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The Effects of Group Music Therapy on Levels of Anxiety, Depression, Well-Being, Functional Disability, and Distress in Adult Congolese Refugees

Elise Hawkes

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Dr. Daniel Tague

ABSTRACT
Refugees have a variety of mental health needs due to their experiences, including trauma, anxiety, and depression. Psychotherapy, one of the main modalities for treatment, presents limitations including language barriers and negative stigmas. Music therapy might help to overcome these limitations due to its reliance upon music, rather than verbal language, as the therapeutic medium, and due to music’s ubiquitous cultural prevalence. Music therapy has been shown to have positive effects on sleep quality, well-being, trauma symptoms, social function, and mood. Music therapy training and research results have demonstrated ways to connect with clients through music and overcome cross-cultural barriers. The objective of this case study was to determine the effects of group music therapy on levels of anxiety, depression, well-being, functional disability, and distress in two adult Congolese refugees. Further, the study explored the themes which the participants reported they preferred and were most likely to use on their own regarding the music interventions. A mixed-methods approach was used to gather both quantitative and qualitative data. The study involved eight weekly, one hour-long music therapy sessions following a protocol that included four themes: socialization, emotional expression, English-learning, and personalized use of music. Levels of anxiety, depression, well-being, and functional disability were assessed using psychometric tests before the first session, after the fourth session, and after the eighth session. The data found overall decreased levels of anxiety, depression, and distress, increased levels of well-being, and little change in level of functional disability. Prevalent themes from the self-report questionnaire were instrument playing, singing, listening, and the hello song. Conclusions and recommendations for future research are included.

1. INTRODUCTION
There are over 20 million refugees worldwide, and the United States has historically admitted more refugees than any other country (UNHCR, 2018). While the upper limit of refugees allowed into the U.S. has significantly decreased under the current administration, there remain many refugees in the U.S. (National Immigration Forum, 2019). Refugees' experiences often leave them with trauma, anxiety, and depression, and these problems frequently go undetected during mental health screenings at intake due to language barriers, different conceptions of mental health across cultures, and reluctance of newly arrived refugees to share their problems with strangers. When mental health needs are detected, current treatment focuses upon talk therapies, including Cognitive Behavioral Therapy (CBT) and Exposure Therapy (Refugee Health TA). These modalities have limitations, even when an interpreter is present, because many words are lost in translation or don’t have equivalent words across languages. Further, these Western approaches are unfamiliar to many refugees from non-Western cultures. Music therapy might overcome these limitations because it focuses on music, rather than words, as the therapeutic medium. While music does not sound the same and is not used in the same ways across cultures, it does play a role in many cultures and can provide a common connection between client and music therapist. Further, group music making is prevalent in many cultures, and might present as less threatening and more familiar than talk therapy. Finally, music has been shown to positively affect people from many cultures through its rhythmic and harmonic properties and the effects of these on the body (Jespersen, 2012; Faulkner, 2017).

2. LITERATURE REVIEW
There is a lack of research relating to music therapy and refugees, and much of the existing research is limited to case studies or includes small sample sizes and minimal use of quantitative data (Quinlan, Schweitzer, Khawaja, and Griffin, 2016). Themes found when working with refugees include avoidance, feelings of loss, distrust, discrimination, and cultural adjustment issues (Choi, 2010; Kim, 2013). Music therapy has been shown to positively impact sleep quality, well-being, behavior, emotion, trauma symptoms, and social function (Beck et al., 2018;
Jespersen, 2012; Quinlan et al., 2016). Shortcomings by music therapists working with refugees include assuming homogeneity among groups, seeing refugees solely through a trauma narrative, and failing to give refugees a voice in research (Comte, 2016). Before music therapists can effectively reach their clients, they must become aware of the unique role of music and perception of healthcare in their clients’ native cultures (Jin, 2016). Further, music therapists working cross-culturally can adapt Western techniques and music to best reach clients (Jones, Baker, and Day, 2004).

