
Experiences of Patients with Type 2 Diabetes Living with their Spouses: a Literature Review

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Received Jan. 18th, 2013; accepted Apr. 28th, 2013.

ABSTRACT

Objective: to review a literature regarding experiences of the spouses who support patients with type 2 diabetes mellitus (T2DM) in their daily lives.

Background: individuals with T2DM which develops after age of 40 years need to incorporate treatments into their daily lives. Therefore, patients' family is a key to continue their treatments. A literature review is required to explore support for their family.

Methods: electronic databases were searched limited to studies published between 1983 and 2009, in Japanese. Reference lists from retrieved studies were also included. In terms of middle-aged spouse, patient with T2DM, and experience, searches were run and combined.

Results and Conclusion: fourteen publications were identified and divided into three terms: patient's experience of dealing with T2DM, patient support system, and middle-aged spouse's experience in patient support. Patient support system was established based on patient's experiences. Patient's spouse has been also recognized as a strong supporter; however, there was a dearth of studies regarding middle-aged spouse's experience in patient support.

Keywords: *patient with type 2 diabetes mellitus, middle-aged spouse, patient support, experience*

1. Introduction

Diabetes mellitus (DM) is a lifestyle-related disease. According to the National Health and Nutrition Survey conducted by the Ministry of Health, Labor, and Welfare in Japan in 2007 [1], diabetes is strongly suspected in approximately 8.9 million individuals, and cannot be ruled out as the source of symptoms in approximately 13.2 million. Thus, 22.1 million people in Japan may have DM in addition to those definitively diagnosed with this illness. This figure is a 1.4-fold increase compared with that estimated in the survey conducted in 2002. In addition, the number of individuals with DM may be expected to increase further as the nation's population ages.

Currently, DM has no cure. Patients with DM must cope with the disease for their entire lives. Type 2 diabetes mellitus (T2DM), accounts for 95% of all cases, and commonly occurs after the age of 40 years. Therefore, education regarding healthy lifestyles and preventive measures associated with diet, exercise, and medication must be provided immediately after diagnosed. All preventive behaviors must be

incorporated into daily-lifestyle by those who receive this education, and self-management behavior must be encouraged.

In addition to self-management, social support is also essential for individuals with T2DM for effective diabetes control. Social support may be received from a variety of sources. Steinglass et al. [2] stated that for patients with chronic illnesses, families were considered as the primary source of social support. Therefore, teaching the family members methods to help their diabetic relatives is important. According to Mishima et al. [3], Ito et al. [4], and Matsuba et al. [5], families must be provided with opportunities to acquire knowledge about and skills for diabetes management.

However, Noguchi [6] emphasized that previous approaches that included providing only support to patients with DM were more recently shifted to the trend of helping them become active learners regarding their own condition, and supporting them in making good lifestyle choices. This shift in trend has also impacted the way medical professionals approach the families of patients with DM. Moriyama [7] noted that families

require support from doctors and nurses as much as the patients.

Previous studies have focused on characteristics of patients with T2DM, the support systems at medical institutions, the relationships between patients and their families, and the burden on families caring for the patients. However, few studies have reported regarding support to the families who care for patients with T2DM. One such study showed that nurses faced various difficulties while providing support to the families of patients with DM. Yokobori et al. [8] quoted nurses, who said that “We hesitate to take a step forward in the intervention for the families” in their study. Thus, issues related to care of families of patients with DM should be addressed.

Patients with T2DM must strive to change their lifestyle to avoid complications and disease progression. During this process, they may experience a change in roles within their families. These changes occurring in the patients’ lives may also affect their families. Nakano [9] reported that DM in one family member may affect the family life for all family members. Family members may also be concerned regarding disease progression and complications, and may be required to make changes in their lifestyles and roles within the family. Furthermore, in patients receiving life-long medical treatment, disease progression may necessitate frequent hospitalization. Nakanishi [10] noted that for the families of patients with DM, family life was centered on disease management, and plans for the future may require changes depending on the patient’s condition.

The feelings of family members while supporting patients with T2DM have not been adequately explored. There is a dearth of literature regarding the experience of families of patients with DM. In particular, the experiences of middle-aged spouses of patients with T2DM have not often been examined. The experiences of the spouses of patients with T2DM need to be understood in order to provide adequate care to patients as well as their spouses.

2. Aim

This study is a review of literature pertaining to the experiences of the spouses of patients with T2DM who support these patients in their daily lives. In this review, the following three questions were addressed: (1) What support systems are available that take into account the characteristics of patients with T2DM? (2) What support do families provide to patients with T2DM? (3) What are the experiences of the spouses who support patients with T2DM?

