

The Socioeconomic Factors Affecting the Mental Health Status of Family Caregivers of Type 2 Diabetic Patients

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Abstract As Japan's 'super aged society' develops, more and more aged caregivers are obliged to take care of patients with chronic diseases. In this study, the family caregivers of type 2 diabetic patients were targeted to identify the socioeconomic conditions that affect their mental health status. The results indicated that when the caregivers were overly concerned about the patients' care, they had higher GHQ (General Health Questionnaire) scores ($r=.685$, $p<0.05$). On the other hand, the more caregivers spoke frankly about their feelings to the patients, the lower their GHQ Likert Scores were ($r=-.718$, $p<0.05$). Suggestions for medical staff were made to establish a support system not only for type 2 diabetic patients, but also for the family caregivers of these patients.

Health Science Research 24(2): 9-15, 2012

Key Words : Type 2 Diabetes · patient · family · caregiver · stress

Received 18 May 2012

Accepted 7 July 2012

Introduction

Diabetes mellitus (hereafter referred to as 'DM') is one of the most pervasive and chronic diseases in Japan and worldwide. DM is called a 'disease caused by an unhealthy lifestyle' in Japan, which reflects how important it is in Japanese culture for people to live a healthy lifestyle, including eating healthy food, getting enough sleep and doing an appropriate amount of exercise, in order to control their health. The statistics of the International Diabetic Federation (2011) showed that the number of DM patients in Japan is approximately 10,700,000 people (including undiagnosed patients), and this is the 6th largest diabetic population in the world.¹⁾

Many previous studies have indicated that DM patients are vulnerable in terms of physical and socioeconomic condition. For example, Zhang et al.²⁾ reported by analyzing type 2 DM patients that the social/family crisis caused by the disease predicted the depression score in diabetic patients even more strongly than did their clinical condition. Fisher et al.³⁾ reported in their Latino and European-American patients with type 2 DM that the disease status and family stress

variables significantly predicted the outcome of their depression. Among the adolescent DM population, Viner et al.⁴⁾ reported that social support from the family was found to be a buffer to the family stress with regarding controlling DM.

Additionally, Jacobson et al.⁵⁾ reported that family relationships that feature high cohesion and low conflict, and also a willingness to address rather than avoid problems, were associated with a better outcome.⁶⁾ In contrast, Elstad et al.⁷⁾ indicated in their descriptive study performed in American Samoa that sometimes the family caused the depression of DM patients.

Through these studies, it has become clear that family plays a central role in the care of DM patients,⁸⁾ in both positive and negative ways, and thus has a major role in the adherence of these patients to self-care treatment plans.⁹⁾

This study focused on the family caregivers of the DM patients with regard to their impact on the outcome for the patients and the impact of living with DM patients on their lives. As mentioned by Parsons (1956), family functions to development the personalities of

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each member of the family as a result of the interactions between the family members.¹⁰⁾ Therefore, one can assume that as patients are influenced by their families, families are also influenced by the patients.

Many DM patients are currently living in the communities with their families. In Japan, there are approximately 26,200 in patients and 188,000 out patients with DM, according to a patient survey conducted by Ministry of Health, Labour, and Welfare in 2008.¹¹⁾ These figures are estimated numbers of patients. We can expect that there are more undiagnosed patients in the communities, as indicated by the International Diabetic Federation mentioned before. Under such conditions, it is not difficult to imagine that the families of the DM patients are supporting patients in their daily life in order to ensure that they live the healthy lifestyle mentioned above. This is an additional role for the family members. Therefore, taking care of patients may be recognized as a stressful life event for the family of the DM patients.

The aims of this study were:¹⁾ To identify the socioeconomic factors of the family that impact the clinical status of the patient, the worries experienced by the family regarding the patient, their dissatisfaction with the medical staff, the stresses associated with caregiving, the social support available in the hospitals and local communities, and the family members' medical literacy about DM.²⁾ To evaluate the mental health status of the family caregivers.³⁾ To find the correlation between the mental health status of the family caregivers and the variables in Aim 1 of this study.

The target population of this study was the family caregivers of the type 2 DM patients. In the Japanese population, more than 95% of the DM patients are categorized as having type 2 disease. The metabolic malfunction underlying this type of DM requires that patients change their lifestyle. For this reason, it can be assumed that the lifestyle of the type 2 DM patients may strongly affect the lifestyle of their families. In order to provide better support, the families of the type 2 DM patients must ensure that they maintain their own mental health. Only a few support system for these family members is currently available, and especially in this era when families are playing a major role in caring for patients with chronic diseases in the community setting, such a system is therefore considered to be needed.

Methods

The participants of this study were the family members of the type 2 DM outpatients of N University Hospital. The sampling of the participants was done in cooperation with the Diabetes Nurse Specialists of the hospital. The researchers were introduced to the eligible participants who were waiting for the patients outside the medical room. After obtaining informed consent from each respondent, the researchers distributed an anonymous six page questionnaire, together with a sealed envelope, in order for participants to send the filled questionnaire back to the researchers. In addition to the questionnaire, individual interviews were conducted to obtain a narrative of the cognitive stress of the family members of the type 2 DM patients.

The questionnaire included questions about the socioeconomic characteristics of the respondents (gender, age, family relationship to the patient, family members who were living together, marital status, educational background, satisfaction with the economic condition of the family, etc), clinical characteristics of the patients' illness (type of DM, year and month that patients were diagnosed with DM, whether or not the patient was taking insulin, the year and month when they started the treatment, whether or not the patients had diabetic complications, and whether or not they were undergoing hemodialysis or peritoneal dialysis treatment), dissatisfaction with the medical staff, whether or not the patients changed doctors, their inter-personal relationship with patients, caregiving stress, social support provided in the hospitals and local communities, and medical literacy regarding DM.

Caregiving stress, assessed by six items, was a concept developed by the authors after carefully studying the previous research. The medical literacy regarding DM was assessed by seven items, and was developed to measure the level of comprehension of the treatment and symptoms of type 2 DM. The researchers carefully studied health education kits and text books to develop the scales. The respondents were asked to choose one out of three options; 'correct', 'incorrect', and 'do not know'. If the respondents answered correctly, they were given 1 point for each question, otherwise no points were given.

In this study, the General Health Questionnaire (hereafter referred to as the GHQ) 12, Japanese version, was used as a marker to measure the mental health status of the family members. The Likert scoring (0-1-2-3) was applied in this study.

The lower the GHQ Likert Score they received, the healthier they were. We conducted this survey to identify the factors which may correlate with the mental health status of the families of the DM patients, so that we can obtain empirical data to develop an effective social support system for the family members of the type 2 DM patients.

Statistical analyses including the t-test, Cronbach's alpha reliability coefficient, and Spearman's rank correlation coefficient were conducted using the JMP Version 9 software program for Windows. The a priori alpha was set at $p \leq 0.05$.

This study was approved by the Research Ethics Committee of the Department of Health Sciences, Nagasaki University.

Results

A total of nineteen questionnaires were distributed at the N University Hospital. Out of these, 12 questionnaires were returned to the authors. The response rate was therefore 63%. As shown in Table 1, the respondents of this study were predominantly females, married, unemployed, and did not have any other person to care for other than the type 2 DM patients. Eleven (91.7%) of the respondents answered that they were the main person caring for the patient. Four

(33.3%) of them were taking care of husbands, followed by mothers (33.3%), wives (16.7%), and others (16.7%). Five people (41.7%) lived together with patients and other members of the family, but four people (33.3%) lived only with the patient. Nine respondents (75.0%) answered that 'I am very likely/ likely to speak frankly about my feelings to the patient.' Eight (66.6%) answered that 'I am very likely / likely to feel that the relationship between me and the patient has deepened since the start of the treatment.'

Table 2 shows the clinical condition of the patients. Six (50.0%) answered that the patients changed doctors. Eight (66.7%) answered that the patients were receiving insulin treatment, and eight reported that the patient had diabetic complications (66.7%), but only 1 person (8.3%) answered that the patient was receiving hemodialysis or peritoneal dialysis.

Regarding the caregiving stress including six Likert scales, Cronbach's alpha reliability coefficient was .89. The average score for the caregiving stress was 13.6 (SD4.9) points, ranging from 6 to 22 points. Figure 1 shows the stress level of the caregiving respondents. Nearly 60% of the respondents answered that 'I am very likely/ likely to worry about the patient's care too much.' Table 3 shows the stress coping style and social support system of the respondents. Seven respondents

Table 1. Socio-economic Characteristics of the Respondents (n=12)

| General Characteristics | | |
|--|---------------------------------------|---------------|
| Gender | male | 2 (16.7%) |
| | female | 10 (83.3%) |
| Average age | years | 63.7 (SD13.9) |
| Marital status | single | 2 (16.7%) |
| | married | 10 (83.3%) |
| Education background | junior high school graduate | 2 (16.7%) |
| | withdrawal from high school | 2 (16.7%) |
| | high school graduate | 4 (33.3%) |
| | University graduate or above | 2 (16.7%) |
| | others | 2 (16.7%) |
| Family relationship to the patient | husband | 4 (33.3%) |
| | wife | 2 (16.7%) |
| | mother | 4 (33.3%) |
| | others | 2 (16.7%) |
| | with patient | 4 (33.3%) |
| Family Living Together | with patient and other family members | 5 (41.7%) |
| | others | 3 (25.0%) |
| | | 1 (8.3%) |
| Currently employed | | |
| Caregiving Condition | | |
| Being a main caregiver for DM patient | | 11 (91.7%) |
| Have family members who need care besides DM patient. | | 9 (81.8%) |
| Relationship with Patient | | |
| I am very likely/likely to speak frankly about my feeling to the patients. | | 9 (75.0%) |
| I am very likely/likely to feel that relationship between me and patient has deepend since the start of the treatment. | | 8 (66.6%) |

Table 2. Clinical Condition of the Patients (n=12)

| | |
|----------------------------------|-----------|
| Have made changes in doctors | 6 (50.0%) |
| Receive insulin treatment | 8 (66.6%) |
| Have diabetic complication | 8 (66.6%) |
| Receive hemo/peritoneal dialysis | 1 (8.3%) |

Table 3. Stress Coping Behavior and Social Supports (n=12)

| | |
|---|------------|
| I have a method(s) for coping with the daily hassles and difficulties. | 5 (41.7%) |
| I have a psychological support that I can speak frankly about my private life. (Emotional support) | 11 (91.7%) |
| I am attending the association for DM patients to obtain the information about DM. (Information support) | 1 (8.3%) |
| I have an informational support that I can ask for help to take care of the patient for me. (Tangible support) | 8 (66.6%) |

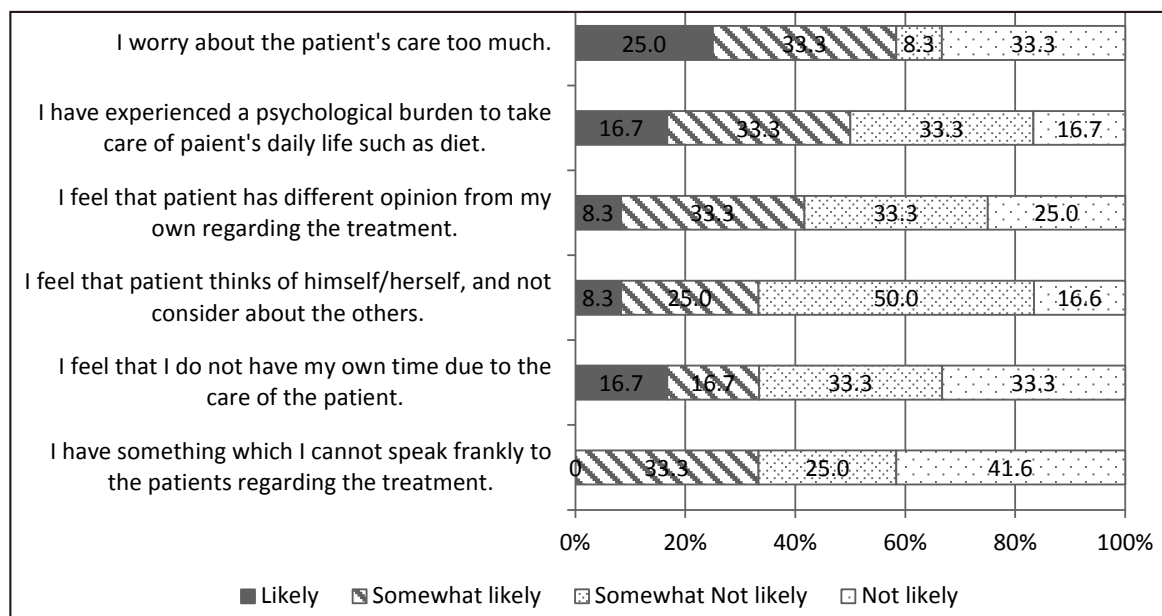


Figure 1. The Level of Caregiving Stress

(58.2%) answered that they had no set method for coping with the daily hassles and difficulties. Regarding the type of social support, they predominantly had emotional support (91.7%), were likely to have tangible support (66.6%), but less likely to have informational support (8.3%).

The average score for the medical literacy regarding DM was 5.3 (SD1.5) points, ranging from 3 to 7 points. The subjects were less likely to answer correctly about the metabolic function of the DM patient.

The average score of the respondents for the GHQ was 24.7 (SD4.9) points, ranging from 18 to 33 points. No correlation was found between the GHQ Likert Score and the socioeconomic characteristics of the

respondents, the clinical status of the patients, worries experienced by the respondents regarding the patients' condition, or the medical literacy of the respondent regarding DM. However, those who answered yes to the question 'The patients changed doctors' were likely to have a significantly lower score (21.5 points) than those who answered no to that question (27.8 points), ($p < 0.05$).

The item 'I am likely to speak frankly about my feeling to the patient' had a significant correlation with the GHQ Likert Score ($r = -.718, p < 0.05$). The more the respondents reported speaking frankly about their feelings to the patients, the lower their GHQ Likert Scores were. However, no significant correlation was

found between subjects who answered 'I am likely to feel that the relationship between me and the patient has deepened since the start of the treatment' and the GHQ Likert Scores ($r=-.100$, n.s.).

Only one item, 'I am likely to worry about the patient's care too much' out of the seven items related to caregiving stress, had a significant correlation with the GHQ Likert Score ($r=.685$, $p<0.05$). The more they worried about the patient's care, the higher their GHQ Likert Scores were.

The following is a narrative from a male respondent, who takes care of his partner at home alone.

"Concern about patients is very stressful for family members taking care of them, as you know. It is sometimes necessary to scold the patient (for her poor treatment of her DM), while other times (when you see her depressed) you must encourage her (to rescue her from her depression), and aside from that, you must take care of your house by cleaning, washing dishes and clothes, --- and earn money for you and your family as well. That's the reality for the family members of the patients with DM. Therefore, DM not only affects the patients, but also the family members of the patients with DM."

Discussion

The majority of the respondents in this study were around retirement age. They were the main caregivers for the type 2 DM patients, and most were part of small, intimate families. Therefore, the respondents in this study had frequent contact with the patients, all day long. Taking care of patients who are of the same generation or the previous generation is difficult, because the caregivers themselves are also old. As shown in the above narrative, some family members who are taking care of the patients are obliged to take on multiple roles, such as managing the household, and earning money for their living, aside from their caregiving role. Ochi et al.¹²⁾ indicated in their descriptive study that middle-aged, employed family caregivers were suffering because they had to take on multiple roles, but they were able to cope because they were relatively young, and had the energy to manage both work and caregiving. However, if the family caregivers are old, as was the case for the respondents in this study, performing multiple roles is a greater burden, due to their own weakness or impairment, particularly if there are only a small number of family

members living together. This phenomenon seems to be widely observed in various societies, especially today in Japan's 'super-aged society'.

It is noteworthy that in the above mentioned narrative, the Japanese expression '*ki wo tsukau*' (concerning others) was used. This expression is often used in daily life, especially when caring for others. The term '*ki*' literally means 'concerning', and it is one of the virtues of Japanese culture. Japanese people are educated to concern about others in their daily life, but they should not let their concern for other people. In other words, being concerned about others is a virtue for the Japanese people, but to let this concern affect your own life is not a good practice, unless the object of concern is a patient or injured, who are expected to take on a patient's role,¹³⁾ and they are free from obligations until they recover from their illness. Of note, Hara et al.¹⁴⁾ reported that Japanese patients are concerned about their caregivers and the burden they may impose on patients.

As indicated by the narrative, the way that 'concern for patients' is shown by Japanese family caregivers is not only by taking care of (even to the point of spoiling) the patient, but also by scolding the patient to show how much they care about their health. Family caregivers are always keep an eye on the patients to check whether they are following their dietary therapy, get enough sleep, do an appropriate amount of exercise, and so on, and provide different types of care based on the condition of the patient. This result is also reported by Kato et al.¹⁵⁾ in their descriptive study about elderly female DM patients.

Nevertheless, for family caregivers, too much concern about the patient's care may degrade their mental health condition. This is in agreement with the results showing that there was a strong correlation observed between the GHQ Likert Scores and the item, 'I am very likely/likely to worry about the patient's care too much.' Those who were likely to worry too much about the care of the patients often experienced deterioration in their mental health. More than 60% of the respondents in this study indicated the same attitude towards patients as did the respondent who provided the narrative. Therefore, considering the situation of the family caregiver is essential, especially when they are taking care of patients with chronic diseases, such as diabetics, because they are exposed to the stressors caused by care giving for a longer duration of time.

On the other hand, it should be noted that the

family caregivers adjust to the stressful caregiving environment. This is reflected by the fact that the respondents who answered that their patients changed doctors had lower GHQ Likert Scores than those who answered that their patients had not ($p < 0.05$). A t-test was conducted to determine the statistical significance of the differences between the length of the treatment period between those who answered that their patients changed doctors and those who had not. The results indicated that the caregivers whose patients had changed doctors were likely to have a longer duration of DM treatment (the average year was 29 years), whereas the average for those whose patients had not changed doctors was 13 years. The Pearson's correlation coefficient was determined to find the significance of the correlation between the duration of treatment and GHQ Likert Scores. Although there was no significant relationship, the correlation coefficient was $-.256$. Therefore, with an increased duration of treatment, there was a decrease in the GHQ Likert Score for the respondents. This suggests that subjects who have been caregivers for a longer duration of time had developed coping strategies to deal with the stress of caregiving, while those who had been caregivers for less time had not yet developed such strategies. Social support should be provided, especially to the family caregivers who have less experience taking care of the patients.

The results of this study also indicated an effective strategy to cope with the stress of caregiving. The respondents who spoke frankly about their feelings to the patients were more likely to have a lower GHQ. This means that sharing opinions by speaking frankly with patients is the one of the effective strategies that can help caregivers to cope with the caregiving life. This will yield a better relationship between family caregivers and patients.

Sady¹⁶⁾ insisted that it is important for hospital staff to support not only patients, but also the family, in cases of brain injury. This may also be applicable to the case of DM patients and their family, too, since the DM patients also need to have a long duration of treatment, and medical staff are obliged to support their family, who are undergoing long-term stress associated with caregiving. In order to support patients and their families, the first step that should be taken by the medical staff is to obtain information about the care environment of the patients. Although it is not easy for medical staff to recognize the relationship between the patients and family members, it is

possible to obtain information regarding the problems they are experiencing, especially if the patients are outpatients and undergo treatment with their family. To extend psychological counseling, such as was provided by Snoek et al.¹⁷⁾, to the family caregivers of the DM patients could help provide family caregivers opportunities to speak out about their problems and conflicts, helping them to be less stressed.

The limitation of this study should be address as follows: The limited number of the respondents with only 12 samples. This condition made a further cross sectional analysis difficult. Therefore, we should notice that the above discussion is applicable especially for the cases of older caregivers of the type 2 DM patients. Further study with a larger number of respondents, including those of various socioeconomic backgrounds (such as various age-groups) should be made. Also, a comparative study with family caregivers of type 2 diabetic inpatients should be performed.

This study targeted to identify the socioeconomic conditions that affect their mental health status of the family caregivers of type 2 DM patients. The results indicated that when the caregivers were overly concerned about the patients' care, they had higher GHQ (General Health Questionnaire) scores ($r = .685$, $p < 0.05$). Based on a virtue of Japanese culture, caregivers who are likely to concern too much about the patients may degrade their mental health, and this may cause a poor caregiving condition. Suggestions for medical staff were made to establish a support system not only for type 2 diabetic patients, but also for the family caregivers of these patients.

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