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# Health as Submission and Social Responsibilities: Embodied Experiences of Javanese Women With Type II Diabetes

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## Abstract

By examining women's experiences with type II diabetes, we explore how illness can provide resources to construct meanings of everyday life in Javanese culture. We conducted in-depth interviews with 30 female participants in Central Java, Indonesia, and adopted grounded theory for data analysis. We identified four themes that diabetes serves as resources for women in Indonesia to (a) normalize suffering, (b) resist social control, (c) accept fate, and (d) validate faith. We concluded by noting three unique aspects of Javanese women's illness management. First, through the performance of submission, our participants demonstrated spirituality and religiosity as essential elements of health. Second, diabetes empowers individuals in everyday suffering through two divergent processes: embracing submission and resisting control. Finally, diabetes provides opportunities for individuals within a social network to (re)negotiate social responsibilities. In summary, diabetes provides unique resources to empower our participants to obtain voices that they otherwise would not have had.

## Keywords

Asia, South / Southeast; Asian people / cultures; diabetes, experiences; illness and disease, lay concepts and practices; lived body; embodiment; bodily experiences; lived experience; health, grounded theory; women's health; gender

Diabetes has become a major global epidemic (Shaw, Sicree, & Zimmet, 2010), with Asian countries among the most vulnerable in the next 20 years (Ramachandran, Wan Ma, & Snehalatha, 2010). Currently, Indonesia ranks ninth among countries with the largest population aged 20 to 79 with diabetes (i.e., 7 million) and is projected to be the sixth by 2030 (i.e., 12 million; Shaw et al., 2010). Despite the large population with diabetes, Indonesia has dedicated little of its health care expenditures for diabetes (Zhang et al., 2010). This reality is particularly disturbing when 5.7% of Indonesians have diabetes, among whom 74% are undiagnosed (Mihardja, Delima, Manz, Ghani, & Soegondo, 2009). Indonesian's failure to aggressively tackle diabetes as a public health crisis can be partially attributed to its illness ideology about diabetes.

In Indonesia, diabetes is considered a Western disease as well as a lifestyle disease (Ferzacca, 2010). The government and the public often portray diabetes as an illness that afflicts only the wealthy and affluent social class (Lieberman, 2003). Indonesian women and marginalized populations are particularly vulnerable to and disproportionally impacted by the illness (Narayan, 2001). Compared with men, Indonesian women face significantly higher prevalence rates for pre-diabetes (11.5% for women vs. 8.7% for men) and diabetes (6.4% vs. 4.9%; Mihardja et al., 2009). Diabetes imposes significant burden on those who have minimal resources.

The cultural and religious contexts in Indonesia often situate women in an inferior position than men, which is also supported by government policies that view women as submissive, passive subordinates to their husband. In Java, the notion of women's nature blends with the thick Javanese sociocultural values, which set boundaries for women's social status/role. Javanese women are mindful of their women's nature (*kodrat*), which is embedded values that define, regulate, and guide their behaviors and life choices (Suryakusuma, 1996). The unique cultural influences on Javanese women's everyday life highlight

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the importance of situating women's experiences in sociocultural, sociopolitical, and socioreligous contexts.

Indonesian women face distinctive challenges as they manage family resources and illness-related challenges at the same time: Competing with the family for limited resources contradicts the ideal womanhood/motherhood identity and obligations prescribed by the sociocultural system. Examining how women maintain their voice and understand their experience in these contested cultural spaces is essential to the theoretical development and practical implications in improving women's health and quality of life (Robinson & Bessell, 2002). A recent study found that family support, particularly support from their children, is essential to the patients' coping with diabetes in Indonesia (Kanbara et al., 2008). As one of the first studies to situate Javanese women's experiences of diabetes in contexts, we aim to (a) examine how they cope with diabetes within their cultural settings, (b) give voice to their experience that goes beyond medical categorization, and (c) explore how the ill condition provides a space for them to manage everyday life.

## Method

### Participants and Procedure

This study aims to examine women's experiences with diabetes in Javanese cultural contexts. Because illness narratives give coherence, symbolism, and meaning to the distinctive events of long-term conditions (Kleinman, 1988), we used semi-structured, in-depth interviews to explore participants' illness narratives, examining the various contexts that shaped their lived stories and embodied experiences (Linde, 1993).

In 2012, the first author visited her home country, Indonesia, and conducted 30 in-depth interviews with women diagnosed with type II diabetes from urban cities in Central Java, Indonesia. Participants were recruited at the Indonesia Diabetes Association (PERSADIA) Central Java branch office, where members of this community group conduct their weekly meetings. Java is an island of Indonesia, with a population of 135 million and is the home of 60% the Indonesian population. As an ethnic group, Javanese accounts for 40.6% of the Indonesian population (Central Intelligence Agency, 2013). The average age of our participants was 52.8 ($SD = 8.7$), with a mean of 6.1 years ($SD = 4.3$) since initial diagnosis. Among the participants, 16 self-identified as Christians and 14 as Muslim. All participants are self-identified as Javanese. Each is assigned a pseudonym.

