FAMILY FUNCTIONING AND VISION LOSS

by

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Vision loss is an increasingly common disability that imposes significant functional limitations on the individual with the vision impairment. Family members are often called upon to provide assistance with a variety of tasks of daily living (e.g., cooking, cleaning, providing transportation). Additionally, family caregivers are often expected to function as informal extensions of the healthcare system (e.g., encourage the use of assistive devices, provide/prepare medications). Unfortunately, the literature on family member adjustment in this area has been significantly understudied. The current project 1) explores the impact of family support on persons with vision impairments and the paucity of research examining the impact of vision loss on the family, and 2) empirically examines the prevalence of psychosocial distress among family caregivers of individuals with vision loss and the extent to which social-cognitive variables such as social problem-solving abilities predict caregiver depressive symptoms and life satisfaction. Thus, two separate studies were conducted.

The first study is a literature review examining the function and adjustment process of family members responding to a relative with low vision. Relevant peer-reviewed empirical studies and critical reviews were identified using MEDLINE and PsycINFO (EBSCO) databases. Current research indicates that the family plays a unique and valuable role in the provision of instrumental and emotional support, although not all types of assistance provided are associated with positive patient outcomes. More empirical re-
search is needed to better understand family member experience of caring for an individual with vision loss. The second study examines 96 adult family caregivers who accompanied their adult relative to their initial low vision rehabilitation eye examination. Of these family caregivers, 35% were identified as at-risk for depression. Dysfunctional social problem-solving abilities were significantly associated with greater depressive symptoms and decreased life satisfaction after accounting for caregiver burden and demographic and medical variables for both the caregiver and the person with low vision. This project highlights the need for investigations examining factors that impact adjustment to caring for a relative with vision loss.
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INTRODUCTION

In the United States, approximately 9% of those 18 and older experience vision-related difficulties characterized by a chronic eye disease that cannot be corrected with glasses and interferes with one’s daily functioning (Lethbridge-Cejku, Rose, & Vickerie, 2006). While there is no universally accepted definition of the term “low vision,” an often used definition is that of the World Health Organization Study Group on the Prevention of Blindness (1972) where low vision refers to visual acuity worse than 20/60 with best refraction in the better eye and/or significant field loss. It has been estimated that approximately 3 million Americans have low vision by this definition. However, this figure is still subject to debate with estimates ranging from several hundred thousand to 16 million (Massof, 2002; Massof & Fletcher, 2001).

As the population continues to age and life expectancies increase in the United States, the proportion of individuals living with low vision is expected to rise substantially over the course of the next several decades (Tielsch, 2001). In fact, the Eye Disease Prevalence Research Group (2004) estimates that by 2020, the number of persons with low vision in the United States will increase by as much as 70%. As the number of individuals living with a vision impairment rises, so will the projected economic costs associated with vision loss, including 1) direct medical care for low vision (e.g., ophthalmologic, optometric, occupational therapy services, orientation and mobility specialists, mental health services), 2) direct medical care for injuries associated with low vision
(e.g., falls, medication mismanagement), and 3) direct non-medical care (e.g., low vision aids, change in work productivity, transportation services; Schmier, Mechelle, & Halpern, 2006). Also expected to increase are the indirect costs of vision loss incurred by family members who function as informal caregivers and who may leave the workforce early or change their work patterns in order to provide some form of assistance (Schmier et al., 2006). Thus, vision impairment is a growing public health concern with significant social, economic, functional, and emotional implications for persons living with vision loss, their family members, and society as well.

Impact of Vision Loss

Unfortunately, many of the leading causes of vision loss, such as age-related macular degeneration (AMD) and diabetic retinopathy, are often irreversible. Despite the number of medical and surgical advancements, these procedures tend only to slow the progression of vision loss in later stages of the eye disease. Therefore, a substantial number of individuals are forced to confront, daily, the unique challenges of living with a vision impairment (Gieser, 2004). It has been well-documented that persons with vision loss often experience significant functional and emotional challenges associated with adjustment to their visual impairment. For example, vision loss has been found to impede performance in a number of important instrumental activities of daily living (IADLS; i.e., reading, managing housework, medication management, shopping, driving, managing financial affairs, preparing meals, self-care, and personal care; Cimarolli & Boerner, 2005; Ivanoff, Sjostrand, Klepp, & Axelsson, 1996; Keller, Morton, Thomas, & Potter, 1999; Lamoureux, Hassell, & Keefe, 2004; LaPlante, 1988; Lindo & Nordholm, 1999;
Vision loss has also been shown to restrict mobility (Colenbrander, 1996; Marron & Bailey, 1982), affect employment opportunities (Jeppson-Grassman, 1989; Leonard, 2002), complicate changes related to old age in general (Pollard, Miner, & Cioffi, 2000; Watson, 2001), decrease safety (Ivers, Cumming, Mitchell, & Attebo, 1998; Keeffe, McCarty, & Taylor, 2005; Vu, Keeffe, McCarty, & Taylor, 2005), impact housing needs (Percival, Hanson, & Osipovic, 2006), and the interfere with the ability to provide support for others (Boerner & Reinhardt, 2003).

Adjustment to the types of issues identified above may subsequently result in varying emotional and social reactions in persons with vision loss. For example, general distress, frustration, depression, anxiety, as well as other adverse emotional responses have been documented (Rovner & Casten, 2001; Rovner, Casten, Hegel, & Tasman, 2006). These types of changes may also result in diminished quality of life (Mangione, Gutierrez, Lowe, Orav, & Seddon, 1999), negatively influence social relationships (i.e., increase withdrawal from social situations and isolation; Bernbaum, Albert, Duckro, & Merkel, 1993), and contribute to feelings of dependency (Lopez-Justicia & Cordoba, 2006). These types of problems are likely to be compounded when persons with vision loss have co-morbid chronic illnesses or disabilities (e.g., diabetes, stroke, Alzheimer’s Disease, hearing impairment, mental illness).
The Role of the Family

Due to the many challenges that may accompany vision loss, persons with visual impairments often rely on others for some form of functional and/or emotional support. Individuals who provide non-paid assistance are often referred to as informal caregivers, whereas formal caregivers include paid health care professionals who have formal training and educational backgrounds in an allied health profession. Informal family caregivers are often not prepared for the physical, psychosocial, and financial demands of caregiving, and they typically do not receive compensation for their services. Moreover, informal family caregivers often assume a high degree of responsibility in the monitoring of patients’ health outcomes. Thus, family members frequently play a highly influential role as informal extensions of the healthcare system. Table 1 in Appendix A summarizes the current research related to family functioning and vision loss.

Research supports the close involvement of family members in health care services for persons with vision loss. For example, Travis and colleagues (2004) found that 48% of older adults were accompanied by a friend or family member to their low vision evaluation. In addition to accompanying family members to their health care appointments, family members of older adults with vision loss provide assistance or support in other aspects of daily living due to functional declines associated with aging (Watson, 2001).

Family Member Adjustment

The degree and type of support provided by family members is likely to vary depending on a variety of factors, which may include the impact of vision loss on everyday
living, the number of co-morbid chronic health conditions, cognitive functioning, living arrangement, financial situation, and access to services and resources (e.g., rural versus urban). Factors that may complicate the experience of providing care often center around concerns about the disabled relative, finances, other family obligations, employment, availability of social support, knowledge about the nature and progression of the illness/disability, severity of the disability, number of caregiving duties, and personal health. Additional factors, such as sudden onset of disability, behavioral and cognitive problems, and personality changes may further hinder optimal caregiver adjustment.

Considerable evidence indicates that expending significant financial, emotional, and physical resources while receiving little in return may result in what is referred to as caregiver burden. When the family caregiver experience of stress becomes heightened, symptoms of depression, anxiety, psychosomatic symptoms, anger, and diminished health may result (Ell, Nishimoto, Mantell, & Hamovitch, 1988; Gallagher-Thompson et al., 1998; Nezu, Felgoise, McClure, & Houts, 2003; Nezu, Nezu, Friedman, & Houts, 1999; Vitaliano, Katon, & Unutzer, 2005; Vitaliano, Zhang, & Scanlan, 2003). When caregiver burden is high, the patient’s rehabilitation and health outcomes may suffer. Identifying caregivers at-risk for high levels of burden will become increasingly important within vision rehabilitation settings as the population ages and those with vision loss experience increasing numbers of co-morbid chronic health conditions. Depending on the type and level of support provided, the role the family plays in providing support is likely to strain family members over time, particularly as relatives struggle to balance their own needs with the needs of the individual with vision loss (Khan, Pallant, & Brand, 2007; Son et al., 2007; for review see White, Lauzon, Yaffe, & Wood-Dauphinee, 2004).
While there is potential for caregiver stress and burnout, family caregivers have been found to vary in the way in which they adjust to their role (Elliott & Shewchuk, 2003). For example, in the broader caregiving literature it is well documented that caregivers differ in their abilities to solve problems in everyday situations (i.e., social problem-solving abilities). Social problem-solving abilities have been found to be associated with health and emotional adjustment of family members of individuals with health-related problems (Elliott, 1999; Elliott, Grant, & Miller, 2004). Despite various empirical investigations supporting an association between adaptive social problem-solving and optimal adjustment to family caregiving, social-cognitive variables such as social problem-solving have been understudied among family caregivers of persons with vision loss.

Social Problem-Solving Abilities

Contemporary models of social problem-solving abilities stipulate that individuals differ in 1) the cognitive-behavioral skills that influence the processing of information about their problems, 2) their ability to regulate emotional experiences when problem-solving, and 3) their ability to implement effective strategies for resolving problems (D'Zurilla & Nezu, 1999). Essentially, social problem-solving involves the cognitive-behavioral processes through which an individual identifies and copes with everyday problems (Nezu, 2004). Specifically, social problem-solving theory and research focus on all kinds of problems in living, including personal (cognitive, emotional, behavioral, health), impersonal (insufficient finances), interpersonal (relationship issues), and broader societal problems (environment, crime; D'Zurilla, Nezu, & Maydeu-Olivares, 2002).
Problem-solving outcomes in everyday living are determined by two general processes: 1) problem orientation (negative or positive), and 2) problem-solving style (rational problem-solving, impulsive/careless style, and avoidant style; (D'Zurilla et al., 2002). The problem orientation component refers to beliefs and attitudes a person has about their overall ability to solve problems, their level of confidence in problem-solving, and their abilities in regulating their emotions so that the individual is motivated to handle minor problems efficiently and work diligently on more time-consuming problems. Problem-solving styles entail both effective (rational) and dysfunctional (impulsive, careless, avoidant) tendencies (D'Zurilla et al., 2002).

Both problem orientation and problem-solving style may have a significant impact on a caregivers’ ability to adjust to the caregiving role. Social problem-solving abilities have been found to be associated with health and emotional adjustment of family members of individuals with health-related problems (Grant, Elliott, Giger, & Bartolucci, 2001; Grant et al., 2006; Rivera, Elliott, Berry, Grant, & Oswald, 2007). In addition, evidence for the efficacy of problem-solving training interventions has been documented in caregiver populations (Gallagher-Thompson et al., 2000; Houts, Nezu, Nezu, & Bucher, 1996; Roberts et al., 1999; Zarit, Anthony, & Boutselis, 1987). Thus, problem-solving interventions hold considerable promise for augmenting low vision rehabilitation programs.

Broad Objectives

The loss of vision presents unique challenges to the family system, and knowledge regarding the effects of these challenges on family functioning remains largely un-
studied. Little is known about the factors that influence successful family adjustment and positive coping. Investigations in these areas are needed given that family members’ ability to adjust to the caregiving role is likely to impact their own well-being as well as the amount and type of support they are able to provide to the individual with vision loss.

Study 1 is a systematic literature review examining the current research related to family member assistance of an adult relative with vision loss. This study was designed to systematically review the literature examining the role and adjustment process of family members assisting an adult with vision loss. The review concludes with a discussion of clinical implications along with directions for future research.

Study 2 is an empirical investigation of the relationship between social problem-solving abilities and distress among adult family caregivers of persons with vision loss. The prevalence of caregivers at-risk for depression was explored as was the extent to which social problem-solving abilities were predictive of caregiver self-reported depressive symptomatology and overall well-being.

As the number of individuals with significant vision loss is expected to increase substantially over the next several decades, it is expected that the number of family members proving assistance to individuals with a vision impairment will also rise. Therefore, a greater understanding of the role of the family and factors that impact patient and family member adjustment to vision loss have become increasingly important. The current investigations aim to expand the knowledge base regarding family caregivers of persons with vision loss.
FAMILY FUNCTIONING AND LOW VISION: A SYSTEMATIC REVIEW

by

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ABSTRACT

This review highlights 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. The majority of the literature to date has focused primarily on the unique role the family plays in providing both instrumental and emotional support to adult persons with low vision. Both positive and negative aspects of providing support have been well-documented. In contrast, the impact of low vision on the psychosocial adjustment of the family has been largely understudied. The review concludes with a discussion on the implications for clinical practice along with directions for future research on the family within the context of low vision rehabilitation.

