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# An Overview of Cancer Care and Survivorship: Advocacy for the Strong Survivors Program

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# An Overview of Cancer Care and Survivorship

## Advocacy for the Strong Survivors Program

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In today's world, cancer reaches into many people's lives. With abundant research and resources, medical advancements continue to lessen the side effects and improve the outcome of an intimidating diagnosis. That said, a sickness stigma still exists causing emotional distress to patients and their loved ones. Often, survivors feel alienated and labeled even after beating the disease.

As an unsung, integral part of cancer recovery, survivorship programs offer a network of educators and participants that understand the social consequences that accompany a cancer diagnosis. These opportunities encourage survivors to work towards a healthy lifestyle to achieve a sustainable quality of life (QOL). Despite the known effectiveness of these programs, they are often expensive or difficult to access. By educating the population of their importance, it is hoped that they will be recognized as an important step into full cancer recovery and become more accessible to those affected by the disease.

### ***A Brief History of Cancer Treatment***

As with all medical advancements, the treatment of cancer continues to evolve. In understanding the integration of social standards and survivorship for cancer care, it is important to reflect on the journey of cancer therapies as a whole. With the invention of anesthetics, surgeries to remove cancerous tumors began in the mid-1800s. Soon after in 1896, X-ray technology was developed and radiation treatment soon followed.

The first major milestone in chemotherapy treatment occurred in 1910 when for the first time rodents exhibited a successful tumor from transplant<sup>2</sup>. This

became an active tool for studying cancer growth and therapeutic effects. During the 1930s, cancer drug screening and hormone therapy became available. With the country consumed by the war in the 1940s, cancer treatment was also affected. Mustard gas had the negative consequence of bone marrow and lymph node depletion, but when applied to tumors of those regions, significant regressions were noted.

The 1950s were accompanied by an abundance of new chemotherapies and cancer research programs. Antitumor antibiotics, thiopurines, and fluoro-compounds contributed to the new wave of targeted cancer therapy<sup>2</sup>. In 1955, the Cancer Chemotherapy National Service Center (CCNSC) began setting standards and screening processes for new drugs. With the validity of chemotherapy still in doubt, the first cured tumor occurred in 1958. This led the way to the developments of the 1960s, and the belief of possible cancer cures. The “Cell Kill” hypothesis of this time considered the fraction of tumor cells killed by a drug rather than the number, placing the determining factor on the number of cells upon diagnosis. This heavily influenced the encouraged use of chemotherapies and eventually combinations of drugs. Remission rates continued to increase as treatment methods such as VAMP (vincristine, amethopterin, 6-mercaptopurine, and prednisone) and MOMP (nitrogen mustard, vincristine, methotrexate, and prednisone) were accepted as normal treatment for leukemia and Hodgkin’s disease respectively<sup>2</sup>. Additionally during this period, side effects of chemotherapy were combatted using transfusions and antibiotics. In 1971, the National Cancer Act greatly increased cancer research funding and contributed to the emergence of university-based cancer centers<sup>7</sup>.

Adjuvant therapy was tested as a supplement to surgical procedures and breast cancer survivorship rates increased, in particular. By the mid 1970s new methods for drug screening were developed to utilize cultured human cell lines. Although targeted chemotherapy was attempted in the early 1960s, success wasn't seen until much later when drugs were developed with ATP binding site compatibility.

In 2003, the Human Genome Project illuminated many genomic determinants and consequences of cancer. This research also indicated that dysfunctional protein kinases are responsible for many of the physical abnormal effects seen with cancer patients. Research to develop kinase inhibitors continues with the hopes of developing target therapies for multiple tumor types<sup>2</sup>. Neoadjuvant therapy has become more commonplace to shrink tumor size for easier and safer surgeries. The cancer mortality rate continues to decline due to early diagnosis and new research.

### ***The Impact and Integration of Survivorship Programs***

The foundation of any healthy lifestyle is wholesome eating and exercise. With cancer survivors, the impact of healthy choices has a greater effect on the maintenance and improvement of QOL. As with any lifestyle change, it is important for cancer survivors to notify their physician and be honest with their limitations.

Research completed by the Strong Survivors program and other institutions has shown that "exercise has beneficial effects on a wide variety of physical fitness and QOL endpoints in cancer survivors including functional capacity, muscular strength, body weight and composition, flexibility, fatigue, nausea, diarrhea, pain, physical well-being, functional well being, depression, anxiety, rigor, anger, mood,

self esteem, satisfaction with life and overall quality of life.”<sup>5</sup> Although the benefits are well known and publicized, the opportunities for structured education and assistance with the lifestyle changes are insufficient.

