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Self-management of diabetes by people in Indonesia: A grounded theory study

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Statement of the Contribution of Others

Nature of Assistance	**Contributions**	**Name and Affiliation**
Intellectual support	Supervision Proposal Writing Papers writing for publication PhD Study process (preparation, data collection, data analysis, data presentation) Thesis writing	Dr Kristin Wicking (Principal Advisor) A/Prof Nichole Harvey (Secondary Advisor) A/Prof Intansari Nurjannah (Co-Advisor) Professor Karen Francis (Advisor Mentor) Professor Jane Mills (former Primary Advisor)
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Abstract

Diabetes is a major population health problem in Indonesia. Health education is one strategy adopted by healthcare professionals to assist people with diabetes to manage their condition. Existing studies have identified that the beneficial impacts of effective diabetes management include healthy glycaemic control, knowledge about diabetes and appropriate self-care management. Throughout the trajectory of living with diabetes, people with diabetes learn about their disease. However, the process of how people with diabetes learn about their disease in the Indonesian context is not well understood, generating the research question guiding this study: 'How do Indonesian people with diabetes learn about their disease?' This research question was answered by employing a grounded theory methodology influenced by constructivism and symbolic interactionism.

This study aimed to generate a theory about the process of how people with diabetes learn about their disease in the Indonesian context. Data collection involved twenty-eight semi-structured interviews with twenty-six participants. The participants included people with diabetes, healthcare professionals, healthcare providers and families. These data were collected during three phases of the study between April 2016 and July 2017. All interviews were conducted in the Indonesian language and thus the process of data analysis involved both English and Indonesian languages.

The study revealed a theory entitled '*Learning, choosing, and acting: Self-management of diabetes in Indonesia*'. This theory explains the process of how Indonesian people with diabetes learn about their disease, which involves both linear and cyclical movements. The process includes five major categories: seeking and receiving diabetes-related information; processing received information; responding to recommendations; appraising the results; and sharing with others.

This study produced six key findings:

1. People with diabetes both actively sought and passively received diabetes-related information.
2. Diabetes-related information was accessed from a variety of sources and places.
3. Before making a decision about using received information, people with diabetes often sifted the information based on their prior knowledge, experiences and personal judgement.

4. Physical, psychological and resource factors highly influenced people's decisions to apply recommendations for managing their diabetes.
5. By appraising the results of their management choices, people with diabetes developed experiential insight, which they often shared with others and which influenced their future management decisions.
6. Families of people with diabetes engaged in all five categories of the process entitled '*Learning, choosing, and acting: Self-management of diabetes in Indonesia*'.

This study has contributed to new knowledge on how to anticipate working with Indonesian people with diabetes who make decisions regarding their self-care management techniques. By understanding this process, healthcare professionals will be better placed to encourage people with diabetes and their families to make informed self-management choices that will improve health outcomes. This study recommends that culturally sensitive assessment of people's prior knowledge about self-management of diabetes is crucial. Further research is required at a national level for identifying issues in selecting appropriate self-management of diabetes and strengthening multidisciplinary care.

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Chapter One: Introduction

Diabetes mellitus has been and continues to be a universal problem. According to the latest report from the International Diabetes Federation (IDF) in 2017, diabetes affects 425 million people in the world, with the number of people impacted by the disease predicted to grow to 630 million by 2045 (International Diabetes Federation, 2017). This report also stated that the Western Pacific countries region, in which Indonesia is grouped, has more than 168 million people living with diabetes and one in three people or 1.7 million people from this region have died because of the disease. Among these Western Pacific countries, Indonesia is ranked second, after China, to have people aged between 20 and 79 living with diabetes (International Diabetes Federation, 2017).

Diabetes has been a concern in Indonesia since the 1980s (Waspadji, Ranakusuma, Suyono, Supartondo, & Sukaton, 1983) and it is one of the four major non-communicable diseases in Indonesia where the prevalence rate is predicted to rise (World Health Organization, 2018). Recently, the International Diabetes Federation (2017) reported that the frequency rate of diabetes in Indonesia has reached 6.2% with more than 10 million people living with diabetes. In 2007, the Indonesian National Institute of Health Research and Development conducted a basic health survey to estimate the prevalence of diabetes in the Indonesian urban population and revealed a rate of 5.7% (Mihardja, Delima, Manz, Ghani, & Soegondo, 2009; National Institute for Health Research and Development, 2008). Five years after this first national survey, the Institute reported that the proportion of people living with diabetes in both urban and rural areas had reached 6.9% (National Institute for Health Research and Development, 2013). These results show an escalation in the number of diabetes cases in Indonesia.

Four principles of diabetes management are: medications, diet, physical exercise and education (Sutanegara & Budhiarta, 2000). The effectiveness of medications as either single therapy or in combination has been found to improve glycaemic control of people with diabetes (Soegondo, Subekti, & Luthariana, 2004). Similarly, various types of insulin have been found to be effective and safe for Indonesian people living with diabetes (Soewondo, Kshanti, Pramono, Langi, & Dalem-Pemayun, 2013b; Soewondo, Lindarto, Wibisono, Renaldi, & Dalem-Pemayun, 2013c; Soewondo, Pramono, Langi, Soetedjo, & Kshanti, 2013d). Diet and education were also found to have a positive effect on glycaemic control (Sinorita, Saadah, & Jazakillah, 2008). Moreover, Kartono (2013) discovered that physical exercise could increase insulin activity to improve the control of blood glucose. The outcome of each of these various types of diabetes management is improved blood glucose control. Soewondo, Soegondo, Suastika, Pranoto, Soeatmadji et al. (2010) also emphasised the importance of applying these principles within a multidisciplinary context.

Diabetes education has significant benefits. Research has found that diabetes education improves glycaemic control, increases the person's knowledge and positively changes their attitudes towards self-care management, which results in improved health outcomes (Aliha, Asgari, Khayeri, Ramazani, Farajzadegan et al., 2013; Banerjee, Macdougall, & Lakhdar, 2012; Korytkowski, Koerbel, Kotagal, Donihi, & DiNardo, 2014; Zareban, Karimy, Niknami, Haidarnia, & Rakhshani, 2014). Although most diabetes education programs provide immediate benefits for people living with diabetes, the long term impact on self-care management is less often examined, with one study finding that healthy glycaemic control is often not maintained over the long-term (Klein, Jackson, Street, Whitacre, & Klein, 2013). Furthermore, as people with diabetes may not maintain appropriate self-care management over a long period, ongoing support and diabetes education are required (Rankin, Barnard, Elliott, Cooke, Heller et al., 2014).

International research studies have revealed both positive and negative aspects of diabetes education. People living with diabetes prefer receiving diabetes education during their regular consultations, rather than having to attend specific courses on diabetes (Tuytel, Leeuw, Gorter, Rutten, Bijl et al., 2010). Generally, diabetes education programs are more successful when provided by nurses (Klein et al., 2013). Unsuccessful diabetes education programs are attributed to varying levels of the educator's expertise and competence, as well as poor structure, planning, management, facilities and supervision (Abazari, Vanaki, Mohammadi, & Amini, 2012). It is evident that providing education is effective in improving people's control and compliance with managing their diabetes (Aliha et al., 2013; Debussche, Rollot, Le Pommelet, Fianu, Le Moullec et al., 2012; Kearns, Bowerman, Kemmis, Izquierdo, Wade et al., 2012; Korytkowski et al., 2014). It is important that nurses adopt an evidence-based approach when providing education to achieve better outcomes. For example, information about what injection technique to use or what follow-up care is required should be based on best practice. Although the majority of nurses in studies examined were diabetic educators (Martin, Warren, & Lipman, 2013) and successful at delivering diabetes education (Klein et al., 2013), Oyetunde and Famakinwa (2014) still found that nurses' knowledge about specific areas of diabetes was incomplete. Interestingly, new graduate nurses were reported to perform much better than senior nurses in delivering education to people living with diabetes (Oyetunde & Famakinwa, 2014).

Nationally, educational interventions for people living with diabetes in Indonesia have been described in several studies (Hartayu, Izham, & Suryawati, 2012a, 2012b; Ng, Nichter, Padmawati, Prabandari, Muramoto et al., 2010; Sae-Sia, Maneewat, & Kurniawan, 2013). These studies examined formal diabetes educational programs in Indonesia to measure their ability to offer new, tailored strategies for educating people with diabetes through support, recommendations and/or interactive approaches. Furthermore, they also demonstrated that positive self-care behaviours, increased knowledge about diabetes self-care, and adherence with self-care management were outcomes from these programs. Despite these achievements, none of these studies adequately provided deep understanding, nor were they culturally sensitive to the process of how people with diabetes receive and engage in education that promotes their health and wellbeing in the Indonesian context. Moreover, there is no evidence to describe and explain how Indonesian people with diabetes learn about their disease once they engage in diabetes education. Furthermore, all studies looked at only one clinical setting. The commonalities highlighted in the current literature led the candidate to ask if a basic social process can be developed to guide how people with diabetes in Indonesia learn about their diabetes. Knowing the process of how people learn about their diabetes in the Indonesian context will better inform policy-makers about developing strategies to enhance diabetes education. Outcomes of this study can also make the work of healthcare professionals (HCPs), in particular nurses, visible and recognised.

Impetus for undertaking this study

The candidate is a nurse academic in Indonesia who has three main roles in her university, particularly at the school of nursing. The roles include teaching, undertaking research and providing community service. Moreover, her areas of teaching and research are in medical surgical nursing, chronic disease, palliative care, education in nursing and health education. The candidate's family influenced her decision to undertake research that explored how people with diabetes learn about their disease. The candidate's mother came to her after visiting a clinic at the hospital and informed her that the doctor (specialist doctor/internal medicine physician) had prescribed insulin injections. Her mother asked her to teach her how to inject the insulin. Although the candidate (her daughter) knew how to teach her mother to inject insulin, she wondered if the doctor had taught her mother how to inject insulin. The candidate's mother said that when she was provided with the insulin injection at the pharmacy, no one, including the doctor had taught her how to inject the insulin. The candidate pondered, 'how could this happen?' 'How could a HCP expect a person with diabetes to inject insulin without being taught the techniques involved?' This situation inspired the candidate to conduct a research study on how people with diabetes learn about their disease.

Aim of the study

This study aimed to generate a theory about the process of how Indonesian people with diabetes mellitus learn about their disease.

Research question

The overall research question addressed by this study was: How do people living with diabetes mellitus in Indonesia learn about their disease?

Significance of the study

This study contributes to knowledge about the current process by which people learn about diabetes and the health education provided to them. The outcomes of this study will provide insight into the process by revealing problems with how diabetes education is provided and by making visible the process of how people learn about their diabetes, thus helping to minimise misunderstanding. This knowledge can provide insights that healthcare professionals can utilise to develop needs based health education for people with diabetes. The outcomes may also inform policymakers when evaluating and monitoring current practice in diabetes care especially related to educating people with diabetes. Finally, the study outcomes are important for creating and targeting strategies to facilitate people with diabetes using information they have learnt to appropriately manage their diabetes.

Methodology Selection

Methodology is defined as "a set of principles and ideas that inform the design of a research study" (Birks & Mills, 2015, p. 4). The choice of the methodology adopted should inform the assumptions and the methods underpinning the processes adopted for conducting the study. These authors emphasise the importance of having methodological congruence where the candidate's philosophical position, research aims and methodological framework are coherent to achieve credibility in conducting a qualitative study. Besides the alignment of research questions and methodology, the methods used in this study were also influenced by the candidate's philosophical position.

Chapter One: Introduction

The aim of the research was to explain and theorise the process of how people learn about their disease. Grounded theory was identified as an appropriate methodology to answer the research question because it asked about the nature of a process. The concept of a process is a distinctive feature of grounded theory. Moreover, this methodology was chosen as there is a lack of knowledge about the learning process (Mills, Birks, & Hoare, 2014). The limitation of a substantive area in the learning process of people living with diabetes in Indonesia has also prompted the candidate to select a grounded theory method as it explicated the research inquiry. Grounded theory can assist the researchers during data generation and analysis to build a process then form a theory, and thus the outcome of this study was a theory with explanatory power (Charmaz, 2006; Corbin & Strauss, 2008; Creswell, 2013). Grounded theory methodology is also appropriate when the final outcome of the study is to build a theory driven with robust explanation (Birks & Mills, 2015).

Glaser and Strauss (1967) described the situation when they produced a popular seminal text, called 'The Discovery of Grounded Theory'. They explained that, in sociological research, there were very few theories in the late 1960s. They continued to describe that available social research method books were mainly about verifying theories and thus had a lack of emphasis on developing concepts. Glaser and Strauss (1967) pointed out that generating a theory consequently became a second choice in sociological research. Therefore, they introduced their first seminal text aiming to offer methods on how to discover theory from data. This book also aimed to help sociological scientists to improve their capacities in building theory and increase theory relevance with the research. Through the book, Glaser and Strauss guided researchers, not limited to those in sociology, to use a grounded theory method for conducting studies looking at social phenomena, with related designated procedures on sampling, analysis and applications. Even though generating a theory is emphasised over verifying a theory, they argue that both aspects cannot be separated as they are both important and can be a supplement to each other; they eventually generate the theory (Glaser & Strauss, 1967).

Collaborative works of Glaser and Strauss (1967) on grounded theory did not continue as they then separated to individually advance grounded theory from divergent perspectives in their respective grounded theory seminal texts. Glaser (1978) became an independent writer on classical grounded theory while Strauss cooperated with Corbin (1900) in producing seminal texts about evolving grounded theory methods. The development of grounded theory has focused on ensuring a compatible relationship between the researchers' stated philosophical positions and the methodology selected. Glaser's first independent publication was about theoretical sensitivity. He emphasised grounded theory methods and its components instead of concentrating on a philosophical stance being congruent with the chosen research methodology (Birks & Mills, 2015). Whereas, Corbin and Strauss (1990) start to take into account philosophical stances into methodological underpinning, by their further work on the procedures and approaches of grounded theory methodology.

Strauss and Corbin (1990) first worked together to write about procedures and techniques in the basics of qualitative research. The focus of their book was to guide researchers step by step in conducting grounded theory studies. Grounded theory methodology is then evolved by different stances. Charmaz (2006) was the first to apply the evolving grounded theory based on a constructivist philosophical stance and then used a constructivist grounded theory. This model is the one most often followed by other researchers. Grounded theory is applied either as a methodology or a method (Birks & Mills, 2015).

This study employed a set of principles of grounded theory from both a constructivism lens (Charmaz, 2006, 2014) and a symbolic interactionism lens (Blumer, 1969; Charon, 2007; Corbin & Strauss, 2008). Constructivism is a social belief acknowledging subjectivity and the view that realities are co-constructed by people and the researchers who are involved in the construction and interpretation of data (Charmaz, 2014). "[The] Constructivist approach assumes that grounded theory is constructed through the researcher's views, research experiences, interactions with other people, including their involvement in the world [they] study, the data [they] collect and the analysis [they] produce" (Charmaz, 2014, p. 17). Meanwhile, symbolic interactionism is an approach that views that people create their meaning through their interactions in life (Blumer, 1969). In addition, through a symbolic interactionism lens, the candidate will understand why people have interactions with each other in the phenomena being studied.

The decision to adopt these lenses was based on their alignment with the candidate's views on reality, relationships with participants and how knowledge is gained. The candidate sees that reality is co-constructed by the candidate and the participants through the participants' meanings and views, hence the need for the constructivism lens. Moreover, the candidate is not separated from the participants during data collection and therefore the candidate needs to establish the relationship of trust and reciprocity with participants by entering the research field herself. The candidate then sees that human beings act based on the meaning of a symbol and the meanings are co-created through social interactions.

The Study Setting

This three-phase study involved twenty-six Indonesian people that included people living with diabetes, healthcare professionals, other healthcare providers and families. The first two phases were undertaken in Indonesia specifically in the province of West Kalimantan. In the last phase, the PhD candidate interviewed the participants in Indonesian through phone calls from Australia. The primary data collection method was individual interviews conducted either face-to-face or via telephone.

Indonesia is an archipelago country, located in Southeast Asia or the Western Pacific region. Having more than 17,500 islands, the size of Indonesia's land mass is 1,890,754 km2. Indonesia has a total population of 252.20 million with the Human Development Index of 0.6955 (Central Bureau of Statistics Indonesia, 2015). Being led by a president, the Republic of Indonesia has 34 provinces, each of which are governed by their own governor. Indonesian people mainly work in agricultural areas followed by trade and service. A map of Indonesia is presented in figure 1.1.

Figure 1.1. Map of Indonesia (Central Intelligence Agency, n.d.).

West Kalimantan is one of the Indonesian provinces located in Kalimantan Island, globally known as Borneo Island, and has a border with a country of east Malaysia. According to the Central Bureau of Statistics Indonesia (2015), the size of West Kalimantan is 7.76% of the total Indonesian land mass. West Kalimantan is 146.807 km2 wide and is inhabited by 4,395,983 people, with 33.1% of those people living in urban areas. There has been no recent data published, but it is predicted that in 2020, the West Kalimantan population will be 5,134.80 million people. Pontianak is the capital city of West Kalimantan.

West Kalimantan province has 16 districts, two of them being municipalities. Even though three main ethnicities in this province are Malay, Dayak and Tiong Hoa, other ethnicities such as Javanese, Bugis, and Maduranese also integrate and live peacefully together in this province. The Indonesian language is an official or national language to be spoken by Indonesian people for both formal communication at work, during business hours and informal, everyday communication. However, people sometimes speak the language of their own ethnicity. The adult literacy rate of Indonesian people at the age of 15 and over is considerably high at 95.44% (UNESCO Institute for Statistics, 2016).

The healthcare system in Indonesia

Indonesia has a healthcare system called the National Healthcare System, which is regulated through Presidential Regulation No. 72 signed by President Susilo Bambang Yudhoyono in 2012 (Republic of Indonesia President, 2012). The regulation legalises how Indonesia as a country manages health for all Indonesian people for the purpose of integratively and supportively achieving high levels of public health. The regulation covers administration of the healthcare system, including human and material resources, funding, health informatics, health science research, legal aspects, public health targets, and community engagement. The regulation also covers all geographical parts of Indonesia including urban and rural areas.

Health indicators.

According to the Presidential Regulation No. 72 in 2012 about the National Health System (Republic of Indonesia President, 2012), Indonesia has attempted to measure the impact of health initiatives through several indicators such as household access to healthcare facilities, the number of public health centres (PHCs), water accessibility, assistance with child birth, sanitation and communicable disease rates. National research and development is undertaken by the national research board to study various health topics. Moreover, these research findings need to be accessed by communities and healthcare related industries, such as the pharmaceutical industry.

Health funding.

Since 2014, Indonesia has introduced a new health cover scheme, called the JKN (*Jaminan Kesehatan National* or national health insurance). According to Presidential Act No. 24 signed by President Susilo Bambang Yudhoyono in 2011 (Republic of Indonesia President, 2011), the JKN is managed by the BPJS (*Badan Penyelenggara Jaminan Sosial* or social security organising board) and it provides health coverage to its members. Presidential Regulation No. 82 signed by President Joko Widodo in 2018 (Republic of Indonesia President, 2018) stated that a member is everyone in Indonesia who has paid the insurance fee or whose insurance fee has been paid by the government (those that cannot afford to pay the insurance fee themselves) or their employer.

Human health resources.

Human health resources in Indonesia consist of healthcare professionals and supportive health personnel according to Act No. 36 signed by President Susilo Bambang Yudhoyono in 2014 regarding Health Workforce (Republic of Indonesia President, 2014). According to this Act, health workers in Indonesia consist of medical doctors including dentists, nurses, midwives, dieticians, pharmacists and other healthcare providers. The Ministry of Health Republic of Indonesia (2015) report that the total number of human health resources are 876 984 with 73.8% of them being HCPs or health workers. There are 101 615 medical doctors in Indonesia, while nurses are the largest number of health worker in Indonesia at 223 910 people. There are 30 329-pharmacy health workers and 15 221-nutrition health workers. One indicator for achieving a ‘Healthy Indonesia’ is the ratio of health workers (like medical doctors and nurses) per 100 000 population. In Indonesia, the ratio of general practitioners per 100 000 is 37.2 nationally while in West Kalimantan it is only 16.6. This ratio is still below the targeted ratio which is 40 per 100 000 people. The ratio of nurses to 100 000 people is 119.2 while the ratio in West Kalimantan is 210, making this ratio above the national ratio target of 117.5, to achieve a ‘Healthy Indonesia’.

Healthcare facilities.

The main healthcare facilities in Indonesia include medical clinics, dental clinics, primary clinics, PHCs, which are well known by their abbreviation as *Puskesmas (Pusat Kesehatan Masyarakat)*, and hospitals (Ministry of Health Regulation No. 28 signed by Minister Nasfiah Mboi in 2014) (Republic of Indonesia Minister of Health, 2014b).

Meanwhile, the two most frequently used healthcare facilities are *Puskesmas* and hospitals. In Indonesia, the total number of *puskesmas* and hospitals are 9754 and 2488, respectively. The *puskesmas* can provide both inpatient and outpatient care (n=3396) or may provide only outpatient care (n=6358). Whereas, based on the hospital management, hospitals are divided into public hospitals (n=1593) and private hospitals (n=895). Hospitals in Indonesia are also divided based on the provision of health services; general hospital and specialty hospital, for example child and maternal hospital, eye hospital, mental health hospital, leprosy hospital and tuberculosis hospital (Republic of Indonesia Minister of Health, 2014a). In West Kalimantan province, the number of *puskesmas* is 244, including 113 inpatient/outpatient *puskesmas* and 131 outpatient only *puskesmas*. Moreover, there are 46 (public and private) hospitals in this province (Dinas Kesehatan Provinsi Kalimantan Barat, 2017).

The burden of diabetes in Indonesia

Indonesia is considered to have a double burden, tackling both communicable and non-communicable diseases, such as diabetes (Ministry of Health Republic of Indonesia, 2015). As a national major health problem, diabetes needs to be managed comprehensively, not only involving multidisciplinary professionals but also non-professionals in healthcare such as government, community and of course people with diabetes themselves. Diabetes is a chronic disease manifested by an increase of blood glucose in the blood. People with classic symptoms of diabetes can present feeling thirsty or hungry, and have frequent urination.

Diabetes Mellitus (DM), is an incurable but controllable chronic disease, it is commonly classified into three types: DM Type 1, DM Type 2 and gestational diabetes mellitus (GDM). These types differ based on the insulin production in the body and on duration, for example, during pregnancy. Insulin is needed by the body to transform blood glucose into energy. In a person with DM Type 1, their pancreas does not produce insulin. Conversely, in people with DM Type 2, insulin is still produced however, the production is not adequate, so the energy transformation from the blood glucose is inhibited, and blood glucose levels are abnormally high. Another case can occur when there is insulin resistance in the body, meaning it requires more than the normal amount of insulin for cells to uptake glucose. The third type of diabetes, which is GDM, occurs during pregnancy. Insulin is less effective during pregnancy, so it will not work well to transform glucose into energy. It will then lead to the increase of blood sugar levels in the body. However, this process may revert when the mother births her baby, or it may persist, meaning that she continues to have diabetes, either DM Type 1 or DM Type 2. However, if the mother increases her physical activity during pregnancy, the risk of GDM progressing to DM Type 2 decreases (Bao, Tobias, Bowers, Chavarro, Vaag et al., 2014).

Several underlying causes contribute to the growing prevalence rate of diabetes in Indonesia. These are: age; family history; central obesity; high triglycerides; smoking; hypertension; gender; socioeconomic condition; physical activity; and food consumption (Mihardja et al., 2009; Pramono, Setiati, Soewondo, Subekti, Adisasmita et al., 2010; Soegondo, Widyahening, Istantho, & Yunir, 2011; Soewondo & Pramono, 2011; Waspadji et al., 1983). Women have a higher diabetes prevalence rate compared to men (Mihardja et al., 2009; Mihardja, Soetrisno, & Soegondo, 2014). The rate for those having diabetes and pre-diabetes is higher in high socioeconomic groups (Mihardja et al., 2014; Soewondo & Pramono, 2011; Waspadji et al., 1983). However, this finding seems to contradict the latest Indonesian Basic Health Research (*Riset Kesehatan Dasar*) to report that the prevalence of diabetes in rural areas is higher than in urban areas (National Institute for Health Research and Development, 2013) which are commonly inhabited by people in lower socioeconomic groups.

The pathogenesis of diabetes can be initiated and/or accelerated by a sedentary lifestyle, because physical inactivity can lead to the progression from normal to high glucose metabolism, which in turn leads to diabetes morbidity and mortality (LaMonte, Blair, & Church, 2005). Physical activity can have many advantages but not many people engage in physical activity (Hayes & Kriska, 2008). As lack of physical activity contributes to diabetes risk, exercise and increased physical activity play important roles for preventing and managing diabetes, either Type 1 or Type 2 DM. Therefore, guidelines and resources about exercise are expected to be informed as recommendations on safe and appropriate exercises (Hayes & Kriska, 2008). Insulin sensitivity may be improved and elevated blood glucose level will be lessened when people with diabetes are physically active (American Diabetes Association, 2004). As the benefits of exercise include reducing insulin resistance, increasing insulin sensitivity and enhancing glucose tolerance, performing 30 minutes of moderate exercise daily may decrease the incidence of developing DM type 2 (Bassuk & Manson, 2005).

Physical activity has become an important health indicator for the evaluation of health programs and further health planning in Indonesia at a national level (National Institute for

Health Research and Development, 2013). According to World Health Organization and UN partners (2012), people lacking physical activity are those who do not do either “active” physical activity or “moderate” physical activity. According to the latest report, 26.1% of Indonesian people meet the criteria for a lack of physical activity (National Institute for Health Research and Development, 2013). Meanwhile, World Health Organization and UN partners (2012) categorise people as having a sedentary lifestyle if they are sitting or lying down on a daily basis at work, at home or during travelling within certain amounts of time: less than 3 hours; within 3 to 5.9 hours; and 6 hours and more; sleep time is not counted. The National Institute for Health Research and Development (2013) reported that 24.1% Indonesian people were in the category of being sedentary for 6 hours or more each day. This contributing factor of a lack in physical activities needs to be avoided to minimise the risk in developing DM Type 2. Therefore, attention must be paid to increase people’s awareness of the risk.

People with unhealthy eating habits also have a high risk of developing diabetes. Nowadays, even Indonesian young people are at risk of developing diabetes as a result of their poor diet (Antara, 2016). A study involving Indonesian communities with diabetes found that psychological stress contributes to unhealthy eating habits while family support and self-efficacy improves healthy eating habits (Putra, Toonsiri, & Junprasert, 2016). Moreover, people do not balance the proportion between carbohydrate and other nutritious food such as vegetables (Yamin, 2016). Sun, Spiegelman, van Dam, Holmes, Malik et al. (2010) found that a high intake of white rice was associated with a higher risk of developing DM Type 2, thus substituting white rice with whole grains can lower this risk. Rice is a traditional staple food and the primary dietary source of carbohydrates for most Asian countries (Fitzgerald, Rahman, Resurreccion, Concepcion, Daygon et al., 2011). Indonesian people used to have a saying: “If we have not eaten rice in a day, we still feel hungry” (Noviyanti, 2017). One day, a person may consume a big meal of burger or noodles and potatoes but this person has not had (white) rice on her/his plate. This person may still feel hungry and thinks that she/he has not had a meal yet because a meal needs to consist of rice. Therefore, this person will then eat another meal that has rice on her/his plate. Hu, Pan, Malik, and Sun (2012) in their review also identified that white rice consumption is associated with DM Type 2 development in both Asian and Western countries and the risk is increased by 10%. Like any Asian people, white rice has become a main food served at all meals, breakfast, lunch or dinner.

Factors contributing to the risk of diabetes in Indonesia need to be lessened by involving comprehensive approaches to manage people with diabetes and to prevent further complications secondary from diabetes. Research into DM risk factors has increased, together with studies to examine the best evidence for managing DM both internationally and nationally. Since diabetes is considered a national problem in Indonesia, wide-ranging approaches are required for screening, prevention and management of this chronic condition (Mihardja et al., 2009; Mihardja et al., 2014). Indonesia has evidence-based guidelines for diabetes management, but these guidelines are only partially implemented across the country (World Health Organization, 2018). Despite the majority of healthcare professionals having a high awareness of the guidelines, very few healthcare professionals in Indonesia use the guidelines when treating people with diabetes (Widyahening, van der Graaf, Soewondo, Glasziou, & van der Heijden, 2014). Compounding this local problem is the knowledge that only half of the people diagnosed with diabetic conditions in Indonesia are regularly treated by a healthcare professional (Waspadji et al., 1983).

Diabetes mellitus is usually reported as diagnosed diabetes, undiagnosed diabetes or pre-diabetes. People with undiagnosed diabetes are not aware of suffering diabetes mellitus until they are screened, at which time their blood glucose levels are high enough to meet the diagnostic criteria for diabetes. These people previously do not either report any clinical symptoms or take any diabetic prescriptions (Pramono et al., 2010). Pre-diabetes is defined as people who have slightly elevated blood glucose levels, but they do not yet reach the threshold to be diagnosed as having diabetes (Berlitz, Hermes, Failace, & Schenkel, 2006). People with either undiagnosed diabetes or pre-diabetes are usually asymptomatic, and it is only by screening blood glucose levels that they are then finally identified as either diabetic, or pre-diabetic. Pre-diabetes can develop into diabetes if people at this stage are not properly treated (Soewondo & Pramono, 2011). In Indonesia, two basic health surveys in 2007 and in 2013 demonstrated escalating numbers of people with either a pre-diabetic condition or diabetes (National Institute for Health Research and Development, 2008; 2013). Moreover, these studies report that the rate of people having pre-diabetes was always higher than those diagnosed with DM. Likewise, there were considerably more people with undiagnosed diabetes compared to those with diagnosed diabetes (National Institute for Health Research and Development, 2008; 2013). Consistent with these survey results, a study by Mihardja et al. (2014) identified that the rate of people with undiagnosed diabetes was far higher than those diagnosed with diabetes. This trend indicates that many people in Indonesia do not realise that they have diabetes until they are screened. People that are unaware of their condition are at a higher risk for severe complications (Pramono et al., 2010). As reported by Soewondo et al. (2010) and Waspadji et al. (2013) poor glycaemic control in diabetes is a notable reason for the growth of this non-communicable disease. During surveys of diabetes centres across Asia, including Indonesia, investigating the effectiveness of insulin, the study baseline demonstrated high blood glucose levels indicating a lack of diabetic control in the diagnosed population (Soewondo et al., 2013b).

Controlling DM is important to avoid those living with the disease developing unexpected complications, either acute or chronic. Over a three-year period, diabetes was considered the third leading cause of death nationally, with 100,400 Indonesians having died from this disease (World Health Organization & UN partners, 2012). A survey of 770 Indonesian people living with diabetes found that the majority had renal dysfunction such as macroalbuminuria (or microalbuminuria), retinopathy and diabetic foot ulcers (Soegondo, Prodjosudjadi, & Setiawati, 2009). A larger scale study in Indonesia also has found that neuropathy, nephropathy, retinopathy and micro-vascular disease are common complications of uncontrolled diabetes (Soewondo et al., 2010). Cardiovascular and renal complications were also identified as complications in most Indonesian studies (Sja'bani, Asdie, Widayati, Subroto, Kariadi et al., 2005; Soebardi, Purnamasari, Oemardi, Soewondo, Waspadji et al., 2009; Soegondo et al., 2009; Soewondo et al., 2010). Todorova, Hnoosh, Bloomfield, and Shiu (2012) note that these two major complications result in the most economic burden for people with diabetes in Indonesia. Consequently, diabetes is predicted to be the fourth highest cause of economic burden for Indonesians by 2020 if this non-communicable disease is not properly managed (Finkelstein, Chay, & Bajpai, 2014).

There are five basic principles that need to be applied when providing diabetes management. These basic principles include interventions to promote and support a healthy lifestyle, medication to control blood glucose level, routine examinations for detection of complications and referral to a higher level of care. As people with diabetes need to understand these diabetes management principles, diabetes education for these people is an important part of the management (World Health Organization, 2016).

The provision of structured health education for people with diabetes considers several important aspects such as the mode of delivery, content and approach, whether or not it is interactive (Malini, Copnell, & Moss, 2017). Thus people with diabetes may have that structured diabetes education from a healthcare professional through counselling or a formal session. However, despite the provision of structured health education, the process of how they learn about their disease, either through passively obtaining information related to diabetes through structured education, or actively seeking to become informed about their diabetes, is unknown. Thus, understanding the process of learning will be an important aspect in the provision of health education. Moreover, no study has been undertaken about health education for people with diabetes that includes all people involved such as HCPs and non-HCPs, people with diabetes, their family members, and other healthcare providers such as health promotion officers and exercise instructors. There has also been no study conducted in more than one city. This study aimed to fill those gaps. The aim of this study was to explain the process and build a theory about how Indonesian people with DM learn about their disease. The overall research question was 'How do people living with diabetes mellitus in Indonesia learn about their disease?'

Thesis outline

This thesis consists of eight chapters. *Chapter One* introduces the thesis by explaining the study's overview, aim, research question and the methodology selection of grounded theory study design. It also presents a brief explanation of the study, followed by an overview of the study setting. The candidate addresses how the healthcare system in Indonesia is arranged. The prevalence, causes, aetiology and impacts of diabetes are described. In the last section of this chapter, the candidate briefly explains how this study contributes to new knowledge, practice and policy.

Chapter Two provides a background to the study. This chapter discusses healthcare provision in Indonesia and specifically diabetes care. Further, this chapter includes a published manuscript entitled: *The profile of diabetes healthcare professionals in Indonesia: a scoping review* that was published in the International Nursing Review journal in 2018. This review addresses the wide range of professionals from multi-disciplinary healthcare in Indonesia who provide diabetes care and how these professional people meet facilitating factors and challenges during the provision of diabetes care.

In *Chapter Three* methodology is discussed. This chapter provides an explanation of the candidate's ontology, epistemology, and methodology. The candidate also explains how her philosophical position influenced her selection of study methodology. Further, two main philosophical stances the candidate used (symbolic interactionism and constructivism) that influenced her implementation of the methods when using grounded theory are also explicated.

Chapter Four addresses the methods of conducting this research study using grounded theory principles. The application of essential methods of grounded theory is also addressed. Moreover, the process prior to data collection, during data collection/generation and data analysis is discussed in detail. In this chapter, the candidate also presents three manuscripts and provides detail of each paper related to the implementation of grounded theory methods. These papers cover theoretical sampling, concept mapping, and storyline.

The findings of the study are presented in *Chapter Five*. This chapter initially introduces the storyline as an explanation of the theory: *Learning, choosing, and acting: Self-management of diabetes in Indonesia*, which is grounded from the data. This chapter includes two manuscripts that report the study findings. One of the manuscripts is written in the Indonesian language that shares the storyline of this study. This manuscript is under review by an Indonesian journal. Another manuscript entitled: *How people living with diabetes in Indonesia learn about their disease: A grounded theory study* has been accepted by the PLoS One journal.

Chapter Six provides an explanation of five main categories that support the theory. The chapter presents the five main categories with supporting evidence from the participants' voices. The categories include 'seeking and receiving diabetes-related information', 'processing received information', 'responding to recommendations', appraising the results' and 'sharing with others'.

Chapter Seven introduces theoretical coding that was utilised in this grounded theory study and related concepts developed from this process. Next, the grounded theory is presented delineating the overarching theoretical code and the categories that are discussed in relationship to the existing literature. The six key findings include:

1. People with diabetes both actively sought and passively received diabetes-related information.
2. Diabetes-related information was accessed from a variety of sources and places.
3. Before making a decision about using received information, people with diabetes often sifted the information based on their prior knowledge, experiences and personal judgement.

4. Physical, psychological and resource factors highly influenced people's decisions to apply recommendations for managing their diabetes.
5. By appraising the results of their management choices, people with diabetes developed experiential insight, which they often shared with others and which influenced their future management decisions.
6. Families of people with diabetes engaged in all five categories of the process entitled: '*Learning, choosing, and acting: Self-management of diabetes in Indonesia'*.

Throughout this chapter, the key findings are highlighted in the context of international and current literature related to people with diabetes learning about their disease. The chapter also includes a manuscript that outlines a key finding, the role of family during the process of *Learning, choosing, and acting: Self-management of diabetes in Indonesia*.

In the final chapter, *Chapter Eight,* the conclusion is presented. This final chapter reflects on the fundamentals of this study by firstly identifying the candidate's reflection during the study process. An evaluation of the study is addressed based on the measures of credibility, originality, resonance and usefulness. Several strengths and limitations of this study are also discussed. Finally, this chapter presents recommendations for policy, education, research and practice at local, national and international levels.

Chapter Summary

This chapter provided an introduction to the study by highlighting the global impact and associated health burden of diabetes. The aim of the study, research questions and methodology selection in this study were also addressed. The chapter described Indonesia as the study setting, based on its situation and health system. Background of the study related to the prevalence of diabetes in Indonesia and the study's significance were also discussed in the final section of this chapter. The following chapter will explain the study background in more detail by looking at the provision of diabetes care in the Indonesian context and the HCPs responsible for this care.

Chapter Two: Background to the Study

There has been extensive debate about undertaking a literature review in the early stage of a grounded theory study, because it is said to compromise theory generation later in the study. This chapter begins with a discussion about the literature review position in a grounded theory study. The literature review was conducted early in this study to develop theoretical sensitivity and because the candidate wanted to ensure her knowledge about diabetes care providers in Indonesia was adequate, before beginning fieldwork. The information about who is involved in diabetes management provision can also be a source for the candidate in pursuing her purposive sampling in the study. The chapter then provides an overview of the model of health service delivery for people with diabetes in Indonesia.

Literature Review in a Grounded Theory Study

Writing a literature review in a grounded theory study is still debatable in terms of when it should be undertaken. This debate can be confusing for a researcher new to this type of research methodology (McGhee, Marland, & Atkinson, 2007). Researchers commonly write a literature review during the early stage of the research process. In a grounded theory study, literature reviews can be undertaken at different times for diverse purposes including providing context for the study and functioning as a method to raise the researchers' sensitivity to the data (theoretical sensitivity), to compare data, to stimulate analytic questions, to supply questions and to confirm findings (Birks & Mills, 2015; Corbin & Strauss, 2015). Literature as a study background for a researcher can function to lay a foundation for knowledge of the area being studied (Strauss & Corbin, 1998). Later, Corbin and Strauss (2015) further suggest that conducting a literature review is required by researchers to familiarise themselves with the professional and disciplinary background of the research question. Therefore, the candidate in this present study conducted an early literature review for the purpose of increasing her theoretical sensitivity (Corbin & Strauss, 2008). She used a scoping framework study to learn about the profile of HCPs. By conducting this review, her theoretical sensitivity about who, what, where and how diabetes management was provided became a valuable source of information when it came to selecting the initial participants, through a purposive sampling method.

Conducting a literature review has been problematic since the debate began on how and when one should be undertaken when conducting a grounded theory study (Dunne, 2011). There are two options recommended for when to conduct a preliminary literature review: after the collection and analysis of data or prior to data collection. These two options will be further explained shortly. The role of the literature review depends on the philosophical position the researchers have (Giles, King, & de Lacey, 2013). Philosophical positions then influence which style(s) of grounded theory the researchers will use. For example, two grounded theory founders (Glaser and Strauss), who have different philosophical stances, have opposing arguments regarding the conduct of grounded theory, including the decision about when to undertake a preliminary literature review.

As highlighted previously there are two recommended points in time for undertaking a literature review. The first recommendation (Glaser & Strauss, 1967) is based on the earliest version of grounded theory, and proposes that a preliminary literature review is conducted once the collection and analysis of data have occurred. Glaser (1978) persists in arguing that researchers need to avoid pre-conceived ideas that may influence their analysis and development of theoretical integration. Therefore, by not conducting a literature review, researchers enter the research field and collect data without having prior knowledge of the field of study. Such knowledge is regarded to contaminate theory generation. Dunne (2011) explains that conducting a review in a related field of research in the early phase of the grounded theory study can impede grounded theory development and thus the originality and the quality of the study can be disputed.

On the other hand, a preliminary literature review is recommended to be conducted prior to data collection to increase the researchers' theoretical sensitivity as the researchers are then up-to-date with the current knowledge around the topic being studied (Strauss & Corbin, 1998). However, Corbin and Strauss (2008, p. 36) warn that a literature review can also obstruct the researchers' creativity as it can make them become "literally paralyzed". Not all, but some concepts may show up frequently and they are important and thus researchers are advised to pay close attention by asking whether the concept they have used does truly come from the data or has resulted from the researchers forcing the concept they were already familiar with onto their new data (Corbin & Strauss, 2008, 2015). Furthermore, Charmaz (2014) adds to the debate by recommending that doing an early literature review is necessary for the researchers to have a better understanding of topics around the substantive area of inquiry. She suggests a secondary review should follow an early literature review, whose topics are more related to the data that was generated during data collection and analysis. This following action is not only to evaluate previous relevant studies, but also to show readers how the grounded theory findings have filled in the existing gaps that were identified from the early review of the literature. The rationale for choosing this option was the need to have some background to inform the conceptualisation and conduct of the study.

McCallin (2003) suggests conducting a literature review should be completed as new knowledge may be identified that will inform the current study. However, the extent of the topic to review needs to be considered. McCallin (2003) did not conduct an extensive literature review about the specific area of inquiry, but rather looked at a more generic topic around the substantive area of research. This approach therefore avoided reviewing literature that was specifically centred on the substantive area of inquiry, which might have unduly biased the researcher. This process was the same approach taken in this present study. The candidate undertook a literature review about the profiles of diabetes HCPs rather than a review of diabetes education in Indonesia, to avoid the risk of potentially developing premature concepts about health education for people with diabetes.

Reflexivity (Bryant & Charmaz, 2007) is when the researchers make transparent their experiences and interpretations conveyed in the study process, so that their influence on the research can be assessed. To prevent prior knowledge altering the researchers' data interpretation, reflexivity is required (McGhee et al., 2007). By reflexively conducting a literature review, the researchers mindfully prevent themselves from developing preconceived ideas and thus will perform this essential grounded theory method in an appropriate manner, letting the theory emerge from the data (Giles et al., 2013).

The Profile of Healthcare Professionals in Diabetes Care in Indonesia

Indonesia has a wide range of HCPs involved in the provision of chronic disease care. In this study, the candidate wrote a scoping review about HCPs in Indonesia that provide diabetes care. The aims of the review were to explore and synthesise evidence about HCPs involved in diabetes management within the Indonesian context. The review also informed the candidate which HCPs should be involved in purposive sampling in the initial data collection. Reading the literature can provide insights where the candidate might go for further investigation (Corbin & Strauss, 2008). The *International Nursing Review* (Ligita, Wicking, Harvey, & Mills, 2018) published this paper (Permission information is in Appendix A). The authors' accountabilities for the aspects of the paper are displayed in Table 2.1.

Chapter Two: Background to the Study

Table 2.1: *Declaration of Authorship*

Chapter Number	**Publication**	**Nature and extent of the intellectual input of each author including the candidate**	**Signature**
2	Ligita, T., Wicking, K., Harvey, N., & Mills, J. (2018). The profile of diabetes healthcare professionals in Indonesia: a scoping review. *International Nursing Review, 65*(3), 349-360. doi: 10.1111/inr.12418	Literature review design and data collection, Literature review analysis and interpretation, Manuscript writing (90%), Critical revisions for important intellectual content	Ligita, Titan Content has been removed for privacy reasons
		Literature review design and data collection, Manuscript writing (4%), Study supervision, Critical revisions for important intellectual content	Wicking, Kristin Content has been removed for privacy reasons
		Literature review design and data collection, Manuscript writing (3%), Study supervision, Critical revisions for important intellectual content	Harvey, Nichole Content has been removed for privacy reasons
		Literature review design and data collection, Manuscript writing (3%), Study supervision, Critical revisions for important intellectual content	Mills, Jane Content has been removed for privacy reasons

The scoping review paper offers information about a wide range of HCPs who provide diabetes care for people living with diabetes in Indonesia. Their roles are described in the paper. Facilitating factors and barriers in the provision of diabetes care are also explicated. From this scoping review, the candidate obtained insight about potential participants (HCPs) to be included in the initial data collection.

Literature Review

International Nursing Review

The profile of diabetes healthcare professionals in Indonesia: a scoping review

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N. Harvey[3] RN, RM, CritCareCert, BN, MNSt, GradCertEd, PhD &
J. Mills[4,5] RN, BN, MN, MEd, GradCertEd, FACN, PhD

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LIGITA T., WICKING K., HARVEY N. & MILLS J. (2018) The profile of diabetes healthcare professionals in Indonesia: a scoping review. *International Nursing Review* **65**, 349–360

Aim: To explore and synthesize evidence of the literature about healthcare professionals involved in the provision of diabetes management within an Indonesian context.
Background: Indonesia is challenged to control the major burden of diabetes prevalence rate that requires a multidimensional approach with the aim to optimize existing health services by involving healthcare professionals who can promote access and provide diabetes management.
Methods: This literature review, which is integrated with a scoping study framework, used the electronic databases including CINAHL, PubMed, Scopus and Web of Science to locate papers particular to the Indonesian context. From the total of 568 papers found, 20 papers were selected.
Results: The literature review identified physicians, nurses, pharmacists, dieticians and diabetes educators as the providers of diabetes care and management in Indonesia. Collaborative management involving either interdisciplinary or intradisciplinary teams was mentioned in several papers. Internal challenges included limited skills and knowledge. External challenges included high patient volumes; a shortage of healthcare professionals and reduced funding.
Conclusions: Overcoming the challenges cannot be undertaken with a workforce dominated by any one single healthcare professional. Coordinating with the government to improve the implementation of different roles in diabetes management will improve patient outcomes and thus reduce the burden of diabetes.
Implication for nursing and health policy: Health policy reform should support nurses and other healthcare professionals in their professional development at all levels of health care. Policy makers can use the review findings to modify the current healthcare system to address key issues in workforce development; funding for services and medications; and fostering multidisciplinary care for diabetes management.

Keywords: Chronic Disease Care, Developing Countries, Diabetes, Health Service Management, Indonesia, Literature Review, Nursing, Nursing Roles, Scoping Review

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Conflict of interest
The authors declare no conflicts of interest.

Introduction

The International Diabetes Federation (IDF) reports that diabetes presents an enormous global burden, with a global prevalence rate of 8.3% and 387 million people living with this disease (IDF 2013, 2014). While developed countries have only a 20% increase in diabetes cases, it is predicted that Indonesia and other developing countries will have a 69% increase within three decades (Shaw et al. 2010).

In Indonesia, diabetes is widely acknowledged as a population health problem. The World Health Organization (WHO) reports that since 2012, diabetes has been a major cause of death in Indonesia (WHO 2014). Indonesia was ranked ninth in the world in terms of having people living with type 1 and type 2 diabetes mellitus in 2010. The same report indicates that by 2030 this ranking will increase to sixth position, with a projected 12 million affected adults (Shaw et al. 2010). However, research results on diabetes prevalence rates usually do not distinguish between diabetes type 1 and 2 (Mihardja et al. 2014; National Institute for Health Research and Development 2013; Soegondo et al. 2011).

Age, family history, obesity, smoking, hypertension, gender and physical activity are identified as diabetic risk factors for the Indonesian population (Mihardja et al. 2009; Soegondo et al. 2011). With a relatively low health expenditure on managing diabetes, adequate resources (Zhang et al. 2012) and wide-ranging approaches are required for screening, preventing and managing diabetes and the complications (Mihardja et al. 2014). These management approaches need to involve healthcare professionals (HCPs) from various health disciplines (Soewondo et al. 2010), as recommended by the WHO (2016) and the IDF (2012).

Diabetes management, which focuses on glycaemic control through lifestyle modification and medication, requires a person-centred approach that involves multidisciplinary HCPs (Chatterjee & Davies 2015). The benefits of multidisciplinary teams include complementary skills; better developed relationships between HCPs; and most importantly, the person with diabetes having improved access to assessment and treatment via additional contacts; all of which results in the person being more supported in their self-management (Ritholz et al. 2011). While Ritholz et al.'s (2011) study provides a solid case for multidisciplinary teams, Shortus et al. (2007) found that a lack of collaboration between HCPs providing care to people with diabetes was a problem with some team members unconvinced that collaboration would improve healthcare delivery in fulfilling individuals' complex care requirements, instead suggesting that working together in this way may decrease the potential for holistic care. The contradiction in the evidence base concerning the provision of care to Indonesian people living with diabetes indicates a gap in understanding about each HCP's role. Identifying the role that each can play in this complex space will provide clarity, avoid role overlap and reduce the likelihood of any one HCP's role becoming dominant. With the global shortage of HCPs able to provide care for those living with diabetes (IDF 2013), a shortage that includes Indonesia (Soewondo et al. 2013), it is important to profile HCPs with expertise in diabetes care as described in the Indonesian literature.

Background

As a low- to middle-income developing nation, Indonesia is challenged to control immense burdens of both communicable diseases and chronic diseases (Ministry of Health Republic of Indonesia 2015). These double burdens require a multidimensional approach (Bygbjerg 2012) with the aim to optimize existing health services. Thus, HCPs can promote access and provide diabetes management for all Indonesians living with diabetes.

In Indonesia, diabetes services are managed at various levels of the healthcare system. People with diabetes usually go to *Puskesmas* (Public/Community Health Centres) to have their diabetes treated (Widyahening et al. 2014). Once provided with a referral, people can choose to either go to a secondary or tertiary healthcare setting to access outpatient and inpatient services, from either a public or private hospital (Hartayu et al. 2012; Soewondo 2011). Healthcare service accessibility is a concern for everyone, not just those with diabetes. Indonesia still struggles with health coverage as not all Indonesians are covered by insurance, especially in remote areas (Kanbara et al. 2008) and only 63% of Indonesians are covered by particular forms of health insurance that pay for chronic care (Simmonds & Hort 2013).

A comprehensive national strategy for diabetes management is required for diabetes prevention and its treatment (Mihardja et al. 2014). The WHO also emphasizes that skilful HCPs should provide accessible diabetes care both systematically and continuously (WHO 2016), ideally within a multidisciplinary team (IDF 2012). There is, however, limited information about which HCPs are providing diabetes care in Indonesia. A previous literature review on diabetes management in Indonesia (Soewondo et al. 2013) mentioned only a few healthcare disciplines and did not provide any specific job descriptions for these roles, giving rise to the concern that there may well be other HCPs involved in diabetes care in Indonesia whose role has not yet been identified, let alone described (Soewondo et al. 2013). There is also little evidence of models of multidisciplinary diabetes care provision, with the national diabetes clinical practice guideline only focusing on a single health discipline; medicine (Indonesian Diabetes Association 2014; Rudijanto et al. 2011). It is vital therefore to explore which HCPs are involved in providing diabetes management and provide a clear description of their roles and the challenges they encounter in deploying their expertise. This work would provide a strong foundation for making recommendations about the role each HCP should perform to support an ideal diabetes care model of service, in the Indonesian context.

Study aim

This review aims to explore and synthesize scholarly literature about HCPs involved in the management of diabetes within an Indonesian context.

Methods

This scoping review paper provides a summary, explanation and interpretation of the breadth of the currently available qualitative and quantitative evidence that addressed the review questions. A scoping study framework uses a systematic approach with five distinct steps as detailed below and does not limit the review to only primary research papers, but allows relevant, high-quality grey literature to also be considered (Arksey & O'Malley 2005; Mays et al. 2005). This method enables the review to extract divergent data and develop it in a meaningful, transparent and systematic way (Grant & Booth 2009). The five essential steps are as follows:

1 Identifying the research question(s)
2 Identifying relevant studies
3 Selecting the studies
4 Making a data chart
5 Collating, summarizing and reporting the results

The following inclusion criteria were used: peer-reviewed research and non-research papers including grey papers (such as government or organizational reports) providing information about HCPs caring for adults with diabetes type 1 and type 2; the role that HCPs perform when caring for adults with diabetes type 1 and type 2; be situated in the Indonesian context; and be written in both English and Indonesian languages. Conversely, exclusion criteria were papers reporting: laboratory-based research about diabetes; children with diabetes; studies involving animal testing and diabetes; and papers discussing diabetes in conjunction with other chronic diseases.

Step 1: identifying the research questions

By having well-defined research questions, the scope of the studies included will be both practical and effective (Levac et al. 2010). For this review, three research questions were addressed:

1 Who are the HCPs that provide care for people living with diabetes mellitus in Indonesia?
2 What roles do different HCPs undertake when providing diabetes management?
3 What challenges do HCPs encounter during the provision of diabetes management?

Step 2: identifying relevant published papers

Before identifying relevant papers, the authors determined keywords based on the research questions. The keyword 'diabet*', from MeSH was used together with the following keywords: 'healthcare professional*', 'healthcare personnel*', 'management', 'service*', 'care' and 'Indonesia*'. Electronic databases including CINAHL, PubMed, Scopus and Web of Science and other sources such as Google Scholar and Research Gate were searched using these terms to locate papers particular to the context of Indonesia that met the inclusion criteria. A hand search was also performed to locate papers ancestrally by searching specific journals and identified papers or reviews. Publication dates were limited to 1970–2016 because a diabetes association was formed in Indonesia in the early 1970s, increasing knowledge and awareness of the condition and marking a new phase in the provision of healthcare services and treatments.

Step 3: selecting relevant papers

From the search, 567 papers were found (430 in English and 137 in Indonesian languages). Among this number, 134 papers were duplicates. After removing duplicate papers, 433 papers were assessed as meeting the inclusion criteria. These 433 papers were further examined based on the inclusion criteria by reading the titles and abstracts. Moreover, grey papers were obtained and were added together with the screened papers. The total of 50 peer-reviewed papers (two of which were in the Indonesian language) and one grey paper were recorded and were read in full before finally selecting those eligible for a full review. After the full texts were read and assessed against the review questions, 20 papers were deemed suitable for inclusion in the final dataset. The selection of relevant papers was based primarily on the research questions, rather than a critical appraisal process, although a minimum standard of quality was required for inclusion. The reviewed research papers' quality is usually not appraised in a scoping review as the review seeks the breadth of all available material (Arksey & O'Malley 2005; Grant & Booth 2009). Undertaking detailed methodological critiques of the studies may unduly limit the number of selected papers, and thus, inappropriately exclude papers that would still provide rich information to answer the research questions; therefore, it is suggested to include a wide range of methods and study designs to provide an appreciation of the scope or extent of literature available on a thinly researched topic (Arksey & O'Malley 2005). The procedure used to select the included papers is displayed in Fig. 1.

Step 4: data charting

Each of the included 20 full-text papers was read thoroughly, several times, to capture all the relevant information and to ensure no important information was missed. A dataset from the papers was constructed by extracting findings relevant to the questions asked. The dataset was refined regularly by considering whether the extracted data were consistent with the review questions and the study aim. The extracted dataset was categorized using authors, study aims, study design, participants or sample, and themes in a practical table (Table 1). The design of this dataset was discussed among the review authors to ensure all relevant information was included.

Step 5: collating, summarizing and reporting of results

The NVivo software (QSR International 2016) was used to organize extracted data and aid the authors in coding data extractions and consequently developing responses to the

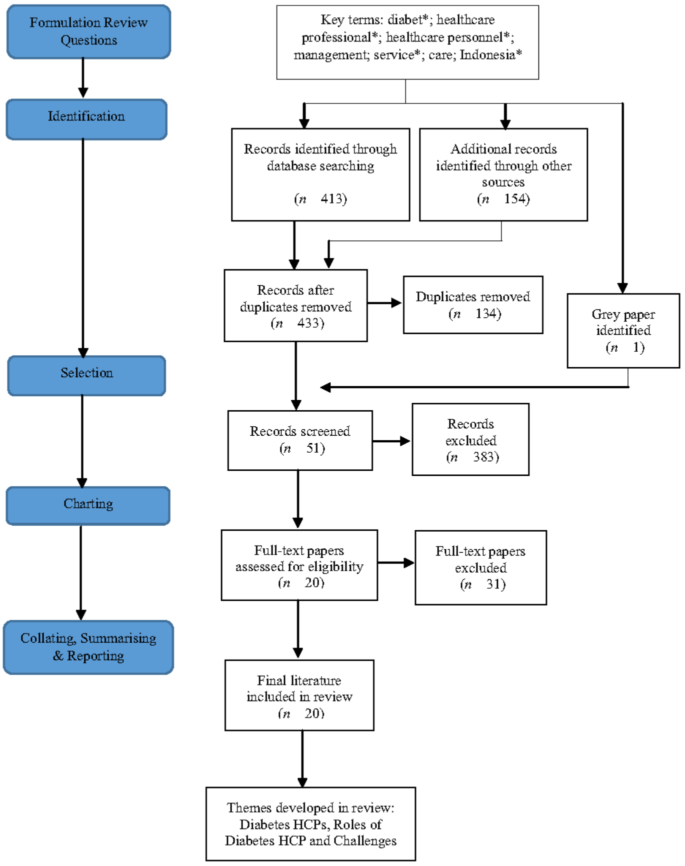

Fig. 1 Search strategy recorded in a flow chart, adopted from Moher et al.'s (2009) PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) and Arksey & O'Malley's (2005) scoping study framework stages.

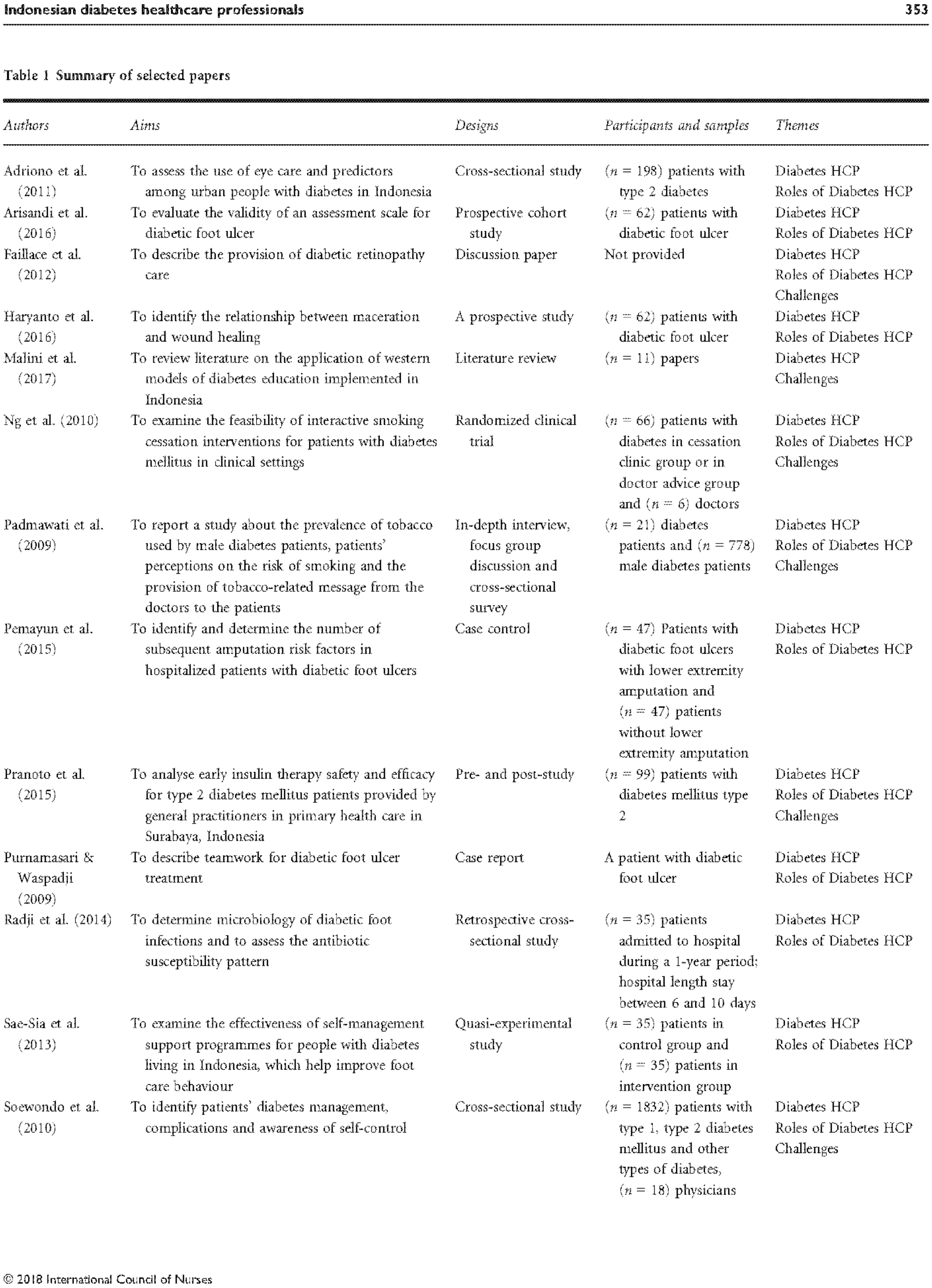

Table 1 Summary of selected papers

Authors	*Aims*	*Designs*	*Participants and samples*	*Themes*
Adriono et al. (2011)	To assess the use of eye care and predictors among urban people with diabetes in Indonesia	Cross-sectional study	(n = 198) patients with type 2 diabetes	Diabetes HCP Roles of Diabetes HCP
Arisandi et al. (2016)	To evaluate the validity of an assessment scale for diabetic foot ulcer	Prospective cohort study	(n = 62) patients with diabetic foot ulcer	Diabetes HCP Roles of Diabetes HCP
Faillace et al. (2012)	To describe the provision of diabetic retinopathy care	Discussion paper	Not provided	Diabetes HCP Roles of Diabetes HCP Challenges
Haryanto et al. (2016)	To identify the relationship between maceration and wound healing	A prospective study	(n = 62) patients with diabetic foot ulcer	Diabetes HCP Roles of Diabetes HCP
Malini et al. (2017)	To review literature on the application of western models of diabetes education implemented in Indonesia	Literature review	(n = 11) papers	Diabetes HCP Challenges
Ng et al. (2010)	To examine the feasibility of interactive smoking cessation interventions for patients with diabetes mellitus in clinical settings	Randomized clinical trial	(n = 66) patients with diabetes in cessation clinic group or in doctor advice group and (n = 6) doctors	Diabetes HCP Roles of Diabetes HCP Challenges
Padmawati et al. (2009)	To report a study about the prevalence of tobacco used by male diabetes patients, patients' perceptions on the risk of smoking and the provision of tobacco-related message from the doctors to the patients	In-depth interview, focus group discussion and cross-sectional survey	(n = 21) diabetes patients and (n = 778) male diabetes patients	Diabetes HCP Roles of Diabetes HCP Challenges
Pemayun et al. (2015)	To identify and determine the number of subsequent amputation risk factors in hospitalized patients with diabetic foot ulcers	Case control	(n = 47) Patients with diabetic foot ulcers with lower extremity amputation and (n = 47) patients without lower extremity amputation	Diabetes HCP Roles of Diabetes HCP
Pranoto et al. (2015)	To analyse early insulin therapy safety and efficacy for type 2 diabetes mellitus patients provided by general practitioners in primary health care in Surabaya, Indonesia	Pre- and post-study	(n = 99) patients with diabetes mellitus type 2	Diabetes HCP Roles of Diabetes HCP Challenges
Purnamasari & Waspadji (2009)	To describe teamwork for diabetic foot ulcer treatment	Case report	A patient with diabetic foot ulcer	Diabetes HCP Roles of Diabetes HCP
Radji et al. (2014)	To determine microbiology of diabetic foot infections and to assess the antibiotic susceptibility pattern	Retrospective cross-sectional study	(n = 35) patients admitted to hospital during a 1-year period; hospital length stay between 6 and 10 days	Diabetes HCP Roles of Diabetes HCP
Sae-Sia et al. (2013)	To examine the effectiveness of self-management support programmes for people with diabetes living in Indonesia, which help improve foot care behaviour	Quasi-experimental study	(n = 35) patients in control group and (n = 35) patients in intervention group	Diabetes HCP Roles of Diabetes HCP
Soewondo et al. (2010)	To identify patients' diabetes management, complications and awareness of self-control	Cross-sectional study	(n = 1832) patients with type 1, type 2 diabetes mellitus and other types of diabetes, (n = 18) physicians	Diabetes HCP Roles of Diabetes HCP Challenges

Table 1 ***Continued***

Authors	*Aims*	*Designs*	*Participants and samples*	*Themes*
Soewondo et al. (2013)	To review evidence on burden, expenditure, complications, treatment and outcomes of diabetes in Indonesia and the implications on health system developments	Literature review	(n = 23) papers	Diabetes HCP Challenges
Sutanegara & Budhiarta (2000)	To describe epidemiology of diabetes and diabetes management in Indonesia	Discussion paper	Not provided	Diabetes HCP Challenges
Wibowo et al. (2015a)	To evaluate current community pharmacy-based services, to identify pharmacists' perceived roles in type 2 diabetes care and to explore characteristics of pharmacy and pharmacists associated with current practice	Survey	(n = 240) pharmacists from 240 community pharmacies	Diabetes HCP Roles of Diabetes HCP Challenges
Wibowo et al. (2015b)	To explore physician and pharmacist perspectives about diabetes service delivery within community pharmacies in Indonesia	In-depth interview	(n = 10) community pharmacists and (n = 10) physicians	Diabetes HCP Roles of Diabetes HCP Challenges
Widyahening et al. (2014)	To identify the level of awareness, agreement, adoption and compliance on the guidelines of type 2 diabetes mellitus	Cross-sectional study	(n = 399) physicians who provide diabetes care, year of practice between 0 and 45 years	Diabetes HCP Roles of Diabetes HCP Challenges
Yusuf et al. (2013)	To investigate the challenge in developing an enterostomal therapy nurse (ETN) outpatient clinic in Indonesia	Retrospective descriptive study	(n = 73) patients with acute and chronic wound care, (n = 18) patients with diabetic foot ulcer	Diabetes HCP Roles of Diabetes HCP Challenges
IDF (2014)	To describe diabetes and diabetes management in Indonesia	Score card	Not provided	Challenges

questions asked. Arksey & O'Malley (2005) state that there are various ways to collate and summarize including organizing the data thematically. Thematic analysis helped to recognize, analyse and narrate patterns identified in the dataset (Braun & Clarke 2006). The themes reflect the key concepts that occurred repeatedly in the texts (Mays et al. 2005) and answered the questions posed.

Results

A total of 20 papers were reviewed. Almost all of the studies were quantitative studies and included both experimental (Ng et al. 2010; Pemayun et al. 2015; Pranoto et al. 2015; Sae-Sia et al. 2013) and non-experimental (Adriono et al. 2011; Arisandi et al. 2016; Haryanto et al. 2016; Padmawati et al. 2009; Radji et al. 2014; Yusuf et al. 2013) designs, which investigated the assessment, management and risk factors for diabetes. Interestingly, the oldest paper regarding HCP profile was published in 2000. After reviewing the literature, three major themes were developed: diabetes healthcare professionals; roles of diabetes healthcare professionals; and challenges encountered by diabetes healthcare professionals. These themes are explained as follows.

Diabetes healthcare professionals

All papers, except one (IDF 2014), identified several HCPs as responsible for caring for people with diabetes. These included physicians; nurses; pharmacists; dieticians; and diabetes educators. Physicians were mentioned in most of the reviewed papers (n = 16) and comprised both general practitioners (GPs) and specialized doctors such as internists, endocrinologists, infectious disease specialists, vascular surgeons, plastic surgeons, cardiologists and orthopaedic surgeons. Conversely, nurses were almost invisible in the context of the literature concerned with diabetes in Indonesia. Some papers (Arisandi et al. 2016; Haryanto et al. 2016; Pemayun et al. 2015; Sae-Sia et al. 2013; Soewondo et al. 2013; Yusuf et al. 2013) briefly mentioned the role of nurses in managing diabetes complications, such as diabetic foot ulcers. Most papers described nurses working in private clinics rather than in public hospitals (Arisandi et al. 2016; Haryanto et al. 2016;

papers, prior to them becoming diabetes educators; nor clearly delineated their new diabetes education role.

Collaborative management involving either interdisciplinary (Arisandi et al. 2016; Haryanto et al. 2016; Pemayun et al. 2015; Purnamasari & Waspadji 2009) or intradisciplinary teams (Adriono et al. 2011; Faillace et al. 2012; Soewondo et al. 2010) was mentioned in several papers. An interdisciplinary collaboration of a dermatologist and a nurse wound specialist resulted in the development of a valid instrument for assessing diabetic foot ulcers (Arisandi et al. 2016), and Pemayun et al. (2015) explored how a team of medical, nursing and nutrition HCPs helped to manage people who had diabetic foot ulcers while monitoring their risk for amputation. Purnamasari & Waspadji (2009) illustrated how medical and nutrition teams worked together to manage diabetic foot ulcers for people living with diabetes, by providing holistic care that included pressure relief management, nutrition therapy, antibiotic provision, wound care and patient education. Two papers described intradisciplinary collaboration of the physicians' established role in different hospital departments, such as the endocrinology clinic and eye clinic (Adriono et al. 2011; Faillace et al. 2012). Both clinics worked collaboratively to provide diabetes education and eye examination to people newly diagnosed with diabetes and annual screening for people previously diagnosed.

Challenges encountered by diabetes healthcare professionals

This review has recognized several challenges faced by HCPs in managing diabetes in Indonesia. The challenges are classified into internal and external challenges.

Internal challenges

Malini et al. (2017) highlighted limited skill of HCPs in delivering diabetes education. The authors asserted that a lack of skill was the result of inadequate training and further described that existing clinicians who provided diabetes education did not have specific training about diabetes and therefore delivered unstructured diabetes education.

Actual limited knowledge and skill in providing diabetes care was also reported by Pranoto et al. (2015), who studied the safety and efficacy of insulin therapy initiation provided by GPs. Pranoto et al. (2015) argued that GPs had limited knowledge in dispensing insulin at PHC clinics and more specifically reported deficits in the areas of indication, dosage, regimen selection, blood glucose self- monitoring and insulin side effects. Fear of the adverse side effects of insulin therapy also made GPs more hesitant to provide insulin in PHC settings (Pranoto et al. 2015).

Besides the actual limited knowledge and skill, perceived limited knowledge and skill was also identified. Wibowo et al. (2015b) claimed that other HCPs were reluctant to support pharmacists in taking on extended roles in direct patient care due to pharmacists' perceived lack of knowledge. In Faillace et al.'s (2012) study, physicians were perceived to have limited skill and knowledge in alerting people to the risk of diabetic retinopathy as well as the need for eye screening. Regardless of whether the people have diabetic retinopathy or not, they need to have their eyes checked regularly every year (Faillace et al. 2012).

External challenges

High patient volumes and a shortage of HCPs are still major issues challenging the provision of diabetes health care in Indonesia. An overload of people with diabetes has resulted in HCPs having limited time to screen all people with diabetes for diabetic neuropathy (Soewondo et al. 2010) and even to educate people with diabetes individually (Sutanegara & Budhiarta 2000). There is also an unequal number of HCPs working in urban and rural areas (Soewondo et al. 2013). For example, diabetes educators are mostly located in major cities (Malini et al. 2017; Sutanegara & Budhiarta 2000).

Underfunding was cited as another challenge faced by HCPs in managing diabetes (Soewondo et al. 2013). Underfunding contributes to reduced distribution of medications to all geographic areas of Indonesia and in certain healthcare levels, for example insulin is not distributed to PHC settings or '*Puskesmas*' (Pranoto et al. 2015; Soewondo et al. 2013).

Discussion

The current scoping review is the first to describe the profile of HCPs working in diabetes care in Indonesia. Information about the role that each HCP performs has also been described. Significant findings from the reviewed papers indicated that some systemic improvements are required for HCPs to better manage and care for Indonesian people with diabetes; the suggested areas for improvement vary, depending on the HCP in question.

The literature reviewed in this study has shown the physician has an established and visible role, opposed to other diabetes HCPs, whose roles were less visible. Even though the role of physicians is more evident in the literature as compared to other HCPs, it does not mean the role of other HCPs is insignificant or non-existent. It merely implies that the role of the physician has been studied more extensively in the literature in reference to the Indonesian context. Other HCPs roles were identified in the literature; however, these roles still need development in the areas of providing patient information and providing diabetes care, for example diabetes foot care (Sae-Sia et al. 2013).

The literature has suggested that both intradisciplinary and interdisciplinary working relationships need to be maintained and improved (Radji et al. 2014; Wibowo et al. 2015b). A collaborative multidisciplinary team is recommended and required for systematic diabetes care (IDF 2012; WHO 2016). Maintaining collaborative working relationships is important for helping each HCP to fully contribute to overcoming the massive burden of diabetes in Indonesia. Collaborative working relationships need to foster the creation of a comprehensive diabetes management plan for individual people that includes education, medication, exercise and diet. Involving HCPs from multiple disciplines will improve patient outcomes and cost effectiveness (Bratcher & Bello 2011). Moreover, intra- and interdisciplinary collaborations are vital in preventing people with diabetes from developing secondary complications; for example nurses working collaboratively with a wound nurse specialist to monitor people at risk of a diabetic foot ulcer and also facilitating individuals to self-manage foot care at home.

The literature reviewed here indicated that HCPs have a lack of skills and knowledge in providing diabetes care and informing people with diabetes of its risks (Faillace et al. 2012; Sutanegara & Budhiarta 2000; Wibowo et al. 2015b). Lack of skill and knowledge was recognized by the HCP themselves or by another group of HCPs; it may then lead to a reluctance to respect and concur with their recommendations (Wibowo et al. 2015b). It is therefore vital for the HCPs to continually increase their skill and knowledge specific to diabetes, because the formal education they have received about diabetes care may not be adequate (Livingston & Dunning 2010) to manage complex diabetic presentations. Having specific skills is necessary to complement each other's roles (Gucciardi et al. 2016) and to improve diabetes care (Ugur et al. 2015). Thus, HCPs need to be more highly skilled in managing people with diabetes with physical complications or psychological impacts in a creative way, especially those who live in rural and remote areas having a deficit of either human or non-human resources.

Unequal distribution of diabetes expertise occurs among clinical settings and among geographic areas where the concentration of diabetes expertise is greater in urban areas than rural areas (Soewondo et al. 2013). Conversely, the diabetes prevalence rate in rural areas is higher compared to urban areas (National Institute for Health Research and Development 2013). Despite a geographical issue in accessing rural areas, the unequal distribution can be further exacerbated by low salaries for HCPs and is hampered by either low health workforce production or reduced HCP graduates' employment capacity (Kanchanachitra et al. 2011). It is the responsibility of government to reform the policy that supports both HCPs and people with diabetes by increasing, supporting and appreciating the commitment of HCPs working in rural areas; for example ensuring the cost of living in rural areas does not outweigh the salary.

While filling the positions for HCPs in rural areas is one problem, it becomes even more imperative to equip those few currently available HCPs with specific, comprehensive diabetes-related knowledge and skills through professional development training. In poor resource areas, it may not be possible to increase the number of HCPs, so a more workable solution can be to increase the skill of the existing HCPs, as another way to achieve a skilful multidisciplinary care team (WHO 2016). Provision of continuing professional education can motivate HCPs working in rural areas (Efendi 2012). As there is an imbalance of expertise at all healthcare levels, HCPs working in PHC settings should have their skills improved to enhance their roles.

In a developing country like Indonesia, a substantial problem hindering the optimum implementation of HCPs' roles is funding issues such as health insurance, affordable diabetes medications for people with diabetes and updating the HCPs' skills. Acknowledging diabetes as a national problem is imperative to ensure that there will be a fair proportion of funding allocated for diabetes management, especially for people with low incomes and/or living in rural or remotes areas. Also, investing human and non-human resources in developing countries is recommended for the prevention of diabetes complications (Ezenwaka et al. 2014) by financially supporting the HCPs to update their skills regularly. Consequently, creative and skilful HCPs will still be able to perform their important role despite the lack of resources available.

Strengths and limitations

A strength of this literature review is that the search was very comprehensive, dating back to 1970. At this time, there was increasing awareness of diabetes in Indonesia that gave rise to the founding of the Indonesian Diabetes Association in 1976. Another strength is that the search included both Indonesian and English language papers. While the electronic databases used may have limited the number of Indonesian language papers located, the use of Google Scholar and Research Gate mitigated this effect.

Implications for education, nursing practice, health policy and research

This review underlines the challenges faced by HCPs' that arise from having limited skills and knowledge in diabetes care (Malini et al. 2017; Pranoto et al. 2015). HCPs need to participate in continuing professional education to more expertly manage people with diabetes, particularly those with secondary complications. This strategy will also help address the shortage of HCPs in both rural and urban geographical areas because each available HCP will be more highly skilled. Healthcare facilities' administrators should provide opportunities for HCPs to continue their professional development.

Only two papers suggested that working collaboratively to provide diabetes care should be maintained and improved (Radji et al. 2014; Wibowo et al. 2015b). Multidisciplinary collaborations are vital in preventing people with diabetes from developing secondary complications. Therefore, healthcare facilities in both rural and urban areas should establish a model of multidisciplinary teams that consist of HCPs who are highly skilled in providing care to people with diabetes.

Nationally, health policy reform must increase funding and improve insurance coverage to cover the cost of diabetes medications and to support HCPs in their professional development, at all levels of health care. Also, findings from this review can be used to inform health policy makers, both in Indonesia and in other countries with similar disease profiles and resourcing challenges, to modify their current healthcare systems. Modifications should address: ensuring an adequately sized, highly skilled diabetes workforce; more appropriate distribution of the workforce across all levels of care and all geographic locations; and fostering both structural and philosophical changes that will establish and sustain true multidisciplinary care.

There were limited studies about what types of tasks the Indonesian nurse performed in the care of people with diabetes. Therefore, it is crucial to conduct research in this area to fully understand the nurses' role in this context. Increasing visibility of the role of the nurse will also serve to illustrate and acknowledge the significant work that nurses do in this area, both nationally and internationally. Illuminating the role of the nurse may be helpful in developing more feasible models of care to promote high-quality diabetes management.

Conclusion

With the current prevalence rates of diabetes expected to increase over time, Indonesia needs a comprehensive strategy to prevent and manage the resultant burden of disease. Developing models of multidisciplinary care, as recommended by international health organizations, will make a significant difference to the future impact this disease has on the Indonesian population. Within a context of very limited scholarly information on diabetes HCPs and the application of the multidisciplinary care models in Indonesia, this study has explored the profile of diabetes HCPs in Indonesia by identifying which professions they belong to and describing their roles. Both internal and external challenges they encounter in providing high-quality diabetes care were also identified in this review. The challenges identified in this study will enlighten global nurses and other diabetes HCPs about the current models of care with a view to improving diabetes management in this country. Also, this study contributes to better understanding of the international context of diabetes care where it is commonly accepted that collaborative management is essential, especially in countries with limited human and non-human resources in the context of rapidly rising rates of chronic conditions.

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Author contributions

Literature review design and data collection: TL, KW, NH, JM
Literature review analysis and interpretation: TL
Manuscript writing: TL, KW, NH, JM
Study supervision: KW, NH, JM
Critical revisions for important intellectual content: TL, KW, NH, JM

References

Adriono, G., Wang, D., Octavianus, C. & Congdon, N. (2011) Use of eye care services among diabetic patients in urban Indonesia. *Archives of Ophthalmology*, **129** (7), 930–935.

Arisandi, D., et al. (2016) Evaluation of validity of the new diabetic foot ulcer assessment scale in Indonesia. *Wound Repair and Regeneration*, **24** (5), 876–884.

Arksey, H. & O'Malley, L. (2005) Scoping studies: towards a methodological framework. *International Journal of Social Research Methodology*, **8** (1), 19–32.

Bratcher, C.R. & Bello, E. (2011) Traditional or centralized models of diabetes care: the multidisciplinary diabetes team approach. *The Journal of Family Practice*, **60** (11 Suppl), S6.

Braun, V. & Clarke, V. (2006) Using thematic analysis in psychology. *Qualitative Research in Psychology*, **3** (2), 77–101.

Bygbjerg, I.C. (2012) Double burden of noncommunicable and infectious diseases in developing countries. *Science*, **337** (6101), 1499–1501.

Chatterjee, S. & Davies, M.J. (2015) Current management of diabetes mellitus and future directions in care. *Postgraduate Medical Journal*, **91** (1081), 612–621.

Efendi, F. (2012) Health worker recruitment and deployment in remote areas of Indonesia. *Rural and Remote Health,* **12** (2), 2008.