Several studies have focused upon themes that both emerge and are addressed within music therapy sessions. A school-based music therapy program with adolescent refugees from North Korea, aimed at promoting social, emotional, and behavioral skills, found five common psychological themes: avoidance, distrust, loneliness, feelings of loss, and fear. These themes emerged during active music experiences focusing on feelings about the self and others, as well as problem solving and coping with loss (Choi, 2010). Another study, involving older adult immigrant women from Korea, aimed to determine the efficacy of using music therapy to address cultural adjustment and issues of gender and race-based oppression. The researcher took a Culturally Informed Music Therapy (CIMT) approach combined with a feminist perspective and the positive results were attributed to the emphasis on empowerment and togetherness. Themes found in the study included power, risk taking, folk songs, improvisation, cultural adjustment issues, and discrimination (Kim, 2013).

Music therapy treatment has focused primarily on improving sleep and social functioning and reducing anxiety. A study analyzing the effects of listening to relaxing music at bedtime found improved sleep quality and well-being. The music was pre-selected by the researcher and was deemed to be relaxing by refugees of various cultures (Jespersen, 2012). A Trauma-focused Music and Imagery (TMI) technique yielded positive effects on Post-Traumatic Stress Disorder (PTSD) symptoms, well-being, sleep quality, and social function (Beck et al., 2018). A school-based arts therapy program comprised of art therapy and music therapy yielded a reduction in negative behaviors and positively affected emotional symptoms (Quinlan et al., 2016).

In a critical interpretive synthesis of literature about music therapy practice with refugees, it was found that researchers tend to assume refugees to be a homogeneous group defined by their trauma narratives rather than recognizing their unique cultures and experiences. Further, the synthesis revealed that the current discourse fails to consider the refugee participants’ voices. In summary, the synthesis said researchers are practicing discourse fails to consider the refugee participants’ voices.

In summary, the synthesis said researchers are practicing discourse fails to consider the refugee participants’ voices. Further, the synthesis revealed that the current discourse fails to consider the refugee participants’ voices. In summary, the synthesis said researchers are practicing discourse fails to consider the refugee participants’ voices.

3. RATIONALE
   The rationale for this study was to develop quantitative data and reported experiences from refugee participants in live music therapy sessions. The results inform health practitioners of specific applications of music therapy with adult refugees and provide music therapists with suggestions for working with adult Congolese refugees. This study explored the effects of music therapy on symptoms of anxiety, depression, well-being, functional disability, and distress, and it revealed which specific aspects of music therapy the refugee participants found to be most effective.

4. METHODS
   Design
   The study was given IRB approval through Southern Methodist University. The group was a convenience sample consisting of two participants. A total of five participants were involved in the music therapy sessions, but due to low rates of attendance, only the data from two participants were included in this study. There was no control group, and the first set of psychometric tests served as the baseline data. The principal investigator (PI) served as both student music therapist and researcher. One Congolese interpreter was present for the consenting process, all sessions, and all testing.

   A mixed methods approach was used in order to include both quantitative and qualitative data. Psychometric tests measuring symptoms of depression, anxiety, well-being, and functional disability were used as pre-tests, mid-tests (first repeated measure), and post-tests over the course of the sessions. The pre-tests were administered at intake, the mid-tests were administered directly following the fourth session, and the post-tests were administered directly following the eighth and final session. A test measuring sudden distress was administered before and after each session. The participants also answered a self-report questionnaire regarding their experiences after each session.

   Setting and Procedure
   The study was carried out in the mental health department of a local non-governmental organization (NGO) in the southwest region of the United States. The organization provides refugee resettlement services to the community, including assistance with immigration, employment, extensive case management, mental health services, academic coaching, and women’s economic...
The World Health Organization Disability Assessment Schedule 2.0 (WHODAS 2.0) is a 12-item questionnaire that assesses disability based upon six domains of functioning: cognition, mobility, self-care, getting along, life activities, and participation. Disability levels are assessed over the last 30 days using a 5-point Likert scale, including none, mild, moderate, severe, and extreme or cannot do. The scores are totaled and compared to a 0-100 scale, in which 100 is full disability and 0 is no disability.

The Subjective Units of Distress Scale (SUDS) is formatted as a thermometer ranging from 0-100, 100 being highest distress/fear/anxiety/discomfort that you have ever felt, and 0 being totally relaxed. This is reported as level of distress in the moment.

