Back to Childhood:

A Study on Urinary Incontinence Perception Among the Female Elderly in Jakarta

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SUMMARY

Urinary incontinence, the involuntary loss of urine so severe as to have social and hygienic consequences, is a major clinical problem and a significant cause of disability and dependency. It affects all age groups and is particularly common in the elderly. According to some geriatric literature, at least 15 to 30 percent of non-institutionalised and over 50 percent institutionalised elderly have some loss of bladder function. However, the issue remains relatively under-researched, particularly in developing countries like Indonesia where aging has not yet become a priority of policy making.

It is therefore not surprising then if in the country where the fieldwork was carried out the national level data on urinary incontinence problem does not exist yet. However, according to some informants more and more people are complaining about their problem to their doctors so that the doctors can no longer neglect its magnitude. The increase of the social and economic status, especially of those living in big cities such as Jakarta has encouraged patients of younger age to search for medical treatment for the condition long considered normal. On the contrary, the incontinent elderly have often adapted to the problem by denying or ignoring it. Most of the core informants interviewed during the fieldwork had other health problems that they considered somewhat more serious. When they see their doctors they will focus more on their other problems and not on their incontinence. Moreover, the elderly tend to consider incontinence something normal for their age and does not need any medical intervention.

The objective of this study is to give an insight into how the incontinent female elderly perceive their condition and the social stigma that might be attached to it, and how they deal with both.

This thesis begins with a brief overview of the international trends in demographic aging and the situation at the national level. It then sketches out the problem of urinary incontinence among the female elderly and how this group of people perceives the health condition in contrast to the biomedical perception. The next part of the thesis deals with the daily consequences of the urinary incontinence that have to be faced by the sufferers and the stigmatisation that follows. The experiences of the younger group of sufferers will also be discussed to give a clearer picture of the problem caused by incontinence. The discussion will also touch on the discourse on the nature of dirt. This part shows that the ambiguous nature of dirt, as well as other social-economic factors, will influence not only the quality of care given by the family or caregivers, but also the idea of space shared by the incontinent people and others.

It must be stressed that the perception and implication of the urinary incontinence are highly variable and, as such, great care should be taken in generalising between the experiences of different groups of older people and between different settings.

Keywords: Urinary incontinence; Elderly; Care; Stigmatisation; Space; Dirt.
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Chapter 1

INTRODUCTION

1.1 Aging and the Problems of Health and Healthcare

Population aging indeed represents a triumph of social-economic development and public health. New medical technologies, including the creation of important drugs such as antibiotics that successfully eradicate various diseases provide the means to prevent death among the middle-aged and the aging and therefore increase life expectancy. In addition, the aging of the world population is also the result of the continued decline in fertility rates.

This phenomenon is not only common among the developed countries, which have been leading in population aging since the beginning of this 20th century; other parts of the globe, namely the developing countries where the pace and patterns of aging are without precedence, are silently dealing with this demographic change. According to the World Health Organisation document on Aging and Health Programme 1998, neither the demographic processes nor the social context in these countries has parallels in the experience of the developed countries. In other words, they will certainly face a tremendous challenge of an aging population in the very near future. This challenge, according to WHO, has four major dimensions i.e. demographic, epidemiological, socio-cultural and resource.

Demographic dimensions: While the population of the world grows at an annual rate of 1.7%, the population over 65 increases by 2.5% per year. The most rapid change of this demographic dimension is now seen in some of the developing countries with predicted increases of 200-400% in their elderly population over the next 30 years. In the developed countries—where the process of socio-economic development has proceeded in conjunction with an aging population—the benefits of development by way of an improved standard of living were shared across the majority of the population. On the contrary, in the developing countries many of those now surviving to adulthood and old age face a longer life of economic deprivation without social support (WHO: 1998).

Epidemiological dimensions: The demographic change in turn influences the alteration in the pattern of disease. Both in the developed and the developing world,
ischaemic heart and cerebrovascular diseases are the main causes of death in old age, followed by neoplasms and then respiratory diseases, largely pneumonia. However, in the developing countries infectious and parasitic diseases are still considered very serious in old age (WHO: 1998). This situation is likely similar to the situation in Indonesia. Aside from infectious and parasitic diseases, cardiovascular and respiratory diseases are also some of the major killers among the elderly. Furthermore, what is important is the fact that the last years of life are frequently accompanied by an increase in disability and sickness, although measurements of longevity do not necessarily indicate the burden of disease. At the individual level, the real crisis of aging is a personal crisis of day-to-day existence, a present reality faced by many older individuals and their caregivers. I will return to this point when discussing the social meaning of old age vis-a-vis the definition of aging applied both in medical and political realms.

**Socio-cultural dimensions**: The population change has a great impact on the socio-cultural dimension of aging societies. Traditional inter-generational relationships are rapidly disappearing along with the urbanisation process that particularly results in social dislocation of young and old, without adequate social security measures being in place. In industrialised countries the inter-generational relationships are built on a level of adequate material well being for both younger and older generations and ongoing economic transfers through public schemes or in the private sphere. In the meantime, in the developing countries there is likely to be a widening gap—both social and economic—between the generations. In many countries, the vast majority of the younger generation will lack the material resources to offer any significant support to the older generation.

**Gender dimensions**: This fourth dimension of aging population, i.e. the dimension of gender on the demographic transition, is often neglected. In the past, fertility control came about the same time as economic development and the education of women. In the field of family planning, development agencies have until recently underestimated the need for parallel, social and economic measures that benefit women. This dimension is thus very crucial because adult women will increasingly constitute the majority of elderly in most of the developing world (WHO: 1998).
Another factor that should be mentioned here is the persistence of poverty which, combined with aging in countries still tackling basic problems of development, creates a huge problem of welfare that has no precedent in the history of mankind (WHO: 1998). In some countries in sub-Saharan Africa and Latin America, according to a study of the World Bank in 1992, there are no real prospects of saving for old age. Even in countries with higher incomes, savings may not be secure over the long term or even remain in the country with increasing international capital transfers.

All these intertwined dimensions create a very complex situation to the world’s societies. The magnitude of the problem is very high that, according to Dr. Bernard Starr, Professor of Gerontology at the Marymount Manhattan College in a United Nations briefing on aging in 1998, the longevity revolution is indeed a revolution “comparable to other great revolutions of history, the Renaissance and the Industrial Revolution ... that transformed every aspect of life in this planet.”

Like other countries Indonesia is also in the middle of this silent revolution. All of the dimensions of population aging discussed above are also reflected in Indonesian society. Thanks to the increased life expectancy and the success of the family planning program, there has been a shifting in Indonesian demographic pyramid from the young population to older one (see Appendix 2). According to the 1971 Indonesian Population Census, the number of the elderly was 5.3 million or 4.5 percent of the total population. This number has been increasing from 8 million in 1980, to 11.6 million in 1990. The percentage has also been increasing from 5.5 in 1980 to 6.4 in 1990. The increase is projected to be 18.4 million (8.1 percent) in 2005, and 32 million (12.0 percent) in 2020.

As in many parts of the world, Indonesian women outlive men. The life expectancy for woman is 66.68 years, whereas for the man it is 62.84 years (BPS, 1998). Hence in the future there will be an increasing number of elderly women who no longer live with a husband.

The table also shows that the increasing number of the elderly is followed by a decreasing number of newborns. Therefore, in the near future the number of old people will exceed the number of children. This structure will bring a host of consequences in every aspect of life, including health and healthcare.
A cardinal feature of disease and disability in the elderly is their tendency to be chronic and often progressive (Hazzard, et. al 1999:xxxii). Thus the primary care given to the elderly patient will have to include the management of chronic disease, which needs the skill and expertise from the physicians and caregivers in dealing with long-term care. Furthermore, the care and management of chronic disease will, as such, raise a serious issue of finance especially for developing countries where the priority of health and healthcare is to reduce mother and infant mortality rates, and overcome the overwhelming problems related to communicable diseases.

Despite of the government rhetoric in addressing the problem of aging, there is still a difference in determining who the old people are. According to government law no. 4/1965 (issued by Department of Health), old people (usia lanjut) are those who have reached the age of 55, while according to government law no. 13/1998, only those who have reached the age of 60 can be categorised as old. However, interestingly, in hospitals the so-called geriatric patients are those who are 60 years old and over, while the retirement age for the government employee is 55. Thus there is a gap between the bureaucratic and the medical definition regarding the so-called elderly, which may create an awkwardness in caring for elderly patients.

Furthermore, there is not yet an agreement among the medical staff on the grouping of this group of people. Prof. Dr. Sumiati Ahmad Mohamad of the School of Medicine, Gadjah Mada University in Yogyakarta stated that 40-65 years old are middle age whereas anyone 65 years old and over are the elderly. Another expert, Prof. DR. Koesoemato Setyonegoro stated that 65-70 year olds are the elderly (geriatric), 70-75 are young old, 75-80 are old, and over 80 are very old. These categorisations are different from the WHO definition on old age (1992). According to WHO 45-59 year olds are called middle age, 60-70 are the elderly, 75-90 are old, and over 90 are very old.

These gerontological definition and classification of the aged, however, is inadequate and even inconsistent with the principle of individual variation. A physician, for example, will probably find it difficult to categorise an 80-year-old runner who may well have better cardiovascular function than a 50-year-old sedentary doctor. Should the physician then hold onto the classification and treat the runner as a very old patient and
the doctor as a middle age patient? Moreover, the place and role of the so-called elderly often has nothing to do with the age classification mentioned above. In Indonesia, to take an example, an ulama (Muslim religious teacher or leader) of 40 years may be considered an elderly and his students will likely kiss his hand to show their admiration. Respect from the community obviously plays an important role in determining the concept of old.

Aging, indeed, is not simply a series of biological changes. It is a time of losses: a loss of social role (usually through retirement), a loss of income, a loss of friends and relatives (through death and mobility). It can also be a time of anxiety: anxiety for personal safety, anxiety of financial insecurity, and of dependency. These losses and anxieties, moreover, are reflected in the situations caused by urinary incontinence, as we shall see in the next pages.

1.2. A Picture of Old Age in Indonesia

Despite the norm to respect the elderly, the picture of them in Indonesian society today is rather somber. According to Kurniadi (1997), Indonesian people, especially those who live in urban areas, often consider the elderly a burden not only for the family but also for the society and development process. Furthermore, the elderly are considered a group of people no longer with any duty or, even worse, any full rights as community members. When, for instance, somebody working as a civil servant has reached the age of 55, he or she will go into retirement (except for educational staff who will go into retirement at the age of 65 or even 70).

For many people, retirement is something unbearable since they feel they still have energy – and normally they do – to do many useful things. Ironically, when they try their best to prove their capability, people will mock them and say that they suffer from post-power syndrome, which is of course not a nice attribute for anybody. Moreover, one of the social norms in the relation between generations is to give the young a chance [memberi kesempatan pada yang muda]. The youth does not only have more energy and spirit but more than that they need opportunities to develop their talents and capacity. To an elderly who is still holding a certain position in a company for instance people will likely say that he prevents the younger generation to improve.
Moreover, the ultimate question for the elderly is about their competency to be productive citizens (Kurniadi: 1997). The ideology of developmentalism, which had been popularised by the New Order regime, had indirectly put the old age aside from the process of development. The idea of progress, which is the basis of developmentalism, implicitly requires healthy and youthful individuals to support the development process. Thus, it goes without saying that being old is an obstacle for – not to mention an agent going against – the process. There is a silent understanding that people cannot expect more from the elderly since they are no longer “productive” as community members.

Strictly speaking, many people will probably say that the elderly represent wisdom, merits and high morals, but at the same time they also agree that very often the elderly are a group of dated individuals. The younger generation will likely listen to the elderly especially for their experience in dealing with certain situation but do so less and less because they think that there is a big difference between their situations today and those that belonged to the generation of their parents.

Moreover, there are stereotypes that are usually attributed to the old people: old, dated, fussy and annoying (Kurniadi: 1997). Furthermore, though aging is related to physical condition, it is said that when you get old you will be sickly. To a certain extent, this stereotype is true, although there are many elderly who stay healthy and physically active until the end of their life. However, it is also true that many others, especially those who only have limited access to health services, have to struggle with some chronic illness that actually can be managed well like diabetes.

In 1994 geriatric departments were set up in some public hospitals in Indonesia. A geriatric department, according to Dr Supartondo, a geriatrician in Cipto Mangunkusumo Central Hospital (RSUPN-CM) in Jakarta, is needed because more and more elderly patients are needing different treatment and care compared to patients of younger group. The multi-pathology nature of geriatric patients, he said, required a more complicated treatment. Moreover, most of the time the main purpose of the treatment is to increase the quality of the patient’s life instead of to cure the diseases (6/6/01).

At the same time, since old age is also considered an illness, many people think that a hospital is a safe place where doctors and nurses are available around the clock and,
in case of emergency, patient would get quick intensive care. There were some cases, according to another geriatrician in the hospital, where patients were not picked up by their family, although the doctors had said that they had recovered. Sometimes the reason was only because the family did not have time to take care of the elderly.

The geriatric department, according to Hazan (1994:14), establishes the social fact that, as a result of shared medical problems, elderly people are assembled under the auspices of the branch of medical science that deals with aging. Elderly people, Hazan says further, are no longer referred to in terms of social identities; rather it is the very absence of other imputed and acceptable identities that generates the concept of the old person as sick and in need of medical care. Interestingly, the bed occupancy ratio (BOR) of the geriatric ward of Cipto Mangunkusumo Hospital (RSCM) in Jakarta reaches 57.5 percent, which can be considered high. So far only a small number of hospitals in Jakarta have geriatric wards, and probably this is the reason why the BOR is high. However, at the same time this figure may also indicate the medicalisation process that is going on in the country. The process has encouraged more and more people to turn to medical staff to seek help for their health problems. The better the service is, the more people are dependent on the health care system.

The medical approach towards the problem of aging can also be seen from the social activities of the physicians. Many doctors involve themselves in the home health care agency, which is under an umbrella organisation for caring for the elderly, namely Pusat Santunan Keluarga (PUSAKA) or the center for family care.

Caring for the elderly raises ethical issues regarding the shifting in family patterns. In a traditional society that consists of extended families, people are not afraid of getting old, as the society will guarantee their role and places. There are values of companionship in the extended family, as daily activities are carried out jointly by a number of kin working together. A further advantage is that the extended family provides a sense of participation and dignity for the older person, who lives out his or her last years surrounded by respectful and affectionate kin. This contrasts with the nuclear family, in which the presumed advantages of privacy and personal autonomy are paid for as people
grow old and are regarded as a burden and a nuisance if they join the household of one of their children (Nanda & Warms, 1998: 176-177, Adi, 1999:194).

The issues are not only economic and private, but also the divided attention of the children and – as the most common complaint among the sons or daughters in-law in Indonesia – the interference of the in-laws to their children’s households. In his research on elderly in 1982, Adi found a medical doctor who preferred to put his mother into a nursing home than to risk a continuous conflict between his wife and his mother concerning the chores. Among the Indonesian, a doctor is considered one belonging to the upper class in a social range. Therefore, the doctor’s decision to exclude his mother from his household was really a moral issue – not to mention scandalous – in the eyes of society, not only because he was financially able to take care for the mother but more importantly because he was a medical doctor who was considered capable of providing the best care for his parents.

Nowadays, partly thanks to the family planning program executed by the government since the beginning of the 1970, there has been a major shift from an extended family to a nuclear family concept in Indonesia. The norm of “small family, happy and wealthy”, which has been the motto of the government program, promotes opportunities to get higher education and better life for the family members. Consequently, the tendency to have a nuclear family (parents with two children) is increasing and is implicated in the relation between parents and children and in-laws. Parents can no longer consider their children their “investment” in their old days, whereas the children, on the other hand, have become less capable of taking care of their parents because of their activities and also the social norm of privacy.

According to Adi (1999: 194), the elderly are divided into two sub-groups, i.e. those who are economically capable of financing themselves, and those who are not. This division is important because the most important issue concerning caring for the elderly is money. Many problems faced by this group of people stems from their economic limitations. According to the Indonesian Central Bureau for Statistics, for example, due to poverty only 20 percent of them have full access to health services (BPS: 1997). This, of course, has an enormous impact on the overall quality of life of the elderly in general.
Ideally speaking, the government should provide the care for those who are in need, including the elderly in order not to burden the family and the society. The problem is whether the government has the ability to support this group that is considered unproductive. The support for the elderly does not necessarily mean financial support since there are many of them who are physically still strong to work and to earn money. Again, however, there is a problem: with a high rate of unemployment, there are almost no job vacancies left for them.

Like other governments in Asia, the Indonesian government only gives a very low priority to the prosperity of the elderly due to their economic situation (Adi, 1999: 202). The absence of old age pensions in many less developed countries, including Indonesia, means that children – whether they are able or not – should continue to be the main support of the frail elderly. However, the economic crisis that hit the country about four years ago has decreased their capability to offer significant support to the parents.

1.3. Urinary Incontinence in Indonesia

In Indonesia, degenerative conditions such as diabetes mellitus and high levels of cholesterol are the major health problems among the elderly (Boedhi-Dharma, 1999:46). Dharmojo also states that diseases like rheumatism, hypertension, heart disease, bronchitis, falls, paralysis, tuberculosis, osteoporosis and cancers are also common among the group. More specifically, Kane et al. (1994:14-15), the common problems of geriatric patients due to various diseases can be summarised as a series of I's, i.e. Immobility, Instability, Incontinence, Intellectual impairment, Infection, Impairment of vision and hearing, Irritable colon, Isolation (depression), Inanition (malnutrition), Impedence, Iatrogenesis, Insomnia, Immune deficiency, and Impotence.

This thesis will discuss urinary incontinence, one of the problems on Kane’s list, among the female elderly. Urinary incontinence is a major health problem that is a significant cause of disability and dependency. The problem has various causes. The

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1 See, for example, Foner (1993:113).
2 Disability is any restriction or inability - resulting from an impairment - to perform an activity in the manner or within a range considered normal for a human being (see International Classification of Functioning Disability and Health (ICIDH-2) Prefinal Draft, WHO: 2000.)
treatment, however, is not only determined by the single cause but also by the perception of the patient suffering from this condition.

The International Continence Society defines urinary incontinence as an involuntary loss of urine that is objectively shown and a social and hygienic problem (Thakar and Stanton 2000). The classification of urinary incontinence is based either on the duration or the pattern of urine loss. In the first classification Setiati (2000) describes two types of urinary incontinence: acute and chronic. Triggering factors for acute (transient) incontinence may be easily recalled using the mnemonic DIAPPERS: Delirium (state of confusion), Infection-Urinary (symptomatic), Atrophic urethritis (vaginitis), Pharmaceuticals, Psychological (especially depression), Endocrine (hypercalcemia, hyperglycemia), Restricted mobility, and Stool impaction (Sirls & Rashid, 1999:88).

Among the factors that cause chronic (established) incontinence is instability (overactivity) of the bladder and urethral sphincter incompetence. Some persistent neurological problems such as stroke, Parkinson's disease and impaired cognitive function such as dementia and Alzheimer's disease, according to Setiati, can also cause chronic incontinence. Furthermore, she states that acute incontinence can be treated well by eliminating the triggering factors, while the chronic incontinence, although it cannot be eliminated completely, can be controlled and reduced by non-pharmacological modalities and also pharmacological treatments.

Another classification scheme for urinary incontinence is based on the pattern of urine loss (urge, stress, overflow, and mixed). According to Setiati (2000) urge incontinence (also known as bladder over-activity) is the most common type of incontinence among the elderly. It occurs when patients sense the urge to void (urgency) but are unable to inhibit leakage long enough to reach the toilet. In most, but not all, cases, uninhibited bladder contractions contribute to the incontinence. Among the causes of urge incontinence are central nervous system lesions such as stroke or demyelinating disease, which impair inhibition of bladder contraction, and local irritating factors such as urinary infections or bladder tumours. In many cases of urge incontinence, no specific aetiology can be identified despite detailed clinical and laboratory evaluation (NIH: 1988).
In stress incontinence, dysfunction of the bladder outlet leads to leakage of urine as intra-abdominal pressure is raised above urethral resistance while coughing, bending, or lifting heavy objects. This type is more common among women than men. Volume of urine leakage is generally modest at each occurrence and, in uncomplicated cases, postvoid residual volume is low. Stress incontinence has many causes, including direct anatomic damage to the urethral sphincter (sphincteric incontinence), which may lead to severe, continuous leakage, and weakening of bladder neck support, as is often associated with parity (NIH: 1998, Setiati: 2000).

