JF&CS Memory Café Percolator
Quarterly Idea Exchange
June 14, 2023

For more than 150 years, Jewish Family & Children’s Service has been helping individuals and families build a strong foundation for resilience and well-being across the lifespan.
Today’s Agenda

1. Housekeeping
2. Announcements
3. Sara Masoud, memory café research, SA Amigos Café and Texas Café Network
4. Funding your café – results from the Percolator survey
5. Next meeting: **Thursday, September 14, 1:30 to 3:30 pm ET**
   - Café de Los Recuerdos, Gail Borden Library, Elgin, Illinois
   - Café Chats: impact so far, with Dementia Action Alliance
Housekeeping

• This meeting is being recorded. The recording will be available at www.jfcsboston.org/Percolator in 1-2 weeks.

• Please activate your video if you are able to do so.

• Please keep your audio muted unless you are speaking.

• Please use the chat box or “raise hand” function to share your questions and comments at any time.
Say hello! Please type your name and location into the Chat box.
Percolator Updates

- All Percolator resources are free and can be found at www.jfcsboston.org/Percolator
  - In-person and virtual/hybrid café toolkit (includes list of promo ideas)
  - Guide to Leadership & Meaningful Roles
  - PSA videos (English, Portuguese, Spanish)
  - Recorded how-to videos
  - Guest artist/activity facilitator directory
  - Join the email list
Percolator Updates - MA

- **Massachusetts cafés** – PLEASE review your listing at [www.jfcsboston.org/MemoryCafeDirectory](http://www.jfcsboston.org/MemoryCafeDirectory)
Your Updates

https://goodwinliving.org/stronger-memory/
Your Updates

Please share your news – briefly, please!
Memory Café Research
SA Amigos Memory Café
Texas Memory Café Network

Sara Masoud, PhD, MPH (She/Her)
Program Manager | Caring for the Caregiver
UT Health San Antonio, School of Nursing
“We Don't Feel so Alone”

A Qualitative Study of Virtual Memory Cafés to Support Social Connectedness Among Individuals Living With Dementia and Care Partners During COVID-19

Sara Masoud, PhD (masoud@uthscsa.edu)
JoAnn Sharman, RN (sharmanj@uthscsa.edu)

Caring for the Caregiver
UT Health San Antonio, School of Nursing
UTcaregivers.org
Individuals living with dementia and their caregivers are at increased risk for loneliness and low social support.

Low social support and loneliness are associated with poorer cardiovascular, immune, and mental health.

Individuals with lower social support are at increased risk of mortality.

COVID-19 exacerbated existing barriers to social connectedness among families impacted by dementia.

Memory Cafés provide a space to socialize without worry of stigma or judgment.

Focused on capacities that remain (ability to connect with others, creative expression, and participation in groups).

Since COVID-19, most either shut down or transitioned to virtual but little is known about how virtual models can support social connectedness.
What is a Memory Cafe?

Originated in Europe, widely implemented globally since late 1990s.

Guided by continual dialogue with attendees.

Activities are typically creatively-focused; planned around a goal to facilitate connection among attendees.

Staff are 'dementia aware' and typically have some professional training (Dementia Friends) or personal experience (past caregiving role).

No requirement to share a diagnosis; inclusive space for people of all abilities.

Since 2019, Caring for the Caregiver has hosted the SA Amigos Memory Cafe.
“We Don’t Feel so Alone”: A Qualitative Study of Virtual Memory Cafés to Support Social Connectedness Among Individuals Living With Dementia and Care Partners During COVID-19

Sara S. Masoud¹*, Kylie N. Meyer¹, Lauryn Martin Sweet¹,², Patricia J. Prado¹,² and Carole L. White¹
The Caring for the Caregiver Program partnered with the Alzheimer's Association and UT Rio Grande Valley to establish the Texas Memory Cafe Network.

A space to work together to accomplish shared goals, workshop ideas and challenges, and develop shared resources.

