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"Program for Partners": Support Groups for Partners of Adults with Visual Impairments

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Abstract: This study of time-limited support groups attended by partners of individuals with visual impairments found that participation increased the attendees' knowledge of their visually impaired partners' situations, improved the quality of communication between the partners, and reduced the sighted partners' negative appraisal of their role.

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Family members play a crucial role in facilitating individuals' successful adjustment to vision loss by understanding the limitations caused by a vision loss (Horowitz, Reinhardt, McInerney, & Balistreri, 1994) and providing emotional support (Reinhardt, 2001). High levels of emotional support from family members can also facilitate successful vision-rehabilitation outcomes (Moore, 1984), such as the successful use of low vision devices (Greig, West, & Overbury, 1986). Furthermore, family members' involvement in rehabilitation programs can significantly reduce the number of problems resulting from vision loss, such as embarrassment and burden (Dumas & Sadowsky, 1984), and increase the number of social activities that the relatives who are visually impaired (that is, are blind or have low vision) engage in over time (Horowitz et al., 1998).

Although any family member can become a caregiver to a relative, spouses or partners (hereafter "partners") of individuals who are experiencing crises, including older adults who are ill or disabled (Booth & Johnson, 1994; Cantor, 1983; Cantor & Brennan, 2000), are frequently the first choice for providing social support and primary care (Beach, Martin, Blum, & Roman, 1993; Burke & Weir, 1977; Cantor & Brennan, 2000). However, a disabled partner's increased need for support, such as help with daily activities or emotional support, can lead to a lack of reciprocity in the relationship, which can create a source of conflict between the partners and lead to distress for both

(Cutrona, 1996) and discord in the partners' relationship (Bernbaum, Albert, Duckro, & Merkel, 1993; Melton, Hersen, Van Sickle, & Van Hasselt, 1995). The lack of equity in the relationship may cause major distress for the recipient of care and even greater distress for the provider of care (Walster, Berscheid, & Walster, 1973), since chronic illness and disability can have a more negative impact on the healthier, nondisabled partner than on the disabled partner in areas like mental health and marital satisfaction (Melton et al., 1995). For individuals who are experiencing stressful medical conditions, negative types of social exchanges, such as anger or hostility, can exacerbate the adverse impact of the conditions and impede their ability to cope (Dunkel-Schetter & Wortman, 1982; Manne & Zautra, 1989; Stephens, Kinney, Norris, & Ritchie, 1987).

Support groups—that is, small groups of individuals who meet to cope collectively with their unique challenges, both physical and psychological—are one way to help consumers of mental health and rehabilitation services and their relatives deal with the stressors that are associated with disabilities and other chronic conditions (Davison, Pennechaker, & Dickerson, 2000). Research on the effectiveness of support groups for caregivers of chronically ill adults may shed light on the potential benefits of such groups for sighted partners of adults with visual impairments. A number of benefits have been cited that caregivers may gain from attending such groups. Those who attended support groups were better able to cope with the caregiving-related stress than were those who did not (Knight, Lutzky, & Macofsky-Urban, 1993; Toseland, Labrecque, Goebel, & Whitney, 1992; Toseland, Rossiter, Peak, & Smith, 1990), and, over time, their subjective caregiving burdens and stresses were significantly reduced (Labrecque, Peak, & Toseland, 1992; Toseland et al., 1992; Ostwald, Hepburn, Caron, Burns, & Mantell, 1999). The quality of life of caregivers who attended support groups improved, and caregivers evaluated their roles as being less difficult (Mohide et al., 1990); thus support groups reduce both personal and role strain (Whitlach, Zarit, & von Eye, 1991). In addition, support groups have been found to be educational and informational, as well as generally helpful (Kaasalainen, Craig, & Wells, 2000; Toseland et al., 1992). The purpose of this study was to evaluate support groups for partners of adults with visual impairments, with the goals of alleviating stress and burdens, improving the sighted partners' understanding of the issues faced by the visually impaired partners, and enhancing the partners' quality of communication regarding these issues.

Method

Participants

The participants were 32 individuals, aged 46–86 (average age, 69) who were living with partners with visual impairments for an average of 40 years. Of the

32 participants, 53% (*n* = 17) were women and 91% were Caucasian. The majority (75%) had an education beyond high school, 22% were high school graduates, and 3% had less than a high school education. In addition, 66% of the participants were retired, 28% were working, and 6% were either unemployed or homemakers. The participants' partners were diagnosed with a variety of eye diseases, including macular degeneration (31%), cataract (22%), and retinitis pigmentosa (19%). These couples had been dealing with vision problems for an average of 3 years (range: 6 months to 20 years).

Support group intervention

The first phase was the development of a discussion-guide curriculum on the basis of input from focus-group meetings held with both visually impaired adults and their sighted partners (Sussman-Skalka & Cimarolli, 2002). The topics that were covered in the guide were Getting Acquainted: Partners Share Concerns and Issues, Understanding Your Partner's Vision Loss, Exploring Emotional Issues, Communication Between Partners, Organizing the Home for Accessibility, Safety and Comfort, Getting Around Safely, Garnering Support from Family and Friends, and Managing Change and Dealing with Stress.

