

UNIVERSITY OF OKLAHOMA

GRADUATE COLLEGE

THE (PASSIVE) VIOLENCE OF HARMONY AND BALANCE:  
LIVED EXPERIENCED OF JAVANESE WOMEN WITH TYPE 2  
DIABETES

A DISSERTATION

SUBMITTED TO THE GRADUATE FACULTY

In partial fulfillment of the requirement for the

degree of

DOCTOR OF PHILOSOPHY

By

DYAH PITALOKA

Norman, Oklahoma

2014

THE (PASSIVE) VIOLENCE OF HARMONY AND BALANCE:LIVED  
EXPERIENCED OF JAVANESE WOMEN WITH TYPE 2 DIABETES

A DISSERTATION APPROVED FOR THE  
DEPARTMENT OF COMMUNICATION

BY

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Dr. Elaine Hsieh, Chair

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Dr. Eric M. Kramer

---

Dr. Clemencia Rodriguez

---

Dr. Suzanne Moon

---

Dr. Tassie Hirschfeld

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For Mom, Dad and Ravi Pradana

## ACKNOWLEDGEMENTS

This dissertation is part of my journey as a Javanese woman and a scholar. Every page represents a story of struggle, a story of love and devotion, a story of patience to undergo hard times in life. In this dissertation there is hope and a prayer that what I do will help promote change, to help these women have their stories heard. I think writing this dissertation has been the most challenging road that I have ever walked. Yet, I never felt alone, because I have been surrounded by many wonderful, thoughtful, and devoted people I wish, now, to thank.

My mom, who was a single mother for my brothers and I for 20 years, taught me how to live my life with less complaining and more gratitude. She has shown me the meaning of submission and living in concern for others. My parents taught me to be a strong woman and never stop fighting for the right things. My parents have made the world a better place. I am grateful because my brothers and I have had the same opportunities to reach our dreams.

This journey would not have been completed without Dr. Elaine Hsieh, my mentor and chair of my dissertation committee. Not once did she ever give up on me. She showers me with her endless support that gives me energy to move on. Her attention to detail and pursuit perfection

made me work hard and to appreciate the time and opportunities I've been given. You encourage me to “swim with a shark;” even when you do not win, you know where you stand.

I have been blessed with a very supportive, insightful, passionate, and kind dissertation committee. Each of you is indeed very special to me. Thank you Dr. Eric Kramer, for sharing your remarkable thoughts, for making me understand what it means, essentially speaking, to be a scholar, for encouraging me to conduct a study that brings a benefit to the people around me and to the development of communication research. Thank you for standing up for me during the hard times, and for your endless support to my son and me. Thank you Dr. Clemencia Rodriguez for being such an inspiration. Through your passion, I have learned that we can make change with our knowledge. Dr. Suzanne Moon, *terima kasih untuk segalanya*. I enjoyed our every discussion with *bahasa campur-campur*, always insightful. Your knowledge of Indonesian history amazes me, and helps me in framing my thinking not only in this study, but also in life. Looking forward to *kongkow* with you at Starbucks Singapore! Finally, I feel so blessed to know Dr. Tassie Hirschfeld. You have given me opportunities to expand my knowledge in medical anthropology, to learn new things in my life as a scholar, and to deliver my ideas to your students.

I want to thank Fulbright Scholarship, IIE and AMINEF, for giving me this golden opportunity to experience life as both a woman and Ph.D. student in the United States. Thank you for the Fulbright Southeast Asia (SEA) grant that allowed me to conduct field research in Indonesia and present the results at ICA-London. Thank you, Pak Piet Hendarjo, for your kind guidance and support, and to my Fulbright supervisor and former supervisors at IIE Chicago. Thank you for making my dreams come true.

My life as a graduate student at the Department of Communication at the University of Oklahoma has been immeasurably beneficial. I wish to thank department chair, Dr. Michael Kramer, for your kind support and encouragement, and for valuing my thoughts and concerns. Thank you, Kristi Wright and Kathy Martin, for assisting me throughout my years at the University of Oklahoma, and for making me feel accepted as an international student.

I want to thank Dr. Steve Ferzacca, who is always willing to discuss diabetes and Javanese culture on Facebook. I have not had a chance, yet, to serve you *camilan* and *kopi tubruk*. *Terima kasih*. To my Fulbright friends, Retno Tanding, Izak Y.M. Lattu, Egawati Panjei, Sri Rejeki Murtiningsih, and Eriana Asri, thank you for all the fun and tears. You are precious to me. I would also like to thank Dr. Merlyna Lim, my

super bright and beautiful professor friend. You have been so encouraging and inspiring, you know that? Thank you and see you in Singapore!

To all my friends in the 2010 cohort, you guys rock! Thank you for the beautiful friendship, Elissa N. Arteburn, Grace Karuga, Garret Castleberry, Bobby Rozzell, and Jerry Overton. Brandon Jones, Madison Richardson, I'm gonna miss you guys! Thank you for being a family in Norman. I wish you all the best. Also Sachiko Terui, Yang (Vivian) Liu and Roni Kay...you are wonderful women. I'm so blessed to have you all in my life. Also, Donald Wang, thank you for being my sweet brother.

The love of my life, Ravi Pradana, you make me proud of you *le*, everyday. You are the strongest man I have ever met, and this dissertation is for you. Thank you for accompanying me throughout these years, for laughing and crying with me throughout the hard times, for hugging me and telling me "I love you" every morning. You will be a star someday *le!* I love you, more than you know. For my forever dear friend, Agus Riyanto, thank you for being there in the final moments of this wonderful experience, and for your tremendous support for Ravi and me. We both love you.

For this wonderful piece of writing, I would like to thank my amazing editor, Ann Hamilton. You don't speak my language, but you made this dissertation alive. I feel that you know what I'm thinking, what



I'm saying...I couldn't have done this without your support Ann. We'll be in touch and I will disturb your days with more stories....thanks a bunch!!

Finally, I want to thank these wonderful women, my participants, who made this project happen. You are precious, strong, and powerful women. It is my sincere hope that your story will help improve health policy and health conditions in Indonesia, that this work will improve the quality of life for women with diabetes throughout Indonesia. It is my hope that your voices will be heard.

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## ABSTRACT

This study is an examination of Javanese women's lived experience with Type 2 diabetes, an exploration of the ways these women maintain interactions with family members and society and how they adapt diabetes management to Javanese cultural beliefs and traditions. Through participant's narratives, this study provides a new conceptual understanding of diabetes and how submission to culture becomes an opportunity for these women to re-construct their identities and manage their disease and their obligations. This study includes data collected through in-depth interviews and observations, which were analyzed using narrative analysis. A total of 60 Javanese women with Type 2 diabetes participated in this study. These women are from middle class and poor socio-economic groups, and reside in urban and rural areas of Central Java, Indonesia. Through the interviews, the influence of cultural beliefs related to Javanese women's health beliefs, and their roles in maintaining harmonious social interactions and obligations are examined, along with issues of self-image and identity formation. Narrative analysis was conducted to analyze individuals' stories and the socio-cultural meanings embedded in the stories. Further, in the analysis, women's narratives are used to capture shared socio-cultural values that shape Javanese women's identities and their understandings about diabetes. The analysis reveals

that harmony and balance are main themes in women's stories of their lived experiences with Type 2 diabetes. Principles of balance and harmony emphasize individuals' abilities to manage disruptions in their lives using specific cultural resources, and attaining balance and harmony, participants say - is required for even constitutive of good health. The author concludes that the prominence of balance and harmony in the narratives indicates that these two obligations substantially affect Javanese people's worldview, providing a fundamental structure for understanding conceptual thinking about disease, health, cures, and ways of managing Type 2 diabetes. More specifically, diabetes challenges harmony and balance on three different levels: the personal level, the familial level, and the social level. Within these levels, participants emphasize the importance of achieving "fit" through submission to Javanese cultural values, especially *tepa selira* (empathy).

## CHAPTER ONE

### **Introduction**

#### **A personal journey**

My mind wondered to a night when I said my prayer to Allah to allow me to get pregnant. I whispered in my prayer many times, “Allah, please let me get pregnant, and please give me a boy...so he can protect me and fight for me one day.” When a woman is labeled by her husband’s family as infertile (*mandul*), regardless of whether it is true or not, she must prepare to face the worst situation. She is left with two options: to be divorced or to let her husband take a second wife. This fate does not happen to a man, even if he cannot father a child.

When a woman cannot conceive, does she deserve all of this? To be ostracized and stigmatized? Humiliated? Abandoned?

No.

Having a bloodline tied to Javanese royalty, I was brought up in a family that upholds traditions and inherits not only material wealth, but also power to control socio-cultural resources. My great grandfather held a position as village chief (*lurah*) and ruled agriculture villages near the Special Region of Yogyakarta. He was a tall and handsome man, with an



aristocratic look and magical energy (which is believed to be ascribed, and therefore reserved for elites), light brown skin, a sharp nose, and a mustache. He fought the Dutch and protected the people in his territory. Javanese spears, ceremonial knives (*keris*), and a big black stallion were symbols of his power.

In contrast were my great grandmother and my grandmother. They were iconic royal Javanese women, with shining light brown skin, long hair, a fine attitude (*halus*), eloquent and elegant, with charming personalities. And, they were faithful companions to their husbands.

Both of these women were professional classic Javanese dancers and skillful wives, who, because of their education, wealth, and status, possessed the power to maintain order and peace, and to promote progress. And, as they have told me, being able to manage your fine attitude is an expression of power, because for Javanese, it can only be achieved through concentration of one's energy to control emotions. And in Javanese royalty (*ningrat*), women are prepared to maintain the order in both private and public spaces. This means, even when a woman is angry, sick, or upset, she must not falter in maintaining order and harmony.

My mother has inherited both the skills as a good *ibu* and as an independent professional. She is a very good dancer, mother, and wife, and, she is a lawyer. My father was a medical doctor, a Javanese man who

spent most of his time studying and working abroad, a man who insisted that boys and girls must have equal opportunities. My father made room for his wife to fulfill her public responsibilities and her personal dreams, and encouraged me to aim high, dream big, and fight for my honor when necessary. He said, “I know we have Kartini, but we also have Cut Nyak Dien, Martha Christina Tiahahu, and also Dyah Pitaloka Citraresmi<sup>1</sup>...and you know why I named you after her? So that you know you have to fight for your life”, he said, as “a *perempuan*.”<sup>2</sup>

However, I discovered a different path of life that changed my understanding about culture. The lives of urban Javanese *priyayi*<sup>3</sup> emphasize material wealth and force women to strictly obey the patriarchal structure, leaving women with no voice to defend themselves. No matter how smart or highly educated they may be, no matter how capable women are to make any argument, there is no social *place* to make the case. So, I learned that Javanese people who claimed to be *priyayi* because of their wealth alone do not embrace the same values that

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<sup>1</sup> These are Indonesian women heroine who fought Dutch colonialist

<sup>2</sup> For my father to use this term is significant: *Perempuan* is a Sanskrit word used in the Indonesian language that means a woman. However the etymology of this word means *master*, or *ruler*, or *support*. This term was not used during the New Order era (1966 to 1998), because of these connotations (Rahayu, 1996; Zoetmulder, P.J, 1982). Yet, my father used it, during this time period, to describe me specifically *because* of these connotations.

<sup>3</sup> Originally *priyayi* comes from a Javanese term *para yayi* (younger brothers of the King). During the Dutch colonial period, this term was extended to include high-ranking government officials, the aristocracy, and noble people (see (Sutherland, 1975).

I learned as a *priyayi*. The former recognizes materiality as a symbol of *priyayi* status, and for women it means they can only gain recognition and exert power in the domestic sphere.

I lost my dignity on the day I was labeled “sterile” and was told that my husband deserved someone better, and when I was labeled as “disobedient” when I chose to have an appendectomy on the day of a large, important family gathering. I lost dignity when I was labeled a “rebel” when I decided not to wear traditional Javanese dress (*kebaya*) and perform a traditional ritual in a wedding because of my pregnancy. And I lost dignity when I was labeled “selfish” for my decision to have only one child.

I was trapped by my own socio-cultural values and suffered negative social judgments when I chose to live in a way that differs from *Kartini* (an aristocratic woman who represents the ideal figure of a Javanese *ibu*). I was trapped by socio-cultural obligations to be responsible for harmony in the world around me, and trapped when I had to struggle to determine my own actions, to determine my own fate. And, it was a struggle to become financially independent. Patriarchs see pursuing a career as chasing an ambition, a cultural taboo for women.

No matter how good a woman is at managing the household, how smart and bright a woman is, her life is determined by Javanese tradition.

A woman's identity is continually negotiated among roles as mothers, and wives, and the cultural values and obligations that dominate her world.

Having a permanent job, health insurance, savings, and access to information secured my independence. I can make my own decisions regarding my health, and I can make my voice heard because of my education and role in society. But I live in a culture in which policies and rules are developed under the direction of men, written in the language of men. In Indonesia, for example, polygamy is legal. It is especially acceptable when a wife cannot conceive. Poor women in particular struggle to get healthcare access, struggle to provide the family with income, and struggle to manage the household. These poor, rural women have few means to make their voices heard.

As a Javanese woman, I know my roles and I am proud to be a good *ibu* and a good wife. But the world needs to listen to these women's stories, their lives, and their suffering; only through listening can we make change. Not to position one above another, but to listen and to give each other ample space in the dialogue. To give everyone in society a place to be.

### **Women in Indonesia**

Geographically the Republic of Indonesia is an archipelago nation located between Asia and Australia. Indonesia consists of approximately

17,000 islands; the five major islands are: Java, Sumatra, Kalimantan, Sulawesi, and Papua, which border Papua New Guinea. Other groups of islands include Maluku and Nusa Tenggara, running from Sulawesi to Papua in the north and from Bali to Timor in the south. Currently, Indonesia's population is 225.6 million people (BPS, 2013).

Defining Indonesian culture is difficult because this archipelago has given rise to diverse cultures and hundreds of ethnic groups, each with their own tradition and ethnic language. As a country rich in myth and legend, Indonesia possesses an extraordinary range of belief systems, material culture, and arts, composing one of the most ethnographically diverse countries in the world. Remarkable cultural heritages can be seen from indigenous people's traditions and rituals, majestic temples, centuries-old palm manuscripts, literature, lavish theatrical performances, graphic arts, sculptures, ancient epic poems (i.e., *I La Galigo*, one of the world's longest epic poems) (Forshee, 2006). Overall, the face of Indonesia represents a mixture of villagers, factory workers, urban professionals, sea nomads, migrant workers, artists, timber harvesters, *becak*<sup>4</sup> peddlers, street vendors, and many others.

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<sup>4</sup>*Becak* is a traditional Indonesian "trishaw", or cart, used for transportation. The word *becak* originally comes from the Hokkien language: *be chiah*, meaning "horse cart". This mode of transportation was introduced in Indonesia in the early 20<sup>th</sup> Century.

With more than 300 ethnic groups, Indonesian women are a heterogeneous group based on ethnicity, education level, political interest/affiliation, and socioeconomic status. They speak hundreds of local languages and follow different traditions and cultural values, making it difficult to generalize anything meaningful amid such diversity. The largest of these ethnic groups resides in Central and East Java. The second largest group is in West Java, and other smaller ethnic groups reside in Celebes (Sulawesi), Sumatra, Bali, and Papua (Poerwandari, Sadli, & Ihromi, 2005). Added to this pluralism are a number of religions. The majority of Indonesians are Muslims, followed by Protestants, Catholics, Hindus, and Buddhists. These differences influence society's norms and values, and make it particularly difficult to provide a single picture that represents the position of Indonesian women generally.

### **Diabetes in Indonesia**

Indonesia currently faces an epidemiological transition in which non-communicable diseases (NCDs) are estimated to account for 63 percent of all deaths in Indonesia. Of this figure, diabetes contributes to three percent of the total number of deaths (Chan et al., 2009). There are three main types of diabetes – Type 1 diabetes, Type 2 diabetes and gestational diabetes. Regardless of specific types, all forms of diabetes occur when one's body cannot produce enough of the hormone insulin or

cannot use insulin effectively. Type 2 diabetes in particular is unique because it is described as “rooted in reversible social and lifestyle factors” (Lancet, 2010, p. 2193) and is strongly tied to cultural practices and traditions. It can go unnoticed and undiagnosed for years, so people affected with Type 2 diabetes are unaware of the physical symptoms and the long-term damage caused by this disease. Ironically, *The Lancet* highlights the fact that 90 percent of diabetes sufferers worldwide are afflicted with Type 2 diabetes (Lancet, 2010). The International Diabetes Federation found that Type 2 diabetes—also commonly known as adult-onset diabetes—amounts to 80 percent of all diabetes cases in developing countries, including Indonesia (Cho & Whiting, 2013). Based on Central Java Health Profile 2012, Type 2 diabetes cases in the Central Java Province are gradually increased and dominate 90-99% of all diabetes cases in this province (DINKES, 2012). Unfortunately this report does not distinguish between male and females.

A study conducted by pharmaceutical company Novo Nordisk identified two main challenges in diabetes prevention and education in Indonesia. The first challenge is barriers to appropriate diabetes care, which potentially prevents people with diabetes from accessing important information and getting proper treatment. The second challenge is a lack of awareness and knowledge about diabetes on the part of healthcare

providers and the public (NovoNordisk, 2013). Furthermore, Novo Nordisk reports that 7.6 million people in Indonesia who are living with diabetes and less than 1 percent of these diabetics are receiving medically recommended treatment (p. 3).

Literature shows that diabetes generally has a more devastating impact and tends to be more difficult to control among women (Beckless & Thompson-Reid, 2001; S. Black, 2002). A recent study found that on average in Indonesia, women have a higher risk of developing diabetes than men (Mihardja, Delima, Manz, Ghani, & Soegondo, 2009). Recent survey data in *Indonesia Basic Health Research* shows that the prevalence of diabetes in Indonesia increases with age and is found to be higher in women, especially housewives (RISKEDAS, 2013). Biological and socio-cultural factors are thought to be factors that influence this condition. For example, hyperglycemia (high blood sugar) eliminates estrogen's ability to protect the body from coronary heart disease (RISKEDAS, 2013).

Socio-cultural factors that aggravate women's burdens are the multiple caregiver roles responsibilities they have in day-to-day family and social life. As the keepers of culture, women play important roles in the family, especially as food preparers. And, women are required to ensure adequate income is available for the household. Women prepare food for the family daily, but also are responsible for preparing food for



community feasts and other social and religious celebrations(C. Geertz, 1960; Newberry, 2006). In this case, women's roles to maintain cultural practices and traditions, and to pass them to the next generation, become potential barriers for lifestyle changes, especially those involving diet. In addition, Indonesian women are assigned significant roles in maintaining family harmony, and under the Suharto's New Order's government (1966 to 1998), this tradition became law with the enactment of the Marriage Law 1/1974(enacted in 1974; see (Sitepu, 2000)).<sup>5</sup> Chapter 24 and chapter 25 of the State Guidelines 1989 (Garis Besar Haluan Negara/GBHN), Indonesian women were expected to dedicate their life to the state. These include: loyal supporter of the husband, producer and educator of future generations, caretaker of the household, additional economic provider of the family, and members of the society.<sup>6</sup>

Data from RISKEDAS (2013) shows that both rural and urban people in Indonesia have the same likelihood of getting diabetes. Further, this disease should no longer be perceived as diseases of affluence (Bennett, 1983)because it is known to affect people across the economic spectrum(RISKEDAS, 2013). The quality of healthcare in Indonesiaand

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<sup>5</sup>Article 31 and Article 34 of the Marriage Law 1/1974, for example, clearly describe women's role in the household as a "housewife" and that a wife is responsible in managing the household affairs (see [www.dikti.go.id/files/atur/UU1-1974Perkawinan.pdf](http://www.dikti.go.id/files/atur/UU1-1974Perkawinan.pdf)).

<sup>6</sup>See [http://www.bappenas.go.id/index.php/download\\_file/view/8646/1724/](http://www.bappenas.go.id/index.php/download_file/view/8646/1724/).

inadequate health insurance coverage combine to create disproportional burdens for poor people with Type 2 diabetes, especially the rural poor. Soewondo, Ferrario, and Tahapary (2013) found a lack of medical expertise and diabetes diagnostic equipment at the primary care level (*Puskesmas* or community health clinics), especially in rural areas. Diabetes care, therefore, is only available at secondary and tertiary care levels (class A, B, and C hospitals), located in cities. This situation contributes to higher costs for the healthcare system, which in turn increases barriers to diabetes care.

While studies have provided data on biomedical and epidemiological aspects of diabetes in Indonesia, little data is available from the socio-cultural perspective. In particular, data focusing on lay people's understandings about diabetes and the daily experiences of people living with type 2 diabetes across gender, socio-economic background, and age (Adams, 2003; Arcury, Skelly, Gesler, & Dougherty, 2003). This current study is of importance in understanding the ways culture influences the way people with Type 2 diabetes, how diabetics make sense of the disease, and how they respond to life changes attributable to the disease. This data is useful for governments, healthcare providers, and related institutions in developing culturally sensitive interventions for Type 2 diabetes. As explained by Malinowski, culture serves as cause, effect,

and also remedy in the production of the disease (as cited in (Ferzacca, 2012). Within the type 2 diabetes contexts, understanding cultural values helps identify specific cultural values and traditions that may support or hamper the daily management of diabetes.

Therefore, to gain better understanding of people and their lived experiences with Type 2 diabetes, and about lay people's understandings of the disease, this current study addresses these following research questions:

RQ1: How does diabetes influence Javanese women's interactions with family members and society?

RQ2: How do Javanese women adapt diabetes management to their cultural beliefs, traditions, and background values?

To answer these questions, this dissertation is divided into the following chapters: the second chapter provides a review of relevant literature focused on Javanese cultural values, cultural conceptualization of health and illness, Javanese concepts of womanhood and women's roles, and the role of narratives in helping Javanese women construct the concept of self and (re)establish their identities as women with type 2 diabetes. The third chapter describes the data collection method used and the fourth chapter provides study results and analysis. Finally, the fifth chapter includes discussion about the contribution of this study toward theory

development, the limitations of the study and suggestions for future research.

## CHAPTER TWO

### **Literature Review**

This chapter provides a review of literature about women and health policy in Indonesia, Javanese cultural values and traditions, the conceptualization of womanhood and women's roles in Java, and the social construction of health and illness. The first section includes discussion about how the prevailing Javanese worldview and cultural values frame women's views of health, disease, and illness, as well as their understanding of Type 2 diabetes.

#### **Java and the Javanese Woman**

Roughly the size of Britain, Java is the fourth largest island in Indonesia, but is home to more than half of the nation's population; Javanese people constitute approximately 70 percent of Java's population. Literature describes the homeland of the Javanese consists of Central Java province, East Java province, and the Special Region of Yogyakarta (Koentjaraningrat, 1985). According to Indonesia Statistical Bureau (BPS), the official 2010 population census showed that there were more than 200 million people live in Indonesia. World population review, in the website, noted that in 2013 there were more than 250 million people in Indonesia: approximately 58 percent of the nation's population lives on the island of Java.

The Javanese women who are the focus of this current study represent women from Central Java. They speak the contemporary Javanese language in their daily conversations. The Javanese language has three speech levels that function as indicators of the degree of respect or formality a speaker shows to an addressee (Berman, 1998). The Javanese explain that to be Javanese means to be a person who knows his/her manner and place, and that to be Javanese is to be civilized (H. Geertz, 1961; Koentjaraningrat, 1985; Mulder, 1978). Maintaining harmony and balance are core values in the lives of the Javanese. As described by Mulder (1978):

*Rukun* is soothing over of differences, cooperation, mutual acceptance, quietness of heart, and harmonious existence. The whole society should be characterized by the spirit of *rukun*, but whereas its behavioral expression in relation to the supernatural and to superiors is respectful, polite, obedient, and distant, its expression in the community and among one's peers should be *akrab* (intimate) as in a family, cozy, and *kangen* (full of the feeling of belonging). (p. 39)

To achieve harmonious living (*rukun*), one must avoid all overt expressions of conflict, anger or frustration. In maintaining social interactions, Javanese people must preserve mutual assistance and the

sharing of burdens (*gotong royong*) within the family and the community. Each individual must know his or her place and duty, and must honor and respect those in higher positions, while remaining responsible for those in lower ones.

### **Javanese kinship.**

Kinship is an important component in the lives of the Javanese. In general, Indonesian people do not become isolated from their families even after they marry: the kinship organization does not break down. Javanese families residing in urban areas commonly live in independent households, i.e., with only the nuclear family in the household, and this family unites with extended family members primarily on special occasions such as weddings and religious celebrations. Studies show that in many villages in Central Java, nuclear families live in the same house with parents. Another common arrangement is for adult children to build houses in the parents' garden or a house attached, typically, to the wife's parents' house. Frequently they have separate kitchens, so that the new couple can manage their own household affairs (Koentjaraningrat, 1985; Peacock, 1973).

Javanese society maintains bonds among sisters even after they marry and move to separate households. An aged father will typically live with a daughter rather than a son, because sons treat fathers with great

deference and formality after early childhood. Thus, it is common that a daughter (and a wife and mother) becomes the central figure in these households. The Javanese household is a woman's domain, where her control over resources is near complete: she makes most of the decisions about household matters. The husband gives his wages to his wife and she manages the money and other resources. The house for a Javanese family is also viewed as maternal, feminine territory, and they demonstrate this in certain traditions in which the back and inner rooms of a house are considered female, and the guest room and/or porch are considered male (Djajadiningrat-Nieuwenhuis, 1987).

Mothers in Javanese families are responsible for teaching their children how to “live in concern for others” (*prihatin*), how to make sacrifices, and to exert strong efforts to achieve desired outcomes (Brenner, 1998). By performing *prihatin*, women show how they willingly accept hardships and misfortunes in life. This contributes to Javanese women being known for their endurance, self-reliance, and strength (Handayani & Novianto, 2004). In addition, women play important roles in maintaining close contacts with their relatives. Children are obliged to care for their parents when they are old and can no longer care for themselves (H. Geertz, 1961). Megawangi, Sumarwan, and Hartoyo (1994) found that this trend is shifting as fewer parents live with their



children when they are old. Relationships with in-laws are considered to be most difficult, requiring near constant politeness and reserve. These relationships are more likely to produce disharmony, especially between parents and a daughter in-law (H. Geertz, 1961).

Among Javanese people, especially those whom Geertz calls *abangan*,<sup>7</sup> it is very important to perform a traditional community feast (*slametan*) to maintain a state of *slamet* (safety, balance, tranquility, and order) throughout one's life, especially during periods of "disorder or crises of life such as birth, circumcision, marriage and death" (C. Geertz, 1960, p. 30). As a Javanese rite, communal feasts (*slametan*) are seen as helpful in maintaining social harmony and inner peace of mind. Typically, only men attend the feast, while women prepare the food.

The practice of communal feasts shows that Javanese behavior focuses on achieving social conformity. *Slametan* contributes to social cohesion and women play an important role in the formation and maintenance of networks to organize this social events ((N. Sullivan, 1994). Based on the value of mutual help (*gotong royong*) and harmonious living (*rukun*). Javanese women create bonds with others, especially relatives and close neighbors, as they, prepare food for such events.

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<sup>7</sup>Geertz (1960) in his classic book *The Religion of Java* divides the Javanese society into three variants: Santri, Abangan, and Priyayi. Abangan, as the largest group, consists of Javanese who syncretize Islam and Hindu-Buddhist traditions and are considered to be less devout Muslims (p. 126-130).

Maintaining good relationships by following socially acceptable behavior is considered a crucial part of preserving the social networks and family support systems (Magnis-Suseno, 1997).

### **Javanese womanhood and women's autonomy.**

Since pre-colonial times (before 1586), women in Indonesia, Thailand, Burma, Philippine, Singapore, Cambodia, Malaysia, Laos, have enjoyed relatively high status than other Asian countries (Errington, 1990; Peacock, 1973; Stoler, 1977). While Reid (1988) argues that women's autonomy and activity in the public domain are exclusively enjoyed by small numbers of wealthy urban businesswomen, Stoler (1977) suggests that the relationships between men and women in rural areas are distinguished by access to resources that cut across sexual lines.

The picture of Javanese women is two-sided. On one side, women are viewed as emotionally, spiritually, and rationally inferior to men (Atkinson & Errington, 1990; Ong & Peletz, 1995; Sears, 1996); but on the other side, women are seen as being equal to men, especially in rural Java and among working class people (Brenner, 1998; Hughes-Freeland, 1995). As explained by Wolf (1988), industrialization in Java during the Dutch colonial period (1800-1942) enhanced the status of female workers. Within agrarian societies, like Java, a woman's status is determined by her class standing and whether or not she possesses land. A majority of rural

women do not have class standing nor do they own or control land, thus they have developed their own income producing strategies to meet subsistence needs (Hart, 1986; Wolf, 1994). Frequently working as market traders, these poor rural women maintain a high degree of economic power although much of the time they have little to control because they are poorly paid for their labor. Studies about the economic power of Javanese women have focused on women's occupations, however little emphasis has been placed on the relationship between industrialization and women's positions or on the position of women since industrialization.

During the colonial Cultivation System (1830-1870), Java became the world's leading sugar producer with more than 200 factories processing sugar cane and selling their output all over the world. To support the production, Javanese men and women contributed directly to the cultivation and export production. As a result, sexual inequalities promoted by the Dutch colonial government through a dichotomization of sex roles did not occur to any great extent in Java (Dewey, 1962; Stoler, 1977).

Since the Dutch colonial period, Javanese girls have been brought up in the spirit of Kartini's<sup>8</sup> ideals, i.e., girls are taught to approach marriage as wives and mothers who look after their families at home (Djajadiningrat-Nieuwenhuis, 1987). Djajadiningrat-Nieuwenhuis adds that the role of a mother or *ibu* is a status symbol of *priyayi* (modern educated Javanese) women. As *ibu*, a woman must ensure that she not only cares for her children, but, at the same time, she also works to increase household income, or to provide it if she is isn't married, or if she is married to a man who produces no income or who is unwilling to provide support to the household. Only by performing these dual roles is a Javanese woman considered a good *ibu*. This tender, caring, and loving image of motherhood was the one promoted by the government during the New Order era<sup>9</sup>. President Suharto, in his development program, embraced and promoted this "loving mother" image in many of his policies, in part because it did not threaten or infringe upon men. He also positioned himself as the "father of development," and the "father of the nation" to whom Indonesians should listen.

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<sup>8</sup>Raden Ajeng Kartini is a Javanese noblewoman whose letters made her an important symbol for the Indonesian independence movement and for Indonesian [feminists](#).

<sup>9</sup>The New Order is the term used to describe the regime of the 2<sup>nd</sup> President of Indonesia, Suharto, as he came to power in 1966. The use of this term was meant to contrast Suharto's period with that of his predecessor, Sukarno, which was known as the Old Order. The New Order era lasted for 32 years (1966 to 1998).

Javanese families value children as God's blessings, and children play an important role in the lives of parents. For women, "giving birth to offspring and nurturing them is a way to pay one's debt to one's parents because by having descendants, only then can one re-experience the kinds of difficulties and suffering that one's parents encountered" (Suleman, 1995). Women's roles in Indonesian society are typically associated with both material and spiritual actions that operate within the larger ideological structures. Women are seen to possess both reproductive and magical powers through giving birth, practicing agriculture, producing and dyeing textile, and cooking. Women also control social information and the tone of messages, thereby affecting family and community relationships. In his article, Reid (1990) argues:

It would be wrong to say that women were equal to men – indeed there were few areas in which they competed directly. Women had different functions from men, but these included transplanting and harvesting rice, weaving, and marketing. Their reproductive role gave them magical and ritual powers, which it was difficult for men to match. These values may explain why the values of daughters was never questioned in Southeast Asia as it was in China, India, and the Middle East. (p. 146)

Women across the Indonesian archipelago control social discourse and this is the most influential role they play in engineering family and community relationships and the directions those relationships take. This situation illustrates how women must deal with many levels of expectations. For example, women are expected to fulfill their roles as good wives and mothers within the family, but are also expected to contribute to local development and to fulfill social obligations at the socio-cultural level, emotional, physical and financial needs, and harmony and progress in the community(Niehof, 1998).

Examples of the organizations women might contribute to in these ways are, first, a rotating credit-and-savings association (*arisan*). The amount of money deposited and the amount to be loaned vary depending on the *arisan* member's ability to pay. Second are religious associations, such as a church community for Christian women, or a recitation group (*pengajian*) for Muslim women. These communication circuits form somewhat hidden yet predominant power in communities (Forshee, 2006; J. Sullivan, 1980; N. Sullivan, 1982). From this point, gender is seen not only as “a cultural system of practices and symbols implicating both women and men” (Errington, 1990), but also as the “need to continuously negotiate and invent forms of identity in postcolonial Indonesia” (Ong & Peletz, 1995).

Javanese mothers typically have stronger bonds with their children than fathers do. Thus, mothers feel obligated to take the burden of securing their descendant's future more heavily onto their shoulders (Brenner, 1995). Consequently, married women are most likely to remain in the house overseeing the household, while men are responsible to maintain the household by working outside the house, and therefore spend much more time away from the family. Women manage the money for the expenses of the household, but in Java, decisions as to how it is spent may be jointly made by a couple (Elmhirst, 2000; Wolf, 1994, 2000). The husband typically pays for daily essentials, including utilities, the children's education, health needs, food, and rent. Any effort that the wife exerts to provide extra income for her family will be viewed as her voluntary contribution to the family (Devasahayam, 2005).

Securing the family's future also means that women must be able to give birth to children. Thus fertility is often a central concern for Indonesians. During the New Order era, under the topic of "development," this reproduction discourse was vigorously institutionalized through the formation of two key government institutions: the Family Welfare Guidance Program (PKK – *Program Kesejahteraan Keluarga*) and *Dharma Wanita* (an Association for Wives of Government Officials) (Parawansa, 2002; Sen, 1998; Suryakusuma, 2011).

It is reasonable to conclude that patriarchal ideology strongly influences the Javanese government's construction of gender roles, which deny women's social and political power and limit their spheres of influence to the household. Women's housekeeping skills remain a primary benchmark used to assess a woman's ability to perform her duty as a good woman and to some extent, this division of labor persists in part because of widespread acceptance of the ideology governing men and women's expectations and social behaviors (Brenner, 1995).

Bennet (2005) posed an argument based on Giddens (1990) concept of modernity, specifically that women are more powerful these days due at least in part to the influence of "accelerated development," defined as:

An epoch that began with the emergence and expansion of capitalism, industrialization, scientific rationalism, nationalism and state claims to military power and the surveillance of citizens. (p. 7)

In many parts of the world, this period was marked by the acceptance of technological change, changes in lifestyle, and cultural transformations, which aligned with patterns of consumption and materialism. Music, cinema, the mass media, and the Internet became key vehicles used by young women to engage modernity and participate in the global culture.



Indonesian women have moved from passivity and operating in the background to the foreground as strong, independent, and effective decision-makers. Societal shifts have advanced notions of equality, and women occupy more prominent roles in the economy and society today, though equity is elusive, and equality a dream.

While modernization has equipped urban women with technology, mobility, and freedom to participate in paid work, lower class women have not been as fortunate. Many of these women are poorly educated, and are marginalized by potential employers. With increasing poverty, women in lower socio-economic groups increasingly leave home to work in other cities or countries as domestic workers, typically. Bemmelen (1992) reveals that women in rural areas in Java share control of the household economy with their husbands. Compared to urban women, women in rural areas are required to work to provide the family's needs. These women become leading actors in the management of the household and are frequently the most significant financial providers in the family.

The modern Javanese woman is no longer described in the Javanese tradition as soft, submissive, obedient, shy, and cowardly. Rather, women have transformed into more courageous, more open individuals, who are better prepared to face challenges and prevail in competition. Women have undergone a process of redefining themselves

in terms of their status, roles, and positions in the family and in the community. Yet, these economic transformations have not automatically changed the way society perceives women and their roles in society. Women do not receive the social appreciation they deserve. Ultimately, Indonesian women continue to shoulder this double burden (as mothers and wage earners), and are negatively affected by the patriarchic ideology.

### **Health Policy in Indonesia**

Health policy and politics in Indonesia cannot be divorced from the history, political attitudes, and socio-cultural complexities surrounding the development in Indonesia. The country continues its struggle to overcome problems related to healthcare such as unequal access, inadequate health services (especially in rural areas), the lack of health insurance coverage, and the lack of information about specific health issues and diseases. In spite of these drawbacks, the social construction of gender and gender roles remains a central issue related to women's health and health policy in Indonesia. Even with contemporary economic growth and the claims made by the New Order government that they have lifted millions from poverty (Cameron, 2002; Timmer, 2007), Indonesia still faces many serious healthcare challenges (Houweling, Kunst, Borsboom, & Mackenbach, 2006).

