

Implementation and Evaluation of a Pilot Support Group for Individuals with Spinal Cord Injuries

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ABSTRACT

It is estimated that 250,000-400,000 individuals are living with spinal cord injuries (SCI), and approximately 7,800 new injuries occur each year. Support for SCI individuals is important for overcoming the challenges of life with a spinal cord injury. The need for a SCI support group was established in the La Crosse and surrounding areas. Therefore, the purpose of this research was to conduct a pilot study of four support group meetings to determine the effectiveness of the support group. This research was conducted in conjunction with healthcare providers from a local hospital. Four meetings were completed in which 6 SCI individuals and 5 family members attended. Following these meetings, a survey was distributed to assess the effectiveness of the support group. Using the Statistical Package for the Social Sciences (SPSS) Version 10.1, it was found that the support group was effective and was desired to continue. The participants concluded that they would like to have the support group meetings continue monthly, on the weekday evenings for one and a half hours at the Health Science Center on the UW-La Crosse campus. The rehabilitation staff at Gundersen Lutheran Medical Center will continue the support groups in June 2003.

Keywords: spinal cord injury, support group, occupational therapy

INTRODUCTION

According to Baldwin, Brown, Johnson, and Rivard (2002) a needs assessment was completed in La Crosse and the surrounding areas and results indicated that there was a need for a SCI support group in the area. Based on this need, a pilot support group was implemented in conjunction with Gundersen Lutheran Medical Center rehabilitation staff. This study evaluated the effectiveness of the pilot support group through a quantitative survey. It was hypothesized that spinal cord injury individuals would benefit from the support group and would desire its continuation after the research project was completed.

Announcements were sent to fifty-five individuals with spinal cord injuries throughout La Crosse and surrounding areas indicating location, date, time of the support group and topics to be discussed. A statement of informed consent was sent with the initial announcement and also distributed during the first support group meeting. Of the fifty-five individuals who were contacted, a total of seven SCI individuals and six family members attended the support group meetings.

The results of this research can be used by occupational therapists and other health care professionals. These professionals often work with individuals that need to cope with a devastating injury that frequently results in a permanent loss of function. Following discharge from the hospital, there may be a lack of resources in the community to help SCI individuals cope with their injury. By developing and facilitating a support group, healthcare providers can present a much-needed service to these individuals. In addition, by attending the support group sessions, occupational therapists and other health care professionals can develop a better understanding of issues and concerns of clients following discharge that they can use to help improve therapy services.

Definition of Terms

Spinal Cord Injury—A spinal cord injury is damage to the spinal cord resulting in a disruption in the motor and sensory pathways at the site of the lesion (Trombly, 1997). Spinal cord injuries can be the result of motor vehicle accidents, diving accidents, falls, and violence.

Paraplegia—An injury that results in total or partial loss of feeling and movement of the lower half of the body with involvement of both legs.

Hemiplegia—An injury that results in total or partial loss of feeling and movement on one side of the body.

Support Group—a group of people with common experiences and concerns who provide emotional and moral support for one another.

LITERATURE REVIEW

Effects of a Spinal Cord Injury

Individuals with a spinal cord injury (SCI) face many changes other than a loss of feeling or motor functioning, which affect their daily life. Matters involving psychological, sociological, interpersonal, and cultural factors may emerge following the stabilization of the injury. Those who are married at the time of injury are less likely to maintain an intact marriage as compared to uninjured, married individuals. Subsequently, the outlook of marriage for single individuals with a spinal cord injury is also reduced (Spinal Cord Injury Facts, 2000). Research completed by Marini & Rogers (1995) shows there is a decrease in employment following a spinal cord injury. Prior to the injury, 76% of those studied were employed compared to 9.5% employed post-injury. Depression and anxiety can occur in individuals with a SCI as a result of bowel and/or bladder dysfunction, sexual dysfunction, and an increased dependence on others. Poor adjustment to the disability has been associated with deaths that could have been prevented, due to self-destructive behaviors (Hanson et al., 1993). If feelings of denial, anger, and frustration are not addressed, poor coping and adjustment skills result (Carter, 2001). These issues reflect the psychological impact of having a spinal cord injury, and are therefore a primary concern of those individuals and their family members. Psychological services for these individuals are vital in the coping process.

