VISUALLY IMPAIRED CAREGIVERS: PERSPECTIVES FROM PATIENT FOCUS GROUPS

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Visually Impaired Caregivers: Perspectives from Patient Focus Groups

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Abstract

Purpose: We typically think of those with severe visual impairment as having to receive care or assistance for tasks in everyday living. However, with the aging of the population, more persons who are severely visually impaired are now caring for a spouse of significant other. Very little is known about visually impaired (VI) caregivers. Thus, the purpose of this qualitative study is to learn more about this vulnerable population of VI caregivers. Methods: Focus groups and one-on-one interviews were conducted with English speaking adults who were legally blind (U.S. definition) and served as informal caregiver of an adult family member. Caregivers discussed the challenges of caregiving and how their visual impairment affected their caregiving responsibilities. Focus group transcripts were analyzed separately, using grounded theory, by three researchers. Standardized questionnaires were also administered to capture demographic and social characteristics. Results: Fourteen adults (M age = 72; 12 male, 2 female) completed all questionnaires, 9 of whom participated in a focus group and 3 completed the one-on-one interviews. Seven major themes emerged from the focus groups: 1) impact of lack of transportation, 2) concern over care recipient’s quality of life, 3) utilization of support, 4) all encompassing demand 5) cyclical adaptations 6) anxieties of the caregivers, and 7) positive aspects of caregiving. Conclusions: In general, VI caregivers experience similar challenges as other caregivers reported in the literature, yet have the added burden that comes with their own visual impairment. Unique to this population was an overriding
concern regarding transportation for themselves and their care recipient. Though expressing a feeling of all encompassing demand in caregiving, the visually impaired caregivers consistently shared their concern for their care recipient’s quality of life and emotional health. VI caregivers reported many adaptations and dependence on low vision devices and techniques to accomplish activities of daily living for themselves and their care recipients. This is to our knowledge the first qualitative study of visually impaired caregivers, and should help healthcare professionals and rehabilitation specialists become aware of the unique problems faced by this special cohort of caregivers.
DEDICATION

I would like to dedicate this work to the visually impaired caregivers who participated in this study. Without their trust and willingness to share their personal experiences with me, this thesis wouldn’t be possible. They are a special group of people and it was an honor to work with them.
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CHAPTER 1
SPECIFIC AIMS

1. Describe the impact of visual impairment on the caregiving responsibilities of visually impaired caregivers. This is an understudied population, and this project is designed to learn more about visually impaired caregivers via interviews and focus group discussions.

2. Identify the problems, experiences, and challenges facing visually impaired caregivers. Gathering data via focus groups will help researchers minimize preconceptions and assumptions about a unique group of people who may have specific needs.

3. Evaluate the impact on visually impaired caregivers related to demographic characteristics and self-reported visual functional abilities, caregiving burden associated with this role, and self-perception of overall health and well-being. Using established questionnaires on the above topics will aid researchers in identifying gaps in knowledge about a specific subset of visually impaired persons.

It is anticipated that the knowledge gained from these focus groups will provide clinicians and low vision rehabilitation professionals with a better understanding of the needs of visually impaired caregivers. In addition, this study may aid researchers in developing future research projects which may lead to interventions conducive to this population’s lifestyle and expectantly improve their quality of life and their ability to provide
care. Future rehabilitation programs developed for visually impaired caregivers may include short term blind rehabilitation programs, telerehabilitation, and outreach programs.
CHAPTER 2

BACKGROUND AND SIGNIFICANCE

Visually impaired caregivers, who serve as a primary caregiver for an ailing, disabled spouse or significant other, compose a unique population who have only recently been recognized and have not been previously studied as a group. This vulnerable population has unique demands placed upon them in which the difficulties of vision loss, (which typically result in diminished function and independence) are combined with the extraordinary multiple burdens that caregiving duties often entail.

Vision Impairment in the United States

Low vision is defined as any chronic visual impairment that interferes with everyday function and is not correctable with conventional eyewear or surgery (National Institute of Health, 1998). Vision loss can be devastating to an active, independent individual. Common problems affecting visually impaired persons may include significant difficulty reading small print, revoked driving privileges, increased risk for injury secondary to falls, as well as numerous other concerns. In addition, individuals affected by visual impairment were reported to be at risk for increased depression and decreased quality of life (Evans, Fletcher, & Wormald, 2007; Hassell, Lamoureux, & Keeffe, 2006). Currently, it is estimated that 3.4 million Americans have some type of visual impairment and that 1 in
28 Americans 40 years and older is affected by low vision (Gohdes, Balamurugan, Larsen, & Maylahn, 2005).

The prevalence of ocular diseases that cause visual impairment, such as age-related macular degeneration, cataracts, diabetic retinopathy, and glaucoma, increases significantly with age. The number of older Americans is expected to double to 70 million over the next 30 years, comprising 20% to 25% of the U.S. population (Greenberg, 2004). Likewise, the number of visually impaired and legally blind patients is expected to increase dramatically by the year 2020 (Gohdes, Balamurugan, Larsen, & Maylahn, 2005). The visually impaired population is of primary importance to the Department of Veterans Affairs (VA), because it is estimated there are 854,000 severely visually impaired veterans in the year 2005 and there will be 890,000 by the year 2010 (Goodrich, 1995). Access to vision rehabilitation will be critical for this increasing number of visually impaired patients.

Informal Caregiving in the United States

Elderly, visually impaired individuals who serve as primary caregivers may have demands placed upon them in many areas, including responsibility for the family’s financial management, meal preparation, emotional support, household chores, medication management, carrying out medical treatments, and arranging transportation to medical appointments. The visually impaired caregiver may be coordinating care for his significant other, as well as assisting with medical decision-making and in the mobility and transfer of that individual from one location to another. In short, all of the problems typically experienced
by an individual involved in caregiving may be exacerbated and compounded for the visually impaired caregiver.

Reports estimate that 125 million people in the U.S. lived with chronic conditions in the year 2000, and that number is forecast to grow to almost 157 million by 2020 (Anderson & Knickman, 2001; Rundall et al., 2002). It is also estimated that at least 44.4 million provide informal (or unpaid) care to family and friends aged 18 years or older with chronic illness or physical disabilities (Pandya, 2005). These caregivers help their loved ones remain at home by providing assistance with activities of daily living (ADLs), such as bathing, eating, and instrumental activities of daily living (IADLs), like money management and transportation. Although the caregivers are unpaid, value of informal caregiving in the U.S. has been estimated to be as much as 257 billion dollars annually (Arno, 2002).

Caregiver related stress and physical and psychological morbidity is well documented in the literature (Beach, 2005; Buck et al., 2000; Hirst, 2005; Mafullul & Morriss, 2000; Navaie-Waliser et al., 2002; Navaie-Waliser, Spriggs, & Feldman, 2002; Pinquart & Sorensen, 2006). This is a public concern as caregivers provide a valuable service. They may be at increased risk for illness (Vitaliano, Zhang, & Scanlan, 2003), such as depression and infection, which has been connected to poor immune function (Kiecolt-Glaser, Dura, Speicher, Trask, & Glaser, 1991; Wu et al., 1999). Certain caregiver characteristics have been identified to predict those most vulnerable to stress, depression, and health problems. Such characteristics include: female gender, younger age, lower income, level of disability of care recipient (i.e. severity of dementia), and increased intensity and hours spent caregiving (Almberg, Jansson, Grafstrom, & Winblad, 1998; Burns
& Rabins, 2000; Covinsky et al., 2003; Hirst, 2005; Scott, Lewis, & Loughlin, 2005). Some suggest that caregivers with compromised mental and physical health result in lower-quality care to the recipient (Beach, 2005).

A large body of literature on caregivers focuses on measuring subjective burden. Burden is typically evaluated by assessing common stressors, such as care recipient functional and behavioral status, disrupted schedule, financial problems, lack of family support, impact on social activities, and health problems of the caregiver (Ankri, Andrieu, Beaufils, Grand, & Henrard, 2005; Farcnik & Persyko, 2002; Given et al., 1992; C. Nijboer, M. Triemstra, R. Tempelaar, R. Sanderman, & G. A. van den Bos, 1999b; Roach, 2005). Several self report questionnaires are available to test for burden including: the Zarit Burden Interview (ZBI), the Caregiver Reaction Assessment (CRA), Caregiver Satisfaction Scale (CSS), Carers’ Assessment of Difficulties Questionnaire (CADI), The Burden Scale, and the Caregiver Burden Inventory (CBI). General and mental health status of caregivers are often measured in tandem with caregiving burden (Almberg, Jansson, Grafstrom, & Winblad, 1998; Beach, 2005; Douglas & Daly, 2003; Lopez, 2005; Navaie-Waliser et al., 2002; C. Nijboer, M. Triemstra, R. Tempelaar, R. Sanderman, & G. A. van den Bos, 1999b).

One reported limitation of studies measuring burden, is that they only measure burden at one given time. Caregiving responsibilities often evolve over time as the health care needs of the care recipient changes. For example, burden may decrease over time, if a care recipient suffering from dementia becomes bed-ridden when they previously had a tendency to wander outside of the home (Miyamoto, Ito, Otsuka, & Kurita, 2002). Likewise, caregiver burden can potentially increase over time, for instance, if a diabetic care
recipient requires dialysis for kidney failure. Dialysis typically involves several weekly treatments and constant management (Alvarez-Ude, Valdes, Estebanez, & Rebollo, 2004; Beanlands et al., 2005). The area of caregiving is extremely broad and complex, ranging from caregivers of the physically to mentally disabled, to caregivers of children to the elderly (Douglas & Daly, 2003).

Considering the prevalence of chronic illness and visual impairment increase with age, the idea of having a caregiver who is visually impaired is not so surprising. Although prevalence estimates of visually impaired veterans who are also caregivers are unknown, a survey of all Visually Impaired Services Team (VIST) coordinators in the U.S. revealed that a surprisingly high number of veterans (more than 350) declined participation in VA-sponsored blind rehabilitation program due to caregiving responsibilities in 2002 (Fuhr, 2003). According to Goodrich, (Veterans Health Administration, 2002) an average of 2,650 veterans become newly legally blind every year. Based on those figures, approximately 13% of legally blind veterans may be acting as a caregiver of an ailing spouse or significant other. Unfortunately, no research has been conducted to evaluate the needs of visually impaired caregivers. A recent study (Stevenson, Hart, Montgomery, McCulloch, & Chakravarthy, 2004) evaluated participants with age-related macular degeneration and their ability to care for themselves and others. These researchers found that decreased visual acuity reduced the person’s ability to care for himself and others. This study was limited to individuals with macular degeneration and did not report on the specific problems faced by the caregivers; nor did it explore the psychological health (i.e. depression, burden, etc.) of the participants.
Current Studies

A pilot study involving visually impaired caregivers is presently ongoing at the Birmingham VAMC. Patti Fuhr, O.D. Ph.D., is the Principal Investigator, and Michael Williams, Ph.D. is the Co-Investigator. Bethany Martinez, O.D. is the project coordinator. The study, approved by the Birmingham and Atlanta VA Institutional Review Boards is entitled Caregiver’s Intensified Low Vision Rehabilitation BRC Program.

The purpose of the Caregiver’s Intensified Low Vision Rehabilitation BRC Program is two-fold: 1) to learn more about visually impaired caregivers and 2) to study the effects of a short, intensive blind rehabilitation (BRC) program on a sample of 10 visually impaired (legally blind) veterans and 10 controls who are also serving as the primary caregiver for an ailing or disabled spouse or family member. The researchers hypothesize those visually impaired veteran caregivers who otherwise are unable to attend a 4 to 6 week inpatient blind rehabilitation program will benefit greatly from a shorter, more intensive low vision rehabilitation program targeted to meet their special needs resulting from the extraordinary circumstances with which they find themselves grappling. The study is testing the effects of an intensive 5-day blind rehabilitation program that places particular emphasis on areas that are of critical importance to caregivers. Outcomes will be assessed with measures of function and independence, caregiver burden, and quality of life. Currently, 15 participants are enrolled. Ten control subjects have completed an initial telephone survey and the second identical survey at least 6 weeks apart. Three participants have completed the 2 surveys mentioned as well as completed the 1-week BRC program. Two participants have completed the initial survey and are pending BRC admittance. Preliminary results show the average age of the visually impaired (VI) caregivers was 81 years. The VI care-
giver sample exhibited low to moderate burden with disrupted schedule (M = 3.45), financial problems (M = 2.38), and lack of family support (M = 1.98) subscales of the Caregiver Reaction Assessment being the most affected. Fifty percent of the VI caregivers indicated potential clinical depression (Center for Epidemiologic Studies Depression Scale score of 16 or higher) and 100% of the sample revealed reduced physical function (Short Form-12 Physical Component Score of 50 or lower). The average National Eye Institute 25 composite score was 60.32, indicating poor vision-specific quality of life. The pilot data for this study indicates that caregivers who are visually impaired may suffer from caregiving burden, physical illness, depression, and poor quality of life. If a short-term, intensified low vision rehabilitation program impacts these negative factors in a positive way is to be determined.

Focus Group Research

Focus groups have become increasingly popular in healthcare research and focus group results are now included in the literature (Reventlow & Tulinius, 2005). For instance, focus groups have been used to develop the language for questionnaires (Globe et al., 2002; Mangione et al., 1998) and for identifying barriers to eye care (Owsley et al., 2006; Pollard, Simpson, Lamoureux, & Keeffe, 2003). They have also been used to explore the experiences of terminally ill patients, caregivers and care recipients (Low, Perry, & Wilkinson, 2005; McSkimming et al., 1999; Scott, Lewis, & Loughlin, 2005). Researchers also utilize focus groups when attempting to explore behaviors and/or perceptions concerning any number of topics, such as cultural diversities. Topics that involve complex personal issues can be explored and understood with more clarity using
unstructured or semi-structured interview methods that are later analyzed using qualitative methods. One-on-one interview is another method that may be used in cases that cover sensitive topics, when subjects may feel uncomfortable sharing their thoughts with a group of people. Researchers have utilized one-on-one interviews when participants live too far to meet at one location, or if the researchers choose to conduct the interviews on location where the participants come for medical appointments or other gatherings.

Focus groups and one-on-one interviews provide researchers with valuable qualitative information that otherwise is not obtainable through quantitative methods. Qualitative research often adds depth and a greater understanding of topics under consideration and is appropriate in this study since a lack of comparative data makes a quantitative methodology inappropriate. Focus group methodology was chosen for this study since group interaction has shown to facilitate participation, debate and introduce valuable group observations (Kitzinger, 1995). A focus group environment may also encourage a shy participant to discuss and share experiences with the group, when they otherwise would avoid one-on-one interviews. Furthermore, focus groups using convenience samples have been used to study specific populations, for example HIV-positive mothers (Marcenko & Samost, 1999), that would be otherwise difficult to recruit in a randomized or large scale fashion.

Even though focus groups are a popular way of collecting data, they must be planned and executed well in order to obtain quality data. Poor planning such as not confirming dates or not providing a quiet conference room, free from disruptions, can result in poor focus in the discussions and unusable material (Cote-Arsenault & Morrison-Beedy, 2005). The moderator of the focus group must be able to stimulate discussion
from each member, change topics without disrupting momentum, establish and enforce ground rules, and avoid influencing participant responses. Likewise, the moderator should be familiar with the topic of discussion and be able to identify and promote discussion on pertinent topics, and steer group members away from speaking on irrelevant tangents. With an effective moderator, focus group data can yield valuable results (Greenbaum, 1988; Krueger & Casey, 2000; Morgan, 1993). Morgan (1993) reported it is advantageous to have the Principal Investigator (PI) or research personnel facilitate focus groups considering they have detailed familiarity with the project goals. He goes on to say “...someone who is directly involved in the project can do a better job of steering the discussion in useful directions.” Research personnel may also facilitate their own focus groups in situations of limited time and budget, considering professional facilitator fees are rather expensive. The PI facilitated the focus groups in this study.

The purpose of the focus group meetings in this study was to collect data in order to explore and evaluate the impact of visual impairment on caregiving responsibilities, and to identify the main problems that are faced by visually impaired caregivers. The strength of this methodology is that it explores the participants’ thoughts and experiences of being a caregiver who is visually impaired rather than depending solely on the perceptions and assumptions of clinicians or researchers. Focus group interviews enable participants to discuss issues important to them, in their own vocabulary, pursuing their individual and shared priorities. “Focus groups are a form of group interview that capitalizes on communication between research participants in order to generate data” (Kitzinger, 1995). Since these caregivers are unable to leave their disabled significant other
for an extended period of time, exploring the problems that impact them most gives researchers a better understanding of what critical needs must be addressed.
CHAPTER 3
RESEARCH DESIGN AND METHODS

Participant Characteristics

Inclusion criteria: Participants included English speaking persons with acquired visual impairment causing legal blindness as defined in the U.S. Participants had to have served as the primary caregiver of their spouse, significant other, or loved one for at least 6 months. The care recipient had to be 18 years of age or older. Caregivers were defined as family members or friends who provide unpaid day-to-day care (i.e. provide assistance with basic and/or instrumental activities of daily living) and are familiar with the care recipient’s medical and social state (Ankri, Andrieu, Beaufils, Grand, & Henrard, 2005). Eye examination records were obtained to confirm visual status, with written authorization by the subject. Participants were asked to complete a screening questionnaire to determine eligibility in order to enroll in the study (Appendix A). The study protocol was approved by the Birmingham Department of Veterans Affairs Medical Center (BVAMC), University of Alabama at Birmingham (UAB), Atlanta VAMC, and Emory University School of Medicine Institutional Review Boards (Appendix B).

Procedures

The study protocol was approved by the Birmingham Department of Veterans Affairs Medical Center (BVAMC), University of Alabama at Birmingham (UAB), At-
Recruitment of participants was accomplished through flyers and advertisements at the BVAMC, UAB Center for Low Vision, UAB School of Optometry, eye care provider offices and community centers that serve visually impaired persons (Appendix C). Verbal informed consent (via Short Form consent document) was obtained from all participants prior to participation in the study (Appendix D). Subjects interested in participating were asked to sign the Short Form consent, HIPAA (Appendix E), and VA Form 10-3203 (Appendix F), for permission for use of voice, when they came in for the focus group. This study was comprised of two phases of activity. Phase 1 included administration of a series of structured, established questionnaires via telephone. Phase 2 included subject participation in one focus group session. Participants were compensated $75.00 for participating in a focus group discussion.

