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# Towards sustainable implementation of music in daily care of people with dementia and their spouses

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ABSTRACT

Primary caregivers (PCs) of people with dementia deal with stressful daily living, especially spouses whose care recipient is at home. Several programs have been developed to aid caregiving by providing musical strategies, yet successful sustainable implementation of music in the daily lives of the couples awaits further research and development. To promote this, in this pilot study we proposed a music therapy program that included 12 weekly sessions with the couple in their home environment. In addition, there were bi-weekly phone counseling sessions with the PC, to reflect on the joint sessions and to help implement music in daily life. Findings based on the description, analysis, and interpretation of two cases showed that the proposed program provided a strong foundation upon which the treatment could succeed; it relied on natural forces such as the use of songs, which can empower each of the spouses individually, as well as together as a couple; and it included elements of ongoing support that enabled preservation of the accomplishments that were achieved during the sessions. Future research is required to examine whether this program is appropriate for couples in other housing contexts, and in different stages of dementia.

## Introduction

Dementia and its rising prevalence[1] is extremely challenging, not only to the people affected, but also to their spouses, especially if they serve as primary caregivers (PC). In the US, 83 % of the help provided to older adults comes from family members, friends or other unpaid caregivers. Thirty four percent (34 %) of PCs are 65 or older, and 66 % live with the care recipient in the community (Alzheimer's Association, 2018). PCs have to attend to the person's health needs, assist with activities of daily living such as bathing and dressing, as well as multiple instrumental activities of daily living, such as paying bills and shopping (Riffin, Ven Ness, Wolff, & Fried, 2017). The long duration of illness is an added challenge and it can affect the PC's physical and mental health, social relationships, and well-being (Birkenhäger-Gillesse, Kollen, Zuidema, & Achterberg, 2018; Cox, 2013; McAuliffe, Ong, & Kinsella, 2018). A large burden is placed on spouses who must deal with the daily stress associated with caregiving, as well as with the realization that they are losing an important intimate relationship in their lives (Cox, 2013; McAuliffe et al., 2018). Studies on the impact or stress associated with caregiving by family members have also highlighted the vulnerability of spouses (Cox, 2013; Savundranayagam, Montgomery, & Kosloski, 2011). Therefore, it is crucial to provide support for people with dementia and their spouses.

Music therapy has been found to be an effective means to aid PCs (Hanser, Butterfield-Whitcomb, & Collins, 2011; Ray, Dassa, Maeir, Davis, & Ogunlade, 2016; Rio, 2018; Särkämö et al., 2013) and several programs were developed with the aim of providing musical strategies to aid PCs in their daily challenges. Due to the limited scope of this manuscript, programs for PCs in general that relate to children or other caregivers were excluded. To enable a focused review of the topic, our search of the literature included only relevant programs for people with dementia and their spouses. For instance, Park and Pringle-Specht (2009) guided PCs to pre-select individualized music for their spouses and they showed that listening to music reduced agitation among people with dementia at home. Hanser et al. (2011) taught PCs to use music to facilitate stress reduction and they showed that this treatment caused the couple's relaxation, comfort, and happiness to increase. Baker, Grocke, and Pachana (2012) trained PCs to use music-sharing

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[1] It is estimated that roughly 5% of the world's elderly population is affected by dementia. A figure of approximately 50 million people appears in the latest World Health Organization's report and is predicted to increase to 75 million in 2030 (World Health Organization, 2017).

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experiences and showed that this was beneficial to the spousal relationship, to satisfaction with caregiving, as well as to the PCs' well-being. Baker et al. (2019) also recently launched a large international three-arm parallel-group randomized controlled trial to determine whether caregiver-delivered music interventions improve caregivers' quality of life and well-being.

The aim of these programs was to find a cost-effective way to introduce music to caregivers by providing them with caregiver-administered music activities. In most cases, the guidance was provided by a music therapist in a single session and the music therapist neither attended the caregiver-administered sessions nor provided further support. As a result, the PCs encountered difficulties and required more support and guidance by the music therapist (e.g., Hanser et al., 2011). Since then, only one study was reported in which a music therapist directly conducted the sessions in the participants' homes (Melhuish, Grady, & Holland, 2019). Indeed, this study showed the importance of the home environment and the music therapist's continuous presence in improving the process and the sustainability of the music in daily life. However, it is clear that this direction awaits further research and development. As the need for services increases there is great potential for music therapists to provide home-based treatment (Hanser et al., 2011).

The proposed program in this pilot study was formed based on the clinical expertise and relevant research in music therapy with dementia of the first author (Dassa, 2018a, 2018b; Dassa & Blum, 2016). Following the experience of the second author regarding home-based music therapy with dementia, and in light of similar programs in the literature as described above, the research team consulted and discussed the best way to implement music.

