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Acceptability of a Personal Contact Intervention among People Living with Dementia: Might Baseline Contact Matter?

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Résumé

Notre étude visait à explorer comment la perception initiale de l'intervention peut influencer l'acceptabilité de Connecting Today, un programme d'intervention personnelle auprès de personnes vivant avec la démence. Elle avait pour but de générer des hypothèses à vérifier dans de futures études. Nous avons analysé un sous-groupe de données tirées d'un essai pilote. Un groupe de 15 personnes atteintes de démence légère à modérée ont participé à Connecting Today. Nous avons examiné comment les perceptions de l'acceptabilité du programme pouvaient varier dans des groupes ayant déclaré des interventions hebdomadaires (n = 8) par rapport à des interventions mensuelles/ou de fréquence inconnue (n = 7) au début de l'étude. Les outils de mesure de l'acceptabilité comprenaient un questionnaire sur les perceptions et les préférences relatives au traitement, ainsi que des paramètres tels que le nombre de nonconsentements, de données manquantes et de retraits de l'étude et les raisons de ces écarts. Nous avons appliqué des méthodes de statistique descriptive et d'analyse de contenu. Au cours de la première et de la deuxième visite, une plus grande proportion des participants bénéficiant d'une faible fréquence d'intervention au début de l'étude (85,7 % – 100 %) ont déclaré qu'ils se sentaient mieux, que les visites les avaient aidés et que celles-ci étaient « relativement » ou « très » faciles, comparativement au groupe bénéficiant d'une fréquence d'intervention élevée au début de l'étude (37,5 % – 62,5 %). La plupart des données manquantes (71 %) et tous les retraits de l'étude ont été constatés dans ce deuxième groupe. Les visites en personne programmées avec des membres de la famille, des amis ou des bénévoles pourraient être appréciées par les résidents d'établissements de soins qui ont peu d'occasions de recevoir régulièrement des visites personnelles.

Abstract

Our study aimed to explore how perceived baseline contact may influence acceptability of *Connecting Today*, a personal contact intervention, among people living with dementia. We aimed to generate hypotheses for testing in future studies. This was a sub-group analysis of pilot study data. Fifteen people living with mild to moderate dementia participated in *Connecting Today*. We explored how perceptions of intervention acceptability may differ in groups reporting weekly contact (n = 8) compared with groups reporting monthly/unknown (n = 7) contact at baseline. Measures of acceptability included a treatment perceptions and preferences questionnaire, and the number of and reasons for non-consent, missing data, and study withdrawal. We used descriptive statistics and content analysis. In visits one and two, a larger proportion (85.7–100%) of low baseline contact participants reported feeling better, and indicated that the visits helped them and were easy "mostly" or "a lot", compared with the high baseline contact group (37.5–62.5%). Most missing data (71%) and all study withdrawals occurred in the high baseline contact group. Scheduled in-person visits with family, friends, or a volunteer may appeal to residents in care homes who have few existing opportunities for routine, one-on-one visits with others. Hypotheses generated should be tested in future studies.

Social connectedness (i.e., feelings of belonging and closeness) (Ashida & Heaney, 2008; O'Rourke & Sidani, 2017) protects against loneliness (i.e., feeling alone or left out) (de Jong Gierveld, 1998; El Sadr, Noureddine, & Kelley, 2009; Weiss, 1973) and poor mental and physical health (Holt-Lunstad, Smith, Baker, Harris, & Stephenson, 2015). Older adults are at risk for loneliness (Cacioppo & Hawkley, 2003; Tomaka, Thompson, & Palacios, 2006), especially when they live in a long-term care home (Bethell et al., 2021), or experience chronic illness, psychological stress (Richard et al., 2017), or social isolation (i.e., lack of contact with others) (O'Rourke

& Sidani, 2017). Although family and friends, uncomfortable with dementia symptoms or care environments, may withdraw from social interactions (Miller, 2019), some people who are socially isolated do not desire more contact or feel lonely (Smith & Victor, 2019). Personal contact interventions (which are sometimes called "visiting programs") are among the most frequently used approaches to prevent loneliness among cognitively intact older adults, but little is known about their use with people living with dementia (O'Rourke, Collins, & Sidani, 2018). The purpose of this study was to explore differences in the acceptability of an in-person personal contact intervention, between groups of people living with dementia in a care home who perceived that they had high (i.e., weekly) as compared with low (i.e., monthly or unknown) contact with their family and friends at baseline.

Personal Contact Interventions

Personal contact interventions are defined by a core component: scheduled contact with a family member, friend, or volunteer (O'Rourke et al., 2018). Studies have found a statistically significant reduction in loneliness following a personal contact intervention when used with older adults without dementia (Moses, 2003; Schwindenhammer, 2014; Tsai & Tsai, 2011; Tsai, Tsai, Wang, Chang, & Chu, 2010; van der Heide, Willems, Spreeuwenberg, Rietman, & de Witte, 2012). However, most studies of interventions aimed to address loneliness have excluded people living with dementia (Quan, Lohman, Resciniti, & Friedman, 2019). Notable exceptions include three small studies (with sample sizes ranging from 3 to 17) that promoted remote visits between people living with mild to moderate dementia and their family and friends (Moyle et al., 2014; Purves, Phinney, Hulko, Puurveen, & Astell, 2015; van der Ploeg, Eppingstall, & O'Connor, 2016). Although remote visits warrant further study, the development of personal contact interventions that help people living with dementia have face-to-face visits with family and friends have been overlooked to date (O'Rourke, Sidani, Jeffery, Prestwich, & McLean, 2020). We do not know if a personal contact intervention that aimed to schedule routine in-person visits would be acceptable to people living with dementia and their family and friends.

