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Psychometric development of the Retinopathy Treatment Satisfaction Questionnaire (RetTSQ)

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Objectives were to evaluate the psychometric properties and to determine optimal scoring of the RetTSQ in a cross-sectional study of 207 German patients with diabetic retinopathy and a wide range of treatment experience. Forty patients (19%) also had clinically significant macular oedema.
Principal components analysis was used to identify factor structures and Cronbach's alpha to assess internal consistency reliabilities. Two highly reliable subscales represented negative versus positive aspects of treatment (both α=0.84). A highly reliable total score can be calculated (α=0.90). Construct validity was examined by testing expected relationships of RetTSQ scores with visual impairment, stage of diabetic retinopathy, additional impact of macular oedema, SF-12 scores and scores of the RetDQoL measure of quality of life in diabetic retinopathy. Worse impairment, worse diabetic retinopathy and macular oedema were associated with less treatment satisfaction. RetTSQ scores correlated moderately with SF-12 scores (r: 0.33-0.53, p<0.001) and RetDQoL scores (r: 0.43-0.51, p<0.001). Answers to an open-ended question indicated no need for additional items. Repeating the analyses in a subsample with experience of more intense treatment showed very similar results.
It can be concluded that the RetTSQ is valid and reliable for people with diabetic retinopathy with or without macular oedema who have experienced different treatments.

Keywords: diabetic retinopathy, macular oedema, treatment satisfaction, patient-reported outcomes, questionnaire development

Introduction

Diabetic retinopathy is one of the leading causes of visual impairment in developed countries (Resnikoff et al., 2004) and the main reason for blindness in the working age population in countries such as Germany (Horle, Gruner & Kroll, 2002). Almost everyone with type 1 diabetes and over 60% of people with type 2 diabetes develop retinopathy (Khaw, Shah & Elkington, 2004). Main risk factors are the duration of diabetes and poorly controlled blood glucose levels, hypertension and hyperlipidemia. The development can be classified into stages; non-proliferative retinopathy is characterised by abnormalities in retinal blood vessels including microaneurysms and haemorrhages. According to the extent of these abnormalities, it can be classified as mild, moderate or severe. If retinopathy advances further, it is classified as proliferative diabetic retinopathy, characterised by the growth of new blood vessels, which are weak and may bleed, causing a sudden

deterioration of vision (figure 1). At any stage, macular oedema can occur, a thickening of the retina that impairs central vision (Fong, Aiello, Ferris & Klein, 2004; Khaw et al., 2004).

[insert figure 1 approximately here]

Currently, the main treatments are laser photocoagulation to destroy abnormal blood vessels or removal of vitreous humour (vitrectomy), accompanied by efforts to improve glycaemic control and blood pressure to reduce the risk of progression of the condition and increase the chance of a small improvement in vision (Khaw et al., 2004; Yam & Kwok, 2007). Possible side effects of laser treatment include pain during treatment, reduced vision or visual field, increased glare and light sensitivity and development of macular oedema. Complications of vitrectomy include haemorrhages and premature cataracts. Newer approaches include intraocular injections to inhibit vascular endothelial growth factors (VEGF) (Yam & Kwok, 2007). In evaluating new treatments, it is important not only to assess their impact on visual function but also to assess patients' satisfaction with the treatments and the impact of diabetic retinopathy and its treatment on their quality of life (QoL) using appropriate measures. Measuring treatment satisfaction shows benefits and shortcomings of new treatments and allows comparison with existing treatments. Treatment satisfaction is linked to adherence (Jordan et al., 2005) and audits can identify areas for improvement, thus assessing satisfaction saves resources. Treatment satisfaction is interrelated with satisfaction with more general aspects of healthcare and individuals' expectations in comparison to their experiences of a particular treatment (Asadi-Lari, Tamburini & Gray, 2004).

The Retinopathy Treatment Satisfaction Questionnaire RetTSQ was designed to measure satisfaction with treatment for diabetic retinopathy (Woodcock et al., 2004; Woodcock et al., 2005) as no measures were available. It is modelled on the widely used Diabetes Treatment Satisfaction Questionnaire (DTSQ) (Bradley & Lewis, 1990; Bradley, 1994) and was designed simultaneously in UK English and German for Germany. Content, wording and format were established in in-depth qualitative interviews with 44 patients attending hospitals in the UK and Germany. All participants

were diagnosed with diabetic retinopathy, 31 also had macular oedema. Methods and findings from these interviews are reported elsewhere (Woodcock et al., 2004; Woodcock et al., 2005).

The objectives of the current analyses were to evaluate the psychometric properties and to determine optimal scoring of the RetTSQ.

