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Elderly Living with Diabetes in Indonesia

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Abstract: Background and purpose: Little is known about how elderly people with diabetes (Type 2) in Indonesia respond to and live with their disease. In this paper perceptions and actions of some elderly Indonesians in relation to living with their disease are reported. Methods: Convenience sampling was used. Elderly people with diabetes who volunteered to participate in a diabetes education program (offered as a trial in three community health centers in Indonesia) were recruited pre-education to attend a focus group interview and completed a demographic survey. Results: Participants (n=45) had a mean (SD) age of 60.78 years; 40% had experienced hospitalization (diabetes related) and 24.4% of participants had had hospitalizations because of blood glucose level (hypo/hyperglycemia). The focus group interview revealed that symptoms such as weight loss, fatigue and changes in vision had led to health assessments and diagnosis of diabetes. Participants reported having limited opportunities post-diagnosis to attend diabetes education programs. Because of these limitations and limited health professional support most of the participants had resorted to alternative medicine to manage their conditions. Alternative treatments used by the participants included herbal medicines; ion therapy, and 'traditional' medications. Conclusion: These findings suggest that there is need for systematic assessment of the knowledge and self-treatment strategies that elderly people in Indonesia may be using to manage their diabetes. Service gap analysis and the potential benefits of structured diabetes education programs for newly diagnosed elderly persons should be assessed.

Keywords: Diabetes, Elderly, Developing Countries and Health Education Programs

Introduction

The increasing prevalence of diabetes Type 2 is an international concern. Diabetes Type 2 is a leading cause of death: the World Health Organization (WHO) in 2004 estimated that 3.4 million people worldwide died because of high blood sugar, and more than 80% of diabetes deaths happened in mid and low income countries. Moreover, WHO predicts that by 2030, the number of people living with diabetes will increase to 346 million, with the greatest burden in low to mid income countries (WHO 2011a). One such country is Indonesia, which faces particular challenges due to a number of factors. The biggest archipelago country in South East Asia, Indonesia consists of 17,504 islands with a total area of 1,910,931.32 km², and a population density of 124 people per km². In 2010, Indonesia had 33 provinces, consisting of 497 districts/cities with a population of 237,641,326, and a rate of population increase per year of 1.49% (Depkes RI 2011, 10). The Indonesian population is predominantly young, with the largest age group being 25-35 years of age. Indonesia has the 4th highest number of estimated cases of diabetes for 2000-2030 after India, China and the United States (Wild et al. 2004). In 2010, diabetes became the 6th leading cause of death in Indonesia. Moreover, it is predicted that by 2030, the number of people with diabetes in Indonesia will reach 21.3 million (WHO 2011b, 93). In 2007, the Indonesian health ministry conducted a survey throughout all provinces in Indonesia to measure health status in general. The study found that in the 45-54 year age group, diabetes accounted for 5.6% of deaths in rural areas (rank 6) and 14.7% of deaths in urban areas (rank 2) (Balitbang Depkes RI 2008, 115-116).

Due to the relative youth of the Indonesian population, health policy has focused mainly on people under 35, with the health needs of the elderly receiving less attention. Health services to the elderly are provided by the Indonesian government through programs in community health centres (*Puskesmas*) (Depkes RI 2012). Indonesia has 9,005 units of *Puskesmas* with a ratio of 3.79 per 100 thousand people. In 2010, the number of health professionals in the *Puskesmas* was 255,563 in total including nurses (78,215); doctors (14,934); dieticians (7,565) and midwives (83,222). Of that number, 50.64% have had only technical training (Depkes RI 2011). Most

Puskesmas have several programs to support government targets and goals to achieve better health in the population. The most common programs are: health promotion; environmental health; nutrition improvement; prevention and eradication of communicable disease; maternal, child and family health; and basic. Information programs are conducted regularly by the *Puskesmas* on topics such as healthy ageing, maternal and child health and family health. However, diabetes as a topic for health education is rarely addressed by health professionals.