The Network provided the infrastructure needed to conduct the activities of this Project.

Adapted quickly post-COVID to meet goals (new partnerships, transitioned activities and interviews to virtual, amended program and IRB to accommodate Spanish-speakers)

The Network meets on an as-needed basis to provide collaborative support for Memory Café coordinators in Texas.
Project Objectives

Describe characteristics of Memory Cafes to develop a Toolkit

To create a checklist of Memory Cafe characteristics, we conducted a literature review, compiled observational fieldnotes at different Memory Cafes, and confirmed final checklist with the Texas Memory Cafe Network.

The checklist was later used to develop a Toolkit.

Describe the experiences of social connectedness among attendees when attending a Memory Café

We conducted in-depth individual interviews with attendees to learn about their perceptions of how the Memory Cafes impacted their experiences of social connectedness.

People living with dementia and caregivers were both included in interviews.

Adapt and implement new Memory Cafes to meet the needs of underserved populations

Partnerships were leveraged to establish two new Memory Cafes in Texas and the adaptation of the SA Amigos Memory Cafe to support families in other regions of South Texas.

Trainings were held for coordinators and volunteers.
## Memory Café Checklist

The following table was generated after reviewing the existing literature on memory cafés. Those identified as “required” are criteria that are typical of most memory cafés globally. Those identified as not required are criteria that are typical to memory cafés but are not essential to meet the definition of a memory café.

<table>
<thead>
<tr>
<th>Criteria</th>
<th>Required</th>
<th>Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Welcoming for persons living with dementia and care partners</td>
<td>Yes</td>
<td>Memory Cafés are for both the family caregiver and the person living with dementia. It is not respite for caregivers or a day program for persons living with dementia.</td>
</tr>
<tr>
<td>“Open” and accessible to anyone</td>
<td>Yes</td>
<td>Persons living with dementia and caregivers who are interested in attending the memory café should be welcomed without discrimination. Virtual memory cafés should be hosted using platforms that do not require attendees to pay for software (Zoom, Skype, Hangouts, Blue Jeans, etc.).</td>
</tr>
<tr>
<td>Location &amp; atmosphere</td>
<td>Yes</td>
<td>In-person Memory Cafés should be hosting in accessible community locations. They should strive to create an atmosphere more like a social gathering rather than a clinical program or class. Virtual memory cafés should also foster an atmosphere that is more socially inclined (use of video, calling people by name, encouraging use of chat box, and allowing time for attendees to speak).</td>
</tr>
<tr>
<td>Scheduled regularly</td>
<td>Yes</td>
<td>Can be weekly, bi-weekly, or monthly but all memory cafés are repeated and regularly scheduled events (typically on a fixed rotation i.e., second and fourth Fridays of each month).</td>
</tr>
<tr>
<td>Activities focused on socialization</td>
<td>Yes</td>
<td>All memory cafés have a primary goal of promoting social interaction between persons living with dementia and caregivers with others in their communities. However, other goals might include educational, creative expression, physical activity, etc. Virtual memory cafés should encourage socialization within households as well as between other participants in the virtual memory café.</td>
</tr>
<tr>
<td>Designated facilitator</td>
<td>Yes</td>
<td>All memory cafés are staffed by at least one “professional” facilitator. This term is loose and includes trained volunteers who are sometimes former caregivers.</td>
</tr>
<tr>
<td>Tailored to attendee interests</td>
<td>Yes</td>
<td>All true memory cafés are designed to be receptive to the needs and interests of their attendees. Some attendees might prefer a less active role in planning but are regularly consulted on their preferences for activities, meetings times and dates, etc.</td>
</tr>
</tbody>
</table>