Ezenwaka, C., Onuoha, P., Sandy, D. & Isreal-Richardson, D. (2014) Diabetes self-management education in a high-income developing country: survey of the opinion of nurses and dietitians. *International Journal of Diabetes in Developing Countries,* **34** (3), 163–168.

Faillace, S., et al. (2012) Helping patients find their way to better diabetic retinopathy care. *Community Eye Health,* **25** (78), 34.

Grant, M.J. & Booth, A. (2009) A typology of reviews: an analysis of 14 review types and associated methodologies. *Health Information & Libraries Journal,* **26** (2), 91–108.

Gucciardi, E., Espin, S., Morganti, A. & Dorado, L. (2016) Exploring interprofessional collaboration during the integration of diabetes teams into primary care. *BMC Family Practice,* **17** (1), 12.

Hartayu, T.S., Mi, M.I. & Suryawati, S. (2012) Improving of type 2 diabetic patients' knowledge, attitude and practice towards diabetes self-care by implementing Community-Based Interactive Approach-diabetes mellitus strategy. *BMC Research Notes,* **5**, 315.

Haryanto, H., et al. (2016) Relationship between maceration and wound healing on diabetic foot ulcers in Indonesia: a prospective study. *International Wound Journal,* **14** (3), 516–522.

IDF (2012) *Clinical guideline task force: Global guideline for type 2 diabetes.* IDF, Brussels. Available at: https://www.idf.org/e-library/guidelines/79-global-guideline-for-type-2-diabetes (accessed 03 May 2017).

IDF (2013) *IDF Diabetes Atlas.* Available at: http://idf.org/diabetesatlas (accessed 11 March 2016).

IDF (2014) *Global diabetes scorecard: Tracking progress for action.* IDF, Brussels. Available at: http://idf.org/global-diabetes-scorecard/ (accessed 10 July 2015).

Indonesian Diabetes Association (2014) Guidelines on the management and prevention of prediabetes. *Acta Medica Indonesiana,* **46** (4), 348–359.

Kanbara, S., et al. (2008) Social support, self-efficacy and psychological stress responses among outpatients with diabetes in Yogyakarta, Indonesia. *Diabetes Research and Clinical Practice,* **80** (1), 56–62.

Kanchanachitra, C., et al. (2011) Health in Southeast Asia 5 Human resources for health in southeast Asia: shortages, distributional challenges, and international trade in health services. *Lancet,* **377** (9767), 769–781.

Levac, D., Colquhoun, H. & O'Brien, K.K. (2010) Scoping studies: advancing the methodology. *Implementation Science,* **5** (1), 69.

Livingston, R. & Dunning, T. (2010) Practice nurses' role and knowledge about diabetes management within rural and remote Australian general practices. *European Diabetes Nursing,* **7** (2), 55–62.

Malini, H., Copnell, B. & Moss, C. (2017) Considerations in adopting a culturally relevant diabetes health education programme: an Indonesian example. *Collegian,* **24** (2), 183–190.

Mays, N., Pope, C. & Popay, J. (2005) Systematically reviewing qualitative and quantitative evidence to inform management and policy-making in the health field. *Journal of Health Services Research and Policy,* **10** (1), 6–20.

Mihardja, L., et al. (2009) Prevalence and determinants of diabetes mellitus and impaired glucose tolerance in Indonesia (a part of basic health research/Riskesdas). *Acta Medica Indonesiana,* **41** (4), 169.

Mihardja, L., Soetrisno, U. & Soegondo, S. (2014) Prevalence and clinical profile of diabetes mellitus in productive aged urban Indonesians. *Journal of Diabetes Investigation,* **5** (5), 507–512.

Ministry of Health Republic of Indonesia (2015) *Strategic plan of Ministry of Health 2015-2019 (Rencana strategis Kementerian Kesehatan tahun 2015-2019).* MoH RI, Jakarta. Available at: http://depkes.go.id/resources/download/info-publik/Renstra-2015.pdf (accessed 17 August 2016).

Moher, D., et al. (2009) Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement. *PLoS Medicine,* **6** (7), e1000097.

National Institute for Health Research and Development (2013) *Basic Health Research (Riset Kesehatan Dasar).* Ministry of Health Republic of Indonesia, Jakarta.

Ng, N., et al. (2010) Bringing smoking cessation to diabetes clinics in Indonesia. *Chronic Illness,* **6** (2), 125–135.

Padmawati, R.S., Ng, N., Prabandari, Y.S. & Nichter, M. (2009) Smoking among diabetes patients in Yogyakarta, Indonesia: cessation efforts are urgently needed. *Tropical Medicine & International Health,* **14** (4), 412–419.

Pemayun, T.G., et al. (2015) Risk factors for lower extremity amputation in patients with diabetic foot ulcers: a hospital-based case-control study. *Diabetic Foot & Ankle,* **6**, 29629.

Pranoto, A., Novida, H., Prajitno, J.H. & Tjokroprawiro, A. (2015) Safety and efficacy in early insulin initiation as comprehensive therapy for patients with type 2 diabetes in primary health care centers. *Acta Medica Indonesiana,* **47** (2), 104–110.

Purnamasari, D. & Waspadji, S. (2009) A good teamwork will save the limb. *Acta Medica Indonesiana,* **41** (4), 213–214.

QSR International (2016) NVivo Qualitative data analysis software. Version 11.

Radji, M., Putri, C.S. & Fauziyah, S. (2014) Antibiotic therapy for diabetic foot infections in a tertiary care hospital in Jakarta, Indonesia. *Diabetes & Metabolic Syndrome,* **8** (4), 221–224.

Ritholz, M.D., et al. (2011) Physicians' perceptions of the type 2 diabetes multidisciplinary treatment team: a qualitative study. *Diabetes Educator,* **37** (6), 794–800.

Rudijanto, A., et al. (2011) The Indonesian society of endocrinology's summary article of diabetes mellitus national clinical practice guidelines. *Journal of the ASEAN Federation of Endocrine Societies,* **26** (1), 17–19.

Sae-Sia, W., Maneewat, K. & Kurniawan, T. (2013) Effect of a self-management support program on diabetic foot care behaviors. *International Journal of Research in Nursing,* **4** (1), 14–21.

Shaw, J.E., Sicree, R.A. & Zimmet, P.Z. (2010) Global estimates of the prevalence of diabetes for 2010 and 2030. *Diabetes Research and Clinical Practice,* **87** (1), 4–14.

Shortus, T.D., et al. (2007) Multidisciplinary care plans for diabetes: how are they used? *Medical Journal of Australia,* **187** (2), 78–81.

Simmonds, A. & Hort, K. (2013) *Institutional analysis of Indonesia's proposed road map to universal health coverage*. Nossal Institute for Global Health, University of Melbourne, Melbourne. Available at: http://ni.unimelb.edu.au/__data/assets/pdf_file/0004/834457/WP_33.pdf (accessed 23 March 2016).

Soegondo, S., Widyahening, I.S., Istantho, R. & Yunir, E. (2011) Prevalence of diabetes among suburban population of Ternate, a small remote island in the eastern part of Indonesia. *Acta Medica Indonesiana*, **43** (2), 99.

Soewondo, P. (2011) Current practice in the management of type 2 diabetes in Indonesia: results from the International Diabetes management Practices Study (IDMPS). *Journal of Indonesian Medical Association*, **61** (12), 474–481.

Soewondo, P., et al. (2010) The DiabCare Asia 2008 study - Outcomes on control and complications of type 2 diabetic patients in Indonesia. *Medical Journal of Indonesia*, **19** (4), 235–244.

Soewondo, P., Ferrario, A. & Tahapary, D.L. (2013) Challenges in diabetes management in Indonesia: a literature review. *Global Health*, **9**, 63.

Sutanegara, D.D. & Budhiarta, A.A.G. (2000) The epidemiology and management of diabetes mellitus in Indonesia. *Diabetes Research and Clinical Practice*, **50** (Suppl. 2), S9–S16.

Ugur, E., Demir, H. & Akbal, E. (2015) Postgraduate education needs of Nurses' who are caregivers for patients with diabetes. *Pakistan Journal of Medical Sciences*, **31** (3), 637–642.

WHO (2014) *Noncommunicable diseases country profiles 2014*. Available at: http://www.who.int/nmh/countries/en/ (accessed 05 April 2015).

WHO (2016) *Global report on diabetes*. Available at: http://www.who.int/diabetes/global-report/en/ (accessed 11 May 2017).

Wibowo, Y., Parsons, R., Sunderland, B. & Hughes, J. (2015a) Evaluation of community pharmacy-based services for type-2 diabetes in an Indonesian setting: pharmacist survey. *International Journal of Clinical Pharmacy*, **37** (5), 873–882.

Wibowo, Y., Sunderland, B. & Hughes, J. (2015b) Pharmacist and physician perspectives on diabetes service delivery within community pharmacies in Indonesia: a qualitative study. *International Journal of Pharmacy Practice*, **24** (3), 180–188. https://doi.org/10.1111/ijpp.12227.

Widyahening, I.S., et al. (2014) Awareness, agreement, adoption and adherence to type 2 diabetes mellitus guidelines: a survey of Indonesian primary care physicians. *BMC Family Practice*, **15**, 72.

Yusuf, S., Kasim, S., Okuwa, M. & Sugama, J. (2013) Development of an enterostomal therapy nurse outpatient wound clinic in Indonesia: a retrospective descriptive study. *Wound Practice & Research: Journal of the Australian Wound Management Association*, **21** (1), 41–47.

Zhang, X., et al. (2012) Access to health care and control of ABCs of diabetes. *Diabetes Care*, **35** (7), 1566–1571.

Model of Health Service Delivery in Indonesia

Access to health services is fundamental to the provision of diabetes care and treatment. A health service is defined by the presence of qualified healthcare professionals in an organised unit to improve a person’s health (Australian Government, 2008; Schwarz, 1967). This definition implies that health service delivery for people living with diabetes is a purposive activity aimed at managing and supporting their health and wellbeing. Therefore, understanding health service delivery for people with diabetes is important to learn about the context in which individuals manage their health and wellbeing.

Indonesia is a developing country and has several classifications of hospitals: Type A; Type B and Type C (Republic of Indonesia Minister of Health, 2010). Definitions of the classifications are explained in Table 2.2. These hospitals can be government or privately owned. In Indonesia three levels of health services are available to individuals, families and communities: primary healthcare, secondary healthcare and tertiary healthcare (Republic of Indonesia Minister of Health, 2009; Republic of Indonesia President, 2012). Primary healthcare services focus on prevention, promotion, cure and rehabilitation and are provided by a variety of healthcare professionals employed at community health centres. Secondary healthcare services focus on providing care to people with complex conditions such as diabetes and are triggered by a referral from a primary healthcare service (World Health Organization, 2014). Specialist doctors provide secondary healthcare services in a hospital setting (Type C), supported by nurses and allied healthcare professionals. Tertiary healthcare services provide people with access to specialty services (i.e. endocrinologist) and focus on diagnosing and treating complications that arise from complex health conditions. These services are triggered by a referral from a primary or secondary healthcare service with specialist doctors, nurses and allied healthcare professionals providing this care within a hospital setting (Type A and B) (Republic of Indonesia President, 2012; World Health Organization, 2014).

Table 2.2: *Types of Hospital*

Classification Type	Definition of Hospital Type
Type A Hospital	Refers to hospitals that have facilities and medical services with at least four basic specialist medical services, five supported specialist medical services, twelve other specialist medical services and thirteen sub-specialist medical services (Republic of Indonesia Minister of Health, 2010)
Type B Hospital	Refers to hospitals that have facilities and medical services with at least four basic specialist medical services, four supported specialist medical services, eight other specialist medical services and two sub-specialist medical services (Republic of Indonesia Minister of Health, 2010)
Type C Hospital	Refers to hospitals that have facilities and medical services with at least four basic specialist medical services and four supported specialist medical services (Republic of Indonesia Minister of Health, 2010)

Increasing levels of diabetes diagnoses in Indonesia has prompted two national research studies investigating risk factors, complications and management of diabetes and prevalence (National Institute of Health Research and Development, 2008; 2013). While other research has been undertaken on this topic in Indonesia, few peer-reviewed studies about the provision of diabetes care have been published internationally. As such, two unpublished reports have been included in this review for completeness (Soewondo, Ferrario, & Tahapary, 2013a; Sutanegara & Budhiarta, 2000). Moreover, no integrative reviews of the literature have been conducted on diabetes health service provision in Indonesia.

Four different models of health service delivery were identified in this integrative literature review for people living with diabetes in Indonesia. These health service models spanned all three levels of health service provision and resulted in four distinct models of health service delivery: primary healthcare model, secondary healthcare model, a combination of secondary and tertiary healthcare models as well as tertiary healthcare model. Each of these models will be described and discussed with reference to the following: setting of the service; funding model for the service; types of interventions and treatments available to people who visited the service; and volume of people that attended the service.

Primary healthcare.

The first of the four models of care to be discussed is primary healthcare. Primary healthcare was delivered in several health facilities in the community that were described using a variety of labels including community or outpatient and public health centres (Abazari et al., 2012; Adriono, Wang, Octavianus, & Congdon, 2011; Soewondo et al., 2013a; Widyahening et al., 2014). The majority of the centres described in the literature were government-funded (Aklima, Kritpracha, & Thaniwattananon, 2013; Widyahening et al., 2014). In terms of patient volume, one public health centre treated approximately 20 patients with diabetes every day (Adriono et al., 2011). Specific diabetes health services at the level of primary healthcare were also provided in private facilities such as private clinics by groups of professionals (Adriono et al., 2011; Widyahening et al., 2014) or by a solo generalist doctor (Widyahening et al., 2014). In terms of daily patient volume, a private clinic in Adriono et al.'s study usually treated fewer than 10 patients with diabetes every day (Adriono et al., 2011).

In a study by Widyahening et al. (2014) diabetes management provided by generalist doctors in primary healthcare services was based on seven recommendations made by the national guideline. The guidelines include providing screening to all patients with high risk, performing one random blood glucose test for diagnosis, offering lifestyle modification, administering medications, maintaining patients' fasting blood glucose and blood pressure within normal ranges, as well as prescribing medication for either middle-aged patients or patients with heart disease (Widyahening et al., 2014).

Secondary healthcare.

Secondary healthcare services are also offered to people living with diabetes in Indonesia. Two identified studies performing this model of health service were private clinics (Ramadhinara & Poulas, 2013; Yusuf, Kasim, Okuwa, & Sugama, 2013). The secondary healthcare services in private clinics were provided by groups of healthcare professionals that provided specialist practice such as wound care. Information regarding funding provision was not identified from the two studies about this type of health service. Patients developing diabetic foot complications had wound care treatments in a wound medical care service (Ramadhinara & Poulas, 2013) or an enterostomal therapy nurse (ETN) clinic (Yusuf et al., 2013). In a retrospective descriptive study, Yusuf et al. emphasised that their private clinic solely provided wound care services for patients with foot problems resulting from their diabetes. Their clinic works collaboratively with physicians and hospitals in order to access medications and diagnostic tests (Yusuf et al., 2013). However, there was no information reported about patient volume in this model.

Secondary and tertiary healthcare facilities and services.

This model includes the studies that specifically mentioned that the provision of diabetes health services was provided in secondary and tertiary healthcare facilities, as well as studies that did not clearly identify the health service setting. The classification of the model always referred to types of health services in Indonesia stated from the Presidential Act and Minister of Health Decree (Republic of Indonesia Minister of Health, 2009; Republic of Indonesia President, 2012).

Several studies have described secondary and tertiary healthcare services that provide diabetes health services (Chuang, Tsai, Huang, Tai, & Diabcare-Asia Study Group, 2002; Eppens, Craig, Jones, Silink, & et al., 2006; Sae-Sia et al., 2013; Soewondo, 2011; Soewondo et al., 2013b; Soewondo et al., 2013d; Soewondo et al., 2010). Diabetes health services were available in outpatient settings such as in diabetes centres or clinics that were located in hospitals (Chuang et al., 2002; Ng et al., 2010; Sae-Sia et al., 2013; Soewondo et al., 2010) and in inpatient care for hospitalised patients (Soewondo, 2011). Funding arrangements were not discussed in the studies that were conducted in this model of health service. In a diabetic clinic in a district general hospital, Sae-Sia et al. (2013) found that most patients visited the clinics to have a regular medical check-up. When visiting the diabetes clinics, patients were provided with a health assessment, either oral or insulin therapy prescriptions as well as consultations about diet, exercise and medications (Chuang et al., 2002; Sae-Sia et al., 2013; Soewondo et al., 2013b; Soewondo et al., 2013d) or sessions from diabetes educators (Soewondo, 2011). The clinics that provided secondary and tertiary healthcare services had patient loads of 100 patients per month (Chuang et al., 2002). Annually, these types of service could also have between 500 and 1000 patients (Ng et al., 2010).

All previously mentioned studies denote an outpatient care setting for adults with diabetes. Two studies by Craig, Jones, Silink, and Ping (2007) and by Eppens et al. (2006)

indicated children with either type 1 or type 2 diabetes mellitus were treated in secondary and tertiary outpatient diabetes centres. In these centres, the patients were provided with clinical and biochemical assessment for diagnosis and identifying glycaemic control. Paediatric patients also regularly visited the centres to have diabetes therapy such as diabetic oral medications or insulin injections (Craig et al., 2007; Eppens et al., 2006) or oral diabetic agents and dietary management (Eppens et al., 2006).

Tertiary healthcare.

Diabetes health services are also available in tertiary healthcare. In this model of service, the delivery of healthcare services is provided in the form of both outpatient (Adriono et al., 2011; Hartayu et al., 2012a, 2012b; Kanbara, Taniguchi, Sakaue, Wang, Takaki et al., 2008; Santoso, Yuliana, Mujono, & Kusdiantomo, 2005; Sinorita et al., 2008; Soewondo et al., 2013a; Triyanti, Suhardjono, Soewondo, & Shatri, 2008) and inpatient care. Several public hospitals had outpatient clinics delivering tertiary diabetes healthcare services, however, the terms used for mentioning those clinics varied, such as endocrinology clinics (Adriono et al., 2011; Sinorita et al., 2008; Triyanti et al., 2008) and internal medicine clinics (Santoso et al., 2005; Triyanti et al., 2008). In a public hospital that was regarded as a teaching hospital in Jakarta, an endocrinology clinic provided diabetes health services (Adriono et al., 2011). Similarly, an outpatient clinic called an endocrinology clinic was also identified from Sinorita et al.'s (2008) study. Patients routinely visited the outpatient clinics to receive medication (Sinorita et al., 2008) and to have medical check-ups from the doctors (Hartayu et al., 2012b). During a medical check-up, diabetes patients had consultations about the disease (Hartayu et al., 2012a; Kanbara et al., 2008), prescriptions of medication such as oral diabetic agents and/or insulin therapy (Sinorita et al., 2008; Soewondo et al., 2010) as well as diet or exercise management (Sinorita et al., 2008). The choice of medication prescribed varied according to the medical practitioner (Soewondo et al., 2013d). Within three months of the patients' first visits to the clinic, the patients underwent physical examination and laboratory tests to screen creatinine, lipid, renal and eye functions (Triyanti et al., 2008).

Internal medicine outpatient clinics in several public hospitals also delivered diabetes health services (Santoso et al., 2005; Triyanti et al., 2008) where patients had a regular visit for follow-up, especially to monitor their risk of developing diabetic foot infections. Patients were not only treated for their diabetes but also for complications such as diabetic foot ulcers (Santoso et al., 2005). Patients who developed either acute or chronic complications from their diabetes were referred to specialist clinics such as an ophthalmology clinic that provided diabetic eye examination using more sophisticated technology (Adriono et al., 2011). In terms of patient volume, outpatient clinics in the tertiary public hospitals had approximately 50 patients a day (Adriono et al., 2011).

Three authors also mentioned tertiary private hospitals as another model of care for providing health services for people with diabetes (Hartayu et al., 2012a, 2012b). In one instance, a charity hospital organised a diabetes mellitus club (Hartayu et al., 2012a, 2012b). Through the club, the patients received regular education programs. The programs consisted of meetings on every Sunday and seminars every two months. Other information about specific services provided was not mentioned in these three studies. No information was provided on patient volume for this tertiary model of care in private hospitals.

Diabetes health services are also provided at a tertiary healthcare level in Indonesia where patients are admitted to stay in hospital for a certain period. Two articles were identified that described diabetes health services in the form of inpatient care. The hospitals were public thereby owned by the government. Patients admitted to the hospitals usually had complications such as diabetic foot ulcers. They stayed in the hospital in a ward called the internal medicine ward (Radji, Putri, & Fauziyah, 2014; Santoso et al., 2005). Patients with diabetic foot infection usually spent between six and 10 days in hospital (Radji et al., 2014). During the stay in the inpatient facility, the patients received therapies including antibiotic administrations and glycaemic control or treatment such as wound dressing, dead tissue removal and limb surgery (Radji et al., 2014). There was no further information provided about patient volume in the clinic.

Several studies highlighted the importance of improving current access to healthcare services for patients living with diabetes in Indonesia (Craig et al., 2007; Eppens et al., 2006; Soewondo et al., 2013a). Craig, Jones, Silink, and Ping argue that patients should have unlimited access to affordable diabetes health services including medication and blood glucose monitoring. Unaffordable healthcare services in Indonesia can only result in larger numbers of people remaining undiagnosed until they experience a dramatic health crisis (Eppens et al., 2006).

Cost of services depends on whether the health service facilities accept government insurance or not. Patients with government insurance can access free services in public hospitals but those who do not have insurance must pay an amount based on the treatment they receive (Adriono et al., 2011). The majority of patients accessing diabetes healthcare services in the study by Kanbara et al. (2008) were not covered by government health insurance. Payment in this case is subject to patients' socioeconomic factors; low income patients can have free services or pay half the cost (Yusuf et al., 2013). The more complicated the diabetic condition is, the higher the cost of healthcare service provision to the patient (Soewondo et al., 2013a). The high cost of supplying and distributing medication throughout Indonesia's wide geographic area has led to people living with diabetes in rural areas having reduced or no access to important medication (Soewondo et al., 2013a).

Clinical guidelines are imperative to support healthcare professionals in delivering appropriate services. Two articles in the review highlighted the importance of guidelines in delivering health services for diabetes patients (Soewondo et al., 2013a; Widyahening et al., 2014). In a study by Widyahening et al., 399 generalist doctors who provided healthcare for diabetes sufferers had variations of awareness, agreement, adoption and adherence toward the guidelines on selected diabetes management for their patients such as screening, diagnosis, life-style modification, the use of sulfonylurea, blood glucose target, blood pressure target and statin use. This study found that the least adherence was in performing a screening for type 2 DM patients with any risk factors. Whereas the highest adherence was in forming a diagnosis using random plasma blood glucose for patients with classic symptoms. It is vital to have an updated framework for constructing health policies and strategic plans to manage the evolving cases of diabetes mellitus (Soewondo et al., 2013a). Thus, implementing current guidelines and referring to the guidelines with an updated framework would be valuable in providing diabetes health service in day-to-day clinical practice.

Health services for people living with diabetes mellitus in Indonesia were provided in primary, secondary and tertiary healthcare settings. Health service delivery was mostly performed in outpatient settings at the secondary and tertiary healthcare levels. Diabetes health services at a tertiary healthcare level in urban areas were delivered mostly by specialists, particularly in outpatient clinics and by generalist doctors in primary healthcare centres. In developed countries such as Canada, the utilisation of health services provided by specialist doctors is subject to generalist doctors as they control clients' access to specialist doctors (Klarenbach & Jacobs, 2003). Generalist doctors therefore were more likely to be visited by people living with diabetes and this situation is similar to Indonesia. However, in the United States (US), people with diabetes also visit certain types of specialist doctors more frequently (Klarenbach & Jacobs, 2003). Hiss, Armbruster, Gillard, and McClure (2007) have further described that most people living with diabetes in the US were treated by specialists in internal medicine and family doctors, rather than by specialist doctors in diabetes mellitus or endocrinologists in community-based care. Moreover, in a developed country such as the United Kingdom, nurses who specialised in diabetes had even more specific extended roles to meet the evolving needs of patients with diabetes, for example paediatric diabetes nurses (Hill, 2009). None of the Indonesian studies reviewed described a diabetes specialist role for nurses. Nurses in Indonesia should be aware of the need to develop and extend their specific roles to be more focused on managing diabetes to achieve better quality care.

A number of barriers to providing health services for people with diabetes in a developing country such as Indonesia have been identified. The first and most concerning barrier was identified as a lack of health service professionals providing diabetes care and treatment, especially in remote areas. In a developed country such as the US limited availability of healthcare professionals in rural areas was also a concern (Coon & Zulkowski, 2002). Coon and Zulkowski argued that difficulties in recruiting healthcare professionals to provide diabetes care and treatment in rural areas was because of reduced salaries and reduced access to continuing professional development required for diabetes mellitus.

Payment for health service provision varied between healthcare settings. Indonesia implemented a national health insurance program in 2008 for financially disadvantaged people and applied the Executive Assembly for Social Protection, which includes health coverage, since early 2014 (Widjaja, 2012). However, the reviewed literature suggested that not all Indonesians were covered by insurance, especially in remote areas (Kanbara et al., 2008). Simmonds and Hort (2013) also showed that particular forms of health insurance covered only 63% of Indonesians. This incomplete coverage may be the result of less expenditure by the government on health service sectors than on general services (Widjaja, 2012). Unclear design of health cover was found to be a limitation leading to inequality of access to diabetes health service for the poor in this review (Simmonds & Hort, 2013). Thus, well defined and standard measurements of health insurance in developing countries should delineate who is covered, what services are covered and what proportion of cost is covered, as these clear demarcations are important factors in improving the quality of service (Lagomarsino, Garabrant, Adyas, Muga, & Otoo, 2012). People who were not covered by insurance were less likely to attend healthcare facilities to obtain regular health services (Zhang, Bullard, Gregg, Beckles, Williams et al., 2012). People with diabetes may not know whether they are entitled to health coverage and, even if they are entitled, may not know how to obtain coverage. As a result, economically disadvantaged people with diabetes may be hesitant to visit healthcare facilities. Therefore, ensuring adequate health insurance coverage for people with diabetes may remove one barrier - finances - and thus encourage them to visit healthcare facilities regularly for examinations or treatments.

Limited access to diabetes health services was also raised as an issue of concern in the literature review. Similar concerns were found in another developing country, Taiwan, where it was noted that diabetes care by healthcare professionals was not received by half of the poor people with diabetes (Hsu, Lee, Wahlqvist, Huang, Chang et al., 2012). Because of this inequality of care access, poor patients with newly diagnosed diabetes delayed examination, lacked medical follow-up and gradually developed more serious complications (Hsu et al., 2012). In contrast, Robinson, Baron, Cooper, and Janson (2009) showed that a developed country like the US provides a wide range of facilities for patients with diabetes and these services were provided equally to the participants in the study, including people who are at risk. In some geographic areas in Indonesia, healthcare professionals struggle with the issue of supplying and distributing medicine (Soewondo et al., 2013a). Thus, one clear strategy to promote high quality health services to people with diabetes is to reduce geographical disparities (Hsu et al., 2012).

Several studies discussed in this review highlighted the importance of complying with clinical practice guidelines for diabetes care service (Soewondo et al., 2013a; Widyahening et al., 2014). Indonesia has published a clinical practice guideline and revised this based on the national consensus (Rudijanto, Soewondo, Waspadji, Yunir, & Purnamasari, 2011). This guideline refers to an international guideline issued by the American Diabetes Association (ADA) and published in 2010. Although one study in Indonesia noted that health professionals were aware of these clinical practice guidelines, most were not complying with them (Widyahening et al., 2014). Similarly, healthcare professionals, including medical doctors and nurses, in the US primary care clinics did not always adhere to the ADA guideline for particular areas in managing diabetes patients (Coon & Zulkowski, 2002; Lenz, Mundinger, Hopkins, Lin, & Smolowitz, 2002). Several reasons for non-adherence to the guidelines include: the healthcare professionals providing diabetes care and treatment might not have recognised the guidelines; might not have obtained a copy of them (Widyahening et al., 2014); or might not have been exposed to the guidelines. Therefore, guidelines for providing diabetes care for patients should be distributed equally to healthcare professionals in urban and rural settings through training or continuing professional development education.

Clearly, having guidelines that are evidence-based is insufficient if they are not actually being distributed and implemented in all parts of Indonesia.

Models of health service delivery for people living with diabetes needs to consider two important aspects: the healthcare professionals providing diabetes care and treatment, and the availability of the delivery of health services. Since the studies identified did not contain extensive descriptions of the provision of healthcare services to people living with diabetes in Indonesia, further research in developing fit for purpose models of health service for people with diabetes would be highly relevant and informative to future policy, workforce and practice decisions in Indonesia. A review of current health services for people living with diabetes in Indonesia should be conducted in order to identify health system disparity with a focus on rural and remote communities. It is crucial to clarify the roles of various healthcare professionals, especially nurses, for providing better quality of care. To support nurses conducting delineated roles and coordinating with other allied healthcare professionals, it would be valuable to provide them with extended specialist education in diabetes. It is also an essential need to ensure suitably trained healthcare professionals are available in remote areas as well as urban areas. Healthcare professionals who are recruited and allocated in rural areas should also be given an opportunity to increase their education level, and be provided with facilities that support their roles, consequently making their work more achievable and visible.

It would be beneficial if the Indonesian government regularly monitored and evaluated the status of communities covered by health insurance. Remote and rural communities are disadvantaged regarding the distribution of medication (Waspadji et al., 2013), therefore, facilitating access to diabetes health services in rural areas is imperative if the burden of this disease is to be addressed. People living with diabetes in Indonesia should have access to necessary diabetic services; therefore, it is crucial to improve infrastructure, including transportation and to provide greater subsidies for health service provision in rural communities. As this review found that guidelines for implementing diabetes management are not adhered to in Indonesia, further research is necessary to explore whether guidelines for healthcare professionals, such as nurses, are readily available to them in the workplace. Barriers preventing them from implementing the guidelines in everyday clinical practice are also important to explore. Therefore, it is necessary to provide them with an updated best practice guideline through relevant continuing professional education in order to encourage their greater understanding and commitment to better quality of care for all Indonesians with diabetes.

Chapter Summary

The role of writing a literature review in a grounded theory study continues to be debated. Undertaking a literature review using a scoping review framework was used to increase the candidate’s theoretical sensitivity and as a requirement for a higher degree research study. As the review was about the profile of healthcare professionals in diabetes care provision, the review facilitated the research by identifying potential participants in the initial purposive sampling phase. This chapter also provided a description of the models of healthcare services in Indonesia for providing diabetes care. The next chapter, Chapter Three, will provide an explanation about the study methodology. In this chapter, firstly, the candidate’s philosophical stance will be outlined. Next, the methodological framework of grounded theory is explained, including a discussion of how the candidate’s philosophical stance has influenced the implementation of grounded theory.

Chapter Three: Methodology

The aim of this chapter is to explain the study's methodology. This methodology section details the candidate's basic beliefs, the rationale of selecting a grounded theory study design and an explanation about symbolic interactionism and constructivism as the philosophical influences on the study design.

While the candidate's primary interest is to understand how people live in the world, she recognises that the research question(s) must determine the choice of the methodology. Methodology refers to the study design. A researcher's philosophical stance can also influence how they see the world and in turn, how they ask questions about the world (Corbin & Strauss, 2008). An individual's beliefs about epistemology and ontology can influence the choice of methodological approach, but the research question/s asked should be the driver for choosing the appropriate study design (Birks & Mills, 2015).

Before starting the research process, it is useful for the candidate to also understand what her views are, as well as what she believes and values. Researcher's views of the world can then influence the application of study design. This process is often referred to as identifying a philosophical position or stance. The candidate aimed to identify her philosophical position by challenging herself with methodological questions about ontology and epistemology that allowed her to explore a self-definition, understand her reality and the beliefs she holds about researcher-participant relationships and the ways of gaining knowledge (Birks & Mills, 2015). To determine the candidate's philosophical stance, three methodological questions about 'ontology', epistemology' and 'methodology' have challenged her. These terms are explained along with the explanation of how the candidate used grounded theory.

Ontology, Epistemology and Methodology Principles

Historically, qualitative research was originally used to establish a body of knowledge in the discipline of sociology and substantiate sociology as a science based academic discipline, with predictions that this type of research would also be widely used in other disciplines such as nursing. The premise is very straightforward: "the observer [researcher/inquirer] enters a foreign setting to study the customs and habits of another society and culture" (Denzin & Lincoln, 2000, p. 1). When doing a research study, a novice researcher who intends to undertake qualitative research has to select approaches that will suit their research questions or perhaps their personal purposes (Creswell, 2013) however, the questions should be primary driver of appropriate choice of methodology. The approach is what other authors call a strategy of inquiry or a research strategy, which is one phase in the research process (Denzin & Lincoln, 2000, 2005). Each discipline has various approaches for conducting a qualitative study. However, before a suitable qualitative study approach is selected, philosophical assumptions need to be understood, since these assumptions can influence a researcher's approach to conducting a study (Creswell, 2013).

Qualitative researchers are guided by basic beliefs or principles such as ontology, epistemology and methodology when undertaking their research; those beliefs will influence researchers' perception and action in their worlds (Denzin & Lincoln, 2000). A paradigm contains these principles (Denzin & Lincoln, 2000). As such, five major paradigms such as positivism, post positivism, critical theory, constructivism, and participatory inquiry, are identified as each having a distinctive ontology, epistemology and methodology (Lincoln & Guba, 2000). Ontology is the basic philosophy associated with the nature of existence and the nature of being a human, whereas epistemology is a knowledge enquiry, which explores the relationship between the researchers and the research participants (Denzin & Lincoln, 2000, 2005; Rawnsley, 1998).

The positivist paradigm has a purpose of explaining prediction and control. There is a closed relationship between positivism and empirical sciences (Crotty, 1998). Ontologically, a positivist researcher is a naïve realist that assumes a reality as actual and obvious. In positivism, knowledge is studied to find the truth by being an objectivist. Researchers will find the truth and verify the hypothesis through undertaking mainly quantitative research such as experimental studies (Guba & Lincoln, 2005).

The development of the post-positivist paradigm is as a result of scientists who see that the research products are not either completely objective or definite (Crotty, 1998). A post-positivist, also called a critical realist, studies knowledge to discover probable truth by presenting the outcomes probably as objective truth (in positivism) or interpretations (in non-positivism) (Crotty, 1998; Guba & Lincoln, 2005). Therefore, researchers that are underpinned by this paradigm employ modified experiments that may also embrace a qualitative type of research (Guba & Lincoln, 2005).

Researchers are considered as having a critical theory paradigm when they perceive the nature of truth as being virtual and influenced by certain values: social; political; cultural; economical; or those based on gender and ethnicity (Guba & Lincoln, 2005). Further Guba and Lincoln describe that these researchers subjectively study knowledge by discovering findings influenced by certain values, such as those mentioned previously. The critical theorist will employ a dialectical/dialogic method to achieve the research outcomes.

Ontologically, the constructivist paradigm admits relativism where the researchers and those who are researched co-create multiple realities (Denzin & Lincoln, 2005; Guba & Lincoln, 2005). Constructivists, through employing dialectical or hermeneutical methods, study knowledge subjectively.

The participatory inquiry paradigm perceives that human beings are part of the whole world, not indistinct. Ontologically, a reality is emerged because of the interaction and how each human's mind engages in the interaction in this world. The world is uttered subjectively and embodied objectively by the knower. The knower enunciates the world in four various approaches: "experiential, presentational, propositional and practical" (Heron & Reason, 1997, pp. 279-280). Heron & Reason further explain that the participatory paradigm supports any forms of action research that allow us and other human beings seeking knowledge by working collaboratively so that the knowledge will inform the actions required.

Why Grounded Theory?

The research aim guides the selection of a suitable research design (Mills, 2014). Given the process nature of the research questions asked in this study, a grounded theory design was deemed most suitable. This study explored the process of how people with diabetes learn about their disease and a grounded theory study design was appropriate to answer this research question. A process consists of actions and stages and the process has an objective to achieve. Throughout this study, how people with diabetes learn, their actions and interactions with their environment and with other people were explained by a theory generated from data. Researchers use grounded theory as a type of qualitative research that pays attention to people's action or interaction to build a process and from this process, a theory is formed (Creswell, 2013).

The definition of grounded theory methodology has evolved over time. Grounded theory was first introduced by Glaser and Strauss through the publication of a book titled *"The discovery of grounded theory: Strategies for qualitative research".* In this book the authors stated that they aimed to discover a theory from the data in a social research study (Glaser & Strauss, 1967). Further, they emphasised that the theory must be "understandable" to the researchers, meaning that the theory "fits the situation being researched and work[s] when put into use" (Glaser & Strauss, 1967, p. 3). Other researchers who have used grounded theory methods in the context of different methodological approaches have followed their work. Reading this book before the other seminal texts, especially for a beginner to grounded theory, is recommended so that they may know the main original tenet of grounded theory methodology. Other later seminal texts from the famous grounded theorists such as Glaser, Strauss, Corbin, Clarke and Charmaz are also recommended for researchers to read, as these books describe what influenced these later generations of grounded theorists to further develop the grounded theory methodology as they applied it in their own research (Birks & Mills, 2015).

For instance, Corbin and Strauss (2008), second generation grounded theorists, defined grounded theory as a methodology that has a purpose of building a theory resulting from the analysis of qualitative data. Similarly, Charmaz (2006) refers to grounded theory as approaches that facilitate researchers in generating and analysing data to build a theory from the data. All scholars from each generation agree that the theory in a grounded theory study is not tested, but rather is generated and grounded from the data the researchers have collected/generated themselves.

Overall, grounded theory research studies generate a theory developed from concurrent processes of data collection/generation and data analysis (Charmaz, 2006; Corbin & Strauss, 2008; Creswell, 2013). Grounded theory is a strong choice to meet the aim of the study as there is little evidence about the topic of interest and thus deeper understanding and knowledge about the basic social process occurring in these situations is required (Mills et al., 2014). The knowledge base of the process of how people receive and engage in health education and how they learn about their disease is limited in the Indonesian context. The decision to use grounded theory as a study methodology was also influenced by this limited information about these people's learning processes. After reading the seminal texts, the candidate discovered what philosophical stance she felt resonated with her worldview, and how that stance was going to influence how she employed the grounded theory methods.

Philosophical Positions of the Candidate and their Influences on the Study

Researchers will effectively employ appropriate research designs that reflect their own viewpoints about reality and the research methodology adopted that best enables them to answer the research question/s posed (Birks, 2014). Therefore, it is appropriate for qualitative researchers to clearly explain their ontological and epistemological orientation (Madill, Jordan, & Shirley, 2000) prior to embarking on the process of data generation and analysis. Before proceeding to data collection and generation, the candidate defined her ontology and epistemology by answering the questions about how she views reality as a human being and her relationship in the research process.

A researcher's belief about ontology will describe their definition of being human and what they perceive as the nature of reality (Denzin & Lincoln, 2000, 2005). In this present study, the candidate's ontological assumptions are that there are multiple realities. She also accepts that individuals are influenced by their past and present experiences and the way in which they view their world. She sees reflection as being important to human's lives. We exist, act and need other people; therefore interactions among us are essential to being in the world.

Whereas ontology describes what reality is, epistemology refers to how the researchers gain knowledge about that reality (Denzin & Lincoln, 2000). Regarding this candidate's position about epistemology, she believes that she gains knowledge through her relationship with her participants, not outside of it. The candidate believes that she cannot be distant from the participants, but must engage with them. Therefore, she needs to make contact with the participants and spend time with them, in order to obtain knowledge about the phenomenon of interest.

After reflecting on how the candidate sees truth and defines the nature of reality, as well as what she believes about how people obtain their knowledge, the philosophical and methodological position was determined to be the most closely aligned with symbolic interactionism and constructivism. Once she understood her philosophical stance, she recognised that constructivism and symbolic interactionism were central concepts that informed her world-view. These ontological assumptions are compatible with relativism and symbolic interactionism.

Methodologically, the use of constructivist grounded theory underpinned by symbolic interactionism has been popular among nurse researchers since this design allows them to understand participants' attitudes and experiences as well as explore a process used in providing healthcare (Higginbottom & Lauridsen, 2014). This study employed a set of principles common to both constructivist grounded theory and evolved grounded theory. Several grounded theorists may use different grounded theory approaches because of the divergence of their philosophical stances (Charmaz, 2009). Nevertheless, grounded theorists with different epistemological stances have successfully employed grounded theory methods in order to obtain substantial research outcomes (Urquhart & Fernández, 2013). This flexible use of grounded theory methods is advocated by most researchers (Charmaz, 2009). Yet, Urquhart and Fernández advise researchers to use knowledgably the opportunity allowed by this flexibility, by knowing well the original tenets of grounded theory (Glaser & Strauss, 1967), having a well-defined study aim, and being aware of the alignment of the researchers' standpoint, skills, and methods of data collection and generation. A researcher, especially one who is new to employing grounded theory methods, will understand grounded theory if they are aware of their philosophical beliefs and the relevant paradigm of enquiry where grounded theory belongs (Annells, 1996).

The responses to ontological and epistemological questions therefore guide the candidate's methodological position (Annells, 1996). There are many examples of recent researchers employing grounded theory methodology who have stated their ontological and epistemological stances to delineate the concepts that will drive the research process (Chamberlain-Salaun, Mills, & Usher, 2013; Corbin & Strauss, 2008; Redman-MacLaren & Mills, 2015). Denzin and Lincoln (2005, p. 22) designate a paradigm as "a net" that consists of a researcher's assumptions about ontology, epistemology and methodology. Therefore, by indicating their research paradigm, the researchers may appropriately position themselves ontologically, epistemologically and methodologically (Mills, 2014). The candidate's paradigms regarding relativism, subjectivism, constructivism, and symbolic interactionism are explicated further in this section.

Relativism.

Relativism accepts multiple realities, which are constructed locally and distinctively (Annells, 1996; Corbin & Strauss, 2008). Relativist researchers seek to gather knowledge about multiple realities and human experiences from many subjective viewpoints (Levers, 2013). Relativism has underpinned Strauss and Corbin's works since the 1990s. Strauss's works were originally influenced by Blumer (Charmaz, 2014). Symbolic interactionism is also an ontological assumption that has featured in Strauss and Corbin's version of grounded theory (Clarke, 2005). Symbolic interactionism is one approach to studying peoples' lives and behaviour (Blumer, 1969). Charmaz explains that symbolic interactionists perceive that individual actions can influence interpretations and vice versa. For symbolic interactionists, language and symbols are an essential part of making meaning and creating actions.

Assumptions made by Corbin and Strauss about self, perspectives, meaning, action and interaction have been highlighted by Chamberlain-Salaun et al. (2013) as being strongly linked to essential grounded theory methods (Birks & Mills, 2015). Therefore, this study employed Strauss and Corbin's (2008) version of evolved grounded theory that relies on symbolic interactionism.

Subjectivism.

Questions regarding epistemology depend on a researcher's response to the question of ontology (Annells, 1996). Epistemologically researchers need to explain their relationship with research participants (Denzin & Lincoln, 2000, 2005) and how they understand what the research participants both do and say (Schwandt, 2000). In this present study, the candidate values that building trust with participants during the research process is crucial. Therefore, the researchers and those they research should never be distant (Charmaz, 2009). Nor should the researchers be isolated from the research methods (Strauss, 1987). These principles have allowed the candidate in this present study to visit and meet with the participants in the research field. Epistemologically therefore, "[t]he knower is subjectively and interactively linked in relationship to what can be known" (Annells, 1996, p. 385). Annells (1996) states that these assumptions are congruent with subjectivism, which assumes that the knower and the known together create meaning. Therefore, both the candidate and her participants in the study created the participants' meanings. Annells argues the process of dialectical transaction enables the research to create knowledge by interpreting the meaning of these data, particularly when there are multiple variations in these data. Relativism, subjectivism and dialectical methods are all part of a symbolic interactionist and constructivist paradigm (Annells, 1996).

Constructivism.

Constructivists believe that people will actively construct and create knowledge during the research process (Lincoln & Guba, 2000). People can create reality because they experience it thus, researchers can explore the process of creation in a research study (Birks, 2014). As this research adopted symbolic interactionism and constructivism in the use of grounded theory methods, the candidate entered the research site with her own history and background, which requires analysis during the research process (Mills, 2014). Constructivist researchers aim to explore the process of how research participants create their reality, in this case, "meanings and actions" from their own experiences, while accounting for the researcher's own influence on the process of reconstruction through analysis (Charmaz & Belgrave, 2012, p. 348). With these principles, the research in this present study explored the process of how Indonesian people living with diabetes learn about their disease. The reality of participants' meaning and actions was created based on the study participants' experiences of receiving diabetes related information and engaging in health education as well as living with diabetes for the purpose of self-managing their diabetes.

People live in a real world and they see the world from various views. Different research participants have diverse views and so do researchers. The researchers' views may contradict with those of participants'. Researchers are part of the world they study and part of the data they collect (Charmaz, 2006). In the constructivist paradigm, researchers cannot be separated from the participants during data generation/collection; rather, researchers attempt to approach the participants by entering the field and collecting the real data as empirically as possible, in order to ascertain the participants' meanings and activities. For constructivist researchers, being involved in their own past and present situations and having interactions with society, the researchers' viewpoints and research process will also contribute to constructing a grounded theory. In this world, both the participants and researchers perform actions, make interpretations and are influenced by conditions and other people. However, these attributions may be implicit. Thus, the reality is co-constructed through developing participants' tacit meanings and perceived views, which result in the researchers' developing a grounded theory (Charmaz, 2006). Knowledge in a constructivist's philosophical belief system is created through dealing with factual data (Charmaz, 2009).

Charmaz (2006) argues that in a constructivist grounded theory study, reality is constructed through participants' meanings and views. Further, Charmaz points out that the researchers, through interacting with the individual participants, in fact, co-construct this meaning during the process of concurrent data collection and analysis. Charmaz highlights that the researcher is the final author reconstructing participants' experiences and the meaning of these experiences from the generated data set. Therefore, an understanding of the philosophical position of constructivist thinking has increased the candidate's awareness of how she located herself as a researcher in relation to the participants, how the candidate's relationship with participants affected the generation and analysis of data, the integrity of her data set, and eventually how she presented the study findings (Mills et al., 2014). A constructivist grounded theorist is highly unlikely to be separated from the research participants during data collection and thus, a relationship of trust and reciprocity between participant and candidate should be established (Charmaz, 2009).

Participants' meanings and actions analysed by the researchers are determined from rich data. Rich data consists of thorough and complete details of participants' standpoints, feelings and actions and is obtained from various grounded theory methods of data collection/generation (Charmaz, 2006). Therefore the constructivist researcher will make the actions, interpretations and influences more obvious by conducting a thorough analysis (Charmaz, 2009).

A grounded theory study uses a qualitative approach where the process of collecting and analysing the data occurs concurrently, to subsequently produce a theory grounded from the data (Charmaz, 2013). Grounded theory influenced by constructivism believes that people's actions, both the participants' and the researchers', have important roles, as both of their actions can create new phenomenon. Charmaz emphasises that constructivists who play an influential and active role in the generation of data admit that the actions of both the researcher and the participants are also influenced by history, society and circumstances. She suggests that researchers in grounded theory should not only study the data but also interact with and become involved in the data. Researchers are also encouraged to follow the iterative process concurrently in data collection and analysis to help advance their emerging analysis. Consequently, this process will help researchers to increase their level of abstraction in analytical thinking. Charmaz then highlights the importance of being involved with the data by abductive reasoning because this reasoning will assist to construct the theory. Abductive reasoning is used when the data show an unanticipated finding during the process of collecting data. "Abductive inference entails considering all possible theoretical explanations for the data, forming a hypothesis for each possible explanation, checking them empirically by examining data, and pursuing the most plausible explanation" (Charmaz, 2006, p. 103-104).

Charmaz (2009) asserts that since constructivism grounded theory is influenced by Glaser's and Strauss' first version (1967) as well as by Strauss' later version (1987) of grounded theory, constructivist researchers embrace the principles of inductive reasoning, comparative method, emergent approach and open-ended questions during their interviews, as well as using abductive reasoning in constructing their grounded theory. These principles also influenced the candidate to ensure that essential grounded theory methods that supported a constructivist stance were used.

With constructivism, the candidate accepts the principle that participants and the researcher construct a shared reality. Constructivism also emphasises that the establishment of a relationship involves reciprocity between the researcher and the participants. Constructivism has influenced how the candidate collected and generated her data by using the grounded theory design. Analysing these data in this grounded theory study was also influenced by the principle that the candidate together with her participants co-created the knowledge though participants' meaning and views.

Symbolic Interactionism

Symbolic interactionism has been labelled as an approach to study people's life and behaviour (Blumer, 1969). Among the remarkable scholars, was George Hebert Mead (1984) who employed this approach and contributed significant knowledge. From Mead, Blumer (1969) developed his own style by considering and emphasising several core aspects implicitly stated by Mead. These core aspects are the self, the act, social interaction, objects and joint action. How the candidate in this study used symbolic interactionism is explicated further to link the principles of this lens with the application of grounded theory study design.

Three important premises proffered by Blumer (1969) have guided the candidate in undertaking this study. The three basic premises have explained the nature of a symbolic interactionism approach. These three premises were (Blumer, 1969, p. 2):

1. Human beings act toward things on the basis of the meanings that the things have for them.
2. The meaning of such things is derived from, or arises out of, the social interaction that one has with others.
3. These meanings are handled in and modified through, an interpretative process used by the person in dealing with the things they encounter.

The first premise states that people act based on what the symbol or object means to them. These symbols include material entities, other individuals, types of people, organisations, standards, people's acts and daily life circumstances (Blumer, 1969). For a symbolic interactionist, "... the meaning that things [symbols] have for a human being is central in their own right" (Blumer, 1969, p. 3). Ignoring the meanings indicates the researcher is misrepresenting the research participants' behaviour toward the symbols. Moreover, if the researcher treats human behaviour as the product of various factors, they will neglect the role that the meaning plays in shaping the person's behaviour (Blumer, 1969).

Significant differences between symbolic interactionism and other methods are emphasized by Blumer (1969) in the second and third premises. According to the second premise, a symbolic interactionist perceives that when people are involved in an interaction and the interaction is defined, they create meaning. A symbol's meaning is defined through the operation of both people's actions toward the symbol. The meaning of a thing or a symbol emerges from a process that involves human interaction. Thus, the definition of a symbol for the person is derived from their actions toward that symbol. Therefore meanings are perceived as "social products" that are created through the activities defined as people interact with each other (Blumer, 1969, p. 5).

Furthermore, the third premise, Blumer (1969) highlights that human beings are engaged in an interpretative process to deal with the matter they encounter. This process of interpretation involves internal processes where the person communicates with himself or herself. Moreover, the process also allows the person to handle the meanings according to their circumstances and actions. The meanings are handled through choosing, verifying, deferring, rearranging and modifying the meanings. This interpretation does not occur automatically, but rather is performed through a process, "a formative process", so that the meanings can be employed as tools to guide and to form peoples' action (Blumer, 1969, p. 5). These three premises have clearly influenced how the pattern of a human being's life and behaviour are analysed.

A symbolic interactionist perceives a human being's life and behaviour through the symbol of six principle ideas called "root images" (Blumer, 1969, p. 6). Researchers who use the approach of symbolic interactionism will consequently establish the research framework and analysis from these root images. These root images are described as the essence of "human groups/societies, social interaction, objects, the human being as an actor, human action, and the interconnection of the lines of action" (Blummer 1969, p. 6). Blumer points out that the validity of the three premises must be tested by having direct examination of the human being's life instead of doing laboratory work or testing a hypothesis. This point has been further emphasised by Blumer about four essential methodological consequences of symbolic interactionism: human beings, human beings' relationships, social actions and dynamic complex actions. Human beings act; based on how they see things defined by themselves, not by others (i.e. researchers). Thus, when the candidate intends to understand human beings' actions, the candidate needs to see the meanings of the objects from the human beings' point of view. People, who live in a group with other people, when they meet in various circumstances, their actions are notified or acknowledged by other people and they also make an interpretation of the acknowledgements made by those other people. Symbolic interactionism also perceives that social actions are the collection of activities involving an individual and people in the process of social interaction. The activities then continue to become a social life of a small or larger group of people. In order to learn about social actions through analytical processes, the candidate needs to learn how the process is formed. Symbolic interactionism views the complexity of human beings' through the formation of societal organisations such as institutions. These complex aspects are also viewed as a dynamic interlinkage of people and their actions (Blumer, 1969).

Symbolic interactionism is an approach that studies people's life and behaviour in natural ways. The way the problems emerges, the way the research is carried out and the ways data are interpreted are all naturalistic approaches (Blumer, 1969). Therefore, in order to study how people with diabetes receive and engage in education that promotes well-being, the candidate will visit and meet the actual people with diabetes to explore and analyse the process of education provided to them. This kind of direct examination is also the feature of a symbolic interactionism approach to guide the research processes. According to Blumer, the importance of employing an approach of symbolic interactionism is to acknowledge and explore "the nature of its empirical world" directly, thoroughly and analytically (p.48). Blumer further explains that instead of doing an approach by a simulation of the world, actual life analysed through interviews can lead to the emerging of research problems, the guidance of concepts, the methods of research quests and the development of the theoretical patterns.

Charon's (2007) introduction on symbolic interactionism provides us with some core insights about symbolic interactionism. These insights are known as five "central ideas" (Charon, 2007, p. 29-30):

1. The human being must be understood as a social person. It is ongoing constant lifelong social interaction that leads us to do what we do.
2. The human being must be understood as a thinking being

3. Humans do not sense their environment directly; instead, humans define the situation they are in.
4. The cause of human action is the result of what is occurring in our present situation
5. Human beings are described as active beings in relation to their environment

Symbolic interactionism does not emphasise types of human beings or how their conduct is affected by certain conditions. Rather, it focuses on social interaction that occurs among human beings. When performing actions, human beings employ their thinking (Charon, 2007). The lens of symbolic interactionism, with its emphasis on the involvement of individuals' thinking, has helped the candidate in this study to understand the reasons why participants interacted with each other within the study phenomena. The interaction and the participants' thinking about that interaction, both influence how they defined the situation. Within each social interaction, the participants' thoughts and definitions of the interaction affected how they acted in that situation. During the candidate's interview with the participants, their thoughts influenced their decisions about what to say in response to the candidate's questions, and how to act during the interview. The role of participants' past experiences or events provided important insights as the candidate interpreted these data. Actions of participants were actively formed. These actions were not shaped as participants' responses to their situation. All participants' actions were organised based on what they thought, how they interacted with others and how they defined the situation they were involved in (Charon, 2007).

Briefly, the candidate perceives that symbolic interactionism views a human being by considering that a human being has a social interaction, is a thinking person, has a definition about their environment, is influenced by a present circumstance and is active in their worlds (Charon, 2007). These five ideas were linked to each other to help the candidate to use the lens of symbolic interactionism to clearly understand human beings and their actions. In addition, as symbolic interactionism influenced the conduct of this grounded theory study, the candidate embedded the principles of 'one's self, action and interaction and meaning' when undertaking the research study such as when collecting and analysing these data.

Symbolic interactionism was featured in this study. Symbolic interactionism is a philosophical position and a sociological theory. The candidate considered this stance to be a strong influence on this study. People learning about their diabetes, as the phenomena being studied, involves the interaction between people with diabetes and HCPs, or other people surrounding them. Thus, with a symbolic interactionism view, participants' meaning about how they learn about their diabetes was explored. Eventually, the process embedded in a robust theory explicated it. Moreover, Charon (2007, p. 42) highlighted that in symbolic interactionism, "we do not simply respond to our environment, but we define, act toward it and use it". Charon (2007) adds that their dynamic perspectives towards the environment influence human actions, where they interact with themselves and others. In relation to how people learn about their disease, symbolic interactionism examines how people define, act and use information they have learnt about their disease.

Chapter Summary

This chapter provided an explanation about the candidate's philosophical position. The candidate chose grounded theory methodology as the research design based on the research question posed. Constructivism and symbolic interactionism influenced the implementation of grounded theory methodology. The following chapter, Chapter Four, addresses the methods of data collection in this study. Three papers are included in this chapter. The papers discuss aspects of the candidate's approach in undertaking essential grounded theory methods during the research process. The papers outline the use of the theoretical sampling method, of concept mapping and of storyline.

Chapter Four: Methods

Throughout this chapter, the candidate explains how grounded theory methods were used. This methods chapter details the implementation of the study using 'essential' grounded theory methods including the sampling methods, how the data was gathered as well as analysed, and ethical considerations. The explanation of the bilingual use of the study process finalises this chapter.

Essential Methods of Grounded Theory

Maintaining the quality of research is essential to achieving credibility in performing a grounded theory study. The candidate rigorously followed these main strategies when conducting this grounded theory study. The candidate demonstrated the ability to conduct a research study based on skills, prior knowledge and experience. Rigour in this study was maintained by showing a congruence of a philosophical position, research aim and grounded theory method. In addition, the candidate followed the procedure of grounded theory methods precisely. Appropriately employing the essential methods of grounded theory is another strategy to maintain study rigour (Birks & Mills, 2015). These essential grounded theory methods used included a purposive sampling method, a theoretical sampling method, concurrent data collection/generation and analysis, constant comparative analysis, coding process, theoretical sensitivity, field notes, memo writing and theoretical saturation.

Sampling Methods

Purposive and theoretical sampling.

Selecting participants through a thoughtful sampling method assisted the candidate in gaining remarkable data (Morse, 2007). Two sampling strategies were generated in this study, purposive sampling and theoretical sampling. Purposive sampling method refers to an approach to target potential participants that are believed to provide information that can reinforce the exploration of the phenomenon being studied (Creswell, 2013). Initially, seven participants were selected by using purposive sampling methods. Inclusion and exclusion criteria were applied. To obtain further participants, then the candidate applied theoretical sampling method. Theoretical sampling method is an approach to select data based on the candidate's analysis of data collection. Adopting a theoretical sampling method allowed the candidate to identify further options for collecting more data. The candidate carefully refined initial categories through obtaining additional pertinent data as the theory emerged (Dey, 2007). Theoretical sampling is used to explain and refine categories by building properties of the categories, rather than randomly selecting populations or their representative distributions, as is done in quantitative designs (Breckenridge & Jones, 2009; Bryant & Charmaz, 2007).

The practical use of a theoretical sampling method in this present study was explained in a paper submitted to *International Journal of Nursing Practice* entitled “Practical Guide for Employing Theoretical Sampling”. The paper details a discussion on how theoretical sampling was used for the selection of further data during the three phases of the study.

Table 4.1: *Declaration of Authorship*

Chapter Number	**Publication**	**Nature and extent of the intellectual input of each author including the candidate**	**Signature**
4	Ligita, T., Harvey, N., Wicking, K., Nurjannah, I., & Francis, K. A Practical Guide for Employing Theoretical Sampling. International Journal of Nursing Practice.	Conception and design of the paper, data collection, data analysis and interpretation, Primary responsibility for writing the paper (85%), corresponding author responsible for preparing the final paper for submission, approval for publication version.	Ligita, Titan Content has been removed for privacy reasons
		Supervision of and contribution to the conception and design of the paper, data analysis and interpretation, writing the paper (15%), critical revisions for important intellectual content, approval for publication version	Harvey, Nichole Content has been removed for privacy reasons
		Supervision of and contribution to the conception and design of the paper, data analysis and interpretation, critical revisions for important intellectual content, approval for publication version	Wicking, Kristin Content has been removed for privacy reasons
		Supervision of and contribution to the conception and design of the paper, data analysis and interpretation, critical revisions for important intellectual content, approval for publication version	Nurjannah, Intansari Content has been removed for privacy reasons
		Supervision of and contribution to the conception and design of the paper, data analysis and interpretation, critical revisions for important intellectual content, approval for publication version	Francis, Karen Content has been removed for privacy reasons

The practical use of the theoretical sampling method has not been extensively discussed by studies employing grounded theory methodology as a research design. Therefore, the preceding article was expected to contribute as a guideline for researchers, especially those who are new to grounded theory. The manuscript provides details of grounded theory method in theoretical sampling. This paper will be useful for other researchers wanting to understand how to apply grounded theory method.

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A Practical Guide for Employing Theoretical Sampling

Journal:	*International Journal of Nursing Practice*
Manuscript ID	Draft
Manuscript Type:	Discussion paper
Key Words:	Data selection, Diabetes, Grounded theory, Qualitative research methods, Theoretical sampling

A Practical Guide for Employing Theoretical Sampling

Abstract

Aim: A discussion of the practical use of theoretical sampling as a method for selecting data that provides a richer and deeper understanding of the phenomenon being investigated.

Background: Theoretical sampling is a well-known method in grounded theory studies to select data based on concepts developed from initial data analysis. This method involves following where the data has led to expand and refine evolving theory during the analytical process. There is however a dearth of information detailing how to undertake theoretical sampling.

Design: ‘Methodology Discussion paper’

Data Sources: Data was collected between April 2016 and July 2017 (16 month period).

Implications for Nursing: When considering using a theoretical sampling method it is essential to consider potential strategies in countering challenges during the application of theoretical sampling in nursing research. Practical recommendations are offered on the use of theoretical sampling during data analysis, for the purpose of building theoretical integration.

Conclusion: Theoretical sampling is a valuable and practical method of recruiting further participants, choosing additional settings, selecting materials and in refining and modifying interview questions, for the purpose of addressing gaps in the data.

SUMMARY STATEMENT

What is already known about this topic?

- Theoretical sampling is a method used to select additional data based on analysis of existing data.
- The use of theoretical sampling is not consistent in grounded theory research

- The process of how to implement theoretical sampling is often invisible in research publications

What this paper adds

- An in-depth description of theoretical sampling as a method for selecting further data using a grounded theory study as an example.
- A practical step by step guideline for nurse researchers who are considering employing theoretical sampling.

The implications of this paper

- Considerations identified during the use of theoretical sampling can increase researchers' awareness when doing grounded theory studies
- Strategies described can be used to surmount the challenges that can be experienced when using theoretical sampling
- A practical, feasible and useful guide for researchers worldwide on how to employ a theoretical sampling method in their own research.

Keywords: grounded theory; data selection; qualitative research methods; theoretical sampling.

1. INTRODUCTION

Theoretical sampling is an essential feature in a grounded theory study, but there is little practical direction on how to implement this method effectively (Ennis et al., 2015; Neill, 2012; Slatyer et al., 2015). McCrae and Purssell (2016) found that the use of theoretical sampling is not consistent in grounded theory research and the process of how to implement theoretical sampling is often invisible in research publications. The authors advocate that it should be used, however warn that novice researchers can be misled if the process has not been adequately explained or implemented by the researchers. Inappropriately using theoretical sampling may lead researchers to collect 'unnecessary and conceptually thin data' (Charmaz, 2014, p. 198). This paper provides an in-depth description of the application of theoretical sampling, as a method for collecting data, using the authors' grounded theory study as an exemplar. Although the study was conducted in Indonesia, the paper would be of benefit to all international researchers using or wishing to use theoretical sampling.

2. WHAT IS THEORETICAL SAMPLING AND WHY IS IT IMPORTANT?

Identifying what data to collect can be a challenge for researchers undertaking grounded theory studies. Corbin and Strauss (2008) emphasise that additional data to be collected is based on the analysis of previous data. As data is analysed questions arise and potential gaps in the data and/or the evolving grounded theory are identified. Theoretical sampling can help address these gaps and expand upon emerging concepts (Charmaz, 2014). During the process of data collection, the emerging theory guides the process of theoretical sampling by directing the researcher where to look and/or who to ask questions of, to obtain further information (Glaser & Strauss, 1967).

Using theoretical sampling means the researcher is being responsive to the data and is therefore flexible to explore the depth of the concepts derived from the data and then decide what concepts will be sought next (Corbin & Strauss, 2008). During the process of data analysis, theoretical sensitivity, or ‘insight into data’, evolves (Corbin & Strauss, 2008, p. 41). Being theoretically sensitive, the researcher is aware of, and able to show how the concepts are grounded in the data and are relevant to the evolving theory. Thus the researcher can triage if the concepts are important or not (Birks & Mills, 2015).

Theoretical sampling facilitates the delineation of a category that has properties, dimensions, variations and relationships (Corbin & Strauss, 2008). All collected data are subjected to constant comparative analysis until saturation is achieved (Glaser, 1978) or when new codes are developed that do not contribute to an already established category (Birks & Mills, 2015). Constantly comparing the conceptual level of data during the analysis guides theoretical sampling because it allows the researchers to raise questions and thus directs the ongoing data collection. The new data generated provides a richer and deeper understanding of the phenomenon, by comparing incident to incident to establish similarities and differences (Birks & Mills, 2015).

Theoretical sampling helps to illuminate and make clear the variations, properties, dimensions and relationships between codes and categories for the purpose of developing a credible and authentic theory. A general rule that grounded theory researchers apply to test the efficacy of categories derived from the data is to implement theoretical sampling. “…[C]onducting theoretical sampling depends on having already identified a category” and theoretical sampling allows us to refine our theoretical categories (Charmaz, 2014, p. 199). The researcher continues to seek further data driven by theoretical sampling, until all concepts are well defined and explained, categories are saturated and a theory explicated (Corbin & Strauss, 2008).

3. DISCUSSION

3.1 Overview of the research study

This grounded theory study generated a theory about the process of providing health education for people living with diabetes mellitus in Indonesia. With the philosophical stances of symbolic interactionism and constructivism, a grounded theory methodology was used to answer the research question: How do people living with diabetes mellitus in Indonesia receive and engage in education that promotes health and wellbeing? The study was conducted in West Kalimantan, Indonesia and received ethics approval from James Cook University, Australia and Universitas, Indonesia.

Figure 1, which has been informed by Birks and Mills (2015) and Charmaz (2014), provides a diagrammatic representation of the research study design. There were three phases conducted over 16 months. During this time a total of 26 participants were interviewed across seven settings. The initial phase involved recruitment of seven participants using purposive sampling. Once data collection and analysis commenced, theoretical sampling was employed as the method for further recruitment of participants, as illustrated in Figure 1.

PLEASE INSERT FIGURE 1 HERE

The theory identified by this research study was entitled ‘Exploring diabetes care’. The theory consists of five major categories that explain how people in Indonesia learn about their disease and how they are provided with diabetes related health education. The categories are: seeking advice and explanation; processing received information; responding to recommendations; appraising the result; and sharing with others.

3.2 How was theoretical sampling useful in this study?

Theoretical sampling helped to direct data collection in three main ways: (1) in identifying additional participants to be interviewed; (2) in identifying what settings to visit to recruit further participants; and (3) in refining the interview questions. Following the first phase of data collection and analysis, a number of additional groups of participants and settings were identified to be interviewed.

Additional participants included: families of people with diabetes; other types of healthcare professionals, such as nursing students; and healthcare providers, such as an exercise instructor and *kader* (lay health worker). Lastly, people with diabetes who had varying characteristics, such as complications associated with their diabetes (i.e. foot ulcers), along with their family members were also selected to be interviewed. The additional information obtained helped achieve data saturation and theoretical integration.

During the constant comparative analysis of data, theoretical sampling guided decisions such as interviewing people with diabetes based on where they lived or received care. For example, participants were recruited from both rural and urban geographical areas and also from different healthcare facilities: outpatient settings, public health centres, inpatient hospital settings, private wound care clinic and nursing educational institutions.

Finally, theoretical sampling helped with modifying and refining the interview questions and interviewing style that was adopted for forthcoming interviews (Glaser, 1978). The researchers were cognisant of Corbin and Strauss (Corbin & Strauss, 2008, 2015) who explained, what has been found from previous analysis should drive the questions for future interviews. Ongoing modification of interview questions occurred from the analysis of the very first interview, as well as during the analysis of all interviews throughout the research study.

3.3 Examples of how theoretical sampling was used in this study

Three examples will be shared, although there were many to choose from, to illustrate how the authors employed theoretical sampling in their research study. The first example describes how after analysing one of the interviews, the principal researcher identified a gap in the data pertaining to a particular type of person that needed to be interviewed; this ‘type’ of person was not included in phase one of the study, when purposive sampling was used. Charmaz (2014, p. 197) claims that "initial sampling in grounded theory gets you started but theoretical sampling guides where you go". Data from an interview and a memo written after the interview, will be used to illustrate how theoretical sampling helped fill this gap.

The following quote is from Betty (pseudonym), who has been living with diabetes for 14 years. When she was sitting in the clinic's waiting room, another person started telling her about complications that could happen because of diabetes. Betty then started asking others if they had any complications.

> *I get this sweet urine disease [diabetes]. "Sweet urine disease will impact to anywhere", he said… can have wound [ulcer], can go kidney disease, can be the liver, having a large stomach. It can impact the knees and can result in rheumatics.* (Betty: G1P4)

Being responsive to the data made the researchers realise, that out of all of the people interviewed so far in their study, not one of them had any known complications from their diabetes. This was a gap in the data. People living with diabetes that had developed complications could add valuable insight into how they engaged in education to promote their health and wellbeing. Questions were raised, such as were there specific resources available that helped people with complications and if so, what were they and how did people access them? Theoretical sampling made it apparent that people living with diabetes, who had developed complications, such as foot ulcers, eye sight problems or kidney disease, needed to be interviewed. Below is the memo written by the principal researcher after Betty's interview.

> *A person with diabetes can learn from others such as fellows or friends. While waiting in the waiting room, the patient actively asked other fellow patients sitting beside her. She looked at what happened to the others. She also asked what*

> *happened to them. They told her what happened. Here, she learned the complications of diabetes such as ulcers and kidney disease. She was also told by her fellow patients that diabetes is not curable (the prognosis). The patient learned about complications from other patients who already had complications. Does it worry her? Yes or no? How powerful was the proximity of patients with the complications for making them become aware or perhaps worry about their disease? Does it make them change their behaviour and act toward promoting health and wellbeing? This person has no complication related to diabetes such as a diabetic foot ulcer. I think a person with diabetes complication needs to be sought and interviewed.* (Principal Researcher, Memo #49)

The second example describes how the researchers identified further settings (and further participants) to include in their study. In the original phase of the study, where purposive sampling was employed, the following health professionals were interviewed: a nurse academic; clinical nurses; pharmacist; dietician and a specialist doctor. The two nurses that were interviewed in phase one of the study, both worked in public outpatient clinics. It came to light during the interview with the pharmacist that people with diabetes, who were admitted to hospital, were receiving education about their diabetes while in hospital.

> *Both my colleague and I provide education for patients in inpatient care. In this room here, we provide education and information about medicines to patients…and provide counselling if the patients ask for counselling. We provide counselling in inpatient care in the patient's room. The room is more private. When the patients plan their discharge, the pharmacist assistant will call the pharmacist to provide education.* (Cahyo: G1P6)

Therefore, in phase two of the study nurses were selected from inpatient hospital settings and also a private wound care clinic. This was to address the gap in the data as to what type of education was being provided by nurses in acute care facilities, such as a hospital, and whether there was a difference in the education being provided between the different healthcare facilities. The following memo was written by the principal researcher in response to the above excerpt from the pharmacist.

> *According to this clinician (the pharmacist), health education is provided to people in inpatient and outpatient settings. He said people discharging from the hospital are given health education. I have not interviewed people with diabetes who are hospitalised. I think they need to be asked about the health education they had. It is also important to interview a nurse clinician who takes care of hospitalised people with diabetes. Is there any differences or similarities in the education provided in outpatient and inpatient settings? What information do they usually deliver to these people? What questions do people with diabetes usually ask the nurse related to their disease?* (Principal Researcher, Memo #40)

The final example is in relation to how theoretical sampling was used to refine the interview questions. Interview questions were modified, refined, expanded and improved upon following the analysis of each interview. Following the analysis of an interview with a nurse academic, where they shared their experiences of providing health education to people living with diabetes, a gap in the data was identified. The gap was pertaining to how people who were recipients of diabetic health education were responding to the information – for example, did they use the information to make changes in their lives. Also a gap in the data existed about what materials or educational aids worked best to assist people with diabetes to understand their disease. Theoretical sampling helped to improve the initial question, which asked *'Could you explain your experiences in providing health education for people living with diabetes?'* to include two follow- up questions, which were: '*How do you think people with diabetes respond after you provide information to them?*'; and '*Could you tell me about what health education materials you use to help people understand their diabetes?*'

4. IMPLICATIONS FOR NURSING

Theoretical sampling increased the authors' awareness in this study, by allowing them to specifically select additional participants or materials that provided them with more information to better understand the phenomenon they were researching. This deeper and more accurate understanding of the process, was then translated into a theory that explicates how people with diabetes in Indonesia learn about their disease, therefore providing the authors with an opportunity to make recommendations aimed at improving this process. However, theoretical sampling is not without its challenges. Two such challenges the authors faced were gaining access to this new data and having to obtain relevant ethical approval with each new phase, as new participants and settings were identified.

An example of having to gain access to new data came in the form of recruiting family members of people living with diabetes, to be interviewed. Theoretical sampling identified that family members played an important part in educating their loved ones who had diabetes. However, recruiting family members from which to generate this further data proved challenging. One strategy the authors implemented was asking previous and existing participants as well as key stakeholders if they knew of any family members that would be willing to be interviewed. This sampling method is commonly known as snowball sampling (Marshall, 1996). Sadler et al. (2010) and Faugier and Sargeant (1997, pp. 792-793) regard using social networks and the snowball method of sampling to find 'hidden' or 'hard-to find' participants, as an effective method to help with further recruitment. Therefore, our strategy in overcoming this challenge was to use snowball sampling.

The other significant challenge was having to obtain ethical approval with the different phases of the research. Grounded theory studies are inductive (Birks & Mills, 2015), which means that the initial planning of the study may not cover all contingencies. It is important to state this in the initial ethics application. As the study evolved, it was necessary to submit amendments to the original ethics application to both University Human Research Ethics Committees, to cover further data collection, such as involving additional types of participants and additional sites. Two amendments were submitted; one for the second data generation phase and another for the third phase of data generation. The second and third phases of data generation did not commence until after each of the ethics amendments were approved. These additional steps need to be considered when creating project timelines and planning field trips.

5. CONCLUSION

Theoretical sampling is a distinctive feature of grounded theory studies. This paper has provided some practical examples on how theoretical sampling was used in the authors' study to gain a better and deeper understanding of the topic area being researched. The paper can be a guideline for both higher degree students and their supervisors when selecting grounded theory as the research design to help them in further data selection. Also, the explanation of applying theoretical sampling in this paper is practical, feasible and useful in facilitating other researchers globally, including nurse researchers, to effectively conduct a grounded theory study.

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REFERENCES

Birks, M., & Mills, J. (2015). *Grounded theory: a practical guide*. Thousand Oaks, CA: SAGE.

Charmaz, K. (2014). *Constructing grounded theory* (2nd ed.). London: SAGE.

Corbin, J. M., & Strauss, A. L. (2008). *Basics of qualitative research: techniques and procedures for developing grounded theory*. Los Angeles: Sage Publications, Inc.

Corbin, J. M., & Strauss, A. L. (2015). *Basics of qualitative research: Techniques and procedures for developing grounded theory* (Fourth ed.). Los Angeles: SAGE.

Ennis, G., Happell, B., & Reid-Searl, K. (2015). Enabling professional development in mental health nursing: the role of clinical leadership: Clinical leadership in mental health nursing. *Journal of Psychiatric and Mental Health Nursing, 22*(8), 616-622. doi: 10.1111/jpm.12221

Faugier, J., & Sargeant, M. (1997). Sampling hard to reach populations. *Journal of Advanced Nursing, 26*(4), 790-797. doi: 10.1046/j.1365-2648.1997.00371.x

Glaser, B. G. (1978). *Theoretical sensitivity: advances in the methodology of grounded theory*. Mill Valley, CA: Sociology Press.

Glaser, B. G., & Strauss, A. L. (1967). *The discovery of grounded theory: strategies for qualitative research*. Hawthorne, NY: Aldine de Gruyter.

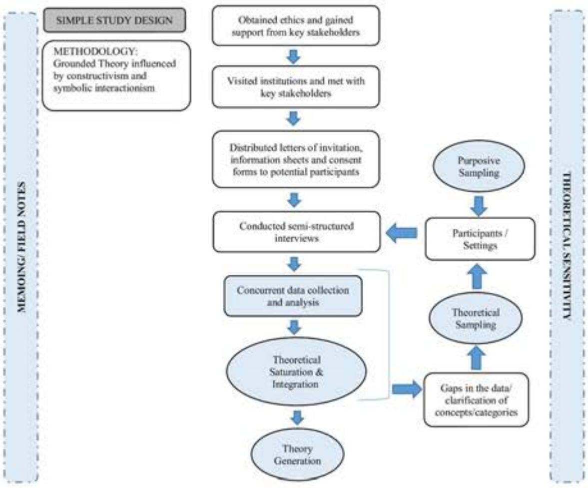
Marshall, M. N. (1996). Sampling for qualitative research. *Family Practice, 13*(6), 522-525. doi: 10.1093/fampra/13.6.522

McCrae, N., & Purssell, E. (2016). Is it really theoretical? A review of sampling in grounded theory studies in nursing journals. *Journal of Advanced Nursing, 72*(10), 2284-2293. doi: 10.1111/jan.12986

Neill, M. (2012). Graduate-entry nursing students' journeys to registered nursing. *Nurse Education in Practice, 12*(2), 89-94. doi: 10.1016/j.nepr.2011.08.002

Sadler, G. R., Lee, H.-C., Lim, R. S.-H., & Fullerton, J. (2010). Research Article: Recruitment of hard-to-reach population subgroups via adaptations of the snowball sampling strategy: Hard-to-reach populations. *Nursing & Health Sciences, 12*(3), 369-374. doi: 10.1111/j.1442-2018.2010.00541.x

Slatyer, S., Williams, A. M., & Michael, R. (2015). Seeking empowerment to comfort patients in severe pain: A grounded theory study of the nurse's perspective. *International journal of nursing studies, 52*(1), 229-239. doi: 10.1016/j.ijnurstu.2014.06.010



Simple study design illustrating where theoretical sampling was employed

209x297mm (300 x 300 DPI)

Study participants.

Table 4.2 and table 4.3 provide details of the study participants including their pseudonyms, gender, and a brief profile. Pseudonyms were used when reporting each of the interview excerpts provided as evidence to support the study findings, to protect their identity and privacy. The participant's pseudonym followed by the transcript number of each participant (T) and the page number where the quote is located (P), are provided in the texts.

Table 4.2: *Participants' details (People with diabetes and their families)*

Pseudonyms	Gender	Brief Profile
Betty	Female	Older adult living with diabetes for 13 years.
Haris	Male	Middle-aged adult living with diabetes for 5 years. No secondary complications of diabetes.
Kevin	Male	Older Adult living with diabetes for 5 years. No secondary complications of diabetes.
Larisa	Female	Older Adult living with diabetes for 4 years. No secondary complications of diabetes.
Mutia	Female	Middle-aged adult newly diagnosed with diabetes. Was hospitalised at the time of interview.
Oscar	Male	Older adult living with diabetes for 6 years. Was hospitalised at the time of interview.
Ranti	Female	Middle-aged adult living with diabetes for 4 years with retinopathy.
Utama	Male	Middle-aged adult living with diabetes for 9 years.
Xeniya	Female	Older adult living with diabetes for 17 years with diabetic foot ulcers for three years.
Zeta	Female	Middle-aged adult living with diabetes for 12 years with retinopathy.
Jovita	Female	Middle-aged adult. A sister of a person with diabetes.
Nirma	Female	Young adult. A daughter of a hospitalised person with diabetes.
Viola	Female	Middle-aged adult. The wife of a person with diabetes (Utama).

Notes: Young adult: 18-39 years old; Middle-aged adult: 40 – 60 years old; Older adult: more than 60 years old.

Table 4.3: *Participants' details (Healthcare professionals and health service professionals)*

Pseudonyms	Gender	Brief Profile
Aditya	Male	Young adult nurse academic and holds a Master of Nursing degree. Also works in a wound care clinic and was interviewed twice (phase 1 and 3).
Cahyo	Male	Young adult pharmacist at a general hospital.
Danur	Male	Middle-aged adult nurse at wound care outpatient clinic in a general hospital.
Elita	Female	Middle-aged adult dietician at a general hospital.
Flora	Female	Middle-aged adult nurse at a PHC.
Galih	Male	Middle-aged adult specialist doctor at a general hospital.
Irena	Female	Young adult general practitioner at a PHC.
Putri	Female	Middle-aged adult lay health worker ('kader').
Qosim	Male	Young adult health promotion officer at a general hospital (Bachelor of Public Health).
Satria	Male	Young adult student nurse.
Tiara	Female	Middle-aged adult ward nurse at a general hospital.
Widya	Female	Middle-aged adult exercise instructor with diabetes for 11 years and was interviewed twice (Phase 2 and 3).
Yoda	Male	Middle-aged adult nurse academic and holds a doctoral degree in nursing. Also works in a wound care clinic.

