Original Article

Prevalence of Diabetes Distress among Adults with Diabetes Mellitus in a Rural Area of West Bengal: A Cross-sectional Study

Arpan Pal, Nivedita Das, Soumalya Ray, Dipta Kanti Mukhopadhyay

Department of Community Medicine, College of Medicine and Sagore Dutta Hospital, Kolkata, West Bengal, India

Abstract

Introduction: Diabetes distress is the emotional burden of diabetics and it may have a devastating impact on the health and well-being of people with diabetes. This study aims to estimate the prevalence of diabetes distress among adults with diabetes mellitus registered in the National Programme for Prevention and Control of Non-Communicable Diseases (NP-NCD) register in a rural area of West Bengal and to identify its distribution across different sociodemographic and treatment-related variables. **Materials and Methods:** This community-based descriptive, cross-sectional study was conducted in Barrackpore II block of North 24 Parganas district between July 2023 and September 2023. The study population consisted of diabetics registered under the NP-NCD register. The minimum required sample size of 155 was selected through a multistage sampling technique. Socioeconomic and sociodemographic data were collected using standardized questionnaire. Problem Areas in Diabetes questionnaire was used for assessing diabetes distress. Medication Adherence Report Scale questionnaire was used to check for medication adherence. Data were collected by house-to-house visits. Data were analyzed using jamovi (v2.4.8). **Results:** Out of the 142 participants, 52 (36.6%) had diabetes distress. Odds of diabetes distress were higher among <50 years of age (6.25 [2.41, 16.18]), females (3.66 [1.46, 9.21]), individuals with poor adherence to medications (8.40 [3.26, 21.59]), and individuals procuring medicines from private shops (3.47 [1.00, 12.00]). **Conclusion:** Diabetes distress is a public health problem among adults living with diabetes, which may have negative impacts on their quality of life and health outcomes. Further research is needed to explore the possible mitigating measures for the same.

Keywords: Diabetes distress, Medication Adherence Report Scale 5, NP-NCD, Problem Areas in Diabetes questionnaire

Introduction

Diabetes distress is a persistent concern of the people living with diabetes, regarding disease management, mental support, emotional burden, etc.[1] Coping with the regular management of diabetes can be a worrisome task, often overwhelming, mainly among people who are already dealing with multiple responsibilities in life. The uncertainty about the future can be daunting, as people with diabetes are at increased risk of serious complications. The financial cost of managing diabetes can be a heavy burden, especially for those who come from resource-constrained backgrounds.[2] Moreover, the worry regarding various life-threatening complications can be a regular companion in day-to-day life, casting a pall over every aspect of life. This emotional burden can have a devastating impact on the health and well-being of people with diabetes.[3] It can lead to poor diabetes management, which in turn can increase the risk of complications such as heart disease, stroke, blindness, kidney failure, depression, and anxiety in the long run.[4] The term diabetes distress was first proposed in the year 1995 by a group of psychologists and psychiatrists from Joslin Diabetes Center.[5] Since then, it has invited attention from public health professionals for improving compliance in relation to diabetes management. Globally, literature has shown that diabetes distress was associated with lower socioeconomic

Submitted: 23-Apr-2024 **Revised:** 03-Jun-2024
Accepted: 12-Jun-2024 **Published:** 29-Aug-2024

Access this article online

Quick Response Code:

Website: http://journals.lww.com/amit

DOI: 10.4103/amit.amit_57_24

Address for correspondence: Dr. Arpan Pal, 578 Barrackpore Trunk Road, Kamarhati, Kolkata - 700 058, West Bengal, India.
E-mail: arpan.pal0208@gmail.com

How to cite this article: Pal A, Das N, Ray S, Mukhopadhyay DK. Prevalence of diabetes distress among adults with diabetes mellitus in a rural area of West Bengal: A cross-sectional study. Acta Med Int 2024;11:126-30.

status, younger age, poor adherence to diabetes management, and poor communication with caregivers. Recognizing the problem associated with the management of diabetes mellitus, it was included in the National Programme for Prevention and Control of Cancer, Diabetes, and Stroke, which was later renamed as National Programme for Prevention and Control of Non-Communicable Diseases (NP-NCD).[6] Under this program, Accredited Social Health Activists (ASHAs) mobilize all individuals aged 30 years or more for screening at subcenters. Individuals found suspects of diabetes mellitus and/or hypertension are referred to the nearest primary health centers (PHCs) for confirmation and subsequent treatment.[7]

