in selected articles were diagnosed by using standard diagnostic criteria (WHO 1992; American Psychiatric Association 2013). This chapter will be divided into seven areas: finding relevant evidence, stakeholder experiences, needs and recommendations for schizophrenia care, service delivery in community settings, gaps in knowledge, research aims, developing research questions and chapter summary.

3.1 Finding relevant evidence

Using clinical questions appears to be useful in terms of focusing on relevant evidence (Melynk and Fineout-Overholt 2005). This literature review consists of three focal points.

3.1.1 Developing the focal points for a literature review

The focal points for evidence searching:

1. Experiences of patients with schizophrenia, their caregivers, primary care staff and health personnel regarding living with, and caring for, schizophrenia.
2. Needs and unmet needs of patients with schizophrenia, their caregivers and health personnel for schizophrenia care at the primary care level.
3. Recommendations for improving schizophrenia care at the primary care setting in rural areas.

3.1.2 Search strategies and article selection

Literature in the following relevant databases was searched: CINAHL, MEDLINE, PsycINFO, Web of Science, AMED, EMBASE, Open grey (the UK grey literature database), ThaiLIS (the Thai grey literature database) and Google scholar. Keywords used for database searching were: schizophrenia, experience, care, live, need, community, rural, carer, patients, and health professional. Some alternative keywords were used (see appendix 8) to ensure that relevant studies using different keywords and medical subject heading (MeSH) were included (EBSCO industries 2015). Inclusion and exclusion criteria were used for this process (see appendix 9). The process of evidence identification is illustrated in figure 2. The relevant evidence will be discussed regarding perspectives of patients, caregivers and community health personnel who are stakeholders for schizophrenia care in rural area communities. The process of evidence identification is illustrated in Figure 2.

Chapter 3 Literature review

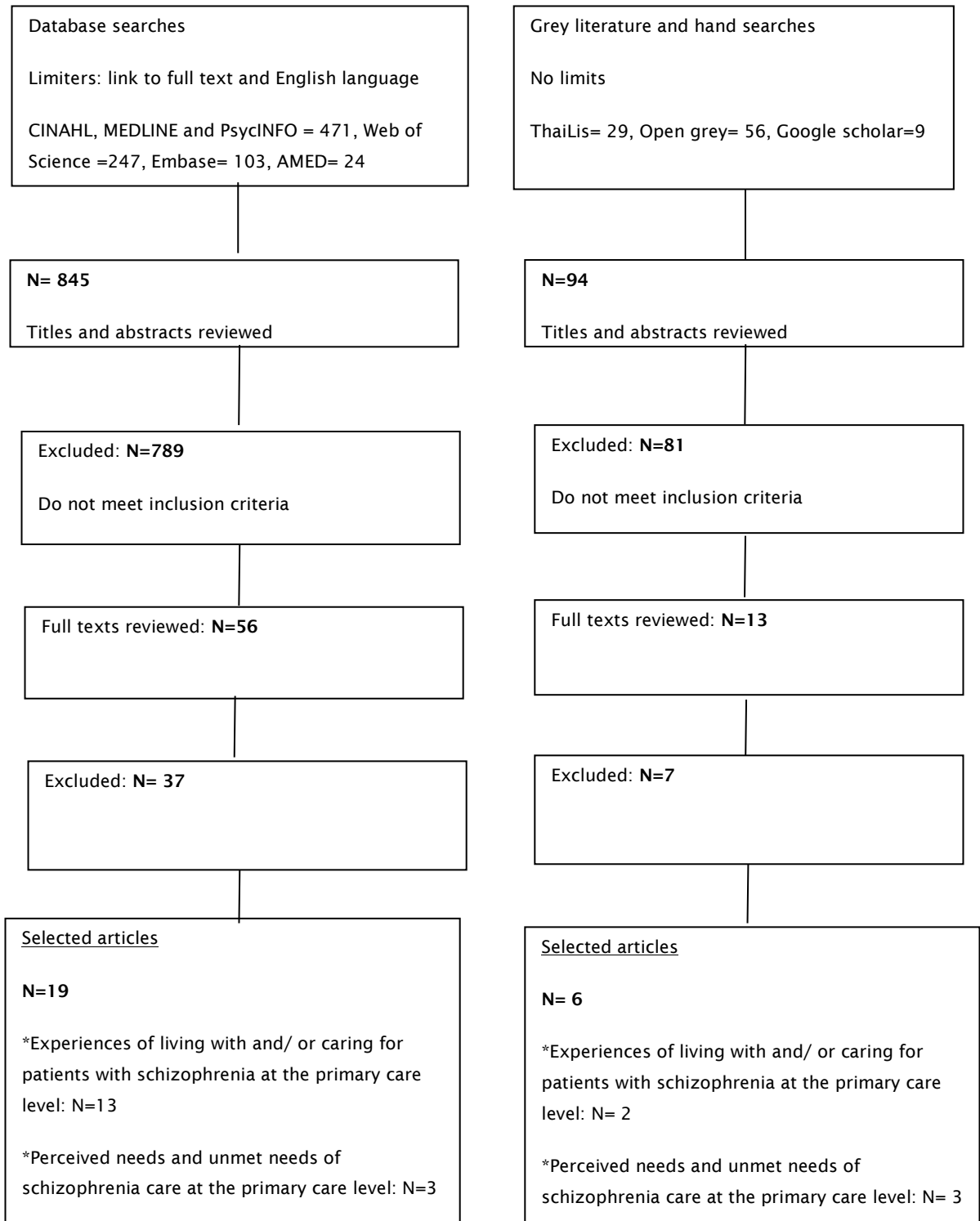


Figure 2 Database search and study identification

Chapter 3 Literature review

3.1.1 Characteristics of selected articles

In total, twenty five studies were selected for this literature review. Two studies were identified that explored patients' experiences of schizophrenia; one a phenomenological study of living with schizophrenia and the other a grounded study of re-entering the community settings (Beal et al. 2005; Ko et al. 2014). A meta- synthesis study explores experiences of people who have a diagnosis with psychosis (McCarthy-Jones et al. 2013) was also chosen.

Fourteen studies were selected for caregiver experiences of living with, and caring for, patients with schizophrenia. These studies comprised of three qualitative phenomenological studies (Rungreangkulkij and Chesla 2001; Sethabouppha and Kane 2005; Huang et al. 2008); four descriptive qualitative studies (Saunders and Byrne 2002; Oud et al. 2007; Mizuno et al. 2011; McAuliffe et al. 2014); one grounded theory study (Dangdomyouth et al. 2008); three cross-sectional survey studies (Kumar and Mohanty 2007; Trangkasombat 2008; Panayiotopoulos et al. 2013); one literature review (Caqueo-Úrizar et al. 2014); one observational study (Seeman 2013) and one British government document (Shepherd et al. 1994).

Three cross-sectional studies (Winefield and Harvey 1994; Ochoa et al. 2003b; Yeh et al. 2008); one qualitative Thai masters' dissertation (Permyao 2004) and one Thai government document (Department of Mental Health 2012) were selected as being relevant to the needs of schizophrenia care in community settings.

Three articles (Lester et al. 2005; Katakura et al. 2010; Kaufman et al. 2012) and one PhD thesis (Meebunmak 2009) were selected for describing perspectives towards schizophrenia care at the primary care level.

The hierarchy of evidence was used to consider levels of identified studies (see Figure 3).

	Effectiveness	Appropriateness	Feasibility
Excellent	<ul style="list-style-type: none"> • Systematic review • Multi-centre studies 	<ul style="list-style-type: none"> • Systematic review • Multi-centre studies 	<ul style="list-style-type: none"> • Systematic review • Multi-centre studies
Good	<ul style="list-style-type: none"> • RCT • Observational studies 	<ul style="list-style-type: none"> • RCT • Observational studies • Interpretive studies 	<ul style="list-style-type: none"> • RCT • Observational studies • Interpretive studies
Fair	<ul style="list-style-type: none"> • Uncontrolled trials with dramatic results • Before and after studies • Non-randomized controlled trials 	<ul style="list-style-type: none"> • Descriptive studies • Focus groups 	<ul style="list-style-type: none"> • Descriptive studies • Action research • Before and after studies • Focus groups
Poor	<ul style="list-style-type: none"> • Descriptive studies • Case studies • Expert opinion • Studies of poor methodological quality 	<ul style="list-style-type: none"> • Expert opinion • Case studies • Studies of poor methodological quality 	<ul style="list-style-type: none"> • Expert opinion • Case studies • Studies of poor methodological quality

Figure 3 Hierarchy of evidence: ranking of research evidence evaluating health care interventions (Evans 2003 p.79)

Although the recruited papers are overall ranked in the ‘fair’ grade, there appears to be a developing body of evidence relevant to this current research topic. The Critical Appraisal Skills Programme (CASP) tools were used to appraise the quality of the selected papers. The CASP tools were chosen for use as main appraisal tools because they are standardised devices recommended by many experts (Melynk and Fineout-Overholt 2005; Greenhalgh 2010; Solutions for Public Health 2013). The literature review will contextualise the current situation with regards to experiences, perspectives towards care, needs and unmet needs, and recommendations for improving care at the primary care level, based on evidence from Western sources, developed Asian countries and Thailand. Thus, the three literature search questions will be answered respectively.

3.2 The experiences of patients with schizophrenia, their caregivers, and health personnel, regarding living with and caring for people with schizophrenia at the primary care level

3.2.1 The perspectives of patients with schizophrenia: community experiences regarding living with schizophrenia

Two themes emerged from the selected literature: the difficulties and coping strategies of living with schizophrenia in community settings. Studies by Beal et al. (2005), McCarthy-Jones et al. (2013) and Ko et al. (2014) illustrate that patients with schizophrenia revealed that it is difficult to cope with psychological distress associated with their own mental illness, as well as needing to adjust themselves for re-entering, and being a part of, the community. A grounded theory study and a meta-synthesis study, found that relating to others in the community is challenging in terms of the patient regaining their own hope, motivation and building or rebuilding relationships with others (Beal et al. 2005). Beal and colleagues (2005) indicated that self-adjustment and community-related skills are crucial for patients with chronic schizophrenia who were hospitalised for more than a year and who wished to re-enter the community. Similarly, many patients with schizophrenia experienced a loss of self-control and would then try to adjust themselves by the 'reframing of self-expectations and redefining the value of life' to cope with any life disturbance (Ko et al. 2014 p.398). Therefore, patients tended to lower their life expectations because they seem to understand the implications of the prognosis of having a diagnosis of schizophrenia, and do not have high expectations about their cognitive capabilities. The patients with schizophrenia found that building good relationships with other people in the community helps patients to stabilise their psychotic symptoms and gain hope. Interestingly, Ko and colleagues (2014) added that Taiwanese patients with schizophrenia reported that they could connect to the spiritual world; wishing to get help from a supernatural power is one coping strategy for reducing their burden. It appears that belief systems tend to affect the community-related experiences of patients with schizophrenia in Asian countries more than in Western ones. From this point, it is still unclear whether expecting to get help

from a supernatural power might be influenced by the presence of psychotic symptoms (delusion/ hallucination) or a patient's belief system.

Using evidence from both studies requires an element of caution. Ko et al. (2014) present a clear study design, participant recruitment and data analysis strategies, but the authors claim that Buddhism and Taoism influence the help seeking behaviour of patients with schizophrenia. It is noticeable that only one Buddhist (n=1; 6.6%) was recruited in this study, whereas almost all of the other participants were Taoist (n=12; 80%). It is arguable whether data from just one Buddhist is enough to identify the 'help seeking pattern' because this study is dominated by Taoists, and therefore can be said to be empirically biased. There are also limitations in the study by Beal et al. (2005), in terms of recruiting only patients with schizophrenia who had been hospitalised for 12 months or longer. This means that transferability of research findings is limited to patients who are experiencing difficulties with activities of daily living and social skills, rather than patients with schizophrenia in general. Furthermore, three participants from Beal et al. (2005) opted out because they were hospitalised and declined to take part in the study. Although the number of research participants does not necessarily affect the quality of a qualitative study, it raises concern about richness of data. Although the meta- synthesis by McCarthy-Jones et al. (2013) offers a high level of qualitative evidence, the synthesis included experiences of patients with more general psychosis as well as schizophrenia. Therefore, caution is needed before transferring the study's recommendations to patients with schizophrenia in rural Thai communities. In addition, it is argued that transferability of the research results from Ko et al. (2014), McCarthy-Jones et al. (2013) and Beal et al. (2005) to Thai communities may be difficult, due to different religious views/ belief systems and health care systems.

3.2.2 Caregivers' perspectives: community experiences regarding caring for patients with schizophrenia.

There are three themes which emerged from the selected articles: i) living with/ caring for schizophrenia causes difficulties, ii) caregiver backgrounds, and iii) caring and coping strategies.

3.2.2.1 Living with/ caring for schizophrenia causes difficulties

Most evidence shows that caregivers expressed their views about living with and/ or caring for patients with schizophrenia in negative ways; such as experiencing stress, suffering, 'tsunami feeling' and it being burdensome (Sethabouppha and Kane 2005; Mizuno et al. 2011; Panayiotopoulos et al. 2013; Caqueo-Urizar et al. 2014; McAuliffe et al. 2014). In addition, there are nine factors that can affect community experiences of the caregivers of patients with schizophrenia: 'family interventions, ethnic groups and cultural aspects, expressed emotion, stress and burden, pre-occupations of caregiver, kind of caregiver, social networks or social support, finances and caregiver coping' (Caqueo-Urizar et al. 2014 pp236-238). It can be clarified that emotional expression (EE), worrying about a patient's deterioration, financial issues and low levels of social support can cause major family stress and burdens. However, caregiver's coping strategies, family interventions and social support are expected to reduce these sufferings. It is noticeable that caregivers' perceptions depend on their background, as well as the support that they have received both from society in general and health professionals in particular.

3.2.2.2 Caregivers' backgrounds

It appears that culture and ethnic background can affect the needs of patients with schizophrenia, patient care, relationships between patients and others, and stigmatisation (Kung 2003 p548; Caqueo-Urizar et al. 2014). The evidence shows that Thai and Taiwanese caregivers value religions/ belief systems regarding having patients with schizophrenia in the family, as well as caring for them. At this point, the impacts of religions/ belief systems can be separated into negative and positive aspects.

For the negative impact Sethabouppha and Kane (2005), authors of a Thai phenomenology study, found that caring for patients with schizophrenia related to 'Boon (merit)' and 'Babb (demerit or sin)'. Similarly, Thai mothers of patients with schizophrenia believed that bad karma from a past life brought schizophrenia upon their children (Rungreangkulkij and Chesla 2001). For instance, stigmatisation is normally due to the oriental belief in karma, which in Buddhist beliefs can cause discrimination against schizophrenia and its sufferers (Sanseeha et al. 2009). This is understood to be due to the perception

that patients with schizophrenia have done bad things in a past life, resulting in the punitive affliction of their illness. It appears that once the caregivers believe that caring for patients with schizophrenia is related to 'Babb' (demerit or sin) that they, and the patients with schizophrenia, have committed in a past life, they would feel upset. Such beliefs are more likely to happen in rural, rather than urban, Thai settings. This may be because people living in the Thai rural areas are likely to know each other, which may not be the case with people in urban areas. Moreover, people in rural settings may be more religious than urban dwellers. For example, Dangdomyouth et al. (2008), in their Thai grounded theory study, found that caregivers worried about patients' psychotic symptoms and how to prevent recurrence of schizophrenia without mentioning religions/ belief systems or spiritual dimensions. Dangdomyouth and colleagues (2008) found that these caregivers did not inform patients that they observed, screened, and monitored their psychotic symptoms; however they gave their patients mental support. It appears that Buddhism did not affect research participants' ways of thinking, regarding schizophrenia care, which may be because the research setting was the capital city. It can be noted that religion/ belief systems' backgrounds affect how caregivers of patients with schizophrenia perceive their caring experiences. Thus, embarrassment may upset rural Thai caregivers and, perhaps, stop them from seeking help and/or encourage them to 'hide' patients at home.

From a positive perspective, it appears that religious beliefs may shape the practice of caring for people with schizophrenia. Relieving stress by letting go and making merit or 'Tham Bun' (Bao 2005 p119), plays an important role in the coping strategies of Thai Buddhist patients with schizophrenia, who are living outside hospitals (Sonpaveerawong 2001). Muslim caregivers in the south of Thailand have positive views towards people with schizophrenia, which can influence the care and social network support available (Vanaleesin et al. 2007). This is because schizophrenia is conceptualised by this community as being a test from Allah (the Muslim's God), so it is believed that people with schizophrenia have undergone the expiation of sin; so both they, and their caregivers, obtain merit. Belief systems, it can be argued, also affect community mental health care provided by various types of health care professionals in addition to patients and their caregivers.

3.2.3 Caring and coping strategies

It appears that caring for patients with schizophrenia is burdensome, therefore a willing caregiver is required for this role. Relationships between caregivers and the patients relate to, and are informed by, a willingness to care. This section will provide the views of caregivers who are a patient's parents (Rungreangkulkij 2001; McAuliffe et al. 2014), siblings (Seeman 2013), family members (Saunders and Byrne 2002; Huang et al. 2008; Sanseeha et al. 2009; Panayiotopoulos et al. 2013), husbands (Mizuno et al. 2011) and other people in the community (Vanaleesin et al. 2007).

The evidence shows that having patients with schizophrenia in the family can be problematic; resulting, for example, in a dysfunctional family (Trangkasombat 2008) and patient neglect (Panayiotopoulos et al. 2013). Trangkasombat (2008) found several dysfunctional families among patients with schizophrenia, 80% of those families being which were considered high percentage. It may be hypothesised that a family's dysfunctional nature may relate to a patient's psychotic symptoms and the family members' capability to resolve problems or issues in the family (Sawant and Jethwani 2010). However, the severity of such perceptions may relate to relationships between patients with schizophrenia and their caregivers. It appears that parents are usually the main caregivers, if compared with other family members. It has been noted that the patient's siblings are normally unwilling to take care of their sibling with schizophrenia, unless their parents (the main caregivers) are unable to take care of them (Seeman 2013). McAuliffe et al. (2014) indicated that older parents have to face the stress and worry caused by their adult children's illness; yet, at the same time, they have to cope with their own psychological distress, as well as long term caring duties, which they perceived as an uncertain pathway. However, the unconditional love from the patient with schizophrenia's parents to their child could influence willingness to care as well as reduce caring burdens.

Caregivers of patients with schizophrenia use several coping strategies to relieve their suffering. In the Rungreangkulkij and Chesla (2001) study, the Thai mother used 'Tham Jai (embrace)' coping strategy to cope with psychological distress and providing care with 'gentle, supportive and non-confrontational manners'. From a phenomenological study, Huang et al. (2008)

found that Taiwanese caregivers of patients with schizophrenia appeared to use two coping strategies: namely, psychological (cognitive, behavioural and emotional coping) and social strategies (peer and health professional support). For the views of the husbands of patients with schizophrenia, Mizuno et al. (2011) found that they perceived living with such patients required them to adjust themselves to respond, support and take care of their wives, but this could also have a negative impact. It could be seen that, although the selected studies were conducted in Asian countries, there are some different views. The Thai mothers and Japanese husbands were more focused on understanding the patient's mental illness, regardless of negative responses from the patients. The Taiwanese caregivers, on the other hand, needed support from outside the family.

It seems that religions/ belief systems, 'krenng-Jai' and 'face' may be barriers to the seeking of medical help, which is a concern for the Thai caregivers. Hence, it can be noted that providing care for patients with schizophrenia requires not only knowledge but also sensitive concern about cultures, religions/ belief systems; particularly regarding those people living in rural settings (Rungreangkulkij and Chesla 2001; Sethabouppha and Kane 2005; Vanaleesin et al. 2007; Sanseeha et al. 2009). A major point made by Sethabouppha and Kane (2005) is the importance of providing antipsychotic medication, psychological support and health education for the rural Thai caregivers. Furthermore, Saunders and Byrne (2002) suggested that prioritising nursing intervention with the caregiver's needs is crucial, as the first priority of nursing care: therefore nurses should assist families to deal with legal and other complicated issues, which are different in different countries. Hence, it is suggested Thailand needs to improve its community mental health care system and service at the primary level (Kaewprom et al. 2011). In contrast, schizophrenia care in the USA community settings employs nursing interventions. Therefore, the identified evidence about caring and coping strategies needs to be applied cautiously, because there are some transferability limitations, due to differing infrastructures for care, as seen in different socio-cultural contexts. Although the study by Sethabouppha and Kane (2005) is transparent and rich, regarding providing care by applying Buddhist philosophy to the act and process of caring, this study did not provide information about ethical approval (only hospital board approval), and

Chapter 3 Literature review

the participants were caregivers who live in the north-east of Thailand. Thus, applying evidence for the whole population in Thailand should only be done with great caution, if at all. Although the research by Mizuno et al. (2011) was rigorous, transparent and credible; it is arguable that there are 'study approach' and 'data analysis' limitations. This study carried out content analysis, paying less attention to context but focusing on what the participants have said. Using phenomenology, to explore the experiences of the husbands of patients with schizophrenia, may be more appropriate than qualitative descriptions, using the content analysis approach, regarding exploring what it is like for the husband-carers living with their mentally ill wives. The participants were recruited from the outpatient departments of a hospital without indicating details of their backgrounds. It is argued that participants' backgrounds may affect their willingness to care, their coping strategies and family responsibilities. For example, Asian husbands may perceive that they are the family leaders who have to be responsible for the whole family. Although Mizuno et al. (2011) can report what husbands say living with their wives, who suffer from schizophrenia, is like, the study's results may be limited in their transferability to Thailand, due to different social and health care contexts. The study by Huang et al. (2008) comprises a mixture of educational, socio-economic, religious and belief backgrounds, but 80% of participants were unemployed and had been caring for patients with chronic schizophrenia for an average of 16 years. This could be considered as selection bias, informed by the dominant views of unemployed participants who are aged above 60 years old. There are some limitations of the study done by Trangkasombat (2008). Although the researcher claimed that the CFI tool used for testing was valid and reliable, the CFI and McMaster questionnaires were not piloted specifically for this study. Hence, the respondents' characteristics may affect the results of the research, because the questionnaires were not necessarily measuring what they were expecting to measure. This possible anomaly may result in there not being any significant difference between the two groups. There is a lack of explanation of the McMaster instrument in terms of whether it was translated into the Thai language and piloted properly. There is no ethical approval statement and the participant recruitment strategy in this study is unclear. The literature review undertaken by Caqueo-Urizar et al. (2014) was limited to the English language, so any relevant non-English articles would have been omitted.

3.2.4 Care providers' perspectives

This section will illustrate health care provider's perspectives towards care provision in community settings in Western and Asian countries. In day to day practice, health professionals perceived providing care at the primary care level in different ways. Certain themes emerged from selected articles, namely: knowledge and skills, attitudes, health care systems, belief/ cultural and political issues (Meebunmak 2009 ; Katakura et al. 2010; Kageyama et al. 2012; Viron et al. 2012).

3.2.4.1 Knowledge and skills

The selected articles indicated that knowledge and good collaboration with patients with schizophrenia are crucial for providing good quality care at this level (Meebunmak 2009 ; Kageyama et al. 2012; Kaufman et al. 2012; Viron et al. 2012). Viron et al. (2012) argue that care at the primary level requires health professionals who understand the nature of schizophrenia, its treatment and how to collaborate with patients, rather than more narrowly focused clinical experts. The selected Japanese article by Katakura et al. (2010) acknowledged that trained home-visit nurses' attitudes influence the effectiveness of schizophrenia care in community settings. Thus, Katakura et al. (2010) seem to complement the study by Viron et al. (2012), in the conclusion that special training may positively affect home-visit nurses' attitudes to improve the care they provide. Similarly, the Thai primary care staff perceived that personal knowledge of and interest in, schizophrenia are important for the quality of community mental health care (Meebunmak 2009).

Collaboration and communication are essential skills which should be considered, because communication problems can occur when the service providers are unaware of language and culture (Kaufman et al. 2012). At this point, it should be noted that knowledge about schizophrenia care itself is not enough to provide good care; also of importance are service providers' attitudes, awareness of culture, communication and collaboration. It is argued that, in reality, it may be difficult to collaborate with the patient directly. Hence, caregivers of patients with schizophrenia are the most important persons to communicate with. Kageyama et al. (2012) recommended that local health care professionals should assist the caregivers of patients with schizophrenia, to encourage the patients to continue to receive care. Such a

decision could improve patients' outcomes regarding their psychiatric symptoms.

3.2.4.2 Mental health policy and primary care staff beliefs

Mental health policy seems to be an important factor for influencing the primary care staff to provide good community mental health care at the primary care level in Thailand (Meebunmak 2009 p204-209). There are differences and similarities between Thai and UK schizophrenia services at the primary care level. Regarding similarities, both countries use a referral system for sending the patients from primary, to a more appropriate, level of care. At the Thai primary care level, a multidisciplinary team, patient's family and the community are all involved in care, as patients' and caregivers' needs are assessed (Department of Mental Health 2008p 11). This is similar to shared care or a 'Needs led management plan' in the UK health care system (Snowden and Marriott 2003 p 264). Furthermore, family members take over patient care during the 'living in the community' stage. The primary care staff follow up the patients in order to monitor any recurrent psychiatric symptoms, medication adherence and other health related issues. For differences, the level of using a 'needs-led' mental health care plan might be different, regarding national and local mental health priorities, as well as the quality of community mental health care, which is likely to produce different patient outcomes (Fakhoury and Priebe 2007). The UK primary care level provides annual physical check-ups regarding medication side effects, risky lifestyles, endocrine and cardiovascular disorders (Leicestershire NHS Plus 2013). However, at present there is no standard guideline for physical and mental health check-ups after a patient is discharged into the Thai community. It seems that the primary care staff in both countries are the frontline health professionals, with roles covering their respective community mental health services. The UK primary care staff seem to have a clear role for providing mental health care, if compared with the Thai primary care staff. From the Thai and UK government documents, it appears that the community mental health care policy in each country's guide, prescribes good practice. However, Reilly et al. (2012) argued that the roles of primary care staff in Western nations may facilitate or conflict with the needs of patients and caregivers.

For the primary care staff, personal beliefs based on 'Buddhist principles' appear to be an influencing factor for providing care for patients with mental illness at the Thai primary care level (Meebunmak 2009). The concept of 'Tham-Bun' seems to dominate Thai's way of thinking in the rural areas.

In summary, it appears that knowledge, attitudes and skills are crucial for care at the primary care level. There is a limitation of transferability of the research results to other health care professionals, especially non- mental health specialists. It is arguable that research by Kageyama et al. (2012) was conducted with experienced nurses who had responsibility for people with schizophrenia. Additionally, Japan (where studies by Katakura et al. (2010) and Kageyama et al. (2012) were conducted) is an anomalous country in the context of Asia as a whole, being highly developed for many decades and having a different socio-economic composition from other Asian countries, including Thailand. Even though a small amount of evidence exists, regarding primary care staff's perspectives towards general mental illness in the Thai community setting, this Japanese research has not concentrated on schizophrenia care but looked at broader mental health issues. This may be different from caring for people with schizophrenia in terms of its severity, duration of having schizophrenia diagnosis and stigmatisation, which may require more concentration from health care providers. This is because people with schizophrenia have complex needs; caring for such patients differs in many ways from caring for patients with general mental illnesses. From the perspective of community mental health nurses, the current Thai community health services are inadequate for improving recovery from schizophrenia, which is the ultimate goal of schizophrenia care (Kaewprom et al. 2011).

3.3 The needs of patients with schizophrenia, their caregivers and health personnel for schizophrenia care at the primary care level

There are different needs and unmet needs among schizophrenia care stakeholders in the community settings, and these will be discussed below.

3.3.1 Patients' needs

The needs of patients with schizophrenia, who are living in community settings, are complicated and individualised.

Ochoa et al. (2003a) found that with a population of Spanish patients with schizophrenia, health care professionals rated control of psychotic symptoms as the first priority need; companionship for patients was second.

Unfortunately, Ochoa et al. (2003a) used questionnaires to survey the patients' needs, so the responses and findings are similar because of the limited nature of answers for the need categories. In addition, the study was conducted in catchment areas in Barcelona, Spain; therefore the data could not reflect the needs and unmet needs of people who live in rural community settings.

Moreover, although this study's results could not be generalised to the rural Thai population, it could be used to further develop interview guides for patients with schizophrenia. However, priorities of needs may be different in an individual patient, influenced by socio-demographic and, perhaps, socio-economic considerations. Perceptions of both needs and unmet needs vary among patients with schizophrenia and health care professionals, since the latter tend to focus on psychological health (96.4%) more than the other dimensions of patients' needs; whereas patients rated their psychological health needs at the 68.2% level.

The survey of Bengtsson-Tops and Hansson (1999) suggested that people with a diagnosis of schizophrenia not only need mental health support, but also care in other dimensions of their lives. This scenario is complicated due to different levels of demand and variance between individual cases. Patients with schizophrenia are affected by both physical and mental health problems when living outside of the hospital environment. The difficulties of mental health patients who are living in community settings relate to prejudice from other

people, arising from the socially embarrassing nature of such illnesses, often resulting in stigmatisation (Lipsedge 2007; Rose 1996). Such circumstances might prevent patients from asking for help, information or care. Additionally, it has been repeatedly pointed out that almost all people with schizophrenia are unemployed, which can cause stress and family arguments between patients and family members (Chien 2010). Patients' views are invaluable in providing holistic care, which fundamentally aims to match such care with the needs of each patient.

In summary, there are five areas of patients' needs: service accessibility, self-care, relevant information for schizophrenia care, social support and economic support (Ochoa et al. 2003a; Department of Mental Health 2008). Patients' needs can be rated by clinicians and patients themselves, which can produce discrepancies between the two sources. The different points of view may lead to needs and services which remain totally or partially unmet. Ochoa et al. (2003a) recommended that the assessment of patients' needs is an initial step for planning mental health care; however, those needs should be rated by both patients and health staff in order to reduce discrepancies.

3.3.2 Sources of patient needs support

Patients with schizophrenia believe that the primary care level is the main source for assisting them when they need help, whereas the health care providers feel they are ill-equipped to provide mental health care at the primary care level (Lester et al. 2005). This may be because of a lack of staff specialised training and limitations of health care resources at the primary level, in the context of a high volume of health care demands, combined with the complexity and range of the patients' needs (Badger et al. 1999 p813; Kaufman et al. 2012). This situation may lead to a disconnection between demands and supply of community mental health care for people with schizophrenia.

Patients with schizophrenia who had been admitted to a psychiatric hospital, for 1 year or over, need to improve their daily living and social skills (Beal et al. 2005). Unfortunately, patient support from families and friends seems no guarantee against relapse and rehospitalisation (Davidson 2005a). One reason for this is because of the unpredictability of recurring events, which is one of

Chapter 3 Literature review

schizophrenia's main disease characteristics. Although we do know that negative symptoms can affect the social skills of patients with schizophrenia (Lieberman and Silbert 2005), it is argued that we do not know whether this relates to acute and/or chronic versions of the illness.

3.3.3 Caregivers' needs

Caregivers are the people who take responsibility for looking after patients who are living outside hospital (Rungreangkulkij 2001; Huang et al. 2009; Sanseeha et al. 2009; Mizuno et al. 2011). In Thailand, caring for discharged patients diagnosed with schizophrenia is seen as a family member's role (Boonthod et al. 2011). Dangdomyouth et al. (2008) suggest that this may not be different from caregivers throughout the country in Thailand, who monitor patients' psychotic symptoms and manage recurrence. It can be argued that it is not only patients themselves who suffer from mental illness but also their caregivers (Kung 2003; Reine et al. 2003; Chien et al. 2007; Awad and Voruganti 2008). Schene et al. (1998) divided caregivers and family burdens into subjective and objective categories. An 'objective burden' is about economic issues, family arguments and other behavioural issues, whereas a 'subjective burden' is about emotional issues (Kung 2003). The caregivers of people with schizophrenia have been found to display care burden symptoms similar to other groups, in terms of depression and anxiety, which are similar among other caregivers who take care of patients with other chronic mental health conditions (Wiwekwan 2000).

With respect to the needs of Taiwanese caregivers (of patients with schizophrenia), there are four clusters: patient care support (77.6%), providing initial information and social support (68.2%), issues relating to schizophrenia care (66.1%), and reducing caregivers' burdens (27.2%) (Yeh et al. 2008). The Chinese and Kenyan studies suggested that discharging patients with schizophrenia may need dedicated preparation on the part of both patients and their caregivers (Huang et al. 2008; Ndeti et al. 2009). The suggestions from these two studies can reflect unmet needs in terms of a patient's discharge preparation and social integration support (Fakhoury and Priebe 2007).

The needs of Thai caregivers who look after people with schizophrenia are: accessibility of care, information for schizophrenia care and treatment, psychotic symptom management, influencing medication adherence, substance misuse management, occupational preparation for the patients, and relieving their role burden (Department of Mental Health 2008). It is argued that the needs of the caregivers of patients with schizophrenia relate not only to physical and mental health issues but also spiritual needs. Permyao (2004) indicated that the spiritual needs of the northern Thai caregivers of patients with schizophrenia comprise of five areas: balance in daily life, having energy to live a life, the need to connect to a belief, obeying social norms, and having holistic well-being.

3.3.4 Sources of caregiver need support

The evidence shows that caregivers of patients with schizophrenia seek for help differently, depending on their educational, socio-economic and belief backgrounds regarding schizophrenia's aetiology (See Chapter 1). Traditional psychological support and religions are the first priority for caregivers of patients with schizophrenia, when those carers have a low educational and socio-economic background. This group includes Buddhists who believe in '*Karma*', and that making '*Boon* (merit)' can reduce a patient's psychotic symptoms (Sanseeha et al. 2009). However, caregivers who believe in schizophrenia's scientific aetiology seek medical help of the type which can be found in developed countries. This latter option is favoured by members of the younger generations who are better educated than their elders (Furnham and Chan 2004).

From a caregiver's perspective, it can be summarised that caregivers of patients with schizophrenia are often worried about the patient relapsing into psychotic symptoms. They need schizophrenia related support regarding information and caring assistance. Living with, and caring for patients, with schizophrenia is difficult and demanding, which could impact upon their economic wellbeing as well as involving a significant time investment in caring for patients. This burden among caregivers may induce depression and anxiety because of the potential for the recurrence of schizophrenia in their patient; an ever-present danger as long as the quality of patient care and caregiver support is poor. This will further destroy the caregivers' hopes for their

patient's recovery (Yeh et al. 2008); hence, psychological and spiritual support is not just helpful, but essential, for those caregivers.

3.3.5 Health personnel needs

British and Japanese primary health care personnel, who provide schizophrenia care for both caregivers and patients with schizophrenia, need to improve their mental health care skills by attending special mental health training programmes (Lester et al. 2005). It is argued that the research results of Lester et al. (2005) may be based on GP's perspectives, because the main participants were 35 GPs and 8 practice nurses. Thus, generalisation potential of those research results is limited, because it is rare to have a GP providing care at the primary care level in Thailand.

The study of Katakura et al. (2010) suggests that improving home-visit nurses' attitudes towards patients with schizophrenia and interpersonal skills is crucial. Although the study by Katakura et al. (2010) was conducted in the Asian country of Japan, the types of primary care staff in Japan and Thailand are different. There are no home-visit nurses in Thailand but general registered nurses and public health workers who visit patients with schizophrenia and their caregivers at their homes. The Thai primary care staff have been trained for home visiting but such staff are not specialised in mental health care.

From the service providers' perspective, it can be summarised that improving mental health knowledge and interpersonal skills are important in order to provide adequate schizophrenia care at the primary care level.

3.4 The recommendations for improving schizophrenia care at the primary care setting in rural areas

In the Japanese primary care context, improving primary care staff's attitudes towards patients with schizophrenia is important because such a change will, or at least should, develop empathy and rapport in those staff members (Katakura et al. 2010). In the British primary care context improving listening skills, providing continuity of care and training personnel to acquire mental health care skills are all points recommended for improving the quality of

mental health service delivery (Lester et al. 2005). Understanding and providing care by noting and accepting the caregiver's cultures and belief systems is crucial (Sethabouppha and Kane 2005; Sanseeha et al. 2009; Ko et al. 2014). This will assist health personnel to improve mental health service delivery to suit the individual and, perhaps, prevent or reduce burdens encountered when dealing with schizophrenia. The evidence presented comes from different studies and participant groups from across the world, where there are differences between health care and cultural contexts. For example, although the study by Lester et al. (2005) was conducted in a UK primary care setting, there are differences between the British and Thai mental health services, at the primary care level, which will be examined more fully in the discussion chapter.

3.5 Service delivery in community settings

3.5.1 The treatment of schizophrenia in the community mental health care setting

Although patients with schizophrenia, who are discharged to live in community settings, have controllable psychiatric symptoms, they still need special care. There are many community mental health care strategies which are intended to facilitate the management of schizophrenia. However, this community based model of caring requires collaboration between partners of care, including the patients, because patient self-management is one of the recovery ingredients (Davidson 2005b).

3.5.2 Key issues for community care in rural Thailand

3.5.2.1 An overview of the Thai community mental health system

A referral system has been used for providing treatment for schizophrenia in Thailand. An individual who seeks mental health treatment and/or care would need to meet the GP at a community hospital (the secondary care level). If there is no psychiatrist at the community hospital, the GP may or may not confirm a diagnosis of schizophrenia, and may use a consultation or referral system. This means that a person who needs mental health treatment or care will have to visit an outpatient department in the first place. People showing

Chapter 3 Literature review

symptoms of severe mental illness, including positive symptoms of schizophrenia, will be admitted to the tertiary care or supra tertiary care level. If the patients fail to comply with the referral system, they would need to pay for any treatment or care. Ideally, community mental health services should include multi- health professionals who will collaborate with patients, caregivers, community leaders and other stakeholders before discharging patients to live in the community. The discharge planning should normally happen before sending the patients back to their homes. Therefore, the health personnel can liaise with patient's caregivers, community and other stakeholders for patient support, if appropriate. The community mental health approach is available, for example, as a case management in community setting (Kong- ngirn 2008). However, this may be not applicable in some places because of the lack of mental health personnel. Hence, rehabilitation programmes for patients with schizophrenia are not well distributed in community settings.

3.5.3 The Thai national mental health policy for schizophrenia care in community settings

The concept of community mental health promotion was implemented in Thailand in 1976, with the aim of offering community mental health services for mental illnesses by integrating care into the community, based on clients' needs (Department of Mental Health 2008 p6). The Thai government embarked on improving community mental health services because of a belief that this can reduce re-hospitalisation and the cost of mental health care. For the period 2012-2016, the 11th National Health Development Plan focuses on the accessibility and equity of mental health care, by using community collaboration, in order to 'strengthen and empower the sub-district health system' (Bureau of Policy and Strategy Ministry of Public Health 2009).

It is arguable that the national health policy was unable to provide adequate mental health care because of the high volume of clients, compared to the number of service providers. This deficit may be because the majority of psychiatric specialists (59%) work in the capital city, where there is one psychiatric specialist for every 27,000 cases, whereas the ratio of psychiatric specialists in provincial towns and rural areas is one to 175,674 cases (Siriwanarangsana et al. 2004). These ratios are similar to community mental

health services in other developing countries (World Health Organization 2003; Ndeti et al. 2007). Thus, it is difficult for people with schizophrenia in rural areas to access mental health care services.

As a result of these challenges, the 'Community Mental Health Well-being Policy' was introduced by the Ministry of Public Health in 2003. This suggested that primary care staff should focus on providing community mental health care and health promotion (Towse et al. 2004). The 11th National Health Development Plan aims to improve primary care networks through Tambon Health Promotion Hospital (THPH) services at the sub-district level, with the aim of empowering primary care staff. Such staff comprise of registered nurses (RNs) and community public health workers who are responsible for providing mental health monitoring and equitable mental health delivery.

The primary care staff will be under the supervision of the tertiary psychiatric hospital; nurses and allied mental health professionals will visit the discharged schizophrenia patients regularly. According to the Department of Mental Health (2008) manual, the supervisory teams from the tertiary care psychiatric hospital will follow-up the groups of patients with schizophrenia who are judged to be 'controllable': every three months for the stabilisation phase and every year thereafter to monitor the stable phase. This entails collaboration among community mental health care professionals from different groups, who are taking care of people with schizophrenia at the sub-district level.

3.5.4 Thai community mental health care for schizophrenia

It is arguable that, although community mental health services have been provided for people with schizophrenia for some time, there is a lack of evidence, from the stakeholders' perspectives, of any improvement in direct schizophrenia care at the primary care level. This may be because a wide range of the research is informed by the traditional biomedical model, which is focusing on psychotic symptoms rather than a holistic bio- social approach; the latter embraces all dimensions of an individual's life (Shah and Mountain 2007). There is evidence that living in the community might increase the risk of relapse, because patients need to cope with mental illness and daily living circumstances at one and the same time (Department of Mental Health 2012).

Chapter 3 Literature review

The cycle of re-hospitalisation of patients with schizophrenia in Thailand is illustrated in Figure 4.

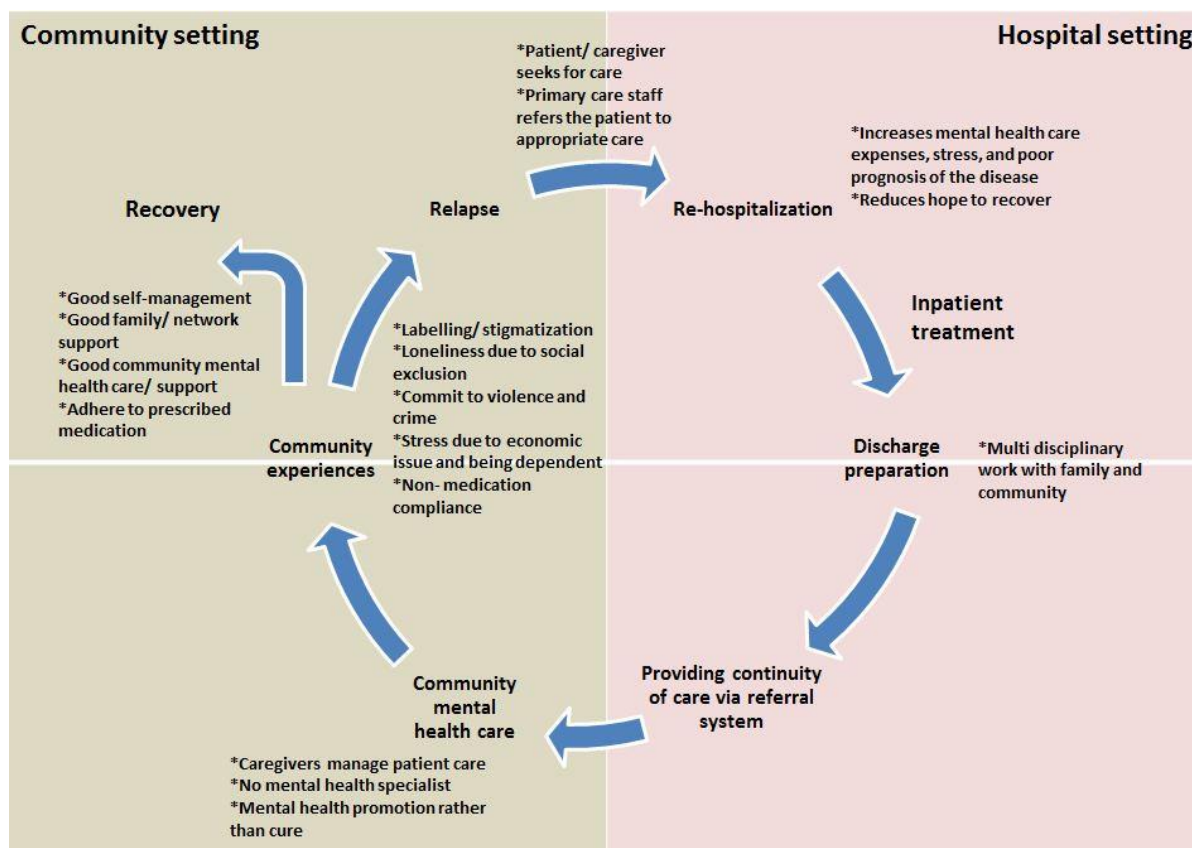


Figure 4 Conceptual framework of re-hospitalisation of patients with schizophrenia in Thailand (developed by the author)

Figure 4 illustrates that not only patients themselves suffer from mental illness but also their caregivers, family, community and health care systems may be affected in various ways. The recurrence of schizophrenia is harder to break because there are many factors that might affect the patient’s life. For instance, community members may be fearful of patients with schizophrenia, since they can be violent and commit a crime or crimes (Rueve and Welton 2008). Undeniably, this might be difficult for social inclusion. Moreover, family members of relatives with schizophrenia have to spend time and money looking after them; a commitment which, in many cases, leads to increasing health care expenses and stress. This cycle would keep moving forward, if the

provision of schizophrenia care in primary care level fails to meet both the patients' and caregiver's needs. However, it might be impossible to serve all of those needs because of the limitation of community health care resources. Hence, integrating both service users' and service providers' perspectives may reduce the gap between 'what is and what might be' of community mental health practice.

3.5.5 The way forward of caring for patients with schizophrenia in community settings

Caring for people with schizophrenia in community settings is recommended (WHO 2014). Recently, clients' views have become important for directing community mental health care. The evolution of patient outcome assessment, regarding people with schizophrenia, has moved from quantitative to qualitative aspects in an attempt to enhance patients' and caregivers' benefits (Burns 2007). This is based on a belief that patients' views should be used to improve their care. Pragmatically, demand and supply should be balanced, based on available resources (Wright et al. 1998). Hence, it is necessary to listen to stakeholders: patients with schizophrenia, caregivers, primary care staff and supervisory team members from the psychiatric hospital, in order to integrate different perspectives towards community mental health care for people with schizophrenia at the sub-district level in rural Thailand. The data will be triangulated in order to strengthen community mental health care evidence. The four groups of people who are stakeholders of schizophrenia care at the sub-district level in rural Thailand comprise the research population of this study: caregivers of people with schizophrenia, the THPH, the supervisory team and patients with schizophrenia.

Although there are some relevant and available studies in this field, existing knowledge needs to be updated and extended with new areas of scientific enquiry, because making decisions to provide or improve health care should be based on rigorous evidence (Melnik and Fineout-Overholt 2005). Hence, it is necessary to strengthen schizophrenia care evidence, prior to managing or improving care that is based on patients', caregivers' and service providers' perspectives. For example, evidence from this current study may be used to inform psychosocial intervention, which requires family involvement, such as family therapy.

3.6 Gaps of knowledge

Current evidence reveals that living with, and caring for, schizophrenia is difficult and burdensome. This allows patients and their caregivers to find ways to cope and seek for help. Help seeking behaviour relates to beliefs about the aetiology of schizophrenia, education, and religion/belief systems. Thus, people who seek traditional treatments may be delayed from receiving modern medical treatment, which can cause a poor prognosis as well as non-therapeutic compliance (Versola-Russo 2006). All of these events may happen in some developing countries, where people believe in supernatural causes of schizophrenia, including in Thailand.

We do know that schizophrenia care at the primary care level is an alternative level of care, which is expected to gain service accessibility and reduce patient readmission rates. However, living in the community is complicated. Some patients with schizophrenia have to cope with their psychotic symptoms, stigma and discrimination, as well as adjusting to living with the disease. Thus, an individual patient with schizophrenia has different needs from other patients, including both physical and psychological care dimensions.

From the literature review, it can be seen there are not only patients with schizophrenia themselves who suffer from a long term mental health condition, but also their caregivers and perhaps non-mental health professional in community settings may be unsure about providing care at the primary care level. Assisting with patient care and providing caring information for people with schizophrenia are the main caregivers' needs. Both patients and caregivers require mental support regarding coping strategies for relieving stress and assisting emotional expression. Primary health care providers perceive that they are not able to provide sufficient effective community mental health care for severe mental illnesses at the primary care level (Lester et al. 2005). This perceived inability may be because of a lack of mental health specialist training, socio- economic and cultural factors, the health care system and local health policies, all of which shape perspectives towards community mental health services, as well as mental health practice (Burns 2007; Patel et al. 2007; Burnard and Gill 2009).

Only relatively few studies have been conducted in Thai community settings (Rungreangkulkij and Chesla 2001; Permyao 2004; Sethabouppha and Kane 2005; Dangdomyouth et al. 2008; Trangkasombat 2008; Meebunmak 2009). These studies had diverse aims, and furthermore were not focused on stakeholders' perspectives regarding schizophrenia care at the sub-district level. Additionally, one of the selected studies is older than 20 years (e.g. Winefield and Harvey 1994). Also, more than half of the reviewed studies were conducted in developed countries, which have different health systems, socio-economic, socio-demographic and cultural conditions when compared to Thailand and particularly rural Thailand. All of the reviewed studies are limited in terms of generalisation, due to their small sample size, different cultures, religious views and belief systems and health systems.

This current research will be a pioneer study to include patients with schizophrenia, their caregivers, primary care staff and supervisory team views towards schizophrenia care, at the sub-district level, in rural Thailand. This focus is because we do not know whether the provision of schizophrenia care at the sub- district level matches patients' and caregivers' needs. This study will be the first step in improving or directing community mental health care, based on strong evidence of patients' and caregivers' needs and unmet needs (Wright et al. 1998). Therefore, evidence from current practice will be used when considering patient care. This is a way to include service users in the decision-making of community mental health care; their 'weight of comment' should be equal to mental health staff, in order to further improve the client-centred care model (Tee et al. 2007 p144).

3.7 Research aims

1. To provide an in-depth understanding of people with schizophrenia, their caregivers and health care providers, regarding schizophrenia care provision at the sub-district level in rural Thailand.
2. To offer a rigorous qualitative study to the policy makers, which may be used to inform the development of community mental health policy in the future.
3. To recommend the importance of future improvement for community mental health nursing care at the primary care level.

In order to focus this study two suitable research questions were developed that combined the population (people with schizophrenia, caregivers of people with schizophrenia's caregivers, THPH staff and the community mental health supervisory team) with the context (THPH at the sub-district level in rural Thai community settings) and the phenomenon to be studied (perception of schizophrenia care in sub-district level, rural areas).

3.8 Developing research questions

Having carefully considered current evidence relating to community mental health perspectives towards schizophrenia care, it is evident that there are significant knowledge gaps, particularly in relation to people living in rural Thailand. This study seeks to fill the gaps by exploring stakeholders' perspectives by ascertaining an in-depth understanding of the individual perspectives of those people receiving, providing and supervising community mental health care in sub-district level, rural Thai community settings.

3.8.1 Research questions

1. What are the needs and unmet needs for schizophrenia care at the sub-district level in rural, Thailand?
2. What are the recommendations for improving schizophrenia care at the sub-district level in rural Thailand?

3.9 Chapter summary

In summary, there is no available evidence regarding the needs, unmet needs and recommendations for schizophrenia care at the primary care level in rural Thai community settings. Almost all studies reveal that family members and caregivers living with patients with schizophrenia perceived schizophrenia care as a burden (Saunders and Byrne 2002; Sethabouppha and Kane 2005; Mizuno et al. 2011; Panayiotopoulos et al. 2013; Seeman 2013; Caqueo-Úrizar et al. 2014). However, Irish parents and Thai mothers viewed this as being their responsibility and they have to accept, keep calm, manage and take care of their children unconditionally (Rungreangkulkij and Chesla 2001; McAuliffe et al. 2014). Service users need physical, psychological and information support

from primary care staff, but the health personnel at primary care level are not ready to provide those services, due to a lack of confidence, lack of knowledge and lack of training. Needs in the patients' and caregivers' and health care professionals' eyes are discrepancies. The evidence is not sufficient to make recommendations for schizophrenia care at the primary care level in rural community settings in Thailand. This is because little is known regarding patients with schizophrenia and health personnel perspectives towards schizophrenia care in primary care settings. Thus, it is worthwhile to pioneer an exploration of the needs and unmet needs of schizophrenia care at the sub-district care level in a rural Thai context. Although there is insufficient literature regarding the needs and unmet needs for schizophrenia care at the primary care level in rural Thailand, themes from available literature were used to develop interview schedules. It is hoped that the research results will be used for improving Thai schizophrenia care, community mental health curricula for both nursing and public health, as well as those results being recruited to assist with developing the Thai community mental health plan.

The next chapter will justify and discuss the research methodology and approach which was used to answer the research questions.

4. Chapter 4 Methodology and method

Introduction

The aim of this chapter is to provide a justification for the selection of the most appropriate research methodology and method for answering the two research questions. Therefore, the researcher's stance, epistemology, research paradigm, method and approach will be justified and discussed. This is because the coherence of ontology, epistemology, research design and methods can assure the validity of research findings (Denzin and Lincoln 2005; Maxwell 2009). Additionally, using the appropriate and logical methodology and method is important in being able to find answer(s) to the research questions, thereby leading to better quality research (Polit and Beck 2008), the results of which can be used for clinical practice, academic work and government plans. This chapter is divided into five topics: methodology, research design, data collection and tools, introduction of data analysis method, and chapter summary.

4.1 Methodology

4.1.1 Ontology and epistemology underpinning this study

Ontology and epistemology guide research methodology (Parahoo 2014). Ontology is concerned with 'what is the nature of reality' and epistemology is about 'the relationships between the researcher and the known', which in turn will influence the researcher's choice of methodology and method (Guba 1990 p.18). In other words, the value of knowledge is based on ontology (the nature of reality and truth) and this will lead to the epistemological stance (the way to find new knowledge). All of this is combined with the researcher's stance and can influence the research strategies, which aim to find answers to the research questions. Hence, all of the above will lead to the research paradigm, methodology and design respectively. This will be illustrated in Figure 5, which sets out the relationships of research ontology, paradigm and methodology.

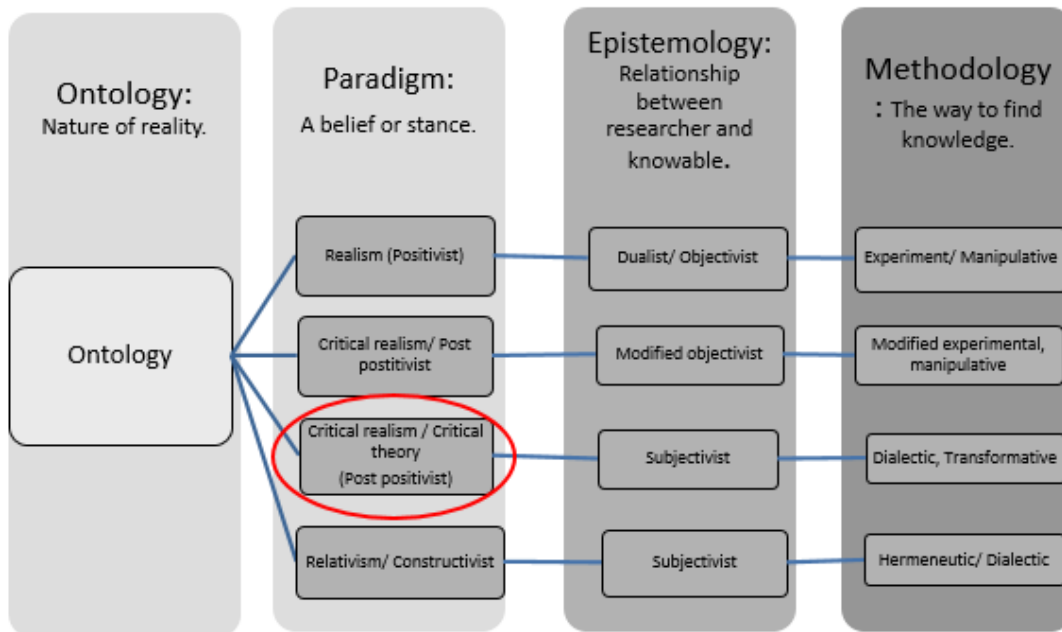


Figure 5 The relationships of ontology, paradigm and methodology adapted from Guba (1990), Denzin and Lincoln (2005) and Parahoo (2014)

There are four research paradigms whose advantages and limitations are open to debate, namely: positivism, postpositivism, critical theory and constructivism (Denzin and Lincoln 2005 p192). From Figure 5, Guba (1990) distinguished ontologies and paradigms that influence methodologies. It is important to choose the most appropriate research paradigm, epistemology and methodology in order to ensure that the research undertaken is valid and rigorous (Denzin and Lincoln 2005). Hence, the justification for choosing a particular research model will now be explained and discussed.

4.1.2 Research paradigm and design

There are two distinct research paradigms which have been used for different research purposes; namely quantitative and qualitative (Vivar 2007; Teddlie and Tashakkori 2009; Creswell and Plano-Clark 2011). Although focusing on quality and usefulness of evidence is more important than arguing about which paradigm is better (Bryman 2006; Griffiths and Norman 2013), justification of a paradigm is an initial step for conducting a rigorous study.

