

Diabetes Self-Management Engagement: A Case Study Analysis of Respect for Patient's Autonomy

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Abstract

Diabetes mellitus prevalence has been growing up rapidly. Consequently, physical, psychological, and socioeconomic burdens were increased due to the treatment and diabetes-related complications. Complications are favorable among poorly controlled diabetic patients. To prevent or delay the complications, then, diabetes self-management is an appropriate way to cope these problems. Presently, patient empowerment in diabetes education and self-management is an effective way to increase the adherence to the diabetes treatment. Education means disclose information about their conditions and management-related DM. Diabetes patients have right to receive information regarding their conditions and treatment needed. This right is related to their autonomy to choose and decide their own treatment. Then, it is not fair if we blame them as not adhering when they did not receive any important information regarding their treatment clearly. This study aimed to describe the ethical issue in diabetes self-management engagement.

Keywords: case study, diabetes self-management, dimensions of autonomy, patient empowerment.

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CASE STUDY

Mr. Bowo (fictitious name) a 64-year-old, married, retired, senior high school background. He lives with his wife and their children. He diagnosed with type 2 diabetes mellitus (T2DM) since 12 years ago. He expressed that he has heart disease, high blood pressure, blur in vision, and sexual dysfunction. He never checks his blood glucose at home by himself. Sometime he goes to the clinic to check his blood glucose. His blood glucose average is 175 to 205 and he never noticed a change in blood glucose levels. He had experience in hypoglycemia a year ago. As a first aid, he dunks hot sweet tea. Then, his family carried out him to hospital. He takes diabetes pills and likely to miss to take the medicine. He did not use any diabetes self-management aid such as diabetes diary, a diabetes app on a cell phone, or other treatment reminder. He just avoids sugar for his diet. He active in diabetes exercise group once a week for 60 minutes. He did not aware and performs good control of diabetes risk complications such as eye, teeth, and foot. He feels overwhelmed and often failing in diabetes routine. He stated that he did not get any health education related to his disease and the self-management. When the author asked some questions regarding his care, his point of view about diabetes mellitus, he described with a

simple sentence "Diabetes mellitus is a disease that incurable". He said that he obey what physician and nurses said. The author also observed that there is no specific informed consent for outpatient related to health education for instance, disclose information about the disease and the treatment, also consent that was signed by patients as a legal aspect form of treatment agreement. Based on that data, Mr. Bowo categorized in poorly controlled T2DM patients.

The ethical issue

The case presents a patient empowerment as a key point of self-management. Patients, whose are illiterate in diabetes self-management (DSM) more likely to not engage in and adherence with his/her care. Such as in Mr. Bowo's case, it is not merely his fault, but health providers fault too. Mr. Bowo case is one of a sample case. According to a survey conducted by the author on February 2014 in Pekalongan city, 43 out of 48 (90%) respondents with T2DM are uneducated in the DSM. Most of the respondents are poorly controlled T2DM and did not follow American Diabetes Association DSM guideline. Fifty four percent respondents did not take medicine regularly, mostly related to missing taking the medication. Ninety percent did not undertake self-monitoring blood glucose, 43% complain the difficulty to manage their diet, 85% did

exercise once a week for 60 minutes and 72% did not perform foot care. This is a serious ethical issue in diabetes self-management that we need to criticize and make changes for better diabetes care.

In Indonesian culture, paternalism still exists and grounded in the society. Patients tend to comply with what health providers say. It was given a negative effect that makes patients as a passive learner and low level of curiosity. As in Mr. Bowo case, he obeys what physician and nurses said even though there is not enough information about the treatment he received and also there is no consent for the treatment was signed. Family-determination, which it leads the decision making based on the family agreement, is another cultural aspect among Indonesian that cannot be separated from their habit.

Based on these phenomena, the question is “Do they still have autonomy as far they are conscious and competent person?” “Do the physician and nurse respect with their autonomy?” To answer these questions, we need to review the definition of self-management, definition of autonomy, and the dimensions of autonomy.

