

This file is part of the following work:

Nurjannah, Intansari (2014) *Connecting care for individuals living with a mental health issue in Indonesia: a grounded theory study*. PhD Thesis, James Cook University.

Access to this file is available from:

<https://doi.org/10.25903/dacc%2Dq275>

Copyright © 2014 Intansari Nurjannah

The author has certified to JCU that they have made a reasonable effort to gain permission and acknowledge the owners of any third party copyright material included in this document. If you believe that this is not the case, please email

researchonline@jcu.edu.au

ResearchOnline@JCU

This file is part of the following reference:

Nurjannah, Intansari (2014) *Connecting care for individuals living with a mental health issue in Indonesia: a grounded theory study*. PhD thesis, James Cook University.

Access to this file is available from:

<http://researchonline.jcu.edu.au/39156/>

The author has certified to JCU that they have made a reasonable effort to gain permission and acknowledge the owner of any third party copyright material included in this document. If you believe that this is not the case, please contact

*ResearchOnline@jcu.edu.au and quote
<http://researchonline.jcu.edu.au/39156/>*

Connecting Care for Individuals Living with a Mental Health Issue in Indonesia: A grounded theory study

Intansari Nurjannah, BSN, MNSc

For the Degree of Doctor of Philosophy

School of Nursing, Midwifery & Nutrition

James Cook University

February, 2014

Supervisory Team

Jane Mills (Principal Supervisor)

Kim Usher (Supervisor)

Tanya Park (Supervisor)

STATEMENT OF ACCESS

I, the undersigned, the author of this thesis, understand that James Cook University Library, by microfilm or by other means, allows access to users in other approved libraries. All users consulting this thesis will have to sign the following statement:

“In consulting this thesis, I agree not to copy or closely paraphrase it in whole or part without the consent of the author; and to make proper written acknowledgement for any assistance, which I have obtained from it”.

Beyond this I do not wish to place any restriction on access to this thesis.

Signed

Date: 26 February 2014

STATEMENT OF SOURCES DECLARATION

I declare that this thesis is my own work and had not been submitted in any form for another degree or diploma at any university or other institution of tertiary education. Information derived from the published, unpublished or oral work of others has acknowledged in the text and a list of references is given.

Signed

Date: 26 February 2014

STATEMENT OF CONTRIBUTION OF OTHERS

Nature of Assistance	Contribution	Names, Titles and Affiliations of Co-contributors
Intellectual support	<p>The supervisory team provided assistance with proposal writing and data analysis within the remit of their roles as described in the policy <i>The Role of the Advisory Panel in Providing Regular Guidance and Support to Research Students</i>.</p> <p>Editorial assistance was provided to the candidate by both the supervisory team and professional editors. Proof reading was restricted to correcting the presentation of the text to conform with standard usage and conventions. Provision of advice in the matters of structure, conventions of grammar and syntax, use of clear language, logical connections between phrases, clauses, sentences, paragraphs and sections, voice and tone and repetition.</p>	<p>Associate Professor Jane Mills, School of Nursing, Midwifery & Nutrition, James Cook University</p> <p>Professor Kim Usher, School of Health, University of New England</p> <p>Dr Tanya Park, School of Nursing, Midwifery & Nutrition, James Cook University</p> <p>Ms Marnie Hitchins, School of Nursing, Midwifery & Nutrition, James Cook University</p> <p>Phillip Thomas, Editing and Proof-Reading Services, 38 Gosfield Crescent Hampstead Gardens S.A 5086</p>
Financial support	Field research Stipend	<p>Australian Development Scholarships</p> <p>School of Nursing, Midwifery and Nutrition, JCU</p> <p>Graduate Research School, JCU</p>
Preparation before data generation	Checking the accuracy of Indonesian translation for informed consent and information sheet	<p>Ramlah Staines.</p> <p>Certified interpreter</p> <p>21B Trucano Close, Whitfield, Cairns 4870</p>
Data generation and analysis	Interview transcription and translation, including back translation	<p>Amin Basuki, English teacher, Faculty of Cultural Sciences, Gadjah Mada University Indonesia</p> <p>Thomas Harding, Certified translator, Indoeasy Language Service, 8 Market Street, Kensington Vic 3031, Australia</p>

ACKNOWLEDGEMENTS

There are many people, colleagues and friends who contributed to the development and completion of this PhD thesis through their time, encouragement, support and advice. I am indebted to Associate Professor Jane Mills, Professor Kim Usher and Doctor Tanya Park who have spent their time and energy supervising me over the past three years. I consider myself to be a very lucky person who was supervised by persons who are experts in their fields. They were also very patient in their support of me at each stage of my PhD study. Their encouragement, support and advice enabled me to realise my potential and become a better person. In particular I became more confident doing research and publishing my findings.

I would like to express my deep and sincere appreciation to the psychiatric hospital directors, Health Department directors, Social Service Department directors in Yogyakarta Special Province and Central Java and the owner of a private shelter, for giving me permission to conduct my study on their premises. My appreciation is also extended to the staff in these institutions for their cooperation and support. My sincere appreciation is also extended to the participants in this study for sharing their time, feelings, ideas and thoughts. This provided me with a great experience and helped me to grow and enrich my knowledge.

Finally, I would like to thank my family, friends and colleagues for their support and understanding throughout my candidature, especially students from Indonesia who are studying at JCU. Staying in Australia with them enabled my family to stay close to Indonesian culture and this brought me much happiness. Thanks to Alexander Salvador who was always ready to help me and my family. Thanks to Marnie Hitchins for her wonderful job in editing my thesis. Last but not least, thanks to my husband, Yulistianto, for his never-ending support and understanding. Finally, I would also like to thank my sons, Diqi and Isa, for their love and understanding when their 'Mummy' had such a busy time. Thanks to all of you; I managed to keep my spirit alive in my PhD journey and for the future. Thank you.

ABSTRACT

Mental health services are not a priority in the Indonesian health system. Insufficient resources are allocated, resulting in shortfalls in key performance indicators for mental health services. Overall, facilities and human resources are inadequate which means that mental health services do not function at their best. The impact of these inadequacies can be seen when individuals living with a mental health issue experience the ‘vicious cycle’ of a ‘revolving door’ between psychiatric institutions and the community. Individuals living with a mental health issue wander on the streets - a visible consequence of an inadequate mental health system. In extreme cases, shackling (or other physical restraint) of individuals living with a mental health issue occurs because the family cannot afford the cost of treatment. To date, there has been little research undertaken in Indonesia that investigates the way in which mental health care is delivered.

The aim of this grounded theory study was to generate a theoretical model of collaborative care for individuals living with a mental health issue in Indonesia. The findings will contribute to the evidence base concerning the provision of mental health care in this country. Data were collected during three field trips between 2011 and 2012. Forty-nine participants were interviewed including health professionals and non-health professionals, individuals living with a mental health issue, cadres (a term that in Indonesia refers to mental health volunteers), families and community leaders. The interviews were recorded and transcribed in Indonesian before being analysed using grounded theory methods of concurrent data collection and analysis: initial, intermediate and advanced coding and theoretical sampling.

The grounded theory of connecting care for individuals living with a mental health issue explains in part how mental health care is delivered in Indonesia. The core category was connecting care. Three categories were constructed in the development of this theory and these categories are decision-making, shifting responsibility and accepting responsibility. Of these three categories, decision-making was found to be central to the provision of care by health professionals and non-health professionals. Decision-making is characterised by four properties,

each one of which influences individual stakeholders to varying degrees. These properties are level of resources; competency of the individual to provide care; willingness to provide care; and compliance with official policies. When making a decision, stakeholders such as doctors, nurses, carers and family members, will either shift responsibility or accept responsibility to provide care. The success and effectiveness of shifting responsibility is largely influenced by the quality of communication between stakeholders. Accepting responsibility is influenced by resources, competency and willingness.

The most influential factor for health professionals is following the rules of institutional policy when they make decisions about whether to shift or accept responsibility to provide care. Decision-making for non-health professionals, however, is influenced more heavily by personal circumstances. These circumstances include competence, willingness, resources and compliance with policy. Negotiations between health professionals and non-health professionals about the provision of care can result in either matched or unmatched decision-making. Matched decision-making leads to the unforced acceptance of responsibility and results in optimum health outcomes. Unmatched decision-making can result in health professionals and non-health professionals (especially families) being forced to provide a level of care that exceeds their competency and resources. Unmatched decision-making also results in individuals being forced into psychiatric institutions for unnecessarily long periods of time. Forced acceptance of responsibility leads to adverse health outcomes and can increase the risk of human rights violations and the burden of care.

Several recommendations arise from this study. The first recommendation is that the Indonesian Government should establish a mental health act and accompanying regulations to serve as a guideline for all stakeholders who make decisions to shift or accept responsibility for care. The second recommendation is to apply a series of strategies aimed at reducing families' burden of care. These strategies include providing social networks (groups) for families and providing education for non-health professionals, such as community members, to help them better understand mental health and the needs of consumers. Mental health services, both in psychiatric institutions and in the community, also need to be more accessible to individuals

living with a mental health issue and for their families. The provision of financial support for individuals living with a mental health issue and their families is also crucial. The final strategy proposed is that the Indonesian Government provides an increased and adequate number of competent health professionals to meet the needs of individuals living with mental health issues and their families in the community.

This grounded theory explains the process of collaborative care for individuals living with a mental health issue. The product of this grounded theory study also can explain the three phenomena that prompted this study: the vicious cycle of the revolving door for people with mental illness, wandering cases and shackling (or other physical restraints). It is hoped that the theory of connecting care can be used as a framework to improve mental health service delivery in Indonesian cities, towns and regions with a subsequent improvement in patient outcomes.

Table of Contents

STATEMENT OF ACCESS	I
STATEMENT OF SOURCES DECLARATION	II
STATEMENT OF CONTRIBUTION OF OTHERS	III
ACKNOWLEDGEMENTS	IV
ABSTRACT	V
CHAPTER ONE: INTRODUCTION	1
Research aim	2
Purpose of the research.....	2
Grounded theory research design	3
Study setting	5
Background.....	8
Outline of the thesis.....	12
Chapter summary.....	14
CHAPTER TWO: BACKGROUND	15
Introduction	15
Manuscript: Discharge planning in mental health care: an integrative review of the literature	19
Indonesia’s mental health services	30
Human rights and mental health legislation in Indonesia	39
Lay people providing care	45
The burden of care.....	46
Chapter summary.....	47
CHAPTER THREE: METHODOLOGY AND METHODS	49
Position of the researcher	49

History of symbolic interactionism	50
Grounded theory	54
Grounded theory methods	56
Ethical considerations	64
Study participants and recruitment	66
Field trip one	68
Field trip two	72
Field trip three	74
Manuscript: Conducting a Grounded Theory Study in a Language Other Than English: Procedures for Ensuring the Integrity of Translation	76
Chapter summary	101
CHAPTER FOUR: FINDINGS.....	102
Introduction	102
Overview of the theory of connecting care	102
Findings	105
Key findings	120
Chapter summary	121
CHAPTER FIVE: DISCUSSION	123
Introduction	123
The importance of policy for health professionals' decision making	123
Non-health professionals' forms of coping	125
Human rights violations as a result of decision making	129
Families carry the heaviest burden of care	132
Chapter summary	134
CHAPTER SIX: CONCLUSION.....	135
Introduction	135

Reflecting on the past three years.....	136
Evaluating a grounded theory study.....	137
Process evaluation.....	138
Product evaluation.....	143
Strengths and limitations of the study.....	145
Recommendations.....	147
Conclusion.....	152
REFERENCES	154
LIST OF APPENDICES	177

List of Tables

Table 1.1		
	<i>Comparison of Characteristics of Central Java Province and Yogyakarta Special Province</i>	<i>p.7</i>
Table 2.1		
	<i>Selected Examples of Mental Health Services as Categorised by WHO (2013c)</i>	<i>p.31</i>
Table 2.2		
	<i>Indonesian Government's Efforts to Develop Health Insurance</i>	<i>p.37</i>
Table 2.3		
	<i>Principles for the Protection of Persons with Mental Illness and the Improvement of Mental Health Care</i>	<i>p.41-2</i>
Table 3.1		
	<i>Terms for Coding</i>	<i>p.62</i>
Table 3.2		
	<i>Study Participants</i>	<i>p.67</i>
Table 4.1		
	<i>Glossary of Terms for the Theory of Connecting Care</i>	<i>p.105</i>
Table 5.1		
	<i>Comparison of Connecting Care and Theory of Coping Concepts</i>	<i>p.126</i>

List of Figures

- Figure 3.1* The Sequence of Field Trips *p.68*
- Figure 4.1* The Theory of Connecting Care *p.104*

Glossary

In the literature there is a lot of discussion about the words or terms employed to label people with a mental illness. For the purpose of this thesis the following words and phrases were used because they suited the context of the study – Indonesia. The terms ‘mentally ill’ and ‘mental disorder’ will be used along with the phrase ‘individual living with a mental issue’ and the word ‘patient’. Other context-specific terms used in this thesis that require further explanation are as follows:

Burden of care	Overload of the responsibility to provide care
Cadres	Indonesian mental health volunteers
Caregivers/carers	Non-health professionals who are responsible for providing care for individuals living with a mental health issue
Collaborative care	All stakeholders involved in mental health care, be they employed in the Indonesian mental health system or lay people in the community who have taken responsibility for care provision, interact and work together to ensure that individuals living with a mental health issue receive appropriate care
Discharge letter	A formal letter provided by a health professional (usually someone working in a hospital) to individuals living with a mental health issue when they are discharged from hospital
Dropping-off program	A program operated by a psychiatric hospital in which individuals who have a good health status are dropped off at home. These individuals have stayed in the hospital beyond their allocated time because a family member or responsible person has failed to pick them up and bring them home.
Institutional policy	A policy designed by an institution such as a hospital, public shelter or private shelter.
Mental health care	The care provided in an institution or in the community to an individual living with a mental health issue
National Health Insurance (NHI)	A social security program for health that covers health service costs for all Indonesians. The NHI is part of the National Social Security System and commenced on the 1 st January 2014.
National Social Security System	A system that is designed to regulate the social security program including health, retirement, accident, pension,

	and life insurance.
Pasung	A word used in Indonesia for the type of shackling that involves chaining a person's feet to a wooden post
Primary Health Care Centre (PHCC)	The frontline health care facility in Indonesia where primary health care services are provided to community members
Private shelter	An institution that is privately owned and operated and provides long-term care for individuals living with a mental health issue
Public shelter	A type of social shelter that is operated by the Indonesian Government's Social Service Department providing services for underprivileged children, prostitutes, homeless people, elderly people and individuals living with a mental health issue who are in a rehabilitation state
Referral letter	A letter written and signed by a health professional to refer individuals living with a mental health issue for advanced treatment
Revolving door	A phenomenon in which individuals living with a mental health issue experience multiple admissions and discharges from hospital
SMS	Short Message Services
Social Security Administrative Body	A legal entity established in 2011 to administer the National Security System in Indonesia.
Social Security for Community	A health care insurance program for the poor in Indonesia that was superseded by the NHI, which commenced on 1 st January 2014
Social shelter	Social shelters are institutions that provide services for underprivileged children, prostitutes, homeless people, elderly people (aged care) and patients with mental disorders. Social shelters can be private or public (managed by government – Social Service Department)
Sweeping-up program	A program that involves actively looking for unwell individuals living with a mental health issue and identifying other people in need of help, such as underprivileged children and prostitutes and people who are wandering or begging on the street (Das, 2011)

CHAPTER ONE: INTRODUCTION

Mental disorders affect individuals, families, communities and nations accounting for more than 13% of the global burden of disease. The impact of mental disorders can be measured at both the macro and micro level. Mental illness is expected to result in a worldwide loss of economic output of approximately US\$16.3 billion in the 19 years between 2011 and 2030. At an individual level people living with mental disorders have higher rates of disability and mortality and their complex health needs require comprehensive health care services. Individuals living with a mental health issue are part of a vulnerable group that often experiences stigmatisation and discrimination that can result in human rights violations (WHO, 2013a).

Indonesia, which is the setting for this grounded theory study, has become increasingly subject to international scrutiny regarding human rights violations of individuals living with a mental health issue. One human rights violation that results in deterioration of mental and physical health is shackling, which involves chaining a person to the floor (Ryan, 2013). This extreme form of physical restraint as a method of managing the healthcare of affected individuals has been reported in the popular press and in the peer-reviewed literature and will be discussed in further detail in chapter two (Irmansyah, Prasetyo, & Minas, 2009; Minas & Diatri, 2008; Puteh, Marthoenis, & Minas, 2011). Recently, BBC News' Asia-Pacific Indonesia bureau brought to the world's attention the practice of shackling mentally-ill individuals (Safitri, 2011). The news team broadcast the story of a young man whose family had used physical restraints to manage his care for a number of years. Such stories were also published by the *Jakarta Globe* (Gale, 2012), the *Sydney Morning Herald* (Allard, 2010; Gale, 2012), and PBS News Hour (Suarez, 2011). In 2011, the *New York Times* published an article on mentally-ill individuals in Indonesia who were shackled in chicken coops (MacDonald, 2011). The Indonesian Government has been quoted in news reports as estimating that there are 18,000 individuals living with mental health issues in Indonesia who are shackled (Faizal, 2012). There

is no official report in the public domain however that confirms the figures in these reports. Shackling has garnered much attention in the popular press but this practice is just one of many adverse outcomes and situations that have arisen in Indonesia because of a lack of resources and limited public awareness of the complexity of mental disorders.

The three adverse mental health outcomes in Indonesia that prompted this study and led the author to investigate the substantive area of mental health care delivery in Indonesia are as follows: poor transition of mentally ill people between the hospital and the community, the situation whereby mentally ill people are forced to wander the streets and the shackling of mentally ill people by their families, carers or communities. Earlier research by the author (Nurjannah, FitzGerald, & Foster, 2009) found that individuals living with mental health issues struggled to make the transition from tertiary care provided in psychiatric hospitals to the community setting. Findings from this 2009 study indicated that family members were often reluctant to accept responsibility for affected individuals. Individuals with mental illnesses who were not picked up by their reluctant families were 'dropped off' at home by hospital staff. A 'vicious cycle' or 'revolving door' ensued when family members were not prepared to provide care and the patient experienced multiple admissions and discharges from hospital for many years. A large number of individuals experience frequent readmissions to psychiatric institutions; a significant number of individuals also wander the streets of Indonesia, acutely ill with a mental disorder (Noor, 2012). No one takes responsibility for these individuals' welfare, which often results in a failure to admit them to psychiatric hospital despite the individual being in great need of a high level of care.

Research aim

The aim of this study was to generate a theoretical model of collaborative care for individuals living with a mental health issue in Indonesia.

Purpose of the research

The purpose of this study was to identify and explain how all stakeholders involved in mental health care, be they employed in the Indonesian mental health system or lay people in the community who have taken responsibility for care provision, interact and work together to ensure that individuals living with a mental health issue receive appropriate care. Recommendations from this grounded theory of connecting care for individuals living with a mental health issue in Indonesia are aimed at influencing education, policy, practice and future research and will provide a framework for action at both a national and grassroots level.

Grounded theory research design

Grounded theory was chosen as the research design to investigate the substantive area of enquiry. Grounded theory is useful when there are no existing theories that explain the phenomenon (Strauss & Corbin, 1998), no testable hypothesis (Curtis, Horton, & Smith, 2012) or little is known about the phenomenon (Chamberlain-Salaun, Mills, & Park, 2011; Coniglio, Hancock, & Ellis, 2012; Kulkarni, 2012). Grounded theory is also appropriate to identify social processes (Haraldsson, Lindgren, Mattsson, Fridlund, & Marklund, 2011) that explain human behaviour embedded in a social context or to explain human interaction (Hall, Griffiths, & McKenna, 2013; Hall, McKenna, & Griffiths, 2012). In addition, grounded theory is suitable for application in a study that aims to explain a phenomenon rather than to verify a theory (Edmunds & Brown, 2012; Strauss & Corbin, 1990; Thompson, Petty, & Scholes, 2012). In this study, the process of care provision for individuals living with a mental health issue in Indonesia was best explained using a grounded theory research design because very little is known about the phenomenon. The limited mental health services in Indonesia are not meeting the increasing need for mental health care (Irmansyah, 2009) but no research studies have yet established why mental health care needs are not being met and what can be done to change the situation.

Grounded theory is a type of qualitative research that can be underpinned by concepts of pragmatism and symbolic interactionism (Corbin & Strauss, 2008). Grounded theory was developed by Glaser and Strauss in 1967. Since then three common types of grounded theory

have evolved and are in use today. The first of these is Glaserian grounded theory which is widely considered to be in agreement with the traditional version of the grounded theory research design and is affiliated with post-positivism (Charmaz, 2006; Dunne, 2010; McGhee, Marland, & Atkinson, 2007). The second strand is Strauss and Corbin's version of grounded theory (Corbin & Strauss, 2008; Strauss & Corbin, 1990, 1998) which is related to symbolic interactionism and constructivism (Chamberlain-Salaun, Mills, & Usher, 2013; Plummer & Young, 2009). The third version of grounded theory is associated with Charmaz's work, (Charmaz, 2006) which is considered to be largely constructivist (Plummer & Young, 2009).

The evolution of grounded theory methods from its traditional roots and the promotion of alternative forms of grounded theory began in 1990 with the publication of '*Basics of qualitative research: grounded theory procedures and techniques*' by Strauss and Corbin. This, in turn, generated a critique from one of the original creators of grounded theory, Glaser, which was published as a book, '*Basics of grounded theory analysis*' (Glaser, 1992). The most substantial differences between traditional and subsequent versions of grounded theory are to be found in the coding procedures and the forms of theoretical outcomes.

Glaser and Strauss's first publication about grounded theory (1967) divided the coding procedure into four phases, while Glaser (1992) later divided coding into two major phases that incorporated several sub-phases. The last versions of the coding procedure, developed by Strauss and Corbin and published in 1990 and 1998, refer to coding in three parts including axial coding.

The form of theoretical outcomes is the second significant difference between traditional and evolved grounded theory. In traditional grounded theory categories are expected to emerge from data to generate theory, while for Strauss and Corbin the concept of verification in the coding process is the method used to construct concepts grounded in the data (Charmaz, 2006).

In this study, Strauss and Corbin's (1990, 1998) version of evolved grounded theory will be used to construct a theory that explains the process of delivering mental health care in Indonesia. This version of grounded theory methodology with its underpinning of symbolic interactionism was chosen because it is 'in tune' with the researcher's values and beliefs

(Hunter, Murphy, Grealish, Casey, & Keady, 2011) about the nature of reality and the importance of interaction in everyday life.

History of the substantive area of enquiry

The study is based on data generated during three field trips between 2011 and 2012. During the first field trip the author's original aim was to generate a theoretical model of discharge planning for individuals living with a mental health issue in Indonesia. In grounded theory, the data guides the researcher's direction, using the key method of concurrent data analysis and collection to construct theory from data acquired through theoretical sampling (Glaser & Strauss, 1967). Early comparative analysis in this study led the author to change from the original aim of investigating discharge planning. After the first field trip, a bigger and more complex picture emerged that needed to be explored and expanded beyond looking simply at the discharge planning process. The results of the first field trip guided the second and third field trips. Over time, the substantive area of enquiry broadened and data generation was widened to include more varied stakeholders. These changes could not be avoided and are characteristic of a grounded theory study where the research direction is determined by the results of concurrent data generation and analysis.

Study setting

This research study was conducted in two provinces in Indonesia: Yogyakarta Special Province and Central Java Province. Yogyakarta and Central Java are two neighboring provinces, have similar cultures (Government of The Republic of Indonesia, 2007), and use Indonesian or Javanese language in their daily life. The dominant religion is Islam and the majority of the population of both provinces is Javanese people. A household commonly consists of parents and two children; sometimes a grandfather or grandmother also lives in the same house (Government of The Republic of Indonesia, 2007).

Population density in Central Java and Yogyakarta is similar. The unemployment rate in Yogyakarta is lower than Central Java but the poverty rate in Yogyakarta is higher than Central Java. Livelihood activities of both provinces are also a little different. Agriculture is the

dominant livelihood activity in both provinces, but it is 6.5% higher in Central Java than in Yogyakarta (see table 1.1).

Health care facilities in these two provinces consist of hospitals and primary health care centres (PHCC). Hospitals are either general or specific (such as a psychiatric hospital). PHCCs provide primary health care services to the community and, if a particular case requires more specialised or high-level care, the PHCCs will refer this type of patient to a psychiatric hospital. The ratio of PHCCs to population is higher in Yogyakarta when compared with Central Java (see table 1.1). The number of psychiatric hospitals is greater in Central Java but the ratio of psychiatric hospitals to population is higher in Yogyakarta (1:1,728,745 people) when compared with Central Java (1:2,490,973 people).

Information on the number of places available in special social shelters for patients with mental disorders was difficult to obtain because social shelters also accommodate underprivileged children, prostitutes, homeless people and elderly people. Data show there are approximately 200 social shelters in Indonesia, 35 of which belong to the government and are managed by the Social Service Department (Ahi, 2014).

Table 1.1

Comparison of Characteristics of Central Java Province and Yogyakarta Special Province

Variable	Central Java Province	Yogyakarta Special Province
Population	32,382,657 (Mnl, 2011)	3,457,492 (Mnl, 2011)
Total Area	32,800.69 km ² (1.72% of total area of Indonesia) (Daftar Provinsi dan luas wilayah Indonesia tahun 2010, 2010)	3.133.15 km ² (0.16% of total area of Indonesia) (Daftar Provinsi dan luas wilayah Indonesia tahun 2010, 2010)
Open Unemployment Rate (OUR*)	5.63% (2012) and 6.02% (2013) (BPS Provinsi Jawa Tengah, 2013)	3.97% (2012) and 3.34% (2013) (Anggraina, 2013)
Poverty rate	14.56% (Susanto, 2013)	15.01% in September 2013 (Badan Pusat Statistik Provinsi D.I. Yogyakarta, 2014)
Livelihood activities in 2005 (% of total activity) (Government of The Republic of Indonesia, 2007)	Agriculture: 42.4% Trade: 20.9% Industries: 15.7% Services: 11% (transportation, finance and construction) Others: 10.0%	Agriculture: 36.1% Trade: 24.3% Industries: 13.6% Services: 26% (transportation, finance and construction) Others: 0%
Number of psychiatric hospitals	13 psychiatric hospitals (Pinoci, 2014)	2 psychiatric hospitals (Pemerintah Daerah Daerah Istimewa Jogjakarta, 2010)
Number of PHCCs	853 (Daftar Puskesmas - Dinkes Jateng, n.d) = 1 PHCC: 37,963 people	121 (Pemerintah Daerah Daerah Istimewa Jogjakarta, 2010) = 1 PHCC: 28,574 people

* OUR: is a measure which indicates the number of unemployment to 100 individuals who belongs to the category of labor force.

This research study was set in psychiatric hospitals, PHCCs, the community in which the PHCCs exist, public shelters, private shelters and the Social Service Department. Of the psychiatric hospitals used as a research location, one was in Yogyakarta and two in Central Java. Three PHCCs in Yogyakarta were visited as well as the Social Service Department in both provinces. One public shelter in Yogyakarta and a private shelter in Central Java were accessed. The psychiatric hospitals in which the research was undertaken were staffed by health professionals such as psychiatrists, nurses and psychologists. The nurses, however, had varying levels of education and training.

Background

Mental disorders are reported increasingly throughout the world at an alarming rate with many communities and families facing an increasing burden of care. Throughout their life most people with severe and persistent mental illness have multiple occurrences of deterioration in their health status (Belcher & DeForge, 2005). The World Health Organisation (WHO) reports that mental disorders now rank fourth in the 10 leading causes of disability worldwide (WHO, 2010). European research studies show mental disorders affect a person's quality of life and ability to work to a greater extent than do most common chronic physical disorders (Alonso et al., 2004). Schizophrenia, for example, has been viewed as a lifelong and recurrent mental illness where a pessimistic outlook predominates (Bellack, 2006). People with severe and persistent mental illness often need a longer period to recover (Davidson, Shahar, Lawless, Sells, & Tondora, 2006) than people experiencing common physical illness. Treatment and recovery might take place both in hospital and, later, in the community.

The manifestation of mental illness is often affected by social, cultural and personal circumstances. People who experience mental illness have a complex situation with which to contend consisting of social, psychological and vocational variables (O'Sullivan, 1986). Unlike non-psychological health problems, people who suffer from mental illness also must cope with stigma after discharge from hospital. As such, discharge planning for individuals living with a

mental health issue will differ significantly from people with other types of physical health problems (Mukotekwa & Carson, 2007).

A trend to deinstitutionalise the care of individuals living with a mental health issue began in the 1970s in western countries such as the United States, Italy, Great Britain, Sweden, France and Spain (Madianos, 2002). Deinstitutionalisation has resulted in a decrease in the number of available psychiatric beds; patients' length of stay in psychiatric hospitals has also declined (Madianos, 2002). Individuals who are discharged early from hospital might still be unwell and need support to facilitate their recovery process. Hence, the number of individuals living with mental health issues in the community is increasing (Forchuk et al., 1998).

Although the trend of deinstitutionalisation has not yet occurred in Indonesia, there is a growing awareness of the need to provide health care in the community for individuals living with mental health issues. This awareness was brought into sharp focus after the tsunami natural disaster of 2004. The tsunami created, not only long-term physical problems, but also psychological problems for many people. As a result, there has been an increase in the number of individuals living with mental health issues in Indonesia. There has been no corresponding increase in beds in psychiatric institutions. Community-based mental health care service provision was increased to cope with this situation. Community-based mental health care services in Indonesia are mostly provided by nurses who have been trained to improve their skills in this specialist area (Keliat, 2008).

Mental health in Indonesia

A number of culturally-based assumptions surround mental health in Indonesia. Some people link mental health problems with sorcery while others associate it with religion (Harnowo, 2013). Suriani and Hadi (2008) also note that in Indonesia few individuals living with a mental health issue are detected successfully and treated in a timely manner because most families are reluctant to bring the person to an acute psychiatric hospital. Families will only bring people to hospital when they are in an acute and undeniable stage of illness. When individuals living with a mental health issue are hospitalised, it is common practice to keep

them in institutions for longer than necessary because their families are reluctant to pick them up and take them home (Nurjannah, FitzGerald & Foster, 2009).

According to Irmansyah (2009) the Indonesian Government has little interest in mental health issues, although it is estimated that about 66 million people amongst the Indonesian population (total population in 2014 of more than 250 million) have experienced a mental health disorder at some stage (Kementrian Sekretariat Negara Republik Indonesia, 2010). Suriani and Hadi (2008) also noted the number of patients who were being treated in psychiatric institutions was increasing.

Indonesia is a very large nation in which basic mental health services are simply not available in many parts of the country. Access to health services is very difficult for many individuals living with a mental health issue, particularly in remote areas. Psychiatric hospitals or general hospitals are mostly located in the provincial capitals. Medical treatment like antipsychotics are not generally available at the PHCC and, if they do exist, resources are limited and usually very out-dated (Irmansyah, 2009).

The ratio of psychiatric hospitals to individuals living with a mental health issue is unsatisfactory (Gale, 2012) with only 8000 psychiatric hospital beds available in Indonesia. Data collected in the 2013 Basic Health Research survey of 294,959 households (n=1,027,763) (Idaiani, 2013) indicates a prevalence of psychosis in the Indonesian population of 1.7 per one thousand population. The same study indicated that 14.3% of individuals living with a mental health issue experienced confinement by their family as a form of treatment (Idaiani, 2013). Physical restraint and confinement is a common 'last resort' treatment strategy for families and community members who care for individuals living with a severe mental health issue at home (Maramis, Tuan, & Minas, 2011; Minas & Diatri, 2008).

Many of these individuals living with a mental health issue are wandering around the city. The Social Service Department requires that wandering mental health patients are brought back to hospital yet this results in a crowded situation in the hospital wards (Das, 2011). One staff member in the Social Service Department confirmed that many of the people in care had originally come from another region and had simply been 'dumped' there because of a lack of

available services in their home province (Das, 2011). In Indonesia, community-based health care services are provided only to mentally-ill individuals who are not considered to be a danger to others.

One research study conducted in Indonesia found that individuals living with a mental health issue hoped to be happy - a concept that is linked to their wish to fulfil their role in their family (Nurjannah, FitzGerald & Foster, 2009). Unfortunately, this study also found such hopes were dashed by the realities of their lives at home and in hospital (Nurjannah, Fitzgerald & Foster, 2009). Many individuals living with mental health issues despaired at this lack of hope and ended their lives by committing suicide. Many more mentally-ill people become the victims of violence at the hands of members of the general public who felt disturbed by their behaviour. Individuals living with mental health issues and their families and carers were confused about how to cope with these problems. Education programs about mental health are generally unheard-of in Indonesia (Irmansyah, 2009).

In the Ministry of Health, the organisation that handles mental health issues is under the Director-General of medical services at the Directorate level. With such a low level of priority in the institutional infrastructure, the ability to cope with mental health problems is far from optimal (Irmansyah, 2009). One of the meaningful ways in which the government could improve this problem is by developing regulatory frameworks. A formal Mental Health Act would provide guidance and structure, requiring the government and broader society to pay attention to and address seriously the issue of mental health (Irmansyah, 2009). Unfortunately, efforts to date to draw up such a Mental Health Act have not shown results. The most recent Act relating to mental health was only an article in the Health Act No. 36 of 2009. In Indonesia, the Health Act mentions the purpose of mental health efforts and outlines how these efforts are to be undertaken. The law states that the responsibility for mentally-ill people who are displaced, disruptive, vagrant, or threatening the safety of self or others was to be shared between the central government, local government and the community in terms of promotion and preventative, curative and rehabilitative strategies. For economically-disadvantaged individuals living with mental health issues, the central and local governments were to accept

responsibility to finance care and treatment. Efforts to develop community-based mental health programs have also been mentioned as a responsibility of the central and local governments. The Health Act outlines the obligation of the government to provide information and education about mental health to prevent the abuse of rights of a person deemed to have a mental health disorder.

In practice, two departments in Indonesia manage mental health services: the Department of Health and the Department of Social Service (AAMH Asia Australia Mental Health, 2013). Although the Ministry of Health, both at the central and regional levels of government, conducts the management of mental health care the Department of Health also has responsibility for other health problems. Unfortunately, the treatment of mental health problems is not a priority for the Indonesian government. One of the reasons for this is that Indonesia is following the targets of the World Health Organization which has launched its Eight Millennium Development Goals to be accomplished by 2015, in which there is no specific coverage of mental health problems (WHO, 2013b). Likewise, the Department of Social Services' scope of management is related mainly to the welfare of the community and does not extend to caring for individuals living with mental health issues (Ministry of Social Affairs of the Republic Indonesia, 2013).

Outline of the thesis

This thesis is presented in six chapters. Chapter one provides the background to the study, explains the research aim and purpose, identifies a fit between the research aim and design, and introduces the context of the study. Chapters two and three contain manuscripts that have been published in peer-reviewed journals. An introduction to each of these publications is provided in the chapter and a conclusion establishes the link between the manuscript and the section that follows.

In chapter two the place of the literature in a grounded theory study is discussed. This is followed by an article published in the *Journal of Clinical Nursing* with the title: 'Discharge planning in mental health care: An integrative review of the literature'. This publication

identified the evidence base regarding discharge planning in the context of mental healthcare service in both hospitals and the community setting. More detail is provided about Indonesia's mental health services and mental health legislation in this chapter with a focus on lay people providing care and the burden of care.

The third chapter outlines the research methodology with particular reference to the history of symbolic interactionism and grounded theory. The researcher then discusses essential grounded theory methods in detail and explains how these methods have been applied in this study. Procedures to ensure the ethical conduct of the study are explained in detail. The sample is described, including the study recruitment process and the final data set. Chapter three concludes with the second publication included in this thesis titled 'Conducting a Grounded Theory Study in a Language Other Than English: Procedure for Ensuring the Integrity of Translation'. This manuscript describes the way the research team managed translation issues during concurrent data generation and analysis.

Chapter four presents the research findings, beginning with an illustration and description of the theoretical model constructed. A short glossary of terms used specifically in this theoretical model follows. The grounded theory is then reported using the three main categories namely 'decision-making', 'shifting responsibility' and 'accepting responsibility' before elucidating the relationships between each of these categories and their respective sub-categories. A detailed discussion of the findings in the context of the contemporary literature is provided in chapter five. Two extant theories, decision making and coping, are used to explain the motivations and role of health professionals and non-health professionals in connecting care for individuals living with a mental health issue. Continuing on from this discussion is a more fine-grained interpretation of the outcomes of unmatched decision-making between stakeholders, which can result in human rights violations, an increase in the burden of care, and adverse health outcomes for individuals living with a mental health issue in Indonesia. Chapter six concludes the thesis as the researcher reflects on the past three years and evaluates the grounded theory study in relation to process and product. To conclude, this chapter outlines the strengths and limitations of the study and makes recommendations for further research.

Chapter summary

This chapter provides the reader with the aim of the study and a discussion of the justification of and need for the study. It furnishes the context of the study by describing the setting and background of mental health service delivery in Indonesia. The following chapter contains more detailed background of this study related to Indonesia's mental health services, human rights and mental health legislation in Indonesia and explains more clearly the provision of mental health care by lay people and the burden of care that they experience.

CHAPTER TWO: BACKGROUND

Introduction

A polemic in grounded theory is the problematic issue of how and when students or researchers should use existing literature during a grounded theory study (Birks & Mills, 2011; Dunne, 2010). Controversy on this topic has become a source of confusion and anxiety, especially for students and novice researchers (McGhee, Marland & Atkinson, 2007). On one hand, Cutcliffe and McGhee assert that the contentious issue is when to search for literature and how extensive these searches should be (Cutcliffe, 2000; McGhee, Marland & Atkinson, 2007). In Glaser's (2008) opinion, however, the issue is more clear-cut; literature is considered to be data and needs to be treated as such. Corbin and Strauss (2008) refer to literature as 'technical literature'. Although the literature can be used as a theoretical framework in other forms of qualitative research, it is used differently in a grounded theory study (Birks & Mills, 2011). Published and unpublished material can be used as sources of data in grounded theory studies and these documents can be searched for during concurrent data collection and analysis (Birks & Mills, 2011).

Originally, Glaser and Strauss (1967) disagreed with the idea that it was essential to review literature at an early stage of a study because they believed this strategy did not fit well with effective grounded theory methods (Glaser & Strauss, 1967). A decade later, Strauss's opinion had changed significantly. Together with Juliet Corbin, Strauss suggested researchers should conduct an early review of relevant literature (Strauss & Corbin, 1990). They listed several reasons why they believed it was valuable to review literature at an early stage in grounded theory study: to stimulate theoretical sensitivity and prompt questions, to provide secondary data, to help in theoretical sampling, and to provide supplementary validity.

The difference of opinion between Strauss and Glaser led to a split between the two grounded theorists. Fundamentally, Glaser (1992) believes an early literature review will contaminate data collection, analysis and the developing theory by leading the researcher to establish a framework that will undermine the authenticity and quality of result. Grounded

theorists must 'learn not to know' and read articles unrelated to the area being studied (Glaser, 1992). He asserted that professional literature should not be examined before researchers collected data (Glaser, 1992). Glaser states that literature should be reviewed when the study is nearly at an end - when codes and categories have begun to emerge during data analysis – when it can be searched and woven into the grounded theory for constant comparison with the data (Glaser, 1998). Glaser's opinion was supported by Nathaniel (2006) and Holton (2007), who added that in grounded theory the researcher did not need a pre-conceived problem statement, protocol for interview or an extensive literature review to enter a research field.

Procter (1995) and McCallin (2003) agree that it was not universally-accepted that a literature review would contaminate the process of data collection. McCallin believed, however, that a 'researcher may be side-tracked by received knowledge and interpretation that support taken-for granted assumptions, which are not relevant in the new area of study' (McCallin, 2003, p. 63). Charmaz (2006) also believed that a researcher's own ideas will be articulated more easily if the researcher delays a literature review, thereby avoiding contamination of their work and ideas. Glaser states that early efforts to review the literature are wasteful and inefficient because grounded theory, by its nature, is unpredictable (Glaser, 1998). This opinion is supported by Dick (2007) and Locke (2001).

Other scholars, however, caution against shunning a literature review in the early stages of study. Stern (2007) claims that a literature review is not only important for academic honesty but also for the process of building a study. A literature review will help the researcher understand how the study might contribute to the current knowledge (Stern, 2007). Also, the idea to delay reviewing the literature is not practical for many researchers (Dunne, 2010). For example, many Doctor of Philosophy (PhD) students need to produce a detailed literature review for ethical approval before they can proceed with data collection (Dunne, 2010; Urquhart, 2013). This issue becomes more important in this present era of evidence-based health care (Cutcliffe, 2005; McCallin, 2003). This issue of evidence-based practise is acknowledged by Glaser (1998), McGhee, Marland & Atkinson. (2007) and Nathaniel (2006), but these scholars still maintain a view that an early literature review is unnecessary. It will be

impossible to identify the substantive area of enquiry without prior knowledge of the field (Dunne, 2010). Glaser's idea that a researcher should read unrelated topics is also contradicted by Dunne (2010) as an inefficient use of time and energy. In addition, the idea that researchers should conduct a study without any prior knowledge is unrealistic (Cutcliffe, 2000) because an awareness of the extent of existing knowledge is important (May, 1994).

There are several benefits of reviewing the literature early in a grounded theory study. A literature review will orient the researcher to the phenomenon that needs to be studied (Urquhart, 2007, 2013) and helps the researcher to understand the current knowledge (Creswell, 1998; Denzin, 2002; Hutchinson, 1993; McMennamin, 2006) which, in turn, helps to find gaps in this knowledge (Hutchinson, 1993). Understanding the existing knowledge base and identifying gaps will help the researcher to justify the study (Antley, 1986) and ensure that no study has been conducted on the topic (Chiovitti & Piran, 2003). The researcher can also outline accurately the research phenomena (Backman & Kyngäs, 1999) and contextualise the study (McCann & Clark, 2003a) after reviewing the relevant literature. Having a knowledge of existing literature will help a researcher choose a specific approach (Coyne & Cowley, 2006; McGhee, Marland & Atkinson, 2007) and avoid conceptual and methodological pitfalls (McGhee, Marland & Atkinson, 2007). In addition, conducting a literature review will help the researcher to develop 'sensitising concepts' (Coffey & Atkinson, 1996; McCann & Clark, 2003a) and gain theoretical sensitivity (McCann & Clark, 2003b; McGhee, Marland & Atkinson, 2007; Strauss & Corbin, 1998). Theoretical sensitivity is defined as 'the ability to recognize and extract from the data elements that have relevance for the emerging theory' (Birks & Mills, 2011, p. 176).

An early review of the literature can give the researcher an awareness of unhelpful preconceptions they might hold (Maijala, Paavilainen, & Astedt-Kurki, 2003) and clarify thinking about concepts and possible theory development (Henwood & Pidgeon, 2006). The preceding benefits of an early literature review also place the researcher in a strong position in which their knowledge makes them less vulnerable to criticism (Coffey & Atkinson, 1996).

In this study, an early review of literature was conducted into discharge planning in mental health care as this related to the original substantive area of enquiry. This integrative review of the literature was published in the *Journal of Clinical Nursing* on the 12th July, 2013, and has been cited since that time. The first part of this chapter includes the published version of this integrated review, followed by literature on Indonesia's mental health services, human rights and mental health legislation in Indonesia, lay people providing care, the burden of care and a chapter summary.

Manuscript: Discharge planning in mental health care: an integrative review of the literature

Declaration of Authorship

Chapter Number	Publication	Nature and extent of the intellectual input of each author including the candidate	Signature
2	Nurjannah, I., Mills, J., Usher, K., & Park, T. (2013). Discharge planning in mental health care: an integrative review of the literature. <i>Journal of Clinical Nursing</i> .	Study design, data collection, data analysis, preparation	Nurjannah, Intansari
		Study design, data collection, data analysis, preparation	Mills, Jane
		Study design, preparation	Usher, Kim
		Preparation	Park, Tanya

Indonesia's mental health services

Providing appropriate and effective services to individuals living with a mental health issue can be challenging (Buckley, Miller, Lehrer, & Castle, 2009). Service providers need to consider available workforce, infrastructure, medical technologies and devices as well as access to essential medicines (WHO, 2013c). In Indonesia, the government does not consider mental health to be a priority leading to scarce resources being allocated to this type of care (Maramis, Tuan & Minas, 2011; Setiawan & Viora, 2006). Furthermore the mental health programme in Indonesia lacks designated key performance indicators (Setiawan & Viora, 2006), which has an impact on the level of service provision. The way the Ministry of Health manages health problems very much depends on the policies set by the government of Indonesia of the day and the budget allocated by the government. The mental health budget of the Ministry of Health is always below 1% of the total health budget and, generally, it is not targeted well towards effective programs (Irmansyah, 2009). According to WHO (2011) this is typical of lower-middle income countries where, on average, only 1.9% of the health budget is allocated to mental health care. In high income countries such as the United Kingdom and Australia approximately 5.1% of the health budget is spent on mental health care. Other problems identified in the delivery of mental health services in Southeast Asia (incorporating Indonesia) include the following: workforce shortages, lack of mental health advocacy, poor protection of the rights of individuals living with a mental health issue, and minimal effort to promote rehabilitation services. Treatment services are also considered to be inaccessible, unaffordable and of poor quality (Maramis, Tuan & Minas, 2011).

