

Research Article

Ethical Analysis of Diabetes Self-management Education: Review on Indonesian Healthcare Services

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Self-management is a crucial part of diabetes treatment to prevent short-term and long-term complications. Self-management education sometimes raises some ethical issues. This paper aims to discuss the ethical issues arising from diabetes self-management education practice. We discuss the ethical issues based on case study of patient self-management education in a public health centre (PHC) outpatient department in Malang City, Indonesia. We observed the patients' education practices and conducted interviews randomly with diabetes patients who visited PHC for their treatment. Findings showed that the central theme of ethical issues arising from the movement toward patient self-management must be raised: preparation, empowerment, predominant assumption of self-management, and lack of standards for patient selection. Putting patient education in its rightful place and respecting patient preferences' was one way to reduce the risk of ethical dilemmas arising from self-management.

Keywords: diabetes self-management, patient education, ethical issues reviewsCorresponding Author: Henik Tri
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Knowledge E

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Selection and Peer-review under the responsibility of the ICMEDH Conference Committee.

1. Background

Diabetes is a chronic non-communicable disease that necessitates medical treatment and ongoing patient self-management education to avoid acute complications and reduce the risk of long-term complications. The number of people with diabetes worldwide has been increasing yearly. Around 463 million adults were living with diabetes in 2019, with an estimated increase of 578 million in 2030, reaching 700 million in 2045 [1]. The increasing prevalence of diabetes is related to the rising prevalence of obesity, a significant risk factor for diabetes. The global age-standardized prevalence of obesity among adults (18 years and older) increased by 150 percent in 2016 [2]. Indonesia was the seventh of the top 10 countries in the West Pacific region, with the highest number of estimated diabetes in 2019. It will continue to rank top eight worldwide in

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2045, with the number of people with diabetes extending to 10.7 million in 2019 and the projected increase to 13.7 million in 2030 and 16.6 million in 2045, respectively [1]. Besides its high prevalence, diabetes is also one of the non-communicable diseases (NCD) leading global causes of premature death [2]. In 2016, the estimated number of deaths caused by NCDs was 41 million, about 71% of total deaths. The deaths directly caused by diabetes were 1.6 million, fourth-ranked after cardiovascular diseases, cancer, and chronic respiratory [2]. Besides, diabetes is showing a 5% increase in premature mortality rate. In Indonesia, diabetes is the third direct cause of death after stroke and cardiovascular disease, and it was also ranked the first burden disease in 2012 due to the high disability-adjusted life years (DALYs) [3]. The DALYs are the sum of years lost due to premature mortality and years of healthy life lost due to disability [4].

Due to poor management of the disease, the high DALYs of diabetes are believed to result from severe complications. Long-term complications of diabetes increase the risk of heart disease, stroke, kidney disease, blindness, and amputation [5]. Diabetes and its complications are not only health issues but also a burden on the economy, culture, and psychology. It impacts the individual, the families, the health systems, and the country. Global health spending on diabetes treatment and complications was estimated at at least USD 760 billion in health expenditure in 2019, about 10 percent of total adult spending [1]. Despite no precise details on Indonesia's diabetes expenditure, the International Diabetes Federation announced that the total diabetes expenditure in the West Pacific region exceeded USD 162.6 billion in 2019 and estimated will increase to 184.7 billion in 2045 [1]. Hence, promoting disease management to control diabetes is a crucial way to reduce the risk of complications and thus can reduce the cost of treatment.

As the costs of treating mal-managed diabetics are high, to avoid the high-cost treatment in severe complications, self-management is believed to be a crucial, vital point [6]. Self-management is defined as an individual's ability to detect and manage symptoms, treatment, lifestyle changes (such as exercise and diet) also physical and psychosocial consequences inherent in living with a chronic condition [7]. Self-management is suggested by many studies that affect improvement in glycosylated hemoglobin levels for persons with diabetes and systolic blood pressure for those with hypertension [8].

