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What is This?

# Staying connected: re-establishing social relationships following vision loss

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**Objective**: To examine the nature of relationship-related challenges experienced by adults with vision impairment, as well as the strategies employed to deal with them.
**Design:** Cross-sectional qualitative study.
**Setting**: Vision rehabilitation agency.
**Subjects**: Fifty-eight young, middle-aged and older adults with vision impairment.
**Method**: Telephone and in-person interviews included an open-ended question about how having a vision impairment has changed relationships. Interviews were coded using a qualitative analytical approach.
**Results**: Participants' responses fell into two categories: difficulty in social situations was due either to other people's lack of understanding and/or one's own lack of visual cues. Responses were either to readjust one's behaviour to maintain relationships or to let relationships go or turn sour. Within these two directions, participants reported specific strategies. For readjusting one's behaviour, participants mentioned explaining themselves more and being more assertive, relying on other senses for information, 'faking' it through interactions, and being more selective about who they interacted with. For letting relationships go, participants reported either withdrawing and making fewer initiatives to socialize, or getting angry and telling people off.
**Conclusions**: Study findings suggest that re-establishing relationships following vision loss is a multifaceted experience in which individuals employ different strategies. These need to be further researched, given their importance to individuals dealing with vision impairment.

## Introduction

Social relationships and support exchanges are viewed as crucial to well-being.[1,2] In particular, in the context of dealing with chronic impairment, one's relationships and support functions play an important role in the adaptation process.[3,4] Facing a chronic illness or disability is likely to involve changes in social relationships because it may affect the way a person interacts with and relates to others. For example, a person may no longer be able to engage in the same social activities or participate in them in the same way; he or she may also be dependent on social network members in different ways than from before the onset of the disability.

Vision impairment due to eye disease, a condition that affects over 10 million adults

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in the USA,[5] is one chronic condition that is likely to affect personal relationships, since social interactions in daily life rely heavily on the availability of visual information.[6] Not surprisingly, a recent study on life goals and vision loss in young and middle-aged adults found that vision impairment was often seen as interfering with relationship-related goals, and that improving one's relationships was reported as a top priority.[7] However, these relationship-related goals were typically not addressed in vision rehabilitation services. There is also evidence for negative change in relationships among older adults with vision impairment, such as a decrease in social network size and perceived receipt of support over time,[8] as well as a decrease in the support that elders with vision loss provided to others.[9] This research further demonstrated that the need for and receipt of support can have negative effects for the psychological well-being of these older adults,[10] and that negativity in social interactions for this population, assessed on multiple occasions, persisted over the 18 months duration of the study.[11]

Taken together, prior research has identified the presence of negativity in the relationships of people who experience visual disabilities, and has shown that such negativity is related to poor adaptation. Furthermore, evidence also clearly suggests that this phenomenon exists across the adult life span. In a recent study comparing life changes due to vision loss among younger adults with those of older adults,[12] a majority of participants ($n = 97$; 61%) said that they experienced changes in their relationships due to vision loss, and among the changes reported, the most prevalent relationship change was the need to re-establish ways of relating with people ($n = 58$; 60%). This change was reported far more frequently than becoming more dependent on others ($n = 33$; 34%), which one might expect to be the more common change in the context of dealing with disability. Interestingly, there were no significant age group differences with regard to the kinds of relationship-related changes that were reported, which justifies the use of an approach that covers individuals across the lifespan in investigating these challenges.

Thus, the few studies that have attempted to understand whether or not and how negativity in the relationships of people with vision impairment

is linked to their having the impairment suggest that a substantial portion of it seems to be disability-related. A common theme among adults of all ages who suffer from vision loss seems to be viewing vision impairment as the source of challenge in social relationships that causes a need to re-establish ways of relating with others. These are issues that could directly be addressed in vision rehabilitation, although prior research suggests that this is rarely the case.[7] A better understanding is required of the specific challenges that people face in relating with others due to their vision impairment, and how they attempt to deal with these challenges, in order to improve vision rehabilitation services. Because quantitative methods are limited in their ability to reveal the richness and complexity of these experiences in people's lives, and because such data do not currently exist, the present study aimed to provide an in-depth qualitative perspective for young, middle-aged, and older adults who experience vision loss during adulthood.