The next type of urinary incontinence, overflow incontinence, is caused by chronic urinary retention, for example because of prostate hyperplasia. This condition is one of the common problems among male elderly. This type of incontinence is thus uncommon among women.

According to Setiati (2000), many geriatric patients have mixed incontinence, primarily a combination of urge and stress incontinence. Among younger patients stress incontinence is more common, whereas among the older ones mixed incontinence is more prevalent.

As mentioned earlier, prevalence rates are twice as high in women as in men due to additional risk factors such as pregnancy and repeated delivery. According to an obstetric gynaecologist, urinary incontinence during pregnancy can be a predisposition for later incontinence. Other risk factors among women include menopause, prolapsed uteri, obesity, and the structure of urinary tract in women's body. Moreover, according Dr Nuhonni (2/6/2001), urinary incontinence among women is usually triggered by the weakness of the muscles in their urinary system.

Although affecting all age groups, urinary incontinence is particularly common in the elderly. Prevalence rates, according to some geriatric literature, range from 8 to 51 percent. In the USA, at least 10 million adults suffer from urinary incontinence, including approximately 15 to 30 percent of community-dwelling older people and at least one-half of all nursing home residents (Setiati 2000; Thakar & Stanton 2000; Mitteness & Barker 1995; National Guideline Clearinghouse1996).
In the geriatric ward at the Cipto Mangunkusumo Hospital, the central hospital in Jakarta, the prevalence rate of urinary incontinence in 1999 was 10 percent, 67.4% of which were women. This prevalence rate increased to 12 percent in 2000. Prevalence rates are twice as high in women as in men because women have additional risk factors such as a higher prevalence of urinary tract infections, menopause, and also lack of postpartum exercise.

Another survey conducted in two hospitals in Jakarta and Semarang (Central Java) shows a higher prevalence of the urinary incontinence problem, that is 11-20 percent of the total population (Yunizaf, 28/5/2001). Yunizaf, an obstetrician gynaecologist in Cipto Mangunkusumo hospital, mentioned that in fact there were a lot of cases of urinary incontinence but they were rarely found by doctors. The sufferers were not only the elderly, but also men and women in their reproductive years, including young adolescents. This, according to him, was due to several reasons range from the idea that this was a common and normal problem among women especially after delivery, shame or embarrassment even to the near-others, a belief that it would recover without any special treatment, and lack of information about how and where to get treatment for the condition. Most importantly, he said further, many medical doctors do not consider urinary incontinence a problem while their patients do.

Unfortunately, the national level data on the problem does not exist yet. However, nowadays more and more people are complaining about the problem to their doctors so that the doctors can no longer neglect it. Another factor mentioned was the increase of the social and economic status especially of those living in big cities. This, he said, increased the quality of life and in turn people started searching for medical treatment for the condition long considered normal. Conversely, the incontinent elderly have often adapted to problems by denying or ignoring them. Most of the core informants I interviewed during the fieldwork had other health problems that they considered somewhat more serious. When they see the doctors, they focused more on their other problems, not their incontinence.

To date, most studies on incontinence – both biomedical and anthropological – have been conducted among the western communities though the problem does occur in...
non-white ethnic groups as well. Therefore, little is known about the stigmatisation of being incontinent in non-western settings. The stigmatisation is not only determined by the condition per se but also by the lay perception of urinary incontinence, the idea of being elderly, the idea of purity and religiosity, and the caring attitudes of close relatives. These ideas and social values are very different from those found in western societies. Thus being incontinent and being potentially stigmatised by the condition also has a different meaning within the concerned society. It is important to understand this meaning in order to help the sufferers, their family and the society in general deal properly with this situation, including the stigma that follows the condition.

1.4. Research settings

The research was conducted in Jakarta, the capital city of Indonesia. Jakarta is a densely populated city with more than 9,605,000 inhabitants or 14,465 persons per square kilometre (Welfare Indicator: 1999). Among the population, 2.69 percent are over the age of 65. There are two main research sites for the fieldwork, i.e. hospital and nursing home, where the data of the incontinence patients are available. However, most of the interviews with the core informants were conducted in their homes.

1.4.1. The Hospital

One of the research sites is Cipto Mangunkusumo Central Hospital (RSUPN-CM), located in central part of Jakarta. The RSCM is part of the school of medicine, at the University of Indonesia. The hospital opened in 1908.

There are 31 departments and 17 units and installations in the hospital. Most of the patients belong to the low or middle-class of the community. Since RSUPN-CM is the highest referral hospital, it has to accept health insurance (ASKES) which is specially

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3 Goffman (1963) defines stigma as an attribute, an undesirable differentness that discredits or disqualifies the individual from full social acceptance. He goes further by explaining a double perspective on stigma. In the first perspective one deals with the discreditable, whose stigma can be and usually is concealed. The discreditable assumes his differentness is neither known nor immediately perceivable by those present. In this context people's incontinence can be either the discreditable or discrediting, depending on their capability in managing their condition. The second perspective deals with the plight of the discredited - a condition in which the stigmatised individual knows that his differentness is known or is immediately evident. In other words, the discredited are those whose stigma is visible and indeed exerted and experienced.
reserved for the government employees. However, there is also a private clinic [klinik swadana] which particularly targets the middle-upper class of the society. Nowadays there are 1182 beds for adult patients and 40 beds for infants.

Since 1994, the geriatric ward has been open. However, not until 1998 did the hospital open the geriatric clinic, which was expanded early this year. The ward and clinic are under the supervision of geriatric division, department of internal medicine. As a journalist who covers health issues, I got acquainted with the medical staff in the division years ago, while I was collecting data and information to write articles on the international day of aging. From then on I was often invited to cover their activities and wrote articles on aging, including the urinary incontinence among this group of people.

Aside from the geriatric division that deals with incontinence, about two years ago an incontinence clinic was opened. This clinic, however, is under the supervision of the urology department. There are some other departments which deal with this problem. Besides the geriatric and urology departments, the obstetric-gynaecology and paediatric departments are also dealing with incontinent patients. Moreover, there is another unit that is medical rehabilitation to which some of the patients who need physiotherapy exercises should be referred. However, as told by a senior physiotherapist in this unit, the departments preferred to treat their patients with the best protocol that they had rather than referring their patients to this rehabilitation unit. She personally believes that most of the cases could be treated with physiotherapy and is sceptical that the doctors would suggest to their patients to do physical exercise.

"I have some experiences with patients who were already validated by their doctors to have permanent incontinence. Usually they are the survivors of serious accidents. However, after doing some exercise several times, they got better and some of them can void normally," she said.

A total of six clinics in the hospital are dealing with incontinence: the incontinence clinic of the urology department, the incontinence clinic in the obstetric gynaecology department, the medical rehabilitation unit, the geriatric clinic, the nephrology clinic in the paediatric department, and the neurological clinic in the neurology department. The co-ordination of these clinics has not run well yet. It is not
surprising then to see the rivalry among the doctors with different specialisations (see chapter 3). My key informant in the geriatric clinic, for instance, told me once that surgery was the mainstay of the urology department, while the person in the urology department said that the geriatric staff was too reliant on a conventional method, namely pelvic floor muscle (Kegel’s) exercise.4

As mentioned by some medical doctors in the hospital, this condition created difficulties in establishing the treatment protocol. Therefore, last year an organisation at the national level was set up. Members of this organisation, the Indonesian Association for Incontinence or “Perkumpulan Kontinensia Indonesia” (Perkina), are all of the schools of medicine in Indonesia. The aim of the organisation is to establish the protocol for the incontinence treatment. It is interesting to note that, as admitted by one of the key informants, many of medical staff in Indonesia do not share the problem and through Perkina they are expected to be able to update their knowledge and skills in diagnosing and treating the patients with incontinence.

As a would-be medical anthropologist, the situation was interesting and challenging at the same time. The fact that there are many departments dealing with the condition I think is a clear sign of the magnitude of the problem in my society. However, the limitation of time made me realise that it was almost impossible to have the “complete” picture of this situation. I should then satisfy myself with answering my research questions while trying to grasp the pieces of the puzzle and making sense of all the information gathered.

1.4.2. The Nursing Homes

The last but not least important setting of my fieldwork was the nursing home. The different circumstances where the elderly live, I think, would give them a different perspective and experiences on the specific problem. There were two nursing homes in

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4 Kegel’s exercise is a pelvic floor muscle (PFM) exercises that have been used since 1948 as a non-surgical method of increasing the tone sphincter and their supporting structures among the urinary incontinence patients. The exercise, first introduced by Arnold H. Kegel, concerns the re-education of PFM by encouraging women to voluntarily contract their muscles. The overall rate of much improvement after five years, according to a medical literature, is about 60%. The compliance of the incontinent patients however, remains relatively low.
Jakarta that I visited during the period of fieldwork. Previously, the nursing home in Indonesia was called *panti jompo* (a place where old people are cared for). As the term is now considered unfavourable to the elderly, it has been replaced by another term, *sasana tresna werdha (STW)*, which literally means "a home to love the elderly."

The reason for the changing was because the word "*panti*" is thought to have a negative connotation. *Panti* means the place to ostracise the elderly, where they are only fed and do not receive affection or proper care. Furthermore, *panti* implies the place where the elderly have nothing to do but wait for their life to end.

At the same time, the word "*jompo*" is nowadays considered pejorative. According to the Indonesian government law no. 4/1965 about the care for the elderly, "*jompo*" means those who have already reached the age of 55, are not able to make a living and need continuous care from others. This definition is no longer used since a lot of people are still active and independent at this age. Furthermore, many elderly consider the term continuous care, which implies dependency and is offensive.

I visited two nursing homes during my fieldwork. The first one was STW Karya Kasih (STW KK), which is located in Kwitang, Central Jakarta. This STW is affiliated with the Indonesian Christian Church (GKI). I contacted the STW before I called the second one. Unfortunately I did not hear anything from the person in charge until almost a week after I sent them my letter of request, so decided to contact to the second place, STW Karya Bakti (STW KB) in Cibubur in the eastern part of Jakarta.

It was quite easy to get the permission to visit and do research in STW KB. I did not have to send any letter first. I only called the head and he gave me permission almost instantly. I visited the place for the first time on June 26, 2001. That morning, when I was on my way to Cibubur, I received a call from STW KK telling me that they would allow me to come to their place. I decided to go to Kwitang the next day. Frankly I did not think it was necessary to go there, but I thought it would give them a bad impression if I just cancelled the plan without a clear reason. I went there on June 27, 2001. It was quite a short visit. I only spent a couple of hours talking with a caretaker and one of the inhabitants.
I spent one night and two days in STW Cibubur. This nursing home was opened on March 14, 1984. The founder was the late Mrs. Tien Soeharto, wife of the former President of Indonesia, Soeharto. This institution is affiliated with RIA Pembangunan, a women’s organisation dealing with social activities. According to Wahjudi, the present head of the nursing home, the objectives of the STW are as follows: (1) to maintain the self-esteem and personality of the older people, (2) to preserve and promote the health of the older people and (3) to ensure that older people can enjoy the last years of their life without depression (29/6/01).

Based on humanity as its principle, the motto of the nursing home is “The strong to carry the weak, and the affluent to help the poor” (Yang kuat menggendong yang lemah, dan yang mampu menggendong yang tidak mampu). Prior to my visit, some friends of mine told me that STW Cibubur was an elite nursing home, since the inhabitants had to pay quite a lot every month, that is 500,000 rupiah. However, some social workers there, some of the inhabitants paid less than the amount and a few of them even lived there for free. The monthly contribution was called “participation money” (uang partisipasi).

Nowadays there are 79 inhabitants (17 men and 66 women), some of whom are couples. They have various levels of education from illiterate to master’s degree as well as religious and economic backgrounds. It was interesting to know that some of the elderly who live there have children who are successful in their career and actually are able to provide their parents with good care.

There are four pavilions in the nursing home: Aster, Bungur, Cempaka and Dahlia. All names are taken from flower names. Aster pavilion is particularly allocated for couples. Each pavilion has a large dining room and recreation hall and a hot water installation. Apart from the facilities, there is also a health clinic, a big kitchen, a laundry room, religion facilities and transportation, including an ambulance. There are also various activities in the nursing home, ranging from religious congregations, music, sports, gardening, knitting, to shopping, celebrating public holidays, and other recreational activities.
The physical environment is very peaceful there. However, as I shall discuss in the next chapters, the interaction among the inhabitants is very alive. Gossiping, making friends, and falling in love with a co-inhabitant are parts of their daily life. For me it makes living there interesting and makes me want to learn more.
Chapter 2
METHODOLOGY

2.1. Study Type and Data Collection Techniques

2.1.1 Study Type

The study type used in this research is a combination of exploratory and descriptive methods. I would like to describe the experiences of the women with urinary incontinence regarding their problem and the way they deal with it. The description is derived from the in-depth interviews, while the questions for the interviews are developed from the research questions.

2.1.2 Data Collection Techniques

During the two last modules in AMMA, I have started making contact with some people whom I think would be my key informants and would introduce me to my core informants. The contact was made through e-mail and by telephone. Doctor Zubairi Djoerban, my first contact person in the Cipto Mangunkusumo hospital (RSCM) agreed to introduce me to Doctor Rochani, the head of the incontinence clinic of the Department of Urology. I found the introduction to Dr Rochani was quite effective and he was more than willing to take me to the clinic, introduced me to his staff and provided me with all the data needed.

Another key informant who also had agreed to help me during the fieldwork was Doctor Siti Setiati. Her concern as a geriatrician to urinary incontinence had allowed me to have good access to the geriatric ward and clinic, and also to the incontinent patients she treated. She encouraged me to tell the core informants about how I got to know them, so, she said, they would be willing to talk to me. She was right. One of my core informants (Mrs. Lita, 67) said that she was happy because for her it meant her doctor still remembered her.

There are some data collection techniques used during the fieldwork. The main technique was in-dept interview, which was semi-structured (especially for interviews with the key informants) and unstructured or conversation with the core informants. Other techniques applied were participant observations, hanging around in the geriatric ward, in
the incontinence clinics, and in a nursing home, and a focus group discussion (FGD) with two physiotherapists. Previously I planned to conduct FGDs with the nurses and family members, but it turned out to be impossible because of the difficulty to find time that suited all participants. However, during my stay in the nursing home I had several occasions to chat with the nurses and social workers there regarding the topic and the incontinent residents.

**In-depth interview**

The main method of data collection I employed during the fieldwork was via in-depth interviews. Doing an ethnographic interview is very much different from a journalistic interview. An anthropologist has to be more observant than a journalist in the sense that an anthropologist is interested in a culture as a whole and thus every detail is important in order to grasp the complete picture of the culture he or she is studying. Even more an anthropologist will treat every informant – no matter how “lay” she or he is – as an expert of the topic. For an anthropologist, every gesture and eye winking, every sigh and silence, all has its specific meaning which is important to capture the emic point of view and thus to understand the web of culture being studied.⁵ On the other hand, a journalist will be more interested in news, the novelty and even the sensational aspects of a certain topic. Moreover, a journalist will also be more interested in what is said and by whom, and on a very specific topic.

I am not saying that an anthropologist is “deep” while a journalist is “shallow”, because as one might know the great journalists are those who had successfully shown to the public the other sides of their own culture. All I want to say is that the basic methods of interviewing people are different from one another. I am very grateful that my experience as a journalist has given me a necessary skill to conduct an interview and to make a transcription, not to mention the skill to write a good report. However, during the interview sessions for the research purpose I found out that there are things I still have to learn in conducting an ethnographic interview. The most important one is that I have to learn how to “bite my own tongue”, that is to listen carefully and to wait patiently instead

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of bombarding the interviewees with questions. This task is particularly difficult when I should interview old people. Not only did they like to tell the interviewer about their life history which is sometimes “irrelevant” to my topic, but also because many of them tend to speak softly and slowly.

Let’s now return to my interview for the fieldwork. Except Mrs. Inneke (68) whom I met when she was in a hospital, other key informants were interviewed in their homes. By interviewing them in their places, I was able to observe closely their socio-economic situation and to feel their relationship with their families. However, sometimes things went much further than I expected before.

During the interview with Mrs. Hidayati at her house, for example, when we reached the financial issue, the mother and one of her daughters had a different argument on it. Obviously it was a sensitive topic in the family. I felt very uneasy, especially when they started yelling at each other. I was annoyed and embarrassed to see the quarrel between mother and daughter right under my nose. At the same time I could do nothing to stop them and I sat still until they finished. Even so, when I asked for permission to go home Hidayati asked me why I was such in a hurry. Then she asked her other child to take her pillow and asked me to help her lie down on the couch in the living room. She was so smelly that I had to hold my breath. Feeling convenience again, she started telling me her life story, especially about her late husband and her wish to spend the rest of her life in her hometown in West Sumatra.

Admittedly, since I already set my research place in Jakarta, the decision to do the interview at their houses was not always easy to implement. I lived at the outskirts of Jakarta, approximately 30 kilometres from the central part of the capital city, and I completely forgot to consider the distance factor in my research plan. Of the informants I met during the fieldwork, only Mrs. Rahima and her husband, Susilo, whose house is close from my own (about 5 kilometres), while the others live very far from my place. Therefore, almost five days a week (except on public holidays) I had to travel at least two hours before I could meet one informant and to go to the hospital located in the central part of Jakarta. Although tiring and expensive, I think it was a good experience for me to know other parts of my own city.
Before going to the field, I used to think to limit the conversation for one hour or one and a half at the most. The reason was that I did not want to make my informants tired of answering my questions about the condition that they might be embarrassed to talk about. Later I found out that the consideration was not always true. Most of the informants would like to talk to me not only on the topic of their incontinence but a lot more than that. Usually they would tell me about their health condition in general, what treatment they got from the doctors, and after a while we would start talking about their daily life and particularly about their relation with other people. The topic of conversation then would stray to any kind of themes that became their concern and interest.

During the interview with Mrs. Tarida (61), for example, after telling me about her condition and the cause of her incontinence, she went on by telling me about her husband and how she felt about him. She told me how, despite her condition, he cheated her by using her pension for his own interests. He also, she said, flirted with a married woman who lived in front of their house. She shared this personal story with me without any obvious hesitance. Sometimes she said, “This is my life, let it be so…” (Sudah nasib saya, Mbak, Biar sajaalah…”). Unfortunately, I could not interview the husband as her caregiver. He said that he had no time to meet me since he had to travel a lot.

First I felt awkward to listen to this kind of story, especially because I still considered myself a stranger to the person. But then I noticed that by sharing their secrets and worries, the psychological barrier that prevented me from asking sensitive questions was melted.

When visiting Mrs. Lita when she was sick, another example, she said that her illness was due to too much thinking (terlalu banyak pikiran). Then she continued by telling me that she was worried about her children who were not married yet. Her first daughter was already 40 years old and did not seem to have a serious boyfriend yet. The informant said that she felt envy towards her sisters and brothers (she was the first child in her family) who already had grandchildren. She wanted so much to hold a grandchild in her arms (sudah kepingin gendong cucu) “I cannot speak like this to my children. They would feel guilty and uneasy towards me. I’m telling you this, but never pass it to them.”

Reading my fieldwork notes, I realised that the life story of the informants was very dominant. For most of the informants the condition they suffer from is inseparable
from their life history. Mrs. Meilani, for instance, the informant of younger age, would like to spend hours telling me about her experience. From her third delivery, which she thought to be the beginning of her incontinence, to her continuing saga of medical treatment and to her present business which was started from her diet as an incontinent.

Listening carefully and attentively, as I had already mentioned, can be very tiring. The first day when I visited the STW Cibubur, I had to listen to Eyang (grandfather) Sasongko who told me about his life experiences. He kept on talking for almost three hours. Although I was already used to listening to other informants’ story by that time, on that evening I went home with a strained face and stiffened shoulders only to find out that the whole story from him was irrelevant to my topic. Yet it was a good start to get acquainted with the community members, and as a stranger I had to be polite. However, the next day I came to the place I intentionally avoided meeting him when I saw he was in my way. I felt a bit guilty, but at the same time my time was very limited. I had to meet some people and interview them.

