Quality of Life of People with Disabilities in a Student Service Learning Program

A thesis submitted in partial fulfillment of the requirements

For the degree of Master of Science in Kinesiology

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First and foremost, I would like to thank my committee members for their unconditional support and indispensable guidance. For as long as I can remember I have felt a calling to help others. Conducting this research has given me the opportunity to help two of the most important people in my life, my closest first cousin and my father, both of whom live with a disability. This research has allowed me to illuminate how relationships between people with disabilities and those who provide care in a variety of ways. It is my hope that this research will highlight the dedication of the students who work with their clients to provide them with a supportive environment to be physically active.
DEDICATION

I would like to dedicate this thesis to my father Mark Brolsma. While I was in high school, my father suffered a spinal cord injury that required him to use a walker or cane for the rest of his life. Watching him continue to be active through variety of programs inspired me to never underestimate the power of resilience.
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ABSTRACT

Quality of Life of People with Disabilities in a Student Service Learning Program

By Donald Brolsma

Master of Science in Kinesiology

It is observed that there is a continuous decline in physical function and associated decline in quality of life (QoL) among individuals with disabilities. It has been documented that participating in physical activity (PA) significantly improves QoL. Despite many studies proving PA improves one's QoL, there is a limited amount of research showing how combining student service learning (SSL) with PA can improve the QoL of individuals with disabilities. The purpose of this study was to qualitatively investigate the perception of QoL of individuals with disabilities and PA during a SSL program. Semi-structured interviews were performed with 10 individuals with various disabilities. Interviews were audio recorded and transcribed verbatim. Thematic analysis was completed using NVivo 12 qualitative analysis software. Three main themes emerged from the qualitative thematic analysis: peers and students were the motivational factors to PA with positive, non-judgmental, and supportive exercise environment, increased adherence to PA, and increased self-confidence performing activities of daily living. PA combined with SSL programs can potentially improve many different aspects of individuals with disabilities QoL. Three main themes emerged: peers & students were motivational factors to PA with positive and supportive environment, increased adherence to PA, and increased self-confidence performing activities of daily living. PA combined with SSL programs can potentially improve many different aspects of individuals with disabilities QoL. Our results show improvement in general well-being, as well as a positive experience of working with students.
This research, and future research in the field, will help establish a base of evidence to tailor this type of exercise program for individuals with disabilities.
Chapter I: INTRODUCTION

While people with disabilities (PWD) encounter a wide variety of challenges in their everyday lives, one of which, regardless of what specific disability, is a persistently low perception of their QoL. The World Health Organization defines QoL as “The state of complete physical, social and mental wellbeing and not merely the absence of disease or infirmity”. More simply, QoL refers to an individual’s well-being and overall happiness. One of the most influential aspects of a person’s QoL is their ability to retain the independence to complete daily tasks and activities (Kamlesk, 2015). Physical activity (PA) in the form of exercise gives PWD the ability, strength, and confidence to perform any activity they may come across in their day.

The benefits of PA have been widely explored in academia and as such has resulted in being one of the most commonly recommended forms of therapy for PWD. PA is prescribed to help alleviate symptoms associated with disabilities and help regain independence in their daily lives. PWD have gone on to accomplish feats like completing triathlons and powerlifting with the assistance of PA.

In addition to helping PWD manage the severity of their symptoms and retain their independence, PA has been shown to drastically increase individual’s perception of their QoL. People often describe significant improvements in overall happiness and well-being after participation in a consistent exercise program, and is widely utilized to help people manage depressive symptoms. Because PA has proven to be such an effective mean to improving QoL in the general population, it makes perfect sense to utilize these benefits for PWD.

How any activity is implemented is a crucial aspect for determining how effective it will be. For PA to be an effective intervention for improving PWD’s perception of their QoL, the exercise facilitators need to gain experience working with such a specific population. There are
numerous situations that need to be considered and adjustments that need to be made when working with PWD, that if not addressed may inhibit progress or make symptoms of certain disabilities more severe. Certain universities across the country offer some form of student service learning (SSL) program that requires its students to work one-on-one with community members. Combining SSL programs with PA for PWD provides an opportunity to improve PWD’s perceptions of their QoL, while giving students exposure to working in real life situations. By bringing students together with PWD, the students can gain valuable experience that will aide their professional development, and the participants feel a sense of empowerment from passing their experiences of living with a disability to the students.

Until recently these perceptions and implications that PA can have on a person’s life have been nothing more than anecdotal experiences. Qualitative researchers have worked tirelessly over the past decades to document and analyze these experiences into reliable themes that are consistent and valid, but they have not analyzed PWD’s perspective on how working with students affects their view of their QoL. This research will explore if PWD will have an increased perception of their QoL after participating in PA facilitated by SSL.

**Statement of Problem**

The ability to perform activities of daily living and remain independent are crucial for PWD to have a positive perception of their QoL (Kamlesk, 2015). Unfortunately, when PWD are interviewed most report that they encounter significant barriers to participation, such as lack of sleep, loss of strength and aerobic capacity after breaks in the program, lack of transportation, lack of specialized personnel, and lack of information about the need to adapt prevent PWD from being as physically active (Alcaraz-Rodriguez et al., 2018; Rossi, et al., 2018). Certain effects regarding the incorporation of SSL into PA for PWD have been explored. However, the
participants whose perceptions were analyzed were either the students, or clients who have been long-time participants of programs. To date, there has been no research that has sought to explore how the inclusion of a SSL program into PA can affect a first-time client’s perception of their QoL.

**Purpose**

The purpose of this research is to qualitatively explore PWD’s perceptions of their QoL during their first-time involvement in a SSL program.

**Assumptions**

- Participant’s answers are truthful, and not purposefully deceptive.
- Participants will have an attendance rate of greater that 85%.

