

# Peer Support in the Community: Initial Findings of a Mentoring Program for Individuals with Traumatic Brain Injury and Their Families

**Objectives:** To evaluate the impact of a community-based peer support program for individuals and their family members following traumatic brain injury (TBI). **Settings:** Community-based sample of family members and individuals with traumatic brain injury. **Participants:** Twenty individuals who had participated in the peer support program (11 individuals with TBI and 9 family members). **Main Outcome Measures:** Quantitative and qualitative approaches were used: a retrospective structured interview assessing self-reported impacts of peer support on empowerment, quality of life, mood, skills and knowledge, and social supports; an in-depth qualitative interview with a subgroup of family members focused on the specific benefits/limitations of the peer support program. **Results:** Participants in the peer support program reported positive impacts of peer support on increasing their knowledge of TBI, enhancing their overall quality of life, improving their general outlook, and enhancing their ability to cope with depression post TBI. The peer support program was reported to have had a minimal impact on enhancing social support from families, friends, and the community, with varying impacts noted on levels of happiness, coping with anger and anxiety, communication with professionals, and control over one's life. Qualitative analysis suggests the merits of this type of community-based support and areas of improvement for the peer support program itself. **Conclusions:** Preliminary data suggest that peer support is a promising approach to enhancing coping for both individuals and their family members after TBI. Key words: *families, participatory action research, peer support, self-help, traumatic brain injury*

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THE CENTERS for Disease Control and Prevention estimate that more than 5 million<sup>1</sup> American individuals with brain injuries live in the community, although some studies suggest that this may be a significant underestimate.<sup>2</sup> They and their family members must face the long-term consequences of traumatic brain injury (TBI). Many of these individuals receive minimal information about the long-term challenges of TBI, its impact on

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the family system, and/or information about community-based resources available to assist with maximal adjustment. These individuals often remain socially isolated from other individuals or family members who have successfully adjusted to these often dramatic changes in day-to-day life secondary to TBI—individuals with TBI and their families who could serve as potential sources of mutual support, education, and information.

The lasting toll of TBI has been well documented.<sup>3-7</sup> In addition to cognitive and physical sequelae, individuals with TBI often experience significant depression, anxiety, and reduced quality of life.<sup>5,8-12</sup> The toll on family members of individuals with TBI is also significant, and many family members experience significant emotional distress.<sup>13-20</sup> Ongoing tensions within the family system often result in increased likelihood of breakdown in marital relationships, decreased social contacts, increasing financial strain, altered or reduced job responsibilities, reduced free time, and reduced personal health for family members.<sup>9,19,21,22</sup>

Issues related to successful and unsuccessful coping in individuals with TBI and their family members have been explored in prior research. Successful family coping during the early adjustment period has been associated with obtaining adequate social support and information, involvement in work, attending support groups, use of religion, and involvement in recreation.<sup>23,24</sup> In the later stages of adjustment, strategies that individuals with TBI and their families found useful included maintaining a healthy outlook, participating in a support group, seeking respite, and obtaining information about the long-term consequences of TBI, especially the behavioral and emotional disturbances that may occur.<sup>25-27</sup> Such research sheds light on the interventions that may best facilitate successful coping and long-term adjustment for both individuals with TBI and their families.

The findings reported previously, and the beneficial effects of adequate social support and information in particular, suggest that community-based peer support programs for individuals with TBI and their family members could be a key component of community-based interventions designed to maximize adjustment post TBI. Peer support has been found to be an effective intervention for individuals and family members when faced with other medical illnesses. More specifically, peer support programs have been shown to provide powerful stress-buffering influences for individuals facing medical crises, with the effect of such interventions generally greater than that attributed to formal support services.<sup>28</sup> In addition, peer support programs have been found to have a positive impact on personal sense of empowerment (ie, helping an individual regain a feeling of mastery over his or her family member's medical situation, the environment, and his or her life) and self-efficacy (ie, enhancing the individual's perceptions of his or her capabilities for handling situations).<sup>29-30</sup>

Although support groups for individuals with TBI exist across the country, more individualized peer support after TBI may be potentially beneficial. To date, peer support programs for individuals and families post TBI have been implemented but not evaluated in a systematic fashion. To address this need, a peer-to-peer support program, referred to henceforth as the TBI Mentoring Partnership Program (TBI-MPP), was implemented to address the community support needs of individuals with TBI and their families. To explore the initial impact of the TBI-MPP and develop an empirical basis for the program's evaluation, two pilot studies were implemented: one involved quantitative analysis, and the second involved qualitative analysis. This article presents the findings from these pilot studies.

With the aim of increasing the validity of research findings and empowering

consumers, a paradigm of participatory action research (PAR)<sup>31-34</sup> was incorporated into all aspects of the TBI-MPP. Strengths of PAR include the innovative adaptation of methods for use in a variety of different contexts, exploration of the knowledge and perceptions of community members, involving members of the community as active participants, and facilitating the equitable distribution of power in the process of research so that community members are regarded by themselves and others as being capable of examining and analyzing their own circumstances.<sup>35</sup> In keeping with a PAR model, individuals with TBI and family members were included in the development of the peer training program, the recruitment of individuals into the program, the implementation of support partnerships, the evaluation of program research methods, and the collection and analysis of data obtained from the program itself.