FAMILY FUNCTIONING AND LOW VISION: A SYSTEMATIC REVIEW

While extensive research has documented the emotional and functional changes that accompany vision loss for persons with low vision (e.g., Dreer, Elliott, Fletcher, & Swanson, 2005; Dreer, Elliott, Berry, Fletcher, & Swanson, 2008), there has been a lack of attention devoted to the study of the adjustment process of their family members. This is surprising, as family members are often responsible for providing varying degrees of instrumental and emotional support for persons with low vision (Cimarolli & Boerner, 2005; Reinhardt, 1996, 2001; Reinhardt, Boerner, & Horowitz, 2006). In this sense, fam-
ily 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 co-morbid chronic health condition requiring assistance (Dreer, Berry, Elliott, & Rivera, 2007; Schmier, Halpern, Covert, Delgado, & Sharma, 2006). Depending on the type and level of support provided, the role the family plays in providing support is likely to strain family members over time, particularly as relatives struggle to balance their own needs with the needs of the individual with vision loss. Thus, a greater understanding of the family member experience is needed in order to promote optimal well-being and successful adjustment on the part of the individual with low vision as well as their family members.

The Role of the Family

Adjustment to vision loss often occurs within the context of a social network of family and friends (Orr & Rogers, 2006; Travis et al., 2003). While research has demonstrated the influential role of both family and friends on well-being throughout the life span (e.g., McIlvane & Reinhardt, 2001), immediate family members in particular share a more intimate role than friends in that they 1) often live or have lived with the person with low vision (e.g., spouses, children, parents, siblings), 2) have first-hand knowledge of the person’s medical history across time, 3) observed how the person with low vision has reacted and coped with vision loss as well as other stressors in life, 4) often accompany their visually impaired relative to their eye examinations and rehabilitation services, and lastly, 5) serve as communicators and liaisons with vision-related health care providers. While the structure and composition of families have changed significantly over the
past several decades, the family remains the primary unit for 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 provided may vary depending on a variety of factors including the relative’s severity of vision impairment, impact of vision loss on everyday living, number and type of other co-morbid health problems, cognitive functioning of the person with vision loss, living arrangement, financial situation, and access to services and resources (e.g., rural versus urban). In this sense, the family is likely to influence the health and rehabilitation outcomes of persons with visual impairments.

Impact of Vision Loss on Family Member Reactions

A diagnosis of vision impairment often has an immediate and lasting impact on family members. While family members may vary in their reactions, the initial diagnosis may cause considerable stress. For instance, Tuttle (1986) suggested that family members experience several phases of adjustment similar to that of their relative diagnosed with the visual impairment including shock/denial, mourning/withdrawal, succumbing/depression, reassessment/reaffirmation, coping/mobilization, and self-acceptance/self-esteem. As families begin to adapt, there is more of a focus on the reality, challenges, and implications of low vision on everyday living and family roles. For age-related visual impairments that are progressive in nature, greater assistance in activities of everyday living may be needed as the disease advances. Additionally, families may face economic stress due to low vision devices not being covered by insurance companies, costs associated with rehabilitation services (e.g., transportation to low vision rehabilita-
tion appointments), and/or loss of wages due to providing assistance. Given the practical, functional, and economic needs of a relative’s low vision, family members may experience distress when attempting to cope with these new demands.

Family-Systems Based Approaches and Family Member Adjustment to Vision Loss

While there is no widely agreed upon model of family adjustment to vision loss, one informative conceptual framework for understanding family member 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 their 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 also 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 their self-identity (Glass & Maddox, 1992). The caregiving experience is further complicated as family members seek to balance offering assistance while maximizing safe independence. This challenge may be ongoing as the vision loss progresses or may be made more difficult if the person with low vision experiences neurocognitive changes due to a co-morbid neurological disease.

Insofar as the family system is flexible, adaptive, cohesive, supportive and high functioning, it fosters a successful transition for the person with the disability and ensures
the continuity of valued family relationships (Glass & Maddox, 1992). However, family dysfunction may exacerbate the difficulties associated with adjusting to loss of vision. Therefore, adjustment for both the person with vision loss and their family members may be viewed as a family process in which one of the core challenges confronting the family is the need to modify existing patterns of interaction, expectations, family norms, and roles to accommodate changes due to 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 the Outcomes of Persons with Low Vision

Families often function by providing varying levels of support to persons 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. 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 for both instrumental and received emotional support (Cimarolli & Boerner, 2005). Support from these family members appears to be critical in the person’s adaptation to vision loss. Evidence suggests that adequate emotional and instrumental support protects against distress and other negative health outcomes (Kleinschmidt, 1999; Ringer & Amaral, 2000) and has a stress-buffering effect when support resources 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 visual impairments have been documented in several recent 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. In another study, instrumental assistance provided by family members was shown to be the most frequent type of positive support received among adults who are visually impaired (Cimarolli & Boerner, 2005). Additionally, family members who provide *instrumental support* to individuals with vision loss have also been shown to enhance patient 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 those individuals with vision loss who also have neurocognitive deficits (Mann, Hurren, & Tomita, 1993) and may benefit from prompts by family members to utilize assistive devices.

There is also evidence that inadvertent negative consequences may also result from *instrumental support*. For example, providing assistance for individuals with visual impairments presents unique challenges to family members who may lack an understanding of how and when to provide assistance as well as what type of assistance to provide. Along similar lines, families may lack knowledge about their relative’s vision impairment and how visual acuity and central vision impacts functional abilities. This lack of knowl-
edge and concern for safety by family members may contribute to overprotection (Ponchillia, 1984).

Evidence demonstrating the impact of family member lack of knowledge regarding visual impairment and overprotection has been recently documented. For example, Cimarolli, Reinhardt, and Horowitz (2006) found that family members have a tendency to underestimate the abilities of adults who are visually impaired. Their findings indicate that overprotection is associated with poorer adjustment to low vision, more depressive symptomatology, and decreased environmental mastery. In a related study by Cimarolli and Boerner (2005), persons with low vision who perceived themselves as receiving only overprotective support reported less optimal well-being than those who perceived themselves as receiving more positive types of support. Thus, research demonstrates the positive as well as negative implications associated with instrumental support provided by family members. The challenge facing the family appears to be learning how to balance when and how much support, along with what type of support provide in order to promote safety while maintaining independence (Orr & Rogers, 2000).

*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 visually impaired older adults who reported positive adjustment also reported good communication with family members and well-established networks of social support, and stressed the importance of positive attitudes on the part of family members. That is, when family members had an understanding of vision loss, the
continued growth and independence of their relatives with visual impairments was enhanced. Perceived and received affective support has also been shown to be related to fewer depressive symptoms in patients with visual impairments (Reinhardt et al., 2006).

Other research in this area has focused on the interactive effect of support from both family and friends on visually impaired older adults’ well-being (Reinhardt, 1996). McIlvane and Reinhardt (2001) found that women with high support from both friends and family experienced better psychological well-being, whereas men with high support from both friends and family or from family alone had better psychological well-being. Additionally, persons with high qualitative friend support (i.e., perceived support quality) and high quantitative family support (i.e., network size) had better adaptation to vision loss. Thus, this study illustrates the complexity of understanding relationships among social support with persons with visual impairments.

Examination of emotional support and functioning of family members and persons with visual impairments has 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 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. Findings from other related studies also appear to corroborate the conclusions about the role of family member support and the impact of distress on one family member also impacting the entire family system (Jacobs, 1984; Moore, 1984).


**Negative Support**

Other investigations have shed light on the detrimental impact of negative support (i.e., unhelpful types of support) on functioning among persons with low vision. Because providing informal, unpaid family caregiving activities to a relative requires giving up time that could have been used for other activities, it may be that this lack of reciprocity and unbalanced exchange between family caregivers and the care-recipient leads to negative exchanges (Oxman, Freeman, Manheimer, & Stukel, 1994). In a study by Cimarolli and Boerner (2005), 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 member support, both positive and negative, might help to better identify those who may be at risk for poor well-being and to refer those who might be appropriate 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). In a review by Crews (1994) it was found that adults with vision impairments were most often institutionalized because of lack of social support rather than a decline in patient health. Additionally, lack of family support was one of three problems that emerged from the 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 vision impairment (Emerson, 1981). In a separate study, perceived inadequacy of social support was found to be related to subsequent development of a depressive disorder among older
adults with vision loss (Horowitz, Reinhardt, & Kennedy, 2005) and lack of social support has also been reported to hinder a patients’ adjustment to vision loss (Allen, 1989).

**Influence of Low Vision on Family Member Functioning and Coping**

Much of what we know about family member adjustment comes from conceptual frameworks, qualitative studies, or individual cases. Only a few empirical studies focusing on adult persons with low vision have investigated the impact on family functioning. For instance, Bernbaum, Albert, and Duckro (1993) found that vision impairment was a significant stressor in the spousal relationship and that it was related to separation and/or divorce, with a greater risk for separation and divorce among those who were legally but not totally blind. Other investigations of persons with low vision and their spouses have shown support for a phenomenon known in the aging literature 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 (e.g., Dreer, Bambara, Simms, Snow, & Owsley, 2008; Goodman & Shippy, 2002). Additionally, a longitudinal investigation by Strawbridge and colleagues (2007) found that spouses of individuals with vision loss had an increased risk for poorer physical and emotional well-being over five years time and that characteristics of one impacted the other.

**Implications for Clinical Practice in Low Vision Rehabilitation**

While rehabilitation specialists routinely incorporate family members into different aspects of rehabilitation services directly tied to helping patients with low vision compensate for vision loss (e.g., orientation and mobility training, occupational therapy sessions,
vision rehabilitation therapy sessions, vocational rehabilitation, home visits/training), the unique effect of vision loss on family members’ own emotional adjustment is often overlooked as a focus of low vision rehabilitation. Most efforts are predominantly patient-oriented (Silverstone, 2000). Given that 1) depression and problems with caregiver burden are high in persons caring for a relative with a chronic health condition, 2) research demonstrates affect similarity in depressive symptomatology among persons with a vision impairment and their family members, and 3) family caregiver influence on patient outcomes, greater emphasis on evaluating family functioning in low vision rehabilitation is warranted.

Low vision rehabilitation specialists are well positioned to recognize and screen for family member adjustment and/or barriers to successful rehabilitation. A proactive assessment approach might consist of administering screening measures (e.g., self-report inventories of caregiver burden, relationship satisfaction, family functioning; see Dreer & Broadfoot, 2008 for a detailed review) and/or inquiring about family functioning and needs during clinical interviews or observation during rehabilitation efforts. It may be helpful to interview family members and patients separately and then together, as family members may feel less inclined to communicate their concerns regarding their adjustment in front of their loved one (i.e., caregiver strain, worry over their loved one continuing to driving). The same may be true for patients not wanting to bring up problems related to their family member with that person present (e.g., poor attitudes of family members, lack of family understanding and empathy about their vision loss, feeling like a burden). This strategy may also help to identify dysfunctional families who may undermine the
visually impaired person’s motivation or capacity to adhere to medical and rehabilitation regimens.

Families identified as being at risk for problems related to caring for a loved one with low vision and/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 the patient’s rehabilitation (e.g., strengths, weaknesses, family cohesion and dynamics) and formally diagnose and treat family members who may be at risk for their own problems with adjustment, which can be successfully treated (i.e., clinical depression, anxiety). When referring a patient and his/her family for mental health services, it is helpful when low vision specialists directly communicate their concerns with the patient and his or her family, discuss the reason(s) for referral, and describe that it is a normal part of providing comprehensive vision rehabilitation services.

While the optimal model for low vision rehabilitation includes a mental health care provider as part of the rehabilitation team (Markowitz, 2006), many low vision rehabilitation programs do not include an in-house mental health service provider (Horowitz & Reinhardt, 2006). Instead, the patient and/or family, if referred, are often referred to an outside source for treatment or independent support group only. 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 (i.e., social workers, clinical psychologists, psychiatrists). Such collaboration may provide persons with visual impairments 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 stress and confusion among low vision rehabilitation specialists who believe a patient and/or a family may be in need of a psychosocial intervention. When partnering with mental health professionals, it would be helpful if these individuals are qualified in areas such as medical rehabilitation, family therapy, vision impairment, and aging. Competence in these areas is important as many older adult persons presenting for low vision rehabilitation services have comorbid health problems that require an understanding of various diseases and the impact on emotional adjustment to the chronic health condition across the lifespan.

The scope of clinical activities can vary between mental health professionals. Mental health practitioners, broadly speaking, are uniquely trained in the application of evidence-based psychological assessment and psychotherapeutic interventions to understand, prevent, and relieve psychological distress and psychopathology, and promote subjective-well being. However, the type of training, clinical experience, and therapeutic orientation (e.g., cognitive-behavioral therapy versus psychodynamic) varies greatly depending on the training program and degree (i.e., masters versus doctorate). Another factor is the skill set of the mental health provider, amount of training in a particular area, and population specialty (e.g., rehabilitation with older adults, pediatric traumatic brain injury). While certain aspects of mental health practice overlap, mental health practitioners typically refer to other mental health professionals if the specific type of treatment needed is outside of their scope of practice (e.g., clinical psychologist to a psychiatrist for medication evaluation as adjunct to psychotherapy). What is critical is that mental health professionals who assess, diagnose, and treat persons the mental health needs of persons with low vision and their families utilize an evidence-based approach to optimize out-
comes. The process is active, includes homework assignments, and training in specific skill sets to modify behaviors and thoughts (problem solving abilities, communication, stress management). Success in treatment is based upon measurable outcomes that can be tracked over the course of treatment. Thus, the role of mental health service providers typically involves much more than providing support or “talk therapy.”