The first author conducted individual interviews in local languages and Javanese ethnic language, which include culturally related expressions. Each interview lasted about 1 hour. All interviews were audio-recorded and transcribed verbatim by the first author. All research procedures have been approved by the Institutional Review Board of the University of Oklahoma.

### Data Analysis

We used grounded theory, a constant comparative analysis, for data analysis (Charmaz, 2006) and NVivo 10 to organize and code all data (i.e., audio data, transcripts, and analytic memos). The two authors first independently coded half of the interviews ($n = 15$) that were translated into English by the first author. Throughout the coding process, we held regular meetings to review our individual memos and the lists of themes together to check for inconsistencies, clarifications, or missing themes and develop a central set of categories. After the central set of categories were developed, the first author then went back to the other 15 interviews and coded the rest of the data. The authors continue to hold regular meetings to discuss necessary modifications of themes and/or categories.

During the open coding, one of the major themes emerged was that our participants do not necessarily view diabetes as an illness condition but strategically construct diabetes as a life experience and life resource in their everyday life. As a result, in the focused coding process, we identified all narratives in which women discuss how diabetes (a) provide meanings to their everyday experiences, (b) facilitate understanding of their roles (e.g., a woman, mother, daughter, and/or wife), and (c) facilitate or compromise their performance of those roles. Then, we adopted axial coding, focusing on how women utilize diabetes as a resources to cope with their social roles in everyday life. We italicized the participants' narratives to highlight our emphasis.

## Results

It is important to note that our participants do not view their diabetes from a Western biomedical perspective, conceptualizing the severity of their illnesses in clinical terms. 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. For our participants, illness generates a space for them to reflect and live the life principles that guide their everyday life. It is from this perspective that we identified four themes/functions that diabetes has provided resources for women in Indonesia to (a) normalize suffering, (b) resist social control, (c) accept fate, and (d) validate faith. In Table 1, we illustrate the theoretical framework generated through grounded theory by summarizing these functions, their existential conditions (i.e., our participants' understanding of these functions in relation to diabetes), and the corresponding beliefs and behaviors.

**Table 1.** Functions of Diabetes as a Resource for Indonesian Women's Everyday Life.

| Functions | Existential Conditions and the Corresponding Beliefs and Behaviors |
|---|---|
| Normalize Suffering | Diabetes as a part of everyday life<br>• Diabetes is one of many minor inconveniences in everyday life<br>• Severity of diabetes is conceptualized through its disruption to individuals' social responsibilities |
| | Normalizing disrupted relationships<br>• Diabetes reinforces their biographies of lifelong suffering in troubled relationships<br>• Diabetes allows them to justify, trivialize, and ignore problems in their social worlds |
| Resist Social Control | Claiming autonomy through personality flaws<br>• Embracing internal locus of control but attributing diabetes and poor illness management as validations of their personality flaws (i.e., who they are) as opposed to problematic behaviors that can be changed |
| | Self-reliance and (passive-) aggressive behaviors<br>• Emphasizing self-reliance in illness management as a way to refuse others' assistance, monitoring, and/or control<br>• Using diabetes to control others by claiming that others' "annoying/upsetting" behaviors contribute to their worsening symptoms or poor illness management |
| Accept Fate | Illness as submission<br>• Diabetes presents opportunities to show patience, grace, and gratitude in face of great difficulties, a testament to their humility<br>• Emotional and physical well-being is achieved through surrendering oneself to hierarchical relationships in social and spiritual worlds |
| | Illness as God's will<br>• One is empowered by the illness experiences as it is all part of God's plan |
| Validate Faith | Health as spiritual well-being<br>• Spiritual well-being is a necessary component of health and requires individuals' active performance and maintenance<br>• Health is an internal state of mind that reflects humility and patience, an ability to accept the reality that was given to them |
| | Diabetes as a test to spiritual strength<br>• Diabetes presents opportunities to re-examine and reaffirm their faith, learning to maintain control over their mind and body and to develop concerns for others<br>• Controlling one's perspectives about illness through faith is an essential part of their management of diabetes |

## Normalizing Suffering

Without prompting, our participants often incorporated their struggles in other contexts (e.g., finance and interpersonal relationships) as part of their illness experiences. It was clear that women in our study struggle with diverse issues in their everyday life. Diabetes, however, allows them to normalize their suffering. Their narratives best reflect the concept of biographical reinforcement (i.e., a reinforcement of identities that had been built prior to their diagnosis; Carricaburu & Pierret, 1995; Olsen, Banwell, & Dance, 2013) as diabetes further reaffirm their lifelong struggles in their everyday life and in interpersonal relationships.