Acceptability refers to whether the person living with dementia perceives an intervention as desirable or appropriate, effective, convenient to use, and associated with minimal risks (Sekhon et al., 2017; Sidani & Fox, 2020). Individuals who find an intervention unacceptable are unlikely to use it or benefit from it (Moore et al., 2015). It is also unknown whether baseline contact could influence acceptability of a personal contact intervention. Researchers tend to assume that people who are isolated (e.g., living alone or in long-term care, or who have few friends) may respond positively to a personal contact intervention (Cattan, Kime, & Bagnall, 2011; Moses, 2003). Although most previous studies describe some social variables at baseline, such as living arrangement, social support, or loneliness (Andrews, Gavin, Begley, & Brodie, 2003; Cattan et al., 2011; Schwindenhammer, 2014; Tsai et al., 2010; Tsai & Tsai, 2011; van der Heide et al., 2012; Van Orden et al., 2013), none have considered participants' perceptions of the amount or nature of personal contact prior to implementing a personal contact intervention. We conducted an exploratory subgroup analysis of data from a pilot study of Connecting Today, an in-person personal contact intervention for use with people living with mild to moderate dementia in long-term care. We conducted this analysis to generate (not test) hypotheses.

Methods

Design

The pilot study aimed to assess the overall feasibility and acceptability of the *Connecting Today* intervention and study procedures. This sub-group analysis is a descriptive, exploratory study focused on the acceptability of *Connecting Today* from the perspectives of participants with high as compared with low perceived contact at baseline. All participants (n = 15) were living with mild to moderate dementia and received *Connecting Today* for 6 weeks in either the intervention or wait-list control groups. Ethical approval was received from the Health Research Ethics Board – Health Panel at the University of Alberta (Pro00084244).

Setting

The pilot study took place in two large long-term care homes (each >100 beds) situated in a mid-size urban setting in Alberta, Canada. The homes were similar in terms of their physical features (e.g., high proportion of shared rooms arranged along corridors) and they both described philosophies of person-centred care on their Web sites.

The Connecting Today Intervention

We are developing *Connecting Today* in phases as per the Medical Research Council recommendations for the development of complex interventions, and this study uses data from a (phase 2) pilot study (Campbell et al., 2000, 2007; Moore et al., 2015). In previous studies, we defined the problem (O'Rourke & Sidani, 2017), clarified the intervention's active ingredient, activities, mode of delivery, and dose (O'Rourke et al., 2018), and assessed the acceptability of personal contact interventions from the perspectives of the family and friends of a person living with dementia (O'Rourke et al., 2020).

The essential component of Connecting Today is regular, scheduled visits for a person living with dementia while they reside in long-term care. We implemented Connecting Today in steps: (1) The person living with dementia (or their designated decision maker [DDM]) chose a family member/ friend (n = 8) or the research assistant (RA) (n = 7) to be the contact. Three residents chose their own visitor (the RA). We encouraged visits to occur face to face at least half of the time, and telephone visits were an option. However, no one chose to schedule regular telephone calls. (2) The RA followed up with the family/friend contact to schedule visits for a minimum of 30 minutes, once per week, for 6 weeks, and before the first visit, sent the contact an Alzheimer Society handout related to communication strategies used with people living with dementia. (3) The RA attended each visit as either the contact or to help set up for the visit (e.g., to help find a quiet location). The RA completed a brief check-in after the first 10 minutes. (4) The resident and their contact determined what to talk about or do at each visit. As with the visiting programs used in other populations, we identified contacts and scheduled visits, but did not provide direction for how the person living with dementia and their contact would interact during visits. Some visitors chose to engage in activities (e.g., going outside, looking at a picture album) as a strategy to promote engagement during the visits.

Inclusion and Exclusion Criteria

Site contacts used their clinical Resident Assessment Instrument (RAI) 2.0 data to identify residents who were 65 years of age or older, diagnosed with Alzheimer's disease or other dementia, had a Cognitive Performance Score between 1 and 3 (Morris et al., 1994), and understood spoken English. The RA completed the Mini Mental Status Examination (Folstein, Folstein, & McHugh, 1975) to confirm eligibility (a score ≥12 was necessary to complete measures). Clinical staff completed the preliminary eligibility screen in January, April, and July 2019 to identify new participants.

