



PRINCESS GALYANI VADHANA
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Exploring the Potential Benefits of Ukulele Classes on the Quality of Life and Well-being of Patients with Hemophilia

Solaiman E Jamisolamin

Pilot Study: Exploring the Potential Benefits of Ukulele Classes on the Quality of Life and Well- being of Patients with Hemophilia

Abstract

The HAPLOS Ukulele Program was a partnership between the University of the Philippines (UP) College of Music and the Hemophilia Association of the Philippines for Love and Service (HAPLOS), a support community that provided free ukulele classes from 2013 to 2016 for Filipino patients with hemophilia. Officially entitled *HAPLOS: Panimulang Klase para sa mga Kababayang may Hemophilia Program*, the program was conceptualized by Assistant Professor Solaiman E. Jamisolamin of the UP College of Music along with student-volunteers, to fulfill the responsibilities stated in the UP Charter—to lead as a public service university by providing various forms of community, public and volunteer service, as well as scholarly and technical assistance to the government, the private sector, and civil society while maintaining its standards of excellence. Last January 2022, in cooperation with the UP Office of the Vice-Chancellor for Research and Development, the program was revitalized to adapt to online learning by conducting ukulele lessons through online classes. This attempt to improve the accessibility of the program coincided with the academic objective of conducting a preliminary study on the potential benefits of learning music for hemophilia patients.

1. Introduction

Hemophilia is a hereditary bleeding disorder that hinders the normal blood

clotting functions of the body. This condition prolongs bleeding following injuries or surgery, or in severe cases may even occur without any obvious injury, also known as spontaneous bleeding.¹ Patient with hemophilia commonly suffers from musculoskeletal pains and mobility impairment as a result of bleeding into joints and muscle tissue.

Hemophilia as a hereditary disease is caused by genes that are located in the X chromosome, one of the two sex chromosomes. Inheritance of this condition follows an X-linked recessive pattern. Since males (XY) have only one X chromosome, the condition is expressed in the male even if it is recessive. Females (XX) need a mutation of the genes in both X chromosomes to have the condition. Thus hemophilia is predominantly seen among males, although their mothers are the carriers for the hemophilia gene.²

As of the 2020 World Federation of Hemophilia Annual Global Survey, there are around 1500 cases of hemophilia diagnosed in the Philippines.³ The Center for Disease Control and Prevention in the United States reports that hemophilia occurs in about 1 in every 5,000 male births in the U.S.¹

The severity of the effects of having hemophilia varies from very mild cases wherein the condition is not apparent until incidents of severe injury, to severe cases with a high incidence of spontaneous bleeding.² Due to the risk of bleeding from injuries which can be a serious concern even for mild cases, hemophilia patients are often unable to engage in strenuous physical activities. These risks have limited the lifestyle of patients to mostly indoor activities.

The inability to enjoy sports or outdoor activities might have an effect on the well-being of patients, particularly among young males who predominantly participate in these activities. According to several hematologists, physical activity can have a significantly positive impact on the quality of life of patients with hemophilia including improving the stability of their joints, their psychological, social, and musculoskeletal well-being.⁴ However, due to the risks involved in sports, there is a need for alternatives that could fulfill the special needs of these patients.

Playing an instrument, aside from being an intellectual exercise, is also a physical activity with varying intensity depending on the instrument and type of music being played. The ukulele is an instrument commonly used for educating beginners and children because of the ease of execution in using the instrument. It has a small form factor which reduces the length that the fingers need to stretch to play, and it uses nylon strings which are thicker with less tension which makes them easier to press compared to their steel variant counterparts. Its overall small size also contributes to its more affordable price as it uses less materials than others, making it a very accessible instrument. The ability to create music can provide hemophilia patients a light physical activity as well as a creative outlet to express themselves.