Indonesia is categorized as a country where nationals earn incomes in the lower middle range. While the most recent WHO (2013c) report concerning international health statistics calculates the number of psychiatrists for most countries, it does not document the equivalent measure of mental health/psychiatric nurses. Interestingly the number of psychiatrists in each low to lower income country is similar (<0.05 per 10.000 population), but the number of nurses and midwives and the number of available psychiatric beds varies widely (see Table 2.1.).

Table 2.1

Selected Examples of Mental Health Services as Categorised by WHO (2013c)

Country	Number of psychiatrists (2005-2012)	Number of nursing and midwifery personnel (2005-2012)	Number of psychiatric beds (2005-2010)
Per 10.000 population			
Low income			
Afghanistan	<0.05	Unavailable	0.1
Nepal	<0.05	Unavailable	0.2
Uganda	<0.05	13.1	0.3
Zimbabwe	<0.05	12.5	1.0
Lower middle income			
India	<0.05	10.0	0.2
Indonesia	<0.05	13.8	Unavailable
Fiji	<0.05	22.4	1.6
Papua New Guinea	<0.05	4.6	0.2
Upper middle income			
Argentina	Unavailable	Unavailable	2.8
Malaysia	0.1	32.8	1.8
Thailand	<0.05	Unavailable	1.3
South Africa	<0.05	Unavailable	2.2
High income			
Australia	2.0	79.7	3.9
Japan	1.0	41.4	27.8
United Kingdom	1.5	94.7	5.0
United States	0.8	98.2	3.4

Trained mental health specialists, psycho-social workers and non-specialist health workers who are able and available to work are essential to the effective provision of mental

health services (WHO, 2013c). The WHO (2011) states that four out of five people with serious mental health problems live in low and middle income countries, including Indonesia, and these people do not receive appropriate health care services.

More evidence is required to identify how the Indonesian mental health system operates at a grassroots level if services are to be improved. Researchers must investigate and identify the impact current models of service provision have on client outcomes. To date there have been very few research reports about the mental health system in Indonesia. Recent publications have focused on the need to protect the human rights of individuals living with a mental health issue (Irmansyah, Prasetyo & Minas., 2009; Minas, 2009; Minas & Diatri, 2008; Puteh, Marthoenis & Minas, 2011).

Psychiatric facilities

Hospitals

Psychiatric facilities in Indonesia include psychiatric hospitals and general hospitals with a psychiatric ward, both public and private. The Ministry of Health's 2013 data reveals there are eight provinces from a total of 34 Indonesian provinces (Kementrian Sekretariat Negara Republik Indonesia, 2010) that do not have a psychiatric care facility. Among these provinces, five provinces do not have a professional mental health worker or psychiatrist. Most of these five provinces are new and have been established because of expansion in the past 10 years (Harnowo, 2013). Other psychiatric facilities which provide outpatient services include primary health care centres (PHCC) and public or private shelters.

Custodial treatment for individuals living with a mental health issue still constitutes the main task of mental health service delivery in psychiatric hospitals. The quality and quantity of services offered in psychiatric hospitals is insufficient. In addition to poor quality medication, the types of services which are recommended by the WHO are not available. Medication is only available to treat 61.7% of those diagnosed with psychosis and 27% of those patients with mental distress (Idaiani, 2013). Electroconvulsive therapy is administered frequently without anaesthetic which is considered to be inhumane (Irmansyah, 2009). Other examples of poor

quality treatment include isolating individuals living with a mental health issue. Traditional methods of restraint like tying the person to the bed are also practised. Low staff-patient ratios mean that many patients are locked in their room before 5pm, ignoring the rights of patients to enjoy a normal life. The unavailability of outreach service programs in the community results in many patients relapsing soon after discharge from the psychiatric hospital or general hospital (Irmansyah, 2009).

Psychiatric hospitals are the responsibility of the national and/or local provincial government. All psychiatric hospitals are similar in that they provide inpatient and outpatient services and additional service at different levels (class I, II, III and VIP). At VIP level, for example, care includes private room accommodation. The costs for each class are different (Bangsal dan kapasitas TT, 2013; Grhasia, 2013; Perawatan, 2013).

In psychiatric hospitals, four types of care are generally offered: individual care (including home visitation), family care, integration care and community care. Individual care can be inpatient or outpatient service. Family care incorporates the care and advice provided for the family of individuals living with mental health issues. This might take the form of health education. Integration care is a term used by hospitals and refers to a program in which hospital staff regularly visit a PHCC at a specific time to provide a service or treatment for individuals living with mental health issues (Grhasia, 2013). Community care is referred to as a program in which hospital staff members provide health education, either via radio or television.

Public shelters

Public shelters are institutions operated by the Social Service Department of the Indonesian Government. There are limited numbers of public shelters in Indonesia. The Social Service Department is concerned with social issues in Indonesia (Ministry of Social Affairs of the Republic Indonesia, 2013), however it does not actively provide care for individuals living with mental illness. Staff members in this Department act as a 'bridge' for individuals to access proper treatment by facilitating financial assistance. A letter from the Social Service Department will ensure people to get financial assistance for health care service.

Public shelter staff are usually health professionals (nurses) and social workers. Public shelters provide services for two groups. Firstly, they support healthy people who are poor and homeless. This group of people are provided with education and the chance to learn skills to help them become more self-reliant. Secondly, they support individuals living with a mental health issue who are already in the recovery phase and have been granted approval by their psychiatrist to stay in a public shelter (Panti Sosial Bina Karya, n.d; Suksmalana & Pramitasari, 2012). The number of individuals living with a mental health issue who can be accepted in a facility is usually very small.

Admission of a mentally-ill person to a public shelter is usually triggered by one of two actions. A psychiatrist involved in the process of assessing the homeless might make a recommendation or a 'wanderer' might be identified during a Social Service Department sweeping-up program. The 'sweeping-up' program involves actively looking for individuals living with mental health issues who are unwell. The program also involves identifying people in need of help, such as those who are wandering, or begging on the street as well as underprivileged children and prostitutes (Das, 2011). There is evidence that homeless 'wanderers' suddenly appear in one city; Social Service Department members of staff have suggested the reason for this sudden influx of people might be that there are low levels of resources in other provinces (Siagian, 2013).

Social Service Department staff work with staff in hospitals, as well as the community leader, family members and PHCC staff after an individual has been returned to their community. Although public shelters have provided many people with new skills, there are still concerns about whether these skills can be applied usefully to real life situations. Often, there are very few jobs available for people leaving shelters, a common issue amongst people living in Indonesia, regardless of whether they have suffered a mental disorder or not. Unlike private shelters, which provide a long-term service for individuals living with a mental health issue, public shelters are a short-term rehabilitation service in which there is an expectation that individuals will be discharged as soon as possible to allow other clients the opportunity to partake in the program (Panti Sosial Bina Karya, n.d).

Private shelters

Private shelters also provide care for individuals living with a mental health issue. These shelters are privately owned and operated and, if the shelter is formally registered with the Social Service Department, will be supported by the Indonesian government (Hidup di Panti Penampungan Penderita Gangguan Jiwa, 2010). Government support of private shelters consists mainly of a budget that can cover only meals. Other costs are usually paid by the family. Staff in private shelters are usually health professionals who provide care based on their available resources (Purnamasari, 2013).

A private shelter is generally a last resort for families when they can no longer cope and do not want to provide care anymore. Private shelters are often utilised by a family to relocate someone deemed to be an outcast and, usually, this person lives in the shelter for the rest of his or her life (Rasuni, 2012). Also, the Social Services Department might take to a private shelter homeless individuals living with mental health issues whose family cannot be found (Rasuni, 2012). The care provided in the private shelter does not have a clear pattern. There is no rehabilitation program in private shelters since resources are limited (Purnamasari, 2013). The quality of care and support offered in private shelters differs from one place to the next.

Primary Health Care Centres (PHCC)

PHCCs are the lowest health care facility unit that provides services to the community (Ministry of Health Republic of Indonesia, 2011b, 2011c) through the Primary Health Care Program (PHCP). PHCP was first introduced in the 1970s by the WHO (Ministry of Health Republic of Indonesia, 2011a). Implementation of the PHCP in Indonesia included the development of Primary Health Care Centres (PHCC). The coverage of a PHCC depends on the population density and is sometimes supported by a mobile unit in which staff go by car from village to village to provide services (Ministry of Health Republic of Indonesia, 2011c). These services might include mental health promotion, prevention, cure/treatment and rehabilitation, but this area of health care is not considered to be a priority (Ministry of Health Republic of Indonesia, 2011c). The director of a PHCC is a general physician. Some PHCCs provide

inpatient care while others only provide outpatient services. The PHCC is the frontline service-provider to the community and if there is a specialised case like acute psychosis the patient will be referred to a psychiatric hospital (Ministry of Health Regulation 2012).

Staff members in PHCCs recruit health volunteers, called cadres in Indonesia. Cadres are lay persons in the community who are trained by a health professional to provide care (like child health checks) (Ma'ruf, 2007). There are many types of cadres: trained, for example in maternal and child health, elderly care (Info puskesmas, 2011) and mental health (Ministry of Health Republic of Indonesia, 2012). Specially-trained cadres are responsible for undertaking screening for mental health problems. Mental health cadres, however, are not always available in the PHCCs (Ministry of Health Republic of Indonesia, 2012) due to limited training opportunities.

Indonesia's health care financial system

Health care costs in Indonesia are paid by either individual patients (private) or health insurance companies. Health insurance was established in 1942 (Patriajati, 2013) in Indonesia but included only cover for accident, illness and/or disease caused by work activities (Patriajati, 2013). Over time, health insurance has expanded to incorporate other kinds of cover but most of the system has failed and is bankrupt (Patriajati, 2013).

The Indonesian Government has introduced a number of initiatives, policies and acts of parliament in recent years to improve the access of all citizens - rich or poor - to healthcare. The following table summarizes some of the key policies, actions and statutes that dealt with health insurance for Indonesian people.

Table 2.2

Indonesian Government's Efforts to Develop Health Insurance

Year	Issue	Comments
1942	First health insurance was established	
1942-2003	Health insurance developed to incorporate other kinds of cover	
2004	National Social Security System signed by President Megawati Soekarno Putri (Act No. 40)	Regulates the social security program including health, retirement, accident, pension, and life insurance. Social security program for health is called National Health Insurance. It contains no operational applications so there is no clear implementation for this plan.
2009	Health Act (No. 36) signed by President Susilo Bambang Yudhoyono	The government is in charge of health insurance for the community through the National Health Insurance system. However, there is no detailed explanation about how the process will be implemented.
2011	Act No. 24 – Social Security Administrative Body established	This is a legal entity established to administer the National Social Security System – signed by the president in 2004.
2012	Presidential Regulation No. 101	Regarding the recipient health insurance assistance was issued.
2013	Presidential Regulation No. 12	Explained the implementation of Presidential Regulation No. 101 (2012) in more detail, covering those phases applying to this obligatory health insurance through National Health Insurance system for all Indonesian.

The Social Security Administrative Body was established in 2011 and this obligatory National Health Insurance for all the Indonesian was to be rolled out in two phases. The first phase was started on January 1, 2014, and covers the poor, members of the Army, civil servants in the Ministry of Defence and all of their families, member of the Indonesian National Police, civil servants in the Office of Indonesian National Police, members of Indonesian Health

Insurance Company program and all of their families, and member of Labor Social Security Company program and all of their families. The second phase will cover all of the people that have not been enlisted as a member of the National Health Insurance and will occur on January 1, 2019 at the latest (Presidential Regulation No. 12 (2013)).

The National Health Insurance system to cover all Indonesians will not be established until 2019 but the Government of Indonesia started to help the poor with health care cost in 2005. The Ministry of Health expanded the policy of health care insurance program for the poor, which was called Social Security for Community, in 2005. The implementation of the Social Security for Community program has been controlled by the Ministry of Health from 2005 to 2013 (Regulasi Jamkesmas, 2013).

The Social Security for Community program has not been successful in providing health care access to all of Indonesia's poor. One example of this problem was reported through mass media (Kompas.com, on 24th October 2012). Trouble with the dissemination of funds and a failure to develop action plans to accompany the rhetoric has meant that some of the good intentions of the government have not translated to real change on the ground. Examples of this can be seen in media reports. One such report was the story of 10 month old baby, Jesica, who was brought to Soetomo Hospital with hydrocephalus but was rejected by staff there because she had no certificate that identified her as poor (Ainun, 2012). The program of Social Security for Community still does not cover everyone in Indonesia.

Health workers are also experiencing difficulties with the Social Security for Community program as demonstrated in a report by kompas.com in March 2009. The media reported that the Social Security for Community fund for the year 2009 had not been disbursed three months into the year. As a result, one of the provinces' clinics decided to skip payment to some of the clinic staff so they could continue to provide services for the poor. The honorarium for some workers like midwives was used to cover the needs of the community health centre until the Social Security for Community fund was disbursed (Jamkesmas Belum Turun, 2009). Similarly, a hospital in another province also chose to cover service costs instead of paying staff in a timely way (Patriajati, 2013). Some heads of the clinics have been reported as saying that

the Social Security for Community program was always late with the disbursement of funds (Jamkesmas Belum Turun, 2009). Accordingly, the PHCC has had to bear big financial burdens (Jamkesmas Belum Turun, 2009).

Currently, the National Health Insurance system is started to run, but as it is feared that this program will fail again as many hospitals might not want to sign contracts with the government to apply to the National Health Insurance system as the costs paid out to the clinics, hospitals and doctors are still below average costs (Sebelum ke RS peserata BPJS wajib dirujuk dokter, 2013). In this case, health care costs have to be paid by the individual patient.

Human rights and mental health legislation in Indonesia

Human rights are fundamental to all human beings and are explained as such: ‘the right to life, liberty and security of person; the right to an adequate standard of living; the right to seek and to enjoy in other countries asylum from persecution; the right to own property; the right to freedom of opinion and expression; the right to education, freedom of thought, conscience and religion; and the right to freedom from torture and degrading treatment’ (United Nations, 2012). Most countries protect human rights through their legal systems but violations still occur. The risk of human rights violations increases when people are vulnerable because of a medical condition like a mental disorder (Walsh et al., 2003). Research studies have found certain individuals with a mental illness are particularly vulnerable to human rights violations, including people who demonstrate severe clinical symptoms (Brekke, Prindle, Bae, & Long, 2001), those who abuse substances, people living a transient life, and mentally-ill individuals with a secondary diagnosis of personality disorder (Brekke et al., 2001; Hiday et al, 1999) . For these individuals, a mental disorder and the social context of their lives puts them at high risk (Hiday, Swanson, Swartz, Borum, & Wagner, 2001). Stigma and misconceptions associated with mental disorders can also be the cause of many human rights violations. Stigma affects a person’s ability to obtain appropriate care, integrate into the wider society and recover from illness (WHO, 2006). Documented cases of violations of the human rights of individuals living with a mental health issue in both the community and psychiatric institutions include the

following: being locked in confined spaces; shackling; being chained to trees (WHO, 2005); being provided with inadequate, unhygienic and inhuman living conditions (WHO, 2004, 2006); undertaking forced labour; experiencing neglect; being deprived of basic health care; experiencing torture and inhuman or degrading treatment such as sexual exploitation; and physical abuse (WHO, 2005).

In 1991, the UN adopted a resolution for the protection of human rights for people with a mental illness that included 25 principles which set out clear and appropriate boundaries for the treatment and protection of affected individuals (see Table 2.3.) (WHO, 1996a). The first principle of this resolution is that all people have the right to fundamental freedoms and basic human rights and states, 'All persons with a mental illness, or who are being treated as such persons, have the right to protection from economic, sexual and other forms of exploitation, physical or other abuse degrading treatment' (WHO, 1996a).

Table 2.3

Principles for the protection of persons with mental illness and the improvement of mental health care

Number	Principle
1	Fundamental freedom and basic rights
2	Protection of minors
3	Life in the community
4	Determination of mental illness
5	Medical examination
6	Confidentiality
7	Role of community and culture
8	Standards of care
9	Treatment
10	Medication
11	Consent to treatment
12	Notice of rights
13	Rights and conditions in mental health facilities
14	Resources for mental health facilities
15	Admission principles
16	Involuntary admission
17	Review body
18	Procedural safeguards
19	Access to information
20	Criminal offenders
21	Complaints
22	Monitoring and remedies
23	Implementation
24	Scope of principles relating to mental health facilities

Since the publication of this landmark resolution, a number of documents have been published about the protection of individuals living with a mental health issue (WHO, 1996a, 1996b, 1997, 2004) including guidance materials to inform and assist countries wishing to formulate mental health legislation (WHO, 2005, 2006). This abundance of policy does not stop human rights violations of individuals living with mental health issues, especially in developing countries. Importantly, while 92% of people in high-income countries are covered by mental health legislation only 36% people in low income countries (WHO, 2013a) enjoy this protection, which compounds the risk of violence against them.

In Indonesia, where this study was conducted, the local media have reported many cases of shackling, a human rights violation that incorporates physical restraint. Putra (2008) in *The Daily News* reported that a man, aged 40 years, was shackled to a big tree behind his house for 16 years before he was brought to hospital. He was protected from the rain and sun by one plastic cover sheet. He ate, defecated and urinated in the same spot. His family had shackled him because they were afraid of him; he tried to strangle and kill his sister many years earlier. In another case a seven-year-old boy was chained for four years before being brought to a psychiatric hospital (Achmada, 2008). Lis, a 29-year-old female, was shackled by her father after she was diagnosed with a mental disorder at 18 years of age. In that time Lis delivered four babies. It was not known who fathered her children (INK, 2009).

A common theme in all of these reported cases was poverty and a resultant lack of access to health care services. While Indonesia's Ministry of Health recognises the relationship between mental disorders, physical problems and poverty (Ministry of Health Republic of Indonesia, 2011d), as discussed in chapter one, there are few mental health services for the poor. Affected individuals who live in poverty are often treated by traditional methods such as shackling, which is considered by Indonesia's government to be 'irresponsible' (Ministry of Health Republic of Indonesia, 2011d). While acknowledging that shackling violates human rights, the government is finding it difficult to eradicate the practice. Efforts are being made,

however, to increase departmental collaboration in a coordinated program to stop shackling (Ministry of Health Republic of Indonesia, 2010a).

In 2010, the Indonesian government provided an online response to national and international news publications reporting human rights violations of individuals living with mental health issues (Ministry of Health Republic of Indonesia, 2010c). This response outlined a Ministry of Home Affairs' directive from 1977 (PEM 26/6/15) which instructed each province's governor to ensure that communities do not shackle individuals living with a mental health issue. Furthermore the directive supported promoting community awareness of the role of psychiatric hospital staff and their ability to look after affected individuals. Instructions for the heads of each sub-district and village to properly manage this issue were also described in this response (Ministry of Health Republic of Indonesia, 2010c).

In relation to health care funding, Indonesia's Ministry of Health devolves responsibility for the distribution of funding for mental health care facilities and services to the National Health Department and health departments located in the provinces. Both these arms of government are tasked with finding and releasing individuals living with a mental health issue who have been shackled and with providing community education aimed at eradicating this practice (Ministry of Health Republic of Indonesia, 2010c). Overall there is a strong government expectation that shackling will be avoided and that community members will recognise mental disorders and help the individuals get treatment if required (Ministry of Health Republic of Indonesia, 2010c). Primary Health Care Centres (PHCCs) are the frontline service providers charged with promoting grassroots action at a village level.

In Indonesia, community advocacy for people living with a mental health issue is mainly enacted through a non-government organization (NGO) known as the Mental Health Union. Members of the Mental Health Union include individuals living with a mental health issue, families, health professionals and other interested parties (Ministry of Health Republic of Indonesia, 2010b). The current leader of the Mental Health Union, Yeni Rosa Damayanti, supports the Indonesian Ministry of Health's strategy to eradicate shackling and hopes that

broadcasting this strategy will also help to eliminate the stigma of having a mental disorder (Ministry of Health Republic of Indonesia, 2010b).

In theory, therefore, families and PHCCs are the frontline of a battle to treat individuals living with mental health issues in Indonesia. Anecdotally, however, it is reported that less than 1% of the total cases treated in PHCCs are mental disorders (Gale, 2012). It is argued that failure to treat can be attributed to insufficient screening for and diagnosis of mental disorders because PHCC clinicians are not skilled in these tasks (Irmansyah, Prasetyo & Minas 2009). Other possible reasons for the failure to treat are difficulty in accessing PHCC services in remote areas and families not being able to afford the cost of this service. The Indonesian government is addressing this problem by providing funds to PHCCs so that individuals who have been shackled in the past can access services in their own communities. This funding can be used for direct service provision, the payment of cadres' training and the up-skilling of PHCC clinicians (Ministry of Health Republic of Indonesia, 2010d). While financial support is now available and services are beginning to be delivered more widely, no effort has been made to evaluate the effectiveness of these new initiatives or to test whether this support to PHCCs is sufficient to operate mental health programs that provide increased access to services.

In Indonesia, psychiatric hospitals provide custodial treatment for individuals living with a mental health issue. Involuntary admission for custodial treatment is commonly instigated if a member of society feels uncomfortable about another person's behaviour (Irmansyah, Prasetyo & Minas, 2009). There is no legal basis for the involuntary admission to tertiary services of people living with a mental health issue because, unlike many other countries, there is no mental health law or statute in Indonesia. The Ministry of Social Service and the Ministry of Health are jointly responsible for providing care for individuals living with a mental health issue (AAMH Asia Australia Mental Health, 2013). Not all cases in which someone experiences a severe deterioration in their mental health status are reported. This lack of reporting means that authorities are unable to intervene and provide treatment. Consequently many affected individuals wander the streets, sometimes naked, because their family is unable, or does not want to provide care.

No consistent and clearly-articulated procedure or guideline exists in Indonesia for involuntary admission to a psychiatric hospital of individuals living with mental health issues because the legislation in place has not been fully implemented. Family members and carers do not know what to do if the health status of a person with mental illness deteriorates to the point where the person can no longer be cared for safely at home, or if the person is at risk of harming themselves or others. Legislative guidance would ensure each stakeholder made an appropriate decision regarding involuntary admission (Priebe et al., 2011) thereby avoiding harmful situations such as those described in this study.

Lay people providing care

Individuals living with a mental health issue need support, not only from health professionals, but also from non-health professionals especially family and community members. The attitude of the Indonesian community and family members towards individuals living with a mental health issue has been documented in three studies (Broch, 2001; Kline, 1963; Kurihara et al., 2006). Kline (1963) explored the attitude of Indonesians toward individuals living with a mental health issue in the early 1960s. Kline's survey respondents held a variety of attitudes regarding individuals living with a mental health issue and results varied greatly from one province to the next. In some locations, community members were open-minded and displayed little fear towards individuals with a mental health issue. In other places there was a certain amount of shame regarding mental health issues. Interestingly, during this period of time, a greater stigma was attached to individuals with leprosy and tuberculosis than to individuals with a mental health issue (Kline, 1963).

Since Kline's study, only two research reports have been published about public opinion or attitudes toward individuals living with mental health issues in Indonesia. One is a descriptive, person-centred ethnographic account of how people living in a remote, small Indonesian island responded to people living with a mental health issue (Broch, 2001). This study found most villagers thought that such individuals were potentially dangerous (Broch, 2001). Another publication by Kurihara et al. (2006) reported families' beliefs regarding the

cause of mental illness. The most commonly held belief was that mental illness was caused by the supernatural. This belief prevented families from seeking medical treatment for individuals living with a mental health issue (Kurihara et al., 2006).

Non-health professionals play an important role in the recovery of individuals with mental health issues. As recovery occurs (in either a hospital or the community setting), the individual may move between settings, making the issue of connecting care even more important to ensure continuity of care. Research is needed to understand how non-health professionals in Indonesia participate in a collaborative model of care for individuals living with a mental health issue.

The burden of care

The burden of care generated by individuals living with a mental health issue is a global problem in both developed and developing countries regardless of society, culture and beliefs (Wai-Chi, 2011). Caring for individuals living with a mental health issue can require much effort and energy (Wai-Chi, 2011). Although studies have found that care giving can be a positive experience (Chen & Greenberg, 2004; Rhoades & McFarland, 1999), many caregivers view their job as a burden (Ferriter & Huband, 2003). The burden of care comprises two dimensions: objective and subjective burden (Awad & Voruganti, 2008; Hoenig & Hamilton, 1966; Maurin & Boyd, 1990). Objective burden includes four areas: financial problems, limitations of personal activity, household disruption and social interactions. Subjective burden refers to feelings, attitudes and emotions related to care-giving in the six domains of shame, stigma, guilt, resentment, grief and worry (Suro & Weisman de Mamani, 2012). Suro and Weisman de Mamani (2012) found that subjective burden influenced the level of objective burden experienced by caregiver and, in turn, the caregivers' own mental health. The literature supports the contention that family caregivers' burden is a multidimensional phenomenon involving their mental health, level of physical fitness, social life, financial status and family function (Wai-Chi, 2011). Finally, the perception of their own burden influences the coping strategies used by caregivers (Tan et al., 2012).

The provision of support to family caregivers can be justified on both social and financial grounds as their care efforts reduce demands on institutional services and relieve funding pressures, thereby contributing to better economic outcomes (Exel, Graaf, & Brouwer, 2007; Lefley, 1997). Family caregivers develop expertise in the provision of mental health care (Buila & Swanke, 2010) which results in them being considered as both legitimate stakeholders and key providers of care (Ridley, Hunter, & Rosengard, 2010). The inclusion of service users in the decision-making and provision of professional mental health care is considered to be an indicator of 'best practice' (Hickey & Kipping, 1998) and is an essential part of modern mental health service delivery (Herrman, Trauer, & Warnock, 2002).

In Indonesia, the family is the fundamental unit of social organisation (Hugo, 2002) and according to Maramis (2006), the family is an important part of the mental health care system. Community mental health nurses work with families and doctors in PHCCs. This interaction between families and service-providers is illustrated in a study that found that individuals living with schizophrenia in Indonesia usually lived with large numbers of relatives who were involved in their care (Kurihara et al, 2006).

Chapter summary

Chapter two describes the position of key grounded theorists on the use of literature in grounded theory study and justifies the reasons for reviewing the literature before data collection and analysis commenced. The chapter also discussed the Indonesian context of study, particularly in relation to human rights and mental health legislation, lay people providing care, and this groups' burden of care. A published journal article reporting discharge planning in the context of Indonesia's mental health services was included. Chapter three will explain the methodology used in this study, which was grounded theory underpinned by symbolic interactionism. The sample and data set will be described before reporting the application of grounded theory methods in this study. Ethical issues associated with the study are discussed and processes for obtaining the required ethics clearance described. The second publication included in the thesis titled 'Conducting a Grounded Theory Study in Language Other Than

English: Procedure for Ensuring the Integrity of Translation' and published in *Sage Open Access* concludes chapter three.

CHAPTER THREE: METHODOLOGY AND METHODS

This chapter will explain the methodological frame of symbolic interactionism that underpinned the grounded theory design and introduce the position of the researcher. The grounded theory methods employed in the study will be explained in detail, and will include the process of acquiring approval to conduct the study from the relevant ethics committee.

Position of the researcher

In her recent book, Urquhart (2013) emphasised that a researcher's philosophical position needed to be in line with the chosen research design. The researcher's beliefs about the nature of reality will guide their epistemological and methodological choices and ensure a robust research design (Mills, Bonner, & Francis, 2008). Schwandt (2007) defines ontology as being "concerned with understanding the kinds of things that constitute the world" (p. 190), or "the study of being" (Crotty, 1998, p. 10). While Denzin and Lincoln (2005) state that ontology "raises basic questions about the nature of reality and the nature of the human being in the world" (p. 138). For qualitative researchers ontology is characterised by the concept of multiple realities in which each person has their own reality that can be reported (Creswell, 2013).

There are two main ontological positions reported in relation to grounded theory methodology, critical realism and relativism (Annells, 1996). In a recent journal article on grounded theory, Levers (2013) agrees with this position, arguing that there are two perspectives a grounded theorist might take regarding reality, firstly that there is a single reality that will emerge from the data, or that there are multiple realities which can be investigated. A researcher must position themselves in relation to one of these two perspectives (Levers, 2013) in the application of grounded theory methods.

In this grounded theory study, the primary researcher considered 'truth' to be a relative stance. The concept of truth is influenced by a person's understanding as informed by their experience, culture, interaction and context. This position is congruent with the statement that

micro, meso and macro social factors influence an individual's reality and that reality is interpreted and cannot actually be 'known' (Strauss & Corbin, 1990).

In the early stages of this study, the researcher was challenged by her advisors to consider her thoughts and beliefs about the nature of truth, ontology and epistemology. Epistemology is defined as "the study of the nature of knowledge" (Schwandt, 2007, p. 87). In a memo written at this time (8/2/2011) the researcher defined herself as part of the world that either voluntarily or involuntarily interacts with and influences others as they influence her. It is this interaction between individuals that will shape thinking, create knowledge and lead to action. In the case of this study it is the interaction between researcher and participant that helped generate a new theory and develop new knowledge about the substantive area of enquiry.

History of symbolic interactionism

Symbolic interactionism was a distinct theoretical perspective created in the early 20th century for the systematic analysis of human social behaviour (Benzies & Allen, 2001); its development was based on the ideas of George Herbert Mead. Mead developed his school of philosophical thought during the 1920s and 1930s when the behaviourist school of psychology led the social sciences (De Laine, 1997). Unfortunately, Mead published little about his ideas despite teaching the basis of symbolic interactionism for approximately four decades. His theory and teaching was influenced by the work of William James, John Dewey and Charles H. Cooley, and W.I Thomas (Fine, 1993). After Mead's death in 1931, one of his students, Herbert Blumer, synthesised and published Mead's work as a theoretical system (Benzies & Allen, 2001). It was Blumer who gave the system a label, 'symbolic interactionism' (Horn, 1998).

Different interpretations of George Herbert Mead's work are acknowledged among scholars but Herbert Blumer's interpretation of Mead's thought is considered to be the main source on symbolic interactionism (Fine, 1993) and is used as a reference on the topic through to the present. Blumer (1969) recognises Mead's role in laying the foundation for symbolic interactionism in his seminal text *Symbolic Interactionism*. Blumer also identified the role of

other scholars in the development of the intellectual underpinnings of symbolic interactionism, including Robert E. Park, William James, Florian Znaniecki, James Mark Baldwin, Robert Redfield and Louis Wirth. Blumer (1969, p. 1) coined the term 'symbolic interactionism' to identify a distinctive method of studying human group life and human conduct. Charon (2001) further refined and developed these ideas, emphasising that symbolic interactionism was a perspective that could depict the essence of human beings more accurately than other methodological perspectives.

Blumer (1969) described three premises of symbolic interactionism related to the process of how human beings act. The first premise is that people use the meaning a thing has as a basis for action. 'Things' are constructed of anything that humans notice in their world. It is important to state that, in symbolic interactionism, there is no fixed meaning of specific things, as their meaning may be sustained, affirmed or transformed depending on interpretation, and that a change of meaning can influence the way people act (Blumer, 1969).

The second premise is that individuals create meaning by interacting with other people. In short, the meaning of an object is a social product. The way in which people behave towards one another (with regard to their interpretation of meaning) can influence people to create a shared meaning of things. The use of symbols mediates human interaction. Symbols will be interpreted or ascertained to produce meaning of one another's action (Blumer, 1969). Charon (2007) defines symbols as 'social objects'. Charon describes these symbols/social objects as meaningful when they are intentionally used for representation and communication. People act on the basis of symbols which they evaluate against a given situation before action is decided (Blumer, 1969). The process of action therefore involves the construction of meaning of a social object.

The third premise of symbolic interactionism is that people use an interpretative process to apply or modify meanings of things as an instrument to inform their actions (Blumer, 1969). The meaning itself is drawn from social interaction. In this interpretative process a human being communicates with himself by identifying, both subconsciously and consciously, things that

have meaning for him. After that 'the meaning' will be used or modified depending on the situation he confronts. Meaning is then used to guide or inform an action (Blumer, 1969).

Blumer (1969) proposes that symbolic interactionism is grounded in six basic ideas which he calls 'root images'. Root images include the following: "the nature of human society or human group life, social interaction, objects, the human being as an actor, human action, and the interconnection of the lines of action" (Blumer, 1969, p. 6). These root images provide an analytical framework that is used to explain human society and human action in the theory of symbolic interactionism.

In addition to root images, Blumer (1969, p. 62) interpreted five important elements of Mead's thought – 'the self, the act, social interaction, object and joint action' - and considered the sociological implications of Mead's thought. Blumer (1969) considered that by having 'self', people can interact with themselves using a reflexive process to structure and guide their action. Social interactions, according to Blumer (1969), assist individuals to construct their behaviour because individuals are continuously interpreting the way other people act and, as a consequence, adjust their own behaviours accordingly. In Blumer's thesis, objects are invested with meaning gained from social interaction. Blumer (1969) defined joint action as combined configurations of action that emerge as a result of activity that corresponds to the lines of behaviour.

The philosophical development of symbolic interactionism

Before Herbert Blumer conceived the label 'symbolic interactionism', the idea was a compilation of evolving methods. The development of embryonic symbolic interactionism early in the 20th century was influenced by the German social theory of Dilthey and Weber and the American pragmatism of theorists such as Mead, James and Dewey (Horn, 1998). Charon (2007) provides a helpful summary of the evolution of symbolic interactionism, summarising three major influences on Mead's thought to aid understanding of the general position of a symbolic interactionist perspective. In particular, Charon identifies the influence of pragmatism, Darwinian theory and behaviourism in Mead's work. Mead is influenced by pragmatism as

evidenced by his statement that human beings are always interpreting or defining objects depending on the goals they have in relation to the situation in which they find themselves. The influence of Darwin's work on Mead is apparent in the way he sees humans as part of a changing universe in which human growth and development is a constant process. Mead added that human beings have developed unique abilities to influence their own evolution through the use of language. Humans, therefore, have become active contributors to their own development and the determination of their surroundings (Charon, 2007). The philosophy of behaviourism is traced through Mead's statement that the observation of human behaviour is a method by which we can come to understand human beings. In contrast to other behaviourist theorists, Mead argued that behaviour consists not only of actions that can be viewed, but also of actions that occur within the human being, including thinking. The ability to think provides humans with the competency to understand, to define, to interpret and to create meaning. Furthermore, Mead suggested that symbols, mind and self need to be taken into account to truly understand human behaviour (Charon, 2007).

The Blumerian period

The Blumerian period of symbolic interactionism is defined as coinciding with the publication of his seminal text in 1969. From 1969 until Blumer's death in 1986, symbolic interactionism was divided into two distinct branches called the Chicago and Iowa schools (Benzies & Allen, 2001; De Laine, 1997). The Chicago school was further divided into two different groups: one that aligned itself with the empirical interest of Everet Hughes and another that used Blumer's theoretical framework (Fine, 1993). At the University of Iowa, Manford Kuhn, influenced by logical positivism, guided a smaller group of interactionists. Kuhn emphasized developing an explanation of universal social behaviour that could be tested and predicted (Benzies & Allen, 2001), while the Chicago school, directed by Blumer, concentrated on the explanatory interpretive process in the formation of meaning (Benzies & Allen, 2001). The Iowa school played a less important role in symbolic interaction after Kuhn's death (Fine, 1993).

Post-Blumerian age

The period after Blumer's death in 1986 is dubbed the 'post-Blumerian age' of symbolic interactionism (Fine, 1993, p. 64). New evaluations of Blumer's work appeared in the post-Blumerian era, (Charon, 2001) resulting in interactionism that combined the 'Blumerian' method with other theoretical approaches. These new approaches include chaos theory and social ecology in which interactionists blended their approach with wider academic knowledge (Fine, 1993).

Charon (2007) developed Mead's and/or Blumer's tenets of symbolic interactionism into five core ideas of which four can be considered similar to Blumer's original framework (Blumer, 1969). These four core tenets are: the role of social interaction, the role of thinking, the role of definition and the role of the active human being (Charon, 2001). A new idea developed by Charon (2007) was the role of the 'present' in symbolic interactionism.

In the post-Blumerian age new leaders emerged: Norman Denzin, Alfred Lindesmith, Anselm Strauss, Sheldon Stryker, Gary Fine, David Maines, Tamotsu Shibutani, Howard Becker, John Lofland, Carl Couch, and Spencer Cahill (Charon, 2001). One of these scholars, Anselm Strauss, had undertaken a master's thesis under Blumer's guidance. Pragmatism and interactionism therefore shaped much of Strauss's thinking during his time as an undergraduate student at the University of Virginia and as a graduate student at the University of Chicago. Strauss was interested in how to hold onto a sense of balance in relation to misinterpretation and conceptualisation in complex social worlds. In his efforts to find answers to his questions, he re-reviewed the premise and problems of Mead and the Chicago School of interactionists. Eventually, grounded theory, developed by Strauss and Barney Glaser in 1967, provided the answer to his questions (Strauss, 1993) about data analysis using a symbolic interactionist lens.

Grounded theory

History of grounded theory

Grounded theory was devised by Barney Glaser and Anselm Strauss in 1967 during a time when social research publications concentrated mostly on theory verification rather than theory generation. This was also a period during which research in quantitative methods was considered to be superior to qualitative methods (Glaser & Strauss, 1967). Hypothetical deductive methods to test theory did not fit these two scholars' area of sociological interest. For both of them, behavioural patterns could not be measured statistically and they believed that intimate interaction was necessary (Strauss, 1987) to understand human behaviour (Stern & Porr, 2011). Strauss and Glaser came from different backgrounds. Strauss, as explained earlier, was influenced by Mead and Blumer (Strauss, 1993). Glaser undertook higher degree studies at Columbia University in New York where he concentrated on the importance of multivariate analysis under the supervision of Paul Lazarsfeld who had codified quantitative research (Charmaz, 2006). Each of these social scientists received very different training which influenced their perception of the development of grounded theory methodology in the years to come.

Glaser and Strauss's book, *The Discovery of Grounded Theory*, (1967) explains the way data can be used to generate theory through systematic methods of data collection and analysis. In grounded theory, comparative analysis is the major technique through which data are compared continuously with one another to construct theory from data acquired through a process of theoretical sampling (Glaser, 1978; Glaser & Strauss, 1967). As discussed in chapter one, the views of its authors, Glaser and Strauss, diverged 30 years after the publication of the original text. The evolution of different schools of thought concerning grounded theory methods started in 1990 with the publication of Strauss and Corbin's book, the '*Basics of qualitative research: grounded theory procedures and techniques*' (Strauss & Corbin, 1990). This text generated critique from Glaser (1992) in his publication called the *Basics of Grounded Theory Analysis*.

In this study, Strauss and Corbin's version of grounded theory will be used to construct a theory that explains the process of providing a collaborative model of care for individuals living with a mental health issue. Because this approach to grounded theory is underpinned by

symbolic interactionism it allowed the researcher to recognise the way social worlds influenced the perspective of participants and their construction of the self. Using evolved grounded theory also allowed the researcher to shape the analysis while cognisant of their identity and experience in the construction of theory.

Grounded theory methods

The previous section described the grounded theory methodology used in this study and explained how the perspective of symbolic interactionism framed the subsequent use of grounded theory methods. One set of grounded theory methods are used consistently in this research design but the treatment of each of these methods differed somewhat depending on the methodological perspective adopted. Birks and Mills (2011) list the following as essential grounded theory methods: initial coding and categorisation of data, concurrent data generation or collection and analysis, memo writing, theoretical sampling, constant comparative analysis using inductive and abductive logic, theoretical sensitivity, intermediate coding, selecting a core category, theoretical saturation, and theoretical integration.

Concurrent data generation and analysis

Sources of data in a grounded theory study can be very varied. Data can be either collected or generated. Data collection is “a process of gathering data in which the researcher has limited influence on the data source, as occurs when data is extracted from static materials such as documents and the literature” while data generation is “the process by which a researcher directly engages with a data source to produce materials for analysis, such as occurs during in-depth interviewing” (Birks & Mills, 2011, p. 174). In this study, data was generated with participants through interaction with the researcher during face to face semi-structured interviews. In this thesis, both data collection and generation will be referred to depending on reference to either the actual study (data generation) or the extant literature (data collection).

An important grounded theory method is concurrent data generation and analysis. The generation of theory results from the interplay between data collection and analysis, which occurs simultaneously (Cutcliffe, 2000). Concurrent data collection and analysis allows the

researcher to compare incidents, which leads them to review the interview questions for the next data collection phase (Idrees, Vasconcelos, & Cox, 2011). Ideally, each field trip should be followed by analysis using initial and intermediate coding before the researcher continues to generate more data. This process, however, is not always practical. In this study, concurrent data generation and analysis was facilitated by organising three field trips to Indonesia thus allowing time for data analysis to occur. During each field trip, preliminary analysis of data was undertaken by listening to recorded interviews and then writing memos. Initial and intermediate coding, however, was conducted after the completion of each field trip. This modification of concurrent data generation and analysis was due to the fact that field trips were conducted in Indonesia while the researcher was based mainly in Australia while conducting her PhD degree. Advanced coding only occurred once the categories were saturated after the third field trip. The process of coding will be described in more detail in the section detailing field trip one later in this chapter.

Theoretical sampling

Theoretical sampling is a method used to decide from which setting to choose the next group of participants (Glaser & Strauss, 1967) and serves as an integral part of the comparative method of data analysis (Corbin & Strauss, 2008; Glaser, 1978). Glaser and Strauss (1967, p. 45) defined theoretical sampling as "... the process of data collection for generating theory whereby the analyst jointly collects, codes, and analyses his data and decides what data to collect next and where to find them, in order to develop his theory as it emerges [sic]". Glaser (1978) further refined the concept of theoretical sampling to define it as a period in which categories, concepts and constructs established by the researcher/s are used to direct further data collection. Similarly, Corbin and Strauss (2008) stated that theoretical sampling was a method to collect data whereby researchers focused on exploring relevant incidents and events, not just a specific population. According to Morse (2010), theoretical sampling is used as a tool for theoretical exploration. Bryant (2009) contends theoretical sampling is employed to develop a researcher's initial analysis and, in the early stages of a study, functions to enhance the concepts

identified. Theoretical sampling therefore is a central tenet of grounded theory (Breckenridge & Jones, 2009; Urquhart, 2001) in contrast to other commonly-used types of sampling such as representational or initial sampling and random sampling (Bryant, 2009). Theoretical sampling is also considered to make the most important contribution to the ‘fit’ of a new theory to existing extant theories, thereby extending explanatory power (Urquhart, Lehmann, & Myers, 2010). In addition, data saturation of categories will not be achieved easily without theoretical sampling (Urquhart, Lehmann & Myers, 2010).

There are several benefits of theoretical sampling. Firstly it allows researchers to obtain rich information from a variety of participants and serves as a selective method to develop questions for the next round of data collection (Jennings, Kensbock, Junek, Radel, & Kachel, 2010). Targeting particular groups of new participants allows for more refined and focused interview questions to generate data that, when analysed, provides a clearer and more thorough progression towards the eventual grounded theory (Dey, 1993; Orlikowski, 1993). According to Charmaz (2006) theoretical sampling will help the researcher to examine categories for similarity or difference, saturate categories, and follow hunches about categories. The second benefit of using theoretical sampling is that theoretical sampling ensures the comprehensive nature of a theory and that it is in fact grounded (Urquhart, Lehmann & Myers, 2010). For Strauss and Corbin theoretical sampling can help “to maximize opportunities to compare events, incidents or happenings to determine how a category varies in terms of its properties and dimensions” (Strauss & Corbin, 1998, p. 202).

Theoretical sampling is not usually applied to data at the beginning of a grounded study, rather it is employed when new codes are identified (Hoare, Mills, & Francis, 2012) and gaps in the data are found as theoretical sampling aims to address these gaps (Bradley, 2010; Harling & Turner, 2012) until categories are saturated (Urquhart, Lehmann & Myers, 2010).

Constant comparative analysis using inductive and abductive logic

The term ‘constant comparative analysis’ is interchangeable with ‘constant comparative method’ (Glaser & Strauss, 1967). The use of the constant comparison method contributes to a

research study's validity (Egerod, Christensen, Schwartz-Nielsen, & Ågård, 2011; Silverman, 2001) and is important to assure the quality of research outcomes. In the process of constantly comparing incident to incident, incident to code, code to code and codes to categories, methods of data collection overlap with analysis, which is useful for building theory (Eisenhardt, 1989).

