

**AGEISM, STIGMA OF TUBERCULOSIS AND ILLNESS
EXPERIENCE OF ELDERLY FEMALE PATIENT IN
YOGYAKARTA INDONESIA**

YUDHANTO EDDY HASTOMO

**A THESIS SUBMITTED IN PARTIAL FULFILLMENT
OF THE REQUIREMENTS FOR THE DEGREE OF
MASTER OF ARTS (HEALTH SOCIAL SCIENCE)
FACULTY OF GRADUATE STUDIES
MAHIDOL UNIVERSITY
2013**

COPYRIGHT OF MAHIDOL UNIVERSITY

Thesis
entitled
**AGEISM, STIGMA OF TUBERCULOSIS AND ILLNESS
EXPERIENCE OF ELDERLY FEMALE PATIENT IN
YOGYAKARTA INDONESIA**

.....
Mr. Yudhanto Eddy Hastomo
Candidate

.....
Assoc. Prof. Pimpawun Boonmongkon,
Ph. D.
Major advisor

.....
Lect. Natthani Meemon,
Ph. D.
Co-advisor

.....
Lect. Thammarat Marohabutr,
Ph. D.
Co-advisor

.....
Prof. Banchong Mahaisavariya,
M.D., Dip. Thai Board of Orthopedics
Dean
Faculty of Graduate Studies
Mahidol University

.....
Assoc. Prof. Luechai Sringermyuang,
Ph. D.
Program Director
Master of Arts Program in Health Social
Science
Faculty of Social Sciences and
Humanities
Mahidol University

Thesis
entitled
**AGEISM, STIGMA OF TUBERCULOSIS AND ILLNESS
EXPERIENCE OF ELDERLY FEMALE PATIENT IN
YOGYAKARTA INDONESIA**

was submitted to the Faculty of Graduate Studies, Mahidol University
for the degree of Master of Arts (Health Social Science)

on
March 27, 2013

.....
Mr. Yudhanto Eddy Hastomo
Candidate

.....
Assoc. Prof. Nartruedee Dendoung,
M.A.
Chair

.....
Assoc. Prof. Chulanee Thianthai,
Ph. D.
Member

.....
Assoc. Prof. Pimpawun Boonmongkon,
Ph. D.
Member

.....
Lect. Thammarat Marohabutr,
Ph. D.
Member

.....
Lect. Natthani Meemon,
Ph. D.
Member

.....
Prof. Banchong Mahaisavariya,
M.D., Dip. Thai Board of Orthopedics
Dean
Faculty of Graduate Studies
Mahidol University

.....
Assoc. Prof. Wariya Chinwanno,
Ph. D.
Dean
Faculty of Social Sciences and
Humanities
Mahidol University

ACKNOWLEDGEMENTS

I would like to express my special thanks to PPHBC Singapore and Care Channels International for the scholarship, and for every support provided during my studies, my commitment while I was in East Timor. This long journey may not be smoothening without your contribution.

My special thanks are extended for Associate Professor Suphot Dendong, the head of the department, Associate Professor Luechai Sringernyuang, the programme director, and all the professors and teachers of the Department of Society and Health for their skillful trainings, teachings, hospitality and kind support during the difficult study period in Thailand.

I would like to express my deepest gratitude to Assoc. Professor Pimpawun Boonmongkon, my major advisor, for her patient guidance, encouragement, useful critiques and assistance in keeping my progress on schedule.

I would like to express my great appreciation to Lecturer Natthani Meemon, and Lecturer Thamarat Marohabutr my co-advisors, for all assistance with the methodology, critiques and the kind teachings.

I would also like to thank the supporting staffs of the Health Social Science International Programme for their support. My thanks are also extended to my friends in Care Channels Indonesia, for their hospitality and assistance during my field trip. My thanks are also for all informants for the resources they provided for my thesis.

I would like to thank Yeoh Seng Eng and Chwen Yeoh, for every support and to journey with me. Rebecca Kistap and KESINDO staff for all encouragement and support during field work in Yogyakarta. To Mas Har, I enjoy so much talking with you and for introduced me the splendid Yogya.

Finally I would like to remember my loving parents Manis Sri Sumartini and Jupiter Yohanes Duling, “ Mom and Dad, I love you so much, I dedicate this for both of you”. To all of my sisters Christina Tri Ayu Lendang, Andrie Yunita Hassan, Arnie Yunita Hassan, Ria Yunita Hassan and Winda Rahayu Hassan for all the cheer up moments, and encouragement to finish this thesis and for those who are not mentioned by name, but who I remember, for all kinds of support provided.

Yudhanto Eddy Hastomo

AGEISM, STIGMA OF TUBERCULOSIS AND ILLNESS EXPERIENCE OF
ELDERLY FEMALE PATIENT IN YOGYAKARTA INDONESIA

YUDHANTO EDDY HASTOMO 5438167 SHHS/M

M.A. (HEALTH SOCIAL SCIENCE)

THESIS ADVISORY COMMITTEE: PIMPAWUN BOONMONGKON, Ph. D.,
NATTHANI MEEMON, Ph. D., THAMARAT MAROHABUTR, Ph. D.

ABSTRACT

This study was aimed at understanding how social context in terms of women's roles and status, ageism, the stigma of tuberculosis (TB), and the health care context influences the elderly female patient's illness experience. An ethnographic study design was conducted involving observation combined with three focus group discussions with 8 elderly females, 8 elderly males, and 8 adults between the ages of 35-55; in-depth interviews with 15 elderly; and semi-structured interviews with 6 health workers.

The elderly female TB illness experience was affected by existing ageism and the stigma of TB that disadvantages their illness experience. Ageism among the elderly female was found in misconceptions, negative beliefs, and prejudice towards ageing patients. Stigmatization of TB affected elderly female patients such as in the expected mutual understanding to keep a distance from others or to have limited contact with the community and family members. Furthermore, this illness experience was unique, personal, and characterized by individual perceptions, irrationality, subjectivity, and perceived illness, which influenced the individual's health care seeking behavior.

Therefore, establishing a TB program among elderly females should involve better comprehension of the illness experience, and the information provided to them should be based on a sensitive approach by assisting and addressing concerns during treatment and medication.

KEY WORDS: CRITICAL MEDICAL ANTHROPOLOGY/ AGEISM/ STIGMA/
ELDERLY ILLNESS EXPERIENCE / MEDICAL PLURALISM/
TUBERCULOSIS

117 pages

CONTENTS

	Page
ACKNOWLEDGEMENTS	iii
ABSTRACT (ENGLISH)	iv
LIST OF TABLES	vii
LIST OF FIGURES	viii
LIST OF ABBREVIATION	ix
CHAPTER I INTRODUCTION	1
1.1 Justification	1
1.1.1 Why do I study Tuberculosis?	1
1.1.2 Why study TB in elderly women in Yogyakarta, Indonesia?	1
1.1.3 Why study TB illness experience?	3
1.2 Research Objectives	3
1.2.1 Specific objectives	3
1.3 Research Question	4
1.3.1 General question	4
1.3.2 Specific questions	4
CHAPTER II LITERATURE REVIEW AND CONCEPTUAL FRAMEWORK	5
2.1 Critical Medical Anthropology	5
2.1.1 Macro-social level: Health of ageing people and tuberculosis	6
2.1.2 Intermediate level: Power of health workers	7
2.1.3 Micro-level: Doctor - patient relationship – health care provider	7
2.1.4. Individual level	8

CONTENTS (cont.)

	Page
2.1.4.1 Aging body	8
2.1.4.2 Disability in ageing	9
2.1.4.3 Frailty	9
2.1.4.4 Subjectivity	9
2.2 Social constructionist perspective of ageing	10
2.2.1 Institutional Practices on ageing	10
2.2.2 Social representation of elderly women from media	11
2.2.3 Ageism	11
2.2.4 Medicalization of ageing and tuberculosis	12
2.3 Social stigma	13
2.3.1. Stigmatization	13
2.4 Social organization of gender	14
2.4.1. Gender Roles	15
2.5 Illness experiences	15
2.5.1 Illness	15
2.5.2 Health seeking behavior	16
2.6 Related literature review	17
2.7 Explanation of conceptual framework	19
2.8 Conceptual framework	20
CHAPTER III RESEARCH METHODOLOGY	20
3.1 Research design	21
3.2 Research site	21
3.3 Informants selection criteria and process	26
3.3.1 Research participant selection	26
3.3.1.1 Focus group discussion	26
3.3.1.2 Semi-structured interview with health workers	27

CONTENTS (cont.)

	Page
3.3.1.3 In-depth interview	27
3.4 Recruitment process	28
3.4.1 Recruitment for focus group discussion	28
3.4.2 Semi-structured interview	29
3.4.3 In-depth interview	30
3.5 Research methods	31
3.5.1 Informal conversation	31
3.5.2 Semi-Structured Interviews	31
3.5.3 In-depth interview	32
3.5.4 Focus group discussion	33
3.5.5 Observation	34
3.5.6 Secondary data collection	34
3.6 Research tools	34
3.6.1 Observation guidelines	34
3.6.2 Semi structured, in-depth Interview, and focus group guidelines	35
3.7 Data analysis	35
3.8 Validity of data	35
3.8.1 Data and methodological Triangulation	35
3.8.2 Trust Building	36
3.8.3 Reflexivity	36
3.8.4. Researcher Identity	36
3.8.5 Inter- subjectivity	37
3.9 Ethical consideration	37
3.9.1 Privacy	37
3.9.2 Confidentiality	37
3.9.3 Informed consent	38
3.9.4 Benefit and reciprocity	38

CONTENTS (cont.)

	Page
4.4.5.1 Elderly fear to engaged with TB patients	61
4.4.5.2 Obligation of physical distance	62
4.4.5.3 Physical distance and limitation to engaged with family member	62
4.4.6 Expected attitude in attending health care	63
4.5 Health care context of the elderly	64
4.5.1 Posyandu (Integrated service post) for elderly	64
4.5.1.1 Treatment and medication of elderly female sickness	66
4.5.2 Puskesmas Pembantu (Health Center Post)	67
4.5.3 Puskesmas (Community health Center), an affordable health service	68
4.5.4 Medical Pluralism and elderly decision for medication	69
4.5.4.1 Jodo (match), an interesting thread to individual elderly medication and treatment	70
4.5.4.2 Knowledge and lay perception toward acute and chronic illness	70
4.5.4.3 Jodo and medicine efficacy	73
4.5.4.4 Perceive toxicity of medicine	74
4.5.4.5 Culture influence in menopause and the elderly female health	75
4.6 TB program and health provider	76
4.6.1 Managements of tuberculosis patients	76
4.6.2 Finding strategy for TB patients	77
4.6.3 TB referral system	77
4.6.4 Home visitation	78

CONTENTS (cont.)

	Page
4.6.5 The role of care giver (PMO – Pemantau Menelan Obat) in elderly TB treatment and medication	79
4.7 Elderly female TB patient illness experiences	80
4.7.1 AH (food vendor)	81
4.7.1.1 Road to health, individual health seeking to care	82
4.7.2 Mrs. AJ (retire)	85
4.7.2.1 It's looks like goiter and now TB?	85
4.7.3 Medication in TB illness experience	87
4.7.4 Expected rules in illness experience	88
4.8 Social context and its impact on TB medication and treatment	88
4.8.1 Women's role and status, and illness experience	88
4.8.2 Stigma and TB illness	89
4.8.3 Treatment failure and consequences	90
CHAPTER V CONCLUSION, DISCUSSION AND RECCOMENDATION	92
5.1 Conclusion	92
5.2 Discussion	94
5.3 Recommendation	95
BIBLIOGRAPHY	102
APPENDIX	107
BIOGRAPHY	117

LIST OF TABLES

Table		Page
4.1	Table of TB etiology by the elderly	56
4.2	Perceive symptoms of TB and physical appearance	59
4.3	Elderly perception on acute and chronic sickness	72

LIST OF FIGURES

Figure	Page
3.1 Administrative Map of Yogyakarta Special Region (BPS 2010)	25
3.2 Administrative Map of Districts of Sleman Regency (BPS 2010)	26
4.1 Entrance to the village and border to west, the paddy field	40
4.2 Hamlet Sumerno, housing and fish farming in the village	41
4.3 Map of hamlet Sumerno	41
4.4 Mbah C in front of her front yard	44
4.5 Mbah Mawar (Pseudonym) is one of the female elderly who live solely	46
4.6 Mbah Putri and her paddy lot	48
4.7 Farmer in hamlet Sumerno, and rice field as border to other hamlet	49
4.8 Posyandu health check card, room use for posyandu	65
4.9 The flow for health check at Posyandu lansia	66

LIST OF ABBREVIATION

WHO	World Health Organization
NTP	National Tuberculosis Program
TB	Tuberculosis
DOT	Directly Observed Therapy
DOTS	Directly Observed Therapy Short Course
PUSKESMAS	Pusat Kesehatan Masyarakat
POSYANDU LANSIA	Pos Pelayanan Terpadu Lanjut Usia
PUSTU	Puskesmas Pembantu
PMO	Pemantau Minum Obat
BPS	Badan Pusat Statistik
BAPPEDA	Badan Perencanaan Pembangunan Daerah
BP4	Balai Pengobatan Peberantasan Penyakit Paru-paru
HIV	Human Immunodeficiency Virus
AIDS	Acquired Immunodeficiency Syndromes
%	Per cent
DALY	Disability-Adjusted Life Year

CHAPTER I

INTRODUCTION

1. 1 Justification

1.1.1 Why do I study Tuberculosis?

Tuberculosis is not just a disease that involves control and eradication, but it is also a social problem. The effort toward solving the TB problem mainly as an epidemiology or medical problem is inadequate as it is influenced by social related factors such as poverty (Paul 1997; Joan E 2004; Russel 2004). TB has been widely reported effecting marginalized groups such as drug users, women, the elderly (Neyrolles and Quintana-Murci 2009; Perlman, Salomon et al. 1995), ethnic groups, poor people (Singh, Jaiswal et al. 2002; Cambanis, Yassin et al. 2005), and prisoners (Fry, Khoshnood et al. 2005), which reflects the social inequality issue, and requires a social science perspective, knowledge and research to tackle the problem (Paul 1997). Lack of information about tuberculosis (Liefoghe, Michiels et al. 1995), delay in diagnostic, constraints in accessing health care services, and socio-economic related issues are some of factors that undermine TB control, which may lead to untreated tuberculosis, and threaten control of infection (Zignol, Hosseini et al. 2006). Moreover, drug resistance as a result of treatment dropout, or treatment interruption makes it possible for existing and new strains to infect others (Cohn, Bustreo et al. 1997), which makes disease control more difficult to handle in the larger population (Stokstad 2000).

1.1.2 Why study TB in elderly women in Yogyakarta, Indonesia?

The number of elderly in Indonesia was reported to be 23,992,553 people in 2010. This number will increase by 11.4% in 10 years time, with Yogyakarta's share the highest percentage with 12.8% of the total elderly in Indonesia (BPS 2010); with such amount of number, Yogyakarta becomes suitable as my research site. In

addition, research on TB among this population has been limited.

Another reason why I study TB among elderly women is because they are more vulnerable than young people or adults because of their immune-compromised condition, which makes diagnosing TB among this population group difficult. For example, they may not have classic presentation like fever and night sweat (Van Den Brande, Vijgen et al. 1991). Furthermore, nonspecific symptoms are common, including changes in activities of daily living, chronic fatigue or weakness, cognitive impairment, weight loss, persistent low-grade fever, and symptoms duration that may be greater in the elderly (Korzeniewska-Kosela, Krysl et al. 1994). Thus, elderly women live in a difficult situation, as they face disability-adjusted life years (DALY), they tend to be either widows and caretakers, are faced with poverty, hard work, are vulnerable to malnutrition, and are at risk to TB drop-out, and reduced success rates of TB treatment.

Davies (1996) viewed that the emergence of HIV associated with tuberculosis, particularly among those of reproductive age, has diverted attention from tuberculosis infection among the elderly. While the incidence of tuberculosis among elderly represent the biggest pool of disease infection within the community in developed countries, in developing nations the number is rising. The presentation of TB among elderly is often uncharacteristic, and even has high potential to develop into extra pulmonary tuberculosis. Thus, increased awareness in disease recognition and better medical investigation is needed. Chand, Bhushan et al., (2007) studied in Recife, Brazil and suggested that women are sharing the problem with men, even though the case findings among women are lower than men. Furthermore, Neyrolles and Quintana-Murci (2009) stated that bias exists in the study of TB in females, in that male causation factors and others factors are being generalized to women. Their finding suggested that biological gender in TB also contributes to the sex bias observed, because of the quality of sputum sample collected. Therefore, research on women, particularly among elderly women, is less than among men. Gender related to TB study in many cases is limited to sex, rather than involving social, cultural, and contextual factors of the gender itself (Allotey & Gyapong 2008).

1.1.3 Why study TB illness experience?

Understanding illness experience is one of the critical aspects to identify patient reaction toward medication and treatment. Illness cannot be simply viewed as an impact of physical problem, which merely needs an alteration of biological structure or functioning (Kleinmaan, 1978), but it also reflects the meaning that is attached to the suffering of patients. Tuberculosis illness experience is also affected by the intertwining of culture, stigma of TB, gender inequality, and ageism that reproduce in semantic health complaints of the elderly patient. Inadequate response and neglect of individual illness experiences will likely lead to elderly female patients being disadvantaged in the process of treatment and medication, and could lead to delay in care and treatment, or the drop off case, that will eventually affect the effectiveness of the TB program. Hence, comprehending illness experience and being able to interpret illness meaning may contribute to the provision of more effective treatment and medication of TB among elderly women. In addition, the continuing study of TB treatment and illness experience will impact on the effectiveness of the TB control program among elderly female TB patients, who may have specific needs and problems related to TB treatment (Sumartojo 1993).

1.2 Research Objective

To understand how social context in terms of ageism, social stigma of TB, and health care context has influenced elderly female patients' illness experiences.

1.2.1 Specific objectives

- 1) To Explain the social context in term of women's roles and status, ageism, social stigma, and health care context exist among elderly female patients
- 2) To understand the elderly female TB patients' illness experiences under the social context.
- 3) To understand how social context in term of ageism, social stigma of TB, and health care context has influenced elderly female patients' illness experiences and their impacts on TB treatment and medication.

1.3 Research Questions

1.3.1 General question

How does social context in terms of ageism, social stigma of TB, and health care context influence elderly female tuberculosis patients' illness experiences and have impacts on TB treatment and medication?

1.3.2 Specific questions

1) How does social context in term of ageism, social stigma of TB, and health care context exist among elderly female patients?

2) What are the elderly female TB patients' illness experiences under the social context?

3) How has social context in terms of ageism, social stigma of TB, and health care context influenced elderly female patients' illness experiences and had impacts on TB treatment and medication?

CHAPTER II

LITERATURE REVIEW AND CONCEPTUAL FRAMEWORK

The first part of the literature review and conceptual framework chapter consists of a critical medical anthropology perspective and its relationship to the TB control program. The second part is a social constructionist perspective on TB and ageing, then followed by the social stigma of tuberculosis. The third part will be an explanation of the social organization of gender and the illness experience. The last part will cover the conceptual framework.

2.1 Critical Medical Anthropology Perspective

Baer, Singer et al., (2003) stated that critical medical anthropology derived from the work of medical anthropology and the gap in the existing problem related to the political economy of health as a result of capitalism that is not addressed in other theoretical concepts in medical anthropology. It analyzes and addresses the nature of health-related issues in an indigenous society, as well as pre-capitalist and socialist-oriented state societies.

Singer and Baer's (1995) view is that critical medical anthropology's array of analysis of biomedicine is not merely a socially constructed system that is integrated within a wider cultural pattern, a mechanistic or depersonalizing structure with an influential social control function within the contemporary world, but it is also an intertwining of biomedicine and the global capitalist world economic system.

The critical medical anthropology approach involves four different levels of analysis, namely the macro-social level, intermediate levels, the micro-social level, and the individual level. The following are descriptions of those levels:

2.1.1 Macro-social level: Health of ageing people and tuberculosis

Baer, Singer et al. (2003) described critical medical anthropology as recognizing that capitalism has progressively shaped and reshaped social life through biomedicine as its product. The progressive capitalist nation reproduces the structure of class relations. Thus the result has been that biomedicine has changed into a capital-intensive endeavor, heavily oriented towards technology, with the massive use of drugs, and the concentration of medical complexes.

Kaufman (1994) viewed that the interaction of ageing and health with culture nowadays is imprinted with the influence of capitalism in the medicalization of ageing and the advancement of medical technology, resulting in age longevity and the physiological betterment of older adults. Ageing has become another platform for capitalism to benefit from human interaction with technology and biomedicines. In addition, (Lock 1984) stated that because of medicalization and advancement of biomedicines in technology, women are sharing greater effects from medical discourse such as in hormone replacement therapy. Reproduction of the structure of class relation and the reshaping of social life has enabled us to place ageing as an abnormality or disease, rather than the process of maturing in later age. Beyond that medicalization too impacts on their morbidity, such in the case of reproductive technology, contraceptive methods, and hormone related therapy (Lock 2004).

The critical medical anthropologist also acknowledges that health social inequality is not merely a stand-alone by the involvement of global capitalism in health, but also by structural-related violence. Farmer (1999) in “Pathologies of power: rethinking health and human rights”, argues that the patterning of tuberculosis in poor countries cannot be understood simply by patterning the disease, because tuberculosis is proven to affect not only the poor nation but also industrialized countries. In his opinion, tuberculosis should be assessed by how the social forces and political violence and racism is expressed as individual pathology. In addition, Singer (2004) suggested that poverty is also impacted by global capitalism, because it has increased the likelihood of people being infected by tuberculosis because of poor living conditions, pre-existent immune system damage, or disruptive economic and social crises in poor families. Thus, the connection of global capitalism and structural

violence works at the highest structural level in the illness of individuals that can be found and identified.

2.1.2 Intermediate level: Power of health workers

The establishment of biomedicine as a capitalist product is allocated in the health care system, such as in the hospital that varies and become the primary space for social relations. The macro level intertwines with the intermediate level to reproduce human power, to ensure the capitalist power structure existing over biomedicine, in its reproduction of medical expertise and structured class relations, for instance, in physicians with specialties, or nursing (Baer, Singer et al. 2003).

Previously in Yogyakarta, Indonesia only the public hospital or community health center implemented NTP (National Tuberculosis Program), while the private hospital seem set apart from TB program inclusion. Irawati, Basri et al. (2007) explored how good coordination between two hospitals eventually will help in case detection of TB, or how referral can be met when a patient is diagnosed with TB in a private hospital and sent for treatment in a public hospital. However, this also posed a challenge, such as in terms of bureaucracy and rapport of TB. The control design focusing on the hospital-based setting will benefit more for the health care provider rather than benefit the patients themselves. In addition, patients also need to bear another burden for regular visitations to hospital, in particular, for elderly with TB, being a regular visitor to hospital can place a challenge for them.

2.1.3 Micro-level: Doctor-patient relationship – health care provider

In this level the physician's role is not solely aimed at answering the needs of the patients, but also the outer objective that encompasses them as part of the health care system intervention, such as the health bureaucracy and its agenda. Physicians at the same time are involved in directing the social system and the existing distribution of power: controlling access to the special prerogative of the sick role and medicalization of social distress (Baer, Singer et al. 2003).

Kleinman, Eisenberg et al. (2006) proposed that the physician should understand the patient beyond the disease, and the effort on diagnosis, treatment and medication should benefit the patients. The physician also needs to develop cultural

awareness that helps to identify the complexity of the illness experience by patients.

In the case of tuberculosis, a negative outcome can result from a neglected aspect of the interpersonal relationship, and lead to the dropout case, and cause drug resistance. A TB study by Dimitrova, Balabanova et al. (2006) in Russia found that an intensive approach by the health care personnel could trigger stigmatization. They found forced medication and checking, and even life surveillance affected the patients; such as involving police to monitor whether a patient attended to take the medication.

2.1.4. Individual level

The individual level entails consideration of the patient's response to sickness or sufferer experience. Scheper-Hughes' and Lock's view in understanding critical medical anthropology's "the mindful body" terminology is a critical part of this perspective. That the individual's body physically feels distress and the bearer it's experiencing (Scheper-Hughes and Lock 1987). The critical approach to the individual level begins with recognition that the sufferer's experiences are constructed and reconstructed in the action arena between socially composed categories of meaning and the political-economic forces that shape the context of daily life (Baer, Singer et al. 2003).