We believed that in order to optimize the sustainable implementation of music in the daily lives of people with dementia and their spouse PCs, it was important to add the following guidelines to the existing models: (1) the treatment should focus on the couple and include the person with dementia as well as their spouse PC; (2) time should be allocated for the couple together but also for the PC individually, thus addressing the couple as an organic unit but also providing support and guidance to the PC; (3) treatment should be conducted by a music therapist in the couple's natural environment, namely, their home. Home based music therapy (HBMT) was conducted successfully with people with dementia (Schmid & Ostermann, 2010), but to a lesser extent with the attendance of the PCs. The home-based context exposes the music therapist to real-time situations, and can enable an in-depth understanding of the couple's strengths and difficulties. In the homes, the music therapist can come up with individually tailored ideas that can improve the daily life of the couple. Ultimately, such a program can delay nursing home admission, which is regarded as an important goal according to the Alzheimer's Association (2018).

The goal of the current pilot study was to present and examine a model that follows the above-mentioned guidelines. According to the model, the music therapist met with the couple at their home for 12 weekly sessions. In these sessions, music was used to help the couple communicate and enjoy by engaging in a joint musical activity. Also, according to the couple's needs, music was offered as a means to alleviate agitation or to promote active engagement in the case of refusal or apathy. The first meeting was an intake session where the music therapist gained important information about both spouses, their relationship, and their cultural and musical backgrounds. In subsequent sessions, the music therapist met with the couple for one hour each time. She brought small instruments that could potentially be used during the session, as well as a smartphone and an amplifier to search for and listen to music with. In addition to the weekly home-based sessions, the music therapist initiated 30-minute phone counseling sessions with the PC every other week. These sessions were aimed to guide and help the PC with ideas regarding the use of music in daily care. Four weeks after the final session, a follow-up phone call was conducted with the PC to document whether and how the couple managed and whether and how they used music in their daily lives.

The first step to examining this model is the current pilot study, where we focused on the description of two cases and analyzed the musical events (primarily the songs chosen by the couple throughout the sessions) and the verbal communications during the sessions. This enabled us to gain insight into the model's advantages and shortcomings in implementing music in the couple's daily life. The follow-up phone calls enabled us to assess the sustainability of the model. The research questions that we addressed were:

1 Does the home-based model for people with dementia and their spouse PCs improve the sustainability of music in daily life? If so – how?
2 What are the recommendations for further implementation of the model?

## Method

Qualitative case-study research design was used in this pilot study (Creswell, 2007). Being a case study, information was gathered from a limited number of cases, although much attention was given to each of the cases by applying multiple sources of information to describe and analyze the cases (audio recordings, documented conversations, reports). Being a pilot study, we knew that there were no prior cases in the literature to which we could compare our descriptions and analyses, and an entirely open approach was adopted. We knew, however, from our prior unreported work with spouses at home, that much of the content of the sessions centered around songs that the couple chose, sang, and referred to, sometimes repeatedly, throughout the sessions.

This research was approved by the Bar-Ilan University Music Department's Ethics Committee (Approval no. E.MUS.2018-7). PCs signed an informed consent form for them and their spouses to participate and to include session content in this study. Names have been replaced by pseudonyms, and all other personal information was kept confidential.

### *Participants*

Participants were recruited through specific organizations in Israel that provide home services for people with dementia. A brochure was drafted and sent to potential participants including explanation regarding the suggested program and the following inclusion criteria: 1) One of the spouses was diagnosed with dementia and the other resided at home, serving as PC; 2) The PC spouse felt that she/he encountered difficulties in her/his role and was willing to participate in this research; 3) The couple had not received music therapy in the past; 4) Both spouses were fluent in either Hebrew or English.

The first two couples that enrolled and met the above criteria participated in the pilot study:

Saul and Fanny[2] : Saul, a retired accounting manager, age 85, was diagnosed with Alzheimer's disease eighteen months prior to the study and he was living with his wife Fanny, a retired sales clerk, age 75. The couple had no paid caregiver aid and Saul struggled with restlessness on a daily basis, and a tendency for depression. Fanny rarely left Saul unattended and devoted herself to his care. The couple had three children and several grandchildren and great-grandchildren, who visited often.

Raphael and Anna: Raphael, a retired businessman, age 67, was diagnosed with Alzheimer's disease five years prior to the study and he lived with his wife Anna, a retired teacher, age 62. There was a paid caregiver residing with the couple at home, since Raphael required constant supervision and assistance with many basic activities. During the day, Anna was busy with hobbies and home maintenance. The couple had four children and several grandchildren, who visited often.

[2] Names have been replaced by pseudonyms, and all other personal information was kept confidential.

*Researchers' stance*

Our research team included three qualified experienced music therapists: The first author has expertise as a music therapist and a supervisor in the field of music therapy and dementia; The second author has experience working at home with people with dementia, and conducted the intervention; and the third author is a supervisor with expertise in developing models in music therapy. As a team we all analyzed the data and discussed the development of this program.