Most of the evidence-based approaches aimed at improving patient and/or family caregiver adjustment to chronic health conditions in general are based within a cognitive-behavioral therapy framework (Dreer & Broadfoot, 2008). Generally speaking, cognitive-behavioral therapies incorporate a structured, short-term psychoeducational framework designed to examine the influence and interaction between 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 errors and patterns of behavior that lead to emotional problems and to help the patient and/or family modify thinking patterns and behaviors to improve well-being and management of problems. Mental health professionals can work directly in collaboration with other low vision rehabilitation specialists to design and implement family-based education and psychosocial approaches, particularly as many are trained in the content areas of 1) family-systems approaches, 2) cognitive-behavioral therapy interventions, 3) designing education curricula for family members, 4) identifying social and leisure needs of persons with visual impairments and their family members, and 5) health behavior modification interventions. Proactive efforts
such as these targeting the entire family system or a family member at-risk for problems with adjustment to their 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 existing literature reviewed thus far. First, there is a lack of empirical research focusing on the impact of vision loss on the family. Second, existing studies have been marked by numerous methodological problems including small sample sizes, a focus on a specific family member (i.e., predominantly spouses) or generation (i.e., family members of older adults), weak theory and designs, lack of randomized clinical trials, 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 investigations focusing solely on individuals with vision loss. Compared to studying patients alone, incorporating family members into studies requires more time for recruitment, assessment, follow-up procedures, cost of family participant reimbursement, and analysis of multiple data points. As such, there is little empirical work regarding the factors that predict successful adaptation among family members. 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).

While these limitations exist, there are a number of directions for future research. Specifically, there is a need to identify the unique needs and concerns of family members
of persons with vision loss. Second, the dynamics between the family and the person with vision loss need greater understanding (e.g., communication styles, problem-solving abilities, family cohesiveness, family stability). Other understudied areas include specific factors that determine how a family divides or shares family caregiving tasks for persons with vision loss across the lifespan, how vision loss affects family members differently (e.g., children, siblings), and how family member roles differ across specific caregiving tasks (i.e., 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 their relative’s diagnosis throughout rehabilitation. Further studies evaluating the interactive role of both families and friends may be useful to understand how these two types of relationships differentially impact outcomes. Examination of family goals and expectations for the future would also be informative for the development of psychosocial interventions designed to help families establish new goals for the future.

As research investigations have shown the critical role of family support throughout the rehabilitation process (Reinhardt & D'Allura, 2000), further examination of the social-cognitive variables associated with family coping and adaptation (i.e., social problem-solving abilities; Dreer et al., 2005; Kurylo, Elliott, DeVivo, & Dreer, 2004) are also needed to understand factors that may potentially mediate successful adjustment. Along similar lines, positive aspects of successful family adjustment (e.g., hope; Owsley et al., 2006) are also deserving of greater attention to understand how to foster adaptive family functioning, closeness, cooperation, and competence. Understanding 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 in vision research is the importance of gender and cultural differences in terms of understanding support from family members of persons with vision loss (Lee & Brennan, 2002). The influence of factors associated with culture is also warranted (e.g., kinship bond, the role of cultural norms, beliefs about disability and illness unique to different cultures, the view of health care providers in comparison to traditional healers in certain cultures). This may help to reduce assumptions, better inform treatment, minimize non-compliance and treatment dropout, and to maximize success in rehabilitation efforts.

With regards to research on interventions and community services, much work is needed in these areas. Little is known about family member utilization of and satisfaction with community resources and community/health care services (e.g., vision rehabilitation, mental health centers, support groups, vision-related organizations, web-based information, 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 visual impairments. Incorporation of the research to date might include a focus on family concerns of persons with vision loss including safety, fitness to drive, knowing how and when to help, what type of support to provide, the risk for overprotectiveness, and resources in the community. These important topics might be included as an educational component along with psychotherapy. While some initial efforts have focused on education programs or support groups, well-controlled, randomized clinical trials with families are lacking.
CONCLUSIONS

It is clear that the impact of vision loss is far-reaching. The evidence to date 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 visual impairments, and that family members may be at risk for their own problems with adjustment that may subsequently impact the quality of support provided and the rehabilitation outcomes. Thus, the need for research investigating family and patient adjustment is more urgent than ever in this particular area.

REFERENCES


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FAMILY CAREGIVER SOCIAL PROBLEM-SOLVING ABILITIES AND ADJUSTMENT TO CARING FOR A RELATIVE WITH VISION LOSS

by

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ABSTRACT

Purpose: To examine the prevalence of persons at-risk for depression among family caregivers of visually impaired persons and the extent to which social problem-solving abilities are predictive of caregiver depressive symptomatology and life satisfaction.

Methods: Family caregivers were defined as adults who accompanied their adult relative to an appointment at a low vision rehabilitation clinic. Demographic variables, depressive symptoms, life satisfaction, caregiver burden, and social problem-solving abilities were assessed in caregivers. Patient visual acuity and depressive symptoms and their relationship to caregiver depressive symptoms and life satisfaction were also examined.

Results: Ninety-six family caregivers were enrolled. Thirty-five percent of caregivers were identified as at-risk for depression. Among caregivers, dysfunctional social problem-solving abilities were significantly associated with greater depressive symptomatology and decreased life satisfaction after adjusting for caregiver burden and demographic and medical variables for both the caregiver and the visually impaired patient.

Conclusions: A substantial number of caregivers of visually impaired adults experience psychosocial distress, particularly those who possess poor social problem-solving skills. These results underscore the need for routine screening and treatment of emotional distress among individuals caring for relatives with vision impairments. Future research should examine the extent to which psychosocial interventions targeting caregiver social
problem-solving skills may be useful for improving the caregiver’s quality of life as well as enhancing rehabilitation outcomes for the visually impaired care recipient.

FAMILY CAREGIVER SOCIAL PROBLEM-SOLVING ABILITIES AND ADJUSTMENT TO CARING FOR A RELATIVE WITH VISION LOSS

Vision impairment is one of the leading causes of disability in the United States and has been estimated to impact approximately 14 million individuals.\(^1\),\(^2\) Because vision loss often interferes with one’s ability to complete instrumental activities of everyday living (e.g., driving, financial management, medication management),\(^3\)-\(^10\) family members are often called upon to provide physical and emotional support.\(^11\)-\(^14\) The level of support provided may increase substantially when a person with a vision impairment also has a co-morbid chronic health condition requiring greater assistance.\(^15\) Family members who serve as informal caregivers may be susceptible to problems with their own adjustment related to their caregiver role and responsibilities. However, little is known about the adjustment process of family members who care for visually impaired adults. This lack of understanding is unfortunate considering the accumulating evidence documenting the influence of family caregiver functioning and support on patient rehabilitation and health outcomes.\(^16\),\(^17\)

Family caregivers often provide assistance without formal training or preparation but are increasingly expected to function competently as informal extensions of health care systems.\(^18\),\(^19\) Caregiver responsibilities with respect to caring for adults with vision impairments include assisting relatives with activities in everyday living (e.g., reading, transportation, financial management, personal care), promoting compliance with medical-behavioral regimens (e.g., routine application of eye drops, checking blood glucose
levels, medication management), and executing therapeutic rehabilitation directives in the home (e.g., utilizing residual vision more effectively, low vision aides/devices). Family caregivers often provide emotional support as well. Despite their valuable function, family members who serve in this important role are rarely compensated for their services or their time and are at risk for neglecting their own needs, leisure pursuits, and personal/family interests.20-22 Thus, caregivers typically receive little positive reinforcement for their efforts.

Considerable evidence indicates that expending significant financial, emotional, and physical resources while receiving little in return may result in what is referred to as caregiver burden. This burden may result in role overload, strain, and stress which may compromise caregiver quality of life and contribute to caregiver depression.20, 23-26 Female caregivers in particular have been found to be at greater risk for experiencing burden and negative outcomes.27-29 In addition to the personal costs of caregiver burden, such strain may negatively impact rehabilitation and health outcomes for care recipients.

While caregivers are at risk for burnout and adjustment difficulties, providing care for a relative is not a uniform experience.30 For example, family caregivers have been found to vary in the way in which they adjust to their role as a caregiver and how they solve problems associated with caregiving.20, 21, 31 Accumulating research implicates social problem-solving skills as important determinants of adjustment to caregiving.21, 32-34 Effective problem-solving abilities are associated with caregiver well-being, and caregivers who possess ineffective social problem-solving abilities are more likely to experience depressive symptomatology, anxiety, and poor health.21 Furthermore, several studies
support the value of interventions based on a problem-solving theory framework for decreasing emotional distress and improving self-management skills.\textsuperscript{35,36}

Social problem-solving abilities consist of 2 components: problem orientation and problem-solving skills. Problem orientation (negative or positive) represents a cognitive and emotional set of beliefs, appraisals, and feelings people have about how they view problems and their motivation toward solving problems. Thus, problem orientation represents their attitudes or outlook on problems in everyday living, whereas problem-solving skills refer to cognitive and behavioral strategies persons use to better understand and efficiently cope with problems. A question of interest is whether social problem-solving abilities can serve as a defense against experiencing negative outcomes related to caregiving for persons with vision loss.

Little is known about the family caregiver experience or the cognitive-behavioral characteristics such as social problem-solving abilities that influence the adjustment process for those who care for persons with vision loss. While there has been a wealth of research documenting the supportive role of family members of persons with vision impairments (i.e., instrumental and emotional support) and the positive influence of family members and friends on rehabilitation outcomes of persons with vision loss,\textsuperscript{33-36} the degree of distress, the prevalence of depression, and factors that protect against the stress experienced by these caregivers remain understudied. This information would be valuable given the influence family members have on rehabilitation and health outcomes of persons with vision loss. Knowledge about the factors that impact caregiver adjustment may promote the development of preventive efforts and psychosocial interventions targeted toward the specific needs of those caring for a relative with vision loss.
Thus, the present study was designed to 1) determine the prevalence of persons at-risk for depression among family caregivers of persons with vision loss, and 2) examine the associations between social problem-solving abilities and depressive symptoms and life satisfaction in these persons. According to the basic tenets of the social problem-solving model, a negative problem orientation should be predictive of negative caregiver emotional experience. It was hypothesized that a negative problem orientation would be significantly predictive of higher caregiver self-reported depressive symptoms and lower general well-being regardless of caregiver age and gender, severity of patients’ visual acuity, or patients’ emotional functioning.

METHODS

Participants

The sample consisted of patients (age 19 or older) with adult-onset vision loss presenting for an initial eye examination at a low vision rehabilitation clinic and the family members who accompanied them. Inclusion criteria for family caregivers were: (1) age 19 or older and (2) identified themselves as the primary family caregiver responsible for providing some form of assistance to their relative due to vision impairment. Individuals were excluded if they (1) received financial compensation for their services, (2) did not provide assistance to their relative, or (3) did not speak fluent English. Interested family caregiver and patient participants who met eligibility criteria gave written informed consent to participate in the investigation. Patients and family caregivers completed all self-report questionnaires separately following the patient’s initial low vision rehabilitation evaluation. The protocol for this study was approved by the Institutional
Review Board of the University of Alabama at Birmingham for the protection of human subjects.

Measures

Caregiver Data

Demographic Information. Family caregiver demographic data included age, gender, race, education, marital status, employment status, and relationship to patient.

Social Problem-Solving Abilities. The Social Problem-Solving Inventory-Revised short form (SPSI-R)\(^3\) is a 25-item self-report measure designed to assess social problem-solving abilities. The SPSI-R assesses two adaptive problem-solving dimensions (positive problem orientation and rational problem-solving) and three dysfunctional dimensions (negative problem orientation, impulsive/careless style, and avoidance style). The five major components, along with sample questions that comprise each scale, are as follows:

Positive Problem Orientation (PPO), “When I have a problem, I try to see it as a challenge or opportunity to benefit in some positive way from having the problem”; Negative Problem Orientation (NPO), “When I am faced with a difficult problem, I doubt that I will be able to solve it on my own no matter how hard I try”; Impulsive/Careless Style (ICS), “When I am trying to solve a problem, I go with the first good idea that comes to mind”; Avoidance Style (AS), “When a problem occurs in my life, I put off trying to solve it for as long as possible”; and Rational Problem Solving (RPS), “When I have a decision to make, I try to predict the positive and negative consequences of each option.”

