



## The Internet Journal of Allied Health Sciences and Practice

<http://ijahsp.nova.edu>

A Peer Reviewed Publication of the College of Allied Health & Nursing at Nova Southeastern University

*Dedicated to allied health professional practice and education*

<http://ijahsp.nova.edu> Vol. 1 No. 2 ISSN 1540-580X

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### The Low Vision Rehabilitative Service Part One: Understanding Low Vision

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**CITATION:** Pizzimenti JJ. The Low Vision Rehabilitation Service Part One: Understanding Low Vision. The Internet Journal of Allied Health Sciences and Practice. July 2003. Volume 1 Number 2.

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#### ABSTRACT

Allied health professionals are becoming increasingly adept at identifying persons that are living with low vision. Low vision rehabilitation is among the emerging areas of practice for various allied health care providers.<sup>1</sup> This paper, the first of a two-part feature, provides background information that will help the allied health professional to better understand the person who will be receiving these services. The paper discusses the impact of functional vision loss, and presents a four-phase, interdisciplinary model of low vision services that can be applied to any setting, whether clinical or non-clinical. Finally, this paper describes the potential roles of the various members of the vision rehabilitation team. Part two of this series, to be presented in a subsequent publication, shall focus on methods of assessing low vision, providing clinical services, and establishing an adaptive training and instructional program.

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#### INTRODUCTION

It has been estimated that there are at least three million Americans with low vision.<sup>2</sup> The impact of low vision on affected patients and their families can be profound. Low vision may affect a person's learning, daily functioning, and psychosocial status. Economic costs related to low vision include medical care and treatment, loss or reduction of income, and the cost of state and federal-funded programs and social services for the blind and visually impaired. Conditions such as age-related macular degeneration (AMD) have contributed to the higher prevalence of visual impairments in the elderly.<sup>3</sup> Families of persons living with low vision often experience financial, physical, psychological, and social problems.

Intervention in the form of vision rehabilitation has enabled many patients to successfully meet and overcome the challenges posed by low vision, thereby resulting in an enhanced quality of life. The ideal philosophy of low vision care is a success-oriented, interdisciplinary, global approach, with the patient/client as the central member of the rehabilitation team.

#### Low Vision Terms and Concepts

Low vision is defined as a permanent visual impairment that is not correctible with conventional spectacles, contact lenses, or surgery, resulting in decreased visual performance. This may occur as a consequence of reduced acuity, visual field deficits, contrast sensitivity loss or poor visual discrimination. Faye and others opine that low vision is not defined by a single condition or numeric equation, but rather it is a functional state or status.<sup>4</sup> A visual impairment is the actual damage to the eye that results in this loss of acuity, field, contrast, or discrimination of detail.

The low vision patient is a person living with an eye disease or condition that interferes with his or her ability to accomplish a particular task or set of tasks. (I use the terms "patient" and "client" interchangeably because of the interdisciplinary nature of this topic). Table 1 lists some common etiologies of vision impairment. Low vision care is a philosophy directed toward making the low vision patient aware of their remaining visual function, as opposed to dwelling on the impairment or sight loss. Vision

rehabilitation is a comprehensive service comprised of functional evaluation, clinical examination, optical and non-optical aid evaluation, patient education and instruction, and proper follow-up and post-follow-up care.

It has been suggested by Jose that the ideal model for vision rehabilitation is an interdisciplinary service that is carried out by a group of professionals who are committed to helping low vision patients overcome the effects of their impairment. In this way, the patient becomes empowered to function (visually, psychosocially, vocationally, and otherwise) at an optimum level and to live well.<sup>5</sup>

**Table 1 Common causes of vision impairment**

Macular degeneration
Cataract (congenital and complicated acquired types)
Glaucoma (congenital and acquired)
Diabetic retinopathy
Optic nerve atrophy
Retinitis pigmentosa
Myopic degeneration
Stargart's disease
Albinism
Retinopathy of prematurity

### **Identifying the Low Vision Patient**

Most people with low vision suffer impairment due to acquired conditions such as AMD, glaucoma, and diabetic retinopathy. The vast majority of these patients are over the age of 65. For many in this group, it is a struggle to incorporate the eye disease into their life. The effects of psychological and emotional stress on affected individuals and their families can be considerable. Many view their condition as a disaster or a burden. According to Feste, it is natural for these people to go through a grieving process similar to that suggested by Elisabeth Kubler-Ross in her work with people who have lost a loved one or are preparing to die themselves.<sup>6,7</sup> The cycle may include such familiar stages of grieving as denial, anger, fear, sadness, and finally, acceptance.

Coping with reduced functional vision, whether it is present at birth or acquired later in life, requires that affected persons accept the challenges posed by their condition, and that the community at large provides resources to assist them in this endeavor. Optometric physicians, ophthalmologists, and primary care medical physicians are typically the initial group of health providers that will encounter a patient with low vision. However, with professional advocacy and legislative changes broadening their scope of practice, various types of health care professionals may be in a position to serve as the initial resource for a low vision patient. This underscores the need for allied health professionals to be cognizant of the visual needs and ocular status of their patients.

As a number of syndromes may present with both a vision and hearing impairment (See Table 2), audiologists should be especially alert to the functional vision aspect of patient care. Usher's syndrome is the most common condition that involves both hearing and vision problems.<sup>8</sup>

**Table 2 Syndromes presenting with both hearing and vision loss**

Syndrome	Ocular Disease(s)	Auditory Component	Other Systems Affected
<b>Alport's</b>	cataract, retina	nerve deafness	renal dysfunction
<b>Cockayne's</b>	cataract, optic nerve, retina	sensorineuronal	mental retardation, early senility
<b>Meniere's</b>	nystagmus	sensorineuronal, tinnitus	peripheral vestibular dysfunction
<b>Refsum's</b>	nystagmus, retinal hemorrhage	partial or complete	cerebellar dysfunction
<b>Rubella (congenital)</b>	cataract, glaucoma, retina	congenital deafness	cardiac defects
<b>Syphilis (congenital)</b>	retinopathy	secondary to CNS infection	mental retardation, dermatologic
<b>Usher's</b>	retinitis pigmentosa	often congenital	vestibular (poor balance)

The entry of a patient into a vision rehabilitation program may be facilitated by health care provider groups, community service groups, or through self-referral (See Table 3). Many organizations and support groups for people with eye diseases hold informative seminars and place valuable information on the Internet, so today's low vision patient is often as well-read about their condition as their physicians.

Once a professional or community service group identifies a person as visually impaired, and the affected individual reaches a point of acceptance (where he/she is amenable to the concept of low vision care), a referral can then be initiated to provide rehabilitative services. Many or all of the referral groups listed in Table 3 then become integral members of the rehabilitation team.

**Table 3 Referral of a Patient For Vision Rehabilitation Services**

Clinician and Allied Health Professional Groups-----
<b>Optometric physicians</b>
<b>Ophthalmologists</b>
<b>Primary care medical physicians</b>
<b>Other physician sub-specialists (i.e. Neurologists, Rehabilitative medicine)</b>
<b>Rehabilitation teachers</b>
<b>Orientation and mobility instructors</b>
<b>Nurse practitioners and Registered nurses</b>
<b>Physician assistants</b>
<b>Occupational therapists</b>
<b>Physical therapists</b>
<b>Audiologists</b>
<b>Pharmacists</b>
Community Service Groups-----
<b>Educators</b>
<b>Counselors</b>
<b>Social workers</b>
<b>Case managers</b>
<b>Organizations that support research for visually impaired (e.g. Macular Degeneration International)</b>
<b>Service clubs (i.e. Lions Club, Rotary)</b>
Patient Self-referral-----
<b>Usually after obtaining information from multi-media resources</b>

### **Compliance-based Management Versus The Empowerment Model**

Chronic disease management has long been accomplished through the use of a compliance-based, medical model. Whether the treatment is medical, surgical, or rehabilitative, patients were simply told what to do, and were expected to comply with the management plan. Using this model, the decision-making power was thought to rest solely with the health professionals. The compliance model, however, does not take into account one crucial factor: people make their own choices <sup>9</sup>. These choices are based upon an individual's values, goals, needs, fears, and problems as human beings living with low vision.

In the empowerment model, people accept the fact that their low vision condition is part of their life, and they adapt their life to accommodate this challenge. This model gives people the opportunity to explore healthy coping strategies, drawing upon the expertise of each member of the rehabilitation team. The power is split between the health professional and the patient, who is no longer a passive member of the team, but a primary decision-maker.<sup>10</sup> Anderson and colleagues describe a program, based on patient empowerment, which was tested in diabetes at the University of Michigan. In a randomized controlled trial, measurable improvements in attitude and self-efficacy as well as a significant (0.71%) reduction in glycosylated hemoglobin resulted from this chronic disease management program.<sup>11</sup> Like the empowerment model, effective low vision care is oriented toward human issues.

### **A Four-Phase Model of Care**

The ideal low vision rehabilitation service uses an integrated, multi-phase system model. The components of this model that are essential to the effective delivery of care are outlined in this section. Jose described a three-phase system model that is predicated upon a strong foundation of communication and professional flexibility.<sup>12</sup> Using these two key elements, I have modified Jose's system and now present a four-phase model of care.

#### **Phase 1**

The goal of the first phase of the model is to accurately assess the visually impaired person's level of independent functioning. This global task is referred to as a "functional evaluation". It is best performed in a non-clinical setting and may be accomplished by various members of the rehabilitation team, including allied health professionals. As opposed to using medical or clinical measures, Phase 1 implements evaluation activities that are functional measures. In addition to functional evaluation, other pertinent information is gathered through an interview, review of medical data, and an assessment of the person's needs. Lampert and Lapolice thoroughly describe the various factors, considerations, and typical measures of visual function.<sup>13</sup> In this paper, they suggest a protocol that is particularly relevant to occupational therapists that provide low vision services.

At the end of Phase 1, a detailed, non-clinical description of the individual is composed and provided to the team members. The most efficient allocation of the low vision service's time and resources is determined in general terms, based upon information garnered during this initial assessment. In this way, the program is designed to provide resources for problem-solving that are tailored for a particular individual and his/her needs.

#### **Phase 2**

The second phase of the model consists of a clinical evaluation of the person's eye health and visual status. This includes a low vision ophthalmic examination, as well as the evaluation of various methods of magnification (for distance and near tasks). Other issues addressed in Phase 2 include illumination, contrast, and glare. The clinician then makes preliminary recommendations of optical devices, adaptive training, and instruction.

The low vision clinician must be keenly aware of the patient's motivation and psychosocial status. In order for optimum problem-solving to ensue, the patient's mindset should be such that he or she is ready to become an active participant in the rehabilitation service.

#### **Phase 3**

Once the clinical evaluation is accomplished, the next phase of the program focuses upon proper instruction and adaptive training with the various techniques, optical devices, and non-optical aids. Phase 3 may include further magnification "trials" for specific tasks, prescription of tentative aids, and referral for other services such as mobility and daily living skills. Constant communication with other members of the service team, the referring professional or group, and especially the patient (and their support system) is vital during this phase in order to ensure successful continuity of care.

#### Phase 4

Phase 4 is the continued delivery of rehabilitative services for the low vision patient, beginning with the dispensing of the final optical and non-optical devices. Other areas that are addressed at this juncture are the education of the patient on the prognosis for continued success, the prognosis of their ocular condition, and post-follow-up evaluation of devices and other aids and services. This phase does not describe the commencement of services, but rather the beginning of a continuous "loop" that addresses any new concerns, assesses patient satisfaction that their needs are being met, and, if necessary, the provision of additional social services and resources.

#### Goals and Roles

A successful model of low vision care cannot be achieved in isolation. That is, the four-phase system detailed in this paper is maximally effective when it becomes an interdisciplinary commitment on the part of several individuals. Just one or two professionals or professions cannot provide a comprehensive service to patients/clients that will appropriately meet their diverse needs.

There must exist an environment of collegiality that is mutually respectful, trustful, and non-competitive. Perhaps the greatest impediment to the success of a person going through the service is the potential clash of professional egos. Sometimes, this consequence seems inevitable, since there is now such widespread overlap among the many disciplines involved. After some case experience in low vision, there is a tendency for the individual team members to feel that they can handle not only their own role, but the job of other professionals on the team as well.

Each member of the team should concentrate on their own area of expertise, and communicate their results and recommendations to the others clearly and, at times, with sufficient tact. We must keep our eyes on the ultimate goal: a well adjusted, empowered, optimally functioning person who has overcome an obstacle by using it as an opportunity to live well.

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