*Tools*

*Documentation of sessions*

All sessions were audiotaped, and a summary of each meeting was written by the music therapist who listened to the recording immediately after each session, documenting both verbal and musical content, particularly, a detailed description of the songs chosen in the sessions.

*Documentation of phone counseling sessions*

All phone counseling sessions with the PC were audiotaped and a summary was written throughout the conversation. At the end of each such session, the PC was asked the following questions, which were documented on tape as well: 1) Did you use music during daily activities throughout the week, and if so, how was it? If no music was used, why not? 2) Did you feel that the music affected you, your spouse, or your relationship? If so, how?

*Documentation of follow-up phone session*

The follow-up phone session was audiotaped and later on transcribed by the music therapist. The same questions that were asked at the end the counseling sessions were asked in regard to the previous month.

*Researcher's log*

The music therapist who conducted the sessions (the second author) kept a reflective journal documenting ideas, feelings, and thoughts that emerged throughout the treatment in order to learn and maintain transparency during the research process. This material was used and discussed in supervision meetings with the researcher (the first author) throughout the intervention period. The material also served as data for analysis.

*Procedure*

The couples who participated in this study were contacted by phone prior to the study. The music therapist explained the procedure, the frequency of the meetings, the duration of the meetings, and what was expected of both the PC and their spouse. It was explained that the treatment would be documented for research purposes and that an informed consent form would be signed during the first session. The sessions then took place every week at the same time at the couple's home.

The sessions were not pre-planned but rather adapted to the couple's mood and desires in the here-and-now. The music therapist encouraged the couple to engage in singing, listening to music, dancing or playing percussion instruments, and matched her musical interventions according to the couple's preferences and reactions at each session. Favorite songs were collected during the sessions and the music therapist used them to elicit reactions and encourage participation. Most songs were sung together while the therapist used guitar accompaniment, and the couple sometimes chose to join the singing while playing small percussion instruments. For some of the songs the therapist used YouTube when it was meaningful for the couple to hear the original performance or as a background for a dancing activity.

As described above, the first session served as an intake session and the subsequent sessions were then dedicated to treating the person with dementia and the spouse. Phone counseling sessions lasting 30 min were conducted with the PC every two weeks and an additional follow-up phone call took place a month after the treatment ended. All sessions were documented for further analysis.

*Data analysis*

Data for analysis included all documented material for two cases. For each couple, the data included: 12 music therapy meeting summaries (verbal and musical material); 6 phone counseling conversation summaries with the spouse; one follow-up phone session summary with the spouse, and reflections, thoughts and interpretations from the researcher's log. Each couple's documented material included approximately 70 pages.

Following Creswell's (2007) proposed method for analyzing case studies, three phases were implemented: (1) *Description*: In this phase the cases were organized and described in chronological sequence. Description was based on listening repeatedly to the home sessions, the phone counseling sessions including the follow-up phone-call session, and the researcher's log; (2) *Analysis*: In this phase we focused on a few key issues (themes) to understand the complexity of the cases. Since much of the case material revolved around songs that the couple chose, sang, and referred to, the analysis referred primarily to the songs. To strengthen the analysis, vignettes from the cases were used to illustrate the categories; (3) *Interpretation*: In this phase we provided a broad interpretation of what we learned from the cases and the themes that evolved from them. This phase is reported in the discussion.

## Findings

*Description*

The descriptions of each of the cases, Saul and Fanny and then Raphael and Anna, are as follows. Each description includes background information, an overview regarding the couples' reaction to the music therapy sessions, and the way each couple integrated music in their daily life.

*Case no. 1 – Saul and Fanny*

Saul, age 85, was confined to his home for the eighteen months since he was diagnosed with Alzheimer's. Saul refused to participate in any community activities and exhibited signs of restlessness on a daily basis. He found it hard to concentrate on any given task at home, wandered during the day from the living room to his bed claiming that he was nervous and had to rest, woke up frequently throughout the night and demanded constant attention. Saul became anxious when his spouse Fanny, age 75, was not at home with him. She rarely left him alone and devoted herself to his care. This posed a massive challenge, since she seldom had time for herself, and mostly depended on her children or grandchildren for help when she wanted to go out for social activities. The couple spent their days mostly at home and went out for short walks around the neighborhood, and some simple errands nearby. They had a daily routine where Saul spent time filling out adult coloring books, an activity that helped him to relax, watching television or staying in bed, which became increasingly more frequent, while Fanny spent her time cooking, cleaning and mostly attending to his needs.

Because Saul avoided meeting new people, Fanny was very concerned that he would refuse to cooperate with the idea of music therapy sessions. Therefore, she told him that the meetings were for herself and if he wanted, he could join in. However, to her surprise, the music therapist helped to motivate Saul to get out of bed and become more active. In most sessions, Saul waited in the living room for the session to begin and greeted the music therapist and reported about his activities that week and about his current mood. Since the sessions took place at home, Saul was able to choose whether to participate, and he would occasionally retreat to rest in his room, and re-joined the session after a few minutes of rest. This allowed Fanny to have some time for herself and to

share with the therapist the difficulties she was experiencing in her role as a caregiver.

