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Music Engagement as Part of Everyday Life in Dementia Caregiving Relationships at Home

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Abstract

Background and Objectives: Emerging evidence suggests music-based interventions can improve the well-being of people living with dementia, but little is known about the ways in which music might support dementia caregiving relationships as part of everyday life at home. This study examined music engagement in the context of daily life to identify patterns of music engagement and potential targets for the design of music-based interventions to support well-being.

Research Design and Methods: This ethnographic, in-home study of people living with dementia and their family and professional care partners used methods from ethnomusicology, including semistructured interviews and in-home participant observation with a focus on music engagement.

Results: A total of 21 dyads were purposively recruited for diversity in terms of gender, ethnicity/race/heritage, caregiving relationship, and music experiences. Despite participants' diverse music preferences, 3 distinct music engagement patterns emerged. (a) Professional care partners intentionally integrated music listening and singing into daily life as part of providing direct care. (b) Family care partners, who had prior dementia care nursing experience or family music traditions, integrated music into daily life in ways that supported their personal relationships. (c) In contrast, family care partners, who lacked dementia care experience and had high levels of caregiver burden, disengaged from prior music-making.

Discussion and Implications: The distinct music engagement patterns reflect different needs on the part of dyads. It is important to continue to support dyads who engage in music daily and to consider developing music-based interventions to support well-being among dyads who have become disengaged from music.

Keywords: Humanities, Musicking, Quality of life, Qualitative research, Social well-being

Across cultures, music can function as an important part of everyday social life (Turino, 2008). Music facilitates the expression of personal identity through performance, serving as a marker of nationality, spirituality, community, or cultural identity (Nettl, 2015; Rice, 2013). Moreover, music reinforces relationships through shared engagement in activities, serving as a key aspect of important relational events including marriage and death (Gill, 2019; Sugarman, 1997). Music involves not only sounds but also observable behaviors and underlying beliefs about different forms of music (Nettl, 2015; Rice, 2013). In this study, we use the term *music engagement* to encompass all aspects of listening, performing, and participating in music. In the context of dementia care, music offers the potential to support identity and relationships because people living with dementia continue to communicate performatively through music after they can no longer communicate clearly with words (Kontos & Grigorovich, 2018). For people living with dementia, music can reinforce key aspects of identity and personal history by supporting different aspects of selfhood (Baird & Thompson, 2018) or underlying sources of meaning (Allison et al., 2021).

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In the United States, music engagement occurs within dementia care settings that have differing levels of support, including long-term care facilities, community-based organizations, and homes. In nursing home settings, interprofessional teams include recreation therapists and other staff dedicated to providing meaningful activities, and nursing staff who may integrate music into everyday care, also called music therapeutic caregiving (Allison et al., 2019; Swall et al., 2020). In dementia-friendly community singing groups, resources may include a choir director or facilitator and space for singing activities (Bannan & Montgomery-Smith, 2008; Hara, 2011; Lee et al., 2020; Mittelman & Papayannopoulou, 2018; Osman et al., 2016; Unadkat et al., 2017). In contrast, the home setting has neither an interprofessional team nor a choir director. Music engagement at home usually depends upon the resources of people living with dementia and their care partners.

Music-based intervention research takes place across all dementia care settings. Several studies suggest that personalized music listening interventions are associated with reduced psychotropic drug use and decreased behavioral symptoms in long-term care facilities (Bakerjian et al., 2020; Hammar, Emami, Gotell, et al., 2011; McCreedy et al., 2019; Stuart-Rohm et al., 2023; Thomas et al., 2017). In the community, music listening interventions can lead to improvements in agitative behavior, verbal communication, cognitive abstraction, remote recall, and social well-being (Dassa & Amir, 2014; Elliott & Gardner, 2016; Hanser et al., 2011; Kulibert et al., 2019; Park & Pringle Specht, 2009; Sarkamo et al., 2014). Two recent trials situated in the home setting demonstrated decreased levels of anxiety, depression, and caregiver burden (Cheung et al., 2022; Kor et al., 2023). Recent systematic and integrative reviews of outcome-based studies note that the heterogeneity of study design and modest findings prevent the generalization of results (Lee et al., 2022; Letrondo et al., 2023). The National Institutes of Health (NIH) recently published a toolkit for developing music-based interventions for brain disorders of aging to support high-quality study design (Edwards et al., 2023).