Interviewing incontinent people about their condition involves dealing with a delicate issue. I have to be careful not to “cross the border” and make the informants too embarrassed when answering to my questions. I realised that by asking them about things that they might not want to share with others, let alone to a stranger, somehow I put them in a vulnerable position of being ashamed. Interviewing them, to put it in other words, could also mean threatening them. Moreover, there was always a possibility they would find my questions or gestures offensive.

To avoid difficulties in gaining their trust and collecting the data needed, I tried to identify myself with them. I tried to put myself in their shoes. For example, I would use a personal pronoun which involves myself when asking sensitive questions. Instead of using “you” I prefer to use the word “we”, which is quite easy to do in bahasa (the Indonesian language). I found this technique quite effective to show my empathy and to make them feel at ease talking about their condition.

I would also tell the elderly informants that my main motive was to learn from their experience in dealing with such a difficult condition. Sometimes I would share my experience with incontinence (my grandmother is incontinent) with them, and I found it was helpful to start the conversation as they seemed to think I understood their situation.
Furthermore, by putting myself in a position of an apprentice and they as the masters, not only did I learn a lot from them but also built a good relationship with them and gained their trust.

Some of the informants, as I noticed later on, failed to manage their condition. Because my expressions and body language can influence my interaction with them, I always had to prepare myself to deal with the smell of urine. Unfortunately I have a rather sensitive nose, and on the first occasions with the informants I often had to hold my breath to put up with the smell. Learning from such an experience, I would not have my meal before the interview and always had some peppermints in my bag to resist the urge to vomit.

**Participant observation**

When visiting STW KK on June 27, 2001, I only spent a couple of hours there. To my regret, the caretaker whom I met seemed reluctant to introduce me to the incontinent inhabitants, although she mentioned several names of the inhabitants who suffered from the condition. Instead, she introduced me to Oma Pinky, who I guessed the most educated inhabitant in the nursing home. I tried to make the best of the meeting by asking about her opinion on incontinence. Although she was more interested in telling me about her life history and her achievement as a lecturer in a university in Jakarta, we ended our conversation gossiping about some incontinent inhabitants.

On the contrary, I spent one night and two days in the nursing home in Cibubur, June 28-29, 2001. Prior to my stay there I had already visited the place twice to introduce myself and to have a picture of the situation. On the first day of my stay I joined the angklung (musical instrument made of bamboo) session in the morning and spent the rest of the day having an informal conversation with some inhabitants and nurses until late at night. The next day I started my activities by joining the physical exercise specially designed for the elderly (senam lansia) from 6 to 7 a.m., before continuing the interview with some of the inhabitants.

Both the angklung session and the exercise was quite a good start because after each activity I knew some new people and learned more about the whole situation in the nursing home. I noticed that the participants of each activity were different. Most of those I met in the morning were not there for the music session. During the music session, a
lady who sat next to me said that those who were sitting at the first row were the most “musical” ones. They sit in the same chairs every time, she told. When I asked her why she did not join them at the first row, she said that she was only a “cheer participant” (penggembira).

Another event started one day, when I was hanging around in the incontinence clinic of the obstetric gynaecology department. I met Yanti, a girl of 18 year-old who was going to go through surgery. She suffered from urinary incontinence since she was a child. About two years ago she had tried to commit suicide by drinking pesticide. Fortunately one of her brothers found her when she was dying. Her family took her to the nearest doctor and her life was saved. Because of her incontinence, Yanti had stopped attending school, and now her main obsession was to continue her education, “after everything [the surgery] has over.”

I was moved by her story, so I decided to give her a visit whenever I had time. On June 20, 2001, after visiting Mrs. Lita who was sick at home, I went to IRNA A ward in RSCM where Yanti was hospitalised. After chatting with her for some time, a nurse came and asked her mother to come to the office. The mother was a bit nervous. I did not know the reason. Finally both of them asked me to accompany her. We found out that she was asked to buy some medicine for Yanti and it had to be done before the surgery, which was planned the next day. So I took her to the drugstore nearby to purchase the medicine.

For many people, I think, buying medicine is such a simple task to do, and yet the way she and her daughter thanked me for accompanying her to the drugstore was really made me feel awkward. Later, when the pharmacist asked us to check the medicine she gave before we left the place, the mother asked me to do it for her. It was only at the moment when I found out that she was illiterate!

During the fieldwork I had an opportunity to attend a physiotherapy session in the medical rehabilitation unit. I got permission from my informant Meilani and Mrs. Kustini, the senior physiotherapist, to come to their session on June 25, 2001. The session was in the morning at 8.15 and lasted one hour. Kustini began the session by guiding Meilani to do some relaxation. This was an important part for Meilani since, as she told me earlier, Meilani was almost always in a tense condition. One of Kustini’s colleagues
even once said that Meilani also suffered from psychosomatic stress because of her incontinence problem.

After the relaxation, they started with Kegel's exercise. The physiotherapist gave me a rubber glove. At first I did not know what the use of the glove was for and why she gave it to me. To my surprise, after practising for a couple of minutes, she asked me to put my hand on Meilani's intimate part of the body (daerah kemaluan)! Though she wore her leggings, I felt uneasy doing that. However she did not mind. She even encouraged me to put my hand deeper in order to feel her muscle contraction and to put aside my embarrassment. "How can you know the right way of doing this exercise? This is the only way to learn, and you should start learning the exercise from now, when you are still young and continent," she said.

Meilani proceeded by telling me that nowadays in gymnastic clubs this kind of exercise started being taught. However, she said, the instructors were unlikely to touch that part of the body. As a result, many women did not know how to do the exercise properly. Another key informant, a specialist in physical and medical rehabilitation, also mentioned the importance of the vaginal touch (colok vagina, June 6/2001). According to her, many of her patients were reluctant to being touched and therefore she had to assure them that it was the only reliable way to know that they were able to do the exercise.

The interesting thing came after the session was over. When I returned the glove, the physiotherapist told me in a soft voice that for other patients she never used it. "But since she is "leaking" [bocor], I have to use the glove."

Hanging around

As I have mentioned earlier, there were several clinics in the hospital I visited during the fieldwork. Although I was not used to doing the activity and felt useless at the beginning, I started to notice that this method allowed me to eavesdrop on the conversation among the patients in the waiting rooms. Sometimes I would get involved in their conversation by asking casual questions. I did not find this difficulty, since most of the patients were willing to share their experience and "expertise" in their illness (see chapter 3 and 4). It was also through this method that I got to know Yanti, my youngest informant.
The first time I went to the clinics, a medical doctor usually accompanied me and introduced me to the staff there. The staff and the nurses would be willing to help. However, the next visits to the clinics, when I came alone, I had to face their reluctance to help. The same thing happened in the geriatric ward, where the nurses seemed reluctant to answer questions. It would be a difficult situation to deal with, especially when I needed specific data or just to ask them a few questions. A friend of mine, a medical doctor in the hospital, told me to bring them some cakes. He said cakes would be considered a nice symbol of attention for the low-ranking employees like them. However, for reasons I cannot explain, I never did that.

Focus group discussion

In my research proposal there is a plan to organise a focus group discussion (FGD) with some people who suffer from urinary incontinence. Unfortunately, the distance became the main obstacle to implement the plan. Another reason was the difficulty in finding the perfect time for every participant to be. This was especially true for the family members. Most of them had to work during the weekdays and preferred to spend their weekend with their families. Some of them said that they could not leave their mother without being accompanied.

I could only manage to have an FGD with two physiotherapists. Since it was difficult to find time during the working hours, we agreed to meet at one o’clock in the afternoon to have lunch together. Their clinic only opened until 12.30, and usually they had their “private” sessions in their clients’ houses. Since Mrs. Kustini had already introduced me two her staff, I found it easy to start the conversation. With their permission I used the tape recorder. At first they seemed uneasy with the recorder, but soon they seemed to forget about the presence of the machine.

These two physiotherapists were chosen because they worked in the geriatric ward for several years and thus had a wide experience with the elderly patients. I met one of them (Prita) in the ward during one of my early hanging around sessions. She was instructing one of the geriatric patients there to do the stretching exercises. I reminded her of the meeting. I found it was a good starting point for the discussion, since after that the conversation ran smoothly. The FGD lasted for two hours.
Tyas (38) has been a physiotherapist for the geriatric patients for 12 years. It was started after she completed a short course in Harapan Kita hospital. A mother of two children, she graduated from a physiotherapist academy in Solo, Central Java. The other participant, Prita (32) has been working as a physiotherapist for 6 years. Unlike Tyas who already has the brevet to treat the geriatric patients, Prita is still a general physiotherapist. However, when recently there was an assessment in her work, she mentioned her intention to take a specialisation in geriatric physiotherapist. Prita lives with her husband (also a physiotherapist) and their son together with her parents. She graduated from the academy in Jakarta. She mentioned that although she was a health worker, she found it difficult to speak to her parents regarding their health condition.

2.2. Study Population and Sampling

As mentioned earlier, this study intends to explore the views or perceptions of different groups of people – the sufferers, the caregivers, and the medical staff – about urinary incontinence, the stigmatisation that might be attached to it and how they deal with the problem. For this purpose, views of the different groups were collected and thus the maximum variation sampling was used. This purposeful sampling was employed to generate key issues as completely as possible.

2.2.1. Core Informants

There were several ways to get the core informants. The first informant I met in the field was Dr. Rochani, the head of the incontinence clinic of the urology department. After interviewing him on June 16, 2001, he took me to the clinic and introduced me to his staff. He then asked one of the staff to hand him the medical record of the patients. They were, to my surprise, very open and let me read the record although they knew well that I am not a medical doctor. At first I thought it was probably because I went there with the head of the clinic. When I told the head about the convention to keep the medical record a secret, he told me that they believed that I would not use the information they gave in an abusive way.

From the medical record I could learn that the patients of the clinic were varied in age, sex, residence and causes of the problem. I decided to choose the ones who fit my
criteria to be my core informants: female over 60 years of age living in Jakarta. I also tried to find the most recent cases. There were seven names that fit these criteria before finally I had three core informants from the clinic. The others were difficult to contact, either because they did not answer the phone or their address was not complete. The three core informants were Mrs. Tarida (61 years old), Mrs. Rasyidah (76), and Mrs. Rahima (60).

The next source was a list of incontinent patients I received from the geriatric unit. Similarly, I applied the same criteria to choose some candidates and managed to find several names. However, some of them were either difficult to contact or had passed away. From this unit I had two names: Mrs. Lita (67) and Mrs. Hidayati (69). One informant (Mrs. Inneke, 68) was introduced by Dr. Zubairi, in his private practice place about one kilometre from the RSCM hospital. I met Mrs. In in the hospital and had a conversation there. She was the only core informant that I did not interview in her home. The other two informants, as I have mentioned earlier, I met in the sasana tresna werdha in Cibubur. They are Mrs. Chomsah (72) and Mrs. Dewi (85). Data about the core informants can be seen in the table 1.

I was lucky because there is a medical doctor, Dr Siti Setiati, who is interested in the incontinence problem among the elderly. These days she is doing the KAP survey on this particular problem. Later she became my key informant with whom I could discuss my findings, especially those related to her expertise as a geriatrician.

Another way to get an informant was from the seminar held by the Perkina Jaya on June 2, 2001. Dr Setiati was one of the steering committees for the seminar. She asked me to write an article on urinary incontinence to be published in the newspaper’s Sunday edition, a week prior to the event. The article also functioned as an announcement of the seminar. I agreed with her suggestion, thinking that it was a possible way to get core informants who belong to the upper class. The seminar was held in a four-star hotel and divided into two parallel sessions. Medical staff attended one session, while the other was designed for the lay people (awam).

Based on the number of participants, it was quite successful. Most of them were women, and some of them were couples. They were very enthusiastic participants and asking various questions. During the break I tried to talk with some of them and finally I
got acquainted with Meilani (51), who suffered from the condition more than 20 years. According to her doctor, Meilani had a very serious problem and she would go on a surgery next October.

Because of her age, I realised though that Meilani should be excluded from my core informant list. However my feeling told me that she could be a good source of how the upper class and younger people would deal with the problem. Later I found out that she was really a special case, not only in terms of how the problem would affect their relations with their near-others, but also how it would lead somebody to undergo a metamorphosis of the self. From her story I could tell that it was not an easy process though; however, she managed to go through the pains and dealing with stigmatisation related to her condition quite well.

Another exception in my research was Yanti, a girl of 18 who have been suffering from urinary incontinence for years. Just like with Meilani, I found Yanti was a special case in which I could learn more of what the suffering really meant. I will be discussing her case in the next chapter.

At the end, the total number of my core informants came to eight people. From these informants, only two were still living with husbands (Tarida and Rahima), while Lita separated from her husband seven years ago and is now living with their three children. The other informants are widows. Data of core informants can be seen in Appendix 3, table 1.

2.2.2. Key and Other Informants

During the fieldwork I interviewed six medical doctors with different specialisations from the RSCM. All of them have experience in treating incontinence and geriatric patients though. Of the six doctors, two of them are geriatricians, an obstetric-gynaecologist, an urologist, an internist, a specialist in physical medicine and rehabilitation and a senior physiotherapist (Appendix 3, table 2).

Aside from the medical doctors and for the triangulation purpose, I also did some interviews with other people with different characteristics (Appendix 3, table 3):

1. Two junior physiotherapists (taped interview and FGD),
2. Three nurses from two nursing homes (informal conversation)
3. Two social workers (informal conversation),
4. Three family members (daughters) of the core informants (taped interview),
5. Two incontinent men (64 and 37 years old, the older one is a spouse of RS, the core informant, taped interview and informal conversation)
6. The head of the nursing home in Cibubur (taped interview)
7. Two non-incontinent inhabitants from the nursing homes (taped and informal conversation).

2.3. Reflections on the Topic and Methodology

Urinary incontinence is not a completely new topic for me. The problem has been there for years in my life, since some of my relatives including my maternal grandmother suffers from the condition. My grandmother, whom we call emak, had lost control over her bladder after a repeated stroke. Today, as she also suffers from dementia, emak is very dependent on her youngest child, my auntie who lives in the same house, in a small village in East Java province. Taking care of an incontinent mother must be a big task for my auntie, because at the same time she also has to raise her two daughters, teach in a junior high school in town about 10 kilometres from the village, and run the family rice paddy field and fruit garden. Although she always has a maid whose main duty is to care for emak, auntie often misses the family gatherings, especially those held in other cities. Her main reason is always that she does not have the heart [tidak tega] to leave her mother only with the maid at home.

Later I became more familiar with the condition when I learned a friend of mine also suffers from incontinence due to a congenital birth defect. He has to deal with the daily hassles of being incontinent: washing large amounts of laundry, wearing pads which is not only inconvenient (of course this is an “etic” perspective) but also likely noticeable by others, and carefully keeping the house from the pervading smell of urine. I never imagined before that these tasks could be so laborious since I did not share the burden of my auntie, which is the most extreme case of incontinence in the family.

In my career as a journalist where my specific coverage area has been health and family issues, instinctively I became attracted to this problem, especially the impacts of incontinence to the overall health condition of the sufferers. I got acquainted with some
physicians – mostly internists – in the Cipto Mangunkusumo Central Hospital (RSUPN-CM) who later became my key informants for the fieldwork. The acquaintance had both positive and negative impacts on my work. Among the positive impacts is that I had good access not only to the patients but also to other specialists who deal with urinary incontinent patients. Secondly, they have been good resources with whom I could discuss some findings which needed medical explanation. Most of the time they also showed their willingness to help me as they understood the topic better—of course from a biomedical perspective.

However, there were times when I thought my own perspective on this topic was very medicalised. This was especially obvious in the first two weeks of fieldwork. Reading back on my notes from that period, I found out that my questions were particularly concerned with the cause and treatment according to the core informant, but the term I employed and the way I asked the questions were affected very much by the biomedical perspective. I felt lucky that from the very beginning Professor Sjaak van der Geest had warned me of the medicalisation pitfall if I conducted the research in medical settings such as a hospital. That is why as far as it was possible I did the interviews in the patients’ homes. The overview of the process and findings, which I usually did every weekend, helped me to rethink about my approach and thus reminded me to start digging the so-called emic perspective of the core informants regarding their own condition.

When I interviewed an obstetric-gynaecologist he tried to persuade me to change the subject of my research from elderly women to women in their reproductive age. He said that there were many cases of fistulae – a post-delivery type of urinary incontinence – that might be more interesting to research from the anthropological perspective. From the cases he told I had to admit that the tremendous impact of fistulae on younger women must be a very challenging research topic. However, the limitation of time, of course, would not allow me to change my research subject. I found it a bit difficult to say no to his suggestion, partly because I thought he is the most authoritative person in the department and secondly because there was a gender and cultural bias. It is not easy for me to argue with a man, especially when he is older and has acknowledged expertise. In any case, I managed to continue and to conduct the research based on the planned schedule.
Speaking about bias, I realised that most of my informants belong to middle and upper class society. There are some factors that influence my choice. First, although I interviewed most of the core informants in their homes, I got to know them from medical records of the hospital. Having access to a service provider, especially to a specialist clinic, is one of the indicators of the social class somebody belongs to, that is middle and upper class. Secondly, from the lists of patients given to me by the health staff, I chose only those who had a telephone number – another indicator of the middle and upper class. These choices were made first and foremost because of the time limitation to do the fieldwork.

However, one informant of the younger group (Yanti) cannot be categorised as belonging to middle class although she has access to the hospital. She and her case are very important to deepen my understanding about the situation that the incontinent people have to face.

2.4. First Notes from the Field

My first step in doing the fieldwork was to establish what my surrounding – friends and relatives – thought about incontinence. I did this step informally, soon after my arrival to Jakarta: calling friends, going to my office, and visiting relatives. After explaining my intention to come home, they usually proceeded with the question about my research topic. Interestingly, their first reaction was nearly the same: many of my friends would laugh and said that it was a peculiar topic to studying.

Deni (34), one of my close friends during my time in the college for instance, while giggling said, “Nung [my nickname at home], is it the purpose of your study in the Netherlands? Why should you bother yourself with such a distasteful topic? Why don’t you find another “fresh” topic to discuss?”

However, when I asked her whether she knew somebody who suffered from the condition, she said, “I think many people would be embarrassed to tell others about their condition, and that’s why nobody would likely come to me and tell me [about this].”

A similar comment later came from a daughter of one of my core informants. When visiting her for the second time, she told me that her daughter curiously asked the purpose of my interview with the mother. My asking her mother about her nocturia (beser
malam hari) was, according to the daughter, definitely a weird and uncommon topic in a normal conversation.

So weird, uncommon and distasteful. These were seemingly what some people thought about this topic. First, I felt okay with the comments. Later, when I visited two medical doctors whom I know well, I was a bit discouraged by their reactions. One of them has been known for years as a doctor who has a deep concern to HIV/AIDS in Indonesia, and the other one is a professor specialising in malignancies. During my short visits to these doctors (I met them separately but on the same day, 16/5/01), they were more focused with their own concerns and I felt like they were telling me the unimportance of my topic. Tired and discouraged, I went home and told my husband that I would not see them again during my fieldwork for I did not want my spirit to be ruined. I felt sorry at that time since I acquainted with both of them quite well.

On the other hand, I got a “positive” comment from another friend, Ira (34). She said that it was a strange topic to learn and that there were not many people who would be interested in urinary incontinence problem among the elderly. “I think nobody minds to take care of babies and to change the diapers every time they get wet. Babies are cute. But who will think that the elderly, especially those with incontinence problems, are cute?”

To a certain extent, these comments and reactions gave an insight of how people perceive the problem. As I shall discuss in the next chapters, urine and other bodily waste are the objects of ambiguity. They can be the objects of disgust and the reason to care at the same time.
3.1. It can be cured: A Biomedical Perception on Urinary Incontinence

As has discussed in the first chapter, there are many factors that cause urinary incontinence among women. According to the biomedical perspective, normal aging is not a cause of urinary incontinence. However, age-related changes in lower urinary tract function predispose the older person to urinary incontinence in the face of additional anatomic or physiologic insults to the lower urinary tract or by systemic disturbances such as illnesses common in older people. Yet, as we shall see later, there is a somewhat different (I think ‘confusing’ might be more appropriate in this context) interpretation on this dictum. On the one hand, all the literature on this condition and the key informants said that normal aging is not a cause of urinary incontinence. On the other hand, aging is said a risk factor of the problem. This “grey” area of interpretation, I think, has allowed another (lay) interpretation that is incorrect according to the biomedical perspective: that incontinence is something normal among the elderly.