**Limitations**

- The limitations associated with this research include a lack of generalizability due to the participants all being from the same location, the responses being self-reported from the participants, and personal biases associated with qualitative research.

**Delimitations**

- Individuals must be first time participants of the exercise program, without any previous experiences of receiving exercise from the location. Additionally, participants must be able to cognitively understand the questions, and verbally respond for the purposes of recording.

**Operational Definitions**

- Quality of Life: Satisfaction with one’s overall well-being based on different aspects such as: Occupational, Emotional, Physical, Spiritual, Intellectual, & Social.
• Student Service Learning: one-on-one, semi-private personal training, facilitated by undergraduate kinesiology students

**Significance of Study**

This research sought to illuminate how the implementation of a SSL program with a PA program for PWD can influence a first-time client’s perception of their QoL. It will provide insight on how student interaction with PWD through PA can influence a first-time client's perception of their QoL.

Chapter II: Literature Review

**Physical Activity & People with Disabilities**

According to a report published by the Center for Disease Control and Prevention (CDC) (2016), there are around 61 million individuals living with a disability on the United States. The data by Behavioral Risk Factor Surveillance System (2018) reported that 1 in 4 adults live with a disability in the U.S., with cognitive disabilities most common for younger individuals and mobility disabilities most common for older individuals. The report also displays how the prevalence of disabilities increases as individuals age, rising to 2 out of every 5 individuals over the age of 65. Despite showing several other statistics, including gender and socio-economic status, and acknowledging the wide differences between how disabilities can manifest, the majority of this population has a greater inherent risk of living a more sedentary life than able-bodied individuals.

The effects of living a sedentary lifestyle have been well documented to result in a myriad of health-related consequences including cardiovascular disease, osteoarthritis, & certain cancers (WHO, 2018). A report from the Center of Disease Control Prevention (2017) showed
that as of 2016 93.3 million adults, 39.8% of the total U.S., were considered obese. In addition to
the country facing an obesity crisis, PWD encounter a variety of extra barriers to PA that only
increase their susceptibility to the health complications related to obesity. PA and exercise is
prescribed to PWD to help combat the negative health consequences associated with a sedentary
lifestyle, in addition to helping help maintain and improve their activity of daily living leading to
a greater satisfaction with their lives.

One study conducted by Bevis, Waterworth, and Mudge (2018) demonstrates how
participation in PA can help PWD achieve any self-determined goals, while increasing
confidence in the ability to perform activities of daily living. Through semi-structured interviews
following participation in a mixed-ability yoga program the researchers identified that the
participants experienced a decrease in the perceived limitations in their daily living. This
decreased perception of their limitations is crucial because how PWD view their limitations can
result in psychological barriers to participating in PA (Bevis et al., 2018). Additional barriers
include lack of transportation, difficulty with registration processes, lack of specialized
personnel, and lack of information about the need to adapt prevent PWD from being as PA
(Alcaraz-Rodriguez et al., 2018). The study by Alcaraz-Rodriguez et al. (2018) sought to explore
the perception of barriers that athletes with visual functional diversity (VFD) have toward
organized trail running competitions. The researchers used a phenomenological analysis of semi-
structured interviews of participants and trail guides to develop categories related to perceived
barriers.

Another study by Rossi, Torres-Panchame, Gallo, Marcus, & States (2018) uncovered
facilitators and barriers to engagement in PA as two major themes from their qualitative analysis.
Their research utilized a convergent mixed-method design attempting to identify certain key
factors that make a group exercise program enduring for people with Parkinson’s Disease (PD). The study explored using triangulation among interviews, written questionnaire, and short written reflection assignment from students assisting with the program. Following analysis, the researchers found that most participants reported the social cohesion of the group setting, improved mood and perceptions of living with PD, and new found energy in other activities to be key facilitators to continuing the exercise classes. Additionally, the theme regarding barriers to the engagement in PA identified as lack of sleep, difficulty waking up in the morning, loss of strength and aerobic capacity after breaks in the program, transportation, health related issues, and conflicting appointments. (Rossi et al., 2018) This study’s facilitators are particularly relevant to QoL due to the involvement of improved mood, social cohesion, and feelings of more energy. Rossi et al. also uncovered a subtheme associated with the quality of the program that emerged regarding how the participants viewed working with student assistants. Many participants reported enjoying working with younger generations and that they felt the students made it more “interesting”. It is the hope of this current research to make student involvement the primary question regarding of the qualitative analysis instead of a subtheme.

Another study by Mullign et al. (2018) sought to explore the perceptions that individuals with Parkinson’s had of an exercise program. A randomized control trial was conducted with an intervention group consisting of 21 members received both an exercise program and a cognitive enrichment program, while a control group of 20 continued with their usual care. Following eight months of a supervised PA program, the intervention group participated in semi-structured interviews to explore their perceptions of the program. After an inductive analysis of the transcriptions the researchers unveiled three main themes regarding the participant’s perceptions of the program. The participants felt that they had to have trust in the facilitators by ensuring that
the physiotherapist had knowledge of how their specific disability affected their body, being able to adapt and modify the exercises based on individual needs, and the facilitators acted in a professional manner. The participants felt that the camaraderie built between others that can empathize about how it feels to live with Parkinson’s helped to establish more adherence to the program by being held accountable by their fellow participants. Finally, the participants described a sense of empowerment they gained by feeling that they “took back control” of their lives through the supportive environment and transferability of exercises to their home (Mulligan et al., 2018). This article provides a tremendous amount of insight into what is necessary to create a successful PA program for PWD. Additionally, this article was selected as guide for the use of semi-structured interviews to gain an insight of participant’s perceptions of an exercise program.

