Helping Factors in a Peer-Developed Support Group for Persons With Head Injury, Part 1: Participant Observer Perspective

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Key Words: brain injuries • self-help groups

Objectives. An ethnographic study of a peer-developed support group for persons with head injury was conducted to identify helping factors. These factors are the peer group experiences and processes, established theoretically and empirically, that provide support through self-help.

Method. The group comprised 13 members who regularly attended sessions for 16 months. In addition to participant observation, the data included audiotapes and videotapes of the group. The data were subjected to thematic analysis to find patterns in the participants’ experience with regard to group helping factors.

Results. Many of the positive attributes of the group seem similar to processes found in successful peer support groups. These attributes include believing and feeling part of the group because members have a common problem and can validate the effects of the injury by sharing and receiving information in a variety of ways through the group.

Conclusion. Legitimization, the acceptance of the head injury itself as real, appears to be the fundamental concept that distinguishes this group from other problem-focused self-help groups and professionally led groups.

There has been growing interest among the rehabilitation disciplines in the long-term daily living problems of persons, such as those with traumatic head injuries, who would not have survived their catastrophic injuries without the advances in medical technology found in postindustrial nations. At the same time, support groups have also gained popularity for those surviving as a result of high-technology medical machinery now found in emergency care, adult, and neonatal intensive care units. Examples of such groups include parent support groups for families of premature babies and support groups for head injury survivors and their families. As of 1990, the National Head Injury Foundation reported a network of 350 self-help groups in the United States (Williams, 1990). These groups, involving outside experts and facilitators, exist for head injury survivors and their families for the purposes of information, education, emotional healing and grieving, and the training of family members as caregivers (Williams, 1987).

Researchers have emphasized problems and group support needs for families of persons with head injury. According to Kozloff (1987), social support assists in the long-term recovery process of persons with head injury and, after the initial phase of recovery, many of these persons are dependent on their primary families for economic, emotional, and task support. However, “as time goes by the resources provided by family, friends, and health care professionals are no longer available to the patient” (Kozloff, 1987, p. 22). Campbell’s (1988) study of the needs and helpfulness of support groups better our understanding of the perceptions of relatives. Although the perspectives of kin are important, we also know that family caregiving is insufficient. No research has examined the usefulness of survivor support groups in directly meeting needs of the victims themselves. As Kozloff recommended, “an analysis of the people likely to be most successful in providing support and the methods that would be most constructive in doing so should be undertaken” (1987, p. 22).

This paper reports on an ethnographic study to identify the helping factors in a peer-developed support group for persons who survived a traumatic head injury. For the purposes of this study, peer support groups, also commonly called self-help groups, are defined as being composed of members who share a common condition, situation, heritage, symptom, or experience. They are largely self-governing and self-regulating. They emphasize self-reliance and generally offer a face-to-face or phone-to-phone fellowship network, available without charge. They tend to be self-supporting rather than depending on external funding. (Lieberman, 1990a, pp. 252–253)

An ethnographic approach was well suited to this study because it has been found that recovery is greater when a match exists between the perceptions of the patient with a head injury and the perceptions of the health care provider (Kozloff, 1987). Furthermore, ethnography has
been used to identify variables related to reintegration of persons after a head injury (Krefting, 1989). Through regular interaction with members of a peer-developed support group, for almost 1½ years and in a variety of settings, I hoped to generate a further understanding and several hypotheses about the helping factors present in their peer support group.

Participants

Participants were all members of a peer-developed support and study group formed by VALT (Vital Active Life after Trauma, Inc.), a nonprofit organization dedicated to create support systems for survivors of head injury, their families, and caregivers. An additional goal of VALT is to educate health care professionals about treatment and recovery from a head injury by having survivors of head injury tell their experiences. After being interviewed by the VALT President, I was invited to help her cofacilitate the organization's newly forming peer support group. I offered to participate as a volunteer and researcher. My role as volunteer and researcher was in keeping with the organization's aims and philosophy to provide service to the public and health professionals. In the exchange, I would describe the group's process for educating occupational therapists through publications, presentations, and curriculum development. I believed reciprocity between my roles as facilitator and educator-researcher was in keeping with VALT's partnership model. It would also discourage the formation of a hierarchical relationship with the group. In their discussion of "self-governance" of self-help groups, Rootes and Aanes (1992) emphasized that "the establishment of a leadership structure with directive authority would be in conflict with other fundamental concepts of personal responsibility, equality, and self-determination" (p. 380).