*Diabetes as part of everyday life.* Javanese society categorizes illness in two different terms: ordinary illness (*sakit biasa*; that is, typically referred to as common cold) and severe illness (*sakit parah*; that is, typically identified by obvious physical disruption). Many participants argued that a person has an ordinary disease if he or she can still actively perform their duties as a mother, a wife, a worker, and many other roles. In other words, it is the social disruption, rather than biomedical markers, that defines the severity of an illness. Nasirah explained, "Well, what can I say? I don't feel anything. My only complaint is this thick sole. . . . Up until now, I've always been normal." Magda echoed, "Diabetes doesn't affect me. My sugar was 505 when I first diagnosed with this disease, but nobody can tell that I'm sick. I feel nothing. . . . I feel weak, that's all! Like if you get a common cold."

Diabetes, in this sense, was viewed as part of everyday life, with minor inconvenience but does not necessarily pose disruptions to their social responsibilities. In fact, because many participants experienced dire financial situations and are involved in heavy labor, they did not view diabetes as part of their suffering. For example, rather than reflecting on the frequent fatigue caused by diabetes, Prapti, who is poor and works long hours as a tofu maker, commented, "I am healthy. This is just because I'm tired." It is the demanding labor, rather than diabetes, that made her feel exhausted all the time.

Many participants talked about friends and family members who died prematurely due to diabetes; however, when reflecting on their own experiences, they often viewed diabetes as a common illness with no immediate threat to life. Many explicitly discussed that they were never in conditions in which they were unable to perform their roles. Lastri emphasized, "I never experienced a condition where I got very sick and forced to lay in bed at home and must be taken to the hospital." Similarly, Yuni commented, "It is just diabetes, not like that other scary diseases. . . . It is not that serious like I can't walk or helplessly stay in bed." Helplessly staying in bed (i.e., *ngadag adag*) represents a powerful distinction in our participants' moral claim about their illness status. Rather than referring to their physical suffering, *ngadag adag* highlights the lack of productivity a sick person imposes on her social system, requiring others to share additional burden. Not being in the status of *ngadag adag* is essential to illness identity.

Ability to perform social roles is central to our participants' understanding about diabetes. They described two forms of diabetes that differentiate the severity of the illness: wet diabetes (*kencing manis basah*) and dry diabetes (*kencing manis kering*). Wet diabetes is more dangerous, because it involves physical presentations (e.g., sticky, wet, and unhealed wound). The possibilities of amputation can significantly disrupt individuals' abilities to perform social roles and responsibilities. As a result, they recognized that others may feel disgusted (*gilo, jijik*) and isolate individuals with wet diabetes. Individuals with wet diabetes may also receive additional social sanctions due to their inability to perform their social roles.

*Normalizing disrupted relationships.* An unexpected finding from our data was the prevalence of social suffering. Many commented about their financial struggles, barriers to claim an illness identity, or inability to perform normal social roles and responsibilities. More importantly, we were surprised by many women's report of difficult and hostile relationships with their family members. Without prompting, some participants disclosed information suggesting highly disrupted relationships in their social network. For example, Lastri said, "My children never entrust their children to me. . . . If in the future my grandchildren do not recognize me as their grandmother, I'm fine." Jeki commented that her son offers her little support and explained, "Javanese elderly used to say that having a son is like playing a lottery, if you are lucky you'll get the advantages out of them, if not . . . then you get nothing."

When asked what kind of support she received to help her cope with diabetes, Puspa responded, "Nobody. I'm on my own (smile)." She then explained that her husband continues to pressure her for sex after her menopause. She also discussed incidents in which her husband presented verbal threats (e.g., suggesting that he would move to a different room if she refuses to have sex with him) and violent acts (e.g., destroying the doctors' notes for her). He also kept all his income and refused to contribute to family finances; as a result, she had to take extra jobs to support the family expenses. She concluded, "If I ran out of something in the house, nobody will help. I have to take care of that problem myself. . . . I often have big fights with my husband." Nana emphasized that she has to take full responsibility of her illness management because "nobody" in her family cares: "I have to manage my disease on my own. Well . . . I don't want to say it but . . . sometimes I wonder—I have a husband, but I feel like I'm completely alone." The disrupted relationships often become the thread of their illness stories as they discuss their experiences of managing diabetes in their everyday life. The unique characteristics of diabetes, which require significant social support and collaboration, may have made the issues of disrupted relationships particularly salient for our participants during the interviews.

However, our participants appeared to use diabetes as a way to trivialize, normalize, or avoid their problematic relationships in their social networks. For example, despite earlier complaint about lack of trust from her children, Lastri said that when her children invite her to stay a few more days with them, she would say, "No. I will run out of drugs!" Rather than planning to take more medication for the trip, she used her diabetes as a reason for not being able to invest more time with her children. Lastri also commented how her children used her diabetes narratives "against" her. She explained, "If I try to carry my grandchild in my arm, my son/daughter-in-law or my children would immediately grab their child and ask me not to carry the child and not to get tired." Such a comment is interesting because typically this could be perceived as a caring act (e.g., not wanting grandchildren to overburden Lastri). However, because Lastri had explicitly discussed the hostile relationships with her children, she viewed it as an excuse used to refuse her access to her grandchildren. When asked whether she actually gets tired, she responded in a high pitch, "It does not matter (smile). I personally feel lazy when I have to carry [them]."