The most dominant musical activity during the sessions was singing. Saul was born in North Africa and immigrated to Israel as a teenager. He mostly recalled songs from his native country. These songs had a fast tempo and rhythmic nature, and he would often add some rhythmic accompaniment to his singing using a percussion instrument, and also enjoyed movement and dancing. Fanny would join in the singing and dancing and helped him to recall words and songs, and to translate his songs to Hebrew. In addition, Saul loved Israeli folk songs from the 1960s that brought back significant memories of his teenage years, and his military service. In his stories he also addressed his role as a father and grandfather. Fanny helped to reminisce by asking him questions and sharing her own memories. At times when Saul retreated to rest, Fanny continued to sing, choosing her own favorite songs. Fanny was born in Israel and memories from her childhood and songs in her parents' mother tongue was very sentimental to her. She also liked quiet slow tempo Israeli popular songs from the 1970s. These quiet songs and lullabies allowed her to take some time for herself.

During the sessions, discussions regarding difficulties in daily care emerged. Fanny said that the main difficulty was to cope with Saul's passivity and refusal to get out of bed and participate in any activity. She would often persuade him to go out for a walk, sit with her, talk or play. Fanny felt that there were times when Saul seemed depressed and this caused her great distress. The music therapy sessions provided a joint enjoyable activity. The therapist chose from Saul's repertoire songs with a rhythmic nature to encourage him to participate and indeed, he participated actively, dancing and playing the drum. Following Saul's active participation during the sessions, the therapist suggested incorporating his favorite rhythmic songs during the day as well, and she prepared a booklet containing their songs to be used throughout the week.

During counseling phone calls with Fanny, it became apparent that implementation of music was becoming increasingly more frequent and that their situation was improving. Fanny reported singing to help Saul calm down when he was distressed. She also used the CD with their favorite music that the therapist prepared for them. Fanny reported that Saul spent less time in bed and resumed his drawing activity. He was more willing to go out and Fanny used rhythmic singing, which helped to motivate him and even extended the duration of their walks. In the follow-up phone call, Fanny reported that Saul was hospitalized. He had lost his balance while getting up, and fell. Even though the time in the hospital was difficult for both of them, Fanny reported using music to help gain Saul's cooperation with the doctors.

*Case no. 2 – Raphael and Anna*

Raphael, 67, had Alzheimer's disease for the past five years. His lack of orientation and poor cognitive condition required close supervision and assistance in all daily activities. He received 24/7 care from Bernard, a paid caregiver who resided with the couple at home. Anna, Raphael's spouse, was 62 years old. She kept busy with her hobbies and home maintenance, and thanks to Bernard's presence, she went out almost every day for several hours. Raphael refused to go out and participate in any social activities. He spent most of his time at home and only went out occasionally for a walk around the neighborhood with Bernard. Anna reported that Raphael experienced difficulties chewing and swallowing food and needed constant supervision and care while eating. The music therapist had witnessed the arguments regarding this difficulty when the session was immediately after mealtimes. Fanny reported that Raphael became agitated when too many people came to their apartment and that he was constantly anxious about his health. He frequently stated something was wrong with his health although no symptoms were apparent, and asked to be examined by a doctor. The couple had four children and grandchildren who came to visit regularly and helped with errands. They also spent time with them almost every weekend.

Anna joined all the music therapy sessions, and once, Bernard the paid caregiver joined the musical activity. Anna was afraid that Raphael would not cooperate. During the initial sessions, Raphael asked a lot of questions about the various percussion instruments the music therapist had brought with her and at times the therapist felt he was confused. Later on, he adapted to the structured session format, and cooperated willingly.

The most dominant musical activity was singing. Raphael was born in North Africa and immigrated to Israel as a young child. He mostly remembered religious songs (*piyyutim*) from his parents' home on the Sabbath. Anna was born in Israel and also grew up in an orthodox family. She was familiar with the same religious songs. These songs had a syncopated rhythmic nature, all written in a harmonic minor scale and mostly in a form of call and response. When listening to these songs, Raphael would add rhythmic accompaniment using the drum and sometimes even initiated movement and dance. Anna helped Raphael follow the lyrics and joined the singing and movement. The therapist prepared a booklet with the *piyyutim* lyrics for the couple to use during the week.

Difficulties between the couple emerged during the sessions. Anna found it very hard to cope with Raphael's unfocused line of thought. Raphael would jump from topic to topic and it was hard to follow him. Anna was mostly impatient with this, tried to correct Raphael, or stop him from talking. This difficulty created a great deal of tension between Raphael and Anna. Anna reported how exhausted she was and she expressed her difficulty in coping with Raphael's cognitive decline. Singing the *piyyutim* served as a regulator, and it helped Raphael focus and stop his repetitive talking. The musical activity allowed them to experience shared moments of singing and to reminisce about their time as a young couple. They danced together during some sessions, both smiling and laughing.