If subjects were unable to participate in the focus group session due to travel difficulties or inability to find temporary care for their significant other, they were given the opportunity to choose to complete a semi-structured one-on-one interview via telephone. The telephone interviews were tape recorded, transcribed, and analyzed similar to the focus group recordings. The required informed consent, HIPAA authorization, and VA Form 10-3203 were sent to the participants for completion and returned before the telephone interviews took place. Previously, focus groups and one-on-one interviews have been used and analyzed concurrently in studies where specific sampling reasons or differing recruitment methods (i.e. recruiting in different settings where focus groups or one-on-one interviews are more appropriate) are required (Collins et al., 2006; Fortin, Hirota, Bond, O'Connor, & Col, 2001; Kimberlin, Brushwood, Allen, Radson, & Wilson, 2004).
Measures

Prior to the focus-group meetings, the participants were interviewed via telephone. A series of standardized questionnaires were used to capture demographic information, caregiver burden, psychological and physical well-being, and visual function. The questionnaires included: Veterans Affairs Blind Rehabilitation Service Data Base (Appendix G), Supervision Rating Scale (SRS), the Zarit Burden Interview (ZBI), Caregiver Reaction Assessment (CRA), Center for Epidemiologic Studies Depression Scale (CES-D), Short Form-12 Health Assessment Survey (SF-12), and the Veterans Affairs Low Vision Visual Functioning Questionnaire (VA LV-FVQ). Each of these questionnaires has been documented in the literature to have high internal consistency and good test-retest reliability. These particular questionnaires were used to complement the data collected from the focus groups. The data collected from these questionnaires were coded directly into a computer program during the interview process.

Zarit Burden Interview

The Zarit Burden Interview (ZBI) consists of 22 questions measuring different aspects of caregivers’ burden associated with functional/behavioral impairments of the patient. It consists of a single global rating of burden. This employs a 5-point Likert scale rating from ‘never’ to ‘nearly always’ and are scored from 1 to 4, with higher scores indicative of greater caregiver distress. The BI has high internal consistency and good test-retest reliability (Hebert, Bravo, & Preville, 2000) (Appendix H).
**Caregiver Reaction Assessment**

The Caregiver Reaction Assessment (CRA) consists of 24 items, which is divided into 5 subscales: disruptive schedule, financial problems, lack of family support, health problems, and impact of caregiving on caregiver’s self-esteem. Respondents are asked to rate the perceived impact of caregiving for each item on a 5-point Likert scale. For each subscale, a total score is computed as the average of the subsequent item scores, with a range between 1.00 and 5.00. A higher score for negative domains correspond with higher burden, while a higher score for a positive domain (impact on self-esteem) corresponds with lower burden. No overall burden scale is defined. The CRA has been demonstrated to be a feasible, reliable and valid instrument for assessing caregiver burden in chronic patient populations (Given et al., 1992; C. Nijboer, M. Triemstra, R. Tempelaar, R. Sanderman, & G. van den Bos, 1999) (Appendix I).

**Center for Epidemiologic Studies Depression Scale**

The Center for Epidemiologic Studies Depression Scale (CES-D) is used to measure caregivers’ depression. The CES-D is a 20-item, Likert-type scale that has been extensively used to measure depression in numerous healthy and physically ill populations. The subject responds how frequently he or she has experienced the symptoms described over the past week. Scores range from 0-60, with scores of 16 or greater accepted as an indicator of potential clinical depression. This scale has been used to determine the depressive symptoms in the general population and has documented acceptable validity and internal consistency reliability (McDowell & Newell, 1996; Frank-Stromborg & Olsen, 1997) (Appendix J).
**Short Form 12 General Health Assessment Survey**

The Short Form 12 (SF-12) General Health Assessment Survey is used as a general measure of overall health status of the caregiver and allow for comparison of caregiver outcomes with various other groups. The SF-12 is a self-report questionnaire and has 12 items in the following areas: physical functioning; role limitations due to physical health; bodily pain; social functioning; role limitations due to emotional problems; vitality; and general health perceptions. The SF-12 has been shown to differentiate among patients with minor medical conditions, serious medical conditions, psychiatric illness only, and those with psychiatric and serious medical conditions (McHorney, Ware, & Raczek, 1993) (Appendix K).

**Veterans Affairs Low Vision Visual Functioning Questionnaire**

The Veterans Affairs Low Vision Visual Functioning Questionnaire (VA LV VFQ) was developed to evaluate visually impaired persons self-report of problems performing activities of daily living before and after completing low vision rehabilitation. The VA LV VFQ has been shown to be reliable and valid to measure visual ability of persons with moderate to severe visual impairment in the VA and private sectors (Stelmack et al., 2004) (Appendix L). The 48-item questionnaire is used in this study to assess self-reported visual function.

**Supervision Rating Scale**

The Supervision Rating (SRS) measures the level of supervision that a patient receives from caregivers. The SRS rates level of supervision on a 13-point ordinal scale
that can optionally be grouped into five ranked categories (Independent, Overnight Supervision, Part-Time Supervision, Full-Time Indirect Supervision, and Full-Time Direct Supervision). The SRS was designed to be rated by a clinician based on interviews with the subject and an informant or caregiver who has observed at first hand the level of supervision received by the subject. Scoring is a one step procedure in which the clinician assigns the rating that is closest to the subject's level. SRS Ratings showed consistent relationships with type of living arrangement and with independence in self-care and instrumental activities of daily living (Boake, 1996; Boake, 2001) (Appendix M).

**Focus Group Discussions**

The goal for this study was to conduct up to four focus groups with 4 to 6 visually impaired caregivers, including male and female participants. The number of focus groups recommended to conduct qualitative analysis varies in the literature, but generally a minimum of three is suggested (Krueger & Casey, 2000) in order to obtain information saturation. Conducting too many focus groups is often very expensive and unnecessary. The goal is to reach saturation, meaning no new relevant information emerges from the data. The number of participants per group was chosen based on literature by Kitzinger (1994, 1995) who suggests the ideal group size is between four and eight people. Conducting small focus groups with 4 to 6 participants is also known as a ‘mini-group’. Mini-groups are often chosen because they are easier to recruit and host, and can be more comfortable for participants (Krueger & Casey, 2000).

Attempts were made to conduct focus groups with caregivers of care recipients with significant physical limitations, and separate focus groups with caregivers of pa-
tients with primarily cognitive impairments, such as Alzheimer’s disease. Separating caregivers of patients with a primary mental or physical disability may prevent awkwardness or lack of participation. For example, someone caring for a person with dementia who often wanders out of the house may not be as inclined to share his experiences with a group of caregivers for physically ill patients, who may not be ambulatory. It was found, however, that many of the care recipients in this study were reported to have both mental and physical impairments secondary to chronic disease.

Permission was obtained by the principal investigator to contact individual participants following the focus group meeting for a brief follow up interview. This follow-up interview was used to clarify statements made in the group to confirm statements are not taken out of context during the data analysis. Recruitment of focus group participants was accomplished through flyers and advertisements at the Birmingham VAMC, local eye care provider offices, and community centers that serve visually impaired persons. The focus group discussions were held at the Southeastern Blind Rehabilitation Center (SBRC) conference room at the Birmingham VA Medical Center. Prior to the meeting date, the PI contacted all participants to confirm their participation, and provide additional information pertaining to the time, location, and parking.

Appropriate steps were taken to ensure a comfortable interviewing environment. The SBRC conference room provided adequate space for group meetings and efforts were made to eliminate any outside disruptions. Refreshments were available for participants prior to the meeting.

Questions were asked to facilitate focused discussion using a discussion guide as a question prompt guide (Appendix N). This guide was reviewed by researchers with
experience in focus group and qualitative research. The question guide was designed to begin by asking more simple introductory questions and transition into key questions prompting for more in-depth insights from the participants. The outline also ensured that the moderator was consistent, asking the same questions in a similar sequence for each group and the groups were provided with a set of standardized instructions. Questions included issues with regard to degree of visual impairment, impact of visual impairment on caregiving responsibilities and activities of daily living, and prioritization of the problems and needs the participants believe will improve efficiency and quality of care given. Prompt questions were listed in case the participants were unsure how to begin answering the questions. The moderator avoided introducing too many prompts unless necessary to circumvent potentially limiting the discussion to certain topics. Each focus group was scheduled to last a maximum of 2 hours. The facilitator remained in the room to introduce ground rules, clarify statements, promote equal contribution from all participants, and introduced prompts if necessary during the discussion.

A clinical psychologist was present as an observer, to take notes and identify any behavior that needed to be addressed following the discussion. Along with assisting the moderator, the observer participated in a debriefing session following the meeting to address any issues and clarify statements. All focus group discussions were audio-taped and transcribed, with the permission of the participants. As a precaution, since caregivers who are visually impaired might have the potential to become depressed or anxious during the discussions, a list of mental health contacts was provided to all participants (Appendix O).
Data Analysis

The sample was profiled in terms of visual and demographic characteristics. The focus group transcripts were analyzed separately, using grounded theory (Strauss & Corbin, 1990; Strauss & Corbin, 1998), by 3 researchers (one who is trained in qualitative research) who independently derived and verified the central themes and trends that emerged from the data. Grounded theory is a method of deriving theories from qualitative data. Grounded theory allows theory to evolve from the data through identification of conceptual themes through a line by line analysis and constant comparison within and across themes (Strauss & Corbin, 1998). Grounded theory was chosen for this study for several reasons. First, grounded theory is a rigorous process, and once completed, provides a comprehensive analysis. Grounded theory is ideal for studying new intricate topics not previously researched since it is essentially designed to understand a research situation. The hypotheses and concepts come from the data collected. This methodology has been used to analyze the experiences of caregivers of patients currently undergoing dialysis treatments (Beanlands et al., 2005), experiences of male caregivers of mentally ill relatives (Mays & Lund, 1999), and coping strategies of visually impaired elders (Brennan et al., 2001). This type of research also relies on the experiences and knowledge of the researchers. Qualitative approaches to research can yield results that otherwise cannot be collected through quantitative methods.

Coding is the first essential step in grounded theory. Coding enables researchers to begin sorting and organizing all the data collected from the interviews. Coding involves reading through interview transcripts, analyzing each line of text, and categorizing the data. Concepts are derived, categorized and eventually clustered around a common
theme. The coders constantly compare categories and discuss any inconsistencies until a consensus is made. Reaching a consensus addresses individual researcher bias, so that it can be addressed and minimized. This allows for a more fully developed and meaningful theory. Coding continues until saturation is obtained, meaning no new relevant data surfaces.

In grounded theory, coding is a three-part process. The first type of coding is called open coding. Open coding involves naming and categorizing of phenomena through close examination of the data. This is the most basic form of coding. Axial coding is the second step. Once the initial categories are identified, the data are put back together in new ways. The researchers begin making connections between the categories. The last stage of coding is selective coding. Researchers will begin conceptualizing the categories by first identifying a “core” category, and then will systematically relate the core to other categories, validating those relationships and further developing categories that need more refinement.

Several methods were employed to maintain the quality of the research and the results. Triangulation involves gathering information from different sources, methods, investigators, and theories (Brown 2002, Russell 2003). Using triangulation helps to enhance the credibility of the research results by incorporating multiple observations to enhance the development of the theory (Malterud, 2001). In this study, information was gathered from focus groups, telephone interviews, and the analysis was agreed upon by 3 research personnel.

The researchers in this study systematically addressed and shared how their assumptions, perspectives, and knowledge of the subject influence the research process. In
other words, reflexivity was used throughout this research project and addressed in the strengths and limitations of the study results. Research bias, or any undesirable limitations, may then be more readily accounted for.

Accurate descriptions of the participants and attempts made to recruit a diverse group of participants increased the transferability of the study. A goal of the researchers was to produce a thorough investigation of the experiences and behaviors of a distinctive population that may be applied beyond the study setting. In this case, the researchers hope that practitioners and researchers will be able to identify and translate the study findings to an appropriate, outside population.

Research Personnel

Bethany Martinez, O.D., Principal Investigator, is an Optometry Research Fellow. She was responsible for overall coordination of the study, oversight of data analysis, report writing and presentations. She also served as the facilitator for the focus group discussions. Michael Williams, PhD, Co-Investigator, is a research scientist at the Atlanta VA RR&D Center. He is experienced in qualitative research. He consulted in the development of the discussion guide and assisted in study design and data analysis. Patti Fuhr, O.D., Ph.D., Co-Investigator, is an optometrist and vision scientist. She is Dr. Martinez’s mentor in the graduate program at the University of Alabama at Birmingham. She consulted in the development of the discussion guide, and assisted in study design and data analysis. Chebon Porter, Ph.D. and Laura Dreer, Ph.D., both clinical psychologists served as silent observers during the focus group sessions. They also assisted the PI with equipment set up and assisted in the development of the discussion guide.
CHAPTER 4

RESULTS

Demographic Data

Fourteen caregivers were enrolled in the study and completed the initial telephone interview. Two of the participants withdrew from the study before completing the second phase of the study and did not participate in a focus group or one-on-one interview. The demographic results for the caregivers who completed both phases of the study are highlighted in Table 1. The average age of the caregivers was 71.79 years (SD 14.73). Cause of visual impairment included macular degeneration, glaucoma, diabetic retinopathy, central retinal vein occlusion, macular hole, trauma, and familial dominant drusen. The majority of caregivers were Caucasian (N= 11 / 85.7%). The remaining three caregivers were African American. Twelve of the caregivers were male and two were female. Eight were caregivers for a spouse; three were caregivers for a parent, and two were caregivers for adult children. Education level ranged from high school graduate (or GED equivalent) to advanced college degrees. Most of the caregivers were living in the same household as the care recipient, and either lived in a house (N = 10), apartment (N = 3) or assisted living facility (N = 1).

The average age of the care recipients was 68 years (SD = 20.79). The health conditions of the care recipients are outlined in Table 2. Several of the care recipients were reported by the caregivers to have suffered from both cognitive and physical dis-
abilities. For example, one care recipient had advanced dementia secondary to Alzheimer’s disease, but also suffered multiple falls which resulted in a broken collar bone and ankle. Another care recipient was reported to have moderate dementia from Alzheimer’s disease and physical complications from polio. Two care recipients had experienced a stroke and developed cognitive problems as well as physical weakness. Another care recipient was diabetic but also was reported to have Alzheimer’s disease.

**Questionnaire Results**

Descriptive statistics of caregiver burden, depression, health, and visual function are presented in Tables 3 and 4. The Caregiver Reaction Assessment has five subcategories that are scored and analyzed separately. The mean scores of the negative experiences were relatively low, indicating the visually impaired caregivers perceived fairly low burden with the exception of the subscale disrupted schedule and lack of family support. However, the mean scores of the self-esteem subscale were relatively high, indicating a positive perception of the caregivers’ self esteem. The caregivers had highest scores in the self-esteem (M = 4.26, SD = 0.32), disrupted schedule (M = 3.19, SD = 0.52), and family support (M = 2.37, SD = 0.30) subcategories. Additionally, the subcategory financial problems (M = 2.24, SD = 0.23) was followed by health problems (M = 2.25, SD = 0.09). The caregiver burden measured by the Zarit Burden Interview (ZBI) revealed similar results. The mean score of the ZBI was 22.64 indicating low caregiver burden.

The mean caregiver depression score was 9.29 (SD = 8.14) with 21.4% (N = 3) of the participants scoring above the CES-D cutoff of 16, indicating potential clinical depression. Secondly, the average level of supervision from the Supervision Rating Scale
(SRS) was 6.89 (SD = 2.03), which corresponds to part-time direct supervision, meaning the caregivers may be absent for longer than an hour but less than the time needed to hold a full-time job away from home. On an individual basis, the level of supervision ranged from 2 for one of the participants to 10 for another participant. Level 2 on the SRS indicates the care recipient is independent at times and can be unsupervised over night while level 10 involves direct full-time supervision (See Appendix M). In addition, the SRS scores for the caregivers who scored above 16 on the CES-D ranged from 6 (N = 1) to 9 (N = 2).

The mean physical and mental component scores (PCS, MCS) of the Short Form 12 Health Assessment Survey (SF-12) were 35.39 (S.D. 10.32) and 50.70 (S.D. 11.27), respectively. The mean MCS score for the visually impaired caregivers was similar to the mean value reported for Americans of a similar age group from the general population (52.10), however, the mean PCS score was considerably lower (43.65) (Ware, 1993). A PCS score of 50 or less indicates a physical condition and a MCS of 42 or less indicates depression. Eleven (78.6%) of the caregivers had a PCS score less than 40, representing more severe levels of physical health problems and three (21.4%) caregivers had a MCS score less than 42 which signifies potential depression.

The VA LV VFQ was used as a part of the VA Blind Rehabilitation Service (BRS) Functional Outcome study. Higher scores on a 4-point scale indicate higher self-reported visual function. The average score of our participants was 2.99 (SD = 0.32). Some of our participants had completed a VA Blind Rehab program, some were participating in a VA Blind Rehab program at the time of focus group participation, and some had only received outpatient low vision services. Therefore, our data is not directly com-
parable with the aforementioned VA BRS Functional Outcome study. The average pre-rehabilitation scores on the VA LV VFQ that were reported for participants from a large number of VA Blind Rehabilitation Centers in 2005 was 2.48 for 157 participants, and in 2006 was 2.46 for 220 participants. The average post-rehabilitation score on the VA LV VFQ for subjects in this study was 3.20 for 157 participants in 2005 and 3.15 for 220 participants in 2006.
<table>
<thead>
<tr>
<th>Interview Type</th>
<th>Gender</th>
<th>Race</th>
<th>Age</th>
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<th>Education</th>
<th>Visual Field Range</th>
<th>Relationship to Care</th>
<th>Race</th>
<th>Gender</th>
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<th>Education</th>
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<td>One-on-One Interview</td>
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<td></td>
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<td>6/200 to 20/200</td>
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Table 1: Characteristics of Visually Impaired Caregivers
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<tr>
<th>Focus Group 1</th>
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<th>Gender</th>
<th>Age</th>
<th>Type of illness</th>
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<td>86</td>
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<td>Male</td>
<td>70</td>
<td>Cellulitis, gout</td>
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<td>Mr. E</td>
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<td>66</td>
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<tr>
<td>Mr. R</td>
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<td>Osteoporosis, hand tremor</td>
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<tr>
<td>Ms. H</td>
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<td>Mr. C</td>
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<td>Mr. J</td>
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Table 4

Means and Standard Deviations of the SRS, CES-D, ZBI, SF-12, and VA LV VFQ-48

<table>
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<th>Subscale</th>
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<tr>
<td>Supervision (SRS)</td>
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<tr>
<td>Depression (CES-D)</td>
<td>9.29</td>
<td>8.14</td>
<td>0 -- 25</td>
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<tr>
<td>Caregiver burden (ZBI)</td>
<td>22.64</td>
<td>13.32</td>
<td>2 -- 45</td>
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<tr>
<td>General Health (SF-12)</td>
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<tr>
<td>Physical (PCS)</td>
<td>35.39</td>
<td>10.32</td>
<td>17.6 -- 53.8</td>
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<td>Mental (MCS)</td>
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<td>11.27</td>
<td>34.9 -- 65.5</td>
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<tr>
<td>VA LV VFQ-48</td>
<td>2.99</td>
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<td>2.65 -- 3.93</td>
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</table>

The analysis of the transcripts was completed and seven core themes were identified: impact of transportation, concern over care recipient’s quality of life, utilization of support, all encompassing demand, cyclical adaptations, caregiver anxieties, and positive aspects of caregiving.