However, the program does not currently include any specific interventions to address the emotional burden associated with diabetes management such as diabetes distress. There is a scarcity of literature on diabetes distress in rural India, catering to two-thirds of the Indian population. This lack of information has hindered the development of targeted interventions under the program. This study aims to bridge this gap in knowledge by estimating the prevalence of diabetes distress among adults with diabetes mellitus registered in the NP-NCD register in a rural area of West Bengal and identifying its distribution across different sociodemographic and treatment-related variables.

Materials and Methods

Study design and settings

This community-based descriptive cross-sectional study was conducted in the Barrackpore – II block of North 24 Parganas district, West Bengal, between July 2023 and September 2023. The study population consisted of individuals with diabetes who were registered under NP-NCD. The ASHAs compile a list of all the people aged 30 years or more and refer them to the nearest subcenters after collecting information on the individual's risk factors for NCDs.[7] After screening at subcenters, individuals having random blood sugar levels ≥200 mg/dL and/or blood pressure ≥130/90 mmHg, i.e., NCD suspects are referred to the PHC for confirmation of diagnosis and further treatment.[7] Confirmed cases are enlisted in the NP-NCD register and provided treatment free of cost, including medication and advice for lifestyle modification.[7] The inclusion criteria were having a confirmed diagnosis of diabetes by a physician or a laboratory test, being a resident of the study area for at least 12 months, and being able to communicate verbally. The exclusion criteria were being severely ill or bedridden and having diagnosed with psychiatric illnesses and disclosed voluntarily.

A study in Odisha in 2019 reported that the prevalence of diabetes distress was 42%.[8] In the absence of any published literature from West Bengal, considering that as the prevalence of diabetes distress along with a 95% level of confidence, absolute precision of 10%, and design effect of 1.5, the sample size was calculated to be 141. After taking the nonresponse rate as 10%, the final sample size was 155.

Due to resource constraints, it was decided to adopt a multistage sampling technique. In the first stage, health and wellness centers (HWCs) were chosen as the primary sampling unit. The study area had 29 HWCs. Keeping in mind about the feasibility, 25% of the HWCs were decided to be selected as the primary sampling unit through simple random sampling. The list of patients with diabetes registered at each selected HWC was obtained and a sampling frame was prepared. The sample size for each HWC was determined using the population proportionate to size method, based on the number of registered patients with diabetes. Within each HWC, a simple random sample of patients with diabetes was selected, according to the allocated sample size.

The data collection tool was a standardized questionnaire that consisted of four sections. The first section collected demographic and socioeconomic data of the participants, such as age, gender, caste, and religion. Age was dichotomized into <50 years and more than 50 years based on the median value. Caste was categorized into general and marginalized (scheduled caste, scheduled tribe, and other backward classes). Education was categorized into Madhyamik (secondary education) and above and others. Although medications are available free of cost, some of the patients prefer to take medications from private shops. Various factors (doubt about the quality of the government supply drug, long queue, etc.,) were associated with this. Buying the medications from outside might produce an additional financial burden on these individuals and thus create emotional burden. Hence, they were inquired about the source of procuring the medications – completely from government supply or from private shops. The second section inquired about the participant's addiction history (beedi, cigarette, gutkha, and alcohol). The third section measured diabetes distress using the Problem Areas in Diabetes questionnaire, which is a 20-item scale that evaluates negative emotions related to diabetes management. Each item has a 5-point Likert scale ranging from 0 (no problem) to 4 (serious problem). The total score is obtained by summing up the item scores and multiplying by 1.25, resulting in a range from 0 to 100. A score of 40 or higher indicates the presence of diabetes distress.[9] The fourth section evaluated medication adherence using the Medication Adherence Report Scale, which is a 5-item self-report measure that asks about medication-taking behavior. Each item has a 5-point Likert scale ranging from 1 (always) to 5 (never). The total score is obtained by summing up the item scores, resulting in a range from 5 to 25. The median value of the total score was calculated to be 21. A score of <21 indicated poor adherence and a score of more than 21 indicated good adherence to medication. The data were collected from the participants through interviews at their households.