Even with numerous drug related advancements and research, the social aspect of cancer and survivorship programs did not see much attention until recently. The importance of QOL for survivors and their families has grown in recent decades. Although physical health maintenance on the micro scale, which includes using chemotherapy, radiation and surgery to remove cancer cells, remains the first priority, making sure patients maintain a livable QOL also has a tremendous impact on recovery and sustainability of health. An individual’s ability to take care of themselves without relying on others contributes greatly to self-confidence and self worth. Without a sense of independence and importance, the will to live will decrease. This reflects in patient compliance with medical suggestions and prescriptions. Not only will this lead to the deterioration of the patient’s life, but also puts a heavy burden on their loved ones. This all accumulates into extra stress and discomfort for all parties involved.

Survivorship programs offer the support of educated professionals as well as a community of survivors to promote healthy lifestyles and attitudes. Exercise programs, in particular, are able to combine a classroom educational setting with a structured physical activity regimen. By joining an exercise program, not only is muscle strength and endurance improved, but self-worth also increases. Improved muscle strength and flexibility increases the participant’s ability to complete tasks associated with daily living. This allows them to regain responsibility for themselves

by completing activities such as climbing the stairs, fixing dinner, or holding a grandchild. The physical improvements are easy to see and track, however arguably more important are the psycho-social improvements. Exercise programs require weekly attendance and attention; this gives participants a scheduled activity for the week. This develops the feeling of purpose, control, accomplishment, and pride. Specifically, just as a survivor relies on the trainer the trainer relies on the survivor to commit to the program and trust their exercise prescriptions. This two-way relationship benefits both individuals involved. When progress is seen, the participant is better equipped to complete activities of daily living, increasing their QOL. From the other perspective, the trainer gets to watch their hard work and attentiveness to the program pay off with improvements in assessed variables. Emotionally, the survivor develops pride in their commitment to the program contributing to their will to fight for a better life.

It is also important to note that despite the intense physical burden of a cancer diagnosis and corresponding treatment, “adherence rate after completion of cancer treatment was 95% or higher and during active therapies was between 72-86%.”<sup>5</sup> Studies completed through the Strong Survivors program showed similar results. This is a testament to human will power, and the overall idea that if an opportunity for improved quality of life is available it will be utilized. For this reason, the development of more survivorship programs will not be futile. With cancer impacting more lives everyday, there is demand for survivorship programs in all communities.

Advocacy for exercise in cancer patients and survivors increased significantly with the introduction of the LIVESTRONG program in 1997<sup>3</sup>. This program brought attention to the social consequences of living with cancer. LIVESTRONG developed a community to educate and support not only survivors, but anyone willing to listen. Famous cyclist Lance Armstrong demonstrated that cancer survivors can still complete physical exercise and take control of their lives. With their platform established, their programs grew. In 2007, they partnered with the YMCA to develop a free exercise program for cancer survivors<sup>3</sup>. Using YMCAs across the nation as hubs, they are able to offer exercise programs to many communities. Specifically, the program is established in 39 states with over 400 locations<sup>3</sup>. Even though this is a tremendous opportunity for survivors, the programs are not individually focused, making it difficult to track progress in detail and cater exercise to different abilities. After the 12-week program, the survivors are then expected to continue their exercise regimen on their own with out the guidance of trainers. In 2006, the Cancer Support Community and LIVESTRONG launched the Cancer Transitions program<sup>3</sup>. This program offers information on exercise, nutrition, and social care for cancer survivors in a classroom setting; however, this program is not connected to the YMCA exercise opportunity and is only offered in approximately 100 locations across the nation<sup>3</sup>. The STAR (Survivorship Training and Rehabilitation) program offers individualized cancer rehabilitation services, but with an associated cost<sup>6</sup>. Even though it is sometimes possible to get the cost covered by insurance, there are still deductibles and co-pays that cause concern. In addition, this program is only offered to cancer survivors, excluding their caregivers, and has a finite end date. In

general, physical therapy greatly contributes to increased QOL in cancer survivors; however, many insurance companies do not cover the cost because it is not considered an integral step in cancer treatment. This would leave the patients with a hefty bill in addition to their other medical payments. The Navitas Cancer Centers of America was a program started in the 2003 “to work with the oncology community, patients, and payers to integrate cancer rehabilitation services into the treatment plan for each cancer patient.”<sup>4</sup> Despite its great need in the community, the program expired after only a few years due to financial instability. The cost of the services was frequently too much for out of pocket payments not covered by insurance.

