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Perceptions of the Strong Survivors Staff Members and Their Experience in the Program

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PERCEPTIONS OF STRONG SURVIVORS STAFF MEMBERS AND THEIR
EXPERIENCE IN THE PROGRAM

by

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B.S., Southern Illinois University, 2015

A Research Paper
Submitted in Partial Fulfillment of the Requirements for the
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Department of Kinesiology
in the Graduate School
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RESEARCH PAPER APPROVAL

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Fulfillment of the Requirements

for the Degree of Master of Science in Education in the field of Kinesiology

Approved by:

Dr. Phil Anton

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TITLE: PERCEPTIONS OF STRONG SURVIVORS STAFF MEMBERS AND THEIR EXPERIENCE IN THE PROGRAM

MAJOR PROFESSOR: Dr. Phil Anton

The purpose of this study was to interview past staff members of the Strong Survivors program to elicit insight into the staff members' experience including their motivation to participate, the knowledge gained while working with the program, and the influence the experience had on their lives professionally and personally after exiting the program. Six past staff members, who have been removed from the program for 1-3 years participated in this study. Those subjects received the consent form and questionnaire via email. The questionnaire consisted of inquiries regarding the Strong Survivors trainer's experience during their time in the program, their motivation to join the program, and how the program benefitted them in their careers. Four themes emerged from the data analysis: (1) gave the participants hands on experience, (2) helped the participants gain confidence, (3) developed a better understanding of the effects of cancer treatments, and (4) developed friendships. The results of this study indicate that being a part of the Strong Survivors staff had a positive impact on the trainers' lives, no matter how long they participated or how many clients they worked with. This study represents an important insight on the people who care for cancer survivors and their caregivers.

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CHAPTER I

INTRODUCTION

Cancer affects many people worldwide and much research exists that has elicited medical advancements for treating, preventing, and in some cases, curing the disease. Cancer rehabilitation is designed to lessen the negative side effects that cancer patients endure during and after their specific treatments. Exercise professionals in cancer rehabilitation focus on treating the painful and debilitating side effects of the treatments and helping survivors live functional lives comfortably (Rogers, 2008).

The incorporation of exercise into the daily routine has been shown to improve a person's quality of life (QOL). There are numerous research studies that have established the fact that exercise can be used as a method of managing the effects resulting from cancer treatment. For example, cancer-related fatigue is a significant problem for those diagnosed with cancer. As of now, there is no distinctive treatment to help overcome fatigue (Kangas, M, Bovbjerg, D., & Montgomery, G., 2008). Numerous studies have been completed to determine if aerobic exercise positively affects the physiological and psychological function in people recovering from cancer. In one of these, eighteen subjects were split between two groups; low exercise intensity or moderate exercise intensity. The results showed a significant increase in quality of life and measure of energy. The different exercise groups were equally effective in improving psychological and physiological functions. Therefore, no matter the intensity, regular aerobic exercise was shown to benefit energy levels and overall quality of life in cancer survivors (Burnham, T. & Anthony, W., 2002). Unfortunately, even with this research, many individuals with cancer are regularly recommended to limit physical

activity. Lack of regular physical activity can often lead to increased fatigue, nausea, depression, muscle weakness, and limited mobility. Being inactive can cause these side effects to become chronic disabilities that hinder any progress being made (Anton, 2016).

The goal for cancer survivors participating in an exercise program as part of their treatment is to maintain their current level of strength or function, or improve on their independence of living. This is often different than healthy persons' common exercise goals, which are typically to lose weight and gain strength (Schwartz, 2009). By incorporating exercise into the daily lives of these individuals, they can increase their stamina and become less fatigued during their day and more effectively complete their activities of daily living (ADL).