Impact of Transportation

Visually impaired caregivers repeatedly described how lack of transportation negatively impacted their lives. This was a central theme in all of the interviews conducted. Some caregivers reported having to give up working because they could no
longer consistently get to their workplace or continue to perform vision related tasks. Their inability to drive due to visual impairment caused them to expend a lot of time and effort to provide transportation to attend to basic needs such as grocery shopping, as well as transportation for medical needs of themselves and the care recipient.

*Arranging Transportation*

Caregivers indicated how losing driving privileges overwhelmingly affected their daily lives and ultimately affected the way they provided care. Activities that included driving, shopping, church attendance, taking the care recipient to the doctor and social endeavors were now much more difficult for most of the caregivers. Caregivers were responsible for the logistics of arranging transportation for the both themselves and the care recipients. Because in most cases the care recipient was unable to drive, they mentioned utilizing church, friends, family, and paid workers for transportation, although several caregivers were reluctant to ask for help.

Caregivers indicated how much of a burden it was to arrange either paid or unpaid drivers, providing enough notice to take the care recipient to the doctor. They also spoke about the lack of dependable help from friends and family for transportation needs, stating “they have their own lives” or “they work”. Two of the caregivers reported they would offer to fill up the gas tank for friends and family, and most of the caregivers disliked the thought of inconveniencing their acquaintances. In cases where the caregivers had to hire drivers, the caregivers had to give them at least 2 days notice in order to secure a ride. Mr. P, a caregiver to his in-laws, did not live with his mother and father-in-law.
Mr. P described how not being able to drive affected him

First off, I had to get someone to take me [to my in-laws’ house]. Transportation became an issue. It’s about 10 or 12 miles [to their house]. So I had to get transportation [from] my wife, my sister, sometimes one of my neighbors would take me. That was one of the bigger ways that I had to make adjustments.

Mr. K reported he and the care recipient, his stepfather, were both veterans and had appointments with the VA medical center in their town. He described the challenges he encountered when he became visually impaired.

Well personally, what I had to do was become more shrewd to what was happening. I had to find supplements to take care of what I no longer could do. Of course, through the VA, it helped out a lot. I had to find more people to take him because people have their own lives, and it’s hard to find somebody who doesn’t work, who’s still capable of driving, and when you find someone like that you have to be so careful you don’t burn them out. Because it’s not just him, it’s myself too, and I try to get the VA to schedule us on the same time.

Surprisingly, two of the visually impaired caregivers reported they still drive for the care recipient, indicating they have no other choice. Mr. R takes care of his two adult sons. He reported one son has a history of Guillain-Barre syndrome which resulted in nerve damage and weakness in the lower half of his body; the other son is cognitively impaired and unable to live on his own. Neither son is capable of driving, so Mr. R is often left in the predicament to drive his sons to appointments.

Medically, I don’t really have to do too much other than if [my son] gets letters from SSI or whatever. When he has to make a meeting, then I have to get him there one way or another. I either have to do it or have to try to find friends to do it. I’m trying to teach the younger one how to drive. The older one, I don’t have the money and/or the vehicle to have equipped for hand controls so that he could learn to drive… because very shortly, I have to stop.

1Quotations throughout text were recorded verbatim from the focus group and one-on-one interviews and consequently may contain grammatical errors or slang.
altogether. I can’t be out there. Medically, that’s where the biggest problem is; getting him to any appointments he has.

Loss of Independence

Loss of driving capabilities had a major impact on the caregivers’ independence. The caregivers who resided in rural communities appeared to be affected the most. These caregivers repeatedly mentioned how the loss of driving privileges due to vision impairment impacted virtually all aspects of their lives. Mr. J reported using public transportation but explained, “Even with alternative transportation, it restrains you.” Loss of independence included the inability to travel on short notice or just “get up and go.” Caregivers were at the mercy of others to drive them wherever they needed to go. This left them with the added burden of planning every trip, most often days in advance.

Mr. B reported

Driving is the biggest thing. Not being able to go like I did before. Having to count on other people to take us around ‘cause I was the type of individual – if I needed something I’d just jump in the car took off and went and got it. We live out in the country so it’s probably about 2 miles into town….

And Mr. G

That’s [loss of driving privileges] the biggest handicap of all – I think is the fact you’re dependent on somebody else to get out and go for a loaf of bread or whatever the occasion may be when you used to just get up and go. You can’t do it anymore. You have to plan ahead. We don’t have a taxi service in [my town]. I have to depend on either neighbors or friends or somebody that I can hire to take me places I need to go.

When asked about what kind of caregiving support would be helpful, Mr. P specifically listed transportation as a need

I think a better transportation service would help. Having to sit down and make transportation arrangements sometimes is a headache in itself. Making the phone calls like to [a public transportation service] for me to get a
ride somewhere – it requires 3-day notice. Sometimes I need shorter notice than that.

Caregivers reported they were left to juggle schedules and organize errands and appointments for themselves and the care recipient on the same day to get the most out of a driver. In cases where the care recipient could drive, the caregiver depended on this as their primary source of transportation. Mr. J used to rely heavily on his wife to drive him to his service organization meetings. He described the stress in their relationship created by his transportation needs.

I spend at least 3 evenings over there – anywhere from 6:00 to 10:30, and she’s got to the point where she resents this. She doesn’t want to drive there anymore. So I’ve got to take a cab or take the bus. And she says “I’m not going to take it!” Here comes the resentment in me toward her. Even though I have this bus system up there now to pick me up, you’ve got to make reservations a day ahead of time for all that. I’m not saying I hate my wife, don’t get me wrong, but what I’m saying is a resentment that builds when – since they took – well, I couldn’t drive. And I had to rely on everybody else to do so.

Transportation is one of the most significant issues for the visually impaired caregivers in this study. The caregivers highlighted how transportation needs affects their independence which ultimately affects the ways they are able to provide care. The caregivers dedicated time to arrange other methods of transportation, or in some instances, they felt they had no choice but to drive despite their vision loss. Some caregivers reported the care recipients were responsible for driving. All of the caregivers were interested in better transportation services. The headache of planning in advance for even the simplest errands or recruiting others without burdening family and friends was a constant challenge.
Concern for Care Recipient’s Quality of Life

Caregivers consistently shared their concern for the mental and emotional health and quality of life of the care recipients. It was evident this concept was something they felt was very important. In most cases the caregivers reported that they neglected their own needs and desires, and concerned themselves with the state of mind of the care recipient. Spending time with the care recipient, eating with them, serving meals outside, and setting up times so the care recipient could reminisce with friends were all strategies the caregivers reported to help make the care recipients happy. Mr. E reported he had trouble getting his mother to eat in order to take certain medications. He later explained how he was able to get her to eat meals and take her medication; “I started eating with her. So as long as I eat with her, she’ll eat. I also found out it makes her a lot happier.” Mr. P also felt that spending time with his in-laws improved both his mood and the mood of the care recipients.

Mr. P gave the following examples

A lot of times I just sit there and play songs on my harmonica for her. I get to practice and she gets to listen, and we’re both satisfied then. I like to get my father-in-law out in the yard so he can...I think that helps his mental and physical situation. Just to get out of the house and get a little physical activity. And the same with [my mother-in-law], it just generally takes two of us to be with her going down steps.

And Mr. K

I take [my stepfather] outside. I’m not supposed to, but I take the oxygen generator outside with the extension cord and set him outside under an umbrella, table and chairs and all that good stuff. He’ll spend most of his day out there because he’s been outside all of his life. When he gets out there he’s more content.
Ms. H reported concern for her husband, who was diagnosed with dementia following a stroke, and would often cry in front of her...

…the crying part, you know, that gets me. I think that when he remembers certain things and he can’t do anything about it. He’s always worked and so he [acts like] he wants to go to work, you know. And he’ll start crying.

Ms. H said that she would leave the room when her husband cried, because there’s “nothing I can do.” She also reported that she takes care of her 6-year-old granddaughter. Ms. H found their granddaughter made her husband happy. She explained he looked forward to seeing his granddaughter off to school and greeted her when she came home. Ms. D pointed out her daughter sometimes developed a poor or depressed mood, mostly when her symptoms from Parkinson’s disease fluctuated. She found that sitting and talking with her daughter helped get her “spirits up.” Caregivers attended to the physical aspects of their role, but also spent time and energy towards maintaining continuity in the recipients’ lives to help sustain or improve their well-being. For instance, some of the caregivers were responsible for feeding, bathing, administering medications, or getting things for the care recipient throughout the day. In addition to these daily tasks, the caregivers described strategies they used to make the care recipients more at ease.

Utilization of Support

The aspect of support was discussed throughout all of the interviews. Participants had various types of support from formal and informal sources. Caregivers sought support from friends, family, neighbors, governmental organizations, non-governmental organizations, and private services. Dependability and availability of support, particularly social support, was a recurring issue. Caregivers relied on caregiving support, but also
needed help themselves due to decreased functional abilities from their visual impairment.

Social Support

A majority of the caregivers relied on a combination of family, friends, and neighbors for various tasks like transportation and temporary monitoring of the care recipient. Caregivers were often reluctant to ask for help. They did not want to inconvenience or “burn out” informal sources of help. The participants referred to family and friends as “having their own lives” or “they can’t even loan you the time because their life is full.” The caregivers were used to having many responsibilities, including caregiving duties. When their sight diminished, they suddenly found themselves in need of support in order to maintain some of those responsibilities. Furthermore, if they did need help, it was not always available. Some of the caregivers did not live close to relatives, and lived in rural areas where neighbors were scarce.

Mr. B relied solely on his family for support.

I let [my son] know what I have to have done that I can’t do anymore. It might take him 3 weeks to get over there, but eventually he’ll get over there and he’ll spend a Saturday and do all the maintenance or whatever needs to be done around.

In addition to friends and family not being available, the caregivers were hesitant to allow anyone else to care for the care recipients. They questioned the quality of care these individuals, including family members, could provide. Mr. K reported he had no family nearby and found it difficult to find adequate help.

Most of them don’t understand the situation that you’re under cannot be modified, it cannot be changed. They don’t know how to handle someone
who has a physical or even a mental problem. They can’t handle the oxygen – they want to help but they can’t.

The caregivers also acknowledged they relied on the care recipients to help with certain activities including reading the mail and driving. Many caregivers were quick to mention if the care recipient helped them in anyway.

For instance, Mr. G reported

[My wife is] as much as a caregiver as I am. She can’t write - she has a shaking… tremor in her hand. So she can’t write. I can write, but I can’t read. So we help each other.

Mr. E shared his experience

…my wife needs me just like I need her. My wife does the things for me and I’m continuing to do for her – because some days I can’t see and I call her.

And Mr. B described how he and his wife depended on each other

…what I’m limited on doing, [my wife] tries to help me and what she’s limited on doing, then I try to help her. You know, so we’re more or less like Barnum and Bailey Circus sometimes at the house.

Formal Support

Several of the caregivers utilized formal services, such as paid sitters, drivers, and cleaning services for household chores, but a rural caregiver mentioned, “It’s not that easy to get to”. Five of the caregivers reported they utilized formal help with caregiving, but two of these caregivers hired people as sitters only. The sitters did not have medical training. The caregivers were responsible for the day-to-day care of the care recipients, and often complained of lack of services available to them. Caregivers who resided in rural areas appeared to have the least access to formal services. When asked what type of support they would want if available, the participants reported recreational activities, sit-
ters, better transportation and help with cleaning and household chores. Sitters were desirable to the caregivers mostly to free up time for themselves to do other things. Several of the caregivers repeatedly reported the time commitment was at times overwhelming, especially since their visual impairment made simple activities much more difficult to accomplish in a typical amount of time.

Mr. P described that he always felt behind in his responsibilities

…what used to take me 30 minutes to do before losing most of my vision, now may take 3 hours. It may take all day. And it’s kind of a personal characteristic I guess, in addition to the fact that I know that it takes longer. And sometimes it’s just a matter of saying “give it up, it just takes longer!”

Mr. J depicted his experience with formal supports

[Help] is not offered to you by organizations. They’re [waiting until you are] down to your last lick, and you go to somebody and say, “Look, I’ve got a big ass problem, and man I need some help!” These organizations, I know they’re out there, because I’m finding out quite a bit on different things. But I guess they don’t come knocking on your door – unless you’re breaking the law or you’re abusing somebody, or somebody says “I think he’s killing that person or that person’s starving to death.” Then they show up, but in the meantime you try to get them some help and [they say] “Well, we’ll put you on the list.”

Mr. J emphasized the lack of available services offered by either state or local organizations in his area. Other caregivers with more intensive responsibilities or who lived in rural settings shared the same frustration with lack of available formal support. It seemed in some circumstances, the caregivers felt they would need to find themselves in a very dire situation before they could have access to services.

Caregivers also described having difficulty allowing others to help take care of their loved ones’ medical needs. Lack of trust and lack of confidence in other individuals’ abilities to properly manage the care recipient was a common theme. This corresponds with none of the caregivers reporting they wanted to give up the role of caregiver
if given the opportunity. Caregivers reported family obligations, love and compassion for the care recipient, as reasons they do not want to give up the role.

Some participants wished they had access to local services, such as a daycare, where the care recipients could spend time with other adults. One caregiver acknowledged that his stepfather becomes upset with him because they are constantly with each other. He wanted a dependable service where his stepfather could spend time with other people.

Mr. K said

I’d like to have somebody [to visit him] close to his age, because he relates to people his age. He doesn’t relate to people 10 years or 20 years younger to him. He has nothing to bring to the table anymore.

And Mr. E

I would like to see my mother in a recreational therapy program that would get her mind focused.

Although caregivers spoke about services they would like to have, many were wary about service organizations that offered respite care. Several caregivers discussed how they were suspicious of such programs, including the individuals that actually frequented the centers. Other caregivers did not believe such services could carry out the medical needs of the care recipients. For instance, one caregiver was upset with a local senior citizen program, complaining that the program didn’t serve nutritious meals and expressing concern that the workers would not know how to properly handle the care recipient. He was definitely interested in a program the care recipient could enjoy, but was disappointed in the services in his community.

All of the caregivers relied on some sort of support to help them carry out their everyday responsibilities. Their visual impairment prevented them from being com-
pletely independent to care for their loved ones. Although they sought help from friends, family, and formal services, they reported their support systems needed improvement.

All Encompassing Demand

It was clear throughout the interviews the caregiving role encompassed every part of the caregivers’ lives. They typically did not identify with many other roles. The majority of caregivers agreed they needed to be available to attend to the care recipients nearly 24 hours a day.

Twenty-four / Seven

A majority of the caregivers indicated they were on-call for their care recipient every day and night. Caregivers needed to be available for any number of tasks, such as helping the care recipient walk about the house, dispensing medication, and accompanying the care recipient to medical appointments. In general, the caregivers tended to whatever the care recipients needed.

Mr. C reported his wife, who has advanced Alzheimer’s disease, followed him around constantly

The only time I have any time without my wife is early in the morning. I’ll get up say 4:30 to 5:00 and I can listen – I bought into the talking book club, so I’ll read a book for an hour or hour and a half and that’s the only time I have by myself. The rest of the time it’s with her, continuously. She’ll go to bed before I do, but she won’t go to sleep until I get into the room.

Mr. J reported he always worried about his wife, but “we’re on a shoe string ourselves.” He continued to try to speak for the group of caregivers

We’re sitting here shedding blood and tears trying to figure out how to keep them alive and worrying about them – and hell, we’re on a shoe string our-
selves, most of us. We don’t have time to think about ourselves, we’ve got to think about the responsibility that we’ve got at home; at least it is for me.

And Mr. R

They affect you in a sense that it’s a 24 – 7 thing, and you’re under each other’s feet. You are all there all the time, and sometimes it can get aggravating or frustrating or whatever you want to call it.

Some of the care recipients could not be left alone at any time due to their propensity to fall or wander from the house. Mr. P reported his mother-in-law, who has polio and Alzheimer’s disease, is always at risk for falling, “She can fall backwards just as easily as forwards; you gotta have a front and rear guard.” Mr. P and his other family members resorted to hiring paid sitters when no one else could monitor his mother-in-law.

Participants mentioned having to constantly remind care recipients to follow through with medically related tasks such as eating or taking medicines. Mr. J had problems with his wife not taking her medications and not using a cane for support. He also reported having to tell his doctors to communicate with him instead of his wife concerning her appointments and treatment plans.

Mr. J said

Tell me, you know, don’t tell her. She don’t ever tell me because she doesn’t like to go to doctors. She’ll try canceling her appointment or changing it to a later date.

Mr. E related because his mother needed to be reminded to eat so she could take her medications with food, he says “…if you don’t watch it, she won’t eat like she should.”

Additionally, several of the care recipients were at risk for falling and needed monitoring in case of accidents. In two cases, the caregivers had to call an ambulance since they were not physically able to lift the care recipient. Mr. G noted his caregiving responsibilities had increased recently since his wife, who has osteoporosis, fell off of
their bed. He was unable to lift her himself, so he had to call 911 in order to lift her off of the floor. She did not suffer any major injury, but she became more apprehensive and wanted to hold his hand every time she walked. Mr. R and Mr. J reported they were anxious sometimes at home with their care recipients, knowing quite well they would be unable to physically lift their care recipients if they would happen to fall. Both caregivers reported continually trying to get the care recipients to use proper mobility techniques to prevent falls, like using a cane on uneven ground. This type of interaction resulted in tension between the caregiver and care recipient, described often as times of anger or resentment. One of Mr. R’s sons had incontinence problems, and Mr. R reported having to monitor his son closely before and during trips outside of the home. He tried to limit his son’s liquid intake before going out of the house, because his son would have accidents in the car which then he would have to clean up.

Mr. R described his situation

Like if we’re going somewhere to make sure he doesn’t drink too much or anything before we go. Otherwise he’ll have accidents on the way, and if you don’t have anything then you’re stuck with him… and it’s kind of odorous to say the least. That’s one of the biggest problems we have with him – because he doesn’t have feeling and he doesn’t always know when he has an accident. That’s a problem.

Lack of Social Life

Lack of social life was likewise a recurring theme in this study. Caregivers spoke about the time commitment involved with their caregiving and how this prevented them from doing other things either inside or outside of the home. Some of the caregivers expressed notable interest in respite care just so they could have time for themselves. The impact of transportation in addition to caregiving responsibilities made it almost impossi-
ble to maintain a social life. The following caregivers shared their experiences on how caregiving affected their social lives.

Mr. E described the changes he had to make

... I was always a person that’s likely to go. It was nothing for me to walk out of the room and end up in New York that night. I had to realize that my mother needed me, you know.

And Ms. H

I’m tied up all day. I can’t even... I’m used to going places. I haven’t been anywhere since Thanksgiving. So as far as leaving home, I’d be afraid if I leave or go outside – he doesn’t need to go outside because he might just leave and keep going, and I won’t be able to find him. We have a lot of steps and I don’t really want him to go near the steps. He’d probably fall down.

And Mr. K

Everything we do; it’s based upon this person being able to live a short period of time longer. There is no social life. You can’t go away. You can’t take them with you because they’re pretty much tied through their existence at the house. There’s no social life, I mean there’s no outside existence other than this.