Recruitment and Informed Consent

We consulted with site managers and selected one or two units within each site that included persons living with mild to moderate dementia. Care home staff reviewed the RAI 2.0 data of all the residents in the selected units to determine eligibility. These staff then approached all residents (or the DDM) who met the inclusion criteria to assess their interest in participating in the study. Clinical staff provided the RA with the names and contact information for those who were interested in learning more about the study. The RA contacted these individuals to explain the study in further detail, confirm eligibility, and obtain written (or audio-recorded spoken) consent from the person living with dementia (or their DDM). The RA assessed all potential participants for their capacity to provide informed consent by asking the person to identify any risks in participating in the study and to report to the RA what was required of them to participate, as recommended (Resnick et al., 2007). If the RA identified a resident who could not consent on their own behalf, then the DDM was contacted. The RA also assessed assent of people living with dementia based on verbal and non-verbal indicators during each visit and data collection session. The sample size calculation was based on the aims of the main analysis to assess overall feasibility and acceptability (testing efficacy is not a recommended aim for a pilot study [Kistin & Silverstein, 2015; Skivington et al., 2021]). Twenty participants were needed to estimate a proportion of 15 per cent (which would be a common estimate of attrition, for example) within 9 points of accuracy with 90 per cent confidence (Hertzog, 2008). Challenges with recruitment resulted in a smaller sample size (n = 15). The small sample size is a study limitation, but the reasons for nonconsent are analyzed and used to generate hypotheses in this exploratory sub-group analysis.

Data Collection

Data were collected to assess participant demographics, perceptions of baseline contact, and indicators of intervention acceptability from March to November 2019, which was before the COVID-19 pandemic.

Demographics

Demographic data were collected from participants' RAI 2.0 records 2 weeks before the intervention group received *Connecting Today* including: age, sex, level of education, marital status, hearing, vision, functional dependence, depression rating, involvement in facility life, conflict with others, absence of family member/friend contact, recent loss of loved one, family member/significant other involved in care planning, and number of medications. Evidence supports the reliability (inter-rater and internal

consistency) and validity (criterion, convergent and predictive) of the RAI 2.0 items (Poss et al., 2008). Our research team confirmed the level of cognitive impairment by using the Mini Mental Status Examination (MMSE) (Folstein et al., 1975). The MMSE is widely used, and has evidence supporting its construct validity and test-retest and inter-rater reliability (Folstein et al., 1975).

Baseline contact data

In this study, we wanted to understand the perceptions of the person living with dementia. We asked people living with dementia about the amount and nature of their current visits prior to Connecting Today. Our team generated relevant items. To enhance comprehension and limit cognitive burden, we wrote the items in simple language, provided a limited set of response options, and applied the response tree strategy (Fox, Sidani, Streiner, McGilton, & Grady, 2011). The RA read each question and the response options aloud in face-to-face sessions. Participants were asked the following. (1) Who visits them other than health care workers, and also about specific types of visitors, one at a time (participant responded yes or no). If a participant stated "yes" to the type of visitor, they were asked how the visits with that person usually happen (in person, over the phone, videoconference, or other). (2) In general, "how often do people visit" (less than once per month, about once per month, about once per week, a few times per week, every day), and whether visits lasted long enough (yes or no).

Acceptability data

Immediately following each *Connecting Today* visit, the RA asked the participant six questions face to face to directly measure acceptability, defined as participants' perceptions of the appropriateness, effectiveness, and convenience of *Connecting Today*. The items were informed by the Treatment Perception and Preference (TPP) measure ($\alpha > 0.85$) (Sidani, Epstein, Fox, & Miranda, 2018). To reduce cognitive burden, item stems were simplified and response options reduced from a five-point to a three-point Likert scale, and presented in a response tree format (Fox et al., 2011). Items asked about whether the participant enjoyed the visit, felt better after the visit, and found it easy to visit. If the participant responded "yes" to the item, then the level of enjoyment, feeling better, or ease was assessed (a little, mostly, a lot).

We used a study log to track attrition, attendance, and reasons for non-consent. These are indirect indicators of acceptability, because withdrawal, non-attendance, and non-consent are associated with perceptions of the intervention. People who find an intervention unacceptable are less likely to agree to participate or to complete all intervention sessions (Sekhon, Cartwright, & Francis, 2017).

Data Analysis

Descriptive statistics (means/standard deviations [SDs] or medians and interquartile ranges for continuous variables, and frequencies, medians, and modes for categorical variables) were used to summarize the demographic characteristics and perceptions of baseline contact. We defined two sub-groups: (1) high baseline contact (i.e., weekly visits) and (2) low baseline contact (i.e., monthly or unknown visits). Frequencies summarized acceptability data (applying complete case analysis). For analysis of attendance, attrition, and missing data, the denominator was the total number of participants in the sub-group at baseline. Conventional content

analysis (Hsieh & Shannon, 2005) was used to summarize the reasons for non-consent and create a categorical variable. We used tables and bar charts to contrast (not test) the results between the two sub-groups for each visit.

Results

Recruitment and Non-Consent

The staff at both sites approached all 103 eligible residents or their DDM and provided information about the study. Of those residents/ DDMs, 69 of 103 (67%) showed interest in learning more about the study. When approached by the RA, 35 of 69 (51%) of persons living with dementia or their DDMs declined to participate and 13 of 69 (19%) did not meet the inclusion criterion of having an MMSE \geq 12, leaving a total of 15 participants.