3. Methods

A search of electronic databases and web platforms was conducted, and researches published between 1983 and 2009 were included. Peer-reviewed research papers, magazines, bulletins, and conference proceedings in Japanese were examined. Electronic database searches for terms defining patients with T2DM and their middle-aged spouses were largely unsuccessful. Therefore, the search was widened to include the following keywords: diabetes, family, support, and experience. A manual search was also undertaken based on the reference lists of retrieved studies in order to include publications that had not been previously identified. Each title and abstract of the retrieved studies was read to determine its relevance to the abovementioned three questions. In total, 14 studies were selected for this review (see Table 1).

4. Results

4.1. Characteristics of patients with T2DM and support systems

Patients diagnosed with T2DM must incorporate diet, exercise, and drug therapies into their daily lives. Therefore, many studies identified for this review described patient educational content, teaching methods, and self-management recommendations, and their effects on treatment outcomes. The motivation level and emotional state of patients with DM are related to disease self-management and compliance with treatment. Therefore, many studies have investigated the patient’s psychological aspects.

The characteristics of patients with T2DM have been examined in previous researches that had two points of view (1) self-management and continuity of treatment and (2) patients’ experiences dealing with T2DM. In addition, reports regarding the support systems and their suitability to the patient have also been investigated.

4.1.1 Self-management and continuity of treatment

For patients with T2DM, which often develops after the age of 40 years, self-management may be difficult because of adult life cycle and the necessity of lifestyle changes. Kaneko et al. [11] mentioned that in the modern society, self-management was difficult for the middle-aged patients with DM. In study of Sugawara et al. [12], work was cited as the primary reason for patients who did not have time for consultation and as the primary cause of treatment interruption. Their priority was to support their families and be part of the society rather than to manage their illness. This was

particularly true in patients of a certain generation [12]. Patients were aware of their failure to manage their illness even if they understood the need for continued treatment. Their responsibilities at work, irregular working hours, and job-changes were cited as reasons for noncompliance. Koga et al. [13] and Koizumi et al. [14] pointed out that inadequate blood glucose control was influenced by the constraints of work duties and consequent treatment interruption in some patients. Condition deteriorates and complications develop due to treatment interruption in many patients with DM; therefore, Sugawara et al. [12] suggested that assessing the possibility of treatment interruption is important in decision-making regarding the treatment of DM.

4.1.2 Patients' experiences after diagnosis and during recuperation

Previous studies have described various experiences of patients with T2DM after diagnosis. Patients experience loss and grief after diagnosis. Kuroe [15] reported that patients experienced a loss of hope regarding their diet and future health. In addition, the day-to-day self-management of DM can be a psychological burden; therefore, motivation wanes, and a possibility of burn out in patients who believed that their daily effort was not rewarded arises [16]. Furthermore, Based on the examination of patients' experiences of anger, Kubo [17] reported that group psychotherapy was used to alleviate patients' negative emotional feelings toward DM. These reports were related to the patients' self-management behavior and motivation to continue treatment. Although many patients found joy in getting support from family, which improved their self-management behavior, Ichikawa et al. [18] noted that the patients felt indebted to their family members. In addition, patients suffered from psychological distress and anxiety regarding symptoms, disease progression, and complications and had difficulty concentrating on treatment in day-to-day life [18].

Because the research in this field continued, the focus shifted to patients' processing their experiences. Among the theories offered, the "transrational model" has been proved to be a useful aid in behavioral psychology [19].

4.1.3 Self-management education for patients with DM

Many studies have been based on improvement of treatment compliance by catering to individual patients' needs. In many medical institutions, patient education programs are available to improve the self-management skills. Soeda [20] described the evening classes in some

institutions for patients who worked during the day to facilitate their participation in the education program. In the education program, both patients and their family members were included. Okada et al. [21] emphasized that such education programs should include families to ensure good treatment outcomes. The goal of education programs is to impart knowledge and help patients with DM and their families develop behavioral skills necessary undergo medical treatment [20]. These programs have effectively improved patients self-management skills. Miyamoto et al. [22] reported that patients felt that they and their families were more in control of the situation after receiving the education and that self-efficacy was enhanced. The patients and their families gave the program a positive review.

In contrast, some patients may worry that the effects of the program may diminish over time. Ichikawa et al. [18] reported that patients said, "for now, my family pays attention to my condition, but I'm worried about whether the support from my family will last or not." Continued family support is essential for these patients. There would be patients' expectancy for their families and discrepancy between patients and their families.