Notes: Young adult: 18-39 years old; Middle-aged adult: 40 – 60 years old; Older adult: more than 60 years old.

Approval to conduct the study was obtained from each research setting in Pontianak, which is the capital city of West Kalimantan province. During the process of writing the proposal, the candidate sent the permission letter regarding conducting a research study to four purposefully selected healthcare settings in Pontianak and its greater regions (Appendix B). All four letters of approval have been obtained and were used as a support to recruit the participants in those settings, especially in phase one of data collection/generation. The process of further phases was similar to that in phase one.

The comprehensive procedure of data collection began by purposively selecting participants then theoretically sampling further needed data. Initially, there was one participant selected from each of these groups: doctor; nurse; dietician; pharmacist; nurse academic and a person with diabetes. The inclusion criteria were used to purposively select these initial participants. For healthcare professionals, the criteria included having experience in diabetes care provision, working in either an inpatient or outpatient care setting and having direct interactions with people living with diabetes in daily practice. Meanwhile, the criteria for the nurse academic was teaching about health education to students, experience in supervising students while providing health education during clinical placement or teaching the subject of diabetes mellitus. Inclusion criteria for the person with diabetes were those who have been diagnosed with pre-diabetes, type 1 or type 2 DM.

The further phases of data collection/generation occurred as a result of data analysis from phase one that used the theoretical sampling method. More HCPs were involved and they included a general practitioner (GP), a nurse academic, and a nurse clinician. Healthcare providers who are unregistered were also involved, for example a lay health worker and an exercise instructor. Moreover, this study involved family members of people with diabetes and a nursing student.

Participant recruitment.

The settings for participant recruitment were in: general hospitals, both outpatient and inpatient settings; PHCs and the school of nursing at a university. Once letters of support (Appendix B) from clinical agencies and ethics approvals were obtained, the candidate visited each site and met with people who held ‘authoritative’ roles (i.e. gatekeepers) from each health facility. In the meeting, the candidate discussed potential participants based on the inclusion/exclusion criteria; this helped facilitate access to particular units within each healthcare facility. The candidate also discussed suitable places to display recruitment flyers at the healthcare facility. The gatekeepers suggested potential participants and recommended areas where the candidate could display flyers.

The process of recruitment can be varied in each setting. When entering the PHC, the candidate also needed to show the letter of permission from the head of Pontianak municipality health office to the head of a PHC. In the PHC, the candidate needed to recruit participants such as people with diabetes, a GP, a patient’s family member and a ‘kader’. A ‘kader’ is a lay health worker who does not hold any degree in health areas or does not have formal health-related education from a higher educational institution. However, a ‘kader’ is trained by other licensed HCPs and is provided with information related to the areas for which they are responsible. A ‘kader’ is like an extension role for the HCPs. A kader lives near the PHC and usually visits people living in the community to provide basic healthcare needs such as health education and vital signs and to inform/remind people to visit the PHC for regular health assessment.

There were different methods of obtaining potential participants, such as patients or people with diabetes. For one PHC, the doctor selected the person with diabetes, where the patient had just had a consultation with the GP. However, in another PHC, the nurse had a record of people with diabetes in the working area of the PHC, so that she selected the potential participants for the candidate. Then at a different PHC, in order to recruit participants, the candidate needed to participate in an exercise program, which is held every Saturday morning. At the exercise session, the candidate met potential participants, who were people with diabetes. After the exercise was finished, the candidate approached some participants and made an appointment with them for when and where the interview would be conducted.

The ‘kader’ works for the community but they are not always at the PHC. To meet the ‘kader’ from the PHC, the candidate approached the head of the PHC to ask his permission because the ‘kader’ works within his PHC. The head of PHC then contacted the candidate after he confirmed that the ‘kader’ was available and agreed to be interviewed. Once the candidate had the contact number of the kader, she then called the ‘kader’ to invite her to participate in the study. Once the kader agreed, she decided the place (at her house) and time for the interview.

When potential participants were identified, the candidate provided an invitation letter together with the information sheet and informed consent form. Initially the information sheet and informed consent form were written in the English language (Appendix C). Then a sworn translator translated these documents into the Indonesian language. The information sheets written in the Indonesian language contained the research study’s aim, a procedure for data collection, ethical considerations and the candidate’s contact information (Appendix D).

The candidate also displayed a flyer on the unit’s notice board in suggested areas. The contents of the flyer were similar to what was provided in the information sheet. The recruitment flyer aimed to seek participants that voluntarily nominated themselves to be in the study. When the participants agreed to participate and contacted the candidate, the candidate and the participants then conferred by phone or email, to decide the preferred time and location for the interview.

Before interviewing, the candidate introduced herself and explained about the research study as outlined in the information sheet. Then, the candidate read the informed consent form to the participants and provided time for the participants to ask questions about the study. A consent form was given to the participants to sign, to confirm their agreement to participate in the research study. The participants were also given a copy of the information sheet and the signed consent form to keep in their own personal records. Once the participant was comfortable and indicated they were ready the digital recorder was turned on and the interview commenced. The same process was adopted in the subsequent two phases of data collection and with the other participants. The original signed consent forms were collated and stored in a secure manner by the candidate in the field and archived at JCU by the candidate with other study documents for five years, as required by National Health and Medical Research Council (NHMRC).

Concurrent Data Collection/Generation and Analysis

The candidate collected data from initial participants selected using purposive sampling based on inclusion/exclusion criteria. Unlike other types of qualitative research, researchers in a grounded theory study will simultaneously analyse the generated/collected data as the study progresses, in order to assist in making decisions from whom to collect/generate further data (Birks & Mills, 2015). Thus, data collection/generation cannot be separated from data analysis (Morse, 2007). Questions to be used in subsequent interviews were composed based on an interest in further exploring emerging categories from earlier interviews, which is reflective of theoretical sampling.

Various data sources were used in this study, namely interviews, related documents and the literature. In addition to these materials, field notes and memos were generated. Interviews with participants, therefore, were guided by semi-structured, open-ended questions that addressed the research question and sub-questions. Participants were asked open-ended questions, as those can be useful to reveal experiences or information that the candidate had not previously considered or expected to find (Charmaz, 2006). The questions asked to participants were open enough to obtain a broad description of their experience, whereas further exploration with focused questions would uncover each participant’s particular experiences (Charmaz & Belgrave, 2012). The process of data generation was conducted by interviewing participants in a language other than English, namely the Indonesian language. The use of this language influenced the process of research including data transcription and analysis.

The interview began by asking a ‘grand tour’ question and then asking additional clarifying and probing questions, to further explore aspects that participants had mentioned, and to allow the participant to lead the initial conversation (Glaser, 1998). Simmons (2011, p. 23) defines grand tour questions as questions that “convey to the respondent that they are being invited to discuss what is relevant to them (not the researchers) about the general topic area, on their terms”. This definition aligns to what Glaser (1998) recommended in his warning to avoiding preconceived questions that can put undue importance on the researchers’ pre-conceived perspective that may lead to studying an inappropriate substantive area of inquiry and/or to having unconnected findings (Glaser, 1998). The grand tour questions that have guided the candidate in interviews were different for each of the participants’ group (Appendix E).

Research activities on the first field trip.

The period of the first field trip was between 14 April 2016 and 8 May 2016. A pharmacist, a dietician, a nurse clinician, a nurse academic, a person with diabetes, a specialist doctor, and a nurse in a PHC were involved in this phase. The process of recruiting has been explained in the previous section under ‘study participants and participant recruitment’. The interview locations were chosen by the participants, and were at participants’ houses, hospitals, the school of nursing and the PHCs.

During this first trip, the candidate transcribed each interview while waiting for the next interview to occur. The transcriptions were directly written in the Indonesian language. Verbatim transcription was used to ensure that no single word was missed and participants’ intonation was captured. During the transcription process, the candidate also wrote memos. The memos were about the candidate’s ideas and thoughts about the interviews’ contents. These thoughts and ideas were used to ask further questions of the next participants. Beside further questions, the thoughts were used to focus the candidate’s next theoretical sampling. They included who to ask, where to ask and how the candidate would get the next data in order to finally generate the grounded theory.

During this first field trip, the candidate regularly contacted her advisors by phone and Skype in Australia, to discuss the ongoing process of the grounded theory study. They provided feedback on participant selection and the ways the interviews were undertaken, to continually improve interviewing effectiveness. Memo writing and field notes were also discussed with the advisors. Content of the questions and deeper important contexts were also discussed with the advisors. Communicating with the advisors was vital during the activities undertaken in the field in order to keep the research process on the right track.

On the last week of the four-week initial field trip, the candidate completed initial coding analysis with her bilingual advisor because the interviews were conducted in the Indonesian language. Prior to coding activities with the bilingual advisor, the candidate had already transcribed all the pertinent excerpts from the seven (7) initial interviews. During the transcription, the candidate also wrote memos about her ideas and insights on the interviews to facilitate her in the initial coding process. The aim of initial coding was to break down the data by comparing one incident to the other, to label early concepts and to be a starting point in code comparison among the excerpts or within an individual excerpt (Birks & Mills, 2015; Glaser & Strauss, 1967). The candidate performed initial coding by scrutinising every line of the transcripts including all the sentences and paragraphs. Birks and Mills (2015) recommend this activity in this early stage of analysis as it helps researchers to carefully examine their data and simultaneously ask questions of their data. Reading and examining this data set carefully developed a number of codes was developed from this initial coding process. To help the candidate in managing her developed codes, NVivo 11 software was used.

In this first field trip, fracturing the codes was achieved in two ways. Code fracturing was performed together with the bilingual advisor. Initially, the candidate and her bilingual advisor each created codes by themselves. Then the candidate compared her developed codes with the codes developed by her bilingual advisor. The approach was then modified to the method by which the candidate read out loud the transcripts line by line and the codes were then created together. For the second to the seventh interviews, the codes were developed in the same language as the transcripts, the Indonesian language. Discussions between the candidate and her bilingual advisor included finding agreement of appropriate terms for the generated codes from the interview excerpts, resolving any disagreement about the developed codes, and clarifying any ambiguity in the developed codes.

After codes were developed from the initial set of data from first field trip, the candidate then returned to Australia to further analyse the data together with her advisors in Australia, who only spoke English. For optimising the analysis of data and getting the non-

Indonesian language speaking advisors closer to the data, the Indonesian language interview excerpts, which led to developed codes, were translated from the Indonesian language to English. The translated codes were also discussed with the bilingual advisor to ensure the meanings did not change and were congruent with the original codes in the Indonesian language. When the English codes were changed, added or collapsed, the codes in the Indonesian language were also updated accordingly. New memos were generated when adding and changing the codes, to create a clear audit trails of the process by which the analytical concepts were developed and advanced.

The candidate also used concept mapping to help her in the process of data analysis. The use of concept mapping was implemented during the first phase of data analysis and used in the following second and third phases. Details about the candidate employing concept mapping were discussed in a paper entitled ‘From Textual to Visual: The Use of Concept Mapping as an Analytical Tool in a Grounded Theory Study’. The paper was submitted to the *Qualitative Research* journal in March 2018 and is ‘currently under review’.

Table 4.4: *Declaration of Authorship*

Chapter Number	**Publication**	**Nature and extent of the intellectual input of each author including the candidate**	**Signature**
4	Ligita, T., Nurjannah, I., Wicking, K., Harvey, N., & Francis, K. From Textual to Visual: The Use of Concept Mapping as an Analytical Tool in a Grounded Theory Study. *Qualitative Research*.	Conception and design of the paper, data collection, data analysis and interpretation, Primary responsibility for writing the paper (80%), corresponding author responsible for preparing the final paper for submission, approval for publication version.	Ligita, Titan Content has been removed for privacy reasons
		Supervision of and contribution to the conception and design of the paper, data analysis and interpretation, writing the paper (5%), critical revisions for important intellectual content, approval for publication version	Nurjannah, Intansari Content has been removed for privacy reasons
		Supervision of and contribution to the conception and design of the paper, data analysis and interpretation, writing the paper (5%), critical revisions for important intellectual content, approval for publication version	Wicking, Kristin Content has been removed for privacy reasons
		Supervision of and contribution to the conception and design of the paper, data analysis and interpretation, writing the paper (5%), critical revisions for important intellectual content, approval for publication version	Harvey, Nichole Content has been removed for privacy reasons
		Supervision of and contribution to the conception and design of the paper, data analysis and interpretation, writing the paper (5%), critical revisions for important intellectual content, approval for publication version	Francis, Karen Content has been removed for privacy reasons

Using a visual tool like concept mapping in grounded studies is beneficial at all stages of the research process. The paper can contribute to assisting researchers in their analytical thinking process during the implementation of a grounded theory method.

Qualitative Research

From Textual to Visual: The Use of Concept Mapping as an Analytical Tool in a Grounded Theory Study

Journal:	*Qualitative Research*
Manuscript ID	Draft
Manuscript Type:	Research Note
Keywords:	Concept mapping, Data analysis, Diabetes, Grounded theory, Health education, Indonesia
Abstract:	Dealing with a large amount of qualitative data during the analytical process can be challenging especially when the data needs to be regularly discussed with other research team members. For researchers employing grounded theory methodology and methods, using visual tools such as concept maps or diagrams can be a beneficial approach at all phases of the research. Concept maps can assist researchers to visualize emerging concepts from raw data, efficiently communicate the developing theory under construction and demonstrate progress in the analytical thinking process. However, despite the usefulness of concept mapping, there is no clear and detailed information on the use of concept mapping to guide novice researchers. This research presents the distinctive experiences of the authors in utilizing concept mapping to facilitate the analytical process of theory generation they undertook when conducting a grounded theory study examining diabetes health education in an Indonesian context. It is recommended that researchers consider the flexibility and efficacy of concept mapping as a tool to assist them with the process of data analysis in qualitative research.

Abstract

Dealing with a large amount of qualitative data during the analytical process can be challenging especially when the data needs to be regularly discussed with other research team members. For researchers employing grounded theory methodology and methods, using visual tools such as concept maps or diagrams can be a beneficial approach at all phases of the research. Concept maps can assist researchers to visualize emerging concepts from raw data, efficiently communicate the developing theory under construction and demonstrate progress in the analytical thinking process. However, despite the usefulness of concept mapping, there is no clear and detailed information on the use of concept mapping to guide novice researchers. This research presents the distinctive experiences of the authors in utilizing concept mapping to facilitate the analytical process of theory generation they undertook when conducting a grounded theory study examining diabetes health education in an Indonesian context. It is recommended that researchers consider the flexibility and efficacy of concept mapping as a tool to assist them with the process of data analysis in qualitative research.

Keywords

Concept mapping; data analysis; diabetes; grounded theory; health education; Indonesia

Introduction

Researchers can chose to use a range of tools to assist them in the process of qualitative data analysis, including concept mapping. Buckley and Waring (2013) state that any form of visual representation can serve as an analytical technique and communications tool. Using visual tools to represent abstract and/or complex thinking in research can facilitate insightfulness during the analytical phases and promote communication of ideas between team members and others often more readily than using a text form (Buckley and Waring, 2013). In grounded theory, a tool that visualizes concepts and their relationships with each other is known as a diagram (Corbin and Strauss, 2008). Together with memos and field notes, the use of diagramming in a grounded theory study is an acceptable tool that assists the researcher in analyzing data for theoretical integration (Charmaz, 2006). Diagrams help researchers to keep records of concepts and their relationships and to systematically explain findings to other researchers (Corbin and Strauss, 2008).

A concept map, the term used in this paper to indicate a diagram, is used as a visual aid to manage and symbolize knowledge, including concepts and their relationships (Novak, 2004). Although evidence on how to use a concept map to aid grounded theory researchers is not well-described, it is a process that the researcher and participants actively engage in to construct and create knowledge (Charmaz, 2006), thereby co-constructing knowledge that can be visualized and organized by the concept map during the analytical process. Through concept mapping, researchers interact with the data and 'their current cognitive structures' to generate knowledge in a creative and meaningful way (Wilson et al., 2016). This research note will explain the use of concept maps in facilitating the analytical process of theory generation and will recommend methods to consider when using an analytical tool like a concept map, by explicating its use in a grounded theory study of diabetes health education in Indonesia.

The study of diabetes health education

The focus of the study described in this paper is health education for people with diabetes in Indonesia. This study used grounded theory as the research methodology to address the basic social process of how people with diabetes learn about their diabetes and engage with health education. Ethical approvals were obtained from the Human Research Ethics Committee James Cook University Australia (H6445) and Faculty of Nursing Universitas Indonesia (0367/UN2.F12.D/HKP.02.04/2016). This study took place in both outpatient and inpatient healthcare facilities in West Kalimantan province, which has a higher diabetes prevalence rate than other provinces in the country (National Institute for Health Research and Development, 2008; National Institute for Health Research and Development, 2013). The study generated data from interviews with people with diabetes, diverse diabetes health care professionals, healthcare service providers and families of people with diabetes.

Analysis in grounded theory

In a grounded theory study, the process of analysis occurs in three coding stages, namely initial, intermediate and advanced (Birks and Mills, 2015). Through these coding processes, constant comparative data analysis allows the researcher to compare incoming data with existing data. Incidents, concepts, codes and categories are compared across the interview excerpts and within the existing interviews. In this analytical process, the researchers need to interact with the data and the interactions should be recorded by writing memos and developing concept maps.

As in other qualitative study methodologies, analytical processes commence after data has been collected using various approaches such as interviews or observations. However, in a grounded theory study generating and collecting data occurs simultaneously with analyzing the data. This means that analyzing data and the subsequent development of a concept map, commences once the initial data set has been collected.

Concept maps

The concept map contains concepts in the form of words (Novak, 2004). Birks and Mills assert that ‘everything is a concept’ when analyzing data in a grounded theory study and as such, due to the large amounts of data, researchers may lose focus as to the intent of the research (2015: 86). Thus, Glaser and Strauss (1967) emphasize that the unit of analysis should be kept in mind when conceptualizing. In our concept maps, the unit of analysis reflected who the actor was, what the action was, and who interacted with the actor. The unit of analysis should be reflected in the concept maps and the concepts and codes should be aligned with the research question, aim and unit of analysis, as was done in our study (Birks and Mills, 2015; Glaser and Strauss, 1967).

To develop concept maps, Novak (2004) suggests referencing a particular question that needs to be answered or events to be understood, in this case, a research question. Thus in concept mapping, knowledge gained from the data/the interviews can be represented. A concept map shows the relationship between concepts by linking them with a connecting line (Novak, 2004). Some concepts may not be related, and thus this data should not be forced because forcing the data may violate the principles underpinning grounded theory methodology.

As mentioned earlier, the grounded theory analytical process occurs in three stages: initial; intermediate; and advanced. Concept maps were developed in each of the coding processes, and differences regarding complexity and the level of abstraction at each stage was evident. As the analytical process increased with each stage, the concept maps also became more advanced in their level of abstraction. The concept maps were labelled according to their level of abstraction and complexity: early, intermediary, penultimate and ultimate concept maps.

The link between philosophical stances and concept mapping

An effective research design is congruent with the philosophical tenants underpinning the research methodology (Birks and Mills, 2015). Our grounded theory study was informed by symbolic interactionism and constructivism. Symbolic interactionism has been regarded as an appropriate and frequently used method that researchers employ to study life and behavior of human beings (Blumer, 1969). Constructivism, refers to the relationships between the researcher/s and the participants who actively co-create and construct knowledge (Charmaz, 2006).

Using the process of concept mapping, researchers can ensure and strengthen methodological alignment. Concept mapping allows researchers to visualise the outcomes of data analysis and the process by which these are achieved. In addition, this methodological tool enables researchers to communicate the research process undertaken and identify relationships between discrete data fragments or emerging concepts. Novak (1993) states that in concept mapping, people construct and reconstruct the meaning of events or objects they observe and thus key concepts are demonstrated. Therefore, the concept mapping process aligns with researchers' philosophical stances of constructivism, which is the belief that knowledge is co-constructed and interpretive (Wilson et al., 2016).

The development of our concept maps were also congruent with tenets in symbolic interactionism. The data analysis involved looking at interactions rather than a single event or object. We considered a unit of analysis consisted of what they did, how they interacted with others and what objects influenced them, rather than looking at single codes for the term or person.

Developing the maps as the analysis proceeds

We discuss below our experiences in using concept maps as an analytical tool in our grounded theory study; entitled exploring the process of how people with diabetes learn about their disease.

Early concept mapping

Early concept mapping was mainly produced during the first data generation. There were seven participants interviewed during the first field trip to West Kalimantan. A total of seven concept maps were initially developed, giving a big picture overview of each of the seven interviews. These early concept maps, which were hand-written, served the purpose of generating initial discussion with supervisors.

The handwritten concept maps were helpful because it did not limit our insightfulness of the data and ability to transfer concepts that we highlighted in the raw data. However, in further developing the early concept maps, the researchers used ‘Bubbl.us’ application. Each of the seven preliminary hand-written concept maps were transferred into an electronic version by using ‘Bubbl.us’, as it was easier to share via email (Novak, 2004). One example of an early electronic concept map is displayed in figure 1.

“[Please insert Figure 1.]”

The early concept maps were a useful communication tool during the analytical process. Each week the concept maps were discussed with the supervisory panel, who were located in Australia and in Indonesia. The electronic concept maps were shared easily and efficiently via electronic means. In addition, memos were written to help explain the generated concepts or codes on the maps. The memos supported the development of further concept maps. By constantly analyzing and comparing the data, a concept map was developed that encapsulated all seven preliminary concepts maps. At this point, discussion sessions with research team members and writing memos are both crucial resources in developing the concept maps.

Discussion sessions, memoing and further development of concept maps enabled the research team to identify gaps or clearly see concepts that did not relate to other concepts on the maps. The concept maps became a valuable tool in asking questions and determining what and where to search next. Birks and Mills (2015) state that this questioning strategy is useful for finding answers to the gaps identified by concept maps.

By discussing the maps, clues were found in our study, which then directed the next stage of theoretical sampling. The gaps identified in the data, led us to find further potential participants and a different research setting that resulted in a second field trip and further data generation.

Intermediary concept mapping

During the second field trip to West Kalimantan, a further 17 participants were interviewed and the data analyzed. During the analytical process, the data from the 17 participants was fractured to create initial codes and three subsequent concept maps were developed. These concepts maps were referred to by the research team as the intermediary concept maps. The first of the intermediary concepts maps was hand written and included all 17 interviews from the second field trip, as well as the seven interviews from the first field trip.

The intermediate coding stage occurred concurrently with the second phase of data collection and analysis using constant comparative analysis. This process validated the further development of a concept map, with nodes/codes containing incidents that supported the data. During the discussion, the primary researcher explained the developed codes to other team members and provided evidence from the data. This process continued until the research team were satisfied that the concept map was true to the data and allowed the researchers to proffer answers to the research question/s. Memos were also produced during this process.

The hand written intermediary concept map, developed as an outcome of data analyzed from both field trips, was transferred into an electronic version using NVivo application. The electronic version of this concept map visually displayed the process of how people in Indonesia with diabetes learn about their disease. This concept map had a higher level of abstraction than the previous concept maps but was not yet at the highest level of abstraction from which a grounded theory could be produced.

Two electronic intermediary concept maps were created by using NVivo software. NVivo was utilised because it was a time efficient approach for managing data. NVivo software allows researchers to link raw data electronically with an evolving hierarchal process of data analysis that can be shared. The codes or concepts were connected to the evidence from the interview excerpts. Figure 2 shows an electronic version of an intermediary concept map which was a compilation and explanation based on the constant comparative analysis of the data from the first and second field trips.

"[Please insert Figure 2.]"

Penultimate concept mapping

Throughout the advanced coding procedure, a core category was developed and a storyline written to explicate the process by which people with diabetes learn about their disease. The crafting of the storyline enabled the development of a further concept map, titled a penultimate concept map consisting of three concept maps. A penultimate concept map realized higher levels of abstraction with only a core category and major categories featured. This concept map was less complex visually than the previous concept maps: early and intermediary. Similar to these previous concept maps, the penultimate concept maps were also produced along with research team discussions and memo writings. In addition to discussion and memo writing, a storyline can also be considered as an element in the developing of penultimate concept maps.

“[Please insert Figure 3.]”

Using a visual tool as a method to verify the initial framework, or theory in our case, can increase trustworthiness (Whiting and Sines, 2012). To increase trustworthiness of the study and to validate the evolving theory, as represented by the storyline and the progressive concept maps, a decision for further data collection/generation was made. This penultimate concept map and the storyline explicated the participants experiences as interpreted by the research team. Thus we chose to provide the storyline and the penultimate concept map to existing and new participants to test, verify or identify missing information in our theory. At this point, we used an Indonesian language translated penultimate concept map. After that, we developed a refined penultimate concept map based on the analysis of the third phase of data generation (Figure 3).

We assert that validation of our theory was achieved as an outcome of this procedure. Corbin and Strauss (2008: 113) emphasize that the term ‘validity’ in a grounded theory study does not refer to ‘testing’, such as in a quantitative study, but rather ‘following’, which can be done by going back and comparing the evolving theory with the raw data as well as presenting and asking feedback of the evolving theory to the participants. During the process of theory integration, theory denotes an abstract version of the raw data as the theory grounded from the data (Corbin and Strauss, 2008).

Ultimate concept mapping

Ultimate concept mapping was developed during the advanced coding analysis. The categories generated in the final version of the concept map had an advanced level of abstraction than the previously generated concept maps. At this advanced level of research stage, an ultimate concept map can serve to explain study phenomena compared to the lower stage, where simpler concept maps serve as analysis augmentation and clarification (Buckley and Waring, 2013).

Initially, one concept map of the overall grounded theory of ‘Exploring diabetes care’ was developed as the storyline was refined (See Figure 4). In the next analytical phase, evidencing the storyline, a more detailed concept map was created for each of the five major categories that contributed to the basic social process of ‘exploring diabetes care’. During this evidencing phase, the overall concept map of the theory as a whole was revised, thus becoming the final version of ‘Exploring Diabetes Care’. Therefore, a total of seven concepts maps were produced in this ultimate stage.

“[Please insert Figure 4.]”

Generally finalized grounded theories are explained in conjunction with a diagram. Corbin and Strauss (2008: 125) state that an initial diagram explaining a grounded theory is generally simple. As in a concept map, the commonly presented diagram in a grounded theory nursing study is the final product of a simple, but robust diagram that reflects a high level of abstraction. In Author and Others’ (2013) study of new graduate nurses in general practice in New Zealand, a final diagram was developed to depict a theoretical model representing how graduate nurses act as knowledge brokers for experienced practice nurses.

Similarly, an Italian study (Palese et al., 2013) that investigated how nursing interventions affect patient outcomes in daily nursing practice also produced a final diagram visualizing theory integration with basic processes on nursing effectiveness. These diagrams typically represent a simplistic overview of the researchers' final theory.

A summary of the main stages of concept map development, and the types of maps that were generated in each stage, are presented in Figure 5.

"[Please insert Figure 5.]"

How memoing supported concept mapping

Memos, are the analytical writing that contains researchers' ideas, thoughts, and perceptions that are closely related to the study (Birks and Mills, 2015). Memo writing was instrumental in this study as it facilitated the evolvement of the initial concept maps from being descriptive to a higher level of abstraction. Categories or concepts and their relationships to each other are visually represented and sharpened through the use of diagramming (Charmaz, 2006), which is how concept mapping was used in our study.

Engaging memos during the mapping process by explaining what the concept map is about is a necessary part of a grounded theory study process. Concept mapping has helped to stimulate our thinking and understanding of the relationship between concepts and if the concepts were distinct or similar to other concepts. Concept mapping allowed us to think and record our thoughts in memos. Conversely, writing memos helped to identify whether changes or refinements were needed to the maps. Thus, writing memos and concept mapping are both the fuel to energize theoretical integration, which is explicated in a storyline. We not only explained the concepts/codes or categories that were in the concept map, but also described the relationships between them in memos. As an outcome of this action we were able to craft a storyline that provided the means for sharing, confirming, and/or gaining additional insights that led to the construction of our grounded theory. Memos provided theoretical linkages between codes highlighted in the storyline and an explanation for each (Williams and Keady, 2012). Memos, together with research team discussion sessions and the storyline, are the elements in developing concept maps. Moreover, we contend that memo writing cannot be separated from concept mapping as these musings help to explain concept maps developed throughout the research trajectory.

Recommendations for using a concept map during analysis

To adequately use the concept map during data analysis in a grounded theory study, several points need to be taken into account. The use of a computer software application tool such as NVivo, can assist researchers in developing theoretical understandings of the data. We advise paying attention to choosing a tool that does not limit capacity to be flexible, allowing for theoretical sensitivity to be accommodated. Drafting handwritten concept maps is advised as these assist researchers to consolidate preliminary ideas and provide direction for further data generation and analysis. In choosing the tool, it is important to consider familiarity with, and the efficiency of the tool to assist researchers to manage, organize, add to, and facilitate manipulation of data throughout the analytical process.

Novak (2004) states that computer programs offer flexibility in the organizing of concepts like movement or restructuring. It can also be shared and is printer friendly. However, in our study, using an available online application at the initial stage was quite challenging because our maps comprised descriptive nodes and details. Using an online tool may have restricted our ideas. Once we developed a further stage that produced categories and relationships, we could use the online tool to help us to systematically map our concepts and easily communicate with each other.

Some aspects need to be considered before adopting an online application tool for making a concept map. First the flexibility of the application. Can the application be easily shared with team member/s and can they easily edit the developing map? Second, cost effectiveness. Generally, the more functions offered, the more expensive the application. Some free applications may provide the functionality required. Thirdly is the application time-saving. Learning a new software application can take time, but we found it did help to advance our level of abstraction in generating concept maps while analyzing the data.

Conclusion

This paper showed the importance of and explained the use of concept mapping in a grounded theory study as an aid to data analysis. A concept map or diagram in a grounded theory study is not only valuable to explain the final theory but is also important for communicating the findings and helps the researchers to increase their conceptual analysis. This paper also showed examples of developed concept maps, from our own study, and the importance of memoing, team discussions and storyline, as essential tools in the research process. This paper also has differentiated and labeled different levels of map which can guide researchers during the analysis process. This paper has discussed a number of considerations that researchers need to take into account when choosing to use concept mapping during data analysis. Such considerations included flexibility and efficacy of the concept mapping application and time available during the analytical process.

Notes

1. The concept maps developed in the study were facilitated by both ‘Bubbl.us’ and ‘NVivo’ applications.
2. Beside concept mapping, we employed other essential methods of grounded theory, such as: purposeful sampling method; concurrent data generation and analysis; theoretical sampling method; theoretical sensitivity, memo writing; coding process; constant comparative analysis; and theoretical saturation and theoretical integration (Birks and Mills, 2015).
3. The study revealed the theory of ‘exploring diabetes care’ represented by a final diagram, which was constructed from multiple versions of concept maps moving from a lower to a higher level of abstraction.

References

Birks M and Mills J. (2015) *Grounded theory: a practical guide,* Thousand Oaks, CA; London: SAGE.

Blumer H. (1969) *Symbolic interactionism: Perspective and method,* Berkeley: University of California Press.

Buckley CA and Waring MJ. (2013) Using diagrams to support the research process: examples from grounded theory. *Qualitative Research* 13: 148-172.

Charmaz K. (2006) *Constructing grounded theory: a practical guide through qualitative analysis,* London: SAGE.

Corbin JM and Strauss AL. (2008) *Basics of Qualitative Research: Techniques and Procedures for Developing Grounded Theory,* Los Angeles, Calif: Sage Publications, Inc.

Glaser BG and Strauss AL. (1967) *The discovery of grounded theory: strategies for qualitative research,* New Brunswick; London: Aldine Transaction.

Author and Others. (2013) Details Withheld for Peer Review.

National Institute for Health Research and Development. (2008) Basic Health Research (*Riset Kesehatan Dasar*). In: Division HRaD (ed). Jakarta: Ministry of Health of Republic of Indonesia.

National Institute for Health Research and Development. (2013) Basic Health Research (*Riset Kesehatan Dasar*). In: Division HRaD (ed). Jakarta: Ministry of Health Republic of Indonesia.

Novak JD. (1993) Human constructivism: A unification of psychological and epistemological phenomena in meaning making. *International Journal of Personal Construct Psychology* 6: 167-193.

Novak JD. (2004) Concept Maps and How To Use Them. *Insight* 6: 15-16.

Palese A, Mesaglio M, De Lucia P, et al. (2013) Nursing effectiveness in Italy: findings from a grounded theory study. *Journal of nursing management* 21: 251-262.

Whiting M and Sines D. (2012) Mind maps: Establishing 'trustworthiness' in qualitative research. *Nurse researcher* 20: 21-27.

Williams S and Keady J. (2012) Centre stage diagrams: A new method to develop constructivist grounded theory - late-stage Parkinson's disease as a case exemplar. *Qualitative Research* 12: 218-238.

Wilson J, Mandich A and Magalhães L. (2016) Concept mapping: a dynamic, individualized and qualitative method for eliciting meaning.

Figure 1. Example of an electronic version of the concept map using ‘Bubbl.us’

Figure 2. An electronic version of an intermediary concept map using ‘NVivo’

Figure 3. Refined penultimate concept map

Figure 4. Version 1 of overall ‘Exploring Diabetes Care’ concept map

Figure 5. Summary of concept mapping

Figure 1. Example of an electronic version of the concept map using 'Bubbl.us'

272x170mm (300 x 300 DPI)

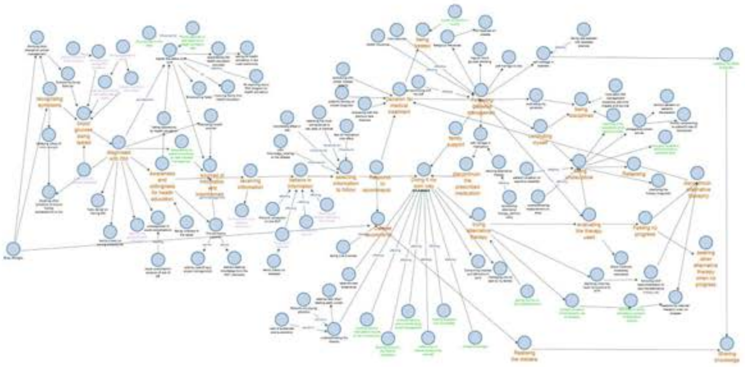


Figure 2. An electronic version of an intermediary concept map using 'NVivo'

217x105mm (300 x 300 DPI)

Figure 3. Refined penultimate concept map

146x43mm (300 x 300 DPI)

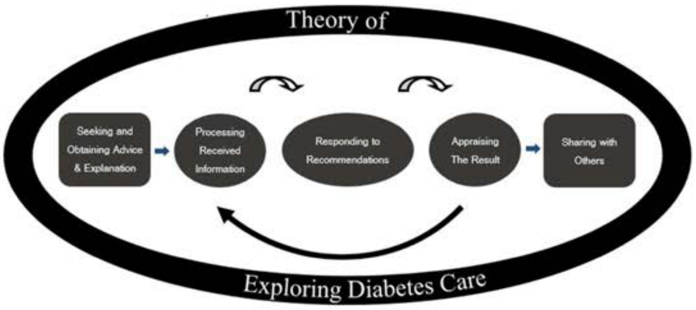


Figure 4. Version 1 of overall 'Exploring Diabetes Care' concept map

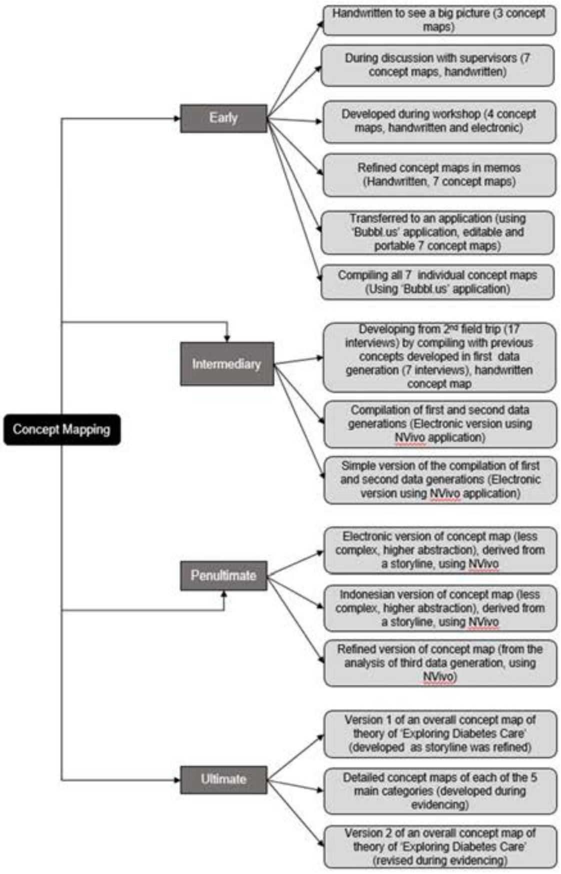


Figure 5. Summary of concept mapping

Research activities on the second field trip.

Before starting to collect and generate data in the second field trip, a research ethics amendment was submitted to the JCU Human Research Ethics Committee (HREC) and on 13 October 2016. On 18 October 2016, JCU HREC approved the amendment. Based on the amendment, an additional research setting was included and this made a total of seven sites: two general hospitals, three PHCs, one private wound care clinic and one school of nursing. In the ethics amendment, modified research questions were also included (Appendix F).

The period of the second field trip was approximately 4 weeks, which started on 28 November 2016 until 27 December 2016. Like the previous field trip, the candidate needed to visit the research settings to meet the gatekeepers and obtain permission to enter the research settings and interview participants.

Considerations during recruitment.

Recruiting participants did not always go smoothly. For example, two participants were recruited while the person who has diabetes was having wound care in the clinic. When she finished, the candidate invited her and her family into the study and they agreed. Then, the participants selected the time and place for the interview. As the place was quite far, a day before the interview, the candidate tried to search for the house so that on the day of the interview the candidate would easily find the house. On the day the interview would be undertaken, the candidate and her advisor visited the house. However, a person in the house said that the patient was brought in to a clinic because she was not going very well. After that, the candidate found that the patient was admitted to the clinic for some days and it was not possible for the candidate to interview her. After that, the candidate required a decision to be made that must was congruent with the ethics requirement. The candidate then searched for another participant who had a similar condition as the previous participant, that of a diabetic foot ulcer. After waiting for almost two hours at the clinic, the candidate approached a couple who were visiting the clinic for wound care for the husband. Then the candidate invited them to participate in the study. They consented and then gave the candidate their contact numbers and address. The couple decided to be interviewed at an agreed time in their house.

Before interviewing family members, the candidate had two ways of approaching the potential study participant. One way was for the candidate herself to ask the family member whether they were available to participate. The family member then decided whether they could provide some information about their relative living with diabetes or not. Another way was for the candidate to ask the person with diabetes to nominate a family member who could be interviewed and provide information about how the person learnt about his/her diabetes. When interviewing the family members, almost all of them remained beside their relative living with diabetes. There was one patient who declined to be interviewed when invited by the candidate. He then pointed to his family to be interviewed instead. When interviewing the family member or the patients, they usually sat together or were in the same room so they could listen to each other. Regarding privacy, it may not have been possible and it was culturally not accepted if the candidate asked the family member to leave the room. Also, this situation was ethically supported by the information sheet where a participant could choose who will accompany them during the interview.

Finding a family member to interview required being alert to unexpected opportunities. In one particular research setting, the candidate obtained information from ward nurses about which patients had diabetes. The candidate then approached the patients one by one. At the time the candidate came to the ward in the late morning (at around 10 am), no person with diabetes could be interviewed as they were all sleeping. The nurses previously suggested this time because nurses complete almost all the basic care interventions by this time. Next, it was suggested to come again in the afternoon (at around 3 pm). While waiting to return to the ward in the afternoon, the candidate approached a family member of a person with diabetes, who was waiting for the person with diabetes at the ward. One of the family members then agreed to be interviewed at that time in the ward.

On this second field trip, the candidate planned to interview people with diabetes while they were hospitalised. Two general hospitals were selected to recruit potential participants. Before approaching the participants, a letter of permission was submitted to obtain a letter of recommendation that the candidate could use to enter the ward. This letter was shown to the head nurse in order to get permission from the head of the hospital ward, so that the candidate was able to approach people with diabetes to invite them into the study. Once the permission was given, the nurse in charge introduced the candidate to potential participants. The process of inviting hospitalised participants differed to those who were invited from the outpatient setting. Patients were not always available at the time the candidate wished to interview them. The candidate needed to ensure patients were well enough to participate in a 30 minute to an hour interview. The interview had to be acceptable to patients, especially regarding the time. Therefore, the candidate invited patients to have the interview when they were not resting, not in pain or not at bedtime.

The first patient was interviewed before lunch time and the patient agreed to be interviewed at the side of the bed. The time varied between the first and the second patients. The candidate stopped the first interview after approximately 12 minutes, as the patient appeared to find it difficult to speak because of dyspnoea. However, for the second participant, the candidate interviewed him for about 22 minutes. The candidate needed to give consideration to the patient's condition when they were hospitalised and closely monitor them for signs of fatigue.

Considerations regarding location and time of the interview.

Choosing the place for the interview was also considered during the second field trip. The participants, including patients who were hospitalised, chose all the interview places. For instance, hospitalised people with diabetes chose to be interviewed at the bedside. Even though the recruitment of the participants was conducted in the healthcare facilities, the places for the interviews varied, from the PHCs, the hospital such as the ward and the hospital administration office, clinic, an office room of the school of nursing and mostly at the participants' houses. For the interviews that were conducted in the participants' houses, the appointment was made at least one day before the interview started. There was one participant who preferred to be interviewed at the PHC rather than at the house. For people who were hospitalised, the interview was conducted on the same day the candidate invited them to the study. Almost all invited participants decided to be interviewed on a later day. However, two participants chose to be interviewed on the same day the candidate invited them, for example, the administration person and the patient who had a diabetic foot ulcer.

The candidate was visited by her primary advisor from Australia during week two and three of the four week field trip in order to have a clear description of the study setting. Also the visit had a purpose for data veracity and maintaining the rigour of the study. The advisor's visit was for observation and supervision during the data generation. The visiting advisor also learnt cultural aspects of interviewing people in Indonesia. The advisor also learnt about healthcare facilities and other research study settings, such as participants' houses and also a nursing academic institution.

Some interviews would occur while the primary advisor was in country and the candidate notified the participant at the time of making the appointment, that her advisor from Australia would accompany the candidate. The candidate asked for their permission to have the advisor present at the interview. All of them agreed to have interviews with the advisor sitting beside the candidate. The candidate interviewed a further five participants with her advisor present. They visited the research settings together: participants' houses, a nursing academic institution and a general hospital. During the interview, the advisor both observed the candidate and wrote field notes about the environment and the way the candidate interviewed the participants. Once the interviews were completed, the candidate and her advisor had discussions about the interviews, the contents and the participants. As the candidate interviewed in the Indonesian language, the advisor asked the candidate about the patients' response, the patients' gestures and asked for clarification about the meanings of these responses and gestures. The advisor also asked the candidate about the environment of the research setting and the cultural aspects before, during and after the interview. They also discussed the most important concepts that came to light during each of the interviews.

Later in the same week, after the primary advisor went back to Australia, her secondary advisor, the bilingual advisor, also visited the candidate. The agenda while she was in Pontianak, Indonesia was to perform the data analysis together with the candidate by using the Indonesian language, which is native to the participants the candidate had interviewed. All interviews were conducted in the Indonesian language. Unlike the previous coding analysis conducted together at the end of the first field trip, this time both the candidate and the bilingual advisor listened to the audio recording together. To maintain the participants' privacy, the candidate used a code number for each of the participant, so that the information the secondary advisor had was only the participants' status such as a person with diabetes or a family member. At every five minutes while listening, the recording was stopped, and the candidate and the bilingual advisor wrote memos. At the end of listening to each interview, they compared what each had written in the memos. After all interviews had been heard and all memos were written, they made another concept map. The concept map was then compared with the focused codes that the candidate had already developed from the first field trip.

Research activities during the third data generation.

During the process of theory integration in this study, an abstract version of the raw data, which was a storyline, was a representation of the emerging grounded theory. Doing so is suggested by Corbin and Strauss (2008) as one of the strategies in facilitating the theory integration process. During the refinement of the storyline, a decision was made to undertake a third data collection. In order to determine whether the abstraction fitted with raw data or whether anything significant was absent from the theoretical scheme, a theory validation was performed. Here, validation is not about testing in the quantitative sense of the word, but rather "following" data (Corbin & Strauss, 2008, p. 113), because a theory is derived from the raw data.

The third data generation was performed from 7 July 2017 to 17 July 2017. Before the data was generated, another ethics amendment was submitted and was approved on 4 July 2017. In this third data generation, the study involved existing and new participants in Indonesia to validate the initial data analysis generated from participant interviews for the final stage of this present study. For member checking or validating the storyline, the participants were asked to give their feedback on the produced storyline. Corbin and Strauss (2008) also state that a theory should fit the area from where it comes and where it will be utilised. Therefore, the candidate decided to involve two new participants within the same groups of existing participants such as HCPs in diabetes care and a layperson (a person with diabetes); and these people lived within the geographic and practice area where the data was generated previously. The subject groups of the new participants were still similar to the participants in previous data collection (as it is stated in the first HREC approval and subsequent amendment): people with diabetes, HCPs who care for people with diabetes, family members, 'kader', diabetes exercise instructor, hospital health promotion officer, and nursing student.

This time, the candidate remained in Australia. The previous participants (n=2) were recruited through their previous contact details. An invitation letter, an information sheet and an informed consent form were sent through an electronic mail. Whereas, new participants (n=2) were recruited through a snowballing sampling method by which the candidate asked the previous/existing participants as informants. The informants provided potential participants that were considered appropriate based on the study's inclusion criteria. After they agreed to participate, they were sent the storyline and a related concept map. Upon receiving and reviewing those documents, they chose to provide their feedback through email, telephone or Skype, where the feedback in Skype would only be audio-recorded. All four participants living in Indonesia agreed to be interviewed by the candidate from Australia through phone calls.

The process of transcription, coding and constant comparative analysis was similar to the process described in the second data generation phase. This time, the candidate listened to all interviews several times alone, and did not involve the bilingual advisor. The candidate developed codes and categories as well as wrote memos. Verbatim transcriptions were also performed. As the aim of this data generation was a validation, the candidate compared the developed codes and categories with the existing categories reflected from the penultimate concept map that the four participants viewed. She also compared the categories with the storyline. The candidate also noticed whether there was any newly developed categories that would add the existing categories reflected on the concept map. In this third phase, the incoming data confirmed the five developed major categories.

Constant Comparative Analysis

In constant comparative analysis, the candidate continuously compared all newly collected data to previously collected data in the form of incidents, codes and categories until the data was integrated into a grounded theory (Birks & Mills, 2015). The candidate transcribed all generated/collected data from interviews verbatim. In transcribing the recordings, the candidate listened to the recording carefully in order to completely transfer all spoken statements into a written document. A word-for-word verbatim transcription process was employed, which includes recording non-verbal vocalisations, such as sighing, laughter, coughing or interruptions (Poland, 1995).

Constant comparative analysis was performed at the beginning of the study; right after the candidate had collected/generated the first set of data, and was ongoing until a grounded theory was developed. What the researchers should compare in this analytical process is events, codes and categories (Birks & Mills, 2015). This comparison strategy sought to ensure that the incoming data aided in developing categories. Then this analytical process continued by defining properties and dimensions of these developing categories (Holton, 2007). Researchers should have a broad collection of dimensions generated from the data before doing a very early comparative analysis (Bowers & Schatzman, 2009). Further Bowers and Schatzman have warned about doing premature analysis since doing so can detach the researchers from the data and lead to a lack of insight about the study phenomenon. Such premature analysis would contradict the aim of a grounded theory being developed from the analysis of data. Therefore, doing constant comparison alone is not enough for a robust grounded theory analytical process, Bowers and Schatzman suggest to also use another process of analysis by considering "what all is involved" and considering dimensions, valuing the identified relevant dimensions and making conclusions about dimensions (Bowers & Schatzman, 2009, p. 94).

Constant comparative analysis techniques were employed to develop codes, categories, properties, dimensions and a core category that realised a theory grounded from the data. Before developing a code, the candidate analysed incidents, which referred to actions, phrases, experiences and explanations identified from the data (Birks & Mills, 2015). Codes were defined as words or phrases that functioned as labels for reoccurring concepts and patterns that have been identified in the data (Birks & Mills, 2015). A category on the other hand was a set of related codes that reflected a higher level of theoretical conceptualisation (Corbin & Strauss, 2008). To increase the depth and breadth of a category, a category has properties and the properties have dimensions (Birks & Mills, 2015). Properties define the category or show the characteristics of the category. Then dimensions are conditions or variations that the property shows; for example, a category from this study was 'appraising the results'. The properties of this category were 'measurement', 'progress' and 'further decisions'. The dimension of 'measurement' was 'subjectively measured' and 'objectively measured'. The relationships between this category and its properties and dimensions are described in Figure 4.1.

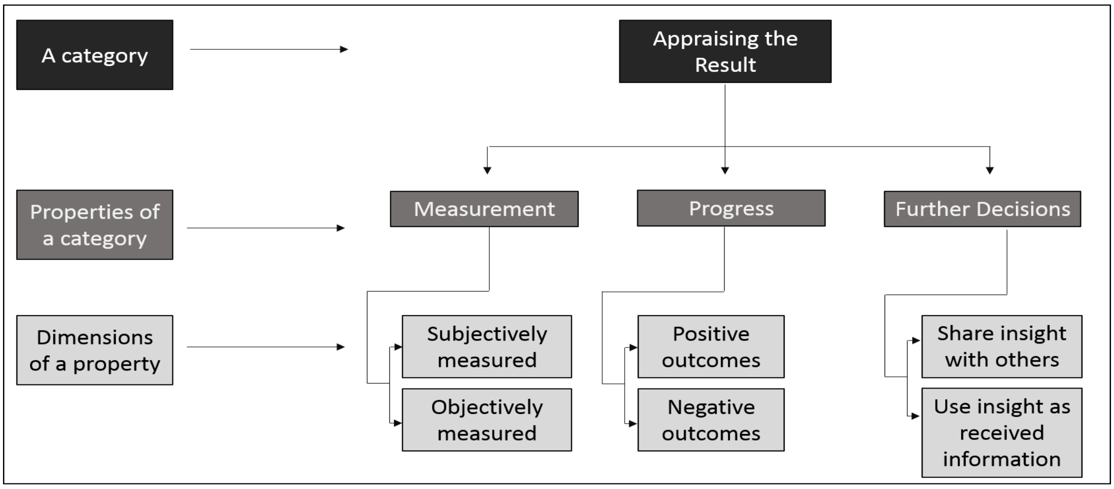


Figure 4.1. An example of a category with its properties and dimensions.

To analyse the data through constant comparative analysis, the candidate compared incidents with incidents, incidents with codes, codes with codes, codes with categories and categories with other categories. The comparisons occurred within existing data or between existing data and incoming data. By using constant comparative analysis, the data led to additional theoretical sampling and further data collection/generation. Figure 4.2 provides an overview of the data generation and data analysis process undertaken in this grounded theory study.

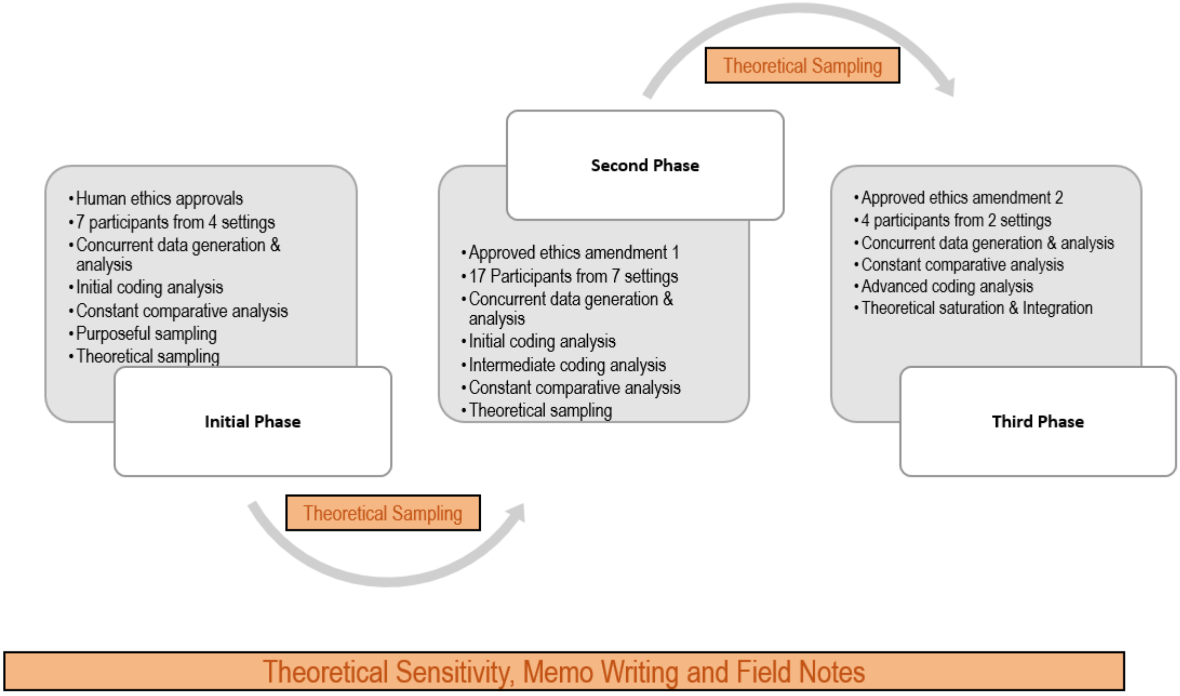


Figure 4.2. The grounded theory process.

Coding Process

In the first phase and third phase, fracturing of codes occurred once the interviews were transcribed verbatim. However, in the second phase of data collection, fracturing of the codes occurred by the candidate and the bilingual advisor directly listening to the audiotape and the transcription was undertaken afterwards. In all three phases, once transcribed in the Indonesian language, the candidate translated the interviews into English. The Indonesian language version was then loaded into the NVivo software program. This software did not analyse the data but assisted the candidate to manage the collected or generated data. All collected data was firstly analysed in the Indonesian language to discover the happenings and the meaning of the happenings.

Coding in grounded theory has a role to build a structure into the theoretical analysis, as bones to support the functions of our body skeleton (Charmaz, 2006). The coding process in this study was part of data analysis. Coding assisted the candidate in delineating what the data has told and the meanings held by the participants. During the analysis of data, this study utilised a coding process consisting of three stages: initial coding; intermediate coding and advanced coding. These stages accomplished the analytical process in this study to eventually integrate in developing a grounded theory. Even when two researchers hear or read the exact same interviews, they may still develop different codes. It is not unusual as interpretation plays an important role in coding (Saldana, 2013). Therefore, any developed codes were discussed between the candidate and her advisors to achieve the most proximate meaning to participants' words.

Initial coding, a term introduced by Charmaz (2006), began with fracturing the data from the interview transcript into segmental parts. The codes in initial coding could be tentative, meaning that the candidate may reword the codes as the process of analysis continued and decided what other data were required for supporting theory development (Saldana, 2013). Searching for "processes", reflecting on participants' actions, was a main characteristic of initial coding and it was suggested to use in In Vivo Coding (actual participants' language) and Process Coding (using gerunds -'ing' words) for its application (Saldana, 2013).

Later, in intermediate coding, the candidate searched for categories arising from the developed codes. The category should reflect its properties and dimensions (Saldana, 2013). For example the category of 'seeking and receiving diabetes-related information' has a property of 'time' when people actively sought the information and dimensions of 'before and after the diagnosis of diabetes'. In the intermediate coding, similar or equivalent codes were collapsed, and this coding process is also known as focused coding (Charmaz, 2006). The candidate linked categories with categories, or linked sub-categories with subcategories, to then select a core category. The preliminary identified core category was 'Exploring diabetes care'. As the candidate moved to the end part of the research process, she further refined the core category and changed the title of the theory to more clearly articulate its explanatory power. The updated theory title is 'Learning, choosing and acting: Self-management of diabetes in Indonesia'. The theory has an analytical power of explaining the phenomena of how Indonesian people with diabetes learn about their disease.

The final stage was advanced coding. At this stage, the research proceeded to reach the level of advancement, a critical stage where the theory was integrated from the data (Birks & Mills, 2015). The storyline was written during this advanced coding stage. The use of storyline aimed to integrate and present the theory (Birks & Mills, 2015). In advanced coding, the candidate developed a theoretical code. The theoretical code was experiential learning theory because the theory of *Learning, choosing, and acting: Self-management of diabetes in Indonesia* builds on this theory. Charmaz (2014) suggests that researchers use theoretical codes to help them in developing a theory from the data. Charmaz (p. 150) further explains that "[t]heoretical codes underlie your substantive codes and show relationships between them, rather than replacing the substantive codes with ones constituting your theory".

Theoretical Sensitivity

Grounded theory researchers develop theoretical sensitivity during the study process. Birks and Mills (2015, p. 12) describe theoretical sensitivity as the researchers' degree of "insight" and "intellectual history" that are necessary to the whole process of a grounded theory study. The researcher's theoretical sensitivity in this study was initially derived from personal experiences and her professional background. Theoretical sensitivity may also be increased by gaining experience during their work in a particular field (Higginbottom & Lauridsen, 2014). The candidate further developed her theoretical sensitivity from data generation in the first and subsequent interviews, which directed her to decide what further data to seek. Having adequate theoretical sensitivity can help researchers in 'self-consciously' form concepts and then build a theory emerging from the data (Glaser, 1978; Glaser & Strauss, 1967). Theoretical sensitivity informed theoretical sampling, which in turn helped the candidate to decide which participants she believed would increase theory development about the process of how people with diabetes learn about their disease.

Glaser (1978, p.2-3) who firstly introduced theoretical sensitivity, points out that the way to initially cultivate the researcher's theoretical sensitivity is to "enter the research field with as few predetermined ideas as possible and these ideas must not limit the researchers' ability to capture 'what is actually happening' in the research field". By entering the research field for data generation, the candidate needed to become aware of the prior ideas/insights she already had so that she could set them aside and actually explore what is really going on with

Indonesian people living with diabetes in learning about their disease. The whole process of this grounded theory study was facilitated by the use of theoretical sensitivity, which is the ability to recognise concepts related to the evolving theory; and memo writing, which captures decision making during an analytical process (Birks & Mills, 2015). For example, the interaction of the candidate's theoretical sensitivity with the data was documented by memo writing. This theoretical sensitivity, initially formed by the candidate's experiences and position, influenced the way the candidate perceived the data, analysed it, and reacted to it (Mills et al., 2014).

Memos and Field Notes

Writing memos was one other vital method used when undertaking this grounded theory study. Memos are not just ordinary notes; rather they contain the researchers' ideas and thoughts created through the analytical process during the grounded theory study (Birks & Mills, 2015; Charmaz, 2006). Therefore, memos can contain feelings and assumption about the research, issues developed and problems encountered in relation to the study, reflection on the research process, decision making during the data collection and generation and importantly codes, categories and development of a theory (Birks & Mills, 2015). Based on the candidate's philosophical position and research questions as well as the application of grounded theory methodology, the candidate used a process of reflexive memoing in order to monitor her influences on the research process, and in particular in the analysis of the data generated by participants. Writing and reflecting on memos throughout the research process also cultivated the candidate's developing theoretical sensitivity (Pidgeon & Henwood, 2009). The candidate wrote a total of 127 memos that assisted her in data analysis until the final theory was formed.

Field notes (n=46) were produced during and after the candidate performed interviews, including four field notes written by the primary advisor during her visit to Indonesia. Birks and Mills (2015) suggest that field notes should contain the candidate's observation of the participants' non-verbal aspects of the conversations and of the contextual details of the physical environment in which the interview is conducted. The candidate wrote field notes to record her impressions while collecting and generating data. They also recorded the candidate's immediate responses to the events in the interviews.

Theoretical Saturation

“Stop when your categories are saturated” (Charmaz, 2006, p. 113). Qualitative research may be criticised by other researchers for stopping data collection/generation prematurely, and therefore not achieving the aim of the study, and not answering the research question. The decision of when to stop data collection/generation is thus a critical one, to ensure rigour in the study. Therefore, the decision needs to be explained, and should be based on reaching theoretical saturation (Dey, 2007). Grounded theorists should not confuse saturation with the reappearance of similar statements (Charmaz, 2006). Charmaz continues to explain that saturation occurs when our incoming data prompt no theoretical hunches and add no attributes into existing categories. Thus, grounded theorist seeks to achieve theoretical saturation by theoretically handling the categories to increase their level of abstraction yet also maintaining the categories being connected to, and arising from, the original data (Charmaz, 2006).

In this study theoretical saturation occurred at the final phase of the study. The candidate provided participants with the developed storyline and concept map. Data from these participants did not add to any new categories rather this process confirmed and refined the developed categories. Therefore, the currently developed categories were secured. The explanation of this process is addressed further under the section ‘Research activities in the third data generation’.

Ethical Considerations

This study involved humans as participants; therefore, human research ethics applications were submitted to the relevant human research ethics committees. Firstly, an ethics application was submitted to the Human Research Ethics Committee (HREC) at the James Cook University (JCU) Australia. After one month, the ethics approval was obtained with an application (Appendix G). Since this study was conducted in Indonesia, an ethics application was also submitted in Indonesia. However, Indonesia does not have a national human research ethics board. In Indonesia, the application of human research ethics is organised by selected institutions such as schools of medicine, research institutions or particular teaching hospitals. West Kalimantan, the province where the study was conducted, does not have a local HREC and neither do the local hospitals or the University of Tanjungpura, where the candidate lectures. Historically, researchers/lecturers in West Kalimantan, that are undertaking research, apply for ethics at the closest ethics committee. In this situation, this would be the Faculty of Nursing at the University of Indonesia in Jakarta. After one and half month application in University of Indonesia, the ethics was approved and the letter of ethical clearance received (Appendix H).

All required ethical approvals were obtained before the process of data collection began. Four main aspects were considered in the study: respect for autonomy, non-maleficence, beneficence and justice (Beauchamp & Childress, 2001, 2009, 2013). Today's society is keenly aware of the importance of employing an ethical approach to human research (Pieper & Thomson, 2014).

Respect for autonomy and confidentiality

One indicator of whether the researcher is conducting a research study in an ethical manner is demonstrated by how they show respect for the participants (Pieper & Thomson, 2014). Pieper and Thomson explain that respecting participants' autonomy indicates that the candidate acknowledged that the participants have their own values and principles that will assist them to decide whether or not to participate in the study. Participation in this research study was entirely voluntary. Therefore, by seeking consent, the candidate designated that the participants could either choose or reject to participate in the study (Pieper & Thomson, 2014). The participants could stop taking part in the study at any time without explanation or prejudice. The choice that the participants made would have no bearing on their job or on any work-related evaluations or reports (healthcare professionals). For the patients, whether they did or did not participate, the services they received at the healthcare facilities would continue. Additionally, the candidate had to explain that participants' details were kept strictly confidential. The candidate and her advisors only had access to all documented information about the participants. These statements regarding the participants' autonomy and confidentiality were provided in an information sheet and an informed consent form.

Non-maleficence.

Although it was highly unlikely that the participants would experience any psychological or physical discomfort, there might be an inconvenience in relation to making an appointment for an interview and giving of their time to participate in the interview. The candidate considered potential risks that might occur to the participants. In this study, participants might experience negligible risk as a result of participating in an interview. This was not anticipated, however, it still needed to be considered.

Beneficence.

The candidate mentioned clearly in the information sheet that although there was no direct benefit to the participants, their participation in the research was of benefit to the community and society. Beneficence to the community and society can exist because the candidate has developed a theory about the process of how people living with diabetes in Indonesia learn about their disease. The theory will then assist the government and health service providers to better understand and apply the process of patient education in the future.

Justice.

The research study has shown the fair selection of participants and avoided forcing them to participate by following the recruitment process as explained earlier in this section. Only participants who voluntarily participated in the study were interviewed.

All required documents regarding the ethics application were also attached. The documents included an information sheet, informed consent form, letter of invitation and a flyer. All documents were prepared in both English and Indonesian languages. This study has two ethics application approved by two institutions. One approval was from the Human Research Ethics Committee at James Cook University and another approval was from the Faculty of Nursing, University of Indonesia. The letter of approval from James Cook University was received in December 2015 with the application ID number H6445 (Appendix G). Subsequently, the approval from University of Indonesia was obtained in February 2016 with the letter of ethical clearance number: 0367/UN2.F12.D/HKP.02.04/2016 (Appendix H). Prior to the second field trip and thus wider range of participants to be interviewed, an amendment research ethics application was submitted to the JCU HREC and an approval was obtained in October 2016. Before the third data collection was performed, JCU HREC also approved an ethics amendment in July 2017.

The Use of Two Languages in this Study

In a qualitative study where the data are largely textual, the process of translation plays a key role. In this study, two main languages were employed in the research process and the study involved three team members who only speak English, and two who speak both English and the Indonesian language.

Communicating data sources is important in a study involving a multilingual team or when the data is generated in a language differed from that spoken by many of the research team members. Communicating raw data is crucial for the advisors to effectively supervise the student in an appropriate way. The target language was English for dissemination of the findings in a thesis and peer reviewed, international journals, however, local participants cannot speak English well or at all, and using their own language ensures that emotional aspects are captured (Baumgartner, 2012). Communicating the raw data in English, to the English speaking advisory team members, was necessary to ensure everyone could engage with the data analysis process and attest to its veracity and credibility.

A valid translation was essential to the process of data analysis as most research team members speak a different language than do the participants. Valid translation has a purpose to provide “conceptual equivalence” in meanings between raw data in the participants’ language (the Indonesian language) and English as a target language for composing the PhD thesis and related peer-reviewed publications (Nurjannah, Mills, Park, & Usher, 2014, p.1). Nurjannah et al. offer a tailored process of translation that was used during analysis. Further Nurjannah et al. explain that the process of translation should have a clear guideline about when the translation is performed, who will do the translation and the procedure of the translation. The translation was undertaken during the analysis so that the rest of the research team with a different language than the participants could be involved in the process of analysis (Nurjannah et al., 2014). To perform more rapid and closer meaning translations, the authors suggest that the original language (the Indonesian language) is used during the three essential coding processes: initial; intermediate and advanced coding (Nurjannah et al., 2014). The principal researcher who speaks both Indonesian and English carried out the translation. As one of the candidate’s advisors also speaks the Indonesian language, she checked the developed codes and categories in the Indonesian language before the principal candidate did the forward translation of the interviews, as well as of the developing codes and categories, to the other research team members (advisors). This decision was made because the candidate interviewed the participants in a local language (the Indonesian language) and knew the research process better than a professional translator. For a back translation of the theory (which is represented by a storyline), before the theory is ready for thesis submission or publication, the candidate asked the bilingual advisor to perform it. The procedure of translation was thus employed in each of the important stages of analysis and in building the grounded theory. Translation process was used in all three levels of the coding process, during research team discussions, in advanced coding and for confirmation of accuracy (Nurjannah et al., 2014).

Several papers have proposed some recommendations on how to deal with multiple languages during the study. For example using interpreters, hiring assistants (Santos, Black, & Sandelowski, 2015), hiring a professional translator and even an English teacher (Nurjannah et al., 2014). This recommendation can be effective for some projects. However, the ethical issue regarding data privacy, time and cost all need to be taken into account if translators are used from outside of the research team.

This study employed external paid professional translators minimally, because translators can distort meaning if they are not fully aware of the methodological/philosophical paradigm for the study. A professional translator was only used during back translation from English to Indonesia for information sheets and consent forms, as these documents did not require deep analysis. Details of the process are discussed further in this chapter.

Below is the summary of the use of two languages in the research process. The use of two languages began in the preparation phase, which was before the data collection/generation started, and continued through data analysis and dissemination.

Preparation for data collection/generation.

Before the data collection started, the candidate needed to prepare an information sheet and an informed consent form. Initially, the forms were produced in English. As the interviews were conducted in the Indonesian language, the forms needed to be translated to the Indonesian language. The candidate employed a professional translator to help her translating the information sheet and the informed consent form from English to the Indonesian language. During the translation process, there was some discussion with the translator about some terms/words to use. Consequently, once the candidate and the translator agreed on the terms, the final forms in the Indonesian language were produced.

Phase 1: data collection/generation.

The interviews were performed in the local language, the Indonesian language. This decision was made by considering the illiteracy rate for Indonesians and English as the second language in Indonesia. Another consideration is by using their local language, the participants can be more expressive in using their native language to explain their experiences and they may describe their experience more accurately (Baumgartner, 2012). The decision was also in line with grounded theory influenced by constructivism, where the researchers must enter the study setting and actually see the participant in person. As the candidate was a fellow local person, it was a proper decision for the candidate herself to conduct the interviews in the Indonesian language.

The candidate used the Indonesian language for performing the transcription and initial coding. However, two languages were used when she discussed the analysed data with her bilingual advisor on week four of the first field trip. When the candidate went back from the study site to Australia, the discussion of data analysis continued with her other advisors, and this time, the English language was used for most of the time. She also needed to translate the evidence written in the Indonesian language to English when explaining to her advisors. The transcript needed to be translated into English because this study included an advisory panel from English speaking country. Even though van Nes, Abma, Jonsson, and Deeg (2010) recommend that staying in an original language as long as possible this would have prevented other researchers engaging with the data and thus the advisory process would not have been effective. Thus the candidate decided to translate the excerpts that had prompted development of codes. This process enabled other advisors to get closer to the data and thus differences in meaning in English and Indonesian contexts could be discussed further to get closer meaning with original data. During the analysis, discussions via Skype and phone call also occurred between the candidate and her bilingual advisor back in Indonesia, especially when developing agreement regarding the most appropriate terms for developed codes or categories.

Phase 2: data collection /generation.

Similar to the previous phase, in this second phase of data generation, all interviews were conducted in the Indonesian language. Likewise, the transcription and initial coding were still undertaken in the Indonesian language. Discussion immediately after the interviews was performed in both languages with the bilingual advisor. Almost all the processes in this second phase were similar to those in phase 1 and so was the use of languages. In the intermediate and advanced coding, English language was used. During the analysis data in this phase, the candidate started to write a storyline in English.

Phase 3: data collection / generation.

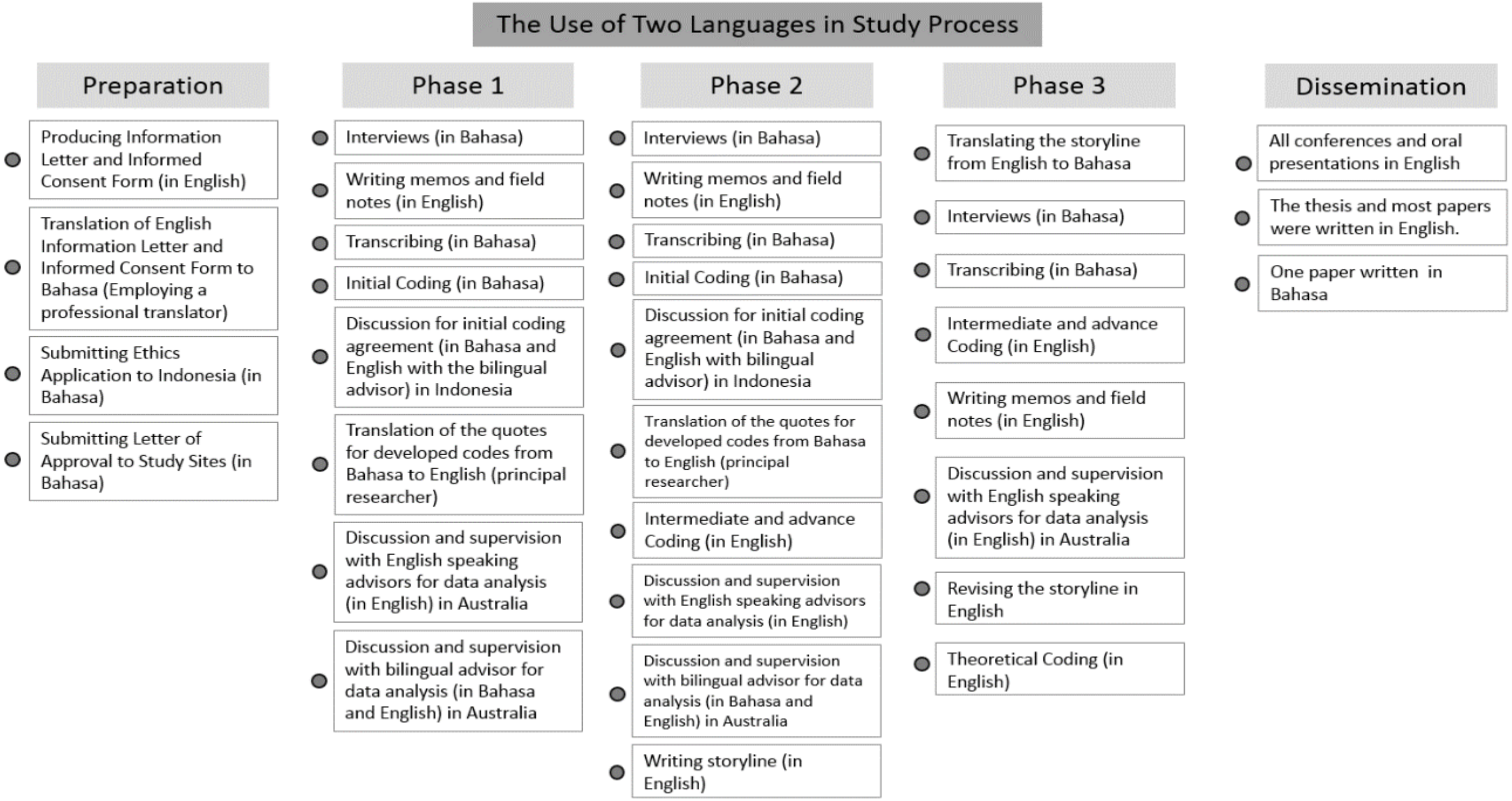
Firstly, the candidate together with her bilingual advisors translated the storyline and the concept map from English back to the Indonesian language. Then, the candidate distributed the storyline and the concept map to the participants. After the participants reviewed those documents, they were interviewed in the Indonesian language and transcriptions were carried out in the Indonesian language. The revised and refined storyline that resulted from this phase was then translated back to English and discussions during the revision were performed in either English or the Indonesian language with all advisors.

Dissemination of the findings.

There are several ways of disseminating research findings. The thesis has been written in English. Most of the related papers are in the process of being published or already published in English as the target language. However, one paper is going to be published in The Indonesian language in an Indonesian scholarly journal. All presentations at conferences were delivered in the English language because they were international conferences with English as the nominated language. Upon the candidate return home to Indonesia, further local and national oral presentations are planned, at conferences and healthcare facility services. Details of the use of two languages in the study process are also displayed in figure 4.3.

Figure 4.3 below shows how the candidate and her advisors had discussions during the analysis of data. For instance, during the development of a code, the candidate discussed the developed code with the bilingual advisor and agreed on the term used for labelling the code in English. Next, the candidate shared the developed code in English with her English speaking advisors. If the developed code was not clear or understandable in the English language, then the advisors asked the candidate to explain the meaning and then offered a better term that has a closer meaning. At this time, there were discussions around denotation versus connotation of the term. Further, the principal went back to the bilingual advisor to discuss the newly suggested term and at the same time the candidate checked the term with the raw data whether it had a closer meaning with the raw data. When it had a similar or closer meaning, the term was used as a code.

The candidate's decision to disseminate the Indonesian language version of the storyline was discussed in a paper entitled 'Using a Storyline for Bilingual Dissemination of a Grounded Theory'. This paper details how the candidate developed a storyline from English language to the Indonesian language and then disseminated the Indonesian language storyline to inform the research findings to Indonesian people in the study setting. The paper was submitted to Nurse Researcher journal and is now under review.



The Use of Two Languages in Study Process

Preparation

- Producing Information Letter and Informed Consent Form (in English)
- Translation of English Information Letter and Informed Consent Form to Bahasa (Employing a professional translator)
- Submitting Ethics Application to Indonesia (in Bahasa)
- Submitting Letter of Approval to Study Sites (in Bahasa)

Phase 1

- Interviews (in Bahasa)
- Writing memos and field notes (in English)
- Transcribing (in Bahasa)
- Initial Coding (in Bahasa)
- Discussion for initial coding agreement (in Bahasa and English with the bilingual advisor) in Indonesia
- Translation of the quotes for developed codes from Bahasa to English (principal researcher)
- Discussion and supervision with English speaking advisors for data analysis (in English) in Australia
- Discussion and supervision with bilingual advisor for data analysis (in Bahasa and English) in Australia

Phase 2

- Interviews (in Bahasa)
- Writing memos and field notes (in English)
- Transcribing (in Bahasa)
- Initial Coding (in Bahasa)
- Discussion for initial coding agreement (in Bahasa and English with bilingual advisor) in Indonesia
- Translation of the quotes for developed codes from Bahasa to English (principal researcher)
- Intermediate and advance Coding (in English)
- Discussion and supervision with English speaking advisors for data analysis (in English)
- Discussion and supervision with bilingual advisor for data analysis (in Bahasa and English) in Australia
- Writing storyline (in English)

Phase 3

- Translating the storyline from English to Bahasa
- Interviews (in Bahasa)
- Transcribing (in Bahasa)
- Intermediate and advance Coding (in English)
- Writing memos and field notes (in English)
- Discussion and supervision with English speaking advisors for data analysis (in English) in Australia
- Revising the storyline in English
- Theoretical Coding (in English)

Dissemination

- All conferences and oral presentations in English
- The thesis and most papers were written in English.
- One paper written in Bahasa

Figure 4.3. The use of two languages in study process.

Table 4.5: *Declaration of Authorship*

Chapter Number	Publication	Nature and extent of the intellectual input of each author including the candidate	Signature
4	Ligita, T., Francis, K., Wicking, K., Harvey, N., & Nurjannah, I. From Using a Storyline for Bilingual Dissemination of a Grounded Theory. *Nurse Researcher.*	Conception and design of the paper, data collection, data analysis and interpretation, Primary responsibility for writing the paper (80%), corresponding author responsible for preparing the final paper for submission, approval for publication version.	Ligita, Titan Content has been removed for privacy reasons
		Supervision of and contribution to the conception and design of the paper, data analysis and interpretation, writing the paper (5%), critical revisions for important intellectual content, approval for publication version	Francis, Karen Content has been removed for privacy reasons
		Supervision of and contribution to the conception and design of the paper, data analysis and interpretation, writing the paper (5%), critical revisions for important intellectual content, approval for publication version	Wicking, Kristin Content has been removed for privacy reasons
		Supervision of and contribution to the conception and design of the paper, data analysis and interpretation, writing the paper (5%), critical revisions for important intellectual content, approval for publication version	Harvey, Nichole Content has been removed for privacy reasons
		Supervision of and contribution to the conception and design of the paper, data analysis and interpretation, writing the paper (5%), critical revisions for important intellectual content, approval for publication version	Nurjannah, Intansari Content has been removed for privacy reasons

The method paper discusses how the candidate crafted the storyline during the analytical process of the grounded theory study. The paper can be a guide for future researchers about how to craft a storyline when using more than one language. Also, the paper can be an example that raises awareness to researchers that disseminating a storyline in the original language of the participants may help to more effectively disseminate the findings to the participants' local healthcare professionals or policy makers.

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Chapter Summary

This chapter has described the essential methods used in the research process. Three main phases of data generation were also described in detail. The candidate also explained the use of ethics approval and its amendments before the data was generated. In this study, several papers related to the study methods were also introduced and briefly discussed in the related section. The papers talked about theoretical sampling, concept mapping, and developing a storyline. In the further chapter, which is Chapter Five, the candidate will explain the study findings that consist of a storyline and the explanation of the theory.

Chapter Five: Findings

Grounded theory studies construct a theory that explains the basic social process that the researchers have investigated. Consistent with the methodology, a theory of *Learning, choosing, and acting: Self-management of diabetes in Indonesia* explains the process by which people with diabetes learnt about their chronic disease.

