

CARE³ (Care Cubed)

Piloting a Caregiver Support Intervention in Chennai, India: Lessons Learned and Next Steps



A collaboration between IIT-M's RTBI and Rama Murali

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What are the issues around Aging and Eldercare in India today?

India facing elderly population time bomb

India is facing an elderly population 'time bomb' according to a United Nations report which revealed its number of old people will triple by 2050.



The report warned that India's current hospital and welfare services are insufficient for the strain they will face as the pace of population ageing increases. Photo: GETTY

By Dean Nelson, New Delhi

Print this article

- 100 million Elderly (over 60 years of age) in India
- 47% of older Indians have at least one chronic disease
- Family Support is decreasing
- By 2050, number of elders will triple to over 300 mil
- 45% of India's disease burden is projected to be borne by older adults in 2030

Issue of Aging/increase in Elderly population in India is a Public Health Issue

FAMILY CAREGIVERS (FC) are the Backbone of Eldercare

- Families have been caring for their elders for centuries
- Hospitals are for emergencies and procedures
- There are not many places for long term care of the elderly/infirm in India
- Care for elders and chronically ill predominantly takes place in home



Challenges of a FC based system for Eldercare

- Types of illnesses that are emerging as we age are more complex and difficult to manage
- FC have limited support
- Physical and emotional health risks to FC
- If we do not begin to address the needs and health of FC, the backbone of the ElderCare system will collapse



In India, Family Caregiver Health is a major Public Health Issue

Pilot a Solution: Build a Peer Support Driven FC Network



- Social support has been shown as a low-cost and effective platform to improve mental/ physical health
 - Allowing sharing and decompressing in a safe and communal environment
 - Fostering peer connections to buffer against stress
 - Helping FC see they are not alone
 - Providing a platform to focus on their needs
 - Empowering FC to help each other



Piloting A FC Support Network



- From January 2013-January 2014 we piloted a FC Support Network model
- This pilot was to determine:
 - (1) whether a social support model, among previously unacquainted FC, would be accepted in Chennai
 - (2) the pressing needs of FC
 - (3) the optimal structure of meetings to keep FC engaged
 - (4) how to recruit FC to the network

Initial Recruitment

- Recruitment Period: Jan 2013-March 2013
- Recruitment Strategy:
 - Doctors/Hospitals – Initial Line, limited success (1)
 - Local Media – Second Line, highly successful (24)
- 25 FC recruited to attend an initial meeting which was treated as a needs assessment; 22 attended



*Article on FC Pilot Program in EVE'S
TIMES April 2013 Magazine*

Needs Assessment: What We Learned

- Interest in topics to help caregiving:
 - caring for bedridden patients
 - palliative care
 - cancer care
 - how to get more information from providers on disease management
- FC willing to open up in peer environment on emotional dynamics of caregiving
 - Guilt
 - “Why me?”
 - Caregiver Burnout

Information on RELIABLE HEALTH CARE SERVICES available in Chennai was *top need*



Monthly FC Meetings: April 2013-January 2014



- 9 monthly FC meetings
- Meeting structure established
 - Guest Speaker/Wellness Session, Informal Tea Time, Group Discussion
- Reaching out to FC:
 - Media (50%)
 - Word of mouth (36%)
 - Referrals from other FC/speakers/network of supporters/etc.



Article in **Times of India**, October 2013

Building FC Support Network



CARE³ (Care Cubed): Caring for Caregivers

- Our name comes from the vision that our programs will support Caregivers in:
 - (1) Caring for themselves
 - (2) Caring for their loved one
 - (3) Caring for other Caregivers
- Together these levels of care can have an exponential effect in building a strong and vibrant community of Caregivers



A CARE³ Support Network Meeting, May 2013, Mylapore



“The meetings have encouraged me to think about myself without guilt. [FC] are expected to play the part without complaint and are made to feel guilty if we think about our own well-being.”

- Mrs. B.K., a FC for her 72-year-old husband with Dementia

Caregivers Connected with CARE³



- Total Caregivers (Current and Former) that we have connected with = 131
- Current Caregivers (n=111), former caregivers (n=20)

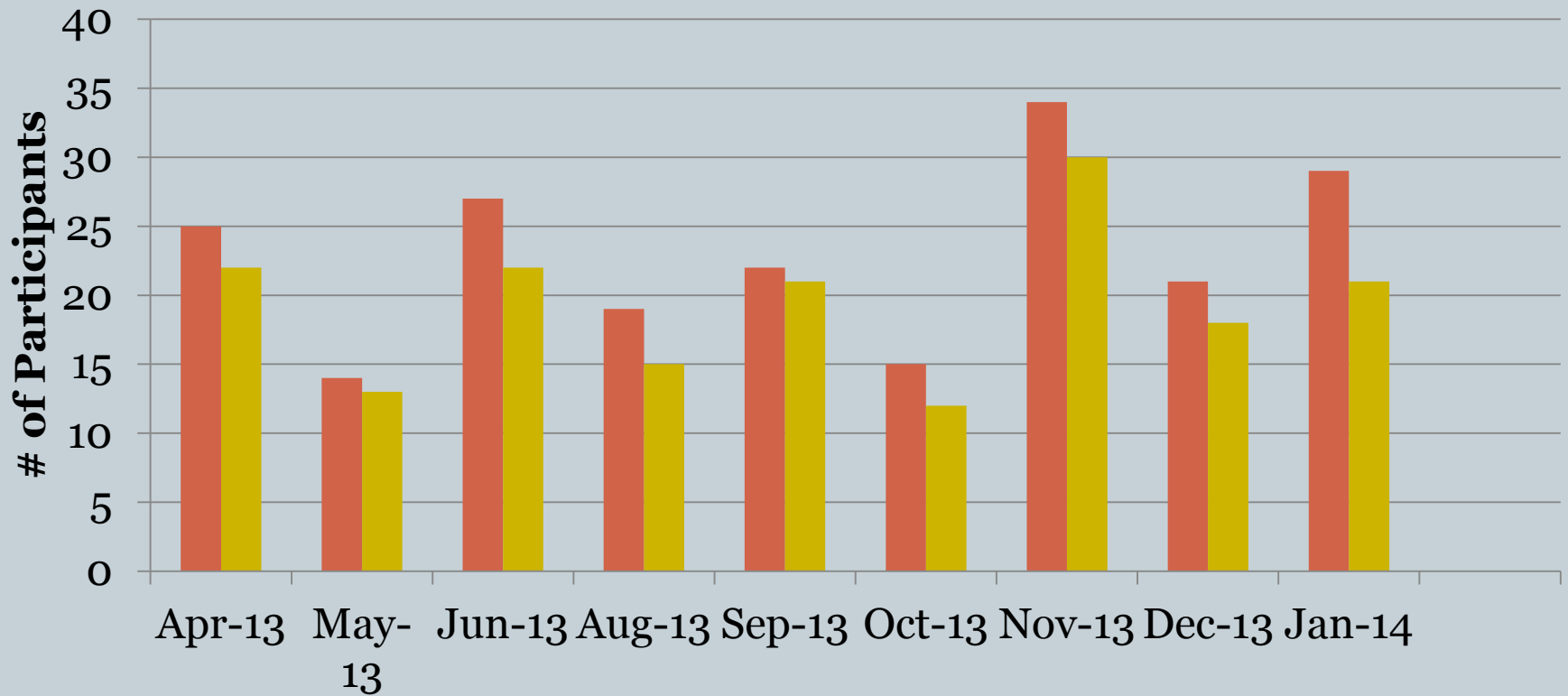
Family Caregivers (Total 126)	Current	Former
Female	70	14
Male	41	6
Total	111	20

Data as of Feb 1, 2014

Monthly Meeting Attendance



- Total Participants (Including Caregivers/Guests/Patients)
- Current/Former Caregivers



Data as of Feb 1, 2014

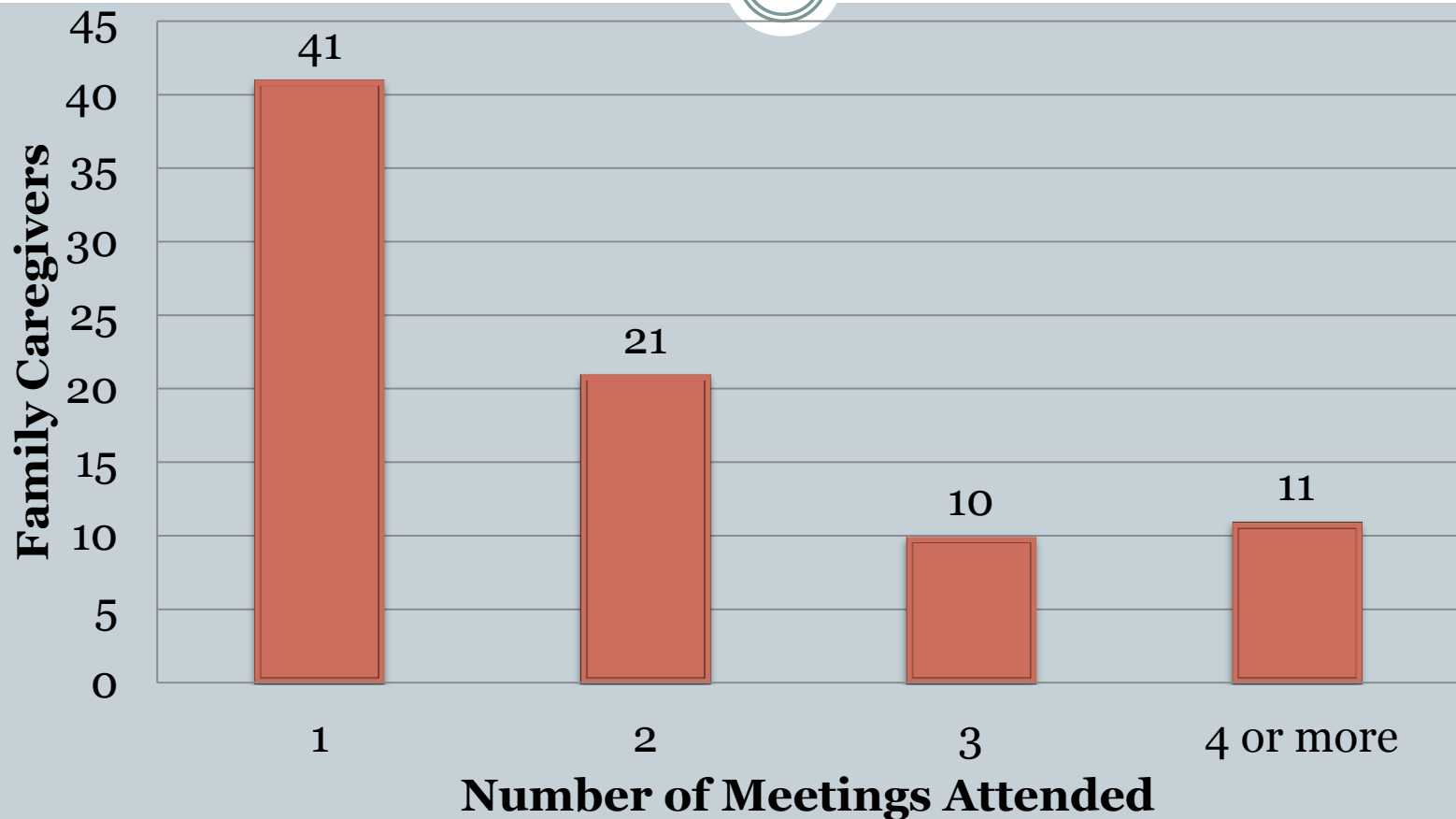
Self and Family Care

Experts speaking
about patient care



Activities focused
on self-care

Monthly Meetings – Repeat Attendees



- 83 Unique Caregivers have attended meetings thus far
- 9 Meetings have taken place since April 2013

Data as of Feb 1, 2014

Building a Peer Support Group



Caregivers
Connecting during
our monthly
meetings



Primary Illnesses/Diagnoses/Conditions of Family Members Being Cared For



Primary Illness/Diagnoses/Conditions	Number
Stroke	19
Aging	14
Aging with mobility	14
Dementia	11
Mental Illness	8
Developmental Disabilities	6
Parkinson's Disease	6
Bedridden	4
Spinal cord injury	4

Data as of Feb 1, 2014

Primary Illnesses/Diagnoses/Conditions of Family Members Being Cared For



Primary Illness/Diagnoses/Conditions	Number
Alzheimer's Disease	3
Unspecified neurological/neurodegenerative conditions	3
Parkinson's and dementia (comorbid)	2
Diabetes	2
Multiple Sclerosis	2
Spinocerebellar Ataxia	2
Cancer	1
Pulmonary fibrosis	1
Alzheimer's and stroke (comorbid)	1
Traumatic head injury	1

Data as of Feb 1, 2014

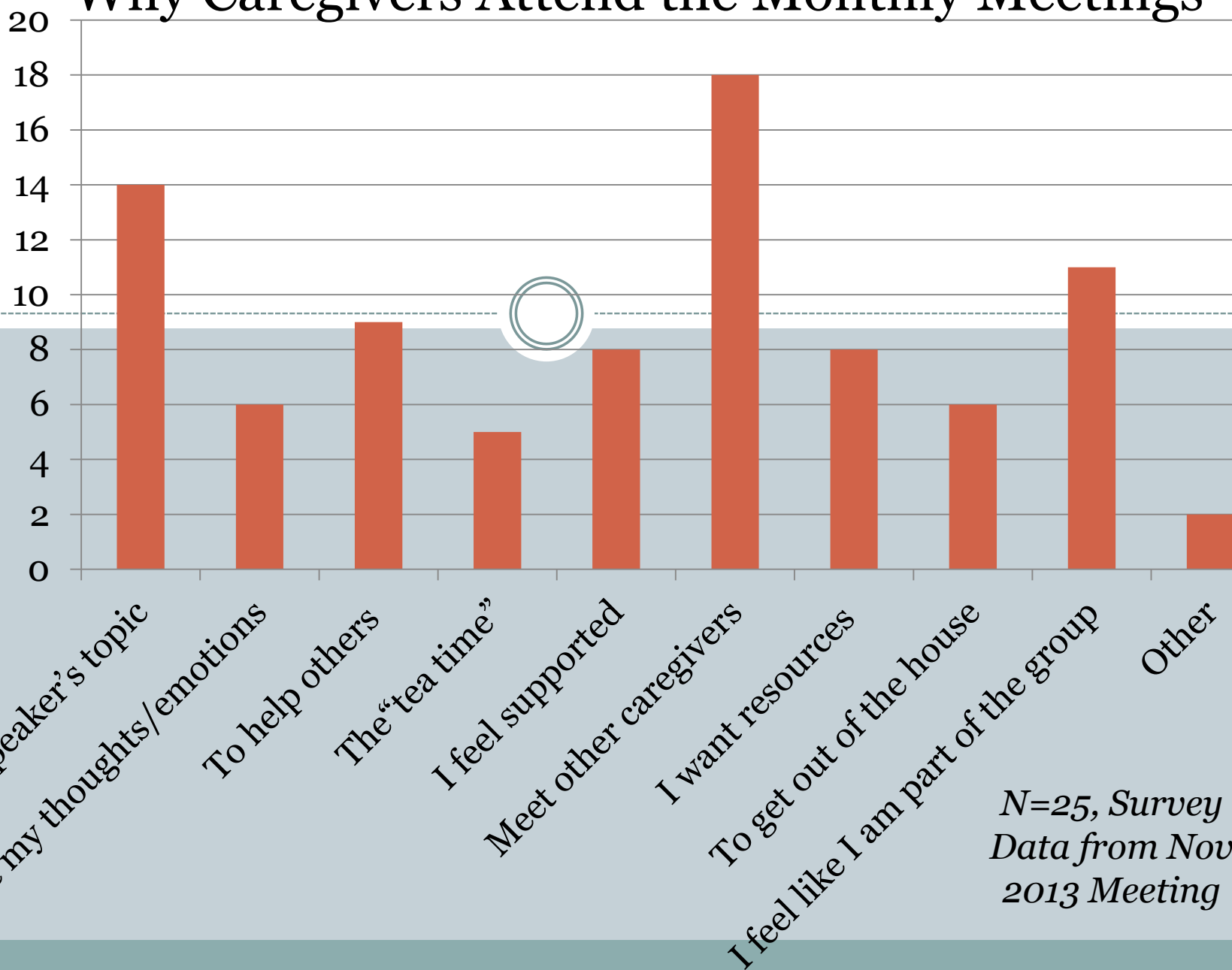
Family Member being Cared For



Family Member who Requires Care	Number
Mother	29
Husband	21
Father	14
Wife	12
Son	7
Parents	6
Mother-in-law	5
Sister	2
Parents-in-law	2
Father –in-law	2
Other	3

Data as of Feb 1, 2014

Why Caregivers Attend the Monthly Meetings



Next Steps



- **Challenges:**

- Many FC cannot come to meetings
- Connecting FC for rest of the month
- Recruiting more FC into the group
- Addressing need for reliable health care resources
- Funding the program



CARE³ Program Components

Peer Support Network

- Building a community of Caregivers that will be the heart of this initiative
- Connecting Caregivers in person and virtually
- Monthly Support Groups
- Mobile/Web based platforms

Build Capacity to Care for self/others

- Provide ongoing education during in person meetings
- Using mobile/web based technology to deliver education/ messages
- Content is driven by caregiver needs

Resource Linkages and Directory

- Caregiver Crowd sourced Resource Directory/Local Resources/Rating System
