An Orientation to Vision Loss Program: Meeting the Needs of Newly Visually Impaired Older Adults

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There is a strong relationship between aging and vision loss. As an individual ages, there are refractive changes, decreases in visual acuity, and increased risk of eye conditions that may result in visual impairment (Goodman, 1985). Visual impairment is defined as "visual acuity which cannot be corrected to normal performance levels" (Faye, 1984, p. 6), and its prevalence is estimated at approximately 8% among those age 65+, rising to around 25% of those over age 85. Among individuals with visual impairment, two-thirds are age 65 and older (American Academy of Ophthalmology, 1994), and, as a handicapping condition, vision loss is third among the elderly, preceded only by heart disease and arthritis (Morello & Fox, 1989).

After a lifetime of using sight to evaluate and test the environment, to perform daily tasks, to satisfy needs, and as a means of enjoying one’s world, loss of vision profoundly affects well-being (Schulz, 1977). The emotional response of older adults to loss of sight is individual and unique; however, research suggests that frequent responses include a sense of loss, isolation, and dependence (Goodman, 1985), loneliness and depression (Evans & Jaureguy, 1982), low morale and lessened satisfaction with life (Gillman, Simmel, & Simon, 1986), a tendency to lower scores on a mental status exam (Snyder, Pyrek, & Smith, 1976), and a sense of incompetence (Ainlay, 1988). Although research is scant and findings mixed, there is evidence that eventually the majority of visually impaired older adults adjust satisfactorily (Gillman et al., 1986; Kaarlela, 1978; Kleinschmidt, 1995).

A Patient Support Program, “Orientation to Vision Loss,” has been developed at the John A. Moran Eye Center, the University of Utah, to address the psychosocial needs of visually impaired patients, to support them through the initial disruption of life and emotional distress, and to facilitate the adjustment process. Individual counseling and support groups are available, and although these services are generally well-received, it became evident several years ago that other needs and concerns were not being sufficiently addressed:

- Although families were seriously affected by their loved ones’ visual impairments, families were too often ignored and left out of support services;
- Too many patients were not informed and not accessing the ample community services and programs available to them;
- Too often, patients were influenced by the stigma associated with counseling, either individual or group, and, although in need of support and encouragement, they refused any services which might imply “mental problems.”

1 Funding for this program is provided by the George S. and Delores Dore Eccles Foundation and Research to Prevent Blindness, Inc.
2 John A. Moran Eye Center, The University of Utah, 50 North Medical Drive, Salt Lake City, UT 84132.
Although more empirical research is needed (Johnson, 1989), the value of grouping people to enhance their well-being is gaining acceptance (Napier & Gershenfeld, 1993; Wuthnow, 1994). Among the elderly, group support has been found to have a positive effect on coping with role changes (Riley, 1982), on reducing a sense of isolation (Levy, 1976), and on adjusting to negative life experiences such as vision loss (Lighthouse, 1992; Van Zandt, Van Zandt, & Wang, 1994). Information shared in groups is beneficial (Borkman, 1976) and is, in fact, one of the “curative factors,” that is, why groups help, cited by Yalom (1985). Other pertinent curative factors include: universality (“I am not alone in struggling with vision loss”); instillation of hope (“If others can cope, so can I!”); development of socialization techniques (learning the social skills required of the visually impaired living in a sighted world), and imitative behavior (“So that’s how she does it, and it seems to work!”).

Thus, Orientation to Vision Loss, a program with a blend of educational and support group qualities, was developed to facilitate the adjustment process for newly visually impaired patients and their families, to quickly and effectively disseminate information on community services, and to present emotional support in a format acceptable to most individuals.

The Orientation to Vision Loss Program

The Moran Eye Center is an ambulatory care facility dedicated to eye clinical care, research, and education. Traditionally, in medical settings, there has been little or no psychosocial support of visually impaired patients other than, at most, a referral to the local low vision services agency (Stetten, 1981). However, out of the conviction that patients struggling with the emotional trauma of vision loss need intervention beyond the traditional eye care, the Patient Support Program was initiated at the Moran Eye Center in July, 1991. In December 1992, the first Orientation to Vision Loss (OVL) was held and has become a key component of the Patient Support Program. Although this program is not limited to older adults, approximately 90% of the attendees are over age 65, the age group most at risk for visual impairment.

The orientations are two-hour, one-time-attendance sessions held once a month on Saturday mornings (to accommodate working family members). The sessions are open not only to Moran Eye Center patients, but to all newly visually impaired individuals throughout the Intermountain West. Orientations are facilitated by the author, who directs the Patient Support Program, an MSW graduate student, and two peer counselors.

The program is advertised by various means, including mailings of program brochures to area ophthalmologists; announcements in the Utah Ophthalmological Society newsletter; education of ophthalmic technicians and staff; brochures available to patients in the clinics; public service announcements in local newspapers including the local aging services newspaper; announcements on the Radio Reading Service, a radio station for the visually impaired; and public interest stories on Salt Lake City television stations.

The orientations are offered free of charge, but in order to manage and organize each session, registration is required. Each session is limited to a maximum of 30 participants.

Program Content

Over the two hours, each orientation consists of components as described below. The time for each varies depending on the size and the “talkiness” of each group, but the introductions, goggles, video, and packet components each take approximately 30 minutes, with a 2- to 3-minute summary concluding the session:

Introductions. — Participants are welcomed and the rationale behind the program is explained. The positive aspects of their participation in this kind of program—their search for support and services—is reinforced. There is much emphasis here and throughout the session on problem-solving as both a means to and a sign of good adjustment to vision loss, and they are welcomed and congratulated for participating.

Introductions of the facilitators and of each participant follow. Attendees are asked to give their names, eye conditions, how long they have experienced the condition, and to describe something that has helped them thus far in adjusting to vision loss. This last point is an important one in the group process because it brings each introduction to a positive, problem-solving perspective.

Throughout the introductions and the entire session, suggestions for coping and for functioning with limited vision are shared as questions and concerns arise. For example, the importance of good lighting, enhancing contrast, and using optical and assistive devices are discussed. Although the facilitators are ready with many suggestions, the attendees also seem pleased to share what is working for them.

Simulation of Vision Loss. — Goggles that simulate eye conditions are tried on by family members, and discussion between the visually impaired person and the family is encouraged. For example, “When I look at that magazine page, what I see is.... What do you see?” A frequent comment from family members is, “Oh my gosh, I had no idea!” The goggled family members are given tasks. In cases of macular degeneration, which obstructs central vision used in reading, one might say, “You have been experiencing abdominal pain all day, you are starting to feel feverish, and you must get ahold of your doctor. Here is a telephone directory. Find your doctor’s number.” If the condition is one which affects peripheral vision (limiting orientation and mobility), the family members are given directions and asked to retrieve an object in another part of the building.

This part of the orientation creates awareness for
the family members of what the vision loss means for their loved one. Often, as they are going through this exercise, families express frustration and impatience with dependence. This newfound awareness seems gratifying to the visually impaired, and their responses are often, “See, it is hard, isn’t it!” On the other hand, this in an opportune time for discussion of the usefulness of residual vision, and suggestions on eccentric viewing are discussed.

**Video — “Focus on Feelings.”** — Although expression and discussion of feelings are encouraged throughout the session, this 16-minute video illustrates well the emotional issues related to vision loss. Six individuals with various conditions discuss their initial responses to vision loss, their feelings about dependence, relationships, coping, and adjustment. After the video, discussion is encouraged, and the helpful video messages are reinforced: Feeling angry, resentful, and depressed is a normal response to vision loss; we need to express those feelings to sympathetic others; we need the help and support of others as do all interactional human beings; there are many services and programs available to help in the process, etc.

This is the ideal time to address the feelings of family members. The fact that vision loss is a “family affair” is emphasized, and that the feelings of family, like the feelings of the one experiencing the vision loss, must be honored. Suggestions for comforting and for helping without creating dependency are discussed and shared.

**Services for Visually Impaired.** — Packets containing flyers, brochures, and application forms for services for the visually impaired are given to each family. The more pertinent services are discussed, questions answered, and accessing of the services encouraged. Services include low vision services, training and adjustment services, activities of daily living training, orientation and mobility training, craft classes, talking books, radio reading service, telephone assistance, property and income tax abatements, discount cab coupons, descriptive video, and television programming, etc.

**Discussion of Issues.** — A session summary highlights the most important points of the session (You are not alone, feelings are OK, there is much to help you in this process, etc.). Again, participants are encouraged in a problem-solving approach to deal with their difficult reality, and the facilitators offer themselves as resources as further concerns and questions arise.

It should be noted that because of the mixed group, one-time-meeting format, the group facilitator must be flexible and ready to respond to the needs and concerns of each unique group. For example, if a particular group includes visually impaired individuals still working or trying to work, vocational rehabilitation services should be emphasized more during the packet discussion. With some groups, communicating needs around vision loss may emerge as more of an issue than with other groups, and the group facilitator must respond accordingly. The uniqueness of each group presents a challenge. However, the organization as described above provides a good foundation but also ample opportunity to adjust and vary according to group needs.

**Organizing the Orientations**

Funding to initiate the OVL program was secured from the Delta Airlines Employees’ Fair Share Committee, which provided for the printing of brochures and packets, mailing costs, refreshments, simulation goggles, and other supplies needed. The program is currently supported by a grant from the George and Delores Dore Eccles Foundation.

The simulation goggles were ordered from Steve Ehrnst, VA Hospital, Birmingham, Alabama, and the proceeds are donated to the Association for the Education and Rehabilitation of the Blind and Visually Impaired (AER). It should be noted, however, that the AER goggles are now ordered from Marshall Flax, c/o Wisconsin Council of the Blind, 354 West Main Street, Madison, WI 53703-3115, telephone (608) 255-6178.

The video, “Focus on Feelings,” was ordered from Universal Health Associates, 1701 K Street, NW, Suite 600, P.O. Box 65465, Washington, DC 20035, telephone (202) 429-9506. Another excellent video specific to visually impaired elderly entitled “See For Yourself” is produced by The Lighthouse Inc. For information call 1-800-334-5497.

A major effort was made to contact all of the agencies and programs for the visually impaired, both local and national, when the packets were compiled. Brochures, flyers, application forms — anything that could be a help to the visually impaired and families — were sought. This process is a continual one with new services, books, etc. frequently uncovered, and with information often changing. Addresses, telephone numbers, names, and prices are frustratingly ephemeral, and the packet contents must be monitored constantly to ensure that the information is current.

The peer counselors are an integral and invaluable part of the orientations. They “have been there” and, because they come from that perspective, they are powerful role models. Both are older adults, and they were selected by the program director based on their own excellent adjustments to vision loss, their outgoing personalities, and their desire to help others faced with vision loss. Prior to the inception of the orientation program, they had six hours of training in basic group work, psychosocial issues related to vision loss, and group communication. Excellent sources of information on these topics include Tuttle (1984), Weber (1991), Orr (1991), Emerson (1984), Griffin-Shirley and Groff (1993), Neer (1994), and The Lighthouse Inc. (1992).

**Evaluation of the Program**

Since its inception in December 1992 and up until April 1995, there have been 22 orientations with a
were health care providers attending to learn about visually impaired persons, 78 were spouses, 112 were other family members, 17 were friends, and 16 were health care professionals. Responses to the Likert questions indicate a strong positive response to the experiences: Respondents indicating either “helpful” or “very helpful” were as follows: goggle experience, — 80% of spouses and 89% of other family members; video — approximately 90% of the visually impaired, spouses, and other family members; discussion — 92% of the visually impaired, 97% of spouses, and 96% of other family members; information packets — 94% of the visually impaired, 97% of spouses, and 96% of other family members.

The open-ended questions also engendered an overwhelmingly positive response. The “What stands out for you” question elicited responses which reflected Yalom’s curative factors: “I had thought I was alone. How wonderful to find out that I am not”; “I hadn’t realized that there was so much to help me”; “I think my family understands me better now”; “It was great to get my questions answered” and “Those ladies [the peer counselors] were wonderful. It makes me think I can do it too!” There were 53 widely varying “suggestions to make the experience better” from the 195 respondents. Ten individuals would have liked more discussion, and five thought the room too crowded. The responses to the “additional comments” question reflected gratitude and thanks.

Follow-up evaluations have not yet been instituted, but they would be of great value in determining whether the above positive responses are sustained over time and the extent to which the program does indeed encourage the utilization of services. The author hopes to add a follow-up evaluation process and certainly encourages those replicating this program to include this component.

Discussion

The Orientation to Vision Loss program has been immensely valuable in meeting the needs of the newly visually impaired and their families, and it is an intervention which can be easily replicated in different settings.

The program continues to evolve. Funding has been secured to purchase a sample of optical and nonoptical assistive devices and a mobile display cabinet. Thus, OVL participants will have the opportunity to try out the various helpful tools (such as check and signature guides, magnifiers, talking watches and clocks, glare control glasses, etc.) instead of just having the items described. This should motivate the participants even more to access Low Vision Services where these items can be purchased.

The experience of vision loss can be overwhelming, but to experience it feeling alone and unsupported needlessly compounds the emotional trauma. The Orientation to Vision Loss program has proven to be a valuable model for filling in gaps in the provision of services and for reaching, teaching, and supporting individuals at a time of great crisis and vulnerability.

References


FREE PRECONFERENCES FOR ALL STUDENTS AND NEW MEMBERS OF THE GERONTOLOGICAL SOCIETY OF AMERICA

Preconference workshops designed for all students and new GSA members will be offered at the Society's Annual Scientific Meeting at the Sheraton Washington Hotel in Washington, DC. There is no charge for these sessions but preregistration is required and attendance is limited. See the July issue of "Gerontology News" or contact the Society for registration forms.

SESSION #1

Perspectives in Gerontology: An Overview for All Disciplines
Saturday, November 16; 12:30 - 2:30 pm, Kennedy Room
This overview session will introduce students and new members of GSA to the structure and function of the Society and its four sections. It will provide information about current research and professional activities.

Speakers: J. Dwyer, PhD (Wayne State Univ.); L. Gwyther, ACSW (Duke Univ.); M. Hobbins, DMD (VAMC, University of NC); C. Longino, PhD (Wake Forest Univ.); R. Miller, MD, PhD (Univ. of MI); P. Teaster, MA (VA Polytechnic Institute & State Univ.).

SESSION #2 (Select One)

Perspectives in the Biology of Aging
Saturday, November 16; 2:30 - 5:00 pm, Lanai Parlor #160
This session offers an overview of some areas of ongoing biogerontological research. Underlying concepts and various aspects of current biological research will be discussed along with: the relationship of processes of aging and the etiology of disease, aspects of public policy, funding of aging research, and the interests of science.

Speakers: G. Baker, III, PhD (Shock Aging Research Fdn. and Gerontology Research Ctr., NIA/NIH); R. Adelman, PhD (Wayne State Univ.); R. Arking, PhD (Wayne State Univ.); A. Passamani, PhD (Gerontology Research Ctr., NIA/NIH).

Perspectives in Social Research, Policy and Practice
Saturday, November 16; 2:30 - 5:00 pm, Lanai Parlor #156
Speakers: M. Neal (Portland State Univ.); L. Branch, PhD (Duke Univ.); E. Kutz, PhD (Portland State Univ.); E. Rivas, MPP, MS (American Assn. of Homes & Services for the Aging); D. Wagner, PhD (National Council on Aging); C. Weber (Univ. of PA); T. Wetle, PhD (National Inst. on Aging).

Perspectives in Clinical Medicine Research
Saturday, November 16; 2:30 - 5:00 pm, Lanai Parlor #152
This session is for graduate students and researchers at the beginning or mid-level of their research career. It provides a multidisciplinary perspective on practice implications and emerging clinical research issues in a changing health care environment.

Speakers: M. McBride, RN, PhD (Stanford Geriatric Education Ctr.); S. Castle, MD (West Los Angeles VAMC); J. Dascher, RN, GNP (Russell Sage Graduate School); M. Haber, MD, MPH (Albert Einstein Medical Ctr.); B. Williams, PharmD (Univ. of Southern California).

Perspectives in Behavioral and Social Sciences Research
Saturday, November 16; 2:30 - 5:00 pm, Kennedy Room
This session will showcase a variety of research topics of interest to and pursued by BSS section members.

Speakers: P. Dilworth-Anderson, PhD (Univ. of NC, Greensboro); R. Adams, PhD (Univ. of NC, Greensboro); M. Crowther (Duke Univ.); B. Miller, PhD (Case Western Reserve Univ.); R. Taylor, PhD (Univ. of MI).