Items on the SPSI-R are rated on a 5-point Likert-type scale (0 = not at all true of me to 4 = extremely true of me). Higher scores on each factor indicate greater intensity on that
particular dimension. The SPSI-R has shown high reliability (alpha coefficients for the subscales ranging from .72 to .85) and has been found to be moderately and significantly correlated with other external measures of psychological distress and well-being.\textsuperscript{37,38}

**Depressive Symptoms.** The Center for Epidemiological Studies - Depression Scale (CES-D)\textsuperscript{39} was used to obtain an index of depressive symptoms. This 20-item, self-report measure assesses current levels of depressive symptomatology. Items are scored on a 4-point scale to indicate symptom frequency during the preceding week, with scores ranging from 0 to 60. Higher scores indicate greater depressive symptomatology. Several studies have supported the discriminant and convergent validity of the scale\textsuperscript{39-42} and acceptable internal reliability coefficients have been reported (ranging from .84 to .90).\textsuperscript{39,43-45} Using the standard criterion for the CES-D, we categorized participants as non-depressed (CES-D score < 16) or at-risk for depression (CES-D score ≥ 16).\textsuperscript{46}

**Life Satisfaction.** The Satisfaction With Life scale (SWLS)\textsuperscript{47} was used to evaluate subjective well-being and overall life satisfaction of family caregivers. The SWLS is a 5-item self-report instrument with items rated on a Likert type response format ranging from 1 (\textit{strongly disagree}) to 7 (\textit{strongly agree}). Higher scores reflect greater subjective well-being. Psychometric studies of the SWLS have evidenced internal consistency (\(\alpha = .87\)) and reliability (2 month test-retest coefficient = .82).\textsuperscript{47}

**Caregiver Burden.** Perception of caregiver burden was measured using the difficulty subscale of the Caregiver Burden Scale (CBS).\textsuperscript{48} The difficulty subscale measures the difficulty associated with 14 direct, instrumental and interpersonal demands common to family caregivers. This scale was used because it is a better predictor of caregiving burden than demand alone or the total score.\textsuperscript{48} Difficulty of activities are rated on a 5-point Lik-
ert scale ranging from 1 (none) to 5 (a great amount/extremely difficult), with higher scores reflecting greater perceived burden. The subscale possesses high reliability (.91) and good internal consistency (Cronbach α range, .87-.91).36,48

Patient Data

Demographic Information and Medical History. Patient demographic data (i.e., age, race, gender) and self-reported medical history were collected from the patient’s medical record following their initial low vision evaluation.

Vision Loss. Patient distance acuity was assessed using the standard protocol for the ETDRS chart49,50 and was expressed as logMAR. For the purposes of this study, logMAR scores in the better eye were used to indicate degree of visual impairment with higher logMAR scores reflecting greater visual impairment. Self-reported onset of vision loss (i.e., sudden or gradual) was determined by the eye care provider.

Depressive Symptoms. The CES-D was administered to patients to assess depressive symptoms in the past week.

Statistical Analyses

Using the criterion of a CES-D score ≥ 16, we determined the percentage of caregivers at-risk for depression. Initial analyses compared continuous and categorical data using independent samples t-test and χ² respectively to assess differences between caregiver demographic variables and caregiver self-report measures by depression status. Correlational analyses examined associations between caregiver demographic variables, depressive symptomatology, burden, satisfaction with life, and social problem-solving
abilities, along with patient demographic/medical variables. Following the procedures used in prior tests of the social problem-solving model, separate hierarchical regression equations were computed to predict caregiver depressive symptoms and caregiver satisfaction with life. We examined the extent to which caregiver problem-solving abilities were predictive of caregiver distress above and beyond the variance attributable to patient and caregiver demographic variables, patient visual acuity, patient distress, and caregiver burden. Statistical significance was set at \( p < .05 \) (two-tailed). All analyses used the SPSS software Version 15.

RESULTS

Of the 133 patients screened, 14 had no identified caregiver and 6 were accompanied by non-family member(s) (i.e., friend, driver, paid caregiver). Of the remaining 113 eligible family caregivers, 17 caregivers declined to participate. The final sample consisted of 96 patient-caregiver dyads. Demographic characteristics of the caregiver and patient sample are provided in Table 1. Focusing first on the caregivers, the average age was 59 years (\( SD = 13.81 \)), and the majority of caregivers were women (70.8%). Caregiver participants were most often Caucasian (90.6%), with the balance African American (8.3%) and one Asian. Most of the caregivers were either spouses (37.5%) or adult daughters (33.3%). The majority of caregivers were married (72.9%). Approximately half of the caregivers were employed (47.9%), a quarter were unemployed (25%), and just less than a quarter were retired (20.8%). The average level of education for caregivers was 13 years.
Table 1. *Demographic and Medical Characteristics of the Caregivers and Patients with Low Vision.*

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Caregivers</th>
<th>Patients</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>58.64 (13.81)</td>
<td>73.48 (13.87)</td>
</tr>
<tr>
<td>Highest Level of Education, M (SD)</td>
<td>13.76 (2.65)</td>
<td>12.32 (3.48)</td>
</tr>
<tr>
<td>Gender, n (%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Women</td>
<td>68 (70.8%)</td>
<td>61 (63.5%)</td>
</tr>
<tr>
<td>Men</td>
<td>28 (29.2%)</td>
<td>35 (36.5%)</td>
</tr>
<tr>
<td>Race/Ethnicity, n (%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Caucasian</td>
<td>87 (90.6%)</td>
<td>85 (88.5%)</td>
</tr>
<tr>
<td>African-American</td>
<td>8 (8.3%)</td>
<td>10 (10.4%)</td>
</tr>
<tr>
<td>Asian</td>
<td>1 (1.0%)</td>
<td>1 (1.0%)</td>
</tr>
<tr>
<td>Marital Status, n (%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Married</td>
<td>70 (72.9%)</td>
<td>48 (50.0%)</td>
</tr>
<tr>
<td>Widowed</td>
<td>4 (4.2%)</td>
<td>33 (34.4%)</td>
</tr>
<tr>
<td>Divorced</td>
<td>9 (9.4%)</td>
<td>6 (6.3%)</td>
</tr>
<tr>
<td>Single</td>
<td>7 (7.3%)</td>
<td>0 (0%)</td>
</tr>
<tr>
<td>Separated</td>
<td>1 (1.0%)</td>
<td>0 (0%)</td>
</tr>
<tr>
<td>Missing Data</td>
<td>5 (5.2%)</td>
<td>7 (7.3%)</td>
</tr>
<tr>
<td>Employment Status, n (%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Employed</td>
<td>46 (47.9%)</td>
<td>8 (8.3%)</td>
</tr>
<tr>
<td>Unemployed</td>
<td>24 (25.0%)</td>
<td>6 (6.3%)</td>
</tr>
<tr>
<td>Retired</td>
<td>20 (20.8%)</td>
<td>64 (66.7%)</td>
</tr>
<tr>
<td>Disabled</td>
<td>0 (0%)</td>
<td>11 (11.5%)</td>
</tr>
<tr>
<td>Missing Data</td>
<td>6 (6.3%)</td>
<td>7 (7.3%)</td>
</tr>
<tr>
<td>Caregiver Relationship to the Patient, n (%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Spouse</td>
<td>36 (37.5%)</td>
<td></td>
</tr>
<tr>
<td>Daughter</td>
<td>32 (33.3%)</td>
<td></td>
</tr>
<tr>
<td>Son</td>
<td>8 (8.3%)</td>
<td></td>
</tr>
<tr>
<td>Mother</td>
<td>5 (5.0%)</td>
<td></td>
</tr>
<tr>
<td>Sister</td>
<td>3 (3.1%)</td>
<td></td>
</tr>
<tr>
<td>Daughter-in-Law</td>
<td>3 (3.1%)</td>
<td></td>
</tr>
<tr>
<td>Brother</td>
<td>3 (3.1%)</td>
<td></td>
</tr>
<tr>
<td>Nephew</td>
<td>2 (2.1%)</td>
<td></td>
</tr>
<tr>
<td>Granddaughter</td>
<td>1 (1.0%)</td>
<td></td>
</tr>
<tr>
<td>Niece</td>
<td>1 (1.0%)</td>
<td></td>
</tr>
<tr>
<td>Son-in-Law</td>
<td>1 (1.0%)</td>
<td></td>
</tr>
<tr>
<td>Unknown</td>
<td>1 (1.0%)</td>
<td></td>
</tr>
<tr>
<td>Best Corrected Visual Acuity (logMAR), M (SD)</td>
<td></td>
<td>0.74 (0.40)</td>
</tr>
<tr>
<td>Total # of Co-Morbid Chronic Health Conditions</td>
<td></td>
<td>2.79 (1.68)</td>
</tr>
<tr>
<td>Patient Primary Vision Diagnosis, n (%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age-Related Macular Degeneration</td>
<td>54 (56.3%)</td>
<td></td>
</tr>
<tr>
<td>Diabetic Retinopathy</td>
<td>8 (8%)</td>
<td></td>
</tr>
<tr>
<td>Glaucoma</td>
<td>8 (8%)</td>
<td></td>
</tr>
<tr>
<td>Other (e.g., Retinitis Pigmentosa)</td>
<td>21 (22%)</td>
<td></td>
</tr>
<tr>
<td>Vision Impairment-Unknown</td>
<td>1 (1%)</td>
<td></td>
</tr>
</tbody>
</table>
As for the low vision patients, the average age was 73, and the majority were women (63.5%). Half of patients were married (n = 48; 50%) and approximately a third were widowed (n = 34; 35.4%). With regards to employment status, most were retired (64.6%), 11 were disabled (11.5%), 6 were unemployed (6.3%), and 8 were missing employment status (8.3%). The average level of education for patients was 12 years (SD = 3.48).

In terms of vision-related characteristics, average visual acuity for patients (best corrected distance acuity in the better eye) was .74 logMAR (Snellen equivalent ~20/110). Age-related macular degeneration was most frequently the primary diagnosis for patients (n = 54; 56.3%). Other causes of vision impairment were diabetic retinopathy, cerebral vascular accident, and glaucoma. The majority of patients reported experiencing gradual onset of vision loss (68.8%), although almost 30% of the sample reported that vision loss was sudden. Patients reported an average of 3 co-morbid chronic health conditions in addition to their vision impairment.

Prevalence of Caregiver Depressive Symptomatology

Table 2 compares at-risk and non-depressed caregivers (61.5%) on patient and caregiver demographic variables, patient medical variables, and caregiver psychosocial variables. Thirty-four family caregivers of individuals with visual impairments (35.4%) were identified as being at-risk for depression (CES-D score ≥ 16). Caregivers at-risk for depression were significantly younger (p < .026), caring for a relatively younger person with vision loss (p < .024), and also providing assistance for a loved one with worse vis-
Table 2. Comparison of Caregivers At-Risk for Depression and Non-Depressed Caregivers on Caregiver Demographics, Patient Medical Characteristics, and Caregiver Psychosocial Variables.