Cyclical Adaptations

The participants described adaptations they had to make secondary to their visual impairments and the ever-changing conditions of the care recipients. Caregivers relied on more help from others, either formal or informal, but several of them were able to complete relatively intense caregiving duties. Many of the adaptations were natural to the caregivers, meaning they would mention changes they made while caring for their loved ones during the interviews, but wouldn’t necessarily mention these changes when asked specifically. One caregiver elaborated, “The changes I’ve made have been so
slight and incremental that it’s – I’ve just got into that point where I’m no longer really aware of what changes because they’re just now second nature to me. “

Dependency on Low Vision Devices

All of the caregivers in this study sought low vision services in their community or through VA sponsored services. Low vision devices, in most cases, were necessary to complete basic caregiving duties such as managing medications, finances, and schedules (i.e. appointments and transportation). Several of the caregivers relied on a closed-circuit television (CCTV) for the labor intensive task of reading both their mail and the mail of the care recipients. Other caregivers without a CCTV relied on the care recipients or other individuals to read material to them. Ms. H did not have a CCTV and was unable to read her mail at all; she vented “I have stacks of letters that I can’t read. I’m used to reading – the Bible, different things like that. I can’t do it anymore.” A caregiver who recently acquired a CCTV indicated how it impacted his daily life, “[The CCTV] changed the way I did everything. It opened many, many avenues…” Ms. D had similar comments about her CCTV, “If I didn’t have the CCTV, I couldn’t take care of my own affairs.”

The participants also used adaptive techniques, hand held magnifiers and CCTVs for preparing meals, reading medically related instructions, and looking for physical changes in the care recipient. One caregiver exclaimed, “You do absolutely nothing without some sort of an enlargement, like a magnifying glass or something.” A majority of the caregivers relied on their CCTVs for all of their long duration reading activities. Mr. P took a CCTV to his in-laws home since he lived over 10 miles away. He used the
CCTV to read his father-in-law’s glucometer and medical documents. Even with a CCTV he admitted having problems, “…and the glucometer, you have to be real quick with that thing – to get it under the CCTV because it will turn off on you.”

Even with the aid of low vision devices, the caregivers were frequently forced to make further adaptations when their vision gradually worsened. One caregiver said, “Every time you develop a way to do something, as your sight goes, you have to change.” Changing meal preparation strategies was a common task for the caregivers. Several caregivers indicated they resorted to preparing microwave dinners instead of preparing a home-cooked meal. If the caregivers did still cook, they mentioned increasing the light levels over the stove, using hand held magnifiers to read the oven dials, or using adaptive techniques. As one caregiver put it, “I no longer cook by sight. I can’t tell when something’s brown. I now cook by time and the temperature of my stove.”

Ms D. gave an example

My vision has been stable, but I find I have to get closer to things. Like this morning, someone changed the setting on my toaster oven and I had to get a magnifier and get my nose right on it to see it. My distance vision isn’t as good as it used to be.

Two caregivers were forced to give up the responsibilities of medication administration for the care recipients.

For instance, Mr. P reported

I don’t feel safe dispensing their medications from the bottle to the organizer. I have to depend on somebody else to organize them mainly because of the sheer volume of the medications and the similarities in appearance, and the names on the prescription bottles.

Mr. C’s children intervened when he began to lose sight gradually. He accidentally gave his own medication to his wife and subsequently gave up that responsibility. He also re-
ported his wife would often refuse to take her medications from him, even when he tried to help his daughter get his wife to take her pain medications after breaking her ankle.

Adaptations were also made for care recipients prone to wander. Two caregivers had to put alarms and locks on the doors to prevent care recipients with dementia from wandering off the property. Most of the care recipients were not capable of being alone for more than a couple of hours. A major adaptation for many caregivers was to seek help from others to compensate for what they could no longer do secondary to vision loss. Basic skills required for caregiving like reading the mail, checking blood glucose levels, preparing care recipients for testing at the hospital, and dispensing medications were extremely difficult. The caregivers either had to find another way to do these things themselves or had to find someone to help them.

Anxieties of the Caregivers

Challenges involving the caregiver role were indicated in a number of situations described by the caregivers. In addition to the caregivers’ everyday challenges with the physical aspects of caregiving and how their visual impairment affects this role, they also admitted to having several emotional or internal challenges. The caregivers regularly faced a number of issues that created anxiety and frustration, including strain on relationships and preparing for the decline in the care recipient’s physical or mental condition.

Preparing for the Unexpected

Caregivers were frequently concerned when the next “incident” involving the care recipient would occur, be it another stroke, a severe mood change, or infection. This re-
sulted in a feeling of uneasiness, because they were unsure when something detrimental might happen to the care recipient. Some of the caregivers admitted acting proactively, and constantly looked for signs of change in the care recipient. For example, Mr. P listened for change in the tone of voice and decreased mobility in his in-laws. When he detected changes, he would communicate with his family to arrange for necessary medical care.

Mr. B described his concern for his wife’s health

Well, like I mentioned earlier, my wife had that stroke about 6 years ago and the doctors told her then... well, didn’t tell her, but told the rest of the family that within 5 years she could have another one – and I’m starting to see little things now. And for lack of another way of describing it – she’s doing stupid things. OK, and I don’t mean that derogatory. I mean, things that are out of her nature that she did before she had her major stroke. I’m starting to see now where she’s starting to do little things right now that go that same route again. So I don’t know what’s coming up in the future.

Mr. B described his uneasiness when he noticed his wife’s cognitive status change. The fact that he didn’t know if and when she could have another stroke appeared to make him relatively anxious. Mr. R reported problems with his son, who is prone to urinary track infections. His son is unable to detect symptoms of pain or other related symptoms secondary to nerve damage. As a result, neither Mr. R nor his son can identify if he has an infection until his son gets physically sick. Finding available transportation to the hospital is also a challenge.

Mr. R said

Well, you go and you’ve always got that on your mind. He could get sick any time like that. Not knowing it, and by the time you know about it it’s serious enough that you have to call for help because you can’t take care of it. We don’t have a local hospital so you have to drive 45 miles to get to a major hospital. Then you have the challenge of being able to get there and get back and everything. Luckily, I have family in that town and I can go there if I have to. It’s just the anticipation.
Need for Self Renewal

The time commitment alone required for caregiving took its emotional toll on several of the caregivers. Participants often described the caregiving role as “constant, 24-7.” The lack of personal time away from the care recipient was an issue for some. This was further exacerbated by the loss of visual-related hobbies and activities such as driving and painting. Walking was one way they could “get away” and obtain personal time. Mr. C reported he had to get up at 4:30 in the morning in order to get some private time before his wife awoke for the day. He expressed a desire for more personal time, but indicated he could not afford to pay for a sitter for his wife.

Mr. C said

The main thing I would like would be to have 3 or 4 hours a week to myself, you know. …you try to get someone to come and sit with your wife, that’s 15 to 20 bucks an hour. …we can’t afford that.

Ms. H expressed her frustrations

For about an hour, let me get some rest, leave me alone. Because sometimes I just feel like locking up my house and leaving him in there and just go about my business.

Another caregiver walked 4 miles most days of the week and reported this was a good way to vent any frustrations before he came back to the house to start his daily routine with his wife. Maintaining leisure time is reported in the literature as an important factor with caregiver satisfaction (Lopez, 2005). Caregiver satisfaction is a term used to describe the positive impacts of caregiving.

The fact that so many of the caregivers spend the majority of their time with the care recipients, created resentment between them at times. Caregivers mentioned they needed to get away for some personal time away from the care recipient and vise versa.
Spending so much time with each other created tension which the caregivers recognized. The majority of caregivers lived with the care recipient and spent nearly all waking hours with each other.

Mr. K acknowledged

You’ve got to be so careful the way that you approach what you’re going to do for [my stepfather]. Because after a period of time they get so much anxiety and they resent so much of being closed up and not allowed to be a part of society anymore that they actually start fighting you – like [my stepfather] stopped eating for a while. Because that was one of the few things he could control.

And Mr. R described the frustration he feels as a result of spending so much time with his care recipients

And then I’ll start snapping and hollering when I shouldn’t. I know I shouldn’t and I’ll apologize, but you don’t get away from it. You can’t get away, you’re there. And that’s one of the biggest things about caregiving that affects you… is the fact that you’re always there.

Mr. R’s comments indicate the stress created in the caregiver/care recipient relationship which appears to be exacerbated by the constant contact between each other. Resentment between the caregiver and care recipient was also mentioned in situations where there is increased dependency or unrealistic expectations between both parties. For instance, the care recipient or caregiver may expect the other to be capable of doing certain tasks like cleaning or managing family affairs and any disagreements may create tension in the relationship.

Watch the Care Recipient Decline

It was difficult for the caregivers to observe the decline in the mental or physical status of the care recipients. Although progression of chronic illness was not unexpected,
it still affected the caregivers in an emotional way. This tended to motivate the caregivers to attempt to enhance the quality of life of the care recipient anyway they could.

Mr. K reflected

When you see the mental gymnastics of a person declining, it’s very sad, but it’s a fact of life and there’s nothing I can do about it. There’s nothing that person can do about it – and hopefully some day the medical profession will be able to do it, but right now they can’t.

And Mr. C

And you don’t ever have a conversation. We can’t sit and talk anymore. [My wife asks] “What did you say?” Well, I don’t know, I don’t know what I said. It’s frustrating to you and I know it’s frustrating to her because she can’t remember what to say, she knows what she wants to say, but she can’t say it. It’s sad a little bit at times. I’m not sorry that she’s uh… I’m having to take care of her, I’m just sorry she’s sick like this. I’m 90 years old and she’s 87, we’ve been married 67 years or so, it’s kind of a little hard on you, you know.

These caregivers highlighted the emotional challenges associated with caregiving. It seemed the caregivers regularly put the needs of their loved ones in front of their own.

Positive Aspects of Caregiving

When asked about rewarding experiences regarding the caregiver role, participants in general were inclined to say they were happy to know they were doing the best job they possibly could. A recurring topic was feeling good about helping the person that had helped them in the past. Seeing the care recipients’ mood and physical health improve was also a reward for the caregivers. Overall, none of caregivers admitted they would give up the role if given the opportunity. It appeared the positive aspects of the caregiving role had an impact on this decision.
Several caregivers felt they were the only ones that could provide the appropriate level of physical and emotional support for the care recipient. This was another reason caregivers were reluctant to give up their role. Secondly, it appeared the caregiver role instilled meaning in their lives and they were content identifying with this role.

For example, Ms. D said

I guess just the fact that I’m able to help [my daughter]. Let’s just say when she wasn’t here and had she not come home I would have worried myself to death. Being able to help her is a comfort.

And Mr. B

We’ve been married for over, well close to 40 years…. She stuck [with] me for 21 years of [military] service and I’ll be there for her and she’ll be there for me.

The caregivers expressed satisfaction with being able to help their loved ones in need, as Mr. W said, “I’m just glad to be able to do what I can to take care of her and she reciprocates.” Some of the reciprocal benefits for the caregivers included the idea they were making a difference in the care recipients’ lives and keeping them in the community, and in most situations, staying together as a family. Other positive aspects of the caregiver role were enjoying the companionship with care recipient and being a stable presence for the care recipient. Although, the caregivers described various adverse experiences, they reported positive feelings related to their caregiver role.
CHAPTER 5
DISCUSSION

To our knowledge, this is the first study of characteristics of visually impaired caregivers. The purpose of this study was to describe the impact of visual impairment on the caregiving responsibilities of visually impaired caregivers by exploring the experiences of the caregivers using data collected from focus group and one-on-one interviews. Standardized questionnaires were also used to capture the demographic characteristics and self-reported visual function, caregiving burden, and self-perception of overall health and well-being of the caregivers. The sample was fairly diverse with regard to demographic backgrounds and level of caregiving intensity. Visually impaired caregivers were shown to be able to provide basic, and in some instances, advanced levels of care to a chronically ill or disabled loved one.

There are numerous studies on visually impaired persons with acquired vision loss. Individuals who become visually impaired are faced with new challenges that affect their independence and daily functioning. These persons are often forced to find alternative ways to complete basic daily activities like reading, writing, driving, and shopping. Currently 3.4 million Americans have some type of visual impairment (Gohdes, Balamurugan, Larsen, & Maylahn, 2005). Visually impaired adults are suggested to be at risk for increased mortality, depression, and decreased quality of life (Evans, Fletcher, &
Wormald, 2007; Freeman, Egleston, West, Bandeen-Roche, & Rubin, 2005; Vu, Keefe, McCarty, & Taylor, 2005). This is a major public health concern in the U. S. since the prevalence of age-related eye diseases and consequential visual impairment is expected to increase substantially over the next 20 years.

Informal caregivers provide long-term supportive services to millions of American adults. While this care is unpaid, the estimated value of these services is $257 billion a year (Arno, 2002). Caregiving responsibilities vary widely and may involve different levels of supervision, medication administration, bathing, meal preparation, transportation, among several other tasks. There are numerous studies involving informal caregivers. Research has reported on the positive impact of caregiving, especially if caregivers are satisfied with their relationship with the care recipient, but the majority of the literature reports on the emotional and physical toll accompanied with this demanding role. Much emphasis is put on caregiver burden, which refers to the physical, psychological, social and financial problems that can arise in the caregiver situation. Caregivers under increased emotional stress appear to be in poorer health and have a higher mortality rate than their non-caregiver counterparts (Schulz & Beach, 1999). Factors cited to possibly reduce caregiver burden include access to quality supportive services, increased social support, health promotion, and increased caregiver personal time (Almberg, Jansson, Grafstrom, & Winblad, 1998; Donelan et al., 2002; Lopez, 2005; Navaie-Waliser, Spriggs, & Feldman, 2002).

There is an abundance of literature covering visual impairment and informal caregiving in the U. S., yet we know very little about visually impaired caregivers. The need for informal caregivers is expected to rise to meet the demand of the increasing eld-
erly population. Older adults who are visually impaired may find themselves in a situation where they are solely responsible for caring for a chronically ill loved one. In this study, visually impaired caregivers reported they experienced problems related to both their visual impairment and their caregiving responsibilities. Seven major themes were identified: Impact of transportation, concern over care recipient’s quality of life, utilization of support, all encompassing demand, cyclical adaptations, caregiver anxieties, and positive aspects of caregiving.

As a group, the caregivers had a mean mental composite score (MCS) on the Short Form Health Survey (SF-12) similar to the general population of a similar age group and likewise had similar mean mental and physical component scores (PCS) compared to visually impaired adults with macular degeneration (Hassell, Lamoureux, & Keeffe, 2006). Over 75% of the older caregivers had low PCS scores indicating more severe degrees of disability. The mean PCS score (35.39) was considerably lower for this sample compared to the mean PCS score (44.9) reported for dementia caregivers 65 years of age and older as well as the general population of a similar age group (43.65) (Bruce et al., 2005; Ware, 1993). More than 20% of the caregivers were indicated to have clinical depression based on their MCS. Poor caregiver physical and mental health has been linked to higher caregiver burden and lower quality care for the care recipient (Beach, 2005; De Frias, Tuokko, & Rosenberg, 2005).

The mean score for this sample on the Clinical Epidemiologic Studies Depression Scale (CES-D) was 9.29, while a score of 16 is considered indicative of clinical depression. Other caregiver studies that included the CES-D as a measurement for depression found higher mean scores (13.55 to 16.48) than this study. These studies included care-
givers of patients with stroke, Alzheimer’s disease, dementia, and long-term ventilator patients (Clark & King, 2003; Douglas & Daly, 2003). A study of caregivers of spouses with mild cognitive impairment (Garand, Dew, Eazor, DeKosky, & Reynolds, 2005) reported a similar mean CES-D score (8.48) to the current sample. The current study is not directly comparable to other caregiver studies that investigated caregivers of persons with specific types of illness or impairment.

In spite of low physical health scores, this sample exhibited relatively low caregiver burden. This group had a lower mean score on the Zarit Burden Interview compared with caregivers of care recipients with various physical and mental disabilities (Alvarez-Ude, Valdes, Estebanez, & Rebollo, 2004; Ankri, Andrieu, Beaufils, Grand, & Henrard, 2005; Lopez, 2005; Miyamoto, Ito, Otsuka, & Kurita, 2002; Morimoto, Schreiner, & Asano, 2003; Takahashi, Tanaka, & Miyaoka, 2005).

Although this sample of caregivers had a low mean global score on the ZBI indicating low caregiver burden, they had higher negative scores on the Caregiver Reaction Assessment (CRA) related to disrupted schedule and lack of family support. Lower scores in these two subcategories correlates with two themes discussed in the study: all encompassing demand and utilization of support. Several caregivers discussed negative experiences concerning the time commitment involved in the caregiver role, including lack of social life and personal time. Four caregivers noted that they did not have any family nearby to help, while three other caregivers had access to family members, but typically asked for help on a limited basis. The caregivers in the current study exhibited similar levels of burden and high levels of self esteem as scored on the CRA compared to caregivers of care recipients with a history of Rheumatoid arthritis or stroke (Brouwer et
al., 2004; Jacobi et al., 2003; van Exel, Brouwer, van den Berg, Koopmanschap, & van den Bos, 2004). However, the visually impaired caregivers had higher mean scores in all the negative subcategories of the CRA (disrupted schedule, financial problems, lack of family support, and health problems) as compared to studies involving caregivers of cancer patients (Jacobi et al., 2003; Nijboer, Triemstra, Tempelaar, Sanderman, & van den Bos, 1999a; Nijboer, Triemstra, Tempelaar, Sanderman, & van den Bos, 1999b). Even though the current study involves a small sample, the majority of the caregivers were male and not employed; both factors are associated with lower caregiver burden (Navaie-Waliser, Spriggs, & Feldman, 2002; Pinquart & Sorensen, 2006).

The aspect of transportation and the need for transportation services is unique to this population of caregivers. Difficulty acquiring transportation is a common issue among visually impaired persons especially in rural areas. The caregivers are in a unique situation as they are often responsible for transportation for not only themselves but the care recipient as well. The caregiver in some cases must diligently set aside time to arrange for transportation and coordinate schedules of all the people involved. This may result in a financial burden as well if the caregiver doesn’t have access to public transportation. The participants in this study implemented a variety of plans and strategies to obtain transportation and they unanimously voiced how the loss of independence and spontaneity of travel negatively impacted their lives.

A majority of the visually impaired caregivers reported the immense time commitment involved in caregiving which was discussed as an all encompassing demand. The caregivers’ visual impairment only appeared to exacerbate the amount of time needed to complete every day tasks. Despite the demanding schedule and lack of social
life, all of the caregivers indicated they wanted to continue their role. In most cases, the caregivers hoped to prevent placing the care recipient in a nursing home or assisted living facility. Some of the caregivers were resistant to placing the care recipient in a nursing home due to a sense of obligation, concern over the care recipient’s well-being, and quality of care.