Methods

Procedures

The data reported here were collected as part of the multicentre, retrospective 'Cost of Illness Study for Diabetic Microvascular Complications - DIMICO –' in 2002/03. Objectives of the main study phase were to assess the prevalence of stages of diabetic complications and to analyse resource utilisation and total annual cost due to diabetic microvascular complications in Germany. Health status and quality of life were assessed. Participants were over 500 adults with diabetes and retinopathy, neuropathy or nephropathy who gave informed consent. The present paper focuses exclusively on those with diabetic retinopathy (n=207). Demographic information and data on diabetes and microvascular complications were collected from medical records and an interview with the participant conducted by their physician. Participants completed questionnaires during a surgery visit before any treatment or examinations. Physicians were asked to check questionnaires for completeness. The following questionnaire measures were used:

- Health status was measured using the SF-12 (Ware, Kosinski & Keller, 1996). Its 12 items can be summarised into a physical health component score (PCS) and a mental health component score (MCS). Higher scores represent better health.

- Quality of Life was measured using the RetDQoL, an individualised measure of the impact of retinopathy on QoL (Woodcock et al., 2004). Scores include two overview items, one about general present QoL and one about retinopathy-dependent QoL, and the average weighted impact of retinopathy on 26 life-domains. Development of the RetDQoL is reported elsewhere (Brose & Bradley, In Press)

- Treatment satisfaction was measured using the RetTSQ (Woodcock et al., 2005). It consists of 13 items asking respondents to rate different aspects of treatment on a scale from 0 (least favourable option) to 6 (most favourable option). Table 1 shows the wording used in this study and the equivalent UK English version. An additional item asks for any further aspects of treatment causing satisfaction or dissatisfaction. The data analysed here were obtained using the 2001 German for Germany version of the questionnaire; the wording of one item has since changed.

[insert table 1 approximately here]

Analyses

Statistical analyses were conducted using SPSS 14. Principal components analyses with varimax rotation were carried out to identify possible subscales. Internal consistencies were assessed with Cronbach's alpha. Corrected item-total correlations and alpha-if-item-deleted statistics indicated the strength of each item's association with the construct.

Construct validity was assessed by examining expected relationships between questionnaire scores and clinical data, using correlation indices, t-tests and one-way or two-way independent analyses of variance (ANOVA) with post-hoc tests. It was expected that greater visual impairment and advanced stages of retinopathy as well as the additional impact of macular oedema would be associated with less treatment satisfaction. However, the subgroups with macular oedema were very small. When stage of retinopathy differed between the eyes of individual participants or data were only available for one eye (n=19, 9.2%), stage of the better eye or the available data respectively were used for categorisation. Moderate significant correlations with subscales of the SF-12 were expected, as was a positive relationship between treatment satisfaction and quality of life scores as measured by the RetDQoL. No significant relationships with socio-demographic variables were expected, however, these were explored. Item distributions and total scores were skewed; therefore, non-parametric tests were performed to check parametric results. If unequal variances were indicated for an ANOVA, an approximation to a permutation test was performed. Neither result altered the conclusion reached from parametric results, thus they are not reported. As an indication

of content validity, answers to the open-ended question were assessed to see if additional items or modifications were needed.

Results

Sample

Data for 207 participants were available. For socio-demographic and condition-related details see tables 2a and 2b.

[insert tables 2a and 2b approximately here]

Visual acuity in the better eye (decimal notation) ranged from 0.01 to 1.25. Participants were classified in five groups from lowest visual acuity (≤0.2) to good vision (>0.8). A high proportion of participants had little or no loss of visual acuity in their better eye; 34 had visual acuities under 0.33, classifying them as severely impaired or blind using criteria of the World Health Organization (WHO, 2007). Stage of retinopathy was categorised using one or more methods of fundus examination.

Instructions in the RetTSQ allow for inclusion of anyone who has visited a doctor or hospital for their diabetic eye problems within the last 12 months. Analyses were repeated for 103 participants who had experienced more intense treatment in that time (table 3).

[insert table 3 approximately here]

Descriptives

Items were missed by very few participants (table 4). Item 7 ‘apprehensive’ had the lowest (least satisfied) mean of 3.75, while item 12 ‘encourage others’ reached the highest mean of 5.71 (table 4).