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>At-Risk for Depression (n = 34)</th>
<th>Non-Depressed (n = 59)</th>
<th>p Value</th>
<th>Total Sample (n = 96)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Caregiver Age</td>
<td>53.97 (14.57)</td>
<td>60.59 (12.85)</td>
<td>.026*</td>
<td>58.64 (13.81)</td>
</tr>
<tr>
<td>Caregiver Education, M (SD)</td>
<td>13.38 (2.47)</td>
<td>14.00 (2.78)</td>
<td>.286</td>
<td>13.76 (2.66)</td>
</tr>
<tr>
<td>Caregiver Gender, n (%)</td>
<td></td>
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<td>Women</td>
<td>31 (91.2%)</td>
<td>36 (61%)</td>
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<td>68 (70.8%)</td>
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<tr>
<td>Men</td>
<td>3 (8.8%)</td>
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<td>Caregiver Race, n (%)</td>
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<td>Caucasian</td>
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<td>African-American</td>
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<td>1 (1.7%)</td>
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<td>1 (1%)</td>
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<td>Caregiver Martial Status, n (%)</td>
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<td>Married</td>
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<td>70 (72.9%)</td>
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<td>Widowed</td>
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<td>2 (3.4%)</td>
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<td>Divorced</td>
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<td>4 (6.8%)</td>
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<tr>
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<td>Caregiver Employment Status, n (%)</td>
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<td>Employed</td>
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<td>Unemployed</td>
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<td>12 (20.3%)</td>
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<tr>
<td>Missing Data</td>
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<td>4 (6.8%)</td>
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<td>6 (6.3%)</td>
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<td>Relationship to Patient, n (%)</td>
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<td>Spouse</td>
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<td>Daughter</td>
<td>14 (41.2%)</td>
<td>18 (30.5%)</td>
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<td>32 (33.3%)</td>
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<tr>
<td>Son</td>
<td>1 (2.9%)</td>
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<td>8 (8.4%)</td>
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<td>Mother</td>
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<td>1 (1.7%)</td>
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<td>5 (5.2%)</td>
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<tr>
<td>Sister</td>
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<td>2 (3.4%)</td>
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<td>3 (3.1%)</td>
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<td>Daughter-in-law</td>
<td>2 (5.9%)</td>
<td>1 (1.7%)</td>
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<td>3 (3.1%)</td>
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<td>Brother</td>
<td>1 (2.9%)</td>
<td>2 (3.4%)</td>
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<td>2 (2.1%)</td>
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<td>Nephew</td>
<td>1 (2.9 %)</td>
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<td>Granddaughter</td>
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<td>1 (1.7%)</td>
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<td>Niece</td>
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<td>1 (1.7%)</td>
<td></td>
<td>1 (1.0%)</td>
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<tr>
<td>Son-in-law</td>
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<td>1 (1.7%)</td>
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<td>1 (1.0%)</td>
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<td>Unknown</td>
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<td>0 (0%)</td>
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<td>1 (1.0%)</td>
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<td>Patient Visual Acuity (logMAR), M (SD)</td>
<td>.899 (.405)</td>
<td>.622 (.337)</td>
<td>.002**</td>
<td>.736 (.386)</td>
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<td>Patient # Co-morbid health conditions</td>
<td>2.74 (1.76)</td>
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<td>.904</td>
<td>2.79 (1.68)</td>
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<td>Patient Primary Eye Diagnosis, n (%)</td>
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<td>.959</td>
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<td>Age-related macular degeneration</td>
<td>16 (47.1%)</td>
<td>36 (61.0%)</td>
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<td>54 (56.3%)</td>
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<tr>
<td>Diabetic retinopathy</td>
<td>5 (14.7%)</td>
<td>1 (1.7%)</td>
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<td>7 (7.3%)</td>
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<tr>
<td>Glaucoma</td>
<td>2 (5.9%)</td>
<td>2 (3.4%)</td>
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<td>4 (4.2%)</td>
</tr>
<tr>
<td>Other (e.g., birdshot choroidopathy, RP)</td>
<td>11 (32.0%)</td>
<td>19 (32.3%)</td>
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<td>30 (30.6%)</td>
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<tr>
<td>Vision impairment with unknown etiology</td>
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<td>1 (1.7%)</td>
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<td>1 (1.0%)</td>
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<tr>
<td>Caregiver Psychosocial Variables, M (SD)</td>
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<tr>
<td>Depressive Symptoms (CES-D score)</td>
<td>23.18 (6.96)</td>
<td>7.32 (4.44)</td>
<td>&lt;.001***</td>
<td>13.12 (9.42)</td>
</tr>
<tr>
<td>Satisfaction with life (SWLS score)</td>
<td>18.28 (7.41)</td>
<td>28.77 (6.16)</td>
<td>&lt;.001***</td>
<td>24.98 (8.37)</td>
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<tr>
<td>Caregiver burden (CBS score)</td>
<td>27.16 (9.90)</td>
<td>22.73 (8.81)</td>
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<td>24.24</td>
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<td>Social Problem-Solving Abilities (SPSI-R)</td>
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<tr>
<td>Negative Problem Orientation (NPO)</td>
<td>8.76 (5.02)</td>
<td>4.00 (2.85)</td>
<td>&lt;.001***</td>
<td>5.58 (4.40)</td>
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<tr>
<td>Positive Problem Orientation (PPO)</td>
<td>11.85 (4.06)</td>
<td>14.44 (3.78)</td>
<td>.003***</td>
<td>13.35 (4.09)</td>
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<tr>
<td>Rational Problem-Solving Style (RPS)</td>
<td>11.64 (3.44)</td>
<td>11.67 (4.25)</td>
<td>.967</td>
<td>11.53 (4.00)</td>
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<tr>
<td>Impulsive/Careless Style (ICS)</td>
<td>7.06 (3.30)</td>
<td>4.81 (3.84)</td>
<td>.006**</td>
<td>5.62 (3.75)</td>
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<tr>
<td>Avoidant Style (AS)</td>
<td>6.27 (4.42)</td>
<td>3.86 (3.24)</td>
<td>.004**</td>
<td>4.65</td>
</tr>
</tbody>
</table>

Note. * Statistically significant (p < .05); ** Statistically significant (p < .01); *** Statistically significant (p < .001); RP = retinitis pigmentosa; CES-D = Center for Epidemiological Studies – Depression Scale; SWLS = Satisfaction With Life Scale; CBS = Caregiver Burden Scale; SPSI-R = Social Problem-Solving Inventory – Revised short form.
ual acuity ($p < .002$) compared to non-depressed caregivers. Additionally, a greater proportion of female caregivers were identified as at-risk for depression compared to males.

**Predicting Caregiver Depressive Symptomatology**

Table 3 contains the univariate correlations for the caregiver self-report measures of depressive symptoms, life satisfaction, caregiver burden, social problem-solving abilities, and caregiver and patient demographic/medical characteristics. Only significant correlations were entered into the prediction of caregiver depressive symptoms. Table 4 presents the depressive symptomatology model. The block of patient and caregiver demographic variables as well as patient demographic, psychosocial, and medical variables (age of patient, patient depressive symptomatology, visual acuity, caregiver gender, age of caregiver) entered at the first step of the equation was significantly predictive of caregivers’ depressive symptomatology, $F(5, 76) = 4.79$, $R^2 = .29$, $p < .001$. Younger age of the patient ($\beta = -.21, t = -2.10; p = .039$), greater patient depressive symptomatology ($\beta = .28, t = 2.83; p = .006$) and women caregivers ($\beta = .23, t = 2.27, p = .026$) were all significantly associated with higher caregiver depression scores; patient visual acuity ($\beta = .16, t = 1.62, ns$) and caregiver age were not significant predictors ($\beta = -.05, t = -.49, ns$).

At the second block, caregiver burden did not significantly augment the equation after controlling for patient and caregiver demographic variables, $F_{inc}(1, 75) = 3.20$, $R_{inc}^2 = .03$, $ns$. However, the third block of caregiver problem-solving styles was significantly predictive of caregiver depressive symptomatology $F_{inc}(2, 73) = 8.80$, $R_{inc}^2 = .13$, $p < .001$. Caregiver avoidant style was associated with higher depression scores ($\beta = .34, t = 3.40$, $p < .001$) above and beyond patient and caregiver demographic variables, patient distress,
Table 3. Correlations for Caregiver Depressive Symptoms, Life Satisfaction, Social Problem-Solving Abilities, and Caregiver/Patient Demographic Variables.

<table>
<thead>
<tr>
<th>Variables</th>
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<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
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<th>12</th>
<th>13</th>
<th>14</th>
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<td>1. C-CES-D</td>
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<td>2. C-SWLS</td>
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<td>3. C-CBS</td>
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<tr>
<td>4. C-PPO</td>
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<td>.47**</td>
<td>-.19</td>
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<td>.37**</td>
<td>-.37**</td>
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<tr>
<td>7. C-ICS</td>
<td>.33**</td>
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<td>-.20</td>
<td>-.11</td>
<td>.35**</td>
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<td>-.26*</td>
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<td>-.25*</td>
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<td>.26*</td>
<td>.06</td>
<td>.01</td>
<td>.09</td>
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<td>.17</td>
<td>-.02</td>
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<td>-.18</td>
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<td>11. P-CES-D</td>
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<td>-.42**</td>
<td>.16</td>
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<td>.27*</td>
<td>-.10</td>
<td>.14</td>
<td>.16</td>
<td>.15</td>
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<td>.06</td>
<td>-.32**</td>
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<td>-.15</td>
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<td>13. P-Age</td>
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<td>-.12</td>
<td>.11</td>
<td>-.29**</td>
<td>.04</td>
<td>-.14</td>
<td>-.10</td>
<td>-.03</td>
<td>.25*</td>
<td>.27**</td>
<td>.24*</td>
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<td>.12</td>
<td>.11</td>
<td>-.12</td>
<td>-.10</td>
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<td>15. P-Acuit</td>
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<td>-.24*</td>
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<td>.04</td>
<td>-.01</td>
<td>.46**</td>
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Note: *Statistically significant (p < .05); ** Statistically significant (p < .01); CES-D = Center for Epidemiological Studies – Depression scale; SWLS = Satisfaction With Life Scale; CBS = Caregiver Burden Scale; PPO = Positive Problem Orientation; NPO = Negative Problem-Orientation; RPS = Rational Problem-Solving Style; ICS = Impulsive/Careless Style, AS = Avoidant Style; Acuity = Best corrected distance acuity in the better eye logMAR scores; Gender = participant gender (0 = men, 1 = women); Onset = Duration of patient vision loss in months; Variables preceded with a “C” indicate caregiver variables; Variables preceded with a “P” indicate patient variables.
Table 4. *Multiple Regressions of Caregiver and Patient Demographic Information, Caregiver Burden, and Caregiver Social Problem-Solving Abilities on Caregiver Depressive Symptoms and Satisfaction With Life.*

<table>
<thead>
<tr>
<th>Variable</th>
<th>$R^2$</th>
<th>$R^2_{inc}$</th>
<th>$\beta$</th>
<th>$F_{inc}$</th>
<th>$p$ Value</th>
</tr>
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<td><strong>Caregiver Depressive Symptoms</strong></td>
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<td>Best Corrected Distance Acuity in Better Eye-LogMAR</td>
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<td><em>Step 2</em></td>
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<td>.18</td>
<td>3.20</td>
<td>.08</td>
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<td>Caregiver Burden (CBS score)</td>
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<td><em>Step 3</em></td>
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<td>.13</td>
<td>.07</td>
<td>8.89</td>
<td>&lt;.001***</td>
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<td>Impulsive/Careless Style (ICS score)</td>
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<td></td>
</tr>
<tr>
<td>Avoidant Style (AS score)</td>
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<td>.07</td>
<td>.34</td>
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<td>.001**</td>
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<td><em>Step 4</em></td>
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<td>.35</td>
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<td>Negative Problem Orientation (NPO score)</td>
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<td>.30</td>
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<td>.002**</td>
</tr>
</tbody>
</table>

| **Caregiver Satisfaction With Life**                        |       |             |         |           |           |
| *Step 1*                                                    | .26   | .24         | 9.36    | <.001**   |           |
| P-Gender                                                    |       |             |         |           |           |
| P-CES-D                                                     | -.40  | -.11        | .11     |           | .30       |
| C-Gender                                                    |       |             |         |           |           |
| *Step 2*                                                    | .32   | .07         | -.26    | 8.27      | .01       |
| Caregiver Burden (CBS score)                               |       |             |         |           |           |
| *Step 3*                                                    | .34   | .11         | -.11    | 1.40      | .24       |
| Avoidant Style (AS score)                                  |       |             |         |           |           |
| *Step 4*                                                    | .10   | .07         | -.37    | 9.12      | .003**    |

*Note. * Statistically significant ($p < .05$); ** Statistically significant ($p < .01$); *** Statistically significant ($p < .001$); CES-D = Center for Epidemiological Studies – Depression scale; Gender = Gender of participant (0 = men, 1 = women); Variables preceded with “C” indicate caregiver variables; Variables preceded with “P” indicate patient variables.*
and caregiver burden. At the final step, components of caregiver problem-orientation further improved the model’s ability to predict caregiver depressive symptomatology and accounted for an additional 14% of the variance, $F_{inc}(2, 71) = 12.70, R_{inc}^2 = .14, p < .001$. A greater negative problem orientation ($\beta = .35, t = 3.20, p = .002$) and lower positive problem orientation ($\beta = -.30, t = -3.42, p = .001$) were both associated with more caregiver depressive symptoms.

Predicting Caregiver Life Satisfaction

A second hierarchical regression equation was used to predict family caregivers’ life satisfaction from caregiver and patient demographics, caregiver problem-solving style, and caregiver problem-orientation. Table 4 presents the caregiver life satisfaction model. As a group, patient and caregiver demographic variables (patient and caregiver gender and patient depressive symptomatology) added at the first step were significantly predictive of caregiver life satisfaction, $F(3, 82) = 9.36, R^2 = .26, p < .001$. Patients who were women ($\beta = .24, t = 2.32; p = .023$) and greater patient depressive symptomatology ($\beta = -.40, t = -4.08; p < .001$) were both significantly associated with higher caregiver depression scores; caregiver gender was not a significant predictor ($\beta = -.11, t = -1.05, ns$). At the second step, caregiver burden significantly augmented the equation, $F_{inc}(1, 81) = 8.27, R_{inc}^2 = .07, p = .005$, after controlling for patient and caregiver demographic variables. At the third step, caregiver avoidant style was not significantly predictive of caregiver life satisfaction, $F_{inc}(1, 80) = 1.40, R_{inc}^2 = .01, ns$, above and beyond patient and caregiver demographic variables and caregiver burden. At the final step, components of caregiver problem orientation further improved the model’s ability to predict caregiver
life satisfaction, $F_{inc}(2, 78) = 9.22$, $R_{inc}^2 = .12$, $p < .001$. Inspection of the beta weights revealed that a greater negative problem orientation ($\beta = -.32$, $t = -2.55$, $p = .013$) and lower positive problem orientation ($\beta = .27$, $t = 2.91$, $p = .005$) were both significantly associated with poorer caregiver satisfaction with life.

**DISCUSSION**

A substantial number of individuals assisting a relative with adult-onset vision loss experience significant emotional distress. About one-third of the caregivers studied had depressive symptomatology consistent with clinical depression. The prevalence of depressive symptoms reported by this sample is higher than expected compared to the general population\textsuperscript{51} but is similar to those found among other caregiver populations caring for persons with long-term chronic health conditions (i.e., stroke, traumatic brain injury).\textsuperscript{20,35,36} The present study also revealed that several patient and caregiver demographic (i.e., patient and caregiver age, patient gender), medical (i.e., patient visual acuity), and psychosocial variables (i.e., patient distress, caregiver burden, and caregiver problem-solving abilities) were related to caregiver well-being.