Observational research, however, has only been conducted in nursing homes and outpatient care settings. In the nursing home setting, studies show improvements in communication between dementia caregiving dyads, described by care partners as supportive of relationships (Dassa & Amir, 2014; Gotell et al., 2003; Hammar et al., 2011; Swall et al., 2020). In studies of community-based group singing and dyadic interviews about past experiences with group singing, family dementia caregiving dyads express enjoyment and a strong sense of community (Bannan & Montgomery-Smith, 2008; Hara, 2011; Lee et al., 2020; Mittelman & Papayannopoulou, 2018; Osman et al., 2016; Unadkat et al., 2017). Personalized music has been identified as an activity that can lead to episodes of lucidity (Gilmore-Bykovskyi et al., 2023). Although the home is the most common site for dementia care (Alzheimer's Disease Facts and Figures, 2023), we lack ethnographic studies focused on music in the context of daily life at home for dementia caregiving dyads.

Understanding the role of music within the context of everyday life for people living with dementia and their care partners is essential to the design of more effective homebased interventions. This requires in-home assessments with participant observation methods to enrich interview findings. What participants report and how they act do not necessarily reflect one another; therefore, engaging in usual activities with participants can deeply enrich interview data (Briggs, 1986). Ethnomusicology, the study of music *in* and *as* culture, involves the detailed examination of music in everyday life (Nettl, 2015; Rice, 2013). In ethnomusicology, methods include ethnography, with its focus on open-ended questioning, listening, observing, and participating in everyday activities, and the study of music performance. Participation in music activities enables people living with dementia to engage in research through performance when unable to participate through words (Kontos & Grigorovich, 2018).

We therefore designed an in-home, ethnographic study to examine the role of music in everyday life at home for people living with dementia and their live-in care partners. This study is informed by two research questions: How do people living with dementia and their live-in care partners engage in music in the context of everyday life? What happens when dementia caregiving dyads intentionally engage in music-making together?

Method

Study Design

This ethnographic study used methods from ethnomusicology, including semistructured dyadic interviews focused on the role of music in everyday life and participant observation involving usual music engagement. Participants included people living at home with dementia and live-in care partners. Care partners could be paid or unpaid, including family members, friends, or professional caregivers. Demographic data and validated measures were collected to further characterize the sample. The study adhered to the Consolidated Criteria for Reporting Qualitative research, COREQ (Tong et al., 2007). Detailed information about the study team, reflexivity, and study design can be found in the Supplemental COREO Checklist in the Supplementary Material. We obtained written consent for all participants, obtained by proxy for those who lacked the capacity to consent to research. Participants lacking decisional capacity received opportunities to assent in writing along with their proxy and received multiple opportunities to assent/dissent during research procedures. Ethical research approval was obtained through the University of California, San Francisco Institutional Review Board (Protocol 18-25894) and reviewed by the San Francisco Veterans Affairs Research and Development Committee.

Participant Recruitment and Setting

Recruitment began with the identification of people living with dementia of any etiology, whose cognitive or functional impairments were significant enough to require support 24 hr a day by live-in family or professional care partners. Care partners were recruited as the primary live-in caregiver for the person living with dementia. Participants were purposively recruited with the assistance of three geriatrics primary care teams, who functioned as local community experts (Schensul & LeCompte, 2012) with detailed knowledge about the medical conditions, care support networks, and music experiences of their patients. Inclusion criteria were the self-reported ability to speak English, diagnosis of dementia (any etiology), and live-in care partner. Clinical teams assisted with purposive recruitment for gender inclusivity and for diversity in music experience, caregiving relationship, dementia stage and type, and racial/ethnic/cultural heritage. Because people living with Table 1. Sample Interview Questions and Probes