As of this writing, in addition to myself, the group comprises 13 members (11 women and 2 men) who have attended the peer support group since February 1990. There was usually a core group of 8 people at every meeting and at least 5 members who attended regularly. The group has an open membership and meets every other week excluding holidays and a summer vacation period. Since its formation, the group membership has been consistent except for 5 persons (3 men and 2 women) who attended a few meetings and decided "not to join at this time." In addition to seeing each other in the group, members also regularly speak on the phone and socialize in each other's homes and in a variety of settings such as parties, museums, plays, and restaurants.

Given the nature of this group and study, it is difficult to quantify the severity of participants' head injuries and their level of functional ability or to provide specifics about persons participating. The following is intended as an impression of this self-selected group. All participants live independently in single-family dwellings or apartments, alone, with family members (children or spouse), or with roommates. Members are approximately 35 to 50 years of age and are college educated. On the basis of coma duration and difficulties seeking and maintaining employment, most members may be considered to have a severe head injury. The cause and nature of the head injuries vary; they include automobile accidents, falls, and serious blows by objects to the skull and brain. Time since injury ranges from 20 years to 6 months. The residual manifestations of the head injury differ widely among group members. To various degrees they include fatigue, impaired cognition (e.g., reported difficulties in organizing and planning, daily memory losses, and judgment problems), speech and language difficulties, and problems in visual-spatial perception and motor performance (e.g., hemiplegia, ataxia), as well as isolation and feelings of poor self-esteem. On a part-time basis, some members work as paid employees, volunteers, or freelance workers or are students. Other members are not employed or have responsibilities of caring for a home and children. All members are ambulatory without a wheelchair; a few require a cane for support while walking or climbing stairs, all appear capable of personal self-care, and some drive while others mostly use public transportation. Meetings take place in a group member's comfortable and attractive home in a predominantly middle- to upper-middle-class suburb in the greater Boston area. The members joined the group upon the recommendation of the President of VALT. Referrals have been made to the President by word of mouth as the group and organization became informally and later more formally recognized.

Method

At the time this narrative was analyzed, the group had met almost every other week, except for periodic planned vacations, for 28 group sessions of 2 hr each over 16 months. According to one of the group's founders, a general purpose of the discussions was "empowerment" of the group members. Through shared responsibility "you think for yourself and that you are, [sic] regardless of what you can do or can't do, you can judge the way others treat you. You think that it is within your capabilities to create a good life for yourself." In addition to these structured meetings, I had informal contacts and conversations with the participants in their homes, at social gatherings, at a professional conference, in car rides to and from meetings, on the phone, over lunch in restaurants, while shopping for food and clothes, and in impromptu meetings on the street. Some members also shared their thoughts through poems, logs, and art work.

Data Collection and Analysis

Before beginning the group, members were informed
that I was the group facilitator and researcher and that
the group was part of an ongoing study to be used in the
education of health care practitioners. Members also un­
derstood in joining the group that the group meetings
were audiotaped by the group for research purposes. On
two occasions the group was also videotaped and those
present gave written informed consent.

For the aims of this ethnographic study, all contacts
with the participants were considered as a basis for un­
derstanding the experience of the group members. The
research question (what are the helping factors in the
group?) was raised after I met to discuss the study with
my colleagues 1 year after the project began. Helping
factors are the peer group experiences and processes
that provide support through self-help. Not under study
were the specific outcomes of this support, such as im­
proved psychosocial functioning of group participants. It
was only after considerable experience with the group
that its unique qualities and the research topic became
apparent. The practice of peer examination or peer de­
briefing is a valuable means of checking findings by clar­
ifying the researcher's perspective and uncovering hidden
biases or meanings (Hasselkus, 1991). Through this peer
review, for example, the term helping factors was substi­
tuted for the terms curative and therapeutic factors be­
because the latter inaccurately implied a medical model
orientation. Additionally, the term peer support group
was deemed more appropriate than self-help group be­
because a self-orientation was antithetical to group cen­
tered patterns emerging in the analysis.

