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Acceptability of personal contact interventions to address loneliness for people with dementia: An exploratory mixed methods study



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ABSTRACT

Background: Personal contact interventions involve routine visits with a person or animal to address loneliness. Research supports the promise of these interventions to address loneliness among cognitively intact older adults, but little is known about their use with people with dementia.

Objective: To assess the acceptability of personal contact interventions for use to address loneliness with older people with dementia, according to formal and informal care providers.

Design: Cross-sectional, mixed methods complementarity design.

Setting: Ontario, Canada

Participants: A purposive sample of 25 family members, friends, and health care providers of people with dementia.

Methods: Participants attended a face-to-face interview to discuss the acceptability of personal contact interventions. Participants completed questionnaires to rate acceptability (adapted Treatment Perception and Preference measure). A semi-structured interview followed to discuss the ratings and features of personal contact (with another person or animal) in more detail. The analysis involved descriptive statistics (quantitative data) and conventional content analysis (qualitative data). During the interpretation of the results, the qualitative findings were compared to the quantitative results to provide context and understand participants' perceptions of intervention acceptability in more depth; these are presented together in the results to demonstrate their distinct and complementary contributions to the findings.

Results: Personal contact with a person or animal was rated as effective, logical, suitable, and low risk to address loneliness by over 80% of participants. Participants' willingness to engage in this type of contact, for example as a visitor or as a facilitator of animal contact, was 72%. Participants emphasized the benefits of personal contact. The findings highlight that individualized, flexible interventions that include appropriate facilitation are needed.

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Conclusions: Future studies to develop and test personal contact interventions should involve flexible delivery, assess the feasibility and acceptability of these interventions (as in a Phase 2 trial of a complex intervention), and focus on the experiences of people with dementia.

Tweetable Abstract: Tailored, routine, and facilitated contact with a person or animal shows promise to address loneliness for people with dementia.

What is already known about this topic:

• Loneliness is emotionally painful and harms the health and quality of life of those that experience it.

• Personal contact interventions refer to routine visits with another person or animal and have been found effective in addressing loneliness among cognitively intact older adults.

What this paper adds:

• Friends, family members and health care providers of people with dementia view personal contact interventions as logical, suitable and effective to address loneliness of older adults with dementia.

• Personal contact interventions are not always easy to implement and do not automatically promote meaningful connection and prevent loneliness for people with dementia.

• Strategies to tailor and facilitate personal contact interventions are needed to promote their effectiveness when used with people with dementia.

1. Introduction

Addressing loneliness experienced by older persons is an international priority (Alzheimer's Society, 2013). Loneliness is emotionally painful and associated with depression (Marshall, 2011; Van Orden et al., 2013) and a 26% increased likelihood of mortality (Holt-Lunstad et al., 2015). Factors related to aging, such as living alone and cognitive impairment, may increase the risk of loneliness among older persons (O'Rourke and Sidani, 2017). In particular, older persons with dementia experience changes that drastically alter their social interactions. Changes like forgetfulness progress to difficulty following conversations and, finally, to severe memory impairment and an inability to formulate recognizable speech (Alzheimer Society of Canada, 2020). To prevent loneliness and promote quality of life, relationships and support systems must adapt to meet the needs of persons with dementia (O'Rourke and Sidani, 2017).

Loneliness is a negative feeling resulting from a perceived deficit in companionship, quantity or quality in one's relationships with an attachment figure or community (El Sadr et al., 2009; Weiss, 1973). It is different from being socially isolated; one can be alone but not lonely (Holt-Lunstad et al., 2015). Social connectedness, the opposite of loneliness, reflects feelings that one is cared about and belongs to a group or community (O'Rourke and Sidani, 2017). Older people with dementia have some needs that differ from those without dementia and are a diverse group. Interventions to promote social connectedness need to be adapted to meet the needs and preferences of diverse groups of older people with dementia; when an intervention meets the needs of the target population, it is more likely to be engaged in and effective (De Las Cuevas et al., 2018; Sidani, 2015).

Personal contact interventions have been used most frequently to address loneliness among cognitively intact older persons (O'Rourke et al., 2018). Interventions are best classified according to their active ingredients which are, in this case, the mechanisms hypothesized to affect loneliness (Campbell et al., 2007; Sidani et al., 2020). A personal contact intervention has one active ingredient: routine, close contact with others (O'Rourke et al., 2018). There are several possibilities for the mode of delivery for this contact. Contact could occur with another person (family member, friend or volunteer) or an animal (live or robotic). The contact with the person or animal may be delivered face-to-face or may involve the telephone or other technology. It is usually delivered in one-to-one sessions, but animal contact has also been delivered in group sessions (O'Rourke et al., 2018).

