The Relationship between Illness Perceptions, Self-Management, and Quality of Life in Adult with Type 2 Diabetes Mellitus

Abstract

Introduction : Few studies have evaluated the relationship between illness perception, self-management, and quality of life in adult with type 2 Diabetes Mellitus (DM), particularly in resource limited setting such as Indonesia.

Objective : This study aimed to evaluate the relationship between illness perception, self-management, and quality of life in adult with type 2 DM in Indonesia.

Method : The inclusion criteria were adult aged over 18 years old and diagnosed with type 2 DM. Convenience sampling was used in this study. This study used the following instrument: World Health Organization Quality of Life-BREF (WHOQOL-BREF), The Brief Illness Perception Questionnaire (B-IPQ), and Diabetes Self-Management Questionnaire (DSMQ). A Hierarchical regression models were constructed by using the score of overall QOL and those for each domain as the dependent variables.

Result : A total of 351 patients with type 2 DM was recruited (response rate= 97.50%). The mean age was 54 (SD=8.14) years old and the mean time living with type 2 DM was 92 (SD=82.88) months. Higher illness perception score was significantly associated with lower physical health scores (β = -.395, SE = .096), psychological health (β = -.365, SE = .110), social relationships (β = -.363, SE = .138), and environment health (β = -.367, SE = .105).

Conclusion : The findings indicated that poorer illness perceptions are associated with a lower quality of life. The findings establish a foundation for future interventions

aimed at altering illness perceptions in order to promote self-care and improved quality of life in people with diabetes.

Keywords: diabetes mellitus, illness perceptions, self-management, quality of life.

Introduction

Diabetes mellitus (DM) is one of the most common health conditions, and its prevalence continues to rise, putting pressure on health-care systems around the world (International Diabetes Federation) (IDF, 2019). DM is estimated to affect 463 million people (9.3 percent of the global adult population (20–79 years) in 2019; this figure is expected to rise to 578 million (10.2 percent) in 2030 and 700 million (10.9 percent) in 2045 (IDF, 2019; Saeedi et al., 2019). In most countries, the number of adults with type 2 diabetes is rising; it now accounts for 90% of all diabetes worldwide (IDF, 2019; Saeedi et al., 2019). In total, DM killed over 4.2 million people, and at least USD760 billion in total medical spending was attributable to it each year in 2019 (IDF, 2019; Saeedi et al., 2019). Indonesia is the country with the sixth highest number of DM in the world. The prevalence of (DM) in Indonesia has increased from 6.9 % in 2013 to 8.5% in 2019. Many people with diabetes who do not routinely take anti-diabetes drugs or insulin injections, with the reason was more than 50% feeling healthy and only 75% of people with diabetes received a treatment (Ministry of Health, 2018). The World Health Organization (WHO) predicted that in 2030, approximately 21,3 million people with DM in Indonesia (WHO, 2018).

Literature review

DM is a chronic disease that can have a negative impact on one's health as well as their quality of life (QOL)(Jing et al., 2018). QOL is defined as the individual

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perception of a person's physical, emotional, and social status (Dickerson et al., 2011; Rubin & Peyrot, 1999). Evidence show that adult with DM have lower QOL than the general population (Bădescu et al., 2016; Norris et al., 2011; Petrak et al., 2015). Presence of complication, longer duration of diabetes, depression, non-adherence to medication and lack of self-care were associated with a worse QOL (Ali et al., 2010; Jing et al., 2018; Pozzo et al., 2016; van der Feltz-Cornelis et al., 2010). In addition, people with DM suffer from low mental well-being due to fear of complications and the overwhelming complexity of self-management regimens (Pintaudi et al., 2015; Rubin & Peyrot, 1999). Incorporating QOL assessment in clinical practices is needed to provide a good estimate of disease control and preventing the patient's QOL to get worse (Saleh et al., 2015).

Many people who have DM struggle to meet the prescribed diabetes treatment guidelines (Gonzalez et al., 2016). The complex behavioral standards for diabetes self-management including daily treatment, blood glucose self-monitoring (BGMS), adjustments in nutrition and physical activity, foot self-care and health care visits (Hunter, 2016). Previous study proved that previous research indicated that a low level of diabetes self-management practices was connected to poorer glucose control, increased hospitalization and mortality rate (Feldman et al., 2014; Hood et al., 2009)(Cho et al., 2011; Currie et al., 2012). Beliefs regarding disease and care have become a priority beyond the comprehension of various theoretical structures for understanding health behavior. A recent study of diabetes health beliefs found that the Common Sense Self-regular Model (CSM), which acknowledges the cognitive and emotional mechanisms involved in disease self-management, has a unique benefit among various theoretical models of health beliefs (Hagger et al., 2017) .