The quantitative paradigm, which is recognised as positivist or pure science, is based on the belief that there is only one truth which can be measured, whereas post-positivism focuses on ‘causes and effects’ (Guba 1990; Parahoo 2014 p36). For example, these two paradigms can be used for laboratory research, such as testing the effectiveness of medication, which the research method should be able to replicate in another study; therefore the results should be the same in every test. Furthermore, the use of quantitative research is to test hypotheses and/ or standardising tools in order to generalise research results so they may be applied to the general population (Teddlie and Tashakkori 2009; Parahoo 2014). The quantitative paradigm is more rigid, if compared to a qualitative paradigm, because it relies on research questions, hypotheses and measurement tools which are prepared in advance (Parahoo 2014). This is because quantitative method uses a ‘deductive’ strategy.

The qualitative or constructivist model focuses on perspectives, experiences and behaviour in order to illuminate the meanings of uncovered phenomena (Guba 1990; Woods 2006; Parahoo 2014). This paradigm is based on the concept of ‘socially constructed knowledge’ which means that humans ‘make sense or interpret’ their perspectives, according to their background and views towards society (Creswell 2003 pp 8-9) . This concept is based on a subjectivist epistemological stance which focuses on individual experiences (Guba 1990; Creswell 2003; Parahoo 2014). Qualitative study gives more detailed, rich and diverse data gained from interaction with the research participants, rather than structured questionnaires. This means that the qualitative paradigm is suitable for explaining and understanding participants’ perspectives (Maxwell 2009). After considering the advantages and limitations of both quantitative and qualitative options, the qualitative paradigm was selected to find answers to the research questions that were set out in chapter 3 above. As the aim of this current study is to explore stakeholder’s perspectives towards schizophrenia care in rural Thailand, using quantitative methodology, such as questionnaires, may overlook or miss some important information, as there has been very little previous research or knowledge in this area. Therefore, it is appropriate to choose a qualitative approach for this research.

4.1.3 Theoretical framework

Qualitative research methodology is chosen for this study because it is the most appropriate method for exploring and understanding the aim of this research (Parahoo 2014). This research aims to explore and understand both met and unmet needs of stakeholders of schizophrenia care at the sub-district level in rural Thailand. The nature of those needs is subjective, unique and various (Mason 2002; Vivar 2007 p65). A qualitative method, as a flexible and inductive approach, is suitable for exploring perceptions and phenomena which are expressed by people who have direct experience of them (Mason 2002; Cohen et al. 2007; Tuli 2010; Creswell 2013 p21; Parahoo 2014). This view is based on a belief that social context can shape human behaviour (Mason 2002). It is because reality is multiple, which depends on subjective data rather than the generalisation of findings to the whole population (Mason 2002; Tuli 2010). There are several qualitative methodologies that may be used for this research, namely: phenomenology, case study, grounded theory, ethnography, narrative and pragmatic approaches. Thus, providing the rationale for selecting the most appropriate approach for the research is necessary.

Phenomenology may be another potential approach for this study, because phenomenology is suitable for uncovering or revealing an in-depth understanding of the meaning of interesting phenomena by using 'how and why' questions to interview people who have direct experience of phenomena without judging cause and effects of any specific phenomenon of interest (Creswell 2013; Edmonds and Kennedy 2013; Parahoo 2014). The phenomenological approach considers that, although community experience is a part of the needs and unmet-needs of stakeholders, schizophrenia care stakeholders' experiences are not a focal point of this study. However, this study aims to explore the needs and unmet needs of schizophrenia care at the primary care level in rural Thai community settings, rather than to attempt to interpret the meaning of needs and unmet needs. Although latent meaning from the interviews is included, the main focus of this study is elaborating the participants' own words. Therefore, this orientation can ensure that the research findings come from the participants, instead of the researcher's interpretations of those words. Hence, the yielded data could be used for clinical and policy improvement.

The case study model is potentially suitable for this research because it is compatible with the research questions and aims. The criteria for using a case study are exploring a phenomenon by using 'how and why' questions, and studying in real-life settings where the researcher 'has little or no control' over the phenomenon of interest (Yin 2009 p2). A case study is similar to phenomenology, regarding asking 'how and why' questions to gain an in-depth understanding, but a case study includes multiple sources to gain insight into a phenomenon (Yin 2011; Edmonds and Kennedy 2013). However, the case study approach seems impractical for this research because this study aims to explore perspectives of 40 schizophrenia stakeholders, which is too large to fit the case-study paradigm.

Grounded theory may be a potential methodology for this research, because it could assist the researcher to gain an in-depth understanding of the unclear and unmet needs of schizophrenia care stakeholders, at the primary care level (Creswell 2013; Edmonds and Kennedy 2013). Grounded theory aims to generate a theory regarding an unclear phenomenon which uses 'abductive data analysis' to construct a theory (Edmonds and Kennedy 2013 p115). However, this research is not aiming to develop a theory but to investigate real life schizophrenia care, regarding the needs and unmet needs of stakeholders.

Ethnography may be a suitable methodology for this research because ethnography focuses on in-depth understanding of an organisation's culture in day to day practice (Creswell 2013; Edmonds and Kennedy 2013). However, it is not suitable for this research because the main researcher is not permitted to work as a mental health nurse in a psychiatric hospital, due to her not working for the Thai Department of Mental Health. Thus, it is unlikely this methodology will be used with this research project, because the main researcher is an outsider regarding this paradigm.

The criterion of narrative study is storytelling, which aims to explore identity and conflict, examining the structure of experience, focusing on how people create meaning in their lives, exploring the interaction of individual stories with cultural narratives (Creswell 2013; Edmonds and Kennedy 2013). Narrative study may be an appropriate approach for this research, because stakeholder's stories regarding schizophrenia care involvement are the phenomenon of interest. However, narrative is not suitable for a novice researcher and it may

Chapter 4 Methodology and method

not be helpful for shaping the research participants to reveal useful information. Although it is worth knowing individuals' stories regarding receiving/ providing schizophrenia care, such knowledge is not the primary or main goal of the study. Narrative design is not an appropriate approach for understanding needs and unmet needs of schizophrenia care at the primary care setting, regarding patients with schizophrenia.

It is considered that the focus of this study is entirely new for the research field in Thailand and the researcher, it should be emphasised, is not an insider in this setting. Therefore, it is crucial to consider a research approach that could be sufficiently flexible to permit the researcher to adapt and apply research strategies to facilitate effective working with the available resources and situations. The pragmatic approach is appropriate because it allows the researcher to choose research methods to answer the research questions (Creswell 2003). The pragmatic approach is flexible because the researcher can choose approaches to find answers for research questions because a pragmatist is not sitting on, or limited by, one particular theory or method (Creswell 2013). This allows the researcher to pragmatically adjust her approach to suit this research. The pragmatic approach will be now discussed in more detail.

4.1.3.1 The pragmatic approach

The pragmatic world view emerged from American thinkers and philosophers; mainly C.S. Peirce, William James, George Herbert Mead and John Dewey (Cherryholmes 1992). A pragmatic world view is different from other philosophical assumptions because it is based on practice outcomes (Robson 2011; Creswell 2013). This is because pragmatists believe in the effectiveness of the research method used, rather than relying on a methodological stance. This approach is not theoretical, but is driven by practical aspects and therefore the researchers can choose expedient research methods for addressing the research problems (Patton 2002; Teddlie and Tashakkori 2003; Bryman 2006). This means that it is worthwhile to focus on the impacts of research answers, rather than the format of research methodology. Therefore, pragmatists are flexible and do not rely on a given philosophy (other than pragmatism) as they believe that there are many ways to seek for knowledge (Creswell 2013). Therefore, this paradigm enables the researcher to adjust her

research method to answer the research question, which can be purely quantitative, purely qualitative and/or mixed methods (Flick 2009; Creswell 2013 p28).

4.1.3.2 My epistemological/philosophical stance

Clearly stating the researcher's epistemological stance does not seem to be a focal point for the pragmatist researcher, because the pragmatic view allows the researcher to use an appropriate epistemological stance to gain new knowledge. However, proclaiming a philosophical stance could help shape the rationale for the research methodology; thereby assisting researchers in finding the most appropriate research methodology and approach for answering their research questions. The positivist approach considers 'how things really are' and 'how things really work' and is linked to the belief that things can be measured in an objective manner. However, post positivists or critical theorists consider the important of subjective values (Guba and Lincoln 1990 p111). The aims of both positivism and post-positivism are similar in terms of seeking for explanations and understanding of a specific phenomenon that is believed to exist in reality (i.e. existing in society and measurable). This is therefore different from constructivism, which believes that knowledge can be constructed by human experiences (i.e. an individual constructs his/ her own reality) (Guba 1990). However, critical theory focuses on emancipation (Guba and Lincoln 1990) which means that the researcher who takes a critical theory epistemological stance would be able to choose the most appropriate methodology and approach for their research. Hence, from Figure 5, it can be seen my philosophical stance is consistent with critical realism, which is aligned to the aims of this study in terms of using qualitative methodology to explore the research questions in a flexible manner. The concept of critical realism denies the concepts of both the positivists and constructivists; however, critical realism could sit between both paradigms (Putnam 1999). Furthermore, thematic analysis is flexible, which can accommodate to the principles of realism, constructivism and critical realism (Bruan and Clarke 2006).

4.1.4 Sampling strategy

The purpose of qualitative research is “discovering multiple realities and in-depth understanding of the meaning of covered issues” (Polit and Beck 2008 p360). Hence, selecting the key informants is the main criterion for an informative qualitative study (Patton 2002; Teddlie and Tashakkori 2003 p713). There are two main sampling strategies which are normally used in qualitative research: purposive sampling and convenience sampling (see Table 1). Table 1 illustrates the advantages and limitations of the two sampling strategies for use in a qualitative study. This current study aims to recruit a mixture of perspectives, as illustrated in Figure 7, because transferability of the research results is important. Hence, purposive sampling was the sampling strategy selected for this study.

Table 1 Advantages and limitations of purposive sampling and convenience sampling

Sampling strategy	Advantage	Limitation
Purposive sampling (judgemental/theoretical sampling)	<p>-Diverse perspectives regarding genders, socio-economics, duration of having a diagnosis with schizophrenia and so on (Polit and Beck 2010 p320).</p> <p>-The research results may be transferable. This is because purposive sampling is recognised as a “rigorous and systematic sampling, if compare with convenience sampling” (Procter et al. 2010 p151).</p>	-It can be biased in terms of using the researcher’s criteria to select the research participants.
Convenience sampling (accidental sampling)	-It is an economical method which can obtain research participants relatively easily. Convenience sampling can be used for the novice researcher who may have difficulty gaining informant accessibility (Procter et al. 2010 p151).	-Biases can occur when the recruited research participants have the same characteristic(s). Moreover, convenience sampling may present meaningless data because the phenomenon of interest is still covered due to non-representative samples (Polit and Beck 2010 p390; Procter et al. 2010 p151; Moule and Hek 2011 p94).

Chapter 4 Methodology and method

Purposive sampling was used for choosing the psychiatric hospital involved in this study, as well as participant selection. The reasons for purposively selecting the psychiatric hospital were the researcher speaks the same local dialect as the participants, regarding the service user groups. Moreover, the researcher is familiar with the research region because her hometown is located there; therefore she would be able to understand the cultural context, belief system(s) and local people's body language. This could assist her to gain an in-depth qualitative understanding of the data, as well as reduce miscommunication with participants and misinterpretation of interview data. The three groups of people who met the inclusion criteria were purposively selected for the interviews. This judgement was made because this study is aimed to use the stakeholders' perspectives regarding schizophrenia care at the sub-district level in rural Thailand, in order to make decisions to improve community mental health care and public health education. It is crucial to gain richness of information and diverse perspectives from the sample, which will be selected from five provinces (see Figure 6).



Figure 6 Thailand map illustrating the five provinces from which participants were selected, namely: Khampaeng phet, Uthai thani, Nakhon Sawan, Chinat and Pichit (source: <http://divezone.net/travel/thailand>).

4.1.5 Type of qualitative approach

4.1.5.1 The type of qualitative approach

There are different types of qualitative interviews: individual, paired or triad interviews and focus group discussions. Focus groups and interviews are the main methods used for data gathering in qualitative research (Ritchie and Lewis 2003).

A focus group is suitable for creative thinking (Ritchie and Lewis 2003 p37), which can be challenging for people with cognitive and communication problems (Bergman et al. 2006). Therefore, taking part in a focus group may be challenging for patients with schizophrenia because of the group setting, personal nature of the questions and perhaps the need for concrete questions rather than abstract questions (Fox and Gamble 2006 p134). Hence, an interview format may be more suitable for people with schizophrenia (Green 2006 p3). The type of interview method used by the researcher is not only crucial for patients with schizophrenia but also the entire, four group, study population. This is because an individual point of view is highly important for this study, which is focused on a sensitive topic area. The individual interview model was chosen for this study because it is suitable for gaining an in-depth understanding of an individual's views and perspective of this sensitive topic (Ritchie and Lewis 2003 p36-37).

Private and confidential issues are involved because this study requires the interviewees to express their personal views towards schizophrenia care at the sub-district level in rural Thailand (Warren 2001). It might be awkward to express opinions openly regarding unmet needs, which might contain intimate relationship issues and/ or negative feelings against others, within or outside the family. Hence, a face to face interview is better than a focus group with regards to reducing embarrassment and fear of any negative impacts after a group discussion. Additionally, there is in the Thai culture the term 'Kreng Jai' means "to be considerate, to feel reluctant to impose upon another person, to take another person's feelings (and ego) into account, or to take every measure not to cause discomfort or inconvenience for another person" (Knutson et al. 2003 cited in Komin 1991 p67). These cultural issues may be seen as a barrier regarding the use of group discussions to explore people's views of community mental health service (Burnard and Gill 2009 ; Meissonier et al.

2013). Additionally, gathering stakeholders of schizophrenia care for a group discussion is impractical. The rationale behind this decision relates to time and funding availability, as well as managing patients with schizophrenia who may relapse during travelling to take part.

4.1.6 The type of interview schedule

It is crucial to consider the structure of the interview, which is the main information gathering tool of the research. Unstructured, semi-structured and structured interview methods can be used for different purposes. An unstructured interview allows the interviewees to talk freely (Berg 2004; Rubin and Rubin 2012). It is argued that it is impossible to allow the interviewee to speak without the interviewer asking questions and presenting their own views and experiences (Britten 2006 p13). Conversely, a semi-structured interview is suitable for exploring and gaining an in-depth understanding of the phenomenon of interest, by using open ended questions (Warren 2001 p83). This interview method is less flexible than an unstructured interview; however semi-structured interviews can facilitate the researcher to achieve rich and thick data by using probes and prompts to elicit in-depth information, in order to answer the research questions (Berg 2004; Britten 2006). For instance, such interview techniques can be used to carry out content mapping (to open up) and data mining (to explore the detail) techniques (Legard et al. 2003, p148). A semi-structured interview format is suitable for the author, a novice researcher, in terms of preventing her from forgetting questions or moving away from the topic area. Importantly, the prepared interview schedules were carefully checked by peer reviewers, mental health experts and ethical committees. These procedures can ensure that the interview will not be a cause of participant stress, regarding the patients with schizophrenia who are considered a vulnerable group (McCann and Clark 2005). Hence, semi-structured interviews will be used to explore the issues of interest in this study.

Chapter 4 Methodology and method

4.1.6.1 Semi-structured interviews

Types of semi-structured interviews

In this study, semi-structured interviews were carried out using both face to face interviews and telephone interviews. However, there are both advantages and limitations associated with these two interview methods.

The first interview method, face to face, allows research participants to express their views freely in order to yield, and for the researcher to access, the richness of data (Rubin and Rubin 2012). For this study, face to face interviews provided the research participants enough time to recall and express their feelings. This research will concentrate on each individual interviewee, in a situation where there is no time limit and no other people to create any pressure. This will facilitate the main researcher to establish good rapport and trust by communicating and interacting with the research participants; therefore, it is hoped this approach will lead to in-depth and rich data (Rubin and Rubin 2012). Field notes were taken during interviews, which can be used to describe the context of study, non-verbal communication observed during the semi-structured interviews and the researcher's reflections.

The second interview method, by telephone, is useful in terms of asking for information about a sensitive issue. Interviewees can express their feelings and opinions more freely. Furthermore, a telephone interview is a safe approach regarding travelling to remote areas and lone interviews, as well as saving cost and travel time. Hence, telephone interviews were used for communicating with some participants who could not take part in face to face interviews, for reasons such as living far away and having limited access to transportation. Moreover, telephone interviews were used to clarify unclear issues and expand upon certain details or issues, such as awkward comments which research participants may feel uncomfortable to express in face to face interviews. All the research participants signed the consent forms before starting the interviews. However, the researcher explained to them that the research participants may be contacted by telephone if necessary; a depersonalising advantage because the interviewer cannot observe the participants when conducting a telephone interview (Gray 2004 p232). The data from the telephone interviews will be used as a source of supplementary information, to

be used as and when needed. Therefore, this will ensure the rigorous nature of the data.

4.2 Method

To enhance patients' and caregivers' benefit, the qualitative interview approach can help the researcher to gain an in-depth understanding of the research participants' perspectives regarding their needs, unmet needs and recommendations for improving quality of care to meet those needs. Three stakeholder groups of schizophrenia care, at the sub-district level in rural areas, were recruited.

4.2.1 Participants

The participants comprised three population groups. Firstly, people with schizophrenia that have had a confirmed diagnosis of the illness for at least one year. Secondly, caregivers who have been taking care of people with schizophrenia for at least one year after patients received a confirmed diagnosis of schizophrenia. Thirdly, the health professional group involving community health professionals who provide schizophrenia care at the sub-district level in rural Thailand. This group includes public health workers, general registered nurses (RNs), and qualified specialists in mental health care or with other specialist qualifications. The third group also comprises of the supervisory team from the selected psychiatric hospital: a supra- tertiary care level of psychiatric hospital and mental health nurses from community hospitals were included in this participant group. Moreover, the RNs from community hospitals (secondary care) who supervise the THPH staff and collaborate with the psychiatric hospital staff, were included in the supervisory team group. This variety of health personnel is considered to complete the line of collaboration in schizophrenia care from a supra- tertiary care level to primary care level. The conceptual framework of integrating stakeholder perspectives towards schizophrenia care is illustrated below (see Figure 7).

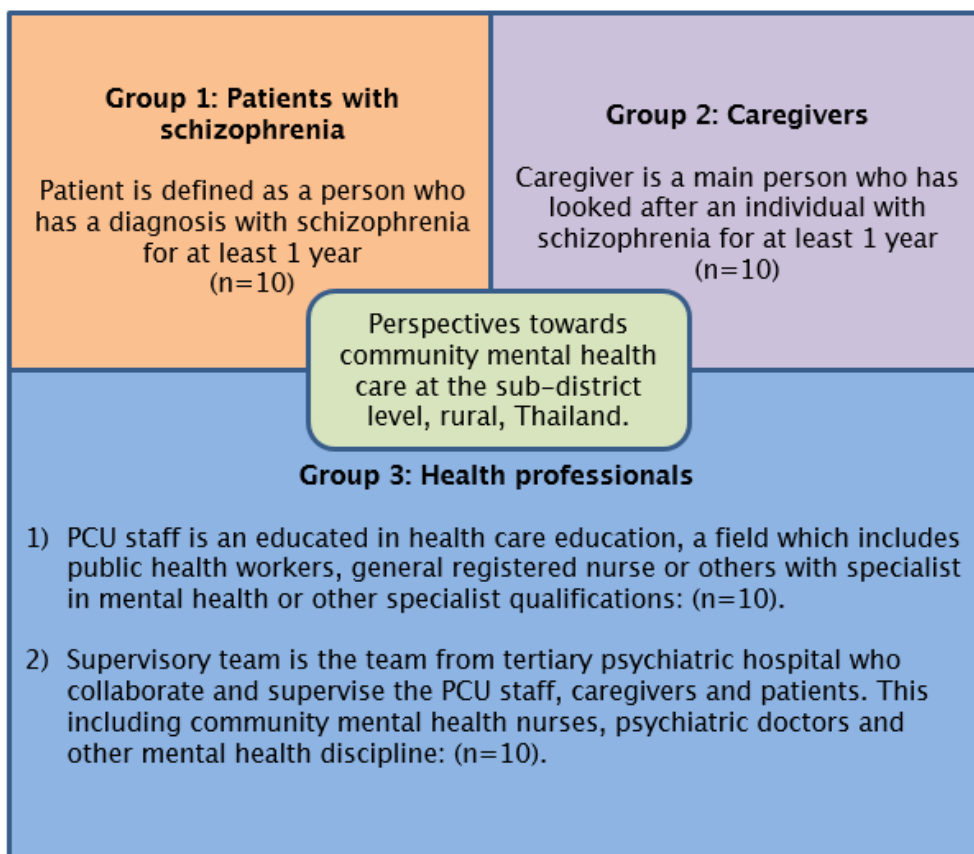


Figure 7 Conceptual framework for stakeholder perspectives towards community mental health service at the sub-district level in rural Thailand

From Figure 7, the rationale for each group’s inclusion and exclusion criteria will now be described.

4.2.2 Inclusion and exclusion criteria

There are inclusion and exclusion criteria for each research participant group, which are presented below.

Table 2 Inclusion and exclusion criteria for patient with schizophrenia group

Inclusion criteria	Exclusion criteria
<p>1) A person who has a confirmed diagnosis with schizophrenia for at least 1 year (both male and female).</p> <p>2) Adulthood (18-59 years old).</p> <p>3) Patients with schizophrenia who are receiving and keeping contact with the selected psychiatric hospital</p> <p>4) Living within one of five rural provinces: namely, Khampaeng phet, Uthai thani, Nakhon Sawan, Chinat and Pichit.</p> <p>5) History of hospital admission at least once.</p> <p>6) Able to consent and willing to participate in this study</p> <p>7) Not too ill to be interviewed. (People with schizophrenia will be screened by psychiatric doctors or psychiatric nurses to ensure that they are not acutely mentally distressed.)</p>	<p>1) Unable to consent due to lack of capacity.</p> <p>2) Individual experiencing acute exacerbation of their condition.</p>

Including all episodes of psychotic symptoms may provide the widest range of patients' views relating to specific needs and, perhaps would be different from responses elicited during a patient's stabilising and stable phases. However, the researcher is not a clinician or specialist in mental health regarding schizophrenia care, but a novice researcher in community mental health nursing. Hence, if the participants had alteration of consciousness and mental health, this could cause harm to both the patients with schizophrenia and the researcher. Any researcher, including this present one, should note that

Chapter 4 Methodology and method

patients are vulnerable and they have no capacity to give consent and take part in the interview if having a psychotic episode (McIntosh and Morse 2009).

Thus, it is the patient's right to be treated ethically and with respect, and not to be disturbed when they have psychiatric symptoms. In addition, biases may occur because the patient's mind is away from the interview (e.g. the patient keeps quiet) but the interviewer can interpret the patient's reactions in different ways (Morse 2011). Therefore, only patients with schizophrenia, who are in a stabilising and stable episode of their psychotic symptoms, were recruited in this research.

Table 3 Inclusion and exclusion criteria for caregivers of a patient with schizophrenia

Inclusion criteria	Exclusion criteria
1) The main person who is taking care of a patient with schizophrenia for at least 1 year. The care giver may be or may not be the patient's relative. 2) Willing to participate in this study.	1) Have a diagnosis with dementia or have symptoms of forgetfulness. 2) Unable to give information about the patient for any reason.

Caregivers of patients with all episodes of schizophrenia were recruited, because this research aims to provide a wide range of the caregivers' perspectives.

Table 4 Inclusion and exclusion criteria for Tambon Health Promotion Hospital (THPH) Staff (primary care staff)

Inclusion criteria	Exclusion criteria
1) A qualified healthcare staff member providing community mental health care for an individual with schizophrenia. 2) Willing to participate in this study.	1) Other health care discipline not involving schizophrenia care.

The THPH staff were mixed between RNs and public health workers; a group which aimed to offer an in-depth understanding from various perspectives via different health disciplines. This should gain a richness of data.

Table 5 Inclusion and exclusion criteria for THPH supervisory team

Inclusion criteria	Exclusion criteria
1) Supervisory team is the team from the supra tertiary care hospital or secondary care hospital whose members collaborate and supervise the THPH staff, care givers and patients with schizophrenia. Personnel can be: -A community mental health nurse -A psychiatrist -Other health professionals involved with the community mental health service for patients with schizophrenia. 2) Have experience of THPH staff supervision regarding schizophrenia care in at least 1 case.	1) Has no experience of supervising schizophrenia care in the THPH. 2) Not one of the main staff who takes responsibility for an individual with schizophrenia.

4.2.3 Recruitment approach

There is no absolute consensus or universal formula as to the optimum number of participants in qualitative research (Mason 2010). For this study, it is considered that 10 participants for each group is sufficient to achieve in-depth and richness of data (Glaser and Strauss 1999; Baker and Edwards 2012). It is also believed such a population is realistic in terms of accessibility of the participants and the timeframes involved.

The gatekeepers (staff nurses) at the mental health and community mental health department, in the selected psychiatric hospital, have agreed to be involved in the study, as the main collaborators and source of participant recruitment.

Participant recruitment was planned to involve two different strategies (see Figure 8). The first strategy involved recruiting participants from the hospital database via the gate keepers. The second strategy involved displaying posters advertising the study on the outpatient department's walls. Both participant recruitment strategies can be used to recruit all the research participants.

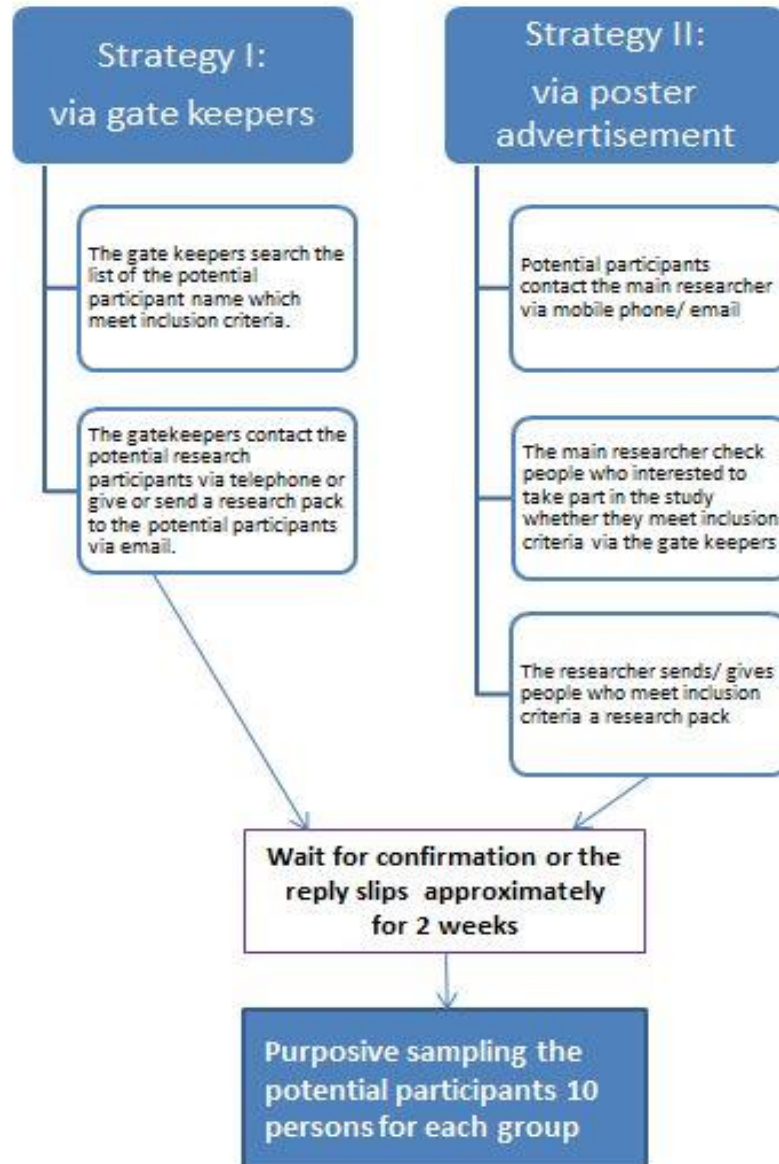


Figure 8 Purposive sampling strategies for participant selection

4.2.3.1 Recruitment strategy 1

The gatekeepers went through the hospital database and selected the patients, caregivers, primary care staff and supervisory team who met the inclusion criteria. The researcher was not involved in searching the database due to data protection and confidentiality issues. The gatekeepers contacted the potential research participants via telephone. Once, the potential research participants showed an interest in taking part in semi-structured interviews, the gatekeepers gave an information pack (containing an invitation letter, a

Chapter 4 Methodology and method

participant information sheet, a consent form and a reply slip) to the potential participants directly, or sent it to them via email. Other main caregivers of patients with schizophrenia were also sent information packs. This is because the persons who were identified as formal caregivers in the hospital database may not be the actual caregivers who were taking care of the patients at home.

4.2.3.2 Recruitment strategy 2

The poster advertising the study was displayed on the notice board in the outpatient department of the selected psychiatric hospital (see Appendix 14). It was expected that the potential participants are literate. The poster contained the researcher's contact details and people interested in taking part in the study were invited to contact the researcher directly. If the potential research participants decided to take part in the study, the researcher would contact the staff of the mental health and community mental health department, in order to confirm that they meet the agreed inclusion criteria and it would be safe to include them in the study.

People who met the criteria and decided to take part in the study were sent or given a research pack. The packages of the research information for each group were prepared beforehand and they were ready to be sent/ given to the potential research participants. The researcher planned to wait for reply slips from the potential research participants for approximately two weeks. The recruitment strategy involved obtaining a purposive sample. In order to do this, all participants were purposively selected, using separate criteria for each group.

4.3 Recruited research participants

Participant recruitment strategy 1 was more effective than strategy 2; in fact no one contacted the researcher after seeing the poster advertisement. In Thailand, contacting potential participants (patients and their caregivers) via telephone is effective, because emailing and posting research packs is time consuming and, perhaps, internet access is limited in rural Thai communities. Patients with schizophrenia were contacted and screened by the gatekeepers and the primary care staff before scheduling the interviews. Mostly, caregivers who decided to take part in the interviews were the main caregivers. There was

only one caregiver, who was not the main caregiver, who took part in the interview. In fact, some patients with schizophrenia have more than one caregiver and they manage their time for taking care of the patients, instead of leaving the duty to be carried out by one person in the family.

4.3.1 Scheduling the interviews

For confidentiality reasons, the researcher only contacted the potential participants after the gatekeepers gave the researcher the list of names and contact numbers. Hence, the researcher gave the inclusion and exclusion criteria for recruiting potential research participants to the gate keepers: the head of mental health and community mental health of the psychiatric hospital, together with the RNs in the department. The researcher only clarified and discussed dilemma cases that may or may not meet the inclusion criteria. The gate keepers were the persons who rang the potential research participants and briefed them about the research project. Once participants expressed interest to take part, the interviews were scheduled by arranging times and places that were convenient for the potential research participants. If the participants were nearby, or living in the same area, the scheduling of time and place for interviewing occurred on the same day, in order to save time and travelling costs. The interview timetable was set according to the routine mental health and community mental health home visits, so the researcher had to rely on those schedules. Although this may appear somewhat coercive, it was for safety reasons regarding interviewing research participants in remote areas that the researcher was not familiar with. To reduce coercion, the health professionals stayed far from the main researcher; however the main researcher followed health and safety guidelines which will be discussed when dealing with the topic of data collection (see section 4.4.4).

4.4 Data collection

4.4.1 Recruited participants

The 10 psychiatric hospital staff were expecting to be recruited for the supervisory group but this is not covering the line of the community mental health supervisory team. Additionally, numbers of the psychiatric hospital staff who worked for community mental health care was less than 10 people. Thus,

Chapter 4 Methodology and method

only the community mental health nurses, who collaborate with health professionals, patients with schizophrenia and their caregivers at secondary care level, were recruited.

4.4.2 Equipment

The semi-structured interview guides were developed and informed by the literature review, research questions and aims of the research. Regarding interviewing people with schizophrenia, this will follow the guide suggested by Fox and Gamble (2006) in terms of using clear and concrete questions. Prompts were prepared in advance and used to influence the interview to move forward, as well as clarifying some unclear answers or issues.

As to the research plan, the interview duration was supposed to be up to 1.5 hours long. However, all research participants were informed that they have the right to stop interviewing at any time they want. Digital tape recorders were used to keep a full record of what was said.

In reality, the interview duration ranged from 7 minutes to 82 minutes, with an average duration of 34 minutes. The shortest interview was with the caregiver of a patient with schizophrenia, who had a diagnosis of depression. He seemed unhappy to talk about taking care of his daughter, so the interview was terminated. Generally, patients with schizophrenia tend to speak less than other groups; whereas health professionals tend to be more fluent in expressing their perspectives than caregivers and patients with schizophrenia. The patients with schizophrenia were wanting to talk but they could not concentrate in the interview for a long time; some of them used body language and facial expression to register that they were bored and wanted to stop the interview. This mild stress may reflect that although rapport is well established, and the patients with schizophrenia and their caregivers are friendly, the interview topic itself is stressful. The caregiver group has to cope with schizophrenia care, causing burdens which sometimes are too heavy to bear; they showed the effects of such burdens when they recalled and talked about them. Such issues can automatically stop them talking about the emotional pain; the researcher understood this and did not try to convince them to talk more.

The plan was that some interviewees might be interviewed in the English language and the interviews would be transcribed and analysed in English; however, there was no one willing to be interviewed in English. This reluctance may be because speaking in Thai was easier, provided more depth and enabled the respondents to communicate clearly and confidently. Hence, all the interviews were conducted in the Thai language; after which they were transcribed verbatim. Thirty five face-to-face and two telephone interviews were analysed in the Thai language. This analysis allowed the researcher to retain an in-depth understanding of both linguistic and cultural contexts. However, there are five transcripts from each participant group that were translated into, and analysed in, the English language. These transcripts can be shared between the researcher and her supervisory team, in order to confirm rigour and credibility of data analysis.

4.4.3 Pilot study

A pilot study was conducted in one case from each participant group, in order to improve interview questions, probes, prompts and other consequences which might occur in the next interviews (Vivar 2007). Almost all interview questions worked well; however there were some questions that some interviewees felt were unclear. Hence, some alternative words were used; for example, using *strengths* interchangeably with *good points*. Additionally, comparing satisfaction between living at home and in the hospital was added to the interview, for patients with schizophrenia. Such an issue may be complicated and abstract for the patients with schizophrenia but it is worth including as an open question, as it aimed to find out whether the patients with schizophrenia are happy to stay at home, in the community setting. Moreover, this question required them to compare what they need when they stay in the community on the basis of primary mental health care provision.

4.4.4 Health and safety

The researcher followed the research health and safety guideline of the University of Southampton. The researcher was concerned about risks that might occur during data collection. Patients with schizophrenia were screened for the status of their mental health by the psychiatric hospital staff before taking part in the interviews. Therefore, this could reduce harm for both

Chapter 4 Methodology and method

patients, who are vulnerable group of people, and the researcher from potential physical harm. The interview times were scheduled to occur during the day: between 8.00 to 16.00 o'clock. If any off-site interviewing was required, the researcher travelled by the psychiatric hospital's car, in which she was a passenger only. Moreover, the researcher was accompanied by a member of the community mental health staff from the selected psychiatric hospital every time she made a community visit. The accompanying mental health professional had the researcher's mobile phone number and he/ she could contact the researcher when or if the situation appeared suspicious or sensitive in any way. This is because the researcher was aware of potential unexpected situations; such as, patients with schizophrenias' psychotic conditions may be unstable or relapse during the interviews.

4.4.5 Ethical considerations

Ethical approvals were gained from the University of Southampton and the psychiatric hospital prior to conducting data collection, in order to ensure there is no harm resulting from this study (See Appendices 12-13). Ethics of conducting research on humans is the most important fundamental concern in any study. All research participants, especially people with schizophrenia, are vulnerable people whose rights are protected by law, as well as medical and academic ethical conventions.

There are six principles of ethical consideration to be taken into account when carrying out research on humans: respect for autonomy, beneficence, non-maleficence, justice, fidelity and confidentiality (Parahoo 1997; Edwards 2009). These are key pillars to protect participants in human research with regard to the principles listed below:

1. The principle of respect of autonomy

All opinions are respected (Edwards 2009). Information from interviews is regarded and valued. This means that the researcher clarifies the research process, regardless of whether all of the potential research participant will take part, or not. All information about this research project is disclosed, which comprises research aims, methodology, risks, benefits and participants' rights (An Bord Altranais 2007). Informed consent was ascertained; in essence, all of the community mental health stakeholders who decided to take part in the

research could understand and accept the research information (Parahoo 1997 p79). Furthermore, self-determination is about considering that all participants, including people with schizophrenia, have their own right to make a decision to take part in, or withdraw themselves from, the study. Also, it is made clear that their decision to withdraw will not affect their treatment in any way (Parahoo 1997; International Council of Nurses 2006; An Bord Altranais 2007).

2. The principle of beneficence

This study is considering the advantages for an individual and for the public, which means that the research project should be advantageous and valuable for the wider community (Parahoo 1997; Polit and Beck 2008). For beneficence, this research aims to improve client-centred care by reflecting the perspectives of stakeholders of schizophrenia care at the sub- district level in rural Thai community settings. Although there will be no immediate benefit to the study participants, it is expected and hoped that information from stakeholders' particular perspectives will be considered as contributing to public health education, mental health care plans and mental health policy procedures in the future.

3. The principle of non-maleficence

Doing no harm is crucial for conducting research on humans. This study will not do physical harm or knowingly exert any other potential negative psychological effects on the research participants (Parahoo 1997 p78). To protect participants from harm in this study, people with schizophrenia were not overloaded by questions in the interview. The interview schedules were reviewed by mental health experts, peers reviewers and the ethical committee of the University of Southampton and the selected psychiatric hospital. Moreover, the research participants were informed that they have the right to pass some questions, to pause and ask any questions of their own, and to quit the interview (e.g. if they feel stressed or uncomfortable, but they can withdraw from participation at any time without citing a reason).

4. The principle of justice

'Justice' is being fair and providing equal care regardless of research objective(s) (Parahoo 1997 p78; Edwards 2009 p88). In other words, research

Chapter 4 Methodology and method

participants' health and welfare is more important than research objectives. The research participants, specifically patients and their caregivers, will have the right to equal treatment, psychotherapy and medication. This project is not attempting to provide any treatment or intervention, but to interview patients and ascertain their experiences. Hence, participation in this research does not affect the general community mental health service received by participants. The researcher is not an employee of the selected psychiatric hospital, so it is not considered that participants will be treated differently in that hospital as a result of participating in this study. The researcher ensured that any scheduled interview was not interrupting the research participants' appointments with psychiatric doctors, or their receiving of any other care. All interviews were scheduled after the patients with schizophrenia received care, and were ready to be interviewed. The research participants will be treated the same before, during and after the research (An Bord Altranais 2007).

5. Fidelity

Good communication and making rapport with the research participants can build trust for the researcher in the quality of communication between the researcher and researched. Furthermore, the researcher will attempt to prevent any potential physical or mental harm that may occur during the interview, especially mental distress (Parahoo 1997 p78). It was planned that, should any situation arise in which participants expressed concern or appeared to suffer harm, the interview will be terminated and the event will be reported to mental health staff at the community and the Community Mental Health Department immediately, in order to ensure that the participants with schizophrenia are safe and receive appropriate care. Regarding this ethical consideration, there was one caregiver who looked unhappy after being interviewed about caring for his daughter, who had been diagnosed with schizophrenia. Hence, the interview was stopped and, in this case, doing a telephone follow up was excluded because this might have caused him more suffering. Later, it appears that he had a diagnosis of depression and received treatment at the community hospital.

6. Confidentiality

Participants' information has been kept confidential. The informed consent forms, for being a research participant, were distributed and returned. The participants were anonymous and all research data will be kept in a password-

protected personal notebook computer. The researcher is the only person who can access the laptop. The tape recorders have been kept in a locked cabinet in the researcher's accommodation during the data collection phase in Thailand. All interview records will be kept in a locked cabinet at the Faculty of Health Sciences, University of Southampton, when the researcher has returned to the UK. The transcribed data will be shared between the researcher and peer-reviewers in order to establish triangulation and ensure accuracy of data analysis checking.

4.5 Interview transcription

All interviews were transcribed by the main researcher, based on the rationale set out and explained below.

1. Transcriptions help the main researcher to have a chance to recall the situation that she has faced at the interview, as well as reminding her of the environment that she has observed. This is very useful in terms of reflecting on something that she may have missed out due to excitement, focusing on scribbling notes and semi-structured interviews, rather than anything else.
2. Restricting people's access to the data is the way to make sure that all interview files will be stored and remain confidential. Only the main researcher and the supervisory team can access the data. At the same time, this aims to prevent arguments among interviewees in the cases of contrary opinions.
3. Some missing pieces of words were added and some ideas in the transcripts complete were completed by writing them in brackets; processes which can help the main researcher and the supervisory team to understand the transcripts as fully as possible, even they were not in the interviews.

4.6 The analytical approach

Data analysis in qualitative research focuses on the credibility of the research process (Parahoo 1997 p354). There are several methods to analyse qualitative data, such as thematic analysis, discourse analysis, grounded theory and interpretive analysis (IPA) (Jones and Forshaw 2012). IPA data analysis is used to understand the meaning of a phenomenon and an individual's experience; an approach which is popularly used in phenomenology, whereas grounded

Chapter 4 Methodology and method

theory is used for developing or refining a theory (Braun and Clarke 2006). Thematic analysis is a flexible qualitative method used for 'identifying, analysing and reporting patterns' (Braun and Clarke 2006 p6). One advantage of thematic analysis is that it enables the categorising of things which are seen by the researcher; the checking of the accuracy of documents and familiarising oneself with data is crucial in thematic analysis (Yin 2011; Rubin and Rubin 2012). Therefore, themes and codes from the analysed data will be translated into English, allowing peers to re-check the accuracy of the data. This will confirm how rigorous the process of data analysis is and provide the opportunity to support the researcher in the accuracy of the analysis. This study aims to explore and understand the patterns of views regarding schizophrenia care, from the stakeholders' perspectives at the sub-district level in rural Thailand. Inductive thematic analysis is suitable in terms of using participants' own words to reflect their views and to categorise the gathered information into themes.

4.6.1 Trustworthiness of data

Trustworthiness is the main criterion for ensuring an acceptable standard for qualitative research which comprises of four key areas: 'credibility, confirmability, dependability and transferability' (Shenton 2004 p64). Hence, the four key criteria for ensuring trustworthiness of this study will now be discussed.

4.6.1.1 Credibility of data

Credibility of data means that the research findings are believable and trustworthy regarding truth and value (Parahoo 2014 cited in Dreher 1994 p383). Triangulation is considered a procedure which can ensure credibility of a study's findings (Patton 2002; Flick 2009; Holloway 2010; Guion et al. 2011). Hence, triangulation of the three participant groups was used in order to strengthen the reliability of the study. This is because some negative cases allowed the researcher to gain better insight into the phenomenon of concern (Patton 2002 p.556). The process of data analysis regarding theme reviewing for this study was repeated until the supervisors and the main researcher confirmed the findings to be credible and consistent. Reflections on conducting this study were written in order to illustrate the researcher's

awareness of potential bias regarding her personal interests and background (Shenton 2004).

4.6.1.2 Confirmability of data

The transcribed documents from interviews may not be shared with the interviewees, but the data checking will be confirmed by the participants during their interviews. This is because opinions may change overtime, as well as due to the time constraints of the research project. The transcribed research results will be reviewed by supervisors, who are experts in qualitative research and mental health care, in order to seek for agreement of the findings (Flick 2009 cited in Lincoln and Guba 1985 p392; Parahoo 2014).

4.6.1.3 Dependability of data

Dependability of qualitative data could be established by critical appraisal of a research project through reflection; such as the effectiveness of interview schedules and interview skills (Shenton 2004). Hence, dependability of data in this study will be considered in Chapter 6.

4.6.1.4 Transferability of data

Transferability of data refers to the possibility of applying the findings from this research to other settings which have similar contexts (Parahoo 2014). This study was conducted in the middle region of Thailand, where almost all participants are Buddhists living in rural Thai communities. Further transferability issues will be discussed in Chapter 6.

4.6.2 Interview translation

The main researcher translated the interviews from the original Thai into English. This is because she is not only the interviewer, so allowing her to understand the situation and interviews, but she is also a native Thai language speaker. This will guarantee that the words and terms that were used will be close to their original meanings. However, some of translated transcripts were sent to a proficient bilingual translator in order to confirm the validity of the translations.

Chapter 4 Methodology and method

Transcribed documents from interviews (in Thai and/or English language) will be analysed using NVivo software package. This is because using computer software for qualitative data analysis is useful for the process of data management, sorting, linking and displaying codes and themes (Flick 2009).

Kawulich (2005) argues that the quality of qualitative data analysis depends on the researcher's experience and world view, which can cause bias; hence, the transparency of the research process is crucial (Mason 2002; Patton 2002; Creswell 2013). The six processes of inductive thematic analysis, set out by Braun and Clarke (2006), were carried out for data analysis.

4.6.3 Data analysis

The six steps of inductive thematic analysis are as follows: 1) familiarising with the data; 2) generating initial codes; 3) searching for themes; 4) reviewing themes; 5) defining and naming themes and 6) producing a report (Braun and Clarke 2006 pp16-23).

Step 1) Familiarising with the data

The main researcher transcribed all the interviews by herself; therefore she had the chance to familiarise herself thoroughly with the data and transcripts. Although this process is time consuming, it is worth doing for other steps of data analysis and reflection, because additional interesting points could be noted during the re-listening and transcribing of the interviews.

Step 2) Generating initial codes

Key information was coded using the NVivo software programme. For example, the 103 codes from 10 face-to-face and 1 telephone interview transcripts of the patient participant group were induced from the interview data (see Figure 9). At this point, using NVivo was helpful because it assisted the main researcher to code, re-code, sort and manage the interview data. Moreover, it is convenient to re-check, adjust and/ or update the code definitions while collating codes into the themes. These applications constitute a considerable time saving process, if compared with using manual coding alone.

Nodes

Name	Sources	References	Created On	Created By	Modified On	Modified By
Hospital experiences	5	6	03/09/2014 11:40	KB	06/09/2014 15:40	KB
Negative experiences	0	0	05/09/2014 17:08	KB	05/09/2014 17:12	KB
Arguments in hospital	1	3	03/09/2014 18:53	KB	03/09/2014 19:02	KB
Crowded	1	2	04/09/2014 18:56	KB	04/09/2014 18:56	KB
Fear of ECT	1	2	04/09/2014 17:50	KB	04/09/2014 17:51	KB
Hospitalisation is compulsory	1	1	04/09/2014 18:25	KB	04/09/2014 18:25	KB
limited activities in hospital	2	5	03/09/2014 19:04	KB	22/09/2014 14:02	KB
Patient zoning	1	1	03/09/2014 18:45	KB	03/09/2014 18:45	KB
Stress in hospital	2	4	02/09/2014 15:09	KB	03/09/2014 12:04	KB
Threaten in hospital	1	2	03/09/2014 11:40	KB	19/09/2014 14:13	KB
Fear	1	2	03/09/2014 11:59	KB	03/09/2014 12:04	KB
Uncomfortable	1	1	04/09/2014 17:48	KB	04/09/2014 17:50	KB
Positive or neutral experiences	1	3	04/09/2014 18:11	KB	05/09/2014 17:12	KB
Community hospital care	2	3	04/09/2014 11:42	KB	05/09/2014 16:05	KB
Group in hospital	2	2	03/09/2014 11:20	KB	05/09/2014 16:05	KB
Polite staff	1	1	04/09/2014 18:12	KB	19/09/2014 12:23	KB
Prefer living at hospital	1	2	03/09/2014 18:06	KB	06/09/2014 19:34	KB
Living at home	7	10	02/09/2014 15:01	KB	26/09/2014 14:48	KB
Being spoiled	1	1	04/09/2014 17:40	KB	05/09/2014 16:05	KB
Communicate with relatives	0	0	03/09/2014 12:40	KB	06/09/2014 19:42	KB
Community support	6	8	02/09/2014 19:02	KB	07/09/2014 14:38	KB
Feeling when living in community	0	0	05/09/2014 16:08	KB	05/09/2014 16:09	KB
Feel lonely	1	5	04/09/2014 17:03	KB	08/09/2014 12:53	KB
Being single	1	1	04/09/2014 17:06	KB	06/09/2014 15:46	KB
Pressures	3	7	03/09/2014 10:58	KB	05/09/2014 16:05	KB
Commit suicide	1	2	03/09/2014 10:59	KB	03/09/2014 11:00	KB
Self-perception	6	18	02/09/2014 18:24	KB	26/09/2014 14:48	KB
Ability to work	3	6	04/09/2014 11:09	KB	06/09/2014 15:46	KB
Agressive	2	4	03/09/2014 19:29	KB	04/09/2014 19:33	KB
Blame	4	7	03/09/2014 11:25	KB	05/09/2014 16:05	KB
Emotional Expression	1	1	04/09/2014 17:59	KB	04/09/2014 17:59	KB
Feel burdensome	1	2	03/09/2014 12:28	KB	05/09/2014 16:05	KB

Nodes

Name	Sources	References	Created On	Created By	Modified On	Modified By
Getting better or Recover	3	3	04/09/2014 17:13	KB	06/09/2014 15:46	KB
Have to be good	1	1	04/09/2014 18:08	KB	04/09/2014 18:08	KB
Insane	1	1	04/09/2014 18:09	KB	04/09/2014 18:09	KB
Irritable	2	2	02/09/2014 15:00	KB	04/09/2014 18:38	KB
Medication side effects	2	4	04/09/2014 11:36	KB	05/09/2014 16:05	KB
No one understand me	2	6	04/09/2014 12:37	KB	06/09/2014 15:46	KB
Latent	2	3	04/09/2014 12:31	KB	05/09/2014 16:05	KB
Others have negative thoughts towards me	2	8	03/09/2014 19:23	KB	08/09/2014 16:19	KB
Proud	1	1	04/09/2014 16:54	KB	06/09/2014 15:46	KB
Self-care	3	5	02/09/2014 17:15	KB	04/09/2014 11:38	KB
Self-contradiction	4	8	03/09/2014 13:01	KB	04/09/2014 18:42	KB
Society surplus	1	3	03/09/2014 19:21	KB	05/09/2014 16:25	KB
Worry about future	1	3	04/09/2014 17:01	KB	06/09/2014 15:46	KB
Free to take shower	1	1	04/09/2014 18:55	KB	04/09/2014 18:55	KB
Freedom	6	12	03/09/2014 11:43	KB	04/09/2014 19:34	KB
Happy	2	4	04/09/2014 17:49	KB	04/09/2014 18:57	KB
Housework	1	1	04/09/2014 18:35	KB	04/09/2014 18:35	KB
Informally	1	1	04/09/2014 17:46	KB	04/09/2014 17:46	KB
Living with familiar people	1	1	04/09/2014 17:48	KB	04/09/2014 17:48	KB
No blame	1	2	02/09/2014 15:03	KB	03/09/2014 12:35	KB
No housework	1	1	03/09/2014 18:32	KB	03/09/2014 18:32	KB
No one control	1	2	02/09/2014 18:30	KB	02/09/2014 18:34	KB
No support for mental disability	1	2	03/09/2014 10:34	KB	05/09/2014 16:05	KB
Relationships	0	0	05/09/2014 16:27	KB	05/09/2014 16:27	KB
Building relationship with community	1	1	02/09/2014 17:27	KB	05/09/2014 16:05	KB
Doubt about relationships with others	3	7	02/09/2014 18:22	KB	05/09/2014 16:05	KB
Sex life	1	1	04/09/2014 19:26	KB	04/09/2014 19:26	KB
Isolation	6	27	02/09/2014 17:25	KB	26/09/2014 14:48	KB
Low mood	1	1	04/09/2014 12:19	KB	04/09/2014 12:19	KB
Smoke	2	3	03/09/2014 10:48	KB	05/09/2014 16:05	KB
Supports	8	19	03/09/2014 12:13	KB	26/09/2014 14:48	KB
Government scheme	3	5	03/09/2014 13:13	KB	06/09/2014 15:46	KB
Medication monitoring	2	4	04/09/2014 18:18	KB	04/09/2014 19:05	KB

Chapter 4 Methodology and method

Nodes

Name	Sources	References	Created On	Created By	Modified On	Modified By
Tired when staying home	1	1	03/09/2014 17:37	KB	05/09/2014 16:05	KB
Needs	0	0	05/09/2014 16:01	KB	05/09/2014 16:05	KB
Accommodation	1	3	03/09/2014 12:11	KB	05/09/2014 16:05	KB
Financial concern	6	27	02/09/2014 18:10	KB	26/09/2014 14:48	KB
Financial dependency	3	10	02/09/2014 17:21	KB	04/09/2014 18:41	KB
Food	4	20	02/09/2014 18:03	KB	05/09/2014 16:05	KB
Not enough food in hospital	1	4	03/09/2014 17:47	KB	03/09/2014 19:05	KB
Weight	2	4	03/09/2014 17:39	KB	22/09/2014 16:13	KB
Regret because of wasting money	1	2	03/09/2014 10:47	KB	03/09/2014 10:49	KB
Work	8	42	02/09/2014 14:58	KB	26/09/2014 14:48	KB
Help seeking	0	0	05/09/2014 16:17	KB	05/09/2014 16:17	KB
Considerate	1	3	03/09/2014 12:52	KB	05/09/2014 16:05	KB
Coping	4	8	04/09/2014 10:32	KB	06/09/2014 15:46	KB
Hope	3	10	04/09/2014 11:12	KB	06/09/2014 15:46	KB
Self-admission	1	1	04/09/2014 19:26	KB	05/09/2014 16:05	KB
Need specialist for schizophrenia care	1	2	03/09/2014 10:06	KB	05/09/2014 16:05	KB
Needs family members supports	3	6	03/09/2014 10:56	KB	04/09/2014 12:35	KB
Needs friends	1	1	04/09/2014 18:20	KB	04/09/2014 18:20	KB
Needs others to understand	2	11	03/09/2014 10:31	KB	04/09/2014 12:56	KB
Needs to be independent	1	2	04/09/2014 19:13	KB	04/09/2014 19:14	KB
Physical health problems	3	5	02/09/2014 18:31	KB	06/09/2014 15:46	KB
Travelling limitation	2	3	04/09/2014 17:37	KB	05/09/2014 16:05	KB
Psychotic symptoms	0	0	05/09/2014 16:13	KB	05/09/2014 16:13	KB
Delusion	2	3	04/09/2014 10:18	KB	05/09/2014 16:05	KB
Hearing voice	1	2	04/09/2014 17:23	KB	05/09/2014 16:05	KB
Not insight the disease	3	6	03/09/2014 11:53	KB	06/09/2014 15:46	KB
Paranoid	2	3	04/09/2014 16:58	KB	06/09/2014 15:46	KB
Reject oral medication	1	2	04/09/2014 19:23	KB	05/09/2014 16:05	KB
Rejected mental illness	1	1	04/09/2014 17:35	KB	05/09/2014 16:05	KB
THPH care	8	16	03/09/2014 13:21	KB	26/09/2014 14:48	KB
Appointment reminder	1	2	02/09/2014 18:51	KB	05/09/2014 16:05	KB
Care at primary care level	3	3	03/09/2014 10:52	KB	04/09/2014 19:35	KB
Compulsory treatment	2	7	04/09/2014 17:21	KB	04/09/2014 19:25	KB

Nodes

Name	Sources	References	Created On	Created By	Modified On	Modified By
Do not ask for help	1	2	04/09/2014 18:46	KB	04/09/2014 18:47	KB
Home-visit	6	10	02/09/2014 18:45	KB	07/09/2014 14:38	KB
Medication at home	5	10	03/09/2014 10:44	KB	07/09/2014 14:38	KB
Village Health Volunteer	1	1	03/09/2014 13:19	KB	03/09/2014 13:19	KB
Medication injection	5	8	03/09/2014 13:23	KB	04/09/2014 19:37	KB
Medication reminder	1	1	04/09/2014 19:36	KB	05/09/2014 16:05	KB
No one-stop service	2	2	03/09/2014 13:25	KB	04/09/2014 19:04	KB
No schizophrenia care available	1	1	04/09/2014 18:03	KB	04/09/2014 18:03	KB
One-stop service at the community hospital	1	1	04/09/2014 17:42	KB	04/09/2014 17:42	KB
Physical care at THPH	2	2	03/09/2014 13:07	KB	04/09/2014 19:35	KB
Physical health care needs	2	3	02/09/2014 18:33	KB	03/09/2014 13:30	KB
Satisfied with THPH care	5	9	04/09/2014 11:25	KB	26/09/2014 14:49	KB
Wanted to be the person before having schizophrenia	2	2	22/09/2014 15:39	KB	22/09/2014 15:45	KB

Figure 9 Open coding using NVivo software package

Step 3) Searching for themes

Similar codes were gathered and searched for themes. Copying all codes and quotes under each theme, via a Microsoft Excel programme, helped the main researcher to see the relevance of potential themes, codes and quotes (see Figure 10). This step assisted the main researcher to gain more insights from the data. Moreover, displaying such information in a Microsoft Excel programme is useful for writing the analysis report, because the researcher

could re-check the accuracy and match of themes, codes and quotes at the same time.

