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Social Support and Well-being in Adults Who Are Visually Impaired

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Abstract: This study explored multiple aspects of social support and their links to the well-being of working-age adults with visual impairments. Instrumental help from family members was the most frequent type of positive support that was received, and underestimation of the participants' capabilities was the most frequent type of negative support that was received. Less-optimal well-being appeared to be linked with experiencing a lack of support and with receiving only negative support.

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Living with a chronic disabling condition often entails relying on family members and friends for help with, for example, certain instrumental tasks and emotional support. For some time, researchers have recognized the potential positive impact of such types of support on the lives of people with chronic conditions. Only fairly recently have they recognized that social support can also have negative facets, such as anger or hostility, which may have an adverse impact on the lives of individuals who are chronically impaired. Because social support can have both positive and negative facets that coexist in an individual's social environment, the literature has discussed the following overarching types of social support: positive social exchanges or positive support (generally considered to be helpful types of support) and negative social exchanges or negative social support (generally considered to be unhelpful types of support) (see, for example, Antonucci, Lansford, & Akiyama, 2001; Diehl & Willis, 2003; Ingersoll-Dayton, Morgan, & Antonucci, 1997; Rook, 2001) .

Conceptualizations of positive social support distinguish between the actual receipt of support and perceived support, which refers to the belief that support will be available if needed (Okun & Keith, 1998). Both received and perceived support have been further categorized in terms of instrumental, emotional, family, and friend support. Instrumental support, also referred to as tangible support, is defined as getting help with tasks of daily living, and emotional support is sometimes referred to as affective support (Kahn & Antonucci, 1980).

In contrast, negative social exchanges or negative support, also referred to as social negativity, negative social ties, social strain, social conflict, social undermining, and social hindrance (Finch, Okun, Pool, & Ruehlman, 1999), encompass such exchanges as interference, demands, insensitivity, criticism, anger, hostility, and impatience (Ruehlman & Karoly, 1991). Overprotective attitudes by providers of support have also been labeled as social negativity (Diehl & Willis, 2003). Vinokur and van Ryn (1993, p. 350) defined social undermining as "behaviors directed toward a target person that (1) display negative affect (anger or dislike), (2) display negative evaluation of the person in terms of attributes, actions, and efforts (criticism), and (3) make difficult or hinder the attainment of instrumental goals."

Research has shown that positive types of social support, particularly perceived and received emotional support and perceived instrumental support, have beneficial effects on the well-being of individuals and promote successful adjustment to stressful life conditions, such as a chronic visual impairment (Cohen, 1992; Hobfoll & Vaux, 1993; Reinhardt, Boerner, & Horowitz, in press; Sarason, Sarason, & Gurung, 1997). The receipt of support with instrumental tasks, however, tends to be either unrelated or negatively related to variables of well-being (Kaul & Lakey, 2003; Lakey & Lutz, 1996; Reinhardt et al., in press). Thus, the perceived availability of support and received affective support, not received instrumental support, seem to have the most positive impact on mental health and the ability to adapt to a chronic impairment.

The receipt of instrumental support may have a negative association with well-being and the ability to cope with stressful life conditions because receiving this type of support can lead to a lack of reciprocity and an unbalanced exchange between providers and recipients of support that can lead to negative exchanges between them (Oxman, Freeman, Manheimer, & Stukel, 1994; Wortman & Conway, 1985). Thus, the study of negative support seems to be particularly important when it comes to stressful life conditions, such as a chronic impairment, in which a person may have to depend on social support to accomplish basic daily needs. However, compared to the bulk of research on positive support and chronic impairment, there have been few studies on the phenomenon of negative support in this context.

Research that has been conducted in the area of negative support has demonstrated that negative social exchanges have a detrimental impact on mental health (Hirsch & Rapkin, 1986; Jackson & Lawson, 1995; Reinhardt, 2001; Rook, 1984) and exacerbate the adverse effect of the stressor when a person is faced with a stressful life condition (Dunkel-Schetter & Wortman, 1982; Manne & Zautra, 1989; Stephens, Kinney, Norris, & Ritchie, 1987). For instance, overprotective attitudes by providers of support have been found to be associated with higher levels of depression in stroke and cancer patients (Kuijer et al., 2000; Thompson & Sobolew-Shubin, 1993) and negatively affect adjustment to age-related vision loss (Cimarolli, 2002).