Diabetes self-management

Diabetes mellitus is a chronic disease that affects many aspects of daily life, compels people to comply with a lifelong treatment regimen [1]. Because the treatment is for a long-life, then self-care is the effective way to make the patient independent in taking care of themselves. The terms of “self-management” some time has been equated with “self-care”, “self-monitoring”, or “self-care management”. Diabetes self-management (DSM) defined as a set of skilled behaviors engaged in to manage one’s own illness. These skills include diet, physical activity, blood glucose self-monitor, medication, and foot care [2]. This emphasizes the responsibility and role of the individual in managing the disease [3]. Additionally, Kisokanth *et al.* states there are two major factors that influence patient in diabetes self-management engagement including intrinsic factors which come from the patient itself and extrinsic factors that consist of social and environmental support. Song & Lipman defined self-monitoring in T2DM as awareness of, interpretation of, and response to a patient’s particular manifestations of T2DM [4]. According to American Diabetes Association, diabetes patients should obtain diabetes self-management education (DSME) and diabetes self-management support (DSMS) which can help them to enhance the effectiveness of their self-management [5]. Education is identical with information disclosure that can enhance patient’s knowledge. Knowledgeable patient will easy to follow the therapeutic regimen and make them aware with their conditions. The educational approach has been changed to the patient empowerment model; focus on helping

diabetes patients make informed self-management choices and decisions [5].

The concept of autonomy

Autonomy is the capacity of an agent to determine its own actions through independent choice within a system of principles and laws to which the agent is dedicated [6]. Autonomy include capacities of self-governance such as understanding, reasoning, deliberating, managing, and independent choosing [7]. Autonomous action in terms of normal choosers who act 1) intentionally, 2) with understanding, and 3) without controlling influences that determine their action [7]. To respect autonomous agents is to acknowledge their right to hold views, to make choices, and to take actions based on their personal values and beliefs. It involves acknowledging the value and decision-making rights of persons and enabling them to act autonomously [7]. The principle of respect for autonomy can be stated as a negative obligation and as a positive obligation. As a positive obligation, this principle requires both respectful treatment in disclosing information and action that foster autonomous decision making [7]. Respect for autonomy is not a mere ideal in health care; it is a professional obligation. Autonomous choice is a right –not a duty-of patients [7].

The dimensions of autonomy in diabetes patient

The dimensions of autonomy were developed by Moser *et al.* This model was established as a result of grounded theory which was explored about autonomy among Type 2 diabetes mellitus (T2DM). According to Moser *et al.*, autonomy is a multi-dimensional, dynamic and complex construct. There are seven dimensions of autonomy in T2DM involved identification, self-management, welcomed paternalism, self-determination, shared decision-making, planned surveillance, and responsive relationship [1]. Identification means that diabetes patients need to determine their lives. Diabetes, as a chronic disease is a dynamic condition due to the stability of blood glucose levels and the treatment that they need. These situations forced them to identify or justify their condition continuously. Self-management is identical with self-care, how diabetes patients manage their condition through self-care activities such as diet control, physical activity arrangement, blood glucose self-monitoring, taking medicine, and foot care. Welcomed paternalism means that diabetes patients acquiesce what others said related to their treatment. It does not mean that diabetes patients are dominated by others, even though they ask others to solve their problem. Self-determination in diabetes patients emphasizes on how they determine their care independently with their awareness. Sometime, diabetes patients need others to share information and make decisions related to their care and treatment. This is the essence of shared decision-making dimension. The complex therapeutic regimen of diabetes makes diabetes patients need others to

contribute in monitoring their care. They realize that they cannot handle their care by themselves. Then, planned surveillance is the best way to help them. Regarding with their complex care, they cannot stand by themselves. The support system behind them who has contributed to their care is their family, peers, and health providers. To keep harmonious relationship, responsive relationship is needed.

These seven dimensions of autonomy in T2DM were developed based on type 2 diabetes patient perspective, so that it's an appropriate and applicable in their care. As health providers, we should be considered these dimensions as a cornerstone of our health services in formed of respect for patient's autonomy. Based on these dimensions, health providers can treat the patients in the patient's side that could be enhanced patient empowerment.

CASE ANALYSIS

Based on the case of Mr. Bowo, there are some data that support an ethical issue of Mr. Bowo care as a T2DM patient. Mr. Bowo suffered from T2DM since 12 years ago, but he is an uncontrolled diabetes patient. He has poor self-care since he did not do daily care properly. He has many DM complications and feels overwhelmed of his diabetes routine. He did not receive information about his condition and treatment comprehensively. He just follows his doctor and nurses' advisement such as take medicine routinely, reduces sugar, and active in exercise. The Moser's model of seven dimensions of the autonomy of T2DM patients could be applied to analyze the case of Mr. Bowo.

The root problems in the Mr. Bowo case are information disclosure and patient empowerment. It is described that he did not receive any education about his disease and the treatment from his physician or even nurses. He had been complying with his treatment, as far as he follows what health providers are saying. Unfortunately, it is not properly. In this study, authors focused on three issues of dimensions of autonomy was emerged involving the identification, welcomed paternalism dimensions and self-determination. Another four dimensions of autonomy; self-management, shared decision-making, planned surveillance, and responsive relationship did not explore in this issue. Since, the four dimensions are already existing and it's not a hot issue to discuss.