4.2. Family issues surrounding patient support

Prevention of onset or worsening of complications is possible in patients with T2DM if they receive support for their self-management skills, if they stay motivated to continue treatment, and if their experiences of and feelings regarding the disease are understood. Therefore, various efforts have been taken to increase patient support, and improve their quality of life. As previously mentioned, educational program for both patients and families is one of these efforts. However, families may experience many difficulties in practice, and patients may express concerns regarding support from their families.

In this paper, in order to determine the experiences of middle-aged spouses in patient support, previous researches focusing on psychosocial aspects of patients with DM and their families, have been reviewed. The following questions have been examined in previous literatures: How do family members, patients' closest social supporters, feel about providing patient support? How are the needs between the patient and family balanced? What is the attitude of family members involved in patient support? In this review, previous studies focusing on the spouse have been described. The spouse is often the key individual involved in care of patients with T2DM. Thus, discussion regarding their feelings and experiences while providing support to patients with T2DM is warranted.

4.2.1 Family involvement in patient support

In a report on family involvement and how it affects the patient's self-efficacy, Miyamoto et al. [22] observed conflicts between the patient and his/her family if the family responded harshly to the patient's behavior. This conflict could have a negative impact on the patient's self-management skills. Methods of patient support from the family may vary, for example, family members may monitor treatment and symptoms or encourage and motivate the patient to continue treatment. In the long term, when the disease progresses and recuperation in hospital is necessary, the family may face an increased psychological burden [10].

4.2.2 Spousal involvement in patient support

Hayakawa et al. [23] identified the spouse as the most significant supporter of a patient with DM. Okamoto [24] reported that 70% of the family members who accompanied patients enrolled in the evening classes were the patients' spouses. However, it cannot be denied that focus during such programs is unilateral, although many individuals may attend lectures by doctors, nurses, and nutritionists that are part of the educational program. Peyrot et al. [25] examined that such a unilateral focus may cause marital friction between patients and their spouses which may in turn lead to treatment interruption.

The high rate of spousal involvement in patient support may influence patient self-management. For example, some studies have explored the relationship between spouses' beliefs regarding the patients' health and condition. Other studies have investigated the influence of marital relationship on DM control. According to these studies, spousal involvement in patient support is a predictor of the future progress of DM. The research on spouses' attitudes toward continuing treatment indicated that spouses play several roles. They reminded patients regarding the time to take medication but at times adopted a harsh attitude that hindered the patient's independence [26]. Beverly et al. [27] noted that "psychosocial conflict often arose, especially when the spouses' perceptions of and comfort with diabetes management were discordant" with those of the patients.

Regarding the relationship between patients who interrupted treatment and their families, Toima et al. [28] revealed the following three patterns of vicious circles: (1) co-dependency between husband and wife, (2) strong dependence of patients and neglect from spouses, and (3) excessive interference from spouses and the patient's desire to escape. They found that patients in these vicious circles were unable to continue treatment because of imbalances in their marital relationship [28]. Because

of the possibility that spousal burden may increase over the long course of DM treatment, conflicts between patients and spouses often arose during periods of recuperation. Studies are lacking on the ways spouses of patients with T2DM understand their new roles as patient supporters and the accompanying changes they make in their lives. Future studies are required to determine how spouses cope with the burden of patient support.

4.3. Spouses' experiences while providing patient support

Several studies are available regarding spouses' experiences while providing patient support. Kawata et al. [29] qualitatively analyzed the experiences of middle-aged and elderly spouses of patients with diabetic nephropathy on dialysis. They reported that the spouses often experienced pangs of conscience regarding the cause of the patient's dialysis and they had even thought of shirking patient support [29]. However, they also stated that the spouses had decided to continue supporting patients due to marital commitment and encouragement from other people [29].

In another study, Mori et al. [30] reported a case that targeted the wife aged 50 of a newly diagnosed patient on hemodialysis. The wife regretted that because she was unable to continue providing appropriate diet, the husband's hemodialysis may get delayed. She experienced fatigue as well as responsibility as his wife [30]. Takemoto et al. [31] performed quantitative research focusing on the burden of middle-aged spouses during recuperation of patients on hemodialysis. According to them, "Only negative feelings had a significant influence on intention not to continue [31]."

Thus, the emotions and experiences of spouses providing patient support have been examined, particularly of those for whom hemodialysis treatment had a profound effect on daily life and quality of life due to the onset and progress of complications of diabetes.

In an analysis of the contents of interviews conducted in 10 couples, Yamaguchi et al. [32] discussed spouses' feelings regarding provision of patient support from the point of view of gender roles and found that gender role belief had an impact on spouses' feelings regarding patient support.