In addition to the former sources of information,
during the group sessions I wrote brief notes on recurring
phrases and themes such as a potent phrase, story, or
joke told in the group. Soon after every group meeting,
and periodically after informal contacts, I prepared ex­tensive field notes about my reactions, including my obser­
vations of events, themes, and hypotheses about the
group's process and meaning.

In this study I used an a posteriori approach to ana­
lyze the data (Schwartzberg, 1982). A thematic analysis
was conducted with the former described data (audio­
tapes, videotapes, transcriptions, and field notes). In ad­
cision, the triangulated data collected by various methods
and sources were “assessed against one another to cross­
check data and interpretation” (Krefting, 1991, p. 219).

I selected one session for first examination because it
was practical to look at a session that had been video­
taped, audiotaped, and transcribed. Reviewing the mate­
rial with the research question in mind, I noted emerging
themes and highly representative member comments. I
kept rereading the transcription from the beginning, each
time getting further and each time making the themes
clearer. At times I added a theme, condensed two where
the topics were the same, and deleted the weaker ones.
Some narrative statements fit with two or more behav­
ioral statements. The narrative was recorded whenever

appropriate. Eventually I converted the themes into beha­
vioral statements because it was easier to identify com­
mentary when there was an action statement. The behav­
ioral statements were termed helping factors.

Recurrent themes or patterns, the behavioral state­
ments, were regularly checked for validity with the par­
ticipants and my colleagues. In addition, weekly phone
conferences between myself and the VALT President were
established by the President for reviewing the group’s
activities and processes. Although topics were not nu­
merically coded in this project as in a previously men­
tioned study (Schwartzberg, 1982), nor were formal hy­
potheses identified, narrative support for each of the
recurrent themes was recorded. When there was no re­
current pattern in the data the theme was dropped. Themes
were retained or discarded when I thought the data
were exhausted. There were no precise quantitative
criteria for these decisions. The stronger conceptualiza­
tions were based on impressions from my observations
and validated by the group members. The sifting through
of themes of sessions to identify salient issues and help­
ing factors was substantially anchored in member narra­
tive and the theoretical-empirical literature. In the find­
ings reported below, a representative sampling of the
narrative is given along with themes within each helping
factor.

Krefting (1991) pointed out that extensive contact
with participants over time and in a variety of settings
encourages genuineness in responses. Furthermore,
with sufficient repeated experience, the researcher has
an opportunity to see recurrent patterns. The triangula­
tion of data from a number of sources further lends to the
credibility of qualitative research. Finally, member check­
ing, through continually reviewing emerging ideas, as­
sures that the participants' views are incorporated into
the findings.

Findings
What are the helping factors in the group? Ten helping
factors are identified and presented along with themes,
the researcher's interpretations of the function these
ideas play for individual members, and narrative repre­
sentative of the group. Statements related to legitimiza­
tion, the acceptance of the head injury as real, is a pattern
found throughout the group narratives.

1. Telling Others About One's Own Pain and Suffering
Themes of lost relationships, status, and capabilities
emerge strongly in member dialogue. Talk about job loss,
divorce, and change in cognitive capabilities is common.
The telling of losses appears to authenticate the reality of
members' experiences.

Member A: I had what they call mild head injury 2½ years ago. A
mild ... it really turned my life upside down. I hit a door frame
with my head and spine when I slipped on a puddle in a wash­room . . . and hit the skull and then landed on the floor and hit on the head . . . I had to learn to get off my own back. Because it wasn’t going to get any better by staying on my back, it just made me feel more miserable. I was in an intimate relationship, and the man couldn’t handle the problems in the early stages and very physically, like I lost my motor skills and my limbs and I had to lie flat for a year, and I lost all control and I lost my speech, my vision changed, my hearing changed, everything changed.