Research on the long-term psychosocial implications of having a spinal cord injury has only recently begun (Whiteneck et al., 1992). An individual's perceived life satisfaction, which is broadly associated with psychological well-being, may be affected. Studies on individuals with a spinal cord injury have indicated some of the factors associated with life satisfaction. These include: good health, emotional stability, positive perception of disability, peer and social interaction, and unconstrained living environment (Kinney & Coyle, 1992). When social isolation occurs, self-esteem may be influenced. Current data suggests self-esteem may be at the most vulnerable state in the second year following the initial injury. Most individuals have made gains in strength and are residing at home, but experience a lower level of social support than during the hospitalization phase (Marini & Rogers, 1995). Community life participation and out-of-home activities have also been shown to significantly influence the quality of life, which is why participation in a support group may be essential. Research suggests the need for practitioners to adopt a stronger effort toward assisting individuals out in the community with a spinal cord injury when difficulties arise (Marini & Rogers, 1995).

Support Groups

“Support groups provide the opportunity to share one's own experiences and benefit from those of others in the group having similar circumstances” (“About Support Groups,” 2002). “At the very least, support groups offer an opportunity to discuss the condition without the fear of burdening or boring friends and family. They can spawn new friendships, offer coping strategies, and alleviate stress.” (“Support Groups,” 2002) The National Spinal Cord Injury Association (1996) stated that, “support groups provide a valuable service not only for counseling and support, but also for socializing and information sharing.” Those who have “older” injuries have information and valuable tips to share with “newer” injuries.

Pascoe, Edelman, and Kidman (2000) studied the prevalence of psychological distress and the use of support services by cancer patients, and found that of the patients who were attending support groups at the time of the study, the vast majority (82%) were not experiencing clinically significant psychological symptoms. Given the high degree of satisfaction expressed by patients who attended support groups, 83% found them to be ‘extremely’ or ‘reasonably’ helpful. Based on this study, it appears that beneficial resources, such as support groups, are being poorly used. Spiegel et al. (1989) completed a study which focused on the effects of support groups on women with metastatic breast cancer and found that those women who attended weekly support groups lived, on average, twice as long as did the other group of women who didn't attend the support group. Support groups, while becoming more common, have generally been an “extra,” not an integral part of cancer management, and not strongly advocated; as a result, only a very small proportion of patients attend them (Cunningham & Edmonds 1996). An additional study was completed on the encouragement and facilitation of support and self-help group use. This study has shown that 87% of attendees found support groups as useful to recommend them to others. Approximately, 67% of interviewees believed a support group would have been beneficial to them in the past, but were not advised about their existence. Only 30% had attended a support group in the past (“Hand in Hand,” 1999). From reviewing the literature, the need for social support, community, and intimacy are shown to be an integral part of our survival.

Process of Starting a Support Group

Step One: The focus of this step is to ascertain the need for a support group. The emphasis should be placed on obtaining the demographics of the group to determine who will attend the group and what topics will be discussed. Another consideration is whether the group will only be for individuals with disabilities, or also for family members and friends. ("Starting a Support Group," 1996).

Step Two: The focus of this step involves planning the support group. It is important to decide on the frequency, location and emphasis of the support group before the first group meeting. Harmon and other experts believe the decision to join a support group should be made after considering one's support needs ("Will a Support Group," 2000). Conducting a needs assessment will assist in obtaining important pieces of information for the planning process, such as, selecting the strategy a program may utilize and gathering information about the perceptions of individuals with a spinal cord injury. This could assist in selecting an appropriate approach to developing a support group to meet their needs (Archer, Cripe, & Mc Caslin, 2002). By administering a needs assessment after a support group has been established and implemented, it is possible to check the headway made in reducing the unmet needs of individuals with spinal cord injury in an area (Archer, Cripe, & Mc Caslin, 2002).

Step Three: The focus of this step involves deciding on the location of the support group. A rotating meeting place may make the meeting more accessible for individuals with limited transportation options, and for those who are traveling a greater distance ("Starting a Support Group," 1996).

Step Four: The focus of this step involves marketing and publicity, which is crucial to starting a support group. Available media to publicize includes: newspapers, radio stations, and television ("Starting a Support Group," 1996).

Step Five: The focus of this step involves programming for the support group. The needs assessment will provide beneficial information in regard to topics the support groups should address ("Starting a Support Group," 1996). The most important things to remember about a support group is that what one gives back to the group can be what helps it perpetuate and be available for others to need to have the same support as that individual ("About Support Groups," 2002).