Emerging theme	Participant	Line	Code	Quote	Translated quote	Duplicatable
Hospital experiences	P2	41-42	Hospital experiences	อยู่โรง (พญา)บาล หมอเค้า... มันอยู่แบบ.. หมอเค้าจะแบบ... มันอึดอัดอะไม่ได้เห็นอะไร ไม่ได้เที่ยว ไม่ได้อะไรเงี้ย ออกเดินไม่ค่อยได้	Living in hospital...the doctors...it's like...the doctors...it's uncomfortable. Didn't see anything. Didn't go anywhere. Things like that. Cannot walking much.	Yes
	P2	56	Hospital experiences	โรงพยาบาล? (หัวเราะ) เขาจับเข้าคุกควบคุมอะ ควบคุมเหมือนคนติดคุกอะไรอย่างเงี้ย	Hospital? (laugh). They caught and controlled...controlled like a prisoner.	Yes
	P3	32	Hospital experiences	โรงพยาบาล...อึดอัด	Hospital...uncomfortable.	
	P6	16	Hospital experiences	(ชอบ) โรงพยาบาลครับ	(like) hospital.	
	P7	33-35	Hospital experiences		The doctors who looked after us said that if a patient who did not escape... If patients are free and did not think about escaping... did not keep thinking about escape... It's a zone. It looks like a place for caring.... Someone said that it's like a prison.	
	P9	30	Hospital experiences	คนมันเยอะ	Crowded.	
	P7	37-41	Argument in hospital		P7: I wasn't satisfied with that. BK: Like, "the hospital is a prison", is it? P7: Yes. I blamed that "this is a hospital and this is a doctor, not police! It's not an iron law. How do you say that?! If this is a prison, why does it have medication for you to take?" I damned them. I stayed there for three days, I quarrelled with (other patients).	Yes
	P7	42-43	Argument in hospital		BK: Oh, you quarrelled with (other patients). P7: I could not punch them, so my eyebrow was broken.	Yes
	P7	45-48	Argument in hospital		P7: I got an eye bruise. Punching with them, it was just only me alone but they were three or four people. BK: I see. Are they like gangsters there? P7: It is. They [the patients] are divided into groups.	Yes

Figure 10 An example of displaying potential themes, codes and quotes

Although there were sub-themes that included only one or two research participants, the whole theme identification exercise is crucial for gathering interesting points of schizophrenia care, regarding the met and unmet needs of the stakeholders. Emerging patterns of data are important for thematic

Chapter 4 Methodology and method

analysis; however, some interesting data could lead to starting points for future research regarding perspectives coming from a wider population.

Step 4) Reviewing themes

Similar codes were gathered in the same themes, which were then reviewed several times, in order to re-check the relevance of the original interview transcripts. Some codes had similar meanings which were collated into the same group; therefore helping to gather thick rich data. Thick and rich qualitative data refers to the data that contain context and description which should be rich enough to enable the research readers to understand the situation in the study (Creswell and Miller 2000). After collating codes, the twelve themes emerged, so they were considered and re-checked several times for accuracy. The themes were printed out from the NVivo programme for manual rechecking. Therefore, all codes under each theme were re-checked to ensure that they were relevant to the particular theme. In step 4, the supervisory team did check the accuracy of coding and the relevance of quotes from the translated transcripts. This helped to ensure that the researcher employed good coding skills of qualitative data analysis and was able to analyse the remaining Thai transcripts. Moreover, the main researcher re-read all forty transcripts and sought to clarify some unclear quotes and some data that might be miscoded and/ or overlooked; therefore the transcripts could be re-coded until the themes, codes and quotes made sense and exhibited credible coherence.

Step 5) Defining and naming themes

The main researcher named the themes, and discussed them with the supervisory team, in order to validate the accuracy of themes and selected quotes. At this stage, the main researcher and her supervisory team refined, defined and re-checked the coherence of themes and quotes, in order to make them explicit.

Step 6) Producing a report

The most interesting quotes were used to support the twelve emergent themes in the analysis report. Research questions and aims were used as the core of the data included in the report. This means that all themes needed to answer research questions and aims.

4.7 Chapter summary

This chapter describes and discusses the philosophy underpinning this research study. A pragmatic approach, using semi-structured interviews, was used as a base for gathering the information relevant to this study. From the beginning, this chapter offers the reader insights into the researcher's journey through the logic of the theoretical framework, methodology and data collection process, which highly respects the ethical considerations relevant to conducting research with human subjects.

The next chapter will present the data analysis for this study.

5. Chapter 5 Findings

Introduction

This chapter aims to present the findings from the three participant groups who are the stakeholders of schizophrenia care at the primary care level, namely: the patient with schizophrenia, the caregivers and the health professional groups (See Figure 7: page 105).

5.1 Overview of the participants

The research participants were recruited from five provinces which were under the psychiatric hospital's responsibility.

Table 6 Characteristics of the patient group

ID	Pseudonym	Gender	Age	Religion/ Belief	Marital status	Duration of diagnosis (years)	Number of admissions	Caregiver	Taking oral medication
P1	Anuman	Male	59	Buddhism	Divorce	10	2	70 yrs. Sister	Yes
P2	Benz	Male	37	Buddhism	Single	2	2	68 yrs. Mother	Yes
P3	Chatchai	Male	23	Buddhism	Single	10	2	51 yrs. Mother	Yes
P4	Duan	Female	42	Buddhism	Divorce	16	5	65 yrs. Buddhist monk	Yes
P5	Eak	Male	40	Buddhism	Single	20	2	32 yrs. Niece	Yes
P6	Harn	Male	35	Buddhism	Single	12 (but P6 reported 2years)	2 (but P6 reported 5times)	Relatives	Yes
P7	Jirasak	Male	44	Muslim	Separated	12	3	83 yrs. Mother	Yes
P8	Kwan	Female	38	Buddhism	Married	19 (but P8 reported 1 year)	Not sure	36 yrs. Husband	Yes
P9	Liam	Male	35	Buddhism	Single	10	2	Mother	Yes
P10	Natchapon	Male	41	Buddhism	Married	20	11	Mother	Yes

Chapter 5 Findings

Table 7 Characteristics of the caregiver group

ID	Pseudonym	Gender	Age	Relationship with the patient	Religion/Belief	Marital status	Duration of caring patients with schizophrenia
C1	Yao	Male	81	Non-relative	Buddhist	Single (Buddhist monk)	N/A (He said it was many years which he could not remember)
C2	Wanchai	Male	49	Cousin	Buddhist	Married	10
C3	Fon	Female	51	Mother	Buddhist	Married	3
C4	Adisak	Male	65	Father	Buddhist	Single (Buddhist monk)	16
C5	Natcha	Female	54	Mother	Buddhist	Married	3
C6	Malee	Female	32	Niece	Buddhist	Married	3
C7	Pakawat	Male	52	Relative	Buddhist	Married	1
C8	Sorrayut	Male	37	Husband	Buddhist	Married	19
C9	Baitoey	Female	61	Mother	Buddhist	Married	20
C10	Namtip	Female	70	Mother	Buddhist	Widowed	35

Table 8 Characteristics of the health professional group

a) The supervisory team

ID	Pseudonym	Gender	Age	Qualification	Schizophrenia care training
S1	Somsiri	Female	41	BNS (RN), PG Psy, PG NP	Yes
S2	Jarunee	Female	48	MSN in mental health	Yes
S3	Sanchai	Male	56	Psychiatrist	Yes
S4	Tidarat	Female	37	BNS (RN), PG Psy, PG NP	Yes
S5	Khim	Female	47	MSN in mental health	Yes
S6	Aroon	Female	39	MSN in mental health	Yes
S7	Poom	Female	49	MSN in mental health	Yes
S8	Kalaya	Female	37	Psychiatrist	Yes
S9	Tawat	Male	48	Master's วิทยาศาสตรบัณฑิต	Yes
S10	Kamlai	Female	53	BNS (RN)	Yes

b) The Tambon Health Promotion Hospital (THPH) staff

ID	Pseudonym	Gender	Age	Qualification
T1	Ittipon	Male	43	BSc in Public Health
T2	Atitaya	Female	43	BNS, PG NP
T3	Krit	Male	45	Master's in Public Health
T4	Kanokwan	Female	46	BNS, PG NP
T5	Noon	Female	41	BNS
T6	Worakarn	Female	53	BNS, PG NP
T7	Chailai	Female	34	BNS, PG NP
T8	Busaba	Female	46	BNS
T9	Lawan	Female	38	BNS, PG NP
T10	Samorn	Female	40	BNS, PG NP

5.2 Summary of the themes from each participant group

The themes of findings from the patients' with schizophrenia group, the caregivers' group and the health professionals' group are shown below.

Table 9 Outline of themes for the patient group

Theme	Sub-theme
Theme1: Fear of rehospitalisation	<ul style="list-style-type: none"> • Sub-theme 1.1: Experience of compulsory care • Sub-theme 1.2: Supports from health professionals
Theme 2: Living in the rural Thai community is good but...	<ul style="list-style-type: none"> • Sub-theme 2.1: Sympathetic culture and mental health support • Sub-theme 2.2: Rebuilding relationships in the community • Sub-theme 2.3: Being an unwanted person • Sub-theme 2.4: job opportunity and income
Theme 3: Seeking empathy	<ul style="list-style-type: none"> • Sub-theme 3.1: Active listening • Sub-theme 3.2: Getting back to be one's pre-morbid self
Theme 4: How to improve services to better medication management.	<ul style="list-style-type: none"> • Sub-theme 4.1: One-stop service at the primary care level is needed. • Sub-theme 4.2: Community medication: medication delivery, medication reminder service. • Sub-theme 4.3: Consultant is needed: medication, physical health and sex life.

Table 10 Outline of themes for the caregiver group

Theme	Sub-theme
Theme 1: Managing adherence to medication	<ul style="list-style-type: none"> • Sub-theme 1.1: The importance of monitoring medication • Sub-theme 1.2: Medication adherence leading to normality • Sub-theme 1.3: Medication as relapse prevention • Sub-theme 1.4: Community support for medication adherence management
Theme 2: Using violence and punishment for management of schizophrenia	<ul style="list-style-type: none"> • Sub-theme 2.1: Illegal punishment • Sub-theme 2.2: Compulsory hospitalisation
Theme 3: Caregivers' mix feelings towards schizophrenia care	<ul style="list-style-type: none"> • Sub-theme 3.1: Unconditional love • Sub-theme 3.2: Ambivalent feeling
Theme 4: Perspectives of support.	<ul style="list-style-type: none"> • Sub-theme 4.1: 'It is my own Karma': Accepting all negative things as my fault • Sub-theme 4.2: Not satisfied with the care and I wouldn't tell you, if I wasn't • Sub-theme 4.3: People were satisfied • Sub-theme 4.4: Thinking of the future: recommendations for improvements

Table 11 Outline of themes for the health professional group

Theme	Sub-theme
Theme 1: Managing adherence to medication.	<ul style="list-style-type: none"> • Sub-theme 1.1: Medication management • Sub-theme 1.2: Compulsory treatment and detention • Sub-theme 1.3: Enhancing medication adherence via referral line and network
Theme 2: Service users' needs and support.	<ul style="list-style-type: none"> • Sub-theme 2.1: Poverty as a huge obstacle: 'They are just not complying with medication and rather spending money to buy food' • Sub-theme 2.2: Dehumanised human care: 'Scheduling timetable like feeding a dog' • Sub-theme 2.3: Devaluing and labelling: 'they (other people) usually said that my children are mad'
Theme 3: The THPH staff and schizophrenia care.	<ul style="list-style-type: none"> • Sub-theme 3.1: The impacts of attitude, knowledge and skill. • Sub-theme 3.2: Improving service users' faith in the primary care staff • Sub-theme 3.3: Workforce limitation, Boon and holistic care
Theme 4: Recommendations.	<ul style="list-style-type: none"> • Sub-theme 4.1: Community mental health care governance • Sub-theme 4.2: Effective referral system is needed • Sub-theme 4.3: Support for service users: medication delivery, financial and rehabilitation

In order to illustrate the key issues, the twelve themes outlined in Table 9 to Table 11 have been categorised into three areas: lived experience, the importance of medication, and service and support needs (see Figure 11). Some sub-themes were merged from different participant groups in order to highlight the key findings, such as Thai cultures and beliefs, and humanised and holistic care.

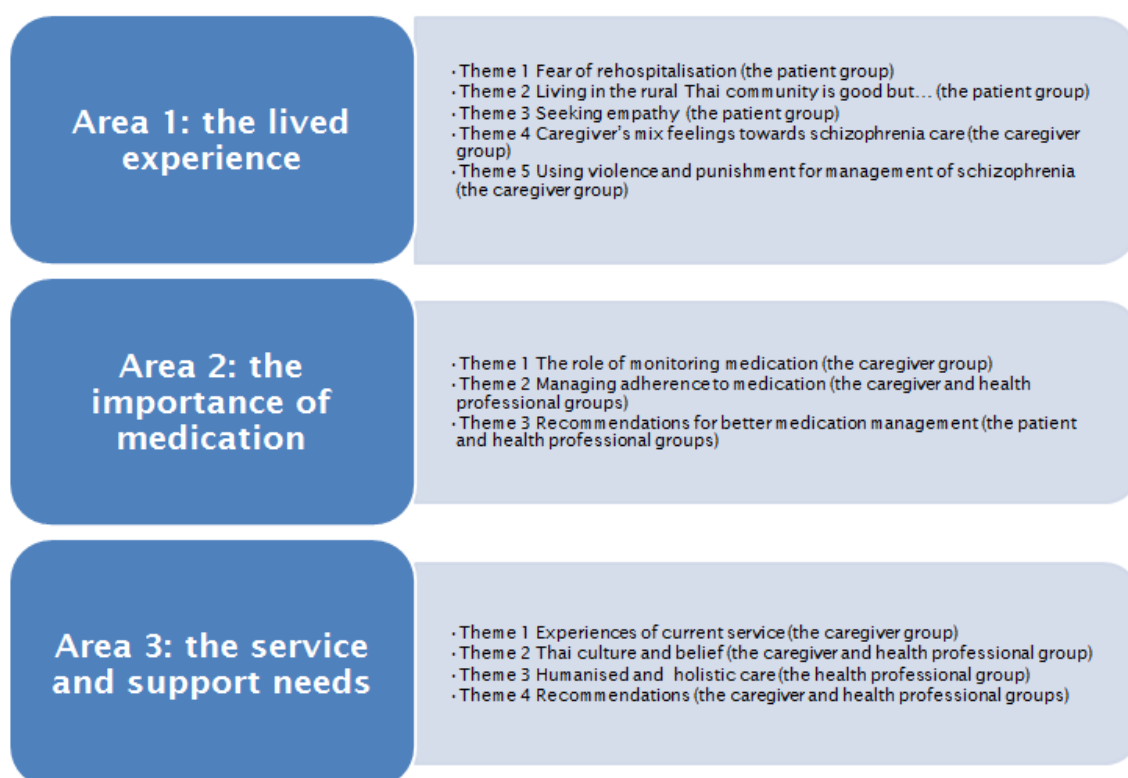


Figure 11 The three areas of findings

5.3 Area 1: The lived experience

The lived experience themes were drawn from the patients with schizophrenia group and the caregiver participant group. This area could reveal the patients' suffering from schizophrenia, experiences of psychiatric hospital admission, as well as the frustration of re-entering the communities, where they felt they did not belong in the way they did before their diagnosis. However, the caregiver

Chapter 5 Findings

group appeared to be in a dilemma of wanting to provide care with unconditional love, whilst also feeling an extreme sense of burden.

5.3.1 Theme 1: Fear of rehospitalisation

From the patients' perspectives, there were some mixed feelings towards receiving schizophrenia care in the psychiatric hospital. Two sub-themes emerged from the data: i) Experience of compulsory care, and ii) Support from health professionals.

5.3.1.1 Sub-theme 1.1: Experience of compulsory care

It appeared that being admitted to the psychiatric hospital was perceived as being unpleasant by most patients. One participant reported that she experienced both stress and anger. The stress induced headaches which the participant attributed to being bombarded with difficult information.

'It's... like... saying something that I didn't know. They kept repeating that and then I got a headache'.

'When I got headache, I will... oh... I will get stressed. It [anger] will pop up'.

Duan (Female patient, 42 years old)

Another reason for their somewhat negative perceptions was the participants perceived that hospitalisation was compulsory. In Thai culture, it appears that mental illness is an embarrassing condition, for which Thai people do not normally seek help before the psychotic symptoms, such as behaving extremely aggressively, causing harm and/or wandering, become obvious. As a result, it seems that when the patients have severe psychotic symptoms, they have to be taken to the psychiatric hospital for initial treatment.

Unsurprisingly, the participants perceived that their schizophrenia treatment and hospitalisation is compulsory and that this always happens to them.

'It was when it (my psychotic symptom) was severe. Relatives took me or sometimes I fought with others, so the police caught me and sent to get medication injection and take me back to the hospital'.

Natchapon (male patient, 41 years old)

It is clear that compulsory treatment is an unpleasant experience; however it is also seen as essential regarding reducing the chance of harm to the patients themselves and to other people. Hence, compulsory treatment for patients with schizophrenia appears to cause a dilemma. Although the participants did not like compulsory treatment and hospitalisation, they had to accept and understand the purposes of compulsory treatment. One participant reflected her frustrated feelings and faith in hospital care.

'Who wants to stay in hospital? No one wants to stay but (I) want to recover. (If I) Want to recover, so (I) have to stay (in the psychiatric hospital)'.

Kwan (female patient, 38 years old)

However, compulsory treatment is completely unacceptable to some participants. One found that staying in the psychiatric hospital was constraining. He expressed that the psychiatric hospital was frightening for him because of receiving ECT.

'If I (you) asked (me) why I felt worried when staying in the hospital. First thing is (I am) afraid of electric shock (ECT)'.

..... 'I am afraid, so I don't want to stay in the hospital'.

Chatchai (male patient, 23 years old)

A number of participants felt frustrated during their time in the psychiatric hospital because options for activities were limited.

Chapter 5 Findings

'If I didn't feel full, I would wake up at 1 or 2 a.m., and then the doctors inhibited me. The doctors inhibited me... stopped me from wandering. When I woke up and sat on the bed, the doctor said 'Jirasak, sleep!' I couldn't sleep sometimes'...'I would like to be discharged on my birthday but I wasn't. I was born on 22nd August. I would like to be discharged to pay my respects to my mom but I couldn't'.

Jirasak (male patient, 44 years old)

'Staying in the hospital, the doctors...it's living like...the doctors like...it's uncomfortable. Didn't see anything...cannot wander'.

'Not allowed to wander, things like that'.

Benz (male patient, 37 years old)

There are different perspectives between participants about categorising patients into groups. A patient believed that the hospital staff divided the patients into different groups. In the Thai psychiatric hospitals, patients who have severe psychotic symptoms are separated, and limited in their activities, in order to ensure that they and other patients are safe. This is normally under the health professional's supervision. One participant seemed to agree with the idea of zoning patients who had schizophrenia, according to the severity of their psychotic symptoms. Zoning in this context could mean requiring the patients to stay in a particular area where the hospital staff could observe the patients' activities.

'The doctors who looked after us said that if a patient who did not escape... If patients are free and did not think about escaping... did not keep thinking about escape... It's a zone. It looks like a place for caring.... Someone said that it's like a prison'.

Jirasak (male patient, 44 years old)

On the other hand, some participants compared the psychiatric hospital to a prison and the patients are the prisoners, because they are limited in their activities during hospitalisation. One participant vented his distress about being admitted to the psychiatric hospital by saying that he felt like he was 'a prisoner'.

'I blamed that 'this is a hospital and this is a doctor, not police! It's not an iron law. How do you say that?! If this is a prison, why does it have medication for you to take?' I damned them. I stayed there for three days, I quarrelled with (other patients).

Jirasak (male patient, 44 years old)

'Living in hospital...the doctors...it's like...the doctors...it's uncomfortable. Didn't see anything. Didn't go anywhere. Things like that. Cannot do much walking

....They caught and controlled us...controlled like a prisoner'.

Benz (male patient, 37 years old)

In the participants' opinions, the environment of hospitalisation is unsafe because of violence. Some male participants revealed that they experienced physical attacks and threats in the psychiatric hospital. A number of participants reported that they suffered physical and verbal abused by the 'gangsters' (the patients with mental illness who acted as the gangsters during being admitted in the psychiatric hospital) when staying in the psychiatric hospital. This abuse caused physical injury as well as fear.

Jirasak: 'I got an eye bruise. Punching with them, it was just only me alone but they were three or four people.'

BK: 'I see. Are they like gangsters there?'

Jirasak: 'It is. They [the patients] are divided into groups.'

Jirasak (male patient, 44 years old)

This is another example of fear in the psychiatric hospital.

Eak: They did not do much. They were just speaking impolitely. They are impolite and acted as a gangster. I don't know.

BK: I see. There are gangster types in there? I didn't know this before.

Eak: Yes. Sometimes, there were some people who have severe symptoms and others with not such severe symptoms who were constrained together. To me, I don't know what (disease) I have had.

BK: Um...

Eak: I was...scared. I had a fear.

Eak (male patient, 40 years old)

5.3.1.2 Sub-theme 1.2: Support from health professionals

Despite the concerns of a few patients, several others had positive attitudes towards schizophrenia care at the psychiatric hospital; views that seemed to relate to not having to do any housework or domestic activities.

'In my personal opinion, I don't have to wash my clothes. I don't have my personal chores [does not have to do housework].'

Jirasak (male patient, 44 years old)

Another reason for preferring living in the psychiatric hospital is the health professionals ('health professionals' can sometimes mean 'doctors') are polite. In the Thai culture, politeness at this point may refer to acceptance and communication with care.

BK: 'So, what is good that makes you prefer living in the hospital?'

Harn: 'The doctor spoke politely.'

Harn (male patient, 35 years old)

5.3.2 Theme 2: Living in the rural Thai community is good but...

The patient participant group reported both advantages and disadvantages of staying in the rural Thai community. Four sub-themes emerged from the data, namely, i) Sympathetic culture and mental health support, ii) Rebuilding relationships in the community, iii) Being an unwanted person, and iv) Job opportunity and income.

5.3.2.1 Sub-theme 2.1: Sympathetic culture and mental health support

Almost all patient participants with schizophrenia expressed a number of reasons as to why they preferred living at home rather than staying in the psychiatric hospital. Some of the participants perceived that living in the community is good because they are free to do their favourite activities, as well as being supported by their community and family. In Thai culture, most people accept that people with disabilities or chronic patients can be dependent on their family members and/or other people who can support them. This may be because Thai people tend to sympathise and support vulnerable groups. Therefore, living in the supportive environment allowed some participants to be happy to stay at home without doing work or housework.

Chapter 5 Findings

'Living at home...before that I washed clothes, washed dishes but now I didn't do much. (Currently, I am) staying at home taking a rest but in the past I cleaned (the house) helped my mom sometimes'.

Chatchai (male patient, 23 years old)

Some participants considered themselves lacking the capability to work because *'their brain did not function well (Duan and Kwan)'*. Therefore they have to rely on their family members and/or the government allowance (around 500 Baht or 10 GBP per month) for their living expenses.

'Frustrating? I'm not frustrated. I'm living well...comfortably. My husband doesn't let me work. If asked 'can I do fortune telling?' I could, but if asked 'can I work?' my brain cannot get it. I can't work and my husband doesn't let me'.... 'All of family income comes from my husband'.

Kwan (female patient, 38 years old)

'When I don't have money, she gives me money, 50 Baht [1 GBP], 40 Baht [80 pence], 20 Baht [40 pence]. It depends on me, whatever I would like to spend. When I wake up, I say 'Mom, give me money', so she gives me'.

Jirasak (male patient, 44 years old)

Food appeared to be an issue for participants when living in the community. One participant reported that she completely relied on her father, who was a Buddhist monk, to bring her food every day.

BK: So where do you get food from?

Duan: From Luang Por [her father, a Buddhist monk which 'Luang Por' means venerable father in English].

BK: Luang Por brings food for you?

Duan: Yes.

BK: 'So, how about earning money for buying food, who can help you for this'?

Duan: 'It's... I think it's just the venerable father (her father: the Buddhist monk) who can look after me'.

Duan (Female patient, 42 years old)

A number of participants reported that they received support from their caregivers, relatives, friends and other people in the community.

BK: How about other people like your relatives; do they give you any help?

Jirasak: They do. They give desserts and food for me all the time. Desserts, food, fish and so on I have got all the time and also dried food.

Jirasak (male patient, 44 years old)

BK: Um... Do people in this community give you something? Do they give you stuff, something like that... Do they help you?

Duan: They... In the Buddhist Sabbath (The day that Buddhist monks stay at the monastery and do religious practicing rather than going out for receiving food from people), I went to eat at grandma's house.*

Duan (female patient, 42 years old)

Chapter 5 Findings

Financial issues appeared to be the main concern for some participants and their social network seemed to be an important source of support. One participant mentioned that he received monetary support from his friends. Although his friends did not give him money straight away, they gave him chances to work for them because the participant's friends were concerned about the participant's financial issues.

BK: As you said, you have to look after your brother when coming back home and without much income, so who can help you for this?

Eak: Sometimes I borrow from my friends and work for them later.

Eak (male patient, 40 years old)

5.3.2.2 Sub-theme 2.2: Rebuilding relationships in the community

It appeared that participating patients perceived the act of re-entering the community, with a diagnosis of schizophrenia, could change their lives regarding the capability to build relationships with their family and community. Their dilemma was that either their symptoms of paranoia or any perceived criticism caused the patients to perceive that other people have negative thoughts towards them.

BK: When coming back home, you can see your mom, which is a good point. However, do you face any difficulties?

Jirasak: I don't have. It's like I'm dissatisfied a little bit. It's not similar to the past. It's just a little that dissatisfied me. However, the others might dissatisfy me. I don't know [laughs].

BK: [laughs]. It's like you're satisfied with living at home.

Jirasak: 'However, if I have done something and then people are dissatisfied with me... other people may have a negative attitude towards me, they may 100% view me in the negative way, but I view them [in the negative way] 20%'.

Jirasak (male patient, 44 years old)

It is clear that having symptoms of paranoia and/ or fear of criticism could inhibit participants from building relationships outside the family, thereby motivating them to choose to isolate themselves from society.

Kwan: '... because my brain cannot get it. If I talked to other people and they gossiped about me, I would be serious'.

BK: I see...Is anyone gossiping about you?

Kwan: It's...I don't know. I don't know about this because I haven't been going out.'

Kwan (female patient, 38 years old)

Self-stigmatisation appeared to be a cause of self-isolation. One male participant reported that he was not confident enough to socialise because he may cause violence or behave violently.

'(I) don't want to cause them trouble and (I'm) not confident... if I go and see them, the other gangs, I used to be assaulted'.

Natchapon (male patient, 41 years old)

Furthermore, participants' behaviour could affect social relationships. One participant revealed his insight into the impacts of alcohol drinking and violence.

Jirasak: It's like if I drink alcohol, I would be totally different: my actions.

BK: How will you be if you drink alcohol?

Jirasak: I will be cruel. You can ask people here, no one is brave enough to see me.

BK: Do you bash people?

Jirasak: If I hold a piece of wood, a knife or an axe, I would definitely hit.

Jirasak (male patient, 44 years old)

5.3.2.3 Sub-theme 2.3: Being an unwanted person

It appeared that almost all participants failed to merge themselves back into the community; therefore some of them felt that they were not a part of the family and community because of having a mental illness. It appeared that being, or forming a self-perception of being, an unwanted person in society could destroy a participant's self-esteem. This negativity was expressed by a number of participants in different ways; one participant stigmatising himself as 'surplus to society'.

'I was already surplus to society'. Jirasak (male patient, 44 years old)

The participants' comments suggest that Thai culture perceives patients with schizophrenia in a negative way. Although the participants did not express stigmatisation directly, it seemed that having schizophrenia results in that patient being blamed as a 'useless person'. A good person, in the participants' perception, is polite and free from psychotic symptoms. One participant reported that he had to readjust himself to become a better person, because having psychotic symptoms induced him to be a bad person.

'Adjust...act...act politely...readjust myself' ... 'In the past, I was mad...didn't know anything'.

Harn (male patient, 35 years old)

5.3.2.4 Sub-theme 2.4: Job opportunity and income

It appeared that low self-esteem affected the participants' hopes and their perceptions towards the future. A number of participants reported that they lacked the capability to work as well as they used to, and were hesitant to ask for work. Therefore, they became passive and waited for someone to offer a job opportunity. It seemed that a part of having lower self-esteem might come from paranoia symptom and/ or fear of criticism.

Jirasak: 'Let them ask me if I am OK. If yes, what do they need me to do? Can I do it? If yes, I would go'.

BK: Is someone calling you (for work) currently?

Jirasak: Not yet. I just let go. I helped some people. They gave me 50 Baht [1 GBP], I accepted it. Giving me three meals, I accepted it. If I walk pass them, they poke their husband and their wife to look at me. I just make it OK, that's all.

BK: Um... How do you view your future?

Jirasak: It's still zero.

Jirasak (male patient, 44 years old)

Although some participants could work and become relatively independent, they did not have secure jobs, which worried them regarding having financial constraints in the future. Unfortunately, there are only low-paid jobs available in the rural Thai community, because the majority of the land is agricultural. Hence, some participants felt that their future could be, and would be, uncertain.

'I have to work until I can't. I think when I reach 60 years (old) it has to stop...no income. ...Don't have money...if I can't work...I think...Oh! I would be worried.'

Anuman (male patient, 59 years old)

It appears that their diagnosis of schizophrenia was not be the only issue causing the participants to have doubts about their future, as there were other issues linked to the responsibilities of living in the community. For example, a patient with schizophrenia may have to look after other family members who also have mental health problems. This is because schizophrenia could be transferred by heredity in the family (Govitrapong et al. 2002; Wong and Van

Chapter 5 Findings

Tol 2003; Lichtenstein et al. 2009; Fleming and Martin 2011; Matheson et al. 2011; Owens et al. 2011; Panichareon et al. 2012a; Panichareon et al. 2012b). One participant reported that he felt frustrated and burdensome because he has a schizophrenia diagnosis and is supposed to be taken care of by his family members. However, he has to take the role of a caregiver to a person with schizophrenia instead.

‘My aunty asked me to carry rice sacks and then spray insecticide in the evening. I can do it but my younger brother does nothing (Eak’s younger brother also has a diagnosis of schizophrenia). It’s like he has an income of 500 baht monthly. (The allowance from government is paid 500 baht monthly) but he cannot earn the extra income. ... ‘It’s like I have to look after a brother. To me, I got sick too (have a diagnosis of schizophrenia)’.

Eak (male patient, 40 years old)

5.3.3 Theme 3: Seeking empathy

Although it appeared that the members of the patient participant group isolated themselves from society, they still needed empathy from people around them. Three themes emerged from the data from both patient and caregiver participant groups; namely, i) active listening and ii) getting back to be one’s pre-morbid self, and iii) health education for the public.

5.3.3.1 Sub-theme 3.1: Active listening

Patient participant group members found that when living in rural Thai communities it was difficult to find someone to understand their feelings and needs. Normally, people in the rural Thai community live with their nuclear family and have close relationships with their family members, but the complexity of the rural Thai culture allows the family members to keep their distance between generations and genders. Hence, it is difficult to express feelings openly among the Thai family members, because people may feel awkward and shy about doing so. Some participants, who stayed with their parents or siblings, reported that no one had any insights into how they felt and no one empathised with them.

'She listens but doesn't realise' is that she listens to what I complain about and vent to her. She listens but she doesn't know what the facts from my mind are.

Jirasak (male patient, 44 years old)

BK: 'I see... So, who can help you when you feel lonely?'

Anuman: 'No one'.

BK: 'No one?'

Anuman: 'Yes'.

Anuman (Male patient, 59 years old)

5.3.3.2 Sub-theme 3.2: Getting back to be one's pre-morbid self

It appeared that not all of the patient participants felt happy with being dependent. Moreover, some of the participants perceived themselves as being discarded; a status attributed by participants as resulting from having a lower level of self-esteem. Being criticised influenced the patient participants to wish they could return to being the person they were before having schizophrenia.

'I heard words [from others], it affects me. Some people, they call me 'shrewd crazy'. Isn't it? I don't want to hear 'know everything', 'shrewd crazy'. What I was in the past? A human? Before I got mad'.

Jirasak (male patient, 44 years old)

Several patient participants expressed how having schizophrenia was frustrating and it limited them in doing what they wanted to do. One participant discussed how he would like to be a person who does not have schizophrenia, so that he could earn money and travel around as he used to do, before he was diagnosed.

Chapter 5 Findings

'I want to have my own money to spend...living like... (if) I wanted to travel, I could go anywhere like the past, before getting ill'.

Liam (male patient, 35 years old)

5.3.3.3 Sub-theme 3.3: Health education for the public

It appeared that the caregiver participants experienced both positive and negative sides of living with, and caring for, patients with schizophrenia in the rural Thai community. It appeared that the caregivers themselves were pressured by patients with schizophrenia, financial circumstances and society. It seemed to be a frustrating situation, but accepting criticism and acting like nothing is happening seemed to be the solution in order to live their lives peacefully in the community. For example, one participant was aware of criticism about her son's mental illness, but she seemed accept it, without expressing and/ or arguing with anyone.

Baitoey: They (other people in the community) did...they did (talk about my son's mental health disease) but they didn't let him hear. They talked to me. My relatives also talked about this. Although they knew, they didn't let him hear.

BK: So, how do you feel then?

Baitoey: It's...it's true like they said. I just let them (criticise)

BK: Can you accept it?

Baitoey: (I) accepted.

Baitoey (female caregiver, 61 years old)

Furthermore, some caregivers revealed that the participants would like society to understand that seeing patients with schizophrenia in terms of social stigmatisation could lower a patient's self-esteem; in particular, that not every patient was violent. Some caregivers expressed their insight into the feelings

of patients with schizophrenia. It appeared that the caregivers were concerned and empathetic regarding the patients' feelings in relation to being stigmatised by members of the community. Half of the caregivers felt that being on the receiving end of social stigma in their community was inevitable for both the patients and their caregivers. One participant expressed her view of the social stigma that patients with schizophrenia had to cope with. She felt that female patients might feel more embarrassed than male patients.

'Like (a female patient's name), she's a lady and (another female patient's name) secretly go to the hospital but my son is male, (so) he doesn't care. Someone asked (a female patient's name) 'why don't you come to sit with others (mentally ill patients)? (And then, she replied that) 'It's like...I don't know. I felt shy (because) other people looking at me... I can't accept this...I knew I have (mental health disease) but it's...I don't know'. I sympathised with her. It's like she knew that she has (a diagnosis on mental illness) but she...doesn't want other people know that she has psychoses.'

Fon (female caregiver, 51 years old)

Additionally, it appeared that these perceptions of social stigma could impact on the levels of self-esteem of people with schizophrenia and could make them feel upset.

After observing the patient's psychological discomfort, the caregivers expressed their emotional reactions which appeared to be empathetic feelings, because they knew that patients with schizophrenia needed to be loved. One participant was concerned that patients with schizophrenia were a group of people who needed to be loved and cared for.

'We shouldn't blame them. Don't aggravate and complain (about them). (Patients who have) these diseases (mental health diseases), they need encouragement and love from us'.

Fon (female caregiver, 51 years old)

Chapter 5 Findings

However, some caregivers did appear to be afraid of being harmed by the patient with schizophrenia and these concerned carers tended to be those who had experienced violent behaviour in the past. Half of the participants said that the most terrifying period was when the patients with schizophrenia had uncontrollable psychotic symptoms, because they were physically harmed and verbally abused. For example, one experienced participant expressed her fear and paranoia thought whilst the patient had uncontrollable psychotic symptoms.

'When he first had (psychotic symptoms), he did not know (because he was not in reality). I was afraid that he would stab me'.

Baitoey (female caregiver, 61 years old)

However, some caregiver participants realised that the patients might do physical harm and this could terrify other people. For example, although Wanchai (male caregiver, 49 years old) himself did not mention about his experiences of physical harm and verbal abuse, he realised that having patients with schizophrenia in the village could terrify other villagers. Therefore, this could stop other villagers from doing their activities. Furthermore, it appeared that fear could affect participants physically and psychologically. Moreover, fear could affect schizophrenia care collaboration: one participant assumed that there was no one in the village willing to care for patients with schizophrenia because of fear.

'Living in the same village, I have tried to see...If I let it being like this, it would be problems afterwards. It's just only one (patient) (but) last time in the village, there were 2 severe cases. If I let it continue like this the villagers feared (and) they would not dare do anything.

...If asked, who wanted to get money? All people, probably, would raise their hands but if asked, who wished to help mentally ill? No one going to... (because they) fear...if I were them, I would fear also'.

Wanchai (male caregiver, 49 years old)

In contrast, it appeared that those who had taken care of a patient with schizophrenia for a longer period of time had better insight into the behaviour of patients with schizophrenia. It seemed that not every patient with

schizophrenia would do physical harm and be verbally abusive. For example, one participant explained that although her relative with schizophrenia could terrify other people, he would not harm anyone.

'Other people might fear him but actually he did not harm anyone. However, he likes to ask for money from strangers'.

Malee (female caregiver, 32 years old)

It appeared that sometimes patients with schizophrenia could be problematic for their caregivers, and other people in the community, when they relapsed. Physical harm was the most terrifying thing that both participants and other people in the community worried about. Therefore, this could be a dilemma for the participants, who seemed to care for the patients with unconditional love and sympathetic feelings.

5.3.4 Theme 4: Caregiver's mix feelings towards schizophrenia care

This theme related to the caregiver participant group only. More than half of the participants in the caregiver group talked about support that they have been giving to patients with schizophrenia, since the patients have been living in the community. For these participants, it seemed common for patients with schizophrenia to be financially dependent. There appeared to be two potential reasons for support and caring for the patient with schizophrenia, namely: i) unconditional love, and ii) ambivalent feelings.

5.3.4.1 Sub-theme 4.1: Unconditional love

It appeared that caregivers who have children with schizophrenia appeared to provide care with unconditional love. Although some of them did not have much money to give their children, they gave other forms of support, such as food. One mother vented her frustration when being criticised by her daughter that:

'She (her daughter) said that I am only concerned about him (the patient's name). Alas! He's being like this. What does she want me to do? I apologised and said to my daughter that 'even dogs also love their child. Although (he is)

Chapter 5 Findings

mad, (he is) still my son. ... I love (my son). They (other people) gave (me food), I couldn't swallow. Maximum I could eat just a bite. I had to keep (food) in my bag (for bringing it to my son). I am concerned (about him)'.

Namtip (female caregiver, 70 years old)

Similarly, religious status could not stop unconditional love from parents. After becoming a monk, Buddhist monks should isolate themselves from the general population and not be involved in family business or society, like they used to be; their status in society has changed. However, Buddhist monks can look after their sick family members, if there was no one else doing caregiving duties. One participant reported that he still took care of his daughter, although he was a Buddhist monk. Providing her food and money seemed to be the way that he could support her to live a life in the community.

'When I (am finishing) charity, I go to my younger brother's house and give to her [the patient]. I give her money 80 Baht/ a day, then I take motorcycle taxi back to the monastery every day.

Adisak (male caregiver, 65 years old)

For non-relatives, a sympathetic and supportive culture appeared to be the starting point for schizophrenia care and support. Moreover, having experiences of schizophrenia care might allow some participants to gain insight into another patient's feelings. For example, one patient's mother expressed her sympathy when seeing other people suffering from mental illness.

'Seeing her (another mentally ill person whom she had met in the psychiatric hospital) have problems, I sympathised with her. (Her son shouted that 'my mom is a compassionate person'). I'm being like this. Sympathise with her. Gave her money. ... I thought why I have to be here: in the psychotic environment? If I didn't help her... Let's help her a bit. So, I helped her.

Fon (female caregiver, 51 years old)

Similarly, one participant expressed his supportive attitude and goodwill of taking care of his non-relatives who have mental health diseases. He was not only donating his money but also his time and effort to take care of the mentally ill in the community.

'In the past, I hired (a car) and paid for everything. By doing this, it doesn't mean I'm rich but I'm proud. It's like seeing them can do, being like normal people. I think this is heaven. It's like I could fly while walking. Other people challenged me that why taking (the patients with schizophrenia to the psychiatric hospital)?... (Other people said that) don't waste time to treat (those patients with schizophrenia). Going there (the psychiatric hospital) is wasting time. (I) told (those people) that we're wasting time already. They (patients with schizophrenia) wasting their time almost all of their life. (Should we) give them chances? Just in case that they can get back to reality'.

Wanchai (male caregiver, 49 years old)

5.3.4.2 Sub-theme 4.2: Ambivalent feelings

It appeared that some caregivers were in a state of ambivalence as they seemed to reveal two sides of their experiences and feelings of living with and caring for a patient with schizophrenia. These ambivalent feelings seemed to relate to showing empathy and suffering which were expressed towards schizophrenia carers. The majority of participants talked about negative behaviour displayed by the people with schizophrenia, such as wandering, aggression and physical attack. As a result, the majority of participants reported that schizophrenia care was a challenging role. In fact, it appeared that an individual with schizophrenia might not be able to control themselves when their mental health condition deteriorated. Wandering seemed to worry the caregivers, who therefore partially limited the activity of an individual with schizophrenia as a solution to this problem. For example, one caregiver expressed his burdensome feeling when he has to keep an eye on his wife, regarding when she relapsed and wandered to other places.

Chapter 5 Findings

Mostly, it will be in the evening. Mostly, the room door will not be opened like this. We will open about a palm width but it's better than the past. In the past, I couldn't trust. If, I wasn't home, (my wife) would wander. Sometimes, she walked for 14 km. from here. She walked until 2 A.M.

Sorrayut (male caregiver, 37 years old)

It appeared that the most unacceptable behaviours were verbal aggression and physical attack. Although some participants expressed how much they loved their children who have a diagnosis with schizophrenia, they sometimes could not tolerate such challenging behaviours. For example, one participant experienced verbal and physical abuse from her son who has chronic schizophrenia, which appeared to be quite traumatising. Therefore, she expressed her ambiguous feeling between pushing her son into the jail or being tolerant and suffering from his negative behaviours forever.

It's like...I was sitting for feeding my grandchildren milk. He called me from upstairs: 'Do you want to die? I will assist you'. I also damned him. After that I continued feeding my grandchildren milk. Then he kicked me hard. His legs are so big; he is big, a lot bigger than me. So, I was unconscious'.

...It's me. (If I) don't give him (money), he would rampage. In the year 2011, may be the year 2011-2012. He had hit me until (I got) bruise. I had to see the doctor. In the end of the year, I had to ask the police to frighten him. ... but the police asked me 'what should we do? The only one way is making him to relate to amphetamine and then push him to the jail. Can you do that?' I'm his (the patient with schizophrenia) mom. I can't. I don't know what to do, so I am just suffering like this'.

Natcha (female caregiver, 54 years old)

5.3.5 Theme 5: Using violence and punishment for management of schizophrenia

This theme related to the caregivers' perspectives towards how to manage patients with schizophrenia when their condition deteriorates to the level

where it becomes challenging. Community compulsory treatment seemed to be the way to overcome the obstacle. Therefore, it appeared that sometimes the caregivers thought that a punitive way of managing patients with schizophrenia might be necessary and to be the only way to stop them from being violent. Two sub-themes emerged from the data, namely: i) illegal punishment, and ii) compulsory hospitalisation.

5.3.5.1 Sub-theme 5.1: Illegal punishment

Using violence to stop a patient's negative behaviour appeared to be a solution that was frequently used by the carers. Although this sounds unfair for the patients with schizophrenia, particularly when they have uncontrollable psychotic symptoms, it seems that the caregivers felt that they have no better option than using punishment and violence. Having children with schizophrenia was a major worry for some caregivers. Although parents seemed to sympathise with their children who had a diagnosis of schizophrenia, they had to comply with other villagers' wishes regarding when their children had arguments with other people in the community. Therefore, it appeared that some parents had a dilemma of either protecting their child or letting other people in the community abuse her/his children in some way. One participant expressed that she had to agree with other people in the community that her son, who has a diagnosis of schizophrenia, would not fight or bother with other villagers, otherwise they could illegally shoot him.

'(He was) hurt but I thought my son is not good (because) his nerve ('nerve' for rural Thai people can mean cognitive capacity, brain or mental health) is not good. (My son) was bothering them (other people in the community), so they hit (my son) which is fine. Next morning, I took him to see the police and consented that (my son) would not bother them again. If he did, they could shoot him dead without being guilty'.

Natcha (female caregiver, 54 years old)

From this extreme example, it seems that the participant has to control the patient's behaviour otherwise she has to allow the other villagers to stop the patient's violence by using potentially fatal violence.

5.3.5.2 Sub-theme 5.2: Compulsory hospitalisation

From some caregiver's perspectives, calling the police to catch the patients, to bring them back to the psychiatric hospital, appeared to be the best way to manage a patient's violent behaviour. This might be because compulsory treatment in the community is sometimes unavoidable. The general population seemed to be panicky when they saw patients with schizophrenia exhibiting psychotic symptoms and wandering. Therefore, using police to catch and control the patients who had been diagnosed with schizophrenia, in order that the patient could receive calming medication as well as compulsory psychiatric hospital admission, appeared to be the action of first choice for preventing other people from experiencing physical harm. Hence, compulsory treatment and hospital admission appear to be crucial, because people would like the patients to be treated for their own good as well as for other people's safety.

'In the first time... last time...we caught the patient. We needed to catch and detain...the patients (with schizophrenia). It's like normal. ... must catch (patients with schizophrenia). In that time...year 2004, it was a male psychiatric patient. The first case that we did was... viewing the problem that was ... other villagers were afraid and paranoid that this man would harm them because he was wandering.

... If (they) refused to take medication when coming back home, there are so many ways of treatments (for example) drop medication. If they don't take (medication), ask the doctor to inject'.

Wanchai (male caregiver, 49 years old)

Another participant also expressed her feelings about having to use the police to manage her son when he had recurring psychotic symptoms. She found this appeared to be a frequent effective strategy to help stop her son when he was being dangerous.

'Afraid. He held a knife. No one could stay near him. He shut the door (the patient's house door) and did not allow anyone to open. ... The police are so kind. Every time calling them, they come. They handcuffed him. They helped us to catch (him). The police tricked him into giving up the knife. (Then) he (the patient) gave up the knife, he's afraid of the police'.

Baitoey (female caregiver, 61 years old)

Having bodyguards to catch patients who relapse, and then sending them to the psychiatric hospital, was a suggested strategy from one caregiver. This concept appeared to confirm that compulsory treatment seemed to be inevitable in the rural Thai community. One participant suggested that, for him, having a bodyguard to catch the patients for compulsory treatment seemed to be a better choice, if compared with seeking for a full-time mental health specialist to work at the THPH, because he felt the government would not support this. Therefore, the patients with schizophrenia have to be referred to the higher level of care when they have uncontrollable psychotic symptoms.

This is difficult because I don't know whether this THPH could care for psychiatric patients, especially, those who are acutely aggressive. This is a suggestion because it has to have a bodyguard (to catch) the patients who become aggressive. We have to lock up (the patients with schizophrenia) after catching them. It's the THPH staff, not a specialist, because the THPH is only for (treating patients who have) headache and fever. If treating that disease (psychiatric diseases), Oh! It would be chaotic. However, if asked should it (the THPH) have a full time (mental health) specialist? It would be possible but, if asked would it have the budget from the government to support that. Believe it or not, the government did not pay attention to this.

Wanchai (male caregiver, 49 years old)

5.4 Area 2: The importance of medication

All three participant groups perceived that medication was the key for schizophrenia treatment in the rural Thai community. The participants felt that medication not only prevents or reduces relapses by the patients but also reduces the caregivers' burdens. Therefore, medication adherence was identified as the heart of schizophrenia care at the primary care level in the rural Thai community; a point which will be expanded below.

5.4.1 Theme 1: The role of monitoring medication

It appeared that different participants had different roles for schizophrenia care. However, the majority of participants in this study were taking on similar roles, namely: i) medication adherence leading to normality, and ii) medication as relapse prevention.

5.4.1.1 Sub-theme 1.2: Medication adherence leading to normality

It appeared that after doing medication monitoring for a while, the caregivers observe patients' recoveries; some participants seemed to link medication taking and recovery together. For example, one participant described his assumption about the effectiveness of medication taking, regarding recovery where he used the term '*normal*'. 'Normal' for the caregivers could mean the patients have controllable psychotic symptoms, and therefore are probably capable of communicating with other people; an outcome which could show that the patients are in reality. Therefore, the carer felt he needed to be sure that an individual with schizophrenia adhered to the prescribed medication.

'Taking them (patients with schizophrenia) back (home) you have to support, like, have to take oral medication, after meal have to take medication something like that; don't stop taking medication. (If the patients are) withdrawing (the caregivers should) notice. We don't need to study medicine something like that. If we are lay people, how to observe them (patients with schizophrenia) is... Do you see? They (patients with schizophrenia) are usually smelly, their hair are unkempt, holding a lot of things. That's their disease.Giving (patients with schizophrenia) medication, giving them to

take, when they take at some point, they will be a normal person (and) when they are normal, then they may think to take a shower and dress up'.

Wanchai (male caregiver, 49 years old)

Similarly, one participant compared her son's habits, before and after adhering to medication, illustrating that the effectiveness of medication taking was obvious to her. Hence, she preferred her son to take medication regularly in order to retain his 'normal' behaviour. It appeared that the participant was keen to monitor her patient's medication taking framed by a Thai idiom: *no matter whether it's raining or sunny*. This idiom could refer to the activity or event that will routinely happen. Therefore, she expressed her strong goodwill to protect her son with schizophrenia from deterioration, by embarking on collecting her son's medication from the hospital and controlling his medication taking.

'I asked him to try to take medication for a week, (and) then he got back. He was like he used to be...his habits like before. It's like my son is normal. Something like that. So, I (laughs) thought he cannot go short of medication.

... Medication...I collect. I usually collect (it for my son). No matter whether it's raining or sunny I have to go (to collect my son's medication). Medication taking, I have to control the situation, like don't let him stop taking medication'.

Fon (female caregiver, 51 years old)

5.4.1.2 Sub-theme 1.3: Medication as relapse prevention

Several caregivers, who monitored their patients' medication taking, seemed to link medication taking with recovery. As a non-health professional, they might determine a patient's recovery based on their experiences and health education they have received. Participants who have observed patients' recoveries, made comments about patients' psychotic symptoms and memory capacity, as well as working capability. This may imply that participants have observed patients with schizophrenia's psychotic symptoms, as well as

Chapter 5 Findings

cognitive and work functioning. For example, one caregiver compared two patients' recovery and relapse profiles, based on his observations regarding religious activities, such as doing making merit activities. In this context, the participant referred to an activity for Buddhists; offering food for the monks and listening to Dharma talk (talking about Buddhist principles) from the Buddhist monk. This activity normally takes around two hours, which requires concentration and a calm manner. Therefore, the participant might judge 'recovery' from these things.

'Err...those 2 (patients with schizophrenia: patient A and B)... Now, I stay away from them. The first one (patient A: the patient with schizophrenia who seems to recover) has been calling for help from the THPH staff and they paid him money in order to show their support. Err...that one his health is better, better. Then, he could offer food (for the Buddhist monk) and make Boon in the Sabbath days. ... The first time he came here he was forgetful'.

... He (patient B: another patient with schizophrenia who shows no evidence of recovery) helped (to do some works) but he cannot be expected to work seriously, (because) he cannot. I acted to ask him to do things. He did, did, did, did. If he got tired, he would give up and leave the tools there. ... His nerve is not 100% full. ...If he was alone, he would not stop talking. Sometimes, he sat with me and told many stories (especially) when he got mad. He was talkative like talking about history, like highnesses. I don't know how he knew this. He's crazy.

Yao (male caregiver, 81 years old)

It could be noticed that the participants mentioned about 'nerve' which could mean cognitive capacity, mental health or brain. From the participant's expression, it seemed that cognitive capacity related to recovery. Therefore, the participants appeared to be strict about monitoring a patient's medication taking, after realising that taking the prescribed medication could prevent a relapse and promote recovery. However, missing prescriptions seemed to be a big mistake for them. For example, one participant experienced seeing her son's relapse and recovery, after trying to control her son's oral medication by

herself. From this example, it appeared that lay caregivers might manipulate patient's prescribed medication without antipsychotic medication knowledge.

'I thought err... If my son took medication and slept, he would get better. (Then), I reduced (medication tablets) from 2 tablets which (made) him sleepy to (only) the main (medication). Then, I gave him only one tablet and kept one tablet (laughs). It was for a week. I noticed my son wasn't quite normal but I didn't tell the doctors. It's like I won't tell the doctors because I knew how I gave him medication.

...It's like actually, I gave him oral medication. I reduced the numbers of medication when he was normal. Later, my son was vague and mad (laughs). He talked muddling...talkative, so I thought oh!...he couldn't be a Buddhist monk. Therefore, I had to give him medication but I didn't tell the doctors. I gave him 2 tablets, then he got back (to reality). It's like he could tune his brain by those 2 tablets'.

Fon (female caregiver, 51 years old)

In the participant's understanding, coffee, alcohol and energy drink appeared to be harmful because of their interaction with anti-psychotic medication. Two participants felt that a patient's addictive behaviour might cause relapses, which left them feeling hopeless regarding the patients' recovery. One participant expressed her exhausted feeling after noticing that her son kept consuming alcohol and a vast amount of instant coffee.

'He is not recovering. He, himself, did not help me. He always drinks alcohol to stimulate his nerves. He does not take amphetamines but he drinks 10 sachets of instant coffee a day. The result is... it is too much. The doctors told me. I don't know what to do, so blaming (each other) and living like this [laughs]... if who died before, it means that one is a loser...

It's hopeless. He cannot recover at all. He did not help himself. If he would like to recover, he had to help himself. If something is bad, if eating something

Chapter 5 Findings

harms nerves... He had to give up... [but] he did not listen. I don't know... and I'm at my wit's end'.

Natcha (female caregiver, 54 years old)

Similarly, one participant has a strong belief that drugs (drugs for Poom: an 81 years old male caregiver) means tobacco, alcohol, coffee and energy drinks) induced schizophrenia. Hence, he perceived that it would be hopeless if the patients with schizophrenia still took drugs.

'Patient B is smoking cigarettes and surreptitiously drinking alcohol. ... Does not recover. This person (patient B) does not recover. Why does not? (It is) because he has not given up drugs'.

Yao (male caregiver, 81 years old)

5.4.2 Theme 2: Managing adherence to medication

Medication appeared to play an important role for schizophrenia treatment in the community. The supervisory team and the THPH staff have been collaborating with patients, caregivers, health care providers and local authorities in the community. The staff from the community mental health department will inform and prepare the community by contacting people who are involved in schizophrenia care, after the psychiatrists decided to discharge a patient from the psychiatric hospital. The village chief (a civil servant), the patient's neighbours and grocery dealers could be invited for community preparation. This aims to gain collaboration between people in the community regarding people who are potentially in contact with the patient and his/her caregivers. The village chief seems to be the most important person who could ask other villagers to collaborate with care. In addition, the supervisors will invite the patient's neighbours and give health education in order to reduce discrimination towards the patient. The grocery dealers will be informally asked not to sell alcohol and energy drinks for/to the patients because of the potential for harmful drug interaction. The majority of health professionals mentioned the importance of antipsychotic medication as relapse prevention. Hence, managing patients to take their prescribed medication appeared to be the most important thing at the primary care setting. The health professionals

talked about their role, which was applying effective medication management suitable for the service users. Additionally, collaborating with the different levels of care, and with the local authorities, appeared to be an effective way to enhance medication management in the rural Thai community. This cooperation aims to facilitate medication provision and service accessibility, which is supported by the ‘service plan’: the Thai national mental health policy (Department of Mental Health). This theme consists of four sub-themes: i) community support for medication adherence management, ii) the importance of monitoring medication, iii) medication management as the heart of the care, iv) compulsory treatment and detention.