Based on the American Association of Diabetes Educators (2014), there are seven domains of self-care behavior, including healthy eating, controlling blood sugar, problem-solving, being active, taking medication, healthy coping, and reducing the risk. Those of all self-management task is not easy. So, people with diabetes need proper preparation, support in implementing good behavior, and help with difficulties. Because of that,

healthcare professionals and other social support, such as their family members, must maximally give their support. However, self-management offers individuals an opportunity for improved expression of goals and preferences, better psychosocial and physiologic outcomes, and a means to manage their chronic disease so that they will be less dependent on health professionals and institutions. Proper preparation for self-management will help them successfully control their behavior. Other potential benefits from adequate training and maintenance of patient self-management skills include quality care personalized to the patient's preferences and life goals, increased problem-solving skills, confidence and success, and generalizable to other parts of the patient's life.

1.1. Self-management currently practiced in Indonesia

Self-management is known to practice worldwide. Unfortunately, it is still limited information and well-practiced, including proper preparation and limited sources of patient education in the Indonesian community. Patient education still used traditional methods, which were not fully maximized in practice. Mostly patient education is only as breaking the obligation to give information to the patient without proper methods, with low quality and limited time education. Besides, there was still a lack of diabetes educator expertise, so the physician and primary nurse were delivering diabetes management information. This condition raises some ethical considerations. Therefore, it needs more discussion related to these issues. Thus, this paper discusses the ethical issues arising from diabetes self-management education practice.

2. Methods

We discuss the ethics rise from a case study of patients' self-management education in an outpatient department of a public health center (PHC) in Malang City, Indonesia. We observed the patients' education practices by nurses and conducted interviews randomly using inconvenience samples to two diabetes patients who visited PHC for their treatment.

3. Findings

3.1. Central Ethical Issues

Based on Barbara K. Redman (2007) [9], at least four ethical issues about the movement toward patient self-management must be raised: preparation, empowerment, predominant assumption of self-management, and lack of standards for patient selection.

The first and most urgent issue is the lack of availability of appropriate preparation so that patients and families are sufficiently competent at self-management to avoid harm. The proper preparation access is still far from certain; for example, the payment system toward the kind of therapy, such as pharmacologic and medical, rather than the level of benefit produced by the treatment, including quality of life. In other words, the current focus on treatment support by insurance is still focused on "curing or therapy," not on "caring or preventing" or education. In the past, the definition of self-management focused on patient compliance with prescribed medical regimens, but nowadays, it has shifted to the more collaborative concept of 'adherence' and, more recently, to "concordance" [9]. Concordance is based on the idea that health care practitioners and patients should work towards a mutual understanding about the development of therapeutic cooperation, balancing retention of professional expertise with a full exploration of patients' views even when they appear to conflict with medical knowledge or viewpoints [10]. Proper preparation means adequate education and the appropriate resources, including facilities, assisting tools or materials, and educators. The unclear payment regulation may hinder the proper delivery of education. Change in payment policies is prolonged; it may delay access to self-management preparation even for diseases such as diabetes, which has been repeatedly shown to be effective [9].

The second issue is the appropriate viewpoint of patient empowerment. In practice, it makes the patient responsible without convincing them they have the resources for self-management or competent medical care. The definition of patient empowerment is helping patients discover and use their innate ability to gain mastery over their disease; empowerment educates patients to make informed decisions and set behavioral goals to make changes of their choosing or preference, which is a seriously needed modification. The philosophy of empowerment supports patients as experts in their own learning needs and able to solve their problems [11]. Previously, patients were treated as disobedient children or wicked or foolish adults.

Moreover, diabetes is frequently depicted as a self-induced 'lifestyle' condition, a disease of excess suffered by those who have overindulged, lack self-control, eat to excess, and are overweight. People with diabetes are frequently blamed for their disease, for 'not looking after themselves and failing to take adequate responsibility for

their health [12]. However, to be successful, Barbara K. Redman (2007) suggests that empowerment must meet three conditions [9]. Firstly, it should not just be a responsibility dumped from providers to patients and their families without assuring that patients have the means and skills to manage [9]. Then, the physician community must resolve poor practice issues in managing chronic diseases, especially diabetes.