Member B: Did your relationship with him change?

Member A: Yeah.

Member B: Did it end?

Member A: Yeah, it did. He started seeing a third party.

Member B: I never saw my boyfriend after my car accident.

Member C: My name is C and I am a victim of a head injury. . . . I had a degree in physics many years ago. . . . And I went skiing for Christmas vacation the first year (that I moved away from home) in Aspen, Colorado and fell asleep at the wheel of my car on the way back. I was driving a sports car, and my foot went heavy on the accelerator, and the car went off the road, and I was ejected through the roof of the car and I landed about 100 feet from where the car ended up, and the car was destroyed. And at 90 miles an hour, being ejected from a car, I broke only one bone, that bone was my skull. A little size of a half dollar right there. I was lucky to survive, they didn’t think that I would and my recuperation . . . I was hospitalized for a year, both inpatient and outpatient, and after a year they put a metal plate in my head. I was in a coma for 5 months. During this time I was . . . they were teaching me how to walk and how to talk. I couldn’t talk or walk at all. . . . After 5 months, I woke up one morning and I didn’t know where I was, I didn’t know how old I was, I didn’t know what had happened, and I had no idea that I’d been in the hospital for 5 months . . . . My mother had been there for 5 months . . . . And she left 1 week (for home) before I came out of the coma, and I had no idea she had even been there . . . . So I learned to walk again and talk again and I went back to work, part-time, I was employed as an engineer and they took me back to work on a temporary basis as a technician and I really wasn’t, they were going to hire me back as an engineer once I proved myself. I couldn’t prove myself. I never got above the technician level. The whole point of this is that I have been, I was totally disabled at the time, this was 20 years ago, the accident was in 1967.

2. Actively Listening to Familiar Pain and Suffering in Others

By actively listening to others, the members are better able to perceive and sense their own experience as genuine and legitimate. Self-knowledge may also be enhanced by external images of other member’s experiences. The visceral exposure in sensing and visualizing may make the experience more concrete and available.

Member C: You know, to listen to you now I’m thinking I’m doing the same thing but I hold it against myself, I take a very negative image of myself. I hate myself at times because I’m so stupid, I’m so awkward, I’m so inappropriate. In listening to what you’re saying . . . I love what you are saying because it’s me and hearing it in retrospect, hearing about myself from the outside is so . . . I want to learn to love myself, and to understand that I am somewhat limited and I have a disability . . . . Very self-negative, very very I’m very self-negative. If I could just stop this, if I could just, like when you tell your story . . . it is real to me and it’s beautiful and I have lots of compassion for you when you’re doing these stupid things. I do the same stupid things, but instead of hating you I love you because we’re the same, and I can see what you’re going through and I have pity for it. If I could only laugh at myself some more and be compassionate with myself I’d get the deal licked.

3. Accepting That There Is a Problem With Group Recognition of the Problem

Members speak of unsuccessful attempts to accommodate to physical and cognitive changes because of a wish to “pass,” to appear nondisabled to others. These stories often include feelings of humiliation. The member’s lack of acceptance of the head injury as real is perceived as exacerbated by family members and health professionals who do not know or deny that the symptoms and problems are real. Group members rarely let such denial slip by when communicating with each other. By sharing similar experiences, members also educate each other about the effects of a head injury. This helping factor seems of particular value to new group members.

Member D: It was hard to find help because it’s closed [the head injury]. no one can see it . . . . But when I had a cast on my foot, people sent me flowers. And they said, “Is there anything I can do for you?”

Member D: I’ve been trying to get together with X for about a year and a half. But in the beginning I kept losing her number. Which is kind of par for the course . . . . But it wasn’t until I went to the conference that I decided that I wouldn’t try to pass anymore because up to that time I wasn’t willing to accept the fact that I really had a head injury. I had a head injury and it’s been awful and hard and a struggle and my whole family has changed because of it, and we’re continuing to live with it. But when I go out into the world, I would make excuses for what was happening and not just tell people, “Hey, I got hit on the head.”

