A CASE STUDY OF PATIENT EMPOWERMENT IN SUPPORTING SELF-MANAGEMENT IN DIABETES CARE IN INDONESIA

By

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Dedication

To my late parents and brother*, I am sure you now smile from the heaven*

To my supervisors Wendy, Eileen, and Fathimath,
thanks so much for being enormously supportive.
You made me climb a mountain

To my lovely husband, Suparto*, thanks for being so patient during my absence.*
I might cook a proper dinner after this

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Abstract

Diabetes is a known worldwide health problem. Indonesia currently has 10.3 million people with Type 2 diabetes mellitus, making it one of the top 10 countries globally, with projections of an increase to 16.7 million by 2045. Most patients with diabetes in Indonesia do not achieve the national recommended care outcomes, as evidenced by the high number of diabetes complications and deaths. Patients with diabetes require self-management support to manage the disease. Patient empowerment and self-management approaches have resulted in improvements in diabetes outcomes in most Western developed countries. However, little is known about how patients with diabetes have been supported by healthcare professionals in Indonesia and whether patient-empowerment approaches would be suitable to be applied.

An integrative review was conducted on how patient empowerment in supporting self-management of patients with Type 2 diabetes mellitus was conceptualised and contextualised, drawing on recent research publications in Southeast Asian Developing Countries, including Indonesia. This review suggested a lack of adoption of the concepts to local contexts. These studies appeared to focus on patient-education programs, rather than self-management or empowerment. The studies on interventions framed under the concept of patient empowerment focused more on the micro-level of providing patient health education and reorganising diabetes care, with less involvement of a diabetes care team.

Given the outcomes of the literature review, this study explored the existing approaches used in the care of patients with Type 2 diabetes mellitus in supporting their self-management skills in Indonesia. It is anticipated that the knowledge gained from this study will contribute to understanding the issues faced in Indonesia, and influence future policies and standards in diabetes care and management.

A single case study strategy with embedded units of analysis and triangulation of participants and data collection methods was used. Forty-two patients with Type 2 diabetes mellitus and 19 healthcare professionals from 3 levels of healthcare provision services in urban and sub-urban areas of Indonesia participated in this study. These were a community centre, a local hospital and a major acute referral hospital in a capital city. Qualitative thematic analysis was applied to the data gathered from direct observations of clinical interaction between patients with Type 2 diabetes mellitus and healthcare professionals, patient interviews, and focus group discussions with healthcare professionals.

The evidence from the 3 healthcare delivery services identified themes and subthemes that prevented diabetes care in supporting patient self-management. These were a scarcity of healthcare resources, lack of healthcare organisation management, medical dominance in all care, gaps in patient–healthcare professional communication, and poor patient outcomes. Existing government support for the national health cover insurance scheme, programs such as chronic care management, and regulations that had been introduced to increase greater access to diabetes care, showed sub-optimal patient outcomes.

A lack of awareness and self-management practices among people with Type 2 diabetes mellitus was evident at all 3 levels of data sourced from a complex hierarchy of systems in healthcare. At the system level (Indonesian healthcare system), there was evidence of inconsistent standards between what is provided through the national healthcare insurance scheme and the clinical guidelines, as well as insufficient numbers and qualified healthcare professionals, especially diabetes educators. At the level of the healthcare organisations (healthcare providers), low levels of collaboration between the healthcare team, scarcity of structured patient-education programs, fragmented care and discontinuity of patient education, medical control over all forms of care and medicalisation of all care were evident. Inadequate communication between healthcare professionals and patients prevented self-management, and there were considerable gaps in patient health literacy with differences in patient and healthcare professional expectations. At all 3 levels of the system, the patients were disempowered, as evident from the poor health outcomes that included practices that were potentially harmful to patient health.

The issues found in this study were consistent with previous studies on diabetes care in Indonesia. Framed by the theoretical concepts of Habermas's communicative action and Honneth's recognition theories, the study found a number of factors prevented patient self-management and empowerment; medical control over patients and other health professionals, government regulations and programs to support patients with a chronic illness such as Type 2 diabetes mellitus were based on instrumental strategic action rather than communicative action. To fill the gaps in existing care, there needs to be recognition of patients' and healthcare professionals' lifeworld so that the tension that exists between them in relation to the regulations and programs are reduced.

Declaration

I certify that this thesis:

1. does not incorporate without acknowledgment any material previously submitted for a degree or diploma in any university
2. and the research within will not be submitted for any other future degree or diploma without the permission of Flinders University; and
3. to the best of my knowledge and belief, does not contain any material previously published or written by another person except where due reference is made in the text.

Signed

Yulia

Date 21/12/2022

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[1] Professional editor, Rosemary Purcell, provided copyediting and proofreading services, according to the guidelines laid out in the university-endorsed national *Guidelines for Editing Research Theses.*

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Glossary

ADEA	Australian Diabetes Educators Association
BGL	blood glucose level
BPJS K	*Badan Penyelenggara Jaminan Sosial Kesehatan*, the Indonesian government insurance scheme
DES	Diabetes Empowerment Scale
FGD	focus group discussion
HbA_{1c}	glycosylated hemoglobin
HCP	healthcare professional
IDF	International Diabetes Foundation
HDL	high-density lipoprotein
JCI	Joint Commission International
LDL	low-density lipoprotein
NPH	neutral protamine hagedorn
PMR	patient medical record
PPE	personal protective equipment
Puskesmas	Indonesian community healthcare centers (referred to as both in the thesis)
RCT	randomised controlled trial study
SBREC	Social and Behavioural Research Ethics Committee
SEADCs	Southeast Asian developing countries

T2DM	Type 2 diabetes mellitus
UKPDS	United Kingdom Prospective Diabetes Studies
UNESCO	United Nations Education, Scientific, Cultural Organization
WHO	World Health Organisation

Chapter 1: Introduction and Background

1.1 Introduction

This chapter introduces the statement of the problem, and presents the research questions, purpose of the study, and its significance and scope. The chapter then provides the background to the phenomena of Type 2 diabetes mellitus (T2DM) as a chronic illness and its management based on biopsychosocial approaches to diabetes care including support for self-management. The magnitude of the problem of uncontrolled diabetes that might be caused by failures in diabetes care provision is outlined. These contextual factors include the epidemiology profiles of patients with diabetes, socioeconomic factors, financial support for health, education and health literacy, culture and religion, the organisation of the healthcare system, and diabetes care in Indonesia. These factors are important as a basis for building an argument to conduct and contextualise this research, and to justify the significance of the study. The final section of this chapter details the organisation of the thesis.

1.2 Statement of the problem

The nature of diabetes as a self-care managed chronic illness requires people with diabetes to make knowledgeable decisions about their daily care. Empowerment approaches seem to be critical in supporting self-management, especially in many Western countries (Palumbo, 2017). In the Indonesian context, little is known of the concepts or the application of empowerment approaches in supporting people with diabetes.

1.3 Research questions

Based on the statement of the problem, the research questions explore the concept of patient empowerment (Funnell & Anderson, 2005; Palumbo, 2017; Zimmerman, 1995) within the context of chronic care management (Austin et al., 2000; Bodenheimer, Wagner, et al., 2002). The 2 questions and 4 sub-questions aim to explore the interrelated real-life phenomena influencing diabetes care in the Indonesian context and draw on multiple sources of data to examine the many factors likely to be relevant to the question.

The main and the sub-research questions are:

1. What approach is currently used in the care of people with T2DM in Indonesia to support self-management?
    a. What are the features of the existing model of care?
    b. What existing programs support diabetes self-management?
    c. How would patients and health care professionals (HCPs) frame self-management and empowerment for patients with T2DM?
    d. How does communication between patients and HCPs support patient self-management?
2. If there was general support for adopting a patient empowerment approach to improve patient self-management, what would be the characteristics of this care?

1.4 Purpose of the study

This study aims to explore the existing approaches used in the care of patients with T2DM in supporting patient self-management. The propose of examining existing approaches is to understand the issues faced in Indonesia, and influence future policies and standards of practice in diabetes care and management by enhancing patient self-management.

Specifically, the study objectives are:

- to determine the perspectives of patients with T2DM and HCPs regarding the approach(es) used in the provision of existing diabetes care
- to seek out how diabetes care is provided at each level of the healthcare system in Indonesia
- to identify clinical supports available to enhance patient self-management
- to uncover from the patient perspective how they understand empowerment in order to support self-management
- to identify the communication styles between patients with T2DM and HCPs that support self-management

- to identify potential issues between patients with T2DM and healthcare organisations and healthcare systems that may hinder patient empowerment to support self-management.

1.5 Significance and scope of the study

It is anticipated that this study will contribute to the body of knowledge regarding the supports required to increase patient self-management in Indonesia. First, this study describes the current approaches used in managing people with diabetes in Indonesia in supporting their self-management. A comprehensive exploration of the current approach(es) used in the care of people with T2DM provides evidence as to whether this approach is empowering or not for patients. It also provides a basis for what a suitable approach for promoting self-management might be. Second, this study aims to provide valuable information on whether a patient-based empowerment approach for the management of diabetes care is compatible with the Indonesian context. The findings may also provide insight into how people with diabetes in Indonesia could be empowered in the future to improve their self-management. In turn, patients with T2DM may benefit as diabetes outcomes may improve. This study is warranted as little is known about the concept and application of patient-empowerment approaches in supporting the self-management of people with diabetes in Indonesia (see Chapter Two).

1.6 Background

This section explains the context of this study by highlighting the epidemiology data of diabetes worldwide, including Indonesia, and elaborating on socioeconomic, education and health literacy, culture and religious factors within the country. In addition, it presents an explanation of the healthcare system, health insurance and related policies, as well as information about diabetes care and management in Indonesia.

1.6.1 Epidemiology profiles

Diabetes is a known worldwide health problem (Alberti, 1993; Cho et al., 2018; Rafieian-Kopaei & Baradaran, 2012; Rodriguez-Saldana, 2019). Diabetes mellitus, specifically T2DM, is a chronic increase of blood glucose levels (BGL) caused by multiple factors

(Poretsky, 2020). Published data by the International Diabetes Foundation (IDF) on the epidemiology of T2DM identifies the increasing trends in prevalence globally (IDF, 2019). The prevalence of adults aged 20–79 years with diabetes worldwide is on the increase (IDF, 2019). The IDF and the World Health Organisation (WHO) predict that the largest increases will take place in countries with lower to middle-income economies (IDF, 2021). Additionally, between 2010 and 2030, it is predicted that there will a 69% increase in the number of adults with diabetes in developing countries, including Indonesia (Shaw et al., 2010). In 2017, Indonesia was listed as one of the top 10 countries for the number of people with T2DM; it is also projected that from 2017 to 2045 that number will grow to 16.7 million (Cho et al., 2018; IDF, 2021).

Indonesia is a developing country facing an epidemic of T2DM (IDF, 2021). Up to 6.2%, or 10,681,400 adults have diabetes in Indonesia (IDF, 2019). The epidemiology data shows that most patients with T2DM in Indonesia do not achieve the nationally recommended care outcomes, which is evidenced by the high number of complications and deaths related to diabetes cases (IDF, 2021). The WHO in 2016 identified that diabetes mellitus caused 26.4 % of deaths among people aged 30–70 years in Indonesia (Soewondo et al., 2010). Furthermore, data from the IDF also shows that 55.6% of deaths were related to diabetes in people under 60 years in 2017 in the country (IDF, 2021).

Socioeconomics and healthcare structural factors have been identified as non-medical determinants of healthcare outcomes (Braveman et al., 2011; Hill-Briggs et al., 2021). Differences in the healthcare delivery systems, resource availability, training and qualifications of healthcare professionals working in diabetes care, and the culture and characteristics of people affected by diabetes potentially influence how diabetes care is provided in any country, including Indonesia. Therefore, it is necessary to explore how the existing models of care have not enhanced patient self-management and seek out approaches that may be more effective. Unfortunately, there has been very little published research on diabetes care in Indonesia. In the absence of adequate information and evidence about how care for patients with diabetes has been provided it is difficult to effectively establish a program that could encourage self-management and empowerment.

1.6.2 Socioeconomic factors

Indonesia is one of the developing countries in Southeast Asia and lies between Asia and the Australian continent. It is the fourth most populous country after China, India and the United States. Up until 2020 Indonesia was classified as an upper-middle-income country (Serajudin & Hamadeh, 2020), economically strong, and politically stable (Jeffreys & Kuncinas, 2009). However, since 2020, the country has been re-classified as a lower-middle-income country (The World Bank, 2022) pointing to poverty being a factor in chronic illness.

Geographically, Indonesia is the largest archipelago country in the world, consisting of around 18,000 islands including the 5 biggest and populous islands of Sumatra, Java, Kalimantan, Sulawesi and Irian Jaya (Jeffreys & Kuncinas, 2009). The geographical landscape of Indonesia contributes to the inequality of access to health care and influences the utilisation of services and the national health insurance scheme (Mulyanto et al., 2019). Therefore, geographical context in studies on healthcare in general, and specifically in Indonesia are still issues for consideration. Access to health care is limited for the poor. Issues include confused leadership roles in the health sector; lack of health equity; a generally weak capacity in the healthcare system, especially in planning and budgeting; and limited coverage of programs for the poor (Agustina et al., 2019; Utomo et al., 2011). In 2017, two-thirds of people with diabetes lived in urban areas (Jeffreys & Kuncinas, 2009; The World Bank, 2022).

1.6.3 Financial support for health

Indonesia has undergone a series of changes in the funding of its health system and health insurance program. The latest change was the implementation of universal health coverage, which began in January 2014 and is widely seen as a significant step forward for Indonesia’s 239.7 million people, covering 52% of the total population (Plummer & Boyle, 2016). To provide an affordable healthcare system to all Indonesians citizens, policymakers committed to covering every citizen by 2019 in a system managed by *Badan Penyelenggara Jaminan Sosial Kesehatan* (BPJS Healthcare or BPJS K), the implementing agency for the Indonesian Government’s healthcare social security and insurance scheme.

However, while there are many Indonesians enrolled in the BPJS K, many are reluctant to use it as the administrative procedures are not practical (Plummer & Boyle, 2016). So, even though the coverage of BPJS K was significantly high, people still used private services as this was simpler (Agustina et al., 2019). Many people seek health services from the private sector, leaving them out of pocket financially, or they go without the required care (Agustina et al., 2019). The private sector delivers 62.1% of all health services compared to 37.9% provided by the government (Agustina et al., 2019). In its first 4 years, BPJS K coverage reached nearly 70% of the population, with the average number of outpatients and inpatient claims increasing from 25.5 million in 2014 to 56.9 million in 2016 (Agustina et al., 2019). The prospective payment arrangements for primary care providers and the structured referral system of the BPJS K were meant to improve efficiency and effectiveness in service delivery and access to health services across regions and income groups. However, challenges remain, such as inadequate numbers and quality of primary care facilities, insufficient availability of specific drugs and medical supplies, mis-targeting of low and middle-income groups, issues of misconduct, and poor health-information systems (Agustina et al., 2019).

1.6.4 Education and health literacy

There is a strong relationship between health literacy levels and health status. Populations with high levels of health literacy have improved self-reported health status, lower healthcare costs, increased health knowledge, shorter hospitalisations, less frequent use of healthcare services (Speros, 2005) and improved health outcomes (Baker, 2006). Part of the discussion about health literacy includes educational levels: the more educated individuals are, the greater their skills in making better-informed health-related decisions (Nutbeam, 2008). Information on patient health literacy is important as this relates to their ability to understand their health status and analyse information regarding health (Nutbeam, 2008). Published research on general health literacy in the context of Indonesia does not provide information about basic health literacy levels. The available research focuses on literacy or knowledge about specific conditions, such HIV-AIDS (Sianturi et al., 2021) or mental health (Novianty & Hadjam, 2017).

One indirect way to measure health literacy levels is by examining educational background and literacy rates. The United Nations Education, Scientific, Cultural Organization (UNESCO, 2021) reported an increase in male adult literacy rates to 92.8 %, and female adult literacy rates to 90.1% in Indonesia in 2011 (UNESCO, 2021). The illiteracy level (in percentages) has varied between provinces (UNESCO, 2021). *Badan Pusat Statistik* (BPS, the Indonesian statistics bureau) reports that the more remote an area, the higher the illiteracy rate (BPS, 2021). In 2018, the literacy rate adult total (% of people aged 15 years and above) in Indonesia was 96%, whereas in the same year in other lower-middle-income countries the rate was 75%, while it was 87% at the world level (The World Bank, 2022).The participation rate of Indonesians in secondary education was 89% in 2018 whereas the rate for other middle-income countries in the same year was 69% and 76% at the world level (The World Bank, 2022). Even though the Indonesian literacy rate and enrolment data in secondary education were higher than other lower to middle-income countries and at the world level, Indonesian numbers were much lower compared to other developed countries in the same region, such as Singapore. In the same year, the literacy rate and enrolment in secondary education in Singapore were 97% and 106% respectively (The World Bank, 2022).

1.6.5 Cultures and religions

As the world's largest Muslim country, Indonesian culture is mainly influenced by Islamic traditions (Haryanto, 2020). Hence, religion and culture are inseparable. Nearly 90% of Indonesians are Muslim with approximately 9.8% Catholic or Protestant Christians (Review, 2022). Indonesia is home to a myriad of traditions and cultures, with more than 1300 major ethnic groups and 2500 languages (BPS, 2010). For instance, a cultural event in Javanese culture is regarded as an expression of gratitude to God the Almighty and reflects belief in the Prophet Muhammed as the messenger of God. The expression of gratitude is held in the form of ceremony. Indonesian people believe no sudden or unplanned occurrence might befall them. Everything happens due to God's determination (Kertamuda & Chrisharyanto, 2008). Indonesians' attitude towards God is *pasrah*, or submission to the will of God (Kertamuda & Chrisharyanto, 2008), including attitudes to, and coping with, illness (Pitaloka & Hsieh, 2015). For adherents, religion provides answers to every question about matters of life, including the purpose of God creating disasters and diseases. Being a faithful person through the declaration of faith is not enough, as God tests His believers with ordeals and difficulties during their life to measure the degree of their true faith pita (Pitaloka & Hsieh, 2015). Yet the relationship between religion, patients' health-seeking behaviours, or clinical decisions in the Indonesian context have been observed differently; related in many cases but not related in other cases (Webster, 2013).

Asian cultures, including in Indonesia, are primarily patriarchal, and this also influences communication between health professionals and patients (Claramita et al., 2020; Claramita et al., 2013).

1.6.6 Healthcare system

The Indonesian healthcare system has a mixture of public and private providers. Public health care is managed by the government, and the private sector is self-funded but also regulated by the government (Mahendradhata, 2017). The public healthcare system is administered in line with the decentralised government system, with central, provincial and district government responsibilities (Mahendradhata, 2017). The central Ministry of Health is responsible for the management of some tertiary and specialist hospitals, strategic directions, setting of standards, regulations, and ensuring the availability of financial and human resources (Mahendradhata, 2017). Provincial governments are responsible for the management of provincial-level hospitals, technical oversight and monitoring of district health services, and coordination of cross-district health issues within the province (Mahendradhata, 2017). District or municipal governments are responsible for the management of district or city hospitals and the district public health network of community healthcare centres (known as *Puskesmas* in Indonesia) and associated subdistrict facilities (Mahendradhata, 2017). Two key laws that support the system are The National Social Security System Law No. 40/2004 (Republic of Indonesia, 2004) and the Implementing Agency of Social Security (BPJS) Law No. 24/2011. There is a range of private providers, including networks of hospitals and clinics managed by not-for-profit and charitable organisations, for-profit providers, and individual doctors and midwives who engage in dual practice (i.e., have a private clinic as well as a public facility role (Mahendradhata, 2017).

Figure 1.1 shows the referral system for patients who utilise the BPJS K for their healthcare service.

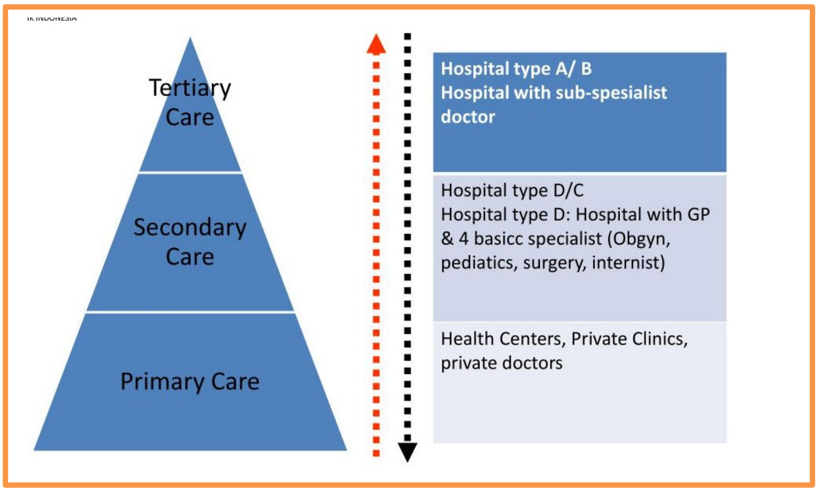

Figure 2.1: Indonesian referral healthcare system

Source: https://www.slideserve.com/lois/vice-ministry-of-health

A *Puskesmas* in the Indonesian healthcare system provides primary healthcare services at the sub-district level (Mahendradhata, 2017). Attending such a centre is a first step into the Indonesian healthcare system for patients before a physician decides whether they will stay enrolled in a *Puskesmas* or be referred to a higher healthcare facility, or provincial or national hospital (Mahendradhata et al., 2017). Following the implementation of universal health coverage by BPJS K, the number of people visiting a *Puskesmas* has increased (Rolindrawan, 2015). However, a *Puskesmas* is perceived by most Indonesians as a service for the poor, so many use their own money for healthcare services and do not use this facility (WHO, 2017).

A *Puskesmas* delivers both curative and public health services, concentrating on 6 essential service areas: health promotion; communicable disease control; ambulatory care; maternal and child health, and family planning; community nutrition; and environmental health, including water and sanitation (Mahendradhata et al., 2017). Should patients require higher levels of care, they are referred from primary healthcare to other services. In reality, many patients go directly to hospitals at their own expense (Mahendradhata et al., 2017). As a result, there are long queues at hospitals for the service (Mahendradhata et al., 2017).

1.6.7 Diabetes care in Indonesia

In general, diabetes care in Indonesia is provided either by tertiary hospitals, private hospitals and clinics, or primary healthcare centres (Mahendradhata, 2017). People covered by the government health insurance scheme who need specialist care can be referred to a secondary healthcare facility or tertiary care if a sub-specialist, such as an endocrinologist, is required (Mahendradhata, 2017). However, to allow better access of care to people with severe diabetes, those without complications have to use primary care facilities, with diabetes care provided by general practitioners at *Puskesmas* (Mahendradhata, 2017). A diabetes care team under the auspices of the Indonesian Society of Endocrinologists (PERKENI), which is only available in major hospitals, includes internists or endocrinologists, diabetes nurse educators and dietitians (PERKENI, 2021).

Clinical medical guidelines for the management of people with diabetes in Indonesia is outlined in *Consensus Management Diabetes Melitus* (PERKENI, 2021). This document provides guidelines for diagnosing, screening, and managing people with diabetes, including the provision of health education (Kedokteran Info, 2010; Eliana et al. (2015). When it comes to the daily practice of diabetes care, doctors report having limited time to manage the diabetes education program to patients (Sutanegara, 2000). Another issue in diabetes care in Indonesia is the lack of availability of diabetes educators. There are fewer than 400 diabetes educators in Indonesia, and they mostly live in Jakarta, the capital city, and other major cities in Indonesia. According to Sutanegara (2000), this number is relatively small compared to the large number of people with diabetes in Indonesia.

In terms of the availability of diabetes medications, and basic technology, it is reported that insulin is not always available at primary care facilities (Soewondo, 2014; WHO, 2016). Therefore, those patients with T2DM who depend on insulin for their diabetes treatment must visit higher-level healthcare facilities (Hidayat et al., 2022), which are normally located significant distances from where they reside. This means people must travel long distances for care, which is costly and possibly explains patient non-adherence with their care. Only first-line oral medications such as *metformin* and *sulfonylureas* are available in primary care facilities. In terms of the technology used to measure diabetes, only blood glucose measurement devices are available in primary care facilities (WHO, 2016). This available data on diabetes healthcare, complication rates and diabetes-related death rates in Indonesia implies that the care provided for T2DM is insufficient (Hidayat et al., 2022; Soewondo et al., 2013).

In 2014, at the national level, the Indonesia Ministry of Health launched a program for people with chronic illnesses called *PROLANIS* (*Indonesion Program Layanan Penyakit Kronis*). This program is a system based on community health care provided for people with chronic illnesses, especially T2DM and hypertension, and focuses on a proactive approach that involves patients and the government healthcare insurance scheme. Unfortunately, existing research shows that the program was ineffective in improving control of metabolic and renal functions (Alkaff et al., 2021). Other problems included lack of human resources, facilities, infrastructure, and lack of standard operating procedures (Rachmawati et al., 2019), which challenged the implementation of the program

1.7 Overview of related concepts

The following is an overview of related concepts regarding diabetes as a chronic illness and patient self-management.

1.7.1 Diabetes mellitus as a chronic illness

Diabetes mellitus is a chronic hyperglycaemia illness caused by multiple aetiologies characterised by disturbances in the metabolism of carbohydrates, fats and proteins resulting from impaired insulin secretion, insulin action or both (Poretsky, 2020). In the long term, the accumulation of glucose in blood vessels produces complications such as eye conditions, cerebral vascular accidents, coronary heart diseases, kidney diseases, infections and other vascular diseases (Poretsky, 2020). In its severest form, short-term complications such as ketoacidosis or a non-ketonic hyperosmolar state may develop and lead to stupor, coma and, in the absence of effective treatment, death (DeFronzo et al., 2015; Holt et al., 2017). The world's longest and largest prospective study on diabetes complications and treatment, the United Kingdom Prospective Diabetes Studies (UKPDS), shows that the impact of T2DM progressiveness, and chronic uncontrolled hyperglycaemia is known to increase the risks of diabetes complications (Lind et al., 2021).

Therefore, maintaining a BGL as close to normal as possible is highly recommended to reduce the risks of diabetes complications (ADA, 2019; Lind et al., 2021).

In addition to these physical problems, people with diabetes also experience psychological and social problems that might be caused by a number of factors, including the diagnosis of diabetes, the related symptoms and a strict treatment regime (Pouwer & Speight, 2017). Some common psychological impacts of diabetes are emotional distress, feelings of boredom and depression, concern about the future, and fear of experiencing short or long-term complications including hypoglycaemia, ketoacidosis, heart disease, cerebral vascular accidents, and other vascular and nerve conditions (Egede & Dismuke, 2012; Pouwer & Speight, 2017). Moreover, people with T2DM perceive their diabetes as demanding and complex (Karlsen et al., 2012). The social problems that have been reported by people with diabetes are caused by the strict treatment regimen, which results in a loss of freedom and the feeling that diabetes management is taking over their lives (Co et al., 2015; Egede & Dismuke, 2012). A global systematic study included 17 countries, the Diabetes, Attitudes, Wishes, and Needs (DAWN-2) that explored healthcare professionals perception on diabetes care and people with T2DM needs suggested the necessity to support self-management and psychology (Holt & Kalra, 2013). Therefore, it is necessary to program and ensure holistic care for people with T2DM that includes biological, psychological and social aspects.

1.7.2 Diabetes care and management

Awareness of the impact of biopsychosocial factors on people with diabetes, and internationally recognised guidelines on diabetes care suggest that people with diabetes take responsibility for their day-to-day care (Garza et al., 2021; Gunton et al., 2014). Much of this care involves keeping their BGL to as near normal as possible. In order to maintain a normal BGL, people with diabetes need to manage their diabetes care, which includes diet, regular exercise, testing their blood glucose and, perhaps, taking oral medications and or insulin (Ahola & Groop, 2013). Self-care largely relies on patients themselves adopting an appropriate program of diabetes care and accepting the consequences of these decisions (Funnell & Anderson, 2004). Concepts of self-care, self-management, patient empowerment, and adherence to regimes are patient-based empowerment concepts that are widely used as foundations in programs aimed at enhancing care outcomes for patients with chronic illnesses, including diabetes (Nolte, 2008; Palumbo, 2017).

The role of self-management in diabetes control has been discussed extensively in the literature and provides evidence of positive outcomes (Heinrich et al., 2010; Van Eikenhorst et al., 2017; Vas et al., 2017). For example, a meta-analysis on pharmacist-led support for self-management (Van Eikenhorst et al., 2017), a group-based diabetes self-management education program (Steinsbekk et al., 2012), and a multidisciplinary, multicentre collaboration that combined the experience of several centres for individuals newly diagnosed with T2DM (DESMOND) (Skinner et al., 2006) respectively resulted in improvements in glucose control (glycosylated hemoglobin – HbA_{1C}), and clinical, lifestyle and psychosocial outcomes. Meta-analysis studies in the area of diabetes care and management suggest a significant correlation between the achievement of quality of life with diabetes self-management (Cochran & Conn, 2008; Fredrix et al., 2018). The existing concepts, theories and empirical studies on managing chronic illnesses such as diabetes also advocate for the importance of self-management, patient-centred care, and patient engagement or participation strategies such as empowerment approaches at the individual and system level(Funnell et al., 1991; Palumbo, 2017).

Although the care of diabetes is highly dependent on patient self-management, evidence suggests that it is suboptimal among patients with T2DM (Ahola & Groop, 2013; Nagelkerk et al., 2006). Health beliefs, self-efficacy, coping and problem-solving skills, low locus of control, and depression are factors known to be patient-related barriers to self-management (Ahola & Groop, 2013). From a wider perspective, self-management has been a challenge for both people affected with chronic illness and the health system (Nolte & McKee, 2008). The existing research perspectives that focus on individual-related factors as barriers to patient self-management, and those identified as contributing, such as the organisation of the healthcare system and social structures, are considered in this study.

1.7.3 Approaches to support diabetes self-management

Patient-empowerment approaches historically emerged in response to dissatisfaction with traditional biomedical approaches to handling chronic illness (Palumbo, 2017). The psychosocial and behavioural dimensions of care were overlooked under the biomedical paradigm that tended to dictate what the patient with T2DM must do (Hewa, 2016).

Supporting self-management in patients with chronic illness such as diabetes, has been discussed in the literature for more than 40 years (Fisher et al., 2005; Pouwer & Speight, 2017). Approaches have included patient level, healthcare organisation, and healthcare system programs. Models supporting patient empowerment (Anderson & Funnell, 2010; Funnell & Anderson, 2004; Pouwer & Speight, 2017); ecological approaches (Fisher et al., 2005); and a chronic care model (Austin et al., 2000; Epping-Jordan et al., 2004), are well known approaches. These various approaches and the models complement each other as concepts promoting patient responsibility, and collaboration in the organisation of health care.

Conceptually, patient empowerment has a psychological component whereby an individual takes responsibility for perceived control and self-efficacy (perceptions of one's ability to achieve desired outcomes), motivation to control, and perceived competence (Anderson & Funnell, 2010; Funnell et al., 1991; Palumbo, 2017; Zimmerman & Warschausky, 1998). Behavioural competence of patient empowerment is used to depict a patient's position in engaging with healthcare professionals and their involvement in their own care (Zimmerman, 1995).

Further, Zimmerman and Warschausky (1998) assert that patient empowerment as a belief system directs how professionals and patients work together. Palumbo (2017) further extends this concept saying that it includes enhancing the levels of communication between the patients and clinicians, involving patients in decision-making about their personal healthcare, sharing health-related knowledge and skills with patients, and encouraging them to assume greater responsibility for their care, to take control, and to negotiate with healthcare professionals (Palumbo, 2017). It also values and considers words, thoughts, feelings, experiences and capabilities of individual patients in the decision-making process (Funnell & Anderson, 2004; Funnell & Anderson, 2005; Funnell et al., 1991). This implies that the relationship between the patient and healthcare professional is an enabling factor in patient empowerment (Palumbo, 2017; Pulvirenti et al., 2014).

Ironically, while the research notes that it is imperative for healthcare professionals to support patient empowerment in diabetes care, they are blamed for creating hurdles in the process of empowering patients (Newton et al., 2011; Scambler et al., 2014). The medical paradigm governing the patient-practitioner relationship is one of domination, where patients are expected to follow instructions rigidly and without question. This is contrary to the philosophy of empowerment (Anderson & Funnell, 2010; Funnell et al., 1991). The medical paradigm in practice has been identified as the main cause of the failure of patient empowerment in diabetes care (Anderson & Funnell, 2005; Palumbo, 2017). A supportive healthcare organisation as proposed in ecological approaches and chronic care models are essential to creating an empowered relationship between patients and healthcare professionals (Nolte & McKee, 2008; Palumbo, 2017).

1.8 Thesis structure

This thesis is structured into 10 chapters. The highlights of each chapter follow.

Chapter 1 is an introduction and background chapter, structured into 3 parts. The first part introduced the magnitude of the problems of patients with T2DM, the aims of the study, research questions and the significance of the study. The second part provided a comprehensive background of the study including the epidemiology of diabetes, the organisation of the healthcare system, and background on the social, economic, cultural and religious features of Indonesia. A comment was also made on education and health literacy levels and diabetes care in Indonesia. The third part reviewed related concepts that included defining diabetes as a chronic illness, patient empowerment and self-management.

Chapter 2 provides an integrative review of published research articles on patient empowerment to support patient self-management in Southeast Asian lower to middle-income countries.

Chapter 3 outlines the philosophical stance used in the study and explains the underpinning theoretical framework: a hybrid of Habermas's theory on communicative action and Honneth's theory of recognition and misrecognition. These 2 theories are used to develop a theoretical framework that guides this research. The concepts of lifeworld and systems from Habermas and domains of recognition from Honneth are also discussed.

Chapter 4 discusses critical theory as the research paradigm, and the research design including the methodology, the justification for adopting the methodology, a single case study with embedded (multiple units of analysis) as the research strategy, ethical considerations, triangulation of data collection methods, the framework for data analysis used for the case studies, and strategies to ensure rigour.

Chapters 5, 6, and 7 provide the results of 3 embedded cases from the *Puskesmas*, provincial hospital, and national hospital. Each chapter commences with a vignette, which provides an understanding of the context where the study was conducted. These 3 chapters present the process of theme and subtheme development outlining how they were generated from the triangulation of data collection methods; observation of clinical encounters, patient interviews and focus group discussions (FGDs).

Chapter 8 presents the final findings of the single case study of diabetes care in the Indonesian context. The chapter provides the process of theme and subtheme generation from each embedded unit of analysis and elaborates the final themes and subthemes.

Chapter 9 provides a discussion of the findings on diabetes care in supporting self-management in the Indonesian context. The discussions focus on the relationship between the findings and the existing literature on patient-empowerment approaches to support self-management and use the theoretical framework to explain the findings.

Chapter 10 concludes the study in relation to the research design, methods and the findings. The chapter also presents the recommendations on features for a future model of diabetes care in an Indonesian context and presents recommendations for future studies. This final chapter also discusses the limitations and strengths of this study.

Chapter 2: Literature Review

2.1 Introduction

This chapter reviews peer-reviewed articles on how concepts of patient empowerment and self-management are used in the care of people with T2DM from Southeast Asian developing countries (SEADCs), specifically in the Indonesian context. The contextualisation of these concepts could be beneficial for researchers wanting to design, implement and evaluate patient interventions to support self-management framed within a philosophy that empowers people with T2DM.

The contexts of social and structural factors are presumably different from one situation to another. Concepts and contextualisation of patient empowerment and self-management have their origins in Western culture. Therefore, the formulation of an empowerment-based intervention is highly dependent upon these concepts and contexts. A sensitivity to the differences between Western and developing countries in terms of socioeconomic and cultural factors, including in health systems is required. The suitability of implementing an empowerment approach to support self-management in the care of people with diabetes in the Indonesian context should be rigorously and systematically explored before it is adopted. Thus, a thorough exploration of how a patient-empowerment approach is conceptualised and used in other contexts is necessary.

This review cannot be generalised to all SEADCs, since it is a diverse region of nations, including diversity within each nation (Evers, 2012; King, 2008). Rather, there are a number of shared common factors in this region. Studies related to this region need to be put into context. Furthermore, any study in the region needs to be sensitive to sociocultural differences.

This literature review is warranted to understand how patient empowerment and self-management are conceptualised and contextualised in the care of people with T2DM in SEADCs in recent publications – first, to identify methodological perspectives of the studies, second, to identify interventions used to support patient empowerment in supporting self-management including the outcomes produced and third, to identify the knowledge gaps in the existing literature.

The following sections report on an integrated review encompassing concept and interventions of patient-empowerment approaches in supporting self-management in the care for patients with T2DM in the SEADCs. In Indonesian context, there had been scarce in-patient empowerment concepts to support patient self-mangement. An integrative review was selected in this study rather than a scoping review because there were limited English publications information in Indonesian context regarding the topic especially the non-research articles, if a scoping review was selected. Therefore, the integrative review was preferred as it facilitated reviews on research and theoretical articles. An integrative review is a method that has the potential for building new knowledge at the level of theory and practice and could inform policy initiatives (Torraco, 2016; Whittemore & Knafl, 2005). This method allows for the inclusion of diverse research methodologies to be reviewed, thus allowing a more complete perspective of various methodologies on the phenomenon of concern to be included (Whittemore & Knafl, 2005).

2.2 Literature review questions

This literature review is guided by the following questions:

1. How is patient empowerment to support self-management conceptualised and contextualised in the care of patients with T2DM in SEADCs?
2. Do empowerment interventions to support self-management framed within a patient-empowerment approach improve diabetes outcomes among adult patients with T2DM in SEADCs?

2.3 Method of literature review: Integrative review

This integrative review was guided by processes outlined by Whittemore and Knafl (2005), which include the stages of problem identification, search methods, data evaluation, data analysis and presentation.

A well specified problem identification and purpose are essential to provide focus and boundaries for the integrative review process (Whittemore & Knafl, 2005). In this integrative review, concepts related to patient empowerment to support self-management in caring for patients with T2DM as a chronic illness provided the framework.

2.3.1 Problem identification

Patient empowerment and patient self-management are important concepts in chronic care management but have not been clearly conceptualised and contextualised (Lorig & Holman, 2003). There is evidence of interventions framed by the patient-empowerment approach in supporting self-management, such as in studies by (Kuo et al., 2018; Mamaghani et al., 2021; Tang et al., 2011) with positive outcomes in caring for patients with T2DM in many Western developed countries. However, there are challenges to its transferability and applicability to other social, economic and cultural systems, including in the SEADCs.

2.3.2 Search for evidence

A literature search on various databases was conducted to ensure the rigour of this review (Whittemore & Knafl, 2005). Three phases of searching were undertaken: databases searches, a manual search and applying inclusion and exclusion criteria.

2.3.2.1 Database searches

Four major databases related to the health sciences (PsycINFO, EMCARE, and SCOPUS PROQUEST) were used to search relevant primary research articles. Search terms relating to the concept of empowerment and patient empowerment, self-efficacy, chronic care illness, self-care management and diabetes mellitus were included. The search was then restricted to Asian countries. Search keywords and Boolean operators included in the search were "diabetes type 2", "patient centred care", "consumer participation efficacy", "Cambodia" OR "Indonesia" OR "Japan" OR "Malaysia" OR "Myanmar" OR "Burma" OR "Philippines" OR "Laos" OR "Thailand" OR "Timor-Leste" OR "Vietnam" OR "southeast Asia" OR "south-east Asia" OR "East Asia". To maximise the number of relevant studies, at first the search was not limited to the year of publication. Then, the search was limited to the last 10 years (2012-2022). The literature search on databases was assisted by an academic librarian. The search also included on a local Indonesian database called Portal Garuda and a manual search from the reference lists of all the articles included in the final review.

2.3.3 *Inclusion and exclusion criteria*

Studies to be included in an integrative review can include all articles or randomly selected studies (Souza et al., 2010). To be included, the articles were required to meet the inclusion criteria for selection: English primary research papers containing key search words in the title and or the abstract; published between 2012-2022; related to patient empowerment, self-management, self-care, T2DM care in the adult population; in a setting context of SEADCs; and with or without interventions to improve self-management. The exclusion criteria included psychometric studies, studies related to drug trials and efficacy, epidemiology studies, study protocols, unpublished manuscripts of theses and in a setting of a social context outside the SEADCs.

2.3.4 *Results*

The results of the search process identified several pertinent facts. First, there were increasing numbers of publications related to patient empowerment and self-management over the last 37 years (1985–2022) worldwide. The number of publications steadily increased, especially after 1997, and reached more than 800 publications by 2018. The literature on this topic was nil before 1985 (see Figure 2.1).

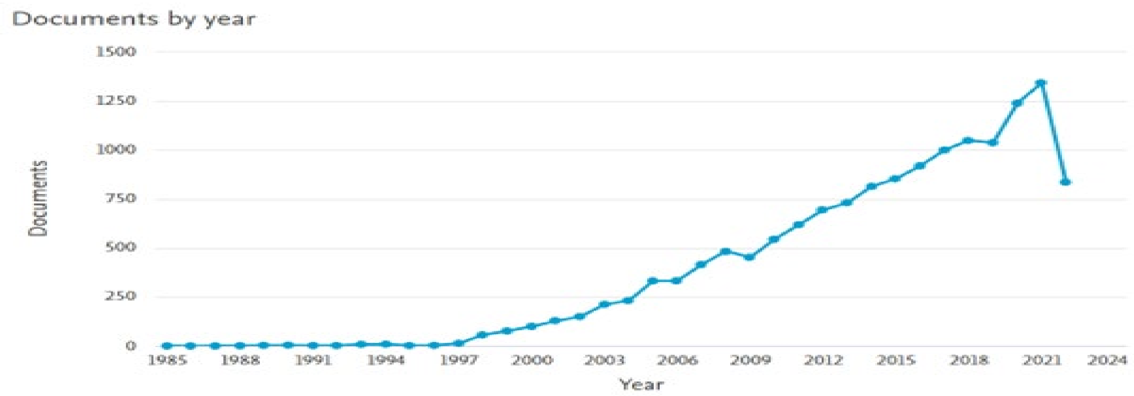

Figure 2.1: The increasing number of peer-reviewed English publications worldwide relating to patient empowerment between 1985 and 2022

Second, the search showed a significant difference in results when limited to Asian developing countries as opposed to all Asian countries. The difference was also evident in the year of the first article published. When the search was limited to SEADCs the first publication was in 1994, nearly 10 years after the first studies. This shows that the exploration of patient-empowerment concepts in publications in SEADC settings in the area of care for patients with T2DM is relatively new.

Thirty-five articles were identified from the final search and selection processes. Figure 2.2 shows the PRISMA diagram of the searching process that included 6 qualitative studies, 1 survey, 18 cross sectional studies, 5 quasi-experimental designs, and 5 randomised controlled trial studies (RCTs).

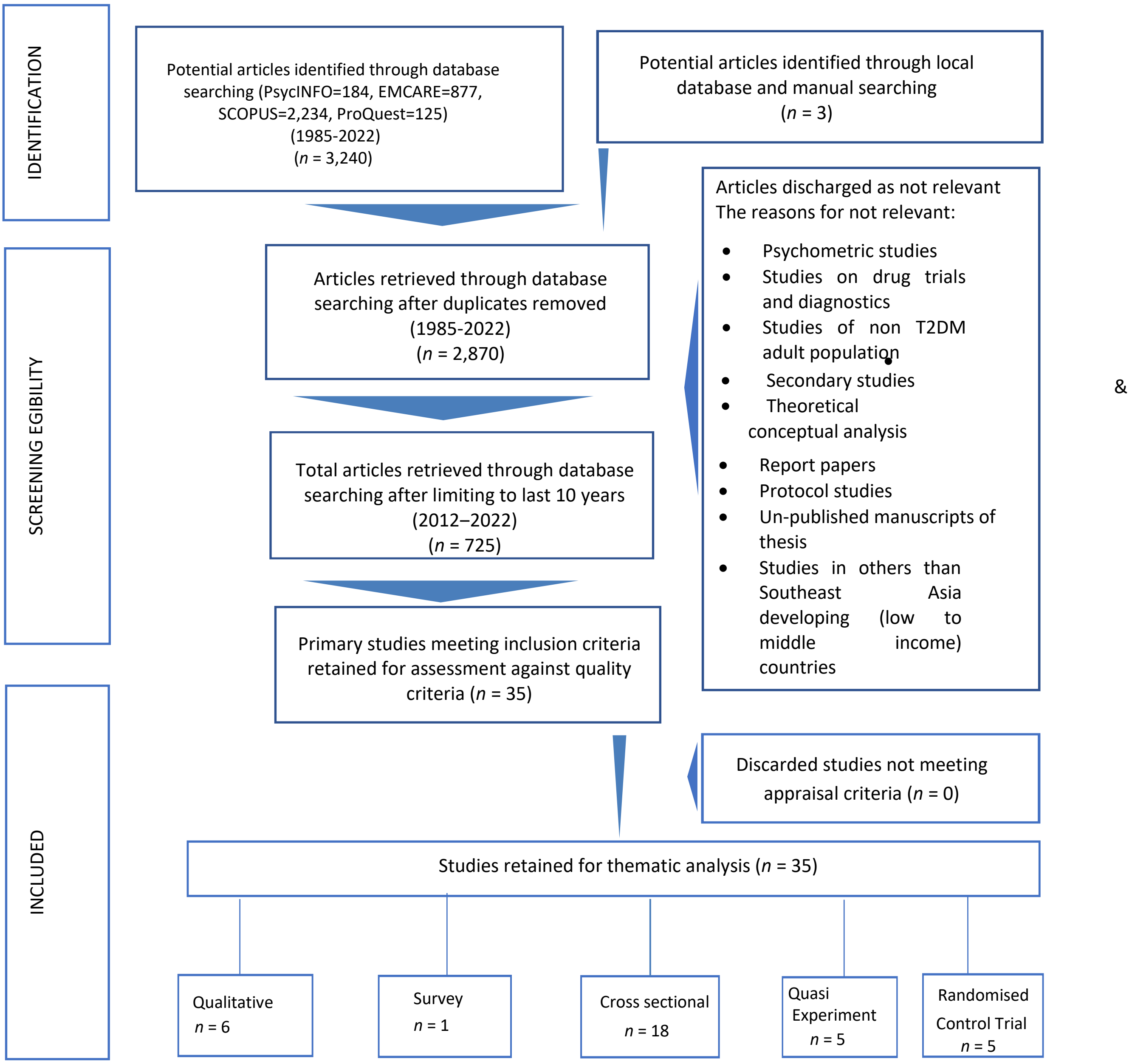

Figure 2.2: Flow diagram of integrative review (adapted from PRISMA, 2009)

2.4 Data evaluation

The final sample for this integrated review included both qualitative and quantitative studies. Countries of origin were Vietnam (1), Indonesia (8), Malaysia (16), the Philippines (2) and Thailand (8). The qualitative studies included phenomenology, a case study, explorative and ethnographic studies. Quantitative studies were cross-sectional, quasi-experiments, RCTs, and surveys. Appendix 1 presents the reviewed studies. Data quality was evaluated based on their methodology using the Joanna Briggs Institute appraisal tools relevant to each research design used in the selected articles (Whittemore & Knafl, 2005).

Studies utilising qualitative methodology were of fair to good quality. The common quality gaps were lack of identification of the culture of the researcher, lack of theoretical orientation; or failure to address the influence of the researcher on the study. No papers were excluded following the appraisal. Regarding the rigour of the 6 qualitative study designs, all stated the study design. Among the theoretical bases used by the researchers were the health-belief model by Lundberg and Thrakul (2018); Yee et al. (2018), self-management in Jaipakdee et al. (2015); Rusdiana and Amelia (2018); Wongrochananan et al. (2015), health education in Susilparat et al. (2014), social cognitive theory in the study by Thojampa and Mawn (2017), self-care deficit nursing theory in Amelia et al. (2018b); Chinh et al. (2017); Khuzaimah et al. (2014); Rusdiana and Amelia (2018), chronic care model in Ramli et al. (2016) and Bandura's self-efficacy model in Hassali et al. (2014); (Ku & Kegels, 2014).

Of the quantitative methodology articles, the main method used was a cross-sectional design (18 research papers) and the least was survey design (1 paper). In most of these studies, there was a lack of identifying confounding factors or details of the inclusion and exclusion criteria. However, overall, the studies were considered as fair to good. Studies based on experimental designs included 5 quasi-experimental and 5 RCT papers. Of the quasi-experimental studies, the main lack of quality noted was the lack of a control group and unreliability of outcome measurements. Except for the study by Chinh et al. (2017) of the appraised RCT studies, the main lack of quality noted was the blinded group of participants and outcome assessors to treatment assignment that were not stated in the reports.

Following these quality appraisal assessments, the articles were critically analysed for their strengths and weaknesses regarding existing evidence related to the research questions.

2.5 Synthesis of evidence

Data were extracted from the reviewed literature and coded into nodes and categories using software NVivo12. The meaningful phrases and sentences (units of analysis) were coded from each paper. The coded units of analysis were then classified into nodes. The frame for creating the nodes was based on the following data classifications:

- concepts of patient empowerment and self-management
- barriers and facilitators to empowering and self-management
- variables used in quantitative studies
- types of interventions experimented or trialled
- measurements of patient empowerment and self-management.

My research supervisors reviewed the NVivo nodes outputs. The themes were then developed guided by the research questions. Finally, 3 key concepts were identified: 1) contextualising and conceptualising patient empowerment in supporting self-management; 2) underlying concepts and related factors of self-management; and 3) patient empowerment-based interventions and outcome measurements.

2.5.1 Contextualising and conceptualising patient empowerment in supporting self-management

The discourse of patient empowerment in supporting self-management in the reviewed papers was loosely defined and contextualised. Very few papers used the empowerment concept in their studies. For example, only (Gunggu et al., 2016; Lundberg & Thrakul, 2018) explicitly defined patient empowerment or addressed the patient-empowerment definition used by Anderson (1996) as one of the seminal works on empowerment for patients with T2DM. The majority of the studies depicted patient empowerment as providing patient-education programs (Eknithiset et al., 2018; Kueh et al., 2017), and delivering emotional or social support as forms of empowerment (Devarajooh & Chinna, 2017; Ishak et al., 2017; Sharoni et al., 2015; Thojampa & Mawn, 2017). Considering that the papers studied particular populations, for example, specific ethnicities such as Thays (people inhibiting Thailand) and Malays (people inhibiting Malaysia and Indonesia), and religious groups such as Buddhists or Muslims, 4 papers adapted patient empowerment to those contexts (Lundberg & Thrakul, 2018; Saidi et al., 2018; Thojampa & Mawn, 2017). Other studies identified family and social aspects (Gunggu et al., 2016; Pamungkas et al., 2021) or cultural aspects such as ethnicity (Khuzaimah et al., 2014), and facilitators or barriers of patients empowerment in supporting self-management (Boonsatean et al., 2016).

2.5.2 Underlying concepts and related factors of self-management

The concept of self-management and self-care behaviours were used interchangeably in the context of care for patients with T2DM. The main underlying concepts used to explain self-management were Bandura’s self-efficacy model (Hassali et al., 2014) ,the health belief model (Lundberg & Thrakul, 2018), social cognitive theory (Thojampa & Mawn, 2017), Pender’s health promotion model (Kurnia et al., 2017), self-efficacy (Tharek et al., 2018) and self-care bahaviour (Khuzaimah et al., 2014). Hassali et al. (2014) used Bandura’s self-efficacy model to explain the reasons for insulin rejection among Malay people with T2DM while Yee et al. (2018) used the health belief model to explain the responses to diabetes and self-management practices of Malay people. Similarly, the self-care deficit nursing theory was used to explain the possible reasons why Thai Buddhists and Muslim people with T2DM did not practice self-management adequately in Thailand (Lundberg & Thrakul, 2018).

The themes that emerged from these qualitative studies included perceived barriers to self-management practices related to misconceptions and lack of knowledge, lack of self-efficacy, the importance of family and social supports, and faith in God. The importance of family supports was identified in (Lundberg & Thrakul, 2018; Pamungkas et al., 2021). Faith in God, identified by (Lundberg & Thrakul, 2018; Saidi et al., 2018) , would be unlikely to be a theme in self-management research in a non-Asian context where issues of religion are not employed to understand the context of self-management in the care of patients with T2DM.

In the quantitative reviewed papers, factors identified as statistically significant in predicting self-management behaviours included knowledge, belief in treatment effectiveness, motivation, self-efficacy, family support, some demographic characteristics and situational influences. Diabetes biomarkers such as HbA_{1C} were found by Thojampa and Mawn (2017) to have a weak correlation with self-management, but self-management in glucose monitoring was reported as having a significant correlation with the quality of life in the study by Kueh et al. (2017). Descriptive and correlation analysis were mainly used to test hypotheses such as empowerment with economic and demographic information, diabetes biomarkers HbA_{1C} and fasting BGL, psychological states, self-efficacy, self-care, and quality of life. Psychological and social behaviour concepts underpinning the reviewed studies contrasted with biomarker evaluations of self-management behaviours, the conceptual basis used to explore self-management. Cultural factors were identified as related to self-management in 3 cross-sectional studies (Boonsatean et al., 2016; Ishak et al., 2017; Khuzaimah et al., 2014; Saengcharoen et al., 2016).

2.5.3 Patient empowerment-based interventions and outcome measurements

Patient education-based programs were the predominant interventions investigated for their effectiveness in non-randomised or RCT studies. Only one of the reviewed studies focused on a technological-based program (Wongrochananan et al., 2015). Diabetes self-management interventions were reported from a pharmacist point of view in a few of the reviewed studies. These 3 studies reported programmed education that was developed based on pharmaceutical-based interventions (Chung et al., 2014; Lee et al., 2018; Saengcharoen et al., 2016) and 1 study developed a culturally modified education program (Damhudi et al., 2021).

In the cross-sectional studies, patient-related problems were identified as being supportive or barriers that were determinants of self-management compared to social-cultural and/or health-system factors. Factors that related to patients included psychological issues such as fear, lack of self-efficacy, motivation and attitude, and cognitive factors such as lack of knowledge of self-management and diabetes, and communication (Devarajooh & Chinna, 2017; Rusdiana & Amelia, 2018; Thojampa & Mawn, 2017). Physical conditions such as microvascular complications, and comorbid diseases, and medical treatments such as therapy preferences and types of therapy, were the least identified barriers in self-care (Abbasi et al., 2018; Ishak et al., 2017; Yee et al., 2018).

Socioeconomic-related factors were less identified than patient-related problems as being barriers to self-management. Those factors included social supports, having a caretaker, financing, family support, monthly income and work status (Eknithiset et al., 2018; Rusdiana & Amelia, 2018; Yee et al., 2018). Culture and religion-related factors were identified as ethnicity, race and religion. One health belief-related factor was a lack of belief in treatment effectiveness (Ishak et al., 2017). While most studies identified patient-related factors that support self-management, no study identified the existing health system as a barrier towards patient self-management.

In terms of evaluation of care for patient diabetes outcomes, biomedical parameters were still used as measurements to identify the effectiveness of patient empowerment-based intervention in the 5 articles (Chinh et al., 2017; Chung et al., 2014; Jaipakdee et al., 2015; Savira & Amelia, 2018). The most common measurements used were blood glucose or HbA_{1C} level, and other biomarkers such as blood pressure, lipids profile and body mass index. The time duration used to follow up the effectiveness of a program in the intervention studies varied from 3 to 6 months. The empowerment-based interventions in the RCTs suggested an improvement of blood glucose performance of HbA_{1c} (Chinh et al., 2017; Jaipakdee et al., 2015). Improved outcomes were also identified in non-biomarker parameters such as health behaviour and quality of life (Damhudi et al., 2021), and in self-management scores (Jaipakdee et al., 2015; Wongrochananan et al., 2015).

2.6 Discussion

Thirty-three articles were selected, appraised and reviewed. The following discussion is framed by the inquiries of this integrated review and the 3 themes. This integrative review explores how patient empowerment in supporting self-management of patients with

T2DM was conceptualised and contextualised in SEADCs in these research publications. The theories and methodological perspectives on patient empowerment used in the reviewed studies are evaluated and discussed. The contextualisation concentrates on how local contexts such as social, economic and cultural factors influenced the studies. The discussion also includes patient empowerment-based interventions used in supporting self-management including how patient-empowerment interventions were evaluated, the measurement and criteria of outcomes applied, theoretical frameworks used to program interventions and the identified knowledge gaps of the existing literature.

2.6.1 Contextualising and conceptualising patient empowerment in supporting self-management

Originating in the 1990s in the United States and some European countries, empowerment can be viewed as part of the growing movement towards greater control for citizens in many areas of life, including health (Roberts, 1999). Patient-centred care was introduced into the healthcare system in response to questions about the effectiveness of the traditional biomedical approach. This approach was seen to focus more on acute care of a diseases rather than on chronic conditions, and increased the dominance of HCPs in the patient–HCP relationship (Palumbo, 2017). Since then, the patient-empowerment movement has been applied in caring for people with chronic illnesses, including diabetes, especially in many Western societies, and interventions framed using this concept suggest improvements in healthcare outcomes (Anderson & Funnell, 2005; Palumbo, 2017).

The literature on patient empowerment points out several issues related to the concept and its practice. There has been ambiguity in defining the terms (Palumbo, 2017; Roberts, 1999) and it has been used loosely in its contexts (Zimmerman & Warschausky, 1998). According to Palumbo (2017) the term *patient empowerment* is regarded as a concept, a process, as well as an outcome.

As a conceptual term, Funnell and Anderson (2005) introduced patient empowerment as a paradigm (new) to educate patients in self-management. It is also a new paradigm introduced to respond to the old paradigm that is a traditional biomedical model approach, which was considered unsuitable for care of people with a chronic illness such as diabetes in which a patient's thoughts, life experiences and voices should be considered in managing patient care (Anderson & Funnell, 2005).

From a process dimension, patient empowerment is seen as a mechanism for supporting patients to take chances, to take control over issues that concern them at the level of organisations and communities, to develop a critical awareness of their environment, participate in decisions that affect their lives and negotiate through good communication with HCPs (Zimmerman & Warschausky, 1998). There are 2 sub-dimensions of the empowerment process that Zimmerman (1995) suggests are psychological and behavioural processes.

First, as a psychological process, patient empowerment occurs inside an individual or, as Zimmerman (1995) asserts, is an intrapersonal component of empowerment; it is the growth of capabilities and how people think about themselves. This intrapersonal component itself is a multidimensional construct that includes domain-specific perceived control and self-efficacy (perceptions of one's ability to achieve desired outcomes), motivation to control, and perceived competence (Zimmerman, 1995). From this point of view, research on patient-empowerment identified themes related-to personal control, such as taking responsibility for self-care behaviours (Ramsay Wan et al., 2012), the process of relinquishing control (Aujoulat et al., 2008) and diabetes self-efficacy (Aujoulat et al., 2008; Lee et al., 2016; Wang et al., 2017). The reviewed papers published in SEADCs seem to apply the patient-empowerment discourse from the perspective of patient empowerment at the patient level.

Second, as a behavioural process, patient empowerment provides individuals with opportunities to develop and practice the skills necessary to take control over their environment, such as decision-making and resource-mobilisation skills, and to learn to critically analyse their environment (Zimmerman, 1995). HCPs are asked to use their power to support patient empowerment at the level of their interaction with patients, especially during clinical encounters (Anderson & Funnell, 2005; Palumbo, 2017). Further, Zimmerman and Warschausky (1998) assert that patient empowerment includes enhancing levels of communication with patients, involving them in decision-making about personal healthcare, sharing health-related knowledge and skills with patients, and encouraging them to assume greater responsibility for their care. Finally, from this perspective, the concept of patient empowerment suggests that HCPs must value and take into account words, thoughts, feelings, experiences and capabilities of individual patients in the decision-making process.

The WHO uses patient empowerment as a framework to encourage people to participate in actions that improve their health by equipping them with sufficient knowledge and skills provided by HCPs (WHO, 2009). From this definition, the WHO positions the role of the HCP as a source of patient empowerment. Understanding patient empowerment from the process dimension should enable researchers to explore patient empowerment from a perspective of the patient's ability to communicate with HCPs, healthcare organisations and the community (Palumbo, 2017). This implies that the patient–HCP relationship is considered an enabling factor of patient empowerment (Palumbo, 2017). This view is consistent with the chronic care model, introduced by Coleman et al. (2009), which argues that patient capabilities in managing their care could be achieved through productive interactions between HCPs and patients. Research using this understanding of patient empowerment explores the concept in relation to the attitudes of HCPs (Asimakopoulou et al., 2011; Scambler et al., 2014; Wisdom et al., 1996). There were no reviewed papers from the SEADCs context that explored the patient-empowerment discourse from this perspective.

2.6.2 Underlying concepts of self-management

Self-care and self-management are used interchangeably in the literature (Barlow et al., 2002; Lorig & Holman, 2003), but in this review, the term *self-management* is preferred as it is a more specific concept than that of self-care. The reviewed papers used psychological-based concepts such as Bandura's self-efficacy model and the health belief model to explore self-management (Lundberg & Thrakul, 2018) . Most of the reviewed papers did not provide a clear definition of what was meant by self-care or self-management. Both terms are presumed to have the same meaning. The self-management concept entails features of active participation of patients in their treatment that aims to minimise the impacts of chronic disease on their physical health status and functioning and to provide them with coping mechanisms for managing the any psychological effects of their illness (Lorig & Holman, 2003; Lorig et al., 1993; Nolte & McKee, 2008). Three important tasks are required for effective self-management – performing clinical tasks (i.e. taking medications), changing behaviours (i.e. change the way patients with low back pain lift heavy objects and dealing with the psychological effects of diseases (i.e. depression) (Lorig & Holman, 2003). However, most of the programs offered in health education were more likely to focus on training patients in clinical tasks (Lorig & Holman, 2003). This is also reflected in the reviewed papers where the tools used to evaluate self-management were based on medical tasks, namely the Diabetes Self-Management Questionnaires (Gunggu et al., 2016). This questionnaire assesses patients for their diabetes medical management – taking medications, following the diabetes diet, doing exercises, seeing a doctor and monitoring blood glucose.

2.6.3 Interventions and outcomes measurement

Measuring patient empowerment has been problematic. From an outcome perspective, patient empowerment it is seen as a result of the ongoing empowering process, so it is an ongoing outcome of the education-based empowering interventions process and it is not a dichotomous variable (Anderson & Funnell, 2010). Based on this perspective, a Diabetes Empowerment Scale (DES) was developed to measure the psychological aspect of the empowerment of self-efficacy (Anderson et al., 2000). This tool has been widely used in research related to patient empowerment (Anderson et al., 2000). The DES has been adapted and translated into multiple languages, for example Spanish and Chinese, but not as yet into Indonesian. The reviewed studies published in the Indonesian context also used the DES to evaluate patient-empowerment programs, although this tool has not been adapted to the Indonesian context through a systematic study such as a psychometric study. A psychometric study to adapt an instrument is useful to ensure the reliability and the validity of the instrument that leads to credible results of the study (Price, 2016).

The patient-empowerment process and outcomes were also evaluated using physical parameters such as HbA_{1C}, body mass index and body weight (Kuo et al., 2014). There was a philosophical inconsistency in the reviewed articles that employed psychological and behavioural-based concepts while also applying a biomarkers approach in evaluating patient empowerment to support self-management. Cross-sectional studies applied theories such as self-care behaviour change (Amelia et al., 2018a; Rusdiana & Amelia, 2018) , health belief model (Yee et al., 2018), and self-efficacy (Devarajooh & Chinna, 2017; Ku & Kegels, 2014; Kurnia et al., 2017). Reviewed studies using these methods focused on predictor factors of self-management behaviours (Ishak et al., 2017; Khuzaimah et al., 2014; Kueh et al., 2017; Rusdiana & Amelia, 2018). The cross-sectional design study included in this review suggests that there was a correlation between patient empowerment measured using DES, and biological markers such as BGL (Kueh et al., 2017). This suggests that the concept of biomedical markers has been explored more as a predictor of patient empowerment than a factor related to non-medical predictors. Such a narrow perspective in understanding patient empowerment might lead to misconceptions about patient empowerment as a concept that is limited to a patient's biomedical factors. How healthcare systems and social and cultural systems contribute to patient empowerment in conceptualisation or in practices that are specific to patients in the context of SEADCs has not yet widely been explored.

All the intervention studies (see Appendix 1: List of integrative review articles) in the SEADCs show statistically significant empowerment-based intervention outcomes within 4 to 12 months of follow up. There were 2 prominent issues on patient empowerment-based interventions in the reviewed studies – a short period in following up the effectiveness of those interventions, and the measurements used for evaluation. Better outcomes of empowerment-based interventions were found when following up 4–12 months of the trialled interventions in the RCT reviewed studies (Chung et al., 2014). Those results report effectiveness of the trialled interventions over short periods (3 and 8 months) (Chinh et al., 2017; Jaipakdee et al., 2015; Wongrochananan et al., 2015). Considering the concept of patient empowerment as an ongoing process, not a dichotomous variable, evaluations on the effectiveness of empowerment-based interventions should have followed the ongoing process principles. An extended duration of following up of the outcomes of the trialled interventions should have been conducted, for instance over 18–24 months.

The existing RCT literature (see Appendix 1: List of integrative review articles) on empowerment to support self-management in patients with T2DM showed inconsistencies in evaluating the patient-empowerment outcomes. This inconsistency was not limited to following up of the outcomes, which varied from short to longer periods, but also to the use of biomarker parameters. Since patient empowerment to support self-management is understood as a psychologically grounded concept, measuring it using biomarkers parameters would be risking attempts to promote a patient's active involvement in their care. The DES should be the main indicator of patient-empowerment outcomes – biomarker and other parameters to show the effectiveness of the programs should become secondary outcomes.

Further, strict and randomly selected participants who were included in the RCT studies, along with the controlled environments set up in the study settings, suggest ideal patient empowerment-based interventions. Contrary to real-life situations, the conditions in the RCT studies could not be simply applied. Potential factors that might contribute to the success of patient empowerment in supporting self-management in the care of people with T2DM, such as culture, social factors and factors related to the healthcare system, were inadequately explored in the reviewed studies. The effectiveness of the trialled interventions in the reviewed studies was followed up within a short period to a maximum of one year. The trials of the empowerment-based interventions might have the potential for their effectiveness to be applied in the context of SEADCs with consideration of other dimensions of patient empowerment as the concept and process.

2.6.4 Barriers and facilitators in empowering and self-management

Experts agree on the influence of social and structural factors on empowerment in health (Angwenyi et al., 2019). Social structures influence people's ability to be empowered (Palumbo, 2017). Anderson (1996) argues that structural inequities have a profound influence on the way people control and manage their chronic illness (the survey study involved Canadian immigrant women who live with chronic illness). The study showed that those who were socially more advantaged (spoke English, had a secure job) had better abilities to manage their illness than immigrant women who did not speak English and worked in poorly paid jobs (Anderson, 1998). The context of social and structural factors are presumably different from one place to another (Anderson, 1998).

Patient empowerment is also influenced by patient preferences for involvement, which may vary throughout an illness, differ across health conditions; and might depend on their level of education, experience, health status, demographics and culture (Palumbo, 2017). Someone with a chronic condition, for example, may have reduced healthcare involvement (Palumbo, 2017). However, how people who live in poverty and are socially and culturally marginalised will be empowered, according to (Angwenyi et al., 2019); Palumbo (2017), was not addressed. Another criticism of the applicability of empowerment was that applying an empowerment approach in a healthcare setting will increase the time spent with patients (Anderson & Funnell, 2010). Although patients value having sufficient time for consultations with HCPs, the medical–industrial model encourages efficiency that leads HCPs to spend less time with their patients (Anderson & Funnel, 2005).

Barriers to patient empowerment were also identified as resistance from HCPs to change their old paradigm when dealing with patients (Anderson & Funnell, 2005). Anderson and Funnell (2005) argue that although HCPs intellectually agreed with the idea of empowerment, when attempts were made to introduce the concept into practice, the old medical model paradigm remained in their minds and was reflected in their interaction with patients. Healthcare professionals still expected patients to follow what they were instructed to do (Funnell & Anderson, 2004). Therefore, creating an empowered relationship between patients and HCPs requires a supportive healthcare organisation, as suggested in the model of chronic care by (Anderson & Funnell, 2010; Bodenheimer, Wagner, et al., 2002; Palumbo, 2017). Reviewed studies in the context of SEADCs showed little exploration of patient–HCP empowerment and healthcare organisations or providers. Further research in this area is warranted.

2.7 Chapter conclusion

Conceptually, in the Western healthcare context, patient empowerment to support patient self-management in the care of patients with T2DM is regarded more than just equipping patients with knowledge. Rather, it is a concept, process and outcome, suggesting a collaborative model of patient–HCP interaction. Reviewed studies in the SEADCs failed to adapt the concept to local contexts. Research evidence on patient empowerment and self-management in the reviewed papers from the SEADCs appears to focus on patient-education programs.

