

# The Psychological Implications of Patients with Diabetes on their Spouse: A Review

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## Abstract

Type 2 diabetes and its management pose a heavy burden for patients and their caregivers causing psychological distress. T2DM often accompanied by life-long treatment regimens and further complications can lead to disability or even death, thus have a serious impact on quality of life for patients and their families. The interaction between patient and family, especially spouse involvement promotes treatment adherence and overall chronic illness self-management of partners. Despite, the positive role of spouse, T2DM management cause marital stress as their non-diabetic partners are also exposed to the same emotional and psychological worries as their counterparts. Besides, partners of people with type 2 diabetes experience severe psychological distress including depression, anxiety, and feeling of isolation, guilt, frustration and anger. The purpose of this review was to summarize the published studies on the psychological implications that T2DM would have on their spouse.

**Keywords:** Psychological Implications, Depression, Anxiety, T2DM, Spouse

## Introduction

Several reports have documented psychological distress among patients with diabetes [1]. The risk of developing psychiatric comorbid conditions was increased with earlier onset of diabetes mellitus (DM) and its management includes lifestyle modification and dependence of oral anti-diabetic drugs including insulin [2]. Because of its impact on health related Quality of Life (QoL) and life expectancy, diabetes can be a frustrating condition affecting psychological wellbeing of patients and their family members [3]. Patients with type 2 diabetes mellitus (T2DM) display higher prevalence of depression and anxiety over time compared to with those without. When a diabetic patient is unable to control or manage his dietary diabetic regimen, it results in psychological stress and depression, a feeling of hopelessness which in turn aggravates the condition over long run [4].

A growing body of literature have consistently proved that, individuals with diabetes who perceive greater levels of available support report higher quality of life [5], fewer symptoms Ashton et al.[6], and are more likely to adhere to their medication [7] and self-management regimens [8]. Notably, spousal support seems to have a stronger impact on treatment adherence thereby positive patient outcomes and emotional well-being than other relationships. Despite the positive role, a diagnosis of T2DM profoundly influence a couple dynamics and interrelationship [9]. Studies have shown that spouses of diabetic patients experience emotional stress and depression related to diabetes, highly when compared to their partners [10]. Also it is believed that spouses of diabetic patients experience heightened emotional stress and depression even if the patient is not [11].

## Methods

### Literature search

This systematic review was conducted according to the PRISMA guidelines [12]. The Institutional Review Board approval was not required as the review does not involve any patients. The PubMed, Science Direct, Web of Science, Medline and PyschINFO and Pysch-Articles as well as hand searching of references lists were searched to find relevant publications between January 2001 and December 31, 2018, using the following terms: “Diabetes mellitus type 2 or T2DM,” “psychological

implications”, “depression” “anxiety”, “psychosocial” “support,” “caregivers,” “family” “care” and “spouse.”. A manual search was also performed by scrutinizing the abstracts and the reference lists of eligible series to identify any further relevant articles.

### Selection criteria

Studies were eligible if the following outcome measures were extractable. Both cross sectional studies and retrospective observational studies published in English as full-length articles between 2001 and 2018, age above 18 years, married and living with spouse and reporting (i) family members with a member with type 2 diabetes and (ii) discussed about psychological implications that spouse have due to the partner. However, due to the limited number of studies on this perspective, the review will also include case reports, case series, review articles, editorials, commentaries, debates and conference abstracts. However, articles irrelevant to the objective of the review and studies focusing on non-psychological aspects, studies focusing only on either the patient or spouse or family perspective will be excluded.

### Results

Total of 880 papers were identified, of which 869 were excluded based on inclusion and exclusion criteria. The following (Fig. 1) schematically represents the flow diagram of study selection and inclusion based on PRISMA guidelines.

