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Role of informal care providers in home based long term care in diabetes mellitus at Kaiwara Primary Health Center area, Karnataka, India

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ABSTRACT

Objective: To find the prevalence of diabetics, identify informal care providers for them in Kaiwara Primary Health Center (PHC) area, assess the level of knowledge and skills of an informal care provider in home based long term care and improve the level of knowledge and skill of the informal care provider through a structured training capsule. **Methods:** A cross sectional and an interventional study was conducted on diabetics and their informal care providers in Kaiwara PHC area. Data were collected using pre-tested, structured questionnaire by an interview method. A structured training capsule was developed and implemented. Evaluation of the knowledge and skills was assessed at the beginning and at the end of the training. Student's paired/unpaired '*t*' tests and correlation analysis were done. **Results:** Improvement scores were calculated by subtracting the pre-evaluation scores from the post-evaluation scores. The mean improvement scores was (2.66±0.32) and was statistically significant ($P<0.001$). No significant difference in mean values was found in the knowledge and skills scores in relation to the socio-demographic variables in the study. **Conclusions:** Knowledge and skills component of the informal care provider in home based care of diabetes could be perceived as a "felt need".

1. Introduction

In India the prevalence of diabetes in adults has been reported to be 2.4% in the rural population and 4.0% to 11.6% in the urban population. The high prevalence of impaired glucose tolerance shown by many studies, ranging from 3.6% to 9.1% indicates the potential for further rise in the prevalence of diabetes in the decades to come[1]. There are inadequacies in the primary health care system, which is not designed to cope with the additional burden created by chronic non-communicable disease. This often results in poor detection of cases, sub-optimal treatment and insufficient follow-up, leading to unnecessary disability and severe complications and often resulting in early disability and deaths.

These developments require the adoption of a very different approach to health sector policy and health care service delivery. Home-based long-term care is already expanding rapidly in developed and developing countries due in part to the increasing impetus to shift from hospital-based care to home and community based care for economic reasons[2].

Family caregivers are the most important human resource in home-based long-term care. They usually provide the greater part of all care, yet the majority of them lack training in health care[2]. Therefore, family caregivers need information, support and skill if they want to succeed in providing the complex care that is required[3]. This could be achieved through empowerment of the informal care provider with the knowledge and skills required to provide home based long term care by a structured training capsule. Therefore, the present communication was aimed to find the prevalence of diabetics, identify informal care providers for them in Kaiwara Primary Health Care area, assess the level of knowledge and skills of an informal care provider in home based long term care and improve the level of knowledge and skill of the informal care provider through a structured training capsule.

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2. Materials and methods

2.1. Study area

The study was carried out in the administrative limits of Primary Health Center (PHC) of Kaiwara, which happens to be the rural field practice area of the Department of Community Medicine of MS Ramaiah Medical College, Bangalore. The Kaiwara PHC caters to a population of approximately 33 336 people living in 36 surrounding villages.

2.2. Study population

Known cases (medically diagnosed) of diabetes under treatment, and their informal care providers, who were identified through house to house survey with a pre-designed, pre-structured questionnaire, were included in the study. Ethical clearance was obtained from the Ethical Committee of MS Ramaiah Medical College, Bangalore.

2.3. Sampling method and selection of clusters

A cluster sampling technique was employed for the selection of clusters from the population. All the villages under Kaiwara PHC along with the population under each of the village were listed in serial order. The cumulative population of all villages was calculated. Considering the availability of resources and other constrains it was decided to include 10 clusters for the study. Based on the total cumulative population of the entire PHC and the number of clusters being included in the study, the sampling interval for selection of clusters was estimated and the same was found to be approximately 3 500.

The first cluster to be surveyed was identified using a random number table and the estimated sampling interval was 3 500. Subsequent 9 clusters for the study were selected by adding the sampling interval to the first selected random number corresponding to the first cluster. Furthermore, the size of the population to be surveyed in each cluster was estimated based on the prevalence of diabetes in the population (2%) through a pilot study. The cluster sample size was calculated based on the prevalence of diabetes in the community. Significance level of 5% and 10% was allowable error. The above computations turned out to be 287 and the same was rounded to 300.

Thus, the total number of persons to be surveyed in a cluster was 300. Since ten clusters were chosen, a total of 3 000 people were enumerated. In each cluster, the center of the village was identified usually with the help of the 'Anganwadi' worker. Using the random number from a currency note, randomly one street was chosen. A total population of 300 people was surveyed in this direction. The known cases of diabetes who were under treatment and their informal care providers were identified.