Domain	Sample questions	Follow-up probes (not exhaustive)	
Social	How does dementia affect your ability to get out of the home? Are there activities that you find more challenging to do together in the home? How does music fit in to your social life? Are some kinds of musical activity either more challenging or easier now?	Shopping? Dining out? Going to events? Traveling? Small talk? Singing? Listening to recordings? Watch- ing videos or musicals? Playing instrument? Concert going? What gets in the way? What makes it easier?	
Emotional	How does dementia affect your mood? What brings joy to your rela- tionship? What causes stress in daily life? How does music fit into this? How does music affect your mood	Worries? Depression? Joy? Laughter? Describe the last time you laughed together. Describe the last time you played music, danced or sang? What music?	
Physical	Have you needed medical care in last 3 months? Do you need help for regular housekeeping? Do you need/help with activities of daily living? Do you ever dance or walk while playing music?	Falls? Exercise? Walking? Dancing? Who does the housework? Bathing? Toileting? Dressing? Transferring? Do you use music with any of these?	
Cognitive	Which memory issues strain your relationship? Does dementia provide opportunity to support one another? How well do you remember songs relative to other things?	Repeated questions or stories? Remembering to eat? Day/night confusion? Forgetting what you used to fight about? What songs do you remember? Can we sing that now?	
Domain	Focus of observations	Questions specific to activity (not exhaustive)	
Social	Telling jokes. Playing games together. Singing songs together. Sharing coffee or snacks.	What kind of games do you play? Do you sing together? Why/why not? Which activities are pleas-ant/stressful?	
Emotional	Reminiscing about the past (with or without music). Listening to favor- ite songs. Watching a favorite musical.	Tell me about when you were young. Travel? How does this song make you feel?	
Physical	With and without music: light housekeeping (washing dishes and fold- ing laundry), going for a walk. Playing tambourine while listening.	Who normally does this task? How has this changed with dementia? How far do you usually walk? Did you play a musical instrument? Can you still play it [musical instrument]?	
Cognitive	Listening to familiar music. Singing along with familiar music. Playing "guess that line" or tune. Introducing new music.	When did you first hear this song? What memories are associated with it? Does it help you find your words? [probe for prosody]. Do you remember the song we sang before this?	

dementia at home participate in complex care support networks (Ceci et al., 2018), additional family members were allowed to participate. The participants were part of a larger study about music, meaningful activities, and caregiving for dementia caregiving dyads at home (Allison et al., 2021). Data collection took place in homes between December 2018 and January 2020, prior to coronavirus disease 2019 (COVID-19) in the United States. Home settings included affordable housing units, apartments, condominiums, and single-family homes in low-, middle-, and high-income neighborhoods in six cities in the San Francisco Bay Area (California, USA).

Data Collection

In-home procedures were conducted by PhD-trained ethnomusicologists, one of whom was also a geriatric house calls physician, and by a trained researcher with a master's in psychology. Visits were intended to last 60–90 min, with three visits per dyad. To support participation by people living with dementia, we minimized distractions during visits, requested additional lighting, encouraged the use of adaptive devices including glasses and hearing aids, used a wireless speaker to boost the volume of music, and used a "pocket talker" (hearing assistive device consisting of headphones connected to a handheld microphone), as necessary.

The first visit included consenting, collection of demographics, brief questions about music and other meaningful activity preferences, and administration of validated measures. Measures included the Katz functional assessment (Katz et al., 1970), dementia severity using the Functional Assessment Staging (Sclan & Reisberg, 1992), and Zarit caregiver burden four-item interview (Bédard et al., 2001). Subsequent visits included semistructured dyadic interviews and participant observation. focused on everyday life, dementia caregiving, and music engagement. Dyads were given the choice to complete interviews together or separately (Eisikovits & Koren, 2010). See Table 1 for sample interview questions and observations.