The songs evoked memories, some of which were good, and others - traumatic, such as memories from Raphael's military service. He participated in a war and during the sessions he frequently recounted the terrible sound of missiles, and the difficult sights of wounded soldiers on both sides. Therefore, an important part of each session was dedicated to documenting the stories he recalled following the singing. This enabled Raphael to gain a sense of validation for his feelings, that is, someone who found his stories important, listened to them, and wrote them down. This act of documentation seemed to have a good effect on Raphael and on Anna. He seemed calmer after documenting, and she reported that this enabled her to better meet Raphael's needs.

In sum, music became an integral part of Anna and Raphael's daily routine. Anna used music several times a day to stimulate Raphael and improve his mood. Sometimes he invited her to dance when she played his favorite music and sometimes Bernard and other visiting family members joined in. Music helped Anna to cope with Raphael's repetitive stories. Instead of trying to stop him from telling them, she listened and used music to navigate him into singing. Raphael's stories gained an important place at home, and instead of diminishing them, Anna used the documented material to calm him down and emphasized their importance.

*Analysis*

Because we found that music making, especially singing songs and listening to them were central in the cases, we based the analysis on the songs that appeared in the sessions and the reports of singing that were made during the phone counseling sessions. To do this, we drafted a table that included the songs that appeared in each session, and we analyzed each song separately. The table displays the song names, the response of the person with dementia to the song, the PC's response to the song, the couple's response to the song, and practical uses of the song that the couple reported beyond the sessions. As a result of the information in these rubrics, we defined the song's role in the treatment. Thus, twelve tables were drafted for each of the cases, all focusing on the

songs' roles during and after the sessions (see Table 1, an example of one such table).

By perusing these tables, we saw how powerful and effective the songs were. We found recurring roles for the songs that can be formulated into three main themes: (1) Singing helped the person with dementia to revive forgotten roles; (2) Singing assisted the spouse in her role as PC; and (3) Singing improved the couple's relationship. We now elaborate on each role and provide short vignettes from the sessions to explain these roles and their importance.

*Role*

1 Reviving forgotten roles

Songs evoked memories and helped both Saul and Raphael to revive forgotten roles as husbands, fathers, and grandfathers. Singing brought

**Table 1**
An analysis of the songs in Saul and Fanny's 4th session and Fanny's subsequent phone counseling session.

| Session no. | Name of song | Saul's response | Fanny's response | Couple's response | Uses in daily life | The song's role |
|---|---|---|---|---|---|---|
| 4 | The 'Finjan song'. An Israeli folk song written in 1947. It is rhythmic and is used frequently as a campfire song. | Sings, complains he cannot recall the words like he used to. Emphasizes that he knew all the popular Israeli songs when he came to Israel as a teenager. | Sings, and reminds Saul the name of the singer that sang the song in the 60's. | Reminisce about the past when they used to listen to this song. | The couple sang the song several times during the week. | - Engages in joint singing activity<br>- Promotes reminiscence of shared memories<br>- Strengthens Saul's sense of identity by emphasizing his knowledge in all the Israeli songs as a teenager. |
| | A song in Saul's native language referring to the traditional wedding ceremony. The music is slow in pace and ceremonial in nature. | Sings and accompanies himself on the drum. Saul translates the lyrics to Hebrew and explains when it was sung. | Laughs and adds that at their wedding there was someone playing the accordion. | Memories of their wedding evoke laughter and reminds them of their children, when they were young. | | - Engages in singing and playing activity<br>- Promotes shared memories from a significant event as a couple – their marriage and their parenthood. |
| | Songs from Israeli television children's programs from the 70's-80 s. | Recalls the theme songs from the TV shows and sings enthusiastically. | Sings with him and plays the drum.<br><br>Fanny emphasizes how Saul attended to the kids, and how also today he has a close relationship with his grandchildren. | Sing together and reminisce about their life as parents with young children, their daily routine at the time, and how devoted Saul was to the children. | | - Engages in joint singing activity<br>- Promotes shared memories as a couple<br>- Strengthens Saul's role as a devoted father. |
| | A lullaby in Fanny's parents' Jewish traditional language | | Talking about their kids, Fanny recalls that she used to sing this song to her kids before bedtime. A song her grandmother used to sing to her.<br><br>She adds that Saul used to sing to them in his own native language. | | | - The PC gained a place to express herself and enjoy the activity of singing.<br>- Strengthens Saul's role as a devoted father. |
| | Jewish *piyyut*. | Recalls memories of their traditional way of life and how Fanny's father sang in synagogue. | | Share memories from Fanny's cultural tradition and family. | At the end of the session the therapist suggests collecting their stories. Although Saul initially dismisses this idea, he later brings it up. | - Engages in joint singing and playing activity;<br>- Provides a place for the PC and her cultural tradition.<br>- Calms Saul down during the week. |
| | A Jewish liturgical poem usually sung during religious services. | He also sings and accompanies himself on the drum and then asks Fanny to tell a story about her grandfather. | | | Saul reports singing this during the week, and it helps to relax him. | |
| **Fanny – 2nd phone counseling session** | | | | | | |
| | | | | | Reports listening to songs during the week to encourage activity. | Songs helped to encourage activity and facilitate cooperation. |