Rather than discussing how the lack of support, love, and care may contribute to her problematic relationship with her husband, Puspa argued that the "sexual desire of a diabetic person is greatly decreased, especially when we had menopause." This attitude is shared by many participants. Diabetes is not simply treated as a contributor to their disrupted relationships; rather, it serves as a resource to understand and cope with problems in their social world. It justifies their actions (e.g., refusing to participate in family activities), normalizing or overlooking already troubled relationships. Diabetes reinforces their existing understanding of their social world (e.g., they are on their own).

## Resisting Social Control

Our participants often commented that a woman has strength to tackle the most dreadful situations, including diabetes. As they discussed their lived experiences as persons with diabetes, it was clear that diabetes became part of their life narratives in resisting social control.

*Claiming autonomy through personality flaws.* Based on the cultural expectations and social norms in Indonesia, women are not in a position to claim autonomy or independence as their lives are dedicated to the well-being of the family. After all, submission to God and one's husband is considered a great virtue for a woman. However, our participants discussed how their personality was the cause of their diabetes or problematic illness management.

The interesting finding here is that, on one hand, they emphasize their internal locus of control. For example, several participants explicitly emphasized that it is not social support but self-discipline that is needed for their illness management. "Self-discipline is the key" is a sentence repeated by many participants. Lastri noted, "I discipline myself. Nobody reminds me about these rituals." Wulan echoed,

> This disease is like a demon, haunted my life. But, we don't have to be afraid, we can become a doctor for ourselves, we are free, we can fly high and determine our life, be independent and not depend on others.

Overall, our participants confirmed that diabetes is just another misfortune and hardship in life that one must experience and endure readily. Nur explained,

> I don't want this disease to limit my activities. I won't let the disease to control my mind and make me afraid of doing everything. It doesn't mean that I am weak, but I need to manage my time and my diet.

When asked about whether they receive sufficient social support or how their family provides additional assistance in their management of diabetes, our participants rejected the notion of seeking external assistance. Instead, they emphasized their agency and responsibility in their illness management.

However, after recognizing the internal locus of control, many were quick to attribute personality flaws that define their management of diabetes, recognizing its negative implications to their identity or illness management. In fact, several participants commented that they were warned by their doctors when they were in pre-diabetic status, but they just cannot help their personality flaws, which eventually resulted in them being officially diagnosed with diabetes. Being stubborn and lacking self-discipline were the two flaws that many referenced.

Even after being diagnosed with diabetes, they cannot change their behaviors. Laras commented, "I admit that I still lack discipline! [laughter] I often do not take medication and treat myself with sweet food! [laughter]." Marni also said, "All of my children always warned me not to drink sweets. . . . But, I can't resist this fruit syrup. I really can't resist it! Hahaha! I sometimes drink three glass of cold syrup!" Surti's narrative best illustrated this tension:

> [By] reading books about diabetes, I know that people with diabetes must take their medicines regularly. Only that . . . I feel bored. Bored because I have to consistently take the medicines, otherwise my blood sugar level will rise up. Sometimes I'm stubborn and I must take risk by myself. The risk is tremendous.

The rhetoric here is interesting in that they do take ownership of the illness but, at the same time, claim that their personality cannot be helped. By framing these behaviors as behaviors that assert their individuality, the participants made it difficult for others to challenge their diet choices as it is not a choice but who they are.

*Self-reliance and (passive-) aggressive behaviors.* Many participants emphasized their agency and self-reliance to rebuff others' attempt to control their diet. It is important to note that the pressure experienced by our participants is not necessarily about having a healthy diet. For example, Magda's son raised concerns about her refusal to participate in family feasts, an important social activity in Javanese culture to demonstrate bonding, respect, and trust with your loved ones by overindulging rich, sweet food. When Magda's son challenged her about her strict diet, she responded, "Why not? I want to live another 1,000 years. . . . Only by disciplining my diet, I can survive another day." Surti commented, "I actually never ask for help, so far. I use to live independently, since I was single. I do everything on my own!" From this perspective, self-reliance is consistent with the earlier emphasis on internal locus of control.

The emphasis on self-reliance, however, also can function as a refusal to others' assistance, monitoring, and/or control. Nana commented that she often goes home exhausted after pretending to be fine all day: "I don't want people to see me as a sick person! I don't want to disturb people with my condition and become their burden. . . . I do everything myself." Later, Nana revealed that her primary reason for pretending to be healthy and energetic, even though she was in great pain, was that she was extremely worried about losing her job if others think that she is weak. When Lastri's daughter refused to buy more Coke for her, she responded, "How dare you! Just because you're financially independent, you can yell at me like that? I don't want to drink your Coke! I have my own money to buy it!" In other words, self-reliance for our participants does not necessarily mean that they are empowered, with high internal locus of control. Instead, it was perceived as a way to avoid others' scrutiny and judgment.