5.4.2.1 Sub-theme 2.1: Community support for medication adherence management

It appeared that medication provision and management was the first priority for almost all participants. To support this role, half of the participants recommended that the THPHs should have good medication collaboration with the psychiatric hospital, and provide medication services at the THPHs. However, the participants have different perspectives about community medication provision and management at the primary care level, because each THPH provided different types and quality of schizophrenia care. Therefore, the participants needed the community to support their medication monitoring role by i) having a psychiatric clinic and mental health specialist to provide and manage community medication and ii) the THPH becomes the medication collection point, as well as collaborating with the psychiatric hospital in an attempt to ensure good medication service provision.

Some participants, who did not receive schizophrenia care at the THPHs, talked about their needs to have schizophrenia care in the community setting. In the participants’ perspectives, ideally the psychiatric clinic in the community should be ready to provide medication services for patients with schizophrenia. This is because travelling from their homes to collect medication seemed to be an immense obstacle regarding poor participants who live far away from the psychiatric hospital. One participant explained her difficulties to collect her son’s medication from the psychiatric hospital, because it is far away from her house (more than 100 km). She pointed out how hard it was for her to manage to collect antipsychotic medication for her son due to the travelling limitation.

Chapter 5 Findings

Therefore choosing to buy psychiatric medication from a private clinic seemed to be a reasonable choice instead of travelling to the psychiatric hospital.

I wish it could have a psychiatric clinic (therefore I could) come to collect medication here because it's burdensome. In this sub-district, it's a lot of people having (mental health problem). Sometimes, older people, who are older than me, take their children (to the psychiatric hospital). It's difficult, therefore coming to the THPH is easier, I can walk there even I have no motorcycle. It's burdensome (for) people who don't have a vehicle. It's good for people who have vehicle but I don't have. Hiring once costs about a thousand (Baht) and there are also food expenses. Going (to the psychiatric hospital) once can cost a lot of money. I wish the psychiatric clinic could be opened in the community. I don't want to go (to collect medication at the psychiatric hospital). It's burdensome. I don't have a vehicle. Although I am now collecting medication at the (private) clinic, I have to go out at 6 A.M. Then, arriving (a district name) at around 7 A.M. and waiting for the bus until around 8 A.M., so I could go to the (private) clinic. I arrived the (private) clinic around 10 A.M. Queuing and waiting. Wait for the bus (to return home). The bus took me to (a district name) around 4 to 5 P.M. which took a whole day just for collecting medication from the (private) clinic, not from the (psychiatric) hospital.

... Oh!...I don't have bus to return from the (psychiatric) hospital. No way. If travelling by bus not by hiring a car, no way, cannot return home. It's difficult (because) it's a lot of patients who come from (three province names) and wherever, everywhere. They said medication here (at the psychiatric hospital) is good. They said like that.

Natcha (female caregiver, 54 years old)

Some participants only focused on medication to be delivered and managed at the THPHs. Therefore, they needed the THPHs to be a medication collection point, as well as providing medication injection service. They suggested that the THPHs should have good collaborations with the psychiatric hospital. Therefore, the patients would receive their medication on time which might reduce non-medication adherence and relapse due to travelling limitation.

If asked where the most convenient place to collect medication is? I thought at the THPH is convenient. (It is) more convenient than coming to the community hospital because there are a lot of patients here. Sometimes, I have to queue for a long time.

Fon (female caregiver, 51 years old)

Additionally, another participant kept repeating his needs both in his face to face and telephone interview. He suggested that the psychiatric hospital should have good collaborations with the THPHs regarding medication transfer.

I wish they (the THPH staff) could collect medication from the psychiatric hospital and then I collect (medication) from the THPH¹.

...I thought the psychiatric hospital should frequently contact the THPH, something like that. Then, send medication on time².

Pakawat (male caregiver, 52 years old)

At this point, it seemed that poverty could be a huge obstacle which pruned the participants' and the patients' ability to access the higher levels of care. Fortunately, sympathy and kindness seemed to be one of the rural Thai people's specific characteristics, which could be seen in different forms of support; such as monetary, food and accommodation. For example, one participant expressed that, without community support, she might be a broke person because her son set fire to the house.

'In that time, the other villagers helped (me). They sympathised with me. Each family helped (donated) 500 Baht or 100-200 Baht. They also donated rice,

¹ Information from face to face interview

² Information from telephone interview

Chapter 5 Findings

cooked rice, clothes and everything which could be eaten for a year. They sympathised. In the year that my house was burnt [Natcha's house was burnt by her son], if the other villagers did not help, we would have nothing left except building a small shelter only'.

Natcha (female caregiver, 54 years old)

Additionally, although neighbours might not be able to give monetary support for the participants, they helped to keep an eye on them when the participant went out to work. This could demonstrate the kindness and goodwill of rural Thai people.

Sometimes, they (the other villagers) would tell me about what my wife ate and (where my wife) went. So, I would be more observing. It's easier (for me). I couldn't think that the neighbours are fussy but they are looking after (my wife) for me because I am working. Sometimes, just my 2 eyes, I couldn't see [he refers that he could not manage to keep an eye on his wife all the time because he has to work.].

Sorrayut (male caregiver, 37 years old)

5.4.2.2 Sub-theme 2.2: The importance of monitoring medication

Medication monitoring appeared to be one of the participant's main duties. The majority of participants discussed how important taking the medication was; appearing to believe that it was effective for controlling schizophrenic symptoms. For example, one participant said that he regularly checked on his wife and confirmed that she took medication according to her medication prescription.

'I am trying to ask 'have you take medication yet?'. It's like reminding. I will look at the medication bottles but if she has severe symptoms, I would consult the doctors'.

Sorrayut (male caregiver, 37 years old)

It therefore appeared that when participants strongly believed that the medication was effective, they took an active role in monitoring the patient's medication taking. However, it could be noticed from the participant's expressions that monitoring a patient's medication taking role had been influenced by the health professional. Hence, neglecting this role could lead them to feel guilty. For example, one participant expressed his guilt because he was unable to manage the patient's medication due to having too many monkhood duties.

'Yes, he (a patient's name) takes (oral medication) which the doctors sent to us. They asked me to take responsibility about medication but I don't have enough time (due to) going out a lot. I'm selfish sometimes and my health is not good. Sometimes, my sleeping time is irregular: sometimes late, not regular. (I) have lots of duties: going out to many places. Then, I asked him (the patient with schizophrenia) to manage his own medication.

...(A patient's name) is smoking and drinking alcohol. Ah! The thing I am concerned about is that I didn't control his medication taking'.

Yao (male caregiver, 81 years old)

5.4.2.3 Sub-theme 2.3: Medication management as the heart of the care

Managing and monitoring the patients to take their prescribed medication appeared to be the first option for a medication management strategy in the community. It appeared that the majority of participants perceived that medication is the heart of schizophrenia treatment, regarding relapse prevention; particularly focusing on the medication which controls patients' violent behaviour.

'(It is) because (when the patient with schizophrenia) having psychotic symptoms, she (the patient's wife) has to run into a room and lock the door. (The patient's wife asked Busaba that) 'Can the door protect (me from) him?'. ...before this happening, we have to do anything to make him taking medication and do not make him (the patient) angry'.

Busaba (female THPH staff, 46 years old)

Chapter 5 Findings

From Busaba's opinion, her faith in the effectiveness of medication for relapse prevention and controlling patient's violence could be clearly seen. This appeared to be similar to some health professionals who perceived that medication was the key for schizophrenia care in the rural Thai community. However, providing care for the service users in the rural areas requires not only supplying medication for the patients, but also insight of the service user's lifestyles and their limitations. For example, some health professionals mentioned their concerns regarding supporting people who are working full-time and/ or long hours (e.g. working in the rice and sugarcane farms), non-literate and forgetful caregivers (e.g. the old age caregivers), and having not enough support from their caregivers. Hence, assisting the caregivers to manage a patient's medication appeared to be one of the health professional's major roles. For example, some medication management techniques were introduced, such as 'unit dose' and 'directly observed therapy' (DOT) techniques. The unit dose technique was designed for the caregivers who could not manage the right medication dose for the patients, whereas the DOT technique was designed for ensuring that the patients are taking their prescribed medication regularly.

First of all, I am trying to ask (and) focusing on oral medication taking. I do not have much time to manage this in the community. If I do not have time, is it OK for managing unit dose? It is more convenient when we manage the medication to be the unit dose. The patient's relatives are pleased. Unit dose is managing medication into separated bags. For example, a patient has five to six medication bags, and then they have to manage them. Moreover, we prescribe medication for the patients for two months, so it is confusing and some service users are forgetful. Therefore, we manage the medication for a day and make the patients take it in front of the relatives. We resolve problem by using this (technique) with which the patient's relatives are satisfied.

Somsiri (female supervisor, 41 years old)

The idea of the DOT medication management technique seemed to pass from the supervisors to the THPH staff and the village health volunteers (VHVs). The VHVs are a group of people who are selected from the local villagers who

volunteer to help the primary care service. The VHVs are not health professionals; however, they will later be educated with a basic knowledge of health education and health assessment. Therefore, they could assist the THPH staff to check regarding when the patients have the signs of a relapse. It appeared that sending medication to the patients in the community seemed to be helpful, regarding the reduction of non-medication adherence caused by travelling limitations. For example, one THPH staff talked about her experience regarding assigning the VHVs to monitor the patient's medication taking by using the DOT medication management technique.

'Asking the VHVs to look after [Kanokwan meant assigning the VHVs to monitor medication taking]. Designing (medication management plan) like (medication management) for patients with TB. (It is) DOT (technique) which attaches medication to the sweet cardboard (เม็ดน้ำตาล). (Therefore, the patients) could take one (set) at a time'.

Kanokwan (female THPH staff, 46 years old)

At this point, medication adherence appeared to be essential for the patients. Hence, the health professionals sought effective medication management which should be suitable for the service users regarding the caregivers. This is because the caregivers appear to be the key persons who are able to monitor the patient's medication taking better than the health professionals can. However, forcing patients to receive antipsychotic medication could happen when, or if, the patients relapse and exhibit the potential to do physical harm to themselves and/or others.

5.4.2.4 Sub-theme 2.4: Compulsory treatment and detention

Some health professionals mentioned the issue of compulsory treatment, which was used for some patients who did not want to take their prescribed medication. For example, dropping antipsychotic medication into patient's food and drinks would be the last option, which can be done by the caregivers. One supervisor from the psychiatric hospital talked about his experience

Chapter 5 Findings

regarding supporting Haloperidol drops for parents who struggled with managing their children to take prescribed medication.

'Using Haldol drops when we don't have any other way to manage the cases. It's like they don't accept to take medication tablets and medication injections. This is the last thing that the patient's relatives come to the psychiatric hospital for; asking for medication drops. Then, they drop it into the patient's food. After the patients getting medication without knowing that they taking it, the psychotic symptoms are improving'.

Tawat (male supervisor, 48 years old)

The supervisory team members discussed the compulsory treatment circumstances of the patients, who have had treatment and had been detained; sometimes necessary due to their deterioration or becoming violent. For the patients' and other people's safety, the patients would be detained by police, rescuers³, local authorities or any other volunteers in the community. The health professionals would communicate with the patients' caregivers and/ or relatives for managing the care further.

'In the case that they (anyone in the community) contact us (the community mental health department), we would bring medication for injection. However, when we were at their houses (the service user's house) and he/she was not ready to inject medication, it was difficult for us to restrain or force them. We only can talk and communicate with the patient's relatives. In this case, we would let the police, rescue or the local authorities take the patient to the hospital'.

Tawat (male supervisor, 48 years old)

³ Rescuer is a volunteer staff who saves someone from a dangerous or unpleasant situation (Macmillan dictionary online 2015)

Similarly, the THPH staff also mentioned about compulsory treatment in the community setting, which sometimes required the cooperation of and collaboration with the non-health professionals.

'Injecting (medication), sometimes he did not want to be injected. Sometimes, (he) was running away, something like that. Sometimes, calling the police, community leader and SAOs to help. Sometimes, we have to catch (the patients) and inject which are a few'. (Laughs)

Noon (female THPH staff, 41 years old)

At this point, it appeared that managing schizophrenia care at the primary care level required not only health professionals, but also the collaboration and cooperation between service users, health professionals, VHVs and other groups who could optimise the care.

5.4.3 Theme 3: Recommendations for better medication management

Participants perceived schizophrenia care differently. The four themes emerged from the data: i) one-stop service at the primary care level is needed, ii) community medication: medication delivery, medication reminder service, iii) consultation is needed: medication, physical and sex life, and iv) enhancing medication adherence via a referral line and network.

5.4.3.1 Sub-theme 3.1: One-stop service at the primary care level is needed

Data from patients with experience of schizophrenia revealed that there were different levels of schizophrenia care provision available at the Thai primary care level. Some participants were quite satisfied with community medication provided by the THPH staff. Participants received medical injections and oral medication; procedures which were managed by the primary care staff.

Chapter 5 Findings

Collect (oral) medication at the THPH. My (oral) medication is nearly running out. I have to collect again.

....

Doctor (the THPH staff name) is the person who injects medication (for me) on every 20th (every month).

Kwan (female patient, 38 years old)

Conversely, some participants mentioned that there was no one-stop service available for them; therefore they had to travel to several places to receive their schizophrenia care.

Eak: For the Tambon Health Promotion Hospital staff, I went there for injecting medication every month. They asked how I am.

BK: I see. Where do you get oral medication?

Eak: At the hospital (the hospital name).

BK: Do you need to collect medication by yourself or they send it to you?

Eak: I go there by myself.

BK: Is that far?

Eak: Not far, it's just over 10 Kilometres.

BK: How do you go to there?

Eak: I ride a motorcycle. My mom bought me a motorcycle.

Eak (male patient, 40 years old)

Although the participants did not express that they needed a one-stop service for schizophrenia care, they complained about the difficulties of seeking that care. One participant commented on his travel difficulties and the fragmented aspect of his schizophrenia care.

BK: Is there any problem or difficulty when you came back to live at home?

Liam (male patient, 35 years old): There is. Travel difficulty.

BK: You mean travel to where?

Liam: To collect medication...going to see a doctor...going to another province.

.....

Liam: I used to come here for medical injection. Then, she (the THPH staff) visited me.

BK: Normally, she came to visit you at home?

Liam: (Sigh) at home.

BK: Is it often?

5.4.3.2 Sub-theme 3.2: Community medication: medication delivery, medication reminder service

This sub-theme relates to the previous sub-theme regarding need for schizophrenia care at the primary care level in rural Thai communities. It appeared that financial and travelling issues were the participants' main obstacles hindering their continuing schizophrenia treatments. Therefore, some of the participants mentioned that community medication delivery and the medication reminder service are essential for them.

Chapter 5 Findings

Duan: Medication injection.... The doctor used to call to remind me but now they don't call to remind me. However, the doctor from psychiatric hospital, x [the psychiatric hospital staff member's name] visits.

...

[I] want only x [the psychiatric hospital staff member's name who visited that day] to come to inject me with medication at my house.

BK: You want the doctor [the psychiatric hospital staff members] to bring medication to inject you at home?

Duan: Yes, I want the doctor [the psychiatric hospital staff members which is not necessarily to be a medical doctor] to come to my house.

BK: Um... because?

Duan: I don't need to go out and spend money... spending for transportation 40 Baht for return [80 pence]. Like, venerable father gives me 80 Baht [1.60 GBP], so I got 40 Baht remaining.

Duan (female patient, 42 years old)

From the participant's perspectives, community medication is crucial for schizophrenia care. One participant mentioned that he wanted the THPH staff to deliver the antipsychotic medication to him in the community.

Jirasak: Looking after the medication is better.

BK: How [do you want them] to look after it?

Jirasak: Deliver medication every month.

Jirasak (male patient, 44 years old)

5.4.3.3 Sub-theme 3.3: Consultation is needed: medication, physical and sex life

Some members of the patient group expressed issues and difficulties relating to the issues of physical health, sex life and antipsychotic medication, about which some of them said they needed consultations.

It appeared that not only schizophrenia, but also physical health considerations, could affect participants' ability to work. Although the participants did not openly express the need for consultation regarding physical health and working, the participants' words show their doubt and worry.

'However now, I have hypertension and stopped working for a week. I have palpitated. I am always allergic to spraying insecticide. I'm not sure that I can do this (in the future). I will try to do it.'

Eak (male patient, 40 years old)

In the Thai culture, it seemed that talking about one's sex-life is awkward and shaming. This is because people who talk about their sex-life will be recognised in the negative way, such as having sexual-addiction and/or psychosis. It appeared that this belief affected participants' perceptions regarding issues and questions relating to their sex-lives, but there was no one to ask for information or to easily discuss these sensitive matters with.

'May it be related to sex? I don't know...but I'm normal...but it may be not like other guys or not...I don't know. She's a woman (his wife). I don't understand her'.

...Like I told you, we, probably, cannot stay together. It's like (we) don't understand each other. I don't understand women because (when I was a child) I wasn't staying with my mom.

Natchapon (male patient, 41 years old)

Chapter 5 Findings

All participants had taken oral antipsychotic medication and some of them had to cope with the medication's side effects. Some participants did not mention about their medication's side effects straight away but talked about the impact of antipsychotic medication, which appeared to have an effect on the participants' bodies and minds. One participant expressed about how gaining weight upset her.

'It makes me feel irritable when gaining weight'.

Duan (female patient, 42 years old)

Some participants intended to seek a consultation about their medication because they thought it is important.

I would like to go to Fah-Sai Clinic [a clinic for drug addicts] sometimes; that is the clinic in the hospital, which is called Fah-Sai Clinic, at the [community] hospital. I want to talk with them (about medication taking) before sleeping and eating time. Sometimes, I took medication before having a meal. Taking medication before meals, maybe I don't want to dream alone.

Jirasak (male patient, 44 years old)

It appeared that living in the community setting seemed to be difficult for the patients with schizophrenia. Almost all patients were unemployed and non-socialising, because they seemed to have paranoid symptoms and low self-esteem. Although being dependent is acceptable for the Thai mental health disabilities, some patients started to worry about their future. Moreover, the patients needed more physical and mental health information, as well as a supportive and empathetic environment. From the patients' perspectives, the THPHs could provide better treatment by providing a one-stop service.

5.4.3.4 Sub-theme 3.4: Enhancing medication adherence via a referral line and network

The majority of health professionals expressed how they endeavoured to improve the patient's oral medication adherence, while the patient was living in the community. A medication delivery service, medication monitoring and health education were suggested as options for enhancing medication adherence in rural Thai communities. Medication delivery in the community, collaborating with the village health volunteers (VHVs) for medication monitoring, and transportation support from the sub-district administrative organisation (SAO⁴), were all mentioned as means of supporting medication adherence. Hence, delivering the patient's prescribed medication through the THPHs and network was viewed as an effective medication management option.

'After we met the network: the THPH staff. They could help. It is the network. It is like sometimes we have so many clinical workloads but short of staff. Therefore, we use the THPH staff as our legs. They will look after the patients in the community for us. For example, the case that...in this district (the service users) have problems with travelling (to the hospital for receiving care). Here is quite far and then the patients cannot come. Recently, we are open for the THPH staff. They could come to collect medication for the patients'.

Aroon (female supervisor, 39 years old)

Using the THPH staff to support the caregiver medication management could improve medication adherence; however, a lack of health professionals able to carry out this role seemed to be a limitation. Some health professionals expressed that the VHVs play an important role in enhancing oral medication adherence. Hence, assigning the VHVs to deliver medication, and to follow up

⁴ Sub-district administrative organisation (SAO) is the government organisation which focuses on improving community infrastructures at the sub-district level. This organisation is not providing health service.

Chapter 5 Findings

medication adherence, appeared to be crucial for some communities. This is because the VHVs often live quite close to the patients and caregivers, and they speak the same language. This means that the VHVs are community residents who may have similar socio-economic levels as the service users. Moreover, the VHVs speak the local accents and dialects, and they are unlikely use any technical jargon. Therefore, this could allow the VHVs to better communicate with the service users, than could the health professionals. Hence, the VHVs would understand the patients and caregivers, whereas the health professionals might not. Therefore, the service users could benefit from this strategy, because travelling from the service user's houses to the psychiatric hospital appeared to be the main problem for hospital service accessibility. In addition, 'the service plan' was launched with the purpose of enhancing service accessibility and receiving continuity of care. The policy aims to enable the medication service via a referral line; hence involving the SAOs, in order to resolve travel limitation, would appear to be an idea worthy of support (Thai Ministry of Public Health 2013). In addition, this policy also supports the availability of medication in the community, regarding continuity of medication prescriptions.

'Delivering medication to the THPHs and then the THPHs will manage medication to the VHVs. The VHVs will deliver medication to the patients. It is working like DOT TB. It is like TB patients who need to be monitored regarding their medication taking. The VHVs have the duty to check on them in the morning, lunch and evening time. It has the VHVs responsible for visiting the patients. ...My role is only prescribing medication and sending it to the THPHs. The VHVs will distribute medication for the patients. In the cases that the patients have to go to the provincial hospital, we manage to send the patients to go there by using the SAOs. If there is not an emergency case, the SAOs staff would come to collect prescribed medication for the patients'.

Tidarat (female supervisor, 37 years old)

In addition, the THPH staff talked about building rapport with the service users, which could help to improve medication adherence.

'Earlier, it was challenging because we (the THPH staff and the service users) were not familiar to each other. After familiarising with each other, we are like siblings. It is like the first time they (the service users) did not want me to see the (prescribed) medication. I found out (the prescribed medication) by myself (and then I said) 'Oh, medication! Why are they still here?'. However, when (the relationship) is good, the relatives will come to me and talk'.

Samorn (female THPH staff, 40 years old)

It appeared that having a good relationship with the service users allowed the THPH staff to understand an individual's reasons for not taking medication; it seemed that the medication's side effects could cause non-adherence. For example, the patients did not want to take their prescribed medication because they could not work due to feeling drowsy. Therefore, the THPH staff mentioned that providing health education for the caregivers was crucial.

'For the caregivers, let them have knowledge about medication. They want to observe the medication's side effects because some medications can cause salivating, drowsiness and stumbling, something like that. We have to know and let them (the caregivers) know what the medications' side effects are. However, if it is like this all the time, they have to go back to see the doctors. (The patients complaint that) taking this (a type of medication) and then it is like this: cannot do anything, drowsy all the time or always salivating (and have) dry mouth, something like that'.

Worakorn (female THPH staff, 53 years old)

It appeared that although the health professionals felt that there was a shortage of health professionals to manage community mental health care, the process of delivering prescribed medication, medication management and medication monitoring in the community seemed to be manageable. However, the idea of collaboration between multi organisations and groups of people

was included to enhance care, regarding the enhancement of medication adherence and support for the service users.

5.5 Area 3: Service and support needs

This area showed the different points of view, from the three participant groups, towards schizophrenia care improvement. This area will expand on how the Buddhist belief and Krong Jai, the specific Thai culture, could affect help-seeking behaviour in the caregiver group. The lack of a health professional workforce in the primary care setting appeared to be the main limitation for schizophrenia care provision. Moreover, the primary care staff themselves felt that they lacked the necessary levels of knowledge and skills to provide the care. Therefore, these concerns should be discussed in the national health policy.

5.5.1 Theme 1: Experiences of current service

The caregivers and health professionals mentioned the coping strategies and support they have been using for relieving their suffering and troubles. It appeared that participants used different coping strategies after facing negative experiences whilst providing care for patients with schizophrenia. Participants used both self-help coping strategies and seeking help from different sources. This theme comprises of four sub-themes, namely, i) unmet needs, ii) primary care staff role in medication concordance, iii) the impact of attitudes, knowledge and skill, and iv) improving service user's faith in the primary care staff.

5.5.1.1 Sub-theme 1.1: Unmet needs

It appeared that there were some caregivers who did not receive the support they needed. One participant expressed her disappointment about impractical suggestions she received from health care staff. Her expression seemed to reveal the process of her help-seeking, disappointment and hopelessness.

'The doctor(s) said 'let him truly hit you before admitting him'. The doctor said like this, so I was hopeless. The doctor(s) said 'don't give him money then'. The doctor(s) can say that but the one who does that, actually, cannot do. Cannot

do it because he is obliging me to give him money. How can I stop giving him money? He will truly hit me. I'm not kidding. If he hit me, I couldn't work. I'm the only one who has duties to take responsibility (the whole family). Duty, the word 'duty'. It's hopeless. Talking to the doctors they did not admit (the patient)'.

Natcha (female caregiver, 54 years old)

Some caregivers felt awkward when talking about the schizophrenia care service that they received. This may be because it is difficult for Thai people to comment on health professionals regarding the quality of care. Therefore, this respectful attitude might cause the participant to feel awkward about making negative comments about the health professionals. One participant avoided making, especially negative, comments about schizophrenia care at the primary care level. For example, although Pakawit (male caregiver, 52 years old) seemed not to be satisfied with the care at the THPH, he chose to laugh and avoid responding to the question.

BK: The THPH (the name of THPH) ... What do you think about their (quality of) working like sometimes they didn't come to visit?

Pakawit: Um...I don't know how to answer (laugh).

Pakawit (male caregiver, 52 years old)

5.5.1.2 Sub-theme 1.2: Primary care staff role in medication concordance

The majority of caregivers felt satisfied with the schizophrenia care that they received at the primary care level. One participant compared schizophrenia care at the primary care and secondary care levels. He preferred the primary care level because the THPH staff provided information he would like to know.

'Yes. I thought it is good. (The two of the THPH's names), both of them are ok. It's better than the hospital because hospital (staff) do not care about us no

Chapter 5 Findings

matter what. Comparing the THPH and the community hospital. I would recommend other people to go to THPH because the THPH here is better than the hospital. Talking to the hospital (staff) is difficult (because they separate in groups. I have many friends (working) there. Difficult to talk (with the hospital staff).

... Mostly here (the THPH) is specific, we can consult them (and) contact them. This one (the community hospital) we go to the hospital we don't talk anymore. It's done. You went there (the community hospital) for whatever reasons (but they refused that 'you should go back home first, I will ask the doctors for you (later)').

Sorrayut (male caregiver, 37 years old)

Some caregivers felt they had received good schizophrenia care, including medication collaboration and management. One participant suggested having good collaboration between the psychiatric hospital and the THPH, regarding the transfer of medication from the psychiatric hospital to the THPH.

I think 'let the psychiatric hospital contact the THPH frequently', something like that. Then, send medication on time.

Pakawai (male caregiver, 52 years old)

One participant expressed her admiration for the THPH staff regarding them being great medication collaborators. The psychiatric hospital and the THPH staff were working quite well in her opinion because she found improvement in her son's psychotic symptoms.

Since there (the THPH) have oral and injected medication, the doctors gave us medication, (the patient with schizophrenia) getting well like this. They provide great help already. I don't want them to help in anything.

...They are helpful already. The doctors there (at the psychiatric hospital) sent medication (to the THPH), so they (the THPH staff) rang (me). It's time for medication injection, they (the THPH staff) rang me (and told me) the date.

Baitoey (female caregiver, 61 years old)

5.5.1.3 Sub-theme 1.3: The impacts of attitudes, knowledge and skill

All of the health professionals discussed the current situation they have seen regarding attitudes, knowledge and skills associated with schizophrenia care. The majority of the THPH staff expressed that they have been thinking about being physically harmed by patients with schizophrenia, during a patient's episode of recurrent psychotic symptoms. In fact, during the interview period, there was news about health professionals being killed by people whose mental illness caused them to become extremely violent. This news may well negatively affect the health professionals' attitudes towards schizophrenia care regarding safety.

'The weak point is about case visiting. Sometimes, it is... It is like, if the VHV was not available, I was also not available to go (to visit the patient) too. It is because I am a woman. If I go (to the patient's house) alone, it is like... If asked (me that) if the patient's (psychotic) symptoms are controllable? However, I do have to safeguard myself (Chailai) meant she needed to make sure that she is safe during visiting the patient with schizophrenia.). ...If I go out (to visit the patient) and it is in the late evening, it would be dangerous for us. It will be a problem in terms of safety'.

Chailai (female THPH staff, 34 years old)

In the supervisory team's opinion, it appeared that the supervisors expected the THPH staff to have positive attitudes towards psychiatric care provision, to be capable of educating the VHVs, and to be able to manage community mental health care efficiently. It was felt that when the THPH staff have positive attitudes towards community mental health care, they would be able to manage the care effectively. Some supervisors used the word 'having mind' to

Chapter 5 Findings

do the job. Being interested to provide community mental health care, the THPH staff would improve their knowledge and skills to manage the care more effectively. This may include collaborating with the VHVs in order to enhance the medication service and to make home visits in the community. In the participants' opinions attitudes, knowledge and skill could affect each other. For example, one supervisor discussed the idea of educating the THPH staff in order to improve their attitudes.

Sanchai: 'The big problem is attitude'.

BK: 'Attitude of whom? Everyone?'

Sanchai: 'Yes. Before starting working together, we have to understand the health professional's attitudes towards the patients. This is because the health professionals we are working with are still negative or (they) do not understand (the patients). Hence, they cannot work or, otherwise, we have to work by ourselves. However, in fact, we do not have the workforce to do that. If our representatives do not have the same attitude as us, they are not the representatives. Can you see (the point)? Hence, the first thing that we have to do is to work out how to improve their (the THPH staff) attitudes. How to improve their attitudes? What we found here was they do not know. Do not know and do not understand about abnormality of psychiatric diseases or they just know superficially or get it wrong. Therefore, we could change their attitudes by educating them first'.

Sanchai (male supervisor, 56 years old)

In addition, it seems that there is not only a problem with attitudes towards the patients but also the THPH staff themselves. In fact, most of the workforce in the primary care level are the certificated public health workers who may feel lower self-confidence if they compare themselves with other levels of health professionals. One supervisor felt that, although the THPH staff may be in lowest level of the health professional hierarchy, they are important. The supervisor raised the point that occupational value in Thai society seemed to affect the THPH staff's self-value and confidence to provide the community mental health care service. Therefore, the THPH staff should be proud of

themselves and their jobs. Thus, improving self-value may help to build positive attitudes and confidence for the THPH staff.

BK: How about the THPH staff? Are there any other factors than knowledge for providing schizophrenia care?

Sanchai: Acceptance. Accepting that this job has its own pride which it's...it's not only in the public health society. It is about attitude which I don't know how this gets established. For example, we see a doctor, Wow! We salute, right?

Sanchai (male supervisor, 56 years old)

It was felt that a possible cause of ineffective community mental health care provision was the lack of knowledge and confidence needed to provide appropriate community mental health care. One THPH staff suggested that the THPH staff should have knowledge about patient assessment and medications' side effects, as basic knowledge for schizophrenia care provision at the primary care level.

'At least (the THPH staff) should be capable to assess the prognosis of the diseases (by using) 2Q, 9Q, 8Q. They should be capable to use tools to manage the psychiatric patients. (For example), the patients reached this level (the THPH staff) have to... Err...hearing voices (and) hallucination, these are the symptoms which relatives cannot control and have to send (the patients) to see the doctors'.

Krit (male THPH staff, 45 years old)

Moreover, some supervisors discussed the need for THPH staff to have health education and management skills regarding the VHV training. Therefore, the VHVs could assist them regarding early relapse detection. For example, one participant realised that the referral system would work well if the THPH staff educated the VHVs regarding detecting the emergency cases in the community, and then referring the cases to the THPHs.

Chapter 5 Findings

'...My expectation from the THPH staff is just that they know (schizophrenia) symptoms; have a quick referral system and being cautious about the emergency psychiatric cases. Quick detection (could be done) by using the VHV's because they are closer (to the patients). This is because we knew their (the THPH staff) context that they could not do regular home visits for every case. (I am) trying to tell them (the THPH staff) to build the network, especially with the VHV's (and) educating them. Then, they could refer the patients to the THPH; therefore the THPH could refer the patients to us via telephone [Somsiri; the THPH staff could report the case information via telephone]'.

Somsiri (female supervisor, 41 years old)

5.5.1.4 Sub-theme 1.4: Improving service users' faith in the primary care staff

The supervisors expressed how they felt that the service users' faith in the capability of primary care service for schizophrenia care provision could gain the patients' and caregivers' trust, and receive continuity of care. Faith in this context means the belief that the THPH staff could handle the patient with care; such as medication management and its side effects and relapse detection. They felt that the THPH staff might lack knowledge about schizophrenia, medication and medications' side effects, as well as home visiting skills. Improving these skills for the THPH staff appeared to be one of the participants' roles. Therefore, this is not only improving the THPH staff's capability, but also the patients' and caregivers' faith in the competence of the THPH personnel.

'If the patients could not hire a car to the hospital, the THPH staff would be frustrated. It's like building faith in them (the THPH staff). For example, they (the patients) have EPS and then the THPH staff could treat them until they (the patients) recover. They (the patients) would have faith (in the THPH staff). It's not just having faith in us (health professionals from the hospitals). It is sharing faith. The THPH staff would also feel great and would like to work on other cases. It's a psychological (tip)'.

Jarunee (female supervisor, 48 years old)

Similarly, one participant suggested that the public health staff should have knowledge about community mental health care, prior to working at the THPHs.

'All staff who work in that place including public health staff and nurses. However, nurses have a course (for community mental health care) but the public health staff do not. They (the public health students) just study a little bit of psychology. I think the persons working at the THPHs should know.

... They (the public health staff) may say that they don't know about the disease, how to do home visit, medication and side effects. Therefore, (community mental health) training after graduation is not enough. They have to have knowledge before'.

Kamlai (female supervisor, 53 years old)

It appeared that the capability of the THPH staff for schizophrenia care provision could be a fact for continuity of care provision. To improve this, community mental health training appeared to be crucial.

5.5.2 Theme 2: Thai cultures and beliefs

Culture and religious beliefs appeared to play an important role in schizophrenia care at the sub-district level in the rural Thai community. The two sub-themes emerged from the data of the caregiver and the health professional participant groups, and were merged into a single sub-theme: caregivers' beliefs inform the care and coping patterns.

5.5.2.1 Sub-theme 2.1: Caregivers' beliefs inform the care and coping patterns

Some of the caregiver participants mentioned several self-help coping strategies which they were using to help relieve their burden. Examples of the strategies include accepting the bad things as their own fault (accepting their sin or bad karma), being patient, 'change from fear to sympathy', and doing good karma (gaining merit or doing good things).

Chapter 5 Findings

Accepting all negative things to be their own fault appeared to be a coping strategy for some Buddhist participants. From these discussions, it can be seen how much they have to suppress their fear, trauma and, perhaps, burnout feelings inside their minds. Therefore accepting their suffering and burdensome emotions, by relying on Buddhist principles, might be the way to help to calm some of the participants. For example, one caregiver reported that she tried to be patient; she compromised where possible and pampered her son. This is because she believed all bad things happened to her because of her bad karma (bad karma in Buddhist belief usually refers to sin which could be in the past and current life) which she must confess. This may be because some Buddhists in Thailand believe that people cannot avoid the effects of their sin. Therefore, cleansing sin may be done by accepting a burden and doing good things.

'(Please) don't let him bully me. Err... In the past, (I) cried all days and nights. Err... Would (I) die because of my children? Sometimes, (my son who has a diagnosis with schizophrenia) used the knife to point at my neck. It's time to die, so just die. People would know that my son is not normal. It's much like that. I can eat only rice with fish sauce, but (the patient's name), I wish he could eat until full. He got sick with this disease. I pamper my son. No matter how old or dirty his clothes are, I have to wash and iron them for him to wear. I won't let it smell because I'm afraid that other people would blame him. He is smelly. He takes shower but just taking. It's not clean but I just let him. What can I do? It's my own karma'.

Namtip (female caregiver, 70 years old)

It seemed that the caregivers tried to cope by accepting all negative things that happened to their life and suppress their negative feelings inside their mind. One participant has the same feeling when she has to control her mind to accept what is happening to her and fight with her own negative feelings. From her expression, it could be seen that she felt hopeless; however she has to carry on with her life because she seemed to be the family's main pillar.

Life is always like this. Sometimes, I couldn't stop my thoughts. Caring for a psychiatric patient is difficult (because) I have to control my consciousness. If I'm thinking too much, I would be like him (have mental health problems). So, I tried to control my mood. It's like I have to stay (normal). I have my parents and niece to take care of. (I) have to fight, isn't it? It is life, cannot stop fighting. If I fall back, it's done. Couldn't stand up again.

Natcha (female caregiver, 54 years old)

The participants provided reasons behind their patience; for example that they wanted their children with schizophrenia to stay with them instead of being admitted into the psychiatric hospital and/ or confined to the jail. Therefore, having patience regarding the patient's negative behaviour, as much as they could tolerate, was the best option to retain their loved ones at home.

'He drivelling talking with himself. I'm patient...very patient. (I) don't want my son to be admitted to the (psychiatric) hospital. I'm being patient like this. This is a mom of a person with a psychotic life, which is tiring. It's tiring...

Fon (female caregiver, 51 years old)

It could be noticed that having positive attitudes towards the patients with schizophrenia could be a good transition point for schizophrenia care in the community setting. Therefore, a 'change from fear to sympathy' strategy was suggested by a non-relative of a patient participant. It appeared that this might not only work for the caregivers of patients with schizophrenia, but also this strategy could be used for persuading other people in the community to sympathise with them; or at least try to understand their situation. Therefore, other people could be involved in schizophrenia care. The rationale behind this might be based on the nature of rural Thai people who, in general, are known to be sympathetic and supportive. For example, one participant suggested that it would be better if the 'change from fear to sympathy' technique could be used to overcome fear of patients with schizophrenia and to gain support from the community.

Chapter 5 Findings

'But this time we will change from fear, from viewing them (patients with schizophrenia) as terrifying to sympathising with them. (I want) you (to) imagine that they will be able to work. If we sympathise, it's fine. No matter what, we have to help (the patients). ...I said, actually, bringing them to treatment and coming back to take medication is not difficult. It's easy but our hearts have to work too. If having heart to do, doing whatever it would be successful. These are the most challenging patients.'

Wanchai (male caregiver, 49 years old):

From the participants' comments, it was quite obvious that some of them have quite strong beliefs in karma and its effects. Therefore, managing the inside of their mind seemed to be a good way to escape unhappiness. Doing good karma (doing good things in order to gain merits) seemed to be an optimistic solution which might be used for both caregivers and patients with schizophrenia. Considering one's own feelings, accepting things that were suggested, were ways to relieve suffering and burdensome feelings. For example, the participant who believed in good karma suggested a patient with mental health disease, who she met in the psychiatric hospital, to make more merits by doing Vipassana. Vipassana is a Buddhist practice which means seeing things as they are. She believed that Vipassana would bring happiness to the one who keeps practicing it.

(I suggested) her (a mental health patient) to do Vipassana. ... (Please) do it (because) it will refresh your mind. We will... we will get rid of suffering and bring happiness from Dharma to our hearts. I taught her.

Fon (female caregiver, 51 years old)

In contrast, it appeared that self-help coping strategies sometimes did not work for some participants; as the times when the patients with schizophrenia relapsed. Therefore, seeking support appeared to be the next strategy to relieve the participants' suffering and troubles. For formal help seeking, some participants mentioned formal help resources that they have been using;

namely the psychiatric hospital, police and other government organisations. The psychiatric hospital seemed to be the main resource that the participants sought for help. Several participants reported that compulsory treatment was one option which they chose for relieving their suffering. One participant wished she could have at least a month's break from patient care by trying to 'push' her son, who is diagnosed with schizophrenia, to be admitted to the psychiatric hospital.

'In that time, I was proceeding to bring (my son) to a foundation. (I wish my son) did not come back...did not see each other forever. I couldn't take it. I couldn't sleep. I proceeded (to bring the patient) to the psychiatric hospital. I told the doctor that 'Doctor, please admit him for a month. I really can't do this. He will kill (me)'.

Natcha (female caregiver, 54 years old)

Some participants were satisfied with schizophrenia care services that they received. However, dealing with a patient's negative behaviour, as well as referring patients with schizophrenia to an appropriate care level, might be a difficult period of time for some participants. Therefore, different points of view were revealed from the participants' comments.

5.5.3 Theme 3: Humanised and holistic care

The supervisors discussed that they felt the THPH staff could provide care better than other levels of care. It seemed that some participants would like the THPH staff to have good contacts and relationships with the service users in the community. This is because the THPHs are located in the community settings. Therefore, the concept of 'Krai ban - Krai jai' was mentioned by some participants. 'Krai ban- Krai Jai' could be translated into English as 'close to the house and close to the heart'. In the health professionals' opinions, the main concerns about schizophrenia care in the rural Thai context appeared to be about financial constraint, dehumanised care and stigmatisation. This theme comprises of four sub-themes, namely: i) poverty as a huge obstacle, ii)

Chapter 5 Findings

workforce limitation, Boon and holistic care, and iii) dehumanised human care: ‘scheduling timetable like feeding a dog’, and iv) devaluing and labelling.

5.5.3.1 Sub-theme 3.1: Poverty as a huge obstacle.

The majority of health professionals discussed how important the role of the caregiver was in terms of managing a patient’s behaviour and his or her oral medication management. However, the health professionals felt that poverty could be a huge limitation in carrying out the supportive role as a caregiver; a condition which could, for some caregivers, lead to discouragement when it came to taking care of the patients. Moreover, it appeared that poverty could affect the continuity of receiving schizophrenia treatment for some patients. It seemed that the caregivers could not afford to travel to the psychiatric hospital. This cost could be paying to take the patients to receive continuity of care, routine follow-up and hospital readmission. Moreover, they have to reduce their working, and therefore earning, hours in order to take care of the patients.

‘If we refer the patients to the community hospitals and the medication are available there... Err...it is not that because of the patients do not want to take their prescribed medication but there is no medication available, poverty and travelling is very difficult. Sometimes they hire a car to come to the psychiatric hospital. Some cases do not have bus services from their houses, so they have to pay around a thousand (baht for travelling which) actually the medication itself is just only 100 or 200 baht. Therefore, some poor patients might think they are better spending money for buying food instead of spending for medication. It is because they do not have money and they do not know where they could earn money from, so they have to borrow money (from the bank or other people). They are just not complying with medication and rather spending money to buy food. Poverty is the key factor which leads to the absence of medication and the presence of service accessibility limitations. This is the main factors for the care limitations. For the past years, I found the combination of living far away (from the hospital), poverty and having no bus

service from their houses, makes the patients not want to take their prescribed medication’.

Tawat (male supervisor, 48 years old)

Additionally, some health professionals pointed out that some caregivers might be discouraged after spending some amount of money for patient treatment, but the patients seemed not to be recovering. Furthermore, it seemed that some caregivers who have lower incomes, might feel worried about earning money for living a life. Therefore, this could affect the continuity of schizophrenia care.

Later the patients’ parents could not deal (with patient care). Therefore, they sent the patient to a psychiatric hospital 3 times. They said that they paid a lot of money (because) they asked the police to detain the patient and hired a car to take the patient to the hospital. They said that they could not deal with this (because) the patient did not take medication after coming back home. They (the parents) said that they are fed up with this. They wasted a lot of money. However, (the patient did physical) harm to the neighbours and his father. Therefore, they (the parents) locked up the patient (at home).

Poom (female supervisor, 49 years old)

‘It is because they (the service users) have problem with economic issues. This happens quite a lot. It is because most of them are not of good economic status. Therefore, renting for a car is... (It depends on) do they (the patients with schizophrenia) have (psychotic) symptoms (or not)? If yes they do not need to pay money. However, if (they have no psychotic symptoms) they need to pay’.

Busaba (female THPH staff, 46 years old)

Some health professionals felt that poverty and caregiver discouragement regarding wasting money for schizophrenia care, could lead to the

Chapter 5 Findings

discontinuity of receiving care. This was viewed as leading to poor schizophrenia prognosis and recurrence of psychotic symptoms. It was believed that this cycle could destroy the caregiver's hopes regarding the patient's recovery. Therefore, after some caregivers found taking patients to receive the care might not be helpful, the caregivers refused to take the patients for treatment and managed the patients in their own way, in their community.

5.5.3.2 Sub-theme 2.2: Workforce limitation, Boon and holistic care.

It appears that there are workforce limitations of community mental health care in the rural settings. Hence, improving the effectiveness of the referral system is crucial. The majority of supervisors mentioned the importance of enabling the THPHs to be able to provide community mental health care, but recognised the challenges involved. Some participants mentioned that there were resource limitations for community mental health care, regarding secondary and primary care levels. Therefore, some participants have had to take the role as schizophrenia care collaborator, in a voluntary capacity during non-working hours; such as in the night time. For example, one participant expressed the reasons for the 24 hours on call and supervisor roles interestingly. She linked hard working and volunteering as having 'Boon' (why not boon?) which could be translated as 'merit' in the English language.

'Mostly, I am 24 hours on call (on my) mobile phone. It's nothing. It's like gaining merit. But I am happy. It's a simple concept that 'one minute we can sleep vs. they (the service users) can survive. It's interesting to do (this job). I'm just not sleeping. My husband understands and he lets me do whatever I would like to do (laughs). I told him that I have to manage my family well, and then I can do this job. However, my family has no problem'.

Somsiri (female supervisor, 41 years old)

It appeared that some staff volunteered to do extra work, which they linked to the Buddhist concept of 'Boon'. However, it seemed that not every staff member could do this because of other personal commitments. Similarly, the majority of the THPH staff reported having high volume workloads, difficulties

in providing care in remote areas and limited numbers of staff; all of which could reduce their availability to provide schizophrenia care.

'For weak points, I think it's like only me alone. Sometimes, I have other jobs to do. For example, I can regularly do home visiting for the cases that need medical injection. However, the other patients will be visited by VHV's. Actually, I wish to visit them at least once a year. It would be good, if I could visit them more regularly than that. This is because there are some patients who are not close to us'.

Atitaya (female THPH staff, 43 years old)

Some THPH staff felt that having a too heavy workload affected the quality of their work, which they described as of 'superficial' quality instead of 'in-depth' quality of care.

'Is it too much responsibility for the nurse staff? It is like (the nurse staff) have to be responsible for every job: NCD (non-communicable diseases), mental health and elderly care, something like that. Too much responsibility, too many jobs. Actually, responsible for many jobs, (working for) every job is only superficial. It is not in-depth; quality of service is affected'.

Worakorn (female THPH staff, 53 years old)

Although all of the THPH staff agreed that they have many jobs to do, some of them seemed to have turned difficulties to opportunity, in order to gain 'Boon'.

Chapter 5 Findings

Krit: (If) the relatives did not (take care of patients), we have to go (to see the patients). I have to look at many factors; not only physical (health).

BK: So, what do you think about being a collaborator between the patients, the caregivers and others.

Krit: Err...I think it is making Boon. It is making Boon and I would like to say that... I would like to give the view of a government officer who is not working for just doing the jobs but working for quality and effectiveness. It is like we do our best and accept the results. We have to do it best, do it to be worth for our salaries. That is enough. We are happy with that and I thought people who work for the Ministry of Public Health are working and making Boon (at the same time).

Krit (male THPH staff, 45 years old)

Similarly, one THPH staff talked about her dilemma towards her mental health care provision.

'Sometimes I felt that I was making Boon. Sometimes I felt that why I have to work (in this job)? It is so tiring, something like that. Sometimes I felt discouraged when a lot of them (the service users) were coming (to receive the care at the THPH). It has two things both good and bad (laughs). Sometimes it was like I do not want to get involved. Sometimes I felt...Err...they (the patients) are getting better or having an accommodation [having a place to stay]. It is like I made Boon'.

Noon (female THPH staff, 41 years old)

From the supervisory team's perspective, the majority of supervisors seemed to understand that the THPH staff had high volume workloads; the supervisors suggested integrating physical and mental health care with home visits as a way to resolve the problem. Therefore, the holistic approach was recommended by the majority of participants. This means that the THPH staff

should provide physical and mental health care for a person in parallel, instead of seeing a person's physical and mental health separately.

'The THPH system, if we think about the reality and workload. If possible, I would like the THPH staff to integrate jobs. I understand their roles and workloads. ...I would like the THPH staff to change their attitudes of working. It is like we have to explain the details for the new staff at the first time of working. It is about working systematically.'

Somsiri (female supervisor, 41 years old)

It appeared that although the participants realised that the THPH staff have high volumes of workload, they thought this seemed to be manageable. Integrating jobs and using the holistic care concept could be helpful for the THPH staff.

5.5.3.3 Sub-theme 3.2: Dehumanised human care: 'scheduling timetable like feeding a dog'

The supervisors discussed how they felt when some caregivers thought that the patients would probably not recover, and then the caregivers might treat the patient differently. Hence, the humanised care concept was raised as the most important thing by some health professionals. It was felt that caring for an individual with schizophrenia should involve both love and care, by considering the patient's body and mind. For example, one supervisor felt that providing care as a form of duty was not helpful. She compared dehumanised care with feeding a dog; in the rural Thai context, 'dogs' could be used to refer to a lower level or quality of responding to something without care.

'Appropriate...like it has a case at (a community name). The patient's relatives are around the patient's house. (Everybody) in the five relative's houses, told that 'doctor (Jarunee: a mental health nurse), could you set a timetable for me? Which day that you want me to take care (of the patient)? You could not assign only me to look after (the patient) because the other one is also the patient's sibling.' It is like...If I managed like this (scheduling the timetable for the

Chapter 5 Findings

patient's relatives), it is not O.K. We could evaluate that it is like taking care (of something) without life. There is no life at all. It's like bringing food to feed a dog, and bringing medication (for the patient) to take without touching and relationship. Our case (the patient) still has a life. If doing like this, it is not O.K.'.

Jarunee (female supervisor, 48 years old)

Similarly, one supervisor also mentioned that some caregivers might feel discouraged after taking care of a patient for a long time.

'We already knew that the patients with schizophrenia are chronic and the care is complicated. Hence, it is difficult for the caregivers to take care (of the patients). In some cases, the caregivers have been caring for a patient for 20-30 years. Therefore, the caregivers suffer burnout when it comes to caring for the patients. From my experience, I found this quite a lot. Therefore...Err...in some cases...Err... Let them (the patients) die (because) they (the caregivers) do not want to take care. It is because they themselves (the caregivers themselves) could not cope'.

Tawat (male supervisor, 48 years old)

This might refer to lacking hope for the patients' recovery. It was reported by one of the health professionals that some caregivers decided to lock the patients in their houses; one reason being a fear of violence. One participant explained the situation that she experienced:

'The mental health clinic here was opened in 2002. It was around the year 2004. Here (in this community) there is a lot of restraining and limiting (the mentally ill). However, we could not admit the patients after unlocking them because the patient's relatives were afraid to going out of the house. Therefore, the patient's relatives still restrain or lock up the patients like before. They restrain (the mentally ill) forever. I visit those houses. There were

like a private house where they built a room or corral (คอก) for (the mentally ill) to stay. The room (or corral) was locked at all times. They (the patient's relatives) served (food) with disposable plates and didn't want them back because of fear to bring them back. (The mentally ill were) eating, pooing and peeing in the same place'.

Jarunee (female supervisor, 48 years old)

It appeared that the health professionals could see the point when the caregivers felt fed up after the long period of managing schizophrenia care. As a result, some caregivers decided to lock up or restrain the patients instead of taking the patients to receive continuity of care. It was felt that this might be a more complicated challenge to resolve than the issues of poverty and lacking any hope for a patient's recovery.

5.5.3.4 Sub-theme 3.3: Devaluing and labelling

Managing the patients to re-enter the community often seemed to be challenging for the health professionals. One of the obstacles seemed to be social stigmatisation, an issue which was raised by some participants. This appeared to be because people in the community often labelled patients as a 'mad person', instead of the person they knew before having a diagnosis of schizophrenia. One participant felt this could affect both patients and caregivers psychologically.

Um...need? This is what we are not frequently asking them. However, the most important thing is the need for acceptance. In the case that I have met, the patient's parents told me that 'they (other people) usually said that my children are mad'. They (the patient's parents) needed the society to accept the patient. It is like more valuing them (the patients) because they have a life or they are a person too. They are valuable. They would like to have a good life but they could not choose. Err...They need the society to be careful about their words. Do not criticise. This is because if this is not happening to them (other people), they would not know. The patients may not suffer because they may not know.

Chapter 5 Findings

The ones who know are the patient's relatives, who seem to suffer more than the patients.

Somsiri (female supervisor, 41 years old)

Similarly, the THPH staff perceived that people in the community did not want to bring the patients back into the community. It seemed that society had labelled the patients as 'rubbish' because of having schizophrenia, regardless of whether the patient recovers or still has mental health problems.

(The patients with schizophrenia) are still rubbish. This is rubbish like there is black colour spill on, so there is still black stain. After washing, it is still stained. For example, Anuman (male patient, 59 years old) could work. They (other people) still view (the patients) the same (as a person who always has recurrence of psychotic symptoms). He went to apply for a job (and the employer knew that he) is an old mental health patient (Krit meant Anuman has history of mental health disease). He (the employer) knew that (the patient) is getting better. He did not accept (the patient to work). (The patient said that) 'He did not accept me because I used to be a psychiatric patient'.

Krit (male THPH staff, 45 years old)

Furthermore, it was felt that having chronic schizophrenia would cause the patients to have lower self-esteem due to losing social functioning and self-control. Therefore, the patients seemed to hide themselves from the society due to embarrassment. One supervisor thought that social exclusion and devaluing people with schizophrenia often developed from other people, including patient's relatives and caregivers, because of their lack of knowledge. Hence, it was felt that the patients were devalued not only by the society but also their relatives. The supervisor believed that this could exclude the patients from society and eventually might limit the patient's social functioning.

'They (the patients) still have lesions of schizophrenia, and then when they (the patients) are going out they are not accepted by society, community and

the villagers. Err...when people see the patients, they turn their faces away. They (other villagers) do not care, disdain and do not talk with the patients as usual. It is like he is a person but he is not being accepted as a usual person. Hence, he does not want to go out. When I sent the patients back to the communities, I saw the patients very glad to greet others. However, the way that other people greeting and talking to them seemed like they are not human. There is not equality. (Other people) see them like very lower level. It makes them being like this. They have to face this which makes them continuously step back. Moreover, (the patients have) chronic illness, not taking medication regularly and nobody taking them out for socialising. Or... (for example) they have no right to walk in the market or eat out. It is like the relatives will limit the patient's behaviours when seeing them gulping. (For example) if the patients would like to have noodle, they would buy take away for them. It is like people around the patients always limit the patient's rights. Other people around them do not understand them too'.

Kamlai (female supervisor, 53 years old)

They (the patient's caregiver) told me that 'It is not because I do not like you. I like when you come to visit but I arrange to go to the (private) clinic. I arrange to go for another psychiatric care service because I do not want anyone to know that my children have (a diagnosis of schizophrenia)'.

Busaba (female THPH staff, 46 years old)

After having a diagnosis of schizophrenia, the patients seem to be devalued, which could affect their confidence to go out and socialise. It seemed that stigmatisation could come from both the society and the patient's relatives. This may be because the patient's relatives seemed to feel embarrassed to have an individual with schizophrenia in the family. Therefore, the health professionals perceived that this appeared to limit the patients from merging back into their communities because of negative labelling and devaluation.

5.5.4 Theme 4: Recommendations

This theme involved recommendations for schizophrenia care improvement from the caregiver and health professional groups. Although schizophrenia care appears to be available in several THPHs, the participants felt that many aspects of service improvements are needed. It seemed that different supervisors recommended schizophrenia care improvement according to their experiences, qualifications, job positions and level of care where they worked. For example, a psychiatrist who is in the 'elite' job category made suggestions relating to national policy improvements, compared to the supervisors from the community hospitals who focused more on service delivery and care. Moreover, the qualified mental health nurse specialists, from the community hospitals, concentrated on the need for more holistic care and humanised human care, if compared with the other supervisory team members. The recommendations theme consists of four sub-themes, namely: i) recommendations for service improvement, ii) community mental health care governance, iii) the need to have an effective referral system, and iv) support for service users through medication delivery, financial help and rehabilitation.

5.5.4.1 Sub-theme 4.1: Recommendations for service improvement

The caregiver participant group provided recommendations for schizophrenia care; implement health education, stop using police for compulsory care, finding new schizophrenia cases and treating them, reducing the referral process and schedule regular patient follow up.

Health education for the patients' caregivers and other people in the community seemed to be essential for schizophrenia care at the primary level. This may be because, when people have more information and understand about schizophrenia, they could change their attitudes and approaches to the patients. For example, one participant explained an example of community preparation regarding how to approach the patients with schizophrenia.