The RA recorded the reasons that people living with dementia/DDMs decided not to participate in the study. The most common reasons for non-consent were perceptions that the intervention or study was not appropriate for the health condition or ability of the person living with dementia (16 of 69; 23%) and concerns with asking the person living with dementia too many questions (9 of 69; 13%). Several people also declined to participate because they perceived that the person living with dementia already received enough visits (5 of 69; 7%) (see Figure 1).

Sample Characteristics

The sample was mainly female (n = 13, 86.7%), the average age was 87.2 years (range = 76–99) and a majority of participants were widowed (n = 9, 60.0%). Nine out of 15 persons living with dementia (60.0%) had hearing impairment and (40.0%) had vision impairment. The average level of functional dependence

was 3, indicating need for extensive assistance in personal hygiene or toilet use (scale range 0–6; 0 = independent to 6 = total dependence). The average depression score was 2.13 (SD 2.61); a score of ≥ 3 indicates a potential or actual problem with depression (scale range 0–14). None of the persons living with dementia had total absence of family member/friend contact or had recently lost a loved one. Most participants (n = 9, 60%) did not have a significant other involved in the RAI 2.0 assessment care planning (see Table 1).

Perceived Baseline Contact

How often a participant perceived that they had a visitor was divided almost equally between groups that perceived high contact (i.e., having visitors at least once per week, n = 8), and those that perceived low contact (i.e., having visitors once per month or not knowing the frequency of contact, n = 7). Participants usually reported that visitors were their children (n = 9, 60.0%) or a friend (n = 8, 53.3%). These visits occurred most often in-person, with children (7 of 9, 77.8%) and friends (5 of 8, 62.5%) (see Table 2).

Attendance, Attrition, and Missing Data

Participant attendance at sessions differed between the high and low baseline contact groups (see Table 3). In the high baseline contact group, four withdrawals occurred between visits two and six, and contributed to the higher non-attendance rates observed in this group. In contrast, no participants from the low baseline contact group withdrew from the study. Two of the four withdrawals were related to perceptions of the study or intervention. The participant who withdrew after visit one stated, "I don't think this will help." She explained that she was too busy in the mornings for the visits and too tired in the afternoons, indicators that the

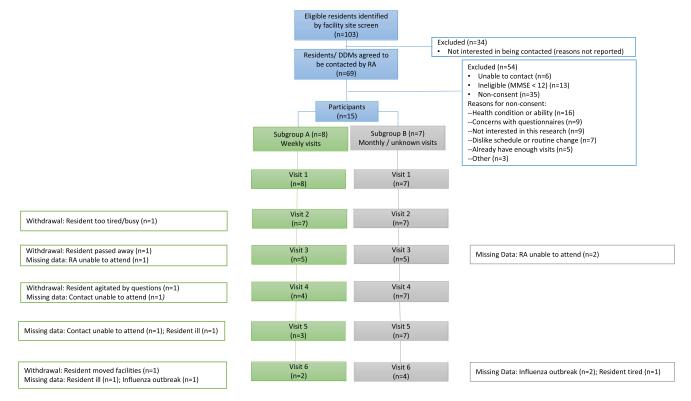


Figure 1. Consolidated Standards of Reporting Trials (CONSORT) flow diagram.

Table 1. Demographics of people living with dementia from the clinical data set (n = 15)

Set (II – 15)	
Variable	n (%)
Sex	
Male	2 (13.3)
Female	13 (86.7)
Not reported	0 (0.0)
Education	
No schooling	0 (0.0)
Grades ≤ 1-8	1 (6.7)
Grades 9-11	2 (13.3)
High school graduate	3 (20.0)
Technical/trade school	0 (0.0)
Some college	0 (0.0)
Bachelor's degree	1 (6.7)
Graduate degree	0 (0.0)
Not reported	8 (53.3) Not assessed at 1 site.
Marital Status	
Never married	1 (6.7)
Married	2 (13.3)
Widowed	9 (60.0)
Separated	0 (0.0)
Divorced	3 (20.0)
Not reported	0 (0.0)
Hearing	
Hears adequately	5 (33.3)
Minimal difficulty	4 (26.7)
Hears in special situations only	2 (13.3)
Highly impaired/absence of useful hearing	0 (0.0)
Not reported	4 (26.7)
Vision	
Adequate	2 (13.3)
Impaired	6 (40.0)
Moderately impaired	1 (6.7)
Highly impaired	2 (13.3)
Severely impaired	0 (0.0)
Not reported	4 (26.7)
Functional dependence	
Independent (0)	0 (0.0)
Supervision (1)	0 (0.0)
Limited (2)	5 (33.3)
Extensive 1 (3)	4 (26.7)
Extensive 2 (4)	6 (40.0)
Dependent (5)	0 (0.0)
Total dependence (6)	0 (0.0)
Not reported	0 (0.0)
1	(5.0)

Table 1. Continued

Variable	n (%)
Conflict	
With staff	
No	14 (93.3)
Yes	1 (6.7)
Not reported	0 (0.0)
With roommate	
No	15 (100.0)
Yes	0 (0.0)
Not reported	0 (0.0)
Other residents	
No	14 (93.3)
Yes	1 (6.7)
Not reported	0 (0.0)
Family member/friends	
No	15 (100.0)
Yes	0 (0.0)
Not reported	0 (0.0)
Absence of family member/friend contact	
No	15 (100.0)
Yes	0 (0.0)
Not reported	0 (0.0)
Recent loss of a loved one	
No	15 (100.0)
Yes	0 (0.0)
Not reported	0 (0.0)
Family member/significant other involved in RAI 2.0 assessment	
No	9 (60.0)
Yes	6 (40.0)
Not reported	0 (0.0)

intervention, which required scheduled visits, was not viewed as appropriate by this participant. Another resident participant was withdrawn by their DDM after visit three because their DDM reported that the resident was agitated and annoyed by the questions that the RA asked. This suggests that the intervention was not viewed as offering benefits that outweighed the inconvenience of the study procedures.

