Medicine and Society

Coping with diabetes as an everyday experience: A study from urban Chennai

D. ARUTSELVI

ABSTRACT

The day-to-day experience of dealing with chronic diseases such as diabetes affects the behaviour and social roles of individuals. The action that individuals seek to redress their suffering is determined by their socioeconomic context and responsiveness of health services. I explored the everyday experience and coping among individuals living with type 2 diabetes. This qualitative study captures the process of coping at the individual, family and healthcare services levels. I conducted in-depth interviews among people with diabetes using a semi-structured interview schedule. Informed consent was taken from the study participants. Narratives of two women belonging to different socioeconomic strata, provide the contrast in how they cope with diabetes in their everyday life in terms of diet, exercise, medication and health-seeking behaviour. This study provides insights into the complexities involved in dealing with diabetes. It highlights how social determinants play a critical role in coping with daily living, health and illness.

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INTRODUCTION

Diseases that are chronic and irreversible pose multiple challenges at the individual and programmatic levels.[1,2] In a highly stratified society such as India, where inequality in health outcomes and access to health services are well recognized, the everyday experience of chronic diseases is bound to vary across the multiple axes of caste, class, religion and gender.[3–5] The experience of illness, diagnosis, treatment, management and the process of coping with a chronic disorder such as type 2 diabetes (hereafter referred to as diabetes) varies across individuals and social groups. The experience of illness is determined by several factors including individuals' perception regarding causation, their awareness of symptoms, the intensity of symptoms that produces suffering and dislocation in their social roles. The action that individuals seek to redress the suffering is determined by the socioeconomic context and responsiveness of health services. The latter includes the availability, accessibility, affordability and acceptability of health services.[6,7]

Several studies done in western countries have highlighted the treatment-seeking behaviour of people with diabetes, which provide insights into the social dimensions of the management of the disease.[8–12] Few studies in India have explored the psychosocial aspects of individuals affected with diabetes.[13,14] These studies describe the link between depression and diabetes, psychosocial support and adherence to treatment. Studies have captured the social dimensions among the urban poor living with diabetes. They explore how people experience and understand diabetes. The narratives of affected persons brings out their perceptions regarding the relationship between stress, distress and diabetes.[12,15] Everyday experience and coping with diabetes is an outcome of multiple levels of interaction between the individual, health services and the social system. Kleinman[9] argues that 'chronic illness is an ongoing process in which personal problems constantly emerge to challenge technical control, social order and individual mastery'. The day-to-day experience of dealing with a chronic disease affects the behaviour and social roles of individuals affected with the disease. This qualitative study conducted in Chennai has tried to explore some of the above dimensions. Through select case studies, I have tried to reconstruct the disease process of type 2 diabetes, perception of causation, treatment-seeking behaviour and everyday management. I have explored the complex interactions between the disease, its clinical management and socioeconomic determinants.

METHODS

This qualitative study was an interdisciplinary enquiry to understand how individuals affected with diabetes understand, experience and manage it in their daily life. This study built on a larger epidemiological survey* on 'cost of illness' conducted in Chennai during 2009–10 among patients affected with diabetes.[16]

This epidemiological survey was used as a baseline and 18 participants (10 women) were purposively selected from different socioeconomic strata on the basis of severity of diabetes to get insights into the processes that determine their coping patterns. The participants included were those without complications of diabetes but with other comorbid conditions. The case studies focused on interactions of social, psychological and economic conditions in experiencing and managing diabetes at the individual, household and health services levels. Interviews were conducted using a semi-structured interview schedule, which had details on sociodemographic profile, current disease and treatment profile, questions about diagnosis and treatment-seeking, everyday management in terms of diet, exercise, drugs and monitoring, social, economic and psychological support. Informed consent was taken from the study participants; their names have been changed to ensure confidentiality.

In the next section, I present the contrast in day-to-day management of diabetes through case studies of two elderly women, one a professional belonging to a middle class family and the other belonging to a working class family. In general, the

Centre of Social Medicine and Community Health, School of Social Sciences, Jawaharlal Nehru University, New Delhi 110067, India; *darutselvi@gmail.com*

* I was associated with this study earlier and hence intended to conduct an exploratory study to understand the social dimensions of coping with type II diabetes for the partial fulfilment of my M. Phil course at the Centre of Social Medicine and Community Health, School of Social Sciences, Jawaharlal Nehru University, New Delhi.

gender and class variation in coping with diabetes was observed within and across social groups. A wider class variation was observed when we looked into the coping process of these two participants in the context of their position in social hierarchy. Hence, these two participants were chosen purposively to showcase the existing unequal social condition and how that condition shapes their handling of their diabetes. This case study explores the process of diagnosis, treatment-seeking behaviour and everyday management of diabetes. It exemplifies social determinants that influence the course of choices made for everyday management of diabetes.

