Original Article

Diabetes self-care management: Experiences of the socio-economically backward sections of Jammu

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1. Introduction

Around 500 million people are suffering from diabetes worldwide and of this half billion population, nearly 80% reside in low and middle income countries [1]. The total number of deaths due to diabetes in India in 2015 were nearly 5 million which was more than combined number of lives lost due to infectious diseases like HIV, cholera, Tuberculosis and malaria [2]. India houses 69.1 million diabetic patients of the world and is next only to China, as per figures of the year 2015 [1]. Indians are found to be centrally obese due to which their Body Mass Index (BMI) remains higher than other races [3]. Body size of Indians is very small whereas their adipose tissue accumulation is very high. It is due to this reason, Indians are *thin-fat.* And in spite of having BMI under 25 kg/m^2, susceptibility of Indians remains very high for diabetes and other metabolic diseases [4]. Since, diabetes is not a curable disease hence self-care management in diabetes is of immense importance. Diabetes self-management may be defined as activities that help a diabetic person to implement and sustain the behaviours required to manage the disease [5]. Some researchers categorised diabetes self-care management into three categories which include strictly following the regimen prescribed by health-care professionals; adapting themselves to that regimen; and finally, to act according to the need of the situation [6].

India has started following the trend of West where Socio-economic Status (hereafter SES) of an individual is found to be inversely proportion to his/her susceptibility towards lifestyle diseases [7]. According to the second phase of Indian Council for Medical Research and India Diabetes (ICMR-INDIAB) cross-sectional study, epidemiological transition is clearly visible in India. Persons belonging to low SES are found to be suffering more from diabetes in urban areas as compared to rural areas [8]. According to World Health Organisation (WHO) representative to India Henk Bekedam, families with poor income bear the highest brunt of diabetes. Drug costs represent costliest affair in the management of diabetes, there by contributing more than 50% in the diabetes expenses [9]. Socio-economic factors such as housing, occupation, education, family income etc. are directly related to diabetes self-care management [10]. Thus, low income and other socio-cultural factors inflict a huge barrier on diabetes management [12]. Houle et. al found that diabetes self-care management has direct association with poor SES as it becomes very difficult for the patients to afford time and other essentialities which are necessary for the disease management [13].

Socio-economic background, thus plays a significant role in determining self-care management techniques of the patients. A lot of studies have been undertaken from medical perspective to assess socio-economic and cultural impact of diabetes, however self-care management in diabetes from sociological perspective is a rarely explored area [8,9,12—16]. In Indian context, self-care management in diabetes from sociological point of view has not been studied. In order to determine, socio-economic status of the patients, modified version of Socio-economic scale, devised by B. Kuppuswamy, has been used to determine SES of the respondents in the study. According to this scale, points are given on the basis of educational qualification and occupation of the respondents; and monthly family income of the respondents [17]. However, changes in the income scale are being incorporated from time to time owing to the changes in Consumer Price Index (CPI). Therefore, SES of the respondents is determined on the basis of Table-1. Table-3 has also been included to mention pseudonyms and socio-economic profile of the respondents so that their experiences could be elaborated in detail in the upcoming sections of the study.

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Table 1
Revised Socio-economic status scale By Kuppuswamy.

Education of head of family				Score
Profession or honours				7
Graduate or postgraduate				6
Intermediate or post high school diploma				5
High school certificate				4
Middle school certificate				3
Primary school certificate				2
Illiterate				1
Occupation of head of family				
Profession				10
Semi-profession				6
Clerical, Shop-owner				5
Skilled worker				4
Semi-skilled worker				3
Unskilled worker				2
Unemployed				1
Monthly income of family				
In 1976	In 1998	In 2007	In 2017 (January 2017 CPI)	
>=2000	13408	19844	>41430	12
1000–1999	6704–13407	9922–19843	20715–41429	10
750–999	5028–6703	7441–9921	15536–20714	6
500–749	3352–5027	4961–7440	10357–15535	4
300–499	2011–3351	2976–4960	6214–10356	3
101–299	677–2010	1002–2975	2092–6213	2
<=100	<676	<1001	<2091	1
Socioeconomic class				**Total score**
I		Upper		26–29
II		Upper middle		16–25
III		Lower middle		11–15
IV		Upper lower		5–10
V		Lower		<5

[17].