The Theory of Learning, Choosing, and Acting: Self-management of Diabetes in Indonesia

The storyline has provided an overview of the process of how people with diabetes in Indonesia learn about their diabetes and are provided with heath education related to diabetes. The process included five major categories, which together led to the development of the theory of *Learning, choosing, and acting: Self-management of diabetes in Indonesia* (Figure 5.1).

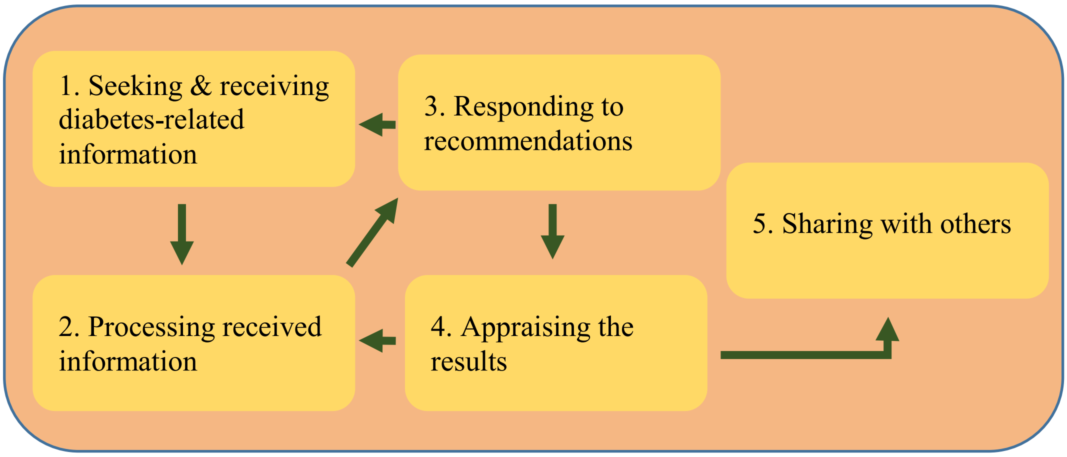

Figure 5.1. The Diagram of the theory of *Learning, choosing, and acting: Self-management of diabetes in Indonesia.*

As can be seen in figure 5.1, the process of *Learning, choosing, and acting: Self-management of diabetes in Indonesia* consists of five major categories and is dynamic, moving in both a linear and cyclical direction. People with diabetes initially proceed through all the first four major categories in a linear fashion. Then, when the person with diabetes moves to the phase of 'appraising the results', the movement can either be cyclical, by moving backward to the phase of 'processing received information'; or be linear by moving forward to the phase of 'sharing with others'.

A storyline which is a narrative explanation of the evolved theory was developed to explicate the grounded theory of how people living with diabetes learn about and access health education regarding their diabetes through the process of *Learning, choosing, and acting: Self-management of diabetes in Indonesia*. This process consists of the following five major categories:

1. Seeking and receiving diabetes-related information;
2. Processing received information;
3. Responding to recommendations;
4. Appraising the results; and
5. Sharing with others.

The storyline of this grounded theory study was regularly updated together with creation of memos and field notes that are considered common analytical tools used by grounded theorists. “A storyline is both an analytical tool and ‘a narrative presentation of a theory” (Birks, Mills, Francis, & Chapman, 2009, p. 410). The authors further explained that the storyline could serve additional purposes namely: facilitation of theoretical integration and dissemination of the results of the study (Birks et al., 2009). It is also used to facilitate a grounded theory researcher bringing the final theory to life and making it more obvious (Birks et al., 2009). In this study’s storyline, there are five major categories that support the process of *Learning, choosing, and acting: Self-management of diabetes in Indonesia,* as the core category.

The Storyline: The Process by Which Indonesian People with Diabetes Learn about Their Disease

People with diabetes learnt about their disease in two ways: by actively seeking information; and passively, by listening to, and reading information about diabetes that has been provided to them (*Category One: seeking and receiving diabetes-related information*). There were two distinct points in time that people living with diabetes sought diabetes-related information to understand their diabetes. Firstly, people with diabetes actively sought health information about their condition before they had been diagnosed, as they recognised body changes and wanted to find out what was happening. Secondly, people living with diabetes began to seek information actively, following confirmation of diabetes via a blood sugar level test and/or diagnosis by a medical doctor.

Actively seeking information was a continuous activity that started before and continued after a diagnosis of diabetes had been made. The approach to accessing information varied from before and after a diagnosis of diabetes was confirmed. Actively seeking information before they were diagnosed included self-initiated blood sugar level testing and seeking information from a medical doctor about body changes they had noticed. Actively seeking information regarding immediately noticed body changes occurred to ensure effective management and it involved anticipating what to do and how to prevent diabetes, clarifying issues of concern and asking recommendations. Sources of health information that people with diabetes actively sought were not limited to healthcare professionals. Relatives with diabetes, acquaintances, books and the Internet were also utilised. Books were read directly while many Indonesian people did not readily access information on the Internet as they were not information technology (IT) literate and/or had limited access to technology. It was more common for people to ask their family members to find the health information they desire on the Internet.

People with diabetes actively sought and passively acquired health information through listening and reading health information accessed from a variety of sources and places. Sources of health information included both healthcare professionals and non-healthcare professionals. Additional sources of information from materials included printed, electronic and audio-visual materials. Places where people with diabetes received information included interacting with others in the community, in healthcare facilities and at health seminars. People with diabetes continued to learn about their disease by processing the received information that included recommendations and explanations to inform their decision-making.

Seeking information was the starting point for people with diabetes; next they processed the received diabetes-related information that included largely recommendations for managing diabetes and explanations about diabetes (*Category Two: processing received diabetes-related information*). In processing received-diabetes related information, people with diabetes firstly sifted the information; that is, they considered all the information they had received and began a process of prioritising and/or dismissing information. People with diabetes used a variety of ways to sift information. Some relied on prior knowledge to determine the efficacy of the recommendations and explanations offered. Others used their experience as a filter when sifting the received recommendations and explanations. While some relied on their personal judgement to sift the information, others sought a second opinion either from people they perceived to have expertise and/or from websites. After people with diabetes sifted their received diabetes-related information, they then either trusted or distrusted that information. People with diabetes were influenced to accept the recommendations and/or explanations offered by the deliverer's expertise and the deliverer's lived experience. Once people with diabetes trusted or distrusted the information they had sifted, they then responded to the recommendations and/or the explanations offered. For those who distrusted the recommendations, they chose to ignore these. People with diabetes, who trusted the recommendations, then chose to either follow or not follow the recommendations.

Once people perceived recommendations as valid, they then made decisions as to what actions they took (*Category Three: responding to recommendations*). There were two ways that people with diabetes responded to the recommendations:

1. following recommendations 'in my own way'; or
2. not following recommendations

Three types of factors influenced how people with diabetes responded to information and recommendations that they perceived as trustworthy: physiological factors, psychological factors and resource factors. The physiological factors mentioned included: the increase of blood sugar level; weight loss; developing a wound; or a worsening complication, such as a deteriorating foot ulcer. There were also a number of psychological factors, which included: fear of the side effects of medication; fear of administering the medication; taking it as it comes; confusion when they are bombarded with information and asked to make choices about interventions; feeling hopeless about the disease; and their own personal preferences. Lastly, resource availability (or lack thereof) either promoted or hindered their response to the information. Relevant resources included: time; funding; pre-existing knowledge; geographical location; and issues of convenience and practicality, such as the availability of herbal components for them to mix up a substance themselves at home.

People who 'followed recommendations in my own way' chose one of these four options:

1. Fully following conventional therapies
2. Partially following conventional therapies
3. Taking non-conventional therapies exclusively
4. Concurrently following conventional therapies and non-conventional therapies

Current accepted conventional diabetes management includes taking prescribed medication, doing exercise, managing diet and monitoring blood sugar levels (BSL). Even though they followed the HCP's recommendations for diabetes management, not all people adhered to all four recommendations for diabetes management (medication, doing exercise, proper diet and monitoring BSL). Self-management by people with diabetes is recommended, however, levels of adherence varied. People with diabetes firstly determined whether they were capable of implementing self-management. If they did not feel capable, then they either delayed following the self-management plan, or they only partially followed the self-management plan. Those who partially followed self-management recommendations experienced feeling unwell and/or relapsed requiring hospitalisation to stabilise their diabetes. Partially following recommendations occurred when people haphazardly applied therapies to manage their diabetes and/or disregarded recommendations. Receiving incomplete information influenced whether a person followed self-management recommendations. For example, people who received incomplete information about what constituted a good diabetic diet, might have misinterpreted what they could eat, which subsequently impacted their BSLs. People who did not adhere to recommendations often experienced episodes of feeling unwell. This then prompted them to adhere to the recommendations, in order to re-establish wellbeing.

When people with diabetes chose to take non-conventional therapies alone, they used homemade traditional or herbal potions that were taken orally, or purchased and ingested factory-made herbal medication and/or wore a device on their body. The effectiveness of traditional or alternative therapies was unclear.

There were some participants with diabetes who followed conventional therapy and non-conventional therapy concurrently. They sometimes for example took herbal medications and sometimes took prescribed medications. Even though the therapies were not taken at the exact same time (hour), within one day these people might use both of these therapies. In other cases, they used different therapies on different days.

People with diabetes compromised their wellbeing by delaying to follow recommendations or choosing not to accept recommendations to manage their diabetes. They deliberated about whether they were able or unable to follow recommendations provided before they responded to the information they trusted. Those who delayed implementing the recommended management plan often chose to follow the recommendations when they perceived they were ready and able to follow the recommendations. Some participants chose not to follow the recommendations, even though they believed the information provided.

People with diabetes who choose not to follow recommendations including the medical treatment plans often underestimated the severity of their diabetes. Underestimating one's own diabetes usually occurred because people were not paying attention to their own wellbeing. Instead, they compared their own experience with those of others who also had diabetes. These persons often perceived others as having more 'serious diabetes' than themselves and thus they considered that their own diabetes was not as bad.

After individuals with diabetes made a decision to select their actions, they then appraised the results (*Category Four: appraising the results*). Their selected actions or responses of following or not following were evaluated at this phase. “Appraising the results' included three elements: 'measurement', 'progress' and 'further actions'. In measurement, they considered how they felt and they observed their bodily changes, either subjectively and/or objectively. Subjective measurement of their body changes included feeling good/comfortable with their body, having clear eyesight, being energetic and being alert. Whereas objective measurement included healing and/or healed wounds, maintenance of desired body weight and stabilised blood sugar levels.

When 'appraising the results', people with diabetes also considered the progress of applying the chosen actions (following or not following). 'Appraising the results' involved both positive and negative evaluations of their therapeutic management plan, their physiological response and other factors such as financial burden and time associated with maintaining the regimes. The product of 'appraising the results' was called experiential insight meaning that they learnt from evaluating their own responses to the recommendations.

These people used their insight to make further decisions that involved:

1. Sharing their insight with others or,
2. Using their insight as received information to be processed in category 2 ('*processing received information*').

When people with diabetes processed their experiences, they 'responded to the recommendations' by either opting to continue to follow them, or choosing to discontinue following them. People with diabetes who chose to discontinue or not to follow the applied recommendations then chose to either: modify the existing recommendations to better suit themselves or they actively sought different recommendations. When they trusted there was a positive result either objective/subjectively, they maintained the applied recommendations as the experience of positive results increased their motivation to continue. When they felt there was negative results or no progress with the treatment or therapy they had been practicing, they discontinued the current therapy and began to alter their actions; for example, by following recommendations of the HCP or by seeking other recommendations. In seeking other recommendations for diabetes management, they went back to *category one ('seeking and receiving diabetes-related information')*. Seeking and trying for another diabetes management action continued until they found a result that convinced them, as their own belief about whether or not it worked for their diabetic condition predominated over the recommendations or information that they had received from other sources outside themselves.

During the application of their selected response to the recommendations, people with diabetes sometimes discontinued the applied recommendations. Discontinuation happened for several reasons. The first reason was that people with diabetes were informed that the currently used diabetes care recommendation was harmful for them. The second reason was that people with diabetes became bored with maintaining a lifetime medication regime. The third reason for discontinuing the application of current recommendation was that the therapeutic substances used were no longer available.

Once people have had the experiences themselves, then they were able to share the insight they gained with other people (*Category Five: sharing with others*). There were various things to share with others such as how to recognise the symptoms of diabetes, the benefit of diabetes management and even the mistakes to avoid. Other people with whom the information was shared were mainly other people with diabetes, but could also include their own relatives or family members who do or do not have diabetes and other people with relatives living with diabetes. The insight shared with a person with diabetes may then become the starting point of that person's own process of *Learning, choosing, and acting: Self-management of diabetes in Indonesia*.

Family had an important role for people living with diabetes. They were involved in the initial phase of actively seeking information and being informed that their family member has diabetes and were also involved in receiving and selecting information regarding planning future diabetes management. The individual with diabetes cannot be separated from their family, and thus the influence of the family members who supported these people was also identified in all five parts of the process of *Learning, choosing, and acting: Self-management of diabetes in Indonesia*.

The Grounded Theory: How Indonesian people living with diabetes learn about their disease

The chapter is inclusive of three peer-reviewed manuscripts, including one in the Indonesian language. The first paper discusses the finding that explains the theory inclusive of the five major categories. Evidence from the participants was included in the paper, however, further evidence that adds more support to each of the categories will be explained in the thesis.

The overall findings of this present study are described in the manuscript 'How people living with diabetes in Indonesia learn about their disease: A grounded theory' submitted to the *PLoS* One journal that is 'Accepted' (Permission information is in Appendix A). The paper is detailed below.

Table 5.1: *Declaration of Authorship*

Chapter Number	**Publication**	**Nature and extent of the intellectual input of each author including the candidate**	**Signature**
5	Ligita, T., Wicking, K., Francis, K. Harvey, N., & Nurjannah, I. (*In press).* How people living with diabetes in Indonesia learn about their disease: A grounded theory study. *PlosONE.*	Conception and design of the paper, data collection, data analysis and interpretation, Primary responsibility for writing the paper (80%), corresponding author responsible for preparing the final paper for submission, approval for publication version.	Ligita, Titan Content has been removed for privacy reasons
		Supervision of and contribution to the conception and design of the paper, data analysis and interpretation, writing the paper (5%), critical revisions for important intellectual content, approval for publication version	Wicking, Kristin Content has been removed for privacy reasons
		Supervision of and contribution to the conception and design of the paper, data analysis and interpretation, writing the paper (5%), critical revisions for important intellectual content, approval for publication version	Francis, Karen Content has been removed for privacy reasons
		Supervision of and contribution to the conception and design of the paper, data analysis and interpretation, writing the paper (5%), critical revisions for important intellectual content, approval for publication version	Harvey, Nichole Content has been removed for privacy reasons
		Supervision of and contribution to the conception and design of the paper, data analysis and interpretation, writing the paper (5%), critical revisions for important intellectual content, approval for publication version	Nurjannah, Intansari Content has been removed for privacy reasons

The first findings paper explains the overall findings of this study by using supporting evidence from the participants’ voices. In this paper, all main categories were included, demonstrating the explanatory power of the theory.

PLOS ONE

How People Living with Diabetes in Indonesia Learn about their Disease: A Grounded Theory Study

--Manuscript Draft--

Manuscript Number:	PONE-D-18-18484R2
Article Type:	Research Article
Full Title:	How People Living with Diabetes in Indonesia Learn about their Disease: A Grounded Theory Study
Short Title:	Indonesian People Learn about their Diabetes
Corresponding Author:	Titan Ligita James Cook University Townsville, QLD AUSTRALIA
Keywords:	Chronic Disease; diabetes care; experiential insight; Grounded theory; health education; Indonesia; learning; process; qualitative research; Type 2 diabetes mellitus; self-management
Abstract:	Background: Diabetes education has been found to impact positively on self-management by people with diabetes although little is known about the process by which they assimilate information. The aim of this study was to generate a theory explaining the process by which people with diabetes learn about their disease in Indonesia. Methods: This study employed a grounded theory methodology influenced by constructivism and symbolic interactionism. A total of twenty-eight face-to-face or telephone interviews with participants from Indonesia that included people with diabetes, healthcare professionals, health service providers and families of people with diabetes were conducted in both Indonesia and Australia. Results: This study discloses a core category of Learning, choosing, and acting: self-management of diabetes in Indonesia as the basic social process of how people learn about their diabetes. The process includes five distinctive major categories. People with diabetes acted after they had received recommendations that they considered to be trustworthy. Factors that influenced their choice of recommendations to adopt are also identified. Conclusions: Awareness of the complexity involved in their decision making will assist healthcare professionals to engage effectively with people living with diabetes.
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Additional Information:	
Question	**Response**

Abstract

Background: Diabetes education has been found to impact positively on self-management by people with diabetes although little is known about the process by which they assimilate information. The aim of this study was to generate a theory explaining the process by which people with diabetes learn about their disease in Indonesia. *Methods:* This study employed a grounded theory methodology influenced by constructivism and symbolic interactionism. A total of twenty-eight face-to-face or telephone interviews with participants from Indonesia that included people with diabetes, healthcare professionals, health service providers and families of people with diabetes were conducted in both Indonesia and Australia. *Results:* This study discloses a core category of *Learning, choosing, and acting: self-management of diabetes in Indonesia* as the basic social process of how people learn about their diabetes. The process includes five distinctive major categories. People with diabetes acted after they had received recommendations that they considered to be trustworthy. Factors that influenced their choice of recommendations to adopt are also identified. *Conclusions:* Awareness of the complexity involved in their decision making will assist healthcare professionals to engage effectively with people living with diabetes.

Introduction

Abundant studies have shown that health education is critical for people living with diabetes, as the information provided assists them to self-manage their condition, maintain their blood glucose level (BGL) within a healthy range and prevent deterioration [1,2]. Health education improves people's health literacy [3]. Health literacy refers to people using their skills, knowledge, abilities and experiences to seek, understand and take action on health information and consequently make a decision about health care as well as find and use health services [4]. Therefore, education allows people to become empowered and autonomous when making important decisions regarding their health [5]. When people engage in educational programs there is a positive link to better health outcomes for that person, which enhances their overall health and wellbeing [6-9]. Conversely, people that do not engage in health educational programs are more likely to make poor health decisions and engage in harmful self-management practices.

Educational programs provide information to highlight the importance of treatments to effectively manage diabetes and prevent complications, with the aim of promoting self-care management [7,10]. Educational guidelines assist people with diabetes to understand the rationales for recommended interventions, such as: regular BGL monitoring; administration of insulin and oral hypoglycaemic medications; low sugar diet; and lifestyle changes [1].

Unfortunately, participation in diabetes educational programs is limited [7] because of financial, medical and logistical (access) reasons [11]. This paper will explicate the process of how people with diabetes in Indonesia learn about their disease, which is crucial in trying to help improve the health outcomes for Indonesian peoples. Furthermore, an exploration of the experiences of people with diabetes will be shared so that the process of how they receive and then engage with education can be better understood, with the aim of providing more effective diabetes educational programs in the future.

Background

Diabetes in Indonesia is considered a major health problem and has been a concern since the early 1980s [12]. With more than 10 million people living with diabetes, Indonesia has a prevalence rate of 6.2% [13] and diabetes is one major cause of death [14]. Indonesia was rated as one of the top ten countries globally with a high number of individuals living with diabetes in 2013 [15]. It is predicted that the same pattern will continue [15] unless interventions to prevent and manage diabetes are implemented.

To address the alarming numbers of Indonesian people with diabetes, diabetes experts have developed guidelines for preventing and managing diabetes [16]. Managing diabetes is crucial to prevent people from experiencing severe complications such as neuropathy, nephropathy, retinopathy, microvascular and cardiovascular disease [17-20]. Pharmacologic therapies such as oral medications and insulin, and non-pharmacologic therapies such as lifestyle modifications are still considered contemporary interventions for managing diabetes [21]. These interventions can only be implemented and achieved through diabetic educational programs that promote self-care management [22].

Healthcare services in Indonesia provide some effective diabetes educational programs [6,8,23]. The availability of certified diabetic educators is limited in Indonesia [24] resulting in a dearth of skilled health care professionals (HCPs) to provide education to people with diabetes [25,26]. There is little evidence available about the process of how people with diabetes learn about their disease after they have received diabetes related information informally or formally through structured educational interventions in the Indonesian context. We used a grounded theory methodology to gain insight into how people with diabetes learn about their disease and the processes by which they received and engaged in diabetes health education. Understanding this learning process has the potential to assist HCPs to develop and make available effective, creative and culturally-responsive diabetes health education to inform people with diabetes in their selection of appropriate self-management strategies.

Grounded theory study

Ethical approvals to conduct the study were obtained from the Human Research Ethics Committee at James Cook University and from the local Research Ethics Board at the Faculty of Nursing, Universitas Indonesia. The research study avoided coercion because only participants who volunteered to participate in the study were interviewed. Before the interviews were performed, we provided the participants with information sheets and written consent forms. The interviews started once the participants had read and signed the informed consent forms.

Methodology

This study employed a grounded theory methodology. Originally established by two scholars Barney Glaser and Anselm Strauss, grounded theory is a qualitative research methodology aiming to generate a theory grounded from the data [27]. The generated theory then explains the study phenomena. Two philosophical stances influenced this grounded theory study. Firstly, symbolic interactionism whereby people's lives and behaviours were explored [28] and secondly constructivism, the process of how people understood their diabetes (meanings) and how that understanding subsequently informed their actions [29]. In this grounded theory study, we generated and concurrently analysed data. To rigorously employ grounded theory methodology, we used the essential methods of grounded theory in the selection of study participants (purposeful and theoretical sampling) and in the collection and analysis of data [30]. When using a purposeful sampling method, potential participants are targeted who are considered suitable to provide insights that will allow exploration of the phenomenon of interest [31]. However, theoretical sampling is unique to grounded theory, and is a method in which more data are gathered to define and refine the relevant developing categories or emerging theory [32].

The data were analysed by using constant comparative analysis through three stages of the coding process: initial coding, intermediate coding and advanced coding. Data were managed and organised through the NVivo software version 10 [33]. The process of analysis occurred through constant comparative analysis, which is referred to as comparing the data, specifically, comparing incidents with incidents, incidents with codes, codes with codes, codes with categories and categories with categories [30]. The comparisons were also applied between existing data and incoming data. For example, in the incoming data, new codes were developed. Then these new codes were compared with the formerly developed codes (existing data). Also, codes developed in one interview excerpt were compared with codes developed in other excerpts of the same interview, or codes developed in other interview excerpts.

Coding is defined when the analyst applies labels to data fragments and as a result the data has a connection to theory development [29]. In the initial coding stage, raw data was broken down into fragments and labels were attached to the data. This process produced codes. A process code was labelled when coding conceptual actions or observable activities and they are written by using the gerund form or ‘ing’ words, for example ‘seeking’ [29,34]. Initial coding took place both during the first and second data generation field trips.

Codes developed during initial coding were collapsed in intermediate coding, which is sometimes referred to as focused coding. At this stage, significant codes were selected to form categories [32]. Categories were then developed from these codes while continuing to apply constant comparative analysis. During the next stage of analysis, advanced coding, one core category was selected and it comprised a theory entitled *Learning, choosing, and acting: self-management of diabetes in Indonesia.* This core category has five major categories that elucidate the process of how people with diabetes learn about their disease.

Additionally, essential research aids such as: memo writing; concept mapping; field notes; and storyline were also employed to assist with analysis and theoretical integration. This study employed concept mapping as an analytical tool to explore the data and to link codes, categories and sub-categories. A storyline was crafted, as a tool for explaining the theory and was regularly updated during data analysis. Both the concept map and the storyline explain the theory entitled *Learning, choosing, and acting: self-management of diabetes in Indonesia.*

Participants and study settings

The study was conducted in West Kalimantan, which is one of the 34 provinces in Indonesia and inhabited by three major ethnic groups. West Kalimantan has a high prevalence rate of diabetes. It was noted by the Indonesian Basic Health Survey that the prevalence rate of diabetes mellitus in that province rose from 0.8% in 2007 to 1% in 2013 [35,36]. A total number of 28 interviews were undertaken with participants from both inpatient and outpatient settings in and around Pontianak, the capital city of West Kalimantan province.

Study Design

This three phase study was undertaken between April 2016 and July 2017. All interviews were carried out in the national Indonesian language. The Indonesian language was also used during the three essential coding processes: initial; intermediate and advanced coding. Hence, a bilingual advisor was included on the research team to assist with the process of translating the interviews and analysing the data. For anonymity and confidentiality, pseudonyms are used when reporting participants' quotes.

Phase one

Purposive sampling was used to select the participants in phase one and a scoping review also helped to inform which HCPs should be involved [25]. A scoping review is a framework that systematically reviews and scopes the available qualitative and quantitative literature to answer the questions and identify the nature of evidence in research studies [37-39]. Participants consisted of a person with diabetes, a nurse academic, outpatient clinic nurses, a pharmacist, a dietician and a specialist doctor. They were recruited from two general hospitals, a public health centre (*Puskesmas*) and a nursing academic institution in Indonesia. Each participant participated in a face-to-face interview, which was digitally recorded and conducted by the lead researcher in West Kalimantan. In this phase, concept mapping was employed.

Phase two

Data from the first phase led to further data gathering. As the analysis proceeded, theoretical sampling was used to select the next data that included a wide range of participants and additional research settings. Ethics amendment approval was obtained and a wider range of participants were recruited from additional settings, such as a private wound care clinic and two other public health centres. Interviews with a further 17 participants were again performed in person in Indonesia. They included eight people with diabetes, a general practitioner, a ward nurse, a nursing student, three family members, a health promotion staff member, an exercise instructor and a *kader* (an Indonesian term for a lay health worker). In this phase, an initial version of the storyline was crafted.

Phase three

Theoretical sampling directed phase three. The aim of this phase was to refine the storyline in order to facilitate the theory integration process. This process was to determine if the theory was suitable for the area from where it was generated and where it will be used [40]. Two participants were re-interviewed who were involved in the previous phases; an exercise instructor living with diabetes and a nurse academic. The two new participants were recruited and interviewed; a clinic nurse and a person with diabetes. All interviews were conducted via telephone from Australia to Indonesia with each of the 4 participants. Before the interviews, participants were provided with a storyline and a concept map written in the Indonesian language.

Results

Learning, choosing, and acting: self-management of diabetes in Indonesia

Learning, choosing, and acting: self-management of diabetes in Indonesia is the core category of this study that explicates the process of how people in Indonesia with diabetes learn about their disease. The process consists of five categories, which are the stages that people with diabetes navigate when learning about their disease: ‘seeking and receiving diabetes related information'; 'processing received information'; 'responding to recommendations'; 'appraising the results'; and 'sharing with others'. The process is displayed in Fig 1.

Fig 1. A process of Learning, choosing, and acting: self-management of diabetes in Indonesia. This diagram represents a theory of *Learning, choosing, and acting: self-management of diabetes in Indonesia*, a basic social process of how people with diabetes in Indonesia learn about their disease. The numbers show the categories of the process that occur in chronological order. This process occurs dynamically, both in linear and cyclical movements.

Category 1: Seeking and receiving diabetes-related information

This category can occur before and after people have been diagnosed with diabetes. Before the diagnosis, people with diabetes noticed or recognised their symptoms and gathered information about their disease through active and passive learning techniques. Active learning means that people asked questions of others or sought information from sources such as the internet, television or written materials. Once they were diagnosed, they actively sought information about the management of the disease, clarification about therapies being used, and explanations about why they were experiencing bodily changes related to the medication used. One example of this was Widya, an exercise instructor who has diabetes:

> *I asked questions about what diabetes is. ... One [recommendation] that I got is to do exercise. I asked my friend who was in the nutrition division. She said, '"Do some exercise, try to do exercise". (Widya: G2P14)*

Passive learning refers to receiving and listening to information from other people, commonly HCPs, without requesting the information themselves. This situation usually occurred when people with diabetes visited healthcare facilities such as an outpatient clinic or during hospitalisation. Information was then offered as part of the clinic consultation or in the case of hospitalisation, by HCPs caring for the person. For example, a pharmacist reflected on the explanations he provided:

> *…to [make people with diabetes] understand about the effect of taking medicine regularly and irregularly. We provide the explanation as such. In educating [them], we provide information in order to prevent complications from diabetes (Cahyo: G1P10).*

The source of the information (i.e. who delivers the information) and the place the information was given, varied. Sources of information, from HCPs, included: doctors (e.g. general practitioners and medical specialist doctors); nurses (eg. ward nurses, outpatient care nurses); dieticians; and pharmacists. In addition, non-HCPs may also be sources of information: *kaders*; health promotion staff at hospitals; nursing students; family members; friends; people with diabetes; and/or individuals who have a relative living with diabetes. The places where information was received included: healthcare facilities such as hospitals and outpatient clinics; within their communities when interacting with others; and/or attending health seminars. Haris is an example of someone who sought information from a non-HCP, his little brother:

> *I was eating and drinking enough... [but] the body was limp, no energy. I just wanted to have a rest. ... I asked my little brother. He has diabetes before me. So I asked my brother why I have this unwell condition. He brought me to the medical [clinic]. I was checked up... everything was checked up. My blood*

> *sugar level was 488 [mg/dL]...very high. My little brother advised me. So, from there I started to learn how... yes... I take care of it [eating or drinking] until now. (Haris: G2P1)*

Category 2: Processing received information

The second category is processing the information received. Before the person could trust the information, they examined the information based on their prior knowledge, own experiences and personal judgement, as well as asking for a second opinion from who or what they believed to be a reliable source. Next, they had a choice, to trust or distrust the information. The distrusted information was dismissed while the trusted information was accepted. Larisa, a person living with diabetes, did not trust information given to her by friends and she decided to dismiss it:

> *They [friends] usually take alternative therapies. I do not trust the alternative therapies. I do not know the measurement, the amount, [and] the dosage. If we have over dosage, we'll have difficulties. ... So when my friends said "take this...take that". I just said "yes... yes... ", but I did not take it. Unless it is authentic and there is a study/research on it, then I can understand it. If not, I do not trust it. I do not easily trust something (Larisa: G2P7).*

Zeta, another person with diabetes, also sought additional information to clarify her understanding of what medication could be used to manage her diabetes:

> *I received other people's opinion and advice or friends' advice. ... I do not just directly execute any received advice. No. I have to look at Google, [for instance, about] the function of leaves A or leaves B. The side effect of them. (Zeta: G3P1)*

Category 3: Responding to recommendations

Individuals responded in either of two ways; they followed the recommendations suggested by either HCPs and/or non-HCPs or they did not follow recommendations from the HCPs or non-HCPs. The HCPs recommended conventional therapeutic interventions while non-HCPs suggested both conventional and non-conventional therapeutic interventions. There were a number of influencing factors that affected a person's decision to follow or not to follow recommendations. These were: financial situation; time; geographical location; recommendations from relatives and friends; physiological reasons such as changes in the body or worsening symptoms; psychological reasons such as fear of side effects from the medication, fear of having to inject medication and underestimating the disease severity; and issues of convenience and practicality (See Fig 2).

Fig 2. Responding to recommendations. This figure shows how people with diabetes responded to recommendations by either following or not following the recommendations. Their decisions were influenced by three factors: physical, psychological and availability of resources. People with diabetes selected one of four variations of responding to the recommendations.

Utama, a diabetic of 8 years, offered that he was influenced by his older sister who told him he would become dependent on insulin, so then he did not follow the HCPs' recommendations:

> *I am afraid of becoming dependent on the medication, my sister said 'don't you use that insulin. If you use once, it will be forever'. My sister continued*

> *to say that right up until her death [from diabetes complications]. (Utama: G2P5)*

The above quote shows that Utama followed his (older) sister's recommendation rather than the recommendations from his HCP. He respected his sister's experiential insight gained from living with the disease, but he also demonstrated respect for someone older than himself, which is a norm in Indonesian culture [41]. Utama was afraid of taking his prescribed insulin for two reasons: the above fear of becoming dependent as per his older sister's recommendation, and an additional fear of injecting insulin:

> *I have been prescribed insulin but I don't use it. I have never [used it]. I have been prescribed [insulin] when being discharged from the hospital. ... I am afraid to inject it [the needle]. (Utama: G2P5)*

Betty, a diabetic of 13 years, delayed commencing insulin injections for a year because of cost, inconvenience and fear of having to give herself an injection:

> *Firstly I didn't want to. For a year I didn't want to. I was really afraid of [injection]. Doctor B who keeps talking to me a lot. It has been a year [since] he told me to have an insulin injection. ... I did not want to because insulin is troublesome. I have to check my blood sugar by myself. Then if [the blood sugar] decreases [too much], [I will have] faintness, [and] I cannot go anywhere. I thought for a year. I did not want. But [I was] getting thinner. (Betty: G2P2,3,5)*

Another reason to delay treatment was when people with diabetes underestimated the severity of the disease when comparing their experience of diabetes with other people's. They often perceived that their diabetes was 'not too bad' compared to other people whose diabetes they believed was more severe. Utama explained his diabetes was not as significant compared to his sister who had died as a result of a diabetic foot ulcer:

> *… in the last four years, I just combat [the disease]. People say that we don't need to… worry about this disease. If I think too much, it will be harder so I don't think about it too much. Now, I think my disease is not too severe. I haven't got the one that my sister had. My sister had a hole [diabetic foot ulcer]… I am not that severe. I only have these boils. It hasn't been severe. Not like other people who have a small wound then it gets swollen…. No, I am not like that [not that severe]. (Utama: G2P2)*

Ranti, a diabetic of four years, was concerned about the drug's side effects on her body:

> *She [the doctor] gave me a medication…. I do not take doctor's medication [anymore]... [because of] the chemical [materials]. I took the medication from the doctor only for one week. (Ranti: G2P1)*

In addition to individuals who chose not to follow recommendations, there were individuals who only followed recommendations that they trusted, but did so with varying levels of commitment. Under the umbrella of following recommendations in their own way (see Fig 2), they either fully followed conventional therapeutic interventions; partially followed conventional therapeutic interventions; used non-conventional therapeutic interventions exclusively; and/or followed conventional and non-conventional therapeutic interventions concurrently.

People who fully followed conventional therapeutic interventions reported adherence to medication(s), exercise, diet and BGL monitoring. People who partially followed conventional therapeutic interventions tended to adhere to one or two interventions only. Kevin, a person with diabetes, stated he only took the medication.

> *I cannot restrict my diet. I still have appetite to eat. [I do] regularly [take my medication]. ... [I] never had [diabetes exercise]. It's in PHC but I do not want to, [because] I am lazy to do [so]. (Kevin: G2P2,5)*

People who used non-conventional therapies exclusively did not take prescribed medication of any kind or any other conventional therapeutic interventions. These people relied on non-conventional therapies such as herbal or traditional medication, factory-made herbal medication or a device worn on their body. One person wore a magnetic girdle, as she believed it to be beneficial in helping with her diabetes.

> *I wear this supporting device. [It is like a corset/waist belt]. For what I have known, it repairs... Diabetes occurs because our pancreas is damaged... The pancreas cells are damaged. Or kidneys [are damaged]... If we take many medications [and] drink less water, it can damage the kidneys. So, I am helped by buying this device so that my kidneys will be good. This device only contains [a] magnet. (Ranti: G2P4)*

The final subset of people used both conventional and non-conventional therapeutic interventions, or alternatively chose to *follow the recommendations,* but *in their own way.* This subset of people chose to trial both therapies either consecutively or concurrently for a short period of time. Kevin, a diabetic of five years, indicated that he sometimes took both conventional and non-conventional therapies concurrently:

> *I take prescribed medication by turns [intermittently], sometimes I also take herbals. (Kevin: G2P1)*

The phenomena of taking conventional and non-conventional therapies concurrently was a concern for HCPs, who feared that people may be at risk of hypoglycaemia. Aditya, a nurse academic and clinician, explained that he occasionally consulted with people with diabetes who took both therapies in the same day. He stated:

> *There were also some patients telling us "I have taken this [non-conventional therapy] but I took medication from the doctor concurrently. I separated it by approximately two hours". After we tested the BGLs, it showed that the BGLs were stable. The most important thing that we educate about is the hypoglycaemia. "If you take the therapy and you have these symptoms [hypoglycaemia symptoms], it means that you have to stop the herbal". (Aditya: G3P2,3)*

Category 4: Appraising the result

Regardless of whether the person followed or did not follow recommendations advocated by HCPs and non-HCPs, these people appraised the results to determine if what they were doing was making any difference to their health. There are three sub-categories of 'appraising the result': measurement, progress and further actions. People with diabetes observed their body changes either subjectively or objectively for positive and negative changes or for no changes. For instance, Oscar demonstrated appraising the result by objective measurement:

> *I tried [herbal therapy] from browsing the internet. It really decreased it [the BGL]. Then I became more motivated to take it [the therapy]. It decreased it [the BGL] again. (Oscar: G2P3,4)*

In the following quote, Zeta found desirable (positive) changes related to her diabetes condition:

> *Zeta: I was suggested to take herbal, a product from New Zealand. It's a capsule... I was observed [by optometrist] regularly on my eyes. Alhamdulillah [thanks be to God] the [blurred eyes] are gone. I feel comfort in my body. (Zeta: G3P3,4)*

Whereas, Haris expressed that he had been taking traditional medication, but when he reflected on how it was working he found it had made no difference to his condition:

> *I firstly didn't want to have chemical medication. By taking the traditional medication that I made by myself, I might find the solution, but in fact, there wasn't. No change [progress]. (Haris: G2P5)*

People in this category used their experience to decide whether they would continue with what they were doing or not, to manage their diabetes. Viola, a spouse of a person with diabetes recounted her decision to modify how they managed her husband's diabetes:

> *We tried a herbal medication for several years. No progress. So, we decide to be managed by a doctor. To regularly go to doctor consultations so that he [the husband] can get better. (Viola: G2P8)*

The outcomes that people identified were based on their lived experiences. The category of *processing received information* refers to the 'experiential insight' that people developed, that in turn then helped them decide whether to continue or discontinue their current treatment and whether or not to return to category 1 to seek further information or recommendations, thus illustrating the cyclic nature of the process.

Category 5: Sharing with others

The last category is 'sharing with others'. Sharing with others encompasses what information to share and with whom to share it. People tended to share their experiences with people they knew best, particularly family members such as children or spouses. Haris recounted:

> *I keep looking forward and prepare myself. I said to my wife and children. 'I have this disease. This disease [can] affect anywhere [inside the body].' I inform them so that they know. I am not frightening them. One day it will happen. With or without the disease, we will all die. But with [me having] this disease, I said, 'you must be aware of... you must change your life concept. You must keep healthy. Don't be careless'. (Haris: G2P8,9)*

Through interactions in the community, people with diabetes shared their own insights with other diabetics and also with people in the community who may have a loved one with diabetes. When people with diabetes shared their experiences with another person, that conversation was often the beginning of that next person starting their own process of *Learning, choosing, and acting: self-management of diabetes in Indonesia.* Fig 3 displays the phenomenon of a person with diabetes sharing insight or experience with another person living with diabetes.

Fig3. A sharing phenomenon among people with diabetes. This figure shows how the process of *Learning, choosing, and acting: self-management of diabetes in Indonesia* occurs from one person with diabetes to another person with diabetes. The process starts when a person with diabetes shares their experience or information with another person with diabetes. The process of sharing information continues from one person, to the next, to the next, etc.

Utama shared his own experiences with other people he knows who are also living with diabetes:

> *I often inform them. It is about the symptoms. They do not know what diabetes looks like. I said, 'if you want to prove whether you have diabetes or no, you collect your urine. If there are ants in there, you may have diabetes. The symptoms are dizzy, fatigue, weakness and thirsty. You just want to drink water or sweet drink.' Those are the symptoms [that] I said to them. (Utama: G2P10)*

Discussion

Where is diabetes related information sourced from?

It is not uncommon for people with diabetes, especially those who experience severe symptoms, to seek information and recommendations from HCPs [42]. People with diabetes involved in our study also sought information from a variety of people other than HCPs, namely: friends, acquaintances and family members. This result is congruent with a study conducted in India, where people with diabetes learned about their disease through a variety of sources such as books, media and friends [43]. When a diversity of sources are used, there is a high risk for people to be exposed to less reliable or unreliable recommendations.

Recommendations from others may influence people's decisions to stop, alter or to maintain their current diabetes care. In this present study, people sometimes discontinued practices after receiving information from non-HCPs. They also may have changed from using conventional therapies to non-conventional therapies, or vice versa. Hjelm and Atwine [42] reported that people seek non-conventional therapies, such as herbal medications or traditional healers, when they perceive that conventional therapy has failed them. This study found that receiving recommendations from HCPs does not preclude people from also seeking information elsewhere, similar to Mendenhall et al.'s [43] findings in India.

Choosing information

People with diabetes selected information based on their prior knowledge, lived experience personal judgementand/or other people's opinions. Additionally, the level of expertise of HCPs and the lived experience of other people with diabetes were also taken into account. People with diabetes trusted the opinions of other people living with diabetes and were sceptical of the recommendations of people who were not diabetic. Sometimes, people with diabetes accepted recommendations from their relatives, who were living with diabetes, rather than the recommendations of their HCPs. The recommendation from the HCPs that people with diabetes in this study chose not to follow usually centred around taking prescribed medications. Many of the study participants believed that the chemical substances in prescribed medications would cause more harm than good, thus they decided not to follow the HCP's recommendation. In contrast, some participants who did follow the recommendation from their HCPs rather than from other people, did so because they acknowledged their HCP's level of expertise. Therefore, they put more trust in their HCPs rather than in non-HCPs.

Building trust between people with diabetes and HCPs is crucial during the provision of care. A previous study did find that in general, satisfaction and adherence with diabetes treatment is associated with better communication between people with diabetes and their HCP [44]. However, this present study provides additional explication of that communication process, by showing how people with diabetes selectively choose which HCP information they will or will not trust and follow. White et al. [45] also found that a high level of mistrust can develop because of poor HCP communication skills and not including people in decision making about their own health. When HCPs do not involve people in their care, it may impair the development of a positive partnership between the person and their HCP.

Following or not following recommended therapeutic interventions

Individuals in this study chose to adopt conventional and/or non-conventional therapies. This phenomenon is similar to that described by Mendenhall et al. [43], where some people reported using medical treatment (conventional) while others also reported using non-allopathic (non-conventional) therapies such as herbal medications, yoga and foods. However, the findings of this study are distinctive in showing that some people with diabetes elected to partially follow recommended conventional therapeutic regimes. Some people sometimes follow the recommendation in their own way by modifying the recommended therapeutic regime based on their own understanding. Their modifications could render the treatment ineffective or even harmful. This finding aligns with those of Webster et al. [46] who found people can develop questionable strategies to manage their diabetes when communication with their HCPs has failed. This phenomenon should be acknowledged by HCPs to ensure people with diabetes understand and are able to implement the therapeutic strategies proposed by the HCP rather than their interpretation or modification of that proposed strategy.

Resource issues, such as affordability and accessibility of therapies, were found to be factors influencing peoples' decisions to follow recommendations in this present study. Others factors were physiological and psychological reasons. Even though people in this study could and did make their own decisions, they ideally should be guided by a HCP so that appropriate therapies are implemented. Therefore, our findings indicate that HCPs need to identify what challenges people with diabetes have encountered in following the recommendations from their HCPs and to then work together to see how those challenges can be resolved. Lee et al. [47] also found that during consultation, the HCP needs to consider each person's knowledge level, personal traits, family supports as well as their awareness of diabetes medications and available treatment options. Our findings echo the Australian College of Nursing's statement that involving the person in decision making demonstrates the HCP's respect for the person and exemplifies a person-centred approach to care [48]. Our findings are congruent with those of Herlitz et al. [49] and Ramsay Wan, Vo and Barnes [50] who found that people who trust their HCPs and feel empowered to ask questions and make informed decisions are more likely to effectively manage their diabetes [49,50].

Respecting one's cultural background should be acknowledged when HCPs work with people with diabetes. Due to cultural influences, some people with diabetes in this study still believed in and preferred the use of natural substances, either solely or in combination with prescription medicines, as their way of managing their diabetes. The use of natural substances has been practiced by Indonesian people for generations for disease treatment [51]. The use of natural substances for disease management may still be practiced by people who live in rural areas and have limited access to prescription medication [52]. The cultural context must be taken into account when working with Indonesian people with diabetes. It is recommended that HCPs provide information regarding the evidence for the effective use, dosage, and the route of administration of natural substances to people with diabetes who use these to manage their disease. Identifying culturally-influenced practices can assist HCPs to understand the rationale for people with diabetes choosing disease management methods. This information will ensure that HCPs are able to provide appropriate health education and support people's diabetes management regimes.

Evaluating the care

Experiential insight gained from this action is a distinctive feature of the theory of *Learning, choosing, and acting: self-management of diabetes in Indonesia*. Learning about diabetes led to people gaining insight in this present study. This finding reflects those of Quandt et al. [53] who claimed that what people learn influences their diabetes related beliefs and their capacity to manage their diabetes.

People in this study appraised their current therapy to decide whether to continue or discontinue their current regime. The literature highlights that people experience positive and negative outcomes following initiation of treatment [54,55]. This current study demonstrated that people with diabetes evaluated their treatment using objective and subjective measurements. They observed their body changes subjectively and objectively to determine desirable and undesirable outcomes. This appraisal action is part of their learning about their diabetes and its management, and resulted in their newfound experiential insight.

People relied on a subjective measurement, which was based on how their body felt, rather than objective biometric assessment. Purchasing a BGL monitor is an expense that many Indonesian people with diabetes were unable to afford. The cost of buying a BGL monitor would currently equate to 25% of the average monthly income of an Indonesian person [56]. Participants reported that access to services such as a community pharmacist that provides BGL monitoring was not always locally available. As a result, regular monitoring of their BGL was not possible.

People in this study compared their experience of diabetes to other people's experience of diabetes. This comparison caused them to underestimate their own disease severity, since they had not yet experienced complications such as foot ulcers or diabetic retinopathy. This finding is confirmed by Pitaloka and Hsieh [57] who found that people with diabetes in Indonesia considered diabetes was not life threatening as they were able to perform every day tasks. Underestimation of the severity of diabetes by participants in our study led to them delaying implementation of treatment or to modifying their treatment plans. Participants who experienced secondary complications subsequently sought medical assistance, although for some people the extent of deterioration limited the therapeutic interventions that could then be implemented. For these people, death was inevitable.

People in the current study altered their diabetes management regimes if undesirable outcomes were experienced, new information regarding their current therapy was received and if they were unable to secure medications or necessary equipment such as insulin or BGL monitors. This study's findings concur with that of Hjelm and Atwine [42] who identified that people may modify their therapeutic regimes when they are not satisfied with the outcome.

Other studies have found that experiences of implementing diabetes self-management can be exhausting and frustrating because people with diabetes have difficulties in balancing their everyday life especially when dealing with medication regimes, meal planning, compensating for a sedentary working life and avoiding self-care exhaustion [54,58,59]. Participants in the present study also reported similar challenges and frustrations. Therefore, it is recommended that HCPs engage early in a thorough, respectful and sensitive discussion with people with diabetes to discuss their understanding and management of diabetes and the difficulties they encounter in following treatment recommendations. These conversations should include provision of information to address knowledge deficits and adaptations if appropriate to treatment recommendations or assistance with addressing identified difficulties.

Informing others about their experiences

A person often acquired information about diabetes from hearing about other people's experiences with diabetes. Consequently, that person then went on to share his/her own experiences of diabetes with other people. In this study, the most likely people that a person shared their experience with were significant others, such as family or friends, and more rarely, acquaintances. People with diabetes will share information about their diabetes to others that they believe can provide feedback including HCPs [60].

People with diabetes can also learn from the stories of others who also have diabetes [61]. For instance, AlQarni, Yunus and Househ [62] found that sharing stories or experiences and information related to diabetes with each other and/or their caregivers occured via electronic mediums such as social media [62]. However, people in this current study still shared their experiences in person, during social interactions with families, friends, neighbours and community groups. In Indonesia, living in a neighbourhood allows people to gather and interact with each other on social occasions, either formally or informally. These occasions provide an opportunity for people with diabetes to discuss with others their experiences of living with diabetes. Consequently, people can both share their experiences and hear experiences from others about diabetes and how others manage it. The information shared may be appropriate or erroneous. Both social media and face to face social interaction can be useful mediums to share experiences. However, HCPs need to be aware that incorrect or misleading information may also be shared in these non-moderated contexts, as was also reported by Edwards et al. [63].

Study limitations

Participation in the study was voluntary, and as in any qualitative study, the use of volunteers may introduce a volunteer bias. The results therefore may not be applicable to the entire population in the study setting. Additionally, the study participants came only from two of the three main ethnic groups in West Kalimantan, which may limit generalisability to all Indonesian people with diabetes.

Conclusion

This study produced a theory entitled *Learning, choosing, and acting: self-management of diabetes in Indonesia*, which helps explain how people with diabetes learn about their disease and engage in health education in the Indonesian context. The process involves five categories which interact with each other in both a linear and cyclical fashion. The first of the five categories demonstrates how people with diabetes initially sought out information; often from family and friends who also had experiences with diabetes. Next the person proceeded to process this received information to make sense of it. From here people responded to the processed information by either following the recommendations or not. This study uncovered evidence of a number of factors that influenced whether a person followed or did not follow recommendations. Some of these factors were related to their financial situation, where they lived, what relatives and friends were advising and psychological reasons such as fear of having to inject medication. The fourth category involved people appraising their results and determining what future actions to take. The final category, sharing with others, was based on sharing information based on their own experiences.

Evidence from this study can inform HCPs to increase their awareness to focus not only on what people with diabetes have to do for managing their diabetes but also to evaluate how people with diabetes can do so, given the unique availability of resources they have, thus exemplifying person-centred diabetes care. The theory of *Learning, choosing, and acting: self-management of diabetes in Indonesia* can be a basis for HCPs to develop a feasible approach in health education that considers people's own prior knowledge, personal judgement and own experience, as these factors can influence their decisions to employ appropriate diabetes self-management. Thus, to enhance monitoring and support of peoples' self-management practices, HCPs need to have close and regular interactions with people with diabetes. Programs of diabetes specialisation in each discipline of health care should include the skills of close observation and detailed evaluation to ascertain how each individual with diabetes has arrived at their own current self-management approach, and how it is currently working for them (or not).

Further research is required to develop and evaluate a feasible model of diabetes care involving various related health disciplines in the provision of health education that exemplifies person centred care. Research could also investigate whether aspects of the theory of *Learning, choosing, and acting: self-management of diabetes in Indonesia* can be applied to other chronic diseases or to people with diabetes in other similar geographical locations.

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References

1. Brunisholz KD, Briot P, Hamilton S, Joy EA, Lomax M, Barton N, et al. Diabetes self-management education improves quality of care and clinical outcomes determined by a diabetes bundle measure. Journal of multidisciplinary healthcare. 2014;7:533-42.
2. Klein HA, Jackson SM, Street K, Whitacre JC, Klein G. Diabetes self-management education: miles to go. Nursing research and practice. 2013;2013:581012-15.
3. Nutbeam D, Kickbusch I. Health promotion glossary. Health Promotion International. 1998;13(4):349-64.
4. National statement on health literacy [Internet]. 2014 [cited 14 May 2018]. Available from: https://www.safetyandquality.gov.au/our-work/patient-and-consumer-centred-care/health-literacy/.

5. Eyuboglu E, Schulz PJ. Do health literacy and patient empowerment affect self-care behaviour? a survey study among Turkish patients with diabetes. BMJ Open. 2016;6(3):e010186.

6. Hartayu TS, Izham M, Suryawati S. Improving type 2 diabetes patients' quality of life by using a community based interactive approach – diabetes mellitus strategy in Yogyakarta, Indonesia. Journal of Pharmaceutical Health Services Research. 2012;3(2):95-102.

7. Powers MA, Bardsley J, Cypress M, Duker P, Funnell MM, Fischl AH, et al. Diabetes self-management education and support in type 2 diabetes: a joint position statement of the American Diabetes Association, the American Association of Diabetes Educators, and the Academy of Nutrition and Dietetics. The Diabetes Educator. 2017;43(1):40-53.

8. Mahdalena M, Ningsih ESP. Effectivity of foot care education program in improving knowledge, self-efficacy and foot care behavior of diabetes mellitus patients in Banjarbaru, Indonesia. Kesmas: National Public Health Journal. 2016;11(2).

9. Naccashian Z. The impact of diabetes self-management education on glucose management and empowerment in ethnic Armenians with type 2 diabetes. The Diabetes Educator. 2014;40(5):638-47.

10. Murray CM, Shah BR. Diabetes self-management education improves medication utilization and retinopathy screening in the elderly. Primary Care Diabetes. 2016;10(3):179-85.

11. Horigan G, Davies M, Findlay-White F, Chaney D, Coates V. Reasons why patients referred to diabetes education programmes choose not to attend: a systematic review. Diabetic Medicine. 2017;34(1):14-26.

12. Waspadji S, Ranakusuma AB, Suyono S, Supartondo S, Sukaton U. Diabetes mellitus in an urban population in Jakarta, Indonesia. The Tohoku Journal of Experimental Medicine. 1983;141 Suppl:219.

13. International Diabetes Federation. IDF Diabetes Atlas. Brussels, Belgium: International Diabetes Federation; 2017.

14. World Health Organization. Indonesia: diabetes country profile. Geneva; 2016.

15. Guariguata L, Whiting DR, Hambleton I, Beagley J, Linnenkamp U, Shaw JE. Global estimates of diabetes prevalence for 2013 and projections for 2035. Diabetes Research and Clinical Practice. 2014;103(2):137-49.

16. Rudijanto A, Soewondo P, Waspadji S, Yunir E, Purnamasari D. The Indonesian society of endocrinology's summary article of diabetes mellitus national clinical practice guidelines. Journal of the ASEAN Federation of Endocrine Societies. 2011;26(1):17-9.

17. Sja'bani M, Asdie AH, Widayati K, Subroto Y, Kariadi SH, Arifin AYL, et al. Microalbuminuria prevalence study in hypertensive patients with type 2 diabetes in Indonesia. Acta Medica Indonesiana. 2005;37(4):199-204.

18. Soebardi S, Purnamasari D, Oemardi M, Soewondo P, Waspadji S, Soegondo S. Dyslipidemia in newly diagnosed diabetes mellitus: the Jakarta primary non-communicable disease risk factors surveillance 2006. Acta Medica Indonesiana. 2009;41(4):186-90.

19. Soegondo S, Prodjosudjadi W, Setiawati A. Prevalence and risk factors for microalbuminuria in a cross-sectional study of type-2 diabetic patients in Indonesia : a subset of DEMAND study. Medical Journal of Indonesia. 2009;18(2):124-30.

20. Soewondo P, Soegondo S, Suastika K, Pranoto A, Soeatmadji DW, Tjokroprawiro A. The DiabCare Asia 2008 study: outcomes on control and complications of type 2 diabetic patients in Indonesia. Medical Journal of Indonesia. 2010;19(4):235-44.

21. Soewondo P, Kshanti IA, Pramono RB, Langi YA, Dalem-Pemayun TG. Clinical experience with insulin detemir: results from the Indonesian cohort of the international A$_1$chieve study. Diabetes Research and Clinical Practice. 2013;100:S47-S53.

22. Funnell MM, Brown TL, Childs BP, Haas LB, Hosey GM, Jensen B, et al. National standards for diabetes self-management education. Diabetes Care. 2010;33(1):S89-S96.

23. Hartayu TS, Izham M, Suryawati S. Improving of type 2 diabetic patients knowledge, attitude and practice towards diabetes self-care by implementing community-based interactive approach-diabetes mellitus strategy. BioMed Central Research Notes. 2012;5(1):315-.

24. Sutanegara D, Budhiarta AAG. The epidemiology and management of diabetes mellitus in Indonesia. Diabetes Research and Clinical Practice. 2000;50:S9-S16.

25. Ligita T, Wicking K, Harvey N, Mills J. The profile of diabetes healthcare professionals in Indonesia: a scoping review. International Nursing Review. 2018.

26. Malini H, Copnell B, Moss C. Considerations in adopting a culturally relevant diabetes health education programme: an Indonesian example. Collegian. 2017;24(2):183-90.

27. Glaser BG, Strauss AL. The discovery of grounded theory: strategies for qualitative research. Hawthorne, NY: Aldine de Gruyter; 1967.

28. Blumer H. Symbolic interactionism: Perspective and method. Berkeley: University of California Press; 1969.

29. Charmaz K. Constructing grounded theory: a practical guide through qualitative analysis. London: SAGE; 2006.

30. Birks M, Mills J. Grounded theory: a practical guide. Thousand Oaks, CA: SAGE; 2015.

31. Creswell JW. Qualitative inquiry and research design: choosing among five approaches. Thousand Oaks, Calif: SAGE Publications; 2013.

32. Charmaz K. Constructing grounded theory. 2nd ed. London: SAGE; 2014.

33. QSR International Pty Ltd. NVivo Qualitative data anlysis software2016.

34. Saldana J. The coding manual for qualitative researchers. 2nd ed. London: Sage Publications; 2013.

35. National Institute for Health Research and Development. 'Riset Kesehatan Dasar'. Division HRaD, editor. Jakarta: Ministry of Health of Republic of Indonesia; 2008.

36. National Institute for Health Research and Development. 'Riset Kesehatan Dasar'. Division HRaD, editor. Jakarta: Ministry of Health Republic of Indonesia; 2013.

37. Arksey H, O'Malley L. Scoping studies: towards a methodological framework. International Journal of Social Research Methodology. 2005;8(1):19-32.

38. Grant MJ, Booth A. A typology of reviews: an analysis of 14 review types and associated methodologies. Health Information & Libraries Journal. 2009;26(2):91-108.

39. Mays N, Pope C, Popay J. Systematically reviewing qualitative and quantitative evidence to inform management and policy-making in the health field. Journal of Health Services Research and Policy. 2005;10(1):6-20.

40. Corbin JM, Strauss AL. Basics of qualitative research: techniques and procedures for developing grounded theory. Los Angeles: Sage Publications, Inc; 2008.

41. Moffatt A. Indonesian culture profile. West End, Queensland: Diversicare; 2012.

42. Hjelm K, Atwine F. Health-care seeking behaviour among persons with diabetes in Uganda: an interview study. BMC International Health and Human Rights. 2011;11(1):11-.

43. Mendenhall E, McMurry HS, Shivashankar R, Narayan KMV, Tandon N, Prabhakaran D. Normalizing diabetes in Delhi: a qualitative study of health and health care. Anthropology & Medicine. 2016;23(3):295-310.

44. White RO, Eden S, Wallston KA, Kripalani S, Barto S, Shintani A, et al. Health communication, self-care, and treatment satisfaction among low-income diabetes patients in a public health setting. Patient Education and Counseling. 2015;98(2):144-9.

45. White RO, Chakkalakal RJ, Presley CA, Bian A, Schildcrout JS, Wallston KA, et al. Perceptions of provider communication among vulnerable patients with diabetes: influences of medical mistrust and health literacy. Journal of Health Communication. 2016;21(sup2):127-34.

46. Webster E, Johnson C, Kemp B, Smith V, Johnson M, Townsend B. Theory that explains an Aboriginal perspective of learning to understand and manage diabetes. Australian and New Zealand Journal of Public Health. 2017;41(1):27-31.

47. Lee YK, Low WY, Lee PY, Ng CJ. Factors influencing decision-making role preferences: a qualitative study of Malaysian patients with type 2 diabetes during insulin initiation. International Journal of Nursing Practice. 2015;21:125-31.

48. Person-centred care [Internet]. 2014 [cited 14 February 2018]. Available from: https://www.acn.edu.au/sites/default/files/advocacy/submissions/PS_Person-centered_Care_C2.pdf.

49. Herlitz A, Munthe C, Törner M, Forsander G. The counseling, self-care, adherence approach to person-centered care and shared decision making: moral psychology, executive autonomy, and ethics in multi-dimensional care decisions. Health Communication. 2016;31(8):964-73.

50. Ramsay Wan C, Vo L, Barnes CS. Conceptualizations of patient empowerment among individuals seeking treatment for diabetes mellitus in an urban, public-sector clinic. Patient Education and Counseling. 2012;87(3):402-4.

51. Tanto A, Syarfina F, Dimas Abdul Azis F, Alifian PH, Adilla S, editors. Tackling Indonesia's diabetes challenge with indonesian traditional herbs as dietary supplementation to reduce development of cardiovascular complications: promotion the use of natural product. Asian Academic Society International Conference Proceeding; 2017; Khon Kaen, Thailand.

52. Pramono LA. Plants and herbs for therapy of diabetes. Medical Journal of Indonesia. 2015;24(2):67-9.

53. Quandt SA, Reynolds T, Chapman C, Bell RA, Grzywacz JG, Ip EH, et al. Older adults' fears about diabetes: using common sense models of disease to understand fear origins and implications for self-management. Journal of Applied Gerontology. 2013;32(7):783-803.

54. Bockwoldt D, Staffileno BA, Coke L, Hamilton R, Fogg L, Calvin D, et al. Understanding experiences of diabetes medications among African Americans living with type 2 diabetes. Journal of Transcultural Nursing. 2017;28(4):363-71.

55. Vos RC, Hermans TGT, Zuithoff NPA, Müller N, Khunti K, Rutten GEHM, et al. What determines treatment satisfaction of patients with type 2 diabetes on insulin therapy? an observational study in eight European countries. BMJ Open. 2017;7(7).

56. Regional/province minimum wages in 2016 [Internet]. 2018 [cited 17 October 2018]. Available from: https://www.bps.go.id/linkTableDinamis/view/id/917.

57. Pitaloka D, Hsieh E. Health as submission and social responsibilities: embodied experiences of Javanese women with type II diabetes. Qualitative Health Research. 2015;25(8):1155-65.

58. Youngson A, Cole F, Wilby H, Cox D. The lived experience of diabetes: conceptualisation using a metaphor. The British Journal of Occupational Therapy. 2015;78(1):24-32.

59. Rehackova L, Araújo-Soares V, Adamson AJ, Steven S, Taylor R, Sniehotta FF. Acceptability of a very-low-energy diet in type 2 diabetes: patient experiences and behaviour regulation. Diabetic Medicine. 2017;34(11):1554-67.

60. Peng W, Yuan S, Holtz BE. Exploring the challenges and opportunities of health mobile apps for individuals with type 2 diabetes living in rural communities. Telemedicine and e-Health. 2016;22(9):733-8.

61. Greenhalgh T, Collard A, Begum N. Sharing stories: complex intervention for diabetes education in minority ethnic groups who do not speak English. BMJ. 2005;330(7492):628-31.

62. AlQarni ZA, Yunus F, Househ MS. Health information sharing on Facebook: an exploratory study on diabetes mellitus. Journal of Infection and Public Health. 2016;9(6):708-12.

63. Edwards DJ, Wicking K, Smyth W, Shields L, Douglas T. Information needs of parents of infants diagnosed with cystic fibrosis: results of a pilot study. Journal of Child Health Care. 2018;22(3):382-92.

Supporting information

S1 Fig. The process of Learning, choosing, and acting: self-management of diabetes in Indonesia. This diagram represents a theory of *Learning, choosing, and acting: self-management of diabetes in Indonesia*, a basic social process of how people with diabetes in Indonesia learn about their disease. The numbers show the categories of the process that occur in chronological order. This process occurs dynamically, both in linear and cyclical movements.

S2 Fig. Responding to recommendations. This figure shows how people with diabetes respond to recommendations by either following or not following the recommendations. Their decisions were influenced by three factors: physical, psychological and availability of resources. People with diabetes selected one of four variations of responding to the recommendations.

S3 Fig. A sharing phenomenon among people with diabetes. This figure shows how the process of *Learning, choosing, and acting: self-management of diabetes in Indonesia* occurs from one person with diabetes to another person with diabetes. The process starts when a person with diabetes shares their experience or information with another person with diabetes. The process of sharing information continues from one person, to the next, to the next, etc.

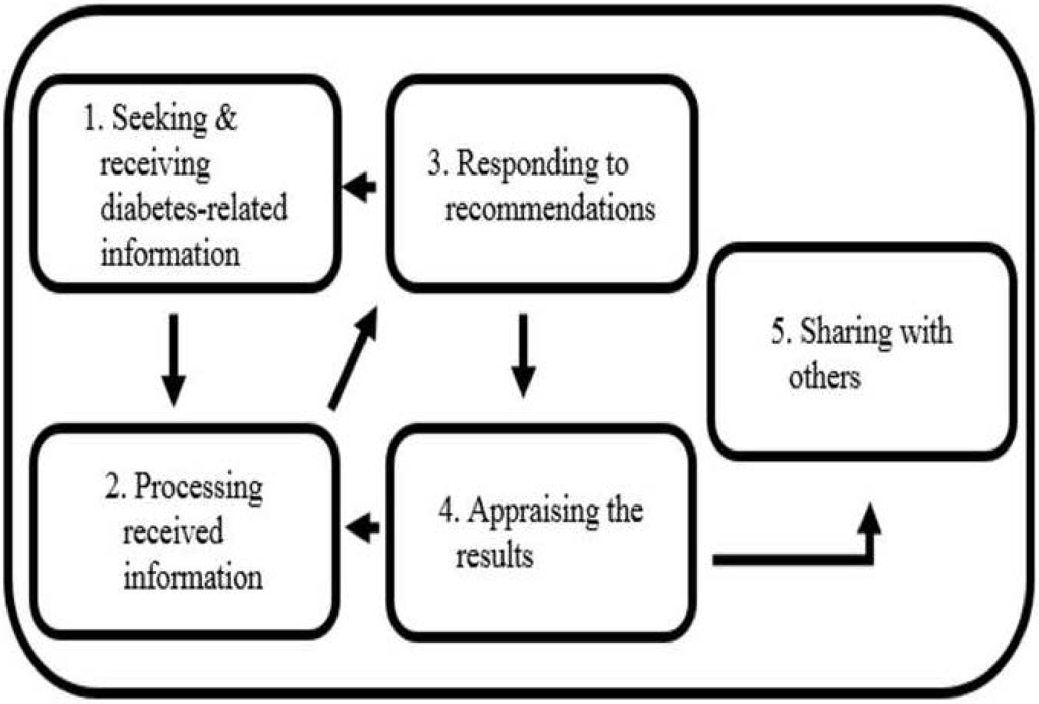
1. Seeking & receiving diabetes-related information
2. Processing received information
3. Responding to recommendations
4. Appraising the results
5. Sharing with others

Figure 2

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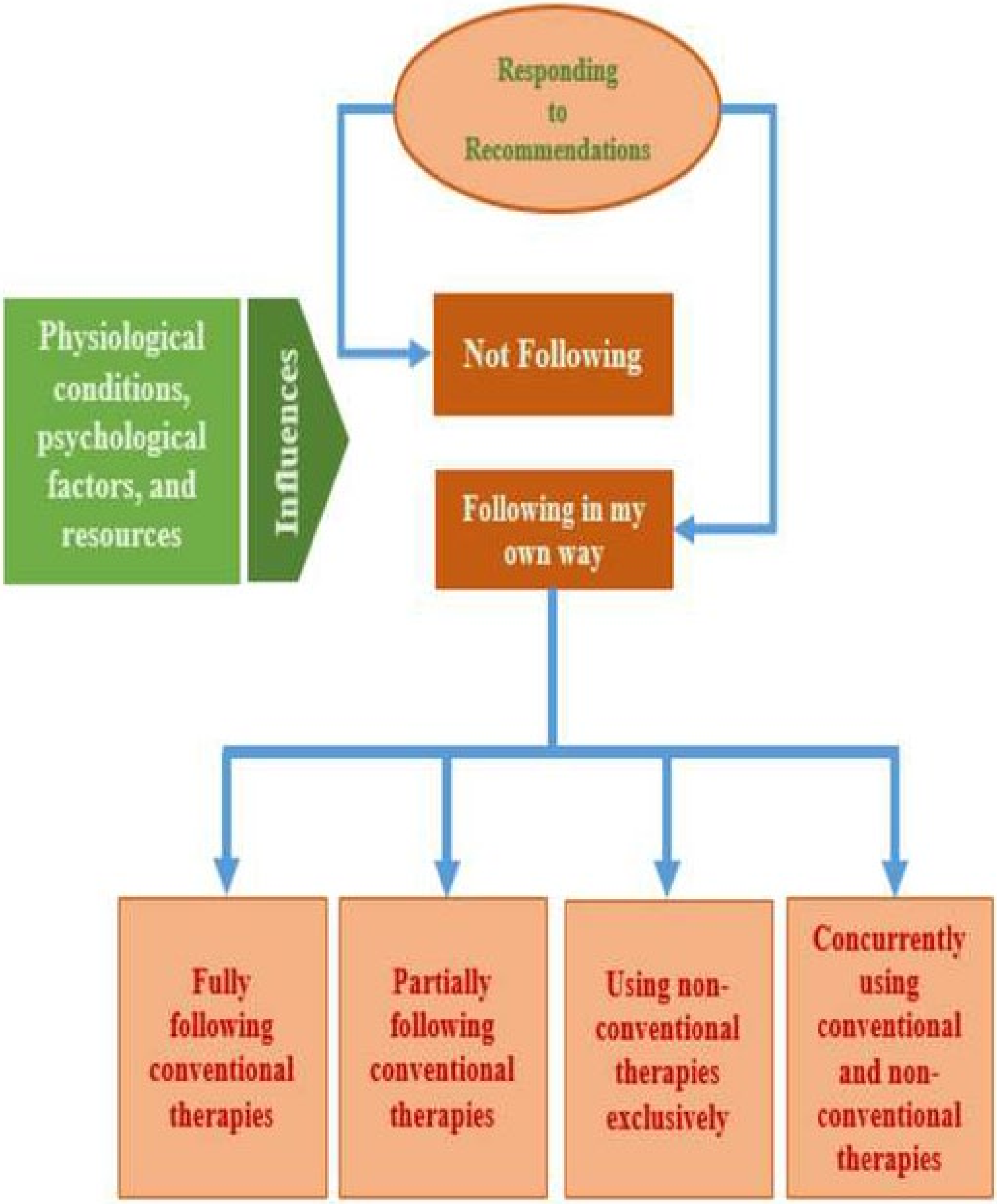

Figure 3

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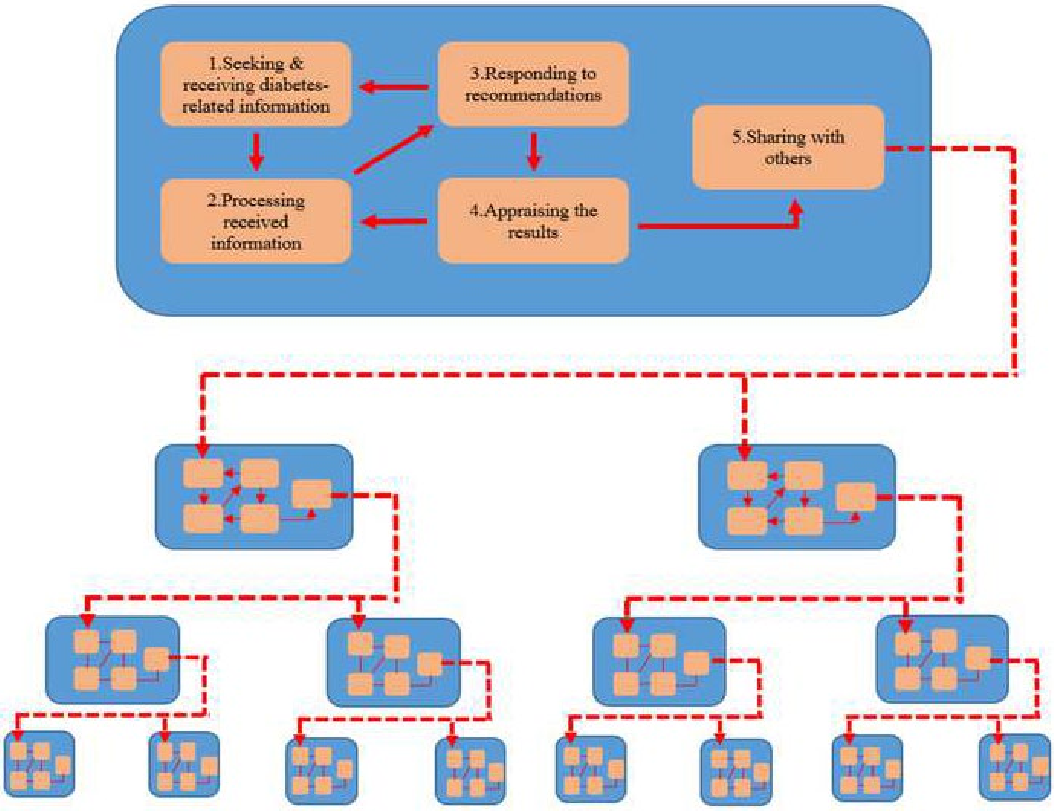

The Storyline Disseminated in the Indonesian Language

The second findings paper was written in the Indonesian language. The manuscript was developed and published in the Indonesian language detailing the storyline to ensure that the outcomes of this study were distributed in an appropriate way to ensure access by a target audience from which the data originated: Indonesia. The storyline translated in the Indonesian language and the study recommendations are addressed in this paper. The paper (Appendix I) is ‘under review’ in a scholarly Indonesian journal (*Indonesian Journal of Nursing Practices*) and has intention to reach not only people with diabetes and their families, but also their HCPs and the academics that both teach and research diabetes management.

Table 5.2: *Declaration of Authorship*

Chapter Number	**Publication**	**Nature and extent of the intellectual input of each author including the candidate**	**Signature**
5	Ligita, T., Nurjannah, I., Wicking, K., Harvey, N., & Francis, K. Sebuah storyline mengenai proses penderita diabetes di Indonesia belajar mengenai penyakitnya (storyline of the process of people with diabetes in Indonesia learn about their disease). *Indonesian Journal of Nursing Practices.*	Conception and design of the paper, data collection, data analysis and interpretation, Primary responsibility for writing the paper (80%), corresponding author responsible for preparing the final paper for submission, approval for publication version.	Ligita, Titan Content has been removed for privacy reasons
		Supervision of and contribution to the conception and design of the paper, data analysis and interpretation, writing the paper (5%), critical revisions for important intellectual content, approval for publication version	Nurjannah, Intansari Content has been removed for privacy reasons
		Supervision of and contribution to the conception and design of the paper, data analysis and interpretation, writing the paper (5%), critical revisions for important intellectual content, approval for publication version	Wicking, Kristin Content has been removed for privacy reasons
		Supervision of and contribution to the conception and design of the paper, data analysis and interpretation, writing the paper (5%), critical revisions for important intellectual	Harvey, Nichole Content has been removed for privacy reasons

		content, approval for publication version	
		Supervision of and contribution to the conception and design of the paper, data analysis and interpretation, writing the paper (5%), critical revisions for important intellectual content, approval for publication version	Francis, Karen Content has been removed for privacy reasons

The storyline paper written in the Indonesian language is expected to reach and be delivered to local people where the data originated. Health consumers such as people with diabetes should be able to engage with the research outcomes through a storyline (Birks & Mills, 2015) as well as the clinicians and academics. Consequently, these people can understand and be involved in the future improvement of diabetes management.

Review of Findings

People with diabetes in Indonesia start the process of Learning, choosing, and acting: Self-management of diabetes in Indonesia, both before and after the diagnosis of diabetes. Five categories or parts of the process explicate how people with diabetes learn about their disease. Relatives or family also support people with diabetes throughout this process; however, the family's actions and activities vary through the five categories.

Through Learning, choosing, and acting: Self-management of diabetes in Indonesia, initially, people with diabetes sought and received diabetes related information, especially recommendations and explanations. Learning about the disease in this category occurs both actively and passively. The sources of and the places where they can seek and receive diabetes related information is varied. Once people with diabetes received the information, they do not directly take actions related to information but they need to process the received information through sifting the information. People with diabetes then decide to believe or not believe the information they have sifted, before they can decide to respond to the trusted information.

In responding to recommendations, people with diabetes are influenced by three factors: physiological and psychological conditions as well as access and availability of resources. People with diabetes who respond to follow or not to follow the recommendations then appraise their chosen actions. It occurs when people with diabetes observe their body changes either subjectively or objectively. By appraising the results of their chosen actions, they can decide what they need to do regarding their chosen actions. They gain insight from learning about their chosen action related to diabetes care and this situation is called experiential insight. Experiential insight is then often shared with others or used as received information. Experiential insight shared with another person with diabetes can be a starting point for that person in his/her own process of Learning, choosing, and acting: Self-management of diabetes in Indonesia. Meanwhile, the experiential insight, which is received as information learnt from their experience, can then influence them to continue or discontinue their chosen actions related to diabetes care. The theory of *learning, choosing, and acting: Self-management of diabetes in Indonesia* has explained how people with diabetes learn about their disease through dynamic processes, in both linear and cyclical movements. The findings of the theory are presented in the paper entitled: “People with diabetes learning their disease: A grounded theory study”.

In conclusion, several key findings arise from this study regarding the theory of people with diabetes *learning, choosing, and acting: self-management of diabetes in Indonesia*. Key findings developing from this study are:

1. People with diabetes both actively sought and passively received diabetes-related information.
2. Diabetes-related information was accessed from a variety of sources and places.
3. Before making a decision about using received information, people with diabetes often sifted the information based on their prior knowledge, experiences and personal judgement.
4. Physical, psychological and resource factors highly influenced people’s decisions to apply recommendations for managing their diabetes.
5. By appraising the results of their management choices, people with diabetes developed experiential insight, which they often shared with others and which influenced their future management decisions.
6. Families of people with diabetes engaged in all five categories of the process entitled ‘Learning, choosing, and acting: Self-management of diabetes in Indonesia’.

Chapter Summary

This chapter reported on the findings of this study, especially the theory. The theory of *learning, choosing, and acting: Self-management of diabetes in Indonesia* is a core category that explains the basic social process of how people with diabetes in Indonesia learn about their disease. This chapter presented the storyline that explicated the process by which Indonesian people with diabetes learn about their disease. Also, this chapter introduced the key findings from this study. In the next chapter, Chapter Six, the five major categories that comprise the theory will be presented, along with evidence from the participants to support the findings.

Chapter Six: The Five Major Categories

Chapter Six presents a detailed explanation about the five major categories within the theory of Learning, choosing, and acting: Self-management of diabetes in Indonesia. Each of the five categories that support the theory is addressed. All categories have subcategories and the subcategories that comprise the categories are explained. Moreover, supporting evidence from participant interview excerpts is provided together with an explanation for each of the categories and the subcategories. The examples of evidence in the Indonesian language are provided in Appendix J.

Category One: Seeking and Receiving Diabetes-related Information

In this section, the candidate explains about category one, which is seeking and receiving diabetes-related information. Figure 6.1 shows the position of category one in relation to the other categories.

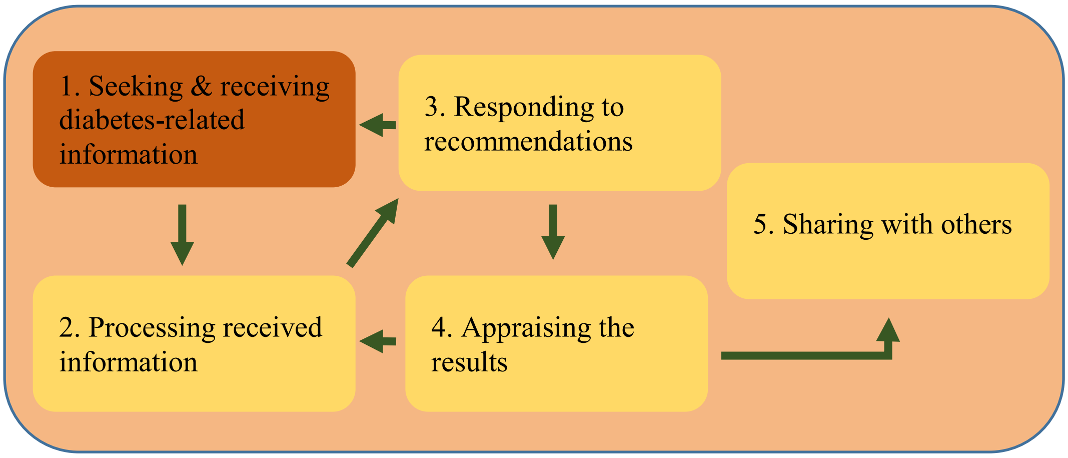

Figure 6.1. Theory of *Learning, choosing, and acting: Self-management of diabetes in Indonesia* (Category One).