Questions focused on music experiences over the life course to capture an overall sense of music engagement. Both dyad members were asked to name favorite songs, artists, and music genres, to describe usual forms of music engagement (e.g., singing or humming favorite songs or playing recordings), and to engage in usual music activities. These are standard research methods in ethnomusicology (Berger & Stone, 2019; Nettl, 2015; Rice, 2013). Participants were asked to describe how and when they engaged in music-making and the musical instruments or listening devices used. When participants could not recall specific pieces of music, more direct probes were used. For example, if a question about preferred music resulted in a genre (e.g., Rhythm and Blues) rather than a specific piece of music, follow-up probes included identification of physical settings and social contexts in which the music was first encountered (e.g., at a dance hall) to encourage recall. If needed, we prompted with names of well-known musicians or music titles until the participant was able to recognize a specific piece. We did not use a formalized questionnaire or matrix as in the Music and Memory program (Kulibert et al., 2019). When participants lacked access to recordings, we used online music services to access preferred music. Semistructured interviews and music activities were audio-recorded, transcribed, and de-identified. Ethnographic field notes were written following each visit (Emerson et al., 2011; Schensul & LeCompte, 2012).

Data Analysis

Ethnographic analysis (Schensul & LeCompte, 2012) was used to integrate multiple data sources, including audiorecorded interviews and participant-observation, written transcripts, ethnographic fieldnotes, demographics, and validated measures. (a) During data collection, fieldnotes and transcripts were concurrently analyzed using a combination of weekly team debriefs of home visit experiences and lineby-line, inductive, open coding assisted by ATLAS.ti software. (b) Open codes were organized in an initial codebook and reviewed with the team. (c) Relationships between codes (axial coding) were explored and emerging themes were identified. (d) Emerging themes were used to refine the interview and participant observation guides, and to guide purposive recruitment of participants with different relationships and musical experience. (e) The researchers developed analytical memos to challenge and refine emerging themes, serving as intermediate forms of analysis. (f) The full team regularly reviewed findings and reconciled differences through discussion. (g) Themes were validated and challenged in an iterative process through purposive recruitment of additional participants to enrich the data set and further inform the results. For example, the initial open codes "musical devices in the home" and "barriers to use of technology" were categorized together as "music" codes and found to be tightly linked to the open code "signs of caregiver burden," leading to the emerging theme "disengagement from prior music." Further recruitment of new dyads and validation of findings with participants, led to the identification of a pattern of disengagement from music as part of daily life. These methods are common to both ethnography and grounded theory (Miles et al., 2014).

Results

Participants

Study participants included 21 people living with dementia and 20 identified care partners, including seven professional care partners and 13 family care partners. One home included two dyads: a husband and wife cared for by one professional care partner. Four adult children, who were not the main care partner, participated in interviews. We conducted a total of 55 in-home visits, each lasting from 45 min to over 2 hr. Visits took place over a 2- to 10-week period. One dyad completed only two visits (due to concerns about COVID-19). Two dyads completed only the initial visit due to health issues and additional caregiving responsibilities.

Dyads reported varied experiences with formal music training, nursing training, informal dementia care experience, and care support networks. Music training included reports of no experience, experiences learning a musical instrument informally as a child, singing in choirs, performing in ensembles, receiving offers of paid music "gigs," and lifelong professional engagement in music. Care partner knowledge about dementia ranged from no prior experience to experiences as a family care partner, nursing assistant, licensed nurse, or physician. See Table 2 for additional participant characteristics.

Diversity of Preferred Music, Types of Engagement, and Listening Devices

Participants reported diverse forms of musical engagement across the lifespan. All care partners articulated preferred

songs, artists, and genres (styles) of music. Fourteen (67%) people living with dementia verbalized preferences, and all responded to music either verbally or nonverbally (e.g., smiling, looking up, or tapping a hand or foot). Participants identified preferred vocal and instrumental music from the sixteenth century to the present, including popular, folk, and classical genres from across the world. Participants shared songs in eight languages (Chinese, English, Italian, Japanese, Latin, Samoan, Shona, and Spanish). Participants reported engaging in music at outdoor festivals, nightclubs, concert halls, places of worship, and cars. They described music as an integral part of other individual and meaningful activities such as religious worship, family gatherings, dancing, and car travel. To listen to music, participants primarily used smartphones, televisions, and laptop computers with wireless speakers. When people living with dementia became unable to leave their home, they were no longer able to engage in activities such as concerts or worship services. See Table 3 for examples of music engagement and listening devices.

