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A NEED ASSESSMENT FOR PEOPLE WHO HAVE MULTIPLE SCLEROSIS AND THEIR SUPPORT GROUPS

A Project
Presented to the
Faculty of
California State University,
San Bernardino

In Partial Fulfillment
of the Requirements for the Degree
Master of Social Work

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by
Eric Lee Markley
June 2010

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ABSTRACT

This paper discusses the problem the researcher finds in the lack of information on what do people with Multiple Sclerosis (MS) are looking for in support groups that are designed around specifically for people with MS. This paper discusses what MS is, the reasoning on designing a study on this topic, and the significance of the project to social work. The social comparison theory is the model that is used when looking at MS individuals' participation in support groups and how the groups affect them. The type of research design that was used to find this information was a survey questionnaire. A total of 58 people completed the survey. Over all, the survey did not find that many significant differences by demographics or by type of MS. The research project did not find any significant information on an actual item that MS individuals are looking for in a support group. These findings possibly prove that a MS support group does not have to be set up in a specific way, just being a place for an individual to find others who can understand what they are going through and give support.

ACKNOWLEDGMENTS

I would like to first acknowledge the love of my life Melissa Hale. She has helped me through out this project, at the MS walk and all the days working on it. With out her support, this project would possibly never been completed. Thank you so much 'smooshie' for your love, compassion, and kindness in helping me to live another day with you.

I would like to acknowledge the help of my academic advisor on this project Carolyn McAllister who was a great advisor and mentor through out the entire project. I would like to thank also my entire cohort who helped me through the three years of grad school. I would also like to thank all of my professors in the MSW program.

I would like to additionally thank the entire MS support group leaders in the Inland Empire who helped me connect to all of their members in the support groups they lead. I would also give a thank you to the Inland Empire Multiple Sclerosis chapter Jill Jones, Director of Regional Programs who guided me initially in the project, facilitate the booth at the MS walk, and presenting to me the 2009 California Statewide MS Community Survey Summary of Results.

DEDICATION

I dedicate this project to first my grand parents Peter and Dolores Koeff who have helped me so much in so many ways through out my entire life. I like to dedicate this project to both of my parents who have helped me before, during, and have supported me now having MS and not having it stop my dreams for a fulfilling life. I like to lastly dedicate this project to all the people out there who took the survey and the people living with MS and fighting the fight to live on.

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CHAPTER ONE

INTRODUCTION

In this chapter the researcher will discuss the problem he finds in the lacking of information on what do people with Multiple Sclerosis (MS) are looking for in support groups that are designed around specifically for people with MS. This chapter will discuss what MS is, the reasoning on designing a study on this topic, and the significance of the project to social work.

Problem Statement

Multiple Sclerosis (MS) is a demyelinating, progressive disease of the central nervous system that can result in different physical impairments for an individual (Peters et al., 2002, p. 19). These impairments are usually ongoing with an increase of the physical impairment over time. MS is most common disabling neurological disease in young adults with a prevalence of 100 cases per 100,000 people, about 350,000 cases in the United States of America (Perkin, & Wolinsky, 2006, p. 7). As there is no known cure for MS, it affects individuals at a young age; MS has a significant effect on the community. People who receive a diagnosis of MS usually experience a feeling of uncertainty about the progression of their disability and the planning for their life (Peters et al., 2002, p. 19). The uncertainty about the course of the illness will impact the quality of life (QOL) of the individual experiencing the condition (McCabe, Stokes, & McDonald, 2007, p. 86). The uncertainty for someone with MS on the course of their disability which impacts their QOL so greatly can cause suicidal tendencies for people who have MS.

There has been a lot of research on the relationship of people with MS, suicidal idealization and lack of social support. It has been found that people who have been diagnosed with MS who have a supportive relationship with others are protected (Long & Miller, 1991). A person who has a physical disability that through time declines is better suited emotionally and has a higher sense of QOL if they have a social support system. Someone with a chronic illness can greatly affect the social support network of the family and it has been found that people who identified themselves with MS tend to socially isolate themselves from their family because of not being able to contribute physically to the family system (Long

& Miller, 1991). This can also work both ways were the caregiver is burdened by so much work caring for their disabled spouse that the disability of their spouse has caused an increase of loneliness and isolation (Ray & Street, 2005, p. 543). Identifying variables in predicting the mental health dimension of QOL among people with MS is vital.