#### **THE TBI MENTORING PARTNERSHIP PROGRAM (TBI-MPP)**

The TBI-MPP, which is still active and funded through 2003, was modeled after the Parent-to-Parent Program (P-to-P)<sup>34,36-38</sup> developed by the Beach Center on Families and Disability at the University of Kansas for parents of children with developmental disabilities. To create a model program of peer-to-peer support for individuals with TBI and their families, the P-to-P program was modified to accommodate the needs of individuals with TBI and their families. In the original P-to-P program, "veteran" parents of children with special needs were matched with parents of newly diagnosed children with similar needs who were seeking peer support. The primary aim of the P-to-P program was to reduce parents' sense of isolation by providing social support and validation of personal experiences by "someone who has been there before."<sup>37</sup> Program evaluation revealed that

the experience of mutual sharing with someone who had experienced a similar challenge was an essential component of intervention success.<sup>37</sup> The process of sharing experiences enabled a special rapport to be established between "veteran" parents and "new" parents through which they could easily express feelings, discuss problems, and obtain emotional and informational support.<sup>34,37,38</sup>

The TBI-MPP was designed to extend this model of support not only to families of individuals with TBI but to the individuals with TBI as well. In the TBI-MPP, TBI "veterans" were matched with individuals with TBI or family members to provide emotional support, knowledge about TBI and resources, and advocacy skills. Unlike the P-to-P program, the TBI-MPP was designed to address both the acute and long-term adjustment needs of individuals with TBI and their family members.

#### **Program structure**

The TBI-MPP was implemented in New York State as a collaborative effort between the Research and Training Center on Community Integration for Individuals with TBI (RTC) and the Brain Injury Association of New York State (BIANYS). The TBI-MPP has five main components: recruitment and training of individuals to provide peer support, recruitment of individuals and family members in need of peer support, creation of mentoring partnerships, technical assistance, and program evaluation. In keeping with the PAR model, the RTC is responsible primarily for program evaluation, whereas BIANYS is responsible for the recruitment of individuals with TBI and family members to serve as "mentors" (who provide peer support) and "partners" (who receive peer support). BIANYS recruited two experienced project coordinators (one "downstate" and the other "upstate") to oversee the clinical administration of the program. One coordinator is a family member of an individual

with a TBI, and the second is an outreach coordinator for BIANYS. The RTC and the BIANYS are jointly responsible for training mentors, ongoing technical assistance for mentors, and program dissemination.

### **Program development**

#### ***Recruitment and training of mentors***

Two consumer advisory groups (Advisory Groups) were convened (one upstate and one downstate) to develop mentor recruitment strategies, plan mentor training, and review program assessment tools. The Advisory Groups consisted of researchers from the RTC, individuals with TBI and family members, the Director of the National Self-Help Clearing House and staff of BIANYS. On the basis of their recommendations, a mentor training manual was developed. The manual was subsequently modified after each training workshop based on feedback from mentors who attended training. (A copy of this manual is available on request from the senior author).

Individuals with TBI and family members of individuals with TBI were recruited as potential mentors through the BIANYS, local professionals, the Advisory Groups, and contacts within the RTC. Multiple criteria were used to select individuals for mentor training. On the basis of phone screening, project coordinators used the following broad criteria to determine the "personal readiness" of potential volunteers to provide peer support to others: (1) a willingness to volunteer time and energy needed to provide support to others in need after TBI; (2) a motivation to "help others" and "give back something" and "be there for people who are where I was"; (3) successful personal adjustment to the challenges of living with a TBI; (4) adequate insight into personal limitations and strengths; (5) an absence of current serious psychiatric problems; (6) an ability to listen and empathize and (7) an abil-

ity to inhibit personal responses and views or opinions when necessary.

A series of eight full-day mentor training workshops was held (both upstate and downstate) over the course of the first 2 years of the project. At these workshops, mentors received training focused on enhancing their communication, listening, and advocacy skills and increasing their knowledge of TBI and community resources. Because most communication between partners and mentors is by telephone, training emphasized communication skills using this modality. All mentors received reimbursement for transportation and other out-of-pocket expenses incurred as a result of the training itself. In addition, mentors are paid \$25 for completion of program evaluation research interviews and questionnaires, some of which were completed during the training. Mentors volunteer their time for ongoing mentoring activities and are not paid for these services; they are, however, reimbursed for long distance telephone expenses incurred as part of mentoring.

A subgroup of mentors received additional training in hospital advocacy skills to play a more active role in recruitment of partners for the TBI-MPP. The mentors called themselves the Hospital Advocacy Teams (HAT). The HAT teams conduct ongoing visits to local community settings and distribute information about BIANYS and the TBI-MPP itself and thus serve a crucial role of ensuring program visibility in the community.

In total, 114 mentors have been trained, most of whom (70%) are individuals with TBI. Eighty-three of these mentors (73%) are still active in the program, whereas 31 mentors (27%), including 21 individuals with TBI and 10 family members, have suspended their involvement in the TBI-MPP temporarily or permanently. The most frequent reasons provided by mentors for leaving the TBI-MPP were: (1) personal illness or disability issues ( $n = 15$ ); (2) too many commitments to other

**Table 1.** Demographics of mentors

	<b>Individuals with TBI (<i>n</i> = 80)</b>	<b>Family members (<i>n</i> = 34)</b>
	N (%)	N (%)
<b>Gender</b>		
Female	48 (60)	30 (88)
Male	32 (40)	4 (12)
<b>Ethnicity</b>		
White	68 (85)	28 (82)
African-American	9 (11)	1 (3)
Hispanic	1 (1)	2 (6)
Other	2 (3)	3 (9)
<b>Age</b>		
Teenagers (<19)	0 (0)	0 (0)
Young adult (19-30)	9 (11)	0 (0)
Adult (31-45)	32 (40)	10 (30)
Older adults (46 and up)	39 (49)	24 (70)

activities (*n*=8); (3) disinterest in being a mentor after training was completed (*n*=6); and (4) electing to limit roles in the TBI-MPP to partner recruitment efforts (*n*=2). Demographic information for the total pool of mentors is provided in Table 1. In this table, differences in individuals and family members who volunteered for program participation can be noted. More specifically, both men and women with TBI volunteered to become mentors; these individuals were predominantly white and older than 30; in contrast, family members who volunteered were predominantly women, white, and slightly older (ie, older than 46).