The process of *Learning, choosing, and acting: Self-management of diabetes in Indonesia* starts with the category of seeking and receiving diabetes-related information. Recommendations and/or explanation are the information that the people with diabetes are seeking and receiving during the period prior to and after being diagnosed with diabetes. Seeking and receiving diabetes-related information involves activities that were performed either actively or passively.

People with diabetes can ask for an explanation and/or recommendations. Recommendations were obtained when a person with diabetes requested suggestions about actions they should take regarding their condition from other people, including healthcare professionals or people who are believed to be able to provide information needed by the person with diabetes.

Besides recommendations, people with diabetes sometimes asked for an explanation. Seeking an explanation refers to a person with diabetes asking other people for further information because something in their condition has changed or they have identified body changes. Betty, a person with diabetes reported to the doctors and asked why there were bruises on her body areas after having insulin injections:

> *There were black [areas] on all the injection marks. "The needle must be changed, mam" he [the doctor] said... "After three days, change the needle", he [the doctor] said...It's only when the insulin is over [I changed the needle]. "Change the needle, Mam, or else there will be black [bruises] on your body", he [the doctor] said (Betty: G1P3-4).*

By asking the doctor about these concerns, the person with diabetes gained understanding and was more able to appreciate the importance of recommendations being offered.

Receiving explanations about issues that people with diabetes experience may not occur if the person does not initiate the conversation by asking HCPs. The HCP can then answer questions and clarify information as requested. Below are the quotes from a nurse (Danur) who worked at a secondary healthcare facility (hospital), who explained that people with diabetes often asked for explanations in relation to their diabetes.

> *The patients [who] commonly [present] here, at first, they have conditions, have wound, they ask why they have a wound. Then why the blood sugar level does not does not come down [despite] being on the medication for a long time. ...the medication is not [enough] to decrease their BSL (Danur: G1P9).*

Seeking and receiving diabetes-related information occurred at two periods of time. Firstly, people with diabetes actively sought health information about their condition before they had been diagnosed because they recognised body changes and wanted to find out what was happening. Secondly, people living with diabetes began to seek information actively following confirmation of diabetes via a blood sugar test and/or diagnosis by a medical doctor.

> *During my second pregnancy, I did not know I had diabetes. Doctor S greeted me "You have delivered your baby, have you?" "Yes, doctor", I said. "How much weight did your baby gain?" "4 Kgs", I said. "You must have diabetes". "No, I don't think so, doc", I said. I was curious. Then [when the BSL was tested], it was more than 300 [mg/dL] (Widya: G2P15).*

People with diabetes use various approaches to access related diabetes information before and after they are diagnosed with diabetes. Other people sometimes informed people with diabetes that they may have diabetes. These informants advised them to see a doctor to have their BSL tested. Both Haris and Betty, people living with diabetes, stated that other people they knew advised that they may have diabetes and then suggested they should see a doctor. Haris stated that his dentist advised he might have diabetes.

> *I went to a dentist. I did not know I had diabetes. The dentist said that my blood sugar level might be high. At that time I did not know my mother had diabetes. I did not remember that. I just thought anyone can have the sugar disease [diabetes]...I said. It is said that it can be as a result of inheritance [heredity] (Haris: G2P2). Betty however said her boss suggested that she may have diabetes. Both sought further information to confirm if they had diabetes. My boss said, "You must have sweet urine disease, have a check". I am afraid… If it's true, that would be on my mind [worry me]. ... Finally, it was true. [I had diabetes] from 2004... [it's]now 2016… 12 years (Betty: G1P12).*

Discovering a diagnosis of diabetes.

Some people with diabetes did not recognise they were experiencing high BSLs until they had a blood test, despite experiencing clinical symptoms of diabetes. These people learnt that the symptoms they were experiencing were symptomatic of having diabetes. For example, Haris explained:

> *From my urine, there were a lot of ants in the toilet. So I [was asking] "why is this toilet like this?" I lived alone there but why were there so many ants. So I started to be suspicious. That what I feel, the body is very limp, no motivation to do anything, I just want to have a rest. I keep urinating frequently. [After] I drink, then I urinate again... drinking [water] and urinating again... to the toilet again. Those are the symptoms that I feel, the strongest ones (Haris: G2P2).*

Ranti also found she had diabetic symptoms after she saw the doctor to find out the reasons for her body's changes:

> *I went to work every day [I ran a stall in a market]. I was sleepy every morning, very sleepy. I did not know I had diabetes. I had coffee every day, the coffee from a pre-packaged sachet [contained instant coffee, milk and sugar]… to get rid of the sleepiness. I became thirsty and I just wanted to have a drink. Cold drink. I worked from morning until at 11 am. I had seven glasses of iced tea. Yes, the sweet iced tea. Eventually, my vision was blurry. I could not see from 1 meter of distance. I went to a doctor. My body was limp. I was sleepy. [I] went to an outpatient care, to an internal medicine doctor. I was checked before I had any breakfast. My blood sugar level was more than 500. It had attacked the eyes. After that, she [the doctor] gave me medication (Ranti: G2P1).*

Information about having a high BSL was usually identified serendipitously. For example, Betty found she had a high BSL when she had to have compulsory general health check-ups, including pathology, during preparation for undertaking a pilgrimage to Mecca.

> *In 2004, I planned to go on a pilgrimage… "Do you have sweet urine disease, Mam?" "No... I have only hypertension". "Have a check, Mam" he said. Then I went to Gadjah Mada [the street where the lab is located]. "Mam, you have sweet urine disease", [said the laboratory staff] (Betty: G1P12).*

There were also opportunities when people accidentally discovered that they have high BSLs. For example information provided at events held in public places such as International Diabetes Day that also included a free BSL testing. Flora, a nurse clinician who worked at a PHC explained:

> *We sometimes go out to have activities for example in RRI [Indonesian Radio station], having activities, events… we go out to have body fat check, random blood sugar check… Last time, at the National Health Day and at the International Diabetes Day. We held the event at a mall. So people who were passing by, we offered them a blood sugar test. It is our collaboration with the Health Office (Flora: G1P2-3).*

People with diabetes continuously sought information after they had confirmation of a diagnosis of diabetes and during the course of living with diabetes. They actively sought information regarding body changes that were immediately noticed. This action occurred for several purposes: to ensure effective management; to anticipate what to do and how to prevent diabetes; to clarify issues of concern; and to ask for a recommendation. Some participants living with diabetes explained how their body changes drove them to seek information for these reasons. Haris, for example, stated:

> *I am coming here [a PHC] for a treatment, to get the medication, for my travelling in four days or more. For my travelling, just in case if I my eating cannot be taken care of [controlled]. When we have gathering, I am afraid it [my food consumption] cannot be taken care of [controlled], I anticipate with this medication. That's what I aim for (Haris: G2P8).*

Another participant living with diabetes, Larisa, said that she sought clarification to ensure that she had no other complications:

> *Last time, I did not feel good on half of my chest. It was like heavy on the side part. My daughter brought me to doctor B [a cardiologist]. From having hypertension, I was afraid of having cardiac disease. I said, "It has just been three years [with diabetes], how can it be cardiac disease". Then I was checked by the cardiologist. It was good, the graph was good. I might just have been tired. From there on, I became more careful. We cannot reject if it [death] comes… illness or anything, but if I can maintain, I will maintain (Larisa: G2P4-5).*

The healthcare provider also stated similarly about clarifying the medication people with diabetes have taken. One participant, Putri, who is a *kader* (a lay health worker in the Indonesian language) explained about a person with diabetes who asked her for clarification about the herbal medication the person has taken orally:

> *Last time, a person with diabetes said to me that someone said that brown rice is for diabetes treatment. I am not the expert so I said to the nutritionist and then he said that he will explain about it. Once, about the herbal medication. The person with diabetes said to me "I take this herbal medication. Is it good or not?" Any medication may be good. The important thing is that there is 'Balai Pengawasan Obat dan Makanan'/Indonesia National Agency of Drug and Food Control" [registration]. "However, if you do not control the eating pattern, the medication cannot work", I said (Putri: G2P7).*

The health education for people with diabetes.

Health education is provided for people living with diabetes in Indonesia. The methods of providing health education for people with diabetes vary, from informal to formal. The places where the health education is delivered to people with diabetes were also diverse including healthcare settings such as in the PHCs, in the hospitals (waiting room; wards; outpatient clinic) and in venues through a health seminar delivered in a hired official building other than the healthcare settings.

The purposes of health education for people with diabetes vary, according to the HCPs and healthcare providers. Health education is provided to prevent complications (such as being readmitted to the hospital with the same condition or with secondary complications). Relapse from hospital admission can be prevented when people with diabetes understand what they should and should not do while they are at home, as cited below by Qosim, the officer in the division of hospital health promotion.

> *The patients should remember what we told them. The patients come to the hospital not only for having care service then going home… No… But in the hospital, besides having care service, they must be given information related to their disease… mainly for diabetes, it's related to eating pattern, life pattern, and then life style. So, if the patients really understand what they have to do… what they cannot do, they will not come to the hospital again… [They] do not experience the same sickness (Qosim: G2P7-8).*

A nurse clinician, Aditya who was also a nurse academic, mentioned the primary aim of providing education for people with diabetes was to prevent them from experiencing secondary complications.

> *Education is very important, as we do not want patients' developing complications. The complications occur because of lack of understanding and the patients do not know about it [their risk of complication]. Therefore, the education, if I may list, it is on number one for managing patients with diabetes mellitus, which is very important. If they have had good education…even though there are complications, it can be minimised... So, patients can do prevention and can identify when there is a disorder (Aditya: G1P5-6).*

Tiara, a ward nurse, stated that people admitted to the hospital with diabetes generally have secondary complications such as renal failure. To minimise the risk of people with diabetes developing secondary complications, delivering health education is a common primary intervention strategy. Tiara however lamented that within her workplace the opportunity to provide health education to patients with diabetes is not always utilised*:*

> *[I] wish in delivering education, the team will be more enthusiastic in collaboration with the dieticians as they understand more about the food…how to count the calories, for example. So, it's to minimize [the number of diabetes cases]. The diabetes cases are increasing in this ward. Commonly, it's [their diabetes] has already [become] complex. [People were] admitted with prolonged diabetes and [they were] admitted with renal failure…so it's already late (Tiara: G2P10).*

Health education is a useful approach for clinicians to employ when explaining diabetes management to people. As one of the pharmacists working in a pharmacy installation/department in a hospital offered:

> *...[to] understand more about what they will get if they take the medicine regularly and what if they take it irregularly. We provide explanation like that. In educating, we provide information to prevent complications from this diabetes disease (Cahyo: G1P10).*

According to several participants that included a pharmacist (Cahyo), a specialist doctor (Galih), and a dietician (Elita), people with diabetes should understand the disease, have knowledge of managing the disease and recognise how their body responds to fluctuations in BSLs.

> *For the pharmacology therapy, in order to promote patients' compliance, we provide education and explanation to patients about how important the diabetes medicines [are] to keep the level of blood sugar at normal (Cahyo: T1P10).*

When people with diabetes understand their disease, they may increase their acceptance of having a chronic disease and improve the management of their diabetes. As it was explained by Galih and Elita:

> *We mainly try to make the [the person with diabetes] understand why his level of blood sugar can be high. Then education, then exercise, then the diet and the medicine he takes and the potential complications, both the disease complications and the medicine's side effect (Galih: G1P5).*

> *Having understanding first, then accepting, then carrying out. If there is no education, the patient commonly does not understand… does not understand, so they cannot accept... [It] is impossible to implement other therapies (Elita: G1P7).*

Health education also serves to help people with diabetes become more independent with their diabetes management. As Galih explained:

> *The aim is [for the patients] be more independent. [When] there is not much progress, he goes to the doctor. [But] it should be handled by himself. So to control the blood sugar, it is not only from the doctor or medical health worker, it must be from the patients themselves. However, if he can understand, sometimes, there is something he can handle at home (Galih: G1P6-7).*

According to several healthcare professionals (Elita, Cahyo and Galih), health education could occur when there is an awareness and willingness from the people with diabetes of the need for health education for themselves. This was when health education occurred purposefully. For example one of the participants who is a dietician said that people with diabetes would come to her for diet management because they had awareness about their disease. Therefore, the delivery of health education occurred.

> *The patients who have awareness [about their] disease… they also come by themselves [with their own awareness]. They see the dietician because [for] people with diabetes, the eating plans have important roles besides medicines and exercise (Elita: G1P2).*

A pharmacist and a specialist doctor concurred with the dietician:

> *If the patients are aware and willing to be provided with information from us, we provide the information to the both patients' family and the patients so that the patients understand about therapy used here (Cahyo: G1P8).*
>
> *To control this, the patient must understand about the diseases because the diabetes is the friend of their life time. He must want to learn about diabetes circumstances, well… it accompanies him for his life time. To achieve the diabetes control, easily achieve… if the patients understand, it's nice, [then] it's easy to control it (Galih: G1P7).*

Educational materials.

'Actively seeking and passively receiving diabetes related information' depended on who firstly initiated the conversation for the information. If a person with diabetes asked for information related to their condition of diabetes, then this action is classified as being actively seeking information. However, when a person with diabetes received information that was initiated by other people, this activity is regarded as a person with diabetes passively receiving diabetes-related information including recommendations and explanations. Passively receiving recommendations and explanations included listening or watching to the information provided by other people (HCP, non-HCP, media) or reading health literature such as the diabetes-related brochures, leaflets or other types of information provided to the person.

Health literature provided in the healthcare facilities varied from printed to audio-visual information. For example, the brochures on diabetes are provided at strategic places in the hospital/healthcare facilities. One of the participants who was employed as a hospital health promotion officer highlighted the role of various communication mediums used to disseminate health information to people with diabetes and their families. For example, he mentioned the leaflet:

> *We here also produce leaflets. One of them is education about diabetes. We have places in every ward to put leaflets… Anyone can take the leaflets. We also have leaflets that are provided for the HCPs to deliver education to patients beside their beds. We have patient bedside counselling. We support with the leaflets. We also [have a] specific leaflet for diabetes, especially diet for diabetics (Qosim: G2P1-2).*

Then Qosim also mentioned using audio-visual aids:

> *We also have this media [pointing to the audio-visual aids] to perform group education. There, they can directly have questions and answers. For the video, you can see like this [he showed me the example of the video]. This is our channel operated from 8 am to 12 pm, only one channel. For diabetes, we have slides in a video. It contains the definition and the prevention. For those who have had diabetes, what they have to do…that's the materials to deliver (Qosim: T1P3).*

Information described by Oosim utilised audio-visual media provided in particular inpatient rooms/wards and in the outpatient waiting room. Thus, people with diabetes and their families can watch health information (including diabetes information) while they are waiting for their turn for a consultation. As Qosim stated:

> *This TV channel [health information] is connected to ten points [areas]. In outpatient care, the waiting rooms in 1st, 2nd, and 3rd floor. Then the waiting room in the pharmacy. The waiting rooms in inpatient care ward, room A and VVIP rooms (Qosim: G2P3).*

Sources of information.

People with diabetes did not only acquire diabetes related information from HCPs. Non-HCPs could also be an acknowledged source of diabetes related information. These groups include relatives who lived with diabetes, acquaintances who lived with it or who have relatives with diabetes; friends; or people who work with HCPs to assist diabetes management.

When people lived with diabetes, they tended to talk about their diabetes with others they met. Betty met other people in a healthcare facility while in the waiting room and they talked to each other about their diabetes. From that occasion, Betty learned about the complications of diabetes from fellow people with diabetes:

> *I get this sweet urine disease. Sweet urine disease will impact anywhere he said. It was said by my friends who have sweet urine disease yesterday, [someone] gets the wound [ulcer], gets the renal [disease], and gets the liver that having a large stomach, the knees, and the rheumatics. The ones who were [sitting] near me, I asked them all who were close to me yesterday [while waiting in the clinic]. "I don't have gastritis Mum, but have this hole" [the ulcer]. When I hear from the friends, I am so afraid. The sweet urine disease cannot be cured… (Betty: G1P4)*

Ranti and Utama received information related to diabetes from their relatives or friends who had relatives living with diabetes. Ranti stated information was received from friends whose families had members with diabetes. While Utama explained that his relative gave him a recommendation for treatment:

> *… just from [my] sister [who had diabetes]. The food… pay attention on the food pattern, mainly the cold drink... the coconut milk [food cooked with coconut milk]. The cold drink which is made from a sachet she said. I rarely take sachet cold drink, but I sometimes take the sacheted drink such as Tropica [syrup] or Luwak [coffee]. Not too much… Now, I take it infrequently (Utama: G2P8).*

A family member, who managed the diet of a person with diabetes, also received information from other people. She responded to the question about where she got information about managing the food for her husband who has diabetes:

> *…from friends. His mother [her mother in law] had diabetes. She taught me about the food. What does and doesn't… For the diabetics, serve the fruits and vegetables. That's it (Viola: G2P1-2).*

Media such as books and the Internet were important sources of information for people with diabetes.

> *So, I was given a prescribed medication. After that, I was looking for books... [about] diabetes. Firstly, I did not want [to read] the books. All this time, I did not understand at all. [I was] looking for books...asking anyone. It seemed that there was no sign [of diabetes] but it is said that diabetes cannot be cured... well…so [I] must take the medication for a lifetime (Larisa: G2P1).*

Some people with diabetes asked their family members to assist them to retrieve information from the Internet. Some family members also suggested to people with diabetes, to read diabetes related information they found on the Internet. As Oscar and Kevin mentioned:

> *I asked my son to search from the Internet, [for] something that can treat diabetes (Oscar: G2P2).*
>
> *Last time, I wanted to know a lot… the Google… My son is good at it [browsing Google]. "Karet Kebo" leaves, it's good. I read it from Google. Google. My son searched it. It was really good (Kevin: G2P7-8).*

Places such as healthcare facilities were also considered a source of information that people with diabetes could exploit. The types of information they obtained at these settings were provided by HCPs, from health literature they collected or from other patients. People with diabetes obtained information from HCPs when they had consultations or were involved in health education sessions offered by the healthcare facility.

The community in which people with diabetes interact with others could also be a place where they obtained health information about diabetes. High levels of social interaction occur in Indonesian communities. People occasionally visited, met and talked/chatted to other people living in the neighbourhoods during a social activity or when walking on the street and greeting each other. They also talked about their diabetes. Thus, the community that consisted of people who may be the relatives with diabetes, friends/acquaintances with diabetes, or friends whose relatives have diabetes, usually delivered information about their experience with diabetes and shared it with the people interacting with them:

> *I asked friends whom I met. [On] how to take care [of] a person with diabetes. Asking them [about] how to prepare the food every day at home. A person with diabetes is sensitive so we have to pay attention to him. (Viola: G2P2)*
>
> *Once, someone said "don't eat this and that". But it would be clearer if [the information comes] from people who have knowledge about health. If it is from the neighbours, I think it is only word of mouth. They are not a physician. (Ranti: G2P4)*

Utama once used herbal medication. When he was asked about where he obtained information about that herbal medication, he said it was from someone with whom his wife spoke to:

> *It was from the person whose mother has the disease, diabetes. Her mother takes it orally. This person has a stall which my wife rents. So I take that medication orally. It might have been long time that I have taken it…more than two years. It is Kratom leaves. (Utama: G2P4)*

Generally, health seminars were provided by HCPs or an expert and were organised by a healthcare facility or an academic institution. At other times, the health seminar might be provided by non-HCPs or conducted by a company selling health products.

> *Last time in 2013, there was Happy Dream [the brand name of the mattress]…the Happy Dream from Korea. There was a bed mattress with [germanium] stones [inside the mattress]. I used that therapy in the morning. (Ranti: G2P2)*

When she was asked about where she learnt about it, she stated:

> *I took part in a Ken Konokai seminar. [It was delivered] all about health including diabetes, stroke and heart. (Ranti: G2P3)*

The category 'seeking and receiving diabetes-related information' is concisely explained through a figure below (Figure 6.2).

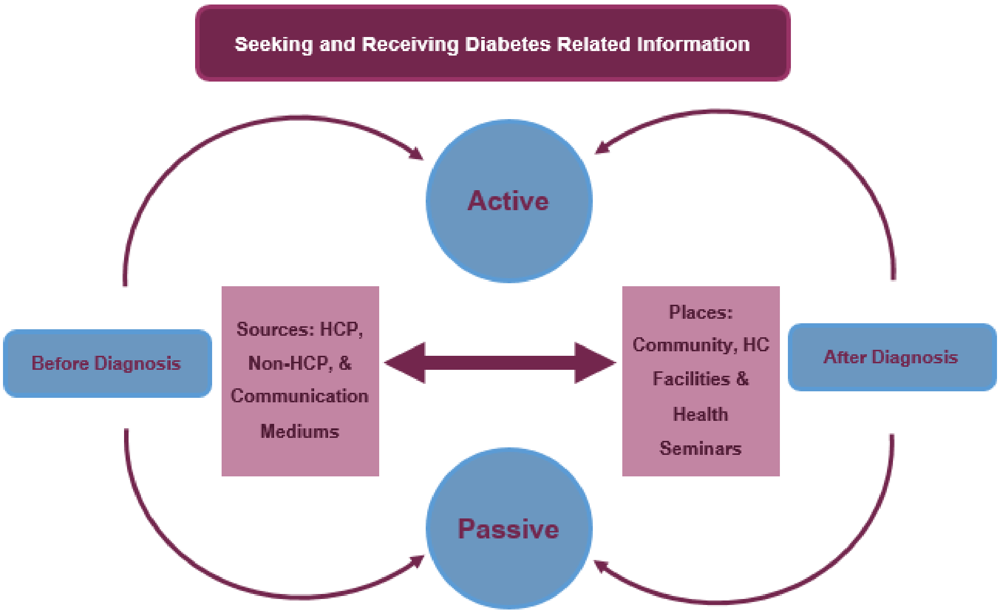

Figure 6.2. Category of 'Seeking and receiving diabetes-related information'.

Category Two: Processing Received Information

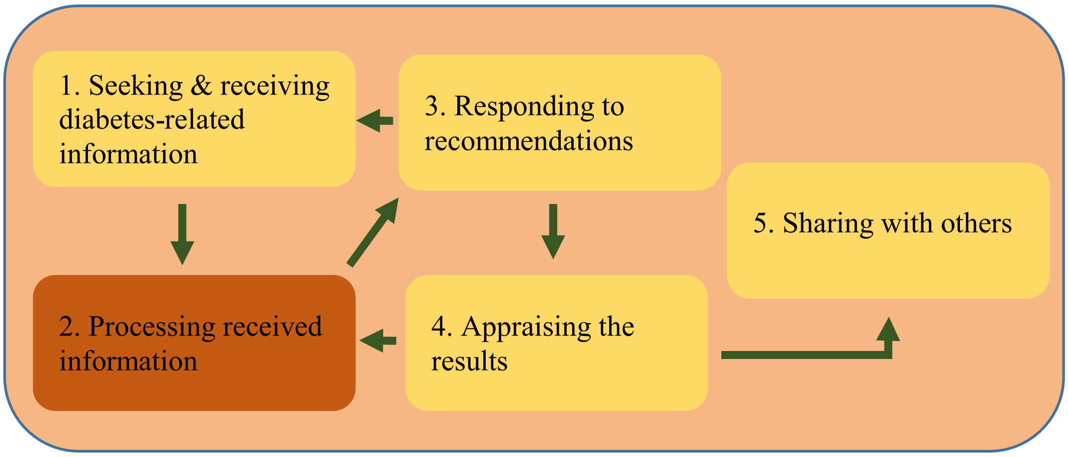

Figure 6.3. Theory of *Learning, choosing, and acting: Self-management of diabetes in Indonesia* (Category Two).

The second category is *processing received information*. There were two sub categories in this category: sifting and trusting. Sifting is an activity when people with diabetes filtered the received information in several ways. The second sub category is trusting, which is an attitude that developed when people determined that the information received was reliable enough for them to consider enacting. As was explained in Category 1, the information included recommendations or an explanation.

In this first sub-category, people with diabetes sifted the received information to decide whether or not to trust the information they received. When sifting the received information, they filtered the information by using their prior knowledge; their own experiences; and their personal judgement; or through asking for a second opinion from other people they considered had expertise, and from other sources such as websites.

Oscar, who was admitted to the hospital during the study, shared his experience in applying treatment that he trusted to have benefits:

> *I asked my son to look from the Internet, something that can treat diabetes. There are many varieties such as the red fruit. The 'Mahkota Dewa'. It's Natural. Then there is 'kumis kucing' (cat whiskers). This is not just a story, I have already felt it. Like my wife, she still consumes Rosella up until now to avoid hypertension. I have tried them all. (Oscar: G2P2-3)*

People with diabetes used their own experience regarding the recommended therapy, which may have been proved to be valid or invalid based on scientific research. Utama, who lived with diabetes since 2008 trusted that consuming natural substance such as leaves or herbal products could have good outcomes for his diabetes, even though there is no research evidence to verify them. He said:

> *I only like herbals. I take herbal medication [orally]. I feel good. I feel good in my body. I take 'kratom' leaves. I stay awake. My body feels good. I have taken it since the last two years. (Utama: G2P3)*

There were people with diabetes who used their personal judgment in the process of filtering information. For instance, Ranti stated:

> *When there is information that does make sense, I will accept [it]; and that which does not make any sense, I will dismiss. I will not [try a therapy until I hear it directly from the person] who proved it' [to be effective]. (Ranti: G2P10-11)*

Another example of a participant using the information is Widya, an exercise instructor living with diabetes:

> *I take the prescribed medication. The doctor said that people with diabetes must take the medication. '…[you] cannot say no', the doctor said. Well, I follow his instruction because this is for my health. (Widya: G2P13)*

When people with diabetes sifted the information related to diabetes care recommendations using their personal judgement, preference became one aspect they took into account. For example, Utama said:

> *I just like the herbals. (Utama: G2P3)*

Beside using their own knowledge; experiences; and personal judgement in sifting the information, people with diabetes also asked for a second opinion. Zeta talked about having other people's opinions in relation to the therapy she took.

> *I usually ask my friends' advice [and] search [the information] from the Google. The cherry leaves or the 'Kersen' leaves. The leaves and two glass of water are boiled. Making them into one glass of water. I told this to Mr S [who she considered as the expert] and he said you may take it. (Zeta: G3P4)*

After sifting that diabetes-related information, people with diabetes decided either to trust or not trust the information and this is where the second sub-category of the processing received information occured. The degree of trust was influenced by the deliverers' level of expertise or level of lived experienced.

People with diabetes decided to trust the deliverer of the information when the deliverer had expertise, including HCPs, or non-HCPs that do have some health knowledge. As Utama said:

> *well, just doctors. Just the doctors I believe. Now I believe to doctors. Doctors know everything. (Utama: G2P14)*

His wife, Viola, also supported his statement:

> *I hope my husband gets better. I think it should be [managed] by the doctor, shouldn't it? (Viola: G2P7)*

Information from other people can be taken from unknown sources. The unknown sources were usually distributed informally by word of mouth. As Ranti explained, she could obtain clear information only from an expert:

> *Once someone said that I cannot eat this and that. The clear information only come from people who have health knowledge. If the information comes from neighbours, it is just word of mouth. In my opinion, they are not doctors. Doctors have been educated. (Ranti: G2P4)*

Information coming from a person with lived experience could have a stronger influence than information coming from someone with expertise. For example, one participant with diabetes shared that his relative who also had diabetes influenced him. He was prescribed insulin injections however he did not adhere to this management recommendation because his sister said that taking insulin can result in dependency:

> *I was given [the insulin when discharged from the hospital]. I am afraid of being dependent [on the insulin]. I am afraid to inject it... [being] dependent on medication… my sister said that "don't you use the insulin". (Utama: G2P5)*

His wife supported his statements by quoting his sister:

> *"Once you use the insulin, it will be [used] forever". (Viola: G2P5)*

> *"My sister, who has passed away, said that". (Utama: G2P5)*

People with diabetes put more trust on the recommendations received from other people who have lived experiences about diabetes.

> *My brother advised me because he has experienced it [diabetes] before me. So taking care of the eating, taking care of the drinking... Well, all is taken care of. Not to drink from the bottles [instead of mineral water] or sachets.*

> *That must be avoided, he [the brother] said. Because he has already known [experienced diabetes] before me... [He] has the experiences. So I learn from somebody's experience as well. (Haris: G2P1,5)*

Sometimes the person was inclined to follow other peoples' recommendation if their lived experience was stronger than their own. For example, again, Haris followed his brother's recommendation, which weighed more than his own opinion about taking conventional medication:

> *I think and infer that this chemical medication can cure what we suffer on the one side but on the other side, the frightening one is the side effect to other parts [of my body]…to kidney….to other parts [of my body]. That was my thought. But now because my brother gave me input 'Don't stop. You must take [prescribed] medication]'. Well, eventually, I follow my brothers' suggestion. (Haris: G2P4-5)*

They also put trust in the information that came from a secondary source of people's lived experience. For example, Utama implemented the suggestion that came from someone's relative with diabetes. When he was asked where he obtained the information about herbal consumption, he explained:

> *someone who have the stall that my wife rents. The stall in the house complex. Her mother has diabetes. Her mother takes it [herbal medication]. So [I] take that [herbal medication]. (Utama: G2P4)*

However, people with diabetes received so much information that they sometimes became confused about what was valid and what was not.

> *Last time I have tried an alternative therapy. I knew it from friends, the family also told [me about it]. Trying this and that… but I am not really sure about it. Yeah... not really sure. These medications vary. I am sometimes confused. When we apply all [medications], it is not known which one will cure. [If] we take the medication from the doctor [and] we have also alternative [therapy], it will be confusing which one is true. (Kevin: G2P3-4)*

Choosing whether to trust or not trust resulted in them responding to the information, which usually consisted of recommendations. When they did not trust the information, they made a choice to dismiss the information. On the other hand, when they trusted the information, they opted to respond to the recommendations by either following it or not. Trusting the deliverer did not guarantee that people with diabetes would follow their recommendations. There were three factors that influenced the decision to follow or not follow recommendations. Responding to recommendations will be explained in the following section: *Category Three*.

People with diabetes sometimes received incomplete information. Not all people with diabetes were exposed to information related to diabetes, thus they might not have received any diabetes related information at all, or they might have received incomplete information about diabetes. This phenomena occurred, for example, as Oscar, who lived with diabetes for six years and was from a rural area, asked to have information about the disease because he had not received information previously.

> *I please ask health expertise who have knowledge about this dangerous disease. Please inform it to people in communities. Thus, please visit the villages to deliver advice to communities so that people can do preventions. (Oscar: G2P10)*

When he was questioned whether there were HCPs delivering information related to diabetes, he said he had never seen that happen once:

> *Not yet. It has not been in our village. Albeit, people will be much more responsive and respectful if there is [health education delivery]. (Oscar: G2P11)*

Barriers to providing complete information were acknowledged by HCPs. Two HCP participants stated that barriers to providing information included limited time and high patient loads as evidenced by Aditya and Yoda:

> *I look at the phenomenon in the field [clinical settings] nowadays, really that the barrier is lacking of time for us to provide education for the patients, because this is actually the important part, because there is not enough time for nurses. In relation to the limitation, it is the bustling. (Aditya: G1P4)*
>
> *Well, when there are many patients waiting for wound dressing, there will be a long queue. Therefore, the health education will be delivered briefly, except for new patients. (Yoda: G3P3)*

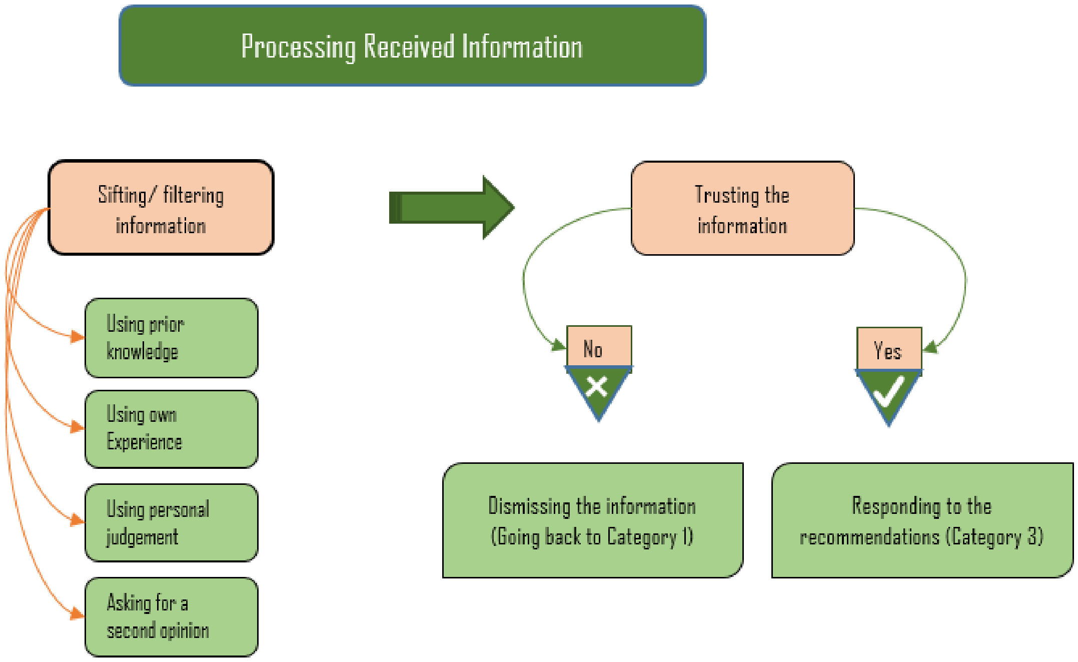

Figure 6.4. Category of 'Processing received information'.

The second category in the process of *Learning, choosing, and acting: Self-management of diabetes in Indonesia*, "processing received information", is concisely explained in the diagram above.

Category Three: Responding to Recommendations

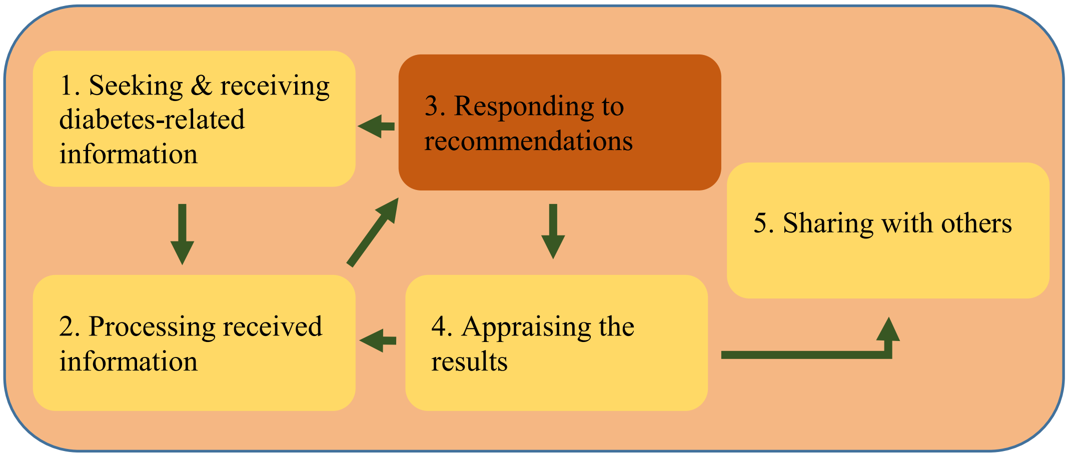

Figure 6.5. Theory of *Learning, choosing, and acting: Self-management of diabetes in Indonesia* (Category Three).

Responding to recommendations was a conscious action taken by people with diabetes when they decided their way to implement something that has been recommended to them. Recommendations were the most dominant information related to diabetes that was received by participants in this study. Therefore, *Category Three* used the term 'recommendations' (instead of diabetes related information). Recommendations come from various sources and places as explained in *Category One*.

There were three factors that influence how people with diabetes responded to the received recommendations that they perceive as reliable. The first factor was physiological. This factor included body changes and worsening symptoms. Psychological aspects were described as the second factor influencing the action taken in response to recommendations. The third factor was resources. These three factors have also been explained in the paper entitled *'How people living with diabetes in Indonesia learn about their disease: A grounded theory study'.*

There were two ways people with diabetes chose to respond to the recommendations they believed were reliable: Not following the recommendations; or following the recommendations in their own way. Each of their chosen responses to managing their diabetes determined the consequences they may have experienced. This section explains each of the possible responses.

Not Following the Recommendations.

People with diabetes also opted not to follow the recommendations they have received. Even though people with diabetes trusted the received recommendations, they also could choose not to follow these recommendations. Two reasons that stopped individuals with diabetes following what had been recommended to them were financial matters and location. One nurse clinician who worked in the wound care clinic at the secondary hospital mentioned that there were people with diabetes who did not take actions for recommended treatments because they could not afford the treatment and had lack of access to the recommended therapy. Additionally, the nurse explained that people with diabetes were thus 'taking it as it comes' since they felt they were doing all right without following the recommendations.

> *We usually suggest the patients to wear [diabetic shoes]. The patients sometimes really want it but because the place [to make the shoes] is difficult [to reach] or far... That is the barrier. There are patients who use diabetic shoes because the foot has become deformed… By using that*

> *[shoes], he can walk. [However] there are also patients who do not use it because of being [living] far away… also the cost…Thus, the patient who feels it is enough, they just accept it. (Danur: G2P14)*

Following the Recommendations in Their Own Way.

In following the recommendations, people followed the recommendations in their own way. The degrees of following varied as the individuals with diabetes applied the recommendations in their own ways: (1) Using non-conventional therapies exclusively; (2) Concurrently using conventional and non-conventional therapies; (3) Partially following conventional therapies and (4) Fully following conventional therapies. Explanations about the sub-categories of following recommendations in their own ways have been addressed in the paper entitled '*How people living with diabetes in Indonesia learn about their disease: A grounded theory study*'. However, this section will present further evidence that supports these sub-categories.

Using non-conventional therapies exclusively.

The contents of recommendations not only included conventional therapies for diabetes self-diabetes management, but also non-conventional therapies, as the sources of the recommendations were diverse. Sources of information usually came from relatives with or without diabetes, friends with diabetes or acquaintances who live with diabetes. These people spread the recommendations based on their own experiences or other people's experiences.

Three forms of taking non-conventional therapies were identified. First, many people with diabetes made their own herbal medication at home. The ingredients might come from their own plants at home or from others' plants. As told by Haris, before he regularly took prescribed medication, he had previously taken home-made herbal medication:

> *Previously I took potions. The potions that my friends informed me. Chinese medication from China. 'Temu lawak' with bay leaves that I usually combined with ant nest. It was brought from Papua. I combined it with red 'sirih'. Then there is insulin plant. Well, I plant many of those plants. (Haris: G2P4)*

He tried to take herbal medication several times because of a reason related to the convenience issue in taking the medicine and obtaining the herbal substance.

> *My principle is taking the simple thing. The substance that is easy to obtain, easy to search for. When we need it, we do not need to buy it, isn't it? I can't withstand [the medicine]. The medicine is commonly bitter. No*

> *medicine tastes good. That's it, when I can't stand for [the medicine], I just leave it. Just the easy one, the easy one to search. Not to make myself or other people be troublesome/difficult. (Haris: G2P6-7)*

Whereas, Kevin made his herbal potion from leaves at home.

> *Last time, I consumed this herbal...'Karet Kebo'. 'Karet Kebo' leaves, it's good. I read it from Google. My son searched it. It was really good. Five leaves are cut then boiled. (Kevin: G2P8)*

The second way of taking non-conventional therapies was to purchase and take factory-made herbal medications orally. For instance, one person with diabetes took herbal medication after being recommended to do so by her relative.

> *Coincidently my daughter works in a chemist so she suggested (to) me to take "Sugar Seal" [a name of a factory-made herbal medication], American made. She told me to try it. (Ranti: G2P12)*

However, this kind of medication was sometimes expensive. They managed to buy it when the price had been discounted, so they could afford it.

> *Well, this [factory-made herbal] medication is expensive. However, I wait for the discount/sale. There is a 25% discount once a month. My daughter also helps me. She said, 'this is for six months in advance'. (Ranti: G2P12)*

Quite a few people with diabetes attended a seminar and bought the product that is claimed to have a good outcome on their diabetes or other diseases. The third way of taking non-conventional therapies was when people with diabetes wore a device that they believed to have an effect to their diabetes. The varieties of the products ranged from a pill the person could consume or a device the person could wear or use. For example, one person with diabetes, consumed and wore some of the products that were believed to have outcomes related to diabetes. Ranti, a person with diabetes explained that she had information about the device from the health seminar organised by a company who sold this health product. This person also implemented two kinds of non-conventional therapies at the same time in which the therapies were believed to be efficacious for their diabetes. Ranti wore a device (magnetic belt) and took factory-made herbal medication regularly every day.

> *[I] bought a device. I wear this supporting device. [She showed me the device that she was wearing on her waist. It's like a corset/waist belt]. For what I have known, it repairs... Diabetes occurs because our pancreas is damaged... The pancreas cells are damaged. Or kidneys [are damaged]... If we take many medications [and] drink less water, that can damage the*

> *kidneys. So, I am helped by buying this device so that my kidneys will be good. This device only contains [a] magnet. (Ranti: G2P4)*

Besides raising an issue of fear of the medicine, especially when a needle was used, another reason that people opted to take non-conventional therapies was they believed conventional medication might do something bad to them. For instance, Utama believed he had less motivation to use oral medication because of being afraid of the chemical effect of the medication to his body.

> *I am, afraid of the chemical substance [from a medicine]. I am afraid as people said it may affect our kidney when we have too much doctor's medicine. (Utama: G2P4)*

Concurrently using conventional and non-conventional therapies.

People with diabetes also opted to take both conventional therapy and non-conventional therapy. In practice, they did not take these therapies at the same time, for example, within the same hour. Healthcare professionals also noted that people with diabetes might have also used conventional and non-conventional substances simultaneously. One nurse clinician described that people with diabetes occasionally told him that they take both therapies on the same day.

> *There are patients who combine [the therapies]. They take medication from the doctor then they also take herbals. It's combined but it's not at the same time. They give an interval for about two hours [before having the other therapy]...on the same day. (Aditya: G3P2)*

Partially following conventional therapies.

People with diabetes considered in this group were those who followed one or some of recommendations for diabetic self-management. They did not follow all diabetic self-management actions recommended to them and their level of adherence varied. When they followed one diabetes care management, for example, exercise, they may not have taken oral medications. For example, Ranti did not take her prescribed medication but she performed regular exercise on a daily and weekly basis. Kevin, who took regular medication, admitted he was unable to restrict his food.

> *I balance [the disease symptoms] with exercise. I do not only have an exercise at the PHC but I also go to the sport building. After I pray at dawn, I take a walk. I exercise because I want to be healthy. Walking is also okay [for me]. Taking a walk for about one hour then going home. (Ranti: G2P6)*

> *I always take the medication. There is no problem. (But) I am not good at restricting [what I eat]. [I eat] all of them [the food]. I drink syrup... I drink coffee. (Kevin: G2P9)*

People with diabetes sometimes underestimated their disease severity. This attitude influenced them to not adequately restrict their diet and to not take their diabetes medication regularly. Sometimes, a person with diabetes underestimated the impact of food she had eaten, as was reported by a family member of a person with diabetes. Nirma, a family member whose mother had diabetes also shared her story about her mother who did not want to listen to her when she told her to reduce her sugar consumption.

> *My mother sometimes likes to eat a cake. In the morning, she sometimes eats one piece of cake, she thinks in her mind, 'just one piece of cake…one piece of cake doesn't have much sugar, a little... it's okay, it's a little'. She thought if it is a little, it would be fine. She said it is okay. She underestimated it. She considered a little amount [of sugar] is okay. (Nirma: G2P2)*

People with diabetes who took into account that restriction in diet was important believed that what they ate would have an impact on their body. Haris linked eating food to 'a boomerang effect' and thus he attempted to be strict in his food selection.

> *I can conclude that what I have eaten [or] water that I have had is actually like a boomerang, Australian people's weapon. It (can) threaten me when it (the food or drink/water) is taken too much. The important thing is, I said, the important thing is it (the food) does not enter (to my body) too much, I said. [Similarly], when the boomerang weapon is thrown, it will be thrown back to us ourselves. When we eat or we drink, it will have an impact on us ourselves. We ourselves will feel the effect. That's the principle. (Haris: G2P8)*

Fully following conventional therapies.

People with diabetes who followed complete recommendations were included in this group. One person with diabetes who lived with diabetes for four years explained that besides taking her oral diabetes prescribed medication, she did some exercise such as weekly exercise at the PHC and daily walking. She also paid attention to her eating habits including food and drink.

> *The doctor told me to have Metformin every day. When it is high, twice a day. I take once a day. So I take it after dinner. Regularly. Now, I never use sugar anymore, (I) have never had any sugar. The sweet fruit is also*

> *reduced (to eat)... the fruit like watermelon, it's just rarely eaten. The bananas are also rarely [eaten]. The sweet turnip (a tuber or root vegetable) is occasionally [eaten]. I like it. (Larisa: G2P2-3)*

When she was asked whether she had routine blood sugar check, she responded that she when health checks were offered at the PHC she attended for weekly exercise classes.

> *I have a regular exercise there [PHC] every Saturday. When there is blood pressure and blood sugar checks, I have a check. Surely, [I have a check] (Larisa: G2P3).*

The figure 6.6 below incorporates the explanation of 'responding to recommendations' briefly (Ligita et al., 2019, *in press*)

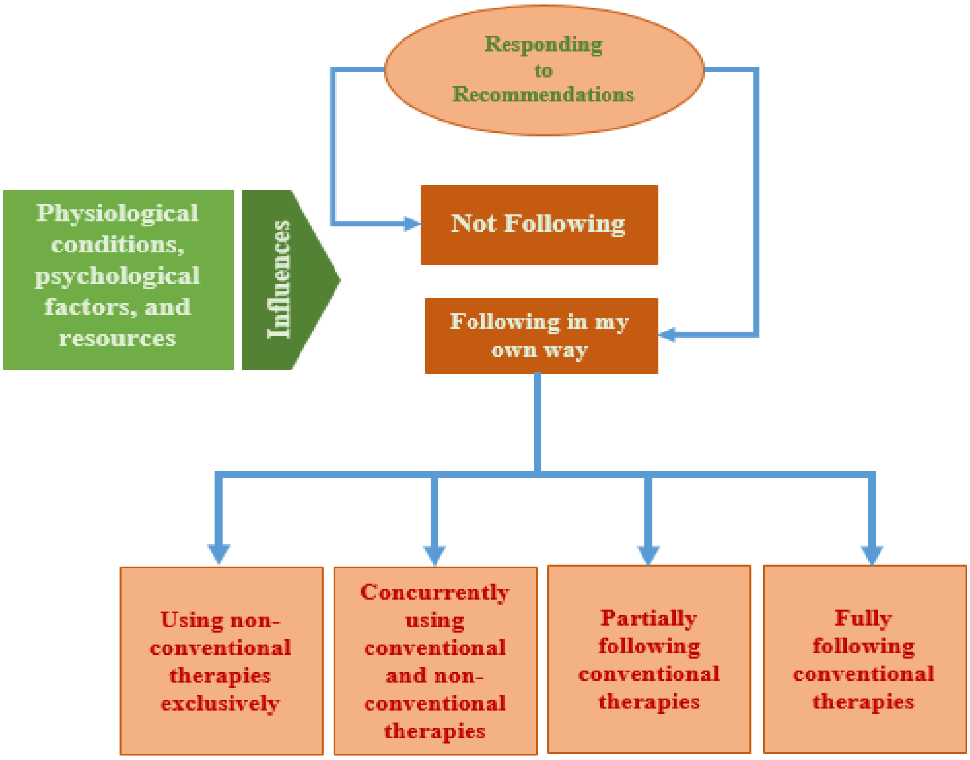

Figure 6.6. Category of 'Responding to recommendations'.

Category Four: Appraising the Results

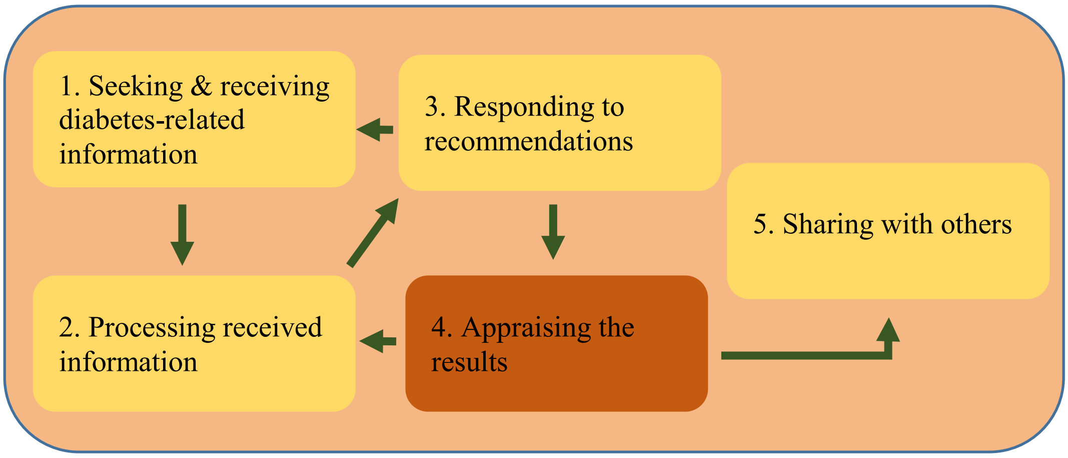

Figure 6.7. Theory of *Learning, choosing, and acting: Self-management of diabetes in Indonesia* (Category Four).

Once people with diabetes applied their chosen actions in relation to received recommendations, they then appraised the results of their chosen actions. Appraising the results can be defined when people with diabetes evaluated the results of applying their chosen actions. The actions were either following or not following the recommendations. In this part of the process of *Learning, choosing, and acting: Self-management of diabetes in Indonesia*, people with diabetes went through three sub-categories consisting of measurement, progress and further actions.

The sub-category of 'measurement' referred to how people with diabetes observed their body to appraise the results of applied actions. In terms of 'measurement', people with diabetes used two ways of appraising their actions. Firstly, they observed their body changes subjectively, based on how they felt. This observation included feeling comfortable or well in their bodies, reporting having clear eyesight and feeling energetic and alert. For example, two persons with diabetes, Haris and Kevin described how they appraised the result subjectively after taking a therapy:

> *I just feel okay on my body. I feel good on my body. I feel different on my body. I have better eyesight. I have headache less often… I don't feel limp anymore. (Haris: G2P2-3)*

> *I have tried this medication. But I didn't take it regularly. After twice or three times (taking the medication), I felt better. (Kevin: G2P3)*

Whereas, in objective measurement, they observed their body after applying their chosen action through measuring with certain equipment such as a weight scale to weigh the changes in body weight or doing a blood sugar test to measure their blood sugar level. Xeniya, who has lived with diabetes for 17 years, explained how she regularly checked her blood sugar level after taking a therapy. Her quote supports the way people with diabetes appraised the results objectively after applying a therapy/medication:

> *...If it is more than 300 [mg/dL], I'll do the injection [insulin]. If 200 or 100s [mg/dL], I don't do the injection. I check [the BSL] everyday… so I know the progress. (Xeniya: G2P3)*

Another example from Haris showed how people with diabetes observed their body change objectively. Haris was concerned about his body weight. Thus, when he took a therapy, he appraised the result by looking at his weight change:

> *Alhamdulillah [Praise to God], I feel fresher and I gain weight. (Haris: G2P4)*

In the second sub category of 'progress', there were two outcomes that people with diabetes noticed when they appraised the results of their chosen actions. Regardless of how they measured or observed their body changes either subjectively or objectively, the progress included positive or negative outcomes. Positive outcomes meant people with diabetes perceived encouraging progress in their body after they applied their chosen actions. Positive outcomes included having normal blood sugar levels, achieving required body weight and having a wound heal.

On the other hand, negative outcomes indicated people with diabetes perceived they had undesirable progress or no progress at all after the selected action was implemented. For instance, a negative outcome could consist of having unstable or increased blood sugar levels, worsening of the wound, or a perception that their diabetes had not been cured.

Other people such as the relatives and the healthcare professionals could also observe the progress of people with diabetes applying a certain kind of therapy. For example, one specialist doctor explained how he frequently saw people with diabetes coming to him after failing with non-conventional therapies:

> *They [people with diabetes] usually will try alternative medication… [but] it is usually a failure and [when] coming back [to the doctor], [they] have already had various complications. The cost will be by far higher. (Galih: G1P7-8)*

Viola, the relative of a person with diabetes, also observed her husband's condition after applying a therapy:

> *I searched a lot of information about medication such as what my husband was told, herbal medication. We search the information, we try. We try in one week or two week. If there is no change, we do not continue. (Viola: G2P1)*

Appraising the results produced experiential insight. After choosing to follow or not follow the recommendations, people with diabetes experienced positive and negative outcomes. These outcomes were measured either subjectively or objectively. Through this experience, people gained experiential insight. Experiential insight can be defined as people's new understanding based on their experience in applying their chosen action of following or not following the recommendations. Experiential insight covers not only the action per se, but also the effect of the implemented action. Experiential insight then determined what further actions that people with diabetes chose to do.

The third sub category is 'further actions'. Further actions refer to those decisions people made and actions they took, after gaining their experiential insight. The actions included sharing the experiential insight with others (which is the category five:'sharing with others') and/or using the experiential insight as received information to be sifted and trusted in category two ('processing received information').

Experiential insight used to share with others is discussed in the next section under category five ('sharing with others'). Besides using experiential insight as information to be shared with others, people with diabetes used experiential insight as received information to be processed in category two ('processing received information'). People with diabetes who used experiential insight as received information then went on to make further decisions: continuing or discontinuing the current applied recommendations. Similar to the other information received, this experiential insight was also sifted, with that experience itself becoming the filter, so that people with diabetes opted to trust or not trust their own newly gained experiential insight. Based on positive or negative results of applying chosen actions, People with diabetes then decided that the applied actions either worked or did not work for their diabetes. When people with diabetes realised that their experiential insight consisted of positive results, they then opted to keep following that currently applied recommendations.

An example of a further action is described in Oscar's statement. Oscar had lived with diabetes for six years. The positive results he noted from the applied therapy he took motivated him to continue applying the therapy.

> *I tried [herbal therapy] from browsing the internet. It really decreased it [the BSL]. Then I become more motivated to take it [the therapy]. It decreased it [the BSL] again. (Oscar: G2P3-4)*

On the other hand, when people with diabetes trusted that their experiential insight had made them aware of a negative outcome regarding their currently applied actions, then people with diabetes decided to no longer follow those applied actions. When people with diabetes discontinued their currently applied action, they then chose to: either alter to another recommendation or to seek more information, thus returning to *Category One* —'seeking and receiving diabetes-related information'.

People with diabetes who did not follow the recommendations from other people, also appraised the result of that action. Firstly, Utama, a person with diabetes, chose not to follow his physician's recommendation about prescribed medication. Viola, Utama's wife, explained that they decided to discontinue his husband's current therapy (herbals) and alter to be managed by a doctor, after having no progress on their current non-conventional therapy.

> *We have tried a herbal medication for several years. No progress, haven't we? So, we decide to be managed by a doctor. To regularly go to doctor consultations so that he [her husband] can get better. (Viola: G2P8)*

People with diabetes who chose to discontinue currently applied recommendation also sought out other recommendations through 'seeking and receiving diabetes-related information. This phenomenon was described in Zeta's story. She tried a factory-made herbal medication for one month, and after noticing she was feeling better in her body, she considered whether she should or should not buy another package. However, she decided to discontinue taking the factory-made herbal medication, because of its high cost. People with diabetes could not continue to repeatedly purchase expensive products over their lifetime therefore they changed to another more affordable therapies. Zeta then tried to search from the website and asked her friends about another option of medication/therapy:

> *I was suggested to take herbal, a product from New Zealand. I was observed regularly on my eyes. Alhamdulillah the [blurred eyes] are gone. I feel comfort on my body. Then I was offered for one more bottle. But for now, I feel comfort on my body, [and I said] what if I search from Google and have friend's recommendations, the cherry leaves/Kersen leaves. It was boiled with two glasses of water then to make one glass of water. (Zeta: G3P4)*

Both continuing and discontinuing the currently applied action occurred in category three ('responding to recommendations'). Experiential insight was insight gained after the actions were applied. Therefore, the theory of *Learning, choosing, and acting: Self-management of diabetes in Indonesia* is a dynamic process because people with diabetes go through the process in both a linear and cyclical movement, and revisit the process more than once in their lives.

Sometimes people with diabetes were influenced by conditions that caused them to discontinue the currently applied action, regardless of positive or negative results. The conditions included unavailability of the substance, unaffordability of the therapy, receiving more recent information about a therapy and feeling bored with having to take medication for their entire lifetime.

People who depended on a specific substance such as a plant sometimes discontinued using it because it was scarce and hard to find. For instance, Kevin stopped taking the homemade herbal medication because the substance was not available anymore.

> *I don't consume it anymore. It's difficult to find it [the leaves]. The substance is difficult to find. I have been looking around here, it's hard [to find]. (Kevin: G2P8)*

Kevin initially did not follow the recommendation to take regular prescribed oral medication. He also once tried some factory-made herbal medication. However, because the products were expensive, he chose to discontinue the herbal medications:

> *There is herbal medication called H [the brand of the herbal medication] and there is also called P [the brand name of the herbal medication]. Those were quite expensive. My niece bought me those medication. Quite expensive, and I also could not finish it. Those were expensive. More than 400…300 [thousand rupiahs or 21.32 USD]. So, I now decide to take*

> *doctor's medication. I regularly take the medicine once a day. (Kevin: G2P4)*

Galih, a specialist doctor, stated that people with diabetes who were feeling bored with their medication regime might try another type of therapy other than conventional therapy. This situation occurs when they do not have a single-minded determination to self-manage their diabetes well.

> *...[patients may] feel overwhelmed because they will have diabetes for the rest of their life. If the patient is not determined enough, they usually will try alternative medication. (Galih: G1P7)*

Utama discontinued his herbal medication after he heard some negative information regarding his current therapy.

> *Last time, when my sister was treated by Mr T, she was delivered with health education last time. I asked about this herbal medication. "Is it good for health?" He then checked from the internet. "Well, this kind is like psychotropic medication, Sir. Don't consume it". "Don't you take it anymore, Sir. It has psychotropic medication", he said. I do not dare to drink it anymore. (Utama: G2P6)*

Category four, 'appraising the results' is an important part of the process in which people with diabetes decided their further actions or next steps regarding their diabetes management. Figure 6.8 shows category four in a concise visual representation.

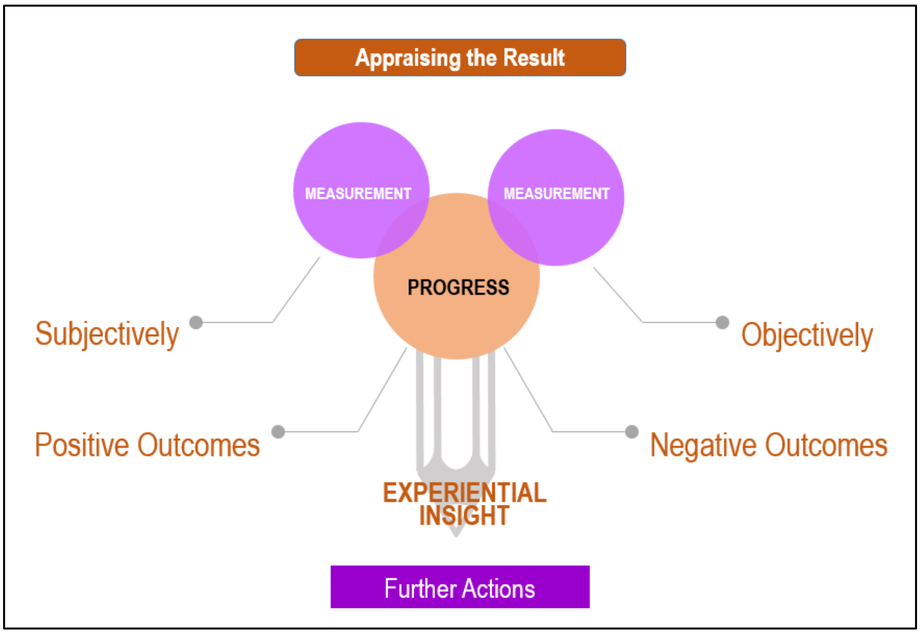

Figure 6.8. Category of 'Appraising the results'.

Category Five: Sharing with Others

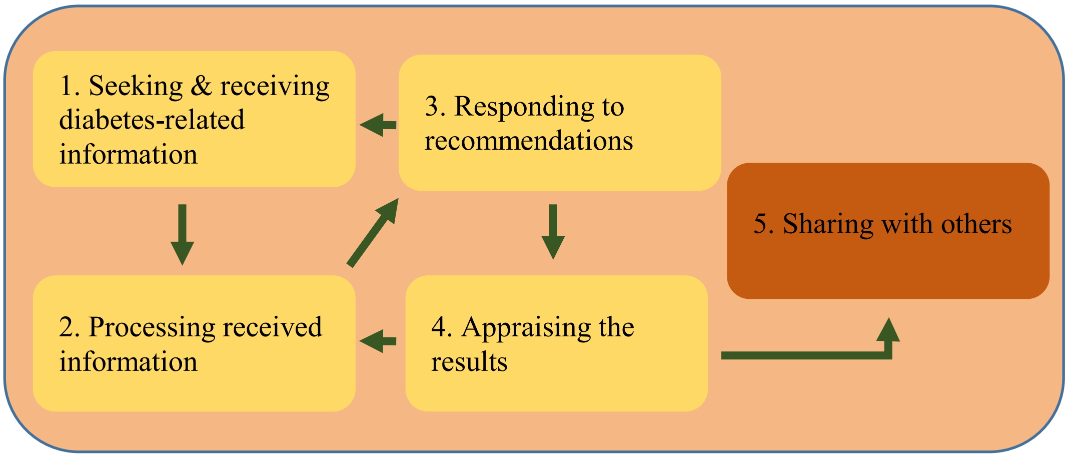

Figure 6.9. Theory of *Learning, choosing, and acting: self-management of diabetes in Indonesia* (Category Five)

'Sharing with others' is the final category. In this phase, people with diabetes disclosed or communicated their experiential insights to other people.

One person with diabetes, Zeta shared her experiences about her disease in hope that other people would help her better control her disease and would wish her well.

> *I told about all my experience, about my illness in the gathering, in my office or anywhere. Any experience was shared anywhere. I am not embarrassed that I have the disease [diabetes]. Thus many friends know about it and many of them also pray for me [wishing me better]. (Zeta: G3P7)*

There are two sub-categories in 'sharing with others': 'what to share' and 'with whom to share'. 'What to share' is mainly people's experiential insight, but this experiential insight can be varied. 'What to share' included how to recognise diabetes symptoms, what benefits occurred from their applied diabetes care management and what mistakes should be avoided.

Betty shared with her friends about her experiences in taking medication. She warned her friends to avoid the mistakes she had made. She also provided some recommendations about actions for diabetes self-management:

> *If you have sweet urine disease, when you feel like having symptoms, don't delay. I felt the symptoms and ate the medicine… then stopped after feeling better. Do not stop because in this sweet urine disease, the doctor said there is no ending. That's what I want to say to friends… Don't… if you have*

> *symptoms of sweet urine disease… Be quick to do something… about the food don't have too much... I had glibenclamide. I am sure to do the right things doc. Doctor Y said, 'do not stop Ma'am'… but it's me, I just wanted to have a short cut. (Betty: G1P13-14)*

Ranti once tried to convince her relatives to use the same herbal medication she used herself, because she considered it to be successful, based on her own experience with it. She believed it was not as harmful as conventional medicine:.

> *I have many family [members] living with diabetes. One of my family takes one big box of medication [conventional therapy] for one month. Ooh... I saw it. Well, she takes a lot of medicine… She is often admitted to the hospital. Therefore, I said to her 'take herbal medication', but she did not believe me. She still believes it [conventional medication]. Thus, her kidney is damaged and now it affects her heart. (Ranti: G2P9)*

Widya, an exercise instructor who has been living with diabetes since 2006 explained how she told about one symptom of the increase of blood sugar and what to do to cope with it, to her relative who was also living with diabetes. Widya also shared her experience in managing her diabetes to other people with diabetes:

> *So I share my talk based on my experiences. I said to other [people with diabetes] who sometimes asking me why I don't lose my weight drastically. Well, I have exercise. Also, I take medication. I have my meal three times a day but with different portions. I reduce the carbs. (Widya: G3P8)*

Another sub-category of 'sharing with others' is 'with whom to share'. This category referred to other people who were told information learnt by the person with diabetes who developed experiential insight. These other people included a person with or without diabetes; for example; family members or relatives living with or without diabetes could also be told of experiential insight. Also, other people who had relatives with diabetes may hear the experiential insight that a person with diabetes wanted to share.

Jovita is a person who took care of her relative living with diabetes. She told a story how she had information about herbal therapy from her other relative who also had diabetes:

> *Once, he [her brother living with diabetes] was told to take traditional medication but I felt sorry for him. It [the traditional medicine] is very bitter. I did not want to give it to him. Many people talk about it. My aunty also has diabetes. She saw other people talking about taking 'mahoni [seeds]'. I never try it [with him]. I plant it. But I am not brave to give [it to] him because it tastes very bitter. (Jovita: G2P4)*

Figure 6.10 illustrates this category of ‘sharing with others’.

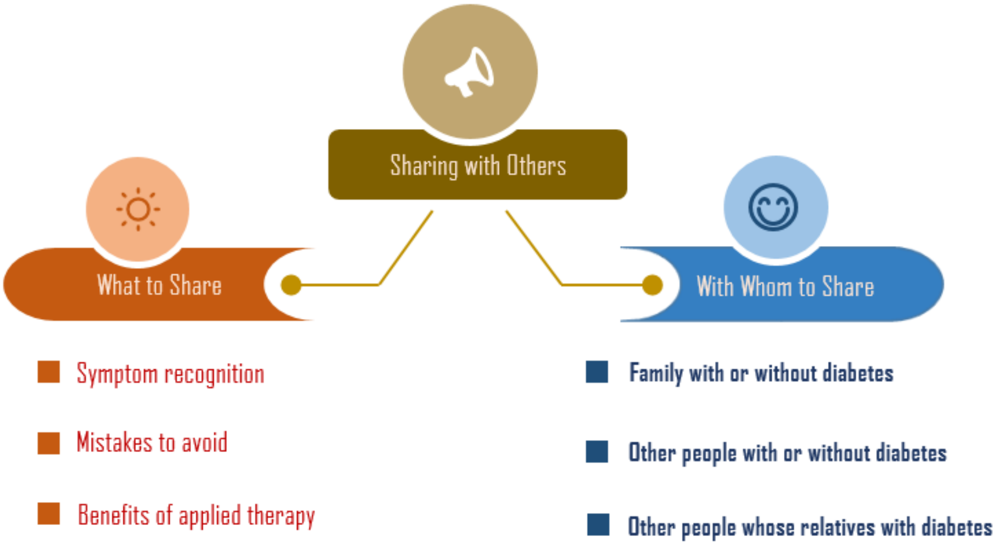

Figure 6.10. Category of ‘Sharing with others’.

Chapter Summary

This chapter initially discussed category one of the process. People with diabetes in Indonesia start the process of *Learning, choosing, and acting: Self-management of diabetes in Indonesia* either before or after the diagnosis has occurred.

This chapter also reported on category two, processing received information. Once people with diabetes received the information, they did not directly take actions related to information but they needed to process the received information through sifting it. People with diabetes then decided to believe or not the information they had sifted, before they decided to respond to the trusted information. The majority of information they received included recommendations on how to manage their diabetes. Once people deemed the recommendation as trustworthy, they responded to the recommendation.

Category Three: ‘Responding to recommendations” was also presented. In responding to recommendations, people with diabetes were influenced by three factors: physiological and psychological conditions as well as access to and availability of resources. People with diabetes decided to follow or not the trusted recommendations. They then appraised the result of selecting these actions.

This chapter then addressed category four of the process *Learning, choosing, and acting: Self-management of diabetes in Indonesia*. People with diabetes who responded by following or not following the recommendations then appraised the results of these chosen actions. This appraisal occurred when people with diabetes observed their bodily changes either subjectively or objectively. By appraising the results of their chosen actions, they decided won their next course of action. They gained new understanding from taking note of the results of their chosen actions and this new awareness was termed 'experiential insight'. Experiential insight that was shared with another person with diabetes could be the starting point for that person in their own process of learning about their diabetes. Meanwhile, the experiential insight that was received as information could then influence them to continue or discontinue their chosen actions related to diabetes care.

Finally, this chapter narrated the last category of sharing with other. People with diabetes shared their experiences in diabetes care with other people including their families, their friends, who do or do not live with diabetes. They mostly shared their experiences in diabetes care with other people with diabetes. In the next chapter, Chapter Seven, discussions related to the theory of *Learning, choosing, and acting: Self-management of diabetes in Indonesia* will be explicated. Additionally, key findings that support the theory will also be discussed with other existing findings both nationally and internationally and with other relevant theories, models and papers.

Chapter Seven: Discussion

Introduction

In this chapter, the findings generated as outcomes of this study will be presented as they relate to the existing literature. Initially an overview of the findings will be affirmed followed by an overview of the theoretical coding concept adopted to explicate the theoretical codes established as outcomes of this study. When discussing the key findings generated from this study, the candidate will relate the findings to other theories and/or models as well as relevant contemporary literature.

Overview of This Grounded Theory Study

This research was the first grounded theory study exploring the process of how people with diabetes in Indonesia learn about their disease. Being informed by symbolic interactionism and constructivism, this study involved a wide range of 26 participants in a total of 28 in-depth semi-structured interviews. The participants were recruited from seven different study sites consisting of two general hospitals, three public health centres (PHCs), a nursing academic institution and a private wound clinic. Healthcare professionals (HCPs), healthcare providers, people living with diabetes, families of people with diabetes and a nursing student were involved in the interviews. By using purposeful sampling and theoretical sampling methods, this study undertook concurrent data collection and analysis followed by the analytical process of constant comparative analysis. *Learning, choosing, and acting: Self-management of diabetes in Indonesia* was revealed as the core category to explain the theory of the basic social process of people learning about their disease. The theory has five major categories, namely ‘seeking and receiving diabetes-related information’, ‘processing received information’, ‘responding to recommendations’, ‘appraising the results’ and ‘sharing with others’. These categories are respectively discussed drawing on the literature to support and further explain nuances and to also challenge existing assumptions.

The Study’s Theoretical Code

Once researchers obtain their data, these data need to be analysed through a coding process. Generally researchers will generate both substantive codes and theoretical codes concurrently (Glaser, 1978). The researcher builds codes from their data which are called substantive codes; whereas theoretical codes are built when researchers sort the substantive codes by relating them to each other and integrate them, as informed by memos. If the sorting of memos are absent, the research may build a thin and linear theory lacking connection between the categories (Holton, 2007). Theoretical codes not only connect the substantive codes, but they also help the researchers to write their analytical story in a theoretical way (Charmaz, 2014).

Glaser (1978, p. 78) proposes 18 family theoretical codes and he acknowledges that researchers can be flexible to see other new families or can think of different names besides these 18 codes because the codes "are not mutually exclusive". The wise and skilful use of the family codes can make the theory be coherent and more precise, by ensuring that the codes fit with the data and the analysis (Charmaz, 2014). The candidate found that one family code fitted with the theory of *Learning, choosing, and acting: Self-management of diabetes in Indonesia*, and that was the 'process family' that reflects 'stages', 'phases', 'steps' and 'cycling' (Glaser, 1978). The theory of this present study contains five major categories to show that the process of how people with diabetes learn about their disease moves dynamically, in both linear and cyclic comportments.

The candidate also linked the theory with another family code, which is the 'strategy family' code that consists of 'dealing with', 'techniques', 'managed' and 'way'. The theory of *Learning, choosing, and acting: Self-management of diabetes in Indonesia* also reflects these aspects. For instance, one of the five major categories from the process of how people learn about their disease is 'responding to recommendations'. This category has two sub-categories to show that people with diabetes had two ways of 'responding to recommendations': 'not following' and 'following'. The 'process' and 'strategy' family code characteristics then have guided the candidate to find any theories related to theory of *Learning, choosing, and acting: Self-management of diabetes in Indonesia*.

Linkages to existing grand theories.

The theory of *Learning, choosing, and acting: Self-management of diabetes in Indonesia* links to the 'Health Belief Model' (HBM). The HBM identifies factors that influence people to perform actions to promote their health (Rosenstock, 1974; Rosenstock, Rosenstock, Strecher, Strecher, Becker et al., 1988):

1. The person believes that they are personally susceptible to becoming affected by the disease (health problem)
2. The person also believes that the disease (health problem) would have at least a moderately severe impact on their life

3. The person further believes that taking a particular health promoting action will either decrease their susceptibility to becoming affected by that disease/health problem, or if the disease does occur, that taking such an action will reduce the severity of the disease.
4. However, they may still not take the action, if they believe there are barriers to doing so, such as inconvenience, pain, cost or embarrassment

The last three factors in particular have strong linkages to the candidate's theory. In the HBM, people sought to take actions for their health when they believed their disease is austere. In this present study, people with diabetes who underestimated the severity of their disease tended to delay implementing their recommended diabetes management, for example taking prescribed insulin injections. Only after they found they had developed secondary complications of their diabetes, did some people finally decide to follow the appropriate actions recommended by their HCPs. In addition, the HBM emphasises that even when people believe the actions would benefit their health, they still may not take those positive actions, if they perceive there are barriers to doing so. In this present study, barriers of cost and of inconvenience also influenced people with diabetes to delay or decline to follow recommended diabetes management, similar to the HBM. Moreover, there were other barriers to action identified by this present study, including physical factors (body changes), psychological factors (fear of the medication's adverse effects and of the act of injecting it) and resource factors (insufficient time, inconvenient location, impracticality of taking the action).

Another theory that relates to this current theory is experiential learning theory (Kolb, Boyatzis, & Mainemelis, 2001) which reflects a process of learning through experience as a central role. This new theory, *Learning, choosing and acting: Self-management of diabetes in Indonesia*, builds upon the 'experiential learning theory' or 'ELT' (Kolb et al., 2001), which is the theoretical code of this present grounded theory study. The ELT refers to a process of learning in which knowledge is constructed by amalgamating two vital actions of "grasping and transforming the experiences" (Kolb, 1984, p. 41). This theory underlines experience as the essential element in the learning process. Historically, this theory was developed during a research study identifying learning styles through clinical observations in the 1970s (Kolb et al., 2001). Kolb et al. also use the term 'experiential' because of the influences of Dewy, Lewin and Piaget regarding learning and development (Kolb et al., 2001). Similarly, this current theory recognised that the experience of applying a self-management action played a significant role for people with diabetes as they were learning about their disease. Kolb et al. distinguished the ELT from cognitive learning theory, which highlights the cognitive more than the affective aspect. Also, ELT differs from behavioural learning theories that de-emphasise subjective experiences in the process of learning (Kolb et al., 2001). In ELT, grasping an experience means a person receives new information either through experiencing a concrete event/situation, or through conceptualising an abstraction of an event/situation. Moreover, in processing the experience, a person can actively do things (active experimentations) or reflect on their observations of others who are experiencing an event/situation (reflective observation) (Kolb et al., 2001).

In this present study, people with diabetes learned about diabetes either when they were diagnosed with the disease, or pre-diagnosis, when they began to experience changes in their body. By going through their experiences of self-managing their disease, people indirectly knew or became aware of their diabetes over time and thereby learned about their disease. This study indicated the process of how people with diabetes learned about their disease by experiencing the search for information related to their disease and how to take care of their disease, the application of the recommended management and even evaluating the results of applying the diabetes self-management actions.

People with diabetes navigated the process in both linear and cyclical movements. They did not always continue the same actions. People with diabetes learned from the self-management they applied. When they were not satisfied with the effect of the current actions, they sought for another diabetes self-management action instead of their current action. This present theory has a relation to a theory of ‘experimentation’ (Low, Tong, & Low, 2016a), as an indication of the process of help-seeking behaviour and patients’ strategies for their treatment. Low et al. (2016a) state that the process of ‘experimentation’ commences as people with diabetes seek information related to treatment and then their decisions about a chosen treatment involve a component of trial and error.

Similar to the theory produced by this study, the process of experimentation in Low et al.’s (2016a) study moves iteratively. The iterative movement in Low et al.’s (2016a) study occurred when people with diabetes failed to achieve their desired outcome following implementation of their current regime. People with diabetes subsequently tried alternative treatments to manage their diabetes. The same phenomenon occurred in this present study where people with diabetes would look for additional information related to diabetes management if they perceived that their existing management regime resulted in negative outcomes. What this present study adds is that the people appraised their experiences in applying their diabetes management and used the appraisal as a new insight (‘experiential insight’) for making further actions.

Six key findings arising from this study representing the explanation of the theory of Learning, choosing, and acting: Self-management of diabetes in Indonesia. These six key findings are discussed in the context of other recent and relevant international research findings.

Key Finding One: People with Diabetes Both Actively Sought and Passively Received Diabetes-related Information

When commencing the basic social process of *Learning, choosing, and acting: Self-management of diabetes in Indonesia*, the first stage undertaken by people with diabetes in this present study was seeking and receiving diabetes-related information. The candidate defined ‘actively seeking diabetes related information’ as people with diabetes searching for information and asking for a recommendation regarding their diabetes condition based on their own motivation and without any influences or suggestions by others. Meanwhile, people ‘passively receiving diabetes related information’ means they obtained information regarding their diabetes as a result of having health education that was initiated and provided by HCPs. Otherwise, the activity of receiving information occurred when people with diabetes spoke to other people about what they had learned about their condition, and as a result, these other people then provided information based on their knowledge of anything related to diabetes conditions and/or management. Moonaghi, Areshtanab, Joibari, Bostanabad, and McDonald (2014) also differentiated between active and passive acquisition of information. ‘Active’ means people proceeded to both seek and consequently acquire information; while ‘passive’ indicated they solely acquired information without any seeking activity.

Seeking information is one part of the process of *Learning, choosing, and acting: Self-management of diabetes in Indonesia* and it fits with information seeking behaviour that people with diabetes perform when they are experimenting with their diabetes treatment, as explicated in Low et al.’s (2016a) study. According to Low et al., conditions that trigger people with diabetes to search for information while experimenting with their diabetes treatment included being diagnosed with DM Type 2, achieving unexpected outcomes and failing to achieve their expectations. Similarly, people having an exacerbation or persistence of symptoms can influence them to ask for guidance (Moonaghi et al., 2014). In illness behaviour (Kasl & Cobb, 1966), people act by complaining and seeking consultation from healthcare providers, friends or families and these actions are undertaken when they feel ill, because they need to know their health status and the appropriate treatment. In this present study, people's bodily changes or diabetic conditions, which were noticeable, observable, notifiable and unpleasant, led them to initiate a conversation with their HCP. This conversation allowed them to ensure effective management, to anticipate what they have to do, to clarify their concerns and to ask for a recommendation. For example, the participants in this present study asked HCPs for reasons why they kept failing in maintaining their BSL, why they still had no progress, and/or why they developed diabetic ulcers. All these active seeking information behaviours were undertaken to learn more about their disease.

Also, this study found that people with diabetes aimed to obtain insight from taking note of their experiences in applying and appraising the chosen therapeutic interventions. In line with Webster et al.'s (2017) statement, in this study, people with diabetes received health education, and as a result, these people learned about diabetes through that provision of health education. This was the situation when people with diabetes passively received diabetes related information. Learning about diabetes could also be as a result of studying from books or any printed or unprinted (audio-visual) materials. "A model of care is about teaching and providing clinical support, yet learning is a result of teaching, studying and experience" (Webster et al., 2017, p. 30).

When people with diabetes passively received information, they did not initiate the process of seeking information. Zare-Farashbandi, Lalazaryan, Rahimi, and Zadeh (2015) point out that people with diabetes passively receive little information related to diabetes from their surroundings. They argue that these people tend to use received information for making decisions regarding their medical conditions. Milewski and Chen (2010) include passively seeking information as a challenge because people may unintentionally grasp information that was available to them, regardless of where the information originated or its credibility. As a result, people may have received inaccurate or incomplete information from those various sources, which results in misconceptions about their diabetes, which in turn results in inappropriate self-management.

