From Contact to Meaningful Connection: Challenges and strategies in research to address loneliness among people with dementia

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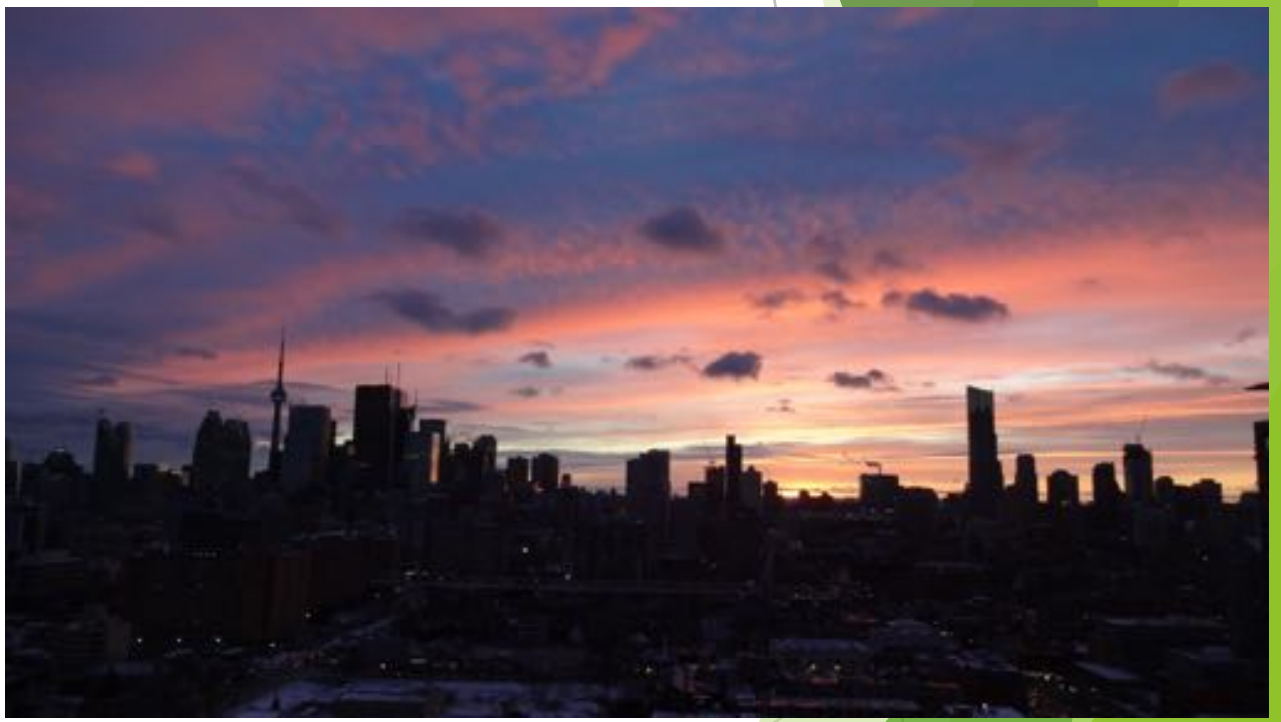
Outline

- The stakes are high
  - Opportunities for quality of life when living with dementia
  - Loneliness hurts
  - Intervention development is needed
- Challenges and strategies
  - Definitions
  - Building intervention theory, understanding effects
  - Addressing stakeholder concerns
  - Measuring outcomes
  - Feasibility (and working in the real world)

High Stakes:
See opportunities for quality of life



Factors that Affect Quality of Life from the Perspective of People with Dementia: A Metasynthesis

Hannah M. O'Rourke, BScN, Wendy Duggleby, PhD,* Kimberly D. Fraser, PhD,* and Lauren Jerke, MA†*