Poorly managed chronic disease in the elderly can result in a significant social and economic burden; where self-management is possible this should be encouraged and enabled. Diabetes is a chronic disease that is amenable to self-management, providing that people have the necessary knowledge (Ockleford et al. 2008). The Indonesian government acknowledges the need to provide the elderly with adequate health knowledge and skills to manage their health status (DepSos RI 2003). However, little is known of how the elderly in Indonesia manage their disease. Hence, the aim of this study was to explore the perceptions and actions of elderly Indonesians in relation to living with diabetes.

Methods

Ethical approval for this study was provided by Monash University and permission granted from Bandar Lampung city health district. Bandar Lampung, the capital city of Lampung province was the setting for this study. In 2009 the total population of Bandar Lampung was 834,637. The elderly population (defined by Depkes RI as >56 years) was 109,488, of which 12% were diagnosed with diabetes type 2 (DinKes Provinsi Lampung 2010, 89-97). The city has 27 *Puskesmas* (with 8 providing in-patient service and 19 only out-patient service), 44 *Puskesmas Pembantu* (sub health centers) and 92 *Polindes* (Village clinics) (DinKes Provinsi Lampung 2010). Three *Puskesmas* located in the center of Bandar Lampung city were chosen as the study sites, based on their provision of complete services and their accessibility to patients.

The study sample consisted of 45 patients aged over 56 years (the Indonesian definition of elderly) with type 2 diabetes, who attended one of the three study sites and agreed to participate in a health education program. There were no other inclusion criteria and no exclusion criteria. Prior to the program the participants took part in a focus group interview to explore their perceptions and experiences of their disease. The interview schedule is included in the Appendix. Demographic data were obtained by questionnaire. The focus group session was audiotaped and transcribed verbatim. Data were subjected to thematic analysis. The transcripts were read several times. Then, initial coding was conducted to identify initial themes. The initial themes were then reviewed by checking against all transcripts. Finally, the core themes were identified and named (Braun and Clarke 2006).

Findings

Demographic data for the participants are shown in Table 1. The participants had a mean (SD) age of 60.78 (4.42) years and females outnumbered males. The majority (64.4%) had completed high school education or higher. A little over half (55.6%) had been diagnosed with diabetes for less than three years. Less than half (40%) had been hospitalized because of their diabetes, with blood glucose level being the most common reason for admission.

Table 1: Demographic data of participants

| Characteristics | N (%) |
|---|--------------|
| Sex | |
| Male | 15 (33.3) |
| Female | 30 (66.7) |
| Age (mean \pm SD) | 60.78 |
| Education level | |
| Elementary | 16 (35.6) |
| High School | 21 (46.7) |
| Diploma/University | 8 (17.8) |
| Employment | |
| Retired/Not working | 35 (77.8) |
| Government employee | 3 (6.7) |
| Entrepreneur | 6 (13.3) |
| Private employee | 1 (2.2) |
| Time since diagnosis of diabetes | |
| <6 months | 7 (15.6) |
| 7-12 months | 7 (15.6) |
| 1-2 years | 11 (24.4) |
| 3-5 Years | 7 (15.6) |
| 5-10 years | 5 (11.1) |
| >10 years | 8 (17.8) |
| Hospitalization due to diabetes | |
| No | 27 (60) |
| Yes | 18 (40) |
| Reason for hospitalization | |
| Blood glucose level | 11 (24.4) |
| Stroke | 1 (2.2) |
| Foot Ulcer | 3 (6.7) |

Analysis of the focus group data elicited three themes: ‘Knowing the symptoms’; ‘supports’; and ‘self-management practices’.

Knowing the Symptoms

The focus group interview revealed that for the majority of participants the experience of symptoms such as fatigue, loss of vision, or weight loss had led to the diagnosis of diabetes type 2. For most of the participants the diagnosis was a surprise as many had attributed their

symptoms to problems arising because they were 'getting older'. Three quotes from focus group participants exemplify these findings.