The 1997 collapse of the economies of Asia and Southeast Asia created huge political turmoil and the fall of the New Order government in 1998. As a result, not only did Indonesia deal with political instability and slow economic recovery, the country also faced problems with unemployment and an incredible increase in the number of people living in poverty - nearly 100 percent in 1998 (WHO, 2008). The major setbacks in Indonesia's economic and political situations have created a dramatic decline in government expenditures on healthcare.

Some old health issues are still prevalent in Indonesia, especially healthcare access, maternal and infant mortality, malnutrition, and vector borne diseases such as malaria. The burden of healthcare becomes increasingly severe because not only must Indonesia reduce the number of communicable diseases as a major cause of morbidity and mortality, but at the same time the country must deal with an increasing incidence in degenerative diseases associated with an aging population. For example, longer life expectancies, and lifestyles characterized by reduced physical activity and increased obesity combine to create more demand for healthcare services. A recent study conducted by *The Economist* reports that, compared to its peers in Southeast Asia, Indonesia has poor performance in both health inputs and outcomes (Wood, 2010).

Indonesia faces problems similar to those in other developing countries: an aging population and sedentary lifestyles. As Indonesian life expectancy improves—now 72 years for women and 68 years for men — Indonesia faces an epidemiological transition from communicable to non-communicable or degenerative diseases (Haub & Kaneda, 2013). Such transitions have forced health care organizations to give substantial attention to chronic diseases (i.e. cancer, diabetes, tobacco dependence, mental health, and diseases related to advanced age), because they are expensive to treat and many have no cure (Kristiansen & Santoso, 2006). Thus, the healthcare system must promote healthy lifestyles, disease prevention, and reducing tobacco dependence.

The landscape of public healthcare in Indonesia has experienced three changes that contribute to major challenges. First, the shift in Indonesia's demographics and lifestyles—the population above age 55 is rapidly growing, from 16 percent in 2000 to 23.5 percent in 2010, and is projected to reach 35 percent by 2025 (as cited in (Berman, Hartanto, & Dewi, 2013)). This creates a susceptible condition for the emergence of non-communicable diseases (NCDs), including diabetes, cancer, stroke, hypertension, and heart disease, and at the same time increases the demand for healthcare support services; infrastructure including clinics, hospitals, and emergency care providers; healthcare professionals;

pharmacies; and adequate health insurance. Provinces in Java and Bali report higher levels of NCDs as compared to other islands in Indonesia (Rokx, Schieber, Harimurti, Tandon, & Somanathan, 2009).

The public healthcare landscape in Indonesia is also influenced by wealth—higher income is associated with better healthcare (Harianto, 2011). Wide differences in health status exist between the wealthy and the poor in Indonesia, with severely limited healthcare choices and opportunities for poor rural people. As wealthy people demand higher quality health care, the poor struggle to access even the most basic medical care. Wealthy Indonesians can obtain high quality private healthcare services abroad, spending nearly 137.3 trillion Rupiah (about \$12 billion USD) per year to travel to Singapore, Malaysia, and Australia for medical treatment (Asrianti, 2009).

Currently about 60 percent of Indonesians are covered by health insurance, but that does not mean the program has successfully reached people with financial hardships. Many districts have not yet developed the capacity to plan and manage their health budgets, to identify local health needs, or to set targets and monitor progress (World Bank, 2006). Local districts are constrained by multiple funding channels with differing reporting requirements, slow budget approval processes that frequently result in resource disbursements delayed for six months or

more, and by the centralized control over worker regulations and placement. In many instances the government is not seeking to make new or better policies, but to support the implementation and refining of existing policies to serve the poor. This has contributed to an imbalance in the implementation of public health policies within the provincial, district, sub-district, and village-level programs.<sup>10</sup>

The heritage of the colonial period and Suharto's New Order government continues to negatively influence public health in Indonesia today. Two urgent health issues that must be addressed are the development of the healthcare system, especially in rural areas, and the need to address both the diseases of the poor (infectious diseases exacerbated by malnutrition, especially tuberculosis and malaria) and diseases of the affluent (heart disease, stroke, diabetes mellitus, cancer) (Ferzacca, 2004). Some areas of health policy and development indicate that serious efforts are needed, including advocacy for healthcare, universal health coverage, quality of health services (public and private), health access for the most vulnerable groups, and rigorous monitoring of results ([www.ino.searo.who.int/EN/Section3\\_29.htm](http://www.ino.searo.who.int/EN/Section3_29.htm)).

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<sup>10</sup>Under the decentralization policies of Act No. 22/1999 and Act No. 25/1999, national health policy is overseen at the national, provincial, district, sub-district, and village levels.

## **Discourse of Health and Illness: Translating Rhetoric to Reality**

The rhetoric of development deployed by Indonesia's second president, Suharto, during the New Order period, has served as an overarching paradigm to coordinate and control individual and collective values and priorities. At the same time, this rhetoric helps the government reinforce its modernization agenda. Thus, the development agenda including health and medicine, is seen merely as ideological instruments designed to impose an authority agenda across contexts and for a variety of purposes (Achmad, 1999).

Throughout the archipelago, the discourse about health and illness continues to be influenced by traditional Western concepts of biomedicine and Suharto's development rhetoric. The development discourse permeates the lives of Indonesians, framed under President Suharto's concept of modernity and the "developmentalism" movement (Halabi, 2013; Heryanto, 2005).<sup>11</sup> Under the development policy, the New Order government in control for 32 years (1966-1998), molded the modern healthcare system into a one-way operation, supported by local officials and bureaucratic structures established by the federal government.

Through the use of newspapers, televisions, radio, and movies, the New

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<sup>11</sup>Heryanto (2005: 60) states that, "it is possible to identify one ideology that was relatively strong in social life during the New Order... This ideology can be defined a number of ways, the most popular being 'Developmentalism.'"

Order government regulated all aspects of society, from work habits and marriage rites to personal sanitation and hygiene. At the same time, media covered issues about lifestyle and how Western or modern lifestyles are contagions, said to be the cause of the increasing prevalence of chronic degenerative diseases in Indonesia.

The New Order government conjured tradition and organized social images designed to conceal class and power inequities (Pemberton, 1994). However, Suharto's imagery and visions of development (*pembangunan*) and health appear illogical and do not articulate the perceptions held by different ethnic groups within Indonesia about health, disease, treatment, and death (Collier & Lakoff, 2005). Scholars argue that the post-independence government assumes that ideas and processes developed by the colonial government are appropriate for Indonesia today (Foster, 1987; Justice, 1987; Stone, 1992).

In understanding modernity and its influences on people's ways of thinking, Clifford Geertz(1996) argues that "modernity may not exist as a unitary thing" (p. 140), meaning that interpretations of a particular culture as a monolithic body based on consensus and shared common values and modes of behavior are untenable in a global society. People live in a paradox in which global transformative processes create uniformity and transnationalism on the one hand, but on the other hand, contribute to a



strengthening of cultural differences within and among distinct societies. Further, Geertz (1996) states, the more people are interconnected, the greater the plurality of senses of belonging and modes of existence. Kearney (1995) adds that present-day local processes and identities cannot be understood without understanding the ongoing global processes and their impacts on local conditions and traditions. In this sense, global processes are directed and shaped by local, culture-specific circumstances. People's constructions of identity serve as pre-requisites for peace, security, and well-being, individually and collectively.

Through culture-centered approach (CCA) theory, Mohan Dutta (2008) argues that understanding one's experience with illness can only be made through connecting health and the shared meanings embedded in socially constructed identities, relationships, social norms, and structures within certain society. Only then, we can understand how these Javanese women construct the meanings of health and illness and what it means to be Javanese women with Type 2 diabetes. It will also allow us to understand the symbolic structural barriers that these Javanese women face in the context of health and how they negotiate socio-cultural pressure and/or structural inequalities in their day-to-day lives as a woman and as a person with diabetes (Dutta & Dutta, 2012)

The experiences of health and illness are major concerns in examining emotional and physical distress in the body and in everyday lives. The work in this area promotes better understanding of health and illness experiences within an immediate cultural context, as well as connecting these individual experiences to their political and economic contexts.

### **Lay Knowledge of Health and Illness**

Lay knowledge about health and illness is derived from numerous sources, from popular culture to traditions and folk understandings. When people with no prior experience or references deal with a new disease, heart disease or diabetes mellitus, for example, the spread of new ideas and notions about these diseases creates multiple variations and combinations of information, both accurate and inaccurate, helpful and dangerous.

Within Western medical science, symptoms related to physical disruptions or changes in one's physical or biological condition are considered a threat to an individual's life or way of life (Helman, 2008; Winkelman, 2009). Relieving physical symptoms becomes a priority, even an obsession in the lives of Westerners. As a consequence, these societies reject irresponsible behaviors that work against the preservation of one's

health, calling such behaviors irrational and ignorant (tobacco use, for example).

In contrast to this Western concept of health, non-Western societies, as in Indonesia, recognize the unity between body and mind as a way of understanding health and illness (Kleinman, 1988). Based on ethnic roots, identity, and language use, Indonesian people belong to the Malays ethnic group<sup>12</sup>(Provencher, 2004). Basic concepts of health and illness in Malay culture have numerous origins, but at the core, Malay people embrace the concept of spirit or soul (*semangat*) to describe individuals with vitality and good health. Thus, simultaneously, the absence or loss of *semangat* and intrusion of evil or bad spirits are believed to be the major causes of illness (Ferzacca, 2001; Provencher, 2004). However, unlike Westerners, Indonesian and especially Javanese people do not necessarily make distinctions between illness and disease. Rather, the Javanese make distinctions among mild disease (*sakit ringan*), the normal coming and going of poor health (*sakit biasa*), and serious sickness (*sakit parah, sakit berat*) (Ferzacca, 2001; Pitaloka & Hsieh, 2013).

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<sup>12</sup>Malays are categorized based on the language used by people of the Malayan Archipelago (modern Indonesia, Malaysia, Southern Thailand, and Brunei).

Javanese cultural conceptualizations of health and illness are characterized by the fluidity of boundaries between wellness and illness. With mysticism as the essence of their culture, Javanese believe that health, illness, and death are socially and culturally embedded in cosmological, spiritual, and holistic notions of the body (Kielmann, 2001; Mulder, 1978). Javanese people understand the effects of sickness as “a state of imperfection” (De Jong & Jordaan, 1985), thus, as will be seen in many narratives in the chapters to follow, even if sickness is seen to cause disturbing physical effects, it need not be disruptive to one’s day-to-day life.

According to Javanese beliefs, a human being is a duplicate of the universe; the body is a microcosm and the universe is the macrocosm. People living in societies who believe in a monistic entity, such as Indonesia, describe the body as “an open system linking social relations to the self, a vital balance between interrelated elements in a holistic cosmos. Emotion and cognition are integrated into bodily processes” (Kleinman, 1988, p. 11). Thus, health must be understood as the integration of “healthy body and mind” (*sehat lahir batin*), balance and harmony between two cosmos – body as the microcosmos and mind as the macrocosmos (Ferzacca, 2001, 2010b; Good, Marchira, Ul Hasanat, Utami, & Subandi, 2010; Handayani & Novianto, 2004; Hay, 2001).

Disruptions or imbalances bring chaos to the cosmos and the individual who lives within it.

Javanese women are considered stronger and healthier (physically and emotionally) than men. Javanese philosophy has three basic principles that underlie people's behavior toward all aspects of life, including illness disruption. These are: patience (*sabar*), surrender (*pasrah*) and being relieved of responsibilities [to God] (*sumeleh*). Only by accepting and implementing these principles can an individual achieve moral maturity (*kematangan moral*) and maintain balance and harmony in life. However, during severe disruptions to life, Javanese people believe that women are physically and psychologically stronger than men (Handayani & Novianto, 2004). Women are believed to possess unique characteristics as a symbol of their power: stoicism (*ketabahan*) (Forshee, 2006) and sincere acceptance or being realistic about one's condition (*nrima*). These characters represent "power" that provide Javanese women with the strength and ability to cope with misfortunes and the worst of life's conditions.

Culturally, Javanese people tend to express and treat their health and ill conditions within symptom-oriented conceptual frameworks organized by the logic of *rasa* (Stange, 1984). Clifford Geertz describes *rasa* as "a complex of concepts that includes 'sense-taste-feeling-

meaning” (1973, p. 124), in which “the flow of subjective experience, taken in all its phenomenological immediacy, presents a microcosm of the universe generally” (1973, p. 134).

As the first, or sensationalist, definition of *rasa* indicates both feeling from without (taste, touch) and from within (emotion), so *rasa* in its second, or semantic, definition indicates both the meaning of events in the *lahir*, the external behavioral world of sound, shape, and gesture, and in the far more mysterious *batin*, the fluid inner world of life. (C. Geertz, 1960, p. 239)

Thus, *rasa* is not a simple physical sense of taste. On the contrary, according to Stange (1984), *rasa* is a “spectrum of meanings” that embraces a deep mystical apprehension that resonates “the inner aspects (*batin*) of personal experience” and the “formation of Javanese selfhood” or the *lahir* of social life (Ferzacca, 2001; Stange, 1992).

The fluidity of *rasa* explains the way Javanese people make sense of their lives. With respect to illness, Javanese people do not typically describe what they feel about their emotions and their physical conditions explicitly; deeper interpretation is required. For Javanese, events in life, including health-seeking behaviors, must be compatible with the other elements of life, i.e., a good “fit” (*cocok, jodoh*). To achieve a healthy body, one must find a health provider or a treatment that “fits” their socio-

economic and health conditions. Compatibility is achieved when things are in a dynamic, or fluid, equilibrium (*selaras*) and harmony (*rukun*) that denote balance (*imbang*). And as Geertz (1960) explains health and illness, and disease, contribute to disequilibrium or an imperfect “fit.”

### **Culture and Diabetes**

In Indonesia, diabetes is considered to be one of the costs of development that emerged during modernity. During the New Order era, the media commonly framed this disease as a “lifestyle disease,” one of several “diseases of affluence” (Bennett, 1983; Hamman, 1983), or as a Western disease (Trowell & Burkitt, 1981). Many Indonesians have few if any encounters with NCDs and, thus, hold the view that “lifestyle diseases” such as diabetes afflict only affluent people.

Lifestyle was used to explain a wide variety of conditions, and appeared in headlines in local newspapers as well as the national newspaper from 1990 to 1998 (Ferzacca, 2010b). Increases in lifestyle diseases reflect the changing patterns of physical activity, also viewed by Indonesians as a primary cause of chronic degenerative diseases. Concerned with the rhetoric of modernity and Westernization, Indonesian reaction was to balance conditions by relying on tradition. Indonesian people describe the idea of modernity as a fluid historical process that is not only fashioned by structural changes that impact entire societies, but is

also accompanied by cultural transformation and the diverse meanings people attribute to such changes (Bennet, 2005; Brenner, 1996).

### **Diabetes and Women's Roles.**

The links among gender, health, and culture are particularly intricate. Women's health is influenced by both biological and by cultural conditions that define gender and power relations, determine household responsibilities and priorities, and influence access to knowledge and resources. Thus, illness in women affects their abilities to maintain self-reliance and to fulfill their responsibilities, both within the household and within society (Manderson, 1997). This is why illness is not just a physical state, but is also a social phenomenon. What many non-Western societies perceive as illness and their lived experiences with illness is actually a form of social disruption that may or may not be the result of physical dysfunction (Lorber & Moore, 2002).

Previous studies have found some important factors that negatively and continuously affect women's health, especially in developing countries. Among these factors are lack of access to health services (that may be further limited by low education and inadequate information); inability to accurately diagnose signs or symptoms related to the disease and to seek appropriate treatment; lack of resources to pay for transportation, doctors, and treatment costs; lack of physical mobility; and



a lack of time (Leslie, 1992b). Furthermore, inappropriate healthcare services and poor quality of care are also important barriers (Mensch, 1993).

The World Health Organization (WHO) has projected that the number of people with diabetes mellitus (DM) in Indonesia will increase from 8.4 million in 2000 to 21.3 million in 2030, ranking Indonesia the fourth highest worldwide (Wild, Roglic, Green, Sicree, & King, 2004). According to the Indonesia Central Statistics Board (BPS), in 2030 people with diabetes will increase in both urban and rural areas by 14.7 percent and 7.2 percent respectively ([www.bps.go.id](http://www.bps.go.id)). Mihardja et al. (2009) found that the prevalence of diabetes is highest among women (6.4 percent), with most cases diagnosed as Type 2 diabetes. These indications demonstrate that diabetes has become a serious threat that requires both lay people and people with diabetes to gain better understandings about the diseases in order to develop a culturally appropriate based intervention program.

Type 2 diabetes (also known as adult onset diabetes) is the most common form of the disease and is highly prevalent among people in the lower and middle socio-economic categories. This particular type of diabetes requires self-management—people must modify and control what they eat, perform regular exercise, regularly test their blood glucose level,

and must take their medications (insulin shots, pills, or both). However, cross-cultural studies have found that cultural beliefs and social constructions of health and illness are sometimes barriers to implementation and maintenance of self-managed treatment programs (Barko, Corbett, Allen, & Shultz, 2011; Jallinoja, Pajari, & Absetz, 2008).

### **Diabetes and The Challenge of Womanhood.**

Government and other health officials recognize women are the consumers and decision makers of health programs, frequently not for their own personal health needs, but because they are caregivers who are responsible for their family's health (Leslie, 1992a; Rathgeber & Viasoff, 1993; Sharan, Ahmed, & Strobino, 2005). For women in Southeast Asia, including Indonesia, the household is the domain of women, a place they have power beyond their work and responsibilities. Women control strategic economic resources, and thereby enjoy high status. The concept of conjugal property gives a wife rights to what her husband earns. Within this concept, wife and husband recognize that each have individual rights to what they bring into the marriage, and what is acquired during the marriage belongs to both (Dube, 1997).

Division of household responsibilities and power among members of the household was developed based on patriarchal values. Roles of husbands and wives are bound to social and cultural norms. Managing

household affairs and performing child bearing and nurturing responsibilities are reasons women are, culturally speaking, required to stay at home (Mulder, 1996). This norm is reinforced through both social norms and marriage laws. Women in traditional communities manage their household affairs and income-earning activities from their homes. Today in Indonesia, the situation is different when women migrate to urban areas for work. These women are away from home during a great portion of the day, or in some situations, months. In their absence, other members of the household must care for their children while they are away. Regardless of this large contribution to the household, when these women return home, they frequently are expected to perform household chores as usual (Suleman, 1995).

Today in Indonesia, about one-third of adult women work. These women have more burdens, because they must earn extra income for the family, as well as the responsibility to do household chores. In addition, they also are expected to attend and perform various social obligations, including preparing and managing community feasts and rituals, managing social gift exchanges, and participating in community events (N. Sullivan, 1994). In rural areas, it is common to see a woman carrying a child while also sweeping the floor, doing laundry, or weaving a bamboo basket. And,

no special designation is given to these women, no special social title to describe her roles. These women are simply referred to as housewives.

Rural women are important actors in the informal sector (e.g., market traders, factory workers, housemaids) of the economy and become significant providers within their families (Kusujiarti, 1997; Tickamyer & Kusujiarti, 2012; Wolf, 1994). As previously discussed, Javanese women's roles and status depend on their abilities and opportunities to access financial and educational resources. However, the decision to get involved in a business or hold a job does not automatically relieve their responsibilities to perform domestic tasks. This means that frequently women are expected to perform all these activities at the same time. In rural areas, Javanese women often work 11 or more hours per day, while men typically spend only eight hours per day at work (Kusujiarti, 1997). The heavy workloads and long hours needed to accomplish many tedious tasks often have adverse impacts on women's health.

These findings demonstrate that culture provides norms for conduct that shape “a *repertoire* or a tool kit of habits, skills, and styles from which people construct strategies of action” (Swidler, 1986, p. 273). *Strategy* in this situation refers to “a general way of organizing action (depending upon a network of kin and friends, as well as individual power) that may allow one to reach several different life goals” (p. 277)

“Strategies of action” incorporate, and thus depend on, habits, moods, sensibilities, and views of the world (C. Geertz, 1973, p. 89).

Through the narratives presented in this study (Chapter Four), Javanese women’s perceptions about Type 2 diabetes and how the disease influences their everyday lives are presented. In particular, this study is an exploration into the ways Javanese women construct their identities as women, mothers (*ibu*), wives, and wage earners, then reconstruct identity as a mother and/or wife and/or wage earner with Type 2 diabetes. Javanese women are expected to do whatever is necessary to fulfill their family’s daily needs. In addition, these women are also expected to successfully manage family and social interactions and to provide continuous support and protection to family members who need it.

Women’s roles and status in Java have long been a source of debate among scholars, especially when discussing women’s power bases and identities. Comparing the Western idea of power with the Javanese, Benedict Anderson (1972) argues that for Western society, “power is abstract ... a word used commonly to describe a relationship or relationships... in which some [humans] appear to obey, willingly or unwillingly, the wishes of others” (p. 5-6). For the Javanese, power is concrete. It falls within the realms of life associated with women, the family, life cycle rituals (*slametan*), religion, and magical lore. However,

Anderson does not clearly define what he means by “power” and the source of power for Javanese women.

Scholars argue that Javanese women’s abilities to mediate familial and social harmony and to perform extended domestic duties including managing social obligations represent power (Handayani & Novianto, 2004; Saptari, 2000). In the discussion about chronic illness and physical disruptions, Javanese women construct their own strategies in coping with illness while providing the necessary attributes of power: order, peace, and well-being (Djajadiningrat-Nieuwenhuis, 1987). A study involving women in Trobriand culture confirmed these Javanese scholar’s arguments. The Western idea of power is irrelevant for understanding gender relations and the meaning of power for Trobriand women. The Trobriand demonstrate that women play dominant roles “which are symbolically, structurally, and functionally significant to the ordering of Trobriand society, and to the roles that man play” (Weiner, 1976, pp. 227-228).

Data provided by the International Diabetes Federation (IDF) in the *Diabetes Atlas* (2012) shows that there are more women between 20 and 79 years old with diabetes than men in the same age group. The *Atlas* also predicts that by 2030 there will be six million more women in Indonesia with diabetes than men, with the majority coming from low and middle economic groups (Cho & Whiting, 2013). The U.S. Centers

for Disease Controls and Prevention (CDC) in its 2001 report explain that diabetes is a serious health condition that affects women in all stages of life (Beckless & Thompson-Reid, 2001).

It is clear from these statistics that women are vulnerable to diabetes. However, explorations of women's experiences with Type 2 diabetes have not been published. And, in Indonesia as in many developing countries, lay people's experiences have yet to be taken into consideration when making health policy decisions. As explained by Good and Good (1981) and Kleinman (1988), cultural interpretations of illness provide important insights into individuals' lived experiences with illness.

Diabetes and the management of it extend beyond and physical realities.

### **Barriers to Women's Management of Type 2 Diabetes**

The International Diabetes Foundation (IDF) and World Health Organization (WHO) explain that output of successful global diabetes education and intervention is an individual's ability to perform "self-management of diabetes." This refers not only to the capability but the responsibility to keep the illness under control, to minimize its impact on physical health status, to cope with the needs of family members, social obligations and the need to contribute financially to the family in spite of the illness. However, potential barriers to diabetes self-management

include cultural norms, health literacy, availability of medicine and money, and the individual's perceptions of health and illness.

This study argues that physical disruptions as a result of Type 2 diabetes affect women of all ages. Diabetes influences identity and productivity as human beings (Bury, 1982; Charmaz, 1983). Javanese women hold many roles in both the family and society. As a family caregiver, women with diabetes realize the burdens and costs of this disease to families and societies, in terms of healthcare costs plus the loss of productivity. Diabetes interrupts women's ability to keep their jobs and businesses in order to maintain their financial autonomy. It also changes interpersonal relationships with family and friends and disrupts their identities as women, mothers, daughters, and wives (Furler et al., 2008; Pitaloka & Hsieh, 2013)

Two main socio-political barriers work to obstruct women's management of diabetes. The first barrier is the lack of governmental efforts to address health disparities by developing effective health policies and equitable access to healthcare. The second barrier is culture and traditions that shape a society's perceptions of health and illness and how they behave toward disadvantaged individuals.

### **Socio-political barriers.**



From the socio-political perspective, the main barrier to diabetes intervention programs today is the impact of decentralization on access to and quality of health services (Kristiansen & Santoso, 2006), especially how dramatically it changed the administration of healthcare services in Indonesia. For poor women, or women who do not have a fixed income, this escalates their economic burdens. Yet, the government's decentralization policy was successfully disguised in the rhetoric of healthcare promises that greater participation would happen by involving citizens in setting priorities, monitoring service provisions, and finding new and creative ways to finance public health programs (Indrawati, 2002).

Today, many poor women without health insurance do not have adequate access to advanced healthcare services, which is a major problem when they have diabetes or other NCDs. From the political perspective, in this decentralization system local free healthcare schemes frequently have their origins in elections (Aspinall & Walburton, 2013). This means promises of free local healthcare is seen as nothing more than a campaign strategy designed to win votes. In addition, reduced government funding of public health facilities due to decentralization has brought more burdens for society and more corruption among healthcare service providers (Junadi, 2001).

Scarce insurance coverage and high out-of-pocket costs are borne directly by patients, and this contributes to Indonesia's governmental healthcare spending being among the lowest in the region. Ashford (2004) found that more differences exist in terms of the availability and the quality of health services today than when programs were first initiated by President Suharto's administration. Many *Puskesmas* (local health clinics) today lack of basic infrastructure such as electricity and many operate without a doctor, relying instead on nurses or midwives to fulfill diagnostic and treatment services for which they are not qualified. These major problems need to be solved immediately, especially when considering rapidly increasing cases of NCDs in society and the fact that, in general, the poor are disadvantaged in all determinants of health (Ashford, 2004).

#### **Cultural barriers.**

Individuals' perceptions of health and illness are strongly influenced by socio-cultural and psychological factors, such as individuals (and their families) emotional responses toward illness (Chesla, Chun, & Kwan, 2009; Kleinman, 1988; Mechanic, 1986; Thompson & Gifford, 2000). In other words, these perceptions are molded by individuals' everyday social interactions, past experiences, and cultural values and traditions that are embraced in varying degrees by individuals in their

daily lives. Culture is of particular importance in understanding perceptions about diabetes because it comprises the values, and symbols, including technology and material artifacts (C. Geertz, 1973) that individuals must know and master to be a functioning member of a society.

Related to health and illness, scholars continue to argue that cultural beliefs, rituals, and traditions have substantial impacts on perceptions of diabetes. In addition, culture and traditions influence the way people perceive the causes of diabetes, the way people react to symptoms and life disruptions, the choices of appropriate treatments, and degrees of compliance with instructions of health professionals (Joe & Young, 1993; Shaw, Huebner, Armin, Orzech, & Vivian, 2009).

For example, many Javanese people say three major causes of illness exist: 1) illness is the result of natural causes, 2) illness happens when one violates one's own spirit; or 3) when one violates the self (*karma*). The distinctions made by society about illness are aimed at determining whether a disease is contagious or chronic. While *semangat* (spirit or soul) symbolizes health, *loyo* (exhausted) symbolizes illness. Only when these two are in order (harmony and balance) can an individual be called healthy (Ferzacca, 2001).

The Javanese worldview or what the Javanese call “the Javanese Way” must guide logic in making sense of everything in life, including illness. To show that one is truly Javanese, an individual must conform to the highly elaborate system of etiquette and manners (C. Geertz, 1968; Magnis-Suseno, 1997). Javanese people, in making sense of illness and other misfortunes in life, are guided by the “logic of *rasa*” (Ackerman, 1990; Daniel, 1984; Stange, 1984). Using this logic, Javanese people determine whether or not their perceptions and actions *fit (cocok)* with certain expectations and conditions.

The way Indonesians, especially Javanese, integrate traditions and indigenous knowledge into their perceptions about health and illness and the strategies they develop and employ to cope with life’s misfortunes are a form of resistance against President Suharto’s development ideology that consistently promoted the idea that adoption of Western medical practices was important to development and nation building. People’s distrust and moral panic about developmentalism evoked public concern about preserving traditions. Traditional concepts of health, illness, and healing are symbols of identity and nationalism that serve to create harmony at times of disharmony (Collier & Lakoff, 2005).

Historically, media have been occupied with political issues about the costs of modernization that Suharto’s development programs brought

to Indonesia, thus they did not disseminate much information about non-communicable diseases or what a critical problem they are until almost two decades later. This created a knowledge gap about diabetes and other disease and about disparities among people in accessing healthcare. More specifically, a lack of governmental commitment exists in addressing the need for sufficient and affordable health care for people with diabetes, especially poor women (Pisani, 2013).

Personal commitment is a pre-requisite for successful diabetes self-management, and this has not been considered to be a crucial component in the healthcare policy development agenda because security issues were a priority during Suharto's regime (Norris, Engelgau, & Narayan, 2001; Warburton & Aspinall, 2013). Today, media do not provide information about the threat of NCDs, especially diabetes, nor do they regularly question government officials about their plans to improve healthcare in Indonesia.

These factors entrench the knowledge gap regarding the severity and threats of non-communicable diseases, especially diabetes. This problem, together with cultural understandings of surrender (*kepasrahan*), keeps the predominant focus of health-care systems on treating illness rather than on prevention and maintaining optimal health (Hayati, Hogberg, Hakimi, Ellsberg, & Emmelin, 2011; Saktiawati et al., 2013).

Culture and traditions sometimes provide support for managing illness, and other times may hamper women's efforts to manage their illness and their daily activities (J. Anderson et al., 1995; Daniulaityte, 2004; Mendehall, Seligman, Fernandez, & Jacobs, 2010).

Modifying unhealthy lifestyle behaviors is difficult, especially considering Javanese women's multiple roles as food preparers, caregivers, and guardians of cosmic balance and order. In addition, limited access to resources and the day-to-day stressors of living in poverty exacerbate women's burden of living with Type 2 diabetes (Rajaram & Vinson, 1997). In addition to their illness, Javanese women are aware of the expected roles they must perform in order to maintain harmonious interactions with others. And, in order to maintain harmony, Javanese women must uphold the notion of consideration and empathy (*tepa selira*) to avoid conflict and ensure that collective needs are fulfilled before considering her own, and her own needs can only be addressed if there are resources left after attending to the needs of all others (H. Geertz, 1961; Koentjaraningrat, 1960).

## CHAPTER THREE

### **Method**

Two major points should be made about this study with respect to method. First is the lack of published studies about health communication in Indonesia, a country with cultural and ethnic complexities. This situation requires a qualitative methodological approach in order to address the specific research concerns: 1) understanding how culture influences women's perception about health and illness in Indonesia; 2) how gender roles are negotiated in the daily lives of certain ethnic groups, specifically Javanese women; and, 3) how Javanese culture influences the actions women can take in their relationships with family and community.

The second major point is the rapid development of diabetes in Indonesia. A 2013 report from the International Diabetes Federation (IDF) indicates that Indonesia ranks seventh in the number of young people with diabetes: 8.5 million, including both Type 1 and Type 2 individuals aged 20-29 years (as cited in (Cho & Whiting, 2013). Frequently considered a Western disease (Trowell & Burkitt, 1981), questions are being raised about whether socio-cultural groups in other parts of the world, in this case Javanese women, perceive disease and treatment in the same ways as those promoted by global public health organizations. In short, how do

these women manage diabetes within the framework of their cultural beliefs and values, their families, and their communities?

In contrast to quantitative research that involves fairly fleeting if any direct contact among researchers and respondents, qualitative research, on the other hand, requires sustained contact with participants in order to eventually see the world through the participants' eyes (Bryman, 1999). Qualitative researchers seek deeper understanding of the participants' worldview, employing methods that yield important cultural context to the behaviors exhibited by the people under study. For this present research, an understanding of Javanese culture, cultural practices, and traditions is central to gaining fuller understanding of health as a cultural construct, and of individual beliefs about diet, disease, food preparation, language, family life, social interaction, religion, and healing beliefs and practices (Barnouw, 1985; Conrad & Barker, 2010; Keval, 2009; Spector, 1985). Consequently, constructing the diabetes experience involves both culture and individual personality. Qualitative research methods are essential to understanding health phenomena within cross-cultural settings because they enable researchers to observe, examine, and assemble multiple images of illness and health to understand and to interpret an individual's perception and behavior toward diabetes (Denzin & Lincoln, 2003). In the lifeworld, qualitative research helps researchers



focus on naturally emerging language that individuals use to describe their lives and the meanings they assign to experience (Berg, 2009). For these reasons, narrative analysis is used to meet the objectives of this study.

### **Narrative Research**

Narratives serve to make sense of personal identity as well as the identity of the community and other people who live in it. Among Indonesians, diabetes and other forms of chronic diseases, such as heart disease, hypertension, cancer, and respiratory disease are viewed as Western diseases in part because of their association with modern patterns of living considered to be Western (Ferzacca, 2012). Related to Type 2 diabetes, this is often the view present in the narratives of medical researchers and global health education organizations that dominate the information about diabetes. This study features narratives from individual Javanese women who explain 1) how culture, traditions, and the history of gender relations in Java influence their experience of living with diabetes; and 2) how Javanese women construct their own identities as wives, mothers, and members of the community with Type 2 diabetes; and 3) how these roles are connected to their roles as primary managers of the household. Personal, social, and cultural functions appear in the participants' stories. From this sociocultural perspective, this study is an

investigation into how diabetes is recognized, interpreted, and responded to by Javanese women.

The importance of narrative in this situation is clear: narrative is central to how individuals perceive, experience, and judge their actions and the course and value of their lives (Hyden, 1997). Narrative analysis is seen as both a term assigned to a text or discourse, or as a method of qualitative research (Chase, 2005; Pinnegar & Dannes, 2007). As a qualitative approach, narrative inquiry has recently gained credibility as a valuable methodology and research approach (Clandinin & Connelly, 2000; Riessman, 2008; Webster & Mertova, 2007). Grounded in interpretive hermeneutics, phenomenology, ethnography, and literary analysis, narrative research is based on the premise that human beings understand phenomena and give meaning to their lives through stories—written, oral or visual. Walter Fisher classifies human beings as *homo narrans* or story-telling animals (Fisher, 1989, p. xi). Fisher argues that human beings “experience and comprehend life as a series of ongoing narratives, as conflicts, characters, beginnings, middles, and ends” (p. 24).

Using a variety of analytic practices, narrative inquiry can be defined as “A way of understanding experience. It is a collaboration between researcher and participants over time...Simply stated...narrative inquiry is stories lived and told” (Clandinin & Connelly, 2000, p. 20). As a

mode of research, narrative inquiry explores the ways individuals construct lived experience and ways to analyze stories in useful ways. The term *narrative*:

Carries many meanings and is used in a variety of ways by different disciplines, often synonymously with story (...) the narrative scholar [pays] analytic attention to how the facts got assembled that way. For whom was this story constructed, how was it made and for what purpose? What cultural discourses does it draw on—take for granted? What does it accomplish?(Riessman & Speedy, 2007, pp. 428-429)

Narrative inquiry involves the analysis of detailed stories that a researcher draws from participants' stories that reveal how the participants view and understand their lives. Narratives are found in numerous forms including written and visual materials. Barthes, quoted in Sontag (1982), describes narrative broadly:

Narrative is present in myth, legend, fable, tale, novella, epic, history, tragedy, drama, comedy, mime, painting, ... stained glass windows, cinema, comics, news items, conversation. Moreover, under this almost infinite diversity of forms, narrative is present in every age, in every place, in every society; it begins with the very history of [hu]mankind and there nowhere is nor has been a people

without narrative ... it is simply there, like life itself (Sontag, 1982, pp. 251-252)

To Barthes' description of narrative, Riessman (2008) adds: "memoir, biography, autobiography, diaries, archival documents, social service and health records, other organizational documents, scientific theories, folk ballads, photographs, and other art work" (p. 4).