Constant comparative analysis involves comparing all types of evidence to control the concept and scope of theory (Orlikowski, 1993). Using constant comparative analysis of data assists in determining the direction of theoretical sampling, which supports the originality of theory (Birks & Mills, 2011; Corbin & Strauss, 2008). In the process of constant comparative analysis in grounded theory both inductive and abductive logic are used (Birks & Mills, 2011). Some authors have suggested that deductive reasoning must also be included to ensure a theory is grounded in the data (Thompson, Petty & Scholes, 2012). For Bryant (2009) induction and deduction are methods used to justify or develop existing knowledge. Innovative insights or creative thinking can only be achieved through abductive thinking that extends knowledge (Bryant, 2009). For Reichertz (2007) rational and imaginative aspects of research are part of the process of abduction. Charmaz (2006) defined abduction as follows:

a type of reasoning that begins by examining data and after scrutiny of these data, entertains all possible explanations for the observed data, and then forms hypotheses to confirm or disconfirm until the researcher arrives at the most plausible interpretation of the observed data (p. 118).

Strauss and Corbin's variant of grounded theory contains an abductive research logic while Glaserian grounded theory is much more reliant on induction (Reichertz, 2007).

Theoretical sensitivity

Theoretical sensitivity is defined as "the ability to recognize and extract from the data elements that have relevance for the emerging theory" (Birks & Mills, 2011, p. 176). Researchers need to be able to develop theoretical insights and abstractions of ideas from various types of data and sources (Morse, 2010) to establish relationships between concepts and to develop a theory (Strauss & Corbin, 1990). Without theoretical sensitivity, the result of an

analysis will only be a description and is unlikely to contain sophisticated concepts developed at an abstract level (Chakraborty, Sarker, & Sarker, 2010). Theoretical sensitivity needs to be accompanied by reflexivity so as to increase an awareness of how the implementation of the research process is affected by the researcher's perspective (Hall & Callery, 2001).

There are several ways to increase theoretical sensitivity (Hoare, Mills & Francis, 2012) including reading the literature, open coding, building categories, writing reflexive memos on analysis followed by returning to the data, and making sure that preconceived ideas are not being imposed (Corbin & Strauss, 2008). Other techniques are questioning, the flip-flop technique, and far-out comparisons (Strauss, 1987; Strauss & Corbin, 1990, 1998) which help to understand data in a different way (Mills, Bonner & Francis, 2008).

Memo writing

In the previous section, it was argued that the researcher must take an active reflexive stance to research. Reflexivity can be documented by writing memos. In grounded theory, these types of records, which are separate from interview data, are fundamental to the research process (Corbin & Strauss, 2008; Lempert, 2007). Reflexivity is defined as “an active, systematic process used by the researcher in order to gain insight into their work that will guide future actions and interpretations” (Birks & Mills, 2011, p. 175). This active and systematic process is guided by questions posed by the researcher to themselves in reference to actions, specific situations and feelings (both negative and positive). Influences on the researcher's thinking and an examination of how this affects data analysis must also be considered. Insight is developed through the active process of reflexivity in which the researcher writes about personal ideas including actions, feelings, and thinking which has influenced the research process (Birks & Mills, 2011).

Memos can also be supported by diagrams that illustrate the relationship among concepts and these diagrams may, in fact, change how the theory is built (van Niekerk & Roode, 2009). Diagrams are a pivotal part of the coding process. Diagrams may start as a simple flow chart but, when undertaking higher levels of analysis, the interplay between different levels of

situations may lead to the diagrams becoming more complex (Mills, Bonner & Francis, 2008; Strauss, 1987; Strauss & Corbin, 1990). Memos will facilitate the iterative process of concurrent data collection and analysis, theoretical sampling, initial, intermediate and advanced coding, and conceptual development (Hutchinson, 1993). Writing memos will help researchers become more aware of the research direction and analysis (Konecki, 2011). Memos regarding the results of each interview can also be written to provide information for the researcher to learn from any mistakes (Birks & Mills, 2011).

Field notes constitute an important source of data in a grounded theory. Birks and Mills (2011) suggest that field notes should cover all observations when the researcher works in the field. Field notes describe events, the physical environment, activities and participants' non-verbal behaviours during interviews. Furthermore the researcher's responses to the interviews and interactions with the participants can also be included in notes written after leaving the field. Here the researcher may also write notes about informal conversations that occurred in the research setting. In this study, field notes were written before and after each interview. The field notes were included in the data set for analysis.

Coding

When using grounded theory methods, coding is considered to be an essential contribution to the development of a theory because coding is a pivotal link between data collection, understanding what the data means, and constructing a theory (Charmaz, 2006). Coding occurs in stages with different authors using different terms for coding as can be seen in table 3.1.

Table 3.1

Terms for coding (Adapted from Birks & Mills, 2011)

Authors and years	Terms		
Birks and Mills (2011)	Initial coding	Intermediate coding	Advanced coding
Glaser and Strauss (1967)	Coding and comparing incidents	Integrating categories and properties	Delimiting the theory
Glaser (1978)	Open coding	Selective coding	Theoretical coding
Strauss and Corbin (1990, 1998)	Open coding	Axial coding	Selective coding
Charmaz (2006)	Initial coding	Focused coding	Theoretical coding

Regardless of the name of the coding schema that the researcher chooses all the stages are required to help the researcher formulate an adequate conceptualization of a theory (Urquhart, Lehmann & Myers, 2010). Strauss and Corbin (1998) define coding as “[t]he analytic process through which data are fractured, conceptualized and integrated to form theory” (p. 3). Coding techniques therefore need to be systematic and complex because this will provide rigour in a grounded theory study exemplified through conceptual density (Strauss, 1987). In this study the terms to be used are initial, intermediate and advanced coding (Birks & Mills, 2011).

Initial coding

Initial coding in this study was conducted after both the first and second field trips. Initial coding is conducted to fracture data (Glaser & Strauss, 1967) and it ceases when categories begin to be developed (Birks & Mills, 2011). Initially the researcher analyses the data generated from interviews using line by line coding and, in this process, employs gerund descriptors where possible to promote a sense of action in the analysis (Charmaz, 2006; Glaser, 1992; Jennings et al., 2010). A researcher uses an inductive approach to generate as much data as possible during the early stages of data coding and comparison in a grounded theory study (Sbaraini, Carter, Evans, & Blinkhorn, 2011). It is important that, during this level of coding,

researchers employ reflexive activities that are documented in memos (Strauss & Corbin, 1990). Initial coding is finished when categories or themes begin to form.

Intermediate coding

Intermediate coding is defined as “the identification of properties, dimensions, patterns and relationships during the process of category development” (Birks & Mills, 2011, p. 174). At this stage the researcher needs to make a decision about which initial codes are the most important and will contribute most significantly to the analysis by pursuing a selected set of central codes throughout the entire data set (Sbaraini et al., 2011). The process of coding and comparison continues to a higher level of abstraction, in which incidents are compared with the properties and categories identified from the initial coding (Idrees, Vasconcelos & Cox, 2011). In the intermediate coding process the researcher must organise categories and subcategories retrieved from the initial coding. Categories and subcategories are then compared to each other and their relationships to each other are established. Explanatory and conceptual patterns are identified and relational statements are developed to progress the analysis.

Advanced coding

Advanced coding is critical to theoretical integration (Birks & Mills, 2011). Advanced coding can lead to both theoretical saturation and the identification of a core category if this has not already occurred during the earlier stages of analysis. There is no predetermined amount of data collection in a grounded theory study (Thompson, Petty & Scholes, 2012) rather concurrent data collection and analysis will stop when no new insights are identified; major categories have been defined and established (Birks & Mills, 2011; Strauss & Corbin, 1998) and any gaps in the storyline have been filled (Birks & Mills, 2011; Corbin & Strauss, 2008; Glaser & Strauss, 1967). The central rationale for the integration of categories into a grounded theory is the identification of a core category that delimits the theory (Hallber, 2006). Identifying a core category can often be achieved by tracing the connections between frequent variables (Birks & Mills, 2011). Morse also (2010) identified that core categories can frequently be found in the data and appear to constitute a stable pattern that relates categories.

Activities in advanced coding begin by sorting memos and field notes to assist the process of integration by identifying relationships and unifying concepts (Corbin & Strauss, 2008). The next activity in advanced coding is writing a storyline that describes each of the categories under the core category and provides links between each of these so as to develop a cogent and saturated theoretical construct (Birks & Mills, 2011). The final conceptualisation of the core category is the completed storyline and this 'conceptual label' has to fit the data it represents (Strauss & Corbin, 1990, p. 121).

In the process of writing a storyline, the researcher in this study employed the TALES principle, which is an acronym for the following process: Theory takes precedence, Allows for variation, Limits gaps, Evidence is grounded, and Style is appropriate (Birks & Mills, 2011, p. 119). Theoretical coding is the next step in this advanced coding process and it 'provides the full and rich understanding of the social processes and human interaction which are being studied' (Cutcliffe, 2000, p. 1482). Theoretical coding is defined as 'the use of advanced abstractions to provide a framework for enhancing the explanatory power of a grounded theory' (Birks & Mills, 2011, p. 176). Glaser introduced theoretical coding with a suggested list of 18 coding families based on sociological theories (Glaser, 1978, p. 119). Corbin and Strauss (2008), on the other hand, suggested a coding paradigm rather than referring specifically to particular theoretical codes or coding families. In this study extant theories of decision making and coping were used to add explanatory power, as suggested by Birks and Mills (2011), to the grounded theory of connecting care.

Ethical considerations

Castellano (2004) refers to ethics as a rule of conduct which articulates and underlines the importance of cultural and social values in society. The first international directive related to research ethics was the Nuremburg Code (Castellano, 2004). The Nuremburg Code responded to experimentation on humans by Nazis in the Second World War (Castellano, 2004). The Nuremburg Code was developed in 1947 as a set of standards for research activity in which human beings are involved (Lurie, 2010). The code was designed to prevent future human

rights violations on human subjects in medical research (Castellano, 2004; Lurie, 2010). In 1964 the Nuremberg Code was expanded to provide more specific guidance for medical research, published as the Helsinki Declaration by the World Medical Association (Castellano, 2004; Lurie, 2010). International and national human research committees (HRECs) apply these legal and ethical guidelines to the conduct of research (Jirojwong, Johnson, & Welch, 2011). In Australia the responsible body for human ethics is the Australian Health Ethics Committee (AHEC), a sub-committee of the statutory body the National Health and Medical Research Council (NHMRC) (Jirojwong, Johnson & Welch, 2011). Ethical principles in research require the researcher to give due consideration to informed consent; beneficence and non-maleficence; rights, privacy and confidentiality; data management throughout the research study and beyond; identification of vulnerable groups; and power relationships between researchers and participants (Jirojwong , Johnson & Welch, 2011).

In this study the process of seeking ethical approval started on May 2011 with approval provided in June 2011 by the Ethics Committee at James Cook University (# H4194; see *Appendix A*) with research permission from psychiatric hospitals to conduct research at their organisation received in May-June 2011 (*Appendix B*). The researcher ensured that research conducted was based on the ethical principles approved by the Research Ethics Committee at JCU. All documents provided to potential participants such as information sheets and informed consent forms were translated from English into Indonesian. A certified interpreter checked the translation of all documents to make sure those translations were accurate (*Appendix C*). Recruitment process will be explained more detail later in this chapter. In this study, the researcher applied for ethics amendments twice as the nature of the grounded theory related to theoretical sampling led to the need to recruit a wider scope of participants. In the process of the first of the ethical amendments to the JCU Research Ethics Committee, there was also a change of the title of the study from ‘The process of planning for patient discharge from an Indonesian psychiatric institution: A grounded theory study’ to ‘Connecting care - Indonesian people living with mental health issues: A grounded theory study’. Additional subject groups were also included in this first ethics amendment to widen the sample to include health professionals who

were working in community health facilities, patients, patients' families, cadres and community leaders. All documents which were needed to be handed over to participants were translated into Indonesian and checked by a certified interpreter. The first amendment for the second field trip was approved in December 2011.

The second ethics amendment for the third field trip was processed in April 2012 and this amendment also requested additional subject groups. In this period, there was no need to change the documents which were handed over to participants, such as information sheets and informed consent, because the title remained the same from the second field trip process.

In the information sheet, ethical principles were mentioned such as information about the goal of the study and the process of data collection/generation. Participants were also informed that taking part in this study was completely voluntary and participants could withdraw from the study without explanation. Information related to confidentiality was also provided and the researcher gave an assurance that she would maintain participants' confidentiality when the research findings were published. All data collected in this study is kept safe in a locked place. All digital data were saved on two computers and two external drives. That data was also kept safe using a password.

In discussions with supervisors during the process of analysis, the researcher only used a code of a respondent when it was necessary to discuss the results of an interview. Only the researcher knows the participant's identity for each code. When the researcher had to discuss the developing analysis via Skype with supervisors, the researcher ensured the best place and time available to maintain confidentiality of participants and used codes to refer to specific participants in the process of the discussion.

Study participants and recruitment

The sample

A detailed list of participants in this study is provided in table 3.2.

Table 3.2
Study Participants

Field trips	Participants	Number
First field trip	Nurses	5
	Nurses	26
Second field trip	Psychiatrist	1
	Psychologist	2
	General practitioners	1
	Cadres (volunteer)	4
	Community leader	2
	Individuals living with a mental health issue	1
	Family	2
Third field trip	Nurses	1
	Social worker	4
Total number of participants		49

In the process of recruitment, a letter about the study (*Appendix D*) was sent via a third party to eligible participants at the research site. If participants were interested in the study, they could contact either the third party or the researcher to indicate that were willing to be involved in the study. The researcher provided an opportunity for each participant to ask questions related to the study before the participant agreed to sign a consent form (*Appendix E*). The recruitment process, including obtained informed consent, was the same for all three field trips.

Sequence of field trips

The sequence of field trips and associated ethics amendments is illustrated in figure 3.1. Each of the field trips will be described in the following section.

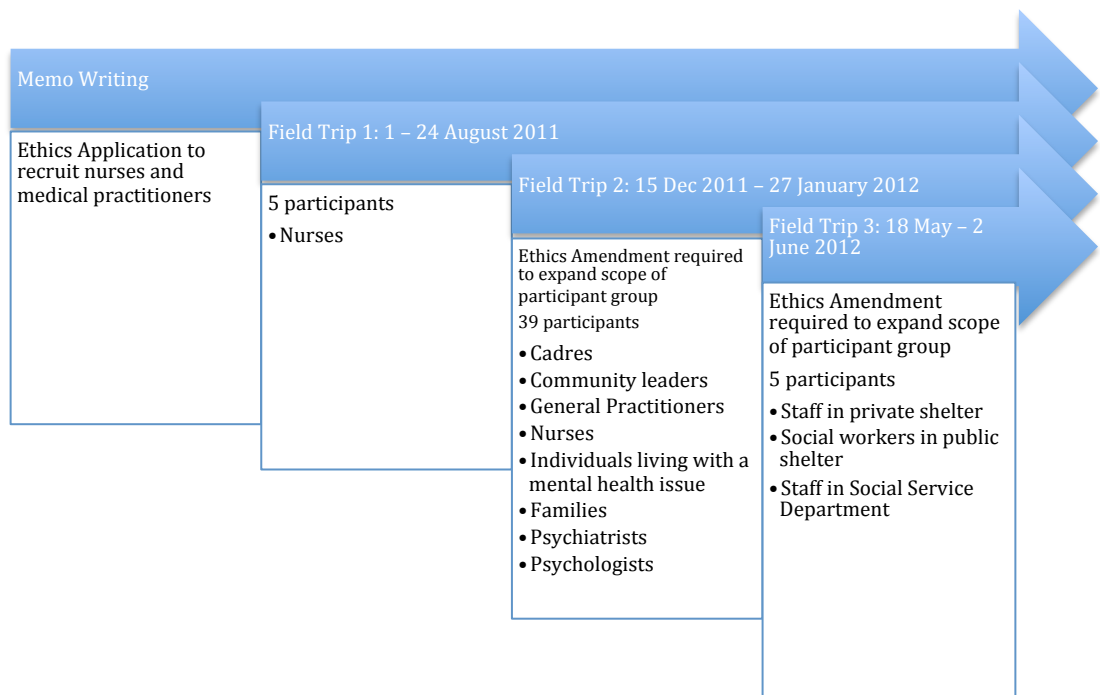


Figure 3.1 The Sequence of Field Trips

Description of the data set

The total number of transcribed pages of interview data generated in this study was 539 pages. In addition, 166 memos were generated for inclusion in the data set. Diagrams were drawn and referred to continuously with 41 diagrams produced during concurrent data generation and analysis. In the process of integrating the final grounded theory, 46 versions of the storyline were produced.

Field trip one

One month after the ethics approval was received the researcher returned to Indonesia to begin generating data. Purposive sampling was used for the first field trip and was guided by the original aim of the research study which was to investigate discharge planning (van Niekerk & Roode, 2009). Purposive sampling was used to identify respondents the researcher believed were knowledgeable about the substantive area of enquiry (Fletcher & Sarkar, 2012). At that

time the research question was: 'What is the process of planning for discharge into the community for people living with a mental illness from an Indonesian psychiatric institution?'. Before the researcher began interviewing participants during the first field trip, a practice interview was conducted with a colleague who spoke the Indonesian language. This was done to obtain constructive feedback with a view to improving the interview technique where required.

The researcher arranged a mutually convenient time and place for participant interviews to be conducted. Participants were interviewed in the Indonesian language and the format was largely unstructured. A set of initial 'prompting' questions, however, was developed to facilitate discussion. The average interview time in the first field trip (five respondents) was 30 minutes. In the first field trip three psychiatric hospitals were canvassed, however only five nurses in one psychiatric hospital in one province were interested in taking part.

Data generation and analysis in this field trip was conducted simultaneously. The researcher prepared for the interview by writing memos. Guides to writing memos were established beforehand to ensure the memo addressed all of the features of grounded theory that the researcher needed to consider during the interview process and subsequent data analysis. This was important because the researcher considered herself to be a novice grounded theorist. Memos included the research questions asked, strategies used to counteract imbalances of power, answering the power differential between the researcher and participant and developing an audit trail. Memo writing was used to increase the researcher's reflexive awareness about creating a space for the participant's voice in the generation and interpretation of data (Mishler, 1991).

After each interview the researcher listened to the interviews several times and wrote a series of memos. The nature of the memos varied. Some memos took the form of field notes that described the physical context and the process of interaction between the researcher and participant. These observations might have included body language such as eye contact, pauses, and the need for probing questions. Other memos were focused on promoting researcher reflexivity about how the researcher might have shaped the interaction during the interview.

Memos also explored the participants' responses and questioned how these responses would influence the research questions to be asked in the next interview. Each of these memos contributed to the audit trail of this grounded theory study, whereby the researcher was able to identify and appraise key moments in the developing grounded theory analysis. An example of an audit trail memo can be seen in *Appendix F*.

The researcher designed different types of memos to become aware about what had to be written because the grounded theory method was still new for her. Memos were written in English or Indonesian or in both languages and the choice of language depended on ease of thoughts and analysis for the researcher.

After the first interview the researcher used Skype to discuss the experience with her supervisor. They decided that the researcher needed to improve her interviewing skills by using more open-ended questions. The researcher also wrote memos about feeling anxious when interviewing participants and considered how this might have affected the level of rich information obtained. This memo was used to guide the researcher in later interviews and helped create a better interviewing technique. The subsequent transcripts revealed that participants were speaking for a longer time, reflecting the researcher's developing skills in interviewing people.

After five nurses had been interviewed, there was still no information about whether health professionals from the other two psychiatric hospitals were interested in participating in this study. At the end of the day of the first field trip, responses were received from health professionals working at these two psychiatric hospitals but the researcher had to return to Australia. Visits to these two psychiatric hospitals were therefore postponed until the researcher could go back to Indonesia. In Australia the researcher transcribed the five interviews and these transcriptions were translated into English. The researcher also wrote memos during the process of transcribing and translating.

After the interviews were translated, a colleague who is fluent in English was asked to check the transcripts. The process of initial coding using NVIVO commenced once the transcripts were translated into the English language. In this process the researcher compared

incidents to incidents, incidents to codes and codes to codes. Preliminary categories/sub categories were constructed. During initial and intermediate coding, the researcher used NVIVO software to assist in organising the data (van Niekerk & Roode, 2009). The results of initial coding showed surprising answers to the research question as discharge planning appeared to be non-existent in Indonesia's mental health system. After the initial coding of the first five interviews, the researcher started to conduct intermediate coding. This process involved activities such as comparing tentative codes and categories to find any gaps/holes and establishing further research questions to be used in the second field trip.

The results of this analysis led to the development of a possible core category known as 'connecting care'. Based on the analysis of the first field trip data, major gaps were identified (as can be seen in *Appendix G*) and this led to the process of designing the second field trip. As shown in the appended memo, the researcher found that discharge planning was just a small part of a bigger and more complex issue in the substantive area of enquiry of the way in which mental health care was delivered in Indonesia. In a memo dated the 5th October, 2011 gaps were identified in the data in relation to the full scope of care provided, which included the following:

- Disconnection between hospital in acute wards and the outside world
- So I need to find information about the outpatient department
- So the questions related to the connection are: who makes this connection, what are the forms of connection and how actually is this connection achieved?
- The possible cause why a patient move around is because there is a lack of support for family (as a family needs to bring the patient again to the hospital) or probably because the patient is very unstable? Or because they haven't manageable in community
- Possible conclusion: No supporting people to stay at home WHAT drives moving around? Is it really lack of support?
- The support provided for patient and family
- What makes fall over --- patient good, discharged and admitted again to hospital

At this stage further changes to the ethics approval for the study were required because of the need to theoretically sample a much greater number of participant types. The researcher started to amend the ethics application and research permissions in preparation for returning to

Indonesia for the second time. An interview guideline was developed before the next round of interviews began which outlined possible topics for further investigation.

Field trip two

On the day the researcher returned to Indonesia for the second field trip, ethical changes had not yet been approved. Data, however, still could be collected because health professionals in all psychiatric hospitals had responded to the invitation to participate which was covered under the original approval. While the researcher was waiting for the ethic amendments to be approved, data was collected using the same procedure as the first round. In the other two psychiatric hospitals, however, the researcher needed to modify the process of concurrent data generation and analysis because these two psychiatric hospitals were far from the researcher's residence which made the process of writing memos before and after interviews more difficult. Data generation was modified by interviewing more than one respondent each day. Writing memos was done before the researcher arrived at the research sites and after leaving the research site. Data generation in these two psychiatric hospitals was conducted over a two-week period. Comparisons could thus be made between the discharge planning processes in the two hospitals. Information related to discharge planning was saturated by the time the researcher had collected data in the three hospitals. New data codes were constructed as the researcher identified and expanded themes concerning wanderers, the homeless and shackled patients. Analysis also showed that other stakeholders, including social workers and staff in public and private shelters, were providing care for individuals living with a mental health issue. This outcome of analysis guided theoretical sampling but, because the process of data generation for new respondents was not covered by previous ethical requirements, the researcher had to wait until this was processed. During this field trip, both ethics approval (*Appendix H*) and research permission (*Appendix I*) to collect data from the institutions involved was received in late December 2012.

Following ethics approval the researcher continued to generate data in January 2012 including the broader scope of participants as documented in table 3.2. The recruitment process

was similar to field trip one in that it was begun by a third party who sent a letter of invitation to the various sites (*Appendix J*). The researcher provided an information sheet and written consent form for completion to potential participants (*Appendix K*).

The researcher started generating data with health professionals in PHCCs, patients, families, cadres and community leaders. Thirty-nine interviews were recorded during this second field trip. Rich information was obtained. Three patients were interviewed but only one interview could be analysed. The researcher had assumed that patients in the community were in the recovery process but this was found to be an incorrect assumption; two of the patients were in no state to be interviewed so the data from these sessions was excluded from the study. At another research site, the researcher cancelled visits to individuals living with a mental health issue at a late stage because health professionals were worried the interviews could spark threats to people's safety. This problem was written about in a memo and increased the researcher's awareness that mental health problems for those in the community could be very acute. Preliminary analysis of the data during the second field trip was conducted using memos and field notes. After the second field trip was finished, the researcher returned to Australia and started transcribing, translating and coding the information. More diagrams were produced during this process. Explanatory and conceptual patterns were identified to help develop relational statements and assist in generating further analysis.

After the second field trip the researcher and supervisory team faced an analytical dilemma in that the original process of translation and checking was very time-consuming. No guidelines for translation in grounded theory study could be found in the published literature. As a result a specific strategy was developed by the author to manage the analysis and translation of data. A paper that described this feature of the research project will be published in Sage Open Access Journals and appears in the last section of this chapter. This procedure was employed for the third field trip.

In this second field trip, the provisional core category of connecting care remained. Further gaps were identified after analysis of the second field trip data using initial and intermediate coding. These gaps concerned 'wandering' individuals and shackling (or other

forms of physical restraints). Theoretical sampling was therefore widened to include the Social Service Department, and private and public shelters. Accessing these participants required a further ethics amendments and refinement of the interview guidelines. After the researcher received ethics approval (*Appendix L*) and research permission (*Appendix M*) to collect data from the institutions involved, the researcher returned to Indonesia for the third field trip. The information sheets and informed consent forms used in the second field trip were suitable for use in the third field trip.

Field trip three

During the third field trip interviews were conducted with social workers, nurses working in private shelters and staff in the Social Service Department, thus making it possible to achieve theoretical saturation of the categories which formed the substance of the grounded theory 'Connecting care for individuals living with a mental health issue in Indonesia'. The researcher stopped theoretical sampling after data saturation was reached and started the process of advanced coding. During this third field trip, the researcher's supervisor visited the research field and visited two PHCCs and one psychiatric hospital. The supervisor also visited two patients to get a sense of how the Indonesian mental health system worked. This visit was very useful in the process of discussing issues with the researcher and helped with the process of theoretical integration.

As the categories were saturated, the researcher started advanced coding by sorting memos and writing the storyline. Writing the storyline included checking back to the original data and diagramming. Writing the storyline and integrating the grounded theory was the most difficult process for the researcher in this study. In total 46 versions of the storyline were produced to integrate the final grounded theory. Memos were drawn upon heavily as the researcher wrote these storylines. Memos were sorted during advanced coding to identify how categories were linked. Two subcategories – matched and unmatched decision-making – were constructed as a result of sorting memos. The process of theoretical integration was much more complicated when the researcher need to discussed data analysis with supervisors who were

Australian and the data was originally produced in Indonesian language. This complicated process lead to creative and critical thinking related to the process of analysis when raw data is not in English. This process of searching, analysing and thinking about the data and about translation resulted in the publication mentioned previously. The publication concerns procedures for ensuring the integrity of translation.

The researcher compared the grounded theory of connecting care with other extant theories in the process of advanced coding and theoretical integration. Decision-making theory (March, 1994) was chosen as a theoretical code to extend the explanation of health professionals' role in connecting care. The theory of coping (Lazarus, 1998) was considered to be more appropriate for application to non-health professionals. Finally the researcher explored issues related to human rights violations and burden of care in the context of the contemporary literature.

The next section is a publication titled: 'Conducting a grounded theory study in a language other than English: Procedure for ensuring the integrity of translation'. This manuscript explains the process of translation used in this study and provides justification for choosing a specific method for the analysis. The following manuscript has been accepted for publication and at the time of submission the authors were awaiting proofs. In order to preserve the integrity of the manuscript as it was submitted the table and figure included in the manuscript have not been included in the listing of tables and figures included in the thesis front matter.

Manuscript: Conducting a Grounded Theory Study in a Language Other Than English: Procedures for Ensuring the Integrity of Translation

Declaration of Authorship

Chapter Number	Publication	Nature and extent of the intellectual input of each author including the candidate	Signature
3	Nurjannah, I., Mills, J., Usher, K., & Park, T. (Accepted). Conducting a Grounded Theory Study in a Language Other Than English: Procedures for Ensuring the Integrity of Translation. SAGE Open.	Study design, data collection, data analysis, preparation	Nurjannah, Intansari
		Study design, data collection, data analysis, preparation	Mills, Jane
		Study design, preparation	Usher, Kim
		Preparation	Park, Tanya

CONDUCTING A GROUNDED THEORY STUDY IN A LANGUAGE OTHER THAN ENGLISH: PROCEDURES FOR ENSURING THE INTEGRITY OF TRANSLATION

Intansari Nurjannah¹, Jane Mills¹, Tanya Park¹, and Kim Usher¹

¹James Cook University, Cairns, Queensland, Australia

Corresponding Author:

Intansari Nurjannah,

James Cook University,

Cairns Campus, P.O.Box 6811,

Cairns QLD 4870, Australia

E-mail: intansari.nurjannah@my.jcu.edu.au

Declaration of Conflicting Interests

The authors declare no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The author discloses the following financial support for the research:

Australian Development Scholarships

Word Count: 7118

ABSTRACT

Translation can be a problem area for researchers conducting qualitative studies in languages other than English who intend to publish the results in an English language journal. Analyzing the data is also complex when the research team consists of people from different language backgrounds. Translation must be considered as an issue in its own right to maintain the integrity of the research, especially in a grounded theory study. In this article we offer guidelines for the process of translation for data analysis in a grounded theory study in which the research was conducted in a language other than English (Indonesian). We make recommendations about procedures to choose when, who and how to translate data. The translation procedure is divided into four steps which are as follows: translation in the process of coding, translation in the process of team discussion, translation in the process of advanced coding and ensuring the accuracy of translation.

KEYWORDS

grounded theory; language / linguistics; qualitative analysis; translation.

Translation can become an area of concern in qualitative or quantitative research. Translation may be required in qualitative research if study participants and researchers speak different languages or if the target language for publication is different from the source of data. Translation processes may also be required to validate the research instrument in quantitative research. In both qualitative and quantitative research, the most important factor in achieving a valid translation is ensuring equivalence of meaning (Brislin, 1970; Sechrest, Fay & Zaidi, 1972). Conceptual equivalence is a term used to describe an accurate translation – both technically and conceptually (Jandt, 2003). In addition, lingual and cultural aspects need to be considered in achieving equivalence of meaning because literal equivalence in the target language does not always express clearly the essential meaning of the source language (Su & Parham, 2002). The translation process used in qualitative research becomes vitally important for researchers seeking to ensure conceptual equivalence (Chen & Boore, 2009).

The aim of this article is to describe the process of data analysis in grounded theory when translation is required. In particular, the authors provide guidelines to address the issue of maintaining conceptual equivalence of data when the data must be translated for analysis by a multilingual research team. A worked example is used to illustrate the process of translation in a grounded theory study. A worked example is a practical illustration of how a process unfolds (Birks & Mills, 2011). The study was approved by the Human Research Ethic Committees of an Australian University (Number H4194) and each participant provided signed informed consent.

The worked example, will be used to answer the following questions:

- When should data be translated for analysis?
- Who should translate data?
- Which translation procedure should be used?
- How should this process be implemented?

THE TRANSLATION PROCESS

The methods for achieving equivalence of meaning vary slightly between qualitative and quantitative research; all methods will ideally involve the use of forward and backward

translation. Forward translation is the process of translating data from the source language to the target language. A forward-only method is insufficient to establish semantic equivalence in translation. Thus backward translation is used as a further method to verify the adequacy of translation (Maneesriwongul & Dixon, 2004).

Back translation is the process of translating back from the target language to the source language (Chen & Boore, 2009; Maneesriwongul & Dixon, 2004). Back translation is a significant step in ensuring the validity of a translation (Maneesriwongul & Dixon, 2004) but is sometimes criticized because it is considered to be focused on closeness of fit rather than on accuracy or truth. In addition, the use of a back-translation method does not reduce problems related to linguistic or cultural differences (Su & Parham, 2002). One benefit of back translation is that it can provide insight into the process of decentering (Brislin, 1970; Brislin, Lonner & Thorndike, 1973; Sechrest et al., 1972; Werner & Campbell, 1970). Decentering in translation is a collaborative process between experts in the two cultures or languages and is used to minimize cultural and linguistic biases (Su & Parham, 2002). The source and target versions are open to revision in the process of decentering, thereby generating a valid translation (Su & Parham, 2002). A third method of translation involves both forward and backward translation.

The forward-backward technique is an intellectually-rigorous translation process, but engaging in this process is not a guarantee of achieving conceptual equivalence. This relatively exhaustive translation process still might not convey attitude (Croot, Lees & Grant, 2011; Larkin, de Casterlé & Schotsmans, 2007). For example, "...some terms may be translated accurately in their literal sense but a literal translation may fail to convey the ideas or attitudes inherent in the original choice of words" (Croot et al., 2011, p. 1003). Furthermore, translation and back translation of all the data collected in, for example, a grounded theory study, might be considered to be excessively expensive and time-consuming (Chen & Boore, 2009) and, as a result, will not always be practical.

Qualitative research, in which researchers are working with words rather than statistical data, is characterized by interpretation of the meaning of participants' words (Fenna, Tineke, Hans & Dorly, 2010). The meaning of these words (data) must be interpreted correctly or the

results of the study will be adversely affected. The results of a qualitative study are considered rigorous if the interpretation of participants' meaning is as close as possible to the participants' experience (Polkinghorne, 2005). The issue of rigor in data analysis becomes a greater concern when the results of the study are published in a language other than the one used to obtain the data. Issues related to the translation process need to be addressed prior to data collection and analysis because there is potential for the meaning and intent of the research to be lost if the process of translation is not appropriate (Fenna et al., 2010). In addition, the quality of data translation can influence the equivalence and accuracy of findings (Frederickson, Acuna & Whetsell, 2005; Schultz, 2004; Temple, 2002)

Cross-language research is defined as studies in which a language barrier is present between researchers and their respondents (Larson, 1988; Temple, 2002). In cross-language research the translation process will differ from one qualitative methodology to another. For example, the translation approach used in ethnography will be different from that employed in a grounded theory study (Twinn, 1998). In phenomenology studies, researchers simply cannot undertake studies in languages other than their native tongue because the language used by the participant will be changed too significantly, even with a rigorous translation process (Squires, 2008). Analysis in phenomenology must be conducted entirely in the language of respondents, with translation becoming an option only in the final reporting and publication stages (Squires, 2008). Cross-language qualitative researchers who use other methodologies also argue that preliminary data should not be translated, only final papers just before publication (Larkin, et al., 2007; Temple, 2002). The process of analysis for each qualitative methodology is different and, as such, the place and timing of translation in the research process differs also. Several researchers make recommendations about the processes of translation to be used in qualitative research as a whole (Chen, 2004; Chen & Boore, 2009; Suh Ft, 2009; Fenna, 2010; Smith, 2008), but there are no clear guidelines about dealing with translation issues encountered specifically in a grounded theory analysis.

TRANSLATION IN A GROUNDED THEORY STUDY

A grounded theory study requires the use of complex data analysis methods (Strauss & Corbin, 1990) including three levels of analysis: initial, intermediate and advanced coding (Birks and Mills, 2011). Coding is a process whereby researchers draw from the substantive area of investigation, personal knowledge and knowledge of extant theory (Birks & Mills, 2011) to create meaningful labels for sections of data. The standard technique of coding in grounded theory includes the preferred use of gerunds (Charmaz, 2006; Glaser, 1978) which are nouns formed from verbs. Grammar and syntax vary enormously across languages and, therefore, pose problems in translation (Su & Parham, 2002). For example there is no equivalent of 'gerund' in Indonesian. Therefore, researchers who want to adhere strictly to grounded theory methodology by using gerunds in coding (Charmaz, 2006) must conduct analysis in English.

Throughout all levels of grounded theory analysis, researchers engage in constant comparison of data and use theoretical sampling, usually recording the outcomes of these methods as memos (Strauss & Corbin, 1990; Birks & Mills, 2011). This active and systematic process is guided by questions posed by the researcher. These questions may be about preconceptions, feelings (both negative and positive), prior thoughts or knowledge, and reactions to situations which arise during interviews, all of which influence the researcher's level of theoretical sensitivity to the data (Birks & Mills, 2011).

The first phase of analysis in a grounded theory study, initial coding, is conducted to fracture the data (Glaser & Strauss, 1967). Fracturing the data means that "the data is broken down into discrete parts which are closely examined, compared for similarities and differences then questions are asked about the phenomena, as reflected in the data" (Strauss & Corbin, 1990, p. 62). In this first stage of coding, researchers conduct a line-by-line analysis of data recorded during initial interviews. Data are coded and compared with each other. This process is called constant comparative analysis and uses inductive and abductive logic (Birks & Mills, 2011). Inductive thought is defined as "a type of reasoning that begins with the study of a range

of individual cases and extrapolates patterns from them to form a conceptual category” (Bryant & Charmaz, 2007, p. 608). Abduction is defined as a

type of reasoning that begins by examining data and, after scrutiny of this data, entertains all possible explanations for the observed data. Hypotheses are used to confirm or disconfirm these explanations until the researcher arrives at the most plausible interpretation of the observed data (Bryant & Charmaz, 2007, p. 603).

Intermediate coding is the next phase of analysis in a grounded theory study. Strauss and Corbin (1990) use the term axial coding to describe intermediate coding. They define this term as “a set of procedures whereby data are put back together in new ways after open coding, by making connections between (and within) categories” (p.96). During intermediate coding the researcher organizes the categories and subcategories which have been retrieved from initial coding. Categories and subcategories are compared with each other and the researcher establishes links and relationships between the concepts. Explanatory and conceptual patterns are identified. It is also considered good practice to develop relational statements to deepen analysis (Mills, Birks & Hoare, in press). Researchers may choose to write a storyline at this stage to explain the relationships between concepts that will make up the theory. The storyline is ‘the conceptualization of the story. This is the core category.’ (Strauss & Corbin, 1990, p. 116). Story line is defined as ‘a strategy for facilitating integration, construction, formulation and presentation of research findings through the production of a coherent grounded theory’ (Birks & Mills, 2011, p. 176). The researcher uses grounded theory principles to begin writing a storyline, which is described and guided with the acronym TALES; that is, “Theory takes precedence, Allows for variation, Limits gaps, Evidence is grounded, [and] Style is appropriate” (Birks and Mills, 2011, p. 119).

Advanced coding is the last level of analysis in grounded theory methodology. The result of advanced coding will be theoretical integration. This is the point at which the theory is consolidated. Activities are started in this phase by sorting memos and field notes to ‘aid the integrative process through the identification of relationship and unifying concepts not previously evident’ (Corbin & Strauss, 2008). The grounded theory storyline is developed

further. Advanced coding uses the storyline technique and, later on, theoretical coding (Birks & Mills, 2011).

The activities of analysis in a grounded theory study are complicated if the data is collected in a language other than English. Further complications occur if members of the research team are multi-lingual (and have different first languages). Although all members of a multilingual research team will be involved in the data analysis, data needs to be collected in the local language of participants. A research team member who is fluent in the local language is the most appropriate person to interview participants. Such a decision will minimize the risk of misinterpretation and prevent the loss of participants' intended meanings when they use phrases and concepts which are securely embedded in the study's context (Smith, Chen & Liu, 2008). It is necessary to translate data into other languages for analysis by all researchers when the team is multi-lingual. Researchers must recognize, however, that this process can be time-consuming, expensive and has the potential to compromise the validity of the data because meaning can be lost easily in translation (Smith et al., 2008). Researchers need to minimize the risk of compromising data by setting out operational guidelines in the research proposal about translation. These guidelines must address the following three issues: when the data will be translated, who will undertake this translation and what translation procedure will be used. The following worked example explains the procedures developed by researchers in this study to address these questions.

PROCEDURES FOR TRANSLATION IN A GROUNDED THEORY STUDY: A WORKED EXAMPLE

The analysis and translation process in grounded theory described here is based on research conducted in Indonesia. The title of this grounded theory study is *Connecting Care for Individuals Living with a Mental Health Issue in Indonesia*. The research team consisted of one Indonesian researcher, who is PhD candidate, and three Australian supervisors (including one supervisor who joined the team at a later phase of data analysis). Data analysis was conducted mostly by the Indonesian researcher and the principal supervisor. The principal supervisor is a

grounded theorist and was involved in the data collection process when she visited the research site. The principal supervisor also worked closely with the Indonesian researcher because, during analysis, the researcher was learning how to apply grounded theory methods.

The Indonesian researcher collected data in the local language in three stages. The first stage in August, 2011 involved interviews with five nurses. The second stage of data collection between December 2011 and January 2012 involved theoretical sampling of general practitioners, psychiatrists, nurses, psychologists, cadres (a term used in Indonesia which refers to non health professional volunteers), community leaders, relatives of individuals living with a mental health issue, and individuals living with a mental health issue. Thirty-nine interviews were conducted and transcribed. The third stage of data collection in May 2012 involved further theoretical sampling of social workers, social department staff and staff from public and private mental health shelters. The primary researcher wrote memos during data collection and analysis. Memo-writing was particularly frequent during the transcribing of interviews, the process of initial, intermediate, advanced coding, and in the preparation of the findings manuscript for publication. Memos were also written as required to account for the researcher's thoughts and decision-making about the study more generally.

When Do Researchers Need to Translate Data?

Language differences may occur in the initial phases of qualitative research during data collection or, later, in the process of analysis and publication (Fenna et al., 2010). Data may be translated at three distinct points in the research process: before analysis, during analysis, or after analysis when the manuscript is ready for publication (Suh, Kagan & Strumpf, 2009). Suh et al. (2009) recommend that translation take place during analysis because they believe this will ensure the authenticity of the findings if the study is to be published in a different language. If data is translated before analysis there is the possibility that meaning will be lost from the participant's implicit expression (Larkin, et al., 2007). The researcher who waits until after analysis to translate the data may find translation difficult because sometimes there is no precise English word or phrase to express the participant's experience (Choi, in Suh et al., 2009).

The composition of the research team must be considered when deciding the point at which translation should take place. Translation before analysis can be an appropriate option if the entire research team does not speak the participant's language. This type of research can be categorized as cross-language research. Translation after analysis, however, may be the best option if all members of the research team speak the same language as the participants. Quality of analysis will be poor if some members of the research team are forced to analyze data presented to them in a language other than their own. It is important to consider the characteristics of the research team members when considering the timing of translation. For example, translation during analysis may be the best fit if one member of the research team speaks a different language from other members. In the grounded theory study, *Connecting Care for Individuals Living with a Mental Health Issue in Indonesia*, the translation-during-analysis approach was applied. This was considered to be the best choice because all members of the research team could then be involved in analysis. The next consideration was choosing a person to translate the data.

Who Should Translate Data?

A translator is defined as a person who transforms the research data from one language to another (Josephine & Maurice, 2010). Researchers need to consider the theoretical or philosophical approach applied in the study to answer the question of who should translate the data (Adamson & Donovan, 2002; Esposito, 2001; Temple, 2002; Temple & Young, 2004; Twinn, 1997). For research conducted from a positivistic perspective in which knowledge is to be discovered, not constructed, translation is considered to be a simple process and language is easily reassigned from one language into another language (Squires, 2008). A technically-precise translation is considered to be sufficient using this view (Temple, 2002) and a professional translator would be the best choice. Ideally, professional translators should possess certification from a professional translator's association as a proof of their language competency (ATA, 2008; Edwards, 1998). A person who meets the standards described by the translator's association is the next best option if it is impossible or too difficult to employ a

certified translator, (Squires, 2009). To summarize, the use of a professional translator is suitable only for research within an epistemology of objectiveness where truth exists to be uncovered, rather than a constructivist or interpretive epistemology in which truth is constructed (Temple & Young, 2004).

The employment of a professional translator will not be acceptable in many grounded theory studies if the research is being done from a social constructionist, non-positivist or interpretive approach. These frameworks assert that the social world influences the perspective of the translator and colors the way the translator interprets and translates the data (Temple, 2002; Temple & Young, 2004). This perspective integrates the cultural interpretation of a participant's statements into the data analysis process. The translator, therefore, becomes a producer of research data who shapes the analysis through their identity and experiences (Adamson & Donovan, 2002; Squires, 2008; Squires, 2009; Temple, 2002; Temple & Young, 2004). From this perspective, the decision to employ a professional translator may be considered inappropriate because translation is not considered to be a neutral technique to change words from one language into another. A technically-accurate translation does not necessarily convey the precision or subtle nuances of the original intent described in text (Bradby, 2002). Translation involves interpreting and conveying the meaning of two languages and is influenced and guided by power relations and social context (Buhler, 2002). Temple (2002) also makes the point that interpretation in the broader sense of the word is the essence of translation. Therefore 'technical' translation may not be an appropriate course to follow except, possibly, when translation is to be employed just prior to publication. Translation in a social constructionist, non-positivist or interpretive study might be conducted effectively by a translator-moderator from within the research team. The researcher will be better-placed than a professional translator to acknowledge and affirm the nature of the research work including the contextualization of data in its transformation from one language to another.