**Recruitment of partners**

Extensive outreach was conducted to disseminate information about the TBI-MPP and recruit individuals with TBI and their family members who were in need of peer support. Partners were recruited through the RTC's web site, BIANYS outreach coordinators, independent living centers, rehabilitation hospitals, and support groups, and presentations

at local and state conferences. Optional referral to the TBI-MPP was included as part of the routine information provided to all individuals who contact the resource hotline at BIANYS.

All potential partners referred to the TBI-MPP complete an initial intake interview with a project coordinator to determine the scope of peer support needed and their suitability for program participation. Persons seeking peer support who are at risk for suicidal or violent behavior and/or have serious psychiatric or substance abuse problems are not accepted into the TBI-MPP. These individuals are provided with referrals for community-based services. Other exclusionary criteria include: (1) an inability (after extensive discussion) to articulate any reasons for wanting peer support from the TBI-MPP; (2) the individual was referred to the program by someone else but has no personal interest in receiving peer support from the TBI-MPP; (3) evidence of excessive negativity, anger, or volatility on screening interview; (4) the severity of cognitive impairments would prevent the person from benefiting

from peer support from the TBI-MPP; (5) the individual has no cognitive awareness of the brain injury and its effects on his or her life; and (6) the individual is solely interested in talking with someone, with no desire to change his or her current life situation. By use of these criteria, approximately 25% of individuals referred for the TBI-MPP have been referred elsewhere in the community.

Team meetings of the program coordinators and the RTC staff are held to discuss the presenting support needs of each individual, and the person is matched with a mentor who the team believes can best meet those needs. Because criteria for matches varied considerably from partnership to partnership, categories of criteria for matching mentors and partners were documented. These criteria included (1) similar demographic background (eg, age, marital status, geographical location, educational background); (2) similar marital or family status (eg, spouse of individual with TBI, single, parent of a school-aged child); (3) similar injury history (eg, cognitive challenges, physical challenges, cause of injury); (4) similar interests (eg, shared religious beliefs, common work or social backgrounds); and (5) the mentor's ability to meet the specific psychological needs of the partner (eg, need for structure, role model, social support).

### ***Mentoring partnerships***

Once the mentor and partner are matched, the project coordinator links the mentor with the partner, and the partnership is begun. The duration of the partnership and its intensity are mutual decisions of the mentor and his or her partner. To date, more than 100 partnerships have been created, with approximately 50% of these relationships completed at present. Approximately 25% of partnerships are ongoing 1 year after they begin. To establish a fixed "end point" of the program for data

collection purposes, these long-term partnerships are officially terminated after 1 year. In such partnerships, mentors and partners typically remain friends and continue contact beyond the "official" end of the partnership. Most partnerships (about 75%) end in less than 1 year. In order of importance, reasons for ending of partnerships before a year is up have included (1) mentoring needs were met; (2) the mentor or partner moved; (3) the mentor or partner was overextended by life demands; (4) the partner's needs were too complex for the mentor or the partner was unable to profit from mentoring; (5) mentor/partner incompatibility; and (6) scheduling conflicts.

### ***Technical assistance***

The project coordinator provides ongoing technical assistance to mentors by telephone for the duration of each partnership. Technical assistance may include providing suggestions, advice, emotional support, and/or recommendations for community resources. The project coordinator monitors the overall quality of each partnership and provides guidance regarding crisis intervention (when indicated) to both mentors and partners. If a partnership is dissolved because the partner is dissatisfied, the coordinator typically reassigns the partner to a new mentor. The project coordinator will also make referrals to the community if the partner's needs are beyond the scope of the program.

### ***Program evaluation***

Traditional research questionnaires were initially selected to assess changes in partner within the domains of empowerment, quality of life, mood, skills and knowledge about TBI, and social supports. Psychometric assessments were to be conducted before and after completion of each partnership. A major unanticipated obstacle was encountered in our initial approach to program evaluation.

Most partners sought out the TBI-MPP primarily because they were interested in receiving peer support and not because they were motivated to participate in a research project. As a result, partner compliance with the "traditional" research aspects of the program was poor. In response to this challenge, three steps were taken. First, all assessment instruments were administered by telephone. Second, to capture the impact of the program on participants who had already completed partnerships in the TBI-MPP, a retrospective quantitative interview was implemented to evaluate partners' self-reports regarding the impact of the TBI-MPP on the areas of research interest (sense of empowerment, quality of life, mood, skills and knowledge about TBI, social supports). Third, a subgroup of partners seen for the retrospective quantitative interview was asked to participate in a retrospective qualitative interview to capture aspects of the program that were either beneficial or needed improvement. Both qualitative and quantitative interviews examined the partners' satisfaction with their partnerships and their mentors. (Findings from these pilot quantitative and qualitative studies are provided below.) This information is currently being used to enhance the TBI-MPP and shape the prospective assessment being implemented for use in the remaining years of the current research project.

## METHOD

### Participants

The first 52 partners to enroll in the TBI-MPP who had completed their partnerships were invited to participate in these pilot studies. Twenty partners (11 individuals with TBI; 9 family members) agreed to participate in a quantitative interview, and 7 partners (all family members) agreed to participate in the qualitative interview. The remaining 32 partners

did not participate in the pilot studies for a variety of reasons, including (1) loss to follow-up ( $n = 14$ ); (2) severe cognitive or emotional impairments ( $n = 11$ ); (3) refusal to participate ( $n = 3$ ); and (4) scheduling problems ( $n = 4$ ). To determine whether the sample of partners who participated in the quantitative study was representative of the larger pool of partners, chi square statistics and *t* tests were computed on select demographic variables comparing partners who participated in the interview (participants) with partners who declined the interview (nonparticipants). No significant differences were found for gender, ethnicity, age, or number of contacts with mentors between the two subgroups. Reasons for termination of partnerships were also compared across the two groups. For both groups, the percentage of partnerships lasting less than 1 year (75%) was identical. Approximately half (53%) of the participants' partnerships v 38% of the nonparticipants' partnerships ended before 1 year because partners' needs had been met. When examining reasons for ending partnerships, 46% of the nonparticipants v 20% of participants had ended their partnerships because of complex needs, excessively busy lives, and/or emotional and cognitive impediments. These findings suggest that although the two groups were demographically comparable, the participant group may slightly over represent the more "successful" partnerships.

