JRRD
Journal of Rehabilitation Research & Development

Journal of Rehabilitation Research and
Development Vol. 36 No. 4, October 1999

Characteristics of AMD patients with low vision receiving visual rehabilitation

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This material is based upon work supported by a NIH/NEI Shannon Award and a VA Rehabilitation Research & Development Service Award.
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Abstract —

The purpose of this retrospective study done on 255 AMD patients evaluated at a low vision rehabilitation service was: 1) to describe the visual function characteristics (VFCs) of AMD patients presenting to visual rehabilitation, 2) to document changes in these VFCs between initial and follow-up rehabilitation visits, and 3) to investigate the relationship of the VFCs found at rehabilitation intake to the length of time between initial diagnosis and initial rehabilitation visit. Standard clinical testing (visual acuity and contrast sensitivity) as well as Scanning Laser Ophthalmoscope (SLO) visual function testing were performed to determine visual function including: 1) macular perimetry for scotoma boundary mapping and 2) PRL (preferred retinal locus) location and abilities in fixation, saccadic, and pursuit eye movements. The difference

between the first and second visit VFCs were compared to the length of time between visits for 44 of the 255 patients returning for a second visit 0.5 to 4.5 years later. Finally, the initial date of AMD diagnosis was found for 51 of the 255 patients to analyze VFCs as a function of the time duration between diagnosis and the intake to the rehabilitation. Most VFCs had a wide range of results at initial intake to rehabilitation while all patients had significant visual impairment by 24 months after initial diagnosis. The majority of low vision patients with AMD have bilateral central scotomas with the corresponding visual function and ADL problems that can often be overcome with visual rehabilitation.

Key words: age-related macular degeneration (AMD), preferred retinal locus, scotomas, visual fields, visual rehabilitation.

INTRODUCTION

Age-related Macular Degeneration (AMD) ranks as the major cause of visual impairment in Western society in people over 50 years of age (1). Several studies have identified visual impairments related to AMD with regard to the early diagnosis of the disease. Visual acuity is impaired by the development of AMD by: 1) serous and hemorrhagic detachment of the retina and retinal pigment epithelium, choroidal neovascularization (occurring in 90 percent of patients with severe visual impairment or legal blindness) and 2) progressive geographic atrophy of the retinal pigment epithelium that occurs in 10 percent of patients with severe visual impairment or legal blindness (2). Exudative or wet AMD (the first cause described in the previous sentence) produces a sudden, dramatic decrease in central visual function while atrophic or dry AMD (second cause from the previous sentence) produces a gradual, slow decrease in central visual function (3). Electroretinograms and static perimetry results suggest that retinal function abnormalities in AMD are confined to the central retina, and the small age-related peripheral changes do not correlate with the progression of AMD (4). However, these studies did not report on the visual function characteristics (VFCs) and rehabilitative characteristics of people with AMD who need visual rehabilitation.

Scotomas are retinal areas with reduced light sensitivity compared to sensitivity results of normally sighted subjects. Scotomas are specified by the retinal location in that central scotomas are retinal areas with reduced light sensitivity involving the fovea, while paracentral scotomas are retinal areas with reduced light sensitivity within the central 20° of the visual field but not involving the fovea. Scotomas are further defined by the light intensity that was used to map out their extent. For example, dense scotomas (sometimes labeled absolute scotomas) are retinal areas that are insensitive to very bright objects, whereas relative scotomas are retinal areas that are insensitive to a light level relatively less than the very bright object. The standard for assessing the central visual field in patients with AMD is the Amsler grid and Humphrey Visual Field Analyzer. Recent results have indicated that macular perimetry with the SLO is more sensitive at detecting small localized scotomas than these standard clinical perimetry equipment (5,6). Therefore, small macular scotomas have been missed in these earlier studies.