In the example grounded theory study, the researchers applied social constructionist, non-positivist and interpretive approaches and chose to use both a translator moderator and professional translators. This combination of translators is recommended by Fenna et al. (2010),

who suggests the researcher who has conducted the interviews in their first language can operate as a translation moderator in cooperation with a professional translator. The twin processes of data collection and analysis are conducted together in a grounded theory study. Thus, it was decided that both translator moderator and professional translator would be employed in the example study, but they had different roles and purposes. The translator moderator was pivotal to the process of concurrent data collection and analysis, whereas the professional translator was employed in the process of finalizing the findings for publication.

The next issue to resolve is choosing the best person to be the translator moderator. Smith (2008) recommends that members of the research team who are fluent in the original language undertake the identification of categories. Thus, the best candidate for translator moderator is the person who is fluent in both the source language and target language (Birbili, 2000; Chen & Boore, 2009; Croot et al., 2011; Squires, 2008; Temple, 1997). Someone who is truly bilingual is even better (Hunt & Bhopal, 2004; Svetlana, 2007). Therefore, it is best practice to nominate a translator moderator who is truly bilingual and who is sufficiently-educated to be familiar with the concepts and with the formal and specialized language used in the data (Chen & Boore, 2009). The benefit of having a bilingual researcher on the team is that she or he will be able to construct meaning, analyze and reflect on this construction, as well as transferring the data into the English language (Edwards, 1998; Temple, 2005).

The bilingual translator moderator is entrusted with many responsibilities which can create potential for a power imbalance within the team. Svetlana (2007) says that the power of a translator moderator is greater than that of research team members, particularly those researchers who do not speak the language of participants because the translator moderator has an apparent monopoly on interpreting the research findings. Situations of mistrust can arise from this power imbalance and can lead to misunderstanding within the team (Tsai et al., 2004). Open communication and negotiation between all team members is therefore vital to prevent misunderstanding and to equitably share power and ownership of the research findings (Svetlana, 2007). Another characteristic the translator moderator needs to possess is an understanding of the people participating in the study and a familiarity with both cultures

because translation is a complex social and cognitive process that can affect the outcomes of the study (Svetlana, 2007).

In this study the translator moderator, a member of the research team, could speak both Indonesian and English. Even though English was a second language and she was not truly bilingual, this researcher was the person who interviewed participants and wrote memos throughout the research process. She had easy access to the memos she wrote and was able to incorporate these memos into the process of analysis. In this worked example, only one translator moderator was used with the intent of ensuring the consistency and conceptual congruency of both the oral and written translation process (Larkin, et al., 2007; Twinn, 1997). A professional translator was employed only to back translate the evidence selected to support the analysis before the findings were ready to be published in an English language journal.

The Translation Procedure

The next section will use a worked example to explain how to translate the data, including translation in the process of coding, translation in the process of team discussion, translation in the process of advanced coding, and ensuring the accuracy of translation.

Translation in the process of coding. In phase one, the translator-moderator (who is the Indonesian researcher) translated five interviews into English. The translation was checked by a colleague - an Indonesian who has an International English Language Testing System (IELTS) score of 6.5, a rating described as competent to good command of English (International Development Program, 2013). The translated interviews were coded in English by the primary researcher. The principal supervisor checked the coding for intellectual rigor, discussed the results of initial coding, and guided the translator moderator about how to move forward with both theoretical sampling and intermediate coding.

During the second field trip, the primary researcher conducted 41 interviews. The team encountered problems managing this quantity of transcribed data using the original process of translation and checking, which was very time consuming. The time involved in this lengthy

process made it difficult to check and translate the data before the third phase began in May 2012. During a 38-day period from the end of January to March 8, 2012, the primary researcher could only finish 19 transcripts and translate those 19 transcripts into English. Time restraints meant these translations could not be checked by a colleague before the translator-moderator started the initial coding. The results of the initial coding of these 19 transcripts were used as the basis for research team discussions (in English) regarding the analysis. It was important to have the initial coding done because, in grounded theory methodology, conclusions cannot be drawn if the coded data cannot be properly compared, and to make sure no new categories have emerged.

The members of the research team discussed ways to solve this problem of slow translation, checking and coding. It was decided that the translator moderator needed to go back to the original data for those 19 transcripts and do the coding again in the original language - Indonesian. The result of this coding process was compared with the results of coding the 19 transcripts in English to examine whether the coding outcomes had been affected by translation. To further test this point, the translator moderator recoded the first five transcripts from the initial data collection phase in the original language and compared the results with the previous coding in English. It was considered important that the same process was followed during the first two phases.

These activities provided useful information to the research team about how to code effectively across languages. Coding in the original language was easier, quicker and tidier than coding done in the translated form. For example, when coding the translated English-language version, there were codes that were considered to be too difficult to categorize. Using Indonesian, all codes could be categorized and there were no 'loose ends' (See Table 1).

Table 1. The result of initial coding using English and Indonesian for the first data collection

The result of initial coding using English translation	The result of coding using original language
Connection	Keluarga (Family)

Community setting = service for patient in community	Perawat (Nurse)
Community setting = family expectation	Pasien (Patient)
Community setting = goal patient after discharge	Hubungan rumah sakit dan komunitas
Community setting = patient problem in community	(Connection between hospital and
Hospital setting = activity before patient is discharge	community)
Hospital setting = daily activity in hospital	Komunitas (Community)
Hospital setting = patient admitted to hospital	Rumah sakit (Hospital)
Patient movement	
Medicine is important	
Uncategorized – patient’s health insurance	
Uncategorized	
Uncategorized – relapse	

The results of coding differed slightly between languages. This was true in the first stage, using five transcripts, and in the second stage, using 19 transcripts. This finding is contrary to that of Chen and Boore (2009) who conducted coded analysis using English and Chinese and obtained a similar result in both languages. The different characteristics of each language – Chinese and Indonesian - may have influenced this result.

Coding in the original language was faster and more accurate than coding the translated data. Fenna at al. (2010) advocated the use of the original language for as long as possible to avoid the potential of limiting the quality of the analysis. The researcher found during this experience that the abstract thinking, required as part of the abductive logic applied in grounded theory data analysis, is less complicated in the original language. A researcher trying to engage in complex, abstract thinking in a language other than their first language may be distracted from important findings in the data because they are trying to understand the finer points of language. The research team decided the translator moderator would use her original language for initial, intermediate and advanced coding in the process of analyzing all data after considering the results from both forms of coding.

Translation in the process of team discussion. The results of initial and intermediate coding guided research team discussions. The aim of this discussion was to develop a grounded theory. The principal supervisor visited research sites in community and hospital settings

resulting in an enhanced theoretical sensitivity for cultural differences. This understanding of cultural aspects of mental health service delivery in Indonesia led to a higher level of conceptual analysis.

During team discussions, different analytical methods were utilized. These methods included diagramming, choosing the most appropriate code, using a dictionary and using a thesaurus. Word choices made by researchers who were not fluent in the participant's language were discussed with the translator moderator to find the closest meaning in English. This process allowed researchers to share meaning making about high level conceptual analysis and also to share understanding of two different cultures. The translator moderator provided the necessary translation and explained each category in-depth as it was constructed. The translator moderator also checked memos related to data analysis and included these memos in discussion. Memo translation was conducted orally.

The translator moderator (who was also the primary researcher) discussed the developing analysis on a weekly basis with the principal advisor. Each discussion was based on the oral translations. In this process, the primary researcher used fluid descriptions of meanings, drawing on various English formulations while checking these against the original transcriptions of interview data to ensure accuracy (Fenna et al., 2010). This approach was supported by Temple (2002) who emphasized that the focus of translation should not be wholly-concentrated on 'precise' word choice because translation, in this sense, is about recreating meaning rather than revealing it (Croot et al., 2011; Temple & Young, 2004). Discussion can be used as a procedural tool for achieving conceptual equivalence because these oral translations aid understanding. Furthermore, discussion can be considered to be a process of decentering, especially when it is found that some phrases cannot be translated accurately into the target language because of differences in culture and language (Su & Parham, 2002).

An outcome of these early discussions was the identification of a possible core category, which was then tested and verified during subsequent field trips. During intermediate coding, the research team identified a gap in the data so theoretical sampling was directed based on this process of analysis. The research team decided it was not necessary to employ a professional

translator during the process of developing the conceptual complexity and abstraction of both the intermediate and advanced coding phases of the study.

The activities in advanced coding were started by sorting memos and field notes. Memos were written in English, Indonesian or a mix of both. The primary researcher worked on this activity. Memos help to identify relationships and unifying concepts not previously evident (Corbin & Strauss, 2008). Memo sorting was carried out in conjunction with the discussion process. Research team members regularly drew diagrams to illustrate possible models of the theory to examine how the established categories might fit together. In this study some 31 diagrams were drawn during research team discussions between August 2012 and March 2013.

Translation in the process of advanced coding. The next activity in advanced coding was writing a storyline. The primary researcher provided the storyline in English so the other team members could read it. There are several ways one might approach writing the storyline. The storyline is considered to be a form of 'free writing' (Birks & Mills, 2011). Data is not put in at this stage as this helps to ensure the flow of writing. Free writing can be understood as a writing process in which the writer does not need to worry about grammar or rules or 'good writing'. This process, however, can be difficult for researchers who endeavor to write the storyline in a language other than their own. In this study, the translator moderator had two alternatives from which to choose: write the storyline in her own language and translate later or write the storyline in English without worrying too much about language conventions. The important priority was for the researcher moderator to write freely without any problem finding the words to express the story.

In this study, the translator moderator wrote the storyline in English – her second language – but could write the storyline easily because of her familiarity with the raw data. The original storyline was not written in grammatically-correct English. The researcher moderator distributed this 'free-flowing' storyline to the research team who worked with her to develop and refine the grounded theory. The principal advisor (who had visited the research site and participated in all stages of the analysis) was very familiar with the data and, therefore, understood the storyline in this raw format. The researcher moderator used memos to develop

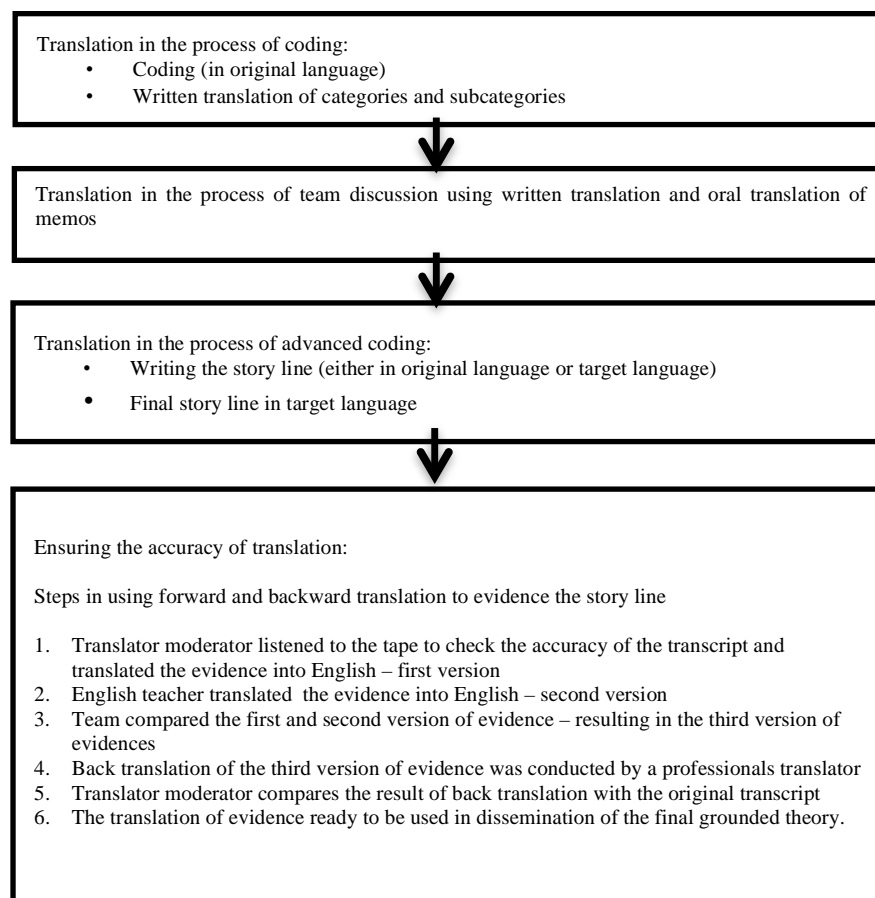
her reflexivity in the process of writing the storyline. Writing memos is an important grounded theory tool that provides a written record of reflexivity. Reflexivity is considered to be an active process in developing insight. The researcher writes about her actions, feelings, influences and thinking, and incorporates these factors into analysis by considering their impact on the data and the theory (Birks & Mills, 2011). Another of the translator moderator's responsibilities was to check whether the storyline was grounded in the data or not. Evidencing the storyline is a very important step in validating a grounded theory. All researchers discussed the storyline weekly for several months. From 8 September 2012 to 8 February 2013 there were 46 versions of the storyline discussed before all members of the research team agreed on the final grounded theory.

Two versions of translated data were used to evidence the storyline during the process described above. The first version was a partial translation of data fragments translated by the translator moderator in response to the developing storyline. These partial translations were discussed with the research team to ensure evidence matched the theory. During this process, several examples of evidence were replaced with alternatives because the research team as a whole considered the alternative examples to more strongly support the theory. During the process of translating these data fragments, the translator-moderator again listened to the tapes to check the accuracy of the original transcription in Indonesian before translating the comments into English. The translator moderator inserted the chosen evidence into the storyline after the last version of the storyline was agreed upon.

Ensuring the accuracy of translation. Forward and backward translation is conducted to ensure the accuracy of the translation process. In this study, the translator moderator's version was subjected to a comparative second translation of the final data fragments. An Indonesian English teacher conducted this comparative translation. The translator-moderator and other team members then compared the first and second versions of translated evidence to check accuracy and meaning. The translator moderator modified her version of translated evidence to improve clarity and understanding. This modification was called the third version of evidence.

At this point, a professional translator back translated the third version of evidence into Indonesian. The back translator did not have access to the original source version before conducting the back translation in accordance with recommendations by Su & Parham (2002). The principal researcher compared the end result of the back translation with the original translator moderator transcription to ensure an accurate representation of participants' meaning in the evidenced grounded theory. Comparison between original and back translated versions is necessary (Maneesriwongul & Dixon, 2004; Su & Parham, 2002). If the two versions are not identical, the back translation process is repeated iteratively until no discrepancies in meaning are found (Su & Parham, 2002). Back translation can be repeated until the researchers are satisfied with the equivalence between source and target languages (Jones & Kay, 1992). The procedure of translation is illustrated in Figure 1.

Figure 1: Translation procedure



CONCLUSION

The process of translation can be a problem area for researchers conducting qualitative studies in languages other than English who intend to publish in English language journals. This article has identified issues experienced during a research project in which the research team consisted of individuals from different language backgrounds – Indonesian and English. The translation procedure outlined in this article was developed from the experience of the research team and includes important advice about when, who and how to translate data in the process of grounded theory analysis. The procedures will assist researchers who are conducting grounded theory studies to maintain the integrity of their data and their findings during the translation process. The authors recommend that following the translation procedure outlined in this article will ensure the quality of findings.

REFERENCES

- American Translators Association (2008). Minimum qualifications for translator certification. Retrieved 24 April, 2013, from <http://www.atanet.org/certification/index.php>
- Adamson, J. & Donovan, J. L. (2002). Research in black and white. *Qualitative Health Research, 12*(6), 816-825.
- Birbili, M. (2000). Translating from one language to another. Retrieved 6 March 2013, from <http://www.soc.surrey.ac.uk/sru/SRU31.html>
- Birks, M. & Mills, J. (2011). *Grounded theory a practical guide*. London: Sage.
- Bradby, H. (2002). Translating Culture and Language: A research Note on Multilingual settings. *Sociology of Health & Illness, 24*(6), 842-855.
- Brislin, R. W. (1970). Back-translation for cross-cultural research. *Journal of cross-cultural psychology, 1*(3), 185.
- Brislin, R. W, Lonner, R. & Thorndike, R. (1973). *Cross-cultural research methods*. New York: Wiley.
- Bryant, A. & Charmaz, K. (2007). *The Sage handbook of grounded theory*. London: Sage.
- Buhler, A. (2002). Translation as interpretation in A. R. (Ed), *Translation studies: Perspectives on an emerging discipline* (pp. 56-74). Cambridge, UK: Cambridge University Press.
- Charmaz, K. (2006). *Constructing grounded theory: A practical guide through qualitative analysis*. London and Thousand Oaks: Sage.
- Chen, H.Y. & Boore, J. R. P. (2009). Translation and back-translation in qualitative nursing research: Methodological review. *Journal of Clinical Nursing, 19*(1-2), 234-239. doi: <http://dx.doi.org/10.1111/j.1365-2702.2009.02896.x>
- Corbin, J. M. & Strauss, A. L. (2008). *Basics of qualitative research: Techniques and procedure for developing grounded theory* Los Angeles: Sage.
- Croot, E. J., Lees, J. & Grant, G. (2011). Evaluating standards in cross-language research: A critique of Squires' criteria. *International Journal of Nursing Studies, 48*(8), 1002-1011. doi: 10.1016/j.ijnurstu.2011.04.007

- Edwards, R. (1998). A critical examination of the use of interpreters in the qualitative research process. *Journal of Ethnic and Migration Studies*, 24(2), 197-208.
- Esposito, N. (2001). From meaning to meaning: the influence of translation techniques on non-English focus group research. *Qualitative Health Research*, 11(4), 586-579.
- Fenna, V. N, Tineke, A., Hans, J. & Dorly, D. (2010). Language differences in qualitative research: is meaning lost in translation? *European Journal of Ageing*, 7, 313-316.
- Frederickson, K., Acuna, V. R. & Whetsell, M. (2005). Cross-cultural analysis for conceptual understanding: English and Spanish perspective. *Nursing Science Quarterly*, 18(4), 286-292.
- Glaser, B. & Strauss, A. L. (1967). *The discovery of grounded theory: Strategies for qualitative research*. New York: Aldine.
- Glaser, B. G. (1978). *Theoretical sensitivity: Advances in the methodology of grounded theory*. Mill Valley: Sociology Press.
- Hunt, S., M. & Bhopal, R. (Cartographer). (2004). Self report in clinical and epidemiological studies with non-English speakers: the challenge of language and culture. Retrieved from <http://jech.bmjournals.com/cgi/content/full/58/7/618>
- Jones, E. G. & Kay, M. (1992). Instrumentation in cross-cultural in cross-cultural research. *Nursing Research*, 41, 186-188.
- Josephine, P. H. & Maurice, K. P. (2010). Bringing translation out of the shadows: translation as an issue of methodological significance in cross-cultural qualitative research. *Journal of Transcultural Nursing*, 21(2), 151.
- Larkin, P. J., de Casterlé, B. D. & Schotsmans, P. (2007). Multilingual translation issues in qualitative research: reflections on a metaphorical process. *Qualitative Health Research*, 17(4), 468-476.
- Larson, M. I. (1988). *Meaning-Based translation: A Guide to Cross-Language Equivalence*. New York, NY: University Press of America.
- Maneesriwongul, W. & Dixon, J. K. (2004). Instrument translation process: a methods review. *Journal of Counseling Psychology*, 48(2), 175-186.

- Polkinghorne, D. (2005). Language and meaning: data collection in qualitative research. *Journal of Counseling Psychology, 52*(2), 137-145.
- Schultz, A. A. (2004). Role of research in reconstructing global healthcare for the 21st century. *Nursing Administration Quarterly, 28*(2), 133-143.
- Sechrest, L. Fay, T. L. & Zaidi, S. M H. (1972). Problems of translation in cross-cultural research. *Journal of cross-cultural psychology, 3*(1), 41.
- Smith, H. J, Chen, J. & Liu, X. (2008). language and rigour in qualitative research: Problems and principles in analyzing data collected in Mandarin. *BMC Medical Research Methodology, 8*, 44.
- Squires, A. (2008). Language barriers and qualitative nursing research: methodological considerations. *International Nursing Review, 55*(3), 265-273. doi: 10.1111/j.1466-7657.2008.00652.x
- Squires, A. (2009). Methodological challenges in cross-language qualitative research: A research review. *International Journal of Nursing Studies, 46*(2), 277-287.
- Strauss, A. L. & Corbin, J. M. (1990). *Basics of qualitative research: Grounded theory procedures and techniques*. Newbury Park, CA: Sage.
- Su, C.T. & Parham, L. D. (2002). Generating a valid questionnaire translation for cross-cultural use. *American Journal of Occupational Therapy*.
- Suh, E. E., Kagan, S. & Strumpf, N. (2009). Cultural competence in qualitative interview methods with Asian immigrants. *Journal of Transcultural Nursing, 20*(2), 194-201. doi: <http://dx.doi.org/10.1177/1043659608330059>
- Svetlana, S. (2007). Double vision uncertainty: the bilingual researcher and the ethics of cross-language research. *Qualitative health research, 17*(4), 529.
- Temple, B. (1997). Watch your tongue: issues in translation and cross cultural research. *Sociology, 31*, 607-818.
- Temple, B. (2002). Crossed wires: interpreters, translators and bilingual workers in cross-language research. *Qualitative health research, 12*(6), 844.

- Temple, B. (2005). Nice and tidy: Translation and interpretation. *10* (2). Retrieved from Sociological Research Online website: <http://www.socresonline.org.uk/10/2/temple.html>
- Temple, B. & Young, A. (2004). Qualitative research and translation dilemmas. *Qualitative Research*, 4(2), 161-178. doi: <http://dx.doi.org/10.1177/1468794104044430>
- Tsai, J. H. C. Choe, J. H., Lim, J. M. C., Acorda, E., Chan, N. L. & Taylor, E. (2004). Developing culturally competent health knowledge: Issues of data analysis of cross-cultural, cross language qualitative research. *International Journal of Qualitative Methods*, 3(4), Article 2.
- Twinn, S. (1997). An exploratory study examining the influence of translation on the validity and reliability of qualitative data in nursing. *Journal of Advanced Nursing*, 26, 418-423.
- Twinn, S. (1998). An analysis of the effectiveness of focus groups as a method of qualitative data collection with Chinese populations in nursing research. *Journal of Advanced Nursing*, 26, 418-423.
- Werner, O. & Campbell, D. T. (1970). Translation, wording through interpreters, and the problem of decentering. In R. Naroll & R. Cohen (Eds.), *A handbook of method in cultural anthropology* (pp. 398-420). New York: Natural History Press.

Chapter summary

This chapter described the philosophical and methodological underpinning of this study: symbolic interactionism and grounded theory. Grounded theory methods were identified and explained. The study sample and the scope of the data set were outlined and the process for gaining ethics approval was described. The application of grounded theory methods in this study was discussed using the three field trips as an organising framework. The place of translation in a grounded theory study conducted in a language other than English was presented in a manuscript for publication. Chapter four provides an overview of the grounded theory ‘Connecting care for individuals living with a mental health issue in Indonesia’ then expands the theory with greater detail. A glossary of key terms is provided. After this, each of the three categories: decision making, shifting responsibility and accepting responsibility are explained in full with supporting evidence. The chapter concludes with an examination of the relationship between the four sub-categories.

CHAPTER FOUR: FINDINGS

Introduction

This chapter begins with an overview of the grounded theory of connecting care. The overview includes a theoretical model, explanation and a glossary of the terms used. A more detailed presentation of the findings will be provided with accompanying evidence under four headings: decision-making, shifting responsibility, accepting responsibility and relationships between subcategories.

Connecting care was identified as the core category of this grounded theory study. The theory of connecting care can be applied to both health professionals and non-health professional stakeholders who provide care to individuals living with a mental health issue in Indonesia. The core category 'connecting care' subsumes three categories: 'decision-making', 'accepting responsibility' and 'shifting responsibility'.

Overview of the theory of connecting care

Decision-making

Decision-making is a cognitive process used by stakeholders to respond to an individual's health status. The primary stakeholder will initiate the process of decision-making and their decisions will in turn influence other stakeholders' decision-making processes. Four types of factors influence stakeholders' decision-making: competency, resources, policy and willingness. Stakeholders may then communicate with each other about their decisions and possibly negotiate about the kind of responsibility required for the provision of care. Negotiations do not always happen; each stakeholder still makes decisions as a response to the individuals' health status. Responsibility is shifted among stakeholders whether the decisions are matched or unmatched. Matched and unmatched decision-making are sub categories of decision-making.

Shifting responsibility

Shifting responsibility consists of two activities: coordinating prospective care and physically transferring people. Shifting responsibility occurs whether decision-making is matched or unmatched. Coordinating prospective care is an activity in which the stakeholders organise time and people to be involved in the process of physical transferring someone and/or getting ready to providing care. Physical transfer is an activity in which the stakeholders literally transfer an individual from one place and carer to another place or carer. The effectiveness of shifting responsibility is influenced heavily by the communication between stakeholders. A lack of quantity and/or quality of communication influences the process of shifting responsibility and the outcomes of the shift.

Accepting responsibility

Accepting responsibility occurs when the individual's health status changes from well to unwell (or vice versa). This acceptance is dependent on stakeholders' levels of competence, resources and willingness to provide care. Accepting responsibility to provide care for an individual living with mental health issues consists of several activities and includes the following: coordinating care, promoting health, maintaining life, supporting and counselling. The types of activities differ between health professionals and non-health professionals. Generally, health professionals have more responsibility than non-health professionals to provide care when individuals are unwell. On the other hand, non-health professionals will have more responsibility for individuals who are becoming well. This ideal scenario, however, does not always occur. The manner in which stakeholders accept responsibility to provide care can be either forced or unforced and these are subcategories of accepting responsibility. Each of these dimensions of acceptance results in different outcomes for all parties.

Forced acceptance to provide care occurs when stakeholders are made to take responsibility even though they do not want to provide care or do not think they should provide care. Forced acceptance to provide care is characterised by low levels of stakeholder competence, resources and willingness. Such a context usually results in adverse outcomes for individuals living with a mental health issue. Forced acceptance is a result of unmatched

decision-making among stakeholders. Unforced acceptance – a situation in which all stakeholders agree on who should provide care and how - is a result of matched decision-making among stakeholders. This path will often lead to an optimal outcome for the individual living with a mental health issue. A model of the grounded theory of connecting care is presented in figure 4.1.

The Theory of Connecting Care

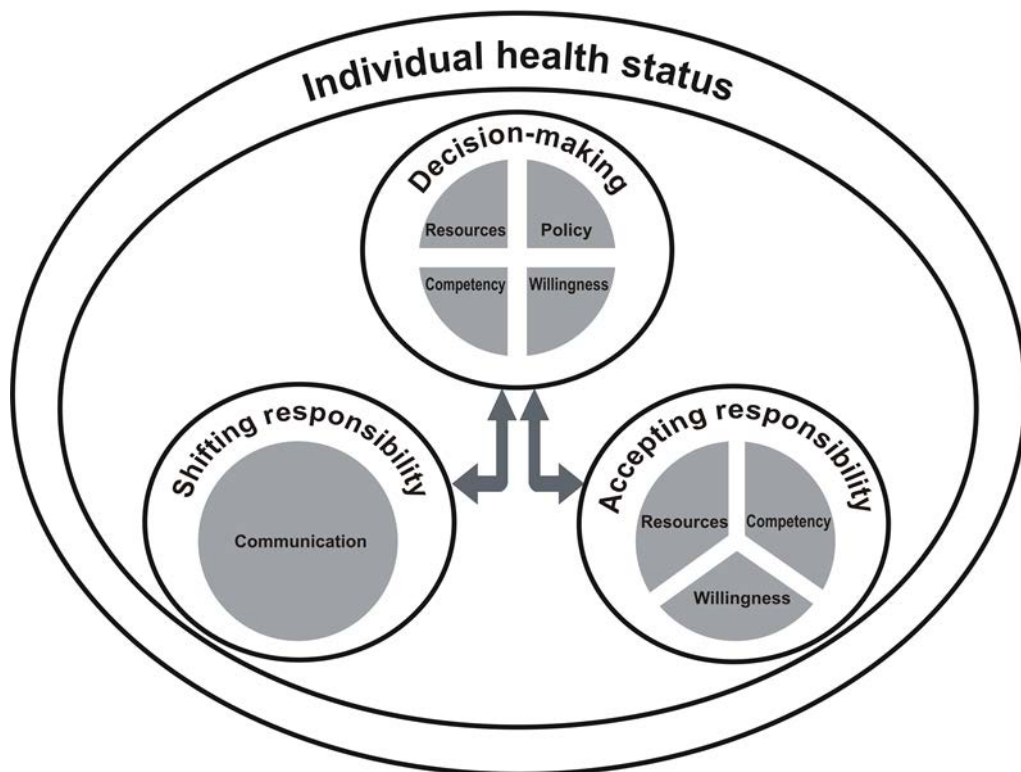


Figure 4.1 The Theory of Connecting Care

In this model, the three categories of connecting care are situated in a circle representing the condition under which this theory operates: the individual's health status. Decision-making as the pre-eminent category is positioned at the top of the model. Within the circle of decision-making are the four properties that influence individual stakeholders to different degrees: resources, competency, willingness and policy. The arrows leading from the decision-making circle indicate the two possible outcomes. Stakeholders will either shift responsibility to provide

care or accept responsibility to provide care after considering an individual’s health status. Shifting responsibility is influenced largely by the quality of communication between stakeholders, while accepting responsibility requires an alignment of need and care provision.

Table 4.1
Glossary of Terms for the Theory of Connecting Care

Terms	Definition
Accepting responsibility	Accepting the responsibility to provide care for individuals living with mental health issues.
Competency	Stakeholders ability to provide care
Communication	Verbal or non-verbal exchange of information among stakeholders in order to send messages
Decision-making	A cognitive process whereby one stakeholder selects either to accept responsibility or to shift responsibility to another person or organisation to provide care.
Individual health status	A range of individual physical and psychological conditions that cover unwell to well.
Policy	All regulations designed by an organisation or institution
Resources	The assets upon which a stakeholder can draw to perform a role
Shifting responsibility	The act of transferring an individual (physically) or transferring information to other stakeholders for them to accept responsibility to provide care for an individual living with mental health issues
Stakeholder	A person who is involved in the process of connecting care. Can be divided into two types: health professionals and non-health professionals
Willingness	The state of being ready to do something

Findings

Findings supporting the theory of connecting care will be presented under four subheadings: decision-making, accepting responsibility, shifting responsibility, and relationship between the subcategories. The category of decision-making will be explained first. The second category of shifting responsibility will illustrate the way communication occurs among stakeholders. Accepting responsibility is the third category. Finally, relationships between

subcategories will be explained with a particular focus on the resultant adverse health outcomes for mentally-ill individuals, like an increased risk of human rights violations and an increase in the burden of care. In this findings section, evidence will be provided in English (translation form). The original language data can be found in *Appendix N*.

Decision-making

Decision-making is a cognitive process. Stakeholders including health professionals and non-health professionals make decisions in response to changes in an individual's health status between well and unwell. Four properties that influence stakeholders' decision-making are: their level of willingness, competency, available resources and compliance with policy. The consideration of these properties by different stakeholders ranges from low to high levels. Decision-making that includes more than one stakeholder can be matched or unmatched with unmatched decision-making resulting in adverse health outcomes for individuals living with a mental health issue.

The logic of appropriateness (March, 1994) is employed when health professionals make decisions. This group prioritised rule-following when making a decision which means health professionals generally obeyed institutional policy and did their duty as professionals. For health professionals the interactions between their levels of willingness, competency, available resources and compliance with policy influenced their decision-making. Compliance with policy is most influential. Institutional policies in psychiatric hospitals dictated to health professionals the type of care that could be provided, the criteria of care that individuals are entitled to receive, and when and where to transfer individuals. Regardless of a health professional's willingness and competence to provide care, resources and hospital policy dominated the decision-making process for health professionals.

For example, although resources are available for extended hospital admissions, hospital policy may state that individuals must be discharged (sometimes through a dropping-off program) after a maximum of three months in the hospital regardless of the individual's condition

... if, for example, for patient with Social Security for Community [type of health insurance scheme] that the maximum treatment is three months... we, if during two months [individual who has a better health status] has not been picked up ... then we have to register [individual] first [for] dropping-off [program]... (26T).

From the health professionals' perspective, resources are also considered to be a very important factor in making decisions to accept or shift responsibility to provide care. Policy also influences the availability of resources and, as a consequence, affects their ability to negotiate a matched decision with families who carry the financial responsibility for professional care provision

The Indonesian [government] has launched a program namely Indonesia Free from Pasung [Shackle] 2014, but what is the contribution of the Regulation of the Minister Health Affairs to this?, what steps have been done? There is no clarity ... If people are shackled, take them to a psychiatric hospital, or a hospital that has facilities [to handle such problem]. However, such a program won't be sustained if we don't have ... If we don't have the ability to take care of these patients, it won't work ... shackle is actually the easiest way usually done by the community. Although shackled people often get rampage [by being shackled], they can't do anything including killing. Meanwhile, once they are going to be taken to a hospital, there is no access while the access to Jamkesmas [Social Security for Community] is not led to... Such a policy [program] exists once a Program namely Free-of-Charge Medication for Pasung [Shackle] has been launched. These policies are not supportive ... (42T).

There is some variation in the data concerning health professionals. Some health professionals working in public shelters report that they often 'bend the rules' for affected individuals because of humane or social considerations "Because of humanity and social consideration [we accept them to be cared here], ... there is a poor family, sometimes in one house there are two or three [members of family] who are being [mentally] sick like this, ...so pitiful" (48T). For health professionals who work in private shelters, their level of willingness to accept responsibility often outweighed institutional policy in the decision-making process. The intention of these health professionals was to help the entire family, rather than to assist simply with the recovery of an individual with a mental health issue. In Indonesia, individuals who are referred to private shelters mostly have chronic conditions with a poor prognosis. Private shelters are considered therefore to be the last resort for an individual when their family has no hope for their relative's recovery and are not willing to care for them at home. Health professionals who work in private shelters, however, are also very aware of their level of

competence and resist providing care outside of their scope of practice which can result in a decision to shift responsibility to provide care

There is [individual who stays here in the shelter] until 20 years,... he/she is physically being sick, until he was what, what is called hepatitis, renal hepatica, the renal too, as well as hepatitis, [in] the morning [his body] swell all, so ... [we go] to general hospital ..., we cannot we cannot [handle the individual] (47T).

Health professionals who work in Primary Health Care Centres (PHCC) are very conscious of their level of competence and the availability of resources when making a decision to provide care. If they do not possess high enough levels of competence or resources (e.g. lack of specific medications) they will decide to shift responsibility by making a hospital referral. “Then yes, if [we] can handle [individual] here [in PHCC] yes we handle [him/her], if [we] cannot [handle the individual], usually [individual] is referred...” (29T).

Non-health professionals, on the other hand, used rational choice (March, 1994) to justify their decisions. This approach is characterised by personal preference when considering the consequences (March, 1994) of a decision. The non-health professionals’ preference is based mainly on their own concerns and does not necessarily take into account what individuals living with mental health issues want or need. For families in particular, this type of decision-making can be viewed as a form of coping when the individual becomes so unwell that it affects the whole family’s well-being.

For non-health professionals, like family members, deciding not to accept responsibility to provide care at home is strongly influenced by a perceived inability to provide adequate levels of care. The data illustrates how one father’s perceived low level of competence and willingness influenced decision-making about his son’s care

The family [said that] ... basically, Sir, I’m no longer willing to accept my son anymore ... I can’t, Sir, I am old ... what I’m saying is even though he is taken here [discharged from the hospital] ... my son, that is, I’m positive [I] can’t manage it ... it is up to the hospital [staff] what they need to do [with my son] ... (15T).

In another case, stigma influenced a family’s decision not to shift responsibility. This family reported feeling ashamed and reluctant to report to health professionals; they denied that any help was needed “... Yes, one or two [patients] were hidden by family, sometimes they feel

ashamed having family like that [having mental disorders] ... usually [patient] is hidden, when we asked questions, they undisclosed [information]” (39T).

Cadres and community leaders reported that they took into account their own competence to provide assistance when making decisions to shift or accept responsibility to provide care. Most of cadres compared their competence and available resources to the individual’s level of need, distress and illness.

... well, we can still deal with those [individuals] who are agitated and talking to themselves, we try to counsel them according to their religion, ... by calming them down, by getting them closer to God, ... Also, well, for example if he [the individuals] get embarrassed, ... then they lock themselves in their rooms, I report those cases, ... because it’s better handled by the doctors ... because it is very difficult [for me to deal with] (41T).

For both health professionals and non-health professionals’ decisions can be reached through a process of consensus resulting in matched decision-making. Matched decision-making ends with one stakeholder agreeing to provide care. In matched decisions there is a good fit between the needs of the individual living with a mental health issue and the stakeholder’s levels of competence, resources and willingness to provide care that often leads to optimal health outcomes.

Discord between stakeholders often leads to unmatched decision-making. Unmatched decision-making occurs when stakeholders have made different assessments of the individual’s health status and associated needs, resulting in conflicting ideas about who should accept the responsibility to provide care. Matched and unmatched decision-making have strong relationships with the subcategory, accepting responsibility (forced or unforced), this will be explained in detail in the section ‘relationship between subcategories’.

Shifting Responsibility

Shifting responsibility is the act of transferring an individual (physically) or transferring information about that individual to other stakeholders who will then accept responsibility to provide care for that individual living with a mental health issue. The major characteristic of shifting responsibility is communication, which can be effective to ineffective. Effective

communication facilitates the smooth movement of a mentally-ill individual from one person, place or organisation to another for better care.

For health professionals, effective communication about discharge, however, rarely occurs unless hospital staff are familiar with personnel working in the PHCC "... if I have I have a good relationship with the nurses [in PHCC] then I will contact [them]" (7T). Ineffective communication is more common in unmatched decision-making, resulting in non-health professionals resisting contact from health professionals. Resisting communication can include discharge letters being 'returned to sender' as the individuals' relatives have moved without informing health professionals of their new address. Family members might also ignore telephone calls and Short Message Service (SMS) contact "... But there was a letter that we sent, but [it] was undelivered, the letter was returned here [psychiatric hospital] because the public used a fake address" (15T).

Physical transfer occurs between healthcare service sites (hospital, community health centre, private/public shelter), home and sometimes the street. Social Service Department staff members shift responsibility by physically transferring wandering, unwell, or homeless people from the street to a psychiatric hospital or private shelter when there are no family members to accept responsibility

[Individual who was found in the sweeping-up program] who were being mentally sick will be referred [for social worker, the term 'referred' means physically transferred] to hospital first, after [individual has get better] it is done from hospital, [individual] will be referred again to Social Service Department (44T).

The second type of shifting responsibility occurs when carers provide specific information in the form of referrals and health education to individuals and their carers

Err, for the health professional yes [to] provide education [for family] how to look after [individual] at home, ... the sign when he/she experience frequent [or more symptoms] what has to be done ..., how about the medicine, for observing [individual] taking medicine, then for the [individual daily] activity [in which family] observe and [to] guide [individual], ... usually that the family are involved for that observation and guidance (3T).

Providing information in the form of referral lets other health professionals or stakeholders know that someone needs to transfer physically an individual from their current

place of care to another. “Err, usually if for example the patient has been decided to be discharged [by psychiatrist], we will contact the family first, so we contact [them] usually through telephone or SMS ...” (3T). For non-health professionals, communication between family members and other stakeholders is important in the process of shifting responsibility

Well, when I took [my wife] at that time it was at night, and [she] was running amok, so ... [I] asked a neighbour to help find a car, so we put [her] into the car [to be taken to the hospital] (35T).

Community leaders sometimes become involved when individuals in their communities become unwell. The leaders hold a position of authority in the village and they shift responsibility by communicating with other stakeholders to enable the transfer of an unwell individual to a psychiatric hospital.

... and after [the individual] was caught by the police, the police contacted the village headwoman, then she contacted me [the nurse], ... and then I tried and contacted their family ... along with the community leaders. [All stakeholders] came to an agreement [so] we took [the individual] to [the psychiatric hospital] (40T).

Accepting responsibility

The third category of connecting care is accepting responsibility for the provision of care (as opposed to shifting responsibility). Three properties influence health professionals to accept responsibility to provide care: their level of willingness, competency and the availability of resources. Accepting responsibility to provide care can be forced or unforced. The form of accepting responsibility has a direct impact on the quality of care provided to the individual living with a mental health issue. Accepting responsibility to provide care for an individual living with mental health issues includes the following: maintaining life, coordinating care, promoting health, support and counselling.

Health professionals are strongly influenced by the availability of resources when they make decisions about the provision of care. For example, minimal allocation of resources to public shelters influences the number of individuals with a mental health issue who can receive rehabilitation services “With the current condition in [name of the city], where over a thousand [individuals] suffering from [mentally ill] ex-psychosis, and only fifty [individuals] can be accommodated ..., it clearly means that our quota is very small” (48T).

Non-health professionals will have first assessed their own levels of competency, resources and willingness and found these to be adequate for the task before accepting responsibility. If a family accepts responsibility to provide care their duties may include monitoring, supporting, facilitating meaningful activity for the person in their care and helping to ensure that medicine is taken “... see, every time I make coffee [she] often asks [for my coffee], so I pour half a glass of coffee, add sugar, and put the medicine [in the coffee] ...” (35T).

For family members, support can include visiting individuals who are receiving care in psychiatric institutions. Family members, however, sometimes have low willingness to do this because of the stigma of going to the psychiatric institution. This outcome influences their willingness as described by a social worker:

... there are many of the families [who experience] [social] stigma, [and] think that having [a member of] their family [who is ill] ...is very humiliating, like that, so sometimes it is difficult to cooperate with the family, for we want that in the process of recovery there is a good cooperation ... so they [the family] could at least come here to visit but the reality is that sometimes the family don't visit [the individual] in two or three months (48T).

A family's willingness to provide care is also influenced by their previous experiences, which in can be frightening, as described by a nurse:

The family's the one who doesn't care, ... it has been three months since [the individual was] last visited ... because the family is afraid ... once I called [the family] [because the individual] had not been picked up for three months, ... the family [felt] traumatized by having the patient home, since s/he [the individual – the patient] wanted to kill, like that, wanted to kill her/his sibling, so there was [a feeling of] fear ... (25T).

Caring for an individual living with a mental health issue can be an exhausting activity. Family members can feel that they are not able to care for the person due to their level of competence and are therefore unwilling to accept responsibility for their care upon discharge from hospital. “Well, the truth is the family wants to take a break ... want to stop giving treatment [to the individuals], that is why [the individual] is put in here, so that [the individual] will receive treatments here ... usually that is the case, ...” (1T).

Lack of resources will influence whether or not individuals will receive appropriate treatment.

If [individual with mental health problems] treated at Primary Health Centre or X [the name of psychiatric hospital] has Social Security for Community [health insurance for poor people] will not experience obstacles, but those who are poor and do not have Social Security for Community often encounter problems because they have to pay the cost of medication and hospitalization to X [name of hospital]. Well, such person is categorised poor (41T).

In other circumstances a family may have a low level of competence but a high level of willingness to care for relatives at home. If an individual living with a mental health issue is very unwell, the family's decision to accept responsibility sometimes results in patients receiving very basic care, sufficient only to sustain life. In some instances inappropriate care may involve shackling

... there is a person who has been put in the shackle for five months....his parent had already run out of money to treat their son, and they also did not have the Jamkesmas card [Social Security for Community card] or any JPKM [name of health insurance]. Eventually, the only solution at that time was continuing to put the person in the shackle (34T).

Accepting responsibility to provide care with low levels of competence results in the family feeling exhausted and experiencing a heavy burden of care due to long-term care giving activity. For one participant, her experience of caring for her husband led to a situation where she was being persecuted

It is so hard [caring] for my husband..... Once he gets tired, he often relapses and will be messed up with our neighbours.... He usually gets angry, damages things, ... throws roof tiles, and even endangers people around. He also likes to hit me.... when he gets tired (33T).

The impact of an individual's behaviour can extend further than their spouse. One nurse tells how "[the individual] has twice strangled his own parents.... The parents once told me they had just been strangled by their son" (40T). Experiencing a heavy burden of care also led to the family not caring whether the affected individual took their medication regularly or not and ignoring the individual

... yes, after arriving home from X [the name of psychiatric hospital] [the individual] did not receive enough attention from the family, it seems as if the family was tired ... taking care of a son/daughter like that, ... so they ignored [the individual], never paid any attention [including] to the medicine, then I also asked what about the medicine, [the family said] if [they] remembered then the individual took the medicine, otherwise the individual didn't, that's what they [the family] said ... (39T).