The demographic characteristics of the partners who participated in the quantitative interviews are presented in Table 2. As noted in the table, partners were predominantly women, white, and adults between the ages of 31 and 45. On average, mentors and partners had 13 contacts with mentors, with wide variation in the number of contacts made per partnership ( $SD = 12.77$ ). One outlier was excluded from these data, because the partnership had included more than 108 documented contacts.

**Table 2.** Demographics of partners who participated in the pilot study quantitative interviews ( $n = 20$ )

Gender	
Male	6 (30%)
Female	14 (70%)
Ethnicity	
African-American	4 (20%)
White	14 (70%)
Other	2 (10%)
Age	
Teenagers (<19)	1 (5%)
Young adult (19–30)	1 (5%)
Adult (31–45)	12 (60%)
Older adults (46 and up)	6 (30%)
Contacts with mentors	
Mean (SD)	13 (12)

## Procedure and measures

### *Quantitative interview*

All participants were telephoned at home by research assistants. After providing informed consent, they were administered the quantitative interview. This retrospective interview was designed to capture participants' impressions of the TBI-MPP's impact on their lives and was divided into two parts. Part I consisted of multiple-choice questions that asked whether involvement in the TBI-MPP had had any impact on five broad areas of functioning: empowerment, quality of life, mood, knowledge and communication skills, and social support. For this article, questions focused on the selective impact of the TBI-MPP on functioning are presented. For each question, participants were asked to rate the degree of program impact by indicating that the program "helped a lot," "helped somewhat," "helped a little bit," or "not at all" within a specified area (eg, "Did the Mentoring Program help you learn about resources

in your community?"). To assess current quality of life, participants were administered the Delighted-Terrible Scale<sup>39</sup> twice during the interview. In Part II, partners were asked to rate their satisfaction with (1) their mentors, (2) the frequency of contacts with their mentors, and (3) the length of their TBI-MPP partnerships (see Appendix A for a list of questions from the quantitative interview).

A panel of three experts on TBI selected and adapted the Part I interview questions from four existing measures: the Questionnaire on Resources and Stress-Short Form (QRS-SF),<sup>40</sup> the Frequency of Family Coping Behaviors (FCB),<sup>25</sup> the Social Support Questionnaire Short Form (SSQ-SR),<sup>41,42</sup> and the Empowerment Scale.<sup>43</sup> Selection criteria for items included question clarity and relevance to the mentoring program. Interviewers were given specific definitions of terms that were potentially ambiguous (eg, "anxiety" = "feeling nervous or worried or edgy and tense") and instructions on how to provide clarification when necessary. Because of limitations imposed by data collection (as outlined previously) and the preliminary nature of this pilot study, validation of the reliability and construct validity of the quantitative interview as a whole was deferred. To assess reliability of participants' responses within the interview, data obtained from the Delighted-Terrible Scale<sup>39</sup> were used to assess consistency of self-report. The Delighted-Terrible Scale consists of a single question ("How have you felt about the overall quality of your life in the past month?"), which was asked twice during the interview (once at the beginning and again at the end). Participants were asked to choose one of seven responses ranging from "Delighted" to "Terrible". Participants' responses to this question were highly correlated ( $r = .926$ ,  $P < .001$ ), suggesting consistency of responses and reliability of this portion of the interview.

**Qualitative interviews**

A subgroup of family members who had participated in the quantitative interview (3 parents and 4 significant others of individuals with TBI) agreed to participate in an in-depth qualitative interview. Most of participants (6 of 7) were interviewed in their homes, with interviews lasting, on average, 1.5 hours. Interviews were conducted by a staff person who was not otherwise involved with the TBI-MPP. Qualitative interviews were designed to provide a richer picture of the nature of participants' mentoring experiences. These interviews consisted of open-ended questions that addressed (1) expectations the partners had before beginning partnerships; (2) the nature of the relationship with the mentors; (3) the qualities that made for a good mentor; (4) the most beneficial aspects of the program; (5) areas of advocacy learned while

participating in the program; and (6) suggestions for program improvements. All interviews were audio taped, and responses were content analyzed to produce themes related to each of the preceding questions.

**RESULTS**

**Quantitative data**

In the quantitative interviews, participants were asked questions regarding the potential impact of the TBI-MPP on each of five domains: empowerment, quality of life, mood, knowledge and communication skills, and social support. The percentages of participants' responses regarding program impact ("don't know," "no impact/not applicable," "some impact," "major impact") for each question are presented in Table 3 for individuals with TBI and in Table 4 for family members.

