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The Experience of Age-related Macular Degeneration

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Abstract: This qualitative article describes the impact of age-related macular degeneration (ARMD) among 15 participants: how a person makes sense of ARMD, the effect of ARMD on the person's quality of life, the psychological disturbances associated with the limitations of ARMD, and the influence of ARMD on social interactions. Such in-depth appreciation of the impact of ARMD will assist in the design of specific and appropriate rehabilitation programs to minimize limitations and enhance participation in people with ARMD.

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Age-related macular degeneration (ARMD) is one of the leading causes of irreversible visual impairment in Western societies. It can have a substantial impact on an individual's quality of life and is associated with high levels of disability. It may cause difficulties with daily living and restrict activities, such as driving, reading, writing, cooking, traveling, and simple social interactions (Keeffe, Lam, Cheung, Dinh, & McCarty, 1998), many of which have been taken for granted previously. Research on the psychosocial impact of ARMD using the Quality of Well-Being Scale has shown that persons with ARMD had similar levels of health-related disability as did those with cancer and stroke (Williams, Brody, Thomas, Kaplan, & Brown, 1998). In addition, nearly a third of people with advanced ARMD met the criteria for having a depressive disorder, twice the rate of the elderly population (Brody et al., 2001).

Despite the large amount of time and resources spent on treatment trials, there is still little effective treatment and limited intervention to help reduce the incidence or progression of ARMD. Low vision rehabilitation that enables people to use adaptive devices and techniques to perform daily activities independently had been the mainstay of management of this condition. Many rehabilitation agencies had incorporated programs to address the psychosocial issues of vision loss, but none was specific to ARMD. Given that individuals with ARMD have greater difficulty with the tasks of daily living for any given level of acuity than do people with other types of visual impairment (Hart, Chakravarthy, Stevenson, & Jamison, 1999) and ARMD is the most common cause of irreversible blindness for those aged 65 and older in Western societies (Buch, Vinding, & Nielsen, 2001; Weih, VanNewkirk, McCarty, & Taylor, 2000), a deeper understanding of the impact of vision loss specific to ARMD and an appreciation of individuals' experiences, needs, and goals are necessary to facilitate the holistic management of these individuals.

Many previous studies have used "closed" questionnaires, whereby there were a selection of predetermined answers, to study the impact of ARMD on the quality of life, providing statistically significant disability ratings for these individuals; however, none has attempted to analyze qualitatively and conceptualize the limitations of activities that were specific to ARMD. The qualitative study presented here is the first step of a larger study in which the ultimate aim is to reduce the impact of vision loss that is due to ARMD by improving vision care support and rehabilitation. The purpose of the study was to conduct in-depth individual interviews to explore a range of issues and perspectives, making sense of individual experiences, and to understand the specific needs in people with ARMD.

Method

A qualitative research method was used that was based on grounded theory (Flick, 1998a; Strauss & Corbin, 1998), whereby an inductive approach was adopted using a systematic set of procedures to arrive at a theory about basic social processes. In this study, the impact and meaning of progressive visual deterioration at various stages of ARMD were studied. The principal theoretical paradigm used was symbolic interactionism, in which the research is based on the subjective meanings that individuals attribute to their activities and environments (Flick, 1998b). The common themes that emerged from the interviews conducted for this study were examined and conceptualized to generate theories to explain the complex interaction between the disease process and quality of life. The study was approved by the Human Research and Ethics Committee of the Royal Victorian Eye and Ear Hospital, Melbourne, Australia.

Participants

The participants were recruited through an ophthalmologist, who is a subspecialist in the retina; the Vision Australia Foundation; and forums held by the Center for Eye Research Australia (CERA). All persons who had vision loss associated with ARMD and were fluent in English could be included. Individuals who met these criteria were invited to participate in the study by the ophthalmologist, personnel at Vision Australia Foundation, or one of the authors at CERA. Details of willing participants were made available to the research staff, who then arranged interviews to be conducted in the participants' homes or in a private meeting room at CERA.

The sampling techniques were based on “theoretical sampling,” developed by Glaser and Strauss (Morse, 1994), in which the decisions about choosing and putting together empirical material are made in the process of collecting and interpreting data (Morse, 1994). There was no predetermined number of participants to be recruited at the start of the study. The sampling process continued until the emerging theoretical categories were saturated (Flick, 1998b).

