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# Home practice and quality of life among patients with neurofibromatosis randomized to a mind-body intervention

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ABSTRACT

*Objectives:* The purpose of this study was to summarize home practice in patients with neurofibromatosis (NF) randomized to an 8-week group mind-body intervention, the Relaxation Response Resiliency Program for NF (3RP-NF). We further examined the association between home practice and changes in four domains of quality of life (QoL).

*Methods:* Data are derived from a single-blind RCT of the 3RP-NF (N = 31) delivered via videoconferencing versus an attention placebo control. 3RP-NF participants submitted weekly home practice logs to the group leader prior to each weekly session, which included information regarding their engagement of relaxation response (RR)-eliciting skills and appreciation skills. Physical, psychological, social and environmental QoL were measured at baseline, post-intervention and at a 6-months follow up.

*Results:* Participants reported engaging in home practice of RR-eliciting skills on average 28.55 days (SD = 10.79) and appreciation skills on average 24.39 days (SD = 13.48) over the 49-day treatment period. Participants reported an average of 383.42 (SD = 274.38) minutes of RR-eliciting skills home practice and an average of 49.13 (SD = 41.90) appreciations skills home practice. A significant association was observed between frequency of RR-eliciting skills home practice and physical QoL at the 6-month follow-up (r = .383, p = .034).

*Conclusions:* Participants with NF are able and willing to practice RR-eliciting skills and appreciation skills outside of treatment sessions. Frequency of RR-eliciting skills home practice may be associated with improvement in physical QoL. Future research should replicate these efforts with larger samples, and attempt to identify additional factors that predict optimal response to mind-body interventions other than home practice.

## 1. Introduction

The neurofibromatoses (NF) encompass three genetically distinct disorders (NF1, NF2, and schwannomatosis), each characterized by an increased risk of tumor formation throughout the central and peripheral nervous system. Most affected individuals inherit NF yet some develop this condition through spontaneous genetic mutations.[1–4] Although symptom severity and prognosis vary by case and type, NF is considered a progressive disorder that worsens over time.[5,6] There is currently no cure for NF; treatment options at this time include the use of pharmacotherapy and surgical interventions.[7]

Patients with NF report poor quality of life (QoL)[8] and symptoms of anxiety and depression,[9] at rates and severities similar to other chronic illnesses.[10] NF patients also report high levels of stress associated with symptom burden, uncertainty of disease, difficulties getting appropriate medical care, and social isolation.[11] Mind-body interventions, which include a variety of skills and exercises designed to facilitate the mind's capacity to influence bodily function,[12,13] may improve psychosocial well-being and reduce somatic symptoms. These interventions have been found feasible and effective in patients with other chronic illnesses[14,15] and thus represent a promising treatment approach in patients with NF. Our team recently found that an evidence-based mind-body intervention, the Relaxation Response Resiliency Program adapted for patients with NF (3RP-NF)[16] is highly feasible and

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acceptable to patients, and also improved multiple indices of QoL relative to an attention placebo. However, we observed variability in the level of improvement among participants who received the 3RP-NF intervention, suggesting a need to identify factors that impede or facilitate optimal response to this mind-body intervention.

The 3RP-NF teaches techniques that induce the relaxation response (RR) (i.e., RR-eliciting skills), including but not limited to deep breathing, yoga, and mindfulness meditation. In addition, the 3RP-NF asks individuals to record instances throughout the day for which they are grateful (i.e., appreciation skills), such as someone holding the door open for you, or spending time with a loved one. Mind body interventions such as the 3RP-NF typically include recommendations to practice such skills and exercises outside of the treatment sessions; home practice of these skills is considered an important factor in clinical outcomes, and may be a factor that explains the variability in QoL improvement observed in the 3RP-NF trial. However, there is no strong empirical foundation to guide evidence-based recommendations for the optimal amount and duration of home practice in mind-body interventions.[17,18] Thus, an important next step in mind-body research is therefore to investigate associations between home practice and improvements in clinical outcomes. Understanding how home practice is associated with outcomes of mind-body interventions could help clinicians and researchers make recommendations that are sufficient but not unnecessarily burdensome for patients, thus increasing the likelihood of adherence and improving intervention outcomes.[19,20]

The purpose of this study was to summarize home practice among patients with NF who participated in the 3RP-NF intervention, and to explore the relationship between home practice and improvements of physical, psychological, social and environmental QoL. We explored two specific home practice exercises: practice of RR-eliciting skills and practice of appreciation skills. We first report the amount of RR-eliciting skills home practice completed across all participants, summarized as total minutes (duration) and number of days per week of practice (frequency) throughout the 49-day treatment period (i.e., the seven weeks when home practice was assigned, following the first week of the intervention). Similarly, we report amount of appreciation skills home practice as total number of appreciations (quantity) and number of days of practice (frequency) throughout the intervention. Lastly, we explore associations between home practice and improvements of QoL from baseline to post-treatment and 6-month follow-up. We hypothesized that grater home practice of RR-eliciting skills and appreciation skills would be associated with greater improvements in each of the four domains of QoL.

## 2. Methods

### 2.1. Participants

A national sample of 252 patients with NF responded to an IRB approved flyer advertising a pilot stress management study for NF patients – the first 65 were screened. Of these, 63 met the following inclusion criteria: (1) diagnoses of NF1, NF2, or schwannomatosis by a medical professional, (2) age 18 or older, (3) able to provide informed consent and comply with study procedures, (4) able to read and comprehend English at the 6$^{th}$ grade level, and (5) self-reported stress and difficulties coping with NF symptoms. Exclusion criteria were: (1) severe psychopathology such as schizophrenia or active substance use that would interfere with the study procedure, or (2) unwilling or unable to participate in videoconference sessions via the Skype application. Only participants randomized to the 3RP-NF (N = 31) were included in the current analysis.

### 2.2. Study design

These data come from a single-blind RCT of the 3RP-NF, an 8-week group mind-body intervention, versus an attention placebo control conducted by our research team.[16] Ethical standards were reviewed and approved by the Institutional Review Board of the Massachusetts General Hospital (Partners Human Research Committee; PHRC). In summary, participants were randomized to the 3RP-NF intervention group or the attention placebo control group; participants were kept blind as to whether they received the 3RP-NF or the attention placebo by being informed that the research team was comparing two stress management intervention curriculums to determine which one was more effective. The intervention group met weekly via live videoconferencing for eight 90-minute sessions, which included rehearsal and repetition of a new skill as well as a review of the previously learned skills. Participants were mailed a patient manual designed for a 6$^{th}$ grade comprehension level to accommodate for learning disabilities and other cognitive impairments typically associated with NF. Participants randomized to the 3RP-NF were are asked to engage in home practice of RR-eliciting skills (e.g., deep breathing and mindfulness meditation) and appreciation skills (e.g., taking a moment to notice, write down and experience gratitude toward particular experiences or event during one's day) on a daily basis, starting with at least 5 min of eliciting the RR and 1 appreciation per day, then increasing to 20 min of eliciting the RR and 3 appreciations per day after the second week of the intervention. To facilitate RR-eliciting skills home practice, participants received a CD with all of the exercises taught during the program. Participants emailed weekly homework logs to the group leader (AMV). If a participant missed a weekly scheduled group sessions, they were offered the opportunity to attend a make-up session.

### 2.3. Measures

Quality of Life – The World Health Organization Quality of Life Brief Version (WHOQOL-BREF) was used to assess four domains of QoL: physical, psychological, social and environmental.[21] The WHOQOL-BREF is a reliable and valid shorter version of the original WHOQOL-100. Higher scores indicate better QoL.

Home Practice – RR-eliciting skills and appreciation skills home practice were assessed through practice logs, in which participants recorded the type and description of RR-eliciting skills practice as well as the number of appreciations engaged on a given day of the week.

*Amount of RR-Eliciting Skills Home Practice* – Two separate variables were used to assess amount of RR-eliciting skills home practice: (1) *duration*, measured by number of minutes of reported practice throughout the intervention and (2) *frequency*, measured by number of days of reported practice throughout the intervention.

*Amount of Appreciation Skills Home Practice* – Two separate variables were used to assess amount of appreciation skills home practice: (1) *quantity*, measured by number of appreciations reported throughout the intervention and (2) *frequency*, measured by the number of days per week on which participants reported practicing appreciations throughout the intervention.

### 2.4. Data collection

Details on data collection for the QoL measures are presented in the parent paper.[16] Briefly, participants were emailed a secure link to the study questionnaire through REDcap[21] and completed the measures from their own home at baseline, immediately after the intervention, and at the 6-month follow-up. Weekly practice logs, emailed to participants at the beginning of the study as a word document, were used to collect data on amount of home practice. Participants emailed the document back to the group leader before the commencement of each session. Home practice (e.g., adherence, increasing home practice of skills) was discussed for the first 15 min of each group sessions. If a participant did not submit a weekly log or was missing some of the information in the log, it was considered missing data.

### 2.5. Statistical analysis

Descriptive statistics were used to summarize demographic information, duration and frequency of RR-eliciting skills home practice, and quantity and frequency of appreciation skills home practice. Zero-order correlations were used to assess the relationship between duration of RR-eliciting skills home practice, frequency of RR-eliciting skills home practice, quantity of appreciation skills home practice, and frequency of appreciation skills home practice with QoL from baseline to post-intervention and 6-month follow-up.

Return rates for weekly practice logs varied with the highest return rate on weeks 2 and 3 (90%) and the lowest return rate on week 4 (70%). We conservatively estimated that participants who did not return a log had not completed any home practice and imputed values of 0 for all measures. Participants were instructed to record all daily practice. Therefore, omitted values within a returned log were considered to indicate no practice and values were recorded as 0.

## 3. Results

### 3.1. Participants

Table 1 summarizes the demographic information of the participants assigned to the 3RP-NF treatment group. Of the NF types, NF1 was most common (N = 19), followed by NF2 (N = 9) and lastly Schwannomatosis (N = 3). Most participants were female (N = 23) and white (N = 26). Many participants were married or living with a partner (N = 16), worked as full-time employees (N = 19), and graduated from college (N = 11). The mean age of the participants was 49.1 (SD = 11.31); ages ranged from 22 to 64 years.

### 3.2. Home practice patterns

Table 2 summarizes the descriptive statistics for RR-eliciting skills and appreciation skills home practice. Across the intervention, participants engaged in RR-eliciting skills home practice for an average of 383.42 min (SD = 274.38), and on 28.55 days (SD = 10.79), or 73% (SD = 29%) of the 49-day treatment period. Participants recorded a mean of 49.13 appreciations (SD = 41.90), and appreciation skills home practice on 24.39 days (SD = 13.48), or 57% (SD = 36%) of 49-day treatment period.

**Table 1**
Demographic Characteristics of Participants.

| NF Type, N (%) | |
|---|---|
| NF1 | 19 (61) |
| NF2 | 9 (29) |
| Schwannomatosis | 3 (10) |
| Age, M (SD), Range | 49.1 (11.31), 22-64 |
| Gender, N (%) | |
| Male | 8 (26) |
| Female | 23 (74) |
| Race, N (%) | |
| White | 26 (84) |
| Asian | 5 (16) |
| Marital Status, N (%) | |
| Single | 12 (39) |
| Married/Living with Partner | 16 (52) |
| Separated/Divorced | 2 (6) |
| Widowed | 1 (3) |
| Work Status, N (%) | |
| Full-Time Employee | 19 (61) |
| Part-Time Employee | 6 (19) |
| Student | 1 (3) |
| Retired | 2 (7) |
| Other | 3 (10) |
| Education, N (%) | |
| Less than High School | 1 (3) |
| High-School Graduate/GED | 1 (3) |
| Some College | 10 (32) |
| College Graduate | 11 (36) |
| More than College | 8 (26) |

*N = 31 for the entire sample.

### 3.3. Relationship between home practice and QoL

Table 3 summarizes the correlations between home practice and QoL improvements from baseline to post-intervention and 6-month follow-up. There was a significant correlation between frequency, but not duration, of RR-eliciting skills home practice and physical QoL at the 6-month follow-up (r = .383, p = .034). There was no association between frequency or duration of RR-eliciting skills home practice and psychological, social or environmental QoL. There were no associations between frequency or quantity of appreciation skills home practice and any domain of QoL.