4. Grieving and Laughing About Daily Situations

At times the group atmosphere is sad as members speak of anger over losses. In these same sessions it is not unusual for members to erupt into laughter as they recognize and speak of daily mishaps.

Member D: A little over a year later, I broke my ankle and it was because two things happened at once. You can’t do more than one thing at a time when you have a head injury.

Member E: You’re lucky if you can do that.

Member D: That’s right. It takes such a long time to do anything.

Member D: For a long time the dinner bell, it got so bad that they [family] took the battery out. we had a fire signal alarm in the kitchen, and I didn’t know for months that you can’t leave a pot on the stove and go out of the room because the minute you go out of the room, you forget that the pot is on the stove. You forget that you are making dinner. You forget you’re hungry. You forget there are people hungry.

Member A: What’s dinner?

Member D: What’s dinner? You forget what time of day it is or what day of the week.
5. Receiving Validation From Others’ Similar Experiences

There is a separate yet related helping aspect to telling one’s own story and listening to others. It comes from the validation of having experiences in common that are recognized and openly talked about.

Member C: I feel a great deal of insight and emotion and perception about our situation.

Member B: And maybe compassion if you see other people dealing with feelings that you've had too.

Member C: You present it as something you walk away from, but you remember when you tell the story, I do the same thing. Burnt pans boil all away, and the pan gets red hot because there is nothing inside to cook and you throw the pan away. But we do the same things. We remember these things. It's a slow learning process trying to readapt to a new situation, a new aspect of mind. It's a tricky business, very frustrating.

Member A: The first 2 years the medical people were very focused on the other injuries, not the head injury. So I was not identified or diagnosed as being head injured. Everybody kept telling me it was all in my head, (that) I was depressed about my divorce, that women get depressed once a month. I wasn't depressed, I was head injured. So there was a lot of ignorance, there was a lot of arrogance, there was a lot of sexism in the medical providers. Oh, there was just a lot of incompetence, people really just didn’t know that.

Member B: And a lot of fear.

Member A: I guess they were fearful. I don’t know. But they missed the boat.

Member B: My theory is this. The reason that medical people miss so much is because it does not fit into their modes of education. They need to develop understanding of variances in the typical situation.

Member E: Amen.

Member B: People who are so technologically and scientifically educated need to put a few teaspoons of heart and compassion in there.

6. Being Accepted by Others and Having a Respite From Hiding One’s Disability

As mentioned earlier, the members spoke of spending considerable energy on attempts to pass. There are fears and many reports of situations of rejection or misunderstanding in the “world of the non-head injured.”

Member D: I try to keep everyone in balance. . . . I don’t want them to see me disabled.

Member F: Why?

Member D: Why? Because it scares everybody.

Member G: The thing that means a lot to me is people, now that I'm getting older, they think I've had a stroke. They don't know that they could get what I have too.

Member B: I understand how people in our group and in groups similar to our group are very helpful to the rest of the world because . . . I remember growing up, people who were disabled or injured were kept in a closet. So when, as we're realizing how we can support each other and grow through this, we are giving people active [sic] to more growth [of their own] rather than being stuck in institutions where people work [directed by others].

Member E: This is not a place for judgment. This is a place for understanding what happened so that we can put it to rest. We can mourn for it and be fully in the present as our new selves. And we can love our new selves because everybody in this room loves us. We care about us, we care about that each one of us is trying our God damn hardest and we know that. And so when you come and you've only written two sentences, that's a triumph. That's not a failure; we don't have failures here. There's no such thing as failures. All we have is we try something, sometimes they work and sometimes they don't.

Member H: What I do when I go to a museum is, 2 days before, I decide how much I am willing to see. Sometimes I find out how much of an exhibit it is and I'll only go to half of an exhibit sometimes because I realize it will overload me.

Member I: I don't think that is a matter of brain injury so much . . . . I think that most artists would feel that they would want anyone to look at their pictures at a time and then come back and get more of it sometime later.

Member E: People enjoy being appreciated.

Member F: Ah, right.

Member I: And there is so much work in any good work of art.