| Coffee, tea, refreshments                      | No       | All in-person memory cafés should offer some form of refreshments which contribute to a more relaxed atmosphere. Virtual memory cafés do not require this criteria though participants can be encouraged to prepare a cup of tea or coffee before sitting down for the virtual event. |
| Registration                                   | No       | Some memory cafés do not require registration and focus on encouraging people to just show up. Most memory cafés, though, have some formalized system of registration to keep track of who is attending. |
| A range of diverse activities                  | No       | Most memory cafés will explore a range of entertaining, education, and/or creative activities. While this is the typical model for a memory café, some prefer to stick to one or two activities each time. |
| Planned activities                             | No       | Not all memory cafés have structured activities. Many simply meet to chat and share coffee with others. |
| Part of a Memory Café “Network”                | No       | Many memory cafés participate in Memory Café Networks to share their experiences and lessons learned with other facilitators. |
| Volunteers                                     | No       | Many memory cafés are staffed by volunteers in addition to a designated facilitator though smaller groups might not need the extra support. |
| Funded by donations and grants                 | No       | Most memory cafés are funded by grants and/or donations though some are funded by private organizations as part of their community service/engagement budgets. |
| Documenting attendees                          | No       | Not all memory cafés take attendance but most do. A sign-in sheet, roll call, and even demographic data collection might occur before, during, or after the scheduled memory café gathering. |
| Evaluation                                     | No       | Many memory cafés will have some way to evaluate whether their gatherings are meeting the needs and interests of their attendees. This might be in a questionnaire given annually, periodically, or after each gathering. Some are collected online and some are collected during the gathering. Many simply “check in” with their attendees before ending their event to see if the event was enjoyed. |
LITERATURE REVIEW (MONTHS 1-2)
Two members of the team conducted independent reviews of the literature to find any publications assessing Memory Cafes. Meetings with Co-PIs were held periodically to refine keywords and compare findings. The review informed the initial draft of the checklist components.

FIELDNOTES (MONTHS 2-4)
Co-PIs observed five Memory Cafe sessions hosted by three members of the Texas Memory Cafe Network. Notes were thematically analyzed and findings were used to refine the initial checklist. The checklist was reviewed at a quarterly Network meetings to invite feedback and recommendations.

CREATING THE TOOLKIT (MONTHS 8-11)
Findings from the literature review, fieldnotes, and thematic analysis of interview data were used to develop the toolkit. The outline of the toolkit was presented to the Network for insight in January 2021. A subgroup of Network volunteers will review and refine the final version of the Toolkit.

PUBLISHING FINDINGS (MONTHS 10-12)
A manuscript of findings was published in Frontiers in Public Health and shared in community presentations, including with the TMCN.
Individual Interviews
Research Participants

17 in-depth individual interviews from three Memory Café partners in the TMCN.

For perspective, interviewed individuals who stopped attending post-COVID (n=2).

Interviews conducted via Zoom, recorded, transcribed, thematically analyzed by two independent coders.

Preliminary findings shared with Network for their insight

Table 1. Participant demographic details

<table>
<thead>
<tr>
<th></th>
<th>N = 17</th>
<th>n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Persons living with dementia</td>
<td>5 (29.4)</td>
<td></td>
</tr>
<tr>
<td>Care partners</td>
<td>12 (70.6)</td>
<td></td>
</tr>
<tr>
<td>Spouse</td>
<td>8 (66.7)</td>
<td></td>
</tr>
<tr>
<td>Adult children</td>
<td>4 (33.3)</td>
<td></td>
</tr>
<tr>
<td>Gender</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>11 (64.7)</td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>6 (35.3)</td>
<td></td>
</tr>
<tr>
<td>Language</td>
<td></td>
<td></td>
</tr>
<tr>
<td>English</td>
<td>15 (88.2)</td>
<td></td>
</tr>
<tr>
<td>Spanish</td>
<td>2 (11.8)</td>
<td></td>
</tr>
<tr>
<td>Format</td>
<td></td>
<td></td>
</tr>
<tr>
<td>In-person only</td>
<td>2 (11.8)</td>
<td></td>
</tr>
<tr>
<td>Virtual only</td>
<td>9 (52.9)</td>
<td></td>
</tr>
<tr>
<td>Both</td>
<td>6 (35.3)</td>
<td></td>
</tr>
</tbody>
</table>
Thematic Analysis