The reviewed intervention studies involved a maximum of one-year follow up to evaluate the effectiveness of a patient empowerment-based program. The results show the statistical significance of diabetes outcomes, illustrating the potential of applying a patient empowerment-based program to support self-management in diabetes care. Although there were no standards of time duration for following up on the effectiveness of patient empowerment-based interventions, more studies with a longer follow up time is warranted when considering the conceptualisation of patient empowerment.

This literature review is not intended to have direct relevance to clinical practice. However, it may provoke clinicians to be socially and culturally sensitive when applying patient-empowerment approaches.

The following chapter, Chapter 3, examines the theoretical framework used in this study. This is followed by Chapter 4 that presents the research design of this study. The next 4 chapters show the research findings. These chapters are followed by Chapter 9 that presents the discussion. The last chapter, Chapter 10 presents the conclusion, recommendations, strengths and limitations of this study.

Chapter 3: Theoretical Framework: The Hybrid of Habermas's Communicative Action and Honneth's Recognition Theories

3.1 Introduction

This chapter presents the philosophical ontological and epistemological positions that underpin the study. The chapter outlines the major ideas behind critical theory, specifically the theories constructed by Jurgen Habermas and Axel Honneth, as the basis for understanding patient empowerment in supporting self-management in the care of patients with T2DM in the Indonesian context. Justifications for adopting a critical theory and a critical realist approach as the theoretical framework and research paradigm are also elaborated.

3.2 Justification

This study utilises the critical theory paradigm as the research framework. Critical theory is used to understand the underlying issues regarding patient empowerment in supporting self-management in the care of patients with T2DM in the Indonesian context. As outlined in the review of literature in Chapter 2, there have been limited studies on how patients with T2DM are supported to self-manage their care in the Indonesian context, and reviews on epidemiological studies show that the majority of patients did not achieve the national targets for diabetes care, which in turn, led to higher mortality rates from the complications of diabetes (Soewondo et al., 2013). The social structure, culture and the existing healthcare system have contributed to failures in improving patient health outcomes (Hill et al., 2013). However, the phenomenon has not been thoroughly explored, particularly in the Indonesian context.

Historically, there is a power imbalance in the relationship between patients and HCPs, hence patients with T2DM are in a vulnerable position within the healthcare system. The results of the integrative review of SEADCs on the management of patients with T2DM highlighted the lack of research on patient empowerment in the Indonesian context (refer to Chapter 2). Therefore, there is a need to study existing patient-empowerment approaches supporting self-management for patients with T2DM in the Indonesian healthcare system in order to formulate better diabetes care approaches and to achieve improved outcomes in the future.

Any study on patient empowerment requires a theory that provides a comprehensive grasp of the social realities and capacities within a country in order to embrace the totality of people's social lives as well as the social processes that constitute it. In this study, a critical theory perspective was chosen as the potential key to uncovering self-awareness among patients, the structures and processes of the healthcare system, and the context of the social and cultural settings of patients. This paradigm was specifically selected to guide this study for several reasons as discussed below.

First, this study requires a theoretical perspective that can uncover unknown information about the organisation of everyday practices within the healthcare system in Indonesia and related policies, and the social and cultural structures. Second, a theory is required that considers the asymmetry of power relationships between HCPs and patients. Third, a theory is required that aims to reveal for individuals the cage of dogmatism and mystification (Kincheloe & Mclaren, 2011). This research attempts to expose the forces that prevent individual patients with T2DM from shaping the decisions that crucially affect their lives.

3.3 Critical theory

Critical theory is a theoretical position developed most notably by Horkeimer, Adorno, and Marcuse within the Frankfurt School (Arato et al., 1982; Thompson, 2017a). The theory has its origins in the conflicting worldviews between capitalism and communism (Held, 1980). The work of Horkeimer, Adorno and Marcuse was a critical response to the ideas of Marx, Kant, Hegel and Weber, particularly Marx (Kincheloe & Mclaren, 2011). A primary goal of critical theory is to understand and help overcome the social structures through which people are dominated and oppressed (Kincheloe & Mclaren, 2011). In this context, critical theory analyses competing power interests between groups and individuals within a society (Kincheloe & Mclaren, 2011). The intention of critical theory is not simply to eliminate one or other abuse, but to analyse the underlying social structures which result from these abuses with the intention of overcoming them (Thompson, 2017a).

3.3.1 Basic assumptions

Critical theorists believe that a theory must adequately explain the social problems that exist (explanatory), offer practical solutions for how to respond to them (practical) and stand by the norms of criticism established by the field (normative) (Thompson, 2017a). Further, critical theory focuses on investigations of deeper consideration of legitimate scientific knowledge through exploration of the connection between politics, values and knowledge that releases human life from oppression. Critical theory contends that:

- a reality is created and shaped by social, political, cultural, economic, ethnic and gender-based forces that have been crystallised over time into social structures that are conceived to be natural
- it is an emancipatory theory proposing a better life for humankind
- there is a relationship between theory and practice
- researchers cannot separate themselves from what they know and this influences their inquiry (research laden) (Thompson, 2017b).

Within this framework, in the context of exploring the existing care approach used in caring for patients with T2DM in supporting self-management in the Indonesian context, a critical and comprehensive theoretical framework, such as advocated by the critical theory paradigm, is essential to unveil the underlying issues that prevent a potential new effective approach towards future care. One of the most prolific 20th century critical theorists, Jurgen Habermas, articulated many of these ideas as an underpinning for a research method (Fultner, 2014).

3.3.2 Habermas's critical theories

This section focuses on Habermas's works on critical theory, which have been used extensively in medical sociology as indicated by Scambler (2001). Habermas's works can be discussed from 2 perspectives; as a metatheoretical methodology of critical theory as a research tradition and as a theory of communicative action (Morrow et al., 2001; Morrow & Brown, 1994; Small & Mannion, 2005). His key concepts; the theory of knowledge and human interest, and the theory of communicative actions and its conceptual foundations: lifeworld and systems are discussed here as they are foundational to understanding his ideas.

3.3.2.1 Habermas's theory of knowledge and human interest

In relation to knowledge development, the first phase of Habermas's work is directed towards a critique of positivism, especially the ideology underpinning science and technology (Habermas,1970 in (Bubner, 1982). Habermas criticises sciences that cannot be understood without reference to the knowledge constitutive interests that govern them (Rehg, 2018a). By this he means that all science is produced purposively and with intention (Rehg, 2018a). The goal of positivism is a unified science to which all disciplines must adhere (Makinen & Tredell, 2003). In contrast, Habermas argues that scientific knowledge is not neutral, instead it is governed by cognitive interest (Rehg, 2018a). These interests are the product of human interests (Makinen & Tredell, 2003). Thus scientific knowledge has its own in-built assumptions that determine the kind of knowledge produced (Makinen & Tredell, 2003).

Further, Habermas argues that science and rationality within the capitalist system have turned against human beings, impoverishing their cultural lives and exacerbating pathological forms (Rehg, 2018b). Bubner (1982) describes this as the slave of instrumental, or purposive rationality, rationality that is driven by human interests. Science thus has contributed to technical rationality, which has enabled capitalism to develop more commodities, as well as products that destroy human life. However, science is incapable of producing a creditable justification for the capitalist system itself. In short, the technical understanding of science as positivistic, is ultimately ideological for it denies the hermeneutic component in science (Rehg, 2018b). To Habermas, knowledge is the key to human liberation (Cannon, 2001). While the positivistic paradigm dominates the world view, it is not capable of understanding humans and social elements (Khanna, 2019). What is required is a hermeneutic or interpretative approach to achieve knowledge that will liberate humans (Cannon, 2001) .

There are 3 types of knowledge produced based on the interests behind them: empirical knowledge, hermeneutic interpretations and critiques of domination (Habermas,1971 in (Bubner, 1982). Empirical-analytic sciences obey technical knowledge and have constitutive interest in the instrumental regulation of objectivity (Rehg, 2018a). Knowledge based on the control of culture is referred to as technical knowledge and can be pursued using empirical-analytic methods (Rehg, 2018a). Historical-hermeneutic sciences, on the other hand, correspond to a practical interest in intersubjective understanding. Historically, hermeneutic techniques reveal practical knowledge based on understanding (Kincheloe & Mclaren, 2011). Practical knowledge in this instance refers to knowledge that allows for inter-subjective and in-depth perception of the social world (Bubner, 1982; Rehg, 2018a). Finally, the emancipatory sciences, are in the service of critical self-reflection (Bubner, 1982). The first 2 forms reflect the traditional division between the natural sciences and the humanities (Rehg, 2018a). The third category, however, is new (Rehg, 2018a). The pursuit of emancipatory knowledge, through a critical dialectic, leads to self-reflection or intra-subjective knowledge and freedom from oppression (Bubner, 1982).

Research in health care adopting a critical theory paradigm has been challenging. In fact, Scambler (2001) suggests that Habermas's critical theories are the most relevant to the healthcare domain, particularly discourses on lay health knowledge, doctor–patient interactions, health politics, inequalities in health care, health movements and rationing. Table 3.1 shows the categories of knowledge according to Habermas's conceptual framework of knowledge, constituting the knowledge interest that provides the framework for thinking about this study in understanding patient empowerment in support of self-management in the context of the Indonesian healthcare system

Table 3.1: Categories of knowledge and knowledge interests according to Habermas

Knowledge	Approach	Knowledge Interest
Empirical-analytical	Objective	Technical
Historical-hermeneutic	Subjective	Inter-subjective
Social critiques	Subjective self (intra-subjective)	Emancipative

Empirical-analytical knowledge is based on a positivistic paradigm (Rehg, 2018a). It is a paradigm that has dominated the world according to Habermas and colleagues (Arato et al., 1982; Habermas, 1985). Habermas defines empirical science as constituted by technical interest, that is, by the goal of successful prediction and control of nature, ensured by the method of generalisation, testing and corrective feedback (Rehg, 2018a) . The biomedical model is one of the oldest frameworks used to understand human functioning under the positivistic paradigm (Hathcoat et al., 2019; Rehg, 2018a). For example, in the reviewed studies on empowerment to support self-management in patients with T2DM in the SEADCs (see Chapter 2), the majority of the articles utilised the positivist paradigm. This highlights philosophical inconsistency; conceptually patient empowerment and the self-management phenomena are rooted in individual psychology and social realities, but these factors were measured using objective tools, for example, the DES. Patient empowerment is not a dichotomous variable, rather it is a continuous process of being empowered (Anderson & Funnell, 2010). Whether patients were empowered or not, the measures used to test were justified by the score in the DES and other biomedical parameters such as BGL. However, conceptually patient-empowerment advocates autonomous and informed decision-making (Anderson & Funnell, 2010). Thus, knowledge of patient empowerment for supporting self-management has been reduced to the quantifications of objective biological measures, which are far from the original ideas of patient empowerment in the context of chronic illness care (Palumbo, 2017). Only 5 studies (Hassali et al., 2014; Lee et al., 2018; Lundberg & Thrakul, 2018; Saidi et al., 2018; Yasa et al., 2018) that explored patient empowerment to support self-management in the SEADCs used inter-subjective or emancipated knowledge.

3.3.2.2 Habermas's theory of communicative action

Habermas's theory of communicative action, developed in 1981, is one of the most influential communication theories of the 20th century (Habermas, 2001). The theory is acknowledged by sociologists as a foundation of contemporary critical theory (Given, 2008; Marinopoulou, 2019). The distinctive approach of Habermas's critical theory is his focus on freedom of interpersonal interactions from domination as is found in ordinary life (Baynes, 2015). Habermas's communicative action theory was built from 2 prominent concepts: *lifeworld* and *systems*, as discussed below.

The background to communicative action

The Habermas theory of communicative action was developed to construct a 2-level concept of society that integrates the lifeworld and system paradigms, and to sketch out a critical theory of modernity that explains its sociopathology in a new way (Baxter, 1987; Fairtlough, 1991). For Habermas, critical theory questions the fact that 'steering media (money and power) attack the communicative infrastructure of a largely rationalised *lifeworld'* (Fuchs, 2016a, p. 4).

The theory of communicative action was developed as Habermas systematically reflected on a breakdown in communication and crisis of reason faced by modern society (Baxter, 1987; Lafont, 2018). Habermas critiqued the modern way of thinking and instrumental rationality as a rationality that is used only as tools to achieve goals (Lafont, 2018). This kind of rationality can be used appropriately only when the relationship is between a subject and object, mainly an object that is natural or material (Lafont, 2018). To Habermas, this kind of subject-object relationship is inappropriate to be practised within society (Thompson, 2017a). The reason for this is that societies and their embedded cultures are controlled by symbols that require interpretation (Baynes, 2015). In contrast to instrumental rationality, a communicative rationality is conceptualised and juxtaposed with the previous concept of instrumental rationality, where rationality governs the choice of means to be given (Scambler, 2001). The communicative rationality approach allows each individual's interests to be expressed and communicated to reach agreement that should satisfy all the individuals and achieve action plans as outcomes. Hence, Habermas's theory of communicative action is an underpinning framework required for emancipatory constitutive interest (Lafont, 2018; Scambler, 2001).

Habermas defines communicative action as a process that aims to achieve mutual understanding (Fairtlough, 1991; Lafont, 2018). According to Fairclough (1991) the human capability to communicate is socially constructed. Habermas and colleagues (1991) suggest that the understanding between or among actors (Habermas refers to them as speakers) cannot be attained through objective reality (Lafont, 2018). Further, Habermas criticises the work of his predecessors, '*Horkheimer and Adorno, who failed to recognise the communicative rationality of the life-world'* (Fuchs, 2016b, p. 29). Rationality, for Habermas, is a characteristic of human subjects who are able to speak and act, which presents in behaviour patterns for which good reasons exist (Lafont, 2018). Communicative competence, the capacity to make oneself understood and to understand others, is based on this rationality, which functions as a tool either to dominate or to emancipate (Lafont, 2018). Analysis of the relationship between the concepts of lifeworld and social system are the central aspects of the communicative action of Habermas's theory (Baxter, 1987; Fairtlough, 1991). Daily lives where people live, shape views and share with others have led to these 2 distinct concepts of lifeworld and systems (Neves, 2018). Hence, they are recognised by his supporters as fundamental for successful communication, or what Habermas contends is a communicative action.

The lifeworld

The concept of lifeworld describes the reality in which each of us exists (Neves, 2018). This is *the world as taken for granted* in which individuals seek to realise pragmatic objectives (Neves, 2018). It is the horizon in which communicative action can take place, or the horizon of consciousness (Habermas, 1985; Neves, 2018) and a symbolic space within which culture, social integration and personality are sustained and reproduced (Fairtlough, 1991). It also consists of private and public spheres respectively, households and mediated arenas of open discussion and debate (Habermas, 1985; Neves, 2018). The lifeworld is comprised of 2 structural components: culture and society (Fairtlough, 1991). Culture refers to the cultural traditions that construct actors' interpretive scheme and standard of values, and society, is the institutional order of society (Baxter, 1987).

In their lifeworld, actors refer to 3 reference worlds that are connected to each other: the objective, social and subjective worlds (Neves, 2018). The objective world questions which statement is true or false (Neves, 2018). In health care, the objective world encompasses various scientific and theoretical knowledge bases of actual cases or organised routines (Fairtlough, 1991). The social world is based on whether a thing can be right or wrong (based on contentions) (Fairtlough, 1991). The subjective world, the world of the speaker's own psyche, is based on whether the speaker can report sincerely or otherwise (Baxter, 1987).

In this example, the lifeworld is the medium or symbolic space within which culture, social integration and personality are sustained and reproduced: it consists of private and public spheres (respectively, households and mediated arenas of open discussion and debate) (Neves, 2018). Habermas shows that lifeworld is built upon 3 structural components of society (Baxter, 2002, p. 491) namely: 1) culture, where systems of knowledge, values, norms and traditions have developed historically and are inherited by members of society; 2) society, where basic institutions exist, such as the economy, politics and legal institutions, and 3) personality that is reflected in personal dispositions, competences, interests and motivations. For Habermas, there are possible changes in social institutions and individual relationships in modern societies, as compared with that of traditional societies (Baxter, 1987). Due to dialogue and interactions among individuals in society, he proposes a concept of communicative rationality where shared understanding is the key to effective communication (Baxter, 1987). The term *communicative rationality* is greatly influenced by Weber's theory of rationalisation. Things that happen in the lifeworld are commonly communicative by nature (Baxter, 1987). Communicative rationality needs the notion of criticisability, which is problematic to the concept of system (Baxter, 1987).

Every individual has the right to critically question a regulation imposed by the government if communicative rationality is to occur. However, due to the control of government, rationality as such hardly happens, for information is not validated through debate. Rational criticism is clearly circumscribed.

The system

The system is developed upon structural components that consist of money, power, influence and value-commitment (Neves, 2018). The economy produces money, the state wields power, the public sphere provides influence, and the private sphere provides commitment (Neves, 2018). The system is related to the material; it plays more as instrumental or strategic action, or action oriented to outcome, and has a tendency to colonise the lifeworld (Knox, 2016; Scambler, 2001). Habermas eventually believed that only money and power were genuine media for transactions in the social system (Baxter, 1987). The economic and administrative systems are media-steered systems (Baxter, 2002). A money-mediated interaction can claim validity of communicative action (Baxter, 1987). Therefore, 'their interaction is coordinated not by communicative consensus, but by the consequences of their respective success-oriented calculations and their mutual strategic influence' (Baxter, 2002, p. 539). Hence, these concepts of system and lifeworld would provide a basis for arguments about how the Indonesian healthcare system contributes to patient empowerment in diabetes care management and provisions. The details of the relevance of the concepts are presented below.

3.3.2.3 Relevance of the study

In health, Habermas's theory of communicative action, with its fundamental concepts of lifeworld and the system have been applied to understand phenomena such as lay health knowledge (Williams & Pay, 2013); doctor–patient interactions (Scambler & Britten, 2013); and class, power and durability of health inequalities as challenges to be interrogated (Scambler, 2013). These concepts are relevant to this study on patient empowerment in the care of people with T2DM towards their self-management as they provide a framework for understanding how the existing Indonesian healthcare system works in supporting patient self-management. This is necessary to understand 3 main issues known in health care to be barriers for empowering patient self-management. First, there are issues of power asymmetry in patient–HCP communication during the medical encounter in supporting self-management for patients with T2DM. Habermas's theory of communicative action provides a framework for systematically identifying potential communication gaps and explaining whether the communication worked, or actions were taken, based on intersubjective mutual understandings. Communicative action also points to possible communication distortion that prevents patient empowerment taking place. Second, if there was a communication distortion at the level of patient and HCP, what might be the lifeworld-patient values, social standards, or order in society that could possibly contribute to constructing this world? Finally, concerns for the system, in this case the health system, tend to dominate a patient's lifeworld. The concept is used to identify constraints of communicative action in diabetes care to support patient self-management that have been dominated by the economic systems, politics and cultural traditions in the Indonesian health-system context.

3.3.3 Axel Honneth's theory of recognition

This next section describes the theoretical direction taken by Honneth that distinguishes it from that of Habermas. Honneth's theory of recognition also underpins this study.

Axel Honneth is a third-generation member of the Frankfurt School of critical theory. He points out that the theoretical foundations of intersubjective relationships is not merely based on communication as indicated by Habermas, but also on the recognition of dimension (Gangas, 2017; Thompson, 2018). Honneth proposes a shift of the normative paradigm from the presuppositions of communicative action to the presuppositions of human identity development (Gangas, 2017; Thompson, 2018). Compared to Habermas, Honneth offers a more humane approach, with concerns about identity and the non-economic dimensions of power with a more comprehensive view of the human subject and inter-subjectivity (Thompson, 2018).

The key claim made by Honneth is that each individual struggles to gain various forms of recognition through interactions with others (Petherbridge, 2013; Thompson, 2017c). Honneth affirms that there are 2 struggles for recognition, one at the level of individuals (the individual's struggle for recognition) and the second at the level of the social (struggle for recognition in social relationships). Recognition, for Honneth, is of vital importance in that individuals and groups need, and often struggle for, something that can both motivate emancipatory political movements, and function as an evaluative criterion for just or good political measures or societal order (Petherbridge, 2013; Thompson, 2017c). Honneth claims that the struggle for recognition lies behind all major social conflicts (Gangas, 2017).

Honneth distinguishes 3 key types of recognition, each associated with a distinct type or sphere of social relationship (Honneth & Farrell, 1997). First, people need to be recognised as a legitimate object of care, recognition that Honneth terms *love* (Thompson, 2014). The primary sphere of love is the family, paradigmatically in maternal love for one's child (Petherbridge, 2013). Second, people require recognition of their equality to others, which Honneth terms *respect* (Petherbridge, 2013). Honneth argues that contemporary Western societies primarily allocate respect through legal rights in civil society (Schmitz, 2019b). Third, people need recognition of their unique social contribution, which Honneth terms *esteem* (Petherbridge, 2013). Honneth argues contemporary Western societies predominately allocate esteem through work (Petherbridge, 2013). According to Honneth, each type of recognition develops a different self-relationship: love develops self-confidence; respect develops self-respect; and esteem develops self-esteem (Schmitz, 2019b; Thompson, 2014). Denial of recognition can undermine these self-relationships, and thereby threaten the fully developed subjectivities autonomous discourse requires (Thompson, 2014).

Another key concept proposed by Honneth is that recognition has both a normative and a psychological dimension (Honneth & Farrell, 1997; Thompson, 2014). Recognition does not only matter normatively, but is also what Honneth criticised about Habermas's theory of communicative rationality (Petherbridge, 2013). Rationality as intersubjective communication will not work if it just relies on communication (Petherbridge, 2013). It is also of psychological importance. Most theories of recognition assume that in order to develop a practical identity, a person fundamentally depends on the feedback of other subjects (and of society as a whole (Petherbridge, 2013). Honneth reconstructs the normative standards for social criticism. The possibility for sensing, interpreting and realising one's needs and desires, in short, the very possibility of being *somebody,* depends crucially on the development of the 3 spheres: self-confidence (gained from recognition in loving and being loved), self-respect (gained from recognition in law) and self-esteem (gained from recognition in solidarity (Petherbridge, 2013). These 3 domains of relating practically to oneself can be acquired and maintained only intersubjectively through relationships of mutual recognition (Schmitz, 2019a). These relationships are not historically given but must be established and expanded through social struggles (Petherbridge, 2013; Schmitz, 2019a).

To summaries, Honneth argues that human emancipation can only be achieved through 3 forms of recognition. Honneth's theory of recognition is relevant to this study as it touches on the mechanisms or dynamics of acceptance between patients and HCPs (in order to gain self-confidence); the internalisation of values, and patient and HCP norms and understanding about self-management; healthcare institutions; and policies (recognition of patient rights). There are potential issues in interactions between patients with T2DM and HCPs in supporting patient self-management as has been shown in the literature; this includes how the formal Indonesian healthcare system including HCPs recognise a patient's health rights and status, and cultural and social integrity that might contribute to their self-management.

3.3.4 Hybrid of Habermas's and Honneth's theories

Finally, the concepts of Habermas's theory of communicative action and Honneth's theory of recognition appear to be suitable for research on patient empowerment. Each theory has its own weaknesses and strengths in exploring the phenomenon of this study. However, if the 2 theories are combined the strengths of the concepts in both can be applied to this research, providing a hybrid theory that strengthens the theoretical framework of this research. The influence of Indonesian healthcare as a system (macro-level) towards supporting care for patients with T2DM can be understood using the concepts of Habermas's lifeworld and systems, and the rationale of communicative action, while Honneth's theory of recognition can be employed at the level of the social relationships in the struggle for recognition. At the micro-level of care there is interpersonal communication between patients and HCPs, and there is interaction between healthcare team members from multidisciplinary healthcare professions; these are relevant as explorations of intersubjective communication.

Lifeworld and systems are not just about spheres of activity or forms of rationality, but methodologically speaking are perspectives that the researchers themselves can find valuable to adopt and explore. Together they provide a dual perspective that situates Habermasian's research within its critical theory framework by enabling the researcher to both interrogate subjective experiences and ways of thinking (the lifeworld perspective) but at the same time locate them objectively within wider economic and political processes (the system perspective). A Habermasian methodology takes subject and object not as exclusive choices, but as dual ways of looking at the same research context at the same time. Figure 3.1 shows the hybrid nature of Habermas's theory on communicative action, including the concepts of lifeworld and systems, and Honneth's theory of recognition. The 3-part system consists of patients with T2DM, HCPs and a healthcare organization linked to form a triangle. The triangle represents the interactions between the 3 that should be in balance. The arrows depict the mutual recognition that ideally occurs in order to get balance within the triangle system. As in Honneth's theory of recognition, the relationship between the 3 may result in positive or negative impacts. The positive impacts may be the recognition of patient self-management as skills that lead to optimal outcomes of diabetes care, both at the level of patient and nationally. The dash lines of the smaller circle represent a lifeworld of patients, HCPs, and the model of care (regardless of the existing or future model of care). The lifeworld according to Habermas is the everyday realities of life. The bigger circle represents the system, the Indonesian healthcare system, that historically, tends to occupy the lifeworld.

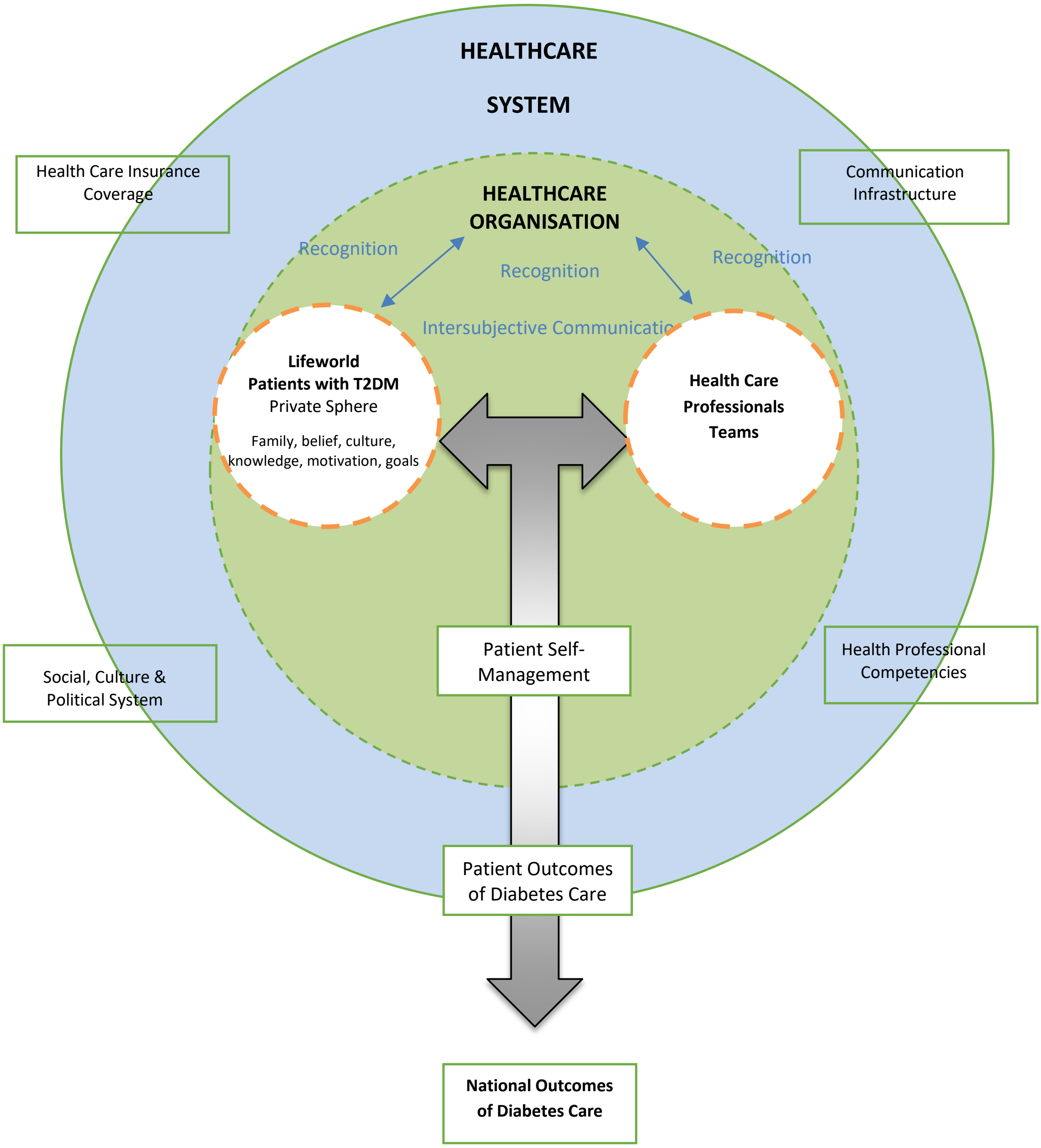

Figure 3.1: Theoretical framework of empowerment in care for patients with Type 2 diabetes mellitus towards self-management based on a hybrid model of Habermas's theory of communicative action and Honneth's theory of recognition

3.4 Critical theory as a research paradigm

Among other known research paradigms, such as positivistic and interpretive approaches, critical theory is located between these 2 competing paradigms (Morrow & Brown, 1994). This section elucidates how critical theory as a research paradigm frames this study, how reality is viewed (ontological position), how the knowledge is produced and truth claimed (epistemological position), and how this research is undertaken (methodological position). Critical theory research is a paradigm that entails a basic belief system, ontological, epistemological and methodological assumptions or worldviews, by which individuals see social reality and its pathologies (Denzin & Lincoln, 2017). The theory attempts to apprehend completely the roles of individuals in their social contexts through social processes by engaging in social criticisms. As a research paradigm, critical theory is a map to define questions and strategies and to explore a phenomena (Kincheloe & Mclaren, 2011).

Finally, as knowledge is value laden, researchers may be influenced in their findings (Hathcoat et al., 2019) as the relationship between the researcher and the participants is also an issue of power and trust that needs to be considered. Further, critical methodology is dialogic and dialectical (Guba & Lincoln, 1994).

3.4.1 Research approaches in health care

Historically, knowledge of human health has largely built on the biomedical sciences to control disease, to understand the epidemiology and to design health systems (Marinopoulou, 2019). Medical knowledge specifically has been developed within a positivist framework (Marinopoulou, 2019; Straus & Brown, 2019). Under this approach phenomenon are quantified and must be able to be measured objectively. Research under this approach denies that humans cannot always be quantified exactly (Morrow & Brown, 1994). Biopsychosocial-based approaches have been applied in studies that consider other than just biological aspects, psychology and social aspects of human function (Marinopoulou, 2019).

The positivist approach, which is mainly used in biomedical research, seeks objectivity in such a way that it fails to understand social phenomena (Hathcoat et al., 2019). In contrast to the biomedical approach, healthcare systems should also be studied as social constructions (Unger et al., 2011). Critical theory as a research framework has not been widely adopted by HCPs, perhaps because it is unclear how the profession would engage in diagnosis and treatment under this perspective (Hathcoat et al., 2019). Research exploring health care to support patient self-management using the critical theory framework has been scarce in Indonesia (see Chapter 2). In fact, the organisation of healthcare services and healthcare systems rely much more on human sciences.

In relation to knowledge production set up by critical theory as a research paradigm, Kincheloe and McLaren cited in Hayes et al. (2011, p. 342) argue:

> that all thought is fundamentally mediated by power relations that are social and historically constituted; that facts can never be isolated from the domain of values or removed from some form of ideological inscription; that the relationship between concept and object and between signifier and signified is never stable or fixed and is often mediated by the social relations of capitalist production and consumption; that language is central to the formation of subjectivity (conscious and unconscious awareness); that certain groups in any society are privileged over others and, although reasons for this privileging may vary widely, …; and finally, that mainstream research practices are generally, although most often unwittingly, implicated in the reproduction of systems of class, race, and gender oppression. (Hayes et al., 2011, p. 342)

From these vantage points, this study took the ontological and epistemological positions aligned with the critique advocated by the critical theory research paradigm that are explained further in the following section.

3.4.2 The ontology position

The first philosophical pillar in generating knowledge is ontology attitudes, that is, questions of being and knowing (Chia, 2002). Ontology is defined as a vantage point of the nature of reality, or an object of investigation and a study of reality structures (Hathcoat et al., 2019). Ontology is a starting point by which researchers imagine and construct a theoretical framework or paradigm for any significant research (Marinopoulou, 2019). The ontological position taken determines how research is to be conducted and what kind of knowledge is produced (Chia, 2002; Hathcoat et al., 2019; Marinopoulou, 2019). By identifying the phenomenon or objects of a study, and viewing them using certain ontological positions, the researcher is assisted in navigating the study through the process of obtaining certain knowledge (epistemological) in philosophically and methodologically consistent ways (Hathcoat et al., 2019).

Universally, reality is categorised into 3 dimensions that are viewed as methodologically important (Strydom, 2011). The dimensions are from the surface empirical manifestation, through to the actual concrete situations (actors, intentions, relationships, things, events, objective structures, real mechanisms), to the reality level as validated and collectively accepted in scientific and public discourse (Strydom, 2011, p. 146). The empirical domain refers to that which the individual can observe and feel or experience (Bhaskar, 2010; Collier, 1994; Strydom, 2011). However, events occur in the actual domain and may not be observed at all or may be understood quite differently by observers (Bhaskar, 2010; Strydom, 2011). Events occur as a result of mechanisms that operate in the real domain (Bhaskar, 2010; Strydom, 2011). It is not the case that the real or actual cannot be observed, but simply that it may not always be capable of being observed (Strydom, 2011). This points to the real powers and liabilities of things that may or may not be manifested as actual occurrences or empirical events (Strydom, 2011); agency that is independent to both mind and society. These 3 dimensions of reality are mutually interdependent (Strydom, 2011). In more detail, realists categorise the reality into things, structures, events and underlying generative mechanisms whether they are observable or not observable (Chia, 2002).

In regard to the objective dimension, critical theory takes a unique point of view that is explained by Strydom (Strydom, 2011, p. 147), who suggests that it adopts a realist ontology:

> Critical theory's option for a weak naturalistic ontology and pragmatic epistemic realist epistemology distinguishes it also from critical realism which, while avowedly focusing on generative mechanisms, nevertheless tends in the direction of an ontological realism. As we have learned from Peirce through Apel, Habermas and Bernstein, reality is a tension-laden concept – a tension given with the fact that reality is in process. As something on which the objectivity of knowledge depends, 'reality' on the one hand refers to an objective actuality and the structures or generative mechanisms underlying it. (Strydom, 2011, p. 147)

Critical theorists believe that reality is a product of social constructs (Paton, 2002). It is historically constituted and a product of power relationships (Marinopoulou, 2019). In short, critical theorists assume that forms of domination are involved in social order and the critical theory interest stresses the struggles to change those relationships of domination-subornation (Morrow & Brown, 1994). Reality is therefore not free from oppression or power (Easton, 2010). To this end, ontologically, this study adopts a critical realist approach.

The objects of reality in this study include the Indonesian healthcare system, related policies and healthcare organisations including HCPs; patient empowerment in supporting self-management; patients and HCP perceptions; and patient and HCP communication or medical encounters. The empirical dimensions include the interactions of HCPs and patients with T2DM in clinical encounters. These objects of reality are empirical as they are observable occurrences, able to be seen, heard and sensed. They have been studied in seminal works by Parson (1951) and others (Scambler & Britten, 2013) for over 50 years. Patient and HCP interactions are also located in the actual and real dimensions of reality.

3.4.2.1 Structures and mechanisms

In relation to its ontology, a structure of entities is ‘a set of internally related objects or practices’ (Sayer, 1992, p. 92). For example, an organisation may be comprised of a series of other entities, such as departments, people, processes and resources that can affect one another. Structures are nested within structures (Easton, 2010). For example, entities can be organisations that have departmental structures (healthcare organisations) and relationships (professional relationships) and, within them, individuals who have particular characteristics such as gender and psychological structures (Easton, 2010). Gender forms part of the internal relationships of a person if gender is to be regarded as a necessary part of the structure that is being built (Easton, 2010). In this study, the healthcare system, the related policies, the organisation of healthcare (clinics or hospitals), the administration, agency, social system and culture are considered as the structures and mechanisms. They are real as they possess certain internal sources of energy that account for the activity of each and for its influence on the course of events. In this case, these structures and mechanisms may or may not influence the events, such as medical encounters between patients with T2DM and HCPs, that may be empowering or disempowering patient self-management (micro-level), or these structures and mechanism could directly empower or disempower patients in their self-care management through the policies within the system (macro-level). The structures, mechanisms and actors are identified as the realities that are believed to be constructed by a dominant power (Strydom, 2011). The realities of these studied objects or phenomenon from the critical ontology perspective are shown in Table 3.2

Table 3.2: Three dimensions of the studied reality in care to supporting self-management for patients with Type 2 diabetes mellitus

Studied Objects or Phenomena	Empirical Domain	Actual Domain	Real Domain
Structures & mechanisms			
Indonesian healthcare systems, policies, organisation of health care centres, administrative, health insurance agents, social system, cultures			√
Events			
Patient empowerment to support self-management of patients with T2DM		√	√
Relationships			
Patients-HCPs communications during medical encounters	√	√	√

Note: T2DM = Type 2 diabetes mellitus; HCP = healthcare professional

3.4.2.2 Events

Events or outcome domains refer to what critical realists investigate, that is, the external and visible behaviours of people, systems and things as they occur, or as they have happened (Easton, 2010). Events occur as a result of mechanisms that operate in the real domain (Chia, 2002). It is not the case that the *real* or *actual* cannot be observed but simply that it is not always able to be observed (Chia, 2002; Easton, 2010). The occurring event in this study is patient empowerment to support self-management. Patient empowerment is considered in the actual domain as it may occur or not occur, but it is controlling the empirical, the interaction between patients and HCPs, hence it is considered a real dimension.

3.4.3 The epistemology positions

Epistemology answers the questions about knowledge: what knowledge is, what the relationship between the knower and the known is and where knowledge is justified

(Guba & Lincoln, 1994; Hathcoat et al., 2019). This next section presents epistemology stances in critical theory and its application to this research.

The 3 positions of epistemology are known as *objectivism, constructivism,* and *subjectivism* (Hathcoat et al., 2019). The epistemological position represents a spectrum of similar approaches rather than a discrete homogeneous approach (Hathcoat et al., 2019). In perceiving the phenomena the positions are consistent with the relationship taken between the knower and the known (Hathcoat et al., 2019). Objectivists hold that the meaning of the reality is set, irrespective of the knower's interpretations (Crotty, 1998; Hathcoat et al., 2019). The meaning of the reality is found using a deductive approach, experiments and robust statistical analysis (Hathcoat et al., 2019). In contrast, constructivists perceive meanings as coming into existence in and out of our engagement with the realities of our world (Hathcoat et al., 2019). There is no meaning without a mind (Crotty, 1998; Hathcoat et al., 2019). Meaning is not discovered, but constructed (Crotty, 1998). Constructionists acknowledge the existence of the meaning of the world as being culturally, socially, historically and politically situated (Hathcoat et al., 2019). Further, the constructionist upholds the possibility of multiple, coexisting meanings (Hathcoat et al., 2019). Methodologies that fit in to the constructionism approach are qualitative (e.g., phenomenology, grounded theory, narrative inquiry) with analyses reflecting inductive techniques (Hathcoat et al., 2019). Finally, the subjectivist upholds the notion that experience and meaning are independent of a fixed reality (Hathcoat et al., 2019). In other words, meaning is firmly situated in culture and social interaction (Hathcoat et al., 2019). A subjectivist might claim that the concepts of a certain reality reflect one of many possible ways to categorise, label and impose order on the human condition. Subjectivist epistemology maintains that meaning is imposed by people's minds without the contribution of the object. This implies that what is perceived is what is real, and that there is no underlying true reality that exists independently of perception (Crotty, 1998).

The main intention of this study is to explore comprehensively empowering approaches in the care of patients with T2DM that enhance self-care management. HCPs and patients with T2DM are the central actors of this research, as the concept of patient empowerment assumes that empowering interactions between patients and HCPs influence their self-management (Anderson & Funnell, 2010; Funnell & Anderson, 2004). Empowerment in the care of patients with T2DM is the phenomena explored and is partly represented by daily medical encounters shown in the interaction between patients and HCPs. This interaction as a reality is believed to have occurred in a certain context which, historically (historic relationship between HCPs and patients), has been shaped or constructed within the Indonesian social, cultural (patriarchal culture) and political (recognition of non-medical patients' need/self-management, regulation of medications) context. Therefore, a constructionist perspective is adopted in this study.

Specifically, this section elaborates on critical theory positions towards knowing about research enquiries. First, critical theory places the epistemological questions at the centre of its research concerns, particularly relating them to their impact on politics and society (Morrow & Brown, 1994). For instance, critical theory situates science within the quest for social and political rationality (Marinopoulou, 2019, p. 133). Knowledge is socially and historically constructed within a complex cultural context (Hathcoat et al., 2019). A fundamental assumption of critical theory is that every form of social order involves some form of domination and that the critical emancipatory interest underlies the struggle to change those relationships of domination-subornation; social, political, cultural, economic, ethnic and gender shape the reality (Marinopoulou, 2019; Morrow & Brown, 1994). Knowledge is endorsed by those who are in power (Hathcoat et al., 2019). The care for patients with T2DM is part of a patient's lifeworld. The policies that govern the health system may also reduce the involvement of HCPs, or the patient's knowledge; where knowledge of lay experts has been ignored or discounted in research (Scambler & Britten, 2013). Referring to the literature review in Chapter 2 of this study, Indonesian publications on diabetes care are dominated by epidemiological and cross-sectional study designs, and there are fewer articles that explore care from the perspectives of patients and HCPs, and how the system the care provided might have contributed to the care. Therefore, new knowledge about how the existing system works and new knowledge about communication within the system should involve both patients and HCPs by listening to their voices through FGDs with HCPs, and interviews with patients with T2DM.

Second, knowledge is emancipating (Knox, 2016). Critical theorists believe there is a relationship between theory and practice (Marinopoulou, 2019). This relationship answers the critical question about what science contributes to the community (Hathcoat et al., 2019; Marinopoulou, 2019), and is relevant to the views of critical theorists who believe that there is a relationship between theory and practice in a studied phenomenon (Scambler, 2001). Thus, critical theorists argue that science and other forms of knowledge have been used as an instrument of oppression, cautioning against a blind faith in scientific progress, arguing that scientific knowledge must not be pursued as an end in itself without reference to the goal of human emancipation (Hathcoat et al., 2019).

This study is about empowering care for patients with T2DM by supporting patient self-management within a particular research setting and context. It was conducted to investigate the underlying issues that might contribute to sub-optimal management outcomes of patients with diabetes where blame is often aimed at the patient's non-compliant behaviours. These behaviours may relate to patients and the system outside the patients, and involve the actors' (patients and HCPs) perspectives in diagnosing and explaining the issues. The study was conducted by adopting a methodological stance that allowed a comprehensive exploration of the subjects involved in the system while at the same time being linked with the lifeworld of the subject. It was hoped that potential models of care would be identified that could provide improved support for patient self-care management.

Finally, the relationship between the researcher and the participant is interactive, with acknowledgement of the issues of power and trust by the researcher to consider. Knowledge is value laden, hence the researcher may influence the findings (Hathcoat et al., 2019). Thus, the methodology applied to this study allowed the use of interactive methods. These methods were a combination of observations of medical encounters between patients with T2DM and the HCPs. Additionally, interviews fostered conversation and reflection by patients with T2DM as well as FGDs with HCPs involved directly in the daily care of the patients with T2DM. This reflective dialogic allowed me, as the researcher, and the participants to question the natural state and challenge the mechanisms that have been utilised in the care of people with T2DM in Indonesia.

The following chapter, Chapter 4, discuses the methodology used in this research. Then Chapters 5 to 8 present the findings of this research project, leading onto Chapter 9 where discussion of the findings is presented. Finally, Chapter 10 presents the conclusion, recommendations and limitations of this research.

Chapter 4: Methodology

4.1 Introduction

The first sections of this chapter review the methodological approach and the research design. The next sections elaborate the research process, which includes ethics, information about the participants and the recruiting process, data management and the framework for data analysis. The final sections discuss rigor of the study and provide a conclusion to the chapter.

4.2 Critical theory methodology

A research methodology is a plan of action or design that determines the methods chosen to gather data (Crotty, 1998; Howell, 2012). In critical theory, methodology refers to a set of assumptions or theories that govern the methods in generating knowledge rather than the methods, procedures and techniques (Strydom, 2011). This following section focuses on the critical theory assumptions that informed the methodology followed by the methods employed in this study.

The selected methodology is consistent with the ontological and epistemological perspectives and the study's question. The ontological and epistemological positions of this study were driven by the critical theory paradigm (see Chapter 3). The critical theory paradigm has no specific methodology; as suggested by Honneth's work, 'there is no need for our own methodological approach'. Rather, all that is required is the pursuit of 'a clear hypothesis of certain social developments, preferably certain social pathologies'. This is 'a clever way of combining existing methods' (Strydom, 2011, pp. 113-114). The methods may include group discussions, structured interviews or qualitative methods (Strydom, 2011). The critical component is in the analysis of the data (Strydom, 2011).

Due to the lack of literature on applying critical theory research, specifically in the area of patient empowerment in diabetes care, the work of Fontana and Strydom was drawn on (Fontana, 2004; Strydom, 2011). This structural methodology is based on 7 assumptions embedded in critical theory (Fontana, 2004) combined with the 7 dimensions of an architectonic structure of critical theory informed by Strydom (2011). These interrelated features or attributes of the methodology are framed under the critical theory perspective of 1) critiques; 2) context; 3) politics; 4) emancipatory intent; 5) democratic structure; 6) dialectic analysis; and 7) and reflectivity (Fontana, 2004). The 7 dimensions of the architectonic position in critical research are 1) transcendental immanent; 2) dialectical; 3) normative; 4) ontological; 5) theoretical; 6) epistemological; and 7) methodological.

The aim of critical theory that makes it distinctive from previous paradigms is to bring emancipation and reflective deliberation for those who are oppressed in a society (Kincheloe & Mclaren, 2011; Strydom, 2011; Thompson, 2017a). Critique, the first attribute, is the tool used to expose forces of injustice and oppression by examining power relationships within societal structures (Fontana, 2004). A key principle in critical theory is transcendent immanent (Strydom, 2011) and is reflected in this study in the 3-fold inquiry that questions whether the existing diabetes care in the Indonesian context empowers or disempowers patients with T2DM at the level of patient and HCP communication during medical encounters, at the level of the health organisation, or at the level of the healthcare system. Framed by the concepts of lifeworld and system as defined by Habermas, system is considered to be a powerful force over the lifeworld (Morrow & Brown, 1994). This study analysed potential competing power relationships between HCPs and individual patients with T2DM in the context of the Indonesian healthcare system. Many studies suggest existing power imbalances exist between HCPs, who are considered more knowledgeable and authoritative, compared to patients, who are perceived as less confident and lacking in medical knowledge (Koeck, 2014; Scambler & Britten, 2013; Snow et al., 2013). HCP attitudes are often perceived as barriers to patient empowerment and self-management (Anderson & Funnell, 2010; Joseph-Williams et al., 2014; Palumbo, 2017). Thus, this study examined and critiqued the power relationships in diabetes care in the Indonesian context.

The second and the third attributes are context and politics. These phenomena should be understood in their historical contexts (Crotty, 1998; Fontana, 2004; Hathcoat et al., 2019; Kincheloe & Mclaren, 2011). The principle that reality is constructed in the context of cultural, social, historical and political domains (Hathcoat et al., 2019) was embraced as the epistemological position of this study. This principle was reflected in the methods applied in this study. Data from patients with T2DM were triangulated with data from the HCPs who provided direct diabetes care. Exposing equal or unequal power in diabetes care in an Indonesian context was considered a political activity, which was reflected in the research inquiry of this study, whether the healthcare system empowers or disempowers patients with T2DM.

Multiple social realities led to the conclusion that knowledge is time, space and context dependent, and naturalistic and relativistic (Hathcoat et al., 2019; Liamputtong, 2019). Naturalistic means no manipulation of the participants occurs during the research, such as experimentation (Liamputtong, 2019). The concepts of *context dependent* and *naturalistic of reality* (Merriam, 2009; Yin, 2014) was the chosen methodology, which comprised a qualitative case study design (case study design will be discussed further later in this chapter). This research was conducted in the real setting – one *Puskesmas* and 2 hospitals – where medical encounters between HCPs and patients occurred daily.

The fourth attribute is emancipatory intention. A fundamental assumption of critical theory is that all forms of social order involve some form of domination and that a critical emancipatory interest underlies the struggles to change those relationships of domination-subornation (Morrow & Brown, 1994). Hence, critical theory is known as an emancipatory theory, proposing a better life for humankind (Thompson, 2017b). This attribute was reflected in the aims of this study, which was to explore a care approach that supports patient empowerment to enhance patient self-management in diabetes care.

The fifth attribute is a democratic structure, a nonhierarchical relationships between researchers and participants (Fontana, 2004). In this study, the nonhierarchical attribute was maintained by avoiding judging on participants thoughts during the interviews and focus group discussions.

The sixth attribute, dialectic analysis, examines contradictory values, interests and conditions in a social phenomenon, between what the situation should be and what the reality is (Fontana, 2004). In this study, the contradictory values that were studied were the empowering versus disempowering communications in supporting patient self-management at the level of patient–HCP medical encounters, and at the level of health organisations and the healthcare system. This exploration was conducted through a dialectic process of 42 interviews with patients with T2DM and 4 FGDs with HCPs (doctors, nurses and dietitians) directly involved in the provision of diabetes care. Normative dimensions of critical theory suggest an aim of enlightenment in critical theory (Strydom, 2011). Therefore, a theory must adequately explain the existing social problem and offer practical solutions (Thompson, 2017a). The study of patient empowerment in diabetes care aimed to explore the possible barriers and enablers occurring in the process of supporting patient self-management. The hybrid of Habermas's communicative action and Honneth's theory of recognition as the theoretical framework were applied in this study (see Chapter 3).

The seventh attribute, reflexivity, recognising the potential historical power and ideological that dominant influence the research (Fontana, 2004). In this study, the form of the reflexivity was maintained in the methodology approach adopted in this study where the active participations such as participants' voices and actions became the main source of constructing the knowledge. Acknowledgement to the research limitations that impaired participants emancipatory goals were also addressed (see Chapter 10). Table 4.1 shows the critical theory research paradigm in relation to the methodology and methods applied in this study.

Table 4.1: Critical theory research paradigm

Studied Objects or Phenomena	Philosophical Stances					
	Critical Realism Ontology			Constructivism Epistemology/Ways of Knowing		
	Empirical Domain	Actual Domain	Real Domain	Qualitative Methodology		
				Methods	Research Design	Data Analysis
Relationships: **Between patients and HCPs shown by communication within medical encounters**	√	√	√	Direct observations of clinical encounters between patients with T2DM and HCPs	Qualitative embedded case study	Thematic analysis
Events: **Patient empowerment to support self-management of T2DM**		√	√	Interviews with patients with T2DM reflecting on the care received to support self-management.		
Structures & mechanisms: **Indonesian healthcare systems, policies, organisation of healthcare centres, administrative, health insurance agents, social system, cultures**			√	Focus group discussions with HCPs reflecting their daily professional practices; related documents		

Note: HCP = healthcare professional; T2DM = Type 2 diabetes mellitus

Case study methodology was selected as a research design for this study given the constructivist epistemological stance and its scope of methods. The following section provides the rationale for applying case study methodology as the research design.

4.3 Case study research design

This section focuses on the justification for employing the case study as a research design.

4.3.1 Justification

A case study research design was applied to this project for two main reasons. First, the research questions posed in this study suggested the need to gain an in-depth understanding of the existing diabetes care provided to patients with T2DM. Interviews allowed for data analysis to establish the links and factors that contribute to the care of patients with diabetes in the Indonesian context. This was in line with Yin's views that a case study is 'an empirical inquiry that investigates a contemporary phenomenon within its real-life context' Yin (2014, p. 1616). In this study, the phenomenon under exploration is empowerment to support patients with T2DM towards self-management in diabetes care in the Indonesian context. Factors that were examined to determine the type of diabetes care provided in the Indonesian context are identified in the framework of this research based on Habermas's theory of communicative action and Honneth's theory of recognition. The lifeworld of patients with T2DM, such as their interactions with HCPs and the Indonesian healthcare system, were factors deemed to contribute to the approach to diabetes care provided.

Second, the case study design provided an ideal methodology and methods to investigate how diabetes care is provided for patients. Case study research is recommended where there is insufficient detailed information available about the phenomenon being studied (Gomm et al., 2000; Yin, 2014). Published studies in the literature dealing with diabetes care in Indonesia, such as in Soewondo et al. (2013) have mainly focused on medical management of the disease and on epidemiological studies. Studies on patients with T2DM in the Indonesian context are primarily based on an ontology and objective epistemology of naïve realism. Studies of diabetes care tend to be epidemiological accounts, correlations or experimental studies. These studies can only capture the biological aspects of patients with T2DM through interpreting biomarker performances such as levels of blood glucose (measuring as HbA_{1C}), cholesterols (triglycerides, high-density lipoprotein [HDL], low-density lipoprotein [LDL]) and make a statistical correlation with the therapy used or with other physical parameters. This kind of research restricts understanding of patients with T2DM and how they are taken care of. The results of the integrative review (see Chapter 2) on patient empowerment to support diabetes self-management in SEADCs publications, including those from Indonesia, were also dominated by research using positivist approaches. This research project is the first case study to examine empowerment in the care of patients with T2DM self-management in the context of the Indonesian healthcare system framed by a critical theory paradigm.

The study explored the beliefs, perceptions and attitudes of patients with T2DM and HCPs regarding the existing approach to care, whether there would be general support for strengthening diabetes self-management and a patient-empowerment approach in the Indonesian context and how such an approach could be implemented.

4.3.2 A single case study design with embedded multiple units of analysis

Depending on the research purpose and questions, 4 basic types of case study design are considered as options; holistic single case study, embedded single case study with multiple units of analysis, holistic multiple cases, and embedded multiple cases (Yin, 2014; Yin, 2003). A case study can be descriptive, explorative or explanatory. Figures 4.1 and 4.2 show the basic designs of a case study and the exploratory single case study with embedded multiple units of analysis design what was applied to this study.

This case study was an exploratory design as the aim was to uncover existing approaches used in diabetes care to support patient self-management in the context of Indonesian healthcare systems. While the units of analyses were the care provided to patients, it was examined in different situations within the systems: at a primary care centre/ *Puskesmas*, a regional/provincial hospital, and a national hospital. Diabetes care provided at each facility level served as one unit of analysis (see Figure 4.1).

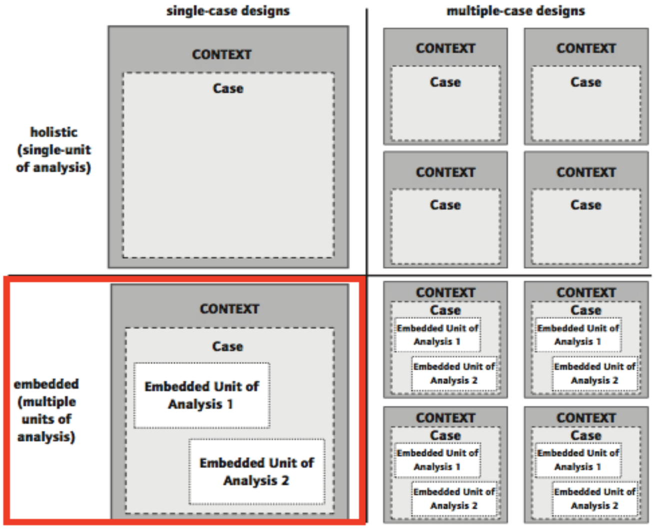

Figure 4.1: Basic types of case study design (Yin, 2014)

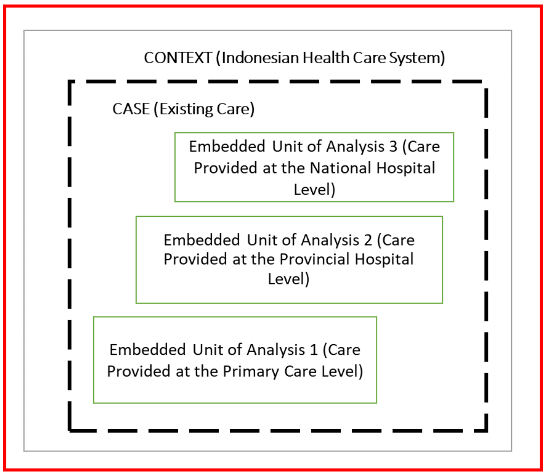

Figure 4.2: Embedded multiple units of analysis single case study design (Yin, 2014)

This single case design was utilised as the aim of this study was to understand the nature of the existing diabetes care that supports patient diabetes self-management and the relevance of a patient-empowerment approach in caring for people with T2DM in the Indonesian context. The case was a single entity of the existing care provided for patients with T2DM by HCPs. There were 3 embedded units of analysis; the existing diabetes care provided at a primary care level, and the care provided at the secondary and tertiary care level. The Indonesian healthcare system served as the context for the case in understanding the phenomena and in assessing the applicability of a patient-empowerment approach.

Five components guided the project: the study questions, the propositions, the unit of analysis, the case study and linking data to the propositions (Yin, 2018). The following section covers the 5 components in more detail, providing explanations in relation to this study.

4.3.2.1 Propositions

Propositions are used in case study research to limit the scope of the inquiry so that research questions are focused (Baxter & Jack, 2008). Propositions may be drawn from a wide variety of sources including research literature, research hypotheses, empirical data, and professional and personal experiences (Yin, 2014). The propositions for this study were derived from the literature dealing with the factors that improve patient self-management of their diabetes treatment and care, and the key propositions were related to the quality of patient interactions with HCPs and the organisational factors affecting the care of patients.

The first proposition was in relation to the interactions between patients with T2DM and HCPs. The quality of these interactions is critical to empowerment approaches because there is evidence that this enhances self-management, increases patient involvement in decision-making, and improves patient satisfaction with their treatment (Funnell & Anderson, 2004). In this study, observations of HCPs and patients during routine clinical interactions were undertaken and compared to the characteristics of empowering interactions described in the literature.

The second proposition dealt with the organisation of care for patients with a chronic illness. A comprehensive approach to reorganising care delivery for patients with a chronic illness that improves patient outcomes is advocated by (Nolte & McKee, 2008; Wagner et al., 1996). This framework suggests that patient outcomes are affected by the conditions under which treatment is provided. Such factors include the design of the delivery system and clinical information systems (Nolte & McKee, 2008; Wagner et al., 1996). In this study, healthcare regulations and policies, and the Indonesian national clinical consensus documents in caring for patients with T2DM, including patient consultation procedures, resources for the care provision of patient’s education programs and health team collaborations, served as the context of the case.

4.3.2.2 Units of analysis and the case

The units and sub-units of analysis used in collecting and interpreting data need to be identified in guiding case study research (Yin, 2018). A unit of analysis is a system of action for understanding what is being examined (Tellis, 1997). In this case study, there were 3 embedded units of analysis; patient empowerment in supporting self-management in a primary care setting, and patient empowerment in supporting self-management in the care of patients in the secondary and tertiary care settings. These 3 units of analysis were analysed as one case.

A case study refers to an event, an entity, an individual or unit of analysis (Yin, 2018). The case in this study was patient empowerment in supporting self-management in the care of patients with T2DM in the Indonesian healthcare context. Figure 4.3 shows the stages of conducting the case study of this research. The case was selected, and 2 pilot interviews were conducted to ensure the viability of the interviews and observation guidelines to be used to gather the data. The case was selected purposively based on the research inquiry which was to explore approaches used in supporting self-mangement in diabetes care in Indonesian context. Three studies were conducted in 3 venues consecutively in order to understand the referral process (from the lower-level institution of health care to the highest) that patients experienced. Each study represented one dataset that was firstly analysed within the individual case then across the cases under the one context.

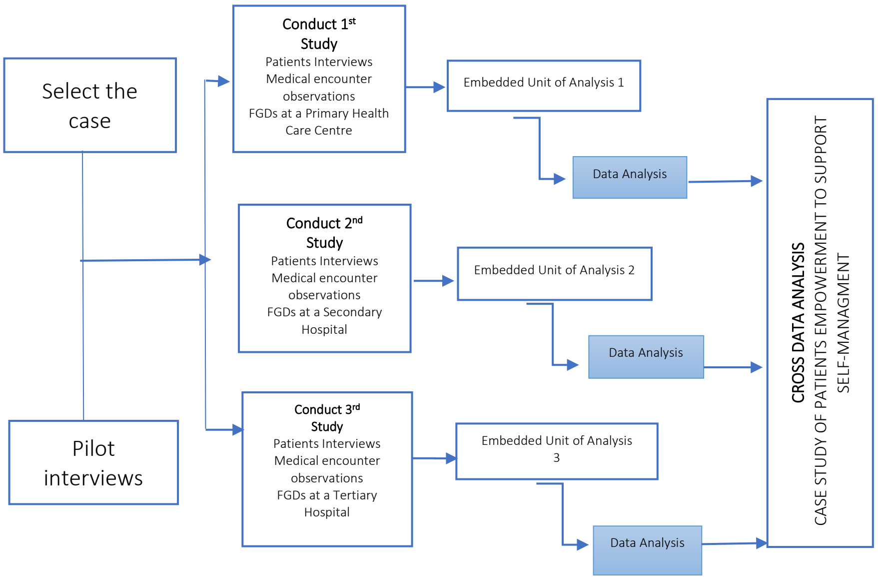

Figure 4.3: Stages in conducting the case study of patient empowerment in supporting self-management in the care of patients with Type 2 diabetes mellitus in the Indonesian context

Note: FGD = focus group discussion

4.3.3 Triangulation of methods

The case study is known as a triangulated research strategy. The need for triangulation arises from the necessity to confirm the validity of the processes because multiple sources provide multiple measures of the same phenomenon, thereby strengthening the findings (Yin, 2014). This case study utilised 4 methods of data collection: 42 direct non-participant observations of medical encounters between HCPs and patients with T2DM, 4 FGDs with HCPs, 42 interviews with patients with T2DM, and a review of related documents such as patients' medical records. Clinical standards and national healthcare policies and regulations were used to support the data collections methods applied in this research.

The observations and FGDs were conducted sequentially. The observations were conducted prior to the FGDs and were followed by a review of patient medical records within the ethics limits. This sequence sought to minimise any effects from the discussions about empowerment as participant behaviour could have been influenced by the discussion, raising their awareness of the topic and increasing their exposure to the concept of patient empowerment and the types of behaviours advocated by this approach. Ten days of direct general observations of the clinical environment was conducted to observe the flow of patient care, including observations of daily care, general facilities in the clinic, any written materials provided to patients and general administrative procedures that patients had to follow through.

4.3.3.1 Observation of clinical encounters

The use of direct observations within a case study approach provides evidence from the natural setting that is needed to supplement or confirm information obtained during interviews (Yin, 2018). Although observation methods are conventionally used in ethnographic research, they are also commonly applied in other qualitative methods of inquiry (Schneider et al., 2007). The main purpose of using structured observations in this study was to gather information on what actually happens in clinical settings (Patton, 1990; Yin, 2014). Observation methods also allow researchers to understand behaviour within its context and this notion is consistent with the interpretive stance (Schneider et al., 2007). The phenomena to be observed were the routines of daily care services in the clinics and the nature of clinical encounters between HCPs and patients with T2DM.

Interaction between HCPs and patients was identified as important in improving healthcare outcomes (Renedo et al., 2015; Stewart, 1995). Patient satisfaction with HCPs is improved when physicians, for example, uses a style of communication involving friendliness, empathy, warmth and other effective methods of communication (Birkhäuer et al., 2017; Stewart, 1995; Ward, 2018). In this study, the observations of clinical encounters between the HCP and the patient with T2DM focused on the nature of the encounters and whether the interactions that occurred were likely to empower or not empower the patient’s self-care management behaviours.

The ethically approved observations also focused on how HCPs allowed patient participation in making decisions about their care, which is an essential element in the empowerment concept (Bravo et al., 2015; Zimmerman & Warschausky, 1998). Further, it is argued that patient participation involves many dimensions, such as rapport, empathy, openness, and the fostering of feelings of equality where the context of interactions must be considered in assessing patient participation (Bensing et al., 2003; Collins, 2007).

In order to systematically find, and avoid overlooking, particular behaviours during the encounter, a guideline for the observations of the clinical encounters between a patient and an HCP was developed utilising the literature related to medical communications and patient empowerment as suggested by Funnell and colleagues (Funnell & Anderson, 2004; Palumbo, 2017). The observation checklist was applied as a guide to reduce bias during the encounters if an observer was familiar with the environment under study. This guideline also allowed me to code the verbal and non-verbal behaviours of the observed participants more systematically. The Hawthorn effect, or behavioural changes of the observed subjects, did not seem to occur during the observations (Oswald et al., 2014). To mitigate the Hawthorn effect, building rapport and establishing a trustworthy partnership with the potential participants and maintaining a relaxed environment during the observation was applied.

The operational definition of an interaction in this study was any scheduled or un-scheduled clinical encounter between an HCP (doctors/nurses/dietitians) and a patient with T2DM that occurred in the areas of the clinic for the purpose of patient care. The observations included verbal communications, non-verbal expressions and the ambience in which the interactions occurred. The observations captured interactions that occurred in several settings: in a physicians’ consultation rooms (between a physician and a patient), in the dietitian’s consultation room (between a dietitian and a patient), in a treatment room (between a nurse and a patient) and in the nurse’s assessment room (between a nurse and a patient), or during a diabetes health education session (between a patient with a nurse or a dietitian).

The ethically approved observation of clinical encounters between a patient and an HCP occurred when a patient entered the room or started interacting with an HCP and concluded when the patient left the room or finished interacting with an HCP. Each observation was documented during an interaction, and I wrote field notes about the clinical encounters including the physical setting and the non-verbal expressions used by both patients and HCPs.

4.3.3.2 Focus group discussions

Four ethically approved FGDs with HCP participants were conducted to gather evidence from the HCP perspective. The initial step in planning a focus group was to develop a discussion guide that was used to facilitate the discussions (Liamputtong, 2011; Morgan, 2002). A guide for the FGDs (Appendix 22) was used to ensure that the designated topic areas were covered and that conversations remained focused. The discussion guide covered all concepts to be investigated (Morgan, 2002) and an FGD guide used in this study was consistent with patient-empowerment concepts.

Probes or follow-up questions were also used to promote discussion and obtain clarification of points discussed. The next step in planning a successful FGD was the selection and recruitment of participants (Hennink, 2013; Morgan, 2002). This study involved 4 FGDs: one in the primary/community health care centre (or *Puskesmas*), one in the regional hospital, and 2 in the national referral hospitals with one FGD involving physicians and another with diabetes nurse educators and dietitians. The reason for having physicians separate from nurses and dietitians was that Indonesian physicians are widely regarded as more powerful than other HCPs such as nurses, dietitians and physiotherapists. Separating the FGDs aimed to reduce any power imbalances within each group and to encourage individuals to express their thoughts and feelings more freely. Another reason for the separation was the differences in time available between nurses and doctors in the national hospital. All FGDs were conducted after the observations of the process of interaction between patients with T2DM and HCPs was completed.

4.3.3.3 Interviews

Under the interpretive philosophical stance, a semi structured interview method in gathering data allows the researcher to enter the lived world of the participants (Silverman, 1997; Whitehead & Whitehead, 2016). The interviews with 42 patients with T2DM were conducted with the aim of gaining insight into the perspective of patients with T2DM about their experiences in the care provided, especially the care in supporting their self-management. To maintain the participants' verbatim voices, the interviews were audio-recorded. The participant interview time varied from 20 minutes to 75 minutes. Ethically approved interviews were conducted at each of the study field sites (primary health care and hospitals) when patients were coming to the healthcare centres for their routine medical consultations. Due to patient constraints, such as other healthcare related issues in the hospital, 2 interviews were conducted online using videocalls, respecting the patient's preference.

4.3.3.4 Documentation

Documentation in this study was used as complementary information that could corroborate other data sources. The reviewed written texts included patient medical records of those who were observed and interviewed. The purpose of accessing patient medical records was to gain information on demographic profiles, diabetes medical care outcome parameters such as HbA_{1C}, fasting BGL, cholesterol levels, diabetes-related complications information, diabetes medical treatments and education programs provided to patients. Participant characteristics, especially demographic data and diabetes-related health profiles were required to be taken into account in the interpretation and these provided a thick description of the phenomena being studied (Houghton et al., 2013). In this case study, patient medical record data reflected participants' medical conditions and what medical and non-medical interventions were planned in supporting their self-management.

4.4 Ethics

Ethical issues that were carefully considered throughout this research process are discussed in the following sections.

4.4.1 Ethics approval

Ethics approvals were obtained from the Flinders University Social and Behavioural Research Ethics Committee (SBREC) **Project Number** 8464 (see Appendix 2), the overseeing institution ethics committee in the research fields and the Ethics Committee Faculty of Medicine University of Indonesia Protocol Number 19-12-1415 (see Appendix 3) to gain access to the national hospital; a Research Permit Letter from the Health Provincial Office (see Appendix 4) to gain access to the provincial hospital; and a Research Permit Letter from Depok-West Java District Health Office (see Appendix 5) to enter the primary healthcare centre (or *Puskesmas*).