Statistical analysis

All the data that were collected were entered in Microsoft Excel™ version 2404. After that, entered data were checked for consistency. In case of any error, the entered data were compared with paper forms. Data were imported into jamovi (v2.4.8). Quantitative data were expressed in

mean (±standard deviation)/median (±interquartile range), depending upon their distribution. Categorical data were expressed in frequency and percentage. Association of the categorical variables was tested using suitable statistical tests such as the Chi-square test. Finally, one binary logistic regression model was prepared for diabetes distress as the dependent variable. Age, gender, caste, religion, adherence to medication, and where they get medicines from were taken as independent variables. Model variability was assessed using Nagelkerke's R^2.

Ethical consideration

After explaining the purpose and procedure of the study to each participant, written informed consent was taken from each one of them. Anonymity and confidentiality of the data were maintained strictly throughout the study period. The study followed all the ethical standards of descriptive epidemiological study and obtained clearance from the Institutional Ethics Committee of the College of Medicine and Sagore Dutta Hospital, Reg No- ECR/1210/Inst/WB/2019/RR-22, Memo No- CMSDH/IEC/76/07-2023. The research followed the guidelines as per the Declaration of Helsinki, updated in 2013.

Results

Out of the 155 individuals who were approached, 142 individuals provided consent for participating in the study. Response rate thus was 91.6%. The mean age was 50.3 ± 11.7 years (30–78). Out of all the participants, 100 (70.4%) were male and 42 (29.6%) were female. More than 80.0% of the study population belongs to the Hindu religion and more than 70.0% of the population were from the general caste.

The present study revealed that among the study participants, 52 (36.6%) had diabetes distress. Among those who had diabetes distress, 37 (71.2%) people had poor adherence to medications. Those who did not have diabetes distress, 31 (34.4%) had poor adherence to medication. On binary logistic regression analysis with diabetes distress as dependent variable after adjusting for caste and religion, it was found that individuals aged <50 years, females, individuals with poor adherence to medications, and individuals who procure medicines from private shops had higher odds of having diabetes distress [Table 1].

Discussion

This study intended to assess the prevalence of diabetes distress and its distribution among adults living with diabetes across various sociodemographic and treatment-related characteristics. Around one-third of the study participants (36.6%) which is slightly lower than the corresponding figures reported by Kumar *et al*.[10] and Patra *et al*.,[8] in their hospital-based studies in Coastal South India and Odisha, respectively. The difference in proportion might be contributed by the study setting, as more serious cases are more likely to attend the hospital.[11] This study also revealed that the individuals of younger age were more likely to have diabetes distress compared to older individuals. This is consistent with the results of Ratnesh *et al*.[12] conducted in a tertiary care hospital in Bengaluru. As diabetes is often perceived as a disease of old age, its diagnosis in young age may lead to more uncertainty and emotional distress.[13,14] Moreover, young people may face additional stressors such as family responsibilities, work, and financial challenges, which may interfere with their diabetes self-management and increase their distress levels.[15,16] Young people are often seen to

Table 1: Distribution of diabetes distress across different socioeconomic and treatment-related variables (*n*=142)

Variables	Diabetes distress		OR (95% CI)	*P*	AOR (95% CI)
	Yes, *n* (%)	No, *n* (%)			
Age (completed years)					
<50	35 (51.5)	33 (48.5)		<0.001	6.25 (2.41–16.18)
50 and above	17 (23.0)	57 (77.0)	0.28 (0.13–0.57)		Reference
Gender					
Male	31 (31.0)	69 (69.0)			Reference
Female	21 (50.0)	21 (50.0)	2.23 (1.06–4.66)	0.006	3.66 (1.46–9.21)
Caste					
General	41 (36.3)	72 (63.7)	1.07 (0.46–2.49)		Reference
Others	11 (37.9)	18 (62.1)		0.65	1.26 (0.44–3.63)
Religion					
Hindu	38 (32.5)	79 (67.5)			Reference
Muslim	14 (56.0)	11 (44.0)	2.65 (1.10–6.38)	0.54	1.40 (0.46–4.26)
Get medicine from					
Private shop	12 (57.1)	9 (42.9)	2.70 (1.05–6.94)	0.049	3.47 (1.00–12.00)
HWC	40 (33.1)	81 (66.9)			Reference
Adherence					
Good	15 (20.3)	59 (79.7)	0.21 (0.10–0.44)		Reference
Poor	37 (54.4)	31 (45.6)		<0.001	8.40 (3.26–21.59)