- E-portal to manage the relationships between Caregiver and vetted and sensitized Hospital/Scan Center/Lab/Taxi (i.e. scheduling transport for hospital visits or intake for scans)

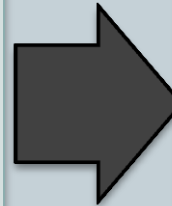
Trained Volunteer Corps

- Trained in Home-based Respite Care
- Students/Other Interested Volunteers
- Build awareness across generations

Snapshot: 2014-2015

Where we are

- Over 100 Caregivers from Chennai connected to network
- Monthly Caregiver support network meetings ongoing since April 2013
- Dozens of home visits to Caregivers for counseling
- RTBI website technology
- Resources systematically gathered to build directory
- Volunteer training development underway with international technical support
- 4 Colleges approached for Volunteer recruitment
- Speaker's Bureau for meetings has over a dozen professionals
- Program is being driven by Rama Murali full time, with mobile technology and technical support from IIT-M's RTBI, and one full time staff (from Jan 2014) supported by RTBI



Where we want to be (June 2015)

- Small , strong team to manage the network and programs
- 200+ active members of the network
- Improved self-reported stress, knowledge, and social support by caregivers in network
- User friendly web and mobile phone apps used by 50% of caregiver network
- Comprehensive resource directory on website and reviewed by Caregivers
- Existing home health care agency staff trained in specialized patient care (dementia and other neuro illnesses)
- Trained peer caregivers leading 2-3 monthly network meetings across Chennai
- Hospitals referring new caregivers into the program
- Healthcare vendors incorporating quality caregiver/ elder needs into services
- Growing based of trained college volunteers providing respite care
- Diversified funding



CARE. CONNECT. COMMUNITY.

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