The visual system of a patient with a central scotoma chooses (unconsciously) a preferred eccentric retinal area to perform the visual tasks that the non-functioning fovea used to perform. This patient must use an eccentric retinal area for visual tasks because the foveal area can no longer perform visual tasks like fixation, reading, or tracking. The visual system may or may not still process eye movements with regard to the nonfunctioning fovea, but the fovea can no longer perform visual tasks. To measure the location and extent of these eccentric retinal areas, the concept of a preferred retinal locus (PRL) has been developed. The concept of a retinal locus is common in low vision research, but in normally sighted persons it is seldom used. For example, the term PRL has typically been reserved for patients who have chosen a preferred eccentric retinal area for visual tasks due to a central scotoma. However, patients with paracentral sensory deficits or even normally sighted patients do "choose" to use the fovea over other retinal areas, and thus the fovea can be referred to as their PRL. For patients with a central scotoma, visual tasks are performed by aiming the eye such that the image of the visual target of regard is placed within the PRL. The reports have indicated considerable variability as to the retinal location of these PRLs. Most studies have reported that the PRL is retinally above the central scotoma (causing the central scotoma to be above the visual target, e.g., the fixation target, in the visual field) with some reporting PRLs to the right, left, or below a central scotoma (7-10).

The purpose of this study is to determine the VFCs (especially the presence, nature, and extent of macular scotomas as well as the characteristics and abilities of the PRLs) in patients with AMD and with sufficient visual impairment for referral to a low vision rehabilitation service. In addition, the change in VFCs is found for patients with AMD who return for follow-up rehabilitation visits. Finally, for those patients who had well defined starting dates of the AMD, the time between the initial diagnosis and the initial rehabilitation evaluation was compared to the VFCs at the time of the initial rehabilitation evaluation.

METHODS

Subjects

This is a retrospective study performed with 255 patients diagnosed with AMD, either exudative or atrophic, who had visual function/performance testing as part of a low vision rehabilitation evaluation. Inclusion was based on those patients who had been tested using the confocal SLO. Patients with best corrected visual acuity that could not be measured by the ETDRS chart at 1 m, poorer than 20/2000 in both eyes, were excluded from the study. Patients were also excluded from the study if visual function test results were considered unreliable, most commonly from poor fixation stability due to undeveloped PRLs in either eye.

Equipment

Retinal visual function was evaluated with the SLO (Model 101, Rodenstock USA, Inc., Danbury, CT). The SLO with graphics capabilities allows the investigator to determine the retinal location of visual stimuli directly on the retinal image in real time. The confocal imaging selectively chooses between direct and scattered components of the laser light to give high contrast and clear retinal images without dilatation of the pupil. This SLO obtains retinal images

continuously with a nearly invisible infrared laser (780 nm) and scans graphics on the retina with a modulated visible red-light laser (632 nm). The stimuli are thus observed by the subject and are seen directly on the subject's retina by the investigator. The retinal illuminance of the stimuli is adjustable by 256 steps within the range of the visible light laser, about 50 to 50,000 Trolands. The SLO provides a 32 × 22° image of the retina with a minimum resolution of about 3.5 minutes of arc (17.5 μm) for measurement of the retinal areas and the positioning of targets.

Procedures

Visual acuity was measured with the ETDRS chart at the appropriate distance (2 m or as close as 0.5 m so that the top line of the chart was read) with a letter-by-letter scoring method (11). Contrast sensitivity was measured at 1 m with the Pelli-Robson Chart, also with a letter-by-letter scoring method (12). Other patient characteristics were gathered from the intake interview as part of the rehabilitation service or from the patient's medical records. These characteristics included rehabilitation goals expressed by the patients, verifying successful rehabilitation outcome, ocular disease diagnosis including no previous macular disease, and, for 51 patients, the specific starting date of the AMD, secondary diagnosis to confirm macular loss strictly due to AMD, and current occupational status.

SLO testing consisted of macular perimetry and PRL testing. Macular perimetry was used to determine the presence and characteristics of dense macular scotomas by using a hybrid perimetry technique with the SLO (13). Briefly, the hybrid perimetry technique combines elements of kinetic and static methods. The stimulus is presented in stationary flashes, as in static perimetry, but successive flashes are moved randomly on the retina to map isopters, as in kinetic perimetry. Dense macular scotomas were defined as the retinal points where the subject no longer had appreciation for the target with retinal illuminance levels of the red-light laser at about 50,000 Trolands. The perimetry target was a square subtending 12 minutes of arc for both retinal illuminances. Dense scotomas were classified according to their presence, number, size, and location within a quadrant. For example, scotomas located within the fovea were classified as central scotomas whereas scotomas located away from the fovea were classified as paracentral scotomas.

PRL abilities and characteristics were based on the patient's ability for pursuit movement, saccade movement, fixation stability, and the size of their fixation area measured in degrees; these are briefly described here but more completely in a previous paper (10). Pursuit was scored by observing a subject's ability to follow a horizontal and then vertical moving target. Fixation stability was determined by measuring the size of the retinal area used for fixation while the subject was instructed to "hold their eye as still as possible on the fixation target" for about 30 s. Saccade ability was scored by observing a subject's ability to make fast eye movements between two spatially separated targets, first separated horizontally 8° apart and then vertically 8° apart. PRL ability was rated for each of these basic eye movements (fixation, saccade, and pursuit) on a scale from 0 (no ability to see the target or perform the eye movement task) to 4 (normal ability to perform the eye movement task) as described in **Table 1.**

Table 1.

Preferred retinal locus (PRL) scoring system.

Fixation Stability Score: "F #/4"

F4/4: Steady consistent fixation in a small discreet area; PRL fixation area less or equal to 600 microns (2°) in diameter; "normal" eye pattern

F3/4: Consistent fixation in a larger discreet area; PRL fixation area greater than 600 microns (2°) in diameter

F2/4: Demonstrates a PRL for fixation but is not stable within the area; wandering fixation eye movements

F1/4: Can appreciate fixation target but no pattern of fixation can be noted; no pattern to fixation efforts or attempts fixation within scotomas; no established PRL

F0/4: No appreciation of steady fixation target

Pursuit Movement Score: "P #/4"

P4/4: Maintains fast moving target within PRL for pursuit; moving target speed greater than 5°/sec; "normal" eye pattern

P3/4: Maintains slow moving target within PRL for pursuit; moving target speed less than 5°/sec; loses fast-moving target

P2/4: Movement of eye in same direction as movement of target but cannot maintain target within PRL; loses fast- and slow-moving targets

P1/4: Can appreciate moving target but cannot move eye in direction of target movement; no established PRL

P0/4: No appreciation of moving target

Saccadic Movement Score: "S #/4"

S4/4: Consistently moves PRL to presented target; consistently fixates targets that are jumping once per second; "normal" eye pattern

S2/4: Inconsistent ability to move PRL to targets that are jumping once per second; may make more than one saccadic eye movement to target

S0/4: No ability to move PRL to the jumping target

From the 255 patients, 44 returned for a second evaluation 6 mo or later. An analysis of the short-term progression of the visual impairments was performed. In addition, definite knowledge of the initial date of AMD diagnosis was found in the medical charts for 51 of the 255 patients, which charts also confirmed normal macular function before the onset of AMD. These 51 patients gave an analysis of the visual function related to the progression of the AMD (time duration between diagnosis and the visual function testing done at intake to the rehabilitation service).

RESULTS

Of the 255 patients, 52 percent were diagnosed with dry (atrophic) versus 48 percent with wet (exudative) AMD. The patients were referred for visual rehabilitation ranging from as soon as they were diagnosed to 274 months (22.8 years) after their initial diagnosis. The most common secondary diagnosis was glaucoma (9 percent), cataract (4 percent), pseudophakia (3 percent), and retinal detachment (1 percent) not associated with central scotomas (retinal detachments in patients of this study were found after the diagnosis of AMD). The most common rehabilitation goals were (in descending order): managing finances (46 percent), reading (27 percent), writing (20 percent), improving contrast and lighting (8 percent), cooking (6 percent), safety (6 percent), driving (5 percent), and face recognition (3 percent). Most (83 percent) were retired or not working at the intake of visual rehabilitation. There was no significant difference in the VFCs (acuity or contrast sensitivity), scotoma characteristics (width or area), or PRL ability characteristics (fixation, saccade, and pursuit) for the groups of patients by rehabilitation goal or by occupational status (retired or working). All patients finished a rehabilitation intervention program that included optical devices, eccentric viewing training, and specialized training depending on the individual rehabilitation goals. The training was performed at the rehabilitation service and in most cases also at the patient's home.

An example of the SLO macular perimetry map of the dense scotomas and PRLs is shown in **Figure 1.**

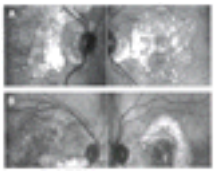

Figure 1. *A SLO map of the dense macular scotomas (labeled ds with solid lines indicating borders) and PRLs location (indicated by the shaded circle) for: A) 87-year-old with dry (atrophic) AMD and visual acuities of 20/101 OD and 20/116 OS. Chief complaints in activities of daily living are reading, writing, shopping, and finances. B) 76-year-old with wet (exudative) AMD visual acuities of 20/333 OD and 20/440 OS. Chief complaints in activities of daily living are reading, O & M, finances, writing, and cooking. The size of the circle indicates the size of the PRL for fixation stability.*

The maximum width and height as well as the areas of each dense scotoma were measured. **Table 2** shows the general characteristics found from the SLO macular perimetry testing and the other clinical testing in the 255 patients with AMD. **Table 3** gives the results of the SLO PRL ability testing in terms of fixation, saccade, and pursuit. A statistical analysis (t-Test analysis of the means) determined no significant difference ($p > 0.05$ for all comparisons) between the dry (atrophic) and the wet (exudative) results of VFCs, PRL ability, and scotoma characteristics.

Table 2.

General characteristics from SLO macular perimetry and other testing.

	Atrophic (Dry)	Exudative (Wet)	All AMD
Age: minimum-maximum (median) years	54-95 (81)	60-96 (79)	54-96 (81)
Gender: Male/Female	27%/73%	36%/64%	31%/69%
Vocation: Retired/Work	82%/18%	84%/16%	83%/17%
Bilateral PRL Location: Bilateral Fovea/ Bilateral Eccentric/Foveal-Eccentric	14%/58%/28%	9%/71%/20%	12%/62%/26%
Bilateral Central Scotoma Frequency:	89%	93%	92%
Time between Dx & Rehabilitation: minimum-maximum (median) months	1-131 (50)	0-274 (20)	0-274 (50)
Scotoma Width: minimum-maximum (median) degrees	1.4-28.8 (19.8)	4.4-28.8 (23.8)	1.4-28.8 (21.8)
Scotoma Height: minimum-maximum (median) degrees	2.0-18.8 (16.6)	4.4-18.8 (18.2)	2.0-18.8 (17.6)
Scotoma Area: minimum-maximum (median) degrees squared	2-541 (211)	13-541 (299)	2-541 (262)
Worse (OD/OS) Acuity: minimum-maximum (median) LogMAR and Snellen Equivalent	0.40-2.00 (1.26) 20/50-20/2000 (20/3600)	0.10-2.00 (1.48) 20/25-20/2000 (20/600)	0.10-2.00 (1.39) 20/25-20/2000 (20/490)
Worse (OD/OS) Contrast Sensitivity: minimum-maximum (median) LogContrast	0.10-1.15 (0.35)	0.00-0.90 (0.25)	0.00-1.15 (0.50)
Best Fixation Stability: minimum-maximum (median) degrees	1.0-8.0 (2.0)	1.0-6.5 (3.5)	1.0-8.0 (3.0)

Table 3.

SLO PRL ability testing in terms of fixation, saccade, and pursuit.

	Rating	Atrophic (Dry)	Exudative (Wet)	Total
Best (OD/OS) PRL for Fixation Ability	4	50%	26%	35%
	3	31%	40%	41%
	2	13%	29%	19%
	1	4%	4%	4%
	0	2%	1%	1%
Best (OD/OS) PRL for Saccade Ability	4	25%	17%	21%
	3	3%	3%	5%
	2	56%	66%	59%
	1	0%	1%	1%
	0	16%	13%	14%
Best (OD/OS) PRL for Pursuit Ability	4	13%	11%	12%
	3	66%	46%	55%
	2	15%	39%	27%
	1	6%	4%	6%
	0	0%	0%	0%

A graph of the visual acuity results from each eye (see **Figure 2**) demonstrates that although some people with AMD can have similar visual acuity between the two eyes (values along the diagonal line), in general there is no relationship of the visual acuity or contrast sensitivity between the two eyes.

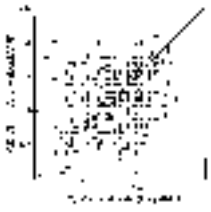

Figure 2. *Right eye (OD) versus left eye (OS) visual acuity results in LogMAR for all patients with AMD. The diagonal line indicates where equal visual acuity values were found between the two eyes.*

Similar relationships were found in the dense scotoma characteristics as well (maximum width and area are shown in **Figures 3** and **4,** respectively).

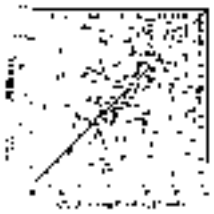

Figure 3. *Right eye (OD) versus left eye (OS) scotoma widths results in degrees for all patients with AMD. These values were found where the scotoma had the maximum width. The diagonal line indicates where equal values of scotoma width were found between the two eyes.*

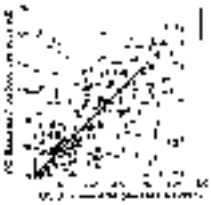

Figure 4. *Right eye (OD) versus left eye (OS) scotoma area results in degrees squared for all patients with AMD. The diagonal line indicates where equal values of scotoma areas were found between the two eyes.*

Finally, although some are tempted to think that the size of the scotoma has a relationship to the visual acuity found at the eccentric PRL, **Figure 5** shows that there is no relationship between these two measurements.

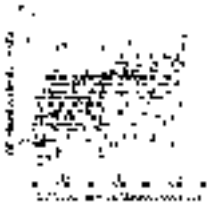

Figure 5. *The values found for the visual acuity (in LogMAR) are shown as a function of the scotoma area (in degrees squared) for the right eye (OD) of each patient with AMD.*

The visual function results, visual acuity shown in **Figure 6A** and scotoma area in **Figure 6B,** from the 51 patients where the initial date of diagnosis of AMD could reliably be determined indicate two trends. First, as previous studies have stated, as the disease progresses, visual function generally declines and scotomas get bigger. Secondly, those patients that were tested within weeks of their initial diagnosis show that visual function can be mildly to severely impaired at the time of initial diagnosis and scotomas can be small (4 to 5° in width) to 28° in width and encompassing the entire central visual field at the time of initial diagnosis.

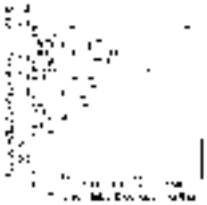

Figure 6A. *The change of visual acuity in LogMAR as a function of the time between the date of initial diagnosis and the date when the visual function evaluation was done at intake in the rehabilitation service.*

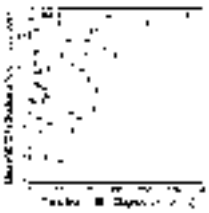

Figure 6B. The change in scotoma area in degrees squared as a function of the time between the date of initial diagnosis and the date when the visual function evaluation was done at intake in the rehabilitation service.

Forty-four patients were followed after rehabilitation intervention for a time period of 0.5 to 4.5 years to determine the change in VFCs, scotoma characteristics, and PRL ability characteristics as a function of time. **Figure 7A** shows the difference in the visual acuity and macular scotoma areas (**Figure 7A**) as they relate to the time period between rehabilitation evaluations. A statistical analysis (regression analysis) determined a lack of correlation (r = 0.19) between visual function change, PRL ability change, and scotoma area change as a function of time.

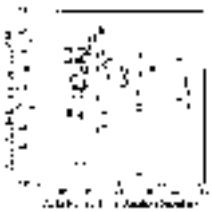

Figure 7A. *The change of visual acuity in LogMAR as a function of the time between the date of initial diagnosis and the date were the visual function evaluation was done at intake in the rehabilitation service.*

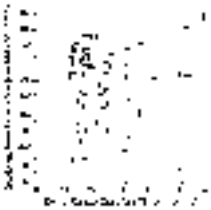

Figure 7B. The change of scotoma area in degrees squared as a function of the time between the date of initial diagnosis and the date were the visual function evaluation was done at intake in the rehabilitation service.

DISCUSSION

The prevalence of patients diagnosed with dry (atrophic) versus wet (exudative) AMD has been typically reported as about 90 percent versus 10 percent, respectively. But, even though more people have dry AMD the prevalence of legal blindness or severe visual function loss caused by dry versus wet AMD has been typically reported as about 10 percent versus about 90 percent, respectively (2). This study indicates that the prevalence of people referred to a vision rehabilitation service with central visual function impairment caused by dry versus wet is nearly 50-50, equal numbers. The progression of the central visual function impairment (**Figure 6**) also indicates that over time these impairments become evenly poorer for all patients with AMD. Thus, the reports of higher prevalence of legally blind patients with wet AMD may be due to the medical nature of the reports which follow the sudden dramatic drop in macular visual function versus the slow gradual drop in macular visual function of the patients with dry AMD. Finally, the follow-up results (**Figure 7**) indicate that rehabilitation intervention can make a difference in visual performance for some patients with AMD. Some people had similar visual function abilities after rehabilitation intervention compared to before rehabilitation intervention. The natural progression of visual function with AMD would be a steady progressive loss of function, and therefore

visual rehabilitation may have helped patients compensate for this steady loss of function. Unfortunately, many patients with AMD are not seen by rehabilitation services when they are first diagnosed, often with significant central visual function impairment.

The visual function results (visual acuity, contrast sensitivity, and PRL abilities) found in the 255 patients with AMD of this study are very similar to the distribution of values found in a general low vision population (10). The prevalence of bilateral central scotomas in patients with AMD, about 92 percent, is a little higher than the prevalence of central scotomas in a general low vision population (10). Research has indicated that the scotoma location relative to the PRL as well as the ability of the PRL is important, if not critical, for visual performance tasks like reading (7,9,14,15), face recognition (16), visual search (17), and space perception (18). Small scotomas are typically found at the very earliest progression of AMD. Unfortunately, previous studies have reported that small scotomas are not detected and it is likely, therefore, that unresolved visual performance complaints are due to these small scotomas (5,6). In addition, patients with atrophic AMD can shift their PRL location as the disease progresses which can introduce variability in standard clinical test results as well as introduce different rehabilitation challenges (3,19). This shift in the PRL location occurs because atrophic AMD causes a paracentral scotoma, at first, which progresses to a horseshoe-shaped, and then ring-shaped, scotoma around the fovea. The retina inside the ring scotoma is typically the fovea, which allows the patient to perform well on visual acuity tests but to have difficulty with other visual tasks like reading while trying to compensate for the ring scotoma. Finally, the ring-shaped scotoma fills in leaving the visual system with no choice but to use an eccentric PRL.

The fact that the majority of people with AMD have bilateral central scotomas and eccentric PRL locations has implications for difficulties in activities of daily living (ADL). The low vision rehabilitation methods used for patients with AMD should accurately evaluate the existence and characteristics of these scotomas as well as the location and abilities of the PRLs. Otherwise, the patient with AMD could lose visual performance capabilities in ADLs that could be regained with a change in the low vision device (magnifier, CCTV, and so forth) and/or additional rehabilitation training. AMD impairs the central visual function painlessly and silently, leaving the peripheral visual function intact except for normal aging processes. As a result, people with AMD may not experience sudden changes in their vision, and they do not appear any different to their friends and family, while their ability to perform an ADL can change radically. The fact that 92 percent of the patients with AMD who sought visual rehabilitation had bilateral central scotomas (and therefore had eccentric PRLs) raises the question as to whether it is the presence of central scotomas in both eyes (and the subsequent need to use an eccentric PRL in one or both eyes) rather than the reduction in acuity (or other types of visual function) that prompts the person with AMD to seek visual rehabilitation.

CONCLUSION

The majority of people with AMD have significant visual function impairments (including central scotomas and impaired PRL movements in fixation, saccades, and pursuit) with corresponding problems with visual tasks and ADLs. While the medical reports have indicated that central visual function impairment is primarily associated with the wet type of AMD, this study showed that both the dry and wet types of AMD are equally prevalent in the visual rehabilitation of central visual impairments. Many people with AMD are not seen in rehabilitation services until their visual abilities are much reduced and often long after they have been diagnosed. AMD has

become a major health issue, and more and more research is searching for cures and for a clearer understanding of what causes AMD. Until a cure is found, visual rehabilitation services, including self-help materials (20) provide the only means for people with AMD to compensate for the visual impairments caused by AMD to maintain, as much as possible, an independent lifestyle.

ACKNOWLEDGMENTS

We thank Dr. Donald Fletcher for the use of patient data. The authors have no financial interest in the Rodenstock SLO.

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Go to TOP.

 **Previous**

 **Contents**

 **Next**

Go to TOP

Contents

Last revised Tue 10/12/1999