Table 2
General Information of the respondents.

	Socio-economic Status	
Upper Middle	Lower Middle	Upper Lower
0	16	9
Gender		
Male		Female
12		13
Physical Workout		
Regular Walk (Including stroll, leisure walks and brisk walk)		No Physical Workout
11		14
Body Mass Index		
Overweight		Obese
17		8
Fiduciary Responsibility		
Family Members motivate respondent to keep a check on diet and workout		Family members do not say anything
20		5

It is important to note here that the type of diabetes which results mainly due to socio-cultural and economic factors is Type2 Diabetes Mellitus (T2DM). Type1 Diabetes Mellitus (T1DM) on the other hand, is considered to be an auto-immune disease which results mainly due to hereditary factors. T2DM is an adult onset disease and lifestyle factors play a prominent role in the onset of this diabetes [18]. The Present study tries to explore management patterns of T2DM patients by employing social constructivism and fiduciary doctor-patient relationship as explained by Talcott Parsons. Social constructivism as propounded by Peter Berger and Thomas Luckmann has emphasised on the importance of language as a measure to transfer knowledge [19]. Thus, social constructivism in the field of health is characterised by Foucauldian ideas of knowledge, power and discourse [20]. Thus, how illnesses are dealt with by the health-care providers and the masses is also characterised by their exposure to the social environment [21]. In addition to this, Talcott Parsons' asymmetric doctor-patient relationship has also been taken into consideration to qualitatively analyse patients' reliance on their doctor for the management of T2DM [22]. While elaborating on the 'sick role,' Parsons [22] talked of fiduciary (meaning "trust" or "confidence" in Latin) responsibility which a doctor is burdened with in order to provide best healthcare to the patients. Parsons, emphasised that this responsibility should be 'asymmetric' in the sense that patient himself/herself should equally participate in taking care of his/her ill health. And it should not be exclusively the responsibility of health care providers. This

Table 3
Socio-economic and Demographic Profile of the respondents.

S.No.	Pseudonym	Sex	Age	Educational Qualification	Monthly Income (Family) (INR)	Employment	Socio-Economic Level
1	Sushma	Female	56	8th	30,000	Housewife	Lower-Middle
2	Tarsem	Male	60	5th	25,000	Peasant	Lower-Middle
3	Rano Devi	Female	42	5th	15,000	Domestic Help	Upper-Lower
4	Parkash	Male	45	8th	20,000	Driver	Lower-Middle
5	Rabia	Female	60	Illiterate	20,000	Housewife	Lower-Middle
6	Surinder Kour	Female	43	5th	12,000	Factory Worker	Lower-Middle
7	Kailasho Devi	Female	62	Illiterate	20,000	Housewife	Lower-Middle
8	Ratna	Female	42	10th	30,000	Housewife	Lower-Middle
9	Meenakshi	Female	44	8th	25,000	Housewife	Lower-Middle
10	Bachan Lal	Male	48	10th	20,000	Owns a shop	Lower-Middle
11	Lacchi Ram	Male	56	Illiterate	20,000	Peasant	Upper-Lower
12	Bishan Das	Male	48	5th	15,000	Daily wager	Upper-Lower
13	Sat Pal	Male	50	10th	20,000	Owns a shop	Lower-Middle
14	Bhola	Male	42	10th	18,000	Driver	Lower-Middle
15	Chanchalo Devi	Female	65	5th	18,000	Housewife	Upper-Lower
16	Darshana	Female	42	Illiterate	15,000	Domestic Help	Upper-Lower
17	Purshotam	Male	65	10th	20,000	Retired Peon	Lower-Middle
18	Chunni Lal	Male	60	5th	20,000	Unemployed	Upper-Lower
19	Trilochan	Male	60	8th	20,000	Retired class-IV employee	Lower-Middle
20	Ashoka	Male	55	8th	12,000	Daily wager	Upper-Lower
21	Fareed	Male	48	5th	15,000	Driver	Upper-Lower
22	Babita	Female	65	Illiterate	25,000	Housewife	Lower-Middle
23	Savitri Devi	Female	62	Illiterate	40,000	Housewife	Lower-Middle
24	Surekha	Female	48	10th	20,000	Housewife	Lower-Middle
25	Tripta	Female	53	12th	13,000	Teacher	Lower-Middle