More specifically, regarding the provision of support to an adult who is visually impaired, both the clinical and empirical literatures have pointed to the fact that family members and friends of visually impaired adults struggle with a number of issues. Providers of support sometimes have overprotective attitudes and behave overprotectively toward older adults with visual impairments because of the safety issues that arise in the context of visual impairment (Horowitz et al., 1998). There is also evidence that they are unclear about their helping behaviors (that is, knowing when to help, how to help, and how much to help) and about the capabilities of the visually impaired persons to whom they are providing support (Crews & Frey, 1993; Horowitz et al., 1998; Horowitz, Goodman, & Reinhardt, 2004). Moreover, some family belief systems may downplay the seriousness of the disability and may lead to unrealistic expectations of a person's capabilities (Plopper, 1990; Silverstone, 1984).

Thus, preliminary evidence shows that the types of negative social support that are faced by adults who are visually impaired may go beyond existing notions of negative social support. Research on negative social support has, for example, only recently recognized that overprotection is a manifestation of negative social support (Cimarolli, 2002; Diehl & Willis, 2003). However, it appears that this type of negative social support is particularly relevant in this population. There may be other facets of negative support that are germane to this population that have not yet been uncovered. Therefore, future research, including research that uses open-ended questions to elicit narrative responses, is needed to explore the phenomenon of negative support in this population, with the ultimate goal of elaborating and refining the definition of negative support.

The implications of support receipt, negative or positive, may also be a function of the point in life at which a person has to depend on the support. Problematic issues around social support and the effects of positive and negative social exchanges on mental health have been studied predominantly in the population of older adults with chronic illnesses. Little is known about the perceptions of young and middle-aged adults with visual impairments regarding the receipt of positive and negative support and its relation to well-being. Studying social support in these age groups is especially important because young and middle adulthood are periods when most individuals achieve important milestones. During early adulthood, for instance, individuals typically strive to get an education, find an occupation, select a partner, and start a family. And in middle adulthood, many individuals strive to maintain their careers, meet the demands of parenthood, nurture their marriages or relationships, and manage their households (Nurmi, 1992). Being confronted with visual impairment and its negative impact on functional ability is likely to lead to interference with a person's involvement in these life domains, but being subjected to negative types of social support that exacerbate the impact of a disability may further interfere with a person's involvement in these life domains. Moreover, to design vision rehabilitation service programs for young and middle-aged adults that address aspects of support that may have negative effects on mental health and hinder successful rehabilitation outcomes, more insights need to be gained on how negative social support is specifically manifested in this younger population.

The purpose of the study reported here was to explore accounts of received positive and negative support reported by a sample of young and middle-aged adults with visual impairments and to establish, in a descriptive manner, possible links between positive and negative types of support that are received and indicators of psychological well-being. In particular, this study sought to identify the different facets and patterns of negative support that may occur in this population and to arrive at some preliminary recommendations about how to address problematic occurrences of social support in the context of vision rehabilitation programs.

Method

Participants

The participants in this cross-sectional study were recruited from a pool of 154 visually impaired adults aged 22–64 who had been first-time applicants at a vision rehabilitation agency serving the greater New York metropolitan area. All potential participants were experiencing significant visual impairment and had their cases closed at the agency prior to contact. Case closure at the agency occurs either after the completion of recommended vision rehabilitation services or before then, such as when an applicant loses interest in receiving services, becomes too ill, or could not be contacted again once the referral information was taken. Therefore, some of the individuals in the pool of first-time applicants from which the study population was drawn had received services, whereas others had not. Other criteria for inclusion were the onset of the visual impairment at 18 years or older, living in the community, fluency in English, and the absence of cognitive or hearing deficits that could interfere with the telephone interview.

Forty-three of the 154 individuals could not be reached even after numerous attempts, 7 were deceased, 86 participated in the interviews, and 18 declined to participate, resulting in a response rate of 83% (based on those who participated and those who refused to participate). Since all potential participants were applicants to a vision rehabilitation agency and demographic information from their case records was available, analyses could be conducted to compare the participants, those who refused to participate, and those who could not be contacted along several demographic variables (age, gender, race, and age at onset of the visual impairment). There were no significant differences among the groups on any of these variables. Data for this study were collected by trained interviewers through telephone interviews that lasted approximately 30 minutes.