*Note*: Five songs appeared in this session and the rightmost column shows that they had several roles, such as evoking memories, promoting joint activity, and strengthening the cultural identities of both partners. Reports at the beginning of the session and in the subsequent counseling session indicated that the songs were used in between sessions as well.

their strengths to life and allowed them to express a more active partnership. Saul relived his role as the amusing husband, over-dramatically singing the national anthem during a session, and making Fanny laugh lovingly. Raphael added dance movements to his singing and invited Anna to join him. In these moments, Saul and Raphael both behaved like the husbands they used to be during their life. These roles had been pushed aside because of dementia and were relived during the music therapy sessions.

Singing also evoked shared memories, which included stories of how the spouses cared for each other. Here are two examples from the sessions' summary and audio recordings:

*After listening to the song "Jerusalem of Gold", the lyrics of the song reminded Saul of their travels abroad and he recalled a specific trip that they enjoyed very much. He reminded Fanny how afraid she was when she had to get on a cable car (because of her fear of heights) and how he supported and calmed her down (session no. 10).*

*The piyyut "Aufa Eshkona" reminded Raphael of his military service and how caring he was to Anna then. He recalled one time when he returned from his service with his military helmet full of delicious cherries for Anna. Anna remembered this, too: "Wherever he went, if they got any goods, he always brought some for me". Raphael described at length another instance when he asked his commander for special leave to visit Anna when she was pregnant. When he eventually got the approval to leave, he hitchhiked all night across the country, and arrived in the morning to Anna's surprise (session no.7).*

2 Assisting the PC

Songs served as a means by which PCs could deal with daily challenges with their spouses. To some extent, songs became an additional caregiving tool. An example of this was when Anna used songs before mealtimes, an idea she got from the music therapy sessions. Mealtimes were very stressful because Raphael resisted them and became anxious and stressed. Anna reported that singing before mealtimes helped to reduce the stress and anxiety for both of them. Another example was when Fanny used to sing during the day and sometimes at night to calm down Saul when he became restless. Fanny used the guidance she got in the music therapy sessions and sang some of Saul's chosen songs. This helped to calm him and reduce restlessness, but also facilitated his cooperation at critical moments. This technique was used by Fanny even after the sessions were over, as we can see in the following vignette:

*Shortly after the sessions were over, Fanny contacted the therapist and told her that Saul was hospitalized due to a head injury. Naturally, this caused Saul to be anxious and restless, and he refused to be examined by the doctor. At one point, when nothing helped, Fanny asked everyone to leave the room, and she began to sing the songs they sang in music therapy. After some time, Saul joined. He calmed down, started to smile, and eventually agreed to be treated by the medical staff (phone call post intervention).*

3 Improving the couple's relationship

Singing was a meaningful joint activity, distracting the couples from their daily frustrations. In these moments during the sessions, Saul was once again the funny and entertaining husband; Raphael was once again the loving husband. Singing together highlighted elements from their relationship as a couple when they were equal partners, allowing a respite from the caregiver-care-recipient relationship. Songs brought them laughter and enjoyment, and for a few moments the couple could enjoy each other. The following vignette from the session's summary and audio recording demonstrated the shift from Anna's role as a frustrated and annoyed caregiver, to a moment of warmth and intimacy between the couple.

*Raphael opened the session with a flood of traumatic memories from his military service. Among them, he repeated stories about eating, which seemed to annoy Anna. "Stories about food are not interesting," she told him, trying to stop his story. "It's enough that we have eating problems," she explained. The couple started arguing: Raphael wanted to continue and Anna asked to move on to another topic. The therapist suggested they sing a piyyut that Anna favored ('beautiful and innocent'). The couple began to sing with the therapist accompanying them on the guitar. Raphael added a rhythmic pattern on the drum. The piyyut evoked memories from their youth. The therapist then suggested they listen to a recording of the 'piyyut'. She prompted Anna to get up and invite Raphael to dance with her. Raphael's smile filled his entire face. He pinched Anna's cheek affectionately, which made her laugh as well. Anna encouraged Raphael to raise his legs, move his hands. Raphael began to twirl Anna around. They laughed and enjoyed together* (Raphael and Anna, session no. 10).

