

To study the impact of diabetic retinopathy on quality of life in Indian diabetic patients

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Purpose: To study the impact of diabetic retinopathy (DR) on the quality of life (QoL) of Indian patients with diabetes. **Methods:** This cross-sectional tertiary health care institution-based study involved 250 patients of DR. They were interviewed using four questionnaires, namely, the General Health Questionnaire (GHQ), Final Quality of Life Instrument for Indian Diabetic Patients (QoLID) questionnaire for diabetes and questionnaire modified for DR, retinopathy dependent quality of life (RetDQoL), and coping strategy checklist (CSCL). **Results:** The mean GHQ score was 1.12, indicating the absence of psychological morbidity. Mean QoLID score for financial worries and treatment satisfaction scores were 15 each for DR compared with 17 and 16, respectively, for diabetes mellitus (DM). The mean RetDQoL score was $-27.94 (\pm 2.14)$, showing the negative impact of DR on QoL. The mean CSCL score was $1.22 (\pm 0.14)$, indicating infrequent use of coping strategies. Scores achieved by all four questionnaires correlated to each other. On subgroup analysis, proliferative DR (PDR) patients had a significantly higher GHQ score, lower treatment satisfaction, and more financial worries, with a poorer QoL than nonproliferative DR (NPDR). The severity of the disease had a negative impact on the QoL. The treatment satisfaction and psychological impact on the patients undergoing all types of eye treatments were comparable. **Conclusion:** DR has a significantly detrimental impact on the QoL, which increases with increasing severity of the disease.

Key words: Diabetes mellitus, diabetic retinopathy, quality of life

Diabetes mellitus (DM) is one of the most significant public health challenges that we face in the twenty-first century because of the increasing disease burden owing to population growth, aging, urbanization, and increasing prevalence of physical inactivity. The increase in the incidence of diabetes in developing countries is especially concerning. Three-fourth of the population affected with diabetes world over is from developing countries.^[1] The main causes of visual impairment in DM are vitreous hemorrhage and macular edema. The treatment modalities include laser, surgery, and pharmacotherapy.^[2] All the treatment modalities require repeated clinic visits and lifelong follow-up. The visual disability from disease and the number of hospital visits required may have an impact on the patient's quality of life (QoL). The World Health Organization (WHO) has defined QoL as an individual's perceptions of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards, and concerns.^[3] It is increasingly recognized that in diabetes, psychosocial factors have an important impact on self-care, acceptance of therapeutic regimens, and treatment success.^[4,5] In this context, a large variety of generic^[3] and disease specific^[6-11] QoL assessment tools have been validated and evaluated in diverse population settings. Vision impairment has been linked with dependency in activities of daily living,^[12-14] social isolation,^[15] and reduced physical activity.^[16] It has been found that presence of diabetic retinopathy (DR) and macular edema,

visual acuity impairment, and patient comorbidities lead to significant impairment of both the physical and mental components of health-related QoL (HRQL).^[17]

There is no study from the Indian subcontinent about the impact of DR on QoL. There is scant data in world literature on the same. Notably, the Western population data may not be valid for our population because of gross social, cultural, and economic differences. In the Indian set-up, Nagpal *et al.* developed and validated questionnaire for DM consisting of 34 items covering eight domains, which included role limitations because of physical health, physical endurance, general health, treatment satisfaction, symptom frequency, financial worries, mental health, and diet advice satisfaction.^[18] Their questionnaire was modified for DR in the present study.

The present study was carried out with the aim to evaluate psychological morbidity, treatment satisfaction, financial worries, and QoL dependant of retinopathy of diabetic patients with at least 5 years duration of DR.

Methods

A cross-sectional tertiary health care institution-based study was conducted on a sample of 250 patients of DR visiting the

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retina services in a tertiary eye care hospital. The patients had been diagnosed with DR for the past 5 years. We excluded the patients suffering from any major illness, which hindered patients' understanding and answering the questionnaire; any other chronic illness that required hospitalization for more than 2 weeks in the previous 1 year; and any comorbid chronic eye disease like uveitis or glaucoma.

Patients were enrolled in the study after getting their written consent. An interview-based questionnaire was administered to each of the participants in the out-patient department (OPD) area in a comfortable position. The interviewer was well-trained in using the questionnaire and knew the local language. No interpreter was used.