“The prevalence of urinary incontinence in Indonesia, I think, is not yet as high as the one found among industrial societies. I have an assumption that it is because there are many people here still using the latrine pit\(^6\) [WC jongkok], and the low prevalence of senility, which relates to the relatively low life expectancy.\(^7\) … The level of vasopresine hormone among the elderly is decreasing. This hormone serves an anti-diuretic hormone. This hormone influences the process of water absorption from the kidney. Therefore, an elderly tends to urinate more often than a young person.” (Dr Siti Setiati, 22/5/2001).

Furthermore, as stated by Sirls and Rashid (1999:88),

The lower urinary tract undergoes significant changes with aging. At a cellular level there are changes in the detrusor smooth muscle causing decreased bladder contractility. An incomplete dysfunctional pattern develops that lead to a higher prevalence of involuntary contractions…. In addition, bladder capacity decreases and the post void residual volume (PVR) increases (usually 50-100 cc). In an aging man, prostatic

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\(^6\) A latrine pit or WC jongkok. It is actually only a hole in the ground that can be either outside the house (in a bushy place), or inside the house. The one found inside the house is usually furnished with porcelain or cement bowl. Jongkok means, “to squat”, so WC jongkok means a latrine that you use while you are in a squatting position.

\(^7\) According to the Indonesian Central Bureau for Statistics data in 1995, the life expectancy of Indonesian people had reached the age of 64.4 years.
enlargement causes bladder outlet obstruction in 50% of cases.... In the aging woman, there is a decline in maximal urethral closure pressure and length.... Finally the elderly excrete most of their fluids at night and have an increase in sleep disorders resulting in 1 to 2 episodes of nocturia.

Both writers proceed by saying “Urinary incontinence depends not only on an intact lower urinary tract but on adequate mentation and mobility which can be precarious in the elderly. Though these age-related changes do not directly cause urinary incontinence they may predispose the individual to urinary loss.”

Biomedicine holds on the Cartesian paradigm which separates mind from body. The human body, according to the biomedical view, is thus a physiological and chemical entity that should follow the natural law (Scheper-Hughes and Lock 1998). The scientific and positivistic characteristics of the paradigm – logical, exact, observable, systematic, universal and neutral – are used to explain all conditions experienced by the body, including urinary incontinence. The micturition process is seen as a highly complicated one, involving several organs as well as range of muscular and neurological controls (Mitteness and Barker 1995:190). Incontinence, according to the biomedical view, is then considered a symptom indicating a disturbance – which is also biological – to the process. Not only are all the causes and complicating factor biological, but also the treatment (Thakar and Stanton 2000, Setiati 2000, National Guideline Clearinghouse 1996).

"Only one out of 12 incontinent people needs continuous care. The rest can be managed with various medical and non-medical treatments. However, usually one will only ask for a doctor’s help when his or her incontinence has become very severe or in the advanced stages. ... Whatever the cause of incontinence and no matter how severe it is, the combination of medication therapy and pelvic floor muscle exercise [latihan otot dasar panggul] as well as bladder training will give optimal results. The exercise should be carried out on an indication and carefully observed by medical staff.” (Dr Nuhonni, 2/6/2001).

3.2. Biomedical Treatment for Urinary Incontinence

“My mother, 69 years old, complained about her inability to control her bladder and wetting her bed. I was a bit shocked when she told me about the problem three months ago, because according to her the problem had started about two years ago. In spite of her complaints she thinks that the condition is normal for her age and she refuses to see the doctor. She told me about her “secret” because she became very tired of having
to change clothes often. Because she has to perform daily prayers five times a day, the problem disturbs her very much since she has to do the ablutions several times ...."

(A letter for a medical consultation column in a newspaper in Jakarta, 8/4/2001)

Nowadays there are various kinds of treatment offered for the incontinent, ranging from non-invasive treatment such as behavioural therapy, which is considered effective and carries minimal risk, to invasive treatments such as surgery. Many "bladder training" programs exist, and include habit training, timed voiding and scheduled "re-training" (Sirs and Rashid, 1999:94). Other treatments are pelvic floor exercises, pharmacological therapy, including the use of hormone replacement therapy (HRT) which is becoming more and more popular among women in their pre-menopausal period today.

Aside from the treatments, there are several methods used by the incontinent to overcome their problem. These methods include the use of diapers, catheters, and toilet devices such as commodes, bedpans, and urinal devices. The choice of treatment, however, is determined not only by the financial reason and support from the family, but also by the idea of the cause of the condition.

As I have mentioned in the introduction, the rivalry among the different groups of doctors dealing with urinary incontinence has a great influence of how an incontinent patient will be treated. The following example may illustrate the situation. One of my core informants (Tarida) has been taking the same medicine given by her surgeon for more than four years and it makes her the expert for her health condition:

**Researcher (R):** When you see the doctor, what does he do to you?

**Tarida (T):** He gives me the medicine [*taking the medicine from a shelf. There are three kinds of pills: Urispas 200, Neuro-beston (vitamin), and Pyridium*].

**R:** Any other treatment? Does he ask you to do some exercise?

**T:** No, just the medicine [*pause*] ... It's expensive, *Mbak* [literally means "sister", but is also used to refer in a respectful manner to a new or a younger person]. If I go to RSCM, I have to pay 70-100 thousand rupiah for the consultation only.

**R:** How long have you used this medicine?

**T:** More or less four years.

**R:** How long will you take this pill?

**T:** I don't know. I want to recover so I just follow what the doctor says.

**R:** Are there any side effects of taking this medication?

**T:** No. If I feel sick, I'll take *Ponstan* [a painkiller]. Once I had warts. Then I went to a doctor and he operated on me. It was so painful [*pedih*] that I asked the doctor to
give me Ponstan 500. Since then the doctor always gives me the painkiller. I do not take less than Ponstan 500. It was at that moment that the doctor noticed that I also have diabetes and high cholesterol. I'm old and have a lot of ailments [Udah tua mah penyakit macem-macem keluarnya, Mbak].

R: And what are these other pills?
T: This one [Pyridium] I take along with antibiotics to treat urethritis. I often get this ailment and go to see the general practitioner to get this pills. I like [cocok] this pill. Once a satpam [member of security guard] said that he had a urinating problem. I gave this medicine to him and the next day he came over to thank me. He had recovered. This is only a vitamin. The surgeon gave me the prescription.

I was surprised to hear that she has been using the same medicine for such a long period, because I think people should only use a certain medicine for not more than a few months. On the other hand, this finding shows that despite the “normality” of the problem among the elderly women, there is always an exception in accepting it. Some people would probably still try to seek medical help and overcome their problem.

To sum up, according to the biomedical perspective, the assumptions that incontinence is normal for the elderly and that it cannot be cured are persistent myths among society. In Indonesia, many people believe that if you restrain the urge to urinate, you risk getting kidney stones (kencing batu) because the urine in the bladder will be hardened and difficult to void. According to Setiati, however, it is sometimes necessary for an incontinent person to restrain the voiding as a behavioural treatment (bladder exercise) though she would not ask her patient to restrain if they had infection in their urinary tract because it would increase the severity of the infection.

3.3. It is normal for my age: Lay Perception on Urinary Incontinence

It is interesting to explore the differences between biomedical and lay perceptions about the causes of urinary incontinence to get a deeper understanding of the reactions toward the condition. However, a clarification should be made on what I mean by “lay” – person or perception – in this study. I use the term lay [awam] as a reference to either a non-biomedical perception or person. The sufferers and their care providers (families and non-family members) are included in this group.

The term incontinence has not yet been made popular in the Indonesian society. To point out the problem, they use the term ngompol or mengompol (to wet the bed or
one's pants) or *ngoprok* (in Javanese, others may say 'ngombrok'), which particularly means wet one's pants. Another term used is *beser*, which means, "to urinate frequently". Both the medical staff and lay people use this term. However, I found some people who used the term *beser* – which implies that the individual may urinate more frequently but still has bladder control – to name their incontinence problem.

If people would like to go to the toilet either for urinating or defecating, they probably would say that they are "going to the back (of the house)" [*ke belakang*]. Another term to refer to the urinating process is *pipis*. Taken from the Javanese language, this word is usually used for children and considered finer that other words such as *kencing*, although the meaning is the same.

Lita (67) used the term *ngewer* for her inability to restrain the micturition process before she reached the toilet.

**R:** Do you "wet" yourself when you are coughing?

**L:** No, because I don’t cough even though I have asthma. My asthma flares up if I get annoyed by the children, and I will wheeze. If it happens, I should get my medication and put it under my tongue. About my incontinence [*pipis*], it usually happens in the morning. As soon as I step into the water [*means: step into the wet floor of her bathroom*], I will *ngewer* (urinate) instantly without being able to stop. Even before I take off my pants, the urine will come out. There is no break anymore [*Sudah ndak ada remnya*] ...(laughing). I can restrain it when I’m still in bed, [I can’t restrain] only when I reach the bathroom. Sometimes I take off my pants before I go to the bathroom [*smiling*].

**R:** Do you feel the urge when you wake up in the morning?

**L:** No, not yet. But when I take off my sandals in the bathroom, it is cold ... then it will come out and cannot hold it.

However, lay people say that urinary incontinence among the elderly is caused by frailty and disintegration resulting in the loss of bodily control along with the increasing of age. In other words, urinary incontinence is just a normal part of the aging process (Mitteness and Barker: 1995). When you get old, your muscles are not as strong and flexible as when you were young. In other words, getting old is synonymous with getting weaker. So it is “normal” that you have a “weaker bladder” or a “weaker sphincter” in your old days, as well as “weaker thinking” (*lemah akal*, senility) and “weaker sight” (*lemah penglihatan*). Consequently, urinary incontinence is also seen as something “normal” among the elderly.
Tarida (61), is a patient of the incontinence clinic in the urology department, RSCM. She used to be a nurse in a private hospital in Jakarta. According to her, she suffered from the condition after giving birth to her third children, a daughter, about 17 years ago. She was 45 years old at the time. “After the delivery I had this beser kencing condition. I went to a doctor and he told me that it was due to persen [some muscles had been extracted] when I was straining during the process of delivery.”

Interestingly, when asked about how she felt about her incontinence, she said that she did not mind wetting. “I can void swiftly. Yes, I cannot withhold the process, but I do not feel the pain either.” [Kalau ngompol mah enak. Lancar kencingnya. Nggak bisa ditahan, tapi saya juga ngerasa sakit.] For four years she has been taking medication from her surgeon to overcome her incontinence.

Hidayati (69), is a patient of the geriatric clinic in RSCM. She lives with her two daughters and one son, two son-in-laws and two grandchildren. Four years ago she was hospitalised because of a stroke attack, which impaired her mobility. “When I was in the hospital, they put a catheter so I could not sense the urge to void. Since then my urine has become excessive and cannot be withheld.”

Every night the informant feels the urge to go to the toilet about 10 times. However, because of her impaired mobility, she fell several times in the bathroom. Her children then used perlak [a plastic or rubber sheer to be used under the bed sheet], and asked her to wet the bed instead of taking a risk to fall down in the bathroom. Her son used to accompany her at night, but lately he refused to sleep in the same room with her mother and she has to be by herself at night. Nobody would help her use the toilet.

Actually, she said, the doctor has referred her to a physiotherapist. “But I would not go. If it worked, then it would be okay. But what if it didn’t work? Besides this is normal for my age. When you’re old, you are a ‘nest of diseases’ [sarang penyakit].”

Lita (67), is a patient of the geriatric clinic in RSCM. She retired from her position as the head of a nurse dormitory 12 years ago and worked in a private hospital as a nurse until 1996. She lives with three children and is separated from her husband – who married to another woman – seven years ago. She is not sure when exactly her incontinence problem started, but as long as she remembers, she never had the problem when she was on duty. She thinks it occurred about five years ago, when she retired from her job. “I was 62 at the time.” However, “I often go to the toilet [beser], because I drink a lot of water, about 2 litres per day. I’m afraid the medicine [given by the doctor to cure her asthma and rheumatism] will precipitate in the kidneys if I do not drink enough water. I’m not on a diet either, as long as I do not eat too much.”

Moreover, she said that her beser worsened when she gets a cold [masuk angin, which literally means, “to get the wind trapped inside the body”]. If I get masuk angin, I would go to the toilet more than five times a night. My oldest daughter will notice it, because she is the one who washes my clothes. [My family] can accept my condition. I’m old already.”

According to the informant, when she talked about the problem in the religious congregation that she attends regularly [pengajian], her friends would say, “Ah, it’s
normal. We’re old, and the brakes have given way [Biasa, sudah tua, remnya sudah dol],” and they will laugh together.

Rasyidah (76), is a patient of the incontinence clinic. She started having the problem less than one year ago, a few months before her husband passed away last December. She does not know exactly the cause of her condition, but she said, as a child, she only stopped wetting her bed when she was 15. “My andung [grandmother] used to take lift my mattress and dry it under the sun. Now Ria, my granddaughter, has the same habit. Her father was angry, but her mother said, ‘Never mind, Pa. It runs in the family.’ [Sudahlah, Pa, sudah keturunan itu].

The informant suffers from rheumatism, which necessitates her going to see the doctor. She started seeing her urologist a couple of months ago, but it seems her incontinence does not bother her as much as her other illnesses. She said, “This is not much of a problem for an old woman like myself. I am only disturbed because sometimes I have to perform ablution more than once since a small amount of urine is usually voided just before I finish.”

Rahima (60), is another patient of the incontinence clinic. Her husband also suffers from urinary incontinence due to his prostatic hypertrophy. Together they went to the clinic but it was only her who received further treatment. She is not sure when the problem really started. All she remembers is that after giving birth to her second child, about 25 years ago, she never feels relief after voiding [tidak lampias]. “My masseur [tukang urut] knows it. She can feel it. This problem has got worse especially these last five years. Whenever I cough a small amount of urine is lost. Sneezing is even worse. I cannot stop the flow of urine.” Moreover, cold wind and water will induce her sense of voiding.

Furthermore, after standing a couple of hours she will void without having a sense first. During the last fasting month (December to January), she visited the clinic and went through minor surgery. “The doctor found a blockage in my urinary tract [tempat kencing] and he said that it was really a bad condition. He decided to operate on me, ‘to widen the tract,’ he said. I wondered at that time and asked whether or not it would make my condition worse. Without the operation my pipis was already too swift, let alone with the operation. He said it was not the aim of the surgery, but he never explained any further.”

The informant should come back for further post-operative examination. However, she thinks there is no real improvement in her condition and does not see the doctor again. She uses massage to relieve her condition, though not regularly. “[Katanya karena kolesterol dan usia kita juga].”

Urinary incontinence, according this lay view, is not only something inevitable (part of the process of growing old), but also irreversible and untreatable. From the eight core informants, only three of them went to the doctor to seek medical help. They are Tarida, Rasyidah and Rahima. Furthermore, only Tarida who sees her doctor on a regular
basis. The other two have their own reasons for not seeing the doctor to continue their treatment. The most common reason — for all informants — is the major illnesses that become their main concern such as asthma, rheumatism, a painful hand, heart disease, diabetes and cholesterol.

Yet, as I noticed during the conversation, aside from the inevitability of the problem, money is still an important issue. Though they did not mention directly, some of their reasons implicitly describe the existence of the financial problem. Some of them (Lita and Rahima), said that they could not see their doctors because, “it [the hospital] is too far from where I live,” “I don’t have a car and going by public transport is very tiring for my age” and “nobody could accompany me there.” Others, for example Hidayati, would give a more skeptical reason. “If it works, then it’s okay. But what if it doesn’t work?”

The similar attitude towards incontinence is also shown by the caregivers in the nursing home. According to Wahjudi, there are some cases of incontinence in the nursing home where he works. He could mention several names of the incontinent and said that there must be more cases of which he did not know yet, since “they must be embarrassed to tell their problem to us even though it is a quite normal situation among the elderly.”

He said that he applied a “no therapy” approach to resolve the problem. “I just ask them [the incontinent residents] not to drink water at least two hours before they go to bed. I also trained them to go to the toilet every hour, whether or not they feel the urgency to void.” When I asked him about using diapers or other absorbent materials to prevent the wetness and smell, he said that it was very expensive and not all of the residents could afford buying them. In other words, the nursing home does not provide them for daily use because it would be too costly.

The result of his approach, according to him, so far is quite successful since some of them are — to a certain extent — able to manage themselves. “But if we stay with Oma Rini for a while, we will smell ‘something’ coming from her,” he said. Oma Rini is the first resident I met in my first visit to the place.

During my stay in the nursing home, I had enough time to hang around with some nurses and social workers working there. One of them (Atika), a social worker, said that
previously there was a physiotherapist who visited the nursing home once a week. She, Atika said, trained the residents with a special exercise for the older people [senam lansia]. However, she stopped coming to the nursing home. I asked Atika why, and she told me that it might be because the nursing home could not afford to pay the physiotherapist.

Aside from old age, another popular idea on the urinary incontinence shared by biomedical staff and the lay people is the “disease of women”. Incontinence, according to some core informants, is something that becomes part of her existence of being a woman, something that is as natural as giving birth to a child. Moreover, an incontinent elderly is compared with an old car which brakes “has given way” or “needs a thorough service” (Susilo, 11/06/01)

“Beser kencing is a women’s disease. In RSPP [a hospital in Jakarta belonging to Pertamina, the National Oil Company where she used to work], there are many men suffering from the condition, but the number of women suffering from the same condition exceeds them. Because of the delivery…” (Tarida, 21/5/2001).

“First I wonder why I had this condition, but my doctor told me that there are many women who also have this [condition]. He said, the more children you have, the more likely you will suffer from the condition,” (Rahima, 11/6/2001).

These reasons, in turn, enhance not only the idea of inevitability but also the irreversibility and untreatability of urinary incontinence among the female elderly people.

3.4. I’m luckier than they are: Perception on the Urinary Incontinence Treatment

Because of this belief of the “normality” and “predictability” of UI, the elderly people do not expect a cure for their incontinence. Instead, while answering my question on why they did not search for medical help to cure their incontinence, they would tell me about other people they knew who suffered from the same problem, especially those who cannot manage their condition well.

“My mommy in Bandung even has to put a bucket in her room to pee. She prefers a bucket to a bedpan because it is higher and all she has to do is to uplift her daster [a house coat, lounging gown] and squat. She never wears panties. She said, ‘Why should I? It gets wet all the time.’ Luckily she never wets herself [ngombrok] in other places.” (Lita, 24/5/2001).
“I have a friend, a man in his late 60’s who has a bucket in his car. So every time he is driving and wants to pee, he just does it there. Yes, in his car. He voids very often, because of his prostate problem and diabetes. He will empty the bucket when he gets home. I thank God that I am not in his position.” (Susilo, husband of Rahima, 11/6/2001)

“I am very grateful to the Lord for my life today, even though I stay in this nursing home. A friend of mine has to live with her married son. She is incontinent, and it makes her very depressed. She needs to go to the toilet often, and it makes her embarrassed towards her daughter-in-law. She [the daughter-in-law] always complains of having to clean the bathroom more often” (Oma Dewi, 26/06/2001).

Oma Dewi, 85 years old, has been living in the nursing home for 14 years. She came for the first time to the place with her older sister, who had passed away in 1990. Atika, the social worker in the nursing home introduced her to me. She is one of the people in the place who are said to be incontinent. Another resident, Oma Tati, who is the head of a pavilion [ketua rukun tetangga], told me also that Oma Dewi and Oma Chomsah are used as objects of criticism and gossip because of their condition.

The first time I met her, she was sitting in the recreational hall and reading the bible. She is a keen bible reader, as I found out later. She asked me to clarify why I chose her as an interviewee, since, according to her, she does not have the problem. “I’m not incontinent. Thank God that I’m not because it would be very embarrassing” [Saya kan tidak inkontinen. Puji Tuhan saya tidak, karena akan sangat memalukan].