A total of 15 participants (7 men and 8 women), ranging in age from 60 to 85 (mean age = 77), were interviewed. The mean age of onset of ARMD was 73. Of the 15 participants, 10 were recruited from the ophthalmologist, 3 were recruited from Vision Australia Foundation, and 2 were recruited from CERA. Six respondents resided in rural Victoria at the time of interviews. Although all the participants were fluent in English, 2 were born overseas and spoke a language other than English at home. All the participants were retired; 8 lived alone, and 7 resided with their spouses. At the time of the interviews, all the participants had been diagnosed with ARMD from 6 months to 7 years. Three had unilateral ARMD and typical vision (visual acuity better than or equal to 6/9 or 20/30) in their better eye, 3 had mild visual impairment (visual acuity of 6/12–6/18, or 20/40–20/60) in their better eye, 4 were moderately affected (visual acuity of 6/24–6/60, or 20/80–20/200), and 5 were classified as severely visually impaired (visual acuity worse than 6/60, or 20/200). Eleven participants were either currently or previously enrolled in vision-related rehabilitation programs.

Interview procedure

Prior to each interview, oral explanations and a large-print information sheet were given to each participant outlining the aims of the study. The participants were informed that the goal of the research was to gain a deeper understanding of the experience of people with ARMD, thus forming the basis for future research aimed at reducing the impact of vision loss by improving vision care support and rehabilitation. Each participant gave informed consent for the disclosure of information given during the interview.

In-depth semistructured interviews were conducted by the first author, who is a medical practitioner with an interest in ophthalmology and trained in public health, to explore the participants' personal accounts of ARMD. After eliciting demographic information, including age, gender, onset of ARMD, and household living arrangements, the interviewer began with an open-ended question such as this: "Tell me about how macular degeneration has affected your life." The line of questioning would then be based on the participant's responses, with the overall aim of getting the participant to talk about his or her experience with ARMD within the broader social and psychological context.

The interviews ranged from 30 to 80 minutes, with the majority lasting 60 minutes (see sample transcription). They were audiotaped, and verbatim transcriptions were produced from the audiotapes and later checked with the original interviews to ensure accuracy.

Data analysis

A qualitative thematic analysis of the transcribed interviews, based on grounded theory, was used (Strauss & Corbin, 1998). After each interview, without the aid of computer programs, the researcher identified the main concepts and keywords used by the participants to form the basic units of analysis, which led to the development of abstract categories and subcategories for analysis. Material in each category reflected both the range and frequency of the participants' views on particular issues and formed the basis for generalizing their experiences. From these categorizations, comparative analyses of different aspects of and variations in experience were possible, and concepts were examined to establish linkages and explanations.

Results

The degree of limitations associated with ARMD was largely dependent on the degree of visual impairment (Keeffe, McCarty, Hassell, & Gilbert, 1999). The three respondents with unilateral ARMD experienced little or no debilitating difficulties in their daily living, compared to the participants with bilateral advanced ARMD. An 80-year-old single man with unilateral ARMD described his experience with ARMD as follows:

> It doesn't affect me at all. I am happy reading with one eye; many people have one eye for a lot of reasons. I have been coping with it quite well right from the beginning, right from the start. It hasn't proved to be any sort of handicap.

Although they remained independent and were able to carry out normal daily activities, these individuals continued to be troubled by the potential deterioration of their remaining vision and thus loss of independence. This possibility was particularly central for the 62-year-old widow who lived alone and for whom the ability to drive was essential: "I try not to dwell on it.… Just one day at a time, and I am hoping, please, God, that this [good eye] will last." In contrast, many participants with bilateral ARMD had different perspectives on life. They had a variety of experiences that had a substantial impact on their daily living, independence, and psychosocial well-being.

Understanding ARMD

Although ARMD is one of the leading causes of blindness in the Western countries (Buch et al., 2001; Klein, Klein, & Cruickshanks, 1999; Klein, Klein, &

Linton, 1992; Mitchell, Smith, Attebo, & Wang, 1995; Vingerling et al., 1995; Weih et al., 2000), little is known about its pathogenesis and etiology (Hyman & Neborsky, 2002). When faced with this progressively deteriorating condition, the participants often felt powerless, despair, and incapacitated.