[insert table 4 approximately here]

Factor structure

Velicer’s minimum average partial method (Zwick & Velicer, 1986) suggested two factors which explained 56.6% of total variance. Negative experiences loaded on factor 1, with ‘side effects’ loading the highest (0.83), followed by ‘discomfort/pain’ (0.80). Factor 2 represents positive aspects

such as safety and efficacy of the treatment, with 'safety' showing the highest loading (0.77), followed by 'encourage others' (0.75). One item, 'influence' loaded similarly and >0.4 on both factors. When all items were forced on one factor, this factor explained 46.02% of variance and all items loaded >0.55 (table 5). Using data for only the 103 participants with more intense treatment lead to similar results although factor 1 and 2 exchanged places. They explained 58.83% of variance. The only item now ascribed to a different factor was 'influence', which loaded 0.74 on the positive subscale and 0.44 on the negative subscale. A forced one-factor solution explained 45.57% of variance. Factor loadings were similar to those of the larger sample; 'influence' showed the biggest increase (0.76 to 0.84), 'time-consuming' the biggest decrease (0.59 to 0.52). This suggests a total score for treatment satisfaction can be calculated by summing scores for items 1 to 13. With a possible range from 0 to 78, the total score in the complete sample ranged from 23 to 78 with a mean (M) of 61.87 (SD=12.62). With 'influence' included in the positive subscale, this subscale has a possible range from 0 to 42; scores ranged from 12 to 42 (M=35.70; SD=6.22). With a possible range from 0 to 36, scores on the negative subscale ranged from 4 to 36 (M=26.22; SD=7.65).

[insert table 5 approximately here]

Reliability and implications for missing values

Internal consistency reliability for the total scale was high, indicated by α=0.90; and almost as high for the subscales (both α=0.85). When deleting, in turn, the items contributing most strongly, α for the total scale stayed above 0.8 with up to four items omitted. For both subscales α stayed above 0.7 as long as four items were included.

Corrected item-total correlations ranged from 0.45 ('encourage others') to 0.71 ('difficult') for the total score, from 0.49 ('time-consuming') to 0.71 ('side effects') for the negative subscale and from 0.58 ('encourage') to 0.70 ('safety') for the positive subscale, far exceeding the minimum value of 0.2 recommended (Kline, 1993). Figures for the subgroup with more intense treatment were very similar (not shown). Test-retest reliability could not be assessed due to the cross-sectional data.

[Insert figure 2 approximately here]

Construct and content validity

Total score

Groups with different levels of visual acuity showed significant differences in the total score ($F(4,166)=13.39$, $p<0.001$). The group of participants with visual acuities ≤0.2 reported significantly less treatment satisfaction than the two groups with the highest visual acuities. Participants with good visual acuities (>0.8) also reported significantly higher satisfaction than those with visual acuity better than 0.2 but not over 0.6 (figure 3). Differences between other groups did not reach significance.

[insert figure 3 approximately here]

Participants with non-proliferative diabetic retinopathy reported significantly higher treatment satisfaction than those with proliferative retinopathy ($t=2.92$, $p<0.01$). Those with mild non-proliferative retinopathy reported significantly higher treatment satisfaction than all other groups ($F(3,191)=6.47$, $p<0.001$). Differences between other groups were not significant (figure 4). Participants with clinically significant macular oedema reported less treatment satisfaction than those without, regardless of stage of diabetic retinopathy ($F(1,184)=10.35$, $p<0.01$).

[insert figure 4 approximately here]

The group with more intense treatment experience scored significantly lower than the other half of the sample ($t=-2.81$, $p<0.01$).

Correlations between the RetTSQ total score and both subscales of the SF-12 indicated a moderate significant correlation with the physical score and a stronger correlation with the mental score. The total RetTSQ score correlated significantly with moderate to high coefficients with general present QoL, retinopathy-dependent QoL and the average weighted impact on QoL as measured by the RetDQoL (table 6).

[insert table 6 approximately here]

Subscales

For visual impairment, the negative subscale ($F(4,168)=11.90$, $p<0.001$) and the positive subscale ($F(4,173)=9.89$, $p<0.001$) showed differences similar to those of the total score.

Participants with proliferative retinopathy reported significantly less satisfaction with negative aspects than participants with non-proliferative retinopathy ($t=3.57$, $p<0.001$). Differences were not significant on the positive subscale ($t=1.57$, $p=0.06$). Correspondingly, the negative subscale showed significant differences when comparing each of the four stages of retinopathy ($F(3,191)=8.44$, $p<0.001$). People in later stages scored lower on this subscale, with those with mild non-proliferative retinopathy being significantly more satisfied than all other groups. An ANOVA was not significant for the positive subscale ($F(3,195)=2.57$, $p=0.06$). However, post-hoc tests found significantly greater satisfaction with positive aspects in participants with mild non-proliferative retinopathy than in those with proliferative retinopathy ($p<0.05$).

As on the total scale, participants with clinically significant macular oedema showed less treatment satisfaction than those without (negative subscale: $F(1,187)=7.2$; positive subscale: $F(1,191)=9.92$; both $p<0.01$).

Participants with more intense treatment experience scored significantly lower on negative aspects ($t=-3.81$, $p<0.001$); all items except ‘apprehension’ differed significantly. Regarding positive aspects, this group scored significantly lower only on item 1, ‘current satisfaction’.