The CSM is a self-regulatory model that views patients as agents acting in a socio-cultural sense, with their behaviors mediated by illness values such as recognition (symptoms and labels), presumed cause, anticipated timetable, consequences, and anticipated controllability, as well as measured feedback on the outcomes of their coping behavior (Gonzalez et al., 2016). The CSM is a framework for investigating the processes that individuals use to manage ongoing and future health threats. A critical component of the CSM is illness perception, which relates to the emotional or cognitive recognition of a health threat. Illness perception encompasses five different dimensions: (1) consequences, (2) causes, (3) identity, (4) timelines, and (5) control or cure (Broadbent, Petrie, Main, & Weinman, 2006; Hagger & Orbell, 2003). Addressing illness perception could be an important information to understand its effect on self-management and quality of life. If it's positive impact, then the healthcare providers need to pay more attention on patients' belief and understanding of a medical condition and its potential consequences in order to improve their quality of life.

Evidence suggested that negative illness perceptions were associated with psychological well-being, adherence to DM management program, and quality of life, (Hudson et al., 2014; Skinner et al., 2014); (Hudson et al., 2014; Scollan-Koliopoulos et al., 2013). Empirical research found that better compliance was related to perceptions of necessity and fewer health problems (Horne et al., 2013). A number of studies previously have examined perceptions of illness, self-care, adherence, and well-being separately. However, only a few studies have tried to look at the perception of illness, self-management, in resource-constrained environments such as Indonesia. Based on the CSM, it was predicted that worse disease perceptions will be linked to poorer self-management and QOL. Thus, we sought to assess the

relationship between illness perception, self-management, and QOL, as well as self-management and QOL among adults with type 2 DM in Indonesia.

Materials

Design

A cross-sectional design was used in this study. The data collection period was June to August 2019. Participants were invited to participate in this study if they visited one of four referral hospitals in Jakarta, Indonesia. Patients in Jakarta have a significantly higher prevalence of diabetes than the national average in Indonesia.

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Sampling

All participants had been diagnosed with type 2 diabetes mellitus and met the following criteria for inclusion: (a) over the age of 18, and (b) capable of understanding written and spoken Bahasa Indonesia. Patients with psychological disorders or cognitive issues, as well as pregnant women, were excluded from the research. We chose not to include this study as those people with special concerns for diabetics and diabetes management are already represented. In this study, convenience sampling was used.

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Data collection

Ethical permission was granted from the hospitals. Adults with type 2 diabetes were recruited when they went to the outpatient department for a routine check-up. The hospital's manager assisted in identifying prospective applicants who met the recruiting requirements. For data collection, two research assistants were qualified and standardized. Researchers obtained written consent from every person who agreed to participate in the questionnaire. This questionnaire took about 30 to 45 minutes to fill out.

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Measurements

The following information was collected: age, time since diagnosis, sex, marital status, education, religion, occupation. Information about time since diagnosis was confirmed with their medical records.

The World Health Organization Quality of Life-BREF (WHOQOL-BREF) was used to assess patient's quality of life specific for diabetic patients. This instrument has been widely used internationally and, in several research, examining QOL in patients with diabetic in Indonesia. The questionnaire consists of 26 items, two question from perspective participants about their general quality of life and general health, the other 24 questions were divided into four domains: physical health, psychological health, social relationships, environment health. The answer of each question was being rated on a 5-point Likert's scale. Raw score in each domain then transformed to 1-100 score according WHOQOL-BREF guideline (WHO, 1998). Highest score is indicated better QOL. In this study, permission to translate the instrument into an Indonesian version was obtained and the results of Cronbach's α coefficients ranging from 0.79 to 0.84.

