The Healing Corridor: A Critical Phenomenology of Severe Illness, Impairment and Care in Java

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April 2020

A thesis submitted for the degree of Doctor of Philosophy
of The Australian National University

Declaration

I declare that this thesis is the result of my own individual work and research and has not previously been submitted for a degree at any tertiary education.

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Yogyakarta, 30 April 2020

Abstract

This dissertation explores subjective accounts among Javanese of the experience of severe illness (namely, osteosarcoma and associated bodily impairment) and care. This thesis argues that the biomedical diagnosis and treatment of illness and disability that has dominated health care for the past few centuries cannot fully treat many kinds of illness. This thesis takes illness narratives as its lens to examine ideas of self and personhood in Yogyakarta, Java, Indonesia. In doing so, the ethnographic research shows that the social structures that construct individuals and social identities through modern notions of body care are complemented by Javanese approaches marked by mysticism and spiritualism. The analysis explores affect as a significant element in cultural meaning and value complementing biomedical treatment and healing. It is shown that practices of spiritual cultivation in particular build up the Javanese ideal of personhood and holistic healing patterns.

Within the special region of Yogyakarta, the influence of the aristocracy, their values, practices and beliefs are still meaningful in local society and are taken to be a powerful tie uniting people with the cosmic order. The embodied mysticality enacted through not only the religion of Islam but also the Yogyakarta Kraton's existence colours the way Javanese individuals make sense of their fate and inspiration. In the Javanese view of life God elevates human *batin* (spiritual selves or lives) above *lahir* (physical lives), signifying the importance of caring for the spirit as well as the body. This study shows how illness and disability are narrated and the emotional context in which Javanese repress their emotions and conceal turmoil through the idioms of *syukur* (acknowledge blessing) and *nrima* (acceptance).

This study contributes to a broader understanding of experiences of embodiment, inclusion and personhood by illuminating people's agentive submission to relations of deprivation and disability. By focusing on how people think and feel about chronic illness, impairment and care, it is suggested that flows of affect that circulate widely in the clinic and everyday life demonstrate that Javanese seek to combine spiritual, moral and physical care in balance. The sick and disabled poor have practices and ways of responding to trauma and are not powerless in the matrix of power and control that regularly targets and disempowers them.

Acknowledgements

First and foremost, I would like to thank God. It was a privileged time and the most profound life experience to have been in touch with clinicians and people who experience chronic illnesses and impairments. This work is dedicated to them and to many families whose loved ones lost their lives after experiencing illness and disabilities.

The part of my life I spent working towards this Ph.D. at the Australian National University was another episode of 'life within Life.' It has been six years of vibrant intellectual stimulation and laborious study under the guidance of an extremely disciplined chair of supervisors, Assoc. Prof. Patrick Guinness. I take this opportunity to express my deepest graduate and sincere thanks to him who inspired me when I needed it most and opened up for me a wide horizon of intellectual life. He has allowed me to grow and develop as an anthropologist and more yet as a person. I also express my sincere thanks to my supervisor panel members Dr. Margaret (Margot) Lyon, Prof. Christine Phillips and to my advisor Dr. Zazie Bowen who initiated me into research in the humanities and has continued to support me since.

I owe a great dept of gratitude to ANU colleagues Philip Taylor, Andrew Kipnis, Assa Doron, and James Fox whose intellectual stimulation molded my ideas. Thanks also to Kirin Narayan who inspired my narrative writing style. Thanks to Dr Philip Kitley, Dr Diana Glazebrook and Dr Carolyn Brewer for editorial assistance throughout the writing of this dissertation. Thanks to Frida, Siti, Moeklas and Adit for field research assistance in Yogyakarta. And thanks to my Anthropology writing group friends, Poonnatree Jiaviriyaboonya, Muhammad Kavesh, Hellen Abbott, Meizhen Wen, Simon Theobald, Xeem (Noorazah) Mohd Noor, Maria Ortega, Karen Hansen who all helped keep me in touch with current streams of research. I will miss the discussions that I had with them in such a strong academic environment.

My PhD life would not have been possible without the critical support of Prof. Dr. dr. Sri Suparyati Soenarto, Sp. A (K), PhD, Prof. Dr. dr. Soenarto Sastrowijoto, SpTHT(K) whose recommendations opened up access to clinical and hospital life in Yogyakarta. Thanks to Prof. Dra. RA Yayi Suryo Prabandari, Msi., PhD, Prof. dr. Mohammad Hakimi, Sp. OG, Ph. D, Prof. dr. Sofia Mubarika Haryana, M.Med. Sc, Ph. D, dr. Edy Moeljono, Sp.Rad, Dr.Dra. Retna Siwi Padmawati, M.A, dr. Azid Mahardinata, dr. Wika Hartanti, MIH who always supported me ever since I joined the Centre of Bioethics and Medical Humanity at the

Medical Faculty, UGM. Their support has given me the opportunity to do research in hospitals in Yogyakarta. I also wish to thank Inez Nimpuno, Fadliya Tjatur and Desi Indrimayutri for unconditional care that inspired enthusiasm in me. Thanks also to Amalinda Savirani, Nicolaas Warouw, and to Nanang Indra Kurniawan who encouraged me ever since I applied for the Australian Leadership Awards and Scholarship. I sincerely thank my peeps—Gita Nasution, Rizki Fillaili, and I Nyoman Sutarsa—for enriching my PhD journey with their fruitful discussion, love and care. Thanks also to Edward Aspinall, Greg Fealy, Colum Graham, Marcus Mietzner, Mbak Nuke, Ade Dungga and Mas Tomy, Riyana Miranti and Mas Oki, Ariane Utomo, Reno Sofwan, Haula Noor, Eni Martina and Dina Yulia for supporting me and my family during our stay in Canberra.

I cannot begin to express my gratitude to my parents papap and mamah, and my brother Rully Saepul for all of the love, support, encouragement and prayers they have sent my way along this journey. My special thanks go to my husband, Bayu Dardias Kurniadi and my children Jilan Nirmada Rencang Kencana and Rezalinajwa Dara Bening, who accompanied me during this research process. Even when they were not sure what I was doing, they trusted me when I was not sure that I trusted myself. They have made me stronger and more fulfilled than I could have ever imagined. I dedicate this study to them with all my love.

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Prologue

In May 2012 Sunarti, a 31-year-old immigrant domestic worker in Oman felt pain in her right thigh and collapsed in the bathroom. After seventeen months of pain, and refusals from her employer and her labour-contracting organisation to repatriate her, she finally returned home with the help of an anti-trafficking charity. In Indonesia, she was swiftly diagnosed as having a tumour in need of tertiary assessment but, for two years, she could not afford to travel to the hospital that could do the assessment. Again, it was only with the support of a charity that she was finally able to travel to a hospital in Yogyakarta for treatment for her tumour. She was finally admitted to hospital for treatment three and a half years after she had first felt a pain in her leg. She now had a swollen, painful, and life-threatening tumour. Sunarti's journey tells us about unequal access to health care.

Her clinical journey started when she had an X-ray in Oman, and her leg was placed in a cast. Sunarti was assured by the doctor that her leg should improve in one week. The doctor prescribed some pain-killers, but her employer would not pay for the medicine. Her employer told her she should continue working regardless of her painful leg. Her pain continued to get worse until she was unable to walk. One week later, she sought funds from her employer to make the trip back to the hospital. The employer accompanied her to the hospital that gave her the X-ray. This time the doctor advised her to have surgery, though the reason was not made clear to her. However, rather than following this medical advice, her employer forced the clinician to remove the cast, withdrew her from the hospital and sought advice from an alternative therapist. One month later, her pain had not improved.

Missing home badly and in pain, she asked her employer to allow her to return to Indonesia. However, her employer stated that he could not afford to pay for her return ticket. Her labour provider organisation (PJTKI, Indonesian Labour Provider Organisation) also refused to repatriate her, in breach of their contract. She turned to Facebook to request support from an international labour agency (ATKI-HK) based in Hong Kong. A global alliance against trafficking advocating for Indonesian women migrant workers, ATKI-HK assisted Sunarti's arrangements to return home. With the agency's advice, she spent 8 million rupiah (AUD 8000)—half of the salary she had earned during sixteen months in the position—to return by plane to Indonesia. Then she travelled to her remote village home in West Java with a non-functioning, painful leg. The diagnosis of osteosarcoma took many more steps.

The main reason for the delay was Sunarti's inability to pay for transport and health care. Because she needed to seek medical treatment for her leg, she registered as a member of the universal health care insurance program BPJS or JKN-KIS (Jaminan Kesehatan Nasional-Kartu Indonesia Sehat) one year before her medical examination in Yogya in 2015. Sunarti contributed monthly to the cheapest scheme in the program. By mid-2015, however, her payments to the health insurance scheme lapsed. Her husband received a very low wage as a *pemulung* (collector of disposed household goods) and he occasionally worked as a fisher with an unstable income. With her own lost wages, she could no longer afford to make the monthly medical insurance contribution.

In the meantime, her upper knee was constantly painful and swollen, becoming even worse at night. The pain limited her activity to the extent that Sunarti and her husband used social media to seek help, posting images and information about her swollen leg. In 2015, a charity organisation, Jalinan Tali Cinta Kasih (JTCK), finally funded Sunarti to travel to the Sardjito referral hospital in Yogyakarta to receive treatment. All costs relating to her treatment, including the cost of travel by car from home to the hospital, and everyday expenses for Sunarti and her husband, were covered by the charity.

I visited Sunarti in the Sardjito Hospital. The corridors of the hospital were marked by the anxiety of people in the wards, waiting hall and emergency unit, and the crowds of people queuing in front of the hospital pharmacy. People had been brought to the hospital to seek health care as a result of the government's Universal Health Care policy. Upon admission to Sardjito Hospital, Sunarti perceived that she had been blessed and regularly thanked God. Sunarti would say, gratefully, '*Bersyukur*', meaning 'I am blessed'. She felt that, in getting admitted, she had been assisted by various agencies and had now entered a professional medical setting. 'Finally, I am benefiting from this very solid team work.' She knew that she was to undergo surgery in two days, and that the only hope of saving her life was through the removal/amputation of her leg. Three years had passed since she had first collapsed from pain in her leg in the bathroom in Oman and now, she had finally found some rest and confidence in the proposed procedure.

Sunarti's story was not my first encounter with patients with cancer. But all of their stories illustrate the challenges faced by poor people in navigating health care for very serious conditions. The stories draw attention to the political economy of unequal access to health care. The three-year delay in definitive treatment for her leg had increased Sunarti's risk of dying from osteosarcoma. Although she had not developed secondaries from her osteosarcoma over this time, she lost her left leg, resulting in the biomedical labelling of her

as *cacat* (disabled). Yet, throughout the ethnographic research for this thesis, I discovered that when a catastrophic event occurs—such as emerging (incurable) diseases, an epidemic, disability or the increase of poverty leading even to death—culture and place shape the way Javanese people respond in their subsequent anxieties, fears and trauma. Typically, they accept the event with resignation (*menerima dengan ikhlas*) and give thanks (*syukur*) for the experience.

This thesis explores these critical moments to understand the way cultures engage within the hospital context. The intersecting perspectives of biomedical practices, social norms, and spiritual insights are the main threads running throughout this thesis. Through examination of the structures and social contestations that shape Javanese subjectivity, this dissertation analyses the contestation in contemporary views between those who focus on the diagnosis of physically disabled and diseased bodies, marginalising patients in liminal space where they are perceived as inferior in terms of physical, spiritual and social standards, and those who through the Javanese cultural practice of *Kebatinan* transcend these outward appearances to an appreciation of the inner personhood of these individuals.

Sunarti's story illustrates the bodily and structural context in which participants experience chronic prolonged illness and physical impairment. Sunarti's illness highlights the relational and affective struggles of people and their families living with forms of chronic illness like cancer, particularly under the influence of spiritual and religious ontologies of illness. This dissertation addresses the trauma of poor individuals, families and societies seeking to find emotional strength, to uphold moral norms and to draw on spiritual relief in the face of uncertainties, disabilities and structural poverty. This thesis offers a sense of how they grieve, face fear, lose hope, experience healing and reconstitute their personhood in Yogyakarta. It asks what shapes the lived experience of people who experience chronic illness and impairment in the context of Java, and their individual trajectories are routinely embodied in their subjectivity.

Sunarti's story shows how state power is expressed and experienced emotionally as it constrains, enables and seeps through the everyday world of individuals. This thesis begins by exploring the procedures and ethics surrounding osteosarcoma 'inside clinic'. Then, I expand the scope from a focus on the cancer disease and the resultant illness to a broader discussion of disability and difference 'beyond clinic'. These later chapters give more attention to the diverse perspectives involved in my analysis. Here, I shift my assessment to the local community forms of discourses that take for granted a shared understanding of 'disease, disability and difference' in Javanese culture. I explore interactions within

community settings where persons whose bodies are clinically identified as deformed and diseased resume their previous social lives and deal with social stigma. Poor amputees find themselves diminished by social stigma but find inner resources that balance spiritual and moral well-being with physical care. One of the key lesson from Sunarti's story and those in similar circumstances is that both state and non-state agencies regard the poor with severe illness and impairment as utterly dependent on and submissive to relations of care. Throughout this dissertation, I suggest that the flow of *rasa* (affect) that dominates social relations in both clinic and community settings not only reflects poor clients' subordinate position but demonstrates their capacity to build a sense of self-esteem and harmony.

Chapter 1
Introduction

The patient's narrative in the Prologue reveals an experience of serious illness that was not only open to biomedical therapies but also to a kind of spiritual flash or awareness that constituted the intuitive effect of biopower and healing. Drawing on an understanding of the subjective power of the emotional state, this thesis attempts to dig deeper into insights about the larger political economy forces that shape poor Javanese people's everyday experiences as social practices and of subjectivity itself. I explore the effects of affective biopower that act through the normalising power of self-regulated bodies and particular desires as much as through institutions.

I use ethnographic literature to unpack the meanings of severe illness and impairments and the way people have, on one hand given care and on the other endured catastrophic events, loss and even death. In this discussion, I have found it necessary to relate the experience of catastrophe and its effects not only to individuals, but also to their families to whom the cause of chronic illness and impairment is attributed (Staples, 2012). Both medical anthropology research in Java (Brown, 1999; Ferzacca, 1996) and ethnographic work on the Javanese (C. Geertz, 1960; H. Geertz, 1961; Guinness, 1986; Magnis-Suseno, 1997; Mulder, 1994, 1998; Woodward, 1989, 2011) have contextualised the lived experiences of Javanese subjects. My research has also benefited from a review of studies of psychosomatic illnesses experienced in varied socio-cultural, political and economic settings. These studies have included marginalised people living in the United States (Mattingly, 2010) or in non-Western countries like China (Kleinman, 1986), Brazil (Scheper-Hughes, 1993), Iran (M.-J. D. Good and Good, 1988), Peru (Farmer, 2004b) and Thailand (Fordham, 2004).

Thus, I ask, what shapes the lived experience of illness and impairment in the context of Java, and how are these everyday experiences routinely bound up with the sense of healing. I argue throughout this dissertation that these lived experiences are the result of the eclectic blend of biomedical and Javanese views, as negotiated in Java today. This entanglement produces a range of responses in patients and their families as they adapt to changed circumstances and changing senses of self and identity. People draw on their experience of *syukur* (giving thanks for blessings), in which, by acknowledging *berkah/anugerah* (blessings) and expressing *nrima/menerima dengan ikhlas* (acceptance) they attain a feeling of balance. Read this way, Javanese responses of *syukur* and *nrimo*/*menerima dengan ikhlas* which, for the moment, we might interpret as internal,

individualised spiritual submission, can also be understood as a form of social suffering and marginalisation. I also argue that within the specific Javanese culture, the production of personhood and social identity is an embodied process—entailing discourses, values, meaning, power and the body itself. People make sense of their own selves and identity by being persistent and adaptable.

1.1. Affect and embodiment: The theoretical framework

In this section, I introduce the analytical scope of this thesis in which affect and embodiment are seen as central in shaping subjects. I have found that along with Javanese cultural factors, poor individuals with severe illnesses and impairment experience a range of biopower coercions from state and non-governmental institutions. These people may experience violence and social suffering resulting from the structured expectations that situate them in relation to the biopower of dominant social institutions. At the same time the Javanese self will be shown to be dependent on the social context that builds a sense of agency through embodied practices of internal discipline, and social and spiritual connectedness. These practices contribute to an individual's ability to re-build a sense of harmony and are instrumental in forging social change and resilience.

1.1.1. Collective affect 'state-phobia': From clinic to everyday life

To begin with, I would like to restate what Foucault terms the collective affect of 'state-phobia' (2008, p. 77). State-phobia refers to a form of affective condition through which state apparatuses develop and organise within subjects certain emotional emplotment. The great insight that Foucault's lecture shows is that the collective affect of 'state-phobia' is signalled by fear or anxiety regarding the state. So, state-phobia can be perceived as a 'sign' of the birth of biopower that takes various forms of affect (Anderson, 2012). On this understanding, the growing affect in the experience of severe illness and impairment through state provision of biomedical treatment can be understood as a form of social suffering and marginalisation. Anderson argued that

> by 'affective condition' I mean an affective atmosphere that predetermines how something – in this case the state – is habitually encountered, disclosed and can be related to. An 'affective condition' shapes and influences as atmospheres are taken up and reworked in lived experience, becoming part of the emotions that will infuse policies or programmes, and may be transmitted through assemblages of people, information and things that attempt to organise life in terms of the market … On this understanding, transformations in ways of 'making live, and letting die', and the emergence of new 'object-targets', are bound up with the organisation of affective life. (2012, p. 37.)

So, state-phobia is generated by the state. In line with Anderson (2012), my research will pay attention to the recent debates about the politics of affect. Anderson added that

> specific organisations of affect – including state-phobia – are essential elements in those conditions, traversing and animating apparatuses … But we might also want to show how state-phobia emerges in everyday life and coalesces in the midst of other ways in which affective capacities and relations are organised, whether that be forms of economic insecurity associated with precarity, apathy, anger and other types of political engagement, or the lived force of ideals of freedom. In short, we might describe how affective life is imbricated in the working out of the neoliberal problem of how to organise life according to the market. (Anderson, 2012, p. 40.)

Organising life in terms of security and redistribution of discipline is approached in two ways (Anderson, 2012). First, the state uses power to discipline bodies through apparatuses and institutions. Second, state power extends its capacity through redistribution of soft power that may shape the moral subject by cultivating values, religion and norms. This program is in line with the neoliberal challenge of how to control life according to competitive market mechanisms resulting in making live, and letting die (Anderson, 2012; Pylypa, 1998). In this sense, the shared and collective affects are part of the 'conditions' for the birth of the biopower—the politics of affect. In these circumstances power may not be seen as repressive, cruel, or oppressive but rather a subtle mechanism of desire that inhabits social interaction and manifests at the micro level of everyday life (Pylypa, 1998; Rabinow and Rose, 2006). So, the practice of government organises a structure of affect through the way the state 'locks in' its population and redeploys surveillance and discipline.

In the instance of organising life, for example, the affective power is viewed as a positive and as having desirable consequences (Anderson, 2012). Following Foucault, previous research into the experience of illness and impairment showed that affective life is structured simultaneously as an object-target of governmentality (Chuengsatiansup, 1999; Farmer, 2004b; French, 1994a; Mattingly, 2010; Seo, 2016). In hospital and public health settings, 'scientific' knowledge spoken by members of the medical profession carries significant power. Power diffuses through the social structures of the state, social cultural norms, and non-state affiliates, in order to discipline and police the population. In this way biomedical discourses tend to categorise people. My research started in a clinical setting/hospital and here I build on the valuable work of Foucault in *The Birth of The Clinic* (2012). I found Foucault's insight particularly useful in that by identifying bodies as deviant or normal, the medical profession acts as a state apparatus in the hospital. The spread of knowledge in the clinic has a continuing impact on the lived experience of people in everyday life. Foucault's work has become an important framework for a range of research in

medical anthropology that looks at the history of public health, the emergence of governmentality, regulated socio-cultural space and self-disciplined bodies (Foucault, 2012).

In tandem with Foucault's approach, Mattingly's ethnographic work in the clinic (2010) proved valuable in guiding my analysis. Her research explored how poor African American families cultivated feelings of 'hope' when faced with chronic illness or disability in their children. When the medical prognosis worsened after multiple medical treatments both clients and clinicians cooperated in cultivating 'hope'. The affective response of *hope* can be understood as a significant treatment for those suffering. Hope, she argues, is a collective affect that is adopted in life-threatening circumstances that fosters delusion even as it creates therapeutic emplotment (Mattingly, 1994, 2010). Further, her analysis contends that in the midst of uncertainty, suffering and precariousness, 'hope' flows as something powerful and active:

> There are no simple solutions. Living with any significant disability, especially when it is coupled with poverty and racial stigma, can be grim work. From one view of reality (a 'realistic' perspective), it is, in fact, cause for despair. And despair is precisely what families fight against. They see despair not as realistic but rather as having its own kind of delusion: a comforting delusion that nothing more is required, that the future is fated, and they can simply 'give up'. (2010, pp. 4–5.)

The important point derived from Mattingly's study is that the practice of 'hope' may be relevant in understanding the dynamics of affective 'state-phobia'. State-phobia follows a particular logic of governing through (bio) power (Anderson, 2012). This function operates at the micro level of everyday life in the emotional spaces of interaction. Biopower is dispersed throughout society, naturally embedded in social relationships, and inherent in networks of practices, institutions and technologies (Pylypa, 1998). Yet, biopower acts not only directly through institutions but, more importantly, indirectly through desires and everyday practices. In this sense, the state's goal of control is not projected through coercion or intimidation. Control is exercised through the spread of knowledge and desire associated with the affect of hope. According to Mattingly (2010), for instance, *hope* implies a contradiction as the affect of 'desperate hope' turns into a 'positive' expression. Through the practice of hope, Mattingly (2010) claims that clinicians and families can bypass negative thoughts and reactions and find common ground for promoting communities of care.

Furthermore, new forms of power and the structuring of affect become manifest as individuals absorb religious forms into their everyday life as a kind of ethics. French's (1994a) research in Cambodia showed that the impact of power on social relations was evident in the way individuals' mutilated bodies were read by others as different and odd.

Power flows through the existing social and cultural systems such as the morality taught in religious organisations of Theravada Buddhism and is then enforced in everyday practices. Re-starting their new lives after medical interventions such as amputation, amputees discovered that they were generally perceived in terms of the category 'disabled' and discovered that losing a limb was read as a 'loss of face' and was a source of shame and irritation. The important point from French's study is that in this setting, the perception of deviance and the 'different' body is not just a matter of medical discourse but is also imbricated with karmic belief. Buddhist perceptions of loss or abnormality are strongly associated with perceptions of karma (the spiritual principle of cause and effect where the intent and actions of an individual in this life and in previous lives influence the future) that is embodied in the person. In a way, individuals become caught in the implications of this ideology, as belief in karma is a widely established and acknowledged way of making sense of the world in Cambodia.

I consider collective affect as an emotional and cultural milieu where state-phobia continuously segregates marginalised groups from accessing economic and social capital. In this sense, affect (feeling/emotion/sentiment) is not about either anatomical responses on their own, nor the psychological symptoms per se. It is about emotional structures that link the body and the social world (Lyon &Barbalet,1994). Through narratives of emotions, this thesis will capture how individuals living in a certain place experience and embody sociality. French (1994b) gave an example of how emotional compassion and social pressures resulted in a perception of a loss of power in the disfigured body in Cambodia. The loss of a limb for amputees led not only to feelings of incapacity and anxiety, but also worthlessness (French, 1994b). French (1994a) explored how hegemonic interpretations of body impairment imposed certain social, cultural and political conditions on those perceived as different. In particular, the language of karma became meaningful in social relations. Its premise, simply put, is that the future of an individual's life is determined by perceptions of good or bad actions. For example, amputee soldiers are perceived as inferior because of their bad karma. Further, the repressive political environment surrounding the disabled body works to trap the disabled individual in economic poverty. The karmic perception precludes amputees from full access to a range of rich, or indeed just varied, social interactions, job opportunities, and economic and political resources. In line with Foucault's teaching, the affective structure of 'compassion' may cause the disfigured body to be marginalised beyond the bounds of social inclusiveness. French (1994b) showed that such perceptions and attitudes do not only

preclude amputee soldiers from getting jobs, but also inhibit their influence in decision-making.

Other medical anthropologists have situated particular collective affects in certain cultures as significant factors in examining the illness experience (M.-J. D. Good and Good, 1988; Jenkins, 1991; Kleinman, 1986). Kleinman's (1986) study in Chinese society, for example, helps us to understand the lived experience of neurasthenia patients. Among these patients, the study found that the bodily expression of distress and anxiety was a consequence of the embodiment of core cultural systems of meaning, norms and power (Kleinman, 1986, p. 500). These psychosocial symptoms of neurasthenia were signs of the imposition of both state power on the population and the practical forms of their daily experience. So, Kleinman's assessment of neurasthenia did not only capture the biomedical interpretations of illness but also investigated the experience of social problems involving family, work, and financial and political harm (Kleinman, 1986). He further argued that the origin of distress and disease played out in the excesses of the Cultural Revolution, as the patients' stories of pain and despair constituted a moral commentary on the sources of suffering (Kleinman, 1986). So, human beings responded to despair not only through biophysical processes, but through life course decisions, social interactions and perhaps spiritual embodiment. The patients absorbed and internalised their suffering and sought transcendence in their illness experience through life patterns. Arthur Kleinman and Joan Kleinman (1991) believed that a broader sense of patients' experiences may enrich care-givers' understandings of the social and psychological sources and effects of illness.

> We live in the flow of daily experience: we are intersubjective forms of memory and action. Our experiences are so completely integrated – narratized moments, transforming narratives – that the self is constituted out of visceral processes as much as expressed through them. Because the order of that flow is historical and cultural, what we feel, and see and recall, is a symbolizing physiology. Because of the social construction of the flow of experience, psychosomatic processes are transmitters and receivers of cultural codes. (ibid., p. 293.)

In Thailand, Seo (2016) gave similar attention to embodied moral discipline among poor migrant patients in their experiences of health care provided by the government. Seo examined the affective experience of patients with chronic illness and looked at the flows of affect that are immanent in social interactions within the Thai health care system. In a context of paternalism, inequality and dependency, people's affective responses reflect their agentive submission to the health care provision offered by the state (Seo, 2016). In addition, it was seen that the vigorous function of the monarchical institution of Thailand extended the capacity of government. In Theravada Buddhist conceptions of kingship, the aura of (the late)

King Bhumibol brought a great source of spiritual and moral strength. The images of the royal family were posted in every public space including hospitals, foregrounding the monarch's moral, symbolic and political overview of the people. In this atmosphere, both state paternalism and Kingship guided the delivery of care and shaped particular subjects (Seo, 2016).

As with Seo's study (2016), my research situated in Yogyakarta is also concerned with the influence of cultural symbols of aristocracy and the power of the Sultan within the nation state. The traditions of the Sultanate constructed ethical ideals, moral principles of personhood and the Javanese world view. These deep beliefs, moral principles and values are still embedded in the lives of most Javanese people (Magnis-Suseno, 1997, p. 1). These disciplines do not only regulate individuals and communities in their bodily practice and social behaviours but affect the management of subjects' souls and emotions. These Javanese ethics reflect how the embodied sense of moral discipline and self-surveillance has infused the self-care management of subjects. So, ethics in a Javanese sense is not only about behaving in a way that follows the 'truth' (*bener*), but they are also about living in a way that Magnis-Suseno (1997, p. 3) calls *pener*. *Pener,* in the Javanese world view, means respecting 'the science of the right life'. The eclectic blend of the notions of *bener* and *pener* inherent in the Javanese ethical system must be part of any academic discussion of how to understand power and its relation to its subjects in Java. Errington (1998b), for example, argued that the Javanese language remains strong in people's conceptions and will never be replaced by the Indonesian language. His study looked at the institutional and interactional dimensions of language used in the social process of everyday life in Java. Errington (1998a) points to the linguistic constitution of both subjectivity and of local modernity. He argues that developmentalism and the saturating influence of the authoritarian state may have shifted identity and language into a form of bilingual interaction, but using Bahasa Indonesia language (hereafter, Indonesian) is simply an instrument for efficient communication rather than a substitute for a Javanese construct. Errington's study is somewhat ambiguous when it comes to understanding how ideas of the self are linguistically structured and articulated within the political and structural constructs of Indonesian subjects. Shifting use of language shows how political authority changes the understanding of Javanese ethics and national hierarchy (Errington, 1998b).

These cultural and anthropological studies have inspired me to further investigate behaviour in the particular context of Yogyakarta and to focus on the linkage between affective life and the organisation of power—and its role in shaping subjectivity. Through the

experience of severe illness, I pay attention to the way the rhetoric of control offers a complex narrative that contributes not only to Javanese people's distress but also to their liberation.

1.1.2. Poverty, inequality and structural violence

This thesis depicts how affective life is influenced by the exercise of power. Drawing on Foucault's concept of biopower, for instance, Rabinow and Rose (2006) argue that certain management and biopower practices might lead to violence. In this thesis, I take Rabinow and Rose's point and look at affect as a form of 'soft violence' or what Foucault calls 'normalising power' on 'self-controlled' bodies:

> In thinking of the mechanisms of power, I am thinking rather of its capillary forms of existence, the point where power reaches into the very grain of individuals, touches their bodies, and inserts itself into their actions and attitudes, their discourses, learning processes, and everyday lives. (Foucault, 1980, p. 39.)

I argue that there are cracks in the state system, and that it is in these breaks that we find that the affective system exerts structural violence upon the poor. Poverty modifies how the poor will fare in their experiences of severe illness and impairment (Sen, 1983). Farmer also argues that there is a strong association between illness and economic status, including income inequalities and impoverishment, and health outcomes such as mortality and morbidity. According to Farmer (1999), income inequality and transnational influences may be correlated with infectious diseases in rural Haiti. Partly inspired by Farmer (2004a), in this thesis I conceptualise the structural violence that operates in a range from direct physical assault to symbolic violence in everyday life and interactions (Farmer, 2004a; Sen, 1983).

In Asian countries such as Nepal, catastrophic illness has economic consequences as it requires households to pay for hospital care and thus impacts on their coping strategies (Adhikari, Maskay and Sharma, 2009). The research shows that healthcare payments cause more than 20 per cent of patients and families to drop below the poverty line, while the surrounding households were pushed into the category of 'marginal poor' (Maskay and Sharma 2009). Although there is still heated debate about the causes of poverty and the impact of inequality on severe illnesses, economic constraints on low-income families may result in their poverty deepening. Farmer (2004b) showed, for rural Haiti, that tuberculosis and AIDS cause millions of premature deaths annually. According to him, living in poverty was the consequence of global free-market mechanisms, and he stressed that poverty was still the world's greatest killer. He suggested that by understanding such social and political

economic phenomena we may protect the most vulnerable people from the abuse of structural violence. Farmer (2004b) warned that improving the situation of the poor within the existing social order may be insufficient. In his remarkable book, *The Pathology of Power*, Farmer (2004b) argued that people become poor not simply because of their heritage but due to the human actions and structural violence that continue to oppress certain groups of people. These situations indirectly impact, not only on the lived experience of people with chronic illness and bodily impairment, but they also shape the intersubjective, social experiences and perceptions of chronic illness and bodily impairment in society in general.

In the context of poverty and social hierarchy, experiencing a catastrophic event such as a chronic illness and disability means enduring struggles over exclusion, categorisation, discrimination and dispossession. We can see from the vignette outlined in the Prologue how difficult the transition to a preferred future is for poor people as they confront the combination of poverty, poor social capital and the prejudices of social and state institutions. By and large this thesis focuses on those who experience poverty and severe illness. I argue that biopower takes a different form when combined with various technical resources. The combination of techniques may lead to a murderous 'thanatopolitics'—a politics of death/life or selective death (Rabinow and Rose, 2006).

Existing studies indicate that analysis of structural violence and devastation must take into account social suffering and wider political economic dimensions. Gupta (2012) and Simmons (2010), for instance, offered a biopolitical analysis about poor people in the corrupt Indian bureaucracy and among Haitian workers. They argued that a systematic form of corruption made poverty permanent and that more people died each year from reasons not directly related to disease. They had in mind the failure of the state to provide such necessities as water, food, housing and medicine. Gupta (2012) found that widespread corruption created a form of oppression of the poor who could not afford to bribe the administration. This enduring form of structural violence perpetuates poor people's accessibility to 'ostensibly' free goods and services.

In respect to global capitalism, we might say that the development agenda and some non-state interventions have been imposed on vulnerable populations in ways that do not consider their ongoing needs and cultural sensitivities. This introduces unexpected paradoxes in the uptake of development assistance. When caring or development interventions are not grounded in the socio-cultural context, disguised resistance will emerge in various forms (Soemardjan, 1962). For example, people with disabilities in low- and middle-income countries are often destitute, forced to look for new forms of access in order to 'get into a

space', and find opportunities and search for resources for their survival (Harriss-White, 2005). These people are positioned as a minority and as such they are expelled from formal institutions. The poor and marginalised must largely become involved in self-advocacy and build their own forms of resistance. Further, Scheper-Hughes (1993) argued that international capitalism has had adverse effects on infant and child mortality. Her research in Brazil showed how global marketing of proprietary health and baby care products trapped poor mothers into dependency. Infant formula was promoted as a sign of exemplary care and this promotion encouraged poor mothers to buy commercial milk produced by international factories to be consumed by their newborn babies. Scheper-Hughes (1993) argued that this form of 'conspicuous consumption' promoted by international capitalism had the effect of leading the disadvantaged into an economic trap.

If, in a particular environment—the embodied social context, emotional or cultural attitudes—where health care and medical treatment can only be accessed by certain classes in society, then the politics of life typically involve different arrangements and choices between 'letting some die' (*laissez mourir*) and 'making (others) live' (*faire vivre*) (Dreyfus and Rabinow, 1982). With special reference to South Asian countries, Harriss-White (2005) illustrated how poverty and destitution flow from embodied social political and economic pressures and the marginalisation of people. Harriss-Whyte's (2005) research showed that these groups of people are subordinated in society not only by the economic, political, social and cultural processes that historically persist, but also by social categorisation and identity-shaping that marginalises and excludes them.

In many developing countries, social exclusion is prevalent within the context of extreme social and global economic development, and its political pressures (Farmer et al., 2006; French, 1994b). Economic growth results in economic allocations to 'assist' the poor, but for diseased and disabled bodies assistance is relatively patchy. Aid, economic resource allocation and the encompassing health systems that target the poor, (including those with body-impairment and those with severe illness) are usually motivated only by occasional or impulsive political tendency (Aspinall, 2014).

Further, the emerging human rights and disability movement through the United Nations' Convention on the Rights of Persons with Disabilities (UNCRPD) has promulgated the idea of the separation of the body and mind. Phillips, (2014) for example, observed the growing disability rights movement in Ukraine. She argued that within the context of a changing welfare state, the disability rights movement categorised a person with disability and transformed him/her into a specific kind of citizen (Phillips, 2014). The movement

objectified the body as detached from the sense of personhood—the self and the soul—by putting the body under the control of state apparatuses, NGOs (Non-Government Organisations) and religious charities. Thus, the acceptance of humanitarian intervention channelled by non-state organisations or burgeoning disability rights movements converted the power of non-state interventions into the objectification of the body. This enabled new governmental and external control. In Foucault's language, resistance is a subtle power. The new activism shaped a new formulation of disguised power (Pylypa, 1998), and was clearly crucial in shaping the subject—or self-identity.

This review of scholarly literature makes it clear how structural violence in many and varied ways creates hardship for some groups (the severely diseased, the disabled, ethnic minorities and poor people) who find themselves vulnerable to moral condemnation and social segregation. The poor's subjugation to biopower deepens inequality and makes poverty endemic or chronic (Mosse, 2010). Structural violence creates specific subjects. Indeed, I found that this complex matrix of powers constructed an ambiguous or fractured sense of Javanese identity among poor people who were experiencing severe illness and impairment. I discovered that the Yogyakarta informants I worked with simultaneously experienced a range of biopower coercions from state and international organisations, and that along with Javanese cultural factors these constructed a distinctive form of subjectivity. I explore this in depth in the chapters that follow.

1.1.3. The Javanese cultural context

The site of my ethnographic research is the Special Region of Yogyakarta where the population is mainly ethnically Javanese, and the aristocratic power of the Sultan remains influential. The Javanese ethnic group is the largest in Indonesia, living mainly in Central, South and East Java. There were 3,802,872 residents in the Special Region of Yogyakarta in 2018 (BPS Yogyakarta, 2019, p. 59). Since 2012, the importance of Javanese culture and politics in Yogyakarta has been exemplified in granting the role of Governor and Deputy Governor of the province to the Sultan and the ruler of the second princely state of Pakualam without election (see Map 1.1).

The American anthropologist Clifford Geertz (1960) noted that in the Javanese social structure, the highest ideals of its culture and its application were manifest in the aristocratic life and practices at the Sultan's palace (C. Geertz, 1960). The *priyayi* (the ruling class of traditional Java), who are found in court and government circles, follow an aristocratic way

of living. The Sultanate and the aristocracy rule the general population, and the feudal system maintains hierarchies and frames relations.

Map 1.1. Yogyakarta on the Island of Java

Source. © CartoGIS CAP 17-342a_KP, The Australian National University

Throughout the history of Java, traditional social hierarchies and the influence of the Sultanate, nation state and globalisation have been instrumental in shaping Yogyanese perceptions of the subject: their body, health and illness. These constructions are formed in part from the mystical and animistic dogmas that are part of Javanese religion today. The beliefs constitute core elements in realising personhood and positing health, illness and healing practice as the legacy of God (C. Geertz, 1960; Woodward, 2011). An understanding of illness and health treatments must therefore consider the social and political context of their occurrence.

Statistical data shows a rising trend in individuals with severe illnesses and impairment in Indonesia (Adioetomo, Mont and Irwanto, 2014). Cancer in particular is categorised as a severe illness that threatens individual's lives and produces impairments disfigured bodies and even death. In Yogyakarta, the Sardjito Hospital recorded 3,466 patients with cancer who were treated as inpatients in 2014. The number of patients diagnosed with cancer in the hospital rose from 3,588 in 2015 to 3,623 in 2016. While patients with cancer recorded in outpatient care in the hospital was 8,212 in 2014. The number increased to 8,409 in 2015. One year later, the hospital recorded a significant increase in the number of outpatients with cancer to 9,502 (*Tribun Yogya*, 5 Apr. 2017). There were 57.23 per cent of impairments have

attributed to diseases, either communicable or non-communicable (Adioetomo, Mont and Irwanto, 2014). Data show that, due to the Yogyakarta earthquake in 2006, the number of people with disabilities (*penyandang cacat*) in Yogya grew from 17,727 to 26,173 (Thohari, 2013, p. 40). Of these, the largest group comprised those who had lost limbs and lacked bodily function. While in terms of severe illness, there were similar trends in the increased number of cancer patients admitted to regional hospitals.

As noted above, Yogyanese perceptions of body, health and illness are derived from mystical and animistic dogmas that are central to Javanese religion today. The beliefs in turn are core elements in realising a sense of personhood that acknowledges *lair* 'outward physical' and *batin* 'inner spiritual' elements. In regard to persons with abnormal bodies, there is a range of traditional Javanese perceptions about the 'deviant' and 'odd'; they are people who are believed to possess magical and supernatural powers because of their internal, spiritual selves. These supernatural perceptions derived from the mysticism and religious practices of *Kejawen* (Islam Java) may supply people with meaning or value that allows them to be tolerated or even elevated socially. Historian Peter Carey (2014) recorded the role of Javanese dwarf people, known as *polowijo* or *nonok* (hydrocephalics and those with other unusual physical deformities) who acted as court jokers (*hansworst*) and warriors against evil in the palace. The *polowijo* are perceived to be loyal and obedient servants of the leader. During the Sultanate's ceremonies, such as the annual *Garebeg*, they appear in procession at the front, guiding the Sultanate's ritual or procession (Carey, 2014; Raap, 2013; Thohari, 2013). This practice, in the past, illustrated that abnormal bodies were accorded social respect and value.

I discovered that the influence of the aristocracy, their values, practices and beliefs are still meaningful in local society and are taken to be a powerful link uniting people with the cosmic order. The embodied mysticality enacted through the Keraton's (a royal palace of Yogyakarta) existence is the way Javanese individuals make sense of their fate and signifies that God elevates human's *batin* (spiritual selves or lives) over the *lair* (physical lives). The notion of the deviant body is best represented in the *polowijo*, and their status is a window onto Javanese sense of the myths and norms of individuals, cultural ceremonies and cosmological views (Thohari, 2013, p. 46). These embodied images of spiritual dimensions and cosmology shape people's lives and their experience of severe illness and impairment (Map 1.2).

Map 1.2. The cultural, hospital, and religious sites in Yogyakarta

Source. © CartoGIS CAP 17-342b KP, The Australian National University

In Yogyakarta, development interventions have involved patients and the families of people with disabilities in education and health promotion and medical treatment programs. The wave of modernisation and health development has led to various program interventions, such as inclusive education for those people with disabilities, an expanded workforce, and advocacy to provide access to medical care. Yogyakarta is a leading province in Indonesia for

Pendidikan Inklusi (Inclusive Education) and *Jamkesus* (Individual Health Insurance) for people categorised as disabled. All of the programs have significantly affected people's lives. However, modernisation and urbanisation have not significantly altered the roots of Javanese religion and its sense of personhood (Woodward, 1985, 1989, 2011).

Meanwhile, Islam, which became influential in Central Java in the seventeenth century (Ricklefs, 2008), distinguishes disadvantaged groups by categorising them as weak persons (*dhaif*) and powerless (*mustadhafin*); this categorisation includes the poor, orphans and sick people. The Qur'an and Hadith in Islam do not explicitly state that the weak and powerless refer to the physically disabled or those with deviant bodies. However, there are Muslims who commonly accept that the weak implies the disabled, much in the same way that giving alms to the poor (*shadaqah*) is a way to help the weak. Weak or powerless persons in Islam are understood as experiencing a period 'given' by Allah as a test (*cobaan*) of their lives and faith. However, while passages from the Qur'an or Hadith are not explicit about the cause of illness, most Muslims believe that the experience of illness is ordained to help an individual get rid of sins. Being patient and accepting Allah's tests, including suffering anxiety, impoverishment, starvation, illness, disability and death, help the patient become close to Him. The experience of illness is a *wasilah* (tool) to clear away sin.

> And we will surely test you with something of fear and hunger and a loss of wealth and lives and fruits, but give good tidings to the patient, who, when disaster strikes them, say, 'Indeed we belong to Allah, and indeed to Him we will return'. Those are the ones upon whom are blessings from their Lord and mercy. And it is those who are the [rightly] guided. (Qur'an Al Baqarah 155–157.)

> And whatever strikes you of disaster – it is for what your hands have earned; but He pardons much. (Qur'an Ash-Shuraa 30.)

> Paradise is not [obtained] by your wishful thinking nor by that of the People of the Scripture. Whoever does a wrong will be recompensed for it, and he will not find besides Allah a protector or a helper. (Qur'an An-Nisa 123.)

Some people may cite these passages and apply them to the experience of misfortune, including the experience of those who live with chronic illness and disability, and this may obviate either compassion or prejudice. This powerful component of Islam not only brands a missing body part as a handicap and sees impairment within the notion of personhood; but also, projects state control of populations through various creative discourses (*othak-athik gathuk*), labels and perceptions into even the rural and remote areas of Yogyakarta. Understood this way, it seems that there is no simple able/disabled binary in Javanese society but something like a range of personhood and social statuses reflected in the body.

In terms of severe illness and bodily impairment, none of these perceptions or passages is derogatory in itself. However, the way the body is read and labelled represents a mix of beliefs that lead people with illness and impairment to feel vulnerable, uncertain, inferior and immoral. People independently interpret and apply the content of the religious passages. Their perceptions, therefore, are ambiguous and the body-self becomes the target of a contestation of power in social relations. The Javanese body is a construct written over and shaped by both mysticism and more modern knowledges, but the perceived curing of individual's *batin* is often seen as a more important priority compared to their physical care. In Java, healing practices require *rasa* (affect) and that involves treating the whole person—to recognise the elements of *lair* (physical) and *batin* (inner self or soul). Affective healing practices encourage particular desires. Thus, I build up my analysis by capturing the rhetoric of self-control as a complex narrative contributing to social suffering and empowerment at the same time. This study demonstrates how communal attitudes and moral and spiritual beliefs frequently act, not only to complicate biomedical diagnoses of chronic illness, but also to complement biomedical treatment and healing approaches.

Woodward (2011, p. 69) noted that the concept of *berkah* (blessing) of saints and descendants of the Prophet Muhammad marks the Javanese understanding of the power related to healing. The application of passages from the Qur'an and beliefs in mysticism encourage a flow of affect so individuals gain a sense of well-being and inner peace. I observed that most Javanese informants and families recognise traditional healers as wise people (*orang pintar*, *paranormal* or *Kyai*) who derive their knowledge, not from biomedical science, but from Javanese spiritual and cultural intuition and religious sources. Their advice typically involves encouraging individuals to 'fit' their bodies (especially their *batin* element) through submission to the cosmic order.

These socio-cultural values together with the political and economic phenomena have shaped Javanese people's subjectivity and social reception of chronic illness and bodily impairment. For example, Pitaloka's research on chronic illness (Type 2 Diabetes) included narratives of poor Javanese women who managed their illness by attaining balance and harmony in three different levels—personal, familial and social (Pitaloka, 2014; Pitaloka and Hsieh, 2015). She argued that women's efforts to gain well-being and inner peace are understood as 'fitting' through their submission to Javanese cultural values. She focused on Javanese women's demonstration of their self-image/esteem as good Javanese women. Cultivating inner peace or self-esteem inspired positive feelings that the Javanese understand as part of being healthy in body, mind and spirit (Pitaloka, 2014).

Ferzacca (1996) and Browne (1999) explored the experiences of illness and health in 1992 and 1997 in Yogyakarta. Their studies examined the way narratives around illnesses can be read as commenting on the politics and poetics of self and social suffering. They looked at the flow of affect and emotion around illness and argued that what they observed was dependent on the political and Javanese cultural context (Browne, 1999; Ferzacca, 1996). Their research took different entry points: Ferzacca (1996) focused on 'Western chronic illnesses such as diabetes, hypertension and cardiovascular diseases, while Browne (1999) gave attention to mental illness. Their research also reflected slightly different times. Ferzacca (1996) carried out research during the New Order Era, while Browne (1999) looked at the phenomenon of mental illness during the decline of the New Order. Browne's study (1999) looked at affective expressions of and perceptions towards mental affliction and healing in Javanese cultural settings. Perceptions of illness in both clinical and quotidian situations, according to Browne, constitute political contestation and should be understood in the setting of the social violence of everyday life (Browne, 1999).

In Yogyakarta, social inequality is large, but life expectancy is also among the highest of all provinces. Yet, despite a decline in the poverty rate, income inequality among individuals continues to be relatively high. I take into account cultural and religious resources as an important element in the healing of bodies through Javanese traditional medicine (Woodward, 2011). Ferzacca (1996) argued in the late 1990s, that Javanese were aware of and meshed in the experience of 'modernity'. The texture of modernity had been introduced through clinical and biotechnology development but adopting the associated modern lifestyle did not fit (*cocok*) with the local Javanese and Indonesian identity. Ferzacca (1996) noted that many still held onto a generic sense of being authentically Javanese (*masih Jawa asli*) through such practices as consulting the paranormal, consuming *jamu* (herbal remedies), and seeking *obat tradisional* (traditional medicine).

In my research, I found echoes of both Ferzacca's and Browne's analyses. My ethnographic research situated the body experiencing severe illness and impairment within the Javanese cultural setting of Yogyakarta Province during the two decades of the Reformation Era (Era Reformasi), which some political scientists consider marks the beginning of democratisation in current Indonesia. After the Soeharto/New Order regime collapsed, many signs of a kind of spirit of social euphoria spread throughout the country. In the '*reformasi'* period, politics appeared intent upon widening social constituencies and opening up social inclusion in policy making (Aspinall, 2014).

1.1.4. Javanese self-identity

Foucault believes that subjectivity is a form of lived experience situated in a larger historical and political context—when the 'subject' (*le sujet*) does not simply refer to a 'person' but it reflects how the wider atmosphere creates an individual as a certain kind of person. I have referred to how political-economic arrangements in the modern state continue to shape subjects. But Foucault's theorising leaves open the question about the way in which the social construction of the body and the self/selves influences how people receive and view their own world—their own freedom.

While Foucault views his analysis of the subject as the result of power production, I see the nature of Javanese personhood as a reflective subject that is shaped by a particular type of agency and power. The Javanese self, in *kampung* life especially, is not only formed by elements generated by state power but is also shaped by the aura of the Sultanate (Woodward, 2011). In the eyes of Javanese, the whole Javanese person is ideally structured by the elements of the physical, *batin* (inner self), and social body. These elements combine in the 'oneness' of an individual situated in the cosmic order. The Javanese idea of power has shaped a sense of self-identity and political consciousness (Anderson, 2007; Antlov, 2005).

> Most often this [identity] has been derived from an idealized account of Javanese village life centred on notion of *gotong-royong* (mutual assistance), *musyawarah* (consensus), *hormat* (respect), and *kekeluargaan* (family-ness), combined with the mysticism of *Kebatinan* (Javanese spiritualism) and *manusia seutuhnya* ('the whole man'). (Antlov, 2005, p. 44.)

This power production, viewed through the Javanese lens is therefore morally ambiguous and is not inherently legitimate as in the Western concept of power (Anderson, 2007; Antlov, 2005). As a result, my analysis of the illness narrative explores Javanese living today as an intersection of different paradigms that locate self and social identity at an *ambang pintu* (threshhold). I argue that the Javanese circumstances and identity are neither modern, as reflected in biomedical (modern) discourses, nor authentically Javanese (*Jawa asli*) (Ferzacca, 1996) in the sense of a reified and idealised concept of the Javanese self.

The affect and embodiment in Yogyakarta that I refer to in this thesis follows the phenomenological tradition (Mattingly, 2010). The phenomenological approach helps me to analyse illness narratives through language, body gesture and habits (Jackson, 1983). As Michael Jackson puts it, 'body movements can do more than words can say' (1983, p. 388). Expressions of depression (*depresi*), stress (*stres*), exhaustion (*senep*), an inward attitude of resignation (*rela*, *menerima dengan iklas*), and even the emotion of gratitude (*syukur* and *anugerah*), were repeated many times throughout my research association with patients and

families seeking medical treatment. This study looks at the ethical world view of Javanese lived under the tireless constriction of serious illness and bodily impairment that are culturally patterned into daily shared forms. I give close attention to the affect that was part of everyday life in clinics and social encounters in Java and explore the idioms of *nrimo* (acceptance) and *syukur* generated from religious faith and Javanese ethics in relation to human adaptation and resilience. Indeed, I observe that many patients and families showed signs of acceptance (*nrimo*)—a culturally accepted way of dealing with uncertainty and ambiguity. Throughout the thesis I argue that even though patients and families often face misunderstandings and confusion that are part of the mix-up of everyday life in hospitals and society, they do not show the sort of anger or frustration expressed by some of Browne's informants (Browne, 1999, 2001). In everyday life Javanese individuals' practices of acceptance challenged the social order by effecting 'flat affect' and putting aside their anxiety and vulnerability.

I also recognised that the nature of community is not static but in a process of transformation of practices, habits, symbols and religion or beliefs (Turner, 2017). The complex intersection of these different power(s) is at the analytical core of this thesis. Yet my argument differs from that of Boellstorff (2005) who argued that nationalism and globalisation shape identities. Rather, I look at self/selves as being constructed through the intertwining of Javanese traditions and modern constructions. Javanese bodies and self/selves, for instance, embody what Scheper-Hughes and Lock (1987) call the three bodies—the psychological, the bio-social, and the political-economic. Scheper-Hughes and Lock (1987) argue that the psychological refers to lived experience of the body as self, the biosocial to representational uses of body as a symbol of nature, culture and society, and the political-economic to the control of bodies.

This form of embodiment allows the subject to re-build their sense of the whole person—regaining the harmonious state. This construct of a Javanese-self constructs an agentive self by building an inner-self dimension, social network and spiritual connectedness while re-building harmonious self-narratives beyond public ideals as a mode of empowerment. Following Giddens (1991), who brings his analysis about personhood, character and culture within the aspect of state power, I contend that the Javanese self is built within a social context that transforms social suffering into various values and meanings.

1.2. Situating myself

My (official) ethnographic research in Yogyakarta began in 2014 and extended for thirteen months, funded by the Australian Department of Foreign Affairs and Trade (DFAT). My childhood experience of a suspected bone tumour, as my late neighbour reminded me,[1] triggered this research. In 2002, I involved myself in the Indonesian Cancer Foundation in Yogyakarta (YKI-Yogyakarta) and worked voluntarily in the Division of Social Support. I wanted to understand about clinical encounters and the disease. I was concerned about people suffering from cancer and their experiences after surgery in a Javanese cultural setting, as I believed this social and political milieu strongly impacted on the patients and on family decisions in seeking healthcare and coping.

Ten years later (in 2012) as part of my work, I was visiting Elok, a sixteen-year-old Junior High School girl patient in the paediatric cancer ward in Sardjito Hospital. Elok had osteosarcoma. As my role was to support her to get medical help, I was insistent that Elok and her family follow the physician's advice to have surgery/amputation. Elok's left hand was becoming swollen and a senior specialist told me that her prognosis could worsen. It seemed to me that the disease threatened her life. Reflecting on my childhood experience, I felt Elok's pain. In order to 'help' Elok, I approached some clinicians at the Sardjito Hospital as I wanted her to get 'priority' treatment. My attempts to assist Elok in these various ways failed. I thought that what I had done for Elok and her family was somehow heroic but, after prolonged reflection, it presented me with a dilemma. When I emotionally shared my intention to help Elok in a discussion with some physicians at the Centre for Bioethics and Medical Humanities, a senior Javanese Radiologist told me in sincere, heartfelt tones 'this is not simple, Erlina, this is a *masalah etik* [ethical problem]'. This *masalah etik* is more complex than the ethical issues addressed in Western clinics. It is more than the bio-technical understanding of health care ethics relating to professionals, patient autonomy and informed consent encountered in the daily practice of medicine. Understanding diseased and impaired body here is not only about the pathological way of seeing but also about personal outlooks and social meanings of abnormality. In the eyes of the radiologist, *masalah etik* refers to the need to further explore 'do no harm' over personal life in the aftermath of the operation. He acknowledges that people's stories of illness, impairment, disease and despair require more assessment of socio cultural problems as well. This approach needs to take into account the

[1] She had breast cancer and passed away in 2016.

individual's life chances affected by emotional, political, and economic conditions. So, his concern contrasts two sets of ethics, the biomedical and that driven by cultural sensitivity— To consider both of these require balancing patient autonomy, care and dignity in social life with biomedical procedures that can be offered to the patient.

I did not understand, at the time, why he (as a clinician) responded in that way. I did not accept my radiologist friend's view and I went back to Elok's ward, giving her books and a bag as motivation for her to undertake the National Examination (*Ujian Nasional SMP*), and hoping that she would be willing to have the surgery and do the school examination afterwards. As it turned out, she showed me a 'flattened affect', as did her brother and mother, although I could still discern something of Elok's smile as she lay on her little bed in the sanitised room where the wall paint was peeling off in places. Her responses ranged from hope to pessimism.

It was these experiences above that triggered my interest in this research subject. I began witnessing various situations experienced by patients and family members, and thought about how ethics, law and medical solutions, together with ideas of human treatment, were all encountered in the ill and impaired body. I finally came to realise that my intention in helping to cure Elok was superficial. I was overly influenced by thinking about biomedical solutions without giving concern to socio-cultural complexities. Indeed, after completing the research for this thesis, and thinking about my conversation with the senior radiologist deeper meanings have been revealed. The experience shifted my focus to the broader picture. Learning about people (my research participants) trying to be good Javanese drove me to look, not only narrowly at the body's pathology, but at the complex issues referred to by my radiologist colleague as *masalah etik*.

I met Elok three times and became frustrated when, even though she wanted to pursue amputation, her mother and brother refused to give permission. At that time, I could hardly understand their mind set. Apart from feeling guilty, I came to reflect on Elok and her family's situation after I had a chat with nurses on the ward. They told me that her older and only brother had worked as a labourer in another province in Java, but had left his job to support Elok in hospital. Her mother rarely came to sit with her in the ward but went on working as a casual domestic worker (*pembantu rumah tangga*). Elok's mother was her father's second wife whom he had married in accordance with Islamic custom. According to a nurse, her father had worked as a royal servant in the Kraton (*abdi dalem*) but had died during Yogyakarta's earthquake in 2006. Since that time, Elok had lived in an orphanage because of her mother's mental illness. I lost contact with her after I moved temporarily to

Jakarta for English preparation as part of the DFAT scholarship. Yet Elok's story was momentous for me. I came to appreciate why her family members reacted in that way—letting Elok have a 'good death' (*khusnul khotimah*) and pass on to life in heaven only two years after my last visit to the ward.

Before leaving Yogyakarta to study in Australia at the end of 2013, I searched for Elok's orphanage to find out more about her family, but I was not able to locate them. The only news I had was from other patients and families who had been hospitalised with Elok. It was these people who became my research informants. I simply followed them in the wards, waiting rooms, halls, emergency rooms and nurses' stations, mainly in the provincial hospital but at times in the district hospital as well. I was involved in their everyday battles to survive by means of seeking health care, running, pushing, calling and, of course, praying during these difficult times. I observed the survival of individuals was underpinned by resilience. Following Kleinman (1988), here I investigate practices of human suffering by exploring particular Javanese people, places, spaces and events, focusing on a group of patients and their families as the central focus of this thesis. Cancer patients and families, known to me through my previous role as a volunteer working in various medical facilities in Yogyakarta, became my research informants. I followed up with interviews and observation in the places where they lived. My interactions with these individuals and their relatives, friends and associates, in both rural and urban areas, assisted me in understanding how society reacts to people who have experienced a catastrophic event such as the loss of a limb. Even though my research setting and selection of informants were precisely identified and mapped, in line with a phenomenological approach, my research was conducted as much by the 'coincidental moments' that I experienced while living in Yogyakarta from 1997.

From the time I met Elok in the paediatric cancer ward, I began to reflect on almost everything that patients and families told me. I saw myself as having multiple roles: as a former patient, as a worker employed in the biomedical institution as well as a social scientist. Thus, my situation in the field was complicated because I represented myself as a biomedical staff member to everyone—clean, higher social rank and 'professional'. While I was often introduced as a staff member who was casually working at the institution to get trust from clinicians, this 'official' status frightened patients and family who were reluctant to seek medical care. This was not dissimilar from the behaviour of Elok's brother and mother who often went into hiding or became silent when I visited. In the hospital setting particularly, it was not easy to enter into the clinical setting without explicit support from the

Indonesian Cancer Foundation or ‘the magical password’ of the Faculty of Medicine, UGM (Gadjah Mada University).

Research on suffering, grief, and death is never an easy topic. This dissertation is also as nothing in comparison with the cost to those who have experienced the illness and impairment described here. One by one, I made contact with participants and gained their trust by listening to their narratives of their own personal experience as a patient and their confidential issues concerning health. This process led to participants giving their consent to my writing about them within the health care system. Similarly, I spent time with with hospital staff empathising with their situation both as health professionals and as a caring individuals.

1.3. Methodological approach

Research in the hospital setting, although tempered by my ‘official status’ and involvement in the Centre for Bioethics and Medical Humanities at the Medical Faculty, was not always pleasant. Once, a staff member prohibited me from entering the cancer ward, saying dismissively, ‘Only doctors are allowed to visit the ward. You are not a doctor, are you?’ Their ‘body language’ responses were even worse, as they were often extremely busy with their jobs and working under pressure and with challenging dilemmas. Very often, I was forced to get research permission through personal contacts and social networks. For example, it was common for me to bring food or snacks for nurses in the ward as a way to approach them, make friends and build trust. A physician advised me that, in order to obtain data, I should not forget to drop snacks to the nurses’ station, saying, ‘They are Javanese and so too is the hospital [space]’. My physician friend was actually emphasising that the clinical setting is not a rigid place characterised by professionalism, but that the nurses were ‘medical professionals and Javanese individuals’.

In the process of conducting research, I utilised ethnographic strategies such as note taking, photography or video-recording, audio-recording, semi-structured interviews, open-ended interviews and observation. Working with Javanese research assistants, I documented conditions in various clinical settings and everyday settings such as villages and suburbs. I explored in depth with informants their traumatic and personal experiences of bodily impairment and ‘being disabled’. I felt intrinsically that I had something in common with my research participants while trying to understand common Javanese responses and values as much as possible. I also participated in some events and celebrations designed to be

‘inclusive’ of people with disabilities who were living in residences or village houses, hospitals and the Rehabilitation Centre (BRTPD) situated in Bantul district.

Disability issues are currently given a privileged place in International Development Projects and poor people are targeted as being ‘at risk’. I would argue, in agreement with Kleinman (1986), that understanding social, cultural, political and economic burdens may create bridges and good relationships between patients, families and clinicians. Through twenty years of clinical research, the American anthropologist and psychiatrist determined that, through empathetic listening to patients’ concerns, practitioners may understand social suffering and the broader social context of family dynamics, life problems and cultural settings that shape the illness experience (Kleinman, 1981, 1986, 1988). According to Kleinman (1988), ethnographic evidence of the lived experience of chronic illness and bodily impairment could be used to plan strategies, to achieve recovery from illness and to reduce social suffering.

Map 1.3. Interlocutors in Yogyakarta

Source. © CartoGIS CAP 18-275a_KP, The Australian National University

During fieldwork, walking, travelling by car and hiring motorcycle taxis (*ojeg*) provided opportunities for me to follow up interviews with cancer patients, amputees and families in hospital. I visited the interlocutors at home in many urban areas and villages (*kampong*) in Yogyakarta (Map 1.3). Additionally, I also observed residents and religious leaders who lived around Masjid Pathok Negoro (Pathok Negoro's Mosques). The Pathok

Negoro Mosques were built as centres of Islamic thought and civilisation. Culturally they are symbols not only of a way to maintain Islamic values but also to spread Islamic thoughts, beliefs and truths. These four mosques surround the Kraton, located at four points, Masjid Ploso Kuning in the north east, Masjid Mlangi in the north west, Masjid Babadan in the south west and Masjid Dongkelan in the south east of Yogyakarta City. The Masjid Gedhe Kauman is in the centre and situated in the Sub-District of Kraton (Map 1.2). The four mosques surround Yogyakarta's Palace, signifying its identity as a centre of the adoption of Islamic Javanese values.

Throughout my writing, I pursue narrative phenomenology. The Kleinmans noted the experience of illness and bodily impairment as an 'intersubjective medium of social transactions in a local moral world' (Kleinman and Kleinman, 1991, p. 277). The experience of illness and bodily impairment elaborated in the Prologue is a painful articulation of a moral commentary on the roots of trauma and calamity. Some anthropologists have conducted research on the experiences associated with illness and death by giving voices to their subjects who became patients, and to the families (Browne, 1999; Kleinman, 1986, 1996; Mattingly, 2010; Pitaloka, 2014; Scheper-Hughes, 1993). Working in the same tradition, in a shantytown in Brazil, Scheper-Hughes (1993) examined women's capabilities that related to their endurance following the loss of many children (infant mortality) where extreme poverty, a military dictatorship, colonisation and the expansion of the sugar industry provided a salient and powerful context. She adopted a phenomenological approach, to explore the way of life of people in Northeast Brazil by setting up a research world of 'personal truth' rather than 'universal and absolute truth'. The personal truth that Scheper-Hughes (1993) recorded and re-presented in her writing may be taken as a subjective and sometimes emotional, personal, anecdotal narrative that includes her observations in engaging with her informants. In the 1960s and the 1980s, she exposed her own feelings while recording the lives of mothers and their children—living and dying amidst poverty and violence.

In doing the research during her early work as a health worker, Scheper-Hughes (1993) made friendships, including with three half-sisters who became central to her research. She followed these shanty-town sisters' lives over the years, witnessing their struggles against poverty, social discrimination, hunger and malnutrition. She became familiar with the men in their lives and the children they bore, and observed their young babies sickening and dying, all the while looking closely at the inspiration with which they endured and survived. Her research writing presents powerful, provocative and deeply moving narratives, based on her

field experiences (Scheper-Hughes, 1993, 2008). Later on, as Mattingly puts it: ‘A narrative phenomenology offers an especially powerful vantage point from which to see how the past and present are saturated by dreams—and nightmares—of the future’(2010, p. 217.) Mattingly (2010) documented her research participant characters as specific docile individuals and extracted their representations of ethnicity, race or disability within the clinical context. Her intention was to look deeply at the relationship between suffering and hope while exploring ‘hope’ as a practice at the levels of personal and communal (Mattingly, 2010). The affective practice is a specific form of disguised power. Mattingly’s works have greatly inspired my own research. While her research emphasised both the individuals and society that are implicated in perpetuating such practices, I consider my analysis does not merely eclipse the struggles of poor patients. I have taken advantage of Mattingly’s useful approach and report, analyse and write in reference to concrete or specific examples from Javanese everyday life that to me exemplify affective practice as a healing journey.

1.4. Thesis outline

In this thesis, I begin by situating patients and their families within the context of biomedical/hospital-based intervention, and then examine how their experiences are lived in the social cultural context of Java. Put more simply, Chapters 2–5 are concerned with poor patients and their support groups in both medical and social care settings. I have taken into account factors such as Javanese culture, the political economy, health care development and structural forces. By focusing on how things work in the local context, I attempt a broad analysis of health care and treatment within the context of the social, political and economic circumstances of the participants.

In Chapter 2, I explore the experience of a poor Javanese patient within the context of public health care and policy. Indonesia adopted the global health agenda through the implementation of universal health coverage (BPJS) in 2014. Social inequality has become a health issue because treatment has classified people according to their ability to pay, and the classes of health treatment result in poorer citizens with chronic illnesses having inadequate access to care.

In Chapter 3, I explore social perceptions in diagnosing the disease of osteosarcoma (bone cancer) and illness in clinical settings and everyday life. From the hospital to vernacular settings, I explore illness experiences in wards, consulting rooms, theatres and the like. The biomedical diagnosis focuses on the dysfunction of the anatomy of the body. However, the patient, family and their community (including clinicians) tend to look at this

more widely, and here I examine the cultural aspects of illness within complex social political settings.

In Chapter 4, I portray those Javanese people living in the ‘corridor’. In the hospital, poor patients in wards do not have sufficient consultation with specialists and medicines are inadequate. The total care of the patient requires community input, not just in terms of blood donations and finances, but also in relation to spiritual and social support. In responding to inadequate health care and inequality, I discovered that the social space of intervention is far wider than the specifically ‘medical spaces’ of the wards. ‘Corridors’ were revealed to provide healing by forming alternate spaces where social care is organised. Corridors may be understood as critical spaces of interaction that are vital for the ongoing support and wellbeing of patients.

Still in the ‘border zone’ of the Javanese hospital setting, Chapter 5 continues to explore the mix of cultures embedded in the medical context. I examine the intersection of the scientific technology of ‘truth’ and Javanese intuition (*rasa*) which emerges in clinicians’ dilemmas of prognosis, and reflects their uncertainties in reference to social suffering. I use stories from patients and families in referral hospitals, observations of their interaction with clinicians and data derived from direct interviews. I argue that there is a certain ambivalence in the practice of diagnosis by Javanese medical staff, and that this leads to some confusion/mix-up in how patients and their families respond to the diagnosis.

In Chapter 6, I explore the community settings where diseased and deformed bodies resume their previous social lives and face social stigma. Here I relate stories about Javanese cultural perceptions of severe illness and disability—such as cancer, amputation and bodily impairment. People commonly see impaired bodies and chronic illnesses as deviant, requiring not only physical but also moral fixes. Communal support focuses on moral and spiritual reform rather than physical recovery, leading to the stigmatisation of people with disability when they return to their communities. This chapter shows the emergence of these moral struggles within the everyday life of Java.

In Chapter 7, disfigured bodies are situated in Javanese socio-cultural settings, conversations, religious narratives and the like. Poor people are likely to find themselves marginalised by community opinion. I draw on the tactics of survival used by poor ‘disabled’ people who are dealing with chronic illness, impairment and stigmatisation. Poor people use tactics of survival based on *Kebatinan* (Javanese mysticism), self-awareness, spiritual development and self-improvement. They take advantage of social networks, and spiritual and ritual means. These tactics aim to provide holistic care by offering cures or *ayem*

(equanimity) through balancing the physical and material body with social and spiritual/inner control. This chapter shows how the interactive engagement between subjects and their culture shapes the vectors of emotional outcome of acceptance (*menerima dengan ikhlas*) and blessing (*syukur*).

In Chapter 8, I explore the idea of 'disabled' people's empowerment offered by various agencies such as state and non-state organisations/affiliations and mosques, particularly in terms of their encounters with biomedical rehabilitation. The focus of my analysis is the interplay between biomedical and traditional Javanese views of the body in the context of illness and disability. Here, extending my analysis to 'outside' structures, I suggest that NGOs should provide another element of remedial care delivery by engaging with a broader sense of illness or disability narratives instead of merely the individual body. In this chapter, I see the demands of their many sponsors pressuring NGOs to encourage dependency in their clients. Following Pylypa (1998), I see the disability movement and health interventions that build on disability rights as resorting to 'controlling' the individual and reinforcing the body's dichotomy. NGOs tend to negate the efforts of the disabled poor to be self-sufficient and tend to reproduce state biomedical discourses.

In the Conclusion, I draw together my argument that to understand the subjective experience of chronic illness and bodily impairment and healing in Java, we must see the rhetoric of control as a complex narrative contributing to social suffering and empowerment. This Javanese case study indicates that social suffering analysis must take into account communal attitudes and spiritual beliefs that frequently act, not only to complicate biomedical diagnoses of chronic illness, but also to complement biomedical treatment and remedial approaches.

Chapter 2
Medical Care Provision for the Poor in Indonesia

2.1. Introduction

This chapter charts how social, political and economic settings impact on poor people with a chronic illness (e.g. osteosarcoma) and severe injury in Java today. When I arrived in Yogyakarta for ethnographic fieldwork at the end of December 2014, the sixth president of Indonesia, Joko Widodo (Jokowi), had been in power for about one year. In addition to prioritising economic growth, the government had begun significant reforms after a series of corruption scandals that had surrounded the previous government of Soesilo Bambang Yudhoyono (SBY). Under Jokowi, Indonesia experienced a successful political and economic recovery from the Asian Financial Crisis. Fuel subsidies were overhauled and political economic strategy was directed towards infrastructure to generate national income. Jokowi's economic growth-led policy strategy copied the New Order's inwardly focused, technocratic agenda and 'developmentalism' rhetoric to design a 'modern' Indonesia (Warburton, 2016).

The ensuing focus on infrastructure, including health facilities, improved conditions that had deteriorated after the 1997 Asian Financial Crisis. Nevertheless, it was noted (e.g. Negara, 2016) that policy on infrastructure development was underpinned by an emphasis on economic growth and poverty reduction. This economic policy is now being implemented through two government strategies. First, the government has shown a persistent intent to focus on openness, transparency and a competitive economy within a globalised trade market. Second, the government has demonstrated a 'reverse course' from the previous administration, using an inward-looking policy—*Keindonesia-an* (National pride)—to engage and participate in selling and promoting unique Indonesian products and tourism in the market economy. In the global context, Indonesia is unusual in sustaining its economic development; yet over the past five years, there has been a slowing in the rate of growth and increasing unemployment. In terms of welfare policy, the Jokowi Government has focused on 'universalisation' to protect the poor (Sumarto, 2017). However, the benefits of economic policies have not trickled down to the lower classes, and donor agencies make frequent warnings about rising income inequality. Consequently, the national attachment to a growing global market economy has pushed the government to design a universalised health policy, Badan Penyelenggara Jaminan Sosial (BPJS), with the inevitable range of impacts on the lives of everyday people.

The BPJS Social Insurance Scheme adopted the biomedical knowledge systems and medical practices dominant in the 'Global North'. This chapter is mainly concerned with the BPJS policy as a form of biopolitics. Biopolitics is the will to control and regulate the population in a preventive way, entailing a process to order people to become disciplined, 'normal', healthy, productive and active (Foucault, 1977). I examine the lived experience of poor people with cancer who receive care and explore how the BPJS Insurance has shaped their experience of poverty, subordination and suffering. The lived experience of chronic disease and bodily impairment reveals contradictions of social policy innate in market economies undergoing rapid growth. The violence that people experience is the result of social structures (Farmer et al., 2006)—economic, political, legal, religious and cultural—that limit individuals achieving their full potential and sense of healing. The state of healing that people desire is a balance between material and spiritual states. I argue that the practices of Javanese religion (*agama Jawa*) in respect of healing mingle with biomedical knowledge and emerge as an alternative and efficacious healing model. Javanese people define healing as the achievement of a harmonious state with the cosmic order (Ferzacca, 1996; Woodward, 2011), and it is understood to be realised through a combination of medical and spiritual practices. Although the BPJS enables access to biomedical treatment for the poor, in the case of severe illness, biomedical treatment is both, in itself, insufficient and unaffordable. The biomedical approach is highly important, but people simultaneously put their trust in religious healers, and this is unlikely to change in the future (Woodward, 2011).

In the first part of this chapter, I will highlight the emergence of healthcare provisions for the poor in Indonesia that started during and after the Asian economic crisis of 1997–98 (the end of the New Order era). I will particularly examine the history of commoditised medical services within the poverty alleviation program. In the broader political economic setting, this chapter asks in the first instance how these schemes have served the poor. Second, how have the poor responded to their (in)adequate health care? I argue that medical care is only readily accessible to those who can afford to purchase it. To be a poor Javanese within the system is to be impacted by the decline in economic growth, to be limited to specific lower-class treatment in hospital inpatient care, and to be *wong nrimo* (people who accept whatever they are given).

2.2. Economic growth and health care policy

Economic growth has characterised the new government's developmentalist approach (Sumarto, 2017; Warburton, 2016). Within its welfare provisions, BPJS constitutes one of the

interventions in the health sector. Indonesia has experienced two core periods in the development of health insurance policy: 1966–97 (Soeharto era) and 1999 to the present (post-Soeharto era). Private health funds had existed before 1968, mostly organised by social or religious organisations such as Muhammadiyah and the labour unions (Vidyattama, Miranti, and Resosudarmo, 2014). During the period from 1966–97, state and private health insurance schemes offered limited coverage and served only public servants and middle-income earners. After the Asian economic crisis in 1998, the health insurance scheme expanded its coverage to poor informal workers under a poverty-reduction program (Sumarto, 2017). By 2014, 9 per cent of people in Indonesia had private health insurance; the government covered another 7 per cent, while about 35 per cent, or 83 million Indonesians, did not have any health insurance (Aspinall, 2014). The size of this underserved population led to government concerns about how to safeguard the wellbeing and welfare of the nation.

In 2014 the Indonesian central government implemented the BPJS, covering all segments of the population—formal and informal workers, middle and low-income earners—within the one scheme, the JKN-KIS or BPJS Insurance. Promoted by the World Health Organization (WHO), the World Bank and other international organisations, the BPJS reflects the global push through the Sustainable Development Goals (SDGs) to adopt universal health care as national goals and to relate that to human security (Reich et al., 2016; Sumarto, 2017). However, the government's administration of health care for the poor has been almost entirely limited to the establishment of practical services and technical economic outcomes; thus focusing much of the government's energy on boosting infrastructure development (Warburton, 2016). The health care insurance policy for the poor has been politically co-opted by ruling regimes and notions of economic growth (Aspinall, 2014; Warburton, 2016). Therefore, despite the initial effort to achieve the universalisation of health care, this pro-poor policy has fallen prey to the limited reach, range, and quality of service delivery that has remained unchanged since SBY's era. Local and national politicians have driven free health care in order to consolidate power, regardless of the quality of service (Aspinall, 2014; Kristiansen and Santoso, 2005).

Alongside the BPJS mechanism, some districts in Yogyakarta offer additional health support programs to residents under Jamkesus (*Jaminan Kesehatan Khusus*) which provides, Special Health Insurance for people with disability and Jamkesda (*Jaminan Kesehatan Daerah*) a Local Health Insurance initiative. However, this has increased the burden at the local government level, because the decentralisation model has opened up a gap in the allocation of health funds between the local and national governments. Within this frame,

districts and provinces that have a higher domestic income can offer better services for their residents while in other districts and provinces the people receive less. There has also been concern that corruption and lack of transparency in funding from the local government may affect the quality of medical services (Kristiansen and Santoso, 2005).

I argue that the health care policy has brought great resources to social needs, but its economic logic has historically hindered its humanitarian engagement in effective care (Boomgaard, Sciortino and Smyth, 1996). Access to medical care is dependent on the purchasing power of households to pay for additional health costs such as travel costs to health services and everyday expenses during hospitalisation.

Prolonged illness can destroy a household's capacity to maintain income earnings, save salary and even pay for additional health care needs. In order to fulfil the health-care needs of people with acute and chronic illnesses, households adopt various strategies in seeking health care in order to cope with the high cost of treatment and associated financial burdens. Patients not only rely on health insurance provided by the state, but may also sell their own assets and borrow money from family members (Aji, Yamamoto and Sauerborn, 2014). Still, poor patients may find themselves abandoned. In the 1990s Sciortino (1995) argued that hospitals struggled with insufficient funds and medical professionals were not able to handle the great number of patients with chronic illness and acute disease, and this situation has continued since then.

2.3. 'All included': Indonesian Universal Health Care (BPJS)

In everyday vernacular, people often refer to the universal health care scheme as 'BPJS Insurance' (*Asuransi* BPJS). The BPJS is a state agency that collaborates with the Ministry of Health (MoH) as the main state agency that manages overall health-care services including the insurance program. This BPJS Insurance aims to provide cover for every citizen to access biomedical treatment through various health-care providers such as primary health care (Puskesmas), public district and tertiary hospitals, and some private hospitals affiliated with the agency.

The program is technically ambitious with the intent to embrace every citizen, without exception, and this has resulted in the BPJS being identified as the largest insurance scheme in the world, covering millions of citizens and requiring a massive allocation of funds (Aspinall, 2014). It attempted to insure at least 121.6 million people by the end of 2014 and about 268 million people by 2019 (WHO, 2017). I examine universal health care as a technology of power with control over citizens' bodies. The BPJS has adopted a form of

social regulation that allows health professionals, as the state apparatus, to place the body with disease or missing organs into the spatialisation and verbalisation of biomedical pathology (Foucault, 2012). As Foucault said:

> What occurred was not a 'psychoanalysis' of medical knowledge, nor any more or less spontaneous break with imaginary investments; 'positive' medicine is not a medicine that has made an 'objectal' choice in favour of objectivity itself. Not all the powers of a visionary space through which doctors and patients, physiologists and practitioners communicated (stretched and twisted nerves, burning dryness, hardened or burnt organs, the new birth of the body in the beneficent element of cool waters) have disappeared; it is, rather, as if they had been displaced, enclosed within the singularity of the patient, in that region of 'subjective symptoms' that—for the doctor—defines not the mode of knowledge, but the world of objects to be known. (2012, p. xi.)

Foucault (1977, 2012) argues that the modern state design has allowed the biomedical gaze to construct the ideal of physical fitness, healing and normalcy into the creation of 'docile bodies' as the target of power (see also Pylypa, 1998). This mode, however, enshrines the doctor's view as more important than the narrative associated with the patient's illness and overlooks the wholeness of the human being within their psychological and socio-cultural settings (Davenport, 2000).

Central to the government's response has been the implementation of the BPJS Insurance scheme, which consolidates the biomedical gaze upon the Indonesians. This central concept underlies the new government's approach (Warburton, 2016), which ambitiously promises to provide all Indonesian people with access to medical care by 2019. However, social inequality has hampered the access of lower-class citizens to this care. State bureaucracy and administrative procedures have created a paradox as their membership selection processes have excluded millions of poor citizens[1] who are required to give evidence of their engagement with their family membership or to list a permanent residential address. Those who fail to provide one of the legal requirements are not eligible to become members and are therefore unable to access the free health care. This excludes groups such as transgender (*waria*), homeless, street children, and poor disabled people who are separated from their families. These cohorts exist in a 'state of exception' under a form of violence that deepens their poverty and suffering (Gupta, 2012; Kleinman, Das and Lock, 1997).

[1] BPJS membership requires every applicant to present proof of their identity card (KTP), and birth registration or Family Card (Kartu Keluarga) (Nanwani and Siagian, 2017).

2.3.1. Treatment from primary health care to the tertiary hospital

The BPJS covers a wide range of services from basic prenatal care or consultation at the primary-care level to the more advanced services such as surgery and cancer therapy at tertiary hospitals. Primary Health Care (Puskesmas) operates as the gatekeeper to the rest of the Indonesian health care system. The Puskesmas manages acute and chronic illnesses, through care from a general practitioner (GP) and a limited range of pharmaceuticals. The local Service Post (Posyandu) provides other primary-care services like health-care promotion and prevention. It is staffed by health assistants recruited as community cadres. The Posyandu offers five areas of preventive care: nutrition, immunisation, diarrheal disease control, maternal and child care, and family planning (Boomgaard, Sciortino and Smyth, 1996). The local government funds the Puskesmas and Posyandu programs and services. In addition, corporations, individual groups, and religious-based organisations may take part in delivering health care services (private clinics or hospitals), but patients are required to pay to access these services. Only a few of these private services are accessible through arrangements with the BPJS.

Local government is responsible for coordinating the private and public health sectors. This mechanism, so far, has resulted in fragmentation of the health system (WHO, 2017). Patients' medical records are poorly integrated across these services. This means that patients may have the same diagnostic procedure or medical check-ups for the same condition performed repeatedly by different providers. In addition to poor integration between and within services, there are ongoing interregional/interdistrict disparities in resources, services and health outcomes. Unequal access to services and poor integration between services are serious challenges for the creation of an effective decentralisation policy (WHO, 2017). Variations between primary care services—in relation to access, quality and information sharing—complicate health care at the tertiary level where the public hospital is the only hospital to offer therapy for the treatment of advanced cancer.

Sunarti's and Elok's stories, presented respectively in the Prologue and Chapter 1, have shown the difficulties experienced by poor people in accessing adequate health care. Friends, health professionals and families whom I have known personally over the years have battled such difficulties. Yet I observed similar experiences during the era of BPJS when even those patients insured under it were reluctant to access health care for advanced treatment in the referral hospital because of cultural and social-economic consequences, associated social stigma and unaffordable additional costs.

In the following, I present the story of two people, Jelita and Julius, who were admitted for the treatment of osteosarcoma to Sardjito Hospital.

Data from the Sardjito Hospital show that an average of fifty-three new patients is admitted to the hospital with osteosarcoma every year (Table 2.1). In providing medical care for these patients, the tertiary hospital plays an important role in curative and rehabilitative treatments.

Table 2.1. Number of patients admitted with osteosarcoma, 2010–17

Year	Upper Limb Amputation	Lower Limb Amputation	Total Number
2010	18	23	41
2011	21	25	46
2012	13	26	39
2013	10	21	31
2014	16	40	56
2015	32	35	67
2016	28	49	77
2017	22	47	69

Source. Instalasi Catatan Medic (Medical Record Centre), Sardjito Hospital, 2018

For in-patient care, Sardjito Hospital provides 819 beds divided into several classes (Table 2.2).

Table 2.2. Number of hospital beds, Sardjito Hospital, 2017

Type of Room	Number	Price (Rp)	Price (AUD)
Suite Room	16	1,055,000	$105
VVIP A	28	955,000	$95
VVIP B	2	755,000	$75
VIP A	0	700,000	$70
VIP B	10	650,000	$65
VIP	44	650,000	$65
Utama (Priority)	6	-	
1st Class	67	326,000	$32
2nd Class	333	217,000	$21
3rd Class	313	196,000	$19
Total	**819**		

Source. Medical Record Department and Administration, Sardjito Hospital 2018

Figure 2.1. In the third-class cancer ward

Source. Photographed by author, 19 Dec. 2015

Figure 2.2. Suite Room at Sardjito Hospital

Source. This picture appeared on the hospital's website. *RSUP Dr. Sardjito*, 2015. Retrieved, 3 Mar. 2016 from: https://sardjito.co.id

Jelita and her mother Bu Sumiati, are part of a Muslim family categorised as having a lower-middle income. In their village situated in the west of Yogyakarta, Bu Sumiati had opened a laundry service. Her husband did not have a stable income, so this small business became the only source of income for the family. Bu Sumiati had two children of whom Jelita is the younger. Her son had worked outside Java (*diluar Jawa*) until his sister's illness.

Jelita had a painful mass on her upper leg—a suspected osteosarcoma—which caused her extreme pain. One month before Jelita was admitted to the hospital, I visited her in a simple house in the village. Simbah ('grandmother' in Javanese language) lived just beside Jelita's house, the back door connecting the two houses. Lying on a mattress covered by colourful pillows in the living room, Jelita welcomed any guests who visited her. With me was Anas, a twenty-four-year-old volunteer and survivor of osteosarcoma of his femur, whom Jelita had met on Instagram. After a while, her mother Ibu Sumiati and Simbah asked Anas about his own experience with the disease that had occurred seven years ago. Anas told

them that the only way for Jelita to recover was amputation and encouraged them to take her to hospital for the operation.

Another neighbour was also present, sitting and giving support to Jelita. Jelita tended to be silent while listening to the conversation. Several times she sprayed acidulated water on to the swollen leg to help relieve the heat of the limb. She continued staring out the window, as though trying to imagine herself far away from the pain. Her face seemed hopeful, and she did not show resentment of her disease or the delay in amputating her limb. One week later, she was admitted to hospital for amputation.

I met 20-year-old Jelita in the third-class ward of the hospital (Figure 2.1). In the hospital, the third-class wards are arranged according to categories of disease. Jelita was in the cancer ward. In the ward, curtains divided the patient's space into cloth cubicles containing six patients. An oxygen bottle was behind the patient's bed; a fan projecting from the wall made little difference to the thick heat of the room. Outside the ward, across the corridor was a general-use toilet shared by all the ward patients and their families. The toilet area was used for various purposes such as laundering sheets, which also hung in the room, and a bin was used for the disposal of biomedical trash and general waste.

Jelita's family held BPJS membership, entitling them to access third-class facilities. Before hospitalisation, Jelita followed the treatment procedures prescribed by the visiting doctor at the Puskesmas, and then went to the district hospital for a consultation and referral letter. Bu Sumiati had to follow the administrative procedure of obtaining the signature of the District Government and taking the signed letter to the health staff in the tertiary Sardjito Hospital, indicating that Jelita was eligible for free health care.

I was told by clinicians that limb amputation for osteosarcoma could be avoided by limb salvage surgery. Limb salvage surgery for osteosarcoma is a complex procedure that involves resection of the tumour and bone transfer (replacement of the defective bone with bone from elsewhere in the body), and the use of an internal or external distractor device to encourage the bones to grow and lengthen. It is a surgical procedure that removes the diseased bone and restores a functional limb by using a metal implant, a bone graft from another person or a combination of both materials. The likelihood of the procedure succeeding is enhanced by a computer-assisted navigation system. Dr Kartika, a surgical resident, told me about the limb salvage surgery and was enthralled by the technology, misrepresenting its potential success in some cases. It was almost certainly never an option for Jelita, as it is highly technical, and not for people who have not been prepared for surgery by the use of chemotherapy. It would have been foolhardy for the hospital to engage in this

surgery and she would have probably died from it (Yang et al., 2018). Internationally, however, limb salvage surgery is now conducted in about 90 per cent of patients with osteosarcoma (Joseph et al., 2013).

In Sardjito Hospital, I met a young orthopaedic resident called Dr Kuncoro. He advised me that for patients with serious injury or possible tumour, an amputated limb could be avoided by using a bone graft and reconstructive surgery. Dr Kuncoro described the procedure, but not the preparation needed for the surgery to succeed or the in-hospital monitoring afterwards, where the patient would have a high risk of developing infection, or the rehabilitation required afterwards. The long-term outcomes of limb salvage surgery versus amputation are similar in terms of quality of life. He did not discuss the hospital's success rates with this procedure (poor, because they don't usually do them). There are in fact very good reasons why the hospital should not authorise this procedure for Jelita. He further described the operation in technical terms, and saw the major obstacles as financial:

> [If] there is tumour here, for example, we'll replace the bone. We take the bone from another area of the body and attach it. Yes, to avoid amputation. It happens in certain hospitals. As far as I know [of the procedure], if there's a tumour on the arm for example, we'd cut it off, remove and replace it with this [bone from elsewhere in the body]. It would be chosen if we see the patient is still of working age, young. BPJS cannot cover everything as some of the instruments are very expensive, above IDR 100 million [AUD 10,000].
>
> However, this has never happened here. During my residency here, replacing a limb due to tumour has never been done yet. We've proposed it, but it was stuck in JAMKESDA [regional health insurance] because the patient was financially disadvantaged. Therefore, we automatically cut off the limb and throw it away … The process to get the procedure approved is a bit complicated. It has to go through a long bureaucratic process. We have to propose the specification of the instruments first. After that, they will check whether or not that instrument is on the list of instruments available in the hospital, and then whether or not there is recovery of the fee from BPJS. It's a long process. Both doctors and patients have to try to get the insurance organised. (Interview, Dr Kuncoro, 2 Dec. 2015.)

Dr Kuncoro then described the case of a disadvantaged person whom he had wished to perform the surgery on, but for whom he had been unable to navigate the bureaucracy.

> As usual, we follow the bureaucracy, send the proposal, do the follow up whether it has been approved or not, then go from one department to another. Just like that.
>
> As far as I know, for the one whom I helped, because it was too late, he finally … [died]. He … eh [frustrated sigh]. The tumour had spread, and we cancelled it [surgery]. We're concerned that the cost we spend for a big operation is not commensurate with the result, for example, the patient finally dies anyway as the cancer has spread. (Interview, Dr Kuncoro, 2 Dec. 2015.)

Dr Kuncoro did not discuss whether an amputation before embarking on the bureaucratic navigation may have prevented the patient from dying. Instead he attributed the patient's death to bureaucratic hold-out. He expressed no doubt about the capacity of the

hospital to do the procedure and get a good outcome, even though he had never previously done the procedure, and the hospital did not have an established rehabilitation program for patients with osteosarcoma having limb salvage surgery—either of which could have been expected to increase the risk of death for the patient.

His own desire for limb salvage surgery procedures, while in fact a less safe option for patients than amputation, was consonant with the patient's desire for limb preservation.

> So far, I mean as long as I have been resident here, most patients have accepted the decision [for amputation]. The worst scenario is that sometimes patients come, and we educate her, 'Madam, this should be amputated,' or 'Sir, this should be amputated.' They don't agree and then seek alternative treatment. When they come back here and request surgery, they usually have accepted their condition. 'Doc, what else can I do?' because it is really painful. We're talking about a tumour here, Mbak, it's painful. For patients with traumatic injuries to their limb, they sometimes disagree. 'Doc, I don't want to be amputated.' We automatically try to preserve it. Quite often, patients with tumours refuse amputation, go home and choose alternative treatment. When they come back here, it is because the tumour is getting bigger and more painful. 'Yes doctor, I agree to undertake any treatment.' They provide informed consent and, if the patient's condition is good, and all surgery requirements are fulfilled, then we perform amputation surgery. (Interview, Dr Kuncoro, 2 Dec. 2015.)

The hospital performed many amputations—two to three per month, some of them for people who had secondary disease.[2] Doctors said they performed amputation for the purposes of palliative care to relieve pain, but very often surgery was conducted so late in the course of the disease that the patient died shortly after the amputation.

Although amputation removed the pain, it increased the social shame. Julius, a twenty-two-year-old university student from a Catholic family background, suffered from osteosarcoma of his left humerus. When he began to feel pain in his arm, the family sent him firstly to a traditional massage (*tukang pijat*), but the pain in his left humerus persisted. Julius' family, like many villagers facing catastrophic illness or cancer in a family member, felt shame for their son's affliction. Julius' family stopped communicating with their neighbours and newcomers after the cancer diagnosis and became more withdrawn. His parents felt even guilty because of the disease.

Julius' family went to the tertiary Sardjito Hospital to admit Julius as a private patient. Although the family held BPJS insurance, they preferred not to use it. They chose the VVIP (Very-Very Important People) room for privacy reasons and were able to access what they thought was the best treatment from a specialist. In the exclusive room, the family paid about Rp 955,000 (AUD 95) per day for the room as well as the AUD 10 daily fee for the specialist

[2] Medical Record Instalation at DR. Sardjito Hospital in 2016

visit and any other medication costs from the pharmacy. The hospital administration organised most of the service fees including the prescribed medicine and the family had to pay for the entire bill at the time of being discharged from the hospital. Pooling all their savings, Julius' family were able to afford two week's care in the VVIP ward at the tertiary Sardjito Hospital. However, they rejected advice that Julius should have an above elbow amputation and chemotherapy, not believing that he had a fatal illness.

Julius told me that, at the time of his first admission to the tertiary hospital, he remained unclear about his condition. He asked for his medical records to educate himself on the doctors' thinking.

> When I was in the VIP room I asked for my medical records [to take home], but the records were not given by the hospital. They only said that the records would first be discussed in a meeting. But we were ignored for several weeks. (Observation at Panti Rahayu Hospital, 18 Mar. 2015.)

Information that was provided did not make any sense to Julius' family, as they did not have a clear understanding of the medical diagnosis explained by their clinician. Dr Agus, the specialist who treated Julius, confirmed to me that he had explained the medical prognosis to Julius and his family, but they did not follow his recommendations for treatment. The information gap between patient, family and clinician within the Javanese cultural context remained the biggest issue. Dr Agus told me:

> What other ways should I go to convince them [patient and family]? As I have [already] told them the prognosis and the consequences of the fatal illness. But, as you probably know, the patient and family here [Indonesia] are always *besar pengharapannya* [full of hope] derived from other sources. (Interview, Dr Agus, 20 Mar. 2015.)

The 'other sources' mentioned by Dr Agus referred to spiritual, mystical resources and even to traditional healers. The spirit of surrendering everything to 'God' is characteristic of Javanese belief, and this attempt to achieve such a surrender (Mulder, 1983, p. 38) is practised when a severe illness afflicts somebody. Religious attitudes are intrinsic to Javanese approaches to health and illness, and biomedicine remains an undistinguished feature of their life view (Woodward, 2011).

The attitude of *rila* (to give oneself up), *nrimo* (acceptance), and *sabar* (trustful patience) in response to illness and even death is central to *Kebatinan* spiritual practice as lived by most Javanese families. Julius focused on these attitudes as he waited in the hospital without certainty or clarification. The explanation he received did not make any sense to either him or his family. Meanwhile the tertiary hospital continued to calculate his hospitalisation costs at the highest rate. Finally, he and his family decided to return home

without having undergone amputation and chemotherapy. Julius went home to obtain home-based treatment from a traditional healer who attracted patients and their families because of spiritual abilities. Guinness (2009) noted that some healers not only offer spiritual and emotional relief, but they also do not charge a set fee, leaving it to the patient to give what they can afford. This close relationship draws the patient to return regularly to the healer. Most patients and their families across all social classes that I observed in Yogyakarta had, at some time, sought treatment from traditional medicine (*pengobatan traditional*). In most cases, people returned regularly to the traditional healer in conjunction with undergoing biomedical treatment. Most people turned to the health care resources of traditional healers because they offered religious legitimacy and a healing through feelings of *ayem* (equanimity).

All insured BPJS patients with cancer must firstly register with the 'gatekeeper' service, either the Puskesmas or their family doctor. The patient or family may seek a second opinion by consulting with another GP, but they are not permitted to randomly access different GPs every time they feel sick (WHO, 2017). Under decentralised administration, primary health care services are managed through a District Government officer, members of the municipal/district parliament, Health Department staff, community leaders associated with *Badan Penyantun Puskesmas* (Primary Health Care Board), and members of the health professionals. After getting a referral letter from the primary health-care provider or family doctor then the patient may be referred to the district-level hospital, and from there a patient with serious illness may be referred to the tertiary hospital. In Indonesia, hospitals are classified as A, B or C; Sardjito Hospital, based in Sleman on the outskirts of Yogyakarta city, is the province's only tertiary referral hospital, and the only hospital categorised as type A. In addition to this pluralistic health care system, there is one private hospital in Yogyakarta (Jogjakarta International Hospital) that is too expensive for the poor. It is said to be built to 'international standards'. This hospital accepts only privately insured patients and cash payments. There are hospitals run by religious orders such as the Muhamadiyah Hospital, the Catholic Hospital, and the Christian Hospital that also apply the cash payment regime. Although the number of hospitals has increased significantly this has not led to a corresponding decline in the acceptability of traditional medicine (Woodward, 2011).

Every patient has a different entitlement for inpatient care depending on their ability to pay through the BPJS insurance scheme. The lowest class is the third class in which people contribute Rp 25,500 (AUD 2.50) a month. People who are categorised by the local authorities as 'poor' are also entitled to access third class health care. The poor people in this

category are defined as beneficiaries of contributory assistance, *Penerima Bantuan Iuran* (PBI). The PBI patients, or those who are categorised as poor, do not have to pay a contribution (Figure 2.3). The second-class in-patient care is available to those who can afford to pay Rp 42,000 (AUD 4) per month while the top-tier entitlement in the first-class facilities is available to a patient who contributes Rp 50.000 (AUD 5) per month. In addition, every patient may upgrade their access to a higher class of in-patient room by paying an additional cost.

Figure 2.3. Indonesian President, Joko Widodo symbolically giving a family the *Kartu Indonesia Sehat* (Indonesian Health Card).

Source. Facebook: *Presiden Joko Widodo,* 29 Nov. 2019. Retrieved on 24 Apr. 2020 from: https://m.facebook.com/Jokowi/photos/a.404578553064333/1347933575395488/?type=3&source=54

Some people (and their families) who work as government servants are eligible to access in-patient care, but they are also differentiated in accordance with their job status and level. For working-class people, for instance, access to UHC relies on employers registering their employee as a member. Employers, with contribution from employees, are required to contribute a total of 5–6 per cent of wages as an insurance premium, but the calculation is complex and inconsistent. For those who work in the informal sector, their membership relies on their employment status (Simmonds and Hort, 2013). This category of people is at risk because the health insurance membership depends on the period of work. If an employer becomes insolvent, terminating a worker's employment, then the worker's membership may be discontinued by the scheme on account of lapsed payments.

Because of class differences in in-patient care, poor people may choose not to seek in-patient care, even when their health care needs are critical. As illustrated by Julius' story, relying on the universal health insurance coverage allowed him to access medical care at the second-class level which was insufficient to get the required care and access to a specialist.

The additional cost that is not covered by BPJS may be another reason for patients' reluctance to go to hospital.

Table 2.3. Table showing class differences based on premiums and benefits for membership classes in BPJS

Category	Applies to:	Premium per person per month:	Paid by:	Benefit
Beneficiaries (PBI)	Jamkesmas and Jamkesda members and/or those who are eligible	Rp 23,000	Respective governments	3rd class ward
Salaried workers and their family members	Civil servants, military/police staff, government officials	5% of salary	Employers, with contribution from employees	(#) Ranks 1 & 2: 2nd class ward; Ranks 3 & 4: 1st class ward
	Non-civil servant government staff;	5% of salary		Married with salary up to 1.5 times non-taxable income: 2nd class ward. Married with salary 1.5–2 times non-taxable income: 1st class ward
Non-salaried workers and non-employees and their family members (Plan for 2019)	Informal, entrepreneur/business owner	Benefit applied Jan. 2014–Mar. 2016; Rp 25,500 (3rd class) Rp 42,500(2nd class); Rp 59,000 (1st class); Apr. onward Rp 30,000 (3rd class); Rp 51,000 (2nd class); Rp 80,000 (1st class)	Individuals	According to the premium
	Pensioners	5% of monthly pension	Government, with contribution from the pensioner	Refer to the rank [see #]
Veterans or their widows	5% of 45% of civil servant basic salary [rank 3]	Government	1st class	

Source. WHO, 2017, pp. 80–81

Care in the referral hospital is designed to deliver curative treatments by highly professional health workers or specialists. Nonetheless, health-care delivery in many developing countries is far from simple. Due to the complexity of the problems, health-care interventions need to be relatively sensible. Access to health care is recognised as a full social and political entitlement that good governance should support (Freedman et al., 2005, p. 37). Pooling insurance funds and local government contributions to BPJS is equally doubtful (Aspinall, 2014; Warburton, 2016). Furthermore, poor people are often indirectly lobbied as potential voters, and free health care is often promised during political campaigns in order to win votes (Aspinall, 2014).

Figure 2.4. This ambulance is the property of a political party, borrowed by neighbours of an active party member for the purpose of transporting the ill to hospital

Source. Photographed by author

2.3.1a. INA-CBG: One visit for one disease

The technology for the measurement of disease and its accounting applies Western and 'modern' formulae. The payment model utilised by the BPJS uses a funding model based on Diagnostic-Related Groups (DRG). This statistical classificatory system divides possible diagnoses into more than twenty major body systems and subdivides them into almost 500 groups (WHO, 2015). The mechanism clarifies the proportion that can be reimbursed by the BPJS agency. Developed countries such as those in Europe and the US have devised their insurance schemes using this system, and it is currently used to fund health-care reimbursement for care in developing countries like Indonesia.

The BPJS agency pays hospitals for services provided to its members using a prospective payment system based on Indonesian Case Mix-Based Groups (INA-CBGs). Health-care costs based on INA-CBGs vary according to region and hospital class. Top-up payments are available only in special cases and use a cost-to-charge ratio. The INA-CBG payment system aims to encourage more patient-focused, efficient and quality services, as well as to avoid over treatment, under treatment, moral hazards and adverse events. INA-CBGs pay the same rate for either public or private hospitals. Drugs and medicines are components in the INA-CBG financing payment system, which is based on a diagnostic package.

The disadvantage of this system is that it treats the diagnosis of one patient in the same way as the diagnosis of other patients. DRG-based payment systems are administratively and technically problematic and, therefore, implementation is compromised (WHO, 2012). Most middle-income countries, including Indonesia, have not developed their own classificatory systems for case-based funding, and continue to rely on the DRG system developed for high-income countries (WHO, 2015). This might result in some of the complexity of cases used for the funding mix being elided.

For example, if an elderly person with osteoporosis fell and fractured a bone the medical cost for treating osteoporosis would not be covered by BPJS, because the DRG covers only the immediate treatment of the fracture. The patient will be required to pay the costs of treatment for osteoporosis in the hospital. Alternatively, a patient is able to get free medical treatment for osteoporosis on their next visit, provided that their visit is explicitly for treatment of osteoporosis. A doctor explained the difficulty in treating a patient's sickness holistically:

> That's the case here. For example, an elderly patient has a fracture because he slipped and fell. People might think that it's just an ordinary fracture, but we who handle the matter medically can't think that simplistically. It does not make sense that he gets a fracture just because he slipped and fell. There must be something else such as osteoporosis, or a possible tumour, and many more [possibilities]. It requires additional treatment and it is not covered. For us as doctors, the management should be done holistically, shouldn't it? The patient can't just come and tell the doctor that he has a fracture and then get operated on. If the patient for example has osteoporosis, then he might need some vitamins and injections that can stimulate his bones. Such treatments are not covered by BPJS. Osteoporosis is something that cannot be seen from outside, [yet] BPJS only considers the outer appearance. Oh ... this is a broken leg or fracture and can be treated through surgery by operation. That's it, without mentioning the other sickness that the patient might have, this and that. (Interview, Dr Radiman, 3 Nov. 2015.)

For catastrophic events, poor patients follow several stages of diagnosis starting from treatment at the Puskesmas or the family doctor. Jelita's first symptom of osteosarcoma, which generally affects adolescents, was chronic pain in her upper leg. Her mother, Bu Sumiati, took her to the nearest primary care centre then went on to the District Hospital using BPJS insurance. On the advice of the doctor at the District Hospital, Jelita was referred to the Provincial hospital where she visited the outpatient surgery clinic. After several pathology checks, a specialist recommended amputation of her leg. During the rigorous medical check-up, Jelita's family commuted from home to the hospital located in the city. Buses were the only form of public transport from her home to the hospital—a slow journey of ninety minutes which was delayed even further by the waiting associated with filling the bus with other passengers going to the city (potentially adding over an hour to the trip). The

buses were unscheduled, infrequent and passengers had to transfer to another bus to reach the hospital. She was often obliged to endure the painful, bumpy journey from the village to the hospital on the back of her father's motorcycle. Jelita's different complaints and pain were treated as functionally distinct from her diagnosis. Because the funding model meant she would be reimbursed for only one medical problem for each visit, Jelita and her family had to travel back and forth to the hospital for different medical checks for the different complaints, and this led to a delay in diagnosis.

Each hospital visit ended up costing Rp 250,000 (AUD 25) once transport, meals and tests were taken into consideration; in total, she spent one quarter of her monthly income on travel and tests in hospital. Bu Sumiati saved money by having tests done within the District, so as to economise on transport. After Jelita had become sick, and had undergone amputation, Bu Sumiati used to borrow an ambulance from her husband's friend's friend, a member of a political party in the district who had control over use of the ambulance vehicle that was the property of the political party. The ambulance could be used for free, but the borrower had to buy petrol and pay the driver.

After Jelita's amputation she endured eight rounds of chemotherapy. Before she could start chemotherapy, she was referred to a private oncologist by the hospital (there was no public oncologist) which cost Rp 115,000 (AUD 11.50), discounted by Rp 35,000 because of her membership of Jamkesda. Further, Jelita was advised to purchase preparatory medications at her own expense from a private pharmacy, costing Rp 100,000 (AUD 10). BPJS thus remained challenged by the continuing high cost of out-of-pocket expenditure (OOP) (WHO, 2017). The sequential health-care services required by patients with severe illnesses and bodily impairment were delivered through a mix of public and private services.

Those patients with catastrophic and severe illnesses may go back and forth to the hospital for various reasons like hospitalisation, pain control or medical check-ups. For Bu Sumiati, the medical investigations and recommendations for Jelita were limited and, she believed, insufficient for understanding severe illness and impairment in Java. Nevertheless, in spite of following traditional and spiritual beliefs herself, Bu Sumiati felt that she could work alongside the orthopaedic specialists and residents. But even so, she felt that she could not fully trust them—unlike her faith in the directions of *orang pintar* 'a person/s of knowledge', and God. She could accept this struggle by putting her trust ultimately in spiritual mediators such as the *kyai* (Muslim prayer leader), *orang pintar* or *dukun* (shaman). But it was not easy—working across different constructions of what was in play made Bu Sumiati tense and *senep* (restless). *Senep* is a Javanese expression for feelings of exhaustion

and restlessness, as well as hate (*menyesakan dada*). But the *orang pintar's* powerful guidance strengthened her, and enabled her to keep going back to the hospital. In a sense, traditional healing is a way of moderating modernity with tradition (Errington, 1998a; Ferzacca, 1996).

Bu Sumiati never begrudged how much money she spent on the medical treatment. As she said, '[I] am blessed because other people [facing serious sickness] must sell their land to pay for [health] treatment, while I don't.' Assistance may come from social connections like relatives, neighbours and friends. Bu Sumiati mentioned gratefully that many good people had given Jelita care, in addition to the universal health coverage BPJS that almost 'covered all' treatment. The poor people in my study who received free health care or partly paid for the care always expressed gratitude (see also Chapter 6). But there was a strong dimension of dependency associated with their subordination and their unequal power relations with the state (Seo, 2016).

2.3.1b. The medical record: Gap in monitoring bodies

Medical records are kept in paper format. In Western biomedical practices, the medical record is highly important in keeping bodies monitored. It works to translate individual body symptoms and contributes to the understanding of the disease by showing how the symptoms fit into ongoing patterns (Berg and Bowker, 1997). At the beginning of a country's rollout of universal health coverage, the need for integrated information systems and reliable data about a patient's history was even more urgent (The World Bank, 2015). However, there were no regulations or robust Indonesian government policy that prescribed use of electronic health records (WHO, 2017). Rather it was assumed that the body could be accurately monitored using the paper format. Yet, during my interviews with clinicians in Sardjito Tertiary Hospital, they often complained about the medical record's inaccuracy and poor availability. As the oncology specialist told me, 'the huge problem is messy medical records which are still manual and paper based.'

The consequence of resource shortages, poor finances, lack of medical resources and poor professionalism is not only social suffering, but also, perhaps, malpractice. Sardjito Hospital is the teaching hospital of Universitas Gadjah Mada and is regarded as one of the top referral hospitals in Indonesia. Nevertheless, nurses and doctors repeatedly told me of the problems of poor communication, scanty written records, and reliance on verbal instructions which confused inter-professional communication and meant that patients were often being given multiple different messages about their investigation and treatment.

A nurse who worked on the cancer ward discussed how she and her colleagues had to follow inadequate advice issued to them and they were sometimes obliged to chase up the clinician by phone to ask for instructions. She said that they were often too busy to accompany the doctors on ward rounds:

> We speak directly to the resident, and then the resident will tell us. If we do not meet the specialist, that's how the communication occurs. Doctors and residents speak together then meet at the nurses' station. If they are speaking between themselves, we don't pay any attention. We will [only] follow verbal or written instructions. (Interview, cancer ward nurse, 5 Nov. 2015.)

According to my observations, nurses were rarely spoken to and the paper medical record was left at the station for them to look at later. It was not uncommon for there to be no record updated after the specialist had visited the ward and spoken to the junior doctors. Nurses were concerned about the lack of direction they received.

> We execute what we are told so that, if there is a mistake, we cannot be blamed … For any mistake, we cannot advocate. It would be difficult to defend [the mistake] if it is not down in black and white [*hitam diatas putih*], like that. That's the way communication occurs. For example, we directly approach the doctor by the patient's bedside: 'Doctor, your plans have not been written yet. For example there are no instructions about taking out the drain [left in after surgery, for a period of some days, but which must be removed]'.
>
> 'O yeah, I forgot. You write it,' he may say and the nurse would be obliged to write up the medical instructions in the medical record. (Interview, cancer ward nurse, 5 Nov. 2015.)

This everyday habit in clinics seems to be usual, and seems to be a work-around that improves safety. Even when doctors write the instructions, they may not be readable. The poor quality of doctors' handwriting is so well accepted in Indonesia that parents tell children with bad handwriting that this is a sign they are suited for a medical career. As one cancer ward nurse explained:

> The doctors' written text is often hard to understand so, sometimes, we must ask our senior nurse, 'Is it readable? Can you read it?' If she cannot read it then we seek out the resident who had accompanied the specialist doctor.
>
> 'Doctor, what did you do when you visited the patient? The instruction is unreadable.'
>
> If the resident is also not able to read it he will phone the specialist doctor.
>
> [The resident will say] 'Sorry Doctor, the written instruction … I forgot what the instruction is. I can't read your written text, Doctor. What was the instruction for this patient?' (Interview, cancer-ward nurse, 2 Nov. 2015.)

Lack of informative medical history may lead to poor treatment and poor outcomes. Patients may visit the hospitals for re-checking and re-diagnosis. The medical record that is supposed to hold the basic information for further medical treatment cannot fully direct the

comprehensive and sustainable treatment of the patient. This clinical routine shows how patients are given multiple interpretations and advice, which is very confusing. Perhaps it is one of the reasons why poor patients, their family and clinicians then cultivate mystical and spiritual resources to complement the biomedical gaze. They use mystical and spiritual resources for deeper reasons than the chaotic nature of the medical record and procedures. One thing that I noted with Jelita and her family was that patients and families in the cancer ward did not show any expression of anger or resentment. Indeed, it seemed that clinicians' social status may even have been embedded in the interactions between patient and doctor. Patients and their families showed an attitude of acceptance (*nrimo*) and followed what had been instructed by the medical professionals. Viewed in this light, bodies may increasingly become the locus of a clash between biomedical and traditional Javanese views and the locus for the exercise of power by state-supported biomedical practitioners (Berg and Bowker, 1997).

2.3.1c. 'Modern dressing'

One nurse told me about the *moderen dresing* way she treated some patients who had an open wound on a limb due to a tumour. She said that *moderen dresing* is a treatment of modern medicine that is 'dropped' on the wound to get rid of maggots or bacteria. 'It is expensive though,' she said. I use the idiom of *moderen dresing* in the context of dropping biomedical knowledge of disease onto the shared set of Javanese traditional religious concepts regarding illness. The development of the BPJS policy and its implementation implies that poor people with chronic illnesses have access to biomedical care. The provision of universal health care in contemporary Yogyakarta marks a transformation whereby people bring traditional healing 'up to date' (Woodward, 2011), syncing it with the broad functional rationality of biomedical improvements.

While the biomedical treatment of BPJS covers curative treatment, in practice poor people experiencing a catastrophic event have been pushed around. The high treatment costs and high out-of-pocket payments for, even, insured households with a family member hospitalised for severe chronic and acute illnesses, impact negatively on a family's illness experience. As a result, they may resort to religious beliefs as another source of healing. Furthermore, health insurance will not be able to fully protect them against the high cost of care and, combined with the costs of labour supply, productivity and livelihood loss, may lead to household poverty (Aji, Yamamoto and Sauerborn, 2014).

In that context, scientific medicine is not the only approach to treat illness but, rather, health care becomes a highly pluralistic transformation of traditional Javanese treatments (Browne, 1999; Ferzacca, 1996). Some scholars have sensitively recognised the overlap between folk healers and modern medical practice (Ferzacca, 1996; Kleinman, 1981). I see it, rather, in Java as a continuity of practices across clinical borders in the ways people mix their understandings in responding to chronic illness and bodily impairment. Traditional medicine and other healing practices and medicines in Yogya such as *pengobatan traditional* or *jampi,* or the advice of *orang pintar* or *kyai*, *pijat* (massage), *jamu* or *ramuan* (herbal, plant-based medicine), *galian* or pills (plant/herb-based compressed) and *parem* (tonics) are still popular. As Woodward argued, Javanese people perceive *obat* or medicine in a broader sense covering the power to alter both the physical and spiritual composition of human beings in contrast to clinical care which might be seen merely as 'the pocket of the universe' (Ferzacca, 1996; Woodward, 2011).

Furthermore, medical professionals are ranked at the top of all professions in prestige. Medicine has been an elite profession since Dutch colonial rule. Doctors are not only well off financially, but have also been influential in government, politics and society (Achmad, 1999). The Javanese hierarchy is reflected in the clinic through the choice of language used in social interactions between patients and physicians conducted in *Kromo* (the formal, respectful register in the Javanese language or 'gentle sense'). Patients, especially poor and/or uneducated villagers, may be reluctant and wary when consulting doctors because of different social statuses and the 'knowledge gap'. The occasional physician who showed humility and sympathy for patients in my study was perceived well by patients and families and was 'popular'. But these physicians are rare.

Patients are often more attached to a traditional healer or nurse or *mantri* (the village-based carer who is the most respected health practitioner in remote areas and the main source of voluntary health information) (Guinness, 2009; Pitaloka, 2014; Sciortino, 2007). A patient's relationship with a village-based healer is more familiar, resembling the relationship with a close neighbour or even 'parent'. Their role is significant in giving a deep sense of security to the patient and their family. Guinness (2009) noted that patients in villages may seek treatment from traditional healers especially *dukun* or *orang pintar* or *Kyai* because the charges for care are voluntary with the patient's contribution noted as a gift to the mosque rather than the healer. Yet, the patients in villages may not only contribute money but also fruits, vegetables and rice.

Julius did have treatment from a traditional healer using herbs, but the treatments were only effective for a few days. As his condition became more painful and his limb swelled, he and his family sought to return to the VVIP room at the tertiary hospital so that he could undergo amputation. However, no financial assistance was available under their BPJS scheme, which provided for access only to the second-class ward that Julius and his family saw as crowded and offering poor care. In any case, there was no bed for him in the second-class ward, as it was already at capacity with other patients. Julius was transferred to the VIP ward of the District Catholic Hospital, even though it did not have facilities to treat osteosarcoma.

Lies, a voluntary social worker, introduced Julius to me. Lies had survived osteosarcoma previously, undergoing a left below-knee amputation in 2010. Afterwards, she established a charity-based community organisation called *Satu Hati Berbagi* (One Shared Heart). It was Lies' role to assist Julius and his family to access biomedical care. She had been unsuccessful in transferring him, for palliative care, to the (at-capacity) second-class ward in the tertiary hospital. The only option was the VIP ward and VVIP room in the tertiary hospital, which the family could no longer afford. A social media campaign was started by Julius' friends to collect donations to send him to the VIP ward at the tertiary hospital as the family wished. Not long after this campaign started, I received the following WhatsApp (WA) (update about Julius on my phone from a provincial NGO worker (The Indonesian Cancer Foundation at Yogyakarta):

> [Julius] is currently in Panti Rahayu [a private Catholic hospital in Gunung Kidul regency] due to *ngucur darah* [the blood haemorrhaging from his tumour]. His condition is a bit worse. Monika [amputee women] and his friends [at university] are ready to donate money for his treatment. Just wait until his condition has improved and he can be delivered to the referral hospital, Dr Sardjito. I hope God gives him *jalan* [a way] for his recovery. Please remain alert to this WA group for updating information. (WA message, received 18 Mar. 2015.)

A recurrent feature of my conversations with Julius and his family was their uncertainty about how to navigate the health system, coupled with their lack of understanding and sense of *aib* (disgrace) about the illness itself. Their house was always closed to visitors, and none of the neighbours knew about Julius' illness. Julius remarked to me that he was *bingung* (confused) when confronted by his uncertain and unpredictable situation. In the Catholic Hospital, everyone felt *panik* (panic) and *gelisah* (anxiety) about his critical condition and wanted to take him to the tertiary hospital.

What was needed there was a specialist's authority to perform either surgery or reduce the patient's chronic pain. In the Catholic Hospital, there were neither oncologists nor cancer

care facilities, not even a general surgeon. There were only five general hospitals in the district; two of them classified as class C while the other three were as yet unclassified, and their facilities were even more limited. The number of in-patient beds, specialists and facilities define the hospital's class. The referral hospital is class A and offers the highest standard of service quality in the province. Meanwhile, class C hospitals are equipped with only limited medical facilities for patients with advanced cancer like Julius' case. In the district Catholic Hospital, as Julius' disease progressed, he began to feel great pain, his arm swelled, and the odour was offensive. In despair Julius called out:

> I want this [arm] to be cut off now so it will not be painful any more. It has been just four months, but it is very painful, and the lump is on the front and on the back. (Observation at Panti Rahayu Hospital, 17 Mar. 2015.)

His mother advised him not to shout in pain but, rather, to call to Jesus for help. Travelling now presented a significant risk for Julius. The only transportation mode was by car and that meant a journey of 90 minutes from the district to the regional hospital. An ambulance was made available with the assistance of Lies' friend who did community work based on a religious charity. But the risk was not simply in transporting Julius, but also the quick spread of the disease, and whether he would, indeed, survive the trip and the horror of amputation. It was the matter of amputation, particularly, that haunted Julius and his family. In the end, Lies was only able to get him admitted to the District Catholic Hospital for palliative care. Julius was treated in the VIP room, but the quality of care was relatively low. He gradually became even thinner, and his arm became infested with *belatung* (maggots). He died five days after being admitted to the District Catholic Hospital.

In such a situation, it was not only Julius' medical condition that made it impossible to travel to the city, nor was it the administrative procedure that the family found complicated. It was the social stigma towards the cancer and the disability that oppressed Julius and his family. 'Letting Julius die' seemed to villagers a better option than living with social stigma and psychological depression. Considering the unpredictability of medical encounters, I (and Julius' friends and the NGOs workers) came to the realisation that we could not control the cancer, nor could we control ourselves. Seen in this light, biopower was dispersed through our shared morality, embedded in social relationships, institutions and technologies (Anderson, 2012; Pylypa, 1998).

Patients, families, clinicians and NGO workers faced significant difficulties when dealing with an established social-cultural and administrative structure. Such circumstances threw them into a precarious situation and surrounded them with uncertainties of many kinds.

They realised they could not rely on the status quo; that everything was in flux, including the ability to survive (Tsing, 2015, p. 10). Julius' friends at university and the NGOs workers wanted to help and were ready to donate money to help him. A senior NGO worker had mumbled to those who were waiting in the corridor that, 'it was *carut marut* [chaos]', as it was very difficult to persuade the family to seek treatment because of the long wait in hospital, the costs (of the VIP room), shortage of blood available for transfusion and the question of whether Julius would get access to oncology facilities in the ward or remain in emergency.

Several times, Lies and Julius' friends insisted that Julius and the family seek treatment, but they refused to go back and get admission to the tertiary Sardjito Hospital. The family did not allow any of Julius' friends to visit him in hospital; again reflecting the stigma about the illness experienced by Julius' family, headed by his father who held a prestigious position in society. Catastrophic events, as illustrated in Julius' story, were poorly managed by health-care insurance schemes. Julius' father, a low-middle ranking public servant, wanted Julius to be accommodated in the VIP room. The family was reluctant to send Julius to the second-class in-patient ward entitled by their health insurance. The different in-patient classes in hospital represented people's position in the social hierarchy, and people's ability to pay. Julius' family regarded themselves as 'non-poor' and public servants (PNS) who, in Javanese society and especially in the villages, are honoured and respected as they are entitled to health insurance, pensions and they have a stable income (Guinness, 1986). In socio-cultural terms, the missing limb and amputation that Julius might have experienced implied a devalued and degraded family status in society. People in the village may perceive the family whose children have a disability (mental or physical) as *aib* (disgraceful). Thus, socio-cultural constraints and perceptions in combination with unequal access to health care characterise the political economy.

After he died at the Catholic Hospital, the WA group that was created to support Julius, sent many messages of condolence. What struck me was that his death was understood by some as a form of 'recovery'. Lies and Julius's friends wrote:

> Have a safe trip, Julius. You have now recovered. Rest in peace.
>
> Julius has been called by God … [*Julius dah dipundut Gusti* …]
>
> God loves Julius more [*Tuhan lebih saying sama Julius*]
>
> This [death] is the best for him. It was important that we spared no effort [to help] … please forgive us Julius [*Ini yang terbaik untuk Julius. Yang penting kita sudah berusaha … maafkan kami Julius*]. (21 Mar. 2015.)

When it comes to severe illness and disability, elusive promises, miracles and hope are familiar reactions (Mattingly, 2010, 2012). Many informants told me that they believed in the *orang pintar* or *Kyai* because these people offered feelings of *yakin* and *manteb* (assurance and conviction). Consequently, poor patients and their families may seek an alternative healing process in which self-reliance, submission, communal support and religious beliefs are still prominent (Pitaloka, 2014). Woodward (1989, 2011) argues that people may continue to hold to the Javanese medical theory that perceives healing as ultimately dependent on moral conduct and God's authority. Most people say that 'God is the only "One" who can cure the disease [*mengangkat penyakit*] while giving patience and strength [*memberi kesabaran dan kekuatan*] to patients and their families.' This direct acknowledgement of God, and spiritual and mystical powers in the context of Javanese health care shows that people still hold to these beliefs even while they may resort to biomedical care that focuses on intervention in relation to the patient's physical state. Thus, although the BPJS coverage offers 'all inclusive' biomedical treatment, it does not necessary heal the people's *batin* (inner and spiritual being). As Woodward found:

> Increasingly, Javanese turn to transitional healers for hospice care in part because prolonged hospitalization is beyond the financial reach of all but the wealthiest of Indonesians. Many realize the value of modern bio-medical practice but are simply unable to afford it. Others feel that when death is inevitable that traditional medical practices are the best form of palliative care. (2011, p. 107.)

2.4. Cancer care is a 'rich' person's privilege

Indonesians tend to repeat the joke that scarcity is caused by *kanker* (cancer), seen as a shortening of *kan(tong) ker(ing)* (a dry pocket). Indeed, disease leads to scarcity for most people, while only the wealthiest are able to access biomedical care. In Java today, social inequality has classified people according to their ability to pay and health care is regarded as a commodity.

Living in an urban area in Yogyakarta, Anas was diagnosed with osteosarcoma in 2010 and tried to access various treatments in both private and public hospitals. Although he finally underwent surgery for amputation, he said that, in the process, he had gone through various, better and worse, treatments. It was like 'shopping' for care; he tried treatments one by one, from one hospital to another, to save the leg. He said that, initially, when he felt terrible pain, he was rushed firstly to the Muhamadiyah Hospital (PKU Muhamadiyah) then, because he needed several medical check-ups, he went to the tertiary hospital. He wanted to be treated in first class but there was no availability. Anas and his family put in a request to

be informed when a room was available for him (he chose the Wijaya Kusuma Room, one of the VIP rooms at Sardjito Hospital). In the meantime, he was taken back home. But due to his terrible pain, he had to seek emergency help and returned to the hospital. They went to the Emergency Room (ER) for medical examination whereupon, he said, 'just like a miracle' he was offered the first-class in-patient room at Wijaya Kusuma that he had initially requested. Anas was given sedation so that, temporarily, he would not feel the pain in his knee. After that, he could sleep and rest.

Through biopsy, the doctor found the tumour on Anas' knee to be malignant. An orthopaedic specialist then offered two options: amputation or radiotherapy. Radiotherapy was chosen but, unfortunately, he needed to wait six months for the schedule of 25 doses of radiotherapy. His parents, unwilling to disappoint him, did not inform Anas about the specialist's advice for amputation, considering his leg was still in good condition (not swollen). He was discharged from hospital after six day's treatment in order to wait for radiotherapy. One month later, his condition had deteriorated, he needed a blood transfusion and the pain in his knee had become more and more unbearable.

Social resources and personal relations helped Anas to access several medical treatments. His father had a doctor acquaintance who was employed in the hospital and who was able to shortcut the process and schedule the radiotherapy three months earlier. Waiting for the radiotherapy schedule in the provincial hospital, Anas had a *tachi* treatment offered by the doctor of his father's acquaintance who also owned a private hospital. *Tachi* is a kind of local radiotherapy (or brachytherapy) involving a catheter inserted through a wide needle into a blood vessel in the groin. Localised, sealed radiotherapy is provided through the closest blood vessel to the tumour, penetrating the tumour. The function of *tachi* is to block the spread of cancer so that it will only stay in one area of the body, and not spread to other organs. 'The cost of *tachi* is not small and for each treatment, we have to pay 10 million rupiah [AUD 1000]', he said. *Tachi* was performed by a team of physicians at the provincial hospital who also worked in private clinics, but regretfully the treatment did not have a significant effect. Julius also sought another opinion from a private clinic/hospital in the south of Yogyakarta where the oncologist offered him another treatment, but again it was not successful.

His standard external radiotherapy was delayed as his haemoglobin level was very low. His mother said his face was pale during the medical check-up before he went through the radiation planning session (simulation) to find the exact location of the tumour on his knee (so that the radiotherapy would be on target). Unexpectedly, the radiotherapy process

encountered a difficulty. According to the physician, his physical condition was not strong enough for radiotherapy and so the doctors proceeded to amputation. Dr Santika had told me about Anas' treatment and how risky the surgery was for Anas, given his anaemia. Reflecting on the experience of amputation in the surgery theatre, Anas said: 'I was reminded of what another patient had said about being made ready for surgery. After the doctor sedated me, I remembered nothing until I opened my eyes in the Intensive Cardiology Care Unit [ICCU],' where he became aware of another patient beside him fighting for his life. For him, the experience was unforgettable.

When he was discharged from ICCU, he no longer felt the heaviness of his leg. He said, 'it felt like being freed from ties' and, yet, it had been removed and lost. In the moment, 'it was an amazing feeling, a mixture of being happy, sad and relieved,' he said. 'The surgery theatre resembled 'a room in outer space' (*ruangan luar angkasa*) with its hygienic surfaces and sophisticated equipment. The vignette of Anas' long journey shows us the various pathways taken by Anas and his family to seek a range of treatments that were extremely expensive. Yet, the religious healers, *tabib* and *orang pintar*, were his family's preferred options.

Muhlisin was another patient who opted for limb salvage treatment. While Muhlisin received the specific treatments required to avoid amputation, he had to pay for an upgrade to access this service. Despite his purchasing power, he often told me that he felt unsatisfied with his health care, as his time for consultation was limited to about 3–5 minutes. Muhlisin told me that he felt ignored when the specialist played on his mobile phone during the consultation. When he was diagnosed with osteosarcoma, his previous employer guaranteed his treatment in a private hospital in the capital city. I visited him in hospital. He had been upgraded to VIP class in a single room with an electric, adjustable bed, a sofa and a private toilet. The facility also had an air-conditioner, a refrigerator, and hot and cold water. Muhlisin came from a middle-class family, was well educated and had previously worked with the mining company, Freeport. His osteosarcoma was below the knee and he had experienced various medical check-ups and treatments in a private hospital in the capital city, including chemotherapy, PAKI, CT-Scan, radiation therapy and surgery. His mother explained to me: 'He had the best medical treatment available here in this nation [Indonesia] when the doctor took out the bone and sterilised it for 8–12 hours to kill the cancer. Through surgery, the doctor then used platinum to strengthen the bone.' One year later after the various surgeries and several rounds of chemotherapy, the doctors pronounced him free of cancer. Five years

later, he developed a lump on the knee. The cancer had recurred, and Muhlisin was obliged to undergo amputation and chemotherapy.

Muhlisin's story shows how Indonesian people receive a different quality of treatment that reflects their purchasing ability, specifically, their ability to pay for out-of-pocket expenses. Medical care for catastrophic illness is a luxury good: not everybody can access the best treatment. The different classes of health treatment result in the poorer citizens having inadequate access to care.

2.5. Conclusion

There is a sharp increase in inequality for the middle- and low-income group that is triggered by their poverty (The World Bank, 2015). Investing in health through BPJS insurance is one measure that appears to reflect economic growth and progressive tax policies while reducing poverty (Reeves et al., 2015). But the low-income family, living in a village or remote area and experiencing chronic illness and bodily impairment, remains trapped by such a capitalist governmentality that limits their access to intensive health treatment and care. As a consequence, Indonesia's economic growth has not brought benefits to all.

The lived experience of osteosarcoma patients and their families reflects that the socio-cultural and political-economic basis of the BPJS policy is in need of revision so that it reflects cultural sensitivity to the lived experience of osteosarcoma patients and their families. Health-care delivery in hospital settings still faces resource shortages, budget constraints, lack of human resources and poor management capacity. For catastrophic and prolonged illnesses, the BPJS coverage has not resulted in equal access to health care nor does it cover holistic healing.

In the next chapter, I will explore further 'ambivalence' in the way that illnesses and bodily impairments are diagnosed by Javanese medical staff, leading to confusion in how patients and their families respond to biomedical diagnoses.

Chapter 3
Understandings of Disease, Illness and Impairment in Contemporary Java

3.1. Introduction

Western biomedical treatments of disease and Javanese practices of dealing with illness have long overlapped (Browne, 1999; Ferzacca, 1996; Woodward, 2011). As I highlighted in the previous chapter, there is an increasingly ambiguous entanglement of biomedical treatment with Javanese traditional medicine, as people find themselves creating new cultural forms, constructing new moral subjectivities and renewing their understandings of their bodies in the process of dealing with disease, illness, disability and health in general. The 'genuine' social constructions that I describe here represent patterns of noticing, seeing, naming and responding to osteosarcoma, bodies with missing limbs or deficiencies, and severe diseases like other types of cancer and stroke. This chapter is an attempt to explore the complex meanings of disease, illness and disability in contemporary 'modern' Yogyakarta. Following Foucault, I argue that biopower diffuses not only through state apparatuses but also through social norms and values. Bodies in modern Java can thus be read against the notion of 'dubbing culture': the body cannot be purely translated in terms of a dichotomy of mind and body (Boellstorff, 2005; Scheper-Hughes and Lock, 1987), but becomes re-translated into 'new forms' of body and personhood.

This chapter focuses on two understandings of bodies. The body becomes the object of medical examination and scientific truth. In his remarkable book *The Birth of the Clinic* Foucault (2012) depicts the doctor's view as the act of looking or gazing that places patients as objects of knowledge. This approach constructs disease and the patient body as a single form. Javanese people in general hold an alternate understanding of the body, viewing severe illness and disability through a mix of Javanese and biomedical paradigms. In contrast with the biomedical diagnosis, the Javanese patient, family and wider community (including clinicians) look at the origins of the deeper social and political economy that are associated with poverty, inequality, unemployment and violence. Although biomedicine is not necessarily free of culture or moral judgement (Browne, 1999), I argue that the biomedical diagnosis importantly confines itself to physical symptoms while the causes of the symptom/s—depression, stress, acute pain, anxiety or even what Bu Sumiati experienced as tense and *senep* (restlessness)—remain untreated and untouched.

Therefore, we might say that this discussion explores the semiotics of osteosarcoma and bodily impairment in Yogyakarta and describes how people of varying backgrounds read the deficiencies, the more or less obvious departures of bodies from some vaguely understood norm of physical wholeness. People's experiences of illness, disability and disease refer to religious beliefs and morality that have persisted among the Javanese people from before the Dutch introduced medical science to Java in the eighteenth century.

3.2. Determining diagnosis and prognosis

Modern society constructs disease and disability based on clinical research and the scientific gaze (Foucault, 2012). Cancer is categorised as one of the world's chronic illnesses that may produce impairment, disfigured bodies and even death. Osteosarcoma especially is the most common primary bone malignancy. It derives from primitive bone-forming mesenchymal cells (Ottaviani and Jaffe, 2009, p. 3). Either surgery or radiotherapy is offered as treatment options for diseased bone as a result of osteosarcoma (Cortes et al., 1974). Research in 2002 (Bacci et al., 2002) claimed that limb-salvage (without amputation) procedures combined with neoadjuvant chemotherapy are moderately safe for the patient. However, this treatment can only be performed in an institution where measurement of surgical excision and the patient's histological reaction to chemotherapy can be accurately evaluated. Yet, the research suggests that if the margin of risk is unacceptable or the histology of the chemotherapy adverse, then amputation should be carried out as 'a safe option' (Bacci et al., 2002). In the clinical diagnosis, the body is pathologised and atomised, and the final option for the osteosarcoma patient involves the amputation of a limb. During my observations in the tertiary Sardjito Hospital, doctors described the need for amputation as preventing the spread of malignancy and morbidity due to infection of a tumour that sometimes had become an open wound (a sign of late-stage tumour).

Cancer of various types is a leading cause of death in Western countries such as the US (Ottaviani and Jaffe, 2009). Living with severe illnesses like cancer or bodily impairment may thus impact on the psychological condition of patient and family, and leave them feeling vulnerable and uncertain (Falvo and Holland, 2018). Although Yogyakarta has recorded the highest life expectancy compared with other provinces in Indonesia, statistical data reveal an increased number of cancer patients admitted to the tertiary hospital. The medical records of the tertiary Sardjito Hospital show that 3,466 patients with cancer were hospitalised in 2014. The number rose to 3,588 in 2015 and to 3,623 in 2016, while patients with cancer seeking outpatient care in the hospital increased from 8,212 in 2014 to 8,409 in 2015. One year later,

a local newspaper *Tribun Yogya* on 5 April 2017 highlighted that the hospital had recorded a significant increase in the number of outpatients with cancer, rising to 9,502. Nationally, the number of people with impairment and disfigurement due to cancer was not specifically recorded but impairment in 57 per cent of people was attributed to disease, either communicable or non-communicable (Irwanto et al., 2010). In Yogyakarta, a rising trend was recorded for the number of disabilities due to the earthquake that occurred in 2006. In 2010, the Indonesian Bureau of Statistics recorded around 26,173 disabled people. Of these, the largest group comprised those who had lost limbs and experienced lack of body function. Five years later, the number of those who had lost limbs and lacked body function was 9,831 or about 21 per cent of all those with disabilities.

3.2.1. The anatomical approach to seeing and knowing the body

Lock (2002) noted that medical knowledge of the human body constructs a general layout that captures the pathological feature. Therefore, assessment of disease and health is limited to the body as a physical object but neglects the patient's psychosocial situation and environment. Biomedicine sees the body of a patient with disease and disability as a universal object.

On a sunny morning in the ward hospital, Suster[1] Tati, the nurse in charge of the cancer ward, pulled open all the curtains around the bed. 'Blood pressure!' she announced, without looking at Jelita but focusing instead on her left arm. She applied and pumped up the sphygmomanometer in one smooth action, and then inserted the thermometer under Jelita's arm. Jelita and Suster Tati made no connection with one another throughout the measuring period. Jelita raised her arm for the thermometer while talking with her friends on the phone. Suster Tati undertook all her activities looking at the bed or Jelita's other arm. This routine disregard for each other during the physical assessment was typical of every monitoring measurement. The blood pressure machine bipped, the nurse whispered the numbers to herself, and took out and checked the reading on the thermometer. Jelita stopped talking on the phone to call out to Suster Tati that she had taken the thermometer out too early. 'Hey … it's not yet finished.' The thermometer was inserted again under Jelita's arm. After several minutes, Jelita took out the thermometer and gave it to me. The nurse took it and rewrote the

[1] *Suster* 'Sister' is the term used to address nurses in hospitals or clinics. Historically, *Suster* is derived from the Dutch language and over time has become a label which ascribes social status for those nurses who work in hospitals.

number again on the small piece of paper. The nurse left Jelita's ward without any greeting, acknowledgement or conversation. She walked in, used the tools, finished and left. Her reading of the body was through a fixed physical examination using devices like a sphygmomanometer and thermometer. Suster Tati's practice reflects Lock's writing (2002) on the way the biomedical regime constructs normalcy and the pathological diseased body or abnormality. Body mass is thus a technical measurement to be understood through a universal gaze that follows the logic of physical examination and individual symptoms (Lock, 2002, p. 192).

Figure 3.1. Nurses in the 3rd class cancer ward
Source. Photographed by author, 6 Dec. 2015

Figure 3.2. Nurses talk in between curtains at the 3rd class cancer ward
Source. Photographed by author, 3 Jan. 2016

The biomedical diagnosis of cancer, for instance, requires several body examinations (e.g. body temperature, blood pressure) that are calibrated to the highest degree of certainty that scientific measures can attain (Foucault, 2012, p. 126). The examination is limited to checking the physical state of the body, neglecting the narrative of the patient's illness or the moral and social significance of the ailment (Lock, 2002). Jelita's detachment from the examination process and Suster Tati's detached monitoring in the clinical setting is routine practice in the ward. Suster Tati was just doing her job. Jelita became engaged only when she wished to make sure the routine practice was performed correctly, and her bodily numbers were enumerated accurately. As Foucault (2012) argued, biomedical 'truth' assumes the correctness of the mathematical calculation and objectifies the body of the patient but separates the patient from their social world.

This biomedical approach has carried the greatest authority in both medical education and the hospital domain over the past century across Southeast Asia (Derrick, 2004; Pols, Thompson and Warner, 2017; Thohari, 2013). The process of the individualisation of bodies with illness and impairment is to find the localised 'problem' in which the preservation of the healthy body becomes the individual's responsibility (Foucault, 2012; Lock, 2002). This view identifies materials inside the body that are associated with the 'final' causes of disease (Lock, 2002, p. 192). Lock adds that the causes of illness situated in the body such as viruses, infection, genes or psychological dysfunction alter the individual body and give the body a

branding of ‘diseased’ (Lock, 2002). The biomedical diagnosis differentiates humans into two categories—abled and disabled persons, or normal and abnormal people. In Java today, the biomedical view has been very influential in shaping social perceptions and understandings of people with disabilities (Thohari, 2013).

Dr Aryo explained to me that, as a radiographer, his job is particularly about localising the ‘problem’ in the specific bodily space. Using an x-ray image, he said that the radiographer focuses only on the abdomen, breasts, neck, or blood vessels. Every specialist focuses and reports on a different part of the body as their specialisation, detaching this from the totality of the body. He put it in this way:

> For example, if blood does not flow through the vessels, I report this is the case. Then [they report to] those who ‘hold the knife’, the surgeon. For example, an osteosarcoma case located on the lower leg. [I] see the spread [of the tumour], but the condition of the bone is uncertain ... The X-ray is to see the size of the tumour and the condition of the bone. A PET-scan is to see the spread of the tumour. Through seeing the X-ray [we] are certainly able to define the cancer. So, through radiology, we can see whether the tumour has spread rapidly [ganas] or not spread [jinak]. Later this [result] is communicated to the surgery division [bagian bedah]. I only read and interpret the picture. (Interview, Dr Aryo, 6 Oct. 2015.)

The vignette illustrates the way the clinician reads the illness through scientific data, focusing on a particular part of the body. Although Dr Aryo describes his position as subordinate to the surgeon, in fact his ‘reading and interpreting of the picture’ remakes the patient for the surgeon’s eye. The clinical examination and consultation through imaging procedures (X-ray, CT scan and ultrasound) obscure the patient’s life story. Diagnosed with osteosarcoma, Jelita began to be classified according to the localisation of the illness, a process that foregrounded the pathological anatomy over her social world. The disease, as Foucault said, was mapped out on the visual screen, anatomising the body as an object (Foucault, 2012). The radiographer identified certain aspects of the patient’s condition in terms of its relationship with the structure of other organs so that the medical staff could make an intervention based on that ‘evidence’. The evidence-based medicine acted to construct the patients within the single knowledge system (Walsh, 2010).

The resident orthopaedic surgeon working with Dr Aryo told me that ‘the most difficult part is doing *penegakan diagnosis* [determining the diagnosis]’—reading the disease in the body of each individual patient. At the beginning of the diagnosis process, patients with osteosarcoma are scored using a series of metrics, which indicate how life-threatening the chance of the disease progression is. He further explained it in this way:

> It is very hard. Because when we are going to perform amputation, it is complex. The psychological downside is very high. If we locate the disease, and we can identify the prognosis

> then we will perform it [amputation] with certainty. However constructing the diagnosis/prognosis is the most difficult. Because medical knowledge [*ilmu kedokteran*] is about determining the diagnosis and identifying the disease. If we know already the disease, then prescribing the medicine is the easiest part. It just needs synchronising [between the disease and the medicine]. We have trouble if we are in the grey zone, when the score system is not too high nor too low. Through the scoring system, [we] need to determine whether the amputation is necessary or not necessary at that particular time. (Interview, orthopaedic surgeon, 7 Oct. 2015.)

No one told either Jelita or her mother about her score. Ibu Sumiati told me that after the senior specialist informed her about Jelita's poor prognosis and that she needed an amputation, Bu Sumiati did not believe it. Jelita's grandmother added that the doctor had told them to throw out (*buang*) the leg. *Buang* usually refers to a material or object that is damaged and therefore useless. The word used by the specialist offended the family. Disappointed by the medical prognosis and advice of the specialist, they refused amputation and sought an alternative healer or *orang pintar* as Bu Sumiati called him. Using holy water, praying and spreading the ritually pure water into the painful area, the *orang pintar* treated Jelita gently. Bu Sumiati said that the healer convinced Jelita of his methods and confirmed that the pain would go. Nevertheless, his treatment provided only two or three days of comfort after which the pain returned. As the pain got worse and the leg became swollen, the family took Jelita to the ward of the tertiary hospital.

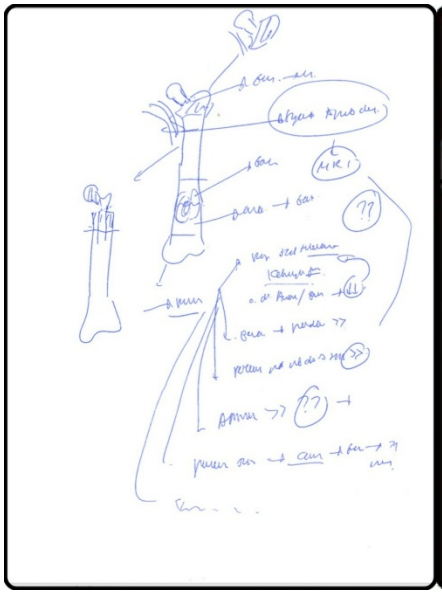

Figure 3.3. A specialist's drawing of the causes of tumour
Source. Photographed by author, 2 Jan. 2015

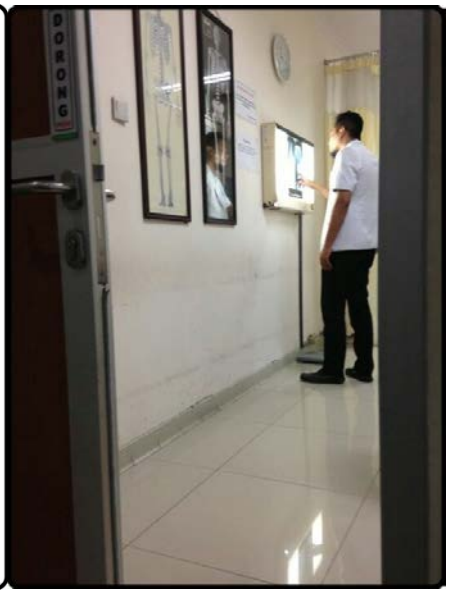

Figure 3.4. A resident doctor using his finger to identify features in an X-ray
Source. Photographed by author, 19 Jan. 2016

Figure 3.5. Jelita's ultrasound check

Source. Photographed by author, 6 Dec. 2015

The concept of abnormality in biomedical knowledge is closely related to a 'disorderly' bio-structure through the process of quantifying and measuring elements of the body and determining such factors as the force and spread of the pulse and body temperature, which allow determination of the intensity of the illness according to biological indicators (Foucault, 2012). In Jelita's diagnosis, the final determination involved the amputation of a limb. Doctors described the need for amputation so it would prevent the spread of the malignancy due to infection, and thereby prevent her death. Amputation would attempt to remove the disease by achieving scientifically objective certainty about the diagnosis and prognosis. A resident told me:

> One thing for sure is that to be able to reach the decision of amputation, the patient has to go through many examinations. The first is when the patient comes with a complaint. The source could be trauma and non-trauma. If it is trauma, we use the term extremities, lower and upper. That's the term we use for legs or arms. One of the scoring systems we use is MESS [Mangled Extremity Severity Score] in order to estimate the viability of an extremity after trauma to determine the need for salvage or not. If the scoring result shows that the limb cannot be saved, based on informed consent from patient and family, we will amputate it … For non-trauma, most are tumours. We do a clinical examination, a CT scan. If we don't do that [CT scan] sometimes we do a biopsy. In biopsy, we take a sample of tissue from the body and examine it in the pathology department, anatomical pathology. However, to be able to get there, there's some controversy. If we do an open biopsy, we're afraid that the tumour cells will spread. (Interview, Dr Siska, 7 Oct. 2015.)

As it had previously been decided that Jelita would not have surgery, I was surprised to receive the message from Bu Sumiati that, 'the doctor will perform surgery and we need two packs of donated blood'. Bu Sumiati explained to me how the decision about surgery had been made. A senior specialist, Dr Agus had visited Jelita in the ward the previous week and she had described him as being like '*a hero*' in a film who, in the midst of pandemonium, arrived to save the victim. Whenever I visited Bu Sumiati and Jelita, I often found them disappointed in their inability to meet face to face with Dr Agus, the specialist. On that day, I

witnessed Bu Sumiati's thrilled expression when she told me not about the prognosis for Jelita, which was now confirmed to be bad, but about meeting with Dr Agus.

Bu Sumiati and Jelita were not alone in their longing for the presence of the specialist. Other patients and family members in the same ward as Jelita explained to me that they were hoping for the specialist in charge to give them confidence and certainty about their treatment and future. Another female senior oncology specialist told me that she knew her patients expected her 'to just see' them in the ward to allay their anxiety and suffering. But, the specialist admitted, she did not have time to visit her patients there. She said, 'Just a little time, I may be able, but it is very difficult.'

On the following day, Bu Sumiati and Jelita were silent. Behind the curtains around Bed 4 on the right, we could hear the doctor telling the family member of a patient that her surgery was to be delayed in favour of Jelita's surgery. Bu Sumiati and Simbah looked at each other with expressions of gratitude; the prioritisation of Jelita's surgery represented a blessing. The patient in Bed 6, Bu Kodi, on the left of Jelita's bed, also had a conversation with the resident. Jelita's grandmother popped over to find out what was happening and reported in a whisper to us that that the patient had not been given certainty about the time of her operation. The resident had told Bu Kodi that the operation 'could be delayed again – Tuesday, Friday, Tuesday and then Friday'. Only Jelita had been given certainty about the time of her operation.

Our conversation was interrupted by the sounds of residents approaching the ward. These routine activities in the ward started every morning from 6 a.m. 'Visit!' said the nurse urgently (using the English word). A *visit* was an attendance by a specialist, and carried a great deal of weight. A *visit* was different from what nurses did every day in the ward or the attendance by residents (and sometimes the specialist) who dealt with paperwork and daily checks. A *visit* was a short, unscheduled event when the specialist and residents would come and pronounce, for the patient, on their future. A *visit* was clearly distinguished from *care,* which was performed by nurses. The length and timing of *visits* could not be predicted for public wards; in the VIP room, however, a *visit* could be arranged by phoning the specialist.

The operation was now scheduled, and the preparation of Jelita began. The residents began to hurry in and out, and to be very short and limited in their communications with Jelita and her family. A resident, Dr Zaenal, poked his head through a gap in the curtains. 'Still fasting?' he asked. Jelita answered 'Yes, I am.' Another resident, Dr Rizki, came to the ward and asked Jelita for her X-ray films. Bu Sumiati told her that another resident had already taken the X-rays, whereupon the resident left without responding.

Surgery is a biomedical procedure that constructs a ‘space’ that is not just the place for observation but also making sense of potential scientific knowledge. Foucault (2012) claimed that clinicians, in seeing the disease, glorify a space over the patient’s body. The space of control lays out signs of the abnormality so as to identify how the body can be examined and understood as a ‘new’ object in society (Foucault, 2012; Walsh, 2010). Foucault said:

> For clinical experience to become possible as a form of knowledge, a re-organisation of the hospital field, a new definition of the status of the patient in society, and the establishment of a certain relationship between public assistance and medical experience, between help and knowledge, became necessary ... It was also necessary to open up language to a whole new domain: that of a perpetual and objectively based correlation of the visible and the expression (2012, pp. 199–200.)

Foucault shows how the clinic in the modern state is a kind of prison where patients are disciplined, observed and punished (1977, 2012). The patients in this sense have been put through the gaze as the anatomical body that is structured of organs that can be interchanged and replaced. This is a formal technique that recognises the body as a machine that can be repaired by outside intervention (Davis-Floyd and St. John, 1998; Mattingly, 2010). The physicians limit themselves to knowing the interaction of medicines and diseases through their operation. They must observe them with care and strive to know their laws and be tireless in the search for anatomical causes. An accurate calculation of disease within the body and the causality of the pain implies a common, homogeneous space, with organic figures and a nosological ordering (Foucault, 2012).

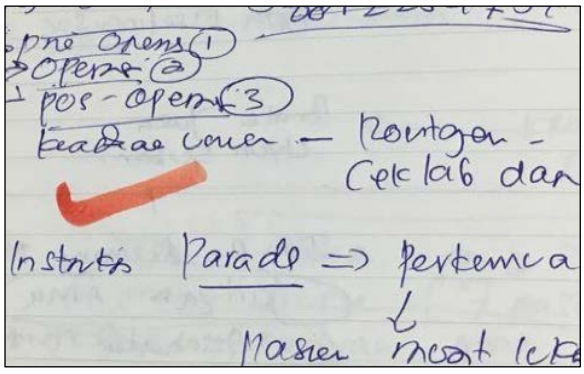

Figure 3.6. The red check mark that I drew in my fieldnotes to resemble that drawn by the ward’s resident, 6 Dec. 2015

Thus, the abnormal body is theoretically and biomedically fixable like a machine (Mattingly, 2010) but, in the vignette concerning Jelita, nobody—patient, family or clinician—was dealing with the complex uncertainties and wider problems that Jelita was experiencing. I observed another resident, Dr Emil, run back to the ward. Without uttering a word, she pulled back Jelita’s hospital blanket. She took a red marker from her white jacket

and drew a little checkmark on Jelita's upper leg carefully while her face looked down considerately (Figure 3.6). The red check mark is routinely made before surgery to ensure that the surgeon removes the correct limb. This small red check at the top of Jelita's leg may have been intended to be subtle. For Bu Sumiati and Jelita the smallness of the mark was immaterial. It marked Jelita as the subject of the hospital apparatus. The red check ticked by Dr Emil was also a sign of the patient's subjection to the medical intervention, a situation that made them feel both anxious and caring. When Dr Sahril and Dr Rizki came to see Jelita that day, their eyes seemed to glance only at Jelita's upper leg. Dr Rizki suddenly turned to me, the person who was not a family member, and shook my hand. 'Give her support, please,' he said anxiously. Dr Sahril advised Jelita, 'Pray, OK? The surgery will be performed on the first round in the morning.'

3.2.3. Sterilising: **ganti semua nggih …** ***(change everything, okay…)***

A sense of unfamiliarity marks the clinical zone as separate from the social sphere. At 8 a.m. on the day of the operation, other patients and family members in the ward were starting to wake up to the smell of concentrated *Wipol* floor-cleaner. The classic, pine smell of the disinfectant floor-cleaner invoked cleanliness and also a suspicion that it was being used to mask the dirty, muddy and unclean marks on the floor. The pine fragrance resembled the chemical cleaner used to clean public toilets across the corridor outside. The ethoxylated alcohol and benzalkonium chloride that were blended in the fluid loaned a sense of sterility and hygiene to the space. The smell was thought to keep hospital infection rates low, kill bacteria, remove oil and dirt and reduce unpleasant odours.

While the ward was being cleaned, I waited with other family members in the corridor. I saw Suster Dian, who was holding green clean clothes, pushing a trolley into the ward. I followed and heard her say gently to Jelita, 'Change everything, okay.' She brought the informed consent paper and Jelita's medical record, a paper to be signed by witnesses, and a paper of agreement granting permission for the doctors to perform the amputation. After Bu Sumiati signed the paper, a fourth resident, Dr Nungki, came to the ward asking again about her X-ray films, which had been taken by another resident.

Figure 3.7. Bu Sumiati trying to help the nurses move Jelita to the trolley bed
Source. Photographed by author, 6 Dec. 2015

Suster Dian began to replace all Jelita's intravenous lines in preparation for her move to the trolley. She peeled away the tape holding the lines in place. Bu Sumiati said, 'That's a bit rough.' Jelita complained of the pain from the tape being pulled off. Then Suster Dian forced Jelita to take her colourful pillows, brought from home, from under her leg. Simbah sighed, 'Ahh … it will hurt her if the pillows are taken out'. Suster Dian told Simbah, 'These pillows on the trolley are against regulations and, in any case, they are ugly.'

Jelita complained so bitterly that she needed the pillow for the pain, that Suster Dian, murmuring unhappily, reluctantly left the three pillows under Jelita's body. She looked around for a male relative. 'Is there a man who can help us push this bed?' Bu Sumiati and Jelita's grandmother were silent. Jelita's father, Pak Sidik, had stayed home to continue running the laundry business and build the coffin for Jelita's leg. Bu Sumiati had phoned him, and he had begun the ninety-minute journey to the hospital.

In the absence of male relatives, Bu Sumiati, Suster Dian and I pushed the trolley along the corridor, past the nurses' station to the Central Surgery Building, 100 metres away. The whole process was so rushed that the family members of other patients barely had time to register that Jelita was being taken away for amputation. Arriving at the operating theatre, a nurse asked Suster Dian for Jelita's medical record and reminded Bu Sumiati of the need for blood supplies. When Pak Sidik arrived, he brought with him a cooler filled with the required packs of whole blood donated by village neighbours who had been on standby waiting for the call from the hospital that Jelita was going to theatre.[2]

[2] Such directed community donations of blood are common in hospitals in Indonesia. Sometimes patients feel fortunate if the blood is donated by someone who is very pious such as a Santri who has studied the Qu'ran.

In the room outside the operating theatre, everything that Jelita usually wore and the things that were close to her were taken away. Suster Dian directed Bu Sumiati, Simbah and me to help her to lift Jelita's body onto the surgical bed. 'One … two … three …,' Sister Dian commanded. I saw Simbah put as much effort as she could into the task. What Simbah and I were trying to do was move Jelita by lifting the sheet under her body and slowly pulling the sheet once the body was moved on to 'the new bed'. Sister Dian grabbed the black waterproof pillow, removed Jelita's hair band and covered her hair with a green surgical cap. Jelita had now been stripped of everything close and familiar to her. 'It is finished,' said Suster Dian, advising Bu Sumiati, Simbah and me to leave. Outside, in the corridor, Bu Sumiati took out her Qur'an and began to pray.

The surgery process removes the social arena and anything familiar to the patient and uni-formalises the individual body instead. Through the medical practices performed in the theatre, power is enacted upon the human body to fix and change it (Foucault, 2012).

The development of new biomedical technology and life-saving procedures like surgery has given patients and clinicians options and expectations. In developed countries, biomedical procedures offer new hope to patients and clinicians and reconstruct science and technology as 'heroic figures in battle narratives' against disease and illness (Mattingly, 2010, p. 66). However, the biomedical procedures also create new challenges for social connection. As Mattingly said:

> In this focus upon the clinician and the disease, patients and family members are often left to one side—the drama can be extremely clinician centered, and the hierarchy of clinical command is often easily evident. Here is an instance not at all uncommon, speaking not only to the genre of detective story but also to another key canonical genre: repairing a broken machine. (2010, p. 57.)

Anas described the unfamiliar theatre as separate from his social life, just as the action of removing Jelita's own pillows separated her from her prior life, from her own society of village, friends and parents. This was a strange transition from the familiar to the unfamiliar. Through such spaces or acts, the patient was put into what I describe, translating Anas' phrase, as 'outer space'; she lost control and contact with her old life and was estranged from her body part. Patients in this process lose contact with themselves, and their self is remade in this clinical space. This form of biopower, a clinical practice in 'modern' Java, shows how

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Receiving this blessed blood may aid the patient's recovery from illness, since it is viewed to be particularly pure.

vulnerability is constructed in the process of 'healing the body machine' (Mattingly, 2010, p. 57).

3.3. Seeking *ayem* (equanimity): Javanese personal and social meanings

The concept of a healthy body in Java is understood as a state of *ayem* (equanimity). The concept is different from the Western construction of the individual body, because a person's existence in Javanese thinking depends upon cosmic forces and a higher social order (Mulder, 1978, p. 40). In particular, the experience of illness and bodily impairment is, as Lock (2002) and Woodward (2011) describe, a circumstance when the microcosm of the individual is not in balance with the macrocosm of social order. Illness experience is both *kehendak Allah* (God's will) and the outcome of tension in social structures and hierarchy. Bodies with illness, disease and disability, therefore, reflect meanings and values of a social kind stamped into bodily processes and experience (Kleinman, 1988).

In Javanese thinking, the body-self is not a secularised private domain of the individual body as in the biomedical construct, but an organic part of the sacred and sociocentric world, in communication and contestation with others (including the divine) (Kleinman, 1988; Mulder, 1986). In other words, the Javanese person is understood as a physical and spiritual unity reflecting moral and spiritual elements basic to religious faith. As Mulder (1994, 1998) explains, the practice of connecting with the *batin* (or inner-self) is part of *Kejawen* (the Javanese spiritual complex). The *Kejawen* refers to a metaphysical elaboration in which the individual dynamic inevitably involves an all-encompassing connection between material and spiritual, and a balance of inner (*batin*) and outer (*lair*) (Mulder, 1998). Within this world view, the anatomical body is referred to by the terms *lair* (Arabic *zahir*) or outer while *batin* or inner refers to both material and spiritual components of reality (Woodward, 2011). The distinction between the outer and inner has shaped most Javanese people's understanding of the structure of the human body.

These Javanese religious understandings complement bodily images. The construction of the person not only consists of the spiritual dimension of personifying dogmas and beliefs based on religious sources but also on the embodiment of a metaphysical sense (Woodward, 2011). Based on rigorous fieldwork in Yogyakarta from the late 1970s, Woodward (1989) showed how Sufi Islamic dogma fundamentally constructed the collective sense of being Muslim. Concepts of illness and health, according to the Javanese norm, tap into a mystical conception of the structure and arrangement of the human body dominated by the Sufi concept of the person's wholeness or, what Woodward calls, the 'perfection of man' (2011, p.

72). People are aware of the distinction of the person's components divided into internal/spiritual and external/bodily and this split guides religious devotion. He stated:

> According to Sufi teaching, each individual must strike a balance between outward forms of devotion including religious law and ritual and the inner quest for purification of the soul and direct knowledge of God. The more radical forms of Sufism, which are common in Southeast Asia, maintain that the human soul is simply one of the aspects of God. Religious life is seen as a struggle between the true, inner soul and the outer, animal soul (*nafs*) for control of the individual's thoughts and actions. Only by traversing the mystical path can the soul emerge victorious. (Woodward, 2011, p. 72.)

Being a [healthy] perfect person is to be morally and spiritually disciplined and the Islamic mystics in Sufism grasp this doctrine as embodied truth and the way to faith and salvation (Woodward, 1989, 2011). Geertz (1966, p. 4) defined religion as a system of symbols that acts to establish powerful motivations for navigating life and offers universal and long-lasting moods and enthusiasms that draw people to see these as real. The ultimate truth, however, is not for everyone and lies beyond the symbols. Rather, the truth is for those who closely follow their initiation into these truths and are capable of holding an intuitive understanding of God and remaining in submission to Him (Woodward, 1989, 2011). Most people in Java embrace spirituality and submission as essential elements of healthy lives. The experience of severe illness and disability may direct individuals' resistance to biomedical efforts to control their body by turning to religious rituals and submission to God. For example, beliefs and behaviours have shaped the way Javanese women respond to diabetes in their everyday lives by normalising suffering, resisting social control, accepting fate and validating their faith (Pitaloka and Hsieh, 2015). Embracing illness and impairment reaffirms the individual's lifelong struggles to attain purification from *sin* and submission to what one of my participants describes as *jihad*. The embodied beliefs and behaviours are about symbolic boundary maintenance and achieving internal purity as a locus of control (Douglas, 1966).

Browne (1999, p. 97) argues that any maladies and illnesses in Java are associated closely with a wide range of beliefs. The causes of misfortunes like chronic illness or limb loss that I collected from my informants both in urban and rural areas, reflect their various beliefs in accordance with not only the formal religiosity of Islam, but also with many people's identification of spirit attack or sorcery as *mukjizat* (a miracle reliant on mysticism) and *buatan manusia* (a social act). This organisation of beliefs is an essential element in giving meaning to bodily experiences: through mysticism, sorcery and ethics found in the Javanese karmic outcomes of *menuai yang kita tanam* (reap what we sow). Grounded in

sociocentric conceptions, the meaning of disability, disease and illness may powerfully give meaning to the lived experience of person, self and individual (Browne, 1999; Ferzacca, 1996) that transform the person into a negotiated societal relationality (French, 1994b; Pitaloka, 2014; Pitaloka and Hsieh, 2015). Thus, there is an overpowering belief that severe illness, disability and even sudden death are the result of enacting spirits.

With respect to the body, health, illness and healing in Java, my ethnographic data show that religious belief in God's will as well as folk beliefs, mysticism, and spiritualism are mingled with biomedical constructions. Javanese people understand life should be in balance between inner-outer, physical-spiritual and individual-social. In everyday conversations, severe illnesses like cancer, limb/organ loss, young or sudden death are very often attributed to spirit intervention (*roh*), such as ancestral spirits (*arwah leluhur*) that are, in effect, spirits of place and social order. Therefore, becoming healthy in Java requires a harmonious state of *ayem* (equanimity) cultivated from the physical state, spiritual stability and social esteem (harmony). Guinness (1986) noted that equanimity, at the village level especially, is integral to the way people imagine the state of *rukun* (equilibrium). Healing for most Javanese is to attain a feeling of *ayem* (equanimity), harmony, or a state of unity with the ultimate essence of all life. Mulder (1994) argued that every individual participates in the all-encompassing union of material and spiritual life. Nature and super-nature in the Javanese lens influence each other and the causality is implied in their coordination (Mulder, 1978, 1986, 1994).

In the following section, I observe the Muslim attitude towards health or illness, disease and disability to capture the logical, spiritual and social struggles, and unpack how Javanese determine and apply these attitudes in religious and social terms.

3.4 *Cobaan* (on trial)

In developing countries, research has shown that biomedical knowledge finds it difficult to measure the incidence of cancer because of the greater mortality from infectious diseases and malnutrition (Ottaviani and Jaffe, 2009). To some extent, following Browne (1999) and Ferzacca (1996), I argue that biomedical knowledge cannot offer a full therapeutic analysis of any kind of illness. The local religious and moral conditions are essential to understand the body 'suffering' from disease, illness and bodily impairment. As a result, the sociocultural context that locates the individual is significant in conceptualising their health and illness experiences.

Most Muslim teachers like *ustadz or kyai* contend that whatever disease, illness or disability happens to an individual is perceived as *nasib* or *takdir* (fate) that is given by Allah.

Bu Nur a female teacher at the Islamic Junior High School in the village, also had a significant role in health-related activities at the Posyandu 'community health centre'. She explained further:

> If somebody was tested (*cobaan)* through an accident [leading to amputation] for example, that person should be able to self-reflect in order to be more watchful. The *hikmah* (meaning) is there. For me, this is not karma. But, how would I say it? It is true, in Indonesian language we say '*menuai apa yang kita tanam* [we reap what we sow]'. So, a body that has experienced limb-loss is actually suffering a consequence (*balasan*) because even the small things we do generate *balasan*. (Interview, Bu Nur, 5 August 2015.)

Ustadz Ali strongly agreed: 'Illness is *cobaan Allah* (a trial or test from Allah). Being *sabar* will help us [the ill person] be closer with Him. The illness experience reduces [our] sin.' (Interview, August 2015). During Jelita's medical examination, Bu Sumiati told me that religious teachers or *orang pintar* acted as powerful guides to strengthen her and Jelita to keep returning to the hospital. She felt that she could not fully trust the clinicians—unlike her faith in the *orang pintar* and God's direction. She could accept this *cobaan* and struggle by putting her trust ultimately in spiritual and social mediators such as the *kyai, ustadz, orang pintar,* or *dukun* (shaman).

In Yogyakarta, Woodward (1989) argued that *shariah* or Islamic Law, together with the Qur'an and Hadith, is fundamental to Sufi Muslim norms. The norms become *life-saving* resources and believers consider them to be Allah's plan for human beings, covering almost every aspect of ritual, political and social life, family and business affairs and health or its bodily treatment (Woodward, 1985, 1989, 2011). The religious teachers have established both doctrines and rituals as guidance for how individuals should conduct themselves in the face of illness so as to obey the will of Allah (Woodward, 1985).

> And we reveal of the Qur'an that which is the healing and the mercy to the believers. (Qur'an, Surah Al-Isra: 82.)

> O Allah, forgive me, and have mercy on me. Guide me, grant me health and provision. (Hadith Sahih Muslim, 2697.)

> O Allah, pour out over the prophet Muhammad the prosperity that is obat (medicine) and healing for our heart, the healer, body therapist, the light, the graceful, and the insurance for physical, spiritual health, and the needs for food and blessing over his family and relatives and bless with *selamat* (the protection). (Sholawat Syfa.)

Cobaan in this sense means that human experience and its goals enact the transformation of the soul. This variation of Islamic practice, generally understood as Sufism, seeks to generate mental states of equanimity rather than physical behaviour (Woodward, 1985). The passage is from *Syfa* or *Sholawat Syfa*, which means *obat* (medication) in Arabic.

The *Sholawat Syfa* is one of the medications for the heart/soul (*obat hati*) used to heal illness and disease. Some religious leaders use this passage as a ritual and practice it in therapy. They advise reading the *Sholawat Syfa* in ritual after the *sholat* (regular prayer) in order to keep the body healthy, protect it from misfortune and attain long-life (*panjang umur*). The *Sholawat Syfa* is therapeutic, invoking the feeling of *ayem* (equanimity). Being patient and accepting the *cobaan* (Allah's tests), including anxiety, impoverishment, starvation, illness, disability and death, will heal the patient and bring them close to Him. Cultivating the Sufi teaching directs each individual with illness, disease and disability to strike a balance between outward forms of devotion, including religious law and ritual, and the inner quest for purification of the *hati* (the heart) and soul and direct knowledge of God. *Du'a, shalawat*[3] and praying are therefore important elements, or *obat* (medication), for recovery.

3.4.1. Mysticism and Javanese spirits

> I was one of the participants joining the Yogyakarta Night at the Museum group that held an event called 'Jelajah Peradaban Mataram Islam Abad 17-18 M' (Mataram Muslim Civilisation in the 17–18th centuries]. The trip visited several cultural heritage and historical places that are the foundation for the current Yogyakarta aristocracy: Kartasura, Patilasan Perjanjian Gianti, Surakarta and Mangkunegaran, Kraton Yogyakarta, Pakualaman and Makam Imogiri. In the Kraton area, while the participants sat in the pavilion beside a full set of gamelan music instruments, a senior guide jumped up and walked outside. She held up some of the sand in the yard. Showing us the beach sand, she said, 'It signifies the supernatural spirit embedded in the Sultan's palace. People may believe it or may not but this grainy sand is part of the legendary Princess of the Southern Sea's (Nyai Lara Kidul) involvement in the spirit or soul of the Javanese and particularly the Kraton's life force.' The sea sand that grounds this *kraton* (palace) is part of the authority of the Princess. (Fieldnote, 31 Oct. 2015.)

The supernatural belief and spirit that the guide demonstrated in the *kraton* demonstrate the traditional sense of living in Yogyakarta whereby Javanese people are caught up in an ancient drama as a background to their lives. Nyai Lara Kidul mentioned by the guide is a beautiful maiden with divine spirit and an especial association with the Mataram Empire. Browne (1999) noted that her existence is ambiguous, as some people consider her haunted spirit to be dangerous for well-being and to cause catastrophic events. While I did not encounter many stories related to Nyai Lara Kidul during my fieldwork, other forms of spirit attack arose in everyday conversation forming a backdrop to people's lives and perceptions in Yogyakarta today. The vignette shows how mysticism is (re)-produced within the social-cultural system, continuously reassembled in different ways. The story to which the guide referred is from

[3] *Shalawat* is a special Arabic phrase, which contains the salutation to the prophet of Islam.

ancient, pre-Islamic history yet it feeds into contemporary Javanese lives and understandings of the world. Mulder (1983) noted that mysticism (*kebatinan)* commonly encompasses the Javanese worldview and gives meaning to their illness experience. Experience refers to not only 'everyday life' itself but also the meanings people attach to that life, so this *Kejawen* (local spiritual) tradition is one, among other, elements in the construction of the Javanese body-self (Browne, 1999; Mulder, 1983).

Pak Broto was a neighbour of the Lies family. In contrast to the Lies family who lived in an off-street residential area, Pak Broto's urban middle-class family lived in a street-side dwelling. His adult daughter passed away due to severe illness. He did not want to clarify specifically the illness but just mentioned a tumour in her brain and that she passed away at a young age, leaving a husband and a baby girl. On the day of his daughter's funeral, I went to his house for the *lajatan* (funeral ceremony). That day, I sat beside a woman who was opening a photo album of Pak Broto's daughter's wedding ceremony. The woman showed me the photo of Pak Broto's daughter wearing *kamboja* (frangipani) flowers in her hair. She told me gently that the *kamboja* flower is usually planted in the cemetery and its use signified her early death, which occurred only a few years after the wedding ceremony. She perceived the loss of Pak Broto's daughter as fate determined by God. The *kemboja* flower was a sign to the *roh tempat* (spirit of place) and it marked the death. Central to my reading of social order in Java is an understanding that belief in mysticism has emerged as a guarantee of social solidarity and harmony against spirit attack. A community leader told me that community-mindedness still persisted among the residents living in the area where Pak Broto and the Lies family reside. An individual needs social solidarity and harmony which provides them and their family with security from potential hazards or vulnerability (Guinness, 1986).

In giving meaning to severe illness or young death, mysticism is an important element commonly seen in 'modern' Yogyakarta. This element embodies Hindu–Buddhist traditions more than Sufi or Islamic religious elements. Geertz (1960) mentioned one of the categories of spirit, the 'haunting spirit' that causes illness and insanity. In everyday conversation relating to severe illness, limb loss, or early or sudden death, most people refer to spirits as *roh.* Koentjaraningrat (1985) included ancestral spirits (*arwah leluhur*) and spirits of place in this category.

Bu Mar's family lived in a village in Gunung Kidul District when her daughter, Desianti, was diagnosed with osteosarcoma in 2013. Desianti, seventeen years old, was the oldest of Bu Mar's three children. The osteosarcoma was located above her knee, leading to Desianti undergoing amputation at Sardjito Hospital. She lost her right leg five months before

I arrived in Yogyakarta for my fieldwork. Bu Mar told me that her relative's son, who lived next door, had displayed similar symptoms and shared the same diagnosis as Desianti. However, her relative's family rejected further treatment at the hospital. She told me that her relative's family believed that the cancer was due to the giant spirit of the tree (*roh pohon*). Unlike Bu Mar who followed the doctor's suggestion for Desianti, her relative believed in treatment by a *dukun* 'paranormal' rather than the medical diagnosis and care offered by a medical specialist. The relative's family rejected amputation. Bu Mar told me that the *dukun* who treated her relative's son said that the illness was due to the giant tree in front of their houses. Bu Mar slowly pointed her finger to the east, and told me gently in this way:

> It is because … [pausing] of the big haunted tree (*pohon angker*) and it should be ripped out or cut down. Villagers cut down the big tree, but my relative's son's illness was not cured. He passed away three days ago. (Fieldnote, Aug. 2015)

For several minutes we sat in silence. I have noted that the spirit narrative exists in both villages and semi-urban areas of Yogyakarta in response to people's desire for living in *rukun* (social harmony) with their environment. *Rukun* is associated with emotional stability and moral authority and is highly valued by Javanese to control one's impulses and 'keep them out of awareness or at least unexpressed, so as not to set up reverberating emotional responses in others' (H. Geertz, 1961, p. 147). Guinness (1986) for instance emphasised the feeling of *tentrem* (equanimity) and the maintaining of *rukun* (harmony) as ideal dimensions of village life. He said:

> The two values of *tentrem* and *rukun* are intricately interwoven in *kampung* people's philosophies, such that the presence of an unstable person within the community is seen to threaten social harmony, just as social discord can affect the equanimity of those involved as either observers or participants. (Guinness, 1986, p. 131.)

In a Javanese village, beliefs about severe illness like cancer and organ loss suggest that practices of divination and healing may provide ways for villagers to express distress when *rukun* is threatened by clashes between cultural values about social communality and individual desires and egocentrism. When I asked why her relative did not send his son to the hospital, Bu Mar told me that 'many people in my village still believe in such mysticism'. Desjarlais' detailed definitions of ailments and their symptoms in Nepal resemble those in Javanese villages. As Desjarlais (1992) argued, there is a connection between social anxiety that results from particular historical transformations in society and the individual's experience and manifestation of social distress and suffering. He explored the patient's subjectivity of the Yolmo people in Nepal and unpacked meanings that the people gave to

their experience of illness and depression such as soul loss and to their sense of healing. Shaman help them to find a meaning for their disrupted lives and to map tensions and threats related to fission and conflict among them.This addresses the need to maintain harmony among kin-based households and within a village-based hierarchical structure. The shaman's healing practice strengthens a Yolmo way of being a social interdependent person. Yet, it facilitates the community's efforts to keep and distribute resources within and outside of the kinship groups (Desjarlais, 1992). The illness narratives show the distress experienced by patients, so cultivating divination and healing practices that provide techniques for individuals to express suffering over conflicting cultural values and resulting from the tensions between interdependence within communities and individual's freedom and autonomy (Desjarlais, 1992). In Java, the individual's embodiment of mysticism and spirituality reconfigures similar meanings in the importance of social solidarity, directing individuals to feel empathy for other people's suffering and to live among others in respect of *rukun* (social harmony). As I capture in Bu Mar's narrative, there is an increasingly ambiguous entanglement of biomedical treatment with Javanese beliefs and traditional ways of healing. Villagers find themselves creating social esteem through a spirit of resignation and the engagement with divine beings in the process of dealing with disease, illness, disability and health.

3.4.2. **Dibuat orang** ***(sorcery, literally 'human concoctions')***

There are not only spirits that cause illness and disability (Browne, 1999, p. 272), but some people still believe in the practice of sorcery. Mas Tohir believed that disability is due to sorcery. Aged forty years, Mas Tohir was living in a semi-urban off-street neighbourhood at *Kelurahan Seloyor* where Soelistyo and his family also lived. Soelistyo's family was Muslim and their socio-economic status was above average compared with other residents. According to Mas Tohir, the cause of his uncle's blindness was due to *dibuat orang* (sorcery), as was Soelistyo's missing limb. Mas Tohir mentioned that *orang dulu* ('people in the past') used to practice *ilmu magis* (magic) to make other people disabled. The sorcerer makes such magic in order to *menjatuhkan orang* (strike down people).

When Mas Tohir was telling me about Soelistyo's missing limb as a result of an accident, he looked anxious and worried. He was silent for some minutes, and then said, 'I am not brave enough to mention that the impairment is due to sorcery.' Mas Tohir was afraid of retaliation (*kwalat*) and *karma* so he disguised the fact that he actually believed that the accident was due to sorcery conducted by a *sate* seller. As Mulder (1994) explained, the

Javanese belief in *karma* is *dibatinkan* or located 'within the inner-self'. The suspect was the *sate* seller who worked with the sorcerer, a neighbour living nearby in the same street.

Later, Soelistyo and his wife confirmed to me that his loss of leg in an accident was because he was targeted by the *sate* seller who used magic to sacrifice (kill) him through an accident. The accident was a motorcycle crash that 'happened' on the way to his guru's place located in the hills of Central Java. Soelistyo told me that *sate* seller's neighbour had asked to accompany him to meet his *guru* (teacher) so that he could get *kesakten* (power) and success in business. Soelistyo's wife said, 'Indeed, the business of *sate* was *laris* (successful) afterward.' Sulistyo told me in this way:

> The motorcycle crash was on Thursday night or Jum'at Kliwon [a mystical night in the Javanese calendar]. I was the passenger and my neighbour was the rider. My leg was broken in the crash. My neighbour sent me to the district hospital, but he abandoned me, running away to meet his guru 'spiritual guide' instead. I was in the Emergency Unit. Only the general practitioner was there and she just gave me an anti-tetanus injection and pain killer, and cleaned the wound. There was no other medical intervention at the time because no family member was there on my behalf. During the hospitalisation, only another patient's family member sat beside my bed helping to clean my body and clothes as well as give me food and assistance when the nurse was absent. The four days in hospital were without quality of care. On Monday, a doctor visited me and said leg amputation was the only treatment to save my life. (Fieldnote, Jan. 2016.)

On Monday afternoon, when Soelistyo's family received the news from other neighbours, they quickly brought him from the district hospital to the private Christian Hospital in the city. 'My father insisted on discharging me from the district hospital as he knew that surgery there would mean suicide,' Soelistyo said. The private hospital repeated some medical checks already done at the district hospital. He said, 'I endured serious medical symptoms at the time and the doctor said that if surgery had been delayed for more than six hours I would have died.'

Belief in sorcery was common in Kelurahan Seloyor and created tension among residents. Soelistyo did not only mention sorcery as the cause of his missing limb but also mentioned the spirit day of Jum'at Kliwon (*roh dino Jum'at Kliwon*), which some Javanese believe is a 'prohibited day' for travel. Seeking health treatment in hospital on Saturday, another 'prohibited day', may also bring bad luck, according to some. So they variously believed that the disability was due to evil spirits and sorcery. Therefore, during the treatment at the private hospital, Soelistyo told me that he also got treatment from one he called Kyai Haji who was also mentioned as *sesepuh kampong* or *mbah kakung* or *bapak saya* (Islam religious teacher, village head, grandfather, my father). This person is the most respected figure in Kelurahan Seloyor. Soelistyo further explained:

> When I was in the [private Christian] hospital, Kyai Haji Ma'mun gave me *obat* (medication) of pure prayer water and I drank it. While in the *kampong* mosque, he was leading the *sholat jama'ah* (communal prayer led by an imam) for *keselamatan* (asking for protection and a good life). Almost all kampong residents participate on the prayer day. I know him to have a strong spirit and close connection with Allah. *Ampuh*! (powerful!). The ritual in Kelurahan Seloyor grabbed all the residents' attention. Yet, some people saw me walking on top of the mosque when Kyai Haji Ma'mun was praying. (Interview, Soelistyo, 19 Aug. 2015.)

Soelistyo told me that most residents believed that what they saw was not an illusion but a sign that he would be *slamet* (saved and live). 'If people had seen a *keranda* [coffin] moving on the top on the mosque, it would mean that I would have died,' he said. The role of Kyai Haji Ma'mun in Kelurahan Seloyor was very important. Not only as a religious leader/imam able to lead the *sholat jama'ah* in the mosque, but also to invoke residents' feelings of *tentrem* and *ayem* (equanimity). His charismatic leadership reduced people's tension, anxiety and conflict. After the ritual prayer, he informed Soelistyo's family of the good news: everything would be fine. Soelistyo would be *slamet* (alive) and the *sate* seller's neighbour would give compensation for the medical costs of Soelistyo's treatment in hospital. Soelistyo told me that 'the *sate* seller has asked my family's forgiveness'.

The therapeutic practices and rituals associated with both Javanese Islam and mysticism demonstrate a narrative of illness and disability that speaks to the wider social cultural setting. In Yogyakarta today, the Javanese religious model of healing still engages patients and their families and convinces them that recovery includes feeling *batin ayem* (calm in one's inner-self), a facet that biomedical care ignores. The ritual prayer led by Kyai Haji Ma'mun shows not only the way residents attempt to hold to the principle of harmony but also how individuals engage with the principle of *slamet social* 'social security' and conflict avoidance (Magnis-Suseno, 1997). Magnis-Suseno wrote:

> The individual, therefore, learns what brings slamet from the traditions of his society. In these traditions, the common experiences of previous generations of his village community are reflected. In the course of decades and centuries, the village community has learned how it must behave if it is to stay in optimum harmony with the cosmic and spiritual world … Whoever respects those traditions enjoys a kind of cosmic insurance and need not fear conflict with spirits. (1997, p. 92.)

3.4.3. Menuai yang kita tanam *(reap what we sow)*

Javanese values have shaped the experience of illness and disability through social ranking based on moral goodness. Bu Nur described to me that the experience of misfortune like severe illness or amputation is not only a *cobaan* but also a *buah* (literally 'fruit' or outcome) of the ancestors' deeds or wishes). The *buah* was also considered to be due to one's behaviour in the past or present. These beliefs expressed by Bu Nur illustrate how Islamic,

mystical and Hindu–Buddhist convictions are mingled and add to beliefs in *cobaan* and the acceptance of the individual's own struggle to endure *karma*. Another form of *karma* in the Javanese world view is *menuai yang kita tanam* (reap what we sow). The Javanese karmic proverb '*menuai yang kita tanam*' is applied to the chronically ill, diseased and disfigured. In an interview, the Javanese Buddhist monk, Dhama Asan, whom I met at the Mendut Temple situated in the border area between South and Central Java, illustrated clearly his belief in the original ideology of *karma*:

> I prefer to look at them [people with illness and disability] from a theological perspective and I perceive this [person] experience from the psychology of Buddhism. I would say to those people 'accept it' [*terima apa adanya*]. You won't be able to change it and even if you keep praying until blood flows from your eyes [*tidak mungkin berdo'a sampai darah keluar dari mata*], your hand won't re-grow like before. Therefore, accept them 'as they are', accept it 'as it is' [using the English words]. As long as you can still breathe, you can do something for society. When we are sick, lying down, not able to say any words and not able to do physical activity, we can still do good things using our mind, praying for everybody, everybody [pause]. You can do something. I avoid preaching theology because, according to the Buddhist view, it [*karma*] is the law of cause and effect. Those who are blind, hearing impaired, and limb deficient [*tidak sempurna*], for us it is the effect of karma, of what they have done in the past. Because it is impossible that something we have experienced is without 'reason'. According to Buddhist preaching, everything that we have experienced—happiness, sorrow, gratefulness—is always for a reason [*ada cause nya, ada sebabnya*]. If I have an accident and my leg is amputated [*potong*], or if I was born with a congenital disability [*dilahirkan cacat*], that absolutely has a reason. If the cause [*sebab*] is not evident in the present, we believe it is in the past or the next life. However, for those who are *cacat*, I usually avoid commenting on it it. The message is not good [*tidak baik*] for them to hear. We come to help [them], not to judge. If I were to judge it would be because of your *karma*, because of your acts. Now, your limb is lost or you were born blind, that is because of your acts in the past, your bad acts. Now you have to behave in a good way so that in the next life you will be physically and mentally healthy. For me, it is not wise [pause] but I have to say, 'Accept it as it is' [*terima apa adanya*]. (Interview, Dhama Asan, 29 Jul. 2015.)

However, the definition of *karma* in Islamic Java is different from Hindu–Buddhist interpretations. The Hindu–Buddhist teachings believe that *karma* is attached to somebody and has some consequences over the supernatural status of individuals in the world and such views are strongly held as a motivating force in the context of reincarnation (the cycle of living before life and after death). In Java, *karma* is not associated with reincarnation but determines that it is one's previous behaviour, considered to transgress accepted values, that affects one's fortunes and misfortunes (Mulder, 1986).

The *karma* discourse derived from Hindu–Buddhist beliefs has affected Javanese people's worldview since Islam was established in Java from the early sixteenth century to the present day. Yet, the language of *karma* associated with illness, disability and disease has been transformed into various 'new knowledges'. These are an expansion of the *karma* idea that refers to the deeds of either ancestors or oneself. I noticed how villagers are often silent

when confronted with disabled people because expressing anything negative (for example, mockery or cynicism) is considered to be ethically impolite, and brings shame and violates another person's privacy (Mulder, 1994). It invites what Magnis-Suseno (1997) calls *mundak kwalat* (retaliation). Mas Tohir's anxiety in relation to sorcery reflected his strong belief in *karma* and *kwalat*. As he explained,

> I have to regard disabled people as equal with other people who are normal, and I should not blame them (*mencela*). I feel compassionate and would be afraid that if I blamed a disabled person, then one day I would probably become disabled too.

With regard to disease, illness and disability, a puppeteer—an able-bodied man who also lived in Kelurahan Seloyor—mentioned that it illustrates an individual's *anugerah* (blessing) and should be *disyukuri* (acknowledged with thanks). He was Soelistyo's neighbour and they knew each other. The puppeteer acted as an interlocutor of sorts and stated that to regard disability as *karma* is rude or coarse (*kasar*). He preferred the use of the words *anugerah* and *syukur*. The terms *syukur* and *anugerah* express a desire to achieve equanimity (*tentrem*) on the surface. The puppeteer said that he would 'behave in terms of *ethok-ethok*, literally meaning 'as if' the puppeteer was himself disabled and the subject of misfortune (Magnis-Suseno, 1997, p. 47). The puppeteer's response revealed the Javanese notion of *tepo seliro,* emphasising his consciousness of Soelistyo's limitations or misdeeds. Another day, the puppeteer expressed his belief that Soelistyo's disability was due to previous wrongdoings such as behaving arrogantly or consuming alcohol to the point of drunkenness. The puppeteer convinced me that his language of *anugerah* and *syukur* concealed his ambiguous feeling towards disability as he said that such remarks are 'just to give the disabled people confidence. Yet, society should be *peduli* (caring) and *semanak* (friendly) to them [the disabled].' The vignette illustrated the way in which Javanese ethics and *kebatinan* contributed to the creation of social order characterised by respect for a benevolent hierarchy (Magnis-Suseno, 1997; Mulder, 1994).

Living in a Javanese village requires refined manners and indirectness (Mulder, 1994). My verbal exchange with the puppeteer and Mas Tohir reveals individuals' *karma* as another social characteristic of illness and disability. As French (1994b) and Fordham (2001) argued, these idioms that I describe as the *language of karma,* may serve to justify unequal power relations or a social 'moral' hierarchy. Nonetheless, put in other words, the complex idioms of *syukur* and *anugerah* and the various languages of *karma* refer to self-control in pursuit of harmonious Javanese living. Thus, people's responses that demonstrate respect for

benevolent social hierarchy, equanimity, faith and *rukun* (harmony) enable an orderly system (Guinness, 1986; Magnis-Suseno, 1997; Mulder, 1994).

3.5. Conclusion

There is growing confidence in biomedical perspectives towards disease, illness and disability in Yogyakarta, but Javanese perspectives also remain strong (Browne, 1999; Woodward, 2011). I argue that modern medicine, analysed by Foucault as particularly relevant to twentieth-century medical practice with its gaze on the pathology of the body, is complemented in Java by a wider socio-cultural dialogue and moral discourses. The way people re-make and re-assess disease, illness and disability reflects these intermingled views. Javanese people understand disease, illness and disability in multiple ways so as to attain the state of *ayem* among social, physical, spiritual and soul elements of their existence. They cultivate their social and moral world and their religious and culturally specific practices in ways that augment their understanding of 'scientific knowledge'. This reflects how biopower is impacting on Javanese life, continuing its regulatory function as a discipline mechanism and panopticon in everyday life discourse (Foucault, 2012). The biomedical gaze, however, is distributed beyond the juridical system of the clinic, where illness, disease and disability perceptions become multifarious. These intermingled views stretch out from the hospital to everyday dialogue and produce a 'new kind of cultural knowledge' over 'abnormal bodies'. The body suffering severe illness and impairment becomes the site for a contest of power between, on the one hand, those poor individuals who are trapped in the 'webs' of power and may continuously push back against the scientific discipline and, on the other hand, the regime of power and its agents (including those prejudiced values expressed by religious leaders, teachers, villagers, or the elite). This contestation continues to generate tension and to drive transformations in the politics of life.

Chapter 4
The Hospital Corridor as a Healing Space

4.1. Introduction

In this chapter I examine the nature of the Javanese living body emplaced in hospital corridors and look at personal, interpersonal and structural connections captured within a larger political and social framework (Mattingly, 2010). Here the corridors can be understood metaphorically—as much a way of talking about vigilant patient care—as real spaces. The corridors are a twilight time or liminal space (Davis-Floyd, 1998; Gennep, 2011; Turner, 2017) where I have found 'a quasi-village character'— constructed in an in-between space in the hospital structure. I suggest the corridor is a space where another element of Javanese social life—what Turner (2017) might describe as *communitas*—is taking place. It occurs when the distinction between subjective and objective aspects of reality, between what is of the mind and of the world are shaped by the attitudes that individuals take up toward the world and by the cultural-historical aspects that inform norms, beliefs, and values embodied within it (Desjarlais and Throop, 2011, p. 89).

As Mattingly (1994) did, this chapter and the following one use narrative phenomenology as a method with which to analyse clinical life as a sequence of habitual social negotiations between clinicians and patients. This method captures how the meaning of the illness experience is constructed, and how therapy is discussed, against the background of individuals sharing their illness stories and the meaning of their lives that must be rebuilt in the face of severe illness and disability. The subjective experience is highly personal and local, but connected with the larger frame of development, national discourse and practices, and the global flow of products (Mattingly, 2010, p. 217).

> Clinical moments and clinical actors (doctors, therapists, and the like) are sometimes key protagonists, but they are never the main characters. Nor is the body itself, as a site of battle or repair. Rather, the main characters are the sufferers themselves. By this I mean not the identified patient alone but the suffering community that surrounds that patient – those intimate others like parents, siblings, and close friends, who also suffer and whose lives are unutterably altered by the fate of the illness. (ibid. p. 166.)

The narrative analysis covers illness and disability experiences within the frame of the clinical gaze but more importantly it allows us to look rigorously at the ethnographic detail in the broad span of historical events and social reality in which core local values are exercised in habitual manners, lived by local actors situated in particular cultural contexts (Kleinman, 1988; Mattingly, 2010). Yet, derived from personal perspectives, this narrative analysis

allows us to reflect on the frame and the structural elements of hospital care and practice (Mattingly, 2010, p. 217).

In particular, this chapter examines how the corridors have served the patients' families in dealing with uncertainties—the *blues* of medical prognosis. When the individual patient, family or society face a catastrophic event, ethics, religion and spirituality work in recreating the real practice of the self while the sense of religion or societal biopower comes to 'animate who we are' (Foucault, 1976; Kleinman, 2006). The lived experience of the illness and disability mediates social and cultural transformations that are ritualised through cultural embodiment: shared feelings, intersubjective and individual relations. In other words, the experience of suffering is a social experience that at least addresses two important points of subjectivity: the embodied modes of the moral dimensions that shape a person's perceptions and responses; and the intersubjective process that indicates particular meanings of culture in a certain time and context (Kleinman and Kleinman, 1997, p. 2). In terms of embodied culture, biopower works alongside disciplinary power, but at the micro level of management that takes place in the 'corridor'. Culture reveals the 'corridor' as a Javanese-textured space and place of meaning in ordinary people's lives that represents Javanese moral elements and signifies the Javanese self/selves in Java today. The corridor accommodates embodied forms of a Javanese cultural self and identity where, against a backdrop of sober medical prognosis, the patients and families I observed developed a sense of acceptance (*nrimo* or *menerima dengan ikhlas*) and an appreciation of the blessings (*berkah* or *anugerah*) of God as the giver of life.

As observed by Ferzacca (1996) in the late 1990s, the Javanese self/selves is known through the lived experience of chronic illness (diabetes, cardiovascular and hypertension). He contended that the idiom of *masih Jawa asli* (being true Javanese) in treating bodies with chronic illnesses sums up the Javanese self and identity and is also found in such aphorisms as *tepo seliro* (each of us trying to put ourselves in the other's situation) which are embodied in the thinking and social interactions of some Javanese in Yogyakarta. Ferzacca said:

> Seeing Javanese as mere bricoleurs, or in the worst case as dupes subject to nationalist political conspiracies and greater historical forces, misses the everyday practices that individually, and ultimately collectively, enact virtual engagements with the present. Masih Jawa asli from this perspective, becomes the touchstone for Javanese bodies, Javanese selves in which the past, the present, and the future are everywhere for everyone in this Javanese urban landscape. (1996, p. 513.)

The contemporary Javanese hospital corridor is simultaneously a material space and a metaphor for social movement. It is in the corridor that agents of global biomedicine

encounter the families and extended social networks that surround patients. This chapter will examine these encounters where, on the one hand, hospital designs seek to exert a form of control over populations and, on the other, where real interactions between people reveal other forms of human expression as patients, families and hospital staff navigate traumatic events. Under the heading 'Hospital Design in Java' I will examine the structures of clinical institutions. Here I argue that biopower inserts itself into the hospital design yet is transformed through the local context. Under the heading 'Corridor Spaces' I argue that the corridor is a profound site of social, emotional and spiritual activity. Here the corridor unfolds the Javanese self, linking patients to an intermingling of inner and outer life. Thus, this chapter depicts cultural interpretations and moral standpoints that offer alternative politics. The aim of this chapter is to show how Javanese life in the hospital corridor reveals the ways in which human experiences of severe illness and disability reflect an intensely local interaction of biomedical, social and spiritual outlooks.

4.2. Hospital design in Java

In Indonesia, patients with severe illness live temporarily in the clinical zone of the hospital—named *rumah sakit*, literally meaning 'pain/sick house'—seeking to recover from pain, from illness and from hurt. It is a powerful structural system which disciplines the sick through its clinical gaze; its separation from the rest of the world is marked in part by smells and sounds. Along the patients' journey, they will encounter a viscerally stimulating place, where smell and sound create a specific 'clean' environment. Somehow this reinforces the power of the institution by making everything feel so hygienic and unpolluted—for the lay person, however, it may also seem unfamiliar as it estranges individuals from their known haptic body.

As in 'Western' basic medical practice, clinicians—general practitioners, specialists, hospital non-specialists and residents—are expected to provide a fundamental clinical gaze as the basic component of a treatment that is objective, measured and scientified (Foucault, 2012b). Dr Ari, the orthopaedic surgeon, stated that it is critically important to be professional in arranging informed consent biomedically and to ensure that the patient is properly 'worked up' (prepared) for surgery. He describes his own standards of practice, using the example of people who suffered a traumatic incident or cancer:

> There is a patient with trauma due to an accident, for example. We have decided to perform amputation and the patient has agreed. But later, there is a problem with the general condition of the patient. The patient might have a head injury and low haemoglobin, and there is a

> problem with his lungs as well. So, we have to postpone the operation and wait for the general condition to improve.
>
> That's the main point and it also applies to tumour cases. The patient needs amputation because the tumour itself sucks blood in forming tumour cells and the patient's condition needs improvement before amputation is performed [pause]. There was a patient who refused amputation although we advised that amputation was required. The operation was postponed again and again. Finally, he was admitted with a tumour that had become bigger and his haemoglobin level was not good, which meant amputation could not be done as soon as we had planned.
>
> When amputation was planned, the patient's condition was normal and so it supported anaesthesia. It only needed approval from patient and family. They refused and took him home. He undertook alternative medication or something else and came again with a bigger tumour and blood levels that had to be corrected first. However, it is not that easy to repair the condition … That's the common problem. Sometimes, we take the risk and perform anaesthesia although it does not follow the 'standard of anaesthesia'. We lower the standard as long as the parameter ... what is it called? [Asking a colleague who was also in the room.] 'What is it called? Just a minute, I'll ask, I forget'. Source control. So, control it from the source. The source that causes the blood level to go down is the tumour. The effect is circular.
>
> The patient died on the operating table because he was not in a proper condition for anaesthesia. The effect makes it difficult to choose which action should be taken. So far, most patients die, not because of the operation, but because they come late, so that the anaesthetist cannot take the risk to sedate the patient. As a consequence, the patient's condition deteriorates which causes organ failure. (Interview with Dr Ari, 5 Jan. 2016.)

Recent research by historians of medicine has demonstrated the inadequacy of such medicalisation in Southeast Asia, resonating with Dr Ari's ethical struggle—specifically about the very difficult processes at play in the local world (Pols, Thompson and Warner, 2017). Differences in attitude are derived from the different cultural contexts of health care. Especially when medicalisation overlooks the patient's own cultural experience, the process meets various social cultural constraints (discussed in Chapter 2). Parallel with this, medicalisation in Java is reflected in Dr Ari's frustration when patients and families do not conform to clinical disciplines and come to the hospital very late, with the patient exhibiting symptoms of advanced cancer. In such circumstances, Dr Ari struggles to bring about health improvements through surgery or biotechnology. But successful surgical outcomes are unlikely to occur where most individuals put folk beliefs and spiritual ideas ahead of scientific understandings of the body (Browne, 1999; Woodward, 2011). At this point in time, the concept of illness and healing in Java is still associated with a concept of humans as metaphysical beings, and behavioural modes of religious devotion determine individuals' health statuses (Browne, 1999; Woodward, 2011), thus constraining the implementation of biomedical discipline.

This disruption and the despair that is embedded in biotechnology in the hospital provokes new concerns about social hope and clinical care (Mattingly, 2010). The hospital therefore may not only smell of alcohol cleanser and floor cleaning chemicals, medicines, sweat, the toilets, the kitchen and the affected body parts—that are so personal or individual—but may also stimulate deeper social intimacy like family crowds and companionship, neighbourhood visits and friendship that enclose the patient with emotional nourishment. My own walking along the hospital's hall, passing the front desk, registration counter, bank counter, waiting rooms, nurses, physicians and more, impressed on me that when these parts of the hospital become embodied as a cultural borderland, they can lend an 'affect' in an unconscious way.

When Western medicine in Java was established in the eighteenth century, Dutch[1] colonialists delivered biomedical practice in hospitals based on Christian religious values. Since then, biomedical modernity has introduced the medical gaze to traditional society and normalised the colonised and disciplined local subjects in the manner of Western medical practices—which required spatial partitioning, modernised mechanisms, order, careful surveillance and detailed inspection (Foucault, 1977, 2012). But, colonial subjects' beliefs and practices of religion (mainly Islam and indigenous spiritual beliefs) remained strong. So, the imported 'Western medical ritual' engaged with basic Javanese theories of the body—leading to the interplay between embodied spirituality and scientific perspectives and practices in hospital structure (Woodward, 2011, p. 73).

In a Javanese hospital, the informal corridor spaces encourage the exchange of caring and allow for more flexible social contact that acknowledges and values social interaction. I observed that it was terrifying for Bu Sumiati when Suster Dian pushed Jelita's bed into the surgery theatre. When Suster Dian insisted Jelita change everything attached to her body and bed (such as her colourful pillows and clothes) it made Bu Sumiati and Jelita deeply upset. Clearly the nurse was following a clinical standard of operating procedure in changing her patient into a standard hospital gown and dressing her bed; she was required to sterilise the patient, observe them with care, and be alert to any physical circumstances which might affect treatment outcomes (Foucault, 2012). And yet, the aura created was awkward, and I saw how emotionally uncertain Bu Sumiati was when she had to leave Jelita alone in the surgery theatre. Bu Sumiati took her little mobile phone from the red backpack, put it just

[1] Namely, Bethesda/Petronella hospital.

near Jelita's ear and said, 'Here, it's from Yanti, and there will be eleven friends coming and waiting for you.' Yanti is Jelita's close friend and neighbour whom I met when Jelita was having her treatment.

Strict biomedical routines in preparation for surgery tend to erase the person as an individual subject. But the social life in the corridor reinstates the individual's identity and sense of self and personhood. The corridor accommodates the extended values resulting from bringing the life of the 'village into the town' and binding the two into a mutually satisfying and meaningful whole. For instance, I vividly recall how the tension in these perceptions played out on the 'corridor' when Jelita emerged from theatre. After seven hours waiting in the corridor while Jelita's surgery was performed, the theatre doors suddenly opened wide. Two nurses from the ward entered the room. They pushed the mobile bed out from the theatre. Jelita's friends, neighbours and I saw that Jelita was already conscious. She said nothing, while Bu Sumiati was silent as usual. Gimbal, Yanti and other friends followed Bu Sumiati and nurses to the ward. Entering the ward, I found Simbah already there. Other patients and families were curious to know who the nurses were transferring. There were five other patients and their families there, including Bu Kodi, Jelita's neighbour, who had been hospitalised at the same time as Jelita for several weeks. I saw her shocked face and startled, open mouth peeking around the curtain. The families of other patients moved past, their bodies bent prone in respect as they passed Jelita's chamber. They pretended to go to the toilet situated outside across the corridor. Some of them pretended to put the plates back in the corridor and returned looking warily towards Jelita's chamber. Everybody was shocked, and I saw Bu Kodi in the ward crying quietly, carefully wiping her tears away with her hair scarf (*hijab*). Walking out to the corridor, she murmured '*amputasiiii*' (amputation), dragging out the last syllable as if she could not bear to cut the word off. The behaviour of Bu Kodi, and other friends and neighbours registered two conflicting perceptions. On the one hand, they showed compassion (*masake*) but, on the other, they drew attention to the strangeness and the otherness of Jelita's body.

4.3. The corridor

Ritualistic and affective embodiment points to something far from static—rather it is embodied and dynamic (Browne, 1999; Lynam et al., 2007), and is associated with human experience and the poetics of suffering (Kleinman, 1996).The patient, family and clinician are, in this sense, not only the open objects for cultural inspection, but also the loci from which the patient experiences being in the world (Desjarlais and Throop, 2011). One week

before Jelita's surgery day, passing the front desk along the corridor, I observed that several nurses on duty seemed quiet and thoughtful. I also saw around six to nine members of patients' families standing around, some sitting on the floor. I walked along the corridor to the ward where Jelita was being treated. Stepping inside, near the cancer ward door, I could hear the repeated sound 'thuing … thuing', rhythmic and very noisy. The ward measures 6 x 8 metres square, with six beds inside, and each chamber is about 2 x 3metres square. There are six beds, each separated by only a blue curtain. I saw Bu Sumiati standing beside Jelita and her grandmother (Simbah Puteri). Jelita was smiling at me, holding a hand fan and spraying her leg with an acetic acid solution. In the chamber there was a bed, a chair for Bu Sumiati and her mother-in-law, Simbah, with whom she lives, and a stool for helping the patient get down from the bed, but which is also often used for visitors to sit on. An oxygen tube and oxygen water were mounted on the wall near the nurse call button, and there was a small shelf and a table where Jelita could put various things she needed. I greeted her while asking Bu Sumiati about what the nurse and Dr Agus and his residents had proposed as the next treatment for Jelita. As usual, I saw that they looked confused and uncertain, and the thud of the medical equipment disturbed our conversation and made it hard to continue.

Stepping across to the window, I noticed that the sounds came from the chamber where another patient in the same ward was being treated urgently. A pump had been inserted into the patient's mouth, and a nurse was pumping air into the mouth. I could hear laboured breathing '*nghek … nghek ... nghek*' repeated along with the sound coming from the ECG machine—a square-shaped gadget with some cables connected to the body of the patient. It was the sounds of the ECG machine that I had heard earlier—'*thuing … thuing … thuing … thuing.*' Above the various noises, I overheard conversation between doctors and nurses regarding whether or not there was a bed available in ICU for treating this patient.

Looking out of the ward window, I saw Pak Tono, the elder brother of Bu Kodi who was being treated on the left of Jelita's bed. Speaking across Jelita's bed, Pak Tono explained the condition of the emergency patient. Worry was evident on the faces of other patients' relatives in the ward set up to treat patients suspected of cancer, but not for end-of-life patients or general emergency patients. Pak Tono said:

> *Kala riyin nguntal gigi palsu ning sampun diangkat, trus infeksi. Ning nggih niki mergo terlambat dibeto mriki, sak derenge ngagem alternatif, ning nggih jenenge usaha nggih ten pundi mawon sae nggih. Niki kawit jam 8 enjang, niku sampun kali doso dinten ten mriki, turene disedot ngoten cairane, terus putrane mboten saget dihubungi turene kalih-kalihipun nyambut damel ten Jakarta.*

> (She swallowed an artificial tooth, which has been retrieved, but it caused an infection. She was not brought here immediately as they first sought alternative medication—she thought that getting health treatment from any place is good as part of the attempt to recover. Unfortunately, it was too late when she was taken to the Sardjito Hospital. Her condition dropped at 8.00 a.m. after twenty days here and even sadder her two children could not be contacted because they work in Jakarta.) (Observation, 31 Oct. 2015.)

Bu Sumiati and I were standing beside Jelita's bed when two more clinicians arrived, roughly pushing a three-tier trolley containing equipment that they set up in the space between the patients' beds. I could see an orange box on the trolley. In the middle of the ward, some curtains were closed tightly, and around the ward other curtains had also been closed. The curtain next to the bed where Jelita lay was drawn while Jelita closed her eyes and held a hand-fan made from plastic. She was fanning herself with her eyes shut. We were still able to hear the sound of the emergency machine and Bu Sumiati told me that it made her feel afraid or worried (*takut*), disturbed (*terganggu perasaan*) and anxious (*cemas*). Behind the side table, there was a rolled-up mat on which Bu Sumiati slept on the floor during the nights when she kept her daughter company. Jelita was in the middle bed space and her oxygen apparatus was being used by the patient next to her bed on the right (Figure 4.1).

Figure 4.1. The situation when the sounds of the ECG were audible throughout the ward
Source. Photographed by author, 27 Nov. 2015

To deal with the feelings of panic (*kepanikan*) and worry (*perasaan takut*) which arose from listening to the sound of the ECG machine and the desperate breathing of the critical patient, nurses came in and opened patients' curtains, saying, 'We're going to clean up, change the bed sheet, ma'am'. Three nurses were busy offering to change the bed sheets and pillow cases. One of them asked, 'Whose mat is this?' 'That's mine', Bu Sumiati answered. '*Nyuwun sewu diparingke nggudang nggih, menawi injing disukakke nggudang*' (Excuse me,

ma'am, please put the mat in the storage room in the mornings). In the face of lives and selves at stake in the clinical encounter, the staff displayed a clinical detachment and flat affect. While the nurses skilfully changed the bed sheets and pillowcases of the beds to the right and left side of Jelita, I did not discern any feeling expressed by the nurses or other people in the ward. Hospital staff performed their daily activities in their usual task-oriented, undistracted manner.

The vignette above shows how the hospital zone does not protect people from an incoherent flux of sensations and unexpected movements. There was always a way out of the critical situation of life and death through which individuals may be guided to gain assurance in a 'particular aspect of life and reality' (Desjarlais and Throop, 2011, p. 90), and escape the domination of the biomedical gaze. An intimate relationship involving physical or emotional intimacy in the ward shows how biopower, dominant in the hospital structure, is transformed through the local context. The nurses' use of Javanese language in the ward demonstrated a desire to establish intimacy with the patient and family, suggesting they shared feelings with them and invited them to lower their defences of Javanese formality. It was when I went out of the ward and walked down the corridor that I saw women crying at the end of the corridor and reflected that the act of crying mediates between patients and family; allowing the expression of feelings, sentiments, moods, sensations, prayers and hopes.

I returned again to Bu Sumiati and Jelita's circumstance, confronted by the ECG machine and clinicians' treatment of the patient in what was an emergency situation. Bu Sumiati lived out Jelita's chronic pain and faced the big decision of limb amputation. With the breakfast tray lying untouched beside the bed, Bu Sumiati said that Jelita had refused to eat because there was a patient undergoing emergency treatment in the room, making her feel stressed (*stress*) and disturbed (*terganggu*). The sounds and activities of doctors and nurses trying to save a patient hovering between life and death disturbed everyone in the ward. The noisy machine gave the feeling of being in a battlefield hovering between life and death.

However, as Robert Desjarlais and Jason Throop (2011) have emphasised, individuals may continually shift their attention among particular things, phrases, instruments or moments. And their movement may be patterned both by ongoing interaction with others and by imaginary and sensory experiences. The emotions, senses and spaces were part of the 'corridor' where the mutual engagement between humans and mystical beings was relatively enhanced. It is worth recalling here that when the biomedical activity took place behind the ward curtains, the emergency procedure and technology could still be seen, as the curtains could not be closed tightly. But the space between the curtain partitions was suggestive of the

metaphysical space and the ongoing intervention constructed by Javanese individuals. The curtains were intentionally left open so that light from the window could get inside window and reveal another side of life—outside the hospital world: the sky, the clouds and the sun. The everyday 'corridor' practice in the Javanese clinic is liminal but meaningful, and socially and naturally powerful.

Medical anthropologist Kevin Browne (1999) argued that when the autocratic New Order regime started to collapse in 1997 the emotional tension in narratives of (mental) illness was evidence of the underlying political tension, and resonated with how Javanese were experiencing the increasing 'modernity'. The emotional corollary of the tension was reflected in emotional outbursts (of *ngamuk* 'disorder') in order to relieve the internal distress and pressure and gain a sense of equilibrium by allowing emotions to spill over. The social and political pressures at that moment contributed to the Javanese self and identity being no longer able to suppress emotion and people became mentally unstable. High levels of poverty, a high unemployment rate and social and political instability contributed to the illness experience and emotional openness. Ferzacca (1996) argued that Javanese people were aware of and meshed in the experience of the biomedical as a 'modern' icon. Nonetheless, many patients still held onto a generic sense of being authentically Javanese (*masih Jawa asli*). Seeking paranormal encounters or traditional medicine became crucial because adopting a modern lifestyle did not fit with their sense of identity.

In my ethnographic research, I found echoes of both Frezacca and Browne's analyses. When first diagnosed at the tertiary hospital, Bu Sumiati and Jelita told me how dissatisfied they were with the biomedical pathology. Hospitalisation locates patients and families (particularly poor families for whom hospital care is an expensive option), in a situation where their own perspectives and understanding of severe illness press up against a biomedical perspective that structures activities and practices of care throughout the hospital. For Bu Sumiati, the medical analysis and recommendations for Jelita were limited. She believed that they were insufficient in understanding severe illness and impairment in Java. Nevertheless, in this 'homely place' as she described the 'corridor', Bu Sumiati felt she could live alongside the Orthopaedic specialists and the Residents, and resist their hegemonic control of the life and death situation. Like most people, she felt that she could not fully trust them and so relied on a combination of biomedical treatment (such as surgery, chemotherapy and radiation therapy) with mystical approaches. Bu Sumiati told me how she and Jelita had sought traditional health care from the *orang pintar*. Although the pain had disappeared for only three days, the therapeutic effect of the *orang pintar's* work impacted on their state of

equanimity. Jelita told me of her feeling of *ayem* when the *orang pintar* sprayed her leg with holy water and prayed over her. The practice of the *orang pintar's* intervention in the case of severe illness, impairment, and human experience was to consider the healing transformation at the level of the physical, the soul and morality. What was distinctive about the *orang pintar*'s care that made it restitutive for Bu Sumiati and Jelita was that the healing practice involved family and identified suitable days for treatment, as certain days, like Saturday, were associated with bad luck.

Orang pintar are regarded by society as wise people who derive their knowledge heavily from intuition and religious sources like the Qur'anic and Hadith texts. The fee for treatment is also negotiable as they can be paid with rice, vegetables or fruit, or perhaps a little gift exchange or barter. Respect and honour are another form of repayment or non-material compensation, and patients make sure that they thank the healer and ask for God's blessing on them. Most patients and family members shared with me their feelings that the treatment from *orang pintar* is highly important and complementary to biomedical care. Biomedical treatments are, for the Javanese, to be complemented by their faith in the *orang pintar* and God's direction. This syncretism unintentionally allows both practices of healing and care (biomedical and traditional associated with spiritual and mysticism) to coexist. The corridor provides an alternative space where such complementary practices, beliefs and values can be negotiated and practised.

4.3.1. Corridor spaces

Different from the wards that are 'clean and controlled', the hospital corridors display different and conflicting views and also bring the tensions between different world views into sharp relief for all people involved—patients, families and friends, their spiritual teachers, religious leaders, hospital staff and NGO workers. No special route in the corridor is marked off for pedestrians, visitors, patients, family, doctors, and nurses, cleaners or even corpses. The corridor is a place where these individuals participate in hospital life and routines in a way that makes the experience of severe illness and disability meaningful and even valuable (Figure 4.2).

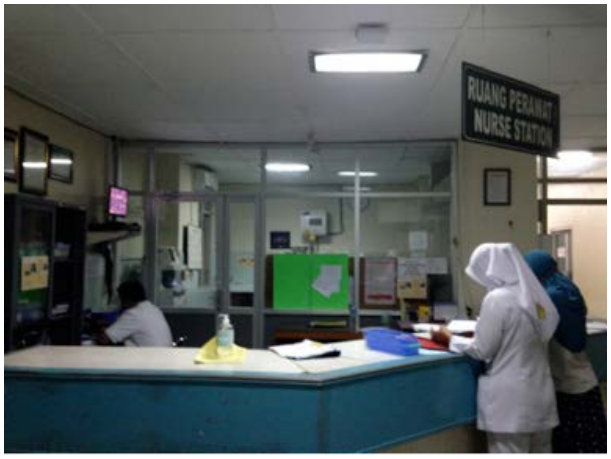

Figure 4.2. The nurse's station on the night after Jelita's surgery
Source. Photographed by author, 11 Dec. 2015

Here I illuminate how it is the hospital corridor that reflects the nature of human existence and cultural attitudes of Javaneseness (Desjarlais and Throop, 2011), assisting patients' families to deal with uncertainties—the 'blues of medical prognosis'—in the wards. I argue that the cultural values of the corridor become habitual and internalised (Bourdieu, 1977). The cultural values become natural in the corridor where an everyday sense of Javanese 'culture' is practised (Jackson, 1983). Yet, persons in the corridor are socialised by the pattern of embodiment that is not just the product of biomedical truth but the seat of agency and meaning-making in social life (Bourdieu, 1989; Csordas, 1994b; Jackson, 1983).

The pattern of social organisation is structured in the liminal space of the corridor—as Jackson (1983, p. 340) has acknowledged. I recognise this as the embodiment of being-in-the-Javanese-world, assuming a common-sense where 'self and other become one'. Put in other words, the corridors open up a path or territory that offers a safe channel for users when they see and sense confronting, intimidating technicalities while facing the terror of strange world views. The corridors thus reflect an interplay of beliefs that embody the social, moral, spiritual and physical landscape of the hospital. The architectural connectivity is an unexpected, serendipitous key to letting people navigate wellbeing—it is a space where Javanese people's persistence and resilience in finding ways of promoting the self/selves and finding (Javanese) healing can be performed.

This daily confrontation in the corridor powerfully affects anxiety, for moral aspirations are central to the meaning and values of Javanese life (Kleinman, 2006; Mulder, 1978). Given the circumstances just elaborated in the first section, I argue that while the 'corridors' exist inside the hospital structure, patients and families as well as clinicians find 'ways out' to

modify and shift toward a recovery that allows for more than just the clinical gaze. Beyond the biomedical and physical reality, there is still a potential horizon in the corridor for individuals to experience a future life that is beyond the merely physical.

The following section will show how the corridor provides a space that enables social harmony through the maintenance of the individuals' stable inner core. I argue that, in fact, the corridor is a compromise space between the material and spiritual, the inner-outer connection (*lahir-batin*) that underpins Javanese social arrangements. This space offers commonness and sacredness, equality and solidarity (Pavel, 1990; Turner, 2017) and generates social esteem and harmony (Guinness, 1986), recalling *Kejawen* practice or *Kebatinan* (Woodward, 1988, 2011).

4.3.2. Inner-outer (lahir-batin) *connection*

Mulder explains the Javanese inner-outer concept as the practice of *Kebatinan*:

> The practice of *Kebatinan* is an individual-centred endeavour that places the deep self, the 'true I' ... at the very centre of all evaluation. It is the development of *rasa* [feeling] that becomes the measuring rod of inner growth. The ultimate stage is to realize the conviction that one lives in step with life, and has access to truth in a direct, unmediated way, drawing power from 'God' while, at the same time, being independent from the source of truth outside the deep self. (1994, p. 88.)

The inner-outer struggle faced by Javanese individuals resonates along the corridors that lead to the cancer wards and back. In the corridor I not only heard discussions about the private problems of chronically ill patients, but more importantly I often saw their family turned 'upside down', confused, curious and 'all over the place'. Their composure, the balance between what they outwardly expressed and experienced and how they inwardly felt and were, was thrown out of balance, and they no longer saw the means to reconstitute their balanced world. As Mulder explained:

> The practice of *Kebatinan* is the quest for communication with ultimate reality; as a branch of knowledge, it studies man's [*sic*] place on earth and in the cosmic. It is based on conviction of the essential oneness of all existence. The position of *Kebatinan* is therefore more encompassing than the position of Islam and Christianity that differentiate between the realms of God and of man. *Kebatinan* mysticism views human existence in a cosmological context, making life itself a religious experience. (1978, p. 20.)

When the scientific biomedical mechanism confuses the inner-self, then the individual's sense of self resists the normative biomedical power by subverting it in different ways. Judith Butler in her book *Gender Trouble* refers to this as subversive resistance. She contends that individuals are not determined by the generated power because normalisation is

not a founding act (1990, p. 185). What produces the self are repetitive norms. In accommodating the repetitive norms, the corridors enable the discipline of the hospital to be resisted but not rejected; rather, in the corridors people are brought into a meaningful and emotionally and morally satisfying relationship of complementarity.

For Bu Sumiati, the medical analysis and recommendations for Jelita were limited. She believed that they were insufficient for understanding severe illness and impairment in Java. Nevertheless, her position was one of *nrimo* or *menerima dengan ikhlas* and *syukur* as she described the 'corridor'. She could accept this struggle by putting her trust ultimately in spiritual mediators such as a *kyai* (religious leader), *orang pintar*, or *saman* (paranormal). In contrast with both Anas and Jelita's family, Ahmad did not seek treatment from either *orang pintar* or *kyai* but relied on Dr Agus to handle his illness when he was diagnosed with osteosarcoma in 2009. His education and internalisation of Western views—higher than that of either Jelita or Anas—may have extended Ahmad's ability to pursue the option of biomedical care in a private hospital. But his spiritual beliefs still played a part in his persistence in seeking help from Dr Agus. Ahmad said that there was little he could do other than hold the connection between *lahir-batin* (outer-inner) and try to be what he called *legowo* (feel unattached to materiality) and *sabar* (patient). His self-surrender in being *legowo* took the *Kebatinan* practice into his life. The *Kebatinan* was enacted in surrendering himself to 'God' (Mulder, 1998). So, for those families like those of Ahmad, Anas and Jelita, I argue that the *orang pintar* was their 'guide and messenger' and he carried the *Kebatinan* practice and spirituality as their core reference in the way Mattingly noted doctors are, by and large, trusted by 'white patients' in the USA (2010, p. 154). The *orang pintar* is not seen as an alternate to a biomedical clinician, but as an expert in a very different domain, contextualising the physical ailments within a spiritual realm of practice.

From these and many similar encounters I found that patients and their families, aided by other patients and their families in the intimate and social environment of the corridor, shared information and helped one another in what was ostensibly the domain and responsibility of hospital staff—nurses, social workers, paramedics, doctors and radiologists. The hospital in its clinical setting is the place of individuals' *lahir* presentation, but the corridor allows them to explore deeper within themselves (Mulder, 1994, p. 62). Thus the corridor accommodates this socio-cultural pattern that is maintained within Javanese values and priorities. Socially, the moral task of individual members lies in the securing of harmonious order by both securing balance within their individual *batin* and faithfully nurturing their social contacts (ibid., p. 45). Various social approaches like *rukun* or *tepo*

seliro function as hybrid and intimate family expressions and when practised in the 'corridor', enable them to help one another.

Javanese world views reflect on persons with chronic illness or disfigured bodies by linking their circumstances to the embodiment of religious beliefs and social norms. Javanese take the view that people have an obligation to fulfil God's order and respond to social demands based on customary religious and social norms. Amidst difficulties and/or contentment about a medical prognosis, Javanese would say God's scenario is beautiful, and they would ask who can stand against Allah's will. No-one! They also subscribe to a belief in the power of fate/resignation (*nasib* or *takdir*) and chance or trial (*cobaan*). People's submission in this sense means that the experience of severe illness and bodily impairment demands the transformation of the soul and the reconstitution of the moral self and society. The biomedical skill reconstructs the patient body through technology.

When the ECG machine bipped, I increasingly sensed a sort of stillness of heart and mind brought about by the machine helping the emergency patient; this feeling was not one of nothingness but a rich space. The battles of silence in the ward were attempts to explain it. This is a kind of Javanese life regardless of what Foucault (1976) said about technology as controlling. Rather, the silence was agentive and enacted. The inner-self or *batin* expressed in silence was one of the key individual Javanese explorations of mystical involvement as well as resignation and submission. Yet, every individual has their own slot and path in life that has been designated (by God) and no-one can resist it (Magnis-Suseno, 1997).

It is for this reason that I found that patients, and family and people around them will often respond to some positive accomplishment or outcome by saying, 'It was a trial and this is his/her fate' (*ini adalah cobaan dan sudah menjadi nasib/takdirnya*) or by expressing gratitude for God's blessings (*syukur, anugerah*). Having said that, these embodied beliefs in understanding world views related to severe illness, health and personhood create social meaning and value (Kleinman, 1988; Woodward, 2011).

Pak Raminto was treated in the cancer ward situated just to the left of Jelita's ward. A 50-year-old, tiny legless patient lying down, he was accompanied by two older women—his aunt and mother. Standing beside him, they told me that the amputation of Pak Raminto's left leg had been performed earlier that month. They had returned to Sardjito Hospital because Pak Raminto continued having fevers and the tumour on his amputated groin had grown bigger. 'It's been nineteen days here after being treated in the district hospital for six days', his mother explained to me. 'Please sit down here', a masked woman from the neighbouring ward said, offering me the stool beside his bed. Other members of patients' families were

standing nearby the window on the other side of the ward—some with masks, others without. On the side table, I saw a small Qur'an while on the floor coffee powder had been spread under Pak Raminto's bed. 'Now the lump of tumour has been covered by a diaper', a woman near the window said to me while his mother and aunt remained silent. I then understood why the coffee powder had been spread around by the neighbour—it was to remove the ghastly smell from the tumour so that the odour did not spread through the entire ward.

Suddenly, my attention went back to Pak Raminto who was shouting, his sorrow-filled eyes looking up to the ceiling. He kept asking to be fanned and was moaning in pain, 'Mum (*biyung*) … I want to pee Mum … ehhhhe ...' I saw his mother take a small bucket and an empty used plastic mineral water bottle confidently. She put the bottle between his thighs, put his penis in the bottle and then Pak Raminto urinated. 'I couldn't see any pot or anything that can be used by patients for urinating, only a small bottle,' she said. After he finished urinating, his mother took the bottle to the shared toilet outside the ward and flushed it away. When I asked what other treatment was planned for Pak Raminto, the two old women looked confused and uncertain. After a moment, the aunty said definitely '*di-kemo*' (chemotherapy). His mum added that, according to the nurses, she had to provide two bags of blood to lower his fever. 'I don't know how to get blood in this hospital, so I made a call to Purworejo[2] to his wife and grandson telling them that we had to provide two bags of blood tomorrow,' she said in Javanese. 'His blood pressure is still very low, thus chemotherapy could not be performed,' a family member of another patient next to Pak Raminto explained to me courteously. He began telling me about Pak Raminto from behind the curtain, and then came out offering a chair and seemed to want me to be sitting in the 'proper' place. I saw that families of other patients in the ward also helped when Pak Raminto's family became overwhelmed by the grievances and pain of Pak Raminto. In this critical moment, other families' patience showed a moral structure in maintaining group solidarity and their obligation to help others (Mulder, 1978, p. 45).

Pak Raminto's mother patiently gave him whatever he asked such as rubbing his stomach with eucalyptus oil or just massaging him gently. Her uncomplaining demeanour suggested equanimity according to Javanese ethics. 'I just arrived this afternoon relieving my daughter-in-law and grandson,' she explained. Not long after that, a nurse came in with afternoon snacks, warm tea and cakes. There was no change in the atmosphere as the nurse

[2] A city located 90 minutes by public transport to the west of Yogyakarta.

came in—no sense of urgency or worry about the situation in the room, even though Pak Raminto kept moaning and babbling due to his pain. For the sake of equanimity (*ayem*), those who grow up as the subordinate or weaker group 'off stage' their true feelings. There is not much room left for individual free expression, will and emotion in the Javanese value system (Mulder, 1978). So, controlling anger, aggression, panic or anxiety was the way that Javanese maintained their inner self. The Javanese individual's gesture of being *rumongso* and *nrimo* (being self-reflective and accepting of suffering) ideologically maintained the morale of the subordinate group and regarded the *life as it is* or *life as such* (Fassin, 2009). So, although some people were not practising religious rules explicitly, the attitude of *nrimo* (acceptance) signified an important religious dimension in responding to severe illness, bodily impairment and even death.

'Paracetamol, Mum … I want paracetamol, Mum.' Pak Raminto's aunt and mother looked nervous and uncertain about what to do until a young man told Pak Raminto's aunt to press the nurse call button. 'Yes, how can I help you, Sir?' the voice from the speaker echoed. Pak Raminto shouted, 'I want paracetamol!' The patient next to him also shouted to the speaker from behind the curtain 'Pak Raminto has a fever!' A few minutes later a nurse came to check and promised to return with paracetamol. She came back with the tablets and I noticed the nurse's face expressed no sense of urgency, no particular concern as she went about her duties. This ideal of concealing emotions was one among many refinements of Javanese society (Mulder, 1978).

Pak Raminto's experience made it clear to me that the corridor often provided more than an imagined sense of *communitas*. The relatives and friends of patients often took it upon themselves to assist patients and hospital staff in both small and more significant ways, as noted above. The corridor spilled into the wards and the community assumed the duties and responsibilities of care that might be assumed to be strictly the work of hospital personnel. There was a flow between the corridor and the wards, and between the hospital staff and the informal community gathered in the corridors. The flow of help—for busy staff as much as patients—reinforced the corridor society's sense of its own identity and value and showed that established social norms and practices of offering help and care seeped into the routines and life of the wards. The profound nature of social interaction had its own mystical discipline or what Didier Fassin (2009, p. 47–48) calls the human association with 'the universal organization of matter' and with the 'experience of individual human beings'—the social demands and cosmic order (Mulder, 1998).

Pak Raminto's story shows that whenever biomedical hardship is at stake, every individual holds onto Javanese social values and in the hospital context these values become remade as a kind of 'technology'. The Javanese individual's eagerness to perpetuate a harmonious totality shapes social interaction.

On the day when the ECG machine beeped in Jelita's ward, I sensed stillness in people's verbal expressions in the ward that resembled the Javanese view of submission to *nasib/takdir* (resignation) the veneration of sacredness and the attraction of *Kebatinan*. In the Javanese view, every individual has their own slot and path in life, such as illness experience, calamity, disaster and death, that has been designated (by God) and nobody can resist it (Magnis-Suseno, 1997). In this context, silence reflects *Kebatinan* and is one of the key individual Javanese means for inner-self immersion towards resignation and submission.

I observed that the meaning and values practised in the corridor represent significant elements of Javanese healing. These meanings and values confirm the diffusion of ritual into both medical knowledge and cosmology that re-emerges into the sense of equanimity (Guinness, 1986; Kleinman, 1988; Pylypa, 1998; Woodward, 2011). As Bu Sumiati often expressed, silence reflects *Kebatinan*—one of the key individual Javanese explorations of the inner-self and mystical submission to God. The growth of the inner self, which is manifest in a sense of resignation, emerges as a state of belief that one's 'arrangements' (birth, economic status, social class and geographical location) are the result of God's will (C. Geertz, 1960; Magnis-Suseno, 1997). In other words, against the backdrop of a sober medical prognosis, a life-threatening condition and even death, most patients' families believe that they should endure these by connecting with the inner (*batin*) as the path for respecting the cosmic order—the connection between *lahir* (outer) and *batin* (inner). Thus, it seems that the ritual pattern of the corridor reveals that patients and their families are probing for points of relief and reconstitution in the domain of constant biomedical pressure (Scott, 2015). In silence, the individual is self-sufficient, developing their *batin* as their stable inner course of 'self-normalisation'. Put in other words, the individual body in the corridor exists at an intersection point from which various embedded factors—social, tradition, spiritual and material—are transacted (Desjarlais and Throop, 2011, p. 89).

4.3.3. Communitas

In the corridor social interaction occurs as a result of the presence of other people visiting family members and neighbours. The social interactions that take place transform the corridor into a place of home; conversations are conducted in Javanese rather than Indonesian or

medical jargon, people sit around talking or napping, sharing food, taking calls, making calls. All of these interactions and activities brought into the corridor create the imagined space of *communitas* for patients where everyone is in harmony. What takes place in the corridor connects the individual body with the logic of social life or communality, even while it is more personal and mediated in nature. The activity on the Javanese hospital corridor shows the anti-structural elements of the society, positing them as the space of harmony and recreating social manners in a new structural form (Guinness, 1986; Turner, 2017).

Corridor is filled with sense of relaxing and ‘peaceful aura’. We might say the corridor facilitates the maintenance of *communitas* and non-hierarchy by wrapping the patient in a relatively structured society based on relations of harmony (*rukun*) (Guinness, 1986; Turner, 2017). I participated several times in visits by neighbourhood groups of women and neighbourhood leaders (RT/RW) in areas where my informants with cancer lived. After amputation, the body is something else—the standardised procedures put Jelita on a road to recovery, but the medical solution performed in the hospital made her a ‘non-standard’ body in the social and ‘moral’ hierarchy that most Javanese still hold onto. Yet, in hospitals in Java, the lively corridor outside the ward reminds patients of a wider social reality and their place in a known social context, helping them achieve a feeling of *keselarasan sosial* (social harmony). In this sense, I have taken a slightly different angle on *communitas* than that presented by Turner (2017), who emphasises the way festival and play can create the sense of belonging. Rather, I look at *communitas* as the twilight moment when there is a space for the imagination and veneration of social relations during times of uncertainty such as when biomedical care projects vulnerable individuals into an alienated position and makes them anxious, even desperate (Figure 4.3).

Figure 4.3. Peer support on the day of Jelita's surgery
Source. Photographed by author, 11 Dec. 2015

Javanese women are leading actors in communal life, initiatives and actions (Pitaloka, 2014). Once they hear news of those who have experienced misfortune, they will organise themselves for hospital visits (Figure 4.4). They usually borrow a seven-seater car or truck, or rent a shuttle bus. Everyone will contribute some money to pay for the rental car, or slip money into a small white envelope and give it to the patient or their family. However, the money contribution is not as important as their visit in person. If there is one who is absent, then he/she might receive some form of 'social sanction', as villagers put it to me. The principle here is one of reciprocity; one should go to visit sick people so that they will assist you in times of trouble. With coordination by the village leaders (RT/RW) or religious leader, village groups visit community members who are hospitalised, and the corridor may accommodate a large number of visitors.

Figure 4.4. Neighbours visit a patient in the hospital
Source. Photographed by author, 17 Sept. 2015

In the following incident, what I describe shows how the corridor reaches into and takes charge of one element of routine medical practice and integrates it into the social structure—the Javanese belief system. The events described concern the disposal of Anas's and Jelita's amputed limbs. Anas' amputated limb was cleaned by Anas' father, Pak Dirman, in the hospital. He was helped by his neighbour and accompanied by Anas' friends who were curious to know what was going on.

On the day of Jelita's amputation, Bu Sumiati's husband arrived in the corridor (Figure 4.5). 'Pak Sidik has been at home preparing a coffin for the amputated leg,' Bu Sumiati mentioned to me gently. In the corner of the corridor I saw the wooden box that Pak Sidik had made especially for the amputated leg (Figure 4.6). It was exactly like a small coffin, made from good quality wood, well painted with a natural colour. In contrast to the medical expression of discarding *buang* the leg as if it were rubbish, Javanese respect the amputated leg and bury it in a funeral ritual, like that performed when a living person dies.

Figure 4.5. Selfie pose by Jelita's father in the corridor, while waitingfor his daughter in the surgery theatre

Source. Photographed by author, 11 Dec. 2015

Figure 4.6. The leg's coffin (wrapped up) in the corner of corridor

Source. Photographed by author, 11 Dec. 2015

Before the amputation was performed, Bu Sumiati and Pak Sidik had called the *modin*, the official religious specialist in the village. Once they received the amputated leg it was bathed in the front yard. This ritual was simpler than the burial for a corpse which requires three different kinds of water for bathing; the amputated leg was washed with only pure water. As in Javanese funerals (*lajatan*), the 'dead' leg was put in the small coffin and buried as soon as possible. I noticed that the amputated leg was the subject of ritual under the direction of the *modin*, like a body in the context of a funeral. Pak Sidik washed the leg and then wrapped it in white muslin and, under the *modin*'s guidance, tied it in three places like a person (feet, waist, and top). Several *santri*, relatives and neighbours in the village began to chant a *surah* from the Qur'an under the direction of the *modin*.

The performance of a funeral for the amputated leg was an exit transition from social suffering, a ceremony designed to obtain blessing or the 'Javanese healing' of *syukur* and *ayem* (equanimity). Additionally, the *slametan* that accompanies the funeral is a social ritual that incorporates the individual into a wider group of social support—and the connection between the social and the mystical cosmic order (Guinness, 1986; Mulder, 1998; Woodward, 2011). As in the funeral for a body, the leg funeral is a Javanese ritual associated with *lajatan* or *syukuran* or *slametan* that is partly aimed at obtaining a sense of social stability. *Slamet* is a term referring to a blessing in Java that is derived from the Qur'anic term, *salam,* which, in the Sufi tradition, signifies peace, tranquillity and blessing (Woodward, 1988). Geertz identified the *slametan* in Java as the core ritual in response to any event individuals may wish to celebrate, sanctify or bless (1960, p. 11). He said furthermore:

> The slametan forms a kind of social universal joint, fitting the various aspects of social life and individuals' experience together in a way which minimizes uncertainty, tension, and conflict—or at least it is supposed to do so.(ibid., p. 11.)

The experience of severe illness resulting in the amputation of a limb is perceived as a catastrophic event or, as Bu Sumiati puts it, doomsday '*kiamat*'—an out-of-the-normal situation or lack of balance. During life's trajectory, the experience of illness is considered to be a period of disorder in which one's situation is no longer normal or harmonious. *Syukur* is then expressed through a *slametan* ritual in order to re-establish social harmony and inner peace of mind. We may consider the *syukur* or *slametan* to be plotted on the continuum of uncertainties in the drama of life and see it as a space for social negotiation. As the disfigured body may lead to social disrepute or shame, in this context the *slametan* resembles a kind of symbolic negotiation by individuals' households towards acquiring community respect and re-establishing balance. It is a transition or exit from the random interruptions that disrupt social harmony (Guinness, 1986; Kleinman, 2006). So, as a Javanese rite, *lajatan* (the funeral *slametan*) is seen as establishing balance by returning the situation to cosmic order.

Furthermore, the leg funeral points to a social space where spiritual blessing can be experienced. The space accommodates senses of *blessedness* and *divine protection* whereby the *modin* and attendants utter *dhikr* (repetitive prayers) ensuring the blessing of the patient and the serenity of the buried body part. Pak Dirman explained to me the ritual meaning surrounding the funeral for Anas' leg. He said:

> How should I say it? It is a respect. It is part of the body given by God. We should not treat it [amputated leg] disrespectfully by just burying it. That's the reason that motivated me. It was

> Anas' leg and used to be useful. How can we abandon it? We couldn't just bury it. We took care of it, cleaned it and buried it properly. We treated it respectfully because the leg used to be very useful for my son. I don't know how to call it [*slametan*]; at that time, I just thought that this leg used to be useful for Anas. Therefore, I pay it back by taking good care of it. That's it.
>
> After the amputation, I met the doctor on duty because I could not meet the doctor [surgeon]. Then, I met the doctor in the ward. 'Doc, if I leave the amputated leg in the hospital, will it be useful for research here?' 'No, it won't be [useful]', the docter said. [From the doctor's explanation, he assumes that it was not going to be washed. He said, probably based on the information from the doctor, the amputated leg will be buried immediately. It might be buried just like that without being cleaned]. 'I'd better take it home, clean it up and bury it'. I used the morgue in the Sardjito Hospital. I washed the amputated leg thoroughly, wrapped it with white cotton cloth and buried it in the family graveyard. [The only one who helped him wash it was his friend or neighbour]. 'He has been my friend since senior high school until now and he has been like family. Thus, he also felt what I felt. He helped me clean up the leg' [in the clinic]. (Interview with Pak Dirman, 10 Jan. 2016.)

Through the clinical gaze, the dead limb is seen as a diseased body part and a disfunctional part of the anatomy. But these notions are in contrast with the Javanese ethic that seeks to construct illusion, feeling (*rasa*) and social instinct to reconstitute the material object and respect it as a living being (Mulder, 1978, 1986). The Javanese world view is essentially animistic, focusing on spiritual unity with the ultimate essence as superior to the material dimension (ibid.). As Mulder puts it, 'Harmony and unity with the ultimate essence is the purpose of all Javanese life, and fosters a devaluation of the material objects of existence' (1978, p. 17).

Figure 4.7. Leg's funeral after surgery, 2010

Source. Anas' photograph, published with his kind permission.

Figure 4.8. The prayer for the buried leg, public cemetery, 2010
Source. Anas' photograph, published with his kind permission

The Anas family lived in an urban *kampung* in the Keraton sub-district where the *slametan* followed *Kejawen* practice. The neighbourhood's living character in the urban *kampung* is considered as one of Indonesia's largest organizations, Muhamadiyah. But Anas told me that he is Gusdurian's fan—the follower of a leading Islamic organization of NU (Nahdlatul Ulama) figure. Anas' father used to work as an ambulance driver at Muhamadiyah Hospital but dropped the job from the time Anas was diagnosed with osteosarcoma—he did not have time to work as Anas's treatment required his involvement and care. Anas's mother continued working in the *Gedung Agung* (Presidential Palace) as a civil servant. For Pak Dirman and family, the leg funeral was an expression of respect for the leg—a practice that re-established self-esteem, social equanimity and the mystical divine.

The *slametan* ritual involves mystical elements associated with Javanese religion, which according to Woodward (1988, 2011) is a 'synthesis culture'—comprising animism predominantly, but also Hinduism, Buddhism and Islam. Yet, the practice of the leg funeral *slametan* was the embodiment of the synthesis I identify as 'dwelling in the corridors'. The *slametan* signifies an important spiritual power as it offers healing. In Java, becoming healthy requires a harmonious feeling of *ayem* (equanimity) cultivated from the embodiment of both physical and spiritual realms. So, the burial of the leg, mirroring well-established funeral rites conducted to mark individual death, was seen as restorative, a way of maintaining spirit and inner peace of mind. Anas had undergone amputation surgery six years previously and he told me about his routine of visiting his leg buried in the family's cemetery. With a picture of him between the gravestones he updated his status on Facebook, writing, 'Here I visit my leg

who is currently playing with my ancestor'. This remarkable respect in visiting his leg's grave and those of his ancestors demonstrated the Javanese engagement with mystical living, as a spiritual objective superior to physical practices.

The ritual of burying the amputated leg showed that Javanese behaviour focuses not only on achieving mystical, moral and spiritual thought, but also harmony with the social and cosmic order. So, it was crucial for Anas' family to practise the ritual in order to not only participate in the supernatural realm and co-ordinate their spiritual disposition, but also to enact social negotiation. In *Kejawen* divination, the mystical path works for the soul while the *slametan* is performed for the reason of socialisation (Woodward, 2011). Although the leg funeral *slametan* only involved family, relatives, close friends and neighbours, its purpose was similar: to express *syukur, anugerah* (thankfulness and blessings) to God, and to achieve a state of *slamet* (safety, balance, tranquillity, and order) (C. Geertz, 1960). Anas responded to the loss of his limb by expressing *syukur* (blessing) for his *slamet* (safety or survival). By comparing the condition of other patients who were considered even more chronic, most informants sought to maintain spirit and hoped to be blessed with survival or were grateful for their survival; so, the point was that they should be grateful regardless of their condition. Anas furthermore told me in this way:

> I give thanks to God [*bersyukur*], as I am now still alive. [To feel] blessing is a weapon to reverse the fact [of loss]. Losing a leg is something big in my life. Because I give thanks and accept [*ikhlas*] this life with only one leg … Praise to the Lord [Alhamdulillah] Allah has given me a way forward.
>
> Yet I always reverse the fact [view the loss as gain]. Since I have been a difable, I have this high emotion [*emosi yang tinggi*], positive emotion. The positive emotion that has brought me to something good. (In-depth interview with Anas, 10 Apr. 2015.)

The discourses of giving thanks (*syukur* and *anugerah)* and acceptance (*nrimo*, *menerima dengan ikhlas*) are replete with the politics of life, a subversive Javanese cultural trait, rather than a life under discipline and moral surveillance. Being *ikhlas* is reflected in an individual sincerity of purpose, ignoring egocentric motives and placing the interests of others before personal intentions (Mulder, 1998, p. 15). Yet, my research stresses the importance of these embodied idioms in the minds of some Javanese in Yogyakarta as a response to health development and modernisation. The idiom of giving thanks and acceptance reflect the imperative to conceal internal suffering and anxiety while striving for a sense of equilibrium. These Javanese elements were made compatible with the biomedical gaze in the corridor (physically and metaphorically) and show how human experiences of

severe illness and disability reflect the interactions of biomedical, social and spiritual beliefs within the community who provided the care.

4.4. Conclusion

Hospitals in Java require corridors where lay people enact seemingly ordinary but very valuable and potent healing roles. It is a space that culturally offers mixed settings where scientific medical perspectives are intertwined with traditional ideas of Javanese moral life and where emotional efficacy reflects social interaction—the notion of the inner-self, and mystical involvement. Patient and family interactions and relations in corridors open up a way of seeking hope when biomedical practices reach their limit, for example, in cases where patients endure disabling accidents, terminal organ failure, physical and mental disability, end-stage neuro-degenerative diagnoses or the end-of-life stage.

The corridor enables patients and their families to survive and recover from the clinical prison. Dwelling in the corridor signifies the important parts of being Javanese (self/selves) through the recognition that both *batin* and community are as important as physical surgery and biomedical diagnosis. The corridors of the hospital are far from being just architectural spaces used to facilitate movement. These are convergent spaces where the tensions of divergent world views and perspectives on healing may be resolved in different ways. The corridors have been shown to be spaces of community, shared care and healing, and mystical practices which assist patients and families reconcile feelings of profound worry, even despair, with Javanese values and beliefs about balance in life and fate.

Thus, I argue that the ‘corridor’ can be characterised as a ‘synchronic moment’ (Sewell, 1999, pp. 39–42), where the intertwined practices of biomedicine and Javanese beliefs and values mutually sustain each other as an integrated whole. The embodied culture takes place in the corridor, revealing a distinctly Javanese texture in relation to selfhood—the bodily aspects of human beings and subjectivity. I contend that Kleinman’s point (2006) about culture can be understood here as a reminder of how three Javanese cultural constructs are lived out in the corridors—the concept of inner-outer (*lahir-batin*) in individuals’ lives, the profound importance of social relations, and the management of social suffering such as dying and death. They point to how important the ‘corridor’ is in the process of Javanese healing. These three Javanese cultural constructs provide culturally mixed settings where traditional ideas of Javanese moral/emotional efficacy are intertwined in a social, mystical and scientific medical nexus. The corridor is an intermediate space where practices and roles are ambiguous—betwixt and between. In fact, I have come to understand the corridor as the

means by which life is made meaningful, and where the individual embodies their own moral commitment, ethics and their own sense of right and wrong (Kleinman, 2006).

The corridor described here as a dynamic, complex interactional space takes Foucault's (1976, 1977) work in a different direction. It is not merely social expression and spiritual development that are assembled like a symphony, brought together into a hierarchical and harmonious state. Spiritual development through mysticism is blended with all other elements and resembles every individual inevitably sharing in the unity of existence. All of these elements are enabled by the 'corridor space', which mediates the all-encompassing unity of physical, social and mystical beings. Following from Foucault's concept of compliance with the hospital gaze, this thesis reflects the politics of life as not the way governmentality works or the way that people further build the power of a regime, but about the negotiation of meaning and values. As Fassin has written:

> Alternative paths would refer to life as the course of events which occurs from birth to death, which can be shortened by political or structural violence, which can be prolonged by health and social policies, which gives place to cultural interpretations and moral decisions, which may be told or written—life which is lived through a body (not only through cells) and as a society (not only as species) (2009, p. 48.)

With a focus on poor Javanese who regulate themselves through micro subversive practices (Fassin, 2009; Pylypa, 1998), I argue that the all-encompassing gaze of power springs from the ward and oppresses patients' and families' bodies and social interactions and spiritual relations. However, the social and spiritual values constructed in the corridor continue to create the sense of a healing ritual, which is complementary to the regime of biopower—rebuilding not only the individual self but the harmony of the social whole.

Chapter 5
The Clinicians' Corridor: Caring and the Building of Trust

5.1. Introduction

This chapter examines practices of delivering health care at the public referral hospital in Yogyakarta. My focus is on the embodied social and cultural context that is embedded in medical care delivery. The experience of caring provides a foundation—for some, and not necessarily all the time—for the production of medical knowledge (B. J. Good and Good, 1993; Kleinman, 1981, 1988). The *ilmu kedokteran* (Western biomedical knowledge) and the clinical staff are state apparatuses that have been discussed in scholarly literature in relation to their focus on *kondisi klinis,* 'the clinical condition' (Foucault, 2012). The *kondisi klinis* perceives that patients experience illness as part of human biology rather than as a sociocultural production of human suffering (B. J. Good and Good, 1993). As Cheryl Mattingly explains:

> The body becomes a thing apart from how it is given human (or cosmological) significance. In Western society generally, the rational and instrumental, in which medicine is squarely placed, are separated from the symbolic, the affective, the spiritual, and the social. (2009, p. 566.)

The internal structures of social power and the hegemonic state support *ilmu kedokteran*. Nevertheless, health professionals enjoy a Javaneseness that sometimes articulates a lack of hierarchical assumptions and structures. These are the moments that I reconstruct as health professionals bring the 'corridor' into their clinical manoeuvres and care; as an additional mode of building medical truth. Mattingly's research was conducted in the urban hospitals of California where popular-culture stories of American cartoon heroes presented an unexpected dimension of patient care. Culture helped overcome the frightening and embattled relations between cancer patients and family and the healer, and thus allowed them to build optimism and hope together (Mattingly, 1994, 2010). Mattingly (1994) calls the process 'therapeutic emplotment' which points to a concrete interaction between the healer and children with cancer and their families in creating the moral meaning of any story during the blues of medical prognosis. The affective reaction experienced by the clinician, patient and family generated an optimistic expectation of recovery, in spite of the knowledge that cancer cells may travel quickly through the body's blood and lymphatic systems. In reference to the scholarly arguments presented by Foucault (1976, 2012), Mattingly (2010) argued that popular culture may be understood as an early stage of diffused power—the affective life is an active power that builds up biomedical structures. Moral discernment is the productive

power of hope (Foucault, 1976) that penetrates through local culture. Mattingly noted that cartoon narratives bridged communication between healer and sufferer and created a shared cosmos across race, class and professionalism (1994, 2010). The imagined Hollywood heroes shifted patients and families away from gloomy realities into a state of superficial courage and social dramas (Mattingly, 2010, p. 217).

In contrast, in what follows I capture how clinicians in hospital draw upon cultural resources in trying to provide treatment that ordinary people care about as well as continue the routines of their professional obligations (See Figure 5.1). I suggest that the care relationship between doctors and their poor patients and families reflects a habitual and performative representation of human living and being. Javanese personhood emphasising *rasa* (affective)—the inner self, mysticism and the spiritual dimension as well as social connection—rests alongside the *ilmu kedokteran*. The affective life in the clinic shapes individuals' thoughts and care practices which, in turn, become internalised as habitus and activism. By 'habitus' I refer to a certain mindset and disposition that enables clinicians to make sense of both the clinical and the social world (Bourdieu, 1977, 1984).

Figure 5.1. Showing the nurses who were organising to send Jelita to the surgery theatre, dealing with routine administrative procedures in the nurses' station while keeping Jelita on the trolley in the corridor
Source. Photographed by author, 2015

So, the merging of *ilmu kedokteran* and Javanese moral and spiritual knowledge represented in the complex integration of different perspectives on 'normalisation' is not the same as the practices of state discipline that Foucault described (1976). What I observed in the urban hospital in Yogyakarta is a practice of clinicians who merge spiritual beliefs, mysticism and belief in God alongside the *kondisi klinis*— the 'pathological gaze'. Here I use

the metaphor of the corridor to signify a space where the two merge as muddled and unseparated entities. I observed the corridor as an integration of the *kondisi klinis* 'pathological gaze' with Javanese social caring practices—making a corridor 'moment' a communication pathway to patients and family.

My ethnographic data show the embodied nature of cultural Javaneseness in the practice of care. In the eyes of Javanese, caring links with the idea of personhood and so that is how I attempt to unpack the meanings and values of clinicians' care in the two sections that structure this chapter. First, I look at the reinforcement of global nationalism in which embodied values illustrate the intersection of both state power and cosmology (Connerton, 1989; Foucault, 1977). Recruiting spirits into clinical spaces illustrates how a synthesis of biomedical and Javanese culture in the urban Javanese hospital reconfigures the ambiguity of the state's either repressive or normalising power. I argue that care delivery in the Javanese hospital reconfigures the power of life in sacred ways and conveys a divine spirit into the healing of the 'whole person'.

Second, I explore how these embedded cultures narratively practised by clinicians in the 'corridor' bridge the gap, especially in the interactions between clinicians and patients with osteosarcoma resulting in limb loss and their families. I observe that the hospital world absorbs Javanese cultural symbols and signifies mysticism or beliefs that moderate biomedical superiority as the only form of power accumulation or perhaps habitus (Bourdieu, 1977; Csordas, 1994b). Health professionals create a shared imaginative space across socio-economic class and, even more, bridge the gap between sufferer and healer as a mode of communication (Mattingly, 1994, 2010). Through the use of local language and observations of everyday life in the clinic this **'**meeting in the corridor' attempts to understand the 'accumulated power' that most clinicians employ in building trust. In other words, in this section I explore an embodied moral narrative in clinics in which some clinicians recognise other authoritative knowledge apart from *ilmu kedokteran*. In response to modernisation, clinicians experience the effectiveness of the 'corridor'—cultivating spiritual discipline, remaking a local (mystical) world and constructing a profound social dimension to health care delivery. Indeed, it is this distinctive mix of knowledges that can be shown to be most important in shaping the everyday experience of care in the 'Javanese world'.

5.2. God's will: Recruiting spirits into clinical life

The embodied mysticism of God's will and spirituality in clinical practice has become a buzzword in biomedical care in Java (Ferzacca, 1996; Woodward, 2011). Represented in

clinical life, I see this phenomenon as a construction of the Javanese-self in search of a more powerful symbol for engaging with the space of being-in-the world (Csordas, 1994b, p. 287; Mulder, 1994) and as individuals responding to the outer world (Hallowell, 1955). The embodied elements of Javanese mysticism, the rituals of *ilmu kedokteran,* and the mythological characters discussed below exemplify an ambiguity—the merging of global knowledge and practice, local tradition and the spirit of nationalism that Benedict Anderson (2006) called the 'imagined community' of Indonesian citizens. Such senses and images represent a structuring of the hospital in particular ways—where devotion, care, mysticism, and holiness all combine to create an unconscious agreement about a society (Bourdieu, 1984, p. 77; Csordas, 1994b).

One Monday morning at the end of November 2015, I visited Jelita and her mother, Bu Sumiati, in the cancer ward at Sardjito Hospital. It was the annual celebration of KORPRI (Public Servant Corps) and this involved most clinicians. As I walked to the unusually crowded courtyard of the outpatients' building, I could faintly hear the national anthem titled *Padamu Negeri* (literally meaning 'to you my country'), which became clearer the closer I drew to the building. A banner to commemorate KORPRI day had been fixed to the entrance gate of the parking area at the hospital. It represented the state's expression of hopes and promises to improve the health service: 'By strengthening neutrality and professionalism, KORPRI is ready to achieve the *Nawa Citra* program of the realisation of public service and social welfare through *ayo kerj*a [let's work]'. The national anthem represents devotion to the nation state, while the patriotic musical composition of the song evokes Indonesian history, national identity, and the heroic struggle of the people against Dutch colonialism in the past.

Biopower is levied in delicate modes, including desire, instinct, affect, symbols and mysticism that people may accept together as their own cultural 'knowledge'. Historians of medicine have demonstrated the disorganised flow of the process of medicalisation in Southeast Asia—specifically in understanding illness and bodies that reveal the very difficult processes at play in the local world (Pols et al., 2017). Such difficulty is derived from the wide range of disorganised and disorganising historical forces in politics and political economy that have transformed individuals' moral lives (Kleinman, 2006) and shaped the spiritual aura of hospital settings (Mattingly, 2010, 2018). Thus, the element of spirituality can have considerable productive influence as evidenced by the way it accompanies biopower.

I argue that the knowledges of tradition through cultural and historical diffusion play out in the practices of hospitals. Biopower derived from Western-teaching operates to ensure

the implementation of *ilmu kedokteran* within an embodied matrix of well-known Javanese norms and practices. Both biomedical techniques and Javanese ownership of knowledge—ethics and desire related to personhood—are bound up into a form of 'habitual aura'. In other words, Javanese norms and morality surround clinical practices and more medically constructed care, while habitus sets the mental disposition of particular clinicians towards rationalising health care delivery in more 'local' and 'acceptable' ways for both sides. For example, a hospital administration may organise various opportunities to contact the spiritual world through the conduct of *slametan* rituals to celebrate such events as national day, anniversary day or any event associated with the Islamic calendar. It is these ritual forms which are constitutive of an internalised habitus (Bourdieu, 1989) for participating in the cosmic order and demonstrating respect to the ancestors or to God's will.

Figure 5.2. The *selametan* ritual in 1925 that used a goat's head on the new surgery bed. The ritual was held in a Stovia teaching hospital, C.B.Z. Salemba now located in Jakarta.
Source. '*Selamatan pemakaian kamar operasi di C.B.Z. Salemba (1925) dengan kepala kambing di atas meja operasi baru,*' in Loedin, 2005, p. 213.

This is evident in Loedin's (2005) reproduced photograph (Figure 5.2) that shows a new surgery bed being ritually welcomed into a Stovia hospital in Jakarta in 1925 with a *slametan* ceremony. The performance of a *slametan* was an essential element to link the spirit of blessing (*barakah*) with place (the clinic in this instance) (Pemberton, 2003; Woodward, 1988). The *slametan* involving the animal head aimed to protect the place, individuals and society in general from unfortunate incidents, spirit attack or ghostly encounters (Pemberton, 2003). Some Javanese *abangan* continue to use animal head sacrifices in particular *slametan* rituals today. Purwani (2014), for example, noted the yearly *Mahesa Lawung* ritual still practised in Surakarta today. The *Mahesa Lawung* is a *slametan* ritual that involves burying a buffalo's head to mediate people's prayers to God for His continuous blessing of a place.

Pemberton (2003, p. 80) also described a *slametan* involving a buffalo head sacrifice performed on the occasion of the opening of renovations to one of Java's most modern sugar mills. Even though animal head rituals are no longer practised in Javanese hospitals, the practice shows how ritual ceremonies can act to wed Javanese cultural practices to modern biomedical practices.

Within the hospital structure, these embedded knowledges show that people need emotional and spiritual support, and not just physical treatment. Hospital administrations recognise the symbolic or emotional impact of rituals and figures in the healing processes within the clinic. On many occasions I observed big banners showing life-sized figures of the shadow puppet (wayang) character Gatotkaca, representing the spirit of Javanese strength and mysticism, displayed in hospital corners or waiting halls. The wayang world is perceived as the model for Javanese ways of living or being in the world. It reflects a cosmological perspective comprised of mystical messages, spiritual knowledge and the practice of 'power' (Mulder, 1998). Anderson (1965) noted that Gatotkaca is a symbol of the bravery and devotion of young people to a country. Derived from the story of the Mahabharata, Gatotkaca is the strongest of five Pandawa brothers who counter forces of destruction in the kingdom. Gatotkaca grew up to become a superhuman hero who conquered the Kurawa army in the Kurushetra War. Projected into a Javanese hospital, this Hindu epic story of Gatotkaca recording his magical powers has inspired Dr Sukma, one of the senior Javanese clinicians. Dr Sukma told me how strong Gatotkaca was when he was born; no weapon could be used to separate the baby Gatotkaca from his umbilical cord. Images of heroic Gatotkaca often decorate hospital corners aiming to transform mundane hospital spaces into places of supernatural power and heroic symbols. Further, the visualisation of Gatotkaca in the clinic shows the importance of the incorporation of spiritual values (drawn from wayang narratives) with biomedical notions, indicating a Javanese construction of self in connection with not just nationalism but a more ancient world view. Dr Sukma elaborated further that the hospital representation of Gatotkaca was, for him, a character who *menakjubkan* (startles). The Gatotkaca heroic character may generate a work ethic for the good of the nation characterised by discipline, honesty, honour and sacrifice. Thus, Gatotkaca and his powerful spirit are viewed as complementing *ilmu kedokteran* in Yogyakarta. Another senior oncologist told me that Gatotkaca is a symbol of power; he has muscles of steel (*otot kawat balung wesi sungsum gegolo)*. As the clinician told me, Gatotkaca is expected to inspire 'power' in healing pain and hardship. He attacks the enemies of the gods (*musuh para dewata*) and this reflects his powerful ability to overcome human illnesses in supernatural ways.

Within the clinic, Javanese ethics acknowledge that 'all forces in nature [are] an outflow of the invisible, continually productive, divine energy that permeates the whole cosmos' (Magnis-Suseno, 1997, p. 101). The image of Gatotkaca in the hospital corridor is a clear acknowledgement of Javanese ethics and beliefs alongside *ilmu kedokteran.* The interpretation of Gatotkaca may differ from one person to another, but, for the hospital staff, Gatotkaca is not only an inspiring figure upholding the principle of the compatriot; his superhuman character inspires the clinician to endure, achieve victory, and gain success in delivering health care (Figure 5.3). This sense of a spiritual element in care also works to calm people, encourage the divine powerful spirit, and soften the enforced nature of biomedical treatment.

Figure 5.3. (Left and top right), Spirits of *Gatotkaca* combating corruption within the hospital and (bottom right), a ceremony involving both Gatotkaca and the Batman icons to support children with cancer

Source. *Gatotkaca* images photographed by author; including batman, Facebook Page: *Anik ve Abe Sasongo.* Retrieved on 6 Jun. 2017 from: https://www.facebook.com/veyo.anik. Permission to use this image was granted.

In Northeast Thailand, anthropological interest in sensory experience has drawn attention to the construction of the Kui's life world and illness experience (Chuengsatiansup, 1998). The research shows how power relations are reiterated within their lived experience of illness, and observes the soundscape of everyday life in the margins. The embodiment of the senses of marginality, vulnerability and powerlessness are felt as illness in everyday Thai life (Chuengsatiansup, 1998). Among the Javanese, however, I observe sensory experience of spirituality and mysticism as crucial elements in restoring inner-self balance and social

harmony. These do not show marginality as what Chuengsatiansup (1998) argued, but the sensory experience reflects agentive feelings and empowerment.

Embodied mysticism in everyday life in the Javanese clinic has layered an apprehension of God onto mainstream biomedical practice. In celebrations such as the *slametan* ritual the hospital shows the role of hospital management and coordination in enabling the construction of Javanese personhood and identity. As a result, the biomedical regime and its penetration in the hospital setting does not repress so much as it incites (Foucault, 1976). This is reflected in the plotting of the sense of spirituality and morality in hospitals in Java both in terms of the senses and spaces. For example, a mosque is located within the grounds of Sardjito Hospital, in the middle of the main buildings. The spirit of Islam is embedded in the centre and that resonates with everyone dwelling in the hospital. It offers clinicians, patients, family and visitors the opportunity to be in contact with the supernatural power of Allah (God)—gaining the divine spirit of caring and healing.

The *slametan* ritual has different forms but the essential element of this practice is bringing people together in their desire for God's blessing and for a sense of communal harmony. Just a few days after Idul Fitri, clinicians and other health workers attended the annual Syawalan (clinician) ritual. The Syawalan ritual reflects the fundamental Islamic value of Idul Fitri as marking the end of the fasting month layered with the *slametan* ritual of *Kejawen*. The Syawalan ritual is driven by the mystical desire to *manunggaling kawula-Gust*i—to become one with God (Magnis-Suseno, 1997; Mulder, 1994) and maintain harmonious relations with society (Woodward, 2011). I was there mixing with the crowd of clinicians, sometimes stepping back and then forward to give space for patients being delivered by ambulance. A strong sense of spirituality was invoked by live and recorded music and a sense of sociality was built up through the communal singing of songs that not only called hospital workers together but filled the hospital with the embodied aura of Islam. The ceremony started in the morning and was held in the hospital's large yard. After the repeated broadcasting of Islamic religious songs, there followed various programs such as prayer (*do'a*), speeches and the Syawalan declaration presented by a doctor's representative (Figures 5.4). The Islamic songs performed as part of the ceremony reflected how Javanese social and spiritual traditions and Javanese Islam were embedded in the scientific medical institution in the hope of achieving a state of harmonious living—between the material and spiritual domains, between individuals, their communities and society. The ritual involved clinical staff recognising the powers of both Allah and the spiritual world in the healing work

of the hospital. In this vignette, the Syawalan ritual invited clinical staff and the public to recognise the ultimate healing power of the spiritual.

> A doctor was reading the Declaration [clinician commitment] intently and stated that all hospital staff are 'a big family'. He stated that the ritual is a moment to maintain our resolve to be and act as good persons, to be self-reflective and correct any shortcomings, and to work together in order to live in harmony as human beings. Advising hospital staff to have good motivations, he furthermore encouraged everyone to build a good relationship with God (*hablumminallah*) and a good relationship with society (*hablumminannas*). (Fieldnote, 22 Aug. 2017.)

Figure 5.4. Syawalan ritual in the hospital's hall in 2017

Source. Jalin Silaturahim Dengan Civitas Hospitalia, RSUP Dr. Sardjito Adakan Halal Bi Halal, *RSUP Dr Sardjito.* Retrieved on 24 April 2019 from: https://sardjito.co.id/2017/07/03/jalin-silaturahim-dengan-civitas-hospitalia-rsup-dr-sardjito-adakan-halal-bi-halal/

After the Syawalan declaration, a senior doctor acting for the hospital director made a speech. He emphasised to the audience the importance of improving their submission (*ketaqwaan*) to Allah through individual piety and submission to social expectations, and through maintaining dignity and social norms. This would convey benefits to the nation state, society and the hospital as an institution. The director's representative went on to say:

> We have passed the Ramadhan month and filled it with frequent submission practices [to Allah] through fasting [*shaum*], night praying [*tarawih*], prayer in the mosque, contributions and charity [*zakat*]. We [all workers] should continually improve our submission to Allah. We have to intentionally improve [the practices] during the next eleven months in order to increase productivity [*kinerja*] and activities. By respecting Allah's will [*ridho* Allah], these [practices]

> may result in self-piety, social submission, sincere and genuine work and responsible workers. These [practices] are to develop individuals or workers who are more qualified and valuable especially when serving consumers [*pelanggan*]. (Speech on Syawalan, 27 Aug. 2017.)

The vignette reveals an embodied mystical sense which illustrates a range of meanings and values. Most people's approach to healing, health, illness and disability in Java exists in an inseparable physical and spiritual state. Thus, health care providers like the hospital have embedded in their practice such spiritual expectations and local Javanese values to encourage both physical and spiritual balance. Recruiting spirituality into daily practice builds subjects within a distinctive socio-cultural context and a specific collective mode of being-in-the world (Chuengsatiansup, 1999; Kleinman, 1996). This is the strategy of the self in search of a more powerful emotional symbol for engaging with the space of being-in-Java (Csordas, 1994a, p. 284; Magnis-Suseno, 1997; Merleau-Ponty, 1962). The space of moral duty signifies that every individual should respect the order of existence. People's existence in the world including their experience of illnesses means one should consciously accept challenging and even painful experience as the path of destiny. Nobody is able to escape from that situation arranged by God's will.

> Illness is culturally shaped in the sense that how we perceive, experience, and cope with disease is based on our explanations of sickness, explanations specific to the social positions we occupy and systems of meaning we employ. These have been shown to influence our expectations and perceptions of symptoms, the way we attach particular sickness labels to them, and the valuations and responses that flow from those labels. (Kleinman, Eisenberg and Good, 1978, p. 252.)

Woodward (2011) has noted that the adoption of purely medical care in Java would be unlikely in the next three decades. In Java today, I argue that this is due to the strong persistence of Javanese ethics and the embodiment of affective *rasa* that complements biomedical regimes. In parallel with a universal health care policy, the textures of modernity have been massively expanded through clinical and biotechnical development. But relying on modern treatment alone is considered insufficient. In the case of chronic diseases like osteosarcoma that may imply amputation, most clinicians and patients still uphold their Javaneseness by incorporating values derived from *Kebatinan* and Islam in their approach to healing. According to Ferzacca (2001), this may be identified as a type of pluralistic medicine that is shaped habitually by the Javanese structure of experience (*pengalaman*) or *laku*. Ferzacca (2001) illustrated the pluralistic character of urban medicine in Yogyakarta as an outcome of combining biomedical intervention and Javanese people's 'own' practices towards health care. Ferzacca's analysis (1996) symbolised bodies as dynamic mediators between self and society (see also Csordas, 1994b). Patients are meshed in social structures

and are consumers of culture, and emotion, in particular, becomes embodied in social or relational processes (Lyon and Barbalet, 1994; Merleau-Ponty, 1962). These embodied practices illustrate important aspects relating to illness, health and cure in the eyes of Javanese people. Their perception emphasises *laku* (social practice) and *ngelmu* (knowledge) (Ferzacca, 2001). I observed that subjects are not just products of obedience to rules, but rather of the practice of spirituality as well—and that embodied mysticism and spirituality are taken-for-granted dimensions of human nature.

Previous ethnographic research in the late 1990s showed a pluralistic practice of blending biomedical and Javanese spiritualism and religiosity in the lived experience of mental illness and chronic illnesses such as diabetes, cardiovascular disease and hypertension among Javanese (Ferzacca, 1996; Woodward, 2011). Apart from 'modern' care, family and patients with chronic illnesses are aware of moral alternatives during their experiences of illness and this often involves recruiting a spiritual dimension to healing (Ferzacca, 1996, 2001). Ferzacca (1996) provided examples of when *dukun* and paranormal practitioners are understood and consulted as healers who are able to reconcile a spiritual balance. These mark Indonesian cultural identity and prove authentically Javanese personhood (*masih Jawa asli*). Further, *jamu*, herb, and *pengobatan cara Rasulullah* remain popular medications and complement biomedical prescription.

What I found in the clinic during President Jokowi's rule is comparable with Ferzacca's research (during Soeharto's era) but also demonstrates a certain modulation of this trend in Indonesia. This cultural phenomenon corresponds with another drive that reflects 'modernisation'. The structural feature of contemporary Indonesia that is marked by the return of developmentalist support (Warburton, 2016) goes together with the preservation of Indonesian/Javanese culture as a mark of national identity. I argue that the mystical thought that continues in contemporary Yogyakarta and the clinicians' resort to spiritual and social resources illustrate a particular response to Indonesian identity formation and social change.

The role of spiritual deities, religious beliefs and mystical intuition for the Javanese are understood as part of a rational way of thinking, and are commonly extended by recommendations that people be patient (*sabar*) and in control of their emotions (*cita-cita*) (Mulder, 1986, p. 43). The pluralist mix of belief and practice that some clinicians rely on, such as blending religious practice, myth and even a kind of hope in the miracle of healing, show no single cultural construction. The abstract 'therapeutic' concepts of personhood, cosmology, power and knowledge remain dominant (Woodward, 2011, p. 69). Additionally, when chronic illness is at stake, life is hard and uncertain for both clinicians and patients and

family members, and this situation encourages the clinician to re-imagine outcomes of healing and well-being. Reading the phenomena of uncertainty or hardship is challenging for clinicians. Yet they are obliged to help chronically ill and disabled patients, and to 'play' in an arena in which the treatment given is bio-ethically and socially acceptable. Thus, they mainly engage with solutions for recovery brought about by 'something else' and emphasise miracles (*keajaiban*) associated with God's will, spiritual restoration, social connection and mysticism.

In his response to the amputation and death of an osteosarcoma patient, senior resident Dr Anton said,

> It is a loss. But we do not avoid when it is going to happen, whether or not we can accept it [severe illness and disability], it has been arranged [by God]. We only need to accept and live with it. It also depends on each individual to respond to it from different points of view. However, in my opinion, no matter what the form and condition is, we can only try and try. Keep trying and be grateful. (Interview, 16 Oct. 2015.)

Clinicians unconsciously 'bypass professionalism' through making cultural connections with social resources, cultivating mystical perspectives and stressing what ethos they share together with patients and families. Dr Anton's narrative speaks the moral language of Islamic Java or *Kebatinan* which offers him a readily available refined and ethereal mode known as *cara halus* (Mulder, 1978). Pak Sudoko calls *Kebatinan* 'a kind of philosophy' for creating not only a sense of common humanity but also a way of imagining and sketching the expected 'good life' amidst moments of clinical hardship. He explained further:

> Have you ever heard of an aeroplane going missing and crashing, yet some of the passengers do not die? That's the power of God. So, we would never know what God's will is. In theory, if doctors said that they could not handle a chronic illness, or the illness cannot be cured, then humans expect a miracle from God, right? Therefore, please return home and find alternative ways elsewhere, go to another place. Perhaps there is a miracle! (Interview, 14 Oct. 2015.)

From the clinicians' narratives, I understand their concerns with *Kebatinan* practice to be about giving positive endorsement of the cosmic dimensions in life, social profundity and religious emplotment. These signify an uneven mystical tribute to Islamic and Javanese culture. Nurse Mas Bambang described his work tasks in treating patients in the orthopaedic department as involving preparation for laboratory tests, checking patients' conditions and watching for improvement as well as assisting patients' psycho-social mood. But Mas Bambang also creates a communal environment in the clinic that enables a close relationship between patient and healer and that opens up the important dimension of Javanese life and the revelation of God. His engagement with spiritual and religious beliefs is as a mode of effective communication. Yet, we can see that the spiritual embodiment layers the

apprehension of God's will onto mainstream biomedical practice. He described his facilitation of psycho-social and spiritual well-being treatment as follows:

> Actually, we used to do all, but now we're more like [pause] we're not even a leader, but we handle it [pause] we can say it that way. We coordinate everything, for example, for patients' psycho-spiritual needs. A patient might need assistance from a religious figure, and we will contact that person. Thus, we manage and coordinate. For patients who are going to lose a part of their body, assistance from a religious figure is usually required. If the patient already has a personal *ustadz* (Islamic spiritual teacher) or someone like that, we will allow him [the *ustadz*] to accompany the family (Interview, 10 Aug. 2015.)

5.3. Meeting in the 'corridor'

Foucault's *The Birth of the Clinic* (2012) contends that clinicians have considerable power in producing knowledge. By articulating arithmetic and scientific calculus biomedical measures are used to make further investigations over bodies. I argue throughout this thesis that clinicians also make normative judgements over poor and disabled people that are based on cultural and social notions of the norm. Their prominent role enables clinicians to make judgements on whether individuals are 'normal' or 'deviant'. Very often, moral judgments operate in dividing patients into deserving and undeserving groups. In particular cultures, stereotypes and stigma may shift the clinician/patient relationship into morally troubling territory. Their poor physical condition, as well as moral judgement, impels poor people to behave in a very humble and underprivileged way (Seo, 2016). Their self-discipline and self-surveillance illustrate the disguised power that circulates to control the entirety of their lives. This repressive power operates not only in terms of 'scientific' knowledge but also in terms of a 'social desire' to conform to traditions or norms on which this knowledge is based (Foucault, 2012; Pylypa, 1998). The social desire in turn becomes a technique of governmentality in the health care relationship that leads people to sustain their own moral repression voluntarily (Seo, 2016).

However, what I argue in this chapter is that meetings in the hospital 'corridor' recognise the power of life (Giddens, 1991). My observation about the health care relationship in Java applies a Javanese concept of 'power' that differs from Foucault's concept (Foucault, 1976, 2012). I argue that meetings in the 'corridor' capture the ambiguous powers that transform into particular activism in clinical settings. These powers are revealed without the use of coercion in the way that Javanese people go about their life habitually and naturally in such pathways as the 'corridor' and that their actions complement the biomedical structure. Through Javanese culture and *ilmu kedokteran,* patients and their families and clinicians build up what 'power' of life they have accepted together. On occasions, if

clinicians need to convey the blues or the sadness of medical prognosis and disability, the 'corridor' offers a space that makes sense of the predicament to produce what we might understand as a sense of equanimity (*ayem*) (Guinness, 1986). Yet, in resorting to the corridor, the clinician demonstrates a certain abandonment of their characteristic role in order to build social relations with the patient that are more intimate. Their intuitive sense allows them to draw on their embodied inner-self dimension, social networks and spiritual connectedness.

5.3.1. Religious or spiritual resources

The norms, religious beliefs and mysticism that reflect social relatedness and embodied spirituality persist at the core of health care coping mechanisms and illness understandings. The inner-self (*batin*) is significant for the clinician in the way it causes patients to reflect on how life should be lived in terms of a framework of *takdir*—divine fate and human responses (Magnis-Suseno, 1997). At the time of my fieldwork, Julius was a twenty-two-year-old university student diagnosed with osteosarcoma of his left humerus. His family went to a traditional healer as their first treatment choice, but Julius did not recover. Pooling all their money, Julius's family was able to go for a short time to the VIP ward at their regional hospital to access better specialist care and comfort. However, they rejected the biomedical advice that Julius should have an above-the-elbow amputation and chemotherapy. Julius family decided against the operation as the cancer metastasis resulting limb lost—as stigma surrounding the cancer disease and disability remains exist (explore further in Chapter 6). Julius' close friend, Rani told me that she lost his contact after Julius received a cancer diagnosis. In village, Julius family was isolating themselves from neighbours. "When I was reaching him in the house, I found its windows were shut and the doors were locked. I thought that it was nobody at home but later his mother opened the door quietly" she said. So, his family decision was made not because they did not accept the fatal character of the illness, nor because the administrative medical procedure was likely to be a complicated and long process. But, the decision more importantly reflected their acceptance of a cosmic order in which expressing the inner self/moral dimension was essential. The moral dimension supplements Javanese narratives on disability that turn a deeply social prejudice.

As I argued in Chapter 4, the interplay of power and resistance that Foucault described allows for alternative paths to emerge from the health care relationship. In the past, for example, Dr Agus found it difficult to encourage his patients to follow medical treatments like chemotherapy, radiotherapy and amputation. It caused him to alter his practice and rely

on various perspectives. In dealing with difficult cases, he often combined *ilmu kedokteran* with social, cultural and spiritual approaches. What can be illustrated from Dr Agus' case outlined in more detail below is that sensory experience and symbols are likely to be politically significant, while the 'corridor' powerfully equips clinicians in their position in the social field (Bourdieu, 1977). In brief, they attempt to achieve health care delivery by building trust through recruiting common (religious or spiritual) beliefs.

When Julius's cancer grew bigger and metastasised to his lung only five months after his first diagnosis in the regional hospital, the immediate family brought Julius to a Catholic district hospital nearby, where the facilities were inferior to the public hospital. I approached Dr Agus to share my intention to force Julius to transfer to the public hospital, but Dr Agus told me in sincere, heartfelt and calm tones 'this is what people normally do'. I did not understand Dr Agus' attitude at the time. But I came to understand his response as more complex than simply an expression of biomedical judgement. Dr. Agus' comment did not just acknowledge the patient's right to make a choice relating to their physical treatment. He also acknowledged the patient's moral and spiritual orientation as critical elements in recovery; 'letting' Julius be treated in the Catholic hospital reflects how most Javanese put spiritual faith ahead of physical courage (Woodward, 2011).

Dr Agus and most clinicians bring contending views together to offer assurance to their patients as they see that approach as a way to achieve equanimity. To reassure (*memantapkan*), as a clinician told me when dealing with clinical hardship, refers to the practice of *Kebatinan* that emphasises morality associated with individual *rasa*, the *batin* or inner self (Mulder, 1994; Woodward, 2011). The moral life in this *Kebatinan* sense is not merely part of the conditions for state control but habits of living that may emerge in the everyday clinic.

Clinicians use their authority not only to consider the individual body in a biological way but to recompose the person's existence in Javanese terms of cosmic forces and a higher social order. *Memantapkan* in this sense means linking the severe illness, impairment and human experience with the transformation of the soul and the patient's moral discipline. The social interaction generated through the practice of *memantapkan* illustrates routine 'cultural' responses made by clinicians that create the self as a repetitive norm or habitus. Social interactions inflected by Javanese norms and values emerge as important moments that naturally appear in the hospital field as a form of social practice that embodies norms that people have internalised and hold as enduring dispositions (Bourdieu, 1990). Suster Nunung explained *kondisi klinis* (clinical condition) as referring to biomedical prognosis, diagnosis

and future osteosarcoma treatment. She structured her clinical sessions around the experience of severe illness and disability by creating a story comprising a mystical fantasy. She described her practice as *memantapkan*, through what Mattingly (1994) calls 'emplotment', a process that allows the clinician to prepare patients and family to build a form of spiritual courage. She said:

> Then we [nurses] need to follow up the treatment of amputation and post amputation. So, we need to reassure the patient and family based on whatever experience we have, we provide them with information, then give spiritual support—so, improving their spirituality. For those who are Muslim, we should continue to encourage them to pray and to draw themselves closer to Allah. (Interview, Suster Nunung, 7 Jan. 2016.)

I observed that clinicians, like Suster Nunung, refer often to the spiritual in order to build trust and communicate with the patient and family in an intimate mode. While other clinicians may or may not believe in the spiritual realm, they may still say these things to appease the patient. Mattingly (1994) furthermore argues that clinicians actively endeavour to create a mode of practice informed by a cultural plot or world view with which they are already familiar. In a Javanese hospital, most clinicians confirm that the individual body cannot be reduced to any single scientific domain, but instead comprises the spiritual layered on top of the biomedical domain.

Dr Agus mentioned the importance of the 'non-clinical' in complementing *ilmu kedokteran*. The 'non-clinical' referred to the humanistic side of individuals, covering social, spiritual and mystical aspects. In applying a Javanese theory of anatomy, most clinicians recruit the spiritual dimension of the person. The body is considered to consist of the inseparable elements of *lair* (physical) and *batin* (inner-self) (Mulder, 1998). So the essential element of personhood is built up by mutable distinctions between body and mind (Woodward, 2011). Dr Agus explained it this way:

> Actually, orthopaedic and oncology work requires 'extreme' interventions. Because this [Julius's case] needs surgery to remove the organ [limb]. The amputation is the truth [*fakta*] or perhaps the only way [treatment] that should be done. […]. I have motivated him by using various perspectives [clinical and non-clinical], but I am not the one who lives with him, but he lives [with the disease and body impairment]. I told him and his family that it was a tumour. The tumour may be a non-malignant or malignant tumour [*jinak atau ganas*]. If it disrupts normal growth of the limb and is at risk of metastasising, the tumour must be surgically removed. However, if the tumour has metastasised surgery would not be an option because it leads to high risk. I told him [Julius] two months ago. (Interview, 18 Mar. 2015.)

So, as Mattingly (2010) said, clinicians practice therapeutic emplotment: remaking lives by plotting a moral world shaped by social interaction or intersubjective experience. Julius' family's decisions reflected their spiritual and cultural understandings of modern

medicine. It was this complex moral construct that meant they could not form a satisfactory understanding of the medical diagnosis explained by Dr Agus. Dr Agus' reference to 'using various perspectives' can be understood as 'plotting' where local morality was used to determine overlapping meanings of illness in both the biomedical discourse and in embodied Javanese socio-cultural values.

He explained his approach to Julius' case as incorporating in his professional response his ultimate trust in God's will. Dr Agus emphasised the contentious nature of Julius' situation through reference to the inner-self, the spiritual and moral dimensions of being human. He put it this way:

> Yes, it [Julius' problem] is not just physical anymore [*tidak organic lagi*]. Not just physical any more means *bukan aslinya* [not just physical]. It [the organic] has overlapped with *psikis* [the psychological]. That is 'common' [*wajar*]. (Interview, 18 Mar. 2015.)

Dr Agus considered Julius' case to be already complicated, and he did not intend to supersede God's will. Dr Agus' dilemma over Julius's case reveals the intricacy of making both a moral and a biomedical diagnosis for a particular clinical occurrence. His professional identity became blurred in a social space where cultural rules and social norms were fundamentally rooted in the socio-cultural order, and it was through that order that he tried to build the trust of his patient and their family.

Dr Agus brought the case into the 'corridor'—not literally of course but in the sense that Dr Agus drew on an informal shared sense of embodied cultural consequences, particularly, a sense of equanimity which we may understand constructs a mode of resistance, a mode of fighting adversity (Mattingly, 2010). We can understand this approach as an illustration of Bourdieu's central argument that embodied culture provides a basis to cope with various situations in predictable ways (1990, p. 53). In this sense, the practice of a moral life as illustrated by Dr Agus provided strong support for overcoming feelings of lifelessness, anxiety, turmoil, or embattled relations between clinicians and patients. Some clinicians, like Dr Agus, were predisposed to a context of familiarity, adopting the view that spiritual intention is intermingled with the delivery of health care. Dr Agus' belief in the power of Allah's blessing when delivering health care was demonstrated in his Facebook post (Figure 5.5). Furthermore, he considered the cultivation of this mystical resource as devotion to God's power.

Figure 5.5. Showing that clinicians receive spiritual essence when dealing with patients; *campur aduk* (a composite of different elements) is merging *kondisi klinis* with moral and religious intentions that inform their treatment of patients.

Source. Facebook page. Retrieved on 2 Nov. 2016 from:
http://m.facebook.com/story.php?story_fbid=10154201498958687&id=751038686

Dr Agus' dilemma in selecting and recommending various therapies outlined below revealed not only his awareness of patients' modes of resistance in the clinic but also that individuals' hardships and suffering were intricately enmeshed in the health-care system delivery and the limits of medicalisation.

> Here, I am not intentionally taking over God's will [*mendahului*], but perhaps the amputation is very difficult. 'Difficult' means that the mass [the tumour] here [pointing into his upper arm] may spread into the lung. So, to be removed it would be difficult. However, I must not think in that way [pessimistically]. For the patients with advanced cancer, if the mass cannot be removed there are no other therapies except reducing the pain. The patient must not be left suffering from throbbing pain. Giving medicine should be done through infusion or at least [the patient] should be hospitalised and given the infusion. We must not overtake [Allah's will]. But if the tumour grows bigger, the risk is higher. The mass may not be in one place but in others [organs].
>
> Apart from reducing the pain, if possible, we give chemotherapy. I advised Julius and his family that if he did not take the surgery as an option, chemotherapy would be his first alternative option. We should see the patient's responses to chemotherapy. I observe Indonesian culture to be an optimistic culture as people believe that a tumour will stop growing and get smaller [even though] … the fact is that the tumour grows but I should not overtake Allah's will because there are miracles (*mukzijat*) and […]. (Interview, Dr Agus, 18 Mar. 2015.)

Reference to shared norms of spirituality is extremely useful, especially when faced with the limits of medical treatment, clinical hardship and the moment when people reject

biomedical care. Dr Emil, an orthopaedic resident, confirmed to me the clinical procedure for osteosarcoma patients facing limb loss. He said that while he relies on science, he also incorporates a mystical interpretation of outcomes and morality along with his interpretation of scientific knowledge. Dr Emil acknowledged that building patient trust might not strictly conform to the dyadic model of the biomedical gaze but is broader than that, involving the mystical and social, and a sense of spiritual divination that allows authorised clinicians to provide cures. In his view, clinical procedures can be accommodated within a scientific frame: once biomedical procedures fail to address the patient's illness then the shared moral domain fills the gap. He expressed his view that a biomedical explanation is often not sufficient to convince or build patient trust, and that the spiritual requirement seems to be adequate in giving priority to the patient and family. He said:

> Most of the problem is with patients who refuse amputation. They still cannot accept that they have to lose part of their body. They cannot accept it since there wasn't any problem before; they can walk and do anything without any problem. Now, they imagine that they have to use crutches or supporting devices, and still cannot accept that. Although we have explained that after amputation there will be a prosthesis such as prosthetic leg, sometimes they refuse to accept it. So, in the end, they decide to go home and seek alternative help [Kyai, paranormal, *orang pintar*] or a second opinion. Some of them come back and others don't. (Interview, Dr Agus, 18 Mar. 2015.)

Memantapkan (providing reassurance) shifts the governmentality notion of normalisation, not to disciplining of life or subjectification (Foucault, 1976), but to the kind of life being enacted by cosmological forces or life as it is (Fassin, 2009; Mulder, 1998). Bringing a sense of the 'corridor' into the formal hospital structure is illustrated through clinical practices that do not uphold a hierarchy of knowledge and seek to reform the unequal power relations between doctor and patient. In terms of Julius' case, I came to understand the clinicians' Javanese world views that linked illness and disability narratives to the embodiment of being in the world (Merleau-Ponty, 1962). Critical to what Fassin (2009) argues is the concrete way in which some clinicians act through the practice of *memantapkan* in parallel with the technologies of power. Yet, the vignette shows how the embodied moral life that most people accept as common sense leads to an overlapping of *Kebatinan* and morality (in relation to Javanese meanings of body, illness, and disability) with the biomedical approach.

Dr Kartika, who performed Anas' upper leg amputation, held such composite views. She told me that she regarded amputation as the key strategy to save Anas and left him to sort out his relationship with God. Another specialist orthopaedic doctor explained that 'even though we may have followed the procedures in accordance with best practice for a specific

type of affliction, we can't decide whether the patient can be cured or not' (reference.) There isn't any special treatment for osteosarcoma and body impairment. Indeed, as the physiotherapist put it 'there is no special treatment for amputees, but we provide "*extra attention*" to patients who tend to have problems with their body image in the future.' Another clinician, Pak Samsudin, a physiotherapist in the medical rehabilitation department, told me that he usually treats patients with bodily impairments by using spiritual competence—he habitually applies both religious faith and bio-physical knowledge in treating patients. He observed patients after amputation and said that most patients were highly stressed. Speaking with some passion, he described how he tailors his interventions by drawing on a mix of biomedical principles and Javanese religious norms. In his view, in facing any difficult situation and uncertainty because of severe illness and bodily impairment, he acknowledged that God determines the outcome. He explained his approach in this way:

> It might be a challenge for other people, but for me it is my job. Our success, our satisfaction is when patients are not handicapped; the ROM [range of movement] is good … Some patients do not address their problem here, so that their leg becomes stiff and cannot move, cannot. There are many cases like that because there was no consultation. Our satisfaction is when someone can fully accept something, and it is done. It is not a challenge, it is our profession.
>
> When I handle a patient, I leave everything in God's hand. We're just human beings and to be honest when patients are in a sick condition, their faith decreases. I can even say that they don't have faith, because they don't believe. 'How can I be like this? How can I suddenly become like this? Why did I choose that way? Why did I fall down?' They blame God, but it is a chance for me to endeavour to rebuild their faith. We have to remind them that we are God's creation; we build their faith first … If patients know that we always have God, everything will change, I'm sure of it. If we return everything to God, especially when they are in a sick condition, they will be touched; everyone will be touched as long as we return everything to God as we're God's creation.
>
> That's what we have to build first. Yes. That's what we have to build first. They do understand that their illness serves as the abolition of sin. There is Hadith on it, why shouldn't we believe it and abolish the sin, shouldn't we? It is also written in Qur'an, Surah 26 Ash-Shu'ara verse 80 '*wa idza maridhtu wa huwa yasyfin* [And when I am ill, it is He who cures me]'. It is clearly written there. We always refer to the Qur'an and the Hadith, if they are Muslims—most of them are Muslims. When we leave everything to God, that will become the power. Patients will stand again without our help.
>
> … [trust] between human and God. His efforts will be his reward. Whether s/he is going to be cured or not, it's God's decision and none of our business. I cannot cure patients, doctors cannot cure patients, the one who cures is '*wa idza maridhtu wa huwa yasyfiin* [and we are ill, it is Allah who cures us. It is only Allah]'. (Interview, physiotherapist Pak Samsudin, 15 Jul. 2015.)

The use of an extensive array of observances rooted in passages from the Qur'an and Hadith also suggests a complementary response to building patient trust, the practice of *memantapkan* focused on spiritual purity. For example, Woodward (2011, p. 72) has argued

for the importance of Sufi teachings in the healing process for Javanese; to get rid of illness, individuals undergo an inner quest for purification of the soul and closeness to God. Sufism has become a favoured strategy in therapy sessions. It gives severe illness and disability meaning and works towards purifying the polluted body (Douglas, 1966; Woodward, 2011). Some clinicians initiate actions in therapy by citing Qur'anic texts or Hadith based on Muhammad's practice. Dr Sutopo, a geriatrician, told me that illness and disease is a 'warning' that is given by Allah to both the patient and the family. In an interview, he told me that individuals who experience illness and disability are urged to control their behaviour to reflect a good moral attitude, to be aware that death is coming and to prepare themselves with various *amal sholeh* (blessed works) and moral discipline. Dr Sutopo provided alternate healing for his patients by requiring them to situate themselves in the metaphorical 'corridor' space—where mysticism was reflected in the culturally embodied individual, in the demonstration of social control and in the fulfilment of being *manunggaling kawula Gusti* (being in harmony with 'God'), where the individual was the servant of God and fully aware of the nature of life.

Picture 5.6. 'The pocketbook for praying' available in Sardjito Hospital

Source. Dr Probosuseno, Sp.PD-KGer, *Teman Kecil di Waktu Sakit*. Geriatric Clinic Department at Sardjito Hospital, Yogyakarta

The pocketbook (Figure 5.6) written by Dr Sutopo was widely available in the hospital. It showed how Islamic practice flowed into biomedicine and was consumed as a healing ritual through prayer and meditation, and through personal, social and human connection with God. It appears from the teachings contained in the pocketbook that curing disease, illness

and disability must engage the physical and spiritual body. For example, if somebody is ill, the individual should seek treatment from biomedical professionals, think positively of Allah, be patient and surrender (to God), be optimistic (to God's will) by not expecting death, and by praying with hopefulness (to God):

> Health is a blessing from God and a sign for humans to live in accordance with Allah's will. Illness can also be seen as a warning and punishment from Allah. Allah gives [human] illness and its medication. Everybody must experience illnesses. The illness experience shows Allah's love and concerns in order to educate, warn and eliminate the sin of people.

5.3.2. Social resources

Apart from explicitly recognising religiosity and mysticism, clinicians also draw on kinship and family in their treatment approach. Like the cosmic order in which inner-self connection is important, social connection is well-ordered in a harmonious whole (Mulder, 1998). Pak Sudoko's narrative invoked *Kejawen* culture, Islam Java or *Kebatinan*, offering a readily available mode, or what he calls 'a kind of philosophy' for creating not only a sense of social connectedness but also a way of imagining and sketching the expected Javanese 'good life' amidst the hardship of *kondisi klinis*. Pak Sudoko told me how he has endured a lack of resources, facilities and support and relied on religious and Javanese ethics to maintain his self-esteem and encourage everybody to be grateful (*syukur*). He recounted to me one of his experiences in responding to patients and family members who were being treated alongside patients with advanced cancer. In the instance recalled, the room was occupied by eight patients. One of the patients had a malodorous tumour, and the other patients could not stand the smell. Pak Sudoko knew there was nothing he could do; he could not move the patient. He asked the other patients to be grateful instead. He went on to explain to me:

> I've experienced this situation. I've been here for quite a long time and have seen many cases or problems. As time goes by we regularly deal with it. This makes us look like resilient nurses. I said to the other patients that this patient with advanced cancer deserves to receive the same treatment that they receive. He just happens to have a noxious-smelling tumour. I can't isolate him somewhere else. If [I] could isolate him, I would do it. But there is no more room here. The patient is a class 3 patient. Finally, I said, 'Sir, you're another patient's family right? You've got to be grateful (*syukur*) for not having a family member who is malodorous like him. Can you imagine how sad his family is to have a family member whose tumour smells offensive and who is shunned by his friends, and yet he has to endure the pain? So, like it or not, you have to accept that his place is here. If you can't bear the smell, just put a mask on. But at least you have to be grateful for not having a family member like him. However, you have choices.' I don't ask him [the tumour patient] to shift elsewhere. 'If you can't stand it, you have the right to move. I mean to move to another room. If there was another room available, I would make a call. But the problem is that all rooms are fully occupied now. So, please stand with the smell a bit.' (Observation, 15 Dec. 2015.)

In the end, other patients and their family members accepted the situation in spite of the smell that came from the diseased patient. He said emphatically that he could not isolate the patient as every patient had the same rights. Pak Sudoko's position is in the 'corridor' where he has intentionally oriented himself and the patients and their family towards the social order. The bodies are positioned as subjects who inhabit the social world while also making up their own self or inner world (Csordas, 2011; Hallowell, 1955; Merleau-Ponty, 1962). He furthermore said that,

> As a nurse, I can't just act like other patients and shun the one with a malodorous tumour. I can't isolate him or show that I feel disturbed by the bad odour. When we don't have a bad-smelling tumour, we should be grateful. The patient himself is already suffering from the bad odour and experiences more emotional pain by making others feel irritated by his odour. The longer we experience the pressure the more resilient we are. (Observation, 16 Dec. 2015.)

Pak Sudoko's consideration follows *Kejawen* ethics by seeking Javanese knowledge and wisdom. As Mulder explains:

> With that, one will know one's place in society and in all-encompassing Life; one will also know the ethical aspects of knowing one's place. People should live attuned to it all. In their phenomenal existence they should respect the order of society, honour elders and superiors, and be considerate of inferiors by taking 'the measure of oneself'. They should care about harmonious relationships, at least outwardly so, and thus avoid conflict. (1998, pp. 79–80.)

These belief-based or moral (*Kebatinan*) ethics have come to legitimate the habits of clinicians, and significantly maintain the latter's self and social esteem (Fabrega and Silver, 1973; Guinness, 1986; Kleinman, 1981). The spiritual, often set to one side in modern medicine, becomes a vital component of healing in many cultural communities (Mattingly, 2009). In the context of this research, the spiritual helps clinicians to bridge the gap between their patients and family by building trust and making clinical information 'culturally' acceptable to the two parties. Everybody in this 'corridor' cultivates and strengthens their inner-self or their *batin* by supressing emotion and situating themselves as inferior to the superior God. Another senior clinician told me that God is the one who cures the disease, while the doctor is only a *perantara* (broker) who connects the human with their God, or that the doctor is only an *alat* (tool) to fix the patient on behalf of Allah's will. I often heard clinicians trying to build a patient's trust by saying jokingly that 'the doctor is only human', showing their equal position as a social being and expressing a similar devotion to the cosmic order. Recalling the patient with the offensive smelling tumour, Pak Sudoko said that he advised everyone in the ward to spread coffee on the floor, wear masks and spray perfume so that they can keep staying in the ward. He told me further about his tactics to help patients endure hardship (*rekoso*) by relying on Javanese ethics that appeal to patients to feel (*merasa*)

another's pain and situation as if it were their own (*tepo seliro*). In his narrative I noted that his clinician's language blended with cultural principles of *Kebatinan* and social norms as he described a way of being-in-the Javanese world.

Suppressed emotion and shared affective dispositions—'tactics' in James Scott's (2015) words or 'habitual appearance' (Bourdieu, 1990)—reflect cultural embodiment in the individual. For example, a clinician's advice to be s*yukur* and *nrima* in the health-care context may thus be seen to promote a 'state' of *ayem* or equanimity while still showing an awareness of their precarious situation. Dr Agus shared his feelings on Facebook writing that 'when you find yourself in a position to help someone, be happy because Allah is answering that person's prayer through you.' When I asked what he meant, he replied that when dealing with patients he feels '*campur aduk*' (a composite of different elements). Merging *kondisi klinis* with moral and religious intention informs his treatment of patients, remaking the blurred hierarchy of knowledges as well as unclear distinctions of social status.

The medical profession embodies a cultural system that not only assists the human to endure the medical problem (C. Geertz, 1973; Kleinman, 1981), but also allows the mapping of human behaviour in a society. For example, the strong communal life in the hospital wards linked to the corridor shows the ways that Javanese behaviour is influenced by interpersonal relationships manifest in such forms as social networks and even the hybrid family. Dr Agus' reiteration of the importance of his former amputee patients motivating other patients undergoing treatment in the hospital shows how clinicians perceive the corridor as a social connector. There was a natural and well-maintained quietness in the room where I met Dr Agus on the day when he clarified the *kondisi klinis* for Julius. He explained calmly: 'actually, orthopaedics and oncologists require "extreme" interventions. In Julius' case he needs surgery to remove the organ [limb]'. He referred to amputation as scientifically right (*fakta*), saying that 'it is perhaps the only way [treatment] that should be done'.

I observed the quietness among those in the room while Dr Agus looked at Lies and took a deep breath. He then continued to explain: 'I often ask cancer survivor friends (*teman teman survivor*) to motivate patients to accept the clinical procedure of amputation'. Bu Purnomo added, 'Yes, because of amputee patients like Lies, Julius was willing to follow the medical procedure.' One day when I visited Julius in the district hospital, his mother told me that after meeting with Lies, her son wanted to take up the offer of surgical treatment. Julius said that he wanted this [arm] to be cut [off] so it would not be painful anymore. He told me that it has been just four months, but it was very painful, and the lump affected the front and back of the limb.

Dealing with Julius's case required Dr Agus to call on social resources. Specialist oncologists and orthopaedic surgeons routinely link with other amputees and draw upon Javanese values to communicate with patients and family to confirm biomedical treatment. For Dr Agus, delivering the bad news of amputation was not an easy task. He tried to '*motivasi pasien dari segala sisi* (motivate the patient from every perspective)', to position himself as family, social help and spiritual aid as he put it. He recalled that he had informed Julius and family about the *kondisi klinis,* the result of diagnosis and the prognosis in the following way:

> Brother [Julius], you should not be pessimistic, because you are still young, and you have many friends who are amputees, and you can/should discuss these [recommendations] with Lies. Because Lies, *Alhamdulillah* [praise to Allah], Lies has helped my friends, I mean, my patients'. (Interview, 19 Mar. 2015.)

The important values of *inner-self* and *social esteem* are thus intricately intertwined in the clinician's philosophy of work in the hospital. The embodied culture provides an alternative path that views life as a sequence of events that connects individuals' experiences from birth to death (Mulder, 1978, 1998). The human existence in the world is to be uniform in purpose and wish—to be one with the God, *manunggaling kawula-Gusti* (Mulder, 1994, p. 53). So, their lives are forced by mystical desire to unite with the cosmic order.

These Javanese views act as a kind of 'moral drug' that significantly contributes to building trust in curing practices and are akin to individuals' feelings of *tentrem* (equanimity). By way of example, I will recall an interaction with a nurse who treated Anas in the ward. Mas Banjar was the nurse who approached patients in a way that contradicted general assumptions about *kondisi klinis* being a setting where nurses and patients only occasionally opened up communication beyond physical symptoms. The intensive face-to-face meetings and interactions in the ward between Mas Banjar and osteosarcoma patients like Anas were not rigidly based on the *kondisi klinis* that tended to individualise bodies, diseases, symptoms, lives and death, but were more expansive—in the vein of a social relation characterised by a certain intimacy.

Indeed, after discharge from the hospital, Anas' relation with Mas Banjar continued as if Mas Banjar was a member of his own family. Mas Banjar's approach reflected the belief that everyone was associated with cultural subsystems (kin terminology, personal names, title) that positioned them in a wider social network (C. Geertz, 1966) and emphasised living in a harmonious state (Guinness, 1986). Mas Banjar inspired Anas a lot during his first diagnosis and therapy. When his leg became swollen and offensive because of a maggot

infestation, Mas Banjar was the one who patiently cleaned it up. Anas said, 'Mas Banjar treated me like his own brother and advised me sincerely to be brave for the amputation. Mas Banjar said, while cleaning the maggots in Anas' leg, "Brother Anas, I think the best treatment is amputation".'

Apart from embodying *kondisi klinis*, embedding morality in a clinical setting signifies the complexities of prolonged recovery and the process of creating a new knowledge of healing (Das, et al., 2001) whereby clinicians may call on values that are familiar to their patients. Life for the Javanese is sacred, and the experience of cancer or limb loss can be considered a trial from God. According to another nurse, Bu Tati,

> What I mean here is that God's blessing for humans is different from one to another. When someone has an accident and then undergoes amputation, it is a trial from God on how as a human I should deal with the amputation. Should I curse God? Or should I be grateful to God? I should be grateful for undergoing amputation rather than being dead as a result of the accident. By having amputation, I was saved and then I can still serve God. It should be like that. So, it is a trial. I can't really say anything about destiny. (Interview, 5 Aug. 2015.)

5.3.3. Edukasi *(coaching)*

Edukasi 'coaching' was incorporated into the 'corridor space', confirming what Mulder (1978, 1998) argued that distinguishing sacred life from secular tradition is non-sense. For the Javanese, all human activity naturally exists in the unity of the cosmos—the all-encompassing unity of material, social and spiritual being. Thus, the practice of *edukasi pasien* 'coaching patients', is considered to be the clinician's responsibility. He/she provides clarification related to *kondisi klinis* in tandem with considerations related to *kondisi pasien*—healing the patient by fitting them into the social and cosmic order (Mulder, 1978). There are no rigidly stated regulations related to *edukasi*. The practice is enacted as a result of stimuli in the behavioural environment, and concerns harmonising the 'inner' and 'outer' worlds. What the *edukasi* practice reveals is that integrative treatment in the metaphorical corridor is central to the process of recovery.

Side by side with biomedical treatment, the intermingled worldviews include belief in mystical healing and other beliefs that clinicians may rely on. They may, for example, reference the belief that the cause of illness is linked to evil deeds, and that illness may lead people into evildoing, and that God can cure but God requires the patient to submit to His will and feel grateful to that 'sacred will'. In the following quote, Pak Sudoko emphasises *edukasi* as a layered process undertaken by most clinicians, for which the expected endpoint is acceptance of the treatment plan by the patient. So, *edukasi* is about preparing the patient morally and emotionally by appealing to the support of spiritual and social resources.

> The patient is given the choice of whether the next treatment will be amputation or not. Then with our explanation of the reason for amputation, our hope is that s/he [the patient] is able to accept [*dia bisa menerima*], able to accept [*nrima*] [repeating his statement]. 'Oh ok, if there is a case, yes all right, please do it [amputation].' If not, ok. We give [the patient] some illustrations of the procedure so that the patient will not blame the hospital afterwards … Together with the doctor when giving patient education [*edukasi*], we [nurses] should know and make sure of the diagnosis. The doctor initiates advice and the rationale [for amputation], but not the nurse. The doctor is the first and then we [follow] … Then we see, what the patient's problem is after being educated [by the doctor]. If the patient is afraid [*takut*] then we educate them how not to be afraid. That's it. In here [the cancer ward] for example, if the doctor stated that the disease is incurable, and the medical team gives up, we should give education to make the patient feel comfortable and hopeful. Citing the religious terms, we think that what we've done is useful for others and a matter of fortune has been arranged by God. (Interview, Pak Sudoko at Bangsal, 10 Jan. 2016.)

Some doctors shared Pak Sudoko's belief that *edukasi* may motivate patients to accept amputation or chemotherapy as treatment options. In saying, 'I gave *edukasi* to patients facing amputation', he upholds scientific medicine through religious and mystical means. Clinicians, thus, pull together scientific knowledge, mysticism and spirituality into 'one package of control' that reproduces a shared moral embodiment and sense of *ayem* (equanimity) (Anderson, 2012; Guinness, 1986; Kleinman, 1992).

I round out this account of the co-mingling of affect in Javanese clinical settings and the dilemmas it often produces by reflecting on Foucault's notion of biopower (Fassin, 2009). An important aspect of Javanese culture is shared *rasa* (in the Javanese language) or affect that recognises human suffering and violence as it shapes medical care delivery and social control (Browne, 1999; Mattingly, 2010). The shared local moral world denotes intersubjective characteristics and relations comprising spiritual, emotional and religious, and points to the reality of social suffering as lived experience (Kleinman and Kleinman, 1997). Such a moral world acknowledges that life flows without coercion or force, but rather through desire or practice that is historically embodied and lived over time as habit (Bourdieu, 1977; Fassin, 2007). We have seen that nurses bring a personal response that translates clinical requirements into matters of social control and spiritual values pertaining to the patient; becoming 'close' to the patient and their family and being conversant with them. To show that a true art of healing does exist in Java, we can understand *edukasi* as a 'synthesis or syncretic ritual gaze' or mode of affect complementing the hospital structure. I see this physical and moral connectivity through *edukasi* therefore as an unexpected key to allowing patient and healer to navigate wellbeing; it is a practice whereby Javanese people's persistence and resilience in finding ways of promoting well-being finds a balance.

Edukasi is a performative representation of human living that reveals how clinicians in a Javanese hospital draw upon cultural resources in trying to generate in the patient a sense of willingness and self-discipline to follow medical treatment without coercion. Pak Sudoko's 'spiritual approach' bridges 'communication gaps' between the patient and clinician. In building the patient's trust, he enables the patient to decide autonomously about their own treatment. *Edukasi* produces new medical knowledge through building emotional strength. It does not, however, necessitate disguised power or the manipulation of desire as Foucault proposes (Pylypa, 1998). Instead, Javanese practise their distinct habits by emphasising *kondisi pasien* 'impersonal life' and the embodied experience of social, spiritual and mystical connection as their subjective experience of personhood. Through the process of *edukasi pasien*, clinicians often mix values that are incorporated in their everyday communication in order to '*membebaskan pasien dari ketidaktahuan*' (free the patient from their position of not knowing) and to achieve recovery. The *edukasi* practice is not rigidly derived from a textbook but, rather, appeals to the Javanese structure of experience (*laku*). The content of a clinician's *edukasi* offers patients and family information about diagnosis and prognoses but involves the distribution of local knowledge that complements more habitual biomedical treatment. Pak Sudoko explained:

> If a patient is cured, then it's God's gift, and if s/he's not, then it just has to be like that God's will. [If] in the end, s/he is cured, it is because of their positive spirit towards the God's will. It can really affect someone's recovery apart from their physical condition. A physical condition such as low Hb level [i.e. anaemia] can be treated with a blood transfusion, and a low albumin level can be handled with an albumin transfusion. It can be controlled. But mental condition depends on the patient alone. Mental state is the most influential aspect in my opinion. Other aspects can be controlled. (Interview, 14 Oct. 2015.)

Pak Sudoko considered that 'in life, humans will also deal with hardship. If they do not want to be bothered by having hardship, then it means they are dead.' He elaborated further, 'I equip [the patient] and my friends [clinicians] with some "philosophies" and knowledge that we accept as true. For us, the easiest way to deal with difficulties in life is to be *bersyukur* [grateful].'

> Be *syukur* [grateful] for still being able to feel exhausted. Be grateful for being able to feel hungry. Patients never complain of being exhausted or hungry. They cannot even finish one stick of satay. Sometimes I think that it's a kind of philosophy. It becomes my anticipation for patient education and motivation to my friends [clinicians]. I've never learned it. It just appears, and I share it with my friends. That's my experience when a painful situation occurs. (Interview, 14 Oct. 2015.)

Kleinman (1996) interprets social suffering as the extension of individual illness that creates shadows—of structural violence, of the political economy, and of the systematic

practice of state control. The illness experience here facilitates and transforms the relationship between the socio-cultural context and the individual person, between meaning and psycho-biology in health and illness and therapeutic practice (Kleinman and Kleinman, 1991). According to Pak Sudoko, all people, including clinicians, are being tested. Similarly, an orthopaedic resident put it this way:

> I believe that it [chronic illness and limb loss] is a trial in a form of sickness given by God to us. Allah does not burden a soul beyond what it can bear. If s/he has to undergo amputation, their job will be disturbed. However, there will always be another way to get money. If it is a fate from God, it should be accepted. I think it's a trial. We are tested so that we can be more faithful or probably it is to test us [the clinicians], really test us. Punishment is not the right term, I think. (Interview, 5 Apr. 2015.)

Indeed, in the co-existence of normative and state powers, clinicians may find themselves complementing their biomedical training with Javanese ideas, finding moments within their own practice when they express these 'moral (clinical) views' which are, nonetheless, in line with their biomedical training. Recalling Julius' story and given such complexities, Dr Agus and most clinicians cultivate the dominant moral norm and practices alongside biomedical treatment. Dr Agus' dilemma illustrates that not only clinical problems, but also individual hardship and suffering are inextricably meshed in health-care system delivery and the limits of medicalisation.

5.5. Conclusion

The clinicians' narratives re-told here unfold a picture of health-care delivery that is not dependent purely or simply on medical practice but requires other things—what I call the clinician's corridor—that patterns a space where clinicians take both their medical and Javanese knowledges and incorporate them in their dealings with patients and families. The embodied moral narrative in clinics where some clinicians bring 'corridor sense' reflects their efforts in empowering patients instead of accepting social suffering per se. I have described how clinicians may find themselves complementing their biomedical training in tandem with moral observations. They have cultivated spiritual, social and inner-self resources and remade a local (mystical) world into the clinical 'corridor'. I argue that the clinicians find the 'corridor' within their practice when they express these alternative care paths. Even so, as I have shown, the corridor is not an easy journey; clinicians may experience dilemmas in choosing which paths to follow.

Chapter 6
Stigma as a Mechanism of Exclusion

6.1. Introduction

In this chapter, my focus shifts from the hospital institution to the social context where individuals and families live with discrepancies (Whyte and Ingstad, 1995). I profile social actors who practise a diversity of philosophies and habits and focus primarily on their views of chronic illness and disability. The informants' narratives about disability reflect Javanese personhood, ethics, hierarchy and suffering (Browne, 1999; Ferzacca, 1996; Magnis-Suseno, 1997). Various discourses construct people's narratives about impairment as biopower (Foucault, 1977, 1980). I look at these discourses as constructing soft power that appears diffused through everyday discourses and acts as a technological operation. This normative power constructs bodies and subjects, reflecting an individual's lost agency at the level of power relations (Csordas, 2011).

In this chapter, I attempt to explore how the experience of chronic illness and physical disability is framed in various discourses (e.g. physical, and historical and socio-religious values). Two of the questions explored include: 1). How does Javanese society construct these discourses (related to severe illness and disability)? 2). How do these perceptions lead to diseased or disabled people experiencing stigma? I argue that the cultural aspect of *rasa* (affect) and the function of mysticism have supplemented Javanese narratives on disability. The local Javanese discourse flows in conjunction with the state discourse on disability or abnormality and layers spirituality on top of physical rehabilitation. This shapes most individuals' thoughts, desires, souls and actions that in turn become the target of discipline.

Drawing on Foucault (1980, 2012), the intermingled discourses derived from social norms, religious views and the biomedical discourses are a core focus in this chapter. Here I am looking at the organisation and social contestation that shape a particular subjectivity. I argue that the views of physically disabled and abnormal bodies are connected with local narratives that allow for people with disability to be kept in the liminal space. They are perceived as inferior in relation to meeting physical, spiritual and social standards.

6.2. Physically different

Since 1960, biomedical discourse has focused on working with *disabled* people in social rehabilitation in Indonesia. In Yogyakarta, the state institution dedicated to disabled people is

the Balai Rehabilitasi Terpadu Penyandang Disabilitas (BRTPD, Rehabilitation Centre for People with Disability), known popularly as the 'Balai'. This form of collective institutional care of disabled people aims to ensure social and vocational rehabilitation. In the Balai, people are assigned to separate rooms according to biomedical categories and they accept this categorisation as an objective and true statement about their 'abnormal' bodies. Those who work there understand people with disabilities as *cacat*, *penyandang disabilitas* or *difable.*[1]

> The Balai [social rehabilitation centre] is a building set in a large open space of about 4.5 hectares of tidy, clean and grassy gardens. At a glance, the design of the building is indeed quite similar to a hospital, school, or governmental offices. It is surrounded by quite a high fence with one entrance guarded by a security guard. Painted white, the villagers understand the Balai as similar to a hospital. The main entrance of the Balai is a large space with staff rooms leading off to the right and left side. The director's office, administrative rooms, and rooms for a psychologist, medical staff and guests are close by. Beyond these rooms is a medical clinic equipped with oxygen tubes, wheelchairs, a simple pharmacy, bed patients, and a body scale that often malfunctions. A physiotherapy room is just a few metres beyond the clinic. (Fieldnote in the Balai, 23 Jan. 2015.)

Figure. 6.1. Showing the arhitecture of the BRTPD building from the villlage street

Source. *BRTPD Website Yogyakarta*. Retrieved in June 2015 from: https://brtpd.jogjaprov.go.id

Workers in the Balai have different skill backgrounds. They include Pegawai Negeri Sipil (PNS, public service officers), honorary staff, casual social workers, teachers,

[1] An abbreviation for *differently abled persons*. Apart from the contemporary label of *cacat* (disabled people), various other labels are used to refer to physical disability in Yogyakarta such as: *penyandang disabilitas* (persons with disability or those who are labelled as disabled and unable); *tuna* (loss, deficit, broken, without, or lacking); *buntung* (cut off, loss), *pincang/pentong* (lame); *lumpuh* (paralysed); *wong ciri* (in the Javanese language means a person with different physical markings); *cacat* (defect, blemish, flaw, stain or defect, disfigurement or shortcoming); *anak inklusi* (this label is popular in educational settings such as pre- and primary school that offer 'inclusion' programs. The *inklusi* label became popular as a term to refer to children with mental and/or physical differences. This label looks at a person as marginal and excluded so they should be included. So '*Anak Inklusi*' which means Children who are included) (Soleh, 2013; Suharto, Kuipers and Dorsett, 2016; Thohari, 2013).

psychologists and physicians. Their responsibility is to deliver basic health services and more importantly to train the *difable* to survive independently of others and to rehabilitate themselves as physically fit and empowered. Labels such as *tunanetra* (the blind), *tunarungu* (people with hearing loss), *tuna daksa* (physically lacking), and *tuna grahita* (the mentally disordered) all foreground the biomedical criteria used in the Balai.

Figure 6.2. Staff of the BRTPD looking for people with disabilities in a village
Source. *BRTPD Website Yogyakarta.* Retrieved in June 2015 from: https://www.facebook.com/BRTPD-DIY-1442520329310498/.

In 2008, the global discourse derived from the UNCRPD (United Nations Convention on the Rights of Persons with Disabilities) frames disability as a consequence of structural inability for people with impairment to participate in social and economic development. In line with the UNCRPD, the Balai offers particular vocational trainings for specifically poor people with disability to function in the society. Its programs apply Indonesian state discourses and the UN discourse in shaping bodily (im)perfections in terms of certain physical and normative standards (Foucault, 2012; Goffman, 1963; Shildrick, 2009; Soldatic and Biyanwila, 2006). The *difable* and/or *penyandang disabilitas* classifications which have become naturalised in everyday Balai discourse position patients in terms of an abled/disabled binary and distinguish individuals largely on the basis of physical assessments. The blind, dwarfs, amputees and the deaf, for example, fall within the category of *difable*.

The label synthesises both the global and national language in a way that ameliorates or attempts to avoid derogatory implications. The term *difable* inscribes hope that differently abled people can do different things.

Figure. 6.3. Rooms for people with physical disabilities in the BRTPD

Source. Photographed by author, 4 Feb. 2015

Mas Bambang's narrative of the *tuna daksa* reveals how state knowledge works, seemingly easily and naturally, as a way to facilitate and exercise a certain kind of power relations where state apparatuses shape bodies, subjects and identities in their care.

Bu Ani, a teacher in a specialist school, told me about the way she supports her students with disabilities. She told me about Wawan, a Year 9 male student who studied in the specialist school. Bu Ani said that Wawan's leg was limp, but he was able to walk, and his IQ was extraordinary compared with 'normal students'. His academic abilities qualified him to enrol in a mainstream school rather than study in a segregated school. Bu Ani however told me about Wawan's experience in this way:

> He was bullied by his friends [*di-jorokke karo koncone*] at the [mainstream] school. He was kicked and beaten. So, he came back to this [specialist] school as he felt that whatever small mistake he made in the [mainstream] school would prompt his friends to kick him. Finally, Wawan is back [to re-enrol to the specialist school] to become an ever-better person [*dadi apik*]. But he is *rumongso* [feels himself inferior] and understands that the world outside is not as friendly as it is here [in the specialist school]. (Interview, 6 Oct. 2015.)

The widespread influence of a dominant biomedical discourse has even contributed to constructing a new deviant subject in schools as these comments from a Yogyakarta school

principal reveal. The provincial regulation (The Yogyakarta Governor Decree No. 21/2013 on Inclusive Education) and national legislation (Indonesian Government Law No. 19/2011 on the Convention of Right of Persons with Disabilities) provide the foundation for running inclusive education in both mainstream public and private schools. The regulations encourage inclusive education by engaging children with disabilities in mainstream schools. Eva, a senior director in a private inclusive school in Yogyakarta told me that although the Indonesian government had endorsed the inclusive school policy initiative, school culture remained unaffected. Yet, she told me that disabled children were called *anak inklusi* 'inclusion children' (Andriana and Evans, 2017) showing that the construction of 'normal or deviant' was strongly context-dependent leading to social prejudice and stigmatisation. The children of middle- or low-income families like Wawan found special education more acceptable for them.

6.3. Spiritual fault

Discourse about the 'abnormal body' in social rehabilitation centres like Balai is promoted alongside culturally valued Javanese discourses circulated in mainstream religious beliefs and the teachings of Islam. My research shows, however, that the sociocultural milieu generated by the spiritual discourse paradoxically offers opportunities for both inclusion and stigmatisation. The stigma towards bodily 'difference' emerges from a diffuse power acting with a technological accuracy and lingers as a stereotyping process or prejudice that is deeply local. Stigmatised identities evolve through spiritual cultivation in which people learn to absorb societal perspectives into their own local worlds (Goffman, 1963). I argue that religious norms and moral narratives practised in everyday life can be understood as what Foucault (1976) calls 'the arm'—as they further embed the assumptions of state discourses as a mode of discipline and control. As Foucault put it:

> The growing importance assumed by the action of the norm, [is] at the expense of the juridical system of law. Law cannot help but be armed, and its arm, par excellence, is death … But a power whose task is the charge of life needs continuous regulatory and corrective mechanisms … Such a power has to quantify, measure, appraise, and hierarchize, rather than display itself in its murderous splendour. (1976, p. 144.)

Pak Mulyono, the Islamic teacher in the Balai, told me the importance of teaching during worship, Islamic values and morality for the people with disabilities. He said the teachings should be about the history of Islam, the Al- Qur'an and the Al-Hadith as they are crucial for the spiritual rehabilitation of *difable*. He explained further in this way:

> They [*difable*] have a lot of problems in their life such as lack of mobility, social problems, and self-acceptance of their disabled condition. Sadly, their religious understanding is still lacking. Yesterday I did an evaluation and found those who can read the Qur'an are rare. Therefore, this preaching aims for them to be able to read the Qur'an properly. I'm sorry to mention (about the *difable* who lack spiritual capacity) but the preaching is therefore aimed for the *difable* to avoid trouble living in this world and the hereafter. (Fieldnote, 28 Jan. 2015.)

Pak Mulyono spoke proudly, pointing out several *difable* females who wear the *hijab* (headscarf) after rehabilitation in the Balai and explained to me further:

> Preaching is substantially to encourage the *difable* to believe in God [Allah], to perform the obligatory prayers [*ibadah fardhu*], to motivate them to engage in society without being timid or fearful, and for *difable* women to wear the *hijab* or headscarf. (Fieldnote, 28 Feb. 2015.)

My fieldnote below shows how practices, assessments and courses in the Balai blend biomedical discourses and spiritual views and naturalise a particular mode of rehabilitation around certain social norms.

> Balai life starts early in the morning when Muslim *difable* perform the early morning prayer (Subuh) at about 5.00 a.m. At 7.00 people get together in the hall to have breakfast. At 8.00 classes begin and continue until 12.30. Then there is a break for one and half hours that gives time for midday prayers, lunch for all, followed by more classes or courses. Classes finish at 4.00 o'clock. Sometimes, but rarely, there are compulsory courses after 4.00. At the end of the day I usually see the *difable* playing around the balai, spending time in their dorm, or just watching television in the staff room. (Fieldnote, January 2015.).

The vignette suggests that the Balai is a centre that is grounded in a perspective of mystical inspiration that accommodates both *zahir* (physical) and *batin* (inner self) considerations. The medical and more spiritual discourses are combined reflecting how biomedical discourses and spiritual discourses from state-licensed and employed religious organisations inform practice delivery and the reception of Balai care. But as I shall discuss below, these intermingled discourses together contribute to representing disabled people in ways that render them spiritually inferior and stigmatised.

In everyday village and urban life, much teaching and preaching from more fundamentalist religious groups uses physically disabled people as an example of the spiritually and morally inferior. Physical disability is seen as a reflection of previous moral or spiritual misconduct and disabled individuals are told to reform themselves in terms of religious standards. In the eyes of God, according to Kyai Salim, Islamic religious discourse sees individuals with severe illness and disfigured bodies as equals as long as they are practising *taqwa*. The notion of *taqwa* is grounded in the principle of 'unity with Allah' (Tauhid), meaning that every person has the chance to become what Kyai Salim described to me as Allah's slave (*hamba Allah).* In a similar vein, Pak Kasiman, a traditionalist Muslim

lecturer at the Yogya Islamic University cited the Qur'an and stated that the most honourable persons in the sight of Allah are those who practise *taqwa*. He focused on the relationship between humanity and divinity that in Islam is understood as a relationship between the inner self (*batin*) of a servant (*kawula*) and 'God' (*Gusti*). The Islamic discourse of *taqwa* implicitly suggests that people who experience chronic illness and disability have more of an obligation to achieve spiritual unity with God. Pak Kasiman added further:

> The *taqwa* [or *at-taqwa*] is willpower and awareness to avoid anything that could lead to a curse [*laknat*], wrath [*murka*] and punishment [*adzab*] by Allah. It is originally from the words *ittaqo yattaqi* and *waqoo yaqii wiqoyah* which mean to avoid, to stay away, and to save life. It is about individual ability to avoid behaviours that lead to Allah's curse. Human dignity is based on the *taqwa* as cited in the Qur'an as '*inna akromakum indallahi atqokum*' [to do Allah's order and avoid Allah's prohibition]. (Interview, Pak Kasiman, 3 Aug. 2015.)

The vignette shows how Islamic religious views were embedded in the way Pak Kasiman perceived *difable* as persons at risk; as those who were particularly obliged to take on their spiritual obligations or religious responsibility. Central to Pak Kasiman and Kyai Salim's view was not only the teaching that disability and illness represented 'evil' domains or sins, but that the disability experience positions subjects as spiritually impure.

The scripture-centred religious discourses circulated by Pak Mulyono, Kyai Salim and Pak Kasiman were complemented by other Islamic and *Kejawen* spiritual discourses which informed rehabilitation patients' and fellow villagers' sense of what it meant to be disabled. Pak Kasiman was a community leader in a village in the South of Yogyakarta who saw the consequences of past sins as opening up opportunities for individuals to grow closer to God. He commented on a fellow villager, Bu Ngadirah, who lost her leg in a traumatic car accident, saying:

> The amputation generated *hikmah* [consequences] [for Bu Ngadirah] as she now starts to regularly pray and so on [practising other religious obligations]. [Before the amputation], she might pray [*sholat*] but only occasionally. Like another villager who only prays on Monday and Thursday and during *poso* [the month of Ramadhan]. (Interview, Pak Kasiman, 14 Jul. 2015.)

These comments suggest that the *difable* should reach out for spiritual rehabilitation or rectification, turning away from materialistic principles. An accident has a special value as it may encourage the disabled individual to learn about morality, spirituality and ethics that bring them 'to be one with God'.

Pak Rekso was a forty-nine-year- old modernist Muslim man working as a casual labourer in urban Yogyakarta. He told me that he was upset by his *abangan* family background and the fact that his sister was a Catholic. Given these circumstances, he told me that he strove to persuade his big family to live in accordance with Islamic law (fiqh) but

always failed. In everyday life, he strove to fulfil Allah's commandments by always practicing the obligatory prayers five times a day in the mosque. But, a combination of both normative piety and *Kebatinan* (*Kejawen*) remained deeply embodied in his awareness of the pathway to participating in unity with the cosmos. As a modernist, Pak Rekso rejected practices associated with honouring deceased religious teachers, ancestors and visiting the graves of local saints as practiced by traditionalist Javanese (Fox, 2004). Pak Rekso told me about a young girl, Desianti, whose amputation he regarded with *aib* (pity) showing how his religious belief had determined his perception of the disability. He also commented on his blind neighbour who was also his previous employee. He expressed his readings on the blindness by saying:

> Having such a condition like that [blindness], he should obey the religion. They are currently 'on trial' (*cobaan*), aren't they? So, they must do God's order which is obligatory prayer. When there is a call for prayer [*adzan*], he and his friends should stop working. The work could be continued after prayer. (Interview, 29 Jan. 2015.)

Bu Nur is another villager who said that it was not easy to change the Javanese mindset which linked disability with previous deeds and faults of the disabled individual, or even their parents and ancestors. What Bu Nur expresses below shows that physical disability gives rise to imposed disciplinary projects and ritual exclusion. Disabled people are marginalised, and the way out of their marginalised position is dependent on their attention to prescribed moral obligations. She told me:

> There would be no critical comment [about disabled people], as long as [pause] [they meet social and spiritual standards]. If they are not humble, showing *rumongso* [acknowledgement of their lower social status], then the community will not care for them and, ethically, the society has its own norms and values whereby those who experience misfortune or bodily impairment should obey the social norms—religious and spiritual. (Interview, 4 Jul. 2015.)

Pak Mulyono and other informants explained for me the argument presented here that a person with a physically impaired body is a highly complex subject structured by a web of contending discourses all of which carry some cultural, historical, legal and social power. The *difable* and, specifically, individuals marked by illness and bodily impairment are considered to be marked by amoral and wrong behaviour. Indeed, to a greater or lesser degree, the body with limb loss is categorised by society as weak, abnormal, different or deviant. Although informants described different ways of responding to and rectifying disability, there was a general consensus that disability signifies spiritual fault, and that individuals bear the responsibility of bringing themselves more in line with normative expectations of behaviour.

6.4. Social inferiority

Physical and spiritual inferiority positions people with physical disabilities as socially inferior. This stigma is particularly directed towards *difable* who live in poor circumstances, with only informal work and no guaranteed livelihood. The Javanese sociocultural system of normalcy was expressed in various programs in the Balai where *penyandang disabilitas* were encouraged to remake themselves in accordance not only with religious but also social expectations. Pak Mukhlis was a senior Muslim PNS in the Balai who believed in the importance of the weekly preaching of Islam for the *difable*. In the rehabilitation centre, *difable* are known as WBS (*Warga Bina Sosial*) or 'People Under Social Control'. He told me, 'the preaching is aimed to encourage WBS Muslim to have faith in Islam and be closer to Allah and that preaching Islam is to develop the WBS' confidence in society.' Pak Muklis' words reflect the social prejudice that physical failure implies spiritual failure and results in social failure.

A sense of predetermined social failure is signified in the term WBS that describes individuals in Balai programs. The WBS discourse emphasises the inferior character of rehabilitation participants as 'abnormal' people in need of re-shaping in accordance with social standards. What is conceived as normal for the always/already disadvantaged WBS means that rehab patients are expected to become productive in performing a very narrowly designed range of programs and training. The programs may change every year, but at the heart of the programs is an assumption that WBS are understood as 'different' subjects who deserve to perform at only a limited standard. The WBS in the Balai are offered a very narrow set of skills to learn, based on very stereotypical notions about how they may get back into society. In many respects these may come to limit rather than enhance the subjectivity of those who participate. Very typical for example, those WBS who are blind usually attend massage courses. Physically disabled patients may attend basic courses in computing, graphic design, handcraft, electronic repairs and service and sewing.

One fine morning I accompanied Anas to practise archery at the soccer field to the south of the Kraton. An old reformist Muslim woman whose daughter had also joined the club asked me cynically about Anas. Showing her contempt and mistrust of Anas' ability in archery, she expressed her low opinion of Anas. 'Why is that [legless], what happened to him?' she asked. I answered, 'He had an amputation six years ago because of a cancer.' Her face still looked skeptical. She looked down upon him and said, 'Oh I thought it happened because of *cacat bawaan lahir* (congenital disability). Indeed, many people, like the old

woman, seeing Anas for the first time often appeared to show him disrespect. With curiosity, I asked her further, 'How do you perceive a person like Anas?' She said 'Arggh'. She discontinued her comments, rather looking down and turning her face away from him. The conversation paused until she whispered 'as long the person can show his *prestasi* (making merit)'. I could see from her body language that she considered Anas to be socially inferior. Being different is often perceived as about being odd and about asking for social acceptance.

The old woman's gesture showed stereotyping and bias about disability that remained strong in social settings. I observed that people with disability were not only offered limited opportunities but that many facilities were inaccessible for them. Most people seemed to perceive that disability meant less abilities and people with disabilities were being restricted, deprived and deviant. These collective social responses erected barriers, as most people regarded them as 'disabled'. In the education sector, people with disability rarely achieve higher levels of education and qualified skill levels. Living with disability remains a barrier to entering schools and the workforce. The stereotype underpins the attitudes of the public and its willingness to accommodate people with a disability. Furthermore, job discrimination in the government sector against people with disabilities is very significant in Indonesia. The selection criteria for government officers (PNS) do not make room for people who are not *sehat jasmani dan rohani* (physically and mentally healthy). These criteria have discouraged people who are physically or mentally disabled from joining the formal sector. Although disabled individuals may meet key criteria and have appropriate qualifications they are often excluded because of their disabilities and the social stigma attached to them.

I discovered that social demands in urban kampung may marginalise people with disabilities if they are unable to meet normative social expectations. Martokasmin was a forty-five-year-old Muslim who worked as a cleaner in one of the Christian NGOs. He was a migrant from East Java. Martokasmin's wife used a wheelchair and had to work every day to boost their limited income. I observed that according to Martokasmin and his wife, their neighbours appeared to not respect and rarely even greeted them. Martokasmin told me that sometimes his neighbours invited them to family celebrations and ceremonies like *syukuran* or *slametan* 'thanksgiving'. Their kampung neighbours believed that donations or labour towards a *selametan* boosted individual esteem. But it was impossible for Martokasmin and his wife to make such contributions. They said that their salary was only enough for everyday spending such as paying rent, groceries and petrol for his motorcycle. Once a neighbour invited him to the *selametan* of his son's wedding. But Martokasmin felt ashamed to contribute only labour. Martokasmin told me that he was willing to volunteer his labour but

that most residents saw a donation as also important. In a *selametan* for a wedding ceremony, the host usually distributes food while those who are invited should also assist in the food preparation and bring donations (*sumbangan*). Martokasmin told me that being formally associated with such celebrations in the kampung meant individuals were expected to contribute at least Rp 50.000 (AUD 5), and that these ceremonies and their built-in expectations occurred often. He explained that he had lost community esteem by withdrawing from these social events, and that his withdrawal was not directly because of his disability but his inability to meet the financial expectations involved. Martokasmin and his wife confided to me that 'it was better for them to just avoid going to any *slametan* or urban kampung celebration'. Martokasmin's story shows how the social trust and intimacy that the couple once enjoyed had declined and had marginalised both him and his wife.

Muslim villager Pak Tugiman (65-years old) was Bu Ngadirah's neighbour. Pak Tugiman told me his personal story and recounted how he had his left upper arm amputated after being electrocuted during *gotong royong* (a mutual help working bee) in the village. His neighbour, Bu Wulan, said that his experience of disability and poverty was a warning from God that he should bring his behaviour into line with the religious and social order (*taubat*). Bu Wulan said that Pak Tugiman had ruined his life as he was addicted to gambling, *ndugal* (doing bad behaviour) and *royal* (arrogant) personalities. She thought Pak Tugiman's life had been spiralling out of control and lacked balance. His money had been spent on gambling rather than sending his children to study at the *pesantren* (Islamic boarding house). But after his traumatic accident, Bu Wulan said that Pak Tugiman brought his life back to normal. She said further that 'by village standards, Pak Tugiman was previously wealthier (*ngunu maune kaya*) than most, but now he is now less wealthy but socially equal (*setaraf*)'. As Bu Wulan saw it, it was unacceptable behaviour that resulted in Pak Tugiman's catastrophic injury—a disability which significantly altered his social status but benefited his sense of inner self and social inclusion. Pak Tugiman is now accepted on a par with other villagers. There was threat to undisciplined individuals and the sense of vulnerability that Pak Tugiman must deal with if he does not meet spiritual and social standard. Since individual depart from such social norm, so she/he may frequently loose social approval. People with disability may be exposed by the identical gossips in village and that may lead to the stigmatised body or in extreme cases a justification for social marginalization and punishment.

Mbah Tin was a villager living in west Yogyakarta who did not usually explicitly label people as *cacat* (which she sees as derogatory). Mbah Tin was more likely to keep silent or use a phrase such as *orang seperti itu* (people like that). While adopting a compassionate

facial expression, Mbah Tin uttered the magical words *amit amit* (‘God forbid’ or ‘don’t let that happen to me’) or *astaghfirullah* (‘God forgive me’). These magical words were expressed verbally to avoid bad karma or *kwalat,* to invoke what was normative and to escape from the curse of retaliation. Her language was a synthesis of Islamic and pre-Islamic Javanese religion. Yet the magical words were part of a mystical orientation as well as being citations from the Qur'an text, and pointed to a cosmic order in which every individual’s interior self is positioned equally. In everyday social relations, however, the *difable* often became the subject of mockery as ‘different’ or ‘odd’ people. Mbak Tin gave an example of her neighbour Pak Mus who was considered physically disabled in her village. Pak Mus put himself forward as a neighbourhood leader which Mbah Tin thought was fine. But most villagers rejected his willingness to hold office. She said: ‘Masyarakat kita belum begitu bisa menerima kondisi semacam itu [Our society is not ready yet to accept people with disability].’ (Interview, 23 Aug. 2015).

In Yogyakarta, however, the engagement of the *difable* in Sultanate rituals was historically recorded. The Kraton recognised and accepted abnormal persons like the dwarf *palawija* and identified their inner self as triumphing over their otherwise abnormal physical form. Historian Peter Carey (2014) noted that dwarves, termed *wong ciri,* in particular such as *palawija* or *nonok* were court servants (*abdi Dalem*) who acted in various roles (Figure 6.4). Carey (2014) noted that *palawijo* acted in multiple roles such as teachers, servants, guardians, advisers, masseurs, and herbalists, interpreters of dreams, and even clowns or jokers. They enjoyed close relationships with aristocrats and members of the royal court (Carey, 2014).

They worked at the palace and were involved in the yearly Kraton ‘Garebeg Sekaten’ ceremony. In a royal ceremony, *palawija* were positioned at the front in order to protect others from ghosts (*mahluk halus*) and were believed to be ‘the doorway’ (*pembuka jalan*) of Kraton affairs. What can be learned from the Kraton tradition is that it is only those with congenital disabilities like the *palawijo* who are accorded special respect and value. Nowadays the mystical supremacy of the *palawijo* does not necessarily extend to those with different physical bodies due to injury or severe illness like Anas or Martokasmin. Today in Java, people with disabilities are stigmatised as individuals who are not worthy of resuming a full place in society. It can only be otherwise if they follow financial, spiritual and social obligations.

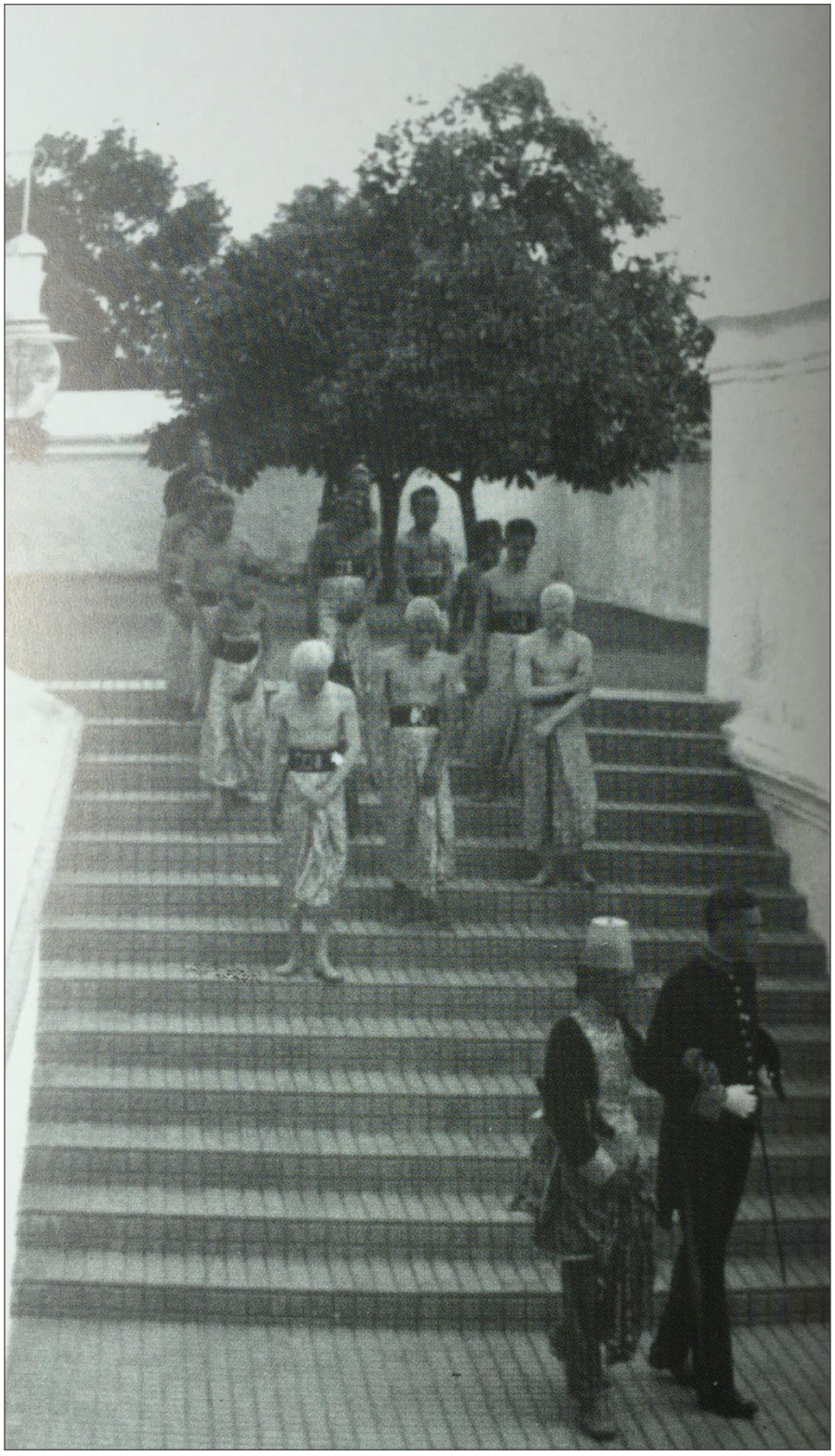

Figure. 6.4. This picture was published with the following caption, '*Polowijo*, albino, *cacat* (defectives) and dwarves during Gerebeg ceremony in an exhibition catalogue,' suggesting that mixed discourses of defective bodies and spiritually powerful bodies are current in contemporary Yogyakarta.

Source. Java-Instituut dalam foto. Museum Senobudoyo Yogyakarta and Erasmushuis Jakarta 2001

We have seen that social marginalisation may be the outcome of an inability to take part in social events. When a person cannot attend social gatherings or contribute in other ways then they lose social status. So, the ideal of *rukun* (harmonious association) does not necessarily extend to those with different physical bodies who are not able to make a larger contribution in communal life. A neighbourhood leader, Mas Jasiman commented about Bu Ngadirah who is a leg amputee:

> Leg amputees remain unable [to be involved in village affairs]. It means we do not include [them]. [They] are unabled! There is only a small chance [to involve them] as [they are] unable to walk. Nowadays they [the *difable*] are 'special' [*diistimewakan*] because of their body difference and disfigurement, so it is not necessary to involve them. Such involvement is unnecessary [*ndak perlu macam itu*]. (Interview with Pak Jasiman, 2 Sept. 2015.)

The central aspect of *rukun* as understood by the kampung leader Mas Jasiman indicates how *kampung* people mimic knowledge of the Kraton. He tried to respect Bu Ngadirah in a different way—by respecting her inner-self capacity of *rasa* rather than pointing out her physical disability.

What I argue here is that embodied differences may be accorded social esteem or may be a reason for withdrawing social esteem. The acknowledgement of an individual's social worth or the withholding of an individual's sense of social worth are both central to an individual's sense of identity and personhood. Stigma does not apply to everyone and not everyone regards people with disability in negative ways. We have seen how historically the Kraton looked differently at the (congenitally) disabled. In this next vignette, we see that it is less common to characterise a wealthy, powerful or educated *difable* person as socially inferior because of their disability.

Mas Johanes was a young Javanese devoted Christian who was born in Yogyakarta. In his view, most people do not have open minds and he said that 'some Christians believe that a physically impaired body may be due to a curse or *kehendak Tuhan* (the will of God) and that these discourses are derived from the old Bible (Old Testament)' (Interview, 12 May 2015). He shared with me that he believed most of society remained disrespectful of people with physical disabilities, but went on to note how impressed he was with his neighbour, Romo Soegi. Romo Soegi had an accident resulting in an amputated upper arm. According to Mas Johanes, Romo Soegi is a Catholic priest who is physically disabled, but his physical condition has not positioned him as morally or socially inferior. Everyone in his neighbourhood regards him highly as having good character—a leader in the Church, with a well-established job, and someone who works hard. Mas Johanes was especially impressed with Romo Soegi's preaching in church. According to Mas Johanes, the way Romo Soegi

looks at his limb loss situation has impressed him and most people in church and everyday life. He said:

> I have often *pakewuh* and *segan* [putting high respect] as Romo Soegi is my leader. The Bible states that being a priest he should not be physically disabled so that he can serve everyone but the fact is that he does not show physical inferiority at all. He often jokingly laughs at his physical condition and looks at himself as not inferior. I think that he *nrima* [accepts his circumstances] and shows *bersyukur* [acknowledgement for blessings], doesn't he? That is great! Romo Soegi is *panutan* [an idol] and highly respected in my neighbourhood. (Interview with Mas Johanes, 29 Apr. 2015.)

6.5. Conclusion

I have illustrated how people with severe illness and impairment are singled out for re-correction in terms of physical and spiritual remedies that complement social restitution. More formal state regulation and the soft power of social expectations work to brand people with physical disabilities and at times become mechanisms of exclusion. The complex blend of socio-religious beliefs and expectations with biomedical discourse and practices in everyday life circulates public constructions of disability that impose certain kinds of unequal social relations and oppression. In other words, the circulation of biomedical knowledges and local perceptions of physically impaired bodies that I have emphasised here to a greater or lesser extent are productive of biopower: the different discourses draw on each other to construct an effective power mechanism.

I argue that within the context of a hierarchical society, these intermingled assumptions become the foundation for a vague consensus that *difable* constitute *kelas 2* (a second class of persons). But we have seen that this does not affect everyone, and that not everyone is affected in the same way. What I have tried to show in this chapter is the threat that disability presents, and the sense of vulnerability that *difable* must deal with if they are to function in society. I argue that the diffused power disguised in various discourses may lead to the stigmatised body or in extreme cases a justification for social death and punishment. The following chapter will reflect on how villagers with severe illness and disability cope with the stigma they experience.

Chapter 7
Anglakoni Urip: Life's Walk of Faith

7.1. Introduction

This chapter focuses on Javanese expressions of personhood, the subjective experience of *anglakoni* and individuals perceived as chronically ill and physically 'different'. I argue that in oppressive environments where subject(s) confront body limitations, stigma and social barriers, there can be a 'negotiated space' of struggle or resistance. This is how I understand *anglakoni urip* (a Javanese phrase which means to walk through life within Life). It is a practice, not simply an emotion or a cultural outlook that celebrates life within Life. Central to the practice of *anglakoni* is *Kebatinan* that carries a transcendental connection with the purest 'immanence' of 'God' (Mulder, 1975).

The practice of *anglakoni* naturally situates every individual on a path where an everyday sense of Javanese 'culture' is not just the product of state structure but a seat of agency and meaning making in social life. It amounts to an embodied series of social practices that are ordered through time and space (Giddens, 1984). In all this there are habits that individuals may embody to 'let life run' through the power of cosmic order. A life invested in *anglakoni* involves practices of moral cultivation that build up the Javanese self or ideal of personhood. *Anglakoni* not only accounts for individuals seeking physical well-being but also the less tangible realisation of a harmonious inner-self (*batin*), spiritual mindfulness and social esteem. In this chapter I will discuss three habitual practices that are constitutive of *anglakoni urip*: the practice of acceptance (*nrimo*), the practice of building and maintaining social connectedness (*srawung*) and the practice of living in a way that embodies God's blessing (*hikmah*). Living or performing in life in ways that embody these values opens up ways for marginalised people to take charge of their lives and fate and balance their sense of themselves with the transcendent moral or cosmic order.

Further, my investigation draws on the phenomenological tradition in order to explore the essential ground of human experience by centring the body as the locus of intention, sensation, perception and interaction (Csordas, 2015; Merleau-Ponty, 1962). It explores individual bodies as distinctive human beings as they live and inhabit particular Javanese settings in a given time and socio-political context (French, 1994a; Hallowell, 1955; Pitaloka, 2014). Their existence of being in the world embodies culturally prescribed activities and coping strategies as a way of providing strength and socially sanctioned means of performing

in larger society. So, being in the Javanese world involves body, soul, pleasure, sensation and physical bodily behaviour that manifest and represent Javanese values and ethics (Csordas, 1994a; Magnis-Suseno, 1997).

7.2. The divine spirit of acceptance (*nrima*)

The relationship between illness, disability and spirit has been extensively explored in medical anthropology. Desjarlais (1992) for example assessed how body, spirit and society become essential to Yolmo villagers' concept of 'health'. Crucial to Desjarlais research was the realisation that there are intuitive mechanisms that allow individuals to gloss the experience of illness and healing in the Himalayas of Nepal. Similar findings have been explored in Javanese society and have revealed a concept of health that is broader and much more comprehensive than the way Western biomedicine maps illness. Central to the Javanese view is the understanding that spiritual practices are part of the crucial process of healing because the divine spirit offers resources for individuals to validate faith and empower them in everyday suffering (Pitaloka and Hsieh, 2015).

Throughout this dissertation, I have recounted instances of humility and deeper sensitivities in the way Jelita and her mother Bu Sumiati *anglakoni* life. In the midst of so much pain, disability and loss, it was not that Bu Sumiati moved past her own grief or resolved her difficulties but about how well she had managed misery, sadness and financial difficulties. Indeed, the stigma in everyday life meant that *penyandang disabilitas* and their family frequently struggled to establish and hold onto their social identity (Goffman, 1963). My discussions and observations showed that Bu Sumiati had embraced and cultivated the Javanese moral disposition of acceptance without protest (*nrima*) when her daughter Jelita was moving back and forth to hospital. Despite the hardship, acceptance was expressed simply as being grateful for Jelita's being alive. The way Bu Sumiati lived out her painful experience signified her understanding within *Kebatinan* that it was vital to bring one's inner life under control.

The disposition of *anglakoni* showed the Javanese individual's gesture to maintain the morale of harmony and accept life as it is; or life 'as such' (Fassin, 2009). So many of the families I write about here who were shaped by disability, poverty and bodily suffering adopted the practice of *nrima* (resigned acceptance), *syukur* (praise to God) and *anugerah* (blessing) into their lives and made these practices the cultural and structural grounds of everyday living.

Nrima in the Javanese sense relates to the ability to concentrate on the cosmic force within oneself (Magnis-Suseno, 1997). By connecting her inner (*batin*) and outer (*lair*) self, Bu Sumiati believed that with simplicity, acceptance and *legowo*, someone can achieve inner peace manifested as a level of self-acceptance. The concept of *legowo* that Bu Sumiati showed may be understood as the face of an inner power that in the Javanese sense is not merely about a moral issue but is also affirmative:

> Power is not used; it is there, it flows from within itself, it is not applied by the ruler, but he lets it flow out and the only thing he can do is to contain it and to let it flow. Any action which proves itself powerful is, in itself, justified. (ibid., p. 113.)

Bu Sumiati was aware that in Javanese society disability is frequently associated with stigma and that society withholds its acceptance of the disabled. But the well-established practice of *legowo* (accepting something unpleasant in a sincere manner and with resignation) opened up powerful opportunities for her to cultivate a sense of inner harmony. Through habits of the inner life, individuals disposed themselves to inward looking and organised the self in terms of time and space by conforming the forces of *lair* and *batin* into the state of *nrima* (Giddens, 1991; Mulder, 1998).

In the eyes of Javanese, there are no coincidences in life. Tio lost his two arms when he was thirteen years old. His account of how he learned to manage the consequences of his catastrophic accident embodies the Javanese mystical practice of managing the *batin* (inner-self) as a way of surviving unexpected hardship in life. During the challenges of repressive social stigma and isolation he experienced after his traumatic injury, Tio believed God would always show him the best way to live and give him the best life—including friends. He believed that anything that happened to him was a sign of a mystical power and justified as the ‘truth’. He felt that up to the present he had colleagues, friends and good people around him who were like family to him. He said, ‘It was difficult in the beginning. But everything has been planned and determined by God,’ including his social life and friends.

Tio was a young Catholic man. When I met Tio, he told me that his mother had just passed away and that his father had passed away three years after he was injured. He was in his third year of junior high school when he was electrocuted while helping his uncle work in a house. His hands were in contact with a live cable for about twenty minutes. Tio was knocked unconscious and neighbours who were at the scene thought that he had died. However, he was finally rushed to the hospital after some people noticed that his heart was still beating. His condition improved after he had been hospitalised for a few days. But when his hands were being cleaned, the flesh kept falling off. Doctors finally advised amputation as

the best action to be taken and Tio and his family accepted that advice. Initially, amputation was done only to Tio's left hand. However, a week later the team of doctors decided to cut off his right hand as well because it could not be saved. The amputation caused him to lose both of his arms below the elbow.

Tio had a very difficult time after the traumatic accident. His emotional state was unstable and scared even him. He admitted that he often got angry easily because of the way people around him treated him distrustfully. People's response made him more depressed and reluctant to move out of the house and thus kept him isolated from wider society. After several years, Tio told me that these experiences shaped his thinking and he resolved to accept whatever life God had given to him, and to be *legowo*—to live with his circumstances with full acceptance (*nrima ing pandum*). Javanese believe that embodying the sense of *nrima* allows individuals to find themselves mystically filled with faith, confidence and balance. Tio came to realise his life should become a continuing effort (*berusaha*) to obtain God's blessing. Thus, *anglakoni urip,* in Tio's sense, was not about finding a 'way out' from destitution and social stigma, but what we might think of as finding the 'way in' and living with it.

As a human, every Javanese individual puts strong emphasis on the nothingness of her/his existence under the highest cosmic forces and order (Guinness, 1986; Mulder, 1998). These beliefs in a cosmic hierarchy were reflected in the way Tio always returned to the philosophical belief that through *Kebatinan* he would be able to create a mystical experience that might instigate self-assurance, hope and stability. Very gently Tio often told me how he responded to people who thought that disability was like an infectious disease. Some people thought that those who stayed close to disabled people would also become disabled. He had experienced this sort of prejudice when anyone avoided contact with him and his disabled friends. At the time he was helping Roni sell 3D artworks on the street in Yogyakarta. Roni was also disabled and used a wheelchair. A child ran to their display and was interested in buying one of the items. However, the child's mother immediately stopped the child because the sellers had physical disabilities. Seeing the reaction of the child's mother, Tio could only stay silent, and keep his sadness and irritation to himself. His prayers for the child's mother were his (positive) contribution to others; he prayed through his *batin* (inner self) that the mother would not suffer the same fate as him. He said, 'I wasn't angry. I just prayed so she would not become like me, that she would be more grateful because she is physically whole, and that she wouldn't become arrogant. It is useful for everyone. It's a blessing for others.'

He was aware of how spiritual power through his prayer activated social and mystical energy that could avoid further disaster or misfortune for others.

So, the embodiment of *Kebatinan* as a cultural practice is a key element in healing and brings flashes of transcendence that create an imaginative frontier to personhood and self-esteem. A heavenly god may cause a hindrance to people's lives or a bad spirit (*saytan*) may cause trouble in the body. Tio often complained about his difficulties in doing daily activities and even seeking a partner in life. The values that he held of *nrima* (acceptance), giving way (*ngeli*), patience (*sabar*) and the idea of God's will of karma, however, offered him support in the hope of miracles to come. Tio finally came to understand that God would give him the best later, including a life partner for him. He told me he longed for a motherly figure as a wife—someone tender hearted, honest and open. He expected to meet someone who was not physically disabled, but like the Indonesian singing star, Agnes Monika. Tio mused:

> For me, the most important thing is that we give it a try [to set standard] first. But God determines the final result. At least we have tried. We should never be ashamed to try even though the result is not what we wished for because if we don't try, we will never know, will we? It's probably like that for everything, including [finding] a life partner. For example, I know a girl, but then my relationship does not go in accordance with my wish. Let it be, there is no need to regret it. God will give me someone who is better later. (Interview, Tio, 16 May 2015.)

What can be sensed from Tio's experience is that the *kraton* discourse on hierarchy is embedded in *Kebatinan* practice. It has given Tio the power to '*anglakoni* and to accept what God, who has given life to me, lays out for me.' He said, 'I learn from life and daily life, bitter process and experiences, and see that unpleasant things are aspects that shape someone. But life goes on.' Tio has put aside his bitter life and transformed it into an affirmative feeling instead. He said that 'as a Javanese, I have tried to practice spiritual values such as simplicity, *legowo* and being patient in response to God's will.' He has been inspired by his teachers who told him that, 'the most essential point as human beings is that we have to be patient. No matter how often you pray, if you can't be patient or *legowo*, it means nothing.' Tio learned the practice of *Kebatinan* through his various village teachers or *orang pintar* and through social interactions and his recognition of the transcendent—the hierarchy of the power of the cosmic force. As he saw it, individuals were to live in a way that maintained balance or order and to behave in a manner that would guide them to rewards (*pahala*) or beneficial karmic effects. Submission to God leads individuals to expect His blessing, to gain reward, and to avoid His wrath or retaliation.

Tio's story shows that the battles of a*nglakoni* can be understood not in terms of agreement with the state nor the regime of technology. The practices of *anglakoni* are a manifestation of a subversive power when *batin* is interwoven with *lair* (physical life) and mystical supremacy through the everyday, courageous behaviour of individuals suffering stigma and social exclusion. This embodied *Kejawen* world reflects a cosmic order where individuals' inner selves (*batin*) are positioned in well-ordered, hierarchical structures and joined together in a harmonious whole. The habitus of *nrima* to use Bourdieu's term provides a way for individuals who are chronically ill, and those with bodily impairments to address and sustain themselves in the face of stigma, but more than that, to embody *nrima* as a pathway to healing through awareness of the unity of life. As Das (1998, p. 183) writes about power, the everyday life is not only surrounded by uncertainties and doubts but somehow also lit by flashes of transcendence. Following Das (1998) and Conrad (2014), I observe that the *anglakoni* through *nrima* may deliver a striking passage:

> Clearly, the process for recovery for individuals and for groups of people often entails not just 'descent into everyday' but also some contact with transcendence that can tip the balance of everyday interaction away from their shadow side, fostering trust rather than doubt. (Conrad, 2014, p. 76)

When it comes to serious illness and disability, the sacramental affect/*rasa* and cultural practices underpin the human condition that enables him/her into a liminal space where s/he lose or gain power. Living with any chronic disability and illness, especially when it is coupled with poverty and beset by hierarchy, can be a grim journey. So, there is no simple solution for Bu Sumiati, but her devotion to the 'owner of Life' provides a way to feel 'cured'. The practice that is reflected in the most private aspect of Bu Sumiati's life reveals the paradox. Foucault said:

> One might say that the ancient right to take life or let live was replaced by a power [of ritual] to foster life or disallow it to the point of death … Now it is over life, throughout its unfolding, that power establishes its dominion; death is power's limit, the moment that escapes it; death becomes the most secret aspect of existence, the most 'private'. (Foucault, 1976, p. 138.)

Yet, what I found here is that *anglakoni* as the everyday form of resilience was an integral part of class-based resistance and a required stimulus to win a solution to the 'problem' (Scheper-Hughes, 2008; Scott, 2015). I was in an online Whatsapp group with Jelita, and aware of her chronic pain and her changing attitudes. She uploaded her picture standing with one leg aided by crutches—showing her smile and pleasure. Jelita had been having intensive treatment continuously for more than one year—back and forth to the Sardjito Regional Hospital. The lengthy hospitalisations and traditional healing practices

were triggered by her blurred vision, ear and chest pain and severe stroke at which point she let go of life, as Bu Sumiati told me one year later. I was deeply upset when I found that she had passed away through the online group Whatsapp. The site was filled with condolences from her online friends:

> Goodbye Jelita. Praise to God who has provided [you] with a beautiful space in heaven. Life or death, married [*jodoh*], rich or poor is all God's secret. We'll never know when we are going to 'leave' [die]. We should feel thankful [*bersyukur*] as [God] scared us with the cancer. Because we are chosen by God and warned by Him to behave as a good [person] before the time comes [for dying]. (Message on WhatsApp Group of Young People with Cancer, 19 Jul. 2017.)

Here, the Javanese-self is a distinct human shaped by social interaction and the embodiment of cosmic, metaphysical and 'religious' components (Browne, 1999; Hallowell, 1955).

In summing up Jelita's life story, Bu Sumiati conveyed to me her deep sorrow, but she also showed a sense of release, strength, praise and the belief that Jelita had been taken by God who put her in 'the best care'. She told me that Dr Agus also sent his condolences when he heard that Jelita had passed away. Bu Sumiati felt release when the specialist applied Javanese values of intimacy in this social relationship. These doctor/patient relationships demonstrated the place of communality that clashed with rigid biomedical norms of behaviour. Dr Agus was trying to be emotionally close to Bu Sumiati, sharing his feelings and empathising in everyday suffering. In Bu Sumiati's experience of heavy burden and loss 'new life' was cherished by *anglakoni* as a kind of holy pathway. God is the most powerful and causes everything to happen in this world, as Bu Sariati said '*Dibandani piro wae tetep ora nutut* (no matter what value people put on it, Jelita's life will not come back).' In my conversation with her on the phone, she held her grief to herself and continued to tell me that she had been trying to *nrimo*, *menerima dengan ikhlas* (accept), ask for forgiveness and often say thanks. 'I shall be thankful [*berterimakasih*] so much to all the people involved especially Dr Agus and the nurses in the hospital,' she said.

Bu Sumiati confessed how accurately the doctor had predicted Jelita's life span, so she should accept the 'truth'. She said 'God be praised that they [the doctors] said Jelita would survive three months to one year. Yet my daughter lived for the maximum time.' She accepted that and stopped expecting the miracle to come again and transform her suffering. She said that 'God may not bless her daughter with long life expectancy as God knows that if God gave her more than one year, she would not have been strong enough to *anglakoni (tidak kuat untuk menjalani).* So, it was God's will and humans just needed to hope and *pasrah* (surrender).'

Anglakoni thus offers a pathway for individuals to experience a future. Life is beyond the material but to live life in the Javanese sense is to reach the goal of 'wholeness' by *nrima* (accepting) God's will. Bu Sumiati put aside the bitterness in her life and transformed it into 'normal' feelings instead. Embodied *Kebatinan* gave Bu Sumiati power to *anglakoni*— to walk through life within God's will, who had taken her daughter to be with Him. On the phone, Bu Sumiati told me she had responded to her daughter's death with what she explained as *introspeksi* (inward-looking). The Javanese self-acceptance of *anglakoni* may be understood as a form of habitus that is learned through social interaction, the experience of social order and hierarchy. Yet, Bu Sumiati spent considerable time in self-evaluating her own feelings (*rasa*) and fostering introspection through her submission to God.

7.3. Social connectedness (*srawung*)

The embodied illness experience opens up individuals to renegotiate social connectedness in more sincere ways (Pitaloka and Hsieh, 2015). Central to the embodied experience of Javanesness is the moral practice of *srawung* that is one part of a culturally specific form of social structure. *Srawung* refers to one of the major practices of *Kebatinan* that provides for social cohesion and maintains solidarity in village life. In the practice of *srawung* individuals meet in a moral habitus that enables their *batin* (soul) to engage in and contribute to a sense of social 'oneness'(Mulder, 1994).

Pak Tugiman, whom we met in Chapter 6, had a close neighbour, Mantri Surono, who was the village health practitioner. Mantri Surono provided health care in the village independently of medical doctors. Tugiman and Mantri Surono had helped each other out since Tugiman's traumatic injury. After the amputation, Tugiman sought routine treatment from Mantri Surono. Although the mantri's care was cheaper than the medical doctor's treatment, the amount he had to pay for the medicine was very costly for him. Tugiman said that he spent about Rp 50,000,000 (AUD 5000) during four months of treatment by Mantri Surono who gave him treatment every afternoon at 3 o'clock. 'Everyday, Mantri Surono used to sterilise cotton in the Puskesmas [where he worked], bring it home, apply cream around my upper wounded body and finally cover it with the cotton. Mantri Surono was patient and his treatment was very gentle. Our relationship was more like family than just neighbours,' he told me with feeling. Beyond health needs, if Tugiman had financial difficulties in everyday life, Mantri Surono would be the one from whom Tugiman sought help such as borrowing money. In turn, Mantri Surono often got Tugiman's advice about his marriage problems.

Both managed to keep good, friendly and close neighbourly relations. If Tugiman felt unwell, Mantri Surono often brought medicine for him from the Puskesmas (Health Care Centre).

Anisa, Tugiman's neighbour, told me that when Tugiman and his family were wealthy (*bergelimang harta*) they were not very close with any neighbours. Tugiman's catastrophic experience brought about a moral change in his social relations. He then showed harmonious good-will and made larger voluntary contributions to village celebrations. Tugiman said that he used to be over ambitious, and he felt their family lacked peacefulness (*terasa kurang damai*). 'Now, even though I have experienced economic hardship [*keterbatasan ekonomi*], my wife and I feel a state of equanimity in this village life,' he told me sincerely. Tugiman believed that even though he was now poor, God gifted him his current harmonious social connectedness. He said that his divine spirit of acceptance brought with it the sense of social harmony. His and his wife's feelings of attachment with neighbours and their feeling of unity with God showed how people with disabilities in villages *anglakoni* by paying attention to social relations and that through *srawung* they create a new sense of identity as social persons who are anchored to a solidarity group.

Another illustration of the way individuals in dire circumstances fight stigma and construct a sense of self-worth through *srawung*—through actively building close social relations with others—is Sriwati's experience of *anglakoni urip*. Sriwati was a thirty-four-year-old Muslim woman who lost her leg due to acute injuries caused by a truck accident. The news about Sriwati's traumatic injury brought most villagers together with her in compassion (*masake*) but also because, as Magnis-Suseno writes, integration in a harmonious social group is central to human well-being, welfare and even existence (Magnis-Suseno, 1997; Mulder, 1994). These writers might have added that social connectedness is more than sociability—*srawung* is a pathway that individuals follow in seeking a sense of balance and spiritual wholeness. *Srawung* is more than tea parties and get-togethers; it is an active practice of living life in a socially sanctioned manner. By establishing habits of *Kebatinan*, Sriwati maintained endurance, refinement and gratitude in experiencing 'misfortune and disability.' As Sriwati put it:

> I got the strength, I did not know where it came from, to get up, live again, and move on [she uses the English words]. It is actually related to my heart (*batin*) as it absorbs the sense of harmony and strength. (Interview, 13 Feb. 2015.)

After Sriwati married Awit, a polio survivor, Sriwati developed a small-scale business in her neighbourhood village. Sriwati's practice of *Kebatinan* helped to integrate Awit into village social relations. Even so, the practice of *srawung* was an individual-centred

expression of the self and Sriwati took care to use her unexpected fortune in starting a business to build close social relations with villagers as a way towards achieving her life goal of spiritual harmony. The couple's involvement in the electronic business gave her a sense of autonomy and positioned her as a negotiating equal with other villagers. Sriwati said that the only thing that made her business come true was determination. Indeed, the business of the electronics repair service was started from scratch without any capital. At that time, the couple saved money from working as a tailor and repairing electronic devices. Sriwati said that strong will and determination were their main capital in starting the business.

Sriwati involved her young brother as a technician in the business and recruited other household members into the team to engage them in productive work (H. Geertz, 1961). Sriwati continued to maintain a personal relationship and contact with her sewing teacher, Bu Dewi, at the rehabilitation centre. Apart from being a sewing teacher in the rehabilitation centre, Bu Dewi had a side job as a tailor. Through Bu Dewi's business, Sriwati serviced orders from the clothes-making business and was eventually trusted enough to handle some of Bu Dewi's orders and work as a piece worker from home for two years. Now Sriwati and Awit are independently running their own businesses and broadening their social relationships impressively. For Sriwati, to live means to appreciate life. Life is a blessing. Sriwati and her husband told me that they regularly contribute money (*sumbangan*) to the Young People's Association in the village (Karang Taruna) every Indonesian Independence Day. Once they contributed (money), the society valued them. Sriwati's husband told me that 'we feel good if we can contribute to society because we feel we are valued as persons [*diwongke*].'

What is always present in the background of Javanese minds is that the intention of every human being is to *srawung* in living life within the Life. The goal of a Javanese individual is to achieve an ideal state of *tentrem* through practices that create social gratitude. Referring to the practice of *Kebatinan*, Sriwati called it a *survival instinct* that gave her energy inspired by the combination of mystical experience, social esteem and Islamic beliefs. In their new lives Sriwati felt that her life was beautiful and wonderful—all that was written (by God) for her life seemed to be the best for her. Sometimes she was surprised and could not believe that she was able to live through the bitter surprises in her life. She imagined that if others had to live like her, there was no guarantee that they could be as strong as her. She went on to express some irritation at having to come to this point through an experience of misfortune. Sriwati told me about feelings of gratitude, and her own feelings of irritation at the same time. As I see it, Sriwati's experience unfolds a paradox and in essence represents

the symbolic violence that leads to the burdens and subordination of individuals with disabilities. *Kebatinan* practice in Java today involves formal discourses of stigmatising those with disabilities as having different bodies or of being shamed. Sriwati sought to find *tentrem* within her *batin* that gave her positive *rasa* and the strength to re-establish social connectedness and business opportunities. The practice of *srawung* is obviously intensive and unremitting.

Further insight into the mutuality of *srawung* practices may be found in the life story of Laksono. He had lost both arms through amputation as a child. I met him as an adult participating fully in the north Yogyakarta urban kampung Karang Gendok even though he was a migrant and not a native of that village. Like Sriwati, Laksono's determination to *srawung* helped him to establish himself in a valued position in the village and give back to his fellow villagers. The neighbourhood leader said that Laksono's ability to lead the kampung residents had built a strong sense of *rukun* in the kampung. Individuals, like Laksono, build self-assurance and practice *srawung* as a crucial element in their empowerment.

Laksono's social connectedness contributed to the peaceful unity of the kampung residents who had always stuck together, and he showed his willingness to share his abilities and others' burdens. During Ramadhan, he gave *tausiyah* (Islamic preaching) to the kampung residents. Solidarity among kampung residents was often clearly expressed by residents' care of their sick neighbours. Laksono often coordinated neighbourhood visits to sick persons. His day-to-day life was taken up with kampung activities like attending neighbourhood meetings, mutual assistance activities (*gotong royong*), working bees (*kerja bakti*) to repair kampung streets, clean the river code, and even taking part in *gamelan* practice and shows.

Being helpful and getting involved in any kampung activity was Laksono's tactic for getting people's acceptance. Laksono participated in gamelan practices held fortnightly in which Pak Ponconi, his neighbour also actively joined. One night I joined them for gamelan practice held in the *dalang's* house. *Tembang Asmarandana* was sung by the *sinden* (the singer) and I saw Laksono playing the *bonang* located in front of the gongs (*kempul)*. To play the *bonang*, a percussion instrument, Laksono used his feet to manipulate the padded beaters (*pemukul*) and was able to produce a good sound on the instrument. When the song was finished every player took a break. They had tea and snacks provided by the *dalang's* wife. I saw Laksono prepare for a cigarette. His toes took the cigarette while Pak Ponconi offered the flame from his lighter. Pak Ponconi brought the flame to the tip of Laksono's cigarette. The easy give and take of their interaction was quite natural. We might say that it is often such

small exchanges that reveal social harmony. Laksono's friendly attitude was not the only way in which he maintained his social network and sense of inner harmony. His skills as a mouth painter, his leadership, and his small business capacity all helped make it possible to *anglakoni urip* through his active practice of *srawung*.

Laksono's practice of *srawung* had changed over time. *Srawung* for Laksono was a practice of giving, but as a child Laksono had benefited from others' willingness to perform *srawung*. The little Laksono grew up in the area of Solo that used to be given the label 'red' (communist) during the Soeharto era. The red label was used during the New-Order era of the 1980s to refer to people who had adopted or were sympathetic to a communist ideology. Laksono was aware about the benefits of living in that society where people are willing to share and help others. Social loyalty was highly appreciated and the little Laksono benefited from it. Everyday life in the poor rural community involved gambling called *kliwonan*[1] held in the traditional market. Laksono benefited from his gambler friends' contribution every time he went to the Kliwonan market. The mysticism behind the *kliwonan* ritual developed in many forms in traditional society during the 1980s. The legend of the odd body or the different body's role and contribution at the social level was reflected in the relationship between Laksono and his friends during that period of time. Believed to be mystically powerful, 'odd people', like Laksono, in the villagers' view was put on the same level as natural objects or powerful heirlooms which might bring security, health and wealth (Guinness, 1986; Woodward, 2011). He often received Rp. 500 as a gift (*jatah*) from his gambler friends. He said his friends often called him *si buntung* (the amputated one) but he did not feel irritated when his friends addressed him that way. Remarkably, he said that 'if I did not go to the *kliwonan* market, they would have someone bring the "shared money" to me.' These basic values constructed Laksono as an individual who had gained full acceptance in the neighbourhood.

For the villagers, it is clear that *batin* attachment, togetherness, compassion, and love are often conflated with mystical practices and values—and that these moral traits hold the

[1] The *Kliwonan* tradition in Java is historically held to practice simple rituals like *selametan* that offer treatment for sick people. This is part of the folklore that is rooted in the beliefs of the original religion of Java that is animistic. *Kliwon* is the fifth day of the Javanese five-day week and Tuesday *Kliwon* and Friday *Kliwon* are still observed as sacred days. The *Kliwonan* is held every Friday *Kliwon* day in accordance with the Javanese calendar and comes around once every thirty-five days. The tradition has developed a different function. It has become a traditional market selling everyday needs or common people's entertainment (*hiburan rakya*t). According to the folk story, the *Kliwonan* has inherited mystical beliefs which are considered sacred and dangerous because of the mystical forces that are believed to be unleashed.

villagers together in ‘oneness’ and mutual social esteem. What can be learned from little Laksono’s story is that impaired individuals may direct the attention of a society’s members to their communal life—where the relationship between man and society is ideally in harmony in the same way that human beings are ideally in a harmonious relation with God and the cosmic order (Mulder, 1998). Thus, the social connectedness of *srawung* is reciprocal and signifies mutual help in the Javanese construction of harmony, hierarchy and the importance of *hubungan batin*. Villagers are morally obliged to be generous with what they have; sharing or dividing it with neighbours without expectation of the need for returns (Guinness, 1986). They affirm that God will always take consideration of their *anglakoni* and reward the subordination of their *lair*. In villagers’ views, the embodied spiritual experience of *anglakoni* through the practice of *srawung* will bring them livelihood in the form of blessings.

7.4. The embodiment of God’s blessing (*hikmah*)

In introducing this chapter, I noted that *anglakoni urip* was a matter of practice; a matter of living in a way that enabled the individual to harmonise their life with the cosmic order. Anthropologist Nancy Scheper-Hughes, when writing about people in a different place, commented on poor Brazilian women’s practice of constructing narratives as a pathway to resilience and acceptance of (apparent) misfortune (1993, 2008). She said that every human is a storyteller and a meaning-making actor. She went on to unfold how resilient narratives re-frame tragedy for shantytown women in rural Northeast Brazil; women whose children had died because of malnutrition and pneumonia. One Brazilian woman said that God was good as He had taken her daughter away from misery. The practice of storytelling became the means of understanding and reconciling tragedy. Individuals made up their own narratives and this practice made them feel joyful in the face of suffering, in their precarious and vulnerable lives.

In contrast to these stories in Brazil, I found in Java that the idiom of *anglakoni* can be understood as a socially constructed ‘truth’ (Magnis-Suseno, 1997). The practices associated with resolving an individual’s truths are shaped by one’s social position or class (Bourdieu, 1984). But the influence of Sufism in individuals’ practice of *anglakoni* may be observed across social class and it becomes a mode of individual response to loss and disability experiences in ways that enable them to embody loss and difference as a manifestation of God’s blessing (*hikmah*). The body becomes subject to certain kinds of biopower and negotiation in everyday life. So, the moral impulse of *anglakoni* accords with Maurice

Merleau-Ponty's assertion (1962) of the affective mechanism as a form of negotiation that he terms ethics. The ethics are embedded in people's habits and belief system (Low, 1994).

Figure 7.1. Shalawat water in the mosque
Source. Photographed by author, 7 Sept. 2015.

Pak Tugiman (among many others) addressed the 'embodiment of pollution' by a mystical practice intended to wash away pollution and incorporate God's blessing. In this sense, severe illness and disability can be seen as representing contamination of the body as an outcome of previous deeds (Douglas, 1966; French, 1994b; Mulder, 1986). Sickness in the Javanese view is understood as a loss of *tentrem* (Guinness, 1986, p. 120). So, drinking Shalawat water was attractive to Tugiman and his wife who hoped to obtain some of the *barakah* (blessings) of the prophet and gain a sense of *tentrem* in their inner lives. Shalawat is a special Arabic phrase or prayer to honour the Prophet Muhamad. Shalawat water may be understood as 'holy water' as it is water that has absorbed the praise, power and blessing of the Prophet in a simple ritual. The blessing may give a sense of curing illness, protection from misfortune as well as it may bring spiritual progress to the devotees (Woodward, 1989, p. 69). In the Sufi tradition, the Prophet Muhammad represents the ideal of mystical devotion for Muslims. Thus, the practice of reading Shalawat to praise Him allows the devoted to ultimately absorb the emulation of the Prophet. It is a salutation to the prophet who is believed to be the key to salvation. Tugiman and his wife consumed Shalawat water as an everyday drink (Figure 7.1). The ritual of drinking of Shalawat water is an embodied practice

that helps individuals to attain a sense of inner self-purification, *tentrem* (equanimity) as well as blessing.

> A gallon of water was placed in the centre of his main room. His wife told me that it was bought by Gus Munir's wife who sold shalawat water at AUD 1 per gallon. In Gus Munir's Islamic boarding house [pesantren], Tugiman's wife told me that the pesantren provides gallons of [Shalawat] water for everyone who needs it, and residents who live around the village often put water in plastic containers and leave them open while the Shalawat was being read. The lids were purposely left off so that the spirit of Shalawat would infuse the gallons of water. Tugiman and his wife consume shalawat water as their everyday drink. They told me the *savour khasiat* of the pure water was beneficial in cultivating their sense of *batin tentrem* [equanimity], endurance and in healing sickness. (Observation, 11 Sept. 2015.)

In the eyes of Javanese, humans must prepare for *urusan akhirat* (life after death). Previously, Tugiman and his wife described themselves as 'having an inharmonious type of family' even though they were wealthier than most people in the village. In practicing *Kebatinan*, Tugiman said that praying regularly in the mosque helped him to feel an inner harmony (*ayem*) despite his current financial difficulties. His neighbour, Bu Nani, confirmed to me that before the traumatic accident Tugiman had never participated in the mosque. She told me that the traumatic accident and limb loss motivated him to turn to religion. 'He is now already normal,' she said, voicing how Tugiman's practice of *srawung* had restored him into the village community. After his accident, Tugiman started to practice Islam regularly at Gus Munir's boarding house (*pesantren*). He mentioned to me that becoming involved in practicing the Shalawat, especially Shimtu Dhurar's Shalawat, had made his *batin* even more *tentrem* (in harmony). Drinking Shalawat water everyday developed his inner-self balance. The normative piety of the Sufi-like ritual of prayer (*shalat*) was an outward (*lahir*) practice that helped him along the path towards obtaining spiritual progress.

One night in the *pesantren*, incense burned so that the scent spread to the mosque. The lights in the mosque glimmered faintly while hundreds of people were standing behind Gus Munir. Tugiman was standing in the middle of the mosque following Gus Munir who was practicing reading the Shalawat. The sound of hundreds of *jamaah* (people attending the religious ritual) practicing the Shalawat was like a stage musical in a theatre. Rebana music resonated within the human spirit signifying the mystical aura inscribed in the Shalawat. Tugiman embodied this belief by practicing the Shalawat which helped him feel blessed and accept his experiences in life, whether he was rich or poor. From his learning in the Islamic boarding house, he believed that life in this world was only temporary. He put it this way: 'So wealth [*masalah dunyo*] only has a value in this world. I clearly understand this situation so I am not shocked. So, accepting being poor provides a way to *anglakoni* by taking life easy.'

He said, '*Seberapa kayanya di dunia kan ora ono artinya neng akhirat*' (However much wealth one has in this world means nothing at the end of life).

While Tugiman's practice of *anglakoni* drew on Islam, I discovered that the influence of the aristocracy was still meaningful in local society and was taken to be a great source of their feelings of being protected by the Sultan as 'God'. In the *kraton* spiritual perspective, humans should surrender to the superior power and adapt themselves to circumstances rather than fight against them. The embodied mysticism enacted through the *kraton* was another way Javanese individual could make sense of their fate and gain inspiration that God regards the human spirit *batin* as superior to their *lair* (physical) (Woodward, 2011).

It has become quite popular to talk about life, dreams and aspirations in Yogyakarta. The dream or hope is perhaps the central social imagination derived from the spirit of *kesakten* 'sacredness' and the related heroic or unique characters in the Yogyakarta palace. I have previously mentioned (in Chapter 6) that it was historically crucial in the royal court to include people with 'odd' bodily differences. At that time, the 'odd' *palawijo* had considerable prestige and were given ultimate respect in the *kraton* where their magical powers and spiritual supremacy in expelling evil spirits was acknowledged. The absence of such people in the palace, for whatever reason, could be viewed as a sign of the collapse of empire and a degradation of the king's power (Anderson, 1990). The inclusion of *palawijo* in ritual ceremonies in the *kraton* was obligatory as the event would 'not be perfectly done' without their participation (Raap, 2013, p. 51). Benedict Anderson (1990, pp. 27–28) noted that *palawijo* represented the Javanese concept of power derived from the Hindu notion of *sakti*. Believed to be mystically powerful, the *palawijo* are put on the same level as natural objects or potent heirlooms (*pusaka*) such as *keris* (traditional daggers), spears, gamelan ensembles, carriages and stones—all of which were once accepted as sources of the mystical power of the Sultan (Anderson, 1990).

Dewi Lastri found the language and practice that situated her experience of illness as something to be grateful for. She defined herself as *difable*, a person who is 'unique' in a way that reflected the way the *kraton* viewed 'odd' bodies as positive and spiritually powerful. She was a twenty-six-year-old woman with a gangrenous right hand due to a traumatic hit and run truck accident (*tabrak lari*). Yet, she had great hope for a miracle, which was her stance or practice of facing what life brought her, and which was empowered by her submission to 'God'. Her way of living life recognised God and the Sultan's power that still carries a political aura in Yogyakarta today.

I visited Dewi Lastri's little house attached to the Kraton wall (Palace wall) in Yogyakarta city and our conversation opened up with her story of prolonged illness:

> From the beginning when I first suffered an accident at the end of 2012 until mid-2013, I believed that Allah would give me a miracle [*keajaiban*]. The miracle was that my hand would recover. At that moment I was full of spirit to seek a way [*jalan*] to recover. I was treated by doctors from Surabaya in East Java and alternative healers in Bogor West Java. I met an orthopaedic doctor in Surabaya whom I heard was the best doctor in Indonesia for curing chronic fractures due to accidents. The alternative healer in Bogor gave me massage, prayers and spring water filled by do'a 'prayer'. At that moment and up to the present, my mum and I certainly believed that God's miracle was possible [*Keajaiban Allah itu ada*]. If Allah heals this [gangrenous] hand that would be a miracle. In the end, our money for seeking health therapies ran out and we were all exhausted [*lelah*] and finally depressed [*depresi*]. In mid-2013 to early 2014, we decided to stop seeking health care. During the time, I prayed that if my right arm did not recover Allah would give me another miracle. (Interview, Dewi Lastri, 15 Mar. 2015.)

Critical elements of the embodied *syukur* 'gratitude for God's blessing' are derived from the *Kejawen* teaching that is illustrated in the stories of Javanese *wayang* (shadow puppet play). The wayang corpus is a royal tradition and the narratives are 'crucial for the kraton which presents itself as a protector of normative Islam piety and other valued cultural traditions held in some kind of conceptual balance understood as a social and religious ideal' (Woodward, 1989, p. 219). The figure of Semar in the show represents the unity of human and divine as Allah's will through him is a guide to all (Woodward, 1989). Semar is represented in the wayang as crude, odd, injured and crippled—in short, different. Mark Woodward (1989) noticed that many Yogyakarta mystics consider Semar to be the most powerful character who possesses great *kesakten* (sacred power). During fieldwork, one of my *Kejawen* informants, the puppeteer (*dalang*) Ki Karsono drew attention to 'odd' humans in *wayang* dramas such as Semar. According to Ki Karsono, while Semar's figure is perceived in terms of physical oddity and difference, the character Semar is extremely wise and even associated with divine powers. He represents the mystical path yet serves humanity, as his powerful character is beyond the normal understanding of what it is to be human. Semar's inner self character is seen in Javanese mysticism as being like that of a 'god' disguised in physical oddity. Magnis-Suseno (1997, p. 187) wrote that 'abnormal' bodies like that of Semar are imagined as individuals whose identities are betwixt and between—neither God nor man, neither masculine nor feminine, holding neither place nor position in the court but always present (Magnis-Suseno, 1997, p. 187). So, inspirational characters such as Semar resemble people with different physical bodies (*kelainan fisik*). Their connection with mysticism and the spiritual power of miracles models a way of living life that embodies God's blessing (*hikmah*).

Dewi Lastri went on to say that the Sultan's blessing (*berkah dalem*) provides power and encouragement in her life. She said vividly that 'it [*syukur*] is like a type of gas system supplying power as a fuel to a vehicle.' Her narrative about the self represents her prolonged illness and disability, her despair in living with the illness and at the same time her practice of *anglakoni* which becomes her way of embodying the Sultan's blessing in life. The affirmative collection of the *Sultan's blessing* manifested in the blessings and praise to God (*syukur*) signifies the life of *anglakoni* that restores the biopower that circulates through individual bodies, social groups and humans in general.

So, the acknowledgement of blessing (*syukur*) is one of the affective elements of *rasa* (feeling) that stems from an individual's submission to 'God'. It can be understood as a form of social suffering and struggle. This is not in response to a regime of state power over people's lives but is a representation or expression of the deeply held belief that submission is the way life should be lived. While individuals' submission and piety are an affective mode of enactment, blessing may rejuvenate the body and soul and allow the individual to rejoice at the experience of loss. People transform their suffering and reproduce it as a power (Mahmood, 2005). Thus, life is that which *anglakoni* orders into a holy journey full of blessings.

7.5. Conclusion

This chapter contributes to a wider understanding of bodies in Java. The discussion here has shown how embodied Javanese cultural practices of *anglakoni* transform the experience of chronic illness and disability and provide a path to individual's empowerment. In this chapter I have argued, drawing on evidence from the close observation of my research participants, that the Javanese cultural practice of *anglakoni* is embodied and called on as a form of living and agency. My analysis of the agency of *anglakoni* here emphasises that individuals' responses in speech, manners and behaviour should be in what *Kebatinan* sees as the right order—right manner, right position and should give proper recognition to degrees in a society which ranks some lower and some weaker than others.

Put in other words, *anglakoni* is a bodily expression that is learned by individuals through comparative experience. *Anglakoni* interprets the subject-making process. It is about the coordination in the Javanese individual of the various elements of person, body, spirit and society. Through the affective system individuals connect with the transcendent and respond to the sociocultural mapping of time and space (Gennep, 2011; Mauss, 1979). These systems cultivate the inner dimension of a stillness of heart, soul and mind which is not an emptiness,

nor merely a conforming to a subordinate social status or submission to the regime of power. *Anglakoni* is a rich space of individually crafted powerful bodies in what Niels Mulder might call ‘wholeness, completeness, and oneness’ (1998, p. 116).

In Chapter 8, I will focus on the dilemma that NGOs face in trying to build on a sense of Javaneseness within the context of their rehabilitation programs designed to meet international measures of individual agency and empowerment.

Chapter 8
Values of Care: NGOs' Dilemma and the Organisation of New Identity

8.1. Introduction

This chapter looks at how a prominent Non-Governmental Organisation (NGO) has transformed a clinical approach into something spiritual and relevant to the village domain. The work of this NGO deals with a tension between the demands of the donors that focus on the physical rehabilitation of the individual and the NGO's own recognition of the need to cater to the spiritual, mental and emotional states of the *difable*. The NGO's dilemma lies in trying to promote the value of care while facilitating the practice of governmentality. The chapter explores the variety of NGO interventions established in response to social exclusion, stigma and discrimination towards people with chronic disease associated with physical disability. Through the lens of a disability activist, I note the dialectic moment between resistance and acceptance of traditional concepts of hierarchy in the community. I argue that power is embodied in such hierarchies and is inherent in all social relationships of 'caring', and embedded in a network of practices, institutions, and technologies dedicated to caring for the *difable*. Data in this chapter are derived from ethnographic vignettes and in-depth interviews with a range of actors and stakeholders. These informants include NGO directors, rehabilitation workers, government officials, academics and members of community associations. They responded to questionsabout how persons with disabilities might be positioned in the state socio-cultural, economic and political structures.

We have seen that physical rectification remains crucial to practices of juridical power and surveillance, but that the interplay of power and resistance that Michel Foucault described allows for new pathways (Fassin, 2009). Having said that, what I want to show is how, in the rich and intermingled paths of power in Java, we can trace a particular approach manifested in NGOs' advocacy programs. The NGOs combine biomedical approaches with Javanese socio-religious values through engaging with social, economic and political situations. They play out the tension between satisfying their donors who require an emphasis on the physical rehabilitation of the individuals and caring for them as a whole person. In Javanese belief, a person characterises three components: the physical body (*badan jasmani*), the spiritual body (*badan rohani*) and the soul (*ingsun, aku, roh suci, roh nurani* and others) (Woodward, 2011). As non-state agencies attempt to work to incorporate the physical,

spiritual, mental and emotional state of the *difable*, we will discover that agencies face dilemmas in care and we will explore how they map out new pathways of power.

This chapter is structured into two parts. The first section examines how stakeholders draw upon physical and cultural resources as the way to 'fight over the space' and contribute to a caring personhood. Their advocacy stems from the contest between biomedical needs and broader socio-cultural concerns and which produce programs of physical rehabilitation, empowerment and social inclusion. The second section shows that the NGO movement that draws on the energies of '*difable* activists' organises new forms of personhood and identities. The demands of various sponsors and donor agencies may press NGOs to encourage dependency in their clients. Their struggle and their efforts are put toward enhancing the *difable* poor's desire to be self-sufficient while reinforcing the mind-body dichotomy that ultimately undermines their clients' empowerment.

8.2. Advocacy: Caring for the person

There are two types of NGOs involved in advocating for people with disabilities. One group provides direct health and welfare services as their mission. They set out to deliver programs designed to effect fundamental changes to existing power relations and promote pro-democracy movements concerned with human rights, economic empowerment or political participation. For example, some agencies are dedicated to the elimination of all forms of discrimination to protect young people, children, the elderly, women and the sick or disabled populations from being further marginalised and excluded. A second group provides community development services that concentrate on providing access to basic services like health, nutrition, shelter, water or sanitation with the end goal of increasing the capacity of vulnerable members of the population. Having said this, the work of NGOs cannot be sharply differentiated into these two types of organisations and programs. Project implementation generally involves an overlap between human development services and social protection (Whitelum, 2003). These overlapping objectives are generally aimed at the grassroots level, and NGOs generally work collaboratively with various local agencies such as foundations, corporations, international donors, faith-based organisations and local or government agencies.

8.2.1. Physical rehabilitation: A biological approach

The physical rehabilitation approach remains crucial in some NGO service delivery. Yayasan Kesejahteraan Masyarakat (Yakkum) is one of the largest NGOs whose approach is based on physical rehabilitation programs. Located on a one-hectare area, the NGO is equipped with facilities such as a swimming pool, a special training room, therapy room, supporting aids room, psychology room and prosthetic and orthotic making workshop. Since its establishment, approximately 15,000 people with physical disabilities have participated in the programs.

> Similar to a hospital clinic or government school, the building is kept environmentally clean and tidy. I saw the pastor's photograph hanging on the wall, just beside the entry door near the reception room. In the front yard, several sespan (motorcycles designed for people with disability) were parked neatly. In the corridor, I met a man with shoes above his knees walking along, dragging his feet. He was dressed neatly and it turned out he was one of the Yakkum staff. Affiliated with Christianity, it operates under CD Bethesda (Community Development Bethesda), a non-government organisation that provides health services and programs. It employs people with disabilities as receptionists, cleaners and in administration roles. Currently, there are more than 70 staff working in the Yakkum ranging from administration staff including those who are employed in the CBR (Community Based Rehabilitation) program and work in Yogyakarta and surrounding areas. Even though it is a Christian affiliated organisation, there are female Muslem staff wearing head scarves working there. (Fieldnote, 22 Apr. 2015.)

Indeed, most NGOs are not purely 'non-government' organisations as they receive support funds from foreign governments (Petras, 1999). They work as private sub-contractors for local government or receive funding from private foundations that are closely attached to state interests (Petras, 1999). Indeed, Yakkum is categorised as a non-government agency that works collaboratively with government.

Apart from Yakkum's institutionally based rehabilitation program, there are other NGOs organised in a semi-formal way, and these bring the biomedical gaze into a very homely and familiar environment. I visited Mas Suryadi's village in West Imogiri where he managed a rehabilitation program based on charity. Mas Suryadi established a non-government organisation after his village was hit by earthquakes in Yogyakarta in 2006. Working collaboratively with other NGOs, the government, private donors, institutions and corporations, he submitted a draft proposal to prospective donors. Then, armed with statistical data from the Social Department, he listed people who required donations such as prosthetic and orthotic limbs and reached out to them using social media and his mobile phone. When I visited it was 'measurement' day. It was like a big carnival and the parking area was already crowded early in the morning. Two medium size buses with a capacity of

twenty to thirty people were parked among the crowds alongside an ambulance, some private cars and modified motorcycles used to carry wheelchairs.

The situation was a little chaotic but for Mas Suryadi's team it was business as usual. In the living room, two workers were busy arranging forms submitted by disabled people who needed prosthetics and orthotics. Mas Suryadi himself acted as 'reception' and dealt with simple administrative and registration matters to make sure that everyone received their aids. He welcomed the people with disabilities as if they were his own guests and friends while allowing them to take the forms, fill them in and return them to him. Sitting on a wooden chair, he tried to turn messy papers on the table into clean and tidy forms, while calling out to guests who needed to provide additional information. Everyone had to answer the questions on the forms and provide specific information about their identity. They noted what part of the body was going to be measured, the cause of the physical disability and whether or not they had used an assistive device before. 'Ahh, this information and the paper organisation is so complicated and messy,' Mas Suryadi said.

Figure 8.1. Prosthetic measurement in village

Source. Photographed by author, 5 Apr. 2015

The turbulence and chaos at Mas Suryadi's charity event were glossed by a general sense of habitual communality and social togetherness. Such strong group loyalties

characterise the psychological and spiritual satisfaction of *tentrem* (Guinness, 1986; Mulder, 1978). People with disabilities were talking and joking and the house became a home for them where one participant told me how they shared the feeling of 'having a similar fate'. Some of the people seemed to know each other, but others just stayed with their friends who had travelled with them from the same village.

> On the verandah, disabled children and families were waiting for the measurement of assistive devices. Some women, although looking tired, were still patiently carrying their children with Cerebral Palsy. These children ranged from under five years to primary school age. Mas Suryadi's house was almost full of people with physical disabilities and their families who gathered in groups of 8–10 people. A set of chairs from the living room had been taken out and placed beside the house. A wide mat was spread on the verandah to accommodate tens of people sitting and waiting there. (Fieldnote, Mas Suryadi's house, 5 Apr. 2015.)

Bu Yeni was one of the mothers whose child needed an ankle and foot orthosis. She looked anxious and tried hard to make her child do what the worker wanted him to do. The team put papers on the floor, and they were asked to place their children's feet on the paper so that the team could draw the shape of the feet. The process took quite a long time because some children were reluctant, anxious and afraid of being measured. The noises of people talking mingled with the sounds of vehicles in the yard made the children anxious. Some children cried and refused to stretch and relax their feet. Although such noises made the atmosphere more stressful and hectic, a general sense of communality helped build a supportive environment. So, much more was achieved that day when men, women and children with disabilities were measured for casts. The casts were made in the living room where everybody could see them. There was no private space. The disabled people were tested for fit and rehabilitation. Patients' photos were taken so the charity's activities could be reported to donors. Through all of this, Mas Suryadi and his team managed to keep their peace and preserve a normal environment. The process allowed everyone to feel welcome and be treated with dignity.

The environment created that day in the village illustrates how the clinical gaze was transformed in what Foucault might call a 'quasi-linguistic sense and a quasi-mathematical sense' (2012, p. 147). The quasi refers to how the very strict and professional clinical gaze was re-shaped in the village domain and then used to ameliorate what can sometimes be a severe scientific practice into something that was cherished and sociable. And this was what the NGO's work was about; bringing the body to the surface and into the public domain. But it can be challenging as it forces organisations to confront different value systems and face dilemmas in their delivery of care. These kinds of events show how practices from different

starting points can be blended and achieve a sense of objectivity and a sense of the whole self in the construction of the required knowledge (Van Dijk, 2005). Yet the photography contributed to making the body transparent and enabled the state to maintain a level of surveillance and control.

8.2.2. Social inclusion and self-esteem

Side-by-side with the physical rehabilitation programs, Javanese social life acknowledges the crucial value of social advocacy grounded in the notion of harmony (Guinness, 1986; Magnis-Suseno, 1997; Mulder, 1994). As I have shown in Chapter 5, community activists such as women's networks in villages have played a significant role in the building of social esteem and support networks in response to biomedical interventions. In the city of Yogyakarta, I observed *Bakti Sosial* (social or community service) activities performed by women whose husbands were executives of a state-owned insurance company, PT Jiwasraya. The women also collaborated with some NGOs based in Yogyakarta and Jakarta. They worked with a national NGO namely Yayasan Peduli Tuna Daksa (Physical Disability Care Foundation) that delivered hundreds of prosthetics and sticks for people with physical disabilities.

Critical to the event described below is that the central values of self-esteem were intricately intertwined in the expectations and activities of all parties involved. The hierarchical environment as (habitually) enacted in such events required deference on the part of the disabled, yet when everyone enjoyed a sense of personal autonomy, the event could be a positive experience for all involved (Mulder, 2005, p. 99).

> One fine morning several policemen and security were controlling the busy street. In the reception area, several women sat behind a table, wearing their uniform of black and white striped T-shirts, welcoming everybody who came. They seemed to be identifying disabled people who were arriving and giving numbers and places to those who had registered to sit on chairs arranged in the centre of the office yard. Women in uniform were busy serving containers of rice to people with physical disabilities sitting segregated in the middle row. Around the outside were houses set up as insurance offices owned by the state. I saw many pedestrians who were mainly people with disability and their families or friends—blind, or with deficient limbs or limb-less. They crossed at a pedestrian crossing on a street heavy with motorcycles, cars and provincial shuttle buses. The buses travelled between provinces and were used by disabled people who were from outside Yogya. The sounds of the vehicles and people talking mixed with the beautiful voice of someone reading from the Qur'an on the stage. Several NGO workers dressed in white uniforms looked busy measuring and making sure of the number of prosthetics and sticks for donation. (Fieldnote, 7 Mar. 2015)

While the women's network finds prestige in their *Bakti Sosial* work, people with disabilities tend to see things simply as the divine spirit of God's will working itself out. On the stage, another member of the women's network addressed the group:

> What an extraordinary event! This touches our hearts [*menggetarkan hati*]. So many people have given attention and care to those who are suffering misfortune. Look, there are aids for a hundred disabled people and a hundred blind people who are participating here. This event shows Allah's blessing. I believe that God blesses this event. Now, I am asking you to pray [do'a], so that our company becomes a national champion. (Fieldnote, 18 Mar. 2015.)

Another of the women involved, Bu Nia, said that 'for me this is partly a promotion' (*bagi kami ada unsur promosi*) and she said that the event was important as a way of boosting the state company's popularity. 'The more popular we are then the more … [benefit] we get,' she said shyly.

Bu Ratih, another woman involved shared with me how she felt about her *Bakti Sosial* work:

> We are able to feel *bersyukur* [thankful for God's blessing] because indeed *Alhamdulillah* [Praise to be to Allah/the God] that we are normal [body]. And we can help them. For myself, it is *kebanggaan* [prestige]. We never make contact with them [the disabled people]. So, this opportunity to help them is a pleasure for me. (Interview, 3 Nov. 2015.)

These vignettes demonstrate that the sense of caring within the individuals' inner self (*batin*) is accompanied by a sense of social esteem. I attempt here to explore claims of 'generosity' and unpack another kind of paradox central to the acknowledgement of God's blessing among the Javanese. This was particularly baffling when the women activists played a very active role in cultivating spiritual power. Even when such promotion occurred, the women's network that at that moment genuinely sought a powerful spiritual journey were also committed to pursuing self-esteem. The wealthy women's network sought acknowledgment of their social status and pride. One of the women on the stage spoke to the disabled people segregated in the middle of the row in this way:

> This Bakti Social event is aimed to support people with disability, and we [the women's network] are concerned for you [*kepedulian*]. I encourage you not to think of the lack [referring to their disability] as an obstacle. Rather think of that physical disability as the strength that is given by Allah. Let's be giving thanks for our lives [*syukuri hidup*] through reflecting on our lives [*memaknai hidup*]. Feeling blessed would make our lives lived, at least for ourselves. Even though you have a lack [disability], it benefits your family. Here, we are showing you concern [kepedulian] because you provide the strength for the wider scope of our nation building. I request you to pray for PT Asuransi Jiwasraya to develop, to be more beneficial so that we can give you sustainable care. I hope this care is beneficial for you. Although it is just simple aid, at least this may support and give you spirit to work harder and give yourselves a colourful life. Thank you. (Women's Network Speech, 18 Mar. 2015.)

A state official involved in the event said to me:

> I hope this kind of celebration is more touching [*lebih menyentuh*] and inspiring others who are willing to donate part of their income. People may donate their income to these people with disability because of their incapacity [*keterbatasan mereka*]. Yet, they [rich] may also make donations to the orphanage. The orphans need funds, but the orphans are physically normal. Honestly, this is how I feel passionate. This celebration has inspired all people and particularly supported the disabled people to be more productive. This [prosthetic] can be an asset for them to be more productive. This event makes long-term sustainability a real and clear target. We feel satisfied as the celebration went well. (Interview, 18 Mar. 2015.)

Figure 8.2. Backstage: The women prepare to fit a prosthetic leg

Source. Photographed by author, 18 Mar. 2015.

Figure 8.3. The procession associated with the *bakti sosial* event. Giving and receiving a prosthetic limb
Source. Photographed by author, 18 Mar. 2015.

These vignettes show how stakeholders recruit Islamic and Javanese values tied to normative understandings of the inner self (*batin*), spiritual security and social intimacy in their social work. Guinness' study (1983) on marginalised homeless people (*gelandangan*) in Yogyakarta showed how moral intimacy and local values are embedded in the ways society perceives people who are seen as 'poor' and 'different'. Kampung residents acknowledged the homeless people through urban interactions and friendships. The ability of the homeless and marginalised to get jobs and work together with the community demonstrates a different approach to the *gelandangan* by residents. They are able to resist stereotypes and take advantage of opportunities offered to them (Guinness, 1983). Javanese society holds moral values of tolerance and sympathy and these have basically allowed the integration of 'different, unfortunate people' into social life. Guinness (1983) noted that mutual assistance (*gotong royong*) and empathy (*tepo seliro*) signify a sense of community and the willingness

to share each other's burdens. The celebration of *Bakti Sosial* similarly revealed the states of peace, harmony and good-will. This *Bakti Sosial* program coloured social life since it was grounded in the desire for harmony, sharing among people and applying the principle of *rukun* (harmonious state).

In this line of thinking derived from the vignettes above, as Guinness (1986) noted and I observed, the lower-ranked group of people seek a guarantee from the community that in their hardest times they can obtain help from others. These occasions of women's social work open up recipients with disabilities to an embodied experience of 'blessing'. Pak A, a man who had lost a leg went to the stage and received a prosthetic leg. He shared with everybody his efforts to get measured for a prosthesis and use it in the course of his everyday activities. He said that working as a meat ball vendor (*tukang bakso*) in village, he pulled his meat ball cart around the village. His voice started to crack when he was trying to speak on the stage. According to some people who usually attend *santunan* (charity) events, Pak A always cried and became hysterical every time he came to such events no matter how hard everyone tried to calm him down. Still standing on the stage, he said, 'Nowadays [in 2015] the government has given more attention to disabled people than in previous years. They [the government] continues to offer to contribute to the measurement of assistive devices. I pray for the officers who provide care for disabled people so that they may be blessed by God,' he said, while tears streamed down his cheeks. His face suddenly got red and blotchy, his eyes bloodshot. Controlling his breath, he continued his speech in this way:

> We have been blessed by Allah who has given opportunities for Madam/Sir, brothers, and me. [I] praise Allah for the honourable head office who has given these aids—although these are only prosthetic legs, hands and sticks all of you have [been] given everything that we ask[ed for]. To the honourable people who are working in this office, we pray that you will be given a long life [*umur yang panjang*] as well as an easy and fruitful income [*rezeki murah dan berkah*]. (Pak A, at the *Bakti Social*, 18 Mar. 2015.)

The practice of *bakti social*, however, inconsistently shapes public opinion. The social charity undermines people's perceptions of physically disabled people: they become positioned as 'weak' (*dhaif)* and powerless (*mustadhafin*) to whom Muslims should offer help. The Qur'an and Hadith in Islam do not explicitly state that the weak and powerless are the physically disabled people. But there are several Muslims who see the disabled as similar to poor people for whom charity and alms (*shadaqah*) are a way to help. Weak or powerless persons in Islam are understood as experiencing a period 'given' by Allah as a test (*cobaan*) of people's lives and faith (as discussed in Chapter 3).

The public performance of charity by the rich women's group is a practice that shapes personhood and from which the women's network builds itself a sense of self-assurance and prestige (Mulder, 2005, p. 99). It also illustrates the 'difference' that is applied only to people with physical disabilities. The acknowledgement of God's blessing allows every Javanese individual to find themselves a place within society. But, within this harmonious and hierarchical society, a disabled person is rendered dependent on others. The *Bakti Sosial* becomes the locus of habitual practices that enhance the self-esteem of workers and recipients and a wider social harmony, but that leaves disabled persons in a socially inferior and dependent position

8.2.3. Spiritual/moral empowerment: Gemblengan

NGOs' adoption of psychological programs or spiritual interventions reflects how they have captured are holistic approach to Javanese personhood. An NGO worker told me that it is a 'soft skill' intervention that allows for healing in the inner-self (*batin*) as a way to maintain balance or self-esteem. According to Sufi teachings, this approach to modes of spiritual devotion is seen as an inner quest for purification of the soul and direct knowledge of God (Woodward, 2011, p. 72). The aim is to maintain a harmonious self within the inner self. For example, a worker at the Yakkum Rehabilitation Centre explained to me about the inner-self-care that is embedded in the Vocational Training Course (VTC):

> There are several approaches here that are more practical. Before they [people with disabilities] were admitted to the program VTC, we gave them training in what I call self-development to strengthen their soft skills, to enable them to build self-acceptance [*menerima keadaan dirinya sendirinya*], and to raise awareness that they won't be able to physically recover. (Interview, NGO worker, 5 Apr. 2015.)

Yakkum is a Christian-based NGO established in 1982 in the north of Yogyakarta and was initiated by Pastor Colin F. A. McLennan MBE from New Zealand. Sriwati's experience in pursuing vocational training assistance from the organisation was not affected by her being of a different faith. She was a Muslim woman who then decided to register for learning sewing training skills with the NGO even though she was still undergoing some medical treatment and therapy in hospital. In her early days when she was categorised biomedically as a 'disabled person', Sriwati told me that her feelings were very sensitive and irritable. She was annoyed at her current disabled physical condition which meant she could not do many things independently as she always needed help from others. But she told me that when she was in Yakkum, she undertook some mental therapies with a psychologist. She considered the spiritual and mental therapy, which she called *gemblengan* (intensive emotional

coaching), to be helpful in restoring her unbalanced mental state. She got strength, not only from the vocational training that she received but also from looking at other clients who were less fortunate. Sriwati explained that when she stayed in Yakkum, there were many earthquake victims whose mental health was broken. Indeed, some even chose to end their lives by lethal injections. However, regardless of the fact that people around her were desperate and hopeless, Sriwati decided not to be like them. As she said, 'Their *takdir* [fate] was not as fortunate as mine. My life is better.' Sriwati learned a lot during her stay in Yakkum. She took the view that her experience of having had a traumatic accident that resulted in the loss of a limb was *anugerah* (a blessing). The embodied feeling of *syukur* (praise to God) marked her as a subject whom God had chosen to experience the traumatic accident and continuing disability. Her body and mind were intertwined and to some extent embodied in devotion and faith.

The psychology course changed 'disabled' participants into positive and self-developed individuals characterised by high levels of self-harmony, optimism, hope and confidence by perceiving any experience in life as a *berkah* (blessing). Sriwati told me that in 2009, there were approximately twenty participants who took part in the self-development class and they were asked to put together a chronological story starting from their birth, school days and accident until the time they felt they could get up again and develop hopes for the future. This work was a sort of biography of the participants with physical disability.

Figure 8.4. Sriwati's journal cover that was compiled during the psychology class she attended in 2008.
Source. Sriwati's own diary, photographed by author and used with Sriwati's permission.

Figure 8.4 shows how the 'life as a blessing' exercise was one of many ingenious ways that helped participants develop their new sense of identity as blessed individuals. The worker in the psychology class trained participants, especially in the transition period, who initially were previously not categorised as disabled people. Sriwati told me that she passed the *gemblengan* period when one trainer told her that she was *sudah jadi* (mentally stable) already. Sriwati told me that the *gemblengan* period was able to prepare her and give her

strength to accept (*menerima dengan ikhlas*) to become an accepting person (*wong nrimo*). Both the NGO mentor and Sriwati have cultivated a habitual understanding of the life principle which suggests that what had happened in Sriwati's life was the best thing for her. She has come to accept her traumatic injury and missing limb as *berkah* (a blessing).

Rather than creating a docile body (Foucault, 1977), the *gemblengan* shifts the practice of normalisation so as not to govern the subject but to open up a pathway that brings spiritual resources into play as a coping mechanism. *Gemblengan* is an approach to life that is enacted by way of mystical forces that embody life as it is—*takdir* (resigned to fate) (Fassin, 2009; Magnis-Suseno, 1997). Through intensive psychological training, Sriwati was brought to the point where she accepted her social designation as a 'different individual', and this was successfully embodied in the way Sriwati perceived her Javanese identity. These kinds of programs and approaches were routine functions of non-state agencies and the way they operated in the social sphere (Gupta, 2012). With the physical and mental rehabilitation given by the NGO, Sriwati could live independently in society.

A similar notion informed the practice in a non-state specialist school. A teacher, Bu Ani, told me her weekly agenda involved taking her students for a walk around the kampung for two hours every Monday morning. She said that her agenda was to prepare children mentally—what she called the *gemblengan* as *bina diri* (self-regulation). She told her students not to feel offended if there were other children who mocked them on the street. She told me how important such mental preparation is in building her children's self-confidence. She coached them not to feel *minder* (inferior) but to feel another kind of strength. She said that 'if other kids mock them then I told them to not to retaliate because being cruel towards others is sinful.'

I have included the figures above and the related the vignettes as a way towards understanding the biopower regime approach of institutions like Yakkum and other agencies. The spiritual intervention of *gemblengan* does not work in the same way as mainstream medical interventions. The *gemblengan* offers an alternative construction, a humanistic value system that sees humans as different in many ways but equally deserving of people's care and respect. But the NGOs' dilemma was in its need to satisfy the funder and government's insistence on surveillance and control. What Sriwati understood was that the psychological class aimed to train her and other participants to accept themselves and erase disappointment or protest over what they used to be as a person, or what was missing (bodily) now. The embodied moral life that Sriwati demonstrated is a habitual practice that shows a combination of physical rehabilitation and emotional training in one package of *gemblengan*—reproducing

a shared moral embodiment and a sense of equanimity (Guinness, 1986; Kleinman and Kleinman, 1991).

The holistic approach was also illustrated through a community-based organisation Satu Hati Berbagi run by Lies. She was previously diagnosed with osteosarcoma and had survived post-treatment for about nine years. Her life story offered spiritual lessons about what it means to be a patient and she wanted to support parents of children with cancer. Lies' life experience revealed struggles in seeking medical care and support through a prolonged illness, missing her father, and enduring poverty. But her experiences made it easy for her to run the NGO by collaborating with health professionals in hospitals. Lies brought the spiritual embodiment approach to her NGO program to assist children with cancer and their families. Yet drugs and biomedical needs remained her NGO's priority and other supplies needed to support religious practices were also important. She collected cancer drugs left by parents of children who had passed away and shared them with those children with cancer who were still alive. Praying attire (*mukena*), prayer books (*buku kumpulan do'a*), nappies and the intravenous fluid NaCL were also donated to patients and families in the cancer wards. Dozens of batik sheets were also part of her NGO's charity donations for patients in hospital. Batik sheets in Java were also used to cover corpses. They are an ancient Javanese textile tradition and represent self or national identity in ways that hospital linen never can.

Figure 8.5. Lies and her NGO's aids and donations that complement the needs of the health-care facility in the hospital.

Source. These images were on the Facebook Page. Retrieved on 18 Oct. 2015 from: https://www.facebook.com/veyo.anik. Permission to use this image was granted.

Lies used to be a Christian but converted to Islam which shaped her belief that cancer may be understood as God's blessing. Spiritual values were incorporated into her program delivery as a way of maintaining the resilience and self-confidence of patients with chronic illness and disabilities. Lies explained her values this way:

> In my world view, everything [chronic illness and disability] is Allah's creation. These are Allah's will and this is *takdir* [fate]. While those who accept the *takdir* should *menjalankan amanah* [do God's will]. (Interview, 16 Sept. 2015.)

Laskar Sedekah is a faith-based NGO run by Mas Harto. It is another example of a non-government agency that provides assistance for poor people with chronic illness and disabilities. In serving ill and disabled people, Mas Harto began by surveying patients and

their families in order to understand their economic conditions. The organisation interviewed patients and families in detail and checked whether medical costs had been covered by the JKN-KIS / BPJS (as discussed in Chapter 2). Mas Harto then asked the patients and families for permission to take their pictures, circulate them on social media and broadcast them via mobile phone. Mas Harto told me that 'One hundred percent of the donations go to the patient and family – we have no interest in the money. Our aim is only one – to seek God's returns and rewards.' The way Laskar Sedekah drew spiritual values into care was an important component that complemented biomedical care in delivering services and helped individuals to accept care with a sense of inner peace.

Mas Harto held composite religious views of *ikhlas* and saw his voluntary work as a way to seek God's will (*mencari ridho Tuhan*). *Ikhlas* means willingness or readiness to leave one's own individual interests and to align one's interests in harmony with the cosmic order on the understanding that one's life span is determined by God (Magnis-Suseno, 1997, p. 141). His religious organisation provided services for overlooked or inadequately served Indonesian poor people. It was demanding work. Mas Harto had to be ready on call if there was a patient who was chronically ill, if there were disabled people needing transport to hospital, or if there were patients and their relatives who needed transport after being discharged from hospital.

In his organisation, Mas Harto lived by the principle that we should work without expecting anything in return (*sepi ing pamrih*). Living in this way produced a sense of inner freedom from the personal desire for possessions. In the Prologue I introduced Sunarti who was an osteosarcoma patient who received assistance from JTCK run by Astuti and donations from Mas Harto's organisation. Mas Harto pooled donations from his own pocket, from other members and a donor from a private company to help Sunarti seek medical treatment in Yogyakarta. The organisation offered a free ambulance service to pick up and drop of Sunarti and her husband. It offered lifts to routine medical check-ups during outpatient care and it covered medical costs and fees not covered by health insurance. Astuti pointed out that Sunarti's husband had had to leave his job when Sunarti was hospitalised. Astuti's companionship in hospital and the Laskar Sedekah provided additional donations to cover Sunarti's family's living costs during her treatment.

Figure 8.6. In the corridor, Astuti (left) and Sunarti's husband (right) handed over blood that had been donated for Sunarti who was being operated on in the surgery theatre.

Source: Photographed by author, 11 Dec. 2015

Mas Harto told me, however, how difficult it was to build and sustain his organisational culture. He set up the religious and cultural norms that enabled all affiliated members to enjoy working voluntarily and feel pleased with their efforts. His organisation sought donations by networking with other mosque and religious-based organisations or by social media advertisements. He and his organisation members mainly worked in the private sector, operating small businesses in their own villages. Even though business was often up and down, he found religious principles enabled them to sustain the organisation. His said his organisation developed in this way:

> In the first year, this organisation was stable because it was still new. The second year, this organisation overwhelmed us and put stress on our families. In my heart, I was drowning trying to choose which one should be given priority. Very often we felt anxious to choose between social work and self-interest. But, *bersyukur* [praise to Allah] that this organisation still exists. The second year was when God gave us 'trials' as some of our members had to close their own business and lost their assets. (Interview, 17 Nov. 2015.)

Mas Harto finds his Islamic religious motivation to be the source of his inner-self and he has shared his thoughts and made them organisational habits and principles. He believes that God ordains in the Qur'an that *sadaqah* (voluntary giving alms) should be shared whatever one's own condition. He believes that individuals should practice *taqwa* through giving *sadaqah* whether their own financial condition is secure or not. In the eyes of Mas Harto, it is fundamental to believe that whenever we give other people *sadaqah* God will return it to us in greater measure. Even so, Mas Harto does not think about imagined gains or attempts to advance his own interests through other people. His motivation refers to the

sacred principle of putting his trust in God. He believes that the experience of illness and disability is a *ganjaran* (reward or heaven-sent trial) given by God. He elaborated further:

> So, our team hopes that when we help others [*membantu sesama*], it makes our life worthwhile. Islamic people have to pray (do'a) *Allahumma thawwil 'umurona* ... so that when we do enjoy a long lifespan, we don't let the long lifespan become worthless [*sia-sia*]. This long lifespan is service for others. I heard that social media spreads info about the meaning of charity [hikmah sedekah], hoping that the charity will realise returns of a certain amount. Our team never thinks in that way which means that as Javanese people we would say that God never sleeps [Gusti Allah mboten sare], that's it … so if Allah orders in the Qur'an ya ayyuhalladzina amanu in tansurullaha yanshurkum [Allah will help those who help His Cause]. That is … so for anyone who is willing to ease others' burdens Allah will ease their burdens too. That is our aim; there is no political interest. (Interview, 29 Aug. 2015.)

8.3. The dilemma: Just call it *difable*

Over the last two decades, most NGOs in Yogyakarta have included the term '*difable'* in their advocacy to replace the discourse of disability in general social perceptions. But I observed that their effort may not change social perceptions but rather create a 'new sense of personhood'. The dominant biomedical discourse of *cacat* (people with disabilities) has been substituted by the term *difable* by NGOs advocating against terms such as *tuna, cacat,* and *disability* that are seen by some as derogatory. The term *difable* is the newest popular label among those who take it to be a more empowering term (Suharto, Kuipers and Dorsett, 2016). *Difable* is popularised to change social perceptions, to confront and resist the negative prejudice which is extended to disabled persons by mainstream society. As Kohrman (2005) found, the label of *difable* has, however, contributed to the production of alterity and new identities as well as the institutionalisation of knowledge, such as was demonstrated in Chapter 6.

The discourse fails disabled subject/s in the sense that the discourse is responsible for the characterisation of people with disability as a new group. In China, Kohrman traced the evolution of the disabled people's category known as *canji* and argued that building a disabled people's federation had framed *canji* as a lived experience of otherness. The Disabled People's Federation may not only plot their own suffering but also play a part in the new formation of disabled persons' categorisation, social labelling and self-identity (Kohrman, 2005). Phillips' research (2011) within the context of the changing welfare state in post-Soviet Ukraine showed that the movement led to the creation of certain categories of people with disabilities or different abilities. She noted that activism transforms individuals and categorises them again into specific kinds of citizens (Phillips, 2011, 2014).

We should note, however, that there are limits to the power of discourse to re-shape normative perceptions. In certain circumstances a *cacat* discourse may be more dominant while in another context the *difable* discourse may hold people's allegiance. One day I joined four middle-class women's groups affiliated with the NGO Yogyakarta Cancer Foundation. The women were discussing how to transfer a cancer patient, Julius, to the regional hospital and encourage him to accept amputation as part of his treatment. They were talking about his physical condition after the amputation. Bu Tejo started the conversation and said gently how Julius would likely be socially labelled as *difable*. She was trying to talk in a natural way and looked worried about saying anything hurtful. Then Bu Bekti suddenly exclaimed, 'Hey, *difable* is the same as *cacat*, isn't it?' It was an awkward moment when Bu Bekti expressed her views in such a clumsy way (*kasar*). I took from this conversation the understanding that bodies with impairments (*cacat* in Bekti's language) are contested in everyday discourses. A label like *difable* that might be natural for organisations or a more policy oriented, activist member of an NGO is contested by another member who tries to assimilate the new discourse within her own social status framework.

State and biomedical discourses circulate public constructions of disability and impairment and have come to impose certain kinds of unequal social relations. The *cacat* discourse fashioned Bu Bekti's perceptions and framed disabled persons as minors or socially unimportant. State narratives, and other terms and language may change within different regimes. But NGOs adopting another label (*difable*) does not necessarily change the way people think about disabled subjects. The conversation in the Cancer Foundation reminds us that bodies become the locus of power contestation and that at any one time global, state and local discourses all shape how programs and people are understood.

Previous ethnographic research on culture and biological conditions, in countries such as India (Staples, 2018), China (Kohrman, 2005) and the Ukraine (Phillips, 2011, 2014), show that an escalation of biopolitics in NGO activities and programs is in play. Veena Das and Renu Addlakha noted that there is a transformation in biotechnology that has indicated a new form of biosociality.

> [M]ajor transformations in biotechnology have led to new forms of community in which people with disabilities and impairment have formed associational relationships in order to act in civil society and to influence, on the one hand, the decisions of the state and on the other, the course of scientific research. But while such political mobilisations are extremely important in changing the environment of the disabled, they locate the subject positions of the disabled firmly within a liberal political regime. (2007, p. 129; see also Rabinow, 1996.)

As Das and Addlakha (2007) argue local practice embedded in NGO care is ambiguous as it may carry the biopower that can either support a healing environment or further ostracise the disabled people. This is what I call the NGOs' dilemma. These practices are enabling new governmentality and external control. In Foucault's language, resistance is a subtle power in the way the actions and resistance of the controlled population shape a new formulation of disguised power (Pylypa, 1998). The NGOs' holistic care programs that involve mental, spiritual and social regulations are not just a local but also a global phenomenon in the way that powerful neo-liberal impulses connect global economics to local cultural and religious care programs.

When I participated in a Disabled People's Organization (DPO) meeting, what the participants and I found really hard to understand was how to bridge people's needs and the rules set by the donor. In order to follow the donor's wishes, we were often forced to come up with an idea that was very sophisticated but which we felt would somehow just touch the surface of what was needed. Disability rights activists appear to be involved in a momentous movement vis à vis unsupportive state programs and law. But as the DPO discovered there is a real disconnect between international norms and the everyday life experience of persons with disabilities (Phillips, 2011, 2014). Phillips's insight was illustrated vividly in a meeting where Wiwin, one of the participants I had got to know, pushed the group to design 'acceptable' programs:

> Busy finding some activities that match both the real needs and the offered program set by The Global Fund donor agency, Wiwin keeps encouraging people in the DPO meeting to come up with a 'brilliant' idea. One goal from the meeting's outcome is to make program activities that take into account disabled people's participation. One legless participant raised his hand and told Wiwin that instead of walking upstairs what he needs in his everyday life is a mobile ramp made from flat wood that can be used for getting him in and out of the Mosque. But Wiwin quickly responded that we would not have support from The Global Fund for this kind of requirement. Let's find another brilliant feasible program, she said to everyone. (Fieldnote, 5 Jun. 2015.)

In the search for funds and support, the DPO finds itself forced to 'play the state game', in particular having to use the language of Western donor agencies in making funding applications and in program delivery services. The dominant Western hegemony was clearly captured in Wiwin's effort to propose activities that fitted with the Global Fund framework.

Wiwin was one of my research participants. She was a young energetic woman activist who took part in a meeting hosted by the DPO in a district in the north of Yogyakarta. Wiwin told me how her husband had left her for another woman. He left her as a single mother with three children under a divorce arrangement in Islamic law. Economic hardship and weak

social support had a significant impact on her as a divorced woman. She therefore worked casually at a tailor for ladies and was involved in the disability organisation to gain additional income.

> Wearing a pink *hijab* that covered her hair neatly, I noticed her enthusiasm in actively speaking up in a meeting of people with disabilities, their family members and friends. Moving in and out of the small sized living room, she helped the house owner prepare snacks and bananas for those attending. Her comments were conveyed loudly and seemed convincing to people who were there. Catching Wiwin in the front yard after the meeting, I asked why she participated in the meeting. 'I did not notice any body differences in you, Wiwin,' I asked her seriously. Unexpectedly, she answered me in this way: 'Hai I am *difable*, a polio sufferer,' pulling up her long dress to show me her left leg that was slightly smaller than the right. To me, however, there was no noticeable difference in her legs. (Fieldnote, 3 Jun. 2015.)

Apart from her willingness to share in the social life that the DPO offered, Wiwin told me that attending the meeting in the DPO benefited her as she would receive approximately AUD 5 for a meeting/transportation fee. 'This pay can be used for my children's consumption,' she told me another day. It is a fact that on a personal level, the DPO projects may benefit the elite activist. Yet, international donors require the DPO to employ people who meet criteria as *difable* people to fulfil the UNCRPD principle about social inclusion in progams. Disability activists like Wiwin mediate the one-size fits all global prescription of the UNCRPD that is translated into targets, instruments, activity plans and associations distinguished in terms of people who are marked by biological differences.

Figure 8.7. *Difable* gathering, on a street in Yogyakarta, celebrating International Disability Day 2016
Source. Facebook Page. Retrieved on 24 Apr. 2020 from: https://www.facebook.com/WaluyoSitiadi. Permission to use this image was granted.

Because welfare policy in Indonesia has struggled within the budget limit, NGOs have addressed the 'well-being' of people with disability in addition to existing biomedical care.

NGO growth in Yogyakarta may be attributed to the support they have received from various international agencies, corporations and national governments. These agencies have lent support because the welfare regime has seen NGO growth as fitting with democracy and the international standards of human rights. For example, in 2015 the state shared thousands of prosthetics all over the islands of Indonesia; a collaboration between NGOs and the Social Department at district level. One of the amputees, Pak Subari, told me that he always makes sure not to miss such charity events and the opportunities they offer. He was excited and satisfied with the event because he would not only be given a new prosthetic leg but also gain new experience and friends. Recently, he had attended an event that gave away free prosthetic legs in Karawang, West Java.

Pak Subari also received prosthetic devices provided by Mas Suryadi's NGO and the *Bakti Sosial* event held by PT Jiwasraya. He felt more comfortable and flexible with the prosthetic leg compared to other types of support aids. His prosthetic leg was crucial in supporting his economic work and other everyday activities. To that point, Pak Subari had had five prosthetic legs from various charity events. Pak Subari worked as a pedicab (*becak*) driver, pushing the pedals with his prosthesis. He told me how important the prosthetic leg was in supporting him and generating family income. He was proud as he often took foreign tourists to different tourist destinations. Having a job, he finally found his life partner and married a widow with one child. He continued his job as pedicab driver after getting married. He told me that he was not getting any younger and had decided to quit driving a pedicab and found a job close to his house. He worked as a brick block maker. Together with his wife, he left home at 5.30 a.m. and started making the mixture for the brick blocks. This activity included digging clay, mixing it with water, loading the mixture into the cart and taking it to the moulding place. It was all done manually with his prosthetic leg because the mixing machine would have been very expensive for him to buy.

> Here, there are more people who use the mixing machine nowadays. I still use my feet to mix the clay. It is very hard for me to get the money to buy the machine. How can I buy a machine? I myself still have difficulty to meet my needs. The machine costs around Rp 6 million, I guess. (Interview, 6 Aug. 2015.)

Thus, the prostheses or orthotics were a step toward normalising the disabled body to be more productive and active. A prosthetic was not only to rectify a lack and modify the individual's appearance in an attempt to replicate the standard body, but also it was a device that made a significant impact on enabling Pak Subari to supply his basic life needs and work. However, the dependence of the poor on accessing the NGOs' aids was inescapable.

At noon, I dropped by Martokasmin (Cak Marto). Sitting in his shoe repair mess, Martokasmin considered how the DPO program could be run in his neighbourhood. He said,

> Participating in the meetings is just wasting time, and continuing my work [shoe repairs] would be more beneficial than joining the meeting. Can you count how much income I would get per day from this shoe repair service? If I can finish 5 pairs of shoes every day, I can get about Rp 100,000 (AUD 10 per day) to feed my family. But if I spend my time in the meeting, I will lose the one hundred thousand or at most I would get Rp 50.000 (AUD 5) from the NGO as a transportation fee instead. From NGOs, I need crutches for my wife. She is an amputee too. (Interview, Martokasmin, 12 Feb. 2015.)

He looked at me with resignation and closed the noon conversation.

Figure 8.8. *Difable* touring group

Source. Photographed by author, 9 Jan. 2015

I argue that in the NGO sector in Yogyakarta, this confusion between global, social and spiritual expectations rubs off onto every day, small-scale human problems; problems where the construction of a shared affect reflects on the realisation of both a 'new' self-identity and a heightened stigma at the same time. We can understand that the term *difable* would not necessarily empower people because sociocultural and political structures perpetuate derogatory social relations and subordination in the construction of difference and otherness. Having said that, however, the NGO pathway is paradoxical. NGOs are powerful agencies that deepen a sense of affiliation, connection, empathy, kinship and social responsibility, but,

as we have also seen, in doing so they unintentionally help to shape a group of people as ‘different’ (Figure 8.8).

8.4. Conclusion

The role of NGOs working in the area of disability to some extent has played an important role in gathering resources to assist disadvantaged populations. But, the cultural influence of spiritual and religious ontologies of disability has interfered in NGOs’ activities, programs and advocacy. This chapter has particularly brought to life different perspectives on disability, contrasting the way the NGOs addressed these approaches and the way both ‘clients’ and NGO activists draw on cultural, religious, and spiritual frameworks to understand and respond to disability. NGO workers deal with the tension between the demands of the donors focusing on the physical rehabilitation of the individual, and what they see as the need to cater to the spiritual, mental and emotional states of the *difable*.

I argue that the NGO dilemma lies in trying to build the value of care while facilitating the practice of governmentality. The intersecting perspectives of biological approaches and social and spiritual insights strengthens the *difable* subjectivity. The practice of giving social care (*kepedulian*) is entangled in generosity but also in domination and power over bodies. Enmeshed in these understandings and motivations, poor disabled people will remain the subjects of suffering and continue to be positioned as ‘weak’ social groups and ‘second-class’ citizens. They are structured in ways that position them as ‘different’ groups (Kohrman, 2005; Mosse, 2010). I have shown that the work of NGOs, therefore, loses its effectiveness of giving social care as it continues to contribute to poverty and marginalisation.

Chapter 9
Conclusion: Locating Self and Social Identity in Java, Indonesia

My analysis of illness narratives explored Javanese living today as an intersection of different paradigms that locate self and social identity at an *ambang pintu* (threshold). This thesis shows how the experience of severe illness, impairment and care in Java is understood by Javanese through their cultural traditions and social system. In the eyes of Javanese, the health-care relationship is more than biomedical as my interviews with patients and clinical staff in hospital, and my observations of hospital practice, village relationships and the delivery of care by state and non-state agencies made abundantly clear. This ethnographic research reveals that the delivery and take-up of health care can be understood as a study of the cultural politics of illness, impaired bodies and health care in Yogyakarta. Throughout the thesis, I have shown that the collective traditions, shared affect and public meanings of severe illness and disability are embedded in the intertwining of biomedical and popular narratives. The ethnography traced this eclectic blend of biomedical diagnosis and treatment with Javanese religio-cultural perceptions of illness and care across a wide variety of settings.

In Yogyakarta, the influence of the aristocracy, their values, practices and beliefs are still taken to be a powerful tie uniting people within the cosmic order. The embodied mysticality enacted through both the religion of Islam and the Yogyakarta Kraton is how Javanese individuals make sense of their fate and inspiration. Lives at stake, in the Javanese eyes, signify God elevating humans' *batin* (spiritual selves or lives) above their *lahir* (physical lives). This study explored how illness and disability are popularly narrated and how this produces emotional repertoires in which Javanese repress their emotions and conceal turmoil through the idioms of *syukur* (thanks for blessings) and *nrimo* (acceptance). Nonetheless, the ethnographic examples demonstrate that the religio-cultural interpretation, emotions, and social hierarchies may also constitute a form of repressive power that simultaneously motivates social prejudice and social segregation. Stigma emerges as a product of moral struggles within the everyday life of Javanese as they face serious illness.

By focusing on how people think and feel about chronic illness, impairment and care, I suggested that the flows of *rasa* (affect) that circulate in clinical and everyday life denote that Javanese work to balance spiritual, moral and physical care. During my research, I kept asking why people often responded in an intensely emotional manner to medical prognoses. As discussed, it was my extended presence and interaction with patients and family in the

hospital ‘corridors’ that helped me understand that affect can be understood as a mode of resistance and struggle as individuals wrestled with bringing different understandings of their circumstances and identities into focus with the biomedical treatment.

9.1. Summary of conclusions

First, it was in the hospital corridor where patients and their familites cultivated the affect of resistance to medical prognoses, and found strength and meaning in their responses of *nrimo* (acceptance) and *syukur* (giving thanks for blessing) in facing medical prognoses. My conclusion from this work is that the flows of affect that are widely used in the way individuals map problems in everyday life show that the Javanese responses *of syukur lan anugerah* (giving thanks for blessing) and *nrima lan ikhlas* (accepting suffering with passion), which we might translate as ‘submission’ and ‘acceptance’, may be understood as forms of social struggle, springing from cultural practices, beliefs and social norms rather than being a submission to a regime of power over life.

Second, this study focuses on poor people who are without adequate resources to access the full support systems offered by the medical and state apparatus. The damaged social system results in exclusion and control and this in turn structures social interactions, resulting in invisible blocks on the capabilities of the poor to act. When the affective system exerts structural violence upon the poor it brought home to me in many different ways that most people perceive illness, health and healing as a moment when only God can restore the vulnerable as human beings. This challenged ‘state-phobia’ and represented an affective condition influencing a patient’s responses. Within these limitations, everyone attempted to make sense of their own experience. Yet state phobia can cripple a patient’s response. At the same time, the discourses of the *kraton*, religion, hospital staff and NGO workers supply interpretations that may not be crippling, as these discourses are not oppressive in themselves. If the Javanese cultural practices are acknowledged and valued by all agencies, and the biomedical gaze and Javanese practices and understanding of illness and care are both esteemed, this combination may transform the experience of chronic illness and disability and contribute to the empowerment of individuals.

I have made a number of claims in this dissertation that although poor people are disempowered by the structures of poverty, these poor people demonstrate an agency that allows them to recover a sense of self-fulfilment and to find a place in society. When I initially encountered Bu Sumiati and her daughter, Jelita, one year after the cancer had been diagnosed, they were in a state of surrender (*ikhlas*). Bu Sumiati had surrendered her life. She

never begrudged how much money she had spent on additional costs during Jelita's medical treatment, right up to the time that Jelita passed away. Looking inside herself, Bu Sumiati expressed thanks to all people who helped her daughter's treatments—clinicians, neighbours, NGO workers, friends, relatives and of course she recognised God's will. She admitted that she had been 'pretty blessed' during that time. Being submissive to God is a critical foundation for the longed-for state of being 'healthy and recovering'. So, being united with God is the strongest place to be. This research has shown that the sick and disabled poor have practices and ways of responding to trauma and are not powerless in a matrix of power and regimes of control that regularly target and disempower them. Rather, they express a desire to gain a sense of harmony and balance in the face of the 'risk' of catastrophic events such as severe illness, disability and even death. In contrast with Foucault's argument then, I have shown that the discourses establish a space for agency that allows for a more holistic intervention of healing (Foucault, 2012; Foucault, 1980).

Notwithstanding the important role of NGOs, the changing aid dynamic is leading to programs that are relatively patchy. In Yogyakarta, I observed that non-state agencies and the ways they give 'care' are positioned within the overwhelming, while productive, dimension of obligation and dependence. When various sponsors press NGOs working with people with disabilities, the NGOs confront a dilemma: if they segregate persons based on physical 'difference', they may disempower their especially poor clients. The practice of inclusive development and the 'modernisation' effort in the wider context of the political economic life in Indonesia is likely to be naïve in dealing with the poor and the vulnerable. The *difable* (disabled) linger on as low-ranked subjects and are treated as clients of the powerful and wealthy. My research shows that their fate is dictated for them by others rather than that they are empowered.

Third, my research has shown that both state and non-state institutions tend to make categorisations of *difable* in terms of the abnormal. Practices tend to stress their social marginalisation. I have shown in my dissertation that disability activism and health interventions based on disability rights in fact assert biomedical control over individuals and further underline the categorical dichotomy of people into abled/*difable* or normal/abnormal. I have shown that from the recipients' perspectives, seeking and receiving care can be understood as entangling themselves in an experience of 'difference'. Disability activism actually drags poor people with severe illness and disabilities into a certain social class or club. Disabled people who receive aid may experience, not only the reality of the catastrophe

of their own circumstances, but it may also prejudice them and others against the ‘different body’ in which they are embedded.

Fourth, research in village settings particularly has foregrounded Javanese participants’ beliefs that *orang pintar* (‘wise persons’ or traditional healers like *dukun, paranormal* or *kyai*) have the knowledge and capacity to draw together psychological, spiritual and social values. They assist by constructing individuals’ sense of feeling *ayem* (equanimity) (Guinness, 1986) and this mode of treatment is complementary to biomedical therapies. My research has not led me to conclude that seeking the interventions of *orang pintar* to heal cancer or impairment is a solution. But rather I argue that complete treatment and intervention should ideally reference the integrated body and self that informs Javanese habitual practice and understanding of what it means to be ‘healthy’. My research suggests that *orang pintar* work effectively in engaging the psychological, spiritual and social but are not competent in dealing with the physical. It is reasonable to conclude that a willing partnership of diverse experts is likely to be valuable in the care of chronically ill and disabled individuals in Java.

Fifth, it was brought home to me in many different ways that illness, health and healing in the Javanese view are understood as moments when only God can structure vulnerable human beings. Central to this belief is the idea of a journey; of an individual working towards achieving a state of *ayem* or inner state of harmony, where healing involves the whole person beyond the merely physical. Becoming a healthy person or body means realising the feeling of *ayem* across a number of lived practices. Individuals in a state of *ayem* are confident they can maintain harmony with God, feel connected to wider society, and achieve balance in their inner selves (*batin*). Being dependent upon God is a critical foundation for the longed-for state of being healthy, with God ever present in the individual’s mindfulness.

Sixth, I discovered that there is a general social acceptance that God tests people through suffering and that everyone must accept such trials. In the eyes of Javanese, these perceptions are representations of the deeply held belief that this is the way that life should be lived. This is the way individuals can make sense of their fate and reject death. Readers will recall the somewhat bewildering strategies into which individuals put their trust for various reasons. However, it also became clear that individuals were not fatalistic about what therapies might be applied and rarely rejected biomedical treatment. It was obvious, however, that there was a cultural preference, even urgency, associated with restoring the inner self, the spiritual and social dimension even before the physical. Thus, much of my analysis led me to

conclude that every individual is located on a journey to attain not just state expectations but their own realisation of being a whole person.

Lastly, this study contributes to a broader understanding of experiences of embodiment, inclusion and personhood. One of the key lessons that can be learned from this study is that the Javanese experience of illness and disability has illustrated that individuals are not potentially cowed into abandoning agency. We have seen that values, habitual practices and religious beliefs are the foundation of agency, but these can also act as oppressive powers of domination that push people with illness and disability onto the margins. Even if the people have deeply held beliefs and have been provided with both culturally informed care and adequate biomedical treatment, some of them cannot avoid marginalisation. So, effective health care needs comprehensive and collaborative understandings between cultural and biomedical sciences. Otherwise, the affective modes of submission may be distorted and shift culturally positive modes of affect into less desirable outcomes.

Acronyms and Abbreviations

BPJS	Badan Penyelenggara Jaminan Sosial (Indonesian Universal Health Care)
BRTPD	Rehabilitation Centre for People with Disabilities
DRG	Diagnostic Related Group
ECG	Electrocardiogram
GP	General Practitioner
ICCU	Intensive Cardiology Care Unit
INA-CBGs	Indonesia-Case Based Groups
Jamkesda	Jaminan Kesehatan Daerah (Local Health Insurance)
Jamkesus	Individual Health Insurance (for people with disability)
JTCK	Jalinan Tali Cinta Kasih (Love and Friendship Network)
KIS	Kartu Indonesia Sehat (Indonesia Health Card)
KORPRI	Public Servant Corps
MESS	Mangled Extremity Severity Score
MoH	Ministry of Health
NGOs	Non-Government Organizations
NU	Nahdlatul Ulama
OOP	Out of Pocket Expenditure
PBI	Penerima Bantuan Iuran (Beneficiaries of Contributory Assistance)
PNS	Pegawai Negeri Sipil (Public Servant/Government Officer)
Posyandu	Local Service Post
Puskesmas	Primary Health Care Board
SBY	Soesilo Bambang Yudhoyono
SDGs	Sustainable Development Goals
UGM	Gadjah Mada University
UHC	Universal Health Coverage
Ujian Nasional SMP	National Examination for Junior High School
UNCRPD	United Nations' Convention on the Rights of Persons with Disabilities
VIP	Very Important People
VVIP	Very-Very Important People
WA	WhatsApp
WHO	World Health Organization
YKI-Yogyakarta	Indonesian Cancer Foundation in Yogyakarta

Glossary

Javanese (J); Arabic (A); Indonesian (I)

abdi dalem (J)	court servant
adat (J)	custom
adi-kodrati (J)	supernatural
aib (I)	pity/disgrace
akhirat (A)	the hereafter
amal (A)	charity
ambang pintu (I)	threshold
amit-amit (J)	God forbid
anglakoni (J)	life's walk of faith
anugerah (I)	blessing
ayem (J)	inclusion; balance; equanimity
badan jasmani (I)	physical body
badan rohani (I)	spiritual body
balai (I)	rehabilitation centre
balasan (I)	retaliation
batin (J)	spiritual; inner self
belatung (I)	maggots
berkah dalem (J)	blessing of God (Sultan)
berkah (I)	blessing; from Arabic *barakah*
bakti social (I)	social solidarity or community service; from Indian *bhakti*
Bismillah (A)	In the name of God
Budi (I)	thought
cacat (I)	deviance; defect; disability
cara halus (I)	ethereal mode
carut-marut (I)	chaos
cemas (I)	anxious
cobaan (I)	God's testing
cocok (J)	fit
depresi (I)	depression
dhaif (A)	weak
dhalang (I)	puppeteer
dibatinkan (I)	internalised
difable (I)	people with different abilities
dhikr (A)	reciting section from the Qur'an or religious formula
diwongke (J)	valued as human
do'a (I)	pray; from Arabic dua
dukuh (I)	head; community leader
dukun (I)	curer; traditional healer
fungsi jasmani (I)	physical capacity
galian or *pill* (I)	plant/herb-based compressed
gelisah (I)	anxious
Garebeg (J)	Feast festival in the Yogyakarta Sultanate during the Prophet Muhammad's birthday, Eid Al Fitr (end of fasting month) and Eid al-Adha
gotong royong (I)	mutual assistanc; a free flow of aid among equals

habib (I)	wise man
Hadith (A)	statements of the Prophet Muhammad
Hallal (A)	permissible
Hidayah (I)	enlighten
hijab/jilbab (I)	veil/hair scarf
hikmah (I)	consequence; a blessing in disguise
hitam diatas putih (I)	legal agreement
hukuman (I)	punishment
iba (I)	compassion
ikhlas (I)	have only good intention
isin (A)	embarrassed
jamu (I)	herbal remedies
Jihad (A)	life as a Holy War between faith and passion
Kalifatullah (A)	Caliph, representative of God
karma (I)	the spiritual principle of cause and effect where the intent and actions of an individual in this life and in previous lives influence the future
Kebatinan (I)	mystical power
Kebeneran (J)	truth
Kejawen (J)	Javanist; Javaneseness
kepanikan (I)	panic
kerja bakti (I)	working bee
kerukunan (I)	self and social harmony
kesakten (J)	magical power
keselarasan sosial (I)	social harmony
keselarasan (I)	harmony
kondisi klinis	clinical condition
kraton (I)	palace
kris (I)	traditional dagger
kwalat (J)	cursed
kyai (I)	religious leader
lair-batin (I)	whole self—physical and spiritual
lair (I)	physical
lajatan (J)	funeral
Lebaran (I)	holiday at the end of the month of Ramadan
legowo (J)	easy going, nothing to lose, accepting something unpleasant in a sincere manner and with resignation; feeling unattached to the materiality
lemah (I)	weak
lumpuh (I)	paralysed
Jawa asli (I)	authentically Javanese
masalah etik (I)	ethical problem
mengganggu perasaan (I)	annoyed
menuai yang kita tanam (I)	reap what you sow
mesake (J)	compassion, empathy
Modin (I)	Muslim officiant of rituals
musibah (I)	disaster
mustadhaafin (A)	powerless
nafsu (I)	passion
nasib (I)	resignation, fate

ndugal (A)	behaving badly
ngamuk (J)	emotional outburst
ngilmu (J)	knowledge
niyah/niat (A)	the intention
nrima (J)	acceptance
obat traditional (I)	traditional medicine
ojeg (I)	motorcycle taxis
orang cebol (I)	dwarf
orang pintar (I)	smart person; wise person; traditional healer
othak-athik gathuk (J)	various creative discourses
pahala (I)	reward
paranormal (I)	shaman; traditional healer (similar to *dukun*)
pasrah (I)	surrender
pembantu rumah tangga (I)	domestic worker
pemulung (I)	collector of disposed household goods
pendidikan inklusi (I)	inclusive education
penerima bantuan iuran (I)	beneficiaries of contributory assistance
pengobatan alternative (I)	alternative medicine
penyandang disabilitas (I)	people with disabilities
pesantren (I)	Islamic boarding house
polowijo (J)	disabled people; congenital disability; dwarf; giant; albino
priyayi (J)	the ruling class of traditional Java
ramuan (J)	plant-based medicine
rasa (J)	emotion/affective
Reformasi (I)	Reformation
Rila (J)	to give oneself up
roh waktu (I)	the spirit of time
roh/Nurani (I)	soul
rukun (J)	equanimity; harmony
rumah sakit (I)	hospital
rumah singgah (I)	transit house
rumongso (J)	being self-reflective and accepting of suffering
sabar (J)	patient
sak dermo (J)	surrender
salam (I)	greetings
salawat (J)	the salutation to the prophet of Islam, from Arabic Shalawat
sangsi social (I)	social sanction
santri (I)	devout Muslim
sederhana (I)	simple life
senep (J)	exhaustion
serakah (I)	greedy
shadaqah (A)	alms
sholat (A)	to pray
slamet (J)	‘peace’ greeting
slametan (J)	communal ritual
stress (I)	stressed
Sunnah (A)	practice (of the Prophet Muhammad)
Syukur (I)	thankful, acknowledge blessing from Arabic *syukron*
Syukuran (J)	ritual of thanksgiving
ta'at (I)	religious duties

tabib (I)	Arabic physician
tabrak lari (I)	hit and run accident
takdir (A)	fate
takut (I)	worried
taqwa (A)	piety; fear of Allah; love for Allah; self-restraint
tata karma (I)	etiquette
Tausiyah (A)	Islamic preaching
tenaga kerja wanita (I)	female migrant worker
tentrem (J)	quietness; equanimity
tepo seliro (J)	each of us trying to put ourselves in the other's situation
tersingkir (I)	marginal
tukang pijat (I)	traditional massage healer
tuna daksa (I)	physically disabled people
tuna grahita (I)	people with a mental disorder
tuna netra (I)	blind people
tuna rungu (I)	hearing impaired people
Ustadz (A)	Religious teacher
Wahyu (I)	divine appointment; will of God
Wali (I)	saints
waria (I)	transgender—male to female
wasilah (I)	way (tool) to get closer to the God
welas tanpa alis (J)	compassion but neglect
wong cilik (J)	'little people'; poor people
wong ciri (J)	people with physical markings; physically different
wong nrimo (J)	people who accept whatever they are given
zahir (A)	physical body
zakat (I)	legally required alms

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