While there is solid research pertaining to the benefits of physical activity and its importance in cancer rehabilitation, there is little research about the impact participating in cancer rehabilitation has on the individuals who create and administer exercise programs for this population. The 2009 IDEA Personal Training Fitness Programs & Equipment Trends Report sheds light on how important it is for trainers to become specialized in working with people who suffer from chronic diseases. The trainers reported working with clients who had either a chronic disease (85 percent) or physical disabilities (54 percent). In an aging population like that of the United States, trainers will be regularly working with these special populations and there are now more specialized fitness programs being offered and implemented to personal trainers (Scott, 2010). This is important in the cancer rehabilitation process because it ensures cancer

survivors will be in the hands of exercise specialists who can utilize their knowledge to best improve the cancer survivors' QOL.

The SIUC Strong Survivors program is an exercise and nutrition program co-sponsored by the SIUC Department of Kinesiology and the Southern Illinois Healthcare Cancer Institute. It has been designed specially for those who have gone through the process, or are still going through the process of fighting cancer, as well as those individuals who serve in a caregiver role. This program utilizes exercise as a therapeutic tool to help with the cancer treatment and recovery process. Each participant is paired with a Strong Survivors staff member, who is typically a SIUC Department of Kinesiology exercise science student who has completed the Strong Survivors Staff Training course (KIN 402). The staff member designs a personalized exercise regimen based on the participants' quality of life goals, current medical/fitness status, and the results of a preliminary assessment. The staff members serve as personal trainers for the survivors and are able to practically apply what they have learned in the classroom to real life situations. This program also helps the staff members to gain professional experience that can be applied to their future careers. Working one on one with cancer survivors and caregivers gives the staff member's insight on the cancer experience first-hand. In the 12 weeks of initial program time, personal relationships often develop as the trainer and client work one-on-one.

Caring for cancer survivors has been described as stressful yet rewarding. Many of the people who have aided in the rehabilitation of cancer survivors, whether it is caregivers, nurses, or any other health-care professionals, have suggested feeling helpless and empathize with the survivor. A study completed by Pearce (1998),

examined the experiences of 10 cancer nurses by the method of open interviews. The researches found that the nurses felt stressed and sometimes unsuccessful in aiding the patients. It was also noted that most of the nurses agreed that it is “such a privilege to be a part of it” when the patients start to show progress.

There is limited research regarding the experience of the exercise specialists working with a cancer population. The purpose of this study is to interview past staff members of the Strong Survivors program to elicit insight into the staff members' experience including their motivation to participate, the knowledge gained while working with the program, and the influence the experience had on their lives professionally and personally after exiting the program.

CHAPTER II

METHOD

Participants were six past staff members of the Strong Survivors Program. Approval for the study was obtained from the Institutional Review Board at Southern Illinois University Carbondale. Participants who have been removed from the program staff participation for 1-3 years were solicited via email and/or text message. Prospective participants were emailed a cover letter explaining the purpose of the study. Out of all the participants who agreed to partake in the study, 12 subjects were randomly pulled from the group. Those subjects received the consent form and questionnaire via email.

The questionnaire consisted of inquiries regarding the Strong Survivors trainer's experience during their time in the program, their motivation to join the program, and how the program benefitted them in their careers (see Appendix I). Once the questionnaire was completed, the participants sent their answers plus the consent form back via mail to the return address provided. An administrative aide removed any identifying marks from the questionnaires and then distributed them to the primary researcher so that the primary researcher remained blinded to the identity of the participants. Six of the twelve returned the consent and questionnaire and were included in the data analysis. Completed questionnaires were thoroughly examined and certain themes were observed.

CHAPTER III

RESULTS

This study investigated the experiences of past Strong Survivors staff members who have been removed from the program for at least six months. Descriptive variables for the participants included how many semesters they served as a staff member, how long it has been since they left the program, and how much professional experience they had with personal training prior to their involvement in Strong Survivors (see Table 1). Four distinct themes emerged from the data analysis: (1) gave the participants hands on experience, (2) helped the participants gain confidence, (3) developed a better understanding of the effects of cancer treatments, and (4) developed friendships.