HWC: Health and Wellness Center, OR: Odds ratio, CI: Confidence interval, AOR: Adjusted OR

participate in work-related social activities to take their career to a higher level, which also affects their dietary restrictions and other self-care management activities and ultimately leading to more distress.[17] Fisher *et al*. also reported that younger participants had higher diabetes distress scores.[18] A study from China also concurred with the findings.[13] Gender was also found to be associated with higher odds of diabetes distress, with women having higher inclination than men. This is in line with the studies by Aronson *et al*.[19] and Huang *et al*.,[20] who reported that women had significantly higher levels of diabetes distress than men in the US and Taiwan, respectively. As evident from earlier studies, women are often given less priority and attention in many societies, and their problems may be ignored or dismissed, which may result in more emotional burden.[21,22] Furthermore, studies have suggested that gender plays an important role in the relationship between spousal support and dietary adherence for people with diabetes.[23] In contrast, women may experience higher family and career conflicts due to their dual roles as caregivers and workers, which may affect their quality of life and interpersonal relationships, as well as their communication with health-care providers.[24] These factors may contribute to higher levels of diabetes distress among women. However, this study was not designed to answer these questions. Further researches are warranted in this regard.

The present study found that adults who obtained medications from private shops had higher chance of developing diabetes distress than those who obtained them from government facilities. Diabetes is a chronic condition that requires long-term use of medications, which may impose a significant economic burden on the patients, especially if they have to buy some medicines from private shops due to their unavailability in government facilities. The increased financial stress and anxiety associated with it along with its negative effect on adherence to treatment may in turn worsen their glycemic control and increase their risk of complications and comorbidities. All these might contribute to the increased level of diabetes distress. Exploring the reason for purchasing medicines from private shops, while it was available free of cost from government facilities, was beyond the scope of this study. Future research may concentrate on this aspect of diabetes distress.

Based on the findings of this study, it may be concluded that diabetes distress is a public health problem among adults living with diabetes in this setting, which may have negative impacts on their quality of life and health outcomes. Therefore, it is important to identify and address the factors that contribute to diabetes distress in this population, such as age, gender, medication adherence, and medication source. Moreover, it is essential to provide adequate psychological support and counseling to people with diabetes distress, as well as to enhance their communication and relationship with health-care providers. Further research is needed to explore the causes and consequences of diabetes distress in different settings and populations and to evaluate the effectiveness of interventions to reduce it.

Due to limited resources and time constraints, gender stratification could not be done. We could not check the HbA1c levels of the patients and thus could not comment on the glycemic control of them. Another limitation of this study was the lack of follow-up of the study participants with proper interventions. Diabetes distress still needs further research in the Indian scenario, and a validated tool should be developed which can be used with ease for diagnosing it.

Financial support and sponsorship

Nil.

Conflicts of interest

There are no conflicts of interest.