A related finding is the impact of social support on the caregivers’ experiences. A majority of the caregivers utilized some sort of social support to accomplish some instrumental activities of daily living. However, many of the visually impaired caregivers reported this as a negative experience and were less likely to ask friends and family for help, as they did not want to burden or inconvenience others. Moreover, some caregivers indicated they did not trust the abilities of other individuals to provide quality care. It seems the caregivers’ vision impairment puts them in a predicament to rely on normally-sighted persons for some daily living tasks. In many cases they rely on help for both themselves and the care recipient. Caregivers reluctant to seek help from informal sources may be at risk for creating an inadequate social support system. Good systems of social support are recognized as significant factors in decreased caregiver burden (Takahashi, Tanaka, & Miyaoka, 2005). In addition, caregivers with increased social support were reported less likely to place their care recipient in a nursing home (Mittelman, Haley, Clay, & Roth, 2006). One study (Winslow, 2003) found the reluctance of the caregiver to use community services was due to hassles for the caregiver, concern over quality, and concern over finance. Caregivers in this study desired accessible, affordable, dependable help in order to enhance the quality of life of the care recipi-
ent. Desire for improved caregiver support and lack of available organizational help were recurring themes in this study.

In general, the visually impaired caregivers emphasized topics consistent with other caregiver studies. Concern for the care recipients’ well-being, anxiety over the unexpected, lack of social life, desire for quality caregiving support and maintaining personal time are common themes among other caregiver studies (Davies & Nolan, 2005; Donelan et al., 2002; Lopez, 2005; Mays & Lund, 1999; Scott, Lewis, & Loughlin, 2005; Winslow, 2003). The visually impaired caregivers described a selfless pattern of behavior in which they put the needs of the care recipient in front of their own. Likewise, many of the caregivers admitted a need for protected private time in order to maintain or improve their well-being. Even though some of them perceived personal time as valuable, several of the caregivers appeared unable to set aside such time.

Caregivers often must confront adaptations when they take on the role of caregiver, but the individuals in this study also had to make additional adaptations secondary to their visual impairment. The visually impaired caregivers were forced to adapt to new situations anytime their vision decreased or the state of the care recipient changed. As one would expect, the visually impaired caregivers reported similar problems reported in the literature on visual impairment (Coyne et al., 2004; Globe, Wu, Azen, & Varma, 2004) like loss of independence and decreased visual functioning such as difficulty reading the mail, administering medications, and cooking. A significant finding in this study was the co-dependency between the caregiver and care recipient. Care recipients were often responsible for carrying out visual tasks the caregiver was unable to accomplish, for instance, driving and reading tasks. The caregivers with less intense caregiving responsi-
bilities appeared to rely more heavily on help from the care recipient. This may indicate that care recipients with less serious physical or mental disabilities require less supervision and are more likely to be capable of offering assistance; however this study did evaluate such.

Caregiving literature consistently states the importance of help for burdened caregivers. A goal for many clinicians and researchers is to lessen the emotional and physical burden of caregivers with the ultimate goal of creating a healthy environment where caregivers can remain in this role and stay in their communities. Covinsky, et al. (2003) found that poor caregiver functional status, among other characteristics, predicted caregiver depression. Likewise, caregivers who have depressive symptoms were shown to have higher caregiver burden, reduced physical health, and potentially provide lower quality care (Beach, 2005; Takahashi, Tanaka, & Miyaoka, 2005). It is evident in this study the visually impaired caregivers utilized low vision rehabilitation services, where they were trained in the use of optical devices and adaptive techniques to increase their functional abilities. Although they reported functional challenges with caregiving duties, low vision rehabilitation enabled them to retain some of their caregiving responsibilities. Awareness and access to low vision services is a priority for the Department of Veterans Affairs, the National Eye Institute and other agencies in the U. S. Magnifying devices and other types of low vision aids may significantly reduce the degree of handicap associated with impaired vision (Lamoureux et al., 2007) and vision rehabilitation is of paramount importance for persons with irreversible vision loss. In a recent study, use of low vision optical devices was associated with declines in functional disability and depressive symptoms over time in visually impaired older adults (Horowitz, Brennan, Reinhardt, &
Macmillan, 2006). Vision rehabilitation has the potential to improve functional capabilities of visually impaired individuals and this study emphasizes the impact of low vision rehabilitation in the lives of a sample of visually impaired caregivers. Findings from this study emphasize the need for accessible low vision services for visually impaired individuals, especially if they have additional responsibilities involving caregiving.

Future Studies

The impact of vision impairment on informal caregivers should be studied further. Caregivers provide a valuable service and should be viewed as an asset. Health professionals should work towards providing services to vulnerable caregivers so they may continue to provide care to their loved ones. We must also keep in mind that all the caregivers recruited in this study had already sought out low vision rehabilitation services and completed or were currently enrolled in inpatient or outpatient programs. Access to optical and other assistive aids have been shown to reduce the time needed to cope with vision loss (Boerner, Reinhardt, & Horowitz, 2006). Further studies of visually impaired caregivers compared with normally-sighted caregivers in similar caregiving situations could provide valuable information, as could studies on the effects of low vision rehabilitation on caregiving responsibilities.

There are some limitations to the current study. This study used a small convenience sample of visually impaired caregivers and the majority of participants were male veterans. Therefore, the applicability of findings from this study is limited by the nature and situation of the study participants. Based on these limitations, we can only look at associations between variables and cannot generalize the data. The extent to which the
investigators comprehensively identified the emerging themes depends both on the analysis strategy, and the sample of participants. As with most qualitative studies, the interpretation of the transcripts may be biased by the investigators’ experiences. In this case, the three investigators with different research backgrounds discussed observations and completed a consensus review in order to guard against this. Despite these limitations, interpretation of the data showed similarities with previously reported findings, but new concepts emerged regarding visually impaired caregivers.

Implications

Eye care professionals, rehabilitation specialists and other health care professionals should become cognizant of the implications of caregiver burden and how stress can impact caregivers. In addition, health care professionals should not assume a visually impaired individual relies on a caregiver since the visually impaired person may well be the primary caregiver in the household. Caregiver physical health, including visual functioning, and well-being should be considered in addition to the healthcare needs of the care recipient. Chronic conditions are increasingly common in individuals over 65 years. Considering the trend towards increased life expectancy in the U.S. and families commonly living farther distances from each other, we should expect to see more elderly couples co-residing in their communities. In households where elderly couples depend on each other for daily activities, vision impairment may afflict the healthier spouse and affect the way the spouse is able to care for the other.

The findings from this study underline the importance of caregiver support and access to low vision rehabilitation. A majority of the caregivers in this study exhibited a
compelling dependence on low vision devices for daily activities. Presently, health professionals should consider referring visually impaired caregivers to low vision rehabilitation specialists and caregiver support programs such as respite care or caregiver support groups. If caregivers are unable to travel secondary to their visual impairment and/or caregiving responsibilities, a referral to state services or other professionals who perform home visits is warranted. This study highlights the implications for low vision rehabilitation professionals in helping these individuals sustain their role at the highest level of functioning possible. Findings from this study may also be useful to researchers involved in caregiver intervention studies. Researchers may need to account for caregivers who are visually impaired when developing interventions, such as adapting educational materials for visually impaired caregivers.

Conclusions

This study presents, to our knowledge, the first qualitative research on visually impaired caregivers. Qualitative analysis of data gathered from focus group and one-on-one interviews identified seven core themes: impact of transportation, concern over care recipient’s quality of life, utilization of support, all encompassing demand, cyclical adaptations, caregiver anxieties, and positive aspects of caregiving. The activities and tasks carried out by visually impaired caregivers are similar to those reported by normally-sighted caregivers. Participants’ accounts showed their commitment and resilience in providing care for chronically ill loved ones while coping with the added burden of their own visual impairment. This research indicates that professionals involved in the care of
visually impaired caregivers and their care recipient should be aware of the increasing
demands made on caregivers and the specific problems they perceive in caregiving.

Although the visually impaired caregivers in this study reported similar responsi-
bilities and challenges reported in both the caregiver and visual impairment literature,
they also described specific issues unique to their situation. Overall, impact of transpor-
tation was a dominant theme among this group of caregivers. The simplest errand or rou-
tine doctor’s appointment for either themselves or the care recipients often took careful
planning days in advance. Secondly, a majority of these caregivers relied on adaptive
techniques and low vision devices to accomplish everyday activities of daily living. Us-
ing these devices certainly allowed them to perform tasks more easily, but many of the
caregivers acknowledged that it still took an increased amount of time to complete certain
visual tasks compared to when they had normal vision. The extra time required to per-
form visual tasks appeared to add to the all encompassing demand of the caregiving role,
which also included diminished personal time. This study also revealed the importance
of and need for social support, which is established to lessen caregiver stress and burden.
Unique to this population is they alluded to needing additional social support in order to
meet their own personal needs in addition to their caregiving duties. Despite the addi-
tional challenges vision loss created in the caregivers’ lives, they described the positive
aspects of their role, and were committed to continue providing care to their loved one.
Understanding the needs of visually impaired caregivers may give researchers, clinicians,
and supportive organizations the knowledge to effectively address the concerns of this
special group of caregivers and help to improve their well-being and ability to provide
quality care.
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APPENDIX A

SCREENING QUESTIONNAIRE
Screening questionnaire

(Administer to confirm eligibility for study after “Consent to be Contacted” has been signed)

1. Do you have problems with your eyesight?
2. Are you legally blind?
3. How long have you been legally blind?
4. What is the cause of your vision loss?
5. Do you know what your visual acuity is?
   a. If so, what is the vision in your right eye?
   b. If so, what is the vision in your left eye?
6. Do you have any reduction in your side vision?
7. Are you a primary caregiver for someone 18 years of age or older?
8. Who do you give care for?
9. What kind of disability or problem does the person you care for have?
10. How long have you been a caregiver for him/her?
11. Do you have someone else who could take care of the person for whom you care?

(If subject is eligible, administer telephone informed consent script).
APPENDIX B

VETERANS AFFAIRS MEDICAL CENTER AND UNIVERSITY OF ALABAMA AT BIRMINGHAM INSTITUTIONAL REVIEW BOARD APPROVALS
Date: July 14, 2006
From: Robert H. Carter, M.D., Chairperson
Investigator: Bethany Martinez, O.D.
Protocol: Visually Impaired Caregivers: Perspectives from Patient Focus Groups
ID: 01242  Prom#: N/A  Protocol#: N/A

The following items were reviewed and approved at the 07/13/2006 meeting:
• Abstract - Abstract (05/08/2006)
• Advertisement - Recruitment Material (05/08/2006)
• Conflict of Interest - PI/Fuhr/Williams (05/08/2006)
• Consent Form - Short Form (05/08/2006)
• Questionnaire / Survey - Caregiver Reaction Assessment (05/08/2006)
• Questionnaire / Survey - Directions for Administration of the VALV VFQ-48 (05/08/2006)
• Questionnaire / Survey - SF 12 (Short Form General Health Survey) (05/08/2006)
• Questionnaire / Survey - The Burden Interview (05/08/2006)
• Questionnaire / Survey - The Center for Epidemiologic Studies (05/08/2006)
• HIPAA Authorization (06/22/2006)
• HIPAA Revocation of Authorization (05/08/2006)
• Miscellaneous - List of Mental Health Contact Information (06/22/2006)
• Miscellaneous - Summary of Informed Consent & HIPAA Authorization (06/22/2006)
• Miscellaneous - Telephone Consent (06/22/2006)
• Miscellaneous - Blind Rehab Database (05/08/2006)
• Miscellaneous - Clinical Trial Data Sheet (05/08/2006)
• Miscellaneous - Consent to be Contacted (05/08/2006)
• Miscellaneous - Current Human Use Training (PI/Fuhr/Williams) (05/08/2006)
• Miscellaneous - Initial Review Application (05/08/2006)
• Miscellaneous - List of Study Personnel (05/08/2006)
• Miscellaneous - Privacy of Information Statement (05/08/2006)
• Miscellaneous - Request for Partial HIPAA Waiver (05/08/2006)

You must report all publications and presentations at meetings to the Office of Research Administration (ORA). VA Central Office has reiterated the importance of appropriate review of these documents by the Research and Development committee.

All published research, including meeting abstracts, must acknowledge the Birmingham VAMC as the location of the research activity, and where applicable, must also acknowledge VA research funding support.
Protection of Human Subjects
Assurance Identification/IRB Certification/Declaration of Exemption
(Common Rule)

Policy: Research activities involving human subjects may not be conducted or supported by
the Department of Health and Human Services, unless the activities are exempted from or approved in accordance with the Common Rule. Sections 101(b) of the Common Rule for exemptions. Institutions submitting applications or proposals for support must submit certification of appropriate institutional review board (IRB) review and approval to the Department of Health and Human Services, in accordance with the Common Rule.

1. Request Type: [ ] ORIGINAL [ ] GRANT [ ] CONTRACT [ ] FELLOWSHIP
[ ] CONTINUATION [ ] COOPERATIVE AGREEMENT
[ ] EXEMPTION [ ] OTHER:

2. Type ofModulation

3. Name of Federal Department or Agency and, if known, Application or Proposal Identification No.

4. Title of Application or Activity
Visually Impaired Caregivers: Perspectives from Patient Focus Groups

5. Name of Principal Investigator, Program Director, Fellow, or Other
MARTINEZ, BETHANY SURREY

6. Assurance Status of this Project (Respond to one of the following)
[ ] This Assurance, on file with the Department of Health and Human Services, covers this activity:
Assurance Identification No.: FWA000000250, the expiration date: 2/14/29, IRB Registration No.: IRB0000190

[ ] This Assurance, on file with the agency/department, covers this activity:
Assurance No.: the expiration date: IRB Registration/identification No.: (if applicable)

[ ] No assurance has been filed for this institution. This institution declares that it will provide an Assurance and Certification of IRB review and approval upon request.

[ ] Exemption Status: Human subjects are involved; but this activity qualifies for exemption under Section 101(b), paragraph

7. Certification of IRB Review (Respond to one of the following if you have an Assurance on file)
[ ] This activity has been reviewed and approved by the IRB in accordance with the Common Rule and any other governing regulations:
by: [ ] Full IRB Review on (date of IRB meeting) or [ ] Expedited Review on (date)

[ ] If less than one year approval, provide expiration date

[ ] This activity contains multiple projects, some of which have not yet been reviewed. The IRB has granted approval on condition that all projects covered by the Common Rule will be reviewed and approved before they are initiated and that appropriate further certification will be submitted.

8. Comments

Title: Visually Impaired Caregivers: Perspectives from Patient Focus Groups

Protocol subject to Annual continuing review.

IRB Approval issued: 07/16/10

9. The official signing below certifies that the information provided above is correct and that, as required, future reviews will be performed to ensure compliance and certification will be provided.

Phone No. (with area code): (205) 934-3789
Fax No. (with area code): (205) 934-1501
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10. Name and Address of Institution
University of Alabama at Birmingham
701 20th Street South
Birmingham, AL 35294

11. Name of Official
Marilyn Doss, M.D.

12. Title
Vice Chair, IRB

13. Signature

14. Date
7-1-2010

15. Date

16. Signature

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APPENDIX C

RECRUITMENT MATERIALS
Visually Impaired Caregivers: Perspectives from Patient Focus Groups
PI: Bethany Martinez, O.D.
Optometry Research Fellow
Birmingham VAMC (124)
700 South 19th Street
Birmingham, AL 35233
Phone: 205-933-8101 x 2719
Fax: 205-558-7060

Practitioner Referral Information

Inclusion Criteria
• Must serve as primary caregiver for a spouse, significant other, or family member age 18 years or older. Caregivers are defined as family members or friends who provide unpaid day-to-day care (i.e. help with basic and/or instrumental activities of daily living) and are familiar with the care recipient’s medical and social state.
• Must have documentable visual system pathology and acquired visual impairment to the level of legal blindness as defined by the U.S.
• If the person is not a VA patient, we will need to obtain a copy of his/her most recent eye exam records in order to enroll them in the study.

Duration and timing of study
• Participants in the focus group will convene for up to two hours duration and possibly one brief telephone follow up interview.
• Participants in the study will undergo one telephone interview prior to the focus group meetings. The interview will take approximately 30 minutes to complete.
• The study is taking place in the VA Medical Center in Birmingham, AL.
• If subjects are not able to attend a focus group, they may complete a 2nd telephone interview of approximately 1 hour duration.

Further details
• Free parking is available in the Birmingham VA Parking Deck located between 4th Ave. and 5th Ave. on 17th Street South.
• Participation is voluntary and subjects will be paid $75 per focus group for participating in this study.

To refer a patient for the study
• Please have the participant read (or present orally) the ‘Patient Information’ sheet and complete and sign the ‘Consent to be Contacted’ form. If you speak with the patient over the phone, please obtain verbal consent to contact.
• Please call regarding verbal consent to contact, fax (205-558-7060) or mail the form to Dr. Bethany Martinez at the address above.
• We will contact the patient by telephone and arrange a convenient time for the patient to participate in the study.
VISUALLY IMPAIRED CAREGIVER’S STUDY

Patient Information

A caregiver is a family member or friend who provides unpaid day-to-day care for a chronically ill or disabled spouse, significant other, or other family member age 18 years or older and is familiar with the care recipient’s medical and social state.

We are aware that there are an increasing number of visually impaired persons who also serve as a primary caregiver for a spouse or significant other who has a chronic, devastating illness. We know that visual impairment can result from a variety of diseases and cause a multitude of problems. There is a growing body of knowledge about the stresses and benefits of caregiving, but little is known about the added stresses or benefits of caregivers who are also visually impaired.

We believe that a caregiver may have demands placed upon him/her in many areas, including responsibility for the family’s financial management, meal preparation, household chores, and medication management. A visually impaired caregiver may very likely be coordinating care for his/her significant other, as well as assisting in the mobility and transfer of that individual from one location to another. In short, all of the problems related to visual impairment may be exacerbated and compounded for the visually impaired caregiver.

The purpose of this project is to learn more about visually impaired caregivers.

- We need caregivers who also suffer from acquired visual impairment. Subjects in this group will have documentable visual system pathology and visual impairment to the level of legal blindness as defined by the U.S.
Subjects will participate in one focus group discussion and one brief telephone follow up interview to answer questions and share their views on the challenges they face as a visually impaired caregiver. The focus group session will last approximately two hours duration. All focus group meetings will be held at the VA Medical Center located in Birmingham, Alabama.

Each subject will also be asked a series of questions over the telephone, using standard questionnaires, regarding health status, vision problems, attitudes about caregiving burdens and responsibilities, and quality of life. The interview session will take approximately 30 minutes to complete.

If you are not able to attend the focus group, you may complete a 2nd telephone interview of approximately 1 hour duration.

If you are not a VA patient, we will need to obtain a copy of your most recent eye exam records in order to enroll you in the study.

From these studies we will learn more about the burdens and needs of visually impaired persons who also take care of a spouse, significant other, or family member. It is our hope to use this information to determine better methods of serving the health and rehabilitation needs of visually impaired caregivers.

If you have any questions about the research project, please contact Dr. Martinez at 205-933-8101 extension 2719 or Dr. Fuhr at extension 5105.