Gaining access to the settings involved negotiations and approvals with the hospitals and primary healthcare centre hierarchies. The ethics approval from the SBREC of Flinders University along with the letter from the Flinders University supervisors and the letter from my home institution (University of Indonesia) were required to be submitted to the local ethics committees to process the ethics approval in each field site. The ethics approvals issued from the authorised institutions were used to obtain an approval letter to enter the field. Once the approval letters were gained, I met with the senior managers of departments at the Medical Department of the 2 hospitals, the endocrinology sub-division of the 2 hospitals and the primary healthcare centres, then formally presented the data collection process.

4.4.2 Informed consent

Participation in this study was entirely voluntary. Information sheets specific to patients and to HCPs (see Appendices 11 and 12) were provided prior to obtaining written informed consent. The potential participants were given time to consider their participation and were welcome to ask any questions about the study. The participants had the right to withdraw at any time without any consequences. One of the participants at the *Puskesmas* negotiated not to have an audio-record of his interview as he indicated that recently in the country lay people were accused more often of misconduct under the new Indonesian Government regulations on Electronic Systems and Transactions. In line with the eligibility criteria of the research participants in this study, this potential participant's involvement was declined. Six out of 8 medical doctors and one dietitian who worked at the endocrine outpatient clinic in the participating national hospital declined to participate due to their workload as they were assigned to the COVID-19 care team in the hospital. However, even though 6 out 8 medical doctors declined to participate, it did not impact the quality of the data. The natural and richness of the data gathered were the focus in this qualitative case study rather than the number of participants. In addition, the recruitments of medical doctors aimed to enquire of understanding a dialogic and dialectical process occurred between a patient – HCP, and reflective process of HCPs that allowed me to question the natural state and challenge the mechanisms that had been in place in the care for people with T2DM in Indonesia.

4.4.3 Anonymity and confidentiality (pseudonyms)

Anonymity refers to the need to protect the privacy and identity of individuals and to assure their confidentiality (Wiles et al., 2008). In this study, the participant information form contained details of their identity and medical history (for patient participants). All participants from the interviews, observations and focus groups were given the opportunity to have a pseudonym. I was also aware that the limited number of participants involved in this qualitative study may be easily identified by readers in Indonesia. All the participants preferred to use their own names during the interviews and FGDs. However, the anonymity principle was still applied by using codes for participants and places (Creswell, 2014).

Participant confidentiality was maintained by keeping the data, which were written and in audio form, in password-protected files that could only be accessed by authorised persons involved in this research. Audio recordings were stored on a computer with password protection in a locked room, only accessible to researchers and supervisors. Code numbers were used in this thesis and when disseminating and publishing the study so that others cannot identify an individual participant or the source of any quotation.

Given that this study was a single (embedded unit of analysis), in which the case study referred to a specific setting in a very specific location, it is possible that it will be recognised. Simons (2009) suggests several reasons for anonymising or non-anonymising in a case study research report. The reasons for anonymising are to allow the participants to speak openly and to prevent unfair judgement from the reader, especially in a highly politicised research context. A decision not to maintain anonymity might be taken when the case is unique. For example, this study involved a high-profile national hospital that is very difficult to anonymise, and I had an open research relationship with the participants.

As the study finished, all the data were stored according to policy on the management of research data and records of Flinders University, South Australia. The general data will be destroyed 5 years after publication or 5 years after the conclusion of project (State Records Act, 1997).

4.4.4 Observation of unsafe practice

During the data collection process, I did not encounter any un-ethical interactions between HCPs and patients, nor observe unsafe practices.

4.4.5 Beneficence and non-maleficence

Beneficence is an ethical principle of doing good to others and preventing harm (Orb et al., 2001). Participating in face-to-face FGDs, direct observations and interviews in this study could potentially create anxiety and distress to the participants, especially when audio recording was being used. To mitigate this, an explanation about the purpose of recording was provided in an open and supportive manner. Participants who were not comfortable with being audio-recorded could withdraw their participation at any stage of the process of data collection as it was stated on the informed consent form (see Appendix 16) and explained to them prior to signing the consent form. One potential participant in this study refused to be audio-recorded and his participation was withdrawn. To minimise risk of patient participants being exploited, which can potentially occur when patients are the subject of a study in a hospital, it was made clear to them that there would not be any discussion of the participants' health problems during the research. The patient participants also were assured that whether or not they agreed to participate in this study would not influence the care they received from the HCPs.

4.4.6 Invasion of participant privacy

It was anticipated that the observations of HCPs and patient interactions and access to their medical records would be an invasion of a participant's privacy. These potential harms were included in the letter to participants explaining and acknowledging this in the informed consent form provided to all potential participants.

4.5 Participants and recruiting process

This section describes the participants involved in this study from each setting and the recruitment process. The recruiting process occurred during January to early March 2020. The recruiting was paused for 6 months due to the COVID-19 pandemic that resulted in a withdrawal of the research permissions by the participating hospitals. The recruitment process then continued from September to October 2020.

4.5.1 Participants

HCPs and patients with T2DM attending participating hospitals and a *Puskesmas* in Indonesia were included in this study. Involving both HCPs and patients in this study was based on several factors. First, there is increasing evidence that positive interactions between patients and HCPs is an important determinant of patient self-management that leads to improved diabetes outcomes (Funnell & Anderson, 2004; van Dam et al., 2003). Second, evidence shows that the approach used by HCPs can support or hinder patient self-management efforts (Miles & Huberman, 1994). Third, within the philosophy of empowerment, considerable emphasis is placed on the importance of enabling individual patients to determine their own goals so that they have a voice in decision-making affecting their care (Pulvirenti et al., 2014; Zimmerman, 1995). Fourth, because the endocrinologists, internists, nurses and dieticians in the Indonesian healthcare delivery system were all directly involved in providing care for patients with diabetes it was important that these groups were all included. Finally, the HCPs and patients with T2DM were chosen because a critical methodology requires a dialogic and dialectical process (Guba & Lincoln, 1994). This reflective dialogic process allowed me, as the researcher, and the participants to question the natural state and challenge the mechanisms that had been in place in the care for people with T2DM in Indonesia.

4.5.1.1 Healthcare professional participants

HCPs who were involved directly in the provision of diabetes care at the case study hospitals and the *Puskesmas* during the time of data collection took part in this study. Health care professionals eligible for this study were physicians, nurses or dietitians who had been involved in the care of patients with T2DM for at least one year. They were indirectly approached to be involved in this study by sending an invitation letter and an informed consent form to their respective departments. The potential participants expressed their interest in volunteering to participate when they responded to the invitation letter by signing the informed consent form and returning it to me through the *Puskesmas* and the hospitals' officers. From all 3 settings, 19 HCPs were involved in this study: 2 general medical doctors, 2 internists, 2 endocrinologists (1 endocrinologist and another was a medical resident of endocrinology), 12 nurses, and one dietitian agreed to participate (see table 5.3, 6.3 and 7.2).

4.5.1.2 Patient participants with Type 2 diabetes mellitus

Patient participants involved in this study were those who attended the outpatient department of the participating *Puskesmas* or the hospitals during the data collection period. The patients were eligible to be involved in this ethically approved study if they had had T2DM for at least one year. Patient participants were invited to volunteer to participate using a flyer and a standing banner that was set up in the patient's waiting room area. I handed out the research flyers to each patient at the front desk. Participants who showed interest in volunteering to participate contacted me through the provided telephone number or directly on seeing me when I was in the field (the outpatient clinics) during the clinics' service hours. Of the 42 patient participants, 4 contacted me with a text message, while the reminder approached me directly in the field.

4.6 Data management

Research data has to be prepared or reasonably managed for analysis, while confidentiality and rigour of the research are maintained (Creswell, 2014; Miles & Huberman, 1994). There were 3 datasets collected from 3 field sites. Each dataset comprised data from interviews, observation of clinical encounters, and FGDs. The data were managed as follows: all data in the Indonesian language were coded and numbered so that the confidentiality of participants and the field sites were maintained. The voice-recorded data obtained from patient interviews and the interviews with the HCPs and focus groups was transcribed verbatim, in the original language (Indonesian Bahasa). I then translated these transcriptions into English. Text-based data, such as in the patient medical records, were translated directly from the original language into English. Back translation from English to Indonesian language was not conducted. As the researcher spoke bilinguals which was Indonesian language and English, and the participants spoke the same language with the researcher, which was Indonesian language, so there were no language differences in data gathering that potentially created lost in data translation.

Each transcription was stored in a separate electronic folder on a password-protected computer file and identified by the file name, such as OBS1 for observation number 1, INTV1 for interview number 1, or FGD1 for focus group discussion 1. These data were stored in different folders based on the setting where they were collected; for example, all the raw data were saved in a Microsoft Word program and transferred to NVivo 12 application software for coding. Only the researcher and supervisors had access to the files.

4.7 Framework for qualitative data analysis

This study used qualitative thematic analysis. Outcomes from the qualitative data analysis included themes and subthemes (Bradley et al., 2007; Saldaña, 2014). Thematic analysis was applied as this approach has the flexibility that is used within various ontological frameworks, including a critical realist approach (Terry et al., 2017). A critical realist approach allows an understanding of participants' experiences as lived realities that are produced, and exists within a broader social context (Terry et al., 2017). In this study, the aim of the data analysis was to generate themes that explained patient empowerment in supporting self-management in diabetes care in the Indonesian context. The research inquiries, along with the theoretical assumptions of critical theory, guided the interpretation of the data and generation of the themes.

As elaborated above, the research design applied to this study was a single case study with multiple (embedded) units of analysis. Three embedded units involved in the study were analysed and interpreted as a single case study. Technically, data were analysed in 3 phases: analysis within each method, triangulation of the methods, then as a whole single case study.

First phase

The first phase included 6 orderly steps of qualitative data analysis informed by Clarke et al. (2015): 1) familiarity with the data; 2) generating initial codes, reviewing codes and generating themes; 3) searching for themes; 4) reviewing themes; 5) defining and naming themes; and 6) producing the report. The details are as follows:

1. Familiarity with the data

The first step in the analysis is to immerse oneself in the data by repeatedly reading the transcriptions to get an overall understanding of the data. The exercise commenced at the beginning of the research process, and during the transcribing. Reading and re-reading the transcripts helped to understand the data in the original language and the English translations.

2. Generating initial codes

The second step in the qualitative analysis is code generating. Coding is a process of taking interesting features and raising them to a conceptual level, The coding process is initiated by labelling the unit of analysis or meaningful unit(s) descriptively (Chen et al., 2010) or interpretatively (Miles & Huberman, 1994) or at the level of semantics (Clarke & Braun, 2014). The unit(s) of analysis may include words, sentences, phrases or scenes. A whole conversation may be considered as a unit of analysis or a meaningful unit (Miles & Huberman, 1994). In this study the units of analysis included the words, sentences and phrases of patients; interviews and FGDs with HCPs; the situations observed at the various sites; whole conversations during medical encounters; and the data from patient medical records.

The process of coding involves the following steps: identifying and labelling potentially interesting events, features, phrases, behaviours, or stages of a process; and differentiating or integrating these so that they may be reworked into a smaller number of categories, relationships and patterns to tell a story or communicate conclusions drawn from the data.

Coding decisions are influenced and affected by the ontological, epistemological and methodological issues in a study. The philosophical positions embraced in this study – the critical ontology (critical realism) and constructivism epistemology, theories in patient empowerment, self-management and chronic illness management – were used as analytical filters in perceiving and interpreting the data. Code structures (list of codes) can be constructed deductively based on previous studies or research questions (Bradley et al., 2007; Miles & Huberman, 1994). In this study, the code structures were identified using a combination of both deductive and inductive approaches, which is known as an integrative approach. As a list of codes was developed (code structures), the next step was to identify the pattern within the codes that emerged from each dataset. Each dataset contained information from patient interviews, observations of medical encounters, the FGDs with the HCPs, and documents of patient medical records.

The NVivo 12 software qualitative analysis was used in this study to manage the codes. The use of NVivo software allows the coding process to occur more efficiently as it facilitates rewinding the audio files as much as required at the same time the coding process is occurring (Bazeley & Jackson, 2013).

3. Searching for themes

The third step was collating codes into potential themes, and gathering all data relevant to each potential theme. Once a coding scheme (list of codes) is developed, the coded data are summarised by looking for patterns of certain behaviours, similarities, differences, sequences, correspondence, and patterns of semantic meaning and/or underlying concepts. Similar meaningful codes are identified then classified into categories and subcategories. The codes, or categories to which each concept was mapped, were then put into context to create themes that were related to the research questions and represented some levels of patterned response or meaning within the dataset.

4. Reviewing themes

The fourth step was to check if the themes worked in relation to the entire dataset and generated a thematic map of the analysis.

5. Defining and naming themes

The fifth step was ongoing analysis to refine the specifics of each theme, and the overall story the analysis tells, generating clear definitions and names for each theme. This was conducted by reiterating the themes and the conceptual and theoretical frameworks used in this study.

6. Producing a report

The final opportunity for analysis is producing the report. This involved selection of vivid, compelling extract examples, final analysis of selected extracts, relating back from the analysis to the research question and literature, and producing a scholarly report of the analysis, which is presented in the chapter findings (Chapters 5 to 8) of this thesis.

Second phase

The second phase of the analysis involved triangulation data analysis from observations, interviews, and a FGD of each unit of analysis; these are presented in Chapters 5, 6 and 7.

Third phase

The third or the final phase of data analysis was to weave all the results from these various data sources (from the 3 side fields) into a case as presented in Chapter 8. Themes that emerged from the first and second phase of data analysis were mapped to areas of agreement, and contradictions or paradoxes as suggested by Saldaña (2021). A case description development strategy was used as a framework for analysis of the case study in order to systematically illustrate the chain of evidence (Yin, 2018). This analysis framework is suggested by Yin (2018) as suitable for a descriptive case study. The descriptive framework used was guided by the research questions, research paradigm and the theoretical frameworks of this study (see Figure 4.4).

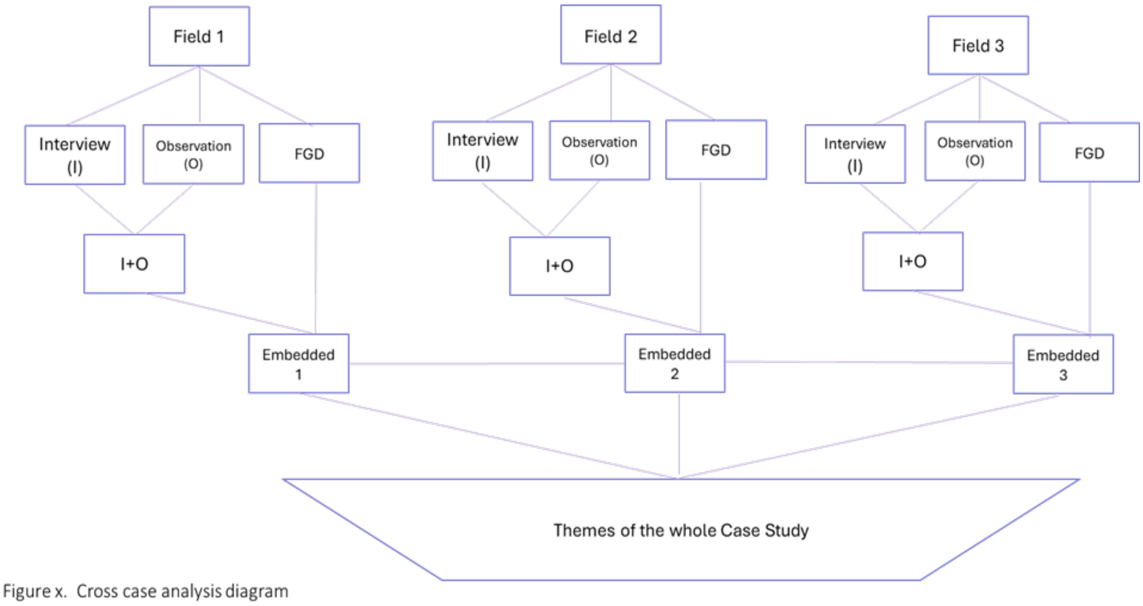

Figure 4.4: Framework for the embedded units of analysis and cross-case analysis

4.8 Ensuring rigour

The criteria for assessing rigour or trustworthiness of this study include the credibility or internal validity, transferability or external validity, dependability or reliability and conformability (Lincoln & Guba, 1986; Yin, 2014).

4.8.1 Credibility (internal validity)

Credibility is concerned with the issue of whether the study is actually measuring what it intends to measure or examine (Lincoln & Guba, 1986). The credibility of case study research is maintained through the use of triangulation of the methods of data collection (Yin, 2014) – FGDs, direct observations of medical encounters, interviews and review of documents, including the care pathway, from endocrinologists, internists, nurses, dietitians and adult patients with T2DM with various demographic, clinical and metabolic profiles. Guba and Lincoln (1994) suggest that the use of different methods compensates for individual limitations of particular research collection methods and exploits the benefits of each method. By using triangulation of data sources, a rich picture of the various points of views and behaviour under investigation can be obtained, providing verification of data derived from different sources (Shenton, 2004).

Member checks, suggested by Lincoln and Guba (1986) provide another method of maintaining the credibility of a study. The participants in this study were given the opportunity to confirm the summary of the key points once each FGD was completed. Here the emphasis was on whether the informants considered that what was said during a session had been accurately presented in a transcribed record. This process ensured the accuracy of the findings and increased the credibility of the study.

Another strategy to maintain the credibility of a qualitative study is for the researcher to engage in reflexivity, which deals with the researcher's awareness of the subjective contributions to the meanings constructed throughout the research process (Creswell & Miller, 2000). The following is an overview of my background that I am aware may have some influence on this research.

Prior to commencing working in academia 10 years ago I worked as a nurse and 'diabetes educator' with adult patients with T2DM in a national hospital in Indonesia. These roles allowed me to work with a group of healthcare professionals such as doctors and dietitians in a national diabetes educator society. This allowed me to engage first-hand with healthcare professionals who understood the challenges of diabetes care in the practical area. Concurrently while working in academia, I worked with patients and health care professionals in the diabetes educator society, ran local and national training programs for diabetes educators, and had dedicated weekly time assigned as one of the diabetes educators in an endocrinology clinic of the national hospital. The practical experiences and academic professional tasks motivated me to examine further the underlying problems in diabetes care in Indonesia. The interest was not only research oriented, but also aimed at gaining insight that could feed back into my professional commitments.

My background in these roles necessitated me to reflect on my interactions with participants in my study. This included being aware of the impact this may have had on data collection, for example, during the observation phase I needed to remain focused on being a researcher rather than a diabetes educator.

4.8.2 Transferability (external validity)

Transferability (Lincoln & Guba, 1986) or external validity (Yin, 2014) requires that sufficient contextual information about the fieldwork sites is provided to enable the reader to evaluate whether the findings generated can be appropriately transferred to another context (Shenton, 2004). The case study methodology has been criticised as a poor basis for making generalisations (Yin, 2014; Yin, 2018), and this is regarded as one misunderstanding about case studies (Flyvbjerg, 2006). This is because the sample used in case studies is regarded as insufficient to generalise. To counter this, Yin (2014) asserts that unlike quantitative methodology where samples are selected to allow statistical generalisation, case studies provide analytical generalisation.

To ensure the transferability of this study, Yin (2018) suggests that the characteristics of the fieldwork site should be provided in sufficient detail to permit the finding of this study to be generalised to other settings. Contextual information was presented above to enhance the transferability of this study and included descriptions of the research context, the Indonesian society and culture, the Indonesian healthcare system, details of the settings and the contexts' settings and the ambience of the venues that was presented in ethnographic vignettes, the demographic characteristics of all participants, and the professional backgrounds of the different HCPs.

4.8.3 Dependability

Lincoln and Guba (1986) use the term *dependability* as closely corresponding to the notion of reliability in quantitative research. In order for a finding to be dependable, it should be able to be reproduced if a similar study is repeated by different investigators (Lincoln & Guba, 1986).

In order to enable future researchers to be able to replicate the research, this study is reported in sufficient detail to enable it to be replicated (Shenton, 2004). In case studies, writing a case study protocol and creating a case study database will provide detailed documentation of the case study's research process (Yin, 2018). A case study protocol contains details of the instruments, procedures and general rules that have been followed (Yin, 2018). According to Yin (2018) the raw data should be separately presented from the interpretation. In the present case study, the raw data were the transcriptions of FGDs and interviews, observations and patient medical records.

4.8.4 Confirmability

Confirmability refers to the degree to which the results can be confirmed by others. There are several strategies to ensure confirmability. In this study triangulation of data sources was applied in promoting confirmability (Lincoln & Guba, 1986).

4.9 Chapter conclusion

This study was conducted by adopting a methodological approach that allowed a comprehensive exploration of the subjects in the system by capturing both patient and HCP perspectives in diagnosing and explaining the issues that exist in diabetes care. Advocated by the critical realist approach, a thematic qualitative analysis was applied to generate themes within 3 phases of analysis. The triangulation methods of data collection, participants and research sites were designed to ensure the comprehensiveness of the exploration. This study has the potential to contribute to improved patient empowerment in the support of self-management in diabetes care in the Indonesian context.

The next 4 chapters present the findings of analysis from the 3 research sites. This is followed by the discussion chapter. The thesis concludes with the final chapter presenting recommendations, limitations and strengths, and the final conclusion.

Chapter 5: Findings from Field Site 1: A *Puskesmas*

5.1 Introduction

This chapter is the first of 3 chapters that present the research findings. This chapter focuses on the data gathered and analysed from a *Puskesmas*. The first section begins with a vignette presenting selected incidences that I observed and recorded as field notes. Following the vignette, the next section identifies the 5 main themes and 9 subthemes generated from patient interviews, observations of clinical encounters, and a FGD with HCPs. The final main themes and subthemes of this research site included are presented in Table 5.1. The last section summarises the findings from this first field site.

Table 5.1: Themes and subthemes of existing diabetes care in a *Puskesmas*

Themes	**Subthemes**
Medical dominance in care provision	Care focuses on medical aspects Physicians decide the care
Communication gaps	Lack of patient involvement Discouraging clinical encounters Disjunction between patients' and HCP perceptions on patient education to support self-management
Regulation-centred care provision	Perceived and healthcare organisation-related barriers to patient empowerment
Care quality	Lack of information infrastructure to promote patient self-management
Self-empowerment	Low health literacy issues At high risk of making harmful decisions

Note: HCP = healthcare professional

5.2 Site vignette

The following vignette provides an understanding of the context in which the daily activities and interactions between the patients and HCPs occurred. The setting was discussed in Chapter 1 in more depth. I start here by describing how the implementation of the new Indonesian universal health coverage program, BPJS K, affected service provision in the *Puskesmas*. This general observation included the impression of the facilities, resources and programs, particularly for those with diabetes. Then, I draw on what I observed during the clinical encounters between patients and HCPs, patient interviews, and a FGD with HCPs.

5.2.1 The *Puskesmas as a gatekeeper*

In the past, seeking health care from a *Puskesmas* was not the first choice for many urban and middle-class Indonesians. However, attending one has become increasingly popular following the launch of the BPJS K in 2014. Under the BPJS K regulation*,* a *Puskesmas* acts as a gatekeeper to accessing specialist services for those Indonesians who are covered by the BPJS K. A patient visits the *Puskesmas* in order to obtain a doctor's approval for more complete and advanced laboratory tests, a prescription to dispense medications, or screening. This is a new role for the *Puskesmas* in the era of this new payment system in the Indonesian healthcare system under the BPJS K since it was introduced in 2014. These new roles were added to the work of HCPs, especially doctors, as observed in the majority of the clinical encounters in this study. As I note in my fieldnotes:

> The doctor's tone of voice is one of irritation. I note that he is upset knowing that the patient does not bring with her the paperwork from the referred hospital. Paperwork is required from the referral hospital for the patient to get further care in the *Puskesmas*. When it was not available, this upset the doctor and the patient is blamed for forgetting to bring it. (Fieldnote, January 10, 2020)

This observation led me to ponder why the paperwork is so administratively important given that it creates a problem during a clinical encounter, and makes the doctor busier when they have to address the deficit. The following describes one of the clinical encounters illustrating how the referral paperwork upsets the doctor when meeting with a 65-year-old female patient who had been diagnosed with diabetes for 15 years:

> The doctor scans the patient's medical record and asks, "Where is the referral paperwork from the regional hospital? You are from the referred regional hospital, so you need to show the referral back paperwork from the referred hospital." The doctor seems upset and continues by saying to the patient: "Why is there no response to my referral letter (referral paperwork) from the [regional hospital]? They [the regional hospital staff] have to return this [the referral paperwork from the *Puskesmas*] with a medical diagnose at least." Further, the patient asks, "So I have to return to the nurse [a nurse at the regional hospital where the patient was previously referred]. "Yes," says the doctor while she writes something on the patient's medical record. "Please ask them [the regional hospital] to record the medical

> therapy [prescribed by the doctor at the regional hospital where the patient was previously referred]. (OBS108P)

The excerpt above highlights that the doctor was focused on the referral paperwork, not the patient. It seems that the paperwork is a form of communication between a doctor at the referred regional hospital with the doctor at the *Puskesmas* to ensure the continuity of patient care. In this case, the patient had to go back to the referral regional hospital to get the paperwork and missed her care that day in the *Puskesmas* as the doctor there was not in a position to provide that care.

As noted in another fieldnote, a focus on the referral paperwork is again prominent during the clinical encounters between a patient and a doctor:

> Today I observe a 79-year-old male patient with T2DM who did not bring the paperwork (the back referral) following being referred to a national hospital. The patient, who has uncontrolled BGLs, hypertension and heart disease, looking slightly confused and somewhat unaware of the surroundings, came to the *Puskesmas* with his wife. His wife, who appeared to be 2 or 3 years younger than him, always spoke on his behalf during the interaction with the nurse and the doctor. The patient and his wife are confused about the administrative procedures for getting their care. It seems that they cannot figure out how the communication system works between the *Puskesmas* and the national hospital where the patient was referred to before. Almost all the time in the clinical encounter is spent talking about the referral papers. (Fieldnote, January 14, 2020)

Further observations of these clinical encounters between a patient and doctor illustrate the central concern about patients having the necessary referral paperwork, independently of the required care:

> The patient and his wife slowly approach the doctor's desk. The doctor kindly greets the patient and offers a seat for him and his wife. The trembling patient sits down, helped by his wife, and his wife just sits beside her husband. The patient's wife hands an envelope with an X-ray film inside that she brings to the doctor and says, "We got this from the pulmonologist" [she meant the specialist doctor she had visited before at a national hospital where the patient was referred to], and my husband now has difficulty in breathing, and we are asking for reference paperwork to go to the national hospital.
>
> The doctor does not reply, instead he takes out the film from the envelope and puts it on an X-ray viewer behind her and looks through it, then asks, "Do you get any medications for your heart?" The wife replies, "We only need to get a drug to ease my husband's breathing." She then asks for referral paperwork, repeating what she was asking before.
>
> After reviewing the patient's medical record for about 30 seconds, the doctor then continues talking to the patient, "After the surgery, have you visited the cardiologist?" [The

> patient had bypass surgery 5 months ago]. The doctor finds that the patient did not return to the hospital for the monthly follow-up care. "I cannot give you the prescription and the referral paperwork from here [*Puskesmas*] unless the hospital has referred you back to *Puskesmas*" the doctor explains. The patient's wife replies, "I think that we are required to get the referral paperwork from the *Puskesmas* to go to the national hospital?" The doctor replies, "No, you have to finish the treatment at the hospital then they will send you back here with a note, and would you please leave a copy of the X-ray film result for us [the *Puskesmas*]?" (OBS103P)

Reflecting on the new role of the *Puskesmas,* I noted that the need for referral paperwork appeared to shift the focus of care during the clinical encounter, failing to identify the actual patient's health problems:

> There appears to be little consideration for the patient's difficulties in comprehending the administrative procedures as well as a lack of energy related to the patient's sickness and his cognitive competence to find out how the system works, or perhaps it is not their primary concern when they need the care. Their interactions with the healthcare professionals lack support for the patient and the family. The daily clinical encounters focus more on accomplishing their gatekeeper role, which are administrative, rather than attending to the patient's clinical concerns. I understand the paperwork is not just an administrative procedure. It is required for the doctor to provide the care at the *Puskesmas* in this case. If it is so important, then why does the patient have to take responsibility for managing the paperwork?
>
> The less than 10 minutes' clinical encounter is far from sufficient to address the important issues brought by the patient. The patient has a serious issue with his heart, hyperglycaemia, not to mention self-management of the diseases. However, in the end, the encounter is just a matter of talking about the referral paperwork. (Fieldnote, January 14, 2020)

5.2.2 Long queues as the norm

Crowded patients in long queues were a common sight each day in the *Puskesmas,* especially before noon. I observed 4 constriction flow points in the *Puskesmas* services that slowed patient movement: the first at the point of patient registration, the second at the doctor consultations, a third at laboratory tests (fasting and post-prandial blood glucose), and finally at the pharmacy. Around 80–100 patients attend the diabetes clinic daily. These patients are attended by one general doctor and a nurse. As I noted in my fieldnotes:

> Normally the nurse starts the clinic by opening the consultation room door and calling up patients waiting in queues at 8:00 am, but the crowds of patients have been waiting since 7:00 am. I have to be ready at the *Puskesmas* early to hand out the research flyers for

> protentional participants who are waiting in the consultation areas as the crowds began to arrive at 7:00 am. I sit with the patients who are waiting for the clinic to be opened in the waiting area. One of the patient participants is a man, aged 65 years, who has had T2DM for 11 years, and comes to the *Puskesmas* monthly to get diabetes prescriptions from the doctor. He states that he has been waiting for at least 30 minutes. I am with him for about 40 minutes. Lining up in the *Puskesmas* is one of the hardest things he has to do as part of his care of his diabetes. He states, "I am so stressed, and many patients are stressed because of this waiting time. I purchase my medications in a pharmacy close to my home, they are cheap. So, I can skip waiting for another long time in the *Puskesmas* pharmacy. We are old already; it is hard for us to sit for a long time in the queues."
>
> I could see that many patients came to the *Puskesmas* as early as possible so they could get an early registration number. By coming earlier, the patients hope to be the first to be seen by the doctor and served at the pharmacy. Some other participants who are in the queue waiting for the doctor consultation tell me that some patients prefer to avoid the busy morning clinics in the *Puskesmas* by attending in the afternoon. For those patients with diabetes who want to see the doctor in order to obtain diabetes medication prescriptions in the afternoon, they had to organise themselves to obtain their own results of their fasting and random blood glucose tests that are checked at a service external to the *Puskesmas* or otherwise the doctor will not give them the prescription. This requires these patients to spend their own money for those tests. By doing so, the patients avoid the morning crowds and long queues at the *Puskesmas*.
>
> There appears to be no appointment system in place when visiting the *Puskesmas*. An online patient registration system is available; however, it is not widely utilised by the patients as the system often fails due to technical difficulties. Consequently, many patients choose to register manually by attending in person and are prepared for a lengthy wait in a long queue. The first-come-first-served system is in place with the queuing numbering system for patient registration managed manually. Once the patients are registered, they are given a card indicating their queuing number. Patients then wait for the service and for their names to be called.
>
> However, it is not always the case that the first who come are the first served. I observe a patient complaining to the nurse that another patient with a later number is called up to see the doctor before him. The nurse then explains that the patient's medical record was not on his desk yet. He could only be called up once his medical record was available on the nurse's desk. Sometimes patients are waiting in uncertainty for the service.
>
> The humidity of the tropical weather, with an area packed full of people in a small open space, where some patients are fasting before their blood glucose is tested, makes the waiting time even more stressful for the patients. (Fieldnotes, January 14, 2020)

The excerpt from my fieldnote above demonstrates that long waiting times in a queue is viewed as 'normal' in the daily care service at the *Puskesmas.* Many patients reported suffering from having to wait for so long in the conditions.

5.2.3 Short and brief clinical encounters

The setting of this observation is a special care clinic of the *Puskesmas* that is dedicated to patients aged above 55 years. The day before my observation, I attended the site to remind the nurse and doctor about my research scheduled for the following day. A senior nurse was assigned to introduce me to the nurse and doctor who were in charge at the clinic.

The clinic is a simple square air-conditioned room without a window, and a big door that is manually operated for entering and leaving the room. There is a reception table just next to one of the entrances equipped with a computer that is used by the nurse as a reception desk. In one corner of the room, 3 or 4 steps from the nurse's reception desk, there is a table, a chair for the doctor and two for patients and the family or companion accompanying them during the medical consultation. There was a simple examination couch next to the doctor's desk and on the wall just behind the doctor' desk, a hanging X-ray film reviewer. A chair for the nurse was situated close by so that they could take the patient's blood pressure with a patient chair alongside. There is a sound system that functions as a loudspeaker to call up patients waiting outside the room. Behind the table there are height and weight scales and a large cabinet filled with papers. Just 2 or 3 steps further, there are 2 extra stools for patients to wait inside the room while another patient is being seen by the doctor, allowing these patients to hear what the doctor says to the patient at the doctor's desk.

I stood about one step away from one of the sides of these clinical encounters in order to remain unobtrusive, watching and taking brief notes on what I saw, heard and thought about the encounters. All my observations of clinical encounters were conducted in the consultation room, except 2 interactions that occurred during a wound care consultation in a nursing care room and a clinical encounter in a general healthcare room. Each of the observed clinical encounters occurred in a relatively short period of time, 5 minutes on average. When each patient's name and the queuing number was called up by the nurse in charge on a loudspeaker from the consultation room, the following repeated process was observed and recorded in my fieldnotes on each of my observation days:

> First, a patient has an encounter with a male senior nurse who looked friendly. The nurse takes the patient's blood pressure using a digital sphygmomanometer and sometimes

> records the patient’s height and weight while also engaging in informal and brief chit chat with the patient while he puts on the sphygmomanometer cuff on the patient’s arm. While waiting for the cuff to inflate, he enters some data into his computer. The time spent in this clinical encounter with the nurse is shorter than with the doctor, around 3 minutes on average.
>
> During the clinical encounter, there is more than one patient in the room. It seems that for the effectiveness of the work, the nurse calls the patients’ queuing number 3 or 4 numbers at once, bringing them into the clinic room. While a patient is with a doctor having a clinical encounter, 2 other patients are seated in the 2 extra stools in the room waiting for their turn to be seen by the doctor, while another patient is with the nurse. All are able to hear what is happening with the other patients.
>
> The patients wait for their turn to go to the doctor’s desk. Finally, from her desk, the doctor calls up the patient’s reading from files that are handed to her by the nurse. The patient then has the interaction with the doctor. (Fieldnote, January 9, 2020)

These brief interactions were usually around 3 topics:

> Today I reflected that there are only 3 topics, which are very straightforward and brief in the patient-doctor clinical encounters: patients’ BGL (whether the results are normal or not) and requests for a prescription or copy of prescription and referral paperwork. The topics of the interaction are brought either by the patients or the doctor. None of the patients nor the doctor ask or talk about other issues.
>
> Once the patients have completed their clinical encounters, they either go to the pharmacy to have their medications dispensed while others who do not want to be in another queue at the pharmacy service, or do not need to get their medications dispensed, left the building. (Fieldnotes, January 21, 2020)

Drawing from the excerpts of the fieldnotes above, I started to question whether patients are encouraged in self-management or feel that they need to be empowered. If so, how do HCPs create an empowerment program that suits the existing system of care culture? What supports in the existing policy, infrastructure, or knowledge about human resources are available to support patient self-management? I hoped that I would get the answers to these questions from interviewing the patients and having discussion with the HCPs.

5.3 Patient participants’ demographic profiles

A total of 14 patients with T2DM who visited the *Puskesmas* were involved in the interviews and observations of their clinical encounters. Table 5.2 shows the demographic and health profiles of patient participants.

Table 5.2: *Puskesmas* patient participant profiles

No	Code	Age (years)	Sex	Education	Marital Status	Occupation	Medical Diagnosis	Lab Results (mmol/L)	Year of Diabetes Diagnosis	Treatment	Health Cost Payer	Government Support Program (PROLANIS)
1	P 101	68	F	Primary School	Married	Housewife	T2DM, Hypertension	RBG 7.6	>20	Glimepiride	BPJS	Not joined
2	P 102	68	F	Finance Academy	Married	Retired	T2DM, Hypertension	RBG 11.8	22	Metformin, Glibenclamide Amlodipine,	BPJS	Not joined
3	P 103	79	M	Primary School	Married	Retired	T2DM, Hypertension, Heart Diseases, Bronchial Asthma	HbA_{1C} 63.9	21	Metformin, Amlodipine, ISDN, Aspilet	BPJS	Not joined
4	P 104	71	F	Primary School	Married	Housewife	T2DM	FBG 5.4	5	Metformin	BPJS	Not joined
5	P 105	64	F	Primary School	Married	Housewife	T2DM	RBG 7.3	6	Metformin	BPJS	Not joined
6	P 106	65	M	Diploma	Married	Retired	T2DM, Hypertension Retinopathy	FBG 4,7 PPBG 6.7	11	Metformin, Glibenclamide	BPJS	Joined
7	P 107	70	F	Primary school	Married	Housewife	T2DM Diabetes Neuropathy	FBG 6.7 PPBG 7.5	15	Metformin, Glibenclamide	BPJS	Not joined
8	P 108	65	F	Senior High School	Married	Housewife	T2DM, Diabetes Neuropathy	RBG 6,4	15	Metformin, Glimepiride	BPJS	Joined
9	P 109	68	F	Primary school	Married	Housewife	T2DM, Diabetes Neuropathy	RBG 7.3	7	Metformin	BPJS	Not joined

No	Code	Age (years)	Sex	Education	Marital Status	Occupation	Medical Diagnosis	Lab Results (mmol/L)	Year of Diabetes Diagnosis	Treatment	Health Cost Payer	Government Support Program (PROLANIS)
10	P 110	72	F	Primary School	Widow	Islamic religious private teacher	T2DM, Hypertension	FBG 5 PPBG 6.8	15	Metformin Amlodipine	BPJS	Not joined
11	P 111	64	M	Masters of Business Administration	Married	Retired	T2DM Heart Diseases	FBG 4.4	15	Metformin ISDN Aspilet	BPJS	Joined
12	P 112	65	F	Primary School	Married	Retired	T2DM	RBG 10.7	13	Metformin, Glibenclamide	BPJS	Not joined
13	P 113	72	F	High School	Widow	Private English Teacher	T2DM Osteoporosis	HbA_{1C} 47.5 mmol/mol	20	Metformin Amlodipine	BPJS	Joined
14	P 114	44	F	Senior High School	Widow	Unemployed (since with diabetes gangrene)	T2DM Diabetes gangrene Retinopathy diabetes	RBG 15.6	3	Rapid Insulin	BPJS	Not joined

Note: T2DM = Type 2 diabetes mellitus; HbA_{1C} = glycosylated haemoglobin; RBG = random blood glucose; PPBG = post-prandial blood glucose; FBG =fasting blood glucose; ISDN =

The age of patients ranged from 44 to 79 years. Of the 14 patient participants, 3 were male. Eight patients had basic primary school educational backgrounds, one patient had a master's degree, 3 had graduated from a senior high school and 2 had a diploma. Twelve patients were married, and 2 were widowed. Most of the patients were housewives either living with a retired spouse and/or their children. Two out of the 14 were still in paid employment – a private Islamic religious teacher and an informal private English teacher. All patients were covered under the BPJS K health insurance system*,* and only 4 were members of PROLANIS[2].

Most of the patients were in stage of diabetes with complications and some had uncontrolled BGL. The majority had at least one or 2 chronic diabetes complication(s), such as hypertension (5 patients), diabetes sensory neuropathy (5 patients), heart disease (2 patients), diabetes retinopathy (3 patients), active gangrene diabetes (1 patient) and loose teeth (1 patient). Two patients also had other comorbidities, such as bronchial asthma and osteoporosis. Five out of the 14 patients had high BLGs (random BGLs ranged from 11.0–12.5 mmol/l and HbA_{1C} 64 mmol/mol or 8%), with most of the patients taking multiple oral hypoglycemia medication. One patient was on insulin therapy. Most participants did not have their HbA_{1C} results from the last 6 months. The period of time of having diabetes varied, with the shortest estimated as 3 to 10 years (4 patients), 6 patients had had diabetes for between 10 and 20 years, and 4 for more than 20 years.

5.4 Healthcare professional participants' demographic profiles

All the participating HCPs (see Table 5.3) had general medical backgrounds; however, none had public health qualifications. Of the 2 participating general medical doctors, one was assigned as the only doctor with daily responsibility for the Special Aged Care Clinic operating within this *Puskesmas* and the other doctor was the head of the Chronic Illness Prevention and Promotion Program. The 2 senior nurses had more than 15 years' experience. One had a bachelor degree and was assigned as the head nurse of the Nursing

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[2] PROLANIS (an acronym in Indonesian for *Program Pengendalian Penyakit Kronis)* or a chronic disease management program funded under the Indonesian health insurance program. It is a multi-faceted intervention that involves pharmacologic and non-pharmacologic strategies (e.g., patient education, physical activity, monitoring, and reminder system) Kesehatan, B. PROLANIS (Program Pengelolaan Penyakit Kronis) https://bpjs-kesehatan.go.id/bpjs/dmdocuments/06-PROLANIS.

Care Clinic. The nurse with the Diploma of Nursing was assigned to the Aged Care Clinic. One dietitian held a Diploma in Nutrition and was assigned as the nutritionist for all medical cases, including diabetes. The HCP participants were predominately female with only one male. The age of the participating HCPs in the *Puskesmas* ranged from 20 to 50 years. None of the HCPs had additional specific training on diabetes care, relying on what was included in the general curriculum in their discipline's formal education.

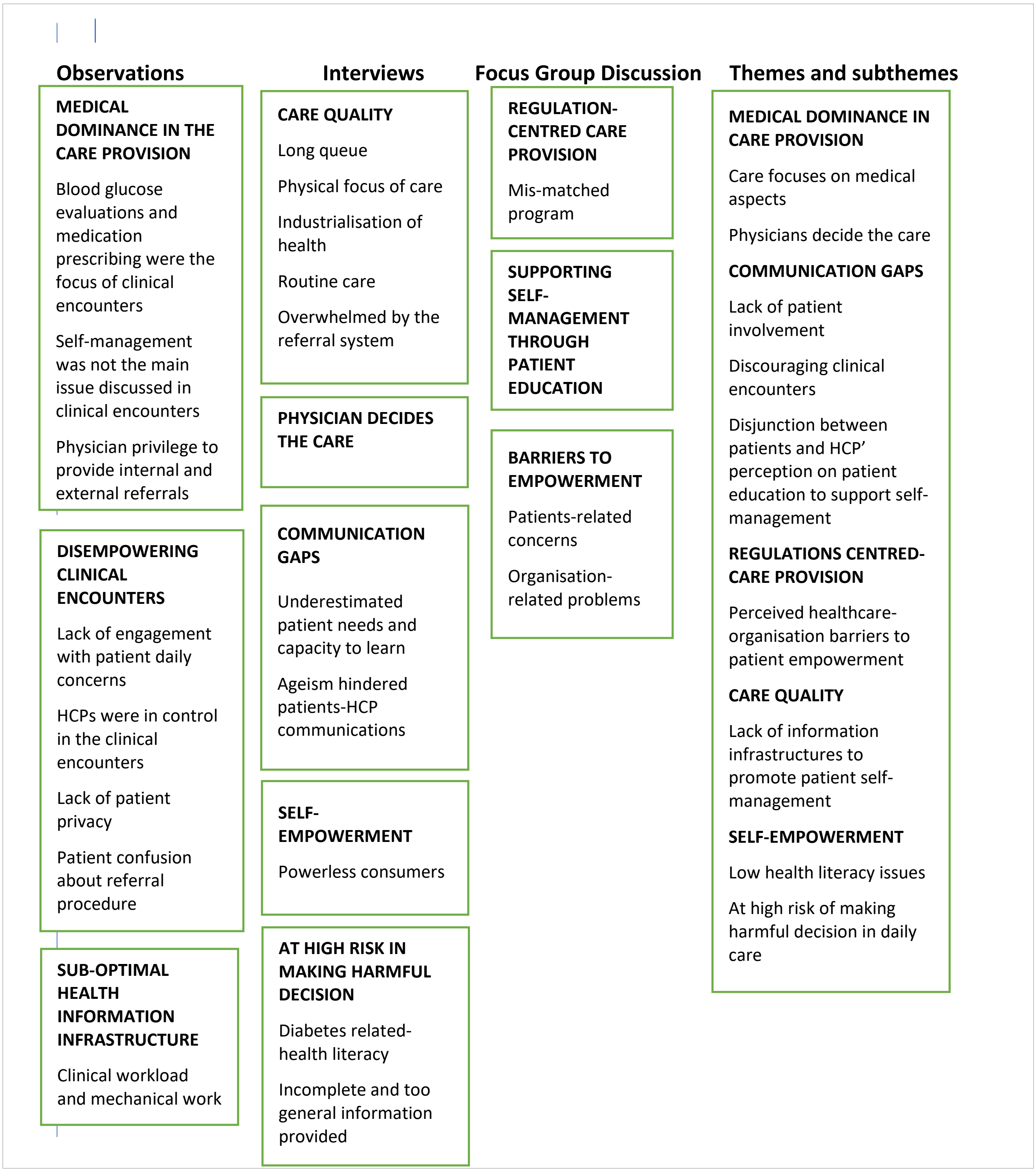
Table 5.3: Demographic profile of participating healthcare professionals at the *Puskesmas*

No	Code	Professional Background	Educational Background	Sex	Age Range (years)	Job Title
1	011	General Medical Doctor	Medical Doctor	F	30–40	Medical Doctor
2	012	General Medical Doctor	Medical Doctor	F	40–50	Head of Community Health Care Centre
3	111	Nursing	Bachelor of Nursing	F	40–50	Head Nurse
4	112	Nursing	Nursing Diploma	M	40–50	Nurse
5	211	Nutritionist	Diploma	F	20 - 30	Nutritionist

5.5 Themes and subthemes in Field Site 1

The first phase of the analysis generated 3 main themes and 7 subthemes from the 28 observed clinical encounters; 5 main themes and 10 subthemes emerged from the 14 patient interviews; and 3 main themes and 3 subthemes were generated from the FGD The list of the themes, subthemes, categories, and the selected code of each theme is presented in Appendices 26, 26, 27.

The second phase of analysis generated 4 themes and 8 subthemes through a cross-case method as discussed in Chapter 4. Figure 5.1 presents the themes and subthemes generated from the triangulated data collection methods – the patient interviews, observations of clinical encounters, and the FGD with HCPs.



Observations

MEDICAL DOMINANCE IN THE CARE PROVISION

Blood glucose evaluations and medication prescribing were the focus of clinical encounters

Self-management was not the main issue discussed in clinical encounters

Physician privilege to provide internal and external referrals

DISEMPOWERING CLINICAL ENCOUNTERS

Lack of engagement with patient daily concerns

HCPs were in control in the clinical encounters

Lack of patient privacy

Patient confusion about referral procedure

SUB-OPTIMAL HEALTH INFORMATION INFRASTRUCTURE

Clinical workload and mechanical work

Interviews

CARE QUALITY

Long queue

Physical focus of care

Industrialisation of health

Routine care

Overwhelmed by the referral system

PHYSICIAN DECIDES THE CARE

COMMUNICATION GAPS

Underestimated patient needs and capacity to learn

Ageism hindered patients-HCP communications

SELF-EMPOWERMENT

Powerless consumers

AT HIGH RISK IN MAKING HARMFUL DECISION

Diabetes related-health literacy

Incomplete and too general information provided

Focus Group Discussion

REGULATION-CENTRED CARE PROVISION

Mis-matched program

SUPPORTING SELF-MANAGEMENT THROUGH PATIENT EDUCATION

BARRIERS TO EMPOWERMENT

Patients-related concerns

Organisation-related problems

Themes and subthemes

MEDICAL DOMINANCE IN CARE PROVISION

Care focuses on medical aspects

Physicians decide the care

COMMUNICATION GAPS

Lack of patient involvement

Discouraging clinical encounters

Disjunction between patients and HCP' perception on patient education to support self-management

REGULATIONS CENTRED-CARE PROVISION

Perceived healthcare-organisation barriers to patient empowerment

CARE QUALITY

Lack of information infrastructures to promote patient self-management

SELF-EMPOWERMENT

Low health literacy issues

At high risk of making harmful decision in daily care

Figure 5.1: Theme and subtheme analysis and findings from field site 1, the Puskesmas

Note: FGD = focus group discussion; HCP = healthcare professional

5.5.1 Medical dominance in care provision

The first main theme, medical dominance, refers to a process of care including the clinical encounters that focus on medical aspects of care, where the patient's concerns are perceived from a medical point of view and the doctor maintains control over the process of care by using medical science to deal with patient concerns. The subthemes are care focuses on medical aspects and physicians decide the care.

5.5.1.1 Care focuses on medical aspects

The medical dominance of the care was evident where the focus of care was more on medical tests over patient self-management matters, which were not discussed in clinical encounters between patients and HCPs. For example, a 64-year-old male patient with a Master of Education with T2DM for 15 years said:

> In here, they [the staff] are friendly, but there is no real care for diabetes patients. They just check my blood glucose and dispense medicines … No information is provided; I mean related to my problems. It's just general information. (INTV, P111 line 56–61)

The excerpt above highlights that patients perceived the care provided in the *Puskesmas* was limited to technical medical actions, such as checking blood glucose and dispensing medications. In the observed clinical encounters at the *Puskesmas*, the interactions between a doctor and a patient were mostly initiated by talking about patient's BGLs and then continued with diabetes medications.

5.5.1.2 Physicians decide the care

Medical dominance was also evident in how the care provision was authorised by physicians. Patients were of the view that the physicians decided the care and made all the decisions without referring to the patient. Most of the services in the *Puskesmas*, such as simple laboratory tests (random blood glucose test) and diet consultations required a doctor's internal referral note. Without the doctor's referral note the patients were not verified to use the services. Medical dominance was also evident in what care the doctor decided to provide. The doctor in the *Puskesmas* decided whether a patient would be treated in the *Puskesmas* or referred to a higher healthcare facility, regardless of whether the patient was happy or not with the decisions made for them. For example, one of the female patients said:

> I am using the government healthcare insurance [the BPJS, the self-support one]. But I am not allowed … to be a patient in there [the hospital] … I was not allowed because they [the doctors] said that I was not sick enough, so, the doctor won't send [refer] me to the hospital … seemingly they waited for me to get a more serious illness, then I will be sent to a hospital. (INTV, P113, line 68–76)

The excerpt above suggests the patient was disappointed about how the doctor just denied her symptoms when she asked the doctor to refer her to a hospital. She wanted the doctor to listen to her, not simply disregard her symptoms. However, the doctor decided not to refer her to a hospital. The doctor indicated that it was not necessary to refer this patient to the higher level of care as the patient's sickness was not severe enough. Other patients reported similar experiences.

5.5.2 Communication gaps

The second main theme, communication gaps, refers to an imbalance in the communication between patients and the HCPs that created an asymmetry of knowledge and power between patients and the HCP. Three subthemes included lack of patient involvement, discouraging clinical encounters, and disjunction between patient and HCP perceptions of support for self-management.

5.5.2.1 Lack of patient involvement

Analysis of the data from the interviews illustrates patient concerns regarding their involvement in their care. A 72-year-old female patient with T2DM for more than 20 years described how she was not involved in her care as she said that her concerns were devalued. She said:

> I told the doctor that my BGL was already less than 11.1 mmol/L [getting back to a normal level]. Then, I asked the doctor whether I could possibly stop taking my medications. But the doctor then said: "Ma'm, your kidneys were affected … moreover if you did not take the medications, it would get worse." What the doctor said really made me feel depressed. I did not know my kidneys were affected … why did they talk in such way, why didn't they just explain it to me in a nicer way. (INTV, P113, line 99–106)

The excerpt above suggests the patient tried to become involved in her own care by asking whether she could stop the medication as she believed that her blood glucose was back to a normal level. Instead of listening and showing empathy with the patient's concern, the doctor told her that her kidneys were already affected by uncontrolled diabetes. The patient did not know this. She felt depressed at the way the doctor told her to continue the medication and by the fact that he had not told her before that her kidneys were damaged. The gaps in communication occurred when the doctor appeared not to be involved in her care, which caused her to feel despondent, and disempowered her in her own diabetes care. This type of interaction between HCPs and patients was reported by a number of other patient participants.

5.5.2.2 Discouraging clinical encounters

Discouraging clinical encounters were also evident between HCP and patients. One example was where a clinical encounter between a doctor and a 44-year-old female patient who had been diagnosed with diabetes for 3 years was observed. The patient attended the *Puskesmas* to have her gangrenous diabetes-related wound cared for by a nurse. The patient passed on the additional information she had obtained from the referral hospital doctor to the *Puskesmas* doctor regarding the plan for her eye surgery:

> A nurse asked the patient to sit in front of the doctor's desk and told the doctor that the patient was the one who was planned for eye surgery at the regional hospital. The doctor did not respond, then she looked at the patient's medical record. Then, she asked the patient, "So when will the surgery be?" "I am not sure" replied the patient. The patient had not finished talking [in fact the patient wanted to say that there was no surgery scheduled yet as her blood glucose was still high], but the doctor harshly interrupted by saying, "You can't be like that, you have to get the surgery as soon as possible, you have to comply with the medical procedures. We are here trying to take care of your diabetes gangrene." The patient did not reply. She seemed tired but said, "Okay, I will ask the doctor [at the regional hospital] about the date for the surgery." The patient thanked the doctor, and this ended the interaction. (OBS14 P114)

The excerpt above demonstrates the powerful role the doctor exercised towards the patient in controlling the communication by blaming the patient for the delay of her eye surgery. The patient had less power than the doctor to control the flow of communication or even to explain the reason for her eye surgery delay. In fact, it was delayed because her BGL was still high. However, the doctor did not really listen to what the patient said, just blamed her instead. Other patients reported similar discouraging interactions when they were attending doctors.

5.5.2.3 Disjunction between patients' and healthcare professionals' perceptions of support for self-management

There was a disjunction between the patients and HCP perceptions regarding patient education to support self-management. The theme refers to the discrepancy in patients' expectations that they would have access to detailed information regarding the knowledge and skills required to support their self-management, and the HCP perceptions and behaviours in providing information to the patients. Some of the patients felt the information provided to them was impersonal, general and incomplete. This was evident from the example below from one patient:

> I wish that the doctor explained things to me clearly … but, I understand this [why the doctor did not explain clearly] … I am just a patient of a *Puskesmas* … In here [at the *Puskesmas*] I was just told by the doctor to get the blood sugar tested, do exercise, that was all … [The doctor] did not explain what kind of the exercise … how to do the exercise … how much I have to do the exercise [it was not explained further]. That was all … So please, explain it [the diseases, the treatments] clearer … but the explanations provided were limited … I understand many other patients are waiting to get the care. So, I was just told [by the doctor] to do exercise … [I] do not know what exercise is and how much the exercise has to be done … So, if I feel unwell then I just reduce my sugar consumption … then I go to the doctor … that is all what I do. (INTV, P108, line 24–34)

The excerpt above suggests that the patient expected to be provided with more details and personal information related to her health condition and care. She indicated that the suggestions to exercise provided were too general and left her confused about what was expected.

This patient's perceptions were confirmed by the behaviours of the HCPs in most of the clinical encounters observed in this field site. Patient encounters with a nurse or a doctor were mostly of 5 minutes duration with no detailed personal information provided to the patients. The following observation of a patient, that took less than 5 minutes, shows how generalised and incomplete the information received by the patient was:

> A 70-year-old female patient with 15 years of T2DM came to the *Puskesmas* on her own. As she approached the doctor's desk and took her seat, the doctor greeted her and asked, "Could I get the results of your blood sugar test please?" "I did not check

> my blood sugar," the patient replied. "Why not? Next time please check your blood sugar before coming because I need to evaluate how you are going with the medications." The doctor then said, "You need to reduce your weight too." The patient said, "I might have had my uric acids increased, I can't go for exercise, I've got painful legs," assuming that the doctor had asked her to do exercise. (OBS, 07P)

The excerpt above shows how general the information passed on from the doctor to the patient about reducing her weight was, with no additional details provided to the patient regarding her weight. Patients consistently perceived that HCPs advice to them was incomplete, too general and lacked detail.

However, the HCPs did not see the necessity to provide details about healthcare information to patients, nor was it seen as a priority. From their perspective, health education delivered to patients was to ensure the education program was in line with the Indonesian Government's programs. One of the doctors explained:

> Thank God, we have reached 80% from just 30% in covering patient education. Our problem was, especially when a patient came in the afternoon when our nutritionist was not available anymore … When there were patients who required dietary consultations, but the dietitian was only available in the morning. So finally, we just provided adequate diet consultations, at least something that they need for that time. (FGD1, P01, lines 34–43)

This excerpt suggests that patient education was seen as adequate if the number of patients seen by the dietician reached the target. The relevance to the patient was not a priority.

The 3 excerpts above reflect the disjunction between patient expectations and HCP understanding of patient education that was reflected in their clinical encounters.

5.5.3 Regulation-centred care provision

The third main theme, regulation-centred care provision, refers to the care and programs provided in the *Puskesmas* that were run according to government regulations as discussed by the HCP participants. The subtheme is perceived healthcare organisation-related barriers to patient empowerment.

The HCPs perceived that the existing care provision for patients with T2DM in the *Puskesmas* had been established in line with the Indonesian Government's regulations for non-communicable disease management. As one of the doctors said:

> Our system has been established as our practices align with the Indonesian Health Ministry regulations, including the programs for diabetes care. The regulation for caring for diabetics is under the non-communicable disease regulations. It has its programs and workforce and each month we have to report. (FGD1, P01, lines 1–3)

This doctor was of the view that the existing care provision and programs, including diabetes care, were on track as long as they followed the mechanisms established by the Indonesian's health ministry regulations. Reports of the achievements of the programs seemed to be an important aspect of the system.

Self-management and patient empowerment were considered by the HCPs to be part of a package of programs from the BPJS K (named PROLANIS) that included membership of an aerobics club and HbA_{1C} testing every 6 months. The program was mentioned by the participants as the national government program to support patients with diabetes. The aim of the program was to achieve 100% compliance every month, otherwise the *Puskesmas* could not claim the capitation funding from the government. A nurse explained:

> The coverage of the PROLANIS program has to reach 100% … if the number of the members is 20 persons, so, in every activity it has to be 20 persons. If the report is not 100% it means that we do not reach the indicators [program successfulness indicators], then the capitation will reduce. (FGD1, P03, line 71–77)

The except above suggests that the PROLANIS program instigated by the Indonesian Health Ministry aimed to prevent diabetes complications progressing through an exercise class. Participants said that the achievement of the program had to be 100%, meaning that all activities in the PROLANIS program had to reach 100% compliance by the patients. The HCPs suspected most patients could not fully commit to joining all the activities in the PROLANIS, therefore the number of the participants was limited to just 20 persons. With this number, it was easier to manage the members and ensure that they were committed to joining all the activities of the program. Therefore, the success of the program could be reported as being 100% successful. Otherwise, the government would not cover the cost of the activities. The PROLANIS program that should be targeted to all patients with diabetes in the community, which aimed to reduce the number of diabetes complications, was not implemented or available to all patients. There were hundreds of patients with diabetes in the *Puskesmas* who did not benefit from the program. The care provided to run the program was based on the government regulation.

The evidence suggests that the focus on the education program was based on the regulations, rather than patient needs. The patients' experience of their care at the *Puskesmas* was limited to measuring their BGL and medications. They regarded the care as impersonal and lacking in concern for their emotional and psychological states. One of the participants said:

> To be involved psychologically in our care … could be explored for the patients … They [physicians might talk to us], then patients might express their problems … They [HCPs] have to understand about psychology … it does not only depend on medicine.
> (INTV, P111, line 67–72)

The excerpt above implies that the only care required is medical care; this is representative of all the HCPs' views. The psychological needs of the patient were not explored or part of the existing care. The existing care catered for blood glucose control and medication, and was driven by the regulations. Although the HCPs suggested that the patient empowerment program (defined by the HCPs as the program in PROLANIS*)* was in line with the government program, it did not meet the needs of patients with T2DM.

The subtheme for regulation-centred provision is perceived healthcare organisation-related barriers to patient empowerment.

The data show various perceived barriers towards patient empowerment to support self-management. Barriers to patient empowerment include blockages that prevent any support to enhance patient empowerment at the level of the patient–HCP interaction and at the level of the organisation of the healthcare system. HCPs have limited time to interact with patients in their clinical encounters, with 5 minutes on average for each patient–doctor interaction and from one to 2 minutes for patient–nurse encounters. This limited time impacts on the topics that could be discussed and the HCP's attitude during the encounters.

Both the patients and HCPs viewed time constraints as a barrier in supporting patient education according to individual patient needs. One of female patients aged 65 years, who had been diagnosed with diabetes for 15 years, and who had a high school educational background, said:

> In here [at the *Puskesmas*] I just was told by the doctor to have my blood sugar tested … do exercise … that was all. I have never been told to look after myself, I have many other problems. My feet … you know … I have got my feet tingling so often then the doctor just dumped [referred] me to another doctor … the doctor here told me to just go to a neurologist. No other words, just that words … Sometimes the doctor seemed to be reluctant just to talk to me.
>
> They [doctors at *Puskesmas*] should prevent my disease from getting worse starting from here, so patients do not need to go to an acute hospital. Well … so, we are the ones [patients of the *Puskesmas*] that have to actively raise questions [with the doctors] … but it was about time limitations. I wish the doctor at least would ask me about my problems. (INTV, P108, line 23–47)

The patient above suggested that a lack of time and the doctor's reluctance to talk with her, limited the time for the clinical encounter in exploring her concerns, such as the abnormal sensation in her feet (tingling sensations), as the encounter just focused on her BGL.

The time constraints on providing longer clinical interactions with patients was confirmed in the FGD with the HCPs. One of the nurses who attended a home visit for a patient who could no longer attend to the *Puskesmas* for his diabetes care said:

> They [the patients] needed more information from us … sometimes they [the patients] did not remember what we had explained, they only memorised 2 out of 10 … In one home visit, I found that a patient was running out of his diabetes oral medications and did not come back to the *Puskesmas* … he [the patient] just did not understand … he just left his wound a month without doing anything … even though he had his one side of his leg amputated because of diabetes gangrene before … But well yes, home visits take longer, which we could not give our patient in the *Puskesmas*. (FGD1, P03, line 219–226)

In the excerpt above the nurse suggested that the patients of *Puskesmas* require frequent patient education as they may find it difficult to remember all the information provided to them about their diseases and medications. To provide patient education that enhances patient understanding to look after themselves is time consuming, and they could not provide it in the *Puskesmas* due to time constraints.

Unlike the patients' views that depicted the doctors' communication as one of the barriers to empowerment, the HCPs perceived that the barriers were mainly related to the patient's motivation and attitude towards their health. According to HCPs, a number of programs were available in the *Puskesmas*, namely health education about a diabetes diet from PROLANIS, and home visits. The HCPs argued that patient factors such as low levels of education, poor health literacy, and lack of awareness and motivation were barriers to empowerment. One of the HCP participants identified the barriers to empowerment by saying:

> Many were lazy … as they kept asking questions such as, "How long the time would be taken to join the program [diabetes morning aerobic]" … Once they [the patients] found out that the program was held on Saturday, and it was starting at 6.30 am, the patients were not motivated. (FGD1, P02, line 213–217)

The excerpt above indicates that the HCPs believed the barrier to patient empowerment was a lack of patient involvement in the PROLANIS program. The HCPs suspected that most of the patients did not join the program as they were not aware of its importance or were too lazy to come because it was held very early in the morning every weekend. The patients' lack of motivation and awareness were regarded as barriers to the empowerment programs.

Health literacy was considered by the HCPs as another barrier to patient empowerment. Health literacy refers to the lack of basic knowledge and skills related to health. The HCPs were of the view that the patients in the *Puskesmas* had a low level of health literacy. Some patients still believed diabetes-related myths and had misperceptions regarding the cause and management of diabetes, even though they had had the condition for more than 10 years. One of the examples of this was a 72-year-old female participant who had finished primary school and been diagnosed with T2DM for 15 years:

> Perhaps I got my diabetes because I got a shot for my family planning hormones when I was younger. Who knows that the needle was a used needle at that time, it was not a sterile needle, it was a used needle … we do not know. (INTV, P110, line 2–3)

This excerpt shows that the patient misunderstood T2DM and exhibited a lack of knowledge about the cause of her diabetes. She perceived that the cause of her diabetes was the transmission of blood through a used needle from another person with diabetes when she was given a family planning hormonal injection when she was young. The misunderstanding shows this patient's limited knowledge about what causes diabetes. The patient had been diagnosed with T2DM more than 15 years ago.

In contrast, some participants perceived that the barrier to support self-management stemmed from HCP attitudes and stereotyping of the elderly. For example, they indicated to patients that their complaints were due to their age. A 72-year-old female patient who had been diagnosed with T2DM for 20 years and was still actively working as a private English teacher said:

> I told the doctor [at the *Puskesmas*] that I had varicose veins on my legs … but the doctor said that was not [varices]. Uhf … if it was not, then what was it? … I am confused … the doctor did not tell me what it was … But, when I asked [the doctors] [they said] your problem was related to your age … All were related to my older age … I told [the doctor] that I had got a headache … again it was said that it was because of my age. I then hesitated to ask further questions … In here they did not really check my health. (INTV, P113, line 61–67).

Communication between patients and doctors was hindered by the health professionals focusing on the physical symptoms experienced by the patient that were justified as being normal for an elderly patient. Consequently, the patient hesitated to talk more about what she felt with the doctor. Such gaps in the communication between a patient and an HCP create barriers towards patient empowerment.

5.5.4 Care quality

The fourth main theme, care quality, refers to perceived low quality of care in the *Puskesmas*. The low quality of care was linked to several problems identified by the patient participants. The subtheme comprised lack of health-information infrastructure to promote patient self-management.

Despite the friendliness of the *Puskesmas* staff, the patient participants were of the view that the care in the *Puskesmas* was of low quality as it provided was not as what the participants sought or wanted. This perception was formulated as a result of the long queues in almost all the services used by the patients in the *Puskesmas*, such as time waiting for medications to be dispensed in the pharmacy and waiting for doctor consultations. Most of the participants also said that the care in the *Puskesmas* was only about obtaining diabetes medications and testing their blood glucose in the laboratory, while their psychological needs were ignored. There was no opportunity to talk with the HCPs about the real-life problems that were affected by their diabetes either directly or indirectly. For example, a female participant, aged 65 years who had used the *Puskesmas* for more than 10 years said:

> The service [the care] was poor … But I understand this is just a *Puskesmas*. I did not blame them [the HCPs]. But to be honest, the care was poor. (INTV, P08, line 44–47)

The excerpt above suggests patient evaluation about the quality of care was low. The patient implied that the care in this *Puskesmas* was poor as it happened in *Puskemas* in general.

The subtheme for care quality is a lack of health-information programming to promote patient self-management

This subtheme refers to the lack of patient-education programs, standards and guidelines, education materials, or interventions in clinical encounters or in programs to improve patient knowledge and skills to foster self-management. In all of the 28 clinical encounters, no health education was provided to the patients. Consultations on a diabetes diet with a dietitian was the only patient-education program prescribed by the doctor and was only provided once. When a nurse was asked about the patient-education program in the FGD, she said:

> I acknowledge my weakness is for documenting. I explained a lot of things, but no records on it. One day a patient came to me and said that we have not explained about a particular thing, in fact I have, but I didn't have any note to prove. (FGD1, line 120–124)

The nurse in the excerpt above indicated that a component of patient education was provided; however, as there was no planning or evaluation of the education program, no documentation or records were written. The records on patient education were focused on the coverage or number of patients who were referred to the dietitians.

5.5.5 Self-empowerment

The last main theme, self-empowerment, refers to patients' coping strategies to gain knowledge about their diabetes and its care given that they saw the health education provided by the HCPs as insufficient. Under this theme, two subthemes were identified:

low health literacy and at high risk of making harmful decisions. The first subtheme relates to the underlying cause of misunderstandings in diabetes and care. The second subtheme relates to the impact of a lack of evidence-based health literacy.

The patients learned about the treatment for diabetes from families or friends, or read books. Some patients also mentioned religiosity, such as believing in God, that strengthened them. Regardless of whether the knowledge gained was just myths, some patients practised what they had heard. For example, a 44-year-old female patient with an academic qualification with T2DM for 3 years, had severe diabetic retinopathy and active diabetes gangrene on her left leg, said:

> I used to try cherry and insulin leaves. Many people told me to use snake blood for my diabetes wounds. Women who had lack of knowledge will trust it. I myself do not trust it. Self-care, self-learning to me is important because we are ourselves who feel it. Because, if I ignore [diabetes treatment] then I will be the one who will get ill. So, I avoid sugary drinks and food. (INTV, P114, line 38–47)

The excerpt above suggests that there was information available to the patient, such as using cherry and insulin leaves to reduce BGL. The patient followed some of the advice, which to the patient made some sense, and ignored the advice she believed was irrational. The patient further explained that she tried to source knowledge on how to look after herself as she was the one who would be impacted on directly if she ignored the disease.