**Table 3.** Reported impact of the TBI-MPP on individuals with TBI (*n* = 11)

	Don't know/ remember	No impact/ not applicable	Some impact	Major impact
Empowerment				
Ability to cope	0%	18%	55%	27%
Control over one's life	0%	46%	18%	36%
Quality of life indicators				
Overall quality of life	0%	37%	27%	36%
General outlook	0%	45%	10%	45%
Mood				
Degree of happiness	0%	55%	27%	18%
Sadness/depression	0%	46%	18%	36%
Anger	0%	55%	18%	27%
Anxiety	0%	64%	18%	18%
Skills and knowledge				
Communication—professionals	0%	73%	9%	18%
Knowledge—TBI	0%	18%	46%	36%
Knowledge—community resources	0%	46%	27%	27%
Social support				
From family members	0%	82%	9%	9%
From friends	0%	82%	0%	18%
From the community	9%	82%	9%	0%

**Table 4.** Reported impact of the TBI-MPP on family members of individuals with TBI ( $n = 9$ )

	Don't know/ remember	No impact/ not applicable	Some impact	Major impact
<b>Empowerment</b>				
Ability to cope	0%	0%	100%	0%
Control over one's life	0%	56%	44%	0%
<b>Quality of life indicators</b>				
Overall quality of life	0%	44%	56%	0%
General outlook	0%	44%	44%	12%
<b>Mood</b>				
Degree of happiness	11%	67%	22%	0%
Sadness/depression	0%	33%	67%	0%
Anger	12%	33%	55%	0%
Anxiety	0%	33%	67%	0%
<b>Skills and knowledge</b>				
Communication—professionals	0%	34%	44%	22%
Knowledge—TBI	0%	33%	67%	0%
Knowledge—community resources	0%	67%	33%	0%
<b>Social support</b>				
From family members	0%	78%	22%	0%
From friends	0%	67%	22%	11%
From the community	0%	89%	0%	11%

Partner responses of “helped a little” and “helped somewhat” were collapsed into the “some impact” category, whereas partners’ responses of “did not help” and “helped a lot” were recorded as “no impact” and “major impact,” respectively, in the tables. A rating of “not applicable” was applied when a partner stated that a specific question was unrelated to his or her own experience (eg, the partner denied experiencing anxiety; therefore, this area was not relevant to his or her view of the mentoring experience) or when the partner felt the area was not one in which he or she needed mentoring help (eg, the family member felt that family support was adequate, and therefore this area was not a focus of the mentoring experience). Interviewers found that in a number of cases it was difficult to clarify whether participants

felt that the program had had “no impact” in a given area or whether they had no needs in that area. For example, a person might state that the program did not help him or her increase support from family members without clarifying whether he or she had any family members in the first place. Because of this ambiguity, responses of “not applicable” and “did not help” were collapsed into a single category “not applicable/no impact.”

Data regarding program impact on individuals and family members are provided in Tables 3 and 4, respectively. Findings are summarized below.

**Empowerment**

Eighty-two percent of individuals with TBI reported that involvement in the TBI-MPP increased their ability to cope with their TBI

(55% "some impact," 27% "major impact"). All the family members who participated in the TBI-MPP reported that the program had "some impact" on their ability to cope with TBI. Approximately half of the individuals with TBI reported that involvement in the TBI-MPP helped them gain better control over their lives (18% "some impact," 36% "major impact"), with a slightly less robust impact reported by family members (44% "some impact").

### *Quality of life*

Over half of the individuals with TBI and family members reported enhanced quality of life as a result of their participation in the TBI-MPP (individuals: 27%, "some impact"; 36%, "major impact"; family members: 56%, "some impact"). Participants also viewed the impact of the TBI-MPP on their general outlook as positive in that more than half of individuals with TBI (10% "some impact"; 45% "major impact") and family members (44% "some impact"; 12% "major impact") endorsed enhanced general outlook as a result of their involvement in the TBI-MPP. Participants' responses to the Delighted-Terrible scale were converted to scores from 1 (terrible) to 7 (delighted). The mean of the two scores from each participant was then calculated: this score represented the participant's final Delighted-Terrible score. The mean Delighted-Terrible score for all participants was 4.45 (SD = 1.66), a score that falls between "mixed" and "mostly satisfied." Unfortunately, prementoring quality of life scores were not available; hence, comparison with prementoring status was not possible.

### *Mood*

The reported impact of the TBI-MPP on coping with negative mood was variable for both individuals with TBI and family members. A beneficial impact of the TBI-MPP was

noted in helping partners cope with feelings of sadness and depression (individuals with TBI: 18% "some impact," 36% "major impact"; family members: 67% "some impact"). The program was also viewed as effective in helping participants cope with feelings of anger (individuals with TBI: 18% "some impact"; 27% "major impact"; family members: 55% "some impact"), as well as anxiety (individuals with TBI: 18% "some impact," 18% "major impact"; family members: 67% "some impact"). The TBI-MPP was also reported to have some impact on degree of happiness (individuals with TBI: 27% "some impact," 18% "major impact"; family members: 22% "some impact").

### *Skills and knowledge*

Participants reported that the TBI-MPP had its strongest impact on enhancing partners' knowledge about TBI. More specifically, 36% of individuals with TBI reported that involvement in the TBI-MPP had a "major impact" in this domain, whereas an additional 46% of individuals with TBI and 67% of family members reported "some impact" of the program in the area of increasing knowledge about TBI. The TBI-MPP was also reported to be helpful in increasing knowledge of community resources by a smaller group of participants (ie, 27% of individuals with TBI reported a "major impact," and an additional 27% of individuals with TBI and 33% of family members reported the TBI-MPP had "some impact" on increasing their knowledge of community resources).

### *Social support*

The reported impact of the TBI-MPP on enhancing family support was minimal in that 9% of individuals with TBI reported a "major impact," whereas 9% of individuals with TBI and 22% of family members reported "some impact" in increasing family support. TBI-MPP impact on social support from friends was reported by a smaller group of participants

**Table 5.** Partners ratings of satisfaction with the TBI-MPP (*n* = 20)

	Individuals with TBI			Family members		
	Dissatisfied, too brief, or infrequent	Dissatisfied, too long, or frequent	Satisfied	Dissatisfied, too brief, or infrequent	Dissatisfied, too long, or frequent	Satisfied
Length of partnership	27%	9%	64%	44%	0%	44%
Frequency of contacts	9%	0%	91%	33%	0%	67%
Satisfaction with mentor	0%	0%	91%	11%	0%	89%

(ie, a “major impact” for friends by 18% of individuals and 11% of family members, with “some impact” for an additional 22% of family members). Minimal impact was noted on enhancing social support from the community at large (ie, 11% “major impact” by family members and 9% “some impact” for individuals).