Part I of the questionnaire consisted of patient sociodemographic cum clinical profile, which included data like age, sex, education, area of residence, duration and type of diabetes, history of diabetic eye disease, treatment for diabetic eye disease, number of hospital visits, etc. Part II of the questionnaire was 60 item General Health Questionnaire (GHQ) to assess any psychological morbidity.^[19] Part III of the questionnaire was the Final Quality of Life Instrument for Indian Diabetic Patients (QoLID) questionnaire for diabetes and questionnaire modified for DR, and it evaluated patient's treatment satisfaction and financial worries.^[18] Part IV of the questionnaire was adapted from retinopathy dependent quality of life (RetDQoL),^[20] which was an individualized measure of the impact of DR on varied domains of life. Part V of the questionnaire evaluated the patient's coping strategies adapted from the Coping Strategy Checklist (CSCL).^[21,22] All the forms were individually scored as per the standard scoring pattern for the respective questionnaire. GHQ questionnaire score of ≥ 3 was taken as psychological morbidity and GHQ score of < 3 was taken as no psychological morbidity.

Statistical analysis

The normality of the measurable data was assessed using Kolmogorov–Smirnov test (KS test). The measurable data, such as age, duration of DM, duration of DR, and various scores were expressed as mean, median, standard deviation (SD), and range. The categorical data were expressed as frequencies and percentages. For comparison between nonnormally distributed data, nonparametric test, i.e., Mann–Whitney test, was applied.

To evaluate the relationship between a categorical dependent variable and one or more independent variables, logistic regression was used. Rasch analysis was done for creating measurement from categorical data for the questionnaire responses. The person's ability and the item difficulty were checked with the help of R software and winstep software. The data showed separation of 1.99, which means that we could separate the persons into two groups with the reliability of 0.80. In item, the separation was 7, which means that the item difficulty has seven levels with 0.98 reliability. We performed the principal component analysis (PCA) to find out the variance explained by the model. The total variance explained by the model was 76%. Of this, 36% variance was explained by individual variation, rest 40% variance was explained by item and 24% variance in data is unknown. The reliability of overall scale was checked. All the questions were loading well in the model and highly correlated with their latent variable, except the question "get out and about" with F1 value of 0.379, so this particular question was questionable.

Results

The mean age of the patients in the study was 57.13 (± 9.7) years, ranging from 19 to 77 years. Of the 250 patients, 136 (54.4%) patients were male and 114 (45.6%) were female. About three-fourth of the patients were from an urban background. Only 40 patients (16%), were illiterate, while 65 patients (26%) were educated up to matric level and 145 (58%) were graduates. Most ($n = 158$, 63.2%) of the patients were earning more than INR 7,000 per month. None of the patients was covered under health insurance in the present study. The majority of the patients had type 2 DM (T2DM; $n = 242$, 96.8%). The mean duration of DM was 146.7 (± 72.5) months, i.e., 12.2 years, median = 12 years, and ranging from 5–30 years. Of the 250 patients, 121 patients (48.4%) had one or more comorbid illness, besides DM. Hypertension associated with the diabetes affected 82.6% of the patients. Maximum ($n = 112$, 44.8%) patients were having NPDR with clinically significant macular edema (CSME), followed by 73 (29.2%) patients having PDR without CSME. Forty-seven (18.8%) patients had PDR with CSME and 18 (7.2%) patients had NPDR without CSME. The mean duration of DR ranged from 5 to 12 years. Of the 250 patients, 18 (7.2%) patients had not been given any treatment for DR and were only on follow-up, 99 (39.6%) had received laser therapy, 39 (15.6%) had received intravitreal anti-vascular endothelial growth factor (VEGF) injections, 68 (27.2%) received both laser and anti-VEGF injections, and 12 patients (4.8%) had undergone surgery (pars plana vitrectomy [PPV]) for the advanced nature of their disease.

The mean GHQ score came out to be 1.12, which indicated the absence of psychological morbidity. Out of the 250 patients, 218 (87.2%) were GHQ negative (GHQ < 3) (i.e., the absence of psychological morbidity), while 32 patients (12.8%) were GHQ positive (GHQ ≥ 3) (i.e., the presence of psychological morbidity).