Experiencing diabetes: Variations across class

I looked into the variations through their socioeconomic characteristics, disease condition and treatment as well as all aspects of everyday management and monitoring of the disease.

Socioeconomic characteristics

There were differences in their social and economic characteristics such as age, education, occupation, income, family type and living arrangement. These socioeconomic characteristics influence a number of processes relating to the extent of support the individuals receive from the family, healthcare institutions and neighbours/ friends for coping with the demands posed by a chronic condition such as diabetes. The support networks are also determined by the location of the person in the social hierarchy.

Clearly, Mrs Gowri is from a working class family while Mrs Rajalakshmi is from an upper middle class background

Mrs Gowri, a 65-year-old housewife, belongs to a most backward community, Vanniyar. She did not receive any formal education and lives with her husband in a rented house. They pay a monthly rent of ₹2000. She is financially dependent on her husband, a 70-year-old construction labourer. On average, he earns ₹9000 to 10 000 per month. Her house has only one room without proper ventilation. All her 6 children (2 sons and 4 daughters) are married and live separately. She does not get any support from her children. She has been suffering from diabetes for the past 15 years and also has a thyroid problem long before the onset of diabetes. She had an operation for cataract in one eye and, due to diabetes, had to undergo an operation for the other eye as well.

On the other hand, Mrs Rajalakshmi, aged 71 years, belongs to a backward community (Nadar) and is a well-educated professional. She is a widow, lives with her younger son, daughter-in-law and a grandson. Her elder son, along with his wife and children, live next to her house. She receives a monthly pension of ₹12 000 and lives in her own house. The total monthly income of the family is around ₹55 000. She has diabetes for the past 21 years and now also has hypertension and hypercholesterolaemia.

Diabetes: Diagnosis and treatment

Mrs Gowri used to get treated for all her ailments at a private clinic since she migrated to Chennai nearly four decades ago. She was diagnosed with a thyroid problem when she was in her 40s and started treatment from the same doctor. Due to economic constraints, she preferred visiting the government hospital where she could get treatment free of cost. A decade later she started experiencing frequent tiredness. She visited the same private doctor, who had a clinic in her neighbourhood and tested for diabetes. She was diagnosed with diabetes and later she started visiting the Diabetology department in the government medical college hospital. She used to visit the Diabetology department twice a month to get the required medication. Another visit was made to get her thyroid medication. Sometimes she would try spending on medicines from a private pharmacy rather than standing in long queues in the government hospital. When she could not afford to spend on her medicines, she would go to the government hospital. She described the travails of the weekly visits to the government hospital to collect medicines.

> *It is very difficult to stand in the queue for long hours to get medicines. If I would not reach there early in the morning, I had to stand for more than half of the day. The queue is not the only problem but also the crowded public transport… could not even breath and again I had to pay for the share auto to catch that bus to reach the hospital.*

In contrast, Mrs Rajalakshmi was diagnosed with diabetes when she had a master check-up after she met with an accident. She started her treatment in a specialty hospital and has continued the same for 21 years. Most often, she is accompanied by her son or daughter-in-law during her visits to the doctor. She used to take oral drugs as well as insulin (8 units before every main meal) for her diabetes. Later aspirin and a statin were added to her prescription. She incurred a monthly expenditure of ₹2000 on the medicines.

Coping with everyday requirements of diabetes

Coping with diabetes is a daily affair and it depends on lifestyle modifications including special diet, regular exercise and intake of medicines. Together these are referred to as the 'three pillars' for the treatment of diabetes. Besides this daily regimen, regular follow-up and monitoring is important. This is achieved through regular visits to the doctor and monitoring the blood glucose level once in 3 months. In addition, annual monitoring is achieved through several tests for lipid profile, kidney function test, eye test, ECG and foot examination in order to prevent complications of diabetes. This is also included as a part of the minimum treatment guidelines.[17–20]

