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Family Functioning and Low Vision: A Systematic Review

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Abstract

This review highlights the literature on the function and adjustment process of family members of persons with adult-onset vision loss. The majority of the literature has focused on the unique role that the family plays in providing both instrumental and emotional support to adults with low vision. In contrast, the impact of low vision on the psychosocial adjustment of the family has been largely understudied. The review concludes with a discussion of the implications for clinical practice, along with directions for future research on the family within the context of low vision rehabilitation.

Although extensive research has documented the emotional and functional changes that accompany vision loss for persons with low vision (see, for example, Dreer, Elliott, Berry, Fletcher, & Swanson, 2008; Dreer, Elliott, Fletcher, & Swanson, 2005), little attention has been paid to the study of the adjustment process of these persons' family members. This lack of attention is surprising, since family members are often responsible for providing various degrees of instrumental and emotional support for persons with low vision (Cimarolli & Boerner, 2005; Reinhardt, 1996, 2001; Reinhardt, Boerner, & Horowitz, 2006). In this sense, family members often function as important, informal extensions of health care with little preparation or training. This role may become even more demanding when the relative with low vision also has a chronic health condition that requires assistance (Dreer, Berry, Elliott, & Rivera, 2007; Schmier, Halpern, Covert, Delgado, & Sharma, 2006). Depending on the type and level of support that is provided, the role that family members play in providing support is likely to cause them strain over time, particularly as they struggle to balance their own needs with the needs of the individual with low vision. Thus, a greater understanding of family

members' experiences is needed to promote the optimal well-being and successful adjustment of both individuals with low vision and their family members.

Role of the family

In this review, we highlight the existing literature examining the function and adjustment process of family members of persons with adult-onset vision loss. Relevant peer-reviewed empirical studies and critical reviews were identified through MEDLINE and PsycINFO (EBSCO) databases.

Adjustment to vision loss often occurs within the context of a social network of family members and friends (Orr & Rogers, 2006; Travis et al., 2003). Although research has demonstrated the influential role of both family members and friends on the well-being of persons with low vision throughout the life span (see, for instance, McIlvane & Reinhardt, 2001), immediate family members share a more intimate role than do friends in that they 1) often live or have lived with the person with low vision (as a spouse, child, parent, or sibling), 2) have firsthand knowledge of the person's medical history across time, 3) have observed how the person with low vision has reacted to and coped with vision loss and other stressors in life, 4) often accompany the relative with low vision to eye examinations and rehabilitation services, and 5) serve as communicators and liaisons with vision-related health care providers. Although the structure and composition of families have changed significantly over the past several decades, the family remains the primary unit for providing physical, emotional, and social support (Palmer & Glass, 2003), and is closely involved in low vision rehabilitation services (Travis, Boerner, Reinhardt, & Horowitz, 2004). Thus, the degree and type of support that is provided may vary, depending on a number of factors, including the severity of the relative's visual impairment, the impact of vision loss on everyday living, the number and type of other comorbid health problems, cognitive functioning of the person with low vision, living arrangement, financial situation, and access to services and resources (such as those living in rural versus urban settings). In this sense, the family is likely to influence the health and rehabilitative outcomes of persons with low vision.

Impact of vision loss on family members' reactions

The diagnosis of visual impairment often has an immediate and lasting impact on family members. Although family members may vary in their reactions, the initial diagnosis may cause them considerable stress. For instance, Tuttle (1986) suggested that family members experience several phases of adjustment similar to those of their relatives with low vision, including shock-denial, mourning-withdrawal, succumbing-depression, reassessment-reaffirmation, coping-mobilization, and self-acceptance-self-esteem. As family members begin to adapt, they focus more on the reality, challenges, and implications of low vision on everyday living and family roles. For example, family members with progressive age-related visual impairment may need greater assistance in activities of everyday living as the disease advances. In addition, families may face economic stress due to the costs associated with purchasing low vision devices that are not covered by insurance companies, rehabilitation services (such as transportation to low vision rehabilitation appointments), and the loss of wages that can result when a family member takes time off work to provide assistance. Given the practical, functional, and economic needs related to assisting relatives with low vision, family members may experience distress when attempting to cope with these new demands.