Many participants also commented that others can make them sicker by making them annoyed or upset. For example, Surti talked about problematic interpersonal interactions and commented, "If I get annoyed, my blood sugar level will rise up to 580. This is so much higher than when I was hospitalized, 511." Lastri admitted that she often threatens to kill herself:

> Sometimes if I feel so upset, I used to say this joke, "Fine! It is easy for me to die!" [laughter]. I often act like that, you know, especially when people seems annoying. "I'll just drink 250 grams of sugar and I will die instantly!"

From this perspective, the patients use their diabetes in a (passive-) aggressive manner in their everyday life, imposing the burden of illness management to anyone who disrupts their preferred state of mind. The persons who made them upset, annoyed, or angry are the ones who contributed to their worsening symptoms. In addition, by referencing their illness as they engage in conflicts with others, they aggressively attack others' insensitivity while making their identity as an ill person salient.

## Accepting Fate

Attitudes of fatalism are pervasive in our participants' narratives. It is important to note that fatalism constructed in their narratives is not a passive resignation to fate. Instead, it is a performance of and a claim to certain virtues. Accepting fate does not signal a defeat. Rather, it is a show of grace in the face of great struggles. Accepting face involves two different dimensions: Illness as a submission reflects a general sense of submission in all aspects of life; in contrast, illness as God's will centers on recognizing God's power in one's life.

*Illness as submission.* Submission (*Pasrah, kepasrahan*) in Javanese culture is a voluntary act of maintaining social harmony. It is a high virtue for women and the basic principle of Javanese teachings, a moral guidance for social interactions between individuals. For example, Jeki commented that even though she experiences pain during sex due to her age, "I realize my role as a wife, I have to *serve* my husband, and if I have to then I just do it. . . . I just fulfill my *duty* [laughter]." Lastri commented, "The most important now is, if my doctor told me to take medication I must *obey* him." The participants' choice of words reflects a strong sense of submission in a hierarchical relationship.

The understanding of fate and submitting oneself to fate are essential to our participants' illness experiences. For example, Siti explained that "many people don't want to concede [their sickness]," but she does not worry herself with these problems. Instead, she coped with diabetes by recognizing that "this sickness is a destiny." Puspa echoed, "I just *pasrah* (leave it to my fate). . . . I am already 60 year old, how far can I go from that point? Not so long anymore, I think."

In addition, accepting fate requires a show of gratitude in the face of great difficulties. Although Anis had an amputated limb due to her diabetes, she noted, "I believe [ . . . God] will heal my illness. I don't want to be ungrateful person." Surti explained,

> My disease is heredity and my two oldest siblings died because of it. Thus, I accept this as my fate. I know I got this disease as a "legacy" [laughter], but I'm grateful for this. If I took this as a burden and deeply saddened [*ngenes*], I will probably die sooner.

Jeki was very concerned about her meager retirement income and discussed how she has made poor health decisions as a result of it. But then, she commented, "Not that I'm not grateful for that, I'm grateful for what I have. We must accept." Despite the hardship experienced by our participants, their illness reinforces their moral worldviews in which suffering was not questioned but accepted with gratitude and grace. There was no attempt to blame anyone, including the social system and/or God. Rather, their coping with diabetes serves as a testament to their humility.

Participants also noted that accepting fate is necessary to achieve happiness. For example, Wulan said,

> We in the diabetes community group (PERSADIA) have the same fate as diabetics. We just enjoy and make ourselves happy. [ . . . My doctor] called me because I had a comma. But I said, "Don't take it too seriously, just relax."

Fitri argued, "The key is 3Bs: pray (*berdoa*), be grateful (*bersyukur*), and surrender (*berserah*)." Ningsih concluded, "You have to give thanks for every blessing, sickness, sadness, and happiness. Not just the happiness. If you enjoy yourself and are grateful for what you've got, you will feel so much better!" In other words, accepting fate is necessary to achieve emotional and physical well-being.

*Illness as God's will.* Submission to the will of God, a higher power, represents the highest stage of faith in Javanese beliefs. "Thank God" and "With God's permission" were repeatedly uttered by our participants. Lastri explained, "Everybody can be dead, this is the power of God. God's will, we cannot refuse. . . . Everything is God's will, because I have this kind of disease [that I may die suddenly]." Susan echoed, "I leave all my problems to God." Marni echoed, "I totally surrender to God. If I must die, then so be it. I have a satisfied life!"

For the participants, recognizing their illness as God's will can be an empowering experience. For example, Marni explained, "I don't want people to visit me in the hospital and cry. I'm so prepared for this, and I feel I'm strong! I resign my fate to God." Surti also explained, "[My diabetes] doesn't make me depressed at all. Rather, it makes me grateful that God still looks after me. Thus, although I get sick, I can still do my daily activities." Dewi commented, "After six years, I feel there is God's grace behind this disease. Now I have more friends! [laughter]." In other words, their understanding of submission is transformed into empowerment, accepting their limitations as human beings. In addition, as they accept whatever happens to their life as a blessing, they are able to find the silver lining in God's plan. Fitri summarized such attitudes:

> God has a beautiful plan for us. Whatever that is, I will accept it with patience. This illness means that God still loves me. He wants me to remember that there are many people out there that live a more unfortunate life than I do. . . . It is part of His blessings.