Several studies have evaluated the effects of personal contact in samples comprised of people who were primarily cognitively intact; findings supported a small, positive impact on loneliness (Reed, 1986; Robinson et al., 2013; Schwindenhammer, 2014; Tsai and Tsai, 2011; Tsai et al., 2020; van der Heide et al., 2012). However, none of the personal contact interventions evaluated in these studies was designed or evaluated specifically for use with people with dementia.

Two small studies have explored the feasibility of dementia-specific interventions aimed to use contact with a person to address loneliness for people with dementia. The first used technology (a telepresence robot and video call) to promote personal contact with family members (n = 5) (Moyle et al., 2017). The second assessed a software program designed to prompt caregivers to have reminiscence-based conversations with people with dementia (n = 3) (Purves et al., 2015).

There are more studies of personal contact delivered via a robotic animal. A systematic review of robotic animals demonstrated a small reduction in loneliness among the cognitively intact and reduction in behavioral symptoms among people with dementia (Bemelmans et al., 2012). This review supported the promise of robotic animal contact interventions, but larger studies that include comparison interventions are required to further examine their feasibility and effectiveness (Bemelmans et al., 2012).

Notably absent in the dementia-specific literature are studies of low-tech personal contact interventions that involve scheduled visits with a person face-to-face or by phone, and visits with a live animal. Also, no studies were identified that aimed to understand

intervention acceptability from the perspectives of key stakeholders, such as family members, friends and health care providers of a person with dementia. Key stakeholders are those people that understand the needs of a person with dementia and can identify whether the intervention addresses the problem in a way that makes sense, based on their experiences. Understanding acceptability from the perspectives of key stakeholders is an important piece of intervention design; it is like an early screen to determine whether the intervention is likely to be appropriate for use in the target population (Sekhon et al., 2017). The use of mixed methods to assess acceptability can help to identify adaptations to optimize an intervention's effectiveness and to improve the extent to which it may be used in practice (Sidani, 2015).

The current evidence is limited in informing the design of personal contact interventions for use with people with dementia. Assessing acceptability is a first step to develop an intervention that will be used by people with dementia and implemented with fidelity by caregivers in practice (Sekhon et al., 2017). The purpose of this study was to explore formal and informal caregivers' perceived acceptability of personal contact interventions aimed to decrease loneliness experienced by people with dementia.

2. Methods

2.1. Design

We used a cross-sectional mixed methods (complementarity) design. Participants rated the acceptability of two personal contact interventions (i.e., with a person and with an animal) in a questionnaire. Immediately following each intervention rating, participants discussed, in a semi-structured interview, their reasons for the ratings and suggestions for how to adapt and improve personal contact interventions for use with people with dementia. Qualitative and quantitative data were collected concurrently from June 2016 to April 2017, weighted equally, and compared in the analysis (Creswell and Plano Clark, 2018).

2.2. Sample

We selected a purposive sample of family members, friends, and formal health care providers of a person with dementia. The person with dementia may have lived in either a residential care setting (i.e., a long-term care home) or was community-dwelling. Participants were ≥ 21 years old and able to read and write in English. We planned to recruit 25–30 participants. This number is typical of qualitative interview-based studies to achieve information redundancy (usually reached at ~ 20 participants) and avoid overly complex analysis (Vasileiou et al., 2018). Participant availability and data saturation (i.e., our observations of information redundancy) determined the final sample (Saunders et al., 2018).

2.3. Recruitment

Recruitment strategies included: advertisement in local newspapers and newsletters; posting flyers in public spaces, on a university campus, and in one large long-term care home in Toronto, Ontario; and word-of-mouth where participants informed their network of the study. Individuals called the research office for more information, to confirm their eligibility, and schedule an interview.

2.4. Data collection

All participants reported on their age, gender, and cultural or ethnic background (in their own words); healthcare providers also indicated their professional title and work setting. The acceptability questionnaires were adapted (to reflect the interventions examined in this study) from the Treatment Perception and Preference measure (Sidani et al., 2018). The Treatment Perception and Preference measure has demonstrated internal consistency ($\alpha > 0.85$) and there is evidence that supports construct validity (i.e., participants' stated preferences for an intervention correlated with their ratings for that intervention) (Sidani et al., 2018). The adapted measure was reliable for personal contact with a person or animal ($\alpha = 0.82$ and 0.93, respectively).