As touched upon briefly earlier, PA has long been utilized as means of improving the perception a person has of their QoL, regardless of being able-bodied or a person with a disability. To understand how PA can influence QoL, it is first important to define QoL. The World Health Organization defines QoL as “The state of complete physical, social and mental wellbeing and not merely the absence of disease or infirmity”. Using this definition, it is easy to see how crucial PA if to one’s QoL. PWD also often have a reduced social network because of the same barriers they might have for PA, such as lack of transportation.

**Six Dimensions of Wellness**

Due to the qualitative nature of this research, the epistemological framework for the study will utilize Dr. Bill Hetler’s Six Dimensions of Wellness established in 1976. Dr. Hetler’s model combines six different aspects of a person’s life to give pathway to a holistic sense of wellness. The model incorporates such aspects as emotional, occupational, physical, social, intellectual, and spiritual. The Six Dimensions of Wellness was selected as this research’s framework.
because of the relationship between wellness and QoL. Additionally, by combining PA with a SSL program PWD can influence four out of the six dimensions of wellness including emotional, physical, social, & intellectual.

**Physical Activity & Quality of Life in People with Disabilities**

One study published by Kamelska and Mazurek (2015) found moderate correlations between PA and QoL. Their research utilized questionnaires that assessed PA and self-assessed QoL. Levels of PA were determined by the International Physical Activity Questionnaire (IPAQ), while QoL was self-reported using the WHO-Quality of Life questionnaire. Despite reflecting moderate correlations between PA and QoL, the questionnaires revealed a close relationship between the satisfaction with QoL and the ability to perform moderate PA around their house. They found that PA performed around their house encouraged the participants to engage in activities outside of their house, thus giving them an improved perception of their QoL (Kamelska, 2015). These findings are significant because if demonstrates how a perception in the ability to complete activities crucial to daily life can impact a person with a disability’s QoL.

While Kamelsak and Mazurek’s research (2015) demonstrated how PA can increase a PWD’s perception of their QoL, a different study by Aggerholm and Moltke Martiny (2017) sought to explore how bodily experiences of PWD affect their QoL. Utilizing a phenomenological framework, the authors sought to explore how three concepts of phenomenology including first-person perspective, embodiment, and life world affect a person with CP’s view of their QoL. QoL was assessed by investigating participants’ embodiment and notions of body schema and image. The study occurred over the course of a ski camp in Denmark for children with CP. Eleven Danish children attended the camp, consisting of ages between 14 and 18. Three semi-structured group interviews were conducted during the study.
occurring one week prior to the camp, one week after the camp, and two months after the camp. Each interview was recorded using visual and auditory methods, and video taken during the camp was show prior to the last interview as a form of simulated recall. After analysis of the interviews three key themes were identified for the children’s experiences including: “yes I can”, “yes I can if I practice”, and “yes we can” (Aggerholm & Moltke Martiny, 2017).

The first theme identified, “yes I can”, referred to participant’s uncertainty and anxiety in participating in skiing related activities. Regardless of if the participants had snow skied previously, most participants reported feeling mixed emotions such as worries, insecurities, and excitement. Once overcoming their initial uncertainty through participating in the camp the children reported feeling a greater command of being in control of their bodies, and having more “faith” in their bodies. Surprisingly, the children also expressed how the newfound confidence in their abilities transferred to other activities such as feeling less anxious during school examinations. The second theme highlighted the growth that can occur through participation in PA by the children expressing a greater confidence in their bodily control after the camp. One 14-year-old participant described how they gained a greater confidence in their abilities by persisting through the skiing training to the point where, since the conclusion of the camp, they have learned how to ride a moped and aspire to drive a vehicle in the future. The third and final theme identified how the children’s social interactions through the camp allowed them to be less self-conscious and understand their abilities in new ways (Aggerholm & Moltke Martiny, 2017). Additionally, their findings regarding increased confidence in their body’s abilities from a sense of social support and schema awareness directly relates to improvements in the emotional, physical, and social dimensions of Dr. Hetler’s Six Dimensions of Wellness.
A different study by Adamson, Adamson, Littlefield, and Molt (2017) found similar themes of confidence in PA for people with Multiple Sclerosis (MS). The primary objective of the study was to explore how individuals with MS view the roles of PA regarding the disability itself and the symptoms associated and how they view their disability as a part of their identity. The way in which an PWD view themselves in relation to their disability is a key component of understanding their perception of their QoL because it is hard to argue that their disability would not make up a large part of their identity. The authors interviewed 15 participants in semi-structured individuals with MS who had recently experienced a relapse of their symptoms. Each interview was recorded and transcribed with notes taking regarding the transcriptions. Through the analysis of the categories three major themes were developed based on the interviews. The first theme that the participants described was feeling that participation in PA would minimize or prevent future symptoms or potentially reduce current symptoms. Participants describes “simply feeling better” while regularly participating in exercise, and a sense of motivation to continue to stay active. Secondly, individuals with MS described a feeling of empowerment by overcoming obstacles related to their disability, and “taking back control” of their lives from their disability. Finally, the third theme revealed a direct effect on their QoL by making PA a means of managing their disability. Participants expressed the desire to continue PA due to a fear of their symptoms becoming more severe. This deeply seeded desire to prevent future symptoms gives PWD a sense of hope and control over their disability (Adamson et al., 2017).

**Student Service Learning & People with Disabilities**

The final component that this current research will investigate is how the incorporation of a SSL can affect PWD’s perception of their disabilities. According to California State University, Northridge’s Office of Community Engagement SSL can be described as “A
teaching and learning strategy that integrates meaningful community service with instruction and reflection to enrich the learning experience, teach civic responsibility, and strengthen communities”. More broadly, Dr. Barbara Jacoby (2014) defines SSL as “education that is grounded in experience as a basis for learning and on the centrality of critical reflection intentionally designed to enable learning to occur. As continuously described by a variety of research articles based on PA and PWD, the inclusion of a social component is crucial to both adherence and satisfaction in PA programs. However, this one aspect is by far the least to be scientifically investigated to date, and a very limited pool of research exists to explain how the programs can be effective.