## Sample and methods

The total sample ($N = 58$) for this secondary data analysis included young, middle aged and older adults with vision impairment who had reported in prior research[12] that relating to other people had become a challenge due to their vision loss. Young and middle-aged participants ($n = 25$), average age 51 (SD = 10.3), were drawn from a study on vision loss among working-age adults[13] (see ref. 13 for more detailed sample information). Older participants ($n = 33$), average age 84 (SD = 5.7), were drawn from an ongoing longitudinal study on coping with age-related vision loss in late life[14] (see ref. 14 for more detailed sample information). It should be noted that although the younger group included people with a variety of eye diseases whereas the older group was limited to those with macular degeneration, the two groups did not differ in terms of their functional vision loss. Both studies were approved by the agency's institutional review board. For a descriptive comparison of the two groups, the reader is referred to Boerner and Wang.[12]

All participants had been applicants at a vision rehabilitation agency serving the greater

New York Metropolitan area and were experiencing significant visual impairment. The average age was 70 (SD = 18.3; range 29–94), 57% ($n = 33$) of the sample were women, the majority were white (78%; $n = 45$) and 81% ($n = 47$) reported an educational level of at least graduating high school. Other criteria for inclusion were: community-dwelling, fluency in English, and absence of cognitive or hearing deficits that could interfere with a research interview. Data were collected by trained interviewers, through either telephone or in-person interviews.

### Assessment and coding of relationship changes

Narrative information about participants' changes in relationships with others was collected with the following open-ended question based on questions developed in a study assessing life changes following victimization[15]: 'How has having a vision impairment changed the ways in which you relate to others?' Interviewers audiotaped the narrative information whenever possible for later transcription by unbiased research assistants. When audiotaping was unavailable during telephone interviews, interviewers typed the narrative information into a document during the interview for later coding.

The coding of the narrative data for the present paper was guided by a qualitative analytical approach to interview data (i.e. grounded theory[16]), and involved a focus on the theme 'need to re-establish relationships with others', which had been identified in prior analyses (for a detailed description of the previously developed coding system, see Boerner and Wang[12]). The first stage of the data analysis entailed the development of a coding system to further explore the challenges of relating with others and how these challenges are managed. Two researchers independently reviewed the narratives of the first five participants, and generated their own initial set of codes to characterize the difficulties and responses found in the narratives. It should be noted that from the beginning of data analysis, the researchers collected quotes that illustrated particular codes, and used them as samples to guide further coding. The authors then met to discuss, clarify and refine these codes. After agreeing on an initial set of codes and clarifying their definitions, the narratives of the next five participants were used to establish inter-rater agreement between two independent coders. Percentage agreement was used to assess inter-rater agreement during the first phase of code development, and was derived by dividing the number of codes in agreement by the total number of codes for each narrative. The first inter-rater agreements for this set of five narratives were at 80% and above, which is generally considered an acceptable agreement rate.[17]

The authors then routinely met to discuss, clarify and refine these codes through systematic stages of qualitative analysis that gradually incorporated the whole sample in a careful process of coding a set of five narratives at a time, meeting to discuss the coding and calculate inter-rater agreement, and then moving forward with another set of narratives. In addition, identified difficulties and responses were then grouped thematically into main categories of phenomena. The coding progressed through this process of analyst triangulation and mutual constraint, where each researcher's interpretation of the data was compared with and constrained by the interpretation of another researcher in aiming for objective accuracy in understanding these data. The finalized codes reflect common themes that emerged from the narratives with respect to both challenges and response strategies in this context (see Figure 1). For all stages of qualitative analysis following code development, the more conservative Cohen's kappa (that takes into account agreement occurring by chance) was used to assess inter-rater agreements on all narratives. These rounds of coding all produced kappa coefficients that consistently ranged from 0.62 to 1.0, with an average kappa of 0.88, demonstrating adequate inter-rater agreement using the coding system.

