

**Surrender: the influence of religion, culture and access
to health care on diabetes self-care for Javanese
Muslim in Yogyakarta**

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Dedication

To Ifah,

For your passion, patience, and... love

Chapter One

Introduction

Topic and the Thesis

This thesis provides an original evidence based on how and if religiosity influences Javanese Muslim adults with type 2 diabetes in managing the condition in their daily life. The study was influenced by the researcher's experiences and background in two significant ways: first, clinical experiences as a general practitioner, and observations of how Javanese people manage chronic health conditions. Second, being a Muslim living in Yogyakarta for the last fifteen years gave insight to how Islam is practised in daily life both through rituals and social relationships.

Further, being employed in the *Universitas Muhammadiyah Yogyakarta* (UMY) also encouraged the researcher to consider the central role of Islam to medicine and academic practice, since UMY has a mission '*to create men and women who possess personal integrity and Islamic morality in the context of individual or social environment*' (Universitas Muhammadiyah Yogyakarta, 2013). Islamic values and principles are core and UMY aims to produce medical doctors that are not only equipped with the latest knowledge and sciences, but also possess an Islamic integrity and personality. All of the above factors encouraged the researcher to explore the role and meaning of religiosity among Javanese people in managing ill-health conditions. For the purpose of the thesis, the focus on diabetes as a chronic health condition serves as an example of how religiosity influences self-care.

This introductory chapter discusses the ideas underpinning the study; highlighting the concepts of religiosity and culture and also explores the role they play in daily life among Javanese people, in particular, and more generally worldwide. The discussion examines the social, economic, and cultural contexts of Indonesia with a particular emphasis on Javanese culture. The role of religion among Indonesian people will be discussed to give a wider view and understanding of how religion may play a role in daily life, especially in trying to answer the question of how people with type 2 diabetes manage their life. The researcher's perspective will be explored in this chapter in order to explain the underpinning idea of the study, although, more detailed explanation will be

found in the Methodology chapter. The aim and objectives of the study will be described in order to identify the gaps that this study attempts to address.

The Importance of Religion in Islamic countries

For many people in many countries, religion is still considered a major influencing part of their daily life (Hassan, 2007; Polzer & Miles, 2007; Newlin et al., 2008; The Pew Forum on Religion and Public Life, 2008). This is particularly manifest among Islamic countries such as Pakistan, Indonesia and Egypt, where a person's faith is evident by how they behave in all domains of their life, not only in the religious domain (Hassan, 2007); in other words, evident through how religiosity embeds in daily life. For example, it is very important for every Muslim to maintain purity through consuming *halal* food wherever possible (Shepard, 2009). Moreover, Islam regards a neighbour as close kin and obliges Muslims to sustain good communal relationships with other Muslims. Thus, this notion highlights how religion and social relationships are interrelated (Esposito, 1988). Qur'an *surah An Nisaa 4 ayat 1* is emphasized the tenet of keeping the *silaturahmi* (ties with one's relation) through social day-to-day activities, as follows:

'O people! Be careful of (your duty to) your Lord, Who created you from a single being and created its mate of the same (kind) and spread from these two, many men and women; and be careful of (your duty to) Allah, by Whom you demand one of another (your rights), and (to) ties of relationship; surely Allah ever watches over you'(The Qur'an, 2012).

A good communal relationship is also evident in the *ibadah* or domain of worship. All adult Muslims are obliged to perform daily *sholat*, which is ideally conducted in a *masjid* (Islamic term for a mosque) along with other fellow Muslims (Shepard, 2009). Therefore, *masjids* can be easily found everywhere in a Muslim majority community as a place to conduct this communal ritual activity.

It is believed to be important for Muslims to demonstrate their faith through their actions (agency), but in Islamic countries, like Indonesia, religion is also embedded as part of a structure. In Indonesia, with almost 88% of its population being Muslim (Statistic Indonesia, 2010), the Ministry of Religious Affairs of the Republic of Indonesia exists that legislates for all religions in Indonesia (Ministry of Religious Affairs, 2014).

Defining the terms

For the purpose of the study, it is considered essential to define the concept of religiosity at the outset, although more detailed discussion will be found in the second chapter. Religiosity is a concept which entails a complex and multidimensional aspect of religion; it is a comprehensive term which comes from numerous aspects of religious values, dedication and activities (Azam, 2010). It is proposed that religiosity is comprised of several dimensions such as belief, ritual, knowledge, consequential, including spirituality (Glock & Stark, 1965; Hassan, 2007). Religious belief is something that a Muslim is expected and required to hold and adhere to, and this involves three aspects: warranting, purposive and implementing beliefs, while, rituals dimension refers to any religious practices as an integral part of formal religion (Hassan, 2007).

Glock & Stark (1965) believed that it is necessary for any religious individual to be aware and well-informed about their faith; an underpinning concept of the knowledge dimension of religion. Nevertheless, Hassan (2007), developed a multidimensional concept of religiosity based on the work of Glock and Stark, argued that knowledge does not stand as an individual concept, rather, as an integral part of the ideological dimension or belief, since one will be able to accept a belief by knowing the very nature of the belief. They also argued that *'belief need not follow from knowledge, nor does all religious knowledge bear on belief'* (p.440). Furthermore, the consequential dimension refers to how individuals use religion in the secular world, which incorporates multidimensional elements of belief, practice, experience and knowledge (Hassan, 2007). Spirituality refers to any feelings, emotions or experiences that are related to God or the Transcendental Being (Glock & Stark, 1965). A more detailed discussion of each dimension will take place on chapter two; Religion, Religiosity and Religious practices.

The discussion of religion does not only focus on the philosophical view of religion in finding answers to how the universe was initially created/ where human-beings comes from/ where we go after death. Instead, in some communities, it involves a practical function in dealing with everyday events, such as ill-health conditions (Newlin et al., 2008; Abdoli et al., 2011). This is an important issue that the researcher will explore throughout this study. Indeed, in some societies, religion is embedded in culture, which is evidenced in dance, paintings, storytelling, etc. (Giddens,

2006). However, levels of religious belief vary among individuals and societies (Adams, 2005). To put the idea into context, there is similarity between certain cultures in expressing different levels of religiousness that can basically be divided into two categories; highly or less religious. The term *abangan* and *santri* have been used in Indonesian settings to determine the more religious person to the less religious, or nominal Muslim, respectively (Peacock, 1973; Koentjaraningrat, 1985; Zieitlin et al., 1995), whereas among Pakistani Muslim, the term '*Muslah Muslim*' or prayer mat Muslim is used to distinguished a less religious Muslim (Hassan, 2007).

It has been argued that religion or spirituality has beneficial effects to the management of chronic illnesses (Samuel-Hodge et al., 2000; Polzer & Miles, 2007; Sacco et al., 2011) and this is evident in Indonesia (Kanbara et al., 2008; Yuniarti et al., 2013), Iran (Abdoli et al., 2008; Abdoli et al., 2011), Malaysia (Chew et al., 2011), and Ghana (Aikins, 2005), as well as other developed countries such as the US (Carlton-LaNey, 2006; Casarez et al., 2010) and the UK (Grace et al., 2008). It has been claimed that religiosity is important in acting as a coping strategy in dealing with the psychological aspect of diabetes management such as anxiety and depression, as mentioned by Kanbara et al. (2008), Yuniarti et al. (2013) and Samuel-Hodge et al. (2000). A large epidemiological study conducted in 41 countries across North America, Asia, Middle East, Australia and Africa has showed that the majority of participants agreed spiritual care is an important part of palliative care (Ramondetta et al., 2013).

Indonesia in context

The focus of this chapter now shifts to present contextual information about Indonesia and the people who live there.

Indonesia - Geographical and Historical perspectives

Indonesia is located between two continents; Asia and Australia, and between two oceans; the Pacific and Indian. It has a tropical climate with two distinct seasons; monsoonal wet and dry (Hendayana et al., 2010) and the temperature varies between a minimum of 17° C in Sleman, Yogyakarta, to a maximum of 38° C in Supadia, West Kalimantan, while, the average humidity ranges from 73% in Kemayoran, Jakarta to 87% in Sicincin, West Sumatera (Statistic Indonesia, 2014). With more than 17,000 islands and 6,000 inhabited islands, have made Indonesia the

largest archipelagic state in the world (Statistic Indonesia, 2014). The capital city of Jakarta is located in Java Island, one of five main islands beside Sumatera, Kalimantan, Sulawesi, and Papua. Furthermore, Indonesia is also comprised of four archipelagos of Riau, Nusa Tenggara, Maluku and Bangka-Belitung. Therefore, according to the World Factbook by the Central Intelligence Agency (2014), the reach of Indonesia's geography makes its coastline the second longest in the world after Canada.

The history of Indonesia as a nation can be traced back to the era of *Indianized* kingdoms, as early as the 7th century (Peacock, 1973). Previously influenced by Buddhism and Hinduism, from the thirteenth century, Muslim merchants arrived from India and this began the influence of Islam, particularly in coastal areas (Peacock, 1973). Following this, the centre of ruling government changed from the *Indianized* kingdom of *Majapahit* to the Islamic kingdom of *Mataram*, which was established by *Panembahan Senopati* in the sixteenth century and had its peak power across Java in the seventeenth century (Baskoro, 2009). The new establishment successfully captured elements of the maritime Islamic culture into the inland Hindu-Javanese life, '*creating the process the most powerful organizational expression of abangan syncretism ever to exist*' (Peacock, 1973, p. 27). The term *abangan* refers to a nominal Muslim. Thus, it is still evident in the event of '*slametan*', a form of a feast shared by neighbours which combines Arabic and Javanese chants to worship *Allah* (Peacock, 1973). Buddhism is still practiced mainly by the Chinese which can be seen in the *Wesak* celebration in the Borobudur temple (Peacock, 1973). This is an annual international event commemorating the birth, enlightenment and death of Buddha Shidarta Gautama; the founder of the Buddhism (PT Taman Wisata Candi Borobudur Prambanan Ratu Boko, 2011).

The influence of western culture started with the arrival of the Portuguese and Spanish Christian missionaries in the 16th century. Portuguese heritage is still evident mainly in the Timor and Maluku regions ("History of Southeast Asia," 2014). Following this, Dutch colonization occurred as a result of missionaries in the seventeenth century with Java as the center of the government (BBC, British Broadcasting Corporation, 2014). In 1811, the British arrived to take over Holland's

government and in the *Tantung* treaty, the Dutch agreed to surrender Java, Kalimantan, Bengkulu, Bali and Maluku and Sir Thomas Raffles was appointed as the Lieutenant Governor for the West Indies (Bagaskara, 2014). The fort of Marlborough in Bengkulu is considered as one of the British heritage along five years colonization in Indonesia, before the imperium was taken over for the second time by the Dutch five years later (Zulthink, 2014). After more than three centuries of ruling Indonesia, Dutch rule was replaced by Japanese in 1942 (BBC, 2014). Independence was declared in 1945, but was only recognized by the Dutch in 1949, following a massive guerilla war (BBC, 2014).

The Heritage of Western Colonization

The influence of Holland's Christianity's mission is also evident through the existence of *Gereja Katedral Jakarta* or the Cathedral of Jakarta, an European neo-gothic structure (Katedral Jakarta, 2014) that was built in the 19th century. This officially operated from the 21st of April, 1901, but the first Indonesian archbishop was appointed later on in 1963 (Katedral Jakarta, 2014). The harmony between different religions is illustrated by the establishment of two religious iconic structures at adjacent neighborhoods in the central of Jakarta, the capital city of Indonesia. Less than 500 m to the South West of the Cathedral lies *Masjid Istiqlal*, the largest *masjid* in South East Asia, which was designed by a Christian architect, Friedrich Silaban (Purba, 2010). Furthermore, along with Borobudur and Prambanan Temples, the Cathedral and the Istiqlal serve as a showcase of multicultural influence in the life of Indonesian people and underscores the tenet of *Bhinneka Tunggal Ika* or unity in diversity; a philosophical concept that has been established by the founding father (Kooistra, 2001).

Western influences are also evident in Indonesian's political affairs (Kroef, 1952). The establishment of *Pancasila*, or the Five principles of the Indonesian state, include several tenets that are similar to western culture and philosophy, such as nationalism and democracy (Kroef, 1952). Recently, Indonesia has been regarded as a developing country which emerged as a '*shining example*' of democracy (East West Center, 2014) with the successful performance of three direct presidential elections after the decline of the authoritarian era of the second president, Soeharto (Anugrah, 2014; East West Center, 2014).

Demographic, Economic and Political perspectives

Indonesia is regarded as one of the lower middle income countries with continuing significant economic growth, with a gross domestic product of \$ 868,3 billion and increasing gross national income from \$ 2,200 in 2000 to \$ 3,563 in 2012 (World Bank, 2014). Indonesia has many natural resources such as oil, coal and gold, whereas, the vast land and ocean resources have also served as potential resources with their contribution to agricultural wealth. However, according to the official report (Statistic Indonesia, 2014), agriculture only contributes to 14.43% of the Gross Domestic Product, compared to industry and service, at 45.69% and 39.87%, respectively.

With a population of almost a quarter of a billion (around 248 million), Indonesia has the fourth largest population in the world after the United States, India and China (World Bank, 2010; Statistic Indonesia, 2014). Among the population of its inhabitants, 11.47% of people are living below the poverty line of \$ 28 and \$ 31 per capita per month in rural and urban populations, respectively (Statistic Indonesia, 2014). The poverty line refers to the minimum amount of income that is required to achieve a basic food consumption of 2100 kcal per capita per day and other non-food basic requirements. Moreover, most of the poor live in rural areas (14.42%) compared to urban (8.52%) (Statistic Indonesia, 2014). According to the same report, among 33 provinces, Jakarta, Bali and Kalimantan Selatan have the lowest rate of poverty with percentages of 3.72, 4.49, and 4.76, respectively. Moreover, Papua, Papua Barat and Nusa Tenggara Timur are three provinces with the highest poverty rate with 31.53, 27.14 and 20.24, respectively. Nevertheless, unemployment trends in 2013 show a significant decrease from 7.9% in 2009 to 6.2% in 2013, slightly better than the Philippines (7.1%). Although, it is below Malaysia (3.1%), Singapore and Thailand, (1.8% and 0.7%, respectively), to place the data in the context of South East Asia (Statistic Indonesia, 2014).

The Education System

Education is regarded as an essential part of human rights due to its impact on life chances (UIS, Unesco Institute for Statistic, 2012). The Indonesian government passed an Educational Law no 20 in 2003 requiring all individuals from seven to 15 years old to attend school, and established a programme of basic-free education. The data from 2013 (Statistic Indonesia, 2014) shows that

literacy rates aged 15+ are 94.1%, with 95.65% for males and 88.05% for females; above the average adult literacy rate worldwide at 84.1% (UIS, 2013). However, if regional context is put into account, almost 17% of the population of Yogyakarta, for example, has never gone to school or completed primary school, while 27.33% graduated from primary and secondary school, and 44.54% graduated from high school and higher education (Statistic of Yogyakarta, 2012). Furthermore, the geography and dispersed population of Indonesia pose challenges in terms of accessing education.

Data from the UNESCO Institute for Statistics (2013) shows that the average time spent in education in Indonesia in 2011 was 7.5 years, a slight decrease from the data in 2006, which was 7.59 years. The percentage of the adult population (25 years old or older) that has completed upper secondary education in 2011 was 21.1%, higher than Thailand at 14.2%, but lower than Malaysia (34.5%) (UIS, 2013). Upper secondary education refers to a stage of education, which the students are generally 15 or 16 years old and have completed a lower education level (OECD, Organization for Economic Co-operation and Development, 2013). While for tertiary education, referring higher education such as at university, including undergraduate, masters and PhD level, Indonesia shows less significant percentage with 7.9%, compared to Malaysia (16.4%) and Thailand (11.8%) (UIS, 2013).

With around 40 million people of school-age, Indonesia has one of the largest school-aged populations in the world (The World Bank, 2004). The increase in uptake of education from the 1970s onwards has evident although there are wide regional differences (The World Bank, 2004). For example, the likelihood for two children to continue to junior high school differs between a well-to-do community in Yogyakarta province and a rural area in South Sulawesi province. A report from the World Bank (2004) further highlights that this disparity is even higher between different districts in the same province. Indeed, the variation in levels of education is important in understanding how participants in this study perceive religiosity in self-care activities since to some extent, cognitive ability is required to apprehend a multi-dimensional nature of religiosity.

Educational attainment is correlated to many aspects of human life. Studies report that people with a higher level of education achieve higher income (van der Berg, 2008; OECD, 2013) and the

converse relates to poor people who would have lack access to education (van der Berg, 2008). Moreover, education through the level of income has also a correlation with healthy lifestyles. Highly educated people who usually have higher income will have more options and access to a healthier lifestyle (OECD, 2013). Among the 34 countries of the Organisation for Economic Co-operation and Development or OECD, it reveals that people with lower level of education are more obese than the higher educated people (OECD, 2013). Another report shows that people with lower level of education tend to smoke more frequently than people with higher levels of education (Research and Development of Health, 2013). While, in regard to physical activity, regardless of the level of education, people tend to lead sedentary lives (Research and Development of Health, 2013)

Indonesia and Religion

Indonesia is considered as a multi-ethnic and plural country with various tribes, six official religions and 'one' religious belief (Statistic Indonesia, 2010). Islam constitutes the main religion affiliation with 87,18% of the population, followed by Christians (6.96), Catholics (2.91), Hindu (1.69), Buddhism (0.72), Konghucu (0.05) (Statistic Indonesia, 2010). Although the true intention of religion is establishing peace in plural communities, nevertheless, religious conflicts have arisen in several areas of Indonesia such as Kalimantan Barat, Maluku and Sulawesi, which is argued to be centred on money, political power and control (Kooistra, 2001; Jones, 2014).

Java in context

Java Island has been the centre of colonial activity (Zieitlin et al., 1995) as it is still evident today. Since 1930 Java already had experienced a long period of agricultural intensification, construction of irrigation facilities, and development of the infrastructure for colonial economic activities; making it the dominant region in Indonesia. Occupying two-thirds of eastern Java Island, with a population of than 60 million Javanese people (Statistic Indonesia, 2010), 36% of the population working in the agricultural sector (Statistic Indonesia, 2014). However, although the population density of the rural Javanese was among the highest in the world, their landholdings were among the smallest (Peacock, 1973).

The island of Java, which houses the capital city of Jakarta, is the main island among the four other main Islands. Comprising 6.77% area of Indonesia, Java was overpopulated with 57.06% of the population of Indonesia (Statistic Indonesia, 2014). Economically, Java has also played a great role in the gross national product. According to the 8th of August edition of *Kompas*, a nationally published newspaper, 58.7% from almost USD 210 trillion of GDP in the second quarter of 2014 was contributed from Java island followed by Sumatera (23.74%), Kalimantan (8.31%), Sulawesi (4.84%), Bali and Nusa Tenggara (2.5%) and Papua with 1.91% (Diah & Setiawan, 2014). With the title of '*Pertumbuhan Ekonomi Quartal I Tak Merata*' or the first quarter of the economic growth is not well-distributed, the report further describes the vast discrepancy between Java and the other main Islands of Indonesia in term of the contribution to the national economic growth and how the current programme of the main plan of the acceleration and distribution of the economic development of Indonesia has unsuccessfully worked in distributing and creating new centre of economic growth outside Java.

The Study Context – Yogyakarta

Yogya is a showcase of a blend of traditional and modern life exists side by side. In addition, motorcycle use has contributed to 74% of overall private vehicles in the streets of Yogya (Sajarwo, 2013); evidence of an inadequate public transportation system and infrastructure. This is significant since it threatens the accessibility of public services, for instance health care services, to the people of Yogya, particularly the poor people. However, with more than 3.5 million people and a population density of 1,147/km², Yogyakarta is among the most populous province in Indonesia, after Jakarta (15,015), Jawa Barat (1.282) and Banten (1.185). Among the workforce of the population, more than a quarter (26.91%) work in the agricultural sector, followed by trading 24.87%, service 18.76%, industry 15.13% and others 14.34% (Statistic of Yogyakarta, 2013).

Among the population of Yogya, 49.43% are male, and 50.57% female. According to the report from the Statistic of Yogyakarta (2013), more people live in urban areas compared to the rural population (66.37% and 33.63%, respectively). In terms of age, the middle-aged (25 – 59 years old) comprise the majority at 53.88%, followed by 0-24 years at 32.74% and older than 60 years old at 13.38%. With life expectancy of 73.22 years (Statistic of Yogyakarta, 2013), makes Yogya a

region with higher life expectancy than average Indonesia as a whole, at 70.4 years (Statistic Indonesia, 2014). However, on the other hand, Yogya has more poor people (15.8%) compared to Indonesia overall at 11.7% (Statistic Indonesia, 2014).

In the health care services sector, Yogya has 66 hospitals with 576 *Puskesmas*, or Community health centres, 181 private healthcare centres and 1526 self-practicing doctors (Statistic of Yogyakarta, 2012). Self-practicing doctors and *Puskesmas* are the most commonly used healthcare services by the people of Yogya in seeking health treatment, at 35.93% and 28.9%, respectively, followed by the hospital at 16.82%.

Javanese Culture.

This section will discuss Javanese culture including the main characteristics and other tenets that are important in understanding how Javanese people perceive life in relation to themselves, other human being, nature and God. Furthermore, it will explore how the *Kraton* plays a role in the lives of Javanese people, in particular in Yogyakarta and Solo.

Peasant and Priyayi

Koentjaraningrat (1985) argued that Javanese people can be distinguished into two categories - *peasant*, living in rural areas, and *priyayi*, living in urban areas, which have their own understanding or perception of several basic concepts of life, such as the meaning of life, the meaning of human labour, and the relationship between men. Indeed, this distinction is important to provide a background to the discussion of how people perceive the end result of their effort in managing self-care in their daily life. However, due to several factors, such as increasing exposure to western education, links with urban communities through the development of infrastructure and transport, as well as the advancement of information technology, isolated areas no longer exist, and these distinctions are not clearly distinguished among younger generation. However, for the elderly, these distinctions still apply and are used in daily life (Koentjaraningrat, 1985).

Tolerance, Accepting Fate and Striving for Harmony; Javanese's Main Characteristics

The main feature of Javanese culture is self-awareness, which is evident in the emphasis of tolerance among Javanese people (Supriyadi et al., 2012). '*Tepa selira*' is a term that refers to the

need for people to place themselves in someone else's position, a requirement in order to maintain a good relationship with their neighbour (Koentjaraningrat, 1985). A tenet that is also shared by Islam with a notion of *silaturahmi* (Fauziah, 2014).

Another main feature of Javanese people is to strive for harmony with other human beings, nature and with the unseen world (Magnis-Suseno, 2013), which also supports the emphasis on Javanese people as spiritual beings and seems to be intertwined with the emphasis on tolerance. Magnis-Suseno (2013) points out that in order to achieve harmony Javanese people are expected to avoid conflict, respect societal hierarchies, and avoid excessive emotions. Furthermore, from a young age, Javanese people are taught to keep an appropriate relationship with others, with the ultimate aim is to maintain harmony by being compliant, avoiding shameful conduct and respecting parents, elders and superiors (Magnis-Suseno, 2013). Indeed, the emphasis on being compliant, avoiding conflict and respecting authority is important to this study as it will have implications on the sustainability of a health care programme in regards of the adherence to a particular program.

It has been suggested that Javanese peasants would not necessarily speculate about the meaning of human labour, or the essence of human life (Koentjaraningrat, 1985), since their beliefs would centre on life as a continuous series of misfortunes and hardships. Thus, they would always *ihitayar* (constantly endeavour) and work hard, in regards to physical endeavour such as in agricultural production or economic life. It has also been suggested that Javanese peasants are inclined to surrender to misfortune - *ingkang nrimah*- or accept fate willingly, or *pasrah lan sumarah* - surrender and accept fate (Koentjaraningrat, 1985). This tenet is also echoed by *priyayi*; who emphasise fate and the negative aspects of life as a continuous calamity. However, with the nature of *priyayi*, their inclination is to think more deeply about the meaning of life, contrary to the peasants. They also believe that *ihitayar* is necessary in '*giving meaning to his life by trying to make the best of it*' (Koentjaraningrat, 1985. p.454), amid the burdens of their life. Therefore, the similar perception of the concept of fate is shared by both groups, although *priyayi* is considered to be less surrendering than the peasant group. Thus, to some extent the tenet of *pasrah lan sumarah* and *ihitayar* is similar, and even correlates to the meanings of some tenets of

surrendering and the need to keep trying in Islamic teachings of *tawakkal*. This represents the different basic thinking between the school of Ash'arite and Mutazila, respectively, as will be discussed in the next chapter. It is clear, then, that culture and religion are closely linked in Javanese culture, in fact it is impossible to separate them.

Social Ties

The concept of social ties among Javanese people has a very important meaning. Javanese people believe that in order to live in harmony one has to rely on fellow human beings, especially relatives (Koentjaraningrat, 1985). Another important aspect of Javanese culture among peasants is how they respect seniors and superiors. Hence, it is important in Javanese etiquette to use the correct style of speech and gestures in interacting with people (Koentjaraningrat, 1985). However, if confronted with difficulties regarding relationships with seniors or superiors, people tend to avoid confrontation by agreeing humbly or refraining from a response '*without any feeling of obligation or sense of commitment; or the agreement is expressed in a particular manner, which actually indicates in a refined way a disagreement*' (Koentjaraningrat, 1985. p. 458). In a more modern society, this attitude may be perceived as an act of hypocrisy. Again, this is important in establishing relationships with healthcare professionals, and this is explored more in the third chapter.

The close social ties among the Javanese are also evident in the existence of the term of *gotong royong*, which refers to mutual and reciprocal assistance evident in Javanese rural communities, although it can also be found in other societies around Indonesia (Bowen, 1986). The term also corresponds to moral obligation and selflessness in the aim of common good (Bowen, 1986); showing the power of social ties in society. There is an old saying in Javanese that underscore the true meaning of selflessness, '*sepi ing pamrih, rame ing gawe, mamayung hayuning bawana*' or avoiding taking advantage, and continue endeavor to achieve a peaceful world. This means that to achieve a better world we have to keep up the good work (together) without thinking of any personal interest (Sya'bani, 2006).

Although, the idea of togetherness, simplicity, and strong social interaction are synonymous with the general concept of social ties among rural communities, these ideas have also been seen in

urban settings, such as in Kotagede, Yogyakarta (Supriyadi et al., 2012). Urbanization has prompted rural agrarian societies, characterized by strong social interaction, togetherness and simple way of living; to be more individualistic, have less strong social interaction and a mechanistic way of living (Supriyadi et al., 2012). Nevertheless, Supriyadi et al. (2012) further argued that among the society of Kotagede, the behaviour of prioritizing the common goal over individuals is still evident by the communal use of one's own terrace, for example.

Javanese Culture and Islam

Explained previously, Javanese culture has been influenced by Hinduism, Buddhism and Confucianism as well as Islam (Zieitlin et al., 1995). Moreover, Islam Sunni has had the most influence among Indonesian (Zieitlin et al., 1995). However, most Javanese Muslims adhere to Islam only by confession and do not practice the teachings and values of Islam or nominal Muslim; known as *abangan* Muslim, a contrary to the more religious Muslim, which called *santri* (Peacock, 1973; Koentjaraningrat, 1985; Zieitlin et al., 1995; Cruikshank, 2009). *Abangan* Muslim take the oath of Islam without adhering to the teaching and values such as *shalat* or fasting, instead, they tend to practice the rituals with greater influence from the indigenous heritage such as seen in *slametan*, a feast shared by neighbours that combines Arabic and Javanese indigenous chants 'to worship Allah, placate the spirits and unify the participants so that they are all peaceful and secure (slamet)' (Peacock, 1973, p. 27).

Mysticism also features in Javanese culture, particularly in regard to how harmony with nature is maintained. However, this type of spirituality has been superseded by Islamic beliefs (Peacock, 1973). Another characteristic that Javanese Muslims possess in regards with the mysticism might appear from how their views about symbolic system of classification (Koentjaraningrat, 1985). Javanese people tend to correlate 'high' with unfamiliar, remote, formal, right, sacred and refined; and on the contrary 'low' with familiar, close, informal, left, profane and crude. Koentjaraningrat (1985) argued, *non-santri* Javanese tend to apprehend Islam as an unfamiliar, formal religion, and informal to the pre Islamic system of beliefs and rituals, which entailed to Hindu's beliefs. Although, it does not necessarily mean that the later concept bears a lower position, since the notion of *Sang Hyang Batara Guru*, a Javanese conception of the deity *Syiwa*

in Hindu Mythology, is regarded as a Holy figure (Koentjaraningrat, 1985). Thus, the notions explain the inclination of Javanese people to make a closer relationship with Javanese mysticism such as *Kejawen* over the least adhere to the Islamic's values.

Nevertheless, the existence of the intertwined tenets of Javanese mysticism and Islamic values has underscored the deep influence of Javanese culture by Islam. Indeed, it poses some potential in the effort of marrying religion and health care program considering the existence of similar tenets, such as surrendering and *ikhtiyar*, as mentioned before, which can serve as a gate to convey any educational program in health care.

The Influence of the Kraton

In Javanese culture, the *Kraton*, or palace, of Yogyakarta and Solo, and the figure of the *Sultan* or the emperor, have played a great role in influencing the culture of Javanese people (Supriyadi et al., 2012). Most Javanese people still believe that *Sultan*, as the leader of the palace, is a Godly figure with power and authority over the universe (Magnis-Suseno in Wardani, 2012). The *Kraton* of Yogyakarta played a significant role in the independence of Indonesia (the Sultan supported this and allowed the Indonesian government to use the *Kraton* as the basis of the independence movement) and as such is distinct from the *Kraton* of Solo, which does not share the same privileges from the government of Indonesia. Furthermore, numerous schools have been established inside the *Kraton*'s properties such as Universitas Gadjah Mada (Wardani, 2012), the largest government's owned university in Yogyakarta and one of the top three universities in Indonesia according to the Times Higher Education 2008 (Maulia, 2008).

The Development of Health Care in Indonesia

The following discussion of the development of health care in Indonesia is considered essential in understanding how the services are delivered and funded.

As a practitioner in health care in Indonesia for the past 17 years, the researcher has seen most of the health care services delivered in the fee-for-services principles. Most people have to pay to receive health care services, except for poor people. While, civil servants and army personnels are deducted from the salary to get healthcare services through the same insurance system as the poor. The categorisation of 'poor people' is based on *Badan Pusat Statistik* or Statistics

Indonesia, which relates to *'the inability to meet the minimum standard of food and non-food basic requirements'* (Listiyono et al., 2012). This standard utilizes 14 parameters, ranging from the physical characteristics of the house, the possession of toilet and bathroom, to dietary input. However, despite government effort, out-of-pocket expenditure on health is still high, which comprise 75.2% of total health expenditure (World Health Organization, 2010). Therefore, it is regarded as essential for the government to establish more coverage for health care services for people in general, which means providing greater funding for health (World Health Organization, 2010).

The establishment of 'Healthy Indonesia 2010' initiatives by the Ministry of Health and Welfare recommends the ministry to take collaborative action with other parties, such as public, other governmental offices and the private sector. This policy was developed as a response to the escalating figure of non-communicable disease-caused mortality in Indonesia, recognising cardiovascular disease as the main cause, and diabetes as one of the main risk factors of the disease alongside hypertension, obesity and dyslipidaemia. This condition is influenced mainly by several factors related to unhealthy behaviours such as being physically inactive, unhealthy diet and smoking (DGDCS, Directorate General Diseases Control and Sanitation, 2009). The goals for this initiative were: (1) to start and lead the health orientation of the nation, (2) to preserve and enhance the individual, family, public and environmental health, (3) to establish and improve affordability, accessibility and quality of health care services, and (4) to endorse public reliance in achieving health (Sarkar et al., 2006).

The Ministry has also developed the latest strategy of health development from 2010–2014, which constituted the vision and mission (DGDCS, 2013b) that aimed at empowering people. The vision is *'to achieve a just and independent healthy society'* with four missions of (p.13):

- 1). Enhancing quality of life of society through empowering people,
- 2). Protecting people's health through ensuring the provision of just, even and excellent health care services,
- 3). Ensuring the availability of well-distributed health care resources,
- 4). Good governance.

Maintaining an active involvement of people, particularly in health care service, is regarded as essential. Currently, the government has tried to support people with the establishment of a community empowerment initiative which is called *Upaya Kesehatan Bersumberdaya Masyarakat* (UKBM), or Community-Based Healthcare Services which consists of *Posyandu*, or *Pos Pelayanan Terpadu* (Integrated Service Post), *Poskesdes* or *Pos Kesehatan Desa* (Healthy Village Post) and *Desa Siaga* (Alert Village). The initiative is aimed at delivering the best service of primary care for the community in order to reach a wider scope of the population (Ministry of Health, MoH 2013b).

Despite the increase in number of the UKBM, the utility rate has remained low. Based on Basic Research Health reports, nationally, the utility rate for the *Posyandu* is 74.5%, and *Poskesdes* is 19.9%, with reasons for low use including '*incomplete facilities*', which accounted for 49.6% and '*the long distance of the facilities*' (26%) (Ministry of Health, 2009). On the other hand, non-communicable diseases are still considered the leading cause of mortality in Indonesia (DGDCS, 2009; MoH, 2012) with several determinant factors such as obesity, physical inactivity, smoking habits, and drinking alcohol.

According to the Basic Health Research 2010 reports in Indonesia (Commission on Health Development and Research, 2010), the obesity rate for children between 6 to 12 years old was 9.2%, while for people older than 18 years old it was 11.7%. Moreover, the Country Health Report from WHO (2006) shows that the main health problems were associated with changes in food habit. For example, the popularity of fast food among adults and children is associated with the higher incidence of obesity. In addition, there is an increasing trend of smoking among young people, which will cause lifestyle related health problems. Other problems that also account for health problems are substances abuse, lack of exercise, sedentary lifestyle and violence. Lack of social support and national commitment, despite several public health initiatives that have been implemented, were identified as main obstacles in managing these problems, especially smoking (WHO, 2006).

Therefore, to face the problems generated from these particular behaviours, the Ministry of Health has generated a specific program called *Posbindu*, Pos Pembinaan Terpadu or Integrated

Counselling Post for non-communicable diseases (DGDCS, 2013a) in order to promote health (DGDCS, 2012). Thus, it encompasses an integrated care of promotion and prevention as well as curative and rehabilitative measures (DGDCS, 2013a). Until 2013, there were 7,225 *Posbindu* around Indonesia. In addition, to enhance the performance of the initiative, the Ministry of Health (Ministry of Health, 2013a) offered a specific program of CERDIK for *Posbindu*, which is translated as 'smart' in English. However, in this context it stands for an acronym of C for *cek kesehatan secara berkala* (doing health check regularly); E for *enyahkan asap rokok* (get rid of the cigarette smoke); R for *rajin aktifitas fisik* (keep physically active); D for *diet sehat dan seimbang* (healthy and balanced diet); I for *istirahat cukup* (taking enough rest); and, K for *kelola stress* (stress management). On the whole, the specific program has resonance for the basic idea of self-care that has been stipulated in many diabetes management guidelines such as NICE, ADA as well as PERKENI, as will be discussed later.

The New Development of Health Care Services in Indonesia

Self-care Development in Diabetes a landmark for the health care delivery system in Indonesia occurred in 2004. The government ruled the National Act no 40 /2004 regarding Sistem Jaminan Sosial Nasional or the National Social Security System with the inherent Jaminan Kesehatan Nasional or National Health Insurance (BPJS Kesehatan, 2013). The National Act required the government to ensure all people of Indonesia acquire basic health insurance that covers primary health care needs. Primary health care comprises of any health promotion and disease prevention program, which was aimed to enhance the well-being of the people with increasing their involvement in conducting any particular supporting programs.

This initiative involves contributions from people who are able to pay and government contribution for the poor, civil servants, and armed forces personnel. The establishment of this act was based on the basic mandatory requirement for every person in Indonesia to have basic health insurance; part of the effort to achieve the overall well-being of the population (National Social Security System, 2004). The underpinning philosophy of the development of the national act was based on the expanding population; the increase in the proportion of older people, and the increase in chronic and acute illnesses potentially compromising productivity (BPJS

Kesehatan, 2013). To implement the act, the government passed legislation on the Badan Penyelenggara Jaminan Sosial or Social Security Organizing Agency which was meant to be introduced by 2014 (BPJS Kesehatan, 2013). Although, it was strongly suggested for people to be registered to a primary health care centre as a part of the requirement; the emphasis is predominantly reinforcing the active responsibility of the population.

To put the concept of self-care into context, diabetes is used as an example because of its increased prevalence and the impact it has on people's lives. According to the International Diabetes Federation's report (2013), more than a third of a billion people (381 million) across the globe suffer from this illness, and this represents an increase of more than 50% from 246 million in 2007 (IDF, 2007), and is predicted to reach more than half a billion (591 million) in 2035. The majority of cases (80%) come from low and middle income countries, which shows that it is a misconception that diabetes is an illness of the wealthy. Furthermore, this illness and its particular complications, such as kidney failure, heart diseases, limb amputations and blindness, have been responsible for high mortality rates across the globe. The World Health Organization (WHO, 2012) reported in 2004 that 3.4 million deaths have occurred due to the consequences of high blood sugar. The provision of healthy behaviour measures such as maintaining a healthy diet, keeping physically active, avoiding tobacco and maintaining a normal body weight can prevent or delay the onset of type 2 diabetes (WHO, 2012). This underscores the notion of (type2) diabetes as a preventable illness. Further discussion on diabetes will take place in the third chapter.

It is argued that the shift of diabetes epidemiology was influenced by changing demography as countries develop; higher life expectancy, aging population and fewer early deaths. However, the development of health systems leads to a better health promotion and disease prevention which can decrease the prevalence of morbidity including diabetes (IDF, 2013). Furthermore, global economic pressures, reduced resources, and the increased prevalence of chronic disease has been influencing the shift in perception from health care providers to take on a more of a supportive rather than active role; to empower the public to take more responsibility for themselves (Barlow et al., 2002; Bodenheimer et al., 2002; Wilkinson & Whitehead, 2009). Moreover, to ensure individuals are more responsible, it is also important for the 21st century

health practitioners to do more than just promote health; they also have to foster 'wellness' (Jamison, 2001). Indeed, the need for individuals to take more active involvement in dealing with chronic illness has become more prominent throughout various chronic conditions such as in low back pain patients (Crowe et al., 2010), cancer (Norris et al., 2001; McCorkle et al., 2011), cystic fibrosis (WHO, 2010), arthritis (Bruce et al., 2007) and diabetes (Funnell & Anderson, 2004). To achieve this, it is necessary to enhance individual's knowledge, modify behaviour or increase health competence, and the capability of a person to deal with the daily problems of the chronic condition; a concept that developed with the emergence of the self-care concept.

Self-care firmly places the control and ownership for an individual's health on themselves (Bhuyan, 2004; Anderson & Funnell, 2005; DoH, 2006). Encouraging self-care provides a humanistic approach to care and promotes the independence of individuals (Anderson, 1990; Anderson et al., 1991). The underlying principles guiding self-care require that the patient be more capable of managing their condition, and the healthcare provider surrenders control and involves patients in their decision making (Lau, 2002; Abdoli et al., 2008; McCorkle et al., 2011). This reflects chronic illness since the patients will have to deal with the conditions in their daily lives; how they are maintaining their lifestyle will affect the long term effects of their conditions. Therefore, to maintain self-responsibility in achieving the ultimate healthy lifestyle is regarded as more important than just staying alive (Cockerham, 2005). In this way, to achieve the enduring effects, one has to maintain a sustainable change not only in the way he or she acts but also the way they think (Anderson & Funnell, 2005; DoH, 2006). Therefore, to be fully involved into this life-long journey, the individual needs to develop a complete understanding of their needs in terms of both internal resources and external support so they can embed the condition and the management into their lives in order to achieve a better quality of life (DoH, 2006). Indeed, it is important to understand the possible obstacles as well as potential in maintaining the activities. Further discussion on self-care will take place in the third chapter.

How Religion Influences Health

The involvement of religiosity in maintaining health and well-being has been well-documented (Koenig, 2012). Due to the multi-dimensional nature of the concepts, it is proposed that how

religiosity might influence health and well-being is not linear or simple. Some studies have revealed that there are several pathways that might play a role such as social support (Koenig, 2002; Bhuyan, 2004; Newlin et al., 2008); religious belief (Koenig, 2002; Parsons et al., 2006; Polzer & Miles, 2007), coping strategies (Seybold & Hill, 2001; Samuel-Hodge et al., 2002; Bai et al., 2009) and religious practices (Levin & Taylor, 1997; McCullough et al., 2000; Coleman et al., 2006). In an Indonesian context, ritual practices (Mardiyono et al., 2011), coping methods and how people regard their relationship with God (Yuniarti et al., 2013) are considered essential in managing their condition.

Unfortunately, Indonesia has a lack of adequate evidence with regard to the role religion plays in self-care practices. There are several reasons for this; including the inaccessibility of a full-text data from the university repository; which still provides one of the main sources for literature searching, or the lack of articles that has been put in the credible international journal that related to the issues, despite of the new development of a search portal that has been put in place. The Ministry of Education Republic of Indonesia has developed a scientific search engine to provide the researcher community as well as lay people across the country with any scientific or popular materials, called Garuda that stands for *Garba Rujukan* Digital or Digital Reference Portal (<http://garuda.dikti.go.id/>). Another reason might come from the inadequate local or domestic search tools that might provide a comprehensive way to search through articles, theses, or dissertations. The lack of evidence also serves to reinforce and underpin idea for the current study.

Researcher and Topic of Interest

Practising in a medical field and previous research experience and supervising students in collecting and analysing clinical data, predominantly involving quantitative studies, meant the researcher originally fitted the positivist research paradigm. New to the University the researcher has limited experience of comprehensive diabetes management but has cared for individuals attending for advice to better manage diabetic complications. The exposure to the environment triggered questions on how people with type 2 diabetes, managed their illness in particular in terms of how they prevented complications from poor glucose control. Furthermore, as

mentioned in the early part of this chapter, an understanding of the influence of religiosity and the interwoven aspects of culture on managing well-being prompted the researcher to look further into Indonesian evidence. Thus, the lack of studies available in Indonesia served as a driving force for the researcher to look further in exploring how religiosity might influence Indonesian people with diabetes in maintaining their daily life. Further discussion on the philosophical stance that influenced the study will be explored in the Methodology chapter.

Therefore, to answer the gap that emerges in relation to the research question, the researcher has developed clear aims and objectives.

Aim and Objectives of the Research

The overarching aim of the study was to explore the influence of religiosity and the interwoven aspects of Javanese culture on self-care activity among Muslim adults with type 2 diabetes in Yogyakarta, Indonesia.

Objectives

- To explore the existence of self-care as a concept in diabetes management in Indonesia
- To identify the barriers and opportunities to diabetes self-care activity for the Javanese people in Yogyakarta, Indonesia
- To explore how and if Islam may influence self-care activity for diabetes management
- To generate new knowledge on how or if religion and culture may be utilised to influence healthy behaviour and inform self-care education programmes
- To make recommendation on how to promote self-care in Indonesia with the utilization of religious and Javanese teachings and values.

Proposed Structure of the Thesis

The thesis is organized into eight chapters, with this chapter providing an introduction.

Chapter 2 discusses religiosity and the inherent concept of spirituality; the meaning of both constructs, and how they developed. The chapter explores the culture of Indonesia, especially Javanese people, in engaging with religiosity and how the cultural perspective might play a role

in influencing religious beliefs and practices. The chapter will also explore current evidence of how religiosity might influence diabetes self-care.

Chapter 3 presents an exploration of the concept of self-care; its historical development; definitions, and the constructs surrounding it; self-care components within diabetes management, and any factors that might influence or hinder the process. The chapter also examines the practice of self-care within Indonesia's setting. Furthermore, the chapter discusses how religiosity might play a role in influencing self-care based on current evidence.

Chapter 4 discusses the methodological approach and the research methods for the study. The chapter also explores the researcher's philosophical framework and how his ontological and epistemological position shifted during the journey of the study. The researcher presents a reflexive account; an endeavour to look into the self, as an individual-general practitioner-cum-researcher to help him understand more in maintaining the journey of his study.

Chapter 5 presents the findings in regard to self-care among the study participants. The discussion explores participants' perceptions of self-care; and how the concept is applied in the management of diabetes. The chapter will also describe the demographic information of the sample, and the levels of self-care and religiosity.

Chapter 6 examines the findings on the relationship between religiosity, Javanese culture and self-care. The chapter explores the experiences and perceptions of the respondents on how and why, if religiosity may be interwoven within the Javanese culture, or if it influences self-care activity in daily life. It uncovers the themes that emerge from the study, and compares and contrasts to existing themes across current studies, and how the cultural aspect of Javanese people engage in these relationships.

Chapter 7 explores the key research findings on self-care and religiosity and self-care, respectively, and generates discussion in context with the wider existing literature. The strengths and weaknesses of the study are highlighted including the uptake of the study findings into national guidelines.

Chapter 8 serves as conclusion along with the summary of the key recommendations for practice; policy and future research naturally emerge from the study findings and concluding remarks.

Chapter Two

Religion, Religious Practice and Religiosity

Introduction

This chapter focuses on the development of religion and the concepts surrounding it, such as religiosity and religious practice; it also explores the position of religion within Javanese culture, with specific reference to influences on health and well-being. Aspects of religiosity in Islam, inherent in the daily life of followers will also be explored.

Religion in context: a world overview

At the beginning of the twentieth century sociologists predicted the decline of religion (Wade, 2009) and some leading figures in philosophy, psychology and anthropology has postulated that ever since the Age of Enlightenment, theological superstitions and sacred practices would be outgrown in the modern era (Norris & Inglehart, 2011). In the West, since the Enlightenment, the traditional role of Christianity and the influence of religion in society has declined (Gill et al., 1998; Wade, 2009; Norris & Inglehart, 2011) and Western societies have become more secular as a result of 'rationalism' (Hill et al., 2000) and religious scepticism (Herberg, 1962; Bell, 1978), evidenced by the writings of the journalist Christopher Hitchens and academics like Richard Dawkins¹.

Furthermore, currently, there have been on-going attempts in questioning the beneficial effects of religion in everyday psychological adjustment. Ellis (in Hackney & Sanders, 2003) argued that religion represents '*institutionalized irrationality and is deleterious to psychological functioning*' (p.43), or is regarded as '*dangerous nonsense*' (Dawkins, 2001) and atheists claim it is dysfunctional (Diener et al., 2011). To put the matter into perspective, other evidence shows the

¹Although see Harvey & Silverman, 2007; Newlin et al., 2008 for evidence that Christianity remains important among Afro-Americans in the US

decline of adherents to religion in the United States (The Pew Forum on Religion and Public Life, 2008) and other developed countries across Europe (Diener et al., 2011).

Recently, Islam has been regarded as the fastest growing religion across the globe (Young, 1997; Zein, 2007), also within countries that were traditionally Christian such as Ireland (Ghosh, 2014). It has been argued that the increase in number of the Muslim population in western countries is due to the influx of Muslim immigrants from the North Africa, South Asia and Turkey, the growth of population in Muslim countries, as well as the conversion of minority groups, such as African Americans in the United States (Young, 1997), for instance, whereas the population of the Western countries tend to be stagnated (Zein, 2007).

Moreover, Islam's prominence was evident not only by increased numbers, but also by how teachings and values were embedded in everyday life, in nation states. Shari'a was considered as an evidence of how religion and the state are inextricably linked in most Islamic countries (Johnson and Sergie, 2011). Unlike Western law, the existence of Shari'a was considered to be independent from any given regimes among Muslim countries; it has been survived through the changing governments (Egger, 2008). This was due to the fact that Muslims consider Shari'a as a reflection of Allah's will (Egger, 2008; Shepard, 2009). Shari'a literally means '*the path leading to the watering place*' (Coulson, 2014). Thus, Shepard (2009) argued the symbolism is clear, particularly in an infertile land such as Arabia: '*it is the path God has laid out for us to walk in our lives to reach the waters of true life*' (p.124). Therefore, it was argued that Shari'a was not similar to Western concepts of 'Law', since it was understood to cover all areas of human life (Shepard, 2009). The practice of Shari'a law can be seen from the implementation of law in marriage to making punishment (Shepard, 2009).

Furthermore, how Islam was interwoven into the life of Muslims is evident in how they perform their beliefs which can be seen in daily social life. Currently, women Muslims or Muslimah have been more apparent in using hijab or veil to cover the head and chest as part of their belief, which was not evident two or three decades ago (Young, 1997). This was also true within Indonesian setting, where hijab has been becoming more popular since the 1980s, following the emergence of the ban of hijab among several senior high schools students around Indonesia from the local

education authority (Budiastuti, 2012). Nevertheless, recently, the hijab was not only considered as a showcase of piety among society of Indonesian's Muslimah, rather, more of a fashion statement (Fajardianie, 2012).

There has been an on-going effort to seek how or if religion affects human life in health aspects. An abundance of evidence demonstrates and confirms the relationship between religion and/or spirituality and well-being in general (Hackney & Sanders, 2003; Koenig, 2012), which was not only found in the elderly (Koenig et al., 1988; McFadden, 1995), but also among younger people (Gail Frankel & Hewitt, 1994; Donahue & Benson, 1995). Other evidence suggests that a belief in God might reduce uncertainty, especially when it was related to meaningful personal experiences (Lupfer et al., 1996; Preston & Epley, 2005), and its ritualistic attributes have placed a stable ground to face any erratic obstacles (Wade, 2009). Evidence has also emerged among Islamic countries in examining whether spirituality serves as coping strategy or hindrance among breast cancer survivors in Iran (Harandy et al., 2010), a part of holistic nursing care in Indonesia (Mardiyono et al., 2011) or terminally ill patients in Egypt (Hamdy, 2009), which will be discussed further in the Self-care, Diabetes Management and Religiosity chapter.

Furthermore, evidence showed that among societies with more difficult life conditions, people were more religious (Diener et al., 2011). To put religion into the scope of functionalism may enlighten how people make a function of religion into their life; whether giving meaning and purpose to life, reinforcing social unity and stability, serving as an agent of social control of behaviour, promoting physical and psychological well-being, and motivating people to work for positive social change (Barkan, 2011a; Hackney & Sanders, 2003). Therefore, the social context has to be considered in measuring the religiosity of a population.

Defining Religion

It is argued that the word religion is assumed to come from the word *religare*, a Latin word for to bind (Wade, 2009); whereas another explanation referred to the origin of *religio*, which refers to a bond between humans and the supernatural power (Hill et al., 2000). Despite the different perspectives that have been used to define it, whether social or spiritual; it bears the same meaning as to bind a relationship.

Definition

Koenig (2002) suggested that *'religion involves beliefs about the transcendent, as well as private or communal practices and rituals that reflect devotion or commitment to those beliefs'* (p. 11). Whereas Glock and Stark (1965) put religion into a more formal way in the structure of community; they proposed that *'religion, or what societies hold to be sacred, comprises an institutionalized system of symbols, beliefs, values, and practices focused on questions of ultimate meaning'* (p.4). Furthermore, they argued that 'institutionalised' refers to an established character of groups to the extent that it will be well maintained in spite of the dynamic of the people in the groups. There appear to be several basic elements to religion across deferent definitions, which consist of: 1) the relationship with what is considered as sacred or transcendent, 2) ritualistic act based on communality, in an organized institution and 3) looking for an ultimate meaning.

Defining Religiosity

While the term religion is used to address the notion of an institutionalized body, religiosity refers to the complex and multidimensional aspects of the concept. Thus, the term religiosity refers to a sociological approach that sees it as a comprehensive term denoting numerous aspects of religious values, dedication and activities (Azam, 2010). Indeed, as mentioned before, to the majority of Muslims, Islam is considered as a 'way of life', which *'provides a social and legal system and governs issues such as family life, law and order, ethics, dress and cleanliness, as well as religious ritual and observance'* (Hussain & El-Alami, 2005. p.1).

Spirituality

Although, it has been argued that spirituality comprises one of the multiple dimensions of religiosity (Glock & Stark, 1986; Hassan, 2007), specific discussion is needed about this aspect for several reasons. Firstly, recently, there has been a move to put spirituality into a broader perspective irrespective of whether it falls into a secular or sacred context (Hill et al., 2000), as argued by many European scholars (Stifoss-Hanssen, 1999), despite many American scholars regarding spirituality as restricted to the transcendent being (Wink et al., 2012).

Secondly, there is abundant evidence showing the correlation between spirituality and well-being, such as in mental health (Hill, 2000; Dalmida, 2006; Delgado, 2007; Faull et al., 2004), or among people with chronic illnesses (Scobie & Caddell, 2005; Harvey & Silverman, 2007), also evident among Muslim countries such as Iran (Harandy et al., 2010), or Indonesia (Mardiyono et al., 2011). Therefore, it was essential to discuss spirituality in more detail.

Definition

The term spirituality comes from the *Latin* word *spiritus*, which means breath or air (Hill et al., 2000). It is argued that the term was not distinguished from religion until the emergence of secularism in this century (Zinnbauer et al., 1997). Consequently, a decline of belief in religion and religious leadership in the last several decades has put the schism in a more prominent view.

Spirituality is defined as *'experiences and feelings associated with the quest for meaning and purpose in life'* (Henningsgaard & Arnau, 2008) or *'a subjective experience of the sacred'* (Vaughan, 1991, p. 105). The notion involves a search for the sacred which is not necessarily related to God as in traditional religious views (Saroglou & Munoz-Garcia, 2008). Recently, further acceptance and understanding of the concept of spirituality has broadened the meaning outside the God-oriented view, such as: a world-oriented spirituality, which refers to the relationships between humans and nature, and human-oriented spirituality which emphasizes the relationships among human beings as the centre of spirituality (Spilka in Hill et al., 2000). All in all, the term spirituality bears more general and broad views that not only relate to the traditional religious of beliefs, although it has the same perspective as religion in term of looking for the sacred.

Religiosity and Spirituality in Islam

'There are signs in the creation of the heavens and the earth, and in the alteration of night and day for people of understanding; who remember God while standing, sitting and (lying) on their sides, and who ponder over the creation of the heavens and the earth, saying, 'Lord, You have not created all this without purpose. Glory be to you! Save us from the torment of the Fire...' (The Family of 'Imran, 3: 190-191)

In Islam, the journey to the meaning of life will bring a Muslim to the ultimate goal of finally reaching out or to be fully submitted to Allah, or God; a final goal of a belief (Abdul Qadir Jawas, 2007), as can be found in the Qur'an surah Adz Dzariaat, 51 ayat 56, '*I created jinn and human being only to worship Me*'. The word Islam means '*to submit oneself under the power of Allah*', which then, is declared into the tenet of *shahadah* or the declaration of faith (Ji and Ibrahim, 2007). Moreover, the word submission in Islam can also be referred etymologically to the word '*ibadat* or worship in English (Abdul Qadir Jawaz, 2007), which will be discussed in great detail later, that is composed of three dimensions of soulful, verbal and physical dimension of '*ibadat*. Soulful '*ibadat* refers to any feeling of afraid of, hope for, being in love with, being dependent to and happy to Allah. While, the utterance of *tasbih, tahlil and tahmid*; and *sholat*, among others, are the examples of verbal and physical '*ibadat*, respectively (Abdul Qadir Jawaz, 2007). Indeed, this emphasizes the strong correlation between the concepts of closeness to Allah the deity, as a core concept of spirituality, with other dimensions of religiosity of rituals. Therefore, again, it reinforces the notion that Islam does not separate the concepts of religiosity and spirituality; rather, they are intertwined into daily life practices.

Moreover, practice was not only related to rituals, which refers to how a Muslim manages his or her relationship with Allah, a concept of *hablum minallah* (establishing the relationship with Allah), but also in establishing the relationship with other human beings; *hablum minannaas* (Suadiah, 2012); two basic concepts of rituals, which will be discussed further in this chapter. Or, what has been suggested by Denny (1985) and Esposito (2002) was a concept of orthopraxy; an intertwined concept of *Imaan*, or faith, and *Ihsan*, or practice. Indeed, this notion was important as a starting point in looking further into this current study; how the Javanese Muslim see their relationship with Allah and correlate that with social interaction, in managing their condition.

The Dimensions of Religiosity

To learn about one's religiosity is not considered an easy task since it entails multidimensional aspects and being religious can mean different things to different people (Hassan, 2007). Moreover, to be religious in one dimension does not always necessarily mean being religious in other dimensions. Several studies have tried to develop a comprehensive way to learn the

multidimensional of religiosity (Glock & Stark, 1965; King & Hunt, 1975; Cornwall et al., 1986; Hassan, 2007; Koenig & Büssing, 2010). The five dimension of religiosity by Glock and Stark was considered a fundamental platform, providing a basic understanding, from which other models were developed (King & Hunt, 1975; Cornwall et al., 1986; Hassan, 2007).²

Religious belief

Glock and Stark (1965) proposed, for any particular religion, the first dimension consists of three sub dimensions: warranting, purposive, and implementing beliefs. They argued that different religions put different emphasis to these sub dimensions. In Islam, there are two systems of beliefs, which consist of the Six Articles of Iman and the Five Pillars of Islam. The Six Pillars of Iman or Faith is considered the main warranting belief, which consists of belief in Allah, Angels, the Qur'an, the prophets, the resurrection, and to *qadha* and *qadhar*, or destiny (Shepard, 2009).

In regard to the act of worshiping Allah as the creator, there are notions of *'Ibadat* and *mu'amalat*. *'Ibadat* refers to 'the acts of worship', duties humans owe to Allah (God), whereas *mu'amalat* is duties humans owe to each other (Shepard, 2009). *'Ibadat* comes from the Arabic word of *'Abd* which means servant or slave, therefore, *'ibadat* refers to a *'submissive obedience to a master'* ("The Encyclopaedia of Islam," 1986, p. 647). As mentioned in Qur'an surah 51 ayat 56, the main objective for the creation of human being is only to serve to Allah, *'And I did not create jin and mankind except to worship Me'* (*The Qur'an*, 2012). Suaidah (2012) argues that *'ibadat* consists of a widespread notion of every deed that Allah has prefers Muslim to perform as proof of their love and obedience to Allah including not only physical but also verbal activity; consists of not only a worshipping ritual act to Allah (*habluminnallah*) but also performing good deeds to other human being (*hablumminannaas*). Therefore, the concept of *'ibadat* encompasses in itself the concept of *mu'amalat*. Thus, according to Islamic legal text, what comprised of *'ibadat* including the Five Pillars of Islam, which is the second system of Islamic beliefs. The Five Pillars of Islam is closely related to implementing beliefs and consists of *shahada*, *sholat*, *zakah*, *shiyam*, *qurban*

²See Cornwall et al., 1986; Glock & Stark, 1965; Hassan, 2007; King & Hunt, 1975; Koenig & Büssing, 2010 for discussion on the multidimensional of religiosity.

and *hajj* (Hussain & El-Alami, 2005), which also have socially related notions that will be discussed in great detail later on in this chapter.

Religious activity

Religious activity refers to religious practice (Glock & Stark, 1965) or to the ritualistic dimension (Hassan, 2007). Hassan (2007) proposed the devotional dimension which is akin to the ritualistic aspect, likewise, King and Hunt (1975). According to the Collins Thesaurus ("Devotion," 2007), devotion refers to '*love, passion, affection, or dedication, commitment, loyalty*'. Thus, it underscores the notion of the tendency to obey based on the feeling of love and affection. Glock & Stark (1965) suggested devotion as a dimension of religious commitment, while Hassan (2007) argued that whilst the ritualistic dimension was often influenced by social or communal engagement, more personal and spontaneous religious activities are important in measuring one's strong will in the relationship with God. Hence, he proposed two items in the Muslim Piety questionnaire including '*consulting the Qur'an for everyday decisions*' and '*performing private prayers*'.

The Five Pillars of Islam, as a manifestation of the implementing beliefs into practice, begins with *Shahada*, the declaration of faith, which is considered as a statement of contract in beginning the life as a Muslim, and followed by *sholat* (prayer), *zakah* (community wealth tax), *shiyam* (fasting), and *hajj* (pilgrimage) (El -Khouly, 1982; Shepard, 2009).

The Arabic word of *sholat* derives from the word *shila*, which means '*link*', or in religious meaning refers to the relationship between the Creator and man, the creation (El-Khouly, 1982). In addition, the relationship is expected to be dynamic and continuously '*renewed and regulated, above any circumstances or any personal or external contingencies*' (El-Khouly, 1982, p. 49). It suggests that what would appear to be ritualistic activity may extend beyond more physical rhythms; expressing a spiritual journey, an experiential dimension of religiosity. Thus, El-Khouly (1982), when considering the deep-religious relationship, refers to *sholat* as the soul of religion. Consequently, a man would be a soulless person unless *sholat* was performed. Indeed, what is considered *sholat* here is that which is performed with *khusyuk* or humbly.

To consider religion in the social context, the second system of beliefs shows a more personal purpose of beliefs, especially in *shahada*, *sholat*, and *shiyam*. However, there is also a more social attribute embedded in them. To be considered properly fulfilling personal rituals, every Muslim will also be evaluated by how they manage their relationship with other human beings and nature. There is a tenet in Qur'an which mentions that by performing *Sholat* with *khusyuk* or humbly, one will be able to avoid wrongdoings against other human beings, as mentioned in surah Al Ankabut 29 ayat 45: '*Surely Sholat keeps (one) away from indecency and evil, and certainly the remembrance of Allah is the greatest*' (The Qur'an, 2012). However, the notion of '*keeping away from indecency and evil*' is regarded as an active act, rather than something that is taken for granted. Surah Al Ma'uun ayat 4–7 mentions that '*[4] Woe, then, to those who pray, [5] but are heedless in their sholat, [6] those who do good (in order) to be seen, [7] and deny people the articles of common necessity.*' Indeed, this tenet reiterates the strong relationship between religious rituals with maintaining good relationships with other human beings; related to the concept of *hablum minallah* and *hablum minannas*.

