Primary caregiver involvement in management of type 2 diabetes mellitus: A community-based observational study from urban Puducherry

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ABSTRACT

Background: Adherence to medication and lifestyle modification is an important predictor of positive outcome of diabetes management among adults in which primary caregiver (PCG) plays an important role.

Objectives: The objectives of this study were to describe the involvement of PCG in adherence to the drugs, diets, and lifestyle changes among patients with type 2 diabetes mellitus in an urban area of Puducherry.

Methodology: A total of 311 type 2 diabetes patients irrespective of their source of diabetes care were included from the service area of an urban health and training center in an urban area of Puducherry. The PCG for each patient was identified, and the PCG and the patient were interviewed separately to obtain the information on adherence and involvement in various aspects of diabetes management, respectively, using an interview schedule. The information on diabetes control status of the patient was obtained from the records available.

Results: About 10% of the patients did not have caregiver. Nearly 90% of the PCGs were involved in either of the lifestyle modification, drug adherence, checking type and frequency of medication, accompanying for consultation, or all. About 80% of the PCGs remind the patient to take medicines when out of station mainly by phone call/short message service. Encouragement toward physical activity was proportionately less compared to diet and drugs, and that was reflected in the patient’s level of adherence in those domains. Overall involvement of spouse was more than the nonspouse. PCG involvement was found to be significantly associated with adherence to diet ($P = 0.027$) but not with drug and physical activity ($P > 0.05$).

Conclusion: The PCG should also be considered while designing health education intervention on various aspects of diabetes management, focusing and highlighting the areas of poor involvement and their importance in disease management. The health system should place special focus on patients without PCG.

Keywords: Adherence, community-based study, primary caregiver, type 2 diabetes mellitus

Introduction

Diabetes has taken the shape of epidemic in India, and soon India will be labeled as the diabetes capital of the world.¹ The International Federation of Diabetes has estimated that by 2030, India will house nearly 87 million diabetes patients. In India, the prevalence of diabetes is higher in the southern part compared to the northern part.² Literature reported poor glycemic control in more than half the diabetics in India.³ Poor glycemic control is associated with micro- and macrovascular complications of diabetes. Complications of diabetes are found to...
be more common among Indians compared to other countries.\textsuperscript{[4]}

The glycemic control among diabetes is important to prevent complications, and the best way is adherence to medication and lifestyle changes.\textsuperscript{[5]} The adherence to medication and lifestyle changes is an important component of diabetes self-care and has been influenced by many factors; however, literature reported low level of adherence among Indian diabetic population.\textsuperscript{[6-8]} An important factor for nonadherence to medication is forgetfulness.\textsuperscript{[9]} Availability of a family member or a caregiver can help avoid such situations. Poor communication between chronic disease patients such as diabetes and physician is another important determinant of nonadherence.\textsuperscript{[10-12]} Dietary habits of diabetics are influenced by the dietary behavior of the family. Availability of a family or a caregiver helps a diabetic in many ways: adherence to behavioral changes, emotional support, alleviation of depression, and strict compliance to medication regimen.\textsuperscript{[13]} Management of chronic disease requires emotional as well as behavioral support by a primary caregiver (PCG) in carrying out day-to-day disease-related activities.\textsuperscript{[14,15]} Many diabetics patients deviate from regular follow-up plan because of nonavailability of family members to accompany them.\textsuperscript{[16]} Literature from Western countries has demonstrated improvement in patient outcomes with the involvement of family members.\textsuperscript{[17]} However, the paucity of scientific literature, especially in the Indian setting, thwarted recognition of structured health education intervention for PCG or family member in the management of diabetes. In this background, the current study was planned to describe the involvement of PCG in adherence to the drugs, diets, and lifestyle changes among patients with type 2 diabetes mellitus (DM) in an urban area of Puducherry.

Methodology

This community-based cross-sectional study was conducted between February and April, 2017, at four wards in an urban slum of Puducherry. An urban health and training center (UHTC) provides family folder-based comprehensive promotive, preventive, curative, and referral health services to a population of nearly 9000 residing in the four urban wards in this slum area of Puducherry. Apart from providing routine care through outpatient department basis, the special clinics are conducted on specific days of the week by the UHTC. The noncommunicable disease (NCD) clinic is conducted on every Wednesday. Apart from providing routine, follow-up, and referral care during NCD clinic, the diabetes patients and their accompanying persons are educated on various aspects of diabetes management including lifestyle changes. The Government Hospital, Puducherry, is about 2 km from this urban slum, and many private practitioners are present in and around this slum area.