## *Validating Faith*

Our participants' understanding of their illness is highly intertwined with their understanding of their faith. Accepting fate highlights our participants' fatalistic attitudes, accepting fate and God's plan with gratitude. In contrast, validating faith reflects how our participants actively (re)frame their experiences of health and illness as experiences of faith.

*Health as spiritual well-being.* Healthy people can be identified by their spirit (*semangat*) and energy. In contrast, according to Ningsih, some people with diabetes look not fresh (*alum*, Javanese word to name dried, thirsty plants). In other words, they had lost the spirit. For our participants, health is a balanced condition of mind and body (i.e., harmony). They defined health as "calming mind, bring physical health (*pikiran tenang, badan sehat*)." Health is a status that cannot be achieved without individuals' spiritual well-being. Ningsih explained,

> It lies here [touching her head and chest]. This is the source of health, but also a source of stress and depression. We need to let go our thoughts, take whatever happens in our life with gratitude, let the spirit flow and you'll be fine.

Javanese worldview emphasizes the importance of achieving spiritual and physical balance, without which the world would be in complete chaos. Spiritual well-being is closely tied to individual's ability to understand life's turmoil in its different faces, such as happiness and sadness, and/or sweetness and bitterness.

Javanese use their feelings and/or senses (*rasa*) to understand and make sense of all kinds of aspects of life, including health and illness (*sehat* and *sakit*). *Rasa* involves a complex state of mind that bound together one's emotional and physical condition. For example, Lastri talked about maintaining her *rasa* as an effort to achieve the harmony with her circumstances. The balance of physical and emotional well-being is not a passive result of good health. Rather, good health requires individuals' effort to actively manage and balance these two elements. Ningsih explained,

> Diabetes is not a terrifying thing (*momok*), it cannot be cured but you need to put the effort in your life. God gives you fortune, but if you don't work on that, you'll get nothing! The same thing with your health.

For many participants, spiritual well-being is understood through their faith. Several participants also commented that keeping their mind and their feelings healthy (e.g., feeling grateful to God) is critical to their physical health. Several participants noted that diabetes must not be used as an excuse to stay in the house and to lament on their unfortunate condition. In addition, the key to their stable condition is patience (*sabar, sareh*), without which one cannot enjoy life. All participants regardless of their religion considered health as God's gift, emerging from an individual's faithfulness to God's command.

In summary, our participants do not view health as an external status to be claimed or achieved through goal-oriented efforts (e.g., exercise five times a week to have good cardiovascular health). Rather, it is an internal state of mind that reflects humility and patience, an ability to accept the reality that was given to them. Being healthy is not a biological achievement, but a testament to an individual's moral character and resilient faith.

*Diabetes as a test to spiritual strength.* Several participants commented that diabetes can be a scary disease, even a curse. Siti noted,

> I never talk to my family about my disease. People in my village think that diabetes is a curse. According to villagers, you get diabetes because you committed many sins in your life. . . . I got divorced from my husband, and I don't want people in my village think that I got diabetes because of my divorce.

Some participants also had the notion that God punished them with diabetes. For example, Trias said that she sometimes questioned God at night, "God, is this disease a punishment of my sins? Was it wrong for me to leave my husband? But he cheated on me so many times."

Many also viewed diabetes as a test for a person's spiritual strength, an opportunity for a person to honor her or his faith. Some participants noted that they are not afraid of the test. For example, Marni said, "I am not afraid, because I have God. Illnesses come from God, and He will also give the cure." Yayuk echoed, "We are lucky to have faith in God. . . . I just help with prayers. I call God's name every time. Ask God to heal." Ningsih explained, "I was so frightened, but then after a while I begin to enjoy my life. . . . I also keep going to the church and praying club, so I feel that God is with me."

Others emphasized the idea that God helps those who help themselves. For example, Ningsih explains,

> When you get so sick, you will blame God, "Oh God tests me, trials me." What I know, God never tests you. . . . God is full of love and grace. He will ease our burden. He shows us the way and all we have to do is to work on it.

Rather than emphasizing on individuals' responsibilities for appropriate diet and exercises, Jeki noted that she has been planning to attend the Hajj, the traditional Muslim pilgrimage to Mecca. She explained, "May God give me health during the pilgrimage. I pray that after I finish the trip, my disease will become better."

In summary, for many participants, diabetes was not a disaster in their life story. Rather, it provides the opportunity for them to re-examine and reaffirm their faith, learning to maintain control over their mind and body, and to develop concern for others. Our participants agreed that acceptance and resignation (*kepasrahan*) are the key to better health. Life is not only about being biologically healthy or ill; rather, it is about controlling your perspectives about illness. As Magda explained,

> We can't argue with this disease, instead we must treat it like a friend and walk together. It must not influence your life or change who you are as a person . . . If God wants to take my life, so be it. I am not afraid.