The HAPLOS Ukulele Club was a partnership between the University of the Philippines College of Music and the Hemophilia Association of the Philippines for Love and Service (HAPLOS), a support community for persons with bleeding disorders, which provided free ukulele classes for Filipino patients with hemophilia from 2013 to 2016. This program was conceptualized to fulfill the responsibilities stated in the UP Charter to “lead as a public service university by providing various forms of community, public and volunteer service, as well as scholarly and technical assistance to the government, the private sector, and civil society while maintaining its standards of excellence”. The *HAPLOS: Panimulang Klase para sa mga Kababayang may Hemophilia* Program is a revitalization effort to adapt the ukulele lessons into online classes in an attempt to improve the accessibility of the program as well as doing a preliminary study on the potential benefits of learning music for hemophilia patients.

Review of Related Literature:

Treatment for Patients with Hemophilia

The primary concern for patients with hemophilia is the risk of hemorrhage due to the low levels of clotting factors in their blood.¹ As a measure to avoid bleeding, clinicians have historically advised against activities that may result in

joint trauma but modern technology has allowed for the production of clotting factor concentrates. These may be administered to increase levels of Factor VIII or Factor IX, which are low among patients with hemophilia, to improve blood clotting and reduce the risk of prolonged bleeding in the event of an injury.⁵ This allows patients who have regular access to this treatment the ability to participate in certain high-intensity sports and activities.

However, the cost of producing these factor concentrates is very high, resulting in limited availability of these for patients.⁵ According to the Annual Global Survey 2020 conducted by the World Federation of Hemophilia, only 4% of the global supply of Factor VIII concentrates are distributed to South East Asia - the second lowest out of six surveyed regions.³ For developing nations, South East Asian countries such as the Philippines, the cost of 250 IUs of Factor VIII concentrate, which is a dosage only suitable for a small child, is around P4,000. An average Filipino adult would end up spending around P20,000 - P30,000 a month should they wish to avail of this treatment once a month. This treatment is not a regular option for many Filipinos due to its very high cost. As such, most patients are left having to avoid any activity that could result in bleeding.

Alternatives to Factor Concentrate Therapy

With factor concentrate therapy being an inaccessible treatment for most affected individuals, it is important to explore the use of alternatives in improving their living conditions. A study by López-Casaus *et al.* investigated the use of non-pharmacological therapies for improving the quality of life among patients with hemophilia and recorded feedback from the participants on the treatment.⁶ A concurrent nested mixed method with a quantitative predominance study design was used in an effort to analyze both quantitative and qualitative data to get a broader understanding of the patient's experience.

A total of 9 participants who were family members of, or a patient themselves with hemophilia participated in this study. The participants were briefed online about physical therapy and health education in hemophilia. Five days after the briefing, participants joined a focus group discussion with study staff and were

given a document with guided exercises and a copy of the presentation used in the online briefing. Quantitative data were obtained from the participants' responses in the Survey on Satisfaction with Care of Patients with Chronic Disease and their Family Caretakers which evaluates the perception of satisfaction with received healthcare among patients with non-communicable diseases (NCD) using a Likert scale where each item can be scored from one (1), meaning lack of satisfaction, to five (5), meaning exceptionally satisfied.

The responses were then analyzed using the IBM SPSS statistical analysis software. Qualitative data were collected from the participants during the focus group discussion with study staff wherein they were interviewed regarding their experiences as patients or family members with their current intervention as well as their previous experience with healthcare. The quantitative data analysis showed that most participants reported a high level of satisfaction, but one respondent reported a low level of satisfaction in the section of kindness of the staff. The qualitative data analysis however showed some contrasting responses with participants speaking about a lack of confidence in the healthcare professionals they went to. They shared that they felt a lack of interest and knowledge from the healthcare professionals. Participants had a positive attitude about research and deemed it necessary to better address the concerns of hemophiliacs in the future.

Regarding physical therapy, the participants reported a calming effect from these activities but did not find great improvements with it as its effects last only while they are in an active therapy program.⁶ The responses of the participants in this study, particularly in the focus group discussion that somewhat contradicted the formal written surveys, expose that there is a certain level of dissatisfaction regarding the currently available non-pharmacological interventions for hemophiliacs.

A survey of clinicians dealing with hemophilia patients was conducted to gather expert opinions on the viability of sports as an activity for improving the quality of life among hemophiliacs as a potential long-term solution. Lassando *et al.* presented that despite the risks associated with sports, in the context of improving Quality of Life, physical activity and exercise are still considered necessary in managing the patient's condition, especially for those in their developmental age.⁴

Reduced physical activity puts people at increased risk of becoming overweight or obese, leading to a higher incidence of osteoarthritis and of cardiovascular events.

All hematologists that participated in the survey recommended regular physical activity and exercise for children and adolescents with hemophilia, while only 40% of the sports physicians shared this opinion. The clinicians also reported that a low percentage of hemophilia patients practice sports. The study concluded based on the consolidated responses of the clinicians that patients with hemophilia are capable of practicing sports under factor concentrate treatment, surveillance of specialists, and expert counseling. However, clinicians still advise against high-intensity activities such as contact sports that could still lead to severe bleeding events and increase the risk of progression to arthropathy even with factor concentrate therapy.⁴

Benefits of incorporating Music in Intervention

A study was conducted in 2006 on the effects of music-listening intervention in enhancing the effects of analgesics, decreasing perceptions of depression and disability, and promoting beliefs of personal power.⁷ A total of 60 recruits with chronic non-malignant pain (CNMP) participated in and completed a randomized controlled clinical trial where they were randomly assigned into a standard music group (n = 22), a patterning music group (n = 18), or a control group (n = 20) that did not receive any music-listening intervention. All participants had a preliminary baseline test across several evaluation tools: feelings of power were measured through the Power as Knowing Participation in Change Tool version II (PKPCT II), perceptions of pain were measured through the McGill Pain Questionnaire and Visual Analogue Scale, perceptions of depression were measured through the Center for Epidemiological Studies Depression Scale, and perceptions of disability were measured through the Pain Disability Index. Participants that received the music-listening intervention were assigned to listen to music for one hour everyday for one week. All participants were tasked to keep a diary for the seven-day observation period.

The standard music (SM) group was assigned to listen to a choice of tapes

that were predetermined by the researchers. The patterning music (PM) group was asked to listen to upbeat, familiar, instrumental, or vocal music of their choice. All participants were evaluated again after their seven-day observation period as a post-test. The results showed that groups that utilized music-listening interventions had statistically significant effects in having more feelings of power, and less perceived pain, depression, and disability compared to the group with no intervention.

There were no statistically significant differences between the SM and the PM group, contrary to the researchers' initial expectations of the PM group performing better than the SM group.⁷ This study shows that simply listening to music has a significant effect on reducing pain and depression for patients with long-term conditions, suggesting its potential in improving their quality of life if regularly practiced.

Summary

In summary, a review of related literature shows that the ideal treatment for managing hemophilia is through factor concentrate therapy which is unfortunately very limited in supply and thus highly inaccessible⁵, especially for developing countries such as the Philippines. As an alternative, studies have been exploring the use of non-pharmacological interventions which although they have been showing positive results also have issues such as low reported enthusiasm and competence of healthcare professionals on hemophilia as it is considered a rare disease, as well as short-term results from physical therapy.⁶ Alternative activities such as sports which the majority of a surveyed group of clinicians reported having benefits for hemophiliacs still require the inaccessible factor therapy treatment to decrease its potential risks.⁴ On the other hand, a study has shown that simple music-listening interventions have a significant effect on reducing perceptions of pain and depression.⁷ It is of note that there does not seem to be any currently available literature exploring the use of instrumental music-making as an activity designed to improve the quality of life among patients with hemophilia or others with similar special needs.