There were nine instances of missing data, and 7 (71%) of these instances occurred in the high baseline contact group. Some missing data in both groups could be explained by reasons that did not have to do with *Connecting Today* or study procedures. These reasons included the RA being unable to attend visit three (this affected 1 in the high contact group and 2 in the low contact group) and an influenza outbreak at the site during visit six (affected 2 in each group). The other instances of missing data occurred because the participant or their family member/friend contact did not attend the session or the participant refused to answer the

(Continued)

Table 2. Perceived baseline contact reported by persons living with dementia (n = 15)

Variable	n (%)
Does anyone visit?	
No	2 (13.3)
Yes	13 (86.7)
Who visits	
Friends	8 (53.3)
Spouse	3 (20.0)
Children	9 (60.0)
Grandchildren	6 (40.0)
Siblings	6 (40.0)
A paid companion	0 (0.0)
Volunteer(s)	6 (40.0)
Cousin(s)	2 (13.3)
Nieces or nephews	4 (26.7)
Other	3 (20.0) [Neighbors, Pastor, Don't know where she came from]
Typically in-person visits	
Friends (n = 8)	5 (62.5)
Spouse (<i>n</i> = 3)	2 (66.7)
Children (n = 9)	7 (77.8)
Grandchildren (n = 6)	5 (83.3)
Siblings (n = 6)	4 (66.7)
A paid companion $(n = 0)$	0 (0.0)
Volunteer(s) $(n = 6)$	5 (83.3)
Cousin(s) $(n = 2)$	1 (50.0)
Nieces or nephews $(n = 4)$	3 (75.0)
Other $(n = 3)$	3 (100.0)
Typically phone visits	
Friends (n = 8)	2 (25.0)
Spouse (<i>n</i> = 3)	1 (33.3)
Children (n = 9)	2 (22.2)
Grandchildren (n = 6)	1 (16.7)
Siblings (n = 6)	2 (33.3)
A paid companion (n = 0)	0 (0.0)
Volunteer(s) (n = 6)	1 (16.7)
Cousin(s) (n = 2)	1 (50.0)
Nieces or nephews (n = 4)	1 (25.0)
Other (n = 3)	0 (0.0)
Typically both in-person and phone	
Friends (n = 8)	0 (0.0)
Spouse (<i>n</i> = 3)	0 (0.0)

(Continued)

Table 2. Continued

Table 2. Continued	
Variable	n (%)
Children (n = 9)	0 (0.0)
Grandchildren (n = 6)	0 (0.0)
Siblings (n = 6)	0 (0.0)
A paid companion (n = 0)	0 (0.0)
Volunteer(s) (n = 6)	1 (16.7)
Cousin(s) (n = 2)	1 (50.0)
Nieces or nephews $(n = 4)$	1 (25.0)
Other (n = 3)	0 (0.0)
Number of visitor types	
0 visitors	2 (13.3)
1 visitor	0 (0.0)
2 visitors	3 (20.0)
3 visitors	4 (26.7)
4 visitors	3 (20.0)
5 visitors	1 (6.7)
6 visitors	2 (13.3)
Frequency of contact	
Every day	0 (0.0)
A few times per week, but not every day	3 (20.0)
Once per week	5 (33.3)
About once per month	4 (26.7)
Less than once per month	0 (0.0)
Don't know	3 (20.0)
Not reported	0 (0.0)
Usual length of visit (in minutes)	
Less than 60	3 (20.0)
60-120	5 (33.3)
More than 120	1 (6.7)
Didn't report in minutes	5 (33.3) [Depends on the day; Doesn't matter; Good enough; Not sure; Hard to say]
Not reported	1 (6.7)
Satisfied with length of visits	
No	3 (20.0)
Yes	9 (60.0)
Don't know	2 (13.3)
Not reported	1 (6.7)
Cultural or ethnic identity	
Does not identify with any	12 (80.0)
Canadian	1 (6.7)
Ukrainian Catholic	1 (6.7)
Don't know	1 (6.7)

Table 3. Perceived acceptability in high (weekly, n = 8) or low (monthly/ unknown, n = 7) baseline contact groups