A new era of medications to combat MS has helped the QOL of this population (Schwartz & Frohner, 2005, p. 209). With an increase of immune suppression medication and interferon therapies as treatment for people with MS, the incidence of relapses has decreased (Matthews & Rice-Oxley, 2001, p. 81). A decrease in relapses and having more choices for therapies for people with MS has helped the QOL of this population.

Purpose of the Study

The collection of support group information from the MS population will help provide and improve individual QOL in this community. The information gathered by the project will give information on what people with MS are looking for in support groups and is given to social workers, doctors, support groups, community planners and anyone living with or connected to someone who has MS. The aim of the survey is to at least have new information that either the MS community could use or individuals could know about to improve the support for this type of individual. Having more information about MS individuals and how they connect to services in their communities is very valuable.

It is obvious that first having more information can be positive for the MS individual. If there is a higher quality of service in the MS community, it will reduce stress for the individual and improve Global Functioning (GAF). Living with MS can be very debilitating, especially doing environment behaviors, and finding more information on what can improve ability for people with MS in their community is needed. Finding out more information to improve health services for people with MS can decrease cost for agencies if they are improving the quality of service for their clients. This study can improve the effectiveness of assistance to MS clients which is extremely beneficial for all in the community.

If it could be found that there is a way to improve assistance to the MS community, it would possibly change social work practice in considerable ways. The findings of this project can be used to change procedures in agencies, to add, delete, increase, or decrease a certain service they provide. Attitudes and Beliefs among people with Multiple Sclerosis: a need assessment can be an over all look, but specific information will be crucial.

Significance of the Project for Social Work

Social support at the mezzo level for people with MS is extremely important (Shwartz & Frohner, 2005). Knowing what kinds of social support MS individuals ask for the most is yet a question that can be looked into more closely. There is a huge divide between self-care and social support when it comes to people with MS (Guilick, 1994). That divide can be decreased if social workers have more information on what are the real social needs of these people such as improvement for transportation, legal representation, education, health care, personal support, etc. This social component is a labyrinth in and of itself that should be looked at with proper care (Gordon, Lam, & Winter, 1997). It is important to have an environmental assessment and to confront the social aspects of people with MS in addition to their medical treatment (Forbes, While, & Taylor, 2007, p. 19).

A key component for individuals with MS is what they identify as their social support group. There is a great deal of research on spousal support and outward from there (Boeiji, Van, 2003). Fulfilling a sense of duty for men and women caring for spouses with MS is interpreted differently. It has been found that women caring for a man with MS are less stressed with the perspective, "I have to become harder and less sacrificing, as opposed to men, do not feel compensated for the care they provide and they suffer from the burden ensuing from it" (Boeije & Doorne-Huiskes, 2003, p. 238). Living with MS is very debilitating, and for the person to survive adequately, they need a great deal of help from their family (Putnam & Tang, 2008). If a person with MS is not getting adequate help for things they need, this social support lack can increase stress significantly. Stress and tension can become a perpetuating cycle of trying to cope and maintain the family unit (Ray & Street, 2005, p. 550). A questionnaire to people with MS on just how they would rate the top people they turn to for help, or kind of help by them can be very informative. A look at the micro level of support might be just as useful for social workers in assessment of care as at the mezzo level.

CHAPTER TWO

LITERATURE REVIEW

Introduction

To improve the Quality of Life (QOL) for people who have MS, a researcher should look at were individuals go to get support like the MS support groups found in their area. The social comparison theory is a good model to use when looking at MS individuals participation in support groups and how the groups affect them in the work force and self-esteem.

The involvement and perceived quality of support groups for people with MS is extremely important (Peters et al., 2003). There has been some good literature on the improvement of overall function of someone who has MS and is regularly going to support groups, and this topic might be good to look into more deeply. This angle can also consist of any group work with other people that have shown to help people with MS (Gordon et al., 1996). It might be obvious to most that it is healthy for people to interact with others, but how they do, and the barriers someone might have to be able to interact with others (MS) should be looked at with more scrutiny.