This study included all the type 2 diabetes patients residing in the service areas of UHTC irrespective of their source of diabetes care. The list of diabetes patients availing diabetes care from UHTC was obtained from the NCD register available at the UHTC. The list of diabetes patients availing diabetes care from other sources but residing in the service area was noted from the census register of UHTC. The addresses of all the diabetes patients were noted down, and house-to-house visits were made by trained MBBS interns who in turn were supervised by resident doctors (investigators). Efforts were made to trace the correct patient if house address was found to be wrong. Verbal informed consent was obtained from the diabetes patient as well as his/her PCG if at all available. Household refusing to participate, found locked even after two visits, and newly diagnosed patients (disease duration <6 months) were not included in the study. If two or more diabetes patients were present in a household, only one was selected randomly through lottery method and enrolled for the study. The study tool included a pretested semistructured questionnaire with three components. The first component included sociodemographic details of the patient and PCG. The second component included involvement of PCG in diabetes care of the patient and the PCG perceived adherence to medication and lifestyle changes by the patient. The third component included the diabetes control status of the patient. Information on first and second components was obtained through direct interview of the PCG. Information on diabetes control status was obtained from the investigation records (for diabetics taking care from outside) and the NCD case sheet available at the UHTC (for diabetics taking care from UHTC). The information obtained was entered into Epidata Manager 3.2 (Epidata Association, Odense, Denmark), and descriptive analysis was done using SPSS 20.0 (IBM Corp., Armonk, NY, USA).

For the study purpose, the PCG was defined as an individual assigned among the family members, other than the patient, in assisting the diabetes patient in the management of the disease. Healthy diet was defined as consumption of fruits and vegetable 5 or more days a week and junk food <3 times a week. Adequate physical activity was defined as leisure time physical activity of more than
30 min a day for at least 5 days a week. In the Likert scale of visiting doctor/investigation, always and most often were categorized as “regular,” and never, rarely, and sometimes were categorized as “not regular.”

Results

Out of the total of 311 patients, majority (64.6%) were female and maximum (37.3%) had no formal education. The median (range) age of diabetes patients was 58 (27–85) years. The median (range) duration of diabetes among the patients was 5 (1–35) years. Majority of the patient with PCG (77%) wanted involvement of PCG in diabetes management. About 9% of the diabetics did not have any PCG. Spouse was the PCG for majority of diabetics (53.7%) followed by son (18%), daughter (15.2%), and others (13.1%).

Maximum (42.8%) numbers of PCG aged between 40 and 59 years. Majority of PCG were females (56.6%), had studied 10th or above (59%), and belonged to above poverty line (APL) family (80.9%). Nearly 17% of the PCG themselves had diabetes [Table 1].

About one-third of the PCG had myth about possibility of contacting diabetes from diabetes patients. Nearly one-third of the PCG felt stressed out on assisting the diabetics in diabetes management. Majority of the PCG reported that they do not regularly accompany the patient for visiting doctor or investigation. Of those who accompany the patient to the doctor, majority (60%) reported to discuss with doctor regarding the disease status of the patient. Almost 85%–90% of the PCG were aware of the name and frequency of medication the patient is taking [Table 2]. Almost all the PCG were aware of importance of fruits and vegetables in diabetes management; however, only 93% encourages taking them regularly. About 90% of the PCGs remind the patients to take medication when PCG is out of station [Table 2], and majority (53%) of them do so through a phone call or short message service (SMS) [Figure 1]. More than three-fourths of the PCGs encourage the diabetics to adhere to the diet prescribed by the doctor and to do yoga/exercise. Twenty-one (81%) of the 26 PCGs where diabetes patients use tobacco products encourage them to quit tobacco use. Similarly, 32 (97%) of the 33 PCG where diabetes patients consume alcohol encourage them to quit alcohol.

PCG involvement was found to be significantly associated with patient adherence to diet. However, no statistically significant association was found between PCG involvements with patient adherence to drugs and physical activity and diabetes control status [Table 3]. Adherence to the drugs, diet, and physical activity was reported to be higher if the PCG was the spouse, although only adherence to physical activity was found to be significantly associated [Table 2]. PCG involvement was found to be more if the diabetes patient is female and elderly. Similarly, PCG involvement in diabetes care was found to be more if the PCG was aged 40–59 years, male, educated standard 10th or more, not going for job, belong to below poverty line family, not spouse, and him/herself had diabetes, albeit statistically not significant.