The Brief Illness Perception Questionnaire (B-IPQ) was used to assess the illness perception of adult with type 2 DM developed (Broadbent et al., 2011). This questionnaire was used to assess illness perception. It contains nine questions, eight of which use a single-item scale from 1 to 10, and one of which is an open-ended question which the participants may reacts with what people perceive to be significant factors contributing to their diabetes. (Broadbent et al., 2011). The B-IPQ measures nine domains: consequences, timeline, personal control, treatment control, identity, concern, understanding, emotional response, and causal representation. The overall score of B-IPQ is the sum of each domain score, with the

exception of the 9th area. The B-IPQ score is 8-10, when higher scores show a more destructive view of disease. The B-IPQ has a standardized Indonesian version that has been used for people with type 2 DM with Cronbach's α coefficients ranging from 0.79 to 0.85 (Indrayana et al., 2019).

Self-management. Diabetes Self-Management Questionnaire (DSMQ) used to measure self-management in patients with T2DM, developed (Schmitt et al., 2013). The DSMQ is a reliable and valid instrument for efficiently assess self-behavior associated with glycemic control (Schmitt et al., 2013). These are all self-administered questionnaires. They consist of 16 individual items in four subcategorized into four separate domains. The measured subdomains include glucose management, control of diet, physical activity and health. An overall measure of the self-care was derived from a sum score. Each item was scored on a four-point Likert's type scale, ranging from 0 (does not apply to me) to 3 (applies to me very much). The highest score indicates greater self-control. This questionnaire has been translated into Indonesian version and used for people with type 2 DM with Cronbach's α coefficients ranging from 0.81 to 0.86 (Ramadhani et al., 2019).

Statistical analysis

The demographic data, the quality of life, the perception of illness, and self-management were analyzed using a descriptive analysis. A QOL was computed using hierarchical regression models with overall quality of life as the dependent variable and those for each of the domains as explanatory variables. Included variables in the regression analysis were decided based on p value of .2 or .25 (Hosmer and Lemeshow). In the first model, demographic data were entered. The second model included illness perception and self-management. The regression model produced the total score and scores for each domain of QOL. To determine

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the significant association, a 2-tailed alpha of 0.05 was used to determine statistical significance. The Statistical Package for the Social Sciences (SPSS) version 22.00 for Windows was used to perform the analyses.

Results

A total of 351 patients with type 2 DM agreed to participate in this study with response rate was 97.50%. The majority of the participants were female (70%), married (87%), 45% had less than senior high education (7% no formal education, 18% elementary, 21% junior high), Islam (88%), and unemployed (70%). The mean age was 54 years old (SD=8.14), ranged from 23 to 65 years old. The mean time living with type 2 DM was 92 months (SD=82.88), ranged from 3 months to 576 months (Table 1).

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The average score for four domains of quality of life was 38.98. The highest mean score of QOL domains was environment domain (45.53 ± 17.29) and the lowest domain was social relationship (33.14 ± 21.25). The mean score of illness perception was 46.73 (SD=8.41), ranged from 11 to 73. The highest mean score was concern domain (7.28 ± 1.80), while lowest mean score was treatment control (3.58 ± 2.64). The mean score of patient's self-management in this study was 28.67 from possible score of 42, with each domain average of 6.73. Glucose management domain was the highest with average score of 9.17 (SD=1.99), while physical activity was the lowest with mean score of 4.37 (SD=1.66) (Table 2).

In bivariate analysis there were no significant association in terms of age (p value=.56), sex (p value=.72), marital status (p value=.43), and religion (p value=.33) with all domains of QOL. Only occupation (employed vs unemployed) and education (≤ 9 years and >9 years) were significantly associated with all domains of QOL. Also, time living with type 2 DM was significantly correlated with all domains of quality of life (Table did not show).

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Table 3 shows a hierarchical regression of the relationship between illness perception, self-management, and quality of life. Higher illness perception score was significantly associated with lower physical health scores (β = -.395, SE = .096), psychological health (β = -.365, SE = .110), social relationships (β = -.363, SE = .138), and environment health (β = -.367, SE = .105). In addition, education was negatively associated with psychological health and social relationships (β = -.120, SE = .096; β = -.133, SE = .965, respectively), and time since diagnosed was also negatively associated with physical health (β = -.100, SE = .009). We did not find a significant association between self-management and quality of life (Table 3).