statement holds good especially in the case of diabetic patients because diabetes is not a 'curable' disease but a 'manageable' disease [22]. Therefore, discourses of the respondents on different aspect of diabetes, and their management patterns resulting from that discourse have been analysed in the light of social construction of illness and doctor-patient relationship (as explained by Parsons while elaborating on sick role).

2. Methodology

2.1. Sample

Data were collected at Government Medical College (GMC), Jammu and Super Speciality Hospital (SSH), Jammu. Ethical clearance was sought from the Institute Ethics Committee of GMC, which also happens to be the parent hospital of SSH. Informed consent was sought from all the twenty-five respondents and privacy of the data collected was ensured. Patients visiting OPDs of medicine and cardiology were contacted for the interview and inclusion criteria were the patients who were suffering from T2DM for more than one year and belonging to socio-economically backward sections.

As per already explained criteria of the socio-economically backward section, receptionists of the OPDs were requested to ask for the income of the patients, their profession and their occupation. And as per the information provided by the receptionist, twenty-five patients were shortlisted. Two of whom were hospitalised in the Cardiac Care Unit (CCU) of SSH. Facility of conducting interview at OPD section, enabled researcher to observe doctor patient relationship practically. And it also made researcher aware of the fact that a doctor who has various roles to perform (sometimes that of a researcher, a spouse, an administrator etc.) has to face numerous difficulties while dealing with the patients who have absolutely no idea of the nature of the disease they are suffering from [22].

2.2. Data collection

Semi-structured interview schedule for the patients consisted of questions related to their socio-economic and demographic profile, family history of diabetes, their eating habits, their work-out regimen, health-seeking behaviour, role of family members in motivating them towards managing their disease, nature of their work (whether physical or sedentary), type of diabetes they were suffering from etc. Researcher tried to establish rapport with the respondents in the beginning by asking questions related to their medical background and family history. This enabled respondents to open up with the interviewer and share their personal perceptions about the disease and ways of managing it. Facility to interview patients in the OPD enabled first author to directly observe the course of interaction between doctor and patients. This enabled researchers to opt for observation method as well. However, observation and interview processes have been combined under the term *field research* which is used by Earl Babbie [23]. Field observation resulted when first author was not conducting any interviews this enabled her to observe activities taking place in the OPD. Interview schedule for the doctors broadly consisted of questions related to their approach towards different kinds of patients, how do they guide patients about the difference in rise and fall in blood sugar levels, their diet management, problem which they face due to the absence of dietitian etc. The respective diabetologist and cardiologist who felicitated data collection in their OPDs were interviewed.

2.3. Data analysis

Entire discussion with the respondents took place in Hindi language and responses were recorded using tape recorder. In addition to this, an observation diary was also maintained. These observations were the result of field research undertaken by first author for data collection. Being aware of Hindi as well as English language, authors themselves transcribed audio recordings in

English language under the supervision of English language experts of the department of Humanities and Social Sciences at Indian Institute of Technology, Roorkee (India). Translated data were analysed using grounded theory approach which was followed by reading and re-reading of the translated scripts by both the authors and results are categorised into popular themes. Responses of the respondents have also been reproduced in the study, and description is made by using pseudonyms.