A study conducted by Ylitalo and Meyer (2018) explored the best methods to develop and evaluate a SSL. The study included three separate SSL programs, which required the students to make two written prompt reflections, one prior to the beginning of the program and the second at the end of the semester. As described by the researchers the primary objective was to generate data that could be helpful for local organizations to implement and improve the delivery of service. Once the analysis was completed three fundamental themes emerged regarding the students’ experiences in the SSL program. First, the students’ expressed how participating in the program gave them a greater understanding of the importance of research. Stating that initially they felt research was boring, but after the second reflection described the importance of the researchers’ attitudes in encouraging participation. The second theme also related to how students value the data collection and research process. Many described lamenting having to write the responses, but by the end of the semester realized how helpful their views and perceptions can be. Lastly, the data revealed the importance of the social component between the students and community members. The students described how illuminating it had been working
in the community by seeing what really needs to be addressed first-hand. The data showed that SSL programs can fill a unique and vital role of bridging the gap between the academic world and the actual needs of the community (Ylitalo, 2018). While Ylitalo and Meyer’s research provided key insight into how valuable SSL programs can be to exposing students to the research process and a new setting, it does not address how the community members regarded the program or how PWD could regard SSL programs.

Another article does in fact combing a SSL program with a PA program for PWD (Woodruff, 2015). However, just like Ylitalo and Meyer, Woodruff and Sinelnikov only analyzed the students’ perceptions of what it is like to work with children with a disability. The authors were interested in discovering what students considered meaningful while teaching children with disabilities, and how perceptions regarding disabilities changed during their experiences with the children. 50 undergraduate students enrolled in an Adaptive Physical Education class were selected to participate in the study. The researchers collected qualitative data from five different sources including formal interviews, informal interviews, analysis of critical incident reports, formalized reflections, and direct observations. The difference between the formal and informal interviews was that only two formal interviews occurred during the semester and followed a semi-structured format with audio recordings. The informal interviews, however, occurred daily on the teaching sites, and included asking questions of the upcoming sessions followed by debriefing at the end of each session. After the analysis of the five different areas, six key themes emerged: 1) gamut of emotions, 2) lack of prior meaningful experiences with PWD, 3) pre-conceived notions of PWD, 4) change in labelling discourse, 5) developing relationships and communication, and 6) focus on the learner. The themes that apply most directly to the current research being conducted are lack of prior experience with PWD, change
of labeling discourse, pre-conceived notions of PWD, and the development of relationships and communication. Regarding PWD’s perception of their QoL, these four themes relate the most to QoL in that by exposing student’s to PWD and changing labelling discourses should have direct impact on PWD’s social dimension by educating society about PWD’s experiences.

Based on the literature presented above there exist of glaring gaps in our knowledge of how the combination of a SSL program can influence a PWD’s perception of their QoL. It has been well documented the effects of PA in PWD (Bevis, Waterworth, & Mudge, 2018; Alcaraz-Rodriguez et al., 2018; Rossi et al., 2018; Mulligan et al., 2018), but there has is a very limited amount of research explored PWD’s perceptions towards their QoL through SSL. While some studies have revealed how QoL can be affected by working with students (Rossi et al., 2018), PWD’s perceptions have not been explored as a primary mean of data collection. Therefore, it is the purpose of this research is to investigate the perceptions of QoL of PWD during involvement in a SSL program.
Chapter III: METHODOLOGY

Sampling procedure and participants

A qualitative study was conducted using semi-structured in-person interviews with participants of university-based therapeutic exercise program in Southern California. The program is a community-based exercise program for individuals with various disabilities combined with academic training program for Kinesiology students. Participants can enroll in either land- or aquatic-based exercise program. The students are enrolled in an elective adaptive therapeutic exercise class through the university’s kinesiology department. All participants in this study were recruited using a convenience strategy using word of mouth. In this study, first time participants in the program were recruited. If someone had been enrolled in the program for more than one semester, than they were excluded from the study.

A total of six participants were interviewed for 30-45 minutes at their selected comfortable location.

Research design

This research was designed with a phenomenological perspective to highlight the participants’ lived experiences. The participants’ experiences were used to develop descriptive data to give a greater understanding of PWD perception of their QoL. To ensure that biases are kept to a minimum the strategy of bracketing was used, that requires the researcher to disregard one’s personal beliefs, feelings, and to perceptions so that the participant’s experiences remain the focus (Cresswell, 2014).

Data collection

Interviews were completed in the middle of the 13-week exercise session to highlight participants’ first time experience in SSL program. The interviewer asked open-ended questions
about participants’ experience in the program and their QoL, including a narrative of the
participants’ experiences in SSL program, addressing three topics: 1) Participants perception of
involvement in PA, 2) Perception of participation in the SSL program, and 3) barriers and
facilitators to participation in PA (Table 1). All interviews were recorded using audio recording
device (WS-853, Olympus, 2015)

Data Analysis

Interviews were recorded and transcribed verbatim. All interviews were analyzed using
NVivo 12 software (QRS International, Melbourne, AU, 2018) and following phenomenological
framework. Phenomenology was picked as the epidemiological framework for analysis because
it seeks to fundamentally understand phenomena by investigating the lived experiences of the
participants. (Standal, 2014) The phenomena in question here is why PWD have a lower
perception of their QoL, and what effect participating in a SSL program has on their perception.
Data was collected and analyzed using an In Vivo coding strategy in which participant’s direct
quotes were assigned coded. All developed codes were divided into categories, then merged
together, summarized, and reconstructed to develop themes.