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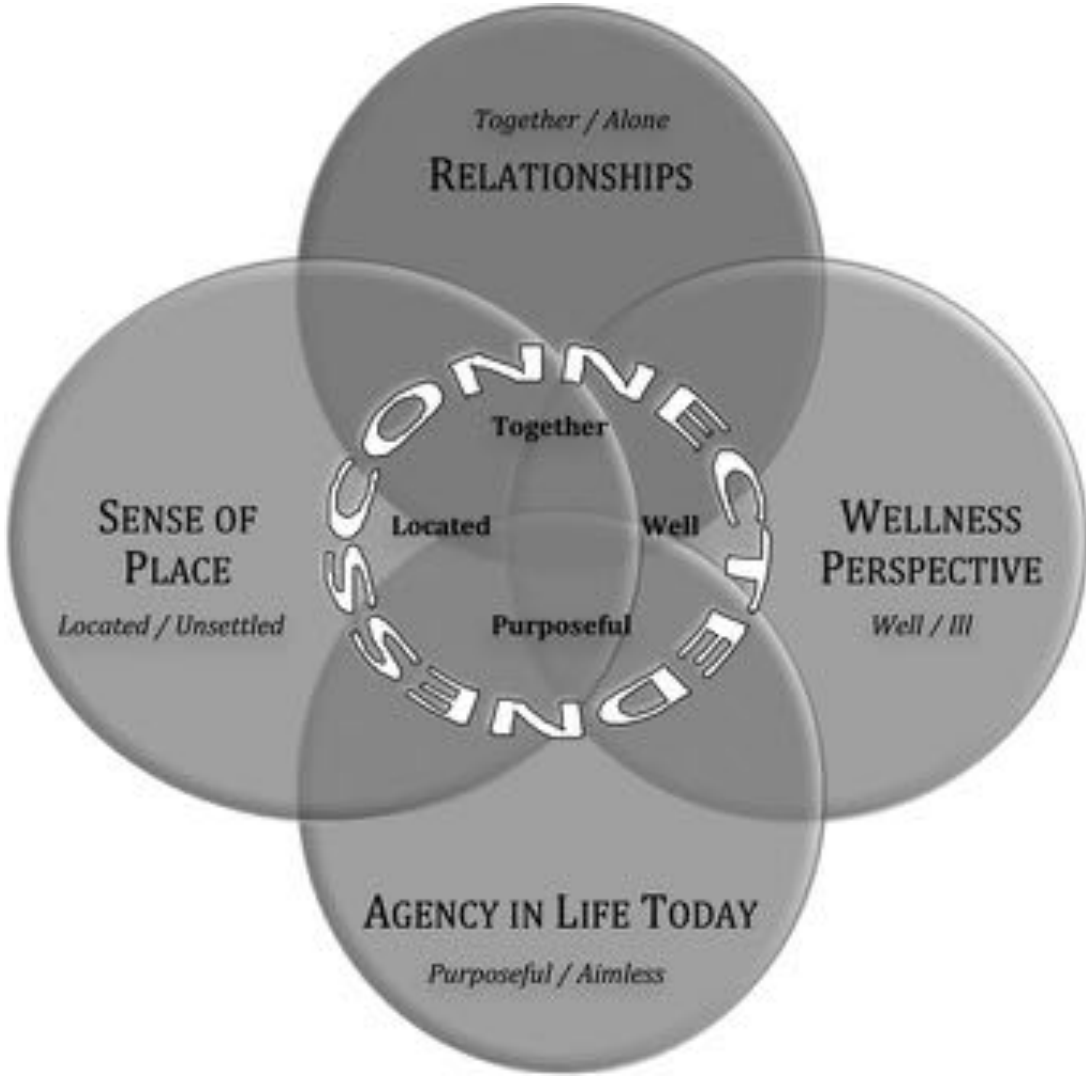

High Stakes

Loneliness and Social Isolation as Risk Factors for Mortality: A Meta-Analytic Review

Julianne Holt-Lunstad[1], Timothy B. Smith[2], Mark Baker[1], Tyler Harris[1], and David Stephenson[1]