Management of diet

Mrs Gowri, who could not afford to have three meals a day, sometimes had to skip breakfast. She used to take two tablets before food, one for thyroid problem and one for diabetes. Whenever she could not cook in the morning, she would not take the tablets so that she could avoid the feeling of hunger. Whenever she experienced dizziness after taking the thyroid medication, she would lie down for some time. Then she would go to the market to buy groceries for preparing lunch. She would eat some food in the afternoon and keep the remaining for dinner. If there would be rice remaining after dinner, she would add water to it. She would boil it and give to her husband the next morning. She cooked mainly rice because she could get it free from the public distribution system. Given the high cost of vegetables, she was able to afford only one vegetable twice or thrice a week. Since tomatoes and onions were cheap, she tended to buy these more often. She tried to avoid buying beetroot and potato, as she believed that they would increase her sugar levels. She was able to afford fish once or twice weekly. Since her neighbours used to cook non-vegetarian food often, Mrs Gowri wanted to do the same. She viewed non-vegetarian food as a symbol of economic prosperity and wished to keep up with her neighbours. She found fish was cheaper than meat and also better for health. She used to fry the fish and used to take only one piece. The remaining used to be served to her husband. She was aware and conscious about using excess oil as

it would add *koluppusathu* (cholesterol). She was also aware that her poor economic condition affected their food intake. As she observed:

> *Sometimes we (she and her husband) used to eat 'thannichoru', 'kanchi' (cooked rice with water) with a pickle chilli… We never expected to have a proper 'kolambu' (a dish containing some vegetable minimum with or without dal). We should eat within our income you know… there are also other matters for which we have to spend money… house rent, gas, loan from moneylenders, etc.*

> *When I fell ill I would visit the doctor in the nearby urban health centre. Doctor would give 'sathumaathirai' (vitamin tablets) and she used to inform always that I am generally weak and I should take good food, vegetables and fruits… But I could not even go near the fruits as the price of one fruit (apple) would be ₹10 or ₹20. Sometimes… maybe once in a month, when I had extra money I used to buy one apple or maximum two. My husband is also aged, every day he could not go for job… I have to manage with whatever he would earn. Sometimes I had to pay the private doctor ₹200 or ₹300 for any urgent treatment.*

She alone is involved in all the household activities such as fetching water from the hand pump, cleaning utensils, washing clothes, cooking, etc. Sometimes she used to carry lunch in the hot sun for her husband to the workplace located 1–1.5 km away from her house. On some days, her youngest son who lives in the neighbourhood and works on the same construction site would collect food for her husband. She would feel tired most of the time and she used to rest whenever she would get time. On being probed further about regular physical activity, she said that:

> *My day would start at 5 a.m. and I am the one doing all the household chores… Whether I am ill or healthy… most of the time I am feeling weak and tired… Even if I think of going for a walk, I could not go… You know… the crowded neighbourhood… narrow roads… my house owner who also has diabetes used to walk on her terrace… Where would I go? I think I am doing enough for my age. No need to go for a walk.*

She also said that when she used to visit her native village, she would not feel tiredness or giddiness. She would stop taking her medicines. She felt that the natural environment and air in the village made her feel relaxed. She used to visit her village once a year.

Mrs Rajalakshmi's daily routine is a contrast to Mrs Gowri's

Mrs Rajalakshmi's day began with a planned schedule. She would wake up by 6:30 in the morning and have a coffee with an artificial sweetener and read the newspaper. Later she would instruct the cook regarding the menu. She would take her insulin between 7:30 and 7:40 a.m. and have breakfast at 8:00 a.m. She preferred to have 'raagi' malt or 'idli' with green leaves/onion chutney in the morning. Around 11 a.m. she would take buttermilk or a cup of tea with biscuits or two slices of apple. As she was involved in local political activities, she would attend public meetings, during which her daughter-in-law would look after her dietary needs. Lunch consisted of rice with sambar and vegetables and for dinner, *chapattis* with a vegetable dish. She stopped consuming non-vegetarian food (including egg) almost 20 years back. A few times when she was attending meetings she would miss her meals. She was very happy in mentioning that:

> *My daughter-in-law used to drive me to Marina beach for a walk every evening and I would spend 20 to 40 minutes walking... I would miss walking if I had to be in the party (political) meetings. I would meet my friends and spend time with them at least once in 15 days, as these are joyful moments, and I used to involve them with other social service activities.*

She was quite particular about her routine. She used to follow her food timings and medication regularly. She was careful because she had seen her husband's illness. Her husband who suffered from renal disease was on regular dialysis for 2 years before he passed away.

Interaction with health services

Initially, Mrs Gowri was prescribed metformin and glibenclamide and vitamin B complex at the Diabetology department of a government medical college hospital. She continued with the same medication since the initial diagnosis of diabetes. She said her healthcare providers never told her about the complications of diabetes nor was she referred for screening of complications. As a routine she would visit the doctor once in 6 months when they would check her blood glucose level. If the test showed a high level of glucose, then the doctor would examine her and increase the dose accordingly. Otherwise, the attendant or nurse at the outpatient department (OPD) would return the patient record with a note 'repeat all' prescribed by the doctor. Every month she would visit the OPD, and get a noting from the attendant or a nurse to get medicines. If she had any discomfort or general ailments, she would visit the OPD of the department of General Medicine. In an emergency she would visit a private clinic.