Overview of Themes

Despite the diversity of the sample and their types of music engagement, three patterns predominated as part of everyday dementia care: two patterns involved daily integration of music into everyday life, and one pattern involved disengagement from prior music activities. (a) All seven professional care partners used music listening/singing as part of professional care for the person living with dementia. (b) Seven family care partners, who had prior dementia care nursing experience and/or strong family music traditions, integrated music into daily life in ways that supported personal relationships. (c) Six family care partners, who lacked dementia care experience and had high levels of caregiver burden, disengaged from prior music activities. For each pattern (theme), we provide a case study to enrich the examples. Minor details have been changed throughout to protect anonymity.

Theme 1: Professional Care Partners Intentionally Integrated Music into Everyday Dementia Care

The seven professional care partners in this study had known the person living with dementia for months to years. All used music as a caregiving tool for specific purposes. They intentionally played music recordings, sang, and danced with people living with dementia in order to calm, relax, or entertain both members of the dyad. Music played in kitchens during cooking and eating, in bedrooms during morning or bedtime care, in living rooms during the day, and occasionally in bathrooms. "I put on the music, and we dance over here" explained one care partner. Sometimes she played her own favorite music to see how it would be received. She described how "I'll be sitting here, and I'll be listening to Christian music on my YouTube and I'm watching him and he's relaxing. He's in a relaxing mood. It takes you into a relaxing mode. Yes, the music." In other cases, professional care partners reported listening to their "own" music privately as a form of self-care or to make housekeeping chores more pleasant.

Because relationships were predicated on caregiving rather than shared family history, professional care partners had limited knowledge of the musical experiences of the person living with dementia. As a result, they used trial and error to identify songs that prompted smiles and social engagement by the people living with dementia, often using internet searches to find music. When asked how she chose the music, another

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Table 2. Participant Characteristics, N(%) or Mean (SD)

Characteristics	People living with dementia (21)	Care partners (20) ^a
Age, years (mean, SD)	84 (8)	59 (16)
People of color	12 (57%)	17 (85%)
Female gender	8 (38%)	17 (85%)
Dependent 3+ activities of daily living	15 (71%)	0
3+ Chronic illnesses	14 (67%)	1 (5%)
Low vision	2 (10%)	0
Significant hearing loss or tinnitus	1 (5%)	0
Positive Zarit four-item burden interview	_	7 (35%)
Dementia stage (functional assessment staging)		
Mild	5 (24%)	1 (5%)
Moderate	13 (62%)	
End-stage (%)	3 (14%)	
Dementia diagnosis		
Alzheimer's disease	7 (33%)	
Vascular dementia	3 (14%)	
Parkinson's disease dementia	1 (5%)	
Not specified	10 (48%)	1 (5%)
Care partner relationship		
Live-in professional	_	7 (35%)
Family	_	13 (65%)
Spouse	_	7 (35%)
Adult child	_	3 (15%)
Friend	_	2 (10%)
Sibling	_	1 (5%)

Note: ^aThere were eight professional caregiving relationships but only seven professional care partners because one professional care partner lived with a couple who both had dementia.

