Understanding the Respite for All Model: Experiences of People Living with Dementia, Caregivers, and Community Members at R Place

GILLINGS SCHOOL OF GLOBAL PUBLIC HEALTH

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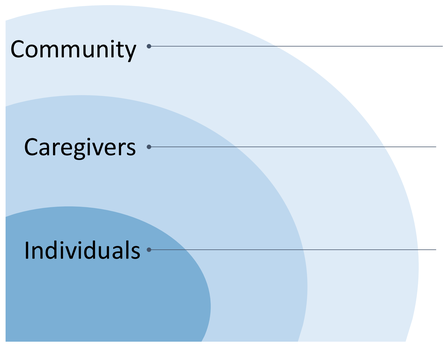
Background

- 1 in 10 adults over 65 in the US experience dementia.
- Dementia prevalence is expected to double by 2060.



High Healthcare Need
- 345 billion per year
- 3x higher average Medicare payments

11 Million Unpaid Caregivers
- 18 billion hours per year
- $339.5 billion per year
- Caregiver Burden

People Living with Dementia
- People living with dementia in the community are **two times** as likely to need support

- Social support is provided formally and informally by non-medical professionals. Social support can be instrumental, informational, and socio-emotional.
- Respite care refers to short-term caregiving services and are classified as an instrumental social support. It is associated with:
  - Reduced caregiver burden and a lower prevalence of depression.
  - Reduced risk of institutionalization for people living with dementia.
- Despite these benefits, access to respite care varies, and it is often underutilized.
- The Respite for All (RFA) model is a framework to deliver respite care through faith-based and community organizations.
  - It is based on a volunteer and social model of care; no medical services are offered during RFA programming.
  - There is a one-to-one or even two-to-one ratio of volunteers to PLWD, and programming can be offered at low cost to participants.
  - The RFA model targets people living with mild to moderate dementia in the community.
  - The model has spread across the country, with 50 iterations of the program spread across 15 states.
- R Place is a derivative of the RFA model in Orange County, North Carolina. The program serves 15 PLWD and their caregivers. It is secular and ran through a local Area Agency on Aging (AAA). It is once a week for four hours.
  - It was selected as a case as it is situated within a resource-rich area for dementia and aging supports. Additionally, it is one of the few secular RFA programs.

Methods

- **Study design:** Qualitative program evaluation based on key informant interviews with RFA leaders and in-depth interviews with people living with dementia, caregivers, and volunteers at R Place.
- **Eligibility criteria:** All RFA program leaders were eligible to participate, including program directors and other leaders. People living with dementia (PLWD), caregivers, and volunteers were eligible to participate if they had participated at R Place for 6+ months. PLWD had to answer a set of comprehension questions prior to the interview and have consent from a legally appointed representative.
- **Qualitative thematic analysis:** Thematic analysis was performed using Braun and Clarke's approach. Transcripts were first read twice. An initial set of codes were generated based on the interview guide and an analysis of memos. A deductive-inductive line-by-line approach was used, and codes were generated on Dedoose. One researcher coded all of the transcripts. Codes were then grouped into themes, and the themes were reviewed and defined.

Results

Sample Characteristics

RFA Program Characteristics (total n=6):

	Program 1	Program 2	Program 3	Program 4	Program 5	Program 6
Participants	7	16	15	9	60	
Volunteers	23	36	28	40	200	
Staff	2	1	2	1	3	
Days per Week	1	1	1	2	4	
Waiting List	0	21	5	9	24	
Host	Church	Church	AAA	Church	Church	Church

PLWD Characteristics (total n=3):
- PLWD were White (n=3).
- PLWD were female (n=1) and and male (n=2).
- PLWD were older than 65 (n=3).

Caregiver Characteristics (total n=5):
- Caregivers were Asian (n=1), White (n=3), and Multiracial (n=1).
- Caregivers were female (n=4) and male (n=1).
- Caregivers were spouses (n=4) and children of PLWD (n=1).

Volunteer Characteristics (total n=5):
- Volunteers were Black (n=1) and White (n=4).
- Volunteers were female (n=4) and male (n=1).