Correlations of RetTSQ subscales with SF-12 and RetDQoL scores were similar to those of the total score; the positive subscale showed slightly lower correlations with some scores than the total score or the negative subscale (table 6).

Men were significantly more satisfied with negative aspects of treatment than women ($t=2.24$, $p<0.05$).

Additional aspects described

Fifteen participants (7.3%) described further aspects causing satisfaction or dissatisfaction. Four described negative effects of laser treatment such as ”Pupil would no longer close after laser”. Feelings of anxiety related to their condition, apparently triggered by treatments or examinations,

were mentioned by two participants, for example, “Psychologically I can’t cope with the fact I may be blind eventually”. Two participants described problems caused by additional medical conditions such as “Extra caution because of asthma”. Further statements included difficulties with travel to clinics and clinic appointment organisation, the wish for a better communication between medical professionals and the statement “naturopathy”.

Discussion

The questionnaire showed a high completion rate and good psychometric properties. Even though scores were non-normally distributed with some unequal variances across groups, non-parametric tests confirmed all results. Participants tended to be satisfied with their treatment as has been reported for other conditions (Taback & Bradley, 2006; Woodcock & Bradley, 2001). However, treatment for retinopathy elicits apprehension, as patients might fear for their residual sight and some treatment procedures are quite distressing to contemplate. Non-anonymous completion in this study minimised non-completion but may have inhibited reports of dissatisfaction.

Principal components analysis suggested that treatment satisfaction could be regarded as consisting of two constructs, one representing negative experiences and the other representing positive aspects like safety and efficacy of the treatment regimen. This structure was replicated in a subgroup with more intense treatment experience. However, an overlap between the constructs was indicated; the factor structure may also be related to positive versus negative wording of items. Compared to negatively worded items, positively worded items tend to have more extreme response anchors and lower scores. Lower scores most likely reflect a genuine difference; this is supported by the very similar means for the items ‘difficult’ with its bidirectional response scale and ‘unpleasant’ with its unidirectional response scale. The effects on scores need monitoring.

Results also justify calculating a single scale score with very high internal consistency reliability. Total score and subscales are robust against missed items and the individual items represent the underlying construct well. Longitudinal data are needed to assess test-retest reliability.

The measure's sensitivity to different stages of disease progression and visual impairment indicates good construct validity. As expected, the greater the impairment or the more advanced the condition, the greater the dissatisfaction with treatment. The measure is also sensitive to the additional impairment caused by macular oedema although these results should be treated with caution due to the small subgroups. It is understandable that patients are less satisfied with a treatment if they are worse affected by retinopathy, a disease that currently cannot be cured and treatment mainly prevents further deterioration. Although recent developments of Anti-VEGF treatments have been shown to bring about improvement in vision in more patients (Yam & Kwok, 2007), data collection predated their availability.

It appears that negative experiences are more strongly linked to stage of the disease than positive aspects. This is not surprising as, with progressing retinopathy, treatment procedures become more invasive with more side effects and discomfort. A sex difference in satisfaction with negative aspects was unexpected but may be linked to previously reported sex differences in negative but not positive well-being (Bradley & Lewis, 1990).

The correlations with the SF-12 indicate that the two instruments share some similarities but do not measure the same phenomenon. By focusing on a particular condition and on treatment satisfaction, the RetTSQ is more specific than the generic health status measure. Relationships between scores of the RetTSQ and the RetDQoL support the validity of the measures. The correlations show a relationship between greater negative impact on QoL and reduced treatment satisfaction but also indicate that the instruments measure different aspects of the experience of diabetic retinopathy.

Answers to the open-ended question do not warrant inclusion of further items. Unwanted after effects of laser treatments are expected to be covered by item 3 (side effects). Additional medical conditions causing problems are not within the scope of the RetTSQ. Feelings of anxiety prior to treatment are expected to be covered by item 7 (apprehensive). The anxieties elicited by the open question seemed to relate to effects of the disease itself. An item concerning such anxieties

would seem inappropriate in a measure of treatment satisfaction. Further statements were only mentioned once or were not clear to understand. Items in the RetTSQ concur with findings in interviews with patients having laser treatment for retinopathy (Scanlon et al., 2005). The most frequently mentioned aspects are all reflected in RetTSQ items.

In future studies it will be interesting to compare treatment satisfaction between differently treated subgroups and investigate experiences and preferences of, for example, laser treatment and anti-VEGF-injections, which will also provide data from samples with more intense treatment experience than the present sample. When linguistically validated versions in other languages are used, the psychometric properties of the RetTSQ will need to be examined for each version. The RetTSQ and the MacTSQ measure of satisfaction with treatment for macular disease (Mitchell, Brose & Bradley, 2007) have underpinned the design of a more general Eye Treatment Satisfaction Questionnaire EyeTSQ (Brose, Plowright, Mitchell & Bradley, 2008).