The Work Force and People with Multiple Sclerosis

There is an increase in research on people with MS and their relation to the work force. Researching on the relation of these two variables can be very informative for people with MS, and improving job placement for this population. With any disability, there comes barriers in acquiring and keeping a job, and be happy in it. The articles "Workplace barriers and job satisfaction among employed people with multiple sclerosis: An empirical rationale for early intervention" by Rumrill et al. and the article, "Employment in individuals with Multiple Sclerosis" by Kronblith et al. are elucidating in the difficulties people with MS have in the work force.

Theories Guiding Conceptualization

Social comparison theory is a good theory to apply when looking at comparisons of individuals in-group settings. Social comparison theory has been applied in different health arenas such as cardiac surgery, fibromyalgia, and rheumatoid arthritis (Peters et al., 2002, p. 20). When people compare themselves to individuals who are worse off, it has been suggested that there is an improvement in well-being. This work has also been used with cancer patients. Social support for cancer patients has been found to be very important and the social context and comparison with other patients in a cancer group influences emotional adjustment to their treatment (Taylor et al., 2007, p. 264). It can be said that individuals who are involved in some aspect with other people who also have MS can benefit from comparing themselves to other individuals who are in the same situation. This comparison can be multifaceted including the knowledge of their medical health, support groups, health care providers, job placement, and/or spiritual needs.

Social Comparison Model and a Need Assessment

In doing a need assessment for people with MS when it comes to support groups and interacting with other members of their community, a social comparison theory can be used to see what individuals with MS find most effective in the content of the interactions. Whatever the benefits offered by support groups are information on new coping strategies and moral support might be evident (Joy & Johnston, 2001, p. 210), but what might not be known is how much an MS individual benefits from being around other MS people specifically to their QOL. Having more information on what a person needs and looks for who has MS might get closer to a specific service satisfaction tool for this population. A better understanding of what to facilitate for the young male population diagnosed with MS and who are extremely susceptible to suicidal idealization could help reduce their stress and bring this target group closer to their kind.

Summary

By asking individuals with Multiple Sclerosis what they are looking for in support, it was found what areas need to be looked at in our MS communities. Looking at MS support groups through the social comparison model, it can be said that support groups over all are beneficial if they meet what the MS individual is wanting in provided services.

CHAPTER THREE

METHODS

Introduction

This chapter will discuss the specific purpose of the proposed study, indicate the research method that will be used, and describe the sample from which data will be obtained. It will state methodological implications as well as limitations of the study.

Study Design

The purpose of this study was to find crucial information from individuals diagnosed with Multiple Sclerosis (MS) about the needs they have right now. The study is important to find out what MS individuals look for in support groups and how MS support groups benefit their clients. The type of research design that was used to find this information is a survey questionnaire. This type of survey was given online to registered people with the MS society and was given physically on paper to individuals at local MS support groups in the area.

The reason for choosing an on-line survey questionnaire is the fact that it will be easier for individuals who have MS and have physical transportation issues or functional impairments. A survey at MS support groups collected current information from individuals who are currently attending the support groups. The implications of this study will try to address concerns of the MS community. The major limitations of the study are how the data is collected. Individuals with MS who do not have knowledge about or access to a computer and or an MS support group cannot be sampled. Individuals who are diagnosed with MS, especially individuals newly diagnosed and those not registered with the MS society, will also not be sampled. The research question is Attitudes and Beliefs among people with Multiple Sclerosis: a needs assessment and going to a support group help the individual?

Sampling

The data source was individuals who are diagnosed with MS. The aim was to get current information from people who are being affected by the disease, and receive some form of social services. The survey asked individuals with MS their particular type of MS (Relapsing Remitting, Secondary, and Chronic), gender, race, age, and level of involvement with social services, and or types of health services. Narrowing the focus of course is trying to control independent variables previously stated. The dependent variables are the services provided that are needed and asked for. What are the best found social grouping for people with MS? Social meeting groups and how they impact the individual was looked at. The description of the job place and the quality of their jobs when it comes to people who have MS is another type of a dependent variable. The goal was to collect around 60 surveys. There should be no concerns about human subjects because the survey is voluntary and the questions will not ask for information that can be construed as harmful to a vulnerable population who has a debilitating disease.