In this current study, the narrative comes as an extended story about diabetes, elicited through in-depth interviews with Javanese women in both rural and urban areas in Central Java, Indonesia. While diabetes is considered a global phenomenon and global interventions to communicate and educate people about the disease have been conducted throughout the world, few studies designed to understand more about how shared cultural schema shape the interpretation and construction of Javanese women's experience with diabetes have been conducted. Narrative mediates between "an inner-world of thought-feeling and an outer world of observable actions and states of affairs" (Garro & Mattingly, 2000, p. 1). In this sense, the process of creating narrative as well as attending to it is an active and constructive one, and depends on both personal and cultural resources. Bruner's (1990) describes "narrative modes of knowing," as narrative that privileges the particulars of lived experience. Thus, meaning is not inherent in act or experience, but is constructed through social

discourse (Bruner, 1990). As a way of knowing, narrative enables the researcher to organize the story told by linking events, perceptions, and experiences (Polkinghorne, 1989, 1995).

Chase (2005) explains that, from the sociological approach, narrative researchers are interested in two things: 1) how people engage in the process of constructing selves within certain system of power and culture, and 2) how people make sense of personal experience in relation to culturally and historically specific discourses, the ways they interpret discourses people offer about themselves, their experiences and realities. In this current study, narratives of Javanese women with diabetes mediate the personal and the cultural. The meaning of becoming a Javanese woman with diabetes is constructed through social discourse, in their relations with family members and members of the community. Narratives are key to discovering identity, personality, and experience with diabetes.

### **Research Design & Procedure**

In-depth interview is the primary data collection method. Field research was conducted during two time periods and involved two groups of Javanese women with Type 2 diabetes. The first round of interviews was conducted from May to August 2011, and included 30 Javanese women in Semarang and Salatiga, two cities in Central Java, Indonesia. This first round was aimed at women in the middle socio-economic group.

The second round of interviews was conducted with another 30 Javanese women in two rural areas in Demak and Muntilan regencies<sup>13</sup> in Central Java, from May to September 2012. The interviews in the second round involved poor women and women from the low socio-economic group. As indicated in the Indonesia Central Statistics Board Report (BPS, 2013), women considered to be in the low-socio economic group have an average income of about 211.829,00 Indonesian Rupiah (approximately \$ 20.00 USD) per month. Poor women are those who make less than this amount or have no monthly fixed income.

The process of interviewing in this context provides a way for the researcher to gain the perspectives of interviewees. A phenomenological approach to interviewing was applied here, specifically in-depth interviews involving open-ended questions designed to elicit genuine views and feelings of Javanese women regarding their experience with diabetes and how they juxtapose the multiple roles they must play in everyday life (Seidman, 1991). Specific to narrative researchers whose studies are based on in-depth interviews, the relationship between the

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<sup>13</sup>Indonesia is divided into 405 regencies. The two mentioned here are in the central part of Java Island. Headed by a Regent (*Bupati*), a regency is a local level of government beneath a province. Regencies, as with cities have local government and legislative bodies; but regencies differ from city in terms of demographics, geographic size, and economics (source: <http://www.kemendagri.go.id/pages/data-wilayah>)

interviewer and the interviewee is transformed into one of narrator and listener. So in posing questions, narrative researchers must bear in mind that in answering the interviewer's questions, interviewees are narrators with stories and voices of their own. Consequently, in the interviewing process, researchers not only attend to the stories, but also play a role in inviting stories (Chase, 2005). Chase explains that in order, to be able to invite interviewees to become narrators, researchers must know what is "storyworthy" in the narrator's social setting (Chase, 1995).

Being born and raised in Semarang, a capital province of Central Java, I am aware of the parameters of the stories these narrators have to tell. For example, the use of different levels of Javanese language to address their husbands or someone who is hierarchically higher than these women. In this context, *parameter* does not mean that narrative researchers develop a "formula story" (Loseke, 2001) as a "result" of the research. Rather, parameters of the narrative in the qualitative realm help researchers frame the social context of the interview so that as participants tell their stories, researchers invite more information, more stories.

Historically, Javanese women are portrayed as having the lead role in the domestic sphere, while at the same time these women are also viewed as lacking control and power in society based on gender ideology within the culture. The interviews in this study are framed to invite stories about

diabetes, personal hardship, and identity, and how Javanese women manage diabetes within the complex socio-cultural environment that requires them to play multiple roles.

Overall, this study explores the influence of culture on illness experiences and narratives, capturing the detailed stories and life experiences of Javanese women with diabetes and their relationships with family members and members of the community. Narrative analysis provide a way of understanding more precisely how narratives are “structured and predicated on certain ways of being in the world” (Desjarlais, 1997, p. 13).

### **Participants.**

The age range of participants in this study is 24 to 70 years, with 46.6 percent (28 participants) being in their 50s. Participants were recruited with the help of the Central Java branch of Persadia, the Indonesia Diabetes Association, a diabetes community group. According to their mission statement, Persadia was established in 1986 as a community organization that works to improve the well-being of diabetes patient (<http://diabetesindo.com/mengenal-persadia/maksud-dan-tujuan/>). With more than 100 branches, including 16 branches in Central Java, this organization is a primary public source for diabetes education in Indonesia ([www.diabetesindo.com](http://www.diabetesindo.com)). Written announcements about this study were



posted in Persadia offices and verbal announcements were also made during physical activities events conducted three times a week in each of the Persadia branches.

Sixty participants were recruited for this study; all are Javanese women with Type 2 diabetes and reside in cities and rural areas in Central Java. Women are the focus in this study for important reasons. First, Javanese women are required to live in two structural worlds: (a) the ideal world of womanhood indicated by the bond between body and daily tasks as a mother and a wife, and (b) the world she wishes to live in, where she has access to power and resources. Second, women in the Javanese culture hold a very important role in maintaining and mediating social harmony, in controlling the balance between the inner world (*rasa, peaceful feelings*) and the outer world, between self-needs and communal needs.

This study focuses on two important questions: (a) How does diabetes influence Javanese women's interactions with family members and society? And (b) How do Javanese women adapt diabetes management to their cultural beliefs, traditions, and background values?

The first round of interviews was conducted mostly in the Indonesian language along with some Javanese. This is in contrast to the second round of interviews: rural women used Javanese, the main language in their day-to-day conversations. As a Javanese woman who

speaks the ethnic language, I had very few difficulties conducting the interviews and capturing the nuances in the talk. Many of the women I interviewed are either retired or housewives who receive pensions from their husbands. Several village women from the second round of interviews share economic burdens with their husbands by working as market traders. Sometimes they make bigger incomes than the husbands. Regardless of the financial contribution, the women's main duty remains the same: looking after the children and the husband, physically, emotionally, and financially.

For the second round of interviews, I initially planned to interview 34 participants, but unfortunately two died due to hypoglycemia (low blood glucose); and two others had strokes attributed to hyperglycemia (high blood glucose). I was quite shocked, because I made an interview appointment with these women on early June and we decided to have the interviews after the Eid celebration on the second week of August 2014. It means, only within one and a half month I had to lose my participants due to Type 2 diabetes.

#### **Informed consent.**

All participants were required to complete written consent forms. The researcher prepared and translated the consent forms into the Indonesian language, the official language of the country. However, in

certain geographic areas the Javanese language is commonly used, especially in the rural areas of Central Java. Occasionally participants asked for and were given further explanations about the wording of the informed consent document.

**Table 1 Characteristics of participants**

	Participants	Age	Years since diagnosis	Religion	Occupation
1.	Lastri	55	12	Muslim	Entrepreneur
2.	Jeki	52	3	Muslim	Retired
3.	Puspa	55	11	Muslim	Retired midwife
4.	Surti	58	18	Christian	High school teacher
5.	Yuni	60	8	Christian	Owens a family business
6.	Nana	38	1	Christian	Works at a nursing home
7.	Marni	51	1	Christian	Housewife
8.	Ningsih	57	7	Christian	Retired
9.	Dewi	46	6	Muslim	Housewife, PE instructor
10.	Nur	40	3	Muslim	Housewife
11.	Siti	45	5	Muslim	Caretaker
12.	Wulan	54	11	Christian	Housewife
13.	Yayuk	53	7	Christian	Retired, small business owner
14.	Laras	60	11	Muslim	Retired midwife
15.	Prapti	51	1	Muslim	Tofu maker/seller
16.	Anis	59	13	Muslim	Housewife
17.	Nasirah	58	3	Christian	Social worker
18.	Karni	24	5	Christian	Social worker
19.	Shinta	67	4	Christian	Retired state officer
20.	Tatik	63	2	Christian	Housewife
21.	Egawati	57	12	Christian	University professor
22.	Magda	58	6	Christian	Retired nurse
23.	Dinuk	50	5	Muslim	Housewife
24.	Yatmi	53	2	Muslim	Traditional massage lady
25.	Susan	43	2	Christian	Self-employed
26.	Etty	59	3	Muslim	Owens a bakery
27.	Parti	50	4	Muslim	Housewife, part-time worker

28.	Sunarsih	50	2	Muslim	Farmer
29.	Fitri	65	7	Christian	Retired
30.	Trias	54	4	Christian	Housewife; traditional singer
31.	Sakirah	47	4	Muslim	Housewife
32.	Ninik	43	5	Muslim	Sells food in market/village
33.	Jati	55	3	Muslim	Maid
34.	Suryo	70	5	Muslim	Housewife
35.	Renggo	64	4	Muslim	Sells fruits in the market
36.	Murtini	69	5	Muslim	Retired teacher
37.	Yatmi	65	5	Muslim	Housewife
38.	Cahya	45	6	Muslim	Housewife
39.	Partinem	68	1	Muslim	Housewife
40.	Darti	60	1	Muslim	Sells meat in the market
41.	Suprih	55	5	Muslim	Traditional massage lady, housewife
42.	Nur	56	5	Muslim	Housewife, recitation leader
43.	Warah	55	1	Muslim	Housewife
44.	Ginah	56	4	Muslim	Housewife
45.	Kristin	50	20	Christian	Housewife
46.	Cici	63	5	Christian	Housewife
47.	Wariyah	67	13	Muslim	Retired store owner
48.	Titin	45	6	Muslim	Self employed
49.	Zulfa	46	2	Muslim	Muslim dressmaker
50.	Rusti	45	3	Muslim	Nurse
51.	Sulistyowati	58	8	Muslim	Sells food in her village home
52.	Raodah	66	8	Muslim	Housewife
53.	Asih	64	12	Muslim	Housewife
54.	Hartuti	50	1	Muslim	Owens lamb satay stalls
55.	Mahmudah	65	3	Muslim	Housewife
56.	Sayuti	63	3	Muslim	Market trader
57.	Warni	26	1	Muslim	Housewife
58.	Ratmi	59	1	Christian	Housewife
59.	Dina	60	1	Muslim	Administrative clerk
60.	Laili	63	4	Muslim	Owens a catering service

*Note:* Names used are pseudonyms.

### **Access to the field.**

Numerous considerations influence a researcher's selection of the research area and method. Access to the participants and the researcher's suitability for a particular study are typically the most important considerations. Access to these sites was made easier because of the researcher's late father's personal connections with Persadia in Central Java. This area was chosen not only because I am a native, but also because this province has higher diabetes prevalence than the national average. As suggested by Persadia and after considering practical aspects such as access and proximity, four geographical areas were chosen for this study: Semarang city, Salatiga city (and nearby villages), Muntilan regency and Demak regency. To reach the participants, I joined their regular meetings and physical exercises. Women who were willing to participate in this study will contact me through email or phone number to set an interview appointment.

According to the Central Java Province Health Report (DINKES, 2012), prevalence of Type 2 diabetes in Central Java province slightly decreased in 2010. However, diabetes cases in many areas in Central Java have gradually increased each year. The highest incidences of Type 2 diabetes cases (20.5 percent; 68,673 cases) are found in Semarang, the capital of Central Java province, between 2007-2010. The other three areas, Salatiga city (including area villages), and Demak and Muntilan

regencies, are among the regions in Central Java with highest number of Type 2 diabetes cases.

## **Procedure**

### **Data collection.**

In-depth interviews were conducted to gain insight and understanding from participants' stories focused on fairly specific questions (Charmaz, 2006, p. 25). Open-ended yet directed questions were designed to invite detailed discussion of topics and for stories to emerge.

The first round of interviews was conducted in two cities in Central Java, Semarang and Salatiga (including Noborejo village). Thirty women with Type 2 diabetes were asked 21 questions from four categories: current health status, current social support, meanings of social support, and appraisal and coping. Interviews varied in length from 50 minutes to 1.5 hours. Interviews were conducted either at the Persadia center after diabetes physical exercise sessions or at the participant's house. In terms of time and location of the interviews, flexibility was crucial because of any given participant's health condition overall, and the individual's medication and schedules. Some participants preferred to have the interviews at home so they could more easily maintain their medicine and eating schedules. Participants who have home-based

businesses or run small grocery store also preferred to have interviews in the home to avoid closing their stores.

Modification to interview questions was made before the second round of interviews and approved by the IRB. Some cultural aspects that were not explored in the first round were added to better explain how Javanese women accommodate culture and tradition in their everyday diabetes management. These additional interview questions covered three categories: women's roles and diabetes, the repressed female voice, and cultural knowledge and adjustment. These questions were designed to produce a better understanding of Javanese women's perceptions about diabetes and how culture influences their day-to-day diabetes management. The first category, women's roles and diabetes, aimed to identify how diabetes influences women's roles and relationships among the Javanese family. The second category, the repressed female voice, consists of five questions focused on Javanese women's identity in the diabetes management process. To gain more in-depth understanding about participants' ability to manage both socio-cultural pressures and their illness, probing questions were used. The final category, cultural knowledge and adjustment questions were designed to promote better understanding of how these women make sense of their illness, and how

culture influences the way they adjust their day-to-day lives (see appendix A and B for the list of questions).

The second round of interviews was conducted in two rural areas—Demak and Muntilan regencies in Central Java. Most interviews were conducted in the participant's home. A few participants from Santren village (part of Muntilan regency) requested the interviews be conducted at the local male paramedic's (*mantri*) house, typically after health education sessions. It is common in Indonesia, especially in remote and rural areas, that the *mantri* is the most respected health practitioner and the main source of health information (Miller & Crabtree, 1999). In this current study, the *mantri* and his wife, a nurse, both serve as volunteer diabetes educators.

During the second round of interviews, a third person was often present. These persons included the immediate relatives of the participant, for example children, her husband, or siblings, who sometimes also serve as caregivers. In my observation, two main reasons exist. First, it is common in Javanese culture to greet any guests coming to their homes. It is a form of courtesy (*unggah ungguh*) that shows the host's acceptance. Second, because people in rural areas live together or close to their extended family members, immediate relatives sometimes play the role of caregiver. Therefore, it is their obligation to make sure the participants are



comfortable and secure. They did not stay for the interview, but occasionally would come into a room where I conducted the interview to check on the participant and smile. I took fieldnotes to capture the situations and the roles played by these other individuals in the lives of the participants.

Two situations of interest occurred during the second round of interviews. First, frequently when I arrived at a participants' house for the interview, I found that a sister, housemaid, or daughter also has Type 2 diabetes. Because these individuals were present during my visit, I asked them if they would participate. Once they agreed and signed the consent forms, these additional participants joined the conversation. Second, I was able to observe several participants' activities. For example, some participants told their stories while making tofu, or preparing and cooking lamb, or accompanying their grandchildren playing, or feeding them. In addition to the interviews, fieldnotes were taken during these opportunities to observe these women performing their daily activities and interacting with their family members and neighbors. The collection of data using these field notes in addition to audio recordings of the interviews were essential to yield a richer account of how these women deal with their social tasks while managing their illness. As a form of observational data,

field notes consist of descriptions of social interactions and the context in which they occur (Stein, 2009).

### **Data analysis.**

Narrative inquiry was undertaken using transcripts and recordings of the in-depth interviews to explore the stories of these Javanese women with Type 2 diabetes. The audio recordings were transcribed and each participant was assigned a pseudonym. Narratives serve as a means of understanding how diabetes disrupts the lives and identities of these women. In-depth interviewing helps gain insights about lived experience; cultural and social values; cultural knowledge and perspectives; and decisions about household, personal, and social matters.

To begin the process of analyzing and interpreting the narratives, verbatim transcripts of the 60 interviews were completed. Once the transcripts were finished, they were reviewed using NVivo software to identify themes, subthemes, common words and phrases in the data. To ensure that this process identifies the core themes and excerpts that stand out, researcher repeatedly reads the transcripts and listens to the recordings. In this study, narratives were used: (a) to understand the ways Javanese women describe their thoughts, feelings, and behaviors in relation to their lived experience with Type 2 diabetes; and (b) to understand how socio-cultural circumstances influence Javanese women's

narratives (Chase, 2005, pp. 657-658). Thus in analyzing each narrative, I focused on two things: (a) the socio-cultural meanings embedded in the individual stories, and (b) repeated storylines, to see how participants share the socio-cultural values in looking at diabetes and their identities as Javanese women.

Each story is unique, full of rich personal nuance, yet patterns also exist, occurring across narratives, that help explain how Javanese women, as part of what some describe as a disempowered group, construct themselves and their world:

Narrative thought consists not merely in telling stories...[rather] human beings perceive any current action within a large temporal envelope, and within that envelope they perceive any given action, not as a response to the immediate circumstances or current mental state of an interlocutor or of oneself, but as part of an unfolding story (Carrithers, 1992, p. 82).

In analyzing these stories, the ways each participant describes her life before and after the diabetes diagnosis are a central focus. How the stories unfold, and the participants' descriptions of their expectations about their future with diabetes are also carefully analyzed. A chronology (Clandinin & Connelly, 2000) helps the researcher understand the way participants make sense of life experiences. In addition, analysis of the story also

includes aspects of social and personal interaction and the life situations of the participants. These aspects are important to understanding the ways individual experiences are shaped by larger social, cultural, and institutional narratives within which these women have lived.

Beyond the chronology, careful attention has been given to the nuances of each example within a common theme. For example, the theme “harmony” suggests a general description of normative conditions within Javanese culture regarding interactions among members of the family or society. The texts that capture these experiences in the words of the participants are discussed, along with distinct characteristics of the individual stories.

Finally, because the interviews were conducted using two languages: Indonesian (as the national language) and Javanese (the ethnic language of individuals in Central Java and Yogyakarta), careful attention has been given to identify the ways certain Javanese terms are used by participants.

## CHAPTER FOUR

### Results

Two research questions are posed here: (RQ1) How does diabetes influence Javanese women's interactions with family members and society? and (RQ2) How do Javanese women adapt diabetes management to their cultural beliefs, traditions, and background values?

As a well-educated, financially independent, urban, middle-class Javanese woman, my knowledge of Javanese culture and gender roles follows several trajectories. I know, for example, that Javanese notions of womanhood emphasize managing household affairs and nurturing children as core values. And misfortunes in life must be considered tests of strength, testing the ability to manage self and to maintain balance and social harmony. The ways that socially desirable constructions of womanhood are formed and perpetuated in Javanese culture are important to informing notions of women's health conditions. And as a Javanese woman, I understand nuances in the lives and voices of Javanese women interviewed for this study. This study reveals socio-cultural complexities and contradictions that surround Javanese women and their experiences with Type 2 diabetes.

Three major themes emerged from the participants' stories: (a) beliefs and cultural framework of health and illness; (b) diabetes and its

effects on social relations; and (c) cultural aspects of adjustment to illness.

This chapter provides a detailed description of Javanese women's experiences with diabetes in three sections: First is an examination of Javanese women's beliefs and cultural frameworks of health and illness. In this study, Javanese refers to people who were born or currently live in Central Java and Yogyakarta. Participants' stories provide information about internal and external sources of diabetes and illuminate the culture and traditions that shape Javanese women's lives and experiences with diabetes. Careful attention is given in the analysis about the how participants from various socio-economic groups and geographical areas (urban and rural) make sense of health and illness.

The second section includes discussion about how diabetes influences family relations within Javanese households. Participants' narratives indicate that women play important roles in accommodating family members' expressed and unexpressed needs. While women who live in urban areas found adequate resources to cope with their everyday lives, rural women have more limited resources. As is clear in the narratives, diabetes influences the interactions with family members in two primary ways. First, diabetes and the management of it challenge balance and harmony. Two solutions to control balance and harmonious relations among family members were identified by participants: (a)

restraining and controlling emotional responses, and (b) finding solutions that fit (*cocok*). The second influence on familial interaction is that diabetes challenges established family roles and responsibilities. In their stories, participants described how prescribed roles of womanhood and gender relations ‘forced’ them to submit to their husbands’ requests and to the rest of the families’ needs. For participants, self-sacrifice was described as the only way to achieve collective satisfaction and to maintain harmony and balance. Further, as the narratives demonstrate, these women say that maintaining harmony and balance is not only expected from them, but also, achieving harmony and balance helps them manage their illness.

The third section presents the cultural adjustment these women make in managing their diabetes, the “Javanese way.” Participants’ narratives show that social relations and social harmony take a huge portion of attention from these women and inevitably influence their reaction to and treatment of diabetes. Participants described diabetes as a disease of the heart (*penyakit hati*). In this context, *heart* is translated to “inner feelings” or a “seat of emotions,” and the descriptions do not refer to the liver, pancreas, or insulin. In the Javanese language, some participants use the word *manah* to indicate feelings. In tackling what they say is a disease of the heart, participants demonstrate their Javanese values

of considering the feelings of others (*tepa selira*) and respect of others as ways to maintain inner peace and social harmony in their day-to-day diabetes management. Using their feelings (*rasa*), participants confirmed their notion that diabetes is centered within the mind (*pikiran*) and the heart (*hati/ati, manah*). In everyday life and in the process of social relations, this view of the disease influences the way Javanese women manage and communicate messages about diabetes. Participants stated many times that messages about diabetes and life disruptions must be delivered in indirect fashion by: (a) protecting everyone's feelings by normalizing the situation, and (b) avoiding conflict and disharmony through evasion and covert disobedience.

Transcripts from 60 interviews are considered here. Each theme is described in detail, and analysis and direct quotations from the interviews are included. The interviews were conducted in either the Indonesian language or in Javanese, and the researcher translated the interviews into English.

### **Diabetes and Javanese Health Beliefs**

Studies about health beliefs and illness experiences across cultures describe illness-related knowledge as complex and occurring within cultural domains, therefore scholars argue that cultural knowledge about diabetes is closely related to the adjustment to the diagnosis and day-to-



day diabetes management (Chesla et al., 2009; Daniulaityte, 2004). The first research question is: How do Javanese women perceive and experience diabetes? In order to address this question, participants' narratives that contain information about cultural values and traditions that frame their health beliefs and behavior toward diabetes were used. Several cultural beliefs that frame these Javanese women's beliefs and experiences with diabetes emerged from their stories: (a) internal and external factors trigger and aggravate diabetes, and (b) the disease is a serious one.

#### **Factors that trigger and aggravate Type 2 diabetes.**

What makes participants' stories unique was the use of *rasa* (the deepest part of a person's emotional experience with something) as a way of telling others about their understanding of diabetes and its symptoms. Rooted in the Javanese philosophy of life, participants in this current study use *rasa* to explain experiences with diabetes that are not always physical. Many Indonesian-speaking participants define diabetes as *sugar disease* (*sakit gula*); the Javanese speakers call it *gerah gendis* (*gerah* means "ill" and *gendis* means "sugar"). Symptoms identified include feeling dizzy (*pusing, gliyeng*), exhausted, listless (*lesu*), having numbness in the hands and/or feet (*gringgingen*), stiffness in the neck and knees, blisters, and trembling (*gemetar*). Participants also indicated they experienced persistent thirst, frequent urination, blurred vision, as well as dry and itchy

skin. Some describe these symptoms as similar to what the Javanese describe as common illness (*masuk angin*). Of the 60 participants, 31 had diabetes due to hereditary factors, and the rest are diabetic because of lifestyle and eating habits.

In their understandings about diabetes and factors that trigger and aggravate it, participants' stories show some similarities. First, participants denied anything was wrong with their diets and lifestyles. Jeki, for example, said, "I don't know why [I got diabetes]. I think I just eat [a] normal [diet] .... I love sports, I go to the gym and play badminton once a week." Magda, another participant, said, "I have no idea how can I get this disease. My doctor asked me if I have a family history of diabetes and I said no. I love sports and eat vegetables." Wulan described diabetes as an "unknown" disease. "I heard that this disease cannot be cured, but I don't know why I have it. I just don't understand it. Was it something that I ate?" A second similarity that emerged is the idea that unfortunate events in life (e.g. natural disasters, financial limitations, or the death of a family member) are the major causes of diabetes. Third, heredity is a puzzling concept for these participants. Participants indicate that diabetes is triggered and possibly aggravated by internal and external factors, described below.

**Internal factors.** Internal factors that participants say trigger Type 2 diabetes involve participants' daily practices, behaviors, or practical knowledge. For example, sugar and rice are two main components in the Javanese diet and are described by participants as an important part of daily life. One of the women, Surti, explains that rice differentiates Javanese people from other ethnic groups in Indonesia:

Besides this heredity factor, I used to eat lots of rice, sweet foods and drinks. You know that all Javanese foods are so good and irresistible. Some of my favorites are *gudeg* [young jackfruit cooked in thick, sweet coconut milk], sweet tea, and *kolak* [a Javanese desert made of banana or sweet potato cooked in sweet coconut milk]. What can I say? We are destined to be sweet, just like our brown sugar [*sawo matang*, is a typical color of Javanese people] skin, right? (Surti)

Another participant, Dewi, owns a small catering business; she corroborated what Surti said,

I used to consume and cook sweet foods and drinks. My neighbors say to me, "Mrs. Dewi, whenever you cook it always taste like *kolak*." Maybe because all of my dishes are sweet. Well, yeah, maybe because I came from Yogya, you know that right? (Dewi)

Indonesians say that Javanese cuisine, especially from Central Java and Yogyakarta, is sweeter than other Indonesian cuisines due to the common use of palm sugar (*gula jawa*) and/or sweet thick soy sauce (*kecap manis*) in generous amounts (Owen, 1999).

Rural women, like Sayuti, describe *lifestyle* as a form of socialization. Women from Santren village in Muntilan regency (see Appendix C) commonly work as market traders. According to Sayuti, sugary drinks give them energy to keep up with the hard work and hot days. People in Santren village often add colored artificial sweetener (syrup) that they call '*tetes*' (drops) to sweeten the taste of their drinks. Popular among market traders because of its low cost and attractive color, *tetes* is sweeter than ordinary sugar. People can buy it for five cents per litre. For market traders, this drink is refreshing and helps them survive the exhaustion and hot days. Sayuti said:

I think the reason why I got diabetes was because I always buy *tetes*. I think something that they use to sweeten the drinks, but I'm not sure...I love sweet drinks and I always drink sweet tea everyday. But you can buy *tetes* for only 5000 [Rupiahs, about five cents] and use it to sweeten your drink. Once every three days I buy *tetes*. Oh God, I didn't know this thing caused *gula* (diabetes).  
(Sayuti)

Compared to ordinary sugar, *tetes* is highly affordable; it has more value (*irit*), economically, so the level of sweetness and the price fit (*cocok*) their tastes and budgets.

Another internal factor identified by participants is tradition. During the second round of interviews, conducted between the end of June until early September 2013, I had the opportunity to observe a few participants at home. They told interesting stories related to the shifting of eating habits and the variety of foods prepared during both Ramadan, the fasting, and the Eid celebration. Of the 30 participants interviewed during this time, 26 are Muslim; three of these were observed. Despite their health conditions, Muslim participants show great passion in performing the fast. Although the Quran exempts sick people from fasting, especially those with chronic illnesses, only two Muslim participants did not fast because of their health. For about 30 days, during Ramadan, Muslims eat only two meals a day: a pre-dawn meal (*suhr*) and a big meal after sunset (*iftar*). These participants fast to purify their faith (*iman*, which lies in the heart and mind) and their relationships with God. Therefore, for these participants, fasting brings positive feelings and peace. They say they feel healthier when they participate in the fast.

Asih, for example, had never fasted. After 12 years of living with Type 2 diabetes, Asih tried to fast for the first time and said she feels

healthier. When I visited her at home for an interview, she had just finished harvesting herbs from her large garden:

Alhamdulillah [thank God], you know, I usually don't have strength to fast. I've never fasted my whole life...so this is the first time and it is so amazing that I did not feel weak at all. I feel strong and full of energy. (Asih)

Renggo, another participant, said, "Fasting doesn't make me weak. On the contrary, I feel so fresh." Similar to Renggo, Warih, who looks after her two small grand children every day, said:

There is a big difference for me when I fast. I feel my body is healthy [*enak*] and light [*entheng*]. I don't feel hungry at all. I've been fasting since I was a teenager, so even now that I have this sugar disease, I feel fine...healthier I guess. I can still look after these two little kids, feed them, and play with them. I also prepare the food for my husband and we break the fast together. (Warih)

During my observation at Suryo's house, I observed the family's eating habits and food preparation during Ramadan. Suryo, who is commonly called *Ibu Kaji* (*Ibu* means madam and *Kaji* is the title given to a Muslim who has finished the Hajj pilgrimage to Mecca), is one of the most respected figures in Santren village in part because of her late husband's socio-economic status. Suryo lives with her housemaid, Jati,

who also has Type 2 diabetes, and her youngest daughter, Ranti, who also has diabetes and suffers from severe injuries that caused paralysis.

Coming from a wealthy family, Suryo lives in a big house with a large kitchen and many bedrooms. Being invited to break the fast with this family, I went to the kitchen to observe and helped Jati prepare the food for that afternoon. Passing the dining room, I saw different kinds of bread and snacks. I asked Jati who eats those foods and she answered, “Well, Ibu Suryo’s oldest daughter who lives nearby always brings those foods for us. So, the food shelf is never empty.” Jati said, laughing. In the kitchen, Jati deep-fried soya bean cake (*tempeh*), 12 slices. On another stove, she cooked *opor ayam* (chicken meat with eggs, cooked in thick, aromatic coconut milk). I was helping cook rice, when a woman suddenly came to the kitchen carrying a medium-sized food container. I asked Jati who she was and she said, “Everyday, Mbak Mamik [*Mbak* is a Javanese title given to a woman because she is older or has high social status] sends some food to her mother.” I peeped inside the container and asked, “No vegetables?” Jati quickly answered, “We rarely eat vegetables. Well, once in a while. In this house, we always eat *iwak* [Javanese word describing side dishes such as: beef, chicken, fish, and eggs].”

In many parts of Indonesia, including Java Island, rice is a status symbol. Rice and side dishes constitute a diet that represents an

individual's socio-economic status. Although a part of managing Type 2 diabetes involves reducing the intake of carbohydrates and sugary foods, rice remains the main part of these participants' diets. Siti, for example, says she knows that her eating behaviors caused diabetes, yet she cannot stop eating rice simply because she does not feel like eating before she has rice. Siti said, "I know that my doctor asked me to control my diet. I did. I eat more vegetables, drink less sugar, and drink less coffee but I can't reduce rice. My Javanese stomach," she adds, laughing. *Javanese stomach* is an idiom used to describe Javanese people as rice lovers.

Another tradition observed during the fasting month is breaking the fast with sweet snacks or drinks such as *kolak* (banana, pumpkin, or sweet potato cooked in sweet coconut milk soup), *es buah* (sweet fruit soup), hot sweet tea, or dates. During my second observation at Sayuti's house, I watched her cooking *mangut lele* (catfish soup). Sayuti's blood sugar level is frequently high and she takes no medicine to treat her diabetes. She says it is perfectly fine for her to break the fast with sweet drinks. In addition to rice and side dishes, she also prepared a pumpkin *kolak* in a small saucepan. While we were preparing the food, her daughter came with lamb curry. When it was time to eat, Sayuti immediately drank the *kolak*. She had two glasses of that 'not so sweet' *kolak* and after about ten minutes, she continued to eat rice, the catfish dish, and the curry. She



offered me a glass of *kolak* to break my fast and as a guest, it would not be appropriate for me to turn down her offer; that would be failing to respect her good will. After the first sip, I could not continue because it was too sweet for me.

Sayuti explains that rice is a source of energy and a form of appreciation of life and God's blessings. Having rice before going to work, especially for rural Javanese women, has a calming effect, and makes them able to do their job without worries, several participants explained. Sayuti said, "For Javanese like me, having a meal means eating rice and side dishes. If not, then you haven't actually eaten." Similar to Sayuti, Asih, another rural woman said:

My friends who also have this sugar disease always measure their meal certain grams for this certain food and so on. You know, having a strict diet. For me, being able to have warm rice on your table gives you calm feelings [*tenang*], because your stomach is full [*wareg*]. You will also have strength and energy [*semangat*] to work all day. Not eating rice makes me weak and lazy. I think diabetes is the "lazy sickness" [*lara wegah*], so you have to eat to gain your strength back. (Asih)

During my observation at Asih's house, I noticed that she cooked lots of rice in her two-liter rice cooker. When I asked her why, she answered, "I

love rice and I can't eat cold rice. It has to be warm, so I can enjoy this *sambal* [Javanese traditional chili paste]!" So, Asih, eats rice as a part of every meal.

Ninik, who works as a market trader, agrees, saying:

I ate corn rice [*sega jagung*] for three months, but I lost weight, was weak, and everything was neglected [*kapiran*], my chores, my job... So, I started to eat rice again, in the same generous portions as I ate previously. After walking across villages all day, I don't feel full if I only eat small amounts of rice. So, three times a day now... I'm supporting the family economy; I have to be strong.

(Ninik)

Ninik asserts that big meals including rice are a requirement for a worker like her to stay healthy and strong.

On the other hand, poor women in this study said that having big meals on the table is a blessing. Therefore, these women spend their available money on food. Spending money for family meals also shows they are grateful to God. Renggo says, "For poor people like me, if you have some money you want to spend it for your family. So they can have a proper meal and be happy."

Zulfa grew up in a devout Muslim family, as the oldest daughter of a *Kyai* (Islamic scholar or teacher) who owns one of the best-known

*pesantrens* (Islamic boarding schools) in Demak. Zulfa explained that both of her parents and many members of her extended family have diabetes.

Yet, she said me that this fact does not make her restrict her diet.

It is important to be grateful to *Allah* [God] for His every blessing.

In *pesantren* there is a student who works diligently to prepare food for all the members of our *pesantren*. Whatever food she prepares for us, my father told me to be grateful for that. So, we always have a table full of foods, usually for dinner. During the Eid celebration, my mother will spoil everybody and serve everybody's favorite meal that day. We will have desserts, such as *es kelapa muda* [young coconut meat served with ice and syrup], cake, and different kinds of main courses. We are so happy and we eat them all. Those are Allah's blessing to our family, so we should never reject them. (Zulfa)

These last few narratives demonstrate that these women enjoy food and the process of eating with their families. Many traditions involve preparing and eating food. Food is considered a source of energy, a blessing, and a source of health even among diabetics for whom many of these foods and the amount of food eaten are clearly not healthy.

The stories from middle socio-economic, urban women varied.

Typically these women have more money for various foods and drinks,

including soft drinks. Lastri told me that she got diabetes right after she returned from Hajj:

After I came back from Hajj, my weight had increased significantly. Maybe because I always drank soft drinks while I was in Saudi Arabia! I love soft drinks and they were so cheap there. I drank two bottles or more everyday. After I came home, I saw my doctor and got [my blood sugar] checked ... it was 200 that time. (Lastri)

A contrasting situation was found in the narratives of poor rural women. Prapti, a participant who works as a tofu maker, said, “Tell me, how can a poor person like me get this sugar disease? I thought only rich people could get this disease.” Without knowledge about diabetes, poor rural women indicate they are puzzled and uncertain about whether their eating habits really cause the disease. What Prapti said is similar to Yatmi’s comments. They both say that being poor means constantly striving (*prihatin*) to achieve their goals. Yatmi said:

For me, being able to help my husband and my children is the most important. My husband can’t cope with this household burden all by himself .... My life is simple. Being healthy means being able to see your children grow. So, we need to keep *prihatin*. This disease teaches us to live *prihatin*, not greedy. Eat as much as you

need, not too much. Save the money for more important things. I

don't need to buy fancy clothes...just enough. (Yatmi)

However, people in the middle and lower socio-economic groups, as well as the very poor consider rice to be the most important part of their diet.

Participants' responses toward diabetes intervention programs as suggested by the *mantri* (local male health paramedics) or doctors show that reducing the consumption of rice means eliminating an essential part of Javanese culture.

Another internal factor that causes Type 2 diabetes, according to these women, is emotional distress. Most of these participants (38 of 60) explained that in addition to hereditary factors, emotional distress aggravates the development of diabetes. Three major forms of emotional distress emerged from participants' narratives: (a) thinking too hard (*mbathek, kemrungsung*); (b) being startled (*kaget*, a feeling of shock arising from unexpected conditions); and (c) feeling annoyed due to certain life experiences. Overall, discussions about these emotional events are more salient than diet, eating habits, or medicine for these participants.

