

How Music Intervention Lowered Participants' Morning Cortisol—Qualitative Case Stories

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Abstract

Non-pharmacological interventions for improved home care of persons with dementia and their family caregiver are and will be increasingly important for society. A music intervention study was performed on persons with persons with dementia and family caregiver. The persons with dementia and family caregiver were instructed to choose a daily routine for joint listening to recorded music. They selected the music they were interested in from a menu. The intervention period lasted for two months. Both persons with dementia and family caregiver provided daily saliva samples for the assessment of stress-related steroid hormones. In previous reports we have reported that the morning cortisol levels decreased significantly among the family caregiver when the intervention group was compared to a control group. In the present study we report narratives from four dyads, two of whom with beneficial effects of the music intervention, one dyad with no clear beneficial effects and one dyad with mixed results. The narratives illustrate the strong cohesive effect that the joint music listening could have, leading to improved social functioning paralleled by decreased morning cortisol levels particularly in the family caregiver. The narratives also illustrate reasons for failed effects.

Keywords

Dementia, Family Caregivers, Music, Stress, Saliva Morning Cortisol

1. Introduction

Dementia, affects around 8 million people in the European Union and places a

significant burden on family caregivers [1]. Given that the majority of persons with dementia (PWD) are living in the community, usually at their homes, family caregivers (FCG) providing 24-hour care face substantial stress. Studies reveal that caregivers, especially spouses, experience higher stress levels than non-dementia caregivers [2] [3]. Efforts to find a better dementia intervention continue evolving [4] [5] [6], and music interventions are known for positively affecting PWD and caregivers [7] [8] [9]. Despite indications that music listening may have a positive impact on PWD and their home caregivers, the effects have been insufficiently studied.

The rationale behind the current study revolves around investigating the impact of a music intervention program and its possible effects on the concentration of the stress-related steroid hormones cortisol and DHEAS. Given the close connection between the PWDs and their caregivers, we decided to study them together. The stress hormone analyses were focused both on possible effects on mean levels of the intervention program and on the patterns of variability. The study design offered a unique opportunity to study day-to-day variations, since the participants were instructed to collect samples every weekday during a two-month period.

The main findings from the cortisol analyses indicate that, at the group level, morning cortisol levels decreased among FCG during the intervention period compared to the control period. However, this pattern was not observed in persons with dementia [10]. Since there were a large number of samples for each subject throughout the study periods—daily samples during two months—it was possible to analyze individual trends. These analyses showed that approximately one-fourth of the individual subjects had significantly decreasing cortisol levels in the morning and in the evening during the intervention period in the music groups. However, the proportion of significantly decreased cortisol levels was slightly higher among caregivers than among PWD [7].

A more detailed analysis of the variability patterns with comparisons between intervention and control groups (Emami *et al.*, in review) showed that there was a significantly higher cortisol variation (standard deviation divided by mean) in the music intervention group compared to the control group among the FCG but not among the PWD. Our impression has been that the FCG may have had a more flexible way of responding physiologically to the intervention than the PWD. If this is true, the underlying explanation could either be psychological or physiological rigidity in the PWD group. The latter phenomenon has been discussed as a possible characteristic of patients with dementia as discussed in [11].

Ratings of stress, coping and depression by caregivers [12] were analyzed before and after the intervention period. These results showed that the rating of coping was significantly better in the intervention group (PWD and FCG together) than in the control group after the intervention period. Analyses of changes of within-group differences in overall stress and coping indicated that the trajectory of the scores during the intervention period was significantly different, with deteriorated scores in the comparison group.

It became evident that a more robust understanding of the data created a need for more detailed descriptions of the clinical progression. To achieve this, we incorporated narrative notes made by the highly experienced occupational therapist responsible for the data collection.

2. Material and Methods

2.1. Sample and Setting

In short, the case study is a part of the more extensive investigation of stress biomarkers for assessing the impact of music on persons with dementia (PWD) and their family caregivers (FCG). Consecutive PWD were recruited from a memory evaluation center in Stockholm with a socioeconomically diverse population. They, along with their respective family caregivers, constituted the participating dyads.