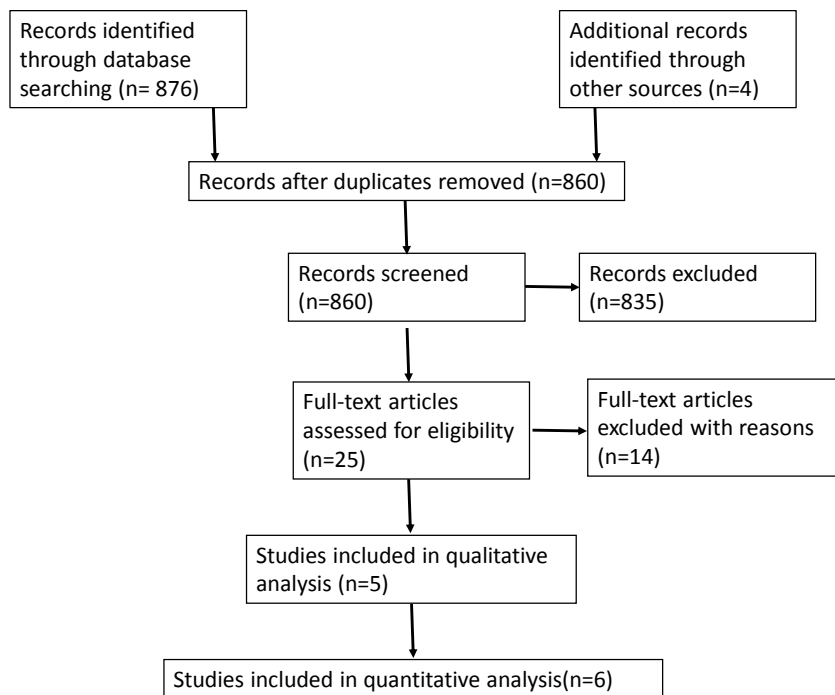


Fig 1: Flow diagram of study selection and inclusion

In this review, 11 full-text articles were included of which 6 were quantitative and 5 were qualitative studies

Table 1: Quantitative study.

Author and Year	Country of study	Study type	Objective	Characteristics	Findings
Pereira et al.[13]	Europe	Prospective study	To assess the relation between sex and diabetes and its impact on patients and spouses	N= 87 Male = Average age = 62 years Female = Average age =59 years Duration of diabetes = $\geq 1$ year Average duration of diabetes (male)= 12 years Average duration of diabetes (female)= 9 years No. of years married = Mean years married = T2DM = 87 patients	Female patients showed better marital adjustments and also sexual dysfunctional believes than male patients. Male showed more sexual satisfaction. People with secondary education reported less sexual dysfunctional believes than elementary educated patients. Younger patients showed more adherence. Older people showed more sexual dysfunctional believes however older women reported better sexual functioning than young women.
Pereira et al.[14]	Europe	Cross-sectional study	Effect of partners perception towards diabetes as mediators for patients perception and self-care adherence	N=340 Male = 60 Mean age = 59.41 years Mean Marriage duration = 32.8 years Duration of diabetes (<6months) = 60.8 Duration of diabetes (7-12months) = 39.2	Partners (regardless of gender) involvement in diabetic management resulted in better adherence to exercise, blood glucose monitoring and foot care
Trief et al.[15]	USA	Pilot study	To assess collaborative problem solving approach in diabetes self-	T2DM =44 with poor glycemic control Male = 16 Age=>21 years Average age =	When participants were randomly assigned to couples intervention, individual intervention or enhanced usual care with 2 diabetes

			care including spouses	59.9 years No. of years married=>1 year Average years of diabetes = 13.4 years	education session with meal plan review, it was observed that, though glycemic control improved in all groups, individual intervention resulted in better outcome.
Dempster et al.[16]	UK	prospective	To assess psychological adjustments to diabetes and its effect on marital quality and relation	N=88 Male = 48 Mean Age = 61.60 years Mean years married = 33.39 years Mean diabetes period = 26.32 years	Non-insulin dependent diabetic patients are better adjusted to diabetes when they share physical activities with their spouses
Trief et al.[17]	USA	Prospective, cross-sectional study	To assess relation between marital quality and self-reported diabetic self-care regimen	N=78 Male = 32 Age = 18-55 years Mean age = 45.7 years Duration of diabetes = $\geq 1$ year Mean duration of diabetes = 16.6 years No. of years married = $\geq 1$ year Mean years married = 19.2 years T2DM = 37 patients	The study moderately positive relationship between marital intimacy and adjustment with several aspects of diabetes self-care regimen such as adherence to diet-caloric intake, diet composition, exercise, blood glucose testing and adherence to physician's recommendations in insulin dependent adults.
Trief et al.[18]	USA	Prospective cross-sectional study	To assess relation between marital intimacy and adjustment with health related QoL (HRQoL) and glycemic control in	N=61 patients Male = 23 Age = 18-55 years Mean age = 47.1 years Duration of diabetes = $\geq 1$ year Mean duration of diabetes = 17	When insulin treated adults were re-assessed for association between marital relationship and adaptation to diabetes, after two years it was found that those who reported better marital adjustments before 2 years had less diabetic related distress after 2

diabetic patients years No. of years married =  $\geq 1$  year Mean years married = 21 years T2DM = 30 patients years. Similarly, better marital intimacy and adjustments resulted in good diabetic care regimen. However, HRQoL and glycemic control was not predicted by marital measures