Another important factor is the added difficulty of the living conditions

in the Philippines. From experiences shared in the HAPLOS support group of patients, many patients report difficulty with public transportation affecting their health and daily activities. Common day-to-day injuries are often attributed to the difficulties of transportation. From hours-long travel times, cramped, physically stressful conditions (such as squatting to get inside jeepneys/pedicabs), to poor infrastructure and uneven roads, causing leg injuries as they move about. As such, it is a common worry for hemophilia patients going outside that any outdoor activity which is supposed to promote their health, might potentially lead to more injury, negating any health benefits. Thus, an online venue where patients may limit the risk of injury while still having a social and skill-building activity may prove valuable.

2. Methodology

Participants were selected from the population of HAPLOS members. Starting December 2021, announcements for registration to the program were made through HAPLOS's social media channels, and during their meetings. Registration was open to all members, although we announced that priority would be given to hemophilia patients. Prospective participants were asked to fill up an online registration form about their contact info, age, and preferred music.

The lessons were conducted through online ZOOM app meetings in a span of twelve (12) weekly sessions from February to June 2021 and a total of twelve (12) participants from the hemophilia patient organization. All the student participants were male. Students' ages ranged from 8 to 22 years old. Eleven (11) out of twelve (12) participants were diagnosed with hemophilia. One participant was a patient's brother who participated alongside them during the ZOOM call. Of the twelve (12) participants, four (4) of them were returning students from the 2013-2016 batch of HAPLOS Ukulele Club.

From June to July 2022, participants were asked to answer a survey to evaluate the effectiveness of this program and explore the impact on the students and their families. For additional data gathering and evaluation, the following was conducted: Students were asked to answer a written survey through an online Google Form. This consisted of eight (8) open-ended questions with follow-up

sub-questions (see Appendix). The questions were based on the literature about the various ways music education could affect patients. Some of the questions include asking the participant to talk about how they felt during the program (*“How do you feel after each lesson?”*), or if they noted any changes they had in their social interactions (*“Did anything change in how you interact with your friends and family, especially those involved in some way in your joining the ukulele classes, after attending the classes?”*).

This survey was originally designed to be conducted through an online call, but was adapted and released as a written survey after difficulties were encountered. Additionally, the researchers were able to conduct a ZOOM call to interview one mother of one of the students, utilizing the written survey questions as guide questions for the interview. The interview was conducted by the three (3) teachers from the UP College of Music, along with one (1) HAPLOS community leader, and lasted around 40 minutes.

Throughout the program, three (3) teachers and one (1) HAPLOS community leader noted observations and feedback on students. Team meetings were conducted regularly right after each class to debrief on impressions and take note of adjustments to be made. At the end of the program, the teachers were also given the same written survey given to the participants but answering from a teacher’s perspective.

3. Results and Discussion

Feasibility of online music lessons for special education, mobility-impaired patients

We noted that students were adequately able to follow most of the curriculum. Throughout the twelve (12) sessions, the students did not report any injuries or physical ailments as a result of learning the instrument where it would be expected (upper body, arms, or fingers). There was however one instance where a student excused themselves from attending a session due to them needing to receive treatment for an unrelated acute symptom of hemophilia (leg/abdomen injury) during that current week.

Music lessons as an alternative and safe physical activity

One of the participants noted a change in their lifestyle since learning the ukulele. This activity gave them another option aside from outdoor hobbies, and allowed them to improve physical conditioning in their hands and arms while remaining indoors. The participant attributed having fewer injuries as a result of doing less outdoor activities. In addition, having better conditioning in their hands was also reported to make their medicine easier to administer through their veins. This is a small, but convenient result, as many patients are now taught to self-administer medicine at home, reducing the need for expensive hospital stays or delays in treatment causing complications.