FIVE FINAL THEMES & SUB-THEMES

• REPRIEVE
  • Something to look forward to
  • Break from daily life

• WHAT IS STILL POSSIBLE
  • Highlighting capacities and strengths that remain when living with dementia or caregiving

• CONNECTEDNESS
  • Feeling of belonging (part of the group)
  • Sense of community (shared experiences; peer support)

• INCLUSIVITY
  • Accessibility (planning; staff; responsiveness)
  • Diversity (culture; language)

• VALUE ADDED
  • Cognitive stimulation
  • Education
  • Resources
  • Helping others
“I get to talk to other caregivers. He gets to talk to people in his situation... it helps because we don’t feel so alone, so isolated I guess, and the understanding of what we’re going through each one of us when we go into the groups, we just - okay, we’re accepted.” – Spousal care partner

“I think it’s the social part that it’s helped with. I would have to say that’s the biggie. You’re not so isolated.” – Person living with dementia
Conclusion

Findings from this study establish a framework for future evaluation of the specific mechanisms that influence the social connectedness experiences of Memory Café participants.

Virtual models may meet important needs for social connectedness, but are often not accessible to everyone (digitally excluded households and persons living with more advanced dementia).

Increased intentionality in planning online models is critical to the facilitation of meaningful engagement between participant households.

Findings have implications beyond COVID-19, especially when trying to extend resources and support to other geographic regions and communities that are excluded from health and service infrastructure and resources.

Future research should investigate the experiences of persons living with dementia who attend Memory Cafés and quantitatively evaluate the extent to which participation improves the health and quality of life of participants.
Project Summary

CREATE MEMORY CAFE CRITERIA CHECKLIST TO DEVELOP TOOLKIT

ASSESS IMPACT ON EXPERIENCES OF SOCIAL CONNECTEDNESS

ADAPT & ESTABLISH NEW MEMORY CAFES TO SUPPORT UNDERSERVED POPULATIONS

SUBMIT MANUSCRIPT OF FINDINGS FOR PUBLICATION

PUBLISH TOOLKIT TO SUPPORT THE SUSTAINMENT OF VIRTUAL MEMORY CAFES
Virtual Memory Cafe Toolkit

Members of the Texas Memory Cafe Network collaborated to develop this resource to support the establishment and sustainment of virtual memory cafes. Our efforts were supported by the UT Health San Antonio Institute for the Integration of Medicine and Science through a Community Engagement Small Projects Award. Our hope is that this toolkit will offer insight and guidance needed for community partners to develop programs that improve the well-being of families living with dementia through opportunities for social engagement.

Toolkit development overseen by:
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Founder, Texas Memory Cafe Network
Community Outreach Coordinator, Caring for the Caregiver
UT Health San Antonio. School of Nursing
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masoud@uthscsa.edu

Memory Café Resource Pack:
https://drive.google.com/drivefolders/10XdsrU8WjWQdxnuBJLbMLLuSOknF5OvA?usp=sharing
Project Team

Carole White, PhD, RN, FAAN (PI)
Sara Masoud, PhD (Co-PI)
Kylie Meyer, PhD (Co-I)
Ginny Funk, MS (Co-I)

JoAnn Sharman, RN (Program Manager)
Lauryn Sweet Martin (Research Assistant)
Patricia Prado (Research Assistant)
Noe Garza, DDS, MPH, DPH (UT RGV Consultant)

Texas Memory Cafe Network

Arden Courts Memory Cafes
Camille’s Memory Cafe
SA Amigos Memory Cafe
The Forget-Me-Nots
Alzheimer’s Association
The Glenn Biggs Institute
Catholic Charities of San Antonio
WellMed Charitable Foundation
Dementia Friendly San Antonio
Memories International
Acknowledgements

The Percolator Network provided the foundation for the start of all this work. In 2018, our program joined the Percolator Network before starting the only Memory Café in San Antonio at the time.

We continue to turn to Beth Soltzberg and the Percolator Network for guidance and support as we try to adapt our programs to meet the needs of our communities here in Texas.

Thank you!
Discussion
Stretch break!
Funding Your Café

Results from the Percolator Funding Survey

…and sharing our pearls of wisdom!
Let’s talk about FUNDING!!

• Results of Percolator funding survey
• Pearls from several café coordinators:
  • Nicolette Farmington, Hummingbird Memory Café, Nevada
  • Gail Sonnesso, Harmony Café, North Carolina
  • Kathi Hayen, Memories in the Making, Wisconsin
  • Vicky Pitner, Engaging in Life!, Florida
  • Mary E. MacDonald, Rest.Stop.Ranch, Massachusetts
• Laundry list of café funding sources
• Open discussion!

The Percolator will compile tips from this discussion and share them with the mailing list!
Percolator Funding Survey (n=71)

- Massachusetts: 38.03% (27)
- Midwest: 28.17% (20)
- Northeast except Massachusetts: 11.27% (8)
- West: 14.08% (10)
- South: 4.23% (3)
- Outside of U.S.: 4.23% (3)
How long has your café been running?

- Under One Year: 16
- 1-3 Years: 19
- Over 3 years: 27
- Other (in planning stage; launch interrupted by pandemic): 9
How frequently does your café meet?

- Weekly: 7
- Monthly: 45
- Other (biweekly; quarterly): 19
Approximately how much does your café cost per year, including staff time?

- I'm not sure: 12
- Under $5,000: 38
- $5,000 - $10,000: 9
- $10,001 - $15,000: 3
- $15,001 - $20,000: 3
- Other (minimal cost): 6
Accounting for cost of Coordinator’s time

Estimates based on 2-hour meeting once per month

<table>
<thead>
<tr>
<th>Task</th>
<th>Hours per month</th>
<th>Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Purchasing food for café</td>
<td>1.5</td>
<td></td>
</tr>
<tr>
<td>Setting up for café</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>Hosting café</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cleaning up from café</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Planning program for café sessions</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Updating flyer</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mailing to café guests and providers</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Entering new guests’ information in mailing list</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Miscellaneous, such as developing and writing policies, answering questions from callers</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Outreach</td>
<td>1</td>
<td>this requires 5+ hours in the early months</td>
</tr>
<tr>
<td>Volunteer coordination</td>
<td>2</td>
<td></td>
</tr>
</tbody>
</table>

**Total hours per month** 20.5

**Estimated cost of Café Coordinator's work**

<table>
<thead>
<tr>
<th>Hours of work per Café gathering</th>
<th>Hourly Rate</th>
<th>Total per gathering</th>
<th>Annual labor cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>20.5</td>
<td>$20</td>
<td>$410</td>
<td>$4,920</td>
</tr>
</tbody>
</table>

English: [www.jfcsboston.org/MemoryCafeToolkit](http://www.jfcsboston.org/MemoryCafeToolkit)  
Spanish: [www.jfcsboston.org/GuiaCafeDeMemoria](http://www.jfcsboston.org/GuiaCafeDeMemoria)
Your sources of funding (check all)

- Business sponsorships - Ongoing
- Business sponsorships – for one or a few gatherings only
- It’s part of my organizational budget
- Federal Funds, e.g., Title III-E from AAA
- State government, e.g. from human services or elder affairs
- Grants from private foundation
- Fundraising events
- Donations from participants
- Participant fees
- Other (ARPA; donations from host or volunteers; city or county funds)
Sources of funding reported to be a **significant** part of the café budget*

- Line item in organizational budget
- Grant from private foundation
- State or federal funds
- ARPA funds
- Donations from volunteers, and honorary/memorial donations from families (including donation of volunteer time to run the café)
- Business sponsorships

*At least some respondents reported that this source of funding comprises a medium part or most of their café budget
Sources of funding reported to be a \textit{smaller} part of the café budget

- Participant fees
- Participant donations
- Fundraising events
It’s not just about the dollars

Do your business sponsors give you in-kind donations, such as refreshments?