You will be paid $75 for participating in a focus group. You will not be paid for completing the telephone interviews.
VISUALLY IMPAIRED CAREGIVERS STUDY

If your vision is impaired and you also take care of a sick or disabled spouse, family member or friend, please consider taking part in this study.

You will be asked to complete one 30 minute telephone interview and attend one 2 hour focus group discussion held at the Birmingham VA Medical Center.

You will be paid $75 for attending a focus group discussion.

If you are not able to attend a focus group, then you may complete a second 1 hour telephone interview. You will not be paid for completing the telephone interview.

From these studies we will learn more about the burdens and needs of visually impaired persons who also take care of a spouse or significant other.

If you have any questions about the research project or would like to participate, please contact Dr. Martinez at 205-933-8101 extension 2719 or Dr. Fuhr at extension 5105 for more information.
VISUALLY IMPAIRED CAREGIVERS STUDY

CONSENT TO BE CONTACTED

I, ____________________________, am interested in participating in the Visually Impaired Caregivers Study conducted by the Birmingham VA Medical Center.

The focus groups will meet for one session for approximately two hours. Topics that will be discussed include the impact of visual impairment on caregiving responsibilities. Participants will also complete a series of questionnaires that take approximately 30 minutes to complete and one brief telephone follow up interview. If you are not able to attend a focus group, then you may complete a 2nd telephone interview of approximately 1 hour duration.

If you are not a VA patient, we will need to obtain a copy of your most recent eye exam records in order to enroll you in the study.

I may be contacted by telephone at:

______________________________________.

_________________________________________
Signature

Please mail to: Dr. Bethany Martinez (124) or Fax to 205-558-7060
Birmingham VAMC
700 South 19th Street South
Birmingham, AL 35233
Announcement of Study to VIST Coordinators and low vision community agency leaders in the Alabama service area

STUDY: Visually Impaired Caregivers: Perspectives from Patient Focus Groups

This is to inform you of a new study funded by the Rehabilitation Research and Development Center (151R), Atlanta VA Medical Center. This is a one-year pilot study to begin in May, 2006. The purpose of this VA Rehabilitation R&D pilot study is to learn more about visually impaired caregivers by holding focus group discussions with a sample of visually impaired persons who are also serving as the primary caregiver for an ailing or disabled spouse or family member. It is anticipated that the knowledge gained from these focus groups will provide clinicians and low vision rehabilitation professionals a better understanding of the needs of visually impaired caregivers and aid researchers in developing future research projects that may lead to interventions that are conducive to this population’s lifestyle and expectantly improve their quality of life and their ability to provide care.

We need your help in recruiting visually impaired caregivers.

If you interview a visually impaired person with acquired vision loss that reports he/she is the primary caregiver for his/her spouse, significant other, or family member age 18 years or older please consider offering them the opportunity to participate in this research study. Caregivers are defined as family members or friends who provide unpaid day-to-day care (i.e. help with basic and/or instrumental activities of daily living) and are familiar with the care recipient’s medical and social state.

The visually impaired caregivers will be asked to participate in one telephone interview of approximately 30 minutes duration, one focus group session of 2 hours duration, and one brief telephone follow up interview. The questionnaires will include questions regarding the person’s health, vision loss, quality of life and perceptions of caregiving responsibilities. During the focus group sessions, the participants will be asked to discuss the challenges and experiences associated with being a visually impaired caregiver. The focus group sessions will be held at the Birmingham VA Medical Center in Birmingham, AL. If subjects are not able to attend a focus group, they may complete a 2nd telephone interview of approximately 1 hour duration.

If the person is not a VA patient, we will need to obtain a copy of his/her most recent eye exam records in order to enroll them in the study.

Attached please find the protocol and copies of recruitment materials, including Practitioner Information sheet, Patient Information sheet, Recruitment flyer, and Consent to Contact forms. You will act as the third party who makes the first contact with the research subject. You should present the potential participant with the patient information and refer the person to the principal investigator. If the person wishes to hear more about the study, he/she should sign or verbally agree (via telephone) to the Consent to Contact, indicating interest in hearing more about the study. Then please call regarding verbal consent, fax or mail the form to Dr. Martinez at the number on the form. The Research Team will then contact the patient to set up the telephone interview and focus group.
meeting. If you have any questions or concerns, please call Dr. Martinez at 205-933-8101 Extension 2719. We look forward to your participation in this research effort and thank you for all your continued good work on behalf of America’s visually impaired persons.
APPENDIX D

INFORMED CONSENT
**Full Telephone Consent**

Hello Mr./Mrs./Ms.________________,

This is Dr. Bethany Martinez with the Birmingham VA Medical Center. I am calling to ask if you would like to participate in the research study we are conducting on visually impaired caregivers. The purpose of this study is to get common themes related to your vision and taking care of your loved one. If you agree, I would like to ask you for about 30 minutes of your time to ask you some questions about your visual impairment and your caregiving responsibilities. During this interview, you will be asked about your ability to perform certain tasks and activities, such as making a phone call, preparing a sandwich, or walking around your house. Other questions asked will be about your general overall health, caregiving burdens, and quality of life. The information that is received from you and others like you will be used by the Veteran’s Health Administration and the University of Alabama at Birmingham to better understand the needs of visually impaired caregivers. Your participation is completely voluntary. This means that you do not have to participate in this study unless you want to. You may refuse to answer any questions asked of you in the telephone interview. You may stop the interview at any time.

We hope to enroll 24 individuals, including men and women, in this study over the next 6 months. If you are not a VA patient, we will need to obtain a copy of your most recent eye exam records in order to enroll you in the study. We will also ask research participants to participate in one focus group discussion held at the Birmingham VAMC and possibly one brief telephone follow up interview. During this meeting you will be asked to share your views and experiences as a visually impaired caregiver. The focus group will last approximately 2 hours and the discussion will be tape recorded. Note that this meeting is not a therapy session, and the research personnel are not therapists. If you are interested in participating you will be asked to sign the short form consent, HIPAA, and the VA Form 10-3203, for permission for use of voice, when you come in for the focus group. Would you like to participate in our study? (If yes, continue. If no, thank them for their time and quickly terminate the call.)

*If they are not able to participate due to travel difficulties:* If you are not able to travel to Birmingham for the focus group, you can choose to complete a second telephone interview. This telephone interview will last approximately one hour and will be audiotaped. The alternative procedure of this study is choosing not to participate. Would you like to participate in this study? (If yes, continue. If no, quickly terminate the call.)

Your confidentiality will be maintained throughout the research project. The information obtained in this study may be published, but your identity will not be revealed. The VA personnel, VA Institutional Review Board (IRB) and other federal oversight agencies reserve the right to inspect both the research data and your medical records. I want to stress upon you that participating in this survey will not affect any of the medical services you may have received in the past, are currently receiving or may receive in the future. No one is being charged for participating in this study. You will be compensated $75 (by check) per focus group meeting to help pay for travel after your participation in the study.
is complete. You will not be compensated for completing the telephone interview. If you withdraw from the study, you will only be compensated for the focus you attend. Free parking is available at the VA parking deck.

The Atlanta Department of Veterans Affairs Rehabilitation Research and Development Center is sponsoring this research. If you decide to participate in the study you will be asked to undergo assessments that may not normally be required for the treatment of your condition. The research assessments will be paid for with the money provided by the sponsor.

Risks from being in this study are thought to be minimal. We realize that persons who are visually impaired or are caregivers may become depressed or anxious, therefore, a list of mental health contacts will be provided to all participants. Taking part in this research study may not benefit you personally, but we (doctors, researchers, and scientists) may learn new things that will help others.

You may refuse to participate at any time without penalty or loss of benefits to which you are otherwise entitled. If you decide to withdraw from this study, you are asked to contact Dr. Bethany Martinez, O.D. at (205) 933-8101, extension 2719. Discontinuation will in no way affect or jeopardize the quality of care you receive now or in the future at this institution or your right to participate in other studies. By agreeing to this informed consent, you are not waiving any of your legal rights.

Do you have any questions? You may contact Dr. Martinez, O.D. at (205) 933-8101 extension 2719 or Dr. Fuhr, O.D. at extension 5105 with questions about the research study or the research use of your health information. For questions concerning your rights as a research subject, you may contact the IRB Administrator who will have the IRB member Subject Representative contact you. The IRB Administrator can be reached at (205) 933-8101, extension 5393 (for VA) or (205) 934-3789 (for the University of Alabama at Birmingham). If the IRB Administrator cannot be reached, contact the R&D Secretary at (205) 558-4747 and she will direct your call to an IRB member. You will be given a copy of this authorization summary for your records.

Do I have your permission to begin asking you questions?
Summary of Informed Consent for Focus Group Participants
Visually Impaired Caregivers: Perspectives from Patient Focus Groups

Dear Mr./Mrs./Ms. ______________,

You are being asked to participate in a research project that seeks information about your experiences as a visually impaired caregiver. The purpose of this study is to get common themes related to your vision and taking care of your loved one. Although you will not directly benefit from participating in this study, the information that is received from you and others like you will be used by the Veteran’s Health Administration and the University of Alabama at Birmingham to better understand the needs and important issues related to persons that are visually impaired and also serve as the primary caregiver for their spouse, family member, or significant other. We hope to enroll 24 individuals in this study over the next 6 months. The study will take place in Birmingham, AL at the Birmingham VA Medical Center. If you are not a VA patient, we will need to obtain a copy of your most recent eye exam records in order to enroll you in the study.

If you agree to participate in this study you will be interviewed over the telephone by a researcher from the Department of Veterans Affairs in Birmingham, AL. During the initial telephone interview you will be asked about your ability to perform certain tasks and activities, such as making a phone call, preparing a sandwich, or walking around your house. Other questions related to your current level of depression, general overall health, and burden associated with caregiving responsibilities will be asked. This telephone interview will take about 30 minutes to complete. You may refuse to answer any questions asked of you in the interview. You may stop the interview at any time. The alternative procedure of this study is choosing not to participate. If you are interested in participating you will be asked to sign the short form consent, HIPAA, and the VA Form 10-3203, for permission for use of voice, when you come in for the focus group.

We will also ask research participants to participate in one focus group discussion held at the Birmingham VAMC and possibly one brief telephone follow up interview. During this meeting you will be asked to share your views and experiences as a visually impaired caregiver. The focus group will last approximately 2 hours and the discussion will be tape recorded. Note that this meeting is not therapy a session, and the research personnel are not therapists.

Your confidentiality will be maintained throughout the research project. The information obtained in this study may be published, but your identity will not be revealed. The VA personnel, VA Institutional Review Board (IRB) and other federal oversight agencies reserve the right to inspect both the research data and your medical records. I want to stress upon you that participating in this survey will not affect any of the medical services you may have received in the past, are currently receiving or may receive in the future. No one is being charged for participating in this study. You will be compensated $75 (by
check) per focus group meeting to help pay for travel once your participation in the study is complete.

You will not be compensated for completing the initial telephone survey. If you withdraw from the study, you will only be compensated for the focus group you attend. Free parking is available at the VA parking deck.

The Atlanta Department of Veterans Affairs Rehabilitation Research and Development Center is sponsoring this research. If you decide to participate in the study you will be asked to undergo assessments that may not normally be required for the treatment of your condition. The research assessments will be paid for with the money provided by the sponsor.

Risks from being in this study are thought to be minimal. Taking part in this research study may not benefit you personally, but we (doctors, researchers, and scientists) may learn new things that will help others. We realize that persons who are visually impaired or are caregivers may become depressed or anxious, therefore, a list of mental health contacts will be provided to all participants.

You may refuse to participate at any time without penalty or loss of benefits to which you are otherwise entitled. If you decide to withdraw from this study, you are asked to contact Dr. Bethany Martinez, (205) 933-8101, extension 2719. Discontinuation will in no way affect or jeopardize the quality of care you receive now or in the future at this institution or your right to participate in other studies.

If you have questions regarding this study or the research use of your health information, please call: Dr. Bethany Martinez, O.D. at (205) 933-8101, extension 2719 or Dr. Patti Fuhr, O.D. at extension 5105.

You have been read this authorization content and have been given the opportunity to ask questions. You have been told of the risks or discomforts and possible benefits of the study. You have been told of other choices of treatment available to you. If you have questions regarding your rights as a research participant, you may contact the IRB Administrator who will have the IRB member Subject Representative contact you. The IRB Administrator can be reached at (205) 933-8101, extension 5393 (for VA) or (205) 934-3789 (for the University of Alabama at Birmingham). If the IRB Administrator cannot be reached, contact the R&D Secretary at (205) 558-4747 and she will direct your call to an IRB member. You will be given a copy of this authorization summary for your records.
Thank you for your interest in this study. By agreeing to this informed consent, you are not waiving any of your legal rights.

Signature of Witness __________________ Date ____________
(Witnessing subject’s signature only)
Witness (printed) __________________________________________

Signature of Person Conducting Consent Discussion __________ Date ____________
Name (printed) ______________________________________________

Sincerely,

Bethany Martinez, O.D.
Birmingham VA Medical Center (124)
700 South 19th Street
Birmingham, AL 35233
(205) 933-8101 ext 2719
Bethany.martinez@va.gov
Dear Mr./Mrs./Ms. ______________,

You are being asked to participate in a research project that seeks information about your experiences as a visually impaired caregiver. The purpose of this study is to get common themes related to your vision and taking care of your loved one. Although you will not directly benefit from participating in this study, the information that is received from you and others like you will be used by the Veteran’s Health Administration and the University of Alabama at Birmingham to better understand the needs and important issues related to persons that are visually impaired and also serve as the primary caregiver for their spouse, family member, or significant other. We hope to enroll 24 individuals in this study over the next 6 months. The study will take place in Birmingham, AL at the Birmingham VA Medical Center. If you are not a VA patient, we will need to obtain a copy of your most recent eye exam records in order to enroll you in the study.

If you agree to participate in this study you will be interviewed 2 times over the telephone by a researcher from the Department of Veterans Affairs in Birmingham, AL. During the first interview, you will be asked about your ability to perform certain tasks and activities, such as making a phone call, preparing a sandwich, or walking around your house. Other questions related to your current level of depression, general overall health, and burden associated with caregiving responsibilities will be asked. This initial telephone interview will take about 30 minutes to complete. During the second telephone interview, you will be asked to share your views and experiences as a visually impaired caregiver. This interview will last approximately one hour and will be tape recorded. Note that these interviews are not therapy sessions, and the research personnel are not therapists. No one is being paid for participating in this study, and no one is being charged for participating in this study.

You may refuse to answer any questions asked of you in the interview. You may stop the interview at any time. The alternative procedure of this study is choosing not to participate. If you are interested in participating you will be asked to sign the short form consent, HIPAA authorization, and the VA Form 10-3203, for permission for use of voice, and then return them to Dr. Bethany Martinez.

Your confidentiality will be maintained throughout the research project. The information obtained in this study may be published, but your identity will not be revealed. The VA personnel, VA Institutional Review Board (IRB) and other federal oversight agencies reserve the right to inspect both the research data and your medical records. I want to stress upon you that participating in this survey will not affect any of the medical services you may have received in the past, are currently receiving or may receive in the future.
The Atlanta Department of Veterans Affairs Rehabilitation Research and Development Center is sponsoring this research. All costs of this project are being funded by the Department of Veterans Affairs Rehabilitation Research and Development Service. If you decide to participate in the study you will be asked to undergo assessments that may not normally be required for the treatment of your condition. The research assessments will be paid for with the money provided by the sponsor.

Risks from being in this study are thought to be minimal. Taking part in this research study may not benefit you personally, but we (doctors, researchers, and scientists) may learn new things that will help others. We realize that persons who are visually impaired or are caregivers may become depressed or anxious, therefore, a list of mental health contacts will be provided to all participants.

You may refuse to participate at any time without penalty or loss of benefits to which you are otherwise entitled. If you decide to withdraw from this study, you are asked to contact Dr. Bethany Martinez, (205) 933-8101, extension 2719. Discontinuation will in no way affect or jeopardize the quality of care you receive now or in the future at this institution or your right to participate in other studies.

If you have questions regarding this study or the research use of your health information, please call: Dr. Bethany Martinez, O.D. at (205) 933-8101, extension 2719 or Dr. Patti Fuhr, O.D. at extension 5105.

You have been read this authorization content and have been given the opportunity to ask questions. You have been told of the risks or discomforts and possible benefits of the study. You have been told of other choices of treatment available to you. If you have questions regarding your rights as a research participant, you may contact the IRB Administrator who will have the IRB member Subject Representative contact you. The IRB Administrator can be reached at (205) 933-8101, extension 5393 (for VA) or (205) 934-3789 (for the University of Alabama at Birmingham). If the IRB Administrator cannot be reached, contact the R&D Secretary at (205) 558-4747 and she will direct your call to an IRB member. You will be given a copy of this authorization summary for your records.
Thank you for your interest in this study. By agreeing to this informed consent, you are not waiving any of your legal rights.

________________________________________                 __________________
Signature of Witness                                        Date                Witness (printed)
(Witnessing subject’s signature only)

_________________________________________               __________________
Signature of Person Conducting                               Date            Name       (printed)
Consent  Discussion                                          Date                Name    (printed)

Sincerely,

Bethany Martinez, O.D.
Birmingham VA Medical Center (124)
700 South 19th Street
Birmingham, AL 35233
(205) 933-8101 ext 2719
Bethany.martinez@va.gov
Short Form Informed Consent for: Visually Impaired Caregivers: Perspectives from Patient Focus Groups

The elements of informed consent have been presented orally to the subject (or the legally authorized representative).

______________________  __________________
Subject’s signature      Date                Subject (printed)

______________________  __________________
Signature of Witness    Date                Witness (printed)
APPENDIX E

HIPAA FORM
Authorization for Release of Protected Health Information for Research Purposes

TITLE: Visually Impaired Caregivers: Perspectives from Patient Focus Groups

SPONSOR: The Atlanta Department of Veterans Affairs Rehabilitation Research and Development Center

INVESTIGATOR: Bethany Martinez, O.D.

You have been asked to be part of a research study under the direction of Dr. Bethany Martinez and her research team. The purpose of this study is learn more about the personal challenges and experiences of visually impaired caregivers.

By signing this document, you will authorize the Veterans Health Administration (VHA) to provide Dr. Bethany Martinez, O.D. and her research team to access the following information about you:

- Demographic data including your name, address, gender, age/birth date, social security number and telephone number;
- Clinical data including your cause of vision loss, type of vision loss, and the results of vision testing including visual acuity and visual fields;
- Questionnaires including the geriatric Depression Scale, the Short-Form Health Survey, the Veterans Affairs Low Vision Visual Functioning Questionnaire, the Burden Interview, and the Caregiver Reaction Assessment.

If you do not sign this authorization, you will not be part of the study.

This authorization to use your information will expire at the end of the research study.

You can revoke this authorization at any time. To revoke your authorization, you can write to Dr. Bethany Martinez, O.D. or you can ask a member of the research team to give you a form to revoke the authorization. If you revoke this authorization, you will not be able to continue to participate in the study. If you are a veteran, this will not affect your rights as a VHA patient.