2.1.4.1 Aging body

Helman (1990) stated that the human body has two realities that are coined and function together, as social and physical. Body representation in society is valued by the individual, and communication information relates to gender, social status, occupation or membership of certain groups, that includes body gestures and postures. Moreover, beyond physical reality, the social body is an important part of the body image because people's own physical and psychological experience is affected by their perception and interpretation. Thus, being ill is influenced by perception and presentation of bodily complaints (Helman 1990).

On ageing, the health institution has deliberately shaped and reshaped the older adult's lived experiences, and it presents multiple outcomes that contribute to the well-being of the elderly. For example, longevity and aging activities and social networking that are intentionally constructed within various social

institutions may reformulate elderly conditions (Katz 2000). Ageing is not only about changing in physical ability, but also how attitudes toward older people are produced and reproduced.

2.1.4.2 Disability in ageing

Estes and Binney (1989) study on elderly stated that disability and the elderly is a natural dimension that is coined in the process of ageing. Disability in ageing is shown through physiological incapability and cognitive decline of the older adult. For instance, the deterioration of the mind's abilities to think because of a biological weakened condition, such in the case of dementia, has an impact on ageing and the caregiving management process. In addition, disability in an ageing population has been influenced by medicalization that has changed the social situation of caregiving into merely pathology or misbehavior of the demented person (Estes & Binney 1989; Lyman 1989).

2.1.4.3 Frailty

Kaufman's (1994) study on elderly discussed the subjective experience of older adult frailty that is understood as medical/social service idioms. Elderly behavior, habits, and lifetime arrangements were analyzed along with symptoms they chose to identify and present as troublesome. Throughout the medical encounter, life occurrence is changed into a delinquent list that is comprised of personal and social behavior as well as physical disorder. Furthermore, the language of surveillance and risk reduction appears as the key in sustaining personal autonomy and independence by the health care provider, and sometimes by the family as well. Medicalization is an attempt to settle the living problem by adapting surveillance strategies to idiosyncratic forms of autonomy embodied by the very old person.

2.1.4.4 Subjectivity

The subjectivity of the older adult toward ageing also contributes to ageing people's own self-perception. Biehl, Good et al. (2007) in "Subjectivity" referred to subjectivity as an essential of one's life, and realization of one's state of perception. This exclusive emphasis on the human mind or individual

experience also implies a kind of affective domination, in which feelings, thoughts, concerns, and perceptions, all supposedly personal, overcome individuals. Kelley-Moore, Schumacher et al. (2006) suggested that subjectivity is perceived through lived experiences and evidence that ageing causes functional limitation, cognitive impairment, incapability of conducting activities as when they were young, or institutionalized at elderly home care.

In conclusion, critical medical anthropology identified that medicalization of ageing and tuberculosis is influenced by the larger set of the health system and its impact at any level within the country where policies are established. Ageing and tuberculosis become the set of medical discourse, where the patient's own illness experience cannot simply come from the individual, but also be perpetuated by the wider health context as an impact of global health capitalism.

2.2 Social Constructionist Perspective of Ageing

Social construction perspective was derived from an extended tradition of analysis within the micro level. Its central study is individual agency and social behavior inside the larger structure, in particular on the subjective meanings of age and the ageing experiences (Thompson, 1992). Ageing is a person process that is socially constructed through social definition and social structure, which helps to develop perception of being an older adult (Kohli & Meyer 1986; Bengston, Putney et al. 2005). The interplay of social arrangement, institutional practices, or aggregate social action rather than the real objective reality in the daily life setting has become the arena for socialist constructionist's observation (Biesta 1998; Tinker 2002; Bengston, Putney et al. 2005).

2.2.1 Institutional Practices on ageing

Katz's study identified the involvement of health professional practices as a representation of the health care institution in ageing is interacting with the elderly health problem, which allowed the health professionals to practice, treat, and monitor the ageing problem (Katz 2000). Furthermore, Lafontaine (2009) stated that the role of institutional practices in deconstructing ageing is involves in extending the effort in

restructuring the elderly health care system, such as in longevity and postponing dying through regenerative medicines that imply the social institution's role in constructing elderly well-being (Lafontaine 2009).

Miller et al.'s view is that physicians are expected by the family to participate in the management and treatment of the elderly condition, thus institutional practices involvement has increased beyond its capacity (Miller, Glasser et al. 1992). In addition, institutional practices directed the family as the caregiver to expected elaborate in constituting the elderly condition following health institutional practices definition of elderly illness, such as in managing illness of the older adult (Young 1994).

2.2.2 Social representation of elderly women from media

Vertinsky and Cousins (2007) found that the representation of women in media is reflected in the form of language, images, and motion pictures. It is carried out in any products of media. This representation may deliver positive and negative outcomes. Positive media can enhance elderly awareness of their wellbeing, how to deal with ageing, and provide psychological empowerment. However, on the other side, it can also enhance mistaken perceptions that enable others to perpetuate stereotyping of being old women. For instance, although elderly women are portrayed as in shape and healthy, the association to having a disability is prominent. In addition, medicalization in ageing has helped to construct new images of ageing, and impacted on women's own perceptions toward the ageing process, their fitness, beauty and longevity. The representation of women delaying ageing is advertised in many forms of media, which imply being old can be avoided or postponed through manipulation of the body's condition, consumption of anti-aging products, and induced medical technology in young preservation.

2.2.3 Ageism

(Palmore 1999) proposed the concept of ageism as any association of prejudice, discrimination, attached rejection, that is expressed in any kind of form of stereotyping because of the ageing process. These expressions can be manifested in perceptions toward older people, for example, as a person that needs constant

protection, in the expected norms in valuing how elderly or older adults should be, charges of being getting too old because they miss a word, or dirty if older people show love affection or sexual feelings, and charges that older people are like children as they are dependent, helpless, and powerless.

2.2.4 Medicalization of ageing and tuberculosis

Gabe and Calnan defined medicalization as “the way jurisdiction of modern medicine has expanded in recent years and now encompasses many problems that formerly were not defined as medical entities” (Helman 1990). Furthermore, Helman stated that this medicalization includes a wide variety of phenomena, such as in female life-cycles (menstruation, pregnancy, childbirth, and menopause), old age, unhappiness, loneliness, and social isolation, and the wider scope of social problems, such as poverty or unemployment (Helman 1990).

Lafontaine (2009) suggested that ageing and health interaction with culture nowadays is imprinted with the influence of the political economy in the medicalization of ageing and the advancement of medical technology, resulting in longevity of age and physiological betterment among older adults. Medicalization is an expression used in viewing social problems as medical discourse. The extension of the medical system within the social problem dimension, through social structure and social institutions, has been acknowledged contributing to the restructuring of society and health.

Kaufman (1994) furthermore suggested that ageing has become another platform for capital owners to benefit from human interaction with technology and biomedicines. Reproduction of the structure of class relation has reshaped social life and enabled it to place ageing as abnormalities or disease rather than the process of maturing in later age (Kaufman 1994). In particular this relates to women, who have been the center of discourse of medicine, medicalization has created enormous impact on their morbidity, for instance, in the case of reproductive technology, contraceptive methods, hormone related therapy, etc. As a result, women have rather shared negative effects from medicalization and the advancement of biomedicines technology (Lock 1984; Vincent 2006).

Reitmanova and Gustafson's (2011) study of tuberculosis among

immigrants in Canada argued that the racialization, and medicalization of the risk infection in social-economically disadvantage populations by contemporary epidemiology models of infectious disease has neglected the role of social conditions in sustaining the unequal distribution of disease in these populations. Health and social inequality among immigrants is perpetuated by TB policies that carry regulation by conducting medical screening and surveillance. Reported cases between 1970 and 2007 have proven that established policies have been ineffective, since the trend has increased from 18% to 66% in 37 years.

To conclude, social constructionist perspective analyzes how the ageing individual, in particular related to tuberculosis, is an intertwined social creation of how ageing people should be, behave, and are reacted to from the society. Ageing is formulated by society and reflected in daily life, and tuberculosis is shaped by health institution through medicalization and extension of power through institutional practices.

2.3. Social Stigma

2.3.1. Stigmatization

Goffman (1963) defined stigma as a profound negative attribution that diminishes a person and degrades his or her well-being into someone that is unfavorable, ostracized, and rejected. In his opinion with this attribution, conduct or traits are implied symbolically and manifested in ways that shame, guilt or disgrace are attached to a person. These manifestations of stigma reveal in different types of representation, such as *abomination of bodies*, which deliver because of the appearance of physical abnormalities, like tattoo scars, obesity, and leprosy. Furthermore, Goffman suggested that stigma affected the individual that it is being inferred to a certain condition that *deviates the quality of person*, which is thought to be a “dangerous individual, unnatural or not commonly accepted, [with a] rebellious attitude”, such as among people with mental disorders, addictions, alcoholism, or infected diseases. In addition, larger scale interaction of stigma is included in the *tribal stigma* of a nation, race, or religious affiliation that can be affected upon the person,

family or group.

Dodor's (2009) qualitative study on tuberculosis in Ghana found that TB stigma exists in many elements of the tuberculosis control program. He suggested that stigma is perpetuated from the community, manifested and affected the patients such as in the obligation of maintain a social-physical distance, participatory limitation, and rules for when unexpected encounters occur among those sufferings from TB in the society. Moreover, the health workers perceptions towards TB contributed to the construction of stigma within the health care services, like judging, blaming, and shaming the patients. In addition, self-stigma is generated within TB patients, which marked the intertwining of causes and effects.

2.4. Social organization of gender

Lorber, (1994) stated that gender is manifest in daily live, and works in any dimension of human biology, activities, routines, and interactions between people. The construction of gender is commenced with the assignment of a sex category from the genitalia at birth. Its development gradually changes by the influence of experiences through interactions with those of the same and opposite gender. It shapes people through gender role, appropriateness of social roles and responsibilities within the context, the maintenance of gender differences, and other related factors that shape gender to be constructed. Gender is not merely an individual experience, but also experienced as asocial institution, in which humans organize their lives, and structure its function. Gender involves social statues that are carefully constructed through those prescribed from teaching, learning, emulation, and enforcement.

Becker (1994) argued that women. in particular elderly women, carry entities of being an older adult and of being a women. Gender as social institution is effecting societal views on elderly women. The devaluation of the elderly exists, and being a women in some context of culture can be even stronger, in particular when dependency because of disability or frailty takes place. Furthermore, Bird and Rieker (2008) argued that a woman's subjectivity of her own condition, elderly woman stereotyping, and weakened policy toward the protection for elderly women contribute as well to their wellbeing.

2.4.1. Gender Roles

Gill (1995) proposed that gender roles are socially constructed based on the difference in the patterns of behavior of men and women. This socially constructed meaning is manifest in biological differences between the male and female. Women's life is inseparable from how gender role is constructed. Across cultures, women's gender role is ascribed in their daily life and is expected to be followed even when it seems against their own will.

Brody (1999) suggested that this gender role is transferred through the learning process, reproduction, and enforcement. Women are constituted to be the caretaker, loving, weak, and dependent on men, inferior, submissive, and devoted. Suggested that this condition can be carried on into ageing process, where older women are projected, too, as the consistent caregiver even in their disability. Furthermore, their role as woman, mother, and grandmother is attached to the domestic sphere, and implies their contribution to housework and maintenance of the family.

A comparison study of three main infectious diseases in Malawi by Simwaka, Makwiza et al. (2006) suggested that women gender roles and relation affect not only their vulnerability to TB, Malaria and HIV, but also their access and adherence to services and the impact of the disease on individuals and households in Malawi. The intertwining of gender and poverty, and women's own health experiences and outcomes, should be the basis to understanding the complexity of tuberculosis or other illnesses upon the establishment of health policy, thus equitable, efficient and sustainable policy can be the result.

In conclusion, ageing and tuberculosis are affected by the ideology of gender and gender roles. Elderly women are expected to follow, abide by the roles, and reproduce them in the family and society. Furthermore, gender roles have influenced women in accessing health, health seeking behavior, and problems in treatment and medication. Thus it has undermined their health, well-being, and perpetuated risk and vulnerability.

2.5 Illness experiences

2.5.1 Illness

Cassell describe illness as a patient's own subjective response especially for the causality and significance of illness through interpretation. This illness experience affects the patient's relationships with others and the meaning they give to that experience. Thus, the patient's own illness can be interpreted differently in different cultures and context that affect their subsequent behavior and types of treatment they seek (Helman 1990).

Kleinman provided an anthropological and sociological dimension to illness. The physical malfunction or maladaptation of biologic and psychophysiological process in an individual has become the center of biomedicine to described disease, while illness represents personal, interpersonal and cultural relations to disease or discomfort. Illness is culturally shaped in the sense of how it is perceived, experienced, and coped with; the disease is based on explanations of sickness, explanations specific to the social position we occupy and system meaning we employ (Kleinman, Eisenberg et al. 2006).

2.5.2 Health seeking behavior

Understanding health-seeking behavior is a critical part from where patients initiated their ability to obtain good health. The pathway model describes initiation for health obtainment starts with the realization of symptoms attached to illness, and in comprehending this, the patient may seek various forms of health services, from home treatment, a traditional healer, and hospital. Realization of symptoms is also influenced by the extended group or family, which affects the patient's own negotiation and management to deal with the presence of illness (Hausman-Muelan, S. Nyamongo 2003).

2.6 Related literature review

WHO is suggesting directly observed therapy short course (DOTS) to be implemented as part of NTP, a policy based approach that entailed aspects of the TB program. Directly Observed Therapy Short Course emphasis is on five clear and solid claims, which are: 1) clear and sustainable political commitment by governments; 2) detecting the TB case through examining sputum, if necessary doing culture and drug resistant testing; 3) Provide standard treatment, with supervision and patients support that include DOT (Directly Observed Therapy) which, can involve either the clinic or the community, or people at home directly observing patients taking their treatment on a daily basis; 4) an effective drug supply and management system: and 5) monitoring and evaluating the TB program and measuring impact (Kidd, Clay et al. 2009). DOTS are the essential approach that has been highly implemented worldwide and a gender approach to treatment is critical for the effectiveness of such a program.

Moss (2002) raised attention to the criticism in response to gaps between providers and clients. Health care providers were criticized for being insensitive to patient needs and cultures, being less informative, gender insensitive, more decisive to patient illness despite the health care costs that mounted and became unaffordable to lower income people, in particular for women which reflected the health inequity that exists for women.

A study by Gosoniu, Ganapathy et al. (2008) identified gender and illness related features of TB. They found that social and cultural features of disease, health system diversity, and the effectiveness of clinic operations contribute to the delay in diagnosis. Furthermore, their findings also identified being a women, particularly a married women in Bangladesh and housewife in Malawi, affected the delay in diagnosing.

A gender study comparison of TB stigma in Bangladesh, India, Malawi and Colombia conducted by Somma et al. found that TB patients and women in particular were concerned about the impact of TB on their marital prospects and how TB was associated with HIV/AIDS, such as in Malawi. Self-stigma is commonly found which is reflected in social distress beyond the somatic burden of disease. Rejection from communities exists, and fears become the primary concern to communities, thus disclosure can be problematic to TB patients. From this research it

was suggested that stigma can be used as an indicator to identify whether the TB control program is effectively working or not (Somma, Thomas et al. 2008).

Nichter's (1994) study in the Philippines provided detailed narrative experiences of the TB patient dealing with the TB control program, and how the people perceived tuberculosis may affect multiple problems and issues in dealing with the illness, and their experiences dealing with the diagnostic process, treatment and medication. There has been criticism that the clinical approach to TB without considering the need for subjectivity of the illness experience may set the program backward.

Zuniga's study on women's experiences with TB treatment among Hispanic women was associated with hustle and complexity for being a patient, due to the demanded supervision of the treatment. Furthermore, the process contributed to isolation, and feeling watched over, and resulted in feelings of paranoia as they became afraid of threat of imprisonment for dropout from treatment. Thus, DOTS has become a stressful and difficult experience (Zuniga 2012).

A study of public and private health providers in Kampala, Uganda shows what can happen when the standard for quality of care is not followed appropriately and affects the TB program. Physicians were found to not fully have understood the DOTS implementation. Particularly, to the private provider the availability of regimes stocks is limited. It was shown that the TB system has not fully transcended within the private health sector (Nshuti, Neuhauser et al. 2001), this has hindered patients from benefiting from health providers in obtaining proper care.

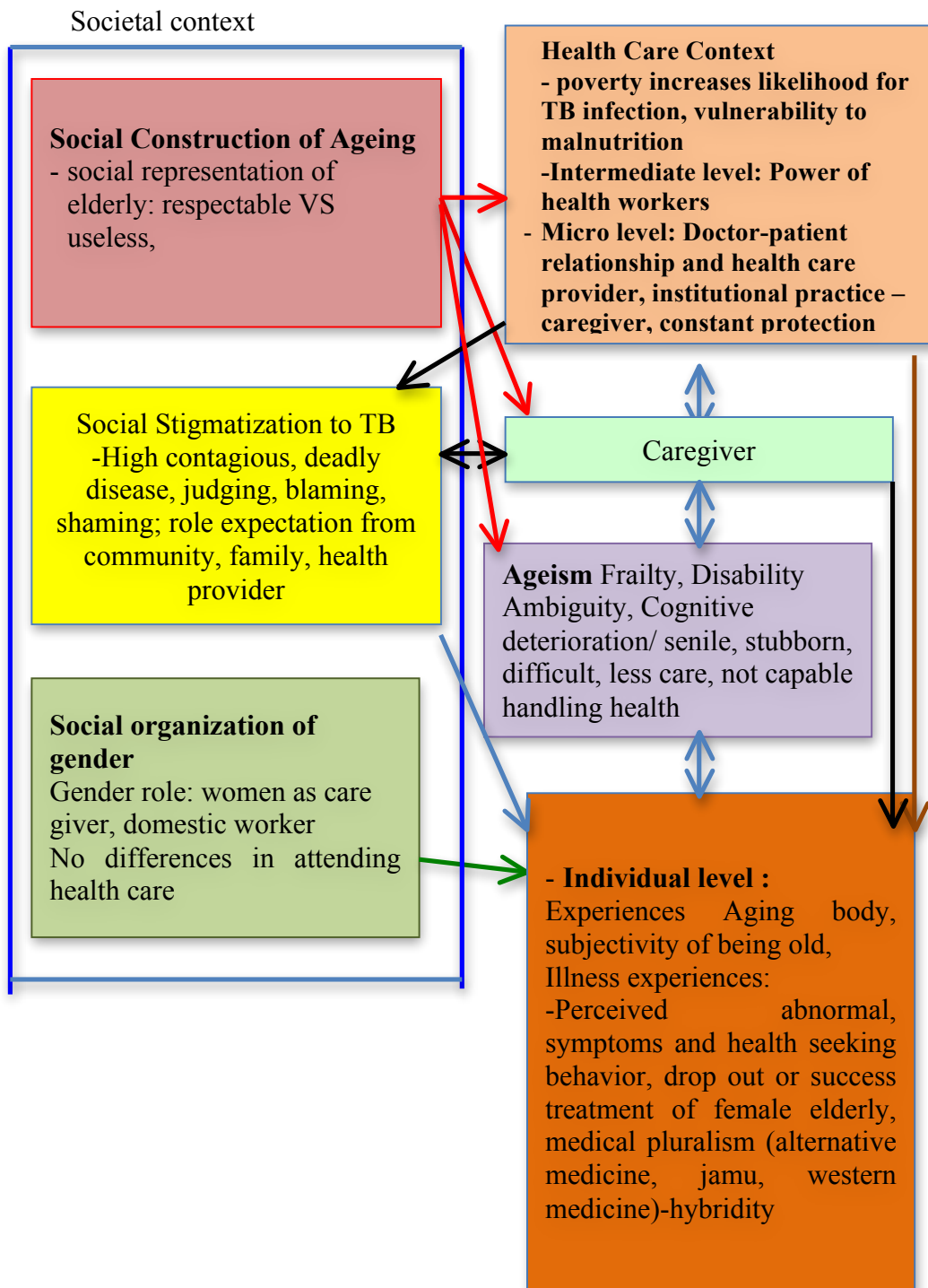
A study by Asch, Kerr et al. (2006) in Nepal associated the patient-physician relationship in TB treatment with its impact on adherence and the successful completion of DOTS treatment. The finding showed that adherence and non-adherence is affected by the quality of the professionals. In Nepal, poor behavior by the health examiner and drug dispenser were identified. In addition, poor quality communication delivered by health workers was associated with non-adherence.

2.7 Explanation of conceptual framework

The tuberculosis problem is influenced as well by the wider scenario of interventions. Critical medical anthropology provides the lens in understanding how policy at the macro level and the role of capitalism has impacted on health care delivery, such as care provision of the hospital. Individual illness experience of TB is not merely caused by a single factor, but also is part of the greater health system like the hospital. Moreover, within the micro level the production and reproduction of health care workers also affects the service delivery to patients. Individual illness experience and subjectivity are present because of the relationship of the bigger system has an effect on their decision to obtain health services. In addition, ageing people carry complex conditions that need to be understood accordingly, because disregarding ageing conditions may undermine the successfulness of TB treatment.

The social context of tuberculosis is a combination of multiple factors. In this, women's roles and status, ageism, social stigma, and society construction on ageing contributes to the well-being of elderly female TB patients. Women's roles and status is influences the elderly female TB patient, such as in accessing the type of health care for diagnosis, treatment and medication. Furthermore, ageism is intertwined in care provided by health workers and caregivers, which influences the illness experience of elderly female patients. Moreover, social stigma associated to TB may hamper and affect individuals and determine or undermine the effectiveness of DOTS for elderly women. Social stigma is influencing communities, health providers, and TB patients and how they are intertwined, and affects the TB control program. In addition, societal construction upon ageing and TB carries multidimensional aspects of health, and how elderly images are ascribed and formulated in society.

2.8 Conceptual Framework



CHAPTER III

RESEARCH METHODOLOGY

Welcome, “*Sugeng rawuh*”, is an expression that I commonly found in many part of Yogyakarta, such as at city halls, towns and village gates. I felt embraced by the words, not just because of the meaning, but rather the culture, nature, and the people, too, a homecoming welcome. This romantic feeling occurred as a personal emotional expression after being away for quite sometime from a place that I have called home recently.

A mixed feeling and anticipation reaction arose within me in realization that my understanding and experience with Yogyakarta was immature, and considerably limited. I shifted from working for my NGO in East Timor (Republique Democratique de Timor Leste – RDTL) to Yogyakarta in 2011, and only experienced a short honeymoon impression with the place before I went to Thailand for study. I was there for only three months from January to March 2011. I felt so inadequate to comprehend the reality of Yogyakarta, and it will always be, and being back home in Yogyakarta did not necessarily bring an instant connection, except a repeated feeling of expectation to adapt and adjust with a new place, new culture, and new people.

I was aware that the research process will experience challenge and obstacles, and assuming that such a situation may occur, I developed within me an attitude of mindfulness, being alert, and contemplative to risks during my research. To deal with nature was one of the challenges I encountered upon my arrival in Yogyakarta. The rainy season had started, and the weather was unpredictable; it may be sunny with massive rays of sunlight, and in hours change into pouring. It happened to me once that throughout an entire week rain was heavy all day long.

3.1. Research design

An ethnographic research design was used to obtain information from subjects throughout my research steps. Through ethnography research I explored and examined the culture that fundamentally is important as it is part of the human experience. The data collection process became the time that I cherish the most as I gained insight directly from subjects of my research, and had daily involvement with the lives of people at firsthand. Being in the field has provided me details of cultural information about the values, norms, opinions, and social context of female elderly and female elderly TB patients. This ethnography study also helped me to understand how culture is embedded in human interaction and perceived and reflects toward others. Furthermore, ethnography as research strategy has the ability to illuminate locally relevant understanding and ways of operating such as behavior, interaction, and conversation that are the manifestation of society and culture in action. (Murchison 2010)

In addition to supporting the research design, I prepared several methods to obtain information from subjects, in particular during my initial research steps; these involved focus group discussion methods, semi-structured and in-depth interviews, essay writings, and observation. However, along the process of data collection, those methods were evolved and adjusted in comprehending tuberculosis quality of service delivery and its impact among elderly female patients in Yogyakarta, Indonesia.