Of the 86 participants aged 24–64 (*M* = 52, *SD* = 9.9), 45% (*n* = 39) were women, and of the 83 who reported their race, 49% were white (*n* = 41), 32% were African American (*n* = 27), 13% were Hispanic (*n* = 11), and 5% were of other races (*n* = 4). The reported onset of vision impairment ranged from .17 to 15 years (*M* = 4.1, *SD* = 3.4). The majority (73%) reported an onset within the past 5 years (*n* = 63), and 27% reported an onset between 5 and 15 years (*n* = 23). Sixty-three participants (73%) reported that they had received some type of vision rehabilitation service.

Measures

The interview included questions on basic demographic characteristics, specifically questions to assess age, gender, and race, and questions related to the participants' vision to assess the onset of functional vision problems and whether or not vision rehabilitation services had been received.

Social support.

To assess social support received (both positive and negative) the following two open-ended questions were asked:

1. "People often get help and support from their family members, friends, and neighbors. They get help with everyday tasks, such as getting rides or running errands, and emotional support, for example, having someone to talk to. Thinking about your social support system, could you please

describe aspects of the support you are currently receiving that you consider helpful to you and that you view as positive?"

2. "Although the people who are close to us can be helpful, they can also make us angry or upset at times, for example, by assisting us with things we could do ourselves or by providing too much help. Could you please describe aspects of your social support system that are not helpful to you or that upset you?"

The interviewers were instructed to use the following probe: "Can you please tell me more about this?" whenever a response seemed short or unclear.

Depressive symptomatology.

Depressive symptomatology was measured with the 10-item Center for Epidemiological Studies Depression Scale (CES-D), a short version of the widely used original 20-item CES-D (Radloff, 1977). Factor and reliability analyses have indicated that scores from this short version have psychometric properties that are comparable to those of the original (Kohout, Berman, Evans, & Cornoni-Huntley, 1993). Participants indicate whether (1) or not (0) they experienced 10 different symptoms of depression over the past week. The potential range of the scale is 0–10. Reliability analyses of the present data showed that the Cronbach's alpha of the short version of the CES-D was .80.

Life satisfaction.

Life satisfaction was assessed with the 5-item Satisfaction with Life Scale (SWLS; Pavot & Diener, 1993). The SWLS is designed to assess a person's global judgment of life satisfaction. Participants are asked to rate their agreement or disagreement with statements concerning their life circumstances on a 5-point scale (1 = strongly disagree to 5 = strongly agree). Scores on the scale can range from 5 to 25. Reliability analyses of the present data produced a Cronbach's alpha of .82 for the SWLS.

Plan of Analysis

The first stage of the data analysis entailed the development of a coding system for the two open-ended questions about social support. Two independent coders reviewed the narrative responses of the first 20 participants to generate codes that reflected common themes. After the coders agreed on this initial set of codes and clarified the codes' definitions, the narratives of the next 10 participants were used to establish interrater agreement between the two coders. The interrater agreement for this first round of coding was close to 60% for both open-ended questions. On the basis of this first round, the coding system was refined. The remaining rounds of coding all produced interrater agreements of at least 80% for both questions.

Next, descriptive analyses were conducted to identify the frequency of occurrence of the different support categories that had emerged from the prior step of narrative coding. In a final step, patterns of combinations of support received—"positive support only," "negative support only," "negative and positive support," and "no support"—were determined, and mean differences on the two indicators of well-being (depressive symptomatology and life satisfaction) were explored among the groups.

Results

Positive support

Seven participants reported that they did not receive any type of positive social support. Furthermore, although the support questions were designed to elicit participants' accounts of the informal support they had received, 13 participants (17%) reported receiving formal assistance, such as instrumental help by a home attendant or emotional support through a support group, and 7 participants described the perceived availability of support. The remaining participants' accounts of positive social support received yielded five distinct categories that are listed in Table 1 with quotes to illustrate the nature of each and their frequency of occurrence. The most frequent type of social support was instrumental support received from family members, followed by emotional support received from family members, received instrumental support from friends, and received emotional support from friends. The frequencies also illustrated that family members were relied upon as the most prominent source of social support, with 83 reported instances of support received from family members versus 53 reported instances of support received from friends. Regarding the type of support received, the participants received instrumental support more frequently than emotional support (75 instances of instrumental support versus 62 instances of emotional support).