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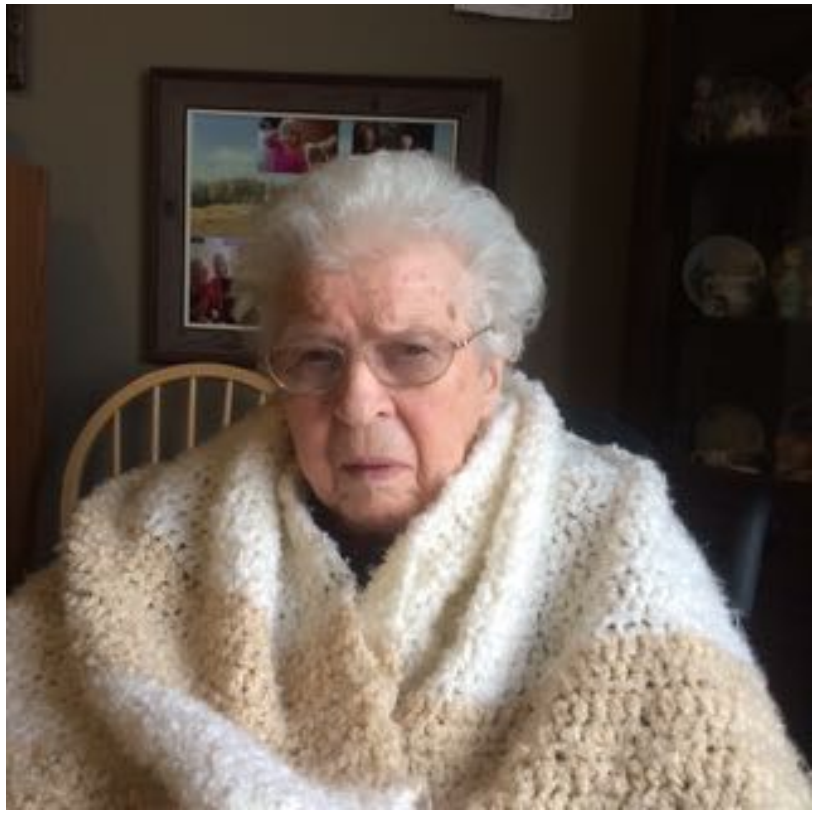
Table 3. Weighted Mean Effect Sizes (Odds Ratios) by Type of Measurement

Measure	*k*	OR_+	*SE*	95% CI
Unadjusted data[a]				
Fully adjusted data[b]				
Social isolation	14	1.29	0.100	[1.06, 1.56]
Living alone	25	1.32	0.075	[1.14, 1.53]
Loneliness	13	1.26	0.099	[1.04, 1.53]
Overall	52	1.30	0.116	[1.16, 1.46]

Note: *k* = number of studies; OR_+ = random-effects weighted odds ratio; CI = confidence interval.
[a]Typically one or two covariates, most often age and gender. [b]Data from the statistical model in studies that contained the most covariates; these adjusted data yielded effect sizes that were statistically significantly ($p < .05$) smaller than unadjusted data.

From Holt-Lundstad et al 2015, p. 231

We must address loneliness



Interventions to Promote Social Connectedness and Quality Of Life for Older Adults With Dementia and their Family Caregivers

A program of research

Challenge 1: Conceptual clarity

- What are we talking about, really?!?

Social Isolation vs. Loneliness

Table 1. Descriptive Coding of the Measures Used to Assess Objective and Subjective Isolation

Type of measure	Description	Example of measure
Objective		
Social isolation	Pervasive lack of social contact or communication, participation in social activities, or having a confidant	Social Isolation Scale (Greenfield, Rehm, & Rogers, 2002) Social Network Index (bottom quartile; Berkman & Syme, 1979)
Living alone	Living alone versus living with others	Binary item: yes, no Number of people in household
Subjective		
Loneliness	Feelings of isolation, disconnectedness, and not belonging	Loneliness Scale (De Jong-Gierveld & Kamphuis, 1985) UCLA Loneliness Scale (Russell, Peplau, & Cutrona,1980)

Note: UCLA = University of California, Los Angeles.