Table 2: Qualitative studies

Author and Year	Country of study	Study type	Objective	Characteristics	Findings
Dimitrakis & Karademas [19]	Europe	Cross-sectional - questionnaire	To assess diabetic illness perception by patients and their spouses and its relation with their well-being	N= 168 Couples = 84 Age of patients = 34-86 years Mean age of patients = 64.65 years Mean age of spouses = 62.83 years Male patients = 29 Mean duration of marriage = 27.39 years Mean duration of diabetes = 14.94 years Insulin treated = 44%	Spouses' negative perception over illness significantly affected patients' physical and psychological well-being independent of their own illness perception
Stephens et al.[20]	USA	Qualitative - descriptive study	Relation between spouses' involvement in patients' diabetes management based on diet related support, persuasion, and pressure and patients' dietary	N= 126 couples T2DM = 63 Non T2DM = 63 Length of study = 24 days Age of patients = 55-85 years No. of years with diabetes = $\geq 1$ year	spouse involvement in managing patients dietary adherence resulted in better adherence to recommended diet, negative form of social support such as persuasion and pressure decreased patient's adherence and increase in patient's diabetes related distress.

Franks et al.[21]	USA	Qualitative study - semi-structured Interview and self-administered questionnaires	adherence and diabetes-specific distress dietary adherence setback and emotional distress in older patients with T2DM and spouses	N=115 couples Mean age of patients = 66.03 years Mean age of spouses = 66.35 years Female patients = 51.3% Female spouses = 48.7% Average period with diabetes = 12 years Average married period = 38 years	patients' difficulties with dietary adherence (i.e. diet setbacks) were associated with increases in diabetes distress and depressive symptoms for patients and for spouses.
Sandberg et al.[22]	USA	Qualitative study - semi-structured Interview	gender differences in spousal supporting behaviors.	N= 72 Patients = 40 Spouse = 32 Male = 16 Married = 29 Age = 18-65 years Average age = 49 years T2DM = 55% T2DM treated with insulin = 88% Average duration of diabetes = 19 years	Gender similarities and differences in supportive and non-supportive behaviors and couple interaction during low blood sugar
Trief et al.[23]	USA	Qualitative study	Study on couples living with Diabetes	N= 72 Patients = 40 Spouse = 32 Married couple = 29 Age = 18-65 years Diagnosed with diabetes = $\geq 1$ year Married = $\geq 1$ year T2DM = 55% T2DM treated	Supportive and non-supportive behavior and couple interaction



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### **Individual Intervention vs Spousal Support**

Trief et al.[15] When participants were randomly assigned to couples intervention, individual intervention or enhanced usual care with 2 diabetes education session with meal plan review, it was observed that, though glycemic control improved in all groups, individual intervention resulted in better outcome. However, in case of older T2DM patients, increase in comorbid conditions like diabetes resulted in poor self-management of daily diabetes regimen. However, the same study reported that in two-third of cases, their spouses have attempted to resume their partner's dietary regimen [21]. Similarly, (M. G. Pereira et al [14] reported that when both patients and partners are fully aware of diabetes consequences and self-care regimen, there is better adherence to exercise, foot care and blood glucose monitoring. Similar finding by Stephens et al., [20] reported that, when 63 T2DM patients was asked to record their dietary adherence and their non-diabetic spouses involvement in managing their partners dietary choice a day for 24 consecutive days, it was reported that though spouse involvement in managing patients dietary adherence resulted in better adherence to recommended diet, negative form of support such as persuasion and pressure decreased patient's adherence.

### **Young vs old age**

Difference in diabetes management among different age group was observed. According to Pereira et al.[13], younger patients showed more dietary adherence and [21] reported that management of one or more chronic illness conditions such as T2DM every day by older adults results in dietary adherence setback and nearly (94%) of T2DM patients had experienced dietary management setback in the past six months and most spouses (88%) have agreed to it.