## Discussion

Following the social constructionist traditions of health and illness (Conrad & Barker, 2010), we recognize that the meaning of diabetes is culturally situated and socially enacted in Javanese women's everyday life. In light of the narratives from these participants, the idea that a lack of knowledge about type II diabetes and the prescribed treatments for it are key determinants of diabetes management behaviors is not supported here (Anderson et al., 1995; Peel, Parry, Douglas, & Lawton, 2005). Rather, for our participants, diabetes management is most related to their personal, familial, and social obligations and the resources available to the family (see also Kong & Hsieh, 2012). 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. We found that for Javanese women, (a) spirituality and religiosity are essential to health, (b) diabetes empowers individuals in everyday suffering, and (c) diabetes provides opportunities to negotiate social responsibilities.

### Spirituality and Religiosity Are Essential to Health

For our participants, health is not just a biological status. Rather, health is enacted through the constant balancing of physical and spiritual/religious well-being. This understanding echoes with the Javanese concept of viewing body and mind as a single entity (*sehat lahir batin*): One simply cannot be healthy without spiritual/religious well-being. A healthy status is accomplished by finding the harmony between one's material and spiritual well-being (Geertz, 1960; Muttaqin, 2012).

In addition, our participants construct health as the performance and accomplishment of a specific cultural virtue, submission. Submission can include multiple forms, such as submission to authorities (e.g., husbands and doctors) and to a higher power (e.g., surrender to God [*Berserah*]). Researchers have argued that spiritual/religious coping can be active, adaptive coping strategies (Thuné-Boyle, Stygall, Keshtgar, & Newman, 2006). For our participants, accepting everything in life as fate (*takdir* or *nasib*) is a form of religious devotion and a moral claim. Submission, as a coping strategy, is the embodiment of the Javanese teaching by achieving a peaceful mind (*tentreming ati*) through patience, grace, and gratitude under stress.

Our participants did not view submission as resignation to fate that negates human agency, a form of passive fatalism or inaction that is often conceptualized in the West (Franklin et al., 2007). Because Javanese philosophy views accepting fate as a sign of emotional and spiritual maturity, illness presents tests and opportunities to perform cultural virtues and to validate faith. It requires individuals' active and persistent effort to demonstrate their humility. Submission allows our participants to achieve emotional equanimity (Geertz, 1960), a condition that enables individuals to control their feelings (*rasa, perasaan*) from being hurt under duress.

This finding echoes with a previous study, in which 95% of Arabic patients (all Muslim) reported to accept illness and bear it calmly, whereas only one third of German patients (87% Christian) reported similar attitudes (Büssing, Abu-Hassan, Matthiessen, & Ostermann, 2007). In the same study, 95% of Arabic patients reported that the illness has no influence on life because it is fixed by fate, whereas 54% of German patients disagreed with such a statement. Büssing, Matthiessen, Ostermann, and Abuhassan (2006) argued that the differences between Arabic and German patients may be caused by cultural *or* religious differences. We believe that Javanese culture, rather than individual faith, shapes how our participants interpret their illness. Our participants constantly praised God/Allah for His mercy and kindness throughout the interviews, regardless of their religions. When asked about their current conditions, Muslim participants often started with, "Alhamdulillah, I'm fine" (*Alhamdulillah, sehat*) and Christians with, "Thank God, I'm fine" (*Puji Tuhan, sehat*). Accepting what God has given to individuals without resisting embodies the Javanese virtue of sincere acceptance (*nrima*).

In addition, because submission is situated within these women's social network, it allows women to maintain social harmony, an essential element of our participants' understanding of spiritual well-being. Rather than complaining about the lack of coping resources and social support, our participants opted for the narratives of self-discipline and self-reliance. The symptoms of diabetes are irrelevant to their identity as long as they can maintain their social functions. By continuing their social roles despite physical discomfort, they create minimal disruption to their social world. More importantly, this performance of submission (e.g., continue to work despite chronic fatigue or have sex with the husband regardless of pain) allows them to achieve the moral claim of health: They are healthy as long as they can perform their social responsibilities.

Submission offers Javanese women the strength to endure suffering (Handayani & Novianto, 2004). By constructing submission as an essential element of spiritual/religious well-being, our participants learn to accept and endure the injustice and inequality as a result of their lower social hierarchy and the lack of resources. Submission encourages women to accept suffering without resistance.

## *Diabetes Empowers Individuals in Everyday Suffering*

Although empowerment traditionally is confounded with control, our findings echo with an emerging understanding of empowerment: "[T]he process of relinquishing control is as central to empowerment as is the process of gaining control" (Aujoulat, Marcolongo, Bonadiman, & Deccache, 2008, p. 1128). For our participants, an ill body is not a deviant to be fixed but a resource to interpret and construct meanings of their everyday suffering (Kelly & Field, 1996). Diabetes empowers our participants through two seemingly opposing processes: embracing submission and resisting/exerting control.