## 4. Discussion

Delivery of an evidence-based mind-body intervention (3RP-NF) via group videoconferencing produced sustained improvements of QoL in patients with NF, yet the magnitude of improvement varied among participants.[16] Although the literature is mixed, there is evidence to suggest that amount of home practice[17,18] could account for differential improvement of intervention outcomes, highlighting the importance of examining home practice and it's associations with mind-body intervention trial outcomes. The current study found generally high rates of home practice, indicating that the skills and exercises taught in the 3RP-NF are acceptable and feasible for NF patients. An association was observed between frequency of RR-eliciting skills home practice (days) and the physical QoL domain, suggesting that greater RR-eliciting skills home practice may be associated with better intervention outcomes.

One important finding from the current study is that RR-eliciting skills and appreciation skills home practice was moderately high, with rates of RR-eliciting skills home practice being greater than that of appreciation skills home practice. This finding was true when examining the duration and frequency of RR-eliciting skills home practice, and the quantity and frequency of appreciation skills home practice. Overall, the rate of RR-eliciting skills home practice was 73%, and 57% for appreciation skills home practice. Together, these findings suggest that patients with NF are willing to engage in the various exercises taught in mind-body interventions and are able to practice the skills between treatment sessions, and may be more inclined to practice RR-eliciting skills rather than appreciation skills.

The current study found that there was a significant correlation between frequency of RR-eliciting skills home practice throughout the intervention and physical QoL at 6-month follow-up. Given that the significant correlations were observed for the frequency of home practice, rather than the duration of practice, it may be that developing a habit of practicing mind-body skills regularly may be more important for QoL improvements than the total amount of time spent on home practice. However, the overall trend suggests home practice is not associated with intervention outcomes. Given the findings of the current study, there may be factors other than home practice that could account for the differential improvements in QoL observed in NF patients in a mind-body intervention. Clinicians and researchers often make home practice recommendations that are lengthy and may not accurately reflect the existing literature, suggesting a need to identify other factors that explain differential improvements in outcomes, such as use of face-to-face intervention delivery as opposed to videoconferencing, formal training and personal practice of the skills coach, and use of different measures of home practice.

The current findings add to the limited literature on home practice and outcomes in mind-body interventions. Although regular and sustained practice of mind-body skills outside of the treatment sessions, as well as continuous practice after program completion, has been

**Table 2**
Amount of Home Practice Throughout the 3RP-NF.

| | Amount of RR Home Practice | | Amount of Appreciation Home Practice | |
|---|---|---|---|---|
| | Duration of RR Practice (min) *M (SD), Range* | Frequency of RR Practice (days) *M (SD), Range* | Quantity of Appreciation Practice *M (SD), Range* | Frequency of Appreciation Practice (days) *M (SD), Range* |
| **Week 1** | 44.90 (38.40), 0-140 | 4.74 (2.66), 0-7 | 8.97 (8.85), 0-28 | 4.29 (2.83), 0-7 |
| **Week 2** | 49.81 (36.23), 0-150 | 5.00 (2.37), 0-7 | 11.03 (8.88), 0-35 | 4.94 (2.77), 0-7 |
| **Week 3** | 75.74 (62.59), 0-276 | 5.52 (2.36), 0-7 | 8.55 (8.26), 0-29 | 4.39 (2.91), 0-7 |
| **Week 4** | 72.97 (122.40), 0-680 | 4.26 (3.10), 0-7 | 6.45 (7.43), 0-26 | 3.68 (3.22), 0-7 |
| **Week 5** | 75.26 (67.36), 0-310 | 5.06 (2.66), 0-7 | 7.81 (8.42), 0-29 | 4.10 (3.17), 0-7 |
| **Week 6** | 46.48 (49.37), 0-160 | 3.97 (2.38), 0-7 | 6.32 (8.36), 0-28 | 3.00 (3.20), 0-7 |
| **Week 7** | 63.16 (61.32), 0-245 | 4.68 (3.04), 0-7 | 6.68 (7.69), 0-25 | 3.35 (3.22), 0-7 |
| **Total** | 383.42 (274.38), 5-1120 | 28.55 (10.79), 2-42 | 49.13 (41.90), 0-175 | 24.39 (13.48), 0-42 |

*N = 31 for the entire sample.