Family systems-based approach to adjustment

Although there is no widely agreed-upon model for the adjustment of family members to the vision loss of relatives, one informative conceptual framework for understanding such adjustment to chronic illness is referred to as the family systems-based approach (Broderick,

1993; Minuchin, Rosman, & Baker, 1978; Rolland, 1989, 1994). From a family-systems perspective, the person with the disability and his or her family members are part of a complex, integrated system with preexisting patterns of relationships, norms, rules, roles, and communication styles (Palmer & Glass, 2003). Thus, a chronic disability, such as low vision, poses a unique challenge to preexisting relationship patterns. Changes occur not only in the sensory capabilities of the person with a chronic disability, but in the broader pattern of social relationships of the family (Glass & Maddox, 1992). Family members serving as informal caregivers who provide assistance may be particularly challenged as they function in new roles and redefine the way in which they identify themselves (Glass & Maddox, 1992). The experience of caregiving is further complicated as family members seek to balance offering assistance with maximizing the person's safe independence. This challenge may be ongoing as vision loss progresses or may be made more difficult if the person with low vision is also experiencing neurocognitive changes due to a comorbid neurological disease.

Insofar as the family system is flexible, adaptive, cohesive, supportive, and high functioning, it fosters a successful transition for the person with disability and ensures the continuity of valued family relationships (Glass & Maddox, 1992). However, family dysfunction may exacerbate the difficulties associated with adjusting to the loss of vision. Therefore, adjustment for both the person with vision loss and his or her family members may be viewed as a family process in which one of the core challenges that the family confronts is the need to modify existing patterns of interaction, expectations, family norms, and roles to accommodate changes that are due to the loss of vision. Acknowledging the family system in which vision loss occurs may provide for a more holistic, comprehensive approach to low vision rehabilitation (Silverstone, 2000).

Impact of family support on persons with low vision

Families often function by providing various levels of support to their family members with low vision (Barron, Foxall, von Dollen, Jones, & Shull, 1994; Cimarolli & Boerner, 2005; Reinhardt, 1996). *Instrumental support*, also referred to as *tangible support*, is defined as providing assistance with tasks of everyday living. In contrast, *emotional support* is referred to as *affective* or *social support* and can be defined as providing encouragement or comfort during difficult times. Support may be further broken down into support received (actual support) versus support perceived (perception of support). Compared to friends, family members are relied on more often by individuals with low vision for both instrumental and emotional support (Cimarolli & Boerner, 2005). Support from family members appears to be critical to an individual's adaptation to vision loss. Evidence suggests that adequate emotional and instrumental support protects against distress and other negative health outcomes (Kleinschmidt, 1999; Ringering & Amaral, 2000), and has a stress-buffering effect when resources for support are responsive to the needs imposed by a stressor (Reinhardt & D'Allura, 2000).

INSTRUMENTAL SUPPORT

Instrumental support is critical for persons with low vision because the majority of these persons have some degree of functional limitations associated with their vision loss. The positive effects of this type of support on the functioning of persons with low vision have been documented in several empirical studies. For example, Reinhardt (2001) found that instrumental assistance from family members was associated with better adaptation to vision loss, greater life satisfaction, and fewer depressive symptoms, and Cimarolli & Boerner (2005) found that such assistance was the most frequent type of positive support received by adults with visual impairments. In addition, family members who provide instrumental support to individuals with vision loss have been shown to enhance these persons' adjustment by encouraging the use of rehabilitative services in the home (Watson, De l'Aune, Stelmack,

Maino, & Long, 1997). Family instrumental support and the use of assistive devices may be especially important for individuals with vision loss who have neurocognitive deficits (Mann, Hurren, & Tomita, 1993), and may benefit from prompts and instruction by family members to use assistive devices.

There is also evidence that inadvertent negative consequences may also result from instrumental support. For example, providing assistance for individuals with low vision presents unique challenges to family members who may not understand how and when to provide assistance and what type of assistance to provide. Similarly, families may lack knowledge about their relative's visual impairment and the impact of visual acuity and central vision on functional abilities. This lack of knowledge and concern for safety by family members may contribute to overprotection (Ponchillia, 1984).

The impact of family members' lack of knowledge of low vision and overprotection has been documented. For example, Cimarolli, Reinhardt, and Horowitz (2006) found that family members tend to underestimate the abilities of adults who have low vision and that overprotection is associated with poorer adjustment to low vision, more depressive symptoms, and decreased mastery of the environment. In a related study by Cimarolli and Boerner (2005), persons with low vision who perceived that they were receiving only overprotective support reported less optimal well-being than did those who perceived that they were receiving more positive types of support. Thus, one challenge that a family faces is to learn how to balance how much support, what type of support, and the appropriate time at which to provide support to promote safety while allowing the relative with low vision to maintain independence (Orr & Rogers, 2006).