5.5.5.1 Low health literacy

The low health literacy subtheme refers to a lack of knowledge and skills about basic health related to diabetes. Some patients had incorrect perceptions regarding managing numbness caused by neurological damages. One of the examples of this was a 68-year-old female participant who had finished her tertiary education with T2DM for 22 years:

> I soak my hands in a warm water to reduce numbness. But I am still having the problem and planning to ask for medications from the doctor. (INTV, P102, line 2–3)

The excerpt above shows that the patient was soaking her hands in warm water to reduce the numbness without realising the potential injury that might occur when a diabetic uses warm water. The practice shows that the patient has limited knowledge of the impact of using warm water on patients with T2DM in which in many neurological related diabetes complications cases have alterations in temperature sensitivity (Jose et al., 2005; Pollock et al., 2004).

5.5.5.2 At high risk of making harmful decisions in daily care

The subtheme of the high risk of making harmful decisions in daily care refers to patient experiences in handling threatening events in diabetes, such as managing hypoglycaemia at home. Episodes of hypoglycaemia might be experienced by people with diabetes, especially those who are elderly and taking hypoglycaemic agents. For example, a 68-year-old participant with T2DM for 7 years explained:

> I had experienced of low blood sugar … I was nearly unconscious and was so weak … Yes. I was taken directly to a nearest clinic at that time … I was afraid that if I put sugar into my drink at that time [when the blood glucose was low] then my blood sugar will increase. That was why I just took the drinking water without sugar at that time [when she experienced a low of blood glucose]. (INTV, P109, line 84–97)

This patient had a hypoglycaemia event. She believed she was not allowed to have sugar products, so she did not take sugar products as first aid to manage her hypoglycaemia. Instead, she drank plain water, and her family took her directly to a clinic for treatment. As hypoglycaemia is one of the emergency events that might occur in patients with diabetes, lack of knowledge and skills in managing this situation put her at a high risk of severe hypoglycaemia. Two other patients were also told that when they experienced hypoglycaemia at home, they should either use corn sugar or drink a glass of low-sugar tea to overcome the problem.

The misconception held by this patient and other patients could have been the result of a combination of low patient health literacy, low educational backgrounds, communication gaps between the patients and HCPs, and the overall lack of support from HCPs.

5.6 Chapter conclusion

The study at the first research site, the *Puskesmas*, showed the majority of patient participants were aged above 40 years and had little educational knowledge of diabetes care. Five out of 14 patient participants had uncontrolled high BGL, the majority had chronic diabetes complications and did not have the results of their HbA1C level in their medical records. The HCPs were aged 40 to 60 years and had a general educational background in medical and nursing areas.

The healthcare service context showed the role of the *Puskesmas* as a gatekeeper. Physicians were assigned to the role. A high number of patients attended daily, there were long queues in obtaining the services, and short and brief medical encounters. Within this context, 5 themes and 9 subthemes were generated from the analysis of 14 patient interviews, 28 observations of clinical encounters between patients and HCPs, and one FGD with HCPs from this first *Puskesmas* research site. There were consistencies and inconsistencies in the themes and the subthemes found across the 3 data sources.

Features of medical dominance in care were shown as the clinical encounters focused on medical aspects, and the care was directed by physicians with little patient involvement in deciding the care. Communication gaps between patients and HCPs were also presented in the clinical encounters where both patients and HCPs had different expectations in their communication. While most of the patients suggested that the approach used in their care was discouraging, this is in contrast to the HCPs, who believed the care included an education program.

The existing diabetes care in the *Puskesmas* also showed care provision centred on government regulations over patient need and lacked any formal healthcare information infrastructure. It was perceived by the patients as low care quality. Finally, within the existing approach used in the care, there was a lack of support from HCPs towards patient empowerment that resulted in a low level of health literacy and lack of capability in making daily health-promoting decisions.

The next chapter presents the findings from the second research site, which was a provincial hospital.

Chapter 6: Findings from Field Site 2: Provincial Hospital

6.1 Introduction

This chapter is the second of the 3 chapters that present the research findings. This chapter focuses on the data gathered and analysed from a provincial general hospital in the metropolitan city of Jakarta, Indonesia. The first section begins with a vignette of selected incidents that I observed and recorded as fieldnotes to provide context. Following this, a cross analysis of themes generated from patient interviews, observations of clinical encounters and FGDs with HCPs is presented. The final section concludes the findings from this second field site.

Three main themes and 10 subthemes were generated. The themes are medical dominance in diabetes care, disempowering systems in supporting patient self-management and unspoken patient challenges to self-management. The subthemes in medical dominance in diabetes care are doctors perceived as a source of diabetes care information and the medicalisation of approaches to clinical encounters. The subthemes of disempowering systems in supporting patient self-management are barriers to doctors providing the best medical diabetes care, lack of team collaboration in supporting patient self-management, restricted patient–HCP communication, ineffectiveness of the new healthcare insurance system and scarcity of patient empowerment programs for diabetes self-management. The subthemes of unspoken patient challenges towards self-management are facing psychological stress related to medication regimens, controlling blood glucose and the social pressures of being a patient with diabetes. Table 6.1. presents these themes.

Table 6.1: Main themes and subthemes in existing diabetes care in a provincial hospital

Themes	Subthemes
Medical dominance in diabetes care	Doctor is perceived as the source of diabetes care information
	Medicalisation approach in the clinical encounters
System-related barriers towards empowering patient self-management	Doctors' barriers to providing best practice medical diabetes care
	Lack of team collaboration in supporting patient empowerment towards self-management
	Limited patient–HCP communication
	Ineffectiveness of the new healthcare insurance system
	Lack of patient-empowerment program and supports towards diabetes self-management
Unspoken patient challenges towards self-management	Facing psychological stress related to medication regimens
	Controlling blood glucose
	Social pressures of being a patient with diabetes

Note: HCP = healthcare professional

6.2 Site vignette

The following ethnographic vignette provides an understanding of the context where daily activities, and interactions between the patients and HCPs occurred. The setting was discussed in more depth in Chapter 1. I start by describing my impression of the facilities, resources and programs, particularly for those with diabetes. Then I draw on what I observed during the clinical encounters between patients and HCPs, patient interviews and an FGD with HCPs. The observations occurred at an internal medical and specialist diabetes care outpatient clinic in a provincial hospital in Jakarta.

6.2.1 Overcrowding as the norm

Nearly every corner and along the corridor of the outpatient area was crowded with patients. The hustle and bustle of morning routines were especially evident at the outpatient clinics, the BPJS K office, the pharmacy and the laboratories. Hundreds of patients were lining up to get approval the representative from the BPJS K government health insurance scheme in the hospital. This was the standard procedure. Patients referred from the *Puskesmas* needed to get approval signed by the BPJS K hospital's administrator to be eligible to get care in the hospital on the same day. Additionally, the noise from beeping announcements and calling up patients by their name from the pharmacy was loud. Most patients who come for these services are referred from the *Puskesmas* and need specialist treatment, laboratory tests and further diagnoses. However, the non-BPJS K patients or privately funded patients are also allowed to access the service with other BPJS K patients. Hence patients accumulating in the outpatient department are seen every day. As I noted:

> This morning, around 7:30 am, I am standing (as there is no vacant chair left) behind crowds of outpatients at the registration front desk. Among the crowds are patients in wheelchairs and their families, and some look sick. I can imagine how hard it is if I was the patient; just to get the registration number, I would need to be in the queue and wait to confirm my registration on the front desk and provide evidence that I was eligible for whatever services I needed today in this hospital: a doctor consultation, laboratory tests and the pharmacy. I also see a patient argue with the officer as the patient did not have all their documents. I feel it is so demanding to bring copies of several documents while all patients have a BPJS K card and identification card to prove their identity. If I were a patient with diabetes, I would have been fasting for my prandial (fasting) blood glucose test because I have to show the results of my blood glucose tests to the doctor. Being in the crowd must be even harder for them.
>
> From where I stand, I can see other people lined up at the registration area. Mixed in with the crowds are food stalls in the corners selling refreshments, breads, and the traditional sweets and savouries. The stall is doing a good business. The patients can buy food without losing their place in the queue. Patients normally spend nearly a day in the hospital before they have seen a doctor, had their laboratory tests, and had medications dispensed from the pharmacy. (Fieldnote, 28 February 2020)

This fieldnote demonstrates that long waiting times and queues is viewed as normal in the hospital. The patients reported suffering from having to wait for so long in these conditions.

6.2.2 Another long wait for a brief doctor consultation

The next stop for getting a doctor’s consultation is to be registered in the specific outpatient clinic, for example the internal medicine and a diabetes clinic outpatient clinic. In this area, the patients must wait for their number to be called by a nurse then wait for a nurse to assess them. As the nurse told me that the patients with diabetes were not registered yet, I decided to go to the diabetes specialist outpatient clinic, which was located behind this outpatient clinic.

The ambience was different in the outpatient clinic, quieter with fewer patients, around 20 patients were seated outside the doctor's consultation room waiting for a nursing assessment and consultation with a doctor. Altogether, the patients waited for at least 30 minutes to an hour before being approached by a nurse.

After getting written consent from the patients, I observed each participating patient while they were having clinical encounters with nurses or doctors. Although the number of patients was not as many as in the internal medicine outpatient clinic, the clinical encounters were just as short. I noted in my fieldnotes:

> A male nurse seated outside the consultation room, in a corner that functions as a nursing station, calls a male patient's queuing number from his seat. Friendly, he greets the patient, "Good morning, sir," and quickly applies the digital sphygmomanometer cuff to the patient's left arm, and while doing so he points a digital thermo gun to the patient's forehead to measure his temperature. The nurse takes off the cuff and instructs the patient to get on the weighing scale next to his desk. Then he gets off his seat, reads the measurements. Then he records all the results on the printed patient's medical record. He tells the patient to go back to his seat and wait for a doctor's consultation. It takes about 2 minutes for this encounter.
>
> After waiting for around 40 minutes, the patient's name is called up by another male nurse who is seated inside the doctor's consultation room. From his seat, the nurse navigates the patient to directly sit with the male doctor who is waiting at his desk. The patient greets the doctor and sits down. The doctor asks the patient for their last blood glucose tests, and the patient hands a laboratory result to the doctor. The doctor records the results on the patient' medical record and says, "Your blood glucose results are under control, but your kidneys have problems, stay with the same dosage for your diabetes pills and I will give you pills for your kidneys." The doctor talks to the patient while he is jotting details on the patient's medical record. "Here are the prescriptions, and request for the next month's labs." The patient just thanks the doctor and moves to the male nurse's desk to get stamps on the documents. The nurse checks and stamps the documents. Then the patient thanks the nurse and leaves the room (Fieldnote 2 March 2020).

All the clinical encounters with the doctor and nurses were brief and focused on patient treatment. One or 2 encounters entailed exercise and diet instructions from the doctor that patients needed to follow. I wondered whether these were the kinds of clinical encounters expected by both patients and HCPs.

6.3 Patient participants’ demographic profiles

A total of 12 patients with T2DM who visited the provincial general hospital were interviewed and observed during their clinical encounters. Table 6.2 presents the demographics and health profiles of the patient participants. The age of the patients ranged from 39 to 70 years with the majority over 60 years. Of the 12 patient participants, 5 were male and 7 were female. The majority had secondary and tertiary (bachelor and master) educational backgrounds. Ten patients were married, one was a widow, and another was a widower. Five were retired and living with their spouse and/or children and 2 were still actively in paid employment, such as a public transport driver and primary school teacher. All patients were covered by BPJS K, with only 3 patients being members of PROLANIS.

All patients were in stage of diabetes with complication(s) had occurred and for some, their BGLs were not under control. All participants had at least one or 2 chronic diabetes complication(s) such as hypertension (6 patients), retinopathy (2 patients), heart diseases (1 patient), nephropathy (1 patient), and 2 patients had a history of suffering from gangrene due to their diabetes. Three patients also had non diabetes-related complications; hypertiroidism and osteoporosis. The majority (10 out of the 12 patients) had high BGL (random BGL ranged from 11.4–22.1 mmol/L and HbA_{1C} 44–69 mmol/mol = 6.2–8.5%), with most taking multiple oral diabetes medications. Six patients were being managed with insulin therapy. Most patients did not have their HbA_{1C} results from the previous 6 months. The period since diagnosis of having diabetes varied, with the shortest time estimated as between 3 to 10 years (5 patients) and 7 for over 10–17 years.

Table 6.2: Provincial hospital patient participant profiles

No	CODE	Age (years)	Sex	Education	Marital Status	Occupation	Medical Diagnosis	Lab Results (BGL mmol/L, HbA1C mmol/mol)	Year of Diabetes Diagnosis	Treatment	Health Cost Payer	Government Support Program (PROLANIS)
1	PH101	65	M	Primary school	Married	Retired	T2DM, uncontrolled diabetes, retinopathy diabetes, nephropathy diabetic, HNP	RBG 22.1 FBG 15.6	10	Metformin Refused Insulin	BPJS K	Not joined
2	PH 102	62	M	Senior high school	Married	Retired	T2DM	FBG 10 RBG 12.8	17	NoVo Rapid Lantus Insulin	BPJS K	Not joined
3	PH 103	65	F	Nursing academy	Married	Retired Nurse	T2DM, hyperthyroidism, osteoporosis	FBG 5.2	13	Rapid Insulin, Lantus Insulin	BPJS K	Not joined
4	PH 104	61	M	Primary school	Married	Public transport car driver	T2DM, hypertension	RBG 8.1	11	Metformin, Amlodipine	BPJS K	Not joined
5	PH 105	68	F	Junior high school	Married	Housewife	T2DM, uncontrolled diabetes, hypertension	FBG 102 GDPP 21.6 HbA1C 69	5	Lantus Insulin Nifedipine	BPJS K	Not joined

No	CODE	Age (years)	Sex	Education	Marital Status	Occupation	Medical Diagnosis	Lab Results (BGL mmol/L, HbA1C mmol/mol)	Year of Diabetes Diagnosis	Treatment	Health Cost Payer	Government Support Program (PROLANIS)
6	PH 106	39	F	Bachelor degree	Married	Primary school teacher	T2DM, uncontrolled diabetes	FBG 13.6 PPBG 14.3 RBG 13.2	11	Acarbose Metformin Glimepiride	BPJS K	Not Joined
7	PH 107	63	F	Senior high school	Widow	Housewife	T2DM, Osteoporosis	RBG 10.0	15	Glimepiride Metformin	BPJS K	Joined
8	PH 108	68	F	Junior high school	Married	Housewife	T2DM/Hypertension Heart Diseases	HbA1C 44	5	Insulin Humalog/	BPJS K	Joined
9	PH 109	64	M	Junior high school	Widower	Retired	T2DM, Uncontrolled Hypertension, Retinopathy, cellulitis	GDS 10.2 HbA1C 48	15	Metformin, Glimepiride, Amlodipine	BPJS K	Not joined
10	PH 110	39	F	Academy	Married	Housewife, and a factory garment worker	T2DM, Hypertension	RBG 11.4	3	Metformin, Glimepiride Amlodipine,	BPJS K	Joined
11	PH 111	70	M	Master of science	Married	Retired	T2DM, Hypertension	FBG 12.8	10	Lantus Insulin Amlodipine, Glimepiride	BPJS K	Not joined

No	CODE	Age (years)	Sex	Education	Marital Status	Occupation	Medical Diagnosis	Lab Results (BGL mmol/L, HbA1C mmol/mol)	Year of Diabetes Diagnosis	Treatment	Health Cost Payer	Government Support Program (PROLANIS)
12	PH 112	60	F	Bachelor degree	Married	Housewife	T2DM, Osteoporosis	RBG 6.6	12	Glimepiride Meticobalt,	BPJS K	Not join

Note: BGL = blood glucose level; T2DM = Type 2 diabetes mellitus; HNP = herniated nucleus pulposus; BPJS K = Indonesian Government insurance scheme; HbA1C = glycosylated haemoglobin: RBG = random blood glucose; PPBG = post-prandial blood glucose; FBG = fasting blood glucose; GDS =

6.4 Healthcare professional participants' demographic profiles

Of the 6 HCP participants interviewed, 2 doctors were specialists: one was a specialist in endocrinology and the other in internal medicine. Of the 4 nurse participants, one had a Bachelor Degree in Nursing and the other 3 had an Academic Degree in Nursing. The HCP participants comprised 4 males and 2 females. The age of the participating HCPs ranged from 30 to 50 years. Only one nurse and one doctor were trained as National Diabetes Educators. Table 6.3 shows the demographic profiles of participating HCPs at the provincial hospital.

Table 6.3: Provincial hospital healthcare professionals' profiles

No	Code	Professional Background	Educational Background	Sex	Age Range (years)	Job Title
1	021	Endocrinologist	Endocrine Specialist	M	40–50	Head/Doctor of Diabetes Clinic of Outpatient Clinic
2	022	Internist	Internist Specialist	M	40–50	Head/Doctor of Medical Clinic of Outpatient Clinic
3	121	Nurse	Bachelor of Nursing	M	40–50	Nurse of Diabetes Clinic
4	122	Nurse	Nursing Diploma	M	40–50	Nurse of Diabetes Clinic
5	123	Nurse	Nursing Diploma	F	30–40	Nurse of Medical Clinic
6	124	Nurse	Nursing Diploma	F	30–40	Nurse of Medical Clinic

6.5 Themes and subthemes in Field Site 2

The themes and subthemes were generated from the second phase of analysis through a cross-case method as discussed in Chapter 4. The first phase of the analysis generated 3 main themes and 8 subthemes from the 24 observed clinical encounters, 5 main themes and 9 subthemes from the 12 patient interviews, and 3 main themes and 7 subthemes from the FGD. The list of the themes, subthemes, categories, and the selected codes of each theme is presented in (see Appendices 27, 28, and 29).

Figure 6.1 shows how the themes and subthemes were generated from the triangulated data collection methods of the patient interviews, observations of clinical encounters and the FGDs with HCPs.

Observations

MEDICALISATION APPROACH IN THE CLINICAL ENCOUNTER

Clinical encounter based on patients' blood glucose level results

Medical discourse dominant in clinical encounters

Few topics on patient self-management

LACK OF TEAM COLLABORATION IN SUPPORTING PATIENT SELF-MANAGEMENT

Nurses focus on administrative work

Unstructured, general and reactive patient education

RESTRICTED PATIENT-HCP COMMUNICATION

One-way communication shown in clinical interaction

Brief clinical encounters with nurses and doctors

Patients do not talk about their concerns about medications

Interviews

THE NECESSITY TO COMPLY WITH THE DOCTOR

SOCIAL PRESSURE OF HAVING DIABETES

Frequent sick leave is not supported

INEFFECTIVENESS OF THE NEW INSURANCE HEALTH SYSTEM

Limited access to sufficient diabetes care

Demanding referral administrations

FACING PSYCHOLOGICAL STRESS RELATED TO MEDICATION REGIMEN

Unpracticality of drugs regimens

Feel bored taking mediations

Discontinuation insulin supply in BPJS K participating pharmacy

Unpracticality of diabetes multidrug oral medications

Less access to get insulin and lancets

LACK OF PATIENT EMPOWERMENT PROGRAM TOWARD DIABETES SELF-MANAGEMENT

Absence of health education infrastructure

Focus Group Discussion

DISEMPOWERING SYSTEM IN SUPPORT PATIENT SELF-MANAGEMENT

Absence of system to delegate patient education to nurses

Limited time to support patient self-management in detail

Lack of support from the management to patient-education program

DOCTORS' BARRIERS TO PROVIDING BEST MEDICAL DIABETES CARE

Patients' perceptions about diabetes long-term therapy prevent best care for patients

Discrepancy between science and regulations

Low level of patient education

PATIENT RELATED PROBLEMS IN SUPPORTING SELF-MANAGEMENT

Low demand for health education

Themes and Subthemes

MEDICAL CONTROL IN PATIENT–HCP RELATIONSHIPS

Doctor is the source of diabetes care information

Medicalisation approach in the clinical encounter

SYSTEM RELATED BARRIERS TOWARDS EMPOWERING PATIENT SELF-MANAGEMENT

Doctors' barriers to providing best medical practice diabetes care

Lack of team collaboration in supporting patient self-management

Restricted patient-HCP communication

Ineffectiveness of the new healthcare insurance system

Lack of patient empowerment program and support for diabetes self-management

UNSPOKEN PATIENT CHALLENGES TOWARDS SELF-MANAGEMENT

Facing psychological stress related to medication regimens

Controlling blood glucose

Social pressure of having diabetes

Figure 6.1: Themes and subthemes analysis and findings from field site 2, a provincial hospital

Note: HCP = healthcare professional; BPJS K = Indonesian Government insurance scheme

6.5.1 Medical control in patient–doctor relationship

The theme of medical control was evident in the observations and interviews. In most of the participant narratives doctors were perceived as the source of diabetes information and medical advice that should be complied with by patients. The patients expected the doctors to provide information on patient conditions and their treatment in detail, while at the same time they expected the doctors to be concerned with their other problems that might influence, or be influenced by, having diabetes. However, in most of the events of patient–doctor clinical encounters, doctors controlled the communication to focus on BGL and medications. The theme of medical control in the patient–doctor relationship has 2 subthemes. First, only the doctors' medical knowledge had any status as the source of diabetes care information; second, all situations and events were medicalized.

6.5.1.1 The doctor is perceived as the source of diabetes care information

The role of doctors was perceived by the patients as central to their care. Most patients mentioned that doctors were the source of credible information about their disease and treatment, even though the information they received was limited. Consequently, patients perceived that they must comply with what their doctors instructed them to do. For example, a female patient aged 68 years who had been diagnosed with diabetes for 5 years said:

> Well, I think we need to comply with all the suggestions and recommendations from the doctor, if the doctor thinks that we need to get injections regularly then we have to do so, if we need to swallow some pills, then do it, no question. (INTV, PH108, line 14–16)

Apart from the limited time and information provided by the doctor, the patient suggested that the doctor was the only source of reliable information she could access, and hence she was more likely to comply with her diabetes care. This concept is supported by my observations where the nurses were observed to be more focused on routine assessments such as measuring patients' blood pressure and weight and dealing with the patient administrative procedures; the nurses were identified less by the patients as a source of information for their diabetes care.

6.5.1.2 Medicalisation approach in the clinical encounters

Patient concerns that might or might not be related to their physical diabetes problems were often regarded and treated as medical problems. In the very brief and focused clinical encounters between a patient and the HCP regarding issues such as BGL or non-medical concerns were not deeply explored, and hence may have been dealt with inaccurately. For example, a female patient aged 39 years, who had been diagnosed with diabetes for 11 years and had refused to use insulin for her diabetes treatment reported:

> If I do not feel anything, why should I test my blood sugar levels? So, I just check it if I want to see my doctor. I am aware if I think too much about my diabetes then I will be stressful and then I will have my blood glucose increase and if my blood glucose is high, the doctor will increase my medications dosage and you know what instead of decreasing my blood sugar, you know that my blood sugar is getting very low. (INTV/PH106/line 31–40)

The excerpt above shows that the patient did not want to overthink her diabetes, and she felt hesitant to check her blood glucose regularly as asked by the doctor. She did not want to get stressed by her diabetes routines. As she said, if she focused too much on her diabetes then she would get stressed. When she was stressed, her blood glucose would increase, and the doctor would give her more medication. The patient implied that the doctor did not understand her psychological concerns. The patient might be in denial of her diabetes, but the doctor disregarded the possibility of psychological problems of the patient and only evaluated her based on her BGL. Hence, regardless the cause of her increased blood glucose, the doctor would give her medication and ignore the possibility of psychological stress that causes the increase in her BGL. From a medical perspective, however, a hyperglycaemia state can be controlled, for some patients, by using medication. However, the patient's psychological concerns in this case were not explored.

During the observation of a clinical encounter of the same patient with her doctor, the patient's concerns that the doctor would increase her medications dosage was confirmed:

> As the patient is seated, the doctor asks, "What is your blood glucose results?" "The fasting blood glucose FBG 13.6, PPBG [post-prandial blood glucose] 14.3 and RBG [random blood glucose] 13.2," the patient read for the doctor the laboratory test results sheet in her hand. "They are high, aren't they doc?" the patient says. "They are high," the doctor replies while he was writing the results down on the patient medical record. "You have to use insulin said the doctor, I told you since January to use the insulin, but you do not want to use it." The doctor continues talking and looks at the patient. "This condition has to be treated with insulin," the doctor continues

> talking and faces me as if explaining to me. I say, “Oh, okay.” “Many young patients had their pancreas damaged so insulin is a must,” the doctor continues talking to the patient. “Okay, I will increase your acarbose to 100,” the doctor says and writes on the patient medical record. “Is the lab opened on Saturday?” asks the patient. “No, there is no service on Saturday,” she replies to the doctor. (OBS6, PH106, line 1–12)

Without investigating other potential non-medical factors that might be the cause of the patient’s hyperglycaemia, the dosage of the medication was increased by the doctor. Moreover, further information about pancreas damage in young patients with diabetes was added by the doctor, and the patient seemed reluctant to discuss this, instead changing the subject and asking about the laboratory open hours. Even though the doctor seemed to be acting in the best interests of the patient based on a medical perspective by providing treatment (increasing the dosage of the medication), the patient’s problem, which was psychological, was disregarded. In this case the doctor controlled the direction of the conversation to a medical aspect of care; hyperglycaemia in young adults might be caused from pancreas damage (Anık et al., 2015). Hence, the medical solution was dominant in identifying and managing the patient’s concerns. Other patients expressed similar experiences.

6.5.2 System-related barriers towards empowering patient self-management

This theme encompasses situations at the level of the healthcare system regulations, healthcare provider, and clinical encounters between a patient and an HCP, leading to a lack of support for patient self-management. Five subthemes were identified in this theme: barriers to doctors providing support for best practice medical diabetes care, lack of collaboration in supporting patient self-management, restricted patient–HCP communication, ineffectiveness of the new healthcare insurance system and lack of patient-empowerment programs in support of self-management.

6.5.2.1 Doctors’ barriers to supporting best practice medical diabetes care

This subtheme was revealed mainly in the analysis of the FGDs and supported by my observation. Doctors reported that the government regulations for insulin therapy were not aligned with the medical guidelines. According to the BPJS K regulation, insulin therapy can only be dispensed to patients with a certain level of HbA_{1C}, which was significantly higher than that recommended by medical standards for doctors to initiate insulin therapy to patients. Based on the medical guideline, insulin is required when the HbA1C level is considered high, while the BPJS K requires a higher level (Kementrian Kesehatan Republik Indonesia, 2019). An internist who was responsible for patient medical care in the outpatient department explained the discrepancy between the medical clinical recommendations and the BPJS K regulations that prevented him from providing the best care for patients. There were restrictions to prescribing insulin as therapy for patients with T2DM. He said:

> Patients who require immediate insulin can't get it straight off because there is a regulation that tells that there is a condition [certain level of blood glucose] based on regulation [BPJS K] that has to be fulfilled before we could provide direct insulin therapy to patients who really require it. (FGD2, 022, line 45–62)

This doctor found that the care he provided to patients with T2DM was hindered by restricted access to insulin therapy for some of his patients as a result of BPJS K regulations in the Indonesian Health Ministry Decree, number HK.01.07/Menkes/659/2017 on National Formulary (Kementrian Kesehatan Republik Indonesia, 2019).

In addition to the gaps between the level of HbA_{1C} required by the BPJS K and that in the medical guidelines, insulin availability was sometimes unpredictable. In one of the clinical encounters, an endocrinologist and a male patient aged 62 years who had been diagnosed with diabetes for 17 years who was prescribed multiple insulin therapies discussed its availability with the doctor and how to manage the problem:

> "Do you regularly inject your insulin?" the doctor asks. "That's the problem," the patient wants to explain. "The insulin is not available in the pharmacy," he continues. "They just gave me half of the dosage last time and I am asked to wait, but they do not give it to me until now," said the patient. "I asked the BPJS K," the patient adds. "What did they say?" the doctor asks, then continues without waiting for the patient's answer, "How about the insulin used before you go to bed?" "That one is still available," replies the patient. "Okay, increase that one to 25 units and the one before meals increase to 20 units," the doctor tells the patient while writing out something on the patient's medical record. (OBS, PH01, line 2–10)

Having heard from several patients that the insulin supply had not been available in the pharmacy, the doctor re-adjusted the daily insulin dosage prescribed to the patient. The patient explained that he only received half the prescription of the insulin the previous month and while promised he would receive the rest, this did not occur. Hoping that the insulin was now available in the pharmacy, the doctor increased the patient's insulin dosages. If he had not done this the patient would have had to use his own money to purchase the insulin. It is unlikely he would have done so given the expense.

Another specialist doctor, an endocrinologist, was concerned about how the regulations limited the dispensing of insulin to patients impacting on clinical outcomes. He said:

> For sure the existing care has not been effective … I see this from the target … the HbA_{1C} target was so far from the treatment targets … far …. The academics argued this way … but the regulations only allow it for that way … The main thing is the system, whether it relates to regulations, protocols, and budgets. The medical academics are clear what is clinically appropriate, but the government are not willing to fund this. The care does not reach the target. (FGD2, 021, line 65–77)

The endocrinologist was of the view that existing diabetes care was ineffective as the HbA_{1C} national target level could not be achieved by patients due to the lack of insulin dosages that he was allowed to prescribe to patients who came in under the BPJS K funding scheme. According to this doctor, efforts to persuade the government to change the regulation have been made by scientists, lecturers and doctor practitioners, but so far they have been unsuccessful in changing the regulations. The consequence is that insufficient insulin treatment is available to patients with diabetes, which in turn impacts on medical best practice care and patient outcomes.

In addition to health regulations impacting on best practice outcomes, the social background of patients, such as education and financial status, were also perceived by the HCPs as factors related to behaviours that impacted on patient self-management. A specialist doctor said that low levels of education and knowledge about medications contributed to hesitancy in using insulin. He said:

> The awareness of the importance of self-management depends on patients themselves. If the patients have sufficient education background, and are middle class, I think automatically they will feel that self-management is important or not, it's really depending on their educational background. (FGD2, 022, line 67–75)

Low financial status and education levels were seen by HCPs as barriers towards patient self-management. The HCPs were of the view that the unsupportive health regulations regarding treatment standards for patients with T2DM, the lack of availability of the medications in the BPJS K pharmacy and the perceived low levels of patient awareness about self-management were all related to their social and educational background.

6.5.2.2 Lack of team collaboration in supporting patient empowerment towards self-management

A diabetes multidisciplinary care team approach that comprised the physicians, nurses and dietitians was not working as intended for empowering patient self-management. The team members worked in isolation rather than in a team as identified in the observations and in the view of the HCPs. The doctors focused on patient care related to medical treatment, while nurses focused on basic patient assessment tasks such as measuring blood pressure and weight, and administrative procedures. One doctor was of the view that the doctor’s role in diabetes care team should focus on medications while other issues should be delegated to other team members. He said:

> It's not really about the time restriction, what we need is delegation. I think this part has been discussed by Dr D [name of a doctor] so it means that doctors can only focus on the questions under problems related to medications or insulin. Other problems related to diet and others we can delegate to nurses or to the dietitian. (FGD2, 021, line 222–241)

Further, the doctor said that time was not really a constraint in empowering patient self-management. In his view the empowerment program, such as patient education, could be provided if a delegation system worked. The doctor expected the nurses to handle patient education, which he reviewed as a non-medical discussion topic.

6.5.2.3 Limited patient–healthcare professional communication

The limited communication between patients and HCPs in clinical encounters encompassed situations where the HCP (a doctor or a nurse) was less engaged with patients or patient problems. This was as a result of a limited amount of time, the clinical encounter being controlled by the nurse or doctors, meaning there was less chance for the patients to talk during the consultation. These features were seen in each clinical encounter and seemed to be acceptable or understandable from the patients’ perspectives. One example that highlights the lack of communication was a clinical encounter between an endocrinologist and a male patient aged 61 years who had been diagnosed with diabetes for 11 years and who had a primary school education background:

> The doctor checks the forms are stamped and asks the patient, “Where did you go for your treatment before?” “At the *Puskesmas* X,” the patient replies, and the doctor scans the patient medical record (PMR) in front of him and says, “Your body weight is 82.9 kg. Why would your body weight not decrease?” “I do not know,” the patient replies. The patient continues, “I do my exercise, take the medications.” The doctor keeps writing on the PMR and says, “Your metformin now is 14 milligrams 3 times a day, reduce your body weight. If you do not do it will be useless because your blood glucose will increase,” the doctor explains while he is writing on the PMR. “What do you do for living, sir?” the doctor asks. “A public transportation car driver,” the patient replies. “Are you still working?” “Well, only a half day,” the patient explains. “Please reduce your body weight,” the doctor stresses and reiterates what he said. Then the doctor hands a prescription to the patient. The patient thanks the doctor and gets off his seat. (OBS4, PH104)
>
> Then the patient approaches the nurse who sat at his desk. “May I get your referral paperwork?” asks the nurse. The patient looks for papers inside his folder and hands them to the nurse. The nurse stamps the papers, and the patient thanks the nurse, ending the interaction. (OBS4.1, PH104)

The 2 clinical encounters took less than 10 minutes, with the doctor directing the topic in the first encounter about the patient’s weight and increasing the metformin dosage. The patient explained his occupation. The doctor raised the topic, but did not pursue the response, and redirected the conversation to the issue of the patient being overweight. The patient might not have understood the connection between bodyweight and the metformin dosage, or the “useless” (as the doctor told him), BGL and why his job was relevant. The doctor did not use the time in that clinical encounter to clarify these concepts with the patient. There was also no opportunity during the clinical interaction with the nurse, she just stamped the paperwork. The patient–HCP communication that supposedly supports patient care, including patient self-management, was unlikely to occur.

The time constraints during clinical encounters were excused by patients as being normal. For example, in one of the interviews with a female patient aged 39 years who had been diagnosed with diabetes for 11 years, said:

> I think also the healthcare professionals need training in communication to understand patients’ psychological conditions and how to give comfort to patients …

> but in the cases, you know, so many patients like 50 to 60 patients a day, I think they don't have much time. (INTV, PH 104, line 62–65)

Personal attention and good communication by HCPs was essential to her care; however, the patient accepted that the HCPs did not have sufficient time with her, which she could understand. The communication between HCPs and patients was still restricted even though the patients understood HCP time constraints.

6.5.2.4 Ineffectiveness of the new healthcare insurance system

BPJS K restricts access to medically prescribed diabetes care. The restrictions, as revealed through the patient interviews and the FGD with the HCPs, included limited access to the health insurance benefits wherever required; poor access to the full dosage of insulin prescribed, insufficient support for personal medical equipment such as insulin pen needles, and ineffective administration within the referral system.

Access to recommended care was reduced under the new system. Patients could only access one-third the number of insulin pen needles prescribed by the doctor. This meant that patients often reused the needles so they were not left without pens for the week. For example, one female patient aged 68 years, who had been diagnosed with diabetes for 5 years and who was prescribed one injection of insulin per night, reported the following conversation with the endocrinologist during her clinical encounter:

> "Of the 10-pen insulin needles you prescribed, I only received 3 of them," she told the doctor (OBS5, PH105)

The patient said that she only received 3 insulin pen needles dispensed by the pharmacy of the 10 needles prescribed by the doctor for a week's supply. With only 3 insulin pen needles supplied, the patient had to then ensure the needles lasted until she could get a new supply.

Lack of availability of insulin and limited access to certain medications under the BPJS K health scheme forced the patients to use their own money to purchase their medications. A 65-year-old female patient with T2DM for 16 years, had hyperthyroidism and osteoporosis, and was on multiple insulin injections per day. She was one example of a participant who had to spend her own pension money to purchase the medicines, saying:

> The medicines here are always unavailable, always, so I buy all of it myself. I usually spend around 4 to 6 million rupiah (A$440–660) every month. Novorapid costs 250,000 (A$25) rupiah per pen, so, let's say I need 8 pens, that means I have to spend almost 2 million rupiah for novorapid only while other drugs for my thyroid and heart disease aren't yet included. And it's almost 8 months now, the medicine is still unavailable, but the doctor keeps prescribing the medication while saying to me that he pities me. The pharmacy always tells me the medicine are not in stock, and the BPJS K hasn't covered for it, and so on, and so on … but we spend all of our pension on medicine. At this point, drugs are my daily meal, every day. It's frustrating, really, because the medicines are really not cheap. (INTV, PH103, line 98–114)

This creates frustration for the patient, including an irregular insulin supply and lack of cover for other medications that are needed from the BPJS K health insurance. In this situation the patients are forced to use their own money to purchase the medicines as they are essential. Patients are forced to spend large amounts of money every month on their own healthcare.

The new health insurance system was also ineffective in relation to administrative procedures required for the referral system that had to be followed by the patients. The administrative referral procedures were described by most of the patients as demanding, complicated, exhausting and illogical. Having to move from one desk to another to hand the referral papers to different doctor specialists in the referred hospital were experienced by the patients using BPJS K insurance, highlighting the impracticality of the referral system. One of the patients said:

> Before coming here I needed to go to the general medical department then be referred here, in fact from the *Puskesmas* I have already been referred to the endocrine department. (INTV, PH110, line 72–74)

This patient, who was referred from a *Puskesmas*, had to go to the medical department first for an assessment each time she came to the outpatient clinic before she could be referred to the endocrine outpatient clinic. This meant that the patient had to be in more than one queue with additional lengthy time-wasting in each medical department.

Patients were only eligible for the insurance benefits if they used the healthcare facilities nearest to their residential address. When patients were away from their home and required medical attention, the health insurance scheme did not cover them and could not be used. For example, one of the patients, a female aged 68 years, with T2DM for 5 years and who was prescribed insulin therapy, explained:

> I have taken those medications regularly. When I went for Hajj, I was so exhausted … When I got home my blood glucose was 33.3 mmol/L. Then, I was admitted to Panti Rapih [name of hospital outside the city where she resides], not in here [this hospital]. I was admitted for a week. Yeah, but I could not pay with my BPJS K. I paid fully from my own money. (INTV, PH 107, line: 32–40)

The patient said that she could not use her health insurance, the BPJS K, and had to pay using her own money for the hospital admission fee when she was admitted to a hospital that is outside the city where she stays, even though she is insured by the BPJS K.

6.5.2.5 Lack of patient-empowerment program and support for diabetes self-management

The limitations of patient-empowerment programs to support diabetes self-management and lack of support from the systems and providers, was also evident in the lack of structured patient educational programs in the care facilities.

Observations of the clinical encounters between patients and HCPs (a nurse or a doctor) showed an absence of structured patient-education sessions. Brief and general information was occasionally provided during the conversations in clinical encounters, but without any further opportunities for the patients and HCPs to discuss the information. One example comes from a clinical encounter between a male patient (aged 64 years with T2DM for 16 years, along with uncontrolled hypertension, retinopathy, and cellulitis on his lower left leg) and an endocrinologist and dealt with the patient’s increasing blood pressure. It highlights the focus being medically oriented, with no education or discussion:

> “Your blood sugar was good, but your blood pressure was quite high,” says the doctor. “I’ll add some more drugs for your blood pressure, is it okay for you?” the doctor offers. “Ok doc,” the patient replies. Then the doctor is busy with his file. The doctor hands the prescription and the paperwork to the patient to end the clinical encounter. (OBS9, PH109)

In this example, medical treatment was the only approach used by the HCP to address the problem. The patient’s increasing blood pressure that could have been related to the patient’s self-management practices was not addressed. There was no patient-education program, care protocols, nor interventions programmed to manage the patient’s problem in the context of diabetes care in the hospital. Therefore, the patient just accepted that medication was the best treatment for his health condition.

The inadequacy of programs and lack of patient empowerment-based interventions was also identified by patients. For example, one female patient aged 60 years, who had been diagnosed with diabetes for 12 years said:

> I think patients need to have the effects of diabetes explained to them, especially the effect of diabetes, the effect of not being able to take care of themselves, because not everyone here understands that, because there is not enough explanations. (INTV, PH 112, line 97–100)

Lack of support from providers and hospital management towards patient-empowerment programs such as patient-education programs was also mentioned by the HCPs. For example, a diabetes educator struggled to get promotional materials to promote the patient-education program he was conducting:

> Like a simple thing … a patient-education promotion banner … it has been 6 months since we asked for a banner … Well, I asked for the banner to be provided by management … I need the banner so that the patients were aware of the program. (FGD2, 121, line 360–370)

The diabetes nurse educator said that his program on patient empowerment, the patient-education session, was not supported by hospital management. Other HCPs reported similar experiences.

Lack of support from the government for patient empowerment was perceived by the HCPs as a barrier to implementing it into daily practice. The endocrinologist identified that time constraints were not the primary cause of the absence of empowerment programs for diabetes care. Lack of knowledge by government personnel, limited involvement of doctor practitioners to plan, and inadequate materials, including the availability of diabetes educators in the hospital, were perceived as impeding factors. The endocrinologist said:

> I think patient empowerment doesn't exist. It is impossible that we have time, we have hundreds of patients every day. So, we could only smile when the patients were complaining. The GERMAS program [name of a patient-education program promoted by the Indonesian Government] doesn't work. First because of a lack of knowledge from the politicians. The second reason is that the Ministry of Health does not have open communication with us. The people at the Ministry of Health are not open to

> discussion. I saw that the people consulted were purely academic at the college. They denied our existence as practitioner. (FGD2, 021, line 222–339)

The endocrinologist indicated that the empowerment program promoted by the Indonesian Government to promote healthy lifestyles did not work. Then he asked whether any of the staff (especially nurses) had provided patient education, as he suspected that the staff may not have the necessary knowledge to provide patient education. A nurse with a nursing academic educational background who was assigned to the internal medicine outpatient clinic replied:

> Well yeah, I do not feel comfortable when I talk to patients. I am not confident with my knowledge. There should be more training programs on diabetes care for nurses like me. (FGD2, 124, line 326–328)

The nurse said that the reason for not providing health education to her patients was because she had limited knowledge about diabetes. The lack of patient-empowerment programs in the existing program of care was identified by the HCPs as being caused by lack of support from the government and from the hospital provider, and limited resources such as the limited number of qualified diabetes educators.

6.5.3 Unspoken patient challenges towards self-management

Patients with T2DM face a number of impediments to diabetes self-management on a daily basis given it is not included in patient–HCP interactions. For example, one female patient aged 39 years who had refused insulin therapy, had diabetes for 11 years and substituted insulin for multiple oral diabetes medications said:

> I want my drugs to be reduced [the number of medication types] so it will be manageable because it was it was hard very difficult to follow … Because there was one of my medications that I have to take it before meals the other one with meals and another one after meals, so it's confusing, so I have been thinking just to tell my doctor, but I think the doctor will **** me off. I have to tell the doctor that I want to change the medication, I've been so stressed with this. So that's why I didn't take this medicine routinely. (INTV, PH106, line 21–27)

In the interview the patient expressed the difficulties she experienced in managing multiple medications as each medication had different regimens, before meals, with meals and after meals. Apart from feeling stressed with the medications, the patient said that it was easy for her to regularly miss taking the mediations. However, she did not discuss her problems with the doctor even though she believed that she should. Other participants reported similar experiences where they hesitated to report their diabetes self-management issues.

6.5.3.1 Facing psychological stress related to medication regimens

A number of patients expressed psychological distress regarding their diabetes, mainly related to medication regimens and controlling their BGL. However, the participants did not discuss the concerns with the HCPs. The distress related to medications included the long-term requirement of taking medications, the impracticality of use, frustration about the efficacy of the medication, and the uncertainty of insulin and pen needle supply from the government health insurance service. One female patient aged 20 years who had been diabetic for 12 years, and taking an oral diabetes medication shared her experiences:

> I sometimes feel bored taking the medication, so I tried other things like brewing some cinnamon, to have other variation, something like that, so that's how I keep my blood sugar. And then, my recent lab results were good overall. (INTV, PH11, line 26–29)

This patient had skipped her diabetes medicines over the past 12 years and sometimes sought alternative treatments.

Another female patient aged 65 years also reported psychological distress regarding the medications and multiple types of insulin injections that she had used for 13 years. This participant used to work as a nurse and was aware that diabetes medications were not curative, rather they were used to treat and manage the symptoms and slow complications. In tears she said sadly:

> I know it's impossible to be totally cured, so the main reason why I keep getting medications is to slow down the dying process, I guess. (INTV, PH103, line 64–76)

Some other patients were anxious regarding maintaining their BGL within the normal range. They were afraid of having diabetes complications because of high BGL and felt incompetent in control their blood glucose. One female patient aged 39 years who had been diagnosed with diabetes for 3 years said:

> My blood glucose was 11.4 mmol/L [RBG] normally it was below that value. I feel fearsome, afraid of getting hypertension and worsening diabetes … I'm afraid that my blood glucose will be high, I'm worried I am having high blood glucose levels so that's why I am so scared when I see food. So, I've been so anxious daily like I want to eat this but I'm afraid of getting the high blood glucose level, I'm not comfortable with my body. (INTV, PHII0, line 32–41)

Controlling blood glucose within normal ranges was a source of psychological burden for the patient participants. However, these concerns were not explored or expressed in any of the observed clinical encounters. Additionally, there were no standards of care nor clinical pathways available in the hospital to manage this aspect of psychological burden.

6.5.3.2 Social pressures of being a patient with diabetes

There were a number of social consequences experienced by the patients with T2DM: lack of support from their employer, cynical attitudes from friends and neighbours, and loss of working days due to the requirement of monthly routine hospital visits that took all day. For example, one female patient aged 39 who worked as a primary school teacher said:

> I didn't routinely come to this hospital because I'm working and to come here [to the hospital] it is a whole day commitment, so I need to get a permission from my office to leave for my hospital visit. (INTV, PH106, line 19–21)

This patient was distressed about having to make a choice between her work and healthcare, and gaining the permission required or compromising her health.

Distress also resulted from the daily social interactions with neighbours and friends. One female patient aged 60 years who had been diagnosed with diabetes for 12 years for example, experienced constant questioning from suspicious neighbours and unsupportive attitudes from less knowledgeable friends about diabetes saying:

> The neighbours, they actually are pretty close-minded, so I've got to be firm to them, an example is when I was on my way to hospital, my neighbours would ask me where I was going. I simply told them that I was going to hospital, then they would ask more questions and why I keep going to the hospital. I would be too speechless to even reply to that as they should've known that I'm a diabetic. My friends, who are my age, kept on joking about my food restrictions, and they keep pushing food on me, and I keep rejecting the food as well, well it was not easy at the beginning. (INTV, PH112, 167–173)

Lack of understanding about diabetes among lay people in the community impacted on the way patients with diabetes were treated in the workplace and in their neighborhood. Emotional and social supports for patients with diabetes were overlooked as the issues were not discussed by the patients when they saw the HCPs.

6.6 Chapter conclusion

Three themes and 9 subthemes were generated from the analysis of 12 patient interviews, 24 observations of clinical encounters between the patient and HCPs, and one FGD with HCPs from this second research site: the provincial hospital. The majority had secondary and tertiary (bachelor and master) educational backgrounds and all were covered by BPJS K, with only 3 patients being members of PROLANIS. All patients were in the stage of diabetes with complication(s) and some did not have their BGLs under control. Most patients did not have their HbA_{1C} results from the previous 6 months. All participants had at least one or 2 chronic diabetic complication(s). Six patients were being managed with insulin therapy and 6 others were being treated with multiple oral diabetes medications.

Overall, the findings from the patient interviews, observations of clinical encounters, and the FGD with HCPs demonstrated consistencies in depicting the diabetes care provided in the provincial hospital. These themes and the subthemes showed that a medical approach was being used in the care of patients. At the higher system level, regulations relating to patient healthcare insurance impeded medical best practice. Lack of government understanding for patient empowerment and implementing it into daily practice were perceived by the HCPs as barriers to supporting patient empowerment. At the level of healthcare provision, a lack of collaboration between the diabetes care team, a lack of support from management, and time constraints due to the high number of patients seen daily, were the main causes of short consultations and the absence of patient-empowerment programs in the care provision. Finally, the patients experienced psychological and social distressed related to their diabetes care, which was not communicated to the HCPs, and they received inadequate prescribed medications due to a lack of supply.

The next chapter discusses the final data collection site which was the national hospital.

Chapter 7: Findings from Field Site 3: National Hospital

7.1 Introduction

This chapter presents the research findings from the data gathered and analysed from a national hospital in Indonesia. The first section presents the site vignette with analysis of typical incidences. This is followed by a description of the participants from this research site. The last section describes the 4 main themes and 9 subthemes generated from patient interviews, observations of clinical encounters, and two FGDs with the HCPs.

7.2 Site vignette

Data were gathered during the COVID-19 pandemic, from 2 September to 30 October 2020, when the number of positive confirmed cases across the 34 provinces was 287,008; with 10,740 deaths from nearly 2 million tests performed (WHO, 2020). The hospital was one of the national referral healthcare centres for COVID-19 patients. Much of the data from this research site was influenced by the restrictions applied in the hospital that were aligned to government efforts to control the pandemic in Indonesia. The following describes the incidences that I observed, noted and reflected on at the time that serve as the context for this chapter.

7.2.1 Providing outpatient care: challenges amid the COVID-19 pandemic

After 6 months in lock down, and significant restrictions on hospital care services, the hospital was reopened, although some restrictions remained. My setting was an endocrine outpatient clinic, one of the 8 clinics under the internal medicine outpatient services, located on the second floor of an outpatient building. The clinic head nurse showed me around and explained the restrictions in the service, which included reducing the number of endocrine patients to be seen in the diabetes clinic from around 150 to a maximum of 50 patients per day. The head nurse also explained that the number of doctors who were assigned daily to the clinic was reduced from 6 to 2 per day. Additionally, the head nurse explained that patient online registration was compulsory, with appointments reduced from monthly to 3-monthly, and the mandated use of first level personal protective equipment (PPE) for all HCPs who had direct contact with patients included a surgical mask and face shield, hazmat and gloves.

With these restrictions, the endocrine outpatient clinic that shared the floor with 7 other outpatient clinics, seemed quiet for this large area of ambulatory services. The visitors wore surgical or cloth masks, were seated with the regulatory distance between each other, and did not chat much among themselves. Every nursing station and doctor's consultation desk was equipped with a transparent acrylic shield protector.

7.2.2 Inefficient patient flow

Lengthy waiting times in a government-run hospital is a normal situation in Indonesia. The requirement for online patient registration and the limited number of 50 patients a day significantly reduced the crowds and decreased the waiting time, although waits still occurred at various points such as at the doctor's consultation clinic and at the pharmacy. Due to the COVID-19 restrictions, only 2 out of 6 doctors who were normally assigned for the daily care service at the endocrine clinic handled the 50 patients. At the pharmacy, the long queues were not significantly reduced by the restrictions as most of the patients were still required to obtain their medications every month. Due to the COVID-19 restrictions, the doctors reduced patient consultations to every 3 months, meaning that the doctors provided 3-monthly prescriptions; however, the patients still had to attend the hospital each month for their medications to be dispensed in the hospital pharmacy. Therefore, long waiting times and crowds at the pharmacy still occurred.

Patients complained about the long waiting times and crowding. Regarding the inefficient patient flows, I noted:

> The patients who only had one disease and had registered online, still have to wait and line up for long waits at least at 7 points: 1) the confirming registration 2) registration to the BPJS K office 3) registration at the laboratories for checking the fasting and post-prandial blood glucose 4) registration at the diabetes clinic 5) waiting for the printed PMR at the nurse's desk and for the nurse to assess the preliminary data 6) waiting for a doctor's consultation and 7) waiting at the pharmacy. If patients had an appointment at more than one clinic then they have to have another 3 waits: the clinic registration, nurse registration and waiting for the doctor consultation. As one patient notes, "I always spend the whole day in the hospital if I have to see a doctor." Some patients were back at the hospital the next day to get their

> appointment or medications in the pharmacy as they felt that they just could not stay any longer in the hospital.
>
> The inefficiencies of the administrative procedures are out of the patients' control and cannot be avoided by the patients. With all these procedures that the patients have to go through each month, I wonder how the patients who come to this service are labelled as non-adherent or non-motivated. I wonder what else I will observe of patient–HCP interactions or hear in the HCPs FGD. (Fieldnote, 10 September 2020)

7.2.3 Lack of patient privacy

Patient privacy was regularly breached, seemingly without awareness, during clinical encounters, especially during a patient's consulting sessions with the doctors. The patient consulting room was designed as a twin room with two entrances separated using a flexible fibre plastic divider from the inside to allow the rooms to be connected. Most of the time, the divider was partly open to allow easy access for the 2 doctors from each room to reach the PMRs that were put on a shared table between the 2 rooms. Consequently, the 2 rooms were within earshot of each other and any conversation in one room could be heard clearly from another room. I noted in my fieldnotes:

> The patient comes into the room in which the room divider screen is intentionally one-third opened. The doctor has just completed the previous interaction with another patient. He is seated with his PPE on (overall hazmat, a mask, a surgical cap and a face shield), protected with a transparent acrylic shield at the desk that separates him from the patient, and holds a thick PMR, then straight off asks the patient who was about to reach her seat, "Have you got your daily blood glucose report?." In another part of the shared room, a doctor is in the middle of clinical encounter with another patient. The doctor and patient seem focused on their interaction. It does not look as though their privacy is breached nor are they annoyed with the noises from the voices in the other room, even though sometimes they overhear each conversation. The patients and doctors may not see the lack of privacy as an issue, perhaps they do not have time to think of this matter. Seemingly they want the interaction to be completed soon by evaluating the blood glucose and other laboratory results and providing the medications. (Fieldnote, 7 September 2020)

Given this lack of privacy in the clinical encounter, regardless of how the doctor managed the interactions, patients were no doubt hesitant to talk further about their self-management problems with the doctors.

7.2.4 Lack of teamwork to support patient self-management programs

I did not observe nurses talking to patients about their concerns, or nurses to a doctor, or doctors talking to patients about their medical issues, or doctors to the nurses in the diabetes outpatient clinic. The doctors and nurses seemed busy with their own tasks. The resident doctors were busy taking patients’ medical histories and providing medical treatments, while nurses focused on the administrative jobs, registering the patient before entering the doctor’s consultation appointment and taking basic patient clinical histories including vital signs, pain scale and fall risks. There were programs that involved other HCPs beside the doctors who ran the clinic, who could have been considered as a diabetes team in supporting patient self-management; namely diabetes patient education, dietary consultations and diabetes foot care. To access these services, however, patients had to get a referral from the doctor. So, the doctors decided what kind of diabetes care support was required by the patients.

7.3 Participants

A total of 16 patient and 8 HCP participants were involved in this component of the study. The profiles are presented below.

7.3.1 Patient participants’ demographic and health profiles

Sixteen patients with T2DM who visited the endocrine outpatient clinic were interviewed and observed during their clinical encounters with HCPs. Table 7.1 shows the demographic and health profiles of the patient participants. The age of the patients ranged from 39 to 64 years. Of the 16 patient participants, 4 were male. The majority of patients had senior high school education, 2 had a master’s degree, one a bachelor’s degree, 4 had diplomas, and 4 had junior high school backgrounds. Fifteen were married, and one was single. Most of the patients were housewives living with a spouse and or their children. Three out of the 16 were still active in paid employment, such as an Islamic religious teacher, finance analyst and in private business. All patients were covered under the BPJS K health insurance system, no patient was member of PROLANIS.

Table 7.1: National hospital patient participant demographics and health profiles

No	CODE	Age (years)	Sex	Education	Marital Status	Occupation	Medical Diagnosis	Diabetes Diagnosis (years)	Lab Results BG (mmol/mol) HbA_{1C}	Treatment	Health Cost Payer	Support Program (PROLANIS)
1	301	58	M	Master of Economics	Married	Private business on property	T2DM, history of gangrene diabetes, neuropathy, post-cerebral vascular accident	10	FBG 154 (8.6) RBG 168 (9,3)	Novo Rapid Insulin Lantus, Metformin,	BPJS K	Not enrolled
2	302	58	F	Senior High School	Married	Home duties	T2DM, thyroidectomy, hypertension	8	RBG 176 mg/dl (9.8)	Metformin, Tirax, Calcium	BPJS K	Not enrolled
3	303	56	F	Senior High School	Married	Housewife	T2DM, retinopathy, lupus erythematosus, scleroderma,	26	HbA_{1C} 7 FBG 185 (10.2)	Novo Rapid Insulin, Lantus, MTX, Allopurinol, Nifedipine, Simvastatin, Folic Acid, Vit. B6, B12, Sucralfate Lemfotane, Laxadin	BPJS K	Not Joined
4	304	39	F	Diploma in Religion	Married	Religious teacher	T2DM, breast cancer	8	RBG 204 (11.3)	Metformin, Gliquidone	BPJS K	Not Joined
5	305	60	F	Junior High School	Married	Housewife	T2DM, hypertension	14	RBG 230 (12.8)	Metformin, Simvastatin	BPJS K	Not Joined

No	CODE	Age (years)	Sex	Education	Marital Status	Occupation	Medical Diagnosis	Diabetes Diagnosis (years)	Lab Results BG (mmol/mol) HbA_{1C}	Treatment	Health Cost Payer	Support Program (PROLANIS)
6	306	64	F	Junior High school	Married	Housewife	T2DM, hypertension, cataract, neuropathy	20	FBG 214 (11.9) RBG 218 (12.1)	Glipalamide, Metformin, Gliquidone, Neurobion	BPJS K	Not joined
7	307	64	M	Academy	Married	Retired Athlete	T2DM, kidney disease, history of diabetes ketoacidosis	7	FBG 90 (5.0) 2PPBG 100 (5.6)	Lantus, Folic acid, Gliquidone	BPJS K	Not Joined
8	308	60	F	Junior High School	Married	Housewife	T2DM, neuropathy, cataract	15	FBG 144 (8.0) GDS 118 (6.6)	Metformin, Novo Rapid Insulin, Lantus	BPJS K	Not Joined
9	309	61	M	Diploma in Hospitality	Married	Retired chef	T2DM, hypertension, hypertrophy prostate	11	FBG 136 (7.6) 2PP 192, R 203	Novo Rapid Insulin, Lantus	BPJS K	Not Joined
10	310	54	M	Bachelor of Economics	Married	Retired Medical Assistant	T2DM, rheumatics, hepatic diseases	5	FBG 180 (10.0) RBG 204 (11.3)	Acarbose Gliquidone, Metformin	BPJS K	Not Joined
11	311	59	F	Master of Economics	Married	Finance Analyst	T2DM, heart diseases, lung TB history	20	HbA_{1C} 8.3	Novo Rapid Insulin, Lantus	BPJS K	Not Joined
12	312	58	F	Senior High School	Married	Housewife	T2DM, gangrene diabetes, history of diabetes coma	13	FBG 174 2PP 210 HbA_{1C} 5.8	Novo Rapid Insulin, Lantus	BPJS K	Not Joined
13	313	50	F	Junior High School	Married	Housewife	T2DM, bronchial asthma, rheumatic	5	FBG 163 (9.1) 2PP 202 (11.2)	Metformin, glimepiride, Acarbose	BPJS K	Not Joined

No	CODE	Age (years)	Sex	Education	Marital Status	Occupation	Medical Diagnosis	Diabetes Diagnosis (years)	Lab Results BG (mmol/mol) HbA_{1C}	Treatment	Health Cost Payer	Support Program (PROLANIS)
14	314	53	F	Senior High School	Married	Housewife	T2DM, breast tumour, osteoporosis	4	FBG 170 (9.4) 2PP 202 (11.2)	Metformin, Lantus, Calcium	BPJS K	Not Joined
15	315	53	F	Senior High School	Single	Unemployed	T2DM, lupus erythematosus, osteoporosis, kidney stones and gallstones	3	FBG 218 (12.1) RBG 300 (16.7)	Metformin, Novo Rapid Insulin, Glucopac, Alpentin, Simvastatin, Captopril	BPJS K	Not Joined
16	316	61	F	Diploma of Teaching	Married	Private Kindergarten Owner	T2DM, history of diabetes ketoacidosis, diabetes retinopathy	15	FBG 118 (6.6) 2PP 250 (13.9)	Novo Rapid Insulin, Lantus	BPJS K	Not Joined

Note: T2DM = Type 2 diabetes mellitus; BG = blood glucose; HbA_{1C} = glycosylated haemoglobin; FBG = fasting blood glucose; RBG = random blood glucose; MTX = methotrexate sodium; TB = tuberculosis

Most of the patients were at the stage of diabetes with complication(s) and some did not have their blood glucose under control. All patients had more than one or 2 chronic diseases, either as diabetes complications or an unrelated disease. Most participants had at least one or 2 chronic diabetes complication(s) such as hypertension (5 patients), diabetes sensory neuropathy (3 patients), lung tuberculosis (1 patient), heart disease (1 patient), diabetes retinopathy (2 patients), a history of gangrene (2 patients), or kidney disease (1 patient). Eight patients also had other chronic illnesses such as bronchial asthma (1 patient), arthritis (2 patients), breast cancer (2 patients), lupus erythematosus (2 patients), hyperthyroidism (1 patient), liver disease (1 patient), osteoporosis (2 patients), kidney stones (1 patient), prostate enlargement (1 patient), or gallstones (1 patient). Three patients had a history of having acute diabetes complications including diabetes coma and ketoacidosis that required emergency interventions.

The period since being diagnosed with diabetes varied, with the shortest time estimated at between 3 and 10 years (8 patients), while 7 patients had been diagnosed for between 11 and 20 years, and one for the past 26 years. Most participants did not have their HbA_{1C} results from the previous 6 months. Most patients' BGLs were not under control, which could be seen from their RBG, FBG or HbA_{1C} level. Fourteen out of the 16 patients had high BGLs in which their FBG ranged from 8.6 to 12.1 mmol/L, their random venous plasma concentration ranged from 11.3 to 16.7 mmol/L, and HbA_{1C} at 8.3% was at the maximum. The complexities of the patients' medical diagnosis, consequently, meant they were taking multiple medications. Fifteen out of 16 patients were prescribed multiple oral diabetes medications, insulin therapies and other medications. All patients were using the BPJS K health insurance system, with no one a member of PROLANIS

7.3.2 Healthcare professional participants' profiles

Eight HCPs were involved in this study. This included 2 medical endocrine and internal medicine interns (aged range 30 to 40 years), and 6 diabetes nurse educators (age range 30–50 years). One nurse held a master's degree, 3 nurses had bachelor degrees, and 2 had a Diploma in Nursing. For a period of 6 weeks the 2 doctors worked on a daily rotation in the endocrine clinic. All the nurses had experience as diabetes educators, ranging between 9 and 19 years. Two nurse educators were based in this diabetes clinic. The rest of the nurses were on-call diabetes nurse educators who worked in other units and came into the diabetes clinic on a weekly-based schedule. Table 7.2 presents the HCP participants' profiles.

Table 7.2: National hospital healthcare professionals' profile

No	Code	Professional Background	Educational Background	Sex	Age Range	Job Title
1	031	Endocrinologist	Endocrine Specialist	F	30–40	Intern Endocrinologist
2	032	Internist	Internist	M	30–40	Intern Internist
3	133	Nursing Diabetes educator (19 years)	Master of Nursing	F	40–50	Head/Nurse of Nursing Education and Training
4	134	Nursing Diabetes educator (18 years)	Bachelor of Nursing	F	30–40	Nurse of Diabetes Clinic
5	135	Nursing Diabetes educator (9 years)	Bachelor of Nursing	F	30–40	Nurse of Medical Ward
6	136	Nursing Diabetes educator (16 years)	Bachelor of Nursing	M	30–40	Nursing Supervisor of Outpatient Department
7	137	Nursing	Nursing Diploma	F	40–50	Nurse of Diabetes Clinic
8	138	Nursing	Nursing Diploma	F	30–40	Nurse of Diabetes Clinic

7.4 Themes and subthemes in Case Study 3

The second phase of analysis generated 4 themes and 9 subthemes as presented in Figure 7.1.

Observations

COMMUNICATION GAPS

Direct and one-way communications

Passive patient in clinical encounters

LACK OF SUPPORT FOR PATIENT SELF-MANAGEMENT

Little guideline

Disregarding patient self-management exploration

Lack of engagement to patient competence in managing insulin

MEDICAL DOMINANCE IN THE CARE

Medical assessment and intervention dominant

Direct medical approach

Interviews

DISEMPOWERING CARE PROVISION MANAGEMENT

Fragmented care for elderly

Longer waiting time

Lack of access for BPJS patients

Discrepancy in medical therapy standards

LACK OF ACCESS TO MEDICATION AND INSUFFICIENT CARE

Discrepancy between medical and payer standard

COMMUNICATION GAPS

Trusting relationship issues

Lack of doctor’s attention

Less friendliness

MISSED CARE ABOUT MEDICATION USED AND SELF-MONITORING

Missed care about insulin and blood glucose monitoring

Lack of direction for multiple medications used

CHALLENGES IN DIABETES SELF-MANAGEMENT

Focus Group Discussion

ABSENT PATIENT EMPOWERMENT DELIVERY SYSTEM

Role ambiguity of diabetes nurse educators

No clinical standard for patient education to support self-management

Discontinuity of patient education

No leadership

Time constraints due to many patients

DISCREPANCY BETWEEN PAYER AND HOSPITAL SYSTEM

Hospital regulates payment system for patient education

Patient education in the hospital tariff system

CHALLENGES IN PROVIDING STRUCTURED PATIENT EDUCATION

System-related problems

Patient-related problems

Education not based on patient need

LACK OF INFRASTRUCTURE FOR DIABETES PATIENT EMPOWERMENT PROGRAM

Unsupportive medical record system

Lack of numbers and competencies of diabetes educators

Diabetes educator was not in the system for diabetes care

No standard in educators and patient education

Time constraints

Themes and Subthemes

LACK OF DELIVERY CARE SYSTEM THAT FACILITATED PATIENT EMPOWERMENT

Role ambiguity of diabetes nurse educators in delivering care

Fragmented care

Discontinuity of patient education

Absence of clinical leadership

COMMUNICATION GAPS

HCPs disempowering communication style

Medical dominance in communication

Lack of trust of HCPs and health care

Perceived lack of interest in patient-education program

UNSUPPORTIVE HEALTHCARE PAYMENT SYSTEM

Discrepancy between medical and payer standards

UNSAFE MEDICATION PRACTICE

Figure 7.1: Themes and subthemes analysis and findings from field site 2, the national hospital

Note: HCP = healthcare professional

7.4.1 Lack of a delivery care system that facilitated patient empowerment

The system for organising patient care did not facilitate patient empowerment or support self-management. Four subthemes under this theme illustrate the inadequacies: role ambiguity of diabetes nurse educators, fragmented care, discontinuity of patient education, and an absence of clinical leadership in care provision that would have enhanced patient empowerment.

7.4.1.1 Role ambiguity of diabetes nurse educators in delivering care

Diabetes nurse educators did not perform as they were expected to as part of the diabetes care delivery system. Two nurse educators were available in the clinic but did not provide patient health education or deal with programs related to patient self-management as part of their daily assigned work as a general nurse. In all my observations of clinical encounters involving patients and the nurses, the pattern of interaction was brief, and focused on patient registration and general patient assessment procedures. A clinical encounter between a female patient aged 60 years and a nurse who was assigned to check registration and primary assessment illustrates how the diabetes nurse educator assessed basic and general data that was not related to diabetes care:

> The patient approaches one of the 2 nurses dressed in PPE and seated at the nurse station, each with a personal computer. The nurse offers the patient a seat in front of her desk and confirms the patient's information on her computer screen, "Are you Mrs X?" [name of the patient of the screen]. "I am," the patient replies. "Do you have any allergies?" asks the nurse, while she pointed the thermometer device at the patient's forehead, then puts on a cuff on the patient's right arm to measure her blood pressure. "No, I do not," the patient replies. While waiting for the digital sphygmomanometer to work, the nurse asks one more question, "Any pain?" "No, I do not have any pain," the patient replies. The nurse then puts a yellow ribbon bracelet on the patient's left wrist, and says, "Ma'm, I put this on you as an alert that you are at risk of falls, so please take care while you are around." "Oh, okay," says the patient. The nurse then hands a paper a form regarding patient education on safety to the patient and says, "Please sign in each of the blocks." The nurse enters the data into the computer, records the results of the patient's temperature and blood pressure on a printed medical record, then says, "You please wait until the doctor calls you". (OBS8, P308, NH)

My observations shows that the nurse who trained as a diabetes educator assessed the patient according to the Joint Commission International (JCI) hospital standard questions on comfort, safety and general assessment. One of the standards from the JCI is to provide patient education on safety, including medication safety (JCI, 2013). However, this encounter did not empower the patient or enhance self-management. Her role as a diabetes nurse educator was totally consumed by the administrative tasks she had to perform.

In the FGD a doctor said that a diabetes management care system that supported patient self-management did not exist in the current clinical arrangements; diabetes nurse educators were impeded by time constraints, had limited competencies and skills in promoting patient self-management education and were underutilised. As one of the nurse educators said:

> Many of diabetes nurse educators at this clinic are not capable of providing patient education … And the problem is that we do not have a system that allows more time for interaction with patients. (FGD3, HCP136, line 58-61)

Besides the lack of skills in supporting patient's health education; there were too many patients, and the organisation of the care was an obstacle for the diabetes nurse educators to provide education on self-management. The 3 main reasons identified by the HCPs were evident during the restrictions imposed by the pandemic. Fifty patients with complex disease conditions were seen by 2 resident training doctors, and the 2 diabetes nurse educators were mainly responsible for ensuring all patients were recorded at the registration desk.