3. Results

3.1. Excess consumption of carbohydrates and increase in BMI

BMI is particularly helpful in assessing adiposity and its association with lifestyle diseases like T2DM, cardiovascular diseases, osteoarthritis, sleep apnea etc. [24]. Metabolic and cardiovascular risk factors among South Asians are very high as compared to Caucasians. So, for Indians, BMI limits have been revised keeping in view the rising menace of lifestyle diseases. Revised BMI limits to categorise an Indian as normal or lean should be $18.5-22.9 \, \text{kg/m}^2$. Person with BMI <18.5 is an underweight whereas any one with BMI $23.0-24.9 \, \text{kg/m}^2$ is overweight and individuals with BMI ≥ 25 are obese [25]. According to a study, collective number of patients of cardiovascular diseases (CVD) in India and China are higher than the entire developed world [26]. As shown in Table-2, all 25 respondents had BMI>23.0 kg/m². Of these 25 respondents, 17 were overweight and 8 were obese.

Excess consumption of carbohydrates is another reason behind increase in BMI. Asian people gorge on high carbohydrate foods which poses a major challenge in diabetes management. Countries with the highest intake of carbohydrates are either developing or underdeveloped in nature; and malnutrition amongst children in these countries is explained by high carbohydrates intake and low protein consumption [3,16]. It has been observed that people provide a meaning to the food which they eat and this meaning is contested by the doctor. And patients again strive to provide a new meaning to it as their attachment with food is not only biological but social and emotional as well. Likewise, main ingredients of the local food are also potential contributors to diabetes. Dalda Ghee (Hydrogenated vegetable oil), which forms a major cooking ingredient in Indian kitchens is full of trans fatty acids, which also leads to abdominal adiposity [16]. Hence, doctors strictly recommend abstaining from high carbohydrates and sugar diet. Symptoms of the onset of diabetes are taught to the doctors. This teaching is then mediated through the experiences of the doctors who themselves happen to be the outcome of certain specific medical and social cultures [21]. This is why different respondents have different ways of expressing their attachment to the food.

Savitri Devi who was obese and was not involved in any kind of workout said that she ate oily and fatty food in abundance before the onset of T2DM. She admitted that she stealthily ate restricted food items in a party or social gathering:

I cannot eat food of my choice as my sons keep a strict vigil on my eating habits. But whenever I go to weddings or parties, I eat foods of my choice as none of my sons can watch me.

Another important thing which she mentioned was that she decided to visit this endocrinologist on the recommendation of a neighbour of hers who himself happened to be diabetic and believes in the medication of this doctor.

Similarly, Surekha changed her endocrinologist because she did not like the behaviour of her pervious doctor. Her brother-in-law recommended this doctor to her because his medication is very effective and costs very less. So, she basically did not consult any doctor for a year and stayed without medication despite of knowing the fact that she was diabetic. She explained her liking to the food as:

We cannot eat Chapatti (Indian Bread) without ghee (clarified butter) or butter as it sticks in the throat. However, I take good care of myself and try to keep a check on my blood sugar.

This statement of hers was interrupted by her daughter who accompanied her to the OPD. She said:

She (Surekha) never tries to control her taste buds and eats whatever she likes. Fruit curd consisting of banana and pomegranate with added sugars is an everyday delicacy in our meals. As far as walk is concerned, it is impossible to send her for walk. She gives us very hard time.

In a study of the impact of Nepalese food habits on the Nepalese diabetic patients residing in Nepal and Australia Sapkota et. al. [27], found that people have a social and emotional attachment with their food and food habits pose a huge barrier to the diabetes self-care management. Preparation of carbohydrates rich food is a way of expressing hospitality during parties and dinners. It is considered very impolite to refuse these dishes; hence, patients face a very tough task in managing their diabetes. This corresponds to the pattern which was observed in the present study as it was found that people were not ready to compromise their eating habits. India and Nepal share cultural affinity and their culinary traditions also form a part of it [11]. Thus, food has sentimental and cultural value with which people cannot compromise so easily. So, to satisfy their taste buds is more important for the patients, than managing their disease. During the course of interviews, a small group of diabetic patients happened to get together and requested doctor to allow them to eat rice. At this the doctor rebuked and said:

Isn't it much better that by restricting yourself from one food item, you can spare yourself from an extra tablet. I left rice long ago and haven't died yet, and so will you. Rest is up to you, if you still want to eat rice, then go ahead because I cannot use physical force to stop you from eating rice. But being your medico, it is my duty to educate you about the harmful effects of rice on your health.