The participants were recruited using a variety of methods: from organizations that serve people with visual impairments and their family members (vision rehabilitation agencies or low vision clinics), direct mailings to consumers, and flyers and newspaper advertisements announcing a time-limited support group program for partners or spouses of people with visual impairments. A total of four support groups for 33 partners (32 of whom agreed to also participate in the evaluation), led by a facilitator, were implemented in New York and New Jersey over the course of about one year. The following four support-group models were implemented to allow for greater participation.

1. Sighted partners' in-person group with two meetings involving their visually impaired partners (using the discussion guide). This group had 10 members and met nine times. Two of the meetings included both the sighted and the visually impaired partners and focused on communication issues and relationships with family members and friends, respectively.

2. In-person group only for sighted partners (using the discussion guide). This group, with 11 members, met nine times. Although it started with monthly sessions, the members requested more-frequent meetings, every three weeks.

3. Sighted partners only by telephone conference call (using the discussion guide). This group met by telephone conference call every two to three weeks. The group had seven members and met for nine sessions.

4. Sighted partners only (self-directed; the members selected the topics). This group was designed as a self-directed group, enabling members to select topics that met their immediate needs and concerns. It began as an in-person group for the first three monthly meetings. Upon the members' request, however, it became a telephone conference call group for the remaining six sessions. The sessions of the telephone group were held every two weeks. The group consisted of five members, several of whom had medical problems. As a result, they found that evening telephone meetings were more convenient than were daytime in-person sessions.

The discussion guide (Sussman-Skalka & Cimarolli, 2002) presents the advantages and disadvantages of the different support-group models and how to implement each one.

Study design

To examine the impact of the support-group intervention, the study used a simple pretest–posttest design. Telephone interviews were conducted with 32 of the 33 participants before the program started, for a response rate of 97% for the preprogram interviews. When the program ended, the participants were contacted again, and 29 agreed to be interviewed, for a response rate of 91%. One person who refused to participate in the preprogram interview agreed to complete the postprogram interview. Four participants who completed the preprogram interviews did not complete the postprogram interviews for the following reasons: one refused, one family member refused for the participant, one could not be reached, and one participant had died. Therefore, 28 partners completed both the pre- and postprogram interviews.

Measures

Each preprogram interview included questions about basic demographic information (age, sex, race, education, and employment status) and about the partner's vision problem (eye disease and duration of the vision problem). Several variables were assessed at both the pre- and postprogram interviews. First, the participants were asked to list the major issues that they were dealing with because of their partners' vision loss. Single-item indicators were used to assess depressive feelings ("How often do you feel sad or depressed?"—from 1 = never to 5 = all the time) and life satisfaction ("All things considered, how satisfied are you with life these days?"—from 1 = not at all satisfied to 4 = very satisfied). Second, the partners were asked to rate their satisfaction with the relationship with their partners on a 4-point scale (from 1 = not at all satisfied to 4 = very satisfied) and to rate their ability to talk openly about stressful situations that arose as a result of vision problems on a 5-point scale (from 1 = never to 5 = all the time).

Third, the participants were asked to rate their level of understanding of what their partners could see and do on a 5-point scale (from 1 = do not understand at all to 5 = understand completely). Fourth, they were asked to rate how sure they were about ways to help, about the amount of help to give, and about when to offer help on a 4-point scale (from 1 = not at all sure to 4 = very sure).

In addition, the Role Captivity Scale (Pearlin, Mullan, Semple, & Skaff, 1990) was administered to the participants. This 3-item scale assesses the sighted partner's appraisal of his or her situation and served as an indicator of how "trapped" the sighted partner felt in his or her role. Role captivity has been associated with caregivers' well-being (Pearlin et al., 1990). A test of interitem reliability (consistency) produced a Cronbach alpha of .69 for the scale, which can be viewed as satisfactory internal reliability.

The postprogram interview included additional questions assessing the participants' subjective evaluations of the program. The participants were asked to rate their satisfaction with the program on a 4-point scale (from 1 = not at all satisfied to 4 = very satisfied) and to indicate, on another 4-point scale, how much the program had helped them function better in their everyday lives (from 1 = not at all to 4 = very much). Finally, the partners were asked to list the ways in which the meetings were helpful.

Analysis of changes from pre-to

postintervention

Because of the small sample size, nonparametric tests using StatXact (Cytel Software Corp., 2000), a statistical software program for small sample sizes, were used to determine whether any significant changes occurred on a number of factors that were assessed both before and after the program. StatXact allows one to test for exact nonparametric statistical inference and, therefore, provides more accurate and powerful tests on small sample sizes than do parametric tests (for example, cross tabulations and *t*-tests, which rely on normally distributed data). Sign tests were run as the appropriate nonparametric statistical tests for ordinal data (Cytel Software Corp., 2000; Pett, 1997), such as pre- to postintervention changes in depression. Wilcoxon signed-rank tests were conducted as the appropriate nonparametric statistical tests for continuous data (Cytel Software Corp., 2000; Pett, 1997); for instance, changes in scores on the role-captivity scale from pre- to postintervention.