3.2. Research site

The research site that I explored is part of Yogyakarta Special region. It is special because it is acknowledged as the cultural capital of Indonesia, where one of the monarchs still lives, and has a special role in governing the people. The region is ruled by the sultan who has a dual leadership, which is as a king and a governor. Yogyakarta is divided into five main areas, which are Yogyakarta capital, Sleman, Bantul, Kulon Progo, and Wonosari. The total of population is 3.5 million covering 1,114.16 km² (430.18 sq. m.) in size, and out of that population, 9.7 % is elderly. At 12.8%, Yogyakarta has a considerable share of the total elderly population in

Indonesia (BPS 2010). As a result, Yogyakarta is the city of an aging population. In addition, the implementation of NTP (the National TB Program) is performing well; however, social studies with a qualitative approach to the TB program have been relatively limited, in particular those related to TB and gender among the elderly female patients. In consideration of the above situation, I chose Yogyakarta as my research area. And to narrow down and to focus the site, I selected the regency of Sleman as my research site.

The regency of Sleman area is substantially large, with the size of 574.82 squares km, and is considerably more dense compared to other regencies in Yogyakarta with a population of 1,090,567 people. It is located on the northwest border of the Yogyakarta special region, between the city of Yogyakarta and the Magelang regency (Central Java), while on the eastern border to Kulon Progo regency and Gunung Kidul regency to southeast. Sleman is also home to one of the active volcanos in the world, Mount Merapi. Sleman features a tropical monsoon climate with the length of the wet season generally running from October until June, and with a short dry season that only covers three months from July to September. Sleman particularly experiences heavy rainfall from November through April. It is also surrounded by many other mountains; however, most of the area is relatively flat terrain, and the greater portion is dedicated for the agriculture sector. The regency is known as the granary to Yogyakarta, with Mataram Canal and River Progo as the essential main irrigation source for the agriculture plantations.

The first three weeks upon my arrival in Yogyakarta was the time for exploration to identify a location for conducting focus group discussions and getting more acquainted with the language. Both of these processes took my full attention. The process of selecting a site, sorting out a location, and observation inevitably continued throughout entering the community process. One unavoidable aspect that rang in my head was how the community would respond to me. I was not certain of their impression concerning visitation, and observation that had taken place within their communities. Though I have gone through procedures like meeting with leaders, and provided information in regards to my research, it still challenged me. Although that case may appear when I encountered people, I tried to relax, and enjoy the other side of beauty from each village that I have visited. I felt being so small amidst the

massive complexities reminded me of how fragile I was as a human, and reflected to that position I could imagine how illness, life, and time, was a blend of personal story, and I was trying to peel off that part in stages. Despite such situations as occurred, I felt so fortunate to have Suharyanto as my colleague, who was willing to assist me along this process, knowing that support was on the back of my shoulders.

I took advantage from previous experiences of using the Javanese language regularly either at home or within the community as an asset to communicate with people. However, this acquisition was in need of being shaped continuously, and being back in Yogyakarta and approaching the community directly has benefited me in adjusting and adapting with the Javanese language and philosophy that is entailed in expressions verbally or written. In conjunction to above situation, the process of learning and relearning was ascribed to me and has helped me to connect with the communities and people I met.

Entering the community is a delicate process; I could describe it as a weaving process, where I need to put all colorful strings attached and connected, and as an outsider I was aware, that this meticulous activity should be done properly and in a mannerly way. I commenced this process through the assistance of my coworker, who worked in the community development sector, and also through his contacts; we explored three communities that were identified to have elderly patients with TB. Exploration was done in a subtle way, informally and in a comfortable manner.

In selecting the site I decided to be more visible for the community, so I went to the chief of the sub-village and explained about the research that I would conduct. I did not mention about researching TB issue in particular, but rather elderly health conditions in the village. I did this to avoid over focusing on TB, and to understand the broader aspect of elderly health in the village through their responses. From the initial three sub-villages that selected, I narrowed it down to one sub-village. Sub-village Sumerno (pseudonym) is located near to the community health center and the community members allowed and welcomed me to stay to do research in that area.

I decided to choose this village for focus group discussions with some consideration. *First*, there are elderly with TB and acknowledged by members of the community itself. For this village identification, I did not involve the health center, the reason was to avoid representation of the health institution in the village, which may

have affected people's perceptions toward the TB itself, such as exaggeration of the issue in the village. I was afraid this would have an effect on the elderly with TB in the village, which I understood during my research that they undergo treatment through the main hospital in Yogyakarta city rather than through the nearest community health center. **Second, the** power relation issue. It was important that the community understand and perceive me as a researcher and not as a health worker. I found a particular unavoidable misconception of people toward me, doing research on a health issue with health worker, doing health issue work in the village. During my informal conversations with members of community, some of them did think I was a medical doctor. Two dimensions were actually coined; the issue that I explore is about health, and my background is as a student in a health social science program. To them the line between the two seems blurred, and I needed to minimize this misconception to keep explaining to the members of community my role as a researcher repeatedly. A doctor is considered to be major in the community, a respectful position. I was afraid that if they thought of me as a medical doctor, it would hinder me in obtaining sincere information from them.

I should admit that the process of identification by community members to me took time, and was gradually changed as I built deeper rapport with the community. **Third,** time allocation and chances to meet with informants. Most of the informants were working during the daytime, and I was just able to meet them in the afternoon or evening. I had also allocated more time in this village for quite sometime to build rapport, which led to a decision for me to stay there and observe informally the daily routine of people, and in particular the elderly women in the village. I did this to understand how the elderly see the ageing process, along with their own understanding of ageing, health and illness-related ageing. I also wanted to explore how stigma toward TB actually exists and is understood by elderly and other age groups in that community.

The next few steps after a focus group discussion were to identify locations for semi-structured interviews with health workers. For this purpose I explored and then decided to observe three community health centers located in the rural and suburb regency of Sleman. The distances between all health centers could be reached in a half hour drive, and were accessible by vehicle. However, access by

public transport was limited only to the main road, while to reach the place people need to ride a motorbike or walk for 20 minutes. For in-depth interviews with informants, these were done in community health centers and the homes of the elderly. In addition, observation took place during a house visitation, at the community health centers, and in sub-village Sumerno.

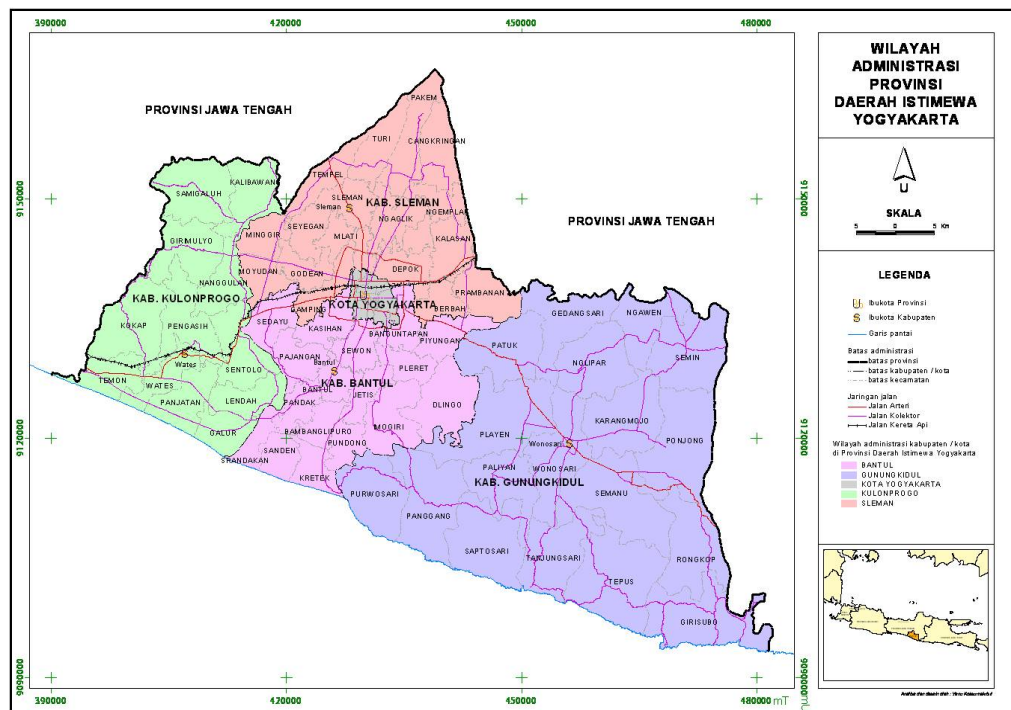


Figure 3.1 Administrative Map of Yogyakarta Special Region (BPS 2010)

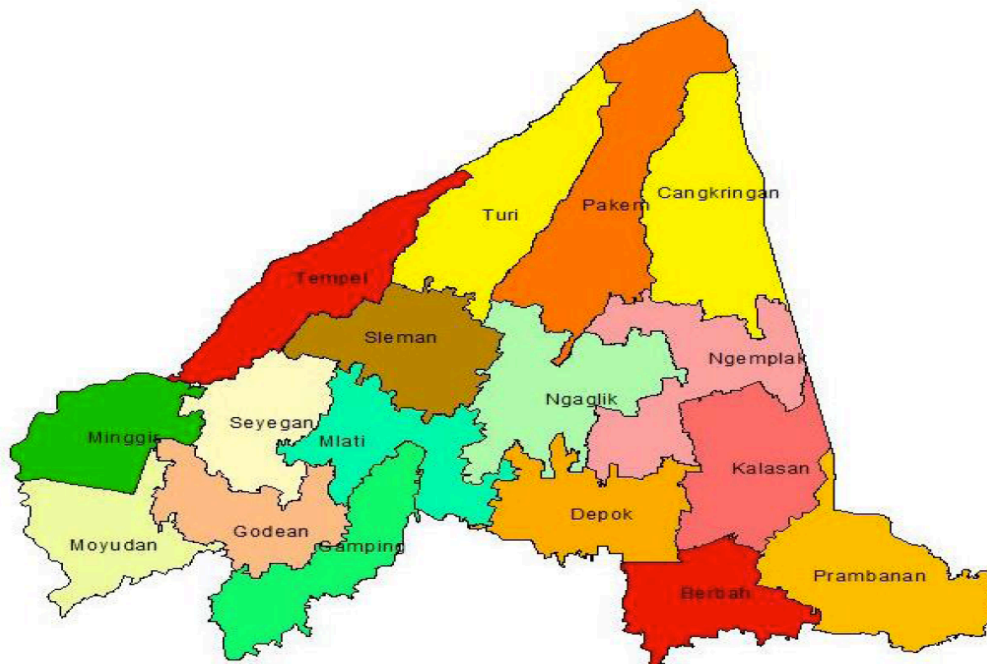


Figure 3.2 Administrative Map of districts of Sleman Regency (BPS 2010)

3.3 Informants selection criteria and process

3.3.1 Research participant selection

The selection criteria for recruiting research participants were determined through the development of the research process, in particular after observation and reflection on the research objective. During the process of research, I divided participants into four main categories according to each method and approach I had initiated during my research preparation and through chronological events.

3.3.1.1 Focus group discussion

For the focus group discussion I decided to involve 8 elderly males from 60 years old and above, 8 elderly females from 60 years old and above, and two members of community, age 35 – 55, both female. All participants were willing to participate in the focus group discussion voluntarily and did so after consent was given. I considered the certain homogenous characteristic of the respondent who would be put in the same focus group discussions, such as elderly who regularly attend

health care, either in or out of the village, were able to come for the discussion, living alone or co-residing with a family member. While for the adult focus group discussion I chosen male and female adults who happen to have elderly in their house, I did not specifically view their educational background, rather focused on their role as caregiver for the elderly.

3.3.1.2 Semi-structured interviews with health workers

In selecting participants for the semi-structured interviews, I included 6 health workers who were involved with the TB program in Yogyakarta at the time the research was being conducted. For this method 2 medical doctors participated from the public hospital and community health center, as well as 3 nurses and one psychologist from the community health centers. I did this to understand how the TB program is implemented, to view health worker perception toward ageing patients, in particular female TB patients, and to understand elderly female TB patient health complaints from their points of view. The recruitment for nurses helped me to understand the TB program from the community level side, as they conduct house visitation and provide support to the patients in the field. The public hospital and community health center is part of the TB referral system, which helped me to acknowledge the referral system for an elderly female TB patient.

3.3.1.3 In-depth interviews

In-depth interview participation involved 15 elderly that were suitable with the following criteria:

- 1) Those who are considered as elders - as define by Javanese cultural context of age.
- 2) Those who indicated having TB illness regardless of attending or not attending tuberculosis treatment and medication at hospital, PUSKESMAS (Community Health Center), or 'POSYANDU LANSIA' (Integrated Health Post for Elderly) that implement NTP at the time of the research conducted.
- 3) Those who were willing to participate in the study and able to give the consent.

3.4 Recruitment process

3.4.1 Recruitment for focus group discussion

The focus group discussion recruitment process was conducted from September until the beginning of October after approval from MU-SIRB was given. At the early stage in entering the community I observed and explored elderly that were suitable to the selection criteria. To reach that purpose I began to specify the research process and explained to the community leader the plan for focus group discussion, and then I asked them the appropriate way to do such activity within the sub-village Sumerno context. I understood that the proper time to conduct FGD was critical, in related to adjustment, preparation, and the elderly's own schedules.

To initiate further response from community members, Mr. Sasongko (Pseudonym), one of the leaders in this community, suggested to me to openly give an invitation for the elderly and see who responded. This was done by attending religious activities and inviting them for FGD. Around sixty percent of sub-village Sumerno members are professing Catholic. In particular between September and October, Catholics from this village dedicate their devotion to Mother Mary. In honoring and celebrating this event, the Eucharist and prayer vigils are held daily in the village. The process of the prayer vigil took place in various places and was conducted from house to house.

In one of those occasions Mr. Sasongko, who happened to be a deacon of the Church, assisted and invited me to explain regarding the focus group discussion. He introduced me again with elderly members. I described to them the plan and details, and I asked for permission to sometime visit their houses before the actual focus group discussion was conducted. This was designed to understand each of informants who may be willing to participate in the discussion, and as preliminary exposure to the participant information sheet. As a result of that introductory session, I was welcomed and allowed to visit their homes, whenever they were available.

After I observed and visited several elderly homes, and discussed the matter with Mr. Sasongko, I selected elderly with the ability to participate in the discussion, in healthy condition, and willing to attend FGD voluntarily. Mobility and movement for the elderly was one of the critical aspects that I looked at carefully, due

to frailty or disability because of certain illnesses could impact on their condition. Some of the participants in these discussions were in regular treatment for hypertension, diabetic mellitus, and regularly check their health condition at a local health provider and in healthy condition. I selected them to share their experiences dealing with the health provider, how illness related to ageing was viewed, and their perception toward peer female elderly with TB. Furthermore, participants of FGD of younger age were selected randomly regardless of gender or backgrounds.

Because some of participants for the focus group discussion were working during days, I decided to time the activity between 5 p.m. and 7 p.m. The venue was Mr. Sasongko place. The place was comfortable for discussion and not far from the elderly home I invited. I also was fortunate that Mrs. Sasongko allowed me to use her living room for the meeting, and helped me to send the invitations to participants' houses.

3.4.2 Semi-structured interview

For the semi-structured interview method, the process took two different approaches. First, I initiated contact with my fellow coworker at the NGO to introduce me to the health worker who was involved with the TB program in Yogyakarta. The process started by contacting the informant informally and setting the time for an interview in a convenient place.

The second process was to access the community health center through a formal approach. Although I already had my permit from the Mahidol University Research Ethics Committee, I still needed to follow required procedures to Research Ethics and Student Internship Board of Local Government (BAPPEDA) in Sleman Regency to obtain a permit for research. In this process I needed to submit a research proposal and letter acknowledgement provided by Mahidol University. After receiving the permit I then submitted all copies of the letter to related government institutions for research recognition, such as for the Regent of Sleman (as a report), the head office of Kesatuan Bangsa, the head of the health department of regency Sleman, the head of the social-cultural department of regency Sleman, the head of the districts, and the head of community health centers.

After I submitted a copy of the letter from the research Ethics and Student Internship Board of BAPPEDA, the head of the community health center or their administrative officer that I visited greatly assisted and introduced me with health workers that are involved with the TB program. I did not find any difficulties to relate and interview the health workers. One of the head officer said, “This is part of our evaluation, to allow student researching will help us to provide better services for the community member”.

3.4.3 In-depth interview

The in-depth interview process involved some of the elderly males and females from the focus group discussion, and some were done through contact provided by health workers. For the informants provided by the health worker, they gave me addresses to look for, and in some cases connected me to the informants after following the health worker doing a house visit or group discussion session with other TB patients. At the beginning the health workers from the community health center introduced me as a student doing research on the tuberculosis issue. I sense a close connectedness between the health worker and the elderly female patients, when they introduced me to the patients. These patients did not feel any discomfort; however, they asked me a lot of question before the initial interview took place. At that stage I let myself be open to every question, being genuine in responding to their curiosity and expanding my personal boundaries beyond certain limitations that I set before the actual interview. In the interview process I began with a polite greeting, and introduced myself as a researcher who was conducting research on TB, being polite it was also needed that I dress formally, so I decided to wear batik, as it is more casual but at the same time formal, which helped me to gain rapport from them quickly.

In addition, I remembered one of the health workers said to me once that it was so important to them that patients feel and experience connectedness, because it is by doing so, patients are willing to share their challenges and experiences dealing with treatment and medication. I took their personal experience as a way to obtain trust from an informant; in fact, I decided to use this approach during interviews either with other health workers or elderly female TB patients.

3.5 Research methods

3.5.1 Informal conversation

In the process of data collection I stressed the importance of informal conversation in building rapport and in understanding the elderly's own experience in illness related to ageing, TB treatment and medication, and their response to their peers with TB. During conversation I listened carefully to their stories and gave them space to open their experience in stages. Conversation was designed in light discussion and flowed with the informants' ways in telling their story. In my opinion, this process was critical as elderly also tried to recall their experiences. I often adjusted myself with the elderly's own chronological events related to their process of treatment and medication, their opinions, and how they understand the process itself. I too positioned myself to regard them as I respect my own mother or grandmother. During this informal conversation I did not record or write down the elderly story, and only made jotting notes after I went home. This informal conversation I gained from community members and also participants from the focus group discussion; I did this to comprehend the overall picture of the TB illness and how people look toward the issue that I was exploring. This informal process usually takes 30-45 minutes, in a relaxing situation, where I usually come to their home when they have come back from their paddy field or during the elderly female nursing her grandchild. I sometimes talked with the elderly male in the paddy field, or when they feed the fish.

3.5.2 Semi-Structured Interviews

For this research I carried out semi-structured interviews for health workers. With this method I was able to explore more information, and guided from interview guidelines, which I adjusted with informant information. This interview method I used in order to avoid repetition of similar information given by the informants, and it enabled me to pattern more evidence from the findings. This semi-structured interview was established through open-ended interviews with 6 health workers to understand their perception toward elderly TB female patients in seeking, diagnosing, treatment and medication of TB. The interview process took place at the community health center and in another place that was convenient for them to share. I

did the interview for each of the health workers one at a time, with the exception that I needed to meet them for several times before the actual interview. For some of the nurses I did the interview 2-3 times. All of the nurses and the psychologist are female, and this helped me to understand better from the women's own perspective toward elderly female TB patients.

3.5.3 In-depth interview

The in-depth interview is the place where the informant is the expert that acknowledges their own personal experience. They are indeed a proper source of information where they are able to report a certain event or phenomenon. The in-depth interview also relies on a direct encounter between the researcher and informant in interviewing. Thus, instant involvement and relational interaction will determine the quality and the flexibility in process of obtaining the informant's own reality. This method too encourages clarification from the informant's side if necessarily information needs to be restated. Moreover, the in-depth interview allows the researcher to hear from the informant previous events that happened in the informant's life, and those that are yet to happen (Darlington and Scott 2002).

For this in-depth interview I visited community health center, integrated health post for the elderly. To obtain information from individuals that fit into the informant criteria I needed to ask permission for research from the health authority to conduct research at their place. Informants were selected from their records, and asked voluntarily to participate in the research. I followed the required approach by providing a participant information sheet and informed consent. If the informant agreed to participate in the research, I then continued with the in-depth interview. All interviews were conducted in a place that was suitable and comfortable for the informants to share their experience.

Furthermore, in exploring elderly perceptions toward tuberculosis, I interviewed ten elderly females, two of them who are TB patients. I did this to understand individual health seeking care; their view toward the long period of medication for other illnesses and TB, the treatment process, their perceptions on symptoms, illness and its interaction with culture. In addition, I also interviewed five elderly males to understand their views toward elderly female TB patients. Most of the

interviews were conducted twice, but informal conversation and building rapport with them was included throughout the ethnography process.

3.5.4 Focus group discussion

Focus groups in research share many advantages of in-depth interviews as means of data collection, like in obtaining in-depth, qualitative data about a person's own explanation of problems, opinions, and feelings, and meaning correlated with different phenomenon. The other advantage is that group interaction will help in maintaining response to certain ideas that are conversed during the focus group discussion, an idea that may reside during the individual interview (Basch in [Darlington and Scott 2002](#)). However, despite of many advantages, focus groups also place a challenge if peer pressure is contributing to the process, or some views are agreed to because of the dominant participant's viewpoint ([Darlington and Scott 2002](#)).

In accommodating this situation I decided to become flexible, the questions were adjusted and rephrased in different ways so that a participant could contribute to the discussion. I followed the flow of the discussion; this was done to avoid disruption of a different topic that might have diverted the discussion to something that was not benefiting me for obtaining the intended information. There were three focus groups discussions; one group was conducted for 8 elderly males, one group of 8 elderly women, and one group of male and female members of the community aged 35 - 55. This focus group discussion was conducted to understand community perception toward elderly with TB.

In conducting this focus group discussion, I approached local communities and established rapport by approaching the head of the village to conduct research in their community. Informants were selected randomly with the head of the village as assistant. Each participant was visited and asked to be involved voluntarily in the research. Those who were willing to participate then were involved in a focus group discussion. This focus group discussion was conducted in a place that was suitable for members of communities to discuss, and the discussion was done in a manner that would comfort participants to express their opinion without disruption from another community member that was not participating in the discussion.

3.5.5 Observation

Observation was one of the continuous processes in this fieldwork. Three main locations were selected in understanding the patient's own perception toward care service delivery. Observation was used to understand the reality behind information given by informants. The observation took place in sub-village Sumerno, three community health centers, and one integrated health post in sub-village Sumerno, all of them closely located to one another.

In this observation process I carefully looked at the process of elderly patients or other TB patients who attended their service at a community health center, the house visitation process, and other activities related to patient support, such as the focus group discussion among TB patients in one of the community health centers. I also observed the daily life of elderly in the village, their family relations, and social networking. I made the decision to buy a Pommy tackle dog name Lucky who accompanied me to visit some of the elderly houses, who happened to have dog as their pet. Lucky was also very helpful in connecting me with some of the elderly, in particular during rapport building process.

3.5.6 Secondary data collection

On this research I will also used secondary data collection. This secondary data collection included field notes, pamphlets, and educational materials for TB information dissemination, standards for tuberculosis care, and pathways to better diagnostics for tuberculosis.

3.6 Research tools

3.6.1. Observation guidelines

In this research, observation was done following observational guidelines, such as patient care service, hospital ward design, drug administration, rapport collection, home care, and TB information dissemination.

3.6.2 Semi structured, in-depth Interview, and focus group guidelines

For this research I followed research questions and interview guidelines like demographics, informant perceptions toward TB, informant perceived information toward patient-doctor relations, health providers, the sputum collection process, the drug administration process, drug intake, side effect treatment, illness experience, and informant perceptions toward comorbidity in TB, as well as how they are dealing with illness and family support in treatment, and how the elderly males perceived TB female patients.

3.7 Data Analysis

Observation data and experiences during observation in the field site was recorded through field notes, and then expanded for analysis. Interviews that were able to be recorded with the permission from informants were transcribed in verbatim. Transcription was analyzed within two days for conformability. In this data analysis I also used thematic content analysis that involved the identification of categories for coding and discourse analysis to understand the social context and reality of informants (Yuen-man 2008). Furthermore, I used photos or drawings from the site and developed them into descriptive notes to support information that had been given before. Pictures or the drawings and field notes were used to help identify the specific needs of elderly women patients and help the researcher to understand how treatment services are delivered.