Furthermore, lastly, all providers must practice in an autonomy-supportive way. Autonomy support can be defined as the extent to which providers elicit and acknowledge patients' perspectives, support patients' initiatives, offer choices about treatment options and provide relevant information while minimizing pressure and control. To support the patient's perceived competence, the clinician offers as much structure as the patient needs. Due to autonomy-supportive, a study of persons with diabetes reported that autonomy support from one's clinician was significantly correlated with patient competence and glycosylated hemoglobin level, so providers can be trained to be autonomy supportive [13].

The third issue is that there is an assumption that education is non-invasive and it does not require formal informed consent. However, it may be very invasive psychologically and socially and can weaken patient/family self-efficacy (confidence). If one fails to learn what is expected, one can be labeled as 'uneducable' and thus not deserve more chances to learn self-management. A correlated assumption that the primary purpose of education is to deliver physician treatment instructions ignores genuine self-management; this current condition is paternalism; the physician's order is mainly closed to patient adherence, not patient compliance or self-management. In education, the psychological or intellectual frame should not create new harm or prolong an old one, such as guilt, depression from the inability to meet self-management standards, or confusion and loss of confidence due to self-management preparation. The vital purpose of education is to assist the patient in managing his disease with as slight interference as possible; medical instructions are only a tiny part of such preparation. In some conditions, patients still need to understand what is known about their illness and receive the best advice on managing it as they seek to control its impact on their lives, not only for diabetes but also for other chronic illnesses [9].

Redman also raises the fourth ethical issue: a lack of standards for patient selection can potentially exclude individuals who could benefit from learning self-management. The potential for spreading the gap between the 'haves' and the 'have nots' in health care is genuine, as the 'have nots' struggle with low literacy and inability to self-educate, and lack access to educational materials and teachers appropriate to their learning needs. Ethnic minorities, older persons, and those with language barriers and

low literacy were less likely to participate and benefit from Diabetes Self-Management Education (DSME). Some study suggests that those who did not receive DSME were four times as likely as those who did to develop a significant complication [14].

Another issue arising from self-management is due to patient adherence and patient self-management. In the past, patient adherence is represented as a paternalistic relationship between physician-patient. It does not recognize patients' autonomy or invest in developing their capabilities to self-regulate their life commitments, despite the effects of a life-threatening disease. While in patient self-management, there must be a commitment to help patients manage the underlying chronic disease, it also can produce better clinical outcomes emphasizing self-control and autonomy and the patient's responsibility to collaborate with treatment. If this responsibility is not met, it affirms the providers' responsibility to investigate why those conditions happen [15].

3.2. Patient Education

Proper education is vitally important to prepare adequately for patients' diabetes self-management. Diabetes self-management education (DSME) is the process of facilitating the knowledge, skill, and ability necessary for diabetes self-care. It refers to the support required for implementing and sustaining coping skills and behaviors needed to self-manage on an ongoing basis. The healthcare team, including nurses, diabetes educators, dietitians, and other healthcare providers such as coaches, community health workers, and others, performed diabetes self-management education and support that may or may not follow the standards of patient education and may not be currently unpaid. Patient education is conducted everywhere, including at hospital discharge, in emergency rooms, and in persons with chronic diseases needing to self-manage their disease control regimen and make lifestyle changes. However, evidence suggests that incomplete education will potentially endanger patients, which might be an ethical concern. Based on Barbara K Redman (2011), there were 3 (three) crucial questions to discuss regarding the ethical issue that was rising in patient education [16].

The three questions that have been adequately explored are: (1) what kinds of ends (outcomes) for patient education best serve the patient's needs? In this term, the capabilities develop what people can do or be guaranteed to an edge level. People who engage in patient education can most contribute, including being able to think and reason, develop emotion, participate in critical reflection about the planning of one's life, and live with others. Such a framework links the education of patients to all kinds

of life education and avoids capture by narrow medical thinking. Recent patient self-management programs have focused on problem-solving, action planning, goal setting, dealing with painful emotions, healthy living, medication, symptom management, and working with health professionals [17], [18].