Thus, to achieve humbleness in sholat, Samad (2009) argues that Muslims have to bring the perception of greatness and holiness of Allah into *sholat*, which only can be achieved by being close to Allah. Therefore, it can be said that closeness to Allah requires all Muslim to perform rituals properly and maintain their good deeds to other human being and nature; as Renard (1996) mentioned '*spirituality both grows out of and gives rise to religious living*' (p.xiv). Again, this notion illustrates correlation between spirituality and religiosity in Islam; and the importance of putting transcendent meaning into every religious activity.

Hence, considering the very essential nature of *sholat*, Qur'an has underscored this tenet in surah An Nisa ayat 103 '*Sholat is enjoined upon the believers at stated times*', and even when travelling (An Nisa: 101), at war (An Nisa: 102), or at the time of illness. To some extent the link might be expanded to social bonds with other men since sholat is preferably done in the *masjid* along with others, especially with the obligatory sholat, which is performed five times during a day (Shepard, 2009). However, in the presence of physical disability, the Prophets has declared that Muslims are allowed to do *sholat* by sitting or even lying down (Baits,2014).

Thus, in adjunction to sholat, Muslims are obliged to clean themselves by performing ablutions (*wudlu'*) beforehand (*The Qur'an*, 2010). The ablution involves washing hands, rinsing the mouth and nose, washing the face, washing the right arm up to the elbow, wiping the head back and forth and washing the feet including the ankles ("Short Guide to Ablution and Prayer," 2012).

Zakah consists of *zakah mal*, which refers to a community wealth tax and *zakah 'id al-fitri* which is particularly done during the festivities of 'Id al-Fitri at the end of the month of Ramadan (Shepard, 2009). All Muslims are obliged to give the value of one meal as charity. While, *zakah mal* is levied on certain categories of wealth above a certain defined threshold called *nisab* and distributed to eight categories of people as Qur'an mentioned in surah 9 ayat 60, namely the poor and needy, those who collect the *zakah*, those who bringing hearts together (for Islam), and to free captives (or slaves), for those in debt and for the cause of Allah, and for the (stranded) traveller (*The Qur'an*, 2012).

Again, to emphasize the close relationship between social and personal relationships, there are many *ayat* that mention performing *sholat* in conjunction with giving *zakah*, such in surah Al Baqarah ayat 83:

'And when We made a covenant with the children of Israel: you shall not serve any but Allah and (you shall do) good to (your) parents, and to the near of kin and to the orphans and the needy and you shall speak to men good words and keep up sholat and pay zakah.'

Or, Al Baqarah ayat 177:

'It is not righteousness that you turn your faces towards the East and the West, but righteousness is this that one should believe in Allah and the last day...and keep up sholat and pay zakah...'

Indeed, these *ayat* illustrate that Islam encourages every Muslim not only to perform personal rituals as an act of devotion, but also to link this with social obligations.

Shiyam refers to fasting from dawn to sunset with the obligation to abstain from food, drink and sexual intercourse (Brown, 2009). All Muslims are obliged to fast in Ramadan, except for those

who are ill or travelling, in order to achieve the level of *taqwa* (righteousness), as mentioned in Qur'an surah 2: 183-184 (*The Qur'an*, 2012). Ramadan endorses the Muslim to become more connected to others in need; '*reinforcing the solidarity of the umma (society)*' (Shepard, 2009, p. 92). Performing *Zakah* also reinforces this, since it is regarded not only as an act of charity but rather as purification, '*a means of distributing a portion of the wealth of the rich among the disadvantaged in the community*' (Waines, 2003, p. 90).

The final and most complex ritual, which comprises many rituals that require strong physical efforts with inherent personal rituals, such as saying prayers and devotion, is the *hajj* or pilgrimage (Waines, 2003). It is obliged, as long as one has the necessary means, to undertake this once in the month of *Dhu al-hijjah*. It is a religious activity with certain rituals including the circumambulation of the Ka'bah, the procession between the hills of *Safa* and *Marwa*, the stoning of three pillars where Ibrahim is said to be tempted by the devil not to sacrifice his son, and a visit to the plain of Arafat (Waines, 2003).

Personal relationship with the transcendent

Glock and Stark (1965) proposed religious feeling as the third dimension, or experiential dimension (Hassan, 2007), or spiritual commitment (Cornwall et al., 1986). This dimension refers to the cognitive function of religiosity which includes any feeling, knowledge or emotions in relation to any experiences with the divine (Cornwall et al., 1986; Hassan, 2007). It can be argued that such events are found in any religion (James, 2013). Glock and Stark (1965) suggest that this notion does not convey a single meaning, but addresses concern, cognition, trust or faith, and fear, indicating that how one perceives the relationship with the deity is very subjective in meaning.

In Islam, believers are obliged to remember Allah, a single construct which appears in Qur'an around 300 times; to acknowledge the importance of this (Shepard, 2009). One way to implement this is by doing *dhikr*, which Shepard (2009) argues is better translated as having in mind or being fully aware of, instead of the common translation of 'remembrance'. *Dhikr* is an expression of a technique used to stimulate this awareness, usually involving reciting the name of Allah. The same

practice has been found in Orthodox Christianity in prayer, or recitations of the name of Amitabha Buddha in Pure Land Buddhism (Shepard, 2009).

As discussed earlier, remembering and being close to Allah needs to be demonstrated through performing physical worship as well as being mindful of Allah's creation, mentioned in the Qur'an surah Ali 'Imran ayat 190-191: '[190] *Most surely in the creation of the heavens and the earth and the alteration of the night and day there are signs for men who understand, [191] those who remember Allah standing and sitting and lying on their sides and reflect on the creation of the heavens and the earth.*'. Indeed, this notion underscores the need for individuals to keep aware of one's position in the relationship with Allah; being spiritual.

The Sufi movement is regarded as another dimension of Islamic views that holds a more inner, emotional, personal relationship with the creator; God (Egger, 2008). It started in the Middle East in the 14th century and by the 18th century was embedded into most of Muslim religious days worldwide, with the establishment in Indonesia in the 16th century (von der Mehden, 1995). A Sufi master or Sufi syaikh has been practicing in various roles within the community; providing spiritual guidance, mediation, as well as medical cures (Egger, 2008). The spirit of Sufi is, therefore, resemblances spirituality and furthermore the movement of *Kejawen*, a Javanese spiritual movement in Indonesia.

Consequential

Hassan (2007) uses the term 'consequential' when referring to how Muslims exercise their religious beliefs, knowledge, practices and experiences in dealing with secular-daily events. This is comprised of any religious prescriptions that every Muslim is required to do as a consequence of being Muslim (Hassan, 2007). Furthermore, the intensity of undertaking religious imperatives in daily life reflects how religion is embedded in the social structure, often with the expectation of rewards for believers (Glock & Stark, 1965; Hassan, 2007). Rewards might be immediate or promised in the future. Immediate rewards such as peace of mind, freedom of worry, or a sense of well-being, whereas future rewards such are salvation and promises of eternal life (Hassan, 2007). King and Hunt (1975) proposed the rewards-expectation behaviour as an extrinsic

orientation, which refers to the inclination of individuals to perform something because of the rewards from outside of his or her personal domain.

To believe in the divine decree is regarded as one of the six articles of beliefs in Islam (Hussain & El-Alami, 2005). This tenet is explained in two terms, *qadha* and *qadar* which mean destiny and fate (*The Qur'an*, 2012). The word *qadha* means to decide; to settle; to judge. Islam believes that Allah's will and knowledge lies behind all events in the world. However, it does not mean that a Muslim is fatalistic, since Allah has given humans the knowledge of every cause and consequence. For example from Surah 30: 41 '*corruption has appeared throughout the land and sea by (reason of) what the hands of people have earned so He (God) may let them taste part of (the consequence of) what they have done that perhaps they will return (to righteousness)*' (*The Qur'an*, 2012).

Hassan (2007) proposed two questions to assess how deeply Islamic values are embedded into one's lives with the consequences therein; '*Would you agree that a person who believes there is no Allah is likely to hold dangerous views?*', and a belief in '*Darwin's theory of evolution could not possibly be true*'. He argued that there is an embedded divine consequence to the statements since the first question is associated with basic warranting Islamic beliefs in the only divine God. While, the second one is related to the belief that human beings are descended from Adam and Eve, which to some extent emphasizing a contradictory between science and religion in the modern age (Hassan, 2007). Thus, with the advancement of science and technology, the nature, purpose and meaning of human conditions in life has resulted in the rejection of such questions that are contrary to core religious beliefs.

However, the utilization of the two items also raises further questions of how those questions might be related to the perceptions of destiny. Moreover, those items are questionable since the statements are very specific and might be related sociologically and historically to some communities but not to others. Most Indonesian Muslims believe that Communists hold atheistic views, which is regarded as dangerous to beliefs of the one divine. This is significant due to the strong politically laden conflict in 1965 in Indonesia, which led to an attempted coup that involved PKI, *Partai Komunis Indonesia* or the Indonesian Communist Party. Furthermore, the unsuccessful movement resulted in the killing of hundreds of thousands of PKI's followers by Muslim youth

(von der Mehden, 1995). Indeed, the disinclination toward communism is not only exclusively possessed by Muslims but also by other people from different religious affiliations, since disbelief in the Divine is against Pancasila; the national foundation of Indonesia which consists of a belief in one and only God as the first of the five ideas (Soguk, 2011). Thus, this illustrates that measuring religiosity was not a straightforward process and only concerned with religious tenets, however, other determining factors, such as socio-politico-economic ones, might also play a role.

Knowledge

Within some theories and models of religion, religious knowledge is explicitly described as a dimension (Glock & Stark, 1965), whereas others refer to salience cognition (King and Hunt (1975). Although, Cornwall et al. (1986) do not isolate religious knowledge they suggest it is embedded throughout the core and other peripheral dimensions.

There is a commonality across various religions regarding the expectation of the religious person to be knowledgeable about their own religion. To some extent, how faithful one is, is related to the level of knowledge one has; although, it is not always the case (Glock & Stark, 1965; Hassan, 2007). Moreover, attitudes toward knowledge are considered to be an important factor, since these will show how one is inclined towards the ritual of prayers or reading scriptures as part of the ritual dimension (Glock & Stark, 1965). Alternatively, the level of religious belief might serve as a powerful element in supporting the implementation of rituals or the experiential dimension, indicating the dimensions are not standalone concepts, rather are interrelated.

Thus, it is argued that Islam has encouraged Muslims to be open toward knowledge and wisdom from whatever source, by whatever carrier; the foundation for the greatest advocates of rationalism (Al Faruqi, 1982). How Islam emphasized the need to seek further knowledge, not only religion-related knowledge, can be found across the Qur'an and also conveyed through the words of the Prophet. Thus, this notion serves as a basic foundation of how a Muslim is encouraged to learn any secular knowledge, including how to do self-care. Below are some examples.

'Recite in the name of your Lord who created, created man from a clinging substance. Recite, and your Lord is the most Generous, who taught by the pen, taught man that which he knew not', surah Al 'Alaq 96 ayat 1-5(The Qur'an, 2010).

'..I heard the Apostle of Allah (pbuh) say: If anyone travels on a road in search of knowledge, Allah will cause him to travel on one of the roads of Paradise... the superiority of the learned man over the devout is like that of the moon, on the night when it is full, over the rest of the stars. The learned are the heirs of the Prophets, and the Prophets leave neither dinar nor dirham, leaving only knowledge, and he who takes it takes an abundant portion' (Center for Muslim-Jewish Engagement, 2011).

In Islam, the Qur'an serves as a major source of basic knowledge of the *shari'a*, or Islamic law along with *Sunna* which refers to every habits or way of life that has been exemplified by the prophet Muhammad through what is said or done; and the unanimous decisions of *ulama* or Muslim scholars (Shepard, 2009). Indeed, *Shari'a* addresses all aspects of human life that involve moral choices.

The Qur'an is regarded as a Book of broad general principles which aims to explain the intellectual and moral foundations of Islam's way of life (*The Qur'an*, 2010). Furthermore, The Sunna works in interpreting and explaining what is in the Qur'an; in general, it provides a model of behaviour for Muslims (Shepard, 2009). The *ulama* work in translating the *Shari'a* in corresponding to contemporary problems in society, which to some extent, were not explained in great detail in the Qur'an or Sunna. Nevertheless, basic principles still apply; Muslims have to base their opinions in accordance with the basic principles of Qur'an and Sunna (Shepard, 2009). Answers or opinions are not always easily arrived at and often involve daunting effort (*ijtihad*) based on an adequate knowledge of a systematic and organized pathway. A consensus (*ijma*) is expected to be drawn out of inquiries (Shepard, 2009), but given that there are different Muslim 'schools' or 'traditions', which have their own *ijma*, it is impossible to have one single understanding of the Muslim religion (Shepard, 2009).

Religion, Religiosity/Spirituality and well-being

It has been suggested that how people embrace and apprehend the meaning of life is influenced by how religious they are; religious people are inclined to value different things compared to non-religious people (Miller & Worthington, 2012). Furthermore, it is believed that highly religious people tend to see various challenges, interpersonal problems, or conflict in life through a religious perceptual lens and deal with them in the same manner (Worthington (1988). The importance of religious orientation might be helpful in explaining how people utilize religion and/or spirituality as a coping strategy in maintaining ill-health conditions. In addition, how individual perceives the outcome of his or her own effort, the concept of locus of control, might influence the inclination to perform particular activity, especially in regards of healthy behaviour.

Intrinsic and Extrinsic Orientation

One perspective of religiosity or spirituality comes from how people verbalise their religious motivation (Miller & Worthington, 2012). Allport and Ross (1967) proposed the concept of intrinsic and extrinsic orientations, which refers to how one conceives his or her own religious motivation. This concept relates to how and why people engage with religious beliefs or activities; whether religion is intrinsic, the main focus and purpose in life, or extrinsic with non-religious things are considered more important (Henningsgaard & Arnau, 2008). The intrinsic person internalizes the total creed of his or her faith and moves into their lives with it, whereas the extrinsic person uses religion as status, sociability and self-justification (Holdcroft, 2006). Nevertheless, the two different views do not stand in isolation, rather they serve as a continuum; and one can be predominantly of one orientation (Henningsgaard & Arnau, 2008).

There are various ways how individuals perceive this concept in everyday lives. For some people with more extrinsic orientations, ethnicity or religious beliefs has tended to make them more prejudiced or intolerant than intrinsic people (Allport and Ross, 1967). The latter hold religious beliefs as overarching values in life, therefore, they regard the life of others as an essential aspect in establishing harmony in their own life. One example in a nursing perspective, suggests that understanding illness through an intrinsic perspective can be beneficial as a coping mechanism in managing the illness (Baldacchino & Draper, 1998).

Locus of Control

Another notion considered important in explaining how religious someone is through the inclination of individuals to take responsibility of his or her own actions; a notion of locus of control. This theory (Rotter, 1966) argues that an individual's behaviour or action will vary according to their own general expectations of the outcomes; in terms of whether their own actions determine the outcomes or whether it is beyond their own control such as fate, luck, under the control of powerful others, or simply unpredictable. Thus, individuals with an internal locus of control believe that their own efforts will determine the outcome, and vice versa. This theory is discussed in great detail in Chapter Three.

God's Role; a Notion of External Locus of Control

It is argued that God is still regarded as the main source in the individuals' life (McAuley et al., 2000) and many people regard religious coping as an alternative to lessen the burden of daily life (Pargament et al., 2000). Evidence varies in regard to how people perceive God in maintaining chronic illnesses. For some people, God is the major actor who gives the disease as well as the cure (Samuel-Hodge et al., 2000; Naeem, 2003; Polzer & Miles, 2007), or is a supportive force in managing the condition (Polzer & Miles, 2007; Abdoli et al., 2008). However, the outcome of such beliefs is not necessarily positive; some people might be fatalistic as a result (Naeem, 2003; Polzer & Miles, 2007). Thus, it was regarded as an essential element of this study to explore how Javanese Muslims perceive Allah in their efforts to pursue wellbeing. Further discussion about how individuals perceive God as the external locus of control will take place in the next chapter of religion and health.

Considering the major role of God in relation to ill-health condition, Welton et al. (1996) developed and proposed a God Health Locus of Control (HLC) as a fourth dimension, using the work from the Multidimensional Health Locus of Control (Wallston et al., 1976). The scale is intended to measure the degree of the belief that God exerts control over one's current disease state. Indeed, some would favour having a psychological problem as a test of faith (Holt & McClure, 2006). Thus, with respect to psychological matters, seeking help from health professionals would be regarded as faithlessness for some people particularly among the Christian affiliated African American community (Neighbors et al., 1998).

The God HLC has been used in assessing the tendency of alcohol abuse (Goggin et al., 2007) and sexual abuse among adolescents (Goggin et al., 2007). It has also been used among people with chronic diseases such as rheumatoid arthritis and systemic sclerosis (Wallston et al., 1999), in relation to psychosocial outcomes and coping measures. It revealed that a stronger belief in God's control related to poor adjustment within a chronic disease group (Wallston et al., 1999), although studies with healthy people did not replicate such findings (Welton et al., 1996).

Smither and Khorsandi (2009) suggest that Islam tends to hold a deterministic view in regard to motivation, for example the tenet that Allah knows what might happen since the individual is born and decides when one's death will occur (surah Al Imran: 145). This represents the notion of a fatalistic view, without any capability of individuals to intervene, which is true to some extent. This tenet became more prominent from the Ash'arite school of theology in around the year of 800 which contended that the intellect has to be made subservient to the will of God (Nasr, 1982); reflecting the concept of fatalism (Acevedo, 2008; Huntington, 1993). Later, the Ashari'ite school became associated with Shafi'i, which has a very strong foundation throughout the South East Asian region (Egger, 2008). While, the school of Mu'tazila or Maturidism emerged as an opposition to the Ash'arite; they contend that to understand God, one is obliged to use one own reason (Nasr, 1982; Shepard, 2009).

Nevertheless, critics argued that applying fatalism to understand the basic concept of relinquishing someone's fate to the high power is incorrect (Nasr, 1982). It is argued that the attitude is *'not in the sense of defeat or subjugation but in the sense of total devotion of the heart and mind to God and living one's life accordingly'* (Hussain & El-Alami, 2005, p. 1). Furthermore, contemporary scholars have regarded such submission as a rational way of comprehending the interaction between human action and cosmological determinism (Acevedo, 2008). Also, when returning to the arguments of the previous deterministic views that humans have no control, it is only relates to ayat on the birth and death, in Surah 3 ayat 145 (*The Qur'an*, 2012), which are considered as natural phenomenon that human beings have no control over whatsoever.

Pargament et al., (1988) proposed a theory which consists of three styles to understand how one will take responsibility in solving their problems in relationship with God; Self-directing,

Collaborative, and Deferring style. A Self-directing style refers to individuals who regard themselves as the main party in problem solving, based on beliefs that God gives the freedom and resources to take responsibility. This style takes on a concept of a more competent personal and lower level of religious involvement. A Collaborative style refers to an active personal exchange with God which appears to be a 'self-incorporated' (p.90) form of religion. This style also reflects a more competent individual. Finally, a Deferring style refers to personal beliefs that God will give the solution for any problem. It reflects the form of lower level of competency and external orientation of religion as the source of problem solving.

Later, Polzer and Miles (2007) introduced a theory which closely resembles that of Pargament et al. (1988), examining how African American people with type 2 diabetes see their relationship with God in managing their condition. They proposed three types of relationship: God in the Forefront, God in the Background, and God as the Healer. The first type, God in the Forefront, refers to the belief that God is taking responsibility for one's condition regardless of the efforts that have been made. The individuals in this type still regard personal efforts of self-management as important. Second, God in the Background which refers to a belief that an individual is the main actor and their efforts are the most important, but God will help them in regard to providing resources such as knowledge, as well as help from health practitioners. Third, God is a Healer which believes that God will give the solution to any problem if the person has a strong faith. There is a clear line that can be drawn out from these two theories in term of how people perceive of who is responsible for their actions with the theory of locus of control from Rotter (1966) served as a basic underpinning philosophical theme to interpret both theories.³

Keep trying and leave the rest to Allah: a concept of Tawakkal

Indeed, discourses on releasing control over one's effort to Allah leads to the concept of *Tawakkal*. *Tawakkal* is an Arabic word that according to the *Al Munawwir* dictionary comes from the word **وكل** which means 'to hand something over' (Munawwir, 1997), or 'lean or entrust to' (Jumantoro & Amin in Rozaq, 2008). Nevertheless, Qur'an in surah 13 ayat 11 has underscored

³For further explanation on the similarities and differences see Polzer&Miles, 2007 and Pargament et al., 1988.

human efforts as an important tenet in pursuing one's will 'God will not change the condition of a people until they change what is in themselves...' or in Al 'Imran 3 ayat 159, 'And when you are resolved on a course of action put our trust in Allah. Surely Allah loves those who put their trust (in Him)' (The Qur'an, 2012). Moreover, Qur'an emphasizes the importance to use common sense and knowledge to make decisions as in surah al Balad ayat 8-10 'Have we not made for him two eyes? And a tongue and two lips? And have shown him the two ways (good and evil)?' (The Qur'an, 2010). Thus, *tawakkal* underscores the tenet of attributing human effort to Allah without ceasing to make effort.

Rozak argues (2006) that being *tawakkal* will lead an individual to possess calmness and peace of mind based on the understanding of Allah's will; he or she will be grateful for any positive response to his or her own action, and keep being patient. This is also in accordance with Radzi, et al. (2014), who argued that by surrendering himself or herself to Allah will lead to a feeling of calmness and less stressful, which will lead to general wellbeing. Moreover, *tawakkal* will lead to a sense of confidence, calmness and firm action in dealing with any problems (Dahlan et al., in Rozak, 2006). To some extent, the notion of submitting trust to Allah or the divine is mirroring what Baldacchino and Draper (1998) address as '*a spiritual coping*' mechanism, which aimed at putting transcend meaning into any events in life that might enhance self-empowerment. Therefore, it is an important notion in how an individual perceives his or her efforts toward health related issues such as self-care, for example.

How to Define the Level of Religiosity: a quantitative approach

Measuring someone's religiosity was considered a difficult task bearing in mind its multidimensional aspects, let alone the different interpretations among people themselves. For some to measure religiosity was more than just ticking a box on a questionnaire; rather, it needs a full observation of one's daily life (Hassan, 2007). This discussion was not intended as a deep and thorough scrutiny of how people perceive religiosity; rather, as a simple and general way to convey examples of methods which attempt to quantifying it.

The multidimensional nature of religiosity has been scrutinized by the Fetzer Institute and the National Institute on Ageing (Fetzer Institute, 2003) by developing ten dimensions of religion and

spirituality measurement, comprising of religious spiritual history, preference affiliation, social participation, private practices, coping styles, beliefs and values, commitment, experiences, sense of support, and motivation for regulating and reconciling relationships. Although the brief multi-dimensional survey has a broad perspective, it could be developed further and be applied to a health-care perspective in the future. Furthermore, the tool contain many concepts that relate more to subjective feelings, personal experiences and other personal relationships with the transcendent which are more related to spirituality.

The God Health Locus of Control scale has been used among various ill-health conditions, such as rheumatoid arthritis (Wallston et al., 1999), as well as among adolescent in regards to assessing the tendency to engage in risky behaviours such as alcohol and sex abuse (Goggin, et al., 2007; Goggin et al., 2007). This tool is very specific in exploring one influencing factor that might play a role in the inclination towards religion; how people see God in relation to efforts towards health. Therefore, this cannot be used to convey the complexity of the multidimensional aspects of religiosity.

A study of Muslim Piety (Hassan, 2007) has been conducted across seven Muslim populated countries using an adapted five dimensions of religiosity from Glock and Stark (Glock & Stark, 1965); focusing on religious beliefs, rituals, spirituality, consequential, and the knowledge aspects of religiosity. However, in using this particular multidimensional tool, it is contended that to have a better understanding of how religious an individual is, one cannot make a single judgment based on the overall dimensions; rather, there is a need to make a separate assessment based on each dimension (Hassan, 2007). It is true in relation to the Muslim Piety questionnaire, since what is considered as a 'true' Muslim, is not only based on how one preserves the warranting beliefs that are contained in the religious dimension. However, it also correlates with how a Muslim adheres to performing *sholat*, in particular, since Islam regards *sholat* as an obligation religious practice (Shepard, 2009). Moreover, discussed further in the findings chapter, how the socio-political aspect in society may influence how individuals respond.

Despite the validity and reliability of the instruments which have been used to make a clear judgement on how religious someone is, the process is not regarded as straightforward and

simple. There are many factors that need to be taken into account, such as social, political, and cultural aspects. Therefore, individual exploration was needed to put the results into an appropriate context; a qualitative way of understanding the phenomena at hand. Although, considering the nature of this approach and, usually, the recruitment of small samples, has not made it easy or realistic to draw generalisations for a wider population; often only in terms of theoretical generalisations.

Summary

In this chapter the development of religion; as an individual characteristic of human beings, and as part of wider of society has been presented. The multidimensional nature of religion has been unravelled and discussed in relation to spirituality. There has been a tendency to limit the boundaries of religion to a more institutionalized system of beliefs and divorce from the more personal aspects of the relationship with the transcendent and it has been argued that spirituality represents a more personal, and deep relationship with anything that human being consider to be important in their lives.

The chapter also explored the dimensions of religiosity and spirituality, and considered the difficulties in attempting to measure both concepts, particularly emphasising that social, political, and cultural factors need to be taken into account when attempting to do so.

Chapter Three

Self-care, Diabetes Management and Religiosity

Introduction

The previous chapters have established the rationale and background to the study and the role of religion in managing self-care for people with long term conditions, particularly diabetes in the context of Indonesia. The operation of the health care system in Indonesia, including barriers to access and the implementation of the self-empowerment program in managing those conditions was explored in conjunction with the impact of religiosity and Javanese culture. It was evident that agency plays an important role in how people use religion in their life, both in terms of religious orientation, and locus of control. However, there are also structurally determining factors such as the influence of culture, society and government policies that need to be considered.

Having defined self-care, this chapter briefly explore the origins and the practices of self-care, in order to generate a clear understanding of the concept. The key components of self-care management are extrapolated, and the surrounding influencing factors in maintaining sustainable self-care practices explored, with particular reference to Indonesia's context in relation to diabetes management. The discussion focuses on how or if religiosity might influence self-care among people with diabetes based from a systematic review on current evidence in regards to this particular topic.

The first chapter highlighted the prevalence of diabetes, as a chronic disease, has been escalating in recent decades (International Diabetes Federation, 2007, 2013), particularly in low and middle income countries. Adopting healthy behaviour, such as avoiding tobacco, maintaining good dietary management and normal body weight, as well as keeping physically active, can delay or prevent diabetes (World Health Organization, 2012). Indeed, these preventive measures act as an underpinning notion of self-care.

Since the prevalence of chronic disease, such as diabetes, increases with age, people living longer is also regarded as the main contributor factor to increase the prevalence of the illnesses, and the attributed cost related to the condition (Thrall, 2005). In 2010, there was an estimated 524 million people older than 65 years of age, projected to reach almost 1.5 billion in 2050, with greater proportions found in developing countries (WHO, 2010). Indonesia, with around 238.5 million people, has an increase in the proportion of the older population (65 years old or older); from 5% in 2010 and is predicted to increase to 10.6% in 2035 (Statistic Indonesia, 2013).

The world demographic and epidemiological shift for the last several decades has affected health and service provision, especially in developed countries (Taylor & Bury, 2007; WHO, 2010a). The shift from the acute-infectious illness to chronic illnesses as the most prevalent cause of death worldwide and the increasing ageing population has put a new burden on the health care provision system (Estes et al., 2000; Bodenheimer et al., 2002; WHO, 2010a). It seems clear then that promotion and preventive medical care needs to be put forward in order to enhance early identification and prompt treatment to improve quality of life.

Furthermore, it has been argued that the increasing cost of health care services has triggered the need to reform health care services, and this has certainly influenced the emergence of self-care (Anderson, 1990; WHO, 2010a). Indeed it is believed that the practice of self-care may ease the burden of overstretched health delivery systems, reduce costs and increase effectiveness (Taylor & Bury, 2007; WHO, 2009). Thus, advocating a move away from the expensive curative biomedical model (Engel, 1977; Wade & Halligan, 2004; Anderson & Funnell, 2005), which is *'heavily oriented in high technology, the massive use of drugs and the concentration of services in huge medical complexes'* (Baer et al., 1986, p.97) to a more participatory preventative self-care model (Taylor & Bury, 2007; WHO, 2009) has been seen as a solution. On the other hand, developments in technology has also been correlated with the improvement of the diffusion of medical knowledge into the public domain, which in turn has accelerated the mutual participatory patient-physician relationship (Cockerham, 2005); which is another aspect of the self-care model. People with chronic diseases need to be able to understand how to manage and care for themselves regarding

the physical and psychological changes associated with their condition within their daily work, family and social life (Delmar et al., 2006; DoH, 2006).

Origins of Self-Care

The practice of self-care has existed alongside human history; self-treatment with locally-produced preparations with unknown efficacy has been common practice in family or community settings for many years (Dean, 1981; WSMI, 2010) and were passed down from generation to generation (Giddens, 2006). The terminology of self-care originated in the West as a new movement in the management of chronic illness (Levin et al., 1977; WSMI, World Self-Medication Industry, 2010) and has since been used in developing countries (WHO, 2009). It is worth noting that the concept of self-care in Indonesia has only recently begun to be accepted at least in scientific environments (Jazilah et al., 2003; Pakasi, 2007; Kusniyah et al., 2010; Yuniarti et al., 2013), along with the term self-management. Both concepts are used in their original English terms without being translated into an official Indonesian term. Prior to such western conventions of self-care being adopted, however, the utilization of *Jamu* as herbal medicine in Indonesia can be understood as being part of self-care activity.

During the 19th and early 20th centuries the development of science and technology in medicine placed a bigger role on the physician to take responsibility for the care of individuals, so the idea of self-care was historically placed in the background (Hull, 1979; World Self-Medication Industry, 2010). The enduring influence of the biomedical model '*medicalizes*' illness (Engel, 1977; Wade & Halligan, 2004) and advances in medical technology and the development of new medicines by large pharmaceutical industries reflects and perpetuates this. This model posits a more curative perspective with little room for preventive action, which is a central characteristic of the self-care concept (Bhuyan, 2004; DoH, 2006). Another set of beliefs that are embedded in the medical model is that the patient is regarded as a passive party in treatment, although cooperation with treatment is still needed. This paternalistic doctor-patient relationship overshadowed the need for individuals to be more involved in their medical treatment until the late 1960s (WSMI, 2010). This view of health and health care remains strong today with evidence across the globe (Hull, 1979; Kiguli et al., 2011; Penn et al., 2011; Claramita et al., 2011).

However, there have been growing concerns from patients regarding communication with the medical profession (Ha & Longnecker, 2010; Kiguli et al., 2011; Claramita et al., 2013). It can be argued that placing greater emphasis on patients' rights and more participatory communication might lead to improve in the quality of decision making and patient's commitment to treatment (Kim et al., 2001) which can lead to better health outcomes (Arora, 2003; Epstein & Street, 2007). This is an important issue for this study, and it will consider how self-care education training among people with diabetes people could lead to patient empowerment.

Since the 1970s, the world has witnessed the emergence of a global movement of self-care. In 1975, at the first international symposium in primary care conducted by the WHO European Regional office, self-care as a concept and more involvement of the individual was discussed (Levin et al., 1977; World Self-Medication Industry, 2010). The fundamental aim of the symposium was to identify ways to improve the quality, availability and accessibility of primary health care resources as the underpinning notion in medical care. Moreover, it was argued that the time had come to look into patient involvement as a health resource in primary care (Levin et al., 1977). Globally, the movement was reinforced by the development of a '*Health for all by the year 2000*' theme from the World Health Assembly in 1977, then later on by the Resolution of Alma Atta in 1978; emphasizing health as a social goal issue with primary care as its foundation (WHO, 2009; WSMI, 2010). Across South East Asian and other developing countries, self-care began to be regarded as a key component of primary health care (PHC), due to its availability and affordability. As a result, further meetings among health care authorities with the support of the WHO have been conducted in taking this concept forward (WHO, 2009).

Definition of Self-Care

Self-care refers to the actions that people take in promoting health, preventing and detecting any illnesses, also in self-treatment (DoH UK, 2006; Levin, 1976), to maintain life, health and well-being (Orem, 1995). By definition, therefore, self-care is led, owned and undertaken by the people themselves (DoH UK, 2006). It encompasses almost all daily activities, ranging from brushing one's teeth to preparing food based on which ingredients to choose, or when to seek medical treatment (Levin, 1983). The notion does not only apply to all individuals but includes their children, family,

friends and others in neighbourhoods and local communities (DoH UK, 2005). Similar definitions exist, demonstrating worldwide consensus of understanding '*self-care is the ability of individuals, families and communities to promote health, prevent disease and maintain health and to cope with illness and disability with or without the support of a health-care provider*' (WHO, 2009; p.17). Orem (1995) proposed that people could develop the capability to self-care, suggesting it is a learned and deliberate action, placing the individual as an agent of self-care. She highlighted the important need for education to perform self-care adequately based '*in the home, at school and from practical experiences in self-care*' (Orem 1995; p.97).

Self-management is regarded as another concept that often is used interchangeably with self-care although the relationship between the two concepts is unclear (Richard & Shea, 2011). Some would argue that self-management is a subset of self-care (Barlow et al., 2002; Wilkinson & Whitehead, 2009), whereas others suggest self-management is a broader concept which includes self-care (Wilde & Garvin, 2007; Richard & Shea, 2011). Self-management is defined as an individual's ability to manage symptoms, manage the consequences of living with a chronic condition, including treatment, physical, social, and lifestyle changes (Lorig et al., 2001; Barlow et al., 2002; Bodenheimer et al., 2002; Gallagher et al., 2008). So often the term self-management posits a notion of health promotion; however, many studies have used it synonymously when describing the management of chronic illness (Lorig et al., 2001; Wilde & Garvin, 2007). Lorig (2003) argued originally the term was used for the first time by Thomas Creer in managing the condition of children with asthma. There are several other articles that use this terminology (Lorig, 2001; Barlow et al., 2002; Lorig, 2003; Holman, 2004; McCorkle, Ercolano, and Lazenby, 2011). Thus, the term tends to relate itself to the more diseases-oriented conditions in managing chronic conditions; rather than the more general meaning of promoting well-being in general that refers to self-care. Therefore, for the purpose of this study, the term self-care is preferred as it encompasses the concept of self-management and has more general meaning.

Self-care in Practice

Self-care is a foundation to achieve health and wellbeing in daily life of a human being. According to the WHO (WHO European Regional Office, 1986), health is a multidimensional concept that

comprises not only physical status but also psychological and social dimensions. Therefore, it is reasonable to argue that self-care is also a multidimensional concept. Moreover, to achieve sustainable behaviour on self-care, there are several prerequisite to agency, which are important not only in the way of thinking, but also of doing, such as; locus of control (Meize-Grochowski, 1990; Metsch et al., 1995; Martinelli, 1999; Kosmala-Anderson et al., 2010), self-efficacy (Lorig & Holman, 2003; Sousa et al., 2005; Atak et al., 2008; Richard & Shea, 2011; Sperl-Hillen et al., 2013), self-regulation (Ofstedal et al., 2010; Bazzazian, 2012) and self-appraisal (Bandura, 1986; Heisler et al., 2003). The first two components will be scrutinized in more detail.

Locus of control

Individuals behaviour or action will vary according to their own general expectations of the outcomes; whether their own actions determine the outcomes or it is beyond their own control such as fate, luck, or under the control of powerful others or simply unpredictable (Rotter, 1990). It is argued that if someone believes that he or she is taking more responsibility for his or her own life, one will behave differently than if it is believed that 'something' (or someone) other than oneself is taking responsibility (Andrews et al., 2011).

It has been suggested that locus of control can be both internal and external: internal refers to an individuals' own actions, and external to those forces beyond an individuals' control (Rotter, 1966, 1990). Moreover, a health locus of control (HLC) is concerned with individuals' actions to control and sustain their health including preventative behaviour, illness behaviour in response to symptoms and sick-role behaviour in response to a diagnosis (Wallston et al., 1976; Wallston & Wallston, 1978). External HLC, however, is considered to include the influence of powerful others, such as medical professionals as well as family and friends (Wallston, 2007), and uncontrollable factors such as bad luck or fate. An alternative view suggests that personal control can be directly influenced by an indifference of the social system, for example, expressed through religious beliefs and gender discrimination (Gurin et al. 1978). Gurin et al. (1978) argued that insufficient personal control is often due to indifference of the social system, rather than due to chance or external control. For example, gender discrimination might prevent women from advancing in careers in traditionally male dominated fields of work. Thus, the dichotomies of

external and internal controls is not a very straightforward process, rather, it is comprised of a multiple aspects of control. This is relevant to the current study when trying to explore how participants perceive religion's influence in their inclination to manage their condition, and also in terms of the impact of culture. In Javanese culture, people believe that life involves continuous hardship, which requires them to keep *ihdiyar*, a tenet of internal locus of control. However, if faced with misfortune they are inclined to *pasrah lan sumarah*, or surrender to an external locus of control (Koentjaraningrat, 1985).

Although inconclusive, it has been suggested that '*internals*', individuals with prominent internal locus of control, are more inclined to adopt healthcare behaviour such as stopping or reducing smoking following medical advice (James et al., 1965; Steffy et al., 1970), or to seek knowledge following a diagnosis patients of diabetes (Lowery & DuCette, 1976). Internal health locus of control is also associated with better inclination in seeking help (Fischer & Turner, 1970; Andrews et al., 2011). Thus, it is proposed that since a person with higher internal HLC is inclined to take more responsibility for the outcome of one's action; he or she will seek any measure required to control their own condition, including seeking professional help.

On the other hand, it has been suggested that people with external locus of control, or '*externals*', benefit from a group intervention, such as a weight loss program (Wallston et al., 1976), smoking control program (James et al., 1965). This suggests that the impetus to lose weight/stop smoking is due to external influences such as peers or powerful others. On the other hand, Martinelli (1999) argued that both internal and external HLC have played a role in smoking cessation among college students, while, other studies revealed no significant relationships (Lichtenstein & Keutzer, 1967). Thus, these results emphasize the varied effect on how locus of control influences the inclination toward healthy behaviour.

It is proposed that one possible answer to the varied results in the relationship between HLC and behaviours affecting glycaemic control is that studies have only examined '*control*' as a single construct instead of one aspect of multidimensional factors related to behaviour, such as agency in terms of self-efficacy as well as other structural aspects including health values and the role of health care practitioners (Lau et al., 1986; Wallston, 1992; Wagner et al., 2001; O'Hea et al., 2009;

Oftedal et al., 2010). A study by Lau et al. (1986) showed a better correlation between locus of control and self-efficacy with the performance of certain preventive health behaviours especially among respondents who placed a higher value on health. Hence, behaviour change is considered to be a result of simultaneous influencing factors related to self-regulation such as life values, self-efficacy and outcome expectancy (Wagner et al., 2001; O'Hea et al., 2009; Oftedal et al., 2010). Indeed, this emphasizes the notion that discussions about locus of control cannot take place in a vacuum and need to be understood in relation to other factors.

It is important to note that beliefs about the locus of control should be distinguished from perceived self-efficacy. The locus of control concept does not discuss perceived efficacy, although it is widely known that belief in personal determination could lead into a sense of efficacy or power (Bandura, 1986). The earlier concept looks into the causal relationship between action and result regardless of the capability and capacity of individuals. Whereas, the notion of self-efficacy would emerge in regards to the achievability of results. Thus, it is proposed that if one believes that the results of his or her actions were beyond expectations because of his or her incapability, then it is said he or she has low self-efficacy. Hence, a sprinter who won a race would say that he or she has high self-efficacy by winning the game. However, if locus of control is put into context, he or she would have a different view on which factors influence winning; whether it is his or her own action (internal locus of control) or by chance, luck, the trainer, or even God (external locus of control). Thus, one that believes results come from one's action would get a terrific feeling out of it, whereas one will be demoralized by losing. In general, people who believe that the outcome of their efforts is determined by their own behaviour tend to be more active than people who take it for granted, and being capable to accurately appraise their own capacity is highly advantageous and often essential for effective functioning (Bandura, 1986).

Self-efficacy

Self-efficacy does not only apply to the knowledge or the ability to perform certain activities; it is more about orchestrating cognitive, social and behavioural sub-skills into an integrated course of action to serve numerous purposes (Bandura, 1986). In addition, it is proposed that perceived

self-efficacy is regarded as a significant determinant of performance that operates partially independently of underlying skills (Locke et al., 1984; Schunk, 1984).

Perceived self-efficacy (PSE) is defined as *'people's judgment of their capabilities to organize and execute a course of action required to attain designated types of performance'* (Bandura, 1986, p. 391). It refers to one's personal judgement of what one can do with whatever skills one possesses. Hence, the more accurately a person is able to appraise their own capability is considered valuable in successful functioning (Heisler et al., 2003; Lippa & Klein, 2008). It is also argued the stronger the PSE, the more vigorous and persistent one can be (Schunk, 1984; Schwarzer & Fuchs, 1995). Thus, a person with higher PSE is inclined to refer their failure to insufficient effort rather than a deficient ability, which a person with lower PSE would tend to believe.

There are several sources of information that can be contributed to PSE; those are enactive attainment, vicarious experience, verbal persuasion and physiological state (Bandura, 1986). Enactive attainment refers to one's own experiences, which provide the most prominent source for PSE (Bandura et al., 1980; Biran & Wilson, 1981). Successful effort will raise the efficacy appraisal whereas repeated failure lowers efficiency appraisal, especially if failure happens early on, or failure cannot be attributed to external obstacles. Witnessing others perform successfully can be useful and can be a source of vicarious experience (Spikmans et al., 2003). One is able to persuade oneself that if someone else is able to do something, why cannot one (Kazdin, 1979; Bazzazian & Besharat, 2012). The same notion works for the failure of others in spite of their efforts, which can be discouraging and lower one's judgement of one's own capability (Brown & Inouye, 1978). Verbal persuasion refers to a personal approach as a source of information. Although it is considered to have limited capabilities in increasing PSE, however, if the communication approach is realistic it can be successful in performing designated action (Bandura, 1986). To some extent, verbal persuasion can be achieved from the emotional support from the family or other social support (Goz et al., 2007; Kanbara et al., 2008; Bai et al., 2009). Moreover, a person's physiological state or emotions might influence perceptions of self-efficacy (Strecher et al., 1986; Maddux, 2000; Feltz & Lirgg, 2001). However, a person's physical state can also serve as a constraint in performing an action (Sarkar et al., 2006).

Self-Regulation and Self-Appraisal

Some authors separate self-regulation and self-appraisal as essential components to self-care to understand, monitor and continually measure the ability and application of self-care within an individual's life (Heisler et al., 2003; Oftedal et al., 2010; Bazzazian, 2012).

Self-regulation involves monitoring behaviour such as maintaining diet, exercise and metabolic control (Oftedal et al., 2010), similar to the self-care behaviour concepts proposed within others studies (Toobert et al., 2000; Toljamo & Hentinen, 2001). However, the implementation and operation of self-regulation in practice is unclear. Studies often focus on the influence of how motivational factors to self-regulation operate among individuals with diabetes (Oftedal et al., 2010; Bazzazian, 2012) not with what and how people self-regulate.

Self-appraisal is similar to self-regulation and refers to how individuals examine their own efforts in managing their condition in daily life (Heisler et al., 2003), and is an important component in self-care practice. The difference with the former is that this notion is referring more to the ability to evaluate the condition, whereas the former focuses more on how to put self-care into practice.

There are several strategies through which healthcare professionals might play a role in influencing an individual's ability to self-appraise, such as the provision of good quality information (Heisler et al., 2002), as well as the using supportive decision making styles (Kaplan et al., 1989; Hays et al., 1994; Heisler et al., 2002). For this study, this is regarded as important in terms of how a successful diabetes education programme to promote self-management should be delivered.

Self-care in Diabetes Management

The discussion of diabetes management will begin with brief exploration about diabetes; in particular type 2.

Diabetes

Diabetes is a chronic disease due to the inability to produce insulin, to use insulin effectively, or through being insulin resistant. There are three main types: type 1, type 2, and gestational diabetes (IDF, 2013). Type 1 is the least prevalent diabetes, occurring due to an auto-immune process, where the body's self-defence system detects insulin producing cells in the pancreas as

'*an enemy*', therefore is unable to produce sufficient. While, gestational diabetes happens among women who develop insulin resistance and subsequent high blood sugar during pregnancy (IDF, 2013). Type 2 diabetes is the most prevalent type of diabetes, and this can happen unnoticed. It is due to an insufficient amount of insulin in the body, the inability of the body to respond to insulin, or insulin resistance, despite the body being able to produce insulin (IDF, 2013).

There are several factors that might influence the generation of type 2 diabetes, or risk factors, those are: obesity, poor diet, physical inactivity, advancing age, family history of diabetes, ethnicity and high blood sugar during pregnancy affecting the unborn child (IDF, 2013). Unlike type 1 diabetes, which requires constant and regular supplies of insulin input, type 2 diabetes does not usually requires insulin; many people able to manage their blood sugar level by maintaining a healthy lifestyle of controlling the diet and keeping physically active, or taking oral medication (IDF, 2013). Although type 2 diabetes is considered to be a metabolically heterogeneous condition, insulin resistance and impaired insulin secretion are regarded as prominent defects and both present in most cases (Krentz & Bailey, 2001). Before type 2 diabetes develops, there is an intermediate condition of impaired glucose tolerance which is usually asymptomatic. This raises concerns since most cases are left undiagnosed (Krentz & Bailey, 2001).

Chronic complications of type 2 diabetes will occur after several years of diabetes and present in two main types: microvascular and macrovascular (Krentz & Bailey, 2001). Microvascular complications are associated with blindness due to damage in retinal tissue (retinopathy), end-stage renal failure due to kidney tissue damages (nephropathy), and foot ulcers that can lead to amputation due to the peripheral and autonomic neuropathy (Krentz & Bailey, 2001). Macrovascular complications consist of coronary heart disease, cerebrovascular disease, cardiac failure, and peripheral vascular disease (Krentz & Bailey, 2001).

Diabetes self-care management

The implementation of self-care in daily life lies in a continuum; from 100% of self-care activity such as brushing teeth regularly to 100% professional care such as a neurosurgery (DoH UK, 2005), and stretches from home, school to the workplace environment (Bhuyan, 2004). Basically, the

self-care spectrum in diabetes management can be categorised using three broad themes (Levin et al., 1977; DoH UK, 2006):

- Health promotion and disease prevention;
- Treatment
- Monitoring and rehabilitation which includes managing long-term conditions such as complications.

It is believed that self-care in diabetes management consists of five elements such medication, self-monitoring blood glucose, foot care, and lifestyle modification actions such as maintaining diet, physical exercise and ceasing smoking (Toobert et al., 2000; van den Arend et al., 2000; Heisler et al., 2003; Perkeni, 2011; WHO, 2012), as well as psychological care (IDF, 2012). Therefore, the discussion about diabetes self-care management activities will be described based on the integrative spectrum of self-care itself.

Health promotion and Disease Prevention

The term health promotion refers to managing well-being and general health and not dealing with particular diseases or disorders (Clark & Leavell, 1965). While the Ottawa Charter (World Health Organization European Regional Office, 1986) has defined health promotion as the process of enabling people to increase control over, and to improve their health. Another definition comes from Green and Kreuter, 1991 (in Glanz et al., 2008), *'any combination of health education and related organizational, economic, and environmental supports for behaviour of individuals, groups, or communities conducive to health.'* The latter definition has explicitly put health education under the broader aspect of health promotion. However, some researchers in the United States used both terms interchangeably (Glanz et al., 2008). Nevertheless, for the purpose of this study, based on the previous definitions, health promotion is regarded as an umbrella concept for health education. While, disease prevention represents any measures in *'identifying risk factors and detecting biological changes early in order to intervene at a stage when the condition is reversible'* (Jamison, 2001, p. 37). Indeed, both terms are usually used as integral concepts aiming at achieving the health and wellbeing of an individual.

As one aspect of health promotion, health education aims to enhance personal knowledge and skills - across the health promotion continuum - of disease prevention, treatment, and rehabilitation (Glanz et al., 2008). Health education is regarded as a prospective strength to help people *'understand risk, assess personal and social priorities, make decisions for themselves, take the initiative for maintaining their health and use professional resources in a self-protecting and economical manner'* (Levin, 1976). It is important to understand how people learn and how and why people behave. Therefore, principles of learning, theories of human behaviour and models are needed to set as a framework of understanding (Butler, 2001).

Structured Education

Structured education, or diabetes self-management education (DSME) as it is often referred to, is regarded as an integral part of managing diabetes. The aim is *'to improve outcomes through addressing the individual health beliefs, optimising the glucose control, addressing the importance to understand the complication, how to improve the behavioural management, improving quality of life and reducing depression, as well as to enhance the behavioural change'* (National Collaborating Centre for Chronic Conditions, 2008, p. 27), and it is not only for the patient but for the whole family (Perkeni, 2011). A structured educational program has been established as the first of the five pillars of diabetes management in Indonesian primary care (Kanbara et al., 2008; Lestari, 2008; Vidiawati et al., 2010; Perkeni, 2011; Soewondo et al., 2013). Therefore it is crucial to consider the individuals in self-management education programmes (Lorig & Holman, 2003; Weinger & Greenlaw, 2009). Therefore, a detailed assessment is needed before commencing any program.

Structured education has been shown to demonstrate beneficial effects in adherence to enhancing lifestyle behaviour change (Atak et al., 2008; Carter et al., 2013; Norris et al., 2001; Rise et al., 2013), improving self-efficacy (Atak et al., 2008; Sperl-Hillen et al., 2013), improving blood glucose monitoring activity (Norris et al., 2001; Norris et al., 2001; Reutens et al., 2012; Atak et al., 2008; , enhancing the frequency of foot care (Balamurugan et al., 2006; Atak et al., 2008), and improving psychological well-being or quality of life (Steed et al., 2003). Some studies highlighted the need for continuing interventions to maintain the long term effects of education on lifestyle behaviour changes (Norris et al., 2001; Sperl-Hillen et al., 2013).

There are several barriers surrounding the implementation of an educational programme. Factors related to individual agency or behaviour such as being reluctant to follow information, aversion to group classes and poor literacy (Balamurugan et al., 2006; Maine Department of Health and Human Services, 2006; Clark, 2008) have played a role. While, other determining factors relate structural issues, for example, the nature of the program; a stand-alone program was proven to be less successful unless equipped with a behavioural change strategy and diabetes treatment regimes (Clement, 1995) or with psychological interventions (Steed et al., 2003); transportation issues (Balamurugan et al., 2006; Maine Department of Health and Human Services, 2006); the socio-cultural environmental context, the nature of the disease and the interaction between patients and education providers; or aspects that related to the HCP, such as a lack of human resources (Kusniyah et al., 2010) or lack of physician's time (Sutanegara & Budhiarta, 2000).

Peer reviewed studies regarding the influence of education among people with diabetes in Indonesia are rarely found (Soewondo et al., 2013). Among existing studies regarding the operation of structured educational programmes, there are different views proposed. The most valid source would be from the existence of PEDI, *Perhimpunan Edukator Diabetes Indonesia* or Indonesian Association of Diabetes Educator (Ministry of Health, 2012). It was established in 2002 and training for the trainers is conducted once a year, however, there is a lack of evidence about how it performs. Therefore, it is difficult to evaluate it.

Nevertheless, several studies reveal various results underlying the lack of evidence of a structured education in place (Sinorita et al., 2004; Kusniyah et al., 2010), or education as an intervention program of research (Chan et al., 2009; Kusniyah et al., 2010), particularly with specific self-care regimes, such as blood glucose control (Sinorita et al., 2004; Hidayati, 2003; Jazilah et al., 2003; Suharjanto, 2004; Kresnowati, 2008; Nugrahani & Sulchan, 2008; Utomo et al., 2011; Dewi, 2013), foot care and self-monitoring blood glucose (Sari, 2013; Suharjanto, 2004), beside the more frequent behaviour of dietary planning, physical exercise, and blood glucose check (Hidayati, 2003; Sinorita et al., 2004; Suharjanto, 2004; Kusniyah et al., 2010; Utomo et al., 2011). A large epidemiological study, which was part of the International Diabetes Management Practice Study (Chan, 2009) showed that 60% of patients out of 674 patients across the nation with type 2

diabetes had never had the opportunity to access an education session. Education was often provided by a specially trained educator during consultation (Soewondo, 2011). This study identified the absence of a structured educational program in Indonesia, amid the existence of PEDI, and raised the question regarding the necessity of implementing such a program, which is already reinforced under existing guidelines that identified a structured education program should be available.

Self-care Approach

As one aspect of maintaining a good education process and in order to encourage self-care management, it has been suggested that health care practitioners (HCP) need to establish good relationships with individuals early on and gain full understanding of their circumstances from the outset. It is important to ensure that plans are in place and that patients are fully informed and also involved in decision-making (Furlong, 1995). Therefore, there are several elements proposed that facilitate the self-care process, including: joint agenda setting, collaborative goal setting and problem solving, clinical or behavioural interventions and goal follow-up (Furlong, 1995; Wagner, 2001).

The first phase of joint agenda is aimed at gaining information about patient's circumstances. This consists of three sub-phases: joint assessment, information giving, and negotiation (Furlong, 1995). Although, these sequences are not exclusively attached to the health promotion and disease prevention theme alone, rather, they also relate to the other themes of treatment, monitoring, and rehabilitation. There is also a right for patients to be aware of their own condition and make choices about treatment. In light of this, Diabetes UK (2000) proposed the first Patients' Charter to *'improve awareness and knowledge of this potentially fatal condition'*. The second phase of collaborative goal setting and problem solving is aimed at helping patients set goals and contribute to problem solving process in improving self-management (Wagner et al., 2001). Furlong (1995) proposed that this phase should contain a plan of action of what will happen. This plan needs to involve the individual and people also need to be fully appraised of their options and potential outcomes. The third phase of clinical or behavioural intervention is about caring process (Furlong, 1995). The aim here is to apply clinical and behavioural interventions to prevent complications and maintain well-being (Wagner et al., 2001). The final phase of goal follow-up

deals with the monitoring process (Wagner et al., 2001) with the purpose not only to provide evaluation from the HCP's view, but also as to allow individuals to reflect on their care experience (Furlong, 1995).

Thus, these phases highlight the need for full collaboration and active involvement from patients and HCP in successfully promoting self-care, since to some extent there will be a delegation of responsibility to the patients themselves. However, for Javanese people, this could pose difficulties as the culture tends to involve people looking to authority figures for solutions to problems.

Diet

The way nutrition plays a role in diabetes management programmes has changed from the one-fits all regimes to a more patient centred approach (Diabetes UK, 2011) taking into account an individuals' ability to change and any cultural aspects (Perkeni, 2011; IDF, 2012) and tailors recommendations to their own preferences and joint decision making (Diabetes UK, 2011). Moreover, there is no suggestion on any specific diabetes diet, since management will be the same as for the non-diabetic person, as well as recommending limiting sugar intake in every meal and following a diabetes meal required for diet management. Perkeni (2011) proposed that considerations have to put in regards of 3 J's, those are *jenis* (type), *jumlah* (amount), and *jadwal* (schedule) of diet. While, Deakin (2003) suggested '*there are no rules for diabetes self-management, only choices and consequences.*' (p. 16). This notion rests on the individual being independent and capable of taking responsibility for them self, making educated choices; which are basic principles of self-care.

Nevertheless, guidance in regard to dietary management still needs to be put in place as a point of reference, although, implementation will have to take into account personal and cultural factors (Diabetes UK, 2011), as mentioned earlier. Therefore, it is proposed that medical nutritional treatment is an appropriate method in managing diabetes (Diabetes UK, 2011; Perkeni, 2011). This involves an evidence-based series of guidance on particular dietary requirements, such as carbohydrates, fat, protein, fibre, and natrium on a daily basis (Perkeni, 2011). Further exploration of this detail is not within the scope of this chapter. Moreover, due to

the technical-dietary matter, a registered dietician with expertise on diabetes care is required to convey a dietary education program into an accessible format for the public (Diabetes UK, 2011).

Several studies provide evidence on how a positive effect to glycemic control (Sinorita et al., 2004) and delaying the onset of diabetes (Daly, 2009) or decreasing the incidence of diabetes (DPPRG, 2002) can be achieved. Other studies from Indonesia show the importance of dietary management among people with diabetes in controlling blood glucose (Pramono et al., 2010; Primanda et al., 2011; Retnaningsih, 2010; Sinorita et al., 2004; Soewondo et al., 2010; Sutanegara & Budhiarta, 2000). Moreover, Pramono et al. (2010) show a higher risk in regard to dietary patterns has contributed to the prevalence of undiagnosed diabetes mellitus. While, Primanda et al. (2011) and Retnaningsih (2010) have addressed the relationship between not managing one's diet and the lack of information. It seems clear then that improved knowledge increased people's inclination to manage their diet.

Physical Activity

Keeping physically active is the basic requirement for every individual, and it has to be introduced gradually. Similar to dietary management, physical activity needs to be introduced in a patient-centred fashion that considers the willingness and ability of an individual and also involve them in goal setting to achieve the best results (Lippke, 2004). General recommendations for physical activity requirements include conducting physical exercise, preferably aerobic activities such as walking, jogging, running, and swimming (PERKENI, 2011; IDF, 2012b). Such activities should be done up to 30-45 minutes on 3-5 days per week, or an accumulation of 150 minutes per week of moderate-intensity aerobic activity (50-70% of maximum heart rate). Thus, in the absence of contraindications, it is encouraged to do resistance training three times a week.

By doing regular physical exercise, along with taking other lifestyle modifications measures, has proven to improve the overall wellness of diabetic individuals by improving glucose control, (Suharjanto, 2004; Utomo et al., 2011; Dewi, 2013), lowering the HbA1c level, lowering insulin demand (Kosaka et al., 2005; Vidiawati et al., 2010), and giving significant improvement in insulin resistance and glucose metabolism disorders (Coppell et al., 2009) to improved body weight among people with higher risk of diabetes (Kosaka et al., 2005). Moreover, an RCT study

(Laaksonen et al., 2005) from Finland revealed that moderate to high impact of leisure-time physical activity were significantly associated with the reducing the prevalence of diabetes among a high risk study population.

Psychological Care

Psychological well-being is considered an ultimate goal in medical care and general well-being encompasses physical and psychological well-being (IDF, 2012), since being diagnosed with diabetes imposes not only physical but also a psychological burden. Studies reveal a significant possible increase in depression among people with diabetes (Anderson et al., 2001; Barnard et al., 2006), which not only affects patients but also those who care for them (Fisher et al., 2002). Moreover, depression leads to poor psychological functioning (Whittemore et al., 2004), and reluctance to undertake physical activity and treatment (Lin et al., 2004) which may lead to poor health outcome and highly cost of diabetes management (de Groot et al., 2001; Egede et al., 2002).

A study across eight countries has showed that monitoring well-being and diabetes-related distress as part of routine diabetes care is feasible and helps to identify and discuss unmet psychosocial needs (Snoek et al., 2011). This is also echoed by several studies from Indonesia (Masfufah, 2008; Yuniarti et al., 2013), which highlight the importance of self-acceptance as a significant factor to minimize anxiety and depression. Therefore, it is necessary to acknowledge psychological issues and embed them into the process of diabetes management between the healthcare professional and the patient (IDF, 2012).

Treatment

If lifestyle modification has unfruitful results, medical treatment should be initiated (Perkeni, 2011; IDF, 2012). Moreover, IDF recommends that each initiation of dose adjustment should be conducted in a period of a three month trial with precautions taken for contraindications, while still maintaining the lifestyle modification regime as a supportive measure. Comprehensive treatment is believed to be necessary in managing diabetes since it has been proven to help in improving blood glucose levels and this involves treatment for co-morbidity such as hypertension and dyslipidemia.

It is argued that maintaining blood pressure in diabetes patients might also help in maintaining blood glucose (King et al., 1999; Laakso, 1999). Moreover, the study showed that blood pressure control is associated with reducing the prevalence of strokes and heart failure by half. Moreover, intensive glycaemic control has proven to have a beneficial effect on the prevention of complications in type 2 diabetes. Several large epidemiological studies conducted in the UK, US and Asia-Pacific region have emphasized the relationship between intensive treatment with glycaemic control and the risk of complication development (DCCCT, 1993; Lauritzen et al., 2000; Colagiuri et al., 2002; Chan et al., 2009).

Monitoring and Rehabilitation

Self-monitoring of blood glucose (SMBG) has been considered an integral part of diabetes management to control blood glucose in the long term (ADA, 2007) and this has been recommended in the guidelines for diabetes management (ADA, 2007; National Institute for Health and Clinical Excellence, 2009; Perkeni, 2011). In addition to patient benefit, it might lead to flexibility to adjust diet, physical activities or, even, medication regimes as well providing the ability to be aware of glucose levels (ADA, 2007; Gavin, 2007). Nevertheless, the applicability of such measures vary across countries (The SMBG International Working Group, 2008).

Major clinical trials have found that complications can be better controlled by the implementation of long term monitoring in insulin-treated individuals, although it is not clear in individuals who are not having insulin treatment (IDF, 2012). Poor glycaemic control has been related to an increased risk of macrovascular and microvascular complications (Klein, 1995; Adler et al., 1997; King et al., 1999; Shogbon & Levy, 2010). Macrovascular complications refer to cardiovascular diseases such as stroke, heart problems, and peripheral vascular problem which lead to insufficient limb vascularisation; while microvascular refers to retinopathy, and renal failure (Klein, 1995; Perkeni, 2011). The poor level of glycaemic control, with HbA1c level of 8% or more, was correlated to the prevalence of complications such as retinopathy, micro albuminuria and neuropathy (DCCCT, 1993; King et al., 1999; Chuang et al., 2002; Soewondo et al., 2010; Soewondo, 2011).