Data Collection and Instruments

The data information that was collected is as follows. First the questionnaire asked demographic information about age, gender, ethnicity, and current living situation. Then the survey asked what is their disability background such as at what age was your diagnosis with MS (type), and how severe you think your disability is. After these questions, the study asked in a Likert scale format from not wanted to very much wanted, specific information on what they are looking for in support groups. These questions covered health, work, recreation, family, finances, community, and transportation, relationship with your significant other, self-improvement, and religion. The study then asked how they see and relate to their disability and the MS community. The last question asked what things they would like to see offered at a MS support group.

Procedures

The data was gathered in a combination of two ways. The first way was online website were individuals took a survey that is solicited through the researcher. The second way was a hand given questionnaire to people with MS who are in attendance at support groups for people with MS. The data was then collected from the website, and collected by hand at the support groups. The timetable for the survey activity to be completed by the participants should be no more than thirty minutes.

Protection of Human Subjects

This study will include an informed consent (Appendix B) and a debriefing statement (Appendix C). The study on the website will not ask for a name and anonymity will be held a priority. Anonymity will also be a factor at support groups at which names will not be asked.

Data Analysis

Inventories that were used in this project were designed by the researcher. The correlation and interpretive association looked at are between the participants and to the 2009 California Statewide MS Community Survey. This includes the participants' demographic information, the description of the MS disability, and involvement with the MS society. This will all be a back drop to the actual answers of what they are looking for in support groups as well (Appendix A). The univariate and bivariate analysis was dependent on what information was recorded between these participants of questions and additional information recorded on what this population is asking for in support groups.

Summary

This study was to find out what the MS community is looking for in support especially in what kind of things they are wanting in support groups. The Inland Empire Multiple Sclerosis Society prepared a booth at the MS Walk 2009 to facilitate the passing of information of the website survey. Gathering the information asked, looking at it through the Social Comparison Theory, and any comparison to the 2009 California Statewide MS Community Survey, there should be amplitude of information that can be analyzed and discussed about in the findings. The results will then be passed along to any agency that can use to modify their support groups, especially the National Multiple Sclerosis Society.

CHAPTER FOUR

RESULTS

Introduction

In this chapter the researcher will discuss the results from the various tests ran on the data set from the MS participants. The researcher will first discuss and review the descriptive statistics and frequencies of every questioned asked in the survey, and then discuss (bivariate analysis) next. Finally, the researcher will summarize the findings of the research.

Presentation of the Findings

A total of 58 people completed the survey (16.5% response rate) out of 350 individuals who were given the survey by card handout of the website link. Forty-five individuals partially or abandoned the survey online. Frequencies were run for each of the questions asked of the participants. The mean of the current age of the participants was $M = 49.1$ with an age range from 27 to 63 having a median of $MDn = 50$. This mean matches the survey done by the National MS Society 2009 statewide survey (National MS Society). Forty-eight females took the survey with only ten males taking it. Over 80% of those with MS are women (National MS Society). The results of this survey are consistent with the general characteristics of someone diagnosed with MS.

Forty-seven out of the 58 respondents described themselves as white (81%) matching the National MS Society statewide survey of 81% being classified as white (National MS Society). Living with a spouse or partner was selected by 29 out of the 58 participants (50%) which matches the National MS Society State survey being the most selected as well (National MS Society). The mean of what age participants selected when they were diagnosed with MS was $M = 38.78$. 34 participants selected that they had relapsing remitting MS (58.6%), 17 participants described that they were progressive (29.3%) leaving 7 participants (12.1) not knowing what type of MS they had.