	Visit 1		Visit 2		Visit 3		Visit 4		Visit 5		Visit 6	
	High	Low	High	Low	High	Low	High	Low	High	Low	High	Low
Variable	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)
Attended session												
No	0 (0.0)	0 (0.0)	1 (12.5)	0 (0.0)	3 (37.5)	2 (28.6)	4 (50.0)	0 (0.0)	5 (62.5)	0 (0.0)	6 (75.0)	3 (42.9)
Yes	8 (100.0)	7 (100.0)	7 (87.5)	7 (100.0)	5 (62.5)	5 (71.4)	4 (50.0)	7 (100.0)	3 (37.5)	7 (100.0)	2 (25.0)	4 (57.1)
Non-attendance because	of											
Withdrawal	0 (0.0)	0 (0.0)	1 (12.5)	0 (0.0)	2 (25.0)	0 (0.0)	3 (37.5)	0 (0.0)	3 (37.5)	0 (0.0)	4 (50.0)	0 (0.0)
Contact (e.g., absent)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	1 (12.5)	0 (0.0)	1 (12.5)	0 (0.0)	0 (0.0)	0 (0.0)
RA sick	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	1 (12.5)	2 (28.6)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)
Resident (e.g., tired)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	1 (12.5)	0 (0.0)	1 (12.5)	1 (14.3)
Site closed	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	1 (12.5)	2 (28.6)
Enjoyed visit												
No	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)
Yes	7 (87.5)	7 (100.0)	7 (87.5)	7 (100.0)	5 (62.5)	5 (71.4)	4 (50.0)	7 (100.0)	2 (25.0)	7 (100.0)	2 (25.0)	4 (57.1)
Missing	1 (12.5)	0 (0.0)	1 (12.5)	0 (0.0)	3 (37.5)	2 (28.6)	4 (50.0)	0 (0.0)	6 (75.0)	0 (0.0)	6 (75.0)	3 (42.9)
How much enjoyed visit												
A little	2 (25.0)	0 (0.0)	2 (25.0)	0 (0.0)	1 (12.5)	0 (0.0)	0 (0.0)	0 (0.0)	1 (12.5)	0 (0.0)	0 (0.0)	0 (0.0)
Mostly	1 (12.5)	2 (28.6)	0 (0.0)	2 (28.6)	2 (25.0)	2 (28.6)	1 (12.5)	3 (42.9)	0 (0.0)	1 (14.3)	1 (12.5)	3 (42.9)
A lot	4 (50.0)	5 (71.4)	5 (62.5)	5 (71.4)	2 (25.0)	3 (42.9)	2 (25.0)	4 (57.1)	1 (12.5)	6 (85.7)	1 (12.5)	1 (14.3)
Missing	1 (12.5)	0 (0.0)	1 (12.5)	0 (0.0)	3 (37.5)	2 (28.6)	5 (62.5)	0 (0.0)	6 (75.0)	0 (0.0)	6 (75.0)	3 (42.9)
Felt better												
No	1 (12.5)	1 (14.3)	0 (0.0)	0 (0.0)	3 (37.5)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	1 (14.3)	1 (12.5)	0 (0.0)
Yes	6 (75.0)	6 (85.7)	6 (75.0)	6 (85.7)	2 (25.0)	5 (71.4)	4 (50.0)	7 (100.0)	1 (12.5)	6 (85.7)	0 (0.0)	4 (57.1)
Missing	1 (12.5)	0 (0.0)	1 (12.5)	1 (14.3)	3 (37.5)	2 (28.6)	4 (50.0)	0 (0.0)	7 (87.5)	0 (0.0)	7 (87.5)	3 (42.9)
How much felt better												
A little	2 (25.0)	0 (0.0)	2 (25.0)	0 (0.0)	0 (0.0)	0 (0.0)	3 (37.5)	1 (14.3)	0 (0.0)	1 (14.3)	0 (0.0)	0 (0.0)
Mostly	0 (0.0)	2 (28.6)	1 (12.5)	2 (28.6)	0 (0.0)	1 (14.3)	0 (0.0)	1 (14.3)	0 (0.0)	0 (0.0)	0 (0.0)	2 (28.6)
A lot	3 (37.5)	4 (57.1)	3 (37.5)	4 (57.1)	1 (12.5)	4 (57.1)	1 (12.5)	4 (57.1)	1 (12.5)	5 (71.4)	0 (0.0)	2 (28.6)
Missing	3 (37.5)	1 (14.3)	2 (25.0)	1 (14.3)	7 (87.5)	2 (28.6)	4 (50.0)	1 (14.3)	7 (87.5)	1 (14.3)	8 (100.0)	3 (42.9)
Easy to visit												
No	2 (25.0)	0 (0.0)	2 (25.0)	0 (0.0)	2 (25.0)	1 (14.3)	0 (0.0)	0 (0.0)	1 (12.5)	0 (0.0)	0 (0.0)	0 (0.0)
Yes	4 (50.0)	7 (100.0)	5 (62.5)	7 (100.0)	3 (37.5)	4 (57.1)	4 (50.0)	7 (100.0)	1 (12.5)	7 (100.0)	2 (25.0)	3 (42.9)
Missing	2 (25.0)	0 (0.0)	1 (12.5)	0 (0.0)	3 (37.5)	2 (28.6)	4 (50.0)	0 (0.0)	6 (75.0)	0 (0.0)	6 (75.0)	4 (57.1)
How easy to visit												
A little	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	1 (12.5)	1 (14.3)	1 (12.5)	0 (0.0)	0 (0.0)	0 (0.0)	1 (12.5)	0 (0.0)
Mostly	1 (12.5)	2 (28.6)	0 (0.0)	0 (0.0)	0 (0.0)	1 (14.3)	1 (12.5)	2 (28.6)	0 (0.0)	1 (14.3)	1 (12.5)	2 (28.6)
A lot	3 (37.5)	5 (71.4)	5 (62.5)	6 (85.7)	2 (25.0)	2 (28.6)	2 (25.0)	5 (71.4)	1 (12.5)	6 (85.7)	0 (0.0)	1 (14.3)
Missing	4 (50.0)	0 (0.0)	3 (37.5)	1 (14.3)	5 (62.5)	3 (42.9)	4 (50.0)	0 (0.0)	7 (87.5)	0 (0.0)	6 (75.0)	4 (57.1)

 ${\it Note}. \ {\it Missing data includes with drawals, non-attendance, and non-response}.$

questions. These instances of missing data could be related to perceptions of *Connecting Today* or study procedures and occurred most often in the high contact group (n = 4) as compared with the low contact group (n = 1). Taken together, the patterns related to

missing data and attrition are signals suggesting that participants with a lower perceived baseline contact may stay in the study longer and participate more regularly than participants with a higher perceived baseline contact.

Perceived Acceptability

At visits 1 and 2, there were little missing data, and the majority of the 15 participants who attended sessions perceived *Connecting Today* as enjoyable and effective in helping them feel better, and that it was easy to visit with the contact (i.e., majority rating ≥ 2 for each item). However, there were some differences between high and low contact groups in the proportion rating *Connecting Today* as enjoyable, effective, and easy (i.e., ≥ 2) during visits 1 and 2. These patterns, which will be described in detail, are signals suggesting that the low contact group may have held more positive perceptions of *Connecting Today*. Missing data after visit 2 limits our ability to draw conclusions about the extent to which these perceptions were maintained over time, and the RA could not attend some visits during week 3, so that week is excluded from this analysis (see Table 3). Findings from visits 4, 5, and 6 are tentative because of missing data.

Appropriateness

During visits 1 and 2, most participants in both the low (100%) and high contact groups (87.5%) enjoyed the visits. However, at visits 1 and 2, a higher proportion of people in the low contact group enjoyed visits "mostly" or "a lot" (100%), as compared with the high contact group (62.5%). At visits 4, 5, and 6, there were several participants in the low contact group who reported enjoying visits "a lot" (n = 4, 6, 1). In contrast, in the high baseline contact group at visits 4, 5, and 6, very few reported that they enjoyed the visit "a lot" (n = 2, 1, 1).

Perceived effectiveness

Perceived effectiveness (as a component of acceptability) refers to the participants' perceptions of the intervention in terms of helpfulness in managing presenting problems (Sidani & Braden, 2011). At visits 1 and 2, most participants in both the low (85.7%) and high contact groups (75%) reported that *Connecting Today* helped them feel better. In visits 1 and 2, a higher proportion of people in the low contact group stated that visits helped them feel better mostly or a lot (85.7%), as compared to the high contact group (just 37.5% in visit 1 and 50.0% in visit 2). In visits 4, 5, and 6, there were several people in the low contact group that reported that visits helped them feel a lot better (n=4, 5, 2). In contrast, in the high baseline contact group, very few reported that visits 4, 5, and 6 helped them feel a lot better (n=1, 1, 0). These patterns suggest that participants who perceive their baseline contact was low may view the intervention as more helpful.

Convenience

The third question was about the ease of the visit from the perspective of the participants, which relates to convenience. At visits 1 and 2, all participants in the low contact group (100%) and about half in the high contact group (50% at visit 1 and 62.5% at visit 2) found it easy to visit. At visits 1 and 2, a higher proportion of people in the low contact group reported the ease of the visit as "mostly" or "a lot" (100.0% at visit 1 and 85.7% at visit 2), as compared with the high contact group (50.0% at visit 1 and 62.5% at visit 2). At visits 4, 5, and 6, there were several people in the low contact group who stated that the ease of the visit was "a lot" (n = 5, 6, 1). In contrast, in the high baseline contact group, very few reported that the ease of the visit was "a lot" at visits 4, 5, and 6 (n = 2, 1, 0).

Discussion

In this study, we explored several indicators of acceptability of an in-person personal contact intervention, Connecting Today, used with people living with mild to moderate dementia in a care home. Our focus was on generating hypotheses for testing in future studies about potential associations between the amount of contact that one perceives that they have at baseline and the participant's perceptions of the routine, scheduled visits that they received in an intervention study. Considering both attendance and perceived acceptability, we found that a majority of those with high and low baseline contact initially reported that Connecting Today was acceptable. However, after visit 3, the patterns and reasons for attrition and missing data support that those who perceived that they already had high contact at baseline found Connecting Today less valuable. A higher proportion of people in the lower contact group also reported that Connecting Today was enjoyable, helped them feel better, and was easy "mostly" or "a lot" during visits 1 and 2.