2.4. Study instrument

The instrument adopted was pre-tested, structured questionnaire using an interview method.

This study instrument consisted of finding the prevalence of known diabetics and relevant socio-demographic variables and assessing the current knowledge and skills of the informal care provider in the care of a diabetic patient.

Based on the analysis of the pre-evaluation data, areas of knowledge and skill were identified and the interventional tool was created. This was further divided into core and support areas and an appropriate curriculum was developed and a lesson plan was prepared. The educational intervention tools consisted of a flip chart and a handout, which were both in the local language.

2.5. Study setting

The teaching-learning sessions were carried out at the patient's own house. Each identified patient and informal care provider had three contacts during this period. The first contact was utilized to build rapport with the patient and informal care provider, explaining the objectives of the intervention and for familiarizing them with the tools and techniques to be used in the intervention to ensure proper understanding. The second contact was utilized to conduct the actual educational intervention session. The third contact was utilized to administer the post evaluation questionnaire. This was done after an interval of two weeks.

The pre and post test questionnaire contained information on several aspects. Each of the questions was framed as a multiple choice question where only one answer was right. One point was given for the right answer and 0 for the wrong. The questionnaire contained a total of 24 questions and the total scores for each subject were compiled.

2.6. Statistical analysis

Student's paired and unpaired 't' tests were used to test the significance of difference between means as per requirement. Analysis of variance (ANOVA) was used to test for difference in means among several groups.

Pre and post differences, scores on the assessment tool were categorized into three levels. Scores of 75% and above were rated 'excellent'; 60% to 75% were rated 'good'; 40% to 60% were rated as 'fair' for better further appreciation.

3. Results

3.1. Prevalence rate of known diabetics

Door to door survey of 3 000 persons revealed 42 known diabetics in the population which worked out to be

prevalence of known diabetics in the study population to be 14/1 000 population (95% *CI*: 9.68-18.24).

The prevalence rates of diabetes were found to be almost nil till the age of 44 years and in the other two age groups the prevalence rate was found to be almost similar (Table1). The differences in the overall prevalence rate of diabetics between 45 to 59 and above 60 years were found to be statistically significant ($P<0.05$).

3.2. Comparison of characteristics of known diabetic patients with informal care providers

As regards the age distribution of informal care providers compared with that of the diabetic patients, it was observed that 70% of the informal care providers were in the age group of 15 to 44 years (2.3% diabetic patients), of which 64.7% were females.

It was observed that a higher proportion of informal care providers were illiterate (23, 54.8%) as compared with diabetic patients (11, 26.2%). Persons with high school and above education constituted (16, 38.1%) and (9, 21.4%) amongst diabetic patients and informal care providers, respectively. Diabectic patients had a higher proportion of primary school or middle school educational status (15, 35.7%) as compared with the informal care providers (10, 23.8%). The differences in the literacy level between the above two groups was found to be statistically significant ($P=0.02$). In the present study 85.2% of informal care providers were female, many of whom were illiterate accounting for the large number of informal care providers.

Table 1
Age and sex wise distribution of population studied and prevalence rate /1 000 of diabetes.

Age group (years)	Females			Males			Total		
	No of persons	No of cases	Prevalence rate/1 000	No of persons	No of cases	Prevalence rate/1 000	No of persons	No of cases	Prevalence rate/1 000
14 and below	467	0	0.0	433	0	0.0	900	0	0.0
15 to 44	734	0	0.0	739	1	1.4	1 473	1	0.7
45 to 59	163	4	24.5	177	19	107.3	340	23	67.6
60 and above	144	3	208.3	152	15	98.7	296	18	60.8
Total	1 508	7	4.6	1 501	35	23.3	3 009	42	14.0

Table 2
Differences in pre and post evaluation mean scores by various characteristics of the informal care providers for knowledge and skills in home based long term care in diabetes mellitus (Mean±SD).