Key Finding Two: Diabetes-Related Information was Accessed from a Variety of Sources and Places

In this study, the candidate identified that the types of information that people with diabetes sought or received were recommendations and explanations regarding their diabetes. A recommendation was the most common type of information that people sought and received. In Low et al.'s (2016a) study, people sought information about the efficacy and the side effect of treatments as well as cost and access to diabetes care. People with diabetes looked for information for the purpose of obtaining 'informational support', which related to medication or treatments and 'emotional support' which include reinforcement and assertion (Menefee, Thompson, Guterbock, Williams, & Valdez, 2016, p. 11) and of seeking help and guidance regarding their persistent and/or exacerbated diabetic symptoms (Moonaghi et al., 2014). The topic that people frequently searched for was information regarding their illness condition and its treatment (Clarke, Moore, Steege, Koopman, Belden et al., 2016; Menefee et al., 2016).

In this study the sources of information that people with diabetes accessed included people, materials and places. The people accessed were HCPs, healthcare providers, family members, friends and other people with diabetes. HCPs were the most common people accessed by people with diabetes (Clarke et al., 2016; Johansson, Almerud Österberg, Leksell, Berglund, Institutionen för hälso- och et al., 2015; Zare-Farashbandi et al., 2015). Materials accessed for information were reading, testing and evaluating information from different sources such as books, journals or study reports and HCPs as well as other people with diabetes (Johansson et al., 2015). Places accessed were the community (Hyman, Patychuk, Zaidi, Kljujic, Shakya et al., 2012; Patel, Kennedy, Blickem, Reeves, & Chew-Graham, 2016), healthcare facilities and health seminars.

This present study acknowledges that a key source of information was materials that people accessed in seeking and receiving diabetes-related information: leaflets, books, and the Internet. Many studies also identified several sources of information as materials in receiving diabetes information. They included books, pamphlet (Javalkar, Williamson, Vaidya, Vaidya, & Ferris, 2016; Wilson & Gyi, 2010), television, newspaper or seminar sources (Javalkar et al., 2016), a diabetes association (Hyman et al., 2012) and magazine (Javalkar et al., 2016; Moonaghi et al., 2014). The participants in this study used the Internet to search information, for example from Google (Clarke et al., 2016; Javalkar et al., 2016; Moonaghi et al., 2014).

Chapter Seven: Discussion

In this era of technological advancement, people are currently interacting through social networking media or sites such as Facebook or Twitter. People in this present study used the Internet to gain information through online media and sought through a search engine to find their information. That is in contrast to a study that found people with diabetes gained diabetes information from a social media, like Facebook (AlQarni, Yunus, & Househ, 2016). Javalkar et al. (2016) purported that the sources of information from the Internet was limited because people with diabetes may have inadequate access to the computer and the Internet, and because searching, reading and sorting information from the Internet can be an overwhelming task for people with low literacy. Participants in this present study asked their relatives (children) to search for information related to diabetes for them on the Internet. The Internet as a source of information requires the considered attention of HCPs because, not all sources from the Internet can provide answers to people’s questions. Crangle, Bradley, Carlin, Esterhay, Harper et al. (2017) examined websites frequented by people with diabetes, and the answers provided by those websites were often too general, too specific, not useful, or otherwise inadequate.

Participants in this present study mentioned some places where they sought diabetes related information. These places included the community, healthcare facilities and health seminars. People in the community such as a neighbourhood can interact with each other during formal and informal occasions. During these interactions, participants indicated that they might talk to other people about their health status including insights into their experiences of living with diabetes. Community networks and support systems should be taken into account as they can provide a basis for enhancing strategies in diabetes prevention and promotion (Hyman et al., 2012). This present study also supports Patel et al.’s (2016) discovery that external sources such as people living in the community can also provide diabetes-related recommendations.

One participant in this present study (who lives in a rural area) requested health education, as he had not received any health information from a HCP. This situation can hinder people with diabetes from having proper information. Although this participant was motivated to receive health education, sometimes people with diabetes lack motivation to pursue diabetes information, because of their pre-existing misconception about diabetes (Milewski & Chen, 2010) and because of feeling satisfied with the current knowledge that they have (Milewski & Chen, 2010; Wei, Du, & Zhang, 2016). Another barrier to receiving health information is people living in rural areas, because the numbers of HCP may not be sufficient to adequately provide the information needed by these people with diabetes (Kalantzi, Kostagiolas, Kechagias, Niakas, & Makrilakis, 2015).

Key Finding Three: Before Making a Decision about Using Received Information, People with Diabetes Often Sifted the Information based on their Prior Knowledge, Experiences and Personal Judgement

When people with diabetes in this present study chose which information to believe, they compared it with their previous knowledge, as a way of confirming new incoming information. The previous knowledge may have been gained from their formal education, as found in this present study. They compared their prior knowledge with the new information. When the prior knowledge confirmed the newly received information, they believed it. However, if it was contrary to their prior knowledge, then they may not accept it. The confirmation of a beneficial impact of diabetes management towards people's knowledge through health education (Banerjee et al., 2012; Heinrich, de Nooijer, Schaper, Schoonus-Spit, Janssen et al., 2012) can be an influence for these people to accept/believe which information is worthwhile to help them choose and undertake a new action.

People with diabetes sometimes had preconceived opinions regarding newly received information. Their pre-existing beliefs were often not based on evidence. New information was evaluated as being true or false according to the participants' own preferences and gut feelings. They listened to other people's experiences, and either rejected or accepted those experiences, based on their own pre-existing preferences or gut feelings. The conclusions they reached about the newly received information could therefore be flawed resulting in the adoption of an inappropriate action to manage their diabetes.

People with diabetes may rely on some other sources to confirm if received information is to be trusted or not trusted. They may consult other people such as HCPs whom they believe have expertise to assist them determine the efficacy of newly received information or they may access the Internet to clarify the legitimacy of the information. The latter method, using a search engine, was found by Cántaro, Jara, Taboada, and Mayta-Tristán (2016) to be positively associated with a very good level of knowledge; however, people may also land on websites that provide unreliable information. Nevertheless, the action of asking for a second opinion is still preferable to immediately accepting that the newly received information is 100% reliable.

The filter that people with diabetes used to sift their information was through their own previous lived experience. This filter is discussed further under ‘key heading five’ where people with diabetes used their lived experience to make further decisions regarding their current use of a therapeutic intervention. People had positive and negative outcomes regarding their application of current regimes. Based on ‘lived experienced’ information, they then decided whether to believe that intervention worked well or not. When the result was positive, they usually continued to use it. If not, they discontinued their current regime. “Participants generally regarded it as obvious that good decisions could not be made without relevant facts” (Entwistle, France, Wyke, Jepson, Hunt et al., 2011, p. e294). Entwistle et al. (2011) suggest that being informed by other people’s experiences can help people to arrive at an accurate decision about their self-management.

Key Finding Four: Physical, Psychological and Resource Factors Highly Influenced People’s Decisions to Apply Recommendations for Managing their Diabetes

This present study is in concert with a review from Brundisini, Vanstone, Hulan, DeJean and Giacomini (2015) that identified that people with diabetes do not necessarily follow the recommended regimes intentionally and purposefully. People with diabetes in this present study decided to respond to the recommendations they have received, by either following or not following them. Three main factors influenced people with diabetes in the present study to follow or not to follow the recommended therapeutic interventions: physical; physiological and resources.

For physical aspects, people’s bodily changes and their worsened symptoms influenced them to choose between those different actions. In relation to psychological aspects, people with diabetes were influenced by fear of medication side effects and its application, and by underestimating the severity of their diabetes. Lastly, resource aspects regarding cost, time, locations, practicality and convenience of applying the interventions also influenced their response to the recommendations. These findings support Low et al.’s (2016b) study that numerous factors influence how people decide to opt for their treatment: personal experiences, perceived treatment efficacy, the ease or complexity of a diabetes management regime, cost-effectiveness and accessibility to the remedy. When people with diabetes have no pre-existing knowledge, and they hear a recommendation from someone they trust, they will not feel they need to give it any further consideration, they will just go ahead and follow the recommendation (Lee, Low, Lee, & Ng, 2015). Therefore, they rely on other people who they trust (Lee et al., 2015) to help them decide whether to follow the advice.

People with diabetes in this present study had a variety of ways of applying their recommended conventional therapeutic interventions. Some people could fully follow conventional therapeutic intervention such as taking the oral medication regularly and implementing the other diabetes self-management actions such as exercise, healthy diet and monitoring. On the other hand, some people with diabetes only partially followed their conventional therapeutic regime. Adherence to the regime was a challenge for these people. People may have concerns about the adverse effects of medication, which then leads them to be non-adherent (Sweileh, Zyoud, Abu Nab'A, Deleq, Enaia et al., 2014), such as reducing the dose (Alzubaidi, Mc Mamara, Chapman, Stevenson, & Marriott, 2015) or switch to other strategies that were believed to be effective. Similarly, people in this present study who did not fully implement their therapeutic interventions usually experienced undesirable secondary complications from their poorly controlled diabetes condition. Because of the inconsistency in implementing diabetes self-management they did not enjoy the expected beneficial impacts of the therapeutic interventions.

People in this present study also took non-conventional therapeutic interventions. The forms of this way of managing their diabetes were by taking homemade herbal therapy, factory-made herbal products and/or by wearing a device believed to have a positive impact on their diabetic conditions. For taking an herbal potion, people with diabetes in this present study either planted the substance in their own yard or obtained it from someone else. People who chose this approach to manage their diabetes mostly said that they were concerned with conventional medication, especially the potential adverse effects of the medicine. Some others explained that taking herbal medication was their preference only because the herbals were more practical to take. Atwine and Hjelm (2016) found that affordability, accessibility and availability were other reasons that people with diabetes chose traditional therapies for treating their diabetes.

Indonesia is rich with natural resources and Indonesian forests provide many plants that can be used for the purpose of treating disease (Tanto, Syarfina, Dimas Abdul Azis, Alifian, & Adilla, 2017) and thus Indonesian people commonly use herbal plants for that purpose. However, there is limited research about medicinal plants in diabetes, especially the clinical trials or studies at a molecular level (Tanto et al., 2017). Some of the plants (‘Kratom’ or *Mitragyna speciose* and ‘Kersen’ or *Muntingia calabura*) mentioned by the participants have not yet been tested with human clinical trials, although some have reached the stage of animal testing (rats).

From this present study, some people chose not to use conventional medication such as insulin or oral diabetic medications. They believed that conventional medication may cause harm to their body especially when are anticipating having to take them over a lifetime, and so they refused. People with diabetes may alter how they enact the regime recommended to them by the HCP. Alternatively, they may access traditional healers instead of HCPs, a practice identified in a study by Atwine and Hjelm (2016). In their study, the main reason for switching to traditional healers was because of the lack of success of western treatments for diabetes management. Likewise, Hinder and Greenhalgh (2012) and Lynch, Fernandez, Lighthouse, Mendenhall, and Jacobs (2012) identified that people with diabetes sometimes omit their medication because of a concern of its side effects. Inconvenience and unusual side effects of the prolonged medication usage were also influences for not following their doctor’s recommendation (Mc Sharry, Bishop, Moss-Morris, & Kendrick, 2013). In this present study, a person with diabetes expressed concerns about becoming dependent on insulin; and Mishra, Gioia, Childress, Barnet, and Webster (2011) identified a similar phenomenon, where people with chronic disease feared becoming dependent on medication, and also were afraid that medication would interfere with their daily routine. Those fears then impeded their adherence to the medication regime. Lynch et al. (2012) also found that people with diabetes did not take oral medication to avoiding becoming addicted. In this present study, being afraid of ‘the needle’ was another reason to refuse to use insulin, as Bockwoldt, Staffileno, Coke, Hamilton, Fogg et al. (2017) study concurred.

Although not many people with diabetes in this present study followed conventional therapeutic regimes it is important to understand what factors influenced their poor adherence. People with diabetes were more likely to follow a regime if they had time to devote to the recommended therapeutic self-management regime. Whereas, people with diabetes in Lynch et al.'s (2012) study highly valued the importance of diabetes self-management actions such as medication, exercise, diet and weight loss, and placing importance on those actions motivated them to follow the recommendations from their HCPs. Other factors that can influence a decision to adhere to conventional therapeutic interventions are self-discipline and a strong sense of personal responsibility (Mishra et al., 2011), which was a positive factor raised by people with diabetes in this present study. Self-discipline made people in this present study strictly follow a recommended diet, for example, preventing them from eating food containing high levels of sugar, and this newly formed habit then became their life style preference.

Key Finding Five: By Appraising the Results of their Management Choices, People with Diabetes Developed Experiential Insight, which they Often Shared with Others and which Influenced their Future Management Decisions

The results of applying the variations in their own way to follow the recommendations also impacted on their outcomes. In the fifth key finding, 'experiential insight' is labelled as people with diabetes appraising the results of applying their chosen actions regarding their diabetes care. Experiential refers to living through an experience while insight is described as the result of encapsulating the inner nature of things or of observing intuitively (Merriam & Webster 2018). Experiential insight was revealed in this present study's findings to describe how people appraised the results/outcomes of employing their chosen actions of diabetes self-management. They also observed whether the action they have chosen and applied worked or not for their own diabetes condition. With this experiential insight, people then decided about further actions.

People with diabetes in this present study sometimes omitted their medication intentionally or unintentionally because they noticed their physical symptoms (for example feeling well or not), reactions of medication, suitability/convenience or the difficulty of applying the recommended regime. People with diabetes sometimes performed BSL monitoring and compared the results of previous and current readings to guide them in determining whether they have done something right or wrong regarding their self-care (Bockwoldt et al., 2017). There are situations where people with diabetes are influenced to decide to adhere more or adhere less to their current medication regime and to take more responsibility regarding their self-management. These situations are what Bockwoldt et al. (2017, p. 368) label as 'turning points'. The turning points in their study included changing body conditions, gaining new knowledge, changing their life status and re-evaluating their selves and situation.

Similarly, people with diabetes in this present study also evaluated the effects they were noticing from the therapies they had applied. The product of this evaluative process was called experiential insight. Experiential insight was then utilised by people with diabetes as information to share with others. They also used their experiential insight as newly received information to be sifted, so that they could make additional future decisions whether to continue or not the applied diabetes therapy, and then switch to following other recommendations, or to seek out more information. Gaining this experiential insight is another way that people learned about their disease. Johansson et al. (2015) investigated how people learn to live with their diabetes by looking at their lived experiences. They found that learning to live with diabetes included having to take control and adopt good diabetes management practices in order to limit adverse effects. As with Johansson et al.'s study, Indonesian people with diabetes in this present study reported feeling anxious and burdened about a lifetime of living with diabetes and having to perform self-management actions.

Sharing with others in this present study happened when people with diabetes informed other people about the experiential insight they had gained about living with diabetes and/or implementing their chosen therapeutic interventions related to their diabetes. Currently, people can share their information, thoughts, or experiences through social media. Even though sharing with others through a social media was not featured in this present study, participants did mention accessing information from the Internet through Google searching of websites. People with diabetes can share information and experience related to their condition through this social media type of communication. AlQarni et al. (2016) found in their study that people with diabetes shared various types of information in social media, including: personal experiences with diabetes and latest study findings about diabetes; doing so served to raise others' awareness about diabetes; provided education related to diabetes; and provided spiritual support for both the people with diabetes and their caregivers. Nevertheless, people with diabetes needed to take into account the accuracy of information provided through this informal type of knowledge sharing on social media, because not all information provided by other people with diabetes was trustworthy. The Internet can provide large amounts of available and easily accessed information. However, people cannot be confident of the accuracy of information, especially from sources that cannot be easily verified as credible or not (Clarke et al., 2016). Consequently, people who receive invalid health information can harm themselves (Clarke et al., 2016). Therefore, people with diabetes need to ascertain the validity of the information before they can directly believe and apply the information, especially when recommending clinical management for diabetes.

Key Finding Six: Families of People with Diabetes Engaged in all Five Categories of the Process Entitled 'Learning, Choosing, and Acting: Self-Management of Diabetes in Indonesia'

The key finding six is an additional major finding of the current research study that sought to understand how Indonesian people living with diabetes learn about their disease. In the process of *Learning, choosing, and acting: Self-management of diabetes in Indonesia*, the families of people with diabetes provided support in every category of the process. The person with diabetes and health care providers acknowledged the role of support from families. This support from the families varied in each category for each person with diabetes. These supports have been explicated in a paper entitled *People with diabetes in Indonesia: Where does their family fit into the picture?*

Family Involvement in the Process of People Learning about Their Diabetes

The process of people with diabetes *Learning, choosing, and acting: Self-management of diabetes in Indonesia*, involves not only HCPs but also non-HCPs such as family members. Family members can be a person who takes care of the person at home or when the person with diabetes is admitted to the hospital. Family members may live with the 'patient' in the same house or they may live separately from the 'patient' but take care of the person with diabetes and know about the person's disease. Family members play an important role for people living with diabetes.

Family members have engaged in all parts of the process of *Learning, choosing, and acting: Self-management of diabetes in Indonesia.* The variety of activities and roles family members undertake differ in each phase of the process. Their involvement commences in the first part of the process, 'seeking and receiving diabetes-related information'. Families have a central role in all five phases of the process. Details on family member engagement in the process are explicated in the paper entitled 'Family involvement in the learning and self-managing processes of people with diabetes in Indonesia'. The paper was submitted to the Asian Nursing Journal.

Chapter Seven: Discussion

Table 7.1: *Declaration of Authorship*

Chapter Number	**Publication**	**Nature and extent of the intellectual input of each author including the candidate**	**Signature**
7	Ligita, T., Harvey, N., Wicking, K., Nurjannah, I., & Francis, K. Family involvement in the learning and self-managing processes of people with diabetes in Indonesia. *Asian Nursing Journal.*	Conception and design of the paper, data collection, data analysis and interpretation, Primary responsibility for writing the paper, corresponding author responsible for preparing the final paper for submission, approval for publication version.	Ligita, Titan Content has been removed for privacy reasons
		Supervision of and contribution to the conception and design of the paper, data analysis and interpretation, critical revisions for important intellectual content, approval for publication version	Harvey, Nichole Content has been removed for privacy reasons
		Supervision of and contribution to the conception and design of the paper, data analysis and interpretation, critical revisions for important intellectual content, approval for publication version	Wicking, Kristin Content has been removed for privacy reasons
		Supervision of and contribution to the conception and design of the paper, data analysis and interpretation, critical revisions for important intellectual content, approval for publication version	Nurjannah, Intansari Content has been removed for privacy reasons
		Supervision of and contribution to the conception and design of the paper, data analysis and interpretation, critical revisions for important intellectual content, approval for publication version	Francis, Karen Content has been removed for privacy reasons

The paper addresses how family members have contributed to the process of Learning, choosing, and acting: Self-management of diabetes in Indonesia. This paper highlights the need for HCPs to acknowledge that families of Indonesian people living with diabetes are intimately involved and therefore must be considered and engaged in the management of their relative's chronic disease.

Manuscript Details

Manuscript number	ASIANNURSINGRESEARCH_2019_25
Title	Family involvement in the learning and self-managing processes of people with diabetes in Indonesia
Article type	Research Paper

Abstract

Purpose: The purpose of this paper is to explicate a major finding of a research study that sought to understand how Indonesian people living with diabetes learn about their disease. The key finding discussed in this paper is how families influence the learning and self-management processes adopted by Indonesian people with diabetes. Methods: A grounded theory methodology was adopted to investigate how Indonesian people with diabetes learn about their disease. Twenty eight semi-structured interviews were undertaken with Indonesian people living with diabetes, families of people living with diabetes, healthcare professionals, and other healthcare providers. Data was analyzed by using constant comparative analysis during three coding stages. Results: With the basic social process emerging: "Learning, choosing, and acting: self-management of diabetes in Indonesia", this study found family engagement was integral to Indonesian people living with diabetes self-managing their disease. The process involves five categories: Families assisted people with diabetes with seeking information, providing recommendations, selecting and implementing actions, appraising the currently implemented actions, and informing other people about their experiences. Conclusions: The involvement of families in diabetes care is a central finding of the study. Families can enhance overall health and well-being of the person with diabetes, aid in early recognition of aberration to health status and trigger the initiation of interventions to re-establish homeostasis.

Keywords diabetes mellitus; family; grounded theory; learning; self-management.

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Family involvement in the learning and self-managing processes of people with diabetes in Indonesia

Running Title

Family in Diabetes Self-management

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Family involvement in the learning and self-managing processes of people with diabetes in Indonesia

Abstract

Purpose: The purpose of this paper is to explicate a major finding of a research study that sought to understand how Indonesian people living with diabetes learn about their disease. The key finding discussed in this paper is how families influence the learning and self-management processes adopted by Indonesian people with diabetes. *Methods:* A grounded theory methodology was adopted to investigate how Indonesian people with diabetes learn about their disease. Twenty eight semi-structured interviews were undertaken with Indonesian people living with diabetes, families of people living with diabetes, healthcare professionals, and other healthcare providers. Data was analyzed by using constant comparative analysis during three coding stages. *Results***:** With the basic social process emerging: "Learning, choosing, and acting: self-management of diabetes in Indonesia", this study found family engagement was integral to Indonesian people living with diabetes self-managing their disease. The process involves five categories: Families assisted people with diabetes with seeking information, providing recommendations, selecting and implementing actions, appraising the currently implemented actions, and informing other people about their experiences. *Conclusions:* The involvement of families in diabetes care is a central finding of the study. Families can enhance overall health and well-being of the person with diabetes, aid in early recognition of aberration to health status and trigger the initiation of interventions to re-establish homeostasis.

Keywords: diabetes mellitus; family; grounded theory; learning; self-management.

Introduction

A grounded theory study was undertaken to generate a theory about the process of how people situated in an Indonesia context learn about their diabetes. A basic social process was found: *Learning, choosing, and acting: self-management of diabetes in Indonesia.* Through this basic social process, people with diabetes learn about their disease during five categories of the process. One of the key findings from the study was that families of people with diabetes are engaged in, and play significant roles in, each and every part of the process. This paper explicates how families are engaged in each of the five categories.

Diabetes mellitus is a chronic disease and becomes a burden as soon as the person is diagnosed. Once diagnosed, people with diabetes are more likely to find information related to diabetes from those around them including their families, who often help them make positive self-care management decisions [1] for example, choosing the right foods to eat. Engaging or involving families in diabetes care can help people with diabetes to promote effective diabetes self-care management [2-4] to improve knowledge about diabetes [3] to promote sustainable positive behavioral change [5] and to improve clinical outcomes [4]. The involvement of family can provide both emotional and psychological support for the person living with diabetes [5], so that they can recognise their condition and consequently promote positive self-management practices. The implementation of adequate diabetes management is found to be associated with family support; therefore, in developing diabetes interventions, family members need to be included in the education program [6].

Despite the beneficial impacts of family engagement, support from families can be either helpful/harmful [7] or encouraging/discouraging. Particularly, family involvement in helping with managing blood glucose levels. Family actions that help people with diabetes adhere to diabetes regimes is an example of a positive impact [8]. The actions of supportive behaviors include: eating and exercising together; positively reinforcing a healthy diet; encouraging physical activities; taking medications on time; planning activities and assisting in decision making [7,9]. People with diabetes perceive that their families' attempts are helpful to increase their confidence in self-care behaviors and to encourage their adherence in managing well [10].

On the other hand, there are also negative outcomes associated with family involvement. People with diabetes occasionally receive discouraging support that is labelled as non-constructive support [2] and as obstructive support [7]. When families are involved, but they provide discouraging support or obstructive support, people with diabetes are more likely to decrease their adherence to self-care management and that manifests as unstable blood glucose levels [7]. Obstructive supports include criticisms (such as criticizing their loved one with diabetes for not engaging in physical activity, or for eating an unhealthy diet); nagging their loved one about diet and blood glucose records; arguing with them about their non-adherence and allowing their loved one to skip their medications [7,9].

The family is central to the Indonesian way of life [11,12]. Family members often live with each other or in very close proximity to each other. Regardless of the type of family unit, nuclear or extended, when a member of the family is ill, it impacts the whole family [13]. This is because there is an expectation that the 'family' will support and care for each other, especially for family members who experience personal challenges or illness [14,15]. Three studies conducted in Indonesia [16-18] found that support from the family can be a source of self-efficacy for Indonesian people with diabetes to enhance their healthy eating lifestyle. However, a dearth of information is currently available about the involvement of family when people with diabetes are learning about their disease and how to manage their diabetes.

Methods

Design

Our grounded theory study was informed by two philosophical positions: symbolic interactionism and constructivism. Symbolic interactionism is the study of people's behavior and actions [19]. This study viewed that people's actions are determined by their thinking, interactions and perceived situations [20]. Exploring how people with diabetes learn about their disease requires understanding their interactions with others during the learning process, including with the family. Additionally, through a constructivism lens [21], this study constructed the knowledge, together with a wide range of participants, to understand the process of how people learn about their diabetes.

Participants

Participants included healthcare professionals (HCPs) that provide diabetes care such as nurses, physicians, dieticians, and a pharmacist; other health service providers including a 'kader' (a lay health worker in Indonesia), a hospital health promotion officer, and an exercise instructor; families of people with diabetes and a nursing student. These participants were recruited initially by purposeful sampling and later by theoretical sampling from seven settings including an academic institution and both private and public healthcare facilities. The participants were provided with a letter of information together with an informed consent form to be signed before the interviews were performed. To conceal all participants' identity, pseudonym names are used in this paper.

Data collection and analysis

Research ethics approvals were obtained from both Human Research Ethics Committee of X University (Approval no. H6445) and Ethical Committee of Nursing Research of the Faculty of Nursing, Y University (Approval no. 0367/UN2.F12.D/HKP.02.04/2016) for conducting this grounded theory study. Purposive and then theoretical sampling methods were used to identify and recruit participants. Twenty-eight in-depth semi-structured interviews were conducted with twenty-six participants. Two of the participants were interviewed twice. Concurrent data collection/generation and analysis were performed as one of the essential steps in grounded theory methods. Memos were used to record interpretation of the interviews as data were generated and concurrently analyzed.

The audio recorded interviews were transcribed verbatim. Constant comparative analysis of the data to compare existing data with incoming data was undertaken throughout the study [22]. Memo writing and concept mapping also informed the process of data analysis.

Results

The core category established from the study revealed a theory enlightening the process of how people with diabetes in Indonesia learn about their disease. This process is inclusive of five major categories illustrated in Figure 1. This paper elucidates how the family engaged with their relative who was living with diabetes as they navigated the process of *Learning, choosing, and acting: self-management of diabetes in Indonesia.*

Category 1: Seeking and receiving diabetes related information

Families supported relatives with diabetes as they learnt about their disease and how to self-manage it. Families were engaged from the very start of the process. In seeking diabetes-related information, family members also frequently asked other people about diabetes care. They asked questions mostly of other people with diabetes or those who had a relative with diabetes.

The questions they asked were mostly about how to treat diabetes. It was not uncommon to ask about therapies other than conventional therapies. Once the family received the information about diabetes treatment, they passed on the information to their own relative with diabetes. In addition, people with diabetes, especially those who were not familiar with using the internet themselves, instead asked their families to search for information about diabetes treatment from a website they perceived as reliable.

> *…I want to know a lot. From the Google. My son is good at it. [I asked him] how to do…exercise… [about] the food, the medication, [and] the herbals. Recently, I took herbal… "karet kebo". The leaves of "karet kebo"… [were searched from] the Google. My son browsed it [from Google]. It was good…"(Kevin: G2P7-8)*

In other situations, family members generally accompanied their relative with diabetes to healthcare services such as outpatient clinics. Information was provided to people with diabetes and their families, by HCPs. As Aditya, both a nurse academic and a clinician explained:

> *…[The] family role is important. When we provide health education, involving families [is] good. It means that there will be a family [member] to remind [the person with diabetes] what [information] we have delivered as there are obedient and disobedient patients. The family will remind [them what was discussed]. When [people with diabetes are] disobedient, the family can [help to] control it…"(Aditya: G1P9)*

Category 2: Processing received information

After receiving information, people with diabetes processed and filtered information that may have been sourced from a variety of people and/or from other channels such as newspapers, social media, television and health promotion materials. They then determined what information they would accept. During this category, families also provided recommendations to their relative with diabetes about which information to believe or not to believe. Family members also received and processed information from a variety of sources, including attending health education sessions. They would then share this information with their loved one who has diabetes.

The excerpt below shows when a person with diabetes had doubts about a decision for injecting insulin. The participant was advised by the physician (a general practitioner or GP) in a medical clinic to have a prescribed insulin injection, which could only be obtained from a specialist doctor (an internal medicine doctor). Therefore, the GP gave this participant a referral letter to see the internal medicine doctor in a hospital, who could prescribe insulin. However, this participant delayed going to see the doctor. The participant's son helped to process the information; and advised the participant to go to the hospital and encouraged and supported the participant to consider taking the insulin injections.

> *...Firstly, I was afraid to inject [the insulin]. I firstly did not want [to have an insulin injection]. My son urged me [to have the insulin]. "Let's go to the hospital", he said..."(Betty: G1P7)*

Category 3: Responding to recommendations

In this category, families supported their relatives with diabetes, before and during the implementation of their relatives with diabetes' chosen recommendations. The supports included encouraging, assisting and teaching. Before commencing a therapy, people with diabetes were influenced by their families regarding therapeutic recommendations. Sometimes families encouraged their relatives with diabetes to continue the current regime, rather than commence a new treatment. As Jovita explained:

> *... Once, Jaka [Jovita's brother living with diabetes] was told to start taking a traditional medication but I felt sorry for Jaka. It [the traditional medicine] is very bitter. I cannot bear to give it to Jaka. Many people talk about it. My aunty also has diabetes. [My aunty] saw other people talking about taking "mahoni" [seeds]. I never tried it. Many people talk about the "mahoni". I plant it. But I am not brave to give it to Jaka because it tastes very bitter... "(Jovita: G2P4)*

When people with diabetes chose to follow recommendations, they implemented the advocated therapeutic interventions or regime. During the implementation of the regime, families assisted by reminding them about diet or about taking their medication and even helped them to purchase medication. Sometimes, the family needed to remind the person to follow the restricted diet. Such reminders may be appreciated or unwelcome as the following participant exemplars demonstrate:

> *...I have my daughter here. The food, for example. When I want to eat sweet food, she reminds me [not to]. 'That food [the donuts brand's name] has a lot of sugar'. Then, it*

> *makes me think. At night, I usually get tired and want to go to sleep. "You haven't taken your medicine", she said. So, there is someone to remind me to take the medicine..."(Larisa: G2P13)*

> *...When I eat any [unhealthy] food, she [my wife] is mad at me. She makes me stop eating that food, [or] having that drink. But, well, it's me, I do not want to follow a strict diet... "(Kevin: G2P11)*

In some instances, people with diabetes did not follow the recommended diabetes care plan and it made their family become anxious and frustrated. People with diabetes sometimes justified their inappropriate behaviors. Nirma, a daughter of a person with diabetes offered:

> *...My mother sometimes prefers eating cake. In the morning, she sometimes eats one piece of cake, she thinks in her mind, "just one piece of cake...one piece of cake doesn't have much sugar, a little... it's okay, it's [just] a little". She thinks if it is a little, it will [still] be fine. She said it is okay. She seems to underestimate it. She believes a little amount [of sugar] is okay... "(Nirma: G2P2)*

Families assisted their relatives with diabetes to adhere to their management plan at home. A member of the person's family would often accompany their relative with diabetes to the clinic. During clinic appointments, the person and their family member receive useful information from HCPs, such as how to administer an insulin injection; thus the family member gains this knowledge, alongside the person who has diabetes. This knowledge then allows the family member to reiterate the information, teach and assist their loved one in managing their diabetes.

In the excerpt below, a person who has lived with diabetes since 2012, accompanied by the son, was taught how to administer insulin by a nurse at the hospital. The participant then explained that when they were at home, the son initially took responsibility for administering the participant insulin, until the participant was able to self-manage:

> *...Firstly, my son [injected the insulin to me]. "Let me do it", I said. "Try it", he said. "Pinch like this", he said. "Mom, you hold like this", he said. "Just hold a little bit", he said... "(Betty: G1P3)*

Although help from the family was often necessary, people with diabetes sometimes did not want to burden their family. As Haris stated:

> *...My wife [helps me at home]. She sometimes makes me a potion [from herbals]. There must be support from the family [in coping with] this disease, mainly from children and wife. [However] I do not force my family to focus too much on my disease because they have their own busy [lives]... "(Haris: G2P5)*

People with diabetes were motivated to be independent in the implementation of their regime. This study found that having a family who understood diabetes could assist people with diabetes to implement their management plan.

Category 4: Appraising the results

During the phase of implementing a diabetes management plan, people with diabetes simultaneously appraised the effect of the regimes by subjectively and objectively measuring outcomes together with their families. In this category, the involvement of families included providing feedback, observing the health status of their relative living with diabetes and providing suggestions on what to do or what not to do regarding the current treatment. They observed together what works and what did not work, as highlighted by Viola:

> *... I searched a lot of information about medication such as what my husband has been told, herbal medication. We search the information, we try [it]... We try it for one week or two weeks. If there is no change [The level of blood sugar is still high], then we will not continue [to take it]..."(Viola: G2P1)*

Family involvement in this process was integral. Indonesian people with diabetes were supported by their families to develop the necessary knowledge and skills to appreciate, implement, maintain or modify therapeutic care plans.

Category 5: Sharing with others

Families were able to assist their relative with diabetes by discussing/sharing their health status with HCPs or with other people living with diabetes including other relatives. Jovita cares for her brother who is living with diabetes. This participant stated that she told the HCP about her brother's condition and asked for a recommendation:

> *…He [my brother living with diabetes] finds it difficult to have a restriction in diet. It is hard to forbid him [not to eat unhealthy food containing plenty of sugar]. I also asked a physician [who said] "The point is that he [my brother] has to control his diet". I said that he [my brother] does not want to. "Then he must take his medication", the physician said… "(Jovita: G2P11).*

On the other hand, the family was sometimes the recipient of information shared by the person with diabetes. In this part of the process, people with diabetes shared their experiences of learning about their disease with their families. People with diabetes hoped that the information they shared would prevent family members from developing diabetes as explained by Haris:

> *…I am not giving them [my family members] a doctrine but an overview that we have to be prepared for any conditions. We have to learn that we must remind, [and] advise each other. With this disease I can advise my children, "you eat properly, [do not eat] carelessly. I am worried that you might have one [diabetes]". I said, "eat well, drink well, take sugar wisely, [and] do not eat it too much. You can have it [sugar], I do not forbid it"… "(Haris: G2P5)*

Discussion

Through the process of learning about their disease, people with diabetes obtained experiential insight, which better equipped them to manage their disease. From seeking and receiving diabetes-related information to sharing experiential insight with others, engagement of the family occurred at each stage of the process.

Consistent with the existing literature [1], this study identified the tendency of people to seek information from people around them, including their families, once they were diagnosed. Families in this current study did not only help people with diabetes by being a source of information, but also by accompanying people with diabetes to obtain health information, for example visiting the HCP together [23]. Families are not only involved in the treatment of diabetes, but also in the education [24]. Hence, by attending the clinic visit together, both families and people with diabetes can be taught about acute complications that may occur at home [24].

This present study found that families could influence management decisions made by the family member with diabetes. The finding concurs with a study [1] that reported that families as a social influence can be an important factor in people's self-management, and that level of influence depends on how close of a relationship exists between them. The HCPs can be a major source of information; however, people with diabetes sometimes based their decision upon their own experimentation with a treatment or their own 'gut feeling' [25]. Their experimentation is similar to the experiential insight, found in this present study.

Confusion was experienced by Indonesian people with diabetes in our study when they were bombarded with multiple sources of information, including from their family. As a result of information overload, some people with diabetes changed their existing diabetes regimes for the worse, which negatively impacted on their health status. These findings are in contrast to other studies where family involvement was found to be only positive and to lead to better self-management of diabetes. For instance, positive care partnerships between people with diabetes and their families can be supportive [26]. Similarly, another study found that family support can be a motivating factor that encourages people with diabetes to follow their care plans to achieve stable blood glucose levels, thus reducing the potential for complications [27].

Families in this present study helped people with diabetes during the implementation of therapeutic interventions. Occasionally, families felt it necessary to remind their relative with diabetes about their management plan, particularly dietary restrictions, but often, these reminders were not heeded, which the family then found disappointing. Similarly, other researchers [28] found that people with diabetes in their study regarded the family involvement in diet to be exhausting and it even caused tension in their relationships. Therefore, families need to be empathetic to the challenges faced by their loved one and carefully consider when and how many recommendations to provide.

This present study also found that some people with diabetes did not want to burden their families by involving them in the management of their diabetes. This finding echoes that of a study [29] that also found that people with diabetes are hesitant to tell their difficulties and to reveal their feelings because they do not want to trouble other people. Training families in communication and coping strategies is imperative to assist them to become aware of the challenges that are being experienced by people with diabetes, so the families can then go on to assist their relative with diabetes to develop coping methods to surmount those challenges. If the family is unaware of the difficulties being experienced by people with diabetes, they cannot support and assist them to manage those difficulties appropriately, and then negative clinical outcomes may ensue.

Finally, although the family greatly influenced their relative living with diabetes, the influence also flows in the other direction. People with diabetes influenced their family members as well. When one family member with diabetes gained valuable experiences from living with diabetes, they then shared those experiences with other family members. The sharing of these experiences highlighted their own successful and unsuccessful self-management of diabetes. This finding concurs with other literature that shows that when one family member lives with diabetes, what they learn can then be passed on to another family member who is also diagnosed with diabetes, to promote successful self-management of the second family member's diabetes [26] and to increase their motivation to avoid future problems [30]. People with diabetes consequently need to take into account which information is beneficial and worth sharing, and which information is not worth sharing. This filtering can prevent inaccurate diabetes information from being disseminated to their family members.

Study strengths and limitations

This study is strengthened by the precise implementation of the methodological principles of grounded theory. Moreover, several distinctive findings arose from this study which were not yet apparent in other existing studies. However, the study was limited by involving only family members from one province in Indonesia. Also, the study involved limited variations of ethnicity and religion, which can link with family issues. Therefore, it may not represent all families in Indonesia.

Conclusions

This study found that Indonesian families played an important role in the lives of their relatives who are living with diabetes. They assisted them with their diabetes management and participated in the process with them as they learnt about their disease, chose recommendations to follow, and acted upon their choices. This process was inclusive of five categories: Seeking and receiving information; Processing received information; Responding to recommendations; Appraising the results; and Sharing with others. The family of people living with diabetes was involved in that each category of the process.

People with diabetes can be empowered to manage their disease as can their families. To increase empowerment of both the family and people with diabetes, HCPs that provide diabetes care need to ensure that families are included in the educational process. The HCPs, especially family nurses, can work with families and people with diabetes to help them select appropriate management strategies. Accordingly, HCPs can assist families by providing credible sources of information, which families can then utilize to help guide their relatives in making informed decisions. Families are the first line of support for their relatives with diabetes, and they should be included at each point along the way, as people with diabetes learn, choose and act to self-manage their diabetes for optimal wellness.

Reference List

1. Low LL, Tong SF, Low WY. Social influences of help-seeking behaviour among patients with type 2 diabetes mellitus in Malaysia. Asia Pac J Public Health. 2016;28(1, Suppl):17S-25S. doi: https://doi.org/10.1177/1010539515596807.
2. Oftedal B. Perceived support from family and friends among adults with type 2 diabetes. European Diabetes Nurs. 2014;11(2):43-8. doi: https://doi.org/10.1002/edn.247.
3. Baig AA, Benitez A, Quinn MT, Burnet DL. Family interventions to improve diabetes outcomes for adults. Ann N Y Acad Sci. 2015;1353(1):89-112. doi: https://doi.org/10.1111/nyas.12844.
4. Keogh KM, Smith SM, White P, McGilloway S, Kelly A, Gibney J, et al. Psychological family intervention for poorly controlled type 2 diabetes. Am J Manag Care. 2011;17(2):105-13.
5. Hu J, Wallace DC, McCoy TP, Amirehsani KA. A family-based diabetes intervention for Hispanic adults and their family members. Diabetes Educ. 2014;40(1):48-59. doi: https://doi.org/10.1177/0145721713512682.
6. Shawon MSR, Hossain FB, Adhikary G, Das Gupta R, Hashan MR, Rabbi MF, et al. Attitude towards diabetes and social and family support among type 2 diabetes patients attending a tertiary-care hospital in Bangladesh: a cross-sectional study. BMC Res Notes. 2016;9(1):286. doi: https://doi.org/10.1186/s13104-016-2081-8.
7. Mayberry LS, Osborn CY. Family involvement is helpful and harmful to patients' self-care and glycemic control. Patient Educ Couns. 2014;97(3):418-25. doi: https://doi.org/10.1016/j.pec.2014.09.011.

8. Mayberry LS, Harper KJ, Osborn CY. Family behaviors and type 2 diabetes: What to target and how to address in interventions for adults with low socioeconomic status. Chronic Illn. 2016;12(3):199-215. doi: https://doi.org/10.1177/1742395316644303.

9. Mayberry LS, Rothman RL, Osborn CY. Family members' obstructive behaviors appear to be more harmful among adults with type 2 diabetes and limited health literacy. J Health Commun. 2014;19(sup2):132-43. doi: https://doi.org/10.1080/10810730.2014.938840.

10. Yang F, Pang JS, Cheng WJY. Self-care adherence and psychological functioning of older patients with type 2 diabetes: effects of persuasion, social pressure, and self-efficacy. J Clin Psychol Med Settings. 2016;23(4):389-401. doi: https://doi.org/10.1007/s10880-016-9470-y.

11. Effendy C, Vernooij-Dassen M, Setiyarini S, Kristanti MS, Tejawinata S, Vissers K, et al. Family caregivers' involvement in caring for a hospitalized patient with cancer and their quality of life in a country with strong family bonds. Psychooncology. 2015;24(5):585-91. doi: http://dx.doi.org/10.1002/pon.3701.

12. Effendy C, Vissers K, Tejawinata S, Vernooij-Dassen M, Engels YM. Dealing with symptoms and issues of hospitalized patients with cancer in indonesia: the role of families, nurses, and physicians. Pain Pract. 2015;15(5):441-6. doi: https://doi.org/10.1111/papr.12203.

13. Scarton LJ, Bakas T, Miller WR, Poe GD, Huber LL. Needs and concerns of family caregivers of persons with type 2 diabetes: an integrated review of cross-cultural literature with implications for the American Indian population. Diabetes Educ. 2014;40(4):444-52. doi: https://doi.org/10.1177/0145721714529831.

14. Moffatt A. Indonesian culture profile. West End, Queensland: Diversicare; 2012.

15. Rochmawati E, Wiechula R, Cameron K. Current status of palliative care services in Indonesia: a literature review. Int Nurs Rev. 2016;63(2):180-90. doi: https://doi.org/10.1111/inr.12236.

16. Putra KWR, Toonsiri C, Junprasert S. Self-efficacy, psychological stress, family support, and eating behavior on type 2 diabetes mellitus. Belitung Nurs J. 2016;2(2):3-7.

17. Mizutani M, Tashiro J, Damiati N, Khasanah U. Urban diabetic women's perception of healthy eating lifestyles from West Java. J Keperawatan Padjajaran. 2017;2(2):98-107. doi: https://doi.org/10.24198/jkp.v2n2.4.

18. Aklima A, Kritpracha C, Thaniwattananon P. Dietary behaviors among patients with type 2 diabetes mellitus in Indonesia. Nurse Media J Nurs. 2013;3(1):499-509.

19. Blumer H. Symbolic interactionism: Perspective and method. Berkeley: University of California Press; 1969.

20. Charon JM. Symbolic interactionism: An introduction, an interpretation, an integration. Upper Saddle River, N.J: Pearson Education; 2007.

21. Charmaz K. Constructing grounded theory: a practical guide through qualitative analysis. London: SAGE; 2006.

22. Birks M, Mills J. Grounded theory: a practical guide. Thousand Oaks, CA: SAGE; 2015.

23. Peyrot M, Egede LE, Funnell MM, Hsu WC, Ruggiero L, Siminerio LM, et al. Ethnic differences in family member diabetes involvement and psychological outcomes: results from the second diabetes attitudes, wishes and needs (DAWN2) study in the USA. Curr Med Res Opin. 2015;31(7):1297-307. doi: https://doi.org/10.1185/03007995.2015.1043251.

24. Meulstee M, Whittemore R, Watts SA. Development of an educational program on prevention of hypoglycemic events among elderly veterans with type 2 diabetes. Diabetes Educ. 2015;41(6):690-7. doi: https://doi.org/10.1177/0145721715606805.

25. Hoffmann TC, Del Mar CB. Exploring the understanding of evidence-based concepts in people with type 2 diabetes. Int J Gen Med. 2012;5:781-7. doi: https://doi.org/10.2147/IJGM.S36557.

26. Vongmany J, Luckett T, Lam L, Phillips JL. Family behaviours that have an impact on the self-management activities of adults living with type 2 diabetes: a systematic review and meta-synthesis. Diabet Med. 2018;35(2):184-94. doi: https://doi.org/10.1111/dme.13547.

27. Carolan M, Holman J, Ferrari M. Experiences of diabetes self-management: a focus group study among Australians with type 2 diabetes. J Clin Nurs. 2015;24(7-8):1011-23. doi: https://doi.org/10.1111/jocn.12724.

28. Knutsen IR, Foss IC, Todorova E, Roukova P, Kennedy A, Portillo MC, et al. Negotiating diet in networks: a cross-European study of the experiences of managing type 2 diabetes. Qual Health Res. 2017;27(3):299-310. doi: https://doi.org/10.1177/1049732315610318.

29. Park H, Wenzel JA. Experience of social role strain in Korean women with type 2 diabetes. J Adv Nurs. 2013;69(6):1400-9. doi: https://doi.org/10.1111/jan.12001.

30. Pollard SL, Zachary DA, Wingert K, Booker SS, Surkan PJ. Family and community influences on diabetes-related dietary change in a low-income urban neighborhood. Diabetes Educ. 2014;40(4):462-9. doi: https://doi.org/10.1177/0145721714527520.

Figure Legend

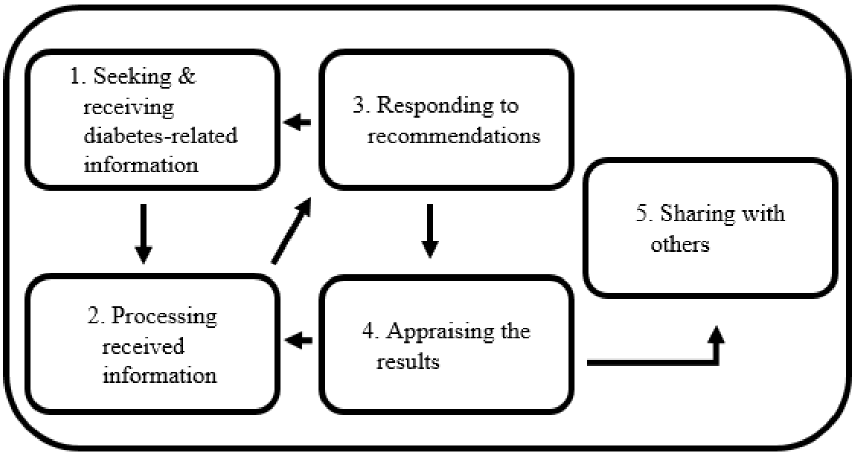

Figure 1. The process of 'Learning, choosing, and acting: self-management of diabetes in Indonesia'.

What the Family Needs during the Process of Learning, Choosing, and Acting: Self-Management of Diabetes in Indonesia

Family members' knowledge in assisting their relative to go through the process of *Learning, choosing, and acting: Self-management of diabetes in Indonesia* is imperative. Families help the person with diabetes decide appropriate ways for selecting diabetes management, evaluating the outcomes, and making further decisions about their diabetes management. Family members should be given adequate and relevant information to counter improper information received by others. When engaging with people with diabetes who are learning about their disease, families also need to have accurate knowledge and to equip themselves with current and relevant diabetes information, to assist their relatives who are living with diabetes. This present study affirms a finding from Knutsen et al.'s (2017) study, where a family member who does not have the requisite knowledge about diabetes can misunderstand how diabetes should be managed. Family members think they need to support their relatives, but sometimes they do not have an adequate knowledge level to do so effectively (Samuel-Hodge, Cene, Corsino, Thomas, & Svetkey, 2013).

Therefore, family members can help people with diabetes to make appropriate decisions about their perception of diabetes management. Families' proper knowledge is then imperative to ensuring that the received information they want to share to the people with diabetes is not only beneficial but also trustworthy. When the family has a broad and better knowledge, they then can help to explain to the person with diabetes, which information is worthy to follow and which is not. People with diabetes in this present study tended to listen to their family member, who they regarded as a reliable person. Through well-informed family recommendation and sharing trustworthy information, people with diabetes will be assisted to follow appropriate recommended therapies.

The success of self-management cannot be separated from families' supportive interventions to achieve desirable clinical outcomes. One of the factors that positively influence the clinical outcomes for the person living with diabetes is support from families or peer support (Joo & Lee, 2016; Shen, Edwards, Courtney, McDowell, & Wei, 2013). This present study identified that the majority of support comes from a close family member such as spouse, children or siblings. Similarly, Mayberry, Harper, and Osborn (2016) also found that familial supports mostly come from mature children or grandchildren, partners or spouse, and brothers or sisters.

Besides supportive behaviour, there were a few identified behaviours of family members in this present study that were unsupportive. Family members sometimes reminded people with diabetes in inappropriate ways, for example nagging. Although the family provided support such as a reminder, a person with diabetes in this present study expressed that when he could not restrict his diet, his relative would complain and be irritated. Some literature cite that nagging is one type of obstructive behaviour that families may do (Mayberry et al., 2016; Mayberry & Osborn, 2014; Oftedal, 2014) and mostly happens regarding diet and medication (Mayberry et al., 2016); with nagging most often centred around the expectation that people with diabetes should eat healthy food (Mayberry et al., 2016). Consequently, patients may decide to exclude families, when the family support has been found to be obstructive in the past, even though they had desired the family's engagement (Mayberry et al., 2016).

People with diabetes can nominate which family members will be their main source of support. This information will help HCPs to be able to work well with families by identifying family as sources of support. The HCPs need to consider whether the family member's contribution is appropriate, and assess their readiness to help the person with diabetes. Improving support for the family can increase better outcomes in diabetes management (Stuckey, Mullan-Jensen, Kalra, Reading, Wens et al., 2016). Identifying earlier behaviours of families can support well-designed patient-centred care that includes effective family engagement (Vongmany, Luckett, Lam, & Phillips, 2018).

It is imperative that more research is conducted about programs that can effectively provide families with sufficient and accurate knowledge regarding how best to support their relative with diabetes condition. Families need to be taught strategies to preventing them from engaging in negative behaviour (Mayberry et al., 2016). Families need to avoid judging the person with diabetes because it can also induce frustration and anger (McEwen & Murdaugh, 2014).

Chapter Summary

Throughout this chapter, the study's key findings were discussed in the context of the international and contemporary literature related to how people learn about their diabetes and explore options for diabetes care. Additionally, the findings were discussed in relation to the experiential learning theories as a theoretical code in this grounded theory study. This study has focused the discussion on six main areas. The first three areas included actively seeking and receiving diabetes-related information, sources and places of information and sifting information before choosing how to act. In addition, factors influencing people's decision making, experiential insight as a result of appraising the therapeutic interventions and the contribution of families in the process were the other main areas discussed in this section. This chapter also included one manuscript about family involvement in the process. In the next chapter, which is the conclusion of the study, a summary of the research process and an evaluation of the grounded theory study process and its outcome will be presented. Finally, strengths and limitations of the study, as well as recommendations arising from it will be discussed.

Chapter Eight: Reflections, evaluations, recommendations and conclusions

Introduction

In this chapter, the candidate explicates her reflections during her PhD candidature. Evaluations of the study and the study's strengths and limitations are also discussed. The candidate also provides recommendations from this study regarding practice, education, research and policy.

This study has established a theory of *Learning, choosing, and acting: Self-management of diabetes in Indonesia*. The theory represents a process of how Indonesian people with diabetes learn about their disease through five main categories. The categories are *seeking and receiving diabetes-related information, processing received information, responding to recommendations, appraising the results and sharing with others.* From this study, six key findings were explicated from the theory of *Learning, choosing, and acting: Self-management of diabetes in Indonesia*. Key finding six in particular, contributes new findings to the body of work on diabetes education. The key findings are as follows:

1. People with diabetes both actively sought and passively received diabetes-related information.
2. Diabetes-related information was accessed from a variety of sources and places.
3. Before making a decision about using received information, people with diabetes often sifted the information based on their prior knowledge, experiences and personal judgement.
4. Physical, psychological and resource factors highly influenced people's decisions to apply recommendations for managing their diabetes.
5. By appraising the results of their management choices, people with diabetes developed experiential insight, which they often shared with others and which influenced their future management decisions.
6. Families of people with diabetes engaged in all five categories of the process entitled '*Learning, choosing, and acting: Self-management of diabetes in Indonesia*'.

Reflections on the Study Process

The candidate has been a nurse academic since 2001. Initially, the candidate worked at the state-nursing academy for seven years and then continued to work as a training organiser in a health-training unit at the province of West Kalimantan for two years. She is passionate about nursing and also health education. Thus, in 2010 she moved to a nursing institution to teach undergraduate nursing students at that province. The candidate loves to teach and to undertake research. Lecturing baccalaureate students of nursing was one of her dreams since she graduated with a Bachelor of Nursing award from the nursing institution at University of Indonesia. In her current workplace at the School of Nursing at the University of Tanjungpura, her roles have been expanded into the three pillars of a higher degree academic professional. She is not only lecturing but also undertaking community service and conducting research.

The candidate is very keen about any research studies related to nursing education, health education, healthcare professionals, chronic diseases and how people and their families manage chronic conditions. Before pursuing her PhD, the candidate firstly had several topics under consideration for her PhD application and the topics were related to significant health problems specific to the province (West Kalimantan) where she lives and works. The health problems included chronic illness and palliative care.

The first year of the PhD was inspiring and encouraging because the candidate needed to prepare for a literature review and the confirmation seminar. She was firstly anxious that she should do the confirmation in less than a year of her candidature. With supportive and close supervision from her advisors, she proceeded through the first year as planned. She then needed to prepare her literature review to be published. Although there was comprehensive support from the university by access to a wide range of databases, undertaking a systematic way of a scoping review was still challenging. Moreover, the process of writing the scoping review was rewarding. The candidate attended several workshops within compulsory and elective professional development hours and those helped her tremendously in carrying out her research project.

At the beginning of the second year, the workload increased. The candidate did not only have to organise her publication plan of the literature review but she also had to deal with both the paper work for the ethics application and permissions for collecting data in Indonesia. What the candidate has learned from arranging the permission to access an institution is the need to build social networking with people from different organisations and institutions. Different technologies between Indonesia and Australia were also a challenge to the candidate. Not all the paper work could be undertaken electronically, and as a result, the candidate needed to go back to Indonesia solely for the purpose of arranging the local ethics application. The candidate was required to submit the ethics application in person in

Indonesia. However, the candidate was delighted as the ethics approval was obtained. During her first and second year of PhD candidature, she did not have a research assistant as she thought she might not need a research assistant. Thus, she really appreciated people who helped her seek permission to have access to healthcare facilities and a nursing educational institution in Indonesia, and who were available to build a communication network within and between two different continents.

During the process of collecting data, the candidate was even more motivated because at this stage, she visited the research field and met the participants. The candidate found it was encouraging to talk with the participants. She learnt about the participants' experiences and processes as they were living with diabetes. She also began to more fully understand how healthcare professionals and non-healthcare professionals were taking care of people with diabetes.

The approach to collection and data analysis in grounded theory is unique. Data are collected and analysed simultaneously, constant comparative data analysis. Unlike other kinds of qualitative studies the candidate had been involved in, this grounded theory data analysis allowed her to more intensively engage with the generated data. Once the first interview was undertaken, for example, she analysed it, which helped build her theoretical sensitivity about what she needed to ask further participants, or what data were required to be searched for during the next data collection. It was performed by modifying her interviews questions or by searching for other materials that related to the development of the categories the candidate had identified.

Another challenging aspect of this research journey was analysing the data in two languages, Indonesian and English. This process was time consuming but was highly valuable. The candidate gained an in-depth understanding of these data that were supported by her bilingual supervisor and her English supervisors.

For the candidate, doing a grounded theory study was demanding but enjoyable. Undertaking the essential methods in grounded theory was not easy. To ensure that the candidate understood and was able to communicate the process of conducting a GT study a number of publications detailing the methods adopted were developed. Her published papers and those under review reported on theoretical sampling, concept mapping, and developing and disseminating a storyline. For example, the candidate was enthusiastic about using visual aids during her analysis of these data. From this interest, the candidate published a paper about concept mapping. The candidate also described her categories in the form of diagrams after going through a concept mapping process.

The candidate learned and is still learning about the process of publishing papers in peer-reviewed journals. The candidate learned from the reviewer feedback that provided guidance on strengthening aspects of the papers. A lesson learned was being considerate of the journals selected for submission of each paper. The candidate initially selected target journals based on the journal ranking. She soon learned, the most important criteria for selecting a target journal is if the scope of the journal aligns with the paper topic and if similar types of papers have been published by that journal. The candidate concluded that some journals prioritised research papers that utilised quantitative research approaches. While it is disappointing that these journals devalue qualitative research, the candidate will continue to contribute to nursing knowledge, as she believes that all research is valuable.

The candidate realised that she had some difficulties writing in English, especially with respect to the use of prepositions and conjunction words. However, her native English supervisors and learning advisors in this university supported her significantly. The candidate also learned from her supervisors' suggestions to her to make her writing have a clear meaning. The candidate also learned from reading other people's published articles, especially the way they expressed their meaning into a sentence. Of course, the Indonesian language differs from English. Commonly when reading and writing, people may think in their original language from childhood. However, the candidate always tried to think, read and write in English, even though it was initially very hard, but then the candidate developed a pattern with it.

Part of the candidate's candidature involved achieving milestones including a pre-completion seminar. This milestone was undertaken four months before submission of the thesis. This challenging time encouraged the candidate to use time wisely, as each draft chapter was provided to the learning centre advisor to review, before being provided to her advisors for their comment. The timely manner of circulating the draft thesis from one advisor to the other helped the candidate very much, because the candidate could have time to refine the chapters every time the feedback was given to the candidate, and before the candidate circulated the next revised version to the next advisor. The candidate was delighted that her writing skills improved during the writing of publications and the thesis draft. Therefore, the candidate appreciated her advisors and learning centre advisor as well as the editors and reviewers from the journals. Rejections from one journal did not discourage her from submitting the paper to another journal. The candidate always kept in mind that one day the papers could find a better home for them to distribute and contribute the new knowledge gained from this present study to the people who would read and learn from the paper.

Evaluation of the Grounded Theory

There is limited consensus on appropriate criteria for evaluating the quality of qualitative research (Corbin & Strauss, 2015), including studies using grounded theory methodology. The evaluation criteria promoted by Charmaz (2014) inclusive of the four criteria — credibility, originality, resonance and usefulness was considered appropriate. The following discussion details each of these criteria with responses demonstrating the quality of this study.

Credibility.

Data collection methods including 28 interviews were analysed using the constant comparative method through three phases of the study, which ensured that the depth of data collection and analysis was achieved. The candidate recorded the decision trail regarding the development of concepts, categories and core category to show the progress and integration of the theory was accomplished through the depth and breadth of analytical thinking.

To show strong logical links between the raw data and the analysis, the candidate in this study always presented evidence through the participants' voices along with the interpretations and concepts developed, to clearly indicate that the theory is grounded from these data. The evidence, which was the participants' excerpt, was presented together with the information about the phase when these data were undertaken and the pages of the transcription where the quote appeared.

Originality.

This study developed a theory entitled *Learning, choosing, and acting: Self-management of diabetes in Indonesia*. The theory is the first one to be evidenced from not only people with diabetes but also their families, multidisciplinary healthcare professionals and healthcare providers. The process consisting of five distinctive categories is dynamic and offers new insights on how people with diabetes in Indonesia learn about their disease.

The five categories have their own definitions that come from the analysis grounded from these data; and they provide new concepts of the linear and cyclical processes of

Learning, choosing, and acting: Self-management of diabetes in Indonesia through learning by experiences. Several unique findings from this study were not apparent in any other studies. These unique findings are known as the key findings (which have been explicated in Chapter Seven, Discussion).

Findings from this study contribute to understanding the participants' experience living with diabetes and the process by which they acquire knowledge. Healthcare disciplines, specifically nursing, and the broader community can both be informed by this study's findings. As this study involved a wide range of HCPs and healthcare providers, the findings offer awareness that people with diabetes will make their own way of implementing their diabetes self-management. Even though many studies have investigated the beneficial impacts of health education for people with diabetes, people with diabetes are not evaluated on what they then do with their knowledge and information received from that formal education program. Moreover, people, have the right to make any decision regarding their disease, can do good or harm to themselves, because of being bombarded with information that they may not be able to determine if it is accurate and reliable, or not. This phenomenon can be taken into consideration by HCPs to anticipate pre-existing misconceptions that people with diabetes may bring with them to a health education encounter. Aimed with this raised awareness, the HCPs will be able to co-create a diabetes self-management regime that the person with diabetes could trust and try to execute.

Findings from this study have added new knowledge about the social environment, for example the wider scope of the family and community surrounding the person with diabetes. Families and communities can recognise that people with diabetes sometimes have difficulties when dealing with their regimes. Thus the family and community can provide encouragement to facilitate people with diabetes making appropriate decisions regarding their diabetes self-management, to help them survive with their disease and to reinforce positive achievements in their proper diabetes regimes.

Resonance.

A theory of *Learning, choosing, and acting: Self-management of diabetes in Indonesia* is a core category that portrays the process experienced by Indonesian people with diabetes regarding how they learn about their disease. Theory in a grounded theory comes from raw data, however during the process of theory integration, the theory is an abstract version of that data (Corbin & Strauss, 2015). They go on to recommend that it is important to validate whether the abstraction (theory) is congruent with these raw data. Consequently, the candidate performed the third phase of data collection aiming to validate the abstract version of these raw data by distributing the developed storyline to selected participants. The participants explained that the provided storyline and the concept map reflected their everyday life dealing with diabetes self-management. Corbin and Strauss (2015) suggest seeking feedback and comments about the findings from participants for the purpose of validation. By performing this process, the candidate has strengthened the resonance of findings in this study.

Through sharing the storyline with existing and new participants, the candidate ensured that the findings have meaning to people who have experienced or are familiar with the process of *Learning, choosing, and acting: Self-management of diabetes in Indonesia*. Also, this step ensured that the findings would make sense to other people who have similar conditions (Charmaz, 2014). Comments and feedback from the participants about the storyline helped the candidate to refine the storyline, which in turn validated the resonance of this study's findings.

The process of *Learning, choosing, and acting: Self-management of diabetes in Indonesia* is the basic social process of what is really going on with Indonesian people living with diabetes. Voices from participants presented together with the findings (in chapters five and six) have reflected the actual process experienced by these people. When presenting the findings in several oral presentations such as conferences and research school seminars, the quotes (with pseudonyms) were also displayed. Findings grounded from these data suggest that the audience senses how Indonesian people have gone through the process. The theory was presented at two conferences: 12th Biennial Conference of the Global Network of WHO Collaborating Centres for Nursing and Midwifery in Cairns, Australia and the Sigma Theta Tau 29th International Nursing Research Congress in Melbourne, Australia. The presentations triggered the audience to ask questions about how Indonesian people followed the recommendations from other people, including their HCPs. The audiences were also interested to know more about Indonesian people's typical cultural diet and their use of herbals made by them for managing their diabetes. The audience also shared a similar phenomenon of the self-management practices of people with diabetes in their own country. In the presentations, the recommendations from the audience were that nurses should know more about information regarding the use of natural products and whether there is scientific research evidence, so that nurses can provide clarification to educate people with diabetes.

Hopefully then, people with diabetes will avoid using substances that may harm them or may not work for their diabetes.

Usefulness.

For the criteria of usefulness, the researchers need to ask themselves whether the analysis provides interpretation which can be used by people in their daily living (Charmaz, 2014). The sharing of the storyline during the analysis of the study (in phase three of data collection), has affirmed the usefulness of the findings. The storyline was written in a vocabulary that was understandable and explains the process that people may experience in their life or people may use every day. The two participants, who were people with diabetes, commented that the storyline was easily understood and represented what they had experienced. Likewise, the two participants who were clinicians believed that the process embodied what they usually saw and have experienced when interacting with and taking care of people living with diabetes.

Disseminating findings is one effective way to ensure that the findings can contribute to global knowledge. Findings from this study are not only published in English international journals, but also in a national journal presented in the Indonesian language. The decision to also publish the storyline in the Indonesian language had the purpose of reaching a wider target audience, such as Indonesian clinicians, academics, researchers and most importantly, people with diabetes. Findings are useful for people with diabetes to understand the process of how they learn about their disease. Whereas, for the clinicians, this theory can be disseminated to patients and consequently can increase their awareness as they work together with people with diabetes in designing individualised diabetes self-management plans. The findings from this study explain the process of learning experienced by people with diabetes in Indonesia, as they are managing their chronic conditions. Also, the study found family involvement in the process was important and thus the clinicians may identify strategies about how they can work with families throughout the process. For researchers, findings from this study can prompt further research studies either about diabetes in other geographical areas or about other chronic diseases in either the same and/or a different geographical area than the present study.

Strengths and Limitations of the Study

Strengths.

The study strengths are described as follows:

- The candidate has clearly stated her philosophical positions (in Chapter Three: Methodology), namely symbolic interactionism and constructivism. These philosophical positions have influenced her in employing grounded theory as a methodology to answer the research question about a basic social process. By having congruence between the philosophical position, research aim and the methodology used, the candidate has ensured the rigour of the study.
- This present study used several essential grounded theory methods that were employed through all phases of the study to contribute to the rigour. The essential methods included sampling methods (purposive and theoretical sampling), field notes, memos, concurrent data collection and analysis, constant comparative analysis, theoretical sensitivity, theoretical saturation and coding process.
- The study consisted of distinctive findings that were not apparent in previous studies.
- The study involved a bilingual advisor, in addition to English advisors.
- This study involved a wide range of participants: people with diabetes, nurses (academics and clinicians), physicians (an internist and a general practitioner), a dietician, a pharmacist, lay health worker, exercise instructor, nursing student, health promotion officer, and families of people with diabetes. The participants came from the West Kalimantan province in Indonesia which is a geographic location having a high prevalence rate of diabetes in Indonesia.
- This present study confirmed similarities of findings, related to how people with diabetes are involved in the process of learning about their diabetes, from other international studies that have differences in geographical and cultural characteristics with Indonesia.

Limitations.

The limitations of the study include:

- The participants were from only one of 34 provinces in Indonesia, and only two of the major three ethnic groups found in that province. Thus, the findings may not represent the whole population in Indonesia or all ethnic groups in Indonesia.
- The process of transcription and translation required a substantial amount of time as it involved both the Indonesian language and English. Therefore, to overcome this issue, the candidate only translated from the Indonesian language to English those selected interview excerpts that generated the codes developed during the initial process of analysis completed in the Indonesian language.
- One interview was conducted with the daughter of a person with diabetes who was hospitalised. During the interview, the person with diabetes urgently needed the interviewee (her daughter) and the interview was discontinued. Previously, the candidate had followed the process outlined in the ethics application, of agreeing that the participant choose the time and place of the interview. She chose to be interviewed in the ward while waiting for her mother (a person with diabetes). In this case, the time and place might not have been suitable. All interviews have the potential to be interrupted and thus the researcher needs to factor in that possibility when agreeing to an interview location.
- In several interviews, a family member accompanied the participants. For example, when performing an interview with a participant living with diabetes, one family member, and sometimes more than one usually accompanied them. The family member occasionally responded to questions being asked of the person with diabetes even though the family member had not been asked to give comments. Only the person with diabetes signed the consent form. Therefore, ethically, the comments of the family member could not be included in the data set, which then may have limited the richness of the data. Consequently, in order to prevent this issue in subsequent interviews, the candidate then developed a strategy to obtain both participants' and the family members' signatures all together in advance, before the interview commenced. Therefore, even if a person with diabetes was the intended interviewee, the comments from the family member who accompanied them during the interviews, could also be included in the dataset.

Recommendations

Recommendations are listed under four sub headings: practice, education, research and policy.

Practice.

Recommendations for practice include:

- Healthcare professionals including nurse clinicians need to ensure they have provided concurrent education to people with diabetes, their families and even their communities, before working with them in diabetes management. Consequently, after the HCPs provide education, they then need to regularly monitor people with diabetes as these people attempt to execute their self-management plan. Thus the principles of person-centred care and family and community centred care can also guide the HCPs in providing education related to diabetes self-management.
- Healthcare professionals need to upgrade their skills especially the skills in recognizing people's difficulties in both learning about their diabetes and managing their diabetes. People with diabetes can have difficulties adhering to their recommended diabetes regime. Through *Learning, choosing, and acting: Self-management of diabetes in Indonesia* they may have positive outcomes and/or negative outcomes as they follow the recommendation in their own way. Consequently, the clinicians need to be aware of this phenomenon and discuss their progress with their regime, to create an open dialogue and thus an opportunity to advocate and support appropriate decision making about their diabetes management.
- Collaboration with members of the multidisciplinary team (MDT) is imperative in developing strategies for providing better health education for people with diabetes, when all members acknowledge that people with diabetes are in the process of *Learning, choosing, and acting: Self-management of diabetes in Indonesia*. Through such collaboration, constant assessment and re-assessment of how people with diabetes are self-managing their planned program will occur by all MDT members, and inappropriate or even harmful decisions and actions of the people with diabetes will be identified and addressed promptly, before secondary complications ensue.

Education.

Several recommendations from this study in terms of education are explicated as follows:

- Introducing the theory of *Learning, choosing, and acting: Self-management of diabetes in Indonesia* to educational organisations/institutions across the country is imperative. Indonesia has an organisation called *Asosiasi Institusi Pendidkan Ners Indonesia [*AIPNI] (The Association of Indonesian Nurse Education) that consists of nursing educational institutions across the country. The association's aim is to advocate and support the members to provide nursing education and to increase their quality of nursing education, including development of curriculum for nursing education. Findings of this present study thus can be included in curriculum development, especially in medial surgical nursing or chronic disease subjects. The subjects will include how to appropriately undertake health education for people living with diabetes since health education skills are fundamental skills for all nursing students to achieve.
- The theory of *Learning, choosing, and acting: Self-management of diabetes in Indonesia* needs to be introduced to both professionals and lay people in communities in order to increase people's awareness of this process regarding factors that facilitate or hinder learning, choosing and acting optimally to survive their diabetes. Also, awareness of this process will assist both HCPs and lay people to anticipate strategies they need to create to support people with diabetes in surviving with their diabetes and in continuing their diabetes regimes.
- The introduction of the theory can also be held during local seminars or workshops across the country as a professional development session for clinicians.
- For graduated nurses or nurse clinicians, the process of *Learning, choosing, and acting: Self-management of diabetes in Indonesia* can be included as a learning experience in health education training for nurses. Therefore, nurses may increase their awareness of the phenomenon of how people with diabetes learn about their disease.

Research.

This study recommends future research in these areas:

- This present study developed a theory of a process of how people with diabetes learn about their disease. Research in other chronic diseases is further required for investigation of whether the process is similar, different or more expanded in other chronic diseases.
- This present study identified that some people with diabetes still had negative outcomes regarding how they followed the recommendations. Thus, a further study involving a large number of people with diabetes across the country is required to examine people who exclusively use non-conventional medication and what outcomes they achieve.
- Research is needed to identify people's difficulties in undertaking their diabetes self-management across the nation, as this present study only involved one province in Indonesia. The multidisciplinary health research team can then conduct intervention research to resolve the difficulties found in clinical settings and the communities.
- Some publications of method papers from this present study can be used as guidelines for other researchers who are doing studies that are either employing grounded theory as a methodology or conducting other qualitative research that employs one or more of the essential grounded theory methods.
- This present study found that some people with diabetes used natural/homemade products they believed would have a beneficial impact on their body when managing their diabetes. Further studies are also needed to generate an evidence base to ascertain whether these natural products can provide positive outcomes in diabetes. Moreover, more studies are required to clarify which substances people are using. For example, people orally took a potion (leaves in boiling water) of 'Kratom' (*Mitragyna speciose*) or 'Kersen' (*Muntingia calabura*) leaves. Therefore the result of research on these natural products can generate evaluative evidence for clinicians to refer to when discussing these substances with people with diabetes..
- As family involvement in the process of *Learning, choosing, and acting: Self-management of diabetes in Indonesia* is one of the key findings from this study, further research is needed to involve the family in the interventions to solve the difficulties of people in self-managing their diabetes.

Policy.

Recommendations for policy include:

- Government and healthcare facilities need to provide reliable sources of information related to diabetes. The development and dissemination of the information is in collaboration with diabetes organizations in Indonesia. For example, the parties establish the website that is accessible to people with diabetes, their families or caregivers, especially for those who are keen to search for a second opinion or to explore about diabetes management.
- Stakeholders and healthcare facilities need to closely monitor the continuity of health education received by people with diabetes, and if/how it is enacted. This implication is to ensure that people with diabetes begin and accurately continue to fully follow the diabetes regime they have co-created with their HCPs on the MDT.
- Government through the information and technology board (bureau) need to review unreliable (hoax) information regarding diabetes therapies (products) that are distributed through social media. This bureau then needs to inform people to increase their awareness to more carefully evaluate the credibility of the information they are considering following.

Conclusion

This present study establishes a theory of *Learning, choosing, and acting: Self-management of diabetes in Indonesia.* This theory explicates a process of how Indonesian people living with diabetes learn about their disease. This process moves dynamically, in both linear and cyclical directions. Five main categories of this process demonstrate how people manage their diabetes through experiential learning. These categories include *seeking and receiving diabetes-related information, processing received information, responding to recommendations, appraising the results and sharing with others.* In addition to the findings of the substantive inquiry of the study, the family involvement in the process is a further finding.

In seeking diabetes related information, people with diabetes tend to actively seek a recommendation and information related to diabetes both before and after the diagnosis of diabetes. Sources of information come from not only HCPs but also other people, including lay people. People with diabetes usually receive the information through health education in healthcare facilities, seminars and during social gatherings or interactions with their communities.

After receiving the information or recommendations, people with diabetes process that information. This category explains that people with diabetes in Indonesia sift the information based on their prior knowledge, own experiences, personal judgement and sourcing a second (or more) opinion. People with diabetes decide to trust or distrust the received information by considering the sources of information or the deliverer's level of expertise (knowledge and qualifications) and level of experience of living with diabetes themselves, or having a family member who lives with diabetes.

Findings from this study have shown that in the process of *Learning, choosing, and acting: Self-management of diabetes in Indonesia*, people with diabetes respond to recommendations they receive from other people including the HCPs. People with diabetes have two ways of responding to the information they regard as trustworthy: following or not following the recommendations. Three factors influence their response: physical, psychological and resource factors. People who follow the recommendations, but in their own way, choose four options. Firstly, they may fully take conventional therapeutic interventions. Secondly, they may partially take conventional therapeutic interventions. Thirdly, they may take conventional and non-conventional therapeutic interventions concurrently. Fourthly, they take non-conventional therapeutic interventions exclusively.

The theory of *Learning, choosing, and acting: Self-management of diabetes in Indonesia* also explicates how people appraised the results of following or not following the recommendations. In this fourth category, people observed their bodily changes objectively and subjectively. People may have had positive and/or negative outcomes after implementing these recommendation(s). Appraising the results produced experiential insight. They then used that experiential insight to make further decisions to continue or discontinue their current therapeutic interventions.

From this present study, the theory of *Learning, choosing, and acting: Self-management of diabetes in Indonesia* also explains how people share their experiential insights with other people. They share their information related to diabetes and/or their insight mainly with other people living with diabetes. Also, they usually share their experiences with their families, friends, or other people who family members living with diabetes. People with diabetes share topics such as how to manage diabetes, mistakes to avoid when managing diabetes as well as diabetic symptoms and complications.

The family cannot be separated from the person with diabetes. People with diabetes have support from their family. Therefore, this study found that family has a very important role to play in each of the five categories of the process of *Learning, choosing, and acting: Self-management of diabetes in Indonesia*.

References

Abazari, P., Vanaki, Z., Mohammadi, E., & Amini, M. (2012). Inadequate investment on management of diabetes education. *Journal of Research in Medical Sciences, 17*, 792-798.

Adriono, G., Wang, D., Octavianus, C., & Congdon, N. (2011). Use of eye care services among diabetic patients in urban Indonesia. *Archives of Ophthalmology, 129*(7), 930-935. doi: 10.1001/archophthalmol.2011.147

Aklima, A., Kritpracha, C., & Thaniwattananon, P. (2013). Dietary behaviors among patients with type 2 diabetes mellitus in Indonesia. *Nurse Media J Nurs, 3*(1), 499-509.

Aliha, J. M., Asgari, M., Khayeri, F., Ramazani, M., Farajzadegan, Z., & Javaheri, J. (2013). Group education and nurse-telephone follow-up effects on blood glucose control and adherence to treatment in type 2 diabetes patients. *International Journal of Preventive Medicine, 4*, 797-802.

AlQarni, Z. A., Yunus, F., & Househ, M. S. (2016). Health information sharing on Facebook: An exploratory study on diabetes mellitus. *Journal of Infection and Public Health, 9*(6), 708-712. doi: 10.1016/j.jiph.2016.08.015

Alzubaidi, H., Mc Mamara, K., Chapman, C., Stevenson, V., & Marriott, J. (2015). Medicine-taking experiences and associated factors: Comparison between Arabic-speaking and Caucasian English-speaking patients with type 2 diabetes. *Diabetic Medicine, 32*(12), 1625-1633. doi: 10.1111/dme.12751

American Diabetes Association. (2004). Diagnosis and classification of diabetes mellitus. *Diabetes Care, 27*(Supplement 1), S5-S10.

Annells, M. (1996). Grounded theory method: Philosophical perspectives, paradigm of inquiry, and postmodernism. *Qualitative Health Research, 6*(3), 379-393. doi: 10.1177/104973239600600306

Annells, M. (2010). Grounded theory method: Philosophical perspectives, paradigm of inquiry, and postmodernism. In P. Atkinson & S. Delamont (Eds.), *SAGE qualitative research methods* (Vol. 1, pp. 13-26). Los Angeles: Sage Publications.

Antara. (2016). Pola makan tidak sehat, banyak pasien diabetes berusia muda. Retrieved 19 May 2017, from http://mediaindonesia.com/read/detail/77065-pola-makan-tidak-sehat-banyak-pasien-diabetes-berusia-muda

Atwine, F., & Hjelm, K. (2016). Healthcare-seeking behaviour and management of type 2 diabetes: From Ugandan traditional healers' perspective. *International Journal of Africa Nursing Sciences, 5*, 17-23. doi: 10.1016/j.ijans.2016.09.002

Australian Government. (2008). *Australian privacy law and practice.* Sydney: Commonwealth of Australia.

Banerjee, M., Macdougall, M., & Lakhdar, A. F. (2012). Impact of a single one-to-one education session on glycemic control in patients with diabetes. *Journal of Diabetes, 4*(2), 186-190. doi: 10.1111/j.1753-0407.2011.00178.x

Bao, W., Tobias, D. K., Bowers, K., Chavarro, J., Vaag, A., Grunnet, L. G., . . . Zhang, C. (2014). Physical activity and sedentary behaviors associated with risk of progression from gestational diabetes mellitus to type 2 diabetes mellitus: a prospective cohort study. *JAMA Internal Medicine, 174*(7), 1047-1055. doi: 10.1001/jamainternmed.2014.1795

Bassuk, S. S., & Manson, J. E. (2005). Epidemiological evidence for the role of physical activity in reducing risk of type 2 diabetes and cardiovascular disease. *Journal of Applied Physiology, 99*(3), 1193-1204. doi: 10.1152/japplphysiol.00160.2005

Baumgartner, I. (2012). Handling interpretation and representation in multilingual research: A meta-study of pragmatic issues resulting from the use of multiple languages in a qualitative information systems research work. *Qualitative Report, 17*, 1-21.