Conclusion

The RetTSQ is a valid and reliable measure of treatment satisfaction for people with diabetic retinopathy with or without macular oedema with a range of treatment experiences. It is likely to be useful for evaluating experiences of new and existing treatments for diabetic retinopathy.

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Access to questionnaires
The RetTSQ and RetDQoL are available from the copyright holder, Clare Bradley, via www.healthpsychologyresearch.com, which provides information about language versions available, guidelines and access to questionnaires.

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Figure 1. A scene as viewed with diabetic retinopathy and with normal (good) vision. (Courtesy: National Eye Institute, National Institutes of Health).

Subscale positive aspects	Subscale negative aspects
Sum of the following 7 items: Item 1 'current satisfaction' Item 2 'treatment working well' Item 8 'influence' Item 9 'safety' Item 11 'information' Item 12 'encourage others' Item 13 'continue/repeat' Possible range 0 - 42	Sum of the following 6 items: Item 3 'side effects' Item 4 'pain/discomfort' Item 5 'unpleasant' Item 6 'difficult' Item 7 'apprehensive' Item 10 'time-consuming' Possible range 0 - 36
Total score Sum of both subscales or items 1 -13 Possible range 0 – 78	

Figure 2. Scoring instructions for the Retinopathy Treatment Satisfaction Questionnaire RetTSQ

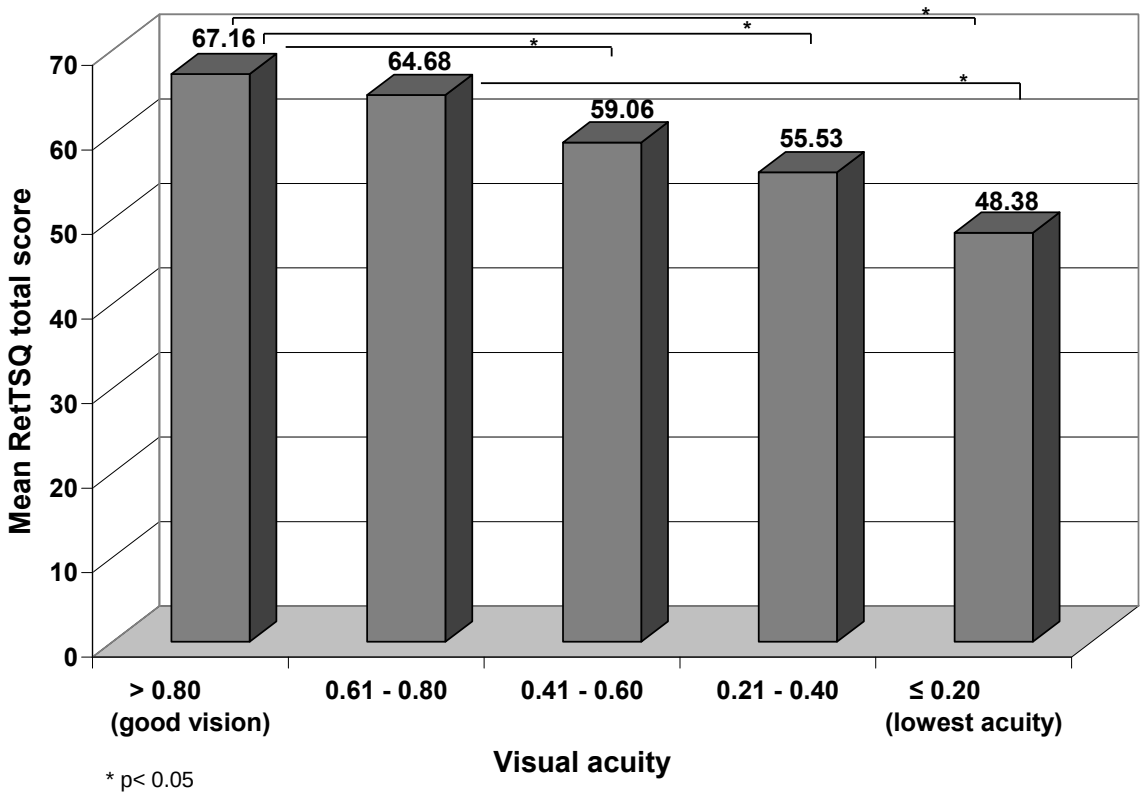

Figure 3. Treatment satisfaction in groups with different levels of visual impairment. Decimal notation, higher values indicate better visual acuity.