I was a bit surprised by her words because it was completely different from what the caregiver told me. I decided to tell her that I would like to hear from her about the problem among the elderly living in the nursing. Moreover, I said, since she had been there longer than some people she might know who suffered from the condition.

She started by telling me that incontinence is something common among the elderly [biasa kalau sudah tua]. However, she thinks it is an embarrassing situation because, “Since we were very young, we were trained to do it in a proper place, that is in a toilet.”

Later, when I asked her about her own condition of health she told that every night she had to wake up 8 to 12 times to go to the toilet. “I am lucky because the bathroom is very near, so I don’t have to walk a long way to reach the toilet.” The proximity to a
toilet, as I shall discuss in the next chapter, is one of the strategies of people with incontinence to remain in control. In this nursing home every room is equipped with a bathroom.

Because of the condition, Oma Dewi said, she prefers to go to bed as early as 9 p.m., because she would almost certainly be woken up around 12 p.m. Usually it will be difficult for her to have a good sleep until the dawn. During the day, she only needs to go to the toilet two or three times.

The daily routine in the nursing home (as well as in the other home), as I noticed during my stay there, starts as early as 3 a.m. A nurse will walk from one door to another, distributing hot water in buckets for bathing. I am not sure whether it is because the residents are used to waking up that early (there is a resident who even starts her day at 1 am by washing her dishes!), or they are waken by the knock on their doors and the voice calling them to take their water. Every pavilion has its own solar heater, but one who needs it has to fetch the water since there is no hot water pipe available in the bathroom. Those who are considered strong enough are encouraged to fetch the water themselves. Nurses and social workers will only help the sick and the very old ones.

Oma Dewi is one of those who needs help regarding the water because she is already too weak to bring a bucket full of hot water herself. However, when I visited her room I was amazed with her tidiness. She puts everything neatly in its place. Her clothes are folded almost symmetrically. She has different shelves for different type of clothes. Despite the pervading smell (not very strong, though) and a small container of soaked underwear, her bathroom is also clean and well lit.

Oma repeatedly told me that she was not incontinent. When I asked her about what was so embarrassing of being incontinent, she said that she was sorry for those who suffer from incontinence. “They must feel uncomfortable [nggak enak] because their underwear is always wet and dirty. They will also feel embarrassed. That’s why I am always thankful to God for not giving me the condition, for blessing me with good health. I don’t want to be incontinent until the day I die. I don’t want people to feel pity for me.”

When I told Atika what Oma Dewi had said to me, she replied, “Of course, nobody would admit openly that he or she is incontinent. Besides, Oma De has become
partially senile [sudah mulai pikun]. I often have to clean her urine or even her defecation. Sometimes when she is walking from the dining room to her own room [which is approximately less than 10 metres], she will urinate or defecate without knowing it.”

However, during my conversation with the lady, I hardly noticed her senility. I think she is only a bit slow, but not necessarily senile. She is able to tell me her life story, to reply to my questions clearly and to keep herself and her room relatively clean. Moreover, she is still able to write two letters to her niece and cousin who live in the Netherlands (she asked me to post the letters from Amsterdam).

Incontinence among women, according to some studies, is associated with depressive symptoms and leads to embarrassment about appearance and odour. On the other hand the incontinent elderly have often adapted to problems by denying or ignoring them. This, I think, explains the denial of Oma Dewi of her condition.

Despite “comparing” oneself to other unfortunate people and denying, another way to normalise one’s situation is describing the acceptance of others, especially the near-others such as family and close friends. By telling others about their good relationship with their family, they seem to emphasis their unproblematic situation despite their condition.

The acceptance from others is somehow considered the “normality” of one’s condition and shows the ability of the self to socialise and to keep in contact with others. However, as I will be discussing further in the next chapter, one’s attitude and acceptance of his or her situation also determine the acceptance of others. Oma Chomsah, is an interesting example in this case. She intentionally ignores her incontinence, even when it becomes very obvious in terms of wetness and particularly smell, and takes a risk to be the object of ridicule. She still attends the angklung session and religious forums although nobody can stand sitting next to her. The social worker in the nursing home, for instance, said that she has to remind Oma Chomsah to change her clothes more often. “But usually she only says, ‘why, you are arrogant now’,” [kamu sombong sekarang].

On the other hand, as shown by Mitteness and Barker (1995:195-196), of their respondents who did mention their incontinence to a physician, nearly half (48%)
reported that the doctor had not responded to their report, either by ignoring the statement of symptoms or by providing a dismissive explanation. They did not send patients for diagnostic evaluations and offered few interventions. Dr Yunizaf, an obstetric gynaecologist, shares this view. “There are many doctors who think that it [urinary incontinence] is a psychological problem, which is beyond their expertise. Other doctors may think that it is not a big deal, while their patients may think differently,” (28/5/2001).

Of course there is a big chance of bias from the side of the patients. They may feel so embarrassed so they cannot speak about their problem clearly, or they may have a assumption that the physician does not have much time to listen to their problem carefully. Therefore it does not necessarily indicate what the physician intended to communicate. Nevertheless, as discussed by Mitteness and Barker, it is clear that whatever occurs in the consultation room has the effect of normalizing incontinence — suggesting that by its very commonality, it is predictable and hence a normal part of aging.

“It is rather problematic to say that incontinence is a kind of disease, because in fact it doesn’t directly threaten your life, although it probably will cause you to want to die,” [tidak mematikan tapi bikin pingin mati] said Yunizaf further.

Another point that is important is the biomedical view on geriatric patients. According to Supartondo, a geriatrician, aside from multi pathological feature, there is also a physiological change that will cause difficulty in establishing diagnosis. An acute disease found in a geriatric patient, according to him, will be more difficult to treat compared to the one found in younger patient because the symptoms are different due to the physiological change. Moreover, the multi pathological feature among the older patients makes the treatment more complicated. “Doctors should make a priority, which disease should be cured first. One should remember that doctors cannot cure all the diseases. It is impossible, because the functions of organs in the old body have undergone a decreasing process,” he said (6/6/2001).

This explanation provides an area where the biomedical staff (doctors and nurses) share the lay perception of urinary incontinence: that “emphasis must be placed on primary health care as many patients can be managed at this level, thus ensuring an
appropriate referral to hospital,” Thakar and Stanton (2000). The complicated causes of the problem and the physiology of the elderly encourage the emphasis on the primary health care. This emphasis also implies that the condition is not easy to treat and the best way to tackle it is by managing and preventing the occurrence of a more complicated problem like urinary tract infections.

Moreover, as mentioned by Dr Nuhonni, the behavioural treatment, although is the best choice in terms of risk, is very complicated to apply. First, the patient should make a careful note on his or her voiding habit, including measuring the urine, for at least five days. The use of medication and exercise, according to her, depends very much on one’s condition and can be “negotiated” with the patient based on the evaluation their pattern of voiding.

“It can be very complicated, and not all doctors are patient enough to handle such cases,” [emang rumit, nggak semua dokter telaten ngurus yang begituan] she said. Usually, she proceeded, the doctors or physiotherapist – especially those who specializing in treating the paraplegic – are able to handle the incontinent patients well, while the others completely ignore the problem.

On the other hand, the compliance of the patients, especially the older ones, is very low.

“Our people do not see it [incontinence] as a problem. If they feel disturbed, they will wear diapers and the problem is settled. They also see it as something normal among the elderly; they don’t complain and thus do not prioritise it. When I explain about the rehabilitation program to treat their incontinence, many would say ‘Oh, why is it so troublesome?’ [Kok repot sekali ya, malakukannya?]. I don’t know. Maybe I have to make a deeper assessment to know every patient’s situation and thus assure them to undergo the rehabilitation process,” (6/6/2001).

The incontinent patient is often emotionally unstable. Therefore, the caregivers need to know whether their patients is under stress, angry, feeling guilty, sad, lonesome, isolated, confused, depressed, or happy (Dr Nuhonni, 2/6/2001). The positive attitude of the caregivers, according some doctors and physiotherapist, is very important for a successful treatment. However, the findings from the field which I will be discussing in the next chapter tells me that to maintain the positive attitude is always very challenging for the family and the caregivers.
3.5. Incontinence Among the Younger People

According to Mitteness and Barker (1995:189), incontinence among younger people – those who are in early adulthood who suffer from spinal cord injury, neurological deficit, or congenital birth defects such as spina bifida – is aggressively treated and managed. This fact is in accordance with the social imagination about the place for each group in a society. Treatment for incontinent younger people is aimed at returning them to their social world, to keep them connected to their society. Therefore, urinary incontinence, which is synonymous with social stigma, should be removed as quickly as possible.

As mentioned in the earlier chapters, during the fieldwork I met three incontinent younger people. Their experiences summarised below are aimed to give a deeper insight of how the young may perceive their problem.

Yanti (18), is a patient of the Urogynaecology Clinic in the Obstetric-Gynaecology department, RSCM. She has suffered from incontinence since she was a little girl. When she was in the fourth year of elementary school, she stopped going to school because she was “always wet and too embarrassed. All my friends mocked me [ngeledekin] so I couldn’t stand it.” Her family, according to her, did not prevent her from leaving the school. Her mother once said to me that she felt pity for her youngest child because she could not complete her basic education.

In 1994, Yanti underwent surgery in a hospital in South Jakarta. She used to have severe PMS every month, during which period she had to stay in bed for days to ease the pain. It happened for years, she said, before the family decided to take her to the doctor. Both the patient and her family did not know very well what was wrong with her. All they knew was that the doctor recommended surgery, during which he drew ‘a bucket’ of blood and pus from her stomach. The painful syndrome eased. However, Yanti said, her incontinence worsened. After the surgery, urine came out of her vagina. “It had never happened before,” she said.

Two weeks before the fasting month (Ramadhan) in the year 2000, Yanti tried to commit suicide by drinking pesticide. According to her mother, the trigger was when Yanti asked some money from her parents to buy a fashionable cloth. Her father refused to give her the money, saying she should think about the coming Ramadhan instead of buying a new cloth. “She is very spoiled. Whenever she has money, she always spends it to buy anything she wants. She likes to eat delicious and expensive food, and rarely eats my cooking when she has money to eat out. She always acts like a rich girl.”

Thakar and Stanton (2000) use the phrase “the last social taboo” to describe the burden caused by incontinence, including the distress, embarrassment, and inconvenience. Other writers, Sirls and Rashid (1999) describe incontinence as a “social cancer,” with risk of embarrassment, isolation and depression.
However, Yanti has different explanation. She said that she determined to end her life because she could not stand her situation. “It is not enough to pray and ask God to recover. We have to try our best first before we surrender. They never take me to the doctor to get the treatment for my ngompol, whereas I got tired and fed up [capek dan kesal]. I cannot wear leggings or stay overnight in my relatives’ homes or hang around with my friends. Sometimes they come over, but I also want to go out with them ... I'm tired of having to wash my clothes, a tub full everyday....”

When she was 8, her family took her to a healer in Bekasi, eastern Jakarta. She said the healer had a “smart” [pintar] cow that could heal all kinds of diseases. The animal licked her stomach with its tongue and Yanti said her pain eased after that. Unfortunately her incontinence still continued, and not until her trying to commit suicide did her family start thinking about medical treatment for her. “After all that, they only did so after one of my aunties who is a masseur told that my problem can only be handled by a doctor.”

On June 19, 2001, Yanti underwent fistula surgery. She had to stay in bed for ten days. It was such a critical period, which determined her recovery. I visited her several times during her stay in the hospital, but not after she went home.

Meilani (51), became incontinent after giving birth to her third child in 1981. The delivery took place in a big private hospital in South Jakarta. “I have signed an agreement to deliver with the help of a certain doctor, but when my baby was already in its way, he had not show up yet. The nurses then tightened up my legs to prevent the baby from coming out.” Even so, she does not want to say that the delivery itself caused her incontinence. “God wants me to have this condition. It is not because of the delivery, I don’t want to put the blame on my child.”

What she suffers most from, according to her, is that the condition troubles her to perform her daily prayers. “It disturbs my praying. I am a mother and I always want to pray for my children. My youngest child [her third child]... she is very unfortunate. She always has problem with her sight....” [crying]. Moreover, she said that if an ailment disturbs other people, then it must be the most difficult one [Kalau penyakit mengganggu orang, itu yang paling berat].

Because her husband is rich, Mei could afford to have the best treatment available. In Jakarta, she asked to be treated by a team consisting of the best doctors in RSCM. She then underwent several operations - in Indonesia and abroad. When I asked her about “conventional” method to treat her ‘stress’ incontinence (she used the term in a rather different way from the definition given by medical doctor), she said that she had been disabled [cacar] after the major trauma, the exercise would not help her.

Next October, Mei will be undergoing another surgery. When I asked what operation it would be, she said that she had no idea. “I don’t know exactly. I only do what the doctors suggest. I only undergo the treatment process, and don’t expect too much for the result.” Interestingly, while preparing herself for the coming surgery, she regularly visits a physiotherapist and has a positive impression on the exercise program. “This helps me to relieve my stress and control my incontinence,” she said.

For her, the condition brings her a blessing in disguise. Tired of having to take medicine, she decided to start her diagnosing program and apply her own detoxification
method. She starts eating only natural food, including drinking goat’s milk which she believes is much better than the cow’s milk. Nowadays she produces and sells the milk and natural vegetables and becomes an entrepreneur. “I do not do it for money because I already have more than enough. This is my missionary endeavour [dakwah]. I only expect the blessing of Allah.”

Endro (37), was born with a congenital birth defect, spina bifida, which caused him urinary incontinence. When he was three years old, he underwent surgery to remove the lump on his lower back. His parents took him to many traditional healers, but in vain. Then they stopped trying and he uses diapers to avoid the wetness. In 1995 a neurologist assured him that it was his destiny to live with the incontinence, and that there was nothing that the biomedicine do to help him. However, he continued his study and got his masters from a university in the USA. Now he works as a computer analyst and still manages to hide the problem. No one in his present work knows his problem.

Four years ago, he had to undergo surgery to remove one of his kidneys. According to his urologist, his incontinence makes him vulnerable to urinary tract infection. Unfortunately, he was never aware of the symptoms and the infection “climbed up” and damaged the organ. He is married to his first girlfriend (“I never thought I would marry at last”, he said once) for five years now and the couple still conceals his condition from the wife’s family. “I don’t mind telling her family about my condition, but I think she is not ready yet,” he said.

The problem, according to him, used to be his source of anxiety. Whenever he saw or listened to something unpleasant or shocking, a small amount of urine would void. “However, during the orientation sessions before I left for the States, a psychologist told me in person that I could be a winner or a loser with my condition. It was all up to me, and I tried not to focus too much on my condition.” Nowadays his main concern is his health, and therefore he regularly has a medical check up.

These cases show how the perception of the younger people on the problem is diametrically different from that of the older people. While incontinence among the elderly is considered normal, the incontinence among the younger people is considered an abnormality which has to be removed as quickly as possible. This view is in accordance to the social imagination about the place of each group in the society. Treatment for incontinent younger people is aimed to return them to their social world and to keep them connected to their society.

Besides the more aggressive treatment to overcome the problem, the condition causes more stress and embarrassment. “One of my patient’s reasons for treating his

9 Spina bifida is a serious condition in which some of the vertical row of bones in the centre of the back are not correctly developed at birth, leaving the nerves in the back without any protection. It may cause physical and mental handicaps.
incontinence is because he is so embarrassed to frequently go to the toilet. He thought that he would disturb others by doing that. Even a joke from one of his colleagues at work about his toilet habits would be very offensive to him,” (Dr Nuhonni, 6/6/2001). And it is the psychological impacts of incontinence that motivates them to seriously get the treatments.
4.1. Coping Strategies of the Incontinent

During the seminar on urinary incontinence session on June 2, I received some brochures containing basic information about urinary incontinence. There are interesting cartoons showing the uncomfortable situations that the incontinent people should deal with. In one of the cartoons there are some older people queueing up for a public toilet, among them are two children who already have wet themselves. Another cartoon shows a woman whose left ankle is manacled to a toilet bowl. She looks fretful and her urine is spilled on the ground, under her feet.

I found this picture particularly interesting, for it depicts almost precisely — although in a caricatural manner — what most of the core informants’ situation in their daily life is. Most of the time the people with incontinence should make a plan for their activities by rescheduling them with the proximity to toilets. Mitteness and Barker (1995:197) call this strategy “planning ahead”.

Secondly, they may try to improve physiological control, e.g. by doing Kegel’s exercise or searching for help from a physiotherapist, or reducing the daily water intake. Knowing that their physicians will forbid them from doing the latter, many incontinent people do not consult such a decision with their physicians.

Thirdly, if other management strategies fail, the most important thing to do is to control the environment that is to prevent or minimise both wetness and odour. The environmental control is not as simple as it sounds. The task includes washing massive amounts of laundry (including bed-covers), and drying mattresses in the sun regularly, and cleaning the room and bathroom more thoroughly to prevent the smell. If the continent person is also a bedridden patient, another task is frequently turning the patient to prevent bedsores. The caregivers, especially female, may find these tasks physically exhausting. Male members of the family are sometimes recruited to assist with care requiring physical strength, such as lifting a patient for a bath. In short, we can say that incontinence adds to the hardness of the care of the elderly. It is not surprising then if any
person will say that dealing with incontinence — just like other chronic illness — is like having a full-time job (Mitteness and Barker 1995:199) or even a lifetime career.

Tarida (61), based her outdoor activities on certain conditions, such as the availability of a rest-room and wearing baby diapers. However she stops attending arisan [regular social gathering whose members contribute to and take turns at winning an aggregate sum of money] in her neighbourhood. “My neighbours know that I have a beser kencing,” the ex-nurse of a private hospital in Jakarta said. She prefers to use baby diapers when going out because they are “comfortable, big and absorb fluid very well” [enak, besar, dan bisa menyerap banyak]. She only wears sanitary napkins – which is thinner than a baby diaper – when she is home, “because the bathroom is near.” Although the baby diapers are very expensive (they cost 7000 rupiah each), she always has a reserve at home. Sometimes she buys four boxes, each box containing 10 diapers, at once.

According to her daughter (Lisa, 18), when they are going out of town, her mother will bring a plastic sheet and put it on her seat because it is sometimes difficult to find a public toilet. With the sheet under her seat, says Lisa, her mother can wet herself [mengompol] if a public toilet is difficult to find, and does not have to suffer very much. Lately, Lisa says further, after her mother broke her arm, her father sometimes helps her wash her clothes and her bedsheet. “When papa is not home, mama never changes her bedsheet, although the stench of her urine has become very strong. She only changes it when papa is about to come home.”

She never does exercise, including Kegel’s exercise. She said that she has has problems with her skin, especially her face. It will have black spots (sunburn) if she stands too long under the sun. The inside part of her house is damp and the unpleasant smell pervades.

Hidayati (69) has been homebound since a stroke she had recently which has also worsened her incontinence. She does not go outside except to see her doctor. “I do not go window shopping anymore,” [tidak lihat-lihat pasar lagi], she said. Because of her impaired mobility, she intentionally reduces water intake. She has urgency and leakage of urine especially at night. Moreover, she refuses to drink enough water because she does not want to bother her children with too much laundry. She used to sleep with her son who would assist her to go to the toilet at night. Now she has to sleep alone because the son refuses to share the room with her. Her daughter puts a plastic sheet on her bed, so she can wet her bed and doesn’t have to wake up and go to the toilet. “But it is very uncomfortably wet,” [Ndak enak, basah-basah kita], she said.

Since the last two months she has been suffering from rashes, which is probably because of her continuous wetness according to one of her daughters who lives separately. She never wears underwear when she is home because she “cannot restrain” [suka keburu].

Hidayati only takes one bath early in the morning. This is usually before 4 a.m., before her son, who helps her bathe goes to work. She seldom takes a bath in the evening because nobody would help her. The son is not home until late, and when he is home it is
already too cold for her mother to take a bath. The son, who apparently is the main
caregiver for his mother, works as a paperboy. According to his sister, he is feeble-
minded.