Family caregivers at-risk for depression reported more dysfunctional problem-solving abilities (greater Negative Problem Orientation, Impulsivity/Careless Style, and Avoidant Style) compared to the general population.\textsuperscript{35} Consistent with the predictions of this study and with prior problem-solving research, problem orientation was significantly predictive of caregiver depressive symptomatology and life satisfaction after accounting for the variance attributed to patient visual acuity, patient age, caregiver gender, patient depressive symptomatology, and caregiver burden. Caregivers of persons with chronic
health conditions who have a greater negative orientation towards problem-solving are more likely to experience greater depressive symptomatology, distress, and other negative health outcomes.\textsuperscript{52-54} A greater negative orientation impairs problem-solving and adjustment by contributing to negative moods and inhibiting positive moods and by interfering with decision-making critical to effective problem-solving performance.\textsuperscript{55, 56} Our data are consistent with this earlier work in that caregivers who had a more negative problem orientation were more likely to report more depressive symptoms and less satisfaction with life compared to those who reported a more positive approach to managing problems in daily living.

These results demonstrate the applicability of a problem-solving framework in understanding adjustment of family caregivers of persons with vision impairments. Caregivers who lack the problem-solving abilities necessary to balance caregiving responsibilities and personal well-being may compromise the health of both the caregiver and the person with a vision impairment. If undetected and untreated, negative outcomes related to caregiver distress may persist or worsen over time. This study found a relationship between the emotional functioning of caregivers and their relatives with vision loss, as caregivers who reported greater depressive symptomatology also provided care for patients who reported greater depressive symptomatology. The relationship between patient-caregiver mood has been previously documented in the low vision literature\textsuperscript{16} as well as among other patient-caregiver populations (e.g., dementia).\textsuperscript{57} Thus, further exploration of how the emotional well-being of individuals with vision loss and their caregivers may change across time appears warranted.
Eye care providers may vary in their awareness of the emotional consequences of vision loss on patients and the extent to which they integrate family members into vision care (e.g., treatment adherence, transportation to eye care appointments) and rehabilitation efforts (i.e., practice of therapeutic directives and appropriate use of devices within the home environment). Unfortunately, various obstacles, such as time constraints, focus on the patient, billing issues, lack of familiarity with treatment indications or medications, and/or resources prevent providers from screening and treating family members at-risk for depression. Further complicating the provision of comprehensive vision care may be the ophthalmologist’s lack of knowledge of vision rehabilitation resources, which would limit referrals to appropriate vision rehabilitation service providers. Our results suggest that a significant number of family members assisting individuals with vision impairments experience emotional distress related to their caregiving role. Encouragingly, psychosocial interventions, such as problem-solving training, may decrease caregiver distress by fostering a more efficient, systematic approach to caregiving that enhances motivation and self-efficacy when providing care for a relative with vision loss.

Evidence exists supporting the efficacy of problem-solving training (PST) for caregivers. PST has been successfully utilized to promote emotional and physical well-being, increase the use of active coping strategies, and treat depression. Problem-orientation components are particularly amenable to treatment and have been found to improve the quality of life of caregivers and patients with chronic health conditions. Psychosocial interventions that include education about eye diseases, increased access to community services and resources, low vision rehabilitation efforts, support groups, home modifications, and treatment of depression may ultimately improve quality of life
for patients with vision loss and their family members who provide ongoing assistance and support. Because caregiver and patient depressive symptomatology appear to be related, caregivers may benefit from education on how to support a loved one coping with vision loss. Integrating family members into psychosocial interventions aimed at optimizing patient well-being has shown benefits beyond patient-only interventions for a range of patient populations. Until treatments and medical advancements to restore vision are available, the addition of psychosocial interventions in conjunction with current medical approaches (i.e., eye drops, surgery, vitamins) may enhance quality of life and prevent negative outcomes for both patients and their family caregivers.

Our results underscore the need to consider the emotional impact of assisting a relative with vision loss. However, limitations must be acknowledged. CES-D scores alone cannot be used to determine whether an individual is experiencing clinical depression. Another limitation of the present study is that the cross-sectional nature prohibits any causal conclusions, and it remains unclear whether it is the specific process of caring for a relative with vision loss that contributes to caregivers’ distress. Longitudinal investigations are needed to better understand the relationship between caregiver demands (i.e., patient visual acuity, caregiver burden, and patient emotional distress) and caregiver adjustment. While the study sample of caregivers was representative of persons presenting to this particular low vision rehabilitation center, the sample consisted of a small number of caregivers representative of different racial and ethnic backgrounds, which limits generalizability. Future studies addressing potential health disparities in persons presenting for low vision rehabilitation are needed, particularly as African-Americans are at greater risk for various eye diseases (i.e., glaucoma). Furthermore, individuals present-
According to a low vision rehabilitation center may be experiencing more functional impair-
ments than those not seeking such services. Investigations examining differences in
caregiver distress among individuals with vision loss who are/are not referred for vision
rehabilitation are also needed.

In summary, the findings highlight the importance of understanding adjustment
among family caregivers of persons with a vision impairment. As the U.S. population
continues to age, the number of individuals living with vision loss is also expected to in-
crease; thus, it is likely that the number of family caregivers serving as informal exten-
sions of the health care system will also rise over the next several decades. Therefore,
identifying caregivers who are at-risk for depression and other negative outcomes is criti-
cal. Appropriate referral for treatment stands to enhance both patient and caregiver ad-
justment to vision loss. Problem-solving training may be especially useful for family
members having difficulty coping with the challenges related to assisting a relative with
vision loss.

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1. Tielsch J. Prevalence of visual impairment and blindness in the United States. In:
Massof R, Lidoff L, eds. Issues in low vision rehabilitation: Service delivery, policy, and


3. Dreer L, Elliott T, Berry J, Fletcher D, Swanson M. Cognitive appraisal and emotional
distress among persons in low vision rehabilitation. British Journal of Health Psychol-

4. Dreer L, Broadfoot A. Lesson ten: Evaluation and intervention for psychosocial is-
can Occupational Therapy Association (AOTA); 2008:271-301.


CONCLUSIONS

Family members of persons with low vision play an important role in their relative’s adjustment to vision loss. Our findings indicate that a substantial number of these family caregivers are at risk for depression, particularly those caregivers who report dysfunctional social problem-solving skills (e.g., view problems as a threat, avoid solving problems, haphazardly select solutions). More empirical investigations are needed to better understand what aspects of the caregiving role are perceived as most distressing so that appropriate psychosocial interventions may be developed.

Psychosocial Interventions for Family Members of Persons with Vision Impairments

While our findings indicate that a substantial number of family caregivers of individuals with vision loss may be at risk for psychosocial distress, unfortunately family-centered and individual family caregiver interventions are generally lacking for this group. Existing family- and caregiver-based interventions for persons with vision impairments have focused predominantly on children/adolescent populations (Janssen, Riksen-Walraven, & Van Dijk, 2003). The psychosocial intervention research that does attend to adult-onset vision loss has primarily involved only the individual with low vision (Brody et al., 2002; Thomas & Urbano, 1993).

Only a few studies have explored psychosocial interventions for adult persons with low vision and their family members, and these efforts have generally been educa-
tional and supportive in nature. For example, Cimarolli and colleagues (2004) evaluated a time-limited support group titled, ‘Program for Partners,’ which was attended by family partners of adult individuals with visual impairments. Results found that participation increased attendees’ knowledge of their visually impaired partners’ situations, improved the quality of communication between partners, and reduced the sighted partners’ negative appraisal of their role.

In another study using a different method of intervention, Siemsen, Bergstrom and Hathaway (2005) explored the efficacy of a 30-minute, private patient-education consultation with adult patients and their family members to enable them to take better advantage of low vision services. The focus of the study was to provide patients and families with more detailed explanations, clarification, and support regarding the patient’s eye disease. In general, key findings indicated that the program was accessible, family members better understood the patient’s visual impairment, and low vision rehabilitation health care providers had positive comments about the program.

In a separate study, Dumas and Sadowsky (1984) evaluated a family training program for 93 family members who had participated in a veterans affairs family training program because of loss of sight in a spouse, sibling, or significant other. Results found that the training program significantly reduced the number of problem areas reported by family members of adventitiously blinded and low vision veterans.

Proactive efforts targeting the entire family system may ultimately improve treatment outcomes and reduce secondary complications. Education efforts targeted toward the family offered within eye clinics may increase family member knowledge regarding
their relative’s eye disease and how it impacts the visually impaired person’s functioning in everyday living.

While some attempts to address family issues have centered on the development and benefits of educational programs or support groups, psychotherapy or multicomponent interventions incorporating a combination of education and psychotherapy are needed to fully address the needs of a family adjusting to vision loss. In designing interventions, future research should investigate 1) the needs of the primary family caregiver alone and the needs of the patient alone, 2) the dynamic between the primary family caregiver and the person with low vision, or 3) the entire family system. This information can then be used to develop theoretically driven interventions. Knowledge of the complex associations among patient-family dynamics, social network size, frequency of contact, communication patterns, coping strategies, and quality of support should all considered when designing psychosocial and educational interventions for individuals with vision loss and their family members.

Proactive psychosocial interventions targeting the entire family system may ultimately improve treatment outcomes and reduce costly medical complications. Previous research from the general literature on caregiving for persons with chronic diseases, adjustment to disability, and issues related to aging may be informative in understanding adjustment-related difficulties and the role of family function on outcomes. However, it is likely that family member and patient adjustment to loss of vision pose unique challenges to these individuals and the dynamic system in which they function. Mental health care specialists with an understanding of family-systems based approaches that integrate theory and illness (McDaniel, Hepworth, & Doherty, 1992; Rolland, 1994), crisis interven-
tion and short-term therapy for medical patients and family members (Pollin & Kanaan, 1995), and provide therapy to couples coping with illness (Schmaling & Goldman-Scher, 2000) are needed.

Implications for Low Vision Rehabilitation Professionals

To enhance efforts aimed at optimizing family member adjustment to caring for a relative with vision loss, there are significant clinical implications for practitioners. While there is variability within the field, low vision rehabilitation teams often include ophthalmologists, optometrists, certified low vision therapists, rehabilitation therapists, orientation and mobility specialists, occupational therapists, vocational rehabilitation therapists, psychologists, and/or social workers (for review see Seidman, 2000). Awareness of family functioning among ophthalmologists may be key, as these providers are well-positioned to promote the acquisition of appropriate resources (e.g., educating patients and families about vision rehabilitation services and outcome expectancies, identifying barriers to treatment; for review see Leinhaas & Massof, 2001). Vision care training programs should stress the importance of multidisciplinary collaborations to provide comprehensive care for patients and their families.

Formal training in the utilization of a family-systems based approach to vision services also appears warranted. Integrating family members into the patient’s eye examination has several benefits, including 1) the facilitation of communication between patients, family members, and low vision rehabilitation professionals; 2) the promotion of the provider’s ability to anticipate adjustment difficulties in patients and family members (e.g., depression, non-adherence to rehabilitation regimes) so that appropriate referrals
can be made to mental health professionals; 3) fostering patient and family member investment in the patient’s eye care; and 4) the encouragement of family member competence in assisting a relative with vision loss.

Directions for Future Research with Family Members of Persons with Low Vision

As clinical studies have shown the critical role of family support throughout the rehabilitation process (Reinhardt & D'Allura, 2000), identifying the mechanisms that underlie the successful adjustment of family members would help direct therapeutic interventions with families throughout the rehabilitation process. Based on our findings, a problem-solving intervention may be particularly well-suited for families having difficulty caring for a relative with vision loss. Further research is needed to identify common concerns among these family members so that a targeted problem-solving training intervention may be developed and implemented.

Continued research on family support is also needed. Most of the research on support for persons with low vision has been studied in relation to the visually impaired person’s perceptions of support. Objective measures of family caregiver behaviors and an assessment of the family’s perception of support provided would offer insight into the caregiving experience and may promote the provision of positive support to minimize patient and caregiver distress. From a cognitive-behavioral standpoint, studies that identify family thoughts, behaviors, and feelings preceding, during, and following specific acts of support may help to better understand family patterns and interactions. Such information would elucidate cognitive and behavioral patterns that either contribute to or impede a family member’s adjustment to caring for a relative with vision loss.
Another area in the vision literature deserving greater attention is the assessment of family functioning. While measures such as the Family Assessment Device (FAD; Epstein, Baldwin, & Bishop, 1983) have been useful, more instruments are needed to study the family’s process of adjusting to a relative’s vision loss. Paper and pencil self-report questionnaires such as the FAD are limited by individual perceptions of family function and may be subject to bias in judgments, guessing/estimates, or problems with metacognition rather than other methods such as direct observation or family interview formats. Design of methods that allow researchers to measure family interaction patterns such as standardized procedures for recording and coding observations of family function are critical for improving the reliability of data and obtaining information that might not otherwise be understood with traditional self-report measures. While self-report measures can provide valuable information, the integration of objective assessment tools measuring family member behaviors/interactions will be essential for a more accurate understanding of family interactions. A further limitation of the current research on family function and adjustment to caring for a relative with vision loss is that the majority of studies are cross-sectional in nature. Longitudinal investigations are needed to better understand how family dynamics related to adjusting to vision loss unfold across time.