Aneeta Minocha [29] talked of the peculiar behaviour of Indian patients because of which they entrust their full faith in the treatment recommended by the doctor in terms of medicine. Patients and their family members seldom try to get into the technical detailing of the medication offered by the doctors and same was witnessed during the present study. These patients still have the conception that mere medicine recommended by the doctor is sufficient to treat their ailment. Oblivious to the role of self-care management in diabetes, these patients still think that the *goli* (tablet) prescribed by doctor is sufficient to cure them.

Thus, Role of the doctor here becomes more challenging because it is very difficult to make such patients understand the role of lifestyle factors.

In this context, the diabetiologist said:

It is not possible for us to make patients understand the importance of different kinds of workouts and the food which they consume. So, depending upon their socio-economic background, which obviously takes into consideration their education level, we prescribe them food restrictions. For example, in the case of a totally illiterate person, it is not possible to make him/her understand the concept of hyperglycaemia and

hypoglycaemia. Hence, we completely proscribe sugars and highly sweetened fruit to such patients.

And such food restrictions pose a challenge for the patients who do not know the importance of diet management.

All the respondents, while replying to the queries related to the change in their eating habits after the inception of diabetes, said that they left eating potatoes and reduced the consumption of rice to less than half of what they used to eat earlier. However, as the narratives depict, respondents have an attachment to their food which makes it very difficult for them to control their taste buds.

3.2. Lack of physical activity

Physical inactivity is one of the main behavioural risk factors for the onset and exacerbation of this disease. Regular workout improves glucose intolerance and insulin insensitivity. It further improves metabolism and accelerates absorption of fatty acids in human body [30]. During pre-diabetic stage, moderate to high level of physical activity can prevent the risk of T2DM [31]. Drenowatz et. al. [14] opine that socio-cultural factors influence physical workout regimen of the people. Individuals belonging to poor socio-economic background, tend to be physically more inactive, mainly due to their inability to afford club sports and other similar kind of activities. Similar trends are emerging in India where socio-economically backwards sections of urban areas are becoming more vulnerable to the pandemic of diabetes which mainly results due to behavioural risk factors like sedentary lifestyle and excess consumption of carbohydrates [8]. Hence, physical inactivity when combined with improper eating habits, provides a very conducive breeding ground for diabetes.

During the study, it has been observed that patients tend to rely more on their own perception of disease management than the one which is medically recommended. Since, social constructivist perspective in the field of health is strongly influenced by Foucauldian ideas of knowledge, power and discourse therefore, people develop their own management techniques [20]. In total, only ten respondents (Table-2) were found to be maintaining regular habit of morning or evening walk. And there existed no difference between brisk walk, leisure walks or stroll for them. So, when respondents were asked about their irregular walking habits, different groups of respondents had different set of replies.

I keep doing household chores entire day. Why do I need to go for a separate walk? (Ratna, a housewife)

I wake up early in the morning to get my children ready for their schools. Then I have to prepare breakfast for my husband who has to go to office. After that, I prepare lunch and do some other chores. Similarly, I remain busy with one or another work and it is practically impossible for me to spare time for walk. (Meenakshi, a housewife)

I am the only bread-winner of my family. And I have to open my shop early in the morning and stay there till 8 in the evening. I cannot afford morning or evening walk. (Bachan Lal, a sweet-meat seller)

Even those who were aware of the role of lifestyle factors in the management of diabetes needed regular motivation to indulge in self-care management activities. According to Parsons [22] individuals rested with fiduciary responsibility in the life of a diabetic patient, plays very important role in motivating them for managing their disease and to keep a check on their eating habits and sedentary lifestyle. It has been observed that motivation plays a key role in the disease management which is a lifelong process in the case of diabetes. Hence patients with high motivation level tend to indulge religiously in self-care management [32].