3.8 Validity of Data

3.8.1 Data and methodological Triangulation

Triangulation data with more than one method and source such as semi-structured interview, in-depth interviews, focus group discussions and observation, journal and essay writing and informants interviews were used to enhance validity of data. Information from each interview was checked for consistency with each other, including the data from informant interviews and observations.

3.8.2 Trust Building

In the trust building process, I allowed myself to be open with informants. This was critical as openness is part of mutual relations and respect. I was hoping by doing this that informants would become more comfortable with my presence. I did this by allowing them to get to know me first, before the actual conversation or interview. This process also entangled with informal conversation and observation, as it integrated throughout the proses of research. Furthermore, attending community ceremony, such as funeral, prayer vigil, and thanksgiving helped me to build rapport, as they more identified me as part of the community.

3.8.3 Reflexivity

In this research reflexivity was intertwined into every aspect of my research. Reflection enabled me to sense and feel the situation as taken from the field, or from informants that I met. Reflexivity also become a mirror in this project, where human complexity is viewed, acknowledged, and practiced towards one another. The Javanese use expression “*getok tular*”, means that to think one aspect should touch different other aspects. For example if I said A, it meant not only for B, but also C, D, and F.

Viewing from the above idea, I noticed that the process of reflexivity was done by the community and to me vice versa. Both the community member and I were simultaneously learning from each other, in seeing value, experience, and belief. This mutual reflexivity can never be established if trust building is blocked or hindered.

3.8.4. Researcher Identity

Being in the field has always been a process of learning. The identification and reflection in some extent has smoothed the way for me to be part of the community, which brings a new identity to me besides being a researcher. As the identification is established and the relationship nourished, I became a community member. The anticipation was slowly changed into trust and bonding. I felt less distance, and my role in the community became more visible as a “community member doing things” rather than “researcher conducting things”. I was fortunate to experience this and learn to embrace the change and to treasure the moment.

3.8.5 Inter-subjectivity

The experiences and stories of every individual that participated in this research project are unique and special; some of it was untold story that slowly revealed itself to me by time and trust. To hear and to grasp the essence of life cannot be simply imagining, or trying to put shoes in every voice I heard. It was also a matter of letting discomfort and changes challenge my mind, values, beliefs, and who I am as a human being. I was hearing a life story of people, their suffering, concerns, blaming, a complexity of cause and effect. Putting aside my own personal judgment, learning new values, and embracing different thoughts and beliefs, were some of the ways that I could think were able to enclose me in understanding their story, perceptions, background, and thoughts.

3.9 Ethical considerations

3.9.1 Privacy

One of the critical aspects that I held tight during research was privacy. This has helped me to set boundaries and acknowledge my limitation and concern for others. My reflection, thoughtful consideration in interviewing, and entering others people's lives was also a part of the mutual respect and gratitude for every person involved in this research project. This includes in location and time that was adjusted for the informants' convenience for interviews, and informants had the liberty to stop any conversation if they found it insecure to answer. This also extended to the freedom to terminate and withdraw from the research.

3.9.2 Confidentiality

For this study, all participants identification is protected and kept secret and under guarantee of safety. Their name, address and all other identity were replaced with pseudonyms to conceal their identity. All material relating to the study, such as field notes, transcription, recorder, and notebook were kept securely and only enabled access by researcher. All records were kept confidential and only used during data

analysis and destroyed after completion of data analysis. Erasing all the data related to data collection accomplished this, and the hard copy data burned.

3.9.3 Informed consent

For the purpose of research, I explained about my identity, the research purpose, its objective, brief interview guidelines, the benefit and possible adverse consequence to participate in the study with local language and terminology. All the informants were recruited voluntarily without using any power from any doctor or contacts. Informed consent was attached in the interview process. I explained to informants that they could refuse to answer any question or stop the interview if they felt the study was inappropriate. In some cases I also experienced informants who were not willing to sign for written informed consent. In this situation I considered an oral informed consent, and assured them that the information resulting from the interview was protected, and the name of the informant and location where they lived changed into pseudonymous to make sure their privacy and personal life information was maintained securely.

3.9.4 Benefit and reciprocity

I also explained that the benefit of the study is to inform policy makers and programmers in designing high tuberculosis care services delivery which is gender sensitive for elderly female patients, which will be key factors to achieve the adherence of TB treatment and medication (DOTS) for this population and valuable in developing better care services delivery for aging people, particularly to elderly women and also enhance ability to control TB in Indonesia. In addition, I gave a small amount of money to compensate for the cost of transportation and giving their time for the interview.

CHAPTER IV

FINDINGS

“The greatest secret that all old people share is that you really haven’t changed in seventy or eighty years. Your body changes, but you don’t change at all. And that, of course, causes great confusion” Doris Lessing

4.1 Setting of community leaving area

The hamlet Sumerno (pseudonym) is situated in Sub-district Minggir on the flat areas approximately twenty-four kilometers west of the city of Yogyakarta. The terrain is mainly used for agriculture sectors. The irrigation canal from Canal Mataram (selokan Mataram), and the Progo River intersect the area to provide an abundant water resource for rice farming (*sawah*). The rice crop could be produced three times a year, with intercropping sometimes integrated in the system. Sumerno also located on the tip of the largest area for rice production in sub-district Minggir, which sustains food supply for the villagers throughout the year.

The access road from district and sub-district roads are well established, and in good condition, which is a benefit to transport agriculture production and accommodate public activities. Sub-district Minggir consists of five main villages, with each village comprised of around sixteen hamlets, and hamlet Sumerno is part of one village in this sub-district. The population of sub-district Minggir is 34,945 with 11.7 percent of its population elderly. (BPS Yogyakarta, 2011)

As part of a larger village, hamlet Sumerno is relatively small compared to other hamlets. Hamlet Sumerno consists of 62 households or about 330 people; 21 per cent of this total are elderly population. The average elderly age in this hamlet starts from 60 years old and some are able to reach above 80 years old. From the total elderly number, forty-six people are female and twenty-two are male at the time data was collected between September and December 2012.

4.1.1 Sensing hamlet Sumerno

To reach this hamlet it took us an hour to drive from the main capital Yogyakarta. Public transport such as bus is limited and only accesses the main road, while to reach the sub-village people need to ride other modes of transport, such as motorbike or bicycle. In Yogyakarta the motorbike is considered to be a convenient transport, modest and faster to ride, especially during traffic.

To access the sub-village from the main road it takes 20 minutes by walking or 10 minutes by motorbike. Like many other villages in Yogyakarta, a welcome invitation is display at the main entrance gate, “*Sugeng Rawuh*”. Two main borders mark this hamlet, the river in the east and paddy fields in the west, while the north is marked by the village road and the south with another hamlet.



Figure 4.1. Entrance to the village and border to west, the paddy field

The houses in this hamlet are typically influenced by Javanese architectural style, such as *joglo* or *limasan*. These houses are relatively big in size and able to accommodate events in the community, like a compound of resort in one building with a large void in the middle and many windows around it. The houses mostly have a large garden with many varieties of fruit trees, such as rambutan, papaya, cocoa, coconut, mango, snake fruit tree, and banana. In addition, almost every house in this village will have a fishpond growing tilapia, Asian carp, or catfish.



Figure 4.2 Hamlet Sumerno, housing and fish farming in the village

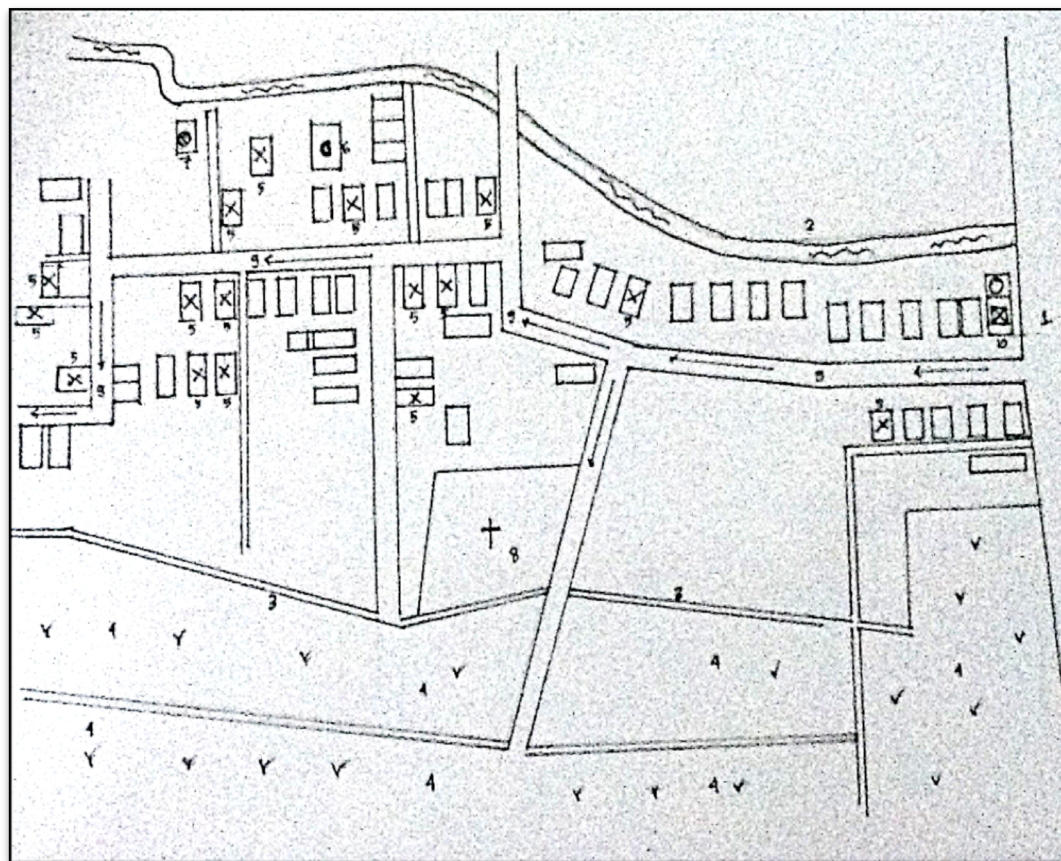


Figure 4.3: Map of hamlet Sumerno

Note: Sub-district main road (1); canal, also borders to another village (2); Irrigation canal (3); Paddy field, also borders to other village (4); Informants house (5); Mosque (6); Researcher's rental house (7); hamlet cemetery (8); hamlet road (9); provision shop (10)

4.1.2 Administrative levels

Structurally a Javanese village (*desa*) comprises certain administrative levels. Starting from village level and divided into hamlets (*dusun* or *dukuh*), which are again divided into neighborhoods (*rukun warga*). A neighborhood is divided into groups of approximately thirty households (*rukun tetangga*).

The chief of a *dukuh* (hamlet) is paid by the government; they receive a regular income and land for temporary use for planting during his/her duties. Once having completed their responsibilities, the land should be handed to the next leader. Usually the chief of *dukuh* are elected once every five years, responsible in addressing issues within the hamlet, and provide assistances to the community members.

4.2 Community ties and social scene

The social activities of hamlet Sumerno are determined by how its members respond and contribute through cultural events, celebrations, and mutual aid. Attachment and sense of belonging to this community also valued through the participation of its member and a common understanding that lies behind those particular activities.

One important aspect we could say we found from this hamlet is the bond among households. The direct neighbors are probably more significant than distant kin because they rely on each neighborhood for support in time of need, such as sickness or death; the whole neighborhood comes to help and provides assistance as required.

4.2.1 The emic concept of old-elderly-age

Keasberry (I 2002) studies explore the elderly care in Yogyakarta and have suggested several emic concepts that are commonly used within the Javanese context. These emic concepts are related to the ageing process and its changes, which impact in the daily life of elderly such as age; increases in high age is correlated with retirement and often obtaining grandchildren, but also decreases in physical strength and health. Less activity is likely to impact on the earning of a living, as is decreasing in control of tasks, responsibilities and property, money, and yield. Also, decreasing levels in

mental health are noted. She suggested the following definition to describe emic concepts of ageing:

Tua means old of age compared to another generation

Jompo means old, aged, decrepit, infirm, not fully in the right mind any more

Pikun means very old, senile, demented

Krepo means disabled, invalid, worthless, poor miserable, not fully in the right mind

Furthermore, to add to the above emic definition, there is also another word use in the hamlet sumerno, which is *sepuh*. Compared to the above definition *sepuh* is carried from Javanese politeness in addressing the old people. It means that the aged simultaneously are attached with experience and quality.

In addition, at hamlet Sumerno people also address the old as *mbah* or *si mbah* and to differentiate by gender they add *putra / kakung/ lanang* for male; and *putri/ wedok* for female. This word also employs a role within family as grandfather or grandmother. Within the context of Javanese, being old does not necessarily depend upon age categorization, such as 60 and above, rather by role in the family. Parents who happened to have a grandchild can be called *mbah*, or *simbah*. In this situation *mbah* or *simbah* can be linear meaning to *sepuh*, aged with experience and quality.

4.2.2 Hamlet life and elderly female routine

The Azan (prayer call) is sounded five times a day to call Moslems to engage in prayer. This daily prayer call always awoke me at 4.30 a.m., the time which activities of this hamlet started. I stayed near *langgar* (small mosque) and the house is surrounded by the semi forest plantation, next to irrigation canal slope or *pereng* they are called. The *langgar* speaker is facing the plantation, and makes the sound that echoes to the surrounding hamlet.

Opposite my rented place is the chief of the hamlet's house, Mr. V (39 years old). He is staying with his mother Mrs. C and his wife and two-year-old son Nano (pseudonym – 4 years old). Mrs. C, I called her *Mbah C*, (grandma C), is 83 years old, a single elderly, as her husband died 12 year ago. Though her body is bent and sometimes she needs to hold her legs when walking, she is considerably active,

and healthy. Her daily routine starts at 4.30 a.m. by cleaning the backyard, feeding the chickens, and collecting *melinjo* (*Gnetum Gnemon*) for making crackers, cooking for breakfast, and babysitting Nano. She sometimes carries him on her back and takes him around her house and the neighbors. Opposite her house is a kindergarten; temporarily occupying Mrs. H (75 years old) house, purposely for education of children from this hamlet and the surrounding neighborhood. Similar to Mbah C, Mbah H always wakes up early, cleans the front yard, and babysits her grandchild.



Figure 4.4 Mbah C in front of her front yard.

4.2.3 Elderly female role in the village

Niehof's (1995) study in Yogyakarta suggested that the elderly carry a natural role model as a mother or *Ibu*. This encompasses that the mother role is respectful, and irrespective regardless of whether they have children or not. In mother-daughter relationship it is assumed that the daughter increasingly becomes like mother while the mother gradually becomes older and dependent. She also suggested that the role of mother could be extended in a modern model where *Ibu* is limited to the spare of family as part of nuclearization and the decrease in household size. This modern housewife will focus her attention and provision exclusively for their own family, which is rather fluid than a natural context of mother.

In my observation and informal conversation, within the hamlet Sumerno, the domestic role of women within a rural setting, in particular among elderly females are remaining and is still dominated with housework, nurturing grandchildren, taking care of livestock such as cattle, chicken and fish, and other women roles that are imbedded in daily life. The house spare become the primarily source of power and domain for women, where domestic rules should be followed and respected, even to their children or in laws. This was done in order to reproduce qualified children with Javanese criteria, such as *bibit* (good offspring), *bebet* (good origins such as in family), and *bobot* (personality, attitudes, skill and capacity). While the male role largely in the community, they are involved in making decisions for community. In some villages nowadays women have started to hold power as chief of the village, too. Ageing people are well respected within the family and among neighbors, and particular for elderly women their role in mothering raises a certain level of appreciation compared to the elderly male. However as overall, male elderly still hold major power over their family members, in contrast, the younger generation mostly share power in the house.

4.2.4 Elderly living arrangement at Hamlet Sumerno

Although elderly still hold power in their house, inevitable dependency will take place when frailty and disability impact their health condition and physical ability. Thus, power could be switched automatically to their children or the spouse of the elderly. For elderly in this hamlet, those powers remain prerogative until such a situation interferes. Furthermore, in the case of elderly living solely, they are usually breadwinner for themselves; for the family member that is co-residing with them, sometimes they depend on their parents' resources. Although they are not dependent financially on the elderly, they share personal resources such as rice field, garden or fishpond as a common practice.

The migration of the younger generation is also influenced with elderly position in providing a chance for their children to obtain fortune by working outside the village, and to allow their grandchild to be entrusted to them until they are settled economically to support their own child independently. Being distant with their children also brings implication to elderly as they expected to be dependent, and if their grandchild remains staying with them, their responsibility increases to support the grandchild. The correlation between living arrangement and children's migration effects is decreasing the number of people to work at the house spare, such as in private paddy field. Elderly need to be dependent working alone or with their spouse in the farmland. Though my observation and informal conversation in hamlet Sumerno elderly female who lives solely in the house could be more independent than the male, as daily activity in the household is part of their routine, while for the elderly male, they found it a challenge to do housework, and more depend on their children or a caregiver.



Figure 4.5 Mbah Mawar (Pseudonym) is one of the female elderly who lives alone

4.2.5 Livelihood of elderly female

Agriculture is a prominent sector that could not be separated from rural livelihood in Yogyakarta, particularly in Sleman Regency. The people are entailed with its dynamic, where culture and activities of rural live revolve around it. The dependency of the agrarian community to the production of crops such as paddy, cassava, or been is critically important to provide the sustainable livelihood of rural live. This broader aspect can be found also in hamlet Sumerno, where around sixty five percent of the households are farmers while the rest are in formal sectors such as nurse, teacher or in public service; and informal sectors like food vendors, or fish seller. The following was one of the examples of livelihood observed during data collection time.

Every morning Mr. M or *mbah* M, a 71 years old farmer will get up at 4 a.m. That day the Sun rose at five, before he went to the paddy field for putting the paddy seedlings in beds or *nandur*, he said. He prepared and sharpened his sickles with a sharpening stone, gently checking the sharpness and shredded over banana leaves to make sure that the sharpness was right. While *Mbah* M was focused with his sickle, *mbah putri* (66 years old) his wife was preparing simple breakfast (in Java *Mbah Putri* or *mbah wedo* is used to address politely the elderly female, while *mbah kakung* or *mbah lanang* is used for the elderly male). Both of them stay alone as a couple, as all of their children have migrated to Jakarta and Surabaya since 1997.

In the kitchen *mbah putri* steamed two-hump of cassava that she took yesterday from the garden, took it out of the pan after its done, and then wrapped it with banana leaves. She put that aside and put it in a small bamboo basket. She then made *tea tubruk*, a rough tea leaves with stone sugar, put it on the table, and asked her husband and me to drink it before we leave the house. The tea tasted very nice and refreshing, while the cassava superbly melted in my mouth. “This is the regular breakfast here, sometimes we ate *getuk*, *gatot* (culinary made of cassava) or just steamed like what we have today”, she said.

It took us only fifteen minutes to walk to his paddies lot; the size is 500 square meters, and it is located next to sub-district road. *Mbah putri* then went down to the paddies, it is deep and reaches to her knees. Gently she moved, took the seedling and began planting it on the rice bed. Years of routine and practice made distance between the seed seem precise and line up tidy. This was done automatically without

looking back and to make sure the line was correct, her back seemed to radar the distance, and I was so impressed with the speed of how she planted the seedling.



Figure 4.6 *Mbah putri* and her paddy lot

On the other side, *Mbah M* cleared another lot belonging to his neighbor; he obtains extra income by preparing the beds for planting, and nurturing the seedlings until harvest. If the harvest comes, he will earn half of the production, and it will help them to secure food for three months, around 150 USD or 1,500.000 IDR. Usually each of the paddy beds can be harvested three times a year, but it depends on landowners. Recently rats have been a rampant problem in the village, and his labor work has not paid off, and they were only able to acquire ten percent out of the total from last year, or 15 USD. The situation was bad until most of the farmers are reluctant to plant the paddy or leave the lot empty. The persistence and laborious work *mbah M* and *mbah putri* put in to farming amazed me. To them it is part of their cycle of life, the ordinary life of a farmer in the village. Age reasoning seems not to be an excuse for them, and continuation of active work is part of daily life even at times of hindrance.



Figure 4.7 Farmer in hamlet Sumerno, and rice field as border to other hamlet

We went home from the field around 11 a.m., and took a rest for awhile, while *mbah putri* was preparing the lunch. After finishing the lunch, *mbah putri* then continued with other activity like cleaning the house and washing clothes. In her spare time, *mbah putri* will clean the bamboo stick and slice it thin as material to make bamboo basket or *mbesek* as they call it. If she is not strong enough to make it then she will buy ready-made material from the market, the cost will be slightly higher compared to her own handmade materials, however to her, being active, productive, and independent is still the main reason why she does so. Though she is not earning much from *mbesek*, only enough to buy sugar and salt, she said; she diligently continues the activity daily.

Mbah Putri is not alone, there are many other elderly females who are still active and working either to work on their own farmland or as farm labor workers on others farms in hamlet Sumerno. This is done to support the daily life of the family. Their burden involves being responsible for domestic work, earning money as paid labor, and working from the early morning until afternoon. In addition, they are also responsible for taking care of their spouse, and grandchildren if they are staying with them. In many cases the elderly female tends to neglect her own personal needs and prioritize care for their grandchild or people that they feel are considerably important within the household.

4.3 Understanding ageism toward elderly health

Palmore (1999) described ageism as an act of prejudice and discrimination. Prejudice is against or in favor of an age group that involves negative stereotyping about the group, or a negative attitude based on that stereotype. Discrimination is inappropriate negative treatment in that age group, for example in compulsory retirement (Palmore, 1999). This prejudice can be related to such things as the physical situation of elderly, frailty and disability, illness, and ambiguity in viewing the emotional state of the elderly.

4.3.1 Ambiguous attitudes toward the emotional state of the elderly person

In Javanese context, elderly (*sepuh* – old and wise) are expected to have an idyllic characteristic that is represented in attitude, norms and traits, such as a person of wisdom, honor in their experience, wise, people of passion, and religious. Thus the emotional state of the elderly person is hoped to be in line with the above expectation. Furthermore, older people are expected to guide the younger generation with characteristics that were gained through their life experiences in order to help them achieve success when facing life in the future. On the other hand there is the role where the younger generation is expected to respect and honor their elderly. However, in daily communal life of hamlet Sumarno, ambiguity toward such a conception is also present; for instance, in viewing the emotional state of the elderly with the role expectation of the elderly, such as was found in the following observation.

It was one of the busy mornings in this hamlet; people were preparing themselves to welcome those whom had migrated to the big cities and were returning home for *sowan* (*asking for blessing and forgiveness*) during the Eid (Festive day of Moslem people). Ramadan (the fasting month before the Eid celebration) was about to end and the spirit of festivity and joy seemed to embrace all, signaling how happy would be this holiday season. People began to clear from their garden unwanted bushes and painted their house. One elderly man came to his garden, which happened to be located just between my rented house and chief of the hamlet's house. He came with his old bicycle, and parked it in the middle of the alley. His property is just a meter away from the chief of the village's house. He then entered his property and

observed awhile with hands on the hips and elbow turned outward, and he shouted, “who put these stones on my property? don’t you have respect on me? clear this land now!”. His tone was raised and it attracted attention from the surrounding neighbor. The stone belonged to one of his neighbors next to his property, and his close relative. Understanding that he made a mistake, the gentlemen was asking for apology and told him he would shift the stones after he completed the renovation. Instead of responding to his sorry petition, this elderly male went home without turning his head to him. This gentlemen was a bit upset, and under his breath he said, *“It is ok, when people are old, they will act like children again, very emotional, and demanding. He is my uncle, I respect him because he is our elder, and I understand if he acts like that”*. Although this scene was considered ordinary. It raised attention to the beneath concept of respect that entitle with pity or ridicules. I noticed that embedded ageism could be recognized through expression in responding to elderly characteristic; where prejudice, misconception of ageing is employ in linguistic and counterfeit norms toward elderly.

4.3.2 Misconceptions of the physical situation of the elderly

In hamlet Sumerno, physical mobility of the elderly is measured by their frailty condition regardless of their age, because mobility is dependent on the individual physical situation. It is common to find active elderly with good physical mobility in rural Yogyakarta. However, at the same time the community or family members may view the ageing process as misfortune. Thus, over control of elderly mobility due to frailty and disability is sometimes exaggerated, and is rationalized by the perception that it is for the sake of elderly’s own protection.

In rural areas, elderly females and males are still very active. They will go to the paddy field and work every day. Sometimes they work very hard, and forget to take a rest, and then they only rest when they get sick or cannot move anymore. They are difficult to be told. (From adult FGD)

In contrast, among the elderly who attended a focus group discussion and through informal conversation, it was suggested that their ageing might not hinder

them to do regular activity. Physical mobility is important for the elderly although their condition may not be strong like they were young.

“...Well ya. our children, or grandchildren. Some of them are sorry for our condition (kasihan), like old but I still do activity”. (Mrs. D from elderly female FGD)

“Are you happy if your family stops you to work? Not really, because we still be able working on our own, if there is no activity it will be difficult, we feel empty, no activity. (Elderly female FGD)

I’m 67 years old; I have 5 children and 4 grandchildren. They all stay at their own house. Every time I need to go for regular health control, one of my sons will come and fetch me, he visits me when he have spare time. He is working, all of my children are working and busy...I stay by myself at home. If there is no one to send me for health control I will take public transport like bus or motor taxi. I still am able to go around by myself, I don’t need others to help me, I can go anywhere I wanted without bothering my relative or children, I went to many place as I wish for. Sometime my children do not know where I was until I called them. Most of my children get angry when they heard it; I told them not to be worried about me, I have angles both on my sides. I used to do everything by myself, why should I bother them now; I only called them if it is critical situation if I cannot do anything. (Mrs. AJ)

4.3.3 Negative stereotypes on cognitive functioning of the elderly

The negative feeling toward cognitive deterioration of the elderly is one aspect that has undermined the health of the elderly. This negative feeling was expressed in stereotyping the ageing as people that are emotionally unstable, careless, and unwilling to listen to other opinions or suggestions. Such opinion was found among the younger generation in hamlet Sumerno. Some of them also associated elderly emotional instability as another type of sickness that is attached to the elderly.

They are difficult to be told, if we suggested them they don’t want to listen, the elderly keep telling that they are alright even when get sick, they said that they will

get better tomorrow, by then it is already difficult, become worse. Sometime we needed to yell at them (mbengok-mbengok) first so they can listen to us, this is what I did last time to my mother in law, she is very difficult. (Mrs. W, from adult FGD)

They are also having another sickness, such as easy to get bad tempered, grumpy (bawel), and stubborn sometimes (Mr. Q and Mrs. S from adult FG)

4.3.4 Misconception on Illness of elderly

Palmore (1999) suggested that the elderly ageing process could be incorrectly misunderstood in misconceptions of elderly-related health, for example, elderly poor health is viewed as a serious problem, that the elderly should spend much more time in bed when they are ill, or it is easier for them to have an accident at home, and the belief that the elderly experience being tired most of the time, and that infection can easily develop among the elderly. Similar views were found also at hamlet Sumerno. The ageing condition of the elderly is associated with multiple health-related problems, and vulnerability of the elderly to sickness.

Older people usually easily get ill, their condition may trigger this easily to get stroke, tired, high blood pressure, cardio problem, masuk angin (humoral wind enters the body) and died. (Mrs. X from Adult FGD)

If my mother is sick, I ask her not to work, and to take a lot of rest, because if she is sick it is difficult to take her to the hospital, she even rejected the medication. (Mrs. S from adult FGD).

4.3.5 Caregiver prejudice in elderly illness

Observing from hamlet Sumerno, the complexity of health of an elderly person is encompassed in two-dimensions: independence and dependency. Independence is the state where an elderly person is still in full control of making personal decisions in accessing health care, while dependency takes place if frailty and disability hinders personal decisions and replaces self-care by caregiver decision making. Accordingly, the caregiver become the solely decision maker for the elderly to

access health care, and the type of care they need in that particular illness situation.

In view of the elderly's health, such assumptions may lead to the attitude of the family member or children to only reluctantly involve the elderly in making decisions for their own health problems, and tend to be authoritative in deciding what is best for the health of elderly. These outcomes can bring negative implications to the elderly and negative results inevitably take place if the caregiver or family member inadequately comprehends the illness of the elderly, which may cause the elderly to delay to access care or to follow false information about medication and treatment. Furthermore, inaccurate decisions on elderly illness may add to problems, and hinder the betterment of elderly health care, or even harm them such as in force termination of medication and treatment.

Most of the time we are the ones that make decisions for the elderly to obtain their medication, we don't ask them. We just took them there. Our priority is for them to access health care. Although like my mother prefers to be checked or treated through Puskesmas (community health center) because it's cheaper. (Mr. U from adult FGD)

Sometimes we also don't have time to send my mother to the health center that she wanted to, so we decided to go to a clinic that is easy for us to visit after finishing our work. (Mr. R from adult FGD)

There is one elderly TB case, but not female. He came with one of his children. He came with cough complaint, and it has been going on and on, difficult to stop, he has started taken his medicines, and he felt that there is no progress on him. Because he never came again for taking the medicines we decided to do home visitation and we asked him, "Why he never comes for regular check again?" We then found out that one of his children had seen no progress on his father's medication then he refused to give the medication to him. He felt no use to give the medicine if he is not seeing any progress. We also realized that the living condition of this patient is not helping him to get better. So it is not only a matter of taking medicine or giving the medicines, but nutrition and good environment is necessary in the process of healing. The patient did not eat nutritious food, he only eat what he can eat. (AD)

4.3.6 Health professional attitudes toward ageing people

Pamore (1999) provided analytical studies in health professional relations to ageism by suggesting that attitudes toward elders are similarly shared among health workers and society. There are several factors why this situation has occurred. For example, professional training has not necessarily corrected the misconception and stereotypes that are common in our culture. Health professionals have had little education about normal ageing processes. They may know more about pathology and disease among the aged, but not about normal physical, psychological, and social ageing.

Furthermore, Palmore added that health professional tend to share a strong fear of death, which they associate with elders. They, too, have a biased experience with elders because they tend to see and treat only the most frail, sick and senile aged, thus they have generalized and assumed that most elders are like their sick patients. In addition, professionals' feelings about their own parents or older relatives can conflict with their dealings with elderly patients. Thus, physicians tend to label elders as resistant to treatment, rigid in outlook, demanding, and uninteresting, assess the elderly narrowly and overlook psychological factors in elders or misdiagnose them with a physical ailment (Palmore 1999).

Similarly, misconception in hamlet Sumerno was also found among the health workers that I interviewed, which featured the elderly male patient as difficult, demanding, needing extra attention, stubborn, unwilling to follow suggestions in their TB medication. While for the elderly female patient to be more emotional, more sensitive, easy to get offended, submissive and abide in treatment and medication of TB, but difficult to understand information and education given to them.

Most of elderly have different emotional aspect than when they are young; Elderly female is more sensitive and easy to get offended. (AD health workers)

It is much easier to work with younger aged patients compared to elderly especially regarding TB information and education, who need extra attention. Sometimes they're half hearted to listen and find out the cause of their sickness...the

elderly male is more recalcitrant, more stubborn, difficult, so to work among elderly needs extra care. (AC, health worker)

The elderly female is difficult to take her medicine, she needs to be reminded about the TB medication and treatment. (AG, health worker)

4.4 Tuberculosis in the eyes of elderly

4.4.1 Belief in TB etiology

Through observation and discussion with the elderly and community members, several descriptions were revealed to identify TB within the community context. The elderly believe that TB is caused by the following:

Table 4.1. Table of TB etiology by the elderly

No	TB Causation	Lay perception
1.	Virus	Small germ, microscopic, need certain technology to find it
2.	Bacillus	Similar to virus, microscopic size, type of germ (<i>kuman</i>)
3.	Smoking and nicotine	Refer to lung condition affected with tobacco, weaken lung
4.	Humoral caused— wind enters the body	Wind enters and affects the lung, weakens body, imbalances body condition
5.	Malnutrition	Eating less nutritious food. Fasting causes body to take less nutritious food, and weakens the body's affected immune system.
6.	Eating stall food	Stall food is cold, affecting the body imbalance
7.	Hereditary	Passed by family member or infected by other.

The elderly at hamlet Sumerno described a virus similar to a bacillus as microscopic and affected weak lungs; the size is very small and capable of penetrating the lung. Smoking and nicotine were associated with weak lungs resulting from

smoking, the lungs become a fragile area to be infected by germs. Humoral wind enters the body and is associated with the habit of sleeping on the floor, a cold floor will affect the lungs and cause the lungs to be filled with water. This belief is also used to picture the wet lung (*paru-paru basah*). While eating stall food or malnutrition is associated with the weakened condition of the body which allows the germ to enter the body so easily.

4.4.1.1 Hereditary of TB

Throughout my observation and interviews, the concept of TB heredity came to the surface. It coined two situations that work at the same time, belief and perceived inheritance by lay perception and conception that is understood by the health worker. The elderly in the community hamlet suggested two situations that may represent the way they understood heredity. First, hereditary predisposition is understood as a TB dormant condition that becomes active at a later age, or after years of inactivity. Thus elders are of the belief that TB becomes a part of the body, existing within them, and perceived as part of the genetic inheritance. Second, hereditary factors are taking place through constant and direct encounters with the TB patient, who happens to be a family member, such as living in the same house, using the same cup, or playing chest together. While on the other side, health workers tend to generalize it in biological and medical terms and avoided individual comprehension in viewing the causation of TB. The following are some opinions regarding the TB hereditary condition in hamlet Sumerno.

*Well, Mr. XY in our community healed because he took the medication regularly. He received injections besides taking pill; he is 65 years old. I think he got it from his father, because his father also had TB before. When they play cards together, and he likes to spit his sputum everywhere, all of his children also have TB, so it was **hereditary**. (From elderly male FGD)*

***Hereditary** can cause TB, it can be infected through someone, if you stay together with that person, live together, so it is spread from sputum from short distance, the virus gets in through air. (From female elderly FGD)*

*Well, we need to help them if they get TB, what can we say; she is our wife, our family. We must help her until she found her jodo with medicines until she gets healed. But if it is **hereditary** what can we say, too. (From elderly male FGD)*

4.4.2 Severity of TB

The elderly at hamlet Sumerno also believe that TB will shorten the life of a person, and leads to death. This assumption was raised from the fact that the community members who knew TB patients were seeing them dying during medication. In comparing that to other illnesses, they also suggested that TB is still difficult to be cured as it can be seen from long treatment and medication. Its impact is can directly be observed, such as in weight loss, and severe cough, and coughing blood which always associated with TB. TB is also believed as a death trigger, as less elderly survive from the sickness, and death which make it worse than HIV/AIDS.

Most elderly who have TB their life is short. Like Mr. XX, he got TB, I don't know about his wife or son, but what I heard his son got TB too, but because he is in the army, I think he checked there. (From elderly male FGD)

Community still believe that TB is not able to be cured, and worse than HIV/AIDS. (AD, health worker)

4.4.3 Symptoms and physical appearance

While for symptoms, they come up with several terminologies to describe illness experience and perceived changes in physical appearance, and unpleasant physical symptoms as the result of TB infection, as the following:

Table 4.2 Perceive symptoms of TB and physical appearance

No	Symptoms	Perceived symptoms
1.	<i>Mengok (heavy cough)</i>	described as an episode of long and frequent heavy coughing
2.	<i>Mengi (wheezing)</i>	in this case the elderly tried comparing it with asthma symptoms.
3.	<i>Ambekan (chest tightness)</i>	described like short suffocation
4.	<i>Watuk ngidam (heavy cough)</i>	heavy cough until stomach hurts, short of pregnancy craving mixed with vomit.
5.	<i>Geger watuk (heavy cough)</i>	heavy cough until your shoulders shake
6.	<i>Batuk darah (coughing with blood)</i>	Frequent coughing with blood
7.	<i>Mulut pahit (mouth bitter)</i>	bitter taste in the mouth
8.	<i>Badan bungkuk (bending body)</i>	reflects the coughing process while holding the stomach at the same time.
9.	<i>Badan melengkung (crooked body)</i>	Body bending
10.	<i>Badan kurus kering (body thin)</i>	severe loss of weight
11.	<i>Dodo jantung goyang</i>	severe chest pounding with shaking
12.	<i>Dodo deg-deg</i>	chest pounding
13.	<i>Jantung keras</i>	hardening heart
14.	<i>Dodo banter</i>	chest pounding with loud sound
15.	<i>Badan rusak (body damaged)</i>	body is damaged, describing the state of illness affects the entire part of body, and frail the person.
16.	<i>Paru-paru basah</i>	Wet lung, with liquid inside the lung, coughing with phlegm.

4.4.3.1 Elderly ways to identify TB problem in community

Through discussions with elderly in hamlet Sumerno, the community also develops certain ways to identify sickness among its members. Observing, and assuming through perceived symptoms of TB, constant cough, and experience being exposed to a TB patient are some of indicators used by elderly in hamlet Sumerno to identify a TB related problem. Following their opinions regarding ways to identify TB, it provided me insight about how the community member himself can produce stigma. Other symptoms that seem similar to what they are perceived can be misunderstood as TB symptoms as well, such as bronchitis, which may show some similarity to TB symptoms.

Furthermore, one important aspect I found from this hamlet is the bond among household. Elderly also rely on each neighborhood for support in time of need, such as sickness or death, where the whole neighborhood comes to help and provides assistance as required. In this, sharing information of health can be one aspect used to acknowledge the sickness of a community member, in particular if the elderly is seeking more information from other elderly regarding their health problem.

Unfortunately, Mr. XX does not want to go there, he received medicines once a month, actually the process is easy, you only need to go to the health center and they will provide you with medicines, but he never wanted to visit the health center. ...If you have long cough, the doctor will check for your sputum (Mr. O from male elderly FGD)

In my opinion we need to go to the doctor so they can find the right medication to kill that germ. They will regularly check the condition such as our sputum (Mr. M from male elderly FGD)

Mr. XY received injections besides taking pills; his condition is getting worse because he doesn't want to take the medicine, he is getting weak and weak, his body is thin. His body is damaged (badanya rusak). (Mr. J From elderly male FGD)

Well I have experienced, when I was young and working in Jakarta, I stayed with two other roommates, one with asthma and one with TB, we

shared the same room, ate in the same place, no choice. I'm still healthy; both of them died 10 years ago. (Mr. N from elderly male FGD)

Well there was one elderly female with TB before, but both wife and husband have died. (Mr. I From elderly male FGD)

4.4.5 Tuberculosis stigma among elderly

This section elaborates tuberculosis stigma, how it exists and is understood, and is transcended in the daily communal life of hamlet Sumerno. This was done by observing the issues within the hamlet of Sumerno, and identifying how the community responds to it within its context.

4.4.5.1 Elderly fear to engage with TB patients

The prominent reaction toward TB revealed through observation and discussion is that fear is still the primary concern for elderly to engage with TB patients. This fear resulted from the perception of TB as a highly contagious disease, easily infecting others by sharing similar cutlery or utensil use by the patient, eating or sitting together at a short distance. The elderly reaction toward TB patients is not vividly shown, and more done in reserved action, such as avoiding the patient, and keeping their distance. Furthermore, the elderly also fear if TB infects them, they may not able to work and earn money and support their daily life.

I am also scared (other nodding), afraid that if will infect us, because if you get TB you cannot work, you cannot earn money to buy food. The doctor said also that it is dangerous. (Mr. I, from elderly male FGD)

They also need to separate the plate, glass, cannot eat together, cutlery should not be mixed, because it's infectious, it can be spread out through the air. Yes and cutlery (Mrs. E, from elderly female FGD)

If you sit together you can get infected. (Mrs. A from elderly female FGD)

I was worried every time I saw them, because I communicate with them a lot, almost every day I worried. If I felt my chest pain or start to cough, I was afraid it will infect me, so then I avoided them, take medicines, either Jamu or medicines, I was so afraid I get infected. (Mr. L From elderly male FGD)

4.4.5.2 Obligation of physical distance

In hamlet Sumerno, elderly and community members also developed certain rules for the TB patients to engage with its members. This is done in a subtle manner, and should be understood without directly confronting the patients. On the other hand, the elderly were also requiring TB patients to distance from them if they are communicating with others. It is considered as part of a mutual understanding between patients and community members.

We still support them, but limited our contact with her, if they have TB, and cough they must keep distance too, we also need to do the same thing, we need to hold ourself when we want to speak with her. (Mr. L from male FGD)

They must understand our position, realizing herself that she have TB, they also need to distance with us...I give you example, simple example, if you talk to someone and his mouth smell not nice you tried to avoid them, that is for mouth problem, now this is TB. They need to distance with us, we suggested them to do it, keep the distance but still able to talk. (Mr. O from elderly male FGD).

4.4.5.3 Physical distance and limitations to engage with family member

One of the concerns raised during the elderly female TB patient treatment is their closeness with their loved ones, particularly the grandchild. Because of the illness, elderly female TB patients need to follow certain expectations in order to protect transmission to their grandchild. This includes the distance from their loved ones and extra precaution, such as wearing a mask. Separation for using cutlery, and sharing utensils is prohibited to other family members.

Most of the time when we are dealing with elderly, we will use the family approach, it means we will involve the family member in their health check and medication. Sometimes we also scared them (medeni) in polite way such as if you don't go for a checkup or take medication, it will infect their grandchildren. Because most of the elderly are very close with their grandchildren, then they will go for checkup to protect their grandchild from being infected with TB. (AA, health worker)

Some of the family members are also scared if the patient infected their children, they are not openly forbid them to connect with their child; most of them will ask their kids to play outside or babysit with other in laws, more in direct way. The elderly female is more afraid of infecting their grandchildren, when we mention about how contiguous the disease was, and because of child immunity is not too good, so when they play with their grandchild they need to wear a mask. (AD)

My daughter also reminds me, "Mom, don't let yourself forget for checking, to take your medication and not to skip it. I know that you want to get cured mom, and be able to meet up with your children and your grand children". (AH)

On the other hand, keeping a distance from their grandchild can be a touching experience, and difficult for the elderly as they are also the source of motivation.

Why I should separate many things, like cutlery and scared me with such statement, I feel myself like an elderly living in a nursing home, need to be separated from things I know or love, I found it not pleasing in my ear. I have extra pulmonary is not infectious, I know because the doctor in hospital already told me about my condition and it is not contagious, I feel so offended, and insecure. All my children are very supportive, also my grandchild. (AJ)

4.4.6 Expected attitude in attending health care

Similar to community and family, TB patients also need to follow certain rules expectation when they attend the service at Puskesmas, like wearing a mask and

not to visit Puskesmas on children immunization day. By following this role elderly TB patients are expected to avoid direct contact with children, and the population at large, by solemnly differentiating patients through direct management of the disease, like fast tracking to medication and treatment (without queuing), and limitation of movement by shortening the time of interaction with other.

When I know that the person is TB positive (BTA+), and the results confirm it I will straight asked them to wear a mask in my room, usually I will give them seven pieces and inform him why it is necessary to wear a mask. And every time they need to come to Puskesmas, I too suggested them to wear it. Also, at home particularly when they have a toddler in the house. (AB)

We prioritize them first, because when they are waiting to be called they need to wait at the lounge together with other people that come for health assistance. We don't want them to infect others, therefore we prioritize them first to check and obtain their medicine. Less exposure to others may reduce TB incident to others. Many times when they have arrived, register staff will inform BP and direct the patient to BP without have to wait for long time. We also suggested them to visit our center not during immunization day. (AG)

4.5 Health care context of the elderly

4.5.1 Posyandu (Integrated service post) for elderly

It was a Tuesday morning; around 10 a.m. and the elderly in hamlet Sumerno started to come and commute at chief of hamlet house to attend *posyandu lansia* (elderly). This *Posyandu* is usually conducted once every first week of the month. A doctor or the nurses from the nearest community health center will come and provide assistance to the elderly in the village. Sometimes if the health workers are not available on the regular date, they will shifted to another week and inform the community before the actual date.

This service has been conducted since 2010, and has helped the elderly to access health care in their own village. The medication is considerably cheaper, and the elderly need only to pay 3.500 IDR or 0.35 USD, and for those who hold an insurance card medicine will be given without charge. Before *posyandu* started the chief of the hamlet had set three tables in line to be used for the health worker to assist the elderly. The first table was stationed for administration and general checks such as for blood pressure, weight, and height and motoric of the elderly, while the second table was stationed for the pharmacy, and the third table for the doctor. Those who had register were divided into two waiting areas, the left side for males and right side for females. The checking process was done openly and each person in the room was able to hear each process, and there are no such differences between males and female in medical checkup process.



Figure 4.8 Posyandu health check card, room use for posyandu;

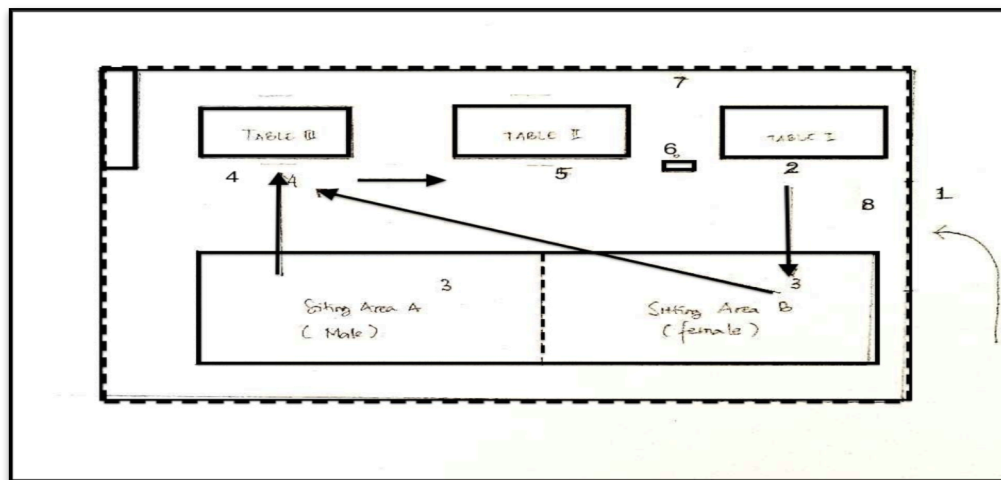


Figure 4.9 The flow for health check at *posyandu lansia*

Note: entrance (1), administrative table (2), waiting area; male of the left and female on the right (3), medical check station (4), pharmacy (5), weighing station (6), height station (7), walking track for physical examination (8)

4.5.1.1 Treatment and medication of elderly female sickness

Health of the female elderly cannot be separated from the fact that the female needs particular ways in dealing with treatment and medication. The influence of menopause and personal factors to health should be understood in its context and in a manner that helps the elderly find comfort in attending a health check and support in treatment and medication.

Two aspects that are commonly found in the health of the elderly female are the avoidance in females for particular health needs, and generalization of illness between male and female patients. For instance, the female elderly health problem is not addressed in a manner that suitable to personal needs during the health check, such as in privacy that is supposedly provided at *Posyandu Lansia*. The room was open for everybody. Either male or female elderly patients could hear about the others' health problem that is considered private and confidential.

The elderly will come during posyandu lansia, and follow the health check. Once after they registered at the administration table the nurse will check their physical movement, weighing the body and measuring the height. This was

done to understand if the elderly have a nutrition or eating problem. After that they all wait to be called. The waiting area is separated into two areas, left for male elderly and right for female... there is no difference between female and male in checking, all was done in this room, and everybody can see each other and chats. (Mr. V chief of hamlet)

4.5.2 Puskesmas Pembantu (Health Center Post)

The health center post is located ten minutes from hamlet Sumerno, and it can be reach in a twenty minute walk. This health center post is considerably smaller and mostly operates to assist primary health issues and child labor purposes as one midwife heads it. It is operated similar to *posyandu lansia*, and provides assistance for people every day. In hamlet Sumerno, the elderly decision to do a health check is determined by the severity of illness, time health costs. Therefore, the use of service mostly is connected with the regular health checkup or a simple health problem. This level of capability in providing service is valuable also through knowledge attainable by the health workers. In one of the discussion sessions with the elderly, it was mentioned that hierarchy of knowledge based on health is critical to the health worker.

*Usually the midwife's knowledge on health is less than the nurse or doctor, we can also see the difference in terms of facilities and service. Of course that community health center is bigger than **Postu** (Puskesmas Pembantu), however the main issue is only midwives to assist. I found them less helpful to assist our health condition. (From elderly male FGD)*

4.5.3 Puskesmas (Community health Center), an affordable health service

Puskesmas is the usual place at district level (*kecamatan*); this health center is providing health assistance to the community level with affordable price. It takes twenty minutes to reach the nearest Puskesmas from hamlet Sumerno. This Puskesmas is considerably bigger with better facilities to provide in-patient service in case it is needed. To rural people, Puskesmas has a wide contribution to assisting health issues.

In responding to the role of Puskesmas, the elderly view several principles relate to their services in community, such as cost of care, reflection of health provider service, and this was done by comparing to the service that they had previously attended. They understand the referral process, how it was done, and learn how the system operates. In this decision to obtain health care among elderly in the rural area is also determined by the referral system, and the process of referring work.

Well, I do not want to say that community health center is bad, only I felt sometimes they only help us for primary things, it is like an experiment, if they cannot solve our problem then they will refer us to the district general hospital, and from there if they cannot handle it, they will refer us to the main general hospital. So the community health center is only for simple illnesses, if it is a difficult or heavy case then they will send us to main hospital. In particular, those who are using health insurance (Mr. P from male elderly FGD)

Usually if elderly under certain coverage like insurance, puskesmas will tend to refer the elderly to RSUD (Rumah Sakit Umum Daerah – General hospital), and if they could not help the elderly, they will be referred again to province general hospital. However the service at general hospital sometimes can be problematic. They will send us from one desk to another desk (dioper-oper), and never in one stop, we are not the only one who complaint about this, but there are many. When you are waiting for the medicines, the other patients are saying the same thing. (From adult FGD)

4.5.4 Medical Pluralism and the elderly decision for medication

Recent medical pluralism in Yogyakarta could not be separated from political order in the past, in particular during the new order. Ferzacca (2002) studied in Yogyakarta and viewed medical pluralism as a crucial element for political organization and how that perception operates in the governance and management of population, and also in the lives of people. Traditional medicines or *jamu*, and its practice as part of that medical pluralism were designed to picture modernity and as an image to Indonesia development in particular on the range of primary health care.

The traditional medicine remnant is still popular in many rural areas of Yogyakarta. In my observation in three traditional markets, traditional medicines are largely used by people and the elderly. The herbalist will prepare the medication according to the health complaints of the elderly. Fatigues, dizziness, loss of appetite, stomach discomfort, fever, are some of the example symptoms to be solved. The elderly who were mostly female who happen to work in the market, or purposely come for groceries, will stand around the stall and just directly ask for a herbal mixture. The herbalist will listen attentively to their complaints, and start to collect the herbal remedy from each symptom mentioned. Usually each of these herbalists will have assistants that help to prepare some fresh ingredients, such as turmeric, ginger, white ginger, and yellow ginger. They grate it and squeeze with a cloth, put in trays. Later the herbalist will scoop it out and mix it with powder herbal, and made concoction to drink. I asked the herbalists, what is the powder? All of them were reluctant to tell me and just answered me as a secret and cannot be shared to everybody, but it seemed almost in the entirety of their remedies they will put that herbal powder.

The concoction is relatively cheap compared to western medicine, around 1.500 – 2000 IDR or 0.15-20 cent of USD. It also can be carried at home, only they put it in plastic bag instead of a bottle. I asked some of the consumers, the elderly ladies, and most of them felt satisfied with the remedies and mentioned that it worked well with their body. When I asked about their preference on medication between western medicine and traditional medicines, most of them prefer herbal medicines as to balance their body condition and for mild illness, while western medicines are mainly for severe or difficult illness that cannot be solved with herbal medicines.

4.5.4.1 Jodo (match), an interesting thread to individual elderly medication and treatment

Jodo or cocok (match) has been use by the elderly in hamlet Sumerno as an individual way to picture personal decisions in accessing health care. Its principles are determined by several individual assumptions, flexibility, knowledge based accusations, and whether the medication is effective to solve their illness. This individual model may not be present as an overall representation of the elderly decision to care; however, the picture of the way it works for illness is fluid and complex. In addition, this perceived individual health seeking should stand on its own nature, and types of illness experiences such as for acute or chronic situations.

Well jodo (match) is not like jodoh; jodoh is marital relationship like male and female, husband and wife. But jodo is more about you finding the right person to medicate yourself. This person helps to identify your sickness and heal it, that's why if one doctor cannot help you, you can look around, to another doctor, that is able to help you with medication, until you find it, their assistance will help us to get healed. And when you have done it for several times, and you still experienced the same thing in your medication and treatment we called that jodo, J-O-D-O not J-O-D-O-H. (from elderly male FGD)

Furthermore, the flexibility of *jodo* covered a wide range of medication, types of treatment, and sources of care. Western medicine has the same function like other types of health systems. This individual seeking behavior can start with western medicine and change to another type of medication or solely western medicines throughout the process. Similarly, alternative medicine can be a start medication, can be combined with western medicine, or remain solely with alternative medicines. The main characteristic to this individual seeking behavior is whether the illness can be solved or cured.

4.5.4.2 Knowledge and lay perception toward acute and chronic illness

The first consideration aspect that is important for the elderly to obtain health care in this hamlet is that the health worker is credentialed and has a level of

knowledge of his own as a folk healer or traditional herbalist. This knowledge obtainment is understood as able to assist in reducing or curing the illness. Furthermore, this level of knowledge is used to differentiate expertise of the health worker or folk healer. This involves a hierarchy of knowledge and the dimension of illness, whether it is acute or chronic.

I have experienced with that too, I went 5 times to doctor, never get better, and I went to alternative, and it become jodo to me, I get healed. (Mr. I from elderly male FGD)

Doctor they observe things that are hidden in our bodies, the things that we could not see with our bare eyes. So traditional healer knowledge is limited, while medical doctor they have better knowledge. (Mr. O from male elderly FGD)

From discussions with the elderly and observation, they have suggested that the medical doctor has better understanding of the invisible body (*bagian yang tidak terlihat*) or internal organs (*bagian dalam tubuh*), which need observation, technology and specific knowledge to deal with the illness, while for alternative medicine, its involved understanding of the outer body, something visible, able to be touched. In some extended combination of faith and magic, that interferes during treatment, is that belief has more influence on the healing process. For example, in the case of paralysis, or unexplained illness condition after the doctor has diagnosed it.

The path to health as mentioned above should also be seen in the context of each person in distinguishing between acute and chronic illness. In this, personal humoral assumption, irrationality and misinterpretation may emerge. In some in-depth interviews and during focus group discussions, some terminologies are used to differentiate acute and chronic, such as the following

Table 4.3 Elderly perception on acute and chronic sickness

No	Type of sickness	Example:
1	<i>sakit yang lama</i> (long sickness)	<i>Kencing manis</i> (diabetic mellitus), <i>sakit ginjal</i> (renal failure)
2	<i>sakit kambuhan</i> (repeated sickness)	Batuk (cough), <i>pegel linu</i> (join pain), <i>asam urat</i> (arthritis)
3	<i>sakit tiba-tiba</i> (sudden sickness)	<i>Serangan jantung</i> (cardio arrest), <i>angin duduk</i> (humoral wind cause stomach cramps), <i>struk</i> (stroke)
4	<i>penyakit orang tua</i> (elderly sickness)	Combination of sickness such as cardio problem, hypertension, and diabetic mellitus, <i>prostat</i> (prostate problem), <i>sering kencing</i> (frequent urination)
5	<i>penyakit ringan</i> (mild sickness)	<i>Letih</i> (Fatigue), <i>panas</i> (fever), <i>sakit kepala</i> (headache), <i>sakit perut</i> (stomach ache), <i>pusing-pusing</i> (dizziness)
6	<i>penyakit keras</i> (terminal ill)	<i>Kanker</i> (cancer)
7	<i>penyakit turunan</i> (hereditary sickness)	TBC (TB), <i>ayan</i> (epilepsy), <i>lepra</i> (leprosy)

The classification of sickness is broadening more than just acute or chronic, and mixed with severity, duration, and subjectivity of person. Furthermore identification of symptoms and discomfort or imbalance health state is measured by feeling (*perasaan*), experience (*pengalaman*), and people story (*cerita orang*) of particular symptoms. In addition, the causal too varies from biological, chemical to humoral cause such as *masuk angin* (wind entering the body), *letih* (weary), *banyak pikiran* (too much to think).

Perceptions toward self-recovery of sickness also influences personal experience in illness, such as in the case of *sakit kambuhan* (repeated sickness). To the elderly in this village, cough is commonly found among the elderly, and it can come any time and recover by itself. Therefore, TB symptoms may not be understood as

part of a TB episode but rather simply as cough. Repetitions of this symptom are generalized as an ordinary situation. Thus the elderly may delay their checkup or even neglect health problems.

If they get very ill and need to be taken to hospital, sometime they refuseThey think that they can recover by themselves. (From adult FGD)

4.5.4.3 Jodo and medicine efficacy

The second aspect is *jodo* in the efficacy of the medicines. In this aspect individual elderly preferences can be varied, and depend on their own personal experience in taking medicine, perceptions on episodes of particular symptoms, and their individual understanding of the medication. For instance, to understand the function of the medicine, the elderly women in hamlet Sumerno did not perceive through name or particular function of the medicines, instead they recognized it by the color or package of medicines. This happened simply because they did not receive adequate information about their medication when it was handed to them from the pharmacy or health worker. They are only instructed to take it by color and how many tablets should be taken daily. For example, orange pills for vitamins and white pills for pain relief. Another example is the use of generic medicines that are recognized by labels, some of the elderly believe that generic medicines provided by the health center are less powerful than medicines provided by hospital.

My parents are of the belief that medicine from the community health center is different from hospital; it's a generic one; usually it's less powerful to heal the sickness. (Mr. U from adult FGD)

Furthermore, *jodo* (match) in the use of medication regardless of its type should overcome illness, therefore its medicinal effect may exceed beyond the purpose of medicine. For example, paracetamol is used as an analgesic. Relief in pain may reduce other discomfort that effects mood, such as anxiety or nervousness. Hence, personal subjectivity on medicine should be answered in determining the path to solve their illness.

Jodo also able to explain about the work of the drug itself, the effect to our body, some medicine is not helping us, we still ill, but once after one drug cured us and we get healed, it means *jodo* (match) with that medicinal, regardless of traditional medicinal or modern drugs (From elderly male FGD)

4.5.4.4 Perceive toxicity of medicine

In one of the discussion sessions with the elderly I asked their opinion regarding treatment for tuberculosis and the duration patients should take to complete the medication. I did this to understand their response toward such chronic illness and response in a female TB patient. Their responses varied and some opinion was generated as reflection from individual experience in taking medication. From the discussion, it was suggested that taking medicine more than a week is considerably boring, difficult, dangerous, and has unintended effects to their health. If it takes a longer period of time, then the medicine may harm the body of the elderly.

Another concern was raised during discussions with elderly females is related to frailty and disability condition. The belief that medicine might harm the body is critical, due to its unbalancing effect or worsening of the body condition. A similar response also has an influence in taking other types of medicine. Thus provide a basis on the understanding that they might terminate or replace their medication if they feel changes in their body discomfort, or feel healthy, although the medication is has not been completely taken. Although the above opinions tend to be personal, presumably it is influencing the elderly female's decision. It is worth to be considered that subjectivity on medication toxicity side effects to the ageing body could trigger and lead to drop off cases.

In addition, the elderly females from the focus group discussions also suggested that interfering medication with herbal medicines (*Jamu*) might have specific benefits for the individual, such as balancing between light and strong medication. The following are some of their opinions.

“Well, long term medication can be boring, we followed what the doctor said, but sometimes we don't really do it... I never take 2 weeks of medication; I only take it until I found myself much better then I stopped... I believe too much medicine

will poison our body, and I am really scared about it. And if I get another illness it will worsen my body, not be strong enough to handle other medication...In my opinion taking only some medicine until you feel much better, when you begin to see the changing you don't have to finish it... I found taking medicine for one whole week is already difficult, I could not imagine taking in such a long period of time... Too much medicines will kill us. We can say to the doctor that we have taken the medicine, even though we are not actually taking it, only some of it". (From female elderly FGD)

Another challenge for elderly is when they feel that their cough has stopped or reduced, and the body weight has increased (sampung lemu maleh), health complaints disappear; and think that they are cured or feel much better, this is the critical time, because at any time they may drop their medication because of these assumptions (AG, health Worker)

*Well, if we are sick we go straight to the doctor for a check, some of us are taking **Jamu** (herbal medicines), especially when we feel much better. (Mrs. E from female elderly FGD)*

4.5.4.5 Culture's influence in menopause and elderly female health

Menopause and health complaints in elderly females simultaneously interact. The body complaint is not merely of hormonal issues but also personal subjectivity toward the ageing life, perception toward the body and problems related to life experience add up the dimension of illness among the female elderly. The individual elderly health complaints are often expressed in the subtle response, and can only be understood if it is explored through stages of openness. This particular aspect also defines the health worker-patient relationship. Sickness and illness experiences need to be understood as they are embedded in social inequality within individuals that are manifested in physical discomfort, and have an effect on medication and treatment.

Through several interviews with health workers it was acknowledged that elderly female patients tend to have multiple health complaints, in particular during treatment. The physical complaints and emotional aspects are entangled. Thus complaints also influence other types of illness, and manifest such as in pain, fatigue,

and insomnia added with a feeling of discomfort, unworthiness, and becoming a burden to others as responses to individual subjectivity. The cultural influence that drives the idea of female submission, as being gentle, polite, has affected the elderly female in encountering sickness and illness. They are not open and tend to be reserved. Instead of keeping their illness as a personal issue, rather than being outspoken to the health worker.

So we just follow whatever they said. We are afraid sometimes with the nurse; if they are angry with us. So we pretend that everything is ok. (From elderly female FGD)

I'm an uneducated women, illiterate, and I only followed what the doctor said, and I will pay attention to it. If they asked me to do this, I will do it, if they asked me to do that, I will do it, too. (Mrs. AH)

This is a cultural influence, sometimes they (elderly females) just say yes...but they are not really mean it, too (Njeh..Njeh tapi ndak kepanggih), is not always that what they said is true, they say yes in their lips but no in their heart. They tend to do so to avoid conflict. They think as long it can please the doctor's ear, and I will be ok, too (kepenak dokternya, aku juga enak), so most of the response is only yes and yes. (AC health workers)

4.6 TB program and health provider

Like other types of disease, the TB program is incorporated with the health provider unit. Synergizing the health sector from the community level up to the national level did this. Within the context of the health provider, the TB program is executed in every sector including hospitals (private or government), community health centers, health posts and the community.

4.6.1 Management of tuberculosis patients

Following international standards on TB management, and its implementation, the TB program in Yogyakarta has followed similar standards applied through implementation of DOTS. The principle action is aimed at reducing mortality

and morbidity, and preventing transmission by means of curing the patients. Surveillance of the disease, management of auxiliary facilities, personnel, record keeping, reporting, evaluation and follow-up planning has been the backbone of the management besides simply ensuring that the patients took the drug until cured.

4.6.2 Finding strategy for TB patients

The initial step of the strategy is finding TB patients and curing them. This will significantly decrease morbidity, mortality, and transmission in the community; while at the same time it effectively functions as a preventive measure to keep tuberculosis from being passed on. This strategy involves the following (Kementrian Kesehatan Republik Indonesia 2010):

1. TB patients finding is carried passively with active promotion.
2. Identification of the TB suspect and patient recruitment in treatment are conducted within the unit of health care, supported with active promotion either by health worker or community to improve coverage of TB patients finding.
3. Active finding from house to house is considered to not be cost effective.

Furthermore, the strategy also incorporated tuberculosis clinical evidence identification of the TB suspect, microscopic sputum smear collection, culture examination, TB resistance, and diagnosis for pulmonary and extra pulmonary TB.

4.6.3 TB referral system

The referral system for TB works in two ways. The health provider such as the hospital and community health center is able to identify the TB suspects and conduct a test to ensure medication and treatment can be provided for the patients. In several particular cases, the community center may need to refer the patient to the hospital for further testing. The community health center only provides the sputum test while for other TB tests they still need to refer them to the main hospital.

In addition, medication and treatment after testing could be obtained by patients either in hospital or Puskesmas, but it is mostly suggested that medicine is taken from the community health center or the nearest health provider to the patient's home. This was done also to minimize cost of care, particularly the transport for TB

patients, while the cost for tuberculosis medication is free. Patients may need to pay only administrative costs in Puskesmas that costs around 3.500 IDR or 0.35 USD, while for the hospital they may need to pay more for extra tests, or if in-patient treatment is needed.

4.6.4 Home visitation

Home visitation is one of the backbones in TB patient treatment and medication. House visitation is used by health workers to provide information and support for patients, such as to ensure that the medication is taken weekly from Puskesmas, to check the condition in case patients do not regularly check their condition, or other issues related to treatment and medication of TB. During my observation period, the health worker will visit the patients in their spare time, as they also are busy with other activities in Puskesmas. The community health center personnel did all these visitations. In some cases, health workers frequently need to visit patients in case difficulties are found with their medication process, for instance for the elderly. In one of the house visitations that I conducted, health workers shared information concerning TB, and asked whether they read the booklet about TB and explained information that was not clearly understood. They provide motivation for the elderly to keep continue taking their medication, and to ensure they are not skip taking it.

I saw health workers were prepared with the process. They approached the patients in a mannerly way, according to Javanese culture. The entire process was done informally and relaxed. House visitation is critical as nurses are trying to help patients to follow treatment and medication. However, this activity also needs specific attention, as mutual communication should be established in order to understand the patient illness experience. There is often a power relationship that may limit this communication, as information or education given focuses on disease rather than the patient itself.

Furthermore, interpersonal skill from each health worker is required, such skill can only be grown and developed if they frequently conduct house visitations, which add up extra responsibility for the health worker, as they are already packed with responsibilities at the health center. This time constraint may lead nurses to

neglect the aspect of subjectivity to illness, encouragement and motivation rather than to base their message on how success in medication will lead to betterment of elderly life, but neglected the process of how the elderly are able to adapt, adjust and develop ways to deal with the problems of illness. The patient's illness may not derived simply from the environment, agent, and host cause but also the perception of connectedness to the illness and how it reflects in body complaints. It is beyond the germ. It takes the whole assumption of illness, such as in the elderly persistent assumption of hereditary factors, and unexplainable symptoms.

4.6.5 The role of caregiver (PMO – Pemantau Menelan Obat) in elderly TB treatment and medication

The caregiver or caretaker is the person who is willing to assist the TB patient take their medication regularly. Their responsibility is also to make sure that the TB drugs are really swallowed by the patients, and in some cases help them during the health check day to take medicines or while testing is needed. For the elderly the role of caregiver becomes critical, particularly when frailty or disability exists.

The difficult part for the elderly, female or male, is they easy get bored with medicines; this is again because of the duration of medication. Therefore, we work together with PMOs to ensure that patients taking the medicine, and to ensure that they swallow the medicines. (AD, health worker)

We always encourage these PMOs, to help this people. Usually they are patient relatives; they are can be spouse, children, or a close relative, and live in the same house. These PMOs also are the ones that regular come and help these elderly visiting our center. (AG, health worker)

The role of caregiver also extends as to representation of health institution, where they are equipped with information and ways to handle medication and treatment for elderly while they are at home. This is done to ensure that the elderly person is not failing to take or is skipping the medication, to monitor the progress of the elderly, and as a main bridge between patients and health workers. Furthermore, this motivation also extends in the way power is exercised beyond the medical

institution. The implication is that this PMO holds control over the elderly, either in a direct or indirect way. For example, the frail may suggest direct interference of the PMO by controlling treatment and medication of the elderly with TB at the front. While indirect interference involves a subtle strategic approach by means of persuasion, so the elderly person might abide with treatment and the medication given. This institutional practice extends through home care and caregiving on the grounds of the elderly's own protection. The elderly's body becomes consistently ordered by the state mechanism by means to control disease, ensuring management of therapy takes place and guidelines or principles are followed.

The PMO needs to motivate elderly patients, to look carefully at nutrition intake during their treatment and medication, also education. (AB, Health worker)

PMOs encourage motivating the male elderly because they are more difficult and unwilling to follow suggestions. (AD, health worker)

Usually we have the caregiver contact number, this is important to ensure that the elderly takes medications. So in case they are not coming for the treatment we can call them, and asked their condition. Usually the day before they are taking their medicine I will text them and make sure they will take the medicine. In case of the frail, the elderly may rest at home, and the caregiver can take the medicine from Puskesmas. Each patient already has their own package of medicines, which is solely provided to each patient, so in case they skip it or are not taking it from us, we will know. (AB, Health worker)

We also give certain understanding for the caregiver, and provide them with leaflets, so they may know what TB is, so they can inform their family and other family members, such as the transmission, prevention, and how they are able to inform the elderly not to spit carelessly. (AD, health worker)

4.7 Elderly female TB patient illness experiences

Kleinmaan et al, (2006) suggested that illness is culturally constructed and closely related to the social system of meaning, and rules of behavior. Moreover, how

they perceive of illness, experience and cope with disease are based on the explanation of sickness, attached to the social system that dominates us, and an engaged system of meaning. Furthermore, fluidity and flexibility of illness is also shaped by cultural governing perceptions, labeling, explanations, and valuations of the discomfiting experience, a process embedded in a complex family, social, and cultural nexus. In addition, subjectivity is also intertwined in the illness experiences. Biehl et al. (2007) suggested subjectivity is derived naturally from social experiences which are constituted by a person, often operates unnoticeably, that conjoins intimate relationships, in between institutions, and functions to gear people to live and die through social encounters by shaping their psychological processes.

The following section is the integral illness experience to understanding individual subjectivity, the coping process to illness, meaning and intertwined social system and culture embedded in the elderly female TB patients. Despite the fact that it may not represent the overall picture of the TB patient's experience, their voices are worth being heard and may stand as a strong repercussion to TB illness experience.

4.7.1 AH (food vendor)

It was on one late afternoon and part of a TB patient house visitation when I first met AH, a 60-year-old woman with three children and grandmother to 5. This regular house visitation was done as part of support for those who are undergoing medication and treatment for tuberculosis from Puskesmas A. She is around 160 cm in height, has dark brown skin, grey hair, and is slightly thin; I assumed that she has been losing weight quite significantly because of TB. To reach her place I needed to ride a motorbike for fifteen minutes from the nearest Puskesmas, but the distance to her house from my rental place was about five minutes by bike.

For her livelihood she depends on selling fried rice everyday from 5 p.m. until 11 p.m. She is also a breadwinner for the family, and depends so much on her daily income. All the expenses for the family come from the profit of selling fried rice every day. She stays together with her husband while all of her children stay in different places. Sometimes their children and grandchildren will come and visit her, especially during the weekend. Before she got sick, her daily routine started in the morning by doing groceries at the local traditional market near her house. At home,

she will prepare all the ingredients and sets them aside to be sold in the afternoon; most of the time she will finish around lunch time, and take rest for awhile before she opens her food shop at the nearest district road. Being ill placed another challenge on her, how to provide food on the table, and how they can sustain their life after closing the shop for nearly a month.

When I visited AH for the first time, she had been following the medication for nearly six weeks. She said her condition was getting better after taking the medicines, although she is still concerned about her body weight. She has lost nearly 11 kilogram in two months, from 49 kg to 37 kg. Her weight has slightly increased by 1 kg, and her cough complaints have reduced significantly after taking the medication.

Sometimes she regrets to her decision and keeps blaming herself for being inadequate with the illness. From the initial symptoms to the time she was diagnosed it was dated between September and November 2012. During the two months period, AH had been shifting from self-medication, midwife, doctor, and traditional healer. Her experience accumulated another week before she was diagnosed with pulmonary TB at the district hospital.

4.7.1.1 Road to health, individual health seeking care

It all began with a simple cough, AH said. At first, she was not fully attentive to the sickness as a cough is commonly found, and she believed it probably was because of fatigue, that caused tiredness and getting a cough. She began with gaining information from relatives, friends, and family who happened to have a similar experience. Following their suggestions, AH started to search for medication that matched with her sickness, she did this because the cough became more frequent and could not be avoided. She decided to purchase non-prescription cough mixture from the local market, which she began to take it regularly. In order to reduce fatigue and tiredness, she put her trust on herbal medicines from the traditional market. Herbal medicine is still commonly found in rural areas, and besides the cost is cheap, and Jamu is considered safe. Moreover, she used to take the herbal medicines (Jamu) and it worked well on her. Although she did not directly state it, the health cost was one of her primary concerns in obtaining health care, and to seek self-medication was

considerably more suitable to her condition at that time. This self-medication journey was done for a month from September until October 2012.

