

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.