### **Emotional distress experienced by patients and spouses**

Franks et al. [21] reported that, diabetes related depression in older T2DM patients significantly cause depression in their non-diabetic partners. Patients feel diabetic related emotional distress as they have to maintain a daily diabetic regimen and they start worrying about living with diabetes. They also feel anxious about poor disease management. Similarly, Stephens et al., [20] reported that negative form of social support such as persuasion and pressure by spouses in managing patients dietary adherence resulted in increased patient's diabetes related distress [19]. who assessed the impact of diabetic illness perception by patients and spouses and its effect on physical and psychological wellness reported that perception of diabetes as chronic, unstable (cyclic) condition with associated troublesome comorbid conditions results in high levels of stress and poor health despite better treatment adherence and self-care. Such physical and psychological wellbeing of a patients is not just affected by his/her own perception, but, also their spouse representations. i.e., spouse perception of diabetes as chronic, unstable condition with adverse consequences significantly affects patients' wellbeing irrespective of their own perceptions. When spouse and patients have same perception towards diabetes, patients reassure their own perception's accuracy which ensures their wellbeing. However, when spouse assume diabetes to be a controllable condition, patients develop a sense of control over the disease condition which in turn nullifies their own negative illness perception. When patients assume diabetes to be troublesome, spouses feel less anxious and vice-versa when patients perceive diabetes as less burden.

### **Self-care, Marital Quality and glycemic control**

Dempster et al., [16] Reported that on assessing the relationship closeness and marital quality using Personal Assessment of Intimacy in Relationships (PAIR) scale it was found that T2DM patients with satisfactory marital quality such as intimacy and adjustment showed better glycemic control, QoL and diabetes self-care management. Same authors in another study [18], assessed the linked between marital quality and diabetic self-care regimen adherence of insulin dependent type 2 diabetes and

reported that there was a positive relationship between them. However, the support was moderate and indicated that as the number of co-morbid conditions increases, it significantly affects the level of satisfaction. Same authors in study [17], failed to find relation between marital quality and blood glucose level in diabetic patients after 2 years assessment due to the fact that other factors such as the level of insulin deficiency, insulin resistance and diet shall affect glycemic control more significantly than marital relationship.

### **Gender disparity**

Pereira et al. [13] reported female patients showed better marital adjustments and also sexual dysfunctional believes than male patients, however, older women reported better sexual functioning than young women. Male showed more sexual satisfaction. According to Sandberg et al.[22] Findings, though both gender spouses offer verbal and instrumental care and support. According to the study female spouses (n=31) and patients have expressed either providing or receiving verbal support such as helpful questions, reminders, or advice when compared to male spouses (n=12) who are more linked to provide instrumental support such as blood sugar testing, insulin injection, buying and organizing diabetic medicines etc.

## **Discussion**

### **Individual Intervention vs Spousal Support**

Trief et al.[18] Marital support in form of spousal involvement with healthcare activities such as keeping track of and delivering medications, buying and preparing foods, performing regular exercise is important in diabetic management. According to patients, consoling words and behaviors such as 'I will be there', 'help', 'encourage' are very supportive. According to Trief et al. [23], supportive attitudes, such as helping, letting to talk and discuss, cooperation, verbal-backing support, helpful communication, problem-solving exchanges, reminders for checking blood glucose levels, medication and snacking, all acts as helpful behavior. However, Trief et al. [18] reported that any strain in marital role due to poorer life adaptations to chronic illness such as diabetes and unmet expectations by both patient and spouse can significantly affect diabetic management and results in poorer quality of life. Hence, it is important for both patients and their spouses to adjust their food choices, eating patterns, medications and other lifestyle modifications. Such changes are mostly observed in intimate and support marriages than distant and less satisfying relationships.

### **Young vs old age**

Pereira et al. [13] Younger patients showed more adherence to diabetes regimen since, they more concerned with the possible complications of diabetes and their impact on sexual performance. Similarly, people with shorter duration of diabetes (10 years) reported more dysfunctional believes than those with longer duration of illness, as people with longer duration of illness have acquired correct sexual information and hence corrected their sexual beliefs in due course of life.