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Discussion

The majority of people with type 2 DM in this study reported moderate level of illness perceptions with the highest score was concern domain and the lowest score was treatment control. A previous study conducted in China found that the timeline dimension had the highest mean score of illness perception domain, while the coherence dimension had the lowest (Nie et al., 2018). Several studies have shown that illness perception is important in diabetes self-management and well-being (Abubakari et al., 2011; Nsereko et al., 2013). According to the common-sense self-regulation model (CSM-SR) (Hagger et al., 2017), People facing a health risk like being diagnosed seem to develop affective and psychological perceptions that decide how to gather coping processes and behavioural patterns, and how to evaluate the results of treatment in reaction to the health condition perceived. Thus, people may also believe these concepts because they have limited diabetes-related health literacy (Hu et al., 2013), despite the fact that the majority of participants were unemployed and had low education. Therefore, it' s very important for healthcare professional to provide comprehensive education package to not only improve their knowledge but also their perception and belief toward type 2 DM.

This study found that majority of people with type 2 DM have sub-optimal of self-management with the highest score in glucose management and the lowest was physical activity. The findings from previous systematic reviews showed that Sub-Saharan Africans were less likely to self-monitor their glucose levels, had low level of activity, and adhered to moderate recommendations about diet and medication routines (Stephani et al., 2018). The American Diabetes Association (ADA) reported that good glycemic control associated with a reduction of complication (Shrivastava et al., 2013). While glucose management appears to be better, it is correlated with

multiple individual and environmental factors that either encourage or impede good self-management but are still sub-optimal self-management. Lack of physical activity, however, poses a significant challenge to healthy glycemic regulation. The previous review reported that the most commonly encountered barriers to getting more physical activity are lack of space, fear of making exercise problematic, and bad weather conditions (Adeniyi et al., 2016). Therefore, further study investigating physical activity among people with type 2 DM is necessary in order to promote concordance with the treatment regimen and improve glycaemic control.

Poorer illness perceptions were associated with poorer QoL. These findings are consistent with past research demonstrating that poorer illness perceptions are associated with poorer QoL (Knowles et al., 2020; Scollan-Koliopoulos et al., 2013). The correlation between understanding of illness and health outcomes may be due to the fact that engaging in self-care activities requires nuanced decision-making that relies on the patient's interpretation of their disease as to whether or not it is controllable, understandable, curable, cyclical and serious (Kugbey et al., 2017). The findings of current studies show that QoL is associated with the way people view their diabetes. Thus, intervention to enhance the understanding of disease is required in order to improve the quality of life of the patient. Previous study has shown that techniques such as mindfulness, intended to help people be more aware and interested in their symptoms, will result in improved symptom control. Research has found that meditation interventions could have a positive impact on general well-of-being and quality of life for people with type 2 DM (Schroevers et al., 2015; van Son et al., 2013).

Surprisingly, this study revealed no association between self-management and QOL. Previous study has reported that self-management in terms of blood

glucose testing, diet, and exercise were significantly associated with QoL (Kueh et al., 2015). Differences in this finding may due to the instrument that was used to measure QOL was not specific for people with diabetes. Previous study emphasised that combination of dietary factors such as fat and sugar, and increased exercise has not only improved glycosylated haemoglobin measures, which indicate positive control of blood glucose levels among people with diabetes, but these lifestyle changes also significantly improve general QoL (Feldman et al., 2014). The combination of diet and exercise may improve quality of life throughout symptoms control, HBA1C level control, or other diabetic complication. About 95% of diabetes care has been reported to be self-treatment or self-management (Gonzalez et al., 2016). Individuals have to control their regular lifestyle activities to regulate diabetes, and sometimes have to adjust long-held habits.

Study Limitation

For this analysis, all variables have been subjectively evaluated using self-report questioning so that reporting biases like the influence of an acceptable social response can occur (Marchini et al., 2019). Furthermore, the lack of administration consistency may have affected the participants' willingness to fill out questionnaires when they were willing to do so was acceptable. The findings' generalizability is limited due to a lack of evidence on disease characteristics (e.g., HbA1c). Future work should include research into possible mediators that influence psychosocial factors, like social support, medication adherence, and trust in providers.