References

1. Diabetes UK. What is Diabetes Distress and Burnout? Available from: https://www.diabetes.org.uk/guide-to-diabetes/emotions/diabetes-burnout. [Last accessed on 2023 Oct 08].
2. Tharkar S, Devarajan A, Kumpatla S, Viswanathan V. The socioeconomics of diabetes from a developing country: A population based cost of illness study. Diabetes Res Clin Pract 2010;89:334-40.
3. Kalra S, Jena BN, Yeravdekar R. Emotional and psychological needs of people with diabetes. Indian J Endocrinol Metab 2018;22:696-704.
4. Yang QQ, Sun JW, Shao D, Zhang HH, Bai CF, Cao FL. The association between diabetes complications, diabetes distress, and depressive symptoms in patients with type 2 diabetes mellitus. Clin Nurs Res 2021;30:293-301.
5. Polonsky WH, Anderson BJ, Lohrer PA, Welch G, Jacobson AM, Aponte JE, *et al.* Assessment of diabetes-related distress. Diabetes Care 1995;18:754-60.
6. Perappadan BS. Government Programme for Non-Communicable Diseases Renamed. The Hindu; 2023. Available from: https://www.thehindu.com/sci-tech/health/new-diseases-and-initiatives-prompt-health-ministry-to-widen-and-rename-ncd-programme/article66816673.ece. [Last accessed on 2023 Oct 10].
7. Available from: https://www.main.mohfw.gov.in/sites/default/files/Module%20for%20ASHA%20on%20Non-communicable%20Diseases_1.pdf. [Last accessed on 2023 Oct 14].
8. Patra S, Patro BK, Padhy SK, Mantri J. Prevalence of diabetes distress and its relationship with self-management in patients with type 2 diabetes mellitus. Ind Psychiatry J 2021;30:234-9.
9. Polonsky WH, Anderson BJ, Lohrer PA, Welch G, Jacobson AM, Aponte JE et al. Assessment of diabetes-related distress. Diabetes care. 1995;18:754-60.
10. Kumar N, Unnikrishnan B, Thapar R, Mithra P, Kulkarni V, Holla R, *et al.* Distress and its effect on adherence to antidiabetic medications among type 2 diabetes patients in coastal South India. J Nat Sci Biol Med 2017;8:216-20.
11. Khalid JM, Raluy-Callado M, Curtis BH, Boye KS, Maguire A, Reaney M. Rates and risk of hospitalisation among patients with type 2 diabetes: Retrospective cohort study using the UK General Practice Research Database linked to English hospital episode statistics. Int J Clin Pract 2014;68:40-8.
12. Sinha R, Shivaprasad KS, Kannan S, Khadilkar KS, Sravani GV, Raju R. Identifying the burden and predictors of diabetes distress among adult type 2 diabetes mellitus patients. Indian J Community Med 2020;45:497-500.
13. Hu Y, Li L, Zhang J. Diabetes Distress in Young Adults with Type 2 Diabetes: A Cross-Sectional Survey in China. Journal of Diabetes Research, 2020:6-8.
14. Jabeen Z, Baig AM, Khawaja KI, Shabbir S, Afzal Z. Diabetes distress among type 1 diabetic adolescents in a tertiary care hospital in Pakistan. Cureus 2022;14:e32392.
15. Carlsund Å, Söderberg S. Living with type 1 diabetes as experienced by

young adults. Nurs Open 2019;6:418-25.
16. Majumder E, Cogen FR, Monaghan M. Self-management strategies in emerging adults with type 1 diabetes. J Pediatr Health Care 2017;31:29-36.
17. Escoto KH, Laska MN, Larson N, Neumark-Sztainer D, Hannan PJ. Work hours and perceived time barriers to healthful eating among young adults. Am J Health Behav 2012;36:786-96.
18. Fisher L, Mullan JT, Arean P, Glasgow RE, Hessler D, Masharani U. Diabetes distress but not clinical depression or depressive symptoms is associated with glycemic control in both cross-sectional and longitudinal analyses. Diabetes Care 2010;33:23-8.
19. Aronson BD, Sittner KJ, Walls ML. The mediating role of diabetes distress and depressive symptoms in type 2 diabetes medication adherence gender differences. Health Educ Behav 2020;47:474-82.
20. Huang LC, Lin CL, Chang YT, Chen RY, Bai CH. Gender impact on diabetes distress focus at medical communication concerns, life and interpersonal stress. Int J Environ Res Public Health 2022;19:15678.
21. Gender and Health. Available from: https://www.who.int/health-topics/gender. [Last accessed on 2024 Apr 15].
22. Vigod SN, Rochon PA. The impact of gender discrimination on a woman's mental health. EClinicalMedicine 2020;20:100311.
23. Albanese AM, Huffman JC, Celano CM, Malloy LM, Wexler DJ, Freedman ME, *et al.* The role of spousal support for dietary adherence among type 2 diabetes patients: A narrative review. Soc Work Health Care 2019;58:304-23.
24. Examining Gender Differentials in Health: The Impacts of *Education, Employment, and Family Roles in Taiwan – ProQuest. Available from: https://www.proquest.com/openview/757cb554c8dba98d2038558ee46c1385/1?pq-origsite=gscholar and cbl=18750. [Last accessed on 2023 Oct 15].