The qualitative questionnaire included two prompts: Question 1, “Describe the activity you liked the best,” and Question 2, “What did we do today that you are most likely to do on your own?” This questionnaire was created by the researcher in order to gain feedback from the respondents regarding their preferred experiences.

Data
All the data was stored and secured online through BOX, which is HIPPA-compliant. The NGO’s Mental Health Department’s team and the principal investigator had access to the data. The data was de-identified through a lettering system. Each participant had an assigned letter (Participant A and Participant B). The data collection sheets were labelled with these letters, and there was one master list connecting name and letter known only to the principal investigator and secured by password on an NGO computer through BOX. Data will be erased from BOX after one year from collection as per the NGO’s request.

Data Analysis
A data-driven approach was used to find the emerging participant-reported themes within the qualitative questionnaires and each theme was supported with text examples. After all the data was collected, the themes were simplified to keywords or phrases. The most frequently repeated keywords and phrases are explored in the Discussion section. Themes and text examples can be found in Table 1 and Table 2.
5. RESULTS

GAD-7

As seen in Figure 1, there was an overall decrease in levels of anxiety for both subjects from pre-test to post-test. From pre-test to mid-test, levels of anxiety remained the same for one subject and increased for the other subject. Possible explanations for this motion will be addressed in the Discussion section. At mid-point testing, both subjects’ scores were within the range of moderate depression. At the post-test, both of their scores were below the minimum requirement for mild depression. These results suggest that group music therapy helps in lowering levels of anxiety in adult refugees.

PHQ-9

As seen in Figure 2, there was an overall decrease in levels of depression for both subjects. Both subjects’ scores began in the range of mild depression and remained in that range at the time of the mid-test but ended in the range for minimal depression at the time of the post-test. Possible explanation for participant A’s increase in level of depression will be addressed in the Discussion section. These results suggest that group music therapy helps to lower levels of depression in adult refugees.

WHO-5

As seen in Figure 3, the upward trend demonstrated an overall increase in well-being, in this situation synonymous with quality of life, for both subjects. The scores continuously increased from pre-test to post-test. This suggests that group music therapy helps increase well-being in adult refugees.

WHODAS 2.0

As seen in Figure 4, level of functional disability decreased from the pre-test to the post-test for one subject. The other subject’s score showed no net change in level of functional disability. These findings will be further explored in the Discussion section.

SUDS

As seen in Figure 5 and 6, for both subjects there was an overall decrease in sudden distress, regarding both initial distress from session to session and distress before and after each individual session. Only in one session did sudden distress increase, and this will be explored in the Discussion section. These results suggest that music therapy can effectively decrease sudden distress.

Themes from Questionnaire

Regarding Question 1 on the questionnaire, the most prevalent themes discussed were instrument playing, the hello song, and music listening. Regarding Question 2 on the questionnaire, the most prevalent themes discussed were singing, instrument playing, and music listening.

6. DISCUSSION

(EXPLANATION OF RESULTS)

GAD-7

The downward trend in the graph showed that levels of anxiety decreased. It is possible that music therapy contributed to this because of relaxation prompted by music interventions. Additionally, the principal investigator taught the participants music and relaxation strategies for at-home use, which they were encouraged to practice. The increase and stagnation in levels of anxiety from pre-test to mid-test could have been due to external factors because the data from the SUDS and questionnaire did not suggest that music therapy impacted the participants in a way that would increase anxiety. Because relaxation was a focus of Session 5 (theme: personalized use of music), it is possible that this greatly affected the participants, reflected in the post-test. Perhaps relaxation was not a big enough focus in the first four sessions, which could help to explain the stagnation at mid-test.

PHQ-9

The downward trend in the graph shows that levels of depression decreased. Relaxation strategies taught in music therapy likely improved sleep quality (Jespersen, 2012), which could in turn help to lower levels of depression. Music therapy also likely elevated the mood (Quinlan et al., 2016) of the participants through drumming and singing.

WHO-5

The upward trend in the graph demonstrates an increase in quality of life. Music therapy might have elevated the mood of participants, increased vitality by improving relaxation skills and sleep quality, and piqued a new interest of music.

WHODAS 2.0

There was not a significant change in level of functional disability. Participant B remained at the same level from pre-test to post-test and was unable to complete the mid-test. The level of disability in Participant A remained the same from pre-test to mid-test and decreased at post-test. The lack of change in level of disability could be explained by the lack of direct impact of music therapy on the six domains of functioning listed in the Methods section. It is also possible that eight weeks was not enough time to see change in this area. Music therapy could affect the getting along domain by providing opportunity for positive socialization, affect the cognition domain through English learning, and affect the self-care domain by teaching relaxation strategies.

SUDS

The downward trends in the graphs illustrate that music therapy lowered levels of distress during each session and over the course of the eight sessions. Relaxation and mood elevation from music interventions may have played a role in this. In Session 8, the level of distress of Participant A increased, as it was 0 before the
session and 10 after the session. The participant reported that their level of distress increased because they felt they did not have enough time to fully relax during the relaxation intervention at the end of the session.

Themes from Questionnaire

Responses to Question 1, “Describe the activity you liked the best.”, on the questionnaire referenced instrument playing, the hello song, and music listening. Instrument playing was a preferred activity because it elevated their moods; it prompted reminiscence; it created a connection amongst group members; it focused their minds on the music and the moment; and the combination of instruments was aesthetically pleasing. The hello song was preferred because it drew the participants into the music, made them feel acknowledged and welcome, and prepared them to make music. Music listening was preferred because it was aesthetically pleasing, encouraged relaxation, and because listening to familiar music prompted reminiscence.

Responses to Question 2, “What did we do today that you are most likely to do on your own?”, referenced singing, instrument playing, and music listening. Participants preferred singing because they can easily do it on their own; it makes them feel better and more relaxed; it can be encouraged by listening to recorded music; and it can be used to help remember English vocabulary words. Participants preferred instrument playing because they can make their own instruments at home and playing gives them peace of mind. However, they mentioned that it is difficult to play as an ensemble because they don’t own a variety of instruments and they don’t have people to play with them. Music listening was preferred because of its ease, accessibility, and ability to help them relax.

7. CONCLUSIONS

In Congolese culture, music is prevalent not only in everyday life for leisure, but also in the church to support spiritual connection. Due to the cultural significance of music to the Congolese, these clients may be highly receptive to music therapy. The participants in the study were self-identifying Christians who used music in worship. Many of the hymns with which they are familiar are also common in the Western world, the only significant difference being language. Because of this familiarity, hymns were used as common ground between participants and the PI, and the PI was able to provide culturally appropriate and relevant music without any formal training in traditional Congolese music. The participants were also very open to instrument playing and singing, despite a lack of formal training, and were open to discussing their thoughts and feelings. The interpreter, who was also a Congolese refugee, informed the PI of relevant aspects of Congolese culture, especially regarding music and mental health. In this way, the interpreter acted as a bridge between therapist and participants. Refugees from other cultures may be less receptive to music therapy depending on the cultural prevalence and uses of music, as well as the culture’s concepts of mental health.

Comte (2016) emphasized the importance of recognizing the differing cultures and experiences of clients. The PI for the current study found it helpful to ask the individual participants about their specific music preferences rather than making assumptions based on prior research about popular Congolese music. The PI also found that participant engagement in the sessions correlated with amount of past music experience and involvement, which informed the PI in their interactions with participants. Specifically, the participant with a more extensive musical background exhibited higher engagement in the session, meaning the PI had to put more effort into engaging the participant with a less extensive musical background. Jin (2016) reported three findings for clinicians to increase cultural competency: learning about clients’ cultures, having an attitude conducive to learning, and developing skills to navigate cultural barriers. The PI for the current study was able to connect with participants by talking about aspects of the participants’ culture, found through readings completed before and during the study, and doing so helped to build rapport. The PI was also willing and able to adapt the session plans as she learned from the participants what aspects of the sessions were beneficial for them.