Unfortunately, the cough episode remained and got heavier, this time the cough simultaneously resulted in phlegm, and sometimes with vomit (*watuk orang ngidam*), it stretched her stomach and affected her in chest tightness (*jantung keras*), and at the same time she felt that her heart was pounding loud (*dodo banter*) like she was almost able to hear the sound. Acknowledging the situation, she set aside the medication she had already taken and decided to attend care from the nearest midwife that she knows closely. She was asking for an injection and medication for her cough, and waited for nearly one and a half weeks to see the effect on her sickness; however, she found no progress. She turned her attention to one private doctor, also near to her place, and told him about her condition. He provided her with another type of medication, and for two times AH attended his service for nearly two weeks.

Again, AH found no progress in her medication, and decided to take a rest and attend the traditional healer. She went to a traditional massager who happened to be her mother, to help in reducing discomfort in her body. Her mother noticed AH physical changes, that her body was becoming thin because she was losing weight, was pale, and look very tired. She asked her to visit the Samalo hospital and check her condition; however, she decided to delay her check and wait for another improvement. A week before she was diagnosed, which was in the first week of November, she experienced a different episode of symptoms that she described as the following.

Just around 10 p.m. I went to nearest doctor. One of my children took me there. Unfortunately he was not at home, only his wife. She checked my condition and comforted me that I was just a bit unstable. She handed me a piece of paper, it was a referral letter, and she suggested me to meet the gentlemen mentioned on the paper at nearest Puskesmas.... Around 11 p.m. I went to Puskesmas with my husband and daughter. He was so worried and confused. He tried to recall my condition at that time. I was so pale (covering her face). And we met the gentlemen from Puskesmas, the one that I should give my referral letter. He checked and said that I was too tired, and eat less. My daughter looked at me and said that I always eat less. I always was working until night, what I should say, I am a fried rice vendor. I was thinking at that

time, I should take a rest, probably for a month. The gentlemen suggested me to visit Puskesmas again on Thursday; it was Tuesday night when I met him... midnight, I was so worried and anxious. I was confused with myself and asked why did my heart beat so fast (holding chest), it sound deg..deg...deg. I asked my husband what was happening with me? My heart was beating so hard. My body started to shake, and it kept shaking for three hours. It was uncontrollable, shivering and felt cold. I came back again on Thursday, but Puskesmas was closed. It was a public holiday. Then I decided to wait, and decided again to turn down being checked at Puskesmas and went to Samalo instead. I went to that hospital on Monday the next week. (Mrs. AH, food vendor)

After the diagnosis, she received TB medication from the hospital and referred her to the nearest Puskesmas so she could get the medication easily. The AH case reflect an individual journey to access health care. It also reveals that illness is not simply a matter of germs or body disorders. Beyond that, illness is a set of intertwined complexities, such as individual experience, subjectivity, system of meaning, and irrationality. Delay to access care in her case was reflect in two dimensions, which are the individual aspect and the external aspect.

Furthermore, the cost for health care, and the power to purchase services may be limited to AH. As a fried rice vendor, her life and family depends on her daily income. Accessing health care facilities might be the last resort. Her self-medication was influenced by the economy of the family. She is the breadwinner, and making sure her family gets daily food on the table is critical, and the need sometime is beyond the illness itself.

Ahmad, Mahendradhata et al. (2011) studied in Yogyakarta and suggested that diagnostic delay is also influenced by care seeking outside of the health facilities. For nearly a month, AH sought care from a private health care provider. Less thorough assessment and a lack of understanding of the patient's complaints may hinder patients direct access to proper treatment and medication. It took her nearly a month until she was diagnosed with TB and received medication and treatment.

4.7.2 Mrs. AJ (retire)

Mrs. AJ is a 67-year-old mother of 5 children and a grandmother to 4 grandchildren. When I first met her, she was attending a focus group discussion at Puskesmas B. This focus group discussion was held to provide support and encouragement among TB patients. She was not alone, Nina (pseudonym) her daughter accompanied her to attend the discussion. Despite her age, AJ is still healthy, although a stroke from last year affected her right arm, and ageing has made her hearing almost impaired. She has been using hearing aid for several months. I needed to speak louder to help her hear what I tried to ask. Her sight is slightly blurred if she is not wearing glasses. She is around 155 cm in height, has dark brown skin, and is slightly skinny.

Mrs. AJ is staying alone, as a retiree most of her day is spent at home, by conducting regular activity around the house. Sometimes she will attend *pengajian* (prayer gathering) at the local mosque. One of her sons decided to convert some of her space at home for fishponds, and started a fish farm since a year ago. This new business has helped AJ occupy her time with a new activity, such as feeding the fish and making sure that they grow healthy. As retired she also receives regular income from a pension, both from her previous office and from her husband's who died several years ago. For AJ, money is not an issue in later age, from her pension she is able to save some funds to fulfill her dream visiting Mekkah, "as a religious pilgrimage to the house of God", she said. If everything follows God's plan she will depart in 2015, the "year that I truly waited to come" she added.

4.7.2.1 It looks like goiter and now TB?

It has been ten years from the first episode to the third episode. To AJ it is not a new experience. The previous two episodes were not clearly diagnosed, but it showed similar symptoms. A lump was growing on her neck, it began like a goiter, she said. The first lump was able to be treated, and get healed. Since she considered it as a skin problem, she took it to Puskesmas, after treatment, the lump was gone. The second time it showed a similar symptom. It was after years of recovery from the first lump. It came up on her left neck; again she went to the

same Puskesmas and asked for similar treatment, because the previous medication was suitable for her problem.

“The third one I found when I was dressing up, and seeing through the mirror, another goiter but this time is different”, she said. The third episode was considered difficult to handle. She went to visit Puskesmas for two times, to treat with similar medication, the first time it still did not work, and she went again to ask for medication because the previous one failed. Unfortunately, she found no progress with the treatment. She then decided to visit Murangan Hospital for a further check. The doctor still needed time to identify the sickness, and she needed to wait until the result came up. Waiting for the result, she went to Pustu (Puskesmas Pembantu) to get another medication and drank it for about a week, but she still found no improvement.

Finally, the doctor from Murangan Hospital asked her to come to find out her sickness, and she was diagnosed with extra pulmonary TB. She never thought that it would be TB, all she knew was it was just a lump. The doctor asked her again to visit on Saturday, five days from the time she was diagnosed, to perform surgery. She was a bit reluctant to do that. On the day of surgery, she found that her lump was reduced in size, and asked the doctor whether it was possible to turn down the surgery and take pills instead. The doctor suggested that the surgery was necessary so that the lump may not come again. She was worried because she believed that through surgery, wind will enter the body so easily, it will enter through the skin that was torn during surgery. It will have an impact on her health; another sickness can come anytime, without protection because of the wound. After the surgery, she attended the previous Puskesmas and received the medication from them.

Throughout the entire process of searching for medication, AJ was depending on western medicine, this was happening because she was also treated for other illness, such as stroke, and cardio problems. She found that she is more familiar with the doctors, she knew them well. In addition, she hadn't found any difficulties in accessing the health care because it was fully covered by insurance.

4.7.3 Medication in TB illness experience

Medication in TB is needed to take a long period of time. The medication involves a combination of medicines which are believed effective to cure sickness. In response to that it is important to understand the elderly female patient's own perception toward duration of medication, side effects, and concerns. The medication of elderly female TB patients is influenced by perceived medication side effects, time to take medication, and discomfort resulting from medication. Furthermore, fear of failing to continue or skipping the medication is associated with repetition in treatment. In addition, the elderly female TB patient also develops self-motivation as part of her management of the symptoms. This aspect has also shown that the elderly are capable of dealing with their illness, understanding the side effects through their experience, and are capable of making their own decisions.

I have started my medication...however I feel dizziness, headache, nausea, like this morning, when I do some work I felt like I'm about to pass out, fall, and most of the time I just sit, make me lazy, this headache keep coming, I feel discomfort...Well actually when the medication is the same I might easy to get bored. The only thing that make me to force me to follow this medication because the nurse told me if I fail this medication, I need to repeat again the medication, so I tried to remember it every day. I even write it down on the wall of my house, so anywhere I go those reminder help me to focus with my medication and treatment. (Mrs. AJ)

I do not have particular assumption at that time. I only think that I should take the medicines, abide with role and not to skip it...ever since diagnosed with TB, I decided only to take the medicine given by Puskesmas, and not to mixed it with other medication or Jamu, I used to take a lot of Jamu to balance my body. The only concern in my mind was my urine color. It turned red, I was a bit shocked at that time, and asked myself. Will I urinate like this during the time of treatment? ...I was not informed that I need to attend six month of medication, with the first two month was intense, and I should not skip it. Every time I ask the doctor, when I will be finishing my medication, they just keep telling me not to think about how long the medication will take, just focus with the medication and if I want to get healed I

should follow what they said. ...I am uneducated woman (orang bodoh), illiterate (nggak sekolah), I only followed what the doctor said, and I will pay attention to it. If they asked me to do this, I will do it, if they asked me to do that, I will do that, too. Not to skip and late taking the medicine. (Mrs. AH)

4.7.4 Expected rules in illness experience

Experiencing TB illness also involves role expectations that need to be followed by the patients, such as the limitation of contact, separation of cutlery, and the expected role in attending the health service.

My daughter also reminded me, “Mom, don’t let yourself forget for checking, to take your medication and not to skip it. I know that you want to get cured mom, and be able to meet up with your children and your grand children. (Mrs.AH)

AJ’s concern over separation and limitation in meeting daily with a family member, as she believed family is also the source of motivation and support for her to get through this illness. Furthermore, severities to TB illness, perceived contagion affected her emotionally. While in AH’s experience, it was family who initiated limitations, and use to direct her attention mainly to complete medication.

4.8 Social context and its impact on TB medication and treatment

4.8.1 Women’s role and status, and illness experience

The AH case has also shown, a woman to hold multiple responsibilities in the family as mother, grandmother, housewife, involved in domestic work, and breadwinner tend to prioritize the needs of the family, while their own needs come in second. AH’s concern to provide daily food on the table raised attention to the vulnerability of the family that depends on her daily income.

Insecurity and less purchasing power will likely determine their decision in seeking health care, in particular, for the woman the vulnerability increases. Although TB medication is free, other supporting tests, which are not available at Puskesmas, may be a hindrance to the poor to fully access the health services. Furthermore, the illness experience cannot be separated from other health complaints.

This health complaint may not be simply needing particular medicines as treatment, but rather the need to be acknowledged as the source in its context and provide assistance in the care process.

4.8. 2 Stigma and TB illness

Stigma brings critical influence to TB illness, as its impact has a wider aspect on patient life, in the family and in the community. Stigma is also able to add a problem in the elderly female illness experience. Mrs. AH and Mrs. AJ believed tuberculosis was a contagious disease, easy to be spread out, and dangerous.

Mrs. AH tended to be reserved in her illness experience. Not because she didn't know what TB was, but rather she did this to avoid stigma which may attach to her family before. Mrs. AH recalled the history of the family, and mentioned one of her sons died of TB several years before. She knew exactly the condition of her son; she was there when he died. She took care of him while he was hospitalized. Her concern also revealed during interview that she was worried that a similar situation might occur to her. She did not expose this to others, only her close kin, family, and her mother who knows the situation.

This aspect also raised my attention, as she did not mention it at an earlier interview. However it helped to understand her decision in seeking health care. This personal subjectivity, self-blaming, and stigma intertwined and influenced her illness experience. Furthermore, not to disclose her illness was aimed to protect her family, and to save family face. Although she said that their close neighbors were not paying attention to their condition, a similar response in hamlet Sumerno may also be taking place in her village. There are many similarities in terms of culture, and her hamlet is very close to hamlet Sumerno. Mrs. AH did not disclose her illness because she was afraid of ostracism, this will impact on her daily income as a fried rice vendor and affect their business.

Similar to Mrs. AH, Mrs. AJ feels discomfort to disclose the illness to her colleagues. She feels that other may not understand the real situation of the illness, and judge it in the wrong way and exaggerate the illness. She is aware of the TB stigma, and prefers to stay at home and avoid her neighbors. She was raising concern over separation that was suggested by one of the health workers at Puskesmas. For

not being allowed to share the same cutlery or utensils at home, she felt like she is *jompo*, and symbolized this as similar to being an elderly person at the nursing home, with them being disconnected from their families. This aspect is critical to her, as support from the family such as through children and grandchildren motivates her in TB medication and treatment.

They asking me to separate all cutleries I use, I feel so offended. They explain it like I have lung TB. Why they treat me the same like people with pulmonary TB. Extra pulmonary is not contagious, it really bother me a lot. Why scared me with such statement, I feel myself like someone at the elderly housing or elderly institution, need to be separated from thing I know or love, I found it not pleasing in my ear (Mrs. AJ)

4.8.3 Treatment failure and consequences

Fear of failing in medication and treatment is placing another concern among the elderly female TB patients. They are suggested not to fail in their treatment, as failure could bring consequences, such as the repetition of treatment and longer medication.

Well, actually when the medication is the same I might easy get bored. The only thing that forced me to follow this medication was because the nurse told me if I fail this medication, I need to repeat again the medication, so I tried to remember it every day. I even write it down on the wall of my house, so everywhere I go those reminders help me to focus with my medication and treatment. (Mrs, AJ)

This consequence also extends such as in over protection to elderly care. The elderly can be viewed as incapable of handling their own illness, not following suggestions, and being blamed as difficult.

To conclude, illness experience features multidimensional aspects that are influenced by the personal and external. The elderly TB experience is not merely solving the germ, control the host, or adjusting the environment. Beyond that it includes the personal experience of TB, the socioeconomics of patients, culture,

individual perceptions about TB, and subjectivity in its treatment and medication. Neglecting the individual's illness experience will affect their treatment and medication process.

CHAPTER V

DISCUSSION, CONCLUSION AND RECOMMENDATION

5.1 Conclusion

This research aimed to understand the ways in which social context such as ageism, the social stigma of TB, and the health care context exist among elderly female patients. Furthermore, it sought to understand the illness experience exists under social context, and how social context influences the illness experience, which can impact upon treatment and medication.

Tuberculosis is not a new problem, up to this present date. It affects a variety of people regardless of their gender, age, and background. By age, in particular for the elderly population, TB appears as a silent killer; as it may impend and become active at a later age, and immunosuppression may increase vulnerability to infection and other factors that contribute to sickness. Learning from hamlet Sumerno, I have learned that the rural community level views TB as a deadly disease, contagious, and one that needs persistent treatment to eliminate the sickness. Sometimes it even demands various forms of extra care and medication to be integrated into the healing process. The fact that TB is not simply a germ makes this issue one beyond the biological or medical sphere, but one that also has a social aspect on human life that makes TB a special phenomenon. This social aspect is intertwined in complexity of illness experiences of the patient. Through the findings it is suggested that social context in elderly female TB patients is intertwined with ageism, stigmatization, and can influence TB treatment and medication.

The health of the elderly cannot be separated from their being male or female. Being female in the context of being Javanese and ill at the same time employs complexity, which bonds to every dimension of being a woman. The illness experience may not be simply determined as a physical disorder by dichotomizes other aspects that seem personal and individual; by neglected and subsided such encounter experience as it presents during the entire process of illness.

Culture to some extent contributes to the making of women's illness experiences. For elderly females in the context of village Sumerno, what they have learned in the past resonates in their present lives. It is entangled and resides in the elderly female being. The cycles of life of rural women in the past have been repeated constantly, and are revolving at the same time as it presents challenges as well with changes and new ideas. Their worldview may not be expected to be idyllic by today's generation; however, what they have believed previously has carried essential value that is important to make their life sustainable. The current generation may not understand this, as gap between them has been constructed and has walled off differences between the two generations.

A misconception on ageing is related to how the younger people view the physical situation, cognitive functioning, and emotional state of the elderly. Ageism is employed in the form of language and norms, which have infiltrated into communal perception, and become generalized and stereotyped. This situation extends and influences the caregivers and health workers in providing assistances to female elderly. Misconception also generated in stereotyping elderly character and attitude, which is belief ascribed in the ageing process. For instance, a male patient is more difficult to handle and female patients are more submissive and tend to abide by rules in medication and treatment. This is done by consolidating the efforts between health workers and caregivers to the elderly's TB treatment and medication.

On the other hand, the elderly, too, have developed strategy for dealing with their illness. Cultural influences have also influenced the individual decision to seek care, where personal perception toward illness, preferences on medication, and choice about whom is able to assist in illness and discomfort comes into paradox and intercedes in medical and public health expectations in treatment and medication. It also reveals the reality that an elderly person is an independent individual who is capable of making his or her own judgments to seek out care by treatment and medication by developing mechanisms to encounter illness, which might be misunderstood by the caregiver or health worker.

5.2 Discussion

5.2.1 Social context and illness of the female elderly

Ember and Ember (2004) suggested that disease is not merely the direct result from a pathogen or physiological disturbance, but instead is derived from various multiple social problems such as political powerlessness, sexism, and gender inequality. The problem of TB among the elderly female also needs to be traced from how culture, poverty, and power shape disease and reflect on female elderly health seeking behavior and illness experiences.

Poverty is well known for women who delay care and who attend health services (Tungdim and Kapoor, 2010; Benatar and Upshur, 2010). Among elderly rural women in hamlet Sumerno, access to health care is related to type of resources and income. Their amount of income is also tied to support from family and the availability of social security for the elderly. For those who depend upon a daily income for subsistence and whose resources are limited, it is more likely that they will delay seeking care. It is also often true that elderly females will have to depend completely on their family because their frailty and disabilities have made them become more vulnerable, so more of the decision to access health care depends on the caregiver. Social security does not necessarily bring instant benefit as well for the needy, as bureaucracy sometimes is a hindrance to access for them, because they may have only incomplete ID documentation.

In term of care, generalization to care service is influenced by the elderly female's view toward the health care service. An insensitive gender approach will likely hinder elderly women to openly mention their health problem specifically. Furthermore, generalizations about the elderly condition can cause other complaints to be viewed as medically related problems, and somatization of complaints will end up in the medicalization of illness complaints, which do not benefit the elderly females and could bring harm to them.

5.2.2 Ageism and medical hegemony of TB treatment and medication for elderly female patients

As previously mentioned, side effects are one of the more important aspects in taking medicine for the elderly. The additional discomfort that comes as a result of medication is viewed as a disadvantage. Health complaints becomes multiple, and it is often physicians who tend to treat this discomfort with another type of medicine, which ends up with the patient taking more medicine than she should, which may lead to boredom or worse. These side effects also affect the daily activity of the female elderly, because of fatigue, dizziness, and the changing color of urine related to the side effects of the medications.

Furthermore, the information given about medication is not fully understood by the elderly female, simply because the information they are given is limited. This is aside from the fact that information is critical for the elderly to recognize and acknowledge side effects and how they are able to prepare, adapt and adjust to the medication. It is often the case that medicine explanation focuses on the use, not the users, such as in the proper administration of pills, how many should be taken daily, etc. without an clearly definition of the known likely side effects of each of the pills. Furthermore, it may not also be explained to them about each particular type of medicine; instead, the pharmacist usually explains the function by the color of the pills.

The TB patients do have not clear information about what will happen with their bodies if they are taking medicines, in particular, if the medication should be taken for a longer period of time. To demand that female elderly patients simply follow their advice is the suggestion, and depending on the knowledge of physicians and health workers is inadequate. Furthermore, the individual subjectivity during treatment and test should be explored comprehensively in order to understand individual opinion toward treatment and its impact after a test is conducted or a treatment is followed. For instance, personal belief in the efficacy of a biopsy or the performance of a surgery has an influence on identifying and treating extra pulmonary TB.

5.2.3 Misconceptions of ageing and female elderly TB illness

The individual care seeking behavior shows that elderly women are capable of handling their own health situation. They are indeed able to decide what is best for their illness experience. Their capabilities are involved in developing strategy to relieve discomfort or to cure the illness. Although their methods are not linear to biomedicine, it reflects the reality that western medicine is not the sole health system that affects elderly female TB patients. The lay knowledge on health also needs to be viewed in its context, instead of as an aside as a mistake or unscientifically. It should be understood as a different mechanism that works simultaneously and engages in many different aspects of the illness experiences of elderly female TB patients. This aspect is also critical for home visitation, information and educational communication of the illness.

Furthermore, elderly women patients tend to be reserved and subtle in order to understand the whole picture of illness. They often are not focused upon the causal as it has already happened, but they observe and collect information so that they may be able to cope with their discomfort and illness. At the same time, they also need to digest the information concurrently with the knowledge gained. They also compare the information they have received, share and ask for opinion from others in order to adapt with the medication. To some extent this may lead to the decision to drop a previous medication, such as *jamu*, and focus on TB medication, or have a combination between the two. This process of managing the illness by the elderly female patient involves compromising belief, perceived symptoms and decisions. Thus flexibility and fluidity become characteristics of the individual seeking care.

The above argument provides evidence that the elderly female TB patient is able to understand TB itself. Therefore, prejudice and misconception that the elderly are less able to care for their illness is proven to be false. This also implies that such misconception needs to be reduced by understanding the illness experience in the female elderly TB patient holistically. Furthermore, health complaints of the elderly female are not necessarily a matter of abnormalities of the body, but also psychological and social aspects of ageing that are intertwined in the illness of female elderly TB patients.

5.2.4 TB stigma and elderly female illness experience

Stigma is widely reported as one of the main causal elements for women to delay and drop medication to TB. A study by Johansson, Long et al. (1999) suggested that sensitivity to interaction with health staff and stigma in society (poor quality health staff and system compliance) were reported as the main obstacles among women to attend health care. A study in Pakistan associated depression of elderly female TB patients to be related to TB stigma (Muhammad Anwar Sulehri and Sheraz Javed 2010). Similarly, TB stigmatization occurs and influences the elderly female. This situation is also intertwined with ageism. The elderly woman is reluctant to disclose her TB status because it may affect her family. By doing this, she can save face for the family. Furthermore, in some cases to disclosure illness may negatively affect an elderly female's family business and thereby impact their livelihood.

5.2.5 Hybridity of elderly female individual health seeking behavior

Although individual health seeking care is considerably scattered and cannot be generalized as an overall health seeking care pattern, its complexity reveals that the illness experience is unique, personal, and involves human life as whole. It cannot be simply determined as a lung problem, organ abnormalities, or an agent of disease transmission. Tuberculosis and its problems work in two cultures, namely, traditional medicine and western medicine, and the hybridity of these cultures operates in parallel, where individual illness is shaped by these two cultures; therefore, neglecting one or the other brings repercussions not only for the patient, but also to the population in general.

The concept of *jodo* or match exists as individual mechanism to encounter sickness. Its basis lies in some consideration such as knowledge, experiences, recommendations, and sources of knowledge, which will be able to be used in managing illness. These considerations also are affected by the concept of harmony of body and nature, and that an imbalanced body condition is reflected as disharmony. Therefore, lay people can come up with irrational relationships and illogical reasons for illness, unfounded beliefs and values, and unexpected perceptions toward treatment and medication.

The concept of *jodo* (match) can be found in any culture. Yuniar (2010) studied the slum area in Depok, West Java, Indonesia and suggested the word “*cocok*”, which means *jodo* in bahasa and is used to interpret the efficacy and compatibility of medicines. She also quotes similar term in the Philippines as “*heyang*” and in Sri Lanka “*behet ahanava*” (cited in Yuniar 2010). The concept of *jodo* in hamlet Sumerno reveals that the individual seeking care is working in every step of the care seeking process, including attempting to find the right person to cure the illness, the right treatment, and the proper medication. The process may involve many steps and many curers until the person feels comfortable enough with the treatment and feels well matched with the medication. In the process of searching for medication, several possibilities might occur, such as diversion in medication, repetition, or even termination of treatment at any time by the patient.

This individual seeking care also evolves as more information is obtained, and each symptom identified carefully. The decision to choose a type of treatment or medication is determined by its efficacy, effectiveness, personal subjectivity in illness, and type of resources owned by the patient. The information gained is used to develop individual self-knowledge, which likely will be used in treatment and medication. If this knowledge base is influenced by traditional beliefs, it is likely that the person will seek traditional care (Whittaker, 2008).

Likewise, the severity of illness is seen through perceived acute and chronic sickness that defines the types of medication they choose for illness treatment. For example, in the case of *sakit kambuhan* (repeated sickness) and *sakit ringan* (mild sickness), the use of *jamu* can be prevalent. Multiple health complaints, such as body pain, fatigue, loss of appetite, is believed to be treated better with *jamu*, like the idea of balancing body, and relaxing muscle stiffness.