In this study, levels of willingness, resources and competence influenced stakeholders' decisions and ability to provide care. In particular, the level of willingness is influenced a stakeholder's hopes for the future. Individuals living with a mental health issue expressed how their hopelessness also impacted on their carer's level of willingness "... the patient themselves, sometimes [feels] desperate, why do I have to take medicine every day, and [the individual] also ask people around them to care" (31T).

Relationship between decision-making and accepting responsibility

Two categories of the theory of connecting care – decision-making and accepting responsibility - have two subcategories. Decision-making subcategories are 'matched' and 'unmatched', and accepting responsibility subcategories are 'forced' and 'unforced'. The two categories and their subcategories influence the process of mental healthcare delivery. Several instances in which nurses described matched decision-making (and how they resulted in unforced provision of care) are presented below. The nurses indicated that when the level of resources, willingness and competence was appropriate, collaborative care was more likely.

... Yes [he was] referred to X [name of a psychiatric hospital], [hospitalised] for three months, and then [when he came home] ... he was a lot better. It was a good thing that his wife was still willing, say, to take care of him and other things. Well, now he raises ducks, goats, and he is considerably healthy, and he takes the medicine regularly, ... and his wife is very proactive, if there's any new symptoms she always sees the psychologist and consults ... still, he is still under continuous supervision, the succeeded one (34T).

... there are patients who only have to take half of the medicine everyday now, he already has goats and raises them, he has also succeeded in raising ducks, ... because of his routine, he is patient and always takes his medicine so... if he can't fetch the medicine, his family members will fetch the medicine [from the Primary Health Care Centre] ... he has an understanding and perseverance ... (31T)

In the following examples the decision to accept care was matched and led to the unforced provision of care because of a high level of willingness and competence. The level of resources, however, were low, and this influenced care provision. One social worker from a public shelter described the impact of a lack of resources.

... well, actually, the supporting facilities for therapy [rehabilitation] ... we are still very lacking in that department, so all this time it has been all about how we get creative, how we.. so there has been nothing, there should have been equipment and

utilities for every activity ..., the vocational [activities], ... what are his/her hobbies, what are his/her needs, what kind of therapy does s/he need, but we don't have such a thing ... (48T).

A similar experience was described by a nurse at a psychiatric hospital:

... sometimes it bores the patient when [they do activities] in the rehab [rehabilitation unit] ... moreover, they have been hospitalised there, [when they go there] at the rehab [rehabilitation unit], the activities are monotonous ... [the patient said] I don't want to, those are the only activities available, Ma'am, I'm bored, ... well, it is normal to be bored, but if [they] don't go to the rehab [rehabilitation unit, then] what will happen? (2T).

Unmatched decision-making that leads to forced care can result in adverse health outcomes, increasing the risk of human rights violations and increasing the burden of care. These poor outcomes are illustrated in the example below. Unmatched decision-making between stakeholders can eventually affect the wider community

... because there was ... [the individual] was already [mentally] troubled, walking around carrying a cleaver, [going] to the mall [a department store], people are scared, but when we went there [to the patient's house] the family shut themselves in, ... [we] couldn't interfere at all, they denied completely the fact that they had a disturbed son, so ... I told them the further symptoms and that once these symptoms appear they should send their son immediately ... to the hospital ... that's the best [we could do] ... [we thought that] the kid had to be referred ... [but] we couldn't because the family completely refused to allow [their son to be referred to psychiatric hospital] (34T).

Sometimes a community will not allow individuals living with a mental health issue to return to their community

... Sometimes there is a kind of rejection from the people to the patient. So, on behalf of the community, they write a letter to resist the arrival of the patient at their neighbourhood because if [individual is being] returned back, the patient will always make troubles in the neighbourhood, so that patient keeps to be denied (13T).

Unmatched decision-making can occur between health professionals and non-health professionals and between health professionals themselves. Unmatched decisions between health professionals and family can mean a family is forced to accept responsibility to provide care when they don't have the necessary level of competence, willingness or resources which can lead to life-limiting outcomes and suicide.

... [I said] Sir, once the [individual's] medicine runs out, please come again [to the Primary Health Care Centre], so some evaluation can be performed, ... [when] the medicine ran out, he refused to go to the Primary Health Care Centre, finally on the 10th

I went [to the individual's house]... yes, so I said, please go to the Primary Health Care Centre tomorrow ... bring your daughter and then [we will] take [the individual] to X [name of a psychiatric hospital]... but the parents wondered why we brought [the individual] to Y [the name of the area the psychiatric hospital is located]..., they [the parents] still quite revolted [that their daughter was being brought to a psychiatric hospital] ... so finally ... although I have told them to please watch over [the individual] for 24 hours a day, and to not leave [the individual] alone ..., well, the family took shifts [in watching over the individual] ... [but] she [still] managed to commit suicide ... [after that] the police asked [information about this case] over here,... there was an audit as well... I was afraid ... [after that] I felt not confidence ... when I want to diagnose (34T).

or the individual does not receive appropriate treatment in the community

... I [nurse] said, ... that [the individual] needs to be immediately treated, and he/she also had a Social Security for Community [the name of the health insurance policy], so we took him/her there [to the hospital] ..., God willing, it ... would get better, at least he/she wouldn't be naked on the streets, ... but well, the father insisted [he said] that it was okay, that later he would sell a piece of land, and he would buy a motorcycle, and he would buy a refrigerator, and he/she would be healed ... (32 T).

An example of unmatched decision-making between health professionals and a family is when a family insists that a relative who has a mental disorder must be discharged from a psychiatric hospital even though that individual still requires to be hospitalised "... forced leave usually [means] that the doctor has not allowed [the patient] to go home, ... but on the family's part, ... they asked [that the individual] be discharged" (20T). In another case, health professionals disagreed about the most appropriate sort of treatment for a individual, resulting in unmatched decision-making between health professionals. In the following example a nurse asked a psychiatrist to adjust a medication schedule to avoid the need to use physical restraint; the psychiatrist refuses to agree. The nurse argued that a reluctance to make this decision led to a 'blame game' between individuals, the psychiatrist and nurses about treatment

... So the problem is when the patients should be restrained but they make a lot of motion. Sometimes they complain to the doctor why wounds on their wrists getting black. Actually, we do have to cope with the emergency first and in this case, unfortunately, the patients cannot be controlled. Usually the doctor also complained when he found the patients' wrists were scuffed after fixation [restraint]. The doctor asked why it happened so I asked him to help the patients by giving [them] injection. Today, a doctor will only use injection only if it has to be. I do not know why, maybe it is because the treatment development which cause much difference, whereas if the patients are assisted by giving them injection, nurses will get much easier in the fixation since in a day, the patient usually can be released [from the restraint]... (14T).

The use of seclusion or physical restraint as a tool for administrative convenience or ward management is considered to be a human rights violation (WHO, 2004). Seclusion should only be used in periods as a form of crisis management or when it is the 'only means available to prevent immediate or imminent harm to the patient or others' (WHO, 2004, p. 32).

The next example shows how unmatched decision-making resulted in forced accepting responsibility (sic) to provide care, leading to individuals wandering on the street. This becomes a burden for the Social Service Department. Social Service Department staff are often seen 'sweeping' individuals living with mental health issues who are wandering the street. They take them to the psychiatric hospital. For example, one individual who was caught in the sweeping-up program was taken to the psychiatric hospital by the Social Service Department staff. After he got better his family address was traced and staff returned him to his family. The unmatched decision-making happened when the family did not want to accept the individual back. On one occasion, a Social Service Department staff member even threatened to call the police if the family did not accept the individual. Although the family finally accepted the individual, the individual was then neglected. He would soon be wandering the street and caught again in the 'sweeping-up' program

Once I went to a particular region [returning patient to his family]. I got there a little late at night [telling the family] if they did not want to accept him [patient], I would call the police. Finally, the family accepted. Well, after getting better, returned to the parents, relapse, then [wandering] on the street again... (46T).

Unmatched decision-making between family members and health professionals also occurs when family members do not allow health professionals working in the local PHCC to transfer an individual whose condition has deteriorated to a hospital where they can receive more intensive care. Even though family members felt a tremendous burden due to the individual's health status deteriorating, they chose to keep the individual at home. The family's attitude in this situation was confusing for health professionals since the family members asked for their assistance to care for the individual. Nevertheless, the family did not agree with the health professional's advice to take the individual to hospital. As a consequence, those who

experienced the burden of care were not only the persons' family but also health professionals whose advice was ignored by the family

A family where one of the members was suffering from a mental disorder once came to me asking for help, the unwell individual was unwilling to work, and he was a staff member of AURI [Air Forces of the Republic of Indonesia]. The household condition was very bad because he refused [to work] and abandoned [his] children... in my opinion, the individual was depressed and already suffering from psychotic symptoms so he should be referred to the psychiatric hospital, but his family members did not know what to do... they [asked me] to help persuade [the individual] to be willing [to be taken to hospital]. I tried to, but [the individual] had no insight. Therefore, I asked a doctor [to see the individual]. [The doctor] said that the individual was psychotic. Then, I have explained it to his family, that he had to be taken by force [to the hospital], but the family insisted not to take him by force to the psychiatric hospital. There was no communication at all between his brother and his family so they just argued over the situation... we came to his house to force him to go to the psychiatric hospital but his brother did not let him be taken by force... I was confused, didn't know what to do. I'd... visited there [the individual] along with doctor X ... three times. We could only suggest referring the individual [to the hospital] because if I had to continuously come over there [the individual's house], it's not possible...his family was unwilling that the individual should be taken to the hospital [but kept asking] how to handle him ... (34T).

Unmatched decision-making can create a feeling of helplessness in PHCC staff resulting in an increased burden of care "...if the family does not give a permission, then how will be our next action, how?" (34T).

Another example of forced acceptance to provide care can be seen in the story of a PHCC staff member who witnessed the 'dumping' of individuals from one region into her own. These unwell individuals increased the burden on health professionals in the place where they were dropped

It seems that those patients [who are wandering in the village] are dropped patients. So, if one night they are dropped, some months later they are taken and replaced; we just don't know [who takes them]suddenly a new person has come ... well... [those patients] has been naked, wearing nothing,..... every few months new people are dropped in the village (31T).

For institutions, unmatched-decision making also leads to forced acceptance to provide care, increasing the psychiatric hospitals burden. Psychiatric hospitals experience an organisational burden of care if, for example, the hospital is flooded with patients who should have been discharged. Their family or staff should have taken the patients from the Social Service Department (for homeless patients), as they no longer need the level of care provided

by the psychiatric hospital. Patients who remained the responsibility of the hospital when they were ready for discharge increased the financial burden experienced by the hospital in which funding is scarce. The psychiatric hospital's strategy can be to pretend to discharge patients (described as administratively discharged) because the period of care to which patients are entitled has been reached— three months according to the regulation of Social Security for Community. The patient might not have family or a place to stay after discharge. This strategy of administratively discharging patients involves the staff reporting to the insurance provider that the patient has been discharged even though the patient remains at the hospital. The insurance provider then processes funding assistance for a further three months. This strategy can be employed repeatedly for patients with no family support. While waiting for the paperwork to be completed, which usually takes three days, the hospital has to guarantee the care of the patient by providing food and a bed. This shortfall is managed by sharing food with other patients

... if [the patient] doesn't have family, where should we drop him? To Social Service Department actually. But if we drop there, I'm sure that it will not be managed well ... If so, it's not a big deal if he is administratively discharged.... For example, if he is discharged today, he is administratively sent to the social service, but the patient is still here. Then, the next two or three days, we hospitalise him again, accompanied with a letter from the social service.... But, [there are] 23 people within three days, and one person eats three times [it means one person eats nine times for three days]. So, nine times multiplied by three multiplied by 23.... that costs belong to the hospital.... Thank God that those in Class III would like to share rice, depending on who divides it. If one rice basket is enough for 10 persons, it can be made to 20 persons, right ???... (T15).

Housing additional patients, as described above, has led to a consistently high bed occupancy rate.

... Well, the BOR [Bed Occupation rate] here is due to such a thing ... because many homeless patients do not go from the hospital, resulting in a very high BOR, even more than 100% I guess50% of them are homeless ... (12T).

The hierarchy of the psychiatric hospital in which individuals are administratively discharged repeatedly have supported the psychiatrist's decision to retain patients regardless of the human rights violations related to the confinement of the affected individual. Specifically individuals are being denied the opportunity to integrate, live and work in the community; a

human rights violation of principles 3, 7 and 8 of the Principles for the Protection of Persons with Mental Illness and the Improvement of Mental Health Care (see Table 2.3).

The phenomenon of individuals staying for a long time in psychiatric institutions is a common occurrence in developing countries and is considered to be another consequence of unmatched decision-making.

For the patients... that the maximum treatment is three months. The problem, which make us difficult, is that when the patients got better, but [the patient] not taken [by his family] (26 T)

Well, there are patients [mentally disordered and neglected] who has been treated for one year [treated in psychiatric hospital], there are also those [treated in hospital] for years ...but [the patients] are not taken [by staff of Social Service Department]... It is such a difficult situation for the hospital (12 T).

A similar situation occurs in public shelters when patients cannot be discharged because no one knows to which place or address the patients should be discharged. For example, in one public shelter there is a quota of 50 people at one time for rehabilitation and each person is able to stay for a maximum of three years. The public shelter is governed by the Provincial government, which sets this quota. Many more people require rehabilitation in this province but, because of the quota, fewer patients receive the opportunity for rehabilitation. The same issue arises in psychiatric hospitals when patients are ready for discharge from a public shelter and the family does not collect them. “There are about 15 to 20 per cent who cannot be discharged anymore...” (48T).

Key findings

In summary, the key findings of the grounded theory ‘Connecting Care for Individuals Living with a Mental Health Issue in Indonesia’ are as follows.

What is already known about the topic?

- Long-term services are necessary to assist the recovery of individuals with mental health issues.

- Mental health service delivery is influenced by the availability of resources including health workforce, health infrastructure, relevant technologies and availability of essential medicines.

What do these findings add?

1. In Indonesia, compliance with policy is the most important factor for health professionals when making decisions concerning the provision of mental health services.
2. In Indonesia, when families of individuals living with a mental health issue make decisions about accepting responsibility to provide care they consider the impact this might have on their whole family and not just the affected individual.
3. Stigma associated with mental illness and poverty is an important factor that influences the actions of the families of individuals living with mental health issues in Indonesia.
4. For families, choosing to accept responsibility to provide care when they are not well-prepared financially, cognitively and emotionally can result in human rights violations if the family opts to use physical restraints and/or provide low levels of care. On the other hand, choosing to shift responsibility to other stakeholders when the individuals should be cared for at home also can result in human rights violation related to individuals' rights to enjoy a normal life.
5. Families carry the heaviest burden of care for individuals living with a mental health issue in Indonesia because of the combination of inadequate mental health service resources, stigma attached to mental health illness, and their own poverty.

Chapter summary

This chapter explained the theory of connecting care accompanied by evidence from the data. Four headings were used to structure the findings: decision-making, shifting responsibility, accepting responsibility and relationships between subcategories.

Unmatched decision-making can lead to adverse health outcomes, increasing the risk of human rights violations and increasing the burden of care to individual stakeholders and institutions. Matched decision-making facilitates stakeholders to provide collaborative care for individuals living with a mental health issue and is influenced by the level of resources, competency, willingness and compliance with policy. The next chapter will discuss the findings in the context of the contemporary literature and the theoretical codes of decision making and coping.

CHAPTER FIVE: DISCUSSION

Introduction

This study found that connecting care for individuals living with a mental health issue in Indonesia is a complex interplay between various stakeholder groups, the most influential of whom are health professionals and families. The five key findings of this study will be discussed in this chapter in the context of the contemporary literature, and using the theoretical codes of decision making and coping.

The importance of policy for health professionals' decision making

In this grounded theory of connecting care for individuals living with a mental health issue in Indonesia, the process of decision-making precedes either a shifting or accepting responsibility to provide care. To date, most of the research into decision making by health professionals in mental health care is concerned with the treatment of mental disorders by encouraging consumers to participate in decisions about their care (Raue et al., 2010).

In a recent study, Anthony et al (2010) examined factors that influenced clinicians in their decision-making regarding individuals living with mental health issues in the United States of America (USA). In this study several factors influenced decisions to refer a patient to a mental health specialist. These factors included the following: the individual patient's resources; the clinician's comfort in prescribing medicine and counselling the patient; and familiarity with a mental health specialist or practice environment. Even though the cultural context of Anthony's study was quite different from the present study set in Indonesia, Anthony's (2010) findings supported aspects of the grounded theory of connecting care. In particular, the present study and Anthony's study report similar findings related to the importance of considering resources when deciding where to shift responsibility for care. Both studies have also highlighted the finding that a decision-maker's familiarity with alternative care providers promoted effective communication between stakeholders.

The motivations and justifications for making a decision can usually be attributed to either rational choice or rule-following (March, 1994). Decision-makers who are relying on rational choice consider consequences and flow-on effects and measure these possibilities against their own needs and preferences before making a decision. Alternatively, rule-following as a motivation and justification for decision-making, is grounded in the logic of appropriateness and refers to three premises: recognition, identity and rules. Recognition occurs when decision-makers use previous experience to identify a situation. Identity – both personal and organisational – also comes into play in this theory of decision-making. Finally, general and situation-specific rules contribute to the decision-making process (March, 1994).

Health professionals in this study mostly based the justifications and motivations for decision-making on rule-following. Health professionals with designated authority assessed an individual's health status before deciding whether the individual met the criteria to receive care in a PHCC or in the community, or whether they needed to be discharged from, or referred to, a psychiatric institution. In making this decision health professionals considered the individual, but prioritised their own identity within the institution. This study found that rules and institutional identities largely underpinned health professionals' decision-making processes when they were connecting care. According to March (1994), "organizations shape... individual action both by providing the content of identities and rules and by providing appropriate cues for invoking them" (p. 71). Health professionals accomplish their tasks mostly by following rules like hospital policies that have become internalised through the education or institutional process as part of their identity.

Although this study found that Indonesian health professionals were rule-following decision-makers there was also evidence that rules or procedures could not be applied universally to each circumstance. In fact, it was sometimes necessary to 'fine-tune' or adapt to a changeable environment (March, 1994). Health professionals were found to 'bend the rules' depending on circumstances or context. This can be seen in instances where health professionals accept responsibility to continue to provide care, contrary to institutional policy,

because the family does not have sufficient resources. This situation will lead to health professionals being forced to provide care that does not comply with institutional rules.

Health professionals' decisions not to follow an institution's rules can be explained by Shibutani's (1962) theory of multiple perspectives of self. Shibutani (1962) posits that individuals have multiple perspectives of themselves tied mainly to their roles in life, such as employee, health professional, parent or member of a religious or cultural group. Decision-makers, therefore, have several identities to consider as they attempt to follow the rules of their various institutions and professional codes of conduct and ethics. In making a decision they must also take into account their responsibilities to society, the individual and the individual's family. These often competing interests explain why social workers and psychiatrists, for instance, sometimes 'bend the rules' to keep individuals living with a mental health issue in public shelters or psychiatric hospital because they know that there is no other place for them to go.

Non-health professionals' forms of coping

Decision-making is a pivotal category in connecting care, and decisions result in either shifting responsibility or accepting responsibility to provide care. Research on decision-making indicates that shifting responsibility or accepting responsibility to provide care by non-health professionals has not been explored. Instead the literature on decision-making in mental health is concerned mainly with the health behaviours of mental health service consumers, particularly in relation to a trend to delay seeking help when individuals become ill (Galdas, Cheater, & Marshall, 2005).

In the present study non-health professionals' decision-making was found to be influenced by a combination of levels of competence, willingness, resources and compliance with policy. To explain this phenomenon in more detail the extant theory of coping will be applied.

Lazarus' (1998) defines coping as the "ongoing cognitive and behavioural efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the

resources of the person” (p. 372). Stress experienced by non-health professionals who connect care for people living with mental health issues in Indonesia is generated by changes in the affected individual’s health status over time. If the researcher applies Lazarus’ theory of coping, decision-making is considered to be a cognitive effort, while shifting responsibility and accepting responsibility can be considered behavioural efforts (table 5.1). Applying Lazarus’ (Lazarus, 1998) theory of coping to the process of connecting care for non-health professionals led the researcher to postulate that making decisions to shift or accept responsibility for care is a form of coping for this group.

Table 5.1

Comparison of Connecting Care and Theory of Coping Concepts

Theory of Coping	Grounded theory of connecting care for individuals living with a mental health issue in Indonesia from the perspective of non-health professionals
Cognitive efforts	Decision-making
Behaviour efforts	Shifting responsibility to provide care
	Accepting responsibility to provide care

Lazarus (1998) outlines two levels of cognitive appraisal in his theory of coping, namely primary appraisal and secondary appraisal. In the primary appraisal stage, a person decides whether the circumstance (in this study - an individual’s health status) is considered to be irrelevant, stressful or benign-positive. If the situation is considered to be irrelevant or benign-positive then little further effort is required by the person to address their situation. A decision is usually necessary when the circumstance is stressful, thereby triggering a subconscious categorisation into one of three types: harm/loss, threat or challenge (Lazarus, 1998). For the family, caring for individuals living with a mental health issue is considered to be a harm/loss situation. For most cadres and community leaders, stressful situations fall into the threat category. An individual living with a mental health issue who is extremely unwell is perceived by non-health professionals to be a threat to community safety and to the function of the community as a whole.

According to Lazarus (1993), individuals take one of two approaches when they are attempting to cope with a stressful situation - a problem-focused approach or an emotion-focused approach. Their level of competency, willingness, availability of resources and compliance with policy influences non-health professionals' decision-making to either shift or accept responsibility to provide care. Based on Lazarus theory (Lazarus, 1993) people might choose either a problem or emotion-focused approach. They might change something practical or physical about the stressful situation (problem-focused) or they may change the mindset or 'lens' through which they view the stressful situation, thereby using emotions to manage their response. A problem-focused approach "changes the troubled person-environment relationship by acting on the environment or oneself" (Lazarus, 1993, p. 238), while emotion-focused approaches "change the way the stressful relationship with the environment is attended to and the relational meaning of what is happening which mitigates the stress even though the actual conditions of the relationship have not changed" (Lazarus, 1993, p. 374). Lavoie (2013) considered these approaches to coping in a study that involved individuals living with a mental health issue. A problem-focused coping style was found to decrease the perception of stress and increase the perception of efficacy, whereas emotion-oriented coping styles negatively affected efficacy and stress levels (Lavoie, 2013).

In this study, two actions might be considered to be behavioural coping. Whether or not these coping actions are focused on problem or emotion depends on the motivation of the person making the decision. For non-health professionals, shifting responsibility to care for an unwell individual to health professionals can be considered to be a problem-focused approach if an individual requires the sort of complex treatment a health professional can provide. Alternatively, however, shifting responsibility can function as an emotionally-focused approach if the family shifts responsibility to health professionals for respite from care and resource provision. This finding is similar to one outlined in a study by Koponen et al. (2012) which found that relatives of individuals living with a mental health issue reported they wanted to distance themselves from the patient because they were pushed to the limit of their endurance.

The choice to shift responsibility as a problem or emotionally-focused approach is also influenced by the level of communication with other stakeholders.

Accepting responsibility can also function as a problem-focused or emotional-focused coping strategy. Families that are prepared to accept responsibility when an individual's health status changes, are considered to be using problem-focused coping methods. Families are encouraged to meet the needs of the individual living with a mental health issue, based on their level of willingness, competence and resources. Elsewhere, however, accepting responsibility to provide care function as an emotional-focused coping strategy. If the family denies the individual needs professional treatment as advised by a health professional their coping strategy to accept responsibility has the hallmarks of an emotional response rather than a problem-focused approach. This emotional response to connecting care of individuals living with a mental health issue can stem from cultural and religious beliefs about the cause of mental disorders. These beliefs might affect a family's willingness to accept responsibility to provide care. One publication by Kurihara et al. (2006) documents public attitudes towards mental disorders in Indonesia, focusing on beliefs held by family members regarding the cause of illnesses. This study found that most families believed schizophrenia had supernatural causes. Supernatural origins involved disturbance by spirits, god's will or fate, karma and witchcraft (Kurihara et al., 2006). Such beliefs led to a reluctance to seek medical treatment – shifting responsibility to health professionals - for individuals living with a mental health issue (Kurihara et al., 2006).

In this study, the results of behavioural efforts in connecting care depended on a range of variables. In shifting responsibility, the level of effective communication influenced whether or not the coping strategy could address and ease the level of stress experienced by a non-health professional. With reference to accepting responsibility, the competence, willingness and resources of non-health professionals also influenced their decisions about whether or not to provide care for family or community members living with a mental health issue.

Non-health professionals' willingness to accept responsibility to provide care was heavily influenced by stigma in this study. Stigma is defined as 'something about a person that causes

her or him to have a deeply compromised social standing, a mark of shame or discredit' (WHO, 2003, p. 11). The level of stigma associated with mental disorders, experienced by both families and communities, is a factor that needs to be considered by policy makers because stigma can increase the number of unmatched decisions made on behalf of people living with mental illnesses. Stigma will often prevent family members from making the right decision for an individual living with a mental health issue because of the impact this might have on their social standing and the perception of their value in the community. Stigma associated with mental disorders prevents people from seeking help (WHO, 2003). Stigma is also a barrier to getting family members involved in care delivery (Kaas, Lee, & Peitzman, 2003). Several emotional states such as feelings of frustration, anxiety, low self-esteem and helplessness are connected to stigma (Tsang, Tam, Chan, & Chang, 2003) which can be experienced by both affected individuals and their family.

Consideration of available resources is also fundamental to the process of decision-making by non-health professionals. This study found that financial circumstances such as having no health insurance could force a family's decision not to shift responsibility to other stakeholders. It is acknowledged that policies, even in economically developed countries, do not recognise the difficulties faced by these stakeholders and financial support is not always available for them since care giving is considered to be a default role.

Human rights violations as a result of decision making

Matched decisions reached through group consensus resulted in the best health outcomes for affected individuals in this study. Unmatched decision-making between stakeholders was a potential trigger point for human rights violations. Human rights violations identified in this present study include prolonged seclusion or restraint practices, shackling and delayed discharge from psychiatric hospitals; health professionals and non-health professionals were both identified as culpable. In this study the majority of health professionals did not intentionally violate individuals' human rights but violations were sometimes an unfortunate consequence of unmatched decision-making. Human rights violations were commonly a result

of unmatched decision-making but violations also arose on some occasions as a result of matched decision-making, particularly when a family accepted responsibility to provide care. Initially, a family's resources, competency and willingness may have been adequate to provide care but, over time, exhaustion can set in and circumstances can change. A perceived last resort for the family in this instance might be to shackle their mentally ill relative to ensure both their own and others' physical safety.

Two research studies investigating the practice of shackling individuals living with a mental health issue in Indonesia have been undertaken (Minas & Diatri, 2008; Puteh, Marthoenis & Minas, 2011). Both studies found this form of physical restraint was used by families to prevent individuals from harming themselves or others. Another reason for shackling, according to Minas and Diatri (2008), was to prevent individuals from wandering when no one was available to care for them. It is interesting that in Minas and Diatri's study (2008), nine of the 15 participants had received medical treatment but this had been discontinued because their families were unable to afford the cost of medicines, a finding similar to that of the present study. Overwhelmingly, a lack of resources was the main reason for families violating affected individual's human rights by shackling with Minas and Diatri (2008) clearly arguing the importance of resource availability to prevent human rights violations. This study found that financial circumstances such as having no health insurance is an important factor that forces a family to decide not to shift responsibility to other stakeholders. Wai-Chi (2011) states that various countries' health care and social welfare systems will influence families' commitment to provide care for individuals living with a mental health issue. The availability of resources, however, depends on the extent of mental health legislation. The fundamental principle, values, aims and objectives of mental health policies and programmes can be assured only if mental health legislation is fully implemented. Such legislation provides a legal and regulatory framework that addresses critical issues for persons with mental disorders in both tertiary and community settings (WHO, 2006).

Mental health legislation will be the most important factor in supporting an increase in matched decision-making between health professionals and non-health professionals in the

process of connecting care for people living with a mental health issue in Indonesia. Indonesia's mental health statute, proclaimed in 1966, no longer exists. Some of the original regulations were integrated in 1992 into one specific law known as Law No. 23 on Health however only four articles in the new law dealt specifically with mental health. Law No. 23 consists of general principles and has no associated regulations, meaning that there is no legislative framework to support the implementation of specific policies (Irmansyah, Prasetyo & Minas, 2009). The lack of fully articulated mental health legislation in Indonesia (WHO, 2011) has resulted in inconsistency in care and treatment across the country. An analysis of why specific mental health legislation in Indonesia has not been fully implemented is beyond the scope of this study, however recommendations from this study include further research into the process of establishing such laws and identifying barriers that make this difficult.

Although the WHO has provided a guideline to help establish mental health legislation, WHO notes the public will not benefit if the guidelines are not formally adopted by official national bodies such as parliament, the ministry of health or welfare and the medical council (WHO, 1996a). In the process of fully implementing mental health legislation in Indonesia both health professionals, non-health professionals and consumers must be consulted (WHO, 2004) so that each point in the process of connecting care can be considered in terms of barriers and enablers to providing the right level of care depending on an individual's health status.

Indonesia requires mental health legislation that will protect and guarantee the human rights of individuals living with a mental health issue; the government must also invest in greater resources for the establishment and ongoing funding of sufficient care facilities. Another strategy may involve a program of involuntary treatment in outpatient settings as this type of program has proven to reduce readmissions (Geller, Grudzinskas Jr, McDermeit, Fisher, & Lawlor, 1998) through increasing access to mental health services. Importantly, a program to tackle stigma should also be introduced in Indonesia so that non-health professionals, particularly families, might better understand the effective management of mental disorders and see the potential for mentally-ill individuals to become effective and valued members of Indonesian society.

Families carry the heaviest burden of care

This study found that family members of individuals living with a mental health issue in Indonesia carried the heaviest burden when it came to decisions to either shift or accept responsibility to provide care. This burden resulted from unmatched decision-making between stakeholders which lead to forced acceptance to provide care. Family responsibility to provide care for those individuals living with a mental health issue included social, emotional and financial support (Clark & Drake, 1994). This responsibility placed an enormous burden on families. In the present study, researchers found that violence was commonly perpetrated against family members caring for someone living with a serious mental disorder, further increasing the stress and burden of carers. A report by Solomon, Cavanaugh & Gelles (2005) estimated that the rate of violence experienced by family members of a relative living with a mental health issue was between 10% and 40% higher than that of the general population. With this high level of burden, families may be forced to relinquish their relatives to the criminal justice system or allow them to wander on the street (Solomon, Cavanaugh & Gelles, 2005), a phenomenon also found in the present study. In the present study, families were expected to provide care for individuals even if they did not have enough understanding of the role required.

Findings in the present study demonstrated that family members felt a sense of hopelessness because there was no other way to cope with their situation. Other studies have also found links between hopelessness and long-term treatment and care giving (Bland & Darlington, 2002; Tan et al., 2012). Loss of hope in turn affects families' ability and willingness to collaborate with the mental healthcare system (Kaas, Lee & Peitzman, 2003). The level of resources available to stakeholders also contributes to the level of burden experienced by them (Tan et al., 2012). Caring for an individual living with a mental health issue may force family members to give up their own social support networks (Rose, Mallinson, & Walton-Moss, 2002) or restrict their social and leisure activities (Lauber, Eichenberger, Luginbühl, Keller, & Rössler, 2003). Eventually, family caregivers will start to feel isolated (Rose, Mallinson & Walton-Moss, 2002). In Asian societies, social support is considered to be the most accurate

predictor of caregiver burden in families (Chien, Chan, & Morrissey, 2007). Providing social support will help families to share care giving tasks (Chien, Chan & Morrissey, 2007; Pakenham, 2012) thereby reducing primary caregivers' burden of care and promoting personal health and wellbeing (Noble & Douglas, 2004). Social support can increase caregivers' quality of life (Fujino & Okamura, 2009) while also increasing the level of functioning of the family as a whole (Saunders, 1999). Family members who serve as caregivers for individuals living with a mental health issue typically have more than one role to play. For example, they might have to cope with both work and care giving at the same time (Tan et al., 2012). Their burden is heavier when mental health and rehabilitation services and financial support structures are lacking (Chien, Chan & Morrissey, 2007; Martens & Addington, 2001; Ohaeri, 2001). Currently in Indonesia there are no respite care facilities available for individuals living with mental illness and their families.

This study also found there was a lack of financial support for carers in Indonesia. A Chinese study (Chien, Chan & Morrissey, 2007) found that the financial situation and number of family members living with a mental health client were important predictors of the burden carried by caregivers. Meanwhile, in Nigeria, Ohaeri (2001) found a relationship between financial distress and a global rating of difficulty nominated by caregivers who responded to a survey.

This study recommends that the starting point to improve mental health care delivery is the consideration of the way stakeholders can arrive at matched decisions in order to minimise the burden of care. If decision-making is not matched between health professionals and non-health professionals, responsibility is shifted continuously until, eventually, one stakeholder is forced to accept responsibility to provide care. Each stakeholder who accepts responsibility must be supported so that they are able to provide care effectively while keeping their own physical and emotional states in balance. When this balance is achieved everyone involved in the situation will have their needs met, including the individuals living with a mental health issue.

Chapter summary

This chapter discussed the key findings of this grounded theory study in the context of the contemporary literature and the theories of decision making and coping. Four areas of discussion formed the focus: the influence of policy on health professionals' decision making, coping strategies employed by non-health professionals, human rights violations as an outcome of unmatched decision making, and the heavy burden of caring experienced by families of affected individuals. Chapter six will conclude the thesis by providing an evaluation of the grounded theory study in terms of process and outcome before identifying the strengths and limitations of the study and outlining a series of recommendations for policy, practice, education and further research.

CHAPTER SIX: CONCLUSION

Introduction

The aim of this study was to generate a theoretical model of collaborative care for individuals living with a mental health issue in Indonesia. The substantive area of enquiry was the way in which mental health care is delivered in Indonesia. This study was originally prompted by three key issues related to adverse health outcomes: individuals living with a mental health issue experience ‘vicious cycles’ or ‘revolving doors’; mentally ill individuals can be seen ‘wandering’; and thousands of mentally-ill individuals are shackled (or physically restrained). The final product of this study, the theory of connecting care, was able to address the context which surrounds these three key issues.

As a doctoral candidate the researcher aimed to contribute new and original knowledge to the evidence base concerning mental health nursing. In claiming originality, the findings of a grounded theory study need to “provide 1) an analysis in a new area, 2) an original treatise in an established or fading area, and [/or] 3) an extension of current ideas” (Charmaz, 2006, p. 153). Prior to this study, there were no research findings able to explain the substantive area of enquiry. When the researcher considers Charmaz’s criteria for originality therefore, this study has analysed a new area of investigation - the findings of which constitute an original contribution to the knowledge base not only in Indonesia, but also internationally. There is potential for the grounded theory of connecting care to be applied and tested in countries other than Indonesia as the final grounded theory demonstrates a level of abstraction that could be relevant to other contexts.

The key findings in this study were as follows. Firstly, different sets of factors influence health professionals and non-health professionals when they make decisions about the care of mentally-ill individual. Secondly, stigma attached to mental illness, a lack of resources in mental health care, and poverty, when combined, lead to human rights violations and a heavy burden of care for families. This chapter will address the researcher’s reflections on conducting this grounded theory study including an evaluation of the quality and rigour of the research

process and outcome, before identifying the strengths and limitations of the study and then providing a series of recommendations for further research, research methods, practice, education and policy arising from the key findings identified in chapter four and discussed in chapter five.

Reflecting on the past three years

The following memo was written by the researcher as a reflection on the process of undertaking a doctoral degree at an English-speaking university. It is provided to illustrate the process of intellectual and professional growth experienced during the three years of candidature.

Doing research is one of my favourite activities. I consider the hassle, hard work, and 'tension' if it exists, as invaluable for me in the process of answering many of my curiosities. I have become interested in research activity since I attended my undergraduate education at the University of Indonesia from 1992 to 1998. After, I graduated with my bachelor degree, and worked as a lecturer in Nursing Science at the Faculty of Medicine of UGM in Yogyakarta, Indonesia. I have done several studies, which has been specifically related to psychiatric nursing.

My dream to do better quality research came true when I received the ADS scholarship to pursue my master's degree at James Cook University in 2005-2007. The learning process at the master's level has strengthened my capacity and my constancy in terms of doing research and has fulfilled its purpose to satisfy my desire to become a nurse researcher. Doing research, no matter how difficult it is, with the flurry of raising my two young boys remains my own preoccupation. Moreover, it has encouraged me to continue to further my studies at the doctoral level in 2010, again by the assistance of the Australian Government through its ADS Scholarship program.

The first year of study was a struggle moment for me because there were many sources to read, such as books and journal articles. This process provided information about what is grounded theory methodology and how to apply it in my research. The most difficult process in this first year was when I needed to understand the philosophical underpinning of grounded theory study. Understanding philosophy is always a challenge, especially when all the relevant studies were in the English language,

which is my second language. The different types of grounded theory methodology added confusion but I gradually found a theoretical version that suited my belief and this helped me to enjoy more the process of understand grounded theory more.

During the data generation and analysis phases, applying grounded theory methods carefully under close supervision helped me to understand what the grounded theory 'looks like'. I was excited about finding new things and surprised about what I had not previously considered in the data generation and analysis process.

The analysis process constituted another 'hard' part of my research. I felt that I struggled regarding how to illustrate what happened in the data, including how to analyse the data; should it be in English or in Indonesian? I even felt a lot of physical pain in trying to translate data from Indonesian into English and this coincided with my confusion about what method I needed to use to code the data.

An invaluable benefit of the process was in the exchange of cultures, beliefs, knowledge, and values when I discussed issues with my supervisors. For me this was a very good experience as I began to know more about English language culture, how the mental health system works in Australia and internationally. For me this was the actual process of constructing my personal knowledge, not only with reference to my topic but also for me personally as well.

Preparing manuscripts for publication also proved to be a challenge during my PhD candidature. I needed to ensure all evidence in the data really did 'illustrate' what really happened. It was not as easy as it had to be done in English and not in my own language. Being rejected by several journals was just part of the learning experience for me about how to express my arguments and findings. This process was priceless to me; not just getting my PhD degree but benefiting from it in the future as well.

Evaluating a grounded theory study

Evaluating the process of conducting a grounded theory study is different to evaluating the product of that same study. In the following section the researcher will appraise how well she conducted the study itself (process) using Birks and Mills' (2011) principles to guide an assessment of the quality of this study. The principles are as follows: researcher expertise, methodological congruence and procedural precision. An explanation of how the researcher

assured the quality of the grounded theory produced is provided under each of these headings. Following this, the product of the study, the theory of connecting care, will be evaluated using Glaser's (1978) criteria of fit, work, relevance and modifiable.

Following on from Beck (1993), Cooney (2011) used 'auditability' to evaluate Strauss's version of grounded theory study which fits with Birks and Mills' (2011) principles of assessing the process of conducting a grounded theory study. Cooney (2011) discussed auditability as "maintaining a comprehensive record of all methodological decisions Such as a record of the source of data, sampling decision, and analytical procedures and their implementation" (p. 20). It is this record that provides evidence of the researcher's expertise in implementing strategies to ensure methodological congruence and procedural precision.

In relation to qualitative research more generally Beck (1993) argued that there are three standards that are appropriate to evaluate rigor. These standards were credibility, fittingness and auditability. Credibility is defined by Beck (1993) as "how vivid and faithful the description of the phenomenon is" (Beck, 1993, p. 264) while fittingness in the context of grounded theory study is related to how the theory fits the substantive area of enquiry (Strauss & Corbin, 1990). Cooney (2011) added that theory 'fits' when it can be applied in different but related contexts. These two standards (credibility and fittingness) are considered to be tools that evaluate the product of a grounded theory study, which is in agreement with Glaser's (1978) original argument.

Process evaluation

Researcher expertise

In a grounded theory study, a researcher's expertise is characterised by scholarly writing, a familiarity with grounded theory methods, the use of a wide range of literature, and understanding the limitations of the design of a study and how these can be addressed (Birks & Mills, 2011). For an international PhD student to be accepted to study in an Australian university there is a specific International English Language Test Score (IELTS) required for admission. During the researcher's candidature she continued study in the English language,

completing required courses provided by the James Cook University Graduate Research School. During the three-year study period, the researcher demonstrated skill in scholarly writing through the acceptance by academic journals of two manuscripts which are now published. As well, at the time of thesis submission, four additional manuscripts related to the study were under review at various journals.

At the beginning of this study the researcher was aware that, although she had previously conducted a qualitative study, she was a novice grounded theorist. During the first year of her candidature, the researcher read a wide range of literature about philosophy, methodology and grounded theory methods to increase her knowledge base prior to entering the field. Once the researcher began the process of concurrently generating and analysing the data her skills in applying the full range of grounded theory methods began to develop as she began to 'feel' how to apply grounded theory methods. The researcher's subsequent mastery of grounded theory methods is demonstrated in one of the manuscripts titled *Conducting a Grounded Theory Study in a Language Other than English: Procedure for Ensuring the Integrity of Translation*. In writing this manuscript, the researcher spent a lot of time reading the broader literature about translation and then thinking through a process by which to manage the issues associated with conducting grounded theory data analysis in a language other than English. Other evidence of the researcher's familiarity with grounded theory methods can be seen in chapter three which documents how each of the essential grounded theory methods was applied in this study. As well, the final product of this grounded theory study – the theory of connecting care - demonstrates that the researcher is able to move beyond description to fully integrate a grounded theory.

Regular weekly discussions with supervisors were another way in which the researcher improved her skills. Raw data was in the original language in which it was collected and much physical and emotional work and thought was needed to ensure the researcher could present this data in English to her supervisors, then work with it to develop the analysis. Rigorous and careful application of concurrent data collection and analysis in this unique circumstance (original data was not in a language which the supervisor was able to understand) led to creative

thinking and the development of a procedure to deal with translation issues in research. This procedure will be a good resource for other researchers in a similar position. The limitations of the study, the identification of which is the final element of researcher expertise, will be described in more detail later in this chapter.

Methodological congruence

The second principle to consider when addressing the quality of the process of conducting a grounded theory study is methodological congruence. Several factors influence methodological congruence and they are listed as follows: justification that grounded theory is an appropriate method to conduct the study; explanation of the researchers' philosophical position; identification by the researcher that her philosophical position and the methodology implemented are consistent or otherwise; achievement of an outcome based on the aim of study; certainty that the end product is a grounded theory (Birks & Mills, 2011).

Grounded theory was chosen as the research design for this study because there was no existing theory that explained the substantive area of enquiry. Grounded theory was also appropriate because the concept of identifying a process of collaborative care for individuals living with a mental issue is consistent with the notion of a basic social process (Glaser, 1978).

In this study the researcher articulated her philosophical position clearly in chapter three where she argued that 'truth' is a relative stance. This philosophical position influenced the choice of methodology, which utilised the perspective of symbolic interactionism in this study.

Three premises of symbolic interactions were fitted into the study process. The first premise is that people use the meaning of 'things' as a basis for their action (Blumer, 1969). In this study, the 'things' for participants are the condition of health status. For each stakeholder in this study, however, the meaning of health status may be different, as consistent with symbolic interactionism, there is no fixed meaning (Blumer, 1969). Meaning can be sustained, affirmed or transformed depending on a stakeholder's interpretation (Blumer, 1969). The second premise of symbolic interactionism is that individuals create meanings by interacting with other people (Blumer, 1969). In symbolic interaction, meaning is a social product in which interaction

among stakeholders will shape stakeholders' interpretations and thus the 'things' may have a different meaning. In this study, for example, the way cadres change their interpretation of health status occurs after they interact with other health professionals in the form of mental health training. The third premise of symbolic interactionism is that people use an interpretative process to apply or modify meanings of things as an instrument to inform their behaviour (Blumer, 1969). Previously, cadres thought that the health status of individuals who are labelled as having a mental illness was all the same. After interaction with health professionals, this perception changed and cadres demonstrated that health status can have multiple meaning to different stakeholders. Their 'new' perception is a result of reflexive thinking and depends on the situations they confront. Reflexive thinking in the theory of connecting care is found in the form of decision-making category. This decision-making is based on stakeholders' interpretation of health status which, in turn, shapes their actions to either to shift responsibility or to accept responsibility to provide care.

Symbolic interactionism also applies in the research process. Data for this research was in the form of interview transcripts, memos and field notes. The meaning of this data was created through interaction between the researcher and participants and also interaction between the researcher and supervisor. In this study, the process of interpreting meaning was much more challenging and complicated as the raw data had to be interpreted across languages; the shaping of meaning was also influenced by interpretations of and between two different languages. The meaning of 'things' was created through reflexivity and was based on interaction with participants and the supervisors, which guided the researcher in her next action in the form of choosing what data needed to be generated and from whom this data should be sought (theoretical sampling). The identification of the core category, categories and sub categories was a product of interaction between the principal researcher, data and supervisors. It is a social product in which the theory was constructed through social interaction.