Participants rated and discussed personal contact with a person and then with an animal as follows. The interviewer read aloud a lay summary of the goal, activities, benefits and risks of the intervention, while the participant read a printed copy. The participant completed five items to rate effectiveness, logic, suitability in ameliorating loneliness, ease of use, and the study participant's will-ingness to engage in personal contact (e.g., as a visitor or facilitator) on 5-point scales. Higher scores indicated higher acceptability (e.g., 0=not at all to 4=very much). The total score for these five items ranges from 0 to 20. An additional item assessed risk severity, and higher scores indicated lower acceptability (0=not bad at all to 4=very much bad). An interview immediately followed to explore perspectives of the intervention's dose (i.e., length and frequency) and mode of delivery, willingness to engage in intervention sessions, and possible modifications to make the intervention highly acceptable and feasible. The lay summaries and interview guides were based on the descriptions of personal contact interventions from the literature. Interviews were audio-recorded and transcribed.

2.5. Analysis

Quantitative data (participant characteristics and ratings) were analyzed with descriptive statistics using SPSS version 22.0. Only the cultural background variable had missing data. Concurrently, the qualitative analytic team (JP, HM, and HMO) completed a conventional content analysis (Hsieh and Shannon, 2005). Our analysis stayed close to the participants' intended meaning, as in qualitative description (Sandelowski, 2000). Lead analysts (JP/contact with a person, HM/contact with an animal) first reviewed

Table 1

Participants	cultural or eth	nic background	in their ov	vn words.

Category	Participants' words	Frequency	Percent
Specified a single ethnic or cultural background		16	64
	African		8
	Arab	1	4
	Asian	1	4
	Originally from/grew up in Guyanag	1	4
	Canadian, Greek descent	1	4
	Caucasian	1	4
	Eastern European	2	8
	Filipino	3	12
	Portuguese	1	4
	Third-generation Japanese Canadian		4
	Uganda; Baganda tribe, Bantu group	1	4
	White; European	1	4
Specified a	Specified a mixed cultural or ethnic background		16
-	Black & Spanish	1	4
	Caucasian/Scottish/French	1	4
	Macedonian /Lebanese/Irish/Canadian	1	4
	Mulato	1	4
Canadian	Canadian	3	12
Not report	Not reported		8
-	I believe in humanity, not any particular culture	1	4
	No response	1	4

transcripts and audio recordings to clean and familiarize themselves with the data. They then added codes to any phrases which described participants' perceptions of the interventions using the comments function in Word. JP and HM analyzed three transcripts each, and agreed on a preliminary list of codes and code definitions for each intervention, in discussion with HMO. The team met regularly to review the audit trail of (i) tables that linked all themes, categories, codes, and supporting data and (ii) memos of analyst impressions of the emerging findings. HMO lead the final stage of the analysis to merge the data sources and generate the final themes. First, she wrote a description of her observations of some key similarities and differences in intervention ratings based on the descriptive statistics. Inferential statistics were not calculated because of the exploratory nature of the analysis (multiple tests increase risk of type 1 error). In addition, because the sample size was based on the needs of the qualitative analysis, it was likely underpowered to detect statistically significant differences (high risk of type 2 error). Second, she reviewed the complete audit trails to compare the qualitative findings for contact with a person to contact with an animal. This was done to identify a set of common themes that helped to describe and explain the acceptability of both interventions. She re-organized the audit trail tables as needed. During this stage, she referred frequently back to the description of the intervention ratings, exploring how the qualitative themes could help to understand the observed similarities and differences in ratings. These comparisons between contact with a person and animal, and between the qualitative and quantitative results, generated a final set of themes. These themes are common to both contact with an animal and person, and provide the context to understand the ratings in more depth. The analytic team approved the final synthesis. To reflect how qualitative and quantitative data were merged in the interpretation phase, statistics are presented with themes in the results section. This integration and presentation gives a more complete and nuanced description of intervention acceptability (Onwuegbuzie and Leech, 2005; Younas et al., 2020).

2.6. Ethical approval and informed consent

Written informed consent was obtained at the research office, before the interview. We provided \$60 as an incentive and to offset the transportation costs to all participants that arrived for an interview, regardless of enrollment. This study was approved by the Ryerson University Research Ethics Board (REB 2016-100).