Forty-three participants (74.1%) selected that they saw themselves having 'Good' health over all. When it came to the questions of what support or help items participants apply to them and what items have been most difficult to manage in living with MS, all items were selected with no significant value for any specific item. The National MS State survey had identified that participants selected option, 'Having the endurance to keep up with family/home/work' the most at 54.9% and 'Managing the physical changes that can be brought on by MS' selected 92.9% of the participants (National MS Society). This does match the researcher's survey with participants selecting help with household tasks 24 (41.4%) the most and 'experiencing new symptoms or worsening of current symptoms selected the most by 45 participants (77.6%). Only 4 participants (6.9%) selected that they currently have no difficulties with managing their MS.

Frequency tests were ran on all likert scale questions with no significant information found. The results of participants rating the importance of each item in wanting that item in a support group, all averaged out with no item more than any other. Forty-six participants (79.3) selected that they have been to a support group. There was no significant result for a specific reason why participants did not go to a support group. Twenty-two participants (37.9%) selected that they currently go to a support group. There were additional tests ran after frequency tests were done.

A multitude of tests were ran to see if there were any significant results between the questions asked of the MS participants. Crosstabs, ANOVA, and Chi-square tests were run on type of MS selected and selected perception of health, and selections of needs. Running a Chi-square test found a significant value with those participants who selected that they had progressive MS selected significantly with a value x.50 and a p.015 value over relapsing remitting and not known the item of needing help with household tasks. Again, this matches what the National MS Society 2009 state survey found (National MS Society). It was found significantly that participants who selected that they had progressive MS selected x.50 value and a p.005 value over relapsing remitting and not known the item of needing help with equipment modifications at home or work. It was also found that participants who selected that they had progressive MS selected x.55 value and a p.005 value over relapsing remitting and not known the item of needing help with keeping up with family and or work. Finally, there were themes found by the researcher in information described in the last self-reporting question in the survey.

The information participants added in their own words to what they look for in a support group did create a couple of patterns found looking at all the results as a whole. Several participants wrote about not liking MS support groups because they were filled with people who in their words, "crying over their situation in life" a great deal. The majority however, described wanting a MS support group to be a place were they can find friendship with people who are similar to them and can truly understand their situation, living with MS. Several participants wrote about wanting a place like a support group that will keep them up to date with treating the disease and information by other people who have MS on what works for them in maintaining their disease.

Summary

This chapter described the tests ran on the results found by the questions answered by the participants of the survey. It was found that the survey results described the general characteristics of someone who is diagnosed with MS. The results of the survey found significant differences in type of MS with the physical needs and difficult items they found hard to manage. The results of the survey found a great deal of information that was not significant between items. There were no significant differences between the items selected on what participants are looking for in a support group. The results of the survey also did not find significant differences between persons attending support groups currently and those who were not. Self-report information accumulated found patterns that participants want to find friendship and new information in a MS support group.

CHAPTER FIVE

DISCUSSION

Introduction

Over all, the survey did not find that many significant differences by demographics or by type of MS. The research project did not find any significant information on an actual item that MS individuals are looking for in a support group. These findings possibly prove that a MS support group does not have to be set up in a specific way, just being a place for an individual to find others who can understand what they are going through and give support.

Discussion

Looking at the results of the survey surprises this researcher in a couple of points and while with other aspects the researcher was expecting. Overall, the research project created enough information that can be useful for people with MS and the agencies and communities they are connected to. The results of the survey with no one item that is stronger than any other item looked for in a support group by the MS participants shows that support groups can consist of a place that can give general information and support in the area of people with MS. A person with MS can also know that if they been to a support group they have found not that comfortable with, there is other MS support groups not that far away who also give support in a general informative and supportive orientation.

The result of the project matches the theory of Social Comparison (Dibb & Yardlev, 2006). Individuals who go to support groups found information on most of the items they were looking for. Members of a group are very similar demographically which is another point of the Social Comparison Model (Dibb, & Yardlev, 2006). Finding information on why a substantial number of people do not go to support groups is still elusive and must be looked at further.

What items surprised this researcher after the findings of the survey were looked at was no specific item in the Likert scale stood out significantly on its own merit and compared to each other. This might be for the fact that generally, the range of people with MS want information in all of the areas asked equally. It was a surprise even though most of the participants who took the survey currently or have gone to a support group, there was still no significant item that popped out in the survey results in being a major reason why people with MS do not go to a support group. The ending results of the survey had several expected outcomes.