Financial issues and opportunity are the main restrictions on a cancer survivor’s ability to join an exercise program. Despite the overwhelming evidence that exercise increases QOL for not only cancer survivors but also their caregivers, many insurance companies will not cover the cost of exercise therapy. Additionally, hiring a personal trainer can be very costly, especially when outstanding medical bills are a factor. For these reasons, many individuals that could greatly benefit from exercise and healthy eating information are unable to afford the instruction. Financial burden is an unwanted liability especially under stressful, costly medical circumstances. These concerns further contribute to the necessity of available and affordable survivorship programs.

As one of the leading causes of death, cancer affects more than those diagnosed. Friends and family often experience emotional and possible physical pain along side their loved ones. A study completed in 2005 found that the psychological distress of patients and their informal caregivers generally was

parallel over time, although when the patient received treatment, caregivers experienced more distress than the patient<sup>1</sup>. For this reason, survivorship programs help more than just cancer survivors. With their loved ones feeling healthier and more independent, family and friends are less likely to experience worry and stress.

### ***The Strong Survivors Program***

Strong Survivors has been running since 2003 under the leadership of Dr. Anton of the Southern Illinois University-Carbondale Department of Kinesiology. This program allows cancer survivors and caregivers to become educated on the day-to-day choices they can make to improve their QOL completely free of charge. To take part in the program, both survivors and their caregivers are responsible for completing some paper work. The forms include general participant information, informed consent, exercise history, cancer treatment history, medical history, nutrition and demographic forms, a social support scale, a fatigue subscale, and QOL questionnaire. To begin, members are enrolled in a 12-week course during which they receive information on nutrition and exercise. Additionally during this time, they are paired with a certified Strong Survivors trainer and complete a bi weekly exercise regimen. An assessment is completed at the beginning and at the end of the program to track the progress of each participant. At the completion of the 12 weeks, the members receive recognition for their achievements and are offered the opportunity to join the Survivors Forever community. The Survivors Forever program allows survivors and their caregivers to continue their exercise regimen with the guidance of a Strong Survivors trainer at SIUC or allows them access to the John A Logan exercise facilities. The participants are permitted to continue with

their training for as long as they like. They form their own schedules with their trainer allowing more flexibility. Their progress is recorded by an assessment every six months and progress reports are recorded every two months. There are many participants that have taken advantage of this program for years and continue to improve or maintain their QOL.

As indicated with the mandate of university-based cancer centers from the Cancer Act of 1971, universities provide an ideal situation for cancer exercise programs<sup>7</sup>. In particular, universities that require research to be conducted by the faculty give way to an environment conducive for an exercise program. The faculty member can use the participants to gather data and track progress. With the isolation of different variables, the research possibilities are abundant. Additionally, students work as trainers and are individually paired up with participants. This gives students the experience they need to learn professional patient care and prepare for the work force, while seeing the research process first-hand. Specifically within the Strong Survivors program, students are educated in assessment techniques, exercise prescription, and professional participant care. The majority of the student trainers are studying in the Department of Kinesiology; however, students with other majors enjoy involvement as well. Working one on one with a participant allows direct application of what exercise science majors learn in the classroom. The trainer realizes what exercises are difficult and which are easy based on the targeted muscle groups and the participants strengths and weaknesses. For this reason, the trainer learns to adapt the workouts to the participant's needs and abilities. Additionally, due to the full medical history on file, the trainer uses the

information to specify exercises that will help diminish the participant's weaknesses. They also understand which exercises to avoid so that discomfort is minimized. This individual partnership is not only conducive to learning, but to building responsibility and social skills. The participant is in charge of all aspects of their participants exercise program. They not only write and facilitate the workouts but also complete assessments, track progress, record new medical issues, and write summary reports. These responsibilities are expected to be fulfilled on time and with reliability. Therefore, a trainer is responsible for knowing their participants. These expectations create a safe environment and promote a lasting relationship.

The partnership formed between a trainer and a participant contributes greatly to the program's success. Two hours a week may not seem like a lot of time, but when these two hours are spent talking to a participant and helping them achieve a healthier lifestyle, a bond quickly forms. This relationship gives way to a much better understanding of the social side of medical care. Although it is important to act as a professional, the trainers form friendships with their participants over time. At first, learning participant care feels unnatural, but with practice, creating a professional relationship while maintaining participant comfort, comes more easily. The social aspect of the Strong Survivors program is arguably the most important for the trainers and the participants. The trainers learn "bedside manner" per se, by treating the participant with respect and understanding. Because the program is offered to cancer survivors, caregivers, and those that are still undergoing treatment, the physical and emotional needs differ greatly. Therefore, it is the responsibility of the trainer to understand what the participant needs even if

it changes from week to week. This level of responsibility is expected from the start, and therefore, the trainer adapts very quickly to their role, even without experience in patient care. This learning process is very valuable for any student, especially those who are interested in a patient care career. The social aspect is very similar to what is expected of any medical professional; however, it could be argued that the expectations of trainers go beyond what is generally demonstrated by a physician, nurse, or physical therapist. More specifically, these professionals juggle busy schedules with many patients, diminishing the opportunity for social interaction. Without the ability to form a personal connection, understanding, respect, and trust are sacrificed. This is reflected in the patient's willingness to share information that could lead to a swifter recovery and increase the efficiency of medical systems. Overall, the social interaction between trainers and their participants facilitates the successful outcomes of the Strong Survivors program.