3. Results

The sample (n = 25) included 16 family members and friends and 9 health care providers of people with dementia. The average age was 42 years (SD 12; range 23–65). The sample was ethnically diverse, typical of the population in Toronto, ON (Table 1). A majority were women (56%, n = 14). The health care providers worked as health care aides (33%, n = 3), registered nurses (22%, n = 2) or licensed practical nurses (44%, n = 4) in home-care (22%, n = 2) or long-term care homes (78%, n = 7).

The mean total Treatment Perception and Preference scores were similar for contact with a person (13.2, SD 3.31) and an animal (11.92, SD 4.58) (Table 2). Differences were observed in the proportions of participants that rated the interventions as effective, logical, suitable, and convenient (i.e., Treatment Perception and Preference item \geq 2) (Table 3). Reasons for differences in ratings are discussed and contextualized with the qualitative findings derived from health care provider (HCP) and family member/friend (FF) participants.

Table 2

Mean acceptability ratings for personal contact interventions (n = 25).

Item	Mean (SD) Person contact	Animal contact
Effect	2.96 (0.841)	2.48 (0.963)
Logic	2.84 (0.688)	2.56 (1.003)
Suitability	3.12 (0.726)	2.48 (1.085)
Risk severity	.36 (0.700)	.48 (0.586)
Ease	2.12 (1.054)	2.16 (1.106)
Willingness to engage	2.12 (1.013)	2.24 (2.24)
Scale total (without risk item)	13.2 (3.31)	11.92 (4.58)

Table 3

Frequency of acceptability ratings of ≥ 2 for personal contact interventions (n = 25).

Item	Person contact			Animal co	mal contact			
	≥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)
Logic	100 (25)	32 (8)	52 (13)	16 (4)	88 (22)	32 (8)	40 (10)	16 (4)
Suitability	100 (25)	20 (5)	28 (12)	32 (8)	80 (20)	24 (6)	40 (10)	16 (4)
Ease	68 (17)	28 (7)	32 (8)	8 (2)	72 (18)	28 (7)	36 (9)	8 (2)
Willingness to engage	72 (18)	36 (9)	28 (7)	8 (2)	72 (18)	32 (8)	28 (7)	12 (3)

Note. 2=effective, logical, suitable, easy, willing to engage; 3= very effective, very logical, very suitable, very easy, very willing to engage; 4= very much effective, very much logical, very much suitable, very much easy, very much willing to engage.

3.1. Effective, logical, and suitable

The large majority of all of the participants rated contact with a person as effective (96%), logical (100%), and suitable (100%). Contact with an animal was also highly rated, but the percentages of participants rating it as effective (84%), logical (88%), and suitable (80%) appeared lower than ratings for contact with a person. The participants' descriptions of the benefits of contact with either a person or animal supported the quantitative findings. Participants' perceptions of the overall benefits of personal contact existed alongside the view that contact with another person was essential to all, while contact with an animal was appropriate for some but not all. Participants emphasized assessing fit of the contact, focusing on meaningful relationships, and flexible delivery of personal contact interventions.

3.1.1. Benefits of personal contact overall

Participants supported the benefits of personal contact, with another person or an animal. Potential benefits of personal contact included providing comfort, promoting happiness, decreasing loneliness or anxiety, helping the person open up, occupying their time, and preventing responsive behaviors: "...of course it helps them to be more calm and settled and decrease anxiety and loneliness." (HCP2). Personal contact interventions may also help care providers see the person with dementia in a new light, or reassure family members and friends that the person with dementia was cared for: "... it eases the burden even for a brief time for the family and friends." (FF2).

The somewhat lower ratings of contact with an animal as compared to contact with a person can be explained by the finding that contact with a person was widely perceived as being essential for everyone. In contrast, the appropriateness of contact with an animal depended more on the individual's preferences and characteristics. "I think that there's no disputing that communication with other people like outside a clinical or outside of a caregiving role is important to people." (FF1) In contrast, "it really depends on which residents are you working with but yeah, so not all enjoys animal contact in my experience." (HCP1)