“Thinking too hard” is considered to cause what is commonly known among the Javanese as stress. For poor women, day-to-day stressors of being poor are said to contribute to the development of and to exacerbate the burdens of living with diabetes. Javanese women explained

that they are responsible for harmony and order in the family. Women are responsible for household chores, for making sure that the money available provides for the needs of the family, for taking care of the children, and other family matters. Nasirah, for example, is the main breadwinner in her family. Working as a social worker, Nasirah was with diabetes four years ago. She continually worries about her economic condition, saying,

I don't know what the long-term effects of this disease are. I have heard people say that there is no cure and that I have to cut down everything. Sometimes, I feel it is better for me not to know anything about this disease, simply because I feel secure and comfortable. If I were a rich person and had plenty of money to do anything, I could easily decide where to seek information and the cure for my disease. Maybe...I would go to see the best internist in town. (Nasirah)

Sumarsih, a rice farmer, said, "Its hard to calm your mind when you have to think about your children, your house. My youngest son is still single...oh so many things on my mind." Similarly, Partinem, a poor housewife, says she never stops thinking about her economic condition and the fact that her four daughters have been taken away by their husbands and live far from her. She says,

I used to sell groceries in the market, but then after my grandmother passed away I decided to open a small porridge stall in front of this house. But, my children disagreed with this decision and asked me to stop working. He [pointing to her husband] also didn't want me to work, but the money can help support our family's economic condition. Now, I feel useless... I just stay at home doing nothing, waiting for some money from his small tire service. How can we survive? (Partinem)

Laili, a participant who had been running a small catering business for 30 years, offers professional catering services throughout her village and sometimes out of town. She is now 63 years old and has been living with diabetes for the past four years. When I asked her why she looks sad, she answered:

I feel that my health has significantly decreased since my only daughter moved with her husband to another city. My life became so quiet and lonely. Now, having diabetes, I really miss my grandson and my daughter. I know that her husband is jobless and will not look after them properly. They can live with me here.

(Laili)

When I visited her house in Santren village, Laili was recovering from hyperglycemia. Her blood sugar level reached 400, but she chose bed rest

at home and temporarily closed her catering service. During this time at home, Laili was in the company of her happy and talkative 110-year-old mother. It was amazing to see her mother, a traditional herbal drink (*jamu*) maker, looking so healthy. She entertained her daughter and greeted me. Laili decided to start working again and that day they both were busy cooking *gudeg* (traditional Javanese food made of young jackfruit cooked in sweet coconut milk and left to dry). While stirring the *gudeg*, Laili's mother talked about the concept of resignation. She said that Laili is always thinking too much, too hard. She needs to learn to let things go, Laili's mother said, to calm her mind, so she will be happier and healthier.

Another source of emotional distress that emerged from the narratives involves a classic Javanese model of devotion (*pengabdian*) and self-sacrifice. Cahya was only 36 when her husband suddenly had a stroke and was forced to leave his job. Her economic condition changed dramatically almost overnight. She had been a professional Javanese dancer and traditional singer, owned a beauty salon, and ran a traditional bridal make-up business with her mother. She could not do any of this after her husband's stroke; she became a full-time wife and mother. To support her family and help her husband, she used all of her savings and sold all of her assets. Six years ago, Cahya was diagnosed with Type 2 diabetes.



It's been ten years since my husband had a stroke and now I feel exhausted. I had my first blood sugar check six years ago and I haven't done it again since then. My life has been fully occupied with my husband and I spend my time everyday to look after him. I never look after myself and I don't pay attention to my health. I don't have time for sickness, and I don't socialize with my friends anymore because I can't leave him alone. My two children live in another city because of their school.

Cahya's father had recently died from diabetes, another heartbreaking event in her life. When I asked her about why she does not look after her own health, she said, "My husband's condition is worse than mine. He lost his voice and he is paralyzed. I can't see him like that." Losing financial and emotional support after her father's death, Cahya struggles financially with only her husband's pension. She has been under constant stress for ten years. It was only during the interview that she realized, "It seems that my diabetes is getting worse. Maybe I should consider my health now. I want to see my youngest daughter grow up."

A few participants mentioned emotional shock (*kaget*) as a common form of distress. Compared to other kinds of shock, Yatmi described that the sudden death of her beloved grandson triggered her diabetes and aggravated her health condition: "I think this disease was

triggered by the sudden death of my grandson. I was so shocked because he had just come to visit me the morning. In the afternoon my son told me that my grandson had died. My body got so cold and I had trouble breathing.” She collapsed and was taken to the nearby hospital.

Ginah, another participant, lost almost all her toes due to this disease. She said that she got diabetes soon after she had a spicy fish soup. Her toes blistered and she could not walk. “It was strange. I don’t have family with diabetes, but I suddenly had it after I had that bowl of fish soup. I felt hot and my toes started to blister ... and that was it...I couldn’t walk.” When I came to her house, Ginah was busy taking care of her two grandchildren. She called her neighbor and asked her to watch over the baby. As she began to share her story, Ginah showed me her feet. Almost all of her toes on both feet were gone, yet she said it didn’t hurt at all. “These toes came off by themselves. Usually when I got *spaneng* (a high degree of stress), they blistered and then popped off.”

Sakirah, who lives near the volcano mountain of Merapi said that she got her disease on the same day that Merapi erupted in 2010.

I feel so shocked [*kaget*] and confused. The sound of the eruption was so loud and the village became chaotic. My house was shaking and everybody was running to save their lives and belongings. The ash began to cover my house so I quickly ran to save my family. I

didn't have a chance to think about myself. My mother, who already had diabetes at that time, was so shocked she fainted. Her blood sugar was 600 at that time. Paramedics took her to the hospital and she was there for four days before she finally passed away. When I was at the evacuation location, I felt dizzy and weak. I lost my strength [*tenaga*] and barely ate, so I asked for a health check and turned out that my blood sugar level was 350.

They said I had diabetes. (Sakirah)

When Sakirah told me this story, she looked sad and depressed. She did not mention the hereditary aspect during the interview. Rather she described experiencing a sudden deep fright that disrupted her health, suggesting that she does not have knowledge about the causes of diabetes. As a villager with a lack of knowledge about diabetes and its effects, Sakirah explained that when she is worried, her blood sugar level increases. However, she said, "What choice do I have? I am poor and poor people must think to survive, must use limited resources to provide my family's needs."

Another form of emotional distress that arose from participants' narratives is being annoyed and irritated by disturbing life experiences. Warni, a participant from Santren village, is only 26. She is cheerful and beautiful, but at her young age, Warni was dealing with diabetes and

hypertension. When I visited her home, she had just returned from picking up her oldest son from school. She told me that her blood sugar was a little bit high that day.

I'm sorry my house is so messed up. I try to clean the house everyday, but I feel exhausted with all the chores, and my kids always make the house dirty. So stressful [*puthek*]!! I just checked my blood sugar and it was 160 this morning. I guess my blood sugar level has increased lately. I really can't...oohh...ease my mind. Oh, me...still young but sickly. (Warni)

She is the only one in her family who has Type 2 diabetes and she does not know why. When I asked if it was due to her lifestyle or eating habits, she said it was not either one. Warni said,

I think it was emotional problems. You see, I've been living with my mother-in-law since I got married, because my husband is the youngest one in his family. I think we just don't get along very well. Plus, my kids...they are all very naughty. You know, kids, making a mess here and there, screaming, and yelling at each other. I feel that looking after your mother-in-law is not an easy thing to do. We often have misunderstandings or arguments about small things, like for example the house interior, or my cooking. I get stressed so easily and my head gets dizzy. (Warni).

Warni talked in a very loud voice, although she did not seem angry. She easily lost her patience, though, when she told me about her relationship with her mother in-law and her husband, saying, “Disharmony can get you into this stressful situation.”

*External factors.* In explaining illness, many participants attributed the cause of diabetes to external factors or at least identified external factors as contributing to the onset of their illness. They did not typically blame themselves for the disease. Many indicated that nothing could be done to prevent or delay it from happening. Heredity factors and social obligations are among the external factors that the women discussed.

Of 60 participants, only five have a formal health education background and seemed to accept heredity as the main factor that triggered their diabetes. However, they did not concern themselves with the condition until they were diagnosed with the disease. Rusti, for example, said, “As a Javanese, you know, we never want to predict before it has actually happened.” Rusti, as with many other participants, said she believed that the major cause of diabetes is emotional distress. However, due to having access to health service facilities and information, middle-class women living in urban areas accept their disease and call diabetes a “family legacy.”

Nur was born into a well-known Muslim family in Demak. Her father was a founder of one of the most reputable Islamic boarding schools (*pesantren*) in Demak, requiring him to travel extensively to teach the Quran and Islamic philosophy. Nur's family has a long history of diabetes. Both of her parents had Type 2 diabetes and died because of it. She readily acknowledged that heredity factors made her a person likely to get the disease, but Nur said that being aware of that, i.e., having this mental burden (*pikiran jero*) may increase her blood sugar level, but

I came from a big family with a long history of diabetes. Here in this city, my recitation students, my neighbors, my friends, almost all of them have diabetes. Well, I'm now very stressed because I have to prepare my youngest son's wedding, but it's so far away from here. *Ya Allah* [Oh God], I don't want to think about the journey. I did a self blood sugar check just now, because I feel a bit weak. It was 130, not bad. I have to be aware of this, you know. Blood sugar is never stable. I feel healthy when my body feels good and comfortable [*penak*]. I have energy [*semangat*] to do things. I don't feel lazy [*malas*] and sluggish [*lesu*]. It runs in the family; it is genetic. We love food and we give thanks to Allah by having feasts with the whole family. So, it's a combination of stress and genetic factors I guess. (Nur)

Kristin and her husband accept the fact that they both have heredity factors and they educate their children about this. Both of them have had Type 2 diabetes for more than 20 years. Being a low-income family, Kristin and her husband face many constraints in coping with daily problems, social obligations, and illness.

I think I have an extraordinary family. Me, my parents, my husband, my parents-in-law, they all have Type 2 diabetes. We are sugar factories (laughing). I can't believe it's been 20 years now and I try to help myself by surrendering to God, easing my mind, and comforting my feelings whenever we face complicated problems. You know, we both have diabetes, but my husband is the one who is often hospitalized because of hypoglycemia. Sometimes, because it's so often, I feel like giving up if I forget God is with us. (Kristin)

Kristin said that she is lucky because her church provides support so that she can see a doctor and get medication for free twice a month. This is part of her church subsidies for poor community members. As a part of church-based community health programs, each poor family member also gets some money and five kilograms of rice per month.

While middle-aged women like Kristin seem to be more able to accept heredity factors as a cause of diabetes, Karni has to struggle to

accept the fact that in she has lived with diabetes since she was 24 years old. When I interviewed her, Karni was taking a short leave to prepare her wedding. She explained how negotiating diabetes with her fiancée was probably the biggest challenge for her. She said:

I told my fiancée that I have diabetes and it may develop into some form of complications in the future. I need to be honest with him, tell him that I can suddenly get sick and need to be hospitalized. It means extra costs for us. I asked him if he is willing to look after me, when I get older and my disease may bring more disruptions in our lives ... I submit my life to God completely, because I don't know if I could ever have a child with my condition. I don't know how long until I can no longer perform my duty as a wife. If my fiancée can accept my condition, then I will marry him. Thank God, he did. (Karni)

Karni says she feels relieved and happy as she told this story. For young Javanese women like Karni, being able to have sex with her husband and giving birth to a child after she gets married are most important. These are important symbols of being a good Javanese woman.

Knowing that some participants have heredity factors does not mean they change their lifestyle or manage their diet. Any precautionary acts may be considered as playing with God, being disrespectful. As Laras



said, “Being Javanese, you don’t want to predict what will happen in your life [*ngentha entha*], because it has not yet happened. So, I feel I don’t need to do anything until I really have diabetes.”

With lack of education, women in rural areas do not have sufficient information about disease such diabetes. For them, diabetes is a strange disease that they cannot easily describe. Hartuti has been diagnosed with diabetes for a year, and ever since then, her blood sugar level has been high. She owns a traditional lamb satay stall and is famous in her village. I went to her stall to help her prepare the satay and talk to her about her illness experience.

I’m still confused about this disease. I thought I only had a common cold [*masuk angin*], but then the doctor said I had diabetes and I was hospitalized. My sugar level was 600. I am fasting now, and I feel healthier. I tried to drink herbal medicine and it works, my blood sugar level decreased to 500 yesterday.

(Hartuti)

Hartuti continued cutting the lamb meat while telling me her story. I was amazed at her physical strength, considering that her blood sugar level was 500 that day. She continued,

Now, I take insulin and my daughter helps me inject it every morning before the meal. I really don’t know what caused this

disease. Maybe because I'm old...I'm 50 now...People said maybe I think too much, I'm stressed, well...we are human and we think about daily life, family needs. I'm just a poor rural woman; I don't have much money. That's why I think a lot. (Hartuti)

Yet, not until I asked Hartuti if she had any family members with diabetes, did she mention that her oldest brother had died two years ago from diabetes. It is possible that Hartuti did not recognize the role of genetics in developing diabetes.

Mahmudah has been selling foods in the Borobudur village market (see Appendix C) for 30 years, and she became depressed when she had to give up this job three years earlier because of her diabetes. Mahmudah acknowledges that she comes from a family with the history of diabetes on both parents' families (*trah*). When I asked her about diabetes, she said:

I don't think it is a dangerous disease. I'm not afraid, because I didn't have this disease before. For 30 years, I've been walking to the market with a heavy basket on my back and have never had a problem with sugar (*gendis* or diabetes). I go to the market at 6:30 in the morning and come home at around 4:00 or 5:00 in the afternoon. The weight that I carry on my back everyday is about 25 to 30 kilos. *Alhamdulillah* [thank God], I never get sick.

Sometimes I feel tired, but after a short rest, I'm fine and start

walking again. Therefore, I was and still am confused about how I can get this disease. I eat green vegetables and walk to the market everyday. What caused this disease? (Mahmudah)

Further, during the interview, she said that diabetes is curable. “Sugar disease is not heavy at all and it is curable, as long as we can control ourselves from eating sweets and forcing our mind too hard [*spaneng*]. It will be cured.”

Participants described social obligation as another external factor that aggravates diabetes. This was prominent in many of these women’s narratives, especially among those who live in rural areas. Titin, for example, has had diabetes for six years, and her husband also has diabetes and has recently developed stroke symptoms. Titin is also the breadwinner in the family. She said, “Even before he got diabetes, my husband never had a fixed job. So he just stayed at home all day.” Having three children, one of whom is getting married soon, Titin must work hard to support her family. She explained:

I didn’t feel well today. I think my blood sugar level had increased. I used to check my blood sugar once a month, but this is a fasting month and I feel so lazy. I need to work. I’ll do anything. I will drive people who rent my old car to whatever destination they wish to go, even out of town. I’ll ride my motorcycle and take my

neighbors' children to school and pick them up later in the afternoon. I also have a small grocery store in my house, which serves people in my village. I make good money from all of these. I need to carefully manage the money, because you know...living in the village means you can't avoid taking part in community activities, and I think social costs drain your pocket. Makes me dizzy. You can have five different occasions in one day: wedding, community meeting, recitation, women's organization meeting, another religious events, and so on and so forth. (Titin)

Titin confessed that sometimes she has to go with her neighbors and friends to attend weddings that sometimes take place out of town. Not only is attending costly, she must also bring a gift (*sumbangan*, usually an envelope with some amount of money in it). Giving this kind of gift is a form of paying back, a situation in which people need to pay back the good deeds of others in the same way or better. Money is the most common gift, though sometimes food and physical assistance are offered. Many participants in this study said they cannot neglect such invitations, although they sometimes have to sacrifice their health needs or family needs in order to fulfill social obligations.

The Eid celebration, for example, means visiting relatives, friends, and neighbors; welcoming them into our homes; and preparing generous

amount of foods and snacks for people who visit. I went to Suprih's house on the third day of Eid and when I came into the house, the living room table was full of colorful jars. When I asked how much she spent for these various foods, she said:

It is tradition in this village that we need to prepare foods [*nyuguh*] and welcome people in our house after the Eid prayer. I hate this tradition, but there is nothing I can do about it. To prepare the Eid feast, I bought 30 duck eggs, three whole chickens, and all of these snacks. People will bring me something when they come, so I need to prepare something for them in return. This tradition really drains your wallet and savings. (Suprih)

Many participants told similar stories, agreeing that as the manager of the household, they must be prepared when unexpected invitations come. Being unable to return a gift brings humiliation to the family. Thus, no matter how limited your resources are, these women indicate they always have to find a way to fulfill these obligations.

Warni, for example, says that even with diabetes, it is these social obligations that give her the worst headache, and potentially increase her blood sugar level. Warni's husband works by taking people places on his motorcycle (*ojek*). Because Warni must look after their three children, her husband is the main breadwinner in the family. She explains:

I think I'm just easily stressed with everything. That's why I had this high blood pressure and diabetes at the same time. Can you imagine, my husband can only make 65 thousand Rupiah per day [about \$7.00]?. He has to spend it for gas, which is more and more expensive, and then my children and me get the rest. Gas is 15 thousand per day now [about \$1.50], so you know how much money I have to manage everyday. Because I live with my mother-in-law, she helps us with some of the expenses. I pay for the electricity and she pays for the water, but Alhamdulillah [thank God] I can manage the money so far. What stresses me are these social costs, you know the wedding gifts, my neighbor's son's circumcision gift, and villagers gatherings...ooh those things seem endless! And you know what? Sometimes I even have to take my health savings. If I have to do that, my own mother will help me buy the medicines.

This condition becomes more salient in Kristin's case, because she lives in a small urban neighborhood (*kampung*). In contrast to the busy and individualistic life in the city, people in *kampung* have their own unique social structures similar to people living in rural villages. People learn to split the household expenses, watching each other's backs and supporting each other's needs. Kristin said,

If I think this disease is hereditary, it is true. But, living in a city with my economic condition makes it even harder. It's hard, sad, especially when you run out of medicine, need to see a doctor, and your children have not yet sent you money. Invitations, name it: circumcisions, weddings, Javanese communal feasts [*slametan*], ...I can't believe the amount of social costs you have to bear every month. In this *kampong* you can't ignore that and I've been living in this place for a long time, since before I had diabetes. Now, people think I'm a senior here...they come for help, for suggestions. My husband has already retired but we still have many needs to meet. This is hard. When you send a gift, at least you have to spend 50 thousand Rupiahs [about \$5.00]. You can't give less than others give; it must be at least equal if not more. If we have more than one invitation in a month and I need to buy the medicines, we will use the food money! [laughing] You know, for Javanese, as long as you can eat rice three times a day, you'll be fine. (Kristin)

### **Seriousness of the Disease**

Culture also provides a framework for Javanese women in this study to understand the seriousness of diabetes. At the start of the interviews, I asked participants about how they felt, about when the

symptoms occurred, and when they were first diagnosed with diabetes. These questions are important for two reasons: First, women's perceptions of diabetes and its symptoms enhance understanding of the relationship between the seriousness of the disease and how the participants define their social roles and interactions with the family members and society in light of the disease. Second, understanding the perceptions of seriousness of the disease helps identify Javanese values that produce certain behaviors in responding and managing diabetes.

Health, as identified in participants' narratives, is a fluid concept. No clear boundaries exist among sick (*sakit*), recurrent symptoms (*kambuh, kumat*), and cure (*sembuh*), or among ordinary illnesses (what the Javanese define as common cold or *masuk angin*) and severe or chronic illnesses. Participants describe how diabetes has very little impact on their daily lives and that the threats are not severe. In the narratives, participants use various expressions to minimize potential complications, including comparisons with more severe diseases and other unfortunate events in life. Many Javanese categorize Type 2 diabetes into dry diabetes and wet diabetes. The narratives show that participants with dry diabetes perceive the disease as less serious.

Raodah, for example, was hospitalized due to hyperglycemia during Ramadan in July 2013. Although she had a history of diabetes in



her family, the way she perceived the seriousness of diabetes and the cause of diabetes are dynamic. At the beginning of her interview, she said, “I’m not sure if my parents had this disease, all I know is that they passed away because of some old-age illness. I think my oldest brother had diabetes though.” Later in the interview she said that she got sick because she thinks too hard and also because she did not pray hard enough. “My finger tips started blistering with blood and pus. I said to myself, maybe it is because I don’t pray hard enough and I don’t use my fingers to read the *tasbih*” (repetitive utterances of short sentences glorifying God). Overall, Raodah said that diabetes only disturbs her when the symptoms suddenly recur. When she is healthy, everything is okay.

This disease disturbs me only when it relapses, because you suddenly lose the spirit [*semangat*, energy] and feel lazy [*wegah*]. All I want to do is sit nicely, doing nothing, and let my empty thoughts occupy me. I don’t do anything, I don’t recite, I don’t eat, I don’t take a bath, I don’t watch TV. I just sit. (Raodah).

As with many others, Raodah recognizes diabetes symptoms as a combination of numbness in the hands and/or feet (*gringginen*, *semutan*), itchy and cracking skin, and a thick feeling in the bottom of her feet. When these symptoms do not occur, she said she is healthy and thus able to do her daily activities. For Raodah, respiratory disease (*sesak napas*)

was considered to be more dangerous and life threatening than diabetes. Her reason is simple: “Diabetes or cancer do not kill you instantly, right? But respiratory problems make you stop breathing right away. Scary...”

Participants who say diabetes as less serious frequently did not treat the disease. Etty, for example, was diagnosed with Type 2 diabetes three years ago, but since then she has not taken any medicines and hasn't seen a doctor about her condition. She also suffers from too much uric acid that makes her wrist swell. In her story, she argues, “For me as long as I can control my diet and do regular exercises it will be fine.” Other symptoms of diabetes such as being physically tired, sleepy, or constantly thirsty are common things for people her age (59), she says. She says she knows about the complications that may occur in the long term, but again, she says her blood sugar level has always been normal, adding,

With regular exercises and proper diet, my blood sugar level has always been under 200 so far. So, I don't think I need to see a doctor ... my concern now is my oldest son's problem, because he will be in the prison for one more year. Reading about him in the newspapers was hard for me. Thank God [*Alhamdulillah*], God gives me patience to deal with these problems. (Etty)

Her time is fully occupied with her family bakery business and religious activities. “I always fast during Ramadan, even after I was diagnosed with

diabetes. I'm busy with this bakery business and all the religious activities...so, I forgot about my disease.”

From Etty's story and others, the perceptions about the seriousness of diabetes appear to be related to two things. First are the hierarchical relations in Javanese society that place each person in a certain place, and with certain responsibilities. In this case, as a mother, Etty must not consider her own problem as most important. A Javanese mother, as with most all mothers anywhere, is the primary source of emotional support for her children. Second, the notion of considering other people's feelings (*tepa selira*) and difficulties as more important than one's own. Being imprisoned for a crime that Etty and her family believe was not her son's fault makes her disease less serious than her son's imprisonment. Together with the notion of consideration for others (*tepa selira* or empathy), Etty shows her sincere acceptance (*nrimo*) in her story: “Life is full of unfortunate events, including this disease. I feel healthy, and I'm grateful for that. God will look after me and my family.” Therefore, although few participants said that they do not have any financial problems that prohibit them from accessing health services or buying the medicines, they decide not to see the doctor nor regularly take medicines because there are other more pressing issues and expenses.

In exploring these Javanese women's perceptions about the seriousness of diabetes, I found that many participants categorize diabetes as a disease without clear symptoms. They describe the changes in bodily functions, but claimed they have no feeling of sickness. This is especially the case with women who say they have dry diabetes, because they indicate they think that this type of diabetes does not show physical changes (e.g. no moist and sticky wounds, certain odors). Consequently, these perceptions form a specific cultural model for an individual's response to illness, when having no symptoms is defined as being cured (*sembuh*).

Zulfa comes from a family with a long history of diabetes. Both of her parents, grandparents, and most of her extended family members have Type 2 diabetes. When she had a blood sugar test two years ago, her doctor warned her that she might have diabetes because of her family history of the disease. She denies this condition because she has not experienced the severe symptoms that both her parents had. Zulfa said,

I think diabetes symptoms are not visible. I only feel weak, nothing else, but if my mind gets stressful, my blood sugar level will increase. This morning, it was 115. Before, it was 227. I looked after both of my parents who also had diabetes and a year ago, I started to feel the same symptoms as my mother had...fatigue and

high uric acid. My blood sugar level also has been constantly high. It's okay and I try to control my diet...but you see, I didn't or [laughing]haven't felt that sickness. I mean, I'm healthy so I'm cheating on my diet sometimes. (Zulfa)

Zulfa also indicated her belief that humans cannot predict anything that happens in this world. Diabetes is “disturbing” (Zulfa used this term—disturbing—rather than dangerous or severe to describe diabetes), but it does not mean one should be imprisoned (*ngrangkeng*) by diet. She said, “I think if my blood sugar level is between 115-120, it's still normal. It doesn't mean I'm diabetic.” Thus, although Zulfa had observed her parents suffer from diabetes, she does not consider diabetes as serious or severe for her because she is healthy.

The fluidity of Javanese concepts of health and illness results in various behaviors toward the disease and treatment processes. Mahmudah, for example, said, “I drink my medicines regularly, but I don't see my doctor on a regular basis. You go and see a doctor only when you're sick and I am not always sick.” Further in the interview she convincingly said, “This disease is curable ... you don't have to drink the medicines once you are in a normal condition. If I don't feel sick, I don't have to drink the medicines.” Mahmudah's explanation shows there is fluidity among the concepts of health, sickness, cure, and relapse. Mahmudah said the

absence of diabetes symptoms is the condition of being cured (*sembuh*) or healthy (*sehat*), requiring no intervention or medication.

Murtini and Yatmi are sisters who both have Type 2 diabetes. For these sisters, “real” diabetes is the wet type because it brings physical damage to the body. While dry diabetes, which they have, does not disturb their health, at least not as much as wet diabetes would, in their view. Murtini said, “Diabetes is not a burden for me. My sister and I both have dry diabetes, so physically we’re fine and healthy. We have no worries. Wet diabetes is dangerous because you’ll have moist, sticky, and smelly wounds that make you sick all the time.”

In their stories, participants state that diabetes symptoms are so vague that they almost cannot feel them. This lack of knowledge means that some participants described diabetes symptoms as being similar to a common cold (*masuk angin*). Ninik, did not distinguish among diabetes symptoms, a common cold, and signs of pregnancy. Because she takes birth control pills, Ninik said it was not a sign of pregnancy. She said,

From what I know, when you are 40 you will not have menstruation, right? I take birth control pills, so I can’t be pregnant. But that time, I didn’t feel well [*meriang*]. I wonder if it was my diabetes or just a common cold [*masuk angin*]? I had a traditional massage, but I still did not feel well. I really did not

expect that I was pregnant. I had diabetes for five years, so I know that when I feel unwell it most probably is that my blood sugar level is increased. So, I vomit, am dizzy and weak, just like when you have a common cold. (Ninik)

Ninik says she doesn't take diabetes medicine because she is healthy. Even during her pregnancy she did not measure her blood sugar level: "My husband was so happy and I also feel very healthy. I still do my job as usual, selling foods around the villages, and going to the traditional market afterward. I don't take my diabetes medicines because I'm healthy. Besides, this pregnancy is God's gift." Ninik put more concern on her hypertension, because she believed that when a person has a stroke there is nothing you can do. "You will be paralyzed [*lumpuh*]."

Several participants in their 60s and 70s said they consider symptoms that occur after they are diagnosed with diabetes as signs of age. Consequently any physical abnormality, such as stiffness or aching joints and bones are considered to be normal conditions, rather than indicating sickness. Fitri is 65 years old and has lived with diabetes for seven years. Unlike other individuals with diabetes, Fitri says she did not feel any common Type 2 diabetes symptoms. She said, "I went to see my doctor just because I lost weight drastically. I don't feel weak or tired, no persistent thirst, and I don't feel sleepy. You know, the diabetes

symptoms.” Fitri responded to a question related to complications or other physical disruptions during those seven years by saying that,

Everything is fine. I constantly drink herbal medicines to help me balance my condition and I feel it fits [*cocok*] my needs. I feel fresh and healthy. Sometimes I feel tired, but I think it’s normal for someone my age. I drink diabetes medicines just to control my sugar, but no complications so far. Cholesterol...hmm, slightly high, but I’m old so it’s normal. Whenever I feel something wrong with my body, I see my doctor, drink the medicines, and everything will be back to normal. I never experience any bad health conditions so far. Signs of age are something that you just have to accept...it’s normal. (Fitri)

Jati has been working as a housemaid for three years and has been managing her diabetes for the same period of time. When I came to interview her, *mantri* (the local male health professional) had just checked her blood sugar level. It was 546. Her boss, Suryo, who was also a participant was shocked and said, “Jati, see...do you want to start controlling your diet or do you want to take another challenge and go higher than that?” Jati casually replied, “I think I forgot my medicine, but already ate too much this morning. The problem is, I haven’t eaten rice. Gosh! It could reach 700 if I had rice,” she said, laughing. While part of



Jati's job is to take care of Suryo's needs, she forgets to remind her about the medicines. With her educational background, Jati does not know what diabetes is nor how serious it is. All she knows is the name "sugar sickness" (*gerah gendis*). Being able to function with such a high blood sugar level makes her proud of her physical strength.

See, I can still do the chores! I don't feel anything. Maybe because I got used to it, I almost don't feel anything. For me it doesn't matter how much my blood sugar level is, because I always feel fine. I feel comfortable and relaxed [*ayem*]. I never change my diet, I love bread and I still make instant noodles everyday. I also cook with coconut milk, and eat fried food. (Jati)

Jati, Sayuti, and Warih are examples of how Javanese women in this study indicate they do not consider high blood sugar level dangerous. They view it as normal and sometimes even joke about it. Sayuti, for example, gave me a calm response when I asked her about her latest condition. "My blood sugar level today is 400, but I'm used to this...so it's okay.

Alhamdulillah (thank God), I'm healthy."

Javanese concepts of health and illness as shown by these women are dynamic and fluid. They shift continually, moving within a cycle, from a healthy (*sehat*) stage, to sickness (*sakit*), to the cure (*sembuh*) stage, and then relapse (*kambuh*). In their stories, these women described that health

or a healthy body means the participants no longer feel diabetes symptoms. To be able to feel emotion (*rasa, merasakan*) is an important cultural concept that can move an individual's sickness stage to the healthy or cured stage. A healthy condition is described as a sign of light (*entheng*) and comfort (*penak*) in the body. Emotionally, these women say they feel healthy when they are happy and full of energy (*seger, sigrak*). Physically, they say they are healthy when they no longer feel weak, are able to do their daily activities without a hitch, or able to walk long distances.

With the possibility of “cure” (as described by the participants, not a cure in traditional or medical terms, but “cure” in this case means the disappearance of diabetes symptoms after some interventions), some women perceive diabetes as a less serious disease. When these women shift from the sickness stage to the healthy stage, in their views, they show an act of simplifying (*nggampangke*), a concept that emerged in various forms including cheating on diet restrictions, irregular blood sugar level check ups, getting medicines without consulting their doctors, and no longer taking their medicines.

### **Diabetes and Social Interactions**

Peace (*damai*) and harmonious integration (*rukun*) are two core concepts in the Javanese world of social interaction. The concept of *rukun* can be described as:

Soothing over of differences, cooperation, mutual acceptance, quietness of heart, and harmonious existence. The whole of society should be characterized by the spirit of *rukun*, but whereas its behavioral expression in relation to the supernatural and to superiors is respectful, polite, obedient, and distant, its expression in the community and among one's peers should be *akrab* [intimate] as in a family, cozy, and *kangen* [full of the feeling of belonging]. (Mulder, 1978, p. 39)

Peace and harmonious integration become the state of mind and an attitude of life on Java. Women, in this case, act as mediators in maintaining harmonious interactions within her family and among members of society generally. Peace and harmony are the ideal conditions that everyone should strive for, in which there are “no intense feelings of resentment, or at least [they] are not expressed...look for compromise solution[s]...to minimize conflict within the family” (H. Geertz, 1961, pp. 149-151). Thus, the values of peace and harmony are closely and deeply held.

Part of the struggle that participants face in their social interactions is maintaining social harmony and peace while at the same time maintaining their own lives. The current study suggests that the concept of harmony (*rukun*) is under constant challenge, especially when women, as the central figure in the family, suffer from a misfortune such as diabetes. Javanese households are part of a complex socio-cultural dimension of relationships among family members, extended family members, and in the surrounding social contexts. Although married children typically leave their parents soon after they get married, in some cases the children remain with their parents or, as commonly practiced by Javanese villagers, children will live close to their parents (e.g. in a house adjacent to their parents house, or a different house in the same yard (*magersari*)).

Yuni and her husband live in the same house with their youngest daughter and her family. It is a common practice that the youngest child stays with their parents to look after them when they grow old. Living in the same house requires extra arrangements and a high degree of tolerance and acceptance from both families, as Yuni experienced:

When you live in the same house with your child and her family, the hardest part is to arrange the functionality of the house, such as bathroom, kitchen, and living room. Diet arrangements for example, each of us in this house organizes ourselves, so I cook for

myself and my husband, and my child cooks for her family. We have different tastes, right? We cook the rice together, but we prepare separate side dishes. (Yuni)

This is why, for Yuni, it is hard for her to manage her diet. She cooks for her husband and usually they eat the same food. With her grandchildren living in the same house, Yuni provides snacks for them. She says that whenever there is leftover food on the dining table, she will eat all of it because throwing away food means throwing away God's blessings.

Nasirah, lives with her two sons, two daughters-in-law, and two grandchildren. Her daughter lives with her husband in another town. With her and her husband, there are eight of them together in the small house.

Nasirah describes it:

Well, I realized that my children still live together with us, so I need to arrange the money, the time, and the house for the eight of us. We have to share the utilities, such as water and electricity, because they are very expensive these days, especially with so many people in the house. Each family washes their own clothes, so we use lots of water everyday. We used to cook separately, but to save the money we decided to share the food. So, if I don't have time to cook I will take my children's food, but if I don't like the menu I just cook for myself. Both of my daughters-in-law are also

working, so my husband and my sons watch over the kids and do the chores. I have to work everyday and sometimes I have to stay at the dorm and look after those old women...so I don't have time to help with the chores. (Nasirah)

As the breadwinner, Nasirah must support the family with her income. "I wish I could see a specialist, but with my income, I can't afford it. My family needs more..." She added that God helps her, because God knows that she does not have the money to look after her health.

In the Javanese kinship system, women bear more domestic and kinship responsibilities than men. Thus, maintaining a harmonious life is not simply among participants and their husbands or children, but also with extended family members. Susan's story shows how a daughter shares more responsibilities than a son. Susan had lived in a local cemetery location for more than 30 years. In Java, public cemeteries are usually located adjacent to or are surrounded by housing. Susan inherited a large graveyard lot from her family and in that yard, she and her mother live adjacent to each other. Every weekend, especially during Eid celebrations and other holidays, Susan cleans the graves and makes money from relatives who visit their family's graves. When I came to interview her, Susan's mother had just died after suffering from a severe sickness for 15 years. Susan told me:

Well, what can I say? . . . Among my other siblings, I'm the only one who is available to look after my mother 24 hours a day. Two of my siblings live in another city. My oldest sister lives in this town, but far from here, and she has to work everyday. My two older brothers and my youngest sister live in different towns. My youngest brother is jobless and I couldn't leave my mother with him. He's very irresponsible and ignorant, only cares about his own business. So, I took this responsibility. I live with two of my sons in this house; my youngest son lives with my oldest sister. I asked her to look after him since he was a baby, because I was a migrant worker at that time. Now, since she couldn't look after my mother, I asked her to keep looking after him. He is a very smart boy and I'm proud of him. He comes to visit me once in a while.

Being her mother's caregiver, Susan explained that she did not have time to look after her own health because she was constantly occupied with her mother and her husband, who also has Type 2 diabetes. "Sometimes I feel so weak, and have stiffness in my feet, but nobody cares. I don't know what to do. If they can... just cut my body in half, so I can do what my husband wants, but can be with my mother at the same time. My husband is always angry when I come home late to cook for him."

While participants' narratives show that economic burdens and conflicts of interest among the family members produce problems, being under the same roof with children and their families also provides a sense of security and comfort for these Javanese women. This means a mother does not need to worry about her children because she has them all under the same roof, safe and sound. With this kind of household structure, Javanese women are able to show their roles in protecting the children and the providing for the needs of their families.