To ensure that the data is valid the transcriptions were member checked by the
participants, then the themes were briefed and discussed with other researchers. Finally, a
triangulation between the member checking, briefing, and comparisons to previous literature
helped to ensure that the generated themes were valid. Regarding reliability, the coded passages
must be 80% in agreement during the member checking process. (Creswell, 2014)

Due to the nature of qualitative research personal biases must be addressed to ensure that
they do not interfere in the analysis process. My personal biases that may influence the how I
view the data are that I was formerly involved in a SSL program during my undergraduate education, and I have personal experiences with hearing how involvement in a SSL program effects a person with a disability. Additionally, the limitations associated with this research include a lack of generalizability due to a relatively small sample size, the validity and reliability of self-reported perceptions of sensitive issues that the research only occurred at a single location, and my personal biases.

Table 1

*Semi-Structured Interview Questions*

1. Please describe your experience here at the center.

2. How do you feel about the overall environment about the center?

3. How important is physical activity to you?

4. In what ways do you think the program encourages or discourages you to be more activity?

5. How does the academic environment affect how you feel about exercising?

6. How would you say that in general your health is?
Chapter IV: RESULTS

A total of six individuals participated in this study. Specific details regarding the participants can be found in Table 2. Out of the six participants, two were enrolled in the land based program, three were enrolled in the aquatic based program, and one based enrolled in both land and aquatic. All participants received exercise instruction from Kinesiology students in SSL program.

Twenty different codes were created to capture participant’s experience regarding PA, QoL, and SSL. Three themes emerged in this study; 1) a sense of motivation from working with the students, 2) increased confidence in performing activities of daily living, and 3) an increased adherence PA.

Table 2

*Participant Demographics*

<table>
<thead>
<tr>
<th>Participants</th>
<th>Disability</th>
<th>Age</th>
<th>Gender</th>
<th>Type of Participation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sara</td>
<td>ACL Surgery</td>
<td>19</td>
<td>Female</td>
<td>Land</td>
</tr>
<tr>
<td>Mary</td>
<td>Lower Back Pain</td>
<td>57</td>
<td>Female</td>
<td>Aquatic</td>
</tr>
<tr>
<td>Jane</td>
<td>Lumbar Stenosis</td>
<td>84</td>
<td>Female</td>
<td>Land</td>
</tr>
<tr>
<td>Bob</td>
<td>Spinal Cord Injury</td>
<td>65</td>
<td>Male</td>
<td>Aquatic</td>
</tr>
<tr>
<td>Ryan</td>
<td>Parkinson’s Disease</td>
<td>82</td>
<td>Male</td>
<td>Aquatic</td>
</tr>
<tr>
<td>Michelle</td>
<td>Bilateral Knee Replacement</td>
<td>68</td>
<td>Female</td>
<td>Aquatic &amp; Land</td>
</tr>
</tbody>
</table>
Overall Quality of Life

When asked about their QoL, participants responded that they do struggles to maintain a positive perspective living with their disabilities. However, they consistently reported that engaging in PA with their students had a positive influence on their perception of their QoL through social interaction and increased confidence through greater strength.

Overall QoL expressed by participants were often positive even they described things that made their lives challenging, difficult, or uncomfortable. Participants also compared themselves with other members of the program, or other individuals with various disabilities, stating, “(one quote comparing themselves with others)”. Participants expressed their QoL to be multidimensional integrating environmental, socialization, physical

Motivation from students and peers

Five out of the six participants expressed that the environment was a key factor in their experience during the program. The participants described the setting as welcoming, inspirational, supportive, and motivational. The participant Bob, who lives with a spinal cord injury, stated:

“I DO LIKE THE ENVIROMENT!! I like seeing the environment of just all-different kind of people and the people are walking in the hallway and they can’t walk but they’re giving their all and that helps me.”

Through this quote, Bob demonstrates how the overall environment of being of the student facilitate program with other PWD is a facilitator to his participation in exercise. Unfortunately, programs like this are very far and few between. He later explains that what he specifically likes about the environment is the encouragement that he feels form the student’s motivation and being in an environment with other PWD.
“You know… if anything, it encourages me. I like seeing all different kinds of people…uh! Some people, I look at them and I kind of see the progress that they’ve made and that really pushes me a lot…probably more than anything else!”

Bob continues to describe a key aspect of the student and client relationship by highlighting that an acclimatization period exists when the students meet their client. However, over the first weeks this quickly dissipates to a relationship built on trust.

“Students at first were kind of (unclear) and were kind of nervous to touch me but I got better by the second or third week. It was just great!”

Another positive experience regarding the environment came from Michelle, who experienced a bilateral knee replacement. Michelle describes how her interactions with the instructors and students has given her a positive experience while being physically active.

“It’s been nothing but positive. The people that are here and the instructors and everyone involves actually”

After describing her overall impression of the environment, Michelle continued to explain how the student that she worked help to motivate her during her sessions.

“He really does encourage you the entire class time. You have trouble moving, he will motivate you and give you more instructions and just encourages you throughout the class.”

Bob and Michelle were not the only participants to describe feelings of motivation from their students and the environment. Jane specifically spoke about how she values the constant support and motivation from her student.

“I really appreciated when I get push a little it’s, I am thankful, yeah! And that there are people around me pushing me”
Increased adherence to physical activity

As the majority of the participants expressed positive feelings regarding how the environment felt supportive and motivating. These positive perspectives among the participants led to statements regarding an increased desire of wanting to come. Many PWD face a variety of barriers to their engagement in PA (Alcaraz-Rodriguez et al., 2018; Rossi, et al. 2018). One quote by Mary conveys this sentiment of how her experience with her student made her want to attend more:

“…except that I kinda looking forward to come in and I can't always come because of, uh, of work commitments but, I really... I want to be here so I think that's the positive”

Similarly, to Jane, Bob expressed how being in a supportive environment provided by the students and clients can be a source of motivation to encourage people to continually attend their sessions.