## Discussion

This pilot study aimed to explore whether a home-based model for people with dementia and their spouse PCs could promote the sustainability of music in their daily lives and if so – how? This question is raised in light of research and clinical literature that points at the benefits of music for people with dementia and their PCs, yet still poses questions regarding the most effective way to implement music in their daily lives (e.g., Baker et al., 2012; Hanser et al., 2011; Melhuish et al., 2019). In the present study we introduced a program that was aimed at improving the longevity of music in the daily lives of people with dementia and their PCs.

The results of this pilot study, which documented the proposed program with two couples, are quite encouraging. Based on the couples' feedback presented in the findings, the processes that took place for both couples were clearly very meaningful and important for their daily functioning. The music therapy sessions helped to revive forgotten roles of the person with dementia, promote the capabilities of the PC, and to improve the couples' relationships. It was also evident that some of the meaningful events occurred between sessions and after the treatment ended, which gives encouraging indications as to the program's self-sustainability.

The findings highlight several aspects of the proposed program that seem to be essential for ensuring its success. First, the program provides *strong foundations* for a solid therapeutic process to take place. Second, it relies on *natural forces* that the couple already possesses, which the music therapist then empowers. Finally, the program includes *ongoing support* for the couple so that they can preserve the accomplishments achieved during the sessions. Let us elaborate on each of these aspects.

*Strong foundations.* The program is based on key elements that helped to create strong foundations for the therapy process to take place and also to incorporate the use of music in the couple's daily life. The program is based on a substantial amount of sessions - 12 sessions and six additional phone counseling sessions, not on single sessions or workshops, thus enabling a continuous process to evolve and subsequently forming a solid structure. Sessions were led by a professional music therapist experienced in working with people with dementia in a home setting (the second author), as recommended by other studies (e.g., Hanser et al., 2011). Music therapists are aware of the intricate complexities of dementia and are equipped with knowledge and experience about music and its abilities to assist with dementia.

Strong foundations are also formed by the fact that the sessions address the couple as a unit. This idea is supported by recent research on the concept of 'couplehood in dementia' (Molyneaux et al., 2012), which demonstrates the advantages of including both members in the treatment, as opposed to focusing on the person with dementia or the PC alone (Moon & Adams, 2013). For example, Ingersoll-Dayton, Spencer, Campbell, and Kurokowa (2016)) implemented life review techniques with couples, encouraging them to reminisce together, and showed how this improved their communication and highlighted their shared identity as a couple.

Another factor that enhanced the strong foundations of the proposed program is that sessions took place in the couples' homes, where the couples could feel at ease and behave naturally, sing and dance, as occurred with the participants in this study. In both cases described in

this study, the person with dementia refused to leave home for any social activities, so that home was their base and foundation and it was essential to reach out and to allow the music therapy sessions to take place there. In both cases, the fact that the sessions took place at home enabled the therapist to witness the couples' daily life including their difficulties, and to then suggest suitable interventions (e.g., using music to promote eating during mealtimes or to promote sleeping at night). Had the treatment not taken place at home, these topics might not have come to the therapist's awareness.

Furthermore, the home environment enhances the 'couplehood in dementia' concept because the home is where the couple spends most of their time, and where they experienced most of their lives together. This idea of working with couples at home is supported by recent studies that showed how it encouraged positive interactions to develop (Melhuish et al., 2019; Baird & Thompson, 2018). Working with couples and working at home not only serve as building blocks for a strong foundation, but also as natural forces that enable positive processes to occur.

*Natural forces.* It is the therapist's responsibility to identify the forces that the couple already possess naturally and then to empower them. In the described cases songs were an accessible natural force for both couples, and this was empowered by singing songs and listening to recorded songs. These were the vehicles upon which much of the clinical development occurred. We could see how songs helped to *revive forgotten roles* and how it *improved the couple's relationship*. The couples in this study enjoyed precious moments together, they sang and danced together, and relived shared memories as a couple. These memories helped to revive forgotten roles. The importance of roles for the person with dementia is documented in a study exploring perceptions of self-identity in people with dementia. The family role was found to be the most important role-identity, with spousal, parental and grandparental roles having the highest likelihood of being designated most significant (Cohen-Mansfield, Parpura-Gill, & Golander, 2005).

Singing and reminiscing helped the couple to transcend their forced roles as caregiver and care-recipient and set aside the hardships of caring activities and concerns during these moments.

This phenomenon could be explained by the fact that songs provided a form of nonverbal communication bypassing the communication barriers that the couples might experience due to cognitive decline and language deterioration of the spouse with dementia (Baird & Thompson, 2018; Dassa, 2018b). Also, songs lead to reminiscing, thus creating paths to renewed memories and to the strong feelings associated with those memories (Osman, Tischler, & Schneider, 2016; Otera, Horike, & Saito, 2013). Finally, singing songs or listening to them is an enjoyable activity that can be done together (Chatterton, Baker, & Morgan, 2011; Rio, 2018), thus providing positive shared moments that might become rare due to the difficulties experienced by people with dementia and their spouses (Ingersoll-Dayton et al., 2016). Similar interactions between couples using singing can be seen in the qualitative and retrospective longitudinal case study by Baird and Thompson (2018), which documented precious moments between the caring husband and TC, a 77-year-old with dementia engaging in musical activity at home. Positive musical interactions between couples through songs were also documented in another case study following spouses who visited their partners with dementia in a long-term care facility setting (2018b, Dassa, 2018a).