The efficacy and compatibility in medicine among the elderly in hamlet Sumerno is influenced by personal perceptions toward the strength and lightness of medicines, their effects on the body and whether it will cause harm or not, perceived toxicity, and period of treatment they should take, and types of medicines they should use during medication.

The elderly hold the belief that taking western medicines for such a long period will harm the body. This perception is also drawn from they way elders view

health as overall and holistic. Illness is not merely abnormalities or disorders to organ function; it reflects integration between the living body, nature, the environment and faith. Health is not about the absence of sickness, but harmony with the living, to themselves, to others and to the nature; thus, disharmony is imbalance in one of these aspects and leads to illness.

The idea of strong and light medicines is also intervening with elders' views about taking western medicines. They believe chemical medicine or pills will have an effect if it is consumed for a long period of time. They consider one week of medication as the strongest time when a medication will take its effect on the body, so some elders prefer injections as they have the belief that it will have an instant impact in relieving illness discomfort. This injection is taken one time, and they combine it with traditional medicine (*jamu*) to balance the body condition. A similar situation occurs after taking pills for a week.

Harming the body is also another aspect that elderly consider in their medication. They are concerned over frailty and disability, and self-ageism influences elders' perception as well, thus being old is view as *jompo*, the body becomes fragile. Therefore, they believe that taking medicines for a longer period of time will exacerbate instability of their body, and they will become weak and vulnerable to other illness. This also relates to the way the elderly feel the side effects of medication, which they believe brings other disadvantage to their health, and could add up to a problem instead of reducing discomfort from illness. Furthermore, the extended time of medication will accumulate chemicals and poisons in the body, and this subjectivity frames fear and concerns in elderly ageing condition.

The prevalent use of *jamu* among the elders in rural area of Yogyakarta needs to be traced in the personal history of illness and their experience in taking traditional medicine. Traditional medicine is believed to have fewer side effects, and is healthier as it comes from natural ingredients. They have seen the efficacy through experience and time, as *jamu* is part of their traditional heritage that has been passed on through generations.

5.3 Recommendations

In this part the research recommendations and other recommendations for involved parties will be explained in detail.

5.3.1 Research recommendations

1. Despite some similarities that have been found concerning illness experience tuberculosis among the elderly female patients, this research was conducted in a very small area, so the findings cannot be easily generalized to other areas. The ethnographic methods used in this research are part of the anthropological approach that is suitable to understand the social context of illness experience and the impact of medication and treatment of the elderly female patient. However, more thorough research needs to explore the influence of the social context of TB impact on the caregiver, in particular when accompanying the elderly to provide support for their illness.

2. Further research is also needed to explore comparative perceived ethno medicine among elderly TB patients, and its impact on the illness experience.

3. The research that I conducted was focused upon the elderly female TB patient during two months of treatment; the limitation of this approach is that the illness experience is not thoroughly recorded until treatment and medication is completed, which would be able to help us understand the coping process in illness experience in detail.

5.3.2 Recommendations for the health professional and policy maker

1. TB treatment among elderly females should also be based from illness experience. Understanding TB holistically will likely lead to success in the TB program. It helps the patient and the health worker at the same to effectively reach the purpose of medication and treatment.

2. Understanding individual health seeking care will help to identify risk and challenge in establishing a TB program at the household and community level, and at the same time provide the opportunity to explore a suitable approach to maximize TB eradication.

3. Providing comprehensive information in helping the patient to deal with their illness experience will benefit the elderly female in coping, adjusting and adapting. Thus, information and education should be based on helping the elderly to address challenges, fears, and expectations of the treatment and medication.

4. A support group for TB patients is one of the aspects that will help patient to cope with the challenges and obstacles during treatment and medication. Providing the chance for the patient to meet, share, and encourage one another will help to eliminate stigma, prejudice, and misperception of TB and ageing. This will benefit the patient, and support for the TB program and maximize outreach and home visitation.

BIBLIOGRAPHY

- Ahmad, R. A., Y. Mahendradhata, et al. (2011). "Diagnostic delay amongst tuberculosis patients in Jogjakarta Province, Indonesia is related to the quality of services in DOTS facilities." Trop Med Int Health **16**(4): 412-423.
- Allotey, P. and M. Gyapong (2008). "Gender in tuberculosis research." INT J TUBERC LUNG DIS **12**(7): 831-836.
- Baer, H., M. Singer, et al. (2003). Medical anthropology and the world system. Westport, Connecticut, London, Praeger.
- Benatar, S. R. and R. Upshur (2010). "Tuberculosis and poverty: what could (and should) be done?" Int J Tuberc Lung Dis **14**(10): 1215-1221.
- Bengston, V. L., N. M. Putney, et al. (2005). "The Cambridge handbook of age and ageing : Problem of theory in gerontology today." 14-15.
- Biesta, G. J. J. (1998). "Mead, Intersubjectivity, and Education: The Early Writings." Studies in Philosophy and Education **17**(2): 73-99.
- BPS (2010). BPS Report 2010. Indonesia
- Cambanis, A., M. A. Yasin., et al. (2005). "Rural poverty and delayed presentation to tuberculosis services in Ethiopia". Tropical Medicine and International Health Vol.10 (4):330-335, DOI: 10.1111/j.1365-3156.2005.01393.x
- Chand N, Bhushan B, Singh D. Tuberculosis in the elderly (aged 50 years and above) and their treatment outcome under DOTS. Chest. 2007;132:640b-640.
- Cohn D. L., F. Buestro, (1997). "Drug-Resistant Tuberculosis: Review of the Worldwide Situation and the WHO/IUATLD Global Surveillance Project". Clinical Infectious Disease, Vol.24(1):121-130.
- Darlington, Y. and D. Scott (2002). Qualitative research in practice, Stories from the field, Allen & Unwin.
- Dimitrova, B., D. Balabanova, et al. (2006). "Health service providers' perceptions of barriers to tuberculosis care in Russia." Health Policy and Planning **21**(4): 265-274.

- Ember C. R and M. Ember, (2004). *Encyclopedia of Medical Anthropology*, New York, Springer US: 23-30.
- Estes, C. L. and E. A. Binney (1989). "The Biomedicalization of Aging: Dangers and Dilemmas." *The Gerontologist* **29**(5): 587-596.
- Farmer, P. (1999). "Pathologies of power: rethinking health and human rights." *American Journal of Public Health* **89**(10): 1486-1496.
- Fry, R. S., K. Khoshnood, et al. (2005) "Barriers to completion of tuberculosis treatment among prisoners and former prisoners in St Petersburg, Russia". *The Int. Journal of Tuberculosis and Lung Disease*. Vol.9(7):1027-1033.
- Goffman, E. (1963). *Stigma: notes on management of spoiled identity*, Prentice-Hall: Englewood Cliffs.
- Helman, C. G. (1990). *Culture, Health and Illness, An Introduction for Health professionals*. London, Boston, Butterworth-Heinemann Ltd.
- Irawati, S. R., C. Basri, et al. (2007). "Hospital DOTS linkage in Indonesia: a model for DOTS expansion into government and private hospitals." *The International Journal of Tuberculosis and Lung Disease* **11**(1): 33-39.
- Joan E, P. (2004). "A social disease/a social response: lessons in tuberculosis from early 20th century Chile." *Social Science & Medicine* **59**(4): 763-773.
- Johansson, E., N. H. Long, et al. (1999). "Attitudes to compliance with tuberculosis treatment among women and men in Vietnam." *The International Journal of Tuberculosis and Lung Disease* **3**(10): 862-868.
- Katz, S. (2000). "Busy Bodies: Activity, aging, and the management of everyday life." *Journal of Aging Studies* **14**(2): 135-152.
- Kaufman, S. R. (1994). "Old Age, Disease, and the Discourse on Risk: Geriatric Assessment in U.S. Health Care." *Medical Anthropology Quarterly* **8**(4): 430-447.
- Kaufman, S. R. (1994). "The social construction of frailty: An anthropological perspective." *Journal of Aging Studies* **8**(1): 45-58.
- Keasberry I, N. (2002). "Elder care, old-age security and social change in rural Yogyakarta." *Ph.D Thesis*.

- Kelley-Moore, J. A., J. G. Schumacher, et al. (2006). "When Do Older Adults Become "Disabled"? Social and Health Antecedents of Perceived Disability in a Panel Study of the Oldest Old." Journal of Health and Social Behavior **47**(2): 126-141.
- Kementrian Kesehatan Republik Indonesia (2010). Pedoman Nasional Penanggulangan Tuberculosis, 2nd Edition.
- Kidd, R., S. Clay, et al. (2009). Understanding and challengeing TB stigma, toolkit for action, Alliance publication.
- Kleinman, A., L. Eisenberg, et al. (2006). "Culture, Illness, and Care: Clinical Lessons From Anthropologic and Cross-Cultural Research." Focus **4**(1): 140-149.
- Kohli, M. and J. W. Meyer (1986). "Social Structure and Social Construction of Life Stages." Human Development **29**(3): 145-149.
- Korzeniewska-Kosela, M., J. Krysl, et al. (1994). "Tuberculosis in Young Adults and the Elderly." Chest **106**(1): 28-32.
- Lafontaine, C. (2009). "Regenerative Medicine, Immortal Body: From the Fight against Ageing to the Extension of Longevity." Body & Society **15**(4): 53-71.
- Liefooghe, R., N. Michiels, et al. (1995). "Perception and social consequences of tuberculosis: A focus group study of tuberculosis patients in Sialkot, Pakistan." Social Science & Medicine **41**(12): 1685-1692.
- Lock, M. (1984). "Licorice in Leviathan: The medicalization of care for the Japanese elderly." Culture, Medicine and Psychiatry **8**(2): 121-139.
- Lock, M. (2004). Encyclopedia of Medical Anthropology, Health and Illness in the World's Cultures. New York, Kluwer Academic/Plenum Publishers.
- Lyman, K. A. (1989). "Bringing the Social Back in: A Critique of the Biomedicalization of Dementia." The Gerontologist **29**(5): 597-605.
- Miller, B., M. Glasser, et al. (1992). "A paradox of medicalization: Physicians, families and Alzheimer's disease." Journal of Aging Studies **6**(2): 135-148.
- Muhammad Anwar Sulehri, I. A. D., Hamza Sohail, Zain Mehdi, Muhammad Azam, Obaid Niaz, M. and I. A. S. Sheraz Javed, Zahid Iqbal (2010). "Prevalence of Depression Among Tuberculosis Patients." A.P.M.C Vol: 4 No.2 July-December 2010.

- Neyrolles, O. and L. Quintana-Murci (2009). "Sexual Inequality in Tuberculosis." PLoS Med **6**(12): e1000199.
- Niehof, A (1995). "Ageing and the elderly in Indonesia; Identifying key issues". In: Bijdragen tot de Taal-, Land- end Volkenkunde 151 (3): 422-437
- Nshuti, L., D. Neuhauser, et al. (2001). "Public and private providers quality of care for tuberculosis patients in Kampala, Uganda." The International Journal of Tuberculosis and Lung Disease **5**(11): 1006-1012.
- Palmore, E. B. (1999). Ageism: Negative and Positive. New York. Springer
- Paul, F. (1997). "Social scientists and the new tuberculosis." Social Science & Medicine **44**(3): 347-358.
- Perlman, D. C., N. Salomon, et al. (1995). "Tuberculosis in Drug Users." Clinical Infectious Diseases **21**(5): 1253-1264.
- Russel, S. (2004). "The Economic Burden of Illness For Households In Developing Countries : A Review Of Studies Focusing On Malaria, Tuberculosis, And Human Immunodeficiency Virus?Acquired Immunodeficiency Syndrome " The American Journal of Tropical Medicine and Hygiene **71**(2 suppl): 147-155.
- Scheper-Hughes, N. and M. M. Lock (1987). "The Mindful Body: A Prolegomenon to Future Work in Medical Anthropology." Medical Anthropology Quarterly **1**(1): 6-41.
- Singer, M. (2004). Critical Medical Anthropology in Encyclopedia of Medical Anthropology. New York, Springer 22-30.
- Sing, V., A. Jaiswal, et al. (2002). "TB control, poverty, and vulnerability in Delhi, India". Tropical Medicine and International Health, Vol. 7 (8):693-700DOI: 10.1046/j.1365-3156.2002.00909.x
- Somma, D., B. E. Thomas, et al. (2008). "Gender and socio-cultural determinants of TB-related stigma in Bangladesh, India, Malawi and Colombia [Special section on gender and TB]." The International Journal of Tuberculosis and Lung Disease **12**(7): 856-866.
- Stokstad, E. (2000). "Drug-Resistant TB on the Rise." Science **287**(5462): 2391.
- Sumartojo, E (1993). "When tuberculosis treatment fails. A social behavior account of patient adherence". Am Rev Respir Dis May; 147(5):1311-20.

- Thompson, P. (1992). "I Don't Feel Old': Subjective Ageing and the Search for Meaning in Later Life." Ageing & Society **12**(01): 23-47.
- Tinker, A. (2002). "The social implications of an ageing population." Mechanisms of Ageing and Development **123**(7): 729-735.
- Tungdim and Kapor (2010). "Gender Differentials in Tuberculosis: Impact of Socio-Economic and Cultural Factors Among Tribals of Northeast India" The Open Social Science Journal, 3: 68-74
- Van Den Brande, P., J. Vijgen, et al. (1991). "Clinical Spectrum of Pulmonary Tuberculosis in Older Patients: Comparison With Younger Patients." Journal of Gerontology **46**(6): M204-M209.
- Vertinsky, P. and S. Cousins (2007). Acting your age: Gender, aging, and physical activity., Oxfrord Univeristy Press.
- Vincent, J. A. (2006). "Ageing Contested: Anti-ageing Science and the Cultural Construction of Old Age." Sociology **40**(4): 681-698.
- Whittaker, M (2002). "Negotiating Care : Reproductive tract infection in Vietnam" Women and Health, 35: 43-57. http://dx.doi.org/10.1300/J013v5n04_04
- Young, R. F. (1994). "Elders, families, and illness." Journal of Aging Studies **8**(1):1-15.
- Yuen-man, S. (2008). "The SARS-Associated Stigma of SARS Vistims in the Post-SARS Era in HongKong." Qual Health Res **18**: 731.
- Yuniar, Y. (2010). "Medicines use among children under five years old with acute respiratory infection (ARI) : an anthropological study in an urban slum area of Depok Municipality, Indonesia " Mahidol University , Master Thesis.
- Zignol, M., M. S. Hosseini, (2006). "Global Incidence of Multidrug-Resistant Tuberculosis". The Journal of Infectious Disease. Vol.194(4): 479-485
Doi: 10.1086/505877
- Zuniga, J. A. (2012). "A woman's lived experience with directly observed therapy for tuberculosis-a case study." Health Care Women Int **33**(1): 19-28.

APPENDIX

INTERVIEW AND OBSERVATION GUIDELINE

I. Interview guidelines for informants

1. Introduction

- Observe and look around situation, and choose appropriate condition in approaching informants
- Explain the purpose of interview
- Ask for their consent upon initial interview process by sign in informed consent after informants agree to participate in the interview. If the condition is not suitable for signing consent, ask for an oral inform consent.
- Interview is conducted in volunteer manner, and not by force
- The interview should be done in proper ways, where informant find it comfortable, in their convenience, appreciate their space and private life, and by taking initiative to be part of the activity while the interview take place
- To interview less than an hour for each and the rest can be done informally
- Ask permission to take a picture and record the interview

2. Demographic data

Personal (socio-demographic data) of the informant, these data will be asked indirectly during interview process:

- Age
- Educational background
- Occupational background, income (not necessarily to be answered)
- Informant spouse occupational background
- Daily/periodically expenditures of informant in order to understand how she support long treatment in tuberculosis
- Environmental and social networking of elderly female TB patient

- Historical background (where she is originated from; why she live in current place; why they decide to stay at current place; how long she has been staying at current place; will they stay in other place because of their treatment and medication)
- Type of housing (rental, private residence, institution) and observe the housing (draw a picture)

3. Semi – structure interview for health personnel

- Explore tuberculosis process for elderly women from the first of diagnosing until finishing treatment and medication
- Explore from health personnel understanding (through their experience) about elderly female TB patient belief about their illness, cause of illness
- Explore from health personnel what are the difficulties for elderly female TB on attending tuberculosis treatment at hospital
- Explore from health personnel (through their experience) how the elderly female patient perceived on DOT
- Explore what are the social support provided by hospital and others to elderly female TB patient
- Explore TB care service delivery that gender sensitive toward TB treatment and medication

4. In-depth Interview for elderly women TB patient

- a. Perceived TB symptoms, etiology, and severity
 - Explore tuberculosis problem among elderly women from the first of diagnosing by probing the symptoms
 - I know it is hard to understand TB symptoms, in your opinion how this symptoms showed and affect you? Please describe. How bad it is?
 - Explore what elderly female TB patient belief about their illness, cause of illness, enquire until information is clear enough

In your opinion what caused your illness? Why you get this illness? (Does this illness resulted from her behavior or affected by other, or because of other things), what do you feel when you are diagnosed with TB?

b. Perceived treatment and medication of tuberculosis (DOTS)

- Explore elderly female TB patient perceived on tuberculosis treatment at hospital

Dealing with TB treatment can be difficult, what do you think about it? Did you get your test properly? What test to help diagnosing your illness? (Identifying type of test such as Tuberculin test, sputum smears microscopic, chest X-Ray, other test) Does this test simple for you? How many times you test for diagnosing?

Being a TB patient need along treatment, how do you feel about long treatment? Did you get information that helps you to understand this illness? Please describe. Do you get information about treatment you need, the outcome of treatment and how this treatment help you overcome your illness?

- Explore elderly female TB patient perceived on TB medication (DOTS)

Following medication is critical to cure your illness; do you understand about this? What are the challenges for you to follow this medication? After taking this medication, what do you feel about your illness? Did you stop taking your medicines sometime? Or forget to take? Is there any one helps you in taking this medication? Are there any other medication beside TB medication that your are taking at the moment?

When you get your medication from pharmacist how do they react toward you? Do they assist you in taking medication? Do they give information about your medication?

- Explore the social support from hospital and others to elderly female TB patient

When you are taking this treatment and medication, do you get any support from health worker, doctor, nurse, or pharmacist?

How about your family, are they supporting you in following the treatment and medication?

What are the challenges if you don't have support in following this treatment and medication?

Did the hospital also have home visit scheduled for you? What do you think about the role of health worker in helping you by monitoring your illness?

c. Gender sensitive of TB care service delivery for elderly female TB patient

- Explore elderly women TB patient gender sensitivity perspective toward TB treatment and medication, their opinion and thought

Being a woman to follow this treatment, do you feel that you find any differences between you and male patient?

When you attend for test do the health worker have certain consideration or different approach toward you? To an elderly woman, how they react toward you?

When you receive and acknowledge diagnose, does the health worker (doctor, nurse, health volunteer, lab technicians, pharmacist) react differently toward you?

When you ask information from the health worker, what are the reaction/answer toward your question? Are they tried to shorten information or they give you detail information that have women approach in it? (For example referring to women health worker; how women get deal with this illness, possible obstacle when dealing with treatment and when exposing the illness to others)

When you follow medication, do the health worker giving different reaction toward you because you are women? Is it in good way or bad ways?

If they have other women's health problem do you also get treatment at the same place or you need to go to other place? Please describe?

Do they provide counseling after initial diagnose, during treatment and medication?

What do you think about doctor-patient relationship, does that important for you?

- Explore women own opinion about gender sensitivity in TB care delivery

In your opinion after going through the process of treatment and medication, what are the best ways for health worker to deal with elderly female TB patient?

Does the counseling service help women need particularly to elderly female patient?

What are the best ways to help elderly women TB patients going through the process of treatment and medication?

Do you think to have one stop service for elderly women are important to assist you during this long treatment?

d. Understanding TB care service delivery affect elderly TB female patient treatment and patient's satisfaction

- Explore elderly women TB patient satisfaction in TB care delivery

Being experiencing treatment and medication, in your opinion, how each phase of treatment able to help you to complete medication?

Are you satisfied with TB care service for you? (Doctor-patient relations, TB tests, assisted in medication (DOTS) from nurse, pharmacist, counseling services, POSYANDU LANSIA service)

In what way they satisfied you?

Which processes of care delivery in your opinion that satisfied you? Which one is not, and your suggestion for better care?

5. Focus group discussion for elderly (male and female)

The following are question guidelines for focus group discussion:

- Explore elderly opinion about ageing
- Explore elderly opinion about tuberculosis
- Explore their opinion about tuberculosis causation
- Explore what elderly belief about tuberculosis illness
- Explore elderly perceived on tuberculosis treatment
- Explore elderly opinion about tuberculosis among elderly
- Perceived on tuberculosis medication (DOT), Do they know?

- Explore the social support from hospital and others to elderly patient with tuberculosis
- Explore elderly TB patient gender sensitivity perspective toward tuberculosis treatment and medication

II. Observation Guidelines

Location: Informant houses and surround, community health center, integrated health post for elderly and hospital.

- Observe the living condition of informant and surround
- Housing condition of informants
- Observe informants process to visit hospital, community health center or integrated health post
- Observe the medication intake (DOTS) or other medication along with TB medication
- Observe patient process in sputum smear or other type of TB test
- Observe patient process in obtaining medicines from pharmacist
- Observe house visit for patient home care

Basic information of informant

Group 1: Elderly female FGD and In-depth interview (*)

No	Name	Age (Years)	Occupation	Education	Living arrangement
1	Mrs. A*	66	Farmer	Elementary	Own house
2	Mrs. B*	70	Public service pension	Senior high school	Own house
3.	Mrs. C*	83	Housewife	Non	Own house
4.	Mrs. D*	68	Cook, food seller	Senior high school	Own house
5	Mrs. E*	69	Farmer	Senior high school	Own house
6	Mrs. F*	72	Farmer	Non	Own house
7	Mrs. G*	60	Fish Seller	Senior high school	Own house
8	Mrs. H*	75	Farmer	Elementary	Own house
9	Mrs. AH*	60	Food vendor		Own house
10	Mrs. AJ*	67	Retire		Own house

Group 2: Elderly male FGD and in-depth interview (*)

No	Name	Age (Years)	Occupation	Education	Living arrangement
9	Mr. I*	60	Construction worker	Junior high school	Own house
10	Mr. J*	62	Farmer	Junior high school	Own house
11	Mr. K	80	Farmer	Non	Own house
12	Mr. L*	71	Farmer and construction worker	Senior high school	Own house
13	Mr. M*	73	Construction worker, farmer	Non	Own house
14	Mr. N	74	Public service pension	Senior high school	Own house
15	Mr. O*	67	Traditional healer	Senior high school	Own house
16	Mr. P	74	Farmer/fish seller	Elementary	Own house

Group 3: Adult age 35-56 FGD

No	Name	Age (Years)	Occupation	Education	Living arrangement
17	Mr. Q	42	Farmer	Senior high school	Cohabitation with parents
18	Mr. R	39	Farmer	Senior high school	Own house
19	Mrs. S	56	Farmer	Junior High school	Own house
20	Mr. T	50	Construction worker	Senior high school	Own house
21	Mr. U	46	Building contractor	Senior high school	Cohabitation with parents
22	Mr. V	39	Public service worker	Senior high school	Cohabitation with parents

Informants for Semi-structure interviews

No	Name	Age	Occupation
25	AA	27	Health worker
26	AB	47	Health Worker
27	AC	29	Health Worker
28	AD	33	Health Worker
29	AF	43	Health Worker
30	AG	45	Health Worker

BIOGRAPHY

NAME	Yudhanto Eddy Hastomo
DATE OF BIRTH	23 December 1978
PLACE OF BIRTH	Jakarta, Indonesia
INSTITUTES ATTENDED	Jakarta Doulos College of Theology, Indonesia (2004-2009) B. Th, (S. Th) Mahidol University (2011-2013) M.A. (Health Social Science)
SCHOLARSHIP RECEIVED	PPHBC and CCI
RESEARCH GRANT	PPHBC and CCI
HOME ADDRESS	Perum. Dutawacana No.2 Jl. Jambon II, Jatimulyo Yogyakarta, Indonesia Email : ed.hasto@gmail.com,
PUBLICATION / PRESENTATION	
AWARD RECEIVED	