Once the ARMD was diagnosed, they were often told by their ophthalmologists that “there’s nothing for you”; “you can’t do anything about it”; or “it is too far gone, there’s nothing we can do.” Although many understood ARMD as “a hemorrhage,” “bleeding,” “a leak in the back of the eye,” or “a drusen,” some participants were still searching for an *answer*. In attempting to understand ARMD, many had developed their own theory of causation. For example, a 75-year-old retired businessman with several medical concerns had formed this thought:

> My simple mind deduced that perhaps in the surgery [an excision on the cheek for skin cancer], perhaps a rush of blood to repair the damage, the rush of blood must have caused the leak. That’s been discounted, I think, but nonetheless that’s my theory.

An 83-year-old housewife, who had received various ophthalmic opinions for the management of her ARMD throughout the years, said: “I was very fearsome of the angiogram—not of the body but of the eyes.… I was resistant to the angiogram because I felt that the angiogram might have brought on the [ARMD].”

Perhaps because of the lack of knowledge and understanding of ARMD, the frustration of having a chronic illness with no proven effective treatment, the perceived lack of health care, or simply the inappropriate manners of medical practitioners, some participants expressed dissatisfaction, anger, or resentment toward their eye care providers. As a result, they had often had multiple consultations with various ophthalmologists or optometrists over the years.

"I Am Half the Man I Used to Be"

These lyrics from the song "Yesterday" by the Beatles, as expressed by one participant, nicely sum up the experience of ARMD for these individuals. Because of their progressively deteriorating visual function, many of the optical aids and adaptive devices that the participants had used had been rendered useless. For the participants with intact visual function, pouring a cup of tea, opening a can of soup, shopping in a supermarket, reading a bank statement, watching television, or crossing a street were easy, undemanding tasks that they performed many times a day. However, for those participants with bilateral ARMD, these simple daily activities required concentration, planning, recall capabilities, and the coordination of sensory modalities like hearing and touching. Every task was challenging and constantly reminded them of their limitations. A 76-year-old woman with bilateral visual acuity worse than 6/60 (or 20/200) revealed:

> When I get a letter, I can't read it. I can get a bill, gas, light bill, you know, like mundane things, and I will go and try to look at it with the glasses, but I can't do that. And they are the sort of things that keep hitting you all the time; they come back to you to remind you, you can't see.

A socially isolated 66-year-old divorcée, who had numerous accidents in the kitchen and other areas of her home, described her experiences this way:

> I have dropped a lot of things, thinking that I am on the bench, but I am not on it. And I have dropped cups, plates, and mugs. Well, it's trial and error. You have to learn instead of just plonking your things down; you have to get to the edge with one hand and then place it with another.

In addition, a 76-year-old woman, who had attended group therapy and vision rehabilitation programs conducted by Vision Australia Foundation, expressed her concerns about decreased vision as follows:

> Simple things like crossing the street. I can't cross the street wherever I want to; I must go to the light and wait and listen to the clicker because I have had a couple of incidents when I thought it was clear [but it was not], and that was very devastating, I can tell you, very frightening.

Examples of these types of difficulties with daily activities were endless. However, the biggest difficulty that the participants experienced was losing their ability to drive and hence their independence. The participants had to rely on family members and friends or public transportation to commute to and from places. One otherwise healthy, independent woman, aged 83, with a supportive partner, said: "It's quite a big thing giving up your car. You just can’t hop into it and go anywhere.”

As a result of this loss of independence and self-autonomy, some participants had become isolated in their homes. They were unable to engage in social activities like meeting friends for afternoon tea or going to a dance without transportation by others. Spontaneous participation in activities was no longer possible, and for many, it had a negative impact on their social health. An 83-year-old Italian woman, who previously enjoyed teaching foreign languages at a university and going ballroom dancing with friends, said: “I have to think my eyes cut off everything.… Before it [life] was full of energy; now it is full of nothing.” A 72-year-old rural participant who was living at home with his wife also held the view that “It [ARMD] cuts your social life by about 99.5%. It doesn’t matter what you do.” A 66-year-old woman, who had been diagnosed with ARMD 14 months earlier, said: “Well, funny as it may seem, all my friends have sort of dropped off. I find that very hard to understand.… They have just completely dropped [me] since they knew that I was losing my eyesight.”