Another measure to serve as an early detection of diabetes complications is cardiovascular risk assessment such as maintaining normal body weight, controlling blood pressure, ceasing smoking, eye screening, and foot care (Toobert et al., 2000; DF, 2012). Foot ulcers due to diabetic neuropathy have been related the limb amputation ([Dorresteijn et al., 2010](#)) which then could lead to medical and non-medical costs of health care. The main risk factors of foot ulcer include a history of foot ulcers or amputation, peripheral neuropathy, peripheral vascular disease and foot deformity. Therefore, foot care as an early detection strategy plays an important role in self-care activity in preventing long term complications.

The foot care strategy, as one strategy in monitoring complication of foot ulcers, must cover active treatments of foot deformity (hammer or clawed toes, bone prominences); visual evidence of neuropathy (dry skin, dilated veins) or calluses (Toobert et al., 2000; IDF, 2012b). Furthermore, Toobert argued that to implement foot care into the daily practice of self-care, it needs to be based on the existence of ulcer development risk factors, whereas IDF guidelines (2012) have suggested it should be performed as an annual assessment. There is limited evidence from Indonesia, which exists from several unpublished studies that have focused on the relationship between foot care, foot care education, and glycemic control (Suharjanto, 2004; Flora et al., 2013; Sari, 2013). Moreover, Sari (2013) argued that family based foot care education training was successful in increasing the knowledge and practice of foot care among people with diabetes. Although evidence is limited, research evidence is slowly developing in Indonesia, although adequate peer-reviewed study is still lacking.

Factors Influencing Self-Care Behaviour

Self-care is a concept that entails multi aspects of human behavior. However, there are several factors that can potentially influence an individual and enhance or reduce self-care activities and behaviour. Recently, new health agendas identify that health experiences are influenced not only by genetics, or lifestyle but also by a wide range of social, economic, political and environmental factors (WHO European Regional Office, 2001). The following discussion will emphasise the concept of agency and structure (Cockerham, 2005) in explaining several factors that might influence self-care behaviour. Agency refers to the capacity of individuals to make decision

toward a course of action based on their past experiences, future and present conditions (Emirbayer & Mische, 1998), whereas, structure refers to any social norms, regulations, rules and resources available, either human or non-human (Cockerham, 2005). Thus, education served as a critical point in self-agency (Cockerham, 2005).

Socio-eco-demographic factors

Several determining factors have played a role in influencing healthy lifestyle decisions among communities which include in gender, age, race, religion, and sexual preferences, as well as other factors such as advertisement and medical campaign (Cockerham, 2000).

Age

Age is considered a determinant factor in health. Due to the awareness among older people of their vulnerability to disease and a higher probability to death compared to younger people, they tend to engage in health behavioural change (Zanjani et al., 2006). However, Zanjani et al. (2006) describe that behaviour change around food consumption, food preparation and seeking medical care are more likely in younger and middle groups but not in the older group. Moreover, negative behaviour change was also found among people in older groups, which might be related to an absence of personal health vulnerability. The awareness of the importance of health is not always contributed to behavioural change among younger people. Deeks et al. (2009) explained that although the majority of younger participants in the study were aware that lifestyle influenced health, few of them engaged in seeking medical treatment or accessing health promotional materials compared to older participants.

Gender

Gender is regarded as *'the most fundamental single characteristic that determines an individual's perception, behaviour and position among society'* (Dean, 1999: p.138). There is varied evidence of how gender relates to self-care behaviour. Some studies show that women are more inclined to engage in more active health promotion behaviour such as not smoking and restricting alcohol intake (Martinelli, 1999); to frequent self-monitoring of blood glucose or SMBG (Aalto & Uutela, 1997) compared to men, which is in resonant with other studies, except for exercise (Ross & Bird, 1994; Dean et al., 1995; Stevens et al., 1995). A study in the US during the period of World War II

revealed that the involvement of a large number of women in the labour force increased the prevalence of smoking among women in spite of negative male attitudes towards the behaviour (Walsh, Sorensen, and Leonard in Cockerham, 2000). Studies propose a different view; that men engage in more self-care compared to women (Bai et al., 2009), or that there were no relationships between gender and self-care (Toljamo & Hentinen, 2001). Differences emerge from the use of different study methods or the implementation of a variety of assessment tools.

Evidence shows a relationship between the level of education and health behaviours such as smoking, obesity, physical activity, and the use of health care services. For first time mothers to be able to enrol in college and stay for a minimum of two years decreased the probability of smoking during pregnancy by 5.8% (Currie & Moretti, 2002). Similar to a study from the United States that showed college education decreased smoking prevalence and increased smoking cessation (de Walque, 2010) as well as seeking HCP's assistance, and inclination toward healthy lifestyle (Simanungkalit, 2011; Budhiarti, 2011; Hasni et al., 2012). Education has also been related to body mass index (BMI), a study in Sweden showed an additional year of schooling improved having a BMI within a healthy range (Spasojevic, 2010), which was resonant with a similar study from Denmark that mentioned the significant protective account of BMI on male participants (Arendt, 2005). While, engaging in adult learning in the UK increased the probability to do more exercise by a factor of almost a fifth of participants (Leon & Hammond, 2004).

There were some explanations to the correlation of education with health. Firstly, the relationship between higher levels of education with a higher possibility of taking advantage of medical care or from new developments in health technologies (Or et al., 2005; Feinstein et al., 2006). Secondly, parental education was associated with better income (Currie & Moretti, 2002), which is then associated with the usage of health care services (Gardner & Oswald, 2004). Thirdly, being able to take more personal control and higher self-efficacy were considered to be mediating factors on how more highly educated people would engage in more healthy behaviour (Mirowsky & Ross, 1998). Indeed, the notion of education does not operate in a vacuum, rather, in collaboration with other social contexts such as the support of others, in a communal type of society, as well as income level, which will be discussed later on.

Education

Evidence shows that there is a relationship between the level of education and social health (Feinstein et al., 2006). Several studies across the United States (Deaton & Lubotsky, 2003), the United Kingdom (Gardner & Oswald, 2004), Switzerland (Bopp & Minder, 2003) and Indonesia (Breierova & Duflo, 2004) have revealed the year of schooling or the level of education is correlated with mortality rate. Breierova & Duflo (2004) showed that an increase of average education in the household would decrease child mortality by 10%. Furthermore, a study by Muller (2002) revealed an association of higher percentage of the population without a high school diploma and an increasing of 2.1 deaths per 1000 population. However, another study showed different results; in males, post graduate education adds nothing to the level of mortality and female post graduates were not more protected than high school graduates (Deaton & Lubotsky, 2003).

Income

Income has been related to the health and well-being of individuals; both to mortality or morbidity. A report from the Joseph Rowntree Foundation (Rowlingson, 2011) proposed that in any society, there is a '*social gradient*' in health where people in the higher income brackets will earn higher levels of health. Muller (2002) has associated lower education with income inequality as a predictor to the mortality variations in the US. It is in resonant with the study from Wilkinson (1997) that shows people in the lower rank of the socioeconomic hierarchy have higher psychosocial stress due to income inequality.

There are some possible explanations to the relationships. Some people perceived increasing cost or less income as barriers to attending health care appointments (Wilson, 2011). The cost of diabetes management refusal to take insulin have been regarded as barriers to diabetes management along with insufficient time for appointments and doctor payments (Reutens et al., 2012). While the cost of implementing self-monitoring of blood glucose has been an important hindrance to some countries such as India and Tanzania (TSIWG, 2008), and including Indonesia (Trisnantoro, 2006).

Social support

Social support has been regarded as a significant factor in the adherence to self-care behaviour regimes. Thus, in respect of the agency and structure discussion, social relationships and social contexts have influence on how individuals would engage with particular action inside a community, as mentioned by Demers et al. (2002, p.422) *'the individual cannot be conceptualized as an autonomous actor making self-governing decisions in a social vacuum.'* Social support is defined by House (in Heaney & Israel, 2008) as *'the functional content of relationships that can be categorized into four broad types of supportive behaviour or acts of: emotional support, instrumental support, informational support, and appraisal support'* (p. 190). Emotional support refers to provision of empathy, love, trust and care; instrumental support refers to the provision of any tangible aid and services direct to individuals' needs; informational support accounts to the provision of advice, and information; and, appraisal support involves any constructive feedback and affirmation (House in Heaney & Israel, 2008).

Several studies have revealed the relationship between social support and overall mortality; some showed that people with lower levels of social support have a greater rate of mortality (Berkman & Syme, 1979; Blazer, 1982; House et al., 1982). A review of how social support might affect overall well-being has shown some ways to explain the relationships (Cohen & Wills, 1985); as a main effect and as stress buffering effect. As for the former effect, in general, large social networks will benefit an individual in gaining positive experiences as well as a source of self-recognition to provide individuals with self-respect which in turn it might help one to gain general well-being. The latter refers to how one would utilize interpersonal resources to cope with any perceived stressful event. There are several type of support in regards to such buffering effects, including: esteem support, informational support, social companionships and instrumental aid (Cohen & Wills, 1985). While, peer support has regarded as an important factor in supporting self-care behaviour (Bai et al., 2009) as well as improving the self-efficacy of people with chronic illnesses (Lorig et al., 2008). In 1986 Persadia, the Diabetes Patient Association in Indonesia was introduced, and aimed to generate volunteers to motivate people to self-care for their diabetes. Now along with *Pandu* Diabetes (Diabetes Champion, established later in 2009), there is

combined pressure and strengthened support for encouraging behavioural change to pursue sustainable effort (SSDC, 2013).

Patient and Health Care Practitioner (HCP) perceived barriers

Perceived self-care barriers influence the act of deliberate self-care in adult patients (Whetstone & Reid, 1991). Thus, in this respect, agency is important and relates to the ability of individuals in utilize the resources available for their own benefit (Emirbayer & Mische, 1998). In an Indonesian setting, cultural aspects may serve as a hindrance to empowering patients. As discussed earlier in the first chapter, Javanese people believe that life is a continuous hardship which requires people, especially peasants, to accept it without reserve (Koentjaraningrat, 1985). This reflects a tendency to surrendering. Another barrier may be a lack of knowledge. Knowledge about a specific diet plan and plan of care were among the perceived barriers from the patients' views in regards of diabetes self-management (Soeharjono et al., 2002; Nagelkerk et al., 2005). Although sometimes knowledge was not associated with poor glycemic control, but rather influenced by cultural factor such as norms (Grace et al., 2008); another tenet that emphasizes the concept of structure.

While, Whetstone and Reid (1991) assumed, that the barriers were found around the basic physiological dimension including blood glucose monitoring (BGM), diet regime and exercise strategies. The perceived cost and lack of perceived benefits of BGM were found to be the main influencing factors in adhering to the regime. Meanwhile, barriers to a dietary regime were found to be more complex; a combination of intrapersonal responses, lifestyle and treatment process demands. Unappeasable hunger and enjoyment of food were regarded as contributing factors to these barriers.

Misperceptions can occur with patients and also HCPs. Cultural norms among Indonesian people, especially Javanese, mean that HCP are of a higher social class, which, then, influences communication style, and may be more one way (Claramita et al., 2013). Although HCP would not necessarily intentionally adopt a particular style, cultural background and medical education affect how the relationship is managed (Claramita et al., 2013). Furthermore, healthcare professionals sometimes are not aware of the patients' self-care practice (Brody & Kleban, 1983).

Whereas misconceptions about the treatment of insulin could arise on both sides: patients would regard it as a failure in adhering to self-management regimes, whereas the physician would want patients to take insulin (Benroubi, 2011). Hence, self-practice could end up as a hindrance in achieving common glycemic control goals (Toljamo & Hentinen, 2001; Chan et al., 2009).

The nature of the relationship between HCP and patients is not solely related to the lack of self-agency from the patients' side or the lack of information from the HCP. There are structural barriers in place, such as norms and cultural values. This is particularly true in a society with a very strong hierarchical strata and a less open culture (Koentjaraningrat, 1985). This is an issue for consideration in this study.

Psychological factors

Stress due to financial crisis and depression were regarded as an influential factors in increasing blood glucose levels (Lerman et al., 2004; Gonzalez et al., 2007; Bai et al., 2009). Despite financial problems, all respondents in these studies showed persistence in adhering to self-care management programmes. A qualitative study revealed that diet is regarded as the most disturbing factor in managing the illness (Hadriami, 1994). Thus, understanding patients' perceived barriers were considered important to achieve better adherence to the medication program. Self-acceptance has a significant relationship with minimizing anxiety and depression (Masfufah, 2008; Yuniarti et al., 2013). Therefore, understanding psychological barriers that may hinder people adhering to self-care regimes will benefit in discovering the potential supporting factors to achieve the goal, by designing a specific educational program based on their specific needs.

A Systematic Review on How Religiosity and/or Spirituality Might Influence Self-Care in Diabetes Management

Structured summary

Abundant evidence exists with regards to how religiosity and/or spirituality plays a role in influencing people with type 2 diabetes manage their daily self-care activity. A systematic review compared and contrasted studies. CINAHL, Ovid MEDLINE and Garuda, an Indonesian search portals were accessed to find evidence regarding self-care, religion and diabetes. A critical

appraisal using an adapted CASP tool was utilized and 31 studies were retrieved. There were several themes that emerged from the evidence these included: relationship with God or the transcendent, religion or spirituality as coping methods; religious practices; and, social support.

Introduction

This section discusses how religiosity influences people with diabetes in managing their activity in daily life, to identify best methods used to explore the concept and to inform the focus of the developing PhD study. The objectives of this section are:

1. To describe about religion; factors that might influence toward particular behaviour
2. To discover and explain about how religion might play a role in diabetes self-care and what factors involved in it.
3. To discover whether Indonesia people has put the self-care concept into practice especially in relationship with religiosity or spirituality to collect current evidence to gather and extract themes that might emerge surrounding this topic.

A systematic review was performed, with adapted PRISMA statement (Moher et al., 2009), utilized to show the rigour and credibility of the strategy (Table 3.1).

Table 3.1 The PRISMA Statement

Section/topic	#	Checklist item	page #
TITLE	1	Identify the report as a systematic review, meta-analysis, or both.	73
ABSTRACT			
Structured summary	2	Provide a structured summary including, as applicable: background; objectives; data sources; study eligibility criteria, participants, and interventions; study appraisal and synthesis methods; results; limitations; conclusions and implications of key findings; systematic review registration number.	73
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of what is already known.	73
Objectives	4	Provide an explicit statement of questions being addressed with reference to participants, interventions, comparisons, outcomes, and study design (PICOS).	73
METHODS			
Protocol and registration	5	Indicate if a review protocol exists, if and where it can be accessed (Web address), and, if available, provide registration information including registration number.	75
Information sources	7	Describe all information sources (databases with dates of coverage, contact with study authors to identify additional studies) in the search and date last searched.	75

Search	8	Present full electronic search strategy for at least one database, including any limits used, such that it could be repeated.	76
Study selection	9	State the process for selecting studies (screening, eligibility, included in systematic review, and, if applicable, included in the meta-analysis).	75
Data collection	10	Describe method of data extraction from reports (e.g., piloted forms, independently, in duplicate) and any processes for obtaining and confirming data from investigators.	76
Data items	11	List and define all variables for which data were sought (PICOS, funding sources) and any assumptions and simplifications made.	76
RESULTS			
Study selection	17	Give numbers of studies screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally with a flow diagram.	76
Study characteristics	18	For each study, present characteristics for which data were extracted (e.g., study size, PICOS, follow-up period) and provide the citations.	248-265
Results of individual studies	20	For all outcomes considered (benefits or harms), present, for each study: (a) simple summary data for each intervention group (b) effect estimates and confidence intervals, ideally with a forest plot.	248-265
DISCUSSION			
Summary of evidence	24	Summarize the main findings including the strength of evidence for each main outcome; consider their relevance to key groups (healthcare providers, users, and policy makers).	84-88
Limitations	25	Discuss limitations at study and outcome level (risk of bias), and at review-level (incomplete retrieval of identified research, reporting bias).	77 - 88
Conclusions	26	Provide a general interpretation of the results in the context of other evidence, and implications for future research.	77 - 88

Search strategy

A search protocol was undertaken using CINAHL, Ovid MEDLINE and Garuda, an Indonesian search portal, to find evidences regarding self-care, religion and diabetes. The latter search engine was developed by the Higher Education of the Indonesian Ministry of Education which is an abbreviation for Garba Rujukan Digital (<http://jurnal.dikti.go.id/>) or Digital References Portal which serves access to the scientific research by Indonesian researchers or academics. It contains of domestic e-journals, final project students and research reports. Other search strategies were implemented through Google Cendikia, an Indonesian version of Google Scholar, an existing search engine through academics resources, and the Indonesia Scientific Journal Database (<http://isjd.pdii.lipi.go.id/>). The last one is a scientific search engine developed by *Pusat Dokumentasi dan Informasi Ilmiah* (Scientific Information and Documentation Center) from LIPI (Indonesian Institute of Sciences, <http://www.lipi.go.id/>), a governmental institute for sciences and research. The search located articles or research report in English or with English abstracts,

initially using simple search terms (Table 3.2). Nowadays, many Indonesian University has obliged their students to write an English abstract for their dissertation or thesis, to expand their relationship with other researchers or students from other countries. A comprehensive search protocol was developed and administered to the different databases (Table 3.2).

Study selection

The systematic search only looking for self-care management among people with type 2 diabetes and inclusion and exclusion criteria were used in two phases to narrow down the search and final retrieval of relevant papers (appendix 1). For the final process, a full reading through abstract and full text was done to gain a better understanding and to select the appropriate evidences.

Once the final papers had been included, each paper was then critically appraised using a format drawn from the CASP tool (<http://www.casp-uk.net/>). The adaptation of the CASP tool (Appendix 13 & 14 examples of evidence appraisal and synthesis) provided a framework for the approach and management of results collected across various method studies requiring specific critical appraisals procedures.

Table 3.2: Search Strategy

	CINAHL	OvidMEDLINE	Garuda	ISJD	Google Cendikia
First attempt	'religion' OR 'religiosity' OR 'spirituality' AND 'self-care' OR 'self-management' OR 'self-efficacy' AND 'diabetes'	keywords 'diabetes mellitus' AND 'self-care' AND 'religiositas' (religiosity)	'diabetes'	keywords 'agama' OR 'religiusitas' AND 'diabetes' di Indonesia'	
	51722 articles	11346 articles	-	62 articles	4 articles
Second attempt	terms 'linked full text', 'references available', 'abstract available' and range of date '1970 to 2012', age range of '19 – 65+' and excluding the 'type 1 diabetes'	'rawat diri' (self-care)	Inclusion and exclusion	'religiosity' OR 'spirituality' AND 'diabetes' in Indonesia'	
	174 articles	118 articles	-	3 articles	3 articles
Third attempt	Inclusion and exclusion (appendix 1)		'religiusitas' OR 'spiritualitas' AND 'diabetes' AND 'Indonesia'	Abstracts and full text	

	113 articles	33 articles	-	-	2 articles
Fourth attempt	Abstracts and full texts		'agama' AND 'diabetes'		
	9 articles	20 articles	-		

Results of the search

The studies retrieved were conducted in various countries including 4 continent; Africa (Ghana, Sudan, and Nigeria), America, Europe (Sweden, and United Kingdom), Australia (New Zealand), and Asia (Iran, Taiwan, Thailand, Malaysia, and Indonesia). With regards to specific racial or ethnic population, most articles were involving African American communities, either as a sole sample or with White American counterpart (17 articles). Five studies were conducted among Asian societies, three among Latino, and four among African countries, four among Indonesia, and three other studies involving Iranian, Arabic, and Maori. Ten articles were associated with Muslim communities, thirty among Christian and Catholic, one Buddhist, and two are a mixed religion. Nineteen articles are involving a wide range of age; from 20 to more than 60 years, eight involved people with more than 40 years old, and there are eight articles that do not mention the range of their respondents, either because they are a literature reviews, or simply provide this information.

The current reviews are not only discussing about the patients themselves, , there were studies regarding the role of the HCP (Polzer, 2007; Taylor et al., 2009) and patients' relatives including one study describing a couple with a diabetic spouse (Cattich & Knudson-Martin, 2009). The role of others were considered an important part of self-care concepts since they influence how patients will cope with illness (Harandy et al., 2010) and seeking assistance from the HCPs is regarded as one of the main components of self-care (Furlong, 1995). In an Iranian study, the patients regarded the physician as 'holy men' (Abdoli et al., 2008). The influence of relatives has been shown to play a major role in supporting patients with chronic illness and specifically diabetes (Carbone et al., 2007; Samuel-Hodge et al., 2000). Evidence showed that partners had shared the same burden with diabetes patients, especially if the partners were women (Fisher et al., 2002). Therefore, it is suggested as important to understand how others who are closely

related to the patients experience and their perceptions in supporting patients with chronic illness.

Appraisal of the Methodological Approaches

Research approaches refer to a systematic way to organize the plan and procedures on how to gain the data, analyse it and interpret it (Creswell, 2014). The decision to choose a particular approach relies on several considerations, such as the nature of the research problem, personal preferences and experiences, as well as, the audiences of the study. In practice, it depends on how accurate the information would be gathered by certain approach; how acceptable it is morally, ethically, and legally; how satisfy will the researcher be with that methods; and, which is the most practical to the researcher (O'Leary, 2008).

Overall, there were 31 articles comprised of 15 qualitative studies, 11 quantitative studies, 1 mixed method and 4 literature reviews. Among the qualitative studies there were two grounded theory, two qualitative descriptive study, one ethnography study; five focus groups, one philosophical hermeneutic approach, and one interview. Moreover, there were five studies that had been done with a collection of various qualitative methods, such as mixing individual and group interviews with ethnography (Aikins, 2005); phenomenology and grounded theory (Handley et al., 2010); a focused ethnographic approach and face-to-face interviews (Sowattanangoon et al., 2009); case study, participant observation and focus group (Austin & Claiborne, 2011); and, focus group and semi-structured interviews. Among the quantitative studies, two were orchestrating a pre and post-test experimental study (Frank & Grubbs, 2008; Taylor et al., 2009).

Qualitative methods

Qualitative methods were often used due to the naturalistic or interpretative nature, to discover individuals' perspectives of the phenomenon and the context of individual in that particular event. Interviews were the preferred method used within certain approaches, such as grounded theory, focus group interviews, or individual interviews, and phenomenology.

Interviews are beneficial in generating new knowledge from a multidimensional of religiosity or spirituality in managing diabetes using grounded theory approaches. It is useful to extract new themes that can be served as a theoretical framework for another study. For example the work from Polzer and Miles (2007) used semi-structured interviews to extract themes among 29 African American individuals and five ministers, which serve as a basic understanding whereas a different study used unstructured interviews, empowering people to generate their own themes without influence (Abdoli et al., 2008). The semi-structured interviews were based on a set of questions to be asked to all respondents, which then enabled the researcher to compare and contrast between interviews. While, the unstructured interview was a more open-ended conversational, which require the researcher to make a decision, at some point, to direct the interviews.

Focus groups interviews were among the commonest approach that had been used to elicit the perceptions of how religiosity or spirituality might influence diabetes management. This approach has been used to identify culturally relevant psychosocial issues and social context variables influencing lifestyle behaviour, especially diet and physical activity of African-American women with type 2 diabetes (Samuel-Hodge et al., 2000). Another study among young adults has used eight groups which separated between men and women (Jones et al., 2006). A study by Leeman et al. (2008) employed 10 focus groups among 70 adults African American women to design a culture and function specific of self-care intervention through one-to-one encounters by the nurse. The church's activities participation has served as a basic of respondent recruitment. Grace et al. (2008) had used a multi-phase focus groups interviews among Bangladeshi people without diabetes, religious leader and Islamic scholar, and health professionals. This study was among the few studies drawing on an Islamic perspective aimed to understand the lay beliefs and attitudes, religious teachings, and professional perceptions in related to diabetes prevention among Bangladeshi community in the UK. The study showed the importance of the religious leader involvement in diabetes management among the community, as also has been shown from the more prominent studies among the Christian population. A study among people from different religious backgrounds in Sweden used a focus group interview to explore the influence of cultural distance of health and illness beliefs and self-care practices among female Muslim with diabetes (Hjelm et al., 2003). The study used theory as a guideline in collecting information such as the lay

theory model of illness causation by Helman, health care seeking behaviour by Kleinman, health belief model, and perceived locus of control, and self-efficacy. Carbone et al. (2007) has conducted a focus group to describe the refinement of self-management interventions tailored to patients with type 2 diabetes among health care practitioner and patients.

Separation between different genders served as a facilitating factor to enhance the involvement among the respondents. To some extent, it is true to certain community in Muslim population. Given the strict requirement not to engage a direct relationship across opposite genders, the separation of groups in interviews might serve well to collect information.

The work from Polzer and Miles (2007) has been used as a parent study for another study form Polzer (2007) which employed a qualitative descriptive study, aimed to explore how when, and if the health care professional (HCP) should address spirituality in their care by using interviews. The same respondents were used to explain individuals' perception on the role of HCP in maintaining their condition. Another qualitative descriptive study has employed an in-depth interview to explore the possibility of differences between two independent samples among African American men and women (Casarez et al., 2010). The study was aimed to describe the different and similarities of men and women from different Christian affiliation in regards of spiritual practices and how they were integrated within spiritual orientation, and how spiritual practices within each orientation may be incorporated into a diabetes self-management intervention.

An ethnography study by Popoola (2005) managed to understand the holistic and transcultural experience of living with and growing older with diabetes for Nigerians and African American. In this approach, interview and direct observation was used to explore not just experience but rather the way of life of participants, where the researcher tried to immerse themselves within the culture being observed for a period of time (O'Leary, 2008).

A combination of approaches have been used across different perspective in gather more comprehensive and holistic results. A study by Aitkins (2005) which employed individual and group interviews with ethnography; a combination of phenomenology and grounded theory approaches (Handley et al., 2010); a focused ethnographic approach and face-to-face interviews

(Sowattanangoon et al., 2009); case study, participant observation and focus group (Austin & Claiborne, 2011); and, focus group and semi-structured interviews (Grace et al., 2008).

Advantages and disadvantages of Qualitative methods

Due to the nature of qualitative methods in gaining a more naturalistic approach in conducting the data collection and analysis, it might help in explaining the fundamental understanding of a phenomenon of how it happened, rather than a mere description of what was happening. As well as gaining data from the information that the respondents conveyed, the researcher can also gaining emotions, expression which, can in turn help to build the true meaning behind the story. It is an appropriate way to gain information about sensitive issues. Indeed, this approach has been useful to explore the existence of religiosity or spirituality, which was considered a multidimensional concept of human being, and for some as a concept that lies in a private domain of individual (Wisker, 2008), in self-care among people with type 2 diabetes across populations and countries. It also has served as a fundamental framework (Polzer & Miles, 2007) for further study (Polzer, 2007), or as a basic in understanding the existing hierarchical phase in an empowerment process, and therefore, is beneficial to choose the appropriate methods of treatment (Abdoli et al., 2008).

The aim of gaining a rich understanding of the phenomenon, for some impeded on the representativeness of the results which were not the objective, a limited number of participants was preferred. Thirty four and 16 participants were recruited for two different grounded theory studies. Within the focus group interviews, each group consisted of 7 to 12 participants. The size of a focus group has been under debate, however, it is proposed that more than three and less than 15 is sufficient in gaining the advantages of group participation (O'Leary, 2008).

Although, the size of the sample is limited, due to the rich information of in-depth interview, the whole process is time consuming being a disadvantage. Furthermore, within the interaction of the interview becoming deeper the process of interviewing itself could go very much off the point, and it could be difficult either to transcribe or to analyse and compare with other interviews (Wisker, 2008). Moreover, due to the limitation of the sample, the studies often cannot be used to generalize the theory into a broader population.

In order to gain richer information there needs to be more varied participants in a certain period of time, it is preferable by some researchers to facilitate the focus group. While, some participants would find a focus group interview more encouraging and less threatening than a face-to-face interview to convey their opinions. Although, it also depends on the subject of the study; in any sensitive issues to certain population, a more private interview is preferred. Focus Groups also contain another disadvantage in regards to analysing and transcribing process. The researcher has to have a certain strategy to determine which particular quotes are from which participant within the recording. Moreover, some participants find the approach of needing to talk in front of others, off putting and a discouraging (O'Leary, 2008).

Quantitative methods

The positivist worldview is used to test a theory by examining the relationship between variables (Creswell, 2014). In addition, the variables can be measured as numerical information, usually as instruments, which require a certain statistical procedures. Instruments have often been used to gain wider perspectives of human characteristics in examining the phenomenon under study.

Several studies employed between one instruments such as Belief and Values Scale (Chew et al., 2011) to several instruments to measure variables in their relationships with glucose control such as the PRQ2000, the Diabetes Self-Care Scale and Taiwan Geriatric Depression Scale (Bai et al., 2009). A study from Newlin et al. (2008b) used several variables that measure the relationship between body mass index, demographic, medication, religiosity/ spirituality well-being, and other psychological factors, with glucose control. Lager (2006) used several measurements to examine the relationship between religious coping, acceptance of diabetes, social supports, diabetes management, and quality of life such as the Religious Problem Solving Scale-Short Form, Ideas About Diabetes-Revised Scale, the PRQ2000, the Religious Support Scale, Summary of Diabetes Self-Care Activities-Revised, and the Diabetes Quality of Life Measure. A multi-dimensional of religiosity prayer, religious reading, religious attendance, and religious belief had been used to examine their relationship with the level of depression (Kilbourne et al., 2009), or to diabetes self-management scale (Yuniarti et al., 2013).

Other studies had been conducted to explore the effect of certain treatment or procedures. Two studies employed a pretest and posttest design to measure the effect of interventional program of a self-study programme to educate nurses about how to talk with patients about spirituality (Taylor et al., 2009), or the effectiveness of a faith based health screening/education to reduce relative risk of diabetes (Frank & Grubbs, 2008). A quasi-experimental design was used to determine the effectiveness of a serenity prayer to control the blood glucose serum (Sacco et al., 2011).

Advantages and disadvantages of Quantitative approaches

The use of certain instruments to measure human being characteristics helped the researcher to explore the phenomenon under study within a large sample. Due to the representativeness, the results then can be generalized to a wider population. The variation or combination of instruments used gives the study more credible stance in examining the research question, as well as providing the researcher more opportunities to explore the variety of human characteristics in a short period of time. It is common for quantitative study to be conducted as longitudinal studies with repeated data measures at different points in time.

Mixed methods

Mixed methods approach uses a combination and integration of qualitative and quantitative approaches and data in a research study. Indeed, Creswell (2014) suggests three primary models of employing methods: converging or merging quantitative and qualitative data in order to provide a comprehensive analysis; using qualitative approach to explain in more details the results from the previous quantitative approach; and, the reverse of the second methods, which employs a quantitative approach based on the qualitative approach to build an instrument. In this review, there is only one mixed method which employed a quasi-experimental design and qualitative questions (Sacco et al., 2011). The study was undertaken to determine whether the recitation of the serenity prayer might affect the serum level of blood glucose. Although methodological information is limited and there is no clarification as to on how the researcher used the qualitative data.

The lack of detail of the approach is disappointing as there are several considerations why combining methods may prove useful to the proposed study. The integration of these both quantitative and qualitative two approaches could add more credibility, with one approach providing explanation to the other by adding depth and insight to 'numbers' through the inclusion of narrative, dialogues, and add precision to 'words' through inclusion of numbers and pictures (O'Leary, 2010); Secondly, the mixed methodology could enable the researcher to overcome many of the shortcomings of each methods.

Religion, Self-Care and Health Evidence Synthesis

The literature review revealed several themes that showed how religiosity might influence individual with diabetes in managing their condition, which includes: relationship with God or the transcendent, religion or spirituality as coping mechanism, religious practices, and social support.

Themes extracted from the review

Religiosity and Self-care

Beliefs about health care are culturally constructed and affect people's decisions regarding treatment (Daly et al., 2002; Wallin & Ahlstrom, 2010). It may affect how people experience and interpret how they should self-manage (Sowattanangoon et al., 2009; Lim et al., 2012). Cultural differences promote different self-efficacy appraisals (Hjelm et al., 2003). Children who are raised in a population based on 'dependent collectivism' with a higher degree of power distance and hierarchical relationships learn to obey authorities, encouraging a less independent behaviour with lowered self-efficacy (Hjelm et al., 2003). Islamic countries have been recognised as being bureaucratic with a large power distance and a strong uncertainty avoidance, which means a high need for rules or regulations in contrast to low power distance and weak uncertainty avoidance in non-bureaucratic western countries (Hjelm et al., 2003). On the other hand, there is a misinterpretation of the Qur'anic teaching about how individual should put themselves between fate and their own effort in term of their survival existence in this world (Grace et al., 2008). There are several tenets in Qur'an that obliged the believers to put their own effort forward before accepting the fate (*The Qur'an. With surah introduction and appendices*, 2012).

Religious belief

Religious belief is regarded as a contributor in maintaining well-being and mental health (Koenig, 2002; Parsons et al., 2006; Polzer & Miles, 2007). One study suggest that religious belief might influence how one will cognitively apprehend the interactions between appraisals, attention and beliefs in preventing emotional disorder (James & Wells, 2003). The belief that God has the control over one's effort in promoting health has been shown among people with chronic illness such as rheumatoid arthritis and systemic sclerosis (Wallston et al., 1999), as well among adolescents who are coping with risky behaviour (Seybold & Hill, 2001; Goggin, Murray, et al., 2007). Nevertheless, studies also revealed the negative influences that religious beliefs might play in hindering self-management of illnesses (Naeem, 2003; Bai et al., 2009). The differences might emerge from how the religious authorities interpret teachings from the scriptures.

Relationship with God or the transcendent

There are various meanings that people use to make sense of their relationship with God in managing their condition. These relationships were established through religious practices (Samuel-Hodge et al., 2000; Polzer & Miles, 2007; Sowattanangoon et al., 2009; Casarez et al., 2010), and listening to religious radio programs (Casarez et al., 2010), or taking religious reading (Kilbourne et al., 2009). Basically, there are three themes that have emerged: supportive, collaborative, and submissive. For some, God is regarded as supportive and as the source of health as well as the illness (Hjelm et al., 2003; Popoola, 2005; Abdoli et al., 2008; Wallin & Ahlstrom, 2010; Yuniarti et al., 2013); in enhancing self-confidence (Casarez et al., 2010) and freedom (Pargament et al., 1988); in managing the disease and empowering patients in taking greater control of the illness (Aikins, 2005; Polzer & Miles, 2005; Popoola, 2005; Abdoli et al., 2008); as a source of knowledge for the patients (Polzer & Miles, 2007) and through the HCP (Jones et al., 2006). Therefore, some would regard HCP as an instrument from God (Polzer, 2007) or holy men (Abdoli et al., 2008), which, then would lead to following medication regimens (Polzer, 2007).

The second perspective from the God-person relationship is a collaborative one. People holding this view regard God as a partner in managing their condition (Pargament et al., 1988; Polzer &

Miles, 2007; Casarez et al., 2010) and in times of need God would act as a source of knowledge or support. At time of action, the individual would be the main actor, although, he or she still believes that God was always around. Furthermore, Pargament et al., (1988) argued that this collaborative style refers to an active personal exchange with God which appears to be '*a self-incorporated form of religion*' (p.90).

Another theme is submission which refers to relinquish self-management to God's will (Polzer & Miles, 2007), or to wait for God to heal the condition (Pargament et al., 1988; Polzer & Miles, 2007; Casarez et al., 2010). This sometimes manifests as a fatalistic view of illness (Bai et al., 2009; Hatcher & Whittemore, 2007; Wallin & Ahlstrom, 2010), which hinder them to properly self-care the condition (Ahmed, 2003; Jones et al., 2006; Polzer, 2007; Polzer & Miles, 2007) and not adhere to medication (Polzer & Miles, 2005; Jones et al., 2006; Casarez et al., 2010). While, to some others being fatalistic do not necessarily have a negative meaning; it has given inner strength to manage their condition (Abdoli et al., 2008). Some Sudanese people regard diabetes as a punishment from the supernatural power such as witches, whereas to others it is regarded as love from God; a test of their faith (Ahmed, 2003), or God's will (Hjelm et al., 2003; Yuniarti et al., 2013).

Religion and spirituality as coping methods

Coping strategies refer to any effort aimed '*at problem management and emotional regulation, give rise to outcomes of the coping process such as psychological well-being, functional status, and adherence*' (Glanz & Schwartz, 2008, p. 213). While, religious coping refers to efforts in seeking a spiritual connection, support or collaboration with God in problem solving (Heo & Koeske, 2012). Religious coping has been regarded as an important strategy in dealing with calamities (Pargament et al., 2000), maintaining self-acceptance (Yuniarti et al., 2013), to facilitate beneficial resolution against psychological impacts of negative life events (Samuel-Hodge et al., 2000; Seybold & Hill, 2001) or to enhance self-empowerment in managing ill-health condition (Ano & Vasconcelles, 2005; de Ridder et al., 2005; Jones et al., 2006; Cattich & Knudson-Martin, 2009). Furthermore, Baldacchino and Draper (2010) argue that due to the more general and universal meaning of spirituality; spiritual coping can be referred to utilizing any spiritual

aspect in life, such as belief in a divine being, performing ritual acts to maintain harmony with others, as a leverage to enhance self-empowerment.

Social support

Many studies have shown significant positive connections between religious involvement and social support (Cohen & Wills, 1985; Koenig, 2002; Koenig & Cohen, 2002; Bhuyan, 2004; Newlin et al., 2008). Studies have shown that the African American community is regarded as more religious than their white counterparts due to their strong relationship with the church (Polzer, 2007; Newlin et al., 2008; Casarez et al., 2010). This is particularly apparent among older people. Another study found lack of social participation to be a risk factor for death after cardiac surgery in elderly people (Oxman et al., 1995). A systematic review conducted by the Centre for Disease Control and Prevention (2001), which resonates with other studies (Frank & Grubbs, 2008; Austin & Claiborne, 2011), has found that involvement in community gathering places such as faith organizations are good to hold health interventions and self-management education programmes among adults with type 2 diabetes.

Evidence showed that support from a pastor or other members of the church have been significant in managing someone's ill-health condition (Samuel-Hodge et al., 2000; Popoola, 2005; Carbone et al., 2007; Abdoli et al., 2008; Newlin et al., 2008b), or in confirming that self-care is in line with the will of Allah and fatalism is a misinterpretation of Qur'anic teachings (Grace et al., 2008). Furthermore, seeking support from others such as family member or doctors is regarded important since they argued that the belief in God is considered incomprehensible; God is invisible (Abdoli, 2008). Closest relatives have been regarded as sources of social support – especially daughters (Abdoli et al., 2008), since daughters were regarded as more reliable in providing support (Samuel-Hodge et al., 2000).

Religious practices

Prayer, as part of religious practice, such as reading scriptures, singing Christian songs and giving testimonies, has been regarded as an important part of illness management. While, among Muslim people, spirituality interventions mainly comprise prayer, Qur'an recitation,

remembrance of Allah, fasting, charity, prophet's methods and modified Islamic methods, particularly among individuals within a critical care setting (Mardiyono et al., 2011).

Studies revealed the relationship between religious practices and ill-health conditions, range from promoting healthy behaviour (Mardiyono et al., 2011), as a coping mechanism, since the patients will turn to God when the condition has become worse to give strength and comfort (Samuel-Hodge et al., 2000; Carbone et al., 2007), or as complementary to the medical therapy (Aikins, 2005), to a significant correlation in decreasing mortality, by frequent attendance to religious service (Strawbridge et al., 1997; McCullough et al., 2000). Despite the beneficial effects of religious practices in maintaining well-being, for some people fasting or pilgrimage (*hajj*) have been considered as hindrance (Ahmed, 2003). They argued that rituals have placed them in difficulties in regards to adhering to medication regimes. This is an issue which the researcher wants to focus on with his participants.

Summary

Self-care is considered as a concept which is '*led, owned and done by the community*' (DoH UK, 2006) which entails actions that are embedded into the daily life of people with chronic conditions. It is a complex concept which involves a wide range of behaviours in maintaining well-being, consisting of health promotion and disease prevention; treatment; and, monitoring and rehabilitation (Levin et al., 1977; DoH UK, 2006). Thus, it is proposed that self-care is placed on a continuum, between full self-caring activities such as brushing teeth, to fully dependent on the health care professional, for example brain surgery (DoH UK, 2005).

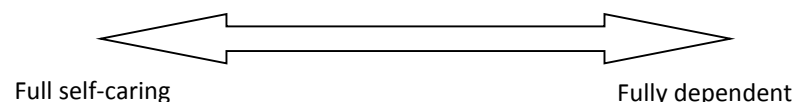


Figure 3. 1 Self-care continuum

The practice of self-care within Indonesia has not been widespread, although guidelines are in place. With regard to self-care in diabetes management there are three key components of health promotion and disease prevention; treatment; monitoring and rehabilitation, and embedded

concepts such as locus of control, self-efficacy, self-regulation and self-appraisal. These components and concepts play a major role in maintaining and establishing self-care behaviours among people with chronic conditions. The importance of religion and self-care practices is considered in the following chapter.

A systematic review is understood to be beneficial in gaining a comprehensive understanding of current evidence in regards of how religiosity might influence people with type 2 diabetes in managing their daily self-care activity. A PRISMA statement was utilized to gain a more structured review of the process.

Chapter Four

Methodology

Introduction

The previous chapters discussed the contemporary relevance of religiosity and self-care among Indonesian Muslims with type 2 diabetes. This chapter focuses on how the researcher conducted the study. It begins with a discussion of the philosophical paradigm that underlies the research, highlighting the researcher's epistemological and ontological positions and the paradigm shift that took place throughout the course of the research process. The chapter focuses on the methodology underpinning the research and the methods used to collect and analyse data. The issues surrounding translation of interview transcripts are also discussed. The chapter concludes with a discussion of reflexivity, or how the researcher sees himself in the process of data collection in order to be transparent and to ensure the quality of the research (Gray, 2014).

Philosophical Paradigm

This first section will explore the ontological and epistemological perspectives that underpin the research. It is necessary to consider such philosophical positions since it will help the researcher to answer the question of '*why (and how) conduct research?*' (Remenyi et al., 1998); to develop understanding of the nature of reality; and to guide understanding of how that '*reality*' becomes knowable (Saunders et al., 2009). Or, to put it another way, '*whatever methods or procedures give us knowledge of what there is must depend, in part, upon what there is to be known about*' (Hughes & Sharrock, 1997). However, it is not the researcher's intention to conduct a theoretical exploration of philosophical paradigms, rather, as an effort to reflect upon the epistemology of choice and to be able to defend it among the alternatives (Saunders et al., 2009).

It has been suggested that how human beings understand the nature of reality can be placed on a continuum between two poles of objectivity and subjectivity (Holden & Lynch, 2004), or positivism and interpretivism (Hughes & Sharrock, 1997). Thus, in the effort of how to gain knowledge and understand the phenomenon under study, objectivists are inclined to follow a

systematic and measurable method (Creswell, 2014), whereas subjectivists tend to explore the subjective meanings of experiences.

Objectivism

At one end of the philosophical spectrum is objectivism which believes that reality and meaning exist apart from our consciousness and the researcher tries to discover and observe it (Crotty, 1998; Avramidis & Smith, 1999; Holden & Lynch, 2004). Thus, objectivists believe that empirical evidence is essential in order to gain knowledge of the phenomenon under study, reducing it into fixed, tangible and permanent matter (Hughes & Sharrock, 1997). In regard to human science, however, this view poses a dilemma and has triggered debate among social scientists in '*overcoming the distinction between "things material and things human"*' (Hughes & Sharrock, 1997, p. 29). To put into perspective, subjectivists challenge how an understanding of beliefs, emotion, morality, and the like can be gained the same way as understanding of the sun, the anatomy of the body, or plants, and so on so forth, which is a very different issue.

Subjectivism/Interpretivism

In subjectivism/interpretivism, temporal, cultural and social factors are involved in generating knowledge, and, as Temple (2006) argues, there is no single objective reality, rather different perspectives that create different meanings and understandings. To put the matter into the context of this research, Javanese culture has its own perceptions of hardship, fate and the world as a whole and these are congruent with Islamic values.

Based on the belief that there is no single reality waiting to be discovered but instead reality is socially constructed, the researcher in this paradigm endeavours to discover individuals' perspectives of phenomena and the context in which these occur. As Saunders et al. (2009) argue, each human being is a '*social actor*' (p.116) and social actors are influenced by context, temporality and culture. This notion is relevant to this research in relation to social ties and norms in Javanese culture: Javanese people regard keeping harmony with others as an ultimate philosophy of life (Koentjaraningrat, 1985). Therefore, considering the complexity of human beings, interpretivists believe that in order to gain knowledge and understand about phenomena,

a subjective approach is appropriate. Within the interpretivist paradigm, a qualitative methodology is often used.

Methodology: The Value of Mixed Methods

A mixed methods approach uses a combination of qualitative and quantitative approaches and data (Creswell, 2014). Mixed research methods in this study are used to complement each other, to *'maximize the ability to bring different strengths together in the same research project'* (Morgan, 1998, p.362). Mixed method approaches highlight differences and similarities, triangulate data and allow for the development of theory (Morgan, 1998; Sandelowski, 2000; Creswell, 2014). Furthermore, Creswell (2014) argued there are three primary models of employing the methods, those are: converging or merging quantitative and qualitative data in order to provide a comprehensive analysis; using qualitative approach to explain in more detail the results from previously conducted quantitative research; and, the reverse of the second method, which employs a quantitative approach based on a qualitative approach to build an instrument. The approach to this study is discussed in the following section.

The potential benefits of using a mixed methods approach are as follows: first, the integration of these two approaches could add more credibility to a study, a qualitative approach provides more explanation to a quantitative study by adding depth and insight to 'numbers' through the inclusion of narrative, dialogues; while a quantitative approach adds precision to 'words' through inclusion of numbers and pictures (O'Leary, 2010). Second, a mixed methodology can help the researcher in providing better opportunities to answer the research questions, as well as to gain more trustworthiness and generalizability (Saunders et al., 2009).

Shifting the Paradigm: a Journey to a New Philosophical Stance

This section will discuss the endeavours that the researcher has made in conducting the study. This involves a personal account as well as an academic journey to a new way of thinking. A more detailed account of reflexivity is included at the end of the chapter.

In engaging with the research, the researcher found himself encountering a new perspective of research in term of ontological and epistemological positions. Before commencing the study, the researcher regarded himself as a novice lecturer and researcher with minimal research

experience in both objective and subjective terms. As a lecturer, the researcher used to engage in supervising undergraduate students' work and with his quasi-experimental research experience for his master degree; such experience shaped his inclination to research in an 'objective' manner. When the researcher started the study, he still had his own perspective as a Muslim lecturer with a more objective background of research with his own perception of reality. The opportunity to seek further study abroad placed him in the advantageous position of being detached from his origins and also able to engage with other ways of thinking. And as time passed, with the support of his new western environment, the researcher began to build a new understanding of how to approach the study. In other words, being native to Indonesia but accustomed with Western culture and practice gives the researcher a multi-dimensional perspective to examine the issues of how religiosity and/or spirituality, with the interwoven Javanese culture, influence Indonesian Muslims in managing their daily self-care activity. Additionally, throughout the research process the researcher's epistemological position shifted along the continuum from a traditional positivist stance to an interpretivist one.

Research Methods

This study used a mixed method research design, combining qualitative and quantitative methods, as to '*maximize the ability to bring different strengths together in the same research project*' (Morgan, 1998, p.362). The Muslim Piety (Hassan, 2007) and the Summary of Diabetes Self-Care Activity (Toobert et al., 2000) questionnaires were used as tools to gain an initial understanding of the diverse and rich sample with respect to levels of religiosity and self-care (Patton, 1990). Therefore, according to Creswell (2014), the study will deploy an explanatory sequential methods approach. It is argued that the uses of a qualitative method will enhance the understanding of how individual perceptions can be gained rather than using a quantitative measure alone (Rogers, 2010); helping in exploring the meaning of constructs and the interrelationships between them (Creswell, 1998). Furthermore, the underpinning aim of the research was to gain an understanding of the experiences and perceptions of people with type 2 diabetes; how they perceive religiosity, within the context of Javanese culture, and apply it to manage their condition in daily life. For this reason exploring patients' experiences as they were 'lived', using semi-structured in-depth interviews is consistent with the study objectives.

Population and Sample

The population of the study was Muslim adults with type 2 diabetes from both the *Rumah Sakit⁴ Pembina Kesehatan Umat Muhammadiyah* (RS PKUM) and the caretaker of the health of community hospital Muhammadiyah, in Yogyakarta, Indonesia. The hospital is a private hospital owned by Muhammadiyah, the second largest Islamic organization in Indonesia, with a majority of Muslim patients. To establish the study context, further discussion of RS PKUM is now provided.

RS PKUM

RS PKUM, as the official website address is, or PKU as people in Yogyakarta know it (and as it will be used throughout this work), is located in the heart of the city of Yogyakarta, the capital city of Daerah Istimewa Yogyakarta (DIY) or the Special Region of Yogyakarta. It was originally built as a small clinic in the village of Jagang, Notoprajan, Yogyakarta in 15th of February 1923 by H M Sudjak, with the full support from KH Ahmad Dahlan, the founder of Muhammadiyah ("RS PKU Jogjakarta," 2014). Initially, it was established by the name of Penolong Kesengsaraan Oemoem (PKO) or the saviour of public misery, to deliver a health care service for the poor or *dluafa'* in Islamic terms. Although it bears the name of Muhammadiyah, it is not necessarily limited the service only to the community of this social organization.

PKU has been established as a B class hospital, with A considered to be the top level, involving such speciality as Internal Medicine, Paediatrics, Obstetrics, Gynaecology, Surgery and sub-speciality health care services such as a Haemodialysis clinic, Trauma Centre and Orthopaedic clinic ("RS PKU Jogjakarta," 2014). PKU has also been serving as an education hospital for students of the Faculty of Medicine and Health Sciences, Universitas Muhammadiyah Yogyakarta, the place where the researcher has been working.

Population

The population of the study was type 2 diabetic patients from the out-patients of the Internal Medicine clinic. According to the 2010 database there were 610 cases of diabetes, which were

⁴*Rumah sakit* is Indonesian term for hospital.

not classified into types. The sample was selected using the following inclusion criteria: Muslim, over 18 years old, male and female, diagnosed with type 2 diabetes for over 12 months, under the care of a consultant and being treated according to the Indonesian Endocrinologist guideline or Perkeni (2011). Patients would be excluded if they were diagnosed and were being treated for a mental health problem, this was to ensure that they were competent to provide consent to be involved in the study.

Sample

The sample for the questionnaire was gained through direct approaches in the waiting room's clinic. During a three month data collection period it was hoped that a minimum of 100 respondents could be recruited to gain a wider perspective of the self-care activity of the people accessing the clinic. All participants who completed the questionnaires, were given the opportunity to take part in an interview, by indicating their contact details on a reply slip attached to the questionnaires, to be contacted by the researcher at a later date. Prior to each interview participants were contacted and their consent to be involved was confirmed before an interview was scheduled. Written consent was obtained from each participant before each interview commenced. Interviews took place in the preferred location of the participant, which was mainly their own home, except for one participant who chose a waiting room of a hospital where she had been taking care of her husband, and another who preferred her office.

Following the deployment of the questionnaires, the semi-structured interviews were conducted. The sample collection technique for this next phase was known as a quota sampling technique (Saunders et al., 2009), which refers to non-random sampling and a procedure to systematically divide participants based on specific characteristics that are relevant to the research question. According to this technique, participants were to be divided into four categories based on the different level of religiosity and self-care, which are each divided into high levels and low levels. Furthermore, each category would have the same amount of participants based on gender and age groups. Hence, it was expected that each category would have six participants with different genders from three age groups, recruiting a total of 24 participants for interview.

Research Assistant

One research assistant, a medical school student, was recruited to help the researcher in finding prospective participants as well as helping with potential language barriers during the interviews. Since most of the participants were Javanese, with some are speaking the Javanese language, and considering the researcher's own ethnicity is Sundanese, a different part of Java with different language, the researcher needed the assistant to translate several terms of phrase that he found difficult to comprehend. However, due to being a student, the assistant was only able to help the researcher in her available time between studies.

The research assistant was also important in assisting the interview in regard to conducting interviews with the female participants. An issue that will be explored in the Ethical section of this chapter.

Data collection

Special consideration has been taken with regard to sampling and collecting the data for the study, given the fact that Indonesian people are not been familiar with the practice of filling in questionnaires without assistance or returning completed questionnaires by post. Within Javanese culture people prefer to have personal face-to-face communication as it is considered a more respectful way of communicating. Thus, direct approach is considered to be a more appropriate way to access respondents.

The researcher and the research assistant are going to wait in the waiting room, and based from the information from the nurse in charge will approach the prospective participants whilst they are waiting to be seen by the physician or waiting for the medicine in the pharmacy. Verbal consent will be gained before the participants participated in completing the questionnaires. A translated patient information sheet (Appendix 4) explaining the whole study (with the researchers contact details), along with the two questionnaires (Appendix 9 and 10) will be distributed by the researcher or the assistant within the waiting room at the out-patient clinic. Before completing the questionnaires, participants are going to be given time to read the information sheet or if they preferred, to listen to the explanation made by the researcher or the research assistant. Then, the participants will be given ample time to consider their participation

and to withdraw from the study. Participants would have the option to take the questionnaires home and complete them and return them to the clinic at a later date if they required more time to decide whether to be involved, or they could complete them in the clinic on the same day.

Another consideration for this approach is the time frame for data collection. The researcher was funded to conduct the study by a scholarship that required him to complete within a three year time frame. Therefore, any decisions regarding the duration of data collection were significant. It was agreed by the researcher and the supervisor to conduct data collection process in a three month period.

Data Analysis

The screening questionnaires provided quantitative data, which served two main objectives. Firstly, these tools of self-care and religiosity were used to identify the overall levels within the sample group for the interviews, enabling identification of various level of self-care activity and religiosity. The SDSCA and the Muslim Piety questionnaires results were used to inform the classification of participants into four groups based from different levels of religiosity and self-care; highly religious and self-care, highly religious and less self-care, less religious and high self-care, and less religious and self-care. However, to gain an accurate and varied representation of participants, discussed further in the findings chapter, the classification was amended into three levels of high, moderate and low. Furthermore, along with the progress of data collection and preliminary analysis of the participants' characteristics, purposive sampling technique was considered more appropriate in answering the research questions, to gain wider and richer participants in the study.

Secondly, the results from the tools also served as additional data that informed and support the categories and themes that emerged from the semi-structured interviews. Indeed, the end result from data analysis will be generated from the triangulation of quantitative data into the qualitative data, which will enrich the qualitative data and put the findings into a more social context.

The interview questions were qualitative in nature, exploring the lived experience of managing diabetes for Muslim patients through the patient's own stories. The interview transcripts were

analysed using a thematic and content analytical method (Graneheim & Lundman, 2004). Following reading and re-reading the transcripts to explore the meaning of the texts, there were several steps taken in adopting this approach.

1. Determining the meaning unit. A meaning unit is a collection of words or sentences that relate to each other through their content and context (Graneheim and Lundman, 2004). Meaning units are extracted from the *manifest* (visible and obvious components of the text) and *latent* content (relationships that required interpretation of the underlying meaning of the text), which were extracted and coded, using phrases, words and statements that related to a particular concept surrounding self-care and/or religiosity. The utilization of latent content was considered important particularly in Javanese culture since it tends to avoid expressing different opinions and keeping true feeling to oneself (Magnis-Suseno, 2013).
2. The next step involved the process of reducing, or condensing the meaning unit into smaller chunks of text. This included the process of shortening the meaning unit without diminishing the meaning (Miles et al., 2014) .
3. The third step was the process of abstraction. This step included the process of generating codes, categories and themes.

Determining the codes was considered important since this *'allows the data to be thought about in new and different ways'* (Graneheim & Lundman, 2004 p. 107), which then, provided the way to the next step of classification of the codes with similar meaning into a higher level of classification. Thus, as Saldana (2009) points out, codes *'represent and capture a datum's primary content and essence'* (p.3). The example of generating codes can be found in the Appendix 16.

Another step of abstraction, which was regarded as a core feature of qualitative analysis, is categorization (Graneheim & Lundman, 2004). This step involved a process of organizing and grouping similar coded data into a category based on similar characteristics they shared (Saldana, 2009). Thus, as Krippendorff in Saldana (2009) explained, the codes represent the question 'what', which can be identified as a continuous line between the codes. However, the process of coding and categorizing were not considered to be a straightforward process. Recoding and re-

categorizing are inevitable throughout the analysis process, and categories can be divided or generated through several sub-categories at various level of abstraction.

The next step of abstraction was the development of themes. Themes connect underlying meaning among categories (Graneheim & Lundman, 2004) and answer the question 'how' (Graneheim & Lundman, 2004). Themes represent the underlying meaning of categories on an interpretative level, and again, themes can be divided into sub-themes.

The typologies proposed by Polzer and Miles (2007) were used to inform the interviews and were used to compare what participants considered their relationship with Allah to be. Polzer and Miles (2007) proposed three typologies: (1) God is Background; (2) God is Forefront (3) God is Healer. The first typology indicates that people are the main actors and accept responsibility for self-management, with God in a supportive role, in the background. The second typology suggests that God is in the forefront and has a major role in managing a condition and people are submissive to God, although they self-manage their diabetes. Similar to the first typology, people believe that God helps them self-manage by giving knowledge, financial support, and improving their health status. However God is seen as a more authoritative figure compared to the first typology. The third typology - God the healer - highlights that with a certain level of faith, self-management is not necessary since God will heal a disease in God's time. These typologies were considered to be an appropriate conceptual framework for this study of the role of God or Allah in influencing the self-management of diabetes conditions and to develop related theory.

Screening Tools

There were two validated questionnaires that were used as screening tools in collecting the sample for the semi-structured interviews. Based on these tools, participants were categorized into three groups with various genders and age group, as mentioned earlier.

The Muslim Piety questionnaire

The Muslim Piety questionnaire (Hassan, 2007) (appendix 10) has been developed for this research and is based on the work of Glock and Stark (1965). It has five dimensions of religiosity: religious beliefs, a ritualistic dimension, a devotional dimension, an experiential dimension, and

a consequential dimension. Each dimension has been explored further in Chapter Two. This questionnaire has been used to explore the religiosity of over 6300 Muslim participants in seven countries including Indonesia, and has been translated into Bahasa Indonesia (Hassan, 2007). For the purpose of this study, the researcher used this version, as it was recommended by the original author.

The optional answers for this tool are not based on a Likert scale; instead, there are a series of responses which respondents can select, apart from questions 6 and 19, which offered a yes/no response. An example is indicated below.

How strongly do you believe in God?

- a. I know Allah really exists and I have no doubts about it
- b. While I have doubts, I feel I do believe in Allah
- c. I find myself believing in Allah some of the time but not at other times
- d. I don't believe in a personal Allah, but do believe in a higher power of some kind
- e. Other

Each question required respondents to indicate only one response. There were 19 questions in total with several alternative answers, and the scoring was done using a score of 0 for an incorrect answer or 1 for the correct one, except for the question number 6 which is not included into the calculations since it needs the exact number to answer ('within a week, how many days do you go to Masjid?'). Whether an answer was deemed correct or not is based on from the prescriptive teachings and values from the scripture, Qur'an, and the teachings from the Prophet, Sunna. Therefore, the score ranged from 0 to 18, and a low level is determined if the score is between 0 and 9, a high level meant a score of 10 to 18.

Summary of Diabetes Self-Care Activity

The adapted version of the Summary of Diabetes Self-Care Activity – SDSCA (Toobert et al., 2000) (appendix 9) consists of 15 items focusing on five main topics such as: diet; exercise; self-monitoring of blood glucose (SMBG); foot care; medication, and an additional item of smoking. There are also 6 supplementary questions which focus on participants' perceptions of the

inclination of health care professionals to convey educational messages related to each item of self-care, except for the foot care item.

The scoring system is based on how many days in a week a participant performs particular activities, ranging from 0 to 7 days in a week: thus score 0 refers to 'never' and 7 refers to 'daily'. The minimum score was 7 and the maximum was 98. The minimum of 7 was gained due to the reversed scoring system for the item number 4, 'On how many of the last SEVEN DAYS did you eat high-fat foods, such as red meat or full-fat dairy products?' For this item the participants would gain a higher score the less they performed this particular activity. Thus, a score of 7 was refers to never and 0 to daily. Within the original study by Toobert et al., (2001) the score gave an indication of the amount of diabetes self-care activity being undertaken, so the higher the score the more an individual performed self-care activities. In general, this tool is considered to have a good reliability with the Cronbach' alpha was 0.74 (Lager, 2006) and high inter-item correlation, with moderate test-retest correlations (Toobert et al., 2000). Similar to the Muslim Piety questionnaire, the Summary of Diabetes Self-Care Activity tool was also used as a screening tool to identify respondents' level of self-care. By combining these two questionnaires variations and different combinations of religiosity and self-care levels could be targeted for in-depth interviews.

Translation Process of the SDSCA

It was important that the tool was translated to Bahasa Indonesia to provide all patients who do not speak or read in English the opportunity to participate in the research. The translation process followed the modified Brislin's model of translation (Jones et al., 2001), a comprehensive step-by-step framework for establishing functional and cultural equivalence of an instrument. It is a well-known method of preparing valid and reliable instruments for cross-cultural research (Jones et al., 2001). This was involved forward and back translation of the instrument by different translators to achieve a consensus of items.

The first phase of translation into Bahasa Indonesia was done by the researcher and a colleague student from a different school in the same university. The colleague is a medical doctor in Indonesia who was studying for a PhD in Biochemistry in the University of Salford. After looking

for similarities and differences, it was revealed that there were no any significant findings. Therefore, the second phase was carried out. The second phase, i.e. the back-translation phase, was proceeded with the support of *Pusat Pengembangan Bahasa* or Language Development Center in Universitas Muhammadiyah Yogyakarta. The final draft of the questionnaire was ready to deploy after discussing the results with the particular centre. Although the questionnaire focuses on diabetes and religiosity, there are no specific medical or religion-specific terms that would be alien to lay people. Therefore, there were no major differences found in term of the content of the translation's results. Furthermore, the researcher managed to send the final English version to the original author, Deborah J Toobert, PhD, as well, to get her comments.