The bedroom where the informant stays does not receive enough light and the
smell of urine is very strong. Sometimes one of her children would take her mattress out
to dry it in under the sun or to allow her to lie in front of the TV set. “It is very hot inside
the room,” she said. There is pile of unfolded clothes put on a chair in the living room;
she was sitting on it when I came to visit her for the second time.

Lita (67) always tries to estimate the availability of a rest room and having extra
underwear when going out. “Wherever I go, my eyes keep looking for the toilet,” [Kalau
pergi ke mana-mana matanya langsung cari wc], she said. She does not wear diapers or
any pads when going out, but extra underwear is a must. She does not wash her clothes
since her daughter does it for her. She only washes her underwear. Yet, when she is sick,
she usually rinses the smell off before her daughter washed them. “I don’t have the heart
[tidak tega] to let her clean my dirty underwear,” she said.

She does not reduce her water intake because she is afraid that the medicine –
which she takes to treat her asthma and rheumatism – will precipitate in her kidneys. She
also does not do Kegel’s exercise, which she thinks will be difficult because of her
weight, “besides, I don’t know how to do it. Maybe if I go to the hospital on every
Wednesday as the doctor suggested they will tell me how to do it, but I’m really sorry
because I can’t [follow the suggestion to go to the hospital]. There is nobody to
accompany me there.”

Like Tarida, Rasyidah (76) does not mind wearing diapers when going out. She
feels comfortable with pads, although it is a bit thicker than just wearing pants.
Furthermore, because she always wears a long kebaya [woman’s traditional blouse], she
is not worried that her diaper will be visible. However, she never uses diapers when she is
home, because the bathroom is just a few steps from her bed. The family has to turn her
bed so the distance to the bathroom is even shorter and her urine will not get spilt.
Although there is a maid to help, she never uses a bedsheets to limit the amount of her
daily laundry. She also prefers to reduce her water intake. Her daughter insisted she
drinks at least 8 glasses of water everyday so that the jamu (traditional herbal medicine)
that she takes to cure her rheumatism “will not precipitate in her stomach”, but she only
drinks 4-5 glasses of water everyday.

Among things that trouble her of being incontinent is that she has to perform
ablutions several times before she prays. “I become so annoyed when a small amount of
urine passes just before I go out of the bathroom. I often have to do it at least 2 or 3 times.
It is tiring and annoying, and it also wastes water.” Sometimes she excretes some urine
on the floor, for which she needs somebody to help her clean, usually the maid will do the
cleaning job.

Rahima (60), would also limits her outdoor activities because of her condition,
except to attend halal bi halal [a gathering held soon after the fasting month of
Ramadhan to ask and give forgiveness]. She uses adult diapers when she has to go out to
Inneke (68) experienced difficulty walking because of her chronic rheumatism and was partially homebound. Despite this, she managed to attend church once a week, although she avoided other religious or social gatherings due to her condition. When her condition worsened, she found it hard to sit on the toilet and had to use the standing position for excretion, which caused difficulties in washing herself. She had to rely on her family and neighbours for help. Despite her isolation, she appreciated the support of her neighbours when she needed something. She was also dependent on her children for medical expenses and food management due to her food restrictions.

For Oma Chomsah (72), washing clothes was the most tiresome task. She had mixed incontinence, necessitating frequent changes of underwear. To ensure her clothes were dry, she tied a rope in her bathroom to hang her washed clothes, which was necessary due to her rheumatism and the challenging rainy seasons. The management of her home care was instrumental in her daily living, providing the necessary support for her condition.
resident to put not more than two pieces of clothes a day in the washing box. “Actually there are three washing machines in the laundry room, but two of them broke a long time ago and they did not repair them,” she said.

Oma Chomsah has become known for the foul smell [pesing] that always pervades strongly from her. It makes some of her co-residents accuse her of being negligent behind her back. On the other hand, she gives the impression that she is unaware of having such a problem. She does not remember when the problem started, but she is positive that she never used to wet her bed when she lived in her own home. Nowadays she is undergoing a medical examination to establish the causes of her incontinence. Though the doctor suggested she do some exercise, she often forgets to do it because, “this television has shifted my attention.”

Because adult diapers are very expensive, Oma Chomsah, like many other residents, can afford to buy them and the management does not provide them except for special cases. “Sometimes there are visitors who donate boxes of adult diapers, but the amount does not meet the actual need. Therefore the best way to tackle the problem is by asking them to do the toilet training so that they can control their voiding,” says Wawan, the head of the nursing home.

The coping strategies can be similarly tiring and frustrating for both groups – the younger people and the elderly. Adult diapers are not yet popular in Indonesia. One can only find them in big drugstores and supermarkets. They are also expensive so that many people who are in need cannot afford to buy them. Some informants also said that disposable pads are inconvenient to wear: some would say it is “stiflingly hot” and “noisy” [gerah dan bersik]. The choice then is to use small towels or other absorbent clothes such as cotton, which can be reused after being washed. Yanti, for instance, would cut off her old T-shirts into pieces and use them as pads. The more active they are, the more pads they will need in a day. Yanti and Endro, to mention some examples, need at least six pieces of towels and several pants every day. This can double when they are sick because they tend to go more often to the toilets. This of course creates a considerable amount of laundry. “Things get worse during the rainy seasons; the laundry will pile up and take longer to dry,” said Yanti (18/8/2001).

Except Hidayati, other informants mentioned that one of their main concerns is not to let any body else smell their urine. Even if they have maids they will rinse off the towel to remove the smell. “Does not have the heart” [tidak tega] to let somebody else doing the job or “ashamed” [malu] are the most common reasons mentioned by the
informants (Rahima, Lita, Inneke, Meilani and Endro). “My maid should not smell my excrement. It would make me embarrassed,” says Meilani.

However, they would let their spouse or children to do it in the absence of the maid or when they are too sick to do it themselves. “If I get too tired, I will leave my laundry and let my mother wash it. I just don’t care [bodo amat], I’m fed up with washing affairs...” said Yanti.

Washing the reusable pads is not as easy as it seems. To remove the persistent odour one needs to use more detergent and rinse the pads several times, because otherwise the distinct odour of stale urine (amis or putrid smell) will still pervade. If affordable a fabric softener will be used because otherwise the pads will be coarsened and inconvenient to wear. Moreover, since it is uncommon for people to use many small towels in one day, “sometimes my wife and I simply don’t know what to say when a relative who is visiting us sees the laundry by chance and ask what we use them for,” says Endro. He lives in a small house with his wife.

The problem of laundry does not only come from the massive amount of pads and underwear, but also from clothes, trousers, sarongs, or bedsheets which are often stained by urine. Among the informants who stay at home, only two have washing machines while others have to do the hand washing every day. Even if they have a maid, it will cause a feeling of guilt because she has to do more than she normally does.

One striking fact is that there are some informants who do not wear panties. Instead they only wear undergarments. According to them, there are many elderly women especially who live in rural areas (including my grandmother, I remember now) who do not wear panties because they often feel the urgency to void. Wearing panties, thus, will only give them trouble [merapotkan] because the urge will not give them enough time to take off the pants. As a result, they often wet their pants [mengompol] and somehow it makes them more incontinent. On the other hand, I think this fact – which can be considered a coping strategy – reveals the commonality of the bladder problem among the female elderly.

Moreover, during the fieldwork I also learned that the prevalence of urinary incontinence is high among the Javanese female elderly. This, according to my informant,
is because the Javanese women are used to wearing tight outfits [jarik] which cause them damage in their urinary organs. Unfortunately I did not have time to look for more information on this interesting point.

To sum up, the life of the incontinent is not only being “manacled” to a toilet, but also to other chores such as washing large amounts of laundry and keeping their home clean. The chores are tiring, time consuming and at the same time affect their relationship with the caregivers. Incontinent elderly is a fine example of the paradox of being dependent, where the main tension is between autonomy and dependency. In most of the cases found during the fieldwork, the elderly expressed their willingness to remain independent as much as possible. Ironically, their condition sometimes compels them to be dependent on other “healthy” people. The relationship between the elderly and their caregivers thus can be difficult, awkward and even tense since the two parties should always settle the indefinite affairs between them. While the incontinent elderly may be unsure of how others will identify or receive them (see Goffman 1963:24), the others may find it difficult how to behave properly towards the elderly.

The image of incontinent elderly described by some informants depicts their condition as an old car where the brakes “have given way” or “never undergoes a thorough service”. This self-description somehow gives them a negative identity, which may homebound them and leads to the limitation of their social life. At the same time the stigma that follows the condition – which is related with the loss of bodily control, will be discussed in the coming section – will prevent others from keeping in contact with the elderly.

Murphy (1990:124) says that isolation is a two-way street. Within this frame, the loss of social life experienced by the incontinent elderly is a resultant of the self-imposed negative identity and the expected stigma from others. The problems that follow the condition, i.e. visible wetness and smell, as well as the financial problem forces many of them to isolate themselves and discourage them from meeting their relatives or neighbours for any social gatherings. Whereas some of the informants said that they still went out sometimes, they also admitted that their contact with other people was limited
except with their immediate family. This situation is particularly difficult for many Indonesian people where the community is still an important part of one’s life.

4.2. “Harusnya jadi contoh, kok ngompol?”: Stigmatisation of Being Incontinent

As mentioned by Meilani, one of the informants of the younger group, the worst thing about an ailment is if it disturbs others. The disturbance, on the other hand, will cause embarrassment for the sick. At the same time, as discussed by Mitteness and Barker (1995: 205), the loss of bladder control such as in the case of urinary incontinence is linked with a loss of control of other aspects of life; to be out of control is to be incompetent.

Among the elderly, the stigmatisation of being incontinent has another dimension: it will result in infantilisation that is the process of considering the elderly infants. In bahasa Indonesia, infantilisation is expressed by saying “tingkah lakunya sudah seperti anak-anak” (the person’s behaviour is becoming like that of a child). An example of infantilisation includes the child-like behaviour like bed-wetting or wetting one’s pants. In children this behaviour is because of lack of toilet training, whereas in the elderly this is because of loss of their bodily control, which is a stigmatised behaviour in society.

“When we were infants, we had been taught by our parents to use the toilet, so it is very shameful when we get old our urine spilt everywhere,” [“Malu kan, sedari kecil kita diajarkan oleh orang tua kita untuk ke kamar mandi, tapi sudah tua kok malah (pipisnya) berceceran di mana-mana?”] (Oma Dewi, 26/6/01).

“We are called granny, and have already become models for our children and grandchildren. How come we will wet our bed?” [“Namanya sudah jadi embah, sudah dijadikan contoh oleh anak cucu, kok ngompol di tempat tidur?”] (Lita, 24/5/01)

The infantilisation does not only come from wetting one’s bed or pants, but also from the habit training that requires someone to go to the toilet in the specified times. According to a key informant, some of her patients say that they feel like small children who are doing toilet training [“Seperti anak kecil yang ditatur”].

There are some explanations linked to the shamefulness of being incontinent mentioned by the core informants. Some elderly informants say that the incontinence would make other people think that they are incapable of taking care of themselves and
controlling the biological process that should be kept private and secret. One informant (Lita) said that her mother, for instance, does not mind being seen half-naked by her children, as long as they do not see her while she is excreting [“Nggak malu kalau cuma dilihat nggak pakai baju sama anak-anak, asal jangan kalau lagi eek atau pipis aja”].

Moreover, Oma Dewi, as has been described in the previous chapter, says that the shamefulness of being incontinent also relates with the pity that comes from others. This, I think, has more or less the same nuances with what the other informant mentions as controlling one’s body: the pity from others shows the incapability to control one’s bladder (body).

From the caregivers’ view infantilisation is something positive that shows an understanding attitude toward a senile elder. Toward a senile and incontinent elderly people will say that he or she is returning back to childhood [Sudah seperti anak kecil lagi]. Taking care of a frail elderly person is like taking care of a baby. The only difference is that you could pamper the baby but not an old person. Therefore, from the patient’s point of view infantilisation can be interpreted as an assault on their sense of adulthood (Mitteness & Barker 1995:196).

According to a caregiver in STW KK, the most challenging task for her is to be patient towards the infantile elderly. “Sometimes I have to watch over an elderly when she is taking her medicine. I have to be sure that she really is taking her medicine. I will ask her to open her mouth to see the pill if necessary, because otherwise there is always a possibility that she will throw her medicine away or just keep it for no reason. They’re even worst than kids,” (Sari, 27/6/2001).

The infantilisation of the elderly is also told by a resident of the nursing home, Oma Pinky (27/6/2001). Every morning, she said, there would be a noise around the toilets. A nurse who was bathing an elderly would command her patient to defecate, “Excrete now!” [Berak sekalian!]. After that she would leave her and take another elderly to another bathroom and also ask her to defecate. The same nurse would bathe 3-4 elderly women at the same time. After settling the last one, she would come back to the first one, cleanse her and ask her to lather herself, and go to the second person and do the same. “She would go around [ngider] until all of them have been done. Sometimes, when
somebody does not want to or cannot defecate, she will be intensely irritated, saying that she won’t take care of her if later she defecate or wet her pants ["Awas ya kalau nanti berak di celana!"]. The nurse’s voice is very loud. Everybody here can hear her.”

As I have already mentioned in the previous chapter, maintaining a positive attitude towards the incontinent (elderly) for many caregivers and families is always a very challenging task. Dealing with the smell, cleaning, bathing the old body, and washing stuff is an inescapably difficult situation that one has to bear every day. During the interview process with some not-so-well-managed incontinent elderly and the caregivers in their homes, somehow I sensed a depressive situation that I find difficult to explain well. However, “inertia” [lembam] was the word that sometimes appeared in my fieldwork diary. The family and caregivers know very likely what they should do, but the daily burden of caring has already taken away their interest to do what they should do.

Another challenge to maintain social life for the incontinent people is to hide the problem and remain socially incontinent. Otherwise, one will be an object of ridicule. Oma Chomsah and Oma Dewi are two of the cases:

“...Their urine gets spilt everywhere. Sometimes it is not only urine, but also their faeces spilled and scattered on the ground. It is very embarrassing [malu-maluin]. Their rooms smell foul! It makes us dizzy [Baunya luar biasa, bikin pusing!]. People will keep distance from them and scorn them [dicibirin orang]. We cannot stand sitting next to them for minutes. However, some will ignore their problem and do not care that they disturb other people, for example Oma Chomsah. You have to meet her and chat with her. She still attends the activities, such as angklung and pengajian (Islamic congregation). No one would like to sit next to her except those who feel pity for her. She is very headstrong [ndableg]. But not every incontinent act like her. Those who are courteous will stay in their rooms...” (Oma Tati, 26/6/2001).

The presence of the socially incontinent person – those whose incontinence is obvious in terms of wetness and smell – will be assumed as an attack to other’s space and will cause embarrassment. During the interview with Tarida’s daughter, Lisa, she mentions several times that she does not mind her mother wetting herself as long as she does not do it in her presence [“Mama boleh ngompol asal nggak di depan saya”]. Sometimes, she says, her mother seems does not care and just wet her pants when she cannot find a rest room, something that will ignite her daughter’s fury. “I always ask her
to wait until she finds a rest room and not just do it wherever she feels the urge,” ["Cari kamar mandi dulu dong, jangan nekat di mana aja begitu"], she says.

Interestingly, while saying that her father objects to her mother's prolonged treatment because of the financial problem, Lisa also says that she wants her mother to be more serious and patient in treating her incontinence. “I want her to recover. It is for her own sake, not for me or for other people. I just don’t want her to be embarrassed of her condition.”

Wawan, the caregiver in the nursing home, shows the same feeling towards the presence of the incontinent. No matter how they can manage themselves, he actually does not like the incontinent elderly to sit and talk for a long time in the meeting room which also functions as his office. His reason is that if the elderly wet themselves in the cushioned chair there, the smell and the stain will be difficult to remove ["Kalau mereka ngompol di sini kan bau dan warnanya susah hilang"]). He is now thinking of changing the cushions with other less absorbent material.

Meilani, an informant of the younger group, knows the stigmatisation of being incontinent. She says that if her time to leave this world comes, she prefers to leave it in a nice way ["Kalau saya harus pergi, saya ingin pergi dengan manis"]). Therefore, she says, she will go through whatever her doctors suggest so she can overcome the problem and leave nicely. However, she admits that her incontinence has caused her so much stress and, as the consequence, she becomes forgetful and always asks her maid to remind her for “trivial things such as to drink milk.” Her forgetfulness, she said, annoys her husband. “He said that I am like a cripple who always forgets to bring her walking stick. It is something that is not supposed to happen.”

Infantilisation experienced by the elderly, as can be seen in the illustrations above, has obviously reversed the role of children and parents, where children are now the patriachs while parents are the “children”. With this role reversion, the children (caregivers) are not only able to differentiate themselves but also to assert their power and superiority over the incontinent elderly.

To be different from the incontinent parents, such as in case of the disabled, is also important since the aura of contamination that often surrounds the incontinent
becomes attached to other members of the family (Murphy 1990:118). To be different thus mean to detach one from the contaminant, or from the source of impurity. Ruefully, the attempts to differentiate oneself from the incontinent as expressed by the informants and their caregivers can be painful for both the children and the parents. However, as we shall see later, the process of infantilisation cannot be generalised because it is also influenced by the social and economic status of the caregivers.

4.3. Caring for the Incontinent Elderly vs. Control Over the Body

During the focus group discussion with two physiotherapists, we touched on the point about the care for the elderly who stay at home. One of the physiotherapists said, "for a woman, having to stay at home is not really a big deal because the are used to staying home every day. But for a man, it could be a big problem," (Prita, 26/6/2001).

However, as I learned during the fieldwork, staying at home at the same time means to remain in the most intimate circle. Home is not only a place where people feel where they belong. It is also a place where individual can be his or herself without having to maintain a social and public persona. On the other hand, home is also a place where somebody has the agency, i.e. the capacity of human beings to affect their own life chances and those of others and to play a role in the formation of the social realities in which they participate.

At the same time, for the incontinent people, home can also be a place where their identity and dignity are questioned. The obvious lost of bodily control has put them in a very vulnerable situation. Their relation with the caregivers is very much challenged.

Incontinence is synonymous with the lost of bodily control, and the meaning may be expanded to the lost of ability to have a full control over one's own life. Hidayati is an interesting but gloomy example of this condition. As a widow of a late government employee, she has a right to receive pension, which amounts to 400 thousand rupiah (about 80 guilders) every month. The money can hardly meet the needs of a household in a capital city like Jakarta where everything is very expensive. Unfortunately, partly because of her impaired mobility, she cannot get the money herself from the bank. One of her daughters represents her to go to the bank every month. However, she does not give
the money to her mother. Instead, she keeps and controls the use of the money. According to Nining, her other daughter who lives in the same house with the informant, her mother had lost some money twice and her children thinks that she is unreliable. “She cannot control her urine, let alone control her money. So she only knows that everything has settled well,” [Tinggal tahu beres saja], the daughter said.

Money has been a sensitive issue for the family; apparently since the informant’s husband passed away a few years ago. Even in my present – when I visited the informant for the first time – they would argue when the conversation dealt with financial matters. Today Hidayati lives with her two married daughters, two son in-laws, two grandchildren and a son. The three men in the household have an unstable income. Two of them – her son and one of the in-laws – work as paperboys, whereas the other one works as a part-time courier. He only works when the delivery service company needs an extra courier to deliver packages. The pension, said Nining, is used to pay the doctor’s fee and to buy her mother’s medicine, especially those not covered by the insurance (ASKES). The rest is used for the daily expenses. However, the informant has another explanation regarding the use of the money. “For the telephone bill and electricity I have to spend 150 thousand rupiah. What is left to eat?”

In the mean time, her other children have to struggle with their own financial problem because of the suspension of their works resulting from prolonged crisis in the country. These days, Hidayati’s children are trying to sell the house. In the fence they put a simple board with signing offer to buy the house. Nining said that they would like to sell the property at the price of 850 million rupiah. “The money will be divided among the children,” she said. When the house is sold, they plan to take their mother to stay with one of her married sons.

Hidayati apparently does not have a say in this decision. One of her daughters keeps the certificate of the house. She did not offer any comment when I asked her about the plan to sell the house. She only said that she wanted to come home to her village in West Sumatra province and spend her old days with her mother who is now more than 80 years old. Her daughter who was there during the first interview interrupted her words. “But who will take you there?” she said bluntly. The mother was silence and all she did
was just stare at her daughter's eyes. The conversation was broken afterwards, and after one or two minutes of silence I asked her another question.