The mean QoLID scores for treatment satisfaction were 17 in DM compared with 15 for DR. QoLID scores for financial worries were 16 for DM and 15 for DR. The QoLID scores for DM and DR showed higher treatment satisfaction and lower financial worries for DM than DR. The patients with DM reported greater financial worries if they were younger (18–30 years), earning below INR 3,500 per month, having longer duration of DM, less satisfaction with treatment for DR, and higher financial worries with the DR treatment.

The weighted impact score was calculated for each domain as "Impact Rating (-3 to $+1$) multiplied by Importance Rating (0 to 3)."²³ The total RetDQoL score was calculated as a sum of the weighted impact score for all domains. The mean RetDQoL score of 250 patients came out to be -27.94 (± 2.14), median = -6.5 . The minimum possible score that could be achieved was -216 , while maximum possible score was $+72$. However, in our study, the total RetDQoL score ranged between -177 and 0 . The average weighted impact (AWI) score for each patient was calculated as: Sum of weighted impact score for all domains \div number of domains, i.e., 24. The possible range was from -9 (maximum negative impact of retinopathy on QoL) through 0 (no impact of DR on QoL) to $+3$ (maximum positive impact of retinopathy on QoL). The mean of the AWI score for 250 patients was -1.164 (median = -0.27), which showed the overall detrimental impact of DR on QoL [Table 1]. Urban background predicted low AWI score. Absence of comorbid

illness predicted high AWI score. Longer duration of DM predicted low AWI score. The treatment of DM with oral hypoglycaemic agents predicted high AWI score while insulin therapy predicted low AWI score [Table 2].

The mean CSCL score was 1.22 (± 0.141). Denial of the disease was the strategy most commonly used by the patients. Minimum number of patients used emotional outlet in the form of crying.

On correlation with the baseline variables, it was seen that the best corrected visual acuity (BCVA) better than 20/60 in both

the eyes or one eye was significantly predicting the absence of psychological morbidity (GHQ score < 3), while BCVA worse than 20/60 in both the eyes was not independently predicting any GHQ score [Table 3]. The severity of DR was also a predictor of higher psychological morbidity.

The DM treatment satisfaction (DM-TS) score < 17 (median) was given code 0, and DM-TS score ≥ 17 (median) was given code 1. It was seen that the absence of comorbid illness was predicting DM-TS score ≥ 17 , i.e., more satisfaction with the treatment for DM. A longer duration of DM was predicting more satisfaction with the treatment of DM [Table 4].

Higher DR-TS score was predicting higher DM-TS score i.e., more satisfaction with the treatment of DR independently predicting more satisfaction with the treatment of DM. DM financial worries (DM-FW) score < 15 (median) was given code 0 and DM-FW score ≥ 15 (median) was given code 1. It was seen that age was one of the independent variable that predicting DM-FW score < 15 , younger age group (18–30 years) strongly predicted it, i.e., younger patients ($\beta = -27.209$) were having more financial worries [Table 5]. Monthly income was also predicting DM-FW score to be < 15 . Monthly income below INR 3,500 per month was predicting more financial worries in the patients. Longer duration of DM was predicting DM-FW score < 15 , i.e., more financial worries. A higher DM-TS score was predicting higher DM-FW score, i.e., more the satisfaction with the treatment of DM, lesser were the financial worries. Similarly, a higher DR financial worries (DR-FW) score was predicting a higher DM-FW score; implying that lesser financial worries with DR treatment predicted lesser financial worries with treatment for DM [Table 5].

The DR treatment satisfaction (DR-TS) score < 16 (median) was given code 0 and DR-TS ≥ 16 (median) was coded as 1. BCVA was one of the independent variable predicting low DR-TS score, where BCVA $< 20/200$ to $20/400$ ($\beta = -17.915$) was strongly predicting it. This meant that presence of a worse BCVA strongly predicted less satisfaction with treatment of DR. A longer duration of DM was predicting less treatment satisfaction [Table 6].