**Overall measures of program satisfaction**

Partners’ satisfaction with the length of partnership, the frequency of contact, and overall satisfaction with their mentors was explored. As summarized in Table 5, more individuals with TBI were reportedly satisfied with the length of partnership than family members (64% v 44%, respectively), whereas family members were more apt to report that the partnerships were too brief. Most individuals with TBI and family members reported that they were satisfied with the frequency of contacts between themselves and their mentors. However, 33% of family members reported dissatisfaction with the infrequency of the contacts. Although individuals with TBI and family members were overwhelmingly pleased with their mentors (91% and 89%, respectively), a small percentage of family members (11%) expressed dissatisfaction with the mentor match.

**Qualitative data**

Content analysis of data from seven qualitative interviews revealed the following themes.

**Greatest benefits of the TBI-MPP**

Shared experience, or the mentor’s having “been there,” was reported to be the most beneficial part of the TBI-MPP, according to all seven participants. Sharing of experience and, therefore, the lessening of “feeling alone” was often part of the expectation family members had before participating in the TBI-MPP. Emphasis was placed on the strength of the mentor’s experiential knowledge or role as the “wounded healer” in contrast with the more distant “book-learned” knowledge of the professional. One family member said of her mentor: “She could really understand me 100%.” Family members stated that they benefited from the hopeful stance of mentors who believed that love and attention to their family member with TBI offered healing power.

**Expectations about the TBI-MPP**

What participants thought they would get from the TBI-MPP varied widely. Four of the seven participants mentioned expecting a support group or support network to be part of the TBI-MPP, in addition to one-on-one

conversations with their mentor. One participant expected more practical supports (eg, help with shopping or child-care). Two family members withdrew from the TBI-MPP because their expectations were not being met. In contrast, some other family members remained in the TBI-MPP, stating that they were grateful for any help received, despite disappointment at not having all of their expectations met.

### ***Logistics of partnerships***

The context of partnerships was variable, ranging from the mentor initiating all phone calls to a mutual exchange of phone numbers or face-to-face meetings in the community as the partnerships developed over time. In the cases in which face-to-face contact was made, relationships tended to continue on an informal basis after the partnership year was completed. Partners who were passive recipients of phone contact from mentors (ie, those who could not initiate contacts with mentors) expressed the desire for greater control over the partnership process. Similarly, when partnerships were limited to a few phone calls, the family member's lack of ability to reach out for support as needed was often cited as the primary reason for ending the partnership. Geographical distance between mentor and partner, prohibiting them from face-to-face contact, was also cited as a frustration.

### ***Qualities of a good mentor***

The abilities of listening and being compassionate and knowledge of community resources were cited by all participants as core qualities of a good mentor. In addition, patience, tolerance, consistency of contact, honesty about the mentor's own negative feelings, emotional stability, respect for the family member's experience, and capacity for in-person contact were mentioned as desirable characteristics. Partnership difficulties arose when mentors seemed "perfect" (ie, having

answers to all problems). These partnerships often ended early, because the family member did not feel comfortable expressing anger or sadness.

### ***Advocacy and self-advocacy***

Partners praised mentors' ability to prepare them for personal "overload" as the medical care and social services "system" began to withdraw. Such advice helped prepare partners by increasing their understanding, if not their tolerance, of the potential lack of "system" responsiveness to their loved one's needs. This knowledge helped partners create new avenues to get what they needed (eg, knowing where to get the most accurate information, knowing the "right" people to talk to). In addition, three family members talked about the need to advocate on behalf of their own needs, in addition to those of the person with a TBI. Family members felt that professionals often focused treatment solely on the person with the brain injury (in keeping with the medical model), failing to place the person with TBI in the context of his or her family relationship, and thus failed to provide services for the family as a whole. As a result, several spouses questioned their ability to remain in their relationships over the long term.

### ***Program improvements suggested by partners***

Several partners requested guidelines for what they could and could not expect within the TBI-MPP. Requests included information about who may initiate phone calls and whether face-to-face contact might be arranged. In addition, they requested more structured schedules of phone calls. In some cases, better matches were requested, with regard to distance, age, and relationship to the person with a TBI. Additional services to enhance support to the entire family, including workshops and support groups, were also suggested.

## DISCUSSION

Although peer support within a group modality has been suggested as useful in enhancing coping skills for both individuals with TBI and their family members,<sup>23,24</sup> research as to the usefulness of individualized peer support is lacking. In this study, preliminary data as to the efficacy and impact of a community-based peer support program were evaluated using retrospective interviews with individuals with TBI and family members who had participated in the TBI-MPP.

Participants' reports suggest that for many among them, the TBI-MPP had a positive impact on their lives. For both individuals with TBI and family members who participated in the TBI-MPP, the areas of greatest reported program impact were in increasing their knowledge of TBI and in helping them cope with the consequences of TBI. Most participants from both groups reported that the program helped enhance their overall ability to cope with TBI, their quality of life, their general outlook, and their ability to cope with depression and sadness. Most participants from both groups stated that the program had little impact on increasing the amount of social support they received from family, friends, and community. Family members and individuals with TBI reported varying degrees of program impact on their happiness, their ability to cope with anxiety and anger, their ability to communicate with professionals, and their sense of control over their lives.

Family members, in general, were more conservative in their evaluation of the extent of the program's impact. They tended to state that the program had "some impact" rather than a "major impact" across most areas explored in the study. It is unclear whether this finding suggests that the program was less effective for family members or whether individuals with TBI were more "grateful" for

any support provided by peers. A possible explanation is that receiving peer support from another person with TBI was particularly empowering (and therefore gratifying) for participants with TBI.