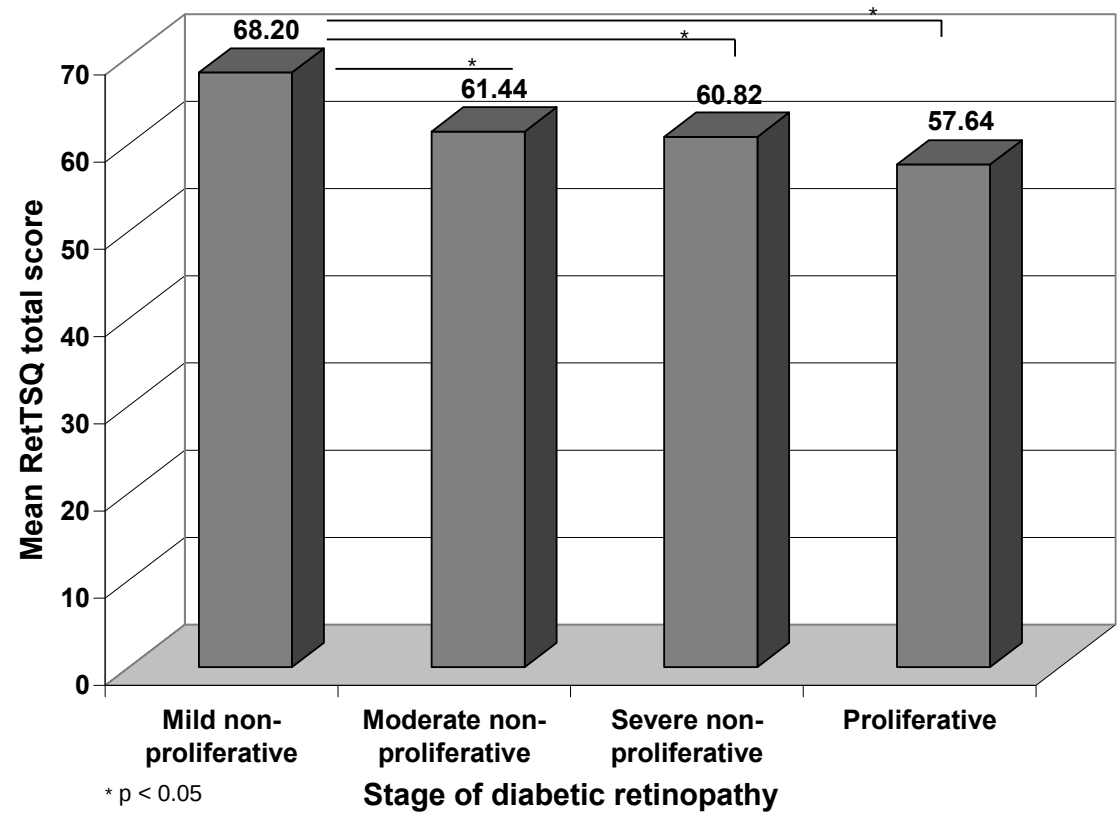

Figure 4: Treatment satisfaction in different stages of diabetic retinopathy.

Table 1. Wording of RetTSQ items 1 – 13 and response options. RetTSQs © Prof Clare Bradley 29.11.01

Item		Item wording	Response options
1	UK[A]	How satisfied are you with the treatment for your diabetic eye problems?	very satisfied - very dissatisfied
	DE	Wie zufrieden sind Sie mit der Behandlung Ihrer diabetischen Augenprobleme?	sehr zufrieden - sehr unzufrieden
2	UK	How well do you feel the treatment for your diabetic eye problems is working?	very well - very badly
	DE	Wie gut verläuft Ihrem Eindruck nach die Behandlung Ihrer diabetischen Augenprobleme?	sehr gut - sehr schlecht
3	UK	How bothered are you by any side effects or after effects of the treatment for your diabetic eye problems?	not at all bothered – very bothered
	DE	Wie belastet sind Sie durch Nebenwirkungen oder Nachwirkungen der Behandlung Ihrer diabetischen Augenprobleme?	gar nicht belastet - sehr belastet
4	UK	How bothered are you by any discomfort or pain from the treatment for your diabetic eye problems?	not at all bothered – very bothered
	DE	Wie belastet sind Sie durch Beschwerden oder Schmerzen wegen der Behandlung Ihrer diabetischen Augenprobleme?	gar nicht belastet - sehr belastet
5	UK	How unpleasant do you find the treatment for your diabetic eye problems?	not at all unpleasant - very unpleasant