Clinical Implications

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The findings from this research have some practical implications for healthcare delivery of diabetes. First, the important correlations observed between the predictor variables (perception of disease and quality of life) indicate the need to train healthcare professionals (nurses) to meet the chronic care needs of diabetes sufferers. Furthermore, to support individual self-management, nurses and doctors should be provided with tools to meet the self-management needs of diabetes patients in the form of information leaflets and other related materials, particularly in Indonesia where such of are not available in all healthcare settings. Such research on self-management may provide research on the causes, prognosis and techniques for management. Finally, since community education is commonly conducted in the different units of diabetes, it is advised that individual needs should also be taken into account due to differences in educational rates and understanding of educational content, especially related to the culture, belief, religion regarding diet and care belief which is part of illness perception and self-management.

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Conclusions

In conclusion, this research reveals an association between illness perception and self-management and QOL in adults with type 2 diabetes in Indonesia. The findings indicated that poorer illness perceptions are associated with a lower QOL. However, there has been no statistically significant relation between self-management and quality of life. The results lay the groundwork for potential initiatives aimed at changing people's views of disease in order to encourage better self-care and QOL in diabetics.

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Table 1. Demographic data for the respondents (n = 351)

Characteristics of respondents	n (%)
Age (years), Mean ± SD	54.12 ± 8.14
Range: 23-65 years old	
Sex	
Male	107 (30)
Female	244 (70)
Education	
No formal education	23 (7)
Elementary	64 (18)
Junior high	74 (21)
Senior high	120 (34)

University	70 (20)
Marital status	
Unmarried	6 (2)
Married	304 (87)
Widowed	41 (12)
Religion	
Islam	309 (88)
Christian	36 (10)
Hindu	2 (1)
Buddha	2 (1)
Confucius	2 (1)
Working status	
Employed	107 (30)
Unemployed	244 (70)
Time since diagnosed (months), Mean ± SD	92.20 ± 82.88
Range	3-576

Table 2. Distributions of means for domains of quality of life, illness perception, and self-management (n = 351)

Variable	Mean ± SD	Range
Quality of life (WHOQOL-BREF)		
Physical health	38.92 ± 15.92	13-88

Psychological health	38.34 ± 18.24	14-94
Social Relationships	33.14 ± 21.25	6-100
Environment health	45.53 ± 17.29	19-88
Illness perception (B-IPQ)		
Total score	46.73 ± 8.41	11-73
Consequences	7.00 ± 1.94	0-10
Timeline	7.16 ± 1.87	0-10
Personal control	3.77 ± 2.52	0-10
Treatment control	3.58 ± 2.64	0-10
Identity	6.79 ± 1.92	0-10
Concern	7.28 ± 1.80	0-10
Understanding	4.22 ± 2.55	0-10
Emotional response	6.91 ± 2.45	0-10
Patient's self-management (DSMQ)		
Total score	28.67 ± 5.34	12-42
Glucose management	9.17 ± 1.99	2-15
Dietary control	7.14 ± 1.84	1-12
Physical activity	4.37 ± 1.66	0-9
Healthcare use	6.25 ± 1.54	0-9

Table 3. Beta Coefficients (Standard Error in Parentheses) of QOL Scores Based on

a Hierarchical Linear Regression in People with Type 2 DM (n=315).

	Quality of life							
	Physical health		**Psychological health**		**Social Relationships**		**Environment health**	
	Model 1	**Model 2**	**Model 1**	**Model 2**	**Model 1**	**Model 2**	**Model 1**	**Model 2**
on	-0.068	-.070 (.720)	-0.114	-0.120	-.130	-.133	-.077	-0.081
	(0.783)		(0.888)*	(0.832)*	(1.034)*	(.965)*	(0.845)	(0.789)
tion	-0.107	-.031	-0.150	-0.08	-.148	-.078	-.158	-0.087
	(2.071)	(1.873)	(2.286)*	(2.164)	(2.663)*	(2.511)	(2.175)*	(2.053)
nce	-0.128	-.100	-0.096 (.012)	-0.065	-.068	-.041	-0.108	-0.080
ed	(0.010)*	(0.009)*		(0.011)	(.013)	(0.013)	(0.011)	(0.010)
erception		0.395		0.365		0.363		0.367
		(0.096)**		(0.110)**		(0.138)**		(0.105)**
nagement		0.057		0.009		0.042		0.031
		(0.150)		(0.173)		(0.201)		(0.164)
	0.038	0.201	0.058	0.188	0.059	0.194	0.051	0.187
hange		0.163		0.130		0.135		0.136