### **Emotional distress experienced by patients and spouses**

Incidences of hypoglycemic condition in diabetic patients pose serious threat to life impairing their cognitive function and imparting mood swings. Sudden reaction while outside house, results in anger among male spouse which depress female patients. Sudden reaction of hypoglycemic condition during early days of diabetes in male patients, results in assertive and aggressive behavior among female spouses, which later changes with ageing. As against patients emotional distress due to low blood sugar levels, spouses, irrespective of gender has also expressed concerns, frustrations and pain when they assist their diabetic partner to deal with such unexpected and dangerous incidences. According to Sandberg et al. [22] findings, It is important for female spouses to learn predict when their spouse go low in blood sugar, as it results in fuzzy, mood swing among male patients and it is important to take control and deal with it. Male spouses have expressed concern when their spouse blood sugar goes low, which annoys and aggravate them as they have to feed their spouse immediately to control blood sugar. Hence, it can be concluded that both patients and spouses find their communication during hypoglycemic conditions as difficult and worrisome.

### **Self-care, Marital quality and glycemic control**



Those who were sexually satisfied showed better adherence to diabetes care regimen than those with sexual dysfunctional believes. Though several literatures suggest that couples intervention results in better outcome in terms of pain, depression and marital satisfaction, none of them report on glycemic control outcomes [15]. Trief et al. [18], reported moderate support for relation between marital quality and diabetes self-care regimen as the number of participants (n=78) and duration of follow-up (2 years) was limited. The marital quality did not predict blood glucose testing adherence. The study reported that poor marital relationship results in poor self-care and marital conflict. Also, lack of adherence to physician's recommendations and inability of the patient to adhere to diabetic self-care regimen results in anger, frustration and worry among spouses about their future. This leads to further distance and greater conflict-laden relationship.

Similarly, Sandberg et al. [22] reported that diabetic patients consider their spouse to be very supportive, if they help in glycemic control. From the study, it is understood that female patients, when compared to male find their spouses to be more supportive. According to female patients, supportive behavior by their male spouses includes, assistance with diabetic medication, insulin-injection, regular monitoring of serum blood glucose, preparation of diabetic meal, grocery shopping according to diabetic requirement etc [23].

According to Sandberg *et al.*[22], there are patients, irrespective of gender willing to self-manage their regular diabetic regimen and reject help from their spouses [22].

### Gender disparity

Both male and female diabetic patients have different desire of support offered by their spouses. According to them, supportive behaviour includes, grocery shopping, preparation of diabetic food, shared diet plan, helping control food intake, better adherence to diabetic diet, adjusting the timing of meal and location according to diabetic patients. The following (table 3) shows desirable and non-desirable behaviour related to dietary control

Table 3: Supportive and Conflict/ Resistance Behavior by spouses related to dietary control

Supportive behaviour	Conflict and Resistance behaviour
grocery shopping	Purchase of non-healthy foods
food preparation	Preparation of non-healthy foods
a shared diet plan	Unshared diet plan
strict adherence to dietary guidelines	Non-adherence to dietary guidelines
adjustments to the timing and location of meals	Change of meal timing and location of meals

Source: Adopted from Trief et al.[23]

According to [22], it is important for spouse whether male or female who arrange and prepare meals to bear in mind that certain foods are restricted to diabetic patients and to avoid preparation of such meals. It is also important for spouses of diabetic patients to plan mealtime essentials such as timing of meal and ingredients added in it based on their partner's diabetic requirements.

However, the same author reported that most of the spouses, irrespective of gender, commented that those patients who self-manage their diabetic regimen are often stubborn, rejecting the help offered through silent or distant messages like walking away or through verbal rejection. With respect to gender, male patients who self-manage their condition are away independent and say they can self-handle their diabetic regimen selves or just buy or prepare their own diabetic meal without considering the help offered by their female spouses [22]. Due to such behaviour, female spouse of these male patients often use cooperative and helpful words like 'ask', 'help' etc. In case of female patients, their male counterparts use authoritative words such as 'make sure', 'do', 'tell' to exhibit control over their diabetic partners.

Irrespective of gender, diabetic patients worry about their spouses nagging behaviour. According to Trief et al. [23], both patients and spouses consider nagging or criticizing to be problematic. Few examples of non-helpful spousal behaviour included, 'bugging', 'harping',

‘critical/constant/controlling’ reminders. The following table shows the list of non-helpful behaviour as described by patients and spouses.

Table 4: Own non-helpful behaviour as described by patients and spouses.