Moser *et al.* stated that welcomed paternalism means that T2DM obey with what the physician or nurses are advised. The paternalism is cultural and society influences. It teaches that health providers are expert in their field. Hence, patients trust that they will do and give a better care based on their skills and knowledge [8]. Such as in Mr. Bowo case, he trusts with health care providers and lead him to obey what they are suggesting. Most of patients give their life to

the physician or healthcare providers. They tend to follow their direction and advice.

The other issue is related to self-determination dimension, which stresses on making decisions and choosing the treatment, health, and behavior [1]. In this dimension, the patient will be able to choose and make a proper decision related to his/her care if he/she has enough knowledge about their condition and the treatment (including the self-management) needed. Additionally, Moser, *et al.* stated that a person's character is formed dynamic and continuous. The autonomy was formed during the developmental stages that influenced by adaptation process with the circumstances. It leads autonomy as a complex and dynamic process. In diabetes patient, the meaning ascribed to autonomy is "competency in shaping his/her life" [1]. In this dimension, patient be expected to make decisions independently. Contrary, family-determination is more commonly used in making-decision in Indonesia. In Indonesian culture, family is a center and powerful in decision making. The family has many contributions in one's life as a social support. This is accordance with Kisokanth *et al.* study that family is one of extrinsic factors which impact patient engagement in diabetes self-management. It is possible in Mr. Bowo case, since he lives with his family.

Identification dimension is the third issue of the Mr. Bowo case. Identification is a process of identifying their condition and the consequences. Moser *et al.* mentioned that the identification process phases are included comprehending, struggling, evaluating, and mastering [9]. The first phase comprehends, which diabetes patients will try to understand and realize their condition and the consequences of it. The dynamic changing of blood glucose among diabetes patients would be a good experience to teach them. While they perceived what happen with their condition and do the proper treatment, they will try to cope this problem. This struggling phase teaches them how to survive and what effort was required. Hence, diabetes patient will reflect what the effort was done and what effect was perceived. In this evaluating phase, reinforcement is needed to appreciate what patient has made. Then, the last phase is mastering. Diabetes patient could be an expert on their self-management. Based on their experiences and information, they will become mastery to solve their problem and increase their adherence in their self-management. In Mr. Bowo case, the identification dimension happens since he suffered from T2DM since 12 years ago and he has an experience on hypoglycemia. These experiences will shape him to be an expert if he has enough information and good care. He can learn from his experience and internalize the treatment should be done.

In Mr. Bowo case, the main cause of his uncontrolled T2DM is education about his disease condition and the treatment. According to American

Diabetes Association, diabetes self-management education is a critical program to enhance patients' knowledge. Knowledge is a basic of self-care that can enhance patient's awareness of her/his care. With an appropriate preparation in the form of diabetes self-management education can increase patient engagement in their treatment or in other word is emerged their "haves" [10]. While education can develop the patient's ability to take responsibility for his/her self-care. It is a formed of patient empowerment in their treatment [11]. While they are engaged in their care, acute or chronic complications of diabetes mellitus can be prevented and reduced.

The diabetes self-management education (DSME) in Indonesia was implemented, but still need to improve and maximize. The implementation of DSME program was in an individual approach and need to update. There are some diabetes educators, but because of working load, they do not have enough time to give education comprehensively. Usually, the education is given to newly diagnosed patients.

CONCLUSION

This Moser's model of dimensions of the autonomy drive this case analysis more easily and systematically. This model is appropriate to determine the ethical issue in diabetes self-management. In accordance with diabetes self-management, health care providers must pay attention of the patient's autonomy. Self-care is not merely an obligation, but also their autonomy. Respect to patient's autonomy in daily care and patient empowerment could be enhanced a good quality care. The limitation of this case study is that author did not assess the family role in Mr. Bowo case. Family as a social support has an important role in patient engagement in their care.

As an implication of this case study, diabetes self-management education and diabetes self-management support is needed to improve in Indonesia. Since, information disclosure is very important as patients' foundation to help them make decisions of their treatment and behavior inline. Diabetes mellitus is an incurable disease, but controlled disease. With good quality care, diabetes complications could be prevented and reduced. Because the DSME is critical and foundation of proper self-care, this program can be scheduled in diabetes patients association as a regular activity. Diabetes educators must take responsibility in this part. Interactive, innovative and interesting learning

strategies can enhance patient's motivation to learn. The DSME also can be one of standard operational procedures in diabetes care. Hence, as an intervention, it is not impossible to have reimbursement from the health assurance.

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