'Before (the patient with schizophrenia) is coming back (to the community), the whole community will be a group. Circle (Wanchai meant selecting) on people who stay in this home and that home, then take them to talk. Like, when (the patient with schizophrenia) comes back (to stay in the community), don't be

rude to her (and) don't call her 'crazy'. We have to talk with her nicely. (The head of community mental health department's name) taught us to talk politely, call her nicely, such as, 'have you eaten?' Don't be compulsive to her to take medication'.

Wanchai (male caregiver, 49 years old)

Stop using the police for compulsory care seemed to be an effective solution for schizophrenia care in the primary care level. However, preventing relapses and promoting recovery seemed to be the best way to avoid using violence as well as bringing patients with schizophrenia back to 'normality'. For example, one participant who suggested this strategy seemed to disagree with compulsory treatment for patients with schizophrenia. However, it was quite obvious that he supported medication adherence, which he believed could prevent relapse in the long term.

It's like we continue doing like this. Detaining and sending (the patients) to the police, the police sending (the patients) to the doctors, the doctors sending (the patients) home: it's not recovery. Therefore, we have to cut the cycle by no more catching and sending (the patient) to the police (but) taking the caregivers...patient's relatives to sit and talk. It's like this time we will manage to take the patients to treat. After finishing treatment, taking them (patients with schizophrenia) back (home) you (the patient's caregivers) have to support, like, have to ensure the patient takes their oral medication, after meal have to take medication something like that but don't stop taking medication. (If the patients are) withdrawn (the caregivers should) notice. We don't need to study medicine something like that. If we are general people, how to observe them (patients with schizophrenia) is... Do you see? They (patients with schizophrenia) are usually smelly, their hair are fluffy, holding a lot of things. That's their disease.Giving (patients with schizophrenia) medication, giving them to take, giving them to take, when they take at some point, they will be a normal person (and) when they are normal, then they may think to take shower and dress up. ...If it's being like this, we don't have to catch and send (the patients). It's not a burdensome for the police, the doctors and community.

Wanchai (male caregiver, 49 years old)

Chapter 5 Findings

Finding the new schizophrenia cases in the community setting, and then treating them, was raised by one of the participants. This job could be done by the village health volunteer (VHV) teams. The rationale behind this was about getting the patients to be treated and preventing violence when the patients were having psychotic symptoms. Therefore, finding the new schizophrenia cases should help to stop violence in the community in the long term.

'The doctors (the health professionals) have created a new group. It's how to seek for psychiatric patients in this sub-district in terms of how to do it. There's a lot of VHVs. Creating VHV teams which it's like 5 VHVs in each village.

...Seeking for how many psychiatric patients have paranoid symptoms and might harm or trouble other people'.

Wanchai (male caregiver, 49 years old)

Simplifying the referral process was a particular concern, as it was felt that having complex and long waiting times for referrals was burdensome to both the caregiver and patient. However, the referral system seemed to be the most important process for poor people, who use the universal coverage care cards. Therefore, following the referral system seemed to be an unavoidable process; otherwise the patients have to be responsible for all treatment expenses. One participant complained about the referral process to the psychiatric hospital, as experienced by her son. She wished the THPH could have authority to refer the patients with schizophrenia directly to the psychiatric hospital, instead of going through the community hospital; a process she thought was exhausting.

It's like they (the THPH staff) can refer (the patients with schizophrenia) straight away. This will be quick. The patients would not suffer.

... It should have a point to have psychiatric department and have an express way. I thought it will not suffer. I used to be like this before. I am the Chatchai's parent. Chatchai (male patient, 23 years old) was ill. I have to walk to that place and this place. Oh! ...It was tiring. I have to go. (Being) patient, patient, patient. My son also has to go (to the psychiatric hospital). (Having)

patience, patience, patience for waiting. (The staff told me that) 'It will be tomorrow (that we will send your son to the psychiatric hospital)'. My son was having psychotic symptoms).

Fon (female caregiver, 51 years old)

Two participants felt that more patient follow-up sessions were needed. Participants who were new to schizophrenia care might not feel confident to look after the patient without health professionals' support. Information about schizophrenia care and psychotic symptom monitoring was what the carers needed. For example, although Pakawat (male caregiver, 52 years old) realised that the patient's blood checking reminder from the THPH was one aspect of schizophrenia care at the primary care level, he still suggested that he needed both THPH staff and psychiatric hospital staff doing more patient follow up.

I wish they (the THPH staff) follow-up frequently, like whether it is normal (when the patient) have a particular symptom.

Pakawat (male caregiver, 52 years old)

Pakawat was followed up by telephone interview and he still recommended that the THPH staff should improve the number and quality of patient home visits. It appeared that more attention was necessary for a new caregiver like him.

I wish they (the THPH staff) follow up their jobs, like is he (the patient with schizophrenia) getting better or not. Paying attention. I wish they (the THPH staff) care (about the patient with schizophrenia).

Pakawat (male caregiver, 52 years old)

5.5.4.2 Sub-theme 4.2: Community mental health care governance

Currently, the Thai people who have mental health problems are the concern of, and are protected by, the Mental Health Act. The Thai Mental Health Act

Chapter 5 Findings

aims to protect people who have mental health problems and other people who may be affected. This law is covering the patients' rights regarding the period of having psychotic symptoms, compulsory treatment and rehabilitation (Thai Mental Health Act 2008). However, it seemed to be ineffective in the participants' opinions. For example, one participant critically remarked:

Mental health law is for everybody both mentally ill and other people. Therefore, having the tool (mental health law), it's like we got direction. It has to manage to use the law and having influencing factors to make it work; otherwise we will have a lot of laws (Sanchai meant laws in general) in our countries that didn't work. Just for talking (laughs) [Sanchai meant having laws for showing other countries that we have laws but they didn't work in reality].

Sanchai (male supervisor, 56 years old)

In addition, the Thai health system has enough resources but, probably, it needs improved resource allocation and management. It seemed that there was a perceived problem with health care resource distribution. One supervisor shared that he felt confused about the national plan for health care resource distribution.

...What criteria do they use to allocate resources for each place? I view that this is important to allocate. Which criteria? Could it be geographic, population or what? This is not only (resources) in the public health system but also the national infrastructure. It has to be in the same direction. However, what we can see nowadays is the ones who have power can allocate it.

Sanchai (male supervisor, 56 years old)

The health professional workforce appeared to be one of the needs for schizophrenia care at the primary and secondary care levels. Some participants expressed that mental health staff were less important, if compared with other staff. Furthermore, working in the mental health field appeared to be risky regarding violence coming from the patient. Therefore, staff burnout seemed

to be one reason for the shortage of mental health workforce members. Some participants recommended the government to consider the major issue of staffing and perhaps offering monthly moral support counselling for mental health nurses at the secondary care level.

'Nowadays, I think many people value the psychiatric work but there is no... It is the government system regarding the position. They have been talking about this like there are (positions for) nurse practitioners but there is not for psychiatric nurses. I would like it to have the positions for mental health nurses. This is because in some places they do not value the psychiatric nurses. Here is not a psychiatric hospital but community hospital which treats every disease. Hence, a psychiatric job is a small job which depends on the nursing department. It has no freedom...no freedom to work. It is because our work is sometimes complicated'.

Aroon (female supervisor, 39 years old)

Although national community mental health care resources and services do exist, the need for resource reallocation and staffing in the rural Thai community settings should be carefully considered.

5.5.4.3 Sub-theme 4.3: The need to have an effective referral system

Some health professionals suggested that using a follow up system could be helpful. The follow up line for schizophrenia care in the rural Thai community should be started from bottom up, beginning with the VHVs, THPH staff, community hospital staff and psychiatric hospital staff respectively. This aims to improve the continuity of schizophrenia treatment, which is necessary for schizophrenia prognosis. However, it might be difficult to follow up some poor service users who have to move their addresses according to their occupations. These patients might be unable to receive continuity of treatment, which could cause a relapse in their mental health condition. One participant suggested that a good patient record system would assist the patients to receive continuity of care, regardless of where they were living.

Chapter 5 Findings

'If there is a follow up system: network. It's like information can be transferred to each other, for example, if the patient came to the psychiatric hospital, we could immediately know that the last month the patient received care from a hospital and the past 2 month was another hospital where medication was prescribed. It's common that the patients hire a car to the psychiatric hospital only once or twice and then they would not come anymore, because they couldn't afford to. If they lived far away from here, they didn't want to come. Therefore, if we could have a follow up system like this, we could follow up that, for example, at the moment we have 5 patients who are taking oral medication, and a patient has moved to Bangkok and continuing his/her treatment there. Having the follow up system will keep the patients in the system and this can provide them continuity of care which is better. It's because there are many times seeing news on media about violence 'Look! the non-medication psychiatric patients ...it's the non-medication psychiatric patients'. I don't want that to happen'.

Kalaya (female supervisor, 37 years old)

It seemed that creating an effective referral system, at the primary care setting, could positively influence schizophrenia care. Moreover, having a good up-to-date patient record system would be able to track the patients' treatment which, in turn, should help to improve the continuity of treatment.

5.5.4.4 Sub-theme 4.4: Support for service users: medication delivery, financial help and rehabilitation

The majority of participants discussed the matter of support regarding medication delivery, financial support for patients and their caregivers, and occupational rehabilitation for the patients. In the short term, medication delivery and financial support for the service users were recommended. Financial constraints could negatively affect therapeutic and mental health care plans and programmes regarding medication management and continuity of treatment. Therefore, delivering medication to the service users was recommended.

'It is like they have to work for living a life. Some patients, who have to go for work, might think that they are better working instead of paying for coming to the hospital. However, if we have a good system and know where patients are, we could provide continuity of treatment. They can access medication easily. It is like some places (that I have seen) when I was studying. They delivered medication to the (homeless) patients on the streets and the train stations. This will help us to care for the patients, such as those who have to work. They can go to work. It is not that we are sitting here waiting for them to come. If we have a network (for medication delivery)...have the system for doing this, it would be good'.

Kalaya (female supervisor, 37 years old)

In the long term, occupational support for the caregivers would be valued by some caregivers who have to stop working just so they are able to look after the patient at home.

'If asked about needs, what I have surveyed about the patient needs... What I have actually surveyed. The first was money. Allowance is always the first rank. It is because we surveyed the patients' needs which they (the patients) would write it down which is money for looking after the patients. It is money from the SAOs which they will get 1,500 Baht. ...The second was the caregivers. They viewed that they thought it was a big burden. It is like, when it is crisis, they need the patients to be admitted in the psychiatric hospital. However, it cannot happen sometimes, but we are improving. ...It is about caring and medication management that some caregivers viewed that they have no time to do. For some families, family members have to take leave (from work) to take care of a psychiatric patient. Sometimes, they lost their incomes. Therefore, we have to find a job for them during the time they are (taking care for patients) at home. We do have to manage occupations for them (the caregivers)'.

Tidarat (female supervisor, 37 years old)

Chapter 5 Findings

It appeared that looking after the patients, in a situation where the caregivers have financial constraints, is a burden. Therefore, the majority of staff agreed that improving patient's work functioning would not only benefit them financially but also psychologically. Working could improve a patient's self-esteem and the feeling of being accepted into the community. Therefore occupational rehabilitation was recommended.

'It may be a capability to do self-support. Sometimes, he (an individual with schizophrenia) can work and earn money. Earning money and not having to depend on other people too much. (Being able to) help himself like this, he should feel more self-valuing. Working and having income, having his own career, something like that'.

Noon (female THPH staff, 41 years old)

For long term improvement, the use of the Thai mental health act and disability-adjusted life year (DALY) was recommended by one participant who commented that currently the mental health act and DALY are not effective. In the participant's opinion, these policies should extend the patient's chance to be employed. If successful they could support themselves.

'Mostly, patients are poor. Most of them are poor. Therefore, working in the community means something to them. However, because of their illness and lower working capability, they are not hired to work in the community. Actually, they have a certain point of working capability but the community might view them as mad. Hence, there is not much work available in the community. Most of them go to work as construction workers in Bangkok. From the factors that I have mentioned and the patients' behaviour, such as not being devoted for work, not reliable, not many have jobs. They work for a while and then they leave. It is like they (other people) do not want to hire the patients. Then, there is no income'.

Tawat (male supervisor, 48 years old)

It appeared that social exclusion and a decline in the patient's work functioning level could be the cause of unemployment in patients with schizophrenia. Some of the patients ended up becoming dependent, which could be the family's burden for some poor families. Furthermore, some of them go to seek work in the capital city which could cause a discontinuity of their care.

5.6 Chapter summary

This chapter presents the research findings from the three participant groups: patients with schizophrenia, caregivers and the healthcare professionals. All of the themes were categorised into the three common areas: the lived experience, the importance of medication, and the service support needs. The themes within the area of the 'lived experience' illustrated the patients' and the caregivers' experiences and perspectives towards living with, and caring for, schizophrenia in the rural Thai community. The patients shared what it was like to live with schizophrenia and illustrated that this did not only relate to mental health problems; there were also physical, psychological and economic aspects to take into account. They expressed a sense of dependence on the family and the community and shared issues relating to a lack of job opportunities.

Similarly, although the caregivers felt that they loved and could support the patient unconditionally, they still felt burdened by the challenges of their carers' role. Some caregivers felt that they could not cope with providing the care needed and therefore took relieving measures, some exceptional, such as locking the patients in a room, allowing others to detain and/ or even suggesting illegally shooting the patient, and admitting the patients to the psychiatric hospital. This illustrates the feelings of extreme, almost unbearable, burden experienced by the care givers, especially when the patient has a relapse.

It was felt that the best way to manage the patients' symptoms of schizophrenia when living in the rural Thai community was through ensuring that patients adhered to their prescribed antipsychotic medication, which was perceived as the key to schizophrenia care at the primary care level. It was also suggested that arranging for the medication to be delivered to the community

Chapter 5 Findings

would reduce the carers' travelling costs and would lead to improvements in medication adherence. In some communities, this service was carried out by the VHVs and was seen as being very useful. However, the caregivers appeared to be the key person who assisted the patients to take the prescribed medication, but they may need additional support with this role. In addition to the use of medication, psychological and economic aspects were also raised as important components of schizophrenia care provision at the primary care level. Health professionals suggested that schizophrenia care should move from focusing on disease treatment *per se* to be more humanised and holistic. However, there are only limited numbers of health professionals at the primary care level. Another challenge to efficiency is the lack of a link between practice and national mental health policy. Therefore, improving community mental health education programmes, an effective patient referral system and competent community mental health care governance, should be considered for schizophrenia care improvement.

The next chapter will present a discussion of the research findings.

6. Chapter 6 Discussion

Introduction

This chapter presents a discussion of the key findings, critical evaluation and recommendations regarding this piece of research. The summary of the study findings was drawn from the integration of themes from the forty participants, which presented the perspectives of both service users and service providers. The structure of this chapter will start with the discussion of the findings in relation to each specific research area, followed by a review of the pragmatic approach used to collect and analyse the data. The study's limitations will be discussed and suggestions for future research offered. The chapter will conclude with a summary of the study's key findings and implications for practice.

6.1 Area 1: Lived experiences

6.1.1 The patients' perspectives towards the psychiatric hospital

The findings from this study appeared to indicate that participants within the patient group were not satisfied with their hospital stay when they had a recurrence of their psychotic symptoms. They described feelings of fear and frustration during the hospitalisation period and compared themselves to being 'a prisoner' who was controlled in an unsafe prison. These negative feelings towards hospitalisation revealed in this study are similar to the findings of Coffey (2012 p496) who found that patients with schizophrenia expressed their experience as 'going through hell'. The participants in the Coffey (2012) research also described how they felt that they were being punished. It should be noted that the Coffey (2012) study was conducted with patients who were admitted to a forensic hospital in the UK. Although both psychiatric hospitals and forensic hospitals sometimes have to detain patients, the patients in the forensic hospital may feel more limited in terms of their personal freedom because of the forensic level of categorisation (NHS 2015). It is possible that the patients were relating to experiences when they were having severe psychotic symptoms, which could explain that patients who have severe symptoms are more likely to feel stigmatised (Lysaker et al. 2007; Chan

Chapter 6 Discussion

and Mak 2014). This may influence their negative attitudes towards the care they received when admitted into the hospital. It can be seen that, after experiencing hospitalisation, patients reveal their unmet needs towards hospitalisation regarding being detained and subjected to compulsory treatment. In addition, violence in the psychiatric hospital coming from 'gangster' patients, was mentioned by some of the admitted participant patients; an experience which caused them to feel unsafe. A literature review which recruited studies from developed countries, albeit mainly from the UK, found that patients with mental illness could be aggressive which could cause arguments with other patients in psychiatric hospitals (Bowers et al. 2012 p30). It may be concluded from this study and other research, that patients with mental illness may experience violence when admitted to a psychiatric hospital, due to their psychiatric symptoms and those of others.

6.1.2 Stigma, social isolation and being dependent

Not surprisingly, it was found that almost all patients prefer to stay at home instead of in hospital, but it was still felt that living in the community was often challenging for them. It was found that some patients perceived themselves as not being able to function at the same level as other community members and this led to feelings of stigmatisation from the wider community. However, it appeared that in addition to feeling stigmatised by society, they also made comments that illustrated they felt a certain stigma towards themselves.

Self-stigma happens when patients view themselves differently after receiving a diagnosis of schizophrenia (Howe et al. 2014). It appeared that the inability to think and communicate is one of the key problems that limit the patients' ability to work and communicate with others. This could be explained by referring to the impact of schizophrenia on cognitive and social functions, which in turn often leads to stigmatisation. Gaebel et al. (2006 p44) found that severe levels of mental illness led to higher 'psycho-social disability' and stigma; the patients in this study experiencing these conditions described themselves as 'a stranger'. Buamann (2015 p132) discussed how people in general may use 'social norms, values and expectations' to judge that the mentally ill are different from them and this can lead to labelling patients as 'a

stranger'. The patients felt that although they had stayed in the community before, other people treated them differently after their diagnosis of schizophrenia, which allowed people to justify avoiding or ignoring them. Similarly, the findings of this study found that patients felt insecure and unsure about their own cognitive capabilities, as well as feeling that they were being criticised by non-family members. These perceptions seemed to suggest that once the patients started to have negative thoughts towards other people (e.g. feeling that they were being criticised or gossiped about by their neighbours, even if they had not actually met their neighbours), they would isolate themselves and stay inside their house watching TV instead of working and/or socialising. Additionally, some patients appeared to have low self-esteem because they believed they behaved wrongly or badly and sometimes talked incoherently. This is similar to the finding in the review by Kertchok (2014 p153) which showed that patients with schizophrenia felt they had shown 'incorrect behaviours'. Kertchok's review recruited studies from developing countries including India and several in Africa. Thailand is classed as a developing country, which is likely to have very different religious and social norms from India and Africa regarding appropriateness of behaviour. However, from the Kertchok (2014) study, it could be implied that the patients may hesitate to socialise because of the feeling of 'not being good enough' and the fear of rejection from society; therefore it could be seen that the patients label themselves in negative ways, which could be similar to patients in other countries. Feeling different from others may cause depression among patients with schizophrenia, which could lead to 'active social avoidance' (Ertugrul and Uluğ (2004 p76). This outcome is similar to the findings reported by Howe et al. (2014) who found that patients tended to isolate themselves from socialising because of the fear of rejection. It could be concluded that self-stigma, and having negative thoughts towards other people, are not helpful for patients with schizophrenia, especially regarding their socialising skills and integration back into society.

On the surface this study has shown that there seems to be a contradiction between the sympathetic and supportive dimension of the Thai culture and the difficulties encountered by patients who have been diagnosed with schizophrenia, when living in the same community. The results of the study

Chapter 6 Discussion

illustrate that aspect of Thai society which shows sympathy from a supportive society, because the patients are supported through the provision of food and money. This may be based on the Buddhist belief regarding the concept of 'Boon', which can be understood as meaning that helping and supporting others, such as schizophrenia sufferers, can gain 'Boon' or 'merit' for that helper. However, it could be argued that society does not really accept the patients because of the high level of fear that the patients will be violent or that there will be reoccurring symptoms. This possibility may worry or even terrify the community; feelings that may be based on knowledge and bad experiences in the past. Hence, society will continue to support the patients kindly, as long as they are not violent. Therefore, this study disagrees with the study by Ertugrul and Uluğ (2004), which was conducted in the Turkish culture and suggested that a supportive culture may prevent patients with schizophrenia from developing self-stigma. It could be expanded that social support in this scenario may refer to positive interactions between other people and the patients, which may reduce stigma from the society and self-stigma in patients themselves (Corrigan and Watson 2002). It is suggested that an in-depth understanding of the patient's specific socio-cultural context is crucial to help de-stigmatisation. The findings of this current study revealed that some patients with schizophrenia, in the rural Thai community, felt that society stigmatises them as 'a mad' person. It was felt that reintegrating oneself into the community would not be easy because the patients thought that their violent behaviour terrified people in their community. This finding is similar to a number of studies which have been conducted in developed and developing countries, showing that patients perceived themselves being labelled as 'a dangerous person' in the community (Knight et al. 2003; González-Torres et al. 2007; Thirthalli and Kumar 2012; Koschorke et al. 2014; Mestdagh and Hansen 2014). It is reasonable to conclude that when patients try to integrate themselves back into the community, they can feel rejected by the wider society, as well as discriminated against. This perception may cause feelings of being an unwanted person which, in turn, may link to the patients labelling themselves as 'surplus to society'. It could be seen that the patients felt lower self-esteem because of being rejected by their society. This conclusion is similar to a survey in Poland, which found that almost all patients with schizophrenia (87%) reported that they felt they were rejected by other people (Cechnicki et al. 2011). Although it is difficult to generalise these

survey findings to patients with schizophrenia in Thailand, this perhaps shows that being the subject of personal stigma is one of the big challenges for patients with schizophrenia in general.

The findings in this study can be understood through the application of the labelling concept offered by Link and Phelan (2013), which outlines the process of labelling and discrimination. The process starts with having a diagnosis of mental illness, which can cause lower physical and mental functions which, in turn, could lead to lower self-efficacy and self-esteem; a situation that eventually could cause stigma (Link and Phelan 2013). Stigma comprises of two keywords, namely 'marking and devaluing' a person who is perceived as different from others in that society (Link and Phelan 2013 p529). 'Blemishes of the individual' is one type of stigma towards people with mental illness (Biernat and Dovidio 2003 p103). This means that a person is labelled because he/she is considered to be different from the society's norms and he/she is devalued as a person who has a negative stereotype, such as, having mental health problems. The process of stigmatisation arises from a combination of a lack of knowledge, negative attitudes and discrimination (Thornicroft 2006 p182). Regarding stigmatisation, it is still unclear whether other people stigmatise members of the patient participant group because of a lack of knowledge about mental illness in general and schizophrenia in particular. However, it is clear that stigmatization does exist in the Thai rural context regarding viewing the patients as dangerous people; a perception which causes social discrimination from the society in which the patients are located.

6.1.3 Violence

Violence seems to be an important part of the contradiction between supportive and sympathetic society in the rural Thai community, yet making no allowance for violent behaviour. The fear of a patient's violent behaviour was mentioned as the key issue for excluding patients with schizophrenia from society. Although the caregivers felt they provided care with unconditional love and goodwill, they felt terrified of the patient's actual or potential violent behaviour. The caregivers seemed to feel a great sense of burden regarding the possibility of the patient having recurring psychotic symptoms. This led to discussions of how they would allow the police or bodyguards to control or

Chapter 6 Discussion

detain patients by using physical force and / or other violent methods. At this point, it could be seen that the caregivers chose to use violence to manage the patient's behaviour, as they felt that there was no other option of help and they were desperate. For example, one caregiver discussed how they would allow the other people in the community to shoot the patient or would lock them in a room. This clearly indicates the level of burden that the caregivers feel towards caring for patients with schizophrenia; especially regarding the issue of violent behaviour. It shows that when a patient relapses and exhibits uncontrollable violent behaviour, the caregivers feel that they have to allow other people to use violence to stop the patients from being violent, from hurting others or hurting themselves. Therefore, it appeared that the caregivers often felt it was their responsibility to resolve the problem; otherwise they have to accept and act on other people's opinions and use violence to manage the patients. This could link to 'Kreng jai' culture, which seems to dominate the rural Thai community. Knutson et al. (2003 p67) cited the work of Komin (1991 p.164) who defined Kreng jai as '...to be considerate, to feel reluctant to impose upon another person, to take another person's feelings (and ego) into account, or to take every measure not to cause discomfort or inconvenience for another person'. Therefore in the case of schizophrenia, 'Kreng jai' could mean that individuals would hesitate to express an opposite or negative opinion in case it caused offence. The caregivers have considered other people's feelings regarding when the patients disturb or are being dangerous to others. For example, a mother said she would allow other people to shoot her son, who has been diagnosed with schizophrenia, if he disturbed them again. It is arguable that Kreng jai in this situation is not only contrasting with the supportive and sympathetic culture, but also the Buddhist principles of not killing. Hence, it could be noted that although the 'Kreng jai' culture denotes a unique characteristic of the Thai people, it seems to be overlooked in this set of circumstances. It appears that Kreng jai may lead to unhelpful decisions and delayed help seeking. This conclusion, regarding negative outcomes, is similar to a Thai qualitative study of parents who have children who had to manage pain; those parents hesitated to ask for support because of Kreng jai (Jongudomkarn et al. 2012).

6.1.4 Schizophrenia care burden

The caregivers felt that unconditional love and support from the patient's family was one of the most important things for schizophrenia care; a conclusion similar to those reached by Mizuno et al. (2011) and McAuliffe et al. (2014). The qualitative study in Japan found that the love and bond between couples could reduce the burden schizophrenia care (Mizuno et al. 2011). It could be seen that the couples in the study had been living together for an average of 19.1 years; therefore they probably adjusted themselves to cope with their conditions, as well as accept the patients. In contrast, the results of this present study illustrated that providing care for patients with schizophrenia could produce a sense of ambivalence for the caregivers; they wanted to care for the patient, but also felt a great sense of burden. This is similar to other research by Trangkasombat (2008) and McAuliffe et al. (2014) that found the psychological distress and long term responsibility of caring for someone with mental health issues could lead to a sense of great burden or family dysfunction. The study by McAuliffe et al. (2014) was conducted with older parents of the patients with schizophrenia; such older carers may feel uncertainty about finding the next caregivers to look after the patients if they could not do so anymore. Hence, caregivers of different ages may have different concerns. Furthermore, the caregivers in the Trangkasombat (2008) survey also illustrated ambivalent feeling about their caring duties. However, caution must be exercised with these findings, because the participants in the Trangkasombat (2008) study were caregivers for both depressive and patients with schizophrenia; two conditions which may elicit different dimensions of feelings.

The results of this current study illustrate that the caregivers felt stressed and burdened when a patient had a recurrence of their psychotic symptoms. This is similar to the study by Roick et al. (2007) which compared UK and German caregivers' burdens. The researchers examined the relationships between the weight of the caregivers' burdens and patients' psychotic symptoms; the relationships between the caregivers and the patients, and the caregivers' coping strategies. Therefore, it could be considered that the patient participant group in this study continued to be dependent on the family members who were struggling to manage both patient care and family income. This conflict caused stress and burden among the caregiver participant group. The

Chapter 6 Discussion

caregivers felt discouraged to take care of the patients when it meant they could not work, and would therefore have to face financial constraint, as well as dealing with the patients' violent behaviour, and spending money for patient care that seemed to be ineffective. After taking care of the patients for a while, and realising that schizophrenia may be untreatable, the caregivers appeared to lose hope. If their patient's relapse cycle kept repeating, the caregivers were likely to experience an ever greater burden and probably, as a final option, avoid taking care of the patients by admitting them into the psychiatric hospital. This is similar to caregivers' experiences in the UK. The caregivers started providing care with love but some of them felt they lacked hope, because there seemed to be little chance of patients recovering (Chandler et al. 2013). In addition, hope appeared to be inversely related to Latino caregivers' burdens (Hernandez et al. 2013). It was found the Latino caregivers became desperate to send their patients to the psychiatric hospital because of the heavy burden and lack of hope for the patients' recovery. However, this study's finding seemed to oppose the research by Thunyadee et al. (2015) which found that although the Thai caregivers had faced financial and psychological burden, they would not avoid trying to cope with the burden of care. They would achieve this combination by resorting to the use of Buddhist practice as a coping strategy.

In contrast, from the patients' perspective, living with schizophrenia is a limited life because they cannot do what they would like to do; such as working and travelling. This study found that the patients themselves do not want to be dependent on the carer or family. However, having schizophrenia was viewed as an obstacle to live one's life if compared to before having a diagnosis. Therefore, the patients wanted to get back to being themselves before the diagnosis of schizophrenia. This is an example of the patient's self-stigmatisation, regarding having negative attitudes about themselves, after receiving social stigma. This is similar to the findings from Oliveira et al. (2015 p4) showing the relationships between 'internalised stigma, social relationship satisfaction and self-esteem'. It could be implied that once patients start to stigmatise themselves, they will develop lower self-esteem. Without psychological support, the patients stigmatise themselves as society stigmatises them. In this study, patients described how social exclusion could lead to feelings of depression. This may have caused the patients to lack any

hope of recovery and choose to be dependent, as the default option which their society has given them.

From the patients' perspectives, they often felt that family members did not listen or show empathy to them. This could be explained in two different ways; namely, family relationship in the Thai context, and labelling. The relationship between the family members in the rural Thai community is different from in western countries. It is a fact that ordinary Thai family members are shy. Expressing love and care to other family members either in verbal or physical contact can be awkward. Additionally, younger family members tend not to talk about their personal life with the older or senior family members, as well as members of the opposite sex. Therefore, there could be social and emotional distance between family members in an ordinary Thai family. The results from this study confirmed that the patients with schizophrenia needed empathy and mental support from their family members. Additionally, the patient with schizophrenia is labelled as a 'mad' and violent person, who is not living in reality. Therefore, patients' words and feelings are not considered reliable and, as such, those patients are thought to be dangerous to society. This perception seems to be a double guard to separate the patients, keeping them in a limited area where nobody understands them, including their family members.

6.2 Area 2: Importance of medication

Currently, the concept of medication management is an ongoing debate regarding the synonyms of compliance, adherence and concordance. The Bissonnette (2008) concept analysis study found that these concepts could be synonymous. In contrast, some studies disagreed (Lambert and Naber 2009; Manmohan et al. 2012; Snowden and Marland 2012) because concordance appears to involve the patients in the therapeutic plan, instead of compliance which seems to involve not listening to patients' opinions. Medication adherence seems to focus on the patient's behaviours regarding how much the patient follows medication advice handed out by the health professionals (Lambert and Naber 2009). Hence, the term medication adherence seems to be appropriate to use in this study context, because all participants mentioned the patient's aberrations in medication taking, instead of collaborating with health professionals.

Chapter 6 Discussion

6.2.1 Improving medication adherence in order to reduce violence

Medication adherence appeared to be the first priority for all participant groups. The findings of this study illustrated that all participants have great faith in antipsychotic medication, particularly relevant for reducing violence when the patients have uncontrollable psychotic symptoms, as well as for promoting recovery. Western studies have linked mental illness with violence (Monahan 1992; Angermeyer and Matschinger 1996). Violence and verbal aggression received from patients with schizophrenia, has been an issue of schizophrenia care, particularly for the patient's family (Ferriter 1999, p.133). These negative issues might reveal some of the public's perspectives towards the stereotyping of patients with schizophrenias, regarding their aggressive behaviour. Negative attitudes towards the patient's violent behaviours could be seen in this study's findings, which were mostly expressed by the caregiver participant group, because they were living with the patients. It could be that some aggressive behaviour might be the early warning signs of a relapse; however, this was unclear in the studies cited above. Although these studies are not up to date, the findings appear to be similar to the current rural Thai context, regarding the views towards patients with schizophrenia. A systematic meta-analysis revealed that substance abuse caused violence and homicidal behaviour in patients with schizophrenia; however this systematic review recruited a population which mixed psychosis and schizophrenia (Fazel et al. 2009). Another review supports the premise that medication adherence could prevent the recurrence of psychotic symptoms in patients with schizophrenia for up to 2 years, which is 3.5 times longer than non-adherent patients (Patel and David 2007 p.358). Additionally, the cohort data between 1988-2001 illustrated that non-medication adherence was one of the causes of homicide in discharged Swedish people who had a diagnosis with psychotic symptoms (Fazel et al. 2010). These studies supported the relationships between non-adherence to medication and violent behaviour. This finding is similar to the discussions held with this study's participants, when both caregivers and health professionals agreed that monitoring the patients to take their prescribed medication was essential to maintain a state of patient 'normality'. Therefore, the strong belief of non-adherence to medication leading to relapse and violence in patients with schizophrenia, appeared to be the reason that all of the caregivers who participated in this study were routinely monitoring their

patient's oral medication taking. Unfortunately, the caregivers were not concerned about the risks and benefits of antipsychotic medication, or the effects of medication mismanagement. For example, Fon (C3: a caregiver) adjusted her son's medication without consulting health professionals because she felt that her son was getting better and she did not want him to feel drowsy; however this led her son to relapse. It is argued that although medication adherence is strongly recommended for schizophrenia and related disorders (Royal Australian and New Zealand College of Psychiatrists 2005, 2015) it should be prescribed cautiously, in part due to concern over long term side effects (Lehman et al. 2004; NICE 2014). The evidence in the UK showed that medication treatment regarding Olanzapine injections could reduce aggression and violence in patients with schizophrenia; however there were signs of metabolic side effects (Baruch et al. 2014). The findings of the study by Baruch et al. (2014) may be of only limited use, regarding generalisation to this current study, in terms of the responsiveness of the patient's body to the medication, regarding data comparison between the western and Thai populations (e.g. body size and weight). Interestingly, the developed country (the UK) considered using antipsychotic medication for controlling patients' violent behaviours in high risk cases. However, the regimen could be flexible for patients who have controllable psychotic symptoms in the community, and who may consider the use of non-medication treatments (NICE 2014). In contrast, instead of seeing both the risks and benefits of medication, this study illustrated that almost all participants only mentioned the benefits of prescribed antipsychotic medication; benefits such as controlling psychotic symptoms, promoting recovery which aimed to reduce patient violence and the caregiver's burden. However, some health professionals mentioned the side effects and physical health problems associated with long term medication treatment. Hence, health education and discussions with the caregivers, of medication related information, covering the risks and benefits of antipsychotic medication, are needed. The guidelines recommended by NICE in the UK (NICE 2015), regarding schizophrenia medication, offer helpful and relevant information. Therefore, service users could make their own choices as to what benefits them the most, as well as being aware of medication's side effects and the dangers of mismanaging prescribed antipsychotic medication.

Chapter 6 Discussion

6.2.2 Factors related to non-medication adherence and discontinuity of care

The reasons for medication adherence and discontinuation among patients with schizophrenia, who participated in this study were: limited service accessibility because of poverty, health care provider-service user relationship, and lack of support. Almost all the patients and their caregivers mentioned the difficulties of accessing the psychiatric hospital and mental health services, which were far from their homes. The five provinces, which were the settings for this research, appeared to have poor or non-existent public transportation to the psychiatric hospital; public transport being the only mode that the service users could afford. Hence, poverty appeared to be the biggest challenge for, and cause of, medication non-adherence and discontinuation of care identified in this study. This is similar to the research by Teferra et al. (2013) which was conducted in Ethiopia where food and medication taking are equally important. Food was necessary before taking medication because the patients felt that they could not tolerate the side effects if malnourished. Interestingly, this may imply that schizophrenia treatment could be ranked as the second priority, if participants only had limited budgets, because they seemed to be more concerned about everyday living. For example, Kalaya (female supervisor, 37 years old) realised that *'It is like they have to work for living a life. Some patients, who have to go for work, might think that they are better working instead of paying for coming to the hospital'*. From Kalaya's quotation, it could reveal her insight into the impact of poverty, which could cause schizophrenia discontinuity of care. Additionally, almost all patients who participated in this research have low incomes, when compared with the national Thai standard income, which is 240-300 Thai Baht (THB) per day (Carpio et al. 2014; Trading economic.com 2015). Additionally, almost all patients have no secure job; some of them have no income and rely on the government allowance and/ or family members for financial support. Unfortunately, the caregivers also have low incomes and have to take the responsibility to care for the patients, which could cause them physical, mental and financial burdens. For example, some caregivers felt worried about the future because the whole family relied on one person's income. Hence, money appeared to be the most challenging issue for the service users to maintain their continuity of care. This is similar to the study by Barbui et al. (2009)

which found that non-adherence to medication was significantly associated with unemployment. However, this current study's finding opposes Barbu et al. (2009), whose research was conducted in India and Bressington et al. (2013), whose study took place in Hong Kong. Bressington and colleagues (2013) believe that stigma in the workplace, together with the state welfare system issue regarding whether patients have to pay for their prescriptions, could affect a patient's medication adherence behaviour. This study is different from the research by Bressington et al (2013) regarding the welfare system. It is argued that although the service users in this study did not have to pay for medication and prescription fees, they still have to pay for travelling, as well as losing income, when obliged to make hospital visits. This was a financial demand which almost all of them could not afford. Hence, delivering medication to the THPHs, transportation support and allowance appeared to be the short term support that the service users most needed.

Positive attitudes towards medication adherence appeared to relate to belief: for example, kind health care providers appeared to positively influence the therapeutic effects of antipsychotic drugs. Therefore, they tended to promote the effectiveness of medication adherence and compulsory medication treatment, especially to the caregivers. This could reflect the rural Thai cultural mind-set that people tend to trust health professionals. Therefore, it could be seen that health professionals could influence caregivers to monitor patients by using their suggested techniques; such as directly observed treatment (DOT) and dropping medication into the patient's food and drink. This suggestion is similar to the cross-sectional study by Svetini et al. (2015) which found that 75% of caregivers perceived that health care professional-patient relationship could enhance patient medication taking. Svetini et al. (2015) highlighted health care professional-patient relationship in 16 EU countries, which are different from what exists within the Thai culture. In the Thai culture it seems that there are more unequal relationships, particularly as between patients and health care staff. The patients who participated in this current study seemed to have no doubts concerning the health professionals, and so they would passively comply with the health professionals' suggestions. In contrast, the untrained mental health THPH staff did not feel confident in their capability to provide schizophrenia care. Therefore, most of THPH staff used their goodwill to provide care. This is similar to the Brown and Gray (2015)

Chapter 6 Discussion

qualitative study which suggested the health professionals' personal beliefs could inform their mental health practice; however, their practice was based on their beliefs rather than any evidence or guidelines. It is argued that although the health professionals felt the health professional-service user relationship could influence the patient's medication adherence (Patel and Davis 2007 p359), medication adherence in the service users' experience did not seem obviously linked with the therapeutic alliance. Almost all service users felt satisfied with support from health professionals regarding the medication delivery service and home visiting. However, some patients and caregivers did not receive support and were not satisfied with the THPH service. For example, one caregiver felt negatively towards the THPH staff, because they seemed to avoid a home visit; however the caregiver continued monitoring the patient's medication adherence without any support from the THPH staff.

Cognitive deficits and lack of support can cause non-adherence to medication taking. Family members appeared to be the most important people to support the patient's medication adherence, as well as ensuring continuity of care. Although medication information is important for medication adherence, surprisingly '40-80% of medical information provided by healthcare practitioners is forgotten immediately' (Kessels 2003 p.219). This finding could apply to the patients with schizophrenia, who potentially have compromised cognitive function levels (e.g. memory and concentration), which may affect their medication adherence. For example, some patients may simply forget to take medication. Therefore, family support could improve that medication adherence (Patel and Davis 2007, p.359). White and Unruh (2013) conducted a qualitative study with the mothers of patients with schizophrenia in Halifax, Canada. It was found that managing a patient's oral medication was seen by the caregivers as taking good responsibility for the patients which, in turn, could help to reduce the burden of the patient's violent behaviour. In contrast, Svettni et al. (2015) conducted a cross-sectional survey which found that half of the caregivers felt that influencing the patients with schizophrenia to take their prescribed medication could be a burden to them. Although this cross-sectional survey was conducted in 16 European countries, generalisation of the study's results needs to be cautious, due to the researchers using convenience sampling for participant recruitment. Additionally, the survey

questions appear to be 'leading' questions, and there was also a lack of an in-depth explanation of the reasons behind the perceived burdens.

It could be concluded that non-adherence to prescribed medication among patients with schizophrenia, appears to be a worldwide problem and is very complicated. This study found poverty and the lack of service at the primary care level could cause both non-adherence and compulsory medication treatment. It is argued that improving medication adherence should not only focus on taking the medication, but also understanding the reasons behind non-adherence to taking prescribed medication; therefore, service improvement could go some way towards meeting the user's needs. Additionally, it is argued that having trust in the health professionals appears to be a positive sign for therapeutic continuation. However, both the risks and benefits of antipsychotic medication should be discussed with the service users, as it appeared that almost all service users in this study tended to know the benefits of such medication but were unaware of the side effects.

6.2.3 Comparing views about the importance of medication

This study found that antipsychotic medication was viewed as the key to schizophrenia care at the primary care level, leading to medication as a compulsory treatment approach for patients who failed to be concordant with it. It could be argued that global mental health care started to move from a biomedical model to a bio-psychosocial model since the 1980s (Engel 1977). This global shift includes the Thai community mental health service, which indicated concern for bio-psychosocial care in the service plan (Thai Ministry of Public Health 2013). Hence, the holistic approach regarding individuals and their specific cultural contexts should be taken seriously by health care providers (Hatala 2012). Holistic care is also promoted as the model of care at the Thai primary care level (Hanucharurnkul 2007). However, in terms of medication, it could be seen from area two of these research findings (see Chapter 5: topic 5.4), the importance of medication for schizophrenia care in the rural Thai community is clear. It seems that, in reality, Thai community mental health care has not moved on from the biomedical model, with its focus on the effectiveness of medication, instead of embracing holistic care; an outcome similar to a Thai qualitative study on geriatric nursing (Choowattanapakorn et al. 2004). The study by Choowattanapakorn et al.

Chapter 6 Discussion

(2004) illustrated the contradiction between the Thai nursing curriculum regarding providing holistic care for the service users; in reality nurses still provided care informed by the biomedical model. However, it is argued that the biomedical model of care seemed to dominate schizophrenia care provision, as seen in this current study's findings. This trend was evident as the health professionals encouraged the patients and caregivers to understand the benefits of adherence to their prescribed medication. Also, the researcher noted that almost all collaborations and communications between schizophrenia stakeholders were about medication management.

Furthermore, medication adherence techniques were used and adjusted for the patients and caregivers to suit the rural Thai lifestyles; such as unit dose and the directly observed treatment (DOT) technique. The Thai caregivers have become serious medication monitors; an outcome which is similar to several studies which have been conducted with patients with schizophrenia (Dangdomyouth et al. 2008; Svettni et al. 2015). This study's findings illustrated that the caregivers believed in the effectiveness of medication and took on the role of medication monitoring, as medication seemed to be the most important part of schizophrenia care. However, the participants in this study felt that schizophrenia care, at the primary care setting, required more than just medication. For example, the caregivers reported that they provided care with unconditional love, and the health professionals mentioned the importance of the humanised care approach. Although the rural Thai community seems to be a supportive and sympathetic society, which could be seen as the right ingredients for holistic care, the lack of community mental health facilities, together with trying to deal with uncontrollable psychotic symptoms regarding a patient's violence, appear to be significant obstacles to a patient's wellbeing. This is because the patients could do physical harm to themselves and others. Moreover, the lack of knowledge regarding schizophrenia emergency case management, seemed to be overwhelming for everyone in the community. Police and local volunteers have been involved in emergency care, often oriented towards human and non-human damage control. Although the Thai public health policy viewed this as the collaboration between the government and local facilities, this seemed to alarm other community members, who perceived patients with schizophrenia as dangerous and unmanageable. Both the caregivers and health professionals have to

control potential harm as a priority, rather than improving care in psychosocial dimensions. Hence, this may be a reason for the social exclusion of patients, and minimal job opportunities for those same patients, as well as explaining failure to provide humanised care.

6.2.4 **Fragmented health care service**

Some patients felt that the schizophrenia care and treatment service seemed to be limited and fragmented, which is similar to the Thai mental health nurses' views in a mixed method study from Kaewprom et al. (2011). That study pointed out that the mental health nurses felt the Thai health care system did not support recovery of patients with schizophrenia, because mental health care was not prioritised as an important aspect of care. Also, the referral system was poor, and accessibility to appropriate medication was limited at both the primary and secondary care levels. Similarly, the current research findings illustrated that the service users needed not only the prescribed medication to be delivered to them, but also a one-stop service which provides information regarding physical care and consultation service at the primary care level. The service users mentioned the importance of having mental health clinics and mental health specialists at the THPHs, while expecting to gain access to, and receive, schizophrenia care. For example, a few patients mentioned certain of their medication's side effects which worried them; such as gaining weight and having problems in their sexual relationships. Although these were not their reasons for non-adherence to medication, they still needed access to the consultation service provided by the mental health staff at the THPHs. It is argued that although medication is recommended for schizophrenia care, its side effects should be of concern (Lehman et al. 2004; Royal Australian and New Zealand College of Psychiatrists 2005, 2015; NICE 2014). At this point, it is strongly recommended that medication information and consultation services should be available at the primary care setting. It is suggested that the shorter the distance from the service user's home to a source of healthcare, as well as shorter waiting times, will help to gain service accessibility and continuity of care.

7. Chapter 7 Recommendations and conclusions

Introduction

This chapter provides recommendations for community mental health service improvement regarding national Thailand's public health policy, community mental health service provision, staff improvement and the cultural/ belief factors which could affect community mental health care.

7.1 Area 3: Recommendations

7.1.1 Structure of mental health services

This study's findings illustrate that the Thai health care structure seems not to support schizophrenia care at the primary care level, when compared to the community mental health service in the UK. The UK operates a community mental health service but there is no such service in the Thai health care system. However, it seems that Thai community mental health care is at the stage of building a foundation, by enabling a fledgling community mental health care service at the primary care level. The study's findings illustrate that the Thai public health department needs to make more effort to improve schizophrenia care at the primary care level, if compared to what is offered by developed countries such as the UK, the USA and Australia. The quantity and quality of mental health staff, qualifications and mental health training could be obstacles in the way of the provision of appropriate and effective schizophrenia care in Thailand. For example, the Thai primary health care level lacks mental health specialists, whereas the UK has a locally focused mental health service, NICE guidelines and NICE pathways to guide and assist the NHS staff to improve the quality of mental health care on offer (NHS England 2014; NICE 2014; NICE Pathways 2015). This study's findings also point out the gap between Thailand's community mental health care in reality and the public mental health policy, as published. Although the Thai service plan (2013) was launched to improve the quality of community mental health care, the Thai health care system requires a huge improvement regarding the number of staff

and their training, the quality of client-centred care and partnership frameworks, and the standards of the rehabilitation and occupational services.

7.1.2 Key recommendations

From the study's findings, there are three key recommendations relating to i) public mental health policy, ii) staff improvement and iii) cultural/ belief concerns.

7.1.2.1 Public health policy for mental health service

The research findings illustrate the contradictions between formal mental health policy, as indicated in the nation's service plan (2013), and real community mental health practice, as found in the rural Thai community. It was found that there are difficulties in applying the bio-psychosocial model, as prescribed in the Thai service plan (2013), into day-to-day community mental health practice. It is argued that the lack of an adequate health care workforce, at the community health care level, may affect the quality of schizophrenia care provision, particularly regarding client centred care. Almost all THPH staff, who participated in this study, felt that they were overloaded in terms of clinical duties and the accompanying paper work. Therefore, they felt that they were unable to be proactive in providing care; some of the THPH staff mentioned that they could only do one yearly home visit, due to their extremely heavy workloads. Almost all THPH staff mentioned that high volume of workloads could affect their mental health care roles, particularly the issue of having less contact with the service users. And it is possible that less contact with the service users may lead to fewer home visits, which may in turn affect patient medication adherence and continuity of care. This situation can be compared to a review from England, which indicated that links between patient experience and continuity of care, regarding patient / health professional relationships, could improve continuity of service and quality of care (Freeman and Hughes 2010). It appeared, however, that some Thai health professionals have volunteered to work for 24 hours on call which, whilst gaining 'Boon' (merit) for that individual, may not be viewed as a realistic or practical long term solution for service improvement. On the other hand, some health professionals suggested that the government should not only improve the number and quality of the community mental health staff in the primary care

Chapter 6 Discussion

level, but should also attend to 'soft' issues such as moral support, job related terms and conditions, and promotion. Moreover, non-trained mental health staff may be unable to provide high quality care to the patient and caregiver groups, as featured in this research, due to their lack of specific knowledge, skill and experience. Hence, it is recommended that the Thai service plan should support health professional training in mental health courses and higher education. This is similar to the NHS England (2014 p21) regarding the improvement of NHS staff numbers and qualifications. Moreover, the NHS has a mental health trust which provides mental health services that are designed to meet different patients' conditions and needs (NHS England 2014 p15).

It should be noted that the Thai Ministry of Public Health has tried to enhance the availability of mental health services by improving health professionals' capabilities and facilities to support community mental health care, as well as connecting to government sectors and village health volunteers (VHVs). For example, the THPHs collaborates with other local government sectors regarding patient transportation to higher levels of care or treatment, as well as working with the VHVs for patient home visits and medication delivery. However, the study's findings reflect the continuing lack of resources at the primary care level in the Thai health care system. Both the Thai service plan (2013) and the NICE clinical guidelines (2014) suggest the benefits of collaborating with local volunteers; however, these information sets from two different cultures and countries have different aims. The Thai service plan (2013) aims to work with non-health care providers in a therapeutic dimension regarding improving medication adherence and gaining accessibility to the higher levels of care; the NICE clinical guidelines (2014) on the other hand, suggest working with local volunteers in order to improve patients' occupational, study and social skills. These goals seem to support the service users to become more independent by enhancing their capabilities, which is in contrast with the Thai social values, where the patients with mental illness are not expected to work. Therefore, adopting the NICE guideline to inform the Thai situation, as described in this research, would support the patients to be independent and reduce the caregivers' burdens.

The health professionals who participated in this study recommended holistic care as a strategy to manage their workload and provide other dimensions of

care. Although this suggestion was similar to the NICE guidelines and the American Psychiatric Association's (APA) (2010) recommendations, it seems that medication appeared to be the first priority for the Thai patients. In other words, the Thai service plan does not seem to be concerned with working in a partnership with the service users. Both NICE and APA guidelines focus on the bio-psychosocial model, which means that the guidelines are not only pointing to pharmacotherapy, but also other dimensions of life such as culture, working, studying and socialising through the formation of working partnerships with service users and local volunteers. It is argued that although the NICE (2014) and APA (2010) guidelines are precise, they might be difficult to apply to the Thai health care system because of the differences between the three health care systems; in particular the lack of trained community mental health staff and different cultural beliefs regarding trust in health professionals. It is recommended that the Thai public health department should develop 'caring for schizophrenia' guidelines which are specific to our own health care system, taking into account people's socio-cultural contexts and belief systems. Therefore, at least the health professionals should be aware of other dimensions of the patients' and caregivers' lives, including knowledge of each patient's cultural belief system; a personal dimension which appears to be overlooked in this current situation, where medication adherence is the main focus for dealing with schizophrenia in rural Thailand. It is expected that this awareness could improve the understanding of each service user's needs, as well as fostering true collaboration between the service users and the service providers. This suggestion aims to improve patients' and caregivers' experiences and quality of care, in order to achieve real client-centred care in practice. Furthermore, this approach may help to improve mental health care access, quality of care and the current referral system which is the service plan's aim (Thai Ministry of Public Health 2013).

7.1.2.2 THPH staff improvement: attitudes, knowledge and practice

Staff development is one of the key recommendations for achieving improvement in the care of people with schizophrenia. Almost all of the health professionals observed that having mental health specialists to provide care at the primary care level could benefit the service users. However, this suggestion does not seem practical for Thailand's current health care system, for two reasons: the limited mental health workforce and a lack of support from the

Chapter 6 Discussion

limited community mental health resources. Therefore, improving attitudes, knowledge and practice regarding community mental health education for nursing and public health students should be a short term management aim for reducing the current shortage in the numbers of community mental health staff.

Positive attitudes or goodwill were raised as the first priority for community mental health care provision, which health professionals should have before improving any other skills. Almost all of the interviewed health professionals recommended that positive attitudes towards care are important, but not always present. This omission could be dealt with by educating the THPH staff, when they are studying at undergraduate degree level, and via their post-graduate qualifications. The two dimensions of the primary care staff's attitudes are i) the attitudes towards the health professionals themselves and ii) towards the patients with schizophrenia. Firstly, the top-down hierarchy of health professionals in the Thai health care system appeared to negatively affect the primary care staff's confidence, in terms of community mental health care provision. The primary care staff perceived themselves as on the lowest level of the hierarchy, which may be because they thought that they have less mental health care knowledge and skills, when compared with RNs and medical doctors. Secondly, the health professionals' attitudes towards patients with schizophrenia were similar to other people's views, labelling the patients as dangerous and violent, which, to be fair, they sometimes are. Therefore, some of the primary carers may hesitate to do home visits, instead preferring to send antipsychotic medication to the patients via the VHVs. This is similar to the review by Thirthalli and Kumar (2012 p.430), which suggested that the psychiatrists' attitudes towards caring for the mentally ill should be improved by developing the psychiatry curriculum. However, the review was based on suggestions from psychiatrists, rather than public health workers and nurses in a different culture. Therefore, there is a limitation to the value of any generalisation of the review's findings.

Knowledge about schizophrenia, patient assessment and patient care appeared to be crucial for effective care at the primary care level. There is evidence to suggest public health staff lack the confidence to provide adequate care for patients with mental health problems. This is because the objectives of public health education programmes are focused on mental health promotion,

whereas community mental health nursing programmes are more in-depth; such as providing care for inpatients' services and community mental health care. The programmes could be expanded so that the Thai nursing students have a placement programme in which they have opportunities to provide inpatient care. However, at present public health students are not required to experience inpatient care tasks during their education. Therefore, the differences between nursing and public health education may affect the students' knowledge and practice.

For staff skills, almost all the THPH staff who participated in this study, had not been trained in any mental health specialisations; some of them already accepted that they lacked the knowledge and skills to provide adequate care. The initial skills for the THPH staff should relate to assessment regarding relapses and medication's side effects. Holistic care was raised as the most effective skill for time management, regarding the primary care staff who have to deal with high volumes of workloads. Moreover, the capability to collaborate with the VHV is also essential for community mental health care; a relationship which, if effective, may reduce the THPH staff's workloads. In addition, both patients with schizophrenia and their caregivers needed empathy and support from the health professionals. For example, one caregiver was desperate about caring correctly for her patient, but she felt that the THPH staff gave her unhelpful advice and did not really understand her difficult situation. Hence, carrying out assessments and giving helpful advice appeared to be essential skills for schizophrenia care at the primary care level.

The supervisory team suggested that the THPH staff should be able to collaborate with the VHV. The benefit of using the VHV to follow up and liaise with the service users is because they could assess the service users' real-life problems: the needs and unmet needs of the patients and their caregivers. This is an appropriate solution because the VHV have similar socioeconomic status, speak the local language without using jargon, and are already in the process of establishing rapport with the patients and their caregivers. This scenario is similar to the Eack and Newhill (2008) study which found significant relationships between knowledge, attitude and contact between the social workers and care provision. Improving the health professionals' knowledge led to positive attitudes which, in turn, reduced the psychological distance between the health care providers and the patients with

Chapter 6 Discussion

schizophrenia. However, there are limitations for generalisation of the findings from the Eack and Newhill (2008) study; it was conducted in a different health care system, with a different participant group, if compared with this current research, which was conducted with Thai participants in the Thai health care context. Moreover, the participants in Eack and Newhill's study were selected by convenience sampling, which may be not representative of the health professionals.

7.1.2.3 Culture/ beliefs and community mental health care

Their attitudes and cultural beliefs could affect patients' and caregivers' help-seeking behaviour. This study's findings illustrated that *karma* and the results of '*bad karma*' could prevent the potential service users from seeking help. The caregivers in this study accepted their care burden as their own bad karma. Karma is a Pali word meaning action; it is called karma in Sanskrit. In its general sense, karma means 'all good and bad actions whether mental, verbal or physical thoughts, words and deeds' (ravadabuddhism.wordpress.com 2007). Karma includes all actions in the past and present which will affect the person and their karma in the future. Although karma comprises both bright and dark sides, the caregivers seemed to interpret karma in a negative way, regarding their carer's situation as an inevitable punishment. Therefore, they felt that they should be patient, take good care of their patient, and accept all violence because they deserved to have these negative things in order to pay back for what they had done wrong in the past. This belief structure illustrates the misunderstanding about the karma concept held by some caregivers, which may lead them to making a decision not to seek help and support regarding their carers' needs. This not only causes a burden for the caregiver but also serves to delay treatment for the patients. Interestingly, the concept of being punished by bad karma is quite similar to being punished by God in the Christian religion because of one's sins (Stompe et al. 2006); however this is different from the concept of being tested by Allah (the Muslim God) in the Islamic religion (Stompe et al. 2006; Vanaleesin et al. 2007). Hence, treating schizophrenia should not only involve the disease itself, but should also be concerned with a person's beliefs and their cultural context, factors which are as important as medication treatment, particularly in a holistic framework.