Wariyah, for example, has three married daughters. In Javanese culture, daughters typically leave when they married. Although the kinship remains strong, a daughter will typically follow her husband. Wariyah describes:

I have three daughters and they are all married. When my youngest daughter was about to get married, I asked her husband to promise me not to take her away. My husband had passed away three years earlier and I was on my own, so I hold on her now...Her husband is a sailor, but he resides in Yogya [a city located one hour from Wariyah's village] doing his business. (Wariyah)

Wariyah owns a building supply store in the village and she has been running the store for 30 years. She wants her children to inherit this business. Wariyah's biggest concern is her oldest daughter who also has



diabetes, but has to financially support her family due to her jobless husband. Knowing that she still is a source of strength for her daughters, a source of calm, Wariyah's says she feels her life is useful and she does not feel the pain from diabetes. She said,

I'm preparing this small business for my children, especially my oldest daughter. I asked her to come here everyday. Poor girl, she has to bear this herself. I think *Allah* (God) has organized everything for us. My children live close to me and my relatives also live in this same village. For me living close to my daughters gives me a peaceful mind. (Wariyah)

Further, participants mentioned solidarity and a sense of awareness of situation and one's limitations (*tepa selira*) as two important values that help them maintain a harmonious life. However, these two values cannot be forced from others. People need to be self-aware about when and to what extent they should show their attention and concern to others. Thus, while one party may wish for the other party to show concern and tolerance, sometimes people are disappointed, ultimately, because others don't show the concern desired.

Suprih said that in addition to being the primary breadwinner in the family, she is also still expected to do all the household chores.

My blood sugar level normally is around 180, never reaches 200...it should be okay, but I don't know why, this morning it was 370! Maybe because I got so tired because of Eid.

Many guests and relatives come to visit and the house was completely messed up. I don't feel like cleaning it, but none of my children knows what to do. They never bother to help. They wash their clothes when they're having a holiday. Otherwise, they just leave it unwashed for several days. My daughter, oh she only puts her motorcycle in the garage. She brings the drinks out for the guests when she feels like she wants to...If she is busy, she won't do anything. (Suprih)

Suprih describes how no one bothers to help her although her children know that she is sick and needs help. Suprih said, "Children—they never understand."

This narrative is in contrast to Warih's story. Warih lives with her extended family in one big yard including five houses. When she was diagnosed with diabetes, Warih decided to stop selling meat at the local market. Her son continues to sell the meat, while her two daughters work in a local factory. Because all of her children and in-laws are working, Warih looks after her two grandchildren, she explains, laughing:

They really entertain me. Both of them are three years old and haven't gone to school yet, so they stay at home with me. Now that I have stopped working, I look after these kids, play with them, and feed them (laughing). Both of their parents are working since morning. I enjoy looking after my grandchildren; I don't want their parents to be worried. I'm old now; it's time for my children to work and continue my job...I used to have my own money, but now it's my husband and my children who give me money. (Warih)

Under the notion of consideration for others (*tepa selira*), people must be empathic. This is an internal, i.e., self-motivated action, and when people practice reciprocation in their day-to-day lives, it promotes social harmony and continued reciprocation.

For Kristin, living with her daughter and her two grandchildren means she has more people to help watch over her husband, and to help her when she is in great need. "My grandchildren are big now. They can watch over their grandpa, and help me to look after him when he suddenly has a seizure from hypoglycemia." Her grandchildren know that if their grandparents are tired or not feeling well, they will give them a massage, just as I saw when I went to their house. The little boy approached his grandpa who was fixing his bike and massaged his shoulder.

It is a common practice among middle- and upper-class Javanese families to have a housemaid (*pembantu*) who helps the wife with physical domestic tasks (e.g. cleaning, cooking, washing, and childcare). In today's Indonesia it is hard to find someone who will work as a maid because poor women choose to work as factory labors or migrant workers because of higher salaries. For Javanese women, maintaining harmonious life and peace in the family means managing both the physical tasks in the house as well as the emotional state of family members and the woman's own inner peace. Although the presence of a housemaid is helpful, described in the narratives here, participants say that there is no role-substitution even with diabetes. Tatik provides an example about the happiness many of these women describe when performing the duties of motherhood:

I've am always very busy everyday. I wake up at 5:00 am, prepare breakfast for my husband and my grandson, select the clothes that my maid will wash later that day, take a shower, and go to the market. My house is so big that if you mop the floor, you'll be sweating all over (laughing). I feel so fresh after I finish doing that light housework. I never ask my maid to go grocery shopping because I love going to the traditional market in the morning after taking my grandson to school. Then I cook for lunch, take another

shower, and rest while waiting for my grandson to come home from school. (Tatik)

Emotional assistance is something that a housemaid cannot give to a wife, and this is what Frida describes. As a retired midwife, Frida has a maid who stays in the house and does all the chores. With her health condition, Frida said she is physically helped with the presence of a maid in the house. As a manager of the house, though, Frida still manages and observes the maid everyday to make sure everything is in order. However, in her narrative Frida does mention a possible source of disharmony—having a maid does not relieve her emotional burden. “I have a housemaid and she does all the housework while I only manage, observe, and tell her what to do. She lightens my physical burdens by doing these chores, but I often still get depressed when my husband makes me upset.”

Participants in this study describe social expectations within Javanese society, specifically that women are responsible for the physical and emotional needs of the family members. However, Frida expressed that she feels like she does not get enough emotional support. She hides her feelings rather than openly complain, which would risk disturbing peace in the household.

Another sign of disharmony arose in participants’ stories when they were asked about the importance of being financially independent as

a Javanese woman. Based on the narratives, five different groups of women were involved in this study: (1) working women (e.g. have their own business, have a professional or formal job, or work as market traders), (2) housewives, (3) retired women, (4) women who used to be financially independent by working outside the house, but voluntarily gave up the job due to her illness, and (5) women who are forced by husbands or children to give up her jobs due to illness. As emerged in the narratives, being self-reliant is an important part of identity for Javanese women. In their narratives, especially those from rural women, they expressed confidence in their decisions and capabilities to manage limited resources to accomplish their duties.

Self-reliance demonstrates strong character and the ability to effectively manage limited resources. These participants optimize their lives given their circumstances, conditions, and resources. However, this current study reveals how self-reliance, which is supposed to encourage social harmony and peace, is sometimes used to challenge the harmony. To be considered self-reliant, participants must show they can simplify problems (*nggampangke*) that may lead to misfortune. As emerged in the narratives, simplifying problems has three meanings in the everyday life of the Javanese: (a) being ignorant, (b) normalizing unfortunate situations to (at least appear to) alleviate one's burden, and (c) protecting the

participants' self-reliance, in order to convince others that the individual is reliable and able to solve problems.

Being self-reliant is mentioned frequently in participants' narratives, described as the woman's ability to support herself, or being financially independent. Cici, for example, used to work as a caregiver for old people when she was younger. After her second marriage 12 years ago, Cici, who is now 63, decided to become a full-time wife and lives with her husband in Borobudur village. Eight children from their previous marriages live separately with their wives and husbands in different cities. When I asked her about how diabetes influences her life, Cici said:

It's just the two of us in this house. Since I got diabetes, to be honest...medicine comes first. Then I think side dishes [*lauk*, meaning food in this context]. Clothes can wait. ... It is important for me to always have my medicine in the house. Itching ointment, and other ointments have to be available. I can live with simple side dishes, or with only ordinary clothes. The most important for me is that I always have my husband's favorite meal on the table, for example, smoked fish in thick, spicy coconut soup [*mangut*], and fried chicken. For me, noodles are enough. I have always prepared something special for my husband, because he's the one who gives me money every month. But, I don't use that money for

my treatment. For my treatment I sell coconuts, eggs, and crops.

(Cici)

As a way of honoring her husband, Cici uses her own money to buy medicines, demonstrating her understanding of the burden that one can be to others.

Self-reliance demonstrates that one has the energy, spirit and power to perform daily activities. For villagers like Sulistyowati, who supports her household with income she earns as a market trader (*mande*), running a small business is a very common thing to do.

Economic demand. I can't just count on my husband, because he doesn't have a definite income. Sometimes he gets money, sometimes there is nothing at all. We need to eat everyday and everything is expensive these days. I love cooking and it's easy to cook porridge. I can have a stable income everyday. Besides, because I love this job, my blood sugar level is more stable. It used to be around 285, but now after I re-opened my stall, it is 100 and I feel healthier. (Sulistyowati)

It has been a year since Sulistyowati re-opened her food stall and she and her husband are a good team. Her husband helps stir the porridge every morning, while she prepares the side dishes to go with the porridge.



For village women, to continue working after their husbands die symbolizes the power a woman has to be self-reliant, and to be able to manage resources to support her family. Darti, for example, had to give up working for 20 years, until she decided to go back to work soon after her husband died. When I asked her why she decided to go back to work despite her sickness, she said,

I've been doing this job since I was 20 years old, but then my husband won the election and became the village head for two periods...that's 20 years. I was too busy accompanying my husband with his duties so I had to give up the job. It is not about the money, because economically I'm fine. This is about me, having my own job, seeing my friends at the local market. And also, I don't like staying in the house doing nothing while I'm still capable of supporting myself and giving things to my grandchildren. I love being busy. Doing nothing makes your mind empty and carried away [*nglangut*], useless. (Darti)

For Darti, self-recognition is important. Having people recognize her ability to keep her job and manage her family economy brings peace to her mind. Being able to give money to her grandchildren is Sayuti's biggest happiness, and she insists on working and has managed her three stores at the local market since her husband's death. These stores have been part of

her life for 43 years, and the reason why she keeps working today is because she does not want to stay at home, feeling lonely and doing nothing. “I have been responsible for myself for a very long time. Working makes me healthy, plus I can give money to my grandchildren, buy them cakes, and help my children if they need me.”

Therefore, sadness and disappointment were salient in the narratives of women who have had to give up their work because of diabetes, whether they did so voluntarily or because their family members asked them to. Giving up a job or business makes participants lose their sense of financial security, identity, and bargaining power. Sakirah told me,

I stopped working two years ago. I suddenly got very sick and my family asked me to stop working, but now I am bored. People in this village work as traders at the local market and I’ve been longing to do it again, but my husband said, “What if you get sick again after a week? You’ll have troubled everybody.” I feel strong enough to go back to work...I can’t understand my husband. He always makes me upset, he yells at me all the time whenever he doesn’t like my cooking or isn’t satisfied with the house. He loves making a sin [*maksiyat*], always starts a fight. (Sakirah)

Sakirah says the only cure for her disease is to go back to work. By having her own money, she will not have to fight with her husband.

I feel so sad when there isn't enough money in the house. The money that we have won't last for a week. I tried to save on expenses, but there is still not enough money. Now, all I want is to be healthy and back to work. I'll try to calm my mind, so I can be healthy [*sehat*] and *waras* [Javanese words meaning a state of wellness and referring to both a healthy body and mind]. (Sakirah)

Sadness and disappointment emerged from Partinem's story, too. Pointing toward her husband who was fixing a customer's tire, she said, with a flat face and tears in her eyes:

I used to sell homemade cooking in the local market, porridge and other various foods. After my grandmother passed away, he and my children asked me to stop working. Now, I'm just sitting here doing nothing. I feel so awful and hopeless, because I used to have my own money and helped the family. You can't just expect from your husband...it's not right. He doesn't have a fixed income so when I get some money I try to spend it carefully, but it is still not as much as when I had my job. (Partinem)

When I asked her what she wants and what she expects from her husband, Partinem remains silent and looks away with tears welling. Her silence

told me that she tried to avoid conflict with her husband due to her position as a wife and her role to maintain harmony. Having a job for these participants is more than just having their own money. It also brings comfort and helps them gain social recognition, while at the same time having others recognize them as self-reliant individuals with bargaining power to manage their lives while accommodating family interests.

**Diabetes challenges family harmony.**

Throughout the interviews, participants shared their psychological and emotional burdens more frequently and in more detail than the physical symptoms they attributed to diabetes. Undesirable social conditions attributed at least in part to diabetes include loneliness, disappointment, confusion, and anger. Many participants become quieter than they had been, and many mention mind wondering (*nglangut*) and worrying when they are alone or have nothing to do.

Based on participants' narratives, diabetes challenges family harmony in two areas: (a) the psychological state of participants and family members (spouses and children), and (b) the family's habits. Despite socio-economic status or background, participants emphasized the importance of relationship satisfaction with immediate family members, extended family members, and with in-laws. Within the Javanese kinship structure, a woman is placed in the center (matrifocality) with multiple

roles to play as part of maintaining peace (*rukun*) and harmony. At the same time, she is expected to recognize and maintain the relationships among family members from both father's and mother's sides equally (bilateral) (H. Geertz, 1961; Tanner, 1974; Wolf, 1994).

The following narratives shed light on the contradictory and dynamic aspects of relationships among participants, their immediate family members and extended family that occurs when diabetes suddenly becomes part of a woman's everyday life. Womanhood in the Javanese perspective is imbued by the philosophy of devotion and dedication to family. This what makes a good Javanese woman. However, participants continually challenge this concept, as the presence of diabetes in these women's lives requires reciprocal actions to always be considerate and understand other peoples' problems (*tepa selira*)

Puspa used what can be categorized as a cynical term— an “all-in-one maid”—to describe her complex roles as wife and mother, and how she thinks her husband and children are treating her. Puspa says,

As a woman, I think I am an ‘all-in-one maid’ [*pembantu luar dalam*]. I have to serve my husband, cook for the family, take care of my children's problems, look after all household affairs, take care of my grandchildren, and deal with my husband's unique attitudes. From leaking roofs to my husband's debt, it is me who

has to take care of these problems myself. Seems backward, doesn't it? To look after the house and make sure that utilities work properly are supposed to be men's tasks, right? So, I do everything, [and], there's no difference before and after I have this disease. I'm the man and the woman of the house. (Puspa)

When I asked if diabetes disrupts her roles, Puspa surprisingly said, "No. I'm totally fine." The hardest thing for her is when her husband asks her to have sex, which she no longer has interest in due to menopause and (she said) diabetes. Yet, she never discusses this problem with her husband because she expects her husband to understand and being a woman she is reluctant (*pakewuh*) to reject her husband's sexual advances or to discuss what she feels. On the other hand, due to her husband's bad habits, Puspa constantly struggles with economic problems and finding solutions to them. "I've been on my own for so long. The children, well, they still depend on me. They still can't stand on their own feet. I still support them financially ... I think it's normal if children ask their mother for help. But, if I have a problem, they don't care."

Puspa's complaint is common among Javanese women when they speak about their domestic tasks. In the Javanese family, the oldest daughter bears more responsibility to provide care and emotional support (sometimes also financial) for her parents and her youngest siblings

(including their immediate families). Thus, although Javanese society values children of both sexes, parents consider having a daughter as an investment for emotional comfort and future care.

Jeki defined Javanese women's roles as: a mother (*ibu*), a wife (*istri*), and a maid (*babu*). Similar to Puspa, she explains that endless housework and other responsibilities place her in the same position as a housemaid. After being diagnosed with diabetes three years ago, Jeki says that her health is her own responsibility. And, inner feelings that she describes are about her son:

My child is rarely at home. He always comes home from work late at night. So, all I have is my husband, but I'm not sure what he thinks about my condition. This disease requires a huge financial commitment and I can't afford it. So, I decided not to see a doctor too often. I can't say that health is my number one priority while my family still has needs. It's my daughter who can understand this situation. She's different from my son. A girl understands their parents better, my burden and my sadness. You know, Javanese elderly used to say that having a son is like playing a lottery; if you are lucky you'll get advantages from them, if not then, you'll get nothing. (Jeki)

Jeki says there is no point in asking a favor from her oldest son, so she decided to handle everything on her own.

Similar ideas emerged from Cahya's story. As a wife and mother, Cahya invested her time and devotion to her family. She is a diabetic and she has cared for her paralyzed husband for ten years. Cahya says she feels exhausted in a way that she cannot describe. The way she moved her hands told me that energy was being drained from her body. She explained how self-conflict (*pertentangan batin*) between her ego and her responsibility as a wife and a mother, makes her lose her spirit (*semangat*) to struggle for her health and future. Having sick parents and limited economic resources, her oldest son had to accept the fact that he could not go to college. Cahya did not blame him for being angry at her, although she once lost her temper because of this:

My son is always angry at me. He yelled at me one day about why I never have money. Exhausted, I spoke to him in a loud voice, Don't you know that your father needs a lot of money for treatment. Don't you see that I am also sick? If you distrust (*maido*) me like this, you can manage the money. I'm trying to fulfill this family's needs, borrowing money, using the resources we have in the best way I can. I can live with your youngest sister;



I'll take her with me and I'll find a job. You can look after your father! (Cahya)

Cahya is aware that her disease may lead to other health complications in the future ... [already] her illness and her husband's condition have caused a big burden for their children, she said, adding, "When I'm thinking about my myself, I want to leave my husband and be with someone who can look after me. But my children would hate me. I pray they'll be able to look after me in the future, especially my youngest daughter."

Yatmi's story highlights the sense of belonging (*nduweni*) that Javanese families desire. Living with her oldest sister who also has Type 2 diabetes, Yatmi repays her sister's kindness by doing the household chores. She is aware (*rumongso*) that her sister has greatly helped her family, and now that her sister had just returned from the hospital, Yatmi is also taking care of her. Being diabetic herself, Yatmi said she often feels tired and hopes that her children know her feelings and will help her with the chores or take her to the local paramedic. Yatmi said,

I know my kids are never home, so I don't expect too much. In this house there are more males than females. My sister and I used to look after these guys, but now that my sister is recovering, I'm the only one to do everything in this house. Everything! From cooking, to cleaning, to washing. The boys always leave very early in the

morning. As long as they are healthy, I'm fine. I can't imagine if my kids are sick, you see...I never have time to rest. I start doing the chores very early in the morning. You can't imagine how tired I am everyday. I am tired, very tired...but I just ignore it. If they don't want to help me, I'll do everything in my rhythm. If I suddenly feel tired, I will rest and continue everything later. These kids, they never have time. (Yatmi)

Yatmi's says that complaining shows insincerity and she does not like this. Javanese society recognizes three domains that a woman must master in order to be considered a "good woman:" the kitchen (*dapur*, means a good woman/wife should know how to cook), the bedroom (*kasur*, bedroom here refers to mattress, meaning the woman's ability to satisfy her husband sexually), and the well (*sumur*, a term describing a source of water for washing her family's clothes and dishes, in the broader meaning, the woman's ability to take care of the house). In their narratives, Puspa, Jeki, and Yatmi did not contest their socially imposed "obligations" as a woman, but these participants did voice disapproval toward the children and/or husband having a passive attitude toward their burdens on the sole basis of social tradition. Jeki described this attitude as lack of understanding (*kurang pangerten*). Related to diabetes, they indicated that they often feel exhausted and these burdens and the lack of

understanding and concern from others result in increased blood sugar levels.

Harmonious life among the family members is also challenged by the presence of diabetes in a mother's life, especially when family members remind participants about their diet. In Zulfa describes this as "imprisoning her appetite." As she explained, with conviction: "I do feel afraid to eat anything that may encourage an increase in my blood sugar level. But we are human and each individual has an appetite that you can't just imprison because we have diabetes. My sister reminds me about this all the time." Being born as a *ning* (a title given to a daughter of Islamic scholars), Zulfa learned from her father that food should not be consumed in solitude because only in togetherness can one obtain the blessings from Allah. So, since she was little, her family members have always eaten together. "Everyday is like a feast," Zulfa said, laughing.

Conflict arises when one of the children hides favorite foods from their diabetic parents. Zulfa's father is typically angry about this, saying, "You're torturing me. All of these foods are a gift from Allah; we can't reject it." What Zulfa means when she talks about "imprisoning" her appetite is that the prescribed diabetes diet is not consistent with her cultural beliefs or desire to eat. Consequently, as she learned from her parents, Zulfa says that food is not only a trigger for increasing blood

sugar levels, and therefore, food restriction is not her choice. When her youngest sister tried to manage her diet and control her food consumption, Zulfa voiced her disagreement:

I feel a bit scared because of this risk factor. My sister gets so paranoid and refuses to eat anything. Even during this fasting month when we are supposed to have a very early breakfast, she rejects it. She just takes one glass of water, and I said, “What?! You’re torturing yourself!” We’re okay, nothing has happened so far. (Zulfa)

Today, whenever Zulfa and her siblings have a family gathering, they have everything on the table. People do not remind others about their health nor what they should and should not eat.

Asih mentioned events similar to those Zulfa described regarding the prescribed diabetes diet. Asih explained, “I stopped eating sugar, but that’s it. Actually I have to avoid 18 different kinds of foods, but I...well, how can a human not eat anything? I can stop drinking sweet beverages, but restricting the food?” Asih says whenever she cheats on her diet, her disease can always be cured with the medicine. Whenever her husband reminds her about her diet, they argue. “He told me not to eat this and that, but I really want to eat it...I live only once, but I can’t eat what I

like? So if you're diabetic, it means you can't do anything, you can't eat anything?"

Participants' narratives show that the prescribed diet not only "imprisons" one's appetite, but also influences participants' interactions with their immediate and extended family members. In Javanese culture, family events such as weddings, circumcisions, births, holidays, and other events that involve communal feasts (*selametan*) require people to respect the ritual, the host, and the food provided for the occasion. Jati explained, "It is taboo [*mboten elok*] to reject or to throw away the blessings that come with the food provided for communal meals." A large number of participants seem to agree with this notion and they do consciously "cheat" on their diets when they attend such events (and as shown, other times, too). Doing, the otherwise frequently disrupts harmony.

Although anger, disappointment, losing patience, anxiety, and doubt color the everyday lives of participants with diabetes, many of them uphold the notions of harmonious life and peace as the most important in life. These principles are a precondition for what these Javanese women describe as a healthy life or well-being. Three solutions emerged from participants' narratives as to how to achieve peace (*rukun*), balance, and harmonious relations among family members: (1) restraining emotional responses, (2) finding solutions that fit (*cocok*), and (3) engaging in self-

sacrifice (*pengorbanan diri*). For these participants, self-sacrifice represents a woman's power and ability to suppress her egos, emotions, and her own needs—even those related to caring for their diabetes and overall health.

***Restraining emotional responses.*** Feelings (*rasa*) in the Javanese perspective represents a “spectrum of meanings” (Stange, 1984, p. 127) that resonates with the “inner aspects” (*batin*) (Ferzacca, 2001, p. 79) of Javanese women's personal experiences with diabetes. As emerged in participants' narratives, emotional outbursts, protests, or silence that occur in their lives are considered to be the result of inner distress (*penderitaan batin*) or uncomfortable feelings. While dealing with their disease, the women in this study must also satisfy the social demands that a good Javanese woman must perform. These women cannot hide their anxiety and their desires and expectations when they talk about the importance of maintaining peace and harmony.

Being the oldest child, Trias says she should be able to manage everybody's feelings and needs, not only those of her husband and children, but also her mother and her siblings. The only physical symptom she has since she was diagnosed with diabetes four years ago was her stiff legs. Trias's second husband is younger than she is and in good health, so

she feels insecure and often times doubts her husband's loyalty because of her disease. Trias said,

My husband is still very young and it's hard for me to trust him. I don't know if he really loves me or not, but now that we are together he turns out to be the one who's willing to stay by my side no matter what. I'm sure if I die, he will still look after me. So, I don't have the heart to hurt him and he has convinced me that he will stay by my side forever. When I feel disappointed or upset with this disease, or myself I always remember the way he has treated me all this time and I don't throw my anger to him. Thank God [*Alhamdulillah*]. (Trias)

Within the Javanese kinship system, the youngest child is responsible to maintain the family and Trias readily upholds this value. However, her stiff legs make her sad; she cannot move easily because of shooting pain in her knee. She says she troubles her sister and feels bad about this.

“Whenever my sister wants me to visit her, I always refuse...I can't go because of these legs. The truth is, I don't want to trouble her. She will hire a car to pick me up, sometimes my other sister will send her car for me and the driver will drive me here and there. Oh, I couldn't trouble them...but they insist, and I feel bad when I keep rejecting their invitations.”

Physical deterioration is one aspect that causes emotional disruption in participants' lives. Losing endurance, Trias says, make her feel physically incapable to mingle and socialize with her family. It is a common practice in Javanese communal gatherings that people spend the whole night chatting to maintain closeness and harmony within the family. As a former traditional singer, Trias could sing at the traditional puppet show all night. Now she easily gets dizzy and this condition makes her feel bad. Therefore, when her family comes to visit her, she will make an exception in an effort to please them:

I used to stay awake the whole night and chat with my family, but now I can't do it anymore. However, if my mother is here I will accompany her to watch a traditional puppet show. I couldn't turn down her request and make her upset. Same thing when my youngest brother is here; we walk around the town until morning and explore the traditional foods ... I just need to take a long nap to maintain my energy and strength. (Trias)

Exhaustion (*loyo*) is discouraging for these women, they explain. When an individual feels *loyo*, he/she just sits for a long time, doing nothing (*mbegogok*) while letting their mind wonder (*ngelamun*). Hartuti also sometimes cannot resist this urge to do nothing, but she has gotten used to this laziness. She says she is sorry when she cannot be heavily



involved in the cooking preparation at her lamb satay stall (*warung sate*), especially because it is a family business. Her satay stall is very popular throughout the village and sometimes people come from different cities to taste her cooking. During the fasting month many people come to break the fast at her stall and on the day I was there, Hartuti was busy preparing soup for the lamb curry (*gule kambing*, the Javanese traditional version). I was amazed, because her blood sugar level was 500 at that time and she was still recovering from hyperglycemia after being hospitalized for a month. She said:

I feel bad if I just sit here doing nothing [*mbegogok*] while my husband and my daughter are busy preparing everything in the kitchen. I feel renewed because I just *mbegogok* all the time, but it's not good. I feel lazy. Besides, I need to prepare this special curry soup and the lamb's head for the curry [*gule*] ... I still need to taste all the food, just a little [laughing] to see if the seasoning is right. This is a complex Javanese dish; [we] must be careful with the ingredients. (Hartuti)

***Engaging in self-sacrifice.*** Sacrificing individual health needs for the family's collective needs is a prominent theme that emerged from participants' narratives, described as part of controlling their inner distress and uncomfortable feelings. In the Javanese family, self-sacrifice is seen

as the habit of obediently giving in (*mengalah*) and is considered a key factor in keeping peace and good relations with others. It is also seen as a form of respect and understanding. Being poor with little education, Dinuk explains that she feels ashamed when she disturbs her youngest sister with her problems:

I really don't know what sugar disease is. I thought it was hemorrhoids [*wasir*]. I've not seen a doctor since I had a blood sugar check five years ago. My youngest sister bought me the medicines and food supplements for diabetic people, but I couldn't take her kindness anymore. I feel awkward [*pakewuh*], because normally the oldest child should support the youngest and not the other way around. So, I stopped taking the medicines and supplements. I couldn't afford it, besides my children still need lots of money. (Dinuk)

Dinuk knows that her children and her husband do not consider her disease to be chronic, so, "Nobody cares about what I do." To support her family economy, Dinuk works for her youngest sister, looking after her children while she and her husband are working. As Dinuk explains,

She helps me with our economic problems, so I repay her kindness by looking after her kids and cooking for her family ... In a big family like this, we should help each other. I get some money for

what I do and it helps our economic condition. I can't just rely on my husband when we have so much to cover, including social costs.

After a short pause and a deep breath, Dinuk explained that she is worried about her condition:

My health worries me a lot actually, but...I try to let it go. I calm myself down by having a chat with my kids or sister. My kids will help me with the chores, take me to the community clinic [*puskesmas*], and sometimes give me some money ... I'm tired and sad, but I need to be patient because I want to buy a house. This is not mine. It's my oldest brother's house. I just look after it for him, because his work is located on a different island.

Self-sacrifice also emerged from Cahya's story, above. For her, it is her devotion to her husband and her responsibilities as a mother that matter. Losing her identity and financial independence are two things that Cahya has to deal during the past ten years. She has learned to be patient because, she says, it is the only thing that keeps her going and keeps her family together.

Another aspect of controlling emotions that emerged from participants' stories was learning to let things go and surrender to God. Laili owns a small but successful catering business, but she feels desperate

now because her only daughter and her children decided not to live with her anymore. “She asked for permission to visit her parents-in-law and celebrate the first week of fasting with them, but when I called her and asked her when she would be back, she said that she had decided to stay in that city.” Laili was shocked, as she expressed, “I’ve been thinking hard since then but I can’t figure it out [*mbathek*].” Her blood sugar level increased and Laili was hospitalized. When I asked about how she feels, she laughed and replied, “I feel tired...too much money perhaps! I have so many jobs lately and also I don’t feel [emotionally] well [*penggalih mboten sekeca*].”

Laili use the word “feel” or *rasato* express her sadness and disappointment about her daughter’s decision. In the original transcript, Laili expressed her sadness by saying, “*penggalih mboten sekeca*” which literally means her heart and feelings are not good. Laili hides her anger toward her son-in-law, although she says this man is irresponsible and jobless. She does not want to hurt her daughter’s feelings, but Laili is also afraid that her son-in-law will abandon her daughter and grandsons. Laili decided to call her daughter the day before I came and ask her to come back. With a sad voice, Laili explained, “My daughter said that her husband wants the children to move to that city, but who will pay for the school? He is jobless! While he was here, he asked for money from me

everyday to buy cigarettes. I tried to be patient, because I don't want to hurt my daughter, but this man...he has no shame!"

Laili's mother's companion calmed her feelings and Laili was able to gain her strength back. She laughed a lot that day, although sometimes I saw an empty look in her eyes as her mind perhaps drifted to her daughter and her grandsons. At the end of my interview, I asked Laili if she would call her daughter again and ask her to come back. She said, "No. She chooses to be with her husband and that's her right. I miss my grandsons a lot ... They cheer me up and make me happy, but I can't force them to be with me. I have my mother here, I'll be fine...I'm just not ready."

Being the breadwinners in their families, poor women in this study explained that the ability to control their emotions is important to keeping their spirits (*semangat*) up and staying healthy. They cannot afford to lose their jobs because of diabetes. Among these women are Nana and Nasirah. Nana was shocked when she was diagnosed with diabetes a year ago. "I felt depressed, I did...because I support myself. When I feel depressed I just stay as quiet as possible." Nana was 37 at that time, with two small children and a jobless husband. She said tried so hard not to show her feelings and her illness to the children and her friends at work. Nana said:

After I get home I usually feel very tired, dizzy, weak, and even almost fainted, because I hold the pain in all day. I don't want

people to see me as a sick person and I don't want to disturb others with my condition and become their burden ... I still want to look after my children and I'm the one who controls everything in my family. I do the chores and I also work to financially support my family. I have a big responsibility. (Nana)

In the narratives, Nana expressed her fear and concern about her children's future. At the same time she faced a dilemma: She is unable to admit her sickness because of her economic burden. As a result, Nana tries to control the disease herself.

I'm afraid that I financially can't pay for the medications. It costs a lot of money to visit the doctor, do a routine laboratory test, and buy the medicines. In my solitude, I cried. I feel so afraid. I don't want to lose my job. So I started to manage my diet on my own. I came across an article from an old science magazine about how to manage my blood sugar level to keep it normal.

So far, Nana has been able to manage her diabetes and reduce her weight from 80 kilograms to 55 kilograms in a year. Her blood sugar level was decreased from 225 to 120, a normal level, according to her paramedic friend. With two small children, it was hard for Nana to stick strictly to her diet, saying that she just needs to be patient with her children and keep them happy.

Previous studies related to diabetes and the stigma that too frequently accompanies it have found that there are certain social stereotypes of individuals with diabetes (i.e., obesity, unhealthy eating), but this is not the case in Java. Nur was the only participant who talked about social stigma, and that was because she is a widow, forced to negotiate her health needs with others. In her small city, religion and culture are mixed and they influence the way people perceive things, including how they view widows. To maintain her health Nur enjoys a morning walk because it is cheap and easy, but people's reactions were beyond her expectations:

It's hard to be a widow here. If a widow takes a morning walk, people will talk about her as if she's trying to attract male's attention by walking slowly! [laughing] You know? I'm confused—when you do a morning walk, you want to walk slowly and enjoy the fresh morning air. I don't know why people have a negative perception of a widow. So I can only take a morning walk if there is a man accompanying me. (Nur)

Although she is sad about being stigmatized in that way, Nur said she does not want to humiliate her family, so she decided to do a different sport. "I decided to ride a bike. It is faster and after the morning exercise, I can always continue with the Quran teaching schedules. So, I ride my bike

throughout *kampong!*” Nur also mentioned that controlling emotions is the key to a happy life, especially for a single parent like her.

It doesn't mean that when you grow older and your children grow bigger, you think less than before. When my children are happy, I'm happy. When they're sad, I'm sad. It's what's inside here [heart, *ati*]. Heart [*ati, rasa/feelings*] is the source of all illness. When you think too hard [*pikiran jero*], you lose your appetite...I think diabetes is about your heart, it's the disease of the heart.

(Nur)

***Finding solutions that fit (cocok)***. How well solutions for diabetes management fit the lives of participants appears in several narratives, along with ways to balance their internal and external conditions in dealing with their sickness and everyday lives. Sometimes what fits according to participants does not always fit with others' concept of a good solution. In this situation, “fit” involves the inner part of one's emotion (*rasa*), which connects the soul (*batin*, inner part of an individual) with one's physical condition (*lahir*). *Rasa* is the part of an individual's life that needs to fit with the rest of day-to-day life.

A salient theme that emerged from the narratives is related to finding the right fit by using the local male paramedic (*mantri*) for their diabetes treatment. It is common in many small villages and remote areas



in Indonesia that the *mantri* is the main health resource for the people. Three main reasons why participants in this study “fit” with *mantri* are: (1) the cost of the treatment and medicines fit with their economic condition, (2) *mantri* typically live near the villagers, so it fits with the limited time they have available and when the *mantri* is within walking distance, these women do not have to rely on others for transportation, and (3) the way *mantri* treat these women fits their expectations and is comfortable for them; they indicate they are more scared or anxious to talk to a doctor than *mantri*.

Suryo’s children do not allow her to go too far from the house. They say that *mantri* is a good fit for their mother; they are comfortable with the way he treats Suryo and the family:

I have seven children—five of them live out of town and two are here with me. My youngest daughter lives with me in this house and her older sister has her own house not far from here. I don’t know what happened to my daughter...I thought she just fell in the kitchen but it turned out she can’t walk anymore. Her wound became severe and created a hole in her body. *Pak Mantri* helped us. He and his wife had always been so nice, patient, and always check on us when he has time. My other children call *Pak Mantri* or his wife to ask about my condition, the medication that I need

and also about their sister. So, I've been relying on *Pak Mantri* for a long time. (Suryo).

Jati, Suryo's maid added: "*mantri* sometimes explains many things about food and diet. Although I didn't understand and didn't care, he keeps telling me the same information again and again...I guess he's very patient with me," she said, laughing.

Renggo feels this fit with *mantri* because it is affordable for her. "I'm a poor woman so I must be careful with money, but so far the treatment at *Pak Mantri* is affordable. I can get treatment, blood sugar check, and medicines for a cheap price."

Marni and Yatmi tell similar stories to those of Renggo and Suryo. Marni said, "*Pak Mantri* is like our own family. He will call me to see if I need him to come and check my health. He knows that sometimes my blood sugar level is quite high, so he wants to make sure that everything is fine." Yatmi confirmed what her sister, Marni, said. When Marni suddenly fell in the bathroom due to hypoglycemia, Yatmi easily reached *mantri* on his cellphone. "I was shocked and quickly called *Pak Mantri* and he came very quickly with the ambulance to take my sister to the hospital." Because of her economic condition, Yatmi prefers to see *Mantri* for her regular check up. "I feel secure and comfortable with *Pak Mantri*...he knows what I need. Besides he's like family to me."

For villagers, *mantri* is a reliable person; they can count on him whenever they need help. He is the main source of health care assistance for these villagers, in spite of economic limitations or family problems. Participants explained that the family members also feel secure with *mantri*, because their mothers or their wives are in good hands. Having someone they can rely on in this way eases participants' emotional burdens and lightens their minds, both preconditions for attaining a peaceful state of mind and a healthy body. Mahmudah added:

*Pak Mantri* works at the state hospital, so if there is an emergency he can quickly call for help. One day I felt itchy all over my body, so I went to *Pak Mantri's* house to get an injection. The next morning, I had fever and felt sick all over my body. My son contacted *Pak Mantri* and he quickly asked me to come to the hospital to be examined.