To accommodate the lack of diabetes nurse educators in this outpatient diabetes clinic, before the pandemic, there was a patient-education program in which diabetes nurse educators who worked in other units in the hospital were on call when there were patients identified by doctors who required diabetes patient education, especially related to the initiation of insulin injections for new patients. The diabetes nurse educators reported that the program had not reached the patients who required specific knowledge and skills to improve their self-management, rather patient education focused on providing patients with general skills to do with giving themselves their insulin injections. Commenting on this aspect of patient-education program, one of the participant nurse educators with more than 15 years' experience as a diabetes nurse educator said:

> The patients were only provided with information in that patient-education program as there was no engagement between the educators and patients because you know that next month, we might not be seeing each other. Patients come just to get materials about educations, yeah, it's only materials on diabetes education. We have no chance to dig in deeper to find out what's really the patients' problems. We all only provide patients with information on how to do technical things like giving insulin injections and monitoring

> their blood glucose. You know those procedures, those are only what we provide to patients so far. (FGD3, HCP135, line 18–24)

Given that the diabetes nurse educators were external to the diabetes care system, and were only supplementary staff in the clinic, it was observed these nurses were limited in what they could teach the patients, such as focusing only on technical procedures such as how to administer an insulin injection and self-monitoring of BGLs.

7.4.1.2 Fragmented care provision for patients with chronic illness

Medical care was provided exclusively based on the sub-specialities. Consequently, patient care services for patients with multiple chronic illnesses were fragmented and separate from members of the diabetes healthcare team who may have been aware of their problems. This lack of integration of care occurred for most of the patients who were at stages of diabetes with complication(s), where diabetes complications occur, and some patients had other complex chronic conditions. For example, one female patient aged 61 years, who had been diagnosed with diabetes for 15 years, stated:

> The geriatric clinic should have made the medication for diabetes available there because so many older patients have diabetes, it's so full of patients. As they're really old it is assumed they can wait a long time for the lab tests, doctor consultations and pharmacy. (INTV, P316, line 99–103)

This patient was referred from the geriatric clinic to the endocrine outpatient clinic as her BGL was not under control. This meant that the patient had to attend the hospital and wait in line for each service twice; lining up at the patient registration, the laboratories and the pharmacy every time she was required to attend the endocrine and geriatric clinics. In fact, all patient participants in this study had multiple chronic diseases. This was likely the situation for other patients who attended the outpatient clinics of this hospital.

The fragmentation of care services also caused confusion for patients regarding their self-management. The patients with multiple medical problems had to deal with various medical treatments with few guidelines, or information that was sometimes contradictory, as one of the patients aged 56 years, with T2DM for 26 years who suffered from multiple chronic diseases (retinopathy, gastropathy, hypertension, lupus erythematosus and scleroderma) reported:

> I was so sick with my medications … have got too many drugs … 4 pills for my heart, 2 in the morning and another 2 in the afternoon. Then for my immune system every Thursday I have to take the MTX [methotrexate sodium] … Every time I have taken this then I vomit. Then, I also I have to take my painkiller, the medications for my stomach from the gastroenterologist. I have to take sucralfate, laxadin, lemfotane, allopurinol, nifedipine for my hypertension … not to mention the vitamin B6, B12, folic acids … I am so confused and get dizzy managing all the medications. … I have to learn by my own how to understand and listen to my body … if I feel weak then I skip my hypertension medications on purpose … but then my blood pressure gets higher … I have gone through many things in managing my medications … I am not sure when I should take this medication and that medication so I can manage the unpleasant effects of the drugs. One time I have got diarrhoea caused by my stomach drugs, and at another time I got constipation because of other drugs … I have been so stressed. Sometimes I just ignore taking my drugs … I just do not take them. (INTV, P303, line 54–68)

The multiple prescribed medications taken by this patient caused debilitating side effects. Lack of collaboration among the HCP teams and the fragmentation of care delivery put the patients with no knowledge and support at risk of side effects.

7.4.1.3 Discontinuity of patient education

Within the existing care system in which medical residents are at the front line, some patients identified discontinuation of care as problematic. The medical residents were only assigned to the outpatient clinic for 6 weeks as they must follow the same academic rotation schedule as residents of medical specialists. A female patient aged 53 years who had been diagnosed with diabetes for 4 years stated:

> Every month I came here I met with different doctors. I don't just need doctors but doctors who really understands my problems, you know right what, even their [doctors'] name we don't know. I sometimes received different advice for instance from the previous hospital they told me not to eat eggs and this doctor said that I am allowed to have eggs, it was confusing. One time I already talked about my problems to a doctor, but then I could not meet her or see her the next month. (INTV, P314, line 62–72)

Discontinuation in care occurred in the education program as well. The materials and discussions occurred in one education meeting with the patients were unlikely to be continued in the next session as the diabetes nurse educator was not assigned based on the cases, but rather on their time availability.

As one of the diabetes educators reported:

> There is no one in charge for patient education on a fixed schedule, the educators keep changing. I think the trust relationship with patients is not built. And patient–nurse interaction do not happen. There is no relationship between patients and nurses because you know next month, they might not see each other. Patients come just to get materials about education, yeah, it's only materials on diabetes education we have.
>
> Well, because it was so unlikely that I met the patients again in their next visit, so I didn't know what's been going on day by day, what I meant … month by month after the patients met me. (FGD3, HCP313, line 16–26)

Discontinuation of care meant patients remained disempowered and unable to self-manage as the nurse educator was not able to provide care based on a trusting relationship and follow-up care.

7.4.1.4 Absence of clinical leadership

Lack of clinical leadership in the management of the outpatient clinics was identified by the HCPs as contributing to a lack of care oriented towards a patient-empowerment program in supporting self-management. While the care was oriented to the provision of medical care provisions and nursing staff focused on the administrative tasks, care to support patient self-management was overlooked. One of the diabetes nurse educators who believed that patient self-management should be supported in the care provision said:

> What's going on here is a lack of leadership. This is a leadership problem that requires someone to activate the program. (FGD3, HCP136, line 161–162)

Absence of clinical leadership was viewed as a barrier to establishing a support program to enhance patient empowerment.

7.4.2 Communication gaps

Ineffective communication between HCPs and patients was analysed mostly through observation of clinical encounters and aligned with the patients' perceptions of the interaction. For this major theme of communication gaps, the subthemes were evident in behaviours that indicated a disempowering approach in clinical communications, medical dominance in communication, lack of trust of the HCPs and the healthcare provided, and a perceived lack of interest about the patient-education program.

7.4.2.1 Healthcare professionals’ disempowering approach in clinical communication

Direct, one-way communication, and sometimes discouraging words from doctors and nurses towards patients were evident in the clinical encounters. Interactions between patients and HCPs were dominated by the taking of a medical history and providing instructions. In one encounter between an endocrinology resident doctor and a female patient aged 60 years who had in diabetes for 14 years I observed:

> As the patient comes into the consultation room and takes her seat. The doctor, who was seated already, straight off asked about the patient’s self-monitoring blood glucose notes, “Have you got the blood sugar results test, and the self-monitoring?” “No, I haven’t, I only check it weekly,” the patient answers. Then the doctor reviews the laboratory test result sheet given by the patient. The doctor seems unhappy with the patient notes and says, “These 4 test results are not sufficient, how about the fasting blood sugar tests? You have been told to do these, these were only random blood test results, and they cannot be used.” “Oh, I see,” the patient mumbles. The doctor continues talking about the blood glucose test results provided by the patient, “These results have expired, and they have not reached the treatment targets, but because you have not had any blood glucose test results, I cannot change your medication dosages okay,” the doctor says. The patient just nods her head. “So, ma’m, next time check also you’re fasting and 2 hours after meals blood glucose.” “Okay, doctor”, the patient seems to understand the doctor’s instruction. (OBS5, P305)

The clinical encounter above focused more on the results of the blood glucose test that was required to be conducted by the patient for the purpose of the doctor making an evaluation of the BGL as the basis for adjusting the patient’s medication dosage. Given the fact that the patient did not really understand the purpose of monitoring or how, the doctor simply directed and instructed her to self-monitor her BGL. Only providing verbal instructions for such a complex and important skill was insufficient and made it difficult for the patient to self-manage her diabetes care.

Discouraging words that were sometimes used by doctors during clinical encounters increases patient stress. For example, one female patient aged 61 years who had been diagnosed with diabetes for 15 years who was confused about her insulin dosage said:

> I think the doctor should not speak over the patients, just tell the patients nicely. When the doctor yells at us, we are even more stressed. We already try very hard at home to make blood glucose levels normal. One time the doctor told me that if my blood glucose is high, I am going to die because of this. Oh my God, I know everybody will die but they

> should not say it like that. I'm a sensitive person, so you know actually, I am the one who wants the [blood glucose] results to be good. (INTV, P316, line 103–115)

Instead of supporting the patient's efforts to get her BGL normal and find out the reason for the increase, the patient was blamed for the results. The doctor's approach caused more stress to the patient. Other patients reported similar experiences.

7.4.2.2 Medical dominance in communication

Most of the clinical interactions with doctors were initiated by asking patients for their blood glucose test results. The rest of the conversation was dominated by topics on medication dosage adjustments and further clinical laboratory evaluations. No time was left for any discussions on how the individual patient might manage their diabetes care themselves. In one of clinical encounters with a doctor, a 58-year-old female patient who had been diagnosed with diabetes for 8 years illustrated how dominant the medical topics were throughout the interaction:

> The doctor has on his PPE (overall hazmat, a mask, a surgical cap and a face shield), holding a thick PMR, then straight off asks the patient who was about to reach her seat, "Have you got your daily blood glucose report?" The patient confusedly looks at the doctor, then shows him a laboratory test results paper from her handbag. "This one is not sufficient," says the doctor. The doctor keeps asking the patient about the ablation schedule and the patient says she has no idea about the schedule and asks the doctor to check it on the PMR or her EHR [electronic health record]. (OBS2, P302)

The dominance of the doctor was evident in this clinical encounter. Medical dominance was also evident in how the doctor positioned the patient as a passive recipient of care. A male patient aged 64 years who had been diagnosed with diabetes for 7 years stated:

> I think doctors in here just provide general explanations and they don't have much time to ask question and sometimes they just don't hear what we ask. My blood glucose was still up and down well yeah that's actually I would like to ask to the doctors what's wrong with me and why, sometimes my blood glucose is high and what happens to me and why it is high at some times and at other times low. I just want to discuss it, but you know. (INTV, P307, line 34–40)

The patient said that during clinical encounters with the doctors, he did not get the opportunity to discuss his concerns and he was just given a general explanation, or the doctor simply ignored what he said. Other patients expressed similar experiences.

7.4.2.3 Lack of trust in healthcare professionals and the health care

Patients had low trust in the HCPs, especially the doctors who provided the daily care in the outpatient diabetes clinic, and the medications they prescribed. One of the male patients aged 54 years, who had been diagnosed with diabetes for 5 years, suspected that on one occasion the doctor did not read his medical records, which caused him concern about the possibility of inaccurate treatment. On another occasion, the patient found that the doctor forgot to order his prescribed medication with the pharmacy, stating:

> The doctors sometimes do not read my medical records properly. They should read them vigilantly so they can treat me accurately. Sometimes, they also forget to prescribe my medication [the prescription made by the doctors online]. So, I had been waiting and waiting at the pharmacy and no medication for me came out. (INTV, P310, line 42–46)

The patient was concerned about the doctor's reliability in dealing with his treatment. The patient suspected that the doctor did not really pay attention to his needs.

Patients also lacked trust in the treatment they received. Some questioned the quality of the medications. For example, a female patient aged 53 years who had been diagnosed with diabetes for 4 years noted:

> The medication quality in here is poor. I remembered when I was in another hospital even though I was using BPJS they gave me the first quality drugs, but not in here. I'm not so sure whether it is good drugs or not, so I'm not so sure. (Interview, P314, line 45–50)

The lack of trust in the patient–doctor relationship is a threat to patient adherence to medical advice and medications prescribed.

7.4.2.4 Perceived lack of interest in patient-education programs

The lack of engagement of some patients in the education programs run by the diabetes clinic was perceived by HCPs as a reluctance by patients to become informed and educated with knowledge and skills in diabetes. Rather they only wanted to be prescribed medications at the national hospital. The pharmacies at the national hospital provided more variety in medications. A diabetes health educator stated:

> You know about 80% of patients refused to join the patient-education program because you know they're afraid that they will miss their turn with the doctor consultation. The patient demand for education is low … they do not want education as they are focused on their visits to get the medications This is because the hospital provides a wider variety

> of medications, while lower-level health services do not, so they are just really focused on getting the medications from the service in this hospital. (FGD3, HCP136, line 68–74)

The diabetes nurse educator perceived that patient lack of interest in education programs conducted by the diabetes clinic was because the patient’s priority was to come to the hospital to access medications.

However, most patients regarded the education program as important in supporting their care, especially in supporting their psychological welfare. One of the female patients aged 59 years who had been diagnosed with diabetes for 20 years said that knowledge about diabetes changed how she coped with her diabetes. She said:

> You know … at the first 6 months of having diabetes I was so shocked, frustrated because my daughter was still little. For me it was not sufficient just to have knowledge on how to manage the diet, monitoring blood glucose … and so on. People with diabetes who were around me we’re so down; one without legs anymore, get amputation, and the other one was using a stick for walking ... Therefore, I tried find out what diabetes was and how it is. At that time Google was not what it is like today. So, I was backwards and forwards doing the course to get better knowledge of my diabetes. (INTV, P311, line 81–89)

Another patient, a male aged 64 years who had been diagnosed with diabetes for 7 years, said that he was keen to gain knowledge about diabetes care, but it seemed that the program was not sustained. He said:

> I think a long time ago there was an education program run by professors but since then I have never heard of any other patient-education program here. If I heard of one, I would join … you know knowledge is expensive. This knowledge for patients with diabetes must be provided. (INTV, P307, line 65–69)

While some patients appeared to prioritise getting their medications rather than attending the education programs, the same patients believed that education was necessary for supporting patients.

7.4.3 Unsupportive healthcare payment system

All patient participants were covered under the BPJS K funding scheme. However, they were not fully covered by the health insurance scheme. There were differences between the standards of the BPJS K and the medical standards provided. This meant patients sometimes received a lower standard of medical care than medical guidelines stated.

The subtheme, discrepancy in standard of care between medical guidelines and payment system, was evident.

With the new healthcare payer, BPJS K, patient access to medical care is limited in the choice of medical practitioners and therapies. Additionally, physicians experience restrictions on the type of treatments they can provide as they are not covered under the BPJS K scheme. In a clinical encounter between a medical resident of endocrinology and a female patient aged 60 years who had been diagnosed with diabetes for 14 years, the doctor asked the patient to purchase a particular medication as the patient's LDL laboratory results test was still lower than the standard required by BPJS K to support free access to the medication:

> "What was your blood pressure?" the doctor asks while she was reviewing the patient's medical records on the computer screen in front of her. "Umm … not sure," the patient replies. "Did you get all the prescribed medications, [dispensed by the hospital pharmacist under the BPJS scheme]?" the doctor asks. "No," the patient replies. The patient tells the doctor that she had to buy the simvastatin as the pharmacist did not give it to her. The doctor told the patient that her LDL was 120 mg/dl, while the BPJS would give the drug if patient's LDL level was 130 mg/dl. The encounter ended with the doctor handing the prescription sheet to the patient for her to purchase the medication out of her own pocket. (OBS5, P305)

Though medically the patient required the medication to treat her hypercholesterolemia, she was not eligible under the BPJS K scheme to get the medication for free as her blood cholesterol level was lower than the recommended level required.

The HCPs also recognised the discrepancy between the payment system and medical standards on diabetes medications. The nurse educator said:

> Most patients who come to this clinic are under the BPJS K healthcare insurance scheme. There are discrepancies between what the diabetes team recommend for clinical care and the what the BPJS funds in regard to the regulations on insulin. (FGD3, HCP134, line 3–6)

The nurse diabetes educator reported that insulin was not dispensed according to the recommended medical guidelines, but to the guidelines sent by the insurance scheme. There were discrepancies between the 2 sets of guidelines. Given these discrepancies, the patients are required to purchase the medications using their own money if the doctor recommends a particular drug. If they cannot afford them, they simply do not take the medication. Thus, the patients covered under the BPJS K may lack access to medically necessary care. This reduces patients' ability to self-manage their care.

7.4.4 Unsafe medication practice

Unsafe practices when using insulin in particular were observed among patients with T2DM, even though they had had diabetes for many years. One of the patients aged 60 years who had been diagnosed with diabetes for 15 years reported that she was confused about her insulin treatment. This patient reported that the doctor kept increasing the insulin dosage while she had normal, and sometimes low, BGL:

> I have been wondering why my insulin has been continuously increased; in fact, my blood sugar levels have been less than 200mg/dl. Sometimes, I have low blood sugar level such as 115 mg/dl. I also, have been worrying about having low blood glucose levels. (INTV, P308, line 14–20)

Another patient, a 61-year-old female who had been diagnosed with diabetes for 15 years was adjusting her insulin dosage without guidance:

> I just play with the insulin dosage specially if I got parties and then yeah, I increase the insulin dosage if I eat too much or I just reduce the insulin dosages if I don't eat much, so just get 10 units of insulin. So, I can feel it … I have never been taught how to adjust my insulin, never, I just try by my own. (INTV, P316, line 50–56)

As insulin is a high-alert medication, it should be used cautiously. However, the patient had received little information and no written guidance on its use, including how to handle adverse reactions. Instead of using high concentrated glucose to manage their hypoglycaemia, the patient used ineffective low-sugar sweeteners as first aid when she was hypoglycaemic. She reported:

> I drink tea with sugar, I am used to drinking with diabetic sugar. I also use the diabetes sugar in my drink including when I have low blood glucose level. (INTV, P308 line 21–22)

Moreover, the patient was ordered to adjust her daily insulin use by the doctor without ensuring its safety. This was observed during her clinical encounter with an internist doctor:

> The doctor is reviewing the patient's insulin therapy, "So you have been in 3 times a day of the 34 units of lantus and the 15 units of novorapid insulin?" "Yes, but I have reduced the dosage to 30 units, I have pain if I take the full dosage," the patient explains her adjustment of the insulin she used. "Did you feel better if you use the 30 units?" the doctor replies while he is working on his computer screen reviewing the patient's medical history for quite a while. The doctor did not clarify further what the patient meant by

> pain. “Yes, I feel much better, and I do not want to have more fats,” the patient says. “So, the 30 and the 15 units of insulin, aren’t they?” the doctor confirms with the patient. Then the doctor talks more about the insulin dosage adjustment to the patient, “Your insulin dosage is still in recommended range, if it is reduced it will be too low and it has to be lowered slowly, now you can have 28 units of the insulin. But, if your blood glucose result is more than 100 mg/dl, then you could increase it back to the 30 units,” the doctor explains to the patient while he is writing out a prescription. The encounter ends with 20 minutes left, but the issues of the patient’s swollen legs, and pain caused by high dosage of insulin injections, and possibly of adverse effects of the insulin used that might be life-threatening to the patient is not discussed. (OBS8, P308)

Detailed information on self-adjustment of insulin was absent in the above clinical encounters. The insulin adjustment program was taken lightly by the doctor while the patient had little knowledge of the treatment, thereby being potentially hazardous to the patient.

7.5 Chapter conclusion

Four themes and 9 subthemes were generated from the analysis of 16 patient interviews, 28 observations of clinical encounters between patients and HCPs, and 2 FGDs with HCPs from this third research site: the national hospital. The age of the patients ranged from 39 to 64 years. The minimum level of patient educational background was junior high school, with the majority having had senior high school education. Two had a master’s degree, one a bachelor’s degree, 4 had diplomas, and 4 had completed junior high school.

Most of the patients were at stage of diabetes with complication(s) and some did not have their blood glucose under control. All patients had more than one or 2 chronic diseases. The shortest time estimated of them having diabetes was 3 years and the longest was about 26 years. Most participants did not have their HbA_{1C} results from the previous 6 months. The complexities of the patients’ medical diagnoses meant they were taking multiple medications. Fifteen out of the 16 patients were prescribed multiple oral diabetes medications, insulin therapies and other medications. All patients were using the BPJS K health insurance system.

The 4 themes and 9 subthemes indicate that there were barriers within the healthcare system related to patient empowerment to support self-management. Communication gaps due to differences in knowledge between patients and HCPs, HCP communication styles, negative perceptions of patients towards healthcare services and HCPs, and time constraints during the clinical encounters between patients and HCPs were prominent issues. The healthcare insurance payments were limited in what they covered and inconsistent with medical guidelines. This also disempowered patient self-management, including restricting patient knowledge and skills in making daily care decisions.

The next chapter, Chapter 8, presents the cross-case analysis of the 3 data collection sites mapping the issues into a single case study. Following this chapter, discussion of the findings is presented which is then followed by the final chapter, which discusses the limitations, strengths and recommendations before concluding the thesis.

Chapter 8: Mapping the Issues in a Single Case Study

8.1 Introduction

As discussed in Chapter 4, a single case study with embedded units was used as the research design for this study. The embedded units of analysis examined care provision at 3 levels of the health service in Indonesia covering both urban and sub-urban locations. Three research sites were chosen to capture a range of different levels of healthcare provision: a community health care centre, a *Puskesmas*, a provincial hospital, and a national hospital. This single case study is an exploration of the existing diabetes care provided for patients with T2DM within the Indonesian context. The previous 3 chapters (Chapters 5, 6 and 7) focused on the findings about diabetes care, and the challenges facing both patients and HCPs in empowering patients with T2DM to take some control over their care. This chapter maps the identified themes outlined in those chapters.

8.2 Themes and subthemes mapped in a case study

Several themes from the 3 healthcare facilities were identified. The themes from the *Puskesmas* were medical dominance in care provision, communication gaps, regulation-centred care provision, care quality and self-empowerment (see Chapter 5). Similar themes of medical control in the patient–doctor relationship, system-related barriers and unspoken challenges towards self-management were identified in the provincial hospital (see Chapter 6). The national hospital also generated similar themes: lack of a delivery care system that facilitated patient empowerment, communication gaps, an unsupportive healthcare payment system, and unsafe medication practice (see Chapter 7).

The cross-case analysis generated a final set of themes and subthemes to create a single case study to explain the provision of diabetes care in the context of the Indonesian healthcare system. Figure 8.1 shows the themes and subthemes generated from each research site and the final concepts of this single case study. Table 8.1 identifies the final 5 themes: inadequate resources, poor healthcare provision management, medical dominance, communication gaps and poor patient outcomes.

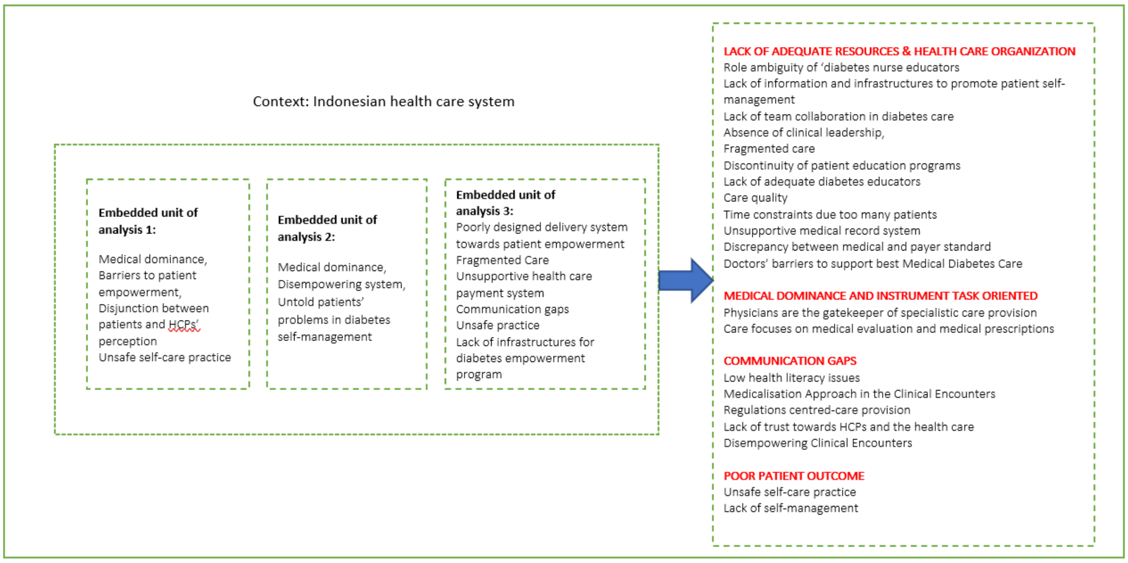


Figure 8.1: Concepts across three embedded unit of analysis

Table 8.1: Themes and subthemes of a case study on diabetes care provision to support patient self-management

Themes	Subthemes
Inadequate resources	Inconsistency between medical insurance and clinical standards
	High patient–HCP ratio
	Inadequate access to better care provision
	Lack of numbers and qualifications of diabetes educators
Poor healthcare provision management	Lack of healthcare team collaboration
	Scarcity of structured patient-education programs
	Fragmentation and discontinuity of care
Medical dominance	Doctors decide all care
	Medicalisation of all care
Communication gaps	Limited health literacy
	Different expectations of patients and HCPs
Poor patient outcomes	Lack of self-management awareness and practices
	Potentially harmful self-management practices

Note: HCP = healthcare professional

8.2.1 Inadequate resources

One of the main themes evident from the 3 research sites suggests that the current diabetes care for patients in the Indonesian context is inadequately resourced at all levels of the healthcare system. The 4 subthemes within this main theme are inconsistency between medical insurance and clinical standards, high HCP to patient ratio, inadequate access to better care provision, and lack of numbers and qualification of diabetes educators.

8.2.1.1 Inconsistency between medical insurance and clinical standards

The inconsistency in national health cover between the BPJS K insurance scheme and clinical standards was experienced by some patients, specifically in the provincial and national hospitals, through restricted access to certain types of insulin, hypocholesterolemia medications, and the number of insulin pen needles dispensed. The discrepancies between BPJS K and medical standards were also evident in clinical encounters. For example, the doctors instructed the patients to purchase their medications themselves as the BPJS K did not cover this cost. In the FGDs, doctors in the provincial hospital said the discrepancy was due to the lack of understanding by the Ministry of Health about clinical standards. Doctors said that the policy prevented them from providing the best medical care.

The Indonesian National Health scheme, BPJS K, stipulates the eligibility of a patient for certain types and amounts of medication, medical evaluation, assessment and referral to specialist medical care. All patient participants in this study were covered under the BPJS K scheme. However, I noted that the standard of medical care provided to patients with T2DM under the BPJS K was suboptimal as patients were unable to obtain some medications and did not receive all laboratory monitoring required because of the gaps between insurance coverage and medical standards. For instance, a medical evaluation such as a patient's HbA_{1C} level that should be performed every 3 months, can only be ordered every 6 months under the BPJS K scheme. Another example is that the BPJS K guidelines state that patients have to have a higher BGL than the medical standard recommendations before receiving prescribed insulin. Additionally, the BPJS K coverage for certain types of insulin used to reduce BGL slowly, namely intermediate-acting insulin, or neutral protamine hagedorn (NPH) insulin, was limited. Thus, the patients covered under the BPJS K lacked access to optimal medical care and equipment (such as insulin pen needles) due to the inadequate financial resources provided by the national government health insurance scheme.

8.2.1.2 High patient–healthcare professional ratio

There were too few HCPs to patients at all 3 levels of the healthcare system. Too few HCPs, especially the doctor–patient ratio, resulted in long queues in the waiting room for a doctor's consultation, pharmacies and laboratories. Long queues were witnessed right from the patient admission register counter for all the healthcare facilities. Patients said their appointment at the *Puskesmas* or at the hospital required a whole day commitment. They had to go early to the venue for registration even though they had already registered online. There were several administration points in the clinics that had to be passed through before joining another long queue to see a doctor. On average one general practitioner and one nurse provided care to 50–60 patients daily in the *Puskesmas*. The ratio of patients to doctors and nurses was even higher in the provincial and national hospitals. In the provincial hospital, an internist attended to approximately 100–120 patients each day, and among them were patients with diabetes. An endocrinologist had to attend to approximately 30–50 patients during a 3-hour specialist clinic. In the national hospital 2 medical endocrinologist residents and 2 nurses attended to approximately 50–60 patients (during the COVID-19 pandemic) and 4 medical residents and 2 nurses attended to 120–150 patients before the pandemic.

The high patient–HCP ratio was also identified by HCPs at all levels of the healthcare facilities as one of the obstacles to providing patient-education programs on self-management during consultations. In the *Puskesmas*, the HCPs had to attend home visits to deliver health education to reach patients who did not return for their follow-up care and who appeared to be non-compliant. As there was only one nurse available for the home visits, only a small number of these patients could be visited in their home. In the provincial and national hospitals, in the fast pace of daily patient care services, there were 100–120 patients daily in the outpatient clinic requiring health education, but only 2 or 3 diabetes educators (nurses and dietitians) in attendance. According to the HCPs, it was impossible to provide a structured and comprehensive patient-education program; rather a few patients received random and unstructured information.

8.2.1.3 Inadequate access to better care provision

This subtheme outlines the inadequate access to care provision experienced by the patients. Limitations and a lack of flexibility in care schedules and appointments were present at all 3 levels of the healthcare service. All the care services that were available for patients who used BPJS K health services opened in the morning at 8:00 am and operated until 2:00 pm. After 1:00 pm patient registration closed, except in the *Puskesmas*, which provided afternoon appointments. However, according to the patients, the evening session was not helpful as they were required to have their FBG level checked before seeing the doctor and this had to be done in the morning. Outside the scheduled time, there were no services for these patients except in an emergency department. The patients who were covered under the BPJS K also had no options for choosing doctors or other HCPs. In the *Puskesmas* and provincial hospital, the same one or 2 doctors were assigned each day, while in the national hospital, the care was delivered by residents of medical specialists who were assigned and rotated every 6 weeks.

Limited access to certain medications also prevented the patients from receiving consistent treatments. The patients were required to have a greater BGL to be eligible for certain medications. This meant that early treatment for patients was not accessible. Moreover, sometimes essential medications such as insulin were not in stock in the BPJS K pharmacies. The discontinuity of medication supply and lack of flexibility prevented patients from getting their care in time, and consequently from receiving adequate diabetes care.

8.2.1.4 Lack of numbers and qualifications of diabetes educators

A lack of staff numbers and qualified diabetes educators, including diabetes nurse educators, was observed in all 3 research settings. The diabetes educators were only available in the provincial and national hospitals, their numbers were low, and they were not optimally utilised. In addition to acknowledging that they lacked the required knowledge and skills, they were hampered by having to conduct administrative work, such as patient registration, which was assigned by the head nurse who was not a diabetes educator.

The diabetes nurses were inadequately trained and were not certified. The national training for diabetes educators, including diabetes nurse educators, is a 3-day training program for each level: basic, intermediate and advanced, or a total of 9 days. However, not all diabetes educators have studied every level of the training, many had just completed the basic level and very few take the advanced level training. In the *Puskesmas* setting, an untrained nurse was responsible for patient health education, working as part of the government's chronic care program or PROLANIS. With these minimal qualifications and training programs, most of the diabetes educators at the provincial and national hospital felt that their knowledge and skills were limited and their confidence to provide patient education, especially for patients with diabetes at the complication(s) stage, was low. Hence, diabetes care provision is challenged by the lack of resources in term of the diabetes educator's workforce.

8.2.2 Poor healthcare provision management

The next major theme, healthcare management, and associated subthemes encompassed situations where the care provided was insufficient. This included a lack of healthcare team collaboration, scarcity of structured patient-education programs, and fragmentation and discontinuity of care.

8.2.2.1 **Lack of healthcare team collaboration**

Collaboration between healthcare teams was lacking at all levels of the health services. For instance, as identified in the observations and as reported by the HCPs, the diabetes multidisciplinary care team that comprised physicians, nurses and dietitians was not effective in empowering patient self-management. The team members worked independently, rather than as a team. The doctors focused on patient clinical care and medical treatment, while nurses mostly conducted basic patient assessment tasks, such as measuring blood pressure and weight, and attending to administrative matters. However, teamwork in diabetes care was still perceived as important by some members of the team. For instance, an internal medicine doctor believed that a doctor should only focus on medications while other issues should be delegated to other team members. This doctor believed that an empowerment program in patient education could be provided if a delegation system was in place. The doctor expected the nurses to provide patient education on non-medical topics.

The only collaboration evident was in a referral process from doctors to diabetes educators. Doctors in the *Puskesmas* or in the hospitals referred their patients who required health education to nurses, dietitians or diabetes educators. However, there was no further communication among the team members regarding the referred patients.

8.2.2.2 Scarcity of structured patient-education programs

Patient-education programs were acknowledged as being an important aspect of T2DM care and management. An endocrinologist participant agreed that T2DM management should include patient-education interventions as part of the 4 main pillars in managing care. Through the BPJS K, a PROLANIS was introduced as a primary care-based program of which patient education was one of the activities included. However, the workload of the HCPs, and lack of suitably qualified diabetes educators, meant that HCPs found that PROLANIS was ineffective in supporting patient self-management. There was no significant planning included for patient-education programs. Those services that did include a program were ad hoc and more focused on activities of a government-mandated program rather than on patient outcomes. Endocrinologists were of the view that the government program was introduced without preparing the necessary infrastructure, such as diabetes educators, guidelines, pathways and standards. The introduced PROLANIS program disregarded the practitioners who were already providing this type of care daily.

Observations of the clinical encounters between a patient and an HCP (a nurse or a doctor) at every level of the healthcare services showed an absence of structured patient-education sessions. Brief general information was occasionally provided during the conversations in the clinical encounters; however, there were no opportunities for the patient and HCP to discuss any information further. While some patients were aware of the need for patient education for their self-management, they found that the information provided by the HCPs, especially doctors, was just too general and brief.

8.2.2.3 Fragmentation and discontinuity of care

In the community healthcare centre and provincial hospital, care fragmentation also occurred as there was a lack of coordination among the services. For instance, in dietary consultations, the service was only available in the morning, while the doctor's clinic still operated in the afternoon. With this fragmented care, the patients then had to return the next day for dietary consultations. However, as stated by a dietitian, many delayed the consultation as most patients had little understanding of the importance of diet as part of diabetes management. Similarly, the pharmacist's focus was limited to dispensing medications and separated from patient care or education about their drugs. This fragmented care resulted in longer or even more frequent visits or appointments to the hospital for the patients to be able to attend the different specialists and receive their medical prescriptions. In turn, this led to issues of self-management for the patients. Patients were confused by the medical advice given by different doctors, so acted on their own information.

At the national hospital where medical residents are at the front line, some patients identified fragmentation and discontinuity of care as problematic. The fragmentation and discontinuity of care specifically occurred in the national hospital, where medical care provided was mainly exclusively based on the sub-specialties. All the sub-specialties had a different focus on the required medical care, as most of the patients were at the stage of diabetes where complications had occurred. Other patients had complex care conditions where the care was split between the medical sub-specialties. Patients who had these multiple chronic conditions found the separation of medical treatments between different sub-specialists and the administrative procedures they passed through from counter to counter, overwhelming. Patients with diabetes complications for instance, had to consult with different doctors and clinics from endocrinology, ophthalmology, neurology, cardiology, nephrology and other medical specialties if they had other diseases not related to diabetes. Additionally, the patients had to decide themselves what advice to prioritise and how to manage the side effects of each medication prescribed by the different specialists and sub-specialists.

Lack of continuity of care was also experienced by patients in the national hospital where the medical residents were assigned to the outpatient clinic for 6 weeks due to the academic rotation schedule. This meant that even though each month the patient attended a 10–15-minute doctor's appointment, they were seen by different resident doctors at each visit. Some patients found that some doctors did not review their case prior to reviewing them. This meant the patient's concerns were not addressed during their appointment.

Lack of continuity of care also occurred in the patient-education programs. There was no program developed to guide each health education session. The materials and discussions that occurred in an education meeting were not documented. The patients were unlikely have the same diabetes nurse educator at the next session as they were not assigned based on the cases, but rather on their time availability. Further, when patients were referred from, and to, other health services, the HCPs had no basis or system to communicate their progress regarding their capacity for self-management. Discontinuation of care meant patients remained disempowered and unable to self-manage.

8.2.3 Medical dominance

Features of medical dominance were consistently identified at all 3 research sites. This theme was portrayed by the authoritative role of medical professionals in deciding the care provided, medical interventions performed, and medical discourses used in clinical encounters between patients and HCPs. The two subthemes are doctors decide all care and medicalisation of all care.

8.2.3.1 Doctors decide all care

Like medical doctors in many other countries around the world, the doctors in the research sites decided most of the medical services. They provided referrals to simple laboratory tests such as a RBGs, and diet consultations and diabetes education required an internal referral note from the doctor to a nurse, a dietitian or a diabetes educator. Further, the doctors appeared to act in the interest of the government when providing care. For instance, doctors act as gatekeepers in controlling access to specialist care for patients insured under the BPJS K scheme. Without these referrals, patients are not permitted to use these services, nor could nurses or other HCPs refer patients to these services.

8.2.3.2 Medicalisation of all care

This subtheme focused more on medical-related actions taken by HCPs that were driven by completing medical tasks rather than by delivering care to fulfil patient needs. A patient’s concerns were always addressed from a medical point of view as opposed to psychosocial aspects.

Medicalisation was also evident in all observed clinical encounters. In these interactions, expert medical language was always used, or the medical aspects of laboratory tests or medications were used to answer patient questions. The HCPs mostly used medical terminology to respond with no attempt to ensure patient understanding.

Besides the blood glucose test results, the focus of clinical encounters with doctors was on referral paperwork, prescribing medications, taking a medical history and providing laboratory test paperwork. The patients were not asked how they were feeling, what had been happening since their last visit, or how they were managing their diabetes. Doctors and nurses engaged in instrumental and medical tasks. For instance, clinical encounters with the nurse were limited to basic clinical procedures, such as taking the patient's blood pressure, weight and height, wound care, and dealing with administrative duties. Little informal patient education was conducted. This pattern of clinical encounters occurred across the 3 healthcare services. Both the HCPs (as expressed in the FGDs) and the patients (during their interviews) perceived the lack of personalised care as a result of too many patients who had to be seen on a daily basis. The clinical encounters with doctors and nurses focused on instrumental medical work, suggesting the dominance of clinical issues over patient concerns.

8.2.4 Communication gaps

This theme and the subthemes of limited health literacy and different expectations of patients and HCPs illustrate the underlying problems perceived by patients and HCPs. The ineffectiveness of patient–HCP communication in patient care, which included low health literacy issues, and different expectations of HCPs and patients in the observed clinical encounters, are described in detail below.

8.2.4.1 Limited health literacy

According to the HCPs, patients have low health literacy levels and little understanding of diabetes care. This contributed to the communication gaps that were evident by the lack of understanding about diabetes care and treatment among some patients who had had diabetes for several years. Of the total 42 patient participants with T2DM, only 3 had been diagnosed with diabetes within the previous 3 years, the other patients had been in care for between 5 and 22 years. Despite this length of experience with diabetes, and routinely visiting the healthcare facilities, some of the patients engaged in practices at home that were potentially harmful. For example, some patients believed in the efficacy of using snake blood to treat a diabetes wound, body massages with a jade gemstone, complementary medications such as herbal remedies, or eating leftover rice rather than cooking new rice as it was believed to have fewer carbohydrates. Some patients suspected that diabetes was transmitted through a used needle or using low, instead of high, calorie diabetes sweeteners as first aid during a hypoglycaemic incident at home. These misunderstandings suggest that patients lack knowledge of diabetes care as a result of limited exposure to credible diabetes education which, from their perspective, would normally be provided by the HCPs.

The HCPs believed the patients failed to comply with treatments, were remiss in attending doctor's appointments, omitted their medication, were disinterested in the PROLANIS programs, failed to maintain normal body weight or monitor blood glucose, or refused to initiate insulin therapy because they lacked health literacy. Patient low health literacy was viewed by the HCPs as hindering their understanding of the medical plan for patient care, thus leading the HCPs to blame them for mismanagement of their T2DM.

8.2.4.2 Different expectations of patients and healthcare professionals

Communication gaps were consistently identified throughout the 3 research sites and across all data methods: interviews with patients with T2DM, direct observation of clinical encounters between patients and HCPs, and FGDs with HCPs. In observations of the clinical encounters between endocrinologists or residents, and patients, authoritative medical knowledge appeared to be used to control the patients. For example, medical reasoning for why a patient's BGL had to be controlled by administering insulin, was explained using complex medical terminology, or the opposite, by providing oversimplified reasons. Patients viewed the doctor's preoccupation with medical investigations as a significant risk to their communication with the doctors. Patients wanted the doctors to listen to their problems and respond to their questions about their health, not just provide medications and laboratory test results.

Since the interaction between patients and doctors was more intense and valued compared to other HCPs such as nurses and dietitians, the communication gaps were more likely to occur between patients and doctors, or to be identified by the patients. Both patients and doctors realised there were gaps in communication during the clinical encounters. However, there was disagreement regarding the underlying problems. While most of the doctors and nurses suggested that the patient's low health literacy level and non-adherence behaviours were the main cause of the problem, patients perceived that certain doctors had a communication style that ignored their concerns and discouraged questions.

Most of the patients in this study perceived that the communication gaps with doctors were more likely to be caused by time limitations during the consultations, while some viewed the gaps being due to a doctor's personal communication style or lack of caring about the patient's problems. Some patients found the doctors' communication styles unacceptable, causing them distress. The patients expected the doctors to have high moral standards and to act in the best interests of the patients.

The data on the clinical encounters concurred with what the patients perceived as the underlying communication gaps. Consultations in the *Puskesmas* and provincial hospital averaged 5–10 minutes, and were dominated by the HCPs, especially doctors, who disregarded patient concerns, blamed patients for their misperceptions of administrative procedures and missed recordings of blood glucose self-monitoring. Greeting the patients was not common by either the doctors or nurses at the beginning of the clinical encounters, but for most of the time they both looked friendly. In the encounters, the HCPs proceeded to complete their tasks, while most patients would have liked to have been listened to first. However, considering the number of patients (100– 120 patients daily) who lined up for a doctor's consultation in the provincial hospital, the referral paperwork that needed to be completed (especially in the case of the *Puskesmas* and provincial hospital diabetes care provision), and the lack of privacy in the consultation room setting and overcrowded ambience, an ideal clinical communication between patients and HCPs was a challenge.

To some extent, the high patient–HCP ratio contributed to the superficial and fast-paced clinical encounters. Brief and superficial clinical encounters gave the impression to the patients that the HCPs were always busy, and few had time to have a conversation with the patients. The long queues of patients outside the doctor's consultation room, meant patients were hesitant to ask further questions of the doctors. The patient participants perceived that the existing care was insufficient in terms of supporting them to have more knowledge about their health care, assisting them in their diabetes, or in access to medications and the chance to have a discussion with doctors.

8.2.5 Poor patient outcomes

The theme of poor patient outcomes comprised 2 subthemes: lack of self-management awareness and practices and potentially harmful self-management practices. These subthemes point to the consequences of practicing diabetes care at home with patients having poor knowledge and a lack of awareness of self-management that impacted on clinical outcomes. This study did not intend to measure clinical outcomes; however, routine patient diabetes medical evaluation data such as BGL, HbA_{1C} values, diabetes complications, patient knowledge and self-management practices suggest poor patient clinical outcomes.

All patient participants in this study had at least one diabetes complication, with most having poor control over their BGLs with an average HbA_{1C} level of 7.3% (56 mmol/mol). Many factors were associated with these sub-optimal diabetes clinical outcomes, such as a lack of self-management of medication, diet and exercise, and psychological distress control resulting in hyperglycaemia, which over time can cause diabetes complications.

8.2.5.1 Lack of self-management awareness and practices

There were similarities in patient self-management awareness and practices evident from patient interviews in the *Puskesmas* and higher healthcare service facilities in the provincial and national hospitals. Most patients were not sure whether they had to self-manage their care at home. Following doctors' orders to take medications and commence a diabetes diet was a common patient response when discussing how they followed orders for self-care at home. Those patients who reported being more confident said that the lack of self-management of their diabetes care was due to alterations in their medications (either missing some dosages or not taking medications) and diet noncompliance.

Lack of self-management practices were similar among patients from the 3 healthcare services, which were due to the interruption of medication supply, absence of a personal care device such as a glucometer, and poor knowledge. Most patients who had undergone insulin therapy explained that their experiences in omitting insulin dosages or administration was due to the shortage of supply of insulin in the BPJS K pharmacies, or that they received fewer insulin dosages and number of needles than they were prescribed. A small number of patients who could afford to purchase the medication themselves did so, but this was not so for most of the patients interviewed. Most were pensioners, only a small number were still employed or supported by their children or family. Missed insulin doses and blood glucose self-monitoring tests were common among the patients, though they regularly visited the healthcare facilities. Most patients who were supposedly self-monitoring their blood glucose at home, did not as they did not have the glucometer or simply were not sure of the purpose. Others were not confident with their recording of the results; however, they took their documentation to the next hospital visit for the doctor to interpret.

Patients' self-management education was provided accidently based on a doctor's order and was taught as fragmented separate skills required for patients with T2DM. In 2 FGDs with HCPs in the provincial and national hospitals they suggested that self-management education was not delivered as a structured or planned patient-education program. Rather, patient self-management education was delivered spasmodically, dependent on the time availability of a nurse educator, and tended to provide patients with required skills of care such as how to perform an insulin injection, use a glucometer, perform foot care and select appropriate food choices. Little was provided that supported patients to manage their weight, or to understand their condition. Patient self-management education in the *Puskesmas* was provided by a nurse and a dietitian who were both untrained diabetes educators. Hence patients with T2DM across all healthcare services researched were not provided with sufficient knowledge or skills in self-management.

8.2.5.2 Potentially harmful self-management practices

Diabetes clinical outcomes were sub-optimal due to the patient having questionable understanding of their diabetes. This was combined with some patients adopting cures that were not prescribed by a medical doctor that could be detrimental. Some patients adjusted their insulin dosages without a doctor's recommendation or used low-calorie sweeteners to overcome hypoglycemia. Some patients who received multiple medications from multiple specialists were confused about the medications or dosage of insulin prescribed to them, but they did not have chance to clarify it with the doctors. Lack of facilities, too few personnel with minimal qualifications, and lack of time given to patients during clinical encounters and no patient-education sessions meant that the patients did not increase their knowledge and skills in diabetes self-management.

8.3 Chapter conclusion

The main themes of this case study suggest that the existing care provision for patients with T2DM to support patient self-management in Indonesia is faced with issues in resource management, healthcare provision management, medical dominance in the healthcare system and provision, communication gaps between patients and HCPs and poor patient outcomes. These issues consistently occurred at all the healthcare services. Issues were found at the level of the healthcare system, healthcare organisation and at the patient level. However, patients with T2DM were the most disempowered.

Government regulations for the healthcare finance system played a major role in determining how health care was provided and what care was to be covered as a priority. The scarcity of resources resulted in the HCPs providing a minimal standard of diabetes care provision including self-management patient-education programs. Additionally, the national program on chronic care management, PROLANIS, was introduced without preparing for the required infrastructure at the healthcare organisation level.

The approach used in the delivery of care was that of medical dominance with limited concerns for the patient as a whole. High patient–HCP ratios, and lack of credible diabetes educators seemed to contribute to the brief patient care provision at all of the healthcare services. The healthcare provision focused more on completing the government-targeted program rather than on patient outcomes, and left patients feeling disempowered to practice self-management. Most of the patients found the existing approach of HCP communication and care provision was not compatible with their needs as patients with chronic illnesses who relied on formal healthcare institutions for their diabetes care. In addition, the systems and the HCPs faced limitations to fulfil patient needs and expectations. The structural aspects of the healthcare provision shaped the interaction of the HCPs and patients.

The next chapter discusses the findings by drawing on the theoretical insights outlined in Chapter 3.

Chapter 9: Discussion

9.1 Introduction

The evidence presented in the results chapters from the 3 healthcare delivery sites shows that the structures of the Indonesian healthcare system situated patients with T2DM as lacking empowerment towards their self-management. The key themes identified in the case study presented in Chapter 8 were inadequate healthcare resources, poor healthcare organisational management, medical dominance, communication gaps and poor patient outcomes. These issues are interrelated and complex as they occur at every level of the healthcare institutions in the Indonesian healthcare system. Despite government support via the BPJS K, existing government chronic care programs such as PROLANIS and regulations introduced to increase greater access to diabetes care, patient outcomes were sub-optimal. This chapter discusses existing diabetes care for people with T2DM with all its challenges, drawing on critical theories in relation to chronic care, self-management and patient-empowerment concepts. Addressing the issues will provide a framework that could be followed for future research and models of care that support patient self-management within the context of chronic illness care.

Specifically, this chapter highlights the results of this study juxtaposed with the existing literature and discusses the results from the theoretical perspectives of critical theory, particularly Habermas's theory of communicative action: lifeworld and systems, and Honneth's theory of recognition, and concepts on patient empowerment and chronic care to improve patient self-management. The theoretical framework of empowering care for patients with T2DM to enhance self-management is based on a hybrid approach to Habermas's theory of communicative action, and Honneth's theory of recognition as described in Chapter 3.

The first part of this chapter presents the framework of patient empowerment to support self-management in the context of chronic care and maps out the themes under this framework. The framework is then used to discuss the main points emerging from this study.

9.2 Framework of patient-empowerment approach for supporting self-management in chronic care

As discussed in Chapter 3, the theoretical framework presents the influences of the Indonesian healthcare system (macro-level) and the healthcare organisation (meso-level) in supporting care for patients with T2DM. These factors are demonstrated using the hybrid concepts of Habermas's theory of communicative action, encompassing the lifeworld and systems, and Honneth 's theory of recognition at the level of the social in the struggle for recognition. At the micro-level of care clinical communication occurs between patients and HCPs and between healthcare team members from multidisciplinary professions. Both forms of communication should support patient self-management and can be explored from the perspective of intersubjective communication (the ideal of communication according to Habermas) and Honneth's theory of recognition.

Under this theoretical framework, the main themes were mapped to each relevant level (macro, meso or micro-level). The framework is portrayed as a 3-layered circle of empowerment drawing on elements of Wagner's chronic care model (Bodenheimer, Wagner, et al., 2002). As shown in Figure 9.1, the outer circle is the level of the healthcare system, the middle circle represents the level of healthcare organisation, and inner circles represent the spheres relating to patients and HCPs. The red line indicates communication gaps in care. The central arrow shows the strong and 2-way interaction between a collaborative HCP team and a patient that is required to achieve patient self-management processes, and the goals needed to improve personal and national outcomes in care. This is a patient-empowerment process achieved through communicative action. Patients and HCPs carry their own lifeworld that influences the interactions between them. The dash lines around the circles suggest that each circle is an open system and is influenced by the broader system represented by the larger circle.

Within the healthcare system, which is represented as the outermost circle, the health resources identified as lacking in this study were the inconsistency in healthcare payers and medical standards, high patient to HCP ratios, lack of access to better care provision and lack of appropriately qualified diabetes educators. The second layer, which represents healthcare organisations, identified a lack of collaboration between the HCPs, and a scarcity of structured patient-education programs with fragmented and discontinuity of care. Communication between HCPs and patients also occurred inside the circle of healthcare organisational management. The 2-way arrows represent an ideal clinical communication event (intersubjective communication) between HCPs and patients in the context of healthcare provision. The issues of medical dominance are mapped in the second layer and at the level of interaction with patients.

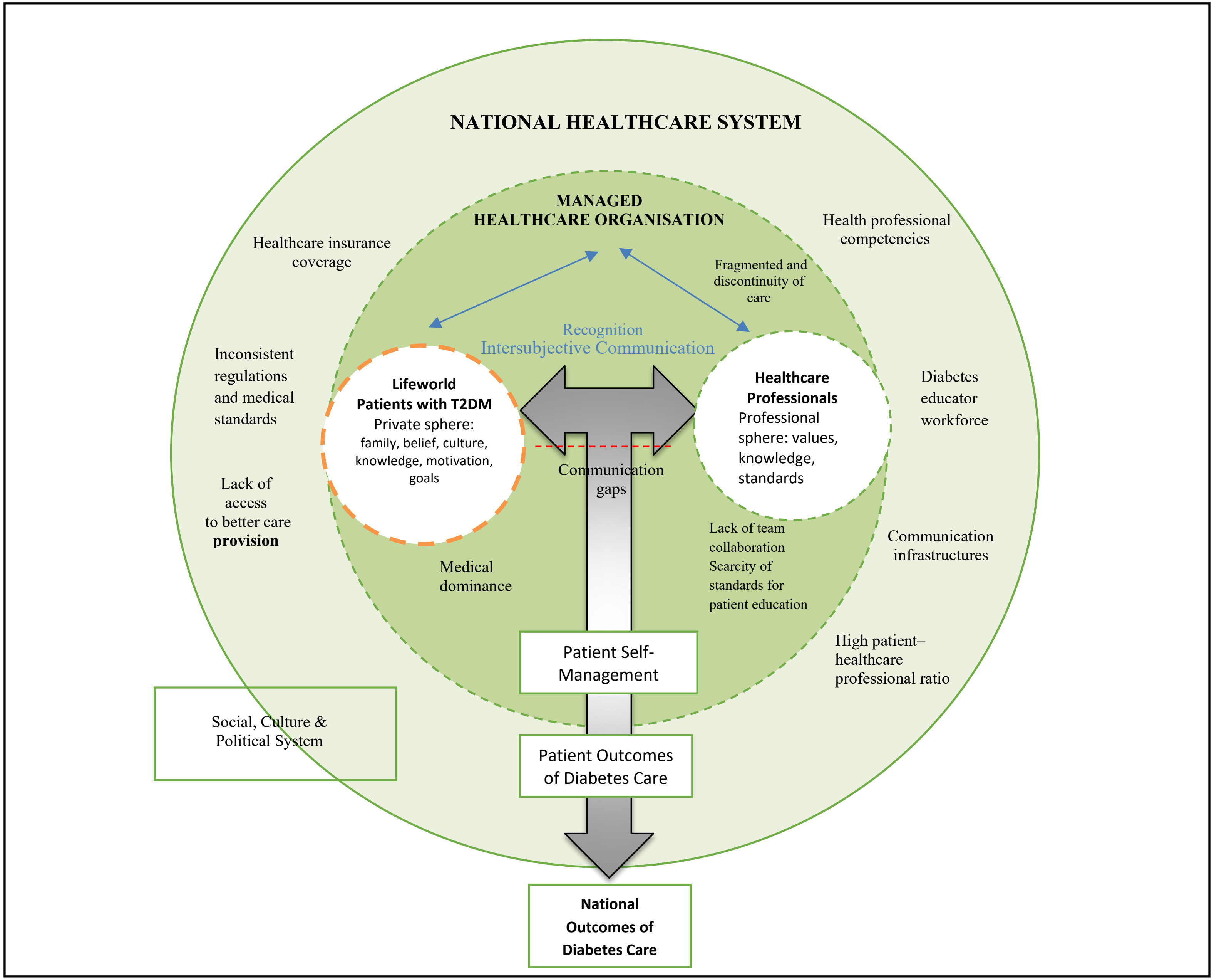


Figure 9.1: Framework of empowerment in care for patients with type 2 diabetes mellitus for self-management based on the hybrid of Habermas's theory of communicative action and Honneth's theory of recognition

9.3 Inadequate healthcare resources: Challenges in empowering patient self-management

A national healthcare system refers to the entire health sector of a country. It is comprised of networks of policies, programs, institutions and actors that provide clinical and health care, and organise efforts to treat and prevent disease (Lipsitz, 2012; Willis et al., 2016). The Indonesian national healthcare system has inadequate resources. Lack of resources was identified as the main challenge to empowering self-management for people with T2DM who were covered under the BPJS K. The key focus areas identified highlight the inconsistency between what the BPJS K covers and the clinical standards, high patient to HCP ratios, lack of appropriately qualified diabetes educators and lack of access to appropriate care provisions. The following sections discuss these issues.

9.3.1 Inconsistency between what the government's medical insurance covers and clinical standards

The Indonesian Government provides universal health cover (BPJS K). It is the largest single-payer system in the world (Agustina et al., 2019; Pratiwi et al., 2021). The system has improved accessibility to healthcare and enhanced treatment of non-communicable diseases (Agustina et al., 2019). Despite improvements in coverage, which reportedly reached nearly 70% of the total population in the first 4 years of its introduction in 2014 (Agustina et al., 2019), challenges remain that need to be addressed. This study identified inconsistencies between medical insurance payments with the guidelines on what is funded and the clinical standards set by doctors as best practice. These findings are similar to previous research. For example, lack of availability of certain drugs and medical supplies, poor health-information systems (Agustina et al., 2019); lack of utilisation of BPJS K and scarcity of healthcare services in remote areas of Indonesia (Pratiwi et al., 2021), and resistance from medical professionals (Erniaty & Harun, 2020) are among some of the problems previously identified within the BPJS K.

The implications of this study's findings and previous research highlight issues that impact patient outcomes. For example, the lack of integration between healthcare policies and management of patients can impede early detection of diabetes complications and related comorbidities. The Indonesian National Consensus on T2DM management (PERKENI, 2021). suggests that before patients are eligible for NPH insulin therapy they are required to have an HbA_{1C} >7% (53 mmol/mol). However, the BPJS K standard suggests a much higher value of HbA1C >9% (75 mmol/mol). Other prescribed medications such as the blood cholesterol lowering agent, simvastatin, require >130 mg/dl (3.362 mmol/L) from the patient's laboratory results on LDL values (Indonesian Health Ministry Decree, number HK.01 .07/MENKES/659/2017 on the National Formulary (Kementrian Kesehatan Republik Indonesia, 2019). This differs from the international medical standard, the American Diabetes Association and the Indonesian National Consensus on T2DM management (PERKENI, 2021), which indicate that patients require medication when LDL values are >70 mg/dl (1.8102 mmol/L). Controlling the level of LDL in patients with diabetes reduces the risk of developing heart disease complications (Koba et al., 2006). Given these discrepancies, in many cases patients are forced to purchase medications using their own money. If they cannot afford these medications, they simply go without; consequently their hypercholesterolemia remains untreated. The Indonesian Government's regulations governing the BPJS K fund does not sufficiently support patient self-management that would potentially reduce morbidity and mortality rates for diabetes. The discrepancy in clinical guidelines between what the insurance system recommends and what doctors believe is clinically required needs to be addressed to improve patient outcomes.

9.3.2 High patient to healthcare professional ratio

This study identified the high ratio of patients to HCPs in diabetes care clinics. According to The World Bank (2019), the patient–doctor ratio in Indonesia is the second highest in Southeast Asia. There were 0.4 doctors to 1,000 people in 2019, meaning that Indonesia had only 4 doctors to serve 10,000 people (World Bank, 2019). This number is far below that of Singapore, which had two doctors for every 1,000 people (World Bank, 2019). Beside doctors, Indonesia lacks sufficient nurses, with a ratio of nurses to people of 2 to 1,000 (The World Bank, 2019). No data exists on the number of diabetes educators including diabetes nurse educators. The ratio of patients to HCPs engaged in diabetes care is even higher at the secondary and tertiary healthcare institutions as there are limited facilities for diagnosis and care for patients with T2DM at the primary care level (Soewondo et al., 2013; WHO, 2016).

The data from this study confirm that the high workloads of the HCPs were due to the high number of patients to be served daily at every level of the healthcare system.

The high patient to HCP ratio observed in this study was a major deterrent to empowering patient self-management. The high ratio caused long wait times and insufficient time spent by the HCPs in clinical encounters with the patient in all 3 healthcare services. The limited time taken in the clinical encounters was the main challenge to empowering patients. Previous studies on patient empowerment indicate that patient empowerment is impeded by high workload of HCPs (Angwenyi et al., 2019), which is an antecedent of patient empowerment (Castro et al., 2016). Time available for comfortable clinician–patient interactions is an antecedent to providing an empowering process for patients. An empowering process is achieved through productive communication; it allows for an ideal form of communication within a chronic care model (Wagner & Groves, 2002). Both patients and HCPs perceived that there was limited time for HCPs to facilitate patient empowerment because of the high ratio of patients to HCPs. To assist in rectifying this deficit in care and improve patient empowerment, greater numbers of suitably qualified medical professionals need to be trained and employed. Additionally, alternative models of care need to be explored.

9.3.3 Lack of qualified diabetes educators

This study identified a scarcity in the number of qualified diabetes educators who attended patients within the existing care structures. Little has been reported about Indonesian diabetes nurse educators in the published English literature. In 2000, Sutanegara (2000) reported on the lack of diabetes nurse educators in Indonesia, but no further reports were published until 2013, some 13 years later. In 2013 (9 years ago) (Soewondo et al., 2013) reported that between 2008 and 2011, there were 61 nurses trained as diabetes educators. Local research studies mostly conducted by nursing students at bachelor or masters level used the term *diabetes educator*. From anecdotal evidence, the Indonesian diabetes educators referred to by nurses or dietitians were mostly not certified nor registered. Diabetes educator training is a 3-day training program provided by Indonesian diabetes educators society and sponsored by a pharmaceutical company for each level: basic, intermediate and advanced, a total of 9 days. Hence, diabetes educators are not considered professionals. Most diabetes educators were nurses or dietitians who were working as a diabetes educator as a part of their role. They were not specifically assigned as diabetes educators.

The complexity and challenges of having a chronic illness such as T2DM requires patients to make daily decisions in self-management (Powers et al., 2020). Hence, a professional diabetes educator is required to address the comprehensive clinical problems, psychological and behavioural aspects, and demands to support the patient in their self-management (Powers et al., 2020). Diabetes educators, such as those in the United States (Powers et al., 2020) and the Australian Diabetes Educators Association (ADEA, 2017) are nationally regulated and credentialled. In Australia, diabetes educators acquire their qualifications through an approved university-based diabetes specific postgraduate degree. Before attaining recognition as a credentialled diabetes educator, the HCPs complete a postgraduate certificate in diabetes education and management, which includes 1,000 hours of practice in diabetes education, a minimum of 6 months in a mentoring partnership and the submission of a referee report from a manager or supervisor that addresses the National Core Competencies for Credentialled Diabetes Educators (ADEA, 2017). With this training background, a qualified diabetes educator can attend to the patient's self-management needs and develop patient-education programs. In this study, diabetes educators were found to be undertrained, which contributed to the lack of patient self-management support. A university level postgraduate diabetes educator degree needs to be developed in Indonesia so that suitably qualified nurses can provide informed quality care that encourages patient self-empowerment strategies. This in turn could reduce the overall comorbidities associated with T2DM, and reduce the impact and costs on the Indonesian healthcare system.

9.3.4 Inadequate access to better care provision

This study found that patients with T2DM who were covered by the BPJS K faced inadequate access to quality care. Adequate access to resources is a basic requirement to support self-management (Nolte & McKee, 2008). Through their narratives the patients in this study demonstrated their powerlessness over the public healthcare services and the BPJS K coverage. The patients, especially those who were on a low income, with numerous medical conditions requiring multiple medications, and lack of access to private healthcare services (mainly due to their low-income status), were the most disadvantaged. This issue highlights the unavoidable conditions faced by patients as a result of being BPJS K users.

Minimum coverage of medical laboratory evaluations, particular types and certain dosages of medications, and limited flexibility or choices of the care in terms of appointment times for regular doctor visits, or doctor of choice, prevented the patients accessing good quality healthcare provision. For instance, for patients with T2DM, HbA1C should be tested every 3 months as this is an important diagnostic tool that provides accurate information about long-term blood glucose control, which is used as a basis for medication evaluations (Yazdanpanah et al., 2017), especially for patients with uncontrolled blood glucose (PERKENI,2021). However, the patients funded under the BPJS K were only eligible to have 6-monthly HbA_{1C} tests. The Indonesian healthcare coverage scheme should be equitable for all Indonesians, including providing access to quality care so that patients with T2DM can better manage their health. In turn, this would improve outcomes by minimising complications of diabetes that could be achieved with better support at the national level.

9.4 Poor healthcare provision management: Challenges of the healthcare delivery system

At the level of the healthcare organisation, a lack of effective management in the healthcare delivery system was identified as a challenge in empowering patient self-management. Sub-optimal management was evident by the lack of collaboration among diabetes team members, the scarcity of structured patient-education programs, and fragmented and discontinuity of care. It has long been held that the complexity of diabetes as a chronic illness requires models of care that support self-management (Coleman et al., 2009; Wagner et al., 1996). These issues are discussed further in the following sections.

9.4.1 Lack of healthcare team collaboration

Lack of healthcare team collaboration was evident in this study. A diabetes care team within the Indonesian healthcare context limited to medical doctors, nurses, dietitians and diabetes educators (nurses or dietitians) (Soewondo et al., 2013). However, this study identified that an underlying issue was a lack of collaboration at the managerial level of the institution that was evident in the time constraints and the orientation of program goals to meeting targets rather than addressing individual patient outcomes. The targets were not designed for chronic illness care needs, and the lack of qualified diabetes educators meant that the nurses were overwhelmed by the complexity of care, which in turn undermined their confidence as diabetes nurse educators.

Research from within Indonesia shows that the lack of healthcare team collaboration occurs in every setting: primary care (Yusra et al., 2019), acute care (Plummer & Copnell, 2016) and long-term care (Mediani et al., 2017). Healthcare team collaboration in diabetes care is more than sending a referral letter from doctors to nurses or dietitians for patients who require insulin injections, blood glucose monitoring skills or diet consultations as has been the case in diabetes care services. Each team member requires an understanding of the concepts of team collaboration in the context of chronic illness care. In general, team collaboration involves 2 or more people engaged in professional interaction, within a single episode or series of episodes, working towards common goals (Patel et al., 2012). The collaboration needs to occur between medical doctors at one side, with other HCPs at the other side (as it has been depicted as 2 opposite sides). Understanding potential opposite sides is required for perceiving diabetes as a chronic illness so that multidisciplinary team-based care in chronic care management is provided collaboratively.

One of the other challenges within teams that needs to be acknowledged is the power dynamics between the various members. While not formally studied in this research project, a factor impeding good communication between medical doctors, nurses and dietitians, is a culture of paternalism in the Indonesian culture that shapes interpersonal interactions (Mulyana & Verity, 2016). This culture results in unequal or hierarchical issues that can affect collaboration. Workplaces often maintain the idea of exercising power and control over others, rather than collaboration and mutually empowering relationships (Todic et al., 2022). Nurses are used to receiving and following doctors' orders rather than engaging in actions that are initiated by them and based on their professional competencies (Tang et al., 2013). In this study, the low levels of competency reported by the diabetes nurses and dietitian educators (as discussed in Section 9.3.3) were more likely to be the cause of the lack of healthcare team collaboration. Given this lack of competency, the diabetes educators' roles are not recognised in the Indonesian healthcare system, resulting in a lack of clinical autonomy that impacts on their capacity to work together with other healthcare team members to provide and manage care that supports patient self-management. This results in HCPs working independently. Thus, to work effectively as a team, members must be willing to suspend any background beliefs that one discipline is superior to another.

9.4.2 Scarcity of structured patient-education programs

This study identified a lack of structure for patient-education programs to support patient self-management in diabetes care provision. Where patient-education programs did exist, they were provided randomly, and focused on teaching patients self-injection techniques, self-blood glucose monitoring, diet management and foot care. These patient-education materials were listed in the national endocrinologist consensus of diabetes management for T2DM (PERKENI, 2021). This study found at all levels of the healthcare system, patient education was not programmed, structured, standardised or followed up by the diabetes educators.

This study identified that the patients had limited knowledge, awareness or understanding of self-management, and that this was related to a lack of standardised and structured patient-education programs in diabetes care in this Indonesian context. There is overwhelming evidence regarding the significance of patient education in managing T2DM. Improved outcomes from participating in patient-education programs are not limited to increases in knowledge. Self-management and empowerment improves, and biological parameters such as glucose and cholesterol levels stabilise. For instance, a meta-analysis study of educational interventions found an increase in glycaemic control (Ellis et al., 2004). Another study found that participation in patient education based on patient empowerment, or the X-PERT program, resulted in improved glycaemic control, reduced cholesterol levels, a more controlled diet, and increased self-empowerment and diabetes knowledge (Deakin et al., 2006). Additionally, a further study found providing structured management education had a significant impact on psychological outcomes (Jarvis et al., 2010). The results of these studies support the need for introducing a structured education program, especially one based on patient empowerment, in managing patients with T2DM in Indonesia.

Standards for patient diabetes education have been developed based on evidence. For instance, evidence from the longest and biggest diabetes prospective study in the world, the

UKPDS) highlights the importance of one-to-one education programs for patients with T2DM (Gallicban, 1999). Recommendations from the American Association of Diabetes Educators note that education programs should be complied with by diabetes educators, and actively involve all patients with diabetes in their self-management. These programs position the diabetes educators as advocates, encourage multidisciplinary team management and education, set treatment goals based on patient needs and willingness or ability to participate in the care, and outline strategies in patient education (Powers et al., 2020).