Member F: Ah, right. You have to see it for a second time.

7. Supporting the Survivor's Survival

With recognition of the head injury also comes frustration about the degree of work involved in change and adaptation to limitations. Members give each other hope and encouragement, again often by legitimating the effects of the injury.

Member C: But the whole point is that I feel that I have capability; what do I do with it? I mean I was . . . married at the time. I had left my wife because I didn't want her. I was a crumb, a louse, maybe it was smart. I don't know. She came back to me. After we were divorced she came back to me, and after we'd been living together for a few months I told her we had to split up.

Member A: Was this after the accident?

Member C: This was after the accident. This was absurd. I am mentally defective; I had a woman who loved me and . . .

Member A: You’re not defective; you had a head injury. It's different.

Member C: I can't. One of my traits is I tend to blame myself. I get
very self-negative. I get into these little mental whirlpools. They’ve sent me right down into them. I hated this woman and I didn’t hate her. I threw her away, and I’ve missed her so much. I’m very lonely. I need someone to love. And I’ve had many women throughout these 20 years, but I’m sort of very come and go.

Member E: But if you can’t love yourself, you can’t let anyone else love you.

Member C: The point of this group is to help us help ourselves. I think that one of my biggest hang-ups is being able to love. I’m a loner, I’m withdrawn. I don’t have companionship. The AA groups have been very instilling, slowly impressing, but I tend to rebel because you raise your hand, you speak your little piece, always about how alcohol has destroyed me, how I’m rising above the whole thing. And I don’t want to talk about alcohol, alcohol, alcohol. I want to forget that.

8. Giving and Receiving Practical Suggestions

Discussion of practical problems and barriers inevitably reinforces the authentic nature of the head injury. The giving and receiving of this type of information make the problems more visible.

Member E: The crowd disturbed me. That exhibit at the MFA.

Member B: It would have made me crazy.

Member I: It almost got to me. I felt like I was at the top of a canyon about to fall down.

Member A: Overwhelming is also the Museum of Science.

Member B: It’s like, it pushes you away. It’s too much.

Member H: What I do when I go to a museum is, 2 days before, I decide how much I am willing to see. Sometimes I find out how much of an exhibit it is and I’ll only go to half of an exhibit sometimes because I realize it will overload me. So that when I go in and start to get overloaded, it’s perfectly OK for me to leave and it has nothing whatsoever to do with my head injury. All it is, this is the way I am now, so therefore I have enjoyed this room or this room and a half and now it is time for me to leave. And that’s the attitude I take before I go because I know that there is a lot of people and there is a lot of stimuli there.

Member E: The reason I got so overloaded was I was so interested in seeing what every woman was wearing. [Group laughter]. And so I didn’t look a lot at the art because I was already overloaded from seeing what everyone had on their feet. [Group laughter, right, right, and where they bought their clothes. You know, the usual.

Member B (jokingly): The more important things.

Member E: So I know that when I go to the museum I need to go when it is not packed.

Member E: I think one thing that is part of the healing is grieving for who you used to be. And it’s not just you that has to grieve, but everybody in the family has to grieve for the person they lost. . . . And you have to, I think it would be very helpful if you start to write about who you used to be and who you are now, because out of that writing it will be clear how much is the same and how much it’s the skills that are different. You’re still the same.

Member H: One of the lessons of this injury of mine has been to really be in the moment and not to be anywhere else. So I can’t do two things at the same time and so I have to choose, and if I have to choose a place I think the moment is the best.

Member E: I know because of my body. I feel lots of things, I start to get irritable; like I started to get irritable when you were having a loud exchange that I couldn’t follow.

Member B: I did too.

Member A: It was the words that were getting in the way for me and my attitude towards the words that were getting in the way. So I took my . . . pens, and I drew and now I can go back and put the words to the drawing anytime I want. I can do a sentence, a word at a time.

Member E: But I have to draw first.

Member D: You draw first too?

Member E: Absolutely.

Member D: I heard someone else did. Maybe I should try it, because I’m really frustrated not being able to write.

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Member E: I don’t know what it is.