Mahmudah said that her youngest son is secure leaving her alone in the house while he goes to work everyday. "If something urgent happens, I can always walk to *Pak Mantri's* house or call for traditional transportation (*becak*) to take me there. My other child also knows how to contact *Pak Mantri* just in case I can't make a call."

The second form of "fit" that helps participants maintain peace and harmonious conditions within their families is the fit between family

economic condition and the selection of treatment. I noted that in their narratives, some women had some disagreement with decisions, but they indicated they prioritized other family member's needs and interests above her own. Cici says that her urgent urination is because of her diabetes and this makes her and her husband uncomfortable. She says,

I don't know how to explain...I have to urinate five, six, to seven times every night. Especially after we go outside or travel out of town, I can't hold it. Most of the time even before I get to the bathroom my urine is already all over the floor and my husband will help me clean it. So he and my sisters suggested I wear an adult diaper because I often travel with my choir friends from church to different cities. I feel very uncomfortable with the diaper, but I don't want to trouble anybody. (Cici)

Cici does not understand why her medicines don't cure this symptom. "I don't understand, because I drink my medicines everyday. Is it because of something that I eat? I know sometimes I cheat on my diet." Cici decided to seek alternative medicine, because she did not want to put more burdens on her husband. She tried various herbal drinks and found one that fits her needs. "Sometimes I really can't take more medicines. I have had enough, plus I don't always have money to buy the medicines, so I tried a few suggestions from my friend and it turned out that I fit [*cocok*] with herbal

drinks made of Javanese bay leaf and red betel.” Herbal drinks (*jamu*) are cheaper than the medicines so she does not have the extra cost. In addition, her husband does not have to worry about her sudden urination in a public place or public transportation.

Sakirah did not challenge her husband’s decision when he asked her to stop selling foods at the local market, but she said she was disappointed with this decision. “I can’t help the family now, I just rely on what my husband gives me.” She decided to make peace with her condition and not to question what happened. For medication, Sakirah decided to combine a religious approach with Javanese traditional herbal drinks (*jamu*). From the religious perspective, Sakirah said that fasting purifies her body and soul. “Whenever my blood sugar is high, I always fast every Monday and Thursday. I feel healthier. So when I’m healthy, I will fast more often.” Regarding the herbal drinks, Sakirah tried whatever her friends or relatives suggested to her. “I’m a stupid woman, I don’t know anything about herbal drinks. I will try everything, until something works. My blood sugar level has decreased and my wound became dry.”

The third form of fit that emerged in the narratives was matching family members’ unexpected needs with participants’ abilities to fulfill their own needs. This includes social obligations and costs that a family must fulfill to maintain social relations and peace. To be able to achieve

“fit” for this particular issue, a woman is required to have a strategy that fits the family’s resources. Traditions and culture pressure members of a society to be a certain way, to think a certain way. Unfortunately, as part of collective beliefs, one cannot simply reject what has been agreed to by the society-at-large without risking social costs. With the financial costs of diabetes, participants are hesitant to spend money on social costs when they don’t have the money for the medicines they need.

Asih realizes that her husband is the oldest son in the family. After his parents died, the family members will come to her house for the Eid feast. Although Asih indicates she does not particularly like to cook lots of food that “will be gone in a blink,” she nevertheless prepares everything herself to honor the guests and the sacred day, saying:

In this house I try to prepare the feast for the extended family and guests who will come for the Eid feast. However, I told my husband that I don’t want to serve *opor ayam* [a traditional chicken dish served at Eid], because I don’t have the energy to cook this complicated food, and besides it’s full of cholesterol and I can’t eat it. People just come and go, they grab the food, drink, laugh, and leave. So, I always prepare two easy dishes in bulk—*soto ayam* [clear Javanese chicken soup] and *sambel tumpang* [beef brisket cooked in a thick liquid of overripe tempeh and coconut milk]. It’s

enough to entertain my husband's extended family members and grandchildren. So, I still have the feast, but with an easy menu.

(Asih)

In her story, Asih accommodates her physical ability and health condition and still does all of the preparation herself for the Eid feast tradition in order to meet her husband's family's expectations. Although her menu does not seem to fit with the Eid celebration, the amount of food that she prepares fits the expectation of having plenty of good food.

Finding a strategy to avoid having to eat food served at family gatherings, communal events, or religious celebrations such as Eid is not easy. Laras discusses this with her children and they came up with the most "fit" strategy. It is a tradition in Javanese society that people will eat the food served at ceremonial events or religious festivities. During Eid, usually the first day of Eid, the youngest family members visit the homes of the elderly family members one by one. Asking for forgiveness, they chat, and eat. For individuals with diabetes, such as Laras, this can be dangerous, yet avoidable:

I need to find a proper and fit strategy to control others and myself from pushing me to eat. This is a family event, so I can't make an excuse for not visiting my relatives. Usually, after I had some food at one family member's home, I will apologize for not being able

to eat more at another family member's house, but you may offend the host. So, my children and I use this strategy: we will take a tip of a spoon of each food and place it in our plate just so to make it look dirty, so people will think we ate the food. Nobody pays attention anyway, right?

Laras says it is hard to pretend in front of family members, because they put a lot of effort into cooking all of the food. It is even harder when she has to go to her husband's family.

Attending family events like Eid is one example of social obligations upheld by the Javanese. However, the culture of exchanging gifts (*nyumbang, munjung*) is perhaps the most difficult to negotiate and to avoid in Javanese culture. By not returning gifts, a Javanese is considered to have a debt to their neighbors, family, or friends. Kristin says she feels exhausted when she has to deal with social events. Sometimes she has to argue with her children because of this tradition. Being a poor family in a big city, Kristin had to balance her needs and her family economic condition with this unexpected social cost:

My son just got married few months ago, and now I have received a circumcision invitation from my neighbor. Now I have to recall how much money my neighbor put in his gift envelope during my son's wedding. If he gave 50 [50 thousands Rupiah, about \$5.00],



we should give him the same. It will be humiliating if we don't attend the communal gathering [*slametan*] and don't send our gift to them.

This social exchange tradition creates pressure for participants. Not only do these traditions increase their expenses, these informal ties and the gift exchange process can also affect family honor. From the narratives, women explain their dominant role in negotiating solutions for meeting these unexpected social expenses. Women make decisions about how the family will fulfill these obligations. In their stories, participants explained that these social traditions drain their savings and challenge family harmony. Kristin, for example, said that if she has to send a gift and there was nothing left in her savings she will call her children and ask each of them to send some money for that purpose. If they refuse, Kristin and her husband use some money set aside for medicine.

Sometimes we have lots of gifts to give at the same time that we both need to buy our medicines. So what I do is cut our food budget. The most important is to buy a sack of rice and cook simple dishes, like tempeh, shrimp, sweet soya sauce, and sambal.”  
(Kristin)

Titin has only her own income to fulfill social obligations. She cannot afford to spend money she needs for her daily expenses for these unexpected gifts:

I have to carefully secure my income in different small boxes.

Thank God [*Alhamdulillah*] I can do it so far [but] these social costs make me stressful. It's a lot! You know that? I can't believe it... [money] just drains from my pocket. I could have used that money for something else important, like paying electricity bills.

(Titin)

These women also said they feel guilty if they cannot fulfill these social obligations. Cici, for example, said, "When my sister's daughter got married, I had to send a gift to her. But sometimes that's the only money I have and I need it to buy diabetes medicine. But she is my own sister and I feel so mean if I don't give her anything. I have to maintain good interaction with my sister." The problem gets more difficult if a woman lives with her in-laws, because it may create a perception that a daughter-in-law is not capable of managing the family money. This is the situation Warni describes:

So far, I can manage my husband's income for our everyday needs.

I just need to spend it wisely. What you can't resist are these social events, gatherings, circumcisions, or weddings. I can't afford all of

these, and sometimes I have to use my health savings, but I won't tell my husband or my mother-in-law. I usually talk to my mother and she will help me out with this problem. (Warni).

During special events like Eid, social obligations often increase. Suprih explains:

It's not only that you need to prepare all of these foods and snacks for the guests, but you also must wrap something for them because they bring something for you. It's such a waste of money and I'm really concerned, but you don't want to humiliate your family by not preparing anything. Well, I just need to carefully select the most economic ingredients for this purpose. (Suprih)

Participants' stories about seeking the right fit (*cocok*) within the context of interactions among the wife/mother and her family members lead to a discovery of a hidden power that these women have in managing their household affairs. Rather than using rationality as their strategy, these women use their feelings (*rasa, ati*) to sense problems and guide their actions.

### **Diabetes challenges established family roles and responsibilities.**

Classic studies about the roles and positions of Javanese women within the family and society point out that women play a dominant role in

household affairs (H. Geertz, 1961; Koentjaraningrat, 1960). This female-dominated arrangement appears in participant's narratives related to diabetes and the challenges posed to the participant, her family members, and the roles and responsibilities she has. At the same time, the narratives also reveal the entrenched dominant attitude of Javanese men in responding to participants' sickness. Women's perseverance and persistence dominate rural women's stories about their illness experiences, and reveal great degrees of both the desire for and the attainment of self-reliance.

Participants strongly agreed that as women and wives they play a lead role as caregiver for the family. Participants discussed the need to ensure the harmony of the family through meeting the emotional and financial needs of the family are met, along with managing all household and social obligations. In this environment, when the lead caregiver of the family is diagnosed with diabetes, established roles and norms in the family are challenged. Conflict about family roles and responsibilities centered on the attitude of concern for others and empathy (*tepa selira*) as mentioned, and participants' expectations toward the Javanese principles of interdependence and reciprocal assistance.

***Concern for family members.*** The term tolerance (*tepa selira*) means one's awareness of his/her own limits, and the ability to control

his/her feelings for the sake of others. With diabetes, many participants explained they sometimes lost their spirit (*semangat*), i.e., the power over themselves, and power to ensure the fulfillment of their responsibilities. Javanese women in this current study perceived power as vitality, energy, and strength to effectively manage themselves, their families, communities, and to deal with day-to-day problems and tasks. These power and responsibilities are, specifically attached to Javanese women, and commonly known in Javanese language as *mrantasi*.

Being sick means one temporarily or permanently loses this ability. The women explained that while the diabetes symptoms sometimes suddenly appear, but even then, the participants said they wanted some understanding and empathy from the family members. Puspa, for example became irritated with her husband's superiority and ignorance, saying:

I know this disease is my responsibility, but nobody wants to have it even when they knew that they had a risk factor. So far, I still perform my duties as a mother, a wife, a grandmother, a midwife...nothing has changed. I'm the one who traveled to Jakarta and looked after my daughter and her newborn baby for a month. My husband is also a paramedic and he knows my condition, but it's not about that. Both my husband and sons

passively respond to my situation. They don't fulfill men's roles, to look after the house and make sure everything is okay.

In her narrative, Puspa also shows her disappointment toward her sons' attitudes. "My children are only concerned with themselves...they only say, 'We are so sorry mom' and that's it." These are the reasons Puspa gives for her need to be self-reliant. Having a motorbike, Puspa is free to make decisions in her life. "I'm free! I can go to my diabetic exercise activities, see a doctor, do grocery shopping, and meet my friend by myself. I don't have to rely on others."

Jeki and Nana do not expect their husbands to understand their disease. However, both of these women said that being sensitive does not require knowledge. It is a matter of empathy, of *tepa selira*, a matter of *caring* about her diabetes rather than *knowing* about the disease. Jeki said,

I don't know why my husband is not able to respond to my disease.

He knows about this disease, but he's being ignorant I guess.

Obviously nobody in this house shares the same burden and fate as I do, but sometimes you need an opinion. I need to see a specialist about this disease, because I haven't consulted with an internist about my health since I was diagnosed with diabetes three years ago. My husband and my children know about the complication

that I have here in my leg (pointing to small bumps on the bottom of her left foot], but nobody asks or suggests anything to me. (Jeki)

Jeki realizes that her husband has not provided financial support to her and the family since he was forced to leave the job due to a financial crisis, but what Jeki wants, she explained, is the emotional attention from him and the children about her condition.

Nana describes a similar situation. “I have a husband, but I feel as if I have no husband. I told him my condition, but his reaction was flat and dry as if he doesn’t have feelings.” Nana wasn’t asking for very much attention; she hoped her husband would at least ask, “What medicine did you get?” or “Is it expensive?” As the breadwinner in the family and given her health condition, Nana said she hoped her husband would help her with some of the chores and watch over the children. Yet, he doesn’t do that either, she says. “I won’t fight him. I don’t want to disturb people with my condition and become their burden. I still do all the chores myself.”

Some women in this study mentioned their relationships with their sons- and daughters-in-law and how they apply the concept of tolerance with them. Partinem and her husband are poor. Having blurred vision, she cannot manage the house as she used to. This couple does not complain

about their lives, rather their concern is for their children. Partinem explained,

My husband sometimes has to go to the small forest (*alas*) to get some grass for other people's kettles, but often he cancels it because he can't leave me alone in the house. I never complaint to my children...well, what can you say? When you have girls and they live separately from you, there's nothing you can do. If their husbands allow my children to come and visit us, it's okay. I don't want their husbands to feel that we disturb them. So, it's just my husband who looks after me now. (Partinem).

Given their economic condition, Partinem is not always able to buy medicine and with physical deterioration, she cannot cook for her husband. So, everyday she and her husband buy food outside or just eat instant noodles. When I asked her if they can contact their children so that at least they can share food, Partinem quickly replied, "Parents must not ask from their children or their children-in-law. If children care about their parents because they feel it from the heart, it's okay. If not, I will never ask for help." The feeling of longing and loss was highly apparent, because Partinem hugged me and held my hands during the interview.

According to Partinem and her humble husband, people should have an awareness of their surroundings to be able to show their tolerance



and understanding about other's difficulties. Tolerance, empathy, and concern for others (*tepa selira*) cannot be forced, but can be learned. That is why Partinem and her husband do not want to contact their daughters for help. Partinem added, "It's not about money; it's about being cared for, cared about. I feel lonely because I rarely seen my grandchildren. They make me happy." So, sometimes Partinem lets the small kids from her neighborhood play in her front yard. "Being cared about," as Partinem says, represents warmth, affection, and comfort. The feeling of missing and longing for attention was considered by participants as the actual cause of diabetes, i.e., sickness of the heart/soul (*penyakit ati, hati, manah*).

***Interdependence and reciprocal assistance.*** Some participants in this study recognized interdependence and reciprocal assistance as the ideal values and foundation of family relationships in the Javanese culture. Kristin and her husband provide a rare example of a couple that has struggled with diabetes for 20 years. Both of Kristin's and both of her husband's parents had Type 2 diabetes, so Kristin is very aware that her six children have a strong possibility of developing this disease someday. Managing the household with limited resources and living with a chronic disease, Kristin must educate her family members to watch over and help each other.

My husband has to be hospitalized very often because of hypoglycemia and his wounds; he has wet diabetes ... My husband does not have a pension, but the children support us every month with food and health checks. Not much, but it helps ease our minds.

In the same house, Kristin lives with her youngest daughter and two grandchildren who have lived with them since they were babies. With her condition, Kristin needs help from her children, especially when her husband has to be hospitalized.

Each of us has a schedule to stay with my husband in the hospital, because someone has to accompany him. Some will help me in the house. We don't live in isolation; we have to care for each other and help each other. These two kids, now they can recognize the symptoms. So, when my husband is startled or half conscious, one of them will yell at me, and his sister will get sugar water and pat my husband's cheek. (Kristin)

If one of her children has a family problem and is a little bit delayed in sending her money, the other children will help. However, Kristin and her husband do not want to live with their children. "It's better to live with my husband; this is our own house. If we need anything, I only need to call...especially if we run out of medicines." Kristin added,

“I once looked after them and nurtured them. Now that we are old and sick it’s their turn to care for their parents. Later when they are old, their children will look after them. It’s a cycle of life.”

As a widow without children, Murtini relies on her youngest sister, Yatmi. Both of them have diabetes, so these sisters look after each other. Financially, Murtini has better economic conditions because she was a kindergarten school headmistress. “[Yatmi’s] husband is just a factory worker and she doesn’t have a house to live in, so my sister and her family live with me. I’m lucky to have her, because she does all the chores and cooks for me when I have to be hospitalized due to hypoglycemia.”

Yatmi is actually not very healthy herself, but she says that her condition is much better than Murtini, so she doesn’t complain about it. Yatmi says,

We both had diabetes for five years now. It’s funny that after we had a blood sugar check, we compared with each other to see who gets the highest score (laughing). My sister helps a lot. Can you imagine? Seven family members live together in this house. I don’t do much work here, most taking care of my sister and looking after my grandson.

Yatmi says that she realizes her family members have to work everyday, from very early in the morning until late at night, so they do not help her

with the chores. She feels bad about this, because it is her sister's house. "None of the men in this house do any housework; they always leave early." Murtini calmed Yatmi down. "It's okay. They work to get some money. You cook and do everything in this house yourself; you wake up early in the morning, while I can only sweep the floor because of my condition."

For Murtini, this is about moral duty and family relations. As the oldest sister, Murtini has a responsibility to her less fortunate sister. The presence of Yatmi and her family provides emotional support for Murtini, so she indicates she feels more secure. At the same time, being able to live in her sister's house provides Yatmi with a sense of security and protection (*pengayoman*), as she explained.

Sunarsih and her family do not know what diabetes is. She is poor, and does not know what caused her disease or how to cure the disease. She has had one finger amputated from her right hand because of diabetes. The decision to amputate the finger was hard for her, but her family supported it. "If this can cure your disease and make you live longer it's okay. Don't worry." Sunarsih's main concern was not her finger, but the housework. As traditional farmers, men are in the paddy field all day, so Sunarsih looks after the house, cooks for the family, and takes lunch to the her husband and son around noon. She explains her feelings: "I did ask for

my family's permission for this surgery. We are farmers, so I have big responsibilities in the house. I'm glad that I had the amputation, but I feel...confused and dizzy, because the house looks disorganized and unmanageable. When a woman is sick, things get out of control.”

Sunarsih's husband, son, and daughter-in-law help her with the chores. Her son washes the clothes, her daughter-in-law cooks for the family, and her husband brings firewood to the kitchen. Because her husband needs to work in the paddy field until sometime in the afternoon, her oldest son takes her to the hospital for post surgery check ups. The youngest son lives out of town, so he cannot always come.

Being unable to perform her duties as a mother and a wife makes Sunarsih sad. She said she feels that she disturbs everyone's life. “I can't lift up the pan because I can only work with my left hand. All this time, I never asked for help in the house, so I feel a little bit awkward when suddenly I have many people in the kitchen.” One thing that Sunarsih will never let her husband does is wash clothes. As she explained, “I told him to go to the paddy field and I will do the washing with one hand. My husband said, “Do you really want to do this?” and I said, “Yes.”

Sunarsih's narrative describes a struggle between a humble village woman and the changing role and responsibility in her family. Being a poor farmer, Sunarsih had always been self-reliant and independent in

order to manage her limited sources. Her reaction toward the support that her family gives her shows Sunarsih's emotional complexity in dealing with diabetes. She learned to accept this condition, saying, "If my husband is able to neglect his job for me, it means he and the others don't blame me for this. So I have to get well soon."

### **Cultural Adjustment to Type 2 Diabetes**

Participants' stories are dominated by their explanations about the importance of maintaining peace and harmony to have relationship satisfaction. However, harmony is not always possible. It is continually challenged and influenced by three main conditions, as described by participants: 1) the cultural expectations for women, 2) Javanese health beliefs and perceptions about diabetes, and 3) the interactions among women and family members. The presence and absence of diabetes symptoms as described by participants, placed this disease somewhere between short-term illness and chronic disease. Short-term illness on the one hand, because there are occasionally periods of time when participants feel cured (*sembuh*) and healthy (*sehat*), although sometimes they experience symptoms similar to a common cold (*masuk angin*) or conditions typically related to the participant's age. On the other hand, diabetes is considered a chronic disease because participants may suddenly experience recurrent symptoms (*kambuh*) that require them to

consume medicines and/or traditional herbal drinks to relieve symptoms. As a consequence, some participants consider diabetes as not such a serious disease, one that can be cured with two things: managing diet and managing the heart (*hati, ati, manah*).

Despite their socio-economic status, participants were controlled by the same social structure that prevents them from rejecting their designated roles as managers of household affairs. In addition to the roles described above, two more roles emerged from participants' stories: those of wage earner and strategic thinker. As wage earners, women contribute, often substantially, to the family's income. This role is more common for rural women. While many rural women work as market traders (*mande*), others earn money as tofu makers or traditional massage ladies. Suprih, for example, has worked as a traditional massage lady for 20 years,

My husband struggles for us, but his work as a grave caretaker doesn't provide him with a fixed income. If people who visit the grave give him some money, he'll get some. If not then it's okay. We tried to encourage him, but he doesn't want to try another job. May his good deeds bring blessings in his afterlife. With this condition, I'm the one who has to struggle and is being squeezed [*diperas*] to get some money. If I don't work, how can we eat?  
(Suprih)

When her husband was sick for almost a month, the family had no income for almost two months, and Suprih became the breadwinner for the entire family. Usually, she received some financial support from her oldest son, but since he and his wife had a traffic accident, she says she is reluctant (*pakewuh*) to disturb him. Her daughter's economic condition is not better than hers, so she does not want to disturb her either. Thus, her massage service is the only source of income for her family. She already had diabetes when she started working as a therapy massager, and to maintain her strength she consumed traditional herbal drinks (*jamu*).

Thank God [*Alhamdulillah*], there are many people that fit [*cocok*] with the way I massage them. I don't do massage for tired therapy, but to help people who have had problems such as twisted or pinched nerves. So, it takes one to one-and-a-half hours to massage one person. (Suprih)

Besides her role a wage earner, Suprih is still the caregiver for her husband, doing all the household chores as well as being a strategic thinker in order to manage her single income to fulfill unexpected needs such as Eid celebrations and other social costs. "I have more time to rest this month, because all my children are here for the Eid holiday. Still they don't bother to help me with the chores."



Rural women in this study expressed their highly salient concern about the importance of having a job and being financially independent. For these women, independence means: 1) being self-reliant, 2) being persistent, 3) being strong, and 4) being responsible. Javanese women described being strong and responsible as the ability to perform multiple roles with minimum assistance and with reliable results (*mrantasi*). Ninik explains,

It is important for husband and wife to have their own incomes...I've been working since I was young, so my husband doesn't mind at all. Throughout my marriage, I've never asked for money from my husband. He offered me some money for my medication after our baby was born. I'm thinking of sharing the household expenses with him now, though, because I have to buy medicine and we also had a baby. So, if he can help me with my medication, I can use my income to buy milk and other baby's needs. The problem now is my husband's income is allocated for utilities and our second child's school fee.

Being flexible is required for Ninik to get additional income. Ninik's oldest daughter helps her to look after her baby brother and buy him some milk and clothes whenever she gets some money from her husband. "Now, I take double shift. I go to the traditional market in the morning and

afterwards I will sell crackers throughout the village. I just need to be flexible so I can do different jobs to have more income. (Ninik)

Ninik explained that spirit and energy are two important keys to moving past difficulties. “People say that this disease cannot be cured. The medicines will only help me to bargain on how long I can survive...It’s up to God. The most important thing is never lose your spirit and energy...and stay healthy [*waras*].” In the original transcript, Ninik used the Javanese word *waras*, which in English has only one meaning: healthy. *Waras* for Javanese refers to being healthy psychologically (*jiwa, batin*) and physically (body, *raga, lahir*). Only when an individual is *waras*, will he or she be able to make good decisions to solve the problems of life and to help others. As Ninik said, “You will be able to find a solution so your children and family will not be neglected (*kapiran*).”

Titin has a similar story to Ninik’s. In her family, Titin plays multiple roles as a mother, a caregiver for her sick husband, and a strategic planner. For Titin to be able to work and be financially independent makes her comfortable. She said,

When I feel sad, my blood sugar level will increase. So, I consider my job as a solace to my hard life. Whenever I go to pick up my neighbors’ kids at school, I’m having fun with myself...riding my

motorcycle. I provide school transportation service for my neighbors and they pay me once a week. Not bad and I'm happy. I'm not complaining; it's my path of life. (Titin)

Ninik explained that she must be flexible to do all kinds of work (*ubet*) and not be picky. Ninik says she is comfortable doing her job, although it makes her tired. "I can buy my own medicine and I can save money for different purposes ... unless I have no money."

Self-reliance also represents a continuous struggle and a personal character of not easily giving up. Laili does not have anyone to support—her husband died, and her only daughter is now moving with her husband to another part of the Java islands. She is completely on her own, but cooking is her hobby and she loves cooking for others. Being self-reliant makes her strong, she says. "As long I'm healthy, as long as people need me, and as long as I live, I will keep working. I'm lonely and stressed out, but I have to live. My mother said to me the other day, 'Life is never easy and if you want to be happy, you have to struggle.'"

Related to age, self-reliance is not a privilege of young, strong, and married women. Older participants such as Sayuti and Renggo, explained that being able to work in their old age makes them happy and gives them confidence to make decisions without depending on others. Sayuti said, "Thank God [Alhamdulillah], I'm happy to be healthy and able to go to

the market everyday. I don't have to burden others. My kids have their own lives...but I enjoy going to the market and meeting my friends.”

While Western doctors state that having a high blood sugar level means that an individual with diabetes must be aware of their health, Sayuti's concept of health did not count blood sugar level as a sign of the sickness. As long as she can walk to the market, she thinks she is healthy even though her blood sugar was 400 at that time. Sayuti has been working as a market trader for 43 years and now she has three kiosks that she prepared for her children.

Although self-reliance is not as salient among the urban women in this study, their notions of the self are tied to the similar aspects, such as energy and spirit (*semangat*), flexibility, and peaceful and comfortable feelings. Dina is easily provoked by what other people say about diabetes and being a diabetic. She said she worries all the time, and was not eating anything until she had hypoglycemia. I had to reschedule my interview because she was hospitalized. Two weeks after the Eid celebration, I went to visit her and she looked happy:

My youngest son came last Eid and I was so happy to see him. He is the youngest child, but he is able to support this family and helps us find a solution for many problems. He's so mature. I miss him a lot because he has to sail for several months, so I rarely see him.

When we talked, my son said, “Ma, are you going to spend the rest of your time worrying about your disease? You have a job, and cute twin grandsons. Don’t listen to what others say about your disease; go to see a doctor and I will pay for everything. (Dina)

Dina said that she lost her spirit and energy (*semangat*) because of diabetes. She was haunted by people’s stories that becoming diabetic means you can’t eat anything, yet you still won’t be cured. She stopped taking medicine and took leave from her job. She explained,

I was so frustrated. But then I remembered my twin grandsons. They’re so cute but they have this lazy and irresponsible father who yells at them all the time. My husband doesn’t want to talk to my son-in-law, because he thinks it’s useless and a waste of his energy. But my son-in-law’s presence in this house arouses feelings of anger and disappointment. Sometimes I want to ask my daughter to leave this man, but I can’t do that. If I’m healthy, I can work and spoil my grandsons, buy them cookies and ice cream, or take them to the mall and get them a robot DVD. (Dina)

Because her husband is already retired, Dina and her children work hand-in-hand to support the family. The problem faced by her middle daughter becomes her responsibility because she and her family live in her house.

By having a job, Dina is secure and has the power to control the house and

protect her family. She said, “My oldest daughter and I think that if we have income we can protect the boys should anything happen to their parents.”

For some other urban women in this study self-reliance does not only mean having a job *per se*, but it also means the ability to perform everyday activities despite their physical limitations or age. Darma’s leg was amputated in 2010. She had diabetes for 13 years, regularly saw her doctor for checks up and consumed both medicines and herbal drinks. Darma was shocked and desperate when her doctor told her that he might need to amputate her left leg due to infection. “I felt so desperate. After all the medications and the diet, I have to lose my leg?” Her late husband was a soldier. “That is why I’ve been a full-time mom and a wife for a long time. I’m responsible for the children and the household, because we have to move from one city to another city. I’m used to doing everything by myself.”

Losing part of her body makes Darma’s life incomplete, she says, but, “I can’t lose myself, you know...it’s a way of being recognized as a woman, as a person. I know that I’m a bit slow now, but I can do everything by myself. I prepare my own meals and go to the church once in awhile. I don’t want to be helped as if I am lame.” Darma realizes that financially she depends on her children, but she does not want to bother

her family with daily chores. She said, “I know that you need your children to look after you when you’re old. I am old, but I’m not disabled. I used to look after eight kids, and now it is just chores.” In her narrative, it was important for Darma to show that she still has strength and energy to live her life and perform her duties.

Being about the same age as Darma, Mulyati realizes that being disabled or not, it is just time for them to be looked after by their children. In her explanation, Mulyati emphasizes that selfishness is not in her life value:

I can’t always disturb my children. I still have my husband’s pension and it’s enough for me. My children take care of the household needs, so I can look after myself and buy my own things with my money. Thank God that I can still use that pension money to help my family or others. I’ve been taught that as long as you have strength and resources, you should make yourself useful.

(Mulyati)

In a similar way, Trias and Firtri described that they want a peaceful way of dying, so they will not disturb their families.

Another participant, Renggo, mentioned the Javanese value of making a social and emotional investment in the children as an important thing to do. This emotional investment will equip children with a sense of

mutual understanding and reciprocal assistance that is highly valued in Javanese culture. For Renggo, the reason she keeps working is to make her useful in the view of others. “I no longer have an obligation to support my family. It’s just me, so I can give something to my children so they can do the same in return when I’m no longer able to do anything.”

In a broader perspective, Renggo and other rural women mentioned in this particular discussion count their jobs and their abilities to financially support themselves and their families as an investment for inner peace and harmonious relationships in the long run. The Javanese concepts of health and illness influence the way these women make sense of diabetes and their experiences with the disease. The health state, the sick state, the cure state, and the relapse state are fluid and can best be explained using the word *rasa* (feelings, emotions) that participants use in explaining their experience with diabetes.

Based on participants’ stories, diabetes is seen as a form of misfortune in life caused by disturbances to an individual’s mind, heart, or what participants described as uncomfortable feelings (*manah mboten sekeca*). Thus, participants’ narratives describe a process of first curing the emotions (psychological symptoms) as a way of treating the physical symptoms of diabetes. Self-reliance, as mentioned by many participants, especially rural women and poor women in suburban areas, creates a



peaceful and comfortable feeling, and increases the energy and spirit (*semangat*) needed to meet the challenges of their lives, including the flexibility and strategic thinking to manage family resources.

In describing their experiences with diabetes, participants focused more on psychological symptoms than physical ones. According to Javanese conceptualizations of health and illness, the combination of physical sense and emotional sense is highly subjective from one participant to another. Participants in this study mentioned several symptoms related to diabetes such as numbness in the hands or feet (*gringgingen*), stiffness in the neck, dizziness, weakness, trembling, and a thick feeling on the bottoms of their feet. Compounding the physical symptoms, but dominating Javanese women's experiences with diabetes was what participants explained as uncomfortable feelings (*kemrungsung, manah mboten sekeca*) and thoughts (*pikiran*). Therefore, Javanese women in this study mentioned that diabetes is about the cure of feelings and it is centered on the efforts to calm the thoughts (*pikiran*) and heart (*ati/hati, manah*).

Women in this study play a dominant role in managing household affairs and social interactions among immediate family members, and also between family members and people outside the household (e.g. extended family, society in general). In performing these roles, participants

recognized the value of sensing the feelings of others (*tepa selira*) and having respect for others that improves the ability to negotiate roles and to make adjustment to diabetes while maintaining peaceful and harmonious conditions.

In the social interaction process, continual negotiations are made by participants to ensure the fit (*cocok*) between participants' needs and family member's expectations. Two overlapping approaches to determining "fit" emerged from participants' narratives: (a) emotional restraint through the process of normalizing situations, and (b) avoiding conflict and disharmony.

#### **Protecting emotions, managing the heart.**

Participants in this study describe diabetes as a "disease of the heart" (*sakit hati*). Consequently, participants' efforts to manage diabetes are focused on maintaining individuals' inner peace, and harmonious relations with other. Only by controlling inner peace can one maintain a calm mind and healthy body, according to participants. For some women, having diabetes means restrictions, inability to meet expectations, and dependency on others. These three aspects contribute to complex psychological conditions that participants identify in their stories as anger, disappointment, guilt, desperation, depression, and sadness. These women frequently normalized the situation to keep their energy and strength

(*semangat*) in remaining self-reliant women and maintaining their bargaining power.

Raodah, for example, was diagnosed with diabetes eight years ago. In addition to the numbness in her hands, she describes the lazy feelings that diabetes has brought to her life. *Lazy* in this instance is in contrast to *semangat*, which describes being energetic, a condition that represents good health to the Javanese. Raodah explained:

These lazy feelings can suddenly come and change my mood. I don't want to do anything. All I want to do is sit for a long time and let my mind wonder [*melamun*]. I don't feel like reciting the Quran, watching TV, or cleaning the house ... No interest in doing anything. I feel I have no future. This is a lazy disease. (Raodah)

When I asked Raodah how she perceived diabetes, she quickly responded by saying that diabetes is just "another way to Rome," one more cause of death that she cannot avoid: just another misfortune. A month before our appointment, Raodah was hospitalized for hyperglycemia. A few days before being hospitalized, Raodah was fasting, but she said she was pale and almost fainted. Her son decided to take her to his house, so he could look after her just in case something happened. She described her feelings about her son's decision:

I don't want to stay in my son's house, because I don't feel comfortable living in another person's house. Strange. I lost my freedom and I can't do whatever I want. My son and his wife watch over me all time. For someone with a disease like me, sometimes you just want to be left alone, to have your own time to relax your mind...besides, I have my own activities. (Raodah)

As with other Javanese women in this study, Raodah says she does not want to disturb others. Her children call her everyday and offer for her to stay in their house, but as Raodah said, "I politely say no, because I have my recitation agendas and I have made promises to the women in my recitation club." Raodah expressed her feelings about being moved from one place to another place, saying, "It makes me feel like a wardrobe; they move me here and there, and such a distance!" However, she appreciates her children's thoughts and concern toward her health and this is why Raodah politely rejects their offers—because she is healthy, she says.

Poverty means living with a constant feeling of concern (*prihatin*), and for poor people like Yatmi, diabetes means "living with concern." Feeling weak all the time, Yatmi's husband asked her to close a small grocery store in her house and to stop running her money lending business. "I sincerely accept my husband's decision and the fact that my

health condition no longer allows me to cope with all of these things. Even though I made lots of money from these two businesses, my husband told me, ‘You’re old. Just give everything up and look after your health.’”

Yatmi respects her husband’s decision, but she also knows that she can still help support the family’s economy. Acknowledging her ability to fulfill her role as a woman and a wife, she proposed: “I can still manage my duty as a wife and a mother. I can still serve my husband, so it’s normal although maybe I’m not as strong as I used to be.” Today, Yatmi uses her talents to do traditional massage and to help people in her house. Although she can no longer travel to her clients, she helps people in her house until 8:00 pm most days, with only short breaks in between. Yatmi shows her respect to her patients by negotiating her needs with their expectations: “I tell my patients that I have to take a break a few times a day, so if they are willing to wait, I will let them wait in the living room if they come when I’m still having a nap or doing my prayer. *Alhamdulillah* [thank God], they understand.”

Giving up the job after 30 years was not easy. Participants in this study overwhelmingly agreed that having a job brings financial stability, self-confidence, and a sense of security, happiness, and power. After being diagnosed with diabetes three years ago, Mahmudah’s children kindly asked her to stop working. She is still confused about whether the decision

was right or not. “If this is diabetes, I feel nothing but this stiff leg. I know it’s in my family, but I have always been able to carry heavy loads on my shoulder and to walk to the market everyday. I also love vegetables, so I thought I was healthy.” When I asked her about how she feels now, Mahmudah said, “My body is fine and I don’t need to see *Pak Mantri* if I’m healthy.”

Mahmudah explains that her children disagree with her plan to go back to work: “They said that it’s time for me to rest. My youngest daughter asked me to contact her if I need anything.” However, Mahmudah asked her children not to contact her daughter who lives on another part of Java Island, because it’s too far. “She will directly come if her brother calls her and she will bring her son with her. Usually they will stay for 15 days, so my grandson skips his school that long.” Mahmudah realizes that all of her children will directly come and help her without her even asking, she says, but she does not want to rely on them that much. She explained the reason: “This disease is not heavy...it was just the stiffness in my knee. I can go to *Pak Mantri*, get the medicine, and it will be okay.”