Note that songs are affordable and accessible, and if prepared properly, they can be used by the couple in daily life, beyond the boundaries of the treatment and in the absence of the music therapist. Other such natural forces that can be developed through the treatment are the couples' partnership qualities, which may have manifested more in the past, and when revived can aid the couple also beyond the boundaries of the treatment. The present study shows how singing together revived precious moments of couplehood, and how these moments further empowered both partners.

*Ongoing support.* We believe that without ongoing support, the accomplishments of the treatment might remain within the boundaries of the sessions and fade away after the treatment ends. In the proposed program, attention was given to what happened between sessions by providing the PC with concrete tools to use throughout the week, and then through phone counseling sessions and a follow-up session, to see how things went.

The question of whether the proposed format, with 12 sessions, 6 phone counseling sessions, and one follow-up session, is enough to support a couple and to obtain self-sustainability should be examined in further research. In fact, with one of the couples in the study, we realized that continuous support is needed since they were struggling with the deteriorating health of the spouse with dementia. Consequently, we continued the sessions at a reduced frequency of once a month plus a phone counseling session every two weeks. Perhaps further tweaking of this program will point at adjustments that may be necessary with some or all of the participants.

To conclude, findings showed that *songs assisted the PCs*, and that the PCs indeed felt capable of using songs to help them deal with caregiving tasks more easily. This is not to be taken for granted. Using music by the PC independently is not always an easy and accessible task for partners who reside at home and deal with the challenges and burden of dementia. However, we believe that the strong foundations of this program (being at home, in a natural setting), the prolonged process during the sessions (providing time for issues and challenges to unfold), the practical guidance of the music therapist in real-time (allowing time to "practice" different uses of music) and the support after sessions enabled this to happen.

### *Study limitations*

We propose further suggestions for better implementation of the program, based on the findings of this study. First, keeping in mind that this was a pilot study and based on a small sample, we suggest testing this program with more couples so that it can be further refined and generalized. Such testing would clarify whether the elements proposed in the study are applicable in different contexts, or if there are other factors involved.

Second, it should be noted that this study was conducted in a specific country, with specific cultural and musical codes. This could lead to culture-specific ideas, which might be less appropriate or less relevant in other cultures and countries. For instance, in some cultures it may not be acceptable to conduct any sort of treatment at the patients' homes. In such a case, a different natural environment for the couple should be found, and adjustments to the program should be made. Another example is the use of songs as the primary medium of music in this program. In other cultures, songs might be considered problematic for different reasons and other musical mediums, such as improvisation or drumming, might be more appropriate and relevant for best results. This issue clearly requires further examination and research.

Third, we used a qualitative methodological framework based on description and interpretation. However, no quantitative measurements were taken before, during, or after the program to assess whether the well-being of the couples improved, whether dementia related symptoms improved, or whether the couples were satisfied or not. We recommend that in future research, more parameters are measured from the participants and it is also important to get the perspective of the persons with dementia. Although the music therapist involved the person with dementia in the discussion regarding their daily difficulties, more emphasis should be put on self-report measurements. Creating a mutual discussion helped the person with dementia participate and regain some control over his life, stating his needs and preferences as much as possible. Although people with dementia are often considered unreliable respondents for self-report measurements, we believe that if given enough thought and care, such assessments can be obtained (e.g., Vanstone, Wolf, Poon, & Cuddy, 2016).

Fourth, being a qualitative research, we did not apply a control group, which could have facilitated an understanding about specific

influences that the program had and a comparison to similar people who did not experience the program. We recommend that future research implement such methodology and aim to conduct RCT studies.

### *Conclusion*

In this pilot study we learned about the experience of two couples who started to integrate music in their daily life. The proposed program combined music therapy sessions with phone counselling sessions, which helped to bridge between sessions and daily life and for the couples to incorporate music in their daily activities. Indeed, the intervention reported in this study resulted in meaningful moments for the couples as well as practical tools to continue using music in daily life for the benefit of the person with dementia and his or her spouse. We believe that further implementation and development of this program is needed, so that it can be relevant for couples from different cultures, in different stages of dementia, and in different housing contexts.

Also, critical situations like the current global COVID-19 pandemic should be addressed in developing this program. Our ongoing research following this pilot transitioned to video meetings, since face-to-face contact with people living with dementia, in their homes, is not allowed. It seems that meeting face-to-face in previous sessions helped to build a rapport between the therapist and the couple, therefore enabled this adaptation to video meetings quite successfully.

## Declaration of Competing Interest

The authors report no declarations of interest.

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