The outcome of this study is a theory of connecting care for individuals living with a mental health issue in Indonesia. This theory is able to explain how stakeholders (health

professionals and non-health professionals) interact in a model of collaborative care to respond to individuals living with a mental health issue under the condition of health status.

Procedural precision

Procedural precision is the third principle used to appraise the quality of the process of conducting a grounded theory. Procedural precision covers several points including the following: using memoing throughout the research process; ensuring the researcher carefully controlled the research process preserved an audit trail; applying essential methods of grounded theory including the process of abstraction and making logical connections between data; describing data and resource management; explaining the credibility and potential application of the final theory; explaining how the theory is grounded in the data.

In this thesis, the researcher demonstrated the application of all essential grounded theory methods in chapter three. A dynamic process was used to generate a grounded theory about mental health care delivery in Indonesia. In particular, theoretical sampling directed the process of concurrent data generation and analysis, resulting in a strong and well-integrated theory. Along with the process of concurrent data generation and analysis, memos were written continuously during the study which increased the researcher's theoretical sensitivity. Increasing theoretical sensitivity helped the researcher in the process of advanced coding. In this study, 166 memos were generated using a mixture of the Indonesian and English languages. Examples are evident in chapter three and in *Appendix N*. Evidence that memos support this study is demonstrated in the way the sub-categories of matched and unmatched decision-making were constructed through sorting memos (Glaser, 1978) (see *Appendix O*). Theoretical sampling was also influenced heavily by memo writing, which illustrated the identification of gaps and guided the need to expand sampling to include different groups of participants.

Researchers create an audit trail by writing memos. Memo writing helped the researcher to summarise and document research activity and any changes in direction that occurred in the research activities. Writing memos also helped the researcher to link memos documenting earlier ideas if and when needed (see *Appendix F*). In this example, it can be seen how the

establishment of a logical connection between the data and abstraction was conducted by the researcher. The researcher in her thesis managed the data and resources in two different ways – hard copy and digital. Both types of data were stored in a locked, secure place and a password for the digital data meant that access was restricted. Interview data was managed separately from the memos to help the researcher identify the two different sources of data.

Product evaluation

The product of a grounded theory is not measured by its level of generalisability but rather by whether the theory produced is relevant and adaptable (Glaser, 1978). Glaser (1978) stated that the quality of a grounded theory can be judged using four criteria, these being fit, work, relevance and modifiable. Fit means “that the categories of the theory must fit the data” (Glaser, 1978, p. 4) while work means “that a theory should be able to explain what happened, predict what will happen and interpret what is happening in an area of substantive or formal inquiry” (Glaser, 1978, p. 4) and that “the theory must be relevant to the action of the area” (p. 5). Modifiability refers to the possibility of future changes in the theory if new data has been identified (Glaser, 1978).

In the theory of connecting care, evidence provided in the findings fits with the categories developed (for example, decision-making, shifting responsibility and accepting responsibility as outlined in chapter 4). In choosing the data fragments to evidence the theory, consideration was given to how well the data illustrated the abstract concept of the category and how compelling the nature of the data used was. Care was exercised in choosing data that engaged the reader in imagining the context of the findings. As well, in manuscripts under review that reported the study findings, data fragments were provided in both the original Indonesian language and English to promote transparency for Indonesian readers in relation to the fit between the data and the theoretical construct.

In this study the theory of connecting care works to explain the substantive area of how mental health care is delivered in Indonesia. The theory of connecting care can be applied to all stakeholders involved in the process of delivering mental health care including health

professionals and non-health professionals. The theory of connecting care explains a process that results in adverse health outcomes including individuals experiencing a 'vicious cycle' between psychiatric institutions and home, the phenomena of individuals living with a mental health issue who are wandering, and the occurrence of human rights violations such as shackling and other forms physical restraints.

Mental disorders are often characterised by frequent relapse. Sometimes this cannot be avoided as a vicious cycle of admission and discharge from psychiatric hospitals occurs whether decision-making among stakeholders is matched or unmatched. Although this vicious cycle for individuals living with a mental health issue will occur in some instances, the frequency of readmission can be reduced if decision-making is matched among stakeholders. Individuals will be in the optimal level of health status even though they shift between psychiatric hospitals and the community/home. Optimum individual health status will be achieved when decision-making amongst stakeholders is matched. Matched decision-making will, in turn, lead to a collaborative care model in which all stakeholders involved in mental health care respond appropriately to changes in an individual's health status by shifting responsibility or accepting responsibility. Unmatched decision-making will lead to unnecessary vicious cycles if stakeholders cannot accept responsibility for care provision.

Wandering is another key issue that can be explained by the theory of connecting care. Unlike the issue of the 'vicious cycle', wandering is a product of unmatched decision-making among stakeholders. Unmatched decision-making, for example, occurs between psychiatric hospital staff and family members in cases where psychiatric hospital staff members decide to discharge an individual and the family has a low level of willingness to accept responsibility to provide care. The individual stays in hospital for longer than necessary - a human rights violation - and becomes a burden on the psychiatric hospital. On the other hand, individuals might be dropped home before the family have agreed to accept responsibility for care. Families eventually are forced to accept responsibility to provide care but might ignore individuals at home and this can lead to cases of 'wandering'. The family has, by neglect, shifted responsibility to the local community which does not have sufficient willingness, resources and

competency to provide care. This leads to adverse health outcomes for individuals living with mental health issues. Psychiatric hospital staff members are tied to hospital policy that they should accept responsibility to provide care for individuals who are in an acute stage of illness. However, if the family makes a decision not to bring an individual to hospital to get treatment due to low resources and willingness, the individual might wander on the street.

Unmatched decision-making among stakeholders is often the motivation for shackling and other forms of physical restraints, as is the case with ‘wandering’. Shackling mostly occurs when there are low resources and competency. A family that makes a decision to provide care but is has insufficient competence, willingness and resources, will tend to apply shackling. Physical restraint, which is one form of human rights violation occurs, not only in the community, but also in hospitals. Unmatched decision-making about treatment can occur between health professionals. These disagreements might be exacerbated by limited resources like availability of medicine or inadequate health insurance cover to pay for certain medicine types. In such circumstances, unnecessary physical restraint may be used, thereby violating human rights.

Strengths and limitations of the study

Strengths

A key strength of qualitative research is its ability to analyse an actual phenomenon – the way in which mental health care is delivered in Indonesia – about which there is very little reported in the literature (Silverman, 2013). Additionally, qualitative research can be used to explain ‘how’ participants perceive their experience and ‘what’ the meaning of that particular experience was to them while also answering ‘why’ questions arising from the substantive area of enquiry (Silverman, 2011).

The major strength of this study is the way the theory of connecting care explains the mental health care delivery in Indonesia by examining in detail the collaboration or interaction between stakeholders. The depth of variation in the data allowed the researcher to examine each stakeholder’s perception of mental health care in terms of delivery and its particular meaning to

them. The product of this study therefore explains the 'why' question related to adverse outcomes for individuals living with a mental health issue including the phenomena of 'vicious cycle', 'wandering' and 'shackling' cases.

The second strength of this study is the way essential methods in grounded theory study were carefully applied, especially theoretical sampling. Ensuring the quality of this study meant that the researcher addressed the issue of translation in a grounded theory study where Indonesian and English terminology had to be precisely interpreted and translated. It is important to address this problem because grounded theory methodology was originally devised by Glaser and Strauss (1967) in the English language. Understanding how to employ their research design in a language other than English was critical to ensuring the quality of this study.

Limitations

The first limitation of this grounded theory study was a reliance on verbal data as the major source of raw data (Rennie, Phillips, & Quartaro, 1988). According to Miller and Glassner (2011) interviewing is a process of interaction in which narrative versions of the social world are created and constructed by both interviewer and interviewee. In this study, this limitation is addressed by using the comparative analysis method that is part of grounded theory. According to Morris (1981), only conscious material can be drawn from verbal reports. Consequently, the researcher needed to consider which verbal report was considered to be appropriate and relevant to the topic (Rennie, Phillips & Quartaro., 1988). In this study, this limitation was addressed through writing memos that included the researcher's impression of participants' non-verbal impressions. These memos helped the researcher to not just generate 'conscious' information from participants but also to identify subtle or hidden emotions or thoughts expressed through for example, a break in eye contact or a pause in the interview conversation.

The second limitation of this grounded theory study relates to the method of analysis. This limitation occurred because the guidelines used to analyse data - which were mostly

'verbal data' in this study– was designed in the English language. An example of this limitation is seen in standard coding technique to use gerunds, (Charmaz, 2006; Glaser, 1978) - nouns formed from verbs. Not all languages have a structure that allows verbs to be expressed as nouns. This limitation needed to be addressed carefully to ensure verbal data still had the same meaning in the process of constructing theory. In this study, coding in the English language, using gerunds as a standard technique, was difficult in the earlier process of analysis because there is no 'gerund' form in Indonesian. Gerunds therefore were only applied appropriately when categories were identified. Gerunds used in this study resulted from later analysis once the data fragments were translation from Indonesian into English.

Recommendations

Recommendations of this study have been divided into four areas: research, practice, education and policy.

Further research

The theory of connecting care can be tested in different regions and in different fields such as physical illness or other chronic illness. In addition, research related to properties in this connecting care also needs to be explored. Because all properties are important factors in which stakeholders make decisions and accept responsibility, research related to the type and amount of resources for example needs to be explored. Research also needs to be conducted to establish an appropriate level of competence for stakeholders who provide care to people living with a mental illness.

The theory of connecting care can be used to underpin future research to evaluate strategies aimed at reducing the incidence of the vicious cycle, wandering and shackling or other form of physical restraints. An action research design or a program evaluation design would be appropriate depending on the type of strategy developed and its point of implementation.

The fact that The Mental Health Act has not been enacted in Indonesia leads to the importance of conducting research to identify the barriers preventing this implementation.

Public policy debate is encouraged in Indonesia and the use of social media is widespread. Future research topics could include an analysis of the interaction between these two parts of Indonesian society in relation to the enactment of mental health legislation.

The burden of care is also a topic that needs to be explored in future research. This information will help each stakeholder to provide a sufficient support for the people who are responsible for providing care to individuals living with a mental health issue. In summary these recommendations are as follows:

1. Test the theory of connecting care in a different cultural context.
2. Explore more deeply the properties of the theory of connecting care.
3. Apply the theory of connecting care so that adverse outcomes of mental illness are reduced or overcome.
4. Investigate the problems or barriers preventing the full implementation of formal mental health legislation in Indonesia.
5. Examine in more detail the factors that contribute to a family's burden of care with the aim of identifying and developing more detailed strategies that could mitigate this.

Practice

Recognition of stakeholders' role in providing care is the first recommendations for practice. Care provision can be recognised by health professionals' affirmation of care giving efforts and a show of empathy for carers and the challenges involved. Health professionals might also make a greater effort to establish contact with a caregiver.

Improving stakeholders' knowledge and skills is the second recommendation for practice. Education could be offered to non-health professionals about common mental health problems and issues including relapse, medication and medication side effects. Also, health professionals would benefit from education and a better understanding of families' needs and burden of care. Knowledge and skills can be acquired through training.

Providing adequate resources for stakeholders is the third recommendation for practice. Resources such as psychiatric institution beds and services, and community based services need

to be accessible and available. One community-based service that must be established in Indonesia is respite care. Support from a social network (group) also needs to be available and accessible.

The last two recommendations for practice are to instil hope and tackle stigma. Instilling hope can be done by improving communication between health professionals, individuals living with a mental health issue and caregivers. The establishment of support networks consisting of family and friends also help to instil hope. Tackling stigma can be done by involving mental health service users and family to change attitudes and raise awareness through social education. In summary these recommendations are to:

1. Recognise non-health professionals for the care they provide.
2. Improve the knowledge and skills of health and non-health professionals.
3. Ensure resources are adequate for stakeholders.
4. Instil hope for stakeholders, particularly families and individuals living with a mental health issue.
5. Tackle stigma.

Research Methods

The recommendations for undertaking a grounded theory study in which a research team consists of people with different language backgrounds relate to the process of concurrent data collection/generation and analysis.

In regard to when data should be translated, it is recommended that translation take place during the analysis, particularly if all members of the research team come from different language and cultural backgrounds. Translation will make it possible for all members of the research team to be involved in analysis. In considering who should translate the data, it is recommended that this decision be based on theoretical or philosophical approaches applied to the study. The combination of translator moderator and professional translator is recommended for studies that apply social constructionist, non-positivist or interpretive approaches.

With regard to the procedure employed to translate the data, it is recommended that data be coded in the original language before translation of the coding into a different language. A combination of oral and written translation is best for the discussion process. A modified forward and backward translation method helps to maintain congruence between the original language and English in order to ensure that the published theory is grounded in the data. The process of translation is often complicated as it involves different stages of coding (initial, intermediate and advanced coding). Following the recommendations we have developed, however, will help research teams with multi-lingual needs to ensure valid and robust research findings. In summary the recommendations are as follows:

1. Identify in the planning phase of a grounded theory study at what point the data should be translated.
2. Nominate who should translate the data based on philosophical approaches used in the study.

Education

As a framework for improving mental health care service delivery in Indonesia, the theory of connecting care needs to be disseminated to academics and nurses to offer them the opportunity to be involved in the process of improving mental health service delivery in Indonesia. The first oral presentation of the findings will be at a national seminar, conducted in Bali, Indonesia, on 15 March 2014. In international scope, the theory of connecting care will be presented at an international conference, the first *Saudi Nursing Research Conference* on 6-8 May 2014.

Several manuscripts detailing the results of this study have been published or are under review. These publications however, are directed to an international audience and not specifically to the Indonesian community. The theory of connecting care will be written as a book in both the Indonesian and English language to expand the possibility for the Indonesian audience to access it. The researcher plans to approach academic publishing group, Elsevier, with a book proposal in the coming months.

To increase access to the findings for the Indonesian community, the researcher plans to write and publish media reports in newspapers or online. Two potential media outlets have been identified as a good place in which to publish the results. These are Kompas.com and *The Jakarta Post*. As well, the researcher will approach two professional nursing organizations, the Indonesian National Nurses Association (PPNI) and The Association of Indonesian Nurse Education Centre (AIPNI/AINEC) with the aim of educating clinicians about the key findings. Disseminating the findings to the PPNI will be important as this group is responsible for developing and regulating nursing care standards in Indonesia. Transferring the research findings to The AINEC is also important as this organisation is responsible for developing the nursing curriculum for undergraduate degrees in Indonesia which the researcher hopes will be influenced by the findings. In a proposal to the AINEC, the researcher will identify subjects in the curriculum where the theory of connecting care could be used with the aim of reducing the stigma of mental health and improving communication between stakeholders. In order to provide feedback to the Indonesian Health Department and Social Service Department, who the main providers of mental health care services, a short report will be provided outlining the findings and recommendations. This same report will be circulated to the study sites.

Policy

Fully implementing the mental health act or statute is the first policy recommendation made in this study. Legislation promotes a situation of matched decision-making and is expected to be a preliminary step in achieving better outcomes for individuals living with a mental health issue and caregivers. The second policy recommendation relates to the way policy should dictate that an adequate level of resources be made available to all stakeholders so that caregivers, either health professionals or non-health professionals, can provide optimum care to individuals living with a mental health issue and themselves. Policymakers also need to consider establishing a 'working system' in which psychiatric institutions work together and synchronise their institutional policy to ensure individuals living with a mental health issue are

cared for in a consistent manner across the country. In summary, the recommendations are as follows:

1. Implement fully a mental health act.
2. Ensure an adequate level of resources to provide care for individuals living with a mental health issue.
3. Promote a process whereby health professionals are able to work together to synchronise institutional policies for the provision of consistent mental health care.

Conclusion

In this study, the grounded theory of connecting care for individuals living with a mental health issue in Indonesia has been explained and evidenced using the data. The core category was connecting care. The three categories subsumed by the core category were decision-making, shifting responsibility and accepting responsibility. Decision-making was found to be central to the provision of care by health professionals and non-health professionals. Decision-making is characterised by four properties, each one of which influence individual stakeholders to varying degrees. These properties are a stakeholder's level of resources, competency, and willingness to provide care, and compliance with official policies. For health professionals, compliance with policy is the most important factor when making decisions while, for non-health professionals, especially family, decisions are influenced more strongly by consideration of the impact on the whole family and not just the affected individual. Stigma was one of the main factors that influenced a family's willingness to shift or accept responsibility to provide care. When making a decision, stakeholders will either shift responsibility or accept responsibility to provide care. The success and effectiveness of shifting responsibility is largely influenced by the quality of communication between stakeholders while accepting responsibility is also influenced by resources, competency and willingness. Decision-making between health professionals and non-health professionals needs to be matched to optimise collaborative care and health outcomes for affected individuals. The establishment of a mental health statute by the Indonesian government will enable decisions made by stakeholders to be

better matched through the provision of consistent guidelines and resources. Whether decision-making is matched or unmatched, shifting responsibility for care occurs and one stakeholder eventually will be appointed to accept responsibility for providing care. For families, low levels of resources, competency and willingness will influence the adequacy of care provided. Unmatched decision making in the context of stigma and poverty can result in human rights violations and a heavy burden of care for families. It is hoped that the theory of connecting care can be used as a framework to improve mental health service delivery in Indonesia.

REFERENCES

- AAMH Asia Australia Mental Health. (2013). Deepening ties with Indonesia in mental health. Retrieved 15 December 2013, from <http://aamh.edu.au/projects/indonesia>
- Achmada, Y. (2008). Adi Saputro Dirantai sejak Umur 4 Tahun. Retrieved 13 December 2013, from <http://regional.kompas.com/read/2008/02/21/13035937/Adi.Saputro.Dirantai.sejak.Umur.4.Tahun>
- Ahi, Y. (2009). Panti sosial akan di revitalisasi. Retrieved 25 January, 2014, from <http://www.republika.co.id/berita/breaking-news/nasional/09/11/09/87877-panti-sosial-akan-direvitalisasi>
- Ainun, Y. (2012). Tak ada SKM, Bayi 'Hydrocephalus' Ditolak di RS. Retrieved January, 10, 2014, from <http://regional.kompas.com/read/2012/10/24/14182276/Tak.Ada.SKM.Bayi.Hydrocephalus.Ditolak.di.RS>
- Allard, T. (2010). The face of Indonesia's shame. Retrieved 25 September, 2013, from <http://www.smh.com.au/world/the-face-of-indonesias-shame-20100618-ymuq.html>
- Alonso, J., Angermeyer, M., Bernert, S., Bruffaerts, R., Brugha, T., Bryson, H., . . . Vollebergh, W., A, M. (2004). Disability and quality of life impact of mental disorders in Europe: results from the European study of the epidemiology of mental disorders (ESEMED) project. *Acta psychiatrica scandinavica*, 1009(s420), 38-46.
- Annells, M. (1996). Grounded theory method: Philosophical perspectives, paradigm of inquiry, and postmodernism. *Qualitative Health Research*, 6(3), 379-393.
- Anthony, J., Baik, S., Bowers, B., Tidjani, B., Jacobson, J., & Susman, J. (2010). Conditions That Influence a Primary Care Clinician's Decision to Refer Patients for Depression Care. *Rehabilitation Nursing*, 35(3), 133-122.

- Antley, M., K. (1986). Writing and evaluating the grounded theory research report. In W. Chenitz, C & J. Swanson, M (Eds.), *From practice to grounded theory* (pp. 146-154). Mill Valley, California: Addison-Wesley.
- Awad, A., & Voruganti, L. (2008). The burden of schizophrenia on caregivers. *Pharmacoeconomics*, 26(2), 149-162.
- Backman, K., & Kyngäs, H. (1999). Challenges of the grounded theory approach to a novice researcher. *Nursing & Health Sciences*, 1(3), 147-153. doi: 10.1046/j.1442-2018.1999.00019.x
- Badan Pusat Statistik Provinsi D.I. Yogyakarta. (2014). Tingkat Kemiskinan D.I.Yogyakarta. Retrieved 25 January 2014, from <http://yogyakarta.bps.go.id/>
- Bangsals dan kapasitas TT. (2013). Rumah sakit jiwa daerah Surakarta. Retrieved 19 December 2013, from http://rsjd-surakarta.jatengprov.go.id/rsjd-surakarta/index.php?option=com_content&view=article&id=18&Itemid=43
- Beck, C. T. (1993). Qualitative research: the evaluation of its credibility, fittingness, and auditability. *Western Journal of Nursing research*, 15(2), 263-266.
- Belcher, J., R., & DeForge, B., R. (2005). The longitudinal discharge planning. *Social work in mental health*, 3(4), 17-35.
- Bellack, A.S. (2006). Scientific and consumer models of recovery in schizophrenia: concordance, contrasts, and implications. *Schisophr Bull*, 32(3), 432-442. Retrieved from doi:10.1093/schbul/sbj044. PMID 16461575. PMC 2632241. <http://schizophreniabulletin.oxfordjournals.org/cgi/pmidlookup?view=long&pmid=16461575>.
- Benzies, K., & Allen, M. (2001). Symbolic interactionism as a theoretical perspective for multiple method research. *Journal of Advanced Nursing*, 33(4), 541-547.
- Birks, M., & Mills, J. (2011). *Grounded theory a practical guide*. London: Sage.
- Bland, R., & Darlington, Y. (2002). The nature and sources of hope: Perspectives of family caregivers of people with serious mental illness. *Perspectives in Psychiatric Care*, 38(2), 61-68.

- Blumer, H. (1969). *Symbolic interactionism: Perspective and method*. Englewood Cliffs, NJ: Prentice Hall.
- BPS Provinsi Jawa Tengah. (2013). Berita Resmi Statistik BPS Provinsi Jawa Tengah. Retrieved 25 January, 2014, from http://jateng.bps.go.id/offrel/brs_pengangguran_1308_33.pdf
- Bradley, S., A. (2010). *Reconstructed grounded theory: beyond comparison?* Paper presented at the Networked Learning Conference 2010.
- Breckenridge, J., & Jones, D. (2009). Demystifying theoretical sampling in grounded theory Research. *Grounded Theory Review*, 8(2), 113-126.
- Brekke, J.S, Prindle, C., Bae, S.W., & Long, J.D. (2001). Risks for individuals with schizophrenia who are living in the community. *Psychiatric Services*, 52(10), 1358-1366.
- Broch, H.B. (2001). The villagers' reactions towards craziness: an Indonesian example. *Transcultural Psychiatry*, 38(3), 275-305.
- Bryant, A. (2009). *Grounded theory and pragmatism: The curious case of Anselm Strauss*. Paper presented at the Forum Qualitative Sozialforschung/Forum: Qualitative Social Research.
- Buckley, P., Miller, B., Lehrer, D., & Castle, D. (2009). Psychiatric comorbidities and schizophrenia. *Schizophrenia Bulletin*, 35(2), 383-402.
- Buila, S., & Swanke, J. (2010). Patient-Centered Mental Health Care: Encouraging Caregiver Participation. *Care Management Journals*, 11(3), 146-150. doi: 10.1891/1521-0987.11.3.146
- Castellano, M. B. (2004). Ethics of Aboriginal research. *Journal of Aboriginal Health January*, 99.
- Chakraborty, S., Sarker, S., & Sarker, S. (2010). An exploration into the process of requirements elicitation: a grounded approach. *Journal of the Association for Information Systems*, 11(4), 212-249.

- Chamberlain-Salaun, J., Mills, J., & Park, T. (2011). Mental health nurses employed in Australian general practice: Dimensions of time and space. *International Journal of Mental Health Nursing, 20*, 112-118.
- Chamberlain-Salaun, J., Mills, J., & Usher, K. (2013). Linking Symbolic Interactionism and Grounded Theory Methods in a Research Design: From Corbin and Strauss' Assumptions to Action: *Sage Open*.
- Charmaz, K. (2006). *Constructing grounded theory: A practical guide through qualitative analysis*. London and Thousand Oaks: Sage.
- Charon, J. (2001). *Symbolic Interactionism an introduction, an interpretation, an integration*. New Jersey: Prentice Hall.
- Charon, J. (2007). *Symbolic interactionism An Introduction, An Interpretation, An Integration*. New Jersey: Pearson Education.
- Chen, F., & Greenberg, J. (2004). A positive aspect of caregiving: The influence of social support on caregiving gains for family members of relatives with schizophrenia. *Community Mental Health Journal, 40*(5), 423-435.
- Chien, W., Chan, S., & Morrissey, J. (2007). The perceived burden among Chinese family caregivers of people with schizophrenia. *Journal of Clinical Nursing, 16*(6), 1151-1161.
- Chiovitti, R., & Piran, N. (2003). Rigour and grounded theory research. *Journal of Advanced Nursing, 44*(4), 427-435. doi: 10.1046/j.0309-2402.2003.02822.x
- Clark, R., & Drake, R. (1994). Expenditures of time and money by families of people with severe mental illness and substance use disorders. *Community Mental Health Journal, 30*(2), 145-163.
- Coffey, A., & Atkinson, P. (1996). *Making sense of qualitative data: Complementary research strategies*. Thousand Oaks, CA: Sage.
- Coniglio, F., Hancock, N., & Ellis, L. (2012). Peer support within Clubhouse: A grounded theory study. *Community Mental Health Journal, 48*, 153-160.
- Cooney, A. (2011). Rigour and grounded theory. *Nurse Researcher, 18*(4), 17.

- Corbin, J., & Strauss, A. (2008). *Basic of qualitative research: Techniques and procedure for developing grounded theory* Los Angeles: Sage.
- Coyne, I., & Cowley, S. (2006). Using grounded theory to research parent participation. *Journal of Research in Nursing, 11*(6), 501-515.
- Creswell, J. (1998). *Qualitative inquiry and research design: Choosing among five traditions*. Thousand Oaks, CA: Sage.
- Creswell, J. (2013). *Qualitative inquiry & research design*. Singapore: SAGE.
- Crotty, M. (1998). *The foundation of social research: Meaning and perspective in the research process*. Thousand Oaks: Sage.
- Curtis, K., Horton, K., & Smith, P. (2012). Student nurse socialisation in compassionate practice: A grounded theory study. *Nurse Education Today, 32*, 790-795.
- Cutcliffe, J. (2000). Methodological issues in grounded theory. *Journal of Advanced Nursing, 31*(6), 1476-1484.
- Cutcliffe, J. (2005). Adapt or adopt: developing and transgressing the methodological boundaries of grounded theory. *Journal of Advanced Nursing, 51*(4), 421-428. doi: 10.1111/j.1365-2648.2005.03514.x
- Daftar Provinsi dan luas wilayah Indonesia tahun 2010. (2010). Daftar Provinsi dan luas wilayah Indonesia tahun, 2010. Retrieved 25 January, 2014, from <http://indonesiadata.co.id/main/index.php/provinsi>
- Daftar Puskesmas - Dinkes Jateng. (n.d). Daftar Puskesmas - Dinkes Jateng. Retrieved 25 January, 2014, from http://www.dinkesjatengprov.go.id/dokumen/yankes/alamat_pusk09.pdf
- Das. (2011). Bangsal Jiwa RSUD Banyumas Disesaki Pasien Hasil Razia. Retrieved 21 December, 2013, from <http://www.pikiran-rakyat.com/node/160317>
- Davidson, L., Shahar, G., Lawless, M., S, Sells, D., & Tondora, J. (2006). Play, pleasure, and other positive life events: "non-specific" factors in recovery from mental illness? *Psychiatry, 69*(2), 151.

- De Laine, M. (1997). *Ethnography theory and applications in health research*. Australia: MacLennan & Petty Pty.
- Denzin, N. (2002). *The interpretive process*. Thousand Oaks, CA: Sage.
- Denzin, N., K., & Lincoln, Y., S. (2005). Introduction: The discipline and practice of qualitative research. In N. Denzin & Y. Lincoln (Eds.), *The SAGE handbook of qualitative research* (pp. 1-32). Thousand Oaks, CA: Sage.
- Dey, I. (1993). *Qualitative Data Analysis*. London, UK: Routledge.
- Dick, B. (2007). What can grounded theorist and action researchers learn from each other? In A. Bryant & K. Charmaz (Eds.), *The Sage handbook of grounded theory* (pp. 398-416). London: Sage.
- Dunne, C. (2010). The place of the literature review in grounded theory research. *International Journal of Social Research Methodology*, *14*(2), 111-124. doi: 10.1080/13645579.2010.494930
- Edmunds, S., & Brown, G. (2012). Doing qualitative research in dentistry and dental education. *European Journal of Dental Education*, *16*, 110-117.
- Egerod, I., Christensen, D., Schwartz-Nielsen, K. H., & Ågård, A. S. (2011). Constructing the illness narrative: a grounded theory exploring patients' and relatives' use of intensive care diaries. *Critical Care Medicine*, *39*(8), 1922-1928.
- Eisenhardt, K. M. (1989). Building theories from case study research. *Academy of Management Review*, *14*(4), 532-550.
- Exel, J., Graaf, G., & Brouwer, W. (2007). Care for a break? An investigation of informal caregivers' attitudes toward respite care using Q-methodology. *Health Policy*, *83*(2-3), 332-342. doi: <http://dx.doi.org/10.1016/j.healthpol.2007.02.002>
- Faizal, E. B. (2012). Mentally ill often taken to traditional practitioners, *The Jakarta Post*. Retrieved from <http://www.thejakartapost.com/news/2012/02/13/mentally-ill-often-taken-traditional-practitioners.html>
- Ferriter, M., & Huband, N. (2003). Experiences of parents with a son or daughter suffering from schizophrenia. *Journal of Psychiatric and Mental Health Nursing*, *10*(5), 552-560.

- Fine, G. (1993). The sad demise, mysterious disappearance, and glorious triumph of symbolic interactionism. *Annual Review Sociology, 19*, 61-87.
- Fletcher, D., & Sarkar, M. (2012). A grounded theory of psychological resilience in Olympic champions. *Psychology of Sport and Exercise, 13*(5), 669-678.
- Forchuk, C., Chan, L., Schofield, R., Martin, M., Sirceli, M., Woodcox, V., . . . Overby, B. (1998). Bridging the discharge process. *The Canadian Nurse, 94*(3), 22-26.
- Fujino, N., & Okamura, H. (2009). Factors affecting the sense of burden felt by family members caring for patients with mental illness. *Archives of Psychiatric Nursing, 23*(2), 128-137.
- Galdas, P., Cheater, F., & Marshall, P. (2005). Men and health help-seeking behaviour: literature review. *Journal of Advanced Nursing, 49*(6), 616-623.
- Gale, B. (2012). Unshackling mental illness mindsets in Indonesia. Retrieved 25 September, 2013, from <http://www.thejakartaglobe.com/opinion/unshackling-mental-illness-mindsets-in-indonesia/489451>
- Geller, J., Grudzinskas Jr, A., McDermeit, M., Fisher, W., & Lawlor, T. (1998). The efficacy of involuntary outpatient treatment in Massachusetts. *Administration and Policy in Mental Health and Mental Health Services Research, 25*(3), 271-285.
- Glaser, B. (1978). *Theoretical sensitivity: Advances in the methodology of grounded theory*. Mill Valley: Sociology Press.
- Glaser, B. (1992). *Basics of grounded theory analysis*. Mill Valley, CA: Sociology Press.
- Glaser, B. (1998). *Doing grounded theory: Issues and discussions*. Mill Valley, CA: Sociology Press.
- Glaser, B. (2008). *Doing quantitative grounded theory*. Mill Valley, CA: Sociology Press.
- Glaser, B., & Strauss, A. L. (1967). *The discovery of grounded theory: Strategies for qualitative research*. New York: Aldine.
- Government of The Republic of Indonesia. (2007). An assessment of people's livelihoods in Yogyakarta and Central Java Provinces pre and post disaster. Retrieved 25 January 2014, from http://www.fao.org/fileadmin/templates/tc/tce/pdf/Yogya_Indonesia.pdf

- Grhasia, S. b. R. J. (2013). Rumah Sakit Jiwa Grhasia. Retrieved 19 December, 2013, from <http://grhasia.jogjaprov.go.id/index.php/profil/sejarah-berdirinya-rs-jiwa-grhasia>
- Hall, H., Griffiths, D., & McKenna, L. (2013). From Darwin to constructivism: the evolution of grounded theory. *Nurse Researcher*, 20(3), 17-21.
- Hall, H., McKenna, L., & Griffiths, D. (2012). Applying Grounded Theory of Midwifery research Problems. *International Journal of Childbirth*, 2(2), 136-141.
- Hall, W., & Callery, P. (2001). Enhancing the rigor of grounded theory: incorporating reflexivity and relationality. *Qualitative Health Research*, 11(2), 257-272.
- Hallber, L. (2006). The "core category" of grounded theory: making constant comparisons. *International journal of qualitative studies on health and well-being*, 1, 141-148.
- Haraldsson, K., Lindgren, E., Mattsson, B., Fridlund, B., & Marklund, B. (2011). Adolescent girls' experiences of underlying social processes triggering stress in their everyday life: a grounded theory study. *Stress and Health*, 27, e61-170.
- Harling, M., R., & Turner, W. (2012). Student nurses' attitudes to illicit drugs: A grounded theory study. *Nurse Education Today*, 32(3), 235-240.
- Harnowo, P., A. (2013). 8 Propinsi di Indonesia Tak Punya Rumah Sakit Jiwa. Retrieved 15 December, 2013, from <http://health.detik.com/read/2013/07/31/104440/2319785/763/8-provinsi-di-indonesia-tak-punya-rumah-sakit-jiwa>
- Henwood, K., & Pidgeon, N. (2006). Grounded theory. In G. Breakwell, M. S. Hammond, C. Fife-Shaw & J. Smith, A (Eds.), *Research methods in psychology* (pp. 342-365). Thousand Oaks, CA: Sage.
- Herrman, H., Trauer, T., & Warnock, J. (2002). The roles and relationships of psychiatrists and other service providers in mental health services. *Australian and New Zealand Journal of Psychiatry*, 36(1), 75-80.
- Hickey, G., & Kipping, C. (1998). Exploring the concept of user involvement in mental health through a participation continuum. *Journal of Clinical Nursing*, 7(1), 83-88.

- Hiday, V.A., Swanson, J.W., Swartz, M.S., Borum, R., & Wagner, H. R. (2001). Victimization: A link between mental illness and violence? *International Journal of Law and Psychiatry*, 24(6), 559-572.
- Hiday, V., A, Swartz, M., S, Swanson, J., W, Borum, R., & Wagner, R. (1999). Criminal victimization of persons with severe mental illness. *Psychiatric Services*, 50, 18-24.
- Hidup di Panti Penampungan Penderita Gangguan Jiwa. (2010). Radio Nederland Wereldomroep Indonesia. Retrieved January, 8, 2014, from <http://archieff.rnw.nl/bahasa-indonesia/article/hidup-di-panti-penampungan-penderita-gangguan-jiwa>
- Hoare, K., J, Mills, J., & Francis, K. (2012). Dancing with data: An example of acquiring theoretical sensitivity in a grounded theory study. *International Journal of Nursing Practice*, 18, 240-245.
- Hoenig, J., & Hamilton, M. W. (1966). Schizophrenia in an extramural service. *Comprehensive Psychiatry*, 7(2), 81-91.
- Holton, J. (2007). The coding process and its challenges. In A. Bryant & K. Charmaz (Eds.), *The Sage handbook of grounded theory* (pp. 265-289). London: Sage.
- Horn, J. (1998). Qualitative research literature. A bibliographic essay. *Library Trends*, 16(4), 602-615.
- Hugo, G. (2002). Effects of international migration on the family in Indonesia. *Asian and Pacific Migration Journal*, 11, 13-46.
- Hunter, A., Murphy, K., Grealish, A., Casey, D., & Keady, J. (2011). Navigating the grounded theory terrain. Part 1. *Nurse Researcher*, 18(4), 6-10.
- Hutchinson, S. (1993). Grounded theory: The method In P. Munhall, L & C. Boyd, A (Eds.), *Nursing research: A qualitative perspective*. New York: National League for Nursing Press.
- Idaiani, S. (2013). Integrating mental health into the national survey. Retrieved 22 January, 2014, from <http://www.ttwud.org/mentalhealth/entry/integrating-mental-health-national-health-survey#.Ut8DMhBAqHs>

- Idrees, I., Vasconcelos, A., C., & Cox, A., M. (2011). The use of grounded theory in PhD research in knowledge management. *New Information Perspective*, 63(2/3), 199-203.
- Info puskesmas. (2011). Macam-macam kader dalam pelayanan kesehatan. Retrieved 24 January, 2014, from <http://coretanpuskesmasku.blogspot.com.au/2011/10/macam-macam-kader-dalam-pelayanan.html>
- INK. (2009). Tergangung Jiwanya, tapi Lis Empat Kali Melahirkan. Retrieved 13 December 2013, 2013, from <http://regional.kompas.com/read/2009/04/21/22291083/Terganggu.Jiwanya..tapi.Lis.Empat.Kali.Melahirkan>
- Irmansyah, I. (2009). Undang Undang Kesehatan Jiwa, Kebutuhan yang Mendesak. Retrieved 15 December, 2013, from <http://noriyu.wordpress.com/2009/01/20/undang-undang-kesehatan-jiwa-kebutuhan-yang-mendesak/>
- Irmansyah, I., Prasetyo, Y., & Minas, H. (2009). Human rights of persons with mental illness in Indonesia: More than legislation is needed. *International Journal of Mental Health Systems*, 3. doi: <http://dx.doi.org/10.1186/1752-4458-3-14>
- Jamkesmas Belum Turun. (2009). Regional. Retrieved 12 December, 2013, from <http://travel.kompas.com/read/2009/03/03/18012593/Jamkesmas.Belum.Turun>
- Jennings, G., Kensbock, S., Junek, O., Radel, K., & Kachel, U. (2010). Lived Experiences of Early Career Researchers: Learning About and Doing Grounded Theory. *Journal of Hospitality and Tourism Management*, 17(1), 21-33.
- Jirojwong, S., Johnson, M., & Welch, A. (2011). *Research methods in nursing and midwifery*. Australia: Oxford University Press.
- Kaas, M., Lee, S., & Peitzman, C. (2003). Barriers to collaboration between mental health professionals and families in the care of persons with serious mental illness. *Issues in Mental Health Nursing*, 24(8), 741-756.
- Keliat, B. (2008). Community Mental Health Nursing (CMHN). Retrieved 4 March, 2011, from <http://budiannakeliat.blogspot.com/search?updated-min=2008-01->

01T00%3A00%3A00%2B07%3A00&updated-max=2009-01-

01T00%3A00%3A00%2B07%3A00&max-results=2

Kementrian Sekretariat Negara Republik Indonesia. (2010). The Geography of Indonesia.

Retrieved January, 13, 2014, from <http://www.indonesia.go.id/en/indonesia-glance/geography-indonesia>

Kline, N., S. (1963). Psychiatry in Indonesia. *The american journal of psychiatry*, 119(9), 809-815.

Konecki, K. T. (2011). Visual Grounded Theory: A methodological outline and examples from empirical work. *Revija za Sociologiju*, 41(2), 131-160.

Koponen, T., Jahi, R., Mannikko, M., Lipponen, V., Åstedt-Kurki, P., & Paavilainen, E. (2012). The diversity of being a relative of a mental ill people- the peer group as the object of research. *Hoitotiede*, 24(2), 138-149.

Kulkarni, V., V. (2012). 'Grounded Theory': An emerging theoretical perspective of social work research. *Review of Research*, 1(12), 1-4.

Kurihara, T., Kato, M., Kashima, H., Takebayashi, T., Reverger, R., & Tirta, I. (2006). Excess mortality of schizophrenia in the developing country of Bali. *Schizophrenia Research*, 83(1), 103-105. doi: 10.1192/bjp.173.1.11

<http://dx.doi.org/10.1016/j.schres.2006.01.018>

Kurihara, T., Kato, M., Reverger, R., & Tirta, I. (2006). Beliefs about causes of schizophrenia among family members: a community-based survey in Bali. *Psychiatric Services*, 57(12), 1795-1799.

Lauber, C., Eichenberger, A., Luginbühl, P., Keller, C., & Rössler, W. (2003). Determinants of burden in caregivers of patients with exacerbating schizophrenia. *European Psychiatry*, 18(6), 285-289.

Lavoie, J. (2013). Eye of the beholder: perceived stress, coping style, and coping effectiveness among discharged psychiatric patients. *Archives of Psychiatric Nursing*, 27(4), 185-190.

- Lazarus, R. (1993). Coping theory and research: past, present and future. *Psychosomatic Medicine*, 55, 234-247.
- Lazarus, R. (1998). *Fifty years of the research and theory of R.S Lazarus An analysis of historical and perennial issues*. New Jersey: Lawrence Erlbaum Associates.
- Lefley, H. (1997). Synthesizing the family caregiving studies: Implications for service planning, social policy, and further research. *Family Relations*, 46(4), 443-450.
- Lempert, L. (2007). Asking questions of the data: Memo writing in the grounded theory tradition. In A. Bryant & K. Charmaz (Eds.), *The Sage handbook of grounded theory*. London, United Kingdom: Sage.
- Levers, M. (2013). Philosophical Paradigms, Grounded Theory, and Perspectives on Emergence. *Sage Open*, 3(4).
- Locke, K. (2001). *Grounded theory in management research*. London: Sage.
- Lurie, S.G. (2010). Nuremberg Code. *Encyclopedia of Research Design*. from http://br9xy4lf5w.search.serialssolutions.com/?ctx_ver=Z39.88-2004&ctx_enc=info%3Aofi%2Fenc%3AUTF-8&rft_id=info:sid/summon.serialssolutions.com&rft_val_fmt=info:ofi/fmt:kev:mtx:book&rft.genre=book%20item&rft.title=Encyclopedia+of+Research+Design&rft.atitle=Nuremberg+Code&rft.date=2010-01-01&rft.pub=Sage+Publications%2C+Inc&rft.isbn=9781412961271&rft.volume=2&rft.space=942&rft.epage=944&rft.externalDocID=1959400290¶mdict=en-US
- Ma'ruf, H., M. (2007). *Peraturan Menteri Dalam Negeri Nomor 7 Tahun 2007*. Jakarta: Kementrian Dalam Negeri/Ministry of Home Affairs Retrieved from <http://www.kemendagri.go.id/produk-hukum/2007/02/20/peraturan-mendagri-no-7-tahun-2007>.
- MacDonald, K. (2011). Chasing Stigma in Indonesia. Retrieved 25 September, 2013, from <http://lens.blogs.nytimes.com/2011/06/14/chasing-stigma-in-indonesia/#/17/>
- Madianos, M. (2002). Deinstitutionalization and the closure of public mental hospitals. *International journal of mental health*, 31, 66-75.

- Maijala, H., Paavilainen, E., & Astedt-Kurki, P. (2003). The use of grounded theory to study interaction. *Nurse Researcher, 11*(2), 40-57.
- Maramis, A. (2006). After the tsunami, building back for better mental health in Aceh. *Journal of Psychiatry, 7*(1), 45-48.
- Maramis, A., Tuan, N.V., & Minas, H. (2011). Mental health in southeast Asia. 377.
<http://www.thelancet.com>
- March, J. (1994). *A primer on decision making: How decisions happen*. New York: Simon & Schuster Inc.
- Martens, L., & Addington, J. (2001). The psychological well-being of family members of individuals with schizophrenia. *Social psychiatry and psychiatric epidemiology, 36*(3), 128-133.
- Maurin, J., & Boyd, C. (1990). Burden of mental illness on the family: a critical review. *Archives of Psychiatric Nursing, 4*(2), 99-107.
- May, K. (1994). Abatract knowing: the case for magic in method. In J. Morse (Ed.), *Critical issues in qualitative research methods* (pp. 10-22). London: Sage.
- McCallin, A. (2003). Grappling with the literature in a grounded theory study. *Contemporary Nurse, 15*(1-2), 7-18.
- McCann, T., & Clark, E. (2003a). Grounded theory in nursing research: Part 1 - Methodology. *Nurse Researcher, 11*(2), 7-18.
- McCann, T., & Clark, E. (2003b). Grounded theory in nursing research: Part 3 - Application. *Nurse Researcher, 11*(2), 29-39.
- McGhee, G., Marland, G., & Atkinson, J. (2007). Grounded theory research: literature reviewing and reflexivity. *Journal of Advanced Nursing, 60*(3), 334-342. doi: 10.1111/j.1365-2648.2007.04436.x
- McMenamin, I. (2006). Process and text: Teaching students to review the literature. *PS: Political Science and Politics, 39*(1), 133-135.