Also, while hemophilia patients are generally encouraged by doctors to participate in outdoor physical activities—given safety precautions, and a reliable supply of medicine in case of injury—living conditions in the Philippines might not always make this a practical or safe practice. Especially for patients with limited access to care, having an indoor alternative is beneficial, particularly one that can be conducted online without needing to go through any risk factors from the outdoors, such as potential risk of injuries while in transit,

Siblings cooperating and bonding

The participants included several sets of siblings. During the lessons, we observed a positive dynamic for two (2) of the younger participants who were brothers, aged 8 and 12. The older brother was seen encouraging the younger brother, who, at times, was feeling stressed about playing the piece. Another set of brothers were also regular attendees.

The researchers noted the possible merit that having family members accompany patients has on motivation and retention. It seems to be a valuable source of relief, when one sibling—perhaps due to stress or anxiety—is unable to play a piece at the moment, that they have their sibling be there, whether to play in their stead to reduce the pressure, or provide words of encouragement and tips.

Special needs cases and promising psychosocial impact

From the interview with one mother of a patient, she noted a significant improvement in the sociability of her young adult child with a diagnosed special need. After being misdiagnosed and given the wrong medication several years ago, her child, in recent years, was reported to have been irritable and reclusive to the point that she was hesitant in resuming schooling for fear of him causing disruptions or negative social interactions. The teachers during the program however observed no notable disruptions from this student, who was actually very polite and dutiful in following the lessons. His mother also reported positive changes in his demeanor which she attributes to the class.

The benefit of returning students as role models

Four (4) of our participants were returning students from the previous iteration. Among them, two (2) were very active and were even chosen as solo performers during the culminating video project. These more experienced patients already had a good rapport with the teachers of the program, and seemed to contribute to a more relaxed atmosphere during the online lessons. They could be called on to give an example of parts of a piece or give more insights into the learning process. They provided younger students an inspiration or guide of a possible skill level that can be attained even by patients.

Music use in positive coping, improving social skills, and building self-esteem

Six (6) students were able to accomplish the online form for the written survey. Based on the written survey answers and the parent interview, the ukulele lessons were perceived as a positive way of coping with their current stress. Students reported feeling lighter, excited, grateful, and relieved. One student reported feeling satisfied with learning a new skill. Other students also reported having better social interactions with others, such as having music playing as another skill to show off to friends and family, or having another thing to talk about and relate with friends.

Developmental and Educational applications

Students mentioned that having patient, skilled, and helpful teachers contributed to their learning and gave them more confidence. Several students stated that the course was challenging, but still fun, giving them satisfaction when they were able to accomplish the more difficult parts. This adds merits to the idea that it is healthy to provide even students with special needs sufficient challenge, alongside enough moral support and guidance. Indeed, this affirms what literature suggests: that immersing a person with chronic illness in learning a skill such as music, gives them back some of the feelings of agency, control and confidence that an upbringing with debilitating illness might have hampered.

Evaluating tools for online music education

The following electronic tools were used in the program: ZOOM, Google Forms (for the survey), Facebook Group, emails, SMS (texting), and Youtube. The HAPLOS community leader noted that few participants responded to SMS texting, and less than half of the participants joined the Facebook group. Participants who regularly attended were the ones more likely to check their emails for any announcements and download copies of the music pieces. In case any participants were missing copies of pieces, they were able to obtain the files through the ZOOM meeting app during the lesson itself. Only half of the participants accomplished the Google Forms, and the researchers speculate that younger participants may have had difficulty with the written survey format, or accessing their emails regularly.

Youtube was also utilized for video sharing of lessons, as well as sharing the produced culminating video to the public. The culminating video consisted of the students playing pieces, alternated by testimonies from the teachers and a parent. This received sufficient viewership and favorable responses from both the hemophilia support community and online comments.