**Table 3**
Correlations Between Home Practice and QoL.

| | RR Home Practice | | Appreciation Home Practice | |
|---|---|---|---|---|
| | Total Duration of RR Practice (min) | Total Frequency of RR Practice (days) | Total Quantity of Appreciation Practice | Total Frequency of Appreciation Practice (days) |
| **Post-Treatment** | | | | |
| Physical QoL | .260 | .345 | .209 | .225 |
| Psychological QoL | .135 | .269 | .175 | .237 |
| Social QoL | .140 | .147 | .238 | .292 |
| Environmental QoL | .183 | .267 | .266 | .335 |
| **6-Month Follow-Up** | | | | |
| Physical QoL | .194 | .383* | .046 | .054 |
| Psychological QoL | .002 | .238 | .192 | .261 |
| Social QoL | .022 | .191 | .217 | .216 |
| Environmental QoL | .172 | .183 | .328 | .340 |

* N = 31 for the entire sample.

proposed as critical components responsible for the therapeutic benefits elicited by mind-body interventions, [17] research has only recently begun to explore these associations and the literature to date has been mixed. A recent systematic review found that the majority of published mind-body intervention studies did not assess the relationship between home practice and outcomes.[18] Among those that did, there was wide variability in the methods used to assess (e.g., daily home practice logs, retrospective reports, daily phone monitoring) and quantify home practice (e.g., quantity vs. frequency, adherence rates using varying cut-off points), and some studies found positive correlations while others found negative or no correlations between home practice and outcomes.[18] Findings of the current study therefore extend this literature by suggesting that among patients with NF participating in a targeted mind-body intervention, home practice may be associated with greater improvements in physical QoL and that the relationship between home practice and QoL may depend on the type of practice and domain of QoL, as well as the home practice measurement used.

Strengths of the current study include the use of an evidence-based mind-body intervention adapted for a specific medical population, the use of data derived from a randomized controlled trial, and the use of two follow-up time-points. There was also a high rate of engagement in the treatment by participants. Additionally, while previous studies tend to explore practice of one specific RR-eliciting skill (e.g., mindfulness meditation practice), the current study explored both RR-eliciting skills and appreciation skills, providing information about a greater diversity of specific mind-body exercises. This study also examined multiple QoL domains to test differential associations between specific mind-body intervention components and specific QoL improvements. Despite these strengths, several limitations bare noting, including a relatively small sample size which may have limited our power to detect significant effects, the number of analyses performed, and our conservative interpretation of missing data. Additional confounding variables (e.g., support from group members or therapist, use of the other skills taught in the program) that were not measured in the current study may also have contributed to the observed improvements in QoL. Results should be interpreted with caution given these limitations, but the results warrant replication studies with larger sample sizes that may better be able to discern the nature of the relationship between home practice and QoL improvements.

Lastly, we were not able to use a validated or standardized measure of home practice because no such measure currently exists. Future research should focus on identifying valid and reliable measures for home practice, as well as standardized quantification of home practice. Attempts should be made to determine whether frequency or duration of home practice is more closely associated with better intervention outcomes. Further, it is not clear if a threshold of practice must be met for clinically relevant outcomes to be produced. A randomized, controlled design that assesses differential frequencies, durations, and quantities of practice may better elucidate the nature of the relationship between home practice and improvements of QoL. Finally, future research should attempt to identify what factors, other than home practice, predict an optimal response to mind-body interventions. More research is needed, in specific populations for specific outcomes given that effects can differ across contexts. Until there is more conclusive evidence, clinicians and researchers should be aware that the relationship between home practice and intervention outcomes is not well established and should, for the time being, make home practice recommendations that best suit the individual patient.

Results of the current study suggest that mind-body skills are acceptable to patients with NF and many patients are willing and able to practice mind-body skills on their own at home. Frequency of mind-body skill home practice may promote clinical improvements in some certain domains of quality of life, though further research on the role of home practice and mind-body intervention outcomes is needed. The

relationship between home practice and intervention outcomes is inconclusive; factors that facilitate and impede treatment should be identified to promote evidence-based home practice recommendations.

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CJF entered and cleaned data, ran the statistical analysis, and wrote the manuscript. ELZ assisted with statistical analysis and manuscript preparation. CML assisted with initial data quality assessment and manuscript preparation. AMV provided mentorship and feedback throughout the manuscript writing process.

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