Mahmudah, along with many other participants, is also convinced that diabetes can be cured. “The medicine for this disease is simple: don’t eat sweets and don’t think too hard.” This statement is in contrast to the

rest of her story, because she does worry. She is convinced that individuals with diabetes do not have to take medicines if their condition is normal. When I asked her about what normal is, she said: “When you can’t feel the [physical] symptoms. If you don’t feel sick, you don’t have to drink medicines.” For Mahmudah, parents should also have sense of concern (*tepa selira*) and not ask for things from their children if the children do not show their willingness to help.

**Avoiding conflict and disharmony.**

The principle of social harmony or harmonious living represents an ideal condition that becomes a primary purpose of life for Javanese people. Expressions that show direct opposition or highly expressive, impolite, angry behaviors are considered to be bad behavior, not socially acceptable. In their social interactions, participants recognized *tepa selira* and respect as ways to control the emergence of such bad behavior. To outsiders, sense of concern (*tepa selira*) and respect may be seen as passive obedience. However, many participants indicate these acts are a form of self-control and politeness. Two forms of conflict avoidance were identified in the narratives: evasion and covert disobedience.

**Evasion.** Evasion is the act of avoiding something that people do not want to do or deal with. To most Javanese, avoidance was described as a passive attitude and a sign of weakness and indecision. However,

avoiding arguments, as many participants said, helps in comforting mind and heart, and is required to control the stability of their blood sugar levels. She did not mention insulin. A part of negotiating self and one's personal agenda is, avoiding sex, for example. Evasion emerged from participants' as a strategy they employ.

Sakirah is aware (*rumongso*) of her health condition and decided not to challenge her husband's decision for her to stop working. She understands that her family has spent so much money for her hospitalization and she could not put them in more trouble by keeping her job. On the other hand, while she respects her husband most of the time, she describes having to hide her anger and disappointment with her husband's behavior:

I need strength to do the chores. I can't think too much, because when I have stress my blood sugar level will increase immediately ... Luckily I have my children. I often talk to them about my problems and they sometimes give me money. I prefer not to talk to my husband, because...he loves making sin, being rude, and yelling at me. I can't deal with that...it's hard. (Sakirah)

Avoiding conflict with her husband is the best way to protect Sakirah's heart (*ati*).



Susan has a complicated marital situation and continual disagreement with her siblings. First, she has an unregistered marriage that creates a dilemma that, she says, increases her blood sugar level. As a *siri* wife (a woman who is religiously, but not legally, married), Susan still is expected to perform her obligation as a wife, however her *siri* husband does not have the obligation to support Susan's children from her previous marriage. Both her *siri* husband and her own mother are sick, and she needs to be a caregiver for both. And, Susan has diabetes:

I feel exhausted, because I have to constantly fight with my husband and my family about the caregiving schedule. I can't rely on my youngest brother to take turns in looking after my mother. My other siblings work and live far from this place. I am often confused about how to divide myself. (Susan)

When her husband gets angry and looks for Susan at her mother's house, she avoids him by hiding at another person's house. Because Susan lives in an urban *kampong*, where the people are attached to each other through a communal form of living, she does not want to humiliate herself and her family by having an argument in front of others. The hardest part is avoiding her husband's demands for sex. When Susan feels tired and weak, she gets help from neighbors. They will hide her from her husband. Susan says,

Sometimes I am so tired because I haven't slept for two days for taking care of my mother when she had diarrhea. But then he called and asked me to come and see him. I don't want to argue with him over the phone, so I go have sex with him. No speech, completely silent and I do it quickly. You would not want to have a fight about this, because you are already too tired. After that I will tell him that I need to rest, so maybe not too soon for the next one.

(Susan)

In Susan's case, she says that, "My husband will stop bothering me after a few moments and I can go back to look after my mother."

Egawati faces a similar problem, but she prefers to find a polite excuse to reject her husband's sexual requests. She says,

Usually I will say that 'I don't feel well, I'm weak,' or 'I ran out of insulin so I feel dizzy and trembling.' Sometimes he understands and leaves me alone in my room, but other times he gets angry because he thinks I am just pretending so I can refuse his request. Thinking about being unable to perform this wife role stresses me out sometimes. I know my husband is fine, but it is also tough for both of us and it influences my blood sugar level. (Egawati)

In avoiding conflict with her husband related to household affairs, Puspa chooses to delegate her decision to her children. She knows that her

husband was being dishonest with about his income. Puspa decided to handle the problem and asked for her oldest son's help to directly speak with his father related to his father's behavior.

I often have a big fight about the way he spends our family money. He is never honest with me, but whenever I ask for the money for our children's needs, he remains silent. I know he uses the money to satisfy his personal happiness. My blood sugar level increased because of this fight, so one day I decided to take his book from the drawer and went to the bank to check his account. After that, I kept the book and did not tell him where it was. I kept silent as he searched for the book in his drawer. I called my oldest son to solve the problems and to warn my husband that we will go to the bank, get all the money, and block his account if he continues being dishonest to us. Well, I'm not sure if this will even work...but [laughing] that's the plan. (Puspa)

***Covert disobedience.*** This form of conflict avoidance appeared in participants' narratives in a vague, nuanced way. While it seems like an act of approving another's request, it frequently means "no" or "maybe." One participant mentioned that this was an act of pretending, to obey or to agree on certain things to avoid conflict. In her story, Puspa describes this particular form of conflict avoidance:

My husband never lets me use his salary. So far, for our daily expenses, I always use my own salary, while he puts all his money in the bank and never uses it. To get extra income, I used to work as a doctor's assistant in the afternoon and saved the money so I could buy whatever I wanted. One day I really wanted to buy a gas stove and he refused my request. I can't use the kerosene stove any longer because with my working schedule and the chores, I need to quickly prepare meals for everybody. He kept saying no, so I just kept quiet. One day, he came home and saw the new stove. "So, you bought the gas stove?" he asked, and I said, "Yes!" and he quietly left, I did the same thing with the refrigerator by the way.

(Puspa)

Puspa's story indicates that covert disobedience to some extent can be a means of supporting self-reliance, in addition to avoiding conflict episodes.

Diet restriction is another instance in which participants use covert disobedience to calm their family members, but at the same time allows these women to make their own decisions. Nur has had diabetes for four years, and she struggles in managing her diet because she used to be obese. Her husband helps her manage her diet, and often reminds her about this. Among the Javanese people, eating rice left over from the

previous day (*sega wadhang*) is part of their cultural beliefs about the diabetes diet. So, Nur's husband prepares the leftover rice for her the next morning. "I always feel stressful when my husband says, "I have prepared *sega wadhang* for you; you shouldn't eat ordinary rice if you want to reduce your blood sugar level." I say yes, but later when he goes to the office, I give the rice to the chickens," she says, laughing.

Nur says that *sega wadhang* has no nutrition. "And I am sick, right? That means I need a lot of nutrition. How can you get energy and nutrition from *sega wadhang*?" Nur had consulted her doctor about this, but at the same time she did not want to hurt her husband's feelings for caring about her health in this way.

A few participants in this study say that managing diet is their own responsibility, because they know their own bodies better than anyone else. Javanese concepts of health and illness play an important role in forming this attitude. Blood sugar level is a common sign to alert an individual with diabetes about their condition, but this does not seem to be an important sign for some of these participants. When I came to interview Jati, *mantri*'s wife, Yayah (a pseudonym), a nurse, had just finished checking Jati's blood sugar level. Yayah said, "Wow, its 564!: Jati quickly responded, "So, should I just go higher or keep the diet? [laughing].

I haven't eaten this morning, I bet it would be 700 if I had my breakfast." It turned out that Jati had forgotten to take her medicine that morning.

Before Yayah left the house, she told Jati to be careful with her diet. It seems that Jati frequently cheats on her diet. In that conversation, Jati replied to Yayah with, "Yes... Yes... I know." When I asked Jati about her diet, her boss, Suryo, who also has Type 2 diabetes, said, "Jati, I think you should start obeying *Pak mantri*'s suggestions. You never listen to what he says [*ngeyel*]; you always just listen to yourself." Jati replied, smiling, "Yes, Yes, I will ma'am. I know."

I love snacking all the time, and besides there is so much food in this house. If you have this abundance of food, are you going to just throw it away? If you open that fridge there is so much food in there. I can't finish it all. I always eat instant noodles everyday, and fried tempeh. I know that I have to control my diet, but so far I'm healthy. I don't feel anything. (Jati).

In this case, Jati is aware of her mistakes, so arguing with Yayah will not get her anywhere. Second, hierarchically Yayah has higher social status and more power than Jati. Thus, Jati is reluctant (*sungkan, pakewuh*) to argue with her.

Marni's case demonstrates the dynamics in a mother and daughter hierarchy. Marni's love for sweet drinks cannot be stopped, as she admits that in her explanation:

Oh, I don't know why I can't stop drinking sugar. I love sweetness!" I also still use sugar in my cooking and my children always remind me about this, especially my daughter. 'Mom, you're not suppose to consume sugar.' Sometimes I will say, 'Oh, just a little bit' but most of the time, I say, 'Yes, no sugar,' but I quickly drop a teaspoonful in my tea when she turns around.

(Marni)

Marni's daughter watches over her when she is busy cooking. Marni says this is kind of annoying, because she knows what to do. "My doctor said my blood sugar level has decreased and I did not get any medicines, so I'm fine now." However, this daughter is the youngest one who accompanies Marni everyday. "Actually I'm angry because someone is constantly reminding me about my sugar consumption. Not just reminding me, but also restricting me. But, my daughter helps me with the chores everyday. She sometimes cancels her own agenda for me if I'm sick," Marni adds.

In several narratives, participants describe how, in certain circumstances, the efforts to achieve peace and a harmonious condition

fail and interactions become highly expressive and emotional. Lastri's and Magda's stories are different from others, because they create a self –an identity- that is independent, headstrong (*keras kepala*), and perhaps rebellious and willing to engage in conflict when necessary. For example, when a women's ability to be self-reliant is restricted, as when family members actively attempt to restrict diets and administer medications to participants whether they want this or not.

Lastri is 55 years old, an upper-middle class urban woman who runs boarding houses for students. Her husband has already retired, so Lastri's income is the main financial source for them. Since being diagnosed with Type 2 diabetes 12 years ago, she explains that she has changed her diet and regularly takes medicine. However, she frequently minimizes her cheating, perhaps to reduce guilt she may feel about it:

I will eat everything that is served at the party. I also eat *tengkleng* [Javanese lamb meat cooked in coconut soup]. One of my friends said, 'Wow, you still eat *tengkleng*?' and I quickly answered, "Why not? I never limit myself; I eat everything I like, no problem!." (Lastri)

Contradictions between Lastri's self-reliant character and her attitude toward her diet frequently appeared in her narrative. The following statement shows that self-reliance affects the power levels between Lastri



and her family members due in part to Lastri's dominant role as a mother, a caregiver, and the primary wage earner in the family.

My daughter is always paying attention. One day when I visited her, she bought some Cokes and gave one to me. She said, "That's it mom, that's yours. No more!" She knows that I have diabetes, but she also knew that I really wanted to have Coke. I was being stubborn I guess. I finished one bottle and I wanted some more. So, she was angry with me and yelled to her maid, "Go to the grocery store and get mom a dozen Cokes! She can drink as much as she wants!" It hurt my feelings so bad! I said to her, "How dare you! Just because you have an income, you can't tell me what to do! I don't want to drink your Coke! I have my own money to buy it!" Since then, she doesn't dare say anything anymore to stop me from doing anything I want. (Lastri)

As a retired midwife, Magda knows what has happened to her health. Her knowledge made her understand that this disease requires patience and strict management. She is very independent and her children, according to her explanation, have not had to look after her so far.

Whatever she does is her own responsibility, including managing diabetes.

I always listen to my doctor. If not, I will be the one who loses.

Now I live my daughter, her maid, and my grandson. Three of us,

but they're not looking after me. I look after myself. I don't need them to tell me what to do. I know! Sometimes my daughter reminds me about my love for tennis. I was angry and I said to her, "Whatever I want to do, I will do it! It's up to me. I don't want to be stopped from playing tennis. I'll be mad. I am a stupid person, but I can handle my strength and myself. If I can't do it, I'll stop!"

Her tone rose as she told me about her anger that day. Being a single mom for 20 years, since her husband died, has turned Magda into a very independent, self-reliant, and strong woman. With her health knowledge, Magda feels disturbed when her daughter questions her decisions in managing her diabetes.

My youngest son always asks me questions about my food whenever I have meal with him. One day, he saw me eat one slice of tempeh, fruit, and vegetables. And he said, "What! How can you eat like that?" I replied, "I can eat what I want. I want to live for another 1000 years! If I can't swallow this, I'll drink water to push it through." (Magda)

Magda explained that her children question her as a parent does. In Javanese culture, this attitude is considered to be disrespectful (*tidak hormat*) and impolite (*tidak sopan*). And, Magda's independence, as she expressed in the narrative, makes her a dominant figure in her house. She

controls everything in her household without ever being questioned by others. Magda repeatedly says, “I’m not afraid of being alone,” and “I’m very self-reliant.” And she emphasizes that her life will be fine even if she is alone. “As long as I have had diabetes, for eight years, I have never asked for anybody’s help.”

Using her disease, Magda told her children about being a good mother and a good wife:

Even if you have a baby sitter or someone who looks after your son in the house, he still has to know you and feel close to you. If you and your husband are home, you should carry him. I don’t like a little boy who grabs people’s clothes, cries out loud and yells to ask for something he wants. Standing on the top of the table, you have to know! My daughter replied, “That’s a common thing”, and I got so angry. “I’m trying tell you what is right, either you take it or leave it, I don’t care!”. You see I have a disease and I never have a maid, but I do the chores....my house is clean and neat.

(Magda)

Magda’s conceptualization of life and what it means to be a good woman appears to contradict what her daughter has learned as a modern, urban Javanese woman. As with other Javanese women, Magda places herself as a moral guardian and a guardian of culture in her family. So, when her

son's wife rejected her husband's request to live with Magda, she was upset. In Magda's view, her daughter-in-law is too busy with her job and neglects her little boy. Now, the boy and her daughter-in-law live with her temporarily, because the boy was sick due to loss of appetite. Magda told her son,

Your little boy has gained some weight now. He has learned to be independent, and he never yells at anybody anymore. If you want to bring your wife back to your in-law's house, go ahead! But in our culture, married women go with the husband's family, not the other way around!(Magda)

### **Summary**

Javanese conceptual frameworks of health and illness suggest the importance of managing the heart (*hati, ati, manah*) as the source of many diseases, including diabetes. In this current study, participants identified diabetes specifically as a "disease of the heart" (*penyakit ati*) evidenced, in part, by psychological symptoms being more dominant than the physical symptoms in the participant's explanations. The way these Javanese women manage diabetes is influenced by the values of respect and social harmony, which guide participants to pay attention to self and their sickness, while at the same time maintaining their roles as managers of the household, mothers, wives, wage earners, and effective strategic planners.

Javanese women in this study recognized their domestic roles as ways of surviving diabetes and other misfortunes in life. Maintaining domestic roles gives these women a sense of peace as well as control and power in the household. In addition to their roles as mothers, wives, and caregivers, Javanese women in this study also play roles as wage earners and strategic thinkers. Earning money supports self-reliance, and at the same time equips these women with bargaining power to manage their household resources to support their diabetes management needs. Being strategic thinkers, these women are able to maintain peace and harmony in the informal space that ties the family to their social environments (e.g. extended family, neighbors). This allows them to meet their own needs to manage diabetes and also to accomplish household tasks and meet social obligations, as they have described.

This disease takes away some identity (e.g. market traders, dancer, singer), but at the same time, it adds some new attributes. As discussed by many participants, especially those living in poverty, diabetes gives them power to manage limited resources, establish endurance to be primary caregivers, and to survive social and cultural pressures (e.g. being a widow with diabetes). At the same time, diabetes also provides these women with the opportunity to harmonize their needs with others (i.e., finding solutions that fit), such as: solutions that fit with family expectations, fit

with unexpected social obligations (e.g. exchanging gifts), fit financial limitations, and solutions that fit with the pressures of tradition (e.g. social costs). Employing respect and a sense of consideration for others (*tepa selira*), Javanese women in this study negotiate their adaptation to diabetes in order to remain self-reliant, seen by many as the source of energy, strength, inner peace, and lower blood sugar levels. These qualities are required to maintain harmonious social interactions and to manage conflict related to the diabetes management process.

## CHAPTER FIVE

### **Behind the Inner Peace and Harmony**

While research about diabetes and diabetes management in Indonesia has heavily emphasized biomedical aspects of the disease, little is known about lay people's perceptions and individuals' experiences, especially women, with Type 2 diabetes (Soewondo, 2011; Soewondo, Ferrario, & Tahapary, 2013). National Indonesian health research reveals the prevalence of diabetes in Indonesia increases with age, and the incidence of diabetes is higher in women than men (2.3 percent and 2.0 percent, respectively: (RISKEDAS, 2013, p. 90). A small body of research describes Indonesian women as experiencing negative impacts from diabetes including reduced physical function and energy level, distress about and health overall, and severity and frequency of symptoms (Andayani, Ibrahim, & Asdie, 2010; Mihardja et al., 2009; Soewondo et al., 2013). However, these studies do not address issues relating to how Indonesian women make sense of and manage their illness within their conceptualizations of the cultural environment and views of womanhood.

More than half of all diabetes cases in Indonesia in 2012 went undiagnosed (Soewondo et al., 2013). Lack of awareness about diabetes and influences of cultural and traditional practices, especially in rural areas in Indonesia, are of interest here. This study provides rich data to aid

understanding of the influences of Javanese cultural beliefs on health beliefs, women's roles, social interactions and obligations, and issues of self-image and identity formation. Findings from this present study support those from previous studies, particularly discussions about the role of cultural beliefs in framing the lived experiences of people with chronic diseases (Chesla et al., 2009; Smith, 2011). Specific to diabetes, culture is found to affect the interpretation and experience of diabetes, as well as affecting the management of the illness including diet restrictions and medications (Sowattanagoon, Kotchabhakdi, & Petrie, 2009).

This present study addresses questions about the impact of diabetes on the day-to-day lives of Javanese women as mothers, wives, workers, household managers, and in other roles. This study focuses on women because of the challenges in fulfilling multiple familial and social roles, including caring for sick family members, nurturing children in the family, and managing household affairs, including financial and social obligations. In a study conducted on women with lupus from various ethnic groups in the United States, Mendelson (2006) found that most women are diagnosed with lupus during their childbearing years. This means they must deal with both medical and social situations, including high social demands and the stigma of illness. Findings suggest that Javanese women's social lives present extra challenges as they battle



chronic disease such as Type 2 diabetes. In addition to their domestic responsibilities, Javanese women must create and sustain harmonious lives and positive social interactions. A large study conducted by the Centers for Disease Control and Prevention (CDC) reveals that diabetes and its long-term risks do affect women's health across life stages (Beckless & Thompson-Reid, 2001). During the reproductive years (18-44 years old), diabetes increases women's chance of getting coronary heart disease, stroke, retinopathy, and hyperglycemia during pregnancy (p.77). In middle age (45-64 years old), women with diabetes face complex issues of diabetes complications, disabilities, and a decrease quality of life.

This chapter provides discussion about how Javanese women's narratives of everyday lives and illness experiences help us better understand the detailed personal, social, and cultural values that contribute to dilemmas when managing Type 2 diabetes. By examining Javanese women's lived experiences with Type 2 diabetes, "thick descriptions" (see Geertz, 1973) of the ways these women make sense of their world and how they negotiate their own identities within nuanced socio-cultural structures are provided, by the women themselves.

### **Balance and Harmony as Components of Health**

Javanese values of balance and harmony are central to understanding disease in this study. Historically, Confucianism has had a

strong influence on cultures and lifestyle in East Asian countries including Indonesia. Confucianism and Javanese values are evident in families and in traditions-the concept of family harmony is a building block for establishing a harmonious society overall. Interaction patterns make apparent these cultural teachings including maintaining social benefits, orientation to groups, acceptance of authority, avoidance of conflict, mutual dependence, awareness of hierarchical seniority, and compliance (Megawangi, Zeitlin, & Colletta, 1995; I. H. Park & Cho, 1995; Rozman, 1991).

Earlier studies have found that balance and harmony are cultural concepts that serve as a conceptual framework for understanding health practices among the East Asian community including Javanese (Dewi, Weinehall, & Ohman, 2010; M. Park & Chesla, 2007). Consistent with earlier findings, this current study suggests that the prominence of balance and harmony in life substantially affects Javanese people's worldview (Dewi et al., 2010; Magnis-Suseno, 1997; Murtisari, 2013), providing a fundamental structure for understanding conceptual thinking about disease, health, cures, and ways of managing Type 2 diabetes. This current study also extends the literature by demonstrating how chronic illness influences daily lives of Javanese women and their conceptualizations of womanhood. These women explained that women's illness might become

a potential source of tension among the family members and with other members of society. This study reveals ways Javanese women integrate cultural values such as the notion of *tepa selira* (empathy, considering the feelings of others and putting one's own feelings aside) and respect, into women's daily experiences and their ideas about the disease, cures, and treatment.

These women explain that in the traditional Javanese worldview, centered on maintaining balance and harmony between body and mind, guides their behaviors in adjusting to and managing Type 2 diabetes. These findings echo previous studies that suggest the principles of balance and harmony are considered to be especially important for people with chronic diseases; balance and harmony are explained by these women as being more important in disease management than medicines are (Becker, 2003; Jiang, Wu, Che, & Yeh, 2013; Struthers et al., 2003). Specific to each culture, principles of balance and harmony emphasize individuals' abilities to manage disruptions in life using specific cultural resources. And in attaining balance and harmony, individuals (re)gain good health, according to many participants.

The concepts of balance and harmony include the notion that the body is a unity among our physical, mental, spiritual, and emotional selves. Consequently, a disturbance in any one part of the self (illness for

example) may contribute to an imbalance in the unified self (Becker, 2003; Chesla et al., 2009; Dewi et al., 2010). The narratives support this in terms of having few mentions of insulin, regular blood sugar level checks, exercise, and certain aspects of diet. Integration of a healthy body and mind (*waras*) is described as a state of balance and harmony between two cosmos – body as the micro cosmos and mind as the macro cosmos. The body as the micro cosmos is seen as a tool for linking social relations to the self. The mind, on the other hand, is the macro cosmos that must be carefully guarded because, as Javanese women explain in this study, a stressed mind and uncomfortable feelings contribute to and worsen Type 2 diabetes.

Mind and heart are used interchangeably in participants' narratives; for them "heavy" thoughts or a stressful mind are both described by these women as producing inner pressure or uncomfortable feelings. Chaos in the mind (translated as heart or *hati*, feelings or *rasa*, or thought or *pikir*) disturbs or devastates (*merusak*) the body. In a study involving Javanese patients with hypertension in Yogyakarta, Indonesia, Ferzacca (2001) found that his participants described thoughts as coming in different forms such as "heavy thoughts," "too many thoughts," and "overly intense thoughts," (p. 124). These Javanese hypertension patients said that thoughts contribute to physical symptoms related to hypertension.

Longitudinal studies in different countries support the argument that thoughts and different forms of emotional distress do increase the development of Type 2 diabetes (Kato et al., 2009; Rod, Gronbaek, Schnohr, Prescott, & Kristensen, 2009).

The concept of a unified body and mind is not exclusive to Javanese culture; Chinese society recognizes this cultural concept as *homeostasis*. The fundamental difference between these two cultural views is related to the locus of balance. Chinese people describe the body as the source of balance, while Javanese say that the mind is the source of balance (Huang, 2013). In this study, Javanese women defined good health as “having a comfortable feeling” and a “peaceful mind.” They indicated that Type 2 diabetes is a disruption in comfortable feelings and a peaceful mind, and this is why, in their narratives, these women repeatedly mentioned diabetes as a “disease of the heart” (*penyakit hati*). Participants’ narratives suggest that the state of equilibrium between a healthy body and a peaceful mind can only be achieved through the process of maintaining inner peace. This means one must be able to control their emotions, must understand the intricacies of their surroundings (e.g., self, family, society, daily life problems, social traditions and obligations), and must seek solutions that “fit.” Following

this premise, every action must be done with an understanding of the effect the action may have on others.

The ability to continually consider other people's situations before sharing his or her problems, thoughts, or concerns is what the Javanese call *tepa selira*. This notion of consideration becomes a mode of life to ensure that social interaction does not interfere with (i.e., is harmonious with, or "fits") the interests of others. Showing consideration and care evokes women's positive self-image and provides inner strength to sincerely understand others and balance the needs of others with the needs of self to achieve solutions that "fit." Javanese people in general, and participants in this current study in particular indicated that a good fit (*cocok*) helps prevent conflict and disagreement, thus people involved in social interaction are more likely to achieve social harmony (Berman, 1998; Santoso, 1997).

Culturally, Javanese women describe their moral obligation to ensure that every effort will be made to find a good fit (*cocok*) when adjusting to chronic disease or other misfortunes. Adjusting fit as explained by Javanese women in this study support what other researchers have found about these women's roles in maintaining social harmony. In managing illness, social interactions, and/or coping with life problems, Javanese women describe strategies they have developed to help them

retain internal harmony, as well as harmony within the family and the community. However, these women must adjust strategies to fit a particular situation or collective expectations in general (Hayati, Eriksson, Hakimi, Hogberg, & Emmelin, 2013; Hayati et al., 2011; Saktiawati et al., 2013).

Javanese women in this study play central roles in mediating harmony while managing their own chronic illness, highlighting the issue of women's agency. Javanese women hold collectivist values above individual values when dealing with the dynamics of their households. Javanese women's narratives suggest that they are aware that the illnesses of mothers, wives, and women in general become a source of tension among family members and within the community. Javanese cultural expectations highlighted in this study support the idea that culture is an integral component in the ways people across cultures define health, achieve and maintain health, and treat illness (Csordas, 1994; Csordas & Kleinman, 1996; Johnson et al., 2004).

Within the Javanese context, as explained by participants in this study, the ability to maintain harmony with others influences the harmony within oneself (inner peace), a requirement for good health. To maintain social harmony based on respect, conflict avoidance, and collectivism,

Javanese women uphold the Javanese values of self-sacrifice and self-reliance. Thus, disease carries strong moral imperatives for them.

A similar concept is found among Chinese women and the expectation that they must sacrifice their own sense of well-being and endure psychological distress for the welfare and convenience of others (Cheng, 2010; Chiu, 2004; Hayati et al., 2013; Saktiawati et al., 2013).

### **Social Construction of Diabetes and Womanhood in Java**

Feminist scholars continue the debate about the role and position of Javanese women in both the domestic and public spheres as they have for more than a century (Jay, 1969; Reid, 1988; Tickamyer & Kusujiarti, 2012). Surrounding this debate are the issues of power and economic autonomy, and responsibilities within the family and the household (B. Anderson, 1972; Nolan, 2013; Saptari, 2000; Wolf, 2000).

Understanding womanhood and Javanese conceptualizations of health and illness are two central explorations undertaken in this study. First, the Javanese cultural model and the representation of women with Type 2 diabetes shape the reconstruction of identity of Javanese women as part of their lived experience after diagnosis. Second, Javanese women's ways of managing Type 2 diabetes through maintaining harmony and peace challenges the paradoxical images of Javanese women as "powerless victim to powerful agent" (Crees, 2001). The prominent role of



Javanese women in maintaining social harmony and positive social interaction in spite of their own chronic illness accounts for the acknowledgement that women have power and agency.

The current study brings together the cultural conceptual framework of health and illness, and the concept of gender roles and gender relations in understanding Javanese women's adjustment to Type 2 diabetes. In their narratives, these women describe Type 2 diabetes as a "disease of the heart," a disease caused by one's burden of mind or "hard" thoughts. The treatment, according to these participants, must focus on the psychological and emotional aspects of the disease. Within Javanese culture, this means retaining balance and social harmony intrinsically (e.g., inner peace, within oneself) and external (e.g., among the immediate family members and society in general). To achieve this state of health, the struggle with Type 2 diabetes presents challenging situations for these women in that they must be good wives and good mothers first, and managers of their own health only after meeting their other social, familial, and financial obligations. Within the Javanese context, the mother is described as a highly respected figure. Although their primary roles are to nurture the children and manage domestic affairs (H. Geertz, 1961), in day-to-day life, as studied here, Javanese women's roles extend beyond nurturing. These women are the source of life and protection for

their children, while at the same time they are wage earners, in order to contribute to the family's financial needs.

Given these expectations, it is important for Javanese women to stay healthy. Participants describe the physical symptoms they experience (e.g., dizzy, stiffness, tingling sensations in legs due to the increase of blood glucose level) are not considered being sick because they are still able to carry out normal daily activities. Thus, having a blood sugar level of 400 or 500 is considered normal by these women, as long as they have the energy and spirit (*semangat*) to work and/or to perform expected daily tasks. A woman is considered sick only when she is immobilized (*ngadag-adag*), unable to do anything (Raharjo & Corner, 1990). How Javanese women define health is influenced by the dialectical tension between the body and the mind, between physical symptoms and emotional states.

As noted in many studies, chronic illness may disrupt individuals' abilities to perform previously taken-for-granted behaviors (Bury, 1982; Charmaz, 1983, 1987) and the reconstruction of identities is needed to set out and maintain their adapted roles. The narratives in this context, especially those of women who did not voluntarily give up their jobs, include acknowledgements that Type 2 diabetes disrupts constructions of self and identity. Many family members doubt these women's abilities to perform multiple roles, and strongly suggested they give up their jobs and

stay home to manage their households. Many of these women also showed a desire to maintain continuity and coherence of self and identity through emphasizing the importance of preserving the roles they had before being diagnosed, including working outside the home (Mattingly, 1998).

As depicted in their narratives, Javanese notions of the self are closely tied to strength, energy, spirit (*semangat*), flexibility, and inner peace. These characteristics serve as a counterbalance for opinions that being sick, especially with a chronic disease like Type 2 diabetes, makes a woman weak, useless, and incapable of handling domestic tasks or mediating social harmony (Cooley, 1992). For these Javanese women, the inability to fulfill social roles and household tasks may have existential implication and pose a threat to their favored identities (G. Williams, 1984, 1993; S. Williams, 2000).

Indonesian feminist scholars have been argued that Javanese women's positions within their culture can be described two ways. First, some say women's roles are demarcated by the concept of private and public spheres as promoted by Western feminist theories (H. Geertz, 1961; Jay, 1969). Others argue Javanese women can strategically balance and negotiate their lives between home and work (Saptari, 2000; Weix, 2000). As stated by Javanese women in their narratives, three aspects of Javanese

womanhood are challenged by Type 2 diabetes: a woman's role, as a wife, including the duty to meet the sexual demands of her husband (Djajadiningrat-Nieuwenhuis, 1987; Rudie, 1994), a woman's role, as a wage earner, that yields financial independence and autonomy (Stoler, 1977), and a woman's roles, as a manager, of household affairs including fiscal management as well as meeting familial and social obligations (Rudie, 1995; N. Sullivan, 1994).

In re-constructing their identities, Javanese women demonstrated that Type 2 diabetes does not prevent them from performing daily chores, nurturing the children, providing care for family members, maintaining their jobs, maintaining social interaction, and managing social costs and obligations with limited support and few personal resources. This is of central importance for these women because the ability to perform daily activities represents a core component of being a good Javanese woman, one who is self-reliant, strong, an effective manager of the household, and therefore makes household financial decisions autonomously and has the power to manage social networks (H. Geertz, 1961; Jay, 1969; Koentjaraningrat, 1967). What these Javanese women described was a process of reconnecting with value aspects of the pre-illness self (Becker, 1997; Reynolds, 2003) in order to maintain inner peace and a sense of well-being. The participants described these aspects as a cure; more than

talk about insulin or exercise, they mentioned food and the freedom to eat it, peace, and maintaining harmonious relationships.

Javanese conceptualizations of womanhood encompass women's roles as mothers, wives, members of communities and societies, and wage earners. In the history of family health care in Indonesia, self-reliance has been described as Javanese women's ability to manage limited household income to fulfill day-to-day needs including health expenses (Hull, 1979). The present study corroborates Hull's findings that Javanese women develop strategies to manage household resources in a way that accommodates Type 2 diabetes management (i.e., dietary needs, costs of medicine and doctor visits, the need for rest) to fit family members' expectations and needs. Fit between self-needs and others' needs marks the most important value that underlies Javanese women's decisions to stop their medications temporarily, or to see *mantri* rather than a doctor in order to save money.

Scholars argue that poverty limits women's lives, autonomy, freedom, and choices (Manderson, 1983; Wieringa, 1988). Many of the participants in this study live at or near the poverty line, and, as they indicated in their narratives, agree that poverty limits family choices. However this is mediated by, as previously explained, the view of Javanese women who see self-reliance as an important value in their lives.

By being self-reliant in spite of illness, these women gain strength, energy, and flexibility to maintain their roles, financial independence, and autonomy. Self-reliance is pictured as a source of empowerment and as a sign to show others that Type 2 diabetes does not exclude them from maintaining family bonds and social interactions.

Wolf (2000) argues that studies conducted on Javanese women's roles and Indonesian households tend to obscure some important issues, one of which is women's lack of control over when to have sex, a domain that in Javanese culture has been viewed as a husband's right. In this study, Javanese women used narratives as more than just a means to reconstruct identity, but also as a means of social empowerment (Hunt, 2000) to control decisions about sexual activities. In the daily lives of Javanese women, refusing a husband's request to have sex is considered to be unusual (Sears, 2007; Suryakusuma, 2004), an act of disrespect, and has the potential to produce conflict. Through their narratives, these women voiced their desires to negotiate about sex, to have a true choice to reject sexual advances for any reason. Some participants were able to negotiate in this way, as they described rejecting the husband's request to have sex because of the husband's rude behavior, the husband's lack of consideration and empathy (*tepa selira*) toward their health condition, or the woman's actual physical symptoms are used as the reason in

successfully (i.e., without open conflict) rejecting unwanted sexual advances.

Type 2 diabetes and the physical symptoms that accompany the disease provide an opportunity to question (and resist) the dominant Javanese ideology about power and women's sexual obligations. These women also use diabetes as a resource to preserve aspects of their pre-diagnosis lives and to construct a new conceptualization of womanhood. Their narratives serve as a means of social empowerment, of addressing conflict and contradiction, and of showing resilience and resistance.

Some scholars (Hull, 1979; Stoler, 1977) argue that self-reliance among village women is not a choice, but rather has been forced upon them by extremely limited personal and social resources. Historically Javanese women have enhanced their status within the family since the early period of industrialization in Java during the 19<sup>th</sup> Century (Wolf, 1988). Javanese women's narratives in this study provide new conceptual thinking, specifically the idea that women's health is contingent upon having the power to maintain domestic roles and social harmony, and to extend social, personal, familial, and professional networks (Djajadiningrat-Nieuwenhuis, 1987). These narratives contribute to the development of more beneficial views of womanhood and offer examples

of Javanese women's status today that demonstrate wives are neither superior nor subordinate to their husbands.

### **The “New Identity” and Type 2 Diabetes Management.**

Javanese cultural concepts of Type 2 diabetes are described as burdens of the mind (thoughts) and feelings of discomfort that are seen by these participants as major factors that trigger Type 2 diabetes and its symptoms. Thus, the lived experience of Javanese women with Type 2 diabetes corresponds with their understanding of emotional distress. This means the construction of illness involves personal and social factors such as socio-economic situation, gender roles within societies and families, and entrenched cultural values, and other non-medical arenas.

“Hard thoughts” potentially disturb one's inner peace and cause imbalance in health and life in general, as many of these participants explain. For women with Type 2 diabetes, this means the presence of diabetic symptoms including increases in blood sugar levels. In the collectivistic Javanese society, women play important roles in maintaining commitment to relationships (e.g., with family members, with the community) and in upholding the notion of consideration and empathy (*tepa selira*) toward other people's feelings and situations in order to maintain balance and harmony (Hardjowirogo, 1984; Irawanto, 2009; Mulder, 1985) on three levels. The lowest level is the woman herself, next



is the immediate and extended family, and finally the society and community level (e.g., in the form of social obligations as described in the narratives). In a study exploring Javanese perceptions of health and cardiovascular disease, balance and harmony were also described as a prerequisite for the well-being of individuals with cardiovascular disease (Dewi et al., 2010). Despite similar notions that emerged from previous studies, this current study identifies specific cultural values that influence Javanese women's behaviors in managing their Type 2 diabetes while simultaneously maintaining balance and harmony on these three levels.