A high DM-TS score DM-FW score were predicting a high DR-TS score, i.e., more treatment satisfaction and less financial worries with diabetes treatment predicted more satisfaction with the treatment given for DR. A high RetDQoL score predicted more treatment satisfaction and high CSCL score, i.e., more usage of coping strategies predicted less treatment satisfaction with the DR treatment [Table 7].

DR-FW score < 17 (median) was coded as 0 and DR-FW ≥ 17 (median) was coded as 1. Urban background was found to be independently predicting low DR-FW score, i.e., more financial worries. A high DM-FW score (less financial worries with DM treatment) and high RetDQoL score were predicting high DR-FW score (less financial worries with DR treatment).

The patients were reporting less treatment satisfaction and more financial worries for the treatment of the DR than DM. BCVA was one of the independent variable predicting low DR-TS score. BCVA $< 20/200$ to $20/400$ was strongly predicting it, which means worse BCVA strongly predicting less satisfaction with the treatment of DR. Longer duration of DM was predicting less treatment satisfaction. High DM-TS score and DM -FW score were predicting high DR-TS score

Table 1: Mean values of domain wise weighted impact score, AWI score, and total RetDQoL score

Item	Mean (\pm SD)
Household Tasks	-2.78 (± 3.384)
Personal Affairs	-3.16 (± 3.606)
Shopping	-1.75 (± 2.278)
Future Feelings	-0.55 (± 1.344)
Past Feelings	-0.18 (± 0.841)
Working Life	-2.51 (± 3.321)
Closest Personal Relationship	-0.32 (± 1.034)
Family Life	-1.40 (± 2.60)
Social Life	-1.52 (± 2.299)
Doing Things for Other	-1.31 (± 1.894)
Get Out and About	-2.24 (± 2.957)
Holidays	-0.56 (± 1.341)
Financial Situation	-1.54 (± 2.391)
People Reaction	-0.23 (± 0.905)
Physical Appearance	-0.05 (± 1.312)
Physical Work	-1.46 (± 2.303)
Leisure	-1.04 (± 2.055)
Self Confidence	-0.75 (± 1.626)
Motivation	-0.46 (± 1.246)
Dependence	-1.13 (± 2.394)
Fear of Mishaps or Losses	-0.92 (± 2.061)
Time is Taken to do Things	-0.71 (± 1.746)
Care of Diabetes	-0.38 (± 1.135)
Enjoy Nature	-0.53 (± 1.336)
Mean RetDQoL score	-27.94 (± 38.14)
AWI score	-1.164 (± 1.589)

AWI=Average weighted impact, RetDQoL=Retinopathy dependent quality of life, SD=Standard deviation

Table 2: RetDQoL

Variable	β coefficient of predictability
Social Background: Urban	-1.506
Absence of Comorbid Conditions	2.434
Treatment of DM with OHA	0.701
Treatment of DM with Insulin	-1.766
Duration of Diabetes	-0.009
GHQ Score	0.713
RetDQoL Score	-0.060

RetDQoL=Retinopathy dependent quality of life, DM=Diabetes mellitus, OHA=Oral hyperglycemic agents

Table 3: BCVA with GHQ scores

BCVA Variable	β coefficient of predictability	P
$\geq 20/60$ in Both the Eyes	-2.142	<0.05
Worse than 20/60 in one eye	-2.529	<0.05
Worse than 20/60 in both the eyes	Not Significant	>0.05

BCVA=Best corrected visual acuity, GHQ=General Health Questionnaire

Table 4: Absence of comorbid illness and duration of DM

Variable	β coefficient of predictability
Absence of comorbid illness	1.336
Duration of DM	0.008
DR-TS score	0.829

DM=Diabetes mellitus, DR-TS=Diabetic retinopathy treatment satisfaction

Table 5: RetDQoL

Variable	β coefficient of predictability
DM-FW score	-0.118
DM-TS score	0.430
DR-FW score	0.353
DR-TS score	0.305

RetDQoL=Retinopathy dependent quality of life, DM-FW=Diabetes mellitus financial worries, DM-TS=Diabetes mellitus treatment satisfaction, DR-FW=Diabetes retinopathy financial worries, DR-TS=Diabetes retinopathy treatment satisfaction

Table 6: Longer duration of DM-FW

Variable	β coefficient of predictability
Age (Years)	
18-30	-27.209
31-40	-1.701
41-50	-3.432
51-60	-3.044
61-70	-3.149
Monthly Income (INR/per month)	
0-3,500	-2.131
3,501-7,000	-1.008
>7,000	Not significant
Duration of DM	-0.010
DR-FW Score	0.493
DM-TS Score	0.188

DM-FW=Diabetes mellitus financial worries, DM=Diabetes mellitus, DR-FW=Diabetes retinopathy financial worries, DM-TS=Diabetes mellitus treatment satisfaction

i.e., more treatment satisfaction and less financial worries with diabetes treatment predicted more satisfaction with the treatment given for DR. Urban background was found to be independently predicting low DR-FW score i.e., more financial worries. High DM-FW score (less financial worries with DM treatment) and high RetDQoL score were predicting high DR-FW score (less financial worries with DR treatment).

All the scores correlated well with each other (Table 3, Pearson’s correlation coefficient 0.176-0.639;

$P = 0.005-0.000$). The severity of DR had significant detrimental impact on the QoL of the patient and affected all the score. The *post hoc* analysis showed the scores to be worse for PDR.

Discussion

QoL has become an important measure of the outcome of care for patients with chronic diseases in the last two decades. It is subjective and should include the essential domains of the physical, psychological, daily role and social functioning, and general health perception. Qualitative and quantitative analysis of QoL helps health administrators identify the needs of patients with DR better so that their services could be more patient-centered.

Out of the 250 patients, 218 were GHQ negative, while 32 patients were GHQ positive who had psychological morbidity. These patients needed psychiatric evaluation and treatment. Diabetes is regarded as a multisystem disease. Systemic investigations and timely referrals to a cardiologist, neurologist, and nephrologist are emphasized in the management of the disease. However, a psychiatric evaluation in this chronic disease to date is neglected. In the present study, 12.8% of the patients had undiagnosed psychiatric problems for which they required psychiatric evaluation and treatment. In our study, the rate of psychological morbidity (13%) is considerably low than that reported for medical and surgical outpatients (30%) and inpatients (33%), respectively.^[23,24]

A much higher rate of GHQ ranging from 25–47% is found in other physical disorders like psoriasis, vitiligo, pemphigus, acromegaly, and Cushing’s disease.^[22,25-28] Hence, it is surprising that GHQ assessed psychological morbidity was not very high in our patients of DR, which could be because the diseases studied in other studies are affecting physical appearance of a patient while DR does not affect physical attributes of the patient.

Using logistic regression analysis, it was observed that “best corrected visual acuity better than 20/60 in both the eyes or one eye” was significantly predicting absence of psychological morbidity (GHQ score < 3), while “best corrected visual acuity worse than 20/60 in both the eyes” was not independently predicting any GHQ score. This is possible because diabetes being a chronic disease, the patients over a period reconcile with the circumstances and learn to live with a poor vision without much fuss while good vision definitely predicts absence of psychological morbidity. Nevertheless, DR patients with psychological morbidity require attention in terms of diagnosis and management.

The QoLID questionnaire evaluated the impact of DM on the QoL. In this study, it was modified and divided into two parts, i.e., Part A (for administration to patients suffering from DM) and Part B (for administration to patients suffering from DR). Higher scores were obtained for “Treatment Satisfaction” for DM than for DR, and lesser “Financial Worries” were reported by patients for treatment of DM than for DR. Seen in combination, the results indicate that the patients were reporting less treatment satisfaction and more financial worries for the treatment of DR than their primary illness, i.e., DM. This could be because the treatment for DR is expensive, especially pharmacotherapy, where cost of each injection takes a big part from their monthly income as none of the

Table 7: BCVA and satisfaction rate in treatment of DR

Variable	β coefficient of predictability
BCVA in Better Eye $\geq 20/60$	-2.972
BCVA in Better Eye $<20/60-20/200$	-3.136
BCVA in Better Eye $<20/200-20/400$	-17.915
Duration of DM	-0.007
DM-TS Score	0.430
DM-FW Score	0.118
RetDQoL Score	0.024
CSCL Score	-0.308

BCVA=Best corrected visual acuity, DM=Diabetes mellitus, DM-TS=Diabetes mellitus treatment satisfaction, DM-FW=Diabetes mellitus financial worries, RetDQoL=Retinopathy dependent quality of life, CSCL=Coping strategy checklist

patients had health insurance in the present study. Greater satisfaction with the treatment of DM was positively correlated with the absence of comorbid illness, longer duration of DM, and more satisfaction with the treatment of DR. On the other hand, patients with DM reported greater financial worries if they were younger (18–30 years), earning below INR 3,500 per month, having longer duration of DM, less satisfaction with treatment for DR, and higher financial worries with the DR treatment. This could be attributed to the uncertainties in future job profile of these people and the treatment expense exceeding their earning capacity. Less satisfaction with the DR treatment was positively correlated with worse BCVA, longer duration of DM, and more severity of DR. This is because laser was the most common treatment given in the present study, which aims at visual stabilization, and visual improvement accounts for a very small subgroup of patients. Most of us, correlate treatment satisfaction with visual improvement. On the other hand, patients with DR reported greater financial worries if they were from an urban background and had lower RetDQoL scores. PDR patients had lower treatment satisfaction and more financial worries as compared with NPDR, probably a reflection of the nature of illness and type of treatment required.

RetDQoL: Mean of AWI score for 250 patients came out to be -1.164 (median = -0.27), which showed the overall negative impact of DR on QoL. However, the AWI score was not very negative in our sample compared with the AWI of -2.05 reported by Brose and Bradley^[29] (2010) from the United Kingdom (UK) and Germany. This relatively better disease-specific QoL in our study could possibly be a reflection of the sociocultural belief system operating in a traditional society like ours in India, wherein the concept of “karma” (fate) operates, i.e., a person tries to explain his good or bad luck, success or failure etc., on the basis of his “karma” (Varma and Gupta, 2008).^[30] When observed individually, DR had negative impact on all the domains with more negative impact on “personal affairs,” “household tasks” and “get out and about” and less negative impact on “physical appearance,” “past feelings” and “care of their diabetes.” Hence, the maximum negative impact of DR was on the individuals’ physical and social activities. Although a similar pattern was observed in the study by Brose and Bradley^[29] from Europe, they additionally showed maximal negative impact on “feelings about the future”; in contrast to a low impact in our study. This is clear from the fact that very

few patients get health insurance in our country. When NPDR was compared with PDR, PDR patients had more negative RetDQoL score indicating poorer QoL in them.

The mean CSCL score was 1.22 ± 0.14 , indicating very infrequent use of coping strategies by the overall sample. Among the various domains, in terms of frequency of use, “denial” was the most common and “emotional outlet” was the least commonly used. On logistic regression, coping strategies were more likely to be used if patients were from an urban background or had high GHQ scores. PDR patients used more coping strategies (as reflected by higher CSCL scores) as compare to NPDR patients.

There are some limitations to our study. This was a one-time questionnaire-based study of patients of DR with vast variation of duration of their disease (DM: 1 year to 30 years and DR: 1 year to 12 years). The treatment facilities available for DR 12 years back were not the same as of today, so the patients with different durations of their disease would have experienced different levels of satisfaction with the treatment, which could not be assessed. Secondly, the study included DR patients with no follow-up assessment of QoL, because of which effect on QoL with time could not be assessed. Longitudinal changes in functional vision with a change in disease condition could not be explored. In addition, in further studies it would indeed be interesting to note that, apart from the patients’ income and socioeconomic class, whether the person is the main earning member of the family and the number of dependents.

The main strength of this study was that it involved different instruments, which evaluated patients’ general psychological well-being, patients’ satisfaction with the treatment given, and financial worries associated with the treatment for DR as well as DM, coping strategies adopted by the patients and not just disease-specific QoL. In this way, this study attempted to assess the QoL along with various psychosocial variables affecting it, in DR patients in India where there is hardly any literature to the best of our knowledge, which has done such a comprehensive analysis.

Conclusion

Diabetic patients need a holistic approach involving various body systems including psychiatric evaluation. About 12% of these suffer from psychiatric problems needing further evaluation and management. The treatment satisfaction is lesser and financial worries are of concern because of DR than DM. DR has negative impact on majority of the day-to-day issues with maximum impact on personal affairs and household activity.

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Conflicts of interest

There are no conflicts of interest.

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