Table 3. Diversity of Music Engagement and Music Devices

Type of music engagement	Listening devices, services, and musical instruments	
Music listening	Car radio Live performance (e.g., concert and church) CD/CD player LP (vinyl) records in home Television (music channel, movie, or streaming service) Smart phone with external speaker Laptop computer with external or internal speaker Internet searches or playlists (YouTube) Streaming service playlists or searches (Spotify and Pandora) AI assistant (Amazon Echo)	
Music singing with recording	Car radio CD/CD player in home or in car Television (music channel, movie, or streaming device) Smart phone Laptop computer Internet searches or playlists (YouTube) Streaming service playlists or searches (Spotify and Pandora)	
Singing without accompaniment	Not applicable	
Music composition	Piano, computer, paper and pencil	
Singing with live accompaniment	Acoustic guitar in home, other instruments outside of home	

Note: AI = artificial intelligence; CD = compact disc; LP = long-playing record.

professional replied, "Oh, pretty much anything like Willie Nelson, mixed-up everything." After learning from a family member that the man living with dementia was an avid jazz fan, she searched for music on her smartphone using the term "jazz." Professional care partners each reported prior experience using music to engage care recipients in nursing homes, adult day health centers, or assisted living settings. They described approaches to caregiving that identified music as essential to social well-being for people living with dementia.

Case Study 1: The mother of the family rarely listened to the radio or sang songs during her daughter's childhood, so the daughter never thought to play music after the diagnosis of Alzheimer's disease. Because the daughter lived out of town, she hired a professional care partner, who immediately asked the mother about her favorite music. To the daughter's surprise, the mother was able to sing songs from her childhood. At the request of the professional care partner, the daughter bought a CD player and several CDs. The professional care partner played the CDs in the kitchen during and between meals every day. The mother recognized them and sang along with enthusiasm and laughter. For example, when the researcher asked the mother if she knew the song "Volare" (Modugno, 1958), she immediately replied, "My father sang that one!" When asked if the song was on her favorite CD, the professional care partner responded by singing, "Volare, whoa, whoa, whoa, whoa." The mother immediately sang back, in time and in tune "Cantare, whoa, whoa, whoa, whoa."

Professionals incorporated music listening into nonmusical activities that they considered important to social well-being. For example, when professional care partners attempted to encourage people living with dementia to leave the house via car rides, they all played music while driving. As one care partner explained, "It makes her feel good because when we get in the car, we turn on the radio and she just loves to listen to the music." The overall philosophy of music engagement in caregiving was described succinctly by one care partner, "I'm thinking all the time, 'Where does music fit in?'" During research visits, care partners demonstrated usual activities such as singing and playing songs on their personal music devices.

Theme 2: Family Care Partners With Dementia Care Nursing Experience and/or Strong Family Music Traditions Integrated Music into Daily Life in Ways That Supported Personal Relationships

Seven of the family care partners played music recordings daily for the person living with dementia. Six care partners had formal dementia care nursing experience; one also came from a family with a strong tradition of music-making. One care partner had no nursing experience but a lifetime of family music-making experience. These dyads primarily listened to or sang along with familiar songs. Although some participants living with dementia expressed interest in singing and listening to music or took delight in certain songs, they rarely articulated reasons why they liked a particular song. Only one participant continued to sing daily, a life-long choir singer whose wife reported that "some days he sings all afternoon." Another man with mild vascular dementia, who previously played ukulele, enjoyed streaming music on the TV using his remote control.

Family care partners with nursing experience used music similarly to professional care partners, intentionally and at predictable times. Other family care partners, who came from families with strong family music-making traditions, used music much as they always had within the family. One adult child, for example, sang to her parent when he became angry, as a means of distraction, leading them both to laugh rather than argue. When asked if they wanted to sing as part of the study, the daughter said "Yeah, I would sing a church hymn." As they prepared to sing, he asked her "Do you remember it?" Laughing, she replied, "Dad, you taught it to me all my life. How would I forget?" Several care partners articulated having faith-based motivations for caregiving. Although care support networks differed greatly, only one of these care partners had a Zarit burden score that screened positive for needing a social work referral.

Unlike professional care partners, however, family care partners chose specific pieces of music, based on their longstanding relationships. They selected songs that they knew had meaning for the person living with dementia or for both members of the dyad. One care partner identified three categories to explain how music brought them together, saying they had "my rock 'n' roll. And he listens to jazz. And then we both love Andrea Bocelli. We both love him." Families reminisced about other aspects of their relationship prior to the onset of dementia when they spoke about music engagement. Although some of the participants living with mild and moderate dementia mentioned singing in choirs or going to concerts, family care partners provided detailed examples, as in the case study below.