The participants needed to accommodate to the disabling responses from the wider social network and arrange their lives around their visual impairments. Moreover, as a consequence of their visual impairments, their retirement plans and dreams had been destroyed. The participants could no longer read the books that they had put away for later enjoyment, travel and see the world, or drive across Australia. ARMD had rendered their lives incomplete and unfulfilled.

Asking for help

Although many participants had profound visual impairment and had been prescribed white canes by orientation and mobility instructors for daily activities, their white canes were often found at the bottom of a drawer or in the corner of a room. None of the participants actually wanted to be seen with a white cane. For them, the white cane was a symbol of blindness, disabilities, and weakness. It may have also represented self-pity and self-insufficiency. One unmarried 76-year-old woman stated: “You don’t want anybody to give you pity, and you think everyone is going to pity you; carrying the white stick or wearing the dark glasses, it’s like a symbol, “Look at me, I am blind!”

Although some participants were comfortable using their social resources, asking their friends and family members to assist them in their daily activities, many others found it extremely difficult to ask for help. They did not want to “trouble,” “burden,” or “get in the way” of their friends and relatives. Instead of asking for help, many would try to perform daily activities independently even if it meant doing them “two, three, or four times.” A 79-year-old married, retired businessman, who had recently moved to a new home in a more central location for greater convenience, said: “Being independent for a long time, most of your life, you feel as if you are putting your carer to an unnecessary burden at times.” Most participants strived to maintain their independence and to remain active to preserve their self-respect, self-worthiness, and self-pride.

“A fraud”

During the interviews, some participants emphasized that they had “failed” the visual acuity tests, unable to read the top line of the Snellen chart, and had restricted central vision such that they had been declared legally blind (visual acuity of worse than 6/60 or 20/200 in Australia) by their ophthalmologists. Not only did legal blindness give them access to the blindness pension and half-priced public transportation, it provided them with the affirmation they needed. The participants needed the official confirmation that although they had intact peripheral vision, they did suffer from visual impairment and were not what others might think, “a fraud.” A 78-year-old man who lived in a rural area and who had given up farming because of his visual impairment said resentfully:

> Well, I told them [friends] that I am legally blind; I can’t see them. They said jokingly, “Well, I wouldn’t like to drop a $10 bill out in front of you to see if you pick it up.”… I feel that people that I have seen many times and told them that I am blind, legally blind, they don’t believe

it.

Given that only 5% of the general population are aware of ARMD and 2% have correct knowledge of ARMD (Livingston, McCarty, & Taylor, 1998), these thoughtless reactions were not surprising. However, it was these unsympathetic and somewhat demeaning responses from others that often provoked emotional disturbance and irritation in the participants. Such responses threatened their integrity and undermined their efforts to maintain their autonomy. Although the participants did not "blame" others for not understanding their condition, they did resent others' unintentional insensitivity toward it. Understanding and acceptance by family members and friends were crucial to their ability to accept and cope with ARMD.

Coping and accepting

The participants' coping strategies and mechanisms were vulnerable to changes in their personal and social circumstances, the negative attitudes of others, and the prospect of deteriorating visual function and health. For most participants, the knowledge of having a chronic debilitating condition was a big "shock" initially. While ARMD caused "inconvenience" and emotional turmoil, the participants with supportive and understanding relatives and friends continued to have a positive outlook on life, continued to discover ways to live with their disability, and managed day-to-day activities without having major crises. Although he had to care for a wife with early Alzheimer's disease, one active 75-year-old man maintained:

> I am not depressed about it [ARMD], I just accept it. I mean, I am 75 years old. Goodness gracious me, I have done very well, I think, to be where I am. But then again, it really does upset your life.

Similarly, an 83-year-old woman with severe visual impairment who was living in a retirement village with her husband said:

> In the beginning, I felt I had to see to write. But I am learning that you don't have to see to write. That you can do it without seeing, you do it from memory. The main worry, I think, is that you do nearly everything from memory, but things keep changing.… [In addition], the difficulty is seeing people,… but I am trying to listen to people's voices more, so that I can tell people by their voices.

Others who were socially isolated often found it extremely difficult to comprehend their misfortune, fell short of developing coping strategies, and had fallen victim to ARMD. In an extreme case, one 66-year-old woman, who became distanced from her family members after she separated from her husband, said: "Some days I think, well, suicide is far better than going through this."