'Boon' could influence the service providers to work for the patients, by providing extra working hours for community mental health care. Additionally, the health professionals in this study mentioned willpower as the most important thing for community mental health care in Thai society. This is similar to Meebunmak's (2009) study, which was conducted with primary care staff in Thailand. It was found that many health professionals linked providing care for the mentally ill with making 'Boon' (doing good things or making merits). Therefore, they devoted their time and knowledge to community mental health care provision. According to the evidence from this current research, the concepts of 'Boon' and 'Karma' exist and affect the services provided by the Thai mental health care system.

'Kreng Jai' also seemed to affect help-seeking behaviour, as well as the way that the service users communicate with the health professionals. The great trust in the health professionals may inhibit the service users from discussing therapeutic plans opposing the health professional's opinions, particularly if the users wish to choose their own options. Hence, the health professionals should be able to establish rapport with their 'customers', until the service users could open their minds to, and share their views and concerns with, the health professionals. The health professionals could then assess the service users' needs without truth concealment caused by 'Kreng jai'. This process may be similar to 'ice breaking', a method for establishing rapport, and also unconditional positive regard (Rogers 1957; Rogers and Maslow 2008), which aims to reduce barriers between service users and service providers. Moreover, the health professionals should be more open-minded to listen to the service user's needs, in order to improve a sense of partnership and collaboration.

Hence, it is recommended that the health professionals should not overlook the service users' ethnic background, gender and class (Culley 2006 p150). Providing care which is sensitive to the service users' cultures, beliefs and social norms is crucial for providing equity of health care (Browne et al. 2009; Wang-Schweig et al. 2014). According to the UK community mental health practice model, the Thai health professionals should assess their service users' cultures and beliefs, prior to providing mental health care. Therefore, this approach could assist the health professionals to be more understanding of the patients' and caregivers' specific culture and beliefs. This study found some significant points regarding cultural beliefs which could influence

Chapter 6 Discussion

schizophrenia care. Therefore, health professionals and community mental health volunteers should understand the nature of the Thai Buddhist people regarding the concepts of Boon, Karma and Kreng Jai, which could affect collaboration of care the most. Therefore, this could help to improve collaborations between health professionals, community mental health volunteers, patients and the caregivers. Understanding the client's cultural context and their belief systems may be applied to the other ethnic groups, whose cultures and beliefs may affect their health and collaboration in mental health care.

7.1.2.4 The need of an emergency service for community mental health care

Adult patients with schizophrenia can exhibit violent behaviour which correlates with a history of antisocial behaviour, having low-income and consuming drugs and alcohol (National Institute of Health 2007). The evidence from the National Institute of Mental Health (NIMH) supports the premise that patients with schizophrenia are not as violent as other people perceive them to be (National Institute of Mental Health 2009). However, the recurrence of violent behaviour appears to be unpredictable and severe for the patients, caregivers, health professionals and other people in the community. Examples of such behaviour are suicide or attempted suicide, arson such as setting fire to their house and physical assault, sometimes with fatal results (Hodgins 2008; Vicky Short et al. 2012). This study's findings illustrated the relationship between the nature of violence in patients with schizophrenia, regarding the patient's characteristics such as having low economic status and alcohol consumption, which led to the patients' violent behaviours. For example, some caregivers suffered from physical assaults which were carried out by their patients. Likewise, mothers of patients with schizophrenia in Halifax, Canada also expressed their worry and fear about their children's violence. They felt that medication compliance could help to control the patient's psychotic symptoms and reduce their carers' burden (White and Unruh 2013). Although the potential for generalisation of the findings from the White and Unruh (2013) qualitative study is limited because the study was conducted in Canada, the experience of fear of a patient's violent behaviour appears to be a mutual experience. It is shown that in this study having an emergency service able to cope with relapsing patients who exhibit violent behaviour appears to be in

demand. Unfortunately, almost all participants mentioned the possibility of using the police and/or volunteers to manage an emergency service for community mental health care; an option which is unavailable in many communities. Therefore, prevention via antipsychotic medication could be the best way for schizophrenia stakeholders to prevent and control a patient's relapse, instead of being required to deal with an outburst of potentially dangerous violence.

7.2 Discussion of the limitations and potential biases

7.2.1 Limitations and potential biases

Limitations and potential biases of this study can be grouped as a) factors related to the study participants, and b) methodology and data gathering approaches used. Although this study was the first large scale qualitative study of its kind in Thailand, there are some potential biases that are important to discuss. The selected research participants appeared to be the most important factor which could shape the research findings. Almost all service users who participated in this study live in Thai rural areas, and have low incomes. Although the participants were selected from five provinces under the psychiatric hospital's responsibility, nearly half of the participants lived in Nakhon Sawan province, located near the psychiatric hospital. Hence, this study may not include different perspectives from other patients with schizophrenia, who live in other more distant provinces and who therefore may have more travelling difficulties. Furthermore, the chronicity of schizophrenia may affect the participants' comments and perspectives. It should be noted that the findings of this study came from ten participants with schizophrenia who had experience of hospitalisation and chronic schizophrenia only.

Therefore, these findings may be limited for transferability to acute episodes of psychotic symptoms. Moreover, although patients with schizophrenia who took part in this study had controllable psychotic symptoms, some of them still have paranoid symptoms, such as having negative thoughts. This means that although a patient's perspective should be respected, the viability of transferring the research findings into practice should be carefully considered, particularly regarding their recurrence of psychotic symptoms. All patients with schizophrenia who participated in this study indicated that they adhere to their

Chapter 6 Discussion

prescribed medication. This conformity might influence how the patients express their faith in the effectiveness of prescribed medication adherence. In addition, the majority of participants are Buddhist; therefore this study's findings appeared to be culturally-centric. The findings reflect Buddhism instead of a mixture of different beliefs and religious views. Therefore, the findings from this study might be limited in their potential to be perceived as applicable to a non-Buddhist population.

Although this study involved a relatively large number of schizophrenia stakeholders, there are limitations regarding the transferability of the research. For example, needs and unmet needs are subjective; individuals can change over time and at any time. Therefore, cross-sectional interview may not be enough to explore and assess the participants' needs and unmet needs. In other words, this study represented the stakeholder's needs and unmet needs at one point in time. Hence, regular assessments of needs and unmet needs are crucial for maintaining quality community mental health care. Furthermore, potential leading questions may cause the participants to hesitate to discuss any non-adherence to their prescribed medication. One piece of information required from the study participants was whether the patient was on medication. This could influence the participants to become concerned about medication adherence or non-adherence; an issue about which they may feel awkward to discuss in the interview.

7.3 Reflections and suggestions for future research

7.3.1 Reflections

In this section, I will reflect on approaches to data collection in the rural Thai context, as well as on carrying out thematic analysis; therefore, this section will be presented in the first person. Reflection is crucial for qualitative research because it allows me, the researcher, to think critically about previous experiences, in order to improve knowledge and research skills for conducting future qualitative research projects (Jasper 2003). This is also important because there is only limited research in the chosen field. It is therefore helpful to spend time considering the key issues relating to data for the patient with schizophrenia, within the specific setting of rural Thailand. Reflection is considered useful for many areas of research, including the topic which is the

focus of this study: schizophrenia. My reflections will take in the wider community, regarding conducting research in rural Thailand, which embraces a specific culture, way of life and health care system (Bolton 2010).

7.3.1.1 Researcher: me as an outsider and in a researcher's shoes

I was excited about conducting my first qualitative study, but I also felt slightly overwhelmed. This was because I found it frustrating and worrying conducting the research project in an unfamiliar environment, where I was an outsider who knew little about the working of the Thai psychiatric hospital system, and who had no personal contact network there. I sought the psychiatric hospital's phone number on the Internet and called them. Many questions about my research project were raised, but after much discussion they found it interesting and promised to be collaborators. I did contact the psychiatric hospital staff informally, before gaining access permission, which I could only get officially after obtaining ethical approval from the Faculty of Health Sciences, University of Southampton, UK. Hence, the management of the Thai psychiatric hospital I had liaised with could not review my research proposal before I had gained ethical approval from my UK university. After my research proposal was approved by the faculty's ethical committee, I was able to gain access to the psychiatric hospital. I was pleased that the psychiatric hospital staff thought my research project could benefit the care offered to psychiatric patients, either in or out of the hospital, in future. Their opinion was because this research can be a part of community care improvement (Kakhon Sawan Rajanagarinda Psychiatric hospital 2013).

My research project was the second project submitted for ethical approval to the Thai psychiatric hospital, because there is a lack of schizophrenia research in this setting. Although my research proposal required a few amendments, regarding its participant recruitment strategy and supervisory team inclusion criteria, these were practical matters aimed at enhancing collaboration with the psychiatric hospital working system and potential participants' life styles. Needless to say, I felt great relief after the research proposal was approved by the psychiatric hospital's ethics committee. I found the psychiatric hospital staff very helpful, which allowed me to feel comfortable to conduct the research project there.

Chapter 6 Discussion

I found 'wearing a researcher's shoes' was different from the role of lecturer or health professional, because sometimes things could be out of control. Hence, there is a high level of research knowledge and collaborative skills necessary for researching in such an unfamiliar research setting. I would also recommend the novice researcher to be enthusiastic to learn all the new things they will encounter; being humble and flexible are also crucial assets. With my researcher's shoes on, I could see things in depth and breadth without judging. People perceived me as a visitor; a person who is flexible and who they could talk with, rather than a remote lecturer or a strict health professional. I realised how much some participants trusted me, as they revealed their true feelings and experiences, which I believed they would not have shared if I acted in the more formal role as a lecturer or a health professional.

7.3.1.2 Research data collection in Thailand

1) Distributing research packs in the Thai context

The original plan for distributing the research packs was sending them by post. However, I decided to adjust the participant recruitment strategy after consulting the head of the hospital's community mental health department. The gatekeeper commented that my participant recruitment strategy regarding sending research packs via post might not be effective for the Thai participants in rural areas, for several reasons. Firstly, patients with schizophrenia might not be bothered to read the invitation letter; therefore they would disregard the research packs and not contact me. Secondly, sending research packs via post can be perceived as one way communication and is too formal; thereby some potential participants might hesitate to participate in the interview and would simply ignore the research packs. Thirdly, distributing research packs in the rural Thai community might be time consuming. It was therefore suggested that I telephoned potential participants instead. This was not only quicker but was also likely to be more effective, as it is a two way communication. Hence, the research protocol was amended and submitted to the university and the psychiatric hospital ethics committees (see appendix 12 and 13). The gatekeeper offered to help me to contact the potential research participants via mobile phone and email (especially the case that they had an email address), which was considered quick and effective. To make the

decision, the comparisons between advantages and disadvantages of each participant recruitment strategy are discussed in table 12.

Table 12 Comparison between advantages and disadvantages of each participant recruitment strategy

My project plan	What worked in reality
<p>Strategy I: the gatekeepers sent or gave research packs to the potential research participants.</p>	<p>Strategy I: the gatekeepers contacted potential research participants formally or informally via telephone. Once, the potential research participants were interested to take part in semi-structured interviews, the gatekeepers gave them research packs and/or sent them a participant information sheet, an invitation letter, a reply slip, and a consent form directly or via email.</p>
<p>Advantages - This participant recruitment seemed to prevent potential biases which could be influenced by gatekeepers.</p> <p>Disadvantages -There was a risk of not receiving contact from potential research participants which might affect the richness of data.</p>	<p>Advantages -Save time and money regarding sending research packs to potential research participants by post.</p> <p>Disadvantages -This could cause bias in that potential research participants might refuse to take part, if they were not working well with the psychiatric hospital or had any conflicts. -This might end up with recruiting all of people who had positive attitudes towards the community mental health care team from the psychiatric hospital.</p>

Chapter 6 Discussion

Another form of participant recruitment was advertising the research project, via posters, which proved to be an ineffective method for this research project. This might be because the potential participants, for example the patients with schizophrenia and their caregivers who came to the psychiatric hospital, were in a rush to see the psychiatrists and catch the bus home.

Eventually, the potential participants responded quite well to mobile phone contact and I was able to move forward to the next data collection step. I felt good having made the right decision based on my research stance, a pragmatist; otherwise I would not have achieved the expected participation in the limited timeframe.

2) Travelling to rural Thai communities

Practically, it appeared that travelling to the participant's houses or the THPH was likely to be the most effective strategy, in comparison to me waiting for them to come to the outpatients' department at the psychiatric hospital. Travelling to the psychiatric hospital seemed an obstacle for the participants; for example, most of the patients with schizophrenia and their caregivers had no car and there were limitations with public transport. Moreover, the THPH staff were unlikely to have a day off for participating in the interviews. As an outsider, I lacked sufficient autonomy to manage interview schedules, so I had to rely on the head of the community mental health department, who was the only person who could allocate staff and vehicles. However, this was the most effective way of gathering data, because the gatekeeper knew everyone that she contacted, therefore the interview plan went well.

I felt thankful to the psychiatric hospital staff who took me to the various community settings within the five provinces; places I had never been before. Most of the time, it was tiring to travel to remote areas but I felt I was so lucky to have a chance to do that. If I had not been to the patients' houses, I would not be able to understand how much they have been struggling to travel to the psychiatric hospital. There were several places that had only limited public transport services; therefore travelling to the psychiatric hospital, queuing for treatments and rushing to catch the bus home are common for those poor patients and caregivers. Some communities have only one bus service to return to their village. If they were unlucky, they had to rent an expensive hired car, which some of them could not afford. For these reasons, I am not surprised

that some patients discontinue their hospital appointment-based schizophrenia treatment; nor am I surprised that patients with schizophrenia are repeatedly returned to the psychiatric hospital for in-patient compulsory care.

3) Interview places

Although the ideal interviewing place should be quiet and private, there was no perfect interview place when I carried out data collection, due to the limitations of suitable available space. Participants had no living room but they tried to arrange the best and most convenient place for interviewing; such as at a bamboo table in front of their house, a bench in front of the grocery shop and at the car park in the back of THPH. These places were noisy and not confidential enough. To overcome the interference, I recommend any future researchers should have good quality audio-recorders, and especially a good microphone. Moreover, the researcher should adapt his/her voice to be louder, but with a polite tone. Being kind and friendly is the nature of the rural Thai people. Thus, sometimes other people came to talk with me and the participants because they did not know about the privacy and confidentiality of the interview. However, what they were doing by talking to me was friendly, as I, an outsider, was their guest. I decided to gently remind them about the privacy and confidentiality of the interview. From my experience of conducting research with rural Thai people, it is necessary to be considerate, polite, respectful and gentle. Such manners could gain rapport and collaboration, not only from participants, but also other people who are involved in the research project, such as hospital staff.

4) Interviewing patients with schizophrenia

Unsurprisingly I found that the participants' psychological conditions often affected the interview process. The patients with schizophrenia, who took part in the research project, had a range of different psychiatric conditions. Some of them had controllable psychotic symptoms which seemed to allow them to deal with interview questions well. Conversely, some participants had symptoms of paranoia, but were not aggressive. Having paranoid symptoms, as well as not being fully recovered, marked the participants' behaviour as different from other people. I had to devote my efforts to building rapport and gaining their trust. Therefore, some conversations were not designed for answering the research questions but rather for building that rapport and

Chapter 6 Discussion

holding the participant's interest. Furthermore, some participants did not talk much and they preferred to reply to only closed-ended questions, rather than explaining things or their feelings. Some participants talked outside of the topic and asked me personal questions, which made me feel uncomfortable. There are several things that I have learnt from interviewing participants with schizophrenia. I would recommend that being polite, patient and flexible is the key to success when interviewing such patients in rural Thailand. Moreover, I found that listening without judging, as well as empathising, was crucial. Additionally, working with participants with schizophrenia might require a researcher to handle unexpected issues; for example, a potential participant cancelled the interview without informing the gatekeepers. Other patients simply stopped talking whilst in an interview situation, and several lacked concentration at times.

5) Interview methods

At this point, I realised that face to face interviews are more useful and effective than telephone interviews. This is because the research participants tended to participate and become more engaged in a face to face scenario, as opposed to during telephone interviews. Generally, patients with schizophrenia and their caregivers used prepaid mobile phones, which are considered to be convenient and cheap. Unfortunately, several of the numbers that they provided were unable to be contacted. This may be because almost all of the research participants with schizophrenia and their caregivers, whom the researcher had interviewed, cancelled their numbers and/ or there was a lack of a mobile phone network in those rural areas. There were two patients with schizophrenia and one caregiver who were successfully followed up by telephone interviews. Interestingly, the telephone interviewees responded to questions well, which was quite similar to the situation with face to face interviews. This may be because of the rapport which was established during face to face interviews or Kreng jai culture.

6) Transcribing interviews and translating transcripts

I found transcribing interviews to be the most exhausting part of the research process, but it is also the most important part of information gathering, which assisted me to make sense of the data. I could repeat hearing the interviews and write some information that I had not concentrated on or noted during

data collection. Although transcribing all interviews took me several months, this helped me to spend less time on data analysis because I understood and remembered the data after listening, transcribing and translating the interviews.

I found that translating Thai interview transcripts into English was challenging, because some meanings could not be replaced by English words, due to limitation of words and cultures/ beliefs that are specific to the Thai context. However, there are some interviews that were translated into English, in order to validate themes with my supervisory team. I translated some transcripts and sent them to a couple of Thai health professionals, who are bilingual and hold doctoral degrees in health, for back translating and rechecking of the transcripts. This procedure was designed to ensure that the translations were not losing the essence of the data. Moreover, all translated transcripts were proofread by a native English speaker, with a master's degree; the researcher then rechecked the proofread transcripts to prevent misunderstanding of some texts, which cultural differences might cause. In addition, the quotations in the findings chapter were proofread by an English native speaker, with a PhD, in order to ensure the accuracy of language. Information relating to cultural/ belief systems, health care and the Thai society context was provided. This is because language and cultural/ belief differences may cause miscommunication and misunderstanding (van Nes et al. 2010). For example Hoffman (1989) explained her doubt of translating a Polish word into an English word, regarding the appropriateness of wording and cultural context, which she felt might be different between Polish and British cultures. Therefore, the supervisory team was able to closely supervise my data analysis process.

7) Impact of media

During the data collection period, there was news about some people with mental health disease who had murdered health professionals at the THPHs. Therefore, this might affect the THPH staff who participated in this study. Some THPH staff expressed their sympathy to the victims as well as their fear to contact the patients with schizophrenia. This unfortunate incident may have affected the atmosphere of care provision at the primary level during the period of the data collection.

Chapter 6 Discussion

8) The data analysis process

The data analysis process was longer than I thought it would be. Data analysis was one of the hardest parts of the qualitative study; the researcher has to be concerned about the quality of the analysed data, as well as ethics of presenting a participant's quotations. Qualitative data analysis requires time and effort to analyse and reanalyse, as well as check and re-check, until there is no doubt about the findings. I would recommend a novice researcher to use Braun and Clarke (2006) for thematic analysis; therefore a novice researcher could follow the six steps which are helpful to recheck their analysed data. Moreover, the process of translating selected quotations is also time consuming. Selecting the participants' quotations sometimes caused me to experience personal dilemmas. Some quotations led me to think that I did not want to embarrass my country, such as noting violence and compulsory treatment associated with patients with schizophrenia. However, if I did not mention these things, how could we improve the service? Hence, I decided to write them and made sure that I did not have any of my own opinion in the findings chapter. Therefore, the data could speak for itself.

7.4 Contribution of knowledge

This study is the first qualitative study to explore the needs and unmet needs of the schizophrenia stakeholders at the primary care level in rural Thailand. This research was carried out to explore and gain an in-depth understanding of the patients' and caregivers' and service providers' perspectives. The forty participants gave face to face interviews in their community settings in rural areas of Thailand; almost all of these places were difficult to reach. Interviews mainly took place at the service user's house, but also at the THPHs, which provided the opportunity to access new knowledge regarding this neglected context. Telephone interviews were used to follow up any missing information, as well as giving a chance to the patients and caregivers who were not ready and/or were unable to provide face to face interviews. All of these interactions were driven by a pragmatic approach, which allowed me to adapt the research approach to suit the unfamiliar research setting. Therefore, being flexible regarding interview techniques and interview places led me to reach the optimum number of research participants, as well as enhance the richness of data. This research obtained a wide range of stakeholder views regarding

caring for people with schizophrenia in the rural Thai community. Such data will contribute new knowledge to fill the gaps of practice in the community mental health field. The contribution of knowledge from this study could be in three areas: i) the gap between the Thai public mental health policy and the reality of community mental health practice, ii) needs and unmet needs for care at the rural Thai primary care level, and iii) the impact of cultural beliefs on community mental health care.

7.4.1 The gap between the Thai public mental health policy and community mental health care practice

Community mental health care appeared to be one of the duties that the THPH staff have to undertake. Although the Thai public health department indicated a framework and criteria for community mental health care, these seemed to be difficult to follow. Some primary care staff were not confident to provide care, and they also had excessive administrative burdens; therefore they were unable to manage the care as they and the patients and caregivers wished. However, the staff's attitudes appear to be the most important driver for suitable community mental health care provision. Some staff used 'Boon' as the goal to work overtime, because the Thai health care system could not and does not promote and pay any allowance for extra working hours.

The biomedical model dominates the Thai health care system; however this may be because of the lack of a strong community mental health service to support the needs of a strategy for community mental health care. Therefore, medication appeared to be the only practical and available way to manage a patient's psychotic symptoms, as well as improving their recovery. Therefore, this could also help to reduce the caregivers' burdens. It was argued in this study that medication adherence seemed not to involve, or be linked to, the patients' and caregivers' opinions regarding medication monitoring and compulsory medication treatment.

7.4.2 Needs and unmet needs for mental health care at the rural Thai primary care level

Needs and unmet needs for community mental health care in this study seemed to be similar to other studies around the world, regarding the need to improve the national community mental health policy, improving the quantity and quality of staff, and providing care by using a bio-psychosocial model, rather than the traditional medication-based model. It could be seen that the government should consider community mental health care provision at the THPH level, where the service users could access the service more easily. Hence improving quantity and quality of the THPH staff, to provide care to meet the patients' and caregivers' needs, appeared to be crucial. Moreover, patients did not just need antipsychotic medication to prevent recurrence of psychotic symptoms, but also required psychological support and de-stigmatisation; the latter to prepare for re-entry into their communities. It is also believed that unlocking stigmatisation in the rural Thai society may enhance job opportunities for the patients. Therefore, the patients could become relatively independent which, in turn, could reduce the caregivers' burdens. At this point, the health professionals should be concerned about the thin line between supportive and sympathetic culture and enhancing patients' capability to be relatively independent. Therefore, patients could receive support they need from society, which could be considered as improving their social skills. However, the patients should be able to use a full range of their capabilities to become self-dependent.

It seems that approaching needs and unmet needs in the rural Thai society may not be straightforward. This may be because needs and unmet needs could be concealed, due to the Thai rural community context. Some specific Thai cultures and beliefs, regarding Krong jai and karma, will be discussed in the next sub-heading.

7.4.3 The impacts of cultural beliefs towards community mental health care.

The Thai culture regarding sympathy and support allows patients with schizophrenia to be dependent, particularly when it comes to their families. Rural Thai society offers dependency as a default option for the mentally ill, who may actually be capable of doing some work. Thus, underestimating the patient's capability, together with full support from society, without insight into the nature of schizophrenia, could affect the patient's rehabilitation further. The implication for community mental health practice is providing information about the essential nature of empowering and rehabilitating patients with schizophrenia, in relation to self-help and becoming relatively independent. Stigma appeared to be one of the negative cultural beliefs which devalued people with schizophrenia in the rural Thai community. There are contradictions between the Thai cultures, Buddhist principles and mental health care. Thai society seems to be ready to provide holistic care provision and social support; however, fear of a patient's violent behaviour appears to inhibit this care model from actually happening.

Family support in the ordinary Thai family is different from a developed Asian country, such as Japan, or in developed western countries. Although the caregivers provide care with unconditional love, which they offer to the patients, there are psychological distances between family members. As a result, many of the patients feel they do not have as much emotional support from their family members as they need, or would like. The community mental health implication could be that the assessing of family relationships may help the health professionals to understand and adjust health education advice for the caregivers, as well as construct a more proactive model for the families of the patients with schizophrenia.

However, the uniqueness of this study is about how to assess the needs and unmet needs of schizophrenia stakeholders who have *Kreng jai* as a philosophy of living: 'do not bother or disturb others with your problems'. Interestingly, some caregivers who participated in this study perceived Karma as accepting negative behaviours from the patients with schizophrenia, as well as accepting the entire care burden as their own responsibility. Such

Chapter 6 Discussion

acceptance could negatively affect the caregivers' health, an outcome which is to be avoided if possible, as they are regarded as the most important group of carers for people with schizophrenia in the community setting. Moreover, faith and respect in the health professionals could inhibit the service users to question them and/or seek more information; but instead passively complying with the health professionals' suggestions. Hence, it is arguable that this culture will not support community mental health care quality improvement, for the reasons set out above.

7.4.4 Suggestion for future research

This study included the three main groups of people who are involved in community mental health care. However, there are key groups of people who should be included in further research: namely VHVs, community leaders and other villagers. Such a study could reveal the different dimensions and perspectives of mental health care in the real world. Moreover, this current study has illustrated the importance of needs and unmet needs for the care of people with schizophrenia at the primary care level setting in rural Thailand. In particular, the results have highlighted the possibility that cultural beliefs could affect both patients' and caregivers' and service provider's care collaboration. Hence, it would be worthwhile for Thai community mental health care research to focus on the psychosocial and rehabilitation aspects of care.

7.5 Final conclusion

This study's findings answer the research questions regarding exploring needs, unmet needs and recommendations for community mental health care at the primary care setting, in rural Thai communities. This study contributes to the understanding of care at the sub-district level in rural Thai communities. From analysis of the lived experience, stigmatisation and violence appeared to be huge barriers for the patients with schizophrenia, who were trying to reintegrate themselves into the community, after having a diagnosis which also appeared to be a burden for the caregivers. Cultural and religious beliefs play an important part in care regarding help seeking behaviour and coping strategies. The Thai cultural and Buddhist beliefs regarding 'Boon' and 'Karma' could influence the caregivers to either seek, or avoid seeking, help and the health professionals to provide care. For example, 'Boon' influenced some

health professionals in this study to be 24 hours on call for community mental health care; 'Karma' may prolong help seeking from the caregivers because they accept any burdens as their own fault. It could be seen that needs and unmet needs for care seemed to be similar to studies both from developed and other developing countries. However, medication was perceived as the heart of care for this group in the researched rural Thai communities, which revealed insufficient care at the primary level. It is recommended that the Thai public health policy should consider improving both the quantity and quality of trained mental health professionals, in order to provide appropriate community mental health care at the primary care level. Moreover, a bio-psychosocial model of care should be introduced within health care education and practice. It is recommended that schizophrenia service evaluation should be a subject for research in the future. The needs of effective care in relation to patients' cultures and beliefs are a topic recommended for future research. The value of this study is the recommendation for health professionals that the assessment of service users' cultures and beliefs is crucial for facilitating effective community mental health provision. This approach may help to reduce barriers between the service users and service providers, as well as improving their collaboration. It will be helpful for the Thai community mental health service if the health professionals and volunteers could provide care by using a humanised, holistic care concept.

Appendices

Appendix 1: Definition of Rural area in Thailand, England and United States of America

Country	Definition of 'rural'	Remark
Thailand (The Royal Institute 2007).	Countryside or the regions that far away from the capital city.	This can be assumed that everywhere in Thailand except Bangkok is defined as rural areas. It is arguable that recently every city center in Thailand may consider urban area instead of rural area. This definition may lead bias, for example, if the researcher did recruit samples from some downtowns of major cities, such as, Chiang Mai, Nonthaburi and Khon Kaen. Hence, inequality of health personnel, medicine and other health equipment may be issues.
England (Department for Environment Food and Rural Affairs 2001 p8).	Mainly, characteristic of rural in England can be categorized into 3 groups, namely, significant rural, rural-50 and rural- 80. Significant rural defines by the rural that has over 37,000 people and 26-50% of them have settlements in rural areas and large market towns whereas rural-50 have 50-79% and rural-80 have at least 80%.	Population density is the main criteria of rural in England; however this has utilization limitation regarding local authority. This, presumably, may need to consider before applying for health research either.
United States of America (Hart et al. 2005b).	In summary, there are several criteria to define rural areas, such as, population density and zip code; however this is not reliable for research in health.	Recruiting research participants in health may not comply with the criteria of rural definition regarding population density and zip code because this may not represent actual rural.

Appendix 2: Keywords for database searching

PIE form	Main keywords	Alternative keywords
Population (Stakeholders)	Patients with schizophrenia	Schizophrenia
	Caregivers	Care taker, caregiver, carer, relatives, family, friend, health volunteer
	Health care professionals	Rural health personnel, health professional, primary care staff, health volunteer, nurse, psychiatrist, mental health worker, public health worker
Intervention/ Exposure (Schizophrenia care)	Community mental health care service	Community mental health service, primary care service, primary health care, primary care level, primary care unit
Evaluation	Perspectives	Perception, view, attitude, experience, opinion, needs, unmet needs
Setting (Community setting, rural areas)	Community, rural areas	Community, rural, developing countries

Appendix 3: Inclusion and exclusion criteria

Inclusion criteria	Rationale
Patients with schizophrenia	The patient group is the centre of the study which it is aiming to provide care, based on client perspectives.
Every age group	Although this study is focusing on adult group of age, it is worthwhile to not limit inclusion criteria in the first place. Therefore, some articles can be used for schizophrenia concept as well as using for predicting schizophrenia impact further.
Thai/ English language	There is translation limitation.
Different perspectives towards schizophrenia causes: biomedical model, environmental and psychosocial factors.	These will illustrate ongoing debates around schizophrenia cause. This is because the belief of schizophrenia cause could lead to selected cares/ treatments.
Schizophrenia's consequences: pharmacotherapy, psychosocial therapy, schizophrenia diagnosis, executive dysfunctions from schizophrenia.	This is crucial information which intends to be used for providing contemporary debates around schizophrenia concepts.
Schizophrenia comorbidity; both physical and mental diseases	This is aiming to explore schizophrenia comorbidity, which may impact patient's life expectancy and quality of life.
Physical care for patients with schizophrenia	Patients with schizophrenia tend to have physical problems due to medication treatments that they receive
Psychosocial interventions, such as cognitive behavioural therapy (CBT) and adherence therapy (AT).	This will be used to confirm if psychosocial interventions are available in for community mental health care in Thailand.
Schizophrenia treatment guidelines.	This will be used to compare available guidelines around the world.
Stigmatisation, relapse, recovery, quality of life, well-being and burden concepts.	All of which is linking with community mental health care in a community setting.
A study about cost-effectiveness of an intervention or medication.	This will be useful for evaluating schizophrenia's impact.
Publication year between 1992-2014	Although publications older than 5 years are considering outdated, it is worthwhile to broaden the publication year according to ICD 10 and DSM IV publication. ICD 10 was published in 1992 whereas DSM IV was published in 1994. The reason for using DSM IV as selecting criteria is DSM V (the most recent edition) was published in 2013 which is quite new. Therefore, there will be a minimal amount of papers available. Moreover, the DSM V may not yet be used broadly.

Appendix 3: Inclusion criteria (continued).

Inclusion criteria	Rationale
Peer reviewed articles and peer reviewed journals	It is aiming to find strong evidence in the literature.
English and Thai language	Although it is aiming to include Thai literature in the literature review, there is no Thai language paper available in international databases. All non-Thai and non-English articles will be rejected due to no translation funding available for this research project.
Human	This literature review proposes to explore the concept of schizophrenia regarding historical background, recent evidence about causes, impairments, diagnostic criteria, treatments and debates around schizophrenia diagnosis. Hence, this literature review will not investigate drug trials and animal testing in depth.

Appendix 4: Database search 3 Databases from EBSCO host

Search ID	Keywords	Options	CINAHL	MEDLINE	PsycINFO	After discarding duplications
S1	(MM 'Schizophrenia') OR 'schizophrenia'	Search modes - Boolean/Phrase	17,570	108,715	101,286	227,571
S2	schizophren*	Search modes - Boolean/Phrase	17,696	113,863	106,000	237,559
S3	S1 OR S2	Search modes - Boolean/Phrase	17,696	113,863	106,000	237,559
S4	'cause'	Search modes - Boolean/Phrase	71,696	663,727	61,673	797,096
S5	influence OR Influen*	Search modes - Boolean/Phrase	107,953	1,006,392	355,893	1,470,238
S6	S4 OR S5	Search modes - Boolean/Phrase	176,369	1,634,515	411,266	2,222,150
S7	S3 AND S6	Search modes - Boolean/Phrase	1,034	9,096	9,256	19,386
S8	(MM 'Genes') OR 'gene'	Search modes - Boolean/Phrase	40,976	1,564,171	45,408	1,650,555
S9	Genetic OR genome OR genomes	Search modes - Boolean/Phrase	72,522	1,358,306	97,827	1,528,655
S10	heredity OR heredit*	Search modes - Boolean/Phrase	7,357	78,243	11,144	96,744
S11	twins	Search modes - Boolean/Phrase	4,913	37,732	12,883	55,528
S12	'parental age'	Search modes - Boolean/Phrase	90	1,368	259	1,717
S13	S8 OR S9 OR S10 OR S11 OR S12	Search modes - Boolean/Phrase	101,821	2,310,783	132,475	2,545,079
S14	(MM 'Environmental Monitoring') OR 'environment OR environment*'	Search modes - Boolean/Phrase	1,497	32,996	315	34,808
S15	'perinatal complication' OR (MM 'Labor Complications') OR (MM 'Pregnancy Complications, Infectious') OR (MM 'Female Urogenital Diseases and Pregnancy Complications') OR	Search modes - Boolean/Phrase	3,642	23,840	6	27,488

	(MM 'Pregnancy Complications, Parasitic')					
S16	S14 OR S15	Search modes - Boolean/Phrase	5,138	56,836	321	62,295
S17	(MM 'Rural Population') OR (MM 'Rural Areas') OR 'rural life OR rural'	Search modes - Boolean/Phrase	5,068	11,570	1	16,639
S18	(MM 'Urban Population') OR (MM 'Urban Areas') OR 'urban'	Search modes - Boolean/Phrase	35,093	139,736	51,394	226,223
S19	S17 OR S18	Search modes - Boolean/Phrase	39,063	147,967		238,425
S20	(MM 'Psychosocial Aspects of Illness') OR 'psychosocial factors'	Search modes - Boolean/Phrase	252,640	8,484	51,395	291,607
S21	(MM 'Cultural Diversity') OR (MM 'Cultural Competence') OR (MM 'Cultural Values') OR (MM 'Culture')	Search modes - Boolean/Phrase	15,416	16,601	30,483	32,017
S22	S20 OR S21	Search modes - Boolean/Phrase	265,196	25,017	0	320,696
S23	(MM 'Brain Diseases, Metabolic, Inborn') OR (MM 'Hypoxia-Ischemia, Brain, Neonatal') OR 'brain abnormalities OR brain anatomy OR brain chemistry OR brain damage OR brain development' OR (MM 'Brain Injuries')	Search modes - Boolean/Phrase	12,427	34,676	0	47,103
S24	(MM 'Neurotransmitters') OR 'neurotransmitters'	Search modes - Boolean/Phrase	1,414	19,810	7,392	28,616
S25	S23 OR S24	Search modes - Boolean/Phrase	13,806	54,406	7,392	75,604
S26	S7 AND S13	Search modes - Boolean/Phrase	109	2,052	1,758	3,919

S27	S7 AND S16	Search modes - Boolean/Phrase	1	11	0	11
S28	S7 AND S19	Search modes - Boolean/Phrase	19	106	96	174
S29	S7 AND S22	Search modes - Boolean/Phrase	242	79	146	439
S30	S7 AND S25	Search modes - Boolean/Phrase	6	100	86	164
S31	S3 AND S13	Search modes - Boolean/Phrase	1,150	14,112	11,411	26,673
S32	S3 AND S16	Search modes - Boolean/Phrase	24	86	9	99
S33	S3 AND S19	Search modes - Boolean/Phrase	178	895	689	1,762
S34	S3 AND S22	Search modes - Boolean/Phrase	3,412	386	882	4,680
S35	S3 AND S25	Search modes - Boolean/Phrase	67	697	613	1,377
S36	S3 AND S25	Limiters - Linked Full Text; Date of Publication: 19920101-20141231; English Language Search modes - Boolean/Phrase	39	279	102	477
S37	S3 AND S4	Limiters - Linked Full Text; Date of Publication: 19650101-20141231; English Language Search modes - Boolean/Phrase	199	1,514	1,156	2,019

Database searching for schizophrenia evidence in Thailand

Search ID	Keywords	Options	CINAHL	MEDLINE	PsycINFO	After discarding duplications
S1	(MM 'Schizophrenia') OR 'schizophrenia'	Search modes - Boolean/Phrase	17,570	108,764	103,705	230,039
S2	(MM 'Thailand') OR 'thailand OR Thai'	Search modes - Boolean/Phrase	21	27	8	52 (after discarding the 4 duplications)
S3	S1 AND S2	Search modes - Boolean/Phrase	0	0	0	0
S4	schizophren*	Search modes - Boolean/Phrase	17,696	4,642,778	415,434	240,012
S5	S1 OR S5	Search modes - Boolean/Phrase	17,696	113,912	108,404	240,012
S6	S2 AND S6	Search modes - Boolean/Phrase	0	0	0	0

AMED: AMED does not provide MeSH terms (4th June 2014)

Search ID	Keywords	Options	Retrieved papers
S1	schizophrenia OR schizophren*	Search modes - Boolean/Phrase	1,023
S2	causes of disease OR cause OR causation	Search modes - Boolean/Phrase	6,733
S3	S1 AND S2	Search modes - Boolean/Phrase	24

EMBASE (22nd May 2014)

Search ID	Keyword	Search mode	Retrieved papers
1	schizophrenia.mp. or *schizophrenia/	Advanced	102,640
2	Schizophrenia/ or schizophreni*.mp.	Advanced	103,460
3	1 or 2	Advanced	103,460
4	Thailand.mp. or Thailand/	Advanced	21,307
5	Thai.mp.	Advanced	10,416
6	4 or 5	Advanced	25,241
7	3 and 6	Advanced	103

Web of Sciences (4th June 2014)

Keyword	Limiters	Retrieved papers
Schizophrenia AND Community AND Rural	limit English language	282
Schizophrenia AND Community AND Rural	Refined by: LANGUAGES: (ENGLISH) AND [excluding] PUBLICATION YEARS: (1979 OR 1981 OR 1986 OR 1982 OR 1985 OR 1987 OR 1967 OR 1972 OR 1973 OR 1976 OR 1975 OR 1978 OR 1989 OR 1980 OR 1988 OR 1991 OR 1970 OR 1990) Timespan: All years. Search language=Auto	247

Thai Library Integrated System (ThaiLIS): the Thai database collects the Thai theses across Thailand (19th May 2014)

Search ID	Keywords	Retrieved papers
S1	Schizophrenia	107
S2	community	6,155
S3	Schizophrenia and community	7
S4	จิตเภท (this word means schizophrenia)	254
S5	ชุมชน (this word means community)	11,593
S6	จิตเภท and ชุมชน	29

*ThaiLIS does not have 'OR' function like the other databases do. Thus, the keywords were searched separately. However, the Thai keyword 'จิตเภท' covers all schizophrenia topics because every thesis comprises an English language abstract.

Additional database search for psychosocial factors cause schizophrenia
(20th October 2015)

Search ID	Keywords	Options	CINAHL, MEDLINE, and PsycINFO
S1	schizophrenia cause	Search modes - Boolean/Phrase	1,481
S2	psychosocial factors	Search modes - Boolean/Phrase	331,197
S3	S1 AND S2	Search modes - Boolean/Phrase	46

Appendix5: The example of selected articles for schizophrenia causes

Title, author and country	Aim/ objective	Participant and sample size	Methodology, method and ethical approval	Finding and implication	Remark
<p>Illness perspectives of Thais diagnosed with schizophrenia (Sanseeha et al. 2009).</p> <p>Country: Thailand</p>	<p>Aim:</p> <p>1.To explore the perceptions of 18 people diagnosed with schizophrenia from 1-10 years to uncover how they perceived themselves and their illness.</p> <p>2.To fulfil the patient with schizophrenia's perspective towards their illness perceptions by interviewing their family members.</p>	<p>i) 18 patients with schizophrenia (duration of diagnosis 1-10 years)</p> <p>ii) 12 relatives of patients with schizophrenia</p>	<p>i) Methodology: Phenomenology (Heidegger's hermeneutic phenomenology)</p> <p>ii) Method:</p> <ul style="list-style-type: none"> - In-depth interview and observation. - Purposive sampling but there is no explanation of how the participants were recruited. 	<p>i) Finding:</p> <p>Four themes emerged, namely, 'perceptions of mental illness, perceptions of the causes of illness, perceptions of discrimination, and attempting to live with schizophrenia.' This means that</p> <ol style="list-style-type: none"> 1. Perceptions of the causes of illness that is from 'karma'. 2. Perceptions of discrimination when they have a diagnosis with schizophrenia. 3. Attempting to live with schizophrenia by adjusting themselves to live happily. <p>ii) implication:</p> <ol style="list-style-type: none"> 1. Mental health policy should be more considering the Thai culture/belief alongside with Westernised mental health care. 2. Patients with schizophrenia in the Thai society felt shamed on having schizophrenia, so it is necessarily to provide a program that can convince the public to be more insight about schizophrenia. Patients with schizophrenia should be trained in communication skills and they should work. Therefore, they can be independent and 3. Mental health professionals should collaborate with the patients to achieve the patient's life goals. 	<ol style="list-style-type: none"> 1. There is no participant recruitment strategy in the report. 2. Data saturation is not discussed in this study. 3. The relationship and potential biases that may cause from the researcher is not discussed in this article. 4. Clinical implications are too broadly suggested.

Appendix 6: The example of using Critical Appraisal Skills Programme (CASP) for critiquing article

Title: Illness perspectives of Thais diagnosed with schizophrenia

Author: Sanseeha et al. (2009).

Screening questions

1. Was there a clear statement of the aims of the research?

The research aims were clearly stated. The research aims were:

- 1) to explore the perceptions of 18 people diagnosed with schizophrenia from 1-10 years to uncover how they perceived themselves and their illness.
- 2) to fulfil the patient with schizophrenia's perspective towards their illness perceptions by interviewing their family members.

2. Is a qualitative methodology appropriate?

Qualitative approach is appropriate for this study because the researchers aimed to explore perspectives towards schizophrenia diagnosis. It considers that qualitative methodology is flexible for including all perceptions.

Detailed questions

3. Was the research design appropriate to address the aims of the research?

The research design can address the research aim. The researchers used phenomenology to explore and illuminate unclear issue regarding illness perception of patients with schizophrenia in Thailand.

4. Was the recruitment strategy appropriate to the aims of the research?

Participant recruitment strategy is explained clearly. Purposive sampling was used for this study but there is no explanation of how the participants were recruited. The participant recruitment strategy is appropriate for the study in terms of diverse perspectives.

5. Were the data collected in a way that addressed the research issue?

The setting of data collection is clearly stated. In-depth interview and observation were used for individual interviews. These allowed the researchers to combine the interview data and their field observation to answer the research questions. However, there is no participant recruitment strategy in the paper.

6. Has the relationship between researcher and participants been adequately considered?

No, the relationships between the research participants and the researchers, and potential biases for this study were not discussed in this article.

7. Have ethical issues been taken into consideration?

Yes, the research was considered by the Institution review board. All of the research participants consented to take part in the study.

8. Was the data analysis sufficiently rigorous?

The researchers indicated that Heidegger's hermeneutic phenomenology was used for data analysis. The researchers reported that they concerned about credibility of the data according to member checking for data analysis process.

9. Is there a clear statement of findings?

Findings are clearly stated. Themes of the findings can answer the research questions. However, it is argued that illness perspectives from patients and their relatives might be different. The opinions of patients who had direct experiences and relatives who were partially involved the care might be, somehow, different.

10. How valuable is the research?

This study is valuable in terms of understanding how the participants with schizophrenia and their relatives perceived schizophrenia in the rural Thai context. This study illuminated what having a diagnosis and living with schizophrenia is like. However, the clinical implications for this study were too broad.

Appendix 7: Comparison between ICD10 and DSM5 criteria for schizophrenia diagnosis

Core criteria	ICD 10	DSM 5	Remark
1. Schizophrenia definition	Schizophrenia is defined as a mental disorder that affects a person's cognitive processes as well as resulting in 'inappropriate perception and blunted affect'.	Schizophrenia involves abnormalities of 'cognitive, behavioural and emotional functions'; however a diagnosis of schizophrenia is not relying upon only one of those psychotic symptoms.	Both ICD 10 and DSM 5 briefly defined schizophrenia by using key symptoms which are cognitive deficit, positive and negative symptoms. Both diagnostic criteria indicated social and occupational dysfunctions due to schizophrenia.
2. Subtypes	10 subtypes, such as, F20.0 Paranoid schizophrenia, F20.1 Hebephrenic schizophrenia, F20.2 Catatonic schizophrenia and etc. 10 schizophrenia classified course, such as, .x0 continuous, .x1 episodic with progressive deficit, .x2 episodic with stable deficit and etc.	No subtype.	Schizophrenia subtype for DSM 5 is cancelled because of diagnosis validity concerns, whereas ICD 10 still provides 10 schizophrenia subtypes. For ICD10 criterion, providing subtypes may enlighten the guideline users as to the specific characteristics. However, clinically, this may require specialists to differentially diagnose those subtypes.
3. Diagnostic criteria contain positive and negative symptoms, mood and motor symptoms and disorganisation.	There is no specific characteristic for schizophrenia diagnosis. However, significant criteria focus on positive and negative symptoms regarding abnormalities of	The patients have 2 or more within 5 criteria which the significant criteria must be 1, 2 and 3: 1. Delusion 2. Hallucination 3. Disorganised speech 4. Grossly disorganised	ICD 10 weights cognitive dysfunctions, positive and negative symptoms as the key criteria; however precautions for other types of mental disorder which may be comorbid with

	thought, perception, catatonic behaviour and social dysfunctions.	or catatonic behaviour 5.Negative symptoms	schizophrenia are indicated. However, DSM 5 focuses more on positive symptoms and cognitive impairment.
4. Cognitive deficits	ICD10 provides unclear criteria for cognitive deficit. However, ICD 10 indicates that schizophrenia affects a person's cognitive process which will lead to cognitive deficit further.	DSM 5 links cognitive deficits with social and occupational dysfunctions which normally occur in patients with schizophrenia.	Both criteria are similar in terms of the extent to which schizophrenia affects the patient's cognitive processes which leads to low capacity for some cognitive processes e.g. memory. Degeneration of brain function, negative and positive symptoms in patients with schizophrenia cause further social and occupational dysfunctions.
5. Duration of diagnosis confirmation	The positive and/or negative symptoms should be present almost all of the time or at least for one month or more.	Psychotic symptoms must be present for 6 months and at least 1 month for active symptoms.	The consensus baseline of duration for confirming that a person has schizophrenia is at least one month.

Appendix 8: Search terms

Search ID	Keywords	Options	CINAHL	MEDLINE	PsycINFO	Three databases
S1	experiences	Search modes - Boolean/Phrase	64,162	122,084	391,963	578,209
S2	schizophrenia	Search modes - Boolean/Phrase	17,730	109,409	104,287	231,426
S3	care OR caring	Search modes - Boolean/Phrase	806,899	1,592,222	338,343	2,737,464
S4	live OR living	Search modes - Boolean/Phrase	86,196	351,205	427,988	865,389
S5	community	Search modes - Boolean/Phrase	157,214	407,056	266,292	830,562
S6	rural	Search modes - Boolean/Phrase	37,704	120,819	32,397	190,920
S7	S5 AND S6	Search modes - Boolean/Phrase	8,262	25,754	11,791	45,807
S8	S3 OR S4	Search modes - Boolean/Phrase	863,124	1,880,305	687,444	3,430,873
S9	S2 AND S7 AND S8	Search modes - Boolean/Phrase	23	99	105	227
S10	S1 AND S2 AND S7 AND S8	Search modes - Boolean/Phrase	2	2	12	16
S11	carer OR caregiver OR care taker OR relatives OR friends OR family OR Husband OR wife OR wives	Search modes - Boolean/Phrase	171,910	816,890	508,217	1,497,017
S12	S10 AND S11	Search modes - Boolean/Phrase	1	1	6	8
S13	S1 AND S2 AND S5 AND S8 AND S11	Search modes - Boolean/Phrase	162	26	20	208
S14	patient OR client OR service user	Search modes - Boolean/Phrase	543,247	1,896,937	627,897	3,068,081
S15	S1 AND S2 AND S5 AND S8 AND S14	Search modes - Boolean/Phrase	23	47	255	325
S16	TI health professional OR TI primary care staff	Search modes - Boolean/Phrase	215,949	262,811	144,264	623,024

	OR TI community health staff OR nurse OR psychiatrist OR health personnel					
S17	S1 AND S2 AND S5 AND S8 AND S16	Search modes - Boolean/Phrase	9	11	52	72
S18	S13 OR S15 OR S17	Search modes - Boolean/Phrase	38	58	339	435
S19	S13 AND S15 AND S17	Search modes - Boolean/Phrase	2	3	11	16
S20	need OR demand OR expectation OR expect*	Search modes - Boolean/Phrase	201,134	974,080	492,679	1,667,893
S21	S2 AND S7 AND S20	Search modes - Boolean/Phrase	13	28	34	75
S22	S18 OR S21	Search modes - Boolean/Phrase	50	85	367	467
S23	S18 OR S21	Search modes - Boolean/Phrase	29	45	162	236
S24	S18 OR S21	Limiters - English Language Search modes - Boolean/Phrase	46	74	347	467
S25	S17 OR S24	Search modes - Boolean/Phrase	46	74	351	471
S26	S17 OR S24	Limiters - Linked Full Text; English Language Search modes - Boolean/Phrase	27	45	161	233

International database searching for evidence of schizophrenia in Thailand

Search ID	Keywords	Options	CINAHL	MEDLINE	PsycINFO	Three databases
S1	(MM 'Schizophrenia') OR 'schizophrenia'	Search modes - Boolean/Phrase	17,570	108,764	103,705	230,039
S2	(MM 'Thailand') OR 'thailand OR Thai'	Search modes - Boolean/Phrase	21	27	8	52 (after discarding the 4 duplications)
S3	S1 AND S2	Search modes - Boolean/Phrase	0	0	0	0
S4	schizophren*	Search modes - Boolean/Phrase	17,696	4,642,778	415,434	240,012
S5	S1 OR S4	Search modes - Boolean/Phrase	17,696	113,912	108,404	240,012
S6	S2 AND S5	Search modes - Boolean/Phrase	0	0	0	0

EMBASE (22nd May 2014)

Search ID	Keyword	Search mode	Retrieved papers
1	schizophrenia.mp. or *schizophrenia/	Advanced	102,640
2	schizophrenia/ or schizophreni*.mp.	Advanced	103,460
3	1 or 2	Advanced	103,460
4	Thailand.mp. or Thailand/	Advanced	21,307
5	Thai.mp.	Advanced	10,416
6	4 or 5	Advanced	25,241
7	3 and 6	Advanced	103

AMED: AMED (4th June 2014)

Search ID	Keywords	Options	Retrieved papers
S1	schizophrenia OR schizophren*	Search modes - Boolean/Phrase	1,023
S2	causes of disease OR cause OR causation	Search modes - Boolean/Phrase	6,733
S3	S1 AND S2	Search modes - Boolean/Phrase	24

Web of Sciences (4th June 2014)

Keyword	Limiters	Retrieved papers
Schizophrenia AND Community AND Rural	limit English language	282
Schizophrenia AND Community AND Rural	Refined by: LANGUAGES: (ENGLISH) AND [excluding] PUBLICATION YEARS: (1979 OR 1981 OR 1986 OR 1982 OR 1985 OR 1987 OR 1967 OR 1972 OR 1973 OR 1976 OR 1975 OR 1978 OR 1989 OR 1980 OR 1988 OR 1991 OR 1970 OR 1990) Timespan: All years. Search language=Auto	247

Thai Library Integrated System (ThaiLIS): the Thai database collects the Thai theses across Thailand (19th May 2014)

Search ID	Keywords	Retrieved papers
S1	Schizophrenia	107
S2	Community	6,155
S3	Schizophrenia and community	7
S4	จิตเภท (this word means schizophrenia)	254
S5	ชุมชน (this word means community)	11,593
S6	จิตเภท and ชุมชน	29

Appendix 9: Inclusion and exclusion criteria

Inclusion criteria	Rationale
Patients with schizophrenia, caregivers, primary care staff, GPs, psychiatrists, nurse sand public health workers.	The patient group is the centre of the study which is aiming to provide care, based on clients' perspectives.
Adult group	Although this study is focusing on adult age group, it is worthwhile to not limit inclusion criteria in the first place. Therefore, some articles can be used for schizophrenia concept as well as used for predicting schizophrenia's impact further.
Schizophrenia treatment guidelines.	This will be used to compare available guidelines around the world.
Stigmatisation, relapse, recovery, quality of life, well-being and burden concepts.	All of which is linked to community mental health care in community settings.
Publication year between 1992-2014	Although the publications older than 5 years are considering out dated, it is worthwhile to broaden the publication year according to ICD 10 and DSM IV publication. ICD 10 was published in 1992 whereas DSM IV was published in 1994. The reason for using DSM IV as a selection criterion is DSM V (the most recent edition) was published in 2013 which is quite new. Therefore, there will be a minimal amount of papers available. Moreover, the DSM V may not yet be broadly used.
English and Thai language	Although it is aiming to include Thai literature in the literature review, there is no Thai language paper available in the international databases. All non-Thai and non-English articles will be rejected due to no translation funding available for this research project. ***

Appendix 10: Example of selected literature for experiences of living with/ caring for schizophrenia

Title, author and country	Aim/ objective	Participant and sample size	Methodology, method and ethical approval	Finding and implication	Remark
<p>Caring for the seriously mentally ill in Thailand: Buddhist family caregiving (Sethabouppha and Kane 2005).</p> <p>Country: Thailand</p>	<p>Research question: 'How Buddhism as a life philosophy was involved in the caregiving process?'</p> <p>Aims: To explore the live experiences from Thai Buddhist family caregivers about Buddhist caregiving.</p>	<p>15 patients with schizophrenia's caregivers</p>	<p>Study design: Qualitative: Phenomenology Data collection: Face to face in-depth interview and observation Tool: Semi-structured interview</p>	<p>i) Finding: Five major themes emerged: 1.Caregiving is Buddhist belief : Boon (merit) and Babb (demerit) 2.Caregiving is compassion : Caring and support 3.Caregiving is management : Stress management, symptom management and treatment management 4.Caregiving is acceptance : Incurable illness and sickness is natural 5.Caregiving is suffering : Physical burden, emotional distress, social problem, economic problem and knowledge deficit Themes have been using for creating the Buddhism and caregiving model.</p> <p>ii) Implication: The researcher claimed that this study can be generalised to other groups of Buddhist around the world. However, this may need to consider the types of Buddhism beliefs because the details of caring under those disciplines may be different from this study.</p>	<p>-Data collection was permitted from the hospital board and the university but there was no ethical approval. -There is no rationale for setting selection for this study available. -This study is very rich in terms of providing explanation about community mental health care using Buddhism life philosophy. - Data analysis is transparency because of member checking. Emerged themes were presented and discussed with the nursing staff at the hospital.</p>

Appendix 11: The example of using Critical appraisal using Critical Appraisal Skills Programme (CASP) for critiquing article

Title: Patients' and health professionals' views on primary care for people with serious mental illness: focus group study

Author: Lester et al. (2005)

Screening questions

1. Was there a clear statement of the aims of the research?

The research aims were clearly stated. The aims of the study were: to explore the experience of providing and receiving primary care from the perspectives of primary care health professionals and patients with serious mental illness.

2. Is a qualitative methodology appropriate?

Qualitative approach is appropriate for this study because the research aimed to explore experiences of receiving and providing care for patients with serious mental illness in the primary care level.