Negative support

About 33% of the participants (*n* = 28) reported that they did not have any types of negative social exchanges with members of their networks. Of these 28, 23 participants said that negative social exchanges simply did not occur between them and their providers of support. One participant reported that social network members were not close enough to have negative exchanges; one reported that negative exchanges happened in the past, but that he or she learned to accept these issues; and the remaining three reported the lack of desired support as negative support received from family members and friends.

Categories that emerged on the basis of the narratives of participants who reported having negative exchanges with their social networks are displayed in Table 2, including frequencies and quotations to illustrate the codes. The most frequently reported type of negative support was "Social network underestimates my capabilities," followed by "Social network doesn't understand my need for personal independence," "Conflict with social network members," and "Social network underestimates my limitations." Thus, in addition to conflict, hostility, or anger—manifestations of negative social support that were most often studied in the past—the provider's lack of understanding of the impact of visual impairment on the recipient of support emerged as a central issue for these chronically impaired adults.

Interplay of positive and negative support

In the next analytical step, categories were formed that combined positive and negative exchanges. It should be noted that the participants who reported formal support in combination with other types of support ($n = 13$) and those who reported perceived support in combination with other types of support ($n = 4$) were excluded from this analytical step. In addition, one participant who refused to answer the question on negative support was also excluded.

First, two variables were created, one for positive support received (yes or no) and one for negative support received (yes or no). Then the different combinations of support received were considered for the remaining 68 participants, resulting in four combination groups. The most frequent combination that emerged was "positive and negative support combined" ($n = 40$, 59%), followed by "positive support only" ($n = 20$, 25%). Five participants received negative support only (7%), and three received no support (4%).

Next, the mean plots of the four support groups for the two indicators of well-being, depressive symptomatology and life satisfaction, were examined to determine descriptively the differences between the combination groups on these two outcome measures. An examination of the mean plots for depressive symptomatology (see Figure 1) revealed that the "no support received group" reported the highest means for depressive symptomatology (*M* = 6.3), followed by the "negative support only" group (*M* = 5.8). The "positive support only" group reported the lowest levels of depressive symptomatology (*M* = 2.6), and the "negative and positive support combined" group reported the second lowest levels (*M* = 3.8). An examination of the mean plots for life satisfaction (see Figure 2) showed that the "positive support only" group had the highest mean levels (*M* = 17.4), followed by the "positive and negative support combined" group (*M* = 13.4), and the "no support" group (*M* = 11.3). The "negative support only" group reported the lowest levels of life satisfaction (*M* = 9.8).

Discussion

This study, designed to explore accounts of both positive and negative support received by young and middle-aged adults with visual impairments, found that these adults more often relied on family members than on friends for help with both instrumental tasks and received emotional support. Thus, family members seemed to be the main source of positive support for these participants. Moreover, the results showed that with regard to positive support, the receipt of instrumental support seemed to be generally more prevalent in this group than the receipt of emotional support.

The results for negative support suggest that the receipt of negative support is a fairly prevalent phenomenon in this younger population. They also yield insights into a type of negative support that appears to be specific to the population of adults with visual impairments, namely, negative social support stemming from the fact that providers of support lack an understanding of both the functional and psychological impact of vision loss. This lack of understanding seemed to manifest itself in an underestimation of the visually impaired person's capabilities and functional limitations and may be due to an insufficient understanding of what the person who is visually impaired actually can or cannot see, since most eye diseases that cause low vision are associated not with a total loss of vision, but with a partial loss of vision. Therefore, it may be confusing for providers of support that a person who is visually impaired can accomplish certain tasks that require vision, but is unable to accomplish other tasks that also require visual input.

The general lack of understanding of the impact of vision loss may also include an insufficient understanding of the need for personal independence by the visually impaired recipient of support. This lack of understanding may occur because, as Horowitz (1997) pointed out, significant others of persons who are visually impaired and society in general have internalized negative stereotypes about the helplessness of people who are visually impaired and, as a result, often accept and promote these individuals' dependence. The lack of understanding of the impact of vision loss may even increase after the visually impaired person receives vision rehabilitation services because the primary objective of these services is typically to help a person maintain or retain maximum functional independence. Family members and friends who were not part of the intervention may find themselves "out of sync" with this goal because they were not exposed to a critical element of this adaptation process.