These narratives include descriptions of power, many participants saying power is an individual's ability to harmonize contradictory elements in life (Tickamyer & Kusujarti, 2012). On the individual level, Javanese women maintain harmony by accepting Type 2 diabetes as just another misfortune in life. Using this logic Javanese women explain that they sincerely accept the illness but resist abandoning family and social obligations. Maintaining the spirit (*semangat*) to fight feelings of laziness (*malas*) that sometimes occur as a symptom of diabetes, helps these women fulfill their domestic roles and obligations. With spirit, Javanese women say, they are able to remain self-reliant, able to show their strength, independence, and power to successfully manage household affairs and interactions with others.

On the family level, Javanese women play important roles in negotiating their own needs in light of the expressed and unexpressed needs of other family members. Self-reliance was salient and influential in women's interactions with family members. Examples of this self-reliance mentioned by the participants include saving for personal needs including health expenses, performing daily chores with limited assistance from family members, and cooking their own meals even when women live together with their children in the same house. Some scholars argue that self-reliance is a way to please others (A. R. Black, 2011; Hull, 1982), and in this study, several participants did say they are able to be reliable by sacrificing their own time, energy, and health needs, and frequently, their own savings to maintain family harmony and avoid conflict.

**Identity, economy, and power to manage Type 2 diabetes.**

In a broader sense, Javanese women negotiate issues of power and powerlessness within their daily lives (Brodwin, 1994) as mothers, wives, and women with Type 2 diabetes. Many rural women interviewed here work as market traders, a job that closely relates to gender roles and women's autonomy in Java (Alexander & Alexander, 2001). The rest are housewives, retired, professionals (i.e., midwives, teachers, university professors), farmers, factory workers, or own a home-based business (i.e., food stall, catering service, bakery, fashion boutique). The first and most

prominent issue of power and powerless addressed in the narratives is that of women's financial independence. This is interesting because the women in this study indicated their awareness of the relationships between husbands and wives as the result of the women's actual and potential economic contributions to their households (Brenner, 1995, 1998; N. Sullivan, 1994; Wolf, 1994).

For Javanese women, especially poor rural women, being financially independent provides them with ability to deal not only with illness and domestic affairs, but also the day-to-day issues of household affairs that involve the larger network beyond her family that directly affect the family's reputation (i.e., social obligations, reciprocal gifts mechanism). Participants' narratives indicate that husbands do not participate in decision-making about social obligation problems because women and men perceive the job as domestic work a woman's responsibility.

At the social or community level, Javanese women maintain balance and harmony by ensuring that the family is able to fulfill social obligations such as exchanging gifts or preparing communal feasts. Social costs, frequently in the form of gifts, are expressions of social bonds and commonality and, as described in the narratives, these extra-domestic economic burdens require the ability to manage limited household

resources. These extra-domestic costs extend Javanese women roles, and as argued in previous studies, giving Javanese women the additional responsibilities of being the dominant partner and the family strategist(H. Geertz, 1961; N. Sullivan, 1994). It is these Javanese women's abilities to manage social obligations and maintain harmonious social interactions that give them the power to negotiate both health needs and, of most importance to them, family dignity.

Javanese women in this study state that gift exchanges and other social costs are cultural burdens, but in the narratives, they also emphasize that it is not just about the money involved; it is about returning the honor and avoiding conflict. This cultural practice supports Mauss's (1990) argument that, "A gift is received with a burden attached" (Mauss, 1990, p. 41). The challenge that Mauss mentions in his book is actually the challenge that Javanese women bear in their everyday lives: to ensure and ultimately prove that one can reciprocate. A family loses face if they do not or cannot reciprocate; it is a woman's task to ensure the family does not lose face regardless of how many misfortunes occur.

The ability to perform domestic responsibilities and to maintain multiple roles within the household and the community is of central importance to these participants. It is through these activities they retain and display their strength and energy. And, self-reliance gives these

women inner peace and a calm mind, as the participants explain. Inner peace and the ability to maintain responsibilities and harmony form social capital that produces positive feelings that the Javanese women in this study call *health*, which refers to both mind and body (Coleman, 1988; McDowell, 2010).

Performing social obligations such as preparing food for the *Eid* feast, and performing gift exchanges that demonstrate to others that women are reliable, for example, bringing happiness and strength, participants explain. Being happy makes Javanese women strong, and strength is equal to health, or what might be called “social well-being.”

Javanese women’s abilities to maintain balance and harmony in their social interactions, in spite of the presence of Type 2 diabetes, provides a glimpse of this hidden power that has become a source of debate among Indonesian and Western feminist scholars for a long time (Cooley, 1992; Nur Hayati, Eriksson, Hakim, Hogberg, & Emmelin, 2013; Wolf, 2000). Javanese women’s narratives present some important facts. For example, these women are leading actors in informal everyday communal life, or what N. Sullivan (1994) calls “communal politics” (p.114) and are dominant in terms of controlling family resources.

The narratives of Javanese women’s lived experience with Type 2 diabetes corroborates Hunt’s (2000) argument that narratives help

Javanese women reconfigure their roles and identities. This current study offers insight into the ways chronic disease affects women's roles. In addition, this study also yields better understanding of Javanese conceptualizations of power that ground local Javanese values and influence issues such as chronic illness and gender roles. Utilizing the cultural values of *tepa selira* (empathy) and respect, Javanese women in this current study have re-defined and re-claimed themselves and their social roles as responsible, independent, and self-reliant Javanese women, with a chronic disease.

Managing gift exchanges sometimes requires that women sacrifice personally in order to meet obligations. In their narratives, these women explained that they could not reject and strongly prefer not to delay giving gifts, even if they need to buy medicine or food. Cici, one of the participants explained how she must immediately assign the duty to come to any social events to her husband or children, if she suddenly has itchy skin, a common diabetes symptom. Sometimes, as Suprih explains, she has to spend her health savings to fulfill unexpected invitations and when that happens, she chooses traditional herbal drinks (*jamu*) rather than buying medicine.

These participants describe how they have been taught to live in a continual state of concern (*prihatin*) for others, and poor village women

live with higher degrees of concern for others, and must strategically manage even more limited resources (Brenner, 1998). To fulfill family social obligations, Javanese women often must sacrifice their own needs and personal desires. As Yatmi explains, as a rural woman, she was taught to live full of concern (*prihatin*) for others when undergoing hardship. Therefore, having Type 2 diabetes means a woman must learn to control hardships (Brenner, 1998) and live full of concern for others by prioritizing family needs above her own health or other needs. Suppressing one's own needs and desires is rather obviously helpful in managing social cohesion and harmony, in reducing the likelihood of conflict, and in maintaining family stability. However, they are frequently detrimental to the health of these women, and therefore, in the long term, not good for anyone.

In managing their lives with Type 2 diabetes, Javanese women in this study work to minimize the financial burden of the disease on their families. This requires sensitivity, especially when a family lives with their in-laws in the same house. By sharing the household, some women describe how they must ensure that their personal expenses do not disrupt the needs of family members. In the narratives, these Javanese women mentioned decisions they made to avoid disruption, such as seeing *mantri* instead of a doctor for routine check-ups because it is more affordable. It is clear that prescribed caregiver roles influence Javanese women's

behaviors and challenge familial and social harmony, for which these women are held responsible. This is a similar problem for women from other cultures (Erin, 2013; Matthew, Gucciardi, De Melo, & Barata, 2012; Samuel-Hodge et al., 2000), and in many cases women with Type 2 diabetes must make adjustments according to the family's financial condition. In certain circumstances participants in this study explain that sometimes they cannot buy medicine, when, for example, another family member is in great need of money or when the husband has no fixed income to financially support the household.

#### **Surviving culture dynamics.**

The presence of chronic illness, in this case Type 2 diabetes, in the lives of Javanese women brings deeper understanding of the worldview of Javanese people, specifically the ideas of harmony and maintaining a harmonious life. Type 2 diabetes challenges the concept of harmony, as described in the narratives, but cultural beliefs provide wisdom that helps Javanese women maintain their health and successfully manage their daily lives while meeting the myriad social obligations imposed on them. At the same time, some participants also noted that culture potentially hampers their efforts.

Being introduced and having lived with the Javanese notion of consideration (*tepa selira*) and mutual help does not mean that every



Javanese individual applies these values automatically, nor to the same degree. A study of African-American women, for example, found that having immediate family members living together or extended family living close to each other does not necessarily mean gaining support (Samuel-Hodge et al., 2000). Javanese women in this study must perform daily chores in addition to their responsibilities to care for sick family members and attend to the financial and emotional needs of others, all made more difficult given their own illness that places more physical burdens on them. Therefore, while looking after sick family members is a Javanese woman's familial responsibility, so too is managing her own illness, a concurrent personal responsibility.

The notion of consideration and empathy (*tepa selira*) as a means of achieving social harmony requires reciprocal actions from family members, mutual respect, and sensitivity to other people's emotional, physical, and financial problems and conditions. This act of consideration is aimed toward achieving good "fit" between one's personal needs and the collective needs of the family and larger community. In their narratives, these Javanese women describe how the burden of maintaining harmonious conditions falls solely on their shoulders.

Javanese society considers women to be stronger and healthier (physically and emotionally) than men (Handayani & Novianto, 2004).

Women are considered to have more endurance than men in dealing with misfortune, including illness (Handayani & Novianto, 2004; Susanto, 1992). The lived experiences of Javanese women with Type 2 diabetes in this current study support these beliefs. Consciously and unconsciously, Javanese women attempt to maintain the image of a strong woman, showing positive characteristics of self-reliance, independence, being responsible and reliable in their daily activities, and meeting social obligations. In these narratives, women focus more on their efforts to restore the spirit and energy needed to maintain health and well-being. These participants emphasized the importance of meeting their domestic obligations in order to keep their identities as good Javanese women intact.

Javanese women are also taught to demonstrate stoicism or to show patience in accepting sufferings (*tabah*), a value that represents strength and a sense of masculinity (Forshee, 2006; Rebel, 2010). With this strength, these Javanese women sincerely accept (*nrimo*) misfortunes as God's blessings. They devalue emotional displays in response to misfortune, including illness, at least in part because of their positions as a primary sources of family strength (Landy, 1977; Suza, Petpichetchian, & Songwhatana, 2007; Woodward, 2011). One of the women in this study, Ninik, explained that she would never complain about feeling weak or

tired to her husband while he is also tired after working all day. Another participant, Partinem, said that she could not disturb her children's lives to complain about her illness because she believed that her children have their own problems. Thus, for Javanese women, disclosing pain or asking for help shows a lack of ability to meet one's obligations. In terms of daily chores, these Javanese women, as Titin described, do not ask for help from family members, because unless the husband or children show their concern and offer their help, they won't ask for it.

Studies of Type 2 diabetes and family support shows that women's adjustments to this disease involve immediate and extended families. This means family members often offer help after women disclose information about their conditions (Kokanovic & Manderson, 2006). However, in societies in which women perform as caregivers, as with the Javanese in this present study or among African-Americans, as cited above, women must nurture their self-reliance, independence, and power to control emotions in order to manage their families and their social obligations (Carter-Edwards, Skelly, Cagle, & Appel, 2004). Conflict between providing care for others and providing care for themselves continually emerges in their day-to-day lives (Burroughs, Harris, Pontious, & Santiago, 1997; Samuel-Hodge et al., 2000). Cahya, for example describes how she has looked after her husband, disabled by a stroke ten years ago,

without being able to care for her own health. The sense of consideration (*tepa selira*) of her husband's condition and respect are two values underlying her decision to care for her husband to the detriment of her own health.

Participants in this study agree that sexual activity should be negotiable between husband and wife. However, looking after the husband when he is sick, preparing food, and other household tasks are held to be women's responsibilities as wives, and are done to show respect. Although it seems paradoxical, these women recognize their responsibilities as wives and their abilities to fulfill these responsibilities evokes inner peace and happiness, and, in the view of these participants, good health. A recent study involving Javanese and Balinese women found that for Balinese women, submission to a husband's sexual advances evokes happiness, found to be strongly associated with health (Hidajat, 2013). Scholars argue that cultural obligations and spousal support are frequently women's biggest obstacles in attempting to balance their interpersonal relationships and the management of Type 2 diabetes (Ali & Jusoff, 2009; Wong, Gucciardi, Li, & Grace, 2007).

Javanese women play important roles in family rituals such as holiday feasts, weddings, and funerals. Although Javanese women in this study admitted that these rituals and community feasts are costly, they also

realized that rituals are ways to reinforce harmonious social relationships and to broaden social networks (Brenner, 1998; H. Geertz, 1961; Kramer, Kwong, Lee, & Chung, 2002; Nolan, 2013). Considering the purpose, preparing for and being involved in community celebrations and rituals gives Javanese women power that men do not have: the power to mediate events to maintain harmony. However, culturally established social gatherings and community celebrations often involve large amounts of food. Muslim women in this current study said that according to their religion, community feasts carry blessings from God (Sumardjan, 1985), thus the Muslim women in this current study describe how they sometimes fail to control the amount of food they eat for the reason of respecting their religious beliefs . As previously discussed, a primary concern for Javanese women is the impact of the advice given by a doctor or *mantri* about eating behavior and prescribed diets on community feasts and other traditions involving food. Not attending the feast or not eating the food when attending community celebrations are considered disrespectful and unacceptable (Ferzacca, 2010a; Weller, 2007). Numerous studies about culture and the management of diabetes mention these traditions as the biggest barriers among collective societies because food for these people is integral to culture and socialization (Gomersall, Madill, & Summers, 2011; Hu, Amirehsani, Wallace, & Letvak, 2013; Weiler & Crist, 2009).

**A moral dilemma: Illness and identity.**

Matrifocality kinship systems, as practiced in Javanese society, place women in dominant roles within families. Research shows that social and family relationships are significant in the lives of Javanese women, not only because they influence and are influenced by the ways Javanese women manage their illness, but also because of the Javanese culture and traditions that are brought into relationships. As shown in the narratives, life events and socio-cultural conditions mean that medical advice and behavioral adaptations needed to respond to Type 2 diabetes are placed at the bottom in terms of importance. The needs of others come first, and when all that need has been addressed, only then are many of these women willing to do what is needed to improve and maintain their own health.

Regardless of their knowledge of Type 2 diabetes and the factors that cause and exacerbate the disease, these women face changes in their abilities to perform their roles as mothers, wives, daughters, sisters, and grandmothers. The Javanese kinship system, for example, carries the moral obligation that women must provide emotional support, protection, attention, and in some cases financial support for relatives. Although labeling and stigmas are not typically attached to people with Type 2 diabetes in Indonesia, Javanese women in this current study have indicated

that the inability to fulfill social obligations poses a threat to their favored identity. Fulfilling moral obligations, viewed from the biomedical perspective, is a form of “unintentional adherence” (Brown & Bussell, 2011; Jimmy & Jose, 2011) or adherence that arises from an individual’s beliefs and attitudes. This, it can be argued, is a result of a kinship system in which women are responsible to maintain networks within the immediate family, as well as relatives in the extended family. Therefore, being healthy, strong, independent, and reliable are key components that enable Javanese women to maintain financial autonomy and the power to control their social networks – to be a good Javanese woman.

Wariyah, a participant, mentioned the Javanese idiom that the older the parents get, the more concerned (*prihatin*) they become about their children. Although she used the term *parents*, it refers to *mother* in this instance. Wariyah did not give up her job as a market trader, she said, because she believes that as a mother she must secure a future for her children. She was a market trader long before she got married and she managed to develop her business and make significant contributions to her family’s resources. In her story, I learned that this woman’s blood sugar is rarely normal. Thus, she endures the discomforts and attempts to improve her health through normal daily activities (such as diet modifications, maintaining daily work, and attending social events). Wariyah says she

cannot risk damaging her identity, her valued social roles, or her children's future for the illness, so she maintains appearances and struggles with the symptoms.

Some studies have observed that people with chronic illnesses tend to develop strategies to help them resist admitting that they have symptoms (Murphy & Fischer, 1983; Radley & Green, 1987). In the case of these Javanese women, managing the disease is not about resisting the illness. Rather it is about harmonizing the numerous personal, familial, and social components of life to achieve balance that, in the view of these participants, is not just necessary for good health and well-being, but is constitutive of it.

### **Theoretical Contributions**

Previous studies have demonstrated that difficulties faced by women with Type 2 diabetes are anchored in their everyday lives and influenced by socio-cultural values (Kokanovic & Manderson, 2006; Mendehall et al., 2010; Tang, Brown, Funnell, & Anderson, 2008; Weiler & Crist, 2009). While these studies successfully identify cultural variations that affect the interpretation and experience of diabetes, along with self-management of illness (Sowattanangoon et al., 2009), they rarely address the intricacies that Type 2 diabetes brings to the daily lives of



women who are culturally assigned multiple roles, multiple identities, and substantial responsibilities.

Findings in this study elucidate the way social constructions of health and illness are used to adjust to Type 2 diabetes in light of these specific cultural values, traditions, and backgrounds. The socio-cultural construction of Type 2 diabetes in this current study is built using the peripheral route of understanding what being a Javanese woman means, what being a wife in Javanese society means, what meeting social obligations means, and so on. Regardless of the participant's knowledge about Type 2 diabetes, the narratives focus on the continuous efforts to maintain both a positive self-image and a public identity as a good Javanese woman. Javanese women in this study categorized Type 2 diabetes as a misfortune in life, and a potential cause of social disharmony. As a result, Javanese women utilize key cultural values and events that help them demonstrate their moral worth as individuals and as members of the community.

Literature about Java explains that Javanese women are bestowed many titles involving numerous identities. Among these are protector of culture and traditions, moral guide, manager of the household, wife, mother, caregiver, wage earner, a source of wisdom, and the source of life itself. (Handayani & Novianto, 2004). And, these women are expected to

deliver. These often overwhelming obligations may be seen as both burdens and as an acknowledgment of the dominance of women in Javanese society. This supports the idea that moral worth is important in order to preserve the favored identity that in large part dictates women's options in adapting to diabetes and other misfortunes (Naemiratch & Manderson, 2006; Robinson, 1990; Townsend, Wyke, & Hunt, 2006).

Harmony and balance are core values in the lives of Javanese people. They serve to guide Javanese women in managing their day-to-day lives with Type 2 diabetes while fulfilling their roles as mothers, wives, workers, household managers, strategic planners, daughters, or grandmothers. Given these responsibilities, and in light of the narratives from these participants, the idea that a lack of knowledge about Type 2 diabetes and the prescribed treatments for it are key determinants of diabetes management behaviors is not supported here (J. Anderson et al., 1995; Millan-Ferro & Caballero, 2007; Peel, Parry, Douglas, & Lawton, 2005). Rather, diabetes management is most related to the number of personal, familial, and social obligations and the resources available to the family. Knowing *how* to manage diabetes is not as significant for these participants as being *able* to address their own health needs in the face of other obligations.

The suggestion here is that managing Type 2 diabetes can be perceived as controlling the impact that the disease brings to the daily life of an individual, to family relationships, to gender roles, and to social interactions and obligations. The few studies that have been conducted about the impacts of diabetes have focused more on how diabetes influences and is influenced by women's roles in the family, especially in food preparation and consumption (Kokanovic & Manderson, 2006; Young, 1999). Javanese women in this study describe similar events, but also explain the numerous socio-cultural circumstances that require them to put their own health needs below the needs of (nearly all) others.

These participants say that a healthy mind results in a healthy body, adding that "heavy" thoughts trigger Type 2 diabetes and its symptoms, thus contributing to disharmony. Under the concept of "sociocentric self," the *body*, in the Javanese cultural conceptualization of health and illness, links all social interactions in life (Koentjaraningrat, 1985, p. 457). This means Javanese women's existence depends on their relationships with others. Therefore, in order to maintain harmonious interactions, also a sign of good health, the body must be able to support an individual's spirit (*semangat*), inner peace, strength, and energy. With these qualities, Javanese women can maintain their autonomy, be financially independent, and self-reliant.

Based on the concept of mind/body unity, Javanese women manage their illness by managing their thoughts and inner peace (heart, feelings) so as to avoid disrupting the body and the interactions that the body facilitates in life. These findings reinforce existing evidence about the relationship between gender roles and women's health in Indonesia. In addition these findings also suggest the need to acknowledge the connection between physical aspects of self and mental aspects such as identity, and the socio-cultural and historical aspects of the day-to-day lives of these women that are involved in their health generally and their management of diabetes in particular.

Javanese women in this study express a strong commitment to their personal, family, and social roles, however the realities of living with Type 2 diabetes requires women continually negotiate their positions within the family and society. This is necessary because harmony can be achieved only when these women's efforts to maintain their health "fit" the needs of the family and community. Research about women's compliance with prescribed diabetes treatments found that women are much more likely to comply with such treatments when they "fit" long-established daily routines (Hunt, Jordan, Irwin, & Browner, 1989). However, this current study suggests that "fit" (*cocok*) in the Javanese cultural conceptualization is recognized as a pre-condition of harmony and

harmonious relations and is achieved through demonstrating *tepa selira* (empathy, consideration for the needs of others) in all aspects of life (Magnis-Suseno, 1997).

It is noteworthy that in reconstructing their roles, these Javanese women demonstrate a seemingly opposing behavior. They embrace their roles as mothers and wives, but at the same time are restructuring those roles that no longer “fit” due to the physical deterioration brought on by Type 2 diabetes (Monks & Frankenberg, 1988). In their study, Pitaloka and Hsieh (2013) provide a detailed analysis about how diabetes empowers Javanese women through submission and resisting/exerting control. Women maintain power to maintain balance and harmony in their day-to-day lives while at the same time employ passive resistance in the face of aggressive control behaviors of others.

In their narratives, these women describe that the (re)appearance of diabetic symptoms makes them lose their sexual passion. While rejecting a husband’s request for sex is considered disrespectful in the Javanese culture, at the same time, through the notion of consideration or empathy (*tepa selira*), women are able to negotiate about having sex with minimal risk of conflict. These Javanese women expect their husbands to understand the disruption that Type 2 diabetes brings to their lives and that the rejection of their sexual advances is not a sign of disrespect.

Findings in this study support the argument brought by Ferzacca (2010c) that more concern should be placed on social interaction as a source of disruption in Javanese women's diabetes management. In their narratives, these women state that their submission to cultural and traditional norms is a strategy designed to maintain inner peace and harmonious social interaction, which in turn improves their health (Hay, 2001; Hidajat, 2013; Pitaloka & Hsieh, 2013).

Novices to Javanese culture may consider that *tepa selira* and respect are forms of passive obedience that hamper women's health overall (Ketcham, 1987; Rozman, 1991), shape attitudes of dependence, and are a potential source of disharmony. However, these cultural values give Javanese women power and ability to undergo hardship, endure adversity, cope with suffering, and manage disharmonious relationships. Because of the influence of Confucianism in Southeast Asian countries, these positive self qualities are also found among Chinese women who adopt Confucianism in managing life with chronic disease (Fu, Xu, Liu, & Haber, 2008; Mok, 2001).

The emerging conceptualization of womanhood and the identity of being a good Javanese woman is reflected in the narratives, and positions Javanese women not only as leading figures in the domestic sphere but also in managing resources for the family and mediating social harmony in

the community. This new identity acknowledges the power these women have in four areas: their ability to be flexible in performing their roles as mothers, wives, and wage earners; their endurance to sustain themselves during hard times (e.g., when looking after their sick relatives or unexpected social costs); their ways of surviving chronic disease; and their management of limited resources.

### **Conclusions**

Through the narratives, Javanese women in this study construct concepts of both health and sickness as individuals with Type 2 diabetes simultaneously. Describing diabetes as a “disease of the heart,” these women view diabetes management as a process of managing heart and mind to achieve harmony within themselves, within their families, and within society. Utilizing the Javanese value of *tepa selira*, these women make every effort to manage the disease finding a way that “fits” both their personal needs and the collective needs of the family and society. As a central figure in the family and the one who is responsible to maintain social obligations and social networks, the woman’s diabetes management must always be considered in light of social interactions and social harmony. Self, which represents these Javanese women’s capacity to fulfill desired social roles, is placed within the social hierarchy and within

the ideal construction of womanhood (Keller, 1987; Kelly & Field, 1996; Pitaloka & Hsieh, 2013).

Each cultural component involved in the process of social interaction among the Javanese influences aspects of their lives. Through these narratives, Javanese women explain that Type 2 diabetes is not solely a misfortune, but is also an expression of health and empowerment. In their narratives, participants go beyond describing the discomfort of the physical symptoms of diabetes to focus on maintaining inner peace to manage the disease. From the Javanese cultural perspective, inner peace and comfortable feelings strongly influence health. As long as these women can still perform their daily activities, high blood sugar level is not typically their main concern. From a sociological perspective, the need to maintain a healthy mind and body is central to the social processes in which these women are the leading actors.

Overall, the management of Type 2 diabetes described by the participants in this current study focus on the impacts the illness has on social relations and inner peace. Harmonious social interaction is the ultimate goal in the lives of Javanese people, and women play a central role in mediating harmony with others. Submission to Javanese cultural values and traditions is a primary strategy for avoiding conflict and social disruption. Conscious and unconscious efforts to manage diabetes must be



made in accordance with Javanese women's "need to treat their authentic identities" Ferzacca (2010a, p. 173). This includes both physical and socio-cultural aspects (Kelly, 1991) such as seeking treatment, performing chores, preparing food, and participating in community events. Thus, Javanese cultural values and traditions become resources used to enhance health and well-being and to nurture women's notions of self.

To conclude, this current study introduces an approach to diabetes management that utilizes local cultural resources to maintain inner peace as an important source of good health. This study suggests that cultural values should be discussed and advocated in Type 2 diabetes intervention programs because participants are continuously attempting to make sense of womanhood and their roles within Javanese culture.

### **Theoretical Implications**

#### **Implications for health and communication research.**

While similar topics have been the focus of studies among Western scholars, the approach taken in this study has not been used in Indonesia. The need to understand the prevalence of diabetes and the epidemiological situation is increasingly important considering the rapid development of the disease in both urban and rural areas in Indonesia. Diabetes, formerly considered to be a "rich person's disease," has spread throughout the population, including the poor and uninsured. Women have higher rates of

diabetes than men in Indonesia. No studies were found that focus specifically on understanding the lived experience of people (especially women) with Type 2 diabetes in Indonesia. So, policy makers do not have sufficient information about the experiences of individuals with diabetes, their suffering and struggles in managing their everyday lives.

Given the varying cultural and ethnic backgrounds, this study cannot represent all Indonesian women. Even Java Island itself is divided into three provinces with different ethnicities, languages, histories, and traditions. Many aspects of life related to culture and health remain undiscovered, as is the case with gender roles, management of diabetes, health disparities, and degrees of social support. The findings here suggest that Javanese women utilize cultural values to manage Type 2 diabetes, leading to questions about whether different ethnic groups in Indonesia adopt similar approaches to health, illness, and treatment. Javanese cultural conceptions of health and illness recognize the importance of maintaining harmony to good health.

From the culture-centered approach (Dutta-Bergman, 2004), the findings in this current study are useful in policy development. These narratives provide detailed stories that can help policy makers understand how Javanese women (and others) make sense of their environment and negotiate ideological constraints. While data in this current study was

gathered in a patriarchal culture, a study of matriarchal societies in Indonesia would enhance substantially our understanding of various socio-cultural issues surrounding diabetes in Indonesia.

### **Implications for policy development.**

Poverty and cultural aspects join to create conditions that require careful policy design. Diabetes is a global issue, and Indonesia faces a battle to decrease mortality rates from the disease. It is apparent that no single solution exists, especially in light of the numerous reasons for increased prevalence of the disease.

Although suggesting specific policies is beyond the scope of this study documenting Javanese women's lived experience with Type 2 diabetes provides valuable information about the day-to-day effects of the disease on the individual, the family, and society in general. Rich descriptions about how women maintain their roles, support their families, and meet social obligations are useful in designing diabetes education programs, commonly known as Diabetes Self Management Education (DSME) in Indonesia. Encouraging individuals to take active roles in managing their disease, including performing regular blood sugar checks, managing their diets, performing regular exercise, and taking medicines as prescribed are crucial. All that many Javanese women know about

managing Type 2 diabetes, according to their narratives, is that they have restricted amounts and varieties of food.

The power distance that exists between doctors and women make women more comfortable talking to *mantri* rather than a doctor, and are more likely to consult *mantri* for all kinds of information. Cultural issues surrounding “fit” that are also considered in this study, are useful in helping organizations and institutions develop culturally-sensitive policies to reduce the incidence and severity of Type 2 diabetes.

Quality of care and the availability of reliable healthcare professionals are problems that women in this study mentioned. In Indonesia, quality care for diabetes patients is hampered by a poor healthcare system (Soewondo et al., 2013). Findings from this study are useful in helping governments and health organizations develop better policies and intervention programs for marginalized groups such as the poor women included here. Participatory programs offer an effective strategy to get people, especially women with Type 2 diabetes, involved in the education process.

### **Limitations of The Study**

This study has several limitations. Limited geographic and demographic coverage is the first. With little funding, geographic and demographic coverage, as well as time to gather data were limited. Ideally,

considering that Java consists of people from Central Java, East Java, and DIY Yogyakarta, this study would provide a more balanced picture of women with Type 2 diabetes if all three parts of Java were included. However, due to the constraints mentioned, this study only includes participants from Central Java and DIY Yogyakarta. In terms of demography, this study includes women from middle socio-economic groups and poor women.

A second limitation is the issue of generalization. Although the sample was appropriate for providing the researcher with valuable insights into the lived experiences of Javanese women with Type 2 diabetes, the findings cannot be generalized to other Indonesian women. Indonesian women belong to various cultural and ethnic groups, therefore what Javanese women with Type 2 diabetes experience may not be the same as Acehese women's experience with the same disease, for example.

A third limitation is the lack of secondary data needed to provide information about the prevalence of diabetes and the development of this disease across the nation, and over time. A rather exhaustive search produced a few journals containing statistical data about diabetes prevalence in Indonesia. The only national basic health research report (RISKEDAS) does not provide detailed descriptions of socio-cultural and demographic information about diabetics in Indonesia.

The fourth limitation is translation. Javanese and Indonesian languages include terms that have no precise equivalent English terms. Capturing certain expressions and nuances in translations diminish the sharpness of the data. A Javanese-English dictionary was helpful in translating the interviews.

### **Directions for Future Research**

This study provides insights into health issues in Indonesia. However, what is discussed in this study covers a small number of issues among myriad health issues surrounding chronic illness, especially diabetes. As mentioned, Javanese women's lived experiences with Type 2 diabetes cannot be generalized to women from other ethnic groups. Issues such as gender roles and health decisions, the influence of socio-economic conditions on diabetes management, language barriers, and the influence of religion in the management of Type 2 diabetes and other chronic diseases should be further studied.

As a country with more than 300 ethnic groups, more intercultural comparison studies should be conducted to enhance understanding about how women from other parts of the country react to the diagnosis of diabetes. Comparative studies of women from different socio-economic and geographic areas is important research that can identify and explore potential barriers to Type 2 diabetes education and management. Although

studies and concepts of lay perspectives of Type 2 diabetes have been widely conducted in Western society, this particular topic has not received enough attention in Indonesia. Information about lay people's perspectives and behaviors toward Type 2 diabetes and the disruptions introduced by this disease would help healthcare providers develop culturally appropriate approaches to diabetes treatment and education.

As found in this current study, Javanese women's cultural conceptualizations of Type 2 diabetes include the definition of diabetes as a "disease of the heart." Their lived experiences with this disease provide deeper understandings of the beliefs about the factors that cause diabetes, the effects that diabetes bring into their lives, how diabetes challenges family relationships and the interactions among women with diabetes and others, and how these women strategically manage the disease while simultaneously maintaining family harmony and harmonious interactions with others.

Broadening research activities to better understand the socio-cultural aspects of Type 2 diabetes will provide a foundation for the development of culturally-sensitive intervention programs, especially those that recognize which cultural values provide the best fit for education programs designed to prevent and treat Type 2 diabetes in Indonesia.

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## APPENDIX A

### Interview Protocol: Interview for Patients with Diabetes

#### Current health status

1. Did you experience any complications or episode of diabetic symptoms in the past three months? [ask the follow-up questions if they answer yes.]
  - i. What happened? How did you manage it?
  - ii. Did you talk to anyone about it? Who did you talk to? Why?
  - iii. Did you talk to your doctor about it? Why or why not?
2. Are you satisfied with your management of diabetes or do you wish to do differently about your current management of diabetes? What are they? Why are you not doing them right now?
3. How much do you feel you currently know about diabetes? (a lot, a moderate amount, not much, nothing at all). Do you wish to know more, or are you comfortable with the information you have? Why?

#### Current Social Support

4. If you need to find information related to diabetes, what would you usually do to find the information?
5. Are there particular person who is important in your management of diabetes? Why?
6. Do you find it comfortable to ask diabetes-related question to your health care providers? Why or why not?
7. Do you talk to anyone in your family about diabetes-related topics? Who do you talk to? Why?

#### Meanings of Social Support

8. Does your husband help you manage your diabetes? In what ways?
9. Do you at times try NOT to ask help from your family members even though you need it? [Ask them to give you an example.] Why?
10. Do you, at times, ask for help (e.g., emotional, instrumental, or relational support) from your family members, even though you don't need it? [Ask them to give you an example.] Why?
11. Do you think your role as a wife presents challenges in your management of diabetes? In what way?

12. Do you think your role as a mother influences your management of diabetes? In what way?
13. What is the most important thing your family can do in supporting your management of diabetes? Why?
14. Do you find any type of support problematic, stressful, or insensitive? What are they? Why do you feel that way

#### Appraisal and Coping

15. Do you experience uncertainty about diabetes in the past 3 months? (e.g., treatment options, symptoms, health maintenance, complications, self-management)
16. Do you talk to anyone about that?
17. Did you talk about your anxiety with your family members?
  - i. if no, why?
  - ii. if yes, do you think it was helpful? Why was he or she helpful (or not helpful)?
18. Are there any other concerns that you'd like to talk to your family members but have not talked about it yet? What are they? Why have you not talked to your support about them?
19. Do you worry about not having the skills and resources to cope with diabetes?
  - i. if no, next question.
  - ii. If yes, what kind of skills and resources do you think you need? Do you think your supportive others can help you with these skills and resources?
20. Does anybody go to the medical appointments with you?
  - i. if yes, why do they go with you? Do they talk to the doctors at all? What do they talk about? How do you feel about that?
  - ii. if no, why do you think they don't come with you? How do you feel about that?
21. Are there any other things that you think may be helpful for our research team to know about how social support can be helpful or unhelpful to your management of diabetes?

## APPENDIX B

### Interview Protocol: Interview for Patients with Diabetes (Modification)

#### **I. Women's role and diabetes**

1. How does diabetes change your life? In what way?
2. Do you worry about how your diabetes may impact your families? In what ways? How do you cope with it?
3. Do you think your role as a mother influence your management of diabetes?
  - i. How do you value your children needs?
4. In what ways does your diabetes influence your relationship with your husband?
  - i. Anything changed?
  - ii. Do you get frustrated (with your husband) sometimes? About what?
5. Does your family complain to your condition? How you deal with it?

#### **II. Repressed voice**

1. Do you worry about not having enough resources to help you manage the disease?
  - i. What kind of resources do you think you need?
  - ii. Who can provide you with these resources?
2. Do you feel concern of what people think about your diet (i.e. during festivity or social events)?
  - i. How they show their concern? How would you deal with this?
3. Do you think expressing what you feel or complaining on your illness makes you look weak and fragile in front of others?
  - ii. If not agree, what do you expect by doing so?
  - iii. If yes, why?
4. Does your husband provide a space (freedom) for you to manage your diabetes?
  - i. If yes, in what ways?
  - ii. If not, or if you think he is not, how do you understand this and how you cope with this?

5. What would be your priority of life now that you have diabetes? Would you consider as the same as before or somehow change? Why?

**III. Cultural knowledge and adjustment**

1. Do you think your diabetes was caused by your previous diet?
  - i. If yes, can you explain what your diet consisted of/looked like? How do adjust to it now?
  - ii. If no, what do you think would be the cause?
2. How do you compare diabetes with other illnesses that you know?
  - i. What makes you want to pay more/less/same attention to your condition compare to other illnesses you mentioned?
  - ii. How more? How less?
3. Do you put more concern on your family health now after you have diabetes? In what way?
4. How do you describe your life priority today? How do you see your health needs compare to your family needs or other family member's health? Why?
5. Do you think you have to surrender your illness to God? Why?
  - i. Do you believe that your medication and your diabetes management is part of appreciating God's will?

## APPENDIX C

### Map of Indonesia



(Source: [www.mapsofworld.com](http://www.mapsofworld.com) - This map was purchased by the researcher for the purpose of this study)