Psychosocial Adjustment to Advanced Proliferative Diabetic Retinopathy

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OBJECTIVE — To identify the major problems with adjustment to the advanced stages of proliferative diabetic retinopathy and to examine the relationship between adjustment and visual acuity.

RESEARCH DESIGN AND METHODS — A cross-sectional descriptive cohort study was conducted at the referral-based eye unit at Joslin Diabetes Center in Boston, Massachusetts. We studied 47 adults with IDDM and advanced proliferative diabetic retinopathy. Thirty reported recent visual loss, and 17 had more stable vision.

RESULTS — Psychosocial Adjustment to Illness Scale scores were significantly elevated relative to a normative diabetic sample ($t = 2.94$, $P < 0.01$). Our proliferative diabetic retinopathy sample reported the most difficulties in the domain of health-care orientation. No significant differences were observed in adjustment scores between those with recent partial visual loss and those with more stable vision. However, visual acuity in the best eye correlated significantly with the proliferative diabetic retinopathy sample's total adjustment score ($r = -0.34$, $P = 0.02$) and with 4 of 7 adjustment subscales.

CONCLUSIONS — These results suggest that advanced proliferative diabetic retinopathy may be associated with particular difficulties in adjustment that are more related to best visual acuity than to recent visual loss. Relatively mild visual impairment may have significant psychosocial impact.

Though complications in diabetes exact a psychosocial toll, the few studies of the psychosocial aspects of complications (1–5) have left us without specific descriptive data on which to build rational approaches to interventions that could minimize this toll. Our review (6) of the few empirical studies of the psychosocial aspects of diabetic retinopathy (6–10) led us to conduct an observational study of a cohort of adults with PDR. The primary aims of the study were to describe patterns of psychosocial adjustment to advanced PDR and to examine the relationship between visual acuity and adjustment.

Most studies of psychosocial functioning in diabetes have assessed populations without complications. On the whole, these studies fail to show that diabetes leads to major alterations in personality or increased risk of psychiatric illness before the onset of major complications (4,11–13). However, complications often introduce the hitherto well adult with diabetes to physical impairments that demand major psychosocial changes.

In a recent study of 114 diabetic patients, most of whom had at least one major complication, Lustman et al. (14) reported a lifetime prevalence rate of major psychiatric disorders close to 71%, considerably exceeding the rates of other rigorous studies of psychiatric disorders in serious medical illnesses.

In the one published study of the psychosocial impact of visual loss in diabetic retinopathy, Oehler (7) used a semistructured interview and two self-report scales for depression in a cross-sectional assessment of 33 adults with diabetic retinopathy or maculopathy and visual loss within the previous five years. Visual acuity was 20/40 or worse in the better eye. She found that in the interval since visual loss, 33% of the sample reported severe depression, 69% reported work difficulties related to vision, 39% lost jobs, 73% could no longer drive, and 39% started receiving financial support from social security income.

Consistent with these findings, Jacobson et al. (9) found that PDR patients reported significantly more psychiatric symptoms than diabetes patients with minimal or no retinopathy. The

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RECEIVED FOR PUBLICATION 26 SEPTEMBER 1990 AND ACCEPTED IN REVISED FORM 29 DECEMBER 1992.

PDR, PROLIFERATIVE DIABETIC RETINOPATHY; TYPE I DIABETES, INSULIN-DEPENDENT DIABETES MELLITUS; PAIS, PSYCHOSOCIAL ADJUSTMENT TO ILLNESS SCALE; MANOVA, MULTIVARIATE ANALYSIS OF VARIANCE; DCCT, DIABETES CONTROL AND COMPLICATIONS TRIAL.

studies by Oehler (7) and Jacobson et al. (9) point toward marked changes in psychosocial functioning with the onset of PDR and visual impairment.

This study adds to existing studies an assessment of specific domains of psychosocial adjustment and a look at the relationship between visual and psychosocial functioning. Neither the literature on diabetes nor the literature on visual impairment has addressed the problems specific to diabetic retinopathy. For example, no other common cause of blindness is associated with a life-threatening chronic illness. The extended period of extreme and rapid fluctuations in visual acuity typical of PDR is unusual in other processes of visual loss. And in no other chronic illness is the prospect of eye disease so unpredictable and at the same time so inevitable (15,16).

RESEARCH DESIGN AND METHODS

— This cross-sectional cohort design assessed the subjects for visual acuity and psychosocial adjustment. Subgroups were defined as *1*) those reporting sudden recent visual loss, and 2) those reporting stable vision over the past 6 mo.

The sample was recruited from the eye unit of the Joslin Diabetes Center in Boston, Massachusetts during a 12-mo period in 1984–1985. Criteria for inclusion consisted of *1*) adults with type 1 diabetes at 18–60 yr of age, and *2*) a previous diagnosis of advanced PDR. All subjects met criteria for level 7 of the ETDRS adaptation of the modified Airlie House classification of diabetic retinopathy (16,17).