She had been admitted to a private hospital on occasions when she had hyperglycaemia. She would spend ₹2000–4000 for admission to the hospital and other direct medical expenses. Her husband would manage these expenses by borrowing from moneylenders or she would pledge her only gold chain to get a loan. She said: '*this is the only valuable asset… we have in life and it helps us all the time*' to borrow money. Later she would try to repay the loan gradually from her husband's income.

After 8 years of diabetes, she had undergone eye surgery for double vision in a private hospital. She said:

> *Doctor had mentioned that it was because of my uncontrolled sugar level and I should have had an eye check-up earlier.*

She also said:

> *I could not even sleep properly, all the children are away, and only one son is living in my neighbourhood. He used to visit me sometimes and the other children would never visit me. One of my daughters used to speak to me on the telephone and if she had time, she would visit me that too once in 6 months or a year. I had my eye operation 4–5 years back. I could not see properly… I had double vision, then I was advised to reduce my sugar for the operation. That time my daughter came here and helped me. She used to prepare chapattis with vegetables and insist that I have more vegetables to control my sugar. Within a week, my sugar became normal and the operation was done… It is because of 0.5–1 acre of land in the village. Everybody started to fight with each other because of that. Now the elder son is doing some cultivation there. All the daughters also want to get a share in that. What to do? That's why thinking all these things, I could not sleep… 'Yaakampaadhi,*

thookampaadhi' (half wish, half sleep) … It was many years back I had good sleep. 'Rombakavalayairrukku' (very sad). In this age, we had to face all these things … my husband is still energetic and he takes care of things well.

In contrast, Mrs Rajalakshmi would visit the diabetologist once in 2 months and have her lipid profile, kidney function test, ECG and foot examination done regularly. She used to monitor her blood sugar with a glucometer. If she had low blood sugar (hypoglycaemia) or high blood sugar (hyperglycaemia), she would immediately visit the doctor and, if necessary, get admitted. She would get all her expenses reimbursed through medical insurance. She used special footwear and wore it regularly inside the house.

During the study period, Mrs Gowri's fasting and post-prandial glucose levels were 254 mg/dl and 365 mg/dl, respectively, while Mrs Rajalakshmi's were 129 mg/dl and 208 mg/dl, respectively. The glycosylated haemoglobin for Mrs Rajalakshmi was 7.8 but Mrs Gowri had never had it tested and was not aware of the need to test it.

DISCUSSION

The information provided by these two individuals with diabetes illustrates the inequality in social and economic status, access to healthcare facilities and treatment and its effect on everyday coping with the disease. The contrast in the everyday coping with the disease is seen in the availability, quality and frequency of appropriate diet. The support structure available to the two women was also an important factor in the quality of treatment and management of the disease.

Studies by Drummond and Mason[8] and Mendenhall *et al.*[11,12] have shown how issues of food, shelter and other livelihood had a higher priority than the daily requirements of treatment in the lives of poor people with diabetes. While Mrs Gowri met her inpatient expenses by taking a loan, Mrs Rajalakshmi used her health insurance.

Social support was visible in every aspect of coping with diabetes in the case of Mrs Rajalakshmi. For example, her daughter-in-law used to track her meal timings, drive her to the beach for a walk everyday and both son and daughter-in-law would accompany her during visits to the doctor. She would also regularly meet her friends. The role of children, relatives or friends was meagre in the case of Mrs Gowri and they were present in case of serious health issues. For example, her daughter was with her for her eye surgery. A neighbourhood where it was inconvenient to walk was a constraint in Mrs Gowri's case. Grinstova *et al.*[21] in a systematic review have shown the association of low socioeconomic status and regional deprivation in health outcomes such as higher risks of micro- and macro-vascular complications among people with diabetes.

While the minimum treatment guidelines were not followed for Mrs Gowri, as she was never screened for complications, the treatment and monitoring was as per guidelines for Mrs Rajalakshmi. Also Mrs Rajalakshmi had better glycaemic control than Mrs Gowri.

To conclude, Mrs Gowri's case gives a clear picture of how poor social situation dominates experiences of one's illness, which further worsen the condition whereas better social situation allows Mrs. Rajalakshmi to maintain good health. The case studies illustrate how the material reality of people's lives plays an important role in treatment-seeking and other aspects of everyday life that has major implications for coping with diabetes.

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