Non-helpful behaviour as described by patients	Non-helpful behaviour as described by spouses
Bugging	Nagging
Harping	Being scared
	Nervous
	Constant, controlling reminders

Source: Adopted from Trief et al. [23]

When spouses were asked about their own behaviour, very few, especially female spouses describe nagging, being scared and nervous as a problem, because, male patients mostly don't like to be told what to do. Hence, they consider it is important to say in such a way, it doesn't upset male patients [15].

## Limitations

The limitations of the study includes, limited number of sample size [15] and follow-up period, limits generalization of results and its interpretation. Similar limitations was observed from study [18], where the study was unable to find significant relation between marital quality and health related QoL or blood glucose level. Also, the sample in Pereira et al.[13] was collected from a very conservative Catholic community. Hence, it is important to increase the sample size and include non-Catholic community to give unbiased results. In study Trief et al. [15], the individual intervention group included patients with short duration of diabetes, hence, this might have positively affected the outcome. Couples interventions results in better outcome with longer follow-up [18], did not assess the underlying personality traits as some individuals may better adapt to both marital life and chronic disease conditions such as diabetes. Other limitations are similar to [18].

Most of the studies included both type 1 and type 2 diabetic patients treated with insulin and not consider patients who manage diabetes by dietary control and oral medication due to the fact that those who control diabetes with insulin face unique challenges such as regular and frequent blood glucose testing, injection of insulin, low blood glucose levels as against non-insulin treated individuals [18]. Also, many studies includes those suffering from diabetes for long term and married for long years. Such findings may be different from those who are married for shorter duration and suffering from diabetes for shorter period of time. In study Dimitraki & Karademas [19], the level of control over diabetes, was not assessed similarly, impact of gender and relationship quality was not assessed due to limited sample size, however an important factor in determining the adaptation to illness [19], Trief et al.[15].

## Conclusion

From the systematic review, it is evident that it is important to provide correct information on sexuality to patients with diabetes to improve self-care adherence and reduce sexual dysfunctional believes. Female patients and partners report more burden associated with diabetes and sexual satisfaction. Also, it is important to educate partners about diabetes as those partners who believe they have better control on diabetes and treatment, results in better patient's adherence to glucose monitoring. Also patients and partners those who are aware of diabetes encourage better adherence to exercise and foot care along with blood glucose monitoring. However, it is important to educate patients that they do not require their partner's help or their perception about diabetes which may affect diabetes self-care regimen. It is understood that individuals with shortened duration of diabetes self-manage it better than couple intervention. Also, a longer follow-up is required to analyse the effect of couple intervention on glycemic control. Non-insulin dependent type 2 diabetes patients who are engaged in shared recreational activities involving physical activity with their partners are

psychologically well adjusted to diabetes. However, increase in co-morbid conditions impact their perceived burden of self-care. There is moderate support in marital quality and diabetes self-care regimen and this varies between gender and personality traits. The review concludes that marital support in form of spousal involvement with healthcare activities is important in management of diabetes. Poorer life adaptations to diabetes and unmet expectations by both patient and spouse can significantly affect its management and quality of life. Hence, it is important for both patients and their spouses to adjust their food choices, eating patterns, medications and other lifestyle modifications and such changes are mostly likely observed in intimate and supportive marriages than distant and less satisfying relationships. It is important for clinicians and healthcare service providers to impart a more adaptive and realistic representation of the disease condition in order to bring a more positive physical and psychological wellbeing. When patients perceive diabetes as less burdensome then spouse feels it as a serious condition making the spouse more anxious, as they assume their partner is underestimating the condition which could increase risk associated with diabetes. A shared and supportive management of diabetes by both patients and their spouses results in better dietary adherence, physical and psychological wellness and decrease in diabetic related distress among patients when compared to those partners who view patients' disease management as the patient's responsibility alone. It is important to positive support patients' dietary choice every day to reinforce their belief that they have the skills and ability to cope with illness. It is also important to note that even slight form of control negatively affects positive perception of disease by chronic ill patients. Emotional distress and depression related to poor management of diabetes not only affects the older patients but also their spouses. Patients and spouses frequently agree that diabetes is a problem that affects the two of them as older patients worry and anxiety about poor daily diabetic regimen management cause depression in their partners. However, older patients with good diabetic knowledge do not experience concerns over lapse in dietary adherence when they take break from their daily dietary regimen. However, their emotional distress increases when there is change in their physical functioning or glycemic control. Hence, it can be concluded that spouses who have greater concerns and worry about their partner's dietary management, become more attentive to their partner's non-adherence to recommended dietary regimen.

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