Results

Descriptives

A qualitative analysis of the list of major issues that the participants reported because of their partners' vision loss during the preprogram interviews demonstrated that the major issue was a change in responsibilities or the assumption of additional responsibilities (50%). Other issues included having a difficult adjustment to the vision loss (22%), the loss of freedom or not having enough time for themselves (19%), and increased driving (19%).

Regarding the participants' satisfaction with the program, 75% reported that they were very satisfied, 21% reported that they were somewhat satisfied, and 4% reported that they were a little satisfied. The participants indicated that the program had helped them function in their everyday functioning; over 70% noted that the meetings helped them function somewhat better (46%) or very much better (25%), 18% said that the program helped them function a little better, and 11% said that the program had not helped them function better. In addition, the participants described the following ways in which the program was helpful to them:

1. Learning from others how to adapt to the situation and how to cope with different problems (45%).
2. Learning that their situation was not unique (41%).
3. Sharing their situation and opening up to others (27%).
4. Realizing that others are worse off (17%).
5. Learning practical information (17%).

6. Having a chance to vent and complain (14%).
7. Having a chance to get out and socialize (10%).

Changes from preintervention to postintervention

Because of the ordinal nature of the variables, sign tests were run for the following variables: life satisfaction; depression; satisfaction with the relationship; understanding of what their visually impaired partners could see and do; their sureness about ways to help, when to help, and how much help to offer; and the ability to talk openly about issues arising because of the visual impairment. In cases of small sample sizes, the binomial distribution is used to evaluate the sign tests (Pett, 1997), and therefore *z*-statistics were not available. Table 1 presents the means, medians, standard deviations, and *p*-values for the variables that were assessed before and after the program was completed.

The sign tests demonstrated that there were no statistically significant changes in life satisfaction, depression, or satisfaction with the relationship from the pre- to the postprogram interviews, but that there were statistically significant changes in the participants' understanding of their visually impaired partners' vision. The participants' ratings of their understanding of what their visually impaired partners could see ($p = .02$) and do ($p = .006$) significantly increased after they participated in the support groups, as did their ratings of their certainty about ways to help ($p = .001$), when to help ($p = .001$), and how much help to offer ($p = .001$) and their ability to talk openly about stressful situations that arose as a result of the vision problems ($p = .035$).

Wilcoxon signed-rank tests were conducted to examine preprogram to postprogram changes in role captivity and the number of major issues that the couples were dealing with because of the vision loss. The Wilcoxon signed-rank tests were chosen for these variables because of their continuous level of measurement. The results demonstrated a significant decrease in role captivity from pre- to postprogram ($z = –2.46$; $p = .002$), as well as in the number of major issues that the sighted participants reported dealing with because of their partners' vision problems ($z = –2.33$; $p = .011$) (see Table 2).

Discussion

The sighted participants were dealing with major issues and changes in their lives as a result of their partners' visual impairments. The evaluation component of the program revealed several benefits of the support groups. First, the participants' self-report evaluations were positive. Most of the participants stated that their everyday functioning was improved; the support groups made them more knowledgeable about what their partners with visual impairments could see and do and increased their certainty about when, how, and how much to help. Second, the groups improved the quality of communication between them and their visually impaired partners, allowing them to talk more openly with their partners. Finally, at the end of the program, the sighted participants felt less "trapped" in their role and were dealing with fewer major issues related to their partners' vision loss.

That the program had no impact on the participants' well-being, namely, their overall life satisfaction and feelings of depression, is not surprising, since the Program for Partners was developed primarily as a support and educational intervention. The short duration of the program and the fact that the participants rated their well-being as very high at the start of the program may have made it difficult to improve the participants' scores on these variables.

The finding that the program improved the partners' understanding of issues related to vision loss is important because research has pointed to the crucial role of supportive family members and significant others in the adjustment process of individuals with visual impairments. Although the adaptation of the visually impaired partners was not evaluated in this study, ideally, such support groups may also have beneficial effects on the partners with visual impairments. Therefore, support groups for partners offer the prospect not only of alleviating some of the pressures that couples experience, but of promoting more optimal adjustment for the partners who are visually impaired.

In conclusion, support-group interventions, such as the Program for Partners, can ameliorate potential problems between partners when one is sighted and one is visually impaired by providing a venue for expressing and resolving issues that arise. However, evaluations of future support groups for partners of people with visual impairments should also examine the impact of the groups on the adjustment of partners with vision loss, including the impact on psychosocial adaptation and the successful use of vision rehabilitation services.

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