Incontinence among female elderly can result in control over their life. In the case of Hidayati the situation is apparent. She always needs help from others even to do a simple activity such as combing her hair or buttoning her dress. "If there's nobody home, I'll be in a mess," she said. Her dependency, on the other hand, will make her an object of complaint. According to her, the children are used to complaining about her sickness, saying that they are tired of taking care of the sickly mother. They also ask her not to think too much, because it will make her wet herself very often. Her children think that her incontinence is because of her stress which, among others, is triggered by her feeble-minded son. "She is always worried who will take care of Pepen [the son’s name] after she died," said her daughter.

When interviewing her on another occasion, Nining mentioned that the tense relation between the siblings concerns her mother. "My youngest sister often quarrels with my older sister. Sometimes, when she is very angry, she will threaten my older sister with a knife. She is really kampungan [meaning “native”, or in this context “somebody who does not know how to behave herself”]. She also fights [berantem] a lot with her husband and cannot settle their problem on their own. They always involve other people in their personal matters.”

Lisa, the daughter of Tatida, says that her father has become irritated every time her mother goes to see her doctor. "One thing that makes papa get irritated is to see mama keeps on seeing her doctor but gets no positive result [berobat melulu tapi nggak ada hasilnya]. He thinks that if her condition cannot be treated, she'd better forget it ... However, her focus now is to treat her painful arms.”

Similarly, another informant, Inneke, says that she has to be careful with her diet. Otherwise the children will get annoyed. Furthermore, like other informants who do not have their own income, Inneke prefers to keep her sickness than tell her children about it. "The doctor's fee is very expensive and he also gives me very expensive medicine. I cannot refuse it because I find the medicine works really well to me. He is the twelfth doctor I have seen, and I feel I'm getting better afterwards. I have no luck with other
doctors.” Moreover, she also says that she does not want to complain because she is afraid God will be angry and not forgive her if she complains too much [“Takut Tuhan tidak alumin kita”].

The control over the life of the elderly, as I found out during the fieldwork, is also influenced by the social-economic status of their near-others. Because they still receive their monthly pension while living with relatively unstable families in terms of income, Hidayati and Tarida, for example, are still the main contributors to their household. Their position, ironically, does not guarantee the quality of care they receive in return. Their frailty has clashed with the lack of material resources of their families. Not only can the family offer any significant support to their parents, but also the income of the parents is used to support other members in the family. To control the parent’s life, to put it in another way, is a mechanism to control the material resource of the household. Inneke, who lives with one of her 10 children and fully relies on their supports, also faces the similar situation.

On the other hand, when the family has a stable income and is able to meet their basic needs, the position of the elderly in the family is relatively more secure. Lita, Rasyidah, and Rahima are examples of such a situation. While living in a small and simple house with her three children and gets no support from her husband, Lita does not have any significant financial problem since the children have already had their own income. She keeps her pension – which is 700 thousand rupiah per month – to buy her own needs. Similarly, Rasyidah lives with her well-to-do married daughter while Rahima is supported by her husband, a pensioner of a government bank.

For the elderly, a stable income such as pension is very important since it helps them to adapt themselves in their social life and maintain their relation with others. As mentioned by an informant, pension gives “a sense of pride” [kebanggaan] and self-sufficiency that will help them to face the role reversal due to their age. Unfortunately, the availability of the pension as well as the income instability of the family can be another source of abuse for the elderly as I have discussed. The loss of bodily control experienced by the incontinent elderly can be interpreted as their frailty and loss of control over their life and, in turn, be an explanation of the necessity of control from others. To put it
briefly, the incontinent elderly should not only deal with the loss of their social life but also control over their own life at the same time, and this can be an example of how the care by the family also have a negative side.
5.1. Dirt and the Problem of Care

During my short stay in one of the nursing homes many diarrhea incidents occurred. Almost all people with whom I spoke said that there was nothing wrong with the food, which is usually the primary cause of diarrhea. Instead, they blamed it on the weather and the communicable nature of the disease. The diarrhea later elicited the topic about dirt and disgust, which was abundant in the place and obviously among the most interesting topics of conversation and gossip.

One of the stories I heard was about a female resident who always complained about her stolen belongings. She always tried to look for her things in all places, including in other residents’ rooms, but in vain. One of the caregivers who was asked to help her started looking for the missing stuff in her own room. When doing so, he found some neatly wrapped boxes under the bed and asked the owner what was inside the boxes. The woman however forbade him to open the boxes and said that they were her valuable things. After looking everywhere and the missing things could still not be found, the management was forced to open the boxes.

“You know what we found? It was her excrement! She put her shit in plastic bags and put the bags in the boxes and then wrapped them with gift-wrapping paper. She treated her excrement as her most valuable thing. We were dumbfounded by the finding. You can never imagine the foul smell when we opened the boxes. Stinky!” [Busuk sekali!] said the caregiver to me. Obviously, he continued, the resident suffered from partial dementia and did not always realise what she did.

Caring for elderly with dementia and incontinence at the same time is considered the most difficult task for the nurses and caregivers in the nursing home. However, it is also a source of amusement for them. Among the residents, there are five people who are staying in the health clinic and receive 24-hour care because of their condition. One of them is Mak (which literally means “mother”) Kar, the oldest resident of the nursing home. She suffers from dementia and most of the time she does not have contact with her
surrounding. She often complains that the people in the nursing home do not take a good care of her and that they never feed her well.

Because of her dementia, she cannot use the toilet. Instead she wets herself and excretes anywhere. “We always have to watch over her and clean her as soon as possible when she excretes or voids. Once there was nobody around. When I visited her in her room, she started eating her own shit. So I quickly cleaned her,” said a male nurse. When I asked him about his feeling, he said that as a nurse he was used to doing it, because of the lack of nurses in the nursing home. “And she is old; that’s why I never feel ashamed to clean her or other elderly,” he said about touching the body of an elderly of different sex.

Mak Kar and other elderly with dementia appear to be a more of a comic than serious problem for the nurses and the caregivers. Some of them said that their job in the nursing home needed extra patience, and therefore they prefer to take things easy [dibawa santai saja]. While cleaning the elderly with dementia for instance, they will likely ask her questions to which she will reply as she likes, without necessarily answering the questions [nggak nyambung]. Such a conversation said one of the nurses, could be a source of amusement when dealing with dirt and would help then to stand the cleaning task.

Caring for incontinent elderly is also an issue for the family and caregivers who live at home. In chapter three I cited only one out of 12 incontinent people needing continuous care, while the rest can be managed with various medical treatments, including the exercises such as Kegel’s or pelvic floor muscles exercises. Whatever the cause of incontinence and no matter how severe it is, according one of the key informants, the combination of medication therapy and the exercises as well as bladder training will give optimal results. However, during interviews and the physiotherapy session there was a strong emphasis on the role of family or caregiver to gain the expected results. The treatment for urinary incontinence is often a complicated procedure, which needs patience and motivation both from the medical staff and the patients. The patients’ motivation, according to the physiotherapists, is very much influenced by support from the family.
The support of the family plays a similarly important role for both younger and older groups. Unfortunately, as mentioned by the two physiotherapists during the focus group discussion, there are only a few of their clients who receive full support from the family or caregivers. Since each client has only half an hour of treatment, the physiotherapist says further, the family and caregivers should also be the therapists at home for the clients. “What do you expect from 30 minutes of exercises? Our main target is thus to teach the patients and their family how to do it correctly. The result depends on their effort. For example, an elderly with bronchial pneumonia will also need mobilisation aside from the ability to cough up their phlegm, and they have to do it ever day and with the help from the family, not only once or twice a week when they come to us,” Tyas says.

Many elderly need more emotional support from their family than just a companion to attend a physiotherapy session. “There are some elderly who will only start the exercises in the presence of their favourite children. Sometimes they just sit [mogok] in the room and do not explain why they are reluctant to start,” (Tyas, 26/6/01). Some incontinent elderly, according to Tyas, would use their condition to get attention from their family or caregivers or to show their protest or dissatisfaction. This is more or less similar to what Lisa, Tarida’s daughter, said. She would feel guilty when her mother said that she has the condition after giving birth to her. In another case, Nining said that her mother would wet her bed more often when she got annoyed with the children ["kalau sedang banyak pikiran"].

From the physiotherapists’ point of view, though, support from the caregivers has a different function. “For example, during a session with a bedridden patient in her home when I was turning her to change her position I saw she was excreting [pup]. It was a difficult situation for me. I couldn’t help her. There was only a maid who was at home. She was rather reluctant to clean the client, because according to her it wasn’t her job. She did it very slowly so time was wasted.”

Similarly, when such accident happens in the geriatric ward, the physiotherapist will ask the nurse to clean the patient before she can continue the exercise. Unfortunately, it often takes long before a nurse comes and cleans the patient and again time is wasted.
“Perhaps because there are only a few nurses in the ward they cannot help the patient immediately,” she explained.

Dealing with urine and excrement is a matter of routine for the physiotherapist and nurses in the geriatric ward. Often, during the exercises, some patients spill their urine in the bed. When I asked them what they would do if it happened, they only smiled and said that it was quite normal and that the cleaning person would clean the spill. Kustini, the senior physiotherapist, has another story. Once, she said, she had an old woman who had difficulty in contracting the right muscles for the Kegel’s exercises. All of a sudden, the patient wet her bed and her urine spilt on her physiotherapist’s lap who was standing next to the patient’s bed. “I just laughed and tried to calm her down because she was in such a panic with the unexpected accident. I had to relax her again; otherwise her stress incontinence would get worse. ... I was okay with the spill, besides it was not me who had to clean her. I just hoped that her urine would not spill on my vagina. ... It is dirty,” she said.

In the Cipto Mangunkusumo hospital, the families of geriatric patients are encouraged to stay in the hospital. The purpose of their stay in the hospital is mainly to facilitate the doctors if there is something that should be communicated to the family. Moreover, they are also needed to purchase the medicine, or to take the blood or urine sample to the laboratory, and even to help the patients when they need to use the toilet. Lack of nurses in the ward is the reason of asking the family to stay at the hospital. The first time I visited the ward (17/5/201), there was a skinny old woman, 74 years of age, attended by her sister who was 63. Although she tended her sister quite well, looking at her taking the patient to the toilet would make one worried. “It is a pity that she is the only caregiver that the patient has. Actually she has children, but maybe they are too busy to attend their mother. My heart is in my mouth [deg-degan] every time I look at two old women [nenek-nenek] walking together to the toilet. There’s always a possibility they would fall and without anybody knowing. If it happened, wouldn’t it be another disaster for us?” [“apa bukannya malah tambah repot kita ini?”], said one of the nurses in the ward.
The nurse also said that the patient suffered from urinary incontinence because of her delirium, and therefore the presence of a caregiver was needed. After introducing me to the patient, the nurse told the patient not to wet her bed again after she went home. The patient seemed insulted. “Wet, what? I didn’t even know anything” [Ngompol apa? Tahu juga enggak], she said dryly. She was, I think, embarrassed being told of her condition and repeatedly told me that she still managed to go to the toilet in her home without assistance and never wet her bed.

Being sick and helpless has put many incontinent elderly in a fragile position. On the one hand they want to maintain their dependency but, on the other hand, help from others is something unavoidable. At the same time, as I have discussed in the previous chapter, having to deal with the foul smell of urine every day is something beyond the imagination of many people. To clean the urine that gets spilt on the floor, or to wash dirty underwear and pads can be very annoying if one has to do it on a daily basis.

When the care is provided against great odds like caring for an incontinent elderly, people often recount how others comment on their patience and strength in caring for the aging parent. The tiredness is often accompanied by a sense of pride in fulfilling the expectation, if this accomplishment compared is favourably against siblings who were not able to undertake the responsibility. At the same time support from siblings or other family members is still expected and appreciated (Blake, 1992:82). The support can be visits and financial contribution. When such support from the siblings is not forthcoming, the caregivers would feel a sense of resentment.

Nining, the daughter of Hidayati, has to take care of her incontinent mother. Therefore she has to stay home every day and give up her stall [warung rokok]. She said that she had to cook for her mother and to look after her because she often falls and hurts herself. “Once when she was alone at home she fell in the bathroom and her head was injured. The wound was so terrible and it required five stitches,” she said.

Since the day she closed the stall she is reliant on her siblings’ contribution to the household. Her married sister who lived at the same house, she said, is very unreliable [“nggak bisa diandelin”] to take care of their mother while her other siblings were too occupied with their own problems. She neither said anything about Pepen – who bathes
the mother and does the laundry every day – nor showed any appreciation for what he has done. Instead, she several times mentioned about her intention to re-open her stall and had her own income.

5.2. Dirt and the Problem of Space

The popular idea about urine is that it is dirty. According to the physiotherapist in the medical rehabilitation unit, urine is dirt because there are germs that contaminate the urine. Another explanation comes from a key informant who is a medical doctor. I asked her opinion regarding the urine therapy – the popularity of which has been increasing, at least as a discourse, in the society – and she said that she would not recommend the therapy to her patients because urine is dirty. The dirtiness of urine, she says, is because it contains certain elements that will endanger human internal organs, particularly the brain. I will discuss the urine therapy in the coming lines.

On the other hand, the non-specialist informants relate the dirtiness of urine with the uncomfortable feeling, for instance when they wet their pants. The dampness [becek] resulting from voiding is considered disgusting and will cause the unpleasant feeling (Oma Dewi, 26/6/01). Others relate the dirtiness of urine to the foul smell [pesing], which is considered detestable.

Nining, Hidayati’s daughter, said that she wanted to take out her mother’s mattress and to dry it under the sun every day so that the smell would not be too strong inside her room. However, she found the mattress was too heavy for her to lift especially when she was four and a half months pregnant while her brother was not always available. Therefore, they could not do it on a regular basis. Besides, she said, “The smell of urine will permeate and disturb the neighbours. The smell of an adult urine is stronger than of an infant.”

In her discussion about excretion and control, Lea (1999: 7) describes the “normal” body as one which shits discretely, appropriately and un-problematically, and does not involve anyone else in the process (italics mine). Thus, once these “rules” of shitting or excreting is broken, as in the case of incontinence, the person’s “normality”
will also be broken. He or she becomes vulnerable to experiencing embarrassment and social exclusion. Known incontinence is hence known vulnerability.\(^{10}\)

For the incontinent, the most crucial task in order to prevent the social stigma is to prevent or minimise both wetness and odour. The visibility of their incontinence is not only a crucial factor that determines their personal identity (Goffman 1963:64-65), but also will disturb others. The disturbance is not only because of the foul smell but more importantly it reminds people of something unwanted, something one should get rid of (Van der Geest n.d: 2). Human excrement is dirt, which has a contaminating characteristic. Therefore it is dangerous and should be kept separate. If someone fails to keep his dirt invisible, or lets it become visible or evident, he becomes the discredited. Visible incontinence means violation to other’s space. Moreover, the visible incontinence also means an attack to other’s sense of purity, and thus it can be interpreted as a non-respectable behaviour.

Oma Chomsah and Oma Dewi, are examples of how incontinent people are expected to behave: Behind their back people do not only deride them but also expect them to avoid the public places. Their presence in such places will cause disturbance to other people and their sense of purity. Since there is no one who wants to be associated with body wastes such as urine and excrement, it is understandable that the incontinent people, unless they are able to hide their condition or to be socially continent, should exclude themselves from social life. Using this frame, the attitude of Lisa who will get irritated and ashamed when her mother wets her pants during her presence is understandable. She does not only want to dissociate herself from the incontinent mother but also because she does not want her space to be contaminated with the dirt.

Space, very often, becomes a significant problem for the incontinent people. Since the first onset of the problem, their space is limited to the proximity of toilet. Furthermore, the space of the incontinent people would be more limited since they should always be careful not to let others smell the urine. The smell that pervades in their own room would not cause a social sanction as much as when it pollutes the public places.

\(^{10}\) Furthermore, because excrement is also linked symbolically to death and decay, says Lea, it is also a reminder that we all return to the same slimy mass of putrefaction in the earth. To be associated with
However, things would be more difficult when they have to share the toilet with others, because the toilet now becomes part of the public sphere that also needs to be carefully taken care of.

There is a popular opinion in the society that a toilet mirrors one's character. A clean toilet shows positive characters of the owner: tidy, neat, careful, reliable, and responsible. On the contrary, a dirty toilet shows negative characters: untidy, messy, careless, unreliable, and irresponsible. Known incontinence, therefore, does not only show the loss of bodily control but also those negative characters of the incontinent.

One intriguing question regarding dirt and space is about the public toilet: Why is there an immediate perception that a public toilet is a dirty, smelly, and disgusting place? Why are people more concerned to keep their private toilet and bathroom clean and do not really care about the public toilet? What is the difference between a private and public toilet in the case of incontinence?

Anonymity is one of the possible explanations. In a public toilet it is pretty unlikely that people do know each other. The anonymity thus serves as the shell of protection of every visitor of the public toilet. Even when somebody does not flush after using the toilet people cannot blame or ask the person to clean it. If the guilt (i.e. not flushing the toilet) becomes publicly known, then the person would probably get socially sanctioned, that is shamed and even punished (Murphy 1990:93). It would not happen in the private toilet where the users are limited and known.

Muslims should be ritually pure to perform prayer which is five times a day, and it means that they should keep their body, their clothes and their prayer sites ritually pure almost all day. Contamination of defiling filth such as urine and excrement will make them unfit for prayer. This impurity feeling is one of the main problems for most informants. “This condition will disturb not only my ablution, but also my praying. I always pray for my children. Sometimes I become very annoyed, but I should not complain. God wants me to have this condition,” said Meilani (8/6/01). In terms of the sense of purity thus the physical aspect cannot be separated from the spiritual aspect.

excrement, to be seen excreting, is to expose the evidence of our corporeality to other people (Lea 1999: 12)
The necessity to always be ritually pure to a certain extent implies incontinence as a state of impurity, which is very challenging not only for the incontinent but for others he or she encounters in daily life. Of course there is always an exception in the fiqh (Islamic law pertaining to ritual obligations) that allows an incontinent to perform prayer without having to repeat the act whenever he or she voids. However, the exception has its limits and unless the incontinent is really sick she should try her best at least to keep herself and her prayer site clean.

Moreover the exception is only valid for the person concerned and not for others. A caregiver, for instance, has to be sure that he or she is free from the defiling substances (najis) every time she is performing the prayer. “Sometimes I wash the pads and underwear with much soap and rinse them several time to make sure that the awful smell disappears. Very tiring, but that’s the way it should be. I also have to check her mukena [cloak, usually white, covering a woman’s head and body worn at prayer] and sajadah [prayer rug] regularly. If I smell something nasty, I will ask her to wash them or I’ll do it myself,” said Mrs. Sani, Yanti’s mother.

This obligation gives another explanation of why the family or caregivers who are Muslims sometimes tend to dissociate themselves from their incontinent family members. “I don’t want to sleep in my mother’s bed. It is always stinky since she doesn’t change the bedsheets often. I wonder how she would perform her prayer in such nasty place,” said Lisa, Tarida’s daughter.

The story about dirt and disgust that I found during the fieldwork did not always relate to urine and excrement. Oma Nani, a resident of the nursing home, once told me that she had asked the management not to accept a Chinese resident again. According to her, Chinese people are dirty [jorok, koprok]. “You see the woman door, she always spits everywhere. I feel so sick that I want to puke when I hear her spitting,” she said. For her, the sound of spitting is as disgusting as the spit itself.

5.3. Dirt and the Problem of Ambiguity

Just like another person who is physically impaired, an incontinent body is malfunctioning, leaving his full humanity in doubt (Murphy 1995:154). In other words,
his or her personal identity will be problematic. A normal self should be able to "keep his secret"; otherwise he would be a disabled or an incompetent – be somebody who loses control of his own body. The loss of bodily control such as in the case of incontinence is considered crossing out the borders, which put the concerned person in a state of impurity. The incontinent person thus must make an extra effort to establish status as a competent, unproblematic individual while at the same time they have to deal with the insecurity and uncertainty in their relationship with others. It is not surprising then if some of the incontinent will find their efforts to maintain their social life as frustrating.