METHOD

Participants

The participants in this study included seven individuals with spinal cord injuries individuals and five family members from the La Crosse and surrounding areas. Four individuals were paraplegic, one hemiplegic, and two individuals had a spinal disease. Five of the participants were family members. The average distance each individual traveled was 25.2 miles with the mileage ranging from 5-35 miles. Eight of the eleven participants were married, two divorced, and one widow/er with their average age being fifty-nine years old. One of the participants was twenty-three years post-injury while the majority of the participants were one to five years post-injury.

Procedure

The need for a spinal cord injury support group was established in a prior study. Researchers received approval from the Institutional Review Board for the Protection of Human Subjects Committee. A multidisciplinary team was formed by Gundersen Lutheran Medical Center to discuss marketing strategies and the format for the support group. An announcement was sent out to fifty-five SCI individuals under Gundersen Lutheran's number coding system to protect confidentiality. An informed consent was also sent out or completed for each new individual before the support group meetings began. A survey was distributed and completed after the fourth support group meeting to determine the effectiveness and recommendations for continuation of the support group meetings. Please refer to Appendix A.

Pilot Support Group Study

Four spinal cord injury meetings were implemented which took place monthly for one hour and thirty minutes. Four student researchers/facilitators were present as well as a UWL OT faculty member or Gundersen Lutheran Medical Center staff. The meetings were held at the Health Science Center on the UW-La Crosse campus from December to March. Beverages and snacks were provided for the participants at each meeting. The informed consent was reviewed and signed by the new participants each week. Introductions amongst all group members occurred at the beginning of each support group meeting. The support group meetings lasted one hour and thirty minutes with an additional thirty minutes for socialization.

Session 1: This session included an introduction of the researchers and participants, an icebreaker, an explanation of our goals of the research project, and review of the informed consent form. The participants established a list of topics they would like to address in the following support group meetings.

Session 2: The topics of bowel and bladder dysfunction, travel, driving, and new technologies were discussed among the participants. Participants shared helpful hints and frustrations regarding these topics.

Session 3: Participants gave insights and helpful hints for daily challenges, especially bowel and bladder. The importance of exercise, keeping active, and wheelchair athletics was discussed.

Session 4: New participants shared their stories and difficulties they face. A survey was given out to the participants at the end of the meeting. We informed the participants that Gundersen Lutheran Medical Center staff would be continuing the support group starting in June 2003.

Data Analysis

A survey was designed to evaluate the effectiveness of the support group meetings. Participants responded to the survey questions using a Likert scale. The Likert scale ranges from 1 to 5 with 1 being a strong agreement and 5 being a strong disagreement. The Statistical Package for the Social Sciences (SPSS) program was used to collect and interpret the results of the survey after the surveys were received.

RESULTS

A Likert scale was used to measure the agreement of each survey question. Eleven individuals completed surveys following the last support group meeting. Descriptive statistical analyses were computed using the Statistical Package for the Social Sciences (SPSS) Version 10.1 for Windows (Cronk, 1999). Frequencies, descriptive statistics, and percentages were the most beneficial tools for analysis of the gathered data.

Pilot Support Group

The pilot support group meetings were held at the Health Science Center on the UW-La Crosse Campus. The members reported that the building was accessible and comfortable. The participants also agreed that the support group meetings fit their schedule. The survey results indicated 91% of the participants reported satisfaction in regards to the support group addressing socialization, 82% reported satisfaction in regards to coping techniques, 73% reported satisfaction in regards to travel opportunities, and 55% enjoyed learning about medical/research updates. Figure 1 indicates the participant's met needs in regards to health issues, networking, socialization, driving modifications, and emotional issues.