Standards for patient education are normally developed by professional organisations, for instance, established associations such as the American Association of Diabetes Educators and the ADEA. The ADEA standards related to diabetes patient education include standards on national competencies for credentialled diabetes educators, diabetes education programs, practice for credentialled diabetes educators, and the role and scope of practice for credentialled diabetes educators (ADEA, 2022). The standards for education programs, for instance, provide guidance on the quality of diabetes education programs, evaluation and improvement of the programs, assist in planning development and provide funding opportunities (ADEA, 2022).

The existing Indonesian national consensus of management for T2DM recommends that patient education is one of the 5 principles in management for patients with T2DM. The recommendation for the topics includes basic knowledge of diabetes and management, skills for blood glucose self-monitoring, insulin injections and foot care (PERKENI, 2021). The Indonesian national program to manage patients with chronic illnesses, specifically diabetes and hypertension at the primary healthcare level (PROLANIS), positions patient education as one of the strategies. However, patient education, as part of chronic illness management in diabetes care in the Indonesian context, has not been fully implemented by the government or practitioners. The recommendation from the consensus and strategy of the PROLANIS have not yet been followed by establishing standards for the programs, follow up, development or infrastructure. Therefore, advocacy is required to encourage stakeholders to implement recommendations based on sound scientific evidence that clearly demonstrate the importance of education programs that encourage self-empowered programs for people with T2DM.

9.4.3 Fragmented care and discontinuity of patient education

This study found that management of diabetes as a chronic illness is fragmented and lacks continuity of care. Lack of smooth and seamless management between the services, specialisations and sub-specialisations of medical care provision resulted in this fragmentation. Patients who had multiple chronic diseases, as is likely to occur for patients with diabetes, had to attend different specialisations for medical treatment without any coordination between the services. The findings of this study are consistent with other Indonesian studies that found that care for patients with cancer was fragmented (Haroen et al., 2021). Another Indonesian study, by Limardi et al. (2019), also found fragmentation of care; in that study the care was provided to children living with HIV in need of palliative care. Additionally, in a scoping review on elderly care services in Hong Kong, Singapore, Malaysia and Indonesia, care in services for the elderly were fragmented (He & Tang, 2021). Overall, care, regardless of the context, is fragmented in the Indonesian context.

To meet the challenge of chronic illness, complex models of care involving collaboration between professions and institutions are required (Nolte & McKee, 2008). One of the approaches that could be adopted to respond to this fragmentation is an integrated care model (Nolte & McKee, 2008). Chronic care policies in many developed countries such as Australia, Canada the United Kingdom and Germany, have been influenced by this framework (Nolte & McKee, 2008). A chronic care model developed by (Wagner et al., 1996) is one influential framework for integrated care (Nolte & McKee, 2008) (see Chapter 1 for an overview of the chronic care model).

The findings demonstrate that the Indonesian healthcare system lacks patient-management support (lack of education programs), a delivery system design where multidisciplinary diabetes teams might work collectively, insufficient clinical information systems and a lack of decision support where standards and guidelines are adhered to. While at the level of patient–HCP interaction, the approach used by the HCPs in communication were more strategic than communicative action. Studies exploring the chronic care model in the Indonesian context are scarce. The Indonesian policy on the management of chronic illness focuses on regulation of the delegation of responsibility to provincial governments (related to the decentralisation system) in preventing and managing chronic illnesses (Kemenkes, 2015). The PROLANIS, which the government claimed was an integrated system that involves patients, HCPs and BPJS K in providing healthcare services for patients with chronic illnesses, was implemented with little consideration of the qualifications of the HCP workforce, standards or guidelines. The success of the program is mainly measured through the number of participants and activities rather than patient outcomes. Given the rising number of people with chronic illnesses in Indonesia, lack of infrastructure for optimal healthcare communication, and the poor referral systems adopted, ensuring the integration and continuity of care is a challenge in the Indonesian healthcare system. Further research needs to be conducted to explore the best way forward to rectify the deficits that currently exist.

9.5 Medical dominance: communication approaches used in the existing care

Early literature on the term *medical dominance* suggested different understandings of its meaning. More recently, there has been a decline in in the term's popularity within the sociological literature (Willis, 2006). Medical dominance was popularised by Freidson in the 1970s as a general term used for describing the power of the medical profession to have control over its own works, and the work of other HCPs (Coburn, 2006). This included control over the allocation of health resources, health policy and the way hospitals are run (Coburn, 2015; Coburn & Willis, 2000; Germov, 2013). In relation to patient–HCP relationships, especially with doctors, the dominant behaviour of doctors is also discussed in the literature (Mast, 2004). In contrast, Navarro in Coburn (2015) argues that medicine was not, and is not, dominant, but rather has a great deal of power, but was previously, and continues to be, dependent on the power of the dominant class. Despite these conflicting concepts, both are relevant in explaining the power of medicine as a factor in curtailing patient empowerment of diabetes care in the Indonesian context.

Drawing on the definition of medical dominance provided by Freidson (Coburn, 2015; Coburn & Willis, 2000; Germov, 2013), medical dominance can be demonstrated in the approach to diabetes care in Indonesia in 3 areas: 1) doctors' roles are assigned in the interest of state (the Indonesian Government); 2) doctors control the work of other HCPs (especially nurses and dietitians); and 3) doctors have control over patients during clinical encounters. The following section illuminates the features of medical dominance identified in this study in relation to the previous concepts of medical dominance, including rationales of the underlying contexts, which are discussed from the theoretical framework of this study; the hybrid of Habermas's communicative action and Honneth's recognition theories.

9.5.1 Doctors decide all care

The first feature of medical dominance in this study was that doctors were assigned a greater role in comparison to other HCPs and acted as gatekeepers in referring patients to more specialist care and approving simple laboratory tests such as blood glucose tests. Without the referral letter from a doctor, a patient covered by the BPJS K was not eligible to be referred for specialist care or have their blood laboratory tests performed. As in many countries with state funded medical insurance schemes, doctors act in the interest of the state by reducing referrals to more expensive care within the system.

Second, medical dominance was evident in how doctors decided what care the patient would receive by controlling patient access to dietitians and education consultations with diabetes educators. An internal referral was required from a doctor for patients to be eligible for consultations or patient education provided by a dietitian or a diabetes educator nurse. This is a form of medical dominance over the work of other HCPs (Germov, 2018), in this case nurses and dietitians. Only doctors, under the Indonesian healthcare system, are allowed to refer a patient with BPJS K healthcare insurance to specialist care and provide approval for laboratory testing. This role is universally recognised as a doctor's clinical autonomy (Germov, 2018).

Third, medical dominance was evident at the level of patient–HCP clinical encounters where doctors, especially, approached a patient's problems from a purely medical perspective. This form of medical dominance is known as the medicalisation of everyday life. Medicalisation is referred to as a process by which social phenomena come to be perceived and treated as illnesses (Ballard & Elston, 2005). There are 3 levels of medicalisation: 1) the conceptual level, where medical language is used to define the problem; 2) the institutional level, where medical collaboration with other authorities is used to gain legitimacy over management of the problem: and 3) the level of interaction between a patient and doctor where the patient's problem is defined as medical, and medical treatment is administered (Busfield, 2017). This study found that doctors continuously dominated clinical encounters at all levels of the healthcare system for patients with T2DM in this Indonesian context.

Similar results from studies on medical dominance in care provision have been reported in different healthcare settings in Indonesia. These include those of Mediani et al. (2017), who raised the issue of a lack of autonomy for nurses to manage paediatric pain; Darmayani et al. (2020) on stereotyping of the medical professions, where doctors were perceived to be the dominant profession among other HCPs; and Suryanto et al. (2016); Trisyani and Windsor (2019), in emergency care settings where professional collaboration was hampered by knowledge and power gaps between physicians and nurses. Those studies support the findings of this study; those issues of medical dominance still occur in the provision of Indonesian healthcare.

The dominance of doctors is acquired through professional autonomy, which includes political, economic and clinical autonomy (Germov, 2019). Like other parts of the world, in this study doctors practised clinical autonomy in diagnosing and treating. A doctor's clinical abilities are recognised by the state; in this case, the healthcare system acknowledges the clinical autonomy of doctors to refer patients to specialist care and laboratory testing. The doctors in these situations are representatives of the Indonesian Government (BPJS K) in controlling access of patients to specialist care, laboratory tests, and services from dietitians and diabetes educators. Besides clinical autonomy, the professional dominance of doctors is due to their ability to exert control over the knowledge base and occupational territory of other health professions; the requirement that doctors request and supervise the work of other health practitioners; and the unequal public status of medicine compared to other health professions (Germov, 2013).

Social class, power structures within the healthcare system and cultural components in society (Coburn, 2006, 2015) contribute to the dominance of doctors in the care of people with diabetes in Indonesia. This is influenced by the long history of the medical profession in Indonesia. Historically, doctors in Indonesia, and in many other countries, are perceived as an affluent profession. During the colonial period, Indonesian doctors participated in political movements and engaged in national politics (Pols, 2018). Indonesian physicians engaged publicly in debates; published articles; joined political parties, organisations and social movements; and became members of city councils and the colonial parliament, thereby strengthening the Indonesian medical profession and advocating health policies (Pols, 2018). After independence, these nationalist physicians continued to take significant roles in government by becoming Indonesia's national physicians and building Indonesia's healthcare system in close association with the state (Pols, 2018). Further, even though there is a scarcity of academic publications regarding the domination of doctors in the Indonesian healthcare system, information provided in the Indonesian Health Ministry webpage shows that the medical profession in the Indonesian healthcare system is overrepresented in bureaucracies compared to other allied health science professionals (Kemenkes, 2016) and high-level hospital management, such as in a national hospital (RSCM, 2017).

In contrast, historically nurses in Indonesia are regarded as doctor's helpers (van Ameijde, 2007). Further, information on how Indonesian nurses developed their profession and engaged in social and political activities is minimal. However, since the declaration of the Nursing Act number 38 regarding the Nursing Profession in 2014, the profession is seen as legitimate (*Undang-Undang Keperawatan, No. 38, 2014*). Under this Act, nurses are allowed to run their own independent practices, or in other healthcare facilities, to provide nursing care that includes patient education, consultation and counselling (*Undang-Undang Keperawatan, No. 38, 2014*, article 30(1)). The nursing legislation implies that it has its own clinical autonomy to practice in relation to patients. With this professional autonomy, nurses, including those providing diabetes education and care, have been recognised by the state as legitimate under the Nursing Act. Additionally, nursing in Indonesia is acknowledged as a profession with attributes of professionalism, as noted by Germov (2013), which includes educational qualifications that are university-based, its own body of knowledge and its own codes of ethics. However, based on formal education, doctors study for 6 years while other HCPs study for between 3 and 5 years. Therefore, doctors are perceived to have more knowledge compared to nurses or dietitians. Medical domination, or the perceived power of doctors (Conburn, 2015) over nursing practices in Indonesia still exists in the care of people with diabetes, as shown in this study of nursing practice in the healthcare facilities, community healthcare centres and hospitals.

9.5.2 Medicalisation of all care

The medicalisation of all care identified from observations in clinical encounters was recognised by the patients. The clinical encounters, especially with doctors, were based on BGL results, and medically dominant topics such as increasing medication dosages or informing patients about their diabetes complications. In these encounters, patient self-management, including psychosocial aspects of care, were rarely discussed or were limited, and psychosocial problems were driven by medical topics and treated as medical concerns.

The issue of using an entirely medical approach in the management of chronic care illnesses is that this approach is not sufficient for interpreting the complexity of a patient's everyday life and other personal circumstances (Nolte & McKee, 2008). Medicalisation of care in this study was interpreted as a result of the interplay among a dominant paradigm (the medical paradigm), the doctor's professional image in Indonesia (powerful profession) the country's social structure, and the organisation and management of care (such as time and space barriers). The medical positivistic paradigm is insufficient in understanding human and social elements (Scambler & Britten, 2013), but it is still the dominant form of care. Medical knowledge, which is rooted in the positivistic paradigm, is used as the basis for dealing with patient concerns as well as for determining the interventions required to treat these concerns. Given doctors are historically well known as the dominant profession in the Indonesian healthcare context (Mulyana & Verity, 2016), communication during clinical encounters is driven by them. Further, the 3–10-minute interaction in a clinical encounter for a patient with T2DM was insufficient to cover other concerns the patients had as there was only time to focus on the patient's medical problems. Therefore, models of care on how to deliver more holistic care in a time-poor environment need to be explored.

9.6 Communication gaps

Ideal communication between a patient and an HCP is conceptualised by Habermas as communicative action (Lafont, 2018), or empowered communication (Nolte & McKee, 2008; Palumbo, 2017) is central to an effective chronic healthcare system (see Figure 9.1 in Section 9.2). The communication that occurs between a patient and an HCP aims to achieve better diabetes outcomes for patients. This study found gaps in patient–HCP communication during clinical encounters. These gaps were outlined within the subthemes of limited health literacy and different patient–HCP expectations. The communication between patients and HCPs did not address either patient or HCP purposes. Since the communication gaps noted in this study were consistently observed and reported by both the patients and HCPs across the healthcare services, it is clearly of major concern, especially when attempting to support patients towards self-management.

Gaps in communication in patient–HCP interactions has not been widely explored in the existing research in the Indonesian context. Among the issues observed were, for instance, doctors adopting strategic action rather than communicative action (Sindhvananda, 2011) and holistic care being challenged by the biomedical approach in patient–doctor communications (Hoppenot et al., 2021; Porter, 1997). Examples from the literature in the Indonesian context show that doctors use a paternalistic style in communicating during clinical encounters (Claramita et al., 2011) and do not provide the patient with time to discuss issues of concern or for the doctor to provide health education (Joseph-Williams et al., 2014). Regardless of the underlying causes (structural, social, cultural, or combinations of all) of the communication gaps between patients and HCPs, there are conceptual and empirical ongoing issues in healthcare provision, including in diabetes care, in the Indonesian context. Ongoing education regarding communication strategies for HCPs may assist in addressing some of the deficits in this area.

9.6.1 Limited health literacy

Limited health literacy is a problem worldwide (Nutbeam, 2008). In this study, limited patient health literacy was regarded by the HCPs as a barrier to patient empowerment and self-management. Health literacy skills refer to a patient’s ability to engage in healthcare information and to navigate the system (Friis et al., 2016; Ladin et al., 2017; Nutbeam, 2008; Palumbo, 2017). Although there has been little research in this area in Indonesia, a systematic review on the impact of the lack of health literacy in the Indonesian context suggests that it has a positive correlation with self-management for patients with chronic renal diseases (Suarilah & Lin, 2022), that inadequate skills and knowledge about diabetes causes misunderstandings about diabetes self-management (Pamungkas et al., 2019) and that there were improvements in health outcomes with health literacy interventions for patients with hypertension (Samsiana et al., 2021). These studies suggest that limited health literacy is not uncommon among patients in Indonesia and interventions for the improvement of patient health literacy increases patient health outcomes.

This study identified two circumstances related to the potential causes of limited health literacy among patients with T2DM who visited the public healthcare services (the outpatient clinic at the community healthcare centre, a provincial hospital and a national hospital). First, limited health literacy came from the lack of health education sourced from the healthcare providers. Most of the patient participants reported that they did not receive any information about diabetes care from the HCPs; rather, what information they did have came from their own searching or from family members who also had diabetes, from word-of-mouth, friends or television. Based on the research framework (see Figure 9.1 in Section 9.2), the healthcare institution did not provide a structured patient-education program.

Second, the majority of the patients who acquired lay knowledge were surrounded by a lifeworld of myths, misperceptions, religious interpretations, cultural misunderstandings, or experiences about diabetes and diabetes care. Hence, the potential for patients to acquire misinformation that was detrimental to their health was high. For instance, people in a study from a rural community in central Java believed that it was impossible for them to have diabetes as no one in their family had diabetes (Pujilestari et al., 2014), and in a study of people in a rural area near Bali the patients believed that diabetes was caused by black magic (*amah leak)* (Asril et al., 2019). These studies provide evidence that misunderstandings and myths are still prevalent in people with diabetes in Indonesia, influencing patients in making decisions for their self-management. The misunderstandings and myths about diabetes and its care among the patient participants in this study reflected a lack of exposure to credible diabetes information sourced from the HCPs or outside healthcare institutions. Unfortunately, even though HCPs have long recognised that lay people may have faulty views on the causes of illness (Scambler, 2001), education about diabetes was neglected by the HCPs and was a barrier to empowering patient self-management.

Limited health literacy contributed to the communication gaps between patients and HCPs. The limited health literacy observed in this study and its contribution to the communication gaps can be viewed as an imbalance of power between patients and HCPs. Distortions in communication between patients and doctors can be explained from Habermas's work on the concept of the relationship between lay and expert knowledge (Williams & Pay, 2013). Doctors were knowledgeable in the medical sciences, including about diabetes care, while the patients had limited knowledge about the medical science on diabetes. Further, the patients, who were considered as lay people, had their own lay knowledge about health (Williams & Pay, 2013). While there was a power imbalance, in this case the doctors' expert knowledge was considered as more powerful than patient knowledge, then the distortion of communication potential occurred as the communication was driven by the more powerful one, in this case doctors. The HCPs, in this case doctors, then *distorted* (the term used by (Scambler, 2001) communication towards the best patient outcomes, which was usually biomedical parameters (BGLs for patients with diabetes).

In contrast to the patients' lifeworld, which in this case was their lay knowledge, the medical knowledge used by doctors during the clinical encounters is based on a positivist paradigm that claims objectivity (in this study, diabetes as a disease) (Scambler & Britten, 2013). Moreover, given the time and resource constraints, the HCPs tended to complete the interaction with patients by performing strategic actions with purpose and rationale to overcome medically acute conditions of patients rather than engaging with communicative action where patient knowledge and concerns were the basis of collaborative goals. Hence there was a clash between the 2 paradigms (patient's health belief and doctor's medical knowledge) causing communication gaps between patients and HCPs in diabetes care provision.

Patients who were literate were not necessarily empowered (Náfrádi et al., 2018; Palumbo, 2017). Patient empowerment is determined by multidimensional factors (Palumbo, 2017). Although these are 2 distinctive concepts (Schulz & Nakamoto, 2013), health literacy is conceptualised as the major component for enhancing patient empowerment (Palumbo, 2017). Patient empowerment is determined by the interplay of personal and institutional determinants (Palumbo, 2017). In this study, there were constraints in healthcare provision related to the management of resources, such as insufficient time and space for effective therapeutic clinical encounters to address the issues and gaps in communication caused by limited health literacy.

As health literacy underpins a patient's ability to analyse information and to use the analysis to gain control over life events and situations, the skills allow a person to derive meaning from available information and to use that information to exercise greater control of, and responsibility for, their health (Nutbeam, 2008). The problems of limited health literacy among the patients in the Indonesian healthcare context leads to the patients engaging in unreliable and false information, influencing their decisions towards health self-management. Moreover, when the healthcare system and HCPs viewed this as being a patient issue, they provided less support to overcome the issues, further reducing patient empowerment in self-management. Continuing education is required to update all HCPs on evidence-based knowledge regarding the issues around health literacy, and programs need to be developed to address the deficits in this area.

9.6.2 Differences in patient and healthcare professional expectations

This study found different expectations between patients and HCPs in the clinical encounters and identified gaps in communication. Clinical communication between a patient and HCP are key to improving patient outcomes as demonstrated in research (Kourakos et al., 2018). Most of the patients in this study expected doctors to have the time to listen to their concerns rather than simply prescribing medication and referring them for laboratory tests. The patients wanted to be listened to without judgement, and treated kindly. On the other hand, due to time constraints, HCPs, mainly doctors, expected patients to comply with their advice and treatment prescribed without discussion or explanation.

However, it was unlikely patients would openly show disagreement or dissatisfaction with the HCPs. At this point consideration needs to be given to the cultural influences in the Indonesian patriarchal society that inherently influences the views held by patients and HCPs. These influences subliminally impact on patient and HCP views during clinical encounters, given patients' lack of health literacy, low socioeconomic background and cultural traditions. These views shaped the patient's lifeworld, and are sometimes contradictory to the HCP's professional lifeworld or healthcare system (in this case the patients were required to adhere the medical programs that were not necessarily based on the patient's interest) (Scambler, 2001; Scambler & Britten, 2013). Patients might still comply with the doctor's advice by becoming passively compliant with their self-management and engaging at a very low state of self-management (Nolte & McKee, 2008). Directing the communications to a doctor's goal preferences about a patient's problems results in a distortion in communications (Vandenburgh, 2004), patient dissatisfaction, suppression and deception (Kalateh et al., 2016), and a feeling of being overwhelmed by their psychosocial problems (Jensen et al., 2020). In contrast, while giving voice to the patient's lifeworld, previous studies demonstrate that doctors can gain more understanding of patient problems (Leanza et al., 2013); and collaborative treatment decision-making (Ravn Jakobsen et al., 2021). Hence, empowering communication between patients and HCPs has the potential to improve patient outcomes. Continuing education programs need to be developed based on the best available evidence that presents known successful strategies that improve communication between patients and HCPs.

9.7 Poor patient outcomes

This study identified 2 sub-optimal patient outcomes in diabetes care: lack of self-management awareness and practices, and potentially harmful self-management practices. Although it was not the intention of this study to measure the levels of patient self-management, the patient and HCP narratives indicated a lack of awareness and practices of patient self-management. Moreover, because of the lack of knowledge, the patients engaged in high-risk self-management practices that were based on their lay knowledge rather than knowledge gained from a healthcare institution. Lack of knowledge was not the only possible factor related to lack of patient self-management. The scarcity of healthcare resources, poorly managed care provision and communication gaps were also identified in this study. This section discusses how the healthcare systems, including the HCPs, recognised, situated and supported self-management as part of patient outcomes.

9.7.1 Lack of self-management awareness and practices

This study identified a lack of self-management awareness and practice. Previous studies also report similar issues of sub-optimal levels of self-management in patients with T2DM in the Indonesian context. For example, a qualitative study of diabetes self-management among patients with T2DM in West Sulawesi-Indonesia, found that most patients lacked knowledge and motivation for self-management, which was identified as a barrier (Pamungkas et al., 2019). Another study, a cross-sectional study on predictors of self-management in patients with T2DM, reported that 68% of the patients had low self-management on the Summary of Self-Care Activity scale (Kurnia et al., 2017).

According to Bodenheimer, Lorig, et al., (2002), self-management is inevitable for patients with chronic illnesses. Other authors also support this concept, reporting that practicing self-management results in better patient outcomes that are not limited to a patient's biomedical laboratory results (Davies et al., 2015; Deakin et al., 2005; Funnell et al., 2004), but also include psychological outcomes (Chai et al., 2018; Steed et al., 2003; Vandenbosch et al., 2018). Selected Indonesian context studies in the integrative review (see Chapter 2) demonstrate positive outcomes from self-management practices for patients with T2DM.

The term *self-management* was not referred to in any of the published guidelines or standards of care in the Indonesian diabetes care context. In the international guidelines, such as in the IDF, ADEA, and the American Diabetes Association for instance, patient self-management is referred to in the standards of diabetes care. In the Indonesian context of diabetes specifically, the purpose of diabetes care management, as recommended by the Indonesian endocrinologists society in the Guidelines for Prevention and Management of Patients with T2DM, is to improve quality of life, reduce symptoms, complications, morbidity and mortality (PERKENI, 2021). These targets focus on biological aspects of care and include enhancing patient knowledge about basic diabetes care and management, self-glucose monitoring, and diabetes foot care (PERKENI, 2021). Patient education is one of the pillars among the 5 recommended by PERKENI (2021) for diabetes management, which include education, diet, exercise, oral diabetes medications and insulin. Hence, patient education in the Indonesian context is positioned as prominent in patient management, based on these Indonesian guidelines for diabetes management.

However, diabetes self-management has not been used as a parameter for assessing patient outcomes in diabetes care. Physical and laboratory parameters are mainly used to measure patient outcomes. For instance, the most common evaluation of patient outcomes from previous epidemiological studies, such as in Soewondo et al. (2013), report that most patients with T2DM in Indonesia had uncontrolled BGLs, high complications and high mortality rates. Assessing self-management can provide insight into patient behavioural issues when managing their diabetes (Schmitt et al., 2016) and facilitate patient self-efficacy (Bodenheimer, Lorig, et al., 2002).

9.7.2 Potentially harmful self-management practices

Lack of awareness and practices of patient self-management among the patients in this study were reflected in their biomedical profiles. The patients' biomedical profiles in this study showed that the majority of them had uncontrolled BGLs and had one or more diabetes complications (see Table 5.1 in Section 5.1, Table 6.1 in Section 6.1 and Table 7.1 in Section 7.3.1). These profiles were similar to the national data, showing that the majority of patients have not achieved the national target of diabetes care, which in turn, results in higher mortality rates from the complications of diabetes (Soewondo et al., 2013). The goals of chronic care entails enhancing a patient's functional status, minimising distressing syndromes, providing secondary prevention and enhancing quality of life (Grumbach, 2003). These goals are recommended through acute care provision; however, the existing care mainly focused on interventions related to biological issues. Support for patient self-management was neglected. Education and training programs need to be developed that encompass the principals of self-empowerment strategies and practices that are tailored to the Indonesian context so that long-term outcomes for patients with T2DM are improved.

9.8 Conclusion

To conclude this discussion, the results of this study demonstrate that the existing care for patients with T2DM who were supported under the BPJS K health cover and who sought healthcare within the public healthcare system in Indonesia were still operating with the focus on the clinical treatment of diabetes. This is a traditional medical approach where medication provision is the primary approach, and the patient is positioned as an object in this healthcare system. The concept of patient participation in their care, to encourage self-empowerment as has been identified in developed healthcare systems in many developed countries, has been proposed. However, this concept is a challenge in the existing Indonesian system.

Self-empowered care is challenged by interrelated and complex issues, which include the scarcity of healthcare resources at the national healthcare system level, insufficient healthcare organisational management within the system, medical dominance and gaps in communication at the patient–HCP relationship level. The sub-optimal patient outcomes of awareness and practices of self-management reflect the sub-optimal performance of the existing healthcare system for supporting patient self-management.

The underlying concerns of the existing approach to diabetes care have been categorised into 3 main interlinked issues. First, the issue of structural constraints, which include inadequate resources in the healthcare system, lack of efficient organisational management and undertrained diabetes educators, are major impediments. Under these structural constraints diabetes healthcare is delivered using strategic actions that focus on government mandates and medical programs rather than communicative actions that advocate for the needs of patients with chronic illnesses. Second, the approach to care used by the HCPs highlights that these HCPs engage in an outdated traditional medical approach where the patient is treated as a sick person who is required to comply with medical programs regardless of whether they have sufficient knowledge or self-management skills. The patient’s psychological and social aspects are not included as a focus of the care, important aspects related to the patient’s lifeworld that impact their self-management behaviour. Finally, the patients and HCPs view empowerment at different levels, which creates different expectations of the care provided. For the patients, empowering them was not limited to providing them with sufficient knowledge and skills for adhering to medical treatment, but also to engaging in detail during clinical encounters so that they could discuss their health concerns (laboratory test results, medications provided and prognosis). Additionally, understanding their personal lifeworld that had been impacted by the disease and treatment program was important to them. For the HCPs, however, who engaged in a traditional medical approach, the concept of empowering patients was perceived as only providing patients with patient education about diabetes, complications and treatments. The HCPs expected the patients to have high health literacy levels and to comply with the education provided.

A patient-empowerment approach and chronic care model for managing patients with T2DM proposed for the Indonesian healthcare system is supported by the evidence presented in this case study. Patients’ voices from across the 3 levels of healthcare services favour an empowerment approach (to have explanations, be listened to and respected, and be involved in their care planning). As discussed in this chapter, positioning patients in a partnership care focused approach will result not just in improvements in their biological marker outcomes, but also in their satisfaction with the care and quality of life. This infers that the existing healthcare system needs to be adapted if this patient-empowerment approach is to be considered.

The next chapter presents the summary of this research, including the implications that contribute to the body of knowledge, healthcare policy, practices and future research. The recommendations are then outlined, and the limitations of this study presented, concluding this case study project.

Chapter 10: Conclusion and Recommendations

10.1 Introduction

Patients with T2DM need to make knowledgeable decisions regarding self-management on a daily basis. The findings of this study support the criticality of self-management in managing chronic illnesses such as diabetes. However, little is known about how patients in Indonesia with T2DM are supported in their diabetes care. This concluding chapter outlines how the research questions and sub-questions were addressed; the contribution of this research to the body of knowledge about empowerment and supporting self-management for people with T2DM; the implications of this research; and the recommendations for transforming healthcare policy and diabetes care practices to empower patient self-management in Indonesia, including proposing further research projects. The chapter concludes with a discussion of the strengths and limitations of this research.

Previous studies regarding diabetes care for patients with T2DM in the Indonesian context have mostly employed a positivism research paradigm, predominantly epidemiological research. This paradigm is limited to capturing and interpreting T2DM patients' biomarker performances such as HbA_{1C}, cholesterol (triglycerides, HDL, LDL) and applying statistical correlation methods to the therapy used or to other physical parameters. This research approach restricts in-depth understanding of patients with T2DM in the context of chronic care and how best to empower patients towards self-management.

This thesis explored patient-empowerment methods for those with T2DM in the Indonesian context (which is experiencing rapidly increasing numbers of diabetes cases) at the level of patient–HCP interactions and the impact of interventions to support self-management on medical outcomes. Previous studies on interventions employed to improve diabetes outcomes overlooked the larger systems, such as the healthcare system and the organisation of healthcare, that contribute to diabetes outcomes.

Critical theories, specifically Habermas's communicative action and Honneth's recognition theories, were adopted in this study to provide a philosophical, methodological and theoretical framework to critically understand the care provided for patients with T2DM in supporting self-management in the Indonesian context. A single embedded unit of analysis case study method was applied to this research as the strategy to comprehensively explore diabetes care in the Indonesian context. A qualitative interpretive research methodology was applied.

This research is noteworthy in demonstrating a comprehensive exploration in understanding how patients with T2DM are cared for and supported in the context of the Indonesian healthcare system. The research critically identified challenges in supporting patient self-management at the level of the national healthcare system, healthcare institutions, and patient–HCP interactions. Existing diabetes care provision across the healthcare services was shown to be lacking in empowering patient self-management due to inadequate resources. The national healthcare insurance scheme failed to provide essential prescribed medications, the required number of insulin pen needles and laboratory tests recommended by medical standards. Furthermore, time constraints due to high patient–HCP ratios and the low competencies of diabetes educators led to inadequate access to better diabetes care. Empowering patient self-management was also hampered by the inefficiencies of the management of the healthcare institution, which saw a lack of collaboration among the diabetes care team members, scarcity of patient-education programs and fragmented care.

Medical dominance driven by the structure of the healthcare system, and historical and cultural factors influencing the interaction between doctors and nurses or dietitians and doctors and patients demonstrated that medical staff made all the decisions, resulting in the medicalisation of all care. Doctor–patient communication in clinical encounters was poor, with many communication gaps. This was partly caused by limited patient health literacy and different expectations between patients and HCPs. Thus, patients with T2DM were disempowered in knowledge about, awareness of, and the practice of self-management. The findings are important for patients with T2DM, HCPs, policymakers and stakeholders engaged in healthcare management for patients with T2DM.

10.2 Addressing the research questions

The following outlines how this study addressed the research questions and sub-questions.

1. What approach is currently used in the care of people with T2DM in Indonesia to support self-management?

The healthcare system is still adopting a traditional medical approach for acute medical conditions where the care is highly focused on medical treatment by providing medication and performing medical tests. This approach is contrary to the empowerment approach in supporting patient self-management. The findings in this study suggest that diabetes care in Indonesia does not operate under the chronic illness care approach.

a. What are the features of the existing model of care?
   - The existing model of care employs a traditional medical approach.
   - The government policy on health cover is not in line with medical standards of care. Consequently, the patients received low standards of medical care.
   - There is a lack of flexibility for patients to schedule appointments or to choose specialists.
   - There is a high ratio of patients to HCPs that results in pressure for patients and HCPs.
   - There is a lack of collaboration among the diabetes healthcare team members.
   - The nurses are assigned to administrative and instrumental tasks.
   - Doctors are the dominant professionals providing diabetes care, and they control the work of other HCPs.
   - There is a lack of support for clinical decision-making due to the scarcity of standards, guideline or protocols, such as standards in diabetes education.
   - Healthcare provision is fragmented and based on medical specialisation rather than integrated care.
   - Care lacks coordination as there is very little communication within the system or among the healthcare providers. The only communication is through a

referral letter, which is limited to medical diagnosis and treatment. This referral letter is also a burden for patients due to not utilising technology in communication systems among the healthcare providers.

- Diabetes care provision is provided by underqualified diabetes educators.
- Diabetes outcomes are defined in terms of the biomedical parameters, which consequently neglect patient self-management, and psychological and social welfare.

b. What existing programs support diabetes self-management?

There are few effective programs supporting patient self-management. Patient-education programs are not structured, standardised, nor followed up by the diabetes care team. Self-management programs are not offered or developed seriously in existing diabetes care.

c. How would patients and HCPs frame self-management and empowerment for patients withT2DM?

Both patients and HCPs agree that self-management and empowerment are important in diabetes care, but as yet they do not exist. However, patients and HCPs have different expectations about what they want. Patients expect to get detailed information about their medical conditions and how to self-manage their diabetes from doctors. At this point, patients expect to have some involvement in their care, while doctors believe patients lack adequate health literacy, creating a barrier to supporting patient self-management and empowerment.

d. How does communication between patients and HCPs support patient self-management?

Disempowering features of communication include: 1) communication with HCPs, which was brief and directed to the patient’s medical problems, disregarding their concerns about self-management, psychological and social problems; 2) communication with HCPs was superficial and lacked details that would have explained patient conditions; 3) communication with HCPs encouraged patients to adhere to medical advice; 4) patients lacked adequate health literacy and an awareness of the skills in self-management.

2. If there was general support for adopting a patient empowerment approach to improve patient self-management, what would be the characteristics of this care?

The approach currently used is not suitable for patients with chronic illness care, which should support self-management. Chronic illness models of patient care were designed to assist patients to manage their care based on their needs and their chronic health problems. Although the scientific evidence shows the effectiveness of these models in developed countries, the findings of this study identified challenges that must be addressed. The existing model of care has some components of chronic care models, but improvements are required.

The Indonesian healthcare system has the potential to adopt a chronic care model if it overcomes the identified barriers or challenges by listening to patient and HCP voices. The research framework of this study (see Figure 9.1) offered characteristics of the model of care that potentially could be adopted in the Indonesian healthcare system. The model of care would include the following characteristics:

- financially supported evidence-based medical standards
- well-equipped and adequate numbers of staff (doctors, nurses, dietitians, and probably expanded to other allied professionals such as pharmacists, psychologists, social workers) and highly competent diabetes educators
- a collaborative team design for care
- supportive decision-making through developing clinical standards and guidelines
- improved clinical communication and information-based technology systems across all levels of the healthcare system
- supported patient-education programs
- supported empowerment approaches in clinical interactions with patients through shifting the HCP paradigm from instructions to be more facilitating and advocating the principles in communicative action.

10.3 Significant contributions of this study to the body of knowledge

This study provided a comprehensive investigation into the challenges of providing diabetes care that supports patient self-management in the Indonesian context. A critical point of view was provided, in contrast to the majority of previous studies on diabetes care in the Indonesian context that employed a positivist research paradigm evident in the research designs applied, such as cross-sectional research or quasi experimental research. The positivistic research paradigm could only partially lead to understanding the concepts of patient empowerment, self-management and chronic illness care in diabetes care. Applying a critical ontology allows a greater understanding of the potential aspects that drive daily care practices.

10.4 Implications and recommendations

This research has implications for related healthcare policies, the clinical practice of diabetes care, education of medical and other healthcare professions, and future research. The implications and the recommendations presented below are structured in accordance with the characteristics of diabetes care models that would improve patient self-management as discussed above.

10.4.1 Transforming policies

Implications

The findings of this study raised issues and awareness for policymakers about the discrepancy between the BPJS K coverage and medical standards, and the reduction in doctors' clinical autonomy to provide the best medical practice, and lack of flexibility for patients to access healthcare facilities in terms of their time and schedules. All of these contribute to a patient's self-management practices.

Recommendations

1. Policymakers to examine the gaps in the national healthcare coverage that results in reduced access to a better diabetes care and patient self-management. This would include

increasing access for BPJS K care and more involvement of private labs and pharmacies in providing care.

2. Policymakers to revisit the existing BPJS K policy regarding the discrepancy between the coverage provided under the scheme and medical standards to fully cover essential medicine and increase access to medical devices such as glucometers and needle pens.
3. Policymakers to evaluate regulation and policy on government healthcare insurance in accordance with medical standards so that the care reaches optimum medical standards.
4. Policymakers to revisit regulations regarding the flexibility of patients to access the care of the specialists and the locations they prefer. This might improve patient involvement in the care that supports self-management.
5. The Indonesian Government to resource BPJS K to cover payment for patient-education and self-management support programs.
6. The Indonesian Government to regulate credible diabetes educators in patient care.
7. The Indonesian Government to ensure healthcare services are established according to medical standards and goals and include care of the patients' psychological and social needs.
8. The Indonesian Government to evaluate the PROLANIS program, which should not be limited to evaluating activities as the targets, but rather seek patient-centred outcomes.
9. The researcher to disseminate the results of this study in local and international journals
10. The researcher to collaborate with related healthcare professionals organisations in diabetes care in Indonesia to hold conferences, scientific and strategic discussions to follow up the recommendations of this study.

10.4.2 Transforming the diabetes care team workforce

Implications

The research framework and findings of this study suggest more highly competent diabetes educators are required to drive diabetes care management, including patient-education programs, in supporting patient self-management. The findings also suggest the complexity of patient needs, especially when they require treatment from multiple medical specialties. Many patients were overwhelmed with the medical treatments they needed, and required the care of pharmacists, psychologists and social workers. These HCPs should be members of diabetes care team.

Recommendations

1. Policy makers, HCPs, stakeholders to redesign training programs for diabetes educators to be recognised at the university level (diabetes educator postgraduate certificate). It is expected that highly trained diabetes educators could confidently perform patient-education programs and conduct research in the area of diabetes education in order to improve practice and care. Future research and training projects with Flinders University as a collaborative partner would be considered to follow up this recommendation.
2. Policy makers, HCPs, stakeholders to involve other allied HCPs as members of diabetes care teams in order to accommodate holistic patient care that addresses physiological and social wellbeing as well as the physical condition.
3. Policy makers, HCPs, stakeholders to consider a benchmarking program in diabetes educator training in Indonesia with programs from other countries, such as Australia, America and European countries.

10.4.3 Shifting the paradigm in clinical diabetes care practice from acute to chronic focused care

Implications

The research framework and the findings of this study suggest that the existing practice of diabetes care is oriented towards acute care. It provides medical treatment and undermines patient education and self-management. By shifting the paradigm to a patient-centred care/patient-empowerment/holistic-care approach based on collaboration, a strong program could be developed. This would require patient education to support self-management, a strong role for diabetes educators in the management of care, productive HCP–patient communication, a one-stop integrated care plan, and information and technology solutions that ensure continuity of patient care.

Recommendations

1. Healthcare professionals to redesign the model of diabetes care using a chronic care approach.
2. Policy makers, HCPs, stakeholders to involve more stakeholders in the design of a future model of practice.
3. Policy makers, HCPs, stakeholders to design a standard for diabetes care that focuses on the management of diabetes.
4. Universities and accredited training centres to integrate communicative action strategies, knowledge and skills into training for HCPs.

10.4.4 Strengthen clinical provision management

Implications

This study found problems in diabetes care that had its origins in poor management at the level of diabetes care provision, raising issues about the healthcare delivery institutions and systems.

Recommendations

1. Policy makers, HCPs, stakeholders to re-engineer clinical care to integrate and ensure continuity of patient care from service to service.
2. Healthcare professionals to strengthen diabetes team communication.
3. Policy makers, HCPs, stakeholders to introduce the use of technology-based services to ensure effective appointment systems for patients, and to overcome long queues and waiting times for patients.
4. Healthcare professionals to redesign patient-education programs based on developed standards conducted by qualified diabetes educators.
5. Universities and accredited training centres to provide more training for doctors and nurses on team collaboration.
6. Healthcare professionals to design standard programs for self-management screening and patient education.
7. Hospital management to facilitate physical conditions so that clinical encounters with HCPs are more conducive to self-management.
8. Policy makers, HCPs, and stakeholders to invite the private sector to diabetes care program development.
9. Policy makers, HCPs, and stakeholders to map the number of doctors and diabetes educators required.
10. Policy makers to increase the coverage of healthcare, including patient training for self-management.

10.4.5 Conduct future research

Implications

The research framework used in this study can be considered as a first step in using critical theory frameworks to analyse diabetes care in the Indonesian context. This theory has not been used extensively by Indonesian nursing and other allied HCP researchers. As shown in this study, the framework allows a wider and more comprehensive perspective in understanding diabetes care in the Indonesian context. The following is recommendations areas for the future research.

Recommendations

1. Conduct more critical studies using critical theory frameworks to understand policy and care, and the impact on patient outcomes.
2. Conduct action research in developing a suitable chronic care model for diabetes care.
3. Conduct research that employs more case study designs, such as comparative designs of diabetes care between private and public health care institutions.
4. Explore patient psychological wellbeing related to the care provided.
5. Explore in-depth issues of safety and effective care delivered in diabetes care.
6. Explore supports to self-mangement practices in weight management
7. Conduct research into patient-education program models.
8. Conduct research into the role and practice of complementary and alternative therapy in diabetes self-management.
9. Conduct studies on conceptual analysis to strengthen the research framework based on the hybrid of Habermas's theory of communicative action and Honneth's theory of recognition.
10. Conduct research on diabetes care and patient empowerment in the private sector context.
11. Conduct research on diabetes care and patient empowerment in the remote area context.
12. Conduct research on diabetes team collaboration in supporting patient self-management.
13. Conduct a multidisciplinary study on diabetes care using chronic care perspectives.
14. Conduct an action research project as a follow up of this exploratory research.

10.5 Study strengths and limitations

Among other previous studies in the area of diabetes care in the Indonesian context, this study has strengths from the philosophical stance, and the methodology and research strategy applied, which allowed a comprehensive exploration of how patients with T2DM are supported towards self-management of their care in the Indonesian context. From the philosophical stance and methodological approach, this study critically explored diabetes care directly with the people involved in diabetes self-management and diabetes care (patients with T2DM and HCPs). This study's strength also comes from the research strategy applied, which was a qualitative single case study with embedded or multiple units of analysis. Using this strategy allowed a comprehensive investigation of diabetes care, using various methods of data collection in the natural settings that covered primary, secondary and tertiary services. All the phenomena gathered from the natural settings were then explained in the context of the Indonesian healthcare system. Hence, this study gathered critical and comprehensive understanding of the whole system.

The limitations of this study also need to be considered. First, this study employed a qualitative case study, which methodologically was not intended to make a generalisation of the results of diabetes care to support patient self-management in the Indonesian context. Rather, the results can be explained within the context of the case study sites. Second, this study was limited to the scope of urban and sub-urban settings and involving government or public healthcare services and patients who used the national healthcare insurance scheme. Thus, this study was not representative of private diabetes care cases, nor Indonesia as a whole, which involves many remote healthcare facilities and diverse geographical challenges. However, diabetes care in the participating national hospital in this study is considered a national benchmark for diabetes care for other services around Indonesia. Care may differ for those patients who seek care in private healthcare facilities and are covered under private healthcare insurance. However, for patients who lack health literacy about their diabetes, and who seek care in the public system, much will be recognisable.

Finally, much of the data collection process was conducted during the COVID-19 pandemic where the participating HCPs, patients and hospitals were under pressure. During the patient interviews for instance, the COVID-19 conditions impacted on the supply of medications at the pharmacies and the number of staff assigned on a daily basis. These interruptions were also recorded in this study. However, the problem of discontinuity of medication supply was also captured in other research sites used in this study before the pandemic. The COVID-19 pandemic was recorded in the site vignette used as the context for this study that impacted patients more in terms of medication supplies.

By appraising the strengths and limitations of this study, future research based on this study should be conducted with a wider scope of the settings and healthcare stakeholders using action research methodology as recommended in Section 10.3.5. At the end of all the related research conducted, patients with T2DM must benefit the most.

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Appendix 1 List of integrative review articles

No.	References	Country of Origin	Aims of Study	Research Design	Underlying Concepts	Findings
1	Hassali, Ching & Yusoff, et. al (2014)	Malaysia	To gain insight into T2DM patients' perceptions & beliefs about the use of Insulin	Phenomenological	Bandura's self-efficacy theory	Themes: Perception about use of insulin Psychological barriers & fear Lack of self-efficacy
2	Saidi, Milnes, & Griffiths (2018)	Malaysia	To explore self-care & self-care support in patients with T2DM in urban Malaysia	A single embedded qualitative case study	Not reported	Themes: Fatalism Faith Fear
3	Lundberg & Thrakul S (2018)	Thailand	To explore self-care management of Thai Buddhists & Muslims with T2DM & inadequate blood glucose levels	An explorative qualitative study	The health belief model	Themes: Becoming a self-care management practitioner, changing daily self-care, Support from family members & social network, & Preventing complications by self-care
4	Lee, Wong, Tan, Sheridan & Janie (2018)	Malaysia	To explore the experiences & views of individuals with T2DM on their diabetes self-management & potential roles for community pharmacists in diabetes self-management education & support (DSME/S) in Malaysia	A qualitative study	Not reported	Themes: Experience & perception of diabetes self-management, Constraints of the current healthcare system, Perception of the community pharmacist & community pharmacies, Perceived roles for community pharmacists in diabetes care, & Challenges in utilising community pharmacies to provide DSME/S

No.	References	Country of Origin	Aims of Study	Research Design	Underlying Concepts	Findings
5	Pamungkas et al. (2021)	Indonesia	To explore the potentially unmet needs of family function to support diabetes self-management (DSM) practices.	Phenomenology	Not reported	Six core themes, with sub-themes critical unmet needs of family function include: 1) Lack of problem-solving skills to deal with poor diabetes management; 2) Ineffective communication and refusal to share the burden of diabetes management; 3) Lack of affective responsiveness to encourage patients' compliance; 4) Lack of affective involvement in DSM; 5) Insufficient family roles in supporting patients; 6) Poor behaviour control of T2DM
6	Yasa , Rahayu, & Widastra (2018)	Indonesia	To explore the barrier of diabetes self-care management to T2DM patients in urban living	Phenomenology-Descriptive phenomenology	Not reported	Themes: Factors related to be the barriers of diabetes self-care management, Lack of knowledge of diabetes management, Lack of glycaemic control & Complications of diabetes
7	Ku & Kegels (2014)	Philippines	To investigate differences in diabetes knowledge, attitudes & perceptions (KAP), self-care practices as related to assessment of chronic illness care among people with diabetes	Cross-sectional	Not reported	Differences in knowledge, attitudes, perceptions, PACIC, utilisation of health services, & adherence to medications & exercise were all statistically significant

No.	References	Country of Origin	Aims of Study	Research Design	Underlying Concepts	Findings
8	Thojampa S, Mawn B (2017)	Thailand	To examine the impact of self-management activities on HbA_{1c} for persons with DM & to examine the impact of social support, self-efficacy & Buddhist values as moderators on the relationship between the self-management activities & HbA_{1c}	Cross-sectional	Social Cognitive Theory	Diabetes self-management activities were more strongly associated with HbA_{1c} under conditions of high social support, self-efficacy & health beliefs with Buddhist values
9	Gunggu, Ching Thon, & Lian (2016)	Malaysia	To determine the predictors for DSM	Cross-sectional	Not reported	Significant linear relationship between DSM & belief in treatment effectiveness, family support, & self-efficacy
10	Kurnia, Amatayakul & Karuncharernpanit (2015)	Indonesia	To identify factors predicting diabetes self-management among adults with T2DM in Malang City, East Java, Indonesia	Cross-sectional	Pender's Health Promotion Model	The significant predictors of diabetes self-management were treatment, perceived self-efficacy, & situational influences
11	Ku & Kegels (2014)	Philippines	To measure factors that could be associated with self-management practices of people with T2DM in terms of diabetes knowledge, attitudes, perceptions of support & self-efficacy, & obesity/adiposity	Cross-sectional	Bandura’s Self-efficacy and Social Cognitive Theory	Differences in knowledge, attitudes, perceptions, & some demographic characteristics between the two health systems & between those with high/ low self-efficacy perceptions were significant. Perceived self-efficacy was significantly associated with all four self-management practices

No.	References	Country of Origin	Aims of Study	Research Design	Underlying Concepts	Findings
12	Tharek, Ramli, & Whitford et al. (2018)	Malaysia	To determine the levels of self-efficacy, self-care behaviour & glycaemic control among patients with T2DM in the Malaysian primary care setting ii) determine the relationship between self-efficacy, self-care behaviour & glycaemic control iii) determine the factors associated with glycaemic control	Cross-sectional	Not reported	There was a moderate positive correlation between self-efficacy & self-care behaviour. A weak negative relationship was found between self-efficacy & HbA_{1c}
13	Khuzaimah, Sharoni & Hassan et. al (2015)	Malaysia	To determine the health- related quality of life & to examine the relationship between social support, distress level, & diabetes self-management towards quality of life among the diabetic elderly who had poor glycaemic control	Cross-sectional	Not reported	Social support gave a significant positive affect towards quality of life; distress and diabetes self-management gave significant negative affects towards quality of life. The respondents with good quality of life had better social support and lower distress level
14	Khuzaimah, , Aini, & Padma, et al. (2014)	Malaysia	To determine the level of self-care behaviour & to examine the differences in self-care behaviour according to T2DM patients' demographic data & health condition	Cross sectional	Not reported (self-care behaviour)	The level of self-care behaviour was moderately high. There were significant differences between self-care behaviour & ethnicity
15	Devarajooh & Chinna (2017)	Malaysia	To examine a conceptual model regarding the association between depression, diabetes distress & self-efficacy with diabetes self-care practices using the partial least square approach of structural equation modelling	Cross sectional	Not reported (self-care self-efficacy)	Self-efficacy had a direct effect on diabetes self-care practice. Self-care was not directly affected by depression & diabetes distress, but indirectly by depression & diabetes distress self-efficacy

No.	References	Country of Origin	Aims of Study	Research Design	Underlying Concepts	Findings
16	Ishak, Yusoff & Rahman, et al. (2017)	Malaysia	To describe diabetes self-care among elderly diabetics & to determine its associated factors	Cross sectional	Not reported (self-care)	Elderly individuals with T2DM have a moderate score of diabetes self-care practice. Determinants for good diabetes self-care include race, social support, having caretakers during periods of illness, diabetes knowledge, & diabetic microvascular complications.
17	Kueh, Morris & Ismail (2017)	Malaysia	To examine the effect of diabetes knowledge & attitudes on self-management & quality of life (QoL) of people T2DM	Cross sectional	Not reported	Diabetes knowledge was a significant predictor of attitudes & self-management (BG monitoring & foot care). Attitudes was a significant predictor of impact of QoL. Self-management (BG monitoring) was a significant predictor of impact of QoL & diet was a significant predictor of satisfaction & impact of QoL
18	Amelia, Lelo, & LIndarto, et al. (2018)	Indonesia	To determine the factors that significantly affect the self-care behaviours of T2DM patients	Cross sectional	Self-care behaviour	Factors that build & shape the self-care behaviour of patients with T2DM: motivation, communication, self-efficacy, family support, financing, attitude, & knowledge

No.	References	Country of Origin	Aims of Study	Research Design	Underlying Concepts	Findings
19	Amelia (2018)	Indonesia	To determine the model of self-care behaviour in T2DM patients in Binjai City (2) to analyse the effect of self-care behaviour on quality of life, metabolic control & lipid control of T2DM patients in Binjai City	Cross sectional	Self-care behaviour	All factors that build T2DM patient self-care behaviour were able to be predictors that shape the patient's self-care behaviour. The self-care behaviour model consists of knowledge, attitudes, communication, financing, family support, motivation, & self-efficacy. Motivation is the most significant predictor of its contribution to the self-care behaviour
20	Yee, Said, & Manaf (2018)	Malaysia	To determine the self-care behaviour, its associated factors & predictors among T2DM patients in government health clinics at a district of Northern Peninsular Malaysia	Cross sectional	Health Belief Model	The predictors of self-care behaviour were self-efficacy, knowledge; female combination oral hypoglycaemic agents (OHA) & insulin & monthly income. The entire group of variables significantly predicted self-care behaviour
21	Samrongthong & Kumar (2018)	Thailand	To explore factors associated with knowledge, perception, & practice towards self-care among elderly type 2 diabetes mellitus patients aged 50–70 years	A cross-sectional study design	Not reported	A significant different existed between gender with Hba$_{1c}$ (<0.05), knowledge, & work status with Hba$_{1c}$ (<0.05)
22	Abbasi, See, and Ping, et al. (2018)	Malaysia	To assess the level of diabetes KAP among T2DM with associated & correlated factors	Cross-sectional	Not reported	Age, academic qualification, occupation, monthly income, current therapy type, comorbid diseases, & therapy preference were associated with KAP

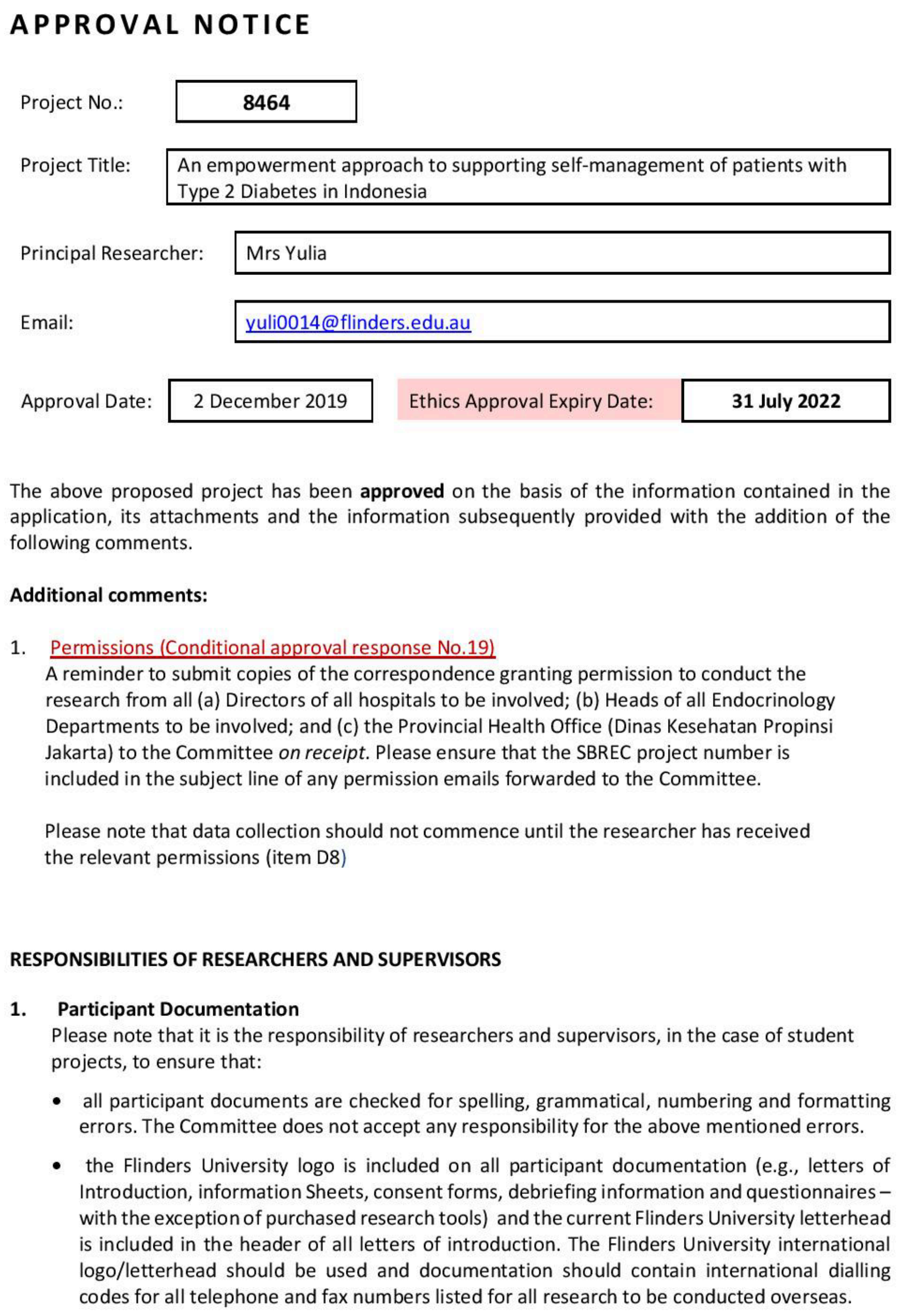
No.	References	Country of Origin	Aims of Study	Research Design	Underlying Concepts	Findings
23	Samsudin,Thambiah,& Asyraf (2015)	Malaysia	To assess patients with T2DM on their awareness of HbA_{1c} & the factors associated with their understanding of HbA_{1c}	Cross-sectional	Not reported	No significant association between HbA_{1c} understanding & glycaemic control, although more patients with good HbA_{1c} understanding had achieved the target glycaemic control compared to those with poor understanding.
24	Boonsatean, Wimonrut, Carlsson Anna, Rosner Irena Dychawy, and Östman, Margareta	Thailand	To investigate the illness perception and self-management among Thai women and Thai men with T2DM & to investigate the psychometric properties of the translated instruments used	Cross-sectional	Not reported	The Thai sociocultural context may influence people's perceptions and affect the self-care activities of Thai individuals, both women and men, with T2DM, Intervention programs that aim to improve the effectiveness of the self-management of Thai people with diabetes might consider a holistic and sex-related approach as well as incorporating Buddhist beliefs
25	Rusdiana, Savira, & Amelia	Indonesia	To evaluate the effect of short-term diabetes self-management education (DSME) on HbA1 & Fasting Blood Sugar in type 2 diabetes mellitus patients attending the Primary Health Care in Binjai city of North Sumatera, Indonesia	Quasi Experiment	Diabetes self-management education	A significant reduction in HbA_{1c} levels. A significant difference of HbA_{1c} value between pre and post-education patients with T2DM

No.	References	Country of Origin	Aims of Study	Research Design	Underlying Concepts	Findings
26	Khuzaimah, Sharoni, Rahman, and Minhat et. al (2016)	Malaysia	To assess the feasibility, acceptability & potential impact of the self-efficacy education program on improving foot self-care behaviour among older patients with diabetes in a public long-term care institution	Quasi Experiment	Self-care behaviour Self-efficacy	The acceptability rate was moderately high. At postintervention, foot self-care behaviour ($p < 0.001$), foot self-efficacy (efficacy-expectation), ($p < 0.001$), foot care outcome expectation ($p < 0.001$), knowledge of foot care ($p < 0.001$), quality of life (physical symptoms) ($p = 0.003$), fasting blood glucose ($p = 0.010$), foot hygiene ($p = 0.030$) and anhidrosis ($p = 0.020$) showed significant improvement
27	Susilparat, Pattaraarchachai S, Songchitsomboon, Ongroongruang (2014)	Southern Thailand	To study outcomes of the specific health care services that providing health education in parallel with counselling by Islamic leader	Quasi Experiment	Health education	Both mean systolic & diastolic blood pressure were well controlled in both groups & slightly decreased after Ramadan. The mean diastolic blood pressure of the experimental group decreased after Ramadan. The patients in the experimental group had consumed less sweetened food.
28	Saengcharoen & Musleemanukul & Lerkiatbundit (2016)	Southern Thailand	To evaluate the effect on diabetic care of an educational DVD in Jawi, the primary spoken language of Muslims in the study area, & pharmacist intervention among Muslim patients with diabetes treated with insulin	Quasi Experiment	Not reported	The combination of language-specific educational DVD & pharmacist intervention appears to improve the short-term outcomes of diabetes care in Muslim patients on correctional insulin therapy

No.	References	Country of Origin	Aims of Study	Research Design	Underlying Concepts	Findings
29	Damhudi et al. (2021)	Indonesia	To evaluate the effect of modified diabetes self-management education and support on self-care and quality of Life among patients with diabetic foot Ulcers in rural area of Indonesia	Quasi Experiment	Not reported	The adapted DSMES was more effective than standard care at improving self-care and QoL and decreasing DFU degree in this sample of Indonesians with DFU, both immediately after and 3 months after the intervention.
30	Chung, Chua, Lai, Chan 2014	Malaysia	To assess the effects of a pharmaceutical care (PC) model on medication adherence and glycaemic levels of people with type 2 diabetes mellitus	RCT	Not reported	Statistically significant differences in FBG and HbA1C values were observed between the control and intervention groups at months 4, 8, and 12 after the provision of PC. Medication adherence was significantly associated with the provision of PC
31	Ramli, Selvarajah, & Daud et al. (2016)	Malaysia	To evaluate the effectiveness of EMPOWER-PAR intervention (based on the chronic care model) in improving clinical outcomes for T2DM using readily available resources in the Malaysian public primary care setting	A pragmatic, cluster-randomised, parallel, matched pair, controlled trial	Chronic care management Chronic care model	Change in the proportion of patients achieving HbA_{1c} < 6.5%, proportion of patients achieving targets for blood pressure, lipid profile, body mass index & waist circumference
32	Jaipakdee,j Jiamjarasrangsi, &Lohsoonthorn, & Lertmaharit (2015)	Thailand	To compare the HbA_{1c} level, health behaviour, depression, & QoL between people with diabetes receiving a DSMS program with CAI & those receiving the routine care	RCT	Diabetes self-management support	Hb A1c, fasting plasma glucose, health behaviours and quality of life were significantly improved in intervention compared to control group

No.	References	Country of Origin	Aims of Study	Research Design	Underlying Concepts	Findings
33	Chinh, Thanasilp, and Preechawong (2017)	Vietnam	To test the effect of the supportive educative nursing program on glycaemic control in Vietnamese patients with uncontrolled T2DM	RCT	Self-care	The mean score of HbA1C level after 3 months in the experimental group was lower than that of the control group. There was a significant higher proportion of glycaemic control level in the experimental group than that of the control group
34	Suwaree, Arunya and Buranarach, et al. (2015)	Thailand	To assess the effectiveness of an IMM technology intervention in increasing self-management support T2DM patients in a 3-month period	Cluster-RCT	Self-management Self- efficacy	Significant difference in A1c level between the groups the self-care management score increased in both groups, but the increase was significantly higher in the intervention group
35	Wibowo, Y., Parson, R., Sunderland., and Hughes, J. (2015)	Indonesia	To investigate, current use of pharmacy services in Indonesia by patients with T2DM, & to evaluate their views regarding community pharmacists' roles, & the characteristics that influence the views	Survey	Not reported	There were mixed views towards pharmacists providing services beyond dispensing

Appendix 2 Final ethics approval from Flinders University



APPROVAL NOTICE

Project No.: **8464**

Project Title: An empowerment approach to supporting self-management of patients with Type 2 Diabetes in Indonesia

Principal Researcher: Mrs Yulia

Email: yuli0014@flinders.edu.au

Approval Date: 2 December 2019

Ethics Approval Expiry Date: **31 July 2022**

The above proposed project has been **approved** on the basis of the information contained in the application, its attachments and the information subsequently provided with the addition of the following comments.

Additional comments:

1. Permissions (Conditional approval response No.19)
   A reminder to submit copies of the correspondence granting permission to conduct the research from all (a) Directors of all hospitals to be involved; (b) Heads of all Endocrinology Departments to be involved; and (c) the Provincial Health Office (Dinas Kesehatan Propinsi Jakarta) to the Committee *on receipt*. Please ensure that the SBREC project number is included in the subject line of any permission emails forwarded to the Committee.

   Please note that data collection should not commence until the researcher has received the relevant permissions (item D8)

RESPONSIBILITIES OF RESEARCHERS AND SUPERVISORS

1. Participant Documentation

Please note that it is the responsibility of researchers and supervisors, in the case of student projects, to ensure that:

- all participant documents are checked for spelling, grammatical, numbering and formatting errors. The Committee does not accept any responsibility for the above mentioned errors.
- the Flinders University logo is included on all participant documentation (e.g., letters of Introduction, information Sheets, consent forms, debriefing information and questionnaires – with the exception of purchased research tools) and the current Flinders University letterhead is included in the header of all letters of introduction. The Flinders University international logo/letterhead should be used and documentation should contain international dialling codes for all telephone and fax numbers listed for all research to be conducted overseas.

- the SBREC contact details, listed below, are included in the footer of all letters of introduction and information sheets.

  This research project has been approved by the Flinders University Social and Behavioural Research Ethics Committee (Project Number 'INSERT PROJECT No. here following approval'). For more information regarding ethics approval of the project the Executive Officer of the Committee can be contacted by telephone on 8201 3116, by fax on 8201 2035 or by email human.researchethics@flinders.edu.au.

2. Annual Progress / Final Reports

In order to comply with the monitoring requirements of the *National Statement on Ethical Conduct in Human Research 2007 (updated 2018)* an annual progress report must be submitted each year on the **2 December** (approval anniversary date) for the duration of the ethics approval using the report template available from the Managing Your Ethics Approval web page.

Please note that no data collection can be undertaken after the ethics approval expiry date listed at the top of this notice. If data is collected after expiry, it will not be covered in terms of ethics. It is the responsibility of the researcher to ensure that annual progress reports are submitted on time; and that no data is collected after ethics has expired.

If the project is completed *before* ethics approval has expired please ensure a final report is submitted immediately. If ethics approval for your project expires please either submit (1) a final report; or (2) an extension of time request (using the modification request form).

First Report due date:	**2 December 2020**
Final Report due date:	**31 July 2022**

Student Projects
For student projects, the SBREC recommends that current ethics approval is maintained until a student's thesis has been submitted, assessed and finalised. This is to protect the student in the event that reviewers recommend that additional data be collected from participants.

3. Modifications to Project

Modifications to the project must not proceed until approval has been obtained from the Ethics Committee. Such proposed changes / modifications include:

- change of project title;
- change to research team (e.g., additions, removals, researchers and supervisors)
- changes to research objectives;
- changes to research protocol;
- changes to participant recruitment methods;
- changes / additions to source(s) of participants;
- changes of procedures used to seek informed consent;
- changes to reimbursements provided to participants;
- changes to information / documents to be given to potential participants;
- changes to research tools (e.g., survey, interview questions, focus group questions etc);
- extensions of time (i.e. to extend the period of ethics approval past current expiry date).

To notify the Committee of any proposed modifications to the project please submit a Modification Request Form available from the Managing Your Ethics Approval SBREC web page. Download the form from the website every time a new modification request is submitted to ensure that the most recent form is used. Please note that extension of time requests should be submitted prior to the Ethics Approval Expiry Date listed on this notice.

Change of Contact Details
If the contact details of researchers, listed in the approved application, change please notify the Committee so that the details can be updated in our system. A modification request is not required to change your contact details; but would be if a new researcher needs to be added on to the research / supervisory team.

4. Adverse Events and/or Complaints

Researchers should advise the Executive Officer of the Ethics Committee on 08 8201-3116 or human.researchethics@flinders.edu.au immediately if:

- any complaints regarding the research are received;
- a serious or unexpected adverse event occurs that effects participants;
- an unforeseen event occurs that may affect the ethical acceptability of the project.

Kind regards
Andrea

Andrea Mather and Rae Tyler (Mon, Wed and Fri morning)
Human Research Ethics Officers (Social and Behavioural Research Ethics Committee)
Research Development and Support

Union Basement Building
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Flinders University Research Development and Support
Proactively supporting our Research

Appendix 3 Final ethics from National Hospital

Content removed for privacy reason.