Beauchamp, T. L., & Childress, J. F. (2001). *Principles of biomedical ethics* (Vol. 5th). New York, N.Y: Oxford University Press.

Beauchamp, T. L., & Childress, J. F. (2009). *Principles of biomedical ethics* (Vol. 6th). New York: Oxford University Press.

Beauchamp, T. L., & Childress, J. F. (2013). *Principles of biomedical ethics* (Vol. Seventhition.). New York: Oxford University Press.

Berlitz, F. A., Hermes, D., Failace, R., & Schenkel, O. (2006). Impact evaluation of pre-diabetes classification in non-diabetic population. *Clinical Chemistry, 52*(S6), A86.

Birks, M. (2014). Practical philosophy. In J. Mills & M. Birks (Eds.), *Qualitative methodology: A practical guide* (pp. 17-30). Thousand Oaks, CA; London: SAGE.

Birks, M., & Mills, J. (2015). *Grounded theory: A practical guide*. Thousand Oaks, CA: SAGE.

Birks, M., Mills, J., Francis, K., & Chapman, Y. (2009). A thousand words paint a picture: The use of storyline in grounded theory research. *Journal of Research in Nursing, 14*(5), 405-417. doi: 10.1177/1744987109104675

Blumer, H. (1969). *Symbolic interactionism: Perspective and method*. Berkeley: University of California Press.

Bockwoldt, D., Staffileno, B. A., Coke, L., Hamilton, R., Fogg, L., Calvin, D., & Quinn, L. (2017). Understanding experiences of diabetes medications among African Americans living with type 2 diabetes. *Journal of Transcultural Nursing, 28*(4), 363-371. doi: 10.1177/1043659616651674

Bowers, B., & Schatzman, L. (2009). Dimensional analysis. In J. M. Morse, P. N. Stern, J. Corbin, B. Bowers, K. Charmaz, & A. E. Clarke (Eds.), *Developing grounded theory: The second generation* (pp. 86-126). Walnut Creek, California: Left Coast Press.

Breckenridge, J., & Jones, D. (2009). Demystifying theoretical sampling in grounded theory research. *Grounded Theory Review, 8*, 113-126.

Brundisini, F., Vanstone, M., Hulan, D., DeJean, D., & Giacomini, M. (2015). Type 2 diabetes patients' and providers' differing perspectives on medication nonadherence: A qualitative meta-synthesis. *BMC Health Services Research, 15*(516), 1-23. doi: 10.1186/s12913-015-1174-8

Bryant, A., & Charmaz, K. (2007). *The SAGE handbook of grounded theory* (Pbk. ed.). Los Angeles: SAGE Publications.

Cántaro, K., Jara, J. A., Taboada, M., & Mayta-Tristán, P. (2016). Association between information sources and level of knowledge about diabetes in patients with type 2 diabetes. *Endocrinology and Nutrition (Endocrinología y Nutrición, English Edition), 63*(5), 202-211. doi: 10.1016/j.endoen.2016.05.007

Central Bureau of Statistics Indonesia. (2015). Population of Indonesia by province 1971, 1980, 1990, 1995, 2000 and 2010. Retrieved 23 June 2015 https://www.bps.go.id/statictable/2009/02/20/1267/penduduk-indonesia-menurut-provinsi-1971-1980-1990-1995-2000-dan-2010.html

Central Intelligence Agency. (n.d.). The World Factbook: Indonesia [Image]. Retrieved rom https://www.cia.gov/library/publications/resources/the-world-factbook/attachments/maps/ID-map.gif

Chamberlain-Salaun, J., Mills, J., & Usher, K. (2013). Linking symbolic interactionism and grounded theory methods in a research design: From Corbin and Strauss' assumptions to action. *SAGE Open, 3*(3), 1-10. doi: 10.1177/2158244013505757

Charmaz, K. (2006). *Constructing grounded theory: A practical guide through qualitative analysis*. London: SAGE.

Charmaz, K. (2009). Shifting the grounds: Constructivist grounded theory methods. In J. M. Morse, P. N. Stern, J. Corbin, B. Bowers, K. Charmaz, & A. E. Clarke (Eds.), *Developing grounded theory: The second generation* (pp. 127-193). Walnut Creek, California: Left Coast Press.

Charmaz, K. (2013). Grounded theory methods in social justice research. In N. K. Denzin & Y. S. Lincoln (Eds.), *Strategies of qualitative inquiry* (4th ed., pp. 291-336). Thousand Oaks: SAGE Publications.

Charmaz, K. (2014). *Constructing grounded theory* (2nd ed.). London: SAGE.

Charmaz, K., & Belgrave, L. L. (2012). Qualitative interviewing and grounded theory analysis. In J. F. Gubrium, J. A. Holstein, A. B. Marvasti, & K. D. McKinney (Eds.), *The Sage handbook of interview research: The complexity of the craft* (2nd ed., pp. 347-365). Thousand Oaks: SAGE.

Charon, J. M. (2007). *Symbolic interactionism: An introduction, an interpretation, an integration* (Vol. 9th). Upper Saddle River, N.J: Pearson Education.

Chuang, L.-M., Tsai, S. T., Huang, B. Y., Tai, T. Y., & Diabcare-Asia Study Group. (2002). The status of diabetes control in Asia: A cross-sectional survey of 24 317 patients with diabetes mellitus in 1998. *Diabetic Medicine, 19*(12), 978-985. doi: 10.1046/j.1464-5491.2002.00833.x

Clarke, A. (2005). *Situational analysis: Grounded theory after the postmodern turn*. Thousand Oaks, Calif; London: Sage Publications.

Clarke, M. A., Moore, J. L., Steege, L. M., Koopman, R. J., Belden, J. L., Canfield, S. M., . . . Kim, M. S. (2016). Health information needs, sources, and barriers of primary care patients to achieve patient-centered care: A literature review.

Health Informatics Journal, 22(4), 992-1016. doi: 10.1177/1460458215602939

Coon, P., & Zulkowski, K. (2002). Adherence to American Diabetes Association standards of care by rural health care providers. *Diabetes Care, 25*(12), 2224-2229. doi: 10.2337/diacare.25.12.2224

Corbin, J. M., & Strauss, A. L. (2008). *Basics of qualitative research: Techniques and procedures for developing grounded theory*. Los Angeles: Sage Publications, Inc.

Corbin, J. M., & Strauss, A. L. (2015). *Basics of qualitative research: Techniques and procedures for developing grounded theory* (4th ed.). Los Angeles: SAGE.

Craig, M. E., Jones, T. W., Silink, M., & Ping, Y. J. (2007). Diabetes care, glycemic control, and complications in children with type 1 diabetes from Asia and the Western Pacific region. *Journal of Diabetes and Its Complications, 21*(5), 280-287. doi: 10.1016/j.jdiacomp.2006.04.005

Crangle, C. E., Bradley, C., Carlin, P. F., Esterhay, R. J., Harper, R., Kearney, P. M., . . . Savage, E. (2017). Soliciting and responding to patients' questions about diabetes through online sources. *Diabetes Technology & Therapeutics, 19*(3), 194-199. doi: 10.1089/dia.2016.0291

Creswell, J. W. (2013). *Qualitative inquiry and research design: Choosing among five approaches*. Thousand Oaks, Calif: SAGE Publications.

Crotty, M. (1998). *The foundations of social research: Meaning and perspective in the research process*. St Leonards, N.S.W: Allen & Unwin.

Daly, A. (2015). The law and ethics of 'self-quantified' health information: An Australian perspective. *International Data Privacy Law, 5*(2), 144-155. doi: 10.1093/idpl/ipv001

Debussche, X., Rollot, O., Le Pommelet, C., Fianu, A., Le Moullec, N., Régnier, C., . . . Favier, F. (2012). Quarterly individual outpatients lifestyle counseling after initial inpatients education on type 2 diabetes: The REDIA Prev-2 randomized controlled trial in Reunion Island. *Diabetes and Metabolism, 38*(1), 46-53. doi: 10.1016/j.diabet.2011.07.002

Denzin, N. K., & Lincoln, Y. S. (2000). Introduction: The discipline and practice of qualitative research. In N. K. Denzin & Y. S. Lincoln (Eds.), *The handbook of qualitative research* (2nd ed., pp. 1-28). Thousand Oaks, Calif: Sage Publications.

Denzin, N. K., & Lincoln, Y. S. (2005). Introduction: The discipline and practice of qualitative research. In N. K. Denzin & Y. S. Lincoln (Eds.), *The SAGE handbook of qualitative research* (3rd ed., pp. 1-32). Thousand Oaks: Sage Publications.

Dey, I. (2007). Grounding categories. In A. Bryant & K. Charmaz (Eds.), *The SAGE handbook of grounded theory* (pp. 167-190). Los Angeles: SAGE.

Dinas Kesehatan Provinsi Kalimantan Barat. (2017). *Health profile of West Kalimantan province in 2017 (Profil kesehatan provinsi Kalimantan Barat tahun 2017).* Pontianak.

Dunne, C. (2011). The place of the literature review in grounded theory research. *International Journal of Social Research Methodology, 14*(2), 111-124. doi: 10.1080/13645579.2010.494930

Entwistle, V. A., France, E. F., Wyke, S., Jepson, R., Hunt, K., Ziebland, S., & Thompson, A. (2011). How information about other people's personal experiences can help with healthcare decision-making: A qualitative study. *Patient Education and Counselling, 85*(3), e291-e298. doi: 10.1016/j.pec.2011.05.014

Eppens, M. C., Craig, M. E., Jones, T. W., Silink, M., & et al. (2006). Type 2 diabetes in youth from the Western Pacific region: Glycaemic control, diabetes care and complications. *Current Medical Research and Opinion, 22*(5), 1013-1020. doi: 10.1185/030079906X104795

Finkelstein, E. A., Chay, J., & Bajpai, S. (2014). The economic burden of self-reported and undiagnosed cardiovascular diseases and diabetes on Indonesian households. *Plos One, 9*(6), 1-8. doi: 10.1371/journal.pone.0099572

Fitzgerald, M. A., Rahman, S., Resurreccion, A. P., Concepcion, J., Daygon, V. D., Dipti, S. S., . . . Bird, A. R. (2011). Identification of a major genetic determinant of glycaemic index in rice. *Rice, 4*, 66-74. doi: 10.1007/s12284-011-9073-z

Giles, T., King, L., & de Lacey, S. (2013). The timing of the literature review in grounded theory research: An open mind versus an empty head. *Advances in Nursing Science, 36*(2), E29-E40. doi: 10.1097/ANS.0b013e3182902035

Glaser, B. G. (1978). *Theoretical sensitivity: Advances in the methodology of grounded theory*. Mill Valley, CA: Sociology Press.

Glaser, B. G. (1998). *Doing grounded theory: Issues and discussions*. Mill Valley, CA: Sociology Press.

Glaser, B. G., & Strauss, A. L. (1967). *The discovery of grounded theory: Strategies for qualitative research*. Hawthorne, NY: Aldine de Gruyter.

Guba, E. G., & Lincoln, Y. S. (2005). Paradigmatic controversies, contradictions and emerging confluences. In N. K. Denzin & Y. S. Lincoln (Eds.), *The Sage handbook of qualitative research* (3rd ed., pp. 191-215). Thousand Oaks, California: Sage Publications.

Hartayu, T. S., Izham, M., & Suryawati, S. (2012a). Improving of type 2 diabetic patients knowledge, attitude and practice towards diabetes self-care by implementing community-based interactive approach-diabetes mellitus strategy. *BioMed Central Research Notes, 5*(1), 315-315. doi: 10.1186/1756-0500-5-315

Hartayu, T. S., Izham, M., & Suryawati, S. (2012b). Improving type 2 diabetes patients' quality of life by using a community-based interactive approach-diabetes mellitus strategy in Yogyakarta, Indonesia. *Journal of Pharmaceutical Health Services Research, 3*(2), 95-102. doi: 10.1111/j.1759-8893.2012.00088.x

Hayes, C., & Kriska, A. (2008). Role of physical activity in diabetes management and prevention. *Journal of the American Dietetic Association, 108*(4), S19-S23. doi: 10.1016/j.jada.2008.01.016

Heinrich, E., de Nooijer, J., Schaper, N. C., Schoonus-Spit, M. H. G., Janssen, M. A. J., & de Vries, N. K. (2012). Evaluation of the web-based Diabetes Interactive Education Programme (DIEP) for patients with type 2 diabetes. *Patient Education and Counseling, 86*(2), 172-178. doi: 10.1016/j.pec.2011.04.032

Heron, J., & Reason, P. (1997). A participatory inquiry paradigm. *Qualitative Inquiry, 3*(3), 274-294. doi: 10.1177/107780049700300302

Higginbottom, G., & Lauridsen, E. I. (2014). The roots and development of constructivist grounded theory. *Nurse Researcher, 21*(5), 8-13. doi: 10.7748/nr.21.5.8.e1208

Hill, J. (2009). The development of diabetes services. *Diabetes and Primary Care, 11*(3), 176.

Hinder, S., & Greenhalgh, T. (2012). "This does my head in": Ethnographic study of self-management by people with diabetes. *BMC Health Services Research, 12*(1), 83-83. doi: 10.1186/1472-6963-12-83

Hiss, R. G., Armbruster, B. A., Gillard, M. L., & McClure, L. A. (2007). Nurse care manager collaboration with community-based physicians providing diabetes care a randomized controlled trial. *The Diabetes Educator, 33*(3), 493-502. doi: 10.1177/0145721707301349

Holton, J. A. (2007). The coding process and its challenges. In A. Bryant & K. Charmaz (Eds.), *The SAGE handbook of grounded theory* (pp. 265-289). Los Angeles: SAGE.

Hsu, C.-C., Lee, C.-H., Wahlqvist, M. L., Huang, H.-L., Chang, H.-Y., Chen, L., . . . Cheng, J.-S. (2012). Poverty increases type 2 diabetes incidence and inequality of care despite universal health coverage. *Diabetes Care, 35*(11), 2286-2292. doi: 10.2337/dc11-2052

Hu, E. A., Pan, A., Malik, V., & Sun, Q. (2012). White rice consumption and risk of type 2 diabetes: Meta-analysis and systematic review. *BMJ, 344*(7851), 15-15. doi: 10.1136/bmj.e1454

Hyman, I., Patychuk, D., Zaidi, Q., Kljujic, D., Shakya, Y. B., Rummens, J. A., . . . Vissandjee, B. (2012). Self-management, health service use and information seeking for diabetes care among recent immigrants in Toronto. *Chronic Diseases and Injuries in Canada, 33*(1), 12-18.

International Diabetes Federation. (2017). IDF Diabetes Atlas (8th ed.). Brussels, Belgium: International Diabetes Federation.

Javalkar, K., Williamson, N., Vaidya, S., Vaidya, A., & Ferris, M. (2016). The association between educational resource utilization and knowledge/self-management among patients with type 2 diabetes in Pune, India. *Diabetes and Metabolic Syndrome: Clinical Research and Reviews, 10*(4), 186-189. doi: 10.1016/j.dsx.2016.06.002

Johansson, K., Almerud Österberg, S., Leksell, J., Berglund, M., Institutionen för hälso- och, v., Fakulteten för Hälso- och, l., & Linnéuniversitetet. (2015). Manoeuvring between anxiety and control: patients' experience of learning to live with diabetes: A lifeworld phenomenological study. *International Journal of Qualitative Studies on Health and Well-being, 10*.

Joo, J. Y., & Lee, H. (2016). Barriers to and facilitators of diabetes self-management with elderly Korean-American immigrants. *International Nursing Review, 63*(2), 277-284. doi: 10.1111/inr.12260

Kalantzi, S., Kostagiolas, P., Kechagias, G., Niakas, D., & Makrilakis, K. (2015). Information seeking behavior of patients with diabetes mellitus: A cross-sectional study in an outpatient clinic of a university-affiliated hospital in Athens, Greece. *BMC Research Notes, 8*(48), 1-7.

Kanbara, S., Taniguchi, H., Sakaue, M., Wang, D.-H., Takaki, J., Yajima, Y., . . . Ogino, K. (2008). Social support, self-efficacy and psychological stress responses among outpatients with diabetes in Yogyakarta, Indonesia. *Diabetes Research and Clinical Practice, 80*(1), 56-62. doi: http://dx.doi.org/10.1016/j.diabres.2007.12.015

Kartono, A. (2013). Modified minimal model for effect of physical exercise on insulin sensitivity and glucose effectiveness in type 2 diabetes and healthy human. *Theory in Biosciences, 132*(3), 195-206. doi: 10.1007/s12064-013-0181-8

Kasl, S. V., & Cobb, S. (1966). Health behavior, illness behavior, and sick role behavior. I. Health and illness behavior. *Archives of Environmental Health, 12*(2), 246-266. doi: 10.1080/00039896.1966.10664365

Kearns, J. W., Bowerman, D., Kemmis, K., Izquierdo, R. E., Wade, M., & Weinstock, R. S. (2012). Group diabetes education administered through telemedicine: Tools used and lessons learned. *Telemedicine Journal and e-Health, 18*(5), 347-353. doi: 10.1089/tmj.2011.0165

Klarenbach, S. W., & Jacobs, P. (2003). International comparison of health resource utilization in subjects with diabetes. *Diabetes Care, 26*(4), 1116-1122. doi: 10.2337/diacare.26.4.1116

Klein, H. A., Jackson, S. M., Street, K., Whitacre, J. C., & Klein, G. (2013). Diabetes self-management education: Miles to go. *Nursing Research and Practice, 2013*, 581012-581015. doi: 10.1155/2013/581012

Knutsen, I. R., Foss, I. C., Todorova, E., Roukova, P., Kennedy, A., Portillo, M. C., . . . Rogers, A. (2017). Negotiating diet in networks: A cross-European study of the experiences of managing type 2 diabetes. *Qual Health Res, 27*(3), 299-310. doi: https://doi.org/10.1177/1049732315610318

Kolb, D. A. (1984). *Experiential learning: Experience as the source of learning and development*. Englewood Cliffs, N.J: Prentice-Hall.

Kolb, D. A., Boyatzis, R. E., & Mainemelis, C. (2001). Experiential learning theory: Previous research and new directions. In R. J. Sternberg & L. F. Zhang (Eds.), *Perspectives on thinking, learning, and cognitive styles* (pp. 227-247). London: Lawrence Erlbaum Associates.

Korytkowski, M. T., Koerbel, G. L., Kotagal, L., Donihi, A., & DiNardo, M. M. (2014). Pilot trial of diabetes self-management education in the hospital setting. *Primary Care Diabetes, 8*(3), 187-194. doi: 10.1016/j.pcd.2013.11.008

Lagomarsino, G., Garabrant, A., Adyas, A., Muga, R., & Otoo, N. (2012). Moving towards universal health coverage: Health insurance reforms in nine developing countries in Africa and Asia. *Lancet, 380*(9845), 933-943. doi: 10.1016/S0140-6736(12)61147-7

LaMonte, M. J., Blair, S. N., & Church, T. S. (2005). Physical activity and diabetes prevention. *Journal of Applied Physiology, 99*(3), 1205-1213. doi: 10.1152/japplphysiol.00193.2005

Lee, Y. K., Low, W. Y., Lee, P. Y., & Ng, C. J. (2015). Factors influencing decision-making role preferences: A qualitative study of Malaysian patients with type 2 diabetes during insulin initiation. *International Journal of Nursing Practice, 21*, 125-131. doi: 10.1111/ijn.12355

Lenz, E. R., Mundinger, M. O. N., Hopkins, S. C., Lin, S. X., & Smolowitz, J. L. (2002). Diabetes care processes and outcomes in patients treated by nurse practitioners or physicians. *The Diabetes Educator, 28*(4), 590-598. doi: 10.1177/014572170202800413

Levers, M.-J. D. (2013). Philosophical paradigms, grounded theory, and perspectives on emergence. *SAGE Open*, 1-6. doi: 10.1177/2158244013517243

Liamputtong, P. (2014). Experiential knowing. In D. Coghlan & M. Brydon-Miller (Eds.), The SAGE Encyclopedia of Action Research. London: SAGE Publications. Retrieved from http://methods.sagepub.com/reference/encyclopedia-of-action-research/n121.xml 13 February 2019. doi: http://dx.doi.org/10.4135/9781446294406.n133

Ligita, T., Wicking, K., Harvey, N., & Mills, J. (2018). The profile of diabetes healthcare professionals in Indonesia: A scoping review. *International Nursing Review, 65*(3), 349-360. doi: 10.1111/inr.12418

Ligita, T., Wicking, K., Francis, K. Harvey, N., & Nurjannah, I. (*In press*). How people living with diabetes in Indonesia learn about their disease: A grounded theory study. *PlosONE*.

Lincoln, Y. S., & Guba, E. G. (2000). Paradigmatic controversies, contradictions and emerging confluences. In N. K. Denzin & Y. S. Lincoln (Eds.), *The handbook of qualitative research* (2nd ed., pp. 163-188). Thousand Oaks, California: Sage Publications.

Low, L. L., Tong, S. F., & Low, W. Y. (2016a). Selection of treatment strategies among patients with type 2 diabetes mellitus in Malaysia: A grounded theory approach. *Plos One, 11*(1), e0147127. doi: 10.1371/journal.pone.0147127

Low, L. L., Tong, S. F., & Low, W. Y. (2016b). Social influences of help-seeking behaviour among patients with type 2 diabetes mellitus in Malaysia. *Asia Pac J Public Health, 28*(1, Suppl), 17S-25S. doi: https://doi.org/10.1177/1010539515596807

Lynch, E. B., Fernandez, A., Lighthouse, N., Mendenhall, E., & Jacobs, E. (2012). Concepts of diabetes self-management in Mexican American and African American low-income patients with diabetes. *Health Education Research, 27*(5), 814-824. doi: 10.1093/her/cys058

Madill, A., Jordan, A., & Shirley, C. (2000). Objectivity and reliability in qualitative analysis: Realist, contextualist and radical constructionist epistemologies. *British Journal of Psychology, 91*(1), 1-20.

Malini, H., Copnell, B., & Moss, C. (2017). Considerations in adopting a culturally relevant diabetes health education programme: An Indonesian example. *Collegian, 24*(2), 183-190. doi: 10.1016/j.colegn.2015.11.002

Martin, A. L., Warren, J. P., & Lipman, R. D. (2013). The landscape for diabetes education: Results of the 2012 AADE national diabetes education practice survey. *The Diabetes Educator, 39*(5), 614-622.

Mayberry, L. S., Harper, K. J., & Osborn, C. Y. (2016). Family behaviors and type 2 diabetes: What to target and how to address in interventions for adults with low socioeconomic status. *Chronic Illn, 12*(3), 199-215. doi: https://doi.org/10.1177/1742395316644303

Mayberry, L. S., & Osborn, C. Y. (2014). Family involvement is helpful and harmful to patients' self-care and glycemic control. *Patient Educ Couns, 97*(3), 418-425. doi: https://doi.org/10.1016/j.pec.2014.09.011

Mc Sharry, J., Bishop, F. L., Moss-Morris, R., & Kendrick, T. (2013). 'The chicken and egg thing': Cognitive representations and self-management of multimorbidity in people with diabetes and depression. *Psychology & Health, 28*(1), 103-119. doi: 10.1080/08870446.2012.716438

McCallin, A. (2003). Grappling with the literature in a grounded theory study. *Contemporary Nurse: A Journal for the Australian Nursing Profession, 15*(1-2), 61-69. doi: 10.5172/conu.15.1-2.61

McEwen, M. M., & Murdaugh, C. (2014). Partnering with families to refine and expand a diabetes intervention for Mexican Americans. *The Diabetes Educator, 40*(4), 488-495. doi: 10.1177/0145721714528996

McGhee, G., Marland, G. R., & Atkinson, J. (2007). Grounded theory research: Literature reviewing and reflexivity. *Journal of Advanced Nursing, 60*(3), 334-342. doi: 10.1111/j.1365-2648.2007.04436.x

Mead, G. H., Huebner, D. R., Joas, H., & Morris, C. W. (1934). *Mind, self and society: The definitive edition*. Chicago: The University of Chicago Press.

Menefee, H. K., Thompson, M. J., Guterbock, T. M., Williams, I. C., & Valdez, R. S. (2016). Mechanisms of communicating health information through Facebook: Implications for consumer health information technology design. *Journal of Medical Internet Research, 18*(8). doi: 10.2196/jmir.5949

Merriam-Webster. (2018). Definition of experiential. Retrieved 18 January 2018 https://www.merriam-webster.com/dictionary/experiential

Mihardja, L., Delima, Manz, H. S., Ghani, L., & Soegondo, S. (2009). Prevalence and determinants of diabetes mellitus and impaired glucose tolerance in Indonesia (a part of basic health research/Riskesdas). *Acta Medica Indonesiana, 41*(4), 169-174.

Mihardja, L., Soetrisno, U., & Soegondo, S. (2014). Prevalence and clinical profile of diabetes mellitus in productive aged urban Indonesians. *Journal of Diabetes Investigation, 5*(5), 507-512. doi: 10.1111/jdi.12177

Milewski, J., & Chen, Y. (2010). Barriers of obtaining health information among diabetes patients. *Stud Health Technol Inform, 160*, 18-22. doi: 10.3233/978-1-60750-588-4-18

Mills, J. (2014). Methodology and methods. In J. Mills & M. Birks (Eds.), *Qualitative methodology: A practical guide* (pp. 31-48). Thousand Oaks, CA; London: SAGE.

Mills, J., Birks, M., & Hoare, K. (2014). Grounded theory. In J. Mills & M. Birks (Eds.), *Qualitative methodology: A practical guide* (pp. 107-122). Thousand Oaks, CA; London: SAGE.

Ministry of Health Republic of Indonesia. (2015). Strategic plan of Ministry of Health 2015-2019 (Rencana strategis Kementerian Kesehatan tahun 2015-2019). Retrieved 17 August 2016, from http://depkes.go.id/resources/download/info-publik/Renstra-2015.pdf

Mishra, S. I., Gioia, D., Childress, S., Barnet, B., & Webster, R. L. (2011). Adherence to medication regimens among low-income patients with multiple comorbid chronic conditions. *Health and Social Work, 36*(4), 249-258. doi: 10.1093/hsw/36.4.249

Moonaghi, H. K., Areshtanab, H. N., Joibari, L., Bostanabad, M. A., & McDonald, H. (2014). Struggling towards diagnosis: Experiences of Iranian diabetes. *Iranian Red Crescent Medical Journal, 16*(7), 1-7. doi: 10.5812/ircmj.16547

Morse, J. M. (2007). Sampling in grounded theory. In A. Bryant & K. Charmaz (Eds.), *The SAGE handbook of grounded theory* (pp. 229-244). Los Angeles: SAGE.

National Institute for Health Research and Development. (2008). *'Riset Kesehatan Dasar'*. Jakarta: Ministry of Health of Republic of Indonesia.

National Institute for Health Research and Development. (2013). *'Riset Kesehatan Dasar'*. Jakarta: Ministry of Health Republic of Indonesia.

Ng, N., Nichter, M., Padmawati, R. S., Prabandari, Y. S., Muramoto, M., Nichter, M., . . . Institutionen för folkhälsa och klinisk, m. (2010). Bringing smoking cessation to diabetes clinics in Indonesia. *Chronic Illness, 6*(2), 125-135. doi: 10.1177/1742395310364253

Noviyanti, S. (2017). Melawan Mitos Susah Kenyang kalau Belum Makan Nasi. Retrieved 21 December 2018, from https://lifestyle.kompas.com/read/2017/07/20/080300320/melawan-mitos-susah-kenyang-kalau-belum-makan-nasi

Nurjannah, I., Mills, J., Park, T., & Usher, K. (2014). Conducting a grounded theory study in a language other than English. *SAGE Open, 4*(1), 1-10. doi: 10.1177/2158244014528920

Oftedal, B. (2014). Perceived support from family and friends among adults with type 2 diabetes. *European Diabetes Nurs, 11*(2), 43-48. doi: https://doi.org/10.1002/edn.247

Oyetunde, M. O., & Famakinwa, T. T. (2014). Nurses' knowledge of contents of diabetes patient education in Ondo - state, Nigeria. *Journal of Nursing Education and Practice, 4*(4), 91.

Patel, N. R., Kennedy, A., Blickem, C., Reeves, D., & Chew-Graham, C. (2016). "I'm managing my diabetes between two worlds": Beliefs and experiences of diabetes management in British South Asians on holiday in the east-a qualitative study. *Journal of Diabetes Research*, 1-8. doi: 10.1155/2016/5436174

Pidgeon, N., & Henwood, K. (2009). Grounded theory. In M. Hardy & A. Bryman (Eds.), *The handbook of data analysis* (pp. 625-648). London: SAGE Publication.

Pieper, I. J., & Thomson, C. J. H. (2014). The value of respect in human research ethics: A conceptual analysis and a practical guide. *Monash Bioethics Review, 32*(3-4), 232-253. doi: 10.1007/s40592-014-0016-5

Poland, B. D. (1995). Transcription quality as an aspect of rigor in qualitative research. *Qualitative Inquiry, 1*(3), 290-310. doi: 10.1177/107780049500100302

Pramono, L. A., Setiati, S., Soewondo, P., Subekti, I., Adisasmita, A., Kodim, N., & Sutrisna, B. (2010). Prevalence and predictors of undiagnosed diabetes mellitus in Indonesia. *Acta Medica Indonesiana, 42*(4), 216.

Putra, K. W. R., Toonsiri, C., & Junprasert, S. (2016). Self-efficacy, psychological stress, family support, and eating behavior on type 2 diabetes mellitus. *Belitung Nurs J, 2*(2), 3-7.

Radji, M., Putri, C. S., & Fauziyah, S. (2014). Antibiotic therapy for diabetic foot infections in a tertiary care hospital in Jakarta, Indonesia. *Diabetes & Metabolic Syndrome, 8*(4), 221-224. doi: 10.1016/j.dsx.2014.09.006

Ramadhinara, A., & Poulas, K. (2013). Use of wireless microcurrent stimulation for the treatment of diabetes-related wounds: Two case reports. *Advances in Skin & Wound Care, 26*(1), 1-4.

Rankin, D., Barnard, K., Elliott, J., Cooke, D., Heller, S., Gianfrancesco, C., . . . Group, U. N. D. S. (2014). Type 1 diabetes patients' experiences of, and need for, social support after attending a structured education programme: A qualitative longitudinal investigation. *Journal of Clinical Nursing, 23*(19-20), 2919-2927. doi: 10.1111/jocn.12539

Rawnsley, M. M. (1998). Ontology, espistemology, and methodology: A clarification. *Nursing Science Quarterly, 11*(1), 2-4.

Redman-MacLaren, M., & Mills, J. (2015). Transformational grounded theory: Theory, voice, and action. *International Journal of Qualitative Methods, 14*(3), 1-12.

Republic of Indonesia Ministry of Health Decree: National health system (*Sistem kesehatan nasional*), 374 C.F.R. (2009).

Republic of Indonesia Ministry of Health Regulation: Hospital classification (*Klasifikasi rumah sakit*), 340 C.F.R. (2010).

Republic of Indonesia Minister of Health. (2014a). Provincial health database (database kesehatan per provinsi). Retrieved 7 December 2017

Republic of Indonesia Ministry of Health regulation: Guideline of national health insurance program (*pedoman pelaksanaan program jaminan kesehatan nasional*), 28 C.F.R. (2014b).

Republic of Indonesia President Act: Social security organising board (badan penyelenggara jaminan sosial), 24 C.F.R. (2011).

Republic of Indonesia President Act: National health system (*sistem kesehatan nasional*), 72 C.F.R. (2012).

Republic of Indonesia Act: Health professionals (*tenaga kesehatan*), 36 C.F.R. (2014).

Republic of Indonesia President Regulation: Health insurance (jaminan kesehatan), 82 C.F.R. (2018).

Robinson, S., Baron, R. B., Cooper, B., & Janson, S. (2009). Does health service use in a diabetes management program contribute to health disparities at a facility level? Optimizing resources with demographic predictors. *Population Health Management, 12*(3), 139-147. doi: 10.1089/pop.2008.0026

Rosenstock, I. M. (1974). Historical origins of health belief model. *Health Education Monographs, 2*(4), 328-335. doi: 10.1177/109019817400200403

Rosenstock, I. M., Rosenstock, I. M., Strecher, V. J., Strecher, V. J., Becker, M. H., & Becker, M. H. (1988). Social learning theory and the Health Belief Model. *Health Education Quarterly, 15*(2), 175-183. doi: 10.1177/109019818801500203

Rudijanto, A., Soewondo, P., Waspadji, S., Yunir, E., & Purnamasari, D. (2011). The Indonesian society of endocrinology's summary article of diabetes mellitus national clinical practice guidelines. *Journal of the ASEAN Federation of Endocrine Societies, 26*(1), 17-19. doi: 10.15605/jafes.026.01.03

Sae-Sia, W., Maneewat, K., & Kurniawan, T. (2013). Effect of a self-management support program on diabetic foot care behaviors. *International Journal of Research in Nursing, 4*(1), 14-21.

Saldana, J. (2013). *The coding manual for qualitative researchers* (2nd ed.). London: Sage Publications.

Samuel-Hodge, C. D., Cene, C. W., Corsino, L., Thomas, C., & Svetkey, L. P. (2013). Family diabetes matters: A view from the other side. *Journal of General Internal Medicine, 28*(3), 428-435. doi: 10.1007/s11606-012-2230-2

Santos, H. P. O., Black, A. M., & Sandelowski, M. (2015). Timing of translation in cross-language qualitative research. *Qualitative Health Research, 25*(1), 134-144. doi: 10.1177/1049732314549603

Santoso, M., Yuliana, M., Mujono, W., & Kusdiantomo. (2005). Pattern of diabetic foot at Koja regional general hospital, Jakarta, from 1999 to 2004. *Acta Medica Indonesiana, 37*(4), 187.

Schwandt, T. A. (2000). Three epistemological stances for qualitative inquiry: Interpretivism, hermeneutics and social constructionism. In N. K. Denzin & Y. S. Lincoln (Eds.), *The handbook of qualitative research* (2nd ed., pp. 189-213). Thousand Oaks, Calif: Sage Publications.

Shen, H., Edwards, H., Courtney, M., McDowell, J., & Wei, J. (2013). Barriers and facilitators to diabetes self-management: Perspectives of older community dwellers and health professionals in China. *International Journal of Nursing Practice, 19*(6), 627-635. doi: 10.1111/ijn.12114

Simmonds, A., & Hort, K. (2013). Institutional analysis of Indonesia's proposed road map to universal health coverage. *Health Policy and Health Finance Knowledge Hub Working Paper, 33*, 1-16.

Simmons, O. E. (2011). Why classic grounded theory. In V. B. Martin & A. Gynnild (Eds.), *Grounded Theory: The philosophy, method and work of Barney Glaser* (pp. 15-30). Boca Raton: Brown Walker Press.

Sinorita, H., Saadah, & Jazakillah, S. (2008). Effects of dietary pattern and education on glycemic control in patients with type 2 diabetes mellitus at Dr. Sardjito Central General Hospital, Yogyakarta. *Acta Medica Indonesiana, 40*(2), 55-58.

Sja'bani, M., Asdie, A. H., Widayati, K., Subroto, Y., Kariadi, S. H., Arifin, A. Y. L., . . . Murtiwi, S. (2005). Microalbuminuria prevalence study in hypertensive patients with type 2 diabetes in Indonesia. *Acta Medica Indonesiana, 37*(4), 199-204.

Soebardi, S., Purnamasari, D., Oemardi, M., Soewondo, P., Waspadji, S., & Soegondo, S. (2009). Dyslipidemia in newly diagnosed diabetes mellitus: The Jakarta primary non-communicable disease risk factors surveillance 2006. *Acta Medica Indonesiana, 41*(4), 186-190.

Soegondo, S., Prodjosudjadi, W., & Setiawati, A. (2009). Prevalence and risk factors for microalbuminuria in a cross-sectional study of type-2 diabetic patients in Indonesia : A subset of DEMAND study. *Medical Journal of Indonesia, 18*(2), 124-130. doi: http://dx.doi.org/10.13181/mji.v18i2.352

Soegondo, S., Subekti, I., & Luthariana, L. (2004). The efficacy of repaglinide monotherapy and in combination with metformin in Indonesian type 2 diabetes mellitus patients. *Acta Medica Indonesiana, 36*(3), 142-147.

Soegondo, S., Widyahening, I. S., Istantho, R., & Yunir, E. (2011). Prevalence of diabetes among suburban population of Ternate, a small remote island in the eastern part of Indonesia. *Acta Medica Indonesiana, 43*(2), 99-104.

Soewondo, P. (2011). Current practice in the management of type 2 diabetes in Indonesia: Results from the International Diabetes management Practices Study (IDMPS). *Journal of Indonesian Medical Association, 61*(12), 474-481.

Soewondo, P., Ferrario, A., & Tahapary, D. L. (2013a). Challenges in diabetes management in Indonesia: A literature review. *Globalization and Health, 9*(63). Retrieved from: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3901560/ 12 October 2015 doi:http://dx.doi.org/10.1186/1744-8603-9-63

Soewondo, P., Kshanti, I. A., Pramono, R. B., Langi, Y. A., & Dalem-Pemayun, T. G. (2013b). Clinical experience with insulin detemir: Results from the Indonesian cohort of the international A_1chieve study. *Diabetes Research and Clinical Practice, 100*, S47-S53.

Soewondo, P., Lindarto, D., Wibisono, S., Renaldi, O., & Dalem-Pemayun, T. G. (2013c). Clinical safety and effectiveness of biphasic insulin aspart 30 in type 2 diabetes patients switched from biphasic human insulin 30: Results from the Indonesian cohort of the A_1chieve study. *Diabetes Research and Clinical Practice, 100*, S41-S46.

Soewondo, P., & Pramono, L. A. (2011). Prevalence, characteristics, and predictors of pre-diabetes in Indonesia. *Medical Journal of Indonesia, 20*(4), 283-294. doi: http://dx.doi.org/10.13181/mji.v20i4.465

Soewondo, P., Pramono, R. B., Langi, Y. A., Soetedjo, N. N. M., & Kshanti, I. A. (2013d). Clinical experience with BIAsp 30: Results from the Indonesian cohort of the international A$_1$chieve study. *Diabetes Research and Clinical Practice, 100 Suppl 1*, S54.

Soewondo, P., Soegondo, S., Suastika, K., Pranoto, A., Soeatmadji, D. W., & Tjokroprawiro, A. (2010). The DiabCare Asia 2008 study: Outcomes on control and complications of type 2 diabetic patients in Indonesia. *Medical Journal of Indonesia, 19*(4), 235-244. doi: 10.13181/mji.v19i4.412

Strauss, A. L. (1987). *Qualitative analysis for social scientists*. Cambridge [Cambridgeshire]; New York: Cambridge University Press.

Strauss, A. L., & Corbin, J. M. (1990). *Basics of qualitative research: Grounded theory procedures and techniques*. Newbury Park, CA: Sage.

Strauss, A. L., & Corbin, J. M. (1998). *Basics of qualitative research: Techniques and procedures for developing grounded theory* (2nd ed.). Thousand Oaks: Sage Publications.

Stuckey, H. L., Mullan-Jensen, C., Kalra, S., Reading, J., Wens, J., Vallis, M., . . . Peyrot, M. (2016). Living with an adult who has diabetes: Qualitative insights from the second Diabetes Attitudes, Wishes and Needs (DAWN2) study. *Diabetes Research and Clinical Practice, 116*, 270-278. doi: 10.1016/j.diabres.2016.04.028

Sun, Q., Spiegelman, D., van Dam, R. M., Holmes, M. D., Malik, V. S., Willett, W. C., & Hu, F. B. (2010). White rice, brown rice, and risk of type 2 diabetes in US men and women. *Archives of Internal Medicine, 170*(11), 961-969. doi: 10.1001/archinternmed.2010.109

Sutanegara, D., & Budhiarta, A. A. G. (2000). The epidemiology and management of diabetes mellitus in Indonesia. *Diabetes Research and Clinical Practice, 50*, S9-S16. doi: 10.1016/S0168-8227(00)00173-X

Sweileh, W. M., Zyoud, S. E. H., Abu Nab'A, R. J., Deleq, M. I., Enaia, M. I., Nassar, S. A. M., & Al-Jabi, S. W. (2014). Influence of patients' disease knowledge and beliefs about medicines on medication adherence: Findings from a cross-sectional survey among patients with type 2 diabetes mellitus in Palestine. *BMC Public Health, 14*(1), 94-94. doi: 10.1186/1471-2458-14-94

Tanto, A., Syarfina, F., Dimas Abdul Azis, F., Alifian, P. H., & Adilla, S. (2017). *Tackling Indonesia's diabetes challenge with Indonesian traditional herbs as dietary supplementation to reduce development of cardiovascular complications: Promotion the use of natural product.* Paper presented at the Asian Academic Society International Conference Proceeding, Khon Kaen, Thailand.

Todorova, L., Hnoosh, A., Bloomfield, E., & Shiu, M. L. (2012). Estimating the direct medical costs associated with diabetes-related complications in Indonesia. *Value in Health, 15*(7), A662-A662.

Triyanti, K., Suhardjono, Soewondo, P., & Shatri, H. (2008). Renal function decrement in type 2 diabetes mellitus patients in Cipto Mangunkusumo hospital. *Acta Medica Indonesiana, 40*(4), 192.

Tuytel, G. H., Leeuw, J. R. J. d., Gorter, K. J., Rutten, G. E. H. M., Bijl, J. J. v. d., & Bensing, J. (2010). Preferences and opinions of patients with Type 2 diabetes on education and self-care: A cross-sectional survey. *Diabetic Medicine, 27*(1), 85-91. doi: 10.1111/j.1464-5491.2009.02886.x

UNESCO Institute for Statistics. (2016). Indonesia. from https://en.unesco.org/countries/indonesia

Urquhart, C., & Fernández, W. (2013). Using grounded theory method in information systems: The researcher as blank slate and other myths. *Journal of Information Technology, 28*(3), 224-236. doi: 10.1057/jit.2012.34

van Nes, F., Abma, T., Jonsson, H., & Deeg, D. (2010). Language differences in qualitative research: Is meaning lost in translation? *European Journal of Ageing, 7*(4), 313-316. doi: 10.1007/s10433-010-0168-y

Vongmany, J., Luckett, T., Lam, L., & Phillips, J. L. (2018). Family behaviours that have an impact on the self-management activities of adults living with type 2 diabetes: A systematic review and meta-synthesis. *Diabet Med, 35*(2), 184-194. doi: https://doi.org/10.1111/dme.13547

Waspadji, S., Ranakusuma, A. B., Suyono, S., Supartondo, S., & Sukaton, U. (1983). Diabetes mellitus in an urban population in Jakarta, Indonesia. *The Tohoku Journal of Experimental Medicine, 141 Suppl*, 219.

Waspadji, S., Soewondo, P., Subekti, I., Soebardi, S., Harbuwono, D. S., Pramono, L. A., & Supali, T. (2013). Ende diabetes study: Diabetes and its characteristics in rural area of East Nusa Tenggara. *Medical Journal of Indonesia, 22*(1), 30-38. doi: http://dx.doi.org/10.13181/mji.v22i1.517

Webster, E., Johnson, C., Kemp, B., Smith, V., Johnson, M., & Townsend, B. (2017). Theory that explains an Aboriginal perspective of learning to understand and manage diabetes. *Australian and New Zealand Journal of Public Health, 41*(1), 27-31. doi: 10.1111/1753-6405.12605

Wei, X., Du, Z., & Zhang, S. (2016). Analysis of barriers to health information seeking and utilizing in patientswith diabetes. *Cross-Cultural Communication, 12*(2), 48-51. doi: http://dx.doi.org/10.3968/%25x

Widjaja, M. (2012). Indonesia: In search of a placement-support social protection. *ASEAN Economic Bulletin, 29*(3), 184-196. doi: 10.1355/ae29-3b

Widyahening, I. S., van der Graaf, Y., Soewondo, P., Glasziou, P., & van der Heijden, G. J. M. G. (2014). Awareness, agreement, adoption and adherence to type 2 diabetes mellitus guidelines: A survey of Indonesian primary care physicians. *BioMed Central Family Practice, 15*(1), 72-72. doi: 10.1186/1471-2296-15-72

Wilson, A., & Gyi, A. A. (2010). The status and perspective of diabetes health education in China: Inspiration from Australia. *International Journal of Nursing Practice, 16*(2), 92-98. doi: 10.1111/j.1440-172X.2010.01817.x

World Health Organization. (2014). The health of the people: What works. Retrieved 11 September 2015, from http://www.who.int/bulletin/africanhealth2014/disease_threats/en

World Health Organization. (2016). Indonesia: diabetes country profile *Global Health Observatory (GHO) data: Indonesia*. Geneva.

World Health Organization. (2018). Indonesia: country profiles Retrieved 31 January 2019 https://www.who.int/nmh/countries/idn_en.pdf?ua=1

World Health Organization, & UN partners. (2012). Indonesia: WHO statistical profile *Country statistics and global health estimates*.

Yamin, F. (2016). Pola makan tak sehat pemicu utama diabetes. Retrieved 19 May 2017, from https://lifestyle.kompas.com/read/2016/11/24/100000723/pola.makan.tak.sehat.pemicu.utama.diabetes

Yusuf, S., Kasim, S., Okuwa, M., & Sugama, J. (2013). Development of an enterostomal therapy nurse outpatient wound clinic in Indonesia: A retrospective descriptive study. *Wound Practice and Research, 21*(1), 41-47.

Zare-Farashbandi, F., Lalazaryan, A., Rahimi, A., & Zadeh, A. H. (2015). How health information is received by diabetic patients? *Advanced Biomedical Research, 4*(1), 126-126. doi: 10.4103/2277-9175.158047

Zareban, I., Karimy, M., Niknami, S., Haidarnia, A., & Rakhshani, F. (2014). The effect of self-care education program on reducing HbA1c levels in patients with type 2 diabetes. *Journal of Education and Health Promotion, 3*(123).

Zhang, X., Bullard, K. M., Gregg, E. W., Beckles, G. L., Williams, D. E., Barker, L. E., . . . Imperatore, G. (2012). Access to health care and control of ABCs of diabetes. *Diabetes Care, 35*(7), 1566-1571. doi: 10.2337/dc12-0081

Appendices

- Appendix A: Copyright Permission Letter and Explanation from the Publishers
- Appendix B: Permission Letters from Study Settings
- Appendix C: Information Sheets and Consent Form in English
- Appendix D: Information Sheets and Consent Forms in the Indonesian Language
- Appendix E: Grand tour Questions for the Participants
- Appendix F: Modified Questions for the Participants
- Appendix G: James Cook University Human Ethics Approval and Amendment Approvals
- Appendix H: Faculty of Nursing, University of Indonesia Ethics Approval
- Appendix I: Storyline Paper in the Indonesian Language
- Appendix J: Examples of Evidence in the Indonesian language

Appendix A

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Appendix B

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Appendix C

JAMES COOK
UNIVERSITY
AUSTRALIA

INFORMATION SHEET

PROJECT TITLE: **"Providing Health Education for People Living with Diabetes Mellitus in Indonesia"**

Dear Participant,
You are invited to take part in a research project, which investigates health education for people living with diabetes mellitus. The aim of this study is to develop a theory about the process of providing health education for people living with diabetes mellitus in Indonesia. The study is being conducted by Titan Ligita and will contribute to the degree, Doctor of Philosophy, at James Cook University, Australia.

If you agree to be involved in this study, you will be invited to be interviewed. The interview, with your consent, will be audio-taped, and should only take approximately 1 hour of your time. The interview will be conducted at the hospital, public health center, School of Nursing at University of Tanjungpura or a venue of your choice. No one else but the interviewer will be present unless you would like someone else to be there.

Your participation in this research study is entirely voluntary. You can stop taking part in the study at any time without explanation or prejudice. The choice that you make will have no bearing on your job or on any work-related evaluations or reports.

Your responses and contact details will be strictly confidential. No one else except my supervisors and I will have access to the information documented during your interview. The documents containing information recorded are confidential and will be destroyed after five (5) years. The overall results of the study may be published in international nursing journals or spoken about at international nursing seminars or conferences. You and your institution will remain anonymous in any way in these publications.

If you have any questions about the study, please contact Titan Ligita, Professor Jane Mills, Dr. Kristin Wicking and Dr. Nichole Harvey.

Principal Investigator
Titan Ligita
College of Healthcare Sciences
James Cook University
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Primary Supervisor
Professor Jane Mills
College of Healthcare Sciences
James Cook University
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Co-Supervisor
Dr. Kristin Wicking
College of Healthcare Sciences
James Cook University
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Co-Supervisor
Dr. Nichole Harvey
College of Medicine and Dentistry
James Cook University
Content has been removed for privacy reasons

If you have any concerns regarding the ethical conduct of the study, please contact:
Human Ethics, Research Office
James Cook University, Townsville, Qld, 4811
Phone: +61 (7) 4781 5011
Email: ethics@jcu.edu.au

JAMES COOK UNIVERSITY
AUSTRALIA

INFORMED CONSENT FORM

PRINCIPAL INVESTIGATOR : Titan Ligita
PROJECT TITLE: Providing Health Education for People Living with Diabetes Mellitus in Indonesia
COLLEGE: Healthcare Sciences (Nursing)

I understand the aim of this research study is to develop a theory about providing health education for people living with diabetes mellitus in Indonesia. I consent to participate in this project, the details of which have been explained to me, and I have been provided with a written information sheet to keep.

I understand that my participation will involve an interview and I agree that the researcher may use the results as described in the information sheet.

I acknowledge that:

- taking part in this study is voluntary and I am aware that I can stop taking part in it at any time without explanation or prejudice and to withdraw any unprocessed data I have provided;

- that any information I give will be kept strictly confidential and that no names will be used to identify me with this study without my approval;

(Please tick to indicate consent)

I consent to be interviewed	☐	**Yes**	☐	**No**
I consent for the interview to be audio taped	☐	**Yes**	☐	**No**

Name:	
Signature:	**Date:**

Page 2 of 2

JAMES COOK UNIVERSITY
AUSTRALIA

INFORMATION SHEET

PROJECT TITLE: **"Providing Health Education for People Living with Diabetes Mellitus in Indonesia"**

Dear Participant,
You are invited to take part in a research project, which investigates health education for people living with diabetes mellitus. The aim of this study is to develop a theory about the process of providing health education for people living with diabetes mellitus in Indonesia. The study is being conducted by Titan Ligita and will contribute to the degree, Doctor of Philosophy, at James Cook University, Australia.

If you agree to be involved in this study, you will be invited to be interviewed. The interview, with your consent, will be audio-taped, and should only take approximately 1 hour of your time. The interview will be conducted at the hospital, public health center or a venue of your choice. No one else but the interviewer will be present unless you would like someone else to be there.

Your participation in this research is entirely voluntary. You can stop taking part in the study at any time without explanation or prejudice. If you choose not to participate, all the services you receive at this hospital or public health centre will continue and nothing will change. You will not be provided any incentive to take part in the research. However, we will give you *lima puluh ribu rupiah* (Rp 50.000 = 5 AUD) for your time and travel expense.

Your responses and contact details will be strictly confidential. No one else except my supervisors and I will have access to the information documented during your interview. The documents containing information recorded are confidential and will be destroyed after five (5) years. The overall results of the study may be published in a nursing journal or spoken about at nursing seminars/conferences. You will remain anonymous in any way in these publications.

If you have any questions about the study, please contact Titan Ligita, Professor Jane Mills, Dr. Kristin Wicking and Dr. Nichole Harvey.

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JAMES COOK UNIVERSITY
AUSTRALIA

INFORMED CONSENT FORM

PRINCIPAL INVESTIGATOR : Titan Ligita
PROJECT TITLE: Providing Health Education for People Living with Diabetes Mellitus in Indonesia
COLLEGE: Healthcare Sciences (Nursing)

I understand the aim of this research study is to develop a theory about providing health education for people living with diabetes mellitus in Indonesia. I consent to participate in this project, the details of which have been explained to me, and I have been provided with a written information sheet to keep.

I understand that my participation will involve an interview and I agree that the researcher may use the results as described in the information sheet.

I acknowledge that:

- taking part in this study is voluntary and I am aware that I can stop taking part in it at any time without explanation or prejudice and to withdraw any unprocessed data I have provided;

- that any information I give will be kept strictly confidential and that no names will be used to identify me with this study without my approval;

(Please tick to indicate consent)

I consent to be interviewed	☐	Yes	☐	No
I consent for the interview to be audio taped	☐	Yes	☐	No

Name:	
Signature:	**Date:**

JAMES COOK
UNIVERSITY
AUSTRALIA

INFORMATION SHEET

PROJECT TITLE: **"Providing Health Education for People Living with Diabetes Mellitus in Indonesia"**

Dear Participant,
You are invited to take part in a research project, which investigates health education for people living with diabetes mellitus. The aim of this study is to develop a theory about the process of providing health education for people living with diabetes mellitus in Indonesia. The study is being conducted by Titan Ligita and will contribute to the degree, Doctor of Philosophy, at James Cook University, Australia.

If you agree to be involved in this study, you will be invited to be interviewed. The interview, with your consent, will be audio-taped, and should only take approximately 1 hour of your time. The interview will be conducted at the hospital, public health center or a venue of your choice. No one else but the interviewer will be present unless you would like someone else to be there.

Your participation in this research is entirely voluntary. You can stop taking part in the study at any time without explanation or prejudice. If you choose not to participate, all the services your family receive at this hospital or public health centre will continue and nothing will change.

Your responses and contact details will be strictly confidential. No one else except my supervisors and I will have access to the information documented during your interview. The documents containing information recorded are confidential and will be destroyed after five (5) years. The overall results of the study may be published in a nursing journal or spoken about at nursing seminars/conferences. You will remain anonymous in any way in these publications.

If you have any questions about the study, please contact Titan Ligita and Dr. Kristin Wicking.

Principal Investigator	**Principal Advisor**
Titan Ligita	Dr. Kristin Wicking
College of Healthcare Sciences	College of Healthcare Sciences
James Cook University	James Cook University
Content has been removed for privacy reasons	Content has been removed for privacy reasons

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JAMES COOK UNIVERSITY
AUSTRALIA

INFORMED CONSENT FORM

PRINCIPAL INVESTIGATOR : Titan Ligita
PROJECT TITLE: Providing Health Education for People Living with Diabetes Mellitus in Indonesia
COLLEGE: Healthcare Sciences (Nursing)

I understand the aim of this research study is to develop a theory about providing health education for people living with diabetes mellitus in Indonesia. I consent to participate in this project, the details of which have been explained to me, and I have been provided with a written information sheet to keep.

I understand that my participation will involve an interview and I agree that the researcher may use the results as described in the information sheet.

I acknowledge that:

- taking part in this study is voluntary and I am aware that I can stop taking part in it at any time without explanation or prejudice and to withdraw any unprocessed data I have provided;

- that any information I give will be kept strictly confidential and that no names will be used to identify me with this study without my approval;

(Please tick to indicate consent)

I consent to be interviewed	☐	**Yes**	☐	**No**
I consent for the interview to be audio taped	☐	**Yes**	☐	**No**

Name:	
Signature:	**Date:**

(Version 3) Page 2 of 2

INFORMATION SHEET

PROJECT TITLE: **"Providing Health Education for People Living with Diabetes Mellitus in Indonesia"**

Dear Participant,
You are invited to take part in a research project, which investigates health education for people living with diabetes mellitus. The aim of this study is to develop a theory about the process of providing health education for people living with diabetes mellitus in Indonesia. The study is being conducted by Titan Ligita and will contribute to the degree, Doctor of Philosophy, at James Cook University, Australia.

If you agree to be involved in this study, you will be invited to be interviewed. The interview, with your consent, will be audio-taped, and should only take approximately 1 hour of your time. The interview will be conducted at the hospital, public health center, School of Nursing at University of Tanjungpura or a venue of your choice. No one else but the interviewer will be present unless you would like someone else to be there.

Your participation in this research study is entirely voluntary. You can stop taking part in the study at any time without explanation or prejudice. The choice that you make will have no bearing on your study or on any work-related evaluations or reports.

Your responses and contact details will be strictly confidential. No one else except my supervisors and I will have access to the information documented during your interview. The documents containing information recorded are confidential and will be destroyed after five (5) years. The overall results of the study may be published in international nursing journals or spoken about at international nursing seminars or conferences. You and your institution will remain anonymous in any way in these publications.

If you have any questions about the study, please contact Titan Ligita and Dr. Kristin Wicking.

Principal Investigator
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(Version 3) Page 1 of 2

JAMES COOK UNIVERSITY
AUSTRALIA

INFORMED CONSENT FORM

PRINCIPAL INVESTIGATOR : Titan Ligita
PROJECT TITLE: Providing Health Education for People Living with Diabetes Mellitus in Indonesia
COLLEGE: Healthcare Sciences (Nursing)

I understand the aim of this research study is to develop a theory about providing health education for people living with diabetes mellitus in Indonesia. I consent to participate in this project, the details of which have been explained to me, and I have been provided with a written information sheet to keep.

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- that any information I give will be kept strictly confidential and that no names will be used to identify me with this study without my approval;

(Please tick to indicate consent)

I consent to be interviewed	☐ **Yes**	☐ **No**
I consent for the interview to be audio taped	☐ **Yes**	☐ **No**

Name:	
Signature:	**Date:**

Appendix D

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has been removed

JAMES COOK
UNIVERSITY
AUSTRALIA

LEMBAR INFORMASI

JUDUL PENELITIAN: **"Pendidikan Kesehatan bagi Masyarakat yang Menderita Diabetes Mellitus di Indonesia (*Providing Health Education for People Living with Diabetes Mellitus in Indonesia*)"**

Yang terhormat partisipan,

Kami mengajak anda untuk berpartisipasi dalam sebuah proyek penelitian yang akan memberikan pendidikan kesehatan bagi masyarakat yang menderita diabetes mellitus. Tujuan dari penelitian ini adalah untuk mengembangkan sebuah teori mengenai proses pemberian pendidikan kesehatan bagi masyarakat yang mengalami diabetes mellitus di Indonesia. Penelitian yang dilakukan oleh Titan Ligita ini akan memberikan kontribusi terhadap program strata tiga, *Doctor of Philosophy*, pada James Cook University, Australia

Jika anda setuju untuk ikut serta dalam penelitian ini, Anda akan diwawancarai. Wawancara, tentunya dengan persetujuan Anda, akan direkam dan berlangsung selama kurang lebih satu jam. Wawancara akan dilakukan di rumah sakit, puskesmas, Program Pendidikan Perawatan Universitas Tanjungpura atau di tempat lain sesuai dengan pilihan Anda. Tidak ada orang lain selain pewawancara yang akan hadir saat wawancara kecuali Anda menginginkan orang lain untuk menemani Anda disana.

Partisipasi Anda dalam penelitian ini sepenuhnya bersifat sukarela. Anda dapat berhenti untuk berpartisipasi pada setiap saat tanpa penjelasan atau prasangka apapun. Pilihan yang anda buat ini tidak akan mempengaruhi pekerjaan anda atau apapun yang terkait dengan evaluasi atau laporan tentang diri anda

Respon dan rincian informasi mengenai Anda akan bersifat sangat rahasia. Tidak ada orang lain selain para supervisor saya dan saya yang akan mengakses informasi yang didokumentasikan selama wawancara. Dokumen berupa rekaman informasi tersebut bersifat rahasia dan akan dimusnahkan setelah lima (5) tahun. Hasil penelitian secara keseluruhan akan dipublikasikan pada jurnal-jurnal Keperawatan internasional dan akan dipresentasikan pada berbagai seminar ataupun konferensi Keperawatan internasional. Anda dan institusi Anda tidak akan diumumkan dengan cara apapun pada publikasi tersebut.

Jika Anda memiliki pertanyaan mengenai penelitian ini, silahkan menghubungi Titan Ligita, Professor Jane Mills, Dr. Kristin Wicking atau Dr. Nichole Harvey.

Peneliti Utama
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Pembimbing
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Pembimbing Pendamping
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Pembimbing Pendamping
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James Cook University
Phone: +61 7 4781 6408
Mobile: +61 4 3930 0211
Email: nikki.harvey@jcu.edu.au

Jika Anda memiliki pertanyaan terkait etika penelitian dalam penelitian ini, silahkan menghubungi:
Human Ethics, Research Office
James Cook University, Townsville, Qld, 4811
Telepon: (07) 4781 5011
Email: ethics@jcu.edu.au

ANDI SUPRIANTO
No. 2228/2001

Page 1 of 2

Lembar Persetujuan

JAMES COOK UNIVERSITY AUSTRALIA

PENELITI UTAMA : Titan Ligita

JUDUL PENELITIAN: Pendididikan Kesehatan bagi Masyarakat yang Menderita Diabetes Mellitus di Indonesia *(Providing Health Education for People Living with Diabetes Mellitus in Indonesia)*

JURUSAN: Healthcare Sciences (Nursing)

Saya memahami tujuan penelitian ini adalah untuk mengembangkan sebuah teori mengenai pemberian pendidikan kesehatan bagi masyarakat yang menderita diabetes mellitus di Indonesia. Saya setuju untuk berpartisipasi dalam proyek penelitian ini, dan keterangan terinci mengenai penelitian telah dijelaskan kepada saya dan saya telah menerima sehelai informasi tertulis untuk saya simpan.

Saya memahami bahwa partisipasi saya ini akan meliputi sebuah wawancara dan saya setuju bahwa peneliti dapat menggunakan hasil-hasil penelitian sebagaimana dijelaskan pada lembar informasi.

Saya mengakui bahwa:

- partisipasi dalam penelitian ini bersifat sukarela dan saya mengetahui bahwa saya dapat berhenti untuk berpartisipasi pada setiap saat tanpa penjelasan atau prasangka apapun atau menarik segala data yang belum diproses yang telah saya berikan;
- informasi apapun yang saya berikan akan dijaga kerahasiaannya secara ketat dan bahwa tidak akan ada satu pun nama yang akan digunakan untuk mengetahui identitas saya dalam penelitian ini tanpa persetujuan saya;

(Silahkan beri tanda √ sebagai tanda setuju)

Saya setuju untuk diwawancarai ☐ **Ya** ☐ **Tidak**

Saya setuju wawancara direkam ☐ **Ya** ☐ **Tidak**

Nama:

Tandatangan: **Tanggal:**

Dengan ini saya menyatakan bahwa Lembar Informasi dan Persetujuan ini diterjemahkan dari teks asli dalam Bahasa Inggeris oleh saya, Andi Suprianto, penerjemah resmi dan tersumpah berdasarkan SK Gubernur KDKI No. 2228/2001 tgl. 31 Juli 2001

ANDI SUPRIANTO
No. 2228/2001

Page 2 of 2

JAMES COOK
UNIVERSITY
AUSTRALIA

LEMBAR INFORMASI

JUDUL PENELITIAN: **" Pendidikan Kesehatan bagi Masyarakat yang Menderita Diabetes Mellitus di Indonesia (*Providing Health Education for People Living with Diabetes Mellitus in Indonesia*)"**

Yang terhormat partisipan,

Kami mengajak anda untuk berpartisipasi dalam sebuah proyek penelitian yang akan memberikan pendidikan kesehatan bagi masyarakat yang menderita diabetes mellitus. Tujuan dari penelitian ini adalah untuk mengembangkan sebuah teori mengenai proses pemberian pendidikan kesehatan bagi masyarakat yang mengalami diabetes mellitus di Indonesia. Penelitian yang dilakukan oleh Titan Ligita ini akan memberikan kontribusi terhadap program strata tiga, *Doctor of Philosophy*, pada James Cook University, Australia.

Jika anda setuju untuk ikut serta dalam penelitian ini, Anda akan diwawancarai. Wawancara, tentunya dengan persetujuan Anda, akan direkam dan berlangsung selama kurang lebih satu jam. Wawancara akan dilakukan di rumah sakit, puskesmas atau di tempat lain sesuai dengan pilihan Anda. Tidak ada orang lain selain pewawancara yang akan hadir saat wawancara kecuali Anda menginginkan orang lain untuk menemani Anda disana.

Partisipasi Anda dalam penelitian ini sepenuhnya bersifat sukarela. Anda dapat berhenti untuk berpartisipasi pada setiap saat tanpa penjelasan atau prasangka apapun. Jika Anda memilih untuk tidak berpartisipasi dalam penelitian ini, semua pelayanan kesehatan yang Anda terima di rumah sakit/puskesmas ini akan tetap berlanjut dan tidak akan berubah. Anda tidak akan menerima insentif melalui partisipasi dalam penelitian ini. Tetapi kami akan memberi anda sejumlah lima puluh ribu rupiah (Rp 50.000) atas waktu yang telah Anda berikan dan perjalanan yang Anda lakukan untuk wawancara ini.

Respon dan rincian informasi mengenai Anda akan bersifat sangat rahasia. Tidak ada orang lain selain para supervisor saya dan saya yang akan mengakses informasi yang didokumentasikan selama wawancara. Dokumen berupa rekaman informasi tersebut bersifat rahasia dan akan dimusnahkan setelah lima (5) tahun. Hasil penelitian secara keseluruhan akan dipublikasikan pada jurnal-jurnal Keperawatan internasional dan akan dipresentasikan pada berbagai seminar ataupun konferensi Keperawatan internasional. Anda dan institusi Anda tidak akan diumumkan dengan cara apapun pada publikasi tersebut.

Jika Anda memiliki pertanyaan mengenai penelitian ini, sllahkan menghubungi Titan Ligita, Professor Jane Mills, Dr. Kristin Wicking atau Dr. Nichole Harvey.

Peneliti Utama
Titan Ligita
College of Healthcare Sciences
James Cook University
Phone: +61
Mobile: +61 4 8128 5994
Email: titan.ligita@my.jcu.edu.au

Pembimbing
Professor Jane Mills
College of Healthcare Sciences
James Cook University
Phone: +61 7 4042 1548
Mobile: +61 4 5752 5990
Email: jane.mills@jcu.edu.au

Pembimbing Pendamping
Dr. Kristin Wicking
College of Healthcare Sciences
James Cook University
Phone: +61 7 4781 4289
Mobile: +61 4 2710 2221
Email: Kristin.wicking@my.jcu.edu.au

Pembimbing Pendamping
Dr. Nichole Harvey
College of Medicine and Dentistry
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Phone: +61 7 4781 6408
Mobile: +61 4 3930 0211
Email: nikki.harvey@jcu.edu.au

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Email: ethics@jcu.edu.au

ANDI SUPRIANTO
No. 2228/2001

Page 1 of 2

JAMES COOK UNIVERSITY
AUSTRALIA

Lembar Persetujuan

PENELITI UTAMA : Titan Ligita

JUDUL PENELITIAN: Pendididikan Kesehatan bagi Masyarakat yang Menderita Diabetes Mellitus di Indonesia *(Providing Health Education for People Living with Diabetes Mellitus in Indonesia)*

JURUSAN: Healthcare Sciences (Nursing)

Saya memahami tujuan penelitian ini adalah untuk mengembangkan sebuah teori mengenai pemberian pendidikan kesehatan bagi masyarakat yang menderita diabetes mellitus di Indonesia. Saya setuju untuk berpartisipasi dalam proyek penelitian ini, dan keterangan terinci mengenai penelitian telah dijelaskan kepada saya dan saya telah menerima sehelai informasi tertulis untuk saya simpan.

Saya memahami bahwa partisipasi saya ini akan meliputi sebuah wawancara dan saya setuju bahwa peneliti dapat menggunakan hasil-hasil penelitian sebagaimana dijelaskan pada lembar informasi.

Saya mengakui bahwa:

- partisipasi dalam penelitian ini bersifat sukarela dan saya mengetahui bahwa saya dapat berhenti untuk berpartisipasi pada setiap saat tanpa penjelasan atau prasangka apapun atau menarik segala data yang belum diproses yang telah saya berikan;
- informasi apapun yang saya berikan akan dijaga kerahasiaannya secara ketat dan bahwa tidak akan ada satu pun nama yang akan digunakan untuk mengetahui identitas saya dalam penelitian ini tanpa persetujuan saya;

(Silahkan beri tanda √ sebagai tanda setuju)

Saya setuju untuk diwawancarai	☐ **Ya**	☐ **Tidak**
Saya setuju wawancara direkam	☐ **Ya**	☐ **Tidak**

Nama:	
Tandatangan:	**Tanggal:**

Dengan ini saya menyatakan bahwa Lembar Informasi dan Persetujuan ini diterjemahkan dari teks asli dalam Bahasa Inggeris oleh saya, Andi Suprianto, penerjemah resmi dan tersumpah berdasarkan SK Gubernur KDKI No. 2228/2001 tgl. 31 Juli 2001

SK Gubernur KDKI Jakarta
ANDI SUPRIANTO
No. 2228/2001

Page 2 of 2

LEMBAR INFORMASI

JUDUL PENELITIAN: **"Edukasi Kesehatan bagi Masyarakat yang Mengalami Diabetes Mellitus di Indonesia (*Providing Health Education for People Living with Diabetes Mellitus in Indonesia*)"**

Yang terhormat partisipan,
Kami mengajak anda untuk berpartisipasi dalam sebuah proyek penelitian yang akan mengidentifikasi edukasi kesehatan bagi masyarakat yang mengalami diabetes mellitus. Tujuan dari penelitian ini adalah untuk mengembangkan sebuah teori mengenai proses pemberian pendidikan kesehatan bagi masyarakat yang mengalami diabetes mellitus di Indonesia. Penelitian yang dilakukan oleh Titan Ligita ini akan berkontribusi terhadap program strata tiga, *Doctor of Philosophy*, pada James Cook University, Australia.

Jika anda setuju untuk terlibat dalam penelitian ini, Anda akan diwawancarai. Wawancara, tentunya dengan persetujuan Anda, akan direkam dan berlangsung selama kurang lebih satu jam. Wawancara akan dilakukan di rumah sakit, puskemas atau di tempat yang sesuai dengan pilihan Anda. Tidak ada orang lain selain pewawancara yang akan hadir saat wawancara kecuali Anda menginginkan orang lain untuk menemani Anda disana.

Partisipasi Anda dalam penelitian ini sepenuhnya bersifat sukarela. Anda dapat berhenti untuk berpartisipasi pada setiap saat tanpa penjelasan atau prasangka apapun. Jika Anda memilih untuk tidak berpartisipasi dalam penelitian ini, semua pelayanan kesehatan yang keluarga Anda terima di rumah sakit/puskesmas ini akan tetap berlanjut dan tidak akan berubah.

Respon dan rincian informasi mengenai Anda akan bersifat sangat rahasia. Tidak ada orang lain selain para supervisor saya dan saya yang akan mengakses informasi yang didokumentasikan selama wawancara. Dokumen berupa rekaman informasi tersebut bersifat rahasia dan akan dimusnahkan setelah lima (5) tahun. Hasil penelitian secara keseluruhan akan dipublikasikan pada jurnal-jurnal Keperawatan internasional dan akan disampaikan pada seminar-seminar ataupun konferensi-konferensi Keperawatan internasional. Anda dan institusi Anda tidak akan diketahui dengan cara apapun pada publikasi tersebut.

Jika Anda memiliki pertanyaan mengenai penelitian ini, silahkan menghubungi Titan Ligita dan Dr. Kristin Wicking.

Peneliti Utama
Titan Ligita
College of Healthcare Sciences
James Cook University
Telp: +61 7 4781 5066
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Pembimbing Utama
Dr. Kristin Wicking
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Jika Anda memiliki pertanyaan terkait etika penelitian selama dalam penelitian ini, silahkan menghubungi:
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Telepon: (07) 4781 5011
Email: ethics@jcu.edu.au

Page 1 of 2

JAMES COOK UNIVERSITY
AUSTRALIA

Lembar Persetujuan

PENELITI UTAMA : Titan Ligita
JUDUL PENELITIAN: Edukasi Kesehatan bagi Masyarakat yang Mengalami Diabetes Mellitus di Indonesia *(Providing Health Education for People Living with Diabetes Mellitus in Indonesia)*
JURUSAN: Healthcare Sciences (Nursing)

Saya memahami tujuan dalam penelitian ini adalah untuk mengembangkan sebuah teori mengenai pemberian edukasi kesehatan bagi masyarakat yang mengalami diabetes mellitus di Indonesia. Saya setuju untuk berpartisipasi dalam proyek penelitian ini, rincian mengenai penelitian telah dijelaskan kepada saya dan saya telah diberikan sebuah lembar informasi tertulis untuk saya simpan.

Saya memahami bahwa partisipasi saya ini akan melibatkan sebuah interview dan saya setuju bahwa peneliti dapat menggunakan hasil-hasil penelitian sebagaimana dijelaskan pada lembar informasi.

Saya menerima bahwa:

- berpartisipasi dalam penelitian ini bersifat sukarela dan saya sadar bahwa saya dapat membatalkan untuk berpartisipasi kapan saja tanpa penjelasan atau prasangka apapun atau menarik segala data yang belum diproses yang telah saya berikan;

- informasi apapun yang saya berikan akan dijaga kerahasiaannya secara ketat dan bahwa tidak akan ada satu pun nama yang akan digunakan untuk mengidentifikasi saya dalam penelitian ini tanpa persetujuan saya;

(Silakan beri tanda petik sebagai tanda setuju)

Saya setuju untuk diwawancarai	☐ **Ya**	☐ **Tidak**
Saya setuju wawancara direkam	☐ **Ya**	☐ **Tidak**

Nama:	
Tanda tangan:	**Tanggal:**

LEMBAR INFORMASI

JUDUL PENELITIAN: **" Edukasi Kesehatan bagi Masyarakat yang Mengalami Diabetes Mellitus di Indonesia (*Providing Health Education for People Living with Diabetes Mellitus in Indonesia*)"**

Yang terhormat partisipan,
Kami mengajak anda untuk berpartisipasi dalam sebuah proyek penelitian yang akan mengidentifikasi pendidikan kesehatan bagi masyarakat yang mengalami diabetes mellitus. Tujuan dari penelitian ini adalah untuk mengembangkan sebuah teori mengenai proses pemberian edukasi kesehatan bagi masyarakat yang mengalami diabetes mellitus di Indonesia. Penelitian yang dilakukan oleh Titan Ligita ini akan berkontribusi terhadap program strata tiga, *Doctor of Philosophy*, pada James Cook University, Australia.

Jika anda setuju untuk terlibat dalam penelitian ini, Anda akan diwawancarai. Wawancara, tentunya dengan persetujuan Anda, akan direkam dan berlangsung selama kurang lebih satu jam. Wawancara akan dilakukan di rumah sakit, puskesmas, Prodi Keperawatan Universitas Tanjungpura atau di tempat yang sesuai dengan pilihan Anda. Tidak ada orang lain selain pewawancara yang akan hadir saat wawancara kecuali Anda menginginkan orang lain untuk menemani Anda disana.

Partisipasi Anda dalam penelitian ini sepenuhnya bersifat sukarela. Anda dapat berhenti untuk berpartisipasi setiap saat tanpa penjelasan atau prasangka apapun. Pilihan yang Anda buat ini tidak akan mempengaruhi studi Anda atau apapun yang terkait dengan evaluasi atau laporan mengenai diri Anda.

Respon dan rincian informasi mengenai Anda akan bersifat sangat rahasia. Tidak ada orang lain selain para supervisor saya dan saya yang akan mengakses informasi yang didokumentasikan selama wawancara. Dokumen berupa rekaman informasi tersebut bersifat rahasia dan akan dimusnahkan setelah lima (5) tahun. Hasil penelitian secara keseluruhan akan dipublikasikan pada jurnal-jurnal Keperawatan internasional dan akan disampaikan pada seminar-seminar ataupun konferensi-konferensi Keperawatan internasional. Anda dan institusi Anda tidak akan diketahui dengan cara apapun pada publikasi tersebut.

Jika Anda memiliki pertanyaan mengenai penelitian ini, silakan menghubungi Titan Ligita dan Dr. Kristin Wicking.

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Telepon: (07) 4781 5011
Email: ethics@jcu.edu.au

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PENELITI UTAMA : Titan Ligita
JUDUL PENELITIAN: Edukasi Kesehatan bagi Masyarakat yang Mengalami Diabetes Mellitus di Indonesia *(Providing Health Education for People Living with Diabetes Mellitus in Indonesia)*
JURUSAN: Healthcare Sciences (Nursing)

Saya memahami tujuan dalam penelitian ini adalah untuk mengembangkan sebuah teori mengenai pemberian edukasi kesehatan bagi masyarakat yang mengalami diabetes mellitus di Indonesia. Saya setuju untuk berpartisipasi dalam proyek penelitian ini, rincian mengenai penelitian telah dijelaskan kepada saya dan saya telah diberikan sebuah lembar informasi tertulis untuk saya simpan.

Saya memahami bahwa partisipasi saya ini akan melibatkan sebuah interview dan saya setuju bahwa peneliti dapat menggunakan hasil-hasil penelitian sebagaimana dijelaskan pada lembar informasi.

Saya menerima bahwa:

- berpartisipasi dalam penelitian ini bersifat sukarela dan saya sadar bahwa saya dapat membatalkan untuk berpartisipasi kapan saja tanpa penjelasan atau prasangka apapun atau menarik segala data yang belum diproses yang telah saya berikan;

- informasi apapun yang saya berikan akan dijaga kerahasiaannya secara ketat dan bahwa tidak akan ada satu pun nama yang akan digunakan untuk mengidentifikasi saya dalam penelitian ini tanpa persetujuan saya;

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Saya setuju untuk diwawancarai	☐ **Ya**	☐ **Tidak**
Saya setuju wawancara direkam	☐ **Ya**	☐ **Tidak**

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Tanda tangan:	**Tanggal:**

Appendix E

Questions for the Interviews

(For Health Professionals)

For Grounded Theory interviewing, I will begin with a 'grand tour' question and then ask additional clarifying and probing questions, to further explore aspects that participants have mentioned, and to allow the participant to lead the initial conversation (Glaser, 1998).

Grand Tour questions:

1. Please tell me about your experiences in providing health education to people with diabetes here in Indonesia.
2. Please describe any factors that facilitated your provision of health education for people with diabetes.
3. Please describe any factors that hindered your provision of health education for people with diabetes

If topics addressed by the sub-questions of the research aim have not been mentioned by the participant in the course of the conversation generated by the grand tour questions, I may then ask additional clarifying or probing questions, such as the ones below:

1. How long have you worked here?
2. How important do you think it is to provide health education for patients with diabetes?
3. Can you explain why you think providing health education is important?
4. Who do you think is responsible for providing health education for patients with diabetes?
5. Please explain what information you provided for them?
6. When do you usually provide health education for people with diabetes?
7. Please describe where you usually provide health education?

Questions for the Interviews

(For People with Diabetes)

These are the lists of Grand Tour Questions I will ask to the participants.

1. Please tell me about your experiences in receiving health education regarding your diabetes condition.
2. Please describe how you felt after receiving that health education.
3. Please explain anything that helped or prevented you from engaging in that health education.

If topics addressed by the sub-questions of the research aim have not been mentioned by the participant in the course of the conversation generated by the grand tour questions, I may then ask additional clarifying or probing questions, such as the ones below:

1. How long have you had diabetes?
2. How often do you go to the health facility?
3. How important do you think it is to be given information regarding your diabetes?
4. When did you first think that obtaining information for your diabetes would be important?
5. Please describe types of information you received regarding diabetes.
6. Who provided you with information about diabetes?
7. Where was the information provided to you?

Appendix F

Modified Questions for further Data Collection

Questions for the Interviews

(For Patients' Families)

For Grounded Theory interviewing, I will begin with a 'grand tour' question and then ask additional clarifying and probing questions, to further explore aspects that participants have mentioned, and to allow the participant to lead the initial conversation (Glaser, 1998).

Grand Tour questions:

1. Please tell me about your experiences in taking care of your relative with diabetes.
2. Please describe anything you do in relation to how your relative learns about his/her diabetes.
3. Please explain anything you do in relation to your relative's diabetes management at home.

If topics addressed by the sub-questions of the research aim have not been mentioned by the participant in the course of the conversation generated by the grand tour questions, I may then ask additional clarifying or probing questions, such as the ones below:

1. How long have you taken care of your relative with diabetes?
2. How often do you accompany your relative to the health clinic?
3. How far do you know about your relative's diabetes condition? How do you know?
4. What do you usually do when your relative do not obey the regimen or forget the regimen?
5. What do you do at home in relation to your relative's diabetes?

Questions for the Interviews

(For Exercise Instructor)

For Grounded Theory interviewing, I will begin with a 'grand tour' question and then ask additional clarifying and probing questions, to further explore aspects that participants have mentioned, and to allow the participant to lead the initial conversation (Glaser, 1998).