If you revoke this authorization, Dr. Martinez, O.D. and her research team can continue to use information about you that has been collected. No information will be collected after you revoke the authorization.

The VHA complies with the requirements of the Health Insurance Portability and Accountability Act of 1996 and its privacy regulations and all other applicable laws that protect your privacy.
We will protect your information according to these laws. Despite these protections, there is a possibility that your information could be used or disclosed in a way that it will no longer be protected. Our Notice of Privacy Practices (a separate document) provides more information on how we protect your information. If you do not have a copy of the Notice, the research team will provide one to you.

**Visually Impaired Caregivers: Perspectives from Patient Focus Groups**

I have read this authorization form and have been given the opportunity to ask questions. If I have questions later about the research study or the research use of my health information, I understand I can contact Dr. Bethany Martinez, O.D. at (205) 933-8101, extension 2719 or Dr. Patti Fuhr, O.D. at extension 5105. For questions concerning my rights as a research subject, I may contact the IRB Administrator who will have the IRB member Subject Representative contact me. The IRB Administrator can be reached at (205) 933-8101, extension 5393 (for VA) or (205) 934-3789 (for the University of Alabama at Birmingham). If the IRB Administrator cannot be reached, contact the R&D Secretary at (205) 558-4747 and she will direct my call to an IRB member. I will be given a signed copy of this authorization form for my records. I authorize the use of my identifiable information as described in this form.

___________________________
Participant’s Signature      Date
APPENDIX F

VA FORM 10-3203
**CONSENT FOR USE OF PICTURE AND/OR VOICE**

**NOTE:** The information requested on this form is collected under the authority of Title 38, United States Code. The execution of this form does not authorize disclosure of the material specified below except for the purposes stated. The specified material may be used within the VA for educational purposes, such as for education of VA personnel or for VA research activities. It may also be disclosed outside the VA as permitted by law. If the material is part of a VA system of records, it may be disclosed outside the VA as permitted in the “VA Privacy Act Systems of Records” published in the Federal Register. A copy of the Privacy Act is available upon request to the administrative office of the VA facility involved. You do not have to consent to have your picture or voice taken, recorded, or used. Your refusal to grant your consent will have no effect on any VA benefits to which you may be entitled.

I hereby voluntarily and without compensation authorize pictures and/or voice recording(s) to be made of me (or of the above-named individual if the individual is legally unable to give consent) by [specify the name of the VA facility, newspaper, magazine, television station, etc.]

While I am [describe the activity, if any to be photographed or recorded]

I authorize disclosure of the picture and/or voice recording to [specify name and address of the organization, agency, or individual(s) to whom the release is to be made]

I understand that the said picture, video and/or voice recording is intended for the following purpose(s):

I have read and understand the foregoing and I consent to the use of my picture and/or voice as specified for the above-described purpose(s). I further understand that no royalty, fee or other compensation of any character shall become payable to me by the United States for such use. I understand that consent to use my picture, video and/or voice recording is voluntary and my refusal to grant consent will have no effect on any VA benefits to which I may be entitled. I further understand that I may at any time exercise the right to cease being filmed, photographed or recorded, and may rescind my consent for up to a reasonable time before the picture, video or voice recording is used.

**Signature of Individual or Other Legally Authorized Person**

**Permission Obtained By [Name, Title, Address]**

**Signature of Interviewer or Individual Obtaining Consent**

**Production Title**

**Production Number**

**Individual’s Name and Address**

**IMPORTANT:** This form must always be completed prior to the making or using pictures, video or voice recording(s) of any VA patient. If any patient health or demographic information is to be provided or released with the picture, video or voice recording, VA Form 10-5345, Request for and Authorization to Release Medical Records or Health Information is required prior to the release of such data to any source.
APPENDIX G

VETERANS AFFAIRS BLIND REHABILITATION SERVICE DATA BASE
VA D-Base

SOCIAL SECURITY NUMBER     ______-_____-_______
NAME (last, first, m.) ________________________________
STREET ___________________________________________
CITY __________________________  STATE _____  ZIP ____________
PHONE NUMBER (_____) _____-_______
AGE (DOB)   ____ / ____ / _____
REFERRING STATION (City, State of VIST) ___________________

GENDER (m/f)

RACE:
1=Black/African-American
2=American Indian or Alaskan Native
3=Asian/Oriental or Pacific Islander
4=Hispanic or Latino
5=Caucasian (White)

LIVING SITUATION:
1=Alone
2=Spouse Only
3=Family
4=Friend or Roommate
5=Other
6=Not Known

PRIMARY PLACE OF RESIDENCE:
1=House
2=Apartment/Condominium
3=Nursing Home
4=Domiciliary
5=State Veterans Home
6=Board and Care
7=Homeless
8=Other
9=Not known

Yes    No

EYE DIAGNOSIS:
☐ ☐ 379.50 Aphakia
☐ ☐ 362.50 ARM - (Age Related Maculopathy)
☐ ☐ 366.10 Cataract
☐ ☐ 363.00 Choroid/Retinal
☐ ☐ 371.00 Corneal Disease
☐  ☐  362.00 Diabetic Retinopathy
☐  ☐  365.11 Glaucoma
☐  ☐  115.02 Histoplasmosis
☐  ☐  363.30 Macular Disease (non-ARM)
☐  ☐  377.10 Optic Atrophy
☐  ☐  377.30 Optic Nerve
☐  ☐  361.00 Retinal Detachment
☐  ☐  362.70 Retinitis Pigmentosa
☐  ☐  362.75 Stargardts
☐  ☐  Trauma
☐  ☐  Other
☐  ☐  Not Known

VISUAL STATUS:

ACUITY:  1=No light perception
         2=LP/HM/CF
         3=1/200 up to and including 5/200
         4=6/200 up to and including 20/200
         5=20/70 up to and including 20/190
         6=20/60 or better

☐  ☐  FIELD:  1=5° or less
               2=6° to 20°
               3=21° or greater

☐  ☐  Yes  ☐  No  MONOCULAR: Defined at LP in poorer eye

DURATION OF VISION LOSS: “When did vision loss begin to interfere with your daily activities”?

☐  ☐  1=Less than 1 year
     2=1 to 3 years
     3=4 to 6 years
     4=7 to 9 years
     5=10 years or more

Ambulation:

☐  ☐  1=No problems noted
     2=Confined to bed
     3=Reduced use or loss of use of lower limb(s)
     4=Reduced stamina for walking
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<tr>
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<th>No</th>
<th>Ambulation Devices:</th>
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<tr>
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<td>Prosthetic limb(s) or brace(s)</td>
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<td></td>
<td></td>
<td>Support Cane</td>
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<td></td>
<td></td>
<td>Walker</td>
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<td></td>
<td>Scooter/electric</td>
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<td></td>
<td></td>
<td>Wheelchair</td>
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<td></td>
<td></td>
<td>Cardiac Involvement?</td>
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<tr>
<td></td>
<td></td>
<td>Cognitive Involvement?</td>
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<tr>
<td></td>
<td></td>
<td>Diabetic=(Injections)?</td>
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<td></td>
<td></td>
<td>Diabetic=(Oral Medication)?</td>
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<td></td>
<td></td>
<td>Neuropathy?</td>
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<td>Neurological Involvement?</td>
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<td></td>
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<td>Pulmonary Involvement?</td>
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<td></td>
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<td>Dialysis?</td>
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<tr>
<th>Hearing Loss:</th>
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<tbody>
<tr>
<td>0= No loss</td>
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<tr>
<td>1= Mild</td>
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<tr>
<td>2= Severe</td>
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<tr>
<td>3= Profound</td>
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<table>
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<tr>
<th>Yes</th>
<th>No</th>
<th>Uses hearing aids/assistive aids</th>
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<tr>
<th>Manipulation:</th>
</tr>
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<tbody>
<tr>
<td>1= No problems noted</td>
</tr>
<tr>
<td>2= Reduced use or loss of use of arm(s)</td>
</tr>
<tr>
<td>3= Reduced use or loss of use of hand(s)</td>
</tr>
</tbody>
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<table>
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<tr>
<th>Yes</th>
<th>No</th>
<th>Manipulation Device:</th>
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<tbody>
<tr>
<td></td>
<td></td>
<td>Permanent arm/hand splint</td>
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<tr>
<td></td>
<td></td>
<td>Prosthetic arm</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Below Knee Amputation:</th>
</tr>
</thead>
<tbody>
<tr>
<td>1= No BKA</td>
</tr>
<tr>
<td>2= Unilateral BKA</td>
</tr>
<tr>
<td>3= Bilateral BKA</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Above Knee Amputation:</th>
</tr>
</thead>
<tbody>
<tr>
<td>1= No AKA</td>
</tr>
<tr>
<td>2= Unilateral AKA</td>
</tr>
<tr>
<td>3= Bilateral AKA</td>
</tr>
</tbody>
</table>

MAJOR ACTIVITIES (select highest level)
0= No well defined activity
1= Gainfully employed
2= Engaged in training or school
3= Volunteer work
4= Socially/Recreationally Active

FINANCIAL STATUS (select highest level)
0= Declined to Answer
1= $0 to $10,000
2= $10,001 to $20,000
3= $20,001 to $30,000
4= $30,001 to $40,000
5= $40,001 to $50,000
6= Greater than $50,000

EDUCATIONAL LEVEL (highest level of completion)
1= 8th grade or less
2= High School (did not graduate)
3= High School Graduate (including GED)
4= College (did not graduate)
5= College Graduate
6= Advance College Degrees
7= Not known
APPENDIX H

THE BURDEN INTERVIEW
The Burden Interview

INSTRUCTIONS: The following is a list of statements, which reflect how people sometimes feel when taking care of another person. After each statement, indicate how often you feel that way; never, rarely, sometimes, quite frequently, or nearly always. There are no right or wrong answers.

1. Do you feel that your relative asks for more help than he/she needs?

2. Do you feel that because of the time you spend with your relative that you don’t have enough time for yourself?

3. Do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work?

4. Do you feel embarrassed over your relative’s behavior?

5. Do you feel angry when you are around your relative?

6. Do you feel that your relative currently affects your relationship with other family members or friends in a negative way?

7. Are you afraid what the future holds for your relative?

8. Do you feel your relative is dependent upon you?

9. Do you feel strained when you are around your relative?

10. Do you feel your health has suffered because of your involvement with your relative?

11. Do you feel that you don’t have as much privacy as you would like, because of your relative?

12. Do you feel that your social life has suffered because you are caring for your relative?

13. Do you feel uncomfortable about having friends over, because of your relative?
14. Do you feel that your relative seems to expect you to take care of him/her, as if you were the only one he/she could depend on?

15. Do you feel that you don’t have enough money to care for your relative, in addition to the rest of your expenses?

16. Do you feel that you will be unable to take care of your relative much longer?

17. Do you feel you have lost control of your life since your relative’s illness?

18. Do you wish you could just leave the care of your relative to someone else?

19. Do you feel uncertain about what to do about your relative?

20. Do you feel you should be doing more for your relative?

21. Do you feel you could do a better job in caring for your relative?

22. Overall, how burdened do you feel in caring for your relative?
APPENDIX I

CAREGIVER REACTION ASSESSMENT
CRA - Caregiver Reaction Assessment

1. I feel privileged to care for _______________.
2. Others have dumped caring for ________________ onto me.
3. *My financial resources are adequate to pay for things that are required for caregiving.
4. My activities are centered around care for ________________.
5. Since caring for ________________, it seems like I’m tired all of the time.
6. It is very difficult to get help from my family in taking care of ________________.
7. *I resent having to take care of ________________.
8. I have to stop in the middle of ________________________________.
9. I really want to care for ________________.
10. My health has gotten worse since I’ve been caring for ________________.
11. I visit family and friends less since I have been caring for ________________.
12. I will never be able to do enough caregiving to repay ________________.
13. *My family works together at caring for ________________.
14. I have eliminated things from my schedule since caring for ________________.
15. *I have enough physical strength to care for ________________.
16. Since caring for ________________, I feel my family has abandoned me.
17. Caring for ________________ makes me feel good.
18. The constant interruptions make it difficult to find time for relaxation.
19. *I am healthy enough to care for ________________.
20. Caring for ________________ is important to me.
21. Caring for ________________ has put a financial strain on the family.
22. My family (brothers, sisters, and children) left me alone to care for ________________.
23. I enjoy caring for ________________.
24. It’s difficult to pay for ________________ ‘s health needs and services.

The response format for the above questions is as follows:

Circle one:
Strongly Agree  Agree  Neither Agree nor Disagree  Disagree  Strongly Disagree

Coding Scheme:
1. = Strongly disagree
2. = Disagree
3. = Neither agree nor disagree
4. = Agree
5. = Strongly agree

*These questions are to be reverse scored.
APPENDIX J

THE CENTER FOR EPIDEMIOLOGIC STUDIES DEPRESSION SCALE
The Center for Epidemiologic Studies Depression Scale (CES-D)

Instructions for Questions: Below is a list of the ways you might have felt or behaved. Please mark the number for how often you have felt this way during the past week.

0 Rarely or none of the time (less than 1 day)
1 Some or a little of the time (1-2 days)
2 Occasionally or a moderate amount of the time (3-4 days)
3 Most or all of the time (5-7 days)

During the past week:
_____ 1. I was bothered by things that usually don’t bother me.
_____ 2. I did not feel like eating; my appetite was poor.
_____ 3. I felt that I could not shake off the blues even with help from my family and friends.
_____ 4. I felt that I was just as good as other people.
_____ 5. I had trouble keeping my mind on what I was doing.
_____ 6. I felt depressed.
_____ 7. I felt that everything I did was an effort.
_____ 8. I felt hopeful about the future.
_____ 9. I thought my life had been a failure.
_____ 10. I felt fearful.
_____ 11. My sleep was restless.
_____ 12. I was happy.
_____ 13. I talked less than usual.
_____ 15. People were unfriendly.
_____ 16. I enjoyed life.
_____ 17. I had crying spells.
_____ 18. I felt sad.
_____ 19. I felt that people dislike me.
_____ 20. I could not get “going”.
APPENDIX K

SHORT FORM 12 GENERAL HEALTH ASSESSMENT SURVEY
The SF-12 Health Survey

1. In general, would you say your health is:

<table>
<thead>
<tr>
<th>Excellent</th>
<th>Very Good</th>
<th>Good</th>
<th>Fair</th>
<th>Poor</th>
</tr>
</thead>
<tbody>
<tr>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
</tbody>
</table>

The following questions are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much?

2. **Moderate activities**, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf

<table>
<thead>
<tr>
<th>Yes, Limited A lot</th>
<th>Yes Limited a Little</th>
<th>No, Not Limited At All</th>
</tr>
</thead>
<tbody>
<tr>
<td>X</td>
<td>X</td>
<td></td>
</tr>
</tbody>
</table>

3. Climbing **several** flights of stairs?

<table>
<thead>
<tr>
<th>Yes, Limited A lot</th>
<th>Yes Limited a Little</th>
<th>No, Not Limited At All</th>
</tr>
</thead>
<tbody>
<tr>
<td>X</td>
<td>X</td>
<td></td>
</tr>
</tbody>
</table>

During the **past 4 weeks**, how much of the time have you had any of the following problems with your work or other regular daily activities as a result of your physical health?

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>X</td>
<td>X</td>
</tr>
</tbody>
</table>

4. **Accomplished less** than you would like?

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>X</td>
<td>X</td>
</tr>
</tbody>
</table>

5. Were limited in the **kind** of work or other activities?

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>X</td>
<td>X</td>
</tr>
</tbody>
</table>

During the **past 4 weeks**, how much of the time have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>X</td>
<td>X</td>
</tr>
</tbody>
</table>

6. Accomplished less than you would like?

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>X</td>
<td>X</td>
</tr>
</tbody>
</table>

7. Didn’t do work or other activities as carefully as usual?

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>X</td>
<td>X</td>
</tr>
</tbody>
</table>

8. During the past 4 weeks, how much did pain interfere with your normal work (including both work outside the home and housework)?
These questions are about how you feel and how things have been with you during the past 4 weeks. For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time during the past 4 weeks…

<table>
<thead>
<tr>
<th>Not at all</th>
<th>A little bit</th>
<th>Moderately</th>
<th>Quite a bit</th>
<th>Extremely</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

9. Have you felt calm and peaceful?  
   ![Selection](x x x x x x)

10. Did you have a lot of energy?  
   ![Selection](x x x x x x)

11. Have you felt downhearted and blue?  
   ![Selection](x x x x x x)

12. During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting friends, relatives, etc.)?  
   ![Selection](x x x x x x)
APPENDIX L

VETERANS AFFAIRS LOW VISION VISUAL FUNCTIONING QUESTIONNAIRE
Directions for Administration of the VA LV VFQ-48

The VA LV VFQ-48 is a self-report questionnaire designed to measure the difficulty a person has performing daily activities. The VA LV VFQ-48 can stand-alone or be used with other data gathering tools. Administration of the questionnaire will take approximately 12 minutes.

Explaining the purpose of the call:

(1) In conjunction with a visit to a rehabilitation center or a low vision appointment:
“I know you are coming to ______________ in the near future. I would like to ask you some questions so we can determine the activities you may have difficulty performing. This will allow us to identify areas where we can better help you.”

(2) Follow-up call:
“I’m calling to follow-up on your visit to ______________. I would like to ask you some questions to determine any difficulty you have performing the activities we previously discussed.”

“I will be asking about activities that you may perform daily or on a regular basis. I am interested in how well you are able to do these activities using ordinary glasses or contact lenses, adaptive techniques and low-vision devices (if you have them). Please consider any special methods or devices you use when you select a response to a question.”

Examples of low vision devices and adaptive techniques:
Interviewers must confirm that the patient understands the terms low vision devices and adaptive techniques. Without this awareness data gathered may not be reliable. The following examples are provided for clarification.

LOW VISION DEVICES:
• Optical aids to make things appear larger
  o Magnifiers
  o Telescopes
• Non-Optical aids to make some tasks less difficult
  o High intensity lamps
  o Large print
• Electronic systems that capture printed material and provide feedback
  o CCTV (large print feedback)

ADAPTIVE TECHNIQUES AND DEVICES:
• Methods using non-visual senses (touch, hearing, smell) to increase independence in performing work, school or other activities.
  o Folding money for easier identification
  o Using a white cane and listening to traffic when crossing the street
  o Scanner (synthesized speech feedback)

Directions reminding the patient to consider low vision device/technique use when responding to the questions are repeated four different times because the
patient often forgets the directions and answers as though we are asking about unaided vision.

Explaining the VA LV VFQ-48 Responses:

“I want you to tell me how difficult it may be for you to do the following activities. The task may be **NOT** difficult, **MODERATELY** difficult, **EXTREMELY** difficult or **IMPOSSIBLE**. You may have trouble performing the task for a reason unrelated to vision loss. Limitations that keep a person from doing an activity for non-visual reasons are important. Some examples include heart conditions, arthritis, using a wheel chair or that you are not interested in performing the task.”
**VA LOW VISION VISUAL FUNCTIONING QUESTIONNAIRE** (VA LV VFQ-48)

These questions relate to reading/near vision activities. Remember if you use a low vision device or adaptive technique to assist with the activity, please respond as though you were using the device or technique.