My son has prepared my diet chart and he keeps a strict vigil on my eating habits. In addition to this, he keeps motivating me to go for regular walk. Actually, my entire family keeps an eye on my diabetes management regimen. (Babita, a housewife)

Similarly, twenty respondents (Table 2) said that their family members keep motivating them to control their lifestyle and to go for regular walk. These family members keep monitoring walking regimen and food habits of the patients. This is usually done keeping in mind *Parhez* (abstinence from high glycaemic and carbohydrates rich food) which is recommended by the doctor.

For the patients already marred by illiteracy and poor SES, it is very difficult to understand the regimen which has to be followed to maintain blood sugar levels, difference between carbohydrates, proteins, vitamins and minerals; difference between physical activity and physical inactivity; what blood sugar level is and why is it necessary to keep a check on it. This is why some patients tend to opt only for regular walks and others rely only on medicines prescribed by the doctors. Therefore, it can be argued that Parsonian asymmetric doctor-patient relationship exists in symmetric manner amongst these patients, who rely on their own perception (substantiated by shared discourses and constructed knowledge) of diabetes management.

4. Discussion

Self-care management experiences of socio-economically backward patients entails various dimensions such as lack of physical inactivity, excess consumption of carbohydrates and increase in BMI which are examined in the current study. All these patients are socio-economically backward in the sense that they can afford diet but they cannot afford a balanced diet. And hence, usually rely on excess consumption of carbohydrates. People in Jammu region follow an eating pattern which consists of eating butter or ghee drenched chapattis three times a day and having rice once a day; and some people consume parathas (stuffed and fried Indian bread) in breakfast every-day. This diet is followed by a sedentary daily routine which consists of no or very less physical workout. According to V. Sujatha [33], type of food and its nutritive value, varies from place to place and culture to culture. And mainly depends upon factors like ecology and lifestyle.

During the course of interviews, Purshottam, one of the respondents, recalled the life which his family members had to lead in the arid regions of Jammu. He said that Jammu was known as *Kandi* (Arid) area and people had to travel miles to fetch water and to perform other necessary works. However, marvels of science made life easier for the people and now they have easy access to water, transport and other necessities of life. This clearly shows that the extent of physical work amongst localities has reduced to a great extent. However, these people are totally oblivious to the concept of lifestyle diseases and for them, diabetes can be cured by consuming medicine prescribed by the doctor. Since, some patients entrust their full faith in the calibre of the doctor, hence, discussions related to diabetes, and knowledge sharing process on account of these discussions, make patients choose one doctor over another. These discourses involve effect of medication which is prescribed by the physician, things which can be eaten in order to keep blood sugar under control (these things form a part of self-medication), generalisation of socially constructed methods of diabetes self-care management (even if these methods are not medicinally

validated) etc. These discussions help them to opt best available treatment which also suits their pockets. So, the semantics conveyed during the discourse helps them in constructing their preference for one doctor over another. And thus, they also take into consideration that cure lies in medicine only and not in workout.

5. Conclusion

The study provides an insight of the self-care management regimen which is being followed by socio-economically backward sections in Jammu region of India. It reflects how socio-economically backward people fail to understand gravity of a degenerative disease like diabetes and rely on their own personal beliefs. However, due to small sample size of the study, results cannot be statistically validated. Another limitation of the study is that whether respondents belonged to urban, peri-urban or rural areas has not been taken into consideration. The majority of Indian population still resides in rural areas, a future course of research could be to focus on a comparative analysis of management regimens of diabetic patients in rural and urban areas.

This study is an increment to the knowledge based on diabetes management regimen of socio-economically disadvantaged sections in the third world. Till now studies are done on the population who know the difference between a manageable disease and a curable disease, and the role which lifestyle factors play in managing the disease. The present study on the other hand focuses on the need to view at diabetes management from a rarely explored perspective. Moreover, sociological perspective on diabetes is also helpful in determining the role of socio-cultural factors in triggering lifestyle diseases.

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Appendix A. Supplementary data

Supplementary data to this article can be found online at https://doi.org/10.1016/j.dsx.2019.01.025.

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