The important of problem is about the numbers of patients with serious mental illness especially schizophrenia and bipolar disorder. These groups of patients have both physical and mental health problems.

Detailed questions

3. **Was the research design appropriate to address the aims of the research?**

The research design can address the research aim. However, there are concerns about combining health professionals and patients in focus groups. This may be a dilemma because patients may be less likely to discuss about their frustrations. The patients may hesitate to express their negative opinions because they have to continue receiving care at that trust.

4. **Was the recruitment strategy appropriate to the aims of the research?**

Participant recruitment strategy is explained clearly. Purposive and snowball sampling were used for this study. These two participant recruitment strategies are appropriate for the study in terms of diverse perspectives.

5. **Were the data collected in a way that addressed the research issue?**

The setting of data collection is clearly stated. The topic guide was used for the focus groups. The researchers explained the pilot study and modification of the

topic guide. Data collection used focus group interview: six focus groups for each participant groups and six focus groups for combination.

Audio tape was used to record. Field notes and transcribed data were analysed by using NVivo computer software package.

Has the relationship between researcher and participants been adequately considered?

There is no indication of the researcher and participant relationship.

6. Have ethical issues been taken into consideration?

N/A

7. Was the data analysis sufficiently rigorous?

The researchers indicated that they use NVivo software to assist data analysis. Moreover, accuracy of the research findings was checked by the research participants.

8. Is there a clear statement of findings?

Findings are clearly stated. The findings and limitations of the study are discussed.

9. How valuable is the research?

This study is valuable in terms of providing care for patients with mental illness in primary care settings. Patients with severe mental illness need more accessible of care.

Mental health expertise is the crucial skill for health professionals because increasing their confident. However, the patients with severe mental illness not quite demand specialise in mental health care but willingness of listening and care.

The research results of this study may be used to generalise across the UK. To transfer the research findings to Thailand, however, the findings may be limited regarding health care system and culture different.

The findings are useful in terms of generating the perceptions of both service users and service providers which are different. Mental health specialist training is still a barrier of providing care for patients with mental illness. Hence, perhaps training is an initial step to provide mental health service for patients with mental illness in primary care level. This study focuses on the GPs who provide health care services in primary care settings. In the Thai primary care settings, the GP is not the main health care providers but Register Nurses and public health workers who are diverse in terms of mental health training. The mixture of different types of diagnosis may be a limited to generalise to a specific patient group.

Appendix 12: Ethical approval in the UK

Kingsaiyhod B.

From: ERGO <ergo@soton.ac.uk>
Sent: 15 August 2013 10:25
To: Kingsaiyhod B.
Subject: Your Ethics Submission (Ethics ID:7100) has been reviewed and approved

Submission Number: 7100

Submission Name: Stakeholder perspectives towards schizophrenia care at the sub-district level in rural Thailand

This is email is to let you know your submission was approved by the Ethics Committee.

You can begin your research unless you are still awaiting specific Health and Safety approval (e.g. for a Genetic or Biological Materials Risk Assessment)

Comments

1.Boon than, thank you for the clarification. I am happy to approve the amendment.

[Click here to view your submission](#)

ERGO : Ethics and Research Governance Online
<http://www.ergo.soton.ac.uk>

DO NOT REPLY TO THIS EMAIL

Kingsaiyhod B.

From: ERGO <ergo@soton.ac.uk>
Sent: 11 October 2013 14:28
To: Kingsaiyhod B.
Subject: Your Ethics Amendment (Ethics ID:7869) has been reviewed and approved

Follow Up Flag: Follow up
Flag Status: Flagged

Submission Number 7869:

This email is to confirm that the amendment request to your ethics form (Stakeholder perspectives towards schizophrenia care at the sub-district level in rural Thailand (Amendment 1)) has been approved by the Ethics Committee.

You can begin your research unless you are still awaiting specific Health and Safety approval (e.g. for a Genetic or Biological Materials Risk Assessment)

Comments

1. Thank you for your request to amend your ethics submission, and for the detail provided in explaining the exact changes for which you are seeking approval. I am happy to approve these amendments and wish you every success in receiving ethics approval in your home country and in the data collection.

[Click here to view your submission](#)

ERGO : Ethics and Research Governance Online
<http://www.ergo.soton.ac.uk>

DO NOT REPLY TO THIS EMAIL

Appendix 13: Ethical approval in Thailand

ที่ สธ ๒๕๕๗  โรงพยาบาลจิตเวช 
๒๕ กันยายน ๒๕๕๖

เรื่อง ผลการพิจารณาจริยธรรมการวิจัย

เรียน คุณบุญแทน กิ่งสายหยุด


ตามที่ท่านได้เสนอโครงการวิจัย เรื่อง มุมมองผู้มีส่วนได้ส่วนเสียที่มีต่อการดูแลผู้ป่วยโรคจิตเภท ในระดับ ตำบล เขตชนบท ประเทศไทย เพื่อขอรับพิจารณาจริยธรรมการวิจัยจากคณะกรรมการพิจารณาจริยธรรมการวิจัย คณะกรรมการฯ ได้พิจารณาครั้งที่ ๑ เมื่อวันที่ ๑๑ กันยายน ๒๕๕๖ ได้เสนอให้มีการปรับปรุงแก้ไข และผู้วิจัยได้ส่งฉบับแก้ไขยื่นเสนอใหม่ ดังรายละเอียดที่แนบมา นั้น

คณะกรรมการฯ ได้พิจารณาโครงการวิทยานิพนธ์ฉบับแก้ไข ครั้งที่ ๒ วันที่ ๒๕ กันยายน ๒๕๕๖ และ มีมติ

- อนุมัติ
- ปรับปรุงแก้ไข และยื่นเสนอใหม่
- ไม่อนุมัติ

ในการนี้ขอให้ท่านประสานติดต่อรายละเอียดในการดำเนินการเก็บข้อมูลวิจัยได้ที่งานการพยาบาลสุขภาพจิตและจิตเวชชุมชน

จึงเรียนมาเพื่อโปรดทราบ


ประธานคณะกรรมการพิจารณาจริยธรรมการวิจัย


ผู้อำนวยการโรงพยาบาลจิตเวช 

กลุ่มงานประชาสัมพันธ์




Ethics committee (Mental health and psychiatry)

Psychiatric Hospital

Approved document for research project

No. 2

Project title (Thai): มุมมองของผู้มีส่วนได้ส่วนเสียต่อการดูแลผู้ป่วยโรคจิตเภท ในระดับตำบล เขตชนบท ประเทศไทย

Project title (English): Stakeholder perspectives towards schizophrenia care at the sub-district level in rural Thailand.

Project code : 1/ 2013

Main researcher : Miss Boonthan Kingsaiyhod

Faculty of Health Sciences, the University of Southampton

Place of conducting research: Mental health and community mental health nursing department
Nakhonsawan Rajanakharind Psychiatric Hospital

Approved documents: 1. Thai research proposal submitted September 2013

Approved date : 24th September 2013

Expired date : 24th December 2013

Ethics committee (Mental health and psychiatry) approved the research project according to the international ethics criteria for conducting research in human subjects regarding Declaration of Helsinki, The Belmont Report, WHO Guideline for IRB and regulations of the Thai Medical Council (2006) section 9 regarding studies and trials in human subjects.

Signature
Dr. [Redacted]

Signature.....
Dr. [Redacted]

Medical Physician (Expert level) and Chair of ethics committee [Redacted] Psychiatric Hospital director

Date 24th September 2013



ที่ สธ. ๗/๙๙๐๐๖๒๒

โรงพยาบาลจิตเวช [redacted]

๒ ธันวาคม ๒๕๕๖

เรื่อง ผลการพิจารณา คำขอแก้ไข และเพิ่มเติมโครงการวิจัย

เรียน คุณบุญแทน กิ่งสายหยุด

ตามที่ท่านได้เสนอขอแก้ไข และเพิ่มเติมโครงการวิจัย เรื่อง มุมมองผู้มีส่วนได้ส่วนเสียที่มีต่อการดูแลผู้ป่วยโรคจิตเภท ในระดับ ตำบล เขตชนบท ประเทศไทย จากคณะกรรมการพิจารณาจริยธรรมวิจัย โรงพยาบาลจิตเวช [redacted] ในประเด็นกลยุทธ์การรับผู้เข้าร่วมวิจัยและเกณฑ์การคัดเลือกผู้ที่มีคุณสมบัติตรงตามข้อกำหนดเข้าร่วมโครงการวิจัย ตามรายละเอียดที่แนบมา นั้น

คณะกรรมการฯ ได้พิจารณาคำขอแก้ไข และเพิ่มเติมโครงการวิจัยฯ เรียบร้อยแล้ว และมีมติ

- อนุมัติ
- ปรับปรุงแก้ไข และยื่นเสนอใหม่
- ไม่อนุมัติ

จึงเรียนมาเพื่อโปรดทราบ

[redacted]
ประธานคณะกรรมการพิจารณาจริยธรรมการวิจัย

[redacted]
ผู้อำนวยการโรงพยาบาลจิตเวช [redacted]

กลุ่มงานประชาสัมพันธ์

โทร. ๐ [redacted]

โทรสาร [redacted]



No. ST 3082

[Redacted] Psychiatric Hospital
[Redacted]

2nd December 2013

Re: Ethical consideration result for the amendment research proposal

Dear Miss Boonthan Kingsaiyhod,

As you submitted the amendment version of the research title "Stakeholder perspectives towards schizophrenia care at the sub-district level in rural Thailand" to the ethics committee, [Redacted] Psychiatric Hospital, regarding participant recruitment strategies and inclusion criteria for supervisory team as details that you provided. The ethics committee did consider and decide to **APPROVE** the amendment research proposal which we suggest you to use the ethic No.2 to reference your data collection.

Yours Sincerely,

Signature [Redacted]
Dr. [Redacted]

Medical Physician (Expert level) and Chair of ethics committee

Signature..... [Redacted]
[Redacted] Psychiatric Hospital director

Public Relations department

Tel. (+66) [Redacted]

Fax (+66) [Redacted]

Appendix 14: Poster advertising the study

Please tell us your views regarding schizophrenia care at the Tambon Health Promotion Hospitals.

You are invited to take part in the study "Stakeholder perspectives towards schizophrenia care at the sub-district level in rural Thailand. This will be an individual face to face interview which will be last not longer than one and half hour.

We are interested in 4 groups of people;

1. persons who have a diagnosis with schizophrenia and living outside the hospital.
2. Caregiver of person with schizophrenia
3. The Tambon Health Promotion Hospital staff
4. The mental health specialists who supervise the Tambon Health Promotion Hospital staff regarding schizophrenia care

Note: your name and data will be anonymous.



For more information please contact :

Boonthan Kingsaiyhod

Tel: 081xxxxxxx

Email: bk1e09@soton.ac.uk

Appendix 15: Participant information sheet (for patients with schizophrenia)



Study Title: 'Stakeholder perspectives towards schizophrenia care at the sub-district level in rural Thailand'

Researcher: Miss Boonthan Kingsaiyhod **Ethics number:**

Please read this information carefully before deciding to take part in this research. If you are happy to participate you will be asked to sign a consent form.

What is the research about?

This is an MPhil/ PhD student research project to fulfil the requirement of Doctor of Philosophy degree at the University of Southampton, the UK. This research concerns the perceptions of people with schizophrenia, their caregivers, the Tambon Health Promotion Hospital staff and the supervisory team from the Psychiatric Hospital about schizophrenia care at the sub-district level in rural Thailand. This research project is trying to understand the key issues related to the care of schizophrenia in the community settings in order to improve future community mental health service.

Research sponsorship

This research project is being carried out by Boonthan Kingsaiyhod who is an international student being funding by the Royal Thai Government.

Why have I been chosen?

You have been chosen because we are hoping to talk to people who have been diagnosed with schizophrenia and fulfil the following criteria:

- 1) Receiving and keeping contact with the Department of community mental health; Psychiatric Hospital.
- 2) Adult (18-59 years old).
- 3) Able to consent.
- 4) Able to participate an interview.

Your view about being cared in the sub-district level is unique, so you are the best person who can tell us about the care that you receive as well as what you may need while living outside the hospital. Hence, it is invaluable to invite you to take part in this study.

What will happen to me if I take part?

The information that you will be asked is about your experiences and views of the care you have received from the Tambon Health Promotion Hospital team.

You will be asked to fill a personal information form which is about your age, marital status, religion/belief, income, number and duration of hospitalization and medication. This form could be filled by you or your carers. This form is absolutely anonymous, and you will not be asked to state your real name in the form. The personal information form is not compulsory, which means that you have right to not give any information that you feel uncomfortable.

You will take no longer than one hour. However, you have right to skip some questions that you do not want to answer. You are free to stop the interview and withdraw from the study at any time. The interview questions will be about your experience of receiving care by the Tambon Hospital Health Promotion and the team.

The researcher may contact you back afterwards via telephone. This is for clarifying some unclear issues of the face to face interview. The telephone interview will no longer than thirty minutes. However, it depends on you whether you will allow the researcher to do telephone interview.

Are there any benefits in my taking part?

This research aims to improve schizophrenia care at the sub-district level in rural Thailand by reflecting the views of people with schizophrenia. Although it will not immediately benefit study participants, it is expected that information from patients' particular perspectives will be considered to be a part of mental health care plans in the future. Moreover, the research results will be information for the public health education.

Are there any risks involved?

The questions in the interview schedule were reviewed by the peer reviewers and ethical committees at the University of Southampton. The Thai version of the interview schedule was reviewed by the ethical committees of the Psychiatric Hospital. This will ensure that no questions cause harm regarding stress or embarrassment.

Will my participation be confidential?

Your information will be kept confidential. Your name will be anonymous and all of your information will be kept in a password-protected personal computer notebook. The researcher is the only person who can access the laptop. The interview tape, transcriptions and hard copies of field notes will be kept in a locked cabinet in the researcher's accommodation during conducting data collection in Thailand. Your interview record(s) will be kept in locked cabinet at the Faculty of Health Sciences (University of Southampton, the UK) when the researcher has returned to the UK. The anonymous transcribed data will be shared between the researcher and peer-reviewers.

What happens if I change my mind?

It is absolutely your choice to make a decision whether to take part in this research study. You have the right to consent or to withdraw your consent for this study unconditionally. This will be definitely not affecting your treatment at all.

Who has reviewed the study?

The research proposal has been reviewed by the supervisory team, peer reviewers and ethical committees of the University of Southampton. The research proposal is also reviewed by the Psychiatric Hospital ethical committees in order to ensure both participant physical and psychological safety.

What happens if something goes wrong?

If you wish to make a complaint you could contact the MPhil/PhD program leader or the Chair of Ethics Committee of the University of Southampton, whose contact details are provided below:

Dr Maggie Donovan-Hall MPhil/PhD programme Lead, Faculty of Health Sciences, University of Southampton Email: mh699@soton.ac.uk Telephone Number: 02380 598880 (x28880)	Dr Martina Prude Head of Research Governance Tel: 02380 595058 Email: mad4@soton.ac.uk
--	---

What will happen to the results of the research study?

The information from this study will be used for PhD thesis, journal article publications and conferences. If you wish to know research results, you could contact the researcher for further information.

Where can I get more information?

If you wish to ask further information, please feel free to contact the individuals named below, using the contact details provided:

Miss Boonthan Kingsaiyhod (the researcher)

Faculty of Health Sciences

University of Southampton

Building 45, Highfield Campus

United Kingdom

SO17 1BJ

Tel:

Email: bk1e09@soton.ac.uk

Thank you for spending your valuable time to read the participant sheet.

Date: DD/MM/YYYY

Appendix 16: Participant information sheet (the caregiver of patients with schizophrenia)



Study Title: 'Stakeholder perspectives towards schizophrenia care at the sub-district level in rural Thailand'

Researcher: Miss Boonthan Kingsaiyhod **Ethics number:**

Please read this information carefully before deciding to take part in this research. If you are happy to participate you will be asked to sign a consent form.

What is the research about?

This is an MPhil/ PhD student research project to fulfil the requirement of Doctor of Philosophy degree at the University of Southampton, the UK. This research concerns the perceptions of people with schizophrenia, their caregivers, the Tambon Health Promotion Hospital staff and the supervisory team from the Psychiatric Hospital about schizophrenia care at the sub-district level in rural Thailand. This research project is trying to understand the key issues related to the care of schizophrenia in the community settings in order to improve future community mental health service.

Research sponsorship

This research project is being carried out by Boonthan Kingsaiyhod who is an international student being funding by the Royal Thai Government.

Why have I been chosen?

You have been chosen because we are hoping to talk to people who have been taking care of the patient with a diagnosis with schizophrenia for at least one year and fulfil the following criteria:

- 1) Keeping contact with the Department of community mental health; the Psychiatric Hospital.
- 2) Able to consent.
- 3) Able to participate an interview.

Your view about needs for schizophrenia care at the sub-district level is unique, so you are the best person who can tell us about the care that you receive. It will be worth to know what you may need and unmet needs when taking care of the patient with schizophrenia while they are living outside the hospital. Hence, it is invaluable to invite you to take part in this study.

What will happen to me if I take part?

The information you will be asked is about your experiences and views of caring the patient with schizophrenia and collaborating schizophrenia care with the Tambon Health Promotion Hospital team.

You will be asked to fill a personal information form which is about your age, marital status, religion/belief, income, number and duration of hospitalization and medication of the patient that you looking after. This form is absolutely anonymous, and you will not be asked to state your real name in the form. The personal information form is not compulsory, which means that you have right to not give any information that you feel uncomfortable.

You will take no longer than one hour. However, you have right to skip some questions that you do not want to answer. You can stop the interview whenever you feel uncomfortable. The interview questions will be about your experience of caring the patient with schizophrenia and collaborating with the Tambon Health Promotion Hospital team for schizophrenia care.

The researcher may contact you back afterwards via telephone. This is for clarifying some unclear issues of the face to face interview. The telephone interview will no longer than thirty minutes. However, it depends on you whether you will allow the researcher to do telephone interview.

Are there any benefits in my taking part?

This research aims to improve schizophrenia care at the sub-district level in rural Thailand by reflecting the views of caring the patients with schizophrenia. Although it will not immediately benefit you and the patient, it is expected that information from your perspective will be considered to be a part of community mental health care plans for patients with schizophrenia. Moreover, the research results will be information for the public health education.

Are there any risks involved?

The questions in the interview schedule were reviewed by the peer reviewers and ethical committees at the University of Southampton. The Thai version of the interview schedule was reviewed by the ethical committees of the Psychiatric Hospital. This will ensure that no questions cause harm regarding stress or embarrassment.

Will my participation be confidential?

Your information will be kept confidential. Your name will be anonymous and all of your information will be kept in a password-protected personal computer notebook. The researcher is the only person who can access the laptop. The interview tape, transcriptions and hard copies of field notes will be kept in a locked cabinet in the researcher's accommodation during conducting data collection in Thailand. Your interview record(s) will be kept in locked cabinet at the Faculty of Health Sciences (University of Southampton, UK) when the researcher has returned to the UK. The anonymous transcribed data will be shared between the researcher and peer-reviewers.

What happens if I change my mind?

It is absolutely your choice to make a decision whether to take part in this research study. You have the right to consent or to withdraw your consent for this study unconditionally. This will be definitely not affecting you and the treatment of the patient who is in your responsible at all.

Who has reviewed the study?

The research proposal has been reviewed by the supervisory team, peer reviewers and ethical committees of the University of Southampton. The research proposal was also reviewed by the Psychiatric Hospital ethical committees in order to ensure both your physical and psychological safety.

What happens if something goes wrong?

If you wish to make a complaint you could contact the MPhil/PhD program leader or the Chair of Ethics Committee of the University of Southampton, whose contact details are provided below:

Dr Maggie Donovan-Hall MPhil/PhD programme Lead, Faculty of Health Sciences, University of Southampton Email: mh699@soton.ac.uk Telephone Number: 02380 598880 (x28880)	Dr Martina Prude Head of Research Governance Tel: 02380 595058 Email: mad4@soton.ac.uk
--	---

What will happen to the results of the research study?

The information from this study will be used for PhD thesis, journal article publications and conferences. If you wish to know research results, you could contact the researcher for further information.

Where can I get more information?

If you wish to ask further information, please feel free to contact the individuals named below, using the contact details provided:

Miss Boonthan Kingsaiyhod (the researcher)

Faculty of Health Sciences

University of Southampton

Building 45, Highfield Campus

United Kingdom

SO17 1BJ

Tel: 07741774249

Email: bk1e09@soton.ac.uk

Thank you for spending your valuable time to read the participant sheet.

Date: DD/MM/YYYY

Appendix 17: Participant information sheet (for the Health Promotion Hospital staff)



Study Title: 'Stakeholder perspectives towards schizophrenia care at the sub-district level in rural Thailand'

Researcher: Miss Boonthan Kingsaiyhod **Ethics number:**

Please read this information carefully before deciding to take part in this research. If you are happy to participate you will be asked to sign a consent form.

What is the research about?

This is an MPhil/ PhD student research project to fulfil the requirement of Doctor of Philosophy degree at the University of Southampton, the UK. This research concerns the perceptions of people with schizophrenia, their caregivers, the Tambon Health Promotion Hospital staff and the supervisory team from the Psychiatric Hospital about schizophrenia care at the sub-district level in rural Thailand. This research project is trying to understand the key issues related to the care of schizophrenia in the community settings in order to improve future community mental health service.

Research sponsorship

This research project is being carried out by Boonthan Kingsaiyhod who is an international student being funded by the Royal Thai Government.

Why have I been chosen?

You have been chosen because we are hoping to talk to qualified healthcare staff that provide community mental health care for an individual with schizophrenia and fulfil the following criteria:

- 1) Be under supervision of the Department of community mental health; the Psychiatric Hospital.
- 2) Able to participate an interview.

Your view about needs for providing schizophrenia care at the sub-district level is unique, so you are the best person who can tell us about the care that you provide as well as collaboration between patient(s), caregiver (s) and the supervisory team from the Department of community mental health; Psychiatric Hospital. It will be worth to know what you may need and unmet needs when providing care for the patient with schizophrenia while they are living outside the hospital. Hence, it is invaluable to invite you to take part in this study.

What will happen to me if I take part?

The information you will be asked is about your experiences and views of providing schizophrenia care at the Tambon Health Promotion Hospital.

You will be asked to fill a personal information form which is about your age, religion/belief, qualification, number and duration of hospitalization and medication of the patient(s) and caregiver(s) that you looking after. This form is absolutely anonymous, and you will not be asked to state your real name in the form. The personal information form is not compulsory, which means that you have right to not give any information that you feel uncomfortable.

The interview will take no longer than one hour. However, you have right to skip some questions that you do not want to answer. You are free to stop the interview and withdraw from the study at any time. The interview questions will be about your experience of providing care at the Tambon Hospital Health Promotion.

The researcher may contact you back afterwards via telephone. This is for clarifying some unclear issues of the face to face interview. The telephone

interview will no longer than thirty minutes. However, it depends on you whether you will allow the researcher to do telephone interview.

Are there any benefits in my taking part?

This research aims to improve schizophrenia care at the sub-district level in rural Thailand by reflecting the views of caring the patients with schizophrenia. Although it will not immediately benefit you, the patient(s) and caregiver(s), it is expected that information from your perspective will be considered to be a part of community mental health care future plans for patients with schizophrenia. Moreover, the research results will be information for the public health education.

Are there any risks involved?

The questions in the interview schedule were reviewed by the peer reviewers and ethical committees at the University of Southampton. The Thai version of the interview schedule was reviewed by the ethical committees of the Psychiatric Hospital. This will ensure that no questions cause harm regarding stress.

Will my participation be confidential?

Your information will be kept confidential. Your name will be anonymous and all of your information will be kept in a password-protected personal computer notebook. The researcher is the only person who can access the laptop. The interview tape, transcriptions and hard copies of field notes will be kept in a locked cabinet in the researcher's accommodation during conducting data collection in Thailand. Your interview record(s) will be kept in locked cabinet at the Faculty of Health Sciences (University of Southampton, UK) when the researcher has returned to the UK. The anonymous transcribed data will be shared between the researcher and peer-reviewers.

What happens if I change my mind?

It is absolutely your choice to make a decision whether to take part in this research study. You have the right to consent or to withdraw your consent for

this study unconditionally. This will be definitely not affecting you and the treatment of the patient who is in your responsible at all.

Who has reviewed the study?

The research proposal has been reviewed by the MPhil/ PhD supervisory team, peer reviewers and ethical committees of the University of Southampton. The research proposal was also reviewed by the Psychiatric Hospital ethical committees in order to ensure both your physical and psychological safety.

What happens if something goes wrong?

If you wish to make a complaint you could contact the MPhil/PhD program leader or the Chair of Ethics Committee of the University of Southampton, whose contact details are provided below:

Dr Maggie Donovan-Hall MPhil/PhD programme Lead, Faculty of Health Sciences, University of Southampton Email: mh699@soton.ac.uk Telephone Number: 02380 598880 (x28880)	Dr Martina Prude Head of Research Governance Tel: 02380 595058 Email: mad4@soton.ac.uk
--	---

What will happen to the results of the research study?

The information from this study will be used for PhD thesis, journal article publications and conferences. If you wish to know research results, you could contact the researcher for further information.

Where can I get more information?

If you wish to ask further information, please feel free to contact the individuals named below, using the contact details provided:

Miss Boonthan Kingsaiyhod (the researcher)

Faculty of Health Sciences

University of Southampton

Building 45, Highfield Campus

United Kingdom

SO17 1BJ

Tel:

Email: bk1e09@soton.ac.uk

Thank you for spending your valuable time to read the participant sheet.

Date: DD/MM/YYYY

Appendix 18: Participant information sheet (the community mental health supervisory team)



Study Title: 'Stakeholder perspectives towards schizophrenia care at the sub-district level in rural Thailand'

Researcher: Miss Boonthan Kingsaiyhod **Ethics number:**

Please read this information carefully before deciding to take part in this research. If you are happy to participate you will be asked to sign a consent form.

What is the research about?

This is an MPhil/ PhD student research project to fulfil the requirement of Doctor of Philosophy degree at the University of Southampton, the UK. This research concerns the perceptions of people with schizophrenia, their caregivers, the Tambon Health Promotion Hospital (THPH) staff and the supervisory team from the Psychiatric Hospital about schizophrenia care at the sub-district level in rural Thailand. This research project is trying to understand the key issues related to the care of schizophrenia in the community settings in order to improve future community mental health service.

Research sponsorship

This research project is being carried out by Boonthan Kingsaiyhod who is an international student being funded by the Royal Thai Government.

Why have I been chosen?

You have been chosen because we are hoping to talk with mixed of mental healthcare professionals who working at the Psychiatric Hospital and officially responsible for THPH staff supervision regarding community mental health service and fulfil the following criteria:

- 1) Have experience of THPH staff regarding schizophrenia care supervision at least 1 case.
- 2) Able to participate an interview.

Your view about needs for supervising and collaborating with the THPH staff, caregivers and the patients with schizophrenia at the sub-district level is unique, so you are the best person who can tell us about the supervision and collaboration between patient(s), caregiver (s) and the THPH staff. It will be worth to know what you may suggest to improve the schizophrenia care at the sub-district level in rural Thailand. Hence, it is invaluable to invite you to take part in this study.

What will happen to me if I take part?

The information you will be asked is about your experiences and views of providing schizophrenia care supervision at the Tambon Health Promotion Hospital.

You will be asked to fill a personal information form which is about your age, religion/belief, qualification, experience of THPH staff supervision. This form is absolutely anonymous, and you will not be asked to state your real name in the form. The personal information form is not compulsory, which means that you have right to not give any information that you feel uncomfortable.

The interview will take no longer than one hour. However, you have right to skip some questions that you do not want to answer. You are free to stop the interview and withdraw from the study at any time. The interview questions will be about your experience of schizophrenia care supervision at the Tambon Hospital Health Promotion.

The researcher may contact you back afterwards via telephone. This is for clarifying some unclear issues of the face to face interview. The telephone

interview will no longer than thirty minutes. However, it depends on you whether you will allow the researcher to do telephone interview.

Are there any benefits in my taking part?

This research aims to improve schizophrenia care at the sub-district level in rural Thailand by reflecting the views of caring the patients with schizophrenia. Although it will not immediately benefit you, the patient(s) and caregiver(s), it is expected that information from your perspective will be considered to be a part of community mental health care future plans for patients with schizophrenia. Moreover, the research results will be information for the public health education.

Are there any risks involved?

The questions in the interview schedule were reviewed by the peer reviewers and ethical committees at the University of Southampton. The Thai version of the interview schedule was reviewed by the ethical committees of the Psychiatric Hospital. This will ensure that no questions cause harm regarding stress.

Will my participation be confidential?

Your information will be kept confidential. Your name will be anonymous and all of your information will be kept in a password-protected personal computer notebook. The researcher is the only person who can access the laptop. The interview tape, transcriptions and hard copies of field notes will be kept in a locked cabinet in the researcher's accommodation during conducting data collection in Thailand. Your interview record(s) will be kept in locked cabinet at the Faculty of Health Sciences (University of Southampton, UK) when the researcher has returned to the UK. The anonymous transcribed data will be shared between the researcher and peer-reviewers.

What happens if I change my mind?

It is absolutely your choice to make a decision whether to take part in this research study. You have the right to consent or to withdraw your consent for

this study unconditionally. This will be definitely not affecting you and the treatment of the patient who is in your responsible at all.

Who has reviewed the study?

The research proposal has been reviewed by the MPhil/ PhD supervisory team, peer reviewers and ethical committees of the University of Southampton. The research proposal was also reviewed by the Psychiatric Hospital ethical committees in order to ensure both your physical and psychological safety.

What happens if something goes wrong?

If you wish to make a complaint you could contact the MPhil/PhD program leader or the Chair of Ethics Committee of the University of Southampton, whose contact details are provided below:

Dr Maggie Donovan-Hall MPhil/PhD programme Lead, Faculty of Health Sciences, University of Southampton Email: mh699@soton.ac.uk Telephone Number: 02380 598880 (x28880)	Dr Martina Prude Head of Research Governance Tel: 02380 595058 Email: mad4@soton.ac.uk
--	---

What will happen to the results of the research study?

The information from this study will be used for PhD thesis, journal article publications and conferences. If you wish to know research results, you could contact the researcher for further information.

Where can I get more information?

If you wish to ask further information, please feel free to contact the individuals named below, using the contact details provided:

Miss Boonthan Kingsaiyhod (the researcher)

Faculty of Health Sciences

University of Southampton

Building 45, Highfield Campus

United Kingdom

SO17 1BJ

Tel:

Email: bk1e09@soton.ac.uk

Thank you for spending your valuable time to read the participant sheet.

Date: DD/MM/YYYY

Appendix 19: Participant invitation letter

‘Stakeholder perspectives towards schizophrenia care at the sub-district level in rural Thailand’

Dear Client/ Health professional

I would like to invite you to consider participating in a research project. The research is about the views of using/ providing schizophrenia care at the Tambon Health Promotion Hospitals; sub-district level in rural Thailand.

In the research information pack contains:

1. A participant information sheet
2. A reply slip
3. A consent form
4. A prepaid envelope

You are invited to read the information provided which will explain you about the importance of the study and what would mean if you decided to take part. If you wish to take part in the study but still have some questions, you could contact the researcher by enclose the reply slip and send to the address provided. This is because the researcher is not allowed to contact you unless receiving your permission. Alternatively, you could contact the researcher by telephone number 08xxxxxxx or email at bk1e09@soton.ac.uk

Thank you very much for your time

Boonthan Kingsaiyhod

MPhil/ PhD student at the University of Southampton

Appendix 20: Reply slip



'Stakeholder perspectives towards schizophrenia care at the sub-district level in rural Thailand'

Thank you for reading the participant information sheet and considering participating this research study about the views of receiving/ providing schizophrenia care at the Tambon Health Promotion Hospital: at the sub-district in rural Thailand. To take part in this research, you may need more information. However, it is necessary to get your permission by enclosing the reply slip and sending to the researcher. This will allow me to contact you.

Please complete the following details and return this form to me in the prepaid envelope. The reply slip is not consent to participate the study but allowing the researcher to contact you. This will be useful for giving more information about the study. All of your personal information will be anonymous and confidential.

If you return the reply slip, I would contact you as soon as possible. You are free to withdraw from the research at any time without giving reason.

Alternatively, you can contact me directly via telephone: 081xxxxxxx or email at bk1e09@soton.ac.uk

Thank you very much for your time.

Boonthan Kingsaiyhod

MPhil/ PhD student at the University of Southampton

Patient/ Caregiver/ Health professional/ Supervisory Code:	(Researcher use only)
Name (Please print) Contact telephone number Good time to phone Time to avoid phoning	

Please put this into the prepaid provided and put it in the post.

Thank you.

Appendix 21: Consent form



Study title: 'Stakeholder perspectives towards schizophrenia care at the sub- district level in rural Thailand'

Researcher name: Miss Boonthan Kingsaiyhod

Study reference: MPhil/ PhD Health Sciences

Ethics reference:

Please initial the box(es) if you agree with the statement(s):

1. I confirm that I have read and understand the information sheet and have had the opportunity to ask questions, any of which have been answered satisfactorily.

2. I understand that my participation is voluntary and I may withdraw from the study at any time, for any reason without my legal rights or medical care being affected.

3. I understand that all the information collected from me, for the project will be retained by the University of Southampton for ten years in line with the university policy.

4. I understand that the data collected may be viewed by the research supervisors. I give permission for these individuals to have access to my data.

5. I agree that the interview can be recorded.

6. I agree to take part in the above study

7. I understand that, although no names or identifying comments will be included, direct anonymised quotes may be used in the reporting of this study, and in the presentation of the findings to other healthcare professionals, academic staff and students.



Data Protection

I understand that information collected about me during my participation in this study will be stored on a password protected computer and that this information will only be used for the purpose of this study. All files containing any personal data will be made anonymous.

.....

Name of participant

Date

Signature

.....

Name of researcher

Date

Signature

Appendix 22: Document sheet for participants' information

A: For the patient with schizophrenia (This form can be filled by yourself, your caregiver or relative)

1. Your age year old
2. Religion/ Belief.....
3. Your marital status (please tick)
() Single, () Married, () Divorced, () Separated
4. Average monthly income..... Baht
5. Duration that do you have a diagnosis with schizophrenia year
6. How many time that you were admitted to the hospital?
7. Who is the main person who looks after you when you are living outside hospital
.....
8. Do you take antipsychotic medication?

B: For the caregiver of patient with schizophrenia

1. Your age..... Year old
2. Religion/ Belief.....
3. Your marital status (please tick)
() Single, () Married, () Divorced, () Separated
4. Average monthly income..... Baht
5. Your marital status.....
6. Duration that your patient has a diagnosis with schizophrenia..... year
7. Duration that you look after the patient with schizophrenia.....
year..... month
8. How many time that your patient was admitted to the hospital?.....
9. Does your patient take antipsychotic medication?.....

C: The Tambon Health promotion Hospital staff

1. Your age..... year old
2. Religion/ Belief.....
3. Your marital status (please tick)
() Single, () Married, () Divorced, () Separated
4. You
qualification.....
5. Have you been trained in mental health care for patients with
schizophrenia?
6. Duration that you provide the care at the sub-district level.....
year Month
7. Duration that you provide schizophrenia care at the sub-district level in
rural area.....

D: The Psychiatric Hospital staff (supervisory team)

1. Your age..... year old
2. Religion/ Belief.....
3. Your marital status (please tick)
() Single, () Married, () Divorced, () Separated
4. You
qualification.....
5. Have you been trained in mental health care for patients with
schizophrenia?.....
6. Duration that you supervise schizophrenia care at the sub-district
level..... year Month
7. Numbers of patients, caregivers and the Tambon Health Promotion
Hospital staff that you collaborate with?.....

Appendix 23: Interview schedule

12.1) Interview schedule for the patients with schizophrenia

1. How long have you been living in the community since you have a diagnosis with schizophrenia?
2. What has been good about living in community?

Probes/ prompts:

Can you explain more about...(or give me an example)?

3. What are the problems or difficulties of living in community?

Probes/ prompts:

Can you explain more about....(or give me an example)?

4. Do you think who/what can help you to fix the problems?

Probes/ prompts:

4.1) the caregiver

4.2) the other family members

4.3) the Tambon Health Promotion Hospital staff and their teams

4.4) people in community/ support group(s)

5. What could be done to help you and perhaps your family also?

12.2) Interview schedule for the caregivers of patients with schizophrenia

1. Can you tell me about what happened when the patient was discharged to the community?

Probes/ Prompts:

Can you expand more about....?

2. Could you tell me about your experience of having a patient with schizophrenia in your family?

Probes/ prompts:

Can you expand more about....?

3. Who can help you to sort out the problems/ difficulties?

Probes/ prompts:

3.1) the other family members

3.2) the Tambon Health Promotion Hospital staff and their teams

3.3) the other caregivers of patients with mental illness (or a support group)

3.4) people in community

4. What do you think about schizophrenia care service at the Tambon Health Promotion Hospital?
5. What can be done to help to improve the schizophrenia care at the Tambon Health Promotion Hospital?

12.3) Interview schedule for the Tambon Health Promotion Hospital

1. Can you tell me about your experience of caring patients with schizophrenia at the Tambon Health Promotion Hospital?

Probes/ Prompts:

- 1.1) What are the most demands from patient with schizophrenia and his/ her caregiver?
- 1.2) How do you find collaboration between patient with schizophrenia, his/ her caregiver and the supervisory team?
2. What are crucial factors for schizophrenia care at the sub-district level?

Probes/ prompts:

- 2.1) From your experience, what are the strengths and weaknesses of providing schizophrenia care at the sub-district level??

Probes:

Elaborate on strengths and weaknesses:

- 2.2) Clarify strengths and weaknesses, who can help to resolve the problems and how?
3. If you could make changes for the Tambon Health Promotion Hospital service, what would you do or suggest the government to do for improving schizophrenia care for both patients and their caregivers?

12.4) Interview schedule for the supervisory team of the Tambon Health Promotion Hospital staff

1. Can you tell me about your experiences of collaboration with patients with schizophrenia, their caregivers, and the Tambon Health Promotion Hospital staff for schizophrenia care at the primary care level?

Probes/ prompts:

- 1.1) What are the most common problems/ difficulties of providing schizophrenia care at the sub-district level?
- 1.2) What are the strengths and weaknesses of providing schizophrenia care at the sub-district level?

Probes/ prompts:

Elaborate on strengths and weaknesses:

- 1.3) Clarify strengths and weaknesses, who can help to resolve the problems and how?
2. From your supervision experience, what are the crucial factors for schizophrenia care at the sub-district level?

Probes/ prompts:

- 2.1) For the patients with schizophrenia
- 2.2) For the caregivers of patients with schizophrenia
- 2.3) For the Tambon Health Promotion Hospital Staff
- 2.4) For the supervisory team
3. If you could make some changes the Tambon Health Promotion Hospital service, what would you do or suggest the government to do for improving schizophrenia care for both patients and their caregivers?

Appendix 24: Example of probes, prompts and cues

Prompts, probes and encouragements will be prepared for influencing the flow of interview (Research Consortium on Educational outcomes & Poverty 2008):

- 1) Prompt is using for reminding research participants about things that the participants have not mentioned or forgotten (e.g. what do you feel about...?)
- 2) Probe is follow up question to get the interviewee to say more about a particular topic;

When did that happen?

Who else was involved?

Where were you during that time?

What was your involvement in that situation?

How did that come about?

Where did it happen?

How did you feel about that?

Examples of Elaboration probes

Would you elaborate on that?

Could you say more about that?

That's helpful. I'd appreciate if you could give me more detail.

I'm beginning to get the picture: but some more examples might help.

Examples of Clarification probes

You said the program is 'xx'.

What do you mean by 'xx'?

What you're saying now is very important, and I want to make sure that I get it down exactly the way you mean it: please explain some more.

- 3) Verbal and non-verbal cues are encouraging the interviewee to continue. These will be specific to different cultures, but could involve, for example, nodding, smiling, maintaining eye-contact, saying 'I see' in an encouraging way.

Glossary

Term	Concept
Stakeholders	People who involve in schizophrenia care which include patients with schizophrenia themselves, patient's relatives and family members, health professional in every level of care, lay people in community who taking care of patients with schizophrenia.
Perspectives	Experiences or opinions towards provided schizophrenia care at the primary care level in community setting. This could be experiences of patients with schizophrenia themselves, patient's relatives and family members, health professional in every level of care, lay people in community who taking care of patients with schizophrenia.
Schizophrenia care	Schizophrenia care and/ or general physical and mental health care which are provided for patients with schizophrenia and their caregivers in community settings. This includes
Sub-district level of care	A local primary care unit or health centre where responds for patients with schizophrenia after discharging from the hospitals.
Experience	Experience in this study means 'something that happens to you, or a situation that you are involved in' (Macmillan publisher limited 2015).
Need and unmet need	Need means 'something that you need in order to be healthy, comfortable, successful etc' whereas unmet need could be defined as 'the need has not been met or provided' (Macmillan publisher limited 2015). In addition, this study includes any demand which may request from stakeholder of schizophrenia care.
Kreng jai	'Kreng Jai' means '...to be considerate, to feel reluctant to impose upon another person, to take another person's feelings (and ego) into account, or to take every measure not to cause discomfort or inconvenience for another person' (Knutson et al. 2003 cited in Komin 1991 p67). Additionally, the term 'Kreng jai' could mean that individuals consider the feelings of other people; they would hesitate in expressing an opposite or negative opinion in case it caused offence.

List of References

- Abi-Dargham A (2004) Do we still believe in the dopamine hypothesis? New data bring new evidence. *International Journal of Neuropsychopharmacology* 7(Suppl1): S1-S5
- Adams J (2015) British nurses' attitudes to electroconvulsive therapy, 1945-2000. *Journal Of Advanced Nursing* 71(10): 2393-2401
- Alarcón RD (2009) Culture, cultural factors and psychiatric diagnosis: review and projections. *World Psychiatry: Official Journal Of The World Psychiatric Association (WPA)* 8(3): 131-139
- Alvarez-Jiménez M, Gleeson JF, Cotton S, Wade D, Gee D, Pearce T, Crisp K, Spiliotacopoulos D, Newman B and McGorry PD (2009) Predictors of adherence to cognitive-behavioural therapy in first-episode psychosis. *Canadian Journal Of Psychiatry. Revue Canadienne De Psychiatrie* 54(10): 710-718
- American Psychiatric Association (2013) *Diagnostic and statistical manual of mental disorders : DSM-5* Arlington, Va. : American Psychiatric Association
- American Psychiatric Association (2014) *Insurance implication of DSM 5*. Available from: <http://www.psychiatry.org/practice/dsm/dsm5> [Accessed 25 March 2014]
- An Bord Altranais (2007) *Guidance to nurses and midwives regarding ethical conduct of nursing and midwifery research*. Dublin: An Bord Altranais
- Ananthawat S (2008) *Perceived Stigma and Self-esteem Among Persons with Schizophrenia, Srisangworn Sukhothai Hospital*. Unpublished Master of Nursing Science (Mental Health and Psychiatric Nursing) thesis, Chiang Mai University University
- Angermeyer MC and Matschinger H (1996) The effect of violent attacks by schizophrenic persons on the attitude of the public towards the mentally ill. *Social Science & Medicine* 43(12): 1721-1728
- Arun P and Chavan BS (2004) Antipsychiatry movement and non-compliance with therapy. *Hong Kong Journal of Psychiatry* 14(2): 21-22 2p
- Ashok AH, Baugh, John, Yeragani, Vikram K. (2012) Paul Eugen Bleuler and the origin of the term schizophrenia (SCHIZOPRENIEGRUPPE). *Indian Journal of Psychiatry* 54(1): 95-96
- Awad A and Voruganti L (2008) The burden of schizophrenia on caregivers: a review. *Pharmacoeconomics* 26(2)
- Ayuso-Mateos JL, Gutierrez-Recacha P, Haro JM and Chisholm D (2006) Estimating the prevalence of schizophrenia in Spain using a disease model. *Schizophrenia Research* 86(1-3): 194-201
- Bachmann S, Bottmer C, Jacob S, Kronmüller KT, Backenstrass M, Mundt C, Renneberg B, Fiedler P and Schröder J (2002) Expressed emotion in relatives of first-episode and chronic patients with schizophrenia and major depressive disorder-a comparison. *Psychiatry Research* 112(3): 239-250
- Badger L, Robinson H and Farley T (1999) Management of Mental Disorders in Rural Primary Care A Proposal for Integrated Psychosocial Services. *The Journal of Family Practice* 48 (10)
- Baker E and Edwards R (2012) How many qualitative interviews is enough?: Expert voices and early career reflections on sampling and cases in qualitative research.

List of references

- Bao J (2005) Merit-Making Capitalism: Re-territorializing Thai Buddhism in Silicon Valley, . *California Journal of Asian American Studies* 8(2)
- Barbato A (1998) *Schizophrenia and public health*. Geneva: World Health Organization
- Baruch N, Das M, Sharda A, Basu A, Bajorek T, Ross CC, Sengupta S, Larkin F and Young S (2014) An evaluation of the use of olanzapine pamoate depot injection in seriously violent men with schizophrenia in a UK high-security hospital. *Therapeutic Advances In Psychopharmacology* 4(5): 186-192
- Bateson G, Jackson DD, Haley J and Weakland J (1976) Toward a theory of schizophrenia IN: Sluzki CE and Ransom DC (eds) *The foundation of the communicational approach to the family*. London: Grune&Stratton
- Battle YL, Martin BC, Dorfman JH and Miller LS (1999) Seasonality and infectious disease in schizophrenia: the birth hypothesis revisited. *Journal Of Psychiatric Research* 33(6): 501-509
- Beal G, Veldhorst G, McGrath J-L, Guruge S, Grewal P, DiNunzio R and Trimnell J (2005) Constituting community: Creating a place for oneself. *Psychiatry: Interpersonal and Biological Processes* 68(3): 199-211
- Bebbington P and Kuipers E (2008) Psychosocial factors IN: Mueser KT and Jeste DV (eds) *Clinical handbook of schizophrenia*. London: The Guilford press
- Bengtsson-Tops A and Hansson L (1999) Clinical and social needs of schizophrenic outpatients living in the community: The relationship between needs and subjective quality of life. *Social Psychiatry and Psychiatric Epidemiology* 34(10): 513-518
- Bentall PR (ed) (1990) *Reconstructing schizophrenia*. London: Routledge
- Bentall R (2003) *Madness explained: Psychosis and human nature*. Taylor & Francis
- Bentall RP (1993) Deconstructing the concept of 'schizophrenia.'. *Journal of Mental Health* 2(3): 223-238
- Berg L (2004) *Qualitative research methods for the social sciences* (5th Edition Edition). Boston: Pearson education
- Bergman F, Preisler G and Werbart A (2006) Communicating with patients with schizophrenia: characteristics of well functioning and poorly functioning communication. *Qualitative Research in Psychology* 3 121-146
- Bhikha AG, Farooq S, Chaudhry N and Husain N (2012) A systematic review of explanatory models of illness for psychosis in developing countries. *International Review of Psychiatry* 24(5): 450-462
- Biddle C (2012) Individualism vs. Collectivism: Our Future, Our Choice. *Objective Standard: A Journal of Culture & Politics* 7(1): 19
- Biernat M and Dovidio JF (2003) Stigma and stereotypes IN: Heatherton TF (ed) *The social psychology of stigma*. London: Guilford Press
- Black DW and Grant EJ (2014) *DSM-5TM guidebook: the essential companion to the diagnostic and statistical manual of mental disorders, 5th edition*. Arlington: American Psychiatric Association
- Bolton G (2010) *Reflective practice : writing and professional development* (3rd edition Edition). London SAGE
- Bonder B and Martin L (2013) *Culture in clinical care: strategies for competence*. Slack
- Boonthod K, Zaito S and Aroonphongpaisarn S (2011) Social support for patients with schizophrenia *Srinagarind Med J* 26 (Suppl)
- Bottas A, Cooke RG and Richter MA (2005) Comorbidity and pathophysiology of obsessive-compulsive disorder in schizophrenia: is there evidence for a

- schizo-obsessive subtype of schizophrenia? *Journal of Psychiatry & Neuroscience* 30(3): 187-193
- Bowers L, Stewart D, Papadopoulos C, Dack C, Ross J, Khanom H and Jeffery D (2012) Inpatient violence and aggression: a literature review. London: Institute of psychiatry Kings college of London
- Brabban A, Morrison T and Read J (2013) Renaming 'schizophrenia': A step too far or not far enough? *Psychological Medicine* 43(7): 1558-1560
- Braehler C, Valiquette L, Holowka D, Malla AK, Joober R, Ciampi A, Pawliuk N and King S (2013) Childhood trauma and dissociation in first-episode psychosis, chronic schizophrenia and community controls. *Psychiatry Research* 210(1): 36-42
- Braun V and Clarke V (2006) Using thematic analysis in psychology. *Qualitative Research in Psychology* 3
- Britten N (2006) Qualitative interviews IN: Pope C and Mays N (eds) *Qualitative research in health care* (3rd Edition Edition). Oxford: Blackwell 12-20
- Brown AS, Schaefer CA, Quesenberry CP, Jr., Shen L and Susser ES (2006) No evidence of relation between maternal exposure to herpes simplex virus type 2 and risk of schizophrenia? *American Journal of Psychiatry* 163(12): 2178-2180
- Brown S, Inskip H and Barraclough B (2000) Causes of the excess mortality of schizophrenia. *The British Journal of Psychiatry* 177: 212-217
- Browne AJ, Varcoe C, Smye V, Reimer-Kirkham S, Lynam MJ and Wong S (2009) Cultural safety and the challenges of translating critically oriented knowledge in practice. *Nursing Philosophy* 10(3): 167-179 13p
- Brüne M (2005) "Theory of mind" in schizophrenia: a review of the literature. *Schizophrenia Bulletin* 31(1): 21-42
- Bryant-Davis T and Ocampo C (2005) Racist incident-based trauma. *The Counseling Psychologist* 33(4): 479-500
- Bryman A (2006) Paradigm Peace and the Implications for Quality. *International Journal of Social Research Methodology: Theory & Practice* 9(2): 111-126
- Bureau of Policy and Strategy Ministry of Public Health (2009) *Health policy in Thailand* Nonthaburi:
- Burnard P and Gill P (2009) *Culture, communication and Nursing*. Harlow: Pearson Education
- Burnard P, Naiyapatana W and Lloyd G (2006) Views of mental illness and mental health care in Thailand: a report of an ethnographic study. *Journal of Psychiatric and Mental Health Nursing* 13(6): 742-749
- Burns T (2007) Hospitalisation as an outcome measure in schizophrenia. *The British Journal Of Psychiatry. Supplement* 50: s37-s41
- Caqueo-Urizar A, Miranda-Castillo C, Lemos Giráldez S, Lee Maturana S-L, Ramírez Pérez M and Mascayano Tapia F (2014) An updated review on burden on caregivers of schizophrenia patients. *Psicothema* 26(2): 235-243
- Carpio XD, Messina J and Sanz-de-Galdeano A (2014) Minimum wage: Does it improve welfare in thailand? :
- Cechnicki A, Angermeyer MC and Bielańska A (2011) Anticipated and experienced stigma among people with schizophrenia: Its nature and correlates. *Social Psychiatry and Psychiatric Epidemiology* 46(7): 643-650
- Centre for Addiction and Mental Health (2012) *Schizophrenia: An Information Guide*. Available from: http://www.camh.ca/en/hospital/health_information/a_z_mental_health

List of references

- [_and_addiction_information/schizophrenia/schizophrenia_information_guide/Pages/schizophrenia_whatIs.aspx](#) [Accessed 11 April 2014]
- Chaichan W (2004) Olanzapine plus fluvoxamine and olanzapine alone for the treatment of an acute exacerbation of schizophrenia. *Psychiatry And Clinical Neurosciences* 58(4): 364-368
- Chakraborty K, Das G, Dan A, Bandyopadhyay G and Chatterjee M (2013) Perceptions about the cause of psychiatric disorders and subsequent help seeking patterns among psychiatric outpatients in a tertiary care centre in eastern India. *German Journal of Psychiatry* 16(1): 7-15
- Chan KKS and Mak WWS (2014) The mediating role of self-stigma and unmet needs on the recovery of people with schizophrenia living in the community. *Quality of Life Research: An International Journal of Quality of Life Aspects of Treatment, Care & Rehabilitation* 23(9): 2559-2568
- Chandler R, Bradstreet S and Hayward M (2013) Voicing caregiver experiences: well being and recovery narratives for caregivers. Sussex: Sussex partnership NHS foundation trust
- Cheng C, Loh E-W, Lin C-H, Chan C-H and Lan T-H (2013) Birth seasonality in schizophrenia: Effects of gender and income status. *Psychiatry and Clinical Neurosciences* 67(6): 426-433
- Cherryholmes HC (1992) Notes on Pragmatism and Scientific Realism. *Educational Researcher* 21(6): 13-17
- Chien W-T, Chan SWC and Morrissey J (2007) The perceived burden among Chinese family caregivers of people with schizophrenia. *Journal of Clinical Nursing* 16(6): 1151-1161
- Chien W (2010) *Stress of family members in caring for a relative with schizophrenia*. New York: Nova Science Publishers
- Chisholm D and Knapp M (2002) The economics of schizophrenia care in Europe: the EPSILON study. *Epidemiologia E Psichiatria Sociale* 11(1): 12-17
- Choowattanapakorn T, Nay R and Fetherstonhaugh D (2004) Nursing older people in Thailand: Embryonic holistic rhetoric and the biomedical reality of practice. *Geriatric Nursing* 25(1): 17-23
- Coffey M (2012) Negotiating identity transition when leaving forensic hospitals. *Health: An Interdisciplinary Journal for the Social Study of Health, Illness and Medicine* 16(5): 489-506
- Cohen L, Manion L and K. M (2007) *Research Methods in Education* (6th Edition Edition). New York: Routledge
- Conrad P and Barker KK (2010) The social construction of illness key insights and policy implications. *Journal of health and social behavior* 51(1 suppl): S67-S79
- Coppock V and Hopton. J (2000) *Critical perspectives on mental health*. London: Routledge
- Corrigan PW and Watson AC (2002) Understanding the impact of stigma on people with mental illness. *World Psychiatry: Official Journal Of The World Psychiatric Association (WPA)* 1(1): 16-20
- Creswell J (2003) *Research design : qualitative, quantitative, and mixed methods approaches* (2nd Edition Edition). London Sage
- Creswell J (2013) *Qualitative Inquiry and Research Design: Choosing Among Five Approaches*. London: Sage
- Creswell J and Plano-Clark V (2011) *Designing and conducting mixed methods research* (2nd Edition Edition). London: Sage
- Creswell JW and Miller DL (2000) Determining validity in qualitative inquiry *Therory into practice* 39(3): 124-130

- Crossley ML and Crossley N (2001) 'Patient' voices, social movements and the habitus; how psychiatric survivors 'speak out'. *Social Science & Medicine* 52(10): 1477-1489
- Crow TJ (2001) Signs of asphyxia at birth and risk of schizophrenia/obstetric complications and risk of schizophrenia: Commentary. *British Journal of Psychiatry* 179(5): 415-416
- Culley L (2006) Transcending transculturalism? Race, ethnicity and health-care. *NURSING INQUIRY* 13(2): 144-153
- Cyrzyk T (2013) Electroconvulsive therapy: why it is still controversial. *Mental Health Practice* 16(7): 22-27
- Dalman C, Thomas HV, David AS, Gentz J, Lewis G and Allebeck P (2001) Signs of asphyxia at birth and risk of schizophrenia: Population-based case-control study. *British Journal of Psychiatry* 179(5): 403-408
- Dangdomyouth P, Stern PN, Oumtane A and Yunibhand J (2008) Tactful Monitoring: How Thai Caregivers Manage Their Relative with Schizophrenia at Home. *Issues in Mental Health Nursing* 29(1): 37-50
- Davidson L (2005a) Commentary on 'Constituting Community: Creating a Place for Onself': More fundamentally human than otherwise. *Psychiatry: Interpersonal and Biological Processes* 68(3): 243-249
- Davidson L (2005b) Recovery, self management and the expert patient - Changing the culture of mental health from a UK perspective. *Journal of Mental Health* 14(1): 25-35
- Deegan PE (1988) Recovery: The lived experience of rehabilitation. *Psychosocial Rehabilitation Journal* 11(4): 11
- Denzin KN and Lincoln SY (2005) Paradigmatic controversies, contradiction and emerging confluences IN: Norman K. Denzin YSL (ed) *The SAGE handbook of qualitative research 3rd ed.* . London: SAGE
- Department for Environment Food and Rural Affairs (2001) *Defra Classification of Local Authority Districts and Unitary Authorities in England: An Introductory Guide*. York: Department for Environment, Food and Rural Affairs
- Department of Mental Health (2008) *Community Mental Health: Thailand Country Report* Nonthaburi:
- Department of Mental Health (2012) *Manual of discharge planning for patients with schizophrenia*. Nonthaburi: Thai Ministry of Public Health
- Desapriya EBR and Nobutada I (2003) Debate over Japanese renaming of term for schizophrenia. *The Lancet* 361(9352)
- Dogar I (2007) Review biopsychosocial model. *A.P.M.C.* 1(1): 11-13
- Doungkaew P (2010) *Situational Analysis of Stigmatization of Persons with Schizophrenia in Suan Prung Psychiatric Hospital, Chiang Mai Province*. Unpublished Master of Nursing Science (Mental Health and Psychiatric Nursing) thesis Chiang Mai University University
- Eack SM and Newhill CE (2008) What Influences Social Workers' Attitudes Toward Working With Clients With Severe Mental Illness? *Families In Society: The Journal Of Contemporary Human Services* 89(3)
- EBSCO industries (2015) *MEDLINE databases*. Available from: <https://www.ebscohost.com/nursing/products/medline-databases> [Accessed 20 October 2015]
- Edmonds WA and Kennedy DT (2013) *An Applied Reference Guide to Research Designs: Quantitative, Qualitative, and Mixed Methods*. London: Sage
- Edwards D (2009) *Nursing ethics: A principle- Based Approach* (2nd Edition Edition). Basingstoke: Palgrave Macmillan