The result of each demographic item description was expected. MS is found more in white females in their middle ages, so it was no surprise that the survey found that result. It was expected for the researcher to find that people who described themselves as having the progressive disease type of MS troubled more with household tasks, equipment modifications at home or work, and keeping up with family and or work. Progressive type of MS is physically more debilitating than Relapsing Remitting MS and individuals who have this type of MS are likely to ask for more help (Perkin & Wolinsky, 2006). The patterns found by the researcher in the survey on the self-report question matches nicely with the Social Comparison Model.

What better place to find out what works and what don't in living with MS than learning it from people who have tried both. A support group is a place were ideas can be shared and individuals can obtain resources from other people similar to them (Social Comparison Theory) on such issues as job employment and keeping of your current job (Dibb & Yardlev, 2006), (Kronblith et al., 1996). The comments in the self-reporting question described individuals who wanted to find friendship. Individuals who had trouble with support groups did not quite identify with the other members at that time. Individuals who do not fully grasp on identifying who they are will not feel comfortable in intimate situations like a support group (Sacks, 1990). If a person is not white or female and is diagnosed with MS (young male) it might be hard for them to identify with a group that is not similar to them. Having just MS in common might not satisfy the reasons in joining. However, Individuals with MS who can relate to others in the support group will invariably compare themselves and build a friendship with other members (Taylor et al., 2006).

Strength and Limitations

The strength of the research project was that the researcher was able to find participants to take the survey from a wide array of places. These different locations included the internet, support groups, doctors' offices, MS pharmaceutical seminars, friends, NMSS (SCC), CSUSB, and the MS Walk. Additional strength of the survey was that it was user friendly and can be taken online and at home. The survey in looking for information on the needs for MS individuals and their relations to support groups was completed in giving information to the participants through the process of participating in it. Over all strength in this survey was that it was short (23 questions); simple, and asked questions MS people would like to know.

The limitations of the research project that were not previously stated are the fact that most of the participants who took the survey were currently in a MS support group. It would have been helpful to find more MS participants who have not been to a support group, and why they have not. Most participants who took the survey did it online, and this researcher would have liked to have had additional locations to give the survey by hand to not discriminate people who may not use a computer. There are limitations in online survey, with an easier ability for the participant to not complete it entirely (Forty five). This survey was also a convince survey which does not include people who have MS who are not registered with the MS Society or the social MS network in some way. This survey only represented individuals who had some relation to the Southern California region.

Recommendations for Social Work Practice, Policy and Research

Recommendations for social work practice is first for social workers in any agency were they found out a person has a debilitating disease like MS and possibly just diagnosed, the social worker should refer the person to the MS society and have a personal connection to them by possibly connecting them to their closest MS chapter were they can get in contact with other people who also have MS if they so choose to. A social worker should be familiar with what comes with having a diagnosis of a neurological disability and what resources the social worker can refer them to. For example, heat affects people with MS negatively exacerbating MS symptoms, so a social worker needs to plan a cooler environment for any interventions or treatment plans.

When it comes to policy, agencies (doctors) should be the first line of help and should have in their policies to connect people with a disease to people NMSS who can connect them to support. This support should be backed up with the support of the social worker in that agency. Increase look in policy to follow any person who is recently diagnosed with MS and making sure to follow risk of suicide. What this researcher recommends for future research is for the NMSS to add questions of needs when it comes to support in their state surveys and other health provider's research on what better ways can support groups facilitate empowering their members and find ways to bring them to join. Social workers should educate themselves on the value of what a person can benefit or not want in general in membership to a support group and education of the benefits or limitations with QOL with someone newly diagnosed and joining a support group that is designed to educate them on a critical change in their life.

Conclusions

This survey did not find significant differences by demographics or by type of MS. The research project did not find any significant information on an actual item that MS individuals are looking for in a support group. The research project did find in places like the self-reporting item that individuals with MS are looking for a place to find friendship and MS information. This item closely follows the tenets of the Social Comparison Model and social workers and health providers should encourage their clients to seek out such groups. More research should be done on the effectiveness and what do people really look for in a support group.