From Holt-Lundstad et al 2015, p. 229

Definition, Determinants, and Outcomes of Social Connectedness for Older Adults

A Scoping Review

Hannah M. O'Rourke, PhD, RN; and Souraya Sidani, PhD

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The opposite of loneliness, a subjective evaluation of the extent to which one has meaningful, close, and constructive relationships with others.

Operationalized as:
a) caring about others and feeling care about by others AND
b) feelings of belonging to a group or community

A few influencing factors

TABLE 2

DETERMINANTS OF SOCIAL CONNECTEDNESS PROPOSED ACROSS INCLUDED INVESTIGATIONS (*N* = 23)

Category	Investigations (*n*, %)	Definition	Reference
Social network	8 (35)	The structural characteristics of one's social ties	Ashida & Heaney, 2008a; Easton-Hogg, 2013; Hawkley, Browne, & Cacioppo, 2005; Hawkley, Gu, Luo, & Cacioppo, 2012; Mellor, Firth, & Moore, 2008; Pan, 2011; Van Orden et al., 2013
Age	6 (26)	Years of age	Chaves, 2008; Hawkley et al., 2005; Hawkley et al., 2012; Pan, 2011; Stanley, Conwell, Bowen, & Van Orden, 2014; Zelenka, 2011
Technology use	4 (17)	Whether the individual was able to use and had access to technology (e.g., webcam, computer, internet)	Culley, Herman, Smith, & Tavakoli, 2013; Easton-Hogg, 2013; Mellor et al., 2008; Pan, 2011
Marital status	4 (17)	Whether one is married, widowed, divorced, single, or in a common-law relationship	Hawkley et al., 2005; Hawkley et al., 2012; Pan, 2011; Zelenka, 2011
Group membership	3 (13)	Formal affiliation with a recognized group	Hawkley et al., 2005; Hawkley et al., 2012; Pan, 2011
Sex or gender	3 (13)	Whether one is male or female, or a man or woman	Chaves, 2008; Hawkley et al., 2012; Pan, 2011; Van Orden et al., 2013
Living arrangement	3 (13)	Whether one lives alone or with a spouse or others	Hawkley et al., 2012; Kim, Hong, & Kim, 2015; Stanley et al., 2014
Income	3 (13)	Yearly household income	Hawkley et al., 2012; Pan, 2011; Zelenka, 2011
Social support	2 (9)	The provision or receipt of emotional (e.g., expression of empathy), instrumental (e.g., a service), informational (e.g., advice), or appraisal (e.g., information) support	Ashida & Heaney, 2008a; Pan, 2011
Self-reported health status	2 (9)	An overall assessment that an individual makes about his/her own health (e.g., excellent, good, fair, bad, poor)	Pan, 2011; Zelenka, 2011

From O'Rourke & Sidani JOGN p. 5

Challenge 2: Intervention design & adaptation

- Limited intervention theory
- Importance of active ingredients
- Can adapt what has been used with cognitively intact older adults

O'Rourke *et al. BMC Geriatrics* (2018) 18:214
https://doi.org/10.1186/s12877-018-0897-x

BMC Geriatrics

RESEARCH ARTICLE Open Access

Interventions to address social connectedness and loneliness for older adults: a scoping review

Hannah M. O'Rourke[1*], Laura Collins[2] and Souraya Sidani[2]

Promising interventions

- **Personal contact**:
  - Scheduled (but un-scripted) one-to-one contact with a human or animal
  - Face-to-face
  - 30 to 60 minutes, once per week, for 6 to 12 weeks

- **Group activity**:
  - Joining a new group of 5-9 people, and engaging in an activity of interest AND with each other
  - Face-to-face
  - 1.5 hours, once per week, for 6 weeks

Challenge 3. Addressing stakeholder concerns

- Part of adaptation is understanding perspectives of key stakeholders
  - People with dementia
  - Their family and friends
  - Health care providers

- Referred to as acceptability

Sidani, S., Epstein, D. R., Bootzin, R. R., Moritz, P., & Miranda, J. (2009). Assessment of preferences for treatment: validation of a measure. *RINAH, 32*, 419–431. doi:10.1002/nur.20329

Acceptability of Personal Contact & Group Activity Interventions

- Mixed methods (concurrent triangulation) design
- Convenience sample of family, friends, and health care providers of people with dementia (n=25)
- Acceptability ratings
  - Intervention descriptions + 6 items to assess perceptions, adapted from Treatment Acceptability and Preference measure *(Sidani et al., 2009)*
- Semi-structured interviews explored perspectives in more depth
- Descriptive statistics, conventional content analysis

Sample

- 56% (n=14) women
- Age: range 23-65; mean=41.76 (SD 12.03)
- 9 Health Care Providers, 16 Family/Friends
- For the 36% (n=9) Health Care providers
  - 3 HCA, 2 RN, 4 LPN
  - 2 home care, 7 LTC

Acceptability measure

- Questions are about whether the intervention is effective, logical, suitable, easy, and whether they are willing to participate
- 5 point scales for each question. Example:

  0=not effective at all

  1=somewhat effective

  2=effective

  3=very effective

  4=very much effective

- An additional question asks about risk (0=not bad at all to 4= very much bad)

Acceptability ratings

Item	Human Contact				Animal Contact				Group Activity			
	≥2 % (n)	2 % (n)	3 % (n)	4 % (n)	≥2 % (n)	2 % (n)	3 % (n)	4 % (n)	≥2 % (n)	2 % (n)	3 % (n)	4 % (n)
Effect	96 (24)	24 (6)	44 (11)	28 (7)	84 (21)	36 (9)	32 (8)	16 (4)	92 (23)	32 (8)	44 (11)	16 (4)
Logic	100 (25)	32 (8)	52 (13)	16 (4)	88 (22)	32 (8)	40 (10)	16 (4)	96 (24)	36 (9)	52 (13)	8 (2)
Suitability	100 (25)	20 (5)	28 (12)	32 (8)	80 (20)	24 (6)	40 (10)	16 (4)	88 (22)	20 (5)	52 (13)	16 (4)
Ease	68 (17)	28 (7)	32 (8)	8 (2)	72 (18)	28 (7)	36 (9)	8 (2)	36 (9)	24 (6)	8 (2)	4 (1)
Willingness to participate	72 (18)	36 (9)	28 (7)	8 (2)	72 (18)	32 (8)	28 (7)	12 (3)	44 (11)	24 (6)	8 (2)	12 (3)

Risk severity

- Animal contact rated the riskiest of the 3 interventions, but:
  - 56% still rated the risk as ‘not bad at all’
  - 40% ‘somewhat bad’
- Group activity was viewed as low risk
  - 64% ‘not bad at all’
  - 32% ‘somewhat bad’
- Human contact was seen as the least risky
  - 72% ‘not bad at all’
  - 24% ‘somewhat bad’

Group activity interventions

Why rated less easy to deliver?

Why lower willingness to participate?

Focus, Attention

Because the attention span for a person with dementia it will not last for an hour. You'll get lucky maybe if you get an hour of attention coming from a dementia client. But 30-45 minutes it's like manageable for them, like the attention (HCP)

Assumptions, Stigma

Just simply on the basis that, you know, an extended period of time once and if that person doesn't have any recollection of it the impact may be lost on them." (FF)

I mean, again, if they're not capable of speaking and expressing their mind, what good would this do? They're better off just talking to a dog. (FF)

Personal contact interventions

Why animal contact somewhat lower in perceptions of effective, logical, suitable?

Human Contact

"Dementia clients need people around them…They need to feel loved, they need to feel respected, they need to feel valued…This one-on-one makes them feel more human. Normally people with dementia…need somebody around. So this is an advantage if they get that one-on-one, this is an advantage" (HCP)

Animal Contact

"…they have different preferences. So if this person likes cats, the other one likes dogs, the other one likes monkeys, so if you are to give each client the kind of pet that person likes, that means you have five patients, you have five different pets." (HCP)

"if someone is an animal lover and the person tries, is not very social, you know, not social with other residents and that in the home, you know, that's something that they can do with themselves. You know, just spend time with the animal, give them comfort." (FF)

To sum up

- All three types of interventions appear promising and low risk.
- Individualizing interventions was important
- Future phase 2 trials should focus on assessing feasibility and acceptability of flexible personal contact and group activity interventions, and on the experiences and perceptions of people with dementia that receive interventions.