The findings match existing research discussed in the literature review. Beck et al. (2018) found increased well-being in adult refugees with PTSD as a result of trauma-focused Guided Music and Imagery. Jespersen (2012) found an increase in sleep quality of adult refugees that correlated with an increase in well-being as a result of relaxation music listening at bedtime. Quinlan (2016) found an increase in emotional symptoms in a group of adolescent refugees in a school-based music therapy program.

To reduce the chance for bias, future research might utilize a larger research team so that the PI would not serve the roles of researcher, data collector, and music therapist. Further, a larger group of participants could yield statistically significant data, which could serve to demonstrate efficacy of the use of music therapy with refugees. In the study, there was supposed to be a total of five participants, but attendance from the three unreported participants was low due to external factors, including long work hours and family responsibilities. The fact that the sessions occurred during the late morning of a weekday and several participants worked overnight shifts could have negatively affected attendance. Offering a financial incentive and finding a more convenient time for the participants to meet might assist in increasing number of participants and ensuring attendance.

8. REFERENCES


9. **FIGURES**

<table>
<thead>
<tr>
<th>Theme</th>
<th>References</th>
<th>Quote</th>
</tr>
</thead>
<tbody>
<tr>
<td>Instrument Playing</td>
<td>9</td>
<td>&quot;When we all play together, that just went to my soul. When you play and sing and we play drums you are teaching us to listen very well and still be connected to what we’re doing.&quot; - Participant A, Session 3</td>
</tr>
<tr>
<td>Hello Song</td>
<td>4</td>
<td>“When we sing in church, we invite the whole spirit in us and sing soft songs. We feel the whole spirit in us and continue to invite. It prepares our hearts and minds to listen to the words of the preacher and I can feel free.” - Participant A, Session 6</td>
</tr>
<tr>
<td>Listening</td>
<td>3</td>
<td>&quot;I liked the music listening that reminded me of many things: childhood, what I passed through when I was young; it was like making a movie. Listening makes me remember the memories, but I feel I can survive the present and see the future God is preparing for me rather than living in the past.&quot; - Participant A, Session 7</td>
</tr>
<tr>
<td>Relaxation</td>
<td>2</td>
<td>“Because I came here stressed out, I now feel I am fresh with all the (relaxation) methods we used I feel I am okay.” - Participant A, Session 6</td>
</tr>
<tr>
<td>Singing</td>
<td>1</td>
<td>&quot;For me, everything made me happy. I don't know which I will choose. The starting song drew me in. When we drummed and sang, it was good too.&quot; - Participant B, Session 2</td>
</tr>
<tr>
<td>Songwriting</td>
<td>1</td>
<td>&quot;I liked writing the song and playing instruments. I felt relaxed and wanted to sleep. I have high morale from playing guitar.&quot; - Participant A, Session 8</td>
</tr>
</tbody>
</table>

Table 1. Themes from Question 1

<table>
<thead>
<tr>
<th>Theme</th>
<th>References</th>
<th>Quote</th>
</tr>
</thead>
<tbody>
<tr>
<td>Singing</td>
<td>6</td>
<td>&quot;What I can pick up is to sing because I can sing alone and feel better.&quot; - Participant B, Session 1</td>
</tr>
<tr>
<td>Instrument Playing</td>
<td>4</td>
<td>&quot;I have made my own drum at home in a cup and then I can beat and sing and dance.&quot; - Participant A, Session 3</td>
</tr>
<tr>
<td>Listening</td>
<td>3</td>
<td>“What I can do at home is listen to the music and relax. Then I can sing with the music and that’s what I can use.” - Participant B, Session 3</td>
</tr>
<tr>
<td>Songwriting</td>
<td>2</td>
<td>&quot;When I am writing the song, I will remember many things: bad things and good things.&quot; - Participant A, Session 7</td>
</tr>
<tr>
<td>Relaxation</td>
<td>1</td>
<td>&quot;I felt (music &amp; imagery) was very helpful, letting the light penetrate throughout my body. When you said, &quot;the light&quot;, I concentrated on it and I could feel it manifesting in my body.” – Participant A, Session 6</td>
</tr>
</tbody>
</table>

Table 2. Themes from Question 2

![Figure 1. Level of anxiety per periodic test](image)

Figure 1. Level of anxiety per periodic test
Figure 2. Level of depression per periodic test

Figure 3. Percentage quality of life per periodic test
Figure 4. Level of disability per periodic session

Figure 5. Level of sudden distress per session, Participant A

Figure 6. Level of sudden distress per session, Participant B
Protocol

I. Introduction
   - Hello song
   - Check in about uses of music over past week

II. Drumming
   - Call and response
   - Structured improvisation
   - Drumming to recorded music

III. Instrument Playing
   - Structured improvisation
   - Themes

IV. Singing and Songwriting
   - Hymns
   - Themes

V. Relaxation
   - Progressive Muscle Relaxation
   - Music and Imagery

Appendix A: Protocol
Appendix B: GAD-7

### Generalized Anxiety Disorder 7-item (GAD-7) scale

<table>
<thead>
<tr>
<th>Over the last 2 weeks, how often have you been bothered by the following problems?</th>
<th>Not at all sure</th>
<th>Several days</th>
<th>Over half the days</th>
<th>Nearly every day</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Feeling nervous, anxious, or on edge</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>2. Not being able to stop or control worrying</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>3. Worrying too much about different things</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>4. Trouble relaxing</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>5. Being so restless that it's hard to sit still</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>6. Becoming easily annoyed or irritable</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>7. Feeling afraid as if something awful might happen</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
</tbody>
</table>

Add the score for each column

---

Total Score (add your column scores) =

If you checked off any problems, how difficult have these made it for you to do your work, take care of things at home, or get along with other people?

Not difficult at all
Somewhat difficult
Very difficult
Extremely difficult

Appendix C: PHQ-9

### PATIENT HEALTH QUESTIONNAIRE-9 (PHQ-9)

Over the last 2 weeks, how often have you been bothered by any of the following problems?
(Use ‘✓’ to indicate your answer)

<table>
<thead>
<tr>
<th></th>
<th>Not at all</th>
<th>Several days</th>
<th>More than half the days</th>
<th>Nearly everyday</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Little interest or pleasure in doing things</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>2. Feeling down, depressed, or hopeless</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>3. Trouble falling or staying asleep, or sleeping too much</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>4. Feeling tired or having little energy</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>5. Poor appetite or overeating</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>6. Feeling bad about yourself — or that you are a failure or have let yourself or your family down</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>7. Trouble concentrating on things, such as reading the newspaper or watching television</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>8. Moving or speaking so slowly that other people could have noticed? Or the opposite — being so fidgety or restless that you have been moving around a lot more than usual</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>9. Thoughts that you would be better off dead or of hurting yourself in some way</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
</tbody>
</table>

**FOR OFFICE CODING**

\[
0 + \_\_\_ + \_\_\_ + \_\_\_ + \_\_\_ = \text{Total Score: } \_\_\_\_\]

If you checked off any problems, how difficult have these problems made it for you to do your work, take care of things at home, or get along with other people?

<table>
<thead>
<tr>
<th>Not difficult at all</th>
<th>Somewhat difficult</th>
<th>Very difficult</th>
<th>Extremely difficult</th>
</tr>
</thead>
</table>

Developed by Drs. Robert L. Spitzer, Janet B.W. Williams, Kurt Kroenke and colleagues, with an educational grant from Pfizer Inc. No permission required to reproduce, translate, display or distribute.
WHO (Five) Well-Being Index (1998 version)

Please indicate for each of the five statements which is closest to how you have been feeling over the last two weeks. Notice that higher numbers mean better well-being.

Example: If you have felt cheerful and in good spirits more than half of the time during the last two weeks, put a tick in the box with the number 3 in the upper right corner.

<table>
<thead>
<tr>
<th>Over the last two weeks</th>
<th>All of the time</th>
<th>Most of the time</th>
<th>More than half of the time</th>
<th>Less than half of the time</th>
<th>Some of the time</th>
<th>At no time</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 I have felt cheerful and in good spirits</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2 I have felt calm and relaxed</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3 I have felt active and vigorous</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4 I woke up feeling fresh and rested</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5 My daily life has been filled with things that interest me</td>
<td></td>
<td></td>
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</table>

Scoring:

The raw score is calculated by totalling the figures of the five answers. The raw score ranges from 0 to 25, 0 representing worst possible and 25 representing best possible quality of life.