3.1.2. Assess fit with contact

Participants saw the effectiveness of personal contact with another person or an animal as contingent upon the creation of close, intimate relational experiences. The fit of the contact with the person with dementia was therefore essential to assess. This assessment would determine whether an intimate bond existed or was likely to develop. Assessment of the fit between a person with dementia and an animal contact depended upon a person's history with or preferences for animals, cultural background, and allergy status: "...*if someone is an animal lover and the person tries, is not very social...that's something that they can do ... just spend time with the animal, give them comfort." (FF3)* For the fit of the person with dementia with another person, assessment included the interests of the person with dementia, their comfort engaging with people whose gender identities differ from their own, whether they enjoyed connecting with people their own age or younger, and language spoken and understood by the person with dementia. Use of simple demographic information such as age, gender or ethnicity to choose or 'match' a contact was not recommended, without such an individualized assessment. *"I would say it depends on ... who they'd prefer to engage with... I mean everybody's different." (HCP3)*

3.1.3. Focus on meaningful relationships

Participants emphasized that the focus on intimate relationships should be maintained when considering intervention modifications to fit the real-world context. For contact with a person, participants discussed whether additional services like transportation, shopping, minor housekeeping and repairs, or meal preparation should be part of the visit. In addition to having affordable help, doing activities together was seen as one way to engage the person with dementia in a familiar, enjoyable activity, to strengthen the relationship, and build trust. However, task completion should not be the focus and the activity should be carefully selected to promote social connection. Ideas for such activities included looking at photos or familiar items, listening to favorite music, or writing letters. *"There are some residents who are very frustrated. They cannot really write so at least have this one-on-one friendly visit and she knows that this lady is going to help her to do this thing ..." (HCP4)*

For contact with an animal, participants considered how one-to-one and group delivery may impact the development of a meaningful relationship with the animal. Many supported one-to-one delivery to enhance intimacy, allow intervention personalization, promote focus, and because people have various allergies and preferences for animals and for participation in a group: "...they just put everybody in the group and they don't personalize now who is this and who that – does she like animals? Are they allergic?" (HCP5). In addition, participants suggested that using the same animal each visit may promote a feeling of familiarity and connection. "It's better with the same animal because they build a relationship..." (FF5)

However, small group sessions (e.g., of four) people with dementia and several animals were also considered potentially appropriate to meet the needs of people with dementia. Participants thought these sessions would still be small enough to ensure a quiet environment and to allow the session facilitator to feasibly manage multiple animals. Some participants thought that personal contact may also occur between group members, amounting to a more potent intervention that would target development of relationships with the animal and with other people: "...so they can share the animal together and talk and play with it. And just having the animal might encourage conversation and more interaction." (FF4)

3.1.4. Flexible program delivery

Opinions of the appropriate length and frequency of personal contact interventions varied. Consistently, the findings demonstrated a need for flexibility in intervention dose to meet individual's needs. The appropriate length of visits could depend on factors including how much other social contact the person receives, and the person's current mood and interest in having more social contact. In some situations, 30-minute visits were seen as appropriate given the limited attention span or energy of the person with dementia. "*Maybe about half an hour. Because you cannot really get the attention of one resident focusing on one animal.*" (*HCP6*) Others suggested longer visits to develop rapport and for bonding, if the person is 'chatty', and to help the person with dementia remember the contact. "*I'm thinking an hour would be good, a good start… You need some kind of bonding time.*" (*FF6*)

Participants thought routine visits may give the person with dementia 'something to look forward to'. Some thought weekly visits were sufficient, while others thought visits should occur more frequently. More frequent visits could help the person with dementia remember the contact, and would give them someone to talk to or connect with more often. *"Even an hour a week I think is too short. Every day someone should pop by and say hello, how are you, good morning..." (FF7)*

3.2. Ease of delivery and willingness to engage

From the descriptive statistics, it appeared that ease of delivery and willingness to engage in personal contact interventions were rated lower than effectiveness, logic and suitability for both contact with an animal and with a person. Participants considered contact with an animal as being about as easy to deliver as contact with a person (68% and 72%, respectively). They appeared equally willing to engage in contact with a person (e.g., as the visitor) or contact with an animal (e.g., as the facilitator) (both 72%). The qualitative findings helped to explain the quantitative results related to ease of delivery and willingness to engage. Participants identified several key issues that should be considered to select and prepare the contact. The participants also described how facilitation of the sessions was essential, and described barriers to participation.