Semi-structured Interviews

In-depth interviews were used to explore patients' lived experiences of how they perceive religiosity and apply it to self-managing their condition in daily life. A semi-structured interview enabled the concepts of religiosity and self-management to be compared and contrasted across individual experiences. The interview guide (appendix 11) did not restrict participants, allowing them freedom to direct the conversation to issues which were important to them in their lives. The interview explored participants' knowledge of diabetes, self-management activities, religiosity, beliefs and practice (using the completed screening tools to prompt exploratory questions). The researcher explored the relationship between God and self-management activity drawing on the theoretical concepts of (Polzer & Miles, 2007). New concepts that arose within interviews were discussed and tested in subsequent interviews to explore consensus and diversity of experience.

Interviews were conducted in Bahasa Indonesian language spoken by the researcher and lasted no more than two hours. They were digitally recorded and transcribed verbatim. Any pauses that emerged within one particular question are represented as a sequence of commas in the text. As mentioned earlier, the research assistant did not need to engage in significant amounts of translation since most participants were able to use the Bahasa Indonesia language. Field notes recorded participants' gestures, facial expressions, reactions and comments.

The interviews were translated by the researcher into English and the translation process is taking into account all contextual meanings based on Indonesian and Javanese culture. This was evident, for example in the case of Mr Fajar, when he mentioned '*dia jual aku beli*' or you sell it, I buy it, in a situation where he was involved in an argument with his friends. This term refers to an Indonesian's term for an attitude of never begin (a fight) but always be ready when it is required. Thus, it is to some extent has similarity with the English expression 'when the going gets tough, the tough get going', in respect of never surrendering to the challenge at hand.

Ethical Issues

Ethical approval was obtained from the University of Salford Research Ethics Committee as well as from the Internal Review Board of RS PKU Jogja Hospital. Permission was also gained from the head of department of the diabetes clinic. Two key ethical issues needed to be considered with respect to this particular study were sample recruitment and the male researcher interviewing female participants. The issue regarding confidentiality of the physicians and participants, which has already been mentioned, was solved with the utilization of pseudonym. Another issue that needs to be put of more concern is regarding the power-relationship between the researcher, who also a medical practitioner, and the participants, who also patients in this particular location setting.

Male researcher/ female participant

The ethical issue of interviewing a female participant by a male researcher needs to be considered carefully. Islam has taught its followers to maintain respectful relationships between genders, restricting private meetings between lone males and lone females who are not legally related (*muhrim*). Because of this, all female participants were asked whether they preferred to be accompanied by a spouse or a relative who could act as a chaperone.

Power-relationship between the researcher and participants

The notion that a power-relationship between the researcher and participants may influence the recruitment and involvement of participants needs to be considered. Seeing the researcher as a doctor in a society where respect for the medical profession authority has the potential to impose a level of coercion to the recruitment process or the inclination to join the study due to an

awareness of the difference in position between the researcher and participants. The researcher at all times wanted to be transparent, to generate a level of trust with participants, by being explicit regarding being a medical practitioner secondary in this instance to being a researcher. It was considered that a level of trust was important to promote the personal willingness to join the research, leading to better outcome of the data collection process, in regards to answering the questionnaire, especially in responding to the interviews.

Therefore, prior to commencing the recruitment process, it was explained to participants that their involvement was voluntary and should they wish to withdraw from the study at any time, it would not affect their statutory rights as patients. Many patients chose to withdraw or not participate having read the information sheet which indicated they did not feel coerced or influenced to take part because the researcher was a medical practitioner.

Insider or Outsider: a Reflexive Account

How well participants engage with the researcher might be influenced by how they perceive their social position or identities (Lumsden, 2009) and those of the researcher. While, it is argued that individuals possess multiple, intersecting and inseparable identities that shape their lived experiences (Brah & Phoenix, 2004); being aware of the complexity of how these identities could affect data collection and analysis is important, (Couture et al., 2012), but difficult to 'measure'. An insight into how the researcher saw him or herself in the study, especially in maintaining the relationship with participants, enhances the quality of the research (Fontana & Frey, 2000; Gray, 2014), as well as in increasing its trustworthiness, transparency and accountability (Finlay, 2002).

Being an insider is considered to be beneficial in gaining access to information as participants can be more open and the researcher could gain an enhanced understanding of participants experiences (Dwyer & Buckle, 2009), especially if sensitive issues are involved (Couture et al., 2012). Therefore, being a Muslim and a Yogyakarta resident to some degree offered the researcher an insider position in relation to participants, which could encourage more openness, or, it could operate in the opposite way. Having similar characteristics, roles and experiences of participants, however, could also mean that they assume the researcher 'already knows' about the topic, therefore, they disclose less information (Dwyer & Buckle, 2009).

On the other hand, being a medical professional and academic simultaneously positioned the researcher as an outsider, which to some extent, gives a sense of authority in relation to participants (Kim et al., 2001). From the beginning of the research, the researcher was known as a doctor and a lecturer who had been undertaking further. Therefore, to some extent, it gave an advantage in regard to the recruitment process since most Javanese people tend to give respect to people regarded as highly ranking in the social hierarchical (Koentjaraningrat, 1985). Nevertheless, a sense of authority has also posed a social distance that might hinder participants' sharing information or cause them to moderate their responses. Indeed, the researcher understood that behaviour was also influenced by the cultural background of Javanese people which means they tend to be less open, yet also be comply with authority (Koentjaraningrat, 1985; Kim et al., 2001;).

Further considerations involved the multidimensional nature of the researcher; who was male, relatively young (since most participants were middle age and elderly group), a medical doctor, a lecturer, and a Muslim. Although, the researcher did not introduce himself as a Muslim, the participants would be aware of this by the Islamic greetings used at the beginning of each interview. Hence, these multiple identities could all have shaped interaction with respondents and could have meant simultaneous insiderness and outsidership based on such characteristics. That said, insider/outsider status is not fixed, instead represents a constant changing and negotiating process depending on who is being interviewed. Therefore, being reflexive and critical is considered essential in negotiating and going beyond insider/outsider status (Hamdan, 2009).

Additionally, the researcher started to see a new perspective in looking at himself while he was engaging with the data. These are in line with the second and first walls of Gossamer's walls (Doucet, 2008), which relate to how the researcher sees the relationship with themselves, and participants. Focusing on the relationship with participants, the second wall, allows the researcher to be in a dynamic interchangeable position of insider or outsider. The first wall allowed the researcher to consider a new perspective, during the interviews and data analysis, the researcher was aware of the dynamics and interchangeable positions of him and the participants. At times, the researcher felt that he was in a position as a lay person, and felt

sympathy with participants' condition. It was useful to understand participants' experiences, but the researcher was also aware that he was 'detached' too and was outside the data. On reflection, it is unfortunate for the researcher that the consideration of reflexivity only came after the data collection process. However, as a novice researcher in qualitative study this new knowledge was part of the journey. Being reflexive was useful for analysing the findings as is discussed later.

Summary

This chapter established the epistemological and methodological principles underlying the study, beginning with a discussion of the philosophical paradigm and how the researcher previously considered himself to be located in the more objectivistic position, given his previous experiences. Considering the nature of this current study allowed the researcher to shift his perspective towards a more interpretivist approach and this influenced the adoption of a mixed method approach (Creswell, 2014). The chapter also outlined how the research was conducted and the logistics and rationale involved in data analysis. The chapter concluded with a discussion of reflexivity, or how the researcher saw himself in relation to research participants in order to be transparent. However, the concepts of insider and outsider were not regarded to be straightforward, instead are a dynamic and interactive process in generating knowledge, as it will be seen in the next chapters of findings and discussion.

Chapter Five

Self-care in diabetes management among Javanese people

Introduction

Several studies identify the series of self-care activities in diabetes management consisting of conducting dietary regulation, keeping physically active, adhere to the medication, performing foot care, and self-monitoring blood glucose (Toobert et al., 2000; Toljamo & Hentinen, 2001). Guidelines from both the International Diabetes Federation (IDF, 2012), and the Indonesian Endocrinologist Association (Perkeni, 2011) emphasize the importance of self-care activities to prevent the risk of complications for people with diabetes, as well as enhance quality of life. Indeed, maintaining a healthy lifestyle and establishing a normal body weight may prevent the development of diabetes as well as potential complications (DoH, 2006; WHO, 2012). Unlike established international diabetes management programs (UK or US), within Indonesia the management of diabetes is not considered a comprehensive and integrated program, with only partial recommendations into separate self-care activity for optimum diabetes care being introduced due to cost and health care structure (Sinorita et al., 2004; Soewondo et al., 2010; Soewondo, 2011). The study explored the self-care activity of people with diabetes in Indonesia and to examine whether self-care was fundamental to their diabetes management. Moreover, it sought a deeper understanding of how and if internal factors such as; self-efficacy, self-appraisal (Bandura, 1986; Heisler et al., 2003), locus of control (Wallston, 2007; Andrews et al., 2011), and external factors such as Islam religion, Javanese culture, community or social support (Koenig, 2002; Hjelm et al., 2003; Bai et al., 2009) influence the practice of self-care among Indonesian people with diabetes.

This chapter presents the overall response rate and study sample for both the quantitative questionnaire and qualitative interviews. The purpose of the Summary of Diabetes Self-care Activity (SDSCA) questionnaire and the Muslim Piety questionnaire was to explore the level of self-care activity amongst people managing diabetes attending a local hospital out-patient clinic, and compare with their level of religious devotion and practice. The idea of the two

questionnaires was not to recruit a representative sample for a reliable and valid result, but to gain a sufficient sample to establish some understanding of the activity of the wider diabetes clinic population with respect to self-care and religion. The wider questionnaire data informed the 'real life' interviews with people managing diabetes to gain a richer understanding of the opportunities and barriers for self-care management within a strong religious and Javanese culture. Whilst religion is touched on in this chapter the results of the Muslim Piety questionnaire, religious practice, devotion and self-care are the focus of Chapter Six.

Seven core themes emerged from the data that exposed the opportunities and barriers to self-care within this community and culture in Indonesia. Analysis investigates whether gender, age, education level and occupation influences self-care activity.

- Levels of self-care
- Self-care activities
- Education and knowledge
- Locus of control
- Javanese way – sensitivity and surrender
- Access to health care
- Health policy

First the response rate and sample characteristics will be examined.

Questionnaire Response rates and sample characteristics

The response rate to the questionnaire was good; 100 people were recruited from a target population of 610 (16.4%) using a direct approach method within the diabetes clinic. Approaching people within a busy clinic environment had its drawbacks, resulting in missed opportunities to recruit some people because of the level of activity, and reduced privacy due to the number of people in the clinic waiting room. During a three month data collection period 200 approaches were made to people attending the clinic, with 105 prospective respondents identified. One person was newly diagnosed and therefore excluded and four did not return their questionnaires, resulting in a convenience sample of 100 people.

Of the 100 people recruited, 57 were women indicating an overall slightly higher percentage of females recruited than present in the target population registered on the hospital clinic database in 2010 (51%) (Table 5.1).

Table 5. 1 Demographic characteristics of questionnaire sample

<i>Gender (n=number of people)</i>		<i>Age - n= (%)</i>		
		18 – 39	40 - 59	≥ 60
Male	43	1 (2.3)	26 (60.5)	16(37.2)
Female	57	2 (3.5)	29 (50.90)	26 (45.6)
Total Number	100	3	55	42
<i>Occupation (n=)</i>			<i>Education (n=)</i>	
Private employee	17		No formal education	5
Pensioner	17		Elementary (primary school)	17
Self-employed	12		<u>Lower education level</u>	22
Government officer	6			
Professional	5		Junior high (secondary)	5
<u>Regular income</u>	57		Senior high (College)	33
Housewife	33		<u>Medium education level</u>	38
Labourer	4			
Farmer	2		Academy/University Degree	36
Housemaid	2		Master/ PhD – higher degree	4
Unemployed	2		<u>Higher education level</u>	40
<u>Non-regular income</u>	43			

Predominantly people attending the clinic that were recruited were aged over 40 years (97%) with only 3% of the sample being aged between 18-39 years. When compared to the target population, the total people attending the clinic aged between 15-44 years was 12.31% compared with 7% of the recruited sample (aged 18-44 years), reflecting a low number of younger adults in both the target and study sample.

The questionnaire participants came from a variety of occupations; the majority of which identified themselves as housewives (33); others were employed in private companies (17), pensioners (17), and self-employed (12). Just less than one third (21) participants described their occupation as other, which included government officers or civil servant (6), professional (5), labourer (4), farmer (2), maid (2) and unemployed (2). The occupations were categorized into two main groups (Table 5.1); the regular income (57) and non-regular income group (43). This categorisation signifies which people had a stable and consistent source of income, as most Indonesian utilize a fee-for-service system of healthcare where people need to pay to receive a primary care services, except for those covered by the government, such as the poor, pensioner, and civil servants. Furthermore, amid the new development of health care service in Indonesia into a more insurance-based system, which required the people who are not eligible to be covered by the government to pay a monthly premium, has given the need to have a sufficient income in order to be able to have a sustainable health care service. Thus, the notion of having a regular and sufficient income is important particularly among people with a long term condition, such as diabetes, to establish sustainable healthcare delivery.

Levels of education were categorized into six items: no-formal, elementary (primary school), junior high (secondary education), and senior high (College), Academy/University degree, and Master/PhD a higher degree. There were participants recruited across all education levels; low (22) medium (38) and high (40), with more individuals higher educated.

Interview response rate and sample characteristics

Questionnaire participants were asked to complete a reply slip to identify if they would be happy to be interviewed. From the reply slips, initially it was envisaged that interview participants would be identified from a pool of people falling into one of four groups based on the high or low level of self-care and high or low level of religiosity, drawing 5-6 people random from each grouping (Table 5.2).

Table 5. 2 Four categories of self-care and religiosity

Highly religious - high self-care	Low religiosity - high self-care
Highly religious - low self-care	Low religiosity - low self-care

However, in reality only 25 of the 100 people completing questionnaires agreed to be interviewed and one person was excluded because he was newly diagnosed. The majority of these people rated themselves as highly religious and high self-care so the quota sampling method was not applied resulting in all participants that came forward being interviewed (Table 5.3).

Furthermore, the categorization into two groups of high and low was proven to be unadvantageous in revealing the true nature of the level of self-care and religiosity among the participants. Therefore, as seen in Table 5.6, the categorization was adjusted into three level of high, moderate and low, which then, shows the majority of participants are in the moderate groups.

Table 5.3 Interview sample characteristics (N=24)

<i>Gender</i>		<i>Age groups</i>		<i>Education level</i>		<i>Income</i>	
Male	10	18 – 39	2	Higher	8	Regular	15
Female	14	40 – 59	14	Middle	10	Non-regular	9
		>60	8	Lower	6		

Within the interview sample there were 14 females and 10 male participants, who predominantly were over 40 years of age and of middle to higher education levels, although there was a spread of characteristics throughout the sample allowing different aspects such as low non-regular income, education level, age and gender to be explored within the data findings. To gain a deeper understanding of the context surrounding individual participants Table 5.4 provides a more detailed overview,

pseudonyms are used to maintain anonymity among the participants, as well as the physicians.

Table 5. 4 Contextual information about the interview participants

	Name	Age yrs	Occupation	Family Context
1.	Mr Adil	56	Business owner	University graduated; living with his wife and four children.
2.	Mr Arif	42	Business owner	University graduated; living with his wife and two children.
3.	Mrs Asti	77	Housewife	Graduated from senior high school; living with a maid in a large property; building a house inside the property for her daughter; children are university graduates; tends to be solitary from social activity.
4.	Mrs Eva	39	Admin officer	University graduated; works in private company, living with her husband who works in the same company, four children, nephew and mother in-law.
5.	Mr Fajar	39	Workshop Mechanic	Graduated from senior high school; living with his wife, no children, his brother who works as a cleaner, and parents-in-law.
6.	Mrs Heti	47	Admin officer	University graduated; works in private University, living with her husband and three children.
7.	Mrs Ismi	71	Retired teacher	Graduated from senior high school a college graduated in Islamic teaching; living with her daughter (a nurse in PKU) and her family, used to be a member of Persadia.
8.	Mr Jawen	64	Unemployed truck driver	Lives with his wife, who has been the breadwinner since he is ill, nephew and his older sister in urban area; acclaimed himself as a <i>Kejawen</i> * and no longer practising Islam.

9.	Mr Kasi	88	Retired	Senior high school graduated; Retired from the Police force as an auditor in the inspectorate division; Living in the city with his wife; children are university's graduates with good social and economic status.
10.	Mr Makmur	58	Business owner	Senior high school graduated; living with his wife and three children.
11.	Mrs Maryam	60	Business owner	University graduated; Living with her husband and a daughter age of 25 years old.
12.	Mr Ripan	48	Labourer	Graduated from elementary school; living with his wife who is running a food stall and his two children; has a higher level of religiosity and self-care.
13.	Mr Sadi	48	Civil servant	University graduated; living with wife and his 12 years old son.
14.	Mrs Santi	56	Business owner (ran from house)	Senior high school graduated; living with her husband and three children, two still in education, a member of Persadia; a breadwinner since her husband has a non-regular job
15.	Mrs Sati	60	Retired civil servant	University graduated; living with her husband, who works as a silversmith, and a daughter, a fifth semester university student.
16.	Mrs Sifa	62	Retired teacher	University graduated; living with her husband in a rural area of Yogyakarta
17.	Mrs Siti	50	Housewife	Graduated from primary school; used to work in the market, but giving up after the illness; living in the area of <i>Keraton</i> settlement in a small house with her husband and three children; husband works in an irregular job as a seasonal batik tulis (handmade) instructor, dependent on children for support

18.	Mr Sujawi	47	Foreman in textile factory	Graduated from senior high school; Living in a rural area of Jogjakarta with his wife and children; the wife is a <i>mu'alaf</i> (a convert) works with the police force; he used to be practicing <i>Kejawen</i> * and still holds the value and several teachings of it.
19.	Mrs Suti	46	Housewife	no formal education; used to work supporting her husband in cleaning cement sacks and selling it in the market; living in a small house in sub-urban of Yogyakarta with her husband and a son who is at university; has a daughter who married and lives in different city.
20.	Mr Suyono	63	Retired civil servant	University graduated; living with his wife and a 30 years old son who is running a small family's shop. He sometimes works as a mining consultant in a remote area.
21.	Mrs Swasti	45	PKU nutrition dept	Senior high school graduated. Living by herself.
22.	Mrs Tata	58	Housewife	Graduated from elementary school; living with her son and his wife and three children.
23.	Mrs Umi	57	Housewife	Junior high school graduated; living with her husband who a retired from an oil company, and three children.
24.	Mrs Wati	57	Housewife	Senior high school graduated; living with a husband, who is running a law firm, three children and two nephews, member of Persadia.

*Kejawen – means Javanese spiritualism

Findings

Self-care findings are presented within seven core themes and a number of sub-themes. The data of perceived levels of self-care and activities are explored for the whole sample and the interview participants. Throughout the themes qualitative data complements the quantitative evidence providing in-depth explanations for some results or identifying influencing factors. This is particularly evident in the explanations of the influencing factors on an individual's locus of control that enables or disables them from undertaking self-care activities (Table 5.5)

Table 5. 5 Themes of emerging findings

<ul style="list-style-type: none"> • Perceived levels of self-care • Activities of self-care <ul style="list-style-type: none"> ○ <i>Taking medication to manage diabetes</i> ○ <i>Managing a healthy diet</i> ○ <i>Physical exercise</i> ○ <i>Self-monitoring of blood glucose</i> ○ <i>Foot care</i> • Education and knowledge <ul style="list-style-type: none"> ○ <i>Lack of structured education</i> ○ <i>Sources of information</i> ○ <i>Persadia: an education source and support</i> 	<ul style="list-style-type: none"> • Locus of control <ul style="list-style-type: none"> ○ <i>Being in control</i> ○ <i>Poor control and lack of responsibility</i> ○ <i>Letting others take control or share control</i> • Javanese way – sensitivity and surrender • Peace of mind and role of Allah • Poor access to health care <p><i>Issues with the SDSCA questionnaire</i></p>
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Each theme is presented in turn; then an additional theme examines the issues with the translated SDSCA captured within the findings and the partially implemented gold standard guidelines for diabetes management in Indonesia that influences opportunities for self-care.

Perceived levels of self-care

Perceived levels of self-care are captured within the first part of the SDSCA questionnaire which asked participants to identify how often they partake in self-care activities, with respect to diet medication, physical exercise, foot care and blood glucose monitoring. This theme presents the overall self-care levels of the whole sample and the interview participants to gain an

understanding of whether self-care in diabetes management is an accepted and practised concept in this cohort of patients, and what activities are considered core diabetes management.

An SDSCA questionnaire scores the responses to items on the questionnaire (Appendix 9) and the low, moderate and high categories were determined by dividing the scores into three approximate groups (low=7-37, moderate=38-68, high=69-98) (Table 5.6).

Table 5. 6 Levels of self-care

		Whole sample (n=100)			Interview sample (n=24)		
		<i>high</i>	<i>moderate</i>	<i>low</i>	<i>high</i>	<i>moderate</i>	<i>low</i>
Overall level of self-care		11	78	11	4	16	4
Self-care/ gender	<i>Male</i>	6	33	3	2	7	1
	<i>Female</i>	5	45	8	2	9	3
Self-care/ age	<i>18-39</i>	0	2	1	0	1	1
	<i>40-59</i>	6	40	9	1	10	3
	<i>>60</i>	5	36	1	3	5	0
Self-care/ education	<i>Higher</i>	4	34	2	2	5	1
	<i>Medium</i>	6	27	5	1	7	2
	<i>Lower</i>	1	17	4	1	4	1
Self-care/ income	<i>Regular</i>	7	44	9	2	11	3
	<i>Non-regular</i>	4	34	2	2	5	1

Out of 100 participants, 11 participants perceived themselves to have a high level of self-care, reporting regular activities of self-care for some items, compared to 78 who indicated moderate self-care activity, and a further 11 who performed less self-care activities or less regular self-care. In the whole sample there was more men (6) reported higher self-care than women (5) and more women (8) reported lower levels of self-care than men (3). The majority of both men and women, across all age groups reported moderate levels of self-care (Table 5.6). People with a lower education level were more evident in the low self-care group and people with a higher education level in the high self-care group. Interestingly, more people with a regular income (9) reported a lower level of self-care than those with a non-regular income (2). A similar pattern of self-care activity to the whole sample was identified across the interview participants with moderate self-care activity being reported.

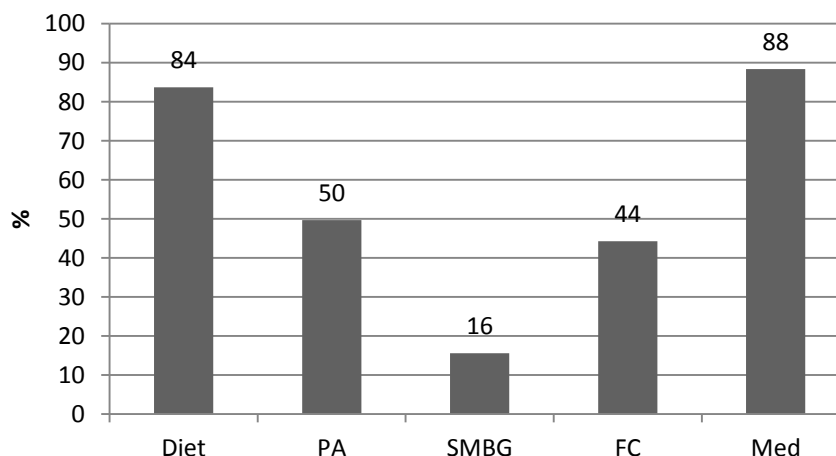
According to the SDSCA questionnaire findings people in Indonesia perceive themselves to have a moderate level of self-care for their diabetes chronic disease management. However, exploration of peoples 'real life' experiences from within the interviews and more detailed analysis of the activities of self-care provide a deeper insight of the reliability of the self-assessment instrument within this sample group.

Activities of self-care

The levels of self-care can be explored through the different activities of the questionnaire to identify which activity is performed most regularly by the sample participants, which includes adhering to medication, following a recommended diet, taking physical exercise, foot care and self-monitoring of the blood glucose. An overview of all activities are presented for the whole sample then each activity is examined in more detail to identify if different people characteristics influence the activity performed and using narrative data from the interviews to better understand the issues people have with the recommended diabetes self-care activities.

From the questionnaire data participants reported that the most frequent self-care activities they were inclined to perform involved taking their medication (M=88%) and following a recommended diet (D=84%) to ensure their blood glucose remains stable (Figure 5.1).

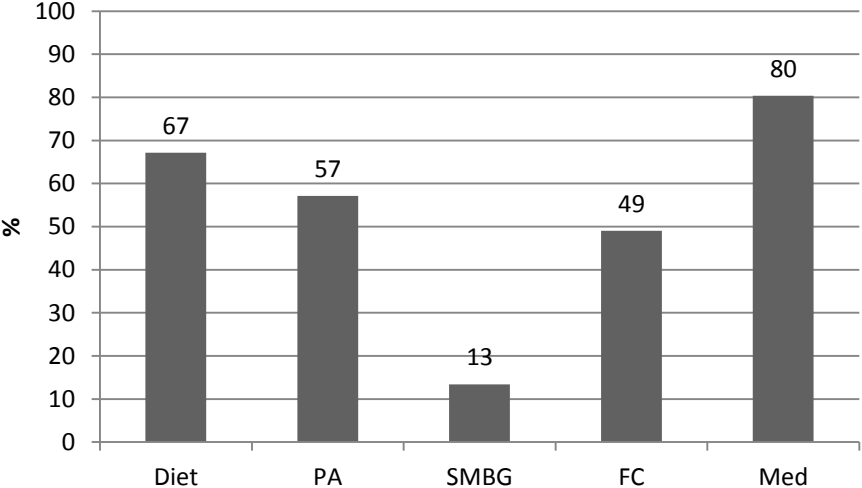
Figure 5. 1 Perceived self-care activity (whole sample n=100)



Physical activity was identified by only half of participants (PA=50%), with foot care (FC=44%) and self-monitoring of blood glucose (SMBG=16%) being the least performed self-care activity (Figure

5.1). Similar to the results from the whole population, the 24 participants for the interviews were more inclined to take medication (80%), although less were inclined to strictly manage their diet (67%), more were inclined to undertake physical activity (57%), more inclined to perform foot care (49%), and comparable self-monitoring blood glucose (13%) (Figure 5.2).

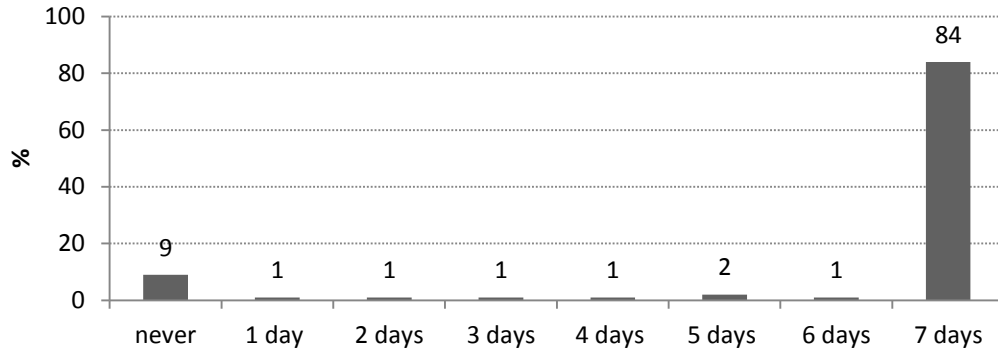
Figure 5. 2 Perceived self-care activity (Interview participants n=24)



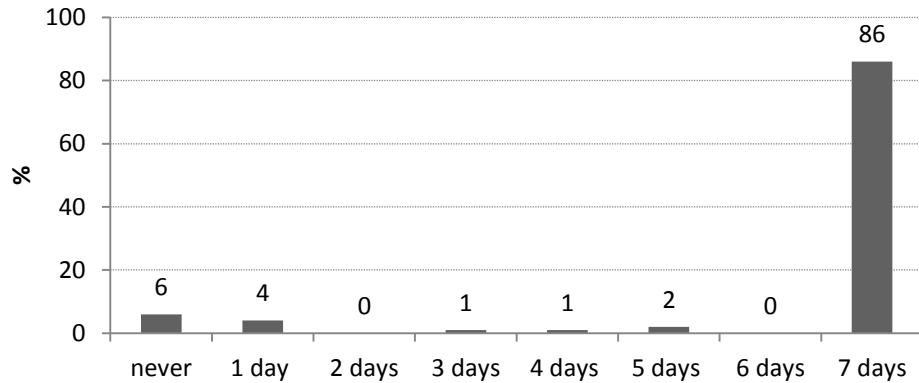
Taking medication to manage diabetes

Taking medication for many was seen as integral to managing diabetes. The questionnaire results suggest that the majority of people are inclined to follow the recommended diabetes medication plan from the doctors, whether this is insulin or tablets (such as Metformin) (Figures 5.3 and 5.4). This was not influenced by gender, age, regular income or education level.

**Figure 5. 3 How many of the last seven days did you take your recommended insulin injections?
(Whole sample n=100)**

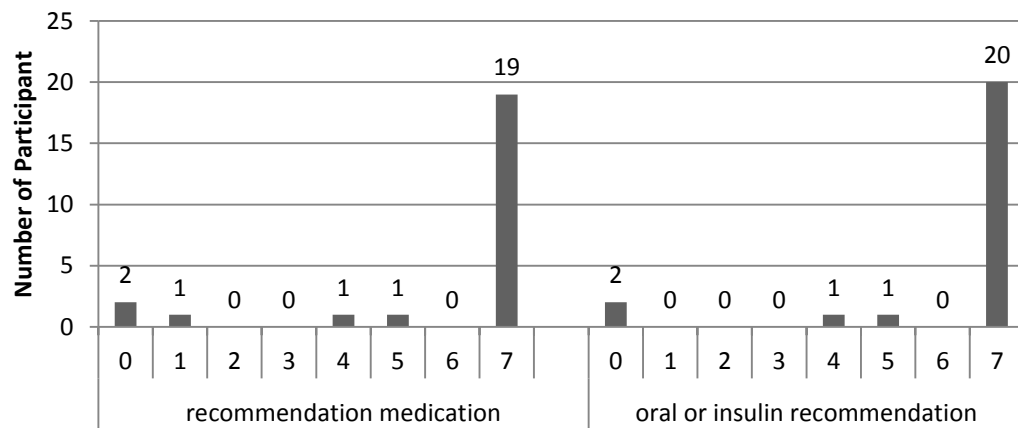


**Figure 5. 4 How many of the last seven days did you take your recommended diabetes pills?
(Whole sample n=100)**



Placing importance on medication was reinforced within the interview participant's questionnaire responses (Figure 5.5).

Figure 5. 5 Interview participants medication self-care activity (number of days) (n=24)



The interviews highlighted that the majority of people reported taking the recommended medication almost always 7 days a week, accepting the recommendations of the doctor which had *'to be followed'*.

'The way is consulting to a doctor, got medications, and also from others information as well' (Mr Jawen)

'Doctor's recommendation has to be... has to be followed' (Mrs Maryam)

'About the treatment (for diabetes), it varies, depend on the person. For me, I try to follow my doctor's advice to take the medicine. I take the medicine every morning,' (Mr Makmur)

However, within the interviews two women, Mrs Suti (low self-care score) and Mrs Santi (moderate self-care score), suggested that they followed the doctors recommendations but then highlighted at times they stop the medication or simply forget to take it, indicating maybe a lack of understanding as to why the medication is necessary (Figure 5.6).

Figure 5. 6 Contradictory self-care management

Follow advice	Don't follow or forget
<i>'Get medication (to get cured). Following doctor's order since doctor has guidance about medicines, this medication is for this illness... have to follow that'</i> (Mrs Suti)	<i>'Yes, the doctor told me... not to stop, every day two times... I stopped the medicines where I should still take it. It's a mistake...'</i> (Mrs Suti)
<i>'There was Dr Irfan (at Persadia) that recommended me to take some medicine. It was the Metformin'</i> (Mrs Santi)	<i>'But lately, I have been so busy, I forgot to take the medicine'</i> (Mrs Santi)

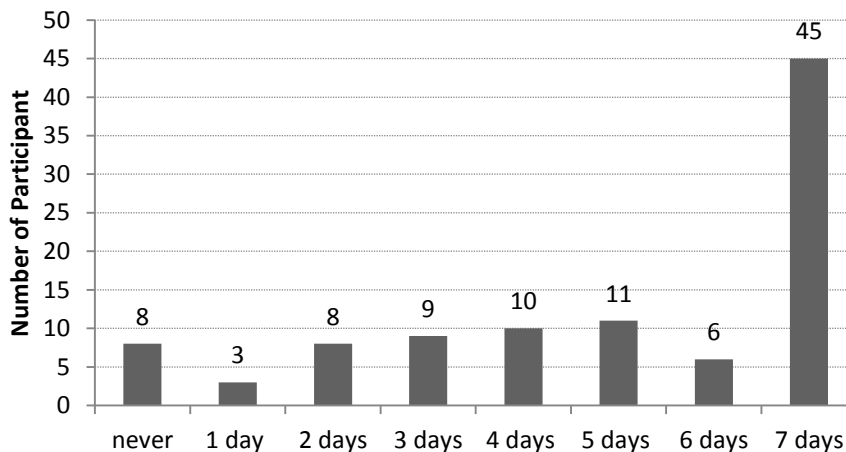
Mrs Heti (low overall self-care score) explained how she did not see the doctor regularly and preferred not to take medication, instead she took it irregular and relied more on herbs to manage her diabetes. The decision of not following medication did not necessarily demonstrate low self-care. However, this case might server as a demonstration of a good self-efficacy in making her mind up to use herbs instead, which may be based on a lack of accurate information and understanding of diabetes medication, preventing adherence to the recommended regime.

'Because I don't... well, see a doctor regularly ... basically, I don't like medicines; if I can I will chose herbs. Basically, don't like medicines. So, if I had medicine with me but the sugar was not so high, I won't take it... I am afraid it would affect my kidneys you see ... Dr Andi told me that it is safe, that, metformin is safe, it will be alright... Then I would stop it sometimes.' (Mrs Heti)

Managing a healthy diet

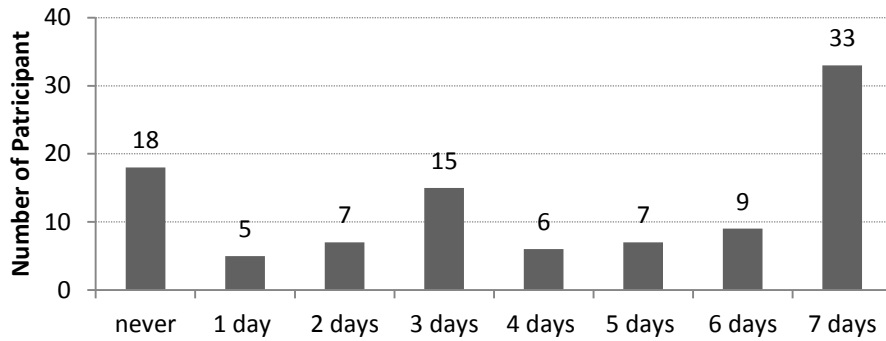
Following a recommended diet, particularly a healthy eating plan, of fruit and vegetables, reduced fat and evenly regulated carbohydrates, can be difficult to sustain. The SDSCA questionnaire highlighted that 84 out of 100 people reported that they self-care for managing their diet. However, on closer scrutiny 72 people indicated they achieved a healthy eating plan for four or more days in the last seven days, highlighting 28 people were only inclined to eat a healthy diet for three or less days in a week, of those 19 did not eat healthy for two or less days per week (Figure 5.7). This suggests that a recommended healthy diet every day was unrealistic to achieve for the majority of people (55%).

Figure 5. 7 How often inclined to follow a healthy eating plan, in last seven days? (n=100)



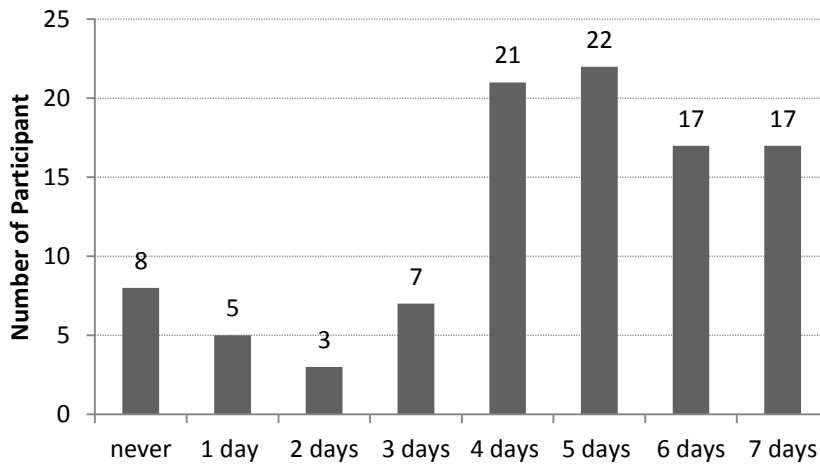
People seemed to have the greatest difficulty avoiding high fat foods and eating sufficient fruit and vegetables. In particular, 45 out of 100 people identified that for three days or less they ate the recommended five or more fruit and vegetables (Figure 5.8).

Figure 5. 8 How often did you eat five or more fruit and vegetables? (n=100)



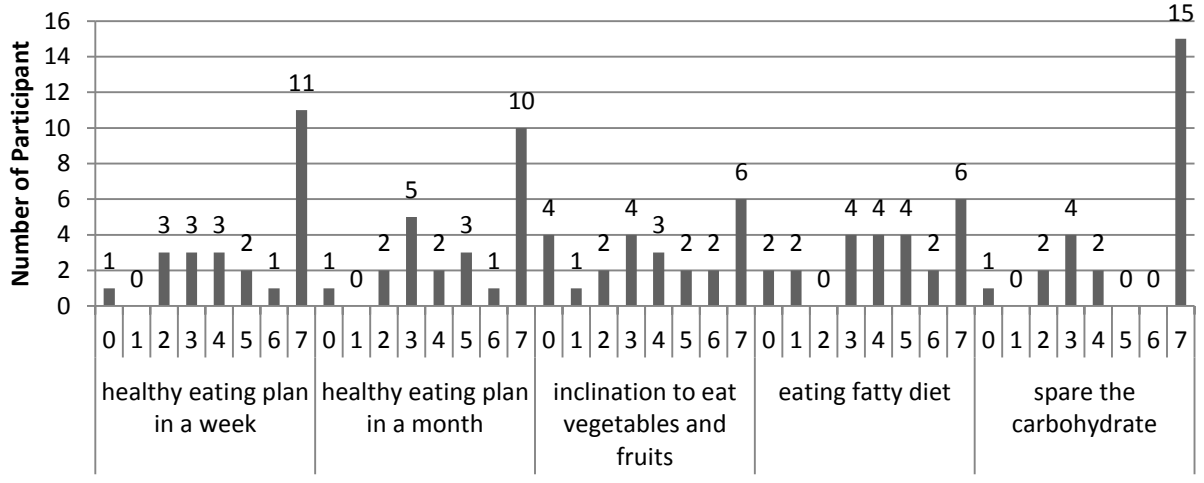
Of the 45 people eating less fruit and vegetables to 3 days a week, 30 received a regular income, suggesting income was not related to being able to afford a healthy diet. Out of 100 people 77 indicated that for four days or more they ate high fat foods, such as red meat or dairy products (Figure 5.9).

Figure 5. 9 How often have you eaten high fat foods over last seven days? (n=100)



There were similar findings within the interview sample, although 11 out of 24 participants highlighted sustaining a healthy eating plan for seven days in a week, 16 reported eating high fatty foods for four days or more, and 11 people only ate five or more fruit and vegetables three or less days a week signifying a healthy eating plan was not strictly maintained (Figure 5.10).

Figure 5. 10 Interview participant responses to SDSCA diet management (n=24)



The interview comments reinforced that maintaining a healthy diet recommended by a dietician or doctor was not so easy, but people recognised that what a person ate directly affected the blood sugar level, and some understood what foods to avoid, and had subsequently checked their blood glucose to measure the effect some foods had.

‘Dietary pattern is the hardest part, perhaps. Uncontrolled diet and drink with excessive sugar, not controlling the diet...So, the ups and downs of the sugar is depending on how we eat. If we eat a lot or have excessive sugar, then, the blood sugar will raise, definitely’ (Mrs Maryam)

‘I have been trying to follow doctor’s recommendation, how it should be done. I finally survived. I mean, beside, well, if I were in any areas which didn’t have any medicine, I would definitely reduce the sweet drinks, we reduce the rice (consumption)’ (Mr Suyono)

‘The important thing is the food, the ones with less sugar. Some corn and yam...That ground Yam and the families...Local banana... Yes, I did (check it after I ate it), it did not raise’ (Mr Jawen)

‘The temptations were stronger... laugh... Initially, it was the thirst... why didn't I drink... anything... a lot. It felt relieving to have a lot of drinks... that was what happened. Now, after I was told (not to) I resisted it...reducing it... only a little bit’ (Mrs Suti)

‘I also taken into consideration on every food I’m about to eat, I also like to move around a lot... Our daily meal, we need to limit rice, fruits, not that it is forbidden, but need to

consider less sugar one, for example a Tangerine, it still contain a lot of sugar, we could eat some Pears, it has less sugar' (Mrs Tata)

'I often have fruits and veggies. For example I bought Kangkung veggie, then I also have a banana, whatever the street vendor have, I bought it' (Mrs Santi)

Mr Adil demonstrated high self-efficacy indicating that the diet regime was important but he fitted it into his own life and followed most of the recommendations but not all.

'Well, like the dietary regimes from the dietician, then, what else...but I am not following it 100% maybe 60%. That's it. But, it turns out that I am still happy.' (Mr Adil)

Similarly, Mrs Heti (low self-care score) indicated at the start of the interview that she controlled her diabetes through her diet well, but later admitted that in real life she felt so hungry that she often forgot and ate more.

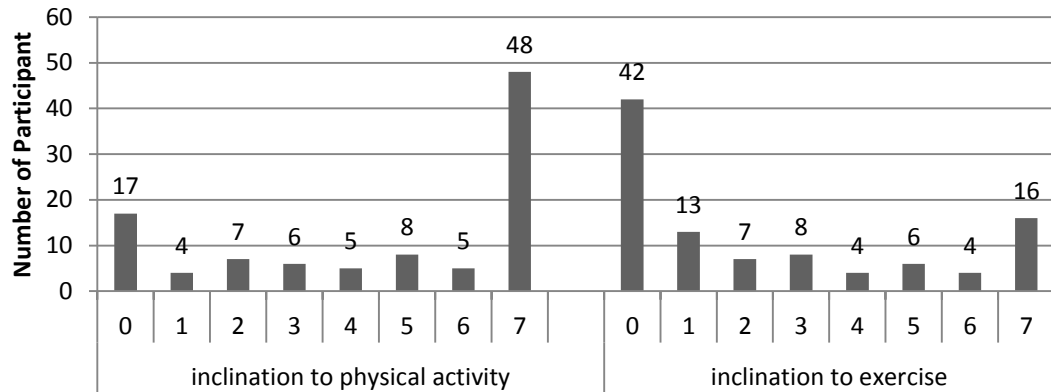
'Well, control it (the diabetes)... the diet... manages the diet and the lifestyle... and dietary pattern...' (Mrs Heti)

'Yes, sometimes forgot (the diet), sometimes it was because of the hunger... sometimes it was causing the forgetfulness... laugh [] no, I haven't done it (dietary recommendations) completely. He (doctor) said that hunger is in the brain...in the mind...but the reality was I was still hungry' (Mrs Heti)

Physical activity

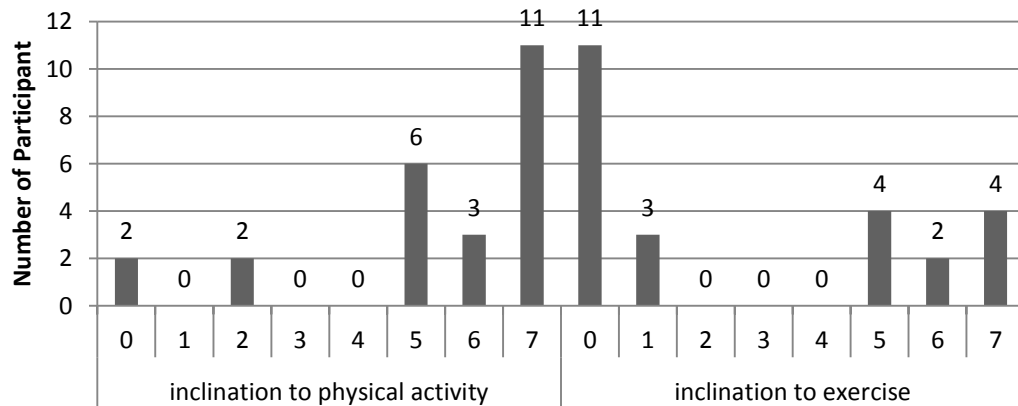
Many people, 66 out of 100, demonstrated an inclination to physical activity, having undertaken at least 30 minutes (for example continuous walking) at least four to seven days a week, recognising the need to take exercise and keep themselves fit, although 17 people admitted being unable to achieve any physical activity (Figure 5.11). Indeed the inclination to undertake an exercise session (such as swimming, walking, biking) was something 42 people had not considered over the last seven days. Levels of physical activity did not seem related to age, gender, or income.

Figure 5. 11 Inclination to undertake physical activity and exercise (whole sample n=100)



A similar result was reflected in the smaller interview cohort with 11 out of 24 being physically active each day, and 11 out of 24 not taking any formal exercise in the last seven days (Figure 5.12).

Figure 5. 12 interview participants inclinations to undertake physical activity and exercise (n=24)



To be physically active was considered important to maintain well-being. Therefore, several participants described various ways they performed physical activity, from walking for shopping, doing simple exercise inside the house, to taking exercise classes.

'Whenever I go shopping for groceries I tend to walk, on further distance, when I wanted to sew something I ride a bicycle to Krapyak' (Mrs Santi)

'My daughter would take me and I can go back easily, if let say I could get out of the house easily, she will take me... if she didn't pick me up I would go home by buses, I still could do it.' (Mrs Ismi)

'I usually only do exercise every day, so I got sweat. So, in the morning, at 5.30, I will walk from here to there. I go from my home at 5.30 and arrive at home again at 7 and I will get sweat. At 7, I took a bath and then went to the office' (Mr Sadi)

'Yes the nutritionist told me to do exercise. I was afraid to do the exercise somewhere else, so, I only did it at home. After I performed the tahajud prayers, I needed to do some exercise for several minutes. Just tried to move my body' (Mrs Sati)

'Yes, once a week, aerobic session...yes, 2000 rupiahs...I felt that the aerobic made me feel fit' (Mrs Suti)

However, several participants perceived unavailable support from friends or family or being busy at work as a barrier to enabling them to be physically active.

'Yes, feel lazy because I did not have any friend by the time I wanted to go here and there (for morning walk) after the subuh shalat' (Mrs Swasti)

'I would walk when I was told by my children, usually on early morning, but I also concern on my children's family, especially the grandchildren, getting up in time, preparing breakfast for them, most of the time' (Mrs Tata)

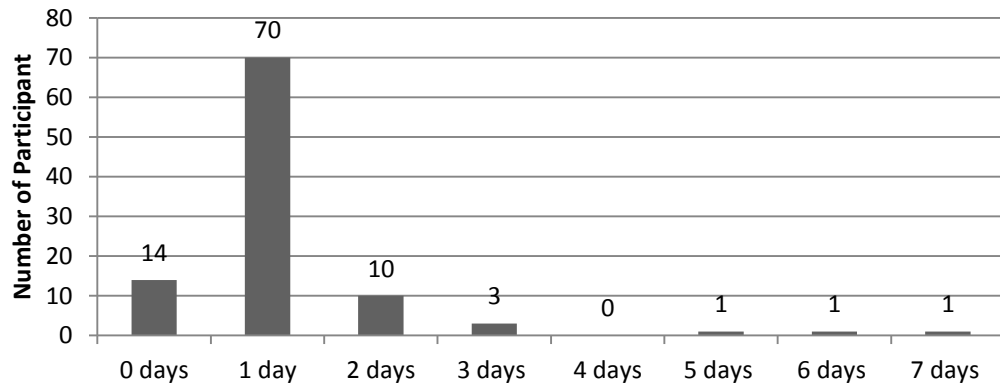
'I have little children at home. Two of them are already grown now, but the other two are still toddlers, so, I am so busy every morning preparing for everything. Even, to prepare their breakfast, it was very hectic. As I finished with that, I should prepare the little one going to kindergarten. Then, I go to have a shower and off to the office. I start my day from dawn. So, I thought, just to complete those routine, I have to start from the dawn' (Mrs Eva)

'Exercise is really important, maybe this is all about age. When I was still young, I used to do a lot of exercises, such as swimming, self-defense workouts, breathing exercise. But, as I get older, I become so busy with my works. Sometimes, I don't do exercise at all.' (Mr Makmur)

Self-Monitoring Blood Glucose (SMBG)

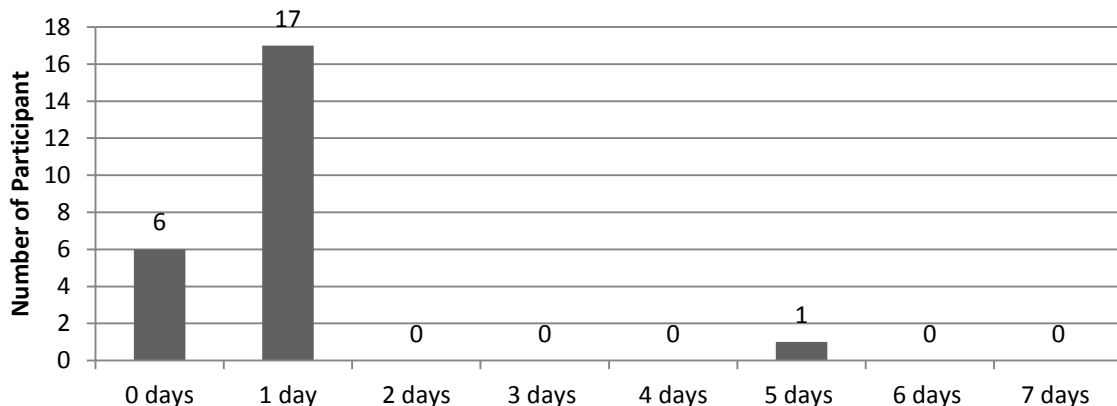
One of the most startling findings from the study was the complete lack of blood glucose monitoring performed by the diabetic patients, one of the core components to self-care for diabetes. For both the whole sample and the interview sample there was no real inclination to measure or monitor blood glucose, the majority either not testing their blood sugar or doing it once a week (Figure 5.13). Only one person out of 100 reported checking their blood sugar each day.

Figure 5. 13 Frequency of self-monitoring of blood glucose (whole sample n=100)



Out of 100 participants 93 people identified that they checked their blood glucose never or maybe one day as recommended by their health care provider. A similar pattern was reflected in the interview cohort with only one person checking the blood glucose five out of seven days the rest once in seven days (17) or not at all (6) (Figure 5.14).

Figure 5. 14 Frequency of self-monitoring of blood glucose (interview participants n=24)



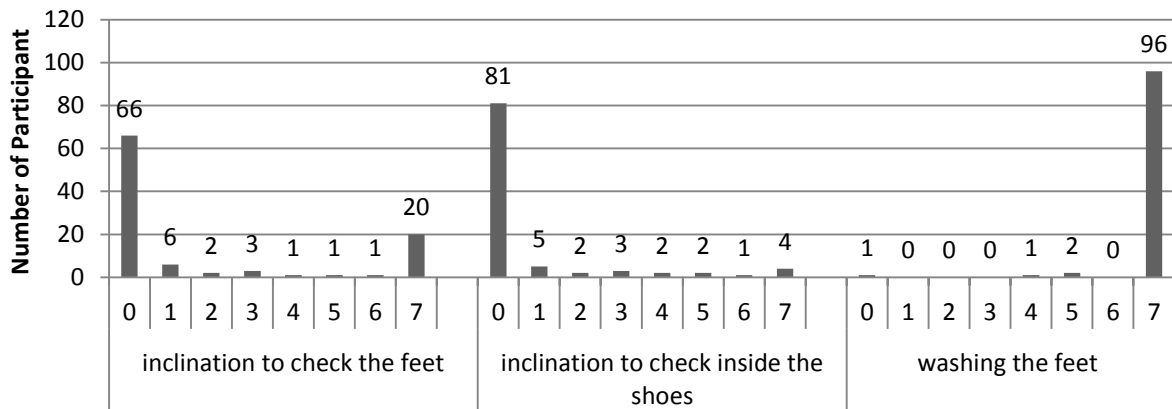
Foot Care

Although foot care was initially reported as an important self-care activity more than physical exercise (see Figure 5.1), on closer scrutiny this was a false result based on one of the items weighting the overall score. The foot care (FC) component of the SDSCA was made up of three items related to how individual maintains their daily activities in taking care their feet:

- On how many of the last seven days did you check your feet?
- On how many of the last seven days did you inspect the inside of your shoes?
- On how many of the last seven days did you wash your feet?

The breakdown of scores indicates that the majority of people did not check their feet (66%) or their shoes (81%) regularly (Figure 5.15), whereas 96% of people indicated washing their feet regularly.

Figure 5. 15 Foot Care activity for the whole sample (n=100)



The contribution of the third item of foot care can be explained with the correlation to the daily religious practice among Muslim; an obligation for every adult Muslim to wash their feet before commencing daily obligatory of *sholat*, not part of diabetes self-care management. This is further reinforced with 17 out of the 24 interview participants having no knowledge that washing and checking feet was important. As such foot care can be considered the second least practised self-care activity amongst the study population.

‘No I haven't been told about foot care’ (Mrs Suti)

'No, I haven't (known about foot care). Who will do the foot care treatment? Is it Dr I? Would he do it? My feet are dirty' (Mrs Asti)

'No (I haven't heard about foot care). Not yet, Sir' (Mr Makmur)

'No, I don't know about foot care' (Mr Suyono)

Access to health care

It is important to fully understand the context of accessing blood glucose checks and the health care system. When the study took place there were three ways of how people could access healthcare services for diabetes management:

1. Health Insurance (*ASKES* or *Asuransi Kesehatan*) for civil servants, army, police officer and pensioners, the premium is deducted direct from their income.
2. Community Health Insurance (*Jamkesmas* or *Jaminan Kesehatan Masyarakat*) is the insurance for the poor, where the government is responsible for paying the premium.
3. For other people, there are two ways of payment, either fee-for-the service or pay a premium for an insurance (such as *ASKES*).

The proportion of people who pay for themselves is larger than those with *ASKES* or *Jamkesmas*. For people who have money and use the fee-for-the service system, they can go anywhere to a community health centre (*Puskesmas* or *Pusat Kesehatan Masyarakat*) or a specialist from the private hospital. If the community health centre considers that the patient needs further treatment from a specialist, they can refer the patient to the designated reference county hospital, which may be located in different county. This works for any patients who hold *ASKES* card or *Jamkesmas* card, from civil servant to the poor. For patients with sufficient funds, they can see a specialist wherever and whenever they want, as most specialists work at their registered place outside of hospital working hours.

The diabetes clinic visit in the hospital was held every month, based on the appointment from particular treating physician, and the study participants could go to the same doctor or a different one, with no obligation to come. Before they commence the consultation, usually they would get their blood checked for the sugar, so the physician would know the progress when the

consultation was held. Persadia also offers a free weekly aerobic session that consists of blood check, dietary and other general consultation.

Access to blood glucose monitoring is not provided by the government; patients have to provide it themselves, despite it being part of the Perkeni guideline on diabetes management (Perkeni, 2011). The price is high, since for many people it costs them half of their minimum monthly wage (500,000 IDR). Indeed, for those people with irregular incomes, such as labour, it is considered a luxury. From the questionnaire, nine people were identified using blood glucose monitor to measure their blood sugar with six took part in the interviews. Despite owning a blood sugar monitor none of the six people used the monitor regularly, except for Mr Suyono who used to use it when he was working away in a remote area until he found out that the tool was unreliable. Others found the equipment either faulty, or not necessary as they could tell their blood sugar level using their own symptoms, or they preferred to adhere to seeing the doctor and having a monthly check.

'I have the tool, but it hasn't been used since last year...sometimes I felt it wasn't working well, so I was afraid if it gave me the wrong results... It's only 500 thousand rupiahs... actually, when I was in a remote area... since from the woods to get to the nearest Puskesmas...it took a day sometimes to get there. Well, then, I just bought it' (Mr Suyono)

'I have the equipment myself but it turned out to be faulty. Laugh. I got it from the nurse at the sugar clinic... yes I have since I was offered one by a nurse from Mitra Sehat (another hospital) once.' (Mrs Sifa)

'My son bought that (blood check tool) for me, you see. Laugh... So his mother could keep on checking...Well, I have used it to check, indeed. If I felt my body somehow reflected my sugar to drop, that was the most...or too high, according to the feeling...' (Mrs Maryam)

'I also bought the blood sugar measurement tools because it was suggested by the doctor. Just in case I felt a drop, I could check the blood sugar by myself, didn't have to go to the pharmacy to do that anymore. I did that.' (Mrs Eva)

Mr Arif (a business owner) used his blood glucose monitor initially but now relies on the monthly check that is performed by the physician in the hospital, before commencing the consultation every month.

'During my earlier period, I used it once every two weeks. But after I consulted to the doctor and had regular medication, I checked monthly. And recently I have never checked regularly unless I went to the hospital' (Mr Arif)

When they used to teach before retiring, Mrs Ismi and Mrs Sifa used the clinic regularly to check their blood sugar in between teaching sessions as they considered it is important to know their own condition.

'I had diabetes then but I went to see the doctor regularly every month... usually I got checked for the fasting level first... I was lecturing at that time, before I arrived to the school, I stopped by at the hospital, got the blood draw then I went to the school, gave lectures, got my breakfast then went to the hospital again... drew my blood again after two hours, it was what I have done every month...' (Mrs Ismi)

'Well, yes...I used to feel a little bit dizzy when I was teaching. Then I stopped by at the Puskesmas, I asked to check for my blood' (Mrs Sifa)

Mr Suyono, to keep aware of his blood test history, he uses the mobile phone to keep a record of his blood sugar levels.

'Well, I write them (the blood sugar result) down in my mobile, I have been doing that since 2007. I wrote them all down.' (Mr Suyono)

For Mr Makmur the blood glucose test is not compulsory and he knows best without using the machine when his sugar level is either low or high.

'Yes, I can. If it's being low, I feel like... gliyer... and when it gets high, I feel so thirsty and weak ... I used to (go to the doctor to check). I don't go to check it anymore. When I come to the situation where I think it gets high... it's only my stupid prediction... I will take a rest and reduce my sugar consumption...So for me the blood sugar check is not a compulsory.' (Mr Makmur)

Lack of structured education

One of the key findings of this study was the gaps in knowledge of effective diabetes management and the concept of self-care, despite the majority of participants demonstrating moderate self-care activity. In general, all participants only really involved in two key self-care activities; adhering to medication and diet, with an awareness of the need for physical activity and exercise. Following on from the previous theme where participants had no knowledge and had not received education on the importance of foot care. The majority of interview participants were unaware of any structured educational program in place and many, when describing their activity, highlighted a complete lack of understanding for any particular self-care activity.

'No, there is no (any educational session)' (Mrs Siti)

'I have no idea (about any educational programs)' (Mrs Asti)

'No (don't know any diabetes program at PKU)' (Mr Makmur)

'No, nobody (doctors) told me' (Mrs Tata)

Some knowledge was evident regarding the doctor recommending managing the diet and taking exercise or deeper knowledge of the effect diabetes can have on wound healing. However conversations indicated a limited or misunderstanding underpinned by fear of the disease getting worse.

'Doctor's recommendation was...the diet, which has to be chosen...rice still has high sugar, reduce it. It is called dietary management. Well, then, we just eat potato. Potato, you see. I was...once, because I was so afraid of (the diabetes) becoming too severe, I was consuming potato with, what was it? Keladi (yam)...at that time' (Mr Suyono)

'His suggestion would be... he told me to do exercise everyday' (Mrs Maryam)

'Yes, if the sugar is high even if you had only a small wound it wouldn't get dry... I have been told that...just be careful...don't you get... wounded... any other restrictions must have taken into account' (Mrs Suti)

Mr Suyono, a well-educated man, identified that he sometimes forgot to take the medicine, but so as not to lose face in front of the doctor he preferred not to tell the doctor the truth. It was

clear from his discussion that he did not appreciate the importance of adhering to medication when evaluating the level of blood glucose on a regular basis. The effectiveness of the medication being assessed by the doctor would influence further treatment regimens; whether there will need a dose adjustment, or even a different type of treatment.

'Well, sometimes this was... the truth is... actually I have lied to doctor (laughs)... when (he told me) 'don't forget to take the medicine at all times', 'yes', I said. But I didn't say that by heart' (Mr Suyono)

Mrs Eva, now confident in evaluating her body's symptoms described an initial clear lack of knowledge and understanding regarding the need for insulin and indeed she thought, based from the information from her peers, she would be healed from diabetes, evidence of how gaining information from peers may lead to misinformation.