Grand Tour questions:

1. Please tell me about your experiences in providing health education to people with diabetes here in Indonesia.
2. Please describe any factors that facilitated your provision of health education for people with diabetes.
3. Please describe any factors that hindered your provision of health education for people with diabetes

If topics addressed by the sub-questions of the research aim have not been mentioned by the participant in the course of the conversation generated by the grand tour questions, I may then ask additional clarifying or probing questions, such as the ones below:

1. How long have you been as an exercise instructor here?
2. How important do you think it is to provide health education for patients with diabetes?
3. Can you explain why you think providing health education is important?
4. Who do you think is responsible for providing health education for patients with diabetes?
5. Please explain what information you provided for them?
6. When do you usually provide health education for people with diabetes?
7. Please describe where you usually provide health education?

Questions for the Interviews

(For Administrative Person)

For Grounded Theory interviewing, I will begin with a 'grand tour' question and then ask additional clarifying and probing questions, to further explore aspects that participants have mentioned, and to allow the participant to lead the initial conversation (Glaser, 1998).

Grand Tour questions:

1. Please tell me about your experiences in managing health education provision for people with diabetes here.
2. Please describe any factors that facilitated your management in the provision of health education for people with diabetes.
3. Please describe any factors that hindered your management in the provision of health education for people with diabetes

If topics addressed by the sub-questions of the research aim have not been mentioned by the participant in the course of the conversation generated by the grand tour questions, I may then ask additional clarifying or probing questions, such as the ones below:

1. How long have you worked to manage health education for people with diabetes here?
2. How important do you think it is to provide health education for patients with diabetes?
3. Can you explain why you think providing health education is important?
4. Who do you think is responsible for providing health education for patients with diabetes?
5. When does the provision of health education for people with diabetes usually occur?
6. Please describe where is the provision of health education given?

Questions for the Interviews

(For Students)

For Grounded Theory interviewing, I will begin with a 'grand tour' question and then ask additional clarifying and probing questions, to further explore aspects that participants have mentioned, and to allow the participant to lead the initial conversation (Glaser, 1998).

Grand Tour questions:

1. Please tell me about your experiences in providing health education to people with diabetes here in Indonesia.
2. Please describe any factors that facilitated your provision of health education for people with diabetes.
3. Please describe any factors that hindered your provision of health education for people with diabetes

If topics addressed by the sub-questions of the research aim have not been mentioned by the participant in the course of the conversation generated by the grand tour questions, I may then ask additional clarifying or probing questions, such as the ones below:

1. How long have you been as a nurse student?
2. How important do you think it is to provide health education for patients with diabetes?
3. Can you explain why you think providing health education is important?
4. Please explain what information you provided for them?
5. When do you usually provide health education for people with diabetes?
6. Please describe where you usually provide health education?

Questions for the Interviews

(For *Kader*)

For Grounded Theory interviewing, I will begin with a 'grand tour' question and then ask additional clarifying and probing questions, to further explore aspects that participants have mentioned, and to allow the participant to lead the initial conversation (Glaser, 1998).

Grand Tour questions:

1. Please tell me about your experiences in providing health education to people with diabetes here in Indonesia.
2. Please describe any factors that facilitated your provision of health education for people with diabetes.
3. Please describe any factors that hindered your provision of health education for people with diabetes

If topics addressed by the sub-questions of the research aim have not been mentioned by the participant in the course of the conversation generated by the grand tour questions, I may then ask additional clarifying or probing questions, such as the ones below:

1. How long have you been a volunteer here?
2. How important do you think it is to provide health education for patients with diabetes?
3. Can you explain why you think providing health education is important?
4. Who do you think is responsible for providing health education for patients with diabetes?
5. Please explain what information you provided for them?
6. When do you usually provide health education for people with diabetes?
7. Please describe where you usually provide health education?

Appendix G

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Appendix H

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Appendix I

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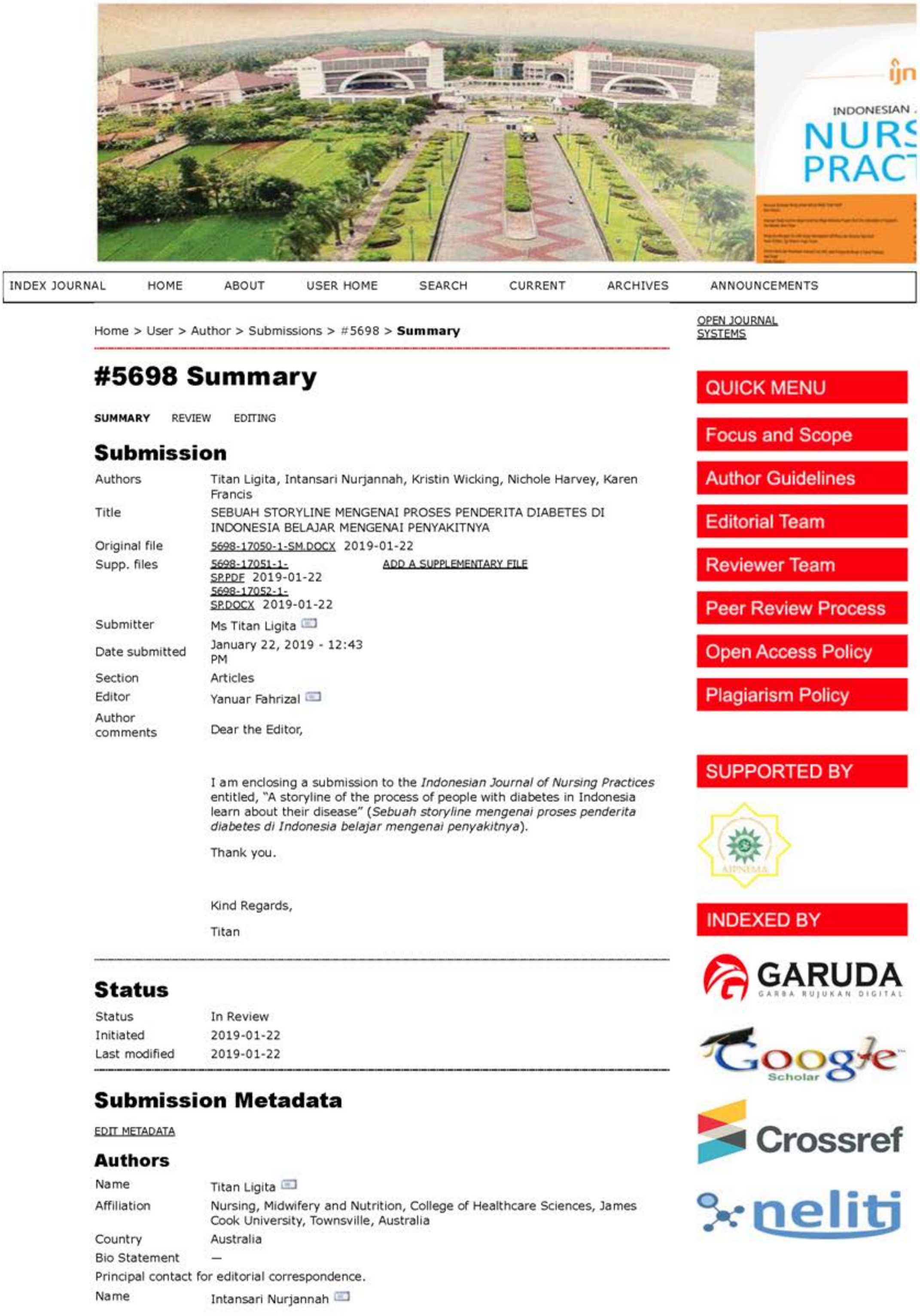

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#5698 Summary

SUMMARY REVIEW EDITING

Submission

Authors	Titan Ligita, Intansari Nurjannah, Kristin Wicking, Nichole Harvey, Karen Francis
Title	SEBUAH STORYLINE MENGENAI PROSES PENDERITA DIABETES DI INDONESIA BELAJAR MENGENAI PENYAKITNYA
Original file	5698-17050-1-SM.DOCX 2019-01-22
Supp. files	5698-17051-1-SP.PDF 2019-01-22 5698-17052-1-SP.DOCX 2019-01-22 ADD A SUPPLEMENTARY FILE
Submitter	Ms Titan Ligita
Date submitted	January 22, 2019 - 12:43 PM
Section	Articles
Editor	Yanuar Fahrizal
Author comments	Dear the Editor,

I am enclosing a submission to the *Indonesian Journal of Nursing Practices* entitled, "A storyline of the process of people with diabetes in Indonesia learn about their disease" (*Sebuah storyline mengenai proses penderita diabetes di Indonesia belajar mengenai penyakitnya*).

Thank you.

Kind Regards,

Titan

Status

Status	In Review
Initiated	2019-01-22
Last modified	2019-01-22

Submission Metadata

EDIT METADATA

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Name	Titan Ligita
Affiliation	Nursing, Midwifery and Nutrition, College of Healthcare Sciences, James Cook University, Townsville, Australia
Country	Australia
Bio Statement	—

Principal contact for editorial correspondence.

Name	Intansari Nurjannah

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Affiliation	School of Nursing, Universitas Gadjahmada, Yogyakarta, Indonesia
Country	Indonesia
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Name	Kristin Wicking
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Bio Statement	—
Name	Nichole Harvey
Affiliation	Medicine, College of Medicine and Dentistry, James Cook University, Townsville, Australia
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Bio Statement	—
Name	Karen Francis
Affiliation	School of Health Sciences, College of Health and Medicine, University of Tasmania, Launceston, Australia
Country	Australia
Bio Statement	—

Title and Abstract

Title	SEBUAH STORYLINE MENGENAI PROSES PENDERITA DIABETES DI INDONESIA BELAJAR MENGENAI PENYAKITNYA
Abstract	Edukasi diabetes bermanfaat pada perbaikan dalam pengelolaan diabetes secara mandiri serta peningkatan pengendalian kadar gula darahnya. Tetapi, sampai dengan saat ini belum terdapat penelitian dan publikasi mengenai proses bagaimana penderita diabetes di Indonesia belajar tentang penyakitnya. Studi penelitian ini bertujuan untuk memahami lebih baik proses ini melalui metodologi grounded theory. Wawancara dilakukan kepada 26 partisipan dan hasil penelitian menunjukan pengembangan sebuah teori "Learning, choosing, and acting: self-management of diabetes in Indonesia" yang merupakan proses penderita diabetes mempelajari tentang penyakitnya, yang bersifat siklus dan linier. Sebuah storyline digunakan untuk menjelaskan teori mengenai proses belajar, memilih dan bertindak dalam manajemen diri diabetes ini. Rekomendasi ditekankan pada perbaikan dalam memberikan edukasi pada penderita diabetes.

Indexing

Keywords	diabetes; grounded theory; manajemen diri; proses belajar; storyline.
Language	en

Supporting Agencies

Agencies	Department of Foreign Affairs and Trade Australian Government

References

References

Australian College of Nursing. (2014). Person-centred care. Retrieved 14 February 2018, from https://www.acn.edu.au/sites/default/files/advocacy/submissions/PS_Person-centered_Care_C2.pdf

Beauchamp, T. L., & Childress, J. F. (2001). Principles of biomedical ethics (Vol. 5th). New York, N.Y: Oxford University Press.

Beauchamp, T. L., & Childress, J. F. (2009). Principles of biomedical ethics (Vol. 6th). New York: Oxford University Press.

Beauchamp, T. L., & Childress, J. F. (2013). Principles of biomedical ethics (Vol. Seventhition.). New York: Oxford University Press.

Birks, M. (2014). Practical philosophy. In J. Mills & M. Birks (Eds.), Qualitative methodology: A practical guide. Thousand Oaks, CA; London: SAGE.

Birks, M., & Mills, J. (2015). Grounded theory: a practical guide. Thousand Oaks, CA: SAGE.

Author and Others. (2009) Details Withheld for Peer Review.

Caballero, A. E. (2007). Cultural Competence in Diabetes Mellitus Care: An Urgent Need. Insulin, 2(2), 80-91. doi: 10.1016/S1557-0843(07)80019-4
Charmaz, K. (2006). Constructing grounded theory: a practical guide through qualitative analysis. London: SAGE.

Corbin, J. M., & Strauss, A. L. (2008). Basics of qualitative research: techniques and procedures for developing grounded theory. Los Angeles: Sage Publications, Inc.

Crangle, C. E., Bradley, C., Carlin, P. F., Esterhay, R. J., Harper, R., Kearney, P. M., . . . Savage, E. (2017). Soliciting and responding to patients' questions about diabetes through online sources. Diabetes technology & therapeutics, 19(3), 194-199. doi: 10.1089/dia.2016.0291

Creswell, J. W. (2013). Qualitative inquiry and research design: choosing among five approaches. Thousand Oaks, Calif: SAGE Publications.

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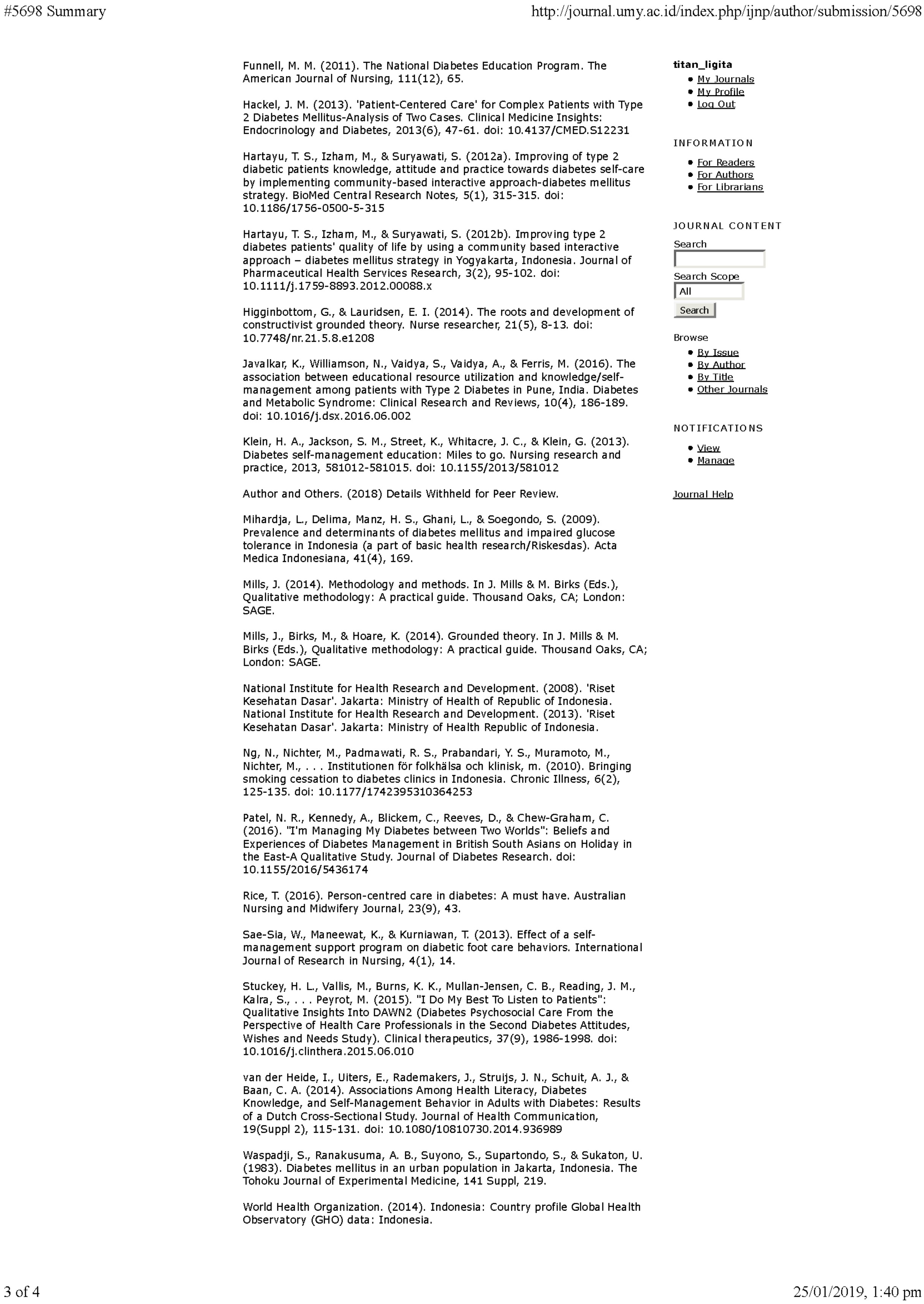

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Funnell, M. M. (2011). The National Diabetes Education Program. The American Journal of Nursing, 111(12), 65.

Hackel, J. M. (2013). 'Patient-Centered Care' for Complex Patients with Type 2 Diabetes Mellitus-Analysis of Two Cases. Clinical Medicine Insights: Endocrinology and Diabetes, 2013(6), 47-61. doi: 10.4137/CMED.S12231

Hartayu, T. S., Izham, M., & Suryawati, S. (2012a). Improving of type 2 diabetic patients knowledge, attitude and practice towards diabetes self-care by implementing community-based interactive approach-diabetes mellitus strategy. BioMed Central Research Notes, 5(1), 315-315. doi: 10.1186/1756-0500-5-315

Hartayu, T. S., Izham, M., & Suryawati, S. (2012b). Improving type 2 diabetes patients' quality of life by using a community based interactive approach – diabetes mellitus strategy in Yogyakarta, Indonesia. Journal of Pharmaceutical Health Services Research, 3(2), 95-102. doi: 10.1111/j.1759-8893.2012.00088.x

Higginbottom, G., & Lauridsen, E. I. (2014). The roots and development of constructivist grounded theory. Nurse researcher, 21(5), 8-13. doi: 10.7748/nr.21.5.8.e1208

Javalkar, K., Williamson, N., Vaidya, S., Vaidya, A., & Ferris, M. (2016). The association between educational resource utilization and knowledge/self-management among patients with Type 2 Diabetes in Pune, India. Diabetes and Metabolic Syndrome: Clinical Research and Reviews, 10(4), 186-189. doi: 10.1016/j.dsx.2016.06.002

Klein, H. A., Jackson, S. M., Street, K., Whitacre, J. C., & Klein, G. (2013). Diabetes self-management education: Miles to go. Nursing research and practice, 2013, 581012-581015. doi: 10.1155/2013/581012

Author and Others. (2018) Details Withheld for Peer Review.

Mihardja, L., Delima, Manz, H. S., Ghani, L., & Soegondo, S. (2009). Prevalence and determinants of diabetes mellitus and impaired glucose tolerance in Indonesia (a part of basic health research/Riskesdas). Acta Medica Indonesiana, 41(4), 169.

Mills, J. (2014). Methodology and methods. In J. Mills & M. Birks (Eds.), Qualitative methodology: A practical guide. Thousand Oaks, CA; London: SAGE.

Mills, J., Birks, M., & Hoare, K. (2014). Grounded theory. In J. Mills & M. Birks (Eds.), Qualitative methodology: A practical guide. Thousand Oaks, CA; London: SAGE.

National Institute for Health Research and Development. (2008). 'Riset Kesehatan Dasar'. Jakarta: Ministry of Health of Republic of Indonesia. National Institute for Health Research and Development. (2013). 'Riset Kesehatan Dasar'. Jakarta: Ministry of Health Republic of Indonesia.

Ng, N., Nichter, M., Padmawati, R. S., Prabandari, Y. S., Muramoto, M., Nichter, M., . . . Institutionen för folkhälsa och klinisk, m. (2010). Bringing smoking cessation to diabetes clinics in Indonesia. Chronic Illness, 6(2), 125-135. doi: 10.1177/1742395310364253

Patel, N. R., Kennedy, A., Blickem, C., Reeves, D., & Chew-Graham, C. (2016). "I'm Managing My Diabetes between Two Worlds": Beliefs and Experiences of Diabetes Management in British South Asians on Holiday in the East-A Qualitative Study. Journal of Diabetes Research. doi: 10.1155/2016/5436174

Rice, T. (2016). Person-centred care in diabetes: A must have. Australian Nursing and Midwifery Journal, 23(9), 43.

Sae-Sia, W., Maneewat, K., & Kurniawan, T. (2013). Effect of a self-management support program on diabetic foot care behaviors. International Journal of Research in Nursing, 4(1), 14.

Stuckey, H. L., Vallis, M., Burns, K. K., Mullan-Jensen, C. B., Reading, J. M., Kalra, S., . . . Peyrot, M. (2015). "I Do My Best To Listen to Patients": Qualitative Insights Into DAWN2 (Diabetes Psychosocial Care From the Perspective of Health Care Professionals in the Second Diabetes Attitudes, Wishes and Needs Study). Clinical therapeutics, 37(9), 1986-1998. doi: 10.1016/j.clinthera.2015.06.010

van der Heide, I., Uiters, E., Rademakers, J., Struijs, J. N., Schuit, A. J., & Baan, C. A. (2014). Associations Among Health Literacy, Diabetes Knowledge, and Self-Management Behavior in Adults with Diabetes: Results of a Dutch Cross-Sectional Study. Journal of Health Communication, 19(Suppl 2), 115-131. doi: 10.1080/10810730.2014.936989

Waspadji, S., Ranakusuma, A. B., Suyono, S., Supartondo, S., & Sukaton, U. (1983). Diabetes mellitus in an urban population in Jakarta, Indonesia. The Tohoku Journal of Experimental Medicine, 141 Suppl, 219.

World Health Organization. (2014). Indonesia: Country profile Global Health Observatory (GHO) data: Indonesia.

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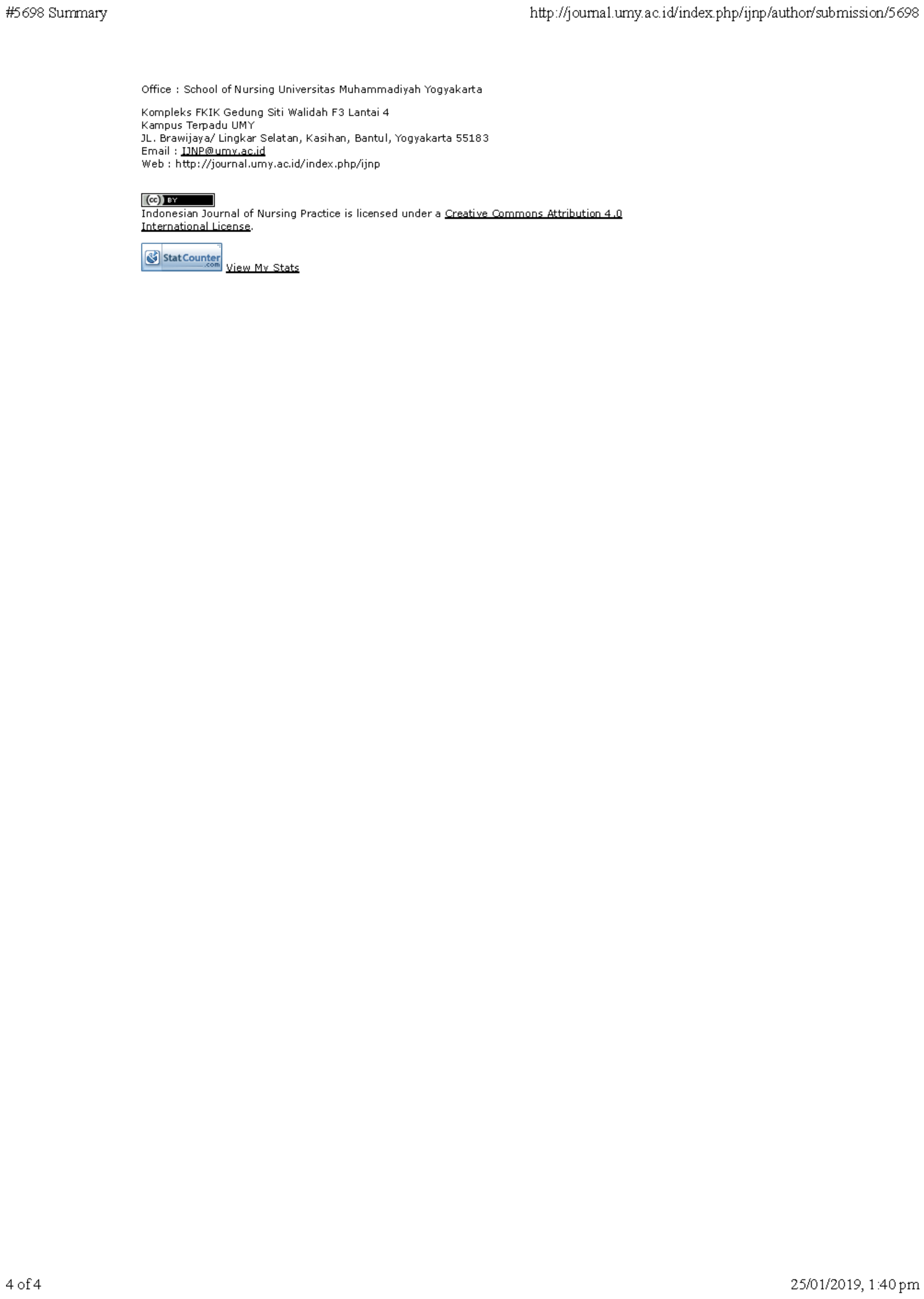

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SEBUAH *STORYLINE* MENGENAI PROSES PENDERITA DIABETES DI INDONESIA BELAJAR MENGENAI PENYAKITNYA

A STORYLINE OF THE PROCESS OF PEOPLE WITH DIABETES IN INDONESIA LEARN ABOUT THEIR DISEASE

Abstract

Diabetes education is beneficial to enhance both knowledge and attitudes towards self-care management and glycemic control improvement. However, little is known about the process of how people with diabetes in Indonesia receive and engage in education that promotes their health. The aim of this study was to better understand this process using grounded theory methodology. Twenty-six participants were interviewed and the results showed a cyclic and dynamic process that lead to the development of a theory entitled Learning, choosing, and acting: self-management of diabetes in Indonesia. *This theory will be explicated using a storyline, along with recommendations to help improve the provision of diabetes education.*

Keywords: diabetes, grounded theory, learning process, self-management, storyline.

Abstrak

Edukasi diabetes bermanfaat pada perbaikan dalam pengelolaan diabetes secara mandiri serta peningkatan pengendalian kadar gula darahnya. Tetapi, sampai dengan saat ini belum terdapat penelitian dan publikasi mengenai proses bagaimana penderita diabetes di Indonesia belajar tentang penyakitnya. Studi penelitian ini bertujuan untuk memahami lebih baik proses ini melalui metodologi grounded theory. Wawancara dilakukan kepada 26 partisipan dan hasil penelitian menunjukan pengembangan sebuah teori "Learning, choosing, and acting: self-management of diabetes in Indonesia" yang merupakan proses penderita diabetes mempelajari tentang penyakitnya, yang bersifat siklus dan linier. Sebuah storyline digunakan untuk menjelaskan teori mengenai proses belajar, memilih dan bertindak dalam manajemen diri diabetes ini. Rekomendasi ditekankan pada perbaikan dalam memberikan edukasi pada penderita diabetes.

Kata Kunci: diabetes, grounded theory, manajemen diri, proses belajar, storyline.

PENDAHULUAN

Diabetes menempati empat besar penyakit tidak menular di Indonesia dengan prevalensi rata-rata yang semakin meningkat (World Health Organization, 2014) dan sejak tahun 1980an, penyakit kronis ini sudah menjadi isu permasalahan yang mengkhawatirkan (Waspadji et al., 1983). Data dari hasil riset kesehatan terkini dalam lingkup nasional menunjukkan peningkatan prevalensi diabetes. Prevalensi diabetes pada populasi penduduk perkotaan tercatat sebesar dari 5.7% dan dalam periode 5 tahun, terdapat peningkatan proporsi diabetes pada populasi penduduk perkotaan dan pedesaan menjadi 6.9%(Mihardja et al., 2009; National Institute for Health Research and Development, 2008, 2013).

Berbagai strategi dilakukan untuk menangani penyakit diabetes melalui pengelolaan diabetes yang tepat, di antaranya adalah melalui pengobatan, pengelolaan diet, olahraga, pemantauan kadar gula darah serta pemberian edukasi. Penderita dituntut pula untuk paham apa tujuan dan bagaimana cara melakukan manajemen diabetes tersebut sehingga mereka dapat mempraktekkan manajemen diabetes tersebut dengan benar. Penderita yang memperoleh informasi yang benar baik secara formal melalui edukasi diabetes maupun informal melalui penyebaran informasi dari orang lain akan mempengaruhi bagaimana mereka memutuskan manajemen diabetes yang tepat bagi dirinya.

Edukasi yang diberikan kepada penderita diabetes menunjukkan hasil yang positif terhadap kondisi pasien, salah satunya adalah dengan bukti adanya perbaikan kadar gula darah penderita. Tetapi, karena penderita diabetes mengalami penyakit sepanjang kehidupannya, mereka membutuhkan dukungan yang berkelanjutan (Funnell, 2011). Seringnya, edukasi yang diberikan tidak memadai sehingga penderita sulit mempertahankan perilaku yang positif. Perawat yang merupakan salah satu tenaga kesehatan yang berinteraksi intensif dengan penderita akan dapat memberikan dukungan yang berkelanjutan melalui edukasi kepada penderita, dimana perawat menunjukkan sumber daya yang membantu penderita dalam mengubah perilaku dan menunjukkan mekanisme pemecahan masalah yang baik (Funnell, 2011). Salah satu contoh bagaimana perawat dapat membantu penderita diabetes adalah dengan cara menyediakan sumber informasi yang benar (misalnya secara *online*) dari sumber yang terpercaya seperti situs web *National Diabetes Education Program* (NDEP) (Funnell, 2011).

Beberapa studi telah dilakukan untuk meneliti mengenai program-program pendidikan diabetes yang diberikan kepada penderita diabetes di Indonesia dengan tujuan untuk menilai kemampuan pasien dalam manajemen perawatan diri (Hartayu et al., 2012a, 2012b; Ng et al., 2010; Sae-Sia et al., 2013). Adapun strategi yang ditawarkan melalui penelitian tersebut adalah dengan memberikan pendidikan bagi penderita diabetes melalui dukungan, nasihat dan/atau pendekatan interaktif. Hasil akhir yang dapat dicapai melalui edukasi diabetes ini adalah perilaku perawatan diri yang positif, peningkatan pengetahuan mengenai perawatan diri dan kepatuhan terhadap manajemen perawatan diri pada diabetes. Akan tetapi, pencapaian yang positif melalui program edukasi diabetes yang dievaluasi melalui penelitian tersebut belum menunjukkan pemahaman yang mendalam mengenai proses pemberian edukasi kesehatan bagi penderita diabetes terutama dalam konteks yang terjadi di Indonesia. Studi yang pernah ada pun tidak memberikan perhatian terhadap siapa saja yang terlibat dalam pembelajaran penderita diabetes melalui edukasi kesehatan terkait penyakitnya. Tidak hanya itu, sebagian besar penelitian yang dilakukan tersebut tidak meneliti tentang peran tenaga kesehatan, khususnya perawat, dalam memberikan pendidikan diabetes (Hartayu et al., 2012a, 2012b; Ng et al., 2010).

Efektifitas edukasi diabetes yang diidentifikasi dari beberapa studi tidak menunjukkan secara jelas proses pembelajaran yang dilakukan oleh penderita diabetes melalui informasi yang mereka dapatkan dari edukasi diabetes tersebut. Proses bagaimana pasien mempelajari penyakitnya sangat penting dalam meningkatkan edukasi yang efisien dan efektif bagi penderita diabetes. Maka dari itu melalui studi *grounded theory*, kami melakukan sebuah penelitian mengenai proses bagaimana penderita diabetes di Indonesia belajar mengenai penyakitnya. Pertanyaan umum penelitian pada studi ini adalah bagaimana proses penderita diabetes di Indonesia mempelajari tentang penyakitnya.

METODE PENELITIAN

Tujuan

Penelitian ini bertujuan untuk menjelaskan proses sosial dasar yang digunakan penderita diabetes di Indonesia untuk belajar mengenai penyakitnya, termasuk di dalamnya proses di mana penderita diabetes menerima edukasi kesehatan yang terkait dengan diabetes. Faktor penghambat dan pendukung dalam pemberian pendidikan kesehatan bagi masyarakat dengan diabetes ini akan diidentifikasi sebagai bagian dari proses tersebut. Hasil dari mengetahui proses ini, diharapkan akan memberikan arahan pada pembuat kebijakan dan praktisi kesehatan terutama perawat dapat mengembangkan strategi yang kreatif melalui pemberiaan edukasi kesehatan yang lebih baik kepada penderita diabetes sehingga penderita dapat memilih dan menerapkan terapi dengan benar dan sesuai.

Desain

Penelitian ini menggunakan pendekatan kualitatif dengan metodologi *grounded theory* sebagai rancangan penelitian. Tujuan penelitian yang sesuai dapat membantu peneliti memilih rancangan penelitian yang sesuai (Mills, 2014). *Grounded theory* merupakan rancangan penelitian yang dianggap sangat cocok bagi pertanyaan penelitian yang ingin mengetahui sebuah "proses". Penelitian *Grounded theory* menghasilkan sebuah teori yang dikembangkan dari proses pengumpulan data dan analisis data yang terjadi secara bersamaan atau dikenal dengan istilah *concurrent data collection and analysis* (Charmaz, 2006; Corbin & Strauss, 2008; Creswell, 2013), dimana proses analisis data dilakukan pada setiap data yang dikumpulkan (misalnya melalui wawancara) sebelum peneliti mulai melakukan wawancara selanjutnya. Berdasarkan hasil proses analisis data ini, peneliti akan menentukan data tambahan apa saja yang perlu dikumpulkan melalui wawancara, yang dikenal dengan istilah *theoretical sampling*. *Grounded theory* adalah pilihan yang tepat dilakukan bagi sebuah topik yang tidak memiliki bukti yang memadai mengenainya dan dengan demikian diperlukan pemahaman dan pengetahuan yang lebih mendalam mengenai fenomena terkait (Mills et al., 2014).

Peneliti dalam penelitian ini menggunakan seperangkat prinsip *grounded theory* yang dipengaruhi oleh filosofi *constructivism* dan *symbolic interactionism*. Penelitian grounded theory memberikan perhatian pada pentingnya mengetahui posisi filosofis peneliti dalam penelitian kualitatif, karena para peneliti akan secara efektif menggunakan rancangan penelitian yang sesuai sehingga dapat mencerminkan sudut pandang mereka mengenai kenyataan/realitas dan metodologi penelitian yang mereka terapkan (Birks, 2014). Secara metodologi, penggunaan *constructivism* yang didukung oleh *symbolic interactionism* pada peneltitian *grounded theory* telah populer di kalangan peneliti perawat karena desain ini memungkinkan mereka untuk memahami sikap dan pengalaman partisipan serta mengeksplorasi proses yang digunakan dalam memberikan pelayanan kesehatan (Higginbottom & Lauridsen, 2014).

Method

Studi penelitian ini menggunakan langkah-langkah penting yang seharusnya dilakukan dalam sebuah penelitian grounded theory, seperti misalnya *purposive sampling method, theoretical sampling method, concurrent data collection/generation and analysis, constant comparative analysis, coding processes, theoretical saturation, theoretical sensitivity* dan *memo writing* (Birks & Mills, 2015). Hal ini dilakukan untuk memastikan kecermatan dan kualitas penelitian dengan pendekatan kualitatif ini.

Penelitian ini dilakukan melalui tiga tahapan pengambilan data. Penelitian tahap pertama dan kedua dilakukan melalui wawancara secara tatap muka dengan 24 partisipan, sedangkan penelitian tahap ketiga dilakukan melalui telepon pada empat orang partisipan. Selain teknik *purposive sampling* dan *theoretical sampling*, teknik *snowballing sampling* juga digunakan untuk memperoleh informasi mengenai partisipan berikutnya dari partisipan sebelumnya, terutama pada saat pengumpulan data pada tahapan ketiga. Partisipan yang terlibat dalam penelitian ini terdiri dari penderita diabetes, keluarga penderita diabetes, perawat, dokter, ahli gizi, apoteker, mahasiswa keperawatan, kader, staf pomosi kesehatan rumah sakit dan instruktur senam. Saat wawancara, partisipan diberikan pertanyaan-pertanyaan terbuka yang dapat mengungkapkan pengalaman partisipan atau informasi lainnya yang tidak pernah dipikirkan sebelumnya oleh peneliti (Charmaz, 2006).

Proses pengambilan data dilakukan secara bersamaan dengan analisis data dan istilah ini disebut dengan *concurrent data collection and analysis*.

Penelitian ini melewati tiga tahapan coding dalam menganalisa data, yaitu *initial coding, intermediate coding* dan *advanced coding*. Adapun teknik di dalam menganalisa data hasil wawancara tersebut menggunakan *constant comparative data analysis,* dimana data hasil penelitian yang berupa kode, kategori dan sub-kategori dibandingkan satu sama lain dan teknik analisis tersebut digunakan untuk membantu peneliti dalam meningkatkan derajat abstraksi dari data yang dikumpulkan (Birks & Mills, 2015).

Etika penelitian

Sebelum melakukan pengambilan data, penelitian ini sudah memperoleh dua persetujuan penelitian dari James Cook University Australia (H6445) dan Fakultas Ilmu Keperawatan Universitas Indonesia (0367/UN2.F12.D/HKP.02.04/2016). Empat aspek utama yang perlu dipertimbangkan dalam penelitian ini adalah *respect for autonomy* dan *confidentiality, non-maleficence, beneficence* dan *justice* (Beauchamp & Childress, 2001, 2009, 2013). Partisipasi dalam penelitian ini adalah sepenuhnya sukarela. Para partisipan dapat diperbolehkan untuk batal atau mengundurkan diri berpartisipasi dalam studi ini setiap saat tanpa penjelasan atau prasangka apapun. Pernyataan-pernyataan mengenai otonomi peserta dan kerahasiaan ini diberikan dalam lembar informasi (*information sheet*) dan lembar persetujuan penelitian (*informed consent*).

HASIL

Hasil penelitian pada penelitian ini dijelaskan dalam bentuk *storyline*. *Storyline* merupakan salah satu bagian/bentuk dari publikasi hasil penelitian pada studi yang menggunakan grounded theory sebagai rancangannya. Melalui *storyline*, teori yang dikembangkan dari sebuah penelitian, akan dijelaskan melalui sebuah narasi yang mempresentasikan hasil dari penelitian tersebut (Author et al., 2009). Author et al. (2009) menambahkan bahwa peneliti perlu menggunakan teknik *storyline* ini sebab teknik ini dapat digunakan sebagai alat analisis untuk menghasilkan teori yang terintegrasi dan berasal dari data, sehingga teori sebagai hasil akhir dari penelitian ini pun dapat disebarluaskan ke masyarakat luas dan pembaca.

Storyline

Berikut ini adalah *storyline* dari sebuah proses mengenai bagaimana penderita diabetes belajar mengenai penyakitnya melalui teori yang dinamakan *Learning, choosing, and acting: self-management of diabetes in Indonesia* atau 'Belajar, memilih dan bertindak: manajemen diri diabetes di Indonesia'. *Storyline* yang sudah diterjemahkan ke dalam Bahasa Indonesia ini merupakan bentuk sederhana dari *storyline* dalam versi berbahasa Inggris. Berikut adalah *storyline* dari hasil penelitian ini:

Mencari dan menerima informasi terkait diabetes (‘Seeking and receiving diabetes-related information’)

Individu-individu yang menderita diabetes belajar mengenai diabetes melalui dua cara: secara aktif mencari informasi dan secara pasif mendengarkan dan memperoleh bacaan mengenai informasi kesehatan yang disediakan tentang diabetes. Terdapat dua periode waktu yang penting dimana individu-individu yang menderita diabetes mulai mencari informasi kesehatan terkait diabetes untuk memahami penyakit diabetes yang mereka alami. Pertama, individu dengan diabetes secara aktif mencari informasi kesehatan mengenai kondisi mereka sebelum mereka didiagnosa, dimana mereka menyadari terjadinya perubahan yang pada tubuh mereka dan pada akhirnya mereka ingin mencari tahu apa yang sebenarnya sedang terjadi. Kedua, individu-individu yang menderita diabetes mulai mencari informasi secara aktif setelah mendapatkan konfirmasi bahwa ia mengalami diabetes yang di dapatkan melalui tes gula darah dan/atau setelah individu didiagnosa oleh dokter.

Pendekatan untuk bisa mendapatkan informasi ternyata bervariasi antara sebelum dan sesudah diagnosa diabetes tersebut ditegakkan. Mencari informasi secara aktif sebelum mereka didiagnosa diantaranya adalah dengan melakukan tes gula darah sendiri dan meminta informasi atau pendapat dari seorang dokter mengenai adanya perubahan pada tubuh yang telah mereka sadari. Sumber-sumber informasi kesehatan yang dicari secara aktif oleh individu-individu yang menderita diabetes tidak terbatas hanya pada tenaga kesehatan professional. Kerabat yang juga menderita diabetes, individu-individu lain yang dikenal, buku-buku dan internet merupakan sumber lain yang digunakan oleh penderita diabetes (untuk memperoleh informasi tersebut).

Individu-individu yang menderita diabetes secara pasif memperoleh informasi kesehatan dengan cara mendengarkan dan memperoleh bacaan pada saat mereka menerima edukasi kesehatan dan informasi dari sumber-sumber yang berbeda. Adapun sumber-sumber yang berbeda tersebut antara lain: tenaga kesehatan professional, kerabat, teman serta orang lain yang memiliki kerabat yang menderita diabetes. Sedangkan sumber informasi lainnya berupa media cetak, elektronik maupun audio-visual.

Memproses/mengolah informasi yang diterima (‘Processing received information’)

Bagi penderita diabetes, mencari informasi terkait diabetes merupakan titik awal untuk mulai memproses informasi terkait diabetes yang mereka terima. Pertama kali, mereka menyaring atau memilah informasi. Ada beberapa cara yang dilakukan untuk memilah informasi tersebut. Beberapa di antara mereka mengandalkan pengetahuan sebelumnya untuk menentukan efektifitas dari informasi atau rekomendasi yang ditawarkan. Kemudian mereka menggunakan pengalaman sebelumnya. Ada juga yang mengandalkan pendapat pribadi serta pendapat orang kedua yang mereka anggap ahli ataupun bersumber dari internet. Setelah mereka memilah, mereka kemudian memutuskan untuk percaya atau tidak mempercayai informasi yang mereka dapatkan itu. Dua hal yang mempengaruhi hal tersebut, yaitu keahlian dan pengalaman hidup si penyampai informasi. Setelah mereka percaya atau tidak percaya, hal yang dilakukan selanjutnya adalah memberikan respon terhadap informasi tersebut. Hampir sebagian besar informasi yang direspon adalah berupa rekomendasi, yang berasal dari tenaga kesehatan maupun orang lain yang bukan tenaga kesehatan professional. Bagi mereka yang tidak mempercayai informasi tersebut, dengan otomatis mereka mengabaikannya. Sedangkan informasi yang dalam hal ini berupa rekomendasi yang mereka percayai, terdapat dua hal yang mereka lakukan: mengikuti rekomendasi atau tidak mengikuti rekomendasi tersebut. Ini yang dinamakan kategori '*responding to recommendations*'.

Merespon atau menanggapi rekomendasi-rekomendasi ('Responding to recommendations')

Tiga faktor yang mempengaruhi bagaimana individu-individu dengan diabetes berespon terhadap informasi/rekomendasi yang mereka anggap benar adalah: faktor fisiologis atau fisik, faktor psikologis dan faktor sumber daya.

Faktor-faktor fisiologis meliputi peningkatan kadar gula darah, penurunan berat badan, timbulnya luka dan komplikasi yang memburuk (misalnya keadaan luka di kaki yang memburuk). Sementara itu, faktor-psikologis antara lain rasa takut terhadap efek samping pengobatan, rasa takut terhadap tindakan medikasi (contohnya penyuntikan), merasa cukup, merasa bingung ketika mereka mendapatkan informasi yang terlalu banyak dan pada saat mereka diminta untuk membuat pilihan terhadap berbagai intervensi yang ditawarkan, merasa putus harapan terhadap penyakit dan preferensi mereka sendiri. Faktor yang terakhir adalah adanya sumber daya yang dapat meningkatkan ataupun justru menghambat respon mereka terhadap informasi. Sumber daya yang terkait tersebut meliputi waktu, dana, pengetahuan yang dimiliki sebelumnya, lokasi geografis dan isu-isu terkait kemudahan dan kepraktisan (seperti adanya bahan-bahan herbal untuk membuat ramuan sendiri/rumahan).

Pada individu yang mengikuti rekomendasi dengan caranya sendiri, ada 4 (empat) pilihan yang mereka dapat lakukan:

- Menjalankan terapi konvensional secara utuh
- Menjalankan terapi konvensional secara parsial
- Menjalankan terapi non-konvensional
- Menjalankan terapi konvensional dan non-konvensional secara bersamaan

Manajemen diabetes yang ada saat ini mencakup pengobatan, berolahraga, mengelola diet dan pemantauan kadar gula darah. Meskipun penderita diabetes mengikuti rekomendasi tenaga kesehatan untuk mengelola diabetesnya, tidak semua orang mengikuti keempat rekomendasi untuk pengelolaan diabetes (pengobatan, pemantauan kadar gula darah, olahraga dan diet yang benar). Hal ini dipengaruhi oleh ketiga faktor- faktor yang telah disebutkan sebelumnya: fisik, psikologis dan sumber daya.

Meskipun pengelolaan manajemen diabetes secara mandiri sangat dianjurkan, bagaimanapun, tingkat kepatuhan masing-masing penderita bervariasi. Penerimaan informasi yang tidak lengkap dapat mempengaruhi seseorang dalam menerapkan rekomendasi pengelolaan diabetes mandiri. Misalnya, orang-orang yang menerima informasi yang tidak lengkap mengenai diet diabetes yang tepat bisa salah menafsirkan jumlah atau porsi makanan yang harus mereka konsumsi, yang pada akhirnya dapat kemudian mempengaruhi kadar gula darah mereka.

Bila penderita diabetes memilih untuk menggunakan terapi non-konvensional saja, mereka umumnya menggunakan ramuan tradisional atau herbal buatan sendiri secara oral, membeli dan mengkonsumsi produk herbal buatan pabrik dan / atau mengenakan sebuah alat di tubuh mereka. Akan tetapi efektivitas terapi tradisional atau terapi alternatif ini belum begitu jelas.

Terdapat penderita diabetes yang mengikuti terapi konvensional dan terapi non konvensional secara bersamaan. Mereka terkadang misalnya mengkonsumsi obat herbal dan terkadang memilih obat yang diresepkan. Terapi tersebut tidak dilakukan pada waktu (jam) yang bersamaan, akan tetapi dalam satu hari, penderita diabetes ini bisa mengkonsumsi kedua terapi tersebut. Ataupun, mereka menggunakan terapi yang berbeda pada hari yang berlainan.

Penderita diabetes yang memilih untuk tidak mengikuti rekomendasi termasuk rencana perawatan medis sering menganggap remeh tingkat keparahan penyakit diabetes mereka. Biasanya ini terjadi karena orang tersebut tidak memperhatikan kesehatan mereka sendiri dengan baik, sebaliknya mereka lebih sering membandingkan pengalaman kondisi mereka sendiri dengan orang lain yang juga menderita diabetes. Orang-orang ini sering menganggap orang lain memiliki penyakit diabetes yang lebih parah daripada diri mereka dan mereka menganggap diabetes yang mereka derita tidak separah orang lain tersebut.

Menilai hasil ('Appraising the results')

Setelah penderita diabetes membuat pilihan tentang rekomendasi mana yang akan mereka ikuti dalam pengelolaan diabetes mereka, mereka kemudian mengevaluasi hasilnya melalui '*appraising the result*' atau penilaian hasil. Tindakan atau respon yang mereka pilih atau tidak pilih tersebut, dievaluasi pada fase ini. 'Penilaian hasil' mencakup tiga elemen: 'pengukuran', 'kemajuan' dan 'tindakan selanjutnya'. Dalam pengukuran, mereka mempertimbangkan bagaimana perasaan mereka dan mereka pun mengamati perubahan yang terjadi pada tubuh mereka, baik secara subjektif maupun obyektif. Pengukuran secara subyektif pada perubahan tubuh mereka termasuk di antaranya mengukur perasaan nyaman atau tidak nyaman, melihat apakah penglihatan mereka jernih atau tidak, dan merasakan apakah mereka bertenaga. Sedangkan pengukuran secara obyektif meliputi pengamatan luka yang mengalami penyembuhan, pengukuran berat badan dan pengukuran kadar gula darah yang stabil.

Saat 'menilai hasilnya', penderita diabetes juga mempertimbangkan 'kemajuan' penerapan tindakan yang dipilih. Kemajuan terhadap tindakan penderita diabetes meliputi hasil yang positif dan negatif. Produk dari 'penilaian hasilnya' disebut '*experiential insight*' (wawasan/informasi yang diperoleh melalui sebuah pengalaman), yang mereka pelajari dari hasil mengevaluasi atau menilai respon mereka terhadap rekomendasi yang mereka terapkan. Penderita diabetes ini menggunakan wawasan mereka untuk membuat keputusan selanjutnya yaitu: berbagi wawasan mereka dengan orang lain atau menggunakan wawasan mereka tersebut sebagai sebuah informasi yang mereka terima melalui pengalaman mereka.

Bila penderita diabetes memproses wawasan pengalaman mereka untuk disaring sebagai informasi yang berdasarkan pengalaman, mereka dapat memutuskan untuk memilih atau tidak memilih untuk melanjutkan rekomendasi atau terapi yang mereka aplikasikan sebelumnya. Penderita diabetes yang memilih untuk menghentikan atau tidak mengikuti rekomendasi/terapi yang mereka terapkan, mereka kemudian memilih terapi lainnya, ataupun mereka mencari rekomendasi/terapi lain yang berbeda. Bila mereka percaya ada hasil positif baik yang diukur secara objektif maupun subyektif, mereka mempertahankan rekomendasi/terapi yang diterapkan karena itu dapat meningkatkan motivasi mereka untuk melanjutkannya. Ketika mereka merasa mendapati hasil yang negatif atau tidak adanya kemajuan dalam pengobatan atau terapi yang telah mereka terapkan, mereka menghentikan terapi tersebut dan mulai mengubah tindakan mereka; misalnya dengan mengikuti rekomendasi dari tenaga kesehatan atau mencari rekomendasi lainnya.

Berbagi dengan yang lain ('Sharing with others')

Pemahaman eksperiensial tidak hanya digunakan oleh penderita diabetes itu sendiri sebagai sebuah wawasan/informasi yang diperoleh berdasarkan pengalaman, tapi juga dibagikan kepada orang lain. Berbagi wawasan ini dengan orang lain biasanya terjadi karena penderita diabetes sudah mengalaminya sendiri. Terdapat berbagai hal untuk dibagikan dengan orang lain yaitu bagaimana mengenali gejala diabetes, manfaat manajemen diabetes dan bahkan kesalahan-kesalahan yang harus dihindari dalam pengelolaan perawatan diabetes. Sedangkan informasi itu dibagikan kepada yaitu penderita diabetes yang lain, anggota keluarga mereka sendiri baik yang menderita diabetes maupun tidak, dan orang lain yang memiliki anggota keluarga yang mengalami diabetes. Wawasan/informasi yang dibagikan dengan penderita diabetes dapat menjadi titik awal baginya untuk memulai proses 'belajar, memilih dan bertindak dalam manajemen diri diabetes'.

Keluarga memiliki peran penting bagi penderita diabetes. Mereka terlibat dalam keseluruhan fase penting dalam proses 'belajar, memilih dan bertindak dalam manajemen diri diabetes'. Maka dari itu, penderita diabetes tidak dapat dipisahkan dari keluarga mereka, dan dengan demikian pengaruh anggota keluarga mendukung orang-orang ini juga diidentifikasi pada proses 'belajar, memilih dan bertindak dalam manajemen diri diabetes'.

PEMBAHASAN

Saat seseorang didiagnosa sebagai penderita diabetes ataupun seseorang yang belum didiagnosa tetapi sudah merasakan gejala diabetes, ia kemudian merasa perlu mendapatkan informasi terkait dengan penyakitnya tersebut. Melalui proses yang dinamakan '*Learning, choosing, and acting: self-management of diabetes in Indonesia*', penderita diabetes mulai mencari informasi melalui sumber-sumber yang ia percayai dapat membantunya dalam melakukan perawatan, pengelolaan dan penanganan diabetes. Sumber-sumber tersebut tidak hanya berasal dari tenaga kesehatan professional seperti perawat, dokter, ahli gizi dan apoteker yang merupakan penyedia pelayanan kesehatan utama diabetes di Indonesia (Author et al., 2018), akan tetapi dapat berasal dari orang lain yang bukan tenaga kesehatan maupun melalui media informasi. Sumber informasi yang berasal dari tenaga kesehatan umumnya diberikan melalui pendidikan atau edukasi kesehatan seperti program edukasi pengelolaan diabetes secara mandiri. Sebagian besar program-program edukasi tersebut hanya berfokus pada aturan dan penatalaksaan yang memandu penderita di dalam mengelola diet dan olahraganya. Selain itu, program tersebut umumnya hanya dapat mengevaluasi pencapaian hasil dalam jangka waktu yang singkat saja karena penderita diabetes sangat sulit mempertahankan kondisi sehatnya dalam keadaan kronis (Klein et al., 2013). Penderita yang memiliki tingkat literasi kesehatan yang rendah ternyata berhubungan dengan rendahnya pengetahuan terhadap diabetes sehingga hal ini berpengaruh juga terhadap kurangnya kontrol mereka terhadap kadar gula darah serta kurangnya melakukan aktifitas fisik (van der Heide et al., 2014).

Tidak jarang penderita diabetes menggunakan terapi selain daripada terapi yang direkomendasikan oleh tenaga kesehatan profesional disebabkan oleh sangat bervariasinya sumber-sumber informasi yang mereka dapatkan tersebut. Penderita diabetes dapat memperoleh pengetahuan tentang diabetes dan belajar mengenai diabetes terutama tentang kondisi penyakitnya tersebut melalui buku-buku, brosur, surat kabar, majalah dan televisi, dimana sumber-sumber ini, menurut Javalkar et al. (2016) terkait dengan hasil indikator positif seperti penurunan kadar gula darah, pengetahuan dan pengelolaan diabetes mandirinya. Penderita diabetes pun dapat memperoleh dan mencari informasi secara *online*. Akan tetapi menurut studi Crangle et al. (2017) sumber informasi *online* umumnya tidak memberikan jawaban yang memadai terhadap pertanyaan-pertanyaan penderita diabetes mengenai penyakit diabetesnya tersebut. Tidak jarang penderita diabetes pun memanfaatkan jaringan sosial (*social network*), seperti anggota keluarga dan orang lain di sebuah komunitas tertentu (misal komunitas muslim), sebagai sumber informasi dan saran serta dukungan dalam pengelolaan diabetesnya (Patel et al., 2016).

Penderita diabetes perlu mendapatkan dukungan psikososial di dalam mengelola diabetesnya dan aspek psikososial ini ternyata sangat kurang diberikan sehingga menjadi penghalang dalam pemberian perawatan diabetes yang efektif (Stuckey et al., 2015). Maka dari itu Stuckey et al. (2015) menyarankan bahwa untuk medukung dan memperbaiki pengelolaan diabetes dengan lebih baik, diperlukan dukungan kepada penderita melalui strategi-strategi berikut ini: menjadi pendengar yang baik bagi si penderita, mengembangkan pendekatan perawatan yg berfokus pada masing-masing penderita sebagai individu, dan memotivasi penderita diabetes serta melibatkan keluarga dalam perawatan.

Penderita diabetes dapat menggunakan terapi diabetesnya baik dalam kurun waktu yang singkat maupun waktu yang lama. Setelah itu, mereka biasanya akan melakukan penilaian terhadap terapi yang mereka gunakan tersebut. Hal ini dilakukan untuk menentukan tindakan selanjutnya terhadap terapi yang mereka gunakan apakah perlu dipertahankan atau dihentikan sehingga perlu diputuskan terapi mana yang lebih tepat bagi mereka. Program edukasi diabetes yang menunjukkan keberhasilan biasanya membutuhkan biaya besar sebab masing-masing penderita akan mendapatkan supervisi dari tenaga kesehatan yang terlatih serta dibutuhkan komitmen dari penderita diabetes dalam pengelolaan diabetes jangka panjangnya ini (Klein et al., 2013). Peran tenaga kesehatan dalam hal ini perawat, sangat krusial dalam memberikan masukan bagi penderita diabetes agar penderita diabetes dapat memilih, menggunakan dan memutuskan rencana pengelolaan diabetes yang lebih baik dan lebih tepat bagi dirinya. Hal ini dapat dilakukan melalui edukasi diabetes yang lebih baik dan kreatif dengan memegang prinsip *person-centered care* (PCC).
Pada prinsip PCC, perawatan berfokus kepada penderita, dalam hal ini penderita diabetes. Menurut Australian College of Nursing (ACN), PCC bermakna menangani penderita sebagai seorang individu, melindungi harga

dirinya, menghargai hak dan pilihannya, mengembangkan hubungan terapeutik antara tenaga kesehatan dan penderita berdasarkan asas saling kepercayaan dan saling pengertian (Australian College of Nursing, 2014). Dengan memberikan pelayanan berbasis PCC, penderita diabetes dapat terlibat dalam pelayanan kesehatan secara tepat dan efisien sehingga mereka dapat membuat keputusan yang terbaik bagi dirinya dan ikut serta dalam pengelolaan diabetes yang disetujui tenaga kesehatan dan penderita (Rice, 2016).

Karena setiap penderita diabetes itu unik dan tidak memiliki kondisi yang sama persis dengan penderita lainnya dikarenakan pengaruh latar belakang yang berbeda baik itu budaya dan sosialnya dan hal ini dapat juga mempengaruhi keberhasilan hubungan penderita dan tenaga kesehatan serta terhadap tingkat kepatuhan penderita terhadap pengelolaan diabetes (Caballero, 2007). Dalam hal ini perawat hendaknya memiliki kompetensi kultural (*cultural competency*). Praktisi kesehatan sangat perlu mempertimbangkan dengan hati-hati terhadap penderita diabetes yang memiliki kebutuhan yang berbeda sesuai dengan sistem pendukung yang bervarasi yang dimilikinya serta bagaimana pengelolaan diabetes beserta kondisi penyerta dalam merencanakan pedekatan yang terbaik di dalam menangani penderita diabetes (Hackel, 2013). Maka dari itu pemberian perawatan dan pengelolaan diabetes termasuk di antaranya adalah pemberian edukasi diabetes pun harus disesuaikan dengan kondisi dan situasi yang dihadapi oleh masing-masing penderita tersebut.

KESIMPULAN

Penderita diabetes mengalami proses pembelajaran terhadap penyakit melalui *Learning, choosing, and acting: self-management of diabetes*. Melalui proses tersebut, penderita diabetes mencari dan menerima informasi terkait diabetes kemudian mereka menerima dan memilih mana yang akan mereka terapkan di dalam pengelolaan diabetesnya. Setelah menerapkan terapi pilihannya tersebut, penderita diabetes akan menilai sejauh mana terapi yang ia gunakan berhasil atau berdampak positif bagi kondisi diabetesnya. Hal ini diperlukan agar penderita diabetes dapat menentukan tindakan selanjutnya. Pengalaman akan penggunaan terapi atau perawatan diabetes biasanya akan dibagikan ke orang lain baik yang menderita diabetes maupun yang tidak. Adanya proses belajar, memilih dan bertindak dalam manajemen diri diabetes tersebut dapat digunakan oleh tenaga kesehatan professional perlu menggunakan pendekatan perawatan yang memang disesuaikan dengan kebutuhan masing-masing penderita diabetes baik itu melalui edukasi kesehatan maupun pengelolaan perawatan diabetes. Penelitian selanjutnya dibutuhkan untuk mengembangkan model perawatan diabetes yang saling disepakati oleh tenaga kesehatan dan perawat yang disesuaikan dengan kondisi penderita per individu dan mengevaluasi model tersebut.

Melalui penelitian ini, tenaga kesehatan terutama perawat perlu mengembangkan pendekatan yang kreatif terhadap edukasi kesehatan pada penderita diabetes. Hal ini dilakukan melalui pengkajian yang cermat terhadap aspek seperti pengetahuan sebelumnya yang dimiliki penderita, pengalaman yang dimiliki terkait pengelolaan diabetes saat ini dan yang pernah ia terapkan, kemudian pendapat pribadi termasuk mitos terkait perawatan diabetes yang penderita miliki. Hal ini dikarenakan aspek tersebut dapat mempengaruhi pengambilan keputusan penderita diabetes terhadap pengelolaan diabetesnya. Adanya keterbatasan waktu dalam setiap konsultasi kesehatan, menyebabkan perlu kiranya pembuat kebijakan menetapkan aturan bahwa setiap konsultasi yang pertama kali bagi penderita diabetes, akan diberikan waktu yang lebih lama oleh tenaga kesehatan sehingga kebutuhan penderita akan pembelajaran terhadap diabetesnya dapat dianalisa dengan tepat.

Selain itu, tenaga kesehatan perlu melakukan perawatan tindak lanjut secara teratur (*follow up care*) untuk meninjau ulang apakah pemberian informasi termasuk diantaranya rekomendasi terhadap pengelolaan diabetes penderita sudah benar-benar diaplikasikan. Hal ini dapat dilakukan melalui kunjungan rumah atau *home review visit*.

Penderita diabetes perlu mendapatkan akses yang mudah terhadap informasi kesehatan terkait diabetes melalui sumber yang benar dan dapat dipercaya. Untuk itu, organisasi diabetes setingkat nasional, misalnya, perlu mengembangkan situs web yang berisi tentang informasi diabetes yang benar, terpercaya, dalam bentuk yang bervariasi (brosur atau leaflet berupa gambar atau simbol) dan menggunakan bahasa yang interaktif dan mudah dipahami oleh penderita diabetes dengan latar belakang pengetahuan yang bervariasi.

REFERENSI

Australian College of Nursing. (2014). Person-centred care. Retrieved 14 February 2018, from https://www.acn.edu.au/sites/default/files/advocacy/submissions/PS_Person-centered_Care_C2.pdf

Beauchamp, T. L., & Childress, J. F. (2001). *Principles of biomedical ethics* (Vol. 5th). New York, N.Y: Oxford University Press.

Beauchamp, T. L., & Childress, J. F. (2009). *Principles of biomedical ethics* (Vol. 6th). New York: Oxford University Press.

Beauchamp, T. L., & Childress, J. F. (2013). *Principles of biomedical ethics* (Vol. Seventhition.). New York: Oxford University Press.

Birks, M. (2014). Practical philosophy. In J. Mills & M. Birks (Eds.), *Qualitative methodology: A practical guide*. Thousand Oaks, CA; London: SAGE.

Birks, M., & Mills, J. (2015). *Grounded theory: a practical guide*. Thousand Oaks, CA: SAGE.

Author and Others. (2009) Details Withheld for Peer Review.

Caballero, A. E. (2007). Cultural Competence in Diabetes Mellitus Care: An Urgent Need. *Insulin, 2*(2), 80-91. doi: 10.1016/S1557-0843(07)80019-4

Charmaz, K. (2006). *Constructing grounded theory: a practical guide through qualitative analysis*. London: SAGE.

Corbin, J. M., & Strauss, A. L. (2008). *Basics of qualitative research: techniques and procedures for developing grounded theory*. Los Angeles: Sage Publications, Inc.

Crangle, C. E., Bradley, C., Carlin, P. F., Esterhay, R. J., Harper, R., Kearney, P. M., . . . Savage, E. (2017). Soliciting and responding to patients' questions about diabetes through online sources. *Diabetes technology & therapeutics, 19*(3), 194-199. doi: 10.1089/dia.2016.0291

Creswell, J. W. (2013). *Qualitative inquiry and research design: choosing among five approaches*. Thousand Oaks, Calif: SAGE Publications.

Funnell, M. M. (2011). The National Diabetes Education Program. *The American Journal of Nursing, 111*(12), 65.

Hackel, J. M. (2013). 'Patient-Centered Care' for Complex Patients with Type 2 Diabetes Mellitus-Analysis of Two Cases. *Clinical Medicine Insights: Endocrinology and Diabetes, 2013*(6), 47-61. doi: 10.4137/CMED.S12231

Hartayu, T. S., Izham, M., & Suryawati, S. (2012a). Improving of type 2 diabetic patients knowledge, attitude and practice towards diabetes self-care by implementing community-based interactive approach-diabetes mellitus strategy. *BioMed Central Research Notes, 5*(1), 315-315. doi: 10.1186/1756-0500-5-315

Hartayu, T. S., Izham, M., & Suryawati, S. (2012b). Improving type 2 diabetes patients' quality of life by using a community based interactive approach – diabetes mellitus strategy in Yogyakarta, Indonesia. *Journal of Pharmaceutical Health Services Research, 3*(2), 95-102. doi: 10.1111/j.1759-8893.2012.00088.x

Higginbottom, G., & Lauridsen, E. I. (2014). The roots and development of constructivist grounded theory. *Nurse researcher, 21*(5), 8-13. doi: 10.7748/nr.21.5.8.e1208

Javalkar, K., Williamson, N., Vaidya, S., Vaidya, A., & Ferris, M. (2016). The association between educational resource utilization and knowledge/self-management among patients with Type 2 Diabetes in Pune, India. *Diabetes and Metabolic Syndrome: Clinical Research and Reviews, 10*(4), 186-189. doi: 10.1016/j.dsx.2016.06.002

Klein, H. A., Jackson, S. M., Street, K., Whitacre, J. C., & Klein, G. (2013). Diabetes self-management education: Miles to go. *Nursing research and practice, 2013*, 581012-581015. doi: 10.1155/2013/581012

Author and Others. (2018) Details Withheld for Peer Review.

Mihardja, L., Delima, Manz, H. S., Ghani, L., & Soegondo, S. (2009). Prevalence and determinants of diabetes mellitus and impaired glucose tolerance in Indonesia (a part of basic health research/Riskesdas). *Acta Medica Indonesiana, 41*(4), 169.

Mills, J. (2014). Methodology and methods. In J. Mills & M. Birks (Eds.), *Qualitative methodology: A practical guide*. Thousand Oaks, CA; London: SAGE.

Mills, J., Birks, M., & Hoare, K. (2014). Grounded theory. In J. Mills & M. Birks (Eds.), *Qualitative methodology: A practical guide*. Thousand Oaks, CA; London: SAGE.

National Institute for Health Research and Development. (2008). *'Riset Kesehatan Dasar'*. Jakarta: Ministry of Health of Republic of Indonesia.

National Institute for Health Research and Development. (2013). *'Riset Kesehatan Dasar'*. Jakarta: Ministry of Health Republic of Indonesia.

Ng, N., Nichter, M., Padmawati, R. S., Prabandari, Y. S., Muramoto, M., Nichter, M., . . . Institutionen för folkhälsa och klinisk, m. (2010). Bringing smoking cessation to diabetes clinics in Indonesia. *Chronic Illness, 6*(2), 125-135. doi: 10.1177/1742395310364253

Patel, N. R., Kennedy, A., Blickem, C., Reeves, D., & Chew-Graham, C. (2016). "I'm Managing My Diabetes between Two Worlds": Beliefs and Experiences of Diabetes Management in British South Asians on Holiday in the East-A Qualitative Study. *Journal of Diabetes Research*. doi: 10.1155/2016/5436174

Rice, T. (2016). Person-centred care in diabetes: A must have. *Australian Nursing and Midwifery Journal, 23*(9), 43.

Sae-Sia, W., Maneewat, K., & Kurniawan, T. (2013). Effect of a self-management support program on diabetic foot care behaviors. *International Journal of Research in Nursing, 4*(1), 14.

Stuckey, H. L., Vallis, M., Burns, K. K., Mullan-Jensen, C. B., Reading, J. M., Kalra, S., . . . Peyrot, M. (2015). "I Do My Best To Listen to Patients": Qualitative Insights Into DAWN2 (Diabetes Psychosocial Care From the Perspective of Health Care Professionals in the Second Diabetes Attitudes, Wishes and Needs Study). *Clinical therapeutics, 37*(9), 1986-1998. doi: 10.1016/j.clinthera.2015.06.010

van der Heide, I., Uiters, E., Rademakers, J., Struijs, J. N., Schuit, A. J., & Baan, C. A. (2014). Associations Among Health Literacy, Diabetes Knowledge, and Self-Management Behavior in Adults with Diabetes: Results of a Dutch Cross-Sectional Study. *Journal of Health Communication, 19*(Suppl 2), 115-131. doi: 10.1080/10810730.2014.936989

Waspadji, S., Ranakusuma, A. B., Suyono, S., Supartondo, S., & Sukaton, U. (1983). Diabetes mellitus in an urban population in Jakarta, Indonesia. *The Tohoku Journal of Experimental Medicine, 141 Suppl*, 219.

World Health Organization. (2014). Indonesia: Country profile *Global Health Observatory (GHO) data: Indonesia*.

Appendix J

Participants' Quotes
…hitam semua bekas suntikan. Jarumya ganti bu kate die [dokter]… tiga hari jarumnya ganti kate die... saye sampe abis jak... "ganti jarumnya" kate die… "[kalau] tadak itam badan kate die"... (Betty: G1P3-4)
Rata-rata pasien disini kalau pertama kali mereka itu dengan kondisi...keadaan luka, mereka bertanya "kenapa bisa luka", habis itu "kenapa gula darahnya tidak turun-turun gitu" atau "kenapa pengobatan yang dilakukan selama ini...minum obat ini tidak mau menurunkan gula darahnya gitu". Itu pertanyaan-pertanyaan mereka gitu. (Danur: G1P9)
Dulu waktu hamil anak kedua kan memang belum tau dengan DM kan, dokter S yang bilang, "udah lahiran yaaa… Udah dokter…Berapa kg anakmu? 4 kg. DM kamu.." naaahh… "nggak lah dokter" saya bilang, saya penasaran nah akhirnya cek..300 lebih. (Widya: G2P15)
Saya ngecek ke dokter spesialis gigi. saya juga nggak yakin kalua saya punya penyakit gula. Jadi dokter itu bilang "mungkin bapak gula darahnya tinggi". Waktu itu saya gak tau ibu saya. gak inget ibu saya pun ada penyakit gula. Saya pikir kan penyakit gula kan siapa aja kena saya bilang. Kan bisa ditimbulkan dari keturunan katanya. (Haris: G2P2)
Bilang bos saye, kate die, "kau kena kencing manis ni... cobe kau perikse badan kau.." saye takut nanti kalo iye jadi buah pikiran.. sekali benar-benar iyee.. dari tahun 2004 [dan] sekarang 2016... 12 tahun. (Betty: G1P12)
…dari buang air seni saya. Di WC itu banyak semut. Jadi saya… "kenapa ini WC ini kok… padahal saya itu sendiri tinggal. …kenapa semut kok berkumpul begini banyak". Nah saya mulai curiga. Tapi ya itu lah yang saya rasakan, badan tu lemaaaaas sekali, ndak ada gairah untuk buat apa aja gitu, pinginnya istirahat, terus buang air seni itu sering sekali. Kita minum pingin keluar lagi, minum keluar lagi, ke WC lagi, begitu gejala-gejalanya yang paling saya rasakan waktu itu bu yang paling kuat. (Haris: G2P2)
Saya kan setiap hari, waktu itu kemarin jualan sarapan pagi. Jadi setiap pagi tu ngantuk, ngantuknye berat sekali, saya ndak tau ni kalau saya tu penderita diabetes, saya tiap hari tu minum kopi, kopi…kopi sachet jadi setiap hari saya minum kopi sachet sama susu untuk ngilangkan rase ngantuk. Saya tuh malar haus pinginnye mau minum..minum es gitu sampe satu hari kadang, dari pagi sampe jam 11, saya kan jualan sampe jam 11,

minumnye 7 gelas teh es. Iye teh es manis, jadi lama kelamaan mata saya ni kabur, ndak keliatan dari jarak satu meter tu nda bise liat gitu, jarak dekat baru saya keliatan, saya periksa ke dokter badan saya lemah, ngantuk kalo tak salah ke antonius saya periksa.. Rawat jalan ke dokter penyakit dalam, jadi diperiksa saya belum sarapan apa-apa, darah saya 500 lebih dah itu sudah nyerang ke mata, sudah itu dia [dokter] kasi saya makan obat. (Ranti: G2P1)
2004 saya mau naik haji.. "ibu pernah kencing manis bu?.. tadaakk.." kalo darah tinggi saye iye.. "periksa ibu yang benar bu yee" kate die.. terus saye pegi gadjah mada.. sebelum makan sesudah makan. "Ibu yee kencing manis". (Betty: G1P12)
Kita juga kadang-kadang kan turun. Turun ngadekan kegiatan misalnya di RRI ada apa..ada kegiatan apa.. ada apa.. ada even-event apa tu naaa kite eee terjun tu ngadekan pemeriksaan body fat, gula darah sewaktu, haaa kemaren hari kesehatan atau hari diabetes sedunia kan.. kami ngadekan di mal. Jadi siapa yang lewat ni kita panggil untuk pemeriksaan gula darah, kerja sama dengan dinas kesehatan ya. (Flora: G1P2-3)
Jadi saya kesini ni berobat, untuk ngambil obat, untuk perjalanan saya lah, ntah itu empat atau lebih dari empat hari, untuk perjalanan saya di jalan, kalau-kalau memang saya ini dalam kondisi makan ndak terjaga, yang namanya kumpul takut ndak terjaga, kita mengantisipasi dengan asbab obat itu, maksud saya gitu. (Haris: G2P8)
Terakhir tuh saya dada saya tuh deg-degan gemetar… apa tuh tak enak kayak masuk angin sebelah gitu.. kayak berat sebelah gitu.. jadi sama anakku nih dibawa ke dokter B [cardiologist], dari tekanan darah saya takut larinya ke jantung.. saya bilang "kok baru tiga tahun lalu masa larinya ke jantung", sekali dicek sama dokter itu, bagus, grafiknya bagus, mungkin karena kecapeaan kah apa juga kan.. jadi sekarang saya juga makin hati-hati lagi supaya…kita sih ndak bisa nolak kalo memang udah ada saatnya kah, mau sakit mau ape, tapi kalo kite bise jage, saye jage.. (Larisa: G2P4-5)
Kalau kemarin tu [pasien dengan diabetes] pernah bertanya gini kata orang… beras merah itu ehhm untuk obat diabet…saya kan juga bukan bukan ahlinya di situ, saya bilang sama, terutama, [ahli] gizi kan…. "oyaa bu nanti saya jelaskan". Pernah sih kemarin tu contohnya obat herbal, obat herbal dia bilang "bu, saya ni makan, obat herbal ini bagus ndak?" Obat apa pun itu mungkin. mungkin bagus, intinya ada balai POM [pengawasan obat dan makanan] bagi saya balai POM tapi kalo ndak dijaga pola makannya obat apa pun, saya bilang ndak bisa. (Putri: G2P7)

Pasien itu harus mengetahui apa yang disampaikan kepada mereka, jadi pasien datang ke rumah sakit itu kan ndak hanya datang, mendapat perawatan, kemudian mereka pulang, tidak. Tetapi di rumah sakit ini lah mereka harus juga selain mendapat perawatan, mereka harus juga mendapatkan informasi terkait penyakit yang mereka alami, nah terutama untuk diabetes karena ini terkait juga dengan pola makan, pola hidup, kemudian gaya hidup, Jadi pasien bener-bener mengerti apa yang harus mereka lakukan, apa yang tidak boleh mereka lakukan, sehingga mereka yaaa tidak lagi datang ke rumah sakit gitu, tidak mengalami sakit yang sama. (Qosim: G2P7-8)
Edukasi itu yaaaa... sangat sangat penting Bu karena kita tidak menginginkan komplikasi yang terjadi pada pasien karena komplikasi itu terjadi karena pemahaman yang kurang, karena ketidaktahuan pada pasien, oleh karena itu edukasi saya kalao saya mengurutkan itu bagian nomor satu untuk penatalaksanaan pasien dengan DM [diabetes mellitus], itu sangat penting, karena kalau edukasi yang baik...komplikasi itu walaupun ada cuma bisa diminimalisir jadi pasien bisa melakukan pencegahan-pencegahan dan bisa mengidentifikasi kalau mungkin itu ada gangguan. (Aditya: G1P5-6)
[Saya] pengen sih untuk edukasi sih lebih ini lagi...tim nya tuh lebih gencar lagi kerja sama dengan ahli gizi kan… mereka lebih paham juga ya makanannya… terus bagaimana cara menghitung kalori.. misalkan. Jadi untuk meminimalkan [kasus diabetes]… karena penyakit kencing manis ni semakin hari kok banyak...di ruangan ini. Rata-rata itu sampai sudah kompleks. [Orang] masuk dengan riwayat kencing manis yang lama, sekarang [mereka] masuk dengan gagal ginjal... jadi sudah terlambat begitu. (Tiara: G2P10)
…[untuk] lebih memahami apa yang didapat mereka apabila mereka minum obatnya secara teratur gitu, apabila mereka minumnya tidak teratur bagaimana.... kita memberikan penjelasan seperti itu. Namanya edukasi kita memberikan informasi ini untuk mencegah terjadinya komplikasi dari penyakit diabetes ini. (Cahyo: G1P10)
Untuk terapi yang farmakologi, itu adalah untuk memberikan kepatuhan kepada pasien. Kita memberikan edukasi dan penjelasan kepada pasien betapa pentingnya obat diabetes ini untuk menjaga kadar gula darahnya normal. (Cahyo: T1P10)
Terutama ya kita usahakan dia [seseorang dengan diabetes] mengerti kenapa gula darahnya bisa tinggi. Terus edukasi, kemudian exercise… olahraganya, kemudian dietnya dan obat-obat yang harus dia pakai, dan komplikasi yang bisa terjadi baik itu komplikasi penyakitnya atau efek samping obatnya. (Galih: G1P5).

Mengerti dulu lah ya.. mengerti dulu baru menerima kan, baru melaksanakan. Jadi kalau misalnya tanpa edukasi… pasien rata-rata tidak mengerti gitu kan.. tidak dapat mengerti jadi tidak bisa menerima mana mungkin bisa melaksanakan kan terapi-terapi yang lain gitu kan. (Elita: G1P7)
…tujuannya itu supaya dia lebih mandiri . supaya ndak ada perubahan sedikit ke dokter dia, harusnya bisa ditangani sendiri... begitu.. jadi untuk mengontrol gula darahnya itu tidak bisa hanya dari dokter atau tenaga medis saja, juga harus dari pasiennya sendiri… …Tapi kalau dia bisa mengerti, kadang-kadang ada hal-hal yang dia bisa tangani sendiri di rumah. (Galih: G1P6-7)
Pasien yang memang sadar gitu yaaa [terhadap] penyakit, dia datang sendiri [dengan kesadarannya itu]. …ada menemui ahli gizi karena kan orang dengan diabetes perencanaan makan berperan penting kan selain dari obat dan olah raga. (Elita: G1P2)
Kalau pasiennya istilahnya sadar dan bersedia untuk kita berikan informasi, kita berikan informasi kepada keluarga pasiennya dengan pasiennya juga kita berikan informasi biar pasiennya juga paham tentang terapi yang digunakan disini tu apa. (Cahyo: G1P8)
Untuk kontrol ini pasien harus paham tentang penyakitnya itu karena seperti diabetes itu kan temennya seumur hidup. Dia harus mau belajar seluk beluk kencing manis.. nah kan mendampingi dia seumur hidup gitu. Nah supaya kontrol kencing manisnya itu tercapai, lebih mudah tercapai.. itu kalau pasien mengerti..enak.. lebih mudah ngontrolnya. (Galih: G1P7)
Kita disini membuat tentang leaflet-leafet, salah satu juga tentang edukasi tentang diabet. kita punya stock di setiap ruangan kita ada tempat, tempat leaflet. Jadi siapa saja boleh mengambil. Dan kita juga punya stock yang ada di petugas, petugas itu untuk menjadi bahan dasar mereka menyampaikan edukasi kepada pasien di bed nya. Kita ada namanya konselling di bed pasien. Nah kita mendukung dari leaflet itu kemudian kita juga ada leaflet khusus kalau untuk diabet khusus yang terkait diet. (Qosim: G2P1-2)