Kubota et al. [33] performed a qualitative research, in which wives aged 30-70 expressed anxiety regarding their husbands discharge. Takahashi [34] focused on middle-aged wives experiences while providing dietary support and receiving information regarding their husbands diabetic control from physicians. The wives had few opportunities to meet physicians in long recuperation. Mori [35] divided wives into three groups according to their husbands' glycemic control. Wives of patients with good glycemic control had built a support system for themselves. In the course of long recuperative

Table 1. Summary of studies

First author (year)	Objectives	Participants	Design	Reference No.
Sugawara et al. (2004)	Analysis of reason for interruption and evaluation of measure to prevent treatment interruption	2,018 outpatients	Quantitative	[12]
Koga et al. (2002)	Clarification of patient's experience	Patients with treatment interruption; 8 male and 1 female	Qualitative	[13]
Koizumi et al. (2002)	Identifying diabetic control influenced by constrain on vocation	270 employed male patients under age of 60 years	Quantitative	[14]
Ichikawa et al. (2004)	Clarifying emotions of male patients with T2DM after discharge	4 male patients with T2DM	Qualitative	[18]
Miyamoto et al. (2008)	Clarifying family involvement for patient support affecting self-efficacy of patient with T2DM	12 patients and 2 spouses	Qualitative	[22]
Hayakawa et al. (2005)	Developing a care model that patients with DM and spouses by stimulating mutual sympathy through diabetes education	11 nurses as diabetes educators and 27 marital couples with one DM partner	Qualitative	[23]
Toima et al. (1999)	Examination of vicious patterns in family causing patients non-compliance	7 families in which patients experienced treatment interruption	Qualitative	[28]
Kawata et al. (2007)	Clarifying experiences of spouses supporting patients on dialysis	3 spouses of patients with diabetic nephropathy	Qualitative	[29]
Mori et al. (2006)	Clarifying feelings of wife of husband with initiation of dialysis	A wife of husband with diabetic nephropathy	Qualitative	[30]
Takemoto et al. (2008)	Clarifying the relationship between care burden and intention not to continue in family caregiver of diabetic nephropathy patients on dialysis	1014 family as a key individual of patient support	Quantitative	[31]
Yamaguchi et al. (2006)	Clarifying feelings of spouses about gender role in patient support	10 marital couples with one DM partner	Qualitative	[32]
Kubota et al. (2008)	Clarifying wives' anxiety after husbands discharge	6 wives of husbands with DM	Qualitative	[33]
Takahashi (2002)	Consideration of approach to patients with DM and their wives with given medical explanation by physicians	3 marital couples in the middle age; 3 patients and their wives	Qualitative	[34]
Mori (2002)	Clarifying differences of wives' support for husbands with DM and consequence of glycemic control in the middle age	9 wives of husbands with DM	Qualitative	[35]

periods, the wives had fewer opportunities to receive information from physicians than at the time of diagnosis [35].

In these four studies, the spouses' feelings and experiences for patient support were clarified to some extent. However, further studies are necessary for thorough clarification on this topic.

5. Discussion

Considerations from this literature review and resulting research challenges have been described below.

Patients with T2DM, which often develops after the age of 40 years, require self-management skills, but acquiring and practicing these skills is difficult due to DM-associated health problems. In addition, challenges with maintaining marital relationships and occupying new social roles exist. In adulthood, the patients would interrupt treatments because of work, and they can increase anxiety regarding disease progression and complications. Family members should provide essential support for the patient but they also need help. In particular, patients' spouses are often recognized as a key to treatment continuation, encouraging patients to adhere to dietary restrictions, and continue exercise programs in daily life. Spouses' cooperation with medical treatment is essential; however, their social activity participation is restricted. In addition, they experience anxiety regarding the patient care and the direction of their future lives.

Some studies have investigated the experiences of patients with T2DM. Other reports have examined the process of their experience during long recuperation periods. The findings of these studies may be utilized in patient support.

Overall, there is a significant lack of research on spouses of patients with T2DM. Four studies, identified during this research, targeted this population. They examined the anxiety of wives before the husbands discharge, the relationship between gender role beliefs and feelings regarding patient support, support behavior of wives for the diet of their husband with DM, and the influence of medical explanations from physicians on patient support. None of these four studies have examined the experience of middle-aged spouses of patients with T2DM, and no other previous research has addressed this topic. During periods of long recuperation, an understanding of the experience of spouses to helping patients with T2DM will aid in reducing spouses' fatigue and burden enabling them to continue being socially strong supporters of patients with T2DM. The experiences of spouses of patients with DM must be examined in the course of long-term patient care.

Findings from studies on these topics would be useful for helping spouses who devote their lives to patient support.

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