Some participants never stopped asking themselves, "why me?" especially during little mishaps, stressful events, and changes in their environment. Questioning why they had ARMD and their inability to accept it were destructive to their psychosocial well-being. Attempts to forget about ARMD and reduce its impact on life were only partially successful. There were times when they could cope better with it than at others. However, anxiety, frustration, and powerlessness prevailed in their lives.

As a result of uncertainties and limitations associated with ARMD, even when their condition had been stable for many years, many participants continued to worry about what the future might bring. One 78-year-old man who had been diagnosed with bilateral ARMD 7 years earlier, said: “So long as I am not totally blind, I will cope. But I will find it very hard if I am totally blind.… I just pray that I am never… gonna be blind!”

Rehabilitation

Of the 15 participants, 11 had been involved in visual rehabilitation programs with Vision Australia Foundation, a nonprofit organization. Three respondents who did not attend such programs had unilateral ARMD and minimal difficulties with daily activities, and the fourth was waiting to visit the foundation at the time of interview.

Of those who had visited the foundation, rehabilitation began within six months of the diagnosis of ARMD. They received optical assistance, such as magnifiers and closed-circuit televisions, but, as we mentioned earlier, many found them to be impractical and difficult to use with the presence of only peripheral vision. In addition to optical devices, a team of outreach workers, including occupational therapists, orthoptists, orientation and mobility instructors, welfare workers, and social workers, taught the participants techniques for living independently and performing household maintenance. The foundation also offered opportunities to participate in social activities, such as group meetings, arts and crafts sessions, football discussions, day excursions, and sports activities.

Many participants had used techniques, such as tactile markings, audiotapes, and color codings, to help them perform daily activities and found that these techniques alleviated many of their anxieties. However, these techniques were not encompassing, and under some circumstances, they were insufficient and limited. For example, a 78-year-old man who was able to maintain his own garden found it difficult to use the techniques. As he put it: “If I sit right up close and turn my head to look outside [to try and see the television screen].… It’s very hard to try and watch television looking at the side of your eye.”

During the interviews, it also became apparent that the participants who engaged continuously in social activities conducted by Vision Australia Foundation or other local organizations tended to remain active, to be less distressed by their physical limitations, to have a positive outlook on life, and to be in better overall psychosocial health. However, despite the benefits found in 7 participants, 2 urban participants failed to attend the social groups because they were “too far away,” and another 2 had stopped attending following their initial participation.

Perhaps part of the reason why those who had participated in rehabilitation appeared to be more contented was that they were more easily motivated and had better coping strategies. People who were introverted, timid, and withdrawn might require special care and attention. Nonetheless, a combination of physical and social rehabilitation was essential in promoting the participants’ overall well-being.

Rural versus urban experience

As discussed earlier, to preserve their dignity and autonomy, many participants faced enormous difficulty in seeking assistance. However, one interesting issue that became apparent during the interviews was that most participants who lived in rural Victoria expressed less difficulty or concern about asking for help than did those who resided in urban Victoria. We could only postulate that this finding was related to the fact that living in smaller communities in rural Victoria, there was a sense of community, and residents were more prepared both to provide and to receive assistance when required. In comparison to the experience in rural Victoria, where “people are very happy to help,” one 76-year-old man described his experience in urban Victoria this way: “People obviously don’t like strangers talking to them. Well, there are a few odd bods out there, a few!” In addition, all the participants from rural Australia invariably felt that they were much better off in the country than in the city. As one 78-year-old man put it: “In the city, you have to be very careful when you cross the street and things like that. This is very convenient here. I cross, I don’t have any fear.… I feel very safe for that!” Perhaps it was also the quietness and friendliness of rural Victoria that enhanced the man’s sense of personal safety.

Discussion

The most striking feature of this study was the importance of “understanding” to the participants’ psychosocial well-being. Visual functioning could be optimized using optical aids and adaptive devices (Scott, Shiffman, Feuer, & Pappas, 1999), but for many participants, their visual function had deteriorated so much that even the use of these devices had proved fruitless. Rehabilitation programs and services that offered peer support groups provided venues for ventilating feelings and frustrations and allowed for the development of comprehensive coping strategies. However, the issues that were central to the participants’ overall well-being, such as understanding ARMD and their choices and their family members’ and friends’ understanding of their impairments had not been adequately addressed.