“It’s really seeing people that had accidents and now are kind of gone from...have gone from a walker to a cane! Kind of an example…and it’s also encourages me to see people that are sicker than I am or more injure I should say!”

Confidence in performing activities of daily living

As previous research has found, remaining independent is a crucial to PWD perception of their QoL (Kamlesk, 2015; Adamson, et al., 2018). PA ties directly in with a person with a disabilities’ ability to remain independent (Kamelsk, 2015). Without PA, a PWD will gradually lose the strength, balance, and ability to perform the necessary activities of daily living crucial to remaining independent. Jane describes that she realized how important her strength to perform activities of daily living:
“Especially now...I realize...you know like my arms...I was strong...you know I thought I was in pretty good shape but...now I can’t even open a bottle...of water...I struggled, so I know it’s very important.”

Jane goes on to explain how an increase in her overall strength can mean away back to independence, and a more positive perception of her QoL.

“think it’s gonna make me feel...you know...to be more active! That’s what I am looking forward to...so you know...so I can get up, stand by myself

Similarly, Bob expressed his desire to target specific physiological components such as balance and lower limb strength. In particular, the use of one key word, ‘unassisted’, speaks to the importance of the ability to perform activities of daily living:

“The primary is really balance exercises and walking, strengthening my legs...uh and I do want to...need to...walk again...uh...hopefully...unassisted.”

Additionally, PWD are aware of how important PA is to their overall well-being. When asked what PA meant to them, Mary had the following to say:

“Well, I think it is important for several reasons! One is...is that...it is something that I'm doing for myself, for self-care and secondly, uh, it uh...you know, it helps other aspects of life, like sleep better…”

This is important because it shows how PWD are aware of the benefits that being physically active can have to their well-being. Mary continues to relate PA to activities of daily living through the following statement:

“it just means moving...and uh, I actually like to...do things like walk or swim or things like that so...”
She describes how being physically active is her key to engaging with the outside world. Other participants expressed similar sentiments regarding how their greatest fears revolve around being able to safely navigate the world, but how student encouragement can help motivate them.

“my fear …probably of falling, loosing my balance, and I really appreciated when I get push…a little bit …and it’s, you know, I am thankful…yeah! And that there are people around me pushing me…”

As seen through these previous comments, mobility is the most common expressed concern with regards to their level of ability, and as research has shown this is commonly expressed by PWD (Kamlesk, 2015). Michelle expresses a similar viewpoint to Mary, in that the ability to remain mobile is her key to being active in the world:

“uh! It means being healthy or getting healthy or staying healthy…uh…it’s just an important part of life and it’s even more important because I had both my knees done…”

Chapter V: DISCUSSION

The goal of this research was to explore the perceptions about QoL PWD through PA in a SSL program.

In general, the first-time participants expressed a positive experience of working with their students. The interactions with their student trainers was shown to be a key component to their over-all experience with PA. They shared that working with their students encouraged them to want to continue to be physically active. This in turn led to improvements in their overall QoL.
by addressing five out of the six dimensions of wellness; physical, social, intellectual, environmental, occupational. The participants all expressed that being physically active was vital to their QoL, and how the inclusion of a student can facilitate motivation to be more physically active.

PWD encounter a number of barriers to the participation in PA (Alcaraz-Rodriguez, et al., 2018; Rossi et al., 2018). Barriers such as lack of sleep, loss of strength and aerobic capacity with breaks between program sessions, lack of transportation, lack of specialized personnel, and lack of information about the need to adapt. These barriers prevent PWD from being as physically active can discourage PWD from participating in PA (Kamelska, 2015; Alcaraz-Rodriguez et al., 2018; Rossi, et al., 2018). While trying to address all the different barriers to PA is daunting, perhaps the issue can be combated through a different approach. In this research, the participants described how the inclusion of students in the facilitation of PA can help motivate PWD to push past the barriers they encounter. Many of the participants looked forward for their sessions with the students, and described the environment as “welcoming”, “supportive”, and “encouraging”. This directly ties to this research’s findings of an increased adherence to PA.

Improvements in the physical dimensions can be linked to the themes of increased confidence in performing activities of daily (Kamelsk, 2015). Many quotes expressed by the participants describes how possessing the necessary strength to complete activities of daily loving is key to their perception of their quality of life. Improvements in the physical dimension of wellness would occur with the participation in any PA program, but the many barriers they face often hinder improvement. Motivation felt by the participants while working with their students can be a facilitator to participation in PA. This is crucial because if a PWD does not
participate in PA because the barriers seem insurmountable, then they will never improve this dimension.

The findings related to the intellectual dimension can also be tied into the themes of increased motivation from students and peers and increased adherence to participation in PA. The intellectual dimension of wellness, while not directly mentioned by any of the participants, plays a distinct role in the structure of the program that they were involved in. Over the semester, participants witnessed first-hand how the students’ skills in working with PWD improved. They saw students become more confident in implementing a variety of exercises through the sessions. This allowed the participants and students to develop a shared experience of overcoming obstacles throughout the semester together. The participants witnessed the students become confident exercise providers while they overcame their personal milestones. Students in this program lean about disabilities and how they affect people. As students gain more knowledge about disabilities, they were able to apply what they have learned in classroom to their clients during their exercise sessions. Additionally, participants were empowered by the fact that their valuable insight about having disability contributed to students’ learning.