Persons with dementia were eligible if they 1) were 65 years of age or older, 2) had received a diagnosis of dementia from a physician, 3) exhibited moderate to very severe cognitive decline as defined by a Global Deterioration Scale (GDS) score [13] of 4 (moderate decline) to 7 (very severe decline), 4) were living at home with a family member, and 5) agreed to participate in the study (or a proxy agreed to their participation).

Family caregivers eligible were those who 1) were at least 18 years of age; 2) identified themselves as primary caregivers of family members with dementia; 3) lived at home with the persons with dementia, and 4) agreed to participate in the study.

Data for the present study was gathered from November 2018 to April 2019. This study was approved by the Karolinska Institutet Institutional Review Board (Dnr: 2018/1596-31/2).

2.2. Intervention

The intervention and the procedures for the education session have been described elsewhere [8]. FCG and the PWD received an education session on the benefits of music and were given access to an online music program with a playlist featuring familiar songs. The online music program was created through a collaboration between FoUNordost, a Swedish research organization, and the Swedish Dementia Centre specifically for PWD and their caregivers. Unlike other studies, the music-based intervention was flexible, allowing caregivers and PWD to play music during care giving or daily activities such as mealtime, before bed.

2.3. Measures

Salivary cortisol samples were collected by the FCG and the PWD, in the morning and evening, 5 days a week, for 8 consecutive weeks [8]. Participants were provided with written instructions, hands-on training, and information about the importance of specific collection times. The study coordinator distributed

labeled saliva tubes to participants before the first week of collection, and conducted a review session covering the collection procedure and pickup details. Two methods, the SalivaBio Children's Swab PWD and the passive drool method (for FCG), were employed. Collected samples were sealed, refrigerated, and kept in the participants' homes until transported to the lab for analysis.

From the 24 dyads enrolled in the study, we opted to include four dyads in this case study. The dyads needed to provide saliva samples for at least 6 weeks, with a minimum of 15 accepted samples. One of the dyads volunteered to sample saliva during weekends. These selected dyads present a diverse range from "success story" two dyads who appeared to have derived substantial psychosocial and physiological benefits from the music intervention—to one classified as a "failure." and one in which the caregiver seemed to experience benefit but the patient did not. These narratives facilitate a more in-depth analysis of the statistical data. Based on this information, it became possible to understand why the music intervention may be more effective for certain dyads than for others.

In the present narrative report, we have focused exclusively on morning cortisol since the narratives describe starting difficulties in the morning and several stress consequences associated with such problems. In addition, morning cortisol was the parameter that differentiated the music intervention group from the control group, in home caregivers.

3. Results

3.1. Sample Characteristics

A total of four dyads were included in this study. The average age of the FCG was 66 years and 74 years for the PWD.

In this case study, all individuals are presented using fictitious names.

3.2. Cases

Mrs. AA1 (FCG) and Mr. AA2 (PWD)

Mr. AA2 was 81 years old and was diagnosed with Alzheimer's disease in the year prior to the intervention. He had always lived a physically active life, had a history of alcohol and drug abuse, and was self-employed.

Mrs. AA1 endeavored to lead an independent life, participating in physical exercise and socializing with friends. Mrs. AA1 managed all household responsibilities, overseeing financial administration, grocery shopping, cleaning, and cooking.

The couple participated in the music intervention for six weeks. They chose the option of listening to music three times a day. The first half of the intervention was an upsetting period. Mr. AA2 had a cold, and this increased his behavioral disturbances, including agitation, anxiety, depressiveness, and poor sleep with nightmares involving him being in war situations. He was obsessed with the thought that he needed morphine-based drugs and managed to receive a prescription from a physician who he had consulted a long time prior. Mrs. AA1

preferred classical music, in particular Chopin, while Mr. AA1 had quite a different preference (Rod Stewart for instance).

During the intervention period, Mrs. AA1 reached out to the study coordinator expressing concerns about the persistent challenge of prompting her husband to engage in music listening. In response to this, three additional visits were conducted with a specific focus on enhancing his motivation for this activity.