These preliminary findings support prior literature suggesting the usefulness of peer support in enhancing an individual's sense of empowerment.<sup>29,30</sup> In this study, select aspects of empowerment (ie, ability to cope) seemed to be more likely to be impacted by peer support than others (ie, control over one's life). These findings highlight the fact that the term "empowerment" may reflect a rather heterogeneous and multifaceted set of experiences.

The lasting and significant toll of TBI on the emotional well-being and quality of life of individuals with TBI<sup>5-7</sup> and their family members<sup>9,13-22</sup> has been well documented in the literature. During training of mentors in the TBI-MPP, specific coping strategies to enable partners to cope with depression, address their anger, and decrease their anxiety were emphasized. The current findings suggest that peer support is helpful in enabling individuals to cope with their emotional challenges, with impact noted most frequently on partners' ability to cope with feelings of depression and sadness and somewhat less frequently on their coping with anger and anxiety. In addition, this peer support program was found to have a positive impact on many participants' overall quality of life. The program's impact on levels of perceived happiness was less emphatic, suggesting that this latter objective was perhaps beyond the scope of this time-limited peer-mentoring program for many participants.

Coping after TBI reportedly is enhanced by provision of adequate information about the challenges of TBI and community resources available to deal with these challenges.<sup>25-27</sup>

To prepare mentors to address these specific peer support needs, training emphasized

short-term and long-term TBI-related challenges and educating mentors about available community resources. In addition, communication and advocacy skills were emphasized as potential tools with which to help partners obtain desired information from professionals and needed community supports. These preliminary findings suggest that this peer support program helped to increase participants' knowledge about TBI, thus providing a mechanism for enhanced coping after TBI. The reported impact of the program on increasing knowledge of community resources was less robust. In part, this finding is reflective of realistic limitations in available and adequate resources in the community for individuals and their families after TBI. It may also have been due to hesitancy observed by program coordinators on the part of mentors to provide specific information about community referral to their peers, feeling this was not part of the "mentoring" role. The project coordinators were familiar with specific community resources and provided these services. These preliminary findings highlight the need for increased education of individuals and families regarding available community resources by professionals early in the rehabilitation phase of TBI recovery (rather than in a peer support situation), as well as the need for expansion of such services in the community.

The current findings suggest that family members viewed the program as more helpful in enhancing communication with professionals than did individuals with TBI. This finding may reflect the reported increase in dependency of individuals with TBI,<sup>9</sup> with a subsequent tendency to delegate communication and advocacy needs to their family members. If this interpretation is correct, a greater focus on this area in mentor training is called for, since lack of personal advocacy can only lead to further disablement for an individual. In contrast, this finding might also reflect solid communication abilities in some individuals with TBI; thus, the lack of impact reported by

individuals with TBI might not indicate a failure of this peer support program but rather an absence of a need for support in this area for select individuals. This finding highlights that the categorical response of "no impact/not applicable" is open to numerous interpretations. In our future research efforts, interviews of program participants will be designed to clarify reasons for reports of "no impact" to eliminate such ambiguities.

Social isolation is a common sequela of TBI for both individuals with TBI and their family members. To address this need in this peer support program, training of mentors focused on techniques to increase a network of support from family, friends, and community members in potential partners. Preliminary results of this study suggest that participants felt that the program did little to increase the amount of social support received from family, friends, and community. These findings are similar to those reported by Santelli et al<sup>34</sup> within the P-to-P program. Combined, these findings may suggest that the goal of building extended support networks may be applicable for a select subset of individuals but should not be viewed as a major focus of peer support efforts.

Given the literature documenting continued emotional challenges for both individuals with TBI<sup>11,12</sup> and their families,<sup>17,18,20,21</sup> it was anticipated that partnership duration and frequency of contact might be greater than reported in other peer support programs aimed at other disability groups. The TBI-MPP was designed to be an open-ended partnership lasting up to 1 year. In the program, mentors and partners jointly determined the duration and frequency of their contacts, and partnerships were concluded in consultation with the project coordinator. Preliminary findings validate our initial assumption that peer support programs for individuals with TBI and their families is of greater intensity and duration than other peer support programs.<sup>33</sup>

Overall program satisfaction in this pilot study was positive in that most individuals with TBI and family members reported satisfaction with both the duration and frequency of contacts. Not all partners were satisfied, however. Some participants requested increased contact and longer partnerships. Family members seemed to be more selective, more verbal, and more demanding about program intensity and duration needs. Qualitative interviews with a small cohort of family members provided further insights into their unique needs, including such issues as more person-to-person contact (as contrasted with phone contact) with mentors, increased control over initiating (as opposed to receiving) contacts with mentors, and longer lasting partnerships.

The qualitative interview also provided contextual information about the benefits of the partnerships for family members, with several family members emphasizing the benefit of having mentors discuss their own feelings and offer suggestions from their own perspective (ie, from a more removed, and settled, yet still compassionate, stance). Family members provided recommendations for program enhancement as well, including suggesting that mentors learn how to share their own negative feelings, as well as their strengths, to help "normalize" family members' negative feelings and the need to provide detailed information to future partners about the scope of the TBI-MPP to decrease frustration caused by unrealistic expectations of the program. Family members also stressed the need to expand peer support to the family system as a whole, either in a one-to-one relationship or in a group format. Future qualitative studies will be necessary to examine the experiences of individuals with TBI in the TBI-MPP.

Combined, these preliminary findings suggest that peer support for individuals with TBI and their family members is an intensive process for both mentors and their partners. The intensity of the TBI-MPP partner-

ships implies a parallel need for ongoing technical assistance for mentors involved in such a program. In the TBI-MPP, these supports have been, and continue to be, provided by two project coordinators who were knowledgeable about TBI and experts about community resources. Coordinators serve the dual role of screening partners to ensure that their needs can be met by peers and serving as a "mentor" for each program mentor to assist in "fine tuning" his or her interventions with a partner. Ongoing technical assistance of this kind is essential to maintaining an effective peer support program in the community. The intensity of project coordinators' involvement in the program will be analyzed during the prospective phase of the study to determine realistic staffing needs when designing future peer support programs.