3.2.1. Preparing for contact with a person

Participants described that the contact should be patient, calm, empathetic, understanding, and easy going. Experience with people with dementia may help to prepare the contact. Three main strategies were discussed to prepare the person to feel comfortable, listen actively, and to promote engagement of the person with dementia. The first strategy was for the community, clinical or research group organizing the intervention to provide education related to the stages of dementia, how to recognize and respond to behaviors, and appropriate verbal and non-verbal communication strategies. "...the person helping them has to be trained in like ...coping strategies and just what it is, and how do deal with those moments, for example, when the person loses their memory." (FF8)

Second, participants identified that some family members and friends may believe that visits no longer mattered because the person with dementia would not remember. Telling family members and friends about potential benefits of one-to-one visits may increase their willingness to engage, and to consent for the person with dementia to participate (in cases where proxy consent is required). "So if there's some type of like educational program or authority outside of the caregiver that can promote the benefits of this to loved ones and maybe it can encourage more participation." (FF4)

Third, participants emphasized having knowledge of the person with dementia including their culture, religion or beliefs, interests, previous hobbies or jobs, and topics to avoid. A volunteer contact could provide family members and friends 'a break' and augment existing visits, but development of knowledge about the person with dementia was critical to forming a meaningful relationship. For some, contact may be more effective with a family member or friend visitor, to capitalize on an existing bond. *"If they are trying to*

reduce loneliness...you have to learn the person, what do they like? ... What are they more interested in? Music? Going out for activities? They like taking walks?" (HCP5)

3.2.2. Preparing for contact with an animal

Participants supported that animals should be temperament tested, free of disease, and vaccinated. To select someone to facilitate contact with an animal, participants discussed assessing allergies, interest and skills with the animal, and ability to support the person with dementia during the session. Participants supported that healthcare providers who met these criteria could be the facilitator, and some considered it their duty. *"If you are in the field of care it's like you are a – you've sacrificed to do that, it's your duty." (HCP7)* However, compensation and workload mattered. *"…I have 12 residents… are you going to pay me for that?" (HCP8)* Many participants identified that family members could bring an animal for a visit, but this would be limited by other demands on their time and energy. *"If they have kids that they really need to look after, like pick up from school, feed, take them to bed, and it's taking a whole lot of their time. And they don't have time for the pet and the dementia folk." (FF9)*

3.2.3. Facilitation is key

For contact with a person, many highlighted videoconference (e.g., Skype) as an excellent option to allow for the person to see their contact, promoting focus and engagement. "... like it's more therapeutic when you see the person, the reaction on the face. You believe okay, this person is still there, they really love me." (HCP9) However, use of a phone or videoconference technology required support by a facilitator because the equipment was potentially unfamiliar"...just the act of holding a phone and knowing that you're supposed to be talking into the receiver or that someone's talking to you on the phone, she wouldn't be able to comprehend I think... (FF4) The facilitator's assessment would determine equipment accessibility, how to introduce the person to the equipment, the response to equipment use, and whether continued support was required following equipment set-up.

For contact with an animal, participants discussed how the facilitator should promote both safety and engagement in sessions. The facilitator would observe the responses of the person with dementia throughout the session, promote positive interactions, and consider the needs of the animal. *"It should be like a room like this with a facilitator and to see there's no violent interaction. Just to make sure nobody's getting hurt." (FF5)* Participants discussed that sessions that were delivered one-to-one or in a small group (e.g., < 5) with multiple animals were ideal to promote one-to-one contact with the animal. Larger groups would prevent the facilitator from giving individualized attention, and undermine feasibility and effectiveness of the session. *"...say with five patients, each patient with a different animal, so you will not be able ...to give them the right time and if it's one hour and you have five people then practically you are doing nothing." (HCP7)*

3.3. Risk severity

Personal contact with either a person or animal was seen as low risk. The majority rated the risk severity as 0='not bad at all' (72% for contact with a person and 56% for contact with an animal), or 1='somewhat bad' (24% for contact with a person and 40% for contact with an animal). Participants identified risks to address in order for personal contact interventions with a person or animal to have a positive effect.

3.3.1. Risks to address

For contact with a person, participants believed that people with dementia may be cautious of new people and situations, undermining effectiveness. "So my mom would go into the room and say "I'm not sitting on the couch with her. I don't even know her. Why would I be there?"...she just didn't like the idea of having a stranger in her home." (FF10) The criteria provided for including animals in the intervention (i.e., temperament tested, free of disease, vaccinated) led many participants to rate contact with an animal as low risk. However, participants considered animals unpredictable. "I don't care how tempered the animal is, animals like to bite and scratch out of love too." (FF6)

Participants supported that a six-week period was sufficient to see benefit from a personal contact intervention, but worried that withdrawing the intervention would lead to feelings of abandonment. Overwhelmingly, participants wished for personal contact to be made continuous, and were concerned that withdrawing the intervention at 6 or 12 weeks would negatively impact the person with dementia who had bonded with the contact. *"The patient might really bond with this person and then three months later you're done with the person and it's almost like a sense of abandonment at that point if the person with dementia can process it."* (FF2)