Limitations and recommendations for the use of online in student socializing, bond-forming and patient outreach

Another important observation was that the online format also seemed to make interactions between students less frequent and bond-forming. Since students only had one hour to participate in class and listen to the lesson from the teachers and any conversations would be heard by everyone in the meeting, there was little opportunity for casual conversation in between. As the socializing and bonding aspect of the previous iteration of the Ukulele lessons program was highlighted as one of its successes, we suggest some modifications to try to improve upon this even through the online mode. It is suggested for future online programs that a dedicated segment for breaking the ice be introduced through the breakout rooms feature, possibly with games and facilitators.

This difficulty for students with expressing themselves online also affected our data gathering. We noticed a difficulty especially for younger students in verbally expressing their opinions or thoughts during the online sessions when asked individually. Perhaps, future data gathering should follow methods more conducive to dealing with younger children or children with special needs that might have difficulty with communication. We should consider guided group sessions with child specialists, or also include more parents or siblings, so that the child may feel at ease.

It might also be important to point out that the recruitment of participants for this program might have an inherent bias, in that only participants with good enough physical conditioning, availability of schedule, financial, and mental stability were more likely to be motivated to participate in the first place.

It is currently difficult to reach out to more reclusive patients in need, or those who are currently undergoing long-term treatment at hospitals, or those unable for any other reason to regularly attend online engagements.

Lastly, we observed that participation and retention was lower than expected. While the online setting already provides a very low barrier to entry—removing any transportation limitations—we still noted several instances of dropout. Since this is a voluntary program to attend and was disseminated through social media, some students who signed up may not have been very motivated or committed to

attending, only joining a few times as a free trial, since there is no consequence to leave, compared to in-person paid lessons. Four out of twelve (4/12) of our participants stopped attending during the middle of the program. For certain individuals, this could also be attributed to scheduling issues, as some of them did indicate that they would not be able to regularly attend in their registration forms. We also noted that participants did not avail of the free data allowance despite being offered regularly, so data availability problems (or a lack of finances for internet use) may not have been a factor for the lack of participation. Future programs should account for a significant amount of dropouts, or find other effective methods for rewarding and incentivizing students if a certain amount of engagement is to be maintained.

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APPENDIX:

Google Form Questions:

1. How did you find the program? Was it easy, or was it difficult? Did you have fun, or were you stressed? (Kamusta sa iyo ang programa? Madali ba ito o mahirap? Nag-enjoy ba kayo, o na-stress?)
2. Are you happy to have joined the program, or do you regret it? (Masaya ba kayo na nakasali sa programa, o may panghihinayang?)
3. How do you feel after each lesson? Was this more or less the same throughout the program, or did certain weeks stand out? (Ano ang pakiramdam niyo pagkatapos ng bawat lesson? Pareho lang ba ang pakiramdam niyo sa kabuuhan ng programa, o meron bang linggo na mas litaw sa iyong alaala?)
4. Did you encounter any issues during the program? You may give any technical or personal issues. (Nagkaroon ba kayo ng isyu habang parte nitong programa? Maari magbigay ng technical o personal na isyu)
5. If you could change something about the program to make it better for you, what would it be? (Kung may papalitan kayo sa programa para maging mas mabuti ito para sa iyo, ano ito?)
6. Did anything about you change after you started attending the ukulele classes? (Attitude, productivity, academic performance, discipline, social interactions, et.c) / May nagbago ba sa iyo pagkatapos mo mag-attend sa klase para sa ukulele?(Sa kilos, sa pagiging produktibo, gawain sa eskwela, disiplina, o pakikitungo sa mga ibang tao?)
7. Did anything change in how you interact with your friends and family, especially those involved in some way in your joining the ukulele classes, after attending the classes? (May pagbabago ba sa iyong pakikitungo sa iyong kaibigan o pamilya pagkatapos mo mag-attend sa klase ng ukulele?)
8. Will you miss attending the ukulele classes after it's over? Why or why not? (Ma-mimiss mo ba mag-attend ng klase ng ukulele pagkatapos nito? Bakit, o bakit hindi?)
9. Pangalan at contact # (optional)