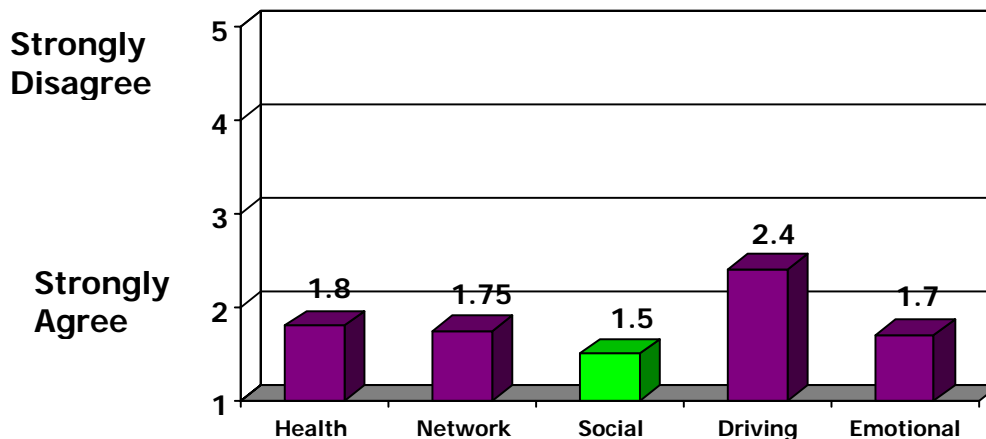


Figure 1. Participant's Needs Met

Figure 2 indicates group participation in regards to having equal opportunity to talk and share ideas with others, feeling comfortable in sharing information, and ability to contribute to the overall group discussion.

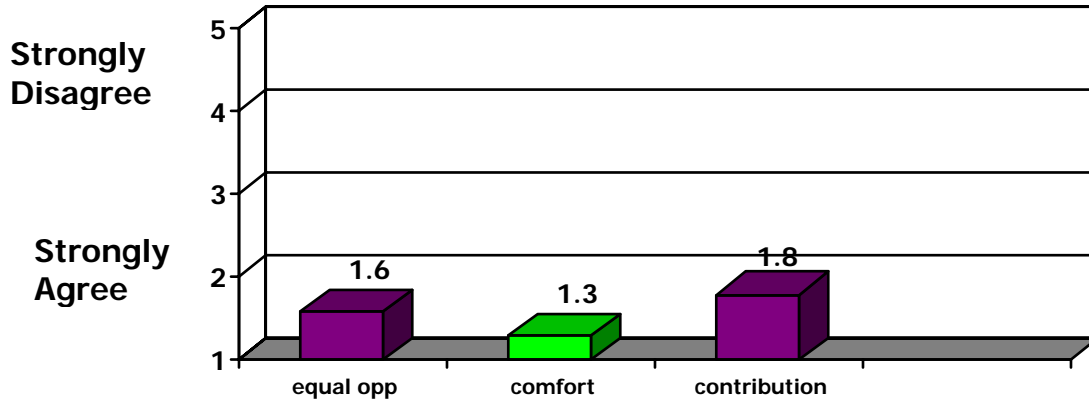


Figure 2. Group Participation

Figure 3 indicates the facilitators' ability to reflect adequate leadership through engaging group members in discussion, providing a comfortable atmosphere for participants, transitioning between topics, and providing advanced notice of meetings.

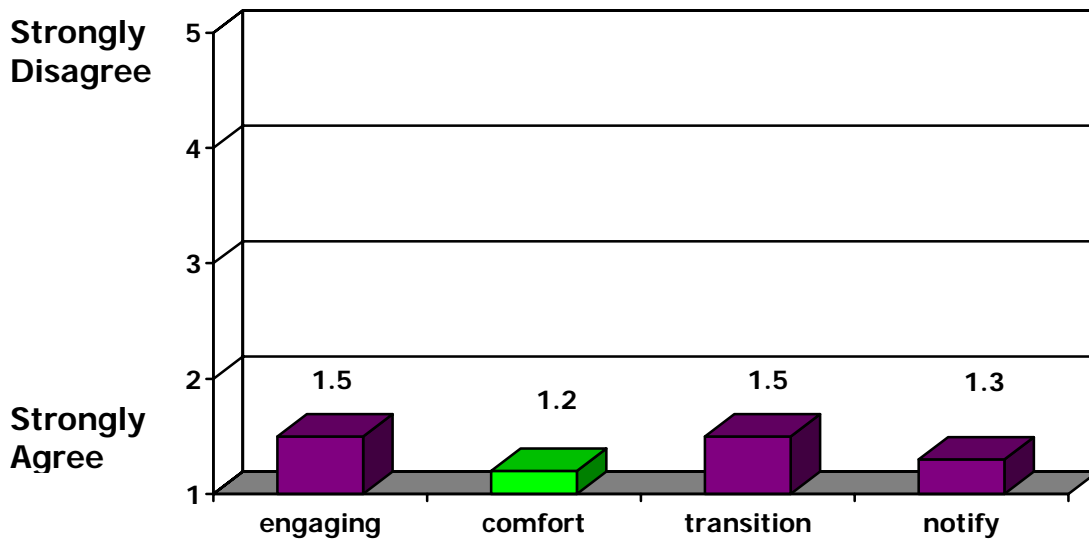


Figure 3. Facilitators' Leadership

Figure 4 indicates the participants preference in having the support group meetings take place through: face-face meetings, email, newsletter, or by phone.