Member D: That’s some helpful idea.

Member E: Absolutely.

Member E: One thing they showed me is recreational therapy; I never gave it up.

Member E: I have to.

Member A: One of the lessons of this injury of mine has been to really be in the moment and not to be anywhere else. So I can’t do two things at the same time and so I have to choose, and if I have to choose a place I think the moment is the best.

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Member E: Absolutely.

Member D: I heard someone else did. Maybe I should try it, because I’m really frustrated not being able to write.

Member E: I have to.

Member A: One of the lessons of this injury of mine has been to really be in the moment and not to be anywhere else. So I can’t do two things at the same time and so I have to choose, and if I have to choose a place I think the moment is the best.

Member E: I know because of my body. I feel lots of things, I start to get irritable; like I started to get irritable when you were having a loud exchange that I couldn’t follow.

Member B: I did too.

Member A: It was the words that were getting in the way for me and my attitude towards the words that were getting in the way. So I took my . . . pens, and I drew and now I can go back and put the words to the drawing anytime I want. I can do a sentence, a word at a time.

Member E: But I have to draw first.

Member D: You draw first too?

Member E: Absolutely.

Member D: I heard someone else did. Maybe I should try it, because I’m really frustrated not being able to write.

Member E: I have to.

Member A: One of the lessons of this injury of mine has been to really be in the moment and not to be anywhere else. So I can’t do two things at the same time and so I have to choose, and if I have to choose a place I think the moment is the best.

Member E: I know because of my body. I feel lots of things, I start to get irritable; like I started to get irritable when you were having a loud exchange that I couldn’t follow.

Member B: I did too.
Member E: In her training they hadn’t focused on anything related to the head.

Member G: It was all mechanical.

Member E: That’s right.

Member F: That’s right.

10. Distinguishing Problems That Result from the Head Injury From Problems That Would Exist Without a Head Injury

The members spend considerable time sorting the manifestations of brain injury from a world without head injury. The distinctions seem to give support and their expression conveys empathy. Many heated debates focus on defining a head injury. Is it an illness, sickness, or disability? How much of the injury is society’s reaction to the person without injury? Often the group facilitator who does not have a head injury is asked to explain her experience in similar situations. Her questions asking for definition of head injury and its symptoms are always welcomed with a full range of energetic responses. Rarely does everyone have enough time to fully respond to such inquiries.

Member G: Your children are wonderful, they really are incredible.

Member E: Except if you have to pick up after them.

Member G: That’s normal. It has nothing to do with your accident.

Member E: No. Tolerating them is the hard part.

Member B: You’re their mother. And the thing that parents tend to do is they tend to smother children and not realize that their children have the spark to grow and develop skills and be happy and maybe they’re thrilled to death to be helping their mom.

Member D: Well, they do, they enjoy it sometimes but sometimes it’s hurtful to them. Like when I can’t hear two of them talking, or sometimes I can’t even understand one of them.

Member B: But look at the world. You know, if you go into a store and you want to get someone’s attention and someone else is trying to get someone’s attention: it’s the kind of thing they’re going to have to become used to.

Discussion

Although the role of a professional in a therapist-led group is essentially different from the role in a peer-led group, Lieberman (1990a) emphasized that “a critical function that group therapists can play in aiding SHGs [self-help groups] is simply to help give them legitimacy” (p. 271). The notion of legitimization, or the acceptance of the head injury as real, is an important theme underlying the findings of this study. In this study, however, more important than the therapist legitimizing the group is the members of the group legitimizing the head injury. This is not surprising given the invisibility of a closed head injury after acute trauma. In this study, it is not the therapist but the group itself that gives legitimacy to both the diagnosis and the residual manifestations of the trauma. The apparent success of this group, as measured alone by its regular attendance and self-direction, can be attributed to two related factors: (a) the group’s ideology is formed around legitimization as a theme and (b) the group format incorporates processes that Lieberman (1990b) described as characteristic of successful peer support groups. He identified four conditions as necessary for positive outcomes in a self-help group: (a) group cohesiveness; (b) saliency, a belief that the group is helpful because of its unique membership and shared problem; (c) cognitive restructuring, the making of comparative judgments leading to new ways of thinking and exchanging information; and (d) diversity of experience. Other things being equal, the overall benefit to the largest number of participants in a group will be maximized if such groups not only permit but encourage a wide range of behavior—what is talked about and how it is talked about as well as a wide range of “curative factors.” (Lieberman, 1990b, p. 33) Factors that help create a feeling of acceptance and belonging, or cohesiveness, are a “shared sense of suffering” and a feeling of being “stigmatized” (Lieberman, 1990a, p. 271). These factors legitimize the experience of head injury as real and in doing so may foster the conditions necessary for the group to thrive. The role of multiple group formats for processing information may be particularly important with persons who have brain injury because of the variety of differences due to cognitive changes.