Our exploration of patterns within this small data set generated three hypotheses for testing in future research: (1) Those with high perceived baseline contact are more likely to withdraw from the study or refuse to answer study questions, as compared with those with low contact at baseline; (2) those with low perceived baseline contact view an in-person personal contact interventions as more acceptable than do those with high perceived baseline contact; and (3) although both those with low and those with high perceived baseline contact may benefit from an in-person personal contact intervention, effects may be stronger among those with low perceived baseline contact because they will be more likely to engage in intervention sessions over the course of a study. This work offers an example of use of the perspectives of persons living with dementia to generate research hypotheses. We were not concerned with whether persons living with dementia had "accurate" insight into the actual amount of contact that they received at baseline. These hypotheses are novel; the influence of perceived baseline contact on acceptability and subsequent intervention effectiveness has not been previously explored among cognitively intact older adults or people living with dementia.

Our findings support that collecting data about perceived baseline contact may help in future studies to identify those who are mostly likely to engage in (and therefore have opportunity to benefit from) an in-person personal contact intervention. Targeting is a commonly used technique that focuses on the development of a single specialized health intervention approach for a defined sub-group of people (Kreuter & Wray, 2003). Our findings highlight that those who perceive that they are socially isolated may be more likely to engage in an in-person visiting program like *Connecting Today*. However, we do not recommend excluding people with high perceived baseline contact from future studies based on the preliminary hypotheses generated in this study; participants in the high baseline contact group still perceived *Connecting Today* as enjoyable and beneficial and saw value in an intervention that promoted weekly visits.

We recommend completing sub-group or interaction analyses to compare feasibility and acceptability (in pilot studies) or effectiveness (in full trials) between groups defined by their level of perceived contact at baseline. Previous studies have overlooked the potential influence of perceived baseline contact or have only included people that the researcher deemed socially isolated (e.g., older people living alone), without assessing the individual's perceptions of their social contact (Andrews et al., 2003; Cattan et al.,

2011; Schwindenhammer, 2014; Tsai et al., 2010; Tsai & Tsai, 2011; van der Heide et al., 2012; Van Orden et al., 2013). Participants' perspectives can help researchers gain insight into what works, what does not work, and why. This kind of understanding supports implementation of interventions at the right time to the right person, enhancing their effects, and addressing the urgent need for precise, theory-informed interventions to address an individual's needs (Akhter-khan & Au, 2020).

Our findings support that participants' perspectives should be taken into account in future research to design and understand the effects of personal contact interventions. In previous studies with the cognitively intact, participant perspectives have been used to address older adults' concerns related to use of technology in a videoconference intervention (Schwindenhammer, 2014), to publicize a telephone befriending service (Cattan et al., 2011), to help select the contact for a befriending program (Andrews et al., 2003), and to identify reasons, such as technical problems, why users were satisfied or dissatisfied with a telehealth intervention (van der Heide et al., 2012). These four studies used the perspectives of cognitively intact older adults related to the intervention to improve adherence, optimize intervention design, and promote better outcomes. Our findings support that those older adults living with dementia have an important perspective that can be used to inform intervention design, and that their perceived baseline contact may be a key component of this in the study of personal contact interventions.

Based on our findings, we will revise Connecting Today to encourage the resident or DDM to tailor the intervention. Most complex interventions do involve some level of tailoring as they are implemented (Moore et al., 2015). Intervention tailoring reflects a process of individual assessment to determine the best strategies for that person based on their characteristics and to address the outcome of interest (Kreuter & Wray, 2003). Tailoring would involve a collaborative discussion to identify how Connecting Today could be used to fit the individual's needs and desires for social connection. By considering participants' interests, goals, and perspectives, there is an opportunity to improve adherence, optimize intervention design, and promote better outcomes (Sidani & Braden, 2011). Our findings suggest that socially isolated individuals may value in-person scheduled visits with a volunteer. Interestingly, no one in our study chose to have regularly scheduled phone calls with their family or friends, suggesting limited acceptability of this mode of delivery for a personal contact intervention, regardless of the level of perceived baseline contact. Future research is needed to assess acceptability of videoconference as a mode of delivery for use in this population.

Strengths and Limitations

The sub-groups in our study were small, limiting the stability of the quantitative estimates, but we generated hypotheses for future testing, demonstrating analytic generalizability (Polit & Beck, 2010). Future prospective studies, powered to detect differences between low and high contact groups, are needed to rigorously test the hypotheses and produce findings with statistical generalizability. After visit 2, it was difficult to interpret perceived acceptability, because of attrition and missing data. Assessing patterns of and reasons for missing data to understand acceptability over 6 weeks helped mitigate this limitation. Additional issues related to overall intervention and study feasibility (e.g., recruitment issues related to DDM's perceptions that the people living with dementia would not benefit from visits given the extent of their impairments) will be discussed in a separate (future) article.

Conclusion

This study supports the growing body of literature related to the importance of understanding and integrating perspectives of end users, including people living with dementia, during the research process (Charlesworth, 2018; Rapaport et al., 2018). Little is known about how perceived baseline contact may influence one's experiences in receiving an intervention aimed at increasing personal contact, and even less is known when the intervention is aimed to support people living with dementia. This exploratory study has identified patterns that suggest that one's perceptions of their baseline contact may influence the acceptability of a personal contact intervention. The novel hypotheses generated in this study warrant testing in larger studies in order to improve understanding of how interventions can be designed to more effectively address diverse experiences of loneliness.

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