EMOTIONAL SUPPORT

The impact of emotional support provided by family members on the well-being of persons with vision loss has also been examined (Goodman & Shippy, 2002). For example, Jacobs (1984) showed that older adults with low vision who reported positive adjustment to vision loss also reported good communication with family members, had well-established networks of social support, and stressed the importance of family members' positive attitudes. That is, when family members understood vision loss, the continued growth and independence of their relatives with low vision was enhanced. Perceived and received affective support was also shown to be related to fewer depressive symptoms in persons with low vision (Reinhardt, Boerner, & Horowitz, 2006).

Other research in this area has focused on the interactive effect of support from both family members and friends on the well-being of older adults who have low vision (Reinhardt, 1996). McIlvane and Reinhardt (2001) found that women with high levels of support from both friends and relatives experienced better psychological well-being, whereas men with high levels of support from both friends and relatives or only from relatives had better psychological well-being. In addition, persons with high levels of qualitative support from friends (perceived quality of support) and high levels of quantitative family support (a large network) adapted better to vision loss. Thus, their study illustrates the complexity of understanding the relationship between various types of social support and the well-being of persons with low vision.

Emotional support and the functioning of family members and persons with low vision have also been investigated from the family-systems perspective. For example, Jackson and Lawson (1995) found that psychological distress was inversely related to the level of cohesion and independence in the family environment and was positively related to the degree of conflict and control. The most favorable outcomes were for families with a healthy degree of closeness and comfort with individual independence. The findings of other related studies appear to

corroborate the conclusions about the role of the support of family members and the impact of the distress of one family member on the entire family system (Jacobs, 1984; Moore, 1984).

NEGATIVE SUPPORT

Other investigations have shed light on the detrimental impact of negative support (unhelpful types of support) on the functioning of persons with low vision. Because providing informal, unpaid care to a relative requires family members to give up time that could have been used for other activities, the lack of reciprocity and unbalanced exchange between family-member caregivers and the recipients of care may lead to negative exchanges (Oxman, Freeman, Manheimer, & Stukel, 1994). Cimarolli and Boerner (2005) found that less-than-optimal well-being was linked with experiencing a lack of support and with receiving only negative support. Thus, greater attention to various aspects of family members' support, both positive and negative, may help to identify those who may be at risk of poor well-being and to refer them for family-centered psychosocial-based interventions.

LACK OF SUPPORT

Another body of work has examined the impact of lack of support on the outcomes of persons with low vision (Bruce, Harrow, & Obolenskaya, 2007). A review by Crews (1994) found that adults with low vision were most often institutionalized because of the lack of social support, rather than a decline in their health. In addition, the lack of family support was one of three problems that emerged from an examination of the histories of young adult and older members of short-term therapy groups who remained ambivalent or mildly to moderately depressed about their visual impairments (Emerson, 1981). Horowitz, Reinhardt, and Kennedy (2005) found that the perceived inadequacy of social support was related to the subsequent development of a depressive disorder among older adults with vision loss, and Allen (1989) reported that the lack of social support hindered the adjustment to vision loss of adults.

Influence of low vision on family members' functioning and coping

Much of what is known about family members' adjustment has come from conceptual frameworks, qualitative studies, or individual cases. Only a few empirical studies focusing on adults with low vision have investigated the impact of vision loss on family functioning. For instance, Bernbaum, Albert, and Duckro (1993) found that visual impairment was a significant stressor in the spousal relationship and that it was related to separation or divorce, with a greater risk of separation and divorce among those who were legally but not totally blind. Other studies have shown support for a phenomenon known in the literature on aging as emotional contagion or affect similarity, which refers to a process by which one's mood or affect spreads to others who are in close contact with them among persons who are visually impaired and their spouses (see, for example, Bambara, Owsley, Martin, Wadley, Porter, & Dreer, in press; Goodman & Shippy, 2002). A longitudinal study by Strawbridge, Wallhagen, and Shema (2007) found that the spouses of individuals with vision loss had an increased risk of poorer physical and emotional well-being over five years and that the characteristics of one had an impact on the other.

Implications for low vision rehabilitation

Although rehabilitation specialists routinely incorporate family members into different aspects of rehabilitation services that are directly tied to helping patients with low vision compensate for vision loss (such as orientation and mobility training, occupational therapy, vision rehabilitation therapy, vocational rehabilitation, and home visits and training), the unique effect of vision loss on family members' emotional adjustment is often overlooked. Most efforts are predominantly patient oriented (Silverstone, 2000). A greater emphasis on evaluating family

functioning in low vision rehabilitation is warranted, since incidences of depression and affect similarity as well as problems with caregiver burden are high among persons who care for a relative with a chronic health condition, and research has demonstrated a similarity of affect in depressive symptoms among persons who have low vision and their family members.