One afternoon during the upsetting period, the study coordinator conducted a home visit. During this time, she witnessed a tantrum with anger during which Mr. AA2 threw items around. He calmed down while listening to Chopin music.

Mrs. AA1 reported that there was increased stress during the first half of the intervention. This could be attributed to the deterioration in AA2's general condition. However, Mr. AA2 showed improvement during the last half. He felt better and was more at ease with his situation, accepting his diagnosis more easily. While he could still be upset at times, it was not as frequent as before. He experienced no nightmares, and the auditory hallucinations disappeared. His suspiciousness towards Mrs. AA1 diminished over time.

Neither Mr. nor Mrs. AA had any systematic changes in morning cortisol concentration (**Figure 1**).

Mr. BB1 (FCG) and Mr. BB2, (PWD)

Mr. BB2 was 72 years old and was diagnosed with vascular dementia during the year preceding the study. He lived at the church campus where he served as a bell ringer during most of his occupational life. Following a divorce four years before the study, he moved in with his son, who assumed the role of family caregiver.

Mr. BB1, a full-time employee with the flexibility to work from home, offers support in various aspects of daily life to Mr. BB2. This includes assisting with hygiene activities, cooking, cleaning, running errands to the bank, and managing contacts with authorities.

Mr. BB1 shared insights into Mr. BB2's challenges in finding the right words, especially in stressful situations. Despite these struggles, words surfaced after a

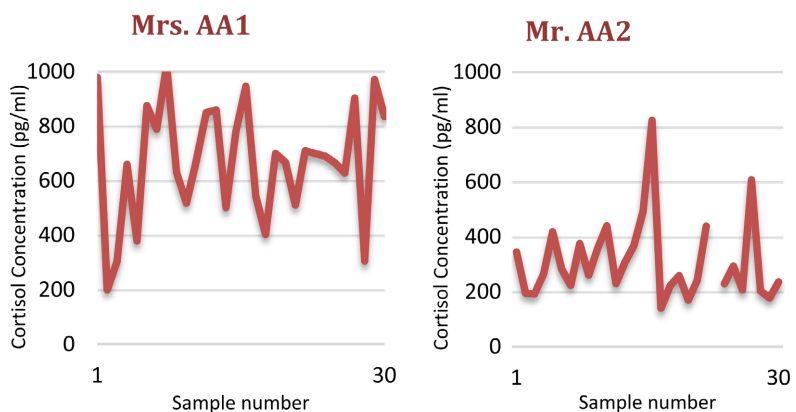


Figure 1. Cortisol concentration picograms per milliliter (pg/ml) each sample day for Mr. and Mrs. AA.

period. Mr. BB2 also faced issues relating to getting lost outdoors. He only took walks in close vicinity to the residence. Mr. BB1 reported restlessness at night, where Mr. BB2 would witness activity between dreams and reality. He would then rise to his feet in order to get out. One night, he woke up in the middle of the night in order to pack his things for a trip. Mr. BB2 was not aware of these events.

Prior to the intervention, Mr. BB1 faced occasional challenges, particularly in offering substantial support to Mr. BB2, resulting in an elevated awareness responsibility. There were instances where Mr. BB2 became completely physically passive, introducing an additional layer of complexity to their care giving dynamic.

This dyad chose to listen to music together three times a day. Throughout the intervention period, Mr. BB2 dedicated a considerable amount of time to music listening. Mr. BB1 played a supporting role by assisting in setting up Spotify on Mr. BB2's mobile phone, providing him the joy of music. Mr. BB1 states enthusiastically that the music not only brings him happiness and strength but also an enhanced sense of energy. He incorporated a compact disc (CD) player at night, promoting better sleep and contributing to a more tranquil home atmosphere. Both Mr. BB1 and Mr. BB2 experienced heightened energy levels and a notable reduction in nighttime disturbances.

Morning cortisol decreased during the intervention period both in the PWD BB2 and in the caregiver BB1 (**Figure 2**).

Mr. CC1 (FCG) and Mrs. CC2 (PWD)

Mrs. CC2 was a 74-year-old woman who was diagnosed with Alzheimer's disease 36 months prior to the intervention. She also had asthma, experiencing frequent attacks that posed challenges for treatment

The couple had transitioned from owning a house to a flat due to the complexities of maintenance. Despite the health challenges, they maintained an active lifestyle, engaging in choir singing, regular physical exercise, and active participation in the local Rotary club.