4. Discussion

Our findings support that formal and informal caregivers value personal contact with a person or animal, and view them as effective, logical, suitable, and low risk interventions to address loneliness for people with dementia. Past research has highlighted that there are several variables, including previous contact patterns, dementia status, and ethnic background, that influence how much current contact a person with dementia is likely to receive as a long-term care home resident (Port et al., 2001). In other words, people with dementia have diverse needs and opportunities to benefit from personal contact interventions, and this was also reflected in our findings. One way to meet diverse needs is by developing a targeted intervention. A targeted (as opposed to tailored) intervention would specify different standardized versions of the intervention for use with different subgroups. The subgroups are typically determined from their demographic features (e.g., age, cultural background) (Tancredi et al., 2013). For example, participants with dementia may be matched with a contact of a similar age, cultural background and gender. Or, the researcher would

select the length and frequency of contact in advance based on their assessment of the amount of baseline contact of the person with dementia. However, most participants in our study did not support using demographic profiles to select a standardized version of personal contact, and did not see this as an acceptable way to meet diverse needs and preferences.

In contrast to targeting, tailoring personal contact would involve a more individualized assessment of each person with dementia to understand their needs and preferences. We found that personal contact should be individually tailored, and flexible to meet the diverse preferences and needs of the person with dementia. Participants in our study held varied perceptions of what was most appropriate for people with dementia, in particular in relation to the length and frequency of visits. A scoping review supports that the one active ingredient of a personal contact intervention is routine, close contact with a person or animal (O'Rourke et al., 2018). Therefore, there are many other features that could be co-designed with the participant or their designated decision-maker without affecting this active ingredient. Components that may be tailored include who the contact is (which person or animal), length of visit (30 min or more), frequency of visit (weekly or divided over multiple visits per week), and mode of delivery (face-to-face or using technology).

Our findings support that tailoring to meet individual expectations will be more acceptable than assigning participants a standardized intervention. Higher acceptability can improve enrollment in trials, treatment engagement, and outcome achievement. Taken together, this leads to increased power to detect significant intervention effects (Sidani, 2015). Evidence supports that tailored interventions can achieve large effect sizes. For example, an activity program tailored to the capabilities of the person with dementia found a large, and statistically significant, improvement in dementia-related behaviors and a reduction in required hours of informal care (Gitlin et al., 2010). Similarly, a review of reviews and guidelines indicated that the effects of psychosocial interventions were maximized when interventions were tailored, embedded in daily care, and considered the individual's life context (Vernooij-Dassen et al., 2010). Furthermore, tailored interventions better reflect practice, as treatment follows clinical assessment (Kovach et al., 2006). However, to mitigate the risk of variability in delivery, tailored interventions should be well designed, implemented using an algorithm, and monitored for fidelity of implementation (Sidani, 2015). The association between treatment variability and outcome achievement can then be formally analyzed (Czaja et al., 2003).

Knowledge of the person with dementia was identified by participants as a key to promoting a meaningful connection. Family members and friends may be especially well suited to serve as contacts or facilitators for this reason. It is especially important to support family members' involvement in interventions with people with dementia who live in long-term care home settings (Vernooij-Dassen et al., 2010), but there are barriers. We identified that transportation, the nature of the relationship with the person with dementia, and time constraints affect family members' and friends' willingness to engage in personal contact interventions. These are similar to the barriers that prevent family members and friends from visiting people with dementia in long-term care homes (Miller, 2019). In short, we cannot rely alone on family members and friends; strategies to prepare volunteers or health care providers to have close and meaningful contact with people with dementia are needed to increase the feasibility and reach of personal contact interventions.

More research to identify how best to facilitate involvement of family members and friends in personal contact interventions is needed. The personal contact intervention, while aimed to promote feelings of social connection for the person with dementia, may also have a secondary impact on visiting patterns of the family member or friend. In a systematic review, psychological barriers had a major impact on whether family members or friends visited a person with dementia in a long-term care home. Psychological barriers included feelings of guilt, depression, being overwhelmed, and discomfort with dementia or long-term care homes (Miller, 2019). A study of a video-conferencing intervention with cognitively intact residents of a long-term care home found that allowing the family member to see parts of the resident's life in the care home was helpful to promote feelings of connection (Schuster and Hunter, 2019). This suggests that using a personal contact intervention to involve the family members or friends in the current life of the person with dementia may help to overcome these psychological barriers and could, in theory, promote more visiting after the study period ends. This is an area for future research.