First, diabetes reframes their experiences of suffering to encourage submission. A recent review found that submission, as adaptive coping strategy in low control situations, empowers individuals by providing "multiple routes for salvation from the anxious uncertainties inherent in human life" (Kay, Gaucher, McGregor, & Nash, 2010, p. 44). Our participants normalized suffering from diabetes and its corresponding symptoms as part of everyday life experiences. In addition, diabetes allows them to justify, trivialize, and ignore suffering in other aspects of life (e.g., deteriorating, dysfunctional relationships). Rather than struggling to maintain control over their everyday life, they acknowledged that diabetes has deprived them the energy, ability, or resources needed to attend to their suffering. In other words, these everyday sufferings were inevitable because they have diabetes. By accepting the loss of control (Aujoulat et al., 2008) and embracing submission (Kay et al., 2010), our participants transform the meanings of suffering and created a new, coherent meaning for their everyday life. In addition, submission provides a valuable resource for them to restore a sense of control by demonstrating their ability to maintain patience, grace, and gratitude in the face of suffering.

Second, diabetes provides our participants voice and power that they otherwise would not have had to resist and exert control. Under the sociocultural pressure for submission through self-control of emotions and attitudes, it is intriguing that our participants readily accept blame for their lack of self-discipline. Rather than appearing ashamed or apologetic, our participants acknowledged and laughed about their deviant behaviors (e.g., uncontrolled diet) and personality flaws (e.g., stubbornness) that contributed to their diabetes. Under the intense pressure for women's performance of humility, it may be difficult for Javanese women to claim independence or self-determination. However, diabetes is the proof that they are born this way. It cannot be helped. Thus, the submission narratives take on an interesting turn. Our participants accept and "submit" to their personality flaws, which presumably were given by God. Their defiance to others' control and subjugation was unavoidable. In addition, for some of our participants, they moved beyond the passive-aggressive claim of flawed identities and aggressively used diabetes as a resource to control others. By threatening to endanger one's life by drinking sweet tea or emphasizing that the worsening of their illness can be caused by annoying others, these women actively exert control on others' behaviors.

In short, our participants adopt a wide range of strategies to cope with their suffering. The embodiment of submission allows them to maintain strength and restore a sense of control in hostile, exhausting conditions. In line with the concept of social body, diabetes allows our participants to make their existence present, and the body that often is unnoticed in everyday life makes its presence known (Fox, 2012; Williams & Bendelow, 1998). From passive resistance to aggressive control of others, our participants strategically reframe the meanings of diabetes to (re)gain and (re)claim power in their social worlds.

### Diabetes Provides Opportunities to Negotiate Social Responsibilities

Diabetes provides resources and opportunities for our participants to (re)construct their social worlds. Although our participants accept and perform the rhetoric of submission, they do not passively accept the social inequality. In fact, they actively manipulate and transform the meanings of their experiences to (re)gain and (re)claim power in their social worlds.

A good example is our participants' repeated emphasis of self-discipline and self-reliance. Our findings show that such narratives differ from the Western understanding of independence, in which self-determining individuality is celebrated (Bulbeck, 1998). These narratives were constructed as a response to the lack of social support. Not imposing additional burden on their social network was a virtue to be claimed. In fact, if they were to have wet diabetes (i.e., illness marked by its physical deformity) or to stay in bed (*ngadag adag*), they are likely to experience social sanction/isolation.

However, many participants also used the same narratives as defiance to others' control. They rejected others' monitoring of their diet and ignored others' needs, claiming that their ill condition made it necessary for them to be self-centered. In addition, by aggressively blaming annoying, unsupportive others for their worsening conditions, they impose the pressure for social harmony on others. The pressure for social harmony is negated as they negotiate social responsibilities with others, claiming autonomy and power in everyday life.

It is important to note that our participants' illness narratives are not without challenge from their social network. Others can utilize the same illness narratives to redefine their social relationship. For example, Lastri's children refused to let her touch her grandchildren because she, as a person with diabetes, would get tired. If Lastri wishes to maintain her illness identity along with its privileges, she will have to agree and accept others' use of the same narratives. From this perspective, the struggles for autonomy, power, and control through illness narratives are not static. Patients do not always have full control of the meanings and consequences of their illness identity, which are constantly negotiated and reconstructed in our participants' social worlds.

## Conclusion

By moving beyond the social construction of illness experience (Conrad & Barker, 2010), we explored how Javanese women's everyday life can be shaped by their illness experiences. Our participants actively weaved diabetes into their lived experiences. Javanese women's body bears inevitable cultural tasks. First, it is a symbol of social order, within which Javanese women embody the harmony of everyday life and balance of physical and spiritual/religious well-being. Second, it is a symbol of social interactions, within which Javanese women maintain their valued identity within the social system and diverse contexts. Diabetes provides unique resources for the sense-making process of their everyday life, empowering them to face their suffering and obtain voices that they otherwise would not have had.

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