Appendix 4 Ethics approval from Provincial Hospital

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Appendix 5 Permission letter for data collection in Community Healthcare Centre/Puskesmas

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Appendix 6 Letter of notification of data collection suspension

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Appendix 7 Letter of introduction to Hospital Director of Indonesian National Hospital

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Appendix 8 Letter of introduction to Hospital Director of Provincial Hospital

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Appendix 9 Letter of introduction to Head of Community Healthcare Centre (Puskesmas)

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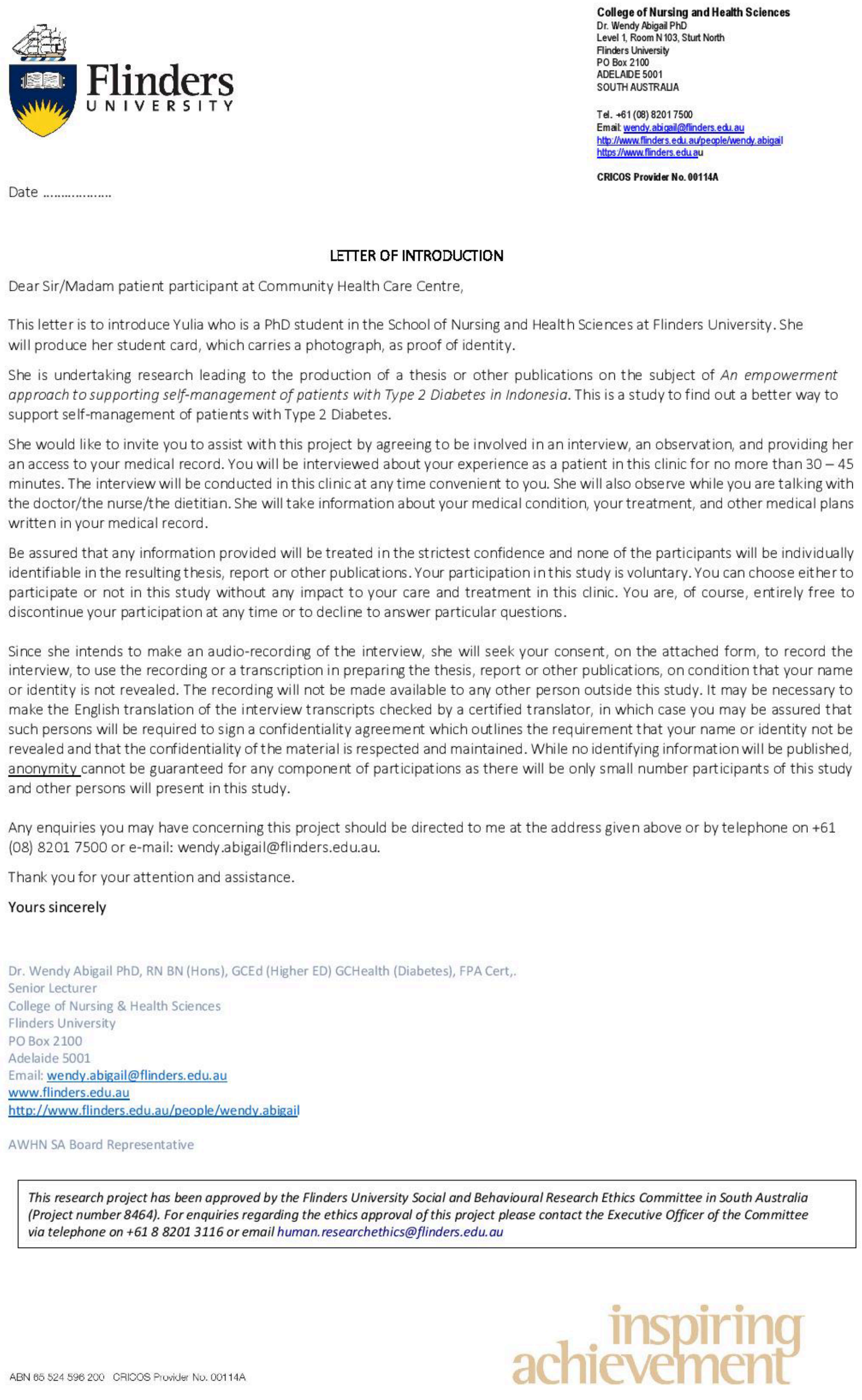
Appendix 10 Letter of introduction to patient participants at Puskesmas



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https://www.flinders.edu.au

CRICOS Provider No. 00114A

Date ………………

LETTER OF INTRODUCTION

Dear Sir/Madam patient participant at Community Health Care Centre,

This letter is to introduce Yulia who is a PhD student in the School of Nursing and Health Sciences at Flinders University. She will produce her student card, which carries a photograph, as proof of identity.

She is undertaking research leading to the production of a thesis or other publications on the subject of *An empowerment approach to supporting self-management of patients with Type 2 Diabetes in Indonesia*. This is a study to find out a better way to support self-management of patients with Type 2 Diabetes.

She would like to invite you to assist with this project by agreeing to be involved in an interview, an observation, and providing her an access to your medical record. You will be interviewed about your experience as a patient in this clinic for no more than 30 – 45 minutes. The interview will be conducted in this clinic at any time convenient to you. She will also observe while you are talking with the doctor/the nurse/the dietitian. She will take information about your medical condition, your treatment, and other medical plans written in your medical record.

Be assured that any information provided will be treated in the strictest confidence and none of the participants will be individually identifiable in the resulting thesis, report or other publications. Your participation in this study is voluntary. You can choose either to participate or not in this study without any impact to your care and treatment in this clinic. You are, of course, entirely free to discontinue your participation at any time or to decline to answer particular questions.

Since she intends to make an audio-recording of the interview, she will seek your consent, on the attached form, to record the interview, to use the recording or a transcription in preparing the thesis, report or other publications, on condition that your name or identity is not revealed. The recording will not be made available to any other person outside this study. It may be necessary to make the English translation of the interview transcripts checked by a certified translator, in which case you may be assured that such persons will be required to sign a confidentiality agreement which outlines the requirement that your name or identity not be revealed and that the confidentiality of the material is respected and maintained. While no identifying information will be published, anonymity cannot be guaranteed for any component of participations as there will be only small number participants of this study and other persons will present in this study.

Any enquiries you may have concerning this project should be directed to me at the address given above or by telephone on +61 (08) 8201 7500 or e-mail: wendy.abigail@flinders.edu.au.

Thank you for your attention and assistance.

Yours sincerely

Dr. Wendy Abigail PhD, RN BN (Hons), GCEd (Higher ED) GCHealth (Diabetes), FPA Cert,.
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http://www.flinders.edu.au/people/wendy.abigail

AWHN SA Board Representative

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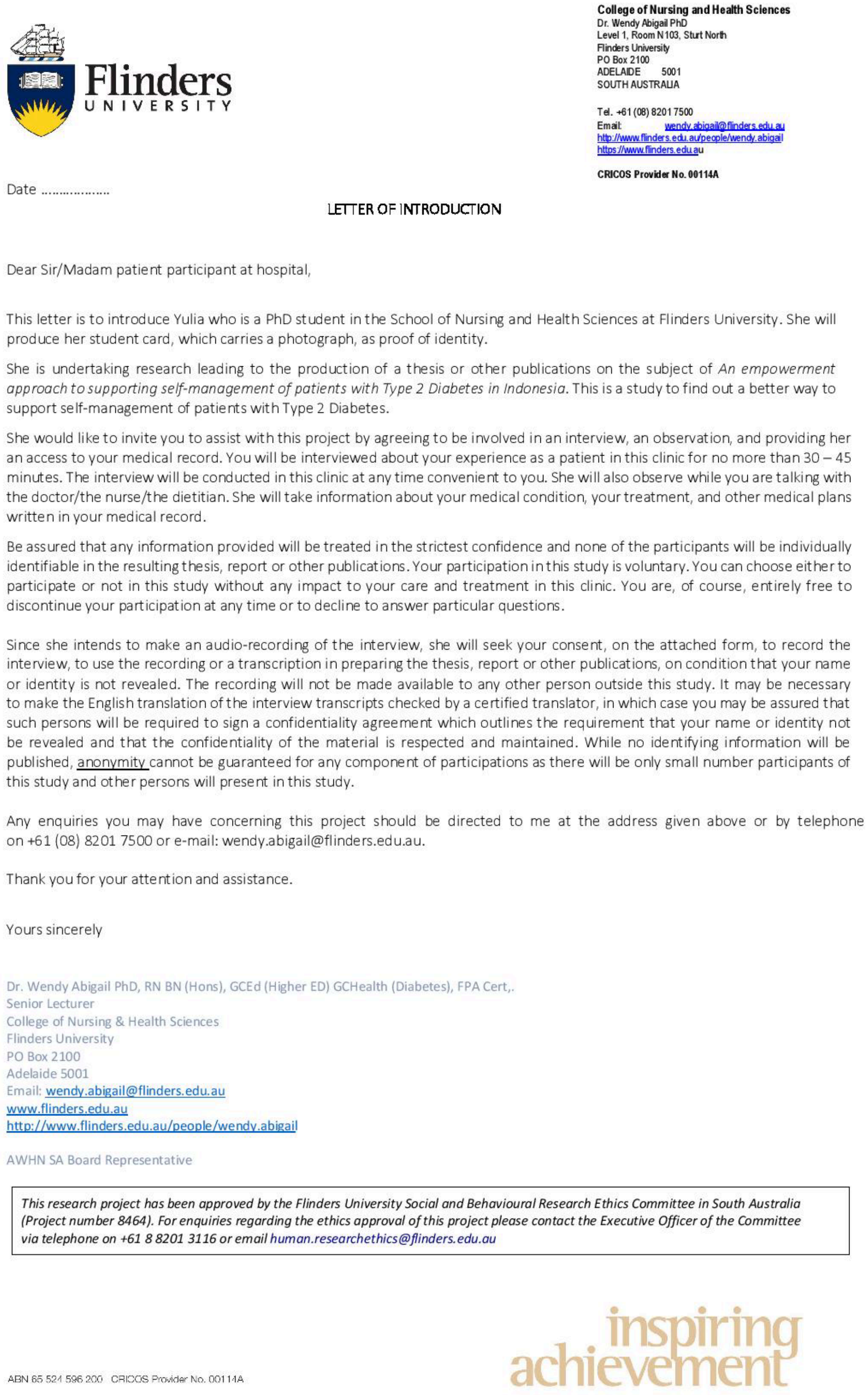
Appendix 11 L:etter of introduction to patient participants at Hospitals



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Thank you for your attention and assistance.

Yours sincerely

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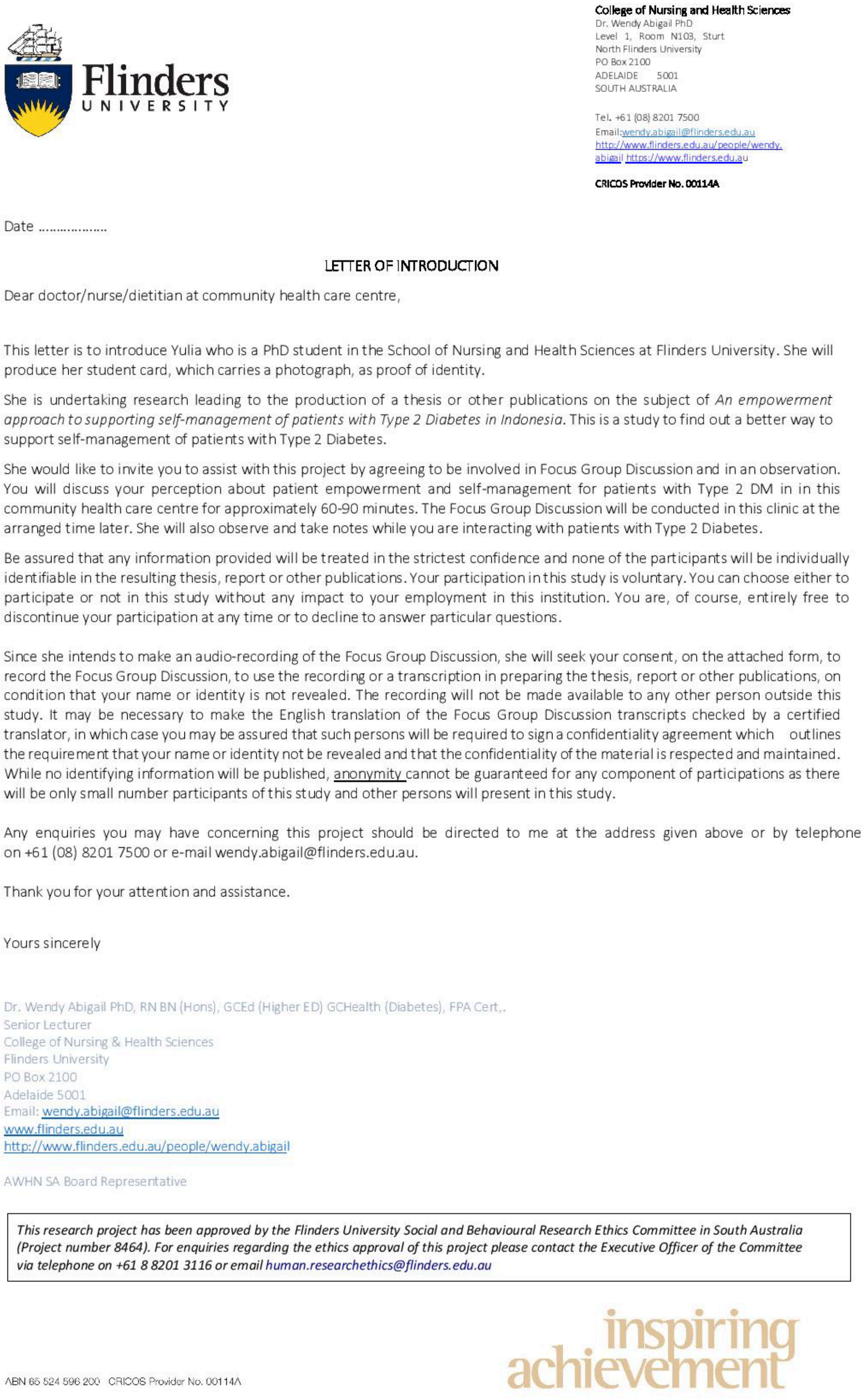
Apendix 12 Letter of introduction to HCP participants at Puskesmas



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CRICOS Provider No. 00114A

Date ………………

LETTER OF INTRODUCTION

Dear doctor/nurse/dietitian at community health care centre,

This letter is to introduce Yulia who is a PhD student in the School of Nursing and Health Sciences at Flinders University. She will produce her student card, which carries a photograph, as proof of identity.

She is undertaking research leading to the production of a thesis or other publications on the subject of *An empowerment approach to supporting self-management of patients with Type 2 Diabetes in Indonesia*. This is a study to find out a better way to support self-management of patients with Type 2 Diabetes.

She would like to invite you to assist with this project by agreeing to be involved in Focus Group Discussion and in an observation. You will discuss your perception about patient empowerment and self-management for patients with Type 2 DM in in this community health care centre for approximately 60-90 minutes. The Focus Group Discussion will be conducted in this clinic at the arranged time later. She will also observe and take notes while you are interacting with patients with Type 2 Diabetes.

Be assured that any information provided will be treated in the strictest confidence and none of the participants will be individually identifiable in the resulting thesis, report or other publications. Your participation in this study is voluntary. You can choose either to participate or not in this study without any impact to your employment in this institution. You are, of course, entirely free to discontinue your participation at any time or to decline to answer particular questions.

Since she intends to make an audio-recording of the Focus Group Discussion, she will seek your consent, on the attached form, to record the Focus Group Discussion, to use the recording or a transcription in preparing the thesis, report or other publications, on condition that your name or identity is not revealed. The recording will not be made available to any other person outside this study. It may be necessary to make the English translation of the Focus Group Discussion transcripts checked by a certified translator, in which case you may be assured that such persons will be required to sign a confidentiality agreement which outlines the requirement that your name or identity not be revealed and that the confidentiality of the material is respected and maintained. While no identifying information will be published, anonymity cannot be guaranteed for any component of participations as there will be only small number participants of this study and other persons will present in this study.

Any enquiries you may have concerning this project should be directed to me at the address given above or by telephone on +61 (08) 8201 7500 or e-mail wendy.abigail@flinders.edu.au.

Thank you for your attention and assistance.

Yours sincerely

Dr. Wendy Abigail PhD, RN BN (Hons), GCEd (Higher ED) GCHealth (Diabetes), FPA Cert,.
Senior Lecturer
College of Nursing & Health Sciences
Flinders University
PO Box 2100
Adelaide 5001
Email: wendy.abigail@flinders.edu.au
www.flinders.edu.au
http://www.flinders.edu.au/people/wendy.abigail

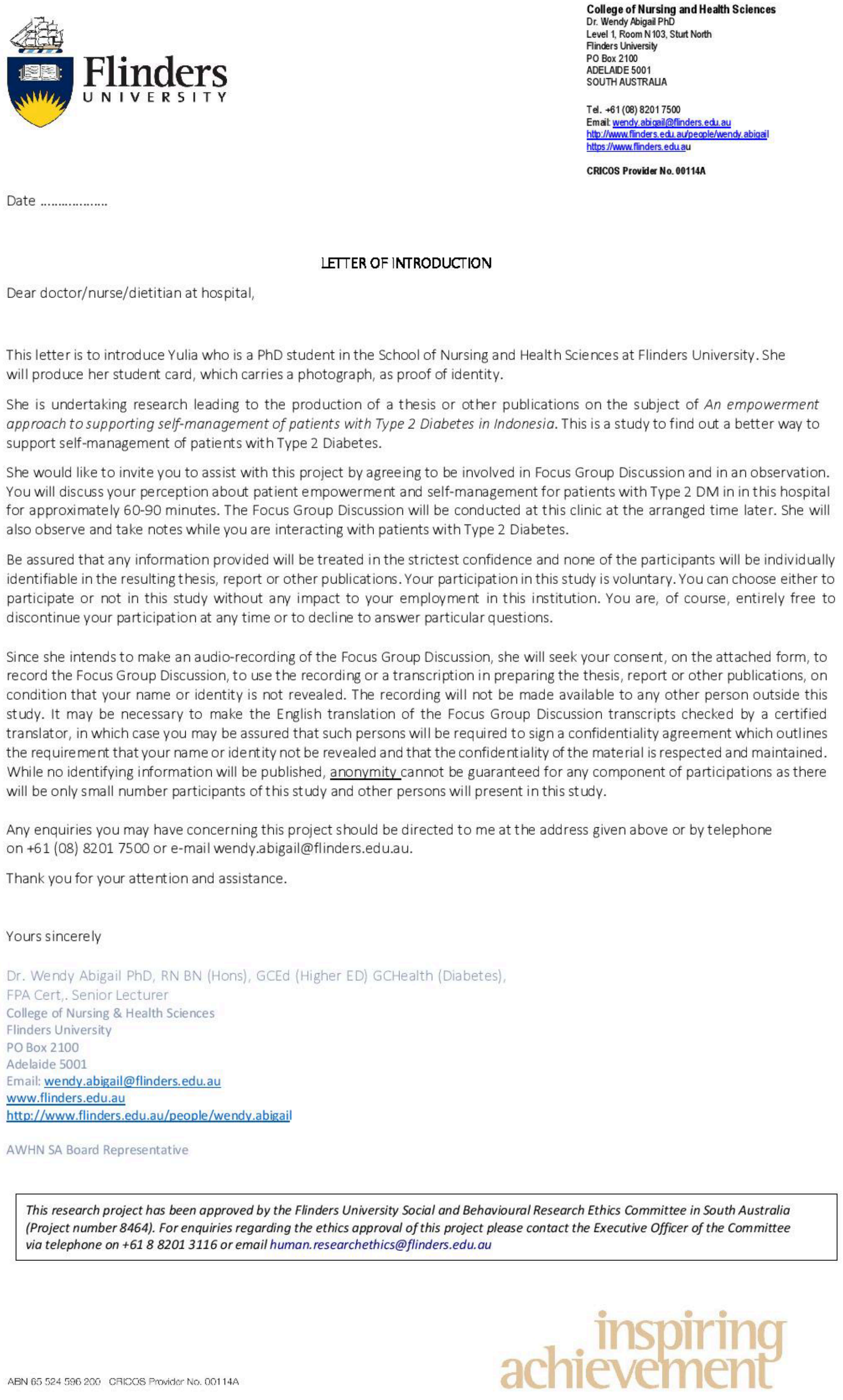
AWHN SA Board Representative

This research project has been approved by the Flinders University Social and Behavioural Research Ethics Committee in South Australia (Project number 8464). For enquiries regarding the ethics approval of this project please contact the Executive Officer of the Committee via telephone on +61 8 8201 3116 or email human.researchethics@flinders.edu.au

ABN 65 524 596 200 CRICOS Provider No. 00114A

inspiring achievement

Appendix 13 Letter of introduction to HCP participants at Hospitals



Flinders
UNIVERSITY

College of Nursing and Health Sciences
Dr. Wendy Abigail PhD
Level 1, Room N103, Sturt North
Flinders University
PO Box 2100
ADELAIDE 5001
SOUTH AUSTRALIA

Tel. +61 (08) 8201 7500
Email: wendy.abigail@flinders.edu.au
http://www.flinders.edu.au/people/wendy.abigail
https://www.flinders.edu.au

CRICOS Provider No. 00114A

Date ………………

LETTER OF INTRODUCTION

Dear doctor/nurse/dietitian at hospital,

This letter is to introduce Yulia who is a PhD student in the School of Nursing and Health Sciences at Flinders University. She will produce her student card, which carries a photograph, as proof of identity.

She is undertaking research leading to the production of a thesis or other publications on the subject of *An empowerment approach to supporting self-management of patients with Type 2 Diabetes in Indonesia*. This is a study to find out a better way to support self-management of patients with Type 2 Diabetes.

She would like to invite you to assist with this project by agreeing to be involved in Focus Group Discussion and in an observation. You will discuss your perception about patient empowerment and self-management for patients with Type 2 DM in in this hospital for approximately 60-90 minutes. The Focus Group Discussion will be conducted at this clinic at the arranged time later. She will also observe and take notes while you are interacting with patients with Type 2 Diabetes.

Be assured that any information provided will be treated in the strictest confidence and none of the participants will be individually identifiable in the resulting thesis, report or other publications. Your participation in this study is voluntary. You can choose either to participate or not in this study without any impact to your employment in this institution. You are, of course, entirely free to discontinue your participation at any time or to decline to answer particular questions.

Since she intends to make an audio-recording of the Focus Group Discussion, she will seek your consent, on the attached form, to record the Focus Group Discussion, to use the recording or a transcription in preparing the thesis, report or other publications, on condition that your name or identity is not revealed. The recording will not be made available to any other person outside this study. It may be necessary to make the English translation of the Focus Group Discussion transcripts checked by a certified translator, in which case you may be assured that such persons will be required to sign a confidentiality agreement which outlines the requirement that your name or identity not be revealed and that the confidentiality of the material is respected and maintained. While no identifying information will be published, anonymity cannot be guaranteed for any component of participations as there will be only small number participants of this study and other persons will present in this study.

Any enquiries you may have concerning this project should be directed to me at the address given above or by telephone on +61 (08) 8201 7500 or e-mail wendy.abigail@flinders.edu.au.

Thank you for your attention and assistance.

Yours sincerely

Dr. Wendy Abigail PhD, RN BN (Hons), GCEd (Higher ED) GCHealth (Diabetes),
FPA Cert,. Senior Lecturer
College of Nursing & Health Sciences
Flinders University
PO Box 2100
Adelaide 5001
Email: wendy.abigail@flinders.edu.au
www.flinders.edu.au
http://www.flinders.edu.au/people/wendy.abigail

AWHN SA Board Representative

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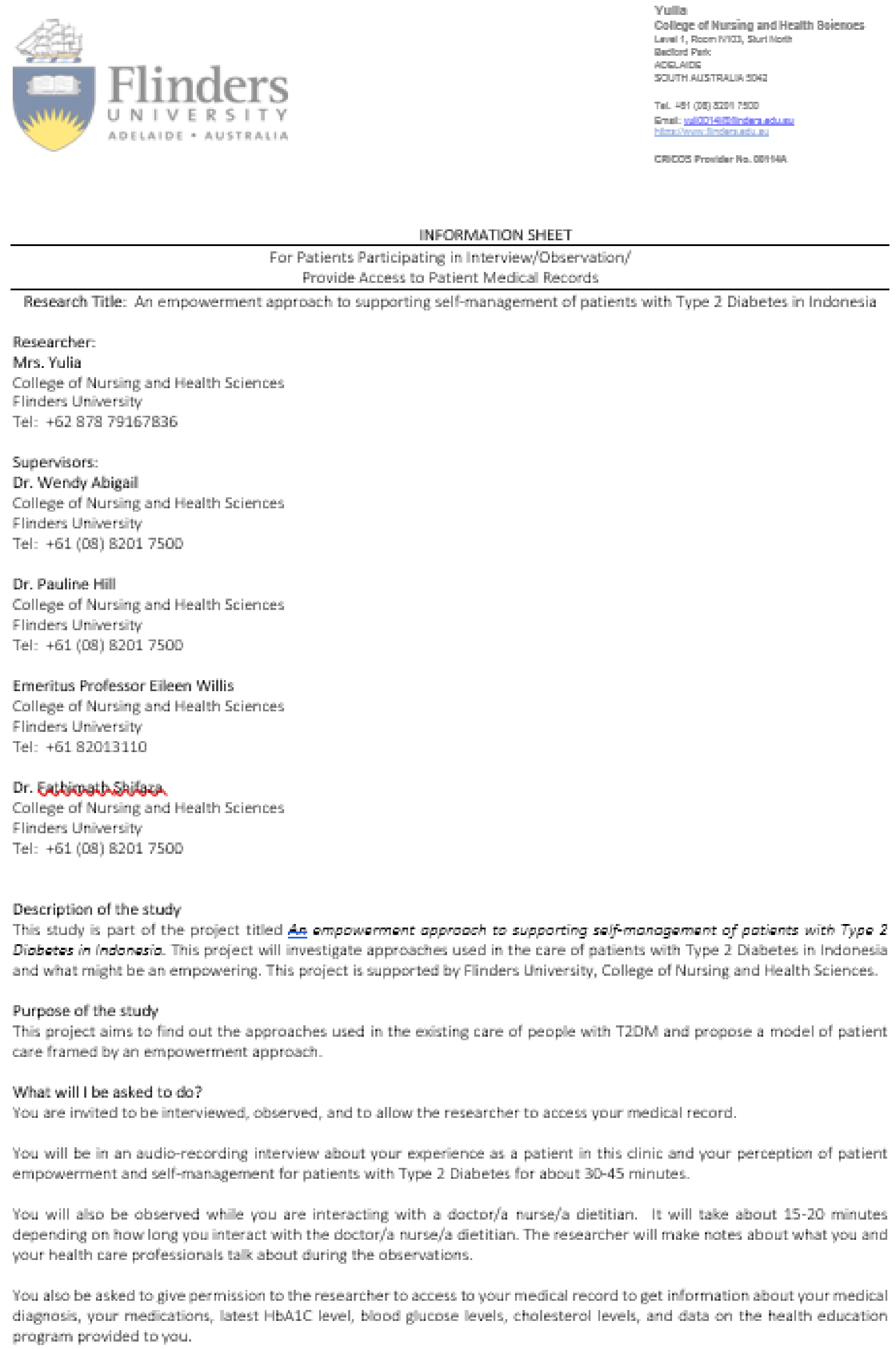
ABN 65 524 596 200 CRICOS Provider No. 00114A

inspiring
achievement

Appendix 14 Information sheet for patient interview



Yulia
College of Nursing and Health Sciences
Level 1, Room N103, Sturt North
Bedford Park
ADELAIDE
SOUTH AUSTRALIA 5042

Tel. +61 (08) 8201 7500
Email: [illegible]
http://www.flinders.edu.au

CRICOS Provider No. 00114A

INFORMATION SHEET

For Patients Participating in Interview/Observation/
Provide Access to Patient Medical Records

Research Title: An empowerment approach to supporting self-management of patients with Type 2 Diabetes in Indonesia

Researcher:
Mrs. Yulia
College of Nursing and Health Sciences
Flinders University
Tel: +62 878 79167836

Supervisors:
Dr. Wendy Abigail
College of Nursing and Health Sciences
Flinders University
Tel: +61 (08) 8201 7500

Dr. Pauline Hill
College of Nursing and Health Sciences
Flinders University
Tel: +61 (08) 8201 7500

Emeritus Professor Eileen Willis
College of Nursing and Health Sciences
Flinders University
Tel: +61 82013110

Dr. Fathimath Shifaza
College of Nursing and Health Sciences
Flinders University
Tel: +61 (08) 8201 7500

Description of the study
This study is part of the project titled *An empowerment approach to supporting self-management of patients with Type 2 Diabetes in Indonesia*. This project will investigate approaches used in the care of patients with Type 2 Diabetes in Indonesia and what might be an empowering. This project is supported by Flinders University, College of Nursing and Health Sciences.

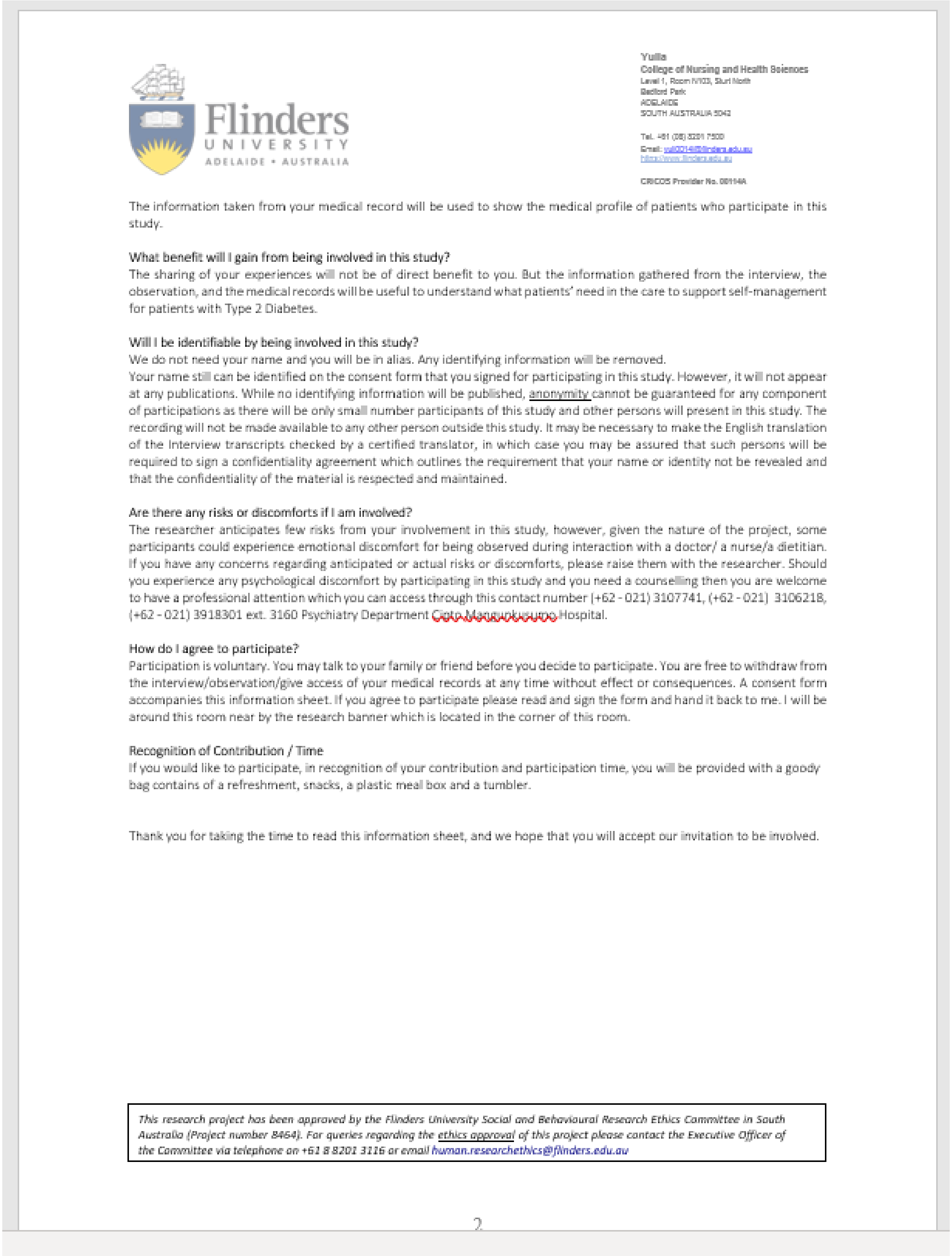
Purpose of the study
This project aims to find out the approaches used in the existing care of people with T2DM and propose a model of patient care framed by an empowerment approach.

What will I be asked to do?
You are invited to be interviewed, observed, and to allow the researcher to access your medical record.

You will be in an audio-recording interview about your experience as a patient in this clinic and your perception of patient empowerment and self-management for patients with Type 2 Diabetes for about 30-45 minutes.

You will also be observed while you are interacting with a doctor/a nurse/a dietitian. It will take about 15-20 minutes depending on how long you interact with the doctor/a nurse/a dietitian. The researcher will make notes about what you and your health care professionals talk about during the observations.

You also be asked to give permission to the researcher to access to your medical record to get information about your medical diagnosis, your medications, latest HbA1C level, blood glucose levels, cholesterol levels, and data on the health education program provided to you.



Yulia
College of Nursing and Health Sciences
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Bedford Park
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SOUTH AUSTRALIA 5042

Tel. +61 (08) 8201 7500
Email: yuli0014@flinders.edu.au
https://www.flinders.edu.au

CRICOS Provider No. 00114A

The information taken from your medical record will be used to show the medical profile of patients who participate in this study.

What benefit will I gain from being involved in this study?
The sharing of your experiences will not be of direct benefit to you. But the information gathered from the interview, the observation, and the medical records will be useful to understand what patients' need in the care to support self-management for patients with Type 2 Diabetes.

Will I be identifiable by being involved in this study?
We do not need your name and you will be in alias. Any identifying information will be removed.
Your name still can be identified on the consent form that you signed for participating in this study. However, it will not appear at any publications. While no identifying information will be published, anonymity cannot be guaranteed for any component of participations as there will be only small number participants of this study and other persons will present in this study. The recording will not be made available to any other person outside this study. It may be necessary to make the English translation of the Interview transcripts checked by a certified translator, in which case you may be assured that such persons will be required to sign a confidentiality agreement which outlines the requirement that your name or identity not be revealed and that the confidentiality of the material is respected and maintained.

Are there any risks or discomforts if I am involved?
The researcher anticipates few risks from your involvement in this study, however, given the nature of the project, some participants could experience emotional discomfort for being observed during interaction with a doctor/ a nurse/a dietitian. If you have any concerns regarding anticipated or actual risks or discomforts, please raise them with the researcher. Should you experience any psychological discomfort by participating in this study and you need a counselling then you are welcome to have a professional attention which you can access through this contact number (+62 - 021) 3107741, (+62 - 021) 3106218, (+62 - 021) 3918301 ext. 3160 Psychiatry Department Cipto Mangunkusumo Hospital.

How do I agree to participate?
Participation is voluntary. You may talk to your family or friend before you decide to participate. You are free to withdraw from the interview/observation/give access of your medical records at any time without effect or consequences. A consent form accompanies this information sheet. If you agree to participate please read and sign the form and hand it back to me. I will be around this room near by the research banner which is located in the corner of this room.

Recognition of Contribution / Time
If you would like to participate, in recognition of your contribution and participation time, you will be provided with a goody bag contains of a refreshment, snacks, a plastic meal box and a tumbler.

Thank you for taking the time to read this information sheet, and we hope that you will accept our invitation to be involved.

This research project has been approved by the Flinders University Social and Behavioural Research Ethics Committee in South Australia (Project number 8464). For queries regarding the ethics approval of this project please contact the Executive Officer of the Committee via telephone on +61 8 8201 3116 or email human.researchethics@flinders.edu.au

Appendix 15 Information sheet for HCP FGD

Yulia
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https://www.flinders.edu.au

CRICOS Provider No. 00114A

INFORMATION SHEET

For Health Care Professionals Participating in Focus Group Discussion/Observation/Access to Medical Records

Research Title: An empowerment approach to supporting self-management of patients with Type 2 Diabetes in Indonesia

Researcher:
Mrs.Yulia
College of Nursing and Health Sciences - Flinders University
Tel: +62 878 79167836

Supervisors:
Dr. Wendy Abigail
College of Nursing and Health Sciences - Flinders University
Tel: +61 (08) 8201 7500

Dr. Pauline Hill
College of Nursing and Health Sciences - Flinders University
Tel: +61 (08) 8201 7500

Emeritus Professor Eileen Willis
College of Nursing and Health Sciences - Flinders University
Tel: +61 82013110

Dr. Fathimath Shifaza
College of Nursing and Health Sciences - Flinders University
Tel: +61 (08) 8201 7500

Description of the study

This study is part of the project titled *An empowerment approach to supporting self-management of patients with Type 2 Diabetes in Indonesia*. This project will investigate a better approach to use in supporting self—management in patients with Type 2 Diabetes in Indonesia and what might be an empowering. This project is supported by Flinders University, College of Nursing and Health Sciences.

Purpose of the study

This project aims to find out the approaches used in the existing care of people with T2DM and proposes a model of patient care framed by an empowerment approach.

What will I be asked to do?

You are invited to participate in a Focus Group Discussion, an observation, and to provide access to Patient Medical Record.

In the 60-90 minutes Focus Group Discussion, you will discuss your views mainly about empowerment approaches to support self-management in patients with Type 2 Diabetes in Indonesia. Participation is entirely voluntary. With your written approval, the Focus Group Discussion will be audio-recorded. You will also be involved in an observation. You will be observed while you are interacting with your patient during the clinical consultation. It will take about 15-20 minutes depending on how long you interact with patient. The researcher will make notes about what you and your patient talk about during the observations.

You also be asked to give permission to the researcher to access to your patients' medical record to get information about patients medical diagnosis, the medications, latest HbA1C level, blood glucose levels, cholesterol levels, and data on the health education program you plan for your patients. The information taken from the medical record will be used to show the medical profile of patients who participate in this study.

What benefit will I gain from being involved in this study?

The sharing of your experiences and thoughts will not be of direct benefit to you. But, your ideas and thoughts shared in the discussion, the observation, and the medical record will be useful information to understand the existing care approaches used to support self-management in patients with Type 2 Diabetes in Indonesia and to develop a new model of care framed by a patient empowerment approach.

inspiring achievement

The information taken from your medical record will be used to show the medical profile of patients who participate in this study.

What benefit will I gain from being involved in this study?
The sharing of your experiences will not be of direct benefit to you. But the information gathered from the interview, the observation, and the medical records will be useful to understand what patients' need in the care to support self-management for patients with Type 2 Diabetes.

Will I be identifiable by being involved in this study?
We do not need your name and you will be in alias. Any identifying information will be removed.
Your name still can be identified on the consent form that you signed for participating in this study. However, it will not appear at any publications. While no identifying information will be published, anonymity cannot be guaranteed for any component of participations as there will be only small number participants of this study and other persons will present in this study. The recording will not be made available to any other person outside this study. It may be necessary to make the English translation of the Interview transcripts checked by a certified translator, in which case you may be assured that such persons will be required to sign a confidentiality agreement which outlines the requirement that your name or identity not be revealed and that the confidentiality of the material is respected and maintained.

Are there any risks or discomforts if I am involved?
The researcher anticipates few risks from your involvement in this study, however, given the nature of the project, some participants could experience emotional discomfort for being observed during interaction with a doctor/ a nurse/a dietitian. If you have any concerns regarding anticipated or actual risks or discomforts, please raise them with the researcher. Should you experience any psychological discomfort by participating in this study and you need a counselling then you are welcome to have a professional attention which you can access through this contact number (+62 - 021) 3107741, (+62 - 021) 3106218, (+62 - 021) 3918301 ext. 3160 Psychiatry Department Cipto Mangunkusumo Hospital.

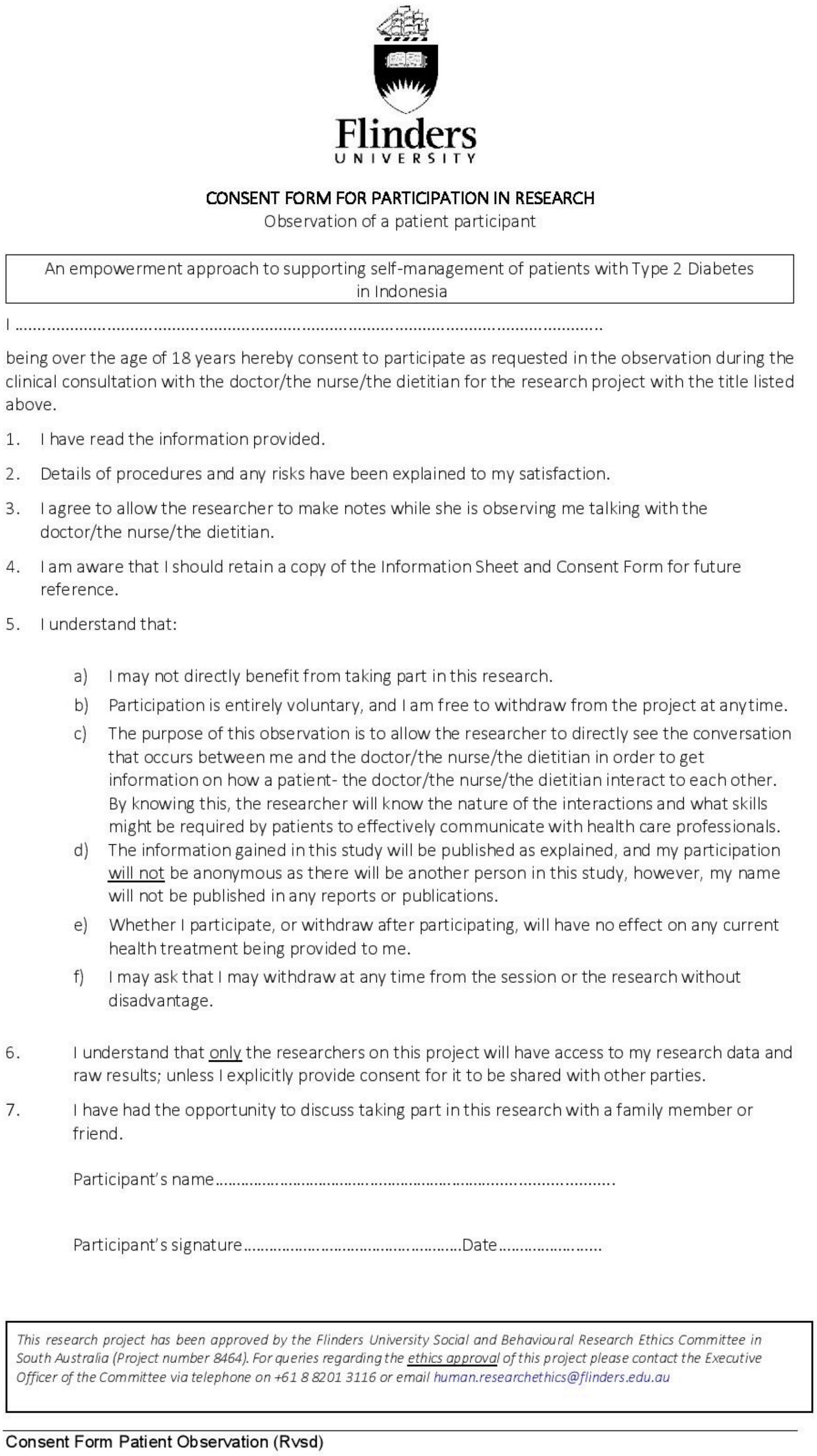
How do I agree to participate?
Participation is voluntary. You may talk to your family or friend before you decide to participate. You are free to withdraw from the interview/observation/give access of your medical records at any time without effect or consequences. A consent form accompanies this information sheet. If you agree to participate please read and sign the form and hand it back to me. I will be around this room near by the research banner which is located in the corner of this room.

Recognition of Contribution / Time
If you would like to participate, in recognition of your contribution and participation time, you will be provided with a goody bag contains of a refreshment, snacks, a plastic meal box and a tumbler.

Thank you for taking the time to read this information sheet, and we hope that you will accept our invitation to be involved.

This research project has been approved by the Flinders University Social and Behavioural Research Ethics Committee in South Australia (Project number 8464). For queries regarding the ethics approval of this project please contact the Executive Officer of the Committee via telephone on +61 8 8201 3116 or email human.researchethics@flinders.edu.au

Appendix 16 Informed consent form for patient participants



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UNIVERSITY

CONSENT FORM FOR PARTICIPATION IN RESEARCH
Observation of a patient participant

An empowerment approach to supporting self-management of patients with Type 2 Diabetes in Indonesia

I ………

being over the age of 18 years hereby consent to participate as requested in the observation during the clinical consultation with the doctor/the nurse/the dietitian for the research project with the title listed above.

1. I have read the information provided.
2. Details of procedures and any risks have been explained to my satisfaction.
3. I agree to allow the researcher to make notes while she is observing me talking with the doctor/the nurse/the dietitian.
4. I am aware that I should retain a copy of the Information Sheet and Consent Form for future reference.
5. I understand that:
   a) I may not directly benefit from taking part in this research.
   b) Participation is entirely voluntary, and I am free to withdraw from the project at anytime.
   c) The purpose of this observation is to allow the researcher to directly see the conversation that occurs between me and the doctor/the nurse/the dietitian in order to get information on how a patient- the doctor/the nurse/the dietitian interact to each other. By knowing this, the researcher will know the nature of the interactions and what skills might be required by patients to effectively communicate with health care professionals.
   d) The information gained in this study will be published as explained, and my participation will not be anonymous as there will be another person in this study, however, my name will not be published in any reports or publications.
   e) Whether I participate, or withdraw after participating, will have no effect on any current health treatment being provided to me.
   f) I may ask that I may withdraw at any time from the session or the research without disadvantage.
6. I understand that only the researchers on this project will have access to my research data and raw results; unless I explicitly provide consent for it to be shared with other parties.
7. I have had the opportunity to discuss taking part in this research with a family member or friend.

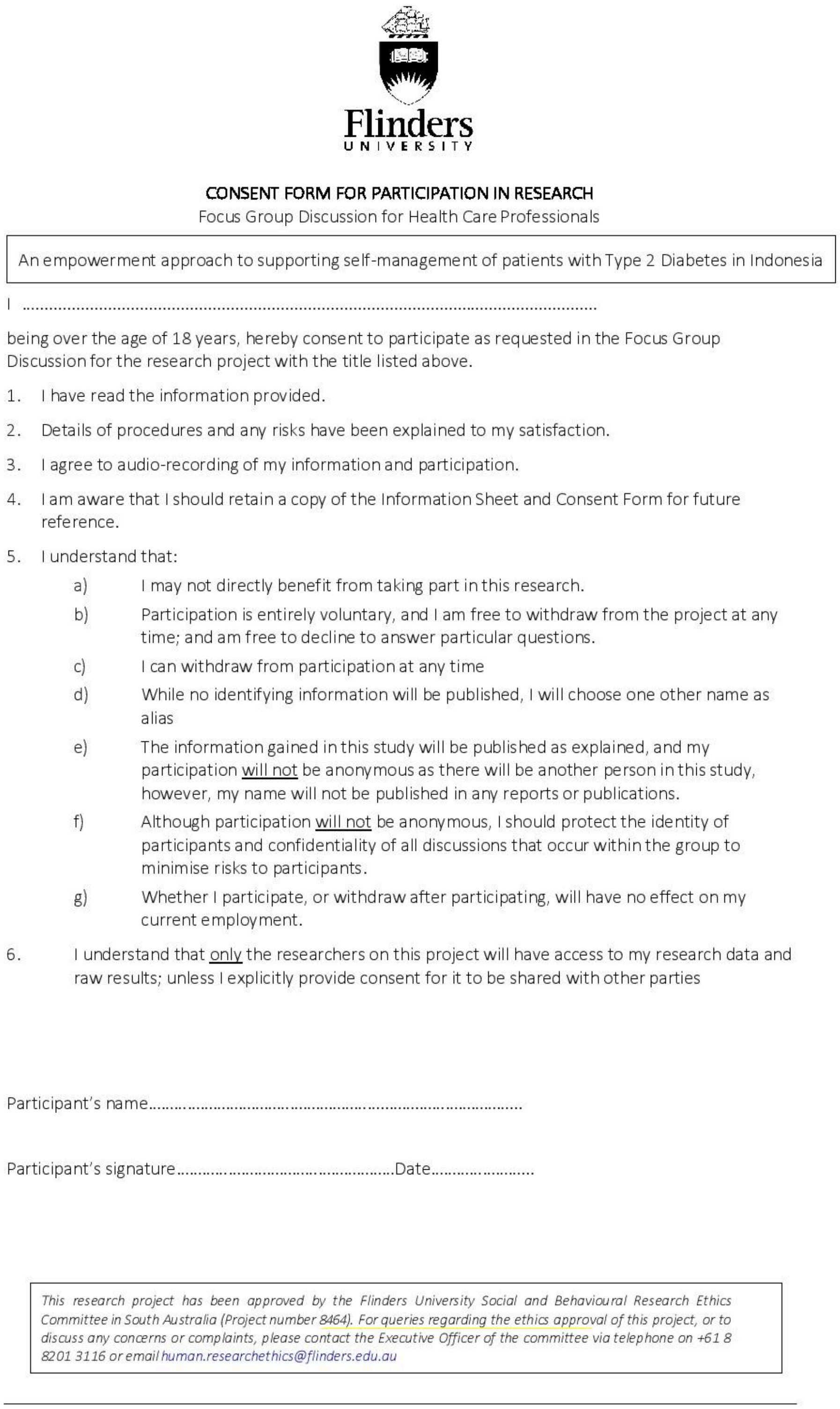
Participant's name……………………………………………………………………………………

Participant's signature……………………………………………Date……………………

This research project has been approved by the Flinders University Social and Behavioural Research Ethics Committee in South Australia (Project number 8464). For queries regarding the ethics approval of this project please contact the Executive Officer of the Committee via telephone on +61 8 8201 3116 or email human.researchethics@flinders.edu.au

Consent Form Patient Observation (Rvsd)

Appendix 17 Informed consent form for HCP participants



Flinders
UNIVERSITY

CONSENT FORM FOR PARTICIPATION IN RESEARCH
Focus Group Discussion for Health Care Professionals

An empowerment approach to supporting self-management of patients with Type 2 Diabetes in Indonesia

I ……

being over the age of 18 years, hereby consent to participate as requested in the Focus Group Discussion for the research project with the title listed above.

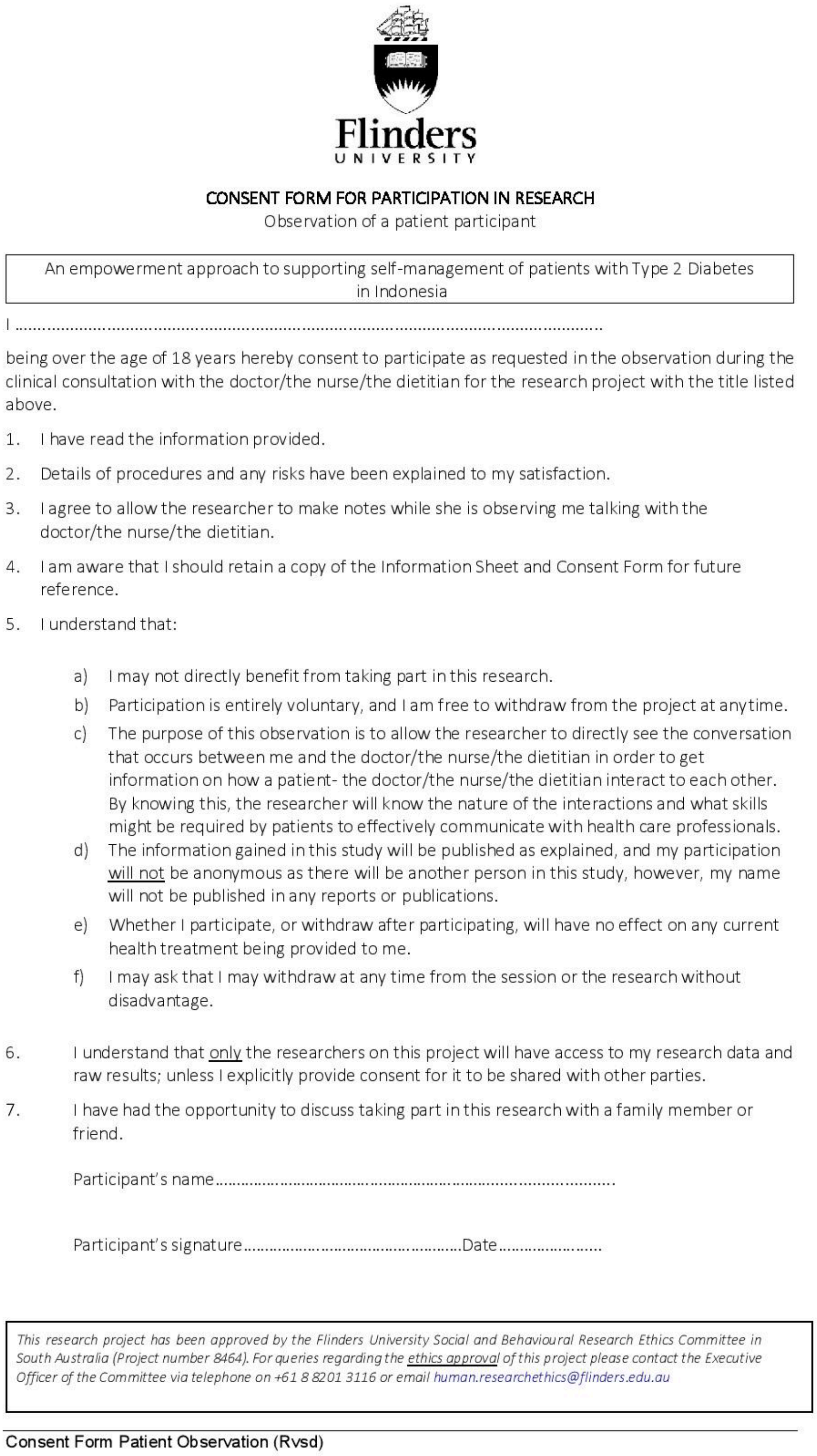
1. I have read the information provided.
2. Details of procedures and any risks have been explained to my satisfaction.
3. I agree to audio-recording of my information and participation.
4. I am aware that I should retain a copy of the Information Sheet and Consent Form for future reference.
5. I understand that:
   a) I may not directly benefit from taking part in this research.
   b) Participation is entirely voluntary, and I am free to withdraw from the project at any time; and am free to decline to answer particular questions.
   c) I can withdraw from participation at any time
   d) While no identifying information will be published, I will choose one other name as alias
   e) The information gained in this study will be published as explained, and my participation will not be anonymous as there will be another person in this study, however, my name will not be published in any reports or publications.
   f) Although participation will not be anonymous, I should protect the identity of participants and confidentiality of all discussions that occur within the group to minimise risks to participants.
   g) Whether I participate, or withdraw after participating, will have no effect on my current employment.
6. I understand that only the researchers on this project will have access to my research data and raw results; unless I explicitly provide consent for it to be shared with other parties

Participant's name……………………………………………………………………………

Participant's signature……………………………………………Date……………………

This research project has been approved by the Flinders University Social and Behavioural Research Ethics Committee in South Australia (Project number 8464). For queries regarding the ethics approval of this project, or to discuss any concerns or complaints, please contact the Executive Officer of the committee via telephone on +61 8 8201 3116 or email human.researchethics@flinders.edu.au

Appendix 18 Informed consent for patient observation



Flinders UNIVERSITY

CONSENT FORM FOR PARTICIPATION IN RESEARCH

Observation of a patient participant

An empowerment approach to supporting self-management of patients with Type 2 Diabetes in Indonesia

I ………

being over the age of 18 years hereby consent to participate as requested in the observation during the clinical consultation with the doctor/the nurse/the dietitian for the research project with the title listed above.

1. I have read the information provided.
2. Details of procedures and any risks have been explained to my satisfaction.
3. I agree to allow the researcher to make notes while she is observing me talking with the doctor/the nurse/the dietitian.
4. I am aware that I should retain a copy of the Information Sheet and Consent Form for future reference.
5. I understand that:
    a) I may not directly benefit from taking part in this research.
    b) Participation is entirely voluntary, and I am free to withdraw from the project at anytime.
    c) The purpose of this observation is to allow the researcher to directly see the conversation that occurs between me and the doctor/the nurse/the dietitian in order to get information on how a patient- the doctor/the nurse/the dietitian interact to each other. By knowing this, the researcher will know the nature of the interactions and what skills might be required by patients to effectively communicate with health care professionals.
    d) The information gained in this study will be published as explained, and my participation will not be anonymous as there will be another person in this study, however, my name will not be published in any reports or publications.
    e) Whether I participate, or withdraw after participating, will have no effect on any current health treatment being provided to me.
    f) I may ask that I may withdraw at any time from the session or the research without disadvantage.
6. I understand that only the researchers on this project will have access to my research data and raw results; unless I explicitly provide consent for it to be shared with other parties.
7. I have had the opportunity to discuss taking part in this research with a family member or friend.

Participant's name……………………………………………………………………………………

Participant's signature………………………………………………Date……………………

This research project has been approved by the Flinders University Social and Behavioural Research Ethics Committee in South Australia (Project number 8464). For queries regarding the ethics approval of this project please contact the Executive Officer of the Committee via telephone on +61 8 8201 3116 or email human.researchethics@flinders.edu.au

Consent Form Patient Observation (Rvsd)

Appendix 19 Informed consent for HCP observation

CONSENT FORM
Observation of Health Care Professional Activity

An empowerment approach to supporting self-management of patients with Type 2 Diabetes in Indonesia

I hereby give my consent to Yulia a research student in the College of Nursing and Health Sciences at Flinders University whose signature appears below, to come into the consultation room where I have a clinical consultation with a patient. I will be observed when I talk or have a conversation with my patient during that clinical consultation. The researcher will take notes on what I explain or discuss with my patient and how my patient responds to me. I give permission for the use of these data, and other information which I have agreed may be obtained or requested, in the writing up of the study, subject to the following conditions: My participation in this study is voluntary, and I understand that I may withdraw from the study at any time, and that I will not be identified by name in the study, but will be given pseudonym.

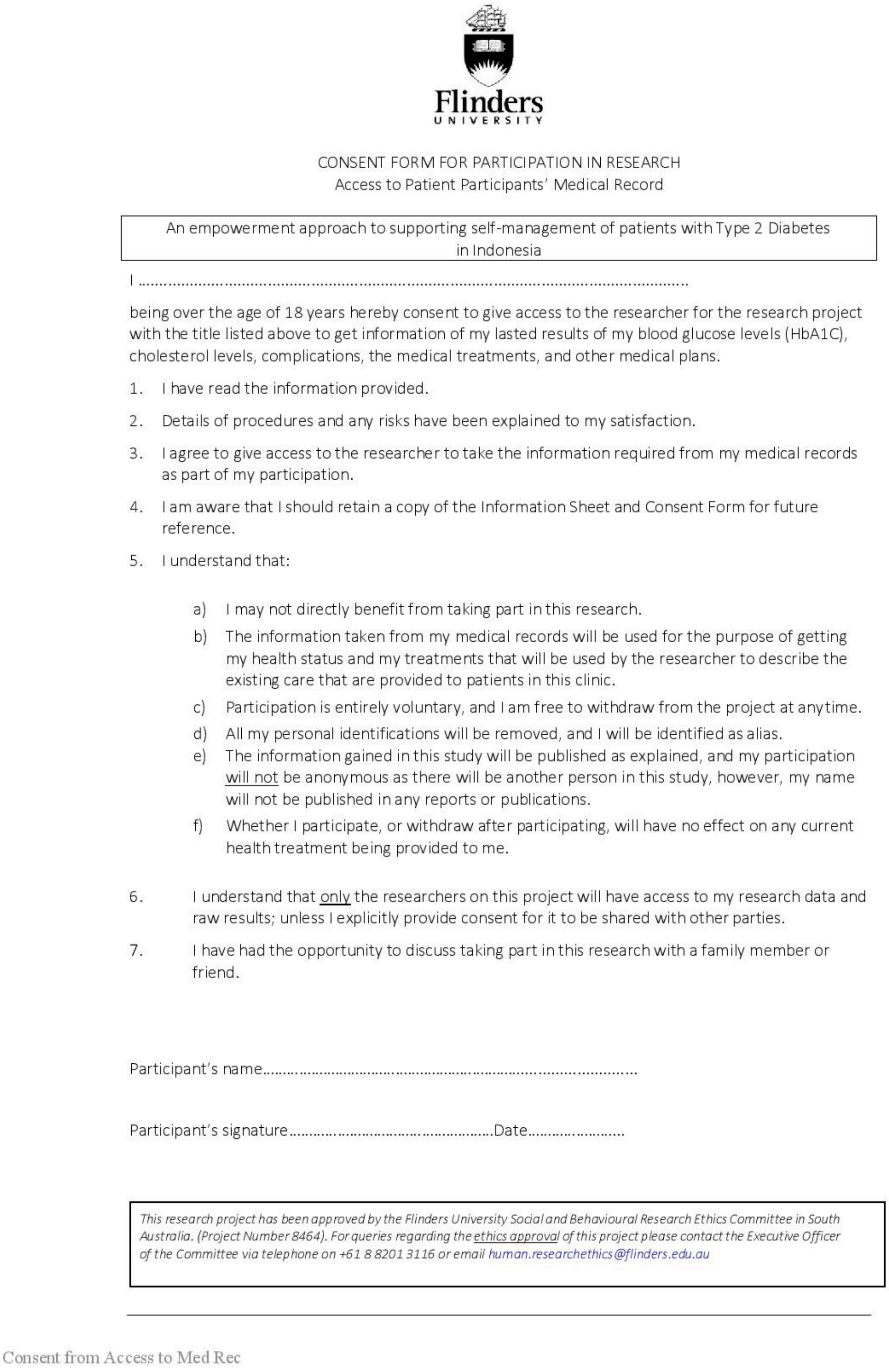
SIGNATURES

Participant……………………………………………Date……………………………

Researcher……………………………………………Date……………………………

This research project has been approved by the Flinders University Social and Behavioural Research Ethics Committee in South Australia (Project number 8464). For queries regarding the ethics approval of this project, or to discuss any concerns or complaints, please contact the Executive Officer of the committee via telephone on +61 8 8201 3116 or email human.researchethics@flinders.edu.au

Appendix 20 Informed consent for access to patient medical record



Flinders
UNIVERSITY

CONSENT FORM FOR PARTICIPATION IN RESEARCH
Access to Patient Participants' Medical Record

An empowerment approach to supporting self-management of patients with Type 2 Diabetes in Indonesia

I ……

being over the age of 18 years hereby consent to give access to the researcher for the research project with the title listed above to get information of my lasted results of my blood glucose levels (HbA1C), cholesterol levels, complications, the medical treatments, and other medical plans.

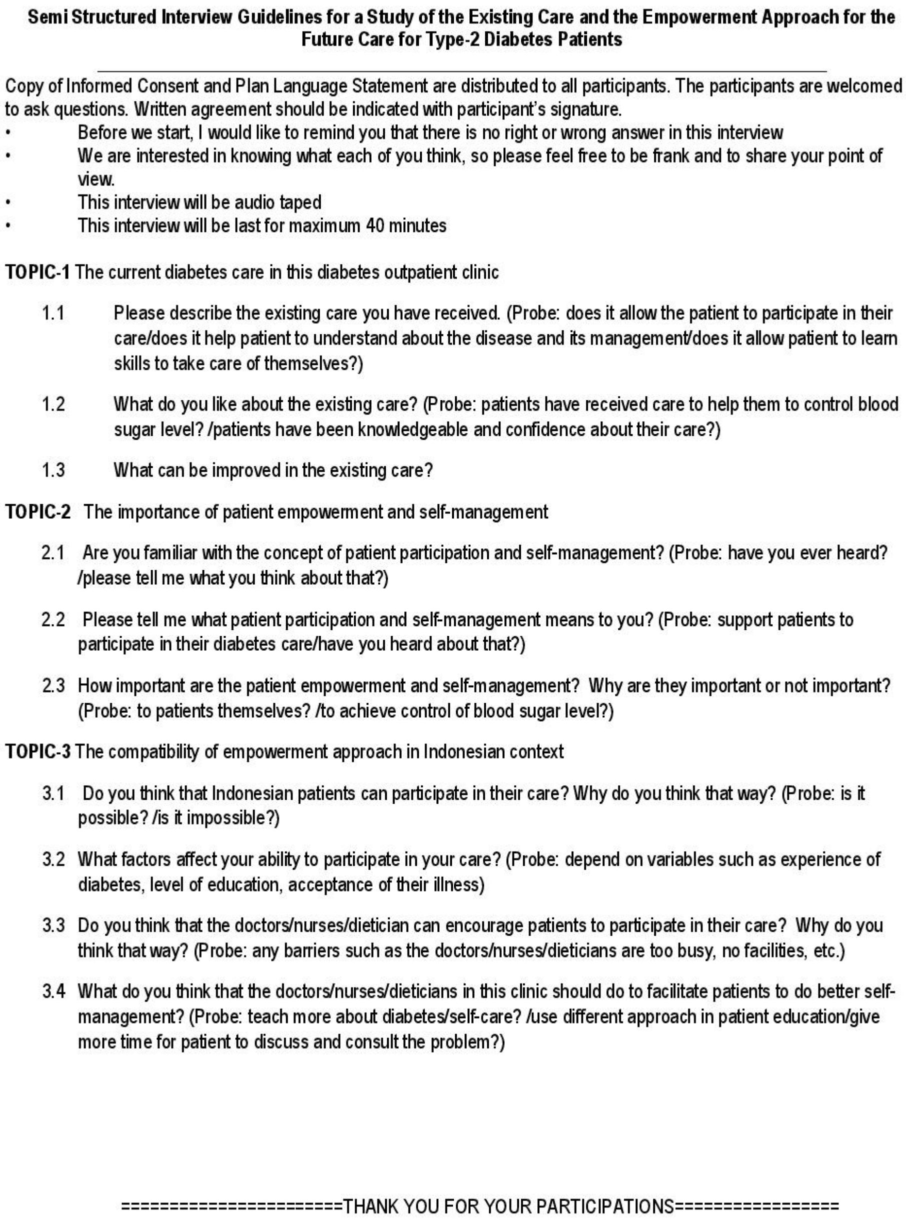
1. I have read the information provided.
2. Details of procedures and any risks have been explained to my satisfaction.
3. I agree to give access to the researcher to take the information required from my medical records as part of my participation.
4. I am aware that I should retain a copy of the Information Sheet and Consent Form for future reference.
5. I understand that:
   a) I may not directly benefit from taking part in this research.
   b) The information taken from my medical records will be used for the purpose of getting my health status and my treatments that will be used by the researcher to describe the existing care that are provided to patients in this clinic.
   c) Participation is entirely voluntary, and I am free to withdraw from the project at anytime.
   d) All my personal identifications will be removed, and I will be identified as alias.
   e) The information gained in this study will be published as explained, and my participation will not be anonymous as there will be another person in this study, however, my name will not be published in any reports or publications.
   f) Whether I participate, or withdraw after participating, will have no effect on any current health treatment being provided to me.
6. I understand that only the researchers on this project will have access to my research data and raw results; unless I explicitly provide consent for it to be shared with other parties.
7. I have had the opportunity to discuss taking part in this research with a family member or friend.

Participant's name………………………………………………………………………………

Participant's signature……………………………………………Date……………………

This research project has been approved by the Flinders University Social and Behavioural Research Ethics Committee in South Australia. (Project Number 8464). For queries regarding the ethics approval of this project please contact the Executive Officer of the Committee via telephone on +61 8 8201 3116 or email human.researchethics@flinders.edu.au

Appendix 21 Interview Guideline



Semi Structured Interview Guidelines for a Study of the Existing Care and the Empowerment Approach for the Future Care for Type-2 Diabetes Patients

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Copy of Informed Consent and Plan Language Statement are distributed to all participants. The participants are welcomed to ask questions. Written agreement should be indicated with participant's signature.

- Before we start, I would like to remind you that there is no right or wrong answer in this interview
- We are interested in knowing what each of you think, so please feel free to be frank and to share your point of view.
- This interview will be audio taped
- This interview will be last for maximum 40 minutes

TOPIC-1 The current diabetes care in this diabetes outpatient clinic

1.1 Please describe the existing care you have received. (Probe: does it allow the patient to participate in their care/does it help patient to understand about the disease and its management/does it allow patient to learn skills to take care of themselves?)

1.2 What do you like about the existing care? (Probe: patients have received care to help them to control blood sugar level? /patients have been knowledgeable and confidence about their care?)

1.3 What can be improved in the existing care?

TOPIC-2 The importance of patient empowerment and self-management

2.1 Are you familiar with the concept of patient participation and self-management? (Probe: have you ever heard? /please tell me what you think about that?)

2.2 Please tell me what patient participation and self-management means to you? (Probe: support patients to participate in their diabetes care/have you heard about that?)

2.3 How important are the patient empowerment and self-management? Why are they important or not important? (Probe: to patients themselves? /to achieve control of blood sugar level?)

TOPIC-3 The compatibility of empowerment approach in Indonesian context

3.1 Do you think that Indonesian patients can participate in their care? Why do you think that way? (Probe: is it possible? /is it impossible?)