	DE	Wie unangenehm finden Sie die Behandlung Ihrer diabetischen Augenprobleme?	gar nicht unangenehm - sehr unangenehm
6	UK	How difficult for you is the treatment for your diabetic eye problems?	very easy - very difficult
	DE	Wie schwierig ist für Sie selbst die Behandlung Ihrer diabetischen Augenprobleme?	sehr leicht - sehr schwierig
7	UK	How apprehensive do you feel about the treatment for your diabetic eye problems?	not at all apprehensive - very apprehensive
	DE	Wie beunruhigt fühlen Sie sich wegen der Behandlung Ihrer diabetischen Augenprobleme?	gar nicht beunruhigt - sehr beunruhigt
8	UK	How satisfied are you with the influence you have over the treatment for your diabetic eye problems?	very satisfied - very dissatisfied
	DE	Wie zufrieden sind Sie mit dem Einfluss, den Sie selbst auf die Behandlung Ihrer diabetischen Augenprobleme haben?	sehr zufrieden - sehr unzufrieden
9	UK	How satisfied are you with the safety of the treatment for your diabetic eye problems?	very satisfied - very dissatisfied
	DE	Wie zufrieden sind Sie mit der Sicherheit der Behandlung Ihrer diabetischen Augenprobleme?	sehr zufrieden - sehr unzufrieden
10 [B]	UK	How time-consuming do you find the treatment for your diabetic eye problems?	not at all time-consuming - very time-consuming
	DE	Wie zeitaufwendig finden Sie die Behandlung Ihrer diabetischen Augenprobleme?	gar nicht zeitaufwendig - sehr zeitaufwendig
11	UK	How satisfied are you with the information	very satisfied - very

		provided about the treatment for your diabetic eye problems?	dissatisfied
	DE	Wie zufrieden sind Sie mit den Informationen, die Ihnen über die Behandlung Ihrer diabetischen Augenprobleme gegeben wurden?	sehr zufrieden - sehr unzufrieden
12	UK	Would you encourage someone else with diabetic eye problems like yours to have your kind of treatment?	yes, I would definitely encourage them - no, I would definitely not encourage them
	DE	Würden Sie jemand anders mit ähnlichen diabetischen Augenproblemen ermutigen, sich auch so behandeln zu lassen?	ja, ich würde ihn oder sie unbedingt ermutigen - nein, ich würde ihn oder sie keinesfalls ermutigen
13	UK	How satisfied would you be to continue or repeat the treatment for your diabetic eye problems?	very satisfied - very dissatisfied
	DE	Wie zufrieden würden Sie damit sein, die Behandlung Ihrer diabetischen Augenprobleme fortzusetzen oder zu wiederholen?	sehr zufrieden - sehr unzufrieden

A. UK: UK English; DE: German for Germany.
B. The wording of this item has been changed in the latest version (December 2006) of the RetTSQ.

Table 2a. Sample characteristics. A total <100% indicates missing data.

		Frequency	Percent
Sex	Women	104	50.2
	Men	103	49.8
	Total	207	100.0
Marital status	Single	18	8.7
	Married / Partnered	148	71.5
	Divorced	16	7.7
	Widowed	23	11.1
	Total	205	99.0
Living situation	Alone	36	17.4
	With partner / Family	144	69.6
	Other (Care home)	1	0.5
	Total	181	87.4
Employment status	Employed	50	24.2
	Not employed [A]	157	75.8
	Total	207	100.0
Visual acuity [B]	≤0.2 (low acuity)	24	11.6
	0.21 to 0.40	15	7.2
	0.41 to 0.60	35	16.9
	0.61 to 0.80	46	22.2
	>0.8 (good vision)	65	31.4
	Total	185	89.4
Age	Mean=60.94. Range 18 – 92 years		

A. 121 were retired; 26 of those had retired early, for 18 of them diabetes or its complications was a reason for early retirement.

B. Decimal notation, higher values indicate better visual acuity. A visual acuity of 1.0 is regarded as normal (i.e. good) vision, visual acuity of 0.3 and worse but better than 0.05 is regarded as low vision, visual acuity of 0.05 and worse as blindness (World Health Organization, 2007).

Table 2b. Sample characteristics, stage of diabetic retinopathy (better eye if different in both eyes) and presence of clinically significant macular oedema per group.

Diabetic retinopathy	Frequency (%)	Sign. macular oedema Frequency
Mild non-proliferative	46 (22.2)	1
Moderate non-proliferative	56 (27.1)	8
Severe non-proliferative	50 (24.2)	9
Proliferative	55 (26.6)	22
Total	207 (100.0)	40 (19.3%)

Table 3. Experience of more intense treatment procedures due to diabetic retinopathy during the past year. Multiple answers possible

Treatment	Frequency	Percent
Panretinal laser coagulation	51	24.6
Focal laser coagulation	33	15.9
Medication related to diabetic retinopathy	43	20.8
Fluorescein angiography [A]	38	18.4
Implant/steroid injection	1	0.5
Total N intense treatment	103	49.8

A. Included based on reports from patients that experiencing this procedure can be very unpleasant and worse than the actual treatment (Mitchell, Brose & Bradley, 2007).