However, being competent has a contextual meaning. For some people who are inescapably dependent on others because of their frailty competency is not a big deal. For a bedridden patient urinary incontinence is less important than their overwhelming health problem that should be taken seriously beforehand. Moreover, care for the incontinent by families or caregivers that involves the touch of bodily waste can have a very different meaning. Van Dongen (1999:77) mentions that changing diapers, cleaning and caring is part of the nurses' profession, but these also are activities of tolerance, loyalty and intimacy.

This explanation fits with the experience of one informant, Lita, whose daughter is used to helping her with the laundry. "She never lets me do the job. She never complains whatsoever. She always tries to please me," she said. In contrast, the feeble-minded son of Hidayati, another core informant, becomes the one who should do the cleaning job: washing the laundry, putting the mattress under the sun sometimes, and even bathing his mother. I have an impression that he is not happy with the task. On one occasion, he asked me why his mother kept on wetting her bed and why the doctors could not cure her incontinence. In replying to his question I only said that I was not a medical doctor and did not know the answer. He seemed dissatisfied with the reply, but his sister hushed him up.

In short, although taking care of other's excrement is perceived as menial, it also helps us to preserve our dignity (Van Dongen 1999:70). Here incontinence raises the ambivalence of respect: why people who deal with disgust feel perceived as having
extraordinary ability and expect to gain respect while others do not want to be polluted by touching the human waste (or other kinds of dirt)?

The discussion of this question will reveal the ambiguity of dirt. Dirt is something unwanted and wanted at the same time. It is something we want to hide in secret to maintain our public persona (including competency and self-esteem in the case of incontinence). Many of us will be stressed if we cannot perform our “morning ritual” successfully. We need to get rid of our dirt in order to feel clean and healthy. It is through our dirt that we get the satisfaction of being clean, health, and fulfilled. Furthermore, as mentioned by Van Dongen (1999:75), elderly excrement is not only dirt but a token of good health as defecating is a necessary condition for well being. When they have problems with constipation they will be helped by medicines. On the whole, the ability to pass the bodily waste is thus as important as to retain it when necessary. Control over one’s own body is the key. Once the control is lost, someone will be in danger and be vulnerable: he or she can be the object of infantilisation and lose her control over his or her own life, such as in the case of Hidayati who no longer has control to her own property.

The discourse of the ambiguity of human excrement in the society recently touched upon a fascinating point: the potency of urine as medication. During the fieldwork I bought three books on urine therapy. According to the authors, the Indian people applied urine therapy more than 5000 years ago. On the cover of one of the books the publisher added information that the book was an international best seller of which more than 100 million copies have been sold. The reference of this unique therapy, according one of the authors, comes from Damar Tantra, an ancient book which is believed to have been written by Hindu’s most powerful god, Shiva. The therapy is particularly discussed in the chapter of “Shiwambu Kalpavidhi”, which means practising urine therapy to rejuvenate the body tissues (Budiarso 2001:19).

The authors claim that the therapy can cure various diseases: from oral ulceration to malignancies, HIV/AIDS and sexual impotency. Because of its potency, urine is called the “holy water”, “water of life,” or “the golden fountain” which can save people’s lives. They also wrote that nowadays this therapy had been known worldwide and more and
more people admitted of its efficacy. Unfortunately, according to Budiarso, despite the admittance there has been a hindrance to acknowledge the treatment. Urine, according to him, is still considered dirt and a useless residue of body metabolism. People cannot talk about urine openly, since it is considered a taboo and one who intentionally brings the topic in an intimate circle will be stigmatised as not having any manners [*tata krama*] (Budiarso 2001:74).

I did not meet anybody who practised it, but a key informant told me that one of his relatives had tried to practise the therapy after much suffering from breast cancer. The patient never disclosed her experience to her doctor because she was so embarrassed and afraid that he would blame her.

Dirt is a negotiable concept which meaning is subject to change in different situation and the state of knowledge (see Douglas 1966:7). Urine, which is the metabolic residue according to the biomedical perspective, is the “water of life”, the “holy water”, according to other medical system. To put it briefly, despite the idea about urine and other bodily wastes which lives among the society, I think the debate over the urine therapy, although not on a wide level, has contributed to the discourse on the concept of place and dirt in the society.
Chapter 6

CONCLUSION

Urinary incontinence, the involuntary loss of urine so severe as for it to cause social and hygienic consequences, is a major clinical problem and a significant cause of disability and dependency. Although affecting all age groups it is particularly common in the elderly. However, as a health condition which is a growing problem along with the increasing number of the elderly, there were only a few social and anthropological studies that have been done on this issue. Most of the studies were conducted among western communities and therefore little is known about the meaning of being incontinent in non-western settings.

While aimed to fill in the blank, this study is also trying to find out the cultural significance of urinary incontinence in a developing country that will be dealing with a tremendous challenge of an aging population in the very near future. The setting of this research thus offers a new approach to the study of this topic. Mitteness and Barker (Medical Anthropology Quarterly 9(2): 188-210) in their early pilot work determined that uncontrolled urinary incontinence was often thought to be a risk factor for institutionalisation. However, this research had been partly carried out in nursing homes, where the experience of the incontinent residents in dealing with the condition is somehow different from the elderly living with their family.

Moreover, this study reveals the aspects of care by the family as caregivers, and the economic motives behind the care for the elderly. The concept of dirt and purity – which are challenged by the incontinence – of the society is the next focus of the study.

Urinary incontinence and the stigmatisation following can be considered the next burden for the elderly, since the experience of being old likely involves feelings of sadness, anger, fear, loneliness and pain. There are different perceptions between the biomedicine and the lay people regarding this condition; while the biomedicine holds on to the view that normal aging is not a cause of urinary incontinence, yet it believes that aging is a risk factor for the condition. Also, according to the biomedical perspective, the
assumptions that incontinence is normal and inevitable for the elderly and that it cannot be cured are the persistent myths in society.

However, the findings of the research say that urinary incontinence among the elderly is caused by the frailty and disintegration resulting in loss of bodily control along with the increasing of age. Getting old is synonymous with getting weaker. It is normal, according to this view, that you have a weaker bladder or a weaker sphincter in your old days, as well as “weaker thinking” and “weaker sight”. Moreover, because one of the risk factors of urinary incontinence is repeated delivery, many women see their incontinence as something that becomes part of their existence of being women [penyakit wanita] and something that is as natural as giving birth itself. Consequently, according to this view it is also something irreversible and untreated.

The lay perception on this condition is enhanced by several factors. First, almost all of the core informants for example, are occupied with their concerns regarding their overall health condition. The financial limitation often compels them to put aside their incontinence from the priority to cure. Second, as mentioned by one of the key informants, there is a problem of lack recognition of incontinence as a significant clinical problem by health providers. There are many doctors in Indonesia who still consider urinary incontinence a psychological problem which is beyond their expertise. Other doctors may also think that the condition is not a big deal for their patients, while in fact it may be a problem for the patients. In other words, within the biomedical perspective there is a formal view and an informal practice which shares the popular view on the problem.

At the same time, although the behavioural treatment is the best choice to treat urinary incontinence in terms of risk, it is very complicated to apply and requires good cooperation between patients and their doctors. There are not many doctors who are patient enough to handle incontinence cases.

Despite the idea of causes and treatment of urinary incontinence, incontinent people have to deal with daily consequences of their condition. Most of them for instance, should make a plan for their activities by rescheduling them with the proximity to toilets.
Another strategy is to improve physiological control. Some people may try to reduce their daily water intake to limit the void and thus limit the risk of being wet and smelly. The elderly who are dependent to their family or caregivers often practise this strategy. Moreover, some of the elderly women do not wear panties to deal with their problem of urgency. Another physiological control, which is often suggested by the doctors, is Kegel’s exercise. The exercises re-educate the pelvic floor muscle and thus increase the tone of sphincters and the supporting structures. Although the overall rate of improvement is relatively high according to some doctors and physiotherapist, the compliance of the elderly patients to do the exercises is low. This is in accordance with the perception of the incontinence among this group as something normal and unavoidable.

The last but not least most tiring strategy applied by the people with urinary incontinence problem is to control the environment, that is to prevent or minimise both wetness and odour. This strategy includes washing massive amounts of laundry, drying the mattress in the sun regularly and cleaning the room and bathroom more thoroughly to prevent the foul smell of urine. If the continent person is a bedridden patient, another task is frequently turning the patient to prevent bedsores. These tasks are often physically exhausting both for the incontinent and the caregivers. Another strategy also mentioned by some of the informants is not wearing underwear. This practice is particularly common among the female elderly to lessen the amount of laundry. At the same time, this practice can be an indicator of the commonality of the problem among this age group.

The loss of bladder control such is in the case of urinary incontinence is linked with a loss of control of other aspects of life. To be out of control is to be incompetent. The obvious lost of bodily control will put them in a very vulnerable situation, and their relation with others, including the caregivers, will be very much challenged.

The failure to control one’s body will result in disturbance to other people, which in turn will cause shame and stigmatisation for the sick. Furthermore, among the elderly the stigmatisation has another dimension. It will result in infantilisation, that is the attitude of considering the elderly infants. Wetting the bed [mengompol] is something associated with infant. While among the children this behaviour is because of lack of
toilet training, among the elderly this is because of the loss of their bodily control, which is a stigmatised behaviour in society. Infantilisation, moreover, not only comes from wetting one's bed or pants, but also from the habit training that requires somebody to go to the toilet in the specified times.

The shamefulness of being incontinent is linked with the pity that comes from others. Some informants say that the recognised incontinence would make others think that they are incapable of taking care of themselves and controlling the biological process that should be kept private and secret. The infantilisation and the loss of bodily control will be interpreted by the incontinent elderly as an assault on their sense of adulthood.

For some informants, the incontinence prevents them from participating in informal local women's organisations such as arisan (a rotating credit-and-savings association) and pengajian (a get-together held to recite the Koran under the guidance of a female religious teacher or a pious woman). Both informal organisations, as discussed by Niehof (1998:252) as well as described by some informants, provide the women an occasion to relax, to gossip and to have fun. It is a way to get out of the house and the daily routine.

The people with incontinence problems are challenged to maintain their social life by hiding their problem and thus to remain socially continent. Otherwise, they will be the objects of ridicule. The presence of a recognised incontinent person – especially in such as religious forum like the pengajian – will be assumed as an attack to other's space and sense of purity and will cause shame.

Compared to the incontinent elderly who live with their family, the nursing home residents with incontinence problems often have to deal with the daily consequences of the condition without significant help from caregivers. This situation is a result of the requirements before the admission to the place. In the two nursing homes where the research was carried out, the management requires independence from every candidate to take care of him or herself. In the case of incontinence, one should be able to manage her self to prevent stigmatisation from other residents; otherwise they will be the object of gossip and ridicule.
The situation, as found during my fieldwork, is different for the elderly who live with their family at home. While the presence of caregivers is more reliable, the incontinent elderly at home cannot hide their problem or give the impression that they are unaware of having such problem. They are vulnerable not only to infantilisation but also to being controlled by their family members. The stigma towards the incontinent elderly living with their family comes from the family or caregivers and probably from the outside community. The second stigma to a certain extent will affect their family and caregivers as well.

In contrast to the view on urinary incontinence among the elderly, the incontinence among the younger group of people is treated and managed more seriously and sometimes at all cost. The place and role of the young people in the society does not allow them to let the condition untreated. The social expectation for the young people makes incontinence among the young tend to cause more stress and embarrassment compared to the similar condition among the elderly.

Incontinence, as has been discusses so far, can be another point of departure to understand the social reality of the situation faced by the elderly who live in an urban setting such as Jakarta. The condition does not only reveal the perception of the aged regarding the health but also the relation of the people from a different age.

The relationship between adult children and aging parents is sometimes marked by ambivalence. Living with adult children, especially those who are married, for instance, can create certain problems. While parents look forward to a role reversal in old age, i.e. that they will be taken care of by their children, they also wish to retain their independence for as long as it is possible. Support from children is sometimes tentative and conditional. The financial status of the elderly can be a serious matter that determines the care from the family: when they lack of funds they will not be able to afford a good care, whereas having money can be abusive to them, especially when they are sickly.

Caring for aging parents, from the children’s point of view, is not less difficult. For many Indonesians, religion is an important determinant, which influences the norm to care for and to respect the elderly. Religious teaching has a strong influence on the attitude of children towards ailing and aging parents. Associated with the principle of
Filial responsibility is the notion of *pahala* (merits) for the afterlife. The more difficult it is to provide the care, the more merits one will acquire. Related to the idea of merits is the concept of sin. Children who abandon their parents, especially when they are old and enfeebled, as seen as committing a major religious transgression (*dosa besar*). The term used in Indonesian is *durhaka* (disloyalty) – a word which has a strong connotation of treachery.

When an elderly lives with her family, for example her children, the quality of care received by the elderly is often determined by the social-economic status of the children. If they have a stable income and are able to meet their basic needs, the position of the elderly in the family is relatively more secure. On the contrary, if their income is unstable, the frailty of the aged parents will likely clash with the lack of material resources of the family. Not only can the family offer any significant support to their parents, but also the income of the parents – for example their pensions, if any – will be used to support other members of the household. The situation will in turn cause control over the life of the elderly as a mechanism to control or secure the material resources of the household.

Despite all that has been said about the care, the focus of the next studies on this topic should be, among others, put on the family and caregivers who have to deal with the difficult situation. Providing continuous care while at the same time struggling for life may cause a burnout situation for the caregivers. The question then is how to approach the problem without being trapped by ageism. Obviously it is not an easy task to do, although not completely impossible.
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WHO
1998 Aging and Health Programme
APPENDICES

Appendix 1: Objective and Research Questions

The objective of this study is to give an insight into how the incontinent female elderly perceive their condition and the social stigma that might be attached to it, and how they deal with both.

The objectives generate the following research questions:
1. What are the local perceptions of “dirt”, “shame”, and “being old”?
2. What local terms refer and relate to incontinence?
3. What is the importance of control over one’s own body according to the sufferers?
4. What are, according to the incontinent, the causes of incontinence problems?
5. What problems result from being incontinent according to the sufferers?
6. To what extent do these views differ or agree with the views of the caregivers and doctors?
7. What are their assumptions about thinking of others regarding this urinary incontinence problem?
8. Does the problem influence their relations with others (family and near-others) and how?
9. Is there any restriction felt by the sufferers and the caregivers following the condition and what restriction is that?
10. What coping strategies – including biomedical therapy – do the sufferers implement and to what extent are these strategies successful or help them?
Appendix 2: Tables

Table 1:
Trend of Children (0-4 Years of Age) and Elderly (60 Years of Age and Over) in Indonesia 1971-2020

<table>
<thead>
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<th>Years</th>
<th>Children</th>
<th>Elderly</th>
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<tr>
<td></td>
<td>Total</td>
<td>Percent</td>
</tr>
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<td>1971</td>
<td>19.098,7</td>
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<tr>
<td>1980</td>
<td>21.190,7</td>
<td>14,4</td>
</tr>
<tr>
<td>1985</td>
<td>21.550,4</td>
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<td>1990</td>
<td>20.985,1</td>
<td>11,0</td>
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<td>1995</td>
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<td>10,5</td>
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<tr>
<td>2000*)</td>
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<td>9,1</td>
</tr>
<tr>
<td>2020*)</td>
<td>20.771,2</td>
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Table 2
Data on Core Informants

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<th>Age (4)</th>
<th>Marital Status (5)</th>
<th>Occupation (6)</th>
<th>Residence (7)</th>
<th>Education level (8)</th>
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<td>Retired</td>
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<td>College</td>
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<td>Widow, 6 children</td>
<td>Housewife</td>
<td>East Jakarta</td>
<td>High school</td>
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<tr>
<td>3</td>
<td>Lita</td>
<td>F</td>
<td>67</td>
<td>Separate, 3 children</td>
<td>Retired</td>
<td>East Jakarta</td>
<td>High school</td>
</tr>
<tr>
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<td>F</td>
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<td>Housewife</td>
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<td>Elementary school</td>
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<td>5</td>
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<td>South Jakarta</td>
<td>High school</td>
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<tr>
<td>6</td>
<td>Inneke</td>
<td>F</td>
<td>68</td>
<td>Widow, 10 children</td>
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<td>High school</td>
</tr>
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<td>7</td>
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</table>
Table 3
Data on Key Informants

<table>
<thead>
<tr>
<th>No</th>
<th>Name</th>
<th>Sex</th>
<th>Age</th>
<th>Occupation/Specialisation</th>
<th>Level of Education</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Zubairi D.</td>
<td>M</td>
<td>54</td>
<td>MD, internist</td>
<td>University</td>
</tr>
<tr>
<td>2</td>
<td>Rochani</td>
<td>M</td>
<td>54</td>
<td>MD, urologist</td>
<td>University</td>
</tr>
<tr>
<td>3</td>
<td>Yunizaf</td>
<td>M</td>
<td>59</td>
<td>MD, obs-gynaecologist</td>
<td>University</td>
</tr>
<tr>
<td>4</td>
<td>Siti Setiati</td>
<td>F</td>
<td>40</td>
<td>MD, geriatrician</td>
<td>University</td>
</tr>
<tr>
<td>5</td>
<td>Supartondo</td>
<td>M</td>
<td>71</td>
<td>MD, geriatrician</td>
<td>University</td>
</tr>
<tr>
<td>6</td>
<td>S.A. Nuhonni</td>
<td>F</td>
<td>52</td>
<td>MD, rehabilitation specialist</td>
<td>University</td>
</tr>
<tr>
<td>7</td>
<td>Kustini</td>
<td>F</td>
<td>40’s</td>
<td>Physiotherapist</td>
<td>University</td>
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Table 3
Data of Other Informants (for triangulation purpose)

<table>
<thead>
<tr>
<th>No</th>
<th>Name</th>
<th>Sex</th>
<th>Age</th>
<th>Occupation</th>
<th>Level of Education</th>
<th>Other information</th>
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<tbody>
<tr>
<td>1</td>
<td>Prita</td>
<td>F</td>
<td>32</td>
<td>Physiotherapist</td>
<td>Academy</td>
<td>RSCM</td>
</tr>
<tr>
<td>2</td>
<td>Tyas</td>
<td>F</td>
<td>38</td>
<td>Physiotherapist</td>
<td>Academy</td>
<td>RSCM</td>
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<td>3</td>
<td>Kartini</td>
<td>F</td>
<td>40’s</td>
<td>Head of a Clinic</td>
<td>Academy</td>
<td>Nursing home</td>
</tr>
<tr>
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<td>Winnie</td>
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<td>24</td>
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<td>Academy</td>
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</tr>
<tr>
<td>5</td>
<td>Sarah</td>
<td>F</td>
<td>25</td>
<td>Nurse</td>
<td>Academy</td>
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</tr>
<tr>
<td>6</td>
<td>Atika</td>
<td>F</td>
<td>30</td>
<td>Social worker</td>
<td>Academy</td>
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<tr>
<td>7</td>
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<td>Head of STW Cibubur</td>
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<td>Nursing home</td>
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<tr>
<td>8</td>
<td>Susilo</td>
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<td>Retired.</td>
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<td>9</td>
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<td>Computer specialist</td>
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<tr>
<td>10</td>
<td>Meilani</td>
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<td>51</td>
<td>Entrepreneur</td>
<td>High school</td>
<td>Incontinent</td>
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<td>11</td>
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<td>18</td>
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<td>-</td>
<td>Incontinent</td>
</tr>
<tr>
<td>12</td>
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<td>?</td>
<td>Resident of STW KB</td>
</tr>
<tr>
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<td>Oma Pinky</td>
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<td>Retired</td>
<td>University</td>
<td>Resident of STW KK</td>
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<tr>
<td>14</td>
<td>Lisa</td>
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<td>17</td>
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<td>F</td>
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<td>Housewife</td>
<td>High school</td>
<td>Daughter of Mrs. Hidayati (core info.)</td>
</tr>
<tr>
<td>16</td>
<td>Mrs. Sani</td>
<td>F</td>
<td>50's</td>
<td>Housewife</td>
<td>?</td>
<td>Mother of Yanti</td>
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</tbody>
</table>