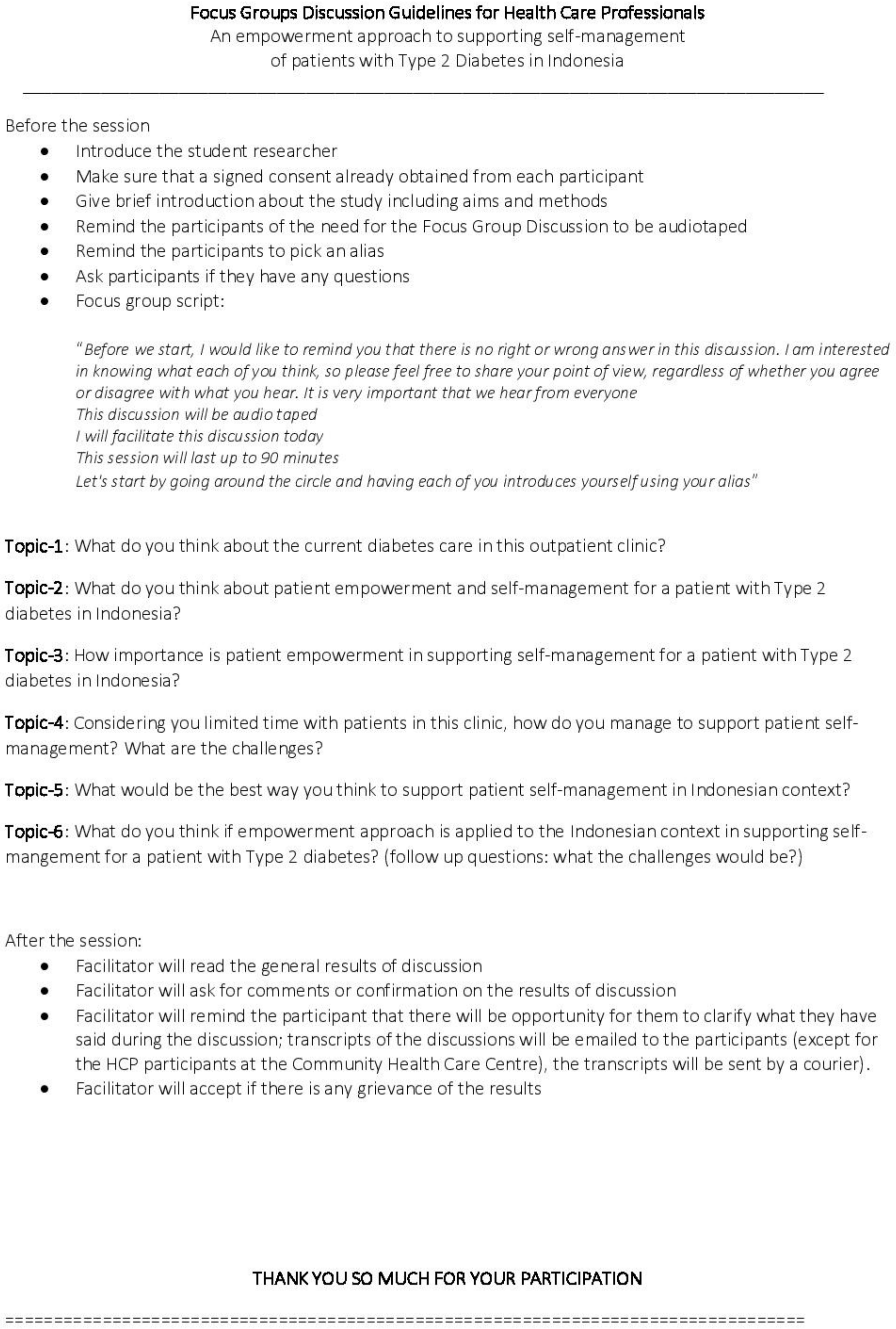
3.2 What factors affect your ability to participate in your care? (Probe: depend on variables such as experience of diabetes, level of education, acceptance of their illness)

3.3 Do you think that the doctors/nurses/dietician can encourage patients to participate in their care? Why do you think that way? (Probe: any barriers such as the doctors/nurses/dieticians are too busy, no facilities, etc.)

3.4 What do you think that the doctors/nurses/dieticians in this clinic should do to facilitate patients to do better self-management? (Probe: teach more about diabetes/self-care? /use different approach in patient education/give more time for patient to discuss and consult the problem?)

======================THANK YOU FOR YOUR PARTICIPATIONS================

Appendix 22 Focus Group Discussion Guideline



Focus Groups Discussion Guidelines for Health Care Professionals

An empowerment approach to supporting self-management
of patients with Type 2 Diabetes in Indonesia

Before the session

- Introduce the student researcher
- Make sure that a signed consent already obtained from each participant
- Give brief introduction about the study including aims and methods
- Remind the participants of the need for the Focus Group Discussion to be audiotaped
- Remind the participants to pick an alias
- Ask participants if they have any questions
- Focus group script:

> *"Before we start, I would like to remind you that there is no right or wrong answer in this discussion. I am interested in knowing what each of you think, so please feel free to share your point of view, regardless of whether you agree or disagree with what you hear. It is very important that we hear from everyone*
> *This discussion will be audio taped*
> *I will facilitate this discussion today*
> *This session will last up to 90 minutes*
> *Let's start by going around the circle and having each of you introduces yourself using your alias"*

Topic-1: What do you think about the current diabetes care in this outpatient clinic?

Topic-2: What do you think about patient empowerment and self-management for a patient with Type 2 diabetes in Indonesia?

Topic-3: How importance is patient empowerment in supporting self-management for a patient with Type 2 diabetes in Indonesia?

Topic-4: Considering you limited time with patients in this clinic, how do you manage to support patient self-management? What are the challenges?

Topic-5: What would be the best way you think to support patient self-management in Indonesian context?

Topic-6: What do you think if empowerment approach is applied to the Indonesian context in supporting self-mangement for a patient with Type 2 diabetes? (follow up questions: what the challenges would be?)

After the session:

- Facilitator will read the general results of discussion
- Facilitator will ask for comments or confirmation on the results of discussion
- Facilitator will remind the participant that there will be opportunity for them to clarify what they have said during the discussion; transcripts of the discussions will be emailed to the participants (except for the HCP participants at the Community Health Care Centre), the transcripts will be sent by a courier).
- Facilitator will accept if there is any grievance of the results

THANK YOU SO MUCH FOR YOUR PARTICIPATION

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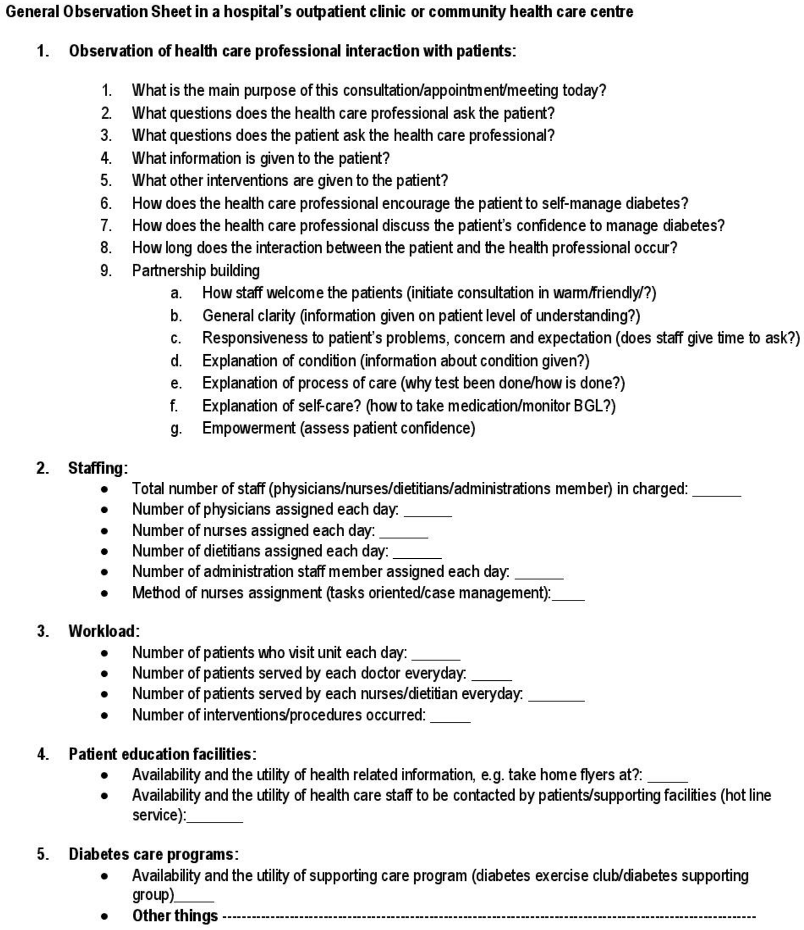
Appendix 23 Observation Grid



General Observation Sheet in a hospital's outpatient clinic or community health care centre

1. **Observation of health care professional interaction with patients:**
    1. What is the main purpose of this consultation/appointment/meeting today?
    2. What questions does the health care professional ask the patient?
    3. What questions does the patient ask the health care professional?
    4. What information is given to the patient?
    5. What other interventions are given to the patient?
    6. How does the health care professional encourage the patient to self-manage diabetes?
    7. How does the health care professional discuss the patient's confidence to manage diabetes?
    8. How long does the interaction between the patient and the health professional occur?
    9. Partnership building
        a. How staff welcome the patients (initiate consultation in warm/friendly/?)
        b. General clarity (information given on patient level of understanding?)
        c. Responsiveness to patient's problems, concern and expectation (does staff give time to ask?)
        d. Explanation of condition (information about condition given?)
        e. Explanation of process of care (why test been done/how is done?)
        f. Explanation of self-care? (how to take medication/monitor BGL?)
        g. Empowerment (assess patient confidence)

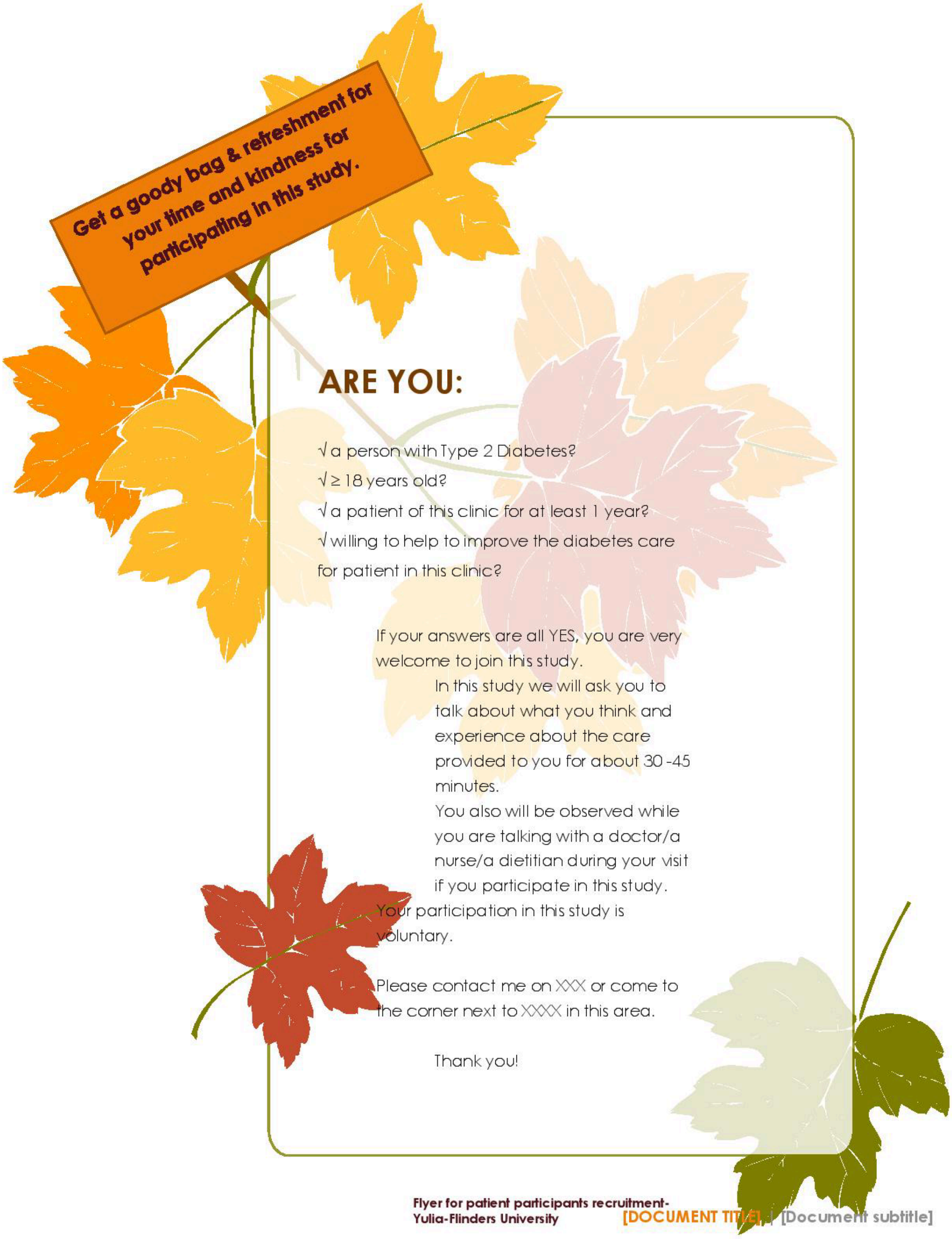
2. **Staffing:**
    - Total number of staff (physicians/nurses/dietitians/administrations member) in charged: ______
    - Number of physicians assigned each day: ______
    - Number of nurses assigned each day: ______
    - Number of dietitians assigned each day: ______
    - Number of administration staff member assigned each day: ______
    - Method of nurses assignment (tasks oriented/case management):____

3. **Workload:**
    - Number of patients who visit unit each day: ______
    - Number of patients served by each doctor everyday: _____
    - Number of patients served by each nurses/dietitian everyday: _______
    - Number of interventions/procedures occurred: _____

4. **Patient education facilities:**
    - Availability and the utility of health related information, e.g. take home flyers at?: _____
    - Availability and the utility of health care staff to be contacted by patients/supporting facilities (hot line service):_______

5. **Diabetes care programs:**
    - Availability and the utility of supporting care program (diabetes exercise club/diabetes supporting group)_____
    - **Other things** ---

Appendix 24 Patient participant recruitment poster



Get a goody bag & refreshment for your time and kindness for participating in this study.

ARE YOU:

√ a person with Type 2 Diabetes?
√ ≥ 18 years old?
√ a patient of this clinic for at least 1 year?
√ willing to help to improve the diabetes care for patient in this clinic?

If your answers are all YES, you are very welcome to join this study.

In this study we will ask you to talk about what you think and experience about the care provided to you for about 30-45 minutes.

You also will be observed while you are talking with a doctor/a nurse/a dietitian during your visit if you participate in this study.

Your participation in this study is voluntary.

Please contact me on XXX or come to the corner next to XXXX in this area.

Thank you!

Flyer for patient participants recruitment-
Yulia-Flinders University

[DOCUMENT TITLE] | [Document subtitle]

Appendix 25 Selected codes, categories, subthemes-themes from patient interview-Puskesmas

Selected Codes	Categories	Sub-themes	Themes
Not get a good care No care on psychology Patients psychologically concern was ignored Feel being inferior Normal blood glucose-oriented care Doctor just focuses on glucose lab Focus on results and glucose medications and disregards other issues Long waiting time The quality of care provided is okay for PBJS users BPJS service was poor Non-humanist care Family problem Social problem Referral issues	Biological care Medical focus care Skeptical towards the care Administration issues	Powerless consumers Long queue up Physical focus of care Industrialization of health pter 11: Routine care Overwhelmed by the referral system	Care quality
Nutritionists wait for doctor referral Doctors' decision to refer or not to refer	Medical voice dominant	–	Physicians decide the care
Reluctant to have discussion with patients Doctors reluctant to talk Hesitance in expressing wishes Aged-related stereotyping Doctor hesitance to talk to patient Doctor seem does not have time listen Doctors are sources of information but no time to educate	Communications issues	Underestimate patient needs and capacity to learn pter 12: Ageism hindered patients-health care professional communications	Communication gaps
Misperception on diabetes cause and care Lack of patient knowledge Herbs remedies as complementary care Unsafe self-management practice Information provided by doctors is too general Un-credible source of information Friends as a source of information Family as learning resource 'Health education' is too general Ignoring patients concern on their body Nurse information less relevant	Health education issues	Diabetes related- health literacy Uncomplete and too general information provided	At high risk in making harmful decisions in daily care
Being motivated Family support Herbs remedy Reading books to find more accurate information	Family supports High motivations Healthier lifestyle Complementary therapy Diabetes care myths	-	Self-empowered

Appendix 26 Selected codes, categories, subthemes-themes from observations-Puskesmas

Selected codes	Categories	Sub-themes	Themes
Blood glucose lab. Tests Prescribing Dr initiate interaction with BGL results Reducing symptoms Referral issues Ask open-ended questions	Physical issues HCPs driven communication Dispensing medications	Blood glucose evaluations and medication prescribing were the focus of clinical encounters Self-management was not the main issue discussed in clinical encounters	Medical dominance in the interactions
Change the subject/topic Greeting patients Non eye contact Referral issues Waiting for another patient No encouragement to talk No questions to patient No question to doctor/nurse Leave the problem to the patient	Encourage participating Doctor patient language Features of empowerment and disempowerment Communication pattern One direct communication Mechanical behaviors Social Lifeworld	Lack of engagement with patient daily problems HCPs were in control in the clinical encounters Lack of patient privacy Patient confusion on referral procedure	Disempowering clinical encounters
Information provided Queue insite the room Routine care	Routine care Crowded Quick service	Clinical workload and mechanical works	Sub-optimal of health information infrastructure

Appendix 27 Selected codes, categories, subthemes-themes from FGD-Puskesmas

Selected codes	**Categories**	**Sub-Themes**	**Themes**
PROLANIS the Under- utilized program Education program 100% report Restricted to 20 Indicator of care quality Barriers lack of patients interest Limited number	Government programs-based Centre care	Mis-match program	Regulations-based care provision
Patient health education is the key standard of diabetes care Effectiveness of home visit Not sure psychosocial care program Benefits of HE programs	HE limited to medication, exercise and diet Helping to understand the diseases	-	Supporting self-mangement through patient education
Health Literacy Lazy patient Not motivated patients Scheduling Time constraint Human resources	Low in health literacy Low educational background Lack of motivation Staff schedule Lack of human resource	Patients-related problems Organizations-related problems	Barriers in ‘empowering’

Appendices 28 and 29 Selected codes, categories, subthemes-themes from observation-Provincial hospital and patient interviews

Selected Codes	Category	Sub-themes	Themes
Initiate the clinical encounter with asking blood glucose levels Adjustment in Insulin as response to blood glucose results only Insulin dosage was increased due high blood glucose level Un-controlled diabetes Run out medications the topic in clinical encounters	Laboratories and adjustment in medication dosage focus on clinical encounters	Clinical encounter was based on patients' blood glucose level results Medical discourse dominant in clinical encounters Little topics on patient self-management	Medicalisation approach in the clinical encounter
Less than 10 minutes clinical encounters Explaining insulin adjustment Telling to reduce body weight Telling to do exercise	Time restriction Reactive patient education	Nurses focus on administrative works Unstructured, general and reactive 'patient education'	Lack of team collaboration in supporting patient self-management
Doctor directs the conversation Patients engage in medical topic Medical topics Brief clinical encounters	Doctor leads the clinical encounter Patients' silence Time restriction	One way communication shown in clinical interaction Brief clinical encounters with nurses and doctors Patients do not talk their concerns on medications	Restricted patient-HCPs communication
Patient negotiates treatment Show respectful	Respectful	Doctor shows respectful to patient decision	Patient decision is respected

Selected Codes	Categories	Sub-themes	Themes
Doctors are the source of information about diabetes Importance of doctor role as information source Doctors do not have much time Pt and dr in rush Time constraint	Doctor roles in providing information	-	Doctor is the source of diabetes care information
CAM/Herbs remedy Nasty neighbours Lack support from employer (Dina) Justified believed in wrong way	Social pressure	Frequent sick leave is not supported	Social pressure of being diabetes
Not get the benefit of BPJS over the ID match personal home address Back and forth worth to refer to other specialists Stressful in queue	Administration Access to services	Limited access to health care Demanding of referral administration	Ineffectiveness of the new insurance health system
Difficulty to do exercise Difficulty to follow diet Difficulty to adhere medication Stressful unpracticality of multidrug used (Retno) Insulin was not always available (Radino) Discontinuity medical supply Insulin supply problems Un-fully covered of insulin & prick needle	Challenge in self-management Obstacle to medical adherence Obstacle to exercise adherence (Radino) Obstacle to regularly self-monitor of BGL	Unpracticality of drugs regiment Feel bored at taking the mediations Discontinuation insulin supply in BPJS participating pharmacy Un practicality of diabetes multidrug oral medications Less access to get Insulin and prick needles	Facing psychological stress related to multiple drugs regiment Diabetes medication adherence impediments Diabetes self-monitoring adherence impediments
Lack of information Cadres had no sufficient knowledge and not acceptable in neighbourhood Need knowledge to make daily life decision Belief in myths Misperception Need more continuing HE (Moelyati) On and off patient HE programs Knowledge about diabetes is very important	Lack of knowledge to support self-management	HE infrastructure	Lack of patient empowerment program toward diabetes self-management

Appendix 30 Selected codes, categories, subthemes-themes from patient FGD-Provincial hospital

Selected Codes	Category	Sub-themes	Themes
Promotion to self-management should be provided in a primary care level Necessity of health education (HE) delegation Doctor role is to delegate HE Doctors' support patient self-management	Pathways of delegation	Absence of system to delegate patient education to nurses Limited time to support patient self-management in detail Lack of support from the management to patient education program	Disempowering system in support patient self-management
Government lack of support Lack of knowledge from government on patient empowerment resulting in lack of patients support Refusing Insulin therapy was perceived as lack of patient knowledge	Ineffective government health insurance	Patients' perceptions on diabetes long term therapy prevent best care for patients Discrepancy between science and regulation Low level of patient education	Doctors' barriers to support best medical diabetes care
Patient motivation	Demand on patient health education	Low demand on health education	Patient related problems in supporting self-management

Appendix 31 Selected codes, categories, subthemes-themes from observations-National hospital

Selected Codes	Categories	Sub-themes	Themes
Share a consultation room Interruptions from the training doctor activity	Patient privacy	Lack of privacy Noises	Unsupportive physical environment towards personal approach
Doctor aske monitoring to show on her Doctors give instructions Less patient involvement Interruption for education purposes Doctor focus on computer Nurses focus on administration/do the job Patient did not ask question Doctors asks more close questions Doctors not happy with the blood glucose monitoring	communications One way communication	Direct communications One way communication Lack of trust towards HCPs and the health care	Communication gap
Less understanding about BG monitoring Assuming patient understand about BG monitoring Not written guideline for insulin adjustment Not asking for the patient self-monitoring Lack of chance to express the problem Patient confused with blood tests	Lack of patient knowledge	Little guideline Disregarding patient self-management exploration Lack of engagement to patient competence in managing insulin	Lack of support to patient self-management
Doctor Focus on computer Nurses focus more on patient registration and collecting basic information for HER More asking for information (assessment purposes) Initiate interaction by asking BG test results	Instrumental works Assessment, prescription, lab evaluation Medical orientation	Medical assessment and intervention dominant Direct medical approach	Medical dominance in the care

Appendix 32 Selected codes, categories, subthemes-themes from patienty interview-National hospital

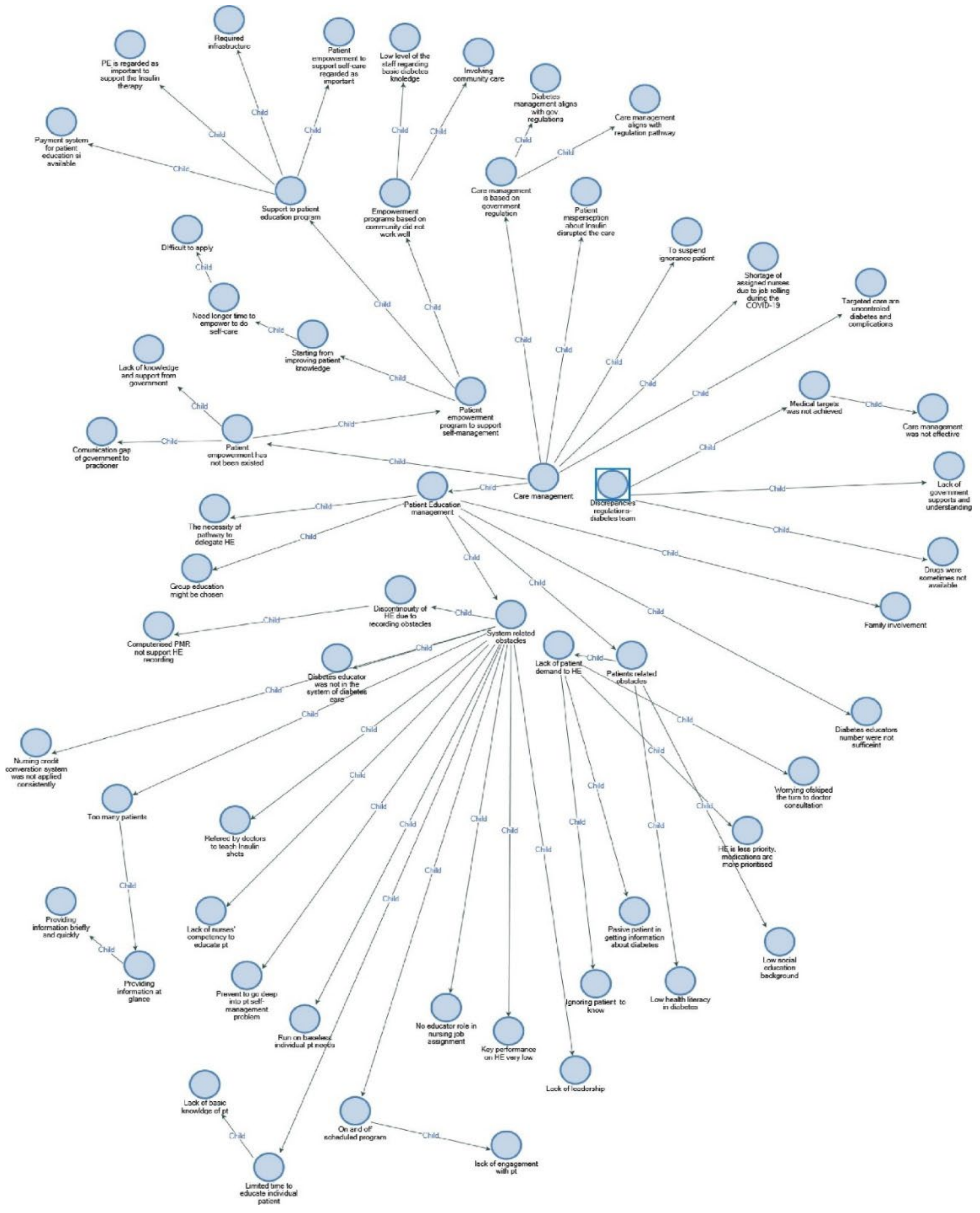
Selected Codes	Categories	Sub-themes	Themes
Geriatric and endocrine fragmented Back and forward for 2 days to go to a hospital (can do in one day lab centred) Long waiting time: doctors and very long at the pharmacy Lack of care Limited care time Ling time at the pharmacies Have to purchase simvastatin (Nani)	Fragmented care in elderly care with diabetes Care provision management for elderly Ineffective care Careless	Fragmented care for elderly Longer waiting time Lack of access to for BPJS patient Discrepancy in medical therapy standard	Disempowering care provision management
Learn about diabetes by her own Learn by own (no diabetes class) Learn from friends Medical standard Vs Payer standar	Lack of information from HCP Lack of information	Discrepancy between medical and payer standard	Lack of access for medication availability and sufficient care
Physical Barriers in accessing the care SBGM to satisfy doctors			Medical voice dominant
Dislike doctors' approach Harsh words The patient brings the notes afraid of doctor does not believe him Unfriendly and not willing to listen Nurses did not face you when they talked to you Nurses more said not her business but doctors' Doctors was not willing to listen to patient question Doctor did not read vigilantly Doctors do not understand patient problem, change very week Not sure about the efficacy and the doctor (whether doctor listening or not)	Communications issues Trust issues Lack of building rapport	Trusting relationship issues Lack of doctor' attentive Less friendliness	Communication gaps
Adjust insulin dosage without doctors'/HCP known Doctors explained in details Little guidance on insulin Little guidance on blood glucose monitoring	Patient health education Lack of guidance for insulin used and blood glucose monitoring	Missed cared of insulin Missed cared of blood glucose monitoring Lack of direction for multiple medications used	Missed cared of insulin used and self-monitoring
Less moving due to the restriction Physical problems barriers to do exercise	Self -management Impacted by the pandemic		Challenges in diabetes self-management

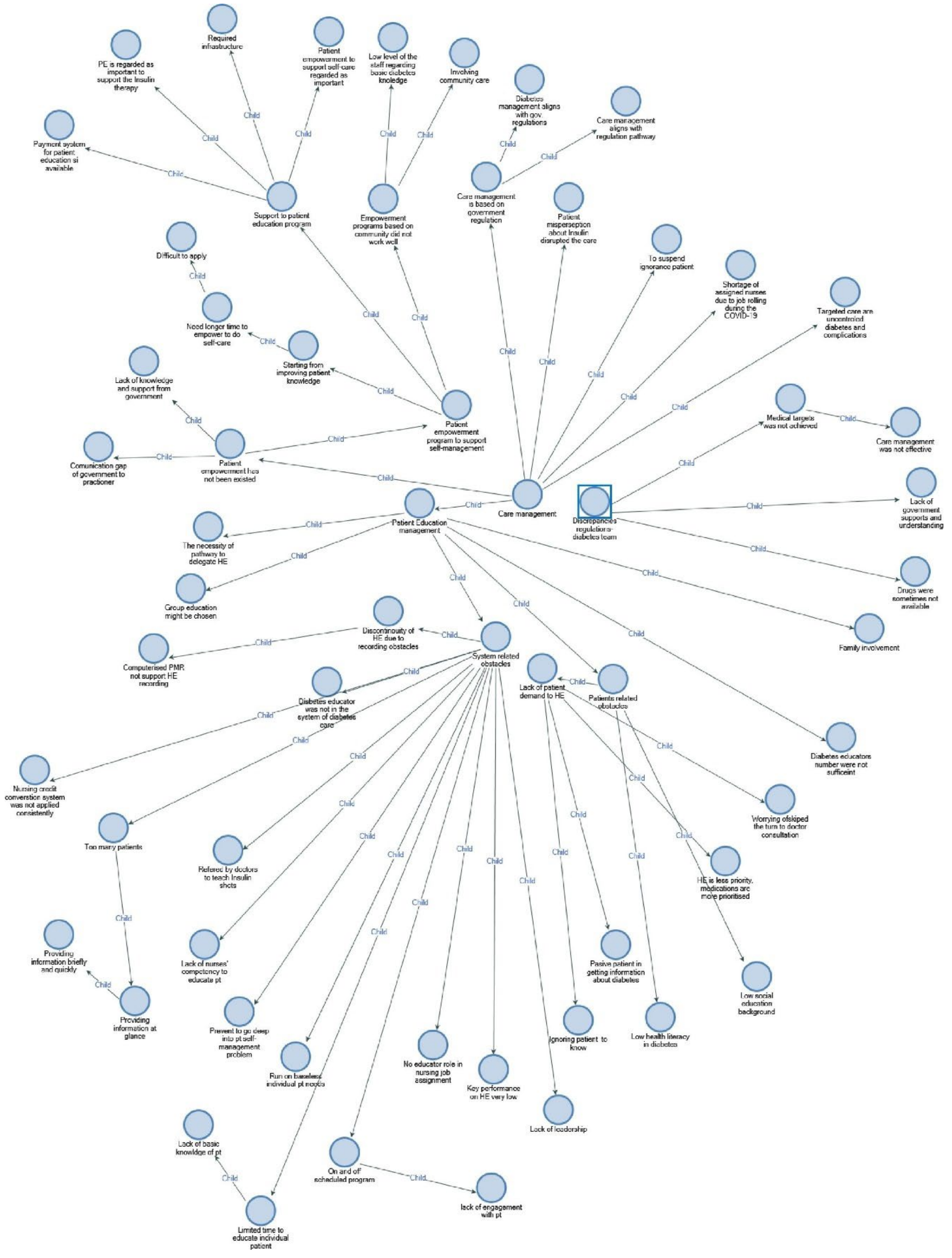
Appendix 33 Selected codes, categories, subthemes-themes from patient FGD Natrional hospital

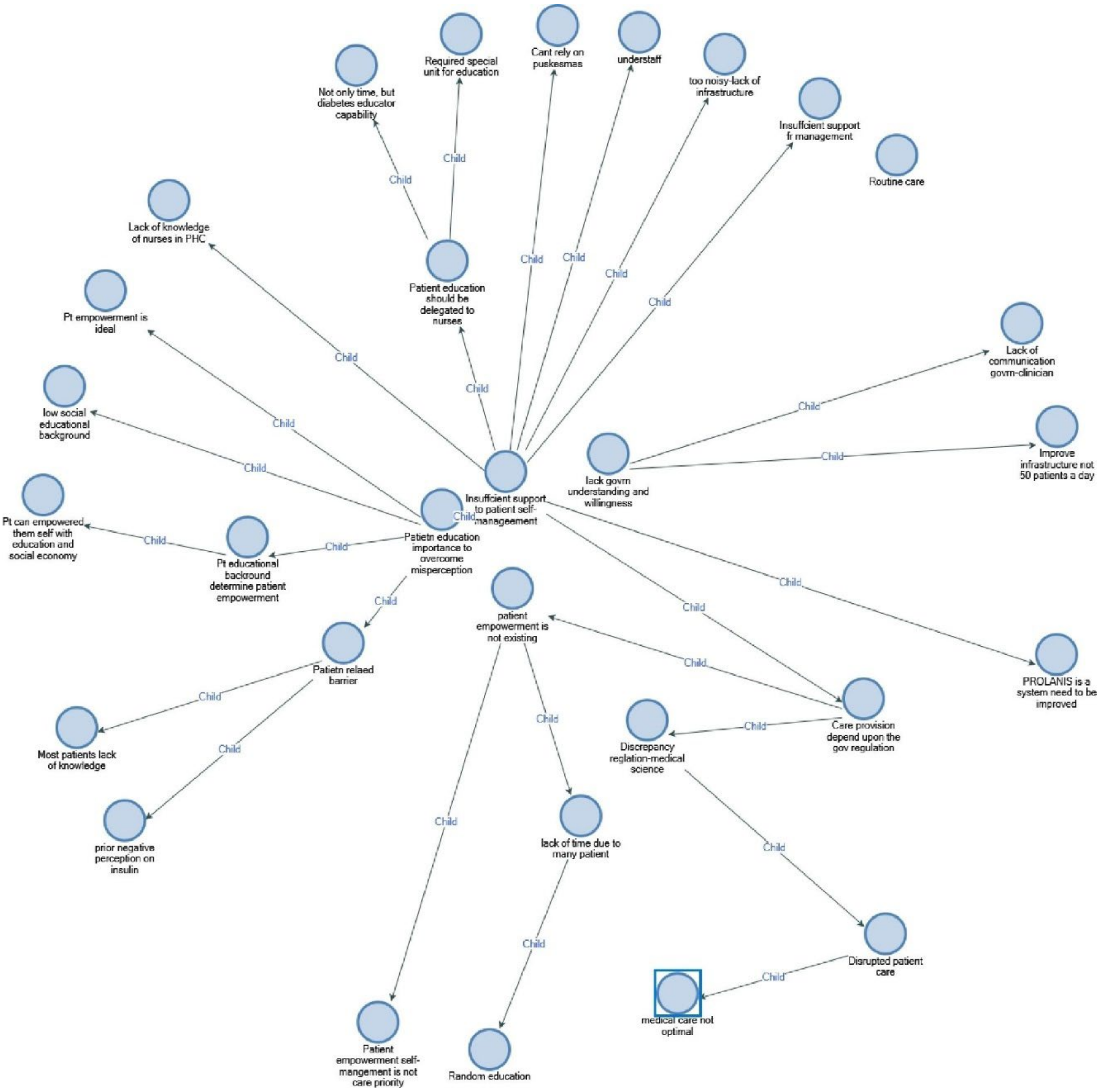
Selected Codes	Categories	Sub-themes	Themes
No interaction in the program education/no engagement Education no tariff system in BPJSK There was tariff system for patient education in the HER Just information about diabetes, not relate to patient needs Discontinuity of patient HE, just once the first and the last one Lack of time and chance due to many patients No educator's role Wait doctor to refer education	Role of diabetes educator nurse Lack of personal patient education program	Role ambiguity of 'diabetes nurse educators' No clinical standard for patient education to support self-management Discontinuity of patient education No leadership Time constraints due to many patients	Undesigned patient empowerment delivery system
No health education tariff from BPJS K There is a payment system for patient education in the HER	HE payment system	Hospital regulates payment system for patient education There is a patient education in tariff system	Discrepancy between payer and hospital system
Many patients did not attend HE program Focus patient was to get medication Low demand in patient education program Worried in missing the doctors consultation time Number of patients (80) Patient worried of missed doctors consultation Patient was in hurry Patient did not need a	Incidental patient HE	System related problems Patient related problems Run not based on patient's need	Challenges in providing structured patient education
Lack of basic knowledge Lack of diabetes nurse educators Lack of nurse Pentium/did not want to improve Lack of structured education program Not supported documentation for education program, not supported by the medical record. Assessment form was insufficient—too general Manage patient flow EHR just for assessment. No education slot on the system No facilitation for evaluation Lack of diabetes educators Limited time to educate individual patient In the system, just educators, or food care --- imbalance with non-educators –related to nursing assignment (There was matrix …of intervention) Education was low as no time according to schedule	Human resource management	Unsupportive medical record system Lack of numbers and competencies of diabetes educators Diabetes educator was not in the system of diabetes care No standard in educators and patient education Time constraint	Lack of infrastructures for diabetes patient empowerment program

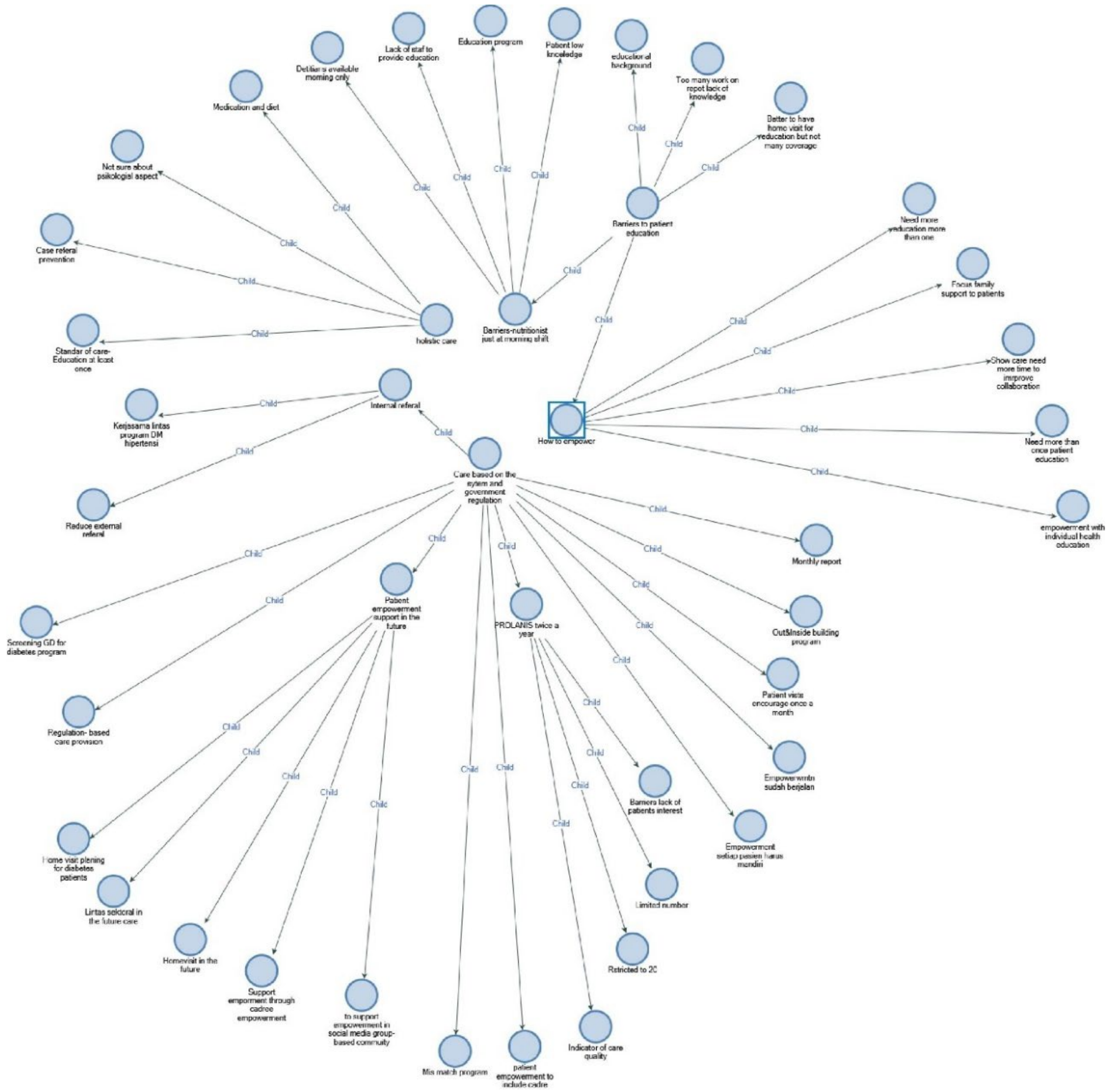
No specific educators System tariff at hospital Nurse educator on patient registration One functional nurse for educator			

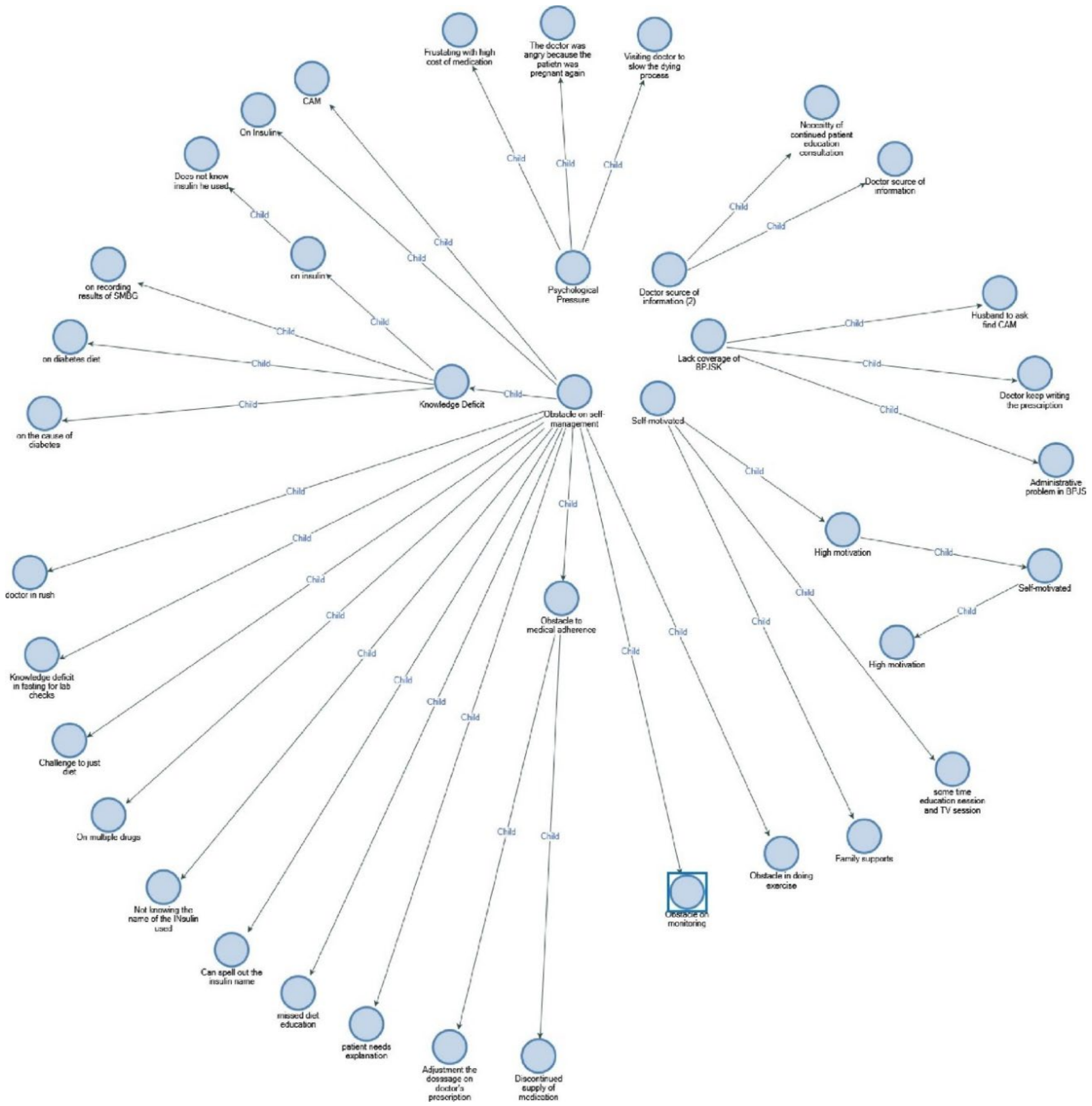
Appendix 34 NVivo output of analysis

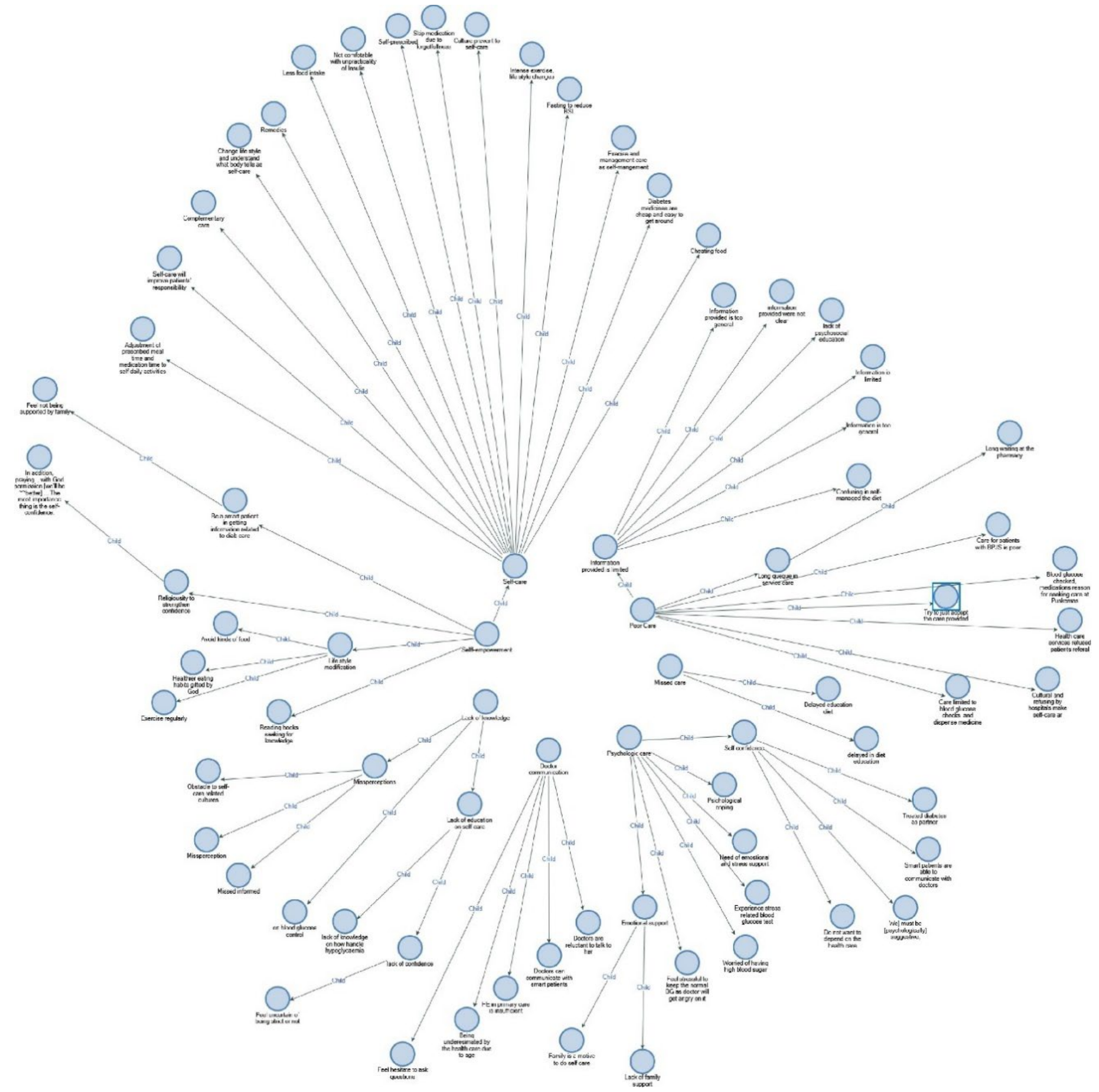


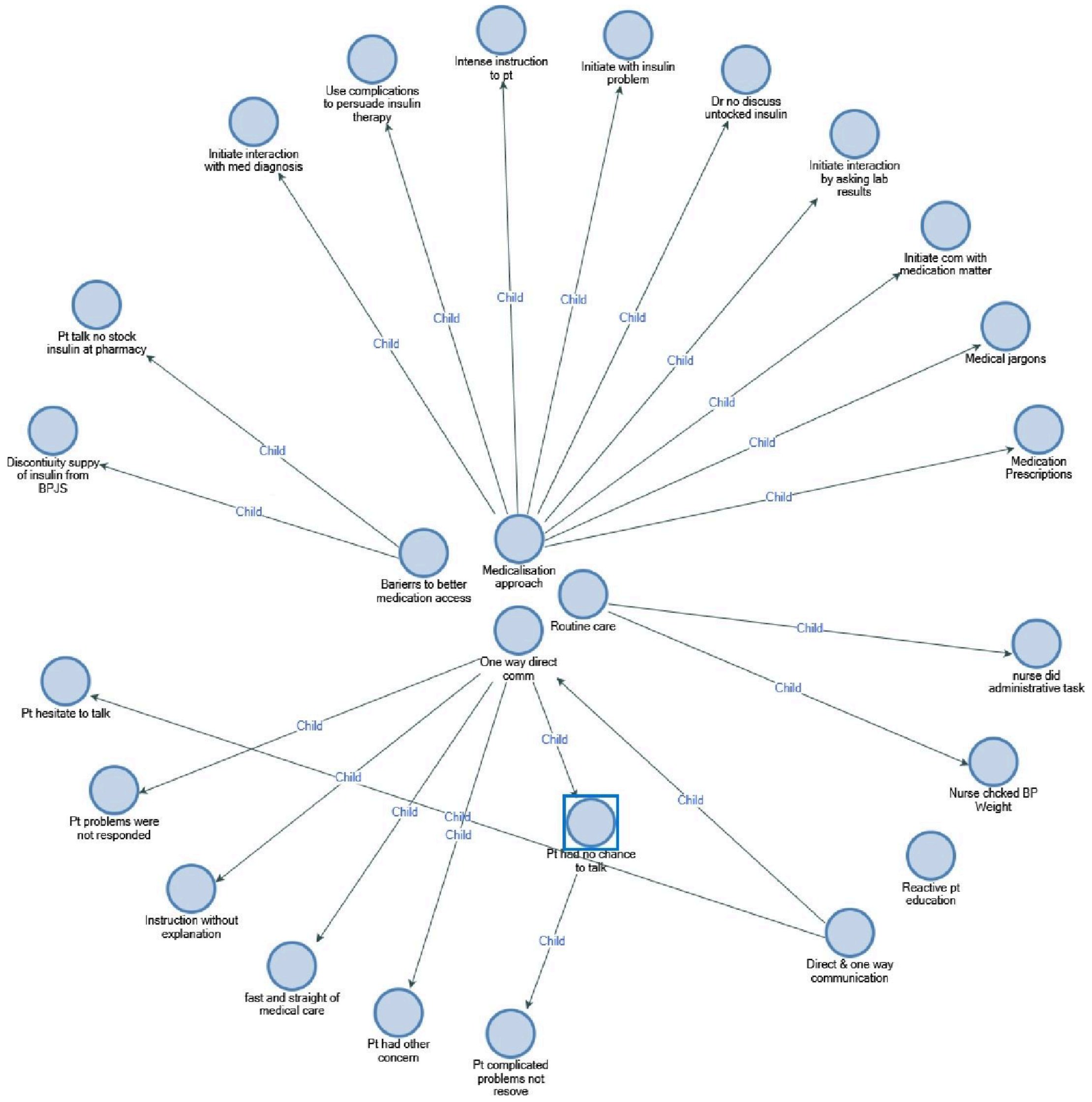

Care management
Patient Education management
Discrepancies regulations-diabetes team
Patient empowerment has not been existed
Patient empowerment program to support self-management
Support to patient education program
Payment system for patient education si available
PE is regarded as important to support the Insulin therapy
Required infrastructure
Patient empowerment to support self-care regarded as important
Empowerment programs based on community did not work well
Low level of the staff regarding basic diabetes knoledge
Involving community care
Care management is based on government regulation
Diabetes management aligns with gov. regulations
Care management aligns with regulation pathway
Patient misperseption about Insulin disrupted the care
To suspend ignorance patient
Shortage of assigned nurses due to job rolling during the COVID-19
Targeted care are uncontroled diabetes and complications
Medical targets was not achieved
Care management was not effective
Lack of government supports and understanding
Drugs were sometimes not available
Family involvement
Diabetes educators number were not sufficeint
Difficult to apply
Need longer time to empower to do self-care
Starting from improving patient knowledge
Lack of knowledge and support from government
Comunication gap of government to practioner
The necessity of pathway to delegate HE
Group education might be chosen
System related obstacles
Discontinouity of HE due to recording obstacles
Computerised PMR not support HE recording
Disbetes educator was not in the system of diabetes care
Nursing credit converstion system was not applied consistently
Too many patients
Providing information at glance
Providing information briefly and quickly
Refered by doctors to teach Insulin shots
Lack of nurses' competency to educate pt
Prevent to go deep into pt self-management problem
Run on baseless individual pt needs
Limited time to educate individual patient
Lack of basic knowldge of pt
On and off scheduled program
lack of engagement with pt
No educator role in nursing job assignment
Key performance on HE very low
Lack of leadership
Patients related obstacles
Lack of patient demand to HE
Ignoring patient to know
Pasive patient in getting information about diabetes
Low health literacy in diabetes
HE is less priority, medications are more prioritised
Low social education background
Worrying ofskiped the turn to doctor consultation
Child

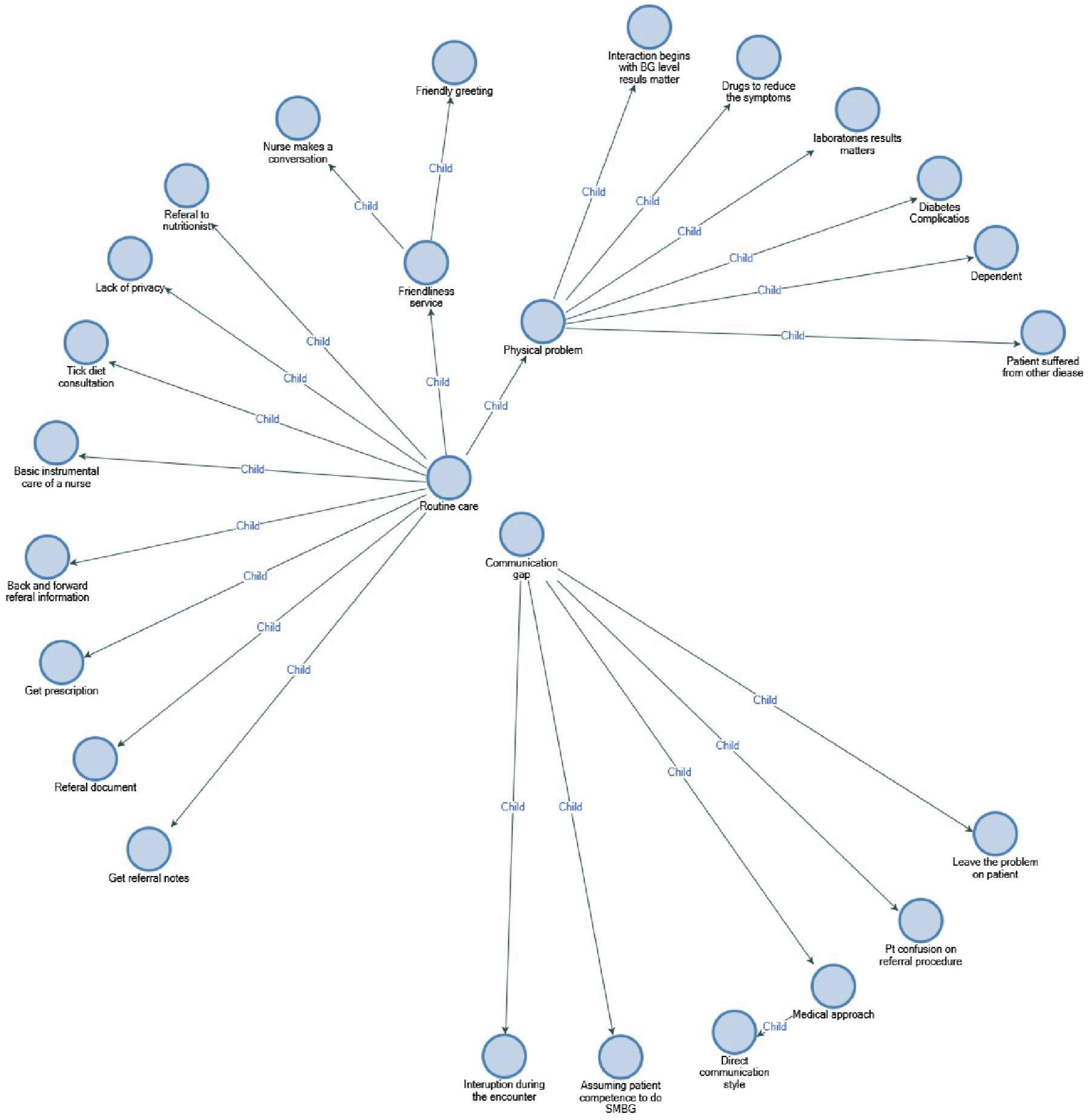

Not only time, but diabetes educator capability
Required special unit for education
Cant rely on puskesmas
understaff
too noisy-lack of infrastructure
Insuffcient support fr management
Routine care
Child
Child
Lack of knowledge of nurses in PHC
Child
Child
Child
Child
Patient education should be delegated to nurses
Pt empowerment is ideal
Child
Child
Lack of communication govrn-clinician
Child
low social educational background
Child
Child
Improve infrastructure not 50 patients a day
lack govrn understanding and willingness
Insufficient support to patient self-manageament
Child
Pt can empowered them self with education and social economy
Child
Child
Patietn education importance to overcome misperception
Pt educational backround determine patient empowerment
Child
Child
patient empowerment is not existing
Child
Patietn relaed barrier
Child
PROLANIS is a system need to be improved
Child
Child
Care provision depend upon the gov regulation
Child
Discrepancy reglation-medical science
Most patients lack of knowledge
Child
prior negative perception on insulin
Child
lack of time due to many patient
Child
Child
Disrupted patient care
Child
medical care not optimal
Patient empowerment self-mangement is not care priority
Random education

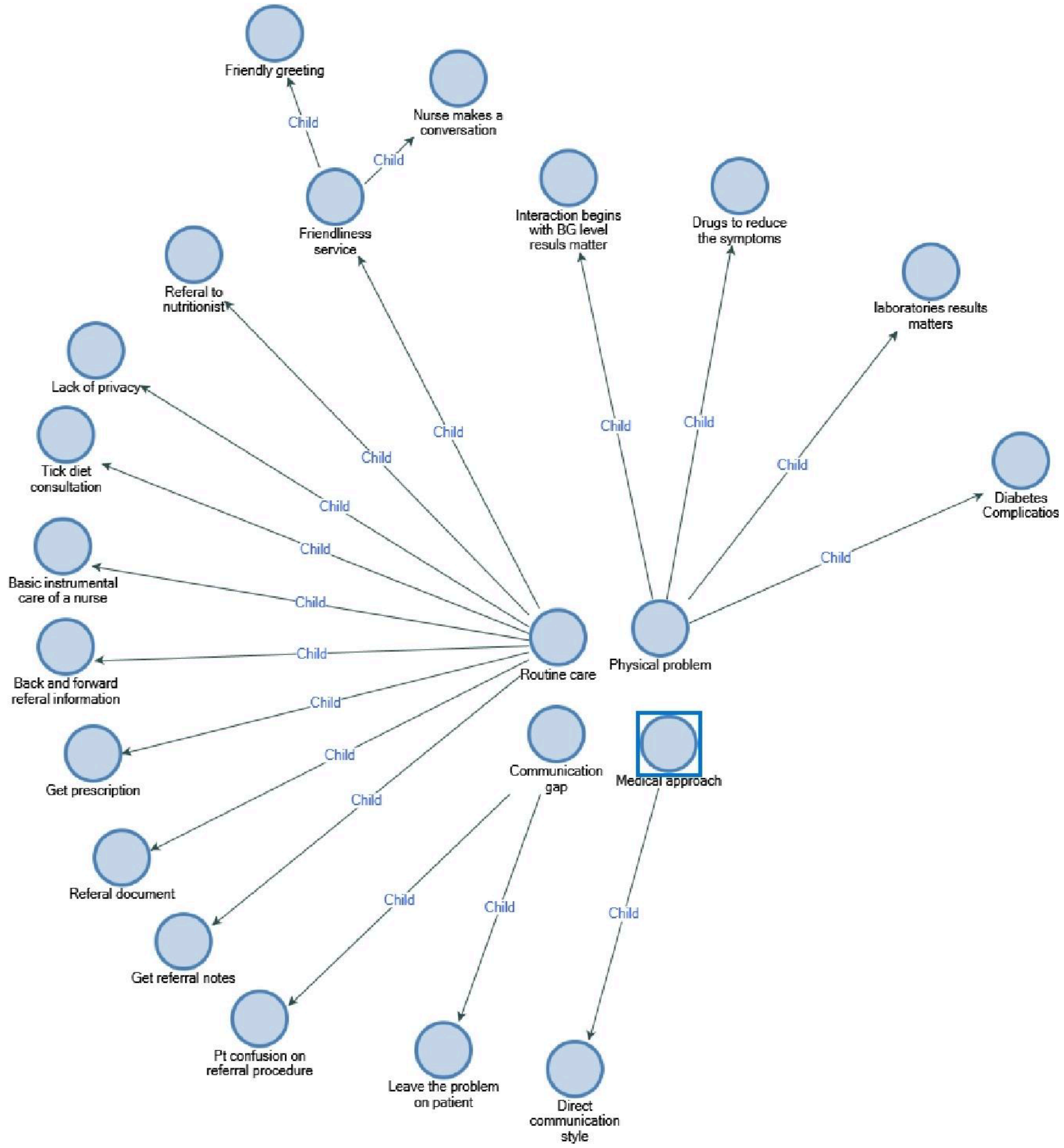

Detitians available morning only
Lack of staf to provide education
Education program
Patient low knceledge
educational background
Too many work on repot lack of knowledge
Better to have home visit for education but not many coverage
Medication and diet
Not sure about psikologial aspect
Case referal prevention
Barriers to patient education
Need more education more than one
Focus family support to patients
Standar of care-Education at least once
holistic care
Barriers-nutritionist just at morning shift
Show care need more time to improve collaboration
Internal referal
Kerjasama lintas program DM hipertensi
How to empower
Need more than once patient education
Care based on the sytem and government regulation
Reduce external referal
empowerment with individual health education
Monthly report
Patient empowerment support in the future
PROLANIS twice a year
Screening GD for diabetes program
Out&Inside building program
Patient vists encourage once a month
Regulation- based care provision
Empowerwmtn sudah berjelan
Barriers lack of patients interest
Empowerment setiap pasien harus mandiri
Home visit plening for diabetes patients
Lintas sektoral in the future care
Limited number
Homevisit in the future
Rstricted to 20
Support emporment through cadree empowerment
to support empowerment in social media group-based commuity
Indicator of care quality
Mis match program
patient empowerment to include cadre
Child


Frustating with high cost of medication
The doctor was angry because the patietn was pregnant again
Visiting doctor to slow the dying process
CAM
On Insulin
Does not know insulin he used
on insulin
Psychological Pressure
Necessitty of continued patient education consultation
Doctor source of information
Doctor source of information (2)
on recording results of SMBG
on diabetes diet
on the cause of diabetes
Knowledge Deficit
Obstacle on self-management
Lack coverage of BPJSK
Husband to ask find CAM
Doctor keep writing the prescription
Administrative problem in BPJS
Self-motivated
High motivation
Self-motivated
High motivation
doctor in rush
Knowledge deficit in fasting for lab checks
Challenge to just diet
On multiple drugs
Not knowing the name of the INsulin used
Can spell out the insulin name
missed diet education
patient needs explanation
Obstacle to medical adherence
Adjustment the dossage on doctor's prescription
Discontinued supply of medication
Obstacle on monitoring
Obstacle in doing exercise
Family supports
some time education session and TV session
Child


Less food intake
Not comfotable with unpracticality of Insulin
Self-prescribed
Skip medication due to forgetfullness
Culture prevent to self-care
Intense exercise, life style changes
Fasting to reduce RSI
Remedies
Change life style and understand what body tells as self-care
Exersie and management care as self-mangement
Diabetes medicines are cheap and easy to get around
Complementary care
Cheating food
Self-care will improve patients' responsibility
Adjustment of prescribed meal time and medication time to self daily activities
Information provided is too general
Information provided were not clear
lack of psychosocial education
Information is limited
Information is too general
Confusing in self-managed the diet
Long waiting at the pharmacy
Feel not being supported by family
In addition, praying... with God permission [we'll be ***better] ... The most importance thing is the self-confidence.
Be a smart patient in getting information related to diab care
Self-care
Information provided is limited
Long queque in service care
Care for patients with BPJS is poor
Blood glucose checked, medications reason for seeking care at Puskesmas
Try to just accept the care provided
Poor Care
Health care services refused patients referal
Religiousity to strengthen confidence
Avoid kinds of food
Life style modification
Self-empowerment
Healthier eating habits gifted by God
Exercise regularly
Reading books seeking for knowledge
Missed care
Delayed education diet
Care limited to blood glucose checks and dispense medicine
Cultural and refusing by hospitals make self-care ar
Lack of knowledge
Doctor communication
Psychologic care
Self confidence
delayed in diet education
Missperceptions
Obstacle to self-care related cultures
Missperception
Missed informed
Lack of education on self care
Psichological coping
Treated diabetes as partner
Need of emotional and stress support
Smart patients are able to communicate with doctors
Experience stress related blood glucose test
on blood glucose control
lack of knowledge on how handle hypoglycaemia
Doctors are reluctant to talk to her
Emotional support
Do not want to depend on the health care
[We] must be [psychologically] suggestive.
lack of confidence
Doctors can communicate with smart patients
Worried of having high blood sugar
Feel stressful to keep the normal BG as doctor will get angry on it
Feel uncertain of being afraid or not
HE in primary care is insufficient
Being underestimated by the health care due to age
Feel hesitate to ask questions
Family is a motive to do self care
Lack of family support
Child


Intense instruction to pt
Initiate with insulin problem
Use complications to persuade insulin therapy
Dr no discuss untocked insulin
Initiate interaction with med diagnosis
Initiate interaction by asking lab results
Initiate com with medication matter
Child
Child
Child
Child
Pt talk no stock insulin at pharmacy
Child
Medical jargons
Child
Child
Child
Discontiuity suppy of insulin from BPJS
Child
Medication Prescriptions
Child
Child
Medicalisation approach
Barierrs to better medication access
Routine care
Child
One way direct comm
nurse did administrative task
Pt hesitate to talk
Child
Child
Child
Child
Pt problems were not responded
Child
Child
Child
Child
Nurse chcked BP Weight
Pt had no chance to talk
Reactive pt education
Instruction without explanation
Child
Direct & one way communication
fast and straight of medical care
Pt had other concern
Pt complicated problems not resove


Friendly greeting
Nurse makes a conversation
Child
Child
Friendliness service
Referal to nutritionist
Lack of privacy
Tick diet consultation
Basic instrumental care of a nurse
Back and forward referal information
Get prescription
Referal document
Get referral notes
Child
Child
Child
Child
Child
Child
Child
Child
Child
Child
Routine care
Interaction begins with BG level resuls matter
Drugs to reduce the symptoms
laboratories results matters
Diabetes Complicatios
Dependent
Patient suffered from other diease
Child
Child
Child
Child
Child
Child
Physical problem
Communication gap
Child
Child
Child
Child
Child
Leave the problem on patient
Pt confusion on referral procedure
Medical approach
Child
Direct communication style
Interuption during the encounter
Assuming patient competence to do SMBG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Leave the problem on patient
Direct communication style
Diabetes Complicatios
Routine care
Physical problem
Communication gap
Medical approach
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Child
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Child