The theme of increased motivation from students and peers is most directly related to the social and emotional dimensions through increased through increased confidence from overcoming obstacles, increased self-esteem, and social interaction. The social dimension was an integral aspect of this research. One study (Sabahat, 2018) reported that social interaction is key to well-being and QoL, particularly between PWD and people without a disability. The study found that interaction between groups that one does not associate with, outgroups, can improve the way PWD perceive themselves in relation to the general population, or outgroups. This in turn led to a higher level of self-esteem reported by the PWD (Sabahat, 2018). Both an improved
outward perception and increased self-esteem caused to participants to experience a sense of empowerment. The participants in this research reflected similar views of empowerment while working with their students.

The participants in this research expressed similar experiences that relate primarily to emotional wellness. One participant expressed how their participation is a form of self-care, increased self-esteem through greater social interaction, and how students motivate to overcome perceived barriers are all examples on improved emotional wellbeing. The improvements in emotional wellbeing can relate directly to the improvements in physical and social wellbeing, both of which help to increase the participants perceived level of ability and self-esteem (Sadahat, 2018). The improvements in emotional wellbeing from student’s involvement supports the idea that the inclusion of SSL programs can positively affect QoL.

The occupational and spiritual dimensions were not directly reported by the participants during the interview. Since the interviews were focused on the effects of PWD’s participation in a SSL facilitated PA program, questions specifically pertaining to perceptions of the occupational and spiritual dimensions. However, because of the holistic design of Dr. Hetler’s Six Dimensions of Wellness both dimensions can be influenced by improving the other dimensions of wellness. By gaining greater physical strength, increasing their self-esteem, and improving the perception of their capabilities of living with a disability the participants have a greater likelihood of seeking an occupation. A similar study (Kim, et al., 2018) showed that veterans with a disability who participate in 3-4 wheelchair games have a higher perception of employment. The increased confidence that they gain through overcoming obstacles with the help of their student can translate to feelings of empowerment to become more independent. Since none of the participants shared views relating to spirituality, it was inconclusive if this
dimension could be improved through student interaction. Any effects on the spirituality dimension would greatly depend on the individual conversations that the PWD have with their students, since it would not be directly addressed through the program.

Analysis of the interviews and themes has shown how PWD’s participation in a SSL program for PA can improve their perception of five out of the six dimensions of wellness: social, intellectual, physical, emotional, and occupational. The findings of this research revealed that PA through a SSL program can be an incredibly useful tool in the improvement in QoL. The desire for interaction with their students, the overall supportive nature of the environment, and the motivation and empowerment gained though PA can directly influence numerous dimensions of their wellness.

**Recommendation**

The results point strongly to the benefits of the incorporation of SSL programs into PA for PWD. The data from this study demonstrated that PWD’s will adhere to exercise sessions, gain a sense of support because of student involvement, and increase perceptions of QoL and acquire sense of empowerment by being an influential factor in students’ learning.

This research provides a greater insight about the perceptions of QoL in PWD and influencing factors of SSL to the perception. When combined with an analysis of current research, the results strongly indicate that engaging in PA with students positively affects the numerous dimensions of the participant’s wellness.

The facility in this study is combined with an academic program in Kinesiology major. Both graduate and undergraduate students receive academic training through their lab. This exercise program began in one small room with the idea of expanding the opportunity for PWD
in participating exercise in a time when most of society still ignored PWD, well before the American with Disabilities Act from 1990 was established. Over the years the program has grown from serving one person with disability to 400 community members and 300 Kinesiology students every semester. The facility expanded in size by adding more rooms with specialized adaptive equipment, and four therapeutic pools for adapted aquatics program. Students are given the opportunity to work with individuals with disability in early stage of their academic life. This can be a fundamental experience for students that are not typically exposed to working with a PWD until later in their professional career (Yitalo, 2019). Between the improvements of PWD perceptions of their QoL and the students being exposed to an underserviced population is a “win-win” for everyone involved. With roughly 1 out of every 4 individuals in the United States living with a disability, it is a reality that once these kinesiology students enter the workforce they will encounter someone with a disability. The further implementation of programs like this in other universities can expand the exposure students have to PWD, while simultaneously helping PWD improve their QoL.

Limitations & Research Implications

This research will provide a greater insight into how PWD perceive their QoL and how student involvement can affect their perception. However, there are certain limitations to this research. Participants in this study were selected based on a convenience sample. This may have given a limited perspective. In addition, the relatively small sample size (n=6) in this study maybe difficult to generalize Nevertheless, the intent of the research was to explore the perceptions of the participants about their QoL through SSL. The specific design of the facility and program mean that the transferability to other institutions would be difficult. However, the variety of different disabilities means that the results can be applied to many types of PWD.
Additionally, the nature of self-reported interviews has been assumed that the participants answered to the best of their abilities, and did not purposefully try to deceive the researcher.

In summary, this study has produced further evidence that PA through SSL can help improve the QoL for individuals with various disabilities. It is this researcher’s hope that these findings can be utilized by other universities and institutions to develop SSL in their programs to give learning opportunities for students to better serve PWD in their community.

Further research is recommended to gain more insight into the influences that SSL can have on PWD perception of their QoL. In addition, the long-term effects of PA through SSL on QoL in PWD. Also, future research can explore how students’ perception on QoL change through SSL experience.