APPENDIX A

QUESTIONNAIRE

QUESTIONNAIRE

Part 1. Demographic Information

1. hat is your current age? __________

2. Gender: Male Female

3. What is your ethnicity?
   White
   Latino
   African-American
   Asian
   Other

4. What is your current living situation?
   Living alone
   Living with a spouse/partner & children
   Single parent living with children
   Living with parents)or other relatives
   Living with friend/roommate(s)
   Living with a support person such as an aide

Part 2 Disability Background information

5. At what age did you become disabled? ____________

6. What types of MS are you diagnosed in having?
   Relapsing/Remitting
   Progressive
   Don't Know

7. In general, how severe do you think your disability is?
   Not at all severe
   Somewhat severe
   Severe
   Very Severe

Part 3 Reasons for a support group rating scale

The following items ask about the level of importance you feel on specific items of information obtained at support groups. Please mark the one that best describes you. Please do not leave any item unanswered. When going to a support group getting information on:

8. Health
Not very much Very Much
* * * * *

9. Work
Not very much Very Much
* * * * *

10. Recreation
Not very much Very Much
* * * * *

11. Family
Not very much Very Much
* * * * *

12. Finances
Not very much Very Much
* * * * *

13. Community
Not very much Very Much
* * * * *

14. Religion
Not very much Very Much
* * * * *

15. Transportation
Not very much Very Much
* * * * *

16. Relationship with your significant other
Not very much Very Much
* * * * *

17. Self-expression/self improvement
Not very much Very Much
* * * * *

Part 4 Identity to support groups

18. Are you currently or have you in the past been to a support group?
    Yes No

19. If you have not gone to a support group, the reason being is.
    Lack of Transportation
    Not knowing where a support group is located
    There are no support groups close to where you live
    There are no support groups that you feel you fit into
    Other ______________________

20. What would you like to learn or experience at a support group?
    ____
    ____
    ____

APPENDIX B

INFORMED CONSENT

INFORMED CONSENT

The study in which you are being asked to participate is designed to explore and gain information on the needs and wants of individuals with Multiple Sclerosis The student researcher, Eric Markley, MSW student is conducting this study under the supervision of Dr. Carolyn McAllister, Assistant Professor of Social Work at California State University San Bernardino (CSUSB). This study has been approved by the Department of Social Work Subcommittee of the Institutional Review Board, CSUSB.

In this study, you will be asked to answer questions about the severity and type of Multiple Sclerosis, on personal identity and the wants and needs you might have. This will be asked and completed during a survey questionnaire. This should take about 20 minutes to complete. All of your responses will be held in the strictest of confidence by the researcher. Your name will not be reported with your responses to the various survey questions. You may receive the results of this study upon completion after September 2010 at the John M. Pfau Library at California State University San Bernardino.

Your participation in this study is totally voluntary. There are no foreseen risks in participating in this study. You are free not to answer any questions and may withdraw at any time during this study without penalty or coercion.

If you have any questions or concerns about this study, please feel free to contact Dr. Carolyn McAllister, at **(909) 537-5559**

By placing a check mark in the box, I acknowledge that I have been informed of, and that I understand, the nature and purpose of this study, and I freely consent to participate. I am 18 years old or older.
*

☐ Place a check mark here to continue

APPENDIX C

DEBRIEFING STATEMENT

Debriefing Statement

Thank you for participating in this study conducted by Eric Markley, MSW student from the California State University San Bernardino (CSUSB). The purpose of this study is to investigate what individuals with Multiple Sclerosis are looking for in support services, information and type of support groups dependent on what type of MS they have. It is hoped that the results of this study will contribute to a better understanding of how the type and severity of one's disability impacts what kind of support and information they are looking for and to relay this information to their health providers, community, and to the National Multiple Sclerosis Society.

The research data were collected through the survey, which you completed. All data collected will be kept confidential and anonymous. The results of this study will be available at The John M. Pfau Library at California State University San Bernardino by September of 2010. If you have any questions or concerns regarding this research project you may contact my research faculty supervisor, Carolyn McAllister, at the CSUSB Department of Social Work at **(909)537-5559**.

Thank you again for your participation and cooperation in this research project.

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