Table 4. Descriptives for RetTSQ items (maximum n possible: 207)

		Response option endorsed by number (percentage) of respondents							
Item (item number)	N	0	1	2	3	4	5	6	Mean (SD)
Current satisfaction (1)	206	3 (1.5)	4 (1.9)	2 (1.0)	9 (4.4)	18 (8.7)	49 (23.8)	121 (58.7)	5.23 (1.25)
Treatment working well (2)	206	1 (0.5)	3 (1.5)	6 (2.9)	9 (4.4.)	24 (11.7)	70 (34.0)	93 (45.1)	5.08 (1.17)
Side effects (3)	200	8 (4.0)	11 (5.5)	17 (8.5)	24 (12.0)	26 (13.0)	28 (19.0)	76 (38.0)	4.34 (1.79)
Discomfort/pain (4)	200	5 (2.5)	4 (2.0)	12 (6.0)	24 (12.0)	20 (10.0)	37 (18.5)	98 (49.0)	4.77 (1.59)
Unpleasant (5)	204	6 (2.9)	6 (2.9)	16 (7.8)	27 (13.2)	25 (12.3)	34 (16.7)	90 (44.1)	4.55 (1.68)
Difficult (6)	203	2 (1.0)	5 (2.5)	11 (5.4)	27 (13.3)	44 (21.7)	43 (21.2)	71 (35.0)	4.56 (1.43)
Apprehensive (7)	203	15 (7.4)	19 (9.4)	23 (11.3)	29 (14.3)	30 (14.8)	33 (16.3)	54 (26.6)	3.75 (1.95)
Influence (8)	203	9 (4.4)	13 (6.4)	14 (6.9)	19 (9.4)	34 (16.7)	58 (28.6)	56 (27.6)	4.24 (1.73)
Safety (9)	203	4 (2.0)	1 (0.5)	6 (3.0)	14 (6.9)	34 (16.7)	59 (29.1)	85 (41.9)	4.91 (1.30)
Time-consuming (10)	205	6 (2.9)	11 (5.4)	15 (7.3)	24 (11.7)	34 (16.6)	45 (22.0)	70 (34.1)	4.36 (1.68)
Information (11)	205	-	2 (1.0)	2 (1.0)	15 (7.3)	9 (4.4)	65 (31.7)	112 (54.6)	5.29 (1.02)
Encourage others (12)	203	1 (0.5)	-	1 (0.5)	6 (3.0)	3 (1.5)	25 (12.3)	167 (82.3)	5.71 (0.79)
Continue/repeat (13)	201	1 (0.5)	-	3 (1.5)	13 (6.5)	16 (8.0)	55 (27.4)	113 (56.2)	5.28 (1.04)

Any other features (14)	196	n/a (not applicable)	n/a	n/a	n/a	n/a	n/a	n/a	n/a

Table 5: RetTSQ component matrices, complete sample (N=206). Items ordered by loadings on subscales, presenting those loading on subscale 1 before those loading on subscale 2.

	Two-factor solution [a]		Forced one-factor solution [b]
	Component		
Item (item number)	1	2	Component 1
Side effects (3)	0.828		0.713
Discomfort/pain (4)	0.802		0.707
Unpleasant (5)	0.735		0.618
Difficult (6)	0.701		0.759
Apprehensive (7)	0.672		0.641
Influence (8)	0.518	0.517	0.759
Time-consuming (10)	0.467		0.588
Safety (9)		0.770	0.758
Encourage others (12)		0.753	0.545
Information (11)		0.709	0.598
Continue/repeat (13)		0.706	0.693
Treatment working well (2)		0.657	0.683
Current satisfaction (1)		0.646	0.711

a. Two-factor solution: rotated component matrix. Extraction method: principal component analysis. Rotation method: Varimax with Kaiser normalization. Rotation converged in 3 iterations.
b. Forced one-factor solution: extraction method: principal component analysis.

Table 6. Correlations with SF-12 and RetDQoL (retinopathy-dependent quality of life) scores. Spearman's rho presented alongside Pearson's r because data not normally distributed.

	RetTSQ total score		RetTSQ negative subscale		RetTSQ positive subscale	
	r	rho	r	rho	r	rho
SF-12 PCS	0.38***	0.36***	0.31***	0.31***	0.35***	0.33**
SF-12 MCS	0.52***	0.51***	0.53***	0.51***	0.38***	0.37**
RetDQoL present QoL	0.51***	0.45***	0.43***	0.39***	0.46***	0.41**
RetDQoL retinopathy-specific QoL	0.43***	0.46***	0.45***	0.45***	0.32***	0.33**
RetDQoL AWI	0.46***	0.53***	0.49***	0.54***	0.30***	0.33**

** p<0.01; *** p<0.001
PCS – physical component score
MCS – mental component score
AWI – average weighted impact on 26 domains of life