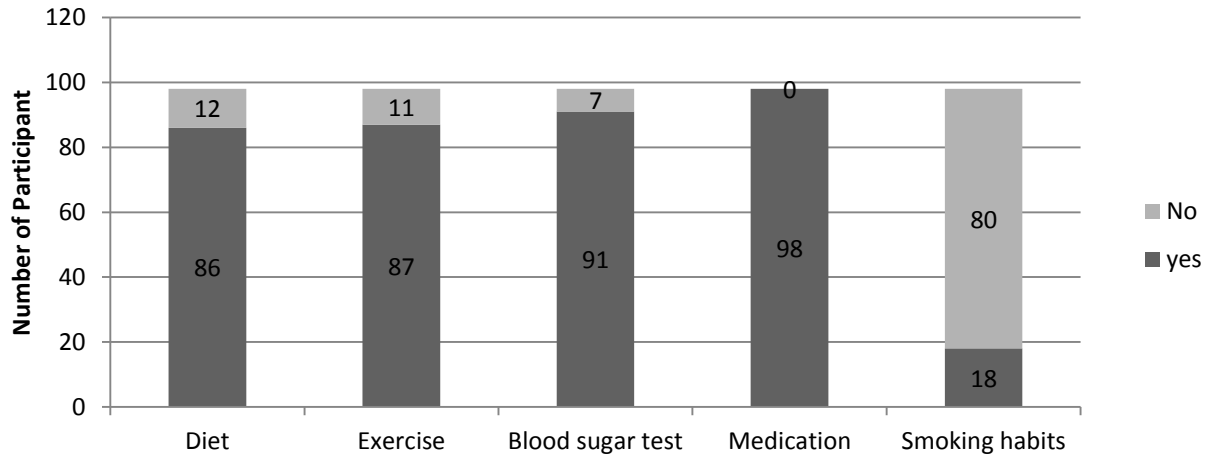
'I regularly controlled my blood sugar and had the insulin injection. My blood sugar was getting normal afterward. Dr Irfan has reminded me to have a regular check-up, but I just ignored it. I was boring to do the same thing. When my blood sugar was normal after 3 months of regular check-up, I decided to stop having injection' (Mrs Eva)

'Actually, I didn't forget it, but I just ignored it. I thought I was fine, you know. People say that if someone has a high blood sugar, he/she would have hypertension. I used to have hypertension if my blood sugar was high. But, I thought my blood pressure was normal, and I felt alright, no cold sweat, no lethargic, never had tingling sensation, and if I got would it was healed completely. So, I thought I wasn't diabetic, I was fine' (Mrs Eva)

Sources of information and education

Instead of an integrated program of self-care activity participants described single tasks such as adhering to medication without the understanding that together the self-care activities could provide improved diabetes management. Diabetes education or information was conveyed from the doctor or any other health care professional, usually on the spot education on certain self-care behaviours in a consultation setting. From the 100 participants, 98 chose to complete the questionnaire items highlighting recommendations from the health care professional, with medication being regarded by all participants as always discussed during the consultation (Figure 5.16).

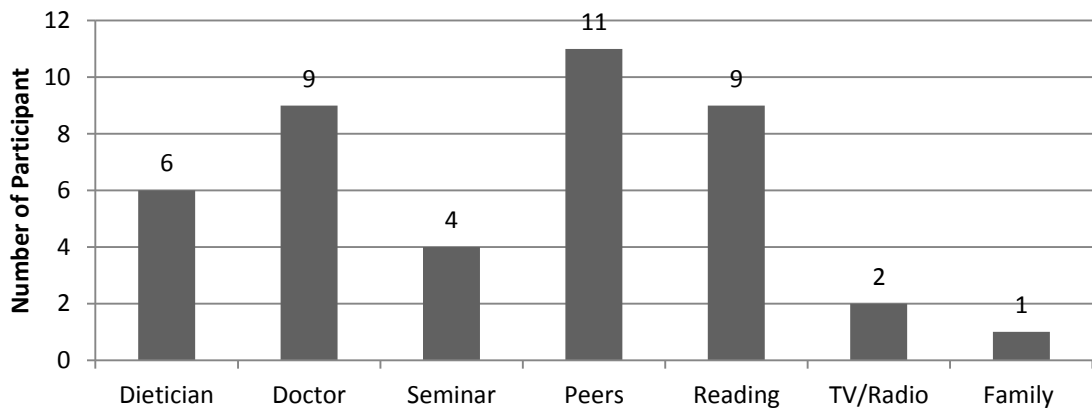
Figure 5. 16 Recommendations from health professionals



Participants regarded the doctor or dietician as the two key sources of information from the health care professionals. The limited discussion regarding smoking habits may be based on the general thought that smoking, for the majority of Islamic population, is perceived as something harmful according to the Islamic value. Furthermore, among Indonesian females in the general population, particularly the middle to older age group, the behaviour is not found to be a common habit.

Participants used a combination of sources to supplement their knowledge (Figure 5.17), these included doctors, dieticians and most used were peers.

Figure 5. 17 Sources of diabetes information



Mr Jawen admitted never being informed about any self-care activity, asked in the questionnaire, but mentioned some recommendations from the doctor with regards to dietary management, as

well as peers as a source of information. Similarly, Mrs Asti described initially being diagnosed with diabetes and that she did not know anything, but felt better now over time have read things in magazines.

'No it's (the knowledge of diabetes) not sufficient [] because I didn't know anything... I didn't know about the diet...I didn't know what drink I should I drink' (Mrs Asti)

'Well, actually I feel I already have much knowledge about diabetes from reading magazines' (Mrs Asti)

Persadia: a source of education and support

Persadia has been promoted by participants as an organisation where they can access valuable knowledge on how to manage their condition. Indeed, this is particularly evident for those people with limited funds; Persadia was the main source of diabetes management and education. It is true for Mr Ripan, a labourer with no health insurance to pay for treatment and Mrs Santi who owned a sewing shop and acts as the breadwinner in her family. Persadia offers access to doctors and health professionals, health seminars, blood tests at an affordable price, nutritional counselling, and foot care presentations. Participants of the study who were also members of Persadia clearly showed a clear understanding of what diabetes is and knowledge of preventive measures to avoid complications.

'After I joined the diabetic club, diabetes is abundant sugar level illness it is something to do with not enough insulin inside the pancreas. That is why the sugar level in the blood is higher' (Mrs Wati)

'The complications... they (the doctors) said that according to pak Irfan sugar is a ruthless disease... It could affect the eyes, the nerves... (laughs)... It could be into almost everything, couldn't it? The medicine, he said to me, we used to have a talk when he was presenting something every two months he told me that taking the medicine would not affect us in any way, you see. But if we let the sugar high, it would' (Mr Adil)

'Yes, from the PKU. They did it often ...gave us the information...It is exclusive to Persadia club. They held several activities to certain place, exercising, and lunch, after that they give you instructions, you can ask anything relating to your illness, your complaint, and medications. Doctor Irfan likes to share some thoughts' (Mrs Wati)

'Well, yesterday at the (aerobic session)... the dietician has told us... Use this and that... If you want to eat egg, eat this much, using dummies. There were various toys there, egg, cake, bread all from plastic, you see. They were belongs to the medical school' (Mr Adil)

'I am going to the aerobic sessions at the PKU regularly, and sometimes they hold health seminars.' (Mr Ripan)

'Yes, I know it from the counselling session. Wherever the aerobic sessions were held, there was a public counselling session... I got more knowledge there (Persadia), there was dietician. She said things about what we need to eat.' (Mrs Santi)

'Blood check was done every week at weekly exercise in hospital after the exercise. Before that we will get a blood pressure check. After the exercise, one will get a blood sugar check for 8,000 rupiah. You would have to pay for a 13,000 in the lab. There, you would only have to pay only 8,000.' (Mrs Ismi)

Mr Adil a devout member of Persadia recited the club's slogan of 'diet-control-exercise' and reinforced that people not accessing Persadia meetings would remain sick.

'That is our slogan, three d-c-e; diet, control and exercise. Persadia, yes! Laugh. It has to be that way. We have to hold the three d-c-e tight... Well anyone who is sick (diabetics) but didn't join something like Persadia...they would only get stuck there' (Mr Adil)

For its members Persadia was a recognised source of information and knowledge, including foot care, dietary management, keeping physically even in the time of Ramadan, when the Muslim perform obligatory fasting for the whole month.

'Persadia had informed this. Every night before we come to bed, we need to rub our feet with warm water, then dried between the toes properly up, and observe for any red freckle, it is recommended to wear sandals in the house, but I like bare feet to feel the coolness... There was info from diet expert on how much calorie any diabetic needed on daily basis. They gave the list as well. For example, if you took rice and... Well, most Javanese would eat rice and noodle all together; it should not be done ...' (Mrs Wati)

'Especially before Ramadan... We were told that during Ramadan we didn't stop exercising, by ripping newspapers with our feet. It was counted as an exercise as well... That's it. So, since I have joined (the aerobic) at the PKU...my knowledge has getting better especially about diabetes' (Mr Ripan)

Persadia meetings also served as a social support by acting as a social hub, gathering people with the similar condition together providing opportunities to share experiences.

'The main thing that I told you about diabetes is if we gathered with other diabetic, we are not alone. We were enjoying ourselves... we're not alone. So, let say, if we got checked and got high, then, we compared to the others who got higher than us. That's it, you see. So, we didn't get so tensed.' (Mr Ripan)

'I would come I did aerobic there, meet a lot of friends, sharing about sugar thing, informed each other on how to manage a treatment....' (Mrs Santi)

Most importantly for Mr Adil, being a member has encouraged him to be more responsible for himself, advocating and promoting self-care.

'That's it... (at Persadia) We were asked to be able ourselves... we were asked... 'you have to do this... I couldn't ask you to do this, you are the one who got it and you will hold it with you, you are the one who control it.' (Mr Adil)

Nevertheless, for others their own circumstances created barriers to attending particular events, such as a fear of falling when out and about, or a lack of motivation. Mrs Swasti was reluctant to join a meeting at the same hospital where she worked, although it was easily accessible. She used work schedules as the obstacle preventing her from attending, but admitted to being lazy.

'Never (participating at Persadia)... Not interested... I am lazy... (laughs)... If I feel lazy, then, I just don't feel of doing anything else...It is held every week, right? Sometimes it is held when I have to work' (Mrs Swasti)

'Yes, there is. I was told once. Every Sunday there is an aerobic sessions at the PKU. From 6 am, maybe... at 6 or 7, I think. That's it. But I haven't done it, yet...It is just because of this hip inflammation, you see. It has made me using the crutch. I am actually not in pain anymore, I am cured already. It is just my imagination that what if I fell off while I was using the crutch. I couldn't bear to fall for the second time' (Mrs Umi)

For others, they were unaware of the existence of the education program at Persadia.

'I don't know (any aerobic activities at PKU)' (Mr Fajar)

'No, never (told anything about any aerobic program)' (Mrs Siti)

'No, (I haven't known about Persadia, yet)' (Mr Sadi)

It was unclear why access to this particular program had not been widely disseminated to the wider community, particularly as one of the doctors treating the participants was the head of the Persadia organization branch in Yogyakarta, but had failed to mention it

Locus of control

The perceptions of who is taking the responsibility for the outcome of someone else's effort might influence the adherence to self-care activity. Several participants have relied on a husband, wife or other important person in taking care of them, or even to rely on their doctors without even considered asking what has happened to their own body.

Being in control

There was evidence of different influences as to whether a person felt empowered to take responsibility for their diabetes management, demonstrating a high locus of control and self-care qualities. This often entailed making decisions regarding their diabetes management and fitting it into their daily life.

Well, that (the ability to control myself and the blood sugar control) comes from my own abilities. If I follow the doctor, I have to eat three times a day, and the vitamins, there are a lot of them. But for me, it is my own (ability)' (Mr Fajar)

'Yes, just following my own conditions, sometimes I was craving to eat when I was hungry, but I just didn't feel like eating, then, I didn't. Later, if I was hungry, and like to eat, than I ate. So, I don't have particular schedule to eat (Laughs). Just adjusting myself...sometimes, 6 o'clock, sometimes at 7, depending on my own availability' (Mr Arif)

In order to be able to manage their own condition and be 'happy' it was important for individuals to understand how to evaluate their diabetes, from maintaining diet to adjusting the dosage of their medication.

'The important thing is the balance dietary pattern, and then lowering sweet drinks, I have done it although not 100%, sometimes at the street vendor stand, I still drink sweet beverage, but not always. And I also tried to eat fruits and vegetables as well' (Mr Arif)

'Some were terrified about it, because they followed the diet strictly... I don't want to be like that... we would control our diet if there was... was an invitation we would take the medicine first... (laughs)... That's what we've done it... Well, like the dietary regimes from the

dietician...I am not following it 100% maybe 60%. That's it. But, it turns out that I am still happy.' (Mr Adil)

'Well, (if I were invited for a meal) I got medication from the doctor, so I raised the dose a little bit... Usually, one extra tablet. If usually I took two tablets, then I took three. There is a Glimepirid, which usually 4 tablets a day. I had one in the morning along with 2 tablets of Metformin. If I had to go to an occasion, I'd take three' (Mr Jawen)

'Well, yes... (laughs)... I lowered the dosage down, myself. I lowered it down to 16 or 14, you see. After I felt that the sugar was normal again, then I would go back to the initial dosage. It was something that...let's see... did the doctor recommend it or not? I am not sure. I forgot about it. But I dare to do that' (Mrs Maryam)

The concern is when medication is changed without the advice or guidance of a doctor, although having the confidence to change the medication themselves demonstrates a high locus of control and perceived self-efficacy.

'When pak Irfan (Dr Irfan) asked me (to take the medicine) I took it, but now I have seldom took it. And usually if I went for the aerobic I didn't take them, and if I didn't then I started again. But at Ramadan, I was completely leaving them, and turned out (alright). It has been three days since the last time I took the medicine, I am fine.' (Mr Adil)

Mr Ripan found an alternative treatment with the guidance of the pharmacist and demonstrated increased self-efficacy to buy different medication and alter his treatment himself.

'No, (I don't feel afraid to buy it by myself). What I have tried with that Glibenspirit, it has 1, 2, 3, and 4. I tried the first one. There's no difference. I mean the sugar was still around 200. I raised it, because the pharmacist also told me to raise it. Neither, were the second, and the third. Finally, I went back to the generic one, cheaper (Glibensipirit) was more expensive. I would buy it for a box' (Mr Ripan)

Poor control and lack of responsibility

Choosing to ignore advice and not manage the diet as strictly as recommended does not necessarily demonstrate a poor locus of control unless lacking the information to understand and make a decision. Mrs Heti does not feel able to follow the dietary management regime from the dietician; instead she just tries to do her own way, which causes a high blood sugar. Similarly Mr Makmur used phrases like *'What am I supposed to do'* or *'I couldn't resist'* suggesting a lack of

responsibility and self-control. Feeling better made Mrs Santi question whether she had diabetes, identifying a lack of understanding.

'It was very strict, you see. The important thing is if you eat, just eat modestly...and supported by exercise... That is why it is still high... (laughs)... because I haven't been so strict about it' (Mrs Heti)

'No, I don't (feel able to manage). Actually, I want to know how I got the diabetes. I want to know that...' (Mrs Suti)

'I can't resist not drinking something like... the like of sweet ice tea, coffee...sometimes, when I visit my friend, they serve me with that kind of drink which I couldn't resist... But, for me, it's not a big deal (forgetting the medication). I don't hesitate to eat the meal...sometimes I take more (food) or less than it, it depends to my mood' (Mr Makmur)

'The children often gave us presents. What could I do... often took it 2... More, then... 2, 3 (pieces)... basically, I would adjust myself to any meal that anyone has made for me... if it was according to the list, I would eat it. (If it was not on the list, and) if they didn't see it, I would take it (laughs)... I often have the urge (to eat).' (Mr Kasi)

'I already knew it (the sugar was high) then...But I was feeling happy, still. There was no way that I got it (diabetes), since I already join the aerobic often' (Mrs Santi)

For Mrs Siti, she has never asked any questions and left the responsibility with the doctor.

'No, I haven't (asked anything). Dr L had never given me any recommendations. It's just "what do you feel, mam?"' (Mrs Siti)

Letting others take control or share control

Six participants described how their family, daughter, maid, wife or husband helped them manage their diabetes, either managing their diet, cooking the right food, testing their blood sugar or encouraging them to take exercise.

'I would then tell my husband about it. Then, he would be quite ruthless, he wouldn't give me anything that the doctor already restricted them... he has been the one who reminded me' (Mrs Suti)

'After a few days, my wife also had me checked and got more than 200. So I tried some promotional product we got from KR (local newspaper), but it was still high, so I consulted to the doctor on regular basis.' (Mr Arif)

'I just often eat what my maid has made for us. So, basically I would eat anything that she has cooked. Actually I was the one who decide what to eat, but it was also for the rest of the employees (to have). That's why... let say, today we already have vegetables, pecel or gubahan or else, but it is not for every day. They would get bored if the same menu was served every day, so it has to be varied, either with meat or anything else' (Mrs Maryam)

'I walk when instructed by my children, usually on early morning, but I also take concern on my children's family, especially the grandchildren, getting up in time, preparing breakfast for them, most of the time' (Mrs Tata)

There were times when the existence of those important others were acting as a positive balancing power; to remind them to keep the dietary regime or keep physically active. Alternatively, there were times when the existence of the family acts as a hindrance in performing physical activity or maintaining to dietary regime. For example Mrs Asti's daughter mentioned that she has just deliberately let her mother eats what she wants.

'She is the one who responsible for it (meal) (pointed to her daughter)... There was time when the season of durian... then I went to see the doctor... why the sugar was up, mam? I had durians (sweet fruit)' (Mrs Asti)

A professional support from the wife and daughter that are working as a nurse is beneficial for Mr Arif and Mrs Ismi in providing them with essential information to know more about the circumstances and how to manage it.

'Yes, my wife often gives me some brochures and suggesting some ideal dietary menu... It usually came from myself, if I was already destined (with this condition) then I have to (be responsible with it) so I would stay in order' (Mr Arif)

'And my daughter happens to be a nurse as well, so sometimes I ask her...' (Mrs Ismi)

Javenese way - sensitivity and surrender

A notion of Javenese culture of *tepo seliro* or being sensitive to others' interest was influential in how people behaved towards their diabetes management, whether it was not pushing to access free services, not wanting to bother anyone else, not taking too long with a doctor so other people

would be seen quicker. Both Mr Jawen and Mrs Ismi can be taken as examples of how Javanese people will put themselves between their own rights and others.

'Being sensitive...It actually tepo seliro (being sensitive to other's situation). Tepo seliro is we respect others. Tepo Seliro...Yes I know (my rights to have a free service), since I had public health insurance. But to the Javanese, let say, being sensitive. We would feel uncomfortable, because it is free, why bother to ask for things...then again, no one said that the service was paid by the government, but my heart wouldn't just do it' (Mr Jawen)

'The time with the doctor was so tight...I mean...I could not have a long consultation time... I was concern of the other patients which was a lot of them waiting... in case I was disturbing them' (Mrs Ismi)

Indeed, the earlier extract of Mrs Eva when socialising accepting the offer of food or drink as a sign of respect, is connected to the Javanese way and culture. Being a Javanese means having to look for others' sake in managing social relationship, taking things slow. Furthermore, life has to be taken like a wheel, there were ups and downs, life is just taken for granted, life will get better there is little control a person has in what is happening. Certainly, for people from lower income families learn to surrender and accept their situation but believe it will get better.

'Basically, according to Javanese way, everything we do we should do it slowly... don't bother to think anything, if you get tired, so be it... after you got better then you can start to work again' (Mrs Suti)

'So, there will come a time, the Javanese would say, 'urip itu kan kayak muter', life is like a circle, sometimes we were up, and at that time, I was at the bottom. Eventually, it would go... there's no way that we always kept at the bottom' (Mr Arif)

'So the people like what I used to be which had a low economic, (we learnt from it) how to surrender, no emotion, no passion, surrender' (Mr Sujawi)

Peace of mind and the role of Allah

Several participants mentioned the importance of keeping the peace of mind to manage their well-being, which to some extent is believed to help them in maintaining their blood sugar level. This notion emerged among participants from the intertwined influence of Javanese culture and Islamic values. Indeed, this finding emphasized the notion of the limitation of the questionnaire to capture what lies beyond the social aspects of human being.

'Peace of mind is number one to support us in curing the illness. The more we believe (in Allah), the more we will be in a calmness' (Mr Makmur).

Mr Jawen believed more on the power of praying and peace of mind, managing his own medication regime based on their own experience.

'Yes of course. The important thing to do is praying. There is no good medication than pray... for me, peace of mind plays big part. If we are happy, no thoughts burden, it will keep the diseases away.' (Mr Jawen)

The influence of religion will be discussed more in the next Chapter but for Mr Adil, Mr Makmur, and Mr Jawen, Allah served as an important external factor that was responsible in influencing their effort to self-care for their diabetes. Mr Jawen, a pious Kejawen practitioner, has mentioned the notion of God as the one who is responsible in maintaining human's well-being. However, for Mr Jawen, this notion might also emerge due to the socio-economical circumstance that he endures, which has forced him to be more surrendering.

'Although, I don't work, but the one that gives life is God. So, one who grows a plant, must also waters it, so one way or another, we must be fulfilled by God' (Mr Jawen)

Mr Adil and Mr Makmur believed that Allah will take care of them when they omit their medication, in the event of hajj and Ramadan, or when they just forget. This belief and reliance on God deflects the responsibility of the health problem, surrendering to Allah's will.

'Just as usual, let's say at the time of Ramadan I didn't even take the medicine...I just had the faith, Allah would guarantee, if I died alhamdulillah (I would go) to heaven (laughs), that's it...I just prepared them (the medicine when I was at hajj), but rarely ate them...it was because of.. I was only thinking of surrendering to Allah.' (Mr Adil)

'I take the medicine every morning, but sometimes I forget. Sorry. And I try to let Allah do the rest...regarding heart problem, whether it still exists or not, that is Allah's problem.' (Mr Makmur)

Poor access to health care

The government provides the basic healthcare service with the provision of Jamkesmas card or *Jaminan Kesehatan Masyarakat* (Community Health Insurance) for the poor, and Askes or *Asuransi Kesehatan* (Health Insurance) for the civil servant. In order to get the benefit of the

service, it has a particular health service system, including the referral system that must be followed. The general practitioner is served as the first line of treatment and the gate keeper for referring to the specialist. Comments reflected that access to health care for the poor consisted of frequent visits that took hours queuing waiting for an appointment and then accessing a clinic every three days for repeated medication. It was regarded difficult for anyone sustaining employment unless they work for themselves.

'It is free (to go to the county hospital), but had to go there every three days, go to communal clinic again, find hospital reference, too much to do, as if we don't have anything else to do. Other than doing my own business, going about to the hospital every three days makes me tired' (Mr Jawen).

It is echoed by Mr Sadi, a civil servant that also shared the same free healthcare services as Mr Jawen, who is considered poor.

'I should go to the puskesmas, then Sarjito hospital. At that time... I had to wake up at 4 and went to Sarjito to take the number... even when I went after dawn; I was in queue in the position number 100. So, I should do the whole process for the whole day. Let say...the laboratory...it opens at 8, if I got number 80, I got my blood drawn at 10. Then, I should eat and after two hours, I should go back. So, it would be finished at least at 2. The next day, I should come back again to take the result and see the internist for a consultation. After that, the internist would give a reference to the cardiologist for the next two days' (Mr Sadi)

For Mr Ripan, he was prevented from seeing a doctor for 6 years managing his diabetes himself as he was a labourer with no health insurance to pay for treatment. The introduction of the Jamkesmas card for the poor has certainly began to increase access to diabetes education and regular blood sugar monitoring, weekly for those members of Persadia, for people who used to be excluded from accessing health care due to their economic status.

'Well, it happened that during the course of this illness for 6 years up until now, I have never got in touch with doctors' (Mr Ripan)

'Before that pak Dukuh (the head of the village) had given me some... Well... I am poor so pak Dukuh is giving his attention to me (by giving the Jamkesmas card). For instance, if I go to the hospital and need something to reduce the burden. All my three children have it. My husband has it. I do too' (Mrs Suti)

'I didn't pay in hospital. I used Jamkesmas. I just came to puskesmas asking for a referral, came to PKU, free. All was free, free consultation, free lab check...Otherwise, I would have pay a lot, at least 200 thousands rupiah for every check.' (Mrs Siti)

Mrs Siti is able to mention the exact cost that she has been supported from, which is very significant due to her condition with no job available and irregular job that her husband occupied. This notion resonates with Mrs Suti, who also benefits from the support of Jamkesmas. She has given up her work since she suffers from the long term illnesses, while her husband has non-regular income.

'I am poor so pak Dukuh is giving his attention to me (by giving the Jamkesmas card). For instance, if I go to the hospital and need something to reduce the burden, all my three children have it, my husband has it. I do too.' (Mrs Suti)

Mrs Wati mentions the need to conduct a promotional program on diabetes to a broader scope of community. She makes a comparison against another governmental prevention program on tuberculosis or haemorrhagic fever, which are still becoming endemics problem in most areas of Indonesia. She is a housewife that has been active in Aisyiyah organization, a ladies Muslim (or Muslimah) organization alongside Muhammadiyah, as the gentleman counterpart.

'What I wanted to say is about the spreading information on diabetes. It should reach broader communities. It became common problem on improper diet pattern, especially to the lower economy people. Many of them got diabetes. One of my neighbours passed away and the foot was bad. I think it is because they also had no money as well.' (Mrs Wati)

Issues with the SDSCA questionnaire

The SDSCA, an established and validated tool in identifying self-care activities (Toobert et al., 2000; Lager, 2000; Toljamo, 2001) was useful in identifying whether people performed self-care activities, such as managing a healthy diet, taking medication, physical exercise, foot care, or monitoring their blood sugar.

However, there were some clear issues that need to be considered when administering the SDSCA within the Muslim population in Indonesia. These include inaccurate reporting, religious practice of washing feet, and sampling self-care activity during times of fasting.

Mr Adil admitted that he did not take any medication while in Ramadan, which was around the time of the questionnaire being administered. However, he gives the questionnaire a full score of 14, which means he reports that he took the medication every day for the last seven days, making the self-care score unreliable. Within the questionnaire there is a need to capture if an individual wanted to perform other fasting rituals such as Daud's fasting; the ritual involves alternate days fasting. Such practice would affect the overall result of the questionnaire, the diet specific scores and the accuracy of the self-care activity.

'I felt like to do more Daud's fasting. That is good on lowering the sugar level, I heard so. One day fasting, the next one on a break, and so forth... I would like to do that, I hope to Allah one day.' (Mrs Santi)

From the outset, the researcher was aware that the third item on the questionnaire regarding foot care could serve as a bias for the Muslim people: *'on how many of the last SEVEN DAYS did you keep your wash your feet?'* The religious practice of washing feet is part of *wudlu* or the ablution before commencing daily *sholat*. After discussions with Dr Toobert there were considerations to remove the item of washing feet from the questionnaire, however the results of the study would then not be comparable to other studies using the instrument and findings could not be compared. It was decided to include the item to see if people used the washing ritual to check and monitor their feet at the same time. Interestingly, people regularly performed the washing of the feet but did not undertake any checking or caring for their feet for diabetes complications, indeed the majority had no knowledge that foot care was important.

According to the author of this questionnaire, the effort to translate and utilize it in this current study was regarded as the first attempt of using it in an Indonesian setting (Toobert, 2012), particularly in a Muslim community. Therefore, different perspectives, especially Muslim's, will be served as an opportunity in enriching the improvement of the tool.

The second part of the questionnaire asks individuals to identify the recommendations and education provided by health care professionals, but the concept of foot care education is omitted, creating bias and limitation of the information the questionnaire will provide.

The findings emphasized the notion of the limitation of the questionnaire to capture what lies beyond the social aspects of human being.

Summary

The findings chapter has explored the real life self-care activity and experiences of Javanese Muslim people managing their diabetes. The key self-care findings have been summarised in Table 5.7.

The majority of people sampled highlighted a moderate level of self-care predominantly taking responsibility for the managing their medication, diet and occasional exercise. There was no evidence of any structured education programmes within the health care sector to educate people on diabetes management; education took more the format of providing ad hoc information during a consultation. Persadia offered health seminars, an excellent source of information and support, and the people accessing these demonstrated more in depth and accurate diabetes education and knowledge. However, other than the sessions provided by Persadia, which not everyone was aware of or accessed, generally health information people received was poor and all the different self-care activities were often perceived as separate tasks, not an integrated programme. Foot care and self-monitoring of blood glucose were the least self-care activities undertaken. The data indicated clear missed opportunities to marry up washing and checking feet with religious practice to increase this aspect of health improvement (Table 5.7).

For people to be self-caring for their diabetes they need to be able to monitor their blood sugar regularly, but access to blood sugar monitors occurs only for those with the income to buy a machine. Despite this, the small number of people who owned a blood sugar machine was minimal, but the value of regular self-monitoring did not appear to be exploited or encouraged by health professionals. Persadia offered weekly not just monthly blood glucose monitoring which enabled people to keep monitor their sugar levels alongside what they had eaten that week to understand what raises their sugar levels the most.

The comprehensive education programme that Persadia offers could be rolled out wider into the community to enable greater access for all people, foster increased self-care and improve

diabetes management, expelling misinformation and increasing knowledge and education regarding diabetes management.

Whilst the SDSCA provided an overview of perceived self-reported self-care activity there were aspects of the questionnaire that need further consideration when administering within a Muslim population, surrounding foot care and religious practice.

Table 5. 7 Key self-care findings

- Javanese people reported a moderate level of self-care but for only three out of the five self-care recommended activities, indicating there is sufficient scope to enhance self-care activity within the community
- Self-monitoring of blood glucose is not performed and needs to be introduced, adequately resourced and encouraged to prevent diabetic complications long term.
- Foot care needs to be encouraged alongside religious practice
- There are no structured-educational programs in place in general health settings and diabetes clinics. Instead, the doctor and other healthcare professionals convey any knowledge in a consultation setting, which most participants regarded it as limited.
- Persadia offers a comprehensive education program of health education, fosters self-care, and social support, a model which could be extended within the community to ensure equitable access and provide psychological support to long-term diabetes management
- The lack of access to medical guidance has increased some individual's internal locus of control increasing their ability to self-care, although some self-care is based on misinformation and lack of knowledge.
- Javanese culture can influence self-care; concepts such as accept and surrender or being sensitive to others or *tepo seliro* influence individuals' perceived self-efficacy
- Muslim religious beliefs influence self-efficacy and self-care
- Family and social support can empower or disempower people to take responsibility for their own self-care activity
- Administration of the SDSCA tool to evaluate self-care activity needs to be carefully considered alongside fasting and religious practice.

Chapter Six

Religiosity and Javanese culture: opportunities and barriers to self-care

Introduction

Moderate self-care activity was evident amongst the majority of the sample participants identified by the SDSCA questionnaire. This chapter draws together the concepts of religiosity, through the exploration of Muslim Piety, to examine religious and cultural opportunities and barriers for self-care in diabetes management. Whilst the self-care activity instrument captures the capability in performing a series of activities in self-care management, the tool fails to consider any social or religion dimension that would influence people's self-care behaviour.

Within the study findings the aspect of religiosity and Javanese culture in influencing the self-care activity will be explored. Islam and Javanese culture are intertwined into the lives of the Javanese people, and at times during the analysis, it was difficult to distinguish both tenets from the interviews, except when explicitly stated by participants. Studies have shown various effects of how religiosity might influence well-being, which will be examined alongside socio-demographic characteristics to better understand participant experiences of self-care in diabetes.

The findings will be considered alongside the theory from Polzer and Miles (2007) and three typologies; God in the forefront, God in the background and God as a Healer. Detail discussion on this theory has been presented in previous chapters. However, the study findings suggest a continuum, with movement across classifications; dynamic and movable entities: surrendering and accepting at one end of the continuum, actively seeking treatment in another end, with keep trying and leave the rest to Allah in the middle.

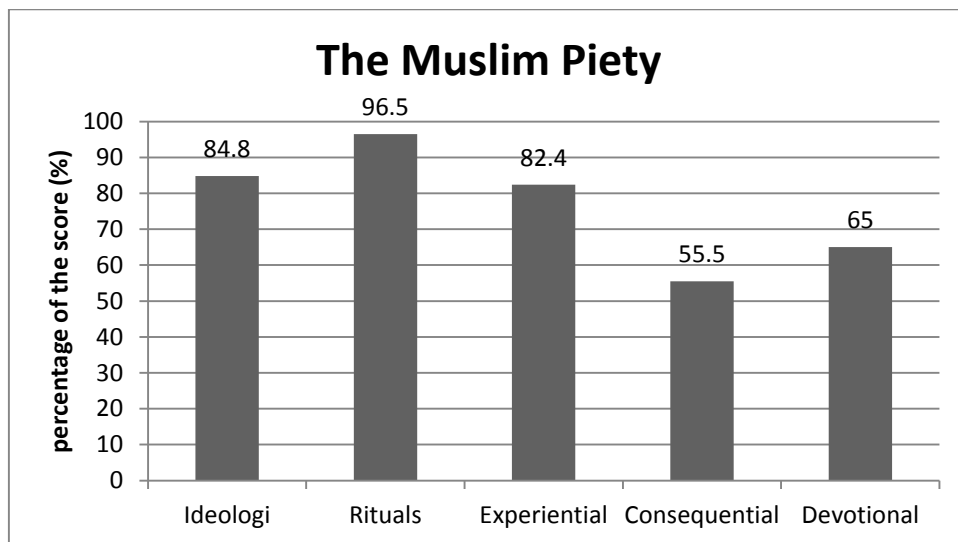
Firstly the chapter will present the results from the Muslim Piety questionnaire to fully understand the religiosity of the participants and the role of Allah or the Almighty among Javanese people through the lens of barriers or opportunities to promote self-care.

Religiosity - The Muslim Piety Questionnaire

Muslim Piety consists of five dimensions of religiosity: Ideology, Rituals, Consequential, Experiential and Devotional. The questionnaire is considered to be heavily embedded with Islamic values and teachings. That is probably the reason for the title of the tool, Piety, which inherent in itself a meaning of acts of devotion; adherence to particular values. The scoring system developed utilizes a 0 or 1 values.

Thus, to give a better understanding of the Muslim Piety, the overall score needs to be broken down into each dimension. Each dimension will be evaluated based on the percentage of each score to the total score of each dimension, instead of to the total of all dimensions. Hassan (2007) recommends that to get an understanding of the level of religiosity, the multi-dimension of religiosity has to be evaluated based on each dimension.

Figure 6. 1 Overall Muslim Piety item score's percentages



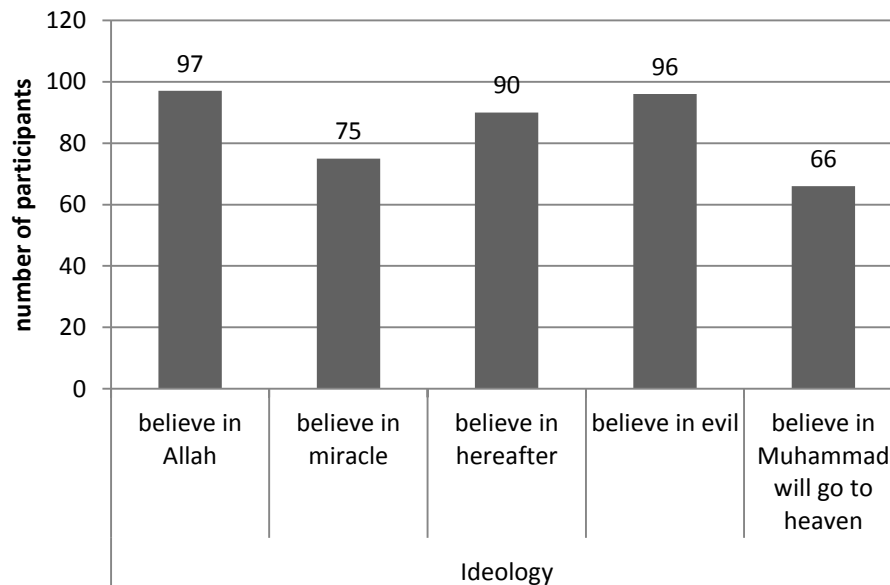
Among the five dimensions of religiosity, the Ritual dimension revealed the highest score (96.5) with Consequential (55.5) was regarded the lowest (Figure 6.1). The figures show that the majority of the participants tend to perform the rituals more than other dimensions of religion. Participants tend to prefer the more practical and obvious aspects, such as religious practices, than more deep thinking, such as the concept of ideological or experiential dimensions. Further

exploration of each dimension is required to give a deeper understanding of the overall religious perceptions of participants.

Ideological

The ideological dimension contains of five items, which are (1) ‘how strong do you believe in God?’ (2) ‘how strong do you believe in miracle?’ (3) ‘how strong do you believe in hereafter?’ (4) ‘the existence of the devil?’ and (5) ‘they who believe the prophet Muhammad is God’s messenger will go to heaven?’ Out of 100, 97 participants believe that Allah exists, 75 believe in miracles, 90 believe in the hereafter, 96 believe the existence of devil, with only 66 believe that if they believe that prophet Muhammad is God’s messenger they will go to heaven (Figure 6.2). There were 13 participants who either lacked belief in Allah or in the hereafter, the majority of which were in older age group, female and from a more regular income occupation, despite being educated to a lower level.

Figure 6. 2 Ideological dimension score



This dimension surrounds belief in the Six Articles of Faith, as discussed in great detail in previous chapter. It is considered essential among the Muslim to know and understand this concept. Therefore, it was not surprising to see a high number of Muslim participants agree with the majority of these concepts. However, for some participants miracle is a vague concept, which needs to be explained by examples. The last item is considered an indirect question, with an

aspect that relates the answer to a consequence, instead of asking '*whether you believe in prophet Muhammad as a messenger of God?*', which the majority of Muslim will answer positively without any doubt. Contradictory responses by three participants (a dentistry student, a self-employed person and a housewife) suggested some degree of doubt across some questions. Therefore, for some participants it was not easy to answer.

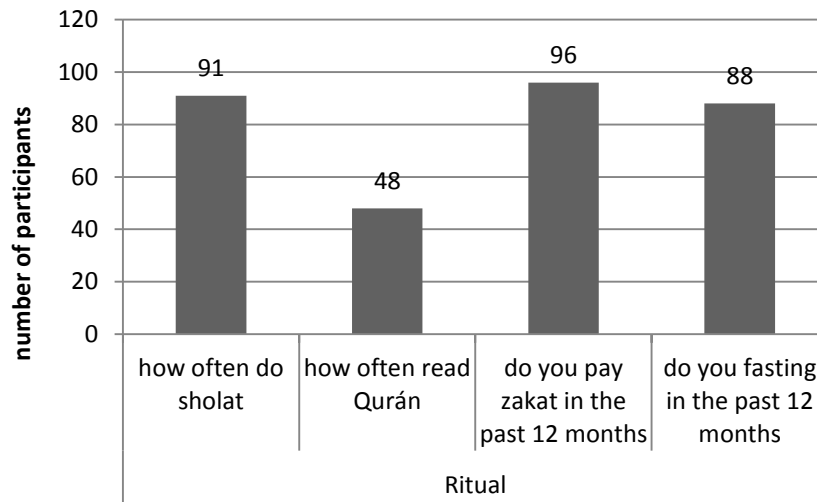
Ritual Dimension

This dimension consists of various worshipping activities, those are: '(6) for man: within a week, *'how many days do you go to Masjid days'* and for woman: *'do you sometimes go to Masjid for sholat? Yes or no'*, (7) *'how often do you sholat in a day?'* (8) *'how often do you read Qur'an?'* (9) *'do you pay zakat during the previous 12 months?'* and (10) *'do you fasted during the previous 12 months?'* Except for questions number (6), (9), and (10) which are the yes or no answer, the rests have a series of optional answer that refers to the frequency of particular religious activity.

Several items of this dimension represent the implementing belief or the Five Pillars of Islam, as discussed previously. Therefore, it is regarded crucial to perform particular activity such as *sholat*, which in this dimension is regarded as an obligatory religious practice.

The results show that almost all participants are adhering to do *sholat*, pay *zakat*, and fasting. Whereas less than half of participants (48) were inclined to read the Qur'an, the main source for knowledge of the way of life among Muslim. These were mostly female, regular income occupation and higher educated. Those participants who did not read the Qur'an, there was no difference in the level of education, gender, and the majority received a regular income (Figure 6.3).

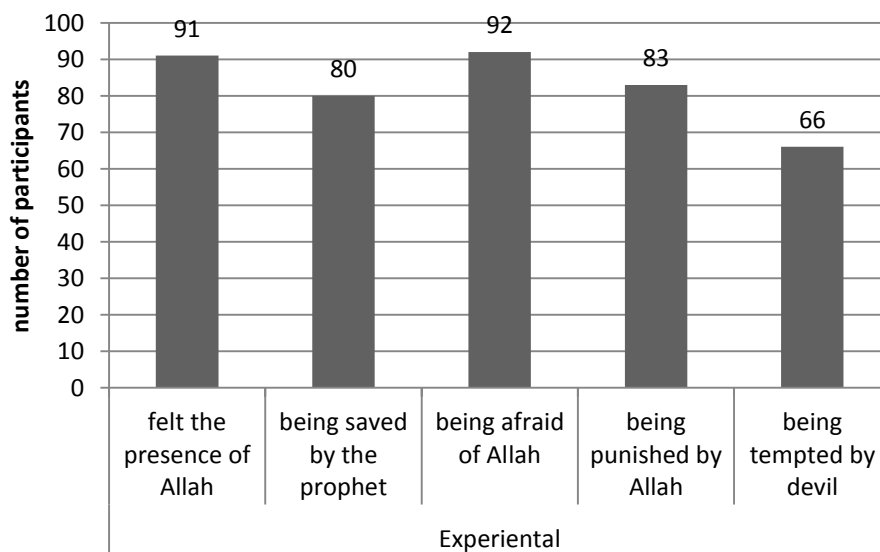
Figure 6. 3 Ritual dimension scores



Experiential Dimension

This dimension contains of five items, those are (11) ‘feeling you were in the presence of Allah’, (12) ‘a sense of being saved by the prophet’, (13) ‘a sense of being afraid of Allah’, (14) ‘a sense of being punished by Allah’, and (15) ‘a sense of being tempted by the Devil’. A higher number of females than males felt the presence of Allah, and those who did not were less educated. The majority of participants, who felt afraid of Allah, were older, female with regular income, although education levels were varied (Figure 6.4).

Figure 6. 4 Experiential dimension scores

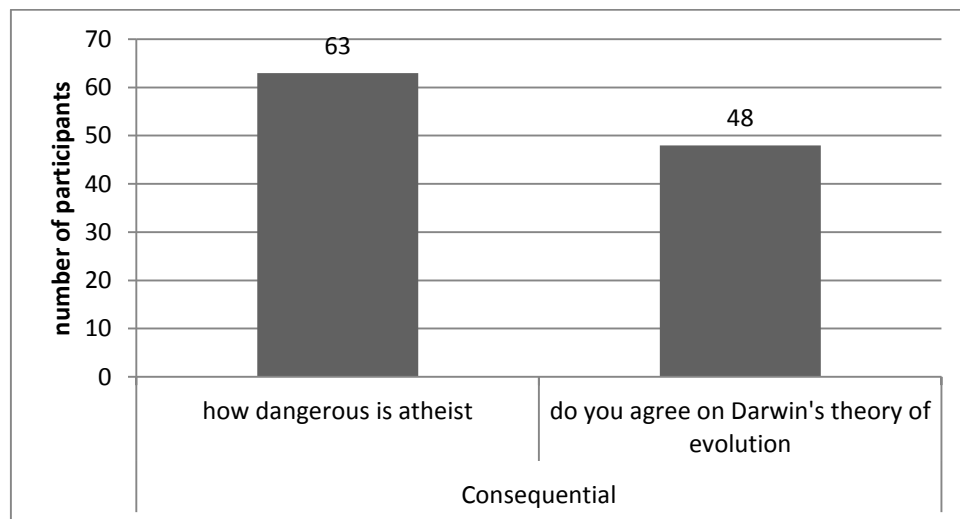


Consequential Dimension

This dimension consists of two items which asked the participant to reflect on the religious consequences to two questions of life: 'would you agree that a person who believes there is no Allah to hold dangerous views?' and 'Darwin's theory of evolution could not possibly true'. The first question was answered by more than 50% of the participants, whereas less than half of the participants managed to answer the second question.

At the time of collecting the data, the researcher found it was quite challenging in explaining about this dimension, since both questions are strongly bound to the socio-historical and academic context. In explaining the first question, the researcher used a term 'atheist' to describe the term 'a person who believe there is no Allah' and related it to the historical context of the event of what most of Indonesian known as *Gerakan 30 September* or the action of 30th of September 1965, where it is believed that the ruling Community Party, which was believed to have an atheist belief, was planning to make a coup against the existing president and was behind the murder of seven generals. Considering the politically and socially important event, this ordeal has been in the historical point of interest in the curriculum of education since the elementary school level until the university. Therefore, the knowledge of this notion will be influenced by the level of exposure that the participants gained whether from school or as a living witness to the event.

Figure 6. 5 Consequential dimension scores



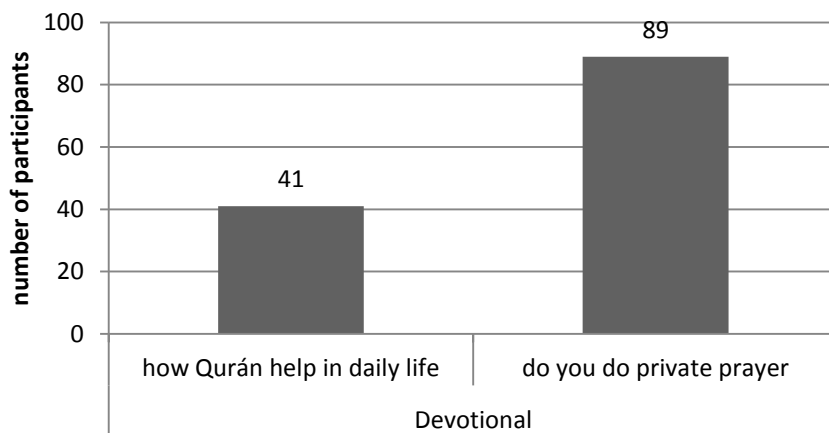
From the Consequential dimension, the majority participants (63) could answer question number 16, but less than half of the participants (48) could answer the question 17 (Figure 6.5). Among the participants who answered the questions, the majority had a lower education level. Whereas more than half of participants do not agree on Darwin’s theory, among them were highly educated and people with a regular income.

Devotional Dimension

Devotional dimension is akin to the ritual dimension; however, it is different in the prerequisite of mental attitude of the tendency towards the activities. Therefore, individuals with higher level of these dimensions showed they have a stronger internal motivation to do the activities.

This dimension consists of two items those are ‘how Qur’an helps you in making every day decisions’ and ‘do you do private prayers’ (Figure 6.6). The result shows less than half of the participants answered the first question, whereas the majority of participants had answered the second one. Most of the participants, majority female, from the older age group and lower education level, were unsure as to how the Qur’an can help in everyday life. Most of those participants doing private prayer or *sholat* were older and higher educated.

Figure 6. 6 Devotional dimension scores



Sample characteristics and levels of religiosity

In general, based from these results that are evaluating each question of each dimension, it reveals that the majority of the participants in this study have a relatively higher level of

religiosity, which is evident from the ritual, ideology, experiential, and followed by devotional and consequential. This result is mirrored by the results from the interviews.

The level of religiosity, which is determined by the overall score from each participants, are distinguished into three categories of high, medium and low. Therefore, based from the 0 or 1 scoring system, and excluding the question number 6 which contains a number, the score ranged from 0 to 18. A higher level of religiosity was determined at range 13-18, medium 6- 12, and low from 0- 5. From this categorization, 79 participants were considered as highly religious and 21 moderately religious, with no participants in the lower level of religiosity (Figure 6.7).

Females (58.5%) were the majority of the highly religious participants compared to male (41.5%). Higher educated participants were predominantly highly religious participants (71%), and less religious participants were educated to a lower level. There was a spread of high and medium levels of religiosity in both high and low self-caring groups (Table 6.1). The typology's found were God in the Forefront (17) and God in the Background (7), no participant viewed God as a Healer, discussed later in the chapter.

Figure 6. 7 High and medium levels of Religiosity (whole sample)

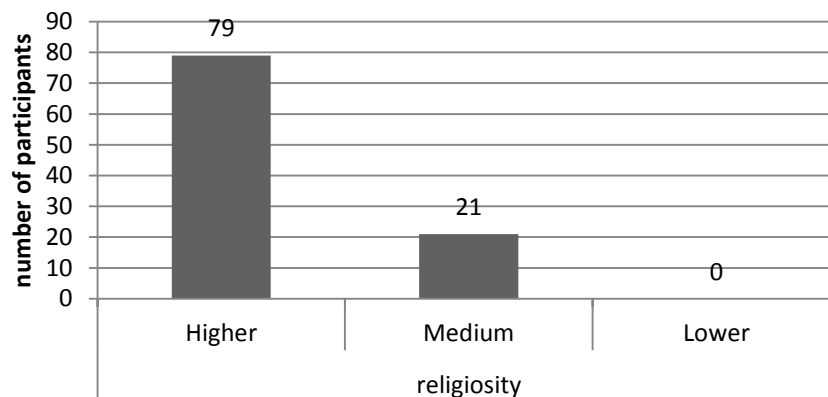


Table 6. 1 Religiosity, Self-Care and Typology

pseudonyms	age yrs	Self-care			Religiosity			Typology*		
		H	M	L	H	M	L	FF	BG	H
Mr Adil	56		1			1		1		
Mr Arif	42		1			1		1		
Mrs Asti	77		1		1			1		
Mrs Eva	39			1	1			1		
Mr Fajar	39		1		1				1	
Mrs Heti	47			1	1			1		
Mrs Ismi	71		1		1			1		
Mr Jawen	64	1				1		1		
Mr Kasi	88		1			1		1		
Mr Makmur	58			1	1			1		
Mrs Maryam	60		1		1				1	
Mr Ripan	48		1		1			1		
Mr Sadi	48		1		1				1	
Mrs Santi	56		1		1			1		
Mrs Sati	60	1			1				1	
Mrs Sifa	62		1		1			1		
Mrs Siti	50		1			1		1		
Mrs Sujawi	47		1			1		1		
Mrs Suti	46			1		1			1	
Mr Suyono	63	1			1				1	
Mrs Swasti	45		1		1			1		
Mrs Tata	58		1		1				1	
Mrs Umi	57		1		1			1		
Mrs Wati	57	1				1		1		
		4	16	4	16	8	0	17	7	0

*FF - God

Forefront

BG - God

Background

H - God

Healer

Themes and findings

As mentioned earlier, the study findings suggested a continuum, with movement across classifications; dynamic and movable entities: surrendering and accepting at one end of the continuum, actively seeking treatment in another end, with keep trying and leave the rest to Allah in the middle. Based on this continuum three core themes emerged and two additional themes warranted examination as supportive roles in society and religious practices to facilitate self-care (Table 6.2).

Table 6. 2 Themes of religious findings

- **Surrendering and accept**
 - Surrender, accept and maintain harmony
 - Surrender accept and Allah will help
 - Surrender accept and self-care
- **Keep trying and leave the rest to Allah**
 - Allah as the determinative factor
 - The medium in human endeavour
 - Human endeavour in self-caring
- **Actively seeking treatment**
- **Religious Practices**
- **Social ties and well-being**

Surrendering and accept

At one end of the continuum towards self-care this theme had three very different dimensions to surrendering and accepting which related to:

- Surrendering, accepting the illness to maintain harmony (Javanese culture) referring to the act of giving up to the illness and accepting it '*as a coincidence*'; something that has to be taken as it is.
- Surrendering and accepting the illness but believing you can do something about it, with self-care
- Surrendering and accepting the illness but believing that Allah will help

All seven participants in this theme, with diverse socio-demographic characteristics, with slightly more male than females, but ages spread across middle and older age groups, and high and low (regular or non-regular income) (Table 6.3).

Table 6. 3 Participants' characteristics of Surrendering and Accept

Characteristics		Number of participants
Gender	Male	4
	Female	3
Age group	< 40	1
	40 – 59	3
	>= 60	3
Level of education	Lower	4
	Medium	3
	High	
Income type	Regular	3
	Irregular	4

Surrender, accept and maintain harmony

The theme refers to the perception of the illnesses as something that is ordinary and might be taken as the way it is.

'Maybe it (any events in life) was just coincidence (instead of destiny)' (Mrs Siti)

'Javanese people will say it is "kersane gusti Allah" (upon Allah's will) if it was being rewarded by God, everyone has to be surrender' (Mr Kasi)

'Just accepting it... I did not know if it was diabetes. I only considered it as common illness' (Mr Jawen)

Accepting a condition as something usual or normal is essential in understanding what further action will be taken by the individuals. Maintaining this attitude is beneficial to lower the level of threat that the condition creates, described by the participants. Indeed, this served as evidence of how participants preserved harmony within their own body; an opportunity of how surrendering might help towards maintaining the level of blood glucose level.

Mrs Suti explained that by keeping our mind in fewer burdens, by not thinking too much about the illness will help her in maintaining her well-being.

'Basically, according to Javanese way, everything we do we should do it slowly... don't bother to think anything, if you get tired, so be it... after you get better then you can start to work again... I followed it, and it would ended up good' (Mrs Suti)

Mr Jawen, admits himself as an *'Islam KTP'* or nominal Muslim, and being an active Kejawen practitioner, a Javanese spiritualism, addresses that it is important to accept it as the way it is or *'nerimo ing pandum'* in Javanese, which have helped him in staying in sanity. This resonates with Mr Sujawi who believes that Allah will help him after he set his peace of mind.

'Well, it is inside our own batin (inner mind). Let say nerimo ing pandum (accepting with sincerity). So, nothing else...accepting the way it is. If we didn't have much thing to eat, just eat a little. If we had a lot, don't be too greedy. I am not keen to do anything else. The important thing is that I can eat every day. Because if I didn't nerimo ing pandum I would go crazy' (Mr Jawen)

Mr Jawen is a good example of someone who moved past surrendering and acceptance to undertake self-care; indeed he reinforces the movement along the self-care continuum.

Surrender, accept and self-care

Maintaining harmony is to accept being a diabetic and become more responsible to one's own well-being. Mr Fajar admits because diabetes is incurable, managing diabetes long-term requires a life time effort. Moreover, along with other participants in this theme, he also believes that Allah has a determinative role in life (described later). He considers himself as the main actor in life, who responsible for his own well-being; a tenet of good self-efficacy and high internal health locus of control. This notion resembles the typology of God in the Background, which puts God as a supporting actor, behind the individual. Indeed, this finding can serve as an example of the dynamic of the continuum of the themes.

'It is not curable for the long run. The disease is not curable, but it is only we ourselves that might control the disease...It has been set by Allah that some people will be successful in their thirties...everything has been set' (Mr Fajar)

Mr Fajar demonstrates good self-efficacy and internal health locus of control. However, the good self-determination has led him off-course to ignore the health care professional's recommendation, relying on prayer and developing his own dietary regime, not restrained by the diet recommended by health professionals.

'I like to have things on my own terms. For example, if I follow the doctors, I will be restrained and not allowed to eat this and that. However, if I am on my own, I am allowed

to eat even though only for a little. So, I take it as a cure for my appetite. Meal time at 11 am and 3.30pm or 4pm... No snacks... This is in order to maintain the level of my blood sugar. Three months ago, my blood sugar was 99' (Mr Fajar)

'Well, for me, we shouldn't give much part (of the effort) to the doctor... but we also have to do more prays' (Mr Fajar)

It will not cure by itself, we need to strive, endeavour for a medication, and pray as well' (Mrs Ismi)

Mrs Ismi believes that human has to do any effort to manage their condition, and the cure will come if she has a greater faith in Allah.

'Definitely... yes... keep on trying and always praying... because, well, insya Allah the best I can... because, every effort, diet, reducing this and following all the rules are just physical effort' (Mrs Ismi)

'First is prayer...then number two is the medications. If we can do them all would be great, isn't it?' (Mrs Suti)

A potential opportunity exists to bridge the gap between one's own determination and how to achieve the health recommendations from the health care practitioner with aim to achieve the better well-being. To stay away from being anxious or stressful is one way of managing diabetes as well, since it also is mentioned in the diabetes guidelines from the International Diabetes Federation.

The feeling of peacefulness can be gained by trying to gain harmony with their own body and mind through any means available such as choosing the right amount of diet, instead of following the more 'strict' regime from the dietician or 'slowing down'; an act of taking everything lightly, or by performing any religious practices such as pray, which most participants in this theme preferred to do.

Alternatively this act of surrendering can also act as a barrier in maintaining a good self-care, especially with the absence of an adequate knowledge for diabetes management. An example is Mr Jawen, with a low level of religiosity believed that pray will help them in maintaining their illness, and demonstrated a good level of self-care. However, his interview reveal both of them

have a lack understanding of best practice self-care with fluctuating blood sugars revealing complications.

'Yes of course. The important thing to do is praying. There is no good medication than prayer...Me for example, last June when I just got back from Sumatera, I got cataract on my left eye, I could barely see. So every night I prayed, asked to God in tears. When I checked myself on Monday, the sugar level was 530, when I must attend medical operation on the next Wednesday. So I was fasting for three days... I only drink plain water. Came Wednesday, I got checked and it was 130, so I could go to surgery... I think because of the fasting, but also we brought it on praying, it got granted. My eye could be operated so I can see now' (Mr Jawen)

Surrender accept and Allah will help

The notion of Allah as the source of ill and health in Islam can be sought further through the Qur'an Surah Ash Shuara ayat 80, which clearly mentions that understanding, *'And when I sicken, then He health me'*. Exactly the same ayat is mentioned by Mr Makmur explaining his perception of how Allah has a role in his current circumstance. This ayat clearly underscores the notion of Allah as the source of ill and health, as for the cure of the illness; a concept of external locus of control in regards of how Muslim perceives who responsible for any condition of ill health (Rotter, 1966, 1990). Illness can refer to the perception of Allah as the reason for the results of poor human effort, thus it reflects to some extent to the reduced responsibility of the individual in managing their own condition. However, it is believed that healthy people who believe that God has control over their well-being show more inclination to the practice of health related behaviour (Welton et al., 1996).

Among these participants, there are several notions that emerge from the interviews range from *'Allah as the source'*, *'Believe in Allah's will'* to *'Life is determined'*, which refer to the determinative nature of Allah as the creator of life. Participants strong descriptions reflects the concept of religious orientation that refers to how individual perceives religion or God in their life; whether as something that has an important meaning for their life or something that serves as a contributing factor to their social life.

'I guess initially we would get peace of mind, firstly, the peace of mind and if we pray, Allah will give way... Yes, if we surrender ourselves, we got the light. Let's say if we do the thinking only about 10% and Allah will give the rest' (Mr Sujawi)

'For me it is Allah, definitely. For everything, if there is no Allah who moves it, there is no way our heart will be moved' (Mrs Umi)

'Yes, exactly... It's been written, including our death. If I have to die in my 50 years old, I'll die. It's all Allah's business' (Mrs Eva)

'So, everything is Allah's destiny. For everything that has happened, I mean. That's Allah's destiny' (Mr Suwaji)

'Everything has been destined. If we believe in the qadr (destiny), we would purely accept everything that has happened to us. That everything is by Allah's permits' (Mr Makmur)

'It appears that in this life, everything had been destined, thoroughly, and we could only walk through it.' (Mr Arif)

'Then, I, well, because I have Allah, I asked only to Allah. Because (Allah) who gave the illness, Allah the one who would give the cure.' (Mrs Maryam)

'But I do believe that Allah gives the illness along with the right medicine, faidza maridu fahuwa yasfi (And when I sicken, then He health me). It's just like the pictures in the PKU. I really believe in it.' (Mr Makmur)

For several participants, including Mrs Ismi and Mrs Tata, Allah has been serving as a determinative role in deciding the end result of her effort. They believe that human has to do any effort to manage their condition, and the cure will come if she has a greater faith in Allah.

'...all the rules are just physical effort, the most important part, believes more in miracle... (Laughs)... that is it... I have a strong belief on that.' (Mrs Ismi)

'By praying, insya Allah if Allah is willing everything will come back to Allah. Whenever Allah desires, we will get a good result. If Allah does not, whatever good our effort it would not succeeded.' (Mrs Tata)

'I of course believe in Allah, insya Allah, they say that for every illnesses there are cures, so what I believe is insya Allah as long as we have faith, that's it' (Mrs Tata)

Because it is Allah's promise to give human what they ask.

'Yes, insya Allah, (Allah will grant) because that is Allah's own promise 'ud 'uni astajiblakum, isn't that right? Just pray so I shall grant you, Allah said, in Qur'an. So I do believe. Insya Allah will' (Mrs Ismi)

If it has not cured yet, then, Mrs Ismi believes that it is the religious effort that has to be increased and wait for Allah to prove His Word. She believes that how someone gets the illness is not only relied on one's own inappropriate effort but also because of Allah's will.

'No, not really (it is not only inappropriate diet that cause the illness). Allah's role still existed' (Mrs Ismi)

'Yes it does have connection (with Allah's will), since man usually got tested, through an illness' (Mrs Tata)

Mrs Siti believes that Allah will help her even without medication. Indeed, the questionnaire shows that she did not take any medication for the whole week before she completed the questionnaire; she showed a lower score of self-care. She also mentions her preparedness to her fate in case the worst would happen to her; this typifies believing God as a Healer, which believes that if the faith is sufficient, self-care is no longer needed.

'Yes, it will be cure, I believe... (Allah will cure me without medication)...No, (I wasn't afraid of dying). I just surrender to Allah. In case that would be my way that I was to die, please do...surrendering. All my children are already on their own, I don't have anything to be bothered' (Mrs Siti)

Mr Sujawi showed a good understanding of perceiving working as a mandate from Allah and a belief that Allah will help him in managing his work better. Indeed, this notion serves as an opportunity to put self-care into a more prominent place; as a mandate from Allah to preserve our own body.

'Everywhere we work, first of all, it is amanah (a mandate) from Allah through the company... If we do it (work) as a worship... as a leader Allah would give as a mind set of an openness in order to manage better'

Mr Sujawi admits that he was an active *Kejawen* practitioner, with higher level of religiosity, based from the questionnaire, although he is more likely to be spiritual rather than religious, he mentions several tenets in maintaining harmony with oneself and the others.