Given the retrospective nature of the current data, several limitations need to be addressed. The retrospective data collected for this initial phase of the study may be biased by several factors: individuals with significant cognitive difficulties may prove to be poor reporters of prior program interventions, and individuals who were dissatisfied with the program itself may have declined participation in the retrospective interviews. Although the two groups (ie, interview participants and nonparticipants) were similar both demographically and in the duration of their partnerships, their reasons for termination of the partnerships varied slightly, in that partners who declined participation in the interview were slightly more likely to have ended their partnerships because of complex needs, being too busy, and/or having greater cognitive or emotional challenges. These potential biases are inherent within retrospective community-based studies.

To address the limitations identified in these preliminary studies, a prospective interview has been implemented with partners being interviewed prior to initiation of partnerships at completion of the partnerships,

and again 1 year after partnership initiation (if the partnership was completed before the 1 year anniversary). This design will permit evaluation of "within person" changes, as well as "program impact" related to these changes, thus exploring the process and impact of peer support more clearly. To determine whether changes in the person are indeed peer program dependent, a second sample of individuals who have not participated in TBI-MPP will be interviewed initially and at 1 year after the initial interview. Comparison of data from both groups will allow for a more rigorous evaluation of program impact.

In summary, the TBI-MPP has been a living model of PAR in action. Individuals with TBI and family members have been empowered to create their own program,

whereas researchers have been called on (and challenged) to evaluate the efficacy of their community-based efforts. Individuals formerly isolated after the onset of their TBI have had the benefit of a connection with "someone who has been there." As a direct result of the TBI-MPP, mentors have been empowered and now serve as resources to others in the community. Inherent in a PAR approach are its many challenges,<sup>34,44</sup> including the need to be flexible in designing (and re-designing) methods for assessment, the need for intense and ongoing technical assistance to mentors, and the need to replace mentors when they "move on" from the program. These challenges are a small price to pay for the potential benefits that a program like the TBI-MPP can offer.

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## Appendix A

### Questions and Response Choices Regarding Impact of TBI-MPP from the Retrospective Questionnaire

#### Part I

##### Empowerment:

1. Did the mentoring program help you cope with you or your loved one's brain injury?  
 A lot  
 Somewhat  
 A little bit  
 Not at all  
 Not applicable  
 Don't know/remember
2. Did the mentoring program affect how much control you have over your life?  
 A lot  
 Somewhat  
 A little bit  
 Not at all  
 Not applicable  
 Don't know/remember

##### Quality of Life Indicators:

1. Did the mentoring program affect the overall quality of your life?  
 A lot (decreased QOL)  
 Somewhat (decreased QOL)  
 A little bit (decreased QOL)  
 Not at all  
 A little bit (increased QOL)  
 Somewhat (increased QOL)  
 A lot (increased QOL)
2. Did the mentoring program contribute to changes in your general outlook on life?  
 A lot  
 Somewhat  
 A little bit  
 Not at all  
 Not applicable  
 Don't know/remember

#### Mood:

1. Did the mentoring program affect how happy or cheerful you are (or how often you feel happy or cheerful)?  
 A lot (happiness increased)  
 Somewhat (happiness increased)  
 A little bit (happiness increased)  
 Not at all  
 A little bit (happiness decreased)  
 Somewhat (happiness decreased)  
 A lot (happiness decreased)  
 Don't know/remember
2. Did the mentoring program help you cope with feeling depressed or sad?  
 A lot  
 Somewhat  
 A little bit  
 Not at all  
 Not applicable  
 Don't know/remember
3. Did the mentoring program help you cope with feeling angry?  
 A lot  
 Somewhat  
 A little bit  
 Not at all  
 Not applicable  
 Don't know/remember
4. Did the mentoring program help you cope with your nervousness or anxiety?  
 A lot  
 Somewhat  
 A little bit  
 Not at all  
 Not applicable  
 Don't know/remember

Skills and Knowledge:

1. Did the mentoring program help you communicate your needs to health care professionals?

A lot  
 Somewhat  
 A little bit  
 Not at all  
 Not applicable  
 Don't know/remember

2. Did the mentoring program help you learn about TBI?

A lot  
 Somewhat  
 A little bit  
 Not at all  
 Not applicable  
 Don't know/remember

3. Did the mentoring program help you learn about resources in your community?

A lot  
 Somewhat  
 A little bit  
 Not at all  
 Not applicable  
 Don't know/remember

Social Support:

1. Did the mentoring program assist you in getting the support you needed from your family?

A lot  
 Somewhat  
 A little bit  
 Not at all  
 Not applicable  
 Don't know/remember

2. Did the mentoring program help you in getting the support you needed from your friends?

A lot  
 Somewhat  
 A little bit

Not at all  
 Not applicable  
 Don't know/remember

3. Did the mentoring program help you in obtaining the support you needed from members of your community (eg, clergy, coworkers)?

A lot  
 Somewhat  
 A little bit  
 Not at all  
 Not applicable  
 Don't know/remember

Part II

1. How satisfied or dissatisfied were you with the length of your partnership?

Dissatisfied (would have preferred a shorter partnership)  
 Dissatisfied (would have preferred a longer partnership)  
 Satisfied (length of partnership was about right)  
 Don't know/remember

2. How satisfied or dissatisfied were you with the frequency of contact that you had with your mentor?

Dissatisfied (would have preferred more contact)  
 Dissatisfied (would have preferred less contact)  
 Satisfied (amount of contact was about right)  
 Don't know/remember

3. How satisfied or dissatisfied were you with your mentor?

Very dissatisfied  
 Somewhat dissatisfied  
 Mixed  
 Somewhat satisfied  
 Very satisfied  
 Don't know/remember