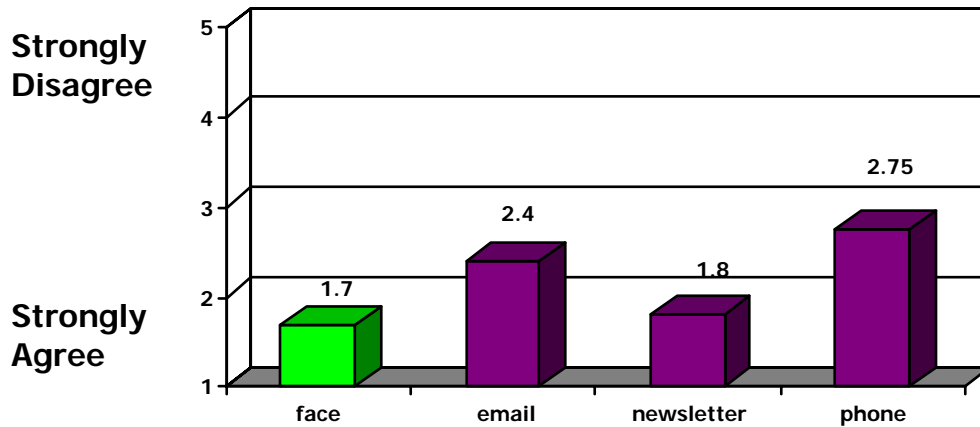


Figure 4. Type of Support Group

Support Group Format

The survey results indicated that if the support group was to continue it should occur monthly, on the weekday evenings for one and a half hours at the Health Science Center on the UW-La Crosse campus. Although there was not a split support group between SCI individuals and family members in the pilot support group, results of the survey indicated an agreement to implement a split in the future support group. Suggested topics to be discussed in the future support group include: aging in a wheelchair, nerve damage, home modifications, work issues, and spinal cord bruising.

DISCUSSION

The research hypothesis was supported stating that individuals with spinal cord injuries would benefit from the support group and desire its continuation. The effectiveness of the support group has been identified, and Gundersen Lutheran Medical Center staff will continue the support group meetings in June 2003.

The survey indicated that the support group met the participant's needs in regards to health issues, networking, socialization, driving modifications, and emotional issues. Similarly, Pascoe et al. (2000), found that cancer patients attending support groups did so for reasons other than psychological morbidity, such as, companionship, information, and relaxation. While attending the support groups, the participants felt very comfortable sharing their ideas with others, felt they had an equal opportunity to discuss, and were able to contribute to the overall group discussion. The facilitators for the support group were non-injured individuals, yet the participants felt they provided adequate leadership skills. These areas of leadership included: engaging group members in discussion, providing a comfortable atmosphere, transitioning between topics, and providing advance notice of the meetings. This differs from a study conducted by Spiegel et al. (1989), in which the group sessions were led by a therapist who had breast cancer, as did the participants. The participants felt that no one understood what it meant to have breast cancer better than someone who has gone through a similar experience and therefore preferred a facilitator who was a cancer survivor.

As a result of the SCI support group, a sense of community and intimacy began developing. The participants felt that the best forum to hold the support group would be a face-to-face meeting to maintain the personal connections. Since the majority of the participants were from rural areas, this group gave them all an opportunity to re-connect each month.

RECOMMENDATIONS

The information gathered from the survey provides Gundersen Lutheran Medical Center with recommendations of structure and content for continued support group meetings. Based on the results of the survey, some recommendations include:

- 1.) holding a monthly face-to-face meeting with a follow-up newsletter of information discussed in the meeting.
- 2.) splitting the support group between caregivers and SCI individuals for a portion of the time.
- 3.) holding the support group on a weekday evening at the Health Science Center for a one and a half hour period of time.

LIMITATIONS

There are a number of limitations that may have affected the results of the study. One limitation of the research was having a small sample size. Increasing the sample size may have enhanced the findings by providing more data. Bad weather conditions and the location of the support group could also have been a limitation. Since three out of the four meetings were held during the winter months, travel was difficult for the majority of the participants who drove from surrounding areas to attend. Another limitation is that only SCI individuals from Gundersen Lutheran Medical Center were notified for the participation in the study. Also, Gundersen Lutheran Medical Center did not have the most recent address for these patients in their database; therefore, some individuals could not be contacted. Some of the participants were not present at all four meetings, which could have impacted their response to certain questions on the survey. Finally, many questions on the survey were left blank by participants, which could have skewed the results.