The second question is, 'How closely should patient education be tethered to a physician's orders?' The ethical conflicts in this issue are that sometimes physicians have over authority to dictate what patients are taught; in actual practice, paternalism is still mainly used even in delivering patient education.

The next question is 'Why is patient education so incompletely practiced, and what can be done about it? There are many reasons for incomplete education. Some are from their facilities, cultural condition, and policy. Although PSM requires patients to be activated, informed, and empowered, the support of clinicians willing to work in partnership with their patients to develop mutually accepted and followed treatment plans is also needed. Skills in collaborative goal setting and follow-up and the ability to respect the patient's choice are part of such training. The focus here, rather than other questions pertinent to the ethics of patient education, is perhaps the most hypocritical—we say that patient education is available in the healthcare system, but for many, this is not true [19].

The critical part of the ethical analysis involves the examination of benefits and harms from alternatives; the principle here is beneficence and non-maleficence. Within patient education, patients should do as much self-management as they want, with both preferences and competencies documented at intervals in the progression of chronic disease because they do change. Benefits from patient education must be optimized and harm minimized. Besides, self-management should not be dependent on literacy, numeracy, or formal educational level, and low health literacy is a strong predictor of poor health outcomes. Incorrect disease-related beliefs may be one of the pathways through which health literacy influences health outcomes. Besides, treatment decisions and their rationale should be transparent to the patient and other team members and open to regular feedback and correction [20], [21].

3.2.1. Patient Education Currently Practiced in Indonesia

In Indonesia, although some healthcare services provide proper health education, many healthcare services were only used traditional methods in performing health education programs to enhance patients' knowledge and self-management. The conventional techniques used in health education include just giving printed media such as brochures

or leaflets with minimal explanation, a small number of videos, or group counseling. There were very few times for face-to-face discussing and counseling. Even in some public health centers, the patients only receive minimal information about managing their condition and disease because of the limited number of health care providers and time. It raises a dilemma of ethics in providing health education, especially on diabetes self-management. Besides, regarding who should give the proper health education, there were still very limited educator specialists in every health care center. Thus, diabetes self-management education was usually only provided by the primary nurse without specialists, which might be health education that cannot be maximal as given by expertise. To solve these problems, if there is a lack of diabetes educator expertise, at least we should improve the healthcare professional capabilities in providing health education by offering them some training on diabetes education programs.

Besides, in Indonesia, paternalism was primarily used as a patient-physician or patient-health care provider relationship. The Indonesian culture may cause this condition where patients must always obey the doctor's order, similar to how students must abide by their teacher or how children must abide by their parents. Some people believe that putting any problem handling by someone who has more capable of it is better than their own. This matter was not false et al.; however, respecting patients' needs and preferences by working with the healthcare provider and patient will be much better. Improving the methods and working with the patient minimally violate ethics, particularly in self-management education.

4. Conclusion

Patient self-management is vitally crucial for patients with chronic diseases such as diabetes. To have self-management successfully, needs cooperation and working together between patients, physicians, and other health professionals in their best own roles. Conducting proper patient education as proper preparation is also significant. To reduce the risk of ethical dilemmas arising from self-management, and it supported, there was some recommendation for patient education, such as put patient education in its rightful place. It means that the ones who have to educate the patient must have expertise in their major, use a proper method in teaching to patient capability, respect and follow patients' needs and preferences, and put the patient as the goal dan center of education. Respecting the autonomy of patient preferences and choices is also essential to support them to success.

5. AUTHORS' CONTRIBUTIONS

The primary author conceives the presented idea, collects data, reviews, and analyses the findings, and writes the paper. Then, author 2 reviewed the findings and manuscript. We declare that there was no conflict of interest in this study.

ACKNOWLEDGMENTS

The researcher wants to thank nurses in the public health center's outpatient department who informed the current patient education practices.

