

Adherence and Continued Participation in a Wellness Class for Individuals with Disabilities

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ABSTRACT

BACKGROUND: For individuals with disabilities, adherence and participation in wellness programs is a challenge. Adherence and participation were explored in a wellness class for people with disabilities.

OBJECTIVE: Understand what factors impact participant adherence and participation in the wellness class.

METHODS: Eight wellness class participants, who have been in the class for 6 to 36 months, were chosen for qualitative interviews. Interview responses were coded and analyzed for overarching themes.

RESULTS: A total of 77 codes were obtained from interview data. The primary theme identified from the codes was related to social interaction with the student-trainers, divided into subthemes of social accountability, motivation, supporting classroom environment, and participant-student interaction.

CONCLUSION: The primary factor influencing adherence and participation was related to social interaction with student-trainers. These results suggest that social interaction can play a major role in continued participation in exercise as well as exercise adherence.

KEYWORDS: adherence, participation, disability, exercise

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Introduction

According to the American Community Survey (ACS), approximately 12.6% of the population in the United States of America identifies as having a disability, which is defined by an affirmative response to any of six questions on the topics of hearing loss or impairment, vision difficulty or impairment, mental and emotional functioning, physical functioning, and the ability to complete activities of daily living.¹ Individuals with disabilities face many challenges with maintaining positive health outcomes over the lifespan. Comorbidities related to physical inactivity, such as type 2 diabetes, obesity, and hypertension, are prevalent in this group.² Therefore, regular exercise is very important in optimizing health for people with disabilities. Exercise programs have been developed specifically for people with disabilities.^{3–6} These programs have been shown to be beneficial and to be associated with positive health indicators.

However, all exercise or wellness programs face issues related to adherence and continued participation, despite ability level of target populations. Previous work has illustrated that participation in exercise for individuals with disabilities is a multifactorial issue.^{7–12} Available resources, transportation, and physical condition or state, among other factors, can negatively impact an individual with disabilities' participation in exercise.⁷ Adherence to exercise can also be affected by bodily function, one's beliefs about his or her function, pain associated with exercise, and among other factors.⁸ Conversely, factors such as

social involvement, increased bodily function, perception of one's self, and belief in the benefit of exercise can positively impact one's physical activity behavior.^{6–8,12,13}

At one academic-affiliated institution, undergraduate students exercise with individuals with disabilities for course credit. These students act as trainers to participants, under the supervision and guidance of the university-appointed instructors of the course.³ Participants are individuals from the surrounding community with various disabilities, such as intellectual disability, Down syndrome, spinal cord injury, cerebral palsy, multiple sclerosis, Parkinson disease, and visual impairment. These participants are of varying age, gender, and race. Participants come anywhere between once and three times a week for exercise and follow the semester schedule. Participants can continue participation in the wellness class for as long as they wish; in fact, some participants have been in the class since it began. Wellness programs for this population do exist but are typically costly to participants or specialized to individuals with a specific disability (ie multiple sclerosis and intellectual disability).^{4,14} However, this class is free for participants and includes participants with a wide variety of disabilities.

Evidence of participation and adherence to exercise and exercise programs is available for this population; however, the student-led aspect of this class is unique when compared with more traditional delivery of exercise programming in a clinic, fitness center, or hospital setting. It is documented that



communication between physicians or clinicians, and even medical students, and individuals with disabilities is an area of potential improvement. Individuals with disabilities have documented feelings of lack of respect or interest, perceived discrimination, lack of quality time, lack of involvement with treatment decisions, and lack of effective communication of treatment.^{15–19} As a result, individuals with disabilities do report inadequate communication at an increased rate.¹⁵

The purpose of this research is to investigate adherence and participation in this wellness class environment. A qualitative approach was taken to ensure that participants were able to respond to open-ended questions and that responses were not given in a binary nature. This approach offers the opportunity for detailed dialogue and obtaining more descriptive data. In addition, a qualitative approach was selected because of the heterogeneity of our sample. Using quantitative methods such as questionnaires, while a useful tool to obtaining data, could be less informative in the context of this study with the sample obtained.