- **Yes**: 15
- **No**: 5

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Your pearls of wisdom

• Search Pro Publica (free!) and look at 990s (www.propublica.org)

• Ask community foundations for grant-writing assistance and to suggest other funders to try.

• Seek a planning grant to start a café.

• If your grant proposal is rejected, ask why. Get feedback!

• Connect with your local branch of Association for Fundraising Professionals and other non-profit marketing groups.

• Consider partnering with other nonprofits to seek a grant together.

• Be prepared to network and establish contacts over time, and to educate potential funders about cafés and dementia friendly concepts.
Your pearls of wisdom

• ASK! Reach out to clubs (Rotary, Lions, etc), local colleges, businesses. Many people have a connection to dementia and talking about it reduces stigma!

• Keep your café simple and sustainable.

• If you hold a café at a bakery or restaurant, participants can purchase their own food.

• Many people will donate their talents and lead programs for free.
Your pearls of wisdom

• Collaborate with other organizations to help with outreach and other resources.

• Some cafés get few donations from participants. Some get sustaining funds from volunteers or families in memory of a participant.

• Tell your story. “When you tug at the heart strings, you pull the purse strings.”

• Social isolation is in the news. Explain how cafés help to connect people.

• Set written guidelines for business sponsors.
Your pearls of wisdom

• Some café providers have seen significant budget cuts and need to simplify their program.

• One café charges $5-10 per person and finds that people are more likely to show up if they pay for it.

• Some large businesses have foundations. Speak to a manager.

• Community banks have small foundations, and may connect you with family foundations.

• Some regions and cities have foundations.
Laundry list of funding sources for cafés

- **Federal, state, county government:** ACL (federal – large grants), Area Agency on Aging (National Family Caregiver Support Program-Title III-E; won’t cover food), state Council on Aging organization

- **Foundations:** corporate foundations (banks, supermarkets, assisted livings, etc.), private/family foundations, community foundations, town foundations

- **Charitable organizations:** United Way, Area Agency on Aging, Alzheimer’s Association

- **Service Clubs:** Rotary, Elks, Lions, Knights of Columbus, etc.

- **Business sponsors:** home care companies, residential communities, “Main Street” businesses, etc.

- **Collaborating organizations:** library, residential community, dementia friendly community initiatives, YMCA, faith-based organizations

- **In-kind:** food (ask grocery stores, restaurants, residential communities), art supplies, guest artist honoraria

- **Participant donations:** in honor/memory of; donation jar or donation envelopes at café gatherings, annual or bi-annual solicitation

- **Participant fees**

- **Fundraising events:** annual pledges, gala events, etc.
Pearls from Café Coordinators

• Nicolette McDermott-Ketchum, Hummingbird Memory Café, Nevada
• Gail Sonnesso, Harmony Café, North Carolina
• Kathi Hayen, Memories in the Making, Wisconsin
• Vicky Pitner, Engaging in Life!, Florida
• Mary E. MacDonald, Rest.Stop.Ranch, Massachusetts
Discussion
Save the date!

Next Percolator Idea Exchange is Thursday, September 14, 1:30 – 3:30 EDT

Learn about:

• Café de los Recuerdos, Elgin, Illinois

• Dementia Action Alliance: debrief from Café Chats; promoting leadership and engagement among your café participants

Coming in December:

• Memory Café Nova Scotia – launching a network of rural cafés

• Update on Alzheimer’s Association resources for your café

Please let Beth know if you’d like to present your café or suggest a topic for a future idea exchange!
JF&CS Memory Café Percolator
Quarterly Idea Exchange
Wednesday, June 14, 2023

For more than 150 years, Jewish Family & Children’s Service has been helping individuals and families build a strong foundation for resilience and well-being across the lifespan.