To obtain a percentage score ranging from 0 to 100, the raw score is multiplied by 4. A percentage score of 0 represents worst possible, whereas a score of 100 represents best possible quality of life.

Appendix D: WHO-5
Appendix E: WHODAS 2.0

12-item version, self-administered

This questionnaire asks about difficulties due to health conditions. Health conditions include diseases or illnesses, other health problems that may be short or long lasting, injuries, mental or emotional problems, and problems with alcohol or drugs.

Think back over the past 30 days and answer these questions, thinking about how much difficulty you had doing the following activities. For each question, please circle only one response.

In the past 30 days, how much difficulty did you have in:

<table>
<thead>
<tr>
<th></th>
<th></th>
<th>None</th>
<th>Mild</th>
<th>Moderate</th>
<th>Severe</th>
<th>Extreme or cannot do</th>
</tr>
</thead>
<tbody>
<tr>
<td>S1</td>
<td>Standing for long periods such as 20 minutes?</td>
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<tr>
<td>S2</td>
<td>Taking care of your household responsibilities?</td>
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<td>S3</td>
<td>Learning a new task, for example, learning how to get to a new place?</td>
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<td>S4</td>
<td>How much of a problem did you have joining in community activities (for example, religious or other activities) in the same way as anyone else can?</td>
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<td>S5</td>
<td>How much have you been emotionally affected by your health problems?</td>
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</tbody>
</table>

Please continue to the next page...

In the past 30 days, how much difficulty did you have in:

<table>
<thead>
<tr>
<th></th>
<th></th>
<th>None</th>
<th>Mild</th>
<th>Moderate</th>
<th>Severe</th>
<th>Extreme or cannot do</th>
</tr>
</thead>
<tbody>
<tr>
<td>S6</td>
<td>Concentrating on doing something for 5 minutes?</td>
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<td>S7</td>
<td>Walking a long distance such as a kilometre or equivalent?</td>
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<td>S8</td>
<td>Washing your whole body?</td>
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<td>S9</td>
<td>Getting dressed?</td>
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<tr>
<td>S10</td>
<td>Dealing with people you do not know?</td>
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<tr>
<td>S11</td>
<td>Maintaining a friendship?</td>
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<tr>
<td>S12</td>
<td>Your day-to-day work?</td>
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</table>

M1 | Overall, in the past 30 days, how many days were these difficulties present? | Record number of days __________ |
M2 | In the past 30 days, for how many days were you totally unable to carry out your usual activities or work because of any health condition? | Record number of days __________ |
M3 | In the past 30 days, not counting the days that you were totally unable, for how many days did you cut back or reduce your usual activities or work because of any health condition? | Record number of days __________ |

This completes the questionnaire. Thank you.
The distress thermometer – Subjective Units of Distress Scale (SUDS)

Try to get used to rating your distress, fear, anxiety or discomfort on a scale of 0-100. Imagine you have a ‘distress thermometer’ to measure your feelings according to the following scale. Notice how your level of distress and fear changes over time and in different situations.

100  Highest distress/fear/anxiety/discomfort that you have ever felt
90   Extremely anxious/distressed
80   Very anxious/distressed, can’t concentrate
70   Quite anxious/distressed, interfering with performance
60
50   Moderate anxiety/distress, uncomfortable but can continue to perform
40
30   Mild anxiety/distress, no interference with performance
20   Minimal anxiety/distress
10   Alert and awake, concentrating well
0    Totally relaxed

Appendix F: SUDS
Participant’s Experience Questionnaire

Instructions: Please read the questions below and take two minutes to think about your answers. After two minutes, you will be asked the questions aloud, one at a time. Please answer each question verbally.

- Describe the activity you liked the best.
- What did we do today that you are most likely to do on your own?

For staff to fill out:

1. Describe the activity you liked the best.


2. What did we do today that you are most likely to do on your own?


Appendix G: Questionnaire