"I never knew that I had diabetes, it just happened one day when I had surgery for an ovarian cyst...the doctor found that I had high blood glucose. I never felt any symptoms but I was obese and then became skinny..." (Female G2.1)

"I experienced weight loss and blurred vision, but I thought it was because I am old...then the doctor checked my blood glucose...it was high." (Male G1.3)

"I knew I had a chance of getting diabetes, it runs in my family...my mother and my brother died from this disease, but I thought I was OK since I did not notice any symptoms. Then last year I lost consciousness and the doctor said I had very high blood sugar." (Female G3.1)

Supports

The participants were asked about their access to and use of health education programs, particularly in relation to diabetes. Some participants had attended health education programs; however, most of the patients had never been given an opportunity for health education in relation to their diabetes. For instance the following quotes exemplify these findings.

"Yes, I have...last year I attended an educational program at a private hospital. Every week I had regular exercise and sometimes a health check on my blood pressure and blood glucose. However, I rarely get information about how to manage my diabetes." (Male G2.2)

"Never have, this will be the first time..." (Female G1.1)

"There was a program from Government health insurance, we went there and we got some information...but that was a long time ago, I don't know whether the program is still available or not" (Male G3.2)

"I was never given information about diabetes in Puskesmas, however... I have attended an alternative medicine for people with diabetes, it was called 'happy feet' ... the therapy offered therapy for feet, claiming that it can reduce blood glucose...they give us some information about diabetes..." (Female G1.3)

Self-management Practices

Some of the participants did have some understanding of how to manage their diabetes by taking medicines and managing their diet and lifestyle. This general understanding is exemplified by the following quotes.

"I believe we need to have medicine and should arrange diets..." (Female G2.3)

"I heard that we need to take medicine, check blood glucose and limit our food intake..." (Female G2.4)

"This disease needs to be managed by medicine, diet and exercise. I know the disease can be experienced by my children someday..." (Female G2.6)

This understanding was limited, however, with a number of participants expressing their belief that their diabetes would eventually be cured.

“I believe that taking medicine can cure my disease...that’s why I take it regularly...”
(Female G3.10)

“I think by taking pills regularly, it can lower my blood glucose, but I don’t know how long I should take the pills” (Female G2.5)

For the majority, the source of this misunderstanding was unclear, but one participant had gained the impression from providers of alternative therapy.

“I have attended an alternative medicine for people with diabetes ... they give us some information about diabetes about what it is, how it can be cured through the therapy.” (Female G1.3)

The participants’ quotes below also reveal intermittent patterns of adhering to their medication regimes (primarily triggered by ‘symptoms’) rather than taking their medications at regular and prescribed times.

“I take pills only when I feel that my blood sugar is high. How do I know my blood sugar is high? I just know, by feeling, if I feel not very well, I assume it is my blood sugar.” (Male G3.5)

Similarly, participants revealed intermittent compliance with the expectation of frequent measurement and monitoring of blood sugars. The following quotes were typical for the group of participants.

“I check my blood sugar once a week...when I come to Puskesmas to get my pills.”
(Female G1.3)

“I check my blood sugar regularly...probably once a month...” (Female G2.5)

“I regularly check my blood sugar twice a week.” (Female G1.4)

Several participants explained that this lack of compliance was due to costs: blood glucose testing was not covered by health insurance. The insurance only covers the cost of consultation and pills, and patients have to pay for their blood glucose to be checked. Some patients had been able to buy a glucometer, but then struggled to afford the test strips.

“I have basic health insurance, however it doesn’t cover for checking the blood glucose...” (Female G2.5)

“I have my glucometer at home ...however, it costs me a lot to buy the strips.” (Female G2.6)

Some participants also tried alternative therapies, both pharmacologic and non-pharmacologic. When asked about how they gained information about these alternative therapies, most participants revealed this knowledge had been gathered from peers, other diabetic patients, and from advertisement of commercial products that claimed to cure diabetes. For example:

Figure 1 shows two commercial products, herbal medicine or pill and shoes. The herbal medicine claims that by taking these pills, patients can be free from several diseases, one of which is diabetes. The shoe product claims that by using the shoe every day, it will enhance blood circulation and can prevent or cure diabetes. Examples of these practices and beliefs are represented in the following quotes.

“I have tried various types of therapy since I was diagnosed with diabetes. I try anything people suggest. I have tried spa therapy, herbal medicine, I try stone therapy...” (Male G3.4)

“People have suggested to me to have therapy such as walking on the warm surface of a paving block...and also soaking my feet in warm water. People told me it could reduce my blood sugar.” (Female G1.4)

Discussion

This study describes findings in relation to 45 elderly people who live with diabetes in Indonesia. Most of the people who participated in this study did not have adequate knowledge about managing their diabetes. Most of the participants had not had opportunities for health education about managing their diabetes. The participants had relied on peers, advertising or on local ‘stories’ about how to manage and to discern what health practices and ‘treatments’ were most appropriate. Consequently, many participants were not managing their disease appropriately.

This situation is compounded by a lack of health insurance. The government provides basic health insurance in Indonesia for people with middle-low income. Government employees are also provided with government health insurance. However, health insurance does not cover the full costs associated with having a chronic disease and needing regular health assessment (Balitbang Depkes RI 2008). Consequently, most patients cannot afford to check their blood glucose every day, even if they understand the importance of doing so.

If the perceptions and experiences of the participants in this study are in any way representative of the Indonesian community then several health problems associated with elderly people who have and live with diabetes are apparent. Limited knowledge of diabetes as a disease, its treatments, and relevant health practices is a hindrance to well-being and to living well (Kirkman et al. 2012). Limited information is likely to be related to lack of or limited availability of health education sessions provided by health professionals in *Puskesmas*. Misinformation also comes from peers and other non-reputable sources. Misleading information comes from commercial advertisements of non-regulated products which claim to cure the disease. With limited income and limited access to health insurance for their condition, most elderly patients with diabetes will have inappropriate care of their disease.

One reason for the lack of information being given to patients is that health professionals are inadequately prepared to provide health education; around half the staff employed in *Puskesmas* have received technical training only (Depkes RI 2011). To gain adequate knowledge of diseases and to develop appropriate health education programs health professionals require training. There is insufficient government or workplace funding and so the cost of the training falls on the health professionals themselves. Even though the government has supported educational programs in the *Puskesmas*, health professionals are not well informed and have limited knowledge about health education for diabetes (Balitbang Depkes RI 2008).

Diabetes is a chronic condition that relies on care for appropriate management. If this situation continues to exist, elderly people with diabetes will have more complex health situations and complications of diabetes where their quality of life becomes even more challenged. Elderly patients with diabetes may be at especially high risk of experiencing poor health outcomes (Prentice et al. 2012).

There is general agreement (Bruce et al. 2003, Skinner et al. 2006, Adachi et al. 2010) that complications from diabetes are minimized when consumers have good health education, monitor their blood sugar regularly, comply with prescribed medication regimes, and actively seek healthy lifestyles. There is a need for specialized health education programs for elderly people with diabetes. It is known that older adults have some specific issues such as possible impairment in sensation (hearing and vision), a decline in muscle mass and strength with age, and age-related alterations to pharmacokinetics. As with all persons with diabetes, educational programs for older adults should be individualized and tailored to the individual unique (Kirkman et al. 2012). Some consensus recommendations for health professionals in treating older people with diabetes need to be considered if the Indonesian government wishes to implement educational programs for diabetics.



Figure 1: Diabetics Commercial Products

Source: (Anonymous 2013)

Conclusion

This small study has revealed challenging data about how some elderly people in Indonesia are living with and managing their diabetes. The results reveal gaps in knowledge, limited access to health education programs, and that people are being misinformed by peers and alternative medication regimes. There is a need to intervene to advance access to health education programs and to better inform older people with diabetes in Indonesia so that they can appropriately self-manage their condition.

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