The lack of knowledge about ARMD and its causes formed the basis of the participants' psychological disturbances (Livingston et al., 1998). With advanced medical treatments and the fact that various life-threatening conditions are treatable, the participants felt frustrated and dismayed when they were advised that little effective treatment was available to preserve one of their most vital sensory modalities—vision. Many did not comprehend why the advanced medical technologies could not provide any improvement in their eyesight and were thus hindered in their ability to accept their impairments.

The lack of familiarity with and awareness of ARMD among providers of health and aged care services and in the wider society meant that the participants with ARMD were often misunderstood. While they struggled to minimize restrictions produced by visual impairment on their day-to-day lives and used resources and strategies to live as fully as possible, negative responses or insensitivity to their impairments undermined their efforts to cope. In addition, the label "legally blind" had generated many misunderstandings. Because of the stigma associated with "blindness," it is difficult for those with ARMD and their families to comprehend how a person can be "legally blind" but still retain useful eyesight. The participants did not realize that the categorization was only of legal importance, in that it gave them certain entitlements, such as blindness disability pensions and travel allowances, and did not have a functional meaning and implications for their abilities. All this confusion, in turn, increased the vulnerability of their coping strategies, so that at times, their lives were overwhelmed by their impairment.

Despite the feelings of frustration and grief, the understanding of the importance of remaining proactive and thus having control over their lives was another pivotal element in their adjustment to their vision loss (Kleinschmidt, 1999). Many participants simply accepted the restrictions that ARMD posed for them, failed to see beyond the boundaries, and became isolated in their own homes. They needed to appreciate and concentrate on the overall picture and the positive aspects of their lives to enhance their satisfaction with life.

Limitations of the study

Although the scope of the data used in this study was limited, and the use of volunteers introduces selection bias, giving more favorable responses to the impact of ARMD, there was evidence of the validity of the study. The information shared during the interviews and the manner in which it was shared suggests that the participants were open and honest about their experience with ARMD. The fact that other than disclosing the negative impact of ARMD, some individuals were able to shed a positive light on living with ARMD suggests that the information presented here was realistic and balanced. Consequently, although only 15 participants were involved in the study, the study allowed us to examine some of the common events experienced by people with ARMD. In addition, we acknowledged that 6 participants did not have visual acuity that satisfied the World Health Organization’s (1992) criteria for visual impairment. However, various studies have shown that despite having a visual acuity better than 6/12 (20/40), individuals may still have difficulty performing the tasks of daily living independently (Rubin et al., 2001; Weih, McCarty, & Taylor, 2000), and thus it was important to include them in this study.

As a result of the nature of qualitative research, we acknowledge that the stories shared by participants reflected their personal experiences, were subject to researchers’ bias, and in no way are representative of all people with ARMD. However, to compensate partially for this limitation, we included a roughly equal number of men and women, a mixture of people from rural and urban areas, and individuals from different ethnic and socioeconomic backgrounds. Despite limitations associated with the sample, this study provided some important insights into the experiences of people with ARMD that are not possible to obtain using questionnaires and analyzing the information quantitatively (Mays & Catherine, 1995).

Implications for practice

The findings of this study emphasize some of the essential issues for low vision rehabilitation. To be effective and efficient, programs need to provide accurate information and education for individuals who are diagnosed with ARMD. Health care providers and rehabilitation agencies need to be aware of and sensitive to the despair that these individuals initially experience and, through explanation, help them resolve some of the frustration and resentment they feel. Behavioral interventions that are designed to reduce emotional distress, assist in overcoming barriers to daily routines, encourage participation in activities, and maintain a positive outlook in life are important. Special care may be required for individuals who are more withdrawn and introverted. In addition, intervention programs should concentrate on developing personal skills, enhancing existing abilities, and empowering a sense of control. Finally, increasing public awareness of and public education about ARMD and the difficulties associated with the loss of vision may help to alleviate some of the unpleasant tension created by the social environment.

Living and coping with ARMD are complex. The ability to cope does not lie entirely in individuals' personal strengths or in the condition itself. The understanding of the condition, social resources, and the responses of society all affect an individual's ability to cope. These factors should be considered when implementing low vision rehabilitation programs.

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