Patients with PDR enrolled in the eye unit routinely come for ophthalmological exams about every 4 mo. Two groups of advanced PDR subjects were recruited, one with relatively stable vision (no significant change in visual acuity over the previous 6 mo) and the other with recent partial visual loss by vitreous hemorrhage and other ocular mechanisms. During a visit to the eye unit (within days after the vitreous hemorrhage for the visual loss group), each patient had an ophthalmological exam and met with the research coordinator or the principal investigator and completed the informed consent form and the self-report questionnaire, the PAIS. Data on visual acuity were abstracted from each subject's medical chart.

Measures

Vision. Optometrists using a procedure similar to that used for the Diabetic Retinopathy Study (18) recorded functional visual acuity in each eye as well as best corrected visual acuity. Because functional visual acuity reflects how the patient sees in daily living (e.g., with prescribed glasses), this variable provided the best estimate of current visual functioning that was relevant to recent psychosocial adjustment. Classifications of impairment were made on the basis of functional visual acuity (Table 2).

Psychosocial adjustment. The PAIS (19) is a 46-item self-report measure that assesses the ways in which a medical illness (we specified "your eye disease, retinopathy") has affected psychosocial functioning over the past 30 days. The PAIS assesses seven domains: health-care attitudes, vocational functioning, domestic roles, sexual relationships, extended family relationships, social environment, and psychological distress. This structure yields a total score and seven subscale scores. A high score reflects poor adjustment.

The PAIS is one of few available measures of adjustment to medical illness. T-scores allow meaningful comparisons across subscales, with the mean set at 50 and the SD set at 10. The total and seven subscale T-scores were calculated from norms for diabetic patients provided by the author of the PAIS (19). The normative sample consisted of 99 adults with type I diabetes, 64% female, almost exclusively white, normally distributed across Hollingshead social classes, and participants in a multicenter trial of "an innovative therapeutic regimen designed to reduce diabetic complications through improvements in glycemic control." No information is available on the duration of diabetes, the frequency or severity of complications, or the glycemic control of the Derogatis sample.

Because no norms were available for patients with eye disease, we chose the norms for type I diabetic patients as the most appropriate sample available from which to calculate T-scores. As a result, our study compares adjustment in patients with diabetes and retinopathy to adjustment in patients with type I diabetes.

We selected the PAIS because of adequate reliability and validity studies (19,20), because its subscale scores allowed identification of specific areas of strength and weakness, because of its proven stability in repeated measures designs, and because of the availability of norms for patients with diabetes. The authors of the PAIS gave us permission to modify the PAIS by specifying "your eye disease, retinopathy" without altering other aspects of the measure.

Statistical analysis

Differences between the study sample and the Derogatis normative sample in PAIS scores were tested with seven separate Student's *t* tests for independent means. Differences between the recent loss group and the stable vision group across the seven PAIS subscale scores were examined with MANOVA without the use of covariates, and using duration of PDR and severity of visual impairment singly and together as covariates. All correlations were Pearson correlations. SAS software (Cary, NC) was used throughout. Data are presented as means ± SD.

RESULTS

— Table 1 describes the characteristics of the sample. The sample is all white, nearly evenly divided among men and women, mostly middle class, with an average of >20 yr duration of type I diabetes and >3 yr of PDR. One subject had PDR diagnosed during a pregnancy 21 yr before the study. Gly-

Table 1—*Sample characteristics of study subjects*

n	47
Male	21
Female	26
Age (yr)	35 ± 8.3 (21–60)
Race	All white
Diabetes duration (yr)	22 ± 7.1 (10–45)
PDR duration (yr)	3.4 ± 3.5 (0–21)
HbA_{1C} (%)	9.5 ± 2.3

Data are means ± SD.

cemic control, as reflected by mean HbA_{1C} (21), was 9.5 ± 2.3% (means ± SD). (By this method the mean HbA_{1C} for type I diabetic patients is normally 8.95 ± 2.08%.)

The recent loss subgroup was similar to the stable vision group with respect to mean age (35 vs. 34 yr), sex (43% vs. 46% male), mean duration of type I diabetes (22 vs. 22 yr), and HbA_{1C} (9.9 vs. 9.3%). The two groups differed on mean duration of PDR (3.8 vs. 2.7 yr).

Vision

The mean visual acuity in the best eye for the sample was 0.84 ± 0.33 or ~20/25. The mean visual acuity for the recent loss group (n = 30) was 0.73 ± 0.34, or somewhat better than 20/30, significantly less than the mean visual acuity for the stable vision group (n = 17), which was 0.97 ± 0.24, or almost 20/20 (t = 2.55, P < 0.01).