In the attempt to address Alzheimer's, Mrs. CC2 had tried Alzheimer retardation medication, but unacceptable side effects such as depressive feelings, loss of

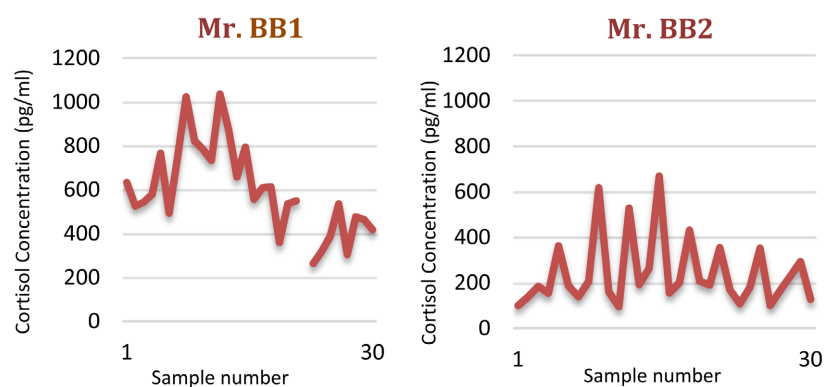


Figure 2. Cortisol concentration (pg/ml) each sample day for Mr. BB1 and Mr. BB2.

appetite, weight, and drive occurred and its use was discontinued. Mr. CC1 expressed a preference for non-pharmacological approaches and enthusiastically participated in the project.

Mrs. CC2 was involved with music every day. She often sat down at the piano to play and participated in two different choirs. Mrs. CC2 participated in gymnastic groups with music and dance several times a week, crediting physical exercise for its beneficial impact. She developed a sense of suspicion concerning Mr. CC1, fearing that he might entertain intentions of relocating her to an institution.

Mr. CC1 expressed concern about the noticeable changes in Mrs. CC2, and while relieved that she could still manage independently he remained worried. She had cognitive symptoms involving episodic and semantic memory functions. There were also problems with time planning. Mr. CC1 still had a substantial workload so Mrs. CC2 had to manage on her own during the day. Friends were helping her get to her activities. Mr. CC1 reminded her about activities but this did not always work. Technical aids had been tried such as telephone signals but that did not function for her. What Mr. CC1 found particularly distressing was that Mrs. CC2 did not eat adequately because she lacked appetite. She had lost weight.

Mr. CC1 and Mrs. CC2, participated in the program for eight weeks, incorporating music into their routine three times daily. Choosing to listen together during meals and even singing together, the couple demonstrated a notable interest in the therapeutic benefits of music. As an addition to their intervention experience, they took on a four-day choir trip.

A chaotic period arose in the middle of the intervention, leading to difficulties in remembering commitments and maintaining personal belongings in order. Mrs. CC2 exhibited less inhibition than usual. Fortunately, this phase subsided, prompting the couple to seek support for their primary physician.

In the case of Mrs. CC2, there were no clear cortisol changes in morning cortisol levels throughout the intervention period. On the other hand, in caregiver Mr. CC1, there was a trend toward a gradual decrease in morning cortisol levels during the intervention period (**Figure 3**).

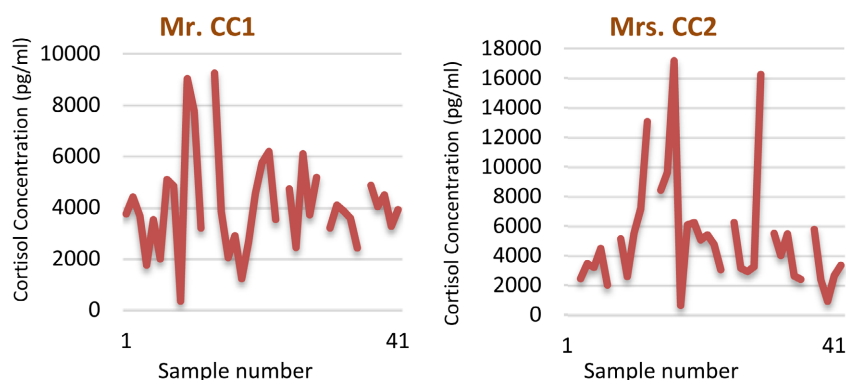


Figure 3. Cortisol concentration (pg/ml) each sample day for Mr. and Mrs. CC.