Methods

Study design

This study uses the traditional interpretive approach to address the study aim. Interpretive tradition positioning states that human interpretation is the beginning of developing knowledge.²⁰ This study also used a narrative inquiry approach to elicit stories from individuals on their experiences of being someone with a disability who participates in the student-led wellness class, as well as past experiences in other medical therapies and exercise-based programs.²¹ This approach attempts to work individual details of individual narratives, related and repeated, into a collective pattern of elements.²¹ In this way, knowledge is co-created by the participant and the researcher, both working in conjunction to create an image of reality that pertains to the participant.²² Using narratives to provide data has been outlined and done in the area of disability studies and experiences of people with disabilities with exercise, which provide researchers with rich context to help determine meaning in areas of perception or opinion.^{23,24}

This study was a companion study to a study focusing on effects of the wellness class on caregivers or family members of those who participate. The companion study data were obtained from interviews with caregivers of individuals selected for this study.²⁵ While these data have been submitted for publication separately, there are significant related contributions of that data to this study. These data are referenced further in this document.

Participant recruitment

Participants were recruited from the wellness class for individuals with disabilities and were contacted directly by the researcher.³ Inclusion criteria included at least one semester of

experience in the course and the ability to understand and comprehensively discuss interview topics. The primary researcher and the principal investigator had previous experience with the participants in the context of engaging in conversation and discussion, which served as the basis for determining perceived ability to understand and comprehensively discuss interview topics. At least one semester of experience was chosen for inclusion in the study to ensure that participants had enough experience with the course to speak to the effects of the course. Exclusion criteria included perceived inability to understand and comprehensively discuss interview topics. This study was approved by the Institutional Review Board of the academic-affiliated institution, and informed consent was obtained from all participants in this study. No participants were coerced into participation. There was no effect of participation in the study on wellness class standing, and this was disclosed to participants before participation.

Data collection

Interview guides were written by the researcher and received review from co-authors before interviewing commenced, following standard narrative practice to engage participants in stories of their experiences.^{26,27} Participants in the wellness class were interviewed using semi-structured interviews. Interview questions from the interview guide were phrased in a way that elicited recollection of certain events, or requests for anecdotal examples, followed by probing questions. Original interview guides written for this study contained nine questions. The topics of the interview included but were not limited to acquisition of disability, duration of participation in the wellness class, perspectives on participation in the wellness class, changes in self due to wellness class, and preferences of the class. These topics were chosen to create an open communication environment for the interview, provide context for the dialogue surrounding the wellness class and its meaning, or lack of meaning, to participants, as well as give a rich depiction of enjoyment, or dislike, of the class.

Interviews lasted approximately a half hour per participant and were done in-person. Location for the interviews was determined before the meeting. Two participants were interviewed in their homes due to transportation limitations. All other participants were interviewed on campus in a small, quiet conference room. All but one interview was conducted one-on-one, with participants interviewing alone. This was done for the sake of collecting authentic data without bias or without social pressure to answer in a manner deemed appropriate by other parties present.

Data were obtained from transcripts of participant interviews. Interviews were recorded and immediately transcribed by the researcher. After transcription, all participants in the course were given a pseudonym. Other identifiable persons mentioned in the interview were given pseudonyms or simple titles (ie “doctor”). Other identifiable data were given simple

Table 1. Participant demographics.

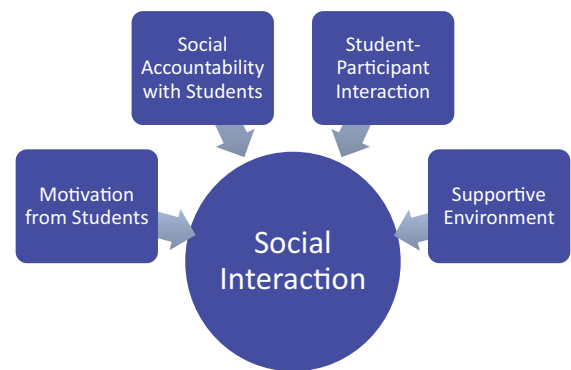
| PSEUDONYM | DISABILITY | AGE | RACE | GENDER | TIME IN PROGRAM (SEMESTERS) |
|-----------|------------------------------|-----|---------------------------|--------|-----------------------------|
| Austin | Cerebral palsy (CP) | 40 | White | Male | 15 |
| Ashley | Cerebral palsy (CP) | 39 | White | Female | 15 |
| Benjamin | Visual impairment | 62 | White | Male | 2 |
| Dustin | Traumatic brain injury (TBI) | 56 | White | Male | 3 |
| Elliot | Stroke | 69 | White | Male | 12 |
| Lionel | Spinal cord injury (SCI) | 73 | Black or African American | Male | 12 |
| Tim | Parkinson disease (PD) | 61 | White | Male | 1 |
| Vicky | Intellectual disability (ID) | 54 | White | Female | 6 |

titles, such as cities, hospitals, or schools. In addition, the researcher took observational notes of the participant's demeanor, interview environment, and any additional information taken in the context of the researcher's observations during the interview. Historical notes of the researcher's previous knowledge of the participants, as well as demographic information of participants, were also taken to provide context to potential topics covered in the interview.

Data analysis

Analysis of narrative uses commonalities threaded throughout narratives to determine overarching aspects of an experience.²¹ Following this guide, after interviews were completed, transcripts from interviews were analyzed for reoccurring themes. This was done by first coding interviews, using verbatim quotes from the transcripts, as per standard protocol in qualitative analysis.²⁶ Each interview was coded separately. Similar codes were then placed into categories. Categories spanned across interviews and participants. Categories were then grouped by similarity of concept into subthemes, which also spanned interviews and participants. These common subthemes were used to analyze overall perspectives of participants. Subthemes were related to one overarching theme, and all contributed to the construction of the overarching theme. Observational notes from interviews were used to help determine aspects of the interview that could not be found in the transcript, like mood, body language, or gestures. This information helped contribute to the primary researcher's assessment of mood during the interview and in particular statements.

All analysis and transcription was completed by the primary researcher, who had received extensive training through coursework in qualitative methodologies and analysis. The primary researcher did take individual reflexivity into account in relation to "distance" from the research participants.^{28,29} Being that the primary researcher was also an instructor of the wellness class, "distance" in reflexivity was very important. The process of reflexivity included evaluating the time spent with each participant in the research study, the perceived level of relationship

**Figure 1.** Contribution of subthemes to create theme.

with that participant, and honest reflection of how interviews could have been different had the primary researcher not been part of the wellness class. Reflexivity was considered during analysis of interview data, as well as interpretation of meaning from the data. External advisement from co-authors was sought at different stages of the analysis, as suggested in the form of peer review.²⁷ The outside consultation was used as a consensus report, as well as a sensitivity and validity check of the primary researcher's conclusions.

Results

From the wellness class total of 23 participants, 8 were selected for participation. Participant demographic information is presented in Table 1. Participants were of varying disability status, age, race, gender, and time spent in the program.

Interview data results suggested that adherence and continued participation were linked to social interaction within the class as an overarching theme. This social interaction was cited by participants to be with student-trainers in the course and was overall, very positive. The social interaction was divided into different subthemes, being: social accountability, motivation, student-participant interaction, and supporting classroom environment. These subthemes were highly inter-related, and all contributed parts to the overall theme. Figure 1 demonstrates how the subthemes contribute to the overall theme.



Figure 2. Social accountability subtheme and constituting codes.

Social accountability with students' subtheme

Participants in this sample discussed the accountability that the class provides for themselves (Figure 2). The accountability was discussed in the context of continued attendance. Ashley, a participant with cerebral palsy, said: "Sometimes accountability is what is needed . . . if I didn't have, if I didn't have some student who was getting a grade for, for me showing up I would not come!" Tim, a participant with Parkinson's disease, said: "I know that every Tuesday and Thursday somebody is counting, is there to help me, but is kind of counting on me to be there." Participants also discussed the accountability from the student perspective; accountability for the students was interpreted as meaning-making within the context of the responsibility that students have in the class. Lionel, a participant with a spinal cord injury, said: "I think it helps them to see the meaning to some of the interaction . . . it's a strength for the young people in training." Participants also discussed willingness to attempt new exercises because of being with new students and the interactions exercise provided.

Motivation from students' subtheme

Participants discussed the creation and sources of motivation within the context of exercise and the class (Figure 3). For some participants, motivation was from an intrinsic source of having meaning. Ashley, a participant with CP said: "It's really, really good to know that we are truly making a difference . . ." Motivation also came from perceived encouragement or genuine caring from students in the class. Tim, a participant with Parkinson's Disease, said: "I had these-your people-encouraging me at each step . . ." Lionel, a participant with a spinal cord injury, said: "I enjoy the people and because I enjoy the people I am more willing to do the exercises . . . I feel like what they

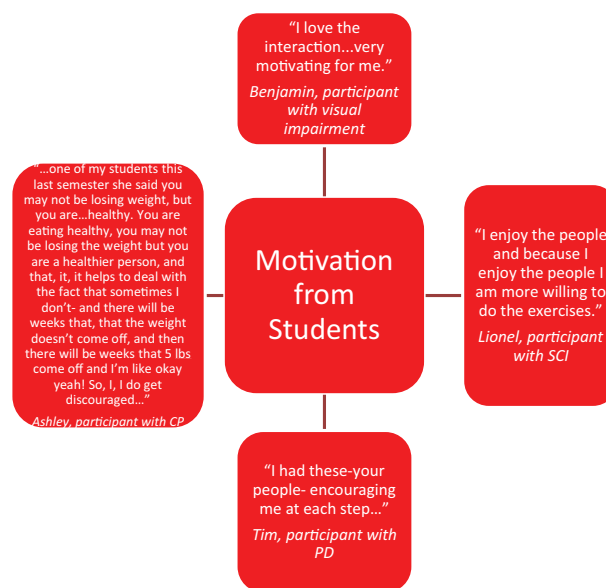


Figure 3. Motivation from students' subtheme and constituting codes.

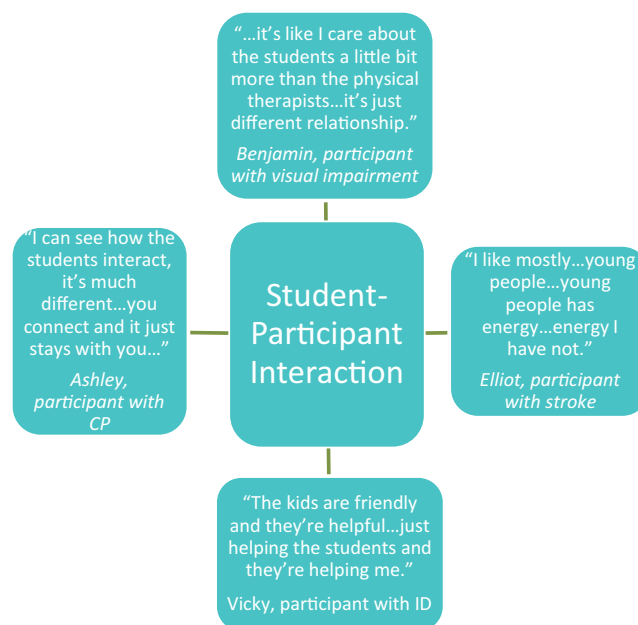


Figure 4. Student-participant interaction subtheme and constituting codes.

are having me do is for my good." Participants also noted that effects of exercise contributed to motivation to continue with exercise. Tim, a participant with Parkinson's disease, said: "I made that kind of a motivation to work on strength training and balance to make sure, to make it less likely that's going to happen again, or that I can deal with it when it does . . ."

Student-participant interaction subtheme. All participants in this sample discussed interacting with students in the class, and different aspects of the interaction (Figure 4). This interaction was talked of in a strongly positive manner. Some participants

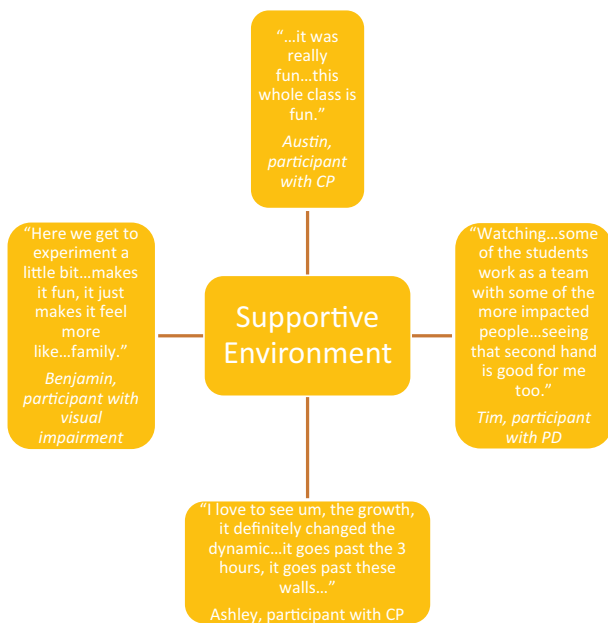


Figure 5. Supportive environment subtheme and constituting codes.

chose to discuss the interaction as a source of social affirmation. Interaction with the students seemed to make them feel affirmed and gave special meaning to the class. Austin, a participant with cerebral palsy, said: "... this class has been, has really been special to me." Lionel, a participant with a spinal cord injury, said: "I like the one-on-one attention that the young people give me . . . so I have been impressed with the youngsters ever since I have been over there." Other participants chose to discuss the interaction as a motivating factor, and discussed how the relationship between themselves and the students provided relief during exercise. Tim, a participant with Parkinson's disease said: "They're always so . . . chatty and positive and encouraging." Participants contrasted their relationships with students to their relationships with other practitioners. Benjamin, a participant with visual impairment, said: "I love the interaction . . . very motivating for me. It's like I care about the students a little bit more than the physical therapists . . . It's just different relationship." Dustin, a participant with a traumatic brain injury and aphasia, said: "They're better. [The students?] Yeah . . . they, they are good, they walk me."

Supporting classroom environment subtheme

Seven of the eight participants in this sample discussed the classroom environment (Figure 5). Participants discussed the environment in terms of the support that it gave them to exercise. Some participants discussed the environment as a place that was free to explore and try new things. Benjamin, a participant with visual impairment, said: "... we're doing a lot of self-discovery . . . here we get to experiment a little bit . . . in the program I always have ideas, I almost treat it like an experiment." Austin, a participant with cerebral palsy, said: "... this whole class is fun . . . this class provides an opportunity that I

do not have otherwise." Other participants talked about the social environment within the class providing support. Tim, a participant with Parkinson's disease, said: "Watching . . . some of the students work as a team with some of the more impacted people . . . seeing that second hand is good for me too." Ashley, a participant with cerebral palsy, said: "... you want to be part of that. You want to be in that circle . . . I love to see um, the growth, it definitely changed the dynamic, to see all of the people . . . it goes past the 3 hours, it goes past these walls."

Discussion

Participants in this sample feel that social interaction plays a major role in adherence and continued participation in the wellness class. This finding is significant for this specific wellness class context because of the low turnover rate that has been documented over the 5 years that the program has been in session. The primary finding is also consistent with other literature on adherence and participation when social interaction was considered.³⁰

Social support, both in preparation for engagement in exercise as well as engagement and adoption of exercise, has been shown to be a facilitator of the behavior in individuals with disabilities.^{7,8,30} In this sample, social support was provided by students in the forms of motivation and encouragement. Participants were able to make connections to behaviors learned in the classroom from the students in the outside environment, such as those related to exercise or eating behavior. The retention of the behavior shows a level of commitment to the behavior and speaks to the significance of the student-trainer. This retention, or discussion of retention, is not without speculation of social desirability bias in reporting.

A meta-analysis by Jansons et al³¹ concluded center-based exercise interventions have been shown to have a slightly higher adherence than telephone-based exercise interventions in adults with long-term health conditions; it was hypothesized that the slight difference could be attributed to social factors such as relationship with other participants or health professionals. This finding is consistent with the participants from this sample, who made connections to relationships with students as being a primary reason for exercise adherence. Conversely, factors such as "exercise alone" and "lack of positive feedback or reinforcement" were cited as being reasons for non-adherence to exercise in clinical populations.¹³ In non-clinical populations, examination of exercise preferences has revealed that individuals prefer to exercise with others rather than alone.³² Finding such commonality on the subject of social interaction and adherence between population groups is significant. It can be concluded that further investigation of the role of social support, social interaction, or personal interaction in adherence to exercise or wellness programs serving all population groups is warranted.

These data were collected as part of another study in which impact of the participant's participation in the class on the

primary caregiver or family member(s) was explored. The importance of the student-trainer to the participant was discussed by caregivers. Caregivers did note that the interaction seen in class was different than interactions their loved ones received elsewhere at other therapies or activities because of the undergraduate students. Marie, the wife of a participant, said: "It's not just . . . the physical but he gets enjoyment out of the talking and the interacting and all of this . . . the interaction with the people that has made the difference."²⁵ In the context of participant adherence and participation, some caregivers were able to identify relationship with students as a contributing factor. For example, Rebecca, the mother of a class participant, said: "She really likes working with the girls, and I think that's why she's changed this attitude towards exercise . . . she is getting the attention of 2 people, for a whole hour."²⁵ While there is no certainty that this phenomena would occur in other populations or with other people, it does present interesting implications on what kinds of relationships people with disabilities would like to have in health care settings.

Several participants in this sample did compare the experience of the student-driven wellness program to standard therapies on their own accord, and follow-up questions stemmed from comments related to their assessment of therapists. Participants discussed that, overall, students were more open with them than practitioners. This dialogue does present important implications for practitioners. Research has been done in the area of patient-practitioner relations and communication, evaluating perspectives on both sides to better assess what is needed for patient buy-in, patient adherence, as well as better outcomes for patients and achievable goals for practitioners.^{12,30,33-35} Existing research does touch on the role that practitioners play in the adoption of and maintenance of exercise as well as suggestions for practitioners to make an impact on exercise behavior for individuals with disabilities.¹² Further research should be done to assess patient desires in communication with practitioners in an exercise or therapy context, especially in relation to patient adherence to treatment.