Lastly, much of the research on family functioning has focused on support received by persons with low vision. An emerging area of research demanding greater attention is the ability of persons with low vision to provide support (emotional and instrumental) to others, and its impact on patient and family adjustment (Boerner & Reinhardt, 2003; Reinhardt, 2001). Related, continued investigations are needed to more thoroughly evaluate how familial roles may change after vision loss (Gill-Williamson, 1991).
Summary

As the aging population continues to rise in the U.S., the number of individuals living with a vision impairment is also expected to rise. Vision loss does not occur in isolation but within the social context of the family. Thus, family members are likely to be increasingly relied upon for the provision of vision-related instrumental and emotional support. Caring for a relative with vision loss challenges the family system. Identifying caregivers at risk for depression and other negative outcomes is important not only to promote caregiver well-being but also to promote optimal adjustment (emotional and functional) among individuals with vision loss. Further research is needed to examine ongoing adaptation to caregiving demands and changes in family roles among family caregivers of persons with vision loss. Appropriate psychosocial interventions, such as problem-solving training, should be developed and integrated into standard vision care.
GENERAL LIST OF REFERENCES


Reinhardt, J. (2001). Effects of positive and negative support received and provided on adaptation to chronic visual impairment. *Applied Developmental Science, 5*, 76-85.


APPENDIX A

SUMMARY OF THE LITERATURE ON FAMILY FUNCTIONING AND ADULTS WITH VISION LOSS
Table 1. *Summary of the Literature on Family Functioning and Adults with Vision Loss.*

<table>
<thead>
<tr>
<th>Author(s)</th>
<th>Year</th>
<th>Sample</th>
<th>N</th>
<th>Design</th>
<th>Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>Barron et al.</td>
<td>1992</td>
<td>Older women (ages 75-94) with low vision</td>
<td>56 women</td>
<td>Cross-sectional</td>
<td>• Higher levels of loneliness were reported by women who were less optimistic and less satisfied with their social support system.</td>
</tr>
</tbody>
</table>
| Barron et al.      | 1994 | Older adults (age ≥ 65) with vision impairments for at least one year | 87 older adults | Cross-sectional | • Loneliness was not directly related to marital status but may be indirectly related through social support.  
  • Those who were unsatisfied with their social network reported more loneliness. |
| Bernbaum et al.    | 1993 | Individuals with diabetes and visual impairment participating in a support group for individuals with diabetes and vision loss | 22 individuals with diabetes and vision impairment | Cross-sectional | • Vision impairment was a significant stressor in spousal relationships.  
  • Separation occurred in 9 of 18 individuals in a committed relationship avg of 1.6 years after the vision impairment.  
  • Those who were totally blind had a higher risk for separation than those who were legally but not totally blind.  
  • Psychological intervention had minimal benefits. |
| Black              | 1999 | Older Mexican Americans (age ≥ 65) with or without diabetes           | 636 with diabetes 2,196 controls | Cross-sectional | • The risk of comorbid vision impairment was significantly higher in depressed compared to nondepressed diabetic individuals. |
| Boerner & Reinhardt| 2003 | Older adults (age ≥ 65) with a chronic, progressive visual impairment  | 449 older adults | Longitudinal    | • Affective and instrumental support provided to family and friends decreased over time.  
  • Age, gender, and education predicted support provided at baseline.  
  • Receipt of support was positively related to support provided at baseline and over an 18-month period. |
| Boerner et al.     | 2004 | Older adults (mean age 80) with chronic vision impairments             | 570 older adults | Longitudinal    | • Social negativity received decreased over time, while social negativity initiated remained stable.  
  • Social negativity was positively related to instrumental support but was stronger for received than initiated negativity. |
• Compared to the general population, those with visual impairments had a significant lack of social support, especially among men.
• The amount of social support was not related to the amount of vision loss or age.
• Unemployed adults of working age reported less social support than those who were employed.
• Those who had someone visiting at least once a month were less likely to report a severe lack of social support.

• Indirect monthly costs per patient for informal care/support averaged $119.51.
• Indirect monthly costs per patient costs including lost production of helper averaged $316.72 (amounts in Australian dollars).

• Median self-reported cost associated with vision loss was $2,417 per year (range $7–$18,610; amounts in Australian dollars).
• Caregivers provided assistance for help at home and with personal affairs (e.g., shopping, banking, and writing).
• Cost of informal care/support accounted for the largest proportion of total costs related to vision loss.

• A support group increased appreciation for visually impaired partner’s situation, improved communication between partners, and decreased sighted partner’s negative appraisal of their role.
• Family members most often provided positive support in the form of instrumental help.
• The most common form of negative support was underestimation abilities.
• A lack of support and receiving only negative support were related to poorer well-being.

• More perceived overprotection was related to poorer adjustment to vision loss.
• Having greater functional impairment and receiving more instrumental support was related to greater levels of perceived overprotection.
<table>
<thead>
<tr>
<th>Author(s)</th>
<th>Year</th>
<th>Description</th>
<th>Sample Size</th>
<th>Methodology</th>
<th>Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cimarolli</td>
<td>2006</td>
<td>Adults (ages 24-64) at a vision rehabilitation agency</td>
<td>114 adults</td>
<td>Cross-sectional</td>
<td>• More perceived overprotection was associated with higher levels of depressive symptomology and higher levels of anxiety.</td>
</tr>
<tr>
<td>Crews &amp; Frey</td>
<td>1993</td>
<td>Spouses and adult children of older adults (age ≥ 55) with blindness</td>
<td>47 family members</td>
<td>Cross-sectional</td>
<td>• Compared to distress prior to patient’s participation in a rehabilitation program, caregivers were less distressed about the patient’s safety and transportation and were less distressed about knowing when, how, and how much to help.</td>
</tr>
<tr>
<td>Dewis &amp; Niskala</td>
<td>1992</td>
<td>Family caregivers of individuals with multiple sclerosis in British Columbia</td>
<td>61 caregivers</td>
<td>Cross-sectional</td>
<td>• Poorer physical and mental health, compromised health behaviors, less participation in and satisfaction with preferred activities, and fewer financial resources did not deter caregivers from desiring to remain in their caregiver role.</td>
</tr>
<tr>
<td>Dumas &amp; Sadowsky</td>
<td>1984</td>
<td>Family members (mean age 57.5) of veterans (mean age 62) with visual impairments or blindness</td>
<td>93 family members</td>
<td>Cross-sectional</td>
<td>• A training program significantly decreased family members’ distress.</td>
</tr>
<tr>
<td>Foxall et al.</td>
<td>1993</td>
<td>Social support for older adults with low vision</td>
<td>-</td>
<td>Cross-sectional</td>
<td>• Living alone with low vision did not increase occurrence of loneliness compared to those living with someone.</td>
</tr>
<tr>
<td>Foxall et al.</td>
<td>1994</td>
<td>Older adults (age ≥ 65) diagnosed with low vision for at least 1 year</td>
<td>87 older adults</td>
<td>Cross-sectional</td>
<td>• Patients living alone most frequently relied on friends and children for support.</td>
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<td></td>
<td></td>
<td>• Patients living with others relied on children most often.</td>
</tr>
<tr>
<td>Goodman &amp; Shippy</td>
<td>2002</td>
<td>Older adults (mean age 74) with recent vision loss and their spouses</td>
<td>123 couples</td>
<td>Cross-sectional</td>
<td>• Spouses who were white, in poorer health, experienced more caregiving burden, had more family conflict, and poorer self-efficacy, and had a partner experiencing depression were more likely to be depressed.</td>
</tr>
<tr>
<td>Greig &amp; Overbury</td>
<td>1986</td>
<td>Patients at a low vision center (ages 53-90) and age-, gender-, and SES status-matched controls</td>
<td>14 patients, 14 controls</td>
<td>Cross-sectional</td>
<td>• Compared to controls, patients worried more about their vision, were more dependent on others when traveling, were in poorer health, and had more changes in appetite.</td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>• Successful use of low vision devices was positively correlated with affective and practical support, delay in seeking low vision services, general cognitive abilities, and experience using near vision in vocational or leisure activities.</td>
</tr>
<tr>
<td>Name</td>
<td>Year</td>
<td>Description</td>
<td>Sample Size</td>
<td>Study Design</td>
<td>Findings</td>
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<tr>
<td>Hersen et al.</td>
<td>1995</td>
<td>Older adults (ages 55-92) receiving services at a low vision rehabilitation facility</td>
<td>100 adults</td>
<td>Cross-sectional</td>
<td>Regardless of sex, diagnosis, age of onset, or duration of impairment, high levels of social support correlated with low levels of depression, low assertiveness was related to high levels of depression, and high assertiveness was related to high social support.</td>
</tr>
<tr>
<td>Horowitz et al.</td>
<td>1991</td>
<td>Older adults (ages 61-88) with low vision and their primary family caregiver</td>
<td>15 dyads</td>
<td>Cross-sectional</td>
<td>Patient need for autonomy did not conflict with caregiver helping.</td>
</tr>
<tr>
<td>Jackson &amp; Lawson</td>
<td>1995</td>
<td>Visually impaired adults (ages 18-94) who had undergone at least 4 mo. of rehabilitation</td>
<td>76 adults</td>
<td>Cross-sectional</td>
<td>Family environment traits strongly influenced patient’s adjustment to vision loss.</td>
</tr>
<tr>
<td>Langa et al.</td>
<td>2002</td>
<td>Data from 1993 U.S. national survey of community-dwelling older adults (age ≥ 70)</td>
<td>7,443 adults</td>
<td>Cross-sectional</td>
<td>Visual impairment was a risk factor for developing depression.</td>
</tr>
<tr>
<td>Lafuma et al.</td>
<td>2006</td>
<td>Two surveys: community-dwelling French citizens, and institutionalized French citizens</td>
<td>16,945 community-dwelling individuals, 14,603 institutionalized individuals</td>
<td>Cross-sectional</td>
<td>Compared to those without vision loss, those with visual impairments reported more financial burden related to higher medical costs, loss of family income, costs of paid assistance, costs social allowances, and costs of unmet needs. Those with blindness reported greater financial losses than those with low vision.</td>
</tr>
<tr>
<td>Lee &amp; Brennan</td>
<td>2002</td>
<td>Older adults (ages 65-100) with visual impairments from two prior studies</td>
<td>155 older adults from Study 1 done in 1990, 343 older adults from Study 2 done in 1992</td>
<td>Cross-sectional qualitative</td>
<td>Among those with diabetes, vision loss predicted time spent providing informal care.</td>
</tr>
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<td></td>
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<td></td>
<td></td>
<td>Women were more likely to rely on non-family social supports compared to men who were more likely to rely on immediate family.</td>
</tr>
<tr>
<td>Author</td>
<td>Year</td>
<td>Study Details</td>
<td>Sample Size</td>
<td>Study Design</td>
<td>Findings</td>
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<tr>
<td>Matsunaka</td>
<td>2002</td>
<td>Individuals with visual impairments</td>
<td>144 patients</td>
<td>Cross-sectional</td>
<td>• Living without a family member predicted increased patient distress.</td>
</tr>
<tr>
<td>McIlvane &amp;</td>
<td>2001</td>
<td>Older adults (ages 65-99) with vision loss who had a close family member and a</td>
<td>241 older</td>
<td>Cross-sectional</td>
<td>• Women who reported greater well-being had high support from both friends and family.</td>
</tr>
<tr>
<td>Reinhardt</td>
<td></td>
<td>close friend</td>
<td>adults</td>
<td></td>
<td>• Men had greater well-being if they reported high support from both family and friends or just from family.</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>• Patients with higher quality friendships and higher amounts of family support had better adaptation to vision loss.</td>
</tr>
<tr>
<td>Milian</td>
<td>1999</td>
<td>Latino family members of students (ages 7-21) with visual impairments</td>
<td>183 family members</td>
<td>Cross-sectional</td>
<td>• Family members felt a need to be involved in their child’s education but lacked confidence in their ability to assist their children in reading and math.</td>
</tr>
<tr>
<td>Moore</td>
<td>1984</td>
<td>Blind and visually impaired adults (ages 17-76) who had not received rehabilitative services since 1982</td>
<td>108 adults</td>
<td>Cross-sectional</td>
<td>• Families that exhibit positive attitudes during the patient’s vision rehabilitation were more likely to succeed in completing a rehabilitation program and obtaining employment later on.</td>
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<td>• Vision impairment was strongly associated with psychological distress.</td>
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<td>• Negative associations were found between vision impairment and one’s performance of ADLs, role functioning, mastery, and self-efficacy.</td>
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<td>• The sighted partner of a spouse with a new visual impairment may tend to be overprotective due to a lack of knowledge, embarrassment, guilt, or desire for control.</td>
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<td>• The visually impaired partner may be pushing for independence beyond his/her capability in response to feeling overprotected.</td>
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<td>• Other family problems included financial strain, changes in roles, dependence reactions, and rejection.</td>
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<td>• Few rehabilitation agencies had formal family services despite 94% of agencies providing counseling.</td>
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<tr>
<td>Ponchillia</td>
<td>1984</td>
<td>Administrators of rehabilitation centers for the blind and visually impaired</td>
<td>38 administrators</td>
<td>Cross-sectional</td>
<td>•</td>
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<td>Ormel et al.</td>
<td>1997</td>
<td>Community-dwelling late middle aged and older Dutch adults (ages 57-84)</td>
<td>5,078 adults</td>
<td>Cross-sectional</td>
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<tr>
<td>Study</td>
<td>Year</td>
<td>Sample Description</td>
<td>Sample Size</td>
<td>Study Type</td>
<td>Key Findings</td>
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<tr>
<td>---------------------</td>
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</table>
| Reinhardt           | 1996 | Community dwelling older adults (mean age 79.22) with age-related vision loss with both a close friend and a close family member | 241 adults   | Cross-sectional  | - Support from friends promotes adaptation to chronic vision impairment.  
- Family provided more instrumental assistance, guidance, reassurance of worth, and nurturance than friends.  
- Females perceived close relationships as beneficial for providing greater attachment while males perceived close relationships as providing greater instrumental assistance and social integration. |
| Reinhardt           | 2001 | Older adults (ages 63-99) with age-related vision loss                                | 570 adults   | Cross-sectional  | - Older adults with more affective support from friends reported fewer depressive symptoms, greater life satisfaction, and better adaptation to vision loss.  
- Instrumental family support was related to more life satisfaction.  
- Affective family support was positively related to better adaptation to vision loss and higher life satisfaction.  
- Initiating and receiving negative exchanges with family was associated with more depressive symptoms. |
| Reinhardt et al.    | 2006 | Older adults (mean age 80) with vision impairment seen at a vision rehabilitation agency | 570 adults   | Cross-sectional  | - After controlling for the positive impact of perceived social support, the receipt of instrumental support decreased well-being, while the receipt of affective support improved well-being. |
| Schmier et al.      | 2006 | Adults (mean age 72.9) with AMD                                                       | 803 patients | Cross-sectional  | - As visual acuity decreased, the need for unpaid help increased.  
- The cost of caregiving was estimated to range from $225 - $47,086, depending on visual acuity.                                                                                                          |
| Seybold             | 1993 | Individuals with visual impairments, orientation and mobility instructors, social workers | 18 patients, 6 OM instructors, 4 social workers | Cross-sectional  | - Patients with vision loss were significantly concerned about the attitudes of family and friends.                                                                                                       |
| Strawbridge et al.  | 2007 | Older couples completed surveys in 1994 (mean age husbands = 65, wives = 62) and 1999 (mean age husbands = 70, wives = 68). | 418 couples | Longitudinal     | - Spousal vision loss negatively impacted partner depression, physical functioning, well-being, social involvement, and marital quality.  
- Husband’s vision impairment had a greater impact on wives’ well-being and perceived marital quality than the reverse.                              |
<table>
<thead>
<tr>
<th>Study</th>
<th>Year</th>
<th>Participants</th>
<th>Design</th>
<th>Intervention</th>
<th>Findings</th>
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</table>
| Thomas & Urbano       | 1993 | Older (age ≥ 60) in the Telelink program for the Association for the Blind | Longitudinal, intervention | Weekly telephone conference calls decreased emotional distress, particularly for those with more recent onset, women who lived alone, and those who had little social support. | • Weekly telephone conference calls decreased emotional distress, particularly for those with more recent onset, women who lived alone, and those who had little social support.  
• Humor and exchanging coping strategies facilitated this effect. |
| Travis et al.         | 2003 | Family members accompanying older (ages 72-97) patients to low vision clinic | Cross-sectional | Family and friends accompanied patients to their low vision appointments 48% of time (12/25, 11 family members, 1 friend) | • Family and friends accompanied patients to their low vision appointments 48% of time (12/25, 11 family members, 1 friend)  
• Vision impairment in residents was an independent predictor of behavioral observations of agitation.  
• Among those with severe cognitive impairments, vision impairment exerted a protective effect against agitation. |
| Vance et al.          | 2003 | Nursing home residents (ages 53.96-101.96) | Cross-sectional | | • Vision impairment in residents was an independent predictor of behavioral observations of agitation.  
• Among those with severe cognitive impairments, vision impairment exerted a protective effect against agitation. |
| Byers-Lang            | 1984 | Older (age ≥ 55), blind peer counselors promoting vision rehabilitation in older adults | Review | After training from rehabilitative professionals, older peer counselor volunteers promoted progress toward rehabilitation goals.  
• Working with peer helpers increased patients’ frustration tolerance, self-esteem, and independence. | • After training from rehabilitative professionals, older peer counselor volunteers promoted progress toward rehabilitation goals.  
• Working with peer helpers increased patients’ frustration tolerance, self-esteem, and independence. |
| Crews                 | 1994 | Literature on social context of vision and aging | Review | Age- and disease-related impairments can lead to depression and isolation.  
• A lack of social support may lead to institutionalization.  
• Institutional care often results from a lack of social support. | • Age- and disease-related impairments can lead to depression and isolation.  
• A lack of social support may lead to institutionalization.  
• Institutional care often results from a lack of social support. |
| Donohue et al.        | 1995 | Older adults (age ≥ 65) with late-onset vision loss | Review | Social skills training for older adults with age-related vision loss should increase the frequency of and assertiveness in interpersonal interactions with other visually impaired older adults. | • Social skills training for older adults with age-related vision loss should increase the frequency of and assertiveness in interpersonal interactions with other visually impaired older adults. |
| Nixon                 | 1994 | Social aspects of family coping with visual impairment | Review | The experience of vision impairment demands adjustment and coping from the patient and their family members. | • The experience of vision impairment demands adjustment and coping from the patient and their family members. |
| Schmier et al.        | 2006 | Individuals with AMD | Review | AMD is a costly disability with high medical costs and indirect costs to family caregivers.  
• Possible interventions are discussed. | • AMD is a costly disability with high medical costs and indirect costs to family caregivers.  
• Possible interventions are discussed. |
<table>
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<tr>
<th>Author</th>
<th>Year</th>
<th>Title</th>
<th>Type</th>
<th>Summary</th>
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</table>
| Schulz & Williamson | 1993 | Review of research on physical frailty in a variety of older adult populations | - Review  | Needs and concerns of patients and caregivers vary depending on the disease duration.  
Caregivers with limited social support and/or had a negative relationship with the patient prior to illness are more vulnerable to negative outcomes.  
Caregivers can promote or hinder patient functioning. |
| Tuttle            | 1986 | Family members of individuals with visual impairments                  | - Review  | Family member’s progress through several stages of adjustment upon learning about a patient’s vision loss is discussed. |
| Warnecke          | 2003 | Older adults (age ≥ 70) with vision loss                               | - Review  | Vision loss often necessitates help from others and is the 3rd most common condition requiring a need for assistance with ADLs |  
Common age-related changes in vision, prevalent age-related diagnoses, and associated functional limitations are discussed.  
Rehabilitation services and support for family/caregivers may promote optimal adjustment to vision loss. |
| Watson            | 2001 | Older adults (age ≥ 55) with visual impairments                        | - Review  |                                                                                                  |
| Swart             | 1981 | Individuals with visual impairments in South Africa                    | - Opinion  | Resources for promoting adaptation to vision loss are discussed.                                 |