## Results

Figure 1 displays the identified challenges and responses, and suggested conceptual links between the categories. As depicted in the figure, the reported vision-related challenges in relating to other people fell into two major categories.
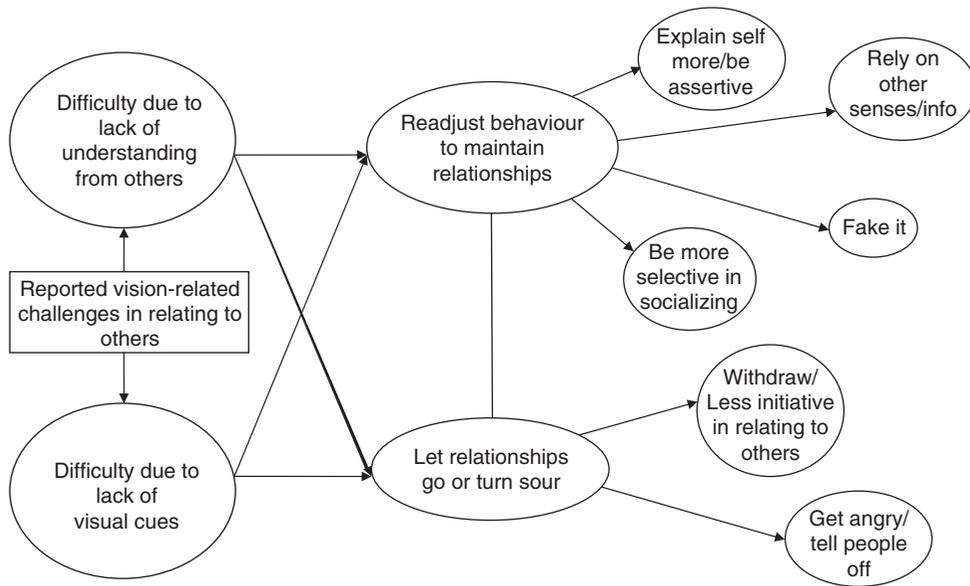
**Figure 1**   Relationship-related challenges and strategies employed to respond to them.

## Challenges

The first category, 'Difficulty in social situations due to lack of understanding from others' (no. = 24), primarily included instances of other people not understanding the implications of vision loss, and either over- or underestimating what the person with vision loss can or cannot see and do. This difficulty due to a lack of understanding from others reflects an externally based challenge caused by factors indirectly related to the functional disability. The following sample quotes illustrate common challenge scenarios in this category:

'*The big thing is how I'm perceived – when I first tell others that I have a visual impairment, they either feel overly sorry for me or they try to overcompensate, or they build distance from me. So you have to re-establish where you're at with other people*.' (M, 55)
'*I think sometimes people make an assumption that I'm not a capable person because of the vision impairment. There are legitimately certain things that I can't do or are difficult for me to do, but sometimes people make assumptions about things that I can do and things that I can't*.' (F, 42)

'*People have been surprised that blindness, even though it's just legal blindness, is as confining as it is. I think people think that because I can walk up an aisle in church, and go to the third row, and find it, that I can see anything.*' (F, 90)

The second major challenge category, 'Difficulty in social situations due to lack of visual cues' (no. = 42), reflected the experience of finding it hard to interact with others without visual cues for information, and therefore not being able to interpret social situations correctly and respond accordingly. Participants responded feeling at a loss for how to interact with others, having lost the visual information accompanying the spoken language that would otherwise help direct and structure social exchange. It should be noted that difficulty due to lack of visual cues was also the more common of the two broad challenge categories described, and refers to an internally based challenge caused by factors directly derived from the functional disability. The following quotes serve to characterize this challenge:

'*It totally changed. With this vision impairment – without being able to see people, the way of*

*flattery – I can't reciprocate compliments . . . Having no eye-contact and no verbal cues – can't really assess what's going on behind the scenes.*' (F, 48)

'*I can't see their features, whether they're smiling or scowling . . . I don't know how to react to them.*' (F, 85)

'*It's very hard to talk to people if you don't see them. It's very hard to make conversation.*' (M, 86)

Figure 1 suggests that these two challenges may be interrelated, with both contributing simultaneously to negative relationship experiences. This view is based on the finding that in some of the quotes, components of both challenges seem to be intertwined in how they contribute to relationship difficulties, resulting in others' misinterpretations of the person's vision-impaired behaviour. The following sample quotes illustrate this phenomenon:

'*Sometimes I don't recognize people. They pass me by and if I say hello, I say hello and if not . . . . Friends often think I am stuck up.*' (M, 85)

'*People might think that because you can't see, you're shunning them. I can't recognize them – can't relate to them at all . . . . Before, you could see them and say, how are you doing? Now they think you're shunning them.*' (M, 57)

'*It's difficult. When lots of people are talking, you can't keep up. Misconstrue things. If someone passes me by – says "how you doing?" I don't realize that they are on a cell phone. People think you're nuts.*' (M, 42)

## Strategies

Participants' responses to both types of relationship challenges could be classified into two main response directions. In addition, within these two response categories, participants reported specific strategies.

One main response direction was to find ways to 'readjust one's own behaviour with the goal of maintaining relationships' (no. = 26). Participants who voiced this response appeared to value the continuation of their social interactions to the extent that they were willing to alter their own actions in order to compensate for their

vision-related challenges. One strategy in this category was to become more outgoing in actively explaining the nature of the vision impairment to others, and also being more assertive in all interactions:

'*People might think that I am being unfriendly . . . the situation will come up where I explain to them . . . so if anybody raises the question, you didn't say hello to me, I will just explain to them the reason why.*' (M, 78)

'*I'm more outgoing now. I tend to introduce myself to people first. I feel like if I don't do that, I would get ignored. I think sometimes people don't know how to deal with someone with a disability, so now I tend to take the first step.*' (F, 42)

Another strategy was to try to rely more on other senses, such as hearing, or other sources of information to compensate for the vision loss:

'*I came from a culture of "see with your eyes and not with your hands," but being blind has allowed me to explore my sense of touch.*' (F, 48)

'*It's changed a little. I can't relate to people because I can't tell who they are and where they are. Now I got to rely on my hearing.*' (M, 58)

In addition, there were also instances of faking one's way through a social interaction in order to make sure that the interaction is not interrupted or discontinued:

'*I just – sometimes you know you just fake it. Someone talks to you as if they know you . . . so I respond the same way, you know I just do what I can at the moment to enjoy what's happening.*' (F, 77)

'*Maybe I cheat a little bit that I'm actually not seeing what I would like to see. They may show me something and I'll agree that I see it, but I may not see it the way I would like to see . . . that's what I mean by cheating.*' (M, 82)

And last, some participants described being more selective when it came to pursuing social relationships:

'*I became much closer with some friends, and I eliminated a lot of acquaintances because of*

the vision. I got closer with some friends. So my circle is much smaller because of the vision. You can't bother with everyone now, you know. Just the important ones.' (M, 60)

The other main response direction in which responses developed was to simply 'let relationships go or turn sour' (no. = 32). Participants who voiced this response appeared to find their vision-related challenges so difficult that pursuing and maintaining relationships no longer seemed worth the effort. One specific strategy of letting relationships go was to withdraw socially or avoid situations that could bring about such vision-related social challenges, as illustrated by the following:

'*I don't like being around people anymore, I can't see them anyway. The ways I relate to other people have changed – I just don't talk to them as much.*' (F, 64)
'*You withdraw, you stay to yourself- you do a lot more listening and try to keep yourself occupied.*' (M, 42)

The other strategy consisted of getting angry and telling people off, suggesting that these participants did not expend personal resources to adjust their own behaviours; rather, they expressed their aversive feelings about their difficulties in the social context and let their relationships turn sour, as expressed by the following sample quotes:

'*If I can't see what someone else's eyes are telling me, that really affects how you relate . . . . If someone says something that I interpret a certain way, and I respond sarcastically and it offends them, then that's just too bad. I let it go. I don't care. It's just too bad for them.*' (F, 29)
'*I got more cranky with people. I don't trust people..*' (M, 56)

## Discussion

The study findings provide important qualitative insights into the relationship challenges faced by

adults across the lifespan due to their vision impairment. Building on prior research that demonstrated the presence of negativity in social relationships in this population,[8,11] the present study identified potential relationship-related challenges faced by this population, as well as potential strategies employed by this population to deal with these challenges. Two key challenges emerged: one related to the lack of visual cues and the other related to a lack of understanding from others about the implications of having a vision impairment. In addition, it was found that responses to these challenges were oriented either toward maintaining relationships or letting them go and turn sour. These findings are important because the impact of vision loss on relationships is an under-addressed area in vision rehabilitation,[7] although it is an area of great importance,[12] and addressing relationship-related challenges ought to be an integral part of rehabilitative programming for individuals with vision loss across the lifespan. Thus, rehabilitation should not only focus on functional challenges but should treat the person more holistically by addressing social challenges as well.