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APPENDIX

SCI Survey Form

Circle one: SCI participant Family member

1.) Please complete the following questions:

Age: _____

Sex: Male _____ Female _____

Marital Status: Single _____ Married _____ Divorced _____ Widow/er _____

Current Living Status:

Alone _____

With family members _____

Assisted living facility _____

I am currently employed? Yes ___ No ___

Type of Injury (if applicable)

Paraplegic _____

Quadriplegic _____

Hemiplegic _____

Number of years since injury (if applicable) _____

How many support group meetings did you attend? _____

What town do you live in? _____

How many miles did you travel each way to attend the support group? _____

Indicate your level of agreement with the following questions using the given five-point scale.

Pilot Support Group Meetings:

2.) The support group met my needs in regards to:

	Strongly Agree				Strongly Disagree
a. Health issues	1	2	3	4	5
b. Networking	1	2	3	4	5
c. Socialization	1	2	3	4	5
d. Driving modifications	1	2	3	4	5
e. Emotional/adjustment issues	1	2	3	4	5
f. Other _____	1	2	3	4	5

3.) In regards to my participation in the group, I felt that I:

	Strongly Agree				Strongly Disagree
a. had equal opportunity to share	1	2	3	4	5
b. was comfortable sharing info.	1	2	3	4	5
c. contributed to the group	1	2	3	4	5

4.) The time of the meeting fit my schedule.

1	2	3	4	5
Strongly Agree			Strongly Disagree	

5.) I felt that the Health and Science Center was:

	Strongly Agree				Strongly Disagree
a. a comfortable meeting place	1	2	3	4	5
b. easily accessible	1	2	3	4	5

6.) The facilitators reflected adequate leadership by

	Strongly Agree				Strongly Disagree
a. engaging group members in discussion	1	2	3	4	5
b. providing a comfortable atmosphere	1	2	3	4	5
c. transitioning between topics	1	2	3	4	5
d. providing advanced notice of meetings	1	2	3	4	5

7.) Transportation to the support group was easily accessible.

1	2	3	4	5
Strongly Agree			Strongly Disagree	

8.) Topics/information that I enjoyed include: (check all that apply)

- a. Medical/Research Updates provided by group members _____
- b. Socialization _____
- c. Coping Techniques _____
- d. Resources _____
- e. Travel _____
- f. Other _____

Future Recommendations:

9.) I would be interested in continuing my participation in a support group for SCI individuals.

1	2	3	4	5
Strongly Agree			Strongly Disagree	

10.) I would be interested in having the group split between family member and injured individuals for a portion of the time.

1	2	3	4	5
Strongly Agree			Strongly Disagree	

11.) I would be interested in having the support group held at: (Check one)

- a. Gundersen Lutheran _____
- b. Franciscan Skemp _____
- c. Health Science Center _____
- d. Other _____

12.) The following type(s) would best interest me in a continued support group.

	Strongly Agree				Strongly Disagree
a. Face-to-Face	1	2	3	4	5
b. E-mail	1	2	3	4	5
c. Newsletter	1	2	3	4	5
d. Phone	1	2	3	4	5
e. Other _____					

13.) I would like the support group to meet:

	Strongly Agree			Strongly Disagree	
a. Monthly	1	2	3	4	5
b. Quarterly	1	2	3	4	5
c. Every other month	1	2	3	4	5

14.) I would prefer the support group to meet on:

	Strongly Agree				Strongly Disagree
a. Weekdays	1	2	3	4	5
b. Weekends	1	2	3	4	5

15.) I prefer the support group to meet in the:

	Strongly Agree				Strongly Disagree
a. Morning 1	2	3	4	5	
b. Afternoon	1	2	3	4	5
c. Evening 1	2	3	4	5	

16.) I would like the meeting to last:

	Strongly Agree				Strongly Disagree
a. 1 Hour	1	2	3	4	5
b. 1 ½ Hour	1	2	3	4	5
c. 2 Hours 1	2	3	4	5	
d. Other _____					

17.) Future topics that I would like to discuss during continued support group meetings are:
