The Needs Assessment of a Supoort Group for Spinal Cord Injury Members of the La Crosse and Surrounding Areas

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ABSTRACT

The devastating effect of a spinal cord injury leads to a large adjustments in an individual's physical and psychosocial abilities. Support for spinal cord injury individuals is important for overcoming the challenges of life with a spinal cord injury. In collaboration between occupational therapy students and local rehabilitation professionals, a lack of services and support for individuals with spinal cord injury in the La Crosse and surrounding areas has been identified. The objective of the research was to assess the needs of spinal cord injury individuals in the La Crosse area in regards to a support group, and, based on those needs, determine the most effective means of providing support to the spinal cord injury members of our community. The information has been obtained through a qualitative survey developed, in conjunction with, a multidisciplinary team at Gundersen Lutheran Hospital. The survey was distributed to thirty-nine spinal cord injury members of the La Crosse community. Of the thirty-nine, fourteen surveys were returned, yielding seven males, six females, and one unknown between the ages of 18 and 66. The findings conclude that the recommended format for a support group would be a newsletter or face to face group meeting taking place quarterly/monthly, for two hours during the week, and in the evening.

INTRODUCTION

The La Crosse area currently does not have a support group for spinal cord injury patients. Gundersen Lutheran Medical Center serves as a major provider of services to local spinal cord injury patients, and has suggested the need for research and development in this area. This study evaluates the interest for beginning a support group in the La Crosse area and also determines the content and form in which the support group will be delivered. It is hypothesized that there is indeed a need and interest for a spinal cord injury support group in the La Crosse and surrounding areas.

A pilot study was conducted to determine the validity of the questions administered through the survey, and adjustments were made according to the responses that were received in order to enhance the quality of the survey. Surveys were sent to thirty-nine individuals with spinal cord injuries throughout the La Crosse and surrounding areas. A statement of informed consent was sent with each survey allowing the subjects to understand the purpose of the research and their willingness to participate in the project. Of the thirty-nine surveys that were distributed, fourteen surveys were returned. Confidentiality was maintained throughout the research project by use of a coding system with the names of the individuals only known by staff at Gundersen Lutheran.

The objective of this research was to assess the needs of spinal cord injury individuals in the La Crosse area in regards to a support group, and, based on those needs, determine the most effective means of providing support to the spinal cord injury members of La Crosse community. Upon determining group needs, researchers will be able to provide an emotionally supportive and educational environment for local SCI individuals. Occupational therapists can apply results of this research in program development, which is an emerging market for the profession. The results can also be used to enhance pre-existing support groups already in progress.

LITERATURE REVIEW

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). It has been currently estimated that 250,000 individuals are living with a spinal cord injury in the United States and 11,000 new spinal cord injuries occur every year ("Living with," 2001). Spinal cord injuries are typically the result of motor vehicle accidents, violence, diving accidents, and falls (Parsons & Lammertse, 1991). Although spinal cord injuries primarily affect young adults, most of the injuries (82%) involve males between the ages of 16 and 30 ("Living with," 2001). Spinal cord injuries result in paraplegia or quadriplegia of the involved individual. Paraplegia is described as an injury that leaves an individual with a loss of feeling and movement in the lower parts of the body. Quadriplegia is described as an injury leaving an individual with a loss of feeling and movement in both the upper and lower parts of the body. Quadriplegia has been found to be slightly more common than paraplegia ("Common Questions," 2002).

Besides a loss of feeling or motor functioning, spinal cord injury individuals may face other changes that affect their daily life. When the injury has stabilized, difficulties involving psychological, sociological, interpersonal, and cultural factors may appear (Piazza et al., 1991). In relation to marital status, those married at the time of the injury are less likely to maintain an intact marriage as compared to uninjured, married individuals. In addition, the outlook for single individuals with a spinal cord injury getting married after injury is also reduced ("Spinal Cord Injury Facts," 2000). In relation to employment status, research has shown there is a decrease in employment following a spinal cord injury. Before injury, 76% of those studied were employed compared to 9.5% employed post-injury (Marini & Rogers, 1995). Individuals with a spinal cord injury may also experience bowel and/or bladder dysfunction, sexual dysfunction, and increased dependence on others. Conflicts, such as these, can lead to depression and anxiety. Evidence shows that poor adjustment to the disability has been associated with deaths that could have been prevented, due to self-destructive behaviors (Hanson, et al., 1993). Individuals with a spinal cord injury face a variety of feelings such as denial, anger, and frustration following the injury. If these feelings are not addressed, poor coping and adjustment skills result (Carter, 2001). The psychological impact of having a spinal cord injury is therefore a primary concern and psychological services for individuals are vital to aid in the coping process.

Researchers have only recently begun to study the long-term psychosocial implications of having a spinal cord injury (Whiteneck, Charlifue, & Frankel, et al., 1992). An individual's perceived life satisfaction following injury is one such psychosocial implication. Life satisfaction is described as a psychological state that may be broadly associated with psychological well-being (Neugarten, Havighurst, & Tobin, 1961). When social isolation occurs, this may influence self-esteem (Nelson, 1987). Current data suggests self-esteem may be most vulnerable in the second year of injury. One explanation is the existence of social support from friends and family initially following an injury. Two years following injury, when individuals with spinal cord injury reside at home, most have made gains in strength, are unemployed, and experience a lower level of social support than during the hospitalization phase (Marini & Rogers, 1995). It is at this point when individuals with a new spinal cord injury have questions and concerns regarding a change of roles within the community. Current research suggests the need for practitioners to put forth greater effort toward assisting individuals with spinal cord injury with the psychological effects of an injury when difficulties arise, out in the community (Marini & Rogers, 1995). Participation in community life and engagement in out-of-home activities has also been shown to significantly influence the quality of life (Fossati, 1990). It has been found that individuals with physical disabilities are least satisfied with their financial status, employment, sexuality, life opportunities, and recreational opportunities (Krause, 1992). Studies on spinal cord injuries in the past 30 years have indicated the following factors are positively correlated with life satisfaction: good health, emotional stability, control, positive perception of disability, economic security, productive activity, peer and social interaction, and unconstrained living environment (Kinney & Coyle, 1992).

The National Spinal Cord Injury Association (1996) has stated that, “support groups provide a valuable service not only for counseling and support, but also for socializing and information sharing.” “Old timers” have information to share with newer injuries, and groups have more influence with vendors or medical professionals to present information and products. The process of beginning a support group can be broken down into five steps. During step one, it is important to get an idea of how many people want a support group. A feel for the demographics will not only affect whom you have in the group, but where you want the group’s emphasis to be. Another important decision is whether you want the meeting to be for people with disabilities or also for family and friends. Step two involves planning. It is important to decide a number of things before the first meeting of the group including frequency, location, and emphasis of the group. 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). A needs assessment would assist in the obtaining of these important pieces of information. A needs assessment can be used in several ways. Sometimes the gap between “what is” and “what should be” establishes the objectives for programs. Needs assessments also help to select the strategy a program might utilize. Information about the perceptions of individuals with spinal cord injury could assist in selecting an appropriate approach to developing a support group to meet their needs. Sometimes information from a needs assessment is used for designing or modifying an instructional program as well as to evaluate progress. 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, & McCaslin, 2002). Step three is deciding on the location for the support group. A rotating meeting place may make the meeting more accessible for individuals with transportation problems. Step four is publicity, which is crucial to starting a support group. Available media to publicize in include newspapers, radio stations, and television. Step five 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). Support groups provide the opportunity to share one's own experiences and benefit from those of others in the group having similar circumstances. The most important thing 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 who need to have the same support as that individual ("About Support Groups," 2002). Research has shown that 87% of attendees found support groups as useful to recommend them to others. 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). All in all, support groups can offer a nice blend of information, emotional support, and social interaction, not to mention their importance to those who are newly injured (Barbara, 1999).