Study findings also provide material to guide such an effort. For example, during an initial assessment of rehabilitation needs, the rehabilitation professional could explore if the type of challenges identified in this study pose a problem for particular individuals, and if so, discuss how these challenges could be specifically targeted. Moreover, since participants' narratives demonstrated that, in some cases, the functional and relationship challenges are intertwined, it may be important to be sensitive to the possibility that both challenges need to be addressed together in an integrated way. In a next step, the person's response to such challenges could be identified. Rehabilitation could involve efforts to teach readjustment strategies that help maintain relationships as well as help reduce withdrawal responses, given the well-documented health benefits of being socially integrated.[18] The present study provided some examples of such responses that can serve as a pool of possible adaptive strategies. The development of personal strategies that

are constructive in terms of relationship maintenance is something that could be facilitated in the context of rehabilitation. Future research should test the feasibility and value of such an intervention model.

Our study was limited by the exploratory approach taken with the data. Although providing valuable grounded insights into the negative interpersonal effects of vision impairment, the qualitative and descriptive nature of the data did not allow us to comment on the relative frequency of these experiences in the population or to provide statistically viable findings. However, this study does use a relatively large sample size for qualitative research, and represents the first study in this field that aims to qualitatively understand the relationship-related difficulties and responses of persons with vision impairment. Because this study used a secondary data analysis on previously collected data from two separate studies, there were slight differences in the method of data collection; however, these differences were minor in nature and did not affect key aspects of the study, such as functional vision loss in the sample or how the key interview item was asked. Last, we assessed retrospectively perceived challenges and responses, an approach that always deals with accuracy of memory.

In a next step, future studies can employ research designs that would permit analysis of the effects of individual differences (e.g. gender, ethnic background, previous life events and experiences) on the use of different strategies and their effectiveness. Multi-methodological approaches that incorporate both quantitative and qualitative methods could be particularly effective in understanding the specifics by which these processes occur. In addition, an important approach to further research on these relationship-related challenges is to look at both sides of the social interactions (e.g. the person with visual impairment and their family members) to fully understand the social dynamics that are occurring.

Another avenue for future research is to examine the impact of vision loss and related disability on relationships over time. Many people who experience vision loss during adulthood face an increase in disability over time due to the progressive and irreversible nature of many eye diseases.[19] Do relationship-related challenges change with varying levels of disability, and if so how? Do those who engage in strategies that help maintain relationships succeed in ultimately reducing or eliminating the challenge, or is it more a matter of learning how to live with it best? These are important questions to be addressed in future work. Furthermore, it would be beneficial for future research to explore on a larger scale what exactly are the typical challenges and strategies of this population, which can be informed by the qualitative information presented in the current study. The insights provided by the present study and future research in this direction are highly relevant for informal network members (i.e. family and friends). A better understanding of potential challenges that those with vision loss face in relating to others, and how they might respond adaptively to these challenges, can help facilitate social interactions for all involved.

While some of the themes we identified are unique to visual disability (e.g. difficulty due to a lack of visual cues), there may be some similar challenges and strategies for people with other disabilities. For example, people with other disabilities may also find difficulty in social situations due to a lack of understanding from others. These difficulties may also come in a different form depending on the disability. For instance, research with hearing impaired older adults has suggested that hearing loss impairs linguistic communication which is related to lower levels of social engagement.[20] People with hearing loss may have social difficulties due to a lack of audio cues that may impact the reconnecting process in addition to causing other unique problems. The strategies for dealing with relationship-related difficulties could be similar across disabilities, such as being more assertive and explaining oneself more, or even withdrawing from people. Future research should study the issue of relationship-related challenges and strategies in people with other disabilities, to see if the core of the present findings can be replicated in other groups.

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