Discussion

Diabetes being a chronic disease, its management needs an integrated patient-centered approach to be developed in discussion between the patient, family members, and the health-care provider. The PCG of the family can act as

| Variable                  | Category     | n (%)  |
|---------------------------|--------------|--------|
| Gender                    | Female       | 160 (56.5) |
|                           | Male         | 123 (43.5)  |
| Age (years)               | <40          | 108 (38.2)  |
|                           | 40-59        | 121 (42.8)  |
|                           | ≥60          | 54 (19)     |
| Education status          | No formal education | 47 (16.6) |
|                           | <10th        | 69 (24.4)   |
|                           | 10th or above| 167 (59.0)  |
| Occupation                | Employed     | 154 (54.4)  |
|                           | Unemployed   | 129 (45.6)  |
| Socioeconomic status      | APL          | 229 (80.9)  |
|                           | BPL          | 54 (19.1)   |
| Relation with patient     | Spouse       | 152 (53.7)  |
|                           | Not spouse   | 131 (46.3)  |
| Diabetes mellitus         | Having       | 47 (16.6)   |
|                           | Not having   | 236 (83.4)  |

APL - Above poverty line, BPL - Below poverty line

Figure 1: Various ways the primary caregiver reminds about the medication when out of station (n = 283)
Table 2: Involvement of primary caregiver in diabetes care of the diabetes patient (n=283)

| Variables                                      | Not spouse, n (%) | Spouse, n (%) | Total, n (%) |
|------------------------------------------------|------------------|---------------|--------------|
| Feel stress                                    |                  |               |              |
| Yes                                            | 39 (29.8)        | 58 (38.2)     | 97 (34.3)    |
| No                                             | 92 (70.2)        | 94 (61.8)     | 186 (65.7)   |
| Accompany to doctor*                           |                  |               |              |
| Regularly                                      | 32 (24.4)        | 65 (42.8)     | 97 (34.3)    |
| Not regularly                                  | 99 (75.6)        | 87 (57.2)     | 186 (65.7)   |
| Discuss with doctor*                           |                  |               |              |
| Yes                                            | 66 (50.4)        | 105 (69.1)    | 171 (60.4)   |
| No                                             | 65 (49.6)        | 47 (30.9)     | 112 (39.6)   |
| Accompany investigation*                       |                  |               |              |
| Regularly                                      | 32 (24.4)        | 63 (41.4)     | 95 (33.5)    |
| Not regularly                                  | 99 (75.6)        | 89 (58.6)     | 188 (66.5)   |
| Check name of medicine                        |                  |               |              |
| Yes                                            | 112 (85.5)       | 132 (86.8)    | 244 (86.2)   |
| No                                             | 19 (14.5)        | 20 (13.2)     | 39 (13.8)    |
| Aware of frequency of intake                   |                  |               |              |
| Yes                                            | 116 (88.5)       | 138 (90.8)    | 254 (89.8)   |
| No                                             | 15 (11.5)        | 14 (8.2)      | 29 (10.2)    |
| Remind to take medicine                       |                  |               |              |
| Yes                                            | 104 (79.4)       | 123 (80.9)    | 227 (80.2)   |
| No                                             | 27 (20.6)        | 29 (19.1)     | 56 (19.8)    |
| Encourage to adhere to diet prescribed by doctor|                  |               |              |
| Yes                                            | 112 (93.1)       | 140 (92.1)    | 262 (92.6)   |
| No                                             | 9 (6.9)          | 12 (7.9)      | 21 (7.4)     |
| Encourage exercise, yoga*                      |                  |               |              |
| Yes                                            | 90 (68.7)        | 121 (79.6)    | 211 (75.6)   |
| No                                             | 41 (31.3)        | 31 (20.4)     | 72 (24.4)    |
| Adherence: Drugs                               |                  |               |              |
| Yes                                            | 122 (93.1)       | 145 (95.4)    | 267 (94.5)   |
| No                                             | 9 (6.9)          | 7 (4.6)       | 16 (5.5)     |
| Adherence: Diet*                               |                  |               |              |
| Yes                                            | 105 (80.2)       | 129 (84.9)    | 234 (82.7)   |
| No                                             | 26 (19.8)        | 23 (15.1)     | 49 (17.3)    |
| Adherence: Physical activity                   |                  |               |              |
| Yes                                            | 61 (46.6)        | 99 (65.1)     | 160 (58.5)   |
| No                                             | 70 (53.4)        | 53 (34.9)     | 123 (41.5)   |
| DM control status                              |                  |               |              |
| Yes                                            | 95 (72.5)        | 116 (76.3)    | 211 (74.6)   |
| No                                             | 36 (27.5)        | 36 (23.7)     | 72 (25.4)    |

* statistically significant. DM - Diabetes mellitus

We found that nearly 9% of the diabetes patients did not have any PCG. These diabetics are prone to nonadherence to medication, lifestyle changes, and regular follow-up as nobody is available to remind. Presence of caregiver has been reported in reduced nonadherence to medication among chronic disease patients.[18] Appropriate mechanism should be developed to identify such diabetics by the health system and bring them in the purview of appropriate diabetic care.