METHODS

Participants

Surveys were distributed to thirty-nine individuals with spinal cord injury in the La Crosse and surrounding areas. Seven males and six females participated in this study. The mean age of the participants was 46.15 years of age and ranged from 18 to 66 years of age. Of the fourteen respondents, 57.1% were paraplegics, 14.3% were quadriplegics, and 21.4% had spinal diseases or were family members. 50% of the participants lived with family, with an equal numbers being either married or divorced.

Procedure

Researchers received approval by the Institutional Review Board for the Protection of Human Subjects Committee. A qualitative survey was distributed to SCI members of the La Crosse community obtaining personal experience while gaining a holistic perspective of the individual. The survey was developed in conjunction with a multidisciplinary team at Gundersen Lutheran. The survey was sent to a list of SCI individuals provided by Gundersen Lutheran Hospital. Implied informed consent was obtained through completing and returning the survey. Please refer to Appendix A.

Pilot Study

Prior to sending out the surveys to our target population, a pilot study was conducted using three individuals with spinal cord injury to establish the validity and effectiveness of our survey. One pilot survey was returned showing that our survey design was comprehensible and useful in obtaining the desired information.

Data Analysis

Participants responded to survey questions using a Likert scale. After surveys were received, SPSS was used to analyze the responses. The use of a Likert scale was chosen due to its compatibility when using the SPSS program. The Likert scale ranges from 1 to 5 with a 1 being strong agreement and a 5 being strong disagreement.

RESULTS

The participants in this study reported a variety of useful responses that will assist in the future implementation of a spinal cord injury group in the La Crosse and surrounding areas. Of the 41 surveys distributed, 14 were returned, providing a return rate of 31.7%.

Descriptive statistical analyses were computed using the Statistical Package for the Social Sciences, Version 10.1 for Windows (Cronk, 1999). Frequencies, descriptive statistics, and percentages were the most beneficial tools for analysis of the gathered data. A frequency table was generated to determine the percent of responses in the demographic portion of the survey as well as question 11 (see appendix A.) Descriptive statistics were used to determine the mean for questions 3-10 using a Likert scale.

Likert Scale

Strongly Agree				Strongly Disagree
1	2	3	4	5

Demographics

Please refer to Table 1 for demographic information.

Table 1

Respondents	
SCI individual	85.7%
No response	14.3%
Type of Injury	
Paraplegic	57.1%
Quadriplegic	14.3%
Other	21.4%
Age	Range 18-66
Sex	
Male	50%
Female	42.9%
Marital Status	
Single	14.3%
Married	35.7%
Divorced	35.7%
Widow/er	7.1%
Living Status	
Alone	42.9%
With family	50%
Employment	
Paid position	42.8%
Volunteer	7.1%
None	42.9%
Years post injury	
.5-1	7.1%
1-2	28.6%
2-3	28.6%
3-4	21.4%
4-5	14.2%
5 and above	14.2%
28.4% **Previous support group involvement**	
Yes	14.3%
No	78.6%

Interest in a spinal cord injury support group

Of the 14 respondents who answered the question regarding interest in a support group, the mean was 2.14, which indicates, based on the designed Likert scale, agreement that there is interest.

Form of the support group

The format of the support group consisted of a variety of choices including a web page, e-mail, newsletter, phone, and scheduled face-to-face group meetings. In response to this question, two choices were identified as being most popular. These were a newsletter with a mean of 2.08 and a face-to-face group meeting with a mean of 2.31. Other responses are summarized in Table 2.