Case Study 2: The wife [care partner] had been taking care of her husband for decades, as early-onset Parkinson's disease progressed to end-stage dementia. By the time we met him, he could no longer speak and his son had to carry him to the shower. When asked about their shared music, the wife handed us a CD and said, "These are the songs we used to sing, Chinese folk songs. We'll play these songs for you. When he first came to America these are the songs he used to love to listen, and he even bought one of the records and sent it back to his younger brothers and sisters." When asked how often they listened, she replied, "Every day."

Like the other family care partners, this spouse chose songs deliberately from their shared experiences, including songs that they loved as children and music they discovered together as adults. Family care partners reported that engaging in familiar music brought back positive memories and allowed them to connect as family members rather than caregivers. In a few cases, the person living with dementia remembered songs that the family care partner had forgotten, and this role reversal delighted the care partner.

Theme 3: Family Care Partners With Health Issues/ High Levels of Caregiver Burden Disengaged From Prior Music-Making Activities

In the six homes in which people living with dementia no longer engaged in music, several common features emerged. Dyads only included family care partners: three spouses, two adult children, and one sibling. None had nursing experience, although one had prior experience caring for a parent who died from dementia. All described prior engagement in music, including concert attendance, professional music performance, and teaching, singing in choirs, listening to music in the car, or listening and singing along with music at home. Three care partners came from families with strong music-making traditions.

Case Study 3: Both spouses were struggling with complex health issues. The husband who was living with dementia

also had diabetes, neuropathy, and visual impairment, while the care partner husband had been injured and was struggling to meet their caregiving needs. Prior to dementia onset, they loved attending live musical theater and listening to music at home on an elaborate sound system that linked their stereo, video recorder, CD player, and cassette player to wall-mounted speakers in their art-filled two-story Victorian home. Yet now they hardly listened to music at all. The care partner spouse described the last time he managed to re-create a romantic evening with background soundtrack by a favorite singer, saying, "It actually did work. We were just talking a lot like we used to and listening to the same music He looked at me with his eves full of love like when our relationship was new. You can't always have it all the time and things change. But I did create the situation." By the time of the study, the sound system was broken, the new wireless speakers were not connecting properly to the smartphone, and their digitized music collection was no longer accessible due to a software upgrade issue. Their music life had been silenced.

Four care partners described a slow, insidious change over time. As new responsibilities emerged, people living with dementia stopped initiating music activities, and care partners became immersed in the stress of caregiving. They said they had forgotten about music as a possible source of joy. As the care partner explained, "At the point that we were at, we were more focused on her care. Eating, drinking, bathing, all that kind of stuff. We had no inkling of even thinking about adding music." Five care partners said they wished they had time to engage in music. When offered the opportunity to engage in preferred music listening, five people living with dementia re-engaged in specific songs, and care partners smiled and laughed, several asking questions about music devices and requesting information on how they might bring music back into their lives.

Discordant and Alternative Findings

Three people living with dementia no longer spoke or sang at all. It was difficult to interpret their responses to music, so we relied on care partners and other family stakeholders to interpret facial expressions, movements, and monosyllabic responses. One son explained, "To me, just opening her eyes up like that looking around to see what's happening is a response." One care partner spouse in a family of arts professionals explained that avoidance of music as part of nonwork life was normal for them, saying "I mean we never listen to music as background, it's simply not part of this house." A spouse who was living with chronic delirium and rapid-onset dementia had a restrained response to listening to an archived recording of his favorite radio station from the 1970s. Instead of cursing at people to get out of his room as usual, he opened his eyes and listened quietly for nearly 10 min, then told the researchers to get out of his room in a normal speaking voice.