- Miller, J., & Glassner, B. (2011). The "Inside" and the "Outside": Finding realities in interview. In D. Silverman (Ed.), *Qualitative Research*. Thousand Oaks, California: SAGE Publications Inc.
- Mills, J., Bonner, A., & Francis, K. (2008). The development of constructivist grounded theory. *International Journal of Qualitative Methods*, 5(1), 25-35.
- Minas, H. (2009). Mental health and human rights: Never waste a serious crisis. *International Journal of Mental Health Systems*, 3. doi: <http://dx.doi.org/10.1186/1752-4458-3-12>
- Minas, H., & Diatri, H. (2008). Pasung: Physical restraint and confinement of the mentally ill in the community. *International Journal of Mental Health Systems*, 2.
- Ministry of Health Republic of Indonesia. (2010a). Jalan sehat peringati hari kesehatan jiwa sedunia. Retrieved 8 October 2013, 2013, from <http://www.depkes.go.id/index.php?vw=2&id=1247>
- Ministry of Health Republic of Indonesia. (2010b). Kesehatan jiwa sebagai prioritas global 2009. Retrieved 8 October, 2013, from <http://www.depkes.go.id/index.php?vw=2&id=392>
- Ministry of Health Republic of Indonesia. (2010c). Menuju Indonesia bebas pasung. Retrieved 8 October, 2013, from <http://www.depkes.go.id/index.php?vw=2&id=1242>
- Ministry of Health Republic of Indonesia. (2010d). Perempuan dua kali lebih banyak terkena gangguan jiwa ringan dibandingkan laki-laki. Retrieved 8 October, 2013, from <http://www.depkes.go.id/index.php?vw=2&id=1101>
- Ministry of Health Republic of Indonesia. (2011a). Implementasi primary health care di Indonesia,. Retrieved January, 8, 2014, from <http://www.depkes.go.id/index.php?vw=2&id=1558>
- Ministry of Health Republic of Indonesia. (2011b). Puskesmas sebagai penggerak pembangunan kesehatan setempat,. Retrieved January, 8, 2014, from <http://www.depkes.go.id/index.php?vw=2&id=1579>
- Ministry of Health Republic of Indonesia. (2011c). Reformasi primary health care. Retrieved January, 8, 2014, from <http://www.depkes.go.id/index.php?vw=2&id=1382>

- Ministry of Health Republic of Indonesia. (2011d). Tujuh kementerian berkoordinasi tanggulangi masalah kesehatan jiwa di Indonesia,. Retrieved 8 October, 2013, from <http://www.depkes.go.id/index.php?vw=2&id=1588>
- Ministry of Health Republic of Indonesia. (2012). Deteksi kesehatan jiwa dilakukan di puskesmas. Retrieved 24 January, 2014, from <http://www.depkes.go.id/index.php/index.php?vw=2&id=1480>
- Ministry of Social Affairs of the Republic Indonesia. (2013). Visi: Terwujudnya kesejahteraan sosial masyarakat. Retrieved 15 December 2013, from <http://kemsos.go.id/modules.php?name=Depsos>
- Mishler, E. (1991). *Research interviewing: Context and narrative*. Harvard, MA: Harvard University Press.
- Mnl. (2011). Hasil final jumlah penduduk Indonesia 2010. Retrieved 25 January, 2014, from <http://indonesiadata.co.id/main/index.php/jumlah-penduduk>
- Morris, P. (1981). The cognitive psychology of self-reports. In C. Antaki (Ed.), *The psychology of ordinary explanations of social behavior*. London: Academic Press.
- Morse, J. (2010). Sampling in grounded theory. *The Sage handbook of grounded theory*, 229-244.
- Mukotekwa, C., & Carson, E. (2007). Improving the discharge planning process: a systems study. *Journal of research in nursing*, 12(6), 667-686.
- Nathaniel, A. K. (2006). Thoughts on the literature review and GT. *Grounded Theory Review*, 5(2/3), 35-41.
- Noble, L., & Douglas, B. (2004). What users and relatives want from mental health services. *Current Opinion in Psychiatry*, 17(4), 289-296.
- Noor, R. (2012). Masalah Perkotaan Berkeliaran Bebas, Orang Sakit Jiwa Berlagak Bak Polantas. Retrieved January 4, 2012, from <http://manado.tribunnews.com/2012/08/14/berkelian-bebas-orang-sakit-jiwa-berlagak-bak-polantas>

- Nurjannah, I., FitzGerald, M., & Foster, K. (2009). Patient's experiences of absconding from a psychiatric setting in Indonesia. *International Journal of Mental Health Nursing*, 18, 326-335.
- O'Sullivan. (1986). Discharge planning for the mentally disabled. *Quality review bulletin*, 12(2), 55-67.
- Ohaeri, J. (2001). Caregiver burden and psychotic patients' perception of social support in a Nigerian setting. *Social psychiatry and psychiatric epidemiology*, 36(2), 86-93.
- Orlikowski, W. (1993). CASE tools as organizational change: investigating incremental and radical changes in systems development. *MIS quarterly*, 17(3), 309-340.
- Pakenham, K. (2012). Caregiving tasks in caring for an adult with mental illness and associations with adjustment outcomes. *International Journal of Behavioral Medicine*, 19(2), 186-198. doi: 10.1007/s12529-011-9155-8
- Panti Sosial Bina Karya. (n.d). Pemerintah Provinsi Daerah Istimewa Yogyakarta Dinas sosial. Retrieved January 8, 2014, from <http://portal.jogjaprov.go.id/attachments/article/166/panti%20sosial%20bina%20karya.pdf>
- Patriajati, S. (2013). Sejarah askes. Retrieved 25 January 2014, from <http://www.slideshare.net/spjati/sejarah-askes>
- Pemerintah Daerah Daerah Istimewa Jogjakarta. (2010). Pemerintah Daerah Daerah Istimewa Jogjakarta. Retrieved 9 December, 2013, from <http://www.pemda-diy.go.id/>
- Perawatan, R. (2013). Fasilitas. Retrieved 19 December, 2013, from http://www.rsjd-klaten.com/index.php?option=com_content&view=article&id=72&Itemid=53
- Pinoci, A. (2014). Daftar rumah sakit di Jawa Tengah. Retrieved 25 January, 2014, from <http://ariepinoci.blogspot.com.au/2012/05/daftar-rumah-sakit-di-jawa-tengah.html>
- Plummer, M., & Young, L. E. (2009). Grounded theory and feminist inquiry: Revitalizing links to the past. *Western Journal of Nursing research*, 32, 305.
- Priebe, S., Katsakou, C., Yeeles, K., Amos, T., Morriss, R., Wang, D., & Wykes, T. (2011). Predictors of clinical and social outcomes following involuntary hospital admission: a

- prospective observational study. *European archives of psychiatry and clinical neuroscience*, 261(5), 377-386.
- Procter, S. (1995). The contribution of inductive and deductive theory to the development of practitioner knowledge. In J. Reed & S. Procter (Eds.), *In Practitioner Research in Health Care* (pp. 62-79). London: Chapman.
- Purnamasari, D., D. (2013). Pusat Rehabilitation Mental Sinai: Pasien Gangguan Mental Dibina Hingga Sembuh. Retrieved 24 January, 2014, from <http://www.sragenpos.com/2013/pusat-rehabilitasi-mental-sinai-pasien-gangguan-mental-dibina-hingga-sem-buh-459712>
- Puteh, I., Marthoenis, M., & Minas, H. (2011). Aceh Free Pasung: Releasing the mentally ill from physical restraint. *International Journal of Mental Health Systems*, 5. doi: <http://dx.doi.org/10.1186/1752-4458-5-10>
- Putra, A. (2008). Suwato 16 tahun Diikat di Batang Pisang. Retrieved 13 December, 2013, from <http://regional.kompas.com/read/2008/01/24/07415249/Suwato.16.Tahun.Diikat.Di.Batang.Pisang>
- Rasuni, S. (2012). Orang Gila Sengaja Di buang ke Jakarta? Retrieved 24 January, 2014, from <http://sosbud.kompasiana.com/2012/09/09/orang-gila-sengaja-dibuang-ke-jakarta-491442.html>
- Raue, P., Schulberg, H., Lewis-Fernandez, R., Boutin-Foster, C., Hoffman, A., & Bruce, M. (2010). Shared decision-making in the primary care treatment of late-life major depression: a needed new intervention? *International Journal of Geriatric Psychiatry*, 25, 1101-1111.
- Regulasi Jamkesmas. (2013). Jamsos.com Indonesia. Retrieved 12 December, 2013, from http://www.jamsosindonesia.com/cetak/print_artikel/34
- Reichertz, J. (2007). *Abduction: The logic of discovery of grounded theory*: Sage.

- Rennie, D., L., Phillips, J., R., & Quartaro, G., K. (1988). Grounded theory: A promising approach to conceptualization in psychology? *Canadian Psychology/Psychologie canadienne*, 29(2), 139-150. doi: 10.1037/h0079765
- Rhoades, D., & McFarland, K. (1999). Caregiver meaning: A study of caregivers of individuals with mental illness. *Health & Social Work*, 24(4), 291-298.
- Ridley, J., Hunter, S., & Rosengard, A. (2010). Partners in care?: views and experiences of carers from a cohort study of the early implementation of the Mental Health (Care & Treatment) (Scotland) Act 2003. *Health & Social Care in the Community*, 18(5), 474-482. doi: 10.1111/j.1365-2524.2010.00920.x
- Rose, L., Mallinson, R., & Walton-Moss, B. (2002). A grounded theory of families responding to mental illness. *Western Journal of Nursing Research*, 24(5), 516-536.
- Ryan, H. (2013). 'Chains free' mental health campaign in Indonesia may end pasung, *Pacific.Scoop*. Retrieved from <http://pacific.scoop.co.nz/2013/05/chains-free-mental-health-campaign-in-indonesia-may-end-pasung/>
- Safitri, D. (2011). Shackling trauma of Indonesia's mental health patients. Retrieved 25 September, 2013, from <http://www.bbc.co.uk/news/world-asia-pacific-15351213>
- Saunders, J. (1999). Family functioning in families providing care for a family member with schizophrenia. *Issues in Mental Health Nursing*, 20(2), 95-113.
- Sbaraini, A., Carter, S., Evans, R., & Blinkhorn, A. (2011). How to do a grounded theory study: a worked example of a study of dental practices. *BMC medical research methodology*, 11(1), 128.
- Schwandt, T. (2007). *The Sage Dictionary of Qualitative Inquiry*. Singapore: Sage Publication, Inc.
- Sebelum ke RS peserata BPJS wajib dirujuk dokter. (2013). Sebelum ke RS peserata BPJS wajib dirujuk dokter,. Retrieved 25 January, 2014, from http://www.bbc.co.uk/indonesia/berita_indonesia/2013/12/131231_bpjs_jalan.shtml

- Setiawan, G., & Viora, E. (2006). Disaster mental health preparedness plan in Indonesia. *International Review of Psychiatry*, 18(6), 563-566. doi:
<http://dx.doi.org/10.1080/09540260601037920>
- Shibutani, T. (1962). Reference groups and social control. In A. Rose (Ed.), *Human behavior and Social processes: An Interactionist Approach*. London: Routledge & Kegan Paul.
- Siagian, Y. (2013). Diduga Kiriman dari Daerah Lain Tiba-tiba Banyak Orang Gila di Lumajang. Retrieved 24 January, 2014, from
http://beritajatim.com/politik_pemerintahan/169582/Tiba-tiba_Banyak_Orang_Gila_di_Lumajang.html#.UuIqOdI_7s0
- Silverman, D. (2001). *Interpreting qualitative data: Methods for analysing talk, text and interaction*. London: Sage.
- Silverman, D. (2011). *Interpreting qualitative data*: Sage.
- Silverman, D. (2013). *Doing qualitative research: A practical handbook*: SAGE Publications Limited.
- Solomon, P., Cavanaugh, M., & Gelles, R. (2005). Family Violence among Adults with Severe Mental Illness A Neglected Area of Research. *Trauma, Violence, & Abuse*, 6(1), 40-54.
- Stern, P. (2007). On solid ground: Essential properties for growing grounded theory. In A. Bryant & K. Charmaz (Eds.), *The Sage handbook of grounded theory* (pp. 114-126). London: Sage.
- Stern, P., & Porr, C. (2011). *Essentials of Accessible Grounded Theory*. United States of America: Left Coast Press, Inc.
- Strauss, A. (1987). *Qualitative analysis for social scientists*. Cambridge, UK: Cambridge University Press.
- Strauss, A. (1993). *Continual permutations of action*. New York: Aldine De Gruyter.
- Strauss, A., & Corbin, J. (1990). *Basics of qualitative research: Grounded theory procedures and techniques*. Newbury Park, CA: Sage.
- Strauss, A., & Corbin, J. (1998). *Basics of qualitative research: techniques and procedures for developing grounded theory*. Thousand Oaks: Sage Publication.

- Suarez, R. (2011). Indonesia's Mentally Ill Face Neglect, Mistreatment. Retrieved 25 September 2013, from http://www.pbs.org/newshour/bb/health/july-dec11/mentalhealth_07-18.html
- Suksmalana, T., & Pramitasari, D. (2012). Panti Sosial Bina Karya di Yogyakarta. Retrieved January, 8, 2014, from http://www.academia.edu/4480949/PANTI_SOSIAL_BINA_KARYA
- Suriani, & Hadi, C. (2008). Kemiskinan jumlah pasien gangguan jiwa meningkat. Retrieved 4 March, 2011, from <http://www.sinarharapan.co.id/berita/0804/28/sh05.html>
- Suro, G., & Weisman de Mamani, A. (2012). Burden, interdependence, ethnicity, and mental health in caregivers of patients with schizophrenia. *Family Process*.
- Susanto, H. (2013). Orang miskin di Jawa Tengah capai 4,733 juta jiwa. *Jawa Tengah dan DIY*. Retrieved 25 January, 2014, from <http://daerah.sindonews.com/read/2013/10/30/22/800181/orang-miskin-di-jawa-tengah-capai-4-733-juta-jiwa>
- Tan, S., Yeoh, A., Choo, I., Huang, A., Ong, S., Ismail, H., . . . Chan, Y. (2012). Burden and coping strategies experienced by caregivers of persons with schizophrenia in the community. *Journal of Clinical Nursing*, 21(17/18), 2410-2418. doi: 10.1111/j.1365-2702.2012.04174.x
- Thompson, O., P, Petty, N., J, & Scholes, J. (2012). Grounding osteopathic research - Introducing grounded theory. *International Journal of Osteopathic Medicine*.
- Tsang, H., Tam, P., Chan, F., & Chang, W. (2003). Sources of burdens on families of individuals with mental illness. *International Journal of Rehabilitation Research*, 26(2), 123-130.
- United Nations. (2012). What are human rights? Retrieved January, 13, 2014, from <http://www.ohchr.org/EN/Issues/Pages/WhatareHumanRights.aspx>
- Urquhart, C. (2001). An encounter with grounded theory: tackling the practical and philosophical issues. *Qualitative research in IS: Issues and Trends*, 104-140.

- Urquhart, C. (2007). The evolving nature of grounded theory method: The case of the information systems discipline. In A. Bryant & K. Charmaz (Eds.), *The Sage handbook of grounded theory* (pp. 339-360). London: Sage.
- Urquhart, C. (2013). *Grounded Theory for Qualitative Research A Practical Guide*. Singapore: SAGE.
- Urquhart, C., Lehmann, H., & Myers, M., D. (2010). Putting the 'theory' back into grounded theory: guidelines for grounded theory studies in information systems. *Information Systems Journal*, 20(4), 357-381.
- van Niekerk, J., C., & Roode, J., D. (2009). *Glaserian and straussian grounded theory: Similar or completely different?* Paper presented at the Proceedings of the 2009 Annual Research Conference of the South African Institute of Computer Scientists and Information Technologists.
- Wai-Chi, C. (2011). Global perspective of burden of family caregivers for person with schizophrenia. *Archives of Psychiatric Nursing*, 25(5), 339-349.
- Walsh, E., Moran, P., Scott, C., McKenzie, K., Burns, T., Creed, F., . . . Fahy, T. (2003). Prevalence of violent victimisation in severe mental illness. *The British Journal of Psychiatry*, 183(3), 233-238.
- WHO. (1996a). Guidelines for the promotion of human rights of persons with mental disorders. Retrieved 18 October, 2013, from http://www.who.int/mental_health/policy/legislation/guidelines_promotion.pdf
- WHO. (1996b). Mental health law ten basic principles. Retrieved 18 October, 2013, from http://www.who.int/mental_health/policy/legislation/ten_basic_principles.pdf
- WHO. (1997). Principle for the protection of persons with mental illness and the improvement of mental health care. Retrieved 18 October 2013, from http://www.who.int/mental_health/policy/en/UN_Resolution_on_protection_of_persons_with_mental_illness.pdf

- WHO. (2003). Mental Health Policy and Service Guidance Package Advocacy for Mental Health. Retrieved 27 January, 2014, from http://www.who.int/mental_health/policy/services/1_advocacy_WEB_07.pdf?ua=1
- WHO. (2004). *The role of international human rights national mental health legislation*. Retrieved October, 18, 2013, from http://www.who.int/mental_health/policy/international_hr_in_national_mhlegislation.pdf
- WHO. (2005). WHO Resource Book on Mental Health Human Rights and Legislation Stop exclusion, dare to care. Retrieved 18 October, 2013, from http://www.who.int/mental_health/policy/who_rb_mnh_hr_leg_FINAL_11_07_05.pdf
- WHO. (2006). WHO mental health and human right project. Retrieved 18 October, 2013, from http://www.who.int/mental_health/policy/mental_health_and_human_rights_october_2006.pdf
- WHO. (2010). Chapter 1: A public health approach to mental health.
- WHO. (2011). Mental Health Atlas 2011. Retrieved 13 June, 2013, from http://www.who.int/mental_health/evidence/atlas/profiles/idn_mh_profile.pdf
- WHO. (2013a). Mental Health Action Plan 2013 - 2020. Retrieved January 7, 2014, from http://apps.who.int/iris/bitstream/10665/89966/1/9789241506021_eng.pdf
- WHO. (2013b). Millenium Development Goals (MDGs). Retrieved December, 15, 2013, from http://www.who.int/topics/millennium_development_goals/about/en/index.html
- WHO. (2013c). World Health Statistic 2013. Retrieved 4 May, 2013, from <http://www.who.int>

Legislation

Ministry of Home Affair's directive from 1977 (PEM 26/6/15)

Act. No. 40 (2004)

Health Act. No. 36 (2009)

Act. No. 24 (2011)

Ministry of Health Regulation No.29 (2012)

Presidential Regulation No. 101 (2012)

Presidential Regulation No. 12 (2013)

LIST OF APPENDICES

Appendix A	Human Ethics Approval James Cook University
Appendix B	Research Permissions
Appendix C	A Proof of Translation Checked
Appendix D	Information Sheet
	Appendix D1 Information Sheet in English
	Appendix D2 Information Sheet in Indonesian
Appendix E	Informed Consent Sheet
	Appendix E1 Information Sheet in English
	Appendix E2 Information Sheet in Indonesian
Appendix F	An Example of Memo Audit Trail
Appendix G	An Example of Memo
Appendix H	Approval for Ethics Amendment
Appendix I	Research Permission
Appendix J	Information Sheets
	Appendix J1 Information Sheet: Family and Carer (English)
	Appendix J2 Information Sheet: Individual Living with a Mental Health Issue (English)
	Appendix J3 Information Sheet: Health Professional (English)
	Appendix J4 Information Sheet: Leader in Community (English)
	Appendix J5 Information Sheet: Health Professionals (Indonesian)
	Appendix J6 Information Sheet: Individual Living with a Mental Health Issue (Indonesian)
	Appendix J7 Information Sheet: Family and Cadre (Indonesian)
	Appendix J8 Information Sheet: Leader in Community (Indonesian)
Appendix K	Informed Consent Sheets
	Appendix K1 Informed Consent Sheet: Family and Cadre (English)

Appendix K2 Informed Consent Sheet: Leader in Community (English)

Appendix K3 Informed Consent Sheet: Health Professional (English)

Appendix K4 Informed Consent Sheet: Individual living with a Mental Health Issue (English)

Appendix K5 Informed Consent Sheet: Individual living with a Mental Health Issue (Indonesian)

Appendix K6 Informed Consent Sheet: Family and Cadre (Indonesian)

Appendix K7 Informed Consent Sheet: Health Professional (Indonesian)

Appendix K8 Informed Consent Sheet: Leader in Community (Indonesian)

Appendix L Ethics Amendment Approval

Appendix M Research Permissions

Appendix N Evidence in Indonesian

Appendix O Evidence Sub-categories were Constructed Through Sorting Memos

This administrative form
has been removed

This administrative form
has been removed

This administrative form
has been removed

This administrative form
has been removed

This administrative form
has been removed

This administrative form
has been removed

INFORMATION SHEET:**Project Title: The process of planning for patient discharge from an Indonesian psychiatric institution:
A grounded theory study**

You are invited to take part in a research project about discharge planning for mental illness patient from mental health professionals' perspective in Indonesia. This project will be conducted to improve our understanding of discharge planning for mental health patients in order to improve mental health services in Indonesia. Intansari Nurjannah as principal investigator is conducting the study. Jane Mills and Kim Usher as her supervisors will contribute to the PhD degree undertaken at the School of Nursing, Midwifery and Nutrition, James Cook University.

Your perspective regarding 'discharge planning' is important and I would like to talk to you. If you agree to be involved in the study, you will be invited to be interviewed. The interview, with your consent, will be audio-taped, and should only take approximately 1 hour of your time. The interview will be conducted at your work venue or a venue of your choice. The principle investigator may also contact you for another time if there will be any clarification from interview needed.

Taking part in this study is completely voluntary and you can stop taking part in the study at any time without explanation or prejudice. You may also withdraw any unprocessed data from the study.

Your responses and contact details will be strictly confidential. The data from the study will be used in research publications and reports. You will not be identified in any way in these publications.

If you have any questions about the study, please contact Intansari Nurjannah or Dr Mills.

Principal Investigator:

Intansari Nurjannah
School of Nursing and Midwifery
James Cook University
Phone JCU: +617 4042 1548
HP Australia: +61 432226952
HP Indonesia: +62 8562916613
Email: intansari.nurjannah@my.jcu.edu.au

Supervisor Details:

Name: Dr Jane Mills
School: School of Nursing, Midwifery and Nutrition
James Cook University
Phone: +617 4042 1548
Mobile: +61 457 525 990
Email: jane.mills@jcu.edu.au

LEMBARAN INFORMASI

Judul Penelitian: Proses perencanaan pemulangan pasien dari institusi psikiatrik Indonesia: *a grounded theory study*

Anda diundang untuk ikut mengambil bagian dalam proyek penelitian mengenai perencanaan pemulangan pasien gangguan jiwa dari perspektif tenaga ahli kesehatan jiwa di Indonesia. Proyek ini akan dilaksanakan untuk meningkatkan pemahaman kita mengenai perencanaan pemulangan untuk pasien gangguan jiwa agar kita dapat meningkatkan pelayanan kesehatan jiwa di Indonesia. Intansari Nurjannah sebagai peneliti utama yang melakukan studi ini, Jane Mills dan Kim Usher sebagai guru pengawasnya akan menyumbangkan dalam pendidikan S3 di *School of Nursing, Midwifery and Nutrition* di *James Cook University*.

Perspektif anda mengenai 'rencana pemulangan' adalah penting dan saya ingin berbicara dengan anda. Jika anda setuju untuk terlibat dalam studi ini, anda akan diundang untuk diwawancarai. Wawancara ini, dengan persetujuan anda akan di rekam suaranya, dan semestinya hanya makan waktu sekitar satu jam. Wawancara ini akan dilaksanakan di tempat kerja anda atau tempat yang anda pilih. Mungkin peneliti utama akan menghubungi anda untuk bertemu lagi jika dibutuhkan penjelasan mengenai wawancara tersebut.

Ikut serta dalam studi ini adalah sukarela dan anda dapat berhenti untuk ikut serta dalam studi ini kapan saja tanpa penjelasan atau purbasangka dan anda juga dapat menarik kembali data yang belum diproses dalam penelitian ini.

Respon anda dalam wawancara dan kontak detil anda akan dirahasiakan. Data dari penelitian ini akan digunakan dalam publikasi riset dan laporan. Anda tidak akan diidentifikasi dengan cara apapun dalam publikasi ini.

Jika anda punya pertanyaan mengenai penelitian ini, mohon menghubungi Intansari Nurjannah atau Dr Mills

Peneliti utama:
Intansari Nurjannah
School of Nursing and Midwifery
James Cook University
Telepon JCU: +617 4042 1548
HP Australia: +61 432226952
HP Indonesia: +62 8562916613
Email: intansari.nurjannah@my.jcu.edu.au

Detil pembimbing:
Nama: Jane Mills
School: School of Nursing, Midwifery and Nutrition
James Cook University
Telepon: +617 4042 1548
HP: +61 457 525 990
Email: jane.mills@jcu.edu.au

INFORMED CONSENT FORM

PRINCIPAL INVESTIGATOR	Intansari Nurjannah
PROJECT TITLE:	The process of planning for patient discharge from an Indonesian psychiatric institution: A grounded theory study
SCHOOL	School of Nursing, Midwifery and Nutrition

I understand the aim of this research study is to investigate patient discharge planning from a mental health professional's perspective. I consent to participate in this project, the details of which have been explained to me, and I have been provided with a written information sheet to keep.

I understand that my participation will involve an interview and researcher may contact me for any clarification needed after interview and I agree that the researcher may use the results as described in the information sheet.

I acknowledge that:

- taking part in this study is voluntary and I am aware that I can stop taking part in it at any time without explanation or prejudice and to withdraw any unprocessed data I have provided;
- that any information I give will be kept strictly confidential and that no names will be used to identify me with this study without my approval;

(Please tick to indicate consent)

I consent to be interviewed

<input type="checkbox"/>	Yes	<input type="checkbox"/>	No
--------------------------	------------	--------------------------	-----------

I consent for the interview to be audio taped

<input type="checkbox"/>	Yes	<input type="checkbox"/>	No
--------------------------	------------	--------------------------	-----------

I consent to be contacted after interview if any clarification/information needed

<input type="checkbox"/>	Yes	<input type="checkbox"/>	No
--------------------------	------------	--------------------------	-----------

Name: *(printed)*

Signature:

Date:

FORMULIR PERSETUJUAN YANG TELAH DIINFORMASIKAN

PENELITI UTAMA	Intansari Nurjannah
JUDUL PENELITIAN	Proses perencanaan pemulangan pasien dari institusi psikiatrik Indonesia: <i>a grounded theory study</i>
SEKOLAH	School of Nursing, Midwifery and Nutrition

Saya memahami bahwa tujuan dari studi penelitian ini ialah untuk mencari tahu perencanaan pemulangan pasien dari perspektif tenaga ahli kesehatan jiwa. Saya menyetujui untuk berpartisipasi di proyek (penelitian) ini, perinciannya telah dijelaskan kepada saya, dan saya telah diberikan lembaran informasi tertulis untuk saya simpan.

Saya memahami bahwa partisipasi saya akan melibatkan saya dalam wawancara dan peneliti mungkin akan menghubungi saya jika membutuhkan penjelasan sesudah wawancara dan saya setuju bahwa peneliti boleh menggunakan hasil wawancara sesuai dengan apa yang diuraikan dalam lembaran informasi.

Saya mengaku bahwa:

- Ikut serta dalam penelitian ini adalah suka rela dan saya tahu bahwa saya dapat berhenti untuk ikut serta dalam studi ini kapan saja tanpa penjelasan atau purbasangka dan menarik kembali data yang belum diproses yang telah saya berikan
- Bahwa informasi apa saja yang saya telah berikan akan dirahasiakan dengan ketat dan tidak ada nama yang akan digunakan untuk mengidentifikasi saya dalam studi ini tanpa persetujuan saya;

(Mohon diberikan tanda tik (V) untuk persetujuan)

Saya setuju untuk diwawancarai	<input type="checkbox"/>	Ya	<input type="checkbox"/>	Tidak
Saya setuju wawancara tersebut direkam suaranya	<input type="checkbox"/>	Ya	<input type="checkbox"/>	Tidak
Saya setuju untuk dihubungi sesudah wawancara jika penjelasan/informasi diperlukan	<input type="checkbox"/>	Ya	<input type="checkbox"/>	Tidak

Nama: (Huruf cetak)	
Tandatangan:	Tanggal:

Memo 2 Oct 2011 MMPI and MMAT after PhD analysis 1

<p>MMPI =</p> <p>Memo Minimizing Power Imbalances</p>	<p>MMPI</p> <p>Researcher will write to evaluate whether researcher:</p> <ol style="list-style-type: none"> 1. Creating a space for participants' voice in the interpretation of data and the eventual findings 2. Ensuring that researchers acts as advocates for participants? (Mishler, 1991)
--	--

MMPI:

1. I think I have given a space for participants' voice in the interpretation of data and the event
2. I also ensure that researcher's acts as a advocated for participants as I tried to prioritize participant need for example change the time to meet me.

<p>MMAT = Memo</p> <p>Maintaining Audit Trail</p>	<p>This memo consists of the summary of research activity, change in research direction and the decision made. This memo will be a general outline of other memos and it will also consist of all information about where to find other memo that need to be referred to.</p>
--	---

MMAT

After PhD analysis 1 which is the first initial coding that has been conducted on the last two weeks of September, I have discussion with Jane and found that the discharge planning is not clearly exist. Then there is big change in this study as I need to find and interview more sample related to this study. Because it is not about discharge planning or even it is not about discharge process. It is about PATIENT'S MOVEMENT from one place to another place

From the first analysis (PhD Analysis1) it is found that the classifications of data are:

1. Activity in discharge planning (It should be discharge process)
 - a. Collaboration
 - b. Dropping
 - c. Evaluation after discharge
 - d. Health education for patient
 - e. Health education for family
 - f. Health education: minimize patient's contact with community
 - g. Health professional activity in discharge planning
 - h. Health professional integrity activity
 - i. Hospital staff involvement with the patient and family
 - j. Nurse and psychiatrist activity related to discharge planning
 - k. Nurse's activity in the process of discharge
-

- l. Nurse's activity toward community
 - m. Nurse's activity when patient re-hospitalized
 - n. Nurse's daily activity
 - o. Psychiatrist activity in the process of discharge
 - p. Reason for discussion planning discussion = patient family reason
 - q. The content of health education
 - r. The reason for nurse's activity in the process of discharge
 - s. Time related to discharge planning
 - t. Tracking
 - u. Who conduct health education and to whom
 - v. Who involve in discharge planning (or discharge process)
-

2. Admission process

3. Authority

4. Community

- a. Community service availability
 - b. Community service history for establishment
 - c. Community service's activity related to patient with mental illness
 - d. Health district facility staff's activity toward patient discharge from hospital
 - e. Health service in the community
 - f. Home care
 - g. Home visit program
 - h. Person who involve in CMHN
 - i. The person who are responsible for patient in the community
 - j. Who organize CMHN here in hospital
-

5. Connection

- a. Connection between inpatient and outpatient service in hospital
 - b. Person who active to make a connection between hospital and community
-

6. Discharge planning definition

- a. The definition of discharge planning
-

7. Expectation

8. Family

- a. Family expectation of patient
 - b. Family role in the process of caring
 - c.I think I should put patient effort to make patient relapse by did not give medicine to patient here.. because this is the power to move patient from community to hospital.. but I have not put this yet in PhD analysis1.
-

9. Form of discharge planning

- a. No written discharge planning
 - b. The contain of letter of control
-

10. Goal of discharge planning

11. Health insurance

12. Nurse's activity in the specific case

- a. Nurse's activity in the specific case

- 13. Nurse's perception

- a. Nurse goal related to discharge
- b. Nurse limitation in the discharge planning process
- c. Nurse limitation in the process of care
- d. Nurse perception related to the patient's status
- e. Nurse perception toward family
- f. Nurse's feeling related to family characteristic
- g. Nurse's feeling related to relapse
- h. Nurse's suggestions

- 14. Patient's condition

- a. Patient's characteristic
- b. Patient's history
- c. Patient's need
- d. Patient's response to treatment

- 15. Policy

- a. Hospital rule related to the process of discharge
- b. Policy
- c. SOP for discharge planning

- 16. Psychiatric activity in the specific case
- 17. Relapse

- a. Nurse's activity to prevent relapse
- b. The cause of relapse
- c. Time related to patient relapse

- 18. Role

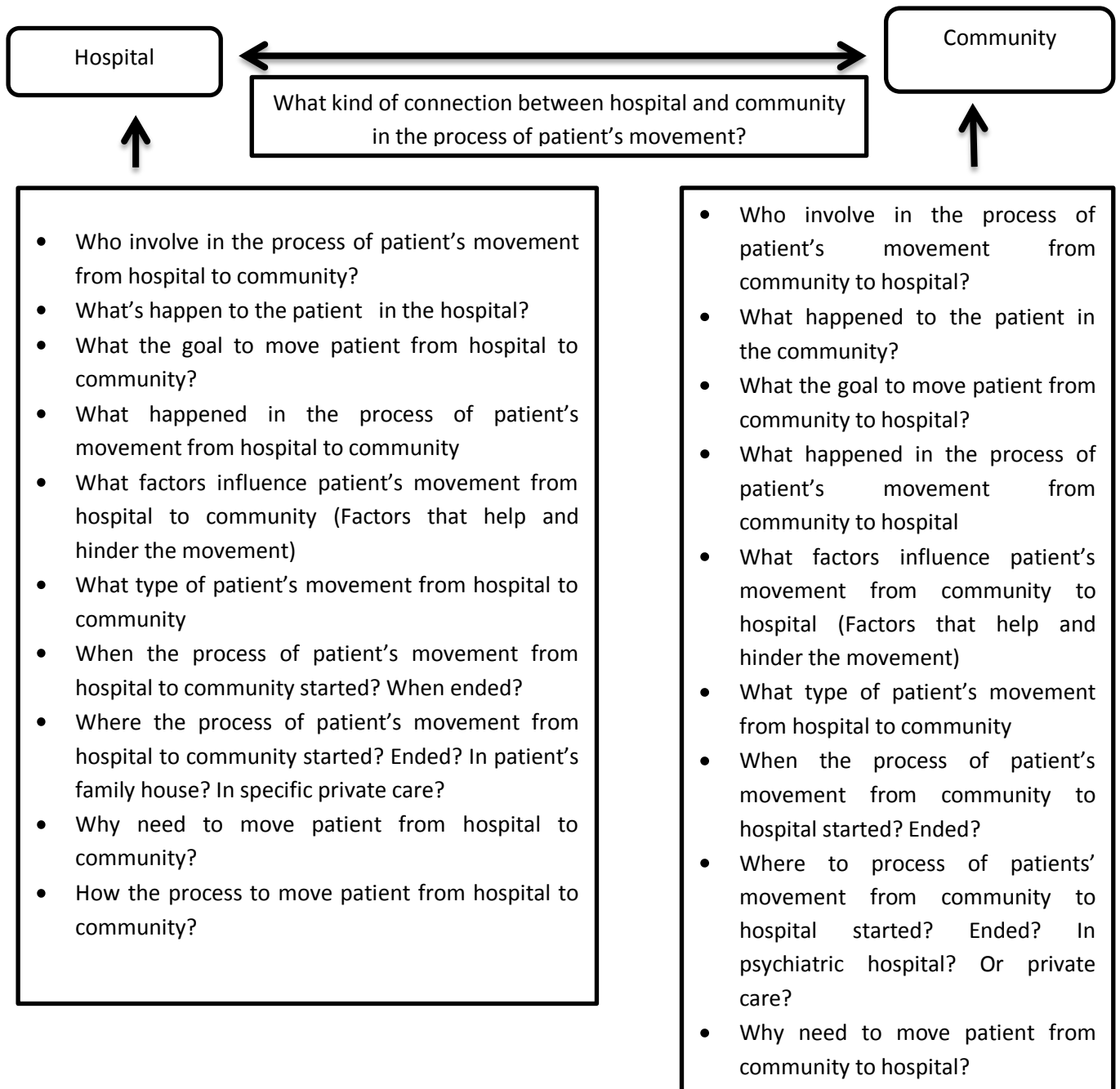
- a. Hospital's nurse role in CMHN
- b. Nurse's role
- c. Patient role and responsibility in the discharge process
- d. Role in the process to design discharge planning

- 19. The process of care

- a. Hospital treatment
- b. Medicine is important
- c. The result of patient treatment in the hospital

Those above are result of the analysis from the first analysis (PhD analysis1). The second analysis (PhD analysis 2) will about to re-code all transcript again but based on my analysis like this below:

The movement of patient from one place to another place



I have tried to put all nodes/Code from PhD Analysis1 in the diagram below to understand what is happened in the data for 'Patient's movement'

In Hospital – Hospital treatment

Health professional activity:

- a. Daily activity care
 - Nurse daily activity
 - Nurse limitation in the process of care
 - Nurse activity and psychiatrist activity in the specific case
- b. Activity before patient discharged
 - Health education for patient and family
 - The content of health education: including minimize patient's contact with community, medicine etc (look at node the content of health education on PhD Analysis 1) and who conduct it
 - Health professional activity in the discharge process: prepare medicine, administration, communicate with patient and family, meet arrangement if needed, tracking
 - No discussion/collaboration between psychiatrist and nurse
 - Nurse's activity in the process of discharge (a bit different based on patient health insurance)
 - Nurse's activity toward community
 - Nurse's activity when patient re-hospitalized
 - Psychiatric activity in the process of discharge
 - Time related to discharge planning
 - Who involve in discharge process
 - Nurse limitation in the process of discharge process
 - Nurse perception related to the patient's status
 - Nurse perception toward family
 - Nurse's feeling related to family characteristic
 - Nurse's feeling related to relapse
 - Nurse's suggestions
 - Goal of discharge (based on nurse opinion)
- c. Activity after patient discharged
 - No Evaluation after patient's discharge (or probably follow up)
 - Connection: between inpatient and outpatient service in hospital :
Only in the form of letter of control: content of the letter of control
- d. Discharge Planning is not exist but There is definition of discharge planning based on interview 1-5, No written discharge planning
- e. Family: Family expectation of patient
- f. Patient: Listen to the nurse, patient characteristic, patient's history, patient's need, patient response to treatment, patient's role and responsibility in the discharge process
- g. Policy (hospital rule related the process of discharge, policy, SOP for discharge planning)
- h. The result of patient treatment in hospital

The method to move patient:

- Dropping
- Family pick patient up

Connection:

- Person who involve in CMHN
- Who organize CMHN here in the hospital
- Person who active to make a connection between hospital and community
- Hospital's nurse role

Community

- Community service availability
- Community service history for establishment
- Community service's activity related to patient with mental illness
- Health district facility staff's activity toward patient discharge from hospital
- Health service in the community
- Home care
- Home visit program
- The person who are responsible for patient in the community
- CMHN (Community Mental Health Nursing) role

Family:

- Family role in the process of caring
- Family did not give medicine – to make patient relapse

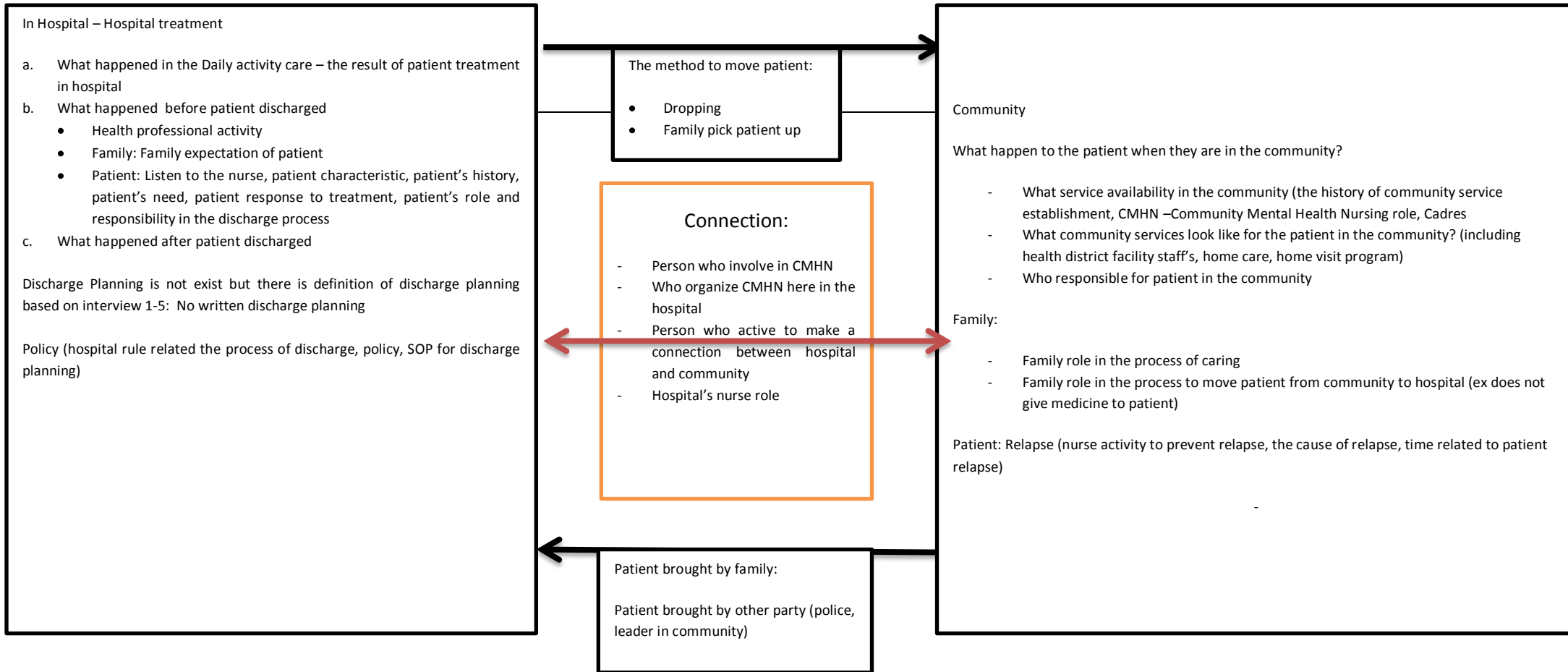
Patient: Relapse (nurse activity to prevent relapse, the cause of relapse, time related to patient relapse)

Patient brought by family

Patient brought by other party (police, leader in community, neighbour)

MEDICINE IS IMPORTANT

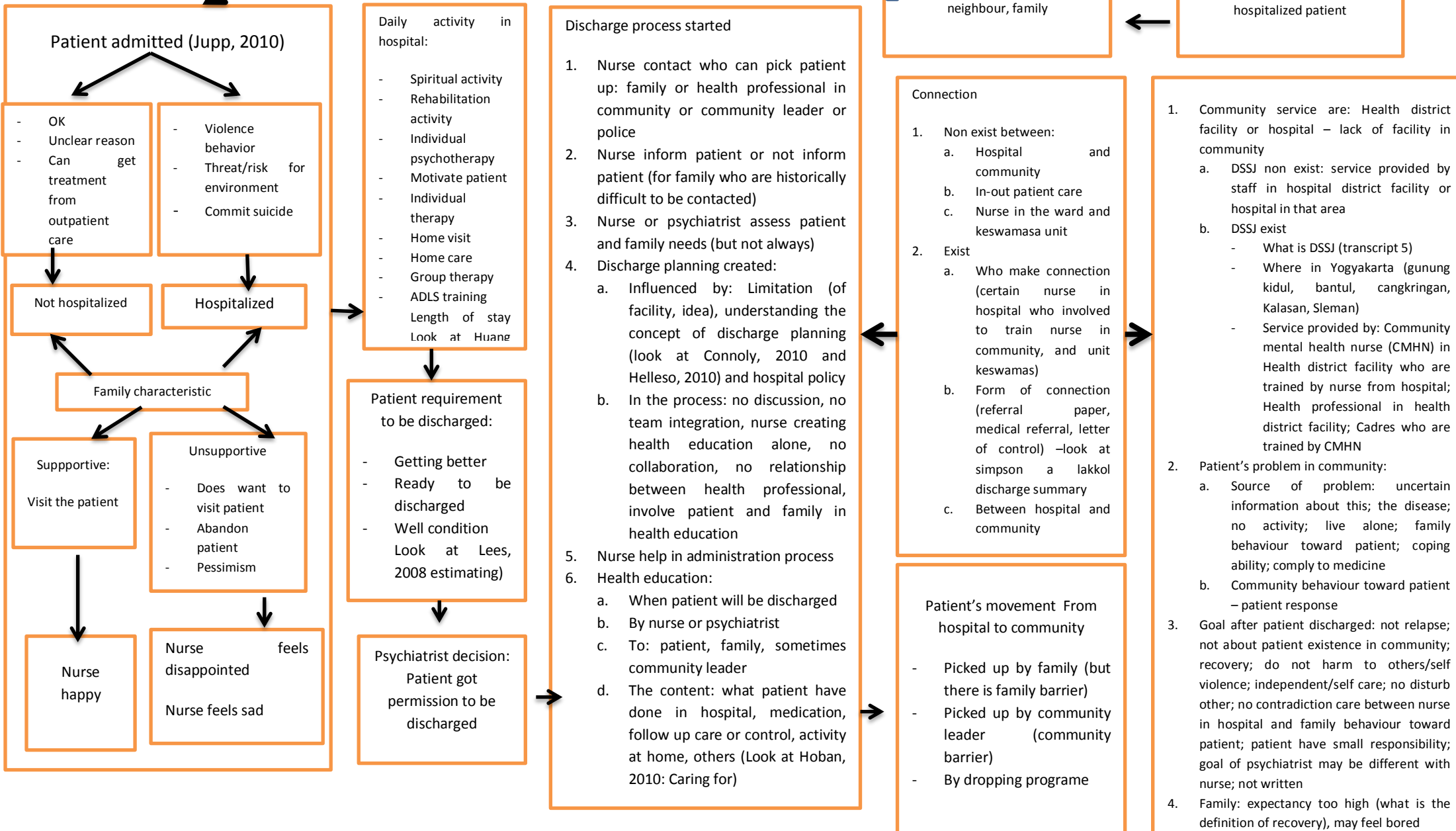
The short version of the model above is



MEDICINE IS IMPORTANT

Memo 5 October 2011

The result of intermediate coding



The data shows:

1. Disconnection between hospital in acute wards and outside world
2. So I need to find out information about the outpatient department
3. So the question related to the connection are: who make this connection, what are the forms of connection and how actually this connection hold together?
4. The possible cause why patient move around is because a lack of support for family (as family need to bring patient again to hospital) or probably because the patient is very unstable? Or because they haven't manageable in community?
5. Possible conclusion: No supporting people to stay at home
6. WHAT drives moving around? Is it really lack of support?
7. The support provided for patient and family
8. What makes fall over --- patient good, discharged and admitted again to hospital

So I need to

1. Make a list question for respondent
Related to: connecting care = where connection and disconnection of care
The connection:
 - What they are?
 - How they work?
 - What does connect care?
 - What does disconnect care?
 - How the nurse in community find information that there was a patient discharged form hospital? – may be from informal information? Maybe from patient's it self?
 - How do people make their way around the system?
 - How do they find out about people with mental illness, how they track patient's down
 - Who make connection between mental health services
 - What the service look like
 - When the family bring patient to hospital have they got information from nurse in community for example or not?
 - Do nurse in community have computer/internet connection or not?
 - Referral look at Tarling (2008)
 -
2. Still to find a clarification about discharge planning from health professional in hospital who are making connection with community
3. Change the ethic – Look at Ethic amendment in which change to title and I need to write four informed consent and four information sheet for:
 - a. Health professional (nurse in community, psychiatrist in community, GP)
 - b. Carers (Family and cadres)
 - c. Community leaders
 - d. PatientsThe informed consent relatively same but I may need to justified language.
The number of sample probably 3 each

HOW the sequence of interview?:

**This administrative form
has been removed**

This administrative form
has been removed

This administrative form
has been removed

INFORMATION SHEET: Family and Carers

Project Title: “Connecting Care - Indonesian People Living With Mental Health Issues: A grounded theory study”

You are invited to take part in a research project about Indonesian people who live with a mental health issue and their movement between the ranges of mental health services available and the community. This project will be conducted to with the aim of improving mental health services in Indonesia. Intansari Nurjannah as principal investigator is conducting the study. Dr Jane Mills and Professor Kim Usher as her supervisors will contribute to the PhD degree undertaken at the School of Nursing, Midwifery and Nutrition, James Cook University.

Your perspective on how people living with a mental health issue move between mental health services and the community in Indonesia is important and I would like to talk to you. If you agree to be involved in the study, you will be invited to be interviewed. The interview, with your consent, will be audio-taped, and should only take approximately 1 hour of your time. The interview will be conducted at your work venue or a venue of your choice. The principle investigator may also contact you to request and additional interview if required for clarification purposes.

Taking part in this study is completely voluntary and you can stop taking part in the study at any time without explanation or prejudice. You may also withdraw any unprocessed data from the study.

Your responses and contact details will be strictly confidential. The data from the study will be used in research publications and reports. You will not be identified in any way in these publications.

If you have any questions about the study, please contact Intansari Nurjannah or Dr Mills.

Principal Investigator:
Intansari Nurjannah
School of Nursing and Midwifery
James Cook University
Phone JCU: +617 4042 1548
HP Australia: +61 432226952
HP Indonesia: +62 8562916613
Email: intansari.nurjannah@my.jcu.edu.au

Supervisor Details:
Name: Dr Jane Mills
School: School of Nursing, Midwifery and Nutrition
James Cook University
Phone: +617 4042 1548
Mobile: +61 457 525 990
Email: jane.mills@jcu.edu.au

*If you have any concerns regarding the ethical conduct of the study, please contact:
Sophie Thompson, Human Ethics and Grants Administrator, Research Office
James Cook University, Townsville, Qld, 4811
Phone: (07) 4781 6575 (Sophie.Thompson@jcu.edu.au)*

INFORMATION SHEET: Individual with mental health issues

Project Title: “Connecting Care - Indonesian People Living With Mental Health Issues: A grounded theory study”

You are invited to take part in a research project about Indonesian people who live with a mental health issue and their movement between the ranges of mental health services available and the community. This project will be conducted to with the aim of improving mental health services in Indonesia. Intansari Nurjannah as principal investigator is conducting the study. Dr Jane Mills and Professor Kim Usher as her supervisors will contribute to the PhD degree undertaken at the School of Nursing, Midwifery and Nutrition, James Cook University.

Your perspective on how people living with a mental health issue move between mental health services and the community in Indonesia is important and I would like to talk to you. If you agree to be involved in the study, you will be invited to be interviewed. The interview, with your consent, will be audio-taped, and should only take approximately 1 hour of your time. The interview will be conducted at your work venue or a venue of your choice. The principle investigator may also contact you to request and additional interview if required for clarification purposes.

Taking part in this study is completely voluntary and you can stop taking part in the study at any time without explanation or prejudice. You may also withdraw any unprocessed data from the study.

Your responses and contact details will be strictly confidential. The data from the study will be used in research publications and reports. You will not be identified in any way in these publications.

If you have any questions about the study, please contact Intansari Nurjannah or Dr Mills.

Principal Investigator:
Intansari Nurjannah
School of Nursing and Midwifery
James Cook University
Phone JCU: +617 4042 1548
HP Australia: +61 432226952
HP Indonesia: +62 8562916613
Email: intansari.nurjannah@my.jcu.edu.au

Supervisor Details:
Name: Dr Jane Mills
School: School of Nursing, Midwifery and Nutrition
James Cook University
Phone: +617 4042 1548
Mobile: +61 457 525 990
Email: jane.mills@jcu.edu.au

*If you have any concerns regarding the ethical conduct of the study, please contact:
Sophie Thompson, Human Ethics and Grants Administrator, Research Office
James Cook University, Townsville, Qld, 4811
Phone: (07) 4781 6575 (Sophie.Thompson@jcu.edu.au)*

INFORMATION SHEET: Health Professionals

Project Title: “Connecting Care - Indonesian People Living With Mental Health Issues: A grounded theory study”

You are invited to take part in a research project about Indonesian people who live with a mental health issue and their movement between the ranges of mental health services available and the community. This project will be conducted to with the aim of improving mental health services in Indonesia. Intansari Nurjannah as principal investigator is conducting the study. Dr Jane Mills and Professor Kim Usher as her supervisors will contribute to the PhD degree undertaken at the School of Nursing, Midwifery and Nutrition, James Cook University.

Your perspective on how people living with a mental health issue move between mental health services and the community in Indonesia is important and I would like to talk to you. If you agree to be involved in the study, you will be invited to be interviewed. The interview, with your consent, will be audio-taped, and should only take approximately 1 hour of your time. The interview will be conducted at your work venue or a venue of your choice. The principle investigator may also contact you to request and additional interview if required for clarification purposes.

Taking part in this study is completely voluntary and you can stop taking part in the study at any time without explanation or prejudice. You may also withdraw any unprocessed data from the study.

Your responses and contact details will be strictly confidential. The data from the study will be used in research publications and reports. You will not be identified in any way in these publications.

If you have any questions about the study, please contact Intansari Nurjannah or Dr Mills.

Principal Investigator:
Intansari Nurjannah
School of Nursing and Midwifery
James Cook University
Phone JCU: +617 4042 1548
HP Australia: +61 432226952
HP Indonesia: +62 8562916613
Email: intansari.nurjannah@my.jcu.edu.au

Supervisor Details:
Name: Dr Jane Mills
School: School of Nursing, Midwifery and Nutrition
James Cook University
Phone: +617 4042 1548
Mobile: +61 457 525 990
Email: jane.mills@jcu.edu.au

INFORMATION SHEET: Leader in community

Project Title: “Connecting Care - Indonesian People Living With Mental Health Issues: A grounded theory study”

You are invited to take part in a research project about Indonesian people who live with a mental health issue and their movement between the ranges of mental health services available and the community. This project will be conducted to with the aim of improving mental health services in Indonesia. Intansari Nurjannah as principal investigator is conducting the study. Dr Jane Mills and Professor Kim Usher as her supervisors will contribute to the PhD degree undertaken at the School of Nursing, Midwifery and Nutrition, James Cook University.

Your perspective on how people living with a mental health issue move between mental health services and the community in Indonesia is important and I would like to talk to you. If you agree to be involved in the study, you will be invited to be interviewed. The interview, with your consent, will be audio-taped, and should only take approximately 1 hour of your time. The interview will be conducted at your work venue or a venue of your choice. The principle investigator may also contact you to request and additional interview if required for clarification purposes.

Taking part in this study is completely voluntary and you can stop taking part in the study at any time without explanation or prejudice. You may also withdraw any unprocessed data from the study.

Your responses and contact details will be strictly confidential. The data from the study will be used in research publications and reports. You will not be identified in any way in these publications.

If you have any questions about the study, please contact Intansari Nurjannah or Dr Mills.

Principal Investigator:
Intansari Nurjannah
School of Nursing and Midwifery
James Cook University
Phone JCU: +617 4042 1548
HP Australia: +61 432226952
HP Indonesia: +62 8562916613
Email: intansari.nurjannah@my.jcu.edu.au

Supervisor Details:
Name: Dr Jane Mills
School: School of Nursing, Midwifery and Nutrition
James Cook University
Phone: +617 4042 1548
Mobile: +61 457 525 990
Email: jane.mills@jcu.edu.au

If you have any concerns regarding the ethical conduct of the study, please contact:
Sophie Thompson, Human Ethics and Grants Administrator, Research Office
James Cook University, Townsville, Qld, 4811
Phone: (07) 4781 6575 (Sophie.Thompson@jcu.edu.au)

LEMBARAN INFORMASI: Health Professional

Judul Penelitian: “Menghubungkan perawatan bagi individu di Indonesia yang memiliki masalah penyakit kesehatan mental: penelitian grounded theory”

Anda diundang untuk ikut mengambil bagian dalam proyek penelitian mengenai proses perpindahan individu dengan masalah kesehatan mental di seputar institusi pelayanan kesehatan mental dan di komunitas di Indonesia. Proyek ini akan dilaksanakan untuk meningkatkan pelayanan kesehatan mental di Indonesia. Intansari Nurjannah sebagai peneliti utama yang melakukan studi ini, Jane Mills dan Kim Usher sebagai guru pengawasnya akan menyumbangkan dalam pendidikan S3 di *School of Nursing, Midwifery and Nutrition* di *James Cook University*.

Perspektif anda mengenai mengenai proses perpindahan individu dengan masalah kesehatan mental antara pelayanan kesehatan mental dan komunitas adalah merupakan suatu hal yang penting dan saya ingin berbicara dengan anda. Jika anda setuju untuk terlibat dalam studi ini, anda akan diundang untuk diwawancarai. Wawancara ini, dengan persetujuan anda akan di rekam suaranya, dan semestinya hanya makan waktu sekitar satu jam. Wawancara ini akan dilaksanakan di tempat kerja anda atau tempat yang anda pilih. Mungkin peneliti utama akan menghubungi anda untuk bertemu lagi jika dibutuhkan penjelasan mengenai wawancara tersebut.

Ikut serta dalam studi ini adalah sukarela dan anda dapat berhenti untuk ikut serta dalam studi ini kapan saja tanpa penjelasan atau purbasangka dan anda juga dapat menarik kembali data yang belum diproses dalam penelitian ini.

Respon anda dalam wawancara dan kontak detil anda akan dirahasiakan. Data dari penelitian ini akan digunakan dalam publikasi riset dan laporan. Anda tidak akan diidentifikasi dengan cara apapun dalam publikasi ini.

Jika anda punya pertanyaan mengenai penelitian ini, mohon menghubungi Intansari Nurjannah atau Dr Mills

Peneliti utama:

Intansari Nurjannah
School of Nursing and Midwifery
James Cook University
Telepon JCU: +617 4042 1548
HP Australia: +61 432226952
HP Indonesia: +62 8562916613
Email: intansari.nurjannah@my.jcu.edu.au

Detil pembimbing:

Nama: Jane Mills
School: School of Nursing, Midwifery and Nutrition
James Cook University
Telepon: +617 4042 1548
HP: +61 457 525 990
Email: jane.mills@jcu.edu.au

LEMBARAN INFORMASI: Individu dengan masalah kesehatan mental

Judul Penelitian: “Menghubungkan perawatan bagi individu di Indonesia yang memiliki masalah penyakit kesehatan mental: penelitian grounded theory”

Anda diundang untuk ikut mengambil bagian dalam proyek penelitian mengenai proses perpindahan individu dengan masalah kesehatan mental di seputar institusi pelayanan kesehatan mental dan di komunitas di Indonesia. Proyek ini akan dilaksanakan untuk meningkatkan pelayanan kesehatan mental di Indonesia. Intansari Nurjannah sebagai peneliti utama yang melakukan studi ini, Jane Mills dan Kim Usher sebagai guru pengawasnya akan menyumbangkan dalam pendidikan S3 di *School of Nursing, Midwifery and Nutrition* di *James Cook University*.

Perspektif anda mengenai mengenai proses perpindahan individu dengan masalah kesehatan mental antara pelayanan kesehatan mental dan komunitas adalah merupakan suatu hal yang penting dan saya ingin berbicara dengan anda. Jika anda setuju untuk terlibat dalam studi ini, anda akan diundang untuk diwawancarai. Wawancara ini, dengan persetujuan anda akan di rekam suaranya, dan semestinya hanya makan waktu sekitar satu jam. Wawancara ini akan dilaksanakan di tempat kerja anda atau tempat yang anda pilih. Mungkin peneliti utama akan menghubungi anda untuk bertemu lagi jika dibutuhkan penjelasan mengenai wawancara tersebut.

Ikut serta dalam studi ini adalah sukarela dan anda dapat berhenti untuk ikut serta dalam studi ini kapan saja tanpa penjelasan atau purbasangka dan anda juga dapat menarik kembali data yang belum diproses dalam penelitian ini.

Respon anda dalam wawancara dan kontak detil anda akan dirahasiakan. Data dari penelitian ini akan digunakan dalam publikasi riset dan laporan. Anda tidak akan diidentifikasi dengan cara apapun dalam publikasi ini.

Jika anda punya pertanyaan mengenai penelitian ini, mohon menghubungi Intansari Nurjannah atau Dr Mills

Peneliti utama:
Intansari Nurjannah
School of Nursing and Midwifery
James Cook University
Telepon JCU: +617 4042 1548
HP Australia: +61 432226952
HP Indonesia: +62 8562916613
Email: intansari.nurjannah@my.jcu.edu.au

Detil pembimbing:
Nama: Jane Mills
School: School of Nursing, Midwifery and Nutrition
James Cook University
Telepon: +617 4042 1548
HP: +61 457 525 990
Email: jane.mills@jcu.edu.au

If you have any concerns regarding the ethical conduct of the study, please contact:
Sophie Thompson, Human Ethics and Grants Administrator, Research Office
James Cook University, Townsville, Qld, 4811
Phone: (07) 4781 6575 (Sophie.Thompson@jcu.edu.au)

LEMBARAN INFORMASI: Keluarga dan Kader

Judul Penelitian: “Menghubungkan perawatan bagi individu di Indonesia yang memiliki masalah penyakit kesehatan mental: penelitian grounded theory”

Anda diundang untuk ikut mengambil bagian dalam proyek penelitian mengenai proses perpindahan individu dengan masalah kesehatan mental di seputar institusi pelayanan kesehatan mental dan di komunitas di Indonesia. Proyek ini akan dilaksanakan untuk meningkatkan pelayanan kesehatan mental di Indonesia. Intansari Nurjannah sebagai peneliti utama yang melakukan studi ini, Jane Mills dan Kim Usher sebagai guru pengawasnya akan menyumbangkan dalam pendidikan S3 di *School of Nursing, Midwifery and Nutrition* di *James Cook University*.

Perspektif anda mengenai mengenai proses perpindahan individu dengan masalah kesehatan mental antara pelayanan kesehatan mental dan komunitas adalah merupakan suatu hal yang penting dan saya ingin berbicara dengan anda. Jika anda setuju untuk terlibat dalam studi ini, anda akan diundang untuk diwawancarai. Wawancara ini, dengan persetujuan anda akan di rekam suaranya, dan semestinya hanya makan waktu sekitar satu jam. Wawancara ini akan dilaksanakan di tempat kerja anda atau tempat yang anda pilih. Mungkin peneliti utama akan menghubungi anda untuk bertemu lagi jika dibutuhkan penjelasan mengenai wawancara tersebut.

Ikut serta dalam studi ini adalah sukarela dan anda dapat berhenti untuk ikut serta dalam studi ini kapan saja tanpa penjelasan atau purbasangka dan anda juga dapat menarik kembali data yang belum diproses dalam penelitian ini.

Respon anda dalam wawancara dan kontak detil anda akan dirahasiakan. Data dari penelitian ini akan digunakan dalam publikasi riset dan laporan. Anda tidak akan diidentifikasi dengan cara apapun dalam publikasi ini.

Jika anda punya pertanyaan mengenai penelitian ini, mohon menghubungi Intansari Nurjannah atau Dr Mills

Peneliti utama:
Intansari Nurjannah
School of Nursing and Midwifery
James Cook University
Telepon JCU: +617 4042 1548
HP Australia: +61 432226952
HP Indonesia: +62 8562916613
Email: intansari.nurjannah@my.jcu.edu.au

Detil pembimbing:
Nama: Jane Mills
School: School of Nursing, Midwifery and Nutrition
James Cook University
Telepon: +617 4042 1548
HP: +61 457 525 990
Email: jane.mills@jcu.edu.au

If you have any concerns regarding the ethical conduct of the study, please contact:
Sophie Thompson, Human Ethics and Grants Administrator, Research Office
James Cook University, Townsville, Qld, 4811
Phone: (07) 4781 6575 (Sophie.Thompson@jcu.edu.au)

LEMBARAN INFORMASI: Tokoh masyarakat

Judul Penelitian: “Menghubungkan perawatan bagi individu di Indonesia yang memiliki masalah penyakit kesehatan mental: penelitian grounded theory”

Anda diundang untuk ikut mengambil bagian dalam proyek penelitian mengenai proses perpindahan individu dengan masalah kesehatan mental di seputar institusi pelayanan kesehatan mental dan di komunitas di Indonesia. Proyek ini akan dilaksanakan untuk meningkatkan pelayanan kesehatan mental di Indonesia. Intansari Nurjannah sebagai peneliti utama yang melakukan studi ini, Jane Mills dan Kim Usher sebagai guru pengawasnya akan menyumbangkan dalam pendidikan S3 di *School of Nursing, Midwifery and Nutrition* di *James Cook University*.

Perspektif anda mengenai mengenai proses perpindahan individu dengan masalah kesehatan mental antara pelayanan kesehatan mental dan komunitas adalah merupakan suatu hal yang penting dan saya ingin berbicara dengan anda. Jika anda setuju untuk terlibat dalam studi ini, anda akan diundang untuk diwawancarai. Wawancara ini, dengan persetujuan anda akan di rekam suaranya, dan semestinya hanya makan waktu sekitar satu jam. Wawancara ini akan dilaksanakan di tempat kerja anda atau tempat yang anda pilih. Mungkin peneliti utama akan menghubungi anda untuk bertemu lagi jika dibutuhkan penjelasan mengenai wawancara tersebut.

Ikut serta dalam studi ini adalah sukarela dan anda dapat berhenti untuk ikut serta dalam studi ini kapan saja tanpa penjelasan atau purbasangka dan anda juga dapat menarik kembali data yang belum diproses dalam penelitian ini.

Respon anda dalam wawancara dan kontak detil anda akan dirahasiakan. Data dari penelitian ini akan digunakan dalam publikasi riset dan laporan. Anda tidak akan diidentifikasi dengan cara apapun dalam publikasi ini.

Jika anda punya pertanyaan mengenai penelitian ini, mohon menghubungi Intansari Nurjannah atau Dr Mills

Peneliti utama:
Intansari Nurjannah
School of Nursing and Midwifery
James Cook University
Telepon JCU: +617 4042 1548
HP Australia: +61 432226952
HP Indonesia: +62 8562916613
Email: intansari.nurjannah@my.jcu.edu.au

Detil pembimbing:
Nama: Jane Mills
School: School of Nursing, Midwifery and Nutrition
James Cook University
Telepon: +617 4042 1548
HP: +61 457 525 990
Email: jane.mills@jcu.edu.au

If you have any concerns regarding the ethical conduct of the study, please contact:
Sophie Thompson, Human Ethics and Grants Administrator, Research Office
James Cook University, Townsville, Qld, 4811
Phone: (07) 4781 6575 (Sophie.Thompson@jcu.edu.au)

INFORMED CONSENT FORM: Family and Cadre

PRINCIPAL INVESTIGATOR	Intansari Nurjannah
PROJECT TITLE:	Project Title: "Connecting Care - Indonesian People Living With Mental Health Issues: A grounded theory study"
SCHOOL	School of Nursing, Midwifery and Nutrition

I understand the aim of this research study is to investigate the process of people living with a mental health issue's movement between mental health services and community in Indonesia. I consent to participate in this project, the details of which have been explained to me, and I have been provided with a written information sheet to keep.

I understand that my participation will involve an interview and researcher may contact me for any clarification needed after interview and I agree that the researcher may use the results as described in the information sheet.

I acknowledge that:

- taking part in this study is voluntary and I am aware that I can stop taking part in it at any time without explanation or prejudice and to withdraw any unprocessed data I have provided;
- that any information I give will be kept strictly confidential and that no names will be used to identify me with this study without my approval;

(Please tick to indicate consent)

I consent to be interviewed

<input type="checkbox"/>	Yes	<input type="checkbox"/>	No
--------------------------	------------	--------------------------	-----------

I consent for the interview to be audio taped

<input type="checkbox"/>	Yes	<input type="checkbox"/>	No
--------------------------	------------	--------------------------	-----------

I consent to be contacted after interview if any clarification/information needed

<input type="checkbox"/>	Yes	<input type="checkbox"/>	No
--------------------------	------------	--------------------------	-----------

Name: *(printed)*

Signature:

Date:

INFORMED CONSENT FORM: Leader in Community

PRINCIPAL INVESTIGATOR	Intansari Nurjannah
PROJECT TITLE:	Project Title: "Connecting Care - Indonesian People Living With Mental Health Issues: A grounded theory study"
SCHOOL	School of Nursing, Midwifery and Nutrition

I understand the aim of this research study is to investigate the process of people living with a mental health issue's movement between mental health services and community in Indonesia. I consent to participate in this project, the details of which have been explained to me, and I have been provided with a written information sheet to keep.

I understand that my participation will involve an interview and researcher may contact me for any clarification needed after interview and I agree that the researcher may use the results as described in the information sheet.

I acknowledge that:

- taking part in this study is voluntary and I am aware that I can stop taking part in it at any time without explanation or prejudice and to withdraw any unprocessed data I have provided;
- that any information I give will be kept strictly confidential and that no names will be used to identify me with this study without my approval;

(Please tick to indicate consent)

I consent to be interviewed	<input type="checkbox"/>	Yes	<input type="checkbox"/>	No
I consent for the interview to be audio taped	<input type="checkbox"/>	Yes	<input type="checkbox"/>	No
I consent to be contacted after interview if any clarification/information needed	<input type="checkbox"/>	Yes	<input type="checkbox"/>	No

Name: *(printed)*

Signature:

Date:

INFORMED CONSENT FORM: Health professionals

PRINCIPAL INVESTIGATOR	Intansari Nurjannah
PROJECT TITLE:	Project Title: "Connecting Care - Indonesian People Living With Mental Health Issues: A grounded theory study"
SCHOOL	School of Nursing, Midwifery and Nutrition

I understand the aim of this research study is to investigate the process of people living with a mental health issue's movement between mental health services and community in Indonesia. I consent to participate in this project, the details of which have been explained to me, and I have been provided with a written information sheet to keep.

I understand that my participation will involve an interview and researcher may contact me for any clarification needed after interview and I agree that the researcher may use the results as described in the information sheet.

I acknowledge that:

- taking part in this study is voluntary and I am aware that I can stop taking part in it at any time without explanation or prejudice and to withdraw any unprocessed data I have provided;
- that any information I give will be kept strictly confidential and that no names will be used to identify me with this study without my approval;

(Please tick to indicate consent)

I consent to be interviewed

Yes

No

I consent for the interview to be audio taped

Yes

No

I consent to be contacted after interview if any clarification/information needed

Yes

No

Name: *(printed)*

Signature:

Date:

INFORMED CONSENT FORM: People living with mental health issues

PRINCIPAL INVESTIGATOR	Intansari Nurjannah
PROJECT TITLE:	Project Title: "Connecting Care - Indonesian People Living With Mental Health Issues: A grounded theory study"
SCHOOL	School of Nursing, Midwifery and Nutrition

I understand the aim of this research study is to investigate the process of people living with a mental health issue's movement between mental health services and community in Indonesia. I consent to participate in this project, the details of which have been explained to me, and I have been provided with a written information sheet to keep.

I understand that my participation will involve an interview and researcher may contact me for any clarification needed after interview and I agree that the researcher may use the results as described in the information sheet.

I acknowledge that:

- taking part in this study is voluntary and I am aware that I can stop taking part in it at any time without explanation or prejudice and to withdraw any unprocessed data I have provided;
- that any information I give will be kept strictly confidential and that no names will be used to identify me with this study without my approval;

(Please tick to indicate consent)

I consent to be interviewed

<input type="checkbox"/>	Yes	<input type="checkbox"/>	No
<input type="checkbox"/>	Yes	<input type="checkbox"/>	No
<input type="checkbox"/>	Yes	<input type="checkbox"/>	No

I consent for the interview to be audio taped

I consent to be contacted after interview if any clarification/information needed

Name: <i>(printed)</i>	
Signature:	Date:

FORMULIR PERSETUJUAN YANG TELAH DIINFORMASIKAN: Individu dengan masalah kesehatan mental

PENELITI UTAMA	Intansari Nurjannah
JUDUL PENELITIAN	“Menghubungkan perawatan bagi individu di Indonesia yang memiliki masalah penyakit kesehatan mental: penelitian grounded theory”
SEKOLAH	School of Nursing, Midwifery and Nutrition

Saya memahami bahwa tujuan dari studi penelitian ini ialah untuk mencari tahu mengenai proses perpindahan pasien dengan masalah kesehatan mental seputar institusi pelayanan kesehatan mental dan komunitas di Indonesia. Saya menyetujui untuk berpartisipasi di proyek (penelitian) ini, perinciannya telah dijelaskan kepada saya, dan saya telah diberikan lembaran informasi tertulis untuk saya simpan.

Saya memahami bahwa partisipasi saya akan melibatkan saya dalam wawancara dan peneliti mungkin akan menghubungi saya jika membutuhkan penjelasan sesudah wawancara dan saya setuju bahwa peneliti boleh menggunakan hasil wawancara sesuai dengan apa yang diuraikan dalam lembaran informasi.

Saya mengaku bahwa:

- Ikut serta dalam penelitian ini adalah suka rela dan saya tahu bahwa saya dapat berhenti untuk ikut serta dalam studi ini kapan saja tanpa penjelasan atau purbasangka dan menarik kembali data yang belum diproses yang telah saya berikan
- Bahwa informasi apa saja yang saya telah berikan akan dirahasiakan dengan ketat dan tidak ada nama yang akan digunakan untuk mengidentifikasi saya dalam studi ini tanpa persetujuan saya;

(Mohon diberikan tanda tik (V) untuk persetujuan)

Saya setuju untuk diwawancarai	Ya	<input type="checkbox"/>	Tidak
Saya setuju wawancara tersebut direkam suaranya	Ya	<input type="checkbox"/>	Tidak
Saya setuju untuk dihubungi sesudah wawancara jika penjelasan/informasi diperlukan	Ya	<input type="checkbox"/>	Tidak

Nama: (Huruf cetak)	
Tandatangan:	Tanggal:

FORMULIR PERSETUJUAN YANG TELAH DIINFORMASIKAN: Keluarga dan Kader

PENELITI UTAMA	Intansari Nurjannah
JUDUL PENELITIAN	“Menghubungkan perawatan bagi individu di Indonesia yang memiliki masalah penyakit kesehatan mental: penelitian grounded theory”
SEKOLAH	School of Nursing, Midwifery and Nutrition

Saya memahami bahwa tujuan dari studi penelitian ini ialah untuk mencari tahu mengenai proses perpindahan pasien dengan masalah kesehatan mental seputar institusi pelayanan kesehatan mental dan komunitas di Indonesia. Saya menyetujui untuk berpartisipasi di proyek (penelitian) ini, perinciannya telah dijelaskan kepada saya, dan saya telah diberikan lembaran informasi tertulis untuk saya simpan.

Saya memahami bahwa partisipasi saya akan melibatkan saya dalam wawancara dan peneliti mungkin akan menghubungi saya jika membutuhkan penjelasan sesudah wawancara dan saya setuju bahwa peneliti boleh menggunakan hasil wawancara sesuai dengan apa yang diuraikan dalam lembaran informasi.

Saya mengaku bahwa:

- Ikut serta dalam penelitian ini adalah suka rela dan saya tahu bahwa saya dapat berhenti untuk ikut serta dalam studi ini kapan saja tanpa penjelasan atau purbasangka dan menarik kembali data yang belum diproses yang telah saya berikan
- Bahwa informasi apa saja yang saya telah berikan akan dirahasiakan dengan ketat dan tidak ada nama yang akan digunakan untuk mengidentifikasi saya dalam studi ini tanpa persetujuan saya;

(Mohon diberikan tanda tik (V) untuk persetujuan)

Saya setuju untuk diwawancarai	<input type="checkbox"/>	Ya	<input type="checkbox"/>	Tidak
Saya setuju wawancara tersebut direkam suaranya	<input type="checkbox"/>	Ya	<input type="checkbox"/>	Tidak
Saya setuju untuk dihubungi sesudah wawancara jika penjelasan/informasi diperlukan	<input type="checkbox"/>	Ya	<input type="checkbox"/>	Tidak

Nama: (Huruf cetak)	
Tandatangan:	Tanggal:

FORMULIR PERSETUJUAN YANG TELAH DIINFORMASIKAN: Petugas Kesehatan Profesional

PENELITI UTAMA	Intansari Nurjannah
JUDUL PENELITIAN	“Menghubungkan perawatan bagi individu di Indonesia yang memiliki masalah penyakit kesehatan mental: penelitian grounded theory”
SEKOLAH	School of Nursing, Midwifery and Nutrition

Saya memahami bahwa tujuan dari studi penelitian ini ialah untuk mencari tahu mengenai proses perpindahan pasien dengan masalah kesehatan mental seputar institusi pelayanan kesehatan mental dan komunitas di Indonesia. Saya menyetujui untuk berpartisipasi di proyek (penelitian) ini, perinciannya telah dijelaskan kepada saya, dan saya telah diberikan lembaran informasi tertulis untuk saya simpan.

Saya memahami bahwa partisipasi saya akan melibatkan saya dalam wawancara dan peneliti mungkin akan menghubungi saya jika membutuhkan penjelasan sesudah wawancara dan saya setuju bahwa peneliti boleh menggunakan hasil wawancara sesuai dengan apa yang diuraikan dalam lembaran informasi.

Saya mengaku bahwa:

- Ikut serta dalam penelitian ini adalah suka rela dan saya tahu bahwa saya dapat berhenti untuk ikut serta dalam studi ini kapan saja tanpa penjelasan atau purbasangka dan menarik kembali data yang belum diproses yang telah saya berikan
- Bahwa informasi apa saja yang saya telah berikan akan dirahasiakan dengan ketat dan tidak ada nama yang akan digunakan untuk mengidentifikasi saya dalam studi ini tanpa persetujuan saya;

(Mohon diberikan tanda tik (V) untuk persetujuan)

Saya setuju untuk diwawancarai

<input type="checkbox"/>	Ya	<input type="checkbox"/>	Tidak
<input type="checkbox"/>	Ya	<input type="checkbox"/>	Tidak
<input type="checkbox"/>	Ya	<input type="checkbox"/>	Tidak

Saya setuju wawancara tersebut direkam suaranya

Saya setuju untuk dihubungi sesudah wawancara jika penjelasan/informasi diperlukan

Nama: (Huruf cetak)

Tandatangan:

Tanggal:

FORMULIR PERSETUJUAN YANG TELAH DIINFORMASIKAN: Tokoh masyarakat

PENELITI UTAMA	Intansari Nurjannah
JUDUL PENELITIAN	“Menghubungkan perawatan bagi individu di Indonesia yang memiliki masalah penyakit kesehatan mental: penelitian grounded theory”
SEKOLAH	School of Nursing, Midwifery and Nutrition

Saya memahami bahwa tujuan dari studi penelitian ini ialah untuk mencari tahu mengenai proses perpindahan pasien dengan masalah kesehatan mental seputar institusi pelayanan kesehatan mental dan komunitas di Indonesia. Saya menyetujui untuk berpartisipasi di proyek (penelitian) ini, perinciannya telah dijelaskan kepada saya, dan saya telah diberikan lembaran informasi tertulis untuk saya simpan.

Saya memahami bahwa partisipasi saya akan melibatkan saya dalam wawancara dan peneliti mungkin akan menghubungi saya jika membutuhkan penjelasan sesudah wawancara dan saya setuju bahwa peneliti boleh menggunakan hasil wawancara sesuai dengan apa yang diuraikan dalam lembaran informasi.

Saya mengaku bahwa:

- Ikut serta dalam penelitian ini adalah suka rela dan saya tahu bahwa saya dapat berhenti untuk ikut serta dalam studi ini kapan saja tanpa penjelasan atau purbasangka dan menarik kembali data yang belum diproses yang telah saya berikan
- Bahwa informasi apa saja yang saya telah berikan akan dirahasiakan dengan ketat dan tidak ada nama yang akan digunakan untuk mengidentifikasi saya dalam studi ini tanpa persetujuan saya;

(Mohon diberikan tanda tik (V) untuk persetujuan)

Saya setuju untuk diwawancarai	<input type="checkbox"/>	Ya	<input type="checkbox"/>	Tidak
Saya setuju wawancara tersebut direkam suaranya	<input type="checkbox"/>	Ya	<input type="checkbox"/>	Tidak
Saya setuju untuk dihubungi sesudah wawancara jika penjelasan/informasi diperlukan	<input type="checkbox"/>	Ya	<input type="checkbox"/>	Tidak

Nama: (Huruf cetak)	
Tandatangan:	Tanggal:

This administrative form
has been removed

This administrative form
has been removed

This administrative form
has been removed

This administrative form
has been removed

This administrative form
has been removed

This administrative form
has been removed

This administrative form
has been removed

Appendix N Evidence in Indonesian

In Indonesian
“... misalnya kan untuk pasien Jamkesmas [nama asuransi kesehatan] itu kan maksimal perawatan tiga bulan ...kita, kalo selama dua bulan [individu yang kondisi kesehatannya sudah membaik] kok ndak diambil.... Itu kita harus daftar [individu] dulu [untuk] dropping [program]...” (26T).
“(Pemerintah) Indonesia (mencanangkan) (program) bebas pasung 2014, tapi apa yang sudah dilakukan (oleh) permenkes untuk ini, tahapan (nya) apa? tidak ada kejelasannya ... kalau ada (kasus) pasung, ya masukkan (pasien) ke RS Jiwa, ke rumah sakit yang punya fasilitas (untuk menangani) itu, tapi keberlanjutan itu bali yo nek kita nggak punya ... nggak punya kemampuan untuk untuk ngrumat pasien ini yo podo wae to ... wong Pasung itu sebenarnya salah satu bentuk yang ... satu satunya paling mudah bisa dipakai masyarakat kok, ngamuk ha (dengan di pasung) dek e ra iso opo opo lagi, (dia tidak bisa) membunuh, nggak bisa apa apa lagi, sementara dia mau ke rumah sakit (dia) nggak ada akses ... sementara akses e jamkes (nama asuransi kesehatan) itu tidak sampai mengarah untuk ... sampai ada (program) pasung bebas biaya, tidak ada kebijakan seperti itu ... kebijakan kebijakan itu tidak mendukung ...” (42T).
“Karena pertimbangan kemanusiaan dan social [kita menerima mereka untuk di rawat di sini], ... ada keluarga tidak mampu, kadang-kadang satu rumah itu ada yang sakit kayak gini [gangguan jiwa] itu ada dua, tiga [anggota keluarga, ...so pityy]” (48T).
“Ada [individu] yang sampai 20 tahun [tinggal di penampungan ini], ..., dia sakit fisik, sampai dia apa ya, apa tu ya namanya hepatitis, renal hepatica, ginjalnya juga, hepatitisnya juga, [waktu] pagi [badannya] mbengkak semua, ...kalau [kita pergi] ke RSUD ..., kita nggak nggak bisa [mengatasi individu]” (47T).
“Kemudian ya kan kalau [kita] bisa ditangani [individu] disini ya disini [dia], kalau [kita] nggak [mengatasi individu] ya biasanya [individu] dirujuk...” (29T).
“Keluarga itu (mengatakan)... pokoknya, pak, saya sudah tidak mau menerima lagi anak saya ... saya ndak bisa pak, saya sudah tua ... wis pokoknya kalau toh di anter ke sini (dipulangkan dari rumah sakit) ...itu e anak saya, saya yakin (saya) tidak bisa mengelola ...wis pokoknya terserah (staff) rumah sakit (anak saya) mau diapakan ...” (15T).
“... yo satu dua ada (patient) yang disembunyikan kan sama keluarganya, kadang ada yang malu malu punya keluarga seperti itu (sakit jiwa) ... biasanya ya (pasien) di sembunyikan, nek ditanya malah ditutup tutupi (informasinya)” (39T).
“... ya (individu) yang masih ngomel-ngomel itu kita masih bisa (menangani), ya kasih tahu ya secara secara agamanya,... dengan menenangkan diri, dengan mendekati diri pada tuhan, Terus.. ya kan umpamanya dia (individual) malah malu,... trus mengurung diri gitu loh, ha itu saya laporkan,... karena monggolah dokter aja (yang mengatasi dia) karena termasuk yang bagaimana ... iya sulit banget (buat saya untuk mengatasi)” (41T)
“... kalau saya punya hubungan baik dengan perawatnya [di puskesmas] saya baru menghubungi [mereka]” (7T).
“...tapi ada pula surat itu kita kirimkan, tetapi ternyata tidak sampai, surat itu kembali kesini (rumah sakit jiwa) karena masyarakat itu menggunakan alamat palsu” (15T).
“[Individu yang ditemukan pada saat program sweeping] Yang sakit jiwa itu dirujuk (istilah di rujuk bagi social worker berarti diantar ke rumah sakit) ke rumah sakit dulu, setelah [individu lebih baik] selesai dari rumah sakit, [individu] nanti di oper lagi ke dinas social” (44T).
“Eee, kalau petugas kesehatannya [untuk] memberikan edukasi itu [pada keluarga] ... bagaimana perawatannya [individu] di rumah, ... tanda-tanda ketika dia sudah mulai terjadi peningkatan [gejala] apa yang harus dilakukan..., obatnya bagaimana, untuk pengawasan [individu] minum obatnya, kemudian untuk aktivitasnya [sehari-hari] untuk pengawasan [keluarga] dan opo bimbingan [pada individu], ..., biasanya itu nanti keluarga dilibatkan untuk pengawasan itu dan bimbingan itu” (3T).

“Eee, biasanya kalau misalnya pasien sudah dinyatakan pulang, kita akan menghubungi keluarga terlebih dahulu, jadi kita hubungi [mereka] biasanya kalau nggak lewat telepon kita sms ...” (3T).

“Ya saya bawa (istri saya) waktu itu kan malem malem, kan trus (individual) ngamuk ngamuk trus itu, trus ...(Saya) minta tolong sama tetangga untuk cari mobil, kan (individual) dimasukkan mobil (untuk di bawa ke rumah sakit)” (35T).

“... kemudian sesudah (individual) ditangkap pak polisi, kan polisi sana menghubungi bu lurah, bu lurah menghubungi saya, ... kemudian coba saya menghubungi keluarganya terus ... ketiganya (urutan ketiga: menghubungi) sama tokoh masyarakat. (semua) Sudah setuju (dan) langsung (individual) di bawa ke Grhasia (nama rumah sakit jiwa)...” (40T).

“Dengan kondisi sekarang di (nama kota) itu seribu sekian (individu) yang menderita (sakit mental) eks psikotik, sementara yang kita bisa tampung hanya limapuluh (individu), jadi itu otomatis kuota kita sedikit sekali” (48T).

“... kan kalo saya bikin kopi itu kan (dia-perempuan) suka minta (kopi saya), saya masukin kopinya setengah gelas saya tambah gula, saya kasih obat (dalam kopi itu)...” (35T).

“Kesulitan yang kedua kadang kadang ntara kita dan keluarga itu jadi pihak keluarga itu banyak sekali stigma bahwasanya mereka mempunyai keluarga seperti ini sangat memalukan seperti itu jadi kerjasama kita dengan keluarga itu juga kadang kadang agak susah kan maunya kita penyembuhan mereka ini kan harus ada kerjasama yang bagus jadi paling tidak ya sebulan sekali kek mereka datang ke sini melihat ini ha ada kadang-kadang sampai 2-3 bulan keluarga tidak melihat” (48T).

keluarga yang tidak peduli, ... sudah tiga bulan itu (individual) nggak ditengok, ... karena keluarga karena (mereka) takut ... pernah (keluarga) saya hubungi (karena individual) tiga bulan tidak diambil, ... keluarganya itu (merasa) trauma kalo pasien itu pulang, dia (individu – pasien) kan ingin membunuh, gitu loh, ingin membunuh sodaranya, jadi ada satu (rasa) ketakutan ... (25T)

“... sebenarnya ya keluargane pingin istirahat ..., pingin leren le ngrawat (individu), dadi (individu) dikeknene, (individu) dirawat ndek kene” (1T).

“Kalo (individu dengan masalah kesehatan mental) yang e ke puskesmas ke Grhasia (nama rumah sakit) yang tidak ada kendala, kan kalo yang sudah punya Jamkesmas (Asuransi kesehatan), tapi bagi mereka yang mereka yang tidak punya jamkesmas, ini yang yang kita punya kendala, ya memang (perawatan) kan harus (dengan) biaya, berobat kan harus mbayar ke Grhasia (nama rumah sakit) pun harus mbayar kalo rawat inap juga, ya jadi kebanyakan yang seperti itu orang yang tidak mampu” (41T).

“... itu ada (individu) yang sudah lima bulan dipasung,... orang tuanya tuh (mereka) katanya sudah habis tanah, semuanya untuk menangani itu sedangkan dia tidak memiliki kartu Jamkesmas dan JPKM (nama asuransi kesehatan) apapun sehingga ... waktu itu solusinya ya masih tetap (si individu) harus dipasung” (34T).

“Repotnya (merawat) ya cuman itu ... suami saya ya kalo lagi pas kecapekan gitu ya sama tetangga itu suka gimana ... maunya gitu cuma marah-marah saja sering merusak apa ... melempar genteng kalau pas kumat itu... membahayakan, ya suka nanganin saya gitu ... asal kecapekan” (33T).

“(Client) pernah, sudah mencekik orang tuanya dua kali,... orang tuanya juga cerita sama saya kalo habis di cekik” (40T).

“... ho oh udah pulang dari Grhasia itu (nama rumah sakit jiwa) (individu) kurang (mendapat) perhatian dari keluarga, kayak kayak mungkin keluarga ne wis capek ... ngurusin anak seperti itu, ... jadi di rumah di cuekin, nggak pernah diperhatikan (termasuk) obat, trus tak tanya juga obatnya, (keluarga mengatakan) kalo (mereka) ingat ya diminum kalo nggak ya enggak, begitu (keluarga) bilangnye ...” (39T).