Table 2

Form	**Mean**
Newsletter	2.08
Meeting	2.31
Web Page	2.89
E-mail	.00
Phone	3.00

Meeting of the support group

The meeting times were responded to using a variety of choices including weekly, monthly, quarterly, once a year, twice a month, and every other month. In response to this question, two choices were indicated as the most popular. These were quarterly with a mean of 2.33 and monthly with a mean of 2.38. Other responses are summarized in Table 3.

Table 3

Time	**Mean**
Quarterly	2.33
Monthly	38
Every other month	2.91
Twice per month	3.45
Yearly	4.10
Weekly	4.36

Length of meeting for the support group

The length of meetings were responded to using a variety of choices including one, one and a half, and two hours. A meeting length of two hours was indicated as being the most popular choice, with a mean of 2.75. Other responses are summarized in Table 4.

Table 4

Length	**Mean**
2 hours	2.75
1 1/2 hours	2.91
One hour	3.09

Time during the week for the support group to meet

The two choices provided for respondents included weekdays and weekends. Weekdays were the top time during the week respondents wanted to meet, as indicated with a mean of 2.31. Weekends followed with a mean of 3.40. Please refer to Table 5.

Table 5

Time	**Mean**
Weekdays	2.31
Weekends	3.4

Time of the day for the support group

The time during the day was responded to using a variety of choices including morning, afternoon, and evening. The most favorable response was for the group to meet during evenings, as indicated with a mean of 2.58. Other responses are summarized in Table 6.

Table 6

Time	**Mean**
Evening	2.58
Afternoon	3.00
Morning	4.00

Transportation

A mean of 2.17 in regards to access to transportation for the spinal cord injury individuals indicates agreement that access is present. A mean of 2.83 was shown for individuals willing to drive others or ride with others to the support group.

Topics/information to be addressed in a spinal cord injury support group

Respondents were requested to check all topics and information that were of personal interest. The most frequently checked response was medical/research updates of a spinal cord injury with a percentage of 85.7%. Another popular choice was a guest speaker, chosen by 78.6% of respondents, who could assist in providing medical/research updates. Other responses are summarized in Table 7.

Table 7

Response Choice	**%**
Medical/Research Updates	85.7
Guest Speakers	78.6
Adaptive Technology	64.3
Coping Techniques	57.1
Resources	7.1
Psychological Issues	50
Social Events	42.9
Financial Issues/Employment	42.9
Brochures 3	8.5
Relationships/Sexuality	5.7

Note: Respondents were requested to check all that apply.

DISCUSSION

The overall results indicated that a there is an interest for a spinal cord injury support group in the La Crosse and surrounding areas, which does support the hypothesis. However, the personal responses to format, meeting time, length of meeting, and time during the week and day the support group varied. The information gathered through distribution of the support group survey reinforces Harmon and experts (2000) findings that express the importance of assessment and consideration of individual support needs when forming a support group. The indicated interest for a support group by spinal cord injury individuals also reinforces literature provided by the National Spinal Cord Injury Association (1996) stating that, "support groups provide a valuable service not only for counseling and support, but also for socializing and information sharing."

Personal information gathered through distribution of the survey also assisted in assessing the need for a support group, providing a valuable resource for future implementation of a support group in the La Crosse and surrounding areas. The specific information gathered through the Likert scale will assist in facilitating the future design and programming provided by the support group. Assessment of spinal cord injury individuals needs is critical to the success of a support group because they hold the specialized and meaningful information that tailors the support group to address their personalized needs. This statement is supported by Archer, Cripe, and McCaslin (2002) who found that information about the perceptions of individuals with spinal cord injury could assist in selecting an appropriate approach to developing a support group to meet their needs.

RECOMMENDATIONS FOR FUTURE SUPPORT GROUPS

The results of this research can be used to assist other healthcare professionals in the establishment of a spinal cord injury support group. The responses from participants assisted in identifying possible formats of the spinal cord injury support group. From our responses, a newsletter and/or face-to-face group meeting would be the most desirable form of a support group. It was most beneficial for the support group to meet quarterly or monthly, for two hours during the week, and in the evening. The top five most advantageous topics or information to be presented/available during the support group include medical/research updates, guest speakers, adaptive technology, coping techniques, and resources.