The disproportionate number of female group members (11) versus male group members (2) may have affected the study. The relational aspects of helping, such as active listening, may be especially important to women. The wish to legitimate injuries may also be an acute need of women with disabilities. There may be extraordinary pressure to pass for a person without disability because in our culture so much emphasis is placed on a woman’s appearance. The peer support group provides a safe place to make visible a brain injury that is invisible to the public. It is a paradox that this same injury manifests symptoms that the victim hides in order to visibly appear like others. Persons with a head injury refer to themselves as victims and survivors. This label should heighten therapists’ attention to feelings of shame in persons with a head injury and to commonly concealed emotional aspects post injury.

The make-up of the support group is not typical or representative of the population of persons who have head injuries. Most people with a head injury are young males. Unlike the participants of this study, who are predominantly female, with prior social roles, and living in their own households, persons with a head injury are probably members of a self-help group.
more apt to be living with a parent and have limited consolidated social roles as a worker, parent, or intimate partner. Before their injury, several participants had intimate relationships; careers in fields such as science, art, writing, and teaching; and were responsible for large households and children. We therefore cannot generalize these findings easily to what may be considered a typical population of persons who have had a head injury.

The occupational therapist’s role with peer support groups is given scant attention in the occupational therapy literature (Sacenti, 1988). Likewise, the health professional’s role with peer support groups for persons with a head injury is hardly covered. Differences between other types of self-help groups and psychotherapy groups are more fully addressed in the group psychotherapy literature (Lieberman, 1990a). Along with the aim of decreasing dependency on the therapist, the roles of learner–participant and role model have been suggested for the occupational therapist assisting persons in deinstitutionalization through a club support group (Auerbach, 1974).

The value of participant observer and learner roles for the group facilitator are also implied in this study’s findings. Knowledge of the functional aspects of disability, community resources, and group activity analysis and adaptation techniques enable occupational therapists to easily assume unique roles in support groups for persons with head injury in helping to establish, facilitate, or act as advocates with such groups. Rather than assuming responsibility for the group of persons with a disability or family members, the therapist can engineer a milieu in which participants function as fully and independently as possible.

This study begins to describe unique self-help qualities in a specialized group for persons with a head injury. One may only tentatively extrapolate some things about the special needs of this population from the data. For example, there may be an important relationship between members’ cognitive difficulties, the facilitator’s role, and helpful group processes. It is recommended that in addition to the researcher–facilitator’s view of the helping factors, the members’ views and objective, behavioral outcomes be studied. The group format and intervention methods used with self-help groups, as well as the education and role of professionals such as occupational therapists, are topics that deserve serious attention. Also indicated is a systematic study of changes in participants’ social networks and their economic and emotional recovery.

Conclusion

Through a qualitative analysis of group discourse, helping factors present in a peer support group for persons with head injury were identified. Helping factors are peer group experiences and processes established theoretically and empirically to provide support through self-help. These processes include believing and feeling part of the group because members have a common problem and can validate the effects of the injury by sharing and receiving information in a variety of ways through the group. The helping and supportive nature of this group is exemplified by themes of legitimization and the group’s processes. Through self-advocacy, members of this peer-developed support group have developed a fellowship network. The achievements of this group will evolve as members chart its direction through stages of development. ▲

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