Characteristics	Sub classes	Number	Scores
Sex	Male	8	3.12±1.28
	Female	23	2.50±1.32
Socioeconomic status	Class I / Class II	6	1.89±0.75
	Class III	13	2.57±0.96
	Class IV / Class V	12	3.18±1.80
Educational status	Illiterate	14	2.89±1.49
	Primary school	3	1.38±0.68
	Middle school	6	2.87±1.20
	High school/ Pre-university/ Degree/Diploma	8	2.54±1.21
Relationship	Husband	4	2.16±1.02
	Wife	15	2.52±1.47
	Son/ Daughter	7	3.27±0.79
	Others	5	2.56±1.38

It was noted that for a majority of diabetic patients, the informal care provider was a member of the family, most frequently the wife (15, 48.3%). While the son/ daughters were (7, 22.6%), husband were (4, 13.0%) and others constituted (5, 16.1%). In the present study, persons in the "others" category were also members of the household, such as daughter-in-law, brother, nephew, *etc*.

It was observed that 38.0% of the known diabetic patients and informal care providers were found in socioeconomic status class III, 28.6% in class II and 31.0% in class IV and class V.

3.3. Training and evaluation of informal care providers

As indicated in the methodology, a training capsule to improve the knowledge and skills of informal care providers in home based long term care in diabetics was conducted. Out of the 42 informal care providers identified only 31 were willing for the training in which 23 were females and 8 were males. Before imparting the training a pre-evaluation regarding the knowledge and skills were carried out. The mean pre-evaluation score was found to be (7.35±1.49). After imparting the training, a post-evaluation was carried out which showed a mean value of (10.01±0.90). The difference in the mean scores in the pre and post evaluation was (2.66±0.32) which was statistically significant ($P<0.001$).

It was observed that informal care providers who were 'fair' (7, 22.6%) in the pre-evaluation became 'good' (2, 100.0%) and 'excellent' (5, 17.2%) in the post evaluation. It was observed that informal care providers who were 'good' (16,

51.6%) became excellent (16, 55.2%) in the post evaluation. Those who were 'excellent' (8, 27.6%) in the pre evaluation remained the same in the post evaluation. An attempt was made to find out the association of the various characteristics such as sex, socioeconomic status, educational status and relationship of the informal care provider to the diabetic patient. Differences in the scores from pre to post evaluation were compared. There was no significant difference in the mean improvement scores with regard to the various characteristics of the informal care providers ($P>0.05$) (Table 2).

3.4. Correlation analysis

Correlation analysis was carried out between age and improvement of knowledge and skills scores of informal care providers. The correlation $r=0.123$ ($P>0.05$) was not found to be statistically significant, indicating no relationship between mean improvement of knowledge and skills scores and age.

4. Discussion

Prevalence of diabetes in the studied population was 5.99%[4]. A large number of diabetics remain undiagnosed in rural India due to various reasons such as lack of facilities, awareness regarding signs and symptoms of diabetes, *etc*. This probably explains the lower prevalence rate of known diabetics in the present study[5].

In a report on the state of care-giving support[6], it was observed that 78% of adults who received long-term care at home got it exclusively from unpaid family members mostly wives and adult daughters. This observation is similar to the one observed in the present study, thus justifying the reliance on family as informal care providers for home based long-term care.

A report on family care giving support in the states of USA[6] has noted that, two out of three older people *i.e.* 67% in the community rely solely on informal help mainly from their wives and adult daughters. This observation was similar to the one made in the present study where majority of the informal care providers were female (85.2%).

It was found that majority of patients with diabetes were in the 45 to 59 age group (54.7%) and majority of informal care providers were in the age group 15-44 (70%). It was also noted that most of the informal care providers were female mainly wives and daughters (85.2%) and most of the diabetes patients were in the socioeconomic class III (38.0%).

It was found that illiterate and high school educated diabetic patients constituted 26.2% each, whereas majority of informal care providers were illiterate (54.8%).

The overall prevalence of known diabetic patients in the study population was found to be 14 per 1 000.

It was noted that majority of informal care providers were wives (48.3%). Sons and other family members constituted 16.1% each and the improvement in the knowledge and skills scores of the informal care provider between the pre evaluation and the post evaluation was statistically significant.

It was also observed that this improvement in knowledge course had no significant relation to the socio-demographic variables studied. Thus the knowledge and skill component of the informal care provider in home based long term care of a diabetic patient could be perceived as a "felt need".

Therefore, we can infer that by empowering the informal care provider with the required knowledge and skills in home based long term care and by linking the care with the three tier system in primary health care, it is possible to improve the quality of care, towards making it more comprehensive than selective and economically beneficial to the patient and the entire health system.

Conflict of interest statement

We declare that we have no conflict of interest.

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