Table 2 shows the proportions of the sample classified as visually impaired. In most of the sample, the better eye functioned in the nonimpaired range, with 20% functioning in the mild to severely impaired range. Most of the subjects in the recent loss group remained in the nonimpaired category, in spite of having noticeable and measurable visual loss.

The mean visual acuity for the worst eye in the sample was 0.52 or 20/40, and 50% of the sample had an impairment in the worst eye of ≤20/40.

Adjustment

Table 3 shows the mean PAIS raw scores and SDs for the sample. T-scores based on the Derogatis normative sample are also provided for comparisons between the two samples and across subscales. (The varying numbers of items per subscale make comparisons of raw subscale scores invalid.) The median PAIS total raw score was 27.

According to a two-tailed Student's t test for independent means, the mean total PAIS T-score (54.7) was significantly higher than the normative mean of 50 for diabetes (t = 2.94, P < 0.01). However, the only subscale that was significantly elevated was that of health-care orientation, whose mean was 61.9 ± 12.5 (t = 6.88, P < 0.01). Five other subscales were elevated, but not significantly, and one subscale, sexual functioning, was lower than the norm.

The mean total PAIS T-score for the recent loss group (n = 30) was 55.6, not significantly higher than the mean total PAIS T-score for the more stable vision group (n = 17), 53.1. The recent loss group reported more difficulties with adjustment on 5 of 7 subscales, compared with the stable vision group, but none of these differences was significant (Table 3). MANOVAs comparing the two groups across all seven PAIS subscales showed no significant difference when the comparison was made without the use of covariates, as well as when PDR duration and PDR severity (singly and together) were used as covariates.

Correlations

For the whole sample, the best visual acuity measurements correlated significantly with the total PAIS scores (r = −0.37, P = 0.02). The negative correlation means that as visual acuity worsened, adjustment problems increased. As Table 4 shows, the four domains that correlated most strongly with best visual acuity were vocational, domestic, familial, and social functioning. Health-care orientation was the only domain that showed a positive correlation with visual acuity.

CONCLUSIONS— Comparison of our sample with the Wisconsin Epidemiologic Study of Diabetic Retinopathy (16) suggests that our sample is typical of the population with advanced PDR in type I diabetes mellitus with respect to age, sex, and duration of diabetes. Our sample contained a somewhat smaller proportion of people in the mild-to-severe range of visual impairment. The extent of visual impairment is greater if the worst eye is considered as well as the best eye. However, no standard method

Table 2—*Distribution of visual impairment as measured by best visual acuity*

		None >20/40	Mild 20/40–20/60	Moderate 20/80–20/160	Severe 20/200 or worse
	n	% (*n*)	% (*n*)	% (*n*)	% (*n*)
Total sample	47	79 (37)	15 (7)	5 (2)	2 (1)
Recent loss	30	70 (21)	20 (6)	7 (2)	2 (1)
Stable	17	94 (16)	6 (1)	0	0

Table 3—*Mean adjustment scores*

	Raw scores sample	T-scores total sample	T-scores recent loss	T-scores stable vision
n	47	47	30	17
PAIS				
Total	31.3 (19.8)	54.7*	55.6	53.1
Health-care orientation	7.4 (3.4)	61.9*	61.9	61.9
Vocational environment	3.6 (3.3)	52.2	53.9	49.2
Domestic environment	5.4 (4.8)	52.2	53.0	50.6
Sexual relationships	2.04 (3.4)	47.2	47.8	46.3
Extended family relationships	1.85 (2.9)	53.0	53.8	51.7
Social environment	4.0 (4.5)	52.7	54.1	50.2
Psychological distress	7.0 (4.5)	52.7	52.1	53.7

Data for raw scores sample are means (SD).
*$P < 0.05$ compared with Derogatis sample.

exists for classifying impairment that includes the worse eye or combined total visual acuity, so in this report we limit our discussion to visual impairments defined by the best eye.

Three findings deserve discussion. The first is that the sample with advanced PDR reported significantly more problems with adjustment than was reported by Derogatis's normative diabetic sample. The meaning of this finding is limited by the characteristics of the Derogatis sample, which was selected for a multicenter clinical treatment trial and therefore may represent a better adjusted group than the general diabetic population. Data on the level and severity of complications in the Derogatis sample are not available. Our results suggest that our sample with advanced PDR experienced more difficulties adjusting to their PDR than Derogatis's sample did adjusting to their diabetes.

The DCCT assessed adjustment to diabetes with the PAIS in the only other study to apply the PAIS to diabetic populations (13). Compared with our study sample, the adult DCCT sample ($n = 136$) was younger (mean age 28 yr), had a shorter duration of type I diabetes (mean duration 8.5 yr), and had no advanced complications of diabetes. The PAIS scores of the DCCT sample were interpreted as "not suggestive of impairment." Raw scores on two of the seven domains were published and were significantly lower than the subscale scores of our PDR sample (for vocation: 1.4 vs. 3.4 for men, $t = 4.2$, $P < 0.001$, and 1.9 vs. 3.8 for women, $t = 3.4$, $P < 0.001$; for domestic: 1.8 vs. 4.5 for men, $t = 3.8$, $P < 0.001$, and for women 2.4 vs. 6.2, $t = 5.19$, $P < 0.001$). The complete DCCT data on the PAIS would be preferable for supporting the suggestion that although diabetes before the complications phase may be associated with no difficulties in adjustment, advanced PDR may be associated with significantly more difficulties.

Although elevations relative to the Derogatis sample occurred in all domains except sexual functioning, the domain of greatest relative dysfunction was health-care orientation. This domain includes 8 items on the subject's attitudes about health and his or her current medical care. Two items address the subject's attentiveness to daily health matters. Two items ask about the quality of available doctors and medical care. Two items ask about expectations of treatment, and two ask about adequacy of information provided about the subject's current health needs. High scores on this subscale reflect difficulties in the subject's relationship with his or her health-care system (e.g., inadequate information

Table 4—*Correlations*

	Visual acuity, best eye	
	r	*P* value
PAIS		
Total	−0.37	0.02
Health-care orientation	0.21	0.15
Vocational functioning	−0.43	0.003
Domestic roles	−0.35	0.02
Sexual relationships	−0.18	0.22
Extended family relationships	−0.33	0.03
Social environment	−0.43	0.002
Psychological distress	−0.18	0.24

$n = 47$.

about PDR, disappointed expectations, shaken trust), but the item scores cannot be expected to reveal the source of the difficulties for any particular person, or even for this sample.

The clinical value of this finding is to draw attention to the possibility that during the advanced stages of PDR the patient may experience unusual difficulties with his or her health-care system. The weakly positive correlation with visual acuity for this subscale in Table 4 suggests that such difficulties may be unrelated to the level of visual acuity. Other factors that may contribute to the difficulties include the meaning of PDR as a threat to vision, the effects of the treatment regimen required at this stage, and other concurrent medical or social complications that tax the patient's relationship to the health-care system. Attempts to replicate this finding in other settings would help identify whether these difficulties are specific to this study site or common to most sites and patients.

The second important finding is that the recent loss group did not report significantly more difficulties with adjustment than the stable vision group, when duration of PDR and severity of visual impairment were controlled for. This implies that recent loss alone was not sufficient to increase adjustment scores in this PDR sample. One factor that may mediate the relationship between vision and adjustment is the subjective appraisal of visual loss and its meaning in the course of PDR. If recent loss does affect adjustment, the effect may only show in a small sample if analyses control for subjective appraisal of the loss. A larger sample followed over time with attention to subjective appraisal of loss is necessary to evaluate the relative importance of visual loss as a variable that may affect adjustment. Other factors that may mediate the relationship between vision and adjustment include laser treatments of retinopathy; the patient's beliefs about health, diabetes, and PDR; and physical health status.

Finally, the significant negative correlation between best visual acuity and adjustment says that in this sample poorer vision is associated with more reported difficulties in adjustment to PDR. Although this finding is consistent with expectations, we know of no reports, other than one (22), linking adjustment and visual acuity in the mild to moderate range of visual impairment. Because it has not been clear at what level of visual impairment psychosocial functioning begins to be adversely affected, our correlation in this sample argues that relatively mild visual impairment may have significant psychosocial impact. Prospective studies of larger numbers of subjects at risk for progressive visual impairment of various etiologies are essential for developing early interventions aimed at minimizing the psychosocial costs of progressive visual impairment.

In a related study (22), we assessed on three occasions in 8 mo a total of 30 adults with PDR and found that visual acuity strongly and significantly correlated with three independent measures of psychosocial functioning: adjustment, psychological symptoms, and coping efforts. The strength of the relationships between visual acuity and each of the three psychosocial measures increased over time. These data suggest that the correlation reported in this study reflects a clinically meaningful relationship between visual acuity and adjustment that endures as PDR progresses.

Acknowledgments— This work was supported in part by National Institute of Mental Health Grant T32 MH-16259, Juvenile Diabetes Foundation Grant 184422, and National Institutes of Health Grant DK-27845.

For help with data collection, our thanks to Peggy Stockman; with data management, thanks to Matt Davis, MD, Rebecca Johnson, MD, Jing Shun Ku, MD, Donna Niemeier, and Susan Saker, MD; with data analysis, thanks to John Barth, Goldine Gleser, PhD, James Henry, Tony Leonard, and Joel Senter, PhD.

Portions of this data were published as an abstract in *Diabetes* (Suppl. 1) in 1989.

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