Discussion and Implications

This ethnographic study of the role of music in everyday life revealed distinct patterns of music engagement among a sample of people living with dementia and their care partners. This diverse group of participants described a lifetime of engagement in vocal and instrumental music genres from across the world, including listening, singing, playing instruments, dancing, engaging in worship, and attending life performances. When travel was no longer possible, music engagement became restricted to the home setting, including primarily listening and singing, but they continued to engage in diverse music genres. Although participants individually and collectively engaged in diverse music genres, they demonstrated three music engagement patterns, involving everyday integration of music into daily life, or near-total disengagement from prior music activities.

When dyads continued to engage in music as part of daily life, they did so intentionally as part of daily caregiving as well as for social and self-care purposes. All professional care partners incorporated music activities into daily caregiving and described a philosophy of caring through music, learned with prior clients and consistent with evidence on personalized music listening (Bakerjian et al., 2020; Thomas et al., 2017) and music therapeutic caregiving (Hammar et al., 2010). Family care partners who engaged in everyday music-making had dementia care nursing experience and/or strong traditions of family music-making. These care partners demonstrated creative approaches that supported well-being. The findings contribute to studies showing how people use music to help make meaning of the dementia process or improve well-being (Birt et al., 2023; Hutmacher & Schouwink, 2021; Sixsmith & Gibson, 2007; Soilemezi et al., 2019). Through direct observation, we found that music engagement deemphasized the caregiver-care recipient aspects of relationships, particularly allowing family relationships to escape the confines of everyday caregiving. The findings expand the literature on group singing (Bannan & Montgomery-Smith, 2008; Hara, 2011; Mittelman & Papayannopoulou, 2018; Unadkat et al., 2017) by showing how the relationship-affirming benefits of singing together occur in dyadic music engagement as well as in larger groups. In family caregiving dyads, personal relationships stretching across decades generate rich sets of shared memories. The act of remembering together while listening to familiar songs created a sense of connection for care partners. These moments of performative, interpersonal moments of connection through music contribute to Kontos and Grigorovich's concept of musicality as embodied and relational (Kontos & Grigorovich, 2018).

The findings were congruent with studies in ethnomusicology that show how music engagement supports relationships through the creation of shared identity and community (Turino, 2008). Similar to other studies (Dewitte et al., 2021; Gubner, 2018), findings were strengthened by the voices of people living with dementia. Music engagement allows people living with dementia the opportunity to contribute their insights performatively as well as narratively (Allison, 2015; Kontos & Grigorovich, 2018). Nonverbal reactions of people living with dementia were congruent with other studies of nonverbal engagement (Staehler et al., 2022).

Study limitations include the relatively brief data collection period (2–10 weeks), which was not intended to observe changes in music engagement over time. Professional and family caregivers brought different perspectives to the dyadic relationship, and this may have biased the findings. The observational study design did not allow the determination of causal relationships between music engagement and care partner experience, or music disengagement and caregiving burden. Future studies should examine these relationships longitudinally. The findings may have been affected by recall bias as participants were asked to provide information about music engagement over the life course. The relatively small sample limits generalizability to the broader U.S. population.

Implications

This study suggests that music can play an important role in everyday life for dementia caregiving dyads, easing the work of caregiving, supporting social relationships, and serving as a form of self-care for care partners, all aspects of social well-being. The encouragement of music as part of everyday life may provide easily accessible opportunities to improve social well-being and support dementia caregiving relationships. The families who disengaged from music as part of everyday life may represent a target population for the development of music-based interventions to promote well-being in the home using the new NIH toolkit (Edwards et al., 2023).

Supplementary Material

Supplementary data are available at The Gerontologist online.

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Conflict of Interest

D. E. Barnes is a co-inventor of the Preventing Loss of Independence through Exercise (PLIÉ) and Paired PLIÉ programs, which are mind-body group movement programs for people living with dementia that include personally meaningful music. She has the potential to benefit financially from research supporting the benefits of music. The other authors have no conflict of interest to declare.

Data Availability

Data are not available due to issues with blinding the data to protect the privacy of participants. This study was not preregistered.

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