Conclusion

This study, by implementing a qualitative approach, provided evidence that PA through SSL improved QoL for individuals with various disabilities. QoL indicators included physical, emotional, social, intellectual, environmental, and spiritual dimensions of wellness. The support, motivation, and encouragement provided by the students proved to be key facilitators to a person with a disabilities QoL. The relationships built between the person with a disability and their student trainer were shown to help the client set and overcome self-determined goals. The realization that a person with a disability can actually overcome their goals through the encouragement of their student was shown to be extremely valuable to the client. This study contributes to the current literature on the impact of PA through SSL for improving the QoL of individuals with disabilities. The results in this study should contribute to improving the QoL in individuals with disabilities by taking into consideration factors impacting it, as well as acknowledging the critical findings of improving all six dimensions of wellness.
References


California State University, Northridge
CONSENT TO ACT AS A HUMAN RESEARCH PARTICIPANT

Perceptions of Quality of Life of People with Disabilities in a Student Service Learning Program

You are being asked to participate in a research study. The *Perceptions of Quality of Life of People with Disabilities in a Student Service Learning Program*, a study conducted by Donald Brolsma as part of the requirements for the M.S. degree in Adaptive Physical Activity, Dept. of Kinesiology. Participation in this study is completely voluntary. Please read the information below and ask questions about anything that you do not understand before deciding if you want to participate. A researcher listed below will be available to answer your questions.

**RESEARCH TEAM**

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**PURPOSE OF STUDY**

The purpose of this research study is to qualitatively investigate people with disabilities’ perception of their quality of life after participating in physical activity facilitated through a 13-week long student service learning program.

**SUBJECTS**

**Inclusion Requirements**
You are eligible to participate in this study if you:
- Are 18 years or older
- Are currently enrolled at Center of Achievement at CSUN.
• It is your first time enrolled at the Center of Achievement.
• You are able to verbally respond to the questions for the purposes of audio recording.

Exclusion Requirements
You are not eligible to participate in this study if you:
• Have participated in a previous semester at the Center of Achievement.
• If you are unable to

Time Commitment
This study will involve approximately 50-60 min. of your time for one day only.

PROCEDURES
The following procedures will occur: After the completion of your 13-week physical activity program, you will be asked to participate in a single one-on-one interview. This interview will last around 50-60 min., and will take place in a private location at the same center where you went for your exercise sessions. The interviews will be recorded using an audio recorder for the researcher to analyze later.

RISKS AND DISCOMFORTS
There are no known harms or discomforts associated with this study beyond those encountered in normal daily life. The possible risks and/or discomforts associated with the procedures described in this study include: mild emotional discomfort- some questions may make the participant feel uneasy, embarrassed, or uncomfortable. The information for University Counseling services or other local medical/mental health professional will be provided to any participant that ask. This study involves no more than minimal risk.

BENEFITS
Subject Benefits
You may not directly benefit from participation in this study.

Benefits to Others or Society
The data collected by his research will help develop a deeper understanding of how People with Disabilities’ perceive their Quality of Life, & how the inclusion of a Student Service Learning program influences their Quality of Life.

ALTERNATIVES TO PARTICIPATION
The only alternative to participation in this study is not to participate.

COMPENSATION, COSTS AND REIMBURSEMENT
Compensation for Participation

You will not be paid for your participation in this research study.

Costs

There is no cost to you for participation in this study.

Reimbursement

You will not be reimbursed for any out of pocket expenses, such as parking or transportation fees.

WITHDRAWAL OR TERMINATION FROM THE STUDY AND CONSEQUENCES

You are free to withdraw from this study at any time. If you decide to withdraw from this study you should notify the research team immediately. The research team may also end your participation in this study if you do not follow instructions, miss scheduled visits, or if your safety and welfare are at risk.

CONFIDENTIALITY

Subject Identifiable Data

All identifiable information that will be collected about you will be removed and replaced with a code. A list linking the code and your identifiable information will be kept separate from the research data. All identifiable data will be destroyed after the completion of analysis.

Data Storage

All research data will be stored on a laptop computer that is password protected or has encryption software, in addition to stored electronically on a secure network with password protection. This laptop will be stored in the locked researcher’s office.

The audio recordings will also be stored in the researcher’s locked office, then transcribed and erased at the end of the analysis process.

Data Access

The researcher and Dr. Mai Narasaki-Jara named on the first page of this form will have access to your study records. Any information derived from this research project that personally identifies you will not be voluntarily released or disclosed without your separate consent, except as specifically required by law. Publications and/or presentations that result from this study will not include identifiable information about you.
Data Retention

Destruction of identifiable data will be performed when the data analysis is completed. Destruction of audio-recording will be performed when the transcription accuracy is confirmed by the participants through email. All de-identified data will be stored for a period of 3 years and then all data will be destroyed.

Mandated Reporting

Under California law, the researchers are required to report known or reasonably suspected incidents of abuse or neglect of a child, dependent adult or elder, including, but not limited to, physical, sexual, emotional, and financial abuse or neglect. If any researcher has or is given such information in the course of conducting this study, he may be required to report it to the authorities.

IF YOU HAVE QUESTIONS
If you have any comments, concerns, or questions regarding the conduct of this research please contact the research team listed on the first page of this form.

If you have concerns or complaints about the research study, research team, or questions about your rights as a research participant, please contact the Research and Sponsored Programs office, 18111 Nordhoff Street, California State University, Northridge, Northridge, CA 91330-8232, by phone at (818) 677-2901 or email at irb@csun.edu.

VOLUNTARY PARTICIPATION STATEMENT
You should not sign this form unless you have read it and been given a copy of it to keep. Participation in this study is voluntary. You may refuse to answer any question or discontinue your involvement at any time without penalty or loss of benefits to which you might otherwise be entitled. Your decision will not affect your relationship with California State University, Northridge. Your signature below indicates that you have read the information in this consent form and have had a chance to ask any questions that you have about the study.
I agree to participate in the study.

___ I agree to be audio recorded
___ I do not wish to be audio recorded

___________________________________________________  __________________
Participant Signature                                           Date

___________________________________________________
Printed Name of Participant

___________________________________________________  __________________
Researcher Signature                                           Date

___________________________________________________
Printed Name of Researcher