*Note. AMD = Age-related macular degeneration; SES = socioeconomic status; ADLs = activities of daily living.*
APPENDIX B

INSTITUTIONAL REVIEW BOARD FOR HUMAN USE FORMS
Form 4: IRB Approval Form
Identification and Certification of Research
Projects Involving Human Subjects

UAB's Institutional Review Boards for Human Use (IRBs) have an approved Federalwide Assurance with the Office for Human Research Protections (OHRP). The UAB IRBs are also in compliance with 21 CFR Parts 50 and 56 and ICH GCP Guidelines. The Assurance became effective on November 24, 2003 and expires on February 14, 2009. The Assurance number is FWA00005960.

Principal Investigator: BAMBARA, JENNIFER
Co-Investigator(s):
Protocol Number: X070905013
Protocol Title: Social Problem-Solving Abilities Among Family Members of Persons with Low Vision

The IRB reviewed and approved the above named project on 09/13/07. The review was conducted in accordance with UAB’s Assurance of Compliance approved by the Department of Health and Human Services. This Project will be subject to Annual continuing review as provided in that Assurance.

This project received EXPEDITED review.
IRB Approval Date: 09/13/07
Date IRB Approval Issued: 09/13/07

HIPAA Waiver Approved?: Yes

Marilyn Doss, M.A.
Vice Chair of the Institutional Review Board for Human Use (IRB)

Investigators please note:

The IRB approved consent form used in the study must contain the IRB approval date and expiration date.

IRB approval is given for one year unless otherwise noted. For projects subject to annual review research activities may not continue past the one year anniversary of the IRB approval date.

Any modifications in the study methodology, protocol and/or consent form must be submitted for review and approval to the IRB prior to implementation.

Adverse Events and/or unanticipated risks to subjects or others at UAB or other participating institutions must be reported promptly to the IRB.
UAB IRB Approval of Waiver of Informed Consent and/or Waiver of Patient Authorization

Approval of Waiver of Informed Consent to Participate in Research. The IRB reviewed the proposed research and granted the request for waiver of informed consent to participate in research, based on the following findings:
1. The research involves no more than minimal risk to the subjects.
2. The research cannot practicably be carried out without the waiver.
3. The waiver will not adversely affect the rights and welfare of the subjects.
4. When appropriate, the subjects will be provided with additional pertinent information after participation.

Check one:  
☐ and Waiver of Authorization (below)  
☐ or Waiver of Authorization (below)  
☐ Waiver of Authorization not applicable

Approval of Waiver of Patient Authorization to Use PHI in Research. The IRB reviewed the proposed research and granted the request for waiver of patient authorization to use PHI in research, based on the following findings:
1. The use/disclosure of PHI involves no more than minimal risk to the privacy of individuals
   i. There is an adequate plan to protect the identifiers from improper use and disclosure.
   ii. There is an adequate plan to destroy the identifiers at the earliest opportunity consistent with conduct of the research, unless there is a health or research justification for retaining the identifiers or such retention that is otherwise required by law.
   iii. There is an assurance that the PHI will not be reused or disclosed to any other person or entity, except as required by law, for authorized oversight of the research study, or for other research for which the use or disclosure of PHI would be permitted.
2. The research cannot practicably be conducted without the waiver or alteration.
3. The research cannot practicably be conducted without access to and use of the PHI.

---OR---

Full Review
The IRB reviewed the proposed research at a convened meeting at which a majority of the IRB was present, including one member who is not affiliated with any entity conducting or sponsoring the research, and not related to any person who is affiliated with any of such entities. The partial waiver of authorization for screening was approved by the majority of the IRB members present at the meeting.

Expedited Review
The IRB used an expedited review procedure because the research involves no more than minimal risk to the privacy of the individuals who are the subject of the PHI for which use or disclosure is being sought. The review and approval of the partial waiver of authorization for screening was carried out by the Chair of the IRB, or by one of the Vice-Chairs of the IRB as designated by the Chair of the IRB.

Date of Meeting

Signature of Chair, Vice-Chair or Designee

Date

Date of Expedited Review

Signature of Chair, Vice-Chair or Designee

Date
# Project Revision/Amendment Form

## 1. Contact Information
- Principal Investigator's Name: Jennifer Bombara Blazer
  - ID: jbombara E-mail: jbombara@uab.edu
- Contact Person's Name: Jennifer Bombara Blazer
  - ID: jbombara E-mail: jbombara@uab.edu
- Telephone: 205-994-0482 Fax: 205-975-6953
- Campus Address: Department of Psychology CH 415, UAB ZIP 1170

## 2. Protocol Identification
- Protocol Title: Social Problem-Solving Abilities Among Family Members of Persons with Low Vision
- IRB Protocol Number: X070905013

### Current Status of Project (check only one):
- [ ] Currently in progress (Number of participants entered: 80 patient-caregiver dyads)
- [ ] Study has not yet begun (No participants entered)
- [x] Closed to participant enrollment (remains active)
  - Number of participants on therapy/intervention: 80
  - Number of participants in long-term follow-up only: 80
- [ ] Closed to participant enrollment (data analysis only)
  - Total number of participants enrolled:

This submission changes the status of this study in the following manner (check all that apply):
- [ ] Protocol Revision
- [x] Protocol Amendment
- [ ] Study Closed to participant entry
- [ ] Study Closure
- [ ] Other, (specify) ______

## 3. Reason for Change
Briefly describe, and explain the reason for, the change. If normal, healthy controls are included, describe in detail how this change will affect those participants.

Include a copy of the protocol and any other documents affected by this change (e.g., consent form, questionnaire) with all the changes highlighted.

In this retrospective review of a research database created from the IRB approved protocol # X040823901, I initially proposed examining the social problem-solving abilities of approximately 80 patient-caregiver dyads. To enhance the statistical power of the current study, I am requesting an amendment that would allow me to increase the number of participants reviewed from approximately 80 patient-caregiver dyads to approximately 120 patient-caregiver dyads.

## 4. Does this change revise or add a genetic or storage of samples component?
- [x] Yes  [ ] No

## 5. Does the change affect subject participation (e.g. procedures, risks, costs, etc.)?
- [x] Yes  [ ] No

## 6. Does the change affect the consent document(s)?
- [ ] Yes  [x] No

If yes, briefly discuss the changes.

Include the revised consent document with the changes highlighted.

Will any participants need to be reconsented as a result of the changes?
- [ ] Yes  [ ] No

If yes, when will participants be reconsented? ______