Challenge 4: Measuring outcomes

- Loneliness/ social connectedness **is a feeling** and is self-reported
- Exclusion of people with dementia from intervention studies

Table 1 Key characteristics of included studies (*N* = 44)

Characteristic	% (N)
Cognitive Impairment	
Cognitively intact	31.8% (14)
Not reported	31.8% (14)
Included some people with mild impairment	29.5% (13)
Majority cognitively impaired to a mild, moderate or severe degree	6.8% (3)

From O'Rourke et al., 2018, p. 5

Some options

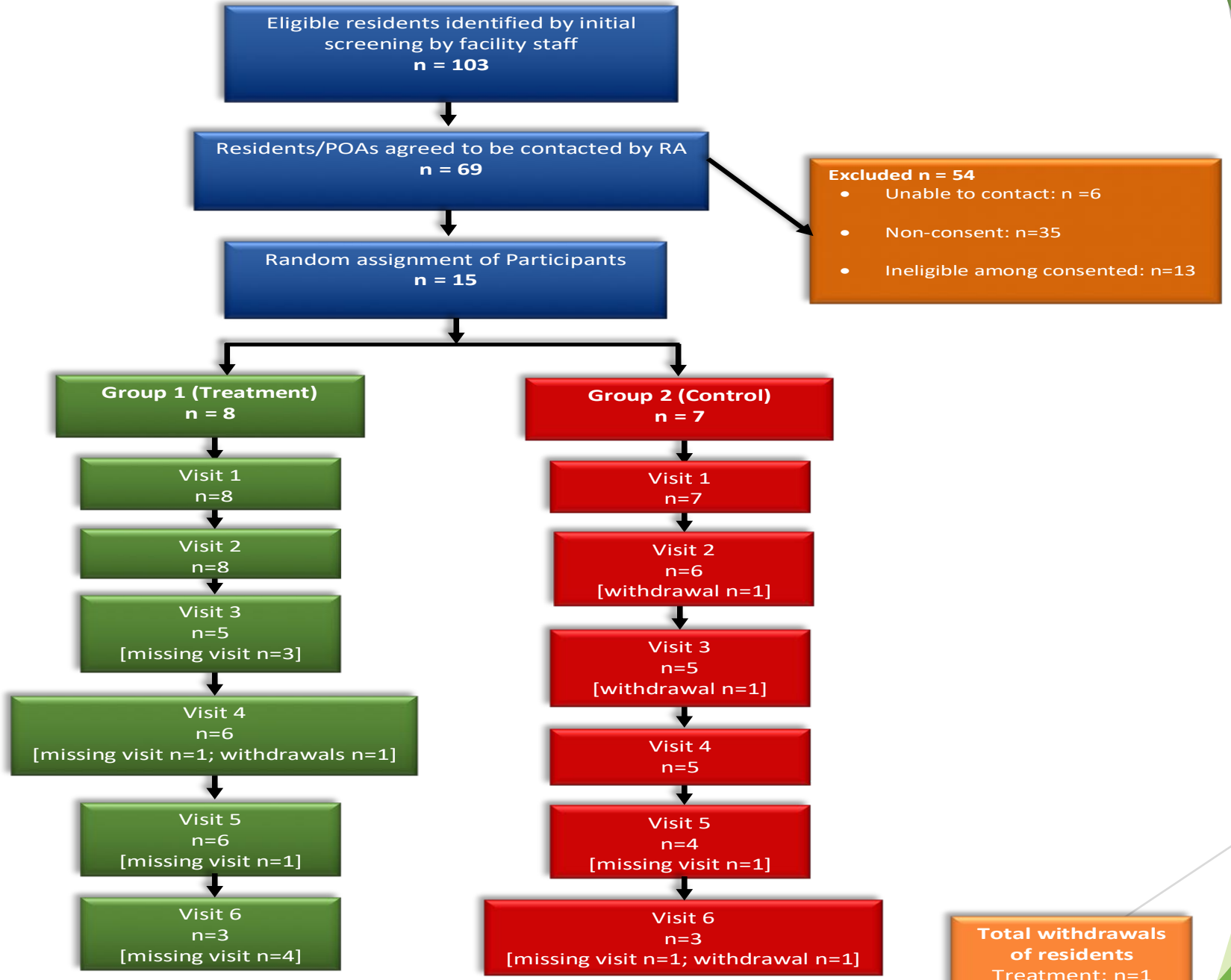
- Measures have been used to assess loneliness among people living with dementia
  - E.g., 3-item loneliness scale (Hughes et al. 2004)
  - But limited validation
- What about relevant QOL subscales?
  - E.g., DEMQOL *social relationships* (Banjeree et al, 2006)
  - E.g., Dementia Quality of Life *social belonging* (Brod et al, 1999)
  - Not perfect, but good enough?
- Look at other indicators that may be linked with loneliness
  - E.g., Engagement, behavioral and psychological symptoms of dementia
  - Need to develop and test theory of links AND measure indicators in meaningful ways

Challenge 5. Intervention feasibility

- What is possible during the research and after it ends?

Example: *Connecting Today* Pilot

- Pilot to assess feasibility and acceptability of a personal contact intervention
- Active ingredient: increasing the amount of time that a person with dementia spends with a visitor while residing in long-term care
  - The person with dementia chooses a family member, relative, friend or a volunteer to talk or spend time with, and interacts with the same contact person for all sessions.
  - Visits occur face-to-face or over the phone
  - Visits are scheduled for a minimum of 30 minutes, once per week, for 6 weeks.
- People with dementia and family asked about perceptions of the visits


Eligible residents identified by initial screening by facility staff
n = 103
Residents/POAs agreed to be contacted by RA
n = 69
Excluded n = 54
Unable to contact: n =6
Non-consent: n=35
Ineligible among consented: n=13
Random assignment of Participants
n = 15
Group 1 (Treatment)
n = 8
Visit 1
n=8
Visit 2
n=8
Visit 3
n=5
[missing visit n=3]
Visit 4
n=6
[missing visit n=1; withdrawals n=1]
Visit 5
n=6
[missing visit n=1]
Visit 6
n=3
[missing visit n=4]
Group 2 (Control)
n = 7
Visit 1
n=7
Visit 2
n=6
[withdrawal n=1]
Visit 3
n=5
[withdrawal n=1]
Visit 4
n=5
Visit 5
n=4
[missing visit n=1]
Visit 6
n=3
[missing visit n=1; withdrawal n=1]
Total withdrawals of residents
Treatment: n=1
Control: n=3

Reasons for non-consent

Not suitable for the resident's conditions or ability (n=16)

- When asked about scheduling phone calls the family member stated phone calls do not work as the resident has difficulty understanding what a phone is.
- Family member stated the resident cannot communicate verbally, has deteriorated a lot in the past month.
- …

Concerns regarding questionnaires (n=9)

- Family member stated that the resident does not give proper answers to questions.
- Not receptive to phone calls, agitated with too many questions.
- …

Example: *Music Connects Us* Pilot

Goal: to reduce loneliness, BPSD, and depression
Targets modifiable influencing factors of: Social Contact & Social Participation
Component / mechanism: Engagement (in music-making and with group members)
Dose: One 60-minute session per week for 8 weeks
Mode of delivery: Three musicians facilitate face-to-face sessions with 8 people with dementia
Outcomes: Social connectedness/Loneliness*, BPSD, Depression, Quality of Life*
Moderators (influence intervention impact): Levels of Engagement, Perceptions of the Intervention

Thank You
Questions?

- The stakes are high
  - Opportunities for quality of life when living with dementia
  - Loneliness hurts
  - Intervention development is needed
- Challenges and strategies
  - Definitions
  - Building intervention theory, understanding effects
  - Measurement
  - Addressing stakeholder concerns
  - Feasibility (and working in the real world)

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