LIMITATIONS

One limitation to this qualitative study was that there was a small sample size and the responses received only yielded a 31.7% response rate. Addresses of the respondents within the Gundersen Lutheran mailing list may have been incorrect due to relocation, which may be a factor in our low response rate. Also, individuals may not have been physically able to fill out the survey. It has been shown that there is greater accuracy in making inferences with larger sample sizes than there is smaller (Polgar & Thomas, 2000). However, the results did support the need that a spinal cord injury support group is of interest to spinal cord injury individuals in the La Crosse and surrounding areas.

Another limitation was the reception of only one of three pilot surveys distributed. However, the responses of individuals to questions posed yielded no apparent difficulty or lack of understanding of the questions. Also, individuals at Gundersen Lutheran Hospital reviewed the survey for clarity prior to distribution.

Some respondents failed to answer all questions asked within the survey. This may have skewed analysis of some of the retrieved statistical data.

Direct interviews with the participants in the study may have helped reveal perceptions more in depth than with use of survey questions. Additional information, not addressed in the survey, could have been obtained as well through interviews. This information may have been beneficial to the implementation and format of the spinal cord injury support group.

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Appendix: A copy of the distributed survey.

SCI Survey

1. Please complete the following questions:

SCI Individual___ or Family Member of SCI Individual___
Age:_____
Sex: Male___ Female___
Marital Status: Single___ Married___ Divorced___ Widow/er___
Current Living Status:
    Alone___
    With family members___
    Assisted living facility___
    Other___
N/A___
Are you currently employed? Yes___ No___
    Full Time___
    Part Time___
    Volunteer___
    Other_____
Type of Injury
    Paraplegic___
    Quadriplegic___
    Hemiplegic___
    N/A___
Number of years since injury____
N/A___

2. Have you ever been in a support group?

Yes___ No___
If Yes:
What type/types of support group(s) were you a member:___________________________

Indicate your level of agreement with the following statements using the given five-point scale.
Example:

1	2	3	4	5
Strongly Agree				Strongly Disagree

3. I would be interested in a support group for SCI individuals? 1 2 3 4 5
4. I would be most interested in participating in a support group in the form of a:

Web Page 1 2 3 4 5
E-mail 1 2 3 4 5
Newsletter 1 2 3 4 5
Phone 1 2 3 4 5
Scheduled face to face group meetings 1 2 3 4 5
Other____

5. I would like the support group to meet:

Weekly	1 2 3 4 5
Monthly	1 2 3 4 5
Quarterly	1 2 3 4 5
Once a Year	1 2 3 4 5
2xs a month	1 2 3 4 5
Every other month	1 2 3 4 5

Other____

6. I would like the meeting to last:

1 Hour	1 2 3 4 5
1 1/2 Hour	1 2 3 4 5
2 Hours	1 2 3 4 5

Other____

7. I would prefer the support group to meet on:

Weekdays	1 2 3 4 5
Weekends	1 2 3 4 5

Other_____________________________________

8. Iprefer the support group to meet in the:

Morning	1 2 3 4 5
Afternoon	1 2 3 4 5
Evening	1 2 3 4 5

Other_____________________________________

9. If travel is required to the support group, I have access to transportation? 1 2 3 4 5

10. I would be willing to drive others or ride with others to the support group? 1 2 3 4 5

11. What topics/information would be you like to see addressed in a SCI support group (check all that apply)

Adaptive Techniques including computer skills_____
Relationships/Sexuality_____
Changes in my life/coping skills_____
Social events/outings_____
Resources_____
Financial issues/employment_____
Psychological issues-anxiety/depression/self-esteem,etc._____
Guest Speakers_____ Any Suggestions?_________________________
Brochures_____
Medical Updates/Research Updates_____
Other____