RFA Model

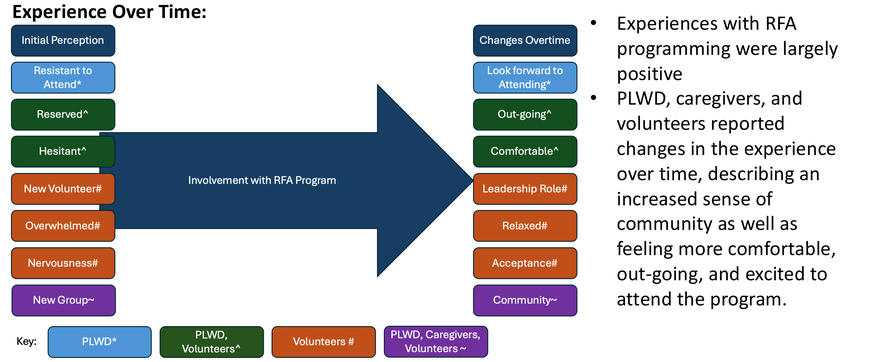
Program Goals:	Inputs	Activities	Outputs	Short-Term Impact	Long-Term Impact
• Dementia Awareness • Acceptance • Engagement • Community • Reduce Isolation • Reclaim Joy • Improve Well-being • Purpose	PLWD Caregivers Volunteers 1:1 PLWD to Volunteer Ratio Funding Space Materials	Recruit and onboard PLWD and caregivers Recruit and train volunteers Develop weekly programming Manage logistics Apply for Funding Connect PLWD and caregivers to other informational, socio-emotional, and instrumental supports Build relationships and a sense of community	Respite care is provided once a week for 4 hours PLWD and Caregivers are connected to additional social support Community is engaged in dementia care	Increased social support for PLWD and caregivers Increased engagement of PLWD Autonomy for PLWD Dementia Awareness	Improved well-being of PLWD, caregivers, and volunteers Increased preparation of caregivers for later stages Dementia Friendly Community Building Sense of Acceptance for PWLD Sense of purpose for PLWD, volunteers, and leadership Capacity for leadership

Facilitators and Barriers

	Program Operation	Programming	Program Access
Facilitator	volunteer availability, organizational support, systems, leadership, donations, marketing, and collaboration	positivity, accessible programming, flexibility, redirection, communication, collaboration, and routine	word-of-mouth, diverse volunteers, geographic proximity, feedback, inclusivity, other program supports, maintaining connection with caregivers, and remembering participants
Barrier	recruitment, learning curve, resources, loose network, rapid growth, burnout, volunteer turnover, and infectious disease	unstructured times, unpredictability, volunteer roles, behaviors, group dynamics, physical challenges, security	stigma, cultural beliefs, capacity, awareness, lack of trust, geographic limits, limited diversity, dementia progression, and cost

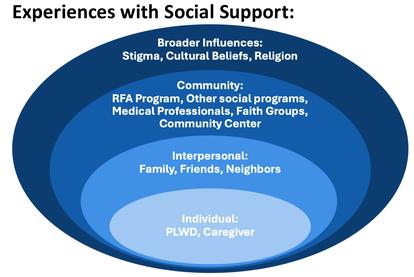
Experiences of PLWD, Caregivers, and Volunteers

Experience Over Time:



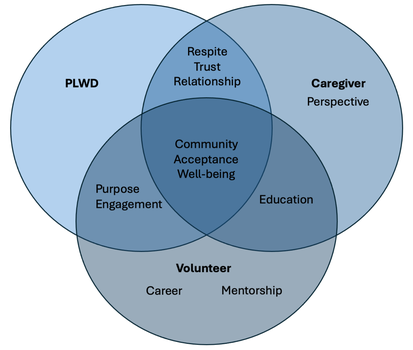
- Experiences with RFA programming were largely positive
- PLWD, caregivers, and volunteers reported changes in the experience over time, describing an increased sense of community as well as feeling more comfortable, out-going, and excited to attend the program.

Experiences with Social Support:



- RFA programming was one source of social support for people, but other factors influenced PLWD and caregivers' overall experience.

Program Impacts:



Discussion

This study is the first qualitative evaluation of the RFA model. It lays an important foundation for future and potentially more rigorous evaluations.

- **Distinguishing Aspects:** Multiple stakeholders expressed that the RFA model was distinct from similar respite and adult day programs, citing its replicability, person-centered care (label-free environment; positive and home environment), and high engagement (1:1 ratio of PLWD to volunteers; active environment; participation; community).
- **Alignment between Goals and Impacts:** Across all four stakeholder groups, six key themes consistently emerged: acceptance, well-being, purpose, engagement, social support, and community. The high level of concordance between the goals and impacts described by PLWD, caregivers, and volunteers suggests that the model is performing well.
- **Key Facilitators and Barriers:** There were key barriers to program operation, programming, and access, as well as facilitators. Considering these facilitators and barriers is critical as the program grows.

Limitations

- **Small Sample Size:** The sample size for each group was small, resulting in limited generalizability.
- **Confounding Factors:** There are many factors which could have contributed to the reported impacts of the program, as PLWD and caregivers are frequently engaged in multiple support programs and medical care.
- **Self-Selection Bias:** RFA leaders, PLWD, caregivers, and volunteers who are more engaged with the RFA Model might have been more likely to participate.

Future Directions

- **Rigorous Evaluation:** Quantitative evaluation of reported impacts is needed.
- **Strategic Planning:** The RFA model should also work to develop strategic plans around facilitators and barriers to enhance the experiences of key stakeholders.

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