List of references

- Eggers EA (2013) A serotonin hypothesis of schizophrenia. *Medical Hypotheses* 80: 791-794
- Engel GL (1977) The need for a new medical model: a challenge for biomedicine. *Science* 196(4286): 129-136
- Ertugrul A and Uluğ B (2004) Perception of stigma among patients with schizophrenia. *Social Psychiatry and Psychiatric Epidemiology* 39(1): 73-77
- Evans D (2003) Hierarchy of evidence: a framework for ranking evidence evaluating healthcare interventions. *Journal of Clinical Nursing* 12(1): 77-84
- Fakhoury W and Priebe S (2007) Deinstitutionalization and reinstitutionalization: major changes in the provision of mental health care *Psychiatry* 6(8)
- Fazel S, Buxrud P, Ruchkin V and Grann M (2010) Homicide in discharged patients with schizophrenia and other psychoses: A national case-control study. *Schizophrenia Research* 123(2/3): 263-269 7p
- Fazel S, Gulati G, Linsell L, Geddes JR and Grann M (2009) Schizophrenia and violence: systematic review and meta-analysis. *Plos Medicine* 6(8): e1000120-e1000120
- Ferriter M (1999) Family transaction models of schizophrenia IN: Ferriter M (ed) *Schizophrenia and parenting*. Ashgate Publishing
- Fitzgerald PB, Montgomery W, de Castella AR, Filia KM, Filia SL, Christova L, Jackson D and Kulkarni J (2007) Australian schizophrenia care and assessment programme: Real-world schizophrenia: Economics. *Australian and New Zealand Journal of Psychiatry* 41(10): 819-829
- Fleming MP and Martin CR (2011) Genes and schizophrenia: a pseudoscientific disenfranchisement of the individual. *Journal Of Psychiatric And Mental Health Nursing* 18(6): 469-478
- Flick U (2009) *An introduction to qualitative research* (4th Edition Edition). London: Sage
- Fors BM, Isacson D, Binge-fors K and Widerlöv B (2007) Mortality among persons with schizophrenia in Sweden: An epidemiological study. *Nordic Journal of Psychiatry* 61(4): 252-259
- Fox J and Gamble C (2006) Consolidating the assessment process: the semi-structured interview IN: Gamble C and Brennan G (eds) *Working with serious mental illness: a manual for clinical practice*. Edinburgh: Elsevier Saunders 133-144
- Frances AJ and Widiger T (2012) Psychiatric diagnosis: lessons from the DSM-IV past and cautions for the DSM-5 future. *Annual Review Of Clinical Psychology* 8: 109-130
- Frances JA and Nardo MJ (2013) ICD-11 should not repeat the mistakes made by DSM-5. *The British Journal of Psychiatry* 203(1-2)
- Freeman G and Hughes J (2010) Continuity of care and the patient experience. The King's fund:
- Furnham A and Chan E (2004) Lay theories of schizophrenia: A cross-cultural comparison of British and Hong Kong Chinese attitudes, attributions and beliefs. *Social Psychiatry and Psychiatric Epidemiology* 39(7): 543-552
- Fusar-Poli P and Politi P (2008) Paul Eugen Bleuler and the birth of schizophrenia (1908). *American Journal of Psychiatry* 165(11): 1407-1407
- Gaebel W, Zäske H and Baumann AE (2006) The relationship between mental illness severity and stigma. *Acta Psychiatrica Scandinavica* 113(Suppl 429): 41-45

- Gainetdinov RR and Mohn RMaC, G.M. (2001) Genetic animal models: focus on schizophrenia. *TRENDS in Neurosciences* 24(9): 527-533
- Gallagher M, Muldoon OT and Pettigrew J (2015) An integrative review of social and occupational factors influencing health and wellbeing. *Frontiers in psychology* 6
- Gearon JS, Kaltman SI, Brown C and Bellack AS (2003) Traumatic life events and PTSD among women with substance use disorders and schizophrenia. *Psychiatric Services* 54(4): 523-528
- Geddes JR and Lawrie S (1995) Obstetric complications and schizophrenia: A meta-analysis. *British Journal of Psychiatry* 167(6): 786-793
- Geoff Shepherd, Alison Murray and Matt Muijen (1994) *The Differing Views of Users, Family Carers and Professionals on Services for People with Schizophrenia in the Community*. London: The Sainsbury Centre for Mental Health
- Glaser G and Strauss L (1999) *The discovery of grounded theory: strategies for qualitative research*. New York: Aldine de Gruyter
- Godoy-Izquierdo D, López-Chicheri I, López-Torrecillas F, Vélez M and Godoy JF (2007) Contents of lay illness models dimensions for physical and mental diseases and implications for health professionals. *Patient Education & Counseling* 67(1-2): 196-213
- González-Torres MA, Oraa R, Aristegui M, Fernández-Rivas A and Guimon J (2007) Stigma and discrimination towards people with schizophrenia and their family members: A qualitative study with focus group. *Social Psychiatry and Psychiatric Epidemiology* 42(1): 14-23
- Govitrapong P, Mukda S, Turakitwanakan W, Dumrongphol H, Chindaduangratn C and Sanvarinda Y (2002) Platelet serotonin transporter in schizophrenic patients with and without neuroleptic treatment. *Neurochemistry International* 41(4): 209-216
- Grant A (2015) Demedicalising misery: Welcoming the human paradigm in mental health nurse education. *Nurse Education Today* 35(9): e50-3 1p
- Gray B (2004) *Doing research in the real world*. London: Sage
- Green M (2006) Cognitive impairment and functional outcome in schizophrenia and bipolar disorder. *J Clin Psychiatry* 67(9): 3-8
- Greenhalgh T (2010) *How to read a paper: the basic of evidence-based medicine (4th edition)*. Oxford: John Wiley & Sons
- Greenhalgh T and Peacock R (2005) Effectiveness and efficiency of search methods in systematic reviews of complex evidence: audit of primary sources. *BMJ: British Medical Journal (International Edition)* 331(7524): 1064-1065
- Griffiths P and Norman I (2013) Qualitative or quantitative? Developing and evaluating complex interventions: Time to end the paradigm war. *International Journal of Nursing Studies* 50(5): 583-584
- Guba EG (1990) *The paradigm dialog* Newbury Park Sage
- Guion A, Diehl C and McDonald D (2011) *Triangulation: Establishing the Validity of Qualitative Studies* Florida: University of Florida.
- Hammer M, Makiesky-Barrow S and Gutwirth L (1978) Social Networks and Schizophrenia. *Schizophrenia Bulletin* 4(4): 522-545
- Hanucharunkul S (2007) Nurses in primary care and the nurse practitioner role in Thailand. *Contemporary Nurse: A Journal for the Australian Nursing Profession* 26(1): 83-93 11p
- Hart LG, Larson EH and Lishner DM (2005a) Critical concepts for reaching populations at risk. Rural definitions for health policy and research. *American Journal of Public Health* 95(7): 1149-1155

List of references

- Hart LG, Larson EH and Lishner DM (2005b) Rural Definitions for Health Policy and Research. *American Journal of Public Health* 95(7): 1149-1155
- Harvey PD and Bowie CR (2012) Cognitive enhancement in schizophrenia: Pharmacological and cognitive remediation approaches. *Psychiatric Clinics of North America* 35(3): 683-698
- Hatala AR (2012) The Status of the "Biopsychosocial" Model in Health Psychology: Towards an Integrated Approach and a Critique of Cultural Conceptions. *Open Journal of Medical Psychology* 1(4): 51-62
- Helman CG (2007) *Culture, health and illness*. CRC Press
- Hernandez M, Barrio C and Yamada AM (2013) Hope and burden among Latino families of adults with schizophrenia. *Family Process* 52(4): 697-708
- Hert DM, Correll UC, Bobes J, Cetkovich-Bakmas M, Cohen D, Asai I, Detraux J, Gautam S, Möller H., Ndeti MD, Newcomer WJ, Uwakwe R and Leucht S (2011) Physical illness in patients with severe mental disorders. I. Prevalence, impact of medications and disparities in health care. *World Psychiatry* 10: 52-77
- Hodgins S (2008) Violent behaviour among people with schizophrenia: a framework for investigations of causes, and effective treatment, and prevention. *Philosophical Transactions of the Royal Society of London B: Biological Sciences* 363(1503): 2505-2518
- Hoffman E (1989) *Lost in translation : a life in a new language*. London Minerva
- Hofstede G (2011) Dimensionalizing cultures: The Hofstede model in context. *Online readings in psychology and culture* 2(1): 8
- Hofstede G (1980) *Culture's consequences: International differences in work-related values*. London: Sage
- Holloway I, and Wheeler, S., (2010) *Qualitative research in nursing and healthcare*. Chichester: Wiley-Blackwell
- Howe L, Tickle A and Brown I (2014) 'Schizophrenia is a dirty word': Service users' experiences of receiving a diagnosis of schizophrenia. *The Psychiatric Bulletin* 38(4): 154-158
- Howes OD and Kapur S (2009) The dopamine hypothesis of schizophrenia: Version III—The final common pathway. *Schizophrenia Bulletin* 35(3): 549-562
- Huang X-Y, Sun F-K, Yen W-J and Fu C-M (2008) The coping experiences of carers who live with someone who has schizophrenia. *Journal of Clinical Nursing* 17(6): 817-826
- Huang XY, Hung BJ, Sun FK, Lin JD and Chen CC (2009) The experiences of carers in Taiwanese culture who have long-term schizophrenia in their families: A phenomenological study. *Journal of Psychiatric and Mental Health Nursing* 16(10): 874-883
- Hughes D and Leethongdee S (2007) Universal coverage in the land of smiles: lessons from Thailand's 30 Baht health reforms. *Health Affairs (Project Hope)* 26(4): 999-1008
- Hultman CM, Wieselgren IM and Öhman A (1997) Relationships between social support, social coping and life events in the relapse of schizophrenic patients. *Scandinavian Journal of Psychology* 38(1): 3-13
- International Council of Nurses (2006) *The ICN code of ethics for nurses* Geneva: International Council of Nurses
- Jablensky A (2010) The diagnostic concept of schizophrenia: its history, evolution, and future prospects. *Dialogues in Clinical Neuroscience* 12(3): 271-287
- Jasper M (2003) *Frameworks for reflection*. Nelson Thornes.]

- Jeste DV, Wolkowitz OM and Palmer BW (2011) Divergent trajectories of physical, cognitive, and psychosocial aging in schizophrenia. *Schizophrenia Bulletin* 37(3): 451-455
- Johannessen OL (2002) Review: lifetime prevalence of schizophrenia and related disorders is about 5.5 per 1000, but there is significant variation between regions. *Evid Based Mental Health* 74(6)
- Jones S and Forshaw M (2012) *Research methods in psychology*. Harlow: Prentice Hall/Pearson
- Jongudomkarn D, Forgeron PA, Siripul P and Finley GA (2012) My Child You Must Have Patience and Kreng Jai: Thai Parents and Child Pain. *Journal of Nursing Scholarship* 44(4): 323-331
- Joseph J, Bae G and Silverstein SM (2013) Sex, symptom, and premorbid social functioning associated with perceptual organization dysfunction in schizophrenia. *Frontiers in Psychology* 4
- Kaewprom C, Curtis J and Deane FP (2011) Factors involved in recovery from schizophrenia: A qualitative study of Thai mental health nurses. *Nursing & Health Sciences* 13(3): 323-327
- Kageyama M, Shirota Y, Toga M, Kawabata K and Taguchi A (2012) [Professional mental health support provided by local government to families of people with schizophrenia in need of treatment]. [*Nihon Kōsh e Eisei Zasshi*] *Japanese Journal Of Public Health* 59(4): 259-268
- Kakhon Sawan Rajanagarinda Psychiatric hospital (2013) *Policy and responsibility*. Available from: <http://www.nph.go.th/index.php/en/aboutus/these-hospitals.html>
- Katakura N, Yamamoto-Mitani N and Ishigaki K (2010) Home-visit nurses' attitudes for providing effective assistance to clients with schizophrenia. *International Journal of Mental Health Nursing* 19(2): 102-109
- Kaufman EA, McDonell MG, Cristofalo MA and Ries RK (2012) Exploring Barriers to Primary Care For Patients with Severe Mental Illness: Frontline Patient and Provider Accounts. *Issues in Mental Health Nursing* 33(3): 172-180
- Kawulich B (2005) Participant Observation as a Data Collection Method. *Qualitative Social Research in Nursing & Health* 6(2)
- Keefe RSE and Harvey PD (2012) Cognitive Impairment in Schizophrenia IN: Rosenthal W (ed) *Handbook of Experimental Pharmacology*. Berlin: Springer-Verlag Berlin Heidelberg 11-38
- Kertchok R (2014) Building collaboration in caring for people with schizophrenia. *Issues in Mental Health Nursing* 35(11): 872-882
- Keshavan MS, Tandon R and Nasrallah HA (2013) Renaming schizophrenia: Keeping up with the facts. *Schizophrenia Research* 148(1-3): 1-2
- Keukens R (2006) Review of 'Deconstructing Schizophrenia'. *Journal of Psychiatric and Mental Health Nursing* 13(3): 379-381
- Khandaker GM, Zimbron J, Lewis G and Jones PB (2013a) Prenatal maternal infection, neurodevelopment and adult schizophrenia: a systematic review of population-based studies. *Psychol Med* 43(2): 239-257
- Khandaker GM, Zimbron J, Lewis G and Jones PB (2013b) Prenatal maternal infection, neurodevelopment and adult schizophrenia: a systematic review of population-based studies. *Psychological Medicine* 43(2): 239-257
- Khumhom A (2009) *Perceived Stigma of Caregivers, Life Skills and Perceived Stigma of Persons with Schizophrenia*. Unpublished Master of Nursing Science (Mental Health and Psychiatric Nursing) thesis Chiang Mai University University

List of references

- Kim Y and Berrios GE (2001) Impact of the term Schizophrenia on the culture of ideograph: The Japanese experience. *Schizophrenia Bulletin* 27(2): 181-185
- Kimura H, Kanahara N, Komatsu N, Ishige M, Muneoka K, Yoshimura M, Yamanaka H, Suzuki T, Komatsu H, Sasaki T, Hashimoto T, Hasegawa T, Shiina A, Ishikawa M, Sekine Y, Shiraishi T, Watanabe H, Shimizu E, Hashimoto K and Iyo M (2014) A prospective comparative study of risperidone long-acting injectable for treatment-resistant schizophrenia with dopamine supersensitivity psychosis. *Schizophrenia Research*
- Kingsaiyhod B (2011) *Does the use of Adherence therapy for adult people with a diagnosis of schizophrenia and related psychoses receiving treatment in inpatient or community settings reduced psychotic symptoms and readmission rates compared with treatment as usual or other interventions?* Unpublished Master's degree thesis Southampton University
- Knapp M, Chisholm D, Leese M, Amaddeo F, Tansella M, Schene A, Thornicroft G, Vazquez-Barquero J-L, Knudsen H-C and Becker T (2002) Comparing patterns and costs of schizophrenia care in five European countries: the EPSILON study. European Psychiatric Services: Inputs Linked to Outcome Domains and Needs. *Acta Psychiatrica Scandinavica* 105(1): 42-54
- Knight MTD, Wykes T and Hayward P (2003) 'People don't understand': An investigation of stigma in schizophrenia using Interpretative Phenomenological Analysis (IPA). *Journal of Mental Health* 12(3): 209-222
- Knoll JLIV, Garver DL, Ramberg JE, Kingsbury SJ, Croissant D and McDermott B (1998) Heterogeneity of the Psychoses: Is There a Neurodegenerative Psychosis? *Schizophrenia Bulletin* 24(3): 365-379
- Knutson TJ, Komolsevin R, Chatiketou P and Smith VR (2003) A cross-cultural comparison of Thai and US American rhetorical sensitivity: Implications for intercultural communication effectiveness. *International Journal of Intercultural Relations* 27(1): 63-78
- Ko C-J, Smith P, Liao H-Y and Chiang H-H (2014) Searching for reintegration: life experiences of people with schizophrenia. *Journal of Clinical Nursing* 23(3/4): 394-401
- Kong-ngirn s (2008) Case Management in Patient with Incarcerated Schizophrenia in Community at Chomthong District, Chiang Mai Province: case study. *Lanna Public Health Journal* 4(3): 424-432
- Kongsakorn R, Leelahanaj T, Price N, Birinyi-Strachan L and Davey P (2005) Cost Analysis of the Treatment of Schizophrenia in Thailand: A Simulation Model Comparing Olanzapine, Risperidone, Quetiapine, Ziprasidone and Haloperidol. *J Med Assoc Thai* 88(9): 1267-1277
- Koschorke M, Padmavati R, Kumar S, Cohen A, Weiss HA, Chatterjee S, Pereira J, Naik S, John S, Dabholkar H, Balaji M, Chavan A, Varghese M, Thara R, Thornicroft G and Patel V (2014) Experiences of stigma and discrimination of people with schizophrenia in India. *Social Science & Medicine* 123: 149-159
- Kumar S and Mohanty S (2007) Spousal burden of care in schizophrenia. *Journal of the Indian Academy of Applied Psychology* 33(2): 189-194
- Kung WW (2003) The illness, stigma, culture, or immigration? Burdens on Chinese American caregivers of patients with schizophrenia. *Families in Society* 84(4): 547-557

- Kurtz MM and Marcopulos AB (2012) Cognition in schizophrenia IN: Marcopulos ABaK, M.M. (ed) *Clinical neuropsychological foundations of schizophrenia*. London: Psychology Press 1-26
- Larquet M, Coricelli G, Opolczynski G and Thibaut F (2010) Impaired decision making in schizophrenia and orbitofrontal cortex lesion patients. *Schizophrenia Research* 116(2-3): 266-273
- Lasalvia A and Tansella M (2013) What is in a name? Renaming schizophrenia as a starting point for moving ahead with its re-conceptualization. *Epidemiology and Psychiatric Sciences* 22(4): 285-287
- Lederbogen F, Haddad L and Meyer-Lindenberg A (2013) Urban social stress--risk factor for mental disorders. The case of schizophrenia. *Environmental Pollution (Barking, Essex: 1987)* 183: 2-6
- Lee IH, Chen PS, Yang YK, Liao YC, Lee YD, Yeh TL, Yeh LL, Cheng SH and Chu CL (2008) The functionality and economic costs of outpatients with schizophrenia in Taiwan. *Psychiatry Research* 158(3): 306-315
- Lee YS, Kim J-J and Kwon JS (2013) Renaming schizophrenia in South Korea. *The Lancet* 382(9893): 683-684
- Leelanuntakit T and Udomratn P (1999) The results of PRELAPSE Program in Thailand : Comparison One Year Before and After. *Journal of the Psychiatrist Association of Thailand* 44(1): 3-11
- Lehman AF, Lieberman JA, Dixon LB, McGlashan TH, Miller AL, Perkins DO and Kreyenbuhl J (2004) Practice guideline for the treatment of patients with schizophrenia, second edition. *American Journal of Psychiatry* 161(2): 1-56
- Leicestershire NHS Plus (2013) *Schizophrenia - Shared Care Information*. Available from: www.mhguidelines-leics.nhs.uk/default.aspx?page=schizophrenia_sharedcareinformation [Accessed 20 April 2013]
- Leiknes KA, Cooke MJ, Jarosch-von Schweder L, Harboe I and Høie B (2013) Electroconvulsive therapy during pregnancy: A systematic review of case studies. *Archives of Women's Mental Health*
- Lester H, Tritter JQ and Sorohan H (2005) Patients' and health professionals' views on primary care for people with serious mental illness: focus group study. *BMJ (Clinical Research Ed.)* 330(7500): 1122-1122
- Lieberman RP and Silbert K (2005) Commentary on 'Constituting Community: Creating a Place for Oneself': Community Re-Entry: Development of life skills. *Psychiatry: Interpersonal and Biological Processes* 68(3): 220-229
- Lichtenstein p, Yip HB, Björk C, Pawitan Y, Cannon DT, Sullivan FP and Hultman MC (2009) Common genetic influences for schizophrenia and bipolar disorder: A population-based study of 2 million nuclear families. *Lancet* 17(373): 1-12
- Link BG and Phelan JC (2013) Labeling and stigma IN: Aneshensel CS, Phelan JC, Bierman A, Aneshensel CS, Phelan JC and Bierman A (eds) *Handbook of the sociology of mental health (2nd ed.)*. New York, NY, US: Springer Science + Business Media 525-541
- Lipsedge M (2007) Severe and enduring mental illness in relation to discrimination, racism, prejudice, ethnicity and culture IN: Russello A (ed) (ed) *Severe mental illness in primary care: a companion guide for counsellors, psychotherapists and other professionals*. . Oxford: Radcliffe 65-83
- Living with schizophrenia (2014) *What is Schizophrenia*. Available from: <http://www.livingwithschizophreniauk.org/what-is-schizophrenia/> [Accessed 11 April 2014]

List of references

- Lotrakul M and Saipanish R (2009) How do general practitioners in Thailand diagnose and treat patients presenting with anxiety and depression? *Psychiatry and Clinical Neurosciences* 63(1): 37-42
- Luethaisong W (2009) *Social stigmatization : case study of Prasrimahabhodi psychiatric hospital, Ubonratchatani* Unpublished Master of Art thesis Ubonratchatani university University
- Lysaker PH, Davis LW, Warman DM, Strasburger A and Beattie N (2007) Stigma, social function and symptoms in schizophrenia and schizoaffective disorder: associations across 6 months. *Psychiatry Research* 149(1-3): 89-95
- Macmillan publisher limited (2015) Experience definition and synonyms. *Macmillan dictionary*.
- Mark G and Opler A (2008) Factors in the Etiology of Schizophrenia: Genes, Parental Age, and Environment. *Primary psychiatry*
- Maruta T, Volpe U, Gaebel W, Matsumoto C and Iimori M (2014) Should schizophrenia still be named so? *Schizophrenia Research* 152(1): 305-306
- Mason J (2002) *Qualitative researching* London: Sage
- Mason M (2010) Sample size and saturation in PhD studies using qualitative interviews. *Forum Qualitative Sozialforschung/ Forum: Qualitative Social Research* 11(3): 1-19
- Matheson SL, Shepherd AM, Laurens KR and Carr VJ (2011) A systematic meta-review grading the evidence for non-genetic risk factors and putative antecedents of schizophrenia. *Schizophrenia Research* 133(1-3): 133-142
- Maxwell AJ (2009) Designing a qualitative study IN: Bickman L and Rog JD (eds) *The SAGE Handbook of Applied Social Research Methods* (2nd Edition Edition). London: Sage 214-253
- McAuliffe R, O'Connor L and Meagher D (2014) Parents' experience of living with and caring for an adult son or daughter with schizophrenia at home in Ireland: a qualitative study. *Journal of Psychiatric & Mental Health Nursing* 21(2): 145-153
- McCann T and Clark E (2005) Using unstructured interviews with participants who have schizophrenia. *Nurse Researcher* 13(1)
- McCarthy-Jones S, Marriott M, Knowles R, Rowse G and Thompson AR (2013) What is psychosis? A meta-synthesis of inductive qualitative studies exploring the experience of psychosis. *Psychosis* 5(1): 1-16
- McGrath JJ (2006) Variations in the incidence of schizophrenia: Data versus dogma. *Schizophrenia Bulletin* 32(1): 195-197
- McIntosh M and Morse JM (2009) Institutional review boards and the ethics of emotion IN: Norman K. Denzin MDG, editors. (ed) *Qualitative inquiry and social justice*. electronic resource: Left Coast Press 81-107
- Meebunmak Y (2009) *Community mental health care in Thailand: care management in the two primary care units*. Unpublished Doctoral thesis Murdoch University University
- Meissonier R, Houzé E and Bessièrè V (2013) Cross-Cultural Frictions in Information System Management: Research Perspectives on ERP Implementation Misfits. *Thailand International Business Research* 6(2)
- Melynk MB and Fineout-Overholt E (2005) *Evidence-Based Practice in nursing and health care: A guide to best practice*. London: Lippincott Williams & Wilkins

- Mestdagh A and Hansen B (2014) Stigma in patients with schizophrenia receiving community mental health care: A review of qualitative studies. *Social Psychiatry and Psychiatric Epidemiology* 49(1): 79-87
- Meyer A (1999) Psychodynamic pathogenic parenting models IN: Ferriter M (ed) *Schizophrenia and parenting*. Hants: Ashgate Publishing
- Michael BF, Harold AP, John BL, Janet BWW, Bedirhan U and Roger P (2004) Clinical Utility as a Criterion for Revising Psychiatric Diagnoses. *The American Journal of Psychiatry* 161(6): 946-954
- Ministry of Health NSW (2011) *Electroconvulsive Therapy: ECT Minimum Standard of Practice in NSW*. Mental Health and Drug and Alcohol Office:
- Mizuno E, Iwasaki M and Sakai I (2011) Subjective Experiences of Husbands of Spouses With Schizophrenia: An Analysis of the Husbands' Descriptions of Their Experiences. *Archives of Psychiatric Nursing* 25(5): 366-375
- Mohr S and Huguelet P (2004) The relationship between schizophrenia and religion and its implications for care. *Swiss Medical Weekly* 134(25-26): 369-376
- Molloy C, Conroy RM, Cotter DR and Cannon M (2011) Is traumatic brain injury a risk factor for schizophrenia? A meta-analysis of case-controlled population-based studies. *Schizophrenia Bulletin* 37(6): 1104-1110
- Monahan J (1992) Mental disorder and violent behavior: Perceptions and evidence. *American Psychologist* 47(4): 511-521
- Moran ME, Pol HH and Gogtay N (2013) A family affair: Brain abnormalities in siblings of patients with schizophrenia. *Brain: A Journal of Neurology* 136(11): 3215-3226
- Morse MJ (2011) What is qualitative health research? IN: Norman K. Denzin and Yvonna S. Lincoln (eds) *The SAGE handbook of qualitative research*. London: Sage 401-414
- Mosher RL, Gosden R and Beder S (2004) Drug companies and schizophrenia: unbridled capitalism meets madness IN: Read J and Mosher LR (eds) *Models of madness*. New York: Brunner Routledge 115-132
- Moule P and Hek G (2011) *Making sense of research: an introduction for health and social care practitioners* (4th Edition Edition). London: Sage
- National Alliance on Mental illness (2014) *Schizophrenia*. Available from: http://www.nimh.nih.gov/health/publications/schizophrenia/index.shtml?utm_source=wordtwit&utm_medium=social&utm_campaign=wordtwit#pub6 [Accessed 25 March 2014]
- National Institute of Mental Health (2009) *What is schizophrenia?* Available from: <http://www.nimh.nih.gov/health/publications/schizophrenia/index.shtml> [Accessed 14 October 2014]
- Ndetei D, Mutiso V, Khasakhala L and Kokonya D (2007) The challenges of human resources in mental health in Kenya *South African Psychiatric Review* 10
- NHS (2015) *Forensic mental health services*. Available from: http://www.mentalhealthcare.org.uk/forensic_mental_health_services#Liaison_and_diversion_services [Accessed 10 August 2015]
- NHS Choice (2012) *Schizophrenia*. Available from: <http://www.nhs.uk/Conditions/Schizophrenia/Pages/Causes.aspx> [Accessed 25 March]
- NHS England (2014) *Understanding the new NHS*. BMJ
- NICE (2010) *Schizophrenia: The NICE guideline on core interventions in the treatment and management of schizophrenia in adults in primary and secondary care*. London: Stanley Hunt

List of references

- NICE (2014) Psychosis and Schizophrenia in Adults: Treatment and Management.
- NICE (2015) *Psychosis and schizophrenia in adults*. London: NICE
- NICE Pathways (2015) *Service user experience in adult mental health services overview*. Available from:
<http://pathways.nice.org.uk/pathways/psychosis-and-schizophrenia>
[Accessed 18th September 2015]
- Nitsuwat S and Paoin W (2012) Development of ICD-10-TM Ontology for a Semi-automated Morbidity Coding System in Thailand. *Methods of Information in Medicine* 51(6): 519-528
- Ochoa S, Haro JM, Autonell J, Pendàs A, Teba F and Màrquez M (2003a) Met and unmet needs of schizophrenia patients in a Spanish sample. *Schizophrenia Bulletin* 29(2): 201-210
- Ochoa S, Haro JM, Autonell J, Pendàs A, Teba F, Màrquez M, Araya S, Asensio P, Autonell J, Benito A, Busquets E, Carmona C, Casacuberta P, Castro M, Díaz N, Dolz M, Foix A, Giralt JM, Gost A, Martínez F, Martínez R, Miguel J, Negredo MC, Osorio E, Paniego E, Pantinat L, Pujol C, Quilez J, Ramon J, Rodríguez MJ, Sánchez B, Soler A, Tous N, Usall J, Valdelomar M, Vaquer J, Vicens E and Zamora M (2003b) Met and unmet needs of schizophrenia patients in a Spanish sample. *Schizophrenia Bulletin* 29(2): 201-210
- Oliveira SEH, Esteves F and Carvalho H (2015) Clinical profiles of stigma experiences, self-esteem and social relationships among people with schizophrenia, depressive, and bipolar disorders. *Psychiatry Research*
- Onitsuka T, Oribe N, Nakamura I and Kanba S (2013) Review of neurophysiological findings in patients with schizophrenia. *Psychiatry and Clinical Neurosciences* 67(7): 461-470
- Os VJ and McGuffin P (2003) Can the social environment cause schizophrenia? *BRITISH JOURNAL OF PSYCHIATRY* 182: 291-292
- Oud MJT, Schuling J, Slooff CJ and Jong BM (2007) How do general practitioners experience providing care for their psychotic patients? *BMC Family Practice* 8: 1-7
- Owens SF, Picchioni MM, Rijdsdijk FV, Stahl D, Vassos E, Rodger AK, Collier DA, Murray RM and Toulopoulou T (2011) Genetic overlap between episodic memory deficits and schizophrenia: results from the maudslay twin study. *Psychological Medicine* 41(3): 521-532
- Panayiotopoulos C, Pavlakis A and Apostolou M (2013) Family burden of schizophrenic patients and the welfare system; the case of Cyprus. *International Journal Of Mental Health Systems* 7(1): 13-13
- Panichareon B, Nakayama K, Iwamoto S, Thurakitwannakarn W and Sukhumsirichart W (2012a) Association of CTXN3-SLC12A2 polymorphisms and schizophrenia in a Thai population. *Behavioral And Brain Functions: BBF* 8: 27-27
- Panichareon B, Nakayama K, Thurakitwannakarn W, Iwamoto S and Sukhumsirichart W (2012b) OPCML gene as a schizophrenia susceptibility locus in Thai population. *Journal Of Molecular Neuroscience: MN* 46(2): 373-377
- Papageorgiou G, Cañas F, Zink M and Rossi A (2011) Country differences in patient characteristics and treatment in schizophrenia: Data from a physician-based survey in Europe. *European Psychiatry* 26(1, Suppl 1): 17-28
- Parahoo K (1997) *Nursing research: principles, process and issues* Basingstoke: Palgrave Macmillan

- Parahoo K (2014) *Nursing research: Principles, process and issues* (third Edition). Basingstoke: Macmillan publisher
- Patel V, Flisher JA, Hetrick S and McGorry P (2007) Mental health of young people: a global public-health challenge. *Lancet* 369: 1302-1313
- Patton Q (2002) *Qualitative research and evaluation methods* (3rd Edition Edition). London: Sage
- Pengtee P (2010) *Situational analysis of stigmatization among caregivers of patients with schizophrenia at Nakornthai Crown Prince hospital*. Unpublished Master of Nursing Science (Mental Health and Psychiatric Nursing) thesis Chaing Mai university University
- Permyao J (2004) *Spiritual needs among caregivers of persons with schizophrenia* Unpublished Master's thesis Chiang Mai University University
- Phanthunane P, Vos T, Whiteford H, Bertram M and Udomratn P (2010) Schizophrenia in Thailand: prevalence and burden of disease. *Population Health Metrics* 8(1): 24
- Phillips LJ, Francey SM, Edwards J and McMurray N (2007) Stress and psychosis: Towards the development of new models of investigation. *Clinical Psychology Review* 27(3): 307-317
- Poels EMP, Kegeles LS, Kantowitz JT, Javitt DC, Lieberman JA, Abi-Dargham A and Girgis RR (2014) Glutamatergic abnormalities in schizophrenia: A review of proton mrs findings. *Schizophrenia Research*
- Poletti S, Radaelli D, Bosia M, Buonocore M, Pirovano A, Lorenzi C, Cavallaro R, Smeraldi E and Benedetti F (2013) Effect of glutamate transporter eaat2 gene variants and gray matter deficits on working memory in schizophrenia. *European Psychiatry*
- Polit F and Beck T (2008) *Nursing Research generating and assessing evidence for nursing practice* (8th Edition Edition). London: Lippincott Williams & Wilkins
- Polit F and Beck T (2010) *Essentials of nursing research: appraising evidence for nursing practice*. Philadelphia: Lippincott Williams & Wilkins
- Procter S, Allan T and Lacey A (2010) Sampling IN: Gerrish K and Lacey A (eds) *The Research Process in Nursing*. London: Wiley 142-152
- Read J (2004a) Biological psychiatry's lost cause IN: Read J, Mosher, R.L. and Bentall, P.R. (ed) *Models of madness*. New York: Brunner Routledge 57-66
- Read J (2004b) Does 'schizophrenia' exist? Reliability and validity IN: Read JM, L. and Bentall, R. (ed) *Models of madness: Psychological, social and biological approaches to schizophrenia*. London: Routledge 43-56
- Read J (2004c) Electroconvulsive therapy IN: Read J, Mosher LR and Bental PR (eds) *Models of madness*. New York: Brunner Routledge 85-100
- Read J (2004d) A history of madness IN: Read J, Mosher, R.L. and Bentall, P.R. (ed) *Models of madness*. New York: Brunner-Routledge 9-20
- Read J (2004e) Poverty, ethnicity and gender IN: Read J, Mosher L and Bentall R (eds) *Models of madness : psychological, social and biological approaches to schizophrenia*. Hove: Brunner-Routledge
- Read J (2010) Can poverty drive you mad? 'Schizophrenia', socio-economic status and the case for primary prevention. *New Zealand Journal of Psychology* 39(2): 7-19
- Read J, Goodman L, Morrison PA, Ross AC and Aderhold V (2004a) Childhood trauma, loss and stress IN: Read J (ed) *Models of madness*. London: Brunner Routledge 223-252

List of references

- Read J and Haslam N (2004) Bad things happen and can drive you crazy IN: Read J, Mosher L and Bentall R (eds) *Models of madness : psychological, social and biological approaches to schizophrenia*. Hove: Brunner-Routledge
- Read J, Seymour F and Mosher LR (2004b) Unhappy family IN: Read J, Mosher L and Bentall R (eds) *Models of madness : psychological, social and biological approaches to schizophrenia*. Hove: Brunner-Routledge
- Reilly S, Planner C, Hann M, Reeves D, Nazareth I and Lester H (2012) The role of primary care in service provision for people with severe mental illness in the United Kingdom *PLOS ONE* 7(5)
- Reine G, Lancon C, Simeoni MC, Duplan S and Auquier P (2003) Caregiver burden in relatives of persons with schizophrenia: an overview of measure instruments. *L'encéphale* 29(2): 137-147
- Remington G, Foussias G, Agid O, Fervaha G, Takeuchi H and Hahn M (2013) The neurobiology of relapse in schizophrenia. *Schizophrenia Research*
- Rhee E, Uleman JS and Lee HK (1996) Variations in collectivism and individualism by ingroup and culture: Confirmatory factor analysis. *Journal of Personality and Social Psychology* 71(5): 1037
- Ritchie J and Lewis J (2003) *Qualitative Research Practice: A Guide for Social Science Students and Researchers*. London: Sage
- Robson C (2011) *Real world research: a resource for users of social research methods in applied settings*. Chichester: Wiley
- Rogers C and Maslow A (2008) Carl Rogers. *Information Theory*: 214
- Rogers CR (1957) The necessary and sufficient conditions of therapeutic personality change. *Journal of consulting psychology* 21(2): 95
- Roick C, Heider D, Bebbington PE, Angermeyer MC, Azorin JM, Brugha TS, Kilian R, Johnson S, Toumi M and Kornfeld Å (2007) Burden on caregivers of people with schizophrenia: Comparison between Germany and Britain. *The British Journal of Psychiatry* 190(4): 333-338
- Roman-Urrestarazu A, Murray GK, Barnes A, Miettunen J, Jääskeläinen E, Mäki P, Nikkinen J, Remes J, Munkkala S, Koivukangas J, Heinimaa M, Moilanen I, Suckling J, Kiviniemi V, Jones PB and Veijola J (2014) Brain structure in different psychosis risk groups in the northern finland 1986 birth cohort. *Schizophrenia Research*
- Rose D (1996) *Living in community*. London:
- Rosenthal DaK, S.S. (ed) (1968) *The transmission of schizophrenia*. London: Pergamon place
- Royal Australian and New Zealand College of Psychiatrists (2005) Royal Australian and New Zealand College of Psychiatrists clinical practice guidelines for the treatment of schizophrenia and related disorders. *The Australian And New Zealand Journal Of Psychiatry* 39(1-2): 1-30
- Royal Australian and New Zealand College of Psychiatrists (2015) *Clinical practice guideline for schizophrenia and related disorders*. Royal Australian and New Zealand College of Psychiatrists: Australia
- Rubin J and Rubin S (2012) *Qualitative Interviewing: The Art of Hearing Data* (3rd Edition Edition). London: Sage
- Rueve E and Welton S (2008) Violence and mental illness *Psychiatry (Edgmont)* 5(5)
- Rungreangkulkij S (2001) *Experience of Thai families of a person with schizophrenia: Family stress and adaptation*. Unpublished 61 thesis ProQuest Information & Learning University

- Rungreangkulkij S and Chesla C (2001) Smooth a heart with water: Thai mothers care for a child with schizophrenia. *Archives Of Psychiatric Nursing* 15(3): 120-127
- Sado M, Inagaki A, Koreki A, Knapp M, Kissane LA, Mimura M and Yoshimura K (2013) The cost of schizophrenia in Japan. *Neuropsychiatric Disease and Treatment* 9
- San L, Bernardo M, Gómez A and Peña M (2013) Factors associated with relapse in patients with schizophrenia. *International Journal of Psychiatry in Clinical Practice* 17(1): 2-9
- Sanders D, Kydd R, Morunga E and Broadbent E (2011) Differences in patients' perceptions of Schizophrenia between Māori and New Zealand Europeans. *Australian & New Zealand Journal of Psychiatry* 45(6): 483-488
- Sanders RA, Duan J and Gejman V (2012) Schizophrenia genetics: What have we learned from genomewide association studies? IN: Brown S.A. and Patterson HP (ed) *The origins of schizophrenia*. New York: Columbia university press 175-209
- Sanseeha L, Chontawan R, Sethabouppha H, Disayavanish C and Turale S (2009) Illness perspectives of Thais diagnosed with schizophrenia. *Nursing & Health Sciences* 11(3): 306-311
- Saravanan B, Jacob KS, Johnson S, Prince M, Bhugra D and David AS (2007) Belief models in first episode schizophrenia in South India. *Social Psychiatry and Psychiatric Epidemiology* 42(6): 446-451
- Sato M (2003) Re-name the Japanese Term of Schizophrenia and Change in the Disease Concept, Treatment and Care. *Seishin Igaku (Clinical Psychiatry)* 45(6): 572-574
- Saunders JC and Byrne MM (2002) A thematic analysis of families living with schizophrenia. *Archives of Psychiatric Nursing* 16(5): 217-223
- Sawant NS and Jethwani KS (2010) Understanding family functioning and social support in unremitting schizophrenia: A study in India. *Indian journal of psychiatry* 52(2): 145
- Schene AH, van Wijngaarden B and Koeter MW (1998) Family caregiving in schizophrenia: domains and distress. *Schizophrenia Bulletin* 24(4): 609-618
- Schoepf D, Potluri R, Uppal H, Natalwala A, Narendran P and Heun R (2012) Type-2 diabetes mellitus in schizophrenia: Increased prevalence and major risk factor of excess mortality in a naturalistic 7-year follow-up. *European Psychiatry* 27(1): 33-42
- Seeman P (2013) Schizophrenia and dopamine receptors. *European Neuropsychopharmacology* 23(9): 999-1009
- Sethabouppha H and Kane C (2005) Caring for the seriously mentally ill in Thailand: Buddhist family caregiving. *Archives Of Psychiatric Nursing* 19(2): 44-57
- Shah P and Mountain D (2007) The medical model is dead--Long live the medical model. *The British Journal of Psychiatry* 191(5): 375-377
- Shenton K (2004) Strategies for ensuring trustworthiness in qualitative research projects. *Education for Information* 22
- Silveira C, Marques-Teixeira J and de Bastos-Leite AJ (2012) More than one century of schizophrenia: an evolving perspective. *Journal of Nervous & Mental Disease* 200(12): 1054-1057
- Singh SP, Harley K and Suhail K (2013) Cultural specificity of emotional overinvolvement: A systematic review. *Schizophrenia Bulletin* 39(2): 449-463

List of references

- Siriwanarangsang P, Liknapichitkul D and Khandelwan K (2004) Thailand mental health country profile. *International review of Psychiatry* 16(1-2): 150-185
- Snowden H and Marriott S (2003) Developing a local shared care protocol for managing people with psychotic illness in primary care *Psychiatric Bulletin* 27
- Solutions for Public Health (2013) *Useful link for critical appraisal*. Available from: <http://www.sph.nhs.uk/what-we-do/resources/links-1/useful-links/?searchterm=CASP> [Accessed 7 May 2013]
- Sonpaveerawong J (2001) *Strategies used by schizophrenic patients to cope with stress in their daily living : a study at Somdet Chaopraya hospital* Unpublished Masters' degree thesis Mahidol University University
- Stompe T, Bauer S, Ortwein-Swoboda G, Schanda H, Karakula H, Rudalevicienne P, Chaudhry HR, Idemudia ES and Gschaider S (2006) Delusions of guilt: The attitude of Christian and Muslim schizophrenic patients toward good and evil and the responsibility of men. *Journal of Muslim Mental Health* 1(1): 43-56
- Strasser HC, Lilyestrom J, Ashby ER, Honeycutt NA, Schretlen DJ, Pulver AE, Hopkins RO, Depaulo JR, Potash JB and Schweizer B (2005) Hippocampal and ventricular volumes in psychotic and nonpsychotic bipolar patients compared with schizophrenia patients and community control subjects: a pilot study. *Biological psychiatry* 57(6): 633-639
- Strauss ME (1993) Relations of Symptoms to Cognitive Deficits in Schizophrenia. *Schizophrenia Bulletin* 19(2): 215-231
- Sugihara G and Takei N (2013) Renaming schizophrenia coupled with proper public education is an optimal way to overcome stigma. *Psychological Medicine* 43(7): 1557-1558
- Sullivan PF, Kendler KS and Neale MC (2003) Schizophrenia as a complex trait: evidence from a meta-analysis of twin studies. *Archives Of General Psychiatry* 60(12): 1187-1192
- Suraratdecha C, Saithanu S and Tangcharoensathien V (2005) Is universal coverage a solution for disparities in health care? Findings from three low-income provinces of Thailand. *Health Policy* 73(3): 272-284
- Svettini A, Johnson B, Magro C, Saunders J, Jones K, Silk S, Hargarter L and Schreiner A (2015) Schizophrenia through the carers' eyes: Results of a european cross - sectional survey. *Journal of Psychiatric and Mental Health Nursing*
- Swartz MS, Swanson JW and Hannon MJ (2003) Does Fear of Coercion Keep People Away from Mental Health Treatment? Evidence from a Survey of Persons with Schizophrenia and Mental Health Professionals. *Behavioral Sciences & the Law* 21(4): 459-472
- Szasz T (2008) Debunking antipsychiatry: Laing, law, and largactil. *Current Psychology: A Journal for Diverse Perspectives on Diverse Psychological Issues* 27(2): 79-101
- Takahashi H, Ideno T, Okubo S, Matsui H, Takemura K, Matsuura M, Kato M and Okubo Y (2009) Impact of changing the Japanese term for "schizophrenia" for reasons of stereotypical beliefs of schizophrenia in Japanese youth. *Schizophrenia Research* 112(1-3): 149-152
- Tandon R, Matcheri SK and Henry AN (2008) Schizophrenia, 'just the facts' what we know in 2008. 2. Epidemiology and etiology. *Schizophrenia Research* 102(1-3): 1-18

- Tandon R, Nasrallah HA and Keshavan MS (2010) Schizophrenia, "Just the facts" 5. Treatment and prevention past, present, and future. *Schizophrenia Research* 122(1-3): 1-23
- Teddlie C and Tashakkori A (2003) Major issues and controversies in the use of mixed methods in methods in social and behavioral sciences *Handbook of mixed methods in social and behavioral research* Thousand Oaks, CA: Sage 3-50
- Teddlie C and Tashakkori A (2009) *Foundations of mixed methods research: Integrating quantitative and qualitative approaches in the social and behavioral sciences* London: Sage
- Tee S, Lathlean J, Herbert L, Coldham T, East B and Johnson TJ (2007) User participation in mental health nurse decision-making: a co-operative enquiry. *Journal of Advanced Nursing* 60(2): 135-145
- Teferra S, Hanlon C, Beyero T, Jacobsson L and Shibre T (2013) Perspectives on reasons for non-adherence to medication in persons with schizophrenia in Ethiopia: a qualitative study of patients, caregivers and health workers. *BMC Psychiatry* 13: 168-168
- Teferra S, Shibre T, Fekadu A, Medhin G, Wakwoya A, Alem A, Kullgren G and Jacobsson L (2011) Five-year mortality in a cohort of people with schizophrenia in Ethiopia. *BMC Psychiatry* 11
- Thai National Statistical Office (2010) *Executive Summary*. Available from: http://web.nso.go.th/en/census/poph/data/090913_ExecutiveSummary_10.pdf [Accessed 1 October 2014]
- The Royal College of Psychiatrist (2014) *Information about ECT (Electroconvulsive therapy)*. Available from: <http://www.rcpsych.ac.uk/healthadvice/treatmentwellbeing/ect.aspx> [Accessed 22 August 2014]
- The Royal Institute (2007) *Rural definition*. Available from: <http://rirs3.royin.go.th/dictionary.asp> [Accessed 7 October 2013]
- The Thai Ministry of Public Health (2013) *Service plan: Mental health and psychiatry branch*. Bureau of Health Administration: The Agricultural Co-operative Federation of Thailand
- Thirhalli J and Kumar CN (2012) Stigma and disability in schizophrenia: Developing countries' perspective. *International Review of Psychiatry* 24(5): 423-440
- Tochigi M, Okazaki Y, Kato N and Sasaki T (2004) What causes seasonality of birth in schizophrenia? *Neuroscience Research* 48(1): 1-11
- Towse A, Mills A and Tangjareonsatien V (2004) Learning from Thailand's Health reform *BMJ* 328: 103-105
- Trading economic.com (2015) *Thailand Minimum Daily Wage* Available from: <http://www.tradingeconomics.com/thailand/minimum-wages>
- Trangkasombat U (2008) Family functioning in mental illness: a study in Thai families with depressive disorders and schizophrenia. *Journal of Family Psychotherapy* 19(2): 187-201
- Triandis HC, Bontempo R, Villareal MJ, Asai M and Lucca N (1988) Individualism and collectivism: Cross-cultural perspectives on self-in-group relationships. *Journal of personality and Social Psychology* 54(2): 323
- Tsuang M (2000) Schizophrenia: Genes and environment. *Biological Psychiatry* 47(3): 210-220
- Tsuang MT, Stone WS and Faraone SV (2001) Genes, environment and schizophrenia. *British Journal of Psychiatry* 178(Suppl40): s18-s24
- Tuli F (2010) Review article: The basis of distinction between qualitative and quantitative research in social science: reflection on ontological,

List of references

- epistemological and methodological perspectives. *Ethiop. J. Educ. & Sc* 6(1): 97-108
- Udomratn P (2009) How Thailand has modified the section on mental disorders in the International Statistical Classification of Diseases and Related Health Problems 10th Revision (ICD-10)*. *Asia-Pacific Psychiatry* 1(2): 88-89
- Udomratn P and Vasiknanonte S (2009) Pattern of prescribing antipsychotic drugs in Thailand. *ASEAN Journal of Psychiatry* 10(1): 1-8
- University of Maryland Medical Center (2014) *Schizophrenia*. Available from: <http://umm.edu/health/medical/reports/articles/schizophrenia> [Accessed 25 March]
- Urbach M, Brunet-Gouet E, Bazin N, Hardy-Baylé M-C and Passerieux C (2013) Correlations of theory of mind deficits with clinical patterns and quality of life in schizophrenia. *Frontiers in Psychiatry* 4
- van E, Theo G.M. G, Douglas N, Rasmussen J, Turner J, Calhoun VD, Young S, Mueller B, Brown GG, McCarthy G, Glover GH, Lim KO, Bustillo JR, Belger A, McEwen S, Voyvodic J, Mathalon DH, Keator D, Preda A, Nguyen D, Ford JM, Potkin SG and Fbirt (2014) A multi-scanner study of subcortical brain volume abnormalities in schizophrenia. *Psychiatry Research: Neuroimaging*
- Van Haren NE, Cahn W, Pol HEH and Kahn RS (2013) Confounders of excessive brain volume loss in schizophrenia. *Neuroscience and Biobehavioral Reviews* 37(10, Part 1): 2418-2423
- van Nes F, Abma T, Jonsson H and Deeg D (2010) Language differences in qualitative research: is meaning lost in translation? *European Journal of Ageing* 7(4): 313-316 4p
- van Os J (2009) 'Salience syndrome' replaces 'schizophrenia' in DSM-V and ICD-11: Psychiatry's evidence-based entry into the 21st century? *Acta Psychiatrica Scandinavica* 120(5): 363-372
- Vanaleesin S, Suttharangsee W. and U. aH (2007) Cultural aspects of care for Muslim schizophrenic patients: an ethn nursing study. *Songkla Med J* 25(5): 361-370
- Varcarolis EM (2004) *Manual of psychiatric nursing care plans: diagnoses, clinical tools and psychopharmacology* (2nd Edition). London: St. Louis
- Vassos E, Pedersen CB, Murray RM, Collier DA and Lewis CM (2012) Meta-analysis of the association of urbanicity with schizophrenia. *Schizophrenia Bulletin* 38(6): 1118-1123
- Versola-Russo J (2006) Cultural and Demographic Factors of Schizophrenia. *International Journal of Psychosocial Rehabilitation* 10(2): 89-103
- Vicky Short, Charlotte Lennox, Caroline Stevenson, Jane Senior and Jenny Shaw (2012) Mental illness, personality disorder and violence: A review scoping review. The Offender Health Research Network
- Viron M, Baggett T, Hill M and Freudenreich O (2012) Schizophrenia for primary care providers: how to contribute to the care of a vulnerable patient population. *American Journal of Medicine* 125(3): 223-230
- Vivar CG (2007) Getting started with qualitative research: developing a research proposal. *Nurse Researcher* 14(3): 60-73
- Waltzer H (1982) The biopsychosocial model for brief inpatient treatment of the schizophrenic syndrome. *Psychiatric Quarterly* 54(2): 97-108
- Wang-Schweig M, Miller BA, Kviz FJ, Altfeld SJ and Miller AM (2014) Building a Conceptual Framework to Culturally Adapt Health Promotion and Prevention Programs at the Deep Structural Level. *Health Promotion Practice* 15(4): 575-584

- Wang M-L (2011) *The cultural beliefs and mental health help-seeking behaviors of people with schizophrenia in Taiwan*. Unpublished 72 thesis ProQuest Information & Learning University
- Wansa P (2006) *Development of ICD-10 Thai modification in Thailand*.
- Warner R (2004) *Recovery from schizophrenia* (3rd Edition). New York: Brunner Routledge
- Warren A (2001) Qualitative interviewing IN: Gubrium F and Holstein A (eds) *Handbook of interview research: content and method*. London: Sage
- Weakland JH (1976) The "Double Bind" hypothesis of schizophrenia and three-party interaction IN: Sluzki CE and Ransom DC (eds) *Double blind: the foundation of the communicational approach to the family*. London: Grune&Stratton
- Weiser M, van Os J, Reichenberg A, Rabinowitz J, Nahon D, Kravitz E, Lubin G, Shmushkevitz M, Knobler HY, Noy S and Davidson M (2007) Social and cognitive functioning, urbanicity and risk for schizophrenia. *The British Journal of Psychiatry* 191(4): 320-324
- White C and Unruh A (2013) Unheard Voices: Mothers of Adult Children With Schizophrenia Speak Up. *Canadian Journal of Community Mental Health* 32(3): 109-120
- Whitford V, O'Driscoll GA, Pack CC, Joobor R, Malla A and Titone D (2013) Reading impairments in schizophrenia relate to individual differences in phonological processing and oculomotor control: Evidence from a gaze-contingent moving window paradigm. *Journal of Experimental Psychology: General* 142(1): 57-75
- Whitley R (2012) The antipsychiatry movement: dead, diminishing, or developing? *Psychiatric Services* 63(10): 1039-1041 3p
- WHO (1992) *The ICD-10 classification of mental and behavioural disorders : clinical descriptions and diagnostic guidelines* Geneva: World Health Organization
- WHO (2011) *WHO Country Cooperation Strategy: Thailand 2012-2016* New Delhi: World Health Organization
- WHO (2014) *Mental health: schizophrenia*. Available from: http://www.who.int/mental_health/management/schizophrenia/en/ [Accessed 25 March 2014]
- Winefield HR and Harvey EJ (1994) Needs of family caregivers in chronic schizophrenia. *Schizophrenia Bulletin* 20(3): 557-566
- Wiwekwan Y (2000) *Mental health and caring behavior of caregivers of schizophrenic patients*. . Unpublished Masters' thesis
- Wong HCA and Van Tol HMH (2003) Schizophrenia: from phenomenology to neurobiology. *Neuroscience and Biobehavioral Reviews* 27: 269-306
- Woods P (2006) *Successful writing for qualitative researchers* (2nd edition Edition). London: Routledge
- World Bank (2014) *Thailand Overview*. Available from: <http://www.worldbank.org/en/country/thailand/overview> [Accessed 1 October 2014]
- World Health Organization (2003) *Adherence to long-term therapies: evidence for action*. Geneva: : World health Organization
- Wright J, Williams R and Wilkinson R (1998) Health needs assessment: Development and importance of health needs assessment *BMJ* 316: 1310-1313
- Wu EQ, Birnbaum HG, Shi L, Ball DE, Kessler RC, Moulis M and Aggarwal J (2005) The Economic Burden of Schizophrenia in the United States in 2002. *Journal of Clinical Psychiatry* 66(9): 1122-1129

List of references

- Yeh L-L, Hwu H-G, Chen C-H, Chen C-H and Wu ACC (2008) Factors related to perceived needs of primary caregivers of patients with schizophrenia. *Journal Of The Formosan Medical Association = Taiwan Yi Zhi* 107(8): 644-652
- Yin K (2009) *Case study research: design and methods* London
- Yin K (2011) *Qualitative research from start to finish*. New York: Guilford Press
- Zubin J and Spring B (1977) Vulnerability: a new view of schizophrenia. *Journal of abnormal psychology* 86(2): 103