Mr. DD1 (FCG) and Mrs. DD2 (PWD)

Mrs. DD2 was a 71-year-old woman who received her diagnosis of frontal lobe dementia 17 months prior to the intervention. She was urgently hospitalized after experiencing a subarachnoidal hemorrhage following a fall at home. Subsequent cognitive assessments revealed deficits in both executive function and memory. As a result of these findings, Mrs. DD was referred to the memory center for further evaluation.

Mrs. DD2 and her husband, Mr. DD1, had been residing in a spacious villa since the 1980s. Though she was a dedicated book enthusiast, her ability to engage in this pastime was hindered during the intervention period, primarily due to diminished visual capabilities. Attempting to go for walks became progressively challenging for her, not only due to knee pain but also because of a growing sense of disorientation.

Mrs. DD2 had limited awareness of her diagnosis, firmly believing that she was not ill at all. This perspective often led to frequent disagreements with Mr. DD1. Previously she enjoyed gardening, but now initiating such activities became challenging for her. She predominantly stayed seated in a chair at home. Mrs. DD2 was very suspicious and questioned the presence of visitors and conveyed a sense of feeling threatened. During conversations, she frequently repeated herself and repeated the same questions. She expressed difficulty maintaining focus and was prone to bouts of anger.

Mr. DD1 felt powerless and the music project sparked some hope for him. Managing the challenging situation with Mrs. DD2, he constantly kept a watchful eye on her. On several occasions, she went out for a walk and could not find her way back home. When Mrs. DD2 had appointments with a physician or physiotherapist it fell to Mr. DD1 to provide motivation and transportation. On these occasions, Mrs. DD2 lost her temper, causing distress. Mr. DD1 perceived his role to be a personal assistant for her. All of this resulted in arguments and repetitions; sometimes he also lost his temper.

The couple was interested in old popular dance music and pop music like ABBA. They selected a number of CD recordings they planned on listening to. They chose to listen to music all day long and to specifically select music at meals.

On the follow up occasion after the intervention Mrs. DD2 felt better. She was happy about the visit. She was again doing gardening and happily showed what she had been doing and tried to explain what had been done. She was welcoming and helped serving coffee. It was a pronounced change for the better. Mr. DD1 was also happier and seemed to feel well. The couple's shared enjoyment of dance pop music and ABBA was evident, as they incorporated daily music sessions. Mr. DD1 had downloaded music from Spotify, enhancing their auditory experience.

In both DD1 and DD2, there was a clear tendency for cortisol concentration to decrease in the morning during the intervention period (**Figure 4**). Both DD1 and DD2 volunteered to sample saliva during weekends.

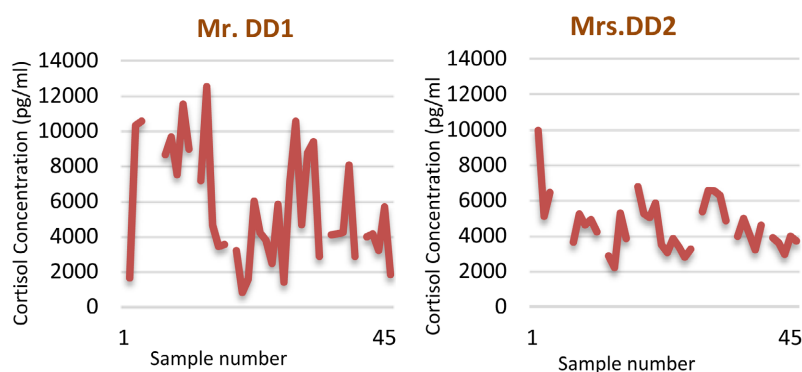


Figure 4. Cortisol concentration (pg/ml) each sample day for Mr. and Mrs. DD.

Comments for all dyads

Emotional state at start: All four PWD exhibited classical symptoms that underscored the challenges faced by the family caregivers. Cognitive issues, such as navigating outdoor spaces and recalling appointments, were evident. Encouraging them to participate in daily routines proved demanding, requiring proactive efforts from caregivers. Alack of illness awareness contributed to potential suspicion and emotional strain between PWD and their caregivers.

Somatic state: During the study period, two of the PWD (AA2 and CC2) experienced somatic complications. These somatic complications were linked to changes in behavior and disturbed the progress of the music intervention.

Music intervention: The four dyads used the music program in very different ways. One couple, composed of established choir singers (CC1 and CC2) and particularly the PWD participated very actively in choirs throughout the intervention. She was also stimulated to play the piano, and during the study period they participated in a short choir trip. All couples opted to share the experience of listening to music according to a daily schedule, typically three times a day. However, in one instance, the PWD showed less interest, prompting a researcher's home visit to boost attention to the music program.

Changes attributable to the music intervention: Two of the PWD (BB2 and DD2) exhibited clear improvement in sociability, positively affecting their caregivers. In the AA dyad, no clear benefits were observed for either the PWD or the family caregiver. This might be explained by the PWD's of lack of interest in the music intervention (despite efforts from the researchers) and somatic complications with behavioural consequences. In the CC dyad there were somatic complications in the PWD, but the caregiver experienced beneficial effects from the intervention. In the two most successful dyads, it was evident that the music listening evoked pleasant shared emotions, fostering cooperation and social well-being.

4. Discussion

The statistical findings have been reported elsewhere. To summarize, there was a statistically significant difference in the development of morning saliva cortisol

concentration during the study period between FCG in the music intervention and the control group [12]. However, no such difference was noted between the corresponding PWD groups.

Individual statistical analyses showed that approximately one-fourth of the participants in the music intervention had a progressively decreased morning cortisol level during the intervention. Notably, caregivers exhibited a slightly higher proportion of this effect compared to PWD, as reported [7]. Thus, a small number of PWD did indeed show a significantly reduced morning cortisol levels, but the sample size was insufficient to establish a significant group difference. Behavioral joint ratings for the dyads indicated that the evolution of the home situation during the music intervention period developed significantly differently, favoring the intervention group.

In conclusion, it appears that the caregiver group may have benefited more distinctly from the music intervention than the PWD although some individuals in the PWD also showed reduced morning cortisol levels.

The individual examples described in this report shed light on mechanisms operating on the individual level. Of particular interest are the morning cortisol levels, given the challenges described by couples. Due to dementia symptoms, the PWD often lacks motivation to start morning activities. Before the music intervention started, the morning routines were described as problematic and often led to angry and irritable moods.

The cases represent three groups of dyads observed. First, there are *success stories* (BB and DD) where both PWD and FCG lowered their morning saliva cortisol levels. Second, there are *failure* instances (AA), where the music intervention showed no documented effect. These failures, are evident in both the PWD and the caregiver. Last, there are *mixed* (CC) stories, where there seemed to be benefit for the FCG but not for the PWD.

The case descriptions illustrate that prevalence of illnesses is high among PWD and highlighting the potential impact of dramatic fluctuations that somatic illness can induce. Such illnesses may disturb the intervention process. Both AA and CC serve as illustrations of this phenomenon. A longer intervention period could have been beneficial in these cases.

The significance of tailoring music choices to individual preferences is evident in the presented cases. Interestingly, there are instances where a collaborative selection of music genre provides benefit in the intervention, as observed in cases BB, CC, and DD. However, it is equally crucial to acknowledge and respect differences within dyads, exemplified by Dyad AA's contrasting preferences for Chopin and Rod Stewart.

When the PWD and FCG listen jointly and explore their diverse music preferences, it can foster careful and enhance mutual understanding. It would have been interesting to follow the dyad AA for a longer period—the intervention was disturbed by PWD's illness (a cold). Dyad AA, despite being disrupted by the PWD's illness, serves as a compelling example. Participants should have access to a diverse music menu, which facilitates choices. This principle aligns with

findings in various contexts where music is employed in treatments, ranging from post-stroke rehabilitation [14] to surgical procedures [15].

A more in-depth discussion of the significance of the saliva cortisol concentration changes as indicators of reduced stress levels in these dyads has been presented [7] [16] [17]. Notably, the difference between the control group's and the intervention's morning saliva cortisol among the FCG was 1.5 pg/ml (2.0 versus 3.5) at the end of the intervention period, following adjustment for starting level. This magnitude of difference is noteworthy and underscores the potential impact of the music intervention. It is essential to interpret this difference as evidence of reduced stress on the condition that the participants had retained the ability to regulate their cortisol level. Our data did not indicate any evidence of "cortisol exhaustion" during the intervention. However, in the PWD group, there was a reduced variation coefficient in morning cortisol for the intervention group. This observation might be attributed to physiological rigidity.

Chu *et al.* [18] reported results from a randomized relatively large study examining the effects of music therapy twice a week for six weeks. One of the measures was midday saliva cortisol before and three times during the course. Interestingly, their study did not show any significant cortisol effects. Although, the number of assessments was much smaller, the outcomes align with our findings. It is important to note that while Chu's study focused on music therapy sessions twice a week for six weeks, our study centered around recorded music without formal music therapy and featured a much higher frequency of sessions. It is worth mentioning that caregivers were not included in the Chu study.

Brown *et al.* [19] followed the effects of a mindfulness-based randomized stress-reduction program for home caregivers of persons with dementia. The eight-week program involved measuring saliva cortisol levels at six points throughout the day, during each of the three study phases (pre- and post intervention as well as at a three-month follow-up). No significant cortisol differences were observed between the study groups. To our knowledge, this is the only previous intervention study of home caregivers for persons with dementia using saliva cortisol as an outcome measure. While it remains challenging to pinpoint the exact cause of the disparity in findings between the Brown [20] study and ours, potential factors could include variations in the study protocol or the nature of the interventions. Our intervention is non-verbal and involves both PWD and FCG. Our intervention does not require therapists, and allocates more time for the patient-caregiver dyad. It provides a more person-centered approach. The flexibility of recorded music enables the intervention encounters to take place at times that the dyads choose. However, we are not in a position to judge from this study whether music therapy or self-administered listening is to be preferred for these kinds of dyads.

As extensively discussed in the literature, caregivers often find themselves in challenging situations, and interventions aimed at reducing stress levels are highly valued. The cases described here affirm that joint music listening is an activity that has the potential of evoking shared memories, thereby enhancing

feelings of togetherness.

Although the music intervention seems beneficial for caregivers as a group, it is evident that it does not consistently work for everyone. Numerous studies highlight the highly individual nature of psychological and psychophysiological responses to music. For instance, a study of 38 younger adults, each selecting two music pieces, one of which they thought would have a calming and one of which they thought would be stimulating effect [20] has been published. Despite self-selection, the physiological responses of listening to these pieces without movements exhibited vastly different physiological responses. For instance, one subject experienced a 20 beats per minute increase in heart rate from the resting level when exposed to the “stimulating” piece, while the corresponding effect of the calming piece was a decrease of 20 beats per minute from the resting level. Several subjects showed no physiological effects at all. This highlights the substantial variation in sensitivity to musical input among individuals, even when they are actively involved in selecting music pieces themselves.

The generalizability of our findings may be limited due to the nature of qualitative case stories. Our study focused on cases, which may not be representative of broader populations or contexts. Therefore, caution should be exercised when applying our findings to other settings or populations.

Additionally, the scope of our study was bounded by the constraints of a small number of cases. While this allowed for in-depth exploration, it may have limited the breadth of our findings. Future research could expand upon our findings by conducting comparative case studies or employing mixed-methods approaches to capture a more comprehensive understanding.

Despite these limitations, our case study contributes valuable insights to the existing literature on music intervention for persons with dementia and their family caregivers.

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Conflicts of Interest

The authors declare no conflicts of interest regarding the publication of this paper.

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