Table 1: Characteristics of the sample

Participants	How many semesters did you participate on the SS staff?	How long has it been since you were a staff member?	Describe your level of professional experience of personal training before SS
1	4	24 months	None
2	1	36 months	Little
3	5	11 months	None
4	4	12 months	Little
5	3	6 months	Little
6	3	10 months	None
Mean Values	3.33 semesters	16.5 months	

Hands on experience

The first theme that was found from the data was the fact that the participants were able to gain hands on experience when training their clients. This theme was mentioned by all of the participants at least once, and was mentioned in response to more than one question. The participants reported they were taught to prescribe effective exercises to people of different ages and health conditions.

It was also reported that they were able to individualize the exercise programs for the different clients they were working with. Some clients were cancer survivors trying to regain strength after treatment, some were still going through treatment, which were different for everyone, and some were caregivers for their loved ones. What helped the participants design individualize programs was the knowledge they gained of cancer types and treatments. Participant three said, "I know that people with different types of cancers who receive different treatments will respond differently. Now that I am educated on this, I can help someone with breast cancer as equally as I can help someone with prostate cancer because I am able to know the differences and help them individually".

With the hands-on experience Strong Survivors provides, motivational skills were also learned. Participant two and three stated, "we were all motivated by different reasons", describing why they got involved with the program. After they realized their motivations and what motivated their peers, they learned to motivate their clients. Participant two said it was very beneficial to get to know their client and find out what motivated them. After learning this, the participant was able to take what they learned and apply it to his/her other clients. The participants reported that most of their clients started with little motivation but shortly after starting the program, they became interested in trying new things and improving. After closely working with their clients, the participants were able to see first-hand the struggles of cancer. Two of the participant's family members were affected by cancer but working with strangers who are battling the disease gave them a different perspective.

All six of the participants reported that they have a better understanding of the struggles that cancer survivors go through, as well as their caregivers.

Gained Confidence

The participants all reported that their experience in Strong Survivors helped them to gain confidence and feel more comfortable when interacting with strangers. Participant one stated that Strong Survivors “helped me interact with people who are not in my demographic. I work with a lot of people that are older than me and it can be awkward forming relationships because the priorities in their life are different than mine. After Strong Survivors, I am better at jumping into conversation with people than I was before”. Participant two said that their goal was to build confidence in themselves as a professional and this program encouraged one on one interaction with people which helped them achieve that goal. Participant five indicated the confidence they gained from this program helped them in the research position they are currently working in. Participant four stated they are confident in what they know and can properly apply it to the clients they work with today. With the confidence the participants gained, it helped them become better leaders.

Participant two declared that they also gained confidence in prescribing exercise. As stated in the methods, before the staff members are allowed to work with a client, they must complete the training course. All six participants agreed that the course or training they received helped them feel confident in prescribing effective exercise programs to their clients. Participant three said the experience they had as a staff member helped give them more confidence in their capabilities as a health professional.

Participant two said they gained enough confidence to be able to speak up more about the benefits of a cancer survivor being involved in some form of physical activity.

Developed a better understanding of the effects of cancer treatments

After working with cancer survivors and their caregivers, four out of six participants reported that they saw improvements in their clients' quality of life (QOL) after training them for just twelve weeks. Participant one reported that after being a staff member, they understood that someone's quality of life could be improved with just small adjustments to habits and lifestyle. The same participant stated, "the cancer journey isn't over when the scan comes back clean, there is still a long road of recovery to regain a healthy QOL". That being said, all of the participants said the people they worked with inspired them. Sometimes the clients did not feel good coming into the exercise session as a result of their treatments, so the staff need to make sure they are attentive and flexible to change the workout that was planned for the day to accommodate the client's condition.

Developed Friendships

All of the participants reported that they developed friendships with their clients. Participant six stated that not only did friendships form between client and trainers, but the clients who exercised in the same time frame interacted with one another and built friendships. Participant four's motivation was to not only be a trainer to the clients but also wanted to build friendships. Participant one said that their clients became some of their closest friends. They were able share aspects about their lives such as details about their families or shared personal advice; the staff really cared about their client's happiness outside of their training time.

