

UNIVERSITI TEKNOLOGI MARA

**AN EXPLORATION OF DIABETES
SELF-MANAGEMENT AMONG
YOUNG PEOPLE WITH TYPE 2
DIABETES MELLITUS**

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ABSTRACT

Life-long patient-driven self-management is the cornerstone in mitigating diabetes-related complications, however, studies showed that diabetes self-management interventions for young people with type 2 diabetes mellitus (T2DM) yielded mixed results in changing behaviours and glycaemic control. Also, information on diabetes self-management practices among young people with T2DM in Malaysia remains scarce. This study aimed to investigate the lived experience of disease management from the perspectives of young patients with T2DM, caregivers and healthcare professionals (HCPs). First, a meta-synthesis was conducted to identify the factors influencing diabetes self-management among young people. A systematic search was conducted using PubMed, Scopus, Web of Science (WoS) and Cumulative Index to Nursing and Allied Health Literature (CINAHL) to identify peer-reviewed articles. Quality appraisal was performed using the Critical Appraisal Skills Programme (CASP). All extracted data underwent thematic analysis using the socio-ecological model as a framework. The meta-analysis identified intrapersonal, interpersonal and institutional factors affecting diabetes self-management among young people with T2DM. Next, series of qualitative studies utilised a phenomenological approach delved into the informants' lived experience of diabetes self-management with the aid of semi-structured interview guides. All informants (young people, caregivers, and HCPs) were recruited using purposive, maximal and snowball sampling methods from endocrine department Hospital Pulau Pinang and Hospital Putrajaya. A total of sixteen young people (13 to 23-years), eleven primary caregivers and sixteen multidisciplinary HCPs [diabetes nurse educators (n=3), pharmacists (n=3), staff nurses (n=3), occupational therapists (n=2), dietitians (n=2), assistant medical officers (n=2) and a medical officer] were interviewed. Data were transcribed verbatim and analysed thematically with the aid of NVivo version 12. Patients' diagnosis route and experiential knowledge could shape diabetes self-management. Awareness, willingness to learn, shared values, caregiver's involvement, social acceptance, open discussion with HCPs, and information seeking through social media and the Internet promote self-management behaviours. In contrast, feeling stigmatised and afraid of judgment, low self-esteem, lack of family understanding, forced autonomy, peer influence towards unhealthy diet, poor interaction with HCPs, lack of healthy food choices and limited exposure to T2DM programmes hinder diabetes self-management. HCPs needed to embrace challenges such as patients underrate disease severity, lack of social support and budget constraint while providing diabetes care. Building rapport, revising diabetes management plans according to patients' capability were deemed effective whilst threatening tactics should be reserved for resistant patients. Interactive educational methods and community-based support should be in place. The study findings enrich our understanding on young patients' diverse experiences in T2DM management, as well as multifactorial influences that could either facilitate or hinder diabetes self-management. These findings lay the groundwork for future young people centred interventions and support systems in supporting young people in life-long diabetes self-management.

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CHAPTER 1

INTRODUCTION

1.1 Introduction

The first chapter of thesis presents the study background, problem statement, research questions, research objectives, significance of the study and overview of thesis structure.

1.2 Study Background

Diabetes mellitus (DM) is a metabolic disease characterised by a prolonged state of hyperglycaemia due to insufficient insulin production and/or insulin resistance (American Diabetes Association, 2021a). The three major types of DM includes type 1 diabetes mellitus (T1DM), type 2 diabetes mellitus (T2DM) and gestational diabetes (GDM) (International Diabetes Federation, 2017). T1DM is characterised by absolute insulin deficiency resulted from autoimmune destruction of the insulin-producing β -cells in the islet of Langerhans (Copeland et al., 2013a). T2DM is characterised by variable defect of insulin secretion and action (Hurtado & Vella, 2018) while GDM refers to glucose intolerance during pregnancy (World Health Organisation, 2019). The other less common types of DM include monogenic and secondary DM (World Health Organisation, 2019).

A total of 537 million adults aged 20-79 were living with DM in 2021 and the prevalence is expected to rise to 643 million by 2030 and 783 million by 2045 worldwide (International Diabetes Federation, 2021). Alarmingly, the prevalence of DM in the Western Pacific region (including Malaysia) was 88 million in the year 2019, increased to 160 million in 2021 and the number is expected to rise to 260 million by 2045 (International Diabetes Federation, 2021). The prevalence of DM in Malaysia had marked a 68.3% increment from 11.2% in year 2011 to 18.3% in year 2019 and expected to affect 7 million (equivalent to 31.3%) Malaysian adults (18 years and above) by 2025 (Institute for Public Health, 2019). Notably, T2DM accounts for 90% of the reported DM cases (International Diabetes Federation, 2021).