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Incorporating Social and Leisure Participation into the Clinical Setting

Karla Sternberg, MOT, OTR, SCLV, CLVT

Social isolation and loss of participation in meaningful social and leisure occupations is common in the general older adult population and has been well documented for those older adults with varying levels of vision impairment. Two significant factors that limit social and leisure participation include vision and depression. Perl-mutter¹ reported that mild vision impairments (20/40) have been found to reduce participation and increase symptoms of depression. A visual acuity of 20/40 is not an acuity that places an

individual into the “low vision” category; however, this visual impairment is significant enough to limit a person’s participation and engagement in social and leisure activities. Depression has been found to be two to five times greater in older adults with low vision than in sighted individuals of the same age.² Vision loss can result in a perceived loss of control, loss of meaningful connections, and loss of social roles, which exacerbate symptoms of depression.³ Visual functioning, co-morbidities, and coping strategies are a greater

predictor of depression than degree of vision loss⁴; therefore, a person with 20/40 visual acuity may have additional co-morbidities and poor coping strategies for their visual changes and is predicted to experience greater symptoms of depression.

Social participation is defined as “organized patterns of behavior that are characteristic and expected of an individual or a given position within a social system”⁵ including peer/friend relationships, family roles, and community interactions. Social participation is a significant

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The mission of the Envision Foundation is to secure funding for the successful delivery of services offered by the Envision Vision Rehabilitation Center and the education programs of the Foundation. Envision Foundation focuses on fundraising to ensure that no patient is ever turned away—regardless of ability to pay; public education to help prevent blindness; and professional education to determine best practices in order to serve patients who are blind or low vision.

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Incorporating Social and Leisure Participation into the Clinical Setting... continued from front page

predictor of quality of life.⁶ Those with vision impairments have been found to participate less in social activities secondary to challenges encountered due to vision loss⁷ suggesting decreased quality of life. Challenges to social participation include lack of understanding by others, lack of visual cues for information including difficulty recognizing facial expressions and body language during social interactions, and a need to re-establish ways of communication⁸ including the use of verbal descriptions during social interactions.

Leisure participation is defined as a “non-obligatory activity that is intrinsically motivated and engaged in during discretionary time.”⁵ This includes both the exploration of leisure activities where interests are identified, as well as participation in leisure activities that encompass planning, participating, and maintaining balance of activities.⁵ Leisure participation has been correlated to the formation of identity through role performance and quality of life. For example, when a person has enjoyed gardening for many years and has identified themselves as a gardener, a sense of role loss may be experienced when the tasks involved in gardening become challenging and unable to be completed independently. Lamoureux, et.al⁹ noted that perceived participation restrictions are related to

reduced distance visual acuity as well as physical factors related to aging.

In the past, the low vision model of practice at the Michael E. DeBakey VA Medical Center VISOR program has focused on basic activities of daily living including bathing, dressing, eating, feeding and grooming, as well as instrumental activities of daily living including communication management, community mobility, financial management, health/medication management, home management and shopping. Through the use of an adaptive approach, patients demonstrated increased independence in these areas of occupation as well as incorporation of adaptive devices and techniques into daily routines, habits and roles. Utilizing standardized measures including

the National Eye Institute Visual Functioning Questionnaire (NEI VFQ-25) and the Geriatric Depression Scale (GDS), the areas of occupation, including social and leisure participation, were noted to demonstrate limited improvement in outcomes from initial evaluation to discharge. Patients continued to verbalize feelings of social isolation and withdrawal following low vision training as well as a strong desire to regain friendships, interactions and leisure activities. These results suggested that the current model of practice would benefit from the incorporation of social and leisure participation.

In order to expand the available programming to more fully address patients’ needs, a social/leisure activity group was created using the Person,

Qualitative Outcomes

Obtained through focus group and transcribed responses.

- “I sort of got disinterested in life, which is not normal for me and stopped being around my friends. This group has been good for me to get out.”
- “I like these guys. We are all dealing with the same stuff.”
- “Getting here is hard. I have to catch the bus at 6:30 am and then don’t get home until late, but I like the chance to get out of my house.”
- “It’s nice to know there are other people out here worried about similar stuff, like protecting ourselves. It’s scary out there.”
- “I went to the multi-service group on Thursday to have lunch. There were 40 people there, all vision impaired.”

Environment, Occupation frame of reference. This frame of reference describes occupational performance as “an outcome that is created among people, occupations, and their environment.”¹⁰ This frame of reference suggests that the person is engaged in ever-changing roles that evolve over time and context. The environment includes the many contexts in which the person engages and can include cultural, social, environmental, physical or organizational. The occupation includes the leisure pursuits in which the person engages. The result is occupational performance where a dynamic experience is created.¹⁰

The formation of this social/leisure activity group required the use of group building blocks to include participation, communication, problem-solving and leadership.¹¹

■ Participation was essential for group development and required that participants have concern for the task and willingness to contribute to the goals of the group, either indirectly or directly. Multiple factors affected participation, including the content of the group, physical atmosphere, psychological atmosphere, personal preoccupations, level of interactions, and familiarity with others in the group.¹¹

Selecting participants played a significant role in the level of participation expected from

the group. The social/leisure group's participants were selected based on results of standardized assessments including the NEI VFQ-25 and Geriatric Depression Scale (GDS). The NEI VFQ-25 measured visual disability and visual symptoms using generic health and task-specific domains.¹² At the time of discharge from basic low vision training, the selected participants demonstrated no improvement in domains specific to social engagement, role performance, dependency and mental health. Levels of depression were determined using the GDS, which is a 15-question non-visual interview that helps to identify symptoms of depression in the geriatric population.¹³ The selected participants demonstrated GDS scores at the same level following basic low vision training.

Initially, participants were selected based on their scores using the NEI VFQ-25 and the GDS. Five male participants were selected between the ages of 50 and 61 with eye diseases including exudative age-related macular degeneration, advanced glaucoma, post cerebrovascular accident with left homonymous hemianopsia, and bilateral retinal detachments with corneal irregularities.

■ Communication included spoken and unspoken

language and required two-way communication from each member. Being able to offer and receive feedback was critical to group development and cohesiveness.¹¹ Communication within the social/leisure participation group was initiated through the use of a semi-structured interview that was utilized during a focus group. This provided an opportunity for group members to meet one another while providing feedback in regards to their individual needs, wants and expectations from this group. The group responses were recorded and transcribed.

■ Problem-solving was initiated through the use of the focus group in which three significant problems were noted as themes from group transcriptions. These problems included:

- Loss of engagement: “The last time I got a book was last year, and I couldn’t see the print and got discouraged and quit my book club.”
- Transportation: “I stay home all the time. I stopped going to my art classes, book club, and spending time with my gardening friends. I feel so different from them now, and I have to find someone to take me.”
- Acceptance of disease and disease process: “I have realized that I need to accept my impairment and reach out

and ask for help. That was a big thing for me: asking people to help and accept me as I am.”

This focus group, as well as subsequent groups, allowed the members to determine commonalities with one another, normalize their problems and feelings regarding vision loss, develop understanding of the causes behind their problems, and generate ideas for one another to help address the problems that were verbalized.

■ Leadership required focusing the participants toward a common goal while maintaining knowledge of interactions, commitment levels, and expectations of the group,¹¹ as well as providing activity-based interventions. Through fostering the leadership role, informal roles within the group began to develop. Soon an informal leader, a task manager, a social butterfly and a wallflower emerged. The activity-based interventions provided an outlet for participants to engage safely and independently. These activities included:

- Creative art projects
- Cooking
- Birthday celebrations
- Game playing
- Community dining experiences at local restaurants
- Accessing public transportation

I (Initial Evaluation) D/C (Discharge) TABLE 2

Participant	Vision-specific Social Functioning		Vision-specific Role Difficulties		Vision-specific Dependency		Vision-specific Mental Health		Geriatric Depression Scale	
	I	D/C	I	D/C	I	D/C	I	D/C	I	D/C
Mr. L	50/100	58.3/100	50/100	50/100	50/100	81.25/100	20/100	45/100	6/1	5 /15
Mr. P	25/100	50/100	0/100	25/100	12.5/100	50/100	0/100	25/100	9/15	7/15
Mr. W	16.7/100	88.3/100	6.25/100	43.75/100	18.75/100	87.5/100	20/100	60/100	8/15	5/15
Mr. D	75/100	83.3/100	50/100	68.75/100	62.5/100	87.5/100	50/100	75/100	11/15	9/15
Mr. F*	50/100	0/100	25/100	0/100	50/100	0/100	40/100	0/100	5/15	0/15

*Did not complete

- Attending community activities including art exhibits at the local art history museum
- Introduction to other community groups for people with visual impairment
- Education sessions from local sheriff’s department
- Movies
- Gardening
- Mentorship through group membership

Over the months, as the group continued to develop and become more cohesive, an additional focus group was conducted to determine qualitative outcomes. Statements obtained during this focus group have been included in Table 1. Positive results were noted with each participant expressing their enjoyment of one another, an opportunity to leave the house, realization that they

are not alone with their vision impairment, and suggestions of additional community group opportunities. In addition, the NEI VFQ-25 domains specific to social engagement, role performance, dependency and mental health were completed to provide quantitative outcomes that offered positive results. The NEI VFQ-25 domain scores range from 0-100 with higher scores representing higher levels of functioning.¹² GDS scores generally decreased (all except one participant) which may be related to increased identification of mental health needs and increased referrals to appropriate mental health professionals upon evaluation. The GDS scores range from 0-15 with the higher scores suggesting higher levels of depression and the need for mental health intervention.¹³ These quantitative results have


been displayed in Table 2.

This group has demonstrated many successes and many challenges. The group became cohesive and supportive of one another. Commonalities beyond vision impairment were identified and participants began disclosing personal needs, asking others for assistance, and supporting one another physically and emotionally. Each group participant developed a level of personal responsibility for the group and demonstrated a strong commitment to one another. Each participant demonstrated improved social interactions, improved quality of life measurements, and improved social/leisure activity engagement outside of the group. Professionally, the formation of this group has been incredibly rewarding. Staff and participants

have been receptive and willing to participate without hesitation.

Creating a group that fit multiple participants' needs, while providing individual support, proved to be a challenge. Acknowledging transportation needs, scheduling conflicts and expenses required for community engagement continues to be an ongoing challenge. The selection of receptive group participants and establishing group norms provided a guide to the group formation and has helped to reduce the significance of these challenges.

The group continues to grow and expand. Opportunities to engage in multiple groups, both through the rehabilitation program as well as in the community, are provided and participants are encouraged to attend and engage in as many as they wish.

Overall, participation in leisure and social activities is important to quality of life for people with vision impairments. A rehabilitation program that includes social and leisure participation programming is essential in holistically addressing participants' needs while providing a transition into the community. 

Karla Sternberg has been an occupational therapist, specializing in low vision for the past three years. Currently, Karla practices as an Occupational Therapist in the Vision Impairment Outpatient Rehabilitation program at the Michael E. DeBakey VA Medical Center in Houston, TX. In 2007, Karla obtained a Master's of Occupational Therapy (MOT) degree from Texas Woman's University in Houston, TX and in 2009 became a Certified Low Vision Therapist (CLVT) through the Academy for Certification of Vision Rehabilitation and Education Professionals (ACVREP). Karla obtained the recognition of Specialty Certification in Low Vision through the American Occupational Therapy Association in 2011. Karla's previous experience includes the development of a low vision program at a world renowned cancer institution based in Houston, TX and has lectured at both the state and national level regarding occupational therapy low vision practice.



References:

1. Perlmutter MS, Bhorade A, Gordon M, Hollingsworth HH, Baum MC. Cognitive, visual auditory, and emotional factors that affect participation in older adults. *Am Occup Ther.* 2010; 64(4): 570 – 579.

2. Rees G, Fenwick EK, Keeffe JE, Mellor D, Lamoureux EL. Detection of depression in patients with low vision. *Optom Vis Sci.* 2009; 86 (12): 1328 – 1336.

3. Teitelman J, Copolillo A. Psychosocial issues in older adults' adjustment to vision loss: Findings from qualitative interviews and focus groups. *Am Occup Ther.* 2005; 59: 409 – 417.

4. Fenwick EK, Lamoureux EL, Keeffe JE, Mellor D, and Rees G. Detection and management of depression in patients with vision impairment. *Optom Vis Sci.* 2009; 86(8): 948 – 954.

5. American Occupational Therapy Association. Occupational therapy practice framework: Domain and process (2nd.). *Am Occup Ther.* 2008; 62: 625 – 683.

6. Fisher AG, Griswold LA. *Evaluation of Social Interaction.* 2nd ed. Fort Collins, CO: Three Star Press; 2010.

7. Lamoureux EL, Fenwick E, Moore K, Klaic M, Borschmann K, Hill K. Impact of the severity of distance and near vision impairment on depression and vision – specific quality of life in older people living in residential care. *Invest Ophthalmol Vis Sci.* 2009; 50(9): 4103 – 4109.

8. Alma MA, Van Der Mei SF, Melis-Dankers BJM, Van Tilburg TG, Groothoff JW, Suurmeijer TPBM. Participation of the elderly after vision loss. *Disabil Rehabil.* 2011; 33(1): 63 – 72.

9. Lamoureux EL, Hassell JB, Keeffe JE. The determinants of participation in activities of daily living in people with impaired vision. *Am Ophthalmol.* 2004;137: 265 – 270.

10. Stewart D, Letts L, Law M, Acheson Cooper B, Strong S, Rigby PJ. The person environment occupation model. In Blesedell, Crepeau ES, Cohn, and Boyt Schell BA, eds. *Willard & Spackman's Occupational Therapy.* 10th ed. Philadelphia: Lippincott Williams & Wilkins; 2003: 227 – 231.

11. Group Dynamics website. <http://getinvolved.uky.edu/Leadership/pdf/Group%20Dynamics.pdf> Accessed August 8, 2011.

12. National Eye Institute. National Eye Institute Visual Functioning, Questionnaire – 25 (VFQ-25). Rand. 1996.

13. Yesavage JA, Brink TL, Rose TL, Lum O, Huang V, Adey MB, Leirer VO. Development and validation of a geriatric depression screening scale: A preliminary report. *Psychiatr Res.* 1983; 17: 37-49

Severe Brain Injury, Vision Loss and Promising Employment Models.....BJ LeJeune, MEd, CRC, CVRT

In January 2007, my husband, who has a congenital vision loss, went out to the woodpile at our mountain home in Tennessee and tripped over a rock in the snow, pitching himself headfirst down the side of a mountain. His downhill journey was stopped by a large tree which probably saved his life, but which also caused considerable damage. Most notably, he suffered a traumatic brain injury known as a subdural hematoma. He was airlifted to the University of Tennessee Medical Center in Knoxville where he had a craniotomy and suffered a stroke. I have been a vision rehabilitation therapist and vocational rehabilitation counselor for years, so I felt as though I had at least some idea of what we were facing. Unfortunately, I found myself in very new territory. During the rehabilitation process, I often felt we were going three steps forward and two steps back. We had wonderful resources throughout the acute and rehabilitation process, but when he was released for us to go home to rural Mississippi, we were on our own.

I began the process of reading and educating myself on traumatic brain injury and vision loss. According to a recently revised definition of traumatic brain injury (TBI) by the Brain Injury Association of America, *traumatic brain injury is defined as an alteration in brain function or other evidence of brain*

*pathology, caused by an external force.*¹

One of the major challenges in working with someone with a brain injury is that each individual is dramatically different. These differences are due to the type of brain injury (i.e. concussion, diffuse axonal, shaken baby syndrome, etc.), the severity of the brain injury (mild, moderate or severe), the age at which it occurs, the rehabilitation resources available, the overall health and intellect of the individual involved, and the type of support system that is available to assist the person in coping with their injury. The additional complication of a related visual impairment caused by brain injury rather than ocular issues makes rehabilitation even more complicated. For someone with a pre-existing visual impairment, it is even more complex.

The typical types of visual impairments related to a brain injury include hemianopsia (a loss of half of the field of vision), visual neglect (seeing but not acknowledging areas, usually on the left), visual spatial disorders (causing difficulties with depth perception, localization and personal space boundaries), impaired eye movements (nystagmus, saccadics or difficulty tracking), lack of visual memory, reading impairments similar to dyslexia, light sensitivity, and visual hallucinations (Charles Bonnet

Syndrome).^{2,3} Visual impairments in some, particularly children, may also include Post Traumatic Vision Syndrome (PTVS) which includes strabismus, ocular motor dysfunction, blurred and double vision and the onset of some blindness-specific mannerisms such as rocking.

Keep in mind that damage to the brain as a result of a traumatic injury may also have characteristics of Cortical Vision Impairments (CVI); it is good to assess these areas as well. The classic CVI characteristics according to Christine Roman-Lansky,⁴ include 1) difficulty with novelty (inability to recognize new things), 2) difficulty with visual complexity, 3) distinct color preferences (red and yellow), 4) non-purposeful gaze, 5) visual latency, 6) atypical motor behaviors (looking away when reaching), 7) absent or atypical reflex responses.

My husband has congenital glaucoma and is aphakic. Neither his neurologist nor his optometrist indicated any difference in visual functioning. However, being a Vision Rehabilitation Therapist (VRT), I found that he did have several symptoms that were not investigated by his medical team. When tested, his visual acuity is the same – about 20/400. However, I have noticed his ability to use his vision has decreased somewhat – especially with novel items or in complex or cluttered environments.

He also seems to need more light although he is less tolerant of the increased lighting. He initially presented with left side neglect, but that seems to be improving, in part because balance issues cause him to walk more slowly and he is more attentive. We are thankful that he does seem to be able to self-regulate some of his symptoms due to the injury, such as fatigue, problem-solving, anxiety triggers and word retrieval.

The challenge for those who have had a brain injury and their caregivers is that once released from acute care facilities, it is difficult to find someone with expertise and experience to manage the complexity of issues created by the injury and accompanying vision loss. As professionals, we may have a few pieces of the puzzle; however, it is critical to involve individuals with specific expertise and interest in order to get a complete picture. This includes an interdisciplinary team made up of the appropriate selection of family members, optometrists, ophthalmologists, certified brain injury specialists, neurologists, psychiatrists, vision rehabilitation therapists, physical therapists, nurses, occupational therapists, orientation and mobility specialists, low vision therapists, behaviorists, vocational rehabilitation counselors, social workers and even pharmacists. Now there are subsets of these groups who often work together, but there are also people on this list that rarely, if ever, come together in a professional setting. It is unlikely that this group

will ever meet, so there needs to be one or two professionals who can coordinate and facilitate the process of sharing information.

In terms of facilitating employment outcomes, there are three models I would like to suggest be investigated for our purposes. No single model will suit all persons as everyone with a brain injury is different. However, these may hold ideas that will facilitate our use. We do know that participation in vocational rehabilitation is a predictor of employment outcomes.^{5,6} Research by Ben-Yishay, Silve, Piasetsky and Ratok⁷ confirms that early vocational rehabilitation services, a supportive work environment, cognitive skills training and assistive technology training were all moderately supportive in returning people to work after brain injury. Three models were investigated by a systematic literature review by Fadyl and McPherson⁸ who were looking at brain injury only – no visual considerations were given. These three models have been used with the brain injury population and may have some value for those with additional vision loss. They are the Case Coordination Approach, the Supportive Employment Model and the Program Based Vocational Rehabilitation (VR) model.

The case coordination approach is a holistic approach based on individual assessments and is implemented by a single case manager. The focus is on early intervention and continuity of care. There is coordination of post-acute

rehabilitation services with integration of vocational rehabilitation (VR) services. During the literature review of nine research articles, Fadyl and McPherson⁸ found that there is a moderate amount of evidence that this model produces higher employment rates and productivity than previously had been reported. They also found that 50 percent of participants continued in paid competitive employment up to one year after placement. The advantage of this model is that there is one case manager that can coordinate communication and service delivery among the various specialists. The ideal person would be a Certified Brain Injury Specialist (CBIS), but could also be a physician, a VR counselor, a family member or any member of the interdisciplinary team. My personal observation is that communication is often scattered at best, and for people in rural areas that travel to specialists in different geographic areas, this may be a very useful tool.

The supportive employment model is based on a quick and early job placement with minimal pre-employment training. Training is primarily delivered in the context of the working environment. The intervention is delivered almost entirely via on-the-job training and continues until competency is reached. Length and depth of the supportive employment intervention is individually determined. The Fadyl and McPherson literature review⁸ found there was weak evidence that there was a slightly higher placement rate for

chronically unemployed persons and the competitive employment seemed to be able to continue on as long as supports were in place. However, when the job coach was removed, the employment may not be sustained. For severely involved persons, those with poor self-advocacy competencies, or those with self-management and behavioral issues, this may be a very viable approach.

The last model is based on the NYU Medical Center Head Trauma Program Model⁷ which involved intensive individualized work skills rehabilitation in a structured center environment with guided work trials outside the center. Job placement with transitional job support was available. According to Fadyl and McPherson⁸, this model was found to show weak evidence that individuals had better vocational outcomes after completing the program. There was also weak evidence that individuals in this type of program were more likely to gain competitive employment, more work hours and receive higher wages. About half of those placed

retained employment for more than a year. The advantage of this type of program is that for those individuals who need restructuring of neural pathways, repetition and structure is necessary. This type of program is comprised of a full array of specialists with individualized strategies that may enhance employability and independence by retraining the brain to think and act differently.

Since my husband began his journey, I have heard physicians say that no one with a severe brain injury will ever be able to return to full-time employment. I have heard others state that with proper interventions and support, employment is a viable option for the same group. My personal observation is that there are a lot of “ifs.” If the person is motivated and able to self-regulate behaviors, if they have the necessary support system, and if they have an active in-place team of persons working to that end, perhaps employment is a viable option. However, I have talked with many VR counselors within the field of blindness and low vision who

are trying to facilitate job placement without either access to successful models or any of the “ifs” in place. My husband is past retirement age so for him, job placement was not a goal. However, since the majority of those with brain injuries are between the ages of 18 and 35, for them, and their families, it is critical that we find ways to facilitate the job development process. 👁

BJ LeJeune is the Training Coordinator at the Rehabilitation Research and Training Center on Blindness and Low Vision at Mississippi State University. She has years of experience working in a variety of direct service positions and currently serves as an agency administrator, college instructor and researcher. She has a master's degree in Rehabilitation Teaching (now known as Vision Rehabilitation Therapy) from the University of Arkansas, and has completed all coursework toward a Doctoral Degree in Rehabilitation Counseling at Mississippi State University. She has served on multiple state and national committees in the areas of aging, education, vision rehabilitation therapy and dual sensory loss.



References:

1. BIAA Adopts New TBI Definition. Brain Injury Association of America Web site. February 6, 2011. Available at www.biausa.org/AnnouncementRetrieve.aspx?ID=66290 Accessed January 9, 2012.
2. Cohen Allen H. Visual Problems associated with acquired neurological events. 2011 Available from http://www.braininjuries.org/brain_injury_double_vision.html.
3. Goodrich G. *The function of the brain in acquired sight loss*. Power Point Presentation, NW Regional TACE 10 Webinar series, October, 2011.
4. Roman-Lansky C. *Cortical Visual Impairment Workshop*; 2006. Sponsored by American Foundation for the Blind. Memphis, TN.
5. Johnstone B, Vessel R et al. Predictors of success for state vocational rehabilitation clients with traumatic brain injury. *Arch Phys Med Rehabil* 2003;84:161-7.
6. Catalano D, Pereira AP, Wu MY, Ho H, Chan F. Service patterns related to successful employment outcomes of persons with traumatic brain injury in Vocational Rehabilitation. *NeuroRehabilitation* 2006; 21: 279–293.
7. Ben-Yishay Y, Silver SM, Piasetsky E, Ratok J. Relationship Between Employability and Vocational Outcome after Intensive Holistic Cognitive Rehabilitation. *J Head Trauma Rehabil* 1987; 2(1):35–48.
8. Fadyl JK and McPherson KM. Approaches to Vocational Rehabilitation after Traumatic Brain Injury: A Review of the Evidence. *J Head Trauma Rehabil* 2009; 24:195–212.

Vision Impairment: The Impact on Social Cognition and Social Ability.....Carolyn D. Palmer, PhD

Vision plays a role in the development of early skills for social cognition which involve perspective-taking and joint-attention behaviors. The impact of vision loss on the development of social cognition and social ability affects a child’s proficiency in perceiving and interpreting the ideas and sensitivities that underlie what people say and do.¹ Decreased visual acuity restricts understanding of the context of social interaction and the ability to choose appropriate initiations or responses. It may also affect competence in processing how peers interact with each other and how they act upon other information such as verbalizations.

This study reports on an aspect of the findings of a much larger study that aimed to investigate the effects of severe vision impairment on children’s social competence, social ability and their involvement in peer relationships. The major focus of the larger study was on children and youth with Albinism. The aim was to investigate whether or not there is a relationship between their vision loss, social information processing, and patterns of social behavior. The major study also involved a parallel investigation of students with vision impairment and those with no vision loss in order to establish similarities and differences in the social competence of the three groups.

THE NATURE OF SOCIAL COGNITION AND SOCIAL ABILITY

Social cognition is a significant aspect of social ability and a mediator in the socialization process.² It underpins how individuals process social cues, operate appropriately in various situations and show appropriate feelings. It is concerned with the capacity to conceptualize others, understand social relationships, “understand the thoughts, emotions, intentions, and viewpoints of others in social situations,”³ and the ability to relate to others. Social cognition is influenced by children’s intelligence, experience and culture.⁴

Social ability is about how individuals make social decisions and how they solve social problems. It involves social understanding, showing appropriate feelings, the ability to process social cues in various situations, and knowing how and when to say and do appropriate things. It represents the integration of socio-cultural knowledge, cognitive, developmental and behavioral experiences.²

IMPACT OF SEVERE VISION LOSS

The literature indicates that social cognition and social information processing is disrupted by severe vision impairment and that children and youth with vision impairment have limited social understanding. Their social behavior indicates impairments in social cognition

that result in significant impediments to successful peer and other relationships.^{6,7} They often have limited social understanding.⁸ This limitation is due to their difficulty in interpreting social cues and body language, monitoring and responding to the interests of peers, monitoring their own behavior in social situations and being aware of how others respond to certain behaviors. The majority of children with vision impairment do not have enough sight to learn about the social nuances being enacted around them.⁹

To gain a picture of the social cognition and social ability of children and youth with vision impairment, the following research questions were posed: Do children and youth with vision impairment:

1. Say things that fit inappropriately with what others say?
2. Do things that fit inappropriately with what others do?
3. Show inappropriate feelings?

METHOD

Data were collected using the Social-Emotional Dimension Scale (SEDS) which relied on informant reports from teachers. Three aspects of the SEDS questionnaire from the section on inappropriate behaviors were examined. These focused on: student says things that fit inappropriately with what others are saying; student does things that fit

inappropriately with what others are doing; student shows inappropriate feelings (e.g. looks or acts happy when should be sad). Class teachers rated each of the items according to whether the behavior had been observed never or rarely, occasionally or frequently.

INSTRUMENTS

The Social-Emotional Dimension Scale (SEDS), which teachers were asked to complete in relation to each participant, is described as a highly structured, norm-referenced rating scale.¹⁰ For the purpose of this study, the SEDS instrument was used as an informant report to judge the behavior of children with vision impairment in their educational setting.

THE PARTICIPANTS

Three groups of students participated in the study: 10 young learners with albinism, six with vision impairment and nine students with no vision problems. The students with albinism were divided into three groups: Those with oculocutaneous albinism: tyrosinase negative (OCA1); oculocutaneous albinism: tyrosinase positive (OCA2); and ocular albinism (OA). The student participants were aged between 8

and 16. The nature of the instruments used in the study were not appropriate for students younger than 8, and students over the age of 16 were either engaged in their final years of study, or were likely to leave school during the collection of data. Table 1 shows the gender, age and visual acuity of the participants with vision impairment. The visual profile of the student participants is presented in percentages in Figure 1.

Why children with albinism were included in the group

Children and youth with albinism differ from other young people with vision impairment because of their

physical appearance (very pale, non-pigmented skin and white hair). The inclusion of children and youth with albinism enabled the researcher to establish whether the additional factors inherent in this condition resulted in significant differences in the social cognition and social ability of these students compared with peers with vision impairment (not albinism) and those with no vision loss.

Why students with albinism were divided into three groups

The reason for differentiating between the three albinism groups was to gauge whether the physical appearance of these children had

Table 1: Profile of students with vision impairment in terms of gender, age, eye condition, date of birth.					
Participants	Gender	Age	Eye Condition	Date of Birth	
1	M	10	Oculocutaneous Albinism Tyrosinase negative (OCA-)	9 years	
2	F	11	Oculocutaneous Albinism Tyrosinase negative (OCA-)	11 years	
3	F	11	Oculocutaneous Albinism Tyrosinase negative (OCA-)	11 years	
4	M	14	Oculocutaneous Albinism Tyrosinase positive (OCA+)	14 years	
5	M	9	Oculocutaneous Albinism Tyrosinase positive (OCA+)	9 years	
6	M	13	Oculocutaneous Albinism Tyrosinase positive (OCA+)	13 years	
7	M	13	Oculocutaneous Albinism Tyrosinase positive (OCA+)	13 years	
8	M	11	Ocular Albinism (OA)	11 years	
9	F	8	Ocular Albinism (OA)	8 years	
10	M	16	Ocular Albinism (OA)	16 years	
11	F	13	Microcephaly progressive degenerative retinal dystrophy	13 years	
12	F	11	Coloboma	11 years	
13	M	13	Retinitis Pigmentosa	13 years	
14	F	13	Encephalitis, vision impairment	13 years	
15	M	12	Congenital nystagmus	12 years	
16	M	12	Bilateral lens implant. Congenital cataracts, micro cornea, astigmatism	12 years	
17	M		No vision loss	10 years	
18	M		No vision loss	12 Years	
19	M		No vision loss	9 years	
20	M		No vision loss	8 years	
21	M		No vision loss	13 years	
22	M		No vision loss	10 years	
23	M		No vision loss	13 years	
24	F		No vision loss	12 years	
25	M		No vision loss	9 years	

an impact on their social ability and social understanding. Although all of the participants had what is considered to be severe vision impairment, their physical characteristics differed, ranging from those in the most severe form of albinism (OCA1) with white hair and skin, to those with the mildest form (OA), whose skin and hair was not affected.

LIMITATIONS AND DELIMITATIONS

This study was limited by the size and nature of the group of students with vision loss under investigation. Vision impairment is a low incidence disability, and albinism is a rare condition. The subjects studied were limited to the children and youth (both vision impaired and sighted) who lived in the metropolitan area in a city in Australia and attended a regular primary or secondary school. The age of the participants was limited to students between the ages of 8 and 16. The sensitivity of the area and the unwillingness of some parents to participate in the study, further limited access to subjects. Because of the low numbers of participants available for the study, findings must be interpreted with care.

RESULTS

The teacher ratings from the SEDS questionnaire showed that the majority of students with albinism were liable to say things that fitted inappropriately with what others were saying and half were apt to show inappropriate feelings

and do things, either occasionally or frequently, that fitted inappropriately with what others were doing. When viewed in relation to their peers with vision impairment (not albinism) and those with no vision problems, students with albinism were liable to show inappropriate feelings more consistently than students in both groups. In addition, they were more inclined to say and

Four students (40%) with albinism (OCA1, 1; OCA2, 3) did so occasionally, while two students (20%) with albinism (OCA1, 1; OCA2, 1) did so frequently. In other words, six (60%) of the group of students with albinism, as shown in Figure 2, exhibited this inappropriate behavior either occasionally or frequently, with students with OCA2 being the most likely group within

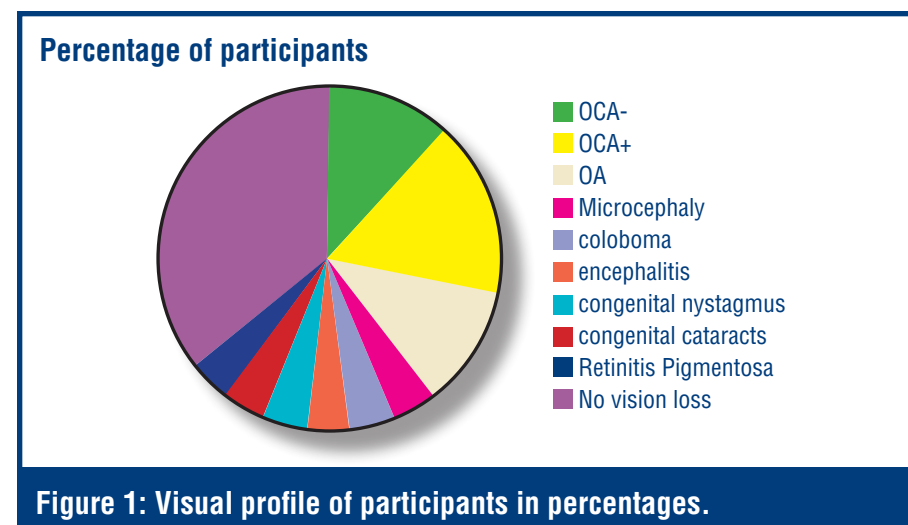


Figure 1: Visual profile of participants in percentages.

do inappropriate things than their sighted peers, but less inclined than students with vision impairment (not albinism). These difficulties can be reasonably blamed on their difficulties in reading body language, interpreting facial expression, and processing social clues, particularly the more subtle innuendos, in various situations. These findings are presented in more detail below.

Students say inappropriate things

The teacher ratings showed that four students (40%) with albinism (OCA1, 1; OA, 3), never or rarely said things that fitted inappropriately with what others were saying.

the albinism group to do so, and students with OA being the least likely.

Teachers of students with vision impairment (not albinism) and teachers of students with no vision loss also rated these groups of students. Their reports showed that students with albinism were more likely to say things frequently that fitted inappropriately with what others were saying than students with no vision loss and students with vision impairment (not albinism), but less likely to do so occasionally than students with vision impairment (not albinism). The sighted group, however, had a higher incidence of never exhibiting

this behavior than students with albinism. The findings are shown in Figure 2.

Students do inappropriate things

Two students (20%) with albinism (OCA1, 1; OCA2, 1) were reported by their teachers to do things frequently that fitted inappropriately with what others were doing, three (30%) were reported to do this occasionally (OCA2, 3), and five (50%) never (OCA1, 2; OA, 3). Figure 3 shows that when the findings on students with albinism were examined in relation to those on students with vision impairment (not albinism) and students with no vision loss, students with albinism had a lower incidence of behaviors that fitted inappropriately with what others were doing than students with vision impairment (not albinism), but a higher incidence than students with no vision loss. Within the group of children with albinism, students with OA were less likely to behave inappropriately in relation to what others were doing compared with children with OCA1 and those with OCA2. The findings are shown in Figure 3.

Students show inappropriate feelings

Only one student (10%) with albinism (OCA2) was reported to show inappropriate feelings frequently, four (OCA1, 1; OCA2, 3) were said to show these feelings occasionally (40%) and five (50%) never (OCA1, 2; OA, 3). When these findings were examined in relation to the teachers' assessment of the

behavior of students with vision impairment (not albinism) and no vision loss, it was found that six students with vision impairment (not albinism) never or rarely showed inappropriate feelings (100%). In addition, seven sighted students (78%) never or rarely showed inappropriate feelings and two (22%) showed them occasionally. These findings are represented in Figure 4.

An analysis of the data for this aspect of the study revealed that students with albinism were more likely to show inappropriate feelings than students with vision impairment (not albinism) and those with no vision impairment, while the students with vision impairment, but not albinism, according to their teachers, were the least likely. Four out of the five students with albinism who showed inappropriate feelings, however, did so only occasionally.

Overall, a small majority of students with albinism (60%) were reported to say things that fitted inappropriately with what others were doing, while half were perceived to behave in a way that fitted inappropriately with what others were doing, and also to show inappropriate feelings either occasionally or frequently. Students with OCA2 were more inclined to behave inappropriately than those with OCA1 and OA, and they were also more likely to make inappropriate comments, and show inappropriate feelings. The findings also concluded that students with albinism were less likely to say and

do inappropriate things than their vision impaired (not with albinism) peers, but more likely than students with sight. However, they were considerably more likely to show inappropriate feelings than children in these other two groups.

CONCLUSION

The examination of the social cognition and social ability of children with vision impairment provides new insights into the social competence of this group of children. This paper focuses on factors that have the potential to affect their social development and peer interactions. In an environment where social competence is valued and perceived to be a crucial element in successful interaction with others, children who behave differently and fail to interpret the subtle messages transmitted to them by their peers, are likely to have difficulty establishing relationships with classmates.

Overall, this study concluded that the social ability of students with vision impairment varied from very competent to not very good in much the same way as the social ability of students with no vision problems. Although there is strong evidence in the literature to support the premise that severe vision impairment has a major impact on the development of social skills,^{11,12} the findings from this study show that in terms of social ability, students with vision impairment, while they have some areas of weakness, are not markedly different from other students. If any aspects of social ability

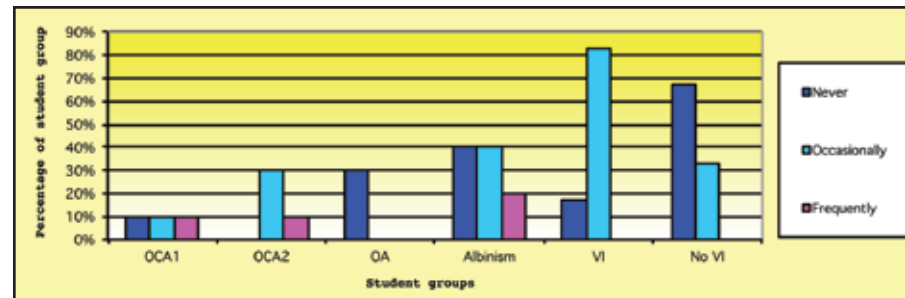


Figure 2: Percentage of students by category (OCA1, OCA2, OA, vision impairment but not albinism, no vision impairment) and rate of response, who say things that fit inappropriately with what others are saying (N=25).

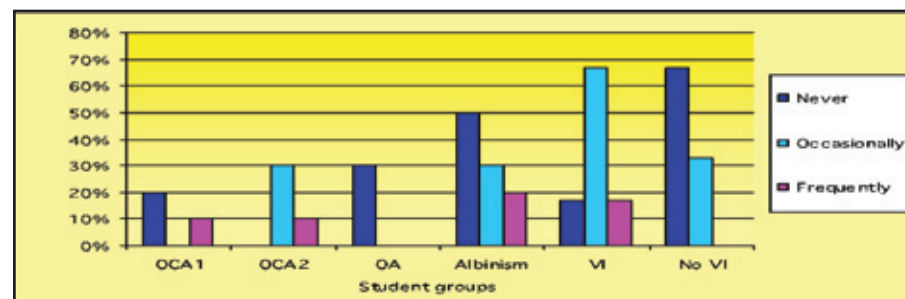


Figure 3: Number of students by category (OCA1, OCA2, OA, vision impairment but not albinism, no vision impairment) and rate of response, who do things that fit inappropriately with what others are doing (N=25).

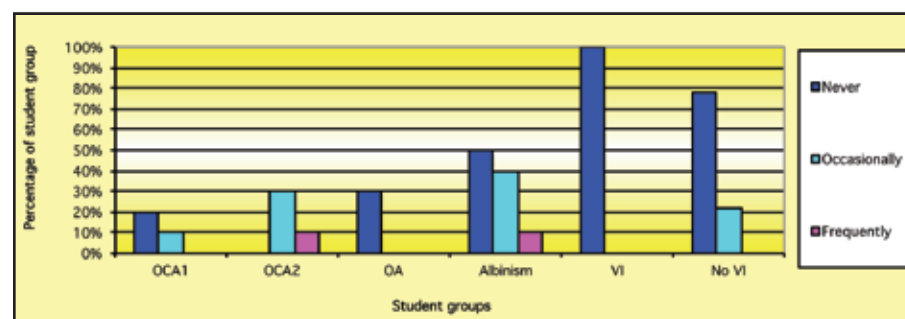


Figure 4: Number of students by category (OCA1, OCA2, OA, vision impairment, but not albinism, no vision impairment) and rate of response, who show inappropriate feelings, e.g. looks or acts happy when should be sad (N=25).

need to be highlighted as areas of concern, the most obvious ones are social cognition, particularly in respect to students with the most severe form of albinism (OCA1), and the likelihood that children with albinism will show inappropriate feelings. Clearly, the tendency of some children and youth with vision impairment (mainly those with albinism) to say and do inappropriate

things, and show inappropriate feelings, increases the likelihood of social rejection and the need for monitoring and intervention.


This research was based on theories of social and cognitive development. The importance of social interaction emerges clearly from the theoretical research, and the notion that social competence evolves through a process of

interaction with peers, observation, modeling and feedback gives insight into the process of socialization and the critical nature of social cognition and social ability. It is acknowledged that the study of small samples imposes limitations on the generalizability of findings. Despite these limitations, this study generated insights into factors related to the social cognition and social ability of students with vision impairment in ways that had not been investigated previously.

In conclusion, this paper reports on a study that involved a small group of subjects. What was being studied was the student and what the researcher sought to understand was the complex, dynamic system of social cognition and social ability in which vision impairment plays an important role. The major focus of this small study, as reflected in its title, was to investigate the effects of vision impairment on children's social cognition and social ability. The use of the Social Emotional Dimensional Scale (SEDS) was well-suited to the investigation because this instrument probed the views of teachers who work with the students on a day-to-day basis. Limitations were imposed by the nature of the participants, the groups involved, and the ages of the students. Recruitment was difficult because of the nature and sensitivity of the condition and its low incidence.

Finally, when children have albinism or other forms of vision impairment which affects their lives in many ways, it is critical that

professionals understand how this condition may limit social learning, social ability, social behavior and social emotional reactions. They need to understand that the inability

to use vision efficiently in social situations and understand social dynamics makes this group of children vulnerable and at risk of social isolation. 

References:

1. Pring L, Dewar H, Brockbank M. Social cognition in children with visual impairments. In Zebehazy KT, Smith TJ, An examination of characteristics related to the social skills of youths with visual impairments. *J Vis Impair Blind*. 2011; 105: 84-95.
2. Andrews J, Lupart J. *The Inclusive Classroom: Educating Exceptional Children*. Scarborough, Ontario: Nelson; 1993.
3. Shantz CU. The Development of Social Cognition. In Hetherington M, ed. *Review of Child Development Research*, Vol. 5. Chicago: University of Chicago Press; 1975.
4. MacCuspie PA. Social Skills in School and Community. In Sacks SZ, Wolfe KE (Eds). *Teaching Social Skills to Students with Vision Impairments: From Theory to Practice*. New York: AFB Press; 2006:243.
5. McNamara C, Wigfield B. A Self-perception of friendship-making ability and perceptions of friends' deviant behaviour: Childhood to adolescence. *Early Adolesc*. 2002; 22:143-172.
6. Bellanti CJ, Bierman KL. Disentangling the impact of low cognitive ability and inattention on social behaviour and peer relationships. *Clin Child Psychol*. 2000; 19:66-75.
7. Palmer CD. Social skills. In Kelley P, Gale G, Towards Excellence: *Effective Education for Students with Vision Impairments*. Sydney: Royal Institute for Deaf and Blind Children; 1998:208-217.
8. Warren DH. *Blindness and Children. An Individual Differences Approach*. New York: Cambridge University Press; 1994.
9. Wolfe KE, Sacks SZ, Thomas KL. *Focused On: Importance and Need for Social Skills*. Study Guide. New York: AFB Press; 2000.
10. Hutton JB, Roberts TG. *Social-Emotional Dimension Scale: A Measure of School Behavior*. Austin, Texas: Pro-ed; 1986.
11. Gumpel TP, Nativ-Ari-Am H. Evaluation of a technology for teaching complex social skills to young adults with visual and cognitive impairments. *Journal of Visual Impairment and Blindness*. 2001; 95:95 – 107.
12. Sacks SZ, Silberman RK. Social skills. In Koenig AJ, Holbrook MC, *Foundations of Education. Volume 11: Instructional Strategies for Teaching Children and Youths with Visual Impairments*. 2nd ed. New York: AFB Press; 2000:616-648.

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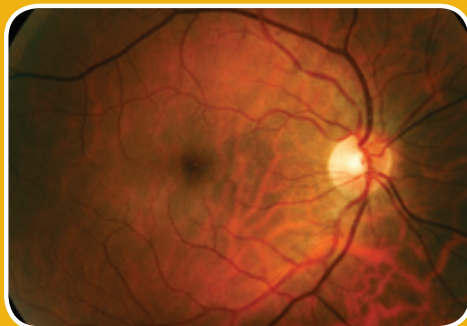
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