Three of the participants still say they keep in touch with their past clients and their clients even attended their trainer's graduation. Participant three said the clients they worked with would give life advice for the problems that were happening with school or their personal lives. Two of the participants stated that they enjoyed working and learning about the different clients backgrounds and stories. The clients were described as inspiring as well as good storytellers. The participants all stated that at one time or another their clients gave them advice on school, life problems, and even suggestions on where to eat or what new shows to watch.

After working with multiple clients, participant one stated that age does not matter when forming connections. The clients that come through the Strong Survivors program are from a range of different demographics, and the trainers are, for the most part, undergraduate students; however, all of the participants said they formed very close bonds with the clients they worked with. They all also agreed that a community of support has a very positive influence. When the clients see each other exercising, they empower each other. Participant five said, "we were a team" when explaining the relationship they had with their clients, with the other trainers, and with the other clients going through the program. They said the community of support was motivating for everyone there. Two of the participants also stated that through interacting with the diversity of clients, they were also able to learn about themselves in the process.

CHAPTER IV

DISCUSSION

While there is an immense amount of previous research on cancer survivorship, and the benefits of exercise during recovery, there is very limited research on the perspective of the doctors, nurses, and exercise professionals that aide in the recovery process. The purpose of this study was to obtain insight into the staff members' experience with the Strong Survivors program, and, more specifically how it influenced their lives.

Although all of the participants reported positive experiences, the only negatives they commented on were their own personal reluctance to start the program with confidence. However, they all were able to gain the confidence needed to help their clients succeed. Participating in the program helped the staff choose their career paths. The participants all reported that their experience helped them to (1) gain hands on experience, (2) acquire confidence, (3) develop a better understanding of the effects of cancer treatments, and (4) form friendships.

While previous research has suggested working to assist in the recovery process of cancer is very stressful, the Strong Survivors staff members described it as beneficial, satisfying, and felt their time in the program was successful. The reasoning for their positive outlooks on their experience could be due to a number of reasons. The study conducted by Pearce (1998) concluded that working with cancer patients can be very stressful, but this could be because they are working with the patients during their stay at the hospital, whereas, the Strong Survivors staff are able to work with the individuals at a fitness facility when they are feeling somewhat more energetic and

motivated. One participant in the Pearce study stated, “Stress was also not just an individual experience but a group phenomenon”. In this study, one of the participants stated that everyone was a team, much like how the nurse felt. However, the Strong Survivors team always remained largely encouraging and positive. If someone was feeling stressed, or had negative feelings, the trainers and other clients were able to alleviate some of that stress. This arrangement enhanced the natural effect of exercise as a stress reliever that can diminish levels of depression and anxiety.

The participants’ motivation to join the Strong Survivors staff team could also be why their experiences were favorable. They reported that their involvement would give research opportunities, and they wanted to make a difference and help those in need. These are promising reasons and their attitudes were positive before starting the program; the participants joined with good intentions. This was shown to be accurate according to a study performed by Deegan, et al (2014). The study found that positive expectations about an event encouraged positive contact, whereas negative expectations restrict the effects on attitudes. It was found that negative expectations predicted negative attitudes, regardless of the actual interaction quality. In contrast, participants that held positive expectations experienced positive interactions. This same group experienced negative interactions; however, they still had a more positive attitude about it than the negative group did. This goes to show that the positive expectancies can influence the actual experience a person has.

The majority of the individuals participating on the Strong Survivors staff are unpaid volunteers, and this could have an impact on why these participants had such great experiences. An article published in the Harvard Heart Letter (2016) discusses the benefits of volunteering. It was found that volunteers have greater increases in psychological well-being and physical activity. It was also stated that people who volunteer have physical, social, and cognitive improvements, which could be why the participants were able to gain confidence during their time as staff members.