References

- [1] International Diabetes Federation. IDF Diabetes Atlas Ninth Edition 2019. 2019, [Online]. Available from: <https://www.diabetesatlas.org/en/resources/>
- [2] World Health Organization. World Health Statistics 2020: Monitoring Health the SDGs. 2020, [Online]. Available from: https://www.who.int/gho/publications/world_health_statistics/2020/en/
- [3] Kementerian Kesehatan Indonesia. Morbiditas dan Multi Morbiditas Pada Kelompok Lanjut Usia di Indonesia. *J. Biotek Medisiana Indones.* 2015;4(2):77–88,
- [4] World Health Organization. Health statistics and information systems: Metrics: Disability-Adjusted Life Year (DALY). 2020.
- [5] Chamberlain JJ, Rhinehart AS, Shaefer CF Jr, Neuman A. Diagnosis and management of diabetes: synopsis of the 2016 american diabetes association standards of medical care in diabetes. *Ann Intern Med.* 2016 Apr;164(8):542–52.
- [6] International Diabetes Federation. IDF Global Guideline on Managing Older People with Type 2 Diabetes. 2013, [Online]. Available from: <http://www.idf.org>
- [7] Barlow J, Wright C, Sheasby J, Turner A. Self-management approaches for people with chronic conditions: a review. *Patient Education and Counseling.* 2002;48(2):177–187.
- [8] Warsi A, Wang PS, LaValley MP, Avorn J, Solomon DH. Self-management education programs in chronic disease: a systematic review and methodological critique of the literature. *Arch Intern Med.* 2004 Aug;164(15):1641–9.
- [9] Redman BK. Responsibility for control; Ethics of Patient Preparation For Self-Management of Chronic Disease. *Bioethics.* 2007;21(5):243–250.<https://doi.org/10.1111/j.1467-8519.2007.00550.x>.

- [10] Stevenson F, Scambler G. The relationship between medicine and public: the challenges of concordance. *Health Educ Behav.* 2005;9:5–21.
- [11] Funnell MM. Implementing an empowerment-based diabetes self-management education program. *Diabetes Educ.* 2005;31(53):53, 55-56. <https://doi.org/10.1177/0145721704273166>.
- [12] Broom D, Whittaker A. Controlling diabetes, controlling diabetics: moral language in the management of diabetes type 2. *Soc Sci Med.* 2004 Jun;58(11):2371–82.
- [13] Williams GC, McGregor HA, King D, Nelson CC, Glasgow RE. Variation in perceived competence, glycemic control, and patient satisfaction: relationship to autonomy support from physicians. *Patient Educ Couns.* 2005 Apr;57(1):39–45.
- [14] Strine TW, Okoro CA, Chapman DP, Beckles GL, Balluz L, Mokdad AH. The impact of formal diabetes education on the preventive health practices and behaviors of persons with type 2 diabetes. *Prev Med.* 2005 Jul;41(1):79–84.
- [15] Gremigni P, Bacchi F, Turrini C, Cappelli G, Albertazzi A, Bitti PE. Psychological factors associated with medication adherence following renal transplantation. *Clin Transplant.* 2007;21(6):710–5.
- [16] Redman BK. Ethics of patient education and how do we make it everyone's ethics. *Nurs Clin North Am.* 2011 Sep;46(3):283–9.
- [17] Lorig K, Ritter PL, Turner RM, English K, Laurent DD, Greenberg J. Benefits of Diabetes Self-Management for Health Plan Members: A 6-Month Translation Study. *J Med Internet Res.* 2016 Jun;18(6):e164.
- [18] Lorig K, Holman HR, Sobel D, et al. *Living a healthy life with chronic conditions.*, 3rd editio. Boulder (CO): Bull Publishing, 2006.
- [19] Kosmala-Anderson JP, Wallace LM, Turner A. Confidence matters: a Self-Determination Theory study of factors determining engagement in self-management support practices of UK clinicians. *Psychol Health Med.* 2010 Aug;15(4):478–91.
- [20] Bernardini J. Ethical issues of compliance/adherence in the treatment of hypertension. *Adv Chronic Kidney Dis.* 2004 Apr;11(2):222–7.
- [21] Falvo DR. *Effective patient education: A guide to increased adherence.* Jones & Bartlett Publishers; 2010.