The manifestations of negative social support described in this study may also be classified as overprotective provisions of support, which have been viewed as a form of inducement of dependence, characterized by an underestimation of the recipient's capabilities. These provisions manifest themselves in unnecessary help, excessive praise for accomplishments, and attempts to restrict activities (Avorn & Langer, 1982; Hyman, 1971). Studies of older adults have shown that overprotection by family members was associated with depression (see, for example, Thompson & Sobolew-Shubin, 1993) and hindered the successful adaptation to age-related vision loss (Cimarolli, 2002). In addition, overprotective attitudes and overhelping behaviors have been found to hinder positive rehabilitation outcomes in older adults (Bolger, Foster, Vinokur, & Ng, 1996). The results from the present study suggest that overprotection as a problematic type of negative support may also be a problem for young and middle-aged adults with visual impairments. Using Vinokur and van Ryn's (1993) definition of social undermining, one could argue that the provision of overprotective support falls into the broader category of negative support that hinders the attainment of instrumental goals. For instance, a visually impaired adult who wants to learn how to use a cane to be able to walk independently will not be able to achieve this goal if the provider of support insists on guiding the person whenever he or she is walking on the street.

Descriptive results on the relationship between types of support received and well-being suggest that individuals who report no support and those who report only negative support may experience less-optimal well-being than may those who report only positive support and those who report receiving a combination of positive and negative support. This finding, although descriptive, confirms the findings of previous research on the detrimental impact of social negativity on psychological well-being (see, for example, Reinhardt, 2001; Rook, 1984). However, the finding could also support the findings of research on personality traits and negative support. Finch et al. (1999), for instance, found that individuals who scored high on neuroticism were more likely to report more negative social interactions and to be depressed. In contrast, individuals who scored high on the personality trait of agreeableness were less likely to report negative social interactions and to be depressed. The authors concluded that individuals who are agreeable may interpret their social interaction with other people more positively and therefore report less negative social interactions as well as depression.

The present study was explorative in nature, with open research questions, a relatively small sample size, and vastly descriptive analytical methods. In addition, since the number of young adults (n = 19) who participated was relatively small, the study did not allow for comparisons between young and middle-aged adults. Furthermore, because of the small sample size, analyses of information on who specifically is providing support (such as a spouse or partner, parents, friends, or neighbors) and the relationship between the source of social support and well-being could not be conducted. Thus, future research is needed to address these aspects with a larger-scale, systematic study. A larger-scale study will allow for the use of a more advanced methodology and will enhance the generalizability of future findings on the effects of both positive and negative support on the well-being of young and middle-aged adults with chronic impairments. However, the findings did identify and illustrate facets of negative support that may have unique relevance for adults who are facing vision loss and therefore allow some preliminary recommendations for how issues related to negative social support could be addressed as part of the rehabilitation process.

Recommendations for vision rehabilitation practitioners

Psychoeducational support groups may be best suited to address the negative types of social support that involve underestimating capabilities, underestimating limitations, and failing to understand a visually impaired person's need to be independent. These support groups, which can consist either of providers of support only or both the providers and recipients of support, could include a curriculum to inform the group about different types of visual impairment and their implications. For instance, the use of vision simulators could facilitate a better understanding of specific types of vision loss and their differential effects on functioning. In this context, providers and recipients of support could also learn that misunderstandings about support, such as what kind of support is helpful or unhelpful or what a person can or cannot see, are common.

In addition, support groups may provide a framework for the ways in which communicating about these issues can be discussed. There is some evidence that support groups with the foregoing suggested curriculum are effective and thus may be helpful to younger adults with visual impairment. Specifically, an evaluation of a support group program for partners of older adults with visual impairments demonstrated several significant changes after the individuals participated in the program, including increased knowledge about what the partner with a visual impairment can see and do, as well as greater certainty about when, how, and how much to help, and an improvement in the quality of communication between the partners (Cimarolli, Sussman-Skalka, & Goodman, 2004).

Other facets of negative support that are likely to reflect more general aspects of the relationship, such as conflictual exchanges or concerns about the provider of support neglecting himself or herself, could be addressed in a counseling-type setting that should include both the recipient and provider of support. Finally, on the most general level, the findings of this study could serve to raise awareness among vision rehabilitation professionals about the phenomenon of negative support and its potentially detrimental effects on the well-being and adjustment of adults who are visually impaired. This alone would be an important step because service providers, who often work closely with family members and sometimes friends, as well as with individuals who are visually impaired, may be in the best position to identify and find ways of addressing problems that are related to support in the course of rehabilitative interventions.

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