Another possible reason confidence was attained was because of their training. The trainers are taught in the KIN 402 class the theory behind cancer rehabilitation and were given the opportunity to practice the assessment and exercise techniques with their fellow classmates and experienced staff members. Following their initial training, they are able to shadow and assist an experienced staff member before being assigned their own client. They familiarize themselves with the client's medical and exercise background and after a few weeks, they are able to lead a portion of the exercise session, eventually leading a whole session. This progressive increase in responsibility and task difficulty/complexity helps the staff members to gain confidence, step by step.

Volunteering also carries with it the potential advantage of greater social connectivity, "it is easier to get information on things like how to find the best deals, or where to get a free flu shot. People also provide one another emotional support" (Kim, E. & Konrath, S., 2015). The participants interviewed in this study mentioned, more than once, how Strong Survivors felt like a team and how they were able to learn about the best local places to visit from their clients.

Overall, volunteering is a positive experience, which, in turn, could be the reason the result of participating as a staff member is positive.

Another reason the participants felt successful with their time in the program is due to the fact altruism typically has a positive outcomes. When a person engages in acts to increase another person's quality of life, there are psychological and physiological benefits for the person who is in the supportive position. It has been shown that there are associations with positive social relations, purpose in life, and self-acceptance when assisting others (Schwartz, C. E., et al, 2009). Because the participants were helping others and genuinely found joy when their clients overcame struggles, they also were frequently able to feel happiness.

The results of this study indicate that being a part of the Strong Survivors staff had a positive impact on the trainers' lives, no matter how long they participated or how many clients they worked with. This study represents an important insight on the people who care for cancer survivors and their caregivers. Further research with this population is warranted as well as from the perspective of other healthcare professionals that work in the rehabilitation of cancer survivors. More insight could be obtained by interviewing oncologists or oncology nurses to get more information on their perspective.

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APPENDICES

APPENDIX I

Strong Survivor's Staff Member Questionnaire

1. Approximately how many semesters did you participate on the Strong Survivors staff?
2. What was your original motivation to join the Strong Survivor's staff?
3. What was the first lesson that you learned as a Strong Survivor staff member?
4. Had those thoughts changed at all by the end of your participation?
5. Please describe your level of experience of personal training before becoming a part of the staff.
6. What did you find most valuable from this experience?
7. What qualities do you feel you gained or improved on during your time as a staff member?
8. Tell me about the relationship you had with your client(s).
9. If you worked with more than one participant, how did those experiences differ?
10. Did you learn anything from the participants you worked with?
11. How has your Strong Survivor experiences impacted you on a personal level?
12. Has your Strong Survivor experience changed the way you interact with cancer survivors or caregivers? If so, why?
13. What do you feel was most beneficial about being a part of the Strong Survivors staff?
14. Overall, was your experience as a staff member satisfying? Why or why not?
15. What kind of difficulties, if any, did you have as a staff member?
16. If you worked in the CRL and at John A. Logan College, how did those experiences differ?
17. What were the benefits of working in the CRL?
 - a. What were the benefits of working with the class at John A. Logan?
18. Did you feel your Strong Survivor staff training course (KIN 402) adequately prepared you to work with your first participant? Why or why not?
19. What do you feel was most beneficial about the Strong Survivors staff training course (KIN 402)?
20. Did your Strong Survivors experience enhance knowledge you gained in your SIUC classes? If so, in what way?
21. How long has it been since you were a staff member?
22. Has this experience helped you in your career? If so, how?
23. What skills did you learn as a staff member that transferred into your career?
24. What did you plan to do immediately after graduating from college?
 - a. Did being a part of the Strong Survivors staff help?
25. Did being a part of the Strong survivors staff help you reach goals in your career? If so, how?
26. How might your experience change the way you interact with people in your career?
27. What would you most want to change about the experience you had?
28. If you have any advice for someone starting out in the program, what would that be?

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