Is it difficult to ____________________________?

<table>
<thead>
<tr>
<th>Item</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>U</th>
<th>Score</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Read newspaper headlines</td>
<td>2.67</td>
<td>0.94</td>
<td>-0.35</td>
<td>-1.89</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>2. Read newspaper or magazine articles</td>
<td>3.88</td>
<td>2.15</td>
<td>0.86</td>
<td>-0.88</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>3. Read mail</td>
<td>3.53</td>
<td>1.80</td>
<td>0.51</td>
<td>-1.03</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>4. Read menus</td>
<td>3.73</td>
<td>2.00</td>
<td>0.71</td>
<td>-0.83</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>5. Read small print on package labels</td>
<td>4.06</td>
<td>2.33</td>
<td>1.04</td>
<td>-0.50</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>6. Keep your place while reading</td>
<td>3.29</td>
<td>1.56</td>
<td>0.27</td>
<td>-1.27</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>7. See photographs</td>
<td>2.84</td>
<td>1.11</td>
<td>-0.18</td>
<td>-1.72</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>8. Find something on a crowded shelf</td>
<td>2.63</td>
<td>0.90</td>
<td>-0.39</td>
<td>-1.93</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>9. Identify medicine</td>
<td>2.24</td>
<td>0.51</td>
<td>-0.78</td>
<td>-2.32</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>10. Identify money</td>
<td>1.98</td>
<td>0.23</td>
<td>-1.06</td>
<td>-2.60</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>11. Tell time</td>
<td>1.63</td>
<td>-0.10</td>
<td>-1.39</td>
<td>-2.93</td>
<td>0</td>
<td>0</td>
</tr>
</tbody>
</table>

These questions relate to distance visual activities. Remember if you use a low vision device or adaptive technique to assist with the activity, please respond as though you were using the device or technique.

Is it difficult to ____________________________?

<table>
<thead>
<tr>
<th>Item</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>U</th>
<th>Score</th>
</tr>
</thead>
<tbody>
<tr>
<td>12. Read street signs and store names</td>
<td>3.30</td>
<td>1.57</td>
<td>0.28</td>
<td>-1.26</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>13. Read signs (example: grocery store aisle)</td>
<td>3.45</td>
<td>1.72</td>
<td>0.43</td>
<td>-1.11</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>14. Watch TV</td>
<td>2.29</td>
<td>0.56</td>
<td>-0.73</td>
<td>-2.27</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>15. Read print on TV</td>
<td>3.41</td>
<td>1.68</td>
<td>0.39</td>
<td>-1.15</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>16. Play table and card games</td>
<td>3.11</td>
<td>1.38</td>
<td>0.09</td>
<td>-1.45</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>17. Work on your favorite hobby</td>
<td>3.13</td>
<td>1.40</td>
<td>0.11</td>
<td>-1.43</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>18. Recognize people up close</td>
<td>2.14</td>
<td>0.41</td>
<td>-0.88</td>
<td>-2.42</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>19. Recognize people from across the room</td>
<td>3.44</td>
<td>1.71</td>
<td>0.42</td>
<td>-1.12</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>20. Go to the movies</td>
<td>2.53</td>
<td>0.80</td>
<td>-0.49</td>
<td>-2.03</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>21. Go to spectator events</td>
<td>3.13</td>
<td>1.40</td>
<td>0.11</td>
<td>-1.43</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>22. Do yard work</td>
<td>2.48</td>
<td>0.75</td>
<td>-0.54</td>
<td>-2.08</td>
<td>0</td>
<td>0</td>
</tr>
</tbody>
</table>

These questions are about other daily living activities. Remember if you use a low vision device or adaptive technique to assist with the activity, please respond as though you were using the device or technique.

1. NOT difficult
2. MODERATELY difficult
3. EXTREMELY difficult
4. IMPOSSIBLE
U. Difficult / don't do for NON-VISUAL reasons

U = Unscored
<table>
<thead>
<tr>
<th>Item</th>
<th>Score 1</th>
<th>Score 2</th>
<th>Score 3</th>
<th>Score 4</th>
<th>Score U</th>
</tr>
</thead>
<tbody>
<tr>
<td>23. Handle finances</td>
<td>2.65</td>
<td>0.92</td>
<td>-0.37</td>
<td>-1.91</td>
<td>0</td>
</tr>
<tr>
<td>24. Make out a check</td>
<td>2.91</td>
<td>1.18</td>
<td>-0.11</td>
<td>-1.65</td>
<td>0</td>
</tr>
<tr>
<td>25. Sign your name</td>
<td>2.43</td>
<td>0.70</td>
<td>-0.59</td>
<td>-2.13</td>
<td>0</td>
</tr>
<tr>
<td>26. Take a message</td>
<td>3.07</td>
<td>1.34</td>
<td>0.05</td>
<td>-1.49</td>
<td>0</td>
</tr>
<tr>
<td>27. Match clothes</td>
<td>1.63</td>
<td>-0.10</td>
<td>-1.39</td>
<td>-3.93</td>
<td>0</td>
</tr>
<tr>
<td>28. Physically get dressed</td>
<td>0.28</td>
<td>-1.47</td>
<td>-2.76</td>
<td>-4.30</td>
<td>0</td>
</tr>
<tr>
<td>29. Keep your clothes clean</td>
<td>0.73</td>
<td>-1.00</td>
<td>-2.28</td>
<td>-3.63</td>
<td>0</td>
</tr>
<tr>
<td>30. Identify food on a plate</td>
<td>1.65</td>
<td>-6.08</td>
<td>-3.37</td>
<td>-2.91</td>
<td>0</td>
</tr>
<tr>
<td>31. Fix a snack</td>
<td>0.65</td>
<td>-3.08</td>
<td>-2.37</td>
<td>-3.91</td>
<td>0</td>
</tr>
<tr>
<td>32. Prepare meals</td>
<td>2.06</td>
<td>0.33</td>
<td>-0.96</td>
<td>-2.50</td>
<td>0</td>
</tr>
<tr>
<td>33. Use appliance dials</td>
<td>2.23</td>
<td>0.50</td>
<td>-0.79</td>
<td>-2.33</td>
<td>0</td>
</tr>
<tr>
<td>34. Groom yourself</td>
<td>1.19</td>
<td>-0.54</td>
<td>-1.83</td>
<td>-3.37</td>
<td>0</td>
</tr>
<tr>
<td>35. Eat and drink neatly</td>
<td>0.87</td>
<td>-0.86</td>
<td>-2.15</td>
<td>-3.69</td>
<td>0</td>
</tr>
<tr>
<td>36. Clean the house</td>
<td>1.75</td>
<td>0.02</td>
<td>-1.27</td>
<td>-2.81</td>
<td>0</td>
</tr>
</tbody>
</table>

The last set of questions deal with issues of mobility. Remember if you use a low vision device or adaptive technique to assist with the activity, please respond as though you were using the device or technique.

<table>
<thead>
<tr>
<th>Item</th>
<th>Score 1</th>
<th>Score 2</th>
<th>Score 3</th>
<th>Score 4</th>
<th>Score U</th>
</tr>
</thead>
<tbody>
<tr>
<td>37. Get around indoors in places you know</td>
<td>0.28</td>
<td>-1.45</td>
<td>-2.74</td>
<td>-4.28</td>
<td>0</td>
</tr>
<tr>
<td>38. Get around outdoors in places you know</td>
<td>1.22</td>
<td>-5.51</td>
<td>-1.80</td>
<td>-3.54</td>
<td>0</td>
</tr>
<tr>
<td>39. Get around in unfamiliar places</td>
<td>2.68</td>
<td>0.95</td>
<td>-0.34</td>
<td>-1.88</td>
<td>0</td>
</tr>
<tr>
<td>40. Go down steps in dim light</td>
<td>2.33</td>
<td>0.60</td>
<td>-0.69</td>
<td>-2.33</td>
<td>0</td>
</tr>
<tr>
<td>41. Go out at night</td>
<td>3.00</td>
<td>1.27</td>
<td>-0.02</td>
<td>-1.56</td>
<td>0</td>
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<tr>
<td>42. Get around in a crowd</td>
<td>2.52</td>
<td>0.99</td>
<td>-0.70</td>
<td>-2.24</td>
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<tr>
<td>43. Avoid bumping into things</td>
<td>1.86</td>
<td>0.13</td>
<td>-1.16</td>
<td>-2.70</td>
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<tr>
<td>44. Cross street at a traffic light</td>
<td>2.56</td>
<td>0.83</td>
<td>-0.46</td>
<td>-2.00</td>
<td>0</td>
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<tr>
<td>45. Use public transportation</td>
<td>3.19</td>
<td>1.46</td>
<td>0.17</td>
<td>-1.37</td>
<td>0</td>
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<tr>
<td>46. Find public restrooms</td>
<td>1.66</td>
<td>-0.07</td>
<td>-1.30</td>
<td>-2.60</td>
<td>0</td>
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<tr>
<td>47. Play sports</td>
<td>3.60</td>
<td>2.07</td>
<td>0.78</td>
<td>-0.76</td>
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<tr>
<td>48. Adjust to bright light</td>
<td>2.48</td>
<td>0.75</td>
<td>-0.54</td>
<td>-2.08</td>
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APPENDIX M

SUPERVISION RATING SCALE
Supervision Rating Scale

Instructions: Circle the rating that is closest to the amount of supervision that the patient actually receives. "Supervision" means that someone is responsible for being with the patient.

**Level 1: INDEPENDENT**

1 The patient lives alone or independently. Other persons can live with the patient, but they cannot take responsibility for supervision (for example, a child or elderly person).

2 The patient is unsupervised overnight. The patient lives with one or more persons who could be responsible for supervision (for example, a spouse or roommate), but they are all sometimes absent overnight.

**Level 2: OVERNIGHT SUPERVISION**

3 The patient is only supervised overnight. One or more supervising persons are always present overnight but they are all sometimes absent for the rest of the day.

**Level 3: PART-TIME SUPERVISION**

4 The patient is supervised overnight and part-time during waking hours, but is allowed on independent outings. One or more supervising persons are always present overnight and are also present during part of waking hours every day. However, the patient is sometimes allowed to leave the residence without being accompanied by someone who is responsible for supervision.

5 The patient is supervised overnight and part-time during waking hours, but is unsupervised during working hours. Supervising persons are all sometimes absent for enough time for them to work full-time outside the home.

6 The patient is supervised overnight and during most waking hours. Supervising persons are all sometimes absent for periods longer than one hour, but less than the time needed to hold a full-time job away from home.

7 The patient is supervised overnight and during almost all waking hours. Supervising persons are all sometimes absent for periods shorter than one hour.
Level 4: FULL-TIME INDIRECT SUPERVISION

8 The patient is under full-time indirect supervision. At least one supervising person is always present, but the supervising person does not check on the patient more than once every 30 minutes.

9 Same as #8 plus requires overnight safety precautions (for example, a deadbolt on outside door).

Level 5: FULL-TIME DIRECT SUPERVISION

10 The patient is under full-time direct supervision. At least one supervising person is always present and the supervising person checks on the patient more than once every thirty minutes.

11 The patient lives in a setting in which the exits are physically controlled by others (for example, a locked ward).

12 Same as #11 plus a supervising person is designated to provide full-time line-of-sight supervision (for example, an escape watch or suicide watch).

13 The patient is in physical restraints.
APPENDIX N

DISCUSSION GUIDE
Visually Impaired Caregivers: Perspectives from Patient Focus Groups

MODERATOR GUIDE SCRIPT AND GUIDE

WARM UP AND EXPLANATION

Good evening and welcome. Thank you for taking the time to join this group to discuss your experiences as a caregiver who is visually impaired. My name is Bethany Martinez, and I represent the Birmingham VA Medical Center. Assisting me is Chebon Porter/Laura Dreer. He/she will be observing the group, helping with the equipment and taking notes. You were all invited here because you are all visually impaired and have reported being the primary caregiver for a loved one. You are a special group of individuals, and we want to learn more about your experiences. I am interested in all your ideas, thoughts, and comments. Please feel free to share your point of view even if it differs from what others have said. There are no right or wrong answers.

We’re tape recording this session because we don’t want to miss any of your comments. No names will be included in any reports. Your comments are confidential. Keep in mind that we’re just as interested in negative comments as positive comments. I will ask that you please speak one at a time so that the tape recorder can pick everything up.

We have name tents here in front of us tonight. They help me remember names, but they can also help you. If you want to follow up on something that someone has said, you want to agree, or disagree, or give an example, feel free to do that. Don’t feel like you have to respond to me all the time. Feel free to have a conversation with one another about these questions. I am here to ask questions, listen, and make sure everyone has a chance to share. We’re interested in hearing from each of you. So if you’re talking a lot, I may ask you to give others a chance. And if you aren’t saying much, I may call on you. We just want to make sure we hear from all of you.

My role today is to facilitate discussion, to keep things moving, and make sure everyone gets a chance to speak. I’ll have an outline to refer to, to make sure we cover all of the topics. We may not have as much time as you’d like for some topics. Please don’t take it personally if I tell you we need to move along. At the end of the meeting, we’ll have about ten minutes to discuss anything you want that we haven’t covered or had to cut short. I will not be able to answer any questions about health during the meeting. You may ask these types of questions after the meeting. This discussion will last up to an hour and a half.

Before we begin, you must sign the appropriate paperwork. Quickly review and have participants sign the informed consent, VA 3203, and HIPAA Authorization.

Let’s start by having everyone introduce themselves and say a little about yourself if you’d like.

Total introduction time: 20 minutes
Visually Impaired Caregivers: Perspectives from Patient Focus Groups

INTERVIEWER SCRIPT AND GUIDE FOR ONE-ON-ONE INTERVIEWS

WARM UP AND EXPLANATION

Thank you for taking the time to discuss your experiences as a caregiver who is visually impaired. My name is Bethany Martinez, and I represent the Birmingham VA Medical Center. You were asked to complete this interview because you are visually impaired and have reported being the primary caregiver for a loved one. You are part of a special group of individuals, and we want to learn more about your experiences. I am interested in all your ideas, thoughts, and comments. You may refuse to answer any questions asked of you in the interview. There are no right or wrong answers.

I am tape recording this session because I don’t want to miss any of your comments. No names will be included in any reports. Your comments are confidential. Keep in mind that I’m just as interested in negative comments as positive comments. I will ask that you please speak clearly so that the tape recorder can pick everything up.

At the end of the meeting, we’ll have about ten minutes to discuss anything you want that we haven’t covered or had to cut short. This discussion will last up to an hour.

DISCUSSION GUIDE

1. **(10 minutes)** Please describe your caregiving during a “typical” week.
   a.) What activities do you do to care for your loved one?
   [Probe: Help with basic or instrumental activities of daily living, such as bathing, meal preparation, dressing/grooming, financial management, appointment management]
   b.) What activities do you do to help your loved one manage her/her illness and treatments?
   [Probe: medication delivery (oral meds, enemas, shots, etc), medical treatments, transferring, transportation to doctor’s appointments, medical decision making]

2. **(5 minutes)** How much time and energy do you spend on these caregiving tasks?

3. **(10 minutes)** If you were a caregiver before your visual impairment, did you have to make any changes to how you take care of your loved one? What?

4. **(10 minutes)** How does the fact that you are visually impaired influence your ability to perform your caregiving activities?
   [Probe: specific difficulties that you’ve experienced]

5. **(5 minutes)** What kinds of caregiving supports do you use (for example, paid services like home health care, nursing aids, day care, or respite care)? How helpful have these been?

6. **(5 minutes)** What kind of caregiving support would be helpful that may not be available to you?

7. **(5 minutes)** Have you used VA-sponsored or private services for the visually impaired, like low vision services orblind rehabilitation? If yes, which services have you used? If not, how does being a visually impaired caregiver prevent you from using such services? [Probe: What kept you from using such services? Lack of information, travel difficulties, lack of substitute care for your loved one?]

8. **(10 minutes)** How do your caregiving activities impact upon your other roles/responsibilities?
9. (10 minutes) How does your visual impairment impact upon your other roles/responsibilities?

10. (5 minutes) Would you give up the role if the opportunity presented itself? If so, why or why not?

11. (10 minutes) What have been some of your most challenging experiences in your caregiving role?

12. (10 minutes) What have been some of your most rewarding experiences in your caregiving role?

13. (10 minutes) Is there anything else that you think I need to know, that we haven’t talked about?

Total time: 120 minutes
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<th>Center</th>
<th>National Alliance for the Mentally Ill</th>
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<tbody>
<tr>
<td>Contact Person</td>
<td>Cecelia Laurie, (205) 348-1976</td>
</tr>
<tr>
<td>Phone</td>
<td>(205) 752-5774</td>
</tr>
<tr>
<td>Fax</td>
<td>(205) 348-7067</td>
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<td>Address</td>
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<tr>
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<td>Jerry Johnson</td>
</tr>
<tr>
<td>Phone</td>
<td>256) 582-3203</td>
</tr>
<tr>
<td>Fax</td>
<td>(256) 582-3216</td>
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<tr>
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<tr>
<td>Contact Person</td>
<td>Susan Lott</td>
</tr>
<tr>
<td>Phone</td>
<td>(334) 289-2410</td>
</tr>
<tr>
<td>Fax</td>
<td>(334) 289-2416</td>
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<tr>
<td>Address</td>
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<tr>
<td>Contact Person</td>
<td>Gary Porier</td>
</tr>
<tr>
<td>Phone</td>
<td>(256) 533-1970</td>
</tr>
<tr>
<td>Fax</td>
<td>(256) 532-4112</td>
</tr>
<tr>
<td>Address</td>
<td>4040 S Memorial Pkwy, Huntsville, AL 35802</td>
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<tr>
<td>Contact Person</td>
<td>Tim Naugher</td>
</tr>
<tr>
<td>Phone</td>
<td>(256) 546-6324 ext. 202</td>
</tr>
<tr>
<td>Address</td>
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<tr>
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<tr>
<td>Contact Person</td>
<td>Steve Scott</td>
</tr>
<tr>
<td>Phone</td>
<td>(251) 990-4190</td>
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<tr>
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<td>Beverly Francis</td>
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<tr>
<td>Phone</td>
<td>(205) 836-7283</td>
</tr>
<tr>
<td>Fax</td>
<td>(205) 836-9594</td>
</tr>
<tr>
<td>Address</td>
<td>129 East Park Circle, Birmingham, AL 35235</td>
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</table>
**Center**  Northwest Alabama Mental Health Center  
**Contact Person**  Jerry Lovett  
**Phone**  (205) 302-9000, 1-800-489-3971  
**Fax**  (205) 387-8270, (205) 221-5911  
**Address**  1100 Seventh Avenue, Jasper, Alabama 35501-4329  

**USA National Suicide Hotlines**  
800-784-2433  
800-273-8255  

**Local, "The Crisis Center" (a suicide/crisis number)**  
(205) 323-7777  

**The "Senior Talk Line" (crisis number of senior citizens)**  
(205) 328-8255