Living with dementia is a risk factor for decreased social contact (in person and over the phone) following diagnosis (Hackett et al., 2019). This issue persists and may worsen over time. People who are admitted to care home environments experience a reduction in weekly visits and number of contacts by about 50%, phone calls decrease by 56% upon admission, and people with dementia have even less contact than residents that are cognitively intact (Port et al., 2001). Similarly, our results emphasize that facilitation of personal contact by a third party is very important in many situations. Such facilitation may be needed to promote engagement by family and friends or to ensure that technology is used appropriately, for example. We should not expect personal contact to 'just happen'. Even among cognitively intact residents, use of videoconference equipment has required facilitation by care staff (Schuster and Hunter, 2019).

Individualizing (or tailoring) interventions, preparing contacts following assessment, and ensuring appropriate facilitation may mitigate risks related to unpredictable animal behaviors or responses to 'strange' visitors. However, participants' desires for an ongoing intervention is challenging to accomplish in a research setting, where funding and activities end. Researchers need to identify ways to support regular personal contact following the study period. For example, the research assistant could discuss with the person with dementia or their decision maker how to facilitate visits from family members, friends or from a voluntary visitor or animal therapy organization after the study period ends.

The current study findings can prompt continuing care providers to consider critically how visits are promoted within their practice settings. Our findings support that health care providers should reflect upon several issues. Relevant questions include: (1) What are my assumptions related to the importance of personal contact for people with dementia? (2) What does my organization do to assess the contact received by people with dementia, and how individualized is this assessment? (3) What could be done within my organization to facilitate people with dementia to have regular contact with others? and (4) What are the opportunities to assess and

promote engagement by the person with dementia during personal contact? Continuing care providers can also use the findings from future intervention studies to inform the implementation of programs aimed to promote regular meaningful visits, prevent loneliness, and promote quality of life of people with dementia.

4.1. Strengths and limitations

This mixed methods study used quantitative ratings and qualitative semi-structured interviews to gain a nuanced understanding of the acceptability of personal contact interventions. A larger sample size would have provided a more stable quantitative estimate of intervention acceptability. However, our sample of 25 met our exploratory aims, allowed for in-depth analysis of the qualitative data with the resources available for the project, and we achieved data saturation (Saunders et al., 2018). Data saturation refers to our observation of similar comments from many participants, and redundant information leading to the generation of very few new codes after about 15–20 interviews. In addition, the final themes have analytic generalizability, in that they can be used to think about the problem beyond the study sample (Polit and Beck, 2010).

The views of older persons with dementia are essential to consider in order to fully understand intervention acceptability. It is a limitation that people with dementia were not included in this study. They were not included because their views may differ from those of their family members, friends, and health care providers and because a study to understand perspectives of people with dementia must employ methods different from those used here. While people with mild dementia may be able to make sense of and recall written descriptions in order to provide ratings and answer questions about personal contact, these approaches are not likely appropriate for use with people with moderate to severe dementia. To understand acceptability and how people with dementia experience and respond to personal contact interventions, data should be collected during future feasibility studies: the researcher can both observe their engagement during visits (for those with mild, moderate or severe dementia) and ask several questions to understand their experiences immediately following each visit (for those with mild to moderate dementia who can respond verbally).

5. Conclusions

Personal contact with a person or an animal was assessed by family members, friends and health care providers of people with dementia. People with dementia are a group at risk of loneliness and subsequent poor quality of life. The findings support that personal contact is potentially effective, logical, and suitable, to address loneliness of people with dementia. A personal contact intervention must involve routine, close contact with others, but it has many other elements that can and should be tailored to meet the individual needs of the person with dementia. Our findings highlight that simply putting someone in contact with another person or animal will not necessarily be effective to prevent loneliness. Personal contact visits should be tailored to meet the individual needs of the person with dementia, have facilitation approaches in place that aim to promote intimacy and meaningful connection, and be flexible enough to meet people's diverse and changing needs. While our findings are important and highlight specific adaptations for use with people with dementia, they are perhaps unsurprising. People with dementia are human beings with an innate need for social connection; their needs for personal contact will resonate with many of us who are (for the moment) counted among the 'cognitively intact'.

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Declaration of Competing Interest

None.

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