Therapeutic practices and medical treatment programs are often evaluated for factors that could increase patient adherence, retention, and compliance. Although these factors are individual to each practice and program, the participants in this study offer useful insight into how these factors are achieved. Codes from our sample do demonstrate a level of personal investment and involvement, as discussed in the form of accountability as partners in student education. Personal investment, in any focus, could be a great influence on patient adherence, retention, and compliance in therapeutic practices and programs. Evidence of this concept has been demonstrated in the literature multiple times.^{11,30,36,37}

Participants in the sample discussed accountability, motivation, and feeling supported as all part of the environment that the student interaction creates. The aforementioned subthemes are highly interactive. To tease out exactly where the lines

demarcate each subtheme is very difficult because participants also talked of the subthemes as being interrelated. In some cases, participants even discussed subthemes in the same sentence, within same context, within the same anecdotal example. Therefore, it can be concluded that the intersection of the subthemes was where meaning-making of participation and adherence occurred for the participants in this sample.

The interview data collected in this study was compared to results of studies that used theoretical models to drive interventions rather than any individual theoretical framework. The interpretive tradition in qualitative research, which was used in this study, relies on the co-construction of reality by participant and researcher. This requires a lack of assumption by the researcher and allowance of knowledge to be co-constructed and meaning-making on the part of the participant to be discovered.²⁰ Therefore, using a theory-driven approach to collecting data by examining primary aspects of a theory only did not seem appropriate for the purpose of this study. In stating that there is previous literature using theory, it is understood that theoretical framework is common practice; however, it could be stated that a strength of this study is the use of participant interview data that is allowed to "speak" for itself without constraint of inclusion of only data related to theoretical premise. Therefore, gaining the breadth and depth of the reasons how and reasons why this particular intervention sparked adherence.

We believe it is important to note the role that generalizability plays in interpretation of qualitative research. Generalizability in qualitative research is not the aim of qualitative research as it is in quantitative studies, but enables researchers to get a depth of understanding from the point of view of participants.³⁸ Standards of quality used in qualitative research include description defined by "sense of circumstantiality and of power in reserve (if an anecdote or an example doesn't sound strained but sounds like you've got fifty others and this is the best one you chose)"³⁹ In this way, the way in which description occurs creates a rhetorical sense of validity in the concepts derived from data, which came straight from participants. This feeds into the notion of transferability, which is the result of an inference readers can make to translate the findings across settings.^{40,41} In this case, the small sample size of this study allowed for deeper examination of the perspectives of the participants, which served to further address the research question. Because of the depth of the data, there could have been points that other people from this population group could relate to. This is referred to as content generalizability.³⁸ Furthermore, expanding on the findings of this study, these sentiments of the importance of interaction in health care delivery and health care engagement could be echoed by individuals with or without disabilities, thus reinforcing the quality of transferability in the data. In this way, the idea that interaction helps facilitate the response to health care could also be generalizable, referred to as inferential generalization.⁴²

Conclusions

In conclusion, the major finding of our study was that the participants strongly valued their personal interactions with their student exercise leaders, perhaps more so than other unique aspects of the wellness program. The participants enjoyed the students and the energy that they brought to the exercise class, and that served as a mechanism for motivation. Being adherent to the exercise class meant showing up for a student, which kept participants accountable. While personal investment and motivation are very intrinsically driven, it is possible that personal interaction and social accountability can be achieved through an inviting and supportive external environment. Within an exercise program, there could be an intentional effort to make the exercise environment friendly and social but also work-centered. In this way, these results can shape exercise program landscapes. Creating environments that encourage participation and adherence through personal interaction and social accountability provides individuals with disabilities the motivation needed to maintain exercise behavior, which is the goal of exercise intervention. These results carry significant implications on wellness programs for other population groups and warrants further investigation of the role of social interaction and a one-to-one fitness model in other population groups and other wellness class environments.

Author Contributions

MW, KD and KM conceived of the research idea. MW, KD, and KM developed the research strategy and data analysis plan. MW performed the data collection. MW performed the analysis with guidance from KD. MW wrote the manuscript with input and revision from KD and KM.

Accessibility

Interview transcripts and data files used for sorting can be accessed by interested readers through request to the first author. This research has been presented in poster form at the national American College of Sport Medicine meeting.

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