Only one-third of the PCG reported accompanying the patient while visiting the doctor and going for investigations. Similarly, low accompanying rate has been reported in routine health care mostly from the west.[16] However, when accompany the patient to the doctor, majority (60%) of the PCG discuss with the doctor regarding the disease status of the patient. This gives an important opportunity to educate the PCG on various aspects of diabetes management to be followed back home. Various studies also support that interventions directed at family member helped improved the diabetes outcomes.[17-19]

We found better adherence to drugs, diet, and physical activity if PCG was involved. However, adherence to drug and physical activity did not show any statistical significant association with involvement of PCG. Possibly, apart from involvement of PCG, patient’s motivation plays a role in the adherence to drugs and physical activity. Similar findings of increased adherence to diabetes management were reported with the involvement of family members or a caregiver.[14,15,20-23] Presence of a care provider and/or family was reported to increase the adherence to diabetes management by 1.5–1.7 times.[21] Glasgow and Toobert reported high regimen adherence among diabetes patients with strong family support scores.[23] Ott et al. also have demonstrated improvement in adherence to diabetes management with the involvement of a caregiver.[25] Stephens et al. have described improvement in adherence to diet by the diabetes patients on spousal encouragement.[23] One interesting finding was that nearly 80% were concerned about medication intake of the patient, and nearly half of them reminded them through phone call/SMS. Research has demonstrated improvement in adherence to medication and lifestyle changes following mobile technology intervention.[26,27] It was found that comparatively less proportion of PCG encouraged the patient to adhere to physical/exercises/yoga as compared to adhering to diet/drugs. This could be due to lack of awareness on benefit of physical activity/exercises/ yoga or lack of conductive neighborhood environment. Neighborhood physical environment has been associated
with practice of physical activity/exercise/yoga. One interesting finding was myth held by the PCG about chance of contacting diabetes from diabetes patients. These findings show that the awareness regarding adherence to drug, diet, and lifestyle changes needs to be told to both patient and PCG as almost always only patient receives counseling regarding these in primary care settings.

We noted that involvement of spouse as PCG showed statistically significant association with physical activity but not diet. Similar spousal support improving medication adherence has been reported among cardiac failure patients. Probably, dietary pattern is a family phenomenon; hence, no significant difference in influence was observed irrespective of whether the PCG is the spouse or nonspouse. Nearly, one-fourth of the diabetes patients in our study did not have adequate glycemic control. The DM control status was not statistically associated with the type of PCG or involvement of PCG. This could be due to inadequate sample size. High level of involvement could also be due to more number of PCG belonging to APL families. The study area frequented by health education from health workers and MBBS interns of the UHTC might be the reason for high level of involvement of PCG. The scenario may be different in a similar area where high-intensity health education of the community is not practiced.

This study first of its kind in Indian setting adopted the community-based design where the PCG and the patient interviewed separately. This study contributes to the literature on PCG support (both spouse and nonspouse) in the context of type 2 diabetes management in a primary care setting.

Despite the strengths of our study, there were certain limitations also. Characteristics of PCG and their involvement in diabetes care from untraceable and refusing households may be different, but could not be compared due to lack of information. Study participants were relatively homogenous; hence, further study with more diverse population can be done. Study being cross-sectional in nature cannot determine temporal relationship between involvement of PCG and adherence to diet, drugs, and lifestyle changes.

**Conclusion and Recommendation**

Our study findings have implications not only to the diabetic patients and their PCG but also for the health-care providers in primary care settings who have the difficult task of managing chronic illness such as DM on a day-to-day basis. Nearly 10% of DM patients did not have PCGs. The health system should keep in place the mechanism to address the support needs of the DM patients who lack PCG. Our study showed varied involvement of PCG across different aspect of diabetes management. Hence, the PCG should also be considered while designing health education intervention on various aspects of diabetes management, focusing and highlighting the areas of poor involvement and their importance in disease management.

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**Conflicts of interest**

There are no conflicts of interest.

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