From the other perspective, participants trust their trainers to be prepared for their workouts and aware of their own strengths and weaknesses. In order for this to happen, the participant must open up and be honest with their trainer about their medical limitations and emotional struggles. Even though it may take time to develop this sense of trust, it is well worth the effort. Trainers that have formed this bond with their participant will be better able to cater the program to their needs, leading to significantly more successful results.

In addition to the bond formed between the participant and trainer, there is also a true sense of community built within the whole Strong Survivors group. Whether it is in the Cancer Rehabilitation Lab on the SIUC campus or in the

classroom or in the exercise facility at John A Logan College, there is always some level of interaction between participants. This facilitates encouragement between a population of individuals experiencing similar medical obstacles. The mutual understanding builds a network of reliable survivors and caregivers that look out for one another. In many cases, survivors can be more at ease when surrounded by people that have also been stamped by society as patients or survivors. In a recent article, a young female cancer survivor described the hardest part of her illness “was the loneliness and isolation felt when many close friends and family members disappeared because they didn’t know what to say or said the wrong thing without realizing it.”<sup>8</sup> When people around each other understand, even vaguely, what one another are going through, they are more likely to respond appropriately thus creating a peaceful and sympathetic environment. This type of network has been cultivated diligently in the Strong Survivors community and greatly contributes to the success of the program.

### ***Reflection of a Trainer***

It is easy to chronicle the physical and emotional improvements seen in both survivors and caregivers; however, benefits are seen in the staff as well. This is my personal reflection on my experience with the Strong Survivors program to conclude my overall advocacy for exercise communities and the Strong Survivors program specifically. I began the program eager to do research that allowed me to interact with people, rather than isolation in a microbiology lab. Despite my biology and chemistry background, I was warmly welcomed and took a Strong Survivors crash course before working with my first client. I met my first participant in late

August of 2013, and it would be a lie to say I was confident in my personal training skills. She was a survivor that had taken a break from the program for a few years before wanting to start back up again. However, this is where the beauty of the program is first illuminated. Although I was nervous, she was in the same situation but from a different perspective. We were both meeting each other for the first time and testing the waters. With physical training it doesn't take long to get comfortable with someone, you are immediately entrusted with understanding their body. This takes somewhat of a leap of faith outside the normal comfort zone of a friendship. Luckily, she was very open with me about her strengths and weakness, and this enabled me to identify exercises that would benefit her most. During this process, there was no lack of conversation. We started with some typical questions about family, work and school and before I knew it I was looking forward to talking to her about my week. In my first few months working just with one participant, I learned about her love-hate relationship with lunges, her sense of accomplishment that came with completing planks, and her ability to surprise me with how hard she could pass a medicine ball. Not to mention, I got to know her husband, kids, friends, dogs, garden, recipes, and TV programs just through our two hours a week of exercise and chatter. I relied on her to show up to our sessions just as much as she required me to have a safe and fulfilling workout ready when she arrived. Her commitment allowed me to learn how to interact with another individual on a personal but professional level. As an aspiring physician, this experience was invaluable.

Over the course of the next year, I picked up a few more participants and took on additional responsibilities within the program. I continued to work with survivors and caregivers, allowing the opportunity to distinguish the impact of the program on the spectrum of individuals affected by cancer. As an undergraduate research assistant, I began to understand more about the organization and time that went into keeping the system reliable and efficient. With each new person I met, I learned their stories, triumphs and the impact cancer had on their life. Through all of this, I was enlightened as to how important Strong Survivors is to the community. The program displays an ideal balance of university-based research, student involvement, and community impact in an affordable manner.

To conclude, survivorship programs have a tremendous effect on the recovery of cancer patients and the peace of mind of their loved ones. Opportunities for those affected by cancer to come together and work towards improved health show resounding effects through out the community. The networking and system of support improve emotional and physical outlook while contributing to the societal growth. Specifically, the organization of Strong Survivors utilizes local resources to supply an exercise and educational program that gives experience to students while bringing fulfillment to cancer survivors. This thesis is a testament to the success of the Strong Survivors program and the belief that the structure could be implemented in other communities in order to improve more lives.

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