'After we did the right way, straight way, we would have a belief that we have a calm life, and not anxious...Yes, if we have more relatives, keep the silaturahmi (good relationship with other) automatically Allah will bless us always, abundantly... But the important thing is we must be sincere to accept all things. Therefore, facing whatever others will tell you or you (said) anything to me, we may never get insulted'.

Keep trying and leave the rest to Allah

The participants in this theme have a firm belief that Allah has a significant role in their ill-health condition; a notion that distinguishes the difference with the first theme. Thus, Allah is regarded as the last place to be relied upon after keep on trying. By keeping on trying means not only undertaking physical-worldly endeavour by doing the self-care management of the illness, but also performing any religious effort, such as saying prays, performing *sholat*, and others. With regards to performing religious practices, the participants in this theme showed a tendency to be more adherence than the majority of participants in the first theme. This theme resembles the typology of God in the Forefront, which believes that despite the awareness of the importance of keeping the effort, Allah is the main actor who responsible for the end results. However, as it will be shown later, this notion exists as a dynamic entity. If the faith is stronger, the participants may reduce the self-care activity; and shift to God as a Healer role.

There were fifteen participants that composed this theme, slightly more women than men (9 out of 15). The level of education is varied across participants but two thirds of the participants have regular income (10 out of 15). All participants show a high level of religiosity and twelve participants a higher level of self-care level.

This theme consists of three sub-themes, which are: Allah as the determinative factor, human endeavour in self-caring, and actively performing worships. The first sub-theme refers to the perception among the participants in how Allah has the major factor in determining human's destiny. The participants also believe that the way Allah helps human being is indirectly; through the medium, such as knowledge, the doctor, or peace of mind. Human endeavour refers to the belief that humans have to do the worldly-effort regardless of the perceptions of fate. The final sub-theme explains how participants believe that if the result of the effort is unfavourable, it is

their obligation to do more worship, so Allah will change their destiny or give easiness in maintaining their condition.

This theme supports the tenet of how individuals are performing religious practices and maintaining physical effort in self-caring for their illness, a collaborative effort in pursuing general well-being, leaving the result to Allah as the Almighty. This notion reflects a concept of *tawakkal* in Islam; a belief that a man has to leave the result of their effort to Allah after striving in maintaining their own well-being, as an act of recognition to the Almighty.

'We could only make the effort and Allah determines the result. I have made the effort, then Allah determine the result' (Mrs Santi)

'I think both ways are going along the way (simultaneously) because we are obliged to make an effort, meaning physically and mentally. The mental effort is through praying to ask for healthiness and the physical effort is through medication, go to a doctor or to an alternative medication. And maybe by doing that, Allah will hear our prayer and make it come true and we are given the cure...The one that determines the end result is Allah, but human should make an effort'(Mr Sadi)

They believe that, although the fate is already destined, prayers can change it. Moreover, if the results of their effort were not favourable, participants believe that they have to do more religious effort. This reflects a cycle of human's physical-mental and religious effort with Allah's destiny, which can lead to healthy body that enable human to do more religious effort. The notion that underlines the difference with the first theme is the importance of pursuing worship as the next step after the effort, and believes that by doing so; Allah will help the management of the illness. While, the first theme indicates the importance of keeping the peace of mind and maintaining harmony as Javanese; a tenet of a broaden concept of spirituality.

'Well it is destiny, but God can change the destiny if the person wants to change their own destiny' (Mr Suyono)

'Preserve ourselves by being healthy, so we can do everything that has been taught by Allah so well, for example sholat (prayer)... if we are healthy we can do sholat perfectly' (Mr Ismi)

Allah as the determinative figure

All participants believe Allah as the major determinative factor in their life; the major figure in deciding any life events that have a great impact on well-being of human being, entwined within the cultural setting of Javanese people. This tenet is important to understand how people will manage their condition based on this belief and what are the barriers and opportunities for self-care.

‘For me it is Allah, definitely. For everything, if there is no Allah who moves it, there is no way our heart will be moved’ (Mrs Umi).

‘Yes, exactly... It’s been written, including our death. If I have to die in my 50 years old, I’ll die. It’s all Allah’s business’ (Mrs Eva)

‘But I do believe that Allah gives the illness along with the right medicine, faidza maridu fahuwa yasfi (And when I sicken, then He heals me). It’s just like the pictures in the PKU. I really believe in it’ (Mr Makmur).

For some this idea of Allah as the determinative, relinquishing the results to Allah has proven to be unhelpful; as also shown by the results of their lower perceived self-care level for Mr Makmur, Mrs Eva, and Mrs Heti (Table 6.4).

Table 6. 4 Difference between high and low self-care level's (n=15)

Level of Self-care	Number (n=15)	Diet	Physical Activity	SMBG	Foot Care	Medication
High	12	76%	69.6%	19%	56.5%	88.1%
Low	3	36.2%	21.4%	0	14.3%	23.8%

All three have a good understanding of several tenets in Islam, even Mr Makmur mentions above several ayat from Qur’an. While, Mrs Eva and Mrs Heti frequently attend *pengajian*, as one source of religious knowledge, described by Mrs Heti addresses as the place for ‘*charging our faith*’. This finding relates to the typology of God as a Healer. Indeed, this notion exposes the dynamic nature of the finding from this study compared to the existing typology differentiation from Polzer and Miles (2007).

These participants come from middle to younger age groups (Mrs Eva 39, Mrs Heti 47, Mr Makmur 58 years old), they all have a relatively stable income; except for Mr Makmur who owned a business, compared to Mrs Heti and Mrs Eva who are employees.

'Charging, I would say, charging our faith. Sometimes we forgot then we become remember again. Knows that something is bad but we do it anyway' (Mrs Heti)

If individual case is put into consideration, Mrs Eva is showing a lack of adherence in term of following the medication recommendation due to the confidence that the insulin injection has been working adequately based on the last three month blood check.

'After that, I regularly controlled my blood sugar and had the insulin injection. My blood sugar was getting normal afterward. Dr Irfan has reminded me to have a regular check-up, but I just ignored it. I was boring to do the same thing. When my blood sugar was normal after 3 months of regular check-up, I decided to stop having injection' (Mrs Eva)

Nevertheless, there are several exception cases from the lower level group. Under the foot care regime two participants admit they have never done that self-care activity, whereas Mrs Eva has been performing foot care, without prior knowledge from the healthcare professional. The questionnaire shows her to see between the toes every day for the last seven days of the week, and six days to see inside her shoes. Moreover, in the interview she mentions on watching for the development of *rangen* or a Javanese term for fungal nail infections that for people with uncontrolled diabetes could lead into an ulcer.

'I just heard that diabetic person could have rotten feet. That's what I know. It also happens to me that if I cut my finger too short, it may become swollen. But I never have rangen because ... while taking wudhu, I always washed my foot between the toes. So, I never have rangen' (Mrs Eva)

The perception of Allah as a determinative role has served as a hindrance to self-care for some participants. However, this finding can act as an opportunity for an intervening factor of a Muslim cleric or 'ulama to enlighten them that Allah would want people to preserve, or look after themselves.

The medium in human endeavour

Some participants believe that in determining their destiny, Allah is working indirectly through different mediums. They believe that Allah is playing a part in respect of the management of the illness by showing the way and knowledge to find appropriate treatment, including the right doctor and medicine, as well as other resources such as dietary management.

'That (dietary management) is only the medium, as a medium, I related that to a hadith from the prophet that said 'eat but not too full', that makes a good combination, you see' (Mr Adil)

'Because cure and illness were coming from Allah... Doctors are only the medium...' (Mr Ripan)

'So when the sickness came, and we seek for the doctors, they all are coming from Allah, the medicine, as a medium... So is the medicine, everything is from Allah' (Mrs Wati)

Several participants address that the reason why he has been looking for the help from the doctor is because he believes the doctor knows best in regards of how to treat the illness.

'Well the main thing is that we keep doing the effort, consulting to the doctor is what I thought to be the best way since they knew better, and I also follows the orders' (Mr Arif)

'Fortunately that I got the medication, if someone has not been treated by the doctor...he would be suffering from the pain... it was really bad, indeed...' (Mrs Ismi)

'Yes... it has been under controlled, I think what Dr I has done is great' (Mr Suyono)

Human endeavour in self-caring

By suggesting illness as a destiny does not necessarily mean that people have to accept it with a fatalistic act. Mr Suyono explains what he perceives is the meaning of destiny. He compares between the acts of keep on eating something that we already know to have an unfavourable effect, which he regards as not destiny, with something good yet showing an unfavourable effect at the end, as destiny. Participants in this theme have a belief that Allah has a role in their life and their circumstances with diabetes. They consider the illness as a destiny in their life, since Allah gives the illness and the cure, accordingly. Even, Mr Suyono quotes an excerpt from Qur'an (*'abundant evidence for everyone who thinks'*) and a title of a book to describe how he perceives

illness. He appears to be a religious person with sufficient knowledge on several tenets in Islam, and sometimes he quotes several ayat from Qur'an throughout the interview.

'Let say, if we ate something spicy and we got stomach ache, then, thought about it (it is not destiny), but if we already managed a good food but still got the illness, well, we don't know what was the real thing, so it was up to Allah (to decide).' (Mr Suyono)

'Then, I, well, because I have Allah, I asked only to Allah. Because (Allah) who gave the illness, Allah the one who would give the cure' (Mrs Maryam)

'For me it is Allah, definitely. For everything, if there is no Allah who moves it, there is no way our heart will be moved' (Mrs Umi)

There is a belief that people are obliged to strive for a better life, which Mrs Ismi believes it is 'a mandate' from Allah to look after our own body. Indeed, twelve out of fifteen demonstrated a higher level of self-care (Table 6.4).

'It will not cure by itself, we need to strive, endeavour... and pray as well' (Mrs Tata)

'It (our body) is amanah (a mandate)... laugh... our body is a mandate from Allah for us to be preserved' (Mrs Ismi)

'Was it a reminder for me so I can increase my worship to Allah? Like it was an admonition... yes, so I should do more worship' (Mrs Ismi).

'Well, we have to try and not only have the faith. It has to be efforts' (Mrs Sifa)

Keep the physical effort could be a preventive measure to gain a meaningful life, or for Mrs Ismi to prevent for being a burden to others; an act of keeping the harmony not only with herself but also with others. For Mrs Sati, religious practices might be a place and time to do physical activity; spending her time wisely. She feels that doing an outdoor activity may increase her chance to fall, due to her age. Therefore, she prefers to do a simple physical exercise right after performing *tahajud sholat*, usually the middle of the night after spending some time to get a sleep. This emphasizes how religion embeds in everyday life of almost all Muslims; as leverage to raise the value of religious practices into a more functional way. Indeed, this finding provides an opportunity to increase the awareness among religious people of embedding religious practices with more worldly behaviour.

'I was afraid to do the exercise somewhere else, so, I only did it at home. After I performed the tahajud prayers, I needed to do some exercise for several minutes. Just tried to move my body...I move my arms, tiptoeing, that's all. That's it... Every day, after I performed the tahajud prayer' (Mrs Sati)

'Self-restrain to me, is to contain my own appetite, since I do want to live longer, stay away from illness and be a bless to anyone, be able to look after my grandchildren' (Mrs Tata)

'Mainly for worship (the purpose of doing all rituals are), worship. Apart from that, the physical effort to (stay healthy)...Because I think a long age if it is quite long will be bothersome not only to anyone else but also ourselves... It is not that I want to die now because I am not prepared for it... (Laughs)...not yet...I still don't have anything to carry if I die... I want to live longer but healthy' (Mrs Ismi)

By keeping striving is a not only limited to physical effort but also religiously. The participants mention performing pray, *sholat* and other religious practices as another means to improve their well-being.

'I thought so (that religion has taught me to deal with the illness). We are to be patient, keep on dzikir, doing sholat on time, at all times' (Mrs Umi)

'We have to return them back (to Allah). We have to introspect ourselves. Maybe we have done wrongdoings' (Mrs Suyono)

'It seems that every time the Ramadhan season came I had the suffering, why does the attack of the mild stroke happen during the Ramadhan. I tried several time to contemplate and sought myself on what things I have done wrong. Is it because the lack of religious matter, because that is what I really lack of' (Mrs Wati)

Actively seeking treatment

This theme composes of another end of the continuum, and is referring to the participants who believe that the illness is coming from Allah as the source of any ill-health condition, and consider that the very next step to be done is to find any treatment available, then surrender the matter to Allah as the last resort. Thus, this notion has served as the different point from previous theme, which emphasizes the belief of Allah as the source of ill-health condition and worshipping is the next step that is more preferable to seek further before self-care. This theme consists of three sub-themes, which are: Allah as the source, keep the effort, and the religious practices.

The participants in this theme consist of two female, Mrs Sifa, age 62 years old, and Mrs Maryam, 60 years old. More details on the characteristics can be found from the table below with further explanation to put a bigger understanding of their contextual socio-economic positions. More details can be found in the table 2 below, followed by further description.

Mrs Sifa, as well as her husband, is both retired teachers who have been working as peasants even when they were still active teachers. They have five children with one has already passed away. She considers herself has a lack of religious knowledge, but managed to get the children spent their education time in Islamic boarding school, which they were taught many Islamic teachings.

'Let, see... I don't know the knowledge (about any teachings about keep on trying to keep healthy). It is there. But I don't know the knowledge of that. I am not good at religion since I graduated from public school. But I managed to get all my son went to pondok pesantren (Islamic boarding school)' (Mrs Sifa)

Thus, it also emphasizes the notion of how she managed to get the advantage of attending any *pengajian* in the effort to increase her knowledge; since she mentions her weekly activities of attending such activities. Although, as it will be explored later on, she also shows a good understanding of several religious practices that closely related to her particular daily activity.

'I will usually have my pengajian at... at the masjid once every week, every Thursday night. If I was sick I wouldn't come... laugh... it is the routine [] it's only pengajian. Also at the A'isyiyah at Moyudan's branch and at the Hajj's gathering as well... There was one in the sub district, my former group (when I went to Hajj). I went for Hajj at 2004, my husband was at 1982. He was quite a while longer. On every selapanan there is a special pengajian, a tadarus and a lesson from an ustad (Muslim scholar)'

Mrs Maryam is an owner of an authorized motorcycle garage. She has been running the business by herself, while her husband, a retired teacher, has been more into a voluntary work of supervising the development project of an elementary school, at time the of the interview was been taken. They are living with a daughter who is still studying in a university, while the other two children have been moving out to another city. She has been put main responsibility of the business since her husband has just recovered from a colon cancer and need more rest. Thus, this

is also a consideration for her when she was thinking of attending any *pengajian*, which usually will be held at night, since she does not want to disturb his resting time.

'It was difficult to enter the house since after Magrib or Isya, my husband would go to sleep and I didn't have the heart to wake him up. So, I didn't go instead. He is old now, you see', laugh. 73 years old. But, Alhamdulillah, he is still healthy. He used to suffer from a colon cancer but, Alhamdulillah, Allah had saved his life'

All participants believe that Allah is the source of ill-health condition in their life.

'It is a test from Allah. I was tested with illness as well with the blessings. I am grateful for that... (If the sugar was still high despite of my effort) yes, maybe it was because I didn't manage myself. I didn't control myself...I have surrendered myself since I already tried everything that I could, that is all I can do. From the herbs until pray. ' (Mrs Sifa)

'Because (Allah) who gave the illness, Allah the one who would give the cure... Well, by maintaining your diet with... well...adhering to doctor's recommendation... Treatment... let see (and)... Surrendering to Allah' (Mr Maryam)

This tenet underscores the important role of human's effort in managing their condition. For the participants in this theme, lack of effort is considered as the reason behind the increasing blood sugar, despite their effort and prays to Allah.

'Yes, maybe it was because I didn't manage myself. I didn't control myself' (Mrs Sifa)

'Well, by maintaining your diet with... Well, adhering to doctor's recommendation [...] Treatment, let see' (Mrs Maryam)

'Was it a reminder for me so I can increase my worship to Allah? Like it was an admonition... yes, so I should do more worship' (Mrs Ismi).

Furthermore, Mrs Sifa mentions that it is important to do the effort and not only having the faith to Allah, while Mrs Maryam reinforces the need to do any endeavour after accepting being diabetes.

'Well, we have to try and not only have the faith. It has to be efforts [] yes, it was own effort and medication all together' (Mrs Sifa)

'But our role would be, in this matter, we also surrender in accepting the condition, and keep on trying, come to see the doctor, diet management and so on so forth' (Mrs Maryam)

Mrs Maryam has echoed a tenet of surrendering and accepting the illness, which was an important part of managing the condition. As mentioned earlier in the previous theme, psychological regime is an essential treatment for diabetes management. While, Mr Fajar shows a good self-efficacy, which helps him manage his condition, although the questionnaire indicated low self-care in the activities stated but he demonstrated high self-efficacy and self-care in other aspects seeking diabetes management.

Maintaining the diet and physically active were considered important in managing diabetes. Mrs Maryam and Sifa have put those regimes into a more religious place by embedding an Islamic teaching. Mrs Maryam is taking moderate diet as what the teaching has addressed with. While, Mrs Sifa is reciting prayer while doing morning walks.

'Well, the prophet in the hadits said 'Eat before... eat... eat (she looked like trying to remember something). 'Finish eating before you full'. It means that we have to keep our stomach from being full; it has to be other components as well. Water, let say, air, let say. It basically shows us that we have to eat regularly and proportionately. Not too full but not too less. Just moderate' (Mrs Maryam)

'I would usually do a morning pray while walking. There is a morning pray, you see. I usually read alfatihah, then the beginning of albaqoroh, ayatkursi, then the end is... let see... Lillahi something. Then I read al Kashr, ikhlas, falaq binnas' (Mrs Sifa).

By doing such practices, Mrs Sifa believes it will help with the treatment. Furthermore, she addresses the belief has emerged as she already experiences some facts of a sensation of being in a constant protection since she always performs certain prays. Another opportunity of embedding religious practices into self-care activity.

'Yes, it (the prayer) helps (the treatment). I believe because it happened when I was travelling alone for several times. Every time I almost got hit, fortunately. The road was quite. It was near the block, anything was just happening. And the other vehicles was just got turned away on time. So, I believe in that [] I believe in that. I was still 'direkso' (being protected) by Allah [] yes, I do have a strong belief in that that is why I believe that Allah is the Entirely Merciful and the Especially Merciful. Allah is the Protector of the believer'.

Mrs Sifa was inclined to seek alternative medicine. She was told by a neurologist who happened to use herbs as one recommendation to treat any illness. The neurologist has suggested her to

use some locally planted herbs that might help her in maintaining her condition, which she finds to be true. Similarly, Mrs Maryam, also takes herbs as her second treatment, since she still believed in the Dr's medication.

'I have taken some kind of herbs...pletek leaves. When I was about to do the operation, I was told by dr Nori. 'Mam, I would give you the pletek leaves.' What kind of leaves is that, what it is in English, I don't know. 'Yes, I would'. I said...There is also kersen fruit, it is said can reduce the sugar as well. There is ceplik piring leaves, I used to boil it and turned out my sugar was declining. It made the doctor at Cempaka amazed...My sugar was a little bit high. 'Doctor, what stressed out is in the heart... it cannot be... (Laughs). 'I promise to lower it down tomorrow'. Then I went home and by the time I came to see the doctor again, the sugar was down below. 'Mam, what did you take that make your sugar down a lot?' 'I did it with herbs. I boiled ceplik piring leaves and... What is that.. spirowalas, which I bought from the market, then it got down'. It was reducing a lot from more than 200 to become 130, you see' (Mrs Sifa).

'I have been taking white turmeric, so far...The brochure did mention about it... It's to cure diabetes' (Mrs Maryam)

Mrs Sifa believes that herbs might help her to manage her condition, and she has been growing it for herself. Thus, to support her treatment, she managed to have the blood sugar monitor; as a confirmation of the difference the herbs made to her blood sugar level. Although, she admits that the tool was not the appropriate one since it is no longer working properly.

'Yes, I believe that we can make medicines from plants... yes, I believe it from my heart...I have them outside the house in the yard.' (Mrs Sifa)

'I have the equipment myself but it turned out to be a fault. Laugh. I got it from the nurse at the sugar clinic. My daughter tried to use it. Let me tried it. 260. I told her that the pharmacist there has the equipment as well, the one at Godean. It was 300 there. I was very distressed at that time, why my sugar was so high. Then I went to PKU, it turned out that the sugar was only 119. Since then, I left my equipment and I have never used it again. It was a fake, it has made me mad'. (Mrs Sifa)

Religious practices

There is one major contributing factor between these participants that might influence how they perceive their relationship with Allah will help their effort in maintaining their condition. They believe that by performing any religious practices such as *sholat*, prayer and giving *zakat* (the

practice of taxation and redistribution) or *shodaqoh* (charity) will help them to get Allah's support in managing their blood sugar through the peace of mind. Mrs Sifa believes that Allah has given her a lot of blessings and the only way to appreciate it is by getting closer to Allah by still adhering to the teachings or being surrender to Allah. Thus, the notion reflects more of a cycle process, rather than a linear one; human asks for something and Allah grants', then human appreciates by doing more religious practices will help them to maintain the relationship with Allah. Although, it is not clear who is commencing the first action.

'And by doing sholat like what has been taught by the prophet we would get that peace of mind. There was surrender in our heart. It has, indeed, a remarkable influence. That is what I feel about it... After I did sholat subuh what I have been doing was praise Allah for gratefulness. Being grateful...Then, I just let myself loose, all of it. I just gave them back to Allah because it has to be good meanings beyond those things; that Allah would never lead me to a wrong path, to make me suffer. No way' (Mrs Maryam)

'Alhamdulillah Allah has given us many blessings, and what I do just appreciate them... Yes, absolutely (believe that Allah will grant if I pray) because I pray only to Allah' (Mrs Sifa)

Another example of how the participant utilizes religious teachings into daily activity is shown by Mrs Sifa, by reciting prayer while she was working in the rice field or walking in the morning as part of her daily self-care activity; one way to put certain self-care activity into a more prominent place by embedding it with religious values.

'There is a pray every time we plant the rice, a specific pray. When they got older, there is another pray' (Mrs Sifa)

While for Mrs Maryam, how she manages her religious practice might not be as rigorous as Mrs Sifa does. However, she also has found how her wealth might serve as an opportunity to put herself and her husband into a more advantageous to their society. She has been supporting an orphan to carry on his school by collecting her zakat, or her husband who is working a voluntary work in supervising a development project of an Islamic elementary school.

'Well, here, I have the garage. So, I have an income every month and it is quite enough. We will gather it, and then from the net profit I will spare 2.5% for zakat, definitely. So, so far I am trying to collect it (zakat) all, before I use it to pay for the elementary school fees

for this orphan child [] Yes, insya Allah (giving infaq will keep me calm), I already prepared for shodaqoh. By the end of every month, all income would be set aside by 2.5%. Then, later on, when it was Ramadan, I would do another zakat [] He (the husband) has been retiring for about 22 years. Laugh. It's been a while. His daily activity is supervising the development of the Islamic elementary school's project.' (Mrs Maryam)

Mrs Maryam also addresses the need to give zakat as a means to keep their wealth cleaned from someone else's rights; a tenet in Islam that underscores the rationale behind a concept of taxation and redistribution. She believes that to do that is also an important way to keep her well-being, so is by performing *sholat*, which she believes as one way to do physical exercise. She is also able to get a religious perspective of other's experience of doing something incorrectly for her own interest.

'The movement of sholat is remarkable, you see. Sholat movement if we do it according to the rule is certainly (amazing) [] Yes, I can. Let say if I did rukuk (bending the back) as it was supposed to be done and felt the incantation by heart, I would feel it in my well-being' (Mrs Maryam)

'I would make the Money clean first, then I would calculate again later in case I still have something to give [] Maybe, just maybe, because of there was something that was not belong to me, so everything that I have eaten could lead to a disease' (Mrs Maryam)

'Though it was not sure 100% but it seemed that a friend of mine has just marked something up so he could get more Money but it wasn't halal Money. The next day afterwards, he just got a back pain. Laugh. It's your own fault. You just marked it up' (Mr Maryam)

Other's experiences or examples have also been serving as influencing factor for Mrs Sifa to do more religious practices, for example her husband demonstrates persistence in performing religious practices.

'I saw my husband with my own eyes he never has any illnesses... always healthy... But then again, every night, masya Allah, he usually does a very long sholat' (Mrs Sifa)

Mr Fajar and Mrs Sifa have faith that Allah plays a determinative role in their long journey of dealing with their illness, with a belief that it is their obligation to seek for medical treatment if the end result of their effort has come to an unfruitful condition. Those are Mrs Sifa 62 years old;

and Mr Fajar, 39 years old. Mrs Sifa is a housewife with no other income source, whereas Mr Fajar is an employee of a private company. Both have a higher and medium level of education, respectively. Both reveals a higher level of religiosity with Mrs Sifa is regarded a higher level of self-care, a contradiction to Mr Fajar.

'Yes, maybe it was because I didn't manage myself. I didn't control myself' (Mrs Sifa)

'It (if we already did the pray and the blood sugar didn't decrease) only comes from the mind and also diet patterns...our efforts weren't great enough' (Mr Fajar)

They believe their effort has not been enough in maintaining their condition; but they believe more that it is their responsibility rather than shifting the responsibility to Allah. As indicated in an earlier theme Mr Fajar fails to control his diet in managing the diabetes, he follows his own rules, rather than following the doctor because he perceives what the doctor offers are more than he can chew.

'My diet patterns were not well regulated, before. I ate whatever I like. Anything... If I follow the doctor, I have to eat three times a day, and the vitamins, there are a lot of them. But for me, it is my own (ability)' (Mr Fajar)

While Mrs Sifa showed sufficient knowledge in dietary management and the inclination to adhere to the doctor's recommendations.

'I have been following all Dr's recommendation. Until now, what I have for breakfast is only a little bit of rice, and boiled vegetables. Then I got the side dishes also boiled, sometimes were fried but I eat only a small bit of it. For lunch I ate boiled banana or anything that was told at the hospital' (Mrs Sifa)

Social ties and well-being

A theme strongly evident among Javanese culture is the existence and importance of social ties and well-being. This underpinned the notion in Islam of *hablumminannaas* or to maintain a relationship with others, or with *silaturahmi*, being good to others. Thus, the notion is trying to expand the understanding that social ties does not necessarily limited to how far the participants engaging themselves with others, such as family, friends and other part of the society or to any social events that are available around them, but also how they perceive their existent as a

member of the society will affect their well-being. Furthermore, *pengajian*, as a common form of religious social activity, has a distinctive role in various ways among Muslim society.

The majority of participants who inclined to be more social were female with more than a half are from middle and older age group, less than a third from lower level education, with equal higher and medium levels. The participants were predominantly coming from a regular occupation. All participants have higher level of religiosity except for one participant. While, predominantly (81.8%) regarded themselves have higher level of self-care. The majority were inclined to maintain a relationship with their society, except one, Mrs Asti tends to prefer a more solitary life; she tends to spend most of her time in her house and sometimes got a visit from her children and grandchildren. Thus, the social tie that she establishes to some extent is only limited to her own family. Mrs Asti, is 77 years old, does not work, and has a full financial support from her University graduate children.

All participants believe that establishing a good relationship with the others is important, not only because it is emphasized by the teaching of Islam, but also as a feature of good social relationship.

'As a Muslim, we should maintain habluminallaahhabluminnanas (maintaining a relationship to God and to other human being)' (Mrs Eva)

'Sharing...(laughs). If I cooked for any events, say arisan (women social gathering) or else, I would make it more to be shared for the neighbour' (Mrs Umi)

This belief is also held by Mrs Asti who tends to keep a more solitary life.

'The interaction between people is important I think in the world in daily life... no, I have never (hanging around with other elderly)... I consider myself as quite lazy person.. I like to stay at home...I found myself a lazy person... I usually follow... like TV program.. but if I have to follow a religious gathering every day...no...I don't come to the gathering... but I usually do Qur'an reciting myself...regularly' (Mrs Asti)

Mrs Suti believes that what others perceive about someone will get back to him or her to the extent of what he or she does to them. Therefore, she believes that she has been a good neighbour to the others when she got a lot of attention from the others when she was ill.

'I felt that I have been paid attention by the community. It meant that I wasn't a (bad person). I am poor and I felt I was embraced by friends, it felt good to have supports, isn't it? [] If I was not (doing good deeds to others),, my name would be bad and no one would... ah, why bother to pay me a visit .. I felt very happy that everyone had come to visit me' (Mrs Suti)

Silaturahmi is an Arabic term that defines as a state of doing good deeds to the others. It varies from being good and gives good gestures to a support someone by giving financial charity, for example. For Mrs Maryam, a business owner, giving charity has a religious meaning as to clean her wealth. While, Mrs Asti believes that Allah has taught Muslims to establish good deeds as a religious effort, especially for the family.

'Maybe, just maybe, because there was something that did not belong to me, so everything that I have eaten could lead to a disease...So, anyway, we have to be clean in spending the wealth don't let us taking someone else's right. I have been very careful in this matter, especially for this matter: give your employees' wages before they got their sweats dried up.' (Mrs Maryam)

'Allah has taught us to do good deeds, it is preferable for one, say, to prevent him or herself, especially from hellfire...(laughs)...better off the family as well... it's said 'qu anfusakum wa ahlikum naroo' (she mentioned a verse from Qur'an which means 'o you have believed, protect yourselves and your families from a Fire')' (Mrs Asti)

Mr Jawen, 64 years old, acclaimed himself as a practicing *Kejawen*, a Javanese spiritualism, believes that the more important is being good to others.

'For me, the important principle is do goodness to others. Being good to my relatives, to the neighbour, and comply with the government.' (Mr Jawen)

Several participants also mention the beneficial effect of particular environments for their own well-being. For Mr Ripan, 48 years old, living close to masjid has a positive effect on his peace of mind. Similarly, Mrs Heti finds that attending *pengajian* may serve as a consolation.

'It (living around the masjid) has some effects to some extent. Since, if we live among the community with different kind of people, it would affect us somehow. But, here, it is very different [...] the environment, you see. It would be too competitive in the society, but here [...] calmer [] We admitted that we would need a more stable financial status in the future,

we believe that. But what good it would be if in order to achieve that we compromise our health. If we got hospitalized, then, our money would run out' (Mr Ripan)

'Maybe from the pengajian we can get the silaturahmi, so we can get consolations as well. Because I have never gone out, hanging out with other neighbours. I will usually have my own relationship there at the pengajian' (Mrs Heti)

Another notion that comes out from the social support and well-being is how engaging with peers might benefit the participants in managing the illness. For Mrs S5 the social ties have provided her a means to enhance her understanding about diabetes, since she is not keen to ask to the doctor.

'(know how to control the diet) from friends...It's just they told me to take a walk in the morning. Because a lot of us got diabetes around here have the wrong diet' (Mrs Siti)

Living in a sub-urban in Yogyakarta where a strong social tie is still evident, other aspects of social support are also including financial and religious support.

'Yes, (it was the way from Allah) we have to help each other, taking turns.. whoever sick, in this village, we will gather money to be given' (Mrs Suti)

A different perspective of how the interaction between participants and their environment and how they establish beneficial effect from it has emerged, as it is mentioned by Mrs Heti, 48 years old, an administrative worker in a department at a private university in Yogyakarta. She underscores how a good religious environment is essential for someone who is less religious but inclines to maintain particular religious activity, such as fasting.

'For me, it was because my religiosity is not too (strong)... you know... if we are talking about fasting, if the office's environment was supportive than maybe I could, but if you were on your own, it would be quite difficult. The others (other friends from the same office) don't do fasting either, except for pak Gindu' (Mrs Heti)

Several participants mention the existence of pengajian in regards of religious social activity. *Pengajian* is a religious social activity, which is usually performed in a masjid with the attendance of a Muslim cleric as a sole source of knowledge. Usually at the end of event, an interactive session will be held, but for most of the time and among most of the Javanese peasants' rural

communities, it is only a one way of relationship of how religious knowledge is conveyed. Many *pengajian* are held separated based on gender as well as on age range.

'There is pengajian. Regularly once for every month. There are groups, you see. So, every month there will be two or three times, but with different group' (Mr Suyono)

'I can have a lot of pengajian if I want to. Sometimes if I was available, I would do it in Sunday morning and the afternoon. Those were the routine. Another will be Thursday night, tonight.. yes.. after sholatnya together then pengajian will start. Then there are the not-routine, there is.. selasa pahing, just the day before yesterday [] It was pengajian keluarga sakinah (about family wellness), and then Jumat (Friday) wage, Rebo (Wednesday) kliwon,, those are the pengajian' (Mrs Sujawi).

There are various advantageous that are perceived by the participants by attending *pengajian*. For several participants, their religious knowledge will increase, which in turn may influence how they think and behave. Mr Sujawi has achieved an understanding that by performing prayer might help him in changing 'from black to white', an expression of how Allah might change one's circumstances.

'They can help me increasing our knowledge; I know what I didn't know before [] they were seldom about health topics. They were usually about our daily life, as something for us to bring if we were already in the other world.' (Mrs Umi)

'Yes... firstly, its about how to do the ritual in correct order, then, we are supposed to be good to Allah, we also have an obligation of hablumminannaas. It means that we should maintain a good communication between humans and to our surrounding environment. Then, about the benefit of zakat (giving charity). Then, also about how to perform the worships, so if we died tomorrow, we will be accepted by Allah' (Mr Sadi)

'I was in the pengajian once, it says that if Allah gave us a lot of hardship then we do a lot of praying, it might change colour from black to white' (Mr Sujawi)

To some extent, the increasing of knowledge might influence the improvement of faith, as well.

'Well, religiosity... to fill my religiosity. Say.. so our faith will get much.. better. Charging, I would say, charging our faith' (Mrs Heti)

Mrs Eva, mentions a slight different perspective of how *pengajian* has been used in a more contemporary way; health issues or any other issues that related to the daily life of the society

such as family life or other socially matters and correlated that matters with the teachings from the Qur'an.

'Yes, we have one. The lecturer from UGM (Universitas Gadjah Mada, a well-known public university in Jogjakarta) Ibu Ani, often shares with us that it is important to have a healthy lifestyle. She is also the one who explains about cancer...Yes she did (related health with the Qur'an). She showed us some of them (the verses), but I forgot. I think I already went home. Laugh. She also talks about how to serve food' (Mrs Eva)

'Usually, when the lecturer from UGM brings the topic on health, including how to serve the food. They said besides the cleanliness, the food we eat should also be... I forgot. Then, about the environment, also about the cattle. They were all from the UGM. Meanwhile, the lecturer from UAD usually discusses the problem of the recent lifestyle, teenagers, how to teach children based on the Islamic norms' (Mrs Eva)

Indeed, it emphasizes the notion on the opportunity of using *pengajian* as a vehicle in conveying any health or other contemporary issues embed with religious teaching that may be helpful in endorsing or promoting such issues. For any pious individuals this will be served as a confirmation on how religion supports particular healthy behaviour, therefore, to enhance the implementation of the program. For any less pious individuals, this may mean an additional worldly benefit of attending to a *pengajian*.

Another advantageous effect of *pengajian* is in serving as a social event such as gathering, or as an event of giving religious support to others.

'They (attending any religious activity) mean a lot to me. Firstly, I could meet friends, we could make fun together' (Mrs Umi)

'In any pengajian (Islamic lessons), if there was someone got sick we would pray together' (Mrs Suti)

Summary

The findings highlight that Islam and Javanese culture are embedded in everyday life, and difficult to be distinguished. Allah has a great role in life among the participants, particularly in ill-health condition. There are three notions of how the participants see how Allah or Gusti Allah in Javanese terminology is correlated with their daily self-care activity, in managing their condition. First by

surrendering to Allah for their condition and accepting it, not necessarily indicating they are fatalistic in nature; they are still trying to follow doctors' recommendations. However, the way they surrender, their effort to important others have demonstrated examples of a lack of determination to self-care which pose a barrier to their well-being. Demographic characteristics such as age, gender, level of education and occupation seem not to be correlated to the level of religiosity or self-care, based on the interview sample.

A potential opportunity to move someone along a continuum towards self-care is to enhance their capability and capacity, self-efficacy and self-belief towards a better well-being, by increasing motivational support. Indeed, this support may be found through social ties, or from the support of a Muslim cleric as to reinforce the need to preserve their body as a mandate from Allah. Develop and foster a collaborative effort with a Muslim imam or cleric in enhancing the awareness of a potential religiosity as a resource in enhancing self-care practices (Table 6.5).

Table 6.5 Key Religiosity and Self-care Findings

Key Findings

- Provides knowledge that Allah has a significant role in life that directly influences self-care activity
- Evidence of the intertwining nature between Islam and Javanese culture
- How participants view their relationship with Allah in managing their condition is both dynamic and interchangeable from surrendering through to accepting, to keeping the effort to seeking self-care and treatment, alongside the significant role of Allah
- The evidence and influence of *tawakkal* in managing self-care; keeping on trying and leave the rest to Allah
- Opportunities to overcome surrender (and relinquishing) barriers and utilise the different motivations of keep trying, human endeavour and the relationship with Allah to drive and influence higher levels of self-care
- Opportunities to drive diabetes education using religious teachings to seek health and treatment and to embrace Islamic and Javanese values, collaborating with Imams to develop teachings into a structured-diabetes educational program.

- Opportunity to maximise religious practice to develop a pattern of foot care activity with *sholat* as normal healthy behaviour
- A concept of *nerimo ing pandum* or accepting with sincerity can serve as psychological support
- Social ties are important among Javanese people and these could be utilised to support self-care activity
- *Pengajian* could become more than a social hub; but a place for enhancing knowledge not only on religious matter but also in other, healthy and worldly matters.

The participants believe that maintaining the effort has to be accompanied by keep doing worship, mirroring the concept of *tawakkal* in Islam; an act of surrendering the end result following rigorous worldly effort. In turn, physical well-being will support the effort to seek more blessings from Allah by doing more worship.

Participants believed that by doing religious practices might support them in achieving physical well-being. Thus, embedding religious practice with any particular self-care activity might enhance the meaning of the practices into a more significant way in regards of ill-health condition.

Pengajian is important it can serve as a social hub, rather than just a religious event, in supporting the well-being of individuals. It offers an opportunity for introducing a more comprehensive educational program and psychological support, embedded with more contemporary issues, such as health and other issues that actual within the society.

Chapter Seven

Overcoming obstacles for Surrender - Opportunities for Self-Care

Introduction

The overall aim of this study is to explore and scrutinize the extent to which religiosity and cultural issues influencing Javanese Muslim in managing their daily self-care activity in Yogyakarta, Indonesia. The study definitely achieved its aim and revealed some interesting and unique findings that contribute to the wider evidence base for self-care in diabetes management in Muslim community, as well as germane local findings applicable in Indonesia. This chapter draws together and discusses these study findings alongside existing evidence in an attempt to construct meaning from the data on Javanese Muslim with diabetes' experiences and perceptions and the relationship with religiosity and cultural values.

This study has revealed the moderate practices of self-care particularly evident in dietary, medication and physical activity regimes. This is in accordance to the study by Primanda (2011) that also found a moderate level of dietary behavior among the participants of her study in a hospital in Yogyakarta. Moreover, the current study has also found self-care is moderately practiced as separate notions instead of an integrated and comprehensive concept in diabetes management, in the lingering of the lack of adequate knowledge and the implementation of guideline, which represents the lack of structural support. This finding is also in resonant to other studies that emphasized the practice of self-care as a separate regime (Ernawati, 2012; Flora et al., 2013; Sari, 2013; Sutiawati et al., 2013). Moreover, it is more prominent in regards of the self-monitoring blood glucose regime, which governmental involvement is required to put this regime into place. Furthermore, the main self-agency factor behind this lack of practices is the attitude of putting something or someone else over themselves in taking responsibility in managing themselves, which resemblances the notion of external health locus of control (Wallston, 2007; Andrews et al., 2011). However, a good self-efficacy has been shown in the effort to manage self-care. Therefore, this study reveals several themes, those are: the healthcare policy access; the notion of sustaining the locus of control; keep trying and leave the rest to Allah, as related to how

Muslim attitude and behavior towards self-care; Keeping the harmony, the influence of Javanese culture; and, the important part of Persadia in managing self-care in diabetes management.

Health policy access

Health policy access underscores the important role that the government, as in a national or regional scope, or the policy maker within the hospital, in a local scope, might play in maintaining the provision of diabetes self-care management. Among other important findings in regards of this issue is the lack of a structured education program in this study. Another finding that needs to be put forward is the lack practice of self-monitoring blood glucose. A discussion on the Indonesian diabetes management guideline from Perkeni is intended to give an overview and a benchmarking on the practice of diabetes management in Indonesia.

Structured diabetes education program

Majority of participants revealed no knowledge of such program in place. Instead the knowledge was conveyed through consultation setting from the physician and/or by the dietician as recommended by the physician. This is in resonant to other studies in Indonesian's setting that emphasize the lack of a structured diabetes management education in place (Salti et al., 2004; Soewondo, 2011; Ernawati, 2012). This is an interesting finding since Indonesia has been implementing a training on diabetes educator program since 2002, which has been done by PEDI, *Perhimpunan Edukator Diabetes Indonesia* or Indonesian Association of Diabetes Educator (Ministry of Health, 2012). Further exploration for the PEDI through the web did not reveal any designated site, which the researcher could look through it, neither studies in regards of how the implementation of this particular program among Indonesian people. Thus, it underscores the lack of evidence base studies among Indonesian's setting, which might help in further improvement of such program.

Another underpinning rationale behind the lack of a structured educational program in place might be coming from financial support. The current healthcare system in Indonesia, with the lingering philosophical paradigm of curing rather than preventing, has not been putting health promotion, with inherent educational program, into a more prominent place, which is required for the educational program as an obligatory and integrated entity, despite the existing guideline

and policy. Therefore, such PEDI training has obliged the participants to pay for a contribution, which to some extent would hinder the participants for this occasion.

The beginning of 2014 witnessed the implementation of a new healthcare service system in Indonesia, which has emphasized the need to put primary care service, with inherent health promotion and disease prevention program, as the front line of the future of Indonesian healthcare service system (National Social Security System, 2011). Indeed, this notion might be served as a huge opportunity to implement such educational program in the primary care service unit, such as *Puskesmas*, to gain wider scope of participants, and with the collaborative work with PEDI might enhance the exposure within the healthcare professionals.

Further exploration from the interviews revealed several other sources of information, such as seminars, which are usually conducted by *Persadia*, reading magazine, watching health program through television or listening to one from the radio, and important other such as family and peer. Even, for Mr Ripan, Mrs Santi, Mr Sujawi, and several other participants, peer is regarded as the first line of gathering the knowledge. Of course, it might lead to a misinformation that might direct to lack of adequate knowledge and behaviour.

Structured education in diabetes management has been proven to have beneficial effects in increasing adherence to enhancing lifestyle behaviour changes (Norris et al., 2001; Atak et al., 2008; Carter et al., 2013; Rise et al., 2013), improving self-efficacy and improving the blood glucose monitoring activity (Norris et al., 2001; Atak et al., 2008; Sperl-Hillen et al., 2013), enhancing the frequency of foot care (Balamurugan et al., 2006; Atak et al., 2008), improving psychological well-being or quality of life (Steed et al., 2003), and improving glycaemic control in a follow-up after the treatment ended (Norris et al., 2001; Reutens et al., 2012). Evidences from Indonesia are varied in regards of educational on diabetes management. However, these studies only sought the effect of education intervention with certain self-care activity, not in explaining the current practice of educational program. Studies show that education effects the enhancement of knowledge, dietary management, foot care knowledge and blood sugar level significantly (Ernawati, 2012; Flora et al., 2013; Sari, 2013; Sutiawati et al., 2013), but insignificant self-care practice (Ernawati, 2012). While, Utomo et al., (2011) showed a different result with

knowledge did not correlate significantly in reducing the blood sugar level along with dietary management and adherence to medication, except for physical activity.

An example of how a diabetes structured management educational program has successfully achieved the aim of enhancing capability and capacity of the participants come from Dr Trudi Deakin, UK (2003). Based on her postgraduate study on structured education on diabetes, she has proposed comprehensive diabetes education training for people with diabetes the UK called the X-pert Diabetes Programme (www.xperhealth.org.uk). Initially, the program targeted the healthcare practitioner that were trained as the X-PERT educator, which then have been permitted to implemented the program to over 100,000 people with diabetes across UK, so far (Diabetes UK, 2015). X-PERT program is a training which is held for 2.5 hours in one day every week for 6 weeks with the goal of increasing the knowledge and capability in self-caring themselves. Comprehensively conducted, the program composed of general information on diabetes including the core knowledge of how the carbohydrate is processed and how diabetes develops, with further explanation on complications, which takes a day session each for those two issues. One major issue is maintaining diet, which is divided into four days of 'weight management', 'carbohydrate awareness', 'how to read and understanding food labels', and 'recipes of the week'. The explanation on medication is done at the last day of the session.

Indeed, this finding emphasizes the need for a more structured education training program and put it as a standard procedure of diabetes management program throughout Indonesia. Moreover, with the provision of the new health care policy of *Jaminan Kesehatan Nasional*, or National Health Security (Ministry of Health, 2013), which aimed in incorporating health promotion program with correlated add-on funding system to achieve the sustainability of this system, has opened an opportunity to conduct an educational program, as what has been doing by the X-Pert Diabetes Programme. Thus, this educational program might serve as an example of a health promotion program, as a tenet in primary healthcare system.

Primary health care is considered to be important in maintaining chronic illnesses since it based on the movement of health promotion and disease prevention (WHO, 2009). Furthermore, in order to achieve the full coverage for the people of Indonesia the educational program can be

done nationally with collaborative work with PEDI and Persadia, and other social organization in a more comprehensive and user-friendly way.

Blood glucose monitoring

This study found the lack practice of the self-monitoring blood glucose. Among five regimes of self-activity, this regime is regarded the least adhere activity in this study. Despite, the existence of this particular regime in diabetes management guideline (Perkeni, 2011), the implementation seems to be lacking. Furthermore, what is regarded as a regular practice among the population in this study is to do a monthly blood sugar check prior to the consultation. Only a few participants that mentioned the utilization of self-monitoring blood glucose as doctor's recommendation. Majority participants who used the tools were considered it as a confirmatory measure towards any amendments in their daily lifestyle. To some extent, this has proven to be a showcase of an internal locus of control in regards of taking control over their own well-being.

There are nine participants who showed from the questionnaires that they are using the tool with six of them were joining the interviews. They are composed of six female and three male with predominantly (six out of nine) from the older age group (≥ 60 years old). Furthermore, two participants came from the lower age group and only one from the middle age group. Majority of participants came from the regular income group with six participants, and middle and higher level of education shared the same number of participants, four, whereas only one participant came from lower level of education. Thus, it can be said that the majority of participants who were able to gain beneficial effect from this particular self-care activity regime were coming from the higher socio-economical status.

One underpinning rationale for this finding might be coming from the availability of the tool. Considering the need for the people to provide the tool by themselves and relatively expensive cost has made it unreachable for common people to possess it. This is mirroring a study done by the SMBG International Working Group (2008), which shows that for several countries in Asia and Africa the cost of the tool and the strips have been serving as a hindrance.

On the other hand, there are examples of how amid the unavailability of particular measure, it does not necessarily mean that people does not have any options on how to make sure their

blood sugar level. Mrs Siti and Mr Kasi show that utilizing their own resources might be beneficial in managing their condition. Mrs Siti, 50 year old, is a housewife who considered poor is given Jamkesmas card by the government through the chief of the village. Utilizing Jamkesmas card has provided Mrs Siti with the convenience of receiving a free blood check to ensure her amendment on dietary regime has achieved what she intended to achieve. While, Mr Kasi, 82 year old, having a more regular income from being a retired police officer who was given a monthly pension from the government, was able to confirm his blood glucose level through the nearest pharmacy, with relatively affordable price following an adjustment on his diet. Indeed, these examples are a showcase of an internal locus of control, where both participants considered their own responsibility in managing their own condition. Indeed, this might be served as an evident to promote a motivational training program, which helping people with limited financial resources to utilize any resources available such as Jamkesmas card.

Moreover, the existence of Persadia, with the weekly blood check activity has been serving as an option for its member to have a more affordable blood check, among other beneficial services that it has. Indeed, this might serve as an opportunity to put the role of Persadia into a more prominent place and encouraging the physicians to endorse it as part of a more comprehensive diabetes management program.

The reliability of the tool available is also playing a role in sustaining particular regime. Among the participants who owned the tool and used it but then leave it, the reliability and sustainability of the tool is important issue to ensure this regime is sustained.

Studies have shown the advantageous effect of blood glucose monitoring in controlling diabetes complications, such as in the large epidemiological study from the Diabetes Control and Complications Trial Research group (1993) or the DiabCare Asia studies (Soewondo et al., 2010), among others. Thus, the utilization of SMBG has been implemented into diabetes management guideline such as IDF (2011) and Perkeni (2011).

Indonesian guideline on diabetes management

Perkeni, *Perhimpunan Endokrinologi* Indonesia or the Association of Indonesian Endocrinology, has established a guideline of type 2 diabetes management. The term *Perkeni* will be used

throughout the discussion. This guideline was established based on the consensus among diabetologists in Indonesia in need of a practical guideline that can be used for all healthcare professional, which has been pioneered by *Perkeni* in 1993. The latest version of the guideline is the fourth revised edition in 2011, which has been following several revisions since the first in 1998, 2002, and 2006. It seems that revision process was taken at four years interval, initially, with the last version took longer. Thus, it is expected that the latest version will arrive soon this year, since it is considered essential to keep updated to the latest evidence. Furthermore, the guideline has mentioned several names of International authorities as the sources for the key issues in diabetes management in Indonesia, such as American Diabetes Association (ADA), International Diabetes Federation (IDF), European Association for the Study of Diabetes (EASD) and American Association of Clinical Endocrinologist (AACE).

Perkeni also mentions the need to be equipped with the current evidence-based principles to gain more practical use of it, particularly with the local evidence. However, further exploration reveals that this guideline is lacking in evidences from Indonesian's setting. References list section shows there are 14 out of 35 references or less than a half that come from Indonesian's sources. Among them, four previous version of the guideline are on the list, along with another study from Asdie (2000) that supported the section of diabetes management. Six studies and two government reports have provided the guideline with the prevalence and incidence rate of people with diabetes in Indonesia. However, there are no evidences based on particular self-care regimes. All in all, the guideline is lacking in original evidences on particular diabetes management activity from Indonesian setting, which is regarded important in setting the benchmarking against the regional and more international evidences from other countries, since diabetes has been regarded as a global epidemic (WHO, 2014).

The guideline is divided into three main sections: the management of type 2 diabetes mellitus; the prevention of type 2 diabetes mellitus; and specific cases, which exploring further into the complications of diabetes as well as particular cases such as 'diabetes with pregnancy' and 'diabetes and fasting'. The later issue will be discussed in more detail later on due to the correlation with current study. The first section explains about how to establish the diagnosis and

how to manage it, follows by the promotion of healthy behaviour, co-morbidity and complications. In this section, the Four Pillars of Diabetes Management is introduced in the sub-section of diabetes management, which includes '*education*', '*medical nutrition therapy (MNT)*', '*physical activity*' and '*pharmacological intervention*'. The four pillars are listed in hierarchical order, which means the newly diagnosis individual is expected to perform the MNT with sufficient physical activity for 2 to 4 weeks, following an educational program. Had the blood glucose level not achieved the target level, oral medication and/or insulin should be commenced. There is no explanation on similar concept of self-care in Indonesian language; instead the Four Pillar has served as the core of diabetes management in this guideline.

Other self-care activities of foot care and self-monitoring blood glucose are discussed further in different sub-section of II.3 *Promosi perilaku sehat* or 'Promotion of Healthy Behaviour'. The self-monitoring blood glucose is put in the section of II.2.4 *Penilaian hasil terapi* or 'Evaluation for therapeutic results' (p. 30), whereas, foot care is located in another section II.3. of *Promosi perilaku sehat* or 'Promotion of healthy behaviour', with another item of '*pemantauan gula darah mandiri*' or self-monitoring blood glucose (p.36). Foot care is discussed in great detail under the section of diabetes education, which will be explored further in more depth in this discussion chapter. Nevertheless, in regards of how these activities are organized, it reveals that they are not put into a more integrated fashion, furthermore, the foot care and SMBG are not considered as one of the pillars in diabetes management.

Diabetes and Fasting in Ramadhan

This section is very brief, consists of nine points regarding recommendations on lifestyle management (3 points), medication (5 points), and one point on the psychological aspect of *Ramadhan* in respect of the need of using the moment of *Ramadhan* as a time to '*enhancing the knowledge and adherence to treatment*' and '*by performing fasting in Ramadhan it is expected to gain psychological adjustment that creating a feeling of healthier among the people with diabetes*'. A notion of considering fasting in *Ramadhan* as a psychological support. Moreover, there is no further exploration in regards of using *Ramadhan* as a time to enhance knowledge and adherence to treatment.

The lifestyle part, the section that only discusses the dietary and physical activity, however, does not have a clear and straightforward way of how to manage those regimes. The point is only served as a more general suggestion as to '*keep adequate water*' and '*to get sahur at latest time as approaching shubuh time*' to prevent the Muslim to get hypoglycaemic attack (Perkeni, 2011, p. 60). *Sahur* refers to time of having dinner before starting the fasting, and *shubuh* refers to the starting time of fasting. However, there is no other suggestion in regards of dividing the menu composition, not the least the kind of food that needed to be taken. Fasting starts before dawn and finishes around dusk, thus, after breaking the fast, most of the people will stay inside the house with minimal physical activity, except for the common *sholat Tarawih*, which only exists in *Ramadhan*. Therefore, fasting will be lasted from 10 to 12 hours daily in any tropical country such as Indonesia.

Indeed, dietary management is regarded paramount in maintaining carbohydrate intake among people with diabetes. While, Diabetes UK (2004) has introduced a clearer guideline in regard to dietary adjustment in *Ramadhan* with mentioning the type of food that need to be taken, such as fruit and vegetables, as well as starchy food, with reducing sugary foods at the breakfast time. This practical guideline is regarded important since Muslim who lives in Western countries with four season's period will have a longer fasting period when *Ramadhan* was due in the summer than Muslim lives in the tropical country, which lasts from 18 to 20 hours a day.

Another part of the section is in regards of medication. *Perkeni* mentions the need to be aware of the potential complication of hypoglycaemic among people who uses insulin, with suggestions on using middle duration regime at the breakfast time, and exempting from fasting for individuals with multi dosage insulin usage. While, other finding from the IDF Guideline for type 2 diabetes mentions the need to adjust the therapy, especially insulin, with respect to the carbohydrate intake (International Diabetes Federation, 2012).

Several studies (Firmansyah, 2013; Ibrahim, 2007) have explored diabetes management during *Ramadhan*, including EPIDIAR study (Salti et al., 2004), a large epidemiological study conducted in 13 Islamic countries including Indonesia. Overall, the studies found that the risk of hypoglycaemic attack is greater during *Ramadhan*, especially among people who adjusted their

diet. Therefore, all studies suggest several main tenets those are: individualized approach for people with diabetes who wants to fast; diet requirements remains the same as in non-fasting time; regular blood glucose monitoring; no excessive sports; and, people should know and able to determine the right time to break their fast, in regards of the development of hypoglycaemia. Thus, this might serve as an opportunity in conducting an education program before or during *Ramadhan* among Muslim with diabetes to prevent the risk of hypoglycaemia during *Ramadhan* or, even, hyperglycaemia after *Ramadhan* finished due to uncontrolled diet. '*Led Al-Fitr* or *Lebaran*, as Indonesian called the festive day after *Ramadhan* is finished, is considered a time of celebration, which is usually involving many sweet or fatty foods. This notion of hyperglycaemia is evident among many participants in this present study who have admitted to have their blood glucose level raised after *Ramadhan* is ended due to uncontrolled dietary behaviour. This fact has served as an evident that during this time a lot of people are not restricting themselves from the dietary management that they had during *Ramadhan*. Indeed, this has contradicted the notion of *Ramadhan* as a moment to achieve *taqwa*, or obedience, among Muslim by restricting themselves from eating, drinking and sexual relations for a certain of time (Waines, 2003), which, then, is expected to be carried out through all the remaining months. These findings are the adequate evidences to put into the guideline as to make it more practical and enhancing its credibility.

All in all, this section is not sufficient to be used as a practical guidance in discussing how Muslim with diabetes, who is in need of performing fasting especially during *Ramadhan*, should maintain their diabetes management, especially the diet. Furthermore, discussion on religious matter is lacking, despite the majority of the Indonesian population are Muslim. It is believed that to embed the guideline with religious matter is essential in encouraging Muslim with diabetes in managing themselves, which is already commenced by the last point of this section in regards of psychological support of *Ramadhan*, '*With performing fasting during Ramadhan, it is expected the people will have a psychological adjustment that might create a sense of well-being among the people with diabetes*'. To put this mater into perspective, many participants of this current study have admitted the need to maintain the peace of mind as the main part of diabetes management, which they believed is important to keep the blood sugar level down, thus,

improving well-being. Indeed, this finding is essential as an opportunity in updating the guideline with the support from the more evidence-based source, as well as conducting a more holistic diabetes management program, which embedding religious support.

Sustain locus of control and self-care

The second main finding from this study is the overarching notion of locus of control. Majority participants believe that Allah or simply destiny has an important role in determining their well-being, including the development of their illness. The tenet of locus of control has been discussed and presented in many studies in regarded of how it influences the people towards healthy behaviour. So far, the evidences are inconclusive, whether people with internal or external locus of control have the main benefit in attitude and behaviour towards healthy behaviour, such as in stop smoking (Steffy et al., 1970; Martinelli 1999; Lindqvist & Åberg, 2002) or in knowledge seeking behaviour (Lowery & DuCette, 1976). Nevertheless, it is argued that locus of control does not stand in a vacuum, rather as a resultant of simultaneous determinant factor such as self-efficacy, as well as other socio-culture factor (Lau et al., 1986). It is true in regards to the current study in how Javanese people see any hardships, such as ill-health condition, as something that happens due to divine being; as a destiny. Social support such as family, friends and important others have influenced how the participants behave towards healthy behaviour, as well. Therefore, under the umbrella of 'Maintaining responsibility to self-care; a notion of locus of control', there are three sub-themes, which are: religion (and culture) and health; culture and health, and social support and health.

Religion (and culture) and health

This sub-theme underlines how religion and the interwoven nature with culture aspect have served as determinant factor for people to rely on their effort in self-caring themselves. By religion it refers to any dimension of the tenet, such as the belief of Allah, religious practices such as prayer, *sholat* or being close to Allah or maintaining a good relationship with other living being. Allah has been considered to have an essential role in life; including as the one who create the illnesses as well as the cure. The notion was emerged from the interviews, which was referred from a tenet in the Qur'an, "*And when I am sick, then He restores me to health*" (Ash Shuara [26]:

80). In addition, Javanese culture, which has many influences from religions such Hindu, Buddha and Islam, believes that any hardship in life as something comes from the divine power (Beatty, 1999). Therefore, several tenet has emerged among the participants in current study, as to define how they express the illness in their life; a test, a warning or admonition, which has also been referred to any hardship in the Javanese life, such as the tragedy of Mount Merapi volcanic eruption in 1994 (Schele, 1996). Under this sub-theme, there are several notions that emerged from the participants: surrendering and accepting; and keep trying and leave the rest to Allah, a notion of tawakkal.

Surrendering and accepting

This notion of Allah or the divine being or simply destiny as the determinative factor in life, to some extent, has provided an underpinning reason of how this belief has led the believers to a more fatalistic way; the tendency to neglect the self-care activities. Nevertheless, how they surrendering to their condition is not the results of a single factor, rather a multi-simultaneous factor of socio-economic and cultural factor, as well as other factor such as self-efficacy. Javanese people refer the surrendering to the term of *nerimo ing pandum* or accepting with sincerity or *ingkang nerimah* or accepting willingly (Koentjaraningrat, 1985). Several participants in this study have addressed this tenet that is represented by Mr Jawen, a Kejawen practitioner, *'Let say nerimo ing pandum (accepting with sincerity). So, nothing else. Accepting the way it is. If we didn't have much thing to eat, just eat a little. If we had a lot, don't be too greedy.'* Similar finding in regard of cultural influence has also been shown by Naeem (2003). This study, which was done among Kashmiri Muslim living in the UK, proposed that the belief of 'enjoying life' and 'leave the rest to Allah', has put the participants in that study to leave the outcome of their effort to Allah. Moreover, cultural aspect has been influencing the perception of ill-health condition. For the majority of South Asian people what considered of being overweight is related to the perception of wealth. Indeed, this cultural norm has hindered the people from seeking more effort towards healthy behaviour, although, again, self-agency is also playing into role in determining the outcome of that behaviour. This is mirroring a study from Polzer and Miles (2007) with the typology of God as a Healer, which believes that with a strong faith in God the illnesses will go away, eventually.

Another determinant factor that influences the belief of surrendering is the economic or financial resource. Mrs Siti, **50 years old, a housewife and elementary school graduated**, admits that she did not maintain her composure in dealing with the incoming 'Ied festive, which for majority of Indonesian people means more expenses to be spent and for her more jobs to do to get more money, and ended up into being too exhausted, *'That was because I was forcing myself until I got so exhausted.. Yes. There was nothing to (worry too much about).. oo, Lebaran will be coming and I have to get money to embrace it that would be the thought, right? It turned out that I got sick after Lebaran.'* On one hand, she has been struggling with her illness, which requires her to get more rest. On the other hand, due to the need to get involve into the social festive she was required to get more money that meant more work. Thus, it emphasizes how socio-economic factor has played into role. The participants in this sub-theme come from various level of socio-economic status, with predominantly from middle and low level status. Indeed, the provision of free healthcare services for the poor has been supporting the people in maintaining their self-care management such as a free laboratory check, as well as free consultation from the physician, which for any regular people it means a higher cost compared to a General practitioner's service.

Keep trying and leave the rest to Allah; a concept of Tawakkal.

Tawakkal is a religious concept that underscores the need to surrender the outcome of our effort. This tenet can be found in Qur'an, which mentions the need to *'rely on'*, or *'turn to'* Allah after performing particular activity. There are several ayat in Qur'an that support the particular tenet such as Surah 3 ayat 159 and surah 13 ayat 11, which emphasize the essential role of surrendering to Allah after performing the action. Indeed, these ayat will act as evidences that Islam is not endorsing fatalistic behaviour. However, it is the different perspective in trying to understand Qur'an's teaching that might lead to the act of total surrendering (Grace et al., 2008), as has been shown by the work of Naeem (2003), which including Kashmirian Muslim in the UK. Nevertheless, the same notion is not exclusively belonged to Muslim. Studies from other religious affiliation, which mainly from Christian reveals similar notion (Pargament et al., 1998; Polzer and Miles, 2007).

Therefore, considering the notion of fatalistic, there are no participants in this current study who was referring to the typology of God as a Healer from Polzer and Miles (2007), which suggesting that with a strong faith in God, it is believed that God will help man eventually; an act of fatalism. Nevertheless, it may also be suggested that the notion of *ihdiyar* or an effort, among the Javanese has prompted the participants in this study to keep on trying regardless of their circumstances. Javanese people believe that life is a continuous hardship and we are obliged to do *ihdiyar* (Koentjaraningrat, 1985).

Moreover, the tenet of relying on the end results to Allah is representing the notion of external locus of control (Rotter, 1990), which puts Allah as the external part who regarded essential in achieving the end results. While, Welton et al., (1996) proposed God Health Locus of Control, which has been used in many aspects, such as drug and sexual abuse (Goggin, Murray, et al., 2007; Goggin, Malcarne, et al., 2007), or other chronic illnesses (Wallston et al., 1999).

To some extent, this tenet is similar to the typology of God is in the Forefront from Polzer and Miles (2007). This typology underlines that the people believe God as the major actor in determining the end results of their effort. They believe that God is helping them in managing resources, and God is the one who responsible for the end result of their own effort. Indeed, this tenet to some extent is in resemblance to the concept of spiritual coping; to put a transcendental meaning over any events in life that in the end will enhance self-empowerment (Baldacchino and Draper, 1998).

The majority of the participants (15 out of 24 participants) in this study have also referred themselves to this particular typology, due to the similarity of belief that Allah is considered as the determinative role in their life. Among these participants, nine were female and five were male, with predominantly 11 out of 15 were coming from the middle age group, followed by older group (three participants) and one participant from the younger group. The majority of participants in this category came from the regular income group and are predominantly coming from the medium and higher level of education. Although, among other participants who hold a belief that referring to another typology of God in the Background also show that they also believe Allah has a major role in human's life. Therefore, it is argued that among Muslim population,

particularly in this current study, the typologies are working in a more dynamic way, rather than a single and separate notion.

Studies are inconclusive as to explain how external locus of control might have a significant relationship with healthcare behaviour (Lichtenstein & Keutzer, 1967; Wallston et al., 1976; Martinelli, 1999). However, it is argued that how the tenet of locus of control affecting human behaviour is not straightforward, rather, other determinant factors, such as self-efficacy and health values, are taken into account (Lau et al., 1986; Wallston, 1992; Wagner et al., 2001; O'Hea et al., 2009; Oftedal et al., 2010).

Keeping the harmony

A notion that comes from the influence of Javanese culture is 'keeping the harmony', which is not only referring to how they are managing their own body and mind (Dewi et al., 2010), but also in maintaining social relationship (Geertz, 1995). Thus, in explaining this notion, there are several paramount tenets in Javanese culture such as *nerimo ing pandum* and *tepo seliro*, and the ultimate role of social ties and family support.

'Nerimo ing pandum' or accepting with sincerity to achieve the peace of mind

To achieve well-being, the participants tend to accept what they consider as the real truth about diabetes, since they have lack of a comprehensive understanding on diabetes. In the effort to keep the harmony with oneself, the participants tend to '*nerimo ing pandum*' or accepting with sincerity and by 'slowing down'; an act of maintaining the psychological well-being, '*Let say nerimo ing pandum (accepting with sincerity). So, nothing else. Accepting the way it is. If we didn't have much thing to eat, just eat a little. If we had a lot, don't be too greedy.*' To some extent this is in accordance to psychological care as one aspect of diabetes management program, which refers to managing any 'worries related to diabetes and self-care' (International Diabetes Federation, 2012, p. 27). However, in the absence of adequate knowledge on how to do appropriate self-care, the effort of maintaining the peace of mind has derailed the participants from their original intentions, which led them to uncontrolled blood glucose level. Indeed, this notion has served as an example of the barrier of Javanese culture on self-care.

'Tepo seliro' to be good to others

Another way of how Javanese people maintain harmony is to establish balance with others by doing *'tepo seliro'* or is the gesture from Javanese people in trying to place himself in someone else's position to maintain a good relationship with others (Koentjaraningrat, 1985). This study has revealed the possibility of this tenet in hindering people in achieving healthcare services that they deserve, such as in a consultation setting where a lot of patients are waiting for the consultation, or a free home care service. The feeling of awkward to let others waiting for her or doing something for him has inclined Mrs Ismi to keep her curiosity on her condition with her, or for Mr Jawen to take his foot care by himself, rather let the nurse did it for him in his house, since it was free, or for Mr Makmur to find a better way to reject the sweet drink when he was offered one on any occasion. On contradictory, Mr Suyono or Mr Fajar have different circumstances that have given them a better way to address their neighbour on the restriction they have without leaving awkward moments, since they understood that their environment already has an awareness and understanding on their condition. These evidences can be served as example of how *tepo seliro* can play from the other side of the relationship; the healthy people. Thus, this opens an opportunity of conducting health promotional program among healthy people with embedding it with cultural aspect of *tepo seliro* of how to pay more respect to others with certain illnesses. Moreover, for the people of diabetes, a motivational training program might benefit them in gaining more confident in maintaining their relationship with others in regards of managing their well-being, without fear of offending others.

The study also shows that the effort to seek the knowledge has been influenced by several tenets in Javanese culture. The belief among Javanese people to pay more respect to the elderly as well as a more authoritative figure, as in this case the HCP (Koentjaraningrat, 1985; Geertz, 1995), has led, to some extent, to a belief that doctor is the one who knows best. Indeed, this act has led them to a tendency of waiting the information from them whenever or whatever the doctors believe is important for them, or gaining inadequate knowledge from peers; an evidence of external locus of control. It is suggested that this finding is emerged as a result of the lack of self-efficacy, which hinder them from trying to gain more knowledge for they own well-being. To some extent, this is served as an intertwine concept of locus of control and self-efficacy, which

emphasized the tenet of trying to understand the human behaviour in a comprehensive manner, rather than from a single and separate concept. Indeed, it is true that to some extent, beliefs in personal determination could lead into a sense of efficacy or power (Bandura, 1986).

A way of how Javanese people might increase their self-efficacy is through their characteristic of strong social ties that they possess. It is suggested that vicarious experiences or witnessing others performed successfully (Spikmans et al., 2003), might serve as sources of supporting information for them to follow suit. As several participants in this study reveal, the example from how their friends have tried some treatment that have proven to be beneficial has led them to try, even before consulting to the doctors. Indeed, this notion might serve as a barrier in the case of unfavourable outcome that hindered them to be more open to the doctor, as it might mislead the doctor in treating them. Nevertheless, for several others the good examples from the peers have led them to a better self-care management.

Social ties

Social relationship is important among Javanese people, thus, maintaining a good relation with the family, the neighbour and bigger society is essential in achieving the harmony in life. In fact, neighbour is regarded as the closest 'kin' in facing hardship in day-to-day basis (Geertz, 1995). Putting the term kin between apostrophes is only to emphasize the importance of neighbour in social relationship among Javanese people. Indeed, this notion has a resemblance with how Islam regards relationship with the neighbour. Qur'an in surah An Nisa (4) ayat 36, has taught every Muslim to pay respect to the neighbour after to the parents, kin and siblings, orphans, and the poor: "And serve Allah and do not associate anything with Him and be good to the parents and to the near of kin and the orphans and the needy and the neighbour of (your) kin and the alien neighbour.." (*The Qur'an*, 2012). Moreover, the close relationship among the society has proven to have a good effect on Mrs Suti. She felt of being respected as a good person, when she found that all neighbour in the society came to see her at the hospital as well as in her house, at time of the illness. She believes that if she was no good in front of others, no one would ever bother to come to see her. Mrs Umi also mentions the close relationship among the society in saying a pray

at the time of *pengajian* if there was someone among them got sick. Indeed, this can be served as an example of utilize *pengajian* as a social hub in maintaining well-being.

Family support

Family has been serving as a determinant factor to self-care among the participants in this study. The strong relation between parents and children, or between husband and wife and vice versa, among Javanese people has made a sense of dependency from the one who is suffering from this condition in this case, to their children or spouse. Example are varied from relying to the daughter for her dietary management to support Mrs Asti, or his wife for Mr Kasi, to the feeling of taking responsibility to take care on her grandchildren in the morning, which hinders Mrs Tata from doing walking in the morning. On one hand, it can be served as example of how Javanese people maintain their close relationship among the member of the family, especially to the parents, since they believe that to have conflicts with the parents will hinder them from the blessings in life, which will lead to a threat in the child's life (Geertz, 1995). On the other hand, it also serves as an example of how people tend to relinquish the responsibility of managing their own self-care activity to others; evidences of external locus of control. In addition, for Mr Makmur, a good family can serve as a good psychological support for him. To have a good behaviour and staying-out-of-the-trouble daughter means a peace of mind since he does not have anything to worry, in respect to any criminal event. Furthermore, he quotes an ayat from Qur'an in regards of the need to have a good kin; "and they who say: O our Lord! Grant us in our wives and our offspring the joy of our eyes, and make us guides to those who guard (against evil)" (*The Qur'an*, 2012).

The role of Persadia in increasing access in the community

Current study has shown the importance of *Persadia* in enhancing capacity and capability in maintaining daily self-care as well as providing more access to healthcare. *Persadia* is a non-governmental organization aimed in establishing a place where people with diabetes along with healthcare professionals and other similar-interested party can find a place together in enhancing the skill and knowledge in managing diabetes (SSDC, 2013). Social support is regarded as an essential factor in influencing general well-being. House (in Heaney & Israel, 2008) mentions there are several types of social support, those are: emotional support, instrumental support,

informational support and appraisal support. Considering this, Persadia, with its aim and objectives, is considered as a place where the members can achieve all type of support. Emotional and appraisal support are provided through the interaction between members, as what Mrs Wati said *'And after I join the club, I met a lot of new friends of fellow diabetic. It felt relieving some of my stress as well. After being checked, we sometimes were teasing each other how high we got but we still live normally. It is so much fun with friends'*. Moreover, members are suggested to *'keep the stress down'*, as mentioned by Mrs Wati, which is in line with the tenet of keeping the peace of mind that several others participants mentioned in regards of how Javanese people tend to do in encountering any hardships. Psychological support can also be gained by having time together with other members; sharing happiness. Psychological management is considered as one tenet in managing diabetes, as mentioned in the guidelines (Perkeni, 2011). A study that employed a meta-analysis approach has found the association between depression and the development of complications (de Groot et al., 2001). While, another large study have found an association between depression and the development of complications through less physical activity, unhealthy diet and lower adherence to medication (Lin et al., 2004).

Instrumental support can be achieved through the provision of blood sugar check in weekly basis. While, members have the beneficial effect of informational support through the dietary educational session with dietician or regular two to three monthly meeting. Moreover, peer can be served as sources of information for some participants, instead of the HCP. Although, the information is not always necessarily correct. Mr Adil underscores the important role of Persadia in enhancing knowledge by mentioning everyone who are not the member will get *'got stuck there'*; referring to a condition of unaware of what to do due to the lack of knowledge.

For several other participants in this study, Persadia has been served as a sole place in achieving healthcare services for their diabetes management. There were five participants of the study who are also members of Persadia, comprised of two male and three female. Three of them have a regular income and coming from medium and higher level of education. Mr Ripan, 48 years old, a labourer, hardly sees the doctor during their time struggling with the illness, instead, utilizes Persadia as a place to gain information about medication and diet, as well as a place to have an

affordable blood glucose check. This notion is essential in understanding how people with lack of financial resources, as both participants, might find beneficial support from such a peer support group.

At this point, *Persadia* has successfully served as an option in self-care services provision amid the lack of an integrated and comprehensive diabetes management system. However, as this study further found, the existence of *Persadia* has not been disseminated in a wider population of people with diabetes. Several participants in this study underline the unawareness of particular program. Therefore, the suggestion to offer the engagement with *Persadia* by the HCP can be put as a standard procedure to every people with diabetes.

Several studies have emphasized the relationship between lower levels of social support with greater rate of mortality (Berkman & Syme, 1979; Blazer, 1982; House et al., 1982). Other studies also found the relationships between social support with improving self-efficacy and supporting self-care activity (Lorig et al., 2008; Bai et al., 2009). It is argued there are several underpinning notion to this relationships (Cohen & Wills, 1985). Firstly, by actively involved in social activity and accepted by the society will beneficial in gaining positive experiences that can enhance the self-esteem, which may lead to general well-being. Secondly, social support may be served as a source of interpersonal support in coping with any perceived stressful event. While, Yuniarti et al., (2012) argued that perceived social support has a significant role on depression, among people with diabetes, through self-acceptance; perceived social support increase self-acceptance before decreasing depression.

The limitation of the study

There are several limitations in this study, which includes the questionnaires and in regards of the involvement from the healthcare professionals and the Muslim cleric.

Questionnaires

As mentioned earlier in this chapter and the finding chapter, several items from the SDSCA questionnaire have inter-correlation with Islamic activity, which poses biases in analysing the outcome since the study was done in a Muslim community. Nevertheless, it also opens an opportunity to establish a more valid tool in assessing self-care among Muslim community. For

several participants, being in a hospital and/or being aware that the researcher is a doctor might pose them with a threat to give a favourable answer. However, further explorations from the interviews revealed that it was not always the case; as the interviews carried on, the participants were willing to be more open in conveying the true experiences. Again, it emphasizes how in particular culture filling particular questionnaire might not be an appropriate way to gain the true knowledge. Although, it does not mean that questionnaire is not useful to be used, due to the ability to make a generalization to the bigger population.

While, the Muslim Piety has served as a very strict and straightforward tool in measuring religiosity, which then, diminishing the flexibility in gaining a more comprehensive understanding of religious human being as a complex entity. Moreover, the tool has a very strong correlation with Islamic values and teachings, which means a less educated in religious teachings would show themselves as less religious, while there are others aspect of religiosity that are not shown adequately such as the spiritual aspects. Indeed, due to the correlation with the Islamic teachings, it would influence on how participants perceive themselves in trying to answer the question, since some people would not want to look less religious by others. Another notion is in regards the social and historical bias that some items in the tool have, which might hinder them in answering the items properly.

The impact of HCP and Muslim cleric

Another limitation from this study is the lack of understanding from another influencing factor that might affecting the participants in managing their illness, i.e. the expert factor such as the HCP and the Muslim cleric.

As the field work went on, the researcher felt and found that complementary data from the expert was needed. The data from HCP in regards of the current practice of self-care is needed to make a balanced opinion in trying to gain a wider and richer understanding from the other side of the research. As well as to know what are the barriers and opportunities, and the determinant factors that have played into role. Similarly, the information from Muslim cleric is also important in explaining more about how in Islamic's view Muslim has to see and apprehend their own effort in maintaining well-being. However, the decision to make adjustments might lead to an ethical

clearance amendment from the School of Nursing, Midwifery and Social Work, as well as the PKU, where the researcher did the study. Thus, this might also mean more time needed, which is considered a luxury that the researcher could not have at that moment, since the field study was done in the original country from where the researcher came.

Indeed, the limitation of this study can be served as potential for further research, when the researcher has finished his study and went back to Indonesia.

The scope of the study

Another limitation might come from the scope of the study. The study was only conducted in the hospital setting (PKU), which is considered as a secondary level of healthcare. It means that due to the capacity and authority that it has, the HCPs are more into the curing level, with less of the health promotion and prevention level, which are the primary care practitioners do. Therefore, the study might miss the true reality beyond what the study was aimed to do. Nevertheless, it also poses to an opportunity for further study conducting in the primary care service, such as the *Puskesmas, Pusat Kesehatan Masyarakat* or community health centre.

Summary

This study has successfully reached the aim of gaining the perception of Javanese Muslim in maintaining their self-care management in daily life. The study has also revealed the moderate level of self-care practice among the participants amid the absence of structured diabetes education program.

It is believed that Allah has a paramount role in life among the participants, which might lead them into various way of achieving well-being; fatalistic or *tawakkal*, a concept of keep trying and leave the outcome to Allah. There are several determinant factors that might play into role such as socio-economical status, self-agency as well as structural aspect. Thus, it is believed that those aspects might act as barrier to self-care, on one hand. On the other hand, they also open opportunities to a better self-care management, not only in personal scope, but also in a wider society, with the involvement of the political will from the authority.

Furthermore, the finding has also addressed the limitation of the study with further opportunity to future study.

Chapter Eight

Recommendations and Conclusion

Introduction

The research within this thesis offers findings that provide a unique perspective on how religiosity and the embedded Javanese culture influence how the people with type 2 diabetes manage their daily self-care activity. The belief that Allah is a determinative factor in life is prominent among study participants, demonstrating a tendency to share the responsibility of managing their illness with a reliance on external control factors other than themselves. This belief in Allah led some people to relinquish the power of their effort to Allah, and with embedded Javanese culture encouraged *nerimo ing pandum* as a concept of surrendering and acceptance. For most of the people with low socio-economic level, the surrendering to Allah is triggered by the lack of resources and finances to ensure access to appropriate healthcare services, including regular blood glucose monitoring, a core self-care activity required for diabetes management. Indeed, social support can also encourage surrendering responsibility, since for Javanese people the social relationship is a very important tenet in maintaining well-being.

Research in the field of religion and health has been conducted and regularly evaluated in several countries throughout the world, especially in western countries (Koenig, 2012; Levin, 1996), which are considered secular. While, research among Muslim countries is been developing, there is still lack of evidence from Indonesia, especially to facilitate comparison on an international platform, particularly the nuance of religiosity among the cultures in the Muslim population in Indonesia. This research adds to this evidence base a robust qualitative study that adds a deeper understanding of opportunities that exist in the community to encourage and foster the concept of self-care in the future to effectively manage the demand such a long term condition can have on health resource, to prevent complication.

The study provided an evidence base of the current practice of self-care in diabetes management, identifying the lack of a structured education program, which led to the inadequate practice of self-care among the participants. Indeed, the findings from this study may be served as a vehicle

to promote the implementation of self-care as a comprehensive concept, focusing on all five self-care activities to ensure an integrated diabetes management program. There were clearly missed opportunities for self-care to take place including the complete lack of access to self-monitoring equipment and training of the importance of sustaining stable blood sugars. There were several examples of good self-determination in successfully utilizing available resources to achieve the best outcome, including the utilization of recently introduced *Jamkesmas* card (health care insurance for the poor). Amid the strong drive to move towards a curative model of healthcare provision in Indonesia, the effort to establish a more preventive way of managing well-being has been placed on a firm and steady foundation with the implementation of *Jaminan Kesehatan Nasional* or the National Health Insurance since 2014. It is important to act now, this provides an opportunity to embed the notion of self-care from the outset, for all conditions, and could develop momentum as the services develop, to meet supply and demand.

This study provides new and unique evidence to inform and provide clear recommendations for a three armed strategic approach to develop self-care in diabetes management for Indonesia. Public health and government policies need to be improved to include and target the notion of self-care in diabetes management, increasing awareness. Education programs need to be developed and embedded in healthcare services managing diabetes, using innovative methods for some participants to marry up religious beliefs and Islamic teaching into the curriculum. Existing structures such a PEDI, *Persadia* or other community organization, such as Muhammadiyah or 'Aisyiyah. *Persadia* need to be encouraged and accessible throughout the community increasing access to and introducing new advanced community social support programmes for people with diabetes.

Recommendations of research findings

- To incorporate and widen the understanding of all five components of self-care into the national guidelines and policies to ensure an evidence-based credibility to each diabetes regime.
- To develop and introduce a more comprehensive diabetes education training program using collaborations between healthcare professional and Muslim clerics to embed Islamic values

into self-care diabetes management training. Create specific expert diabetes educators, with collaborative work with PEDI, *Persadia* or other community organization, such as Muhammadiyah or 'Aisyiyah.

- Consider the benefit of *Persadia*, particularly the comprehensive education provided and enhance the exposure of *Persadia* within services and appropriate referral mechanisms for health professionals.
- To utilize the findings as additional evidence for development of existing Islamic curriculum in the University and where the researcher works.
- To introduce the slogan to underpin a comprehensive self-care in diabetes activity, which is originated from the integration between the self-care activity and the tenet of *tawakkal*; a concept of '*keep trying and leave the rest to Allah*'. The slogan is composed of an abbreviation of a word DIABET in Indonesia, which stands from D for '*Diet*', I for '*Ingat untuk bergerak*' (remember to keep active), A for '*Ambil obatnya*' (take the medication), B for '*Bersihkan kaki*' (keep the feet clean), E for '*Evaluasi gula*' (evaluate the sugar), and T for '*Tawakkal*' (keep trying and leave the rest to Allah). Placing the core components of self-care activity into an already well-known abbreviated term will help people with diabetes to remember it in daily life.

- **D** – Diet
- **I** – *Ingat untuk bergerak* (remember to keep active)
- **A** – *Ambil obatnya* (take the medication)
- **B** – *Bersihkan kaki* (keep the feet clean)
- **E** – *Evaluasi gula* (evaluate the sugar)
- **T** – *Tawakkal* (keep trying and leave the rest to Allah)

Dissemination of Research Findings

A way to begin such a huge strategic development is to ensure the findings from this study are disseminated widely, through presentations and peer reviewed publications. Therefore, the following plan is envisaged to facilitate such a process:

- Two peer reviewed publication presenting the findings of the study and raising awareness of how religiosity along with Javanese culture has an impact on diabetes self-care management. A methodological peer reviewed publication will be developed on the application of the SDSCA within an Indonesian Muslim and Javanese cohort, the first adaption in this setting.
- Presentations of the findings on a local, national and international platform to raise awareness on the important role of religiosity, along with embedded local culture, in influencing well-being. These already include:
 - Permana, I (2014). Keep trying and leave the rest to Allah: How diabetic Indonesian Muslim adults manage self-care and religion. Oral presentation. European Conference on Religion, Spirituality and Health. Malta, 22nd – 24th of May.
 - Permana, I (2014). Keep trying and leave the rest to Allah: How diabetic Indonesian Muslim adults manage self-care and religion. The reflexivity point of view. University of Salford, Postgraduate Research Day. School of Nursing, Midwifery and Social Work, 9th May.
 - Permana, I (2013). The influence of religiosity to self-care among Muslim with type 2 diabetes in Yogyakarta, Indonesia. University of Salford, PhD Research Day. School of Nursing, Midwifery and Social Work, 24th of May.

Recommendation for future works

Further research is necessary to fully comprehend the issues raised by this research study. Areas to take forward include:

- The role of the doctor and Muslim cleric in supporting the people with long term condition in managing well-being.
- The amendment of self-care activity measurement for Muslim with diabetes.
- The strategic development of diabetes management of health care services based on evidence and the evaluation of the impact on patient self-care
- The impact of blood glucose monitoring on the prevention and reduction of diabetes complications.

Concluding Remarks

This study has provided the first evidence on how religiosity and cultural aspects influence self-care activity among Javanese people with diabetes. Religiosity, along with culture, is an important factor in daily life of the Javanese Muslim and the needs to be fully understood to inform healthcare provision and health education so it can be targeted in a way that meets the needs of the people in everyday life. This study revealed a relatively moderate of self-care practices, and a lack of structured education on diabetes management. It is envisaged that this is just the start and future work will come from and be inspired by the findings of this thesis, even if they stimulate debate and open discussion within health professionals and governmental departments responsible for public health.

APPENDICES

Appendix 1. Inclusion and Exclusion Criteria

Phase 1 (Abstract)

Inclusion	Exclusion
<p>Self-management in chronic illness, Quality of life in chronic illness, Quality of life in diabetes, Spirituality and chronic illness, Adult and elderly, Health behavior determinants, Structured education in diabetes Coping with diabetes, Implementation of theoretical models: Health Belief Models, Social Cognitive Theory, Theory of Reasoned of Planned Action, A model for advancing in spirituality and spiritual in nursing, Participants' perception of self-care, Self-empowerment, Self-efficacy, Community based diabetes prevention program, Evaluative instrument for diabetes education, Health beliefs and care seeking behavior, Muslim breast cancer coping strategy,</p>	<p>mental health, psychosis sickle cell anaemia, end stage renal failure, dietitian counselling, healthy food intentions, chronic fatigue syndrome, nutrition intervention, education in arthritis, asthma, pain in lung cancer, youth with diabetes, insulin therapy low back pain, HIV, kidney transplant, chronic obstructive pulmonary disease, wellness recovery, organ transplant, chronic renal disease, haem dilution, intervention of nursing telephone calls, disaster aftermath, suicidal behaviour, gender perspectives, nurse's coping, dying patient, children with diabetes, child protection, breast cancer, death and meaning, diabetes and complications, death, nurse case management, feasibility test of certain measurements tools, gender differences in work, religion and extramarital, sexual education Complementary and alternative medicine, symptom disclosure, type 1 diabetes, reviews articles, Pathophysiology, Gestational diabetes, Biomedical markers, In vitro intervention program, Cost of diabetes management, Dental problem in diabetes management</p>

Phase 2 (full text)

Inclusion	Exclusion
<p>Religion and/or spirituality Psychosocial factors as mediating factors among religion and spirituality and glycemic control The use of CAM in diabetes Models of health beliefs Explanatory models of diabetes</p>	<p>Small number of sample in quantitative study Barriers to behavior and diabetes control without addressing religion and/or spirituality Care delivery to type 2 diabetes in primary care based on Chronic Care Model Psychosocial factors and poor self-care management A model for successful ageing A descriptive analysis of anxiety in diabetes patients Non adherence to dietary regimen Factors influencing the physical activity regimen Mental health problems The distress in diabetes patients due to overprotection of the partners Self-efficacy and exercise Chronic fatigue Dose adjustment for normal eating Patients' spiritual to develop health care decision The theoretical frameworks analysis for breast cancer The perceived efficacy of community based nursing Parents' perceived barriers of adolescents patients Economic barriers Nursing religiosity Health-care seeking behavior Patient autonomy A model for advancing spirituality and spiritual care within nursing Religious coping to anxiety</p>

Appendix 2. Ethical Approval from University of Salford Ethical Committee



Research, Innovation and Academic
Engagement Ethical Approval Panel

College of Health & Social Care
AD 101 Allerton Building
University of Salford
M6 6PU

T +44(0)161 295 7016
r.shuttleworth@salford.ac.uk

www.salford.ac.uk/

1 August 2012

Dear Iman,

RE: ETHICS APPLICATION HSCR12/50 – The influence of religiosity on self-care among muslim adults with type 2 diabetes in Yogyakarta, Indonesia

The College Research, Innovation and Academic Engagement Ethical Approval Panel have reviewed your application, which they felt was well written and thorough. Before ethical approval is granted they have just asked if you can make a couple of very minor amendments:

1. Research Instrument – Appendix 1 Summary of Healthcare Activities: On Q12 please correct the typographical error 'On how many of the last seven days did you wash your feet'. Similarly on Q16 remove the scoring item '11a'.

There is no need to re-submit any documents to the Panel. Please ask your Supervisor to confirm via e-mail that these changes have been made and I can then forward your approval letter.

Yours sincerely,

Rachel Shuttleworth

Rachel Shuttleworth
College Support Officer (R&I)

Appendix 3. Ethical Approval from RS PKU Muhammadiyah, Yogyakarta



RS PKU MUHAMMADIYAH YOGYAKARTA

Jl. KH. Ahmad Dahlan No. 20 Yogyakarta 55122
Telp. (0274) 512653 Fax. (0274) 566129, IGD : (0274) 370262, E-mail : pkujogja@yahoo.co.id
UNIT II : Jl. Wates Km. 5.5 Gamping, Sleman, Yogyakarta 55294
Telp. (0274) 6499704, Fax : (0274) 6499727 IGD : (0274) 6499118 E-mail : pkujogja@yahoo.co.id

بِسْمِ اللَّهِ الرَّحْمَنِ الرَّحِيمِ

28 Sya'ban 1433 H / 18 Juli 2012

Nomor : 2132 /PI.24.2/VII/2012

Hal : Ijin Studi Pendahuluan

Kepada Yth.
dr Iman Permana, M.Kes
College of Health and Social Care University of Salford

Assalamu'alaikum wr.wb.

Memperhatikan surat Saudara Nomor : tanggal 1 Juli 2012 tentang permohonan Studi Pendahuluan untuk kepentingan penelitian dengan :

Judul Penelitian : Aspek Religiositas dalam Hubungannya dengan Self-Care pada Penderita Dewasa Muslim Tipe 2 Di Yogyakarta

Bersama ini disampaikan bahwa pada prinsipnya, kami dapat mengabulkan permohonan tersebut dengan ketentuan :

1. Bersedia mentaati peraturan yang berlaku di RS PKU Muhammadiyah Yogyakarta.
2. Bersedia mengganti barang yang dirusakkan selama menjalankan Pengambilan Data..
3. Bersedia menyerahkan pas foto 2 x 3 sebanyak 2 lembar untuk arsip dan tanda pengenal.
4. Bersedia memberikan biaya administrasi sebesar 500.000,- (lima ratus ribu rupiah) berlaku untuk kurun waktu 6 (enam) bulan dan diselesaikan sebelum pelaksanaan.
5. Setelah selesai studi pendahuluan bisa dilanjutkan dengan penelitian di RS PKU Muhammadiyah Yogyakarta,
6. Setelah selesai penelitian, peneliti wajib melapor ke Sic. Diklat dengan membawa hasil penelitian yang belum diujikan untuk dikoreksi dan dibuatkan surat keterangan selesai penelitian.
7. Peneliti wajib menyerahkan hasil penelitian yang telah diujikan dan disyahkan kepada RS PKU Muh. Yk. melalui Sic. Diklat dan menyerahkan resume hasil penelitian kepada pembimbing dari rumah sakit.

Catatan:

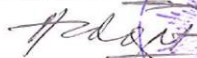
1. Sebelum melaksanakan penelitian kepada yang bersangkutan diminta menghadap Supervisor Diklat (Sulis Mukaryannah Widarti, S.Kep.Ns)
2. Selama melakukan Studi Pendahuluan berkonsultasi dengan Pembimbing dari rumah sakit, yaitu :
- Edy Supriyanto, Amd

Jika ketentuan-ketentuan diatas tidak dapat dipenuhi maka dengan terpaksa kami akan meninjau ulang kerjasama dengan institusi bersangkutan untuk waktu-waktu selanjutnya.

Demikian, untuk menjadikan maklum

Wassalamu'alaikum wr.wb.

Direktur Utama


dr. H. Ahmad Hidayat, Sp. OG., M.Kes.
NBM. 773.295

Tembusan:

1. Supervisor Sic. Perbendaharaan
2. Supervisor Sic. Diklat
3. Pembimbing yang bersangkutan
4. Peneliti yang bersangkutan ()
5. Arsip RS PKU Muhammadiyah Yogyakarta

Cepat - Mutu - Nyaman - Ringan - Islami

Appendix 4. Lembar Keterangan Peserta (Participants Information Sheet)



Pengaruh Tingkat Keberagamaan (Religiusitas) terhadap Kegiatan Rawat Diri Penderita Diabetes Tipe 2 Dewasa

Skripsi di Yogyakarta, Indonesia

Pengantar:

Saya adalah dosen di Fakultas Kedokteran dan Ilmu Kesehatan, Universitas Muhammadiyah Yogyakarta. Saat ini, saya sedang menempuh studi S3 di University of Salford, Inggris dan sedang meneliti bagaimana tingkat keberagamaan dapat atau mungkin mempengaruhi kegiatan rawat diri penderita diabetes tipe 2 muslim dewasa di Yogyakarta, Indonesia.

Saya tertarik untuk mempelajari bagaimana tingkat keberagamaan bisa mempengaruhi kegiatan rawat diri penderita muslim. Rawat diri dijelaskan sebagai 'setiap usaha aktif seseorang untuk tetap sehat dan segala kemampuan untuk secara aktif mencari segala bentuk cara pengobatan pada tingkatan perawatan dasar'. Pada prakteknya hal tersebut bisa berarti luas, mulai dari usaha mandiri seseorang untuk mencari tahu berapa kadar gula darah saat mengetahui orangtuanya menderita diabetes, sampai dengan usaha mandiri seseorang untuk menguji kadar gula darah secara rutin dengan menggunakan alat *glucose meter*.

Lebih lanjut, banyak penelitian membuktikan adanya hubungan antara tingkat keberagamaan dengan tingkat kesehatan. Banyak aspek dari keberagamaan seperti berdoa, tingkat kepercayaan, atau menghadiri kegiatan di tempat ibadah juga dukungan dari anggota perhimpunan ibadah yang terbukti mempunyai hubungan dengan usaha pengendalian kadar gula darah ataupun tingkat kesejahteraan diri.

Islam adalah agama dengan berbagai bentuk kegiatan ritual seperti sholat, dzikir, puasa dan kegiatan yang bersifat sosial seperti zakat, shodaqoh dan qurban. Semua kegiatan tersebut termasuk dalam bentuk keberagamaan yang mungkin mempunyai hubungan dengan tingkat kesejahteraan bagi mereka yang mempercayainya. Banyak kaum muslim yang melakukan berbagai aktifitas keberagamaan dikeseharian mereka tanpa memiliki pemahaman yang mendalam atas apa yang dilakukan; singkatnya, bisa saja seseorang melakukan sholat hanya karena kewajiban tanpa mengerti tujuan dan fungsinya. Oleh karena

itu, penelitian ini akan berusaha untuk memahami pengalaman keberagaman dalam kehidupan sehari-hari dalam hubungannya dengan usaha rawat diri penderita diabetes.

Apa manfaat penelitian ini?

Penelitian ini bertujuan untuk memahami lebih dalam apa arti perawatan diri bagi penderita diabetes tipe 2 dewasa muslim; apa artinya menjadi lebih religius dan apa pentingnya menjadi lebih religius; dan bagaimana tingkat keberagaman bisa membantu usaha perawatan diri dalam usaha pengendalian diabetes secara menyeluruh. Pada akhirnya, hasilnya diharapkan bisa membantu praktisi kesehatan untuk membentuk suatu program rawat diri dengan pendekatan yang lebih menyeluruh untuk meningkatkan mutu dari program pengendalian diabetes yang sudah ada dan pada akhirnya kualitas kesejahteraan penderitanya.

Mengapa anda diminta untuk ikut penelitian ini?

Anda diminta untuk ikut serta dalam penelitian ini karena anda adalah seorang muslim dewasa yang menderita diabetes mellitus tipe 2 dan mendapatkan penanganan di Bagian Penyakit Dalam PKU Yogyakarta.

Apa yang akan anda lakukan bila setuju untuk ikut serta?

Anda akan menerima lembar informasi ini dan lembar persetujuan untuk ikut serta dalam pengisian dua kuesioner. Bila anda setuju untuk ikut serta, anda akan menerima paket penelitian yang berisi dua macam kuesioner; yang pertama mengenai tingkat keberagaman anda dan yang kedua mengenai tingkat rawat diri anda sebagai penderita diabetes mellitus tipe 2, selain juga lembar persetujuan untuk mengikuti wawancara tatap muka. Kuesioner mengenai keberagaman dan rawat diri terdiri dari 41 pertanyaan yang dapat anda jawab dalam waktu kurang lebih antara 30 – 40 menit sementara anda menunggu waktu konsultasi anda, atau anda isi di rumah. Peneliti, dr Iman Permana, akan menjawab semua pertanyaan mengenai penelitian ini dan akan menegaskan keputusan anda untuk mengikuti wawancara. Wawancara akan dilakukan pada waktu dan tempat yang disesuaikan dengan kenyamanan anda dan akan berlangsung sekitar 1 – 2 jam. Penting bagi saya untuk bisa melakukan wawancara tatap muka ini secara pribadi, akan tetapi bila anda memilih untuk ditemani oleh orang lain, anda boleh meminta keluarga anda atau seorang perawat (yang akan dihadirkan oleh peneliti) untuk hadir dalam wawancara ini. Tolong diingat, bahwa wawancara ini akan direkam untuk keperluan penelitian semata.

Apa yang akan dilakukan terhadap semua informasi yang didapat?

Semua informasi yang didapat dari penelitian ini akan digunakan untuk menggali lebih dalam mengenai pengaruh tingkat keberagaman terhadap tingkat rawat diri. Tidak ada yang tahu bahwa anda ikut serta dalam penelitian ini karena nama anda terpilih dari kumpulan data yang dirahasiakan (hanya peneliti dan perawat pembantu peneliti yang tahu).

Saat anda menyetujui untuk ikut serta dan mengirimkan kembali data kontak anda, peneliti (dr Iman Permana) akan mengetahui siapa anda. Akan tetapi, informasi tersebut tetap bersifat rahasia dan semua data pribadi mengenai anda akan disimpan ke dalam computer yang terlindungi dengan kode rahasia. Semua hasil wawancara akan diketik ulang dan disimpan kedalam computer tanpa menyebutkan nama karena sudah dirubah menjadi kode sehingga keikutsertaan anda tetap terahasiakan. Semua hasil wawancara dalam bentuk digital akan dihancurkan setelah penelitian ini selesai. Tidak seorangpun yang mengetahui anda mengikuti penelitian ini kecuali anda memilih untuk menceritakannya.

Apa yang terjadi bila anda tidak ingin ikut serta?

Kebersertaan penelitian ini bersifat sukarela. Bila anda tidak ingin terlibat anda tidak perlu memberikan alasan apapun. Program perawatan anda pun tidak akan terpengaruh karenanya.

Apa yang terjadi sekarang?

Bila anda setuju untuk ikut serta, mohon lengkapi lembar persetujuan kebersertaan dan isilah kuesioner yang ada. Bila anda ragu atau ada pertanyaan mengenai apapun, jangan sungkan untuk bertanya atau menghubungi peneliti, dr Iman Permana. M.Kes., di nomor 0852 1076 2991 atau 0878 2478 3717

Terima kasih

Appendix 6. Participant Information Sheet



The Influence of Religiosity on Self-Care Activity among Muslim Adults with Type 2 Diabetes in Yogyakarta,

Introduction:

I am a lecturer from the Faculty of Medicine and Nursing Sciences, Universitas Muhammadiyah Yogyakarta. At the moment, I am a PhD student with the University of Salford, UK and am doing a study on how the religiosity might influence the self-care activities among Muslim adults with type 2 diabetes in Yogyakarta, Indonesia.

I am interested in exploring how religiosity might play a role on self-care behaviors among Muslim patients. Self-care is defined as 'every efforts on behalf of a layperson to keep actively healthy and capabilities to actively seek treatment in the level of primary care'. It could mean a varied range of activities, from someone who actively checks for a blood sugar test when he/she knows his/her parents were diagnosed with diabetes; to, actively do a regular self-monitoring blood glucose with a glucose meter.

Furthermore, researches across the world have proven that there are relationships between religiosity with health. Many aspects of religiosity such as beliefs, prayer, or attending to religious place as well as support from member of religious activities have proven to have a significant relationship with glucose control or well-being.

Islam is a religion with a variety of ritual activities such as sholat, dzikir, fasting, as well as any other socially related activities such as zakat, shodaqoh, and qurban. Those are activities that comprised the aspects of religiosity that might be related significantly to the well-being of those who believe in them. Many of Muslim will act to religious day-to-day activities without a deep understanding of what is being religious; it might be said that a person might do a prayer or sholat because it is a compulsory action without a deep understanding of the purpose. Therefore, this study will try to seek the understanding of the experience of a day-to-day religious activity in diabetes self-care management for the patients.

Why is the research study useful?

The study will explore what does it mean to be self-caring among the Muslim adults with type 2 diabetes; what does it mean to be religious and is it importance to be religious; and, how religiosity will help the self-caring in diabetes management. Then, the finding will help health practitioners in establishing a more holistic approach of self-care diabetes program to improve the quality of diabetes management program and in the end the quality of well-being.

Why have you been asked to take part?

You have been invited to take part in this research study because you are an Muslim adult with type 2 diabetes patient cared for within the Internal Medicine service at PKU Jogja Hospital.

What will you have to do if you take part?

You have received this information sheet and an informed consent to fill a survey consists of two questionnaires. If you want to be involved in the research study you will be given a pack of questionnaires regarding the level of self-care and religiosity and consent form to take part in a face-to-face interview. The self-care and religiosity questionnaires consist of 41 questions that you can fill for about 30 – 40 minutes while waiting for your call. The researcher dr Iman Permana will answer all the questions regarding the research and confirming if you want to take part to the interview process. The interview will take place at a time and place which is convenient to you and probably take 1-2 hours of your time. It is important for the researcher to have an individual face-to-face interview, however, if you prefer to be accompanied by a third person you may ask your spouse or a nurse as an observer which the researcher will try to provide. Be mindful that the interview will be audio-taped for the purposes of research only.

How will this information be used?

The information gained from all the patient interviews will be used to gain a deeper understanding of religiosity in self-care. No one will know you have been invited to be involved, as your name will be selected from a confidential database (known only to the researcher or the assisting nurse) and attached only to the envelope.

Once you agree to take part and send back your contact details the researcher (dr Iman Permana) will know who you are. This information however, will remain confidential and any personal details regarding you will be placed on a password protected computer. All the interview tapes and information will be typed electronically onto a computer where it will be stored with a code so your name will not be attached

and your identity will remain anonymous. The tapes will be destroyed when the study is complete. No one will know you have been involved in the study unless you choose to tell them.

What if you don't want to be involved?

Your participation in the study is voluntary. If you prefer not to take part you do not have to give a reason. Your care and treatment will not be affected in any way.

What happens now?

If you wish to take part in this survey, please complete the informed consent and fill the questionnaires. If you have any questions or doubts whatsoever after the completion of the questionnaires, please do not hesitate to telephone **Iman Permana (phone no. to be obtained)**

Thank you

Code :

Appendix 8. Demographic Information

Sex : Male Female

Date of birth :

Current occupation

- Government employee
- Private company employee
- Private business owner
- Professional (doctor, lawyer, etc.)
- Housewife
- Other _____

What is your HIGHEST level of education attainment?

- No formal qualification
- Elementary school
- Junior high school
- Senior high school
- College/ University First degree
- Higher degree

Thank you.

Appendix 9. The Summary of Diabetes Self-Care Activities

Below are questions regarding self-care in diabetes. Please answer the questions by circling or crossing the following options. The questions are asking about how many days in a week that you perform specific behavior. Before you answer think back to the last 7 days that you were not sick. Please do not hesitate to choose whatever you believe is true since there is no right or wrong answer. This is only for the research purpose. Therefore, the identity will be kept confidential.

Diet

		<u>Number of Days</u>							
1	How many days of the last SEVEN DAYS have you followed a healthful eating plan	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6	<input type="checkbox"/> 7
2	On average, over the past month, how many DAYS PER WEEK have you followed your eating plan?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6	<input type="checkbox"/> 7
3	On how many of the last SEVEN DAYS did you eat five or more servings of fruits and vegetables?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6	<input type="checkbox"/> 7
4	On how many of the last SEVEN DAYS did you eat high-fat foods, such as red meat or full-fat dairy products?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6	<input type="checkbox"/> 7
5	On how many of the last SEVEN DAYS did you space carbohydrates evenly through the day?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6	<input type="checkbox"/> 7

Physical Activity

Number of Days

- 6 On how many of the last SEVEN DAYS did you participate in at least 30 minutes of physical activity?(Total minutes of continuous activity, including walking). 0 1 2 3 4 5 6 7
- 7 On how many of the last SEVEN DAYS did you participate in a specific exercise session (such as swimming, walking, biking) other than what you do around the house or as part of your work? 0 1 2 3 4 5 6 7

Blood Sugar Testing

Number of Days

- 8 On how many of the last SEVEN DAYS did you test your blood sugar? 0 1 2 3 4 5 6 7
- 9 On how many of the last SEVEN DAYS did you test your blood sugar the number of times recommended by your health care provider? 0 1 2 3 4 5 6 7

Foot Care

Number of Days

- 10 On how many of the last SEVEN DAYS did you check your feet? 0 1 2 3 4 5 6 7
- 11 On how many of the last SEVEN DAYS did you inspect the inside of your shoes? 0 1 2 3 4 5 6 7
- 12 On how many of the last SEVEN DAYS did you keep your wash your feet ? 0 1 2 3 4 5 6 7

MEDICATION

- Number of Days
- 13** On how many of the last SEVEN DAYS, did you take your recommended diabetes medication? 0 1 2 3 4 5 6 7
- OR**
- 14** On how many of the last SEVEN DAYS did you take your recommended insulin injections? 0 1 2 3 4 5 6 7
- 15** On how many of the last SEVEN DAYS did you take your recommended number of diabetes pills? 0 1 2 3 4 5 6 7

Smoking

- 16** Have you smoked a cigarette, even a puff, in the past SEVEN DAYS? 0 No 1 Yes
- 17** How many cigarettes did you smoke on an average day? Number of cigarettes:

Additional Items for the Expanded Version of the

Summary of Diabetes Self-Care Activities

Self-Care Recommendations

1A. Which of the following has your health-care team (doctor, nurse, dietitian, or diabetes educator) advised you to do? *Please check all that apply.*

- a Follow a low-fat eating plan
- b Follow a complex carbohydrate diet
- c Reduce the number of calories you eat to lose weight
- d Eat lots of food high in dietary fiber
- e Eat lots (at least 5 servings per day) of fruits and vegetables

- f Eat very few sweets (for example, desserts, non-diet sodas, candy bars)

- g Other (*specify:* _____)
- h I have not been given any advice about my diet by my health-care team

2A. Which of the following has your health-care team (doctor, nurse, dietitian, or diabetes educator) advised you to do? *Please check all that apply.*

- a Get low level exercise (such as walking) on a daily basis
- b Exercise continuously for a least 20 minutes at least 3 times a week
- c Fit exercise into your daily routine (for example, take stairs instead of elevators, park a block away and walk, etc.)
- d Engage in a specific amount, type, duration, and level of exercise
- e Other (*specify:* _____)

- f I have not been given any advice about exercise by my health-care team

3A. Which of the following has your health-care team (doctor, nurse, dietitian, or diabetes educator) advised you to do? *Please check all that apply.*

- a Test your blood sugar using a drop of blood from your finger and a color chart
- b Test your blood sugar using a machine to read the results
- c Test your urine for sugar
- d Other (*specify:* _____)

e have not been given any advice about my blood or urine sugar level by my health-care team

4A. Which of the following medications for your diabetes has your doctor prescribed?

Please check all that apply.

- a An insulin shot 1 or 2 times a day
- b An insulin shot 3 or more times a day
- c Diabetes pills to control my blood sugar level
- d Other (*specify:* _____)
- e I have not been prescribed either insulin or pills for my diabetes

Smoking

5A. At your last doctor's visit, did anyone ask about your smoking status?

0 No 1 Yes

6A. If you smoke, at your last doctor's visit, did anyone counsel you about stopping smoking or offer to refer you to a stop-smoking program?

0 No 1 Yes 2 Do not smoke

7A. When did you last smoke a cigarette?

- a More than two years ago, or never smoked
- b One to two years ago
- c Four to twelve months ago
- d One to three months ago
- e Within the last month
- f Today

Thank you for your participations.

Code :

Appendix 10. The Muslim Piety

Below are questions regarding muslim religiosity. Please answer the questions by circling or crossing the following options. Before you answer think about the options and choose the one that you perceive is the truth. Please do not hesitate to choose whatever you believe is true since there is no right or wrong answer. This is only for the research purpose. Therefore, the identity will be kept confidential.

1. How strong do you believe in God?
 - a. I know Allah really exist and I have no doubts about it
 - b. While I have doubts, I feel I do believe in Allah
 - c. I find myself believing in Allah some of the time but not at other times
 - d. I don't believe in a personal Allah, but do believe in a higher power of some kind
 - e. Other
2. How strong do you believe in miracle?
 - a. I believe that miracles happened the way the Qur'an says they did
 - b. I believe that miracles can be explained by natural causes
 - c. I do not believe in miracles
3. How strong do you believe in the hereafter
 - a. Completely true
 - b. Probably true
 - c. Not sure
 - d. Probably not true
 - e. Definitely not true
 - f. Do not know
4. The existence of devil
 - a. Completely true
 - b. Probably true
 - c. Not sure/ probably not true/definitely not true/don't know
5. They who believe the prophet Muhammad is God's messenger who will go to heaven
 - a. Completely true
 - b. Probably true
 - c. Not sure

- d. Probably not true
 - e. Definitely not true
 - f. Do not know
6. For man : Within a week, how many days do you go to Masjid? day(s)
- For woman : Do you sometimes go to masjid for sholat? Yes No
7. How often do you sholat in a day?
- a. 1 – 4 times daily
 - b. 5 times a day
 - c. More than 5 times a day
 - d. Only on Friday
 - e. Only on special occasions
 - f. Never
 - g. Occasionally/sometimes
8. How often do you read Qur'an?
- a. I read it regularly once a day or more
 - b. I read it regularly several times a week
 - c. I read it regularly once a week
 - d. I read it quite often but not at regular intervals
 - e. I read it once in a while
 - f. I read it only on special occasion
 - g. I never read the Qur'an or read it rarely
9. Do you pay Zakat during the previous 12 months? Yes No
10. Do you fasted during the previous 12 months? Yes No
11. Feeling you were in the presence of Allah
- a. Yes, I'm sure I have
 - b. Yes, I think I have
 - c. No
12. A sense of being saved by the Prophet
- a. Yes, I'm sure I have
 - b. Yes, I think I have
 - c. No

13. A sense of being afraid of Allah
- a. Yes, I'm sure I have
 - b. Yes, I think I have
 - c. No
14. A sense of being punished by Allah
- a. Yes, I'm sure I have
 - b. Yes, I think I have
 - c. No
15. A sense of being tempted by the Devil
- a. Yes, I'm sure I have
 - b. Yes, I think I have
 - c. No
16. Would you agree that a person who says there is no Allah is likely to hold dangerous political views?
- a. Agree
 - b. Disagree
 - c. Uncertain
17. Do you agree or disagree with Darwin's Theory of Evolution?
- a. The theory is almost certainly true
 - b. The theory is probably true
 - c. The theory is probably false
 - d. The theory could not possibly be true
 - e. I never thought about this before
18. How Qur'an helps you in making everyday decisions
- a. I hardly think of the Qur'an as I go about my daily life
 - b. I can't think of specific examples, nevertheless I feel sure that Qur'an still help in my daily life
 - c. I can remember specific times when it has helped me in a very direct way in making decisions
 - d. I often consult the Qur'an to make specific decisions
 - e. Other
19. Do you do private prayers? Yes No

Thank you for your participation.

Appendix 11: Draft Interview Guide

Introduction

My name is Iman Permana, I am undertaking a large research project as part of my PhD study and am interviewing you today to explore how you manage your diabetes and whether religion or the level of religiosity you have influences your disease management. As a researcher I am not asking you any questions to make a judgment on how you manage your diabetes or how you embed religious practice within your life, but just to understand your experience.

A: General

- Who do you live with, family, other?
- How many children do you have, ages?
- Is there any relative other than core family, grandparents, grandchildren, brother, sister?
- What do you do for a living/work? Are you a breadwinner?
- How often do you socialize? Who with do you have a network of friends, community?

B: Knowledge

- Do you feel you have a good knowledge about your diabetes?
- What information have you received? From whom?
- Do they have a training programme for diabetic patients at the hospital? If yes what?
- Have health professionals explained the complications of diabetes to you, if so what have you been told, what do you understand?
- Do you feel you understand your condition enough to be able to manage it effectively? If yes how or No why?

B: Management of diabetes

Management	Family, social daily life	Religion (prompt)
How do you manage your diabetes day to day? What does self-care mean to you? Would you say that your diabetes is well controlled, uncontrolled, stable etc?	How does the management of your family life influence how you care for your diabetes? (work, children, friends)	Do you believe that religion directs how you live your life and manage your diabetes? (If so how?) Being charitable?

<p>Do you feel that the health professional is more in charge of your diabetes than yourself?</p> <p>Do you follow the advice of the health professional? – if so what?</p> <p>Who makes the decisions on when to and how to change your diabetes regime?</p>		<p>Frequently attending the mosque?</p> <p>What are your perceptions of Allah towards your illness?</p>
<p>What activities do you undertake that help you stay healthy?</p> <p>What strategies do you use to stay healthy – for the following activities (see questionnaire results – high/low self-care / religiosity)</p>		
<p>Diet</p> <p>Do you eat healthy? If so what?</p> <p>Do you follow the advice of the health professional, with respect to your diet?</p> <p>Do you eat what you want and adjust your insulin accordingly?</p> <p>What strategies do you use to eat healthy? (such as small regular meals, reduced carbohydrate)</p>	<p>Who cooks the food at home?</p> <p>Do you have to manage a different meal to the rest of the family?</p> <p>How do you manage when you socialize and eat meals with friends?</p> <p>What strategies do you use to control your diabetes with the family?</p>	<p>Do you think that Allah wants you to actively stay healthy?</p> <p>What impact does Ramadan (or other religious festivals such as Aqiqah, Idul Fitri or Qurban) have on how you organize your diet?</p> <p>Do you feel confident to keep fasting? What self-caring strategies do you do to keep during fasting to stay healthy?</p> <p>How does your day-to-day religion practice impact on your diet and eating healthy?</p>
<p>Medication-</p> <p>Do you feel that the health professionals are more in charge of your diabetes than yourself?</p>		<p>Do you believe that Allah will help you if you adhere to the health care professional's regime?</p>

<p>Do you follow the advice of the health professional or adapt it to fit your lifestyle?</p> <p>Who makes the decisions on when to and how to change your diabetes regime?</p> <p>What strategies do you use to with respect to your medication to stay healthy?</p>	<p>How do you manage your medication when you socialize and go out?</p> <p>Do you adjust you insulin or take it with you to administer as necessary?</p>	<p>Do you use other modes of treatment? If yes, what and why (spiritual healing, complementary therapy)? If no, why?</p> <p>Do you believe that Allah has sent you different treatment through other modes of therapy?</p>
<p>Physical activity</p> <p>What do you know about physical activity in managing diabetes?</p> <p>Do you have difficulties to adhere to the physical activity regimes?</p> <p>What strategies do you use to stay physically healthy?</p>	<p>How does your work influence how you stay healthy?</p> <p>If a house wife, how does this influence your diabetes self-care, physical activity?</p> <p>Do your family or friends assist you to undertake physical activity?</p>	<p>What strategy to keep active during Ramadan?</p> <p>Frequently attending the mosque?</p>
<p>Foot care</p> <p>What do you know about why foot care is important for diabetic patients?</p> <p>What do you look for when you inspect your feet?</p> <p>Do you have difficulties to do foot care in daily life?</p> <p>What strategies do you use to keep healthy feet?</p>	<p>Do your family or friends help or remind you about foot care?</p>	<p>How does foot care affect your daily prayer activities, such as sholat?</p>

<p>blood glucose monitoring</p> <p>What advice have you been given regarding how often you should measure your blood glucose?</p> <p>Do you follow the advice of the health professional?</p> <p>Are you confident in doing it yourself? Do you have a blood glucose monitor?</p> <p>What strategies do you use to understand when and how to measure your blood glucose, or how do you know if your blood glucose is stable?</p> <p>Is there a time of the day you particularly measure your blood glucose?</p>	<p>Do your family or friends assist you in monitoring your blood glucose?</p>	<p>Do you do your blood glucose monitoring differently during Ramadan? (not allowed to draw blood)</p> <p>Do you confident in changing the way your measure blood glucose during this time?</p> <p>Do you measure your glucose around your religious practice?</p>
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C: General Religion

<p>What do you think about Allah's role in every event in your life?</p> <p>Do you think Allah is the major actor of every event or is there any human involvement in it?</p> <p>If something bad or good happens, who is responsible for it?</p> <p>Where does your illness come from? Do you think that Allah has punished you with the illness, or do you think you have this illness because of doing wrong to Allah?</p> <p>If you have a strong beliefs that Allah will help you, do you think your illness will go away?</p> <p>Do you know whether there is a teaching in Islam about encouragement to be self-motivated in self-caring?</p>
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Code :

D: Which of the following reflects the way you see your relationship between Allah and self-management?

<p>Allah is supporting: in the background</p> <p>I have the responsibility for self-management of my diabetes with Allah as a supportive role, in the background. Emphasis is placed on the self-management of the condition over the spiritual/religious belief and practice. I take responsibility of the self-management process.</p>	
<p>Allah is the major influence: in the forefront</p> <p>Allah helps me and supports my self-management by giving knowledge, financial support, improving their health status. Religious faith is more important and comes first before my self-management or spiritual practice. Allah is more of an authoritative figure in my life any good outcome from my self-management behaviour is contributed to Allah.</p>	
<p>Allah the Healer:</p> <p>Allah will heal the disease in time: Allah the healer. There is no need to self-manage my diabetes because Allah will look after me.</p>	
<p>I have no religious relationship with Allah</p>	
<p>Other (please describe)</p>	

E: Final Thoughts

What would be your best advice for new patients regarding self-care?
 What would you change if you could?
 What would make it better or improve your ability to self-care?
 Who do you think the most responsible to all the decisions regarding self-care activities?
 Do you think to be more independent is good to your well-being?

Thank You for your time

Appendix 12: Training List and Conference

Training

1. College Research Methods module, semester 1, September 2011, including:
 - critical review of existing research
 - methods of data collection: interview, questionnaire, experimental research
 - sample and access to study populations
 - presentation, analysis and interpretation of quantitative data.
2. English for Academic Purposes started 13th of October 2011 for 10 weeks.
3. Post Graduate Research training program, semester 1, including:
 - doing a literature review for your PhD, 6th October 2011
 - what to do with the literature once you have got it, 10th November 2011
 - gaining ethical approval, 17th November 2011
 - how write academically, 8th December 2011
4. Study skills from the university Student Life, Careers & Employability:
 - academic writing skills
 - giving a presentation, 10th October 2011
 - training on Microsoft Words, 24th November 2011
5. NVIVO training 1-2nd December 2011
6. EndNote training 12th October 2011
7. Literature review training 7th December 2011
8. Critically thinking and critical writing at doctoral level, 26th January 2012
9. Academic writing, 31st January 2012
10. Evidence Based Practice for Patient Care, Semester 2, from 2nd February – 9 March 2012, including:
 - what is EBP
 - systematic reviews
 - appraising Qualitative research
 - 11. Post Graduate Research Training program, semester 2, started 2 February until May 2012, comprised of:
 - phenomenology
 - conducting qualitative research (interviews)
 - grounded theory

- fieldwork in qualitative research
- what to do with the literature when I've got it
- analysing qualitative research (interviews)
- thinking and writing critically
- writing academically

11. Wordscope training, from February – April 2013.

12. The X-pert Diabetes Programme. It is a training on how to empower the people with diabetes in managing their condition. I have been acted as an observer to see how the training was conveyed. It is a once a week training which was conducted for 6 weeks.

13. Advanced SPSS and statistical training, 3 December 2014.

Conference

1. The 4th Annual Conference on Religion, Spirituality, and Health, in Malta, 22 – 24 May 2014. Oral presentation.
2. University of Salford, Postgraduate Research Day. School of Nursing, Midwifery and Social Work, 9th May 2014.
3. University of Salford, PhD Research Day. School of Nursing, Midwifery and Social Work, 24th of May 2013.

Appendix 13. Critical Appraisal

No	Study	Method	Aim and key findings	Sample	Analysis	self-care concept	Religiosity concept	Appropriateness	Overall
1	Polzer and Miles (2007), America	Grounded theory	To develop a culturally based theory that explains relationships between concepts such as African American spirituality, religion, health and health management. Core concepts: self-management through a relationship with God.	29 African American (men 10, women 19), including 5 ministers, ages 40 – 75 from the Bible Belt area. Majority of Protestant fundamentalism.	Semi structured Interviews were audio taped and transcribed verbatim, except for the five participants. The relationships were influenced by the reading from biblical scripture. 3 typologies: (a) relationship and responsibility: God is Background; (2) relationship and responsibility” God is in Forefront; and (3) relationship and relinquishing of self-management: God is Healer.	Taking medication, diet and check blood sugar. Although there is one question about ‘what do you do to self-care?’, it was not explained in details	Ideological , ritual, experiential and intellectual dimension. This concept is based on Biblical reading. Similar to Islam which has put Qur’an as guidance in daily life.	Adequate sample size, including 5 ministers to gain understanding from the religious authorities. Although they were gained from different affiliation, it would be good to know from another religion point of view such as Islam. The concept can be served as an underpinning theory to seek the relationship from another religious perspectives	GOOD
2	(Samuel-Hodge et al., 2000), America	Focus group interviews	to identify culturally relevant psychosocial issues and social context variables influencing lifestyle behaviour, specifically diet and physical activity of southern African-American women with type 2 diabetes.	10 focus groups interviews with 70 participants. Two places of recruitment were chosen; university based internal medicine practices and community based clinic.	Particular interest: social support, self-efficacy, stress, coping and quality of life. 6 categories: 1. The role of spirituality/religiosity: Reading the bible and talking to God were strategies used to cope with daily hassles and stresses. Respondents mentioned asking God for help in controlling diabetes and when faced with difficult problems, they would turn it over to the Lord. 2. Diabetes impact: physical and physiological 3. Multi-caregiver role 4. Stress 5. Coping: frequently used were self-reliant, prayer/ God reliant 6. Social support: <i>Daughters were regarded as a more reliable</i>	Diet and physical activity. It did not explain about the whole concept of self-care	<i>Religiosity and spirituality were argued as a coping strategy based on ideological dimension, faith. Reading the bible and talking to God as emotional support → religious practice</i>	<i>In this study, elements of self-care, especially diabetes self-care was not discussed in more details. However, social and environmental factors that might influence the self-care, such as social support from the family and church have regarded to be a major role in patients’ self-management process.</i>	GOOD

3	(Casarez et al., 2010), America	Qualitative descriptive	To explore whether the spiritual orientations of Afro-American with diabetes in 2 independent samples are similar, to examine spiritual practices used by AA with t2d and how they are integrated within spiritual orientation, and to explore how spiritual practices within each orientation may be incorporated into a diabetes SM intervention	In-depth interview with AA 40 yo and older, purposive sampling from AA church and community setting. Sample: 4 AA men and 14 AA women, mean age 64 from different Christian affiliation	Interviews were transcribed verbatim. Thematic content analysis was used: reading and analysing; determining codes or identifying segments of the text according to similarity, a coding schema or list of codes was developed. This coding schema was applied to the entire data set and further modifications were made until the schema was validated by the best fit with the data. Findings: 3 orientations: 1. Spiritual practice as effort toward SM: SP enhanced strength, self-confidence to SM (14 participants) 2. Spiritual practice and SM as effort toward healing: SP can help SM (2 participants) 3. Spiritual practice as effort toward healing: rely on to God to heal the illness; not adhere to medication (2 participants) These orientations confirmed the typologies from the earlier study (Polzer and Miles, 2007)	Diet and physical activity, adherence to medication however, did not explained thoroughly according to self-care concept of activities	Spiritual practice including: prayer, reading bible, going to church, listen to religious radio → it represented the ritual and spiritual dimension of religion Dimension of religion has been scrutinize quite intensively, as well as the self-care activities	Sample are not distributed evenly and all of them are interested in spirituality. Therefore, the findings might not give diverse and rich perspectives. It would be better to gain more diverse sample from different religion. The emphasis is only on spiritual practices, and yet religion lend itself a very diverse aspects (see Glock and Stark, 1965)	GOOD
4	(Polzer & Miles, 2005), America	Literature review	to summarize the literature on African American spirituality, health, and self-management of chronic illness, with a particular focus on diabetes in African American adults. GOOD	A search through CINAHL, PubMed, Psycinfo and Sociological Abstracts. Published between 1980 to 2004. Revealed 55 articles and 5 books.	Spirituality has varied aspects including relationship with the divine, the universe and with other human being. Turn to God as coping strategy Turn it over to God → less adherence to health care professional	Diet, physical activity, SMBG and adhere to medication	Spirituality and religion were explored through beliefs and intellectual dimensions	Appropriate in explaining how religiosity play a role in a strong devotional community which quite similar with Indonesian Muslim which is regarded as a religious country	GOOD
5	(Jones et al., 2006), America	Focus groups interviews study	To explore the use of CAM therapy and the role of religion and spirituality in dealing with diabetes among AA adult with t2d	Focus groups with 68 participants in 8 groups, each have 8-12 part. Men and women separated groups. Age range 23-39. All from Protestant/Baptist. A wide range of educational attainment.	SM approach other than prescribed: variety of teas, dietary products and supplements. Spiritual beliefs and religion impacts: majority reported that faith in God and prayer were important in their lives. Prayer as a method to help manage their diabetes. 3 themes: prayer and faith in God are coping mechanisms; God provides knowledge to healthcare providers; there is a relationship between faith and conventional treatment. One female did not believe that prayer helps to do self-management, such as adherence to the doctor. Several part believed that God give healthcare providers the knowledge and skill. Many believed in conventional treatments in conjunction with prayers and faith. It is in conjunction with the typologies from Polzer and Miles.	The study did not explain about self-care practices, only emphasise about how faith on God and religion will help the self-efficacy and self-confident to self-caring	The study explored greatly on prayer as a ritual dimension of religion as well as faith as a ideological dimension.	It is a quite appropriate study regarding self-care and religion. Although it did not explore self-care dimensions in more details, it helps to understand how prayer influenced the confident of using it as a coping strategies.	GOOD

6	(Sacco et al., 2011), America	A quantitative quasi-experimental design. There are qualitative question, however, further explanation is not available in regards of how the author used both data.	To determine whether the recitation of the Serenity Prayer affected serum blood glucose levels in patients with type 2 diabetes with starting HbA1c more than 7.5%	There was no explicit description of the participants in regards of cultural or racial background. Of the original 79 patients, only 49 were able to be contacted. 1 refused. 36 (55% attrition rate) were enrolled and 9 completed all phases of study.	Prayer, considered CAM, was used by 89% of study population. Of 9 participants: 4 showed no change in serum blood glucose level over 6 weeks, 3 had increases in their serum blood glucose levels, 2 had decreased levels. The serenity prayer was recited between 1 and 3 times a day for the 9 participants. From the qualitative data, the participants had more control of their diabetes and their lives. From Q4: 5 parts said no change; 3 parts said they were stronger and more determined to change and live a healthier life. However they showed no change in their serum blood glucose. 4 parts said participating in the study affected their diet, exercise and overall diabetes management. This study had failed to find significant association between serenity prayer and blood glucose levels due to the limited participants. It did not explain why blood glucose level was not improved among parts who felt stronger after prayer.	Self-care concepts were not explored in deep understanding. What standard that has been used to evaluate this concept did not discussed further.	Prayer as one of the dimension of religion (ritualistic) were explained.	The study is appropriate for the current study to help in revealing how prayer as ritualistic dimension might influence the glycemic control. However, the study failed to show the significant relationships between the serenity prayer and blood glucose level due to the lack of participants. The interview s did not explain about the discrepancy between the practice of prayer and blood glucose level	POOR.
		POOR	POOR	POOR		POOR	AVERAGE		
7	(Chew et al., 2011), Malaysia	Cross-sectional study	To determine the relationships between religiosity, religions and glycaemic control of t2d. Using a Beliefs and Values Scale (BV), 20 items, measures religious belief. Glycaemic control was measured by the mean of the latest 3 fasting plasma glucose and HbA1c.	212 participants, including 24 from pilot study mean age 62.7. Inclusion criteria incl: affiliated and non-affiliated to any religion to allow for a full integration and effect of the religiousness. A structured questionnaires to measure: demographic data, frequency of exercise, alcohol, cigarette, religion and duration of religious beliefs.	Correlation between BV and glycaemic control: with FPG was significant and negative ($r = -.16$; $p .0029$). no correlation between BV and HbA1c levels. Stepwise regression analysis: BV and PFG were independently associated after controlling for age, employment status and insulin use. Correlation between religions and glycaemic control: There was no significant association with FPG but there was with HbA1c. muslims had the highest mean rank of HbA1c, whereas Christians, atheists, roman catholic and Buddhist had lower. Religion-Specific BV scores and GC: no significant correlation was found except amongst muslim: negative correlation between BV and HbA1c.	Self-care was explained by the glycaemic control but the study did not describe the strategy any further in regards of the self-care regime	The study failed to show the difference between religious belief and religion with GC, since both terms correlated to the GC differently. However it was explained sufficiently	The Beliefs and Values Scale contains several dimensions of religious beliefs, including a self-rated religiousness. It comprises of religious beliefs, spiritual, consequential dimensions in 20 items. It is a good self-rating scale of religiousness.	GOOD
		GOOD	GOOD	GOOD		AVERAGE	GOOD		

8	(Lager, 2006), America	A quantitative cross sectional study using questionnaires	To examine the relationship among religious coping, acceptance of diabetes, social support, diabetes management, and quality of life among individuals with t2d. Religious coping, acceptance of diabetes and social support were hypothesized to encourage adherence to self-management.	Convenient sample of 247 was recruited from local churches, clinics and diabetes support groups and a diabetes education class. Instruments: the BMMRS from Fetzer, 10 page comprising; Religious Problem Solving Scale-short form, Ideas About Diabetes-Revised Scale (IAD-R), the PRQ2000, the Religious Support Scale, SDSCA-revised and the diabetes Quality of Life Measure. Mean age 54 from protestant affiliation.	Gender and ethnic differences in religious coping, acceptance of diabetes and SM coping. AA and women used religious coping than non Hispanic whites and Hispanic. AA are more religious than Hispanic. AA more inhibited by DM than NHW. Females are more religious, use more collaborative religious coping strategies and conduct regular foot care. Self-directive religious coping was associated with poor quality of life and less religious social support. Multiple regression analysis were performed to examine religious coping, acceptance of diabetes and social support as predictors quality of life in DM. male, less inhibited by diabetes, and having higher general social support predicted greater QoL	5 dimension of self-care from Toobert was used.	Religious coping, religiosity by BMMRS Fietzer Institute Social support is more beneficial in helping people maintaining the QoL	This study is appropriate in examining the relationship of multiple factors that might influence quality of life. The use of many measurements are helpful to describe a more comprehensive feature of human being.	GOOD
9	(Abdoli et al., 2008), Iran	A grounded theory	To explore the empowerment process in Iranian people with diabetes.	Theoretical sampling of 16 men and women, age 21-73. 11 patients and 5 health prof (3 physicians and 2 nurses) Constant comparative analysis was undertaken to identify key categories. In-depth unstructured interviews	<p>Phase 1: being embarrassed by diagnosis → The beliefs to their physician as 'holy men'.</p> <p>Phase 2: thirsting to learn → relevant information from peers, health prof, media. But health education is still important.</p> <p>Phase 3: living in the shadow of fear. fear of complications.</p> <p>Phase 4: accepting diabetes as reality Accepting diabetes → religious beliefs strengthened them to endure diabetes and linked their faith to God. Their faith was a form of fatalism that gives inner strength.</p> <p>Phase 5: managing diabetes → Fear as a strong facilitator of control; afraid to become liability to other Positive life values underpin the religious belief → life as a divine gift. Relationship with god → important to accept diabetes and as support.</p> <p>Phase 6: feeling empowered. Important aspect of the empowerment is the beliefs that they can control the illness.</p>	The self-care was only seen as how to control the blood glucose. It did not explain further on how the participants did it.	Ideological beliefs plays significant role to underpin the self-control process	This study revealed the importance of religious beliefs that give them inner strength to take responsibility. Social support from family, especially daughters was important. personal and cultural beliefs influenced participants' sense of control (life is God's gift)	GOOD
		GOOD	GOOD	GOOD		GOOD	GOOD		POOR

10	(Newlin et al., 2008), America	A cross-sectional, descriptive, correlational design. An ancillary to the RCT testing the effect of a 12 week, culturally competent, cognitive-behavioral intervention GOOD	To Examine the relations of religion and spirituality to GC. Hypothesis 1: holding demographic and clinical factors constant, R/S will be related to GC in black women with GC. Hypothesis 2: holding demographic and clinical factors constant, the relationships of R/S to GC will be mediated by DSED and DSSS in black women with diabetes GOOD	Convenience sample of 109 black women. Mean age 48. Measure: demographic, BMI, medications, psychosocial (emotional distress and social support), religious and existensial well-being, and HbA1c. Theoretical foundation from Koenig, et al (2001). R/S are linked distally to GC with mental health and social support as mediating factors. GOOD	Bivariate analysis: Income and education were related inversely to HbA1c. DSED and medications were related positively to HbA1c. The inverse relationship of EWB to HbA1c. Multivariate analysis: Supporting hypothesis 1, the R/S were significantly related to GC positive and inversely, respectively. Hypothesis 2 addressed the in direct pathways by which spirituality and religion may be linked to GC, with DSSS and DSED as putative mediators but the support was lacking. Income, education, BMI, medication held constant, R/S showed significant relations with GC. Evidence of emotional distress and social support as mediators in mediating in the relationships of R/S to GC was lacking. RWB more directive, supportive and personal relation with God, EWB not related to religion, more personal.	<i>Self-care concepts are not explained in details. Only judged by the BMI and the use of medication.</i> POOR	<i>Religiosity was assessed by a standardized measurements (RWB) and (EWB).</i> GOOD	<i>The study is appropriate in explaining the relationship between R/S and GC. However, it did not explain how did the relationship happen. The theoretical model helps to guide the approach</i>	GOOD
11	(Wallin & Ahlstrom, 2010), Swedia	Cross-cultural interview study GOOD	To investigate how immigrants from muslim Somalia living in Sweden experienced receiving the diagnosis and describe their beliefs about health GOOD	19 adults with diabetes born in Somalia now living in Sweden. Analysis through qualitative content analysis GOOD	Receiving the diagnosis: Existential brooding: preoccupied with the disease, anxiety about the future Avoiding the diagnosis: doubt the diagnosis, try to repress the diabetes Accepting what is fated: always be grateful to God, find some advantages, positive comparison Beliefs about health: Health as absence of disease: biomedical antipoles, properly functioning body. Health as general well-being: health as value, independent in everyday life Fated by a higher power: gifts from God, God is ultimately responsible. Women tended to express the experiences based on supernatural beliefs than men.	<i>No self-care concept was discussed</i> POOR	<i>Belief in high power underpinned the faith</i> GOOD	<i>The study was appropriate in searching for the experience of the minority. However, in regards of self-care exploration the current study, this study is lacking on one but it has a quite deep discussion into religios belief.</i>	AVERAGE

12	(Bai et al., 2009), Taiwan	A correlational design	to examine the factors related to self-care behaviour in t2d age > = 65. Also to tested the effect of the important explanatory factors on self-care behaviour.	165 patients selected using convenience sampling. Mean age 72.8. Interview used the Personal Resource Questionnaire 2000, Diabetes Self-Care Scale and Taiwan Geriatric Depression Scale. Data were analysed using descriptive and multiple regression.	<p>Gender difference: male were more self-caring than female.</p> <p>Education difference: One with senior high school or univ → better self-care than the illiterate. College and univ grad had higher self-care level than elementary school.</p> <p>Incomes difference: Part with income < 10,000 were less self-caring than those with > 20,000.</p> <p>Religious beliefs : Non-religious part had higher self-care score than the religious. The religious would neglect self-care.</p> <p>Economic status and diseases duration were positively correlated with self-care: Higher economic status and longer diseases duration → better self-care</p> <p>Social support: highly related. Better support, better self-care.</p> <p>3 variables significantly predictive of self-care: social support, education and disease duration.</p> <p>Social support: were positively correlated with self-care.</p> <p>Depression: was negatively correlated with self-care due to the in-adherence to medication.</p>	<p><i>Self-care behaviour was assessed well with a standard measurement (diabetes self-care scale) which contains of exercise, diet, medication, blood sugar monitoring, foot care and prevention of unstable blood sugar levels.</i></p> <p><i>It has 27 items with a 5 point likert scale (1, not following to 7 following instructions)</i></p>	<p><i>The study did not explain more about the religious beliefs. The correlation must have been emerged from the PRQ2000 which only describe relation without deep understanding of the how it might happen.</i></p>	<p><i>The study was appropriately describe the multifaceted of predictive factors of self-care.</i></p> <p><i>Although for the current study, it did not describe more about how religious beliefs were gathered.</i></p>	GOOD
13	(Aikins, 2005), Ghana	Longitudinal qualitative study with Individual, group interview and ethnography	To provide counterevidence to exist lit on healer shopping; to outline app towards improving patient centred health care and policy	From a contact list of patients from the hospital, door to door recr and snow balling; 3 method: ind interv, group intev and ethnography. Ind int: 20 partc→ subj acc of illness experience and practice; Group intv→ structure, process and outcomes of social comm. 6 FGD with 44 part. Ethno to powerfull analysis of these process.	4 kinds of illness practices: biomedical management, spiritual action, cure seeking, and medical inaction.	<p><i>Self-care concept was discussed in term of seeking medical attention which in this study as hindered by the high cost of biomedical cure. However, most part believed in biomedicine than others.</i></p>	<p><i>Spiritual healing, as in Christions prayer was preferred.</i></p> <p><i>Spiritual cause of diabetes does not related to the divine but rather to witchcraft and sorcery.</i></p>	<p><i>The study did not show how religiosity aspects might influence self-care as explained in the self-care concepts and religiosity dimension.</i></p>	GOOD

14	(Carbone et al., 2007), America	Qualitative study with focus groups	To describe findings from qualitative research to inform the refinement of self-management interventions tailored to patients with t2d	Two practitioner focus groups assessed perceptions of patients' knowledge, attitudes and behaviours and 4 patients focus groups, examined knowledge, beliefs, practices, barriers and facilitators. 37 patients from 30 – 79 years old, and 15 practitioners.	<p>ethnicity and heredity as major causes. Controllable factor such as diet were also mentioned. Also stress. Most part know or experience with complications.</p> <p>Beliefs and attitudes regarding self-management:</p> <p>Discrepancy in mutual understanding between HCP and participants on the underpinning lack of knowledge.</p> <p>Self-management practices:</p> <p>Patients know to do: personal hygiene, diet, exercise, and medication. Goal-setting is not believed as a specific self-management strategy.</p> <p>Perceived barriers:</p> <p>1. Culture. 2. Structural/environmental. Socioeconomic hardship. Multiple co-morbid such as hypertension.</p> <p>Perceived facilitators:</p> <p>1. Culture: Spirituality and faith is perceived as an important factor for patients but not by pract. Patients attributed positive behaviours to God's assistance and the strength and comfort from prayer and thanks for God's guidance.</p> <p>2. Structural/environment: help from friends and family, as well as church groups.</p> <p>2 key facilitators of diabetes SM : family and religious faith.</p> <p>Practitioners did not realize the impact of religion in locus of control.</p>	<i>Diet and physical exercise were discussed as tools to gain glycemic control.</i>	<i>Prayer, and faith are regarded as an important factor by the patients not by the practitioners.</i>	<i>The study is good in addressing the basic understanding from patients and practitioners point of view and successful in describing the difference point of view between two regarding goal settings.</i> <i>For example, difference regarding the quality of life. The practitioners believed the patient can live a normal live with the diseases, whereas, the patients regarded normal life as a diseases-free life.</i> <i>The most important, how practitioners engaged with the SM strategy; due to the limit of time, they prefer a long term strategy rather than short term counselling and tailored goal.</i>	GOOD
		GOOD	GOOD	GOOD		AVERAGE	GOOD		

15	(Ahmed, 2003), Sudan	<p>Literature review.</p> <p>However, the rigor of the literature search is not exposed; there is no search strategy as the foundations in looking for the evidences.</p>	<p>To discuss the impact of cultural factors such as religious factors including fatalism, religious practices, cultural misconceptions, dietary aspects and family and gender issues; on the progress and care of diabetes in Sudanese patients.</p> <p>Sociocultural aspects of diabetes are as important as clinical and technical aspects.</p> <p>Diabetes care should be aware of the cultural beliefs of the patients such as body size, dietary, sex, sports. Islamic believes and fatalism, fasting and pilgrimage as negative impacts on self-care. Diabetes management should be sensitive on gender issues.</p>	<p>Sample was not available since this is a literature reviews, neither are the list of the evidences.</p>	<p>Fatalism → religious concept. African → diabetes as a punishment by supernatural power. Some muslim → diabetes is sign of the love of God, a test their faith and lead to rewards in the afterlife. The disease → an eraser of sin.</p> <p>Religious practices. fasting and hajj pilgrimage.</p> <p>Cultural misconceptions: the acute symptoms paradigm is still strongly attached to most of the people's mind. → stop medication when the symptom of polyuri or polydipsi are over.</p> <p>The patriarchal cultural view has play a major role → man as a main breadwinner and the sign of virility in term of husband and wife relationships. Based on Arabic culture, body posture is regarded important views in the society. Weight gain is regarded as beauty for women or sign of affluence and wealth for men. In Arabic term healthy also refers to overweight instead of slim. Sport is regarded as younger people's activity. Economical aspects as limits. The reaction of family depends on the health beliefs, educational status and the family composition. Sudanese assume women as a lower rank person in socioeconomic reasons. A women with diabetes will have a poor glycemic, poor compliance, lack of family support. Mothers are more likely to help their sons than daughters. different dietary regimes between rural and urban population. Custom to provide guest with lots of food and drink.</p>	<p><i>poor compliance, lack of glycemic control, lack of knowledge of chronic illness symptoms, no availability of evidences of foot care, lack of knowledge of proper diet.</i></p>	<p><i>Religious beliefs that might lead to fatalism, religious practice that led to lack of glycemic control.</i></p>	<p><i>This literature review is good to understand the perspective of one of muslim country and in regards of how cultural beliefs might influence the self-care. However, due to the lack of rigor for the methodology, it provides less the sense of reliability and validity</i></p>	AVERAGE
		POOR	GOOD	POOR		GOOD	GOOD		

16	(Frank & Grubbs, 2008), America	<p>A quantitative study with pre-post test education program of 20 min education program which was taken along in a routine weekly bible study night.</p> <p>GOOD</p>	<p>To examine the effectiveness of a faith based health screening/education to reduce RR for diabetes, CVD and stroke AA.</p> <p>Research questions:</p> <ol style="list-style-type: none"> 1. the impact of a faith based edu/screen program on increasing knowledge 2. socio-cultural, demographic and gender variables? 3. What is the feasibility of offering health edu program within churches in AA rural population? <p>GOOD</p>	<p>Over 120 parishioners, 89 completing the pretest. Age range 18 - 83</p> <p>GOOD</p>	<p>Overall results: t-test indicated that overall pretest and posttest scores did not differ significantly across groups.</p> <p>Gender and overall knowledge: there is no significant difference, only that higher percentage of female that attend the Bible study group. 88% participants would recommend the program to others. Barriers: over 60 y.o with limited literacy and lack of transportation. Information must be given in a simple terminology. Dietary information leaflets are regarded the least important, which may be due to barriers to healthy nutrition and exercise such as financial constraints, safety, lack of transportation, or the burden of family duties.</p> <p>Talking directly to the pastors to establish trustworthy is important part.</p>	<p><i>Eating habits, knowledge.</i></p> <p>POOR</p>	<p><i>Attending bible study groups</i></p> <p>POOR</p>	<p><i>The study has used a faith based educational program which work properly to the more religious people. However, it does not with non religious. While the composition between the groups was not shown it is better to do a more universal education programs. The study did not explain how the education matter was delivered.</i></p> <p><i>Furthermore, the role of the pastors and the church was not explained. Which is my question in regards of how the parishioners will take benefit from the role of the church apart from only serves as a place for the education program.</i></p>	POOR
17	(Handley et al., 2010), New Zealand	<p>A qualitative study using phenomenology and grounded theory to inform the study design, namely an iterative thematic content data collection and analysis process.</p> <p>GOOD</p>	<p>To better understand the day-to-day lived experiences of those adults with t2d, in particular, their historical and current ability to self manage this condition.</p> <p>The respondents age range was 43 – 79 y.o</p> <p>GOOD</p>	<p>9 depth interviews with purposively selected sample of adults with t2d: 5 f and 4 m. purposive due to the consideration of : typical of the study population and deemed information rich of the purpose of the study.</p> <p>The collection of the sample was done through the help of the primary health practitioner that gave a written information to the prospective. The researcher was contacted after there were prospective participants collected.</p> <p>Semi structured interviews was used along with an iterative analytic process.</p> <p>GOOD</p>	<p>7 data categories were developed from the data and subsequently evolved to become three themes: loss of control, gaining control and being in and staying in control.</p> <p>LOC: at the time of diagnosis, with emotional state. Some predisposing factors: age and family background.</p> <p>GC: start to understand that the efforts are time consuming and the result is not evident in short term.</p> <p>BSC: reflect the development of a sense of empowerment and integration or acceptance of diabetes which was enhanced by their spiritual beliefs and visions.</p> <p>Contact with dietician and diabetes nurse was provide no comprehensive understanding on how to manage the condition. it led to non adherence to treatment which then led to clinical and psychological outcome: guilt, anxiety.</p> <p>Support for management came from spiritual beliefs, family, and friends rather than the HCP.</p>	<p><i>Not available</i></p> <p>POOR</p>	<p><i>Spiritual beliefs which related to a more broad terms and not related to God.</i></p> <p>POOR</p>	<p><i>The sample collection process was assured to inhibit coercion by using mediator of the practitioner. The researcher used a phone call to contact the prospective participants.</i></p> <p><i>Understanding the perception of control will help the health practitioner to deal with patient according to their needs.</i></p> <p><i>However, no details in regards of the spiritual beliefs that might influence the self-management process.</i></p>	AVERAGE

18	(Kilbourne et al., 2009), America	A cross-sectional design combining clinical and community sample of people with diabetes from low-income neighbourhoods. A face-to-face interview was done GOOD	To examine the impact of multiple dimension of religiosity on depression among a lower income population. Results; 5 distinct dimension of religiosity: religious belief, reading religious materials, prayer, religious attendance, engaging others in religious discourse. GOOD	The combine sample of 222 self-identified person gathered from 2 distinct places. A convenience sample of patients presenting for primary care in a family medicine and internal medicine clinic constituted the clinical sample. The community sample was collected from randomly selected households in the catchment area o patients seen in the clinic. GOOD	Bivariate correlation and hierarchical linear regression revealed robust and inverse associations between four of the five dimensions and level of depression. Prayer, religious reading, religious attendance, and religious belief proved protective against depressive symptoms. But not social/interactive religion. Analysis suggest that religious resources increase psychological resiliency among those managing the chronic stress of diabetes. POOR	<i>Psychological aspects</i> GOOD	<i>Five dimensions of religiosity: prayer, religious reading, religious attendance, social/interactive religiosity, and religious belief.</i> GOOD	<i>The using of multidimensional aspects of religion is important to give more perspective to the current study.</i> GOOD	GOOD
19	(Popoola, 2005), America and Nigeria	Ethnographic study among Nigerian and AA. The decision to do the study in two different country based on the researcher background. GOOD	To understand the holistic and transcultural experience of living with and growing older with diabetes for nigerians and AA. GOOD	35 participants, 20 nigerians and 15 AA. 60 – 82 years. GOOD	5 primary themes: diabetic experience, economic insecurities experience, spiritual experience, complementary and alternative therapy experience, and the holistic experience. in addition to the inherent final themes of fear and hope. DE: The burden of living with diabetes, the cost of treatment, hospitalization, surgery and most important the fear of needle. EIE: one N called it expensive illness. Older AA prefer to stay jobless because of the social security benefit or hiding the current job status. SE: loss of spiritual fellowship and not being able to go to church, but still kept their faith to God. The visit from their pastor, family and friend as very inspirational while reading bible or praying. CATE: all part used 1 or more CAM. In addition of using prayer and spiritual icons for faith healing. Ginger, honey, garlic and onion and visit traditional healer for N. HE; the time of diagnosis as the event they feel changed their lives. Likewise, at the time of complication or disability. For AA it is common to do SMBG, but not for the N since it is expensive. GOOD	<i>Foot care, wound care, insulin injection, SMBG, food intake and others.</i> GOOD	<i>Spiritual beliefs that God helping them in giving hope. Social support in religious activities, from pastors, family and friend.</i> GOOD	<i>The study is good to have a better understanding of religiosity across culture and have several similarities with Indonesia in regards of the health care services system and the similar attitude in facing hardship especially with Javanese custom.</i> GOOD	GOOD

20	(Sowattanagoon et al., 2009), Thailand	A focused ethnographic approach, face-to-face interviews from two hospitals. Thematic analysis was done to analyse the interviews.	To explore the way Thai patients perceive and manage their diabetes.	27 semi-structured interviews with were audio-taped and transcribed verbatim. Age range 20-75, mean 56. Data analysis contain two phases: a line-by-line analysis of the original Thai transcripts. Emerging theme then coded using a general inductive approach. And, all interviews are translated into English by 2 prof translators. All authors independently reviewed the English transcripts, discussed the underlying reasoning and met agreement.	GOOD	Thai's perceptions of illness → mix of Indian and Chinese medicine, as well as spiritual beliefs and practices. Theravad Buddhism is central to modern Thai identity and belief and is practices by 94.6% population. Rice is very important. Key themes: the lay views of sugar, perceived cause of diabetes, importance of food and Buddhism. LVS: diabetes = sweet urine as an important role in the initial diag. Originally it was believed as non-fatal illness that only related to blood and urine. This led to how they perceived reducing sugar is the most important measure. CD: the cause → bio psychosocial views: heredity, age. Therefore, some patients believed it is related to the natural aging process. BP: illness and aging are natural parts of the birth-and-death life cycle. Illness as the result of one's past karma. The law of karma or cause and effect means there are inescapable results of one's action. By believing that the Thai's is gaining their psychological well-being and enhance acceptance and contentment. IF: rice is considered a principal food. Dietary advice to reduce rice as major problem. Sweet fruits as a daily dessert. B: practising Buddhist can be divided into 2: active and nominal. Active= regularly meditate which more adhere to treatment recommendation and aware of diabetes as the cause of physical and psychological suffering. Nominal = perceive Buddhism as an ideology of living. Less likely to meditate, but doing other practices: charity, chanting or listening to Dharma tapes. The ideas of Buddhism helps to manage the diabetes A: 2 basic Buddhism acceptance and let go.	<i>Dietary pattern, adhering to recommendations,</i>	<i>Religious practice of meditation that helps in maintaining peace of mind as well as help in encouraging one to adhere to medication. Religious beliefs help in managing lives in facing the hardship.</i>	<i>There are many similarity with Indonesian people: In holding a major belief of one principles: islam and Buddha. in principles in live: acceptance and let go to the Javanese principles of nrima ing pamrih, and in dietary pattern give this study an important part in supporting my own study.</i>	GOOD
		GOOD	GOOD				AVERAGE	GOOD		

21	Hatcher & Whittlemore, 2007). AMerica	Integrative literature review focused on hispanic adults' beliefs about t2d from published research reports using multiple computerized databases and by searching reference lists of published reports.	To understand the Hispanic adults' beliefs about t2d so health prof will be able to offer more culturally competent health care.	Total of 15 research reports. Using PsychInfo, cinahl, medline and the search terms Hispanic american, diabetes, mellitus and attitude or beliefs about health. Inclusion criteria: descriptive study using quan or qual about Hispanic adults beliefs about t2d.	<p>Though there was some variance, in general, the understanding of the etiology come from an integration of biomedical causes such as hereditary, religious (Puerto rico) and traditional or folk beliefs such as susto (Mexican), which is the concept of strong emotions. Hispanic adults believe that diabetes is a serious illness and they could identify many of the symptoms.</p> <p>Negative attitudes toward insulin were common.</p> <p>Susto or fright of surprise, developed from a very emotionally strong events.</p> <p>God's will or punishment as a etiology from some. Other see God as a support system.</p> <p>Family as supporting factor to make decision, to help them taking care of, to exercise and to prescribe medications. Thus, for some it will lead to the reversal of family's function: the children will tell parents what to do.</p> <p>Many believe that diabetes unpreventable since it is hereditary. The fondness of traditional food as a barrier to eating healthy diet. Varied beliefs of physical exercise. Barriers such as physical complaints, embarrassment, lack of knowledge, social isolation, lack of safety.</p> <p>Fear of insulin. Using insulin as a sign of an advanced disease.</p> <p>Practice of CAM is preferable since cheaper and regarded as natural.</p> <p>Hispanic adults believe that prayer is beneficial as well as believe in God. God has a direct influence by helping them follow their medical treatment plan.</p>	Dietary pattern, exercise, insulin	God's will as the cause of diabetes. however, belief in god as a helping factor. Practising prayer to reduce stress.	The religiosity dimensions of beliefs and practices as supporting factor in the study. There are many similarities to the Indonesian setting	GOOD
		GOOD	GOOD	GOOD		GOOD	GOOD		

22	(Hjelm et al., 2003), Sweden	<p>Focus group interviews.</p> <p>Children brought up on a dependent collectivism with high degree of power distance and hierarchical relationship learn to obey authorities → less independent and lower self-efficacy.</p> <p>Islamic countries as being bureaucratic with large power distance and a strong uncertainty avoidance.</p> <p>GOOD</p>	<p>To explore the influence of cultural distance of health and illness beliefs and self-care practices in females with DM from different religious background in Sweden among ex-yugoslavian muslims and Arabic muslims.</p> <p>Using the lay theory model of illness causation by Helman; health care seeking behaviour by Kleinman, health belief model, and perceived locus of control, and self efficacy.</p> <p>GOOD</p>	<p>41 females with DM, age range 22-63 with mean 52. 13 born in Arabic countries, 13 born ex-yugoslavia and 15 born in Sweden. Low education level. the number of resp was based on the principle of saturation in data analysis.</p> <p>GOOD</p>	<p>All resp → the cause of DM is individual (non-swedish : sorrow and emotional stress; hereditary. Swedish: hereditary, obesity and infection). Non Swedish → supernatural cause: God's or Allah's will.</p> <p>Arab females refer to only God knows and others as a chronic disease.</p> <p>Consequences: Arabs refer to mental discomfort, others to physical discomfort and being outsiders.</p> <p>To health care support seeking: arabs have a lower threshold than others and lack of self-care practice.</p> <p>Arabs don't do anything, others would adjust the lifestyle: exercise and diet.</p> <p>Uncontrol HbA1c: Arabs refer to wrong diet, wrong time or didn't know. Yugos → fatalistic view, and passive. Swedes, changes diet, SMBG, 'they had to pull themselves together'.</p> <p>Swedes – Arabs – Yugos .</p> <p>Arabs and Yugos said never had any info about footcare. Swedes are well informed.</p> <p>BG monitoring: Yugos prefer to have it by the nurse. Arabic and Swedish tested by themselves, but the later do it on a routine basis and changed strategy accordingly.</p> <p>Diet: arabs prefer the rich fat one.</p> <p>Exercise: Arabs and Yugos don't participate in self-help groups because don't like to hear any discussion about the illness.</p> <p>Arabs and Swedish → economy as limiting factor but not Yugos.</p> <p>Being health: Arabs → being important for health, Yugos and Swedish → individual and social.</p> <p>Arabs and yugos → don't concern family as support.</p> <p>Religion as important for all except 2 arabs.</p> <p>Traditions: Ramadan was considered less important for the majority of arabs due to the disruption of extended family. But not Yugo and Sw</p>	<p><i>Dietary, SMBG, foot care, health care seeking</i></p> <p>GOOD</p>	<p><i>Religious beliefs of the cause of DM.</i></p> <p>GOOD</p>	<p><i>The study is adequate in showing the difference between muslim and on muslim in a country. There are some similarities among one another. Using some theoretical stances good in capturing a very deep and varies views.</i></p>	GOOD
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23	(Polzer, 2007), America	<p>Qualitative descriptive analysis.</p> <p>The parent study was using grounded theory</p>	<p>To examine how spirituality affected self-management of diabetes in AA.</p> <p>Based on 3 typologies: God in background, God in forefront, and God as a healer.</p> <p>Research questions: what are the perception of AA with diabetes regarding how, if and when nurses and other HCP should address spirituality in their care, and how do these perceptions differ by typology of SM.</p> <p>Can a HCP help you manage your diabetes from a spiritual perspective? If so, how? How does your spiritual care affect your SM?</p>	<p>29 AA men and women and 5 ministers of AA churches. Age range 40-75.</p>	<p>Spiritual relationship with their HCP was important.</p> <p>BG. HCP is viewed as partners. Spiritual nature does not have to be address explicitly, rather in behaviour. Helping in spiritual way helps patient to accept responsibility in SM.</p> <p>FF. HCP is viewed as instruments of God. Some of them wanted the HCP to talk about spirituality. Some prefer the same denominations due the comfort in discussing spiritual beliefs and matters.</p> <p>GH. HCP as spiritual partner in health care → they supposed to be supportive to the patients that relinquish their SM to God since the ultimate physician is God and HCP as a spiritual partner. HCP should be helping in spiritual in 2 ways: instill confidence the the patients could deal with diabetes; HCP could analyze the spiritual maturity of the patients and allow for the role of God in treating the patients. HCP can ask the patient to pray together or read bible.</p> <p>Communication as important factor.</p>	<p><i>Health seeking behaviour, adhere to the HCP.</i></p>	<p><i>Religious belief that God relates to the conditions and HCP will help them.</i></p>	<p><i>The study appropriate and adequate in discussing the role of HCP in spiritual ways that the patients need. And the role for the HCP to engage explicitly in discussing some spiritual or religious decreed.</i></p>	GOOD
		GOOD	GOOD	GOOD		POOR	GOOD		
24	(Austin & Claiborne, 2011), America	<p>A case study design, participant observation and a focus group were used.</p>	<p>To explore the faith-based community residents' collaboration development, and design and implementation of the health promotion program among AA.</p>	<p>Case study involving 4 case of educational program in churches. A focus group contained of 23 partic. no age discussed</p>	<p>The implementation program is:</p> <p>The development of the health ministry in each of the 4 churches; the process in which the 4 ministries coordinated their activities to create the diabetes education program, the process delivering the diabetes education program, and the challenges in promoting the diabetes education program across the community.</p> <p>Minister sponsorship is essential for making community and black churches collaboration successful. The health ministries were the engine of the infrastructure development.</p>	<p><i>Dietary regime, foot care, exercise based on the Project Power educational program from ADA</i></p>	<p><i>Faith based program, there was no discussion about religiosity or spirituality aspects social support.</i></p>	<p><i>The study is appropriate in showing the example of a faith based educational program which explained the involvement of churches organizational structure in supporting and conducting the educational program. However, there was no spiritual or religious contents that have been used as a supportive materials.</i></p>	AVERAGE
		GOOD	GOOD	AVERAGE		GOOD	POOR		

25	(Cattich & Knudson-Martin, 2009), America	Qualitative analysis of interview applying a philosophical hermeneutic framework to the research process that places an emphasis on how participant couples' narrative explain and negotiate their mutual experience of living with diabetes.	To explore how couples' spirituality and relationship process holistically interact to inform diabetes management. 3 preliminary conclusions: Couples who maintain an engaged connection describe an empowering connection with transcendent that helps them explore new options. Couples whose spiritual coping style emphasize emotional acceptance of what is and making it through are usually resigned to their relationship and to enduring their disease. In this case god serves as a source of solace. The spiritual style couple bring to their circumstances seems to determine how actively they approach their disease, the degree of their optimism and the creativeness and skill they apply to manage their illness.	Interviews from 20 heterosexual couples. 14 hispanic, 12 caucasian, 9 asian, 4 AA, 1 native American. Age ranged 20-78, mean .	identified 5 spiritual coping styles based on the spiritual meaning they ascribed to the situation and the nature of their relationships with God and each other: Opportunists approach the illness as an opportunity for growth, mutual problem solvers collaborate with their partners to respond to their disease, individualistic problem solvers take personal responsibility for managing their disease, accepters endure their disease, victims take a hopeless, discouraged approach. Spirituality and couple communication and problem solving patterns appear intertwined and integral to the practice of family therapy. 4 of the couples regarded their relationship as discontinuous to let the spouse alone for a while, after the illness and one as hostile. 8 resigned, proven difficulty in maintaining relationship	n/a	<i>Religious belief, turn to God as guide, judge, provider, refuge, anchor</i>	<i>This study is appropriate in explaining the function of spouse as supporting factor and how to relate it to managing the condition. Based on the characteristic of the couple, we can see how they might see the relationship with god and the illness. The acceptors tend to see god as refuge, judge or provider with a bad relationship among the couple.</i>	AVERAGE
		GOOD	GOOD	GOOD		POOR	GOOD		

28	(Leeman et al., 2008), America	A qualitative study with focus groups	To design a culture and function specific intervention the author developed a symptom focused self-care counselling intervention delivered by a nurse through one-to-one encounters. The intervention includes: initial assessment, 4 teaching/counselling visits and a participant handbook.	10 focus groups with a total of 70 part. All of AA women with most were 55 y.o or more.	Spirituality and participation in church activities were central as a means of coping and a source of emotional support. Many women had multiple caregiving responsibilities. The role as caregiver was central and could serve as both a barrier and facilitator to self-care. Women reported being cared for by their daughters, an important source of both emotional and instrumental support. Women report high level of stress which is a barrier to self-care. Oral story telling was a frequent means of sharing information. Women in the groups commented on the value of being able to talk to others. Cultural background and environment have a strong influence on one's behaviour and beliefs. Health behaviours are also influenced by functional abilities, which often change as a person ages. Therefore, tailoring interventions to cultural and functional differences has the potential to increase their effectiveness. Rural AA cultural values often encompass religiosity, spirituality and extended family. Older AA women often place high value on their role as multi-caregivers of numerous members of the extended family.	<i>The self-care interventions including: meal plan, daily foot care, a regular program of physical activity, medication and SMBG.</i>	<i>Spirituality and participating in church activities as influencing factors.</i>	<i>This study use a symptom focus intervention therefore, it preferred to do an individual treatment session which can serve as a good example as a tailored model of improving self-care. However, it will need a large number of personnel.</i>	GOOD
29	(Mardiyono et al., 2011), Indonesia	A literature review based on searching for electronic journals and books that were published since 1994-2010. However, the strategy was not explained in details, hence, the rigor cannot be evaluated.	To examine the effects of Islamic spirituality interventions on health outcomes in nursing.	The number of articles or books are not available.	Spirituality intervention mainly composes of prayer, Qur'an recitation, remembrance of Allah, fasting, charity, prophet's methods, and modified Islamic methods. 13 studies in nursing: stimulating baby's cognitive ability in maternal nursing, promoting health during eating halal food, fasting, and abstinence of alcohol and tobacco consumption, regular exercise, reducing anxiety, and pain in medical-surgical nursing. In mental health nursing: 6 studies explored effects of prayer and religious psychotherapy to enhance happiness and physical health and alleviate anxiety, and depression. 3 studies reported Islamic cognitive therapy to alleviate the auditory hallucination, bereavement, and depression. Critical care nursing: 3 studies employed reciting the holy Qur'an and talqin in end of life care.	No further explanation provided	<i>Prayer, religious activities</i>	<i>This study is trying to discuss about the practice of Islamic values with lack of evidence. The strategy for literature search was not put into consideration which has made another downside.</i>	POOR

30	(Yuniarti et al., 2013), Indonesia	An integrative quantitative study between 3 studies.	To examine the mediation states of the variables in the 3 quantitative studies and regression analysis used to test the hypothesis.	3 studies comprise of 65 people with diabetes between 40-75 y.o. among muslim, Christian and catholic	<p>There was a negative correlation between perceived social support and depression.</p> <p>Self acceptance has negative correlation with depression, with or without social support.</p> <p>There is no correlation between perceived social support on depression after controlling self-acceptance.</p> <p>Perceived social support has a significant role on depression through self-acceptance.</p> <p>There is a significant negative correlation between religiosity and anxiety.</p> <p>There is a highly significant positive correlation between religiosity and self-acceptance. Indirect effect of religiosity on anxiety through self-acceptance; self-acceptance mediated the relation between religiosity and anxiety.</p> <p>Most people attributed the main cause of diabetes to the risk factors of eating habits, unhealthy behaviours, heredity. 8.2% regarded it as the will of God.</p>	Diabetes management explained by diabetes self-management scale by ayusmi	Religiosity explained by religiosity scale which has 5 dimensions: faith, worship, charity, deeds, and science	The study is appropriate to explain the relationship between religiosity and the variables involved.	AVERAGE
		GOOD	GOOD	GOOD		GOOD	GOOD		
31	(Grace et al., 2008), United Kingdom	Qualitative study (focus groups and semistructured interviews)	To understand lay beliefs and attitudes, religious teachings, and professional perceptions in relation to diabetes prevention in the Bangladeshi community. Thematic analysis was used iteratively to achieve progressive focusing and to develop theory. The PEN-3 multilevel theoretical framework was used to inform data analysis.	Bangladeshi people without diabetes (phase 1), religious leaders and Islamic scholars (phase 2), and health professionals (phase 3). 17 focus groups using purposive sampling based on sex, age, bmi, and family history in 3 sequential phases. Adults >=20 y.o	<p>Most lay part accepted the concept of diabetes prevention.</p> <p>The main barrier to pos lifestyle changes is not lack of knowledge but a complex value hierarchy in which what is accepted to be healthy (small portion size, limited rich and fatty food, regular act) is seen as less important than the social norms of hospitality, the religious requirement for modesty, and the cultural rejection of a sporting identity or dress, especially for women, older people and senior members of society.</p> <p>The powerful effect of social norms on individual's behaviour.</p> <p>Family support is v important in the prevention of diabetes.</p> <p>Religious leader agreed that to reject the importance of self-care and rely solely on Allah to protect health was a misinterpretation of Islamic teaching and must be addressed through religious education. They also saw the most fruitful approach for diabetes prevention in the community to be some form of collaborative working between health educators and faith based organisations.</p>	Dietary and physical activities	The importance of knowledge, either Islamic values or related to the diabetes management is important.	The study is appropriate in conveying the important role of religious leader as a collaborative factor in conducting a proper educational program for diabetes management	GOOD
		GOOD	GOOD	GOOD		GOOD	GOOD		

Appendix 14. The Summary of Critical Appraisal

No	Method study	Location	Sample	Tools	Key points	Themes	Rating
1.	Grounded theory	America	AA, ministers, protestant fundamentalism	n/a	The relationship with God in self-management based on the scripture (belief in God)	Supportive, collaborative, Fatalistic	Good
2.	Focus group interviews	America	AA women, Christian	n/a	Religiosity and spirituality as coping mech: reading bible and talking to God, as well as prayer. Turn it over to God. Social support from church, and esp from daughters. Multi-caregiver role.	Spirituality: reading bible and talk to God. Coping: ask to God. Soc support, from daughter. Multi-caregiver role for women	Good
3.	Qualitative descriptive (interview)	America	AA, various Christian	n/a	Spiritual practices as effort toward SM, SP and SM as effort toward healing and SP as effort toward healing. Spiritual practice (SP): reading bible, prayer, listen to religious radio. Going to church. SP: supportive (enhanced self conf), collaborative (along with SM) and fatalistic. God as coping to heal the illness → not adhere to medication.	Supportive, collaborative, fatalistic	Good

No	Method study	Location	Sample	Tools	Key points	Themes	Rating
4.	Literature review	America	AA.	Cinahl, PubMed, Psychinfo, and sociological abstracts. 55 articles	Spirituality: relationship with the divine, universe and other human being. Turn to God as coping strategy. Turn it over to God and less adherence to HCP	Spirituality: God, universe and human being. God as coping mechanism. Fatalistic.	Good
5.	Focus group interviews	America	AA adult	n/a	Prayer and faith in God as coping mechanism. God provides knowledge to HCP.	Coping mechanism. Faith and conventional treatment correlated.	Good
6.	Quasi experimental with qualitative question	America	Not mention (AA, Hispanic, Asian, white)	n/a	There was no significant relationship between serenity prayer and blood glucose level. Prayer as CAM among 89% part.	Prayer	Poor
7.	Cross sectional	Malaysia	Asian, Christian, Buddhist, Atheist, Muslim	Belief and Value scale	BV was negatively correlated with FPG. Religion was not associated with FPG, but was with HbA1c. muslim had the highest mean rank of HbA1c. no significant correlation between BV and HbA1c except for the muslim.	Religious belief, consequential, spirituals,	Good

No	Method study	Location	Sample	Tools	Key points	Themes	Rating
8.	Cross sectional	America	AA, Caucasian, hispanic	BMMRS, SDSCA, IAD-R, PRQ2000, Religious support scale. QoL measure	AA and women used religious coping more than others. Females are more religious, use more religious collaborative coping strategies, and conduct regular foot care. Self-directive religious coping→ poor QoL. Significant correlation between acceptance, religious coping, social support and QoL.	Religious coping. Acceptance, religious coping, social support, and QoL	Good
9.	Grounded theory	Iran	16 men and women, 21 – 73 yo. 11 patients and 5 HCP	n/a	6 phase of acceptance:1. Embarrassed, passively follow HCP→ holy men. 2. Thirsting to learn. Esp. from peers. Regarded education is important. 3. Fear of complications. 4. Accepting as reality. Religious beliefs strengthened the acceptance, and linked to the faith of God. God who made the decision. 5. Managing diabetes: self-aware. Positive life values underpin the religious beliefs→ life is a divine gift. Relationship with God→ important to accept diabetes and as support. Faith in God is invisible→ family member, daughter and doctor. 6. Feeling empowered.	God as supportive. Fatalistic but give inner strength. Social support: daughter	Good
10.	Correlational design	America	109 AA women, mean age 48	RWB, EWB,	RWB, EWB related significantly with HbA1c holding demographic and clinical factors constant. EWB mediated by DSED to control HbA1c	Spirituality : God, and nature.	Good
11.	Interviews	Swedia	19 adults muslim	n/a	Accepting the fate→ grateful to God, find some advantages, as gift from God, God is ultimately responsible. Women tends to express experiences based on supernatural beliefs than men	Fatalistic	Average

No	Method study	Location	Sample	Tools	Key points	Themes	Rating
			Somalia born				
12.	Correlational design	Taiwan	165 pt >= 65 yo.	PRQ2000, DSSS, TGDS	Male more SC than female. Higher edu more SC. More income is more SC. Non religious are more SC. The religious neglected SC. Better soc supp, is better SC.	Fatalistic.	Good
13.	Personal and group interviews, ethnography	Ghana	Personal intv: 20. 6 FGD with 44 part.	n/a	Spirituality based concept of illness due to witchcraft. Spiritual healing such as prayer. High cost as biomedical treatment.	Spirituality healing and beliefs	Good
14.	FGD	America , latino	FGD with 15 HCP and 37 pts. 30-79 yo.	n/a	Gap in perspectives between HCP and pts. Part: know how to do SM, but difficult due to culture. Goal setting is not believed as a specific self-management strategy. HCP: viewed pts as lack of confident and abilities. Social support from family. Pts believed spirituality and faith as important but HCP didn't . god is supportive. Prayer as coping.	Supportive. Coping Social support.	Good
15.	Literature review with no rigor	Sudan muslim	n/a	n/a	Fatalism → diabetes as punishment by supernatural power. Some muslim → love of God, a test of faith. Disease: eraser of sin. fasting and hajj have negative impact on SC. Cultural misconception: symptomatic based SM. Cultural: man as main breadwinner and hold the sign of virility. Body posture as important. Women regarded lower rank hence lack family support, and poor GC.	Fatalism. Religious practice as hindrance. Cultural Social support	Average

No	Method study	Location	Sample	Tools	Key points	Themes	Rating
16.	Quantitative, pre-post test	America	89 parishioners , 18-83 yo.	n/a	More female attending the bible study group. Faith based educational program.	Social support Faith based organization	Poor
17.	Phenomenology and grounded t	New Zealand	5 female and 4 male	n/a	3 themes: Loss of Control, Gaining Control, and Being in and Staying in Control. LoC: at diagnosis with emotional state. Age and family as predisposing factors. GC: begin to understand that treatment takes time. BSC: sense of empowerment and acceptance, enhanced by spiritual beliefs and visions. Not adhere to treatment due to the complexity of information from HCP. Have more support from spiritual beliefs, family and friends rather than HCP	Spirituality Social support from family and friends	Average
18	Cross sectional with interviews	America	Convenient sample of 222	n/a	4 of 5 dimensions of religiosity proved to be protective against depression: prayer, religious reading, religious attendance, and religious beliefs. But not social/interactive dimension.	Religious ritual, spirituality. Social support negatively with depression.	Good
19.	Ethnography	America and Nigeria	35 part. 60-82 yo.	n/a	5 themes exp.: diabetic, economic insecurities, spiritual, CAT, holistic experiences. DE: Cost of treatment and fear of needle are the hindrance. SE: loss of spiritual fellowship and not be able to go to church, still keep the faith to God. Visit from pastor and friends as supportive while reading bible. CAT: prayer and spiritual icons. SMBG common in AA than N	Social support Faith to God. Spirituality	Good

No	Method study	Location	Sample	Tools	Key points	Themes	Rating
20.	Ethnography and interviews	Thailand	27 part, 20-75 yo.	n/a	Theravad Buddhism as principle identity and beliefs. Rice is very important. Themes: lay views of sugar, perceived cause of diabetes, important of food, Buddhism. LVS: reducing sugar. CD: diabetes as age related. Illness as the result of karma. IF: reducing sugar (rice) is difficult. B: active meditation are more adhere to treatment. Nominal Buddhism regarded Buddhism as ideology of living.	Spiritual practice of meditation	Good
21	Literature review	America	15 research report using psychinfo, cinahl, medline.	n/a	Biomedical causes: hereditary. Religious causes (Puerto rico), or folk beliefs as susto (Mexican). Negative attitude toward insulin. Some: God's will or punishment as a cause. Family support to SM, but diabetes has reversed the family's role. Another barriers: traditional food, physical act., social isolation. Prayer and believe in God as beneficial in SM through helping following treatment.	Fatalistic views Supportive views Social support	Good
22.	FGD	Swedia	41 female, 22-63 yo, muslim: Arabic born, ex yugo born and sweden's born	n/a	Diabetes cause: Swedish→ hereditary, non Swedish→ Allah's will. Arabic, Allah knows so do no SM. Swedes are more knowledgeable and SM. Arabs and Yugo don't concern family as support. Most arabs don't regard Ramadan as important due to the disruption of extended family. But not yugo or Swedish	Fatalistic Social support	Good
23.	Qualitative descriptive	America	29 AA and 5 ministers. 40-75 y.o	n/a	Spiritual relationships with HCP is important. 3 themes: BG→ HCP as partners. Spirituality in behaviour, helping pt to accept responsibility of SM. FF→ HCP as instruments of God. HCP needs to talk about spirituality, same denominations. GH→ HCP as spiritual partner, they should support the	Fatalistic. Social support based on the spirituality.	Good

No	Method study	Location	Sample	Tools	Key points	Themes	Rating
	with parent study of GT				decision to relinquish their SM to God. God as ultimate healer, and HCP as spiritual partner.		
24.	Case study, FGD, participant observation	America	4 case. FGD of 23.	n/a	A church based educational program. Minister sponsorship is important for making the collaboration successful.	Social support by minister and church.	Average
25.	Philosophical hermeneutic framework	America	20 couples. 14 hispanic, 12 caucasian, 9 asian, 4 aa, 1 native America. 20-78 yo.	n/a	5 spiritual coping based on the spiritual meaning. Opportunist: illness as an opportunity to growth. Mutual Problem Solver: collaborate with partner to manage the illness. Individualistic Problem Solver: personal responsibility. Accepters: endure their disease. Victim: takes a hopeless, discouraged approach.	Religious beliefs. God as coping mech.	Average
26.	Pre-post test experimental	UK	4 group of 200.	DSE, SCPS, ES.	Workbook of how to talk spirituality to patients were strongly recommended to enhance the attitude toward spiritual care, to create an emphatic response. Students' spiritual care attitude and spiritual experience were more impressionable than RN. The frequency of religious service and spiritual experience contribute to attitude toward spiritual care. Thus, spiritual care to some degree can be taught.	Spirituality toward humanity of the patients	Average

No	Method study	Location	Sample	Tools	Key points	Themes	Rating
27.	Cross sectional	America	50 part. >= 65 yo.	n/a	96% elders use prayer to cope with stress. Female and black used prayer to cope to stress more than male and whites. Other regime such as spiritual alternative treatment: music, relaxation, humor, meditation. younger uses active, problem focused coping. Older uses passive, transcendent coping.	Prayer as coping.	Average
28.	FG	America	10 group of 70, AA women >=55 yo	n/a	Spirituality and religious service attendance are important as coping and emotional support. Multi caregiver role of women: as facilitator or barrier. Daughter as main support. Oral story telling as means of sharing information. Behaviour toward health influenced by cultural and functional ability. Rural AA cultural values encompasses religiosity, spirituality and extended family.	Spirituality Religious activity Social support Multi role of women as barrier and facilitator	Good
29.	Literature review	Indonesia	Journal and books from 1994-2010 with no search strategy	n/a	Spirituality intervention: prayer, qur'an recitation, remembrance of Allah, fasting, charity, prophet's method, and modified Islamic methods. Promoting health: eating halal food, fasting, abstinence to alcohol and tobacco. Reducing anxiety, regular exercise. Prayer and religious psychotherapy to enhance happiness and physical health. Islamic cognitive therapy to alleviate the auditory hallucination, bereavement, and depression. Qur'an reciting and talqin in end of life care.	Spirituality intervention: prayer, qur'an recitation, remembrance. Ritual Promoting health with Islamic behaviour.	Poor
30.	Integrative quantitative	Indonesia	3 studies of 65 part 40-75 yo, muslim,	BDI, SSPS, SAS, ASPS, BIPQ, RS of: Faith, worship,	Negative correlation between perceived social support and depression. Self-acceptance has negative correlation with depression with or without social support. Perceived social support has a significant role on depression through self-acceptance. Negative correlation between religiosity and anxiety. Highly significant positive correlation between religiosity and self-acceptance. Self-	No further explanation of religiosity. Fatalistic	Average

No	Method study	Location	Sample	Tools	Key points	Themes	Rating
			Christian and catholic	charity, deeds, and science. fatalistic, COPE, DSMS	acceptance mediated the religiosity and anxiety. 8.2% people regarded diabetes as the will of God		
31.	FG and Interviews	UK	17 FG among people without diabetes, religious leader and Islamic scholar	n/a	Barrier to behavioural change is not lack of knowledge but a complex value of hierarchy: healthy is more of social norms of hospitality. The religious requirement of modesty. Social norms have huge powerful effect on individual's behaviour. Family support is very important in SM. Religious leader agreed of the important of self-care and just to rely on Allah is a misinterpretation.	Social support from family. Religious knowledge is important.	Good

Appendix 15. The Process Of Data Collection And Waiting Room Layout

1. Following registration, the patients will come to the nurse station to confirm and wait in the waiting room no 2 (as pictured in the consultation layout).



Waiting room no 3

2. While the patients are waiting to be called in to the waiting room no 3, the researcher or the assistance will try to approach the prospective patients which were gained based on the information from the nurses. This approach was chosen based on the previous discussion with the Research Ethical Committee of the hospital, the field supervisor, as well as with the senior nurses available.
3. Had the patients agreed to join, they will be given the research information kit which including the patient information and the consent form, along with the questionnaires while they are waiting to be called to the waiting room no 3. The package also contains consent to join for the interview session which is located at the preferred place of the participants.
4. Had the patients agreed to join but willing to fill the questionnaire at home, further appointment of collecting the questionnaire then determined.
5. A standing banner was placed in front of the internal medicine consultation room. The banner consists of a background of the study, how the study is performed, the confidentiality of the participants, and contact person's details.



Standing banner of the research

Appendix 16. Coding process by Granaheim and Lundman (2004) (1 example)

1-A1. Meaning unit	Condensed meaning unit	code
I live with my daughter (she pointed to her daughter to her left).. other children have left the house and live far away.. I am building a house at the back for her.. I have 8 children.. I gave them all a place (to build a house-IP)	Live with her daughter, building a house for her	Mother's affection
Yes, I do have (a large property).. Alhamdulillah (thank you God)	Have a large property	landlord
Sometimes they come here to console me.. there are 18 of them	Grandchildren as consolation	Grandchildren as consolation
I am jobless,,	Jobless	Jobless
I am jobless,, that's why I .. I always try to read Qur'an everyday.. yes, that's it.. all I usually do is pray.. pray for children and grandchildren	Jobless, read Qur'an and pray for the family	Daily activities, mother's affection
because all my children are university graduates, so they make a lot of money.. so, I can get a lot of money too from them every month	The children have a lot of money, they give her money every month	Financial support from the children
I just bought a car for one of my grandchildren just now because she just passed to Gajah Mada University without a test..	Bought a car for her grandchildren, have her own money	Grandmother's affection
I can buy her a car.. I have my own money too..	Have money to buy a car	Feeling of having a lot of money
no, I haven't (received any information about diabetes)	Haven't received any information about diabetes	Not well informed
Yes, I would read anything about diabetes from any magazine I read.. so, I know a little bit	Read from magazine,	Insufficient sources
Well, as far as I know.. it is like a common disease	Common disease	Common disease
if there are any disorder being caused, then.. just do a lot of prayer.. just pray to Allah so the disease will not become uncommon.. that has been my pray..	Pray to Allah so the disease will not become uncommon	Pray to Allah for the disease
yes, I believe so (the prayer will help).. yes, with that prayer,, it will make everything easy.. yes,, so I do believe that if we pray Allah will help us.. it has been my understanding since a long time ago..	Believes that Allah will help if we pray, make everything easy	The power of prayer
but what made me confuse was when the time I called dr L.. she asked me to come down to the hospital.. turned out, I was in a quite bad shape, actually.. I got a transient ischemic attack, she said..	Confuse about the symptoms, got transient ischemic attack	Confuse to get the TIA
just usual.. I just prayed.. if it was my time to die, just die, I felt ready for it, that's ok,,	Prayed for the disease, felt ready to die	Felt ready to die
if I can live longer then please give me more time	Pray for a longer live	Pray for a longer live
Then I did reciting some verses of Qur'an.. because I can memorize some of the verses	Reciting Qur'an, memorizing some verses	Able to memorize Qur'an

quite well.. even I can recite the chapter of yasin off my head..		
yes, get a medication.. just like what every diabetic person would do	Get a medication, like what other diabetic would do	Normal medication
and I surrender.. Surrender just like if Allah wants to take me know i would not mind	Surrender to Allah	Would not mind
but, yes, I am asking for a cure as well..	asking for cure	Asking for cure
I didn't know (whether the sugar was down) because i haven't get checked.. i didn't check because the schedule was not due	Didn't know because didn't check, the schedule was not due	Not keen to know
I believe it was because of my own effort with the support from Allah	Own effort with Allah's support	Own effort with Allah's support
I also believe that if you are close to Allah, Allah will get close to you too	You are close to Allah, Allah will get close to you	Close mutual relationship
I have this belief since I was young.. because my grandparents were also a kyai (a muslim priest or cleric-IP).. maybe because of that.. all my greatgrandparents' teachings were all like that	Have the belief since young, grandparents were a kyai (muslim cleric)	Background of Islamic knowledge
No it's (the knowledge of diabetes) not sufficient	The knowledge is not sufficient	Perception of lack knowledge
I was told that if you were diabetic you would get your body swollen ... I didn't know about it..	Being told of diabetes related symptoms	Inadequate information

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