Low vision rehabilitation specialists are well positioned to recognize and screen for family members' adjustment and barriers to successful rehabilitation. A proactive assessment approach may consist of administering screening measures caregiver burden, satisfaction with relationships, depression, and family functioning; see Dreer & Broadfoot, 2008, for a detailed review) and inquiring about family functioning and needs during clinical interviews or observations during rehabilitation efforts. It may be helpful to interview family members and patients separately and then together, because family members may feel less inclined to communicate their concerns regarding their own adjustment in front of their loved one. The same may be true for patients who do not want to bring up problems that are related to their family members with these persons present. This strategy may also help to identify dysfunctional families who may undermine the motivation or capacity of the person with low vision to adhere to medical and rehabilitation regimens.

Families who are identified as being at risk for problems that are related to caring for a loved one with low vision or who demonstrate dysfunctional family dynamics that may interfere with rehabilitation efforts should be referred for a mental health consultation. Mental health service providers can assist in formally evaluating the role of the family in an individual's rehabilitation (strengths, weaknesses, family cohesion, and family dynamics) and can formally diagnose and treat family members who may be at risk of problems with adjustment (for example, those with clinical depression or anxiety). When referring a person with low vision and his or her family for mental health services, low vision specialists need to communicate their concerns directly with the person and his or her family, discuss the reason or reasons for the referral, and indicate that referral is a typical part of providing comprehensive vision rehabilitation services.

Although the optimal model for low vision rehabilitation includes a provider of mental health care as part of the rehabilitation team (Markowitz, 2006), many low vision rehabilitation programs do not include such in-house providers (Horowitz & Reinhardt, 2006). Instead, the person and his or her family, if referred, are often referred to an outside source for treatment or to an independent support group. Thus, it is important for low vision rehabilitation specialists who do not have integrated mental health services on-site to develop close and collaborative partnerships with local mental health care professionals (such as social workers, clinical psychologists, and psychiatrists). Such collaborations may give persons with low vision and their families access to services to alleviate serious problems with adjustment, clinical depression, or dysfunctional family dynamics. Identifying a contact person in the mental health field can minimize the stress and confusion of a low vision rehabilitation specialist who believes that a person with low vision and his or her family may need psychosocial intervention. The mental health professionals to whom individuals with low vision are referred should optimally be qualified in such areas as medical rehabilitation, family therapy, visual impairment, and aging. Competence in these areas is important, because many older adults who require low vision rehabilitation services have comorbid health problems that require an understanding of various diseases or conditions and the impact of emotional adjustment to chronic health conditions across the lifespan.

The scope of clinical activities may vary among mental health professionals. Mental health practitioners, broadly speaking, are uniquely trained in the application of evidence-based psychological assessments and psychotherapeutic interventions to understand, prevent, and relieve psychological distress and psychopathology and to promote well-being. However, the type of training, clinical experience, and therapeutic orientation (such as cognitive-behavioral

therapy versus psychodynamic therapy) varies greatly, depending on the training program and the provider's academic degree (master's versus doctorate). Another factor is the skill set of the mental health provider, the amount of training in a particular area, and the population in which the provider specializes (for instance, rehabilitation with older adults, treating pediatric traumatic brain injury). Although certain aspects of mental health practice overlap, mental health practitioners typically refer patients to other mental health professionals if the specific type of treatment that is needed is outside their scope of practice; for example, a clinical psychologist refers a patient to a psychiatrist for an evaluation of the need for medications as an adjunct to psychotherapy). What is critical is that mental health professionals who assess, diagnose, and treat the mental health needs of persons with low vision and their families use an evidence-based approach to optimize outcomes. The process is active and includes homework assignments and training in specific skill sets to modify behaviors and thoughts (such as problem-solving abilities, communication, and stress management). Success in treatment is based on measureable outcomes that are tracked over the course of treatment. Thus, the role of providers of mental health services is much more than providing support or "talk therapy."

Most of the evidence-based approaches that are aimed at improving the adjustment of patients and family caregivers to chronic health conditions in general are based on a cognitive-behavioral therapy framework (Dreer & Broadfoot, 2008). Generally, cognitive-behavioral therapies typically incorporate a structured, short-term psychoeducational framework that is designed to examine the influence of and interaction among a person's cognitions (thoughts), emotions (feelings), and behaviors regarding problems. This perspective espouses that certain thoughts or ways of interpreting the world can cause emotional distress or result in problems in daily living. Likewise, certain behaviors, such as avoidance of situations, also maintain distress. Thus, the goal of most cognitive-behavioral therapies is to discover the biased or maladaptive thinking and patterns of behavior that lead to emotional problems and to help the patient and his or her family modify thinking patterns and behaviors to improve well-being and to manage problems. Mental health professionals can work directly in collaboration with other low vision rehabilitation specialists to design and implement family-based educational and psychosocial approaches, particularly since many such professionals are trained in the content areas of family-systems approaches, cognitive-behavioral therapy interventions, designing educational curricula for family members, identifying social and leisure needs of persons with visual impairments and their relatives, and health behavior modification interventions. Proactive efforts such as these that target the entire family system or a family member who is at risk of problems with adjustment to a loved one's vision loss may ultimately improve treatment outcomes and reduce secondary complications.

Directions for future research

There are several obvious weaknesses in the literature that we reviewed. First, there is a lack of empirical research on the impact of low vision on the family. Second, studies have been marked by numerous methodological problems, including small samples, a focus on a specific family member (predominantly a spouse) or generation (family members of older adults), weak theory and designs, the lack of randomized clinical trials, a focus on a particular eye disease, cross-sectional nature, and the absence of control comparison groups. Another limitation is that studies involving family members are often more labor intensive than are those that focus solely on individuals with vision loss, since they require more time for recruitment, assessment, follow-up procedures, analyses of multiple data points, and more funds for reimbursement of participants. Thus, there has been little empirical work on the factors that predict successful adaptation by family members of individuals with low vision. Such efforts are needed to guide the development of family-based psychosocial interventions or family caregiver-only

interventions that are lacking among family members of persons with low vision (Dumas & Sadowsky, 1984; Rees, Saw, Larizza, Lamoureux, & Keefe, 2007).

Despite these limitations, there are a number of directions for future research. Specifically, there is a need to identify the unique needs and concerns of the family members of persons with low vision. Second, the dynamics between the family and the person with low vision (such as communication styles, problem-solving abilities, family cohesiveness, and family stability) need to be better understood. What is also unknown are the specific factors that determine how a family divides or shares caregiving tasks for persons with low vision across the lifespan or how low vision affects family members (such as children and siblings) differently and across specific caregiving tasks (like the decision-making process for fitness to drive). Third, the impact on the family's emotional and physical health should be investigated prospectively from the onset of the relative's diagnosis throughout rehabilitation. Further studies of the interactive role of both families and friends may be useful to understand how these two types of relationships differentially affect outcomes. An examination of family goals and expectations for the future would also be informative for the development of psychosocial interventions that are designed to help families establish new goals for the future.

Since studies have shown the critical role of family support throughout the rehabilitation process (Reinhardt & D'Allura, 2000), a further examination of the social-cognitive variables that are associated with family coping and adaptation, such as social problem-solving abilities (Bambara et al., in press; Dreer et al., 2005; Kurylo, Elliott, DeVivo, & Dreer, 2004), are also needed to understand factors that may mediate successful adjustment. Along similar lines, positive aspects of successful family adjustment, such as hope (Owsley et al., 2006) are also deserving of greater attention to understand how to foster adaptive family functioning, closeness, cooperation, and competence. Families who are able to benefit from the challenge of vision loss and negotiate new family goals may serve as models of ideal coping.

Another area that has been largely understudied is the importance of gender and cultural differences in support from family members of persons with vision loss (Lee & Brennan, 2002). The influence of factors that are associated with culture (including kinship bonds, the role of cultural norms, unique beliefs about disability and illness, and the view of health care providers in comparison to traditional healers) is also warranted. Understanding these issues may help to reduce assumptions, better inform treatment, minimize noncompliance with and dropout from treatment, and maximize success in rehabilitation efforts.

Much work in the areas of research on interventions and community services is needed. Little is known about family members' use of and satisfaction with community resources and community or health care services (such as vision rehabilitation, mental health centers, support groups, vision-related organizations, web-based information, and community churches) as they relate to assisting a person with low vision. This knowledge would be helpful in planning effective interventions and developing community partnerships. Along these lines, more work is needed to develop meaningful and effective psychosocial interventions for families of persons with low vision. Incorporation of the research to date may include a focus on family members' concerns about their relatives with low vision, including safety, fitness to drive, knowing how and when to help, what type of support to provide, the risk of overprotectiveness, and resources in the community. These important topics may be included as an educational component along with psychotherapy. While some initial efforts have focused on educational programs or support groups, well-controlled, randomized clinical trials with families are lacking.

Conclusion

It is clear that the impact of low vision is far reaching. The research evidence appears to demonstrate that family members play a significant role in the lives of persons with low vision, that several aspects of family function are associated with better outcomes for persons with low vision, and that family members may be at a risk of their own problems with adjustment that may subsequently affect the quality of support they provide and